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INSTITUTIONAL DISCRIMINATION IN MENTAL HEALTH SERVICES:

A COMPARATIVE ANALYSIS OF SCHIZOPHRENIA AND DIABETES IN ROMANIA

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Declaration

This is to certify that the thesis comprises only my original work towards the PhD, that due acknowledgement has been made in the text to all other material uses and that the thesis is less that 100,000 words in length, exclusive of tables, figures, bibliographies and appendices.

Abstract

Background

This thesis aims to ascertain the extent and nature of institutional discrimination against people with mental illness in specialist health care settings in Romania. The hypothesis is that such discrimination exists. Building on the definition in EU directives, discrimination is defined, for the purposes of this thesis, as harm that is caused to individuals or groups on the basis of identifiable characteristics bearing negative connotations. Harm is defined as the receipt of care that is less good than, inequitable in comparison to that received by others with similar needs, (long-term physical and mental illness), on grounds of stigma against people with mental illness. To assess the presence of discrimination, two groups were identified suffering from disorders that, although at first sight quite different, actually have much in common. They are schizophrenia and type 1 diabetes.

Methods

The research method was Rapid Assessment, involving initial assessment, study area profile, contextual assessment, and health intervention assessment. The presence of horizontal inequity was determined by means of a *de jure* and a *de facto* assessment of specialist health care for people with schizophrenia and type 1 diabetes, using a set of criteria for aspects of care that are equally applicable to the management of both conditions, namely: 1) accessibility of specialist services; 2) availability of evidence-based treatment and care; 3) delivery of care; 4) quality of facilities; 5) protection of human and civil rights. The presence of stigma was determined the by ascertaining whether those in a position of authority and influence, namely the health professionals interviewed during the fieldwork, displayed stigmatising of attitudes and beliefs, language or approaches to treatment.

The research triangulated data collected using a range of methods that include systematic review and comparative analysis of laws, policy documents and other literature, interview strategies (focus groups, group interviews and semi-structured interviews) and observations of practice. Analysis of the data involved three methods: content analysis, narrative structure analysis, and critical appraisal.

For the fieldwork, a total of 228 participants (service users and health professionals) were selected using multi-stage sampling, covering each condition in each specialist setting (mental health acute and chronic inpatient services and outpatient services as well as inpatient and

outpatient services for type 1 diabetes) in two selected locations in Romania (Bucharest and Slatina). Data collection took place between the 19th of September 2007 and the 8th of January 2008.

Findings

In assessing equity, weaknesses were found in management of both conditions, particularly poor access to medication for associated health problems and lack of follow-up after discharge, poor continuity of care. In many areas, treatment and care for people with schizophrenia was worse generally, though some aspects were equitable: access to care in community-based settings, geographical accessibility of services, access to services when needed (temporal access), access to different parts of the system, as needed (referral system), financial access to appropriate care, access to social care, availability of enough staff in all settings, involvement of service users in shaping the services, involvement of families and carers, protection of service users' privacy and safety, decent living environment and hygiene of health facilities. Patients with schizophrenia were significantly disadvantaged in: access to a comprehensive range of evidence-based specialized services and to qualified and competent multidisciplinary staff, the quality of health facilities, access to care for other health conditions and, availability of individual treatment plans developed for each patient, empowerment of service users to care for themselves and live as independent a life as possible, and respect of all human and civil rights on health facilities and a number of patient rights.

In assessing stigma, I found that all types of mental health professionals, in all settings, stigmatised people with schizophrenia, manifest through their attitudes and beliefs, language and approaches to treatment.

Conclusions

This research found that people with schizophrenia suffer direct institutional discrimination in Romania, manifest inequities in both the legislation that applies to them and the specialist care delivered when compared with people with type 1 diabetes, and that these inequities arise in a context of stigmatising attitudes to people with severe mental health problems by those in a position of authority and influence (health professionals).

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Last, but not least I would like to thank the participants who accepted to be part of this research, both patients and health professionals, I hope the findings of this research will contribute to improving the quality of services they are receiving.

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Chapter 1 Introduction

What this thesis is about

This thesis is about how the health system treats people with mental illness in Romania. Mental illness is a major contributor to the overall burden of disease in Europe yet the needs of those afflicted by it are seldom given priority commensurate with the disease burden. This is especially so in the countries of central and eastern Europe, as has been made apparent by scenes of neglect and, in some cases, abuse that emerged after the fall of communist regimes in this region.

The thesis tests the hypothesis that those suffering from mental illness are discriminated against, even when compared with those who have other chronic diseases. It is the latter comparison that is relevant; it is self-evident that those with mental illness in central and eastern Europe are disadvantaged relative to the healthy population. The question is whether having a mental disorder leads to an additional disadvantage over someone with a physical one.

I test this hypothesis by comparing and contrasting the care given to those suffering from two disorders that, although at first sight quite different, actually have much in common. They are schizophrenia and type 1 diabetes. Both are life-long disorders that can be treated but not cured. Both can be compatible with a relatively normal life but equally, both can be severely disabling. Both require the input of inter-professional teams of health workers, providing organised care that is delivered in the right way, to the right people, at the right time, and in the right place.

To test this hypothesis I look at the formal position, including the laws, regulations, and systems for providing health care that are in place for these two groups of people, comparing and contrasting how, in theory, they should be treated. However, as theory and practice can be quite different, so I also look at how they are cared for in practice, allowing them and those health workers caring for them to speak of their experiences. I am interested in whether those with mental illness are discriminated against. Discrimination is defined as harm that is caused to individuals or groups on the basis of identifiable characteristics with negative connotations, in this case suffering from mental, as opposed to physical illness. But what is harm? For my purposes it arises where one group receives care that is less good that others with broadly similar needs. Conceptually, this is what has been described as horizontal inequity. The question then arises as to why one group might be treated less well relative to another. This leads me to explore the concept of stigma, whereby those with certain characteristics, in this case mental illness, are viewed as less deserving than others.

To gather the information required to make a judgment on the care provided to these two groups I use an approach developed by the World Health Organisation termed Rapid Assessment and Response. Building on an earlier body of work under the umbrella of rapid appraisal methods, it draws together information from a range of sources in a structured manner to provide an assessment of a public health issue, taking account of the setting and context, the groups affected, and the consequences for them, identifying opportunities for intervention. In this way I can capture both what should happen in theory and what does happen in practice. First, however, to place my research in a broader context, I will review the burden of disease attributable to mental illness in Europe and the adequacy of the response to it.

Background

Mental health problems – a staggering burden of disease across Europe

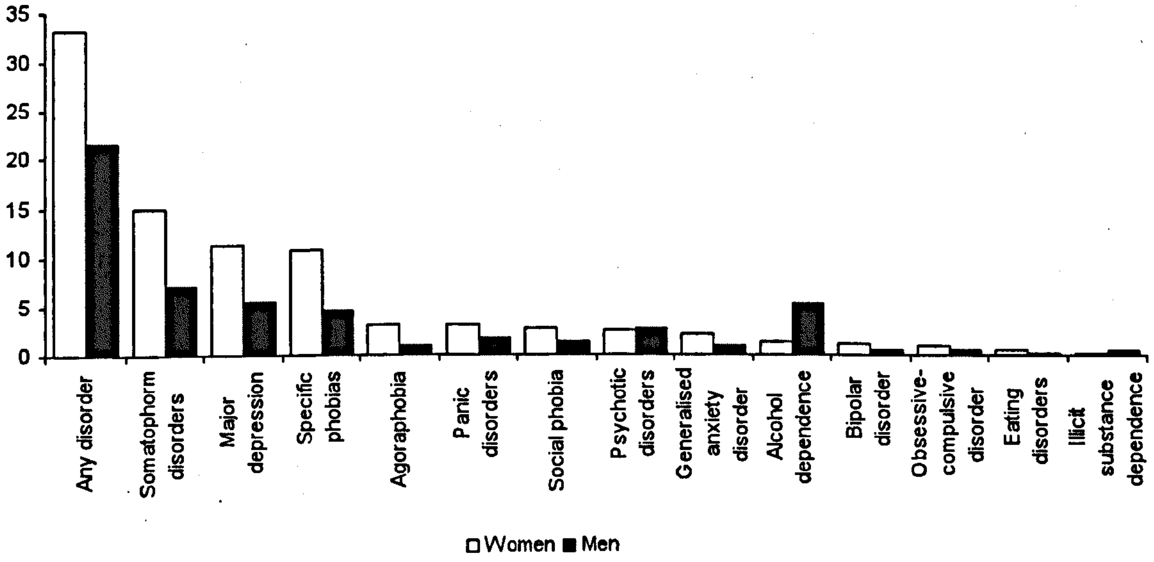
Mental health problems are among the leading public health challenges in Europe, making a major contribution to the overall burden of disease in the European population.

Data on the burden of disease attributable to mental ill health are available in three main forms: (1) prevalence of mental disorders, (2) Disability-Adjusted Life Years (DALYs) lost due to neuropsychiatric disorders, and (3) Years Lived with Disability (YLDs) due to neuropsychiatric disorders (1, 2). Each of these provides information on different elements of the burden of disease in Europe.

There is one other indicator that is often used to capture the disease burden attributable to mental illness, the suicide rate (3). This is not a measure of a particular mental disorder, but its routine availability has made it attractive to those searching for some simple, albeit extremely limited, indication of the prevalence of mental illness.

A systematic review of the prevalence of mental health disorders, derived from community studies, estimated that 27% of the adult population (aged 18-65) in the European Union (EU), Iceland, Norway and Switzerland have experienced at least one mental disorder within a 12-months period (1). The mental disorders included range from somatoform disorders, depression, anxiety, psychosis, to substance use or eating disorders (Figure 1). Women were more commonly affected than men. These figures represent an enormous human toll of ill health, with an estimated 83 million people being affected. Yet even these figures are likely to underestimate the scale of the problem as only a limited number of mental disorders were included in this meta-analysis. Additionally, this study did not collect data on those aged over 65, a group whose risk of mental health problems is elevated. These figures also fail to capture the complexity of the problems that many people with mental disorders face. Thirty-two percent of those affected had one additional mental disorder, while 18% had two and 14% three or more.

Figure 1 **12-month prevalence rates by disorder among men and women**

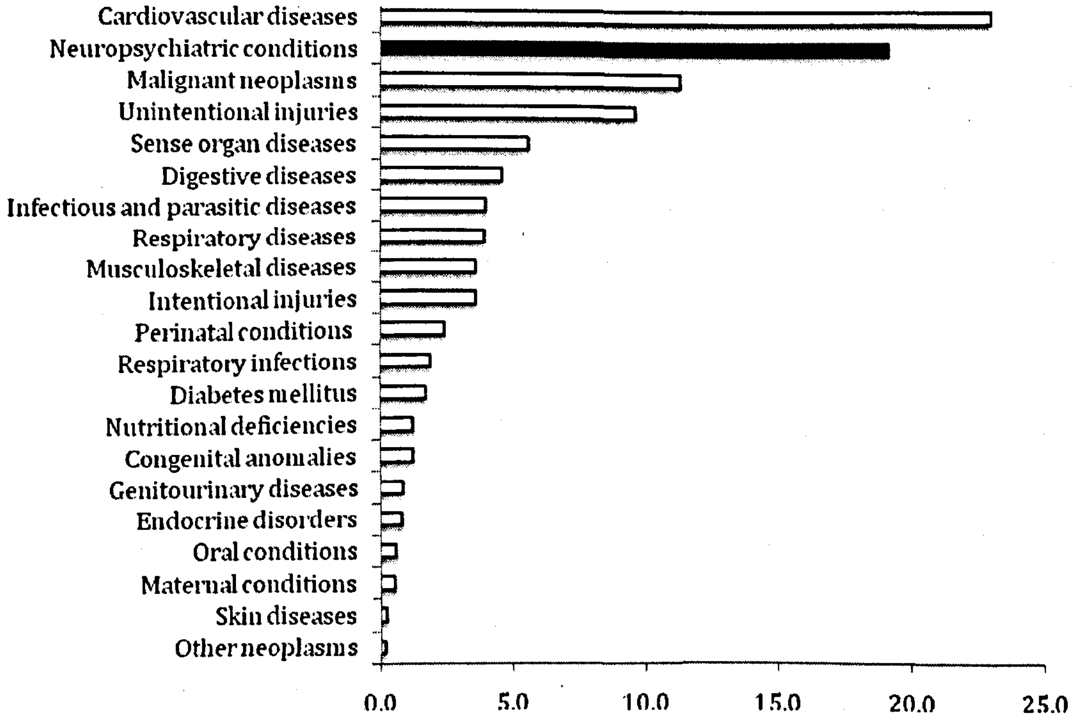


Source: based on data from Wittchen & Jacobi, 2005

The burden of mental health problems can also be reported as lost years of 'healthy' life, by measuring the gap between current health status and an ideal situation where everyone lives into old age free of disease and disability (2). This conventional health gap measure, called Disability-Adjusted Life Years (DALYs), introduced by the World Health Organization (WHO) in its Global Burden of Disease project, is particularly relevant to mental health. This is because it extends the concept of potential years of life lost to include not only premature death but also years of life in states of less than full health, broadly termed disability.

The most recent available data shows that neuropsychiatric disorders are the second largest cause of Disability-Adjusted Life Years (DALYs) lost in Europe[a] and account for 19% of the total, only 4% less than the leading cause, cardiovascular disorders (Figure 2). They are among the top ten conditions in all European countries, typically ranking 1 or 2 in EU countries, 3 or 4 in South Eastern European countries and 5-6 in the Commonwealth of Independent States[b] (4).

Figure 2 **Disability-Adjusted Life Years in the WHO European Region**



Source: based on data from WHO, 2008

Four of the top 15 diseases responsible for lost years of 'healthy' life are specific mental health disorders: unipolar depressive disorders are the third leading cause of lost years of 'healthy' life (5.6 % of all DALYs), alcohol use disorders rank 6th, accounting for 3.3 % of all DALYs,

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[a] Europe as defined in the UN system, with 53 Member States.

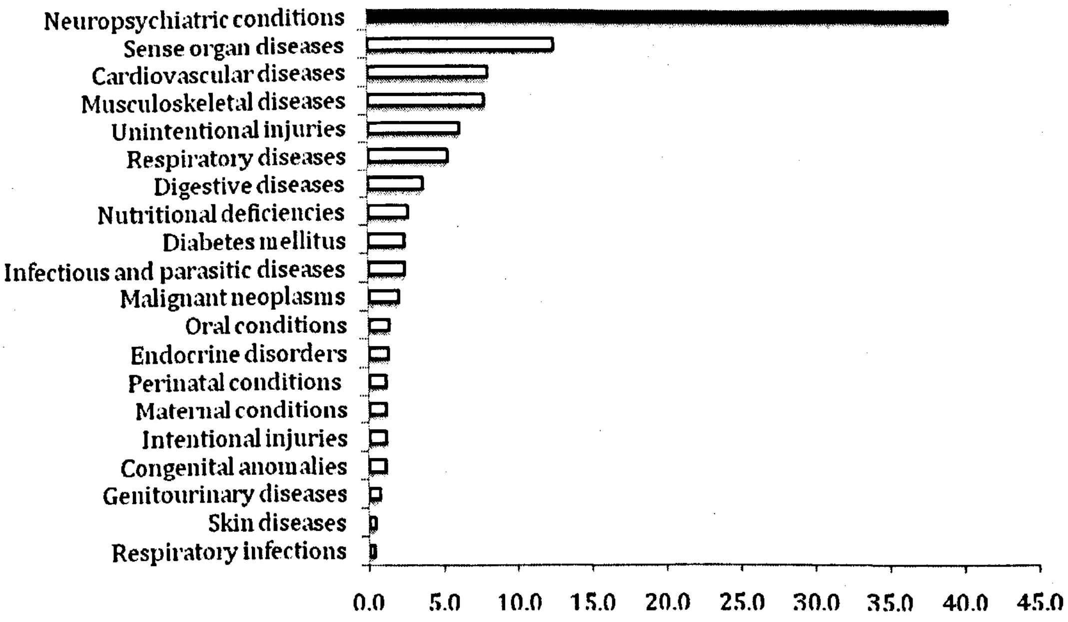
[b] The Commonwealth of Independent States (CIS) is a partnership on the basis of sovereign equality between 12 of the former Soviet Union republics (Azerbaijan, Armenia, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Republic of Moldova, Russian Federation, Tajikistan, Turkmenistan, Uzbekistan and Ukraine) formed in December 1991 (Source: http://www.cisstat.com/eng/cis.htm)

self-inflicted injuries are the 11th leading cause of DALYs (2 % of all DALYs) and Alzheimer's Disease and other dementias are the 14th leading cause of DALYs (2 % of all DALYs).

Years Lived with Disability (YLDs) are another useful indicator as they capture the demands on health systems. Using this measure, mental disorders are by far the most significant of the chronic conditions afflicting the population of Europe, accounting for 39.7% of the total burden of chronic conditions (Figure 3) (2).

Unipolar depressive disorder alone contributes 13.7% of all YLDs, making it the leading chronic condition in Europe. This is followed closely by alcohol-related disorders, accounting for 6.23% of the total. Alzheimer's Disease and other dementias are in seventh place, accounting for 3.8% of the total, ahead of schizophrenia and bipolar disorders, each responsible for 2.3% of all YLDs.

Figure 3 **Years lived with disability in the WHO European Region**



Source: based on data from WHO, 2008

Ideally, policy makers would have access to adequate information on the scale and nature of mental health problems, to ensure that the representation of mental health on the political agenda is commensurate with its magnitude, and to promote sufficient investment in strategies and interventions to address mental ill health. To achieve this, one would seek data from household surveys based on nationally representative samples, with internationally standardised data collection methods and agreed definitions and diagnostic instruments. Such surveys would be repeated at frequent intervals. In practice, the situation in which European countries find themselves today is far from ideal. This is due to conceptual and technical obstacles involved in collecting data, some of which are not unique to mental health. A review by Wittchen & Jacobi cited a number of barriers to the systematic collection of epidemiological data on mental health. First, they noted that Europe does not have a tradition of standardised surveys for mental health, comparable to the United States National Survey on Drug Use and Health. The evidence on the burden of disease presented above relies heavily on extrapolations from findings in those few countries where epidemiological studies are carried out. Second, the term of "mental disorders" includes a wide range of different clinical conditions, of which only a few have ever been systematically explored in epidemiological studies. Furthermore, many mental health disorders co-exist with one another so there is a risk of double-counting when adding prevalence estimates for single disorders. Another challenge identified was that methodological and diagnostic standards in surveys vary greatly across countries. Finally, they noted that socio-demographic and socio-economic characteristics, differences in cultural, legal, social and health care system-related traditions, and different psychopathological traditions all complicate the conduct of studies and the interpretation of data.

While a far from perfect measure, one source of information that is available in almost all European countries is the suicide rate. According to the most recent available data 121,028 people commit suicide every year in Europe, out of which almost 80% are men (3). The average suicide rate in Europe is 13.4 per 100,000, with the highest rates in the Commonwealth of Independent States (CIS) (19.2 per 100,000), followed by the post-2004 European Union (EU) countries (15 per 100,000). Within the EU, where the average rate is 10.4 per 100,000 population, this figure rises as high as 31.5 per 100,000 in Lithuania, 21.8 per 100,000 in Hungary, 20.7 per 100,000 in Latvia and 18.7 per 100,000 in Slovenia.

Men are almost five times more likely to commit suicides than women, a pattern that is similar across all countries of the European region (with an average rate of 22.9 per 100,000 population for men versus 5.1 per 100,000 for women). The highest male/female ratio occurs in CIS countries and the post-2004 EU member states (at a rate of 5.7 times more frequently in men than women, respectively).

In summary, therefore, despite the many methodological difficulties involved in data collection, the resultant limitations of available data, and the scarcity of measures, what evidence exists indicates that mental health problems, and especially those that are chronic, should be a leading health concern in Europe. People suffering from chronic and severe conditions require long-term care and need support from the health care system. Considering the severity of the situation, one would expect mental health to be high on the health policy agenda and for efforts to be made to ensure that appropriate treatment and care are available to those in need. Yet this is not the case and the next section examines the low priority given to mental health and the reasons for this situation, focussing particularly on the roles of stigma and discrimination.

Roles of stigma and discrimination in mental health care

Despite the staggering burden of disease, there is a large gap between the need for care and what is provided[a]. It is estimated that even in countries with well developed mental health systems, over 90% of people suffering alcohol abuse and dependence receive no effective treatment, nor do around 60% of those with anxiety disorders, almost 50% of those with panic disorders, 45% of those with major depression, 40% of those with bipolar affective disorder, 25% of those with obsessive compulsive disorder and 18% of those with schizophrenia and non-affective psychosis (5).

Scarcity of mental health services is only one reason for this treatment gap. It is striking that many people with mental health problems often avoid or delay seeking health care. This is true both for people who experience symptoms for the first time and for those who have been diagnosed as having a mental disorder but choose not to maintain contact with mental health services, even where such services are available. A common theme in the literature relates to the presence of stigma and discrimination as key barriers to treatment of mental illness (6-9). These are two facets of the same reality faced by people with mental health problems; stigma has been linked to attitudes and discrimination to behaviours (10-12).

Attitudes towards people with mental health problems have evolved over time: from ignoring them, to punishing them and finally, to empowering them. People with mental health problems have suffered discrimination in health care since the first services were organised. Often referred to as "the Cinderella" of health services, the profile of mental health care (as opposed to

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[a] The treatment gap has been defined as "the absolute difference between the true prevalence of a disorder and the treated proportion of individuals affected by the disorder" (Kohn R, Saxena S, Levav I, Saraceno B. The treatment gap in mental health care. Bulletin of the World Health Organization. 2004 Nov;82(11):858-66.).

containment) started to change only in the 1960s in industrialised Western countries. This occurred in part because of the new therapeutic options becoming available (13, 14) and the emergence of critiques of traditional psychiatric practice (15) but also because the magnitude of the problem and its major economic implications became apparent at this time, leading to an acute need for solutions.

The World Health Report 2001 (16) identifies three main factors that have influenced the change in attitudes towards persons with a mental illness over the last 40 years:

- "Psychopharmacology made significant progress, with the discovery of new classes of drugs, particularly neuroleptics and antidepressants, as well as the development of new forms of psychosocial interventions, that enabled people to control their symptoms while living in the community.
- The human rights movement became a truly international phenomenon under the influence of the newly created United Nations, and democracy advanced on a global basis, albeit at different speeds in different places (17).
- Social and mental components were firmly incorporated in the definition of health set out by the newly established WHO in 1948." (p. 49)

However, the shift towards "not just bricks and mortar" (18) took time, while policy makers often under-estimated the need for support required by the people who previously lived in asylums, especially those who were severely disabled (18). In 1977, a working group appointed by the European Office of the WHO (19), with experts from 9 countries from across the Region, stated that the main constraints to development of mental health services (some of which are still valid today) included: lack of adequate information about the size and the nature of mental health problems and resources available to cope with them; lack of national mental health policy; unavailability and inaccessibility of services; inadequacy of staffing; lack of financial resources; ineffective coordination and administration of resources; outdated and inappropriate legislation; lack of relevant research; lay and professional bias against the against persons with a mental illness; resistance to change; and lack of political will.

It is, however, the presence of bias, prejudice, fear and ignorance among the public, mental health professionals and decision makers that have been identified as the root causes of inertia and even resistance to provision of adequate mental health services. They lead to low levels of investment in mental health, which constrain progress. The report concluded that the "greatest impediment to progress lay in the minds of men rather than in their pockets and purses."

While both stigma and discrimination have a damaging impact on people with mental health problems, there are clear advantages to focusing initially on the concept of discrimination. The concept of "enacted stigma", used interchangeably with the concept of "discrimination" in the literature on mental health, is a useful term which shows the causal relationship between stigma and discrimination. However, the concept of "stigma" does not have any legal consequences, while "discrimination" does. The concept of "discrimination" is operationalized in a wide range of national and international anti-discrimination legislation (e.g. the UK's Disability Discrimination Act (20-22) and EU directives (23, 24)). Legal sanctions arise from actions that are demonstrated to be discriminatory. The concept of "discrimination" makes it possible to align mental health with the broader context of fighting against discrimination in societies. "Using the law can be a very powerful means of upholding human rights and of combating discrimination and social exclusion. Legislation can include human rights laws and treaties; laws to prevent discrimination on grounds of mental health problems or disability; as well as mental health legislation." (25)(p. 18). People with mental health problems are reported to encounter discrimination in all areas of their life: from accessing employment, education, housing, social security, and public services, to their treatment in and experience of the justice system, their communities and social networks, home and personal life and intimate relationships (26).

The World Health Report 2001 recognises that discrimination in health care is a major barrier to implementing effective mental health interventions. The report stresses the role of health authorities, as "ultimate stewards of any health system", to address discrimination in the provision of treatment and care against people with mental disorders (16) (p. 4).

Summary

Mental illness is a major contributor to the overall burden of disease in Europe, yet there is a substantial gap between need and provision of services. I have argued that this is at least in part due to the stigma associated with mental illness and the resulting discrimination against those afflicted by it. In the following chapter I will explore these concepts, of stigma and discrimination, in more detail and examine how they can be operationalized.

Chapter 2 Discrimination, a key barrier to good mental health care (a review of the literature)

Introduction

As set out in the previous chapter, the focus of this thesis is the potential discrimination against people with mental health problems within the health care system on the grounds of their mental illness. I will argue that while members of the general population may display stigmatizing attitudes and treat people with mental health problems as "second class citizens", governments have a responsibility to protect people with mental health problems from such treatment and ensure that no form of discrimination against them is tolerated within its structures and services. Discrimination in health care is a subset of discrimination in general, involving wider society, employment, education, and many other sectors and policy-makers cannot shirk their responsibility to address it (27).

To begin, I report the findings of two literature reviews that I have undertaken to understand the wider European context. The first will scrutinize the commitments made by European governments in various fora to protect people with mental health problems against discrimination in the provision of health care. The aim of the review is to determine whether the current international policy and legislation makes specific requirements to protect this target group.

In the second review, the literature documenting the scale of discrimination against people with mental health problems in health care on grounds of their mental illness will be reviewed so as to determine whether political commitments are being honoured at the country level. Such documentation is a necessary pre-requisite to enable effective action to be taken to tackle discrimination invoking governmental commitments.

In both of these reviews I take the terms discrimination and stigma at face value. I will examine in detail the definitions of these words and their usage in the following chapter but, for now, the questions relate to the commitments that governments have made to tackle discrimination, whatever that means, and the extent to which health professionals and patients perceive it.

Political commitments to tackling discrimination in mental health care

> *"if it proves impossible, for example, to remove stigma, it is often possible to focus on removing discrimination by legal and other means."* (28) (p. 38)

Progressively, European governments have committed themselves to protect the rights of people with mental health problems and to tackle discrimination against them in the provision of treatment and care. These commitments have been made in various fora, as member states of the United Nations and its specialised agency, the World Health Organization, or in the Council of Europe or the European Commission. They were joined in their commitments by other key stakeholders, such as service users and mental health professionals who have also declared their determination to fight discrimination in mental health care.

I reviewed international commitments to tackling discrimination in health care produced by these lead international organisations with competence in health and human rights. The review excluded similar documents produced by national health authorities or documents produced by international experts outside any organisational framework. The detailed methods employed in this review are set out in Box 1. In reading the following sections, it is important to distinguish between those measures that are legally binding, which are European Union Directives and the European Convention on Human Rights, from those that are only recommendations and non-binding policy commitments, albeit with considerable normative value.

Box 1 Methods of the systematic review of international political commitments to tackling discrimination in health care

Inclusion criteria: All international commitments, legally binding or not, promoted in the fora of international organisations, in which one or more European Member States committed themselves to tackle discrimination against people with mental illness or people with disabilities (including mental disability) in health care.

Exclusion criteria: a) International commitments that do not address discrimination against people with mental illness or people with disabilities (including mental disability) in health care; b) International document adopted or endorsed by Member States other then from the European Region; c) International commitments that address discrimination against people with mental illness or people with disabilities (including mental disability) in health care, promoted by other groups, such as professional organizations, not of countries.

Search strategy and findings: The main international organisations and agencies that have mandate to work in this areas are: the United Nations and its specialised health agency - the World Health Organization, the European Commission and the Council of Europe. A search on their websites resulted in 12 relevant documents, as follows:

- On the website of the United Nations, I found four documents directly relevant to the review's topic (29-32);
- On the website of the World Health Organization Headquarters, I found one document directly relevant to the review's topic (16);
- On the website of the World Health Organization Regional Office for Europe, I found five documents directly relevant to the review's topic (33-37);
- On the website of the European Commission, I found one document directly relevant to the review's topic (38);
- On the website of the Council of Europe, I found two documents directly relevant to the review's topic (39, 40).

I also consulted experts to ensure that there were no major documents I may have missed:

- Dr Matt Muijen, Regional Adviser for Mental Health, WHO EURO;
- Mr Hedinn Unnsteinsson, Technical Officer, Mental Health, Collaboration with Civil Society (at the time of the research).

Analysis and synthesis of findings: The contents of each document reviewed were critically analysed. The specific commitments to the protection of the rights to non-discrimination of people with mental health problems in the provision of health care were identified and described in the analysis included in this section.

United Nations

There are many United Nations[a] documents that address the issue of discrimination in its various forms. Some, such as the Universal Declaration of Human Rights (41), the International Covenants on Civil and Political Rights and on Economic, Social and Cultural Rights (42, 43), the International Convention on the Elimination of All Forms of Racial Discrimination (44) or the Convention on the Elimination of All Forms of Discrimination against Women (45), have a broad scope. Others refer specifically to discrimination in the provision of health care for people with mental health problems.

Among the last of these, the most recent is the Convention on the Rights of Persons with Disabilities adopted by the United Nations General Assembly in 2006 and entering into force in

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[a] All countries in Europe, with the exception of Kosovo and the Vatican City, are members of the United Nations.

2008 (30). This Convention sets out the legal obligations of States to promote and protect the rights of persons with disabilities, including those with mental health problems.

The Convention builds on previous documents, as follows.

1. The 1975 UN Declaration on the Rights of Disabled Persons documented the rights of persons with disabilities (29). The preamble promoted "assist[ing] disabled persons to develop their abilities in the most varied fields of activities" and "promoting their integration in normal life". In the main document, "disabled people" are defined as "any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life as a result of deficiency, either congenital or not, in his physical or mental capabilities" (para. 1). The Declaration sets out the rights of persons with disabilities to receive special treatment for special needs, to obtain medical and psychological treatment, to equal treatment as far as residence is concerned and the right to environmental and living conditions as close as possible to those of healthy people of their age when it is found to be necessary to admit them to a specialised establishment.
2. The 1993 UN Standard Rules on the Equalizations of Opportunities for Persons with Disabilities (32). These aim "to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others" (para. 15). These Rules require that governments guarantee persons with disabilities (including mental disabilities) the same level of medical care within the same system as other members of society and develop national programmes for all groups of persons with disabilities, based on the actual needs of the persons with disabilities and on the principle of full participation and equality. Moreover, in countries with social security, social insurance or other social welfare schemes, governments are required to ensure that these systems do not exclude or discriminate against persons with disabilities.

What is different about the 2006 Convention is the way in which persons with disabilities are as viewed. The 2006 Convention conceptualises persons with disabilities as "subjects" with rights and who are entitled to their "physical and mental integrity on an equal basis with others" (Article 17) and who are capable of making decisions about their lives based on their free and informed consent. They are not, as previously considered, "objects" of charity, medical treatment and social protection. Governments are required to ensure that people with disabilities, including those with mental health problems, have "access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community" (Article 19b).

The Convention confirms a number of civil rights such as freedom to choose place of residence and nationality as well as rights to personal mobility, to property, to enter into contracts, to manage one's own financial affairs, to marry, work, and retain custody of one's children, and to participate in political and public life. It prohibits discrimination against people with disabilities in health insurance, employment and education, and requires Member States to prevent discriminatory practices in the delivery of health care.

Another key document adopted by the UN General Assembly is the 1991 Resolution on the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (the "MI Principles"), which remains, to this day, a reference document for much national mental health legislation (31). The document stresses the importance of non-discriminatory practices within the health care system. The rights to which mental health service users are entitled, according to the MI Principles, include the right to access mental health facilities equivalent to the access provided to any other health facility for any other illness, the right to treatment and care that meet the same standards as for people with other illnesses and the right of persons admitted to mental health facilities to the same level of resources as in any other health establishment. Though the document is not legally binding, it stipulates that Member States are expected to implement these principles fully. In the present context, it provides a clear normative basis for arguing that access to care by patients with mental health problems and somatic health problems should be essentially the same.

World Health Organization

In 2001 the World Health Organization (WHO) took the initiative of dedicating, for the first time, the World Health Report, the technical discussions at the World Health Assembly, and the World Health Day, to mental health (16). In the report, entitled "Mental Health: New Understanding, New Hope", Member States were urged to improve care for people with mental health problems, stressing that "Effective solutions for mental disorders are available" (p.109). The document states that governments are as responsible for the mental health as they are for the physical health of their citizens and they should ensure that effective mental health policies are developed and implemented. The report calls for the assurance, by countries, of universal access to appropriate and cost-effective services for people with mental health problems, the provision of adequate care for service users and the protection of human rights for people with mental health problems. While acknowledging that the care required by people with severe and persistent mental health problems is similar to that of people with chronic physical problems, the document denounces the significantly poorer conditions in psychiatric hospitals as compared with other hospitals, again providing a basis for this thesis. It is recommended that ministries of health "trade some efficiency gains to reallocate resources in the pursuit of equity" (p. 93) when developing their mental health strategies. The report formulates recommendations for Member States to address the challenges faced in various areas of mental health, including the fight against discrimination. By adopting the report, governments committed themselves to implementing its recommendations, based on the resources available to each of them.

Pledges made at the global level have been tailored to the regional context in the form of regional or sub-regional commitments. The most important WHO European Region policy documents are the Mental Health Declaration and the Action Plan for Europe (33, 34). Both of these instruments were endorsed by European health ministers in January 2005, at the first Ministerial Conference on Mental Health[a] in the Region. Hosted by Finland, the Helsinki Conference generated the political commitment to move from general agreement to detailed policy decisions within countries. Other key stakeholders such as organisations representing users, carers, and mental health professionals also contributed to the preparation of these two documents that set five priorities for the seven years, the second priority being to "Collectively tackle stigma, discrimination and inequality, and empower and support people with mental health problems and their families to be actively engaged in this process." (p. 2).

Health ministers who attended the Helsinki Conference committed themselves "to recognizing the need for comprehensive evidence-based mental health policies and to considering ways and means of developing, implementing and reinforcing such policies" (p. 3) in 12 priority areas for action. The Action Plan set out in detail the responsibilities of both Member States and the WHO. These include, on the part of Member States, reductions in stigma and discrimination,

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[a] According to WHO regulations, the purpose of ministerial conferences is to transmit new knowledge or review and discuss new policies and principles of interest to Member States. They bring together representatives of Member States, normally at ministerial level, to review broad strategic approaches to problems and seek a measure of agreement on important elements of particular problems, to further the application of the most recent knowledge and to foster common action on priority issues. They can also "round up" activities in a particular field to provide a springboard for practical application of the knowledge gained.

access to good primary health care, effective care in the community, partnerships across sectors, a competent workforce, and adequate and fair funding.

Some sub-regional commitments to mental health service provision are worth mentioning. Some were made prior to the Helsinki Conference or in the immediate lead up to it. The last one was developed as a follow up to Helsinki.

In June 2001, mental health professionals linked to national governments and mental health organisations in Southern and South Eastern Europe signed the Athens Declaration on Mental Health and Man-made Disasters, Stigma and Community Care, subsequently endorsed by the WHO Regional Committee for Europe (35). In the document, governments were requested:

a) to implement programmes aimed at reducing stigma and discrimination and to uphold the principle of equity in their mental health policies, programmes and services; and to accelerate the transfer of mental health care into the community;

b) to pursue vigorously and systematically the process of de-stigmatisation and the development of community mental health services that will lead to guarantees of the patients' civil and human rights. These rights refer to the appropriate mental health services, as well as to education, housing and employment, so that the integration of service users in the society is based on solidarity, humanity and pragmatic grounds.

The same year, health ministers from eight European countries signed the Dubrovnik Pledge: Meeting the health needs of Vulnerable Populations in South East Europe (36). This instrument expresses for the first time a strong political commitment by the respective countries to work in partnership to ensure equity in provision of health care, to increase access to appropriate, affordable and high-quality health care services, to address inequalities in health infrastructure and work on improving the balance between primary and secondary services in six health areas, including mental health. This event took place within the framework of the Stability Pact project for South Eastern Europe, developed in partnership with the Council of Europe and the governments of other European countries (e.g. Greece, Italy, and Sweden).

Finally, in 2008 the WHO National Counterparts from 8 CIS countries signed the Merano Declaration on Mental Health in CIS countries (37). On the basis of similarities in the historical organisation of mental health services and the provision of mental health treatment and care in their countries, this document acknowledges a number of common challenges. These challenges are related to implementation of national policies and legislation, availability of mental health care in primary care settings, and poor conditions in mental health institutions which remain the main provider of mental health services in these countries, limited availability of specialist mental health staff and poor funding. The document sets a common agenda in these areas and asked the WHO Regional Office for Europe to support these countries to further this work.

European Commission

The European Commission (EC) has two main policy initiatives on mental health, namely the Green Paper on Improving the Mental Health of the Population and the European Pact for Mental Health and Well-Being (46, 47). Neither of these imposes any specific obligations on member states to tackle discrimination against people with mental health problems.

The Green Paper was launched in 2005, shortly after the WHO Conference in Helsinki, and sought to initiate a public consultation on how better to tackle mental illness and promote mental well-being in the EU and how best to develop a comprehensive EU strategy on mental health. The document recognises that "Stigmatisation, discrimination and non-respect for the human rights and the dignity of mentally ill and disabled people still exist, challenging core European values" (46) (p.3), but discrimination is not included among the 4 priority areas proposed for a potential EU strategy.

Key stakeholders had the opportunity to comment on the Green Paper and give feedback to the Commission. The response to the consultation process concluded that there is indeed a need for an EU strategy in the area of mental health. However, instead of a strategy, the EC launched a European Pact. This Pact emerged from a high-level meeting organized in June 2008; the recommendations contained within the Pact were further endorsed by a European Parliament Resolution on Mental Health in 2009. The Pact highlighted 5 areas of action, among which was "Combating Stigma and Social Exclusion" (p. 5), but did not identify discrimination specifically. This is significant given that the EC has enacted anti-discrimination legislation in other areas.

The most specific commitment at the EU level to fighting discrimination against people with mental health problems materialised in 2003, in Council Conclusions 9688/1/03 REV 1 on combating stigma and discrimination in relation to mental illness (38). However, this document does not contain explicit requirements to act against discrimination in health care. It only asks Member States "to give specific attention to the impact of stigma and discrimination related problems due to mental illness in all age groups, and ensure that these problems are recognised, in this context giving special attention to the reduction of risks of social exclusion" (p. 13).

Council of Europe

As with the UN, a number of key resolutions and recommendations of the Council of Europe are not aimed specifically at mental health but nevertheless address issues relevant to the treatment and care of psychiatric patients. These include the Convention on Human Rights, the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, out of which a monitoring Committee was established, the Revised European Social Charter, and the Convention on Human Rights and Biomedicine (48-51).

In 1994, the Parliamentary Assembly of the Council of Europe adopted Recommendation 1235 on Psychiatry and Human Rights. This recommends that Member States promote legal measures guaranteeing respect for the human rights of psychiatric patients (39).

Complementing the documents that seek to protect human rights in general, including the right to health care, the 2004 Council of Europe Recommendation 10 Concerning the Protection of the Human Rights and Dignity of Persons with Mental Disorder aims to enhance protection of the dignity, human rights and fundamental freedoms of persons with mental disorders, in particular those who are subject to involuntary placement or treatment (40). The Recommendation promotes the principle of non-discrimination against people with mental health problems. Article 3 states that "Any form of discrimination on grounds of mental disorder should be prohibited". The attached Explanatory Memorandum elaborates on this, noting that "Discrimination may also arise within health services themselves, for example by patients with mental disorder being given a lower priority for treatment of their physical illness (...). On a wider scale, whether the allocation of personnel and financial resources to mental health services is fair in comparison to the allocation made to physical health services warrants consideration." (para. 43).

Member States are expected to implement fully the provisions of this Recommendation. The Preamble to the document recommends that "the governments of the member states should adapt their laws and practices to the guidelines contained in this recommendation".

To conclude, European countries have indeed committed themselves to protect people with mental health problems against discrimination in health care. While most of these commitments are statements of political intent, and not legally binding, they give service users, carers and their advocates legitimacy in their pursuit of fair, non-discriminatory treatment in health care.

Evidence of discrimination in health care against people with mental health problems on grounds of their mental illness

The next literature review examines the published evidence on the extent and nature of discrimination on grounds of mental illness within health services. The search strategy is summarised in Box 2.

Box 2 Methods used in the systematic review on discrimination in health care against people with mental health problems on grounds of mental illness

Inclusion criteria: All documents that address discrimination in health care against people with mental health problems on grounds of mental illness

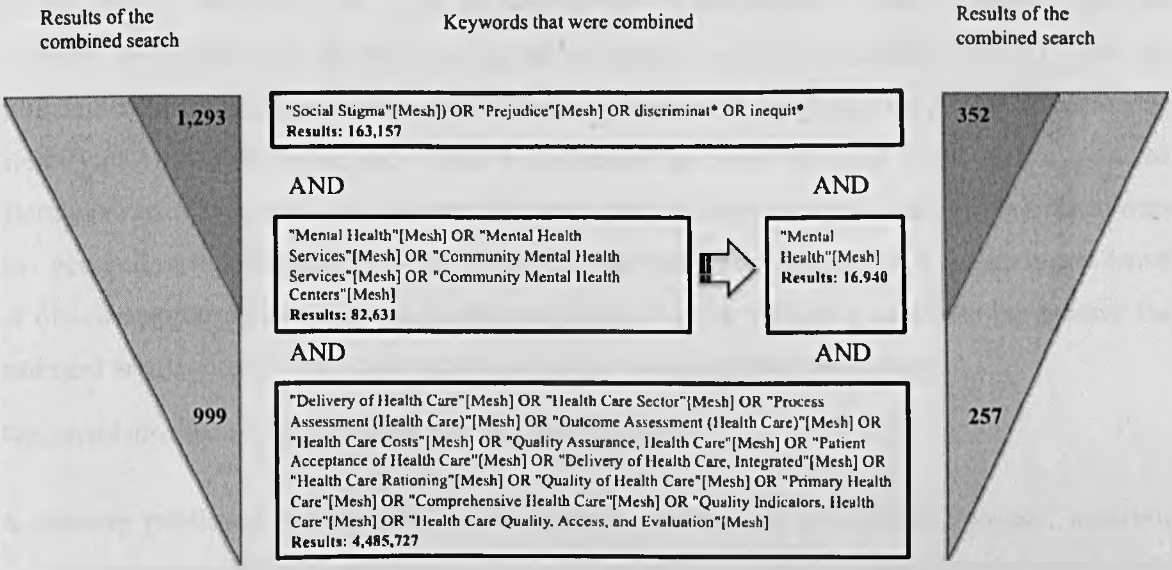
Exclusion criteria: a) Documents focusing on discrimination against people with mental disabilities; b) Documents focusing on discrimination against people with neurological disorders; c) Documents that address discrimination against people with mental health problems in areas other than health care; d) Documents that address discrimination against people with mental health problems in health care on grounds other than their mental illness (e.g. race, gender, sexual orientation)

Search strategy and findings: The initial search was conducted in August 2006, for the upgrading thesis. The following databases were used: Pubmed, PsycINFO, Embase and Web of Knowledge, using and relating the key-words for the entire time period covered by each database. The search strategy was customized to each database (see Annex 1). The articles selected were integrated with manual search (publications of the same authors, articles linked to relevant articles and cross-references). The manual search of grey literature was based on availability. Websites of the Sainsbury Centre for Mental Health, Mental Health Foundation, Rethink, OpenUp were searched for relevant reports. 1,878 documents were found. The literature review was updated in April 2011, but restricted to the 2 databases that yielded most in the 2006 search, Pubmed and PsychInfo. The total number of documents retrieved, excluding duplicates was 1859. Search strategies are presented in Figures 4 and 5.

Screening and selection: All references were downloaded into bibliographic software (EndNote). Duplicates were identified and deleted. First, references were scrutinized by title and any irrelevant were discarded. Second, abstracts of remaining references were scrutinized and those irrelevant were discarded. The purpose was not to analyse all the articles related to discrimination in health care against people with mental health problems, but only to focus on those articles that study discrimination independent of other confounding factors. Therefore, only those articles were analysed and the synthesis of the findings is included in this chapter. The initial scrutiny was expanded to include all the articles retrieved, to ensure I did not miss out on any that were relevant.

Limitations: The search did not include syntaxes such as "BUT NOT" to exclude articles that addressed discrimination on grounds other than mental illness or in areas other than health care. This was done on purpose, to make sure that no relevant study was missed. Scrutiny of articles retrieved, however, showed that the large majority of them focussed on discrimination against people with mental health problems in health care only on grounds other than their mental illness (e.g. race, gender, sexual orientation). As such, they were discarded. Another limitation was that the search strategy included also search words such as "inequity", "stigma" and "prejudice". While aware of the risk of retrieving articles that did not in fact address discrimination, I decided to expand the search to these search words since the boundaries between these concepts are not always clear and sometimes they are used interchangeable, even if they are not actually synonymous. "Discrimination" *per se* is not a MeSH term in PubMed.

Figure 4 **Search strategy employed on Pubmed database in 2011**



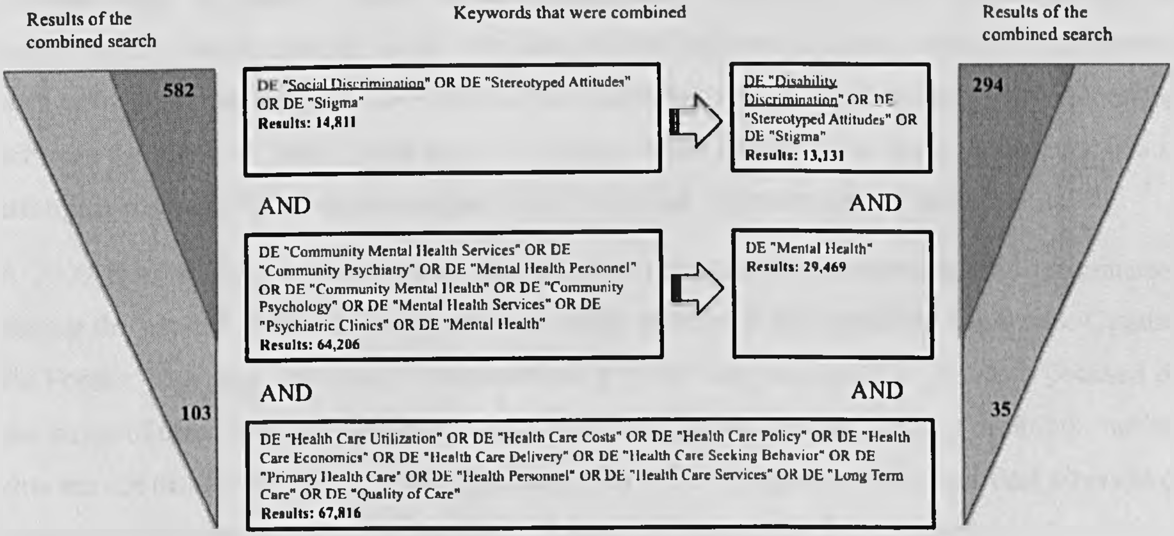
"Social Stigma"[Mesh]) OR "Prejudice"[Mesh] OR discriminat* OR inequit*
Results: 163,157

"Mental Health"[Mesh] OR "Mental Health Services"[Mesh] OR "Community Mental Health Services"[Mesh] OR "Community Mental Health Centers"[Mesh]
Results: 82,631

"Mental Health"[Mesh]
Results: 16,940

"Delivery of Health Care"[Mesh] OR "Health Care Sector"[Mesh] OR "Process Assessment (Health Care)"[Mesh] OR "Outcome Assessment (Health Care)"[Mesh] OR "Health Care Costs"[Mesh] OR "Quality Assurance, Health Care"[Mesh] OR "Patient Acceptance of Health Care"[Mesh] OR "Delivery of Health Care, Integrated"[Mesh] OR "Health Care Rationing"[Mesh] OR "Quality of Health Care"[Mesh] OR "Primary Health Care"[Mesh] OR "Comprehensive Health Care"[Mesh] OR "Quality Indicators, Health Care"[Mesh] OR "Health Care Quality, Access, and Evaluation"[Mesh]
Results: 4,485,727

Figure 5 **Search strategy employed on PsychInfo database in 2011**



DE "Social Discrimination" OR DE "Stereotyped Attitudes" OR DE "Stigma"
Results: 14,811

DE "Disability Discrimination" OR DE "Stereotyped Attitudes" OR DE "Stigma"
Results: 13,131

DE "Community Mental Health Services" OR DE "Community Psychiatry" OR DE "Mental Health Personnel" OR DE "Community Mental Health" OR DE "Community Psychology" OR DE "Mental Health Services" OR DE "Psychiatric Clinics" OR DE "Mental Health"
Results: 64,206

DE "Mental Health"
Results: 29,469

DE "Health Care Utilization" OR DE "Health Care Costs" OR DE "Health Care Policy" OR DE "Health Care Economics" OR DE "Health Care Delivery" OR DE "Health Care Seeking Behavior" OR DE "Primary Health Care" OR DE "Health Personnel" OR DE "Health Care Services" OR DE "Long Term Care" OR DE "Quality of Care"
Results: 67,816

Of all the documents retrieved, 118 address discrimination in health care against people with mental health problems on grounds of their mental illness. These can be divided into those that describe self-reported and observed experiences of discrimination.

Self-reported experiences of discrimination

Of the studies retrieved that focus on self-reported experiences of discrimination, some are accounts by patients (52-71) while others are by mental health professionals (72-117). The key themes within this literature were identified by means of a process of inductive reasoning, identifying key messages in each paper and comparing them with each other. As the available literature varies extensively in terms of subjects, methods, and contexts, it is not possible to draw any generalisable inferences, but it is possible to provide some indication of the scale and nature of discrimination against those with mental illness. In the following sections, the themes that emerged are illustrated with those examples that are most illustrative of them.

Perceived discrimination in mental health care provision

A recently published study on the scale of discrimination was the INDIGO project, involving 732 individuals with schizophrenia in 27 countries (68, 71). This cross-sectional survey used a validated discrimination and stigma scale to assess self-reported discrimination in key areas of everyday life. These included making or keeping friends, intimate or sexual relationships, finding and keeping a job, applying for work, training, or education, but did not cover discrimination in mental health services specifically. However, it did inquire about the experiences of discrimination in the provision of physical care. Fifteen percent of respondents with schizophrenia reported that having that diagnosis was a disadvantage when accessing services for physical health problems, 6% when accessing services for dental problems, 6% in arranging payment for medical treatment, and 2% during pregnancy or childbirth.

A 2009 Special Eurobarometer study appraised perceptions and experiences of discrimination among the general public in 27 EU member states and the three Candidate Countries: Croatia, the Former Yugoslav Republic of Macedonia (FYROM) and Turkey (65). The study focused on the forms of discrimination that are covered by EU legislation, among which is disability, but the data are not disaggregated by type of disability. Only 8% of respondents with chronic physical or mental problems report experiencing discrimination on grounds of their disability.

A qualitative study in Germany, using focus group interviews with mental health service users explored the experience of self-reported discrimination (54) and found that "poor quality of mental health services is perceived as the strongest form of structural discrimination" (p. 306). Participants thought that this was reflected in the absence of community-based services, comprehensive treatment and rehabilitation plans, support for social integration and employment upon discharge, continuity of treatment and care between different levels of health care, as well as in inadequate crisis intervention and violations of human rights. However, only a small proportion (around 13%) of service users or mental health professionals participating in this study identified structural discrimination as a major problem. At the same time, almost 30% of carers reported experiences of structural discrimination. The authors note how such large differences in reports by these different groups raise questions about the validity and of the methods. The same research group also conducted a narrative review of recent literature and concluded that people with mental health problems who reported that they anticipated facing discrimination were less likely to seek help from health services when they would need it (62).

A cross-sectional study in the USA using a Discrimination Questionnaire, adapted from the Experience of Discrimination Questionnaire showed that of people who reported that they had experienced discrimination due to their psychiatric disability, 27.5% identified traditional mental health services as the area in which they had encountered the discrimination, compared with 9.8% in consumer-operated services (53, 56)

A 2003 study in New Zealand among people with mental health problems that used a mixture of qualitative and quantitative questions sought the most commonly reported areas of discrimination facing people with self-reported mental health problems. Among these, discrimination by mental health services was rated as the 4th most common area of discrimination (34%) (61).

A 2006-2007 qualitative study in Brazil reported on experiences of people with mental health problems of discrimination both in somatic and mental health services (66). A psychiatrist reported that patients were ignored and denied essential health care when in somatic facilities, even in life and death situations. However service users and their families also reported stigmatizing attitudes of mental health professionals – though interestingly no discriminatory practices *per se* were described.

Attitudes of mental health professionals

There is a substantial body of research on attitudes of mental health staff towards people with mental health problems (72-116). Some of these studies capture the experiences of people with mental health problems as manifest by incidents of discrimination when in contact with mental health professionals. For example, a study in England (89) found that as many as 44% of mental health service users reported having experienced discrimination by a GP, while 32% of service users had experienced discrimination from other health professionals. Another study in Germany (105) found that, of all members of the mental health team, psychiatrists had the most stigmatizing attitudes towards people with mental health problems, whom they considered more 'dangerous', less 'skilled' and more 'socially disturbing' than people without mental health problems.

A UK-based research group has developed a scale for measuring self-reported experience of stigma. It includes an item on experiences of discrimination from health professionals (though not specifically mental health professionals) on grounds of mental illness. However, the paper does not report on findings but only on the validation of the scale (117).

Yet while each of these studies identified stigmatizing attitudes by health professionals, and others showed how people with mental health problems reported experience of discrimination by mental health professionals, I was unable to find research showing that stigmatising attitudes of health professionals translated into actual discrimination, or research showing examples of such self-reported discrimination. In many instances, while service users reported they were discriminated against, the examples given were of being stigmatised.

Observed experiences of discrimination

Of the papers that address discrimination in the provision of mental health care on grounds of mental illness, few compare health care received by mental health service users with that received by those with other (physical) health problems. They concentrate on two areas of discrimination: financial accessibility to health services (insurance coverage), and access to health care for co-morbid physical health problems.

Discrimination in insurance coverage of people with mental health problems

The comparability of care packages for mental and physical disorders has been the focus of many American studies (118-162). However, these concerns are of limited relevance to Europe, where health care (including mental health care) is covered by the public health system for most of the population.

European studies focus on other two aspects of discrimination in insurance coverage for people with mental health problems. The first relates to coverage by the full range of evidence-based interventions for the treatment of mental health problems. For example, participants in the German-based study mentioned above (54) reported that the insurance package for people with mental health problems does not cover all the evidence-based interventions required for their treatment. In particular they offer limited coverage of talking therapies. The second issue raised by European studies relates to unfair budget allocation in health care, to the detriment of mental health care (139, 163). However, none of the studies retrieved systematically assess either of these two issues and thus fail to produce conclusive evidence of discrimination against people with mental health problems.

Discrimination in health care provision for co-existing physical health problems

Access to and quality of physical health care for people with mental health problems was addressed in a number of primary studies and some literature reviews.

A non-comprehensive review of literature on the physical health of people with schizophrenia found that the prevalence of somatic disorders in people with schizophrenia is higher than in the general population. This was attributed to people with mental health problems having poorer access to health care compared to people without mental health problems (164).

Other studies showed that even when people with mental health problems did access services, their physical complaints were not taken seriously, leading to poor somatic health care outcomes (54, 165-167). Excess mortality among mentally ill people was documented in a number of studies (e.g. (168-170)) and was blamed on "unhealthy lifestyles", "failed recognition and poor treatment of medical disease and poor treatment compliance" (p. 217). However, these studies do not demonstrate a direct link between poor treatment of somatic conditions and the subsequent poor health outcomes with discrimination against people with mental health problems.

The most extensive study retrieved was an assessment conducted by the UK Disability Rights Commission on physical health outcomes and access to and quality of primary health care services available to people with people with mental health problems (171). The UK Disability Rights Commission (renamed the Equality and Human Rights Commission) is an independent body established in 2000 with a mandate to monitor the implementation of anti-discrimination legislation. It has the capacity to conduct formal investigations to ensure that anti-discrimination duties are met. What is unique about this investigation is, firstly, that it used the mandate given by anti-discrimination legislation to ascertain the occurrence of discrimination. Secondly, it used as its criteria for assessment the anti-discrimination duties set out in the Disability Discrimination Act (DDA). As the authors of the report state, this is "the most comprehensive study of primary care records and mental health issues in the world (eight million primary care records), coupled with Area Studies in four areas, extensive consultation with service users and providers and evidence reviews." (p. 4). It found that people with mental health problems experience significant physical problems. However, in addition, some standard treatments and tests, such as cholesterol tests, prescription of statins for people with heart disease, and spirometry for respiratory illness, are received less often by those with mental illness than by those without. People with mental health problems experience 'diagnostic overshadowing', in which reports of physical ill health are viewed as a manifestation of the mental health problem and so are not investigated or treated. There was little or no evidence that information on the physical health needs of people with mental health problems was either regularly collated or used by commissioners to develop services. The investigation concluded that primary health care services fail to meet their legal duties under the Disability Discrimination Act, and that primary health care services discriminate against people with mental health problems.

Discrimination in provision of specialist mental health care

Several studies refer to discrimination in mental health care provision on the grounds of mental illness. Some find that people with mental health problems have limited access to mental health care (64, 68, 71, 167, 172, 173), that they choose not to seek care and not to comply with treatment (55), and that even when they do seek care, the quality of services provided is poor (174). One paper that describes well the relationship between structural stigma and discrimination, from a historical perspective on disability discrimination and its applicability in the area of mental health, confines itself to defining theoretical concepts rather than providing empirical evidence (175). While these studies note that stigma and discrimination are common, none provide clear evidence of a causal relationship with inadequate provision of care.

The World Health Report 2001 provides a list of headings under which discrimination may exist at the level of the health system, but it does not propose means of assessing any discrimination therein (Box 3).

Box 3 Indicators of discrimination at the level of the health system

Large tertiary institutions
Stigmatization, poor hospital conditions, human rights violations and high costs
Inadequate treatment and care
Primary health care
Lack of awareness, skills, training and supervision for mental health
Poorly developed infrastructure
Community mental health services
Lack of services, insufficient resources
Human resources
Lack of specialists and general health workers with the knowledge and skills to manage disorders across all levels of care
Psychotropic drugs
Inadequate supply and distribution of psychotropic drugs across all levels of care
Coordination of services
Poor coordination between services including non-health sectors

Source: The World Health Report 2001

No study was found that compared directly the experience of people with mental and somatic health problems receiving specialist care. Further, no study was found that described actual discrimination, be it direct or indirect, in mental health care on the grounds of mental illness, rather than on some other grounds.

Discussion

One of the challenges in undertaking this review was that while studies often report that people with mental health problems have experienced discrimination, they rarely specify what discrimination entails and do not define the nature or characteristics of discrimination in mental health care. In many studies, the concepts of "structural stigma", "enacted stigma", "rejection", "devaluation" and "discrimination" are used interchangeably. While the concept of stigma is widely defined and discussed, the concept of "discrimination" is not always clearly defined and the criteria for assessing its occurrence in health care are specified only, and variably, in particular areas or specific studies (e.g. primary health care, in the UK Disability Rights Commission study).

Another challenge was that while both stigma and discrimination are often cited in studies, papers commonly conflate them or focus on only stigma.

A final observation is that the available literature on discrimination in mental health care is dominated by case studies, which are ranked as low-level evidence with regard to causal relationships (e.g. (64, 167)). Also, the available reviews are typically narrative and unsystematic, making it difficult to assess their conclusions. Many of the studies identified purport to show evidence of discrimination, but most of them fail to provide it. A notable exception is the report of the UK Disability Rights Commission (171).

Conclusions

Governments throughout Europe have committed themselves to tackling discrimination against people living with mental health problems. However, the extent to which they have succeeded is questionable, as it is clear that many people with mental illness do view themselves as being discriminated against at the level of the health system. Identifying a causal chain is, however, difficult. First, studies on discrimination in mental health care mainly look at people with mental health problems who are vulnerable or marginalised in some other respect, such as race, age, gender, or genetic status, rather than on the grounds of mental illness. Second, studies showing the problems faced by people with mental health problems (independent of their other characteristics) in the provision of mental health services, and especially the short-comings of mental health care, rarely identify discrimination as the root cause of these difficulties. Third, while there is evidence that health professionals have discriminatory views and consider patients with mental illness to be stigmatized, it is not clear that this translates into discriminatory behaviour. None of the studies retrieved offer a framework for systematic identification and tackling of discrimination within the provision of mental health care on grounds of mental illness. Many studies struggled to define the boundaries between related concepts such as structural stigma, enacted stigma, or discrimination and did not define what discrimination in mental health care entails.

Chapter 3 Conceptual framework

Introduction

The previous chapters have raised concerns about the presence and extent of discrimination against those with mental illness. They suggest that those with mental illness are discriminated against in health care and that this may be a consequence of the nature of their illness. However, the research to back up these concerns has been weak; there is no doubt that people suffering from mental illness are often treated poorly but it has not been possible to establish the extent to which this is because they have mental rather than physical illness. Much of the literature on discrimination has concerned itself with other characteristics of the individual, such as their gender, age or race. The question to be answered in this thesis is whether a person with a mental illness can expect to be treated as well as someone who has the same characteristics and has an otherwise comparable physical illness. On theoretical grounds, there are reasons why this may not be the case, in particular, because of the stigma that has often been associated with mental illness. In moving forward, it is first necessary to review what is meant, in practice, by discrimination.

The concept of discrimination – a call for clarity

The concept of discrimination is defined in similar terms in dictionaries that adopt diverse disciplinary perspectives. Thus, the Oxford American Dictionary of Current English defines it as "Unfavorable treatment based on prejudice" (176). Similarly, the Oxford Dictionary of Philosophy defines it as "the unfavourable treatment of particular groups of individuals, on prejudiced and irrelevant grounds." (177). So too, the Dictionary of Economics, defines discrimination as the "Differences of treatment on what are considered irrelevant grounds." (178).

Other dictionaries elaborate on these definitions, providing insight into the reasons why discrimination occurs. Thus the Dictionary of Business defines it specifically but narrowly as "The illegal practice of treating some people less favourably than others because they are of a different sex (sexual discrimination), race (racial discrimination), or religion (religious discrimination) (179). Similarly, the definition provided by the Cambridge Advanced Learner's

Dictionary is "To treat a person or particular group of people differently, especially in a worse way from the way in which you treat other people, because of their skin colour, religion, gender, etc." (180). Banton defines discrimination as "...the differential treatment of persons supposed to belong to a particular class of persons..." (181). Thompson extends the consideration of the disadvantage that discrimination entails, stating that it is "...the process (or set of processes) by which people are allocated to particular social categories with an unequal distribution of rights, resources, opportunities and power. It is a process through which certain groups and individuals are disadvantaged and oppressed."(182).

None of these definitions, so far, mention discrimination on grounds of illness or disability. This is, however, found in the Oxford Dictionary of Law which states that "Treating one or more members of a specified group unfairly as compared with other people. Discrimination may be illegal on the grounds of sex, sexual orientation, race, religion, **disability**, or nationality" [emphasis added] (183) . This somewhat general mention of disability is developed further, in this case in relation to health care, by the Committee on Economic, Social and Cultural Rights as "any discrimination in access to health care and the underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, **physical or mental disability**, health status (including HIV/AIDS), sexual orientation, civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health" [emphasis added] (184) (para. 18). In this case, both physical *and* mental disabilities are specified.

Historically, the first step in combating discrimination was to recognise that it existed. However, it soon became clear that this would not be enough and that legislation would be necessary. This process was exemplified in the struggle for racial equality in the USA, leading to the passage of the 1964 Civil Rights Act that has banned discrimination based on "race, color, religion, sex or national origin" in employment practices and public accommodations (185) (titles VI, VII). This was followed, in 1965, by the International Convention on the Elimination of All Forms of Racial Discrimination, as well as by a wide range of legislation in many individual countries, progressively extending the concept of discrimination and the groups that it is illegal to discriminate against. It was, however, some time before illness or disability was included, illustrated by the 26-year gap between the passage by the US Congress of the Civil Rights Act and the 1990 Americans with Disabilities Act (186).

At the level of the European Union there have been a number of laws on discrimination. However, it is only in respect of employment and training that the criterion of disability is included, among racial or ethnic origin, sexual orientation, religion or belief, and age. In other areas such as education, social security, health care, access to goods and services and housing, the scope of discrimination is more circumscribed to include only racial discrimination. A draft directive "...on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation" was introduced in July 2008 but is still stuck in the legislative process (187).

The enactment of legislation on discrimination required that certain characteristics of discrimination be defined more precisely than had been the case previously. First, it recognised that discrimination can take a number of forms, some more obvious than others. Specifically, as set out in, for example, the two EU directives, Directive 2000/43/EC (23) (Article 2, paragraph 1, a and b) and Directive 2000/78/EC (24) on discrimination, it can be direct or indirect[a]. These are defined as follows:

"a) direct discrimination shall be taken to occur where one person is treated less favourably than another is, has been or would be treated in a comparable situation, on any of the grounds referred to in Article 1"; and

"b) indirect discrimination shall be taken to occur where an apparently neutral provision, criterion or practice would put persons having a particular religion or belief, a particular disability, a particular age, or a particular sexual orientation at a particular disadvantage compared with other persons unless: (i) that provision, criterion or practice is objectively justified by a legitimate aim and the means of achieving that aim are appropriate and necessary, or (ii) as regards, persons with a particular disability, the employer or any person or organisation to whom Directive applies, is obliged, under national legislation, to take appropriate measures in line with the principles contained in Article 5 in order to eliminate disadvantages entailed by such provision, criteria or practice."

Second, the legislation had to state explicitly how discrimination would be recognised. For example, the EU Directives require the presence of two elements *sine qua non* for unlawful discrimination to be present.

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[a] Directive 2000/78/EC covers the grounds of religion or belief, disability, age or sexual orientation as regards employment and occupation, Directive 2000/43/EC covers the grounds of race or ethnicity as regards education, social security, health care, access to goods and services and housing.

The first element is harm. In the case of direct discrimination, this is manifest as the less favourable treatment of one person than another in a similar, comparable situation. In the case of indirect discrimination, the harm is manifest as a disadvantage unduly affecting a particular group of people, resulting from measures that are apparently neutral.

The second element is causation. It must be shown that harm was inflicted on the individual or group because they had some explicit characteristic. As noted above, the potential characteristics are race or ethnicity, religion or belief, disability, sexual orientation, and age. However, the EU legislation fails to explain why these characteristics were chosen among the many that could define vulnerable and marginalized groups.

It is also important to be clear about what is not needed to demonstrate the presence of discrimination. There is no need, according to the EU Directives, to prove intentionality. The European Court of Justice has established that "All that has to be established is that "but-for" their race, religion, or the like, they would have received more favourable treatment. ... Of course, it needs to be added that there may be a malign motive for either direct or indirect discrimination" (188) (p. 12).

In summary, therefore, I have shown how the concept of discrimination has evolved to establish explicit criteria for ascertaining its presence. In the EU legislation these are that harm must result and that this must be caused by the characteristics of the individual or group. Whether this is intentional or not is irrelevant. Although much of the existing European legislation does not specify disability, including mental disability, as grounds for determining whether unlawful discrimination is taking place, the principles that have been used in determining the presence of racial, age or sexual discrimination can equally be applied to mental illness.

I can now consider how to operationalize these concepts as they relate to the care of those with mental illness. First, it is necessary to identify individuals and groups who are similar, and in comparable situations, *other than* the presence of mental illness. It is not sufficient to compare the treatment of those with mental illness with those who do not. The simple facts of being unwell and seeking care differentiate someone from those not in this position and impose both obligations and rights (189). For the present purposes, therefore, it is appropriate to compare the treatment of those with mental illness with individuals who also require health care but do not have mental illness.

Second, and equally important, it is necessary to recognise that, within the population seeking health care, there will be many people with quite different needs. It is important that health care respects these different needs. All patients should not be treated in exactly the same way simply because they are patients. However, to the extent that their needs are similar, then they should be treated in the same way. In other words, equal needs should be treated equally but unequal needs may be treated unequally. This takes us to the concept of equity and, in particular, its two dimensions, horizontal and vertical equity.

Inequity as the harm of discrimination

In this section I will examine the concept of inequity. The Oxford English Dictionary defines equity as "the quality of being fair and impartial" (190) and the Merriam-Webster Online Dictionary (191) notes that equity implies "freedom from bias or favouritism". Equity is the concept, or idea, of fairness or justice that is being applied in different fields. In economics, it refers to the idea of fairness, particularly with regards to taxation or welfare systems. In health care, it is one of the dimensions of health care quality, along with effectiveness, efficiency and humanity (192).

Equity is closely linked to human rights. The WHO Health for All policy document notes: "In considering equity in the legal human rights framework, the importance of providing equal opportunities for health becomes evident. Inequity in health status refers to differences that are not only systematic and quantifiable but avoidable as well. Inequity thus refers to differences that are unfair and avoidable. Equity is a normative ethical value that entails fair distribution of resources and access within and among various population groups." (192) (p.34).

Equity has been defined and operationalized in a variety of ways, in some respects reflecting the diversity seen in definitions and specifications of discrimination. Thus, the International Society for Equity in Health (ISEqH) defines equity as "the absence of systematic and potentially remediable differences in one or more aspects of health status" and then specifies that these may exist "across populations or population subgroups defined socially, economically, demographically, or geographically"(193). Importantly, this definition does not include the nature of the individual's illness.

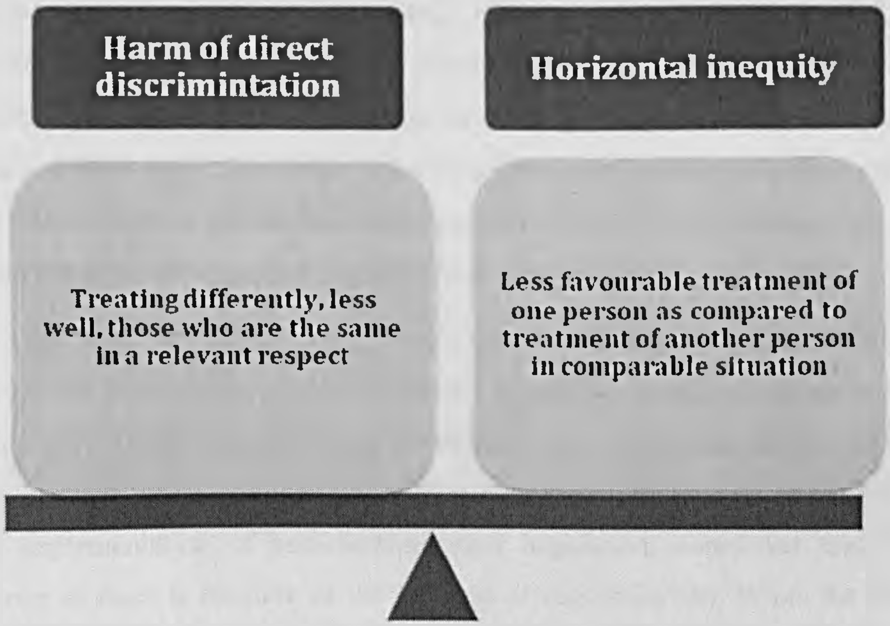
Other definitions say rather less about the determinants of inequity. Thus, in the WHO document "Equity and Ethics in Health" (194), Margaret Whitehead states that "Equity in health implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that no one should be disadvantaged from achieving this potential, if it can be avoided." (p. 2) She adds that inequities in health "are not only unnecessary and avoidable, but, in addition, are considered unfair and unjust" and that equity in health care implies "equal access to available care for equal need, equal utilisation for equal need, equal quality of care for all". However, she does not specify the characteristics that might lead to individuals being treated inequitably.

At this point, it is important to note that equity is not the same as equality. This has led to the conceptualisation of two dimensions of equity. The Dictionary of the Social Sciences states that "Horizontal equity refers to treating similar individuals similarly" whereas "Vertical equity refers to distribution according to differences in relevant circumstances ..." or, in other words, treating individuals differently according to their needs (195).

In the present context, therefore, treatment of two groups of patients will be horizontally equitable where it meets those of their needs that are similar in the same way. It will be vertically equitable where it provides treatment that is sensitive and appropriate to their different needs. In other words, someone who is a patient in a hospital ward can expect that their environment will be clean and comfortable regardless of their age, race, sex or illness, although the facilities used to treat someone in great distress due to an acute psychosis may be different from those used to diagnose someone undergoing routine investigations for a suspected a physical disorder but who is otherwise well.

The concept of inequity, with its two dimensions, can help to operationalize the harm that is associated with discrimination, and which, in the literature on discrimination is often poorly and variably defined. Direct discrimination is intrinsically horizontally inequitable, in that it results in two people being treated differently, despite having similar needs (Figure 6). Indirect discrimination can lead to people who have needs that are different from the majority being disadvantaged because the system is tailored to the needs of the majority, thus giving rise to vertical inequity (Figure 7).

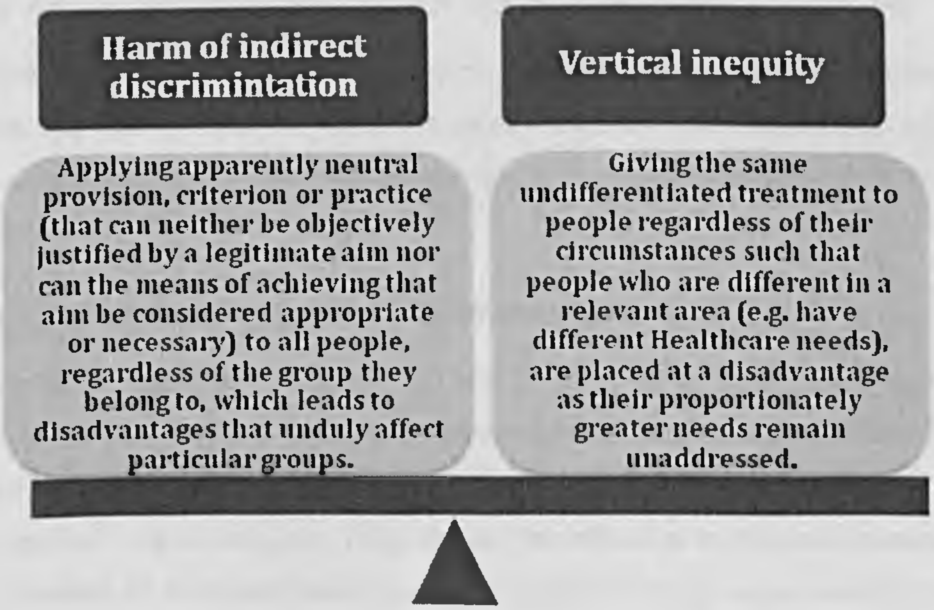
Figure 6 **Horizontal inequity, consistent with the harm of direct discrimination**



Treating differently, less well, those who are the same in a relevant respect

Less favourable treatment of one person as compared to treatment of another person in comparable situation

Figure 7 **Vertical inequity, consistent with the harm of indirect discrimination**



Applying apparently neutral provision, criterion or practice (that can neither be objectively justified by a legitimate aim nor can the means of achieving that aim be considered appropriate or necessary) to all people, regardless of the group they belong to, which leads to disadvantages that unduly affect particular groups.

Giving the same undifferentiated treatment to people regardless of their circumstances such that people who are different in a relevant area (e.g. have different Healthcare needs), are placed at a disadvantage as their proportionately greater needs remain unaddressed.

Having established the correspondence between discrimination and inequity, it is next necessary to explore the grounds on which individuals might be discriminated against, or treated inequitably. To constitute discrimination, for example as in the EU legislation, one would have to demonstrate that "but-for" the race, religion, or other defined characteristics, individuals and groups would receive more favourable treatment than they actually do. The review of the literature on discrimination identified a large number of such characteristics that give rise to discrimination and unequal treatment. But how were they selected?

The choice is not easy. For example, the EU legislation lists a series of protected groups, defined on grounds of race or ethnicity, religion or belief, disability, sexual orientation and age, but it fails to clarify why these subgroups need protection against discrimination or why they were selected while others were excluded. A review commissioned by DG EMPLOY, assessing progress in implementation of anti-discrimination legislation, concluded that "Difficulties emerge as soon as there is mention of the grounds of discrimination. While the directives are explicit about a certain number of characteristics to be considered as grounds of discrimination, they do not provide a definition, and the list is neither exhaustive nor limited in scope. (...) For several grounds of discrimination, in particular those related to race and ethnic origin, the groups that can be considered discriminated-against minorities are not necessarily the same from one country to the next and are not designated via identical lexical means."(196) (p. 24).

A common characteristic of all of the groups identified as subject to discrimination in EU legislation, and others, is that they are, to a greater or lesser extent, stigmatised. Consequently, the next section will examine in detail the concept of stigma and its relevance to the emergence of discrimination.

Stigma – the underlying grounds for discrimination

Erving Goffman stated that "Stigma has been thought of as an attribute that is 'deeply discrediting' so that stigmatized persons are regarded as being of less value and 'spoiled' by three kinds of stigmatizing conditions: 'abominations' of the body, such as physical deformities, 'tribal identities' such as **race, sex, religion, and 'blemishes of individual character' such as mental disorder or unemployment**" [emphasis added] (197). It is noteworthy that Goffman includes mental disorder among the more common characteristics associated with those suffering discrimination.

A key aspect of stigma is its visibility. Goffman described how the term "stigma" originated in ancient Greece and referred to "bodily signs designed to expose something unusual and bad about the moral status of the signifier: The signs were cut or burned into the body and advertised that the bearer was a slave, a criminal, or a traitor – a blemished person, ritually polluted, to be avoided, especially in public places.". This idea of stigma as a way of marking someone out as different was reinforced by Hinshaw. He describes how the "term stigma connotes a deep mark of shame and degradation carried by a person as a function of being member of a devaluated social group. Stigmatization encompasses those interpersonal processes whereby other members come to devalue the group or characteristics in question and begin to interpret all of the person's attributes and characteristics in terms of this flawed identity." (198) (p.26).

Nowadays, however, the concept of stigma has become somewhat diluted, coming to mean "any attribute, trait or disorder that marks an individual as being unacceptably different from the "normal" people with whom he or she routinely interacts" (199) (p. 10). This may arise from a process of "labelling, stereotyping, separation, status loss and discrimination"(200) (p. 367). However, Hinshaw argues that while "The process of stigmatization draws upon stereotyping, prejudice and discrimination" it also "goes further, invoking notions of a fundamental mark or stain related to membership in a devalued group. When individuals are stigmatized, social interactions may be strained as a result of the "marked" attribute or the fear of its emergence (as is often the case for concealable stigmas). Stigma also has a major impact on the self-perceptions and coping styles of those who are its recipients, reverberating throughout families and communities."(198) (p.157-158). Thornicroft notes how stigma "elicits some form of community sanction."(199) (p. 10) In this way, stigma is linked to attitudes, and while discrimination is linked to behaviours. As such, discrimination is a form of "enacted stigma"(201).

The nature of stigma relates to its "'visibility', or how obvious the mark is, 'controllability', which relates to the origin or the reason for the mark and whether it is under the control of the bearer, and 'impact' or how much those who do the stigmatizing fear the stigmatized"(202) . Arboleda-Florez notes that the higher the scores for each of these 3 characteristics, the greater the stigma (203). Hinshaw adds three other dimensions of the concept: course/chronicity, disruptiveness, peril/danger (198).

Stigma is not, however, a "static concept" and the attributes that give rise to it vary across societies, cultures and times. "Stigma develops within a social matrix of relationships and interactions so that new conditions could be stigmatizing and conditions that may be stigmatizing at one time or within a given culture, could become accepted later so that their bearers stop being stigmatized." (203) (p.3). "Stigma is both universal and specific to individual cultures. All societies and cultures are motivated to find out groups to degrade and stigmatize, but the specific forms of what constitutes deviance vary across cultures and over time" (198) (p.26). However, in Christianity visible injuries to Christ and the saints (stigmata) became seen as marks of holiness. Similarly, in contemporary youth culture, images and clothing seen by the mainstream population as signifying anti-social behaviour are worn as badges of honour.

In the present context, it is important to recognise that mental illness is not stigmatised in all societies and, indeed, in some, especially those adhering to shamanistic beliefs, sufferers may be attributed with privileged status.

The impact of stigma

The consequences of stigma can be profoundly damaging. Often used as "a license to the societal majority to perpetuate and escalate their judgemental attitudes and responses" (198) (p.24), stigma can lead to violations of human rights, hinder access to health care, employment and housing (26), [55], (204). "When perceivers begin to view a devalued, marked and stigmatized person as less than fully human, the potential for punitive and even deadly responses is not far behind. Perceptions of sub-humanity will come to justify exclusionary and, at times, lethal responses on the part of those with social power, in that the victim is seen to lack the fundamental attributes that would mandate any form of respect. "(198) (p.26).

Stigma becomes important when there is an imbalance of power between two groups, as in the providers and recipients of health care. Link and Phelan highlight how "it takes power to stigmatize" (200) (p.375). Hinshaw notes that "When low-status individuals within a society gossip or verbally degrade those of higher status, there are typically no important social consequences; it is only when those in power devalue others that stigma occurs. As power shifts, however, formerly stigmatized traits and attributes may be upgraded in status, signalling that there is malleability in stigma processes" (198) (p.25). Therefore "Stigma occurs when negative and prejudicial attributes are accepted by the dominant culture as defining the stigmatized person, and become ascribed to all members of the group."(205) (p. 8). This is why people who are stigmatized need to be protected, for example by anti-discrimination legislation.

Thus, stigmatization occurs when the mainstream population, in a power position, considers the characteristic marks (such as the dark colour of the skin, or the preference for the same sex, or the diagnosis of a mental disorder) of a particular group in society that has lower influence and power in the society, to be disgraceful, signalling the flawed, deviant nature of the bearer. The mainstream population therefore considers people bearing these marks as less worthy or in some way degraded or devaluated.

In summary, I have characterised discrimination as involving harm to individuals or groups caused by certain of their characteristics. The presence of harm can be demonstrated by identifying either horizontal inequity, whereby individuals are treated differently from others who have the same needs, or vertical inequity, whereby the different needs of individuals are not recognised, causing some of them to be disadvantaged. I then examined the characteristics that lead people to be discriminated against and concluded that this is often because they bear a particular stigma, or visible sign that differentiates them from others.

Levels of discrimination: individual versus institutional discrimination

Discrimination can occur both at an individual level and at a structural, or institutional, level. Individual/interpersonal discrimination happens when individuals (or single institutions) use different rules for stigmatized groups, by choosing to ignore the rules.

- "Individual discrimination refers to the behaviour of individuals that is intended to have a differential or harmful effect on the members of a stigmatized group" (62) (p. 32).
- "Interpersonal discrimination refers to discriminatory interactions between individuals, which usually can be directly perceived" (206) (p.624).

On the other hand, institutional discrimination refers to laws, policies, rules or practices of organizations (such as within educational systems, employment, financial institutions, or social agencies) that are unfair to a social group (whether based on race, ethnicity, age, sex, religion, and so forth), or have the effect of placing that social group at a significant disadvantage for reasons that are not based on equality, fairness and human rights (207, 208).

- "Structural discrimination involves processes that typically represent collective and macrolevel units rather than individuals; for example, how the insurance systems of national governments limit mental health benefits. The aggregate of individual properties serves as an index of macrolevel constructs" (55) (p.619).

Institutional/structural discrimination is systematic - it is built into laws, policies, and rules as well as institutional practices ("the way we do things around here"). Unless specifically sought, it may remain invisible as incidents of discrimination can appear as isolated or random events. It is only when a broader analysis reveals that these events are part of a generalised pattern.

The concept of institutional discrimination has been especially well documented in the non-health literature. The *Stephen Lawrence Inquiry Report* defined the related concept of institutional racism as "the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtless, and racist stereotyping which disadvantage minority ethnic people."(209) (para. 6.34). This concept has since been extended into other sectors, revealing evidence of how ethnic minorities often receive unfair treatment in areas as diverse as mortgage acquisition, wages, and job opportunities, illustrating the extent of direct institutional discrimination. They reside in poorer quality and more overcrowded accommodation, work in less desirable occupations and experience longer periods of unemployment than their ethnic majority counterparts (206, 209).

This phenomenon links to the definition used by the Oxford Dictionary of Sociology whereby "discrimination against some groups in society can result from the majority simply adhering unthinkingly to the existing organizational and institutional rules or social norms." (210). As institutional discrimination is often built into the normal working processes of institutions, its perpetuation requires only that people continue with "business as usual." Its eradication requires much more than good will; it requires active review of the assumptions and practices by which the institution operates and changes to those found to have discriminatory results (211).

Recalling the earlier differentiation of direct and indirect discrimination, direct institutional discrimination is the process whereby institutions employ intentionally discriminatory practices, which are purposefully carried out by their individual representatives, acting on the institution's behalf. Indirect institutionalized discrimination is not purposely meant to be harmful to a group, yet nonetheless has a negative impact on a minority group. For example, institutions that use hiring practices and standards that are traditionally disadvantageous to a particular group may not be intentionally biased against that group, yet such practices may result in discrimination by presenting unrealistic barriers which cannot be easily be overcome by those facing historical disadvantage (212).

To conclude, institutional discrimination is embedded into the structures, processes and procedures of organizations and institutions. It is not an isolated, random event, but rather a systematic phenomenon - it is built into the laws, rules and regulations and procedures of institutions.

Direct institutional discrimination – against whom, in which health care setting and in which country?

Having defined the concept of discrimination and set out the means by which to operationalize it, it is apparent that discrimination is a complex phenomenon and a comprehensive analysis is beyond the scope of a single PhD. In selecting aspects to study, certain criteria were employed. First, how easy is it to observe the discrimination? Direct discrimination will be easier to observe; indirect discrimination is often more subtle. Institutional discrimination can be observed through the study of legislation and policies, whereas individual discrimination requires prolonged observation of the behaviour of health professionals and other decision-makers, an approach complicated by the likelihood that they will adopt different behaviours when they are being observed. For these reasons, this thesis will focus on direct institutional discrimination.

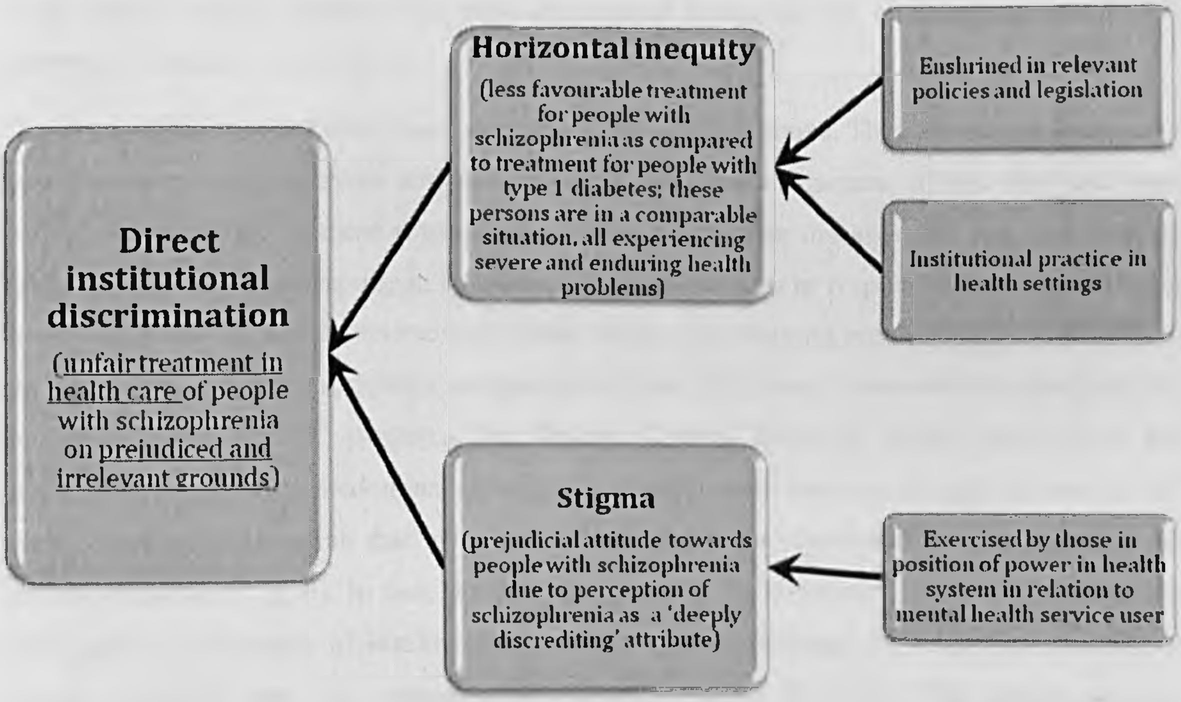
Research hypothesis

The aim of this thesis is to ascertain the extent and nature of any direct institutional discrimination against people with mental illness in specialist health care settings in Romania. The hypothesis is that such discrimination exists and results from the stigmatisation of mental illness.

As already noted, to establish this it is necessary to identify two groups, those with a mental illness and those with a physical illness that is, as far as possible, similar in terms of health needs. The criteria for selection are that the conditions should: a) be sufficiently common and have clear diagnostic criteria; and b) should involve long-term treatment requiring inputs from a range of professionals in different settings. It is important to compare the actual management of each, rather than comparing what should happen with some sort of gold standard, such as that set out in clinical guidelines (although obviously these should inform the comparison) so that the analysis can control, as far as possible, for the underlying characteristics of the health system. The rationale for the choice of conditions selected is set out below.

The hypothesis will be tested in two stages (Figure 8). The first operationalizes the concept of institutional discrimination by seeking the presence of horizontal inequity in the structures and processes of specialist health care settings. The second enquires whether persons in a position of power and influence in specialist mental health services stigmatise their patients.

Figure 8 Hypotheses tested in the thesis



Choice of health conditions

For the purposes of this thesis, it was necessary to identify two conditions, one relating to mental health and one somatic. These should be chronic conditions for whom those affected will have substantial experience with interactions at all levels of the health system, from primary to specialist and in outpatient and inpatient (short and long-term) settings. From among the large group of mental health problems that could have been selected, I chose schizophrenia, for the reasons described below. The choice of comparator condition was not easy. I wanted to select a condition that is quintessentially somatic, so that it could be clearly differentiated from a mental condition. As such, I excluded neurological conditions. The potential chronic somatic conditions included diabetes (type 1 and 2) cardiovascular disorders, respiratory disorders, and cancers. However, unlike schizophrenia, most of these conditions, with the exception of type 1 diabetes, develop during adult life, and their onset is in most cases linked to exposure to defined risk factors, such as smoking, poor diet, lack of physical exercise. As such, they were not ideal comparators with schizophrenia. Also, the prevalence rates of type 2 diabetes, cardiovascular disorders, respiratory disorders, or cancers is significantly higher than that of schizophrenia, so that they occupy more of the mainstream of health services. As such, their management within health system is often prioritised not only over mental illness but also other somatic conditions, rendering themunfair comparators.

The two conditions selected for study meet the criteria set out above. They are schizophrenia and type 1 diabetes. Schizophrenia and diabetes are both chronic diseases, in that they are long-lasting and recurrent. In these respects they differ from acute diseases that are short-lasting, either because they result rapidly in recovery, being self-limiting or responsive to treatment, or in death. Traditionally, health services have been designed to respond predominantly to the latter, not least because, beyond sympathy and general support, there were few treatments available for the former until the 20th century. The Disease Control Priorities Project highlighted the 'convergence towards a predominance of non-communicable diseases in most regions of the world', arguing for research that will "deliver[ing] important interventions that might rely on lifelong medication" (213). In fact, the turning point may be considered to have taken place in 1921, with the discovery of insulin, while safe and effective drugs for schizophrenia did not become available until the synthesis of Chloropromazine in 1950. The definitions and epidemiology of the two conditions are described below, along with the rationale for their selection.

Why schizophrenia?

According to the WHO International Statistical Classification of Diseases (214), "schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and affects that are inappropriate or blunted. Clear consciousness and intellectual capacity are usually maintained although certain cognitive deficits may evolve in the course of time. The most important psychopathological phenomena include thought echo; thought insertion or withdrawal; thought broadcasting; delusional perception and delusions of control; influence or passivity; hallucinatory voices commenting or discussing the patient in the third person; thought disorders and negative symptoms. The course of schizophrenic disorders can be either continuous, or episodic with progressive or stable deficit, or there can be one or more episodes with complete or incomplete remission.".

Though not the most common mental health disorder, the prevalence of schizophrenia in European countries is similar, regardless of the economic status or political system. It is one of the most debilitating psychiatric conditions, posing a great burden on the affected individuals, their families, the health system and society. Its management requires a combination of interventions including medication, psychosocial interventions, social care, support to facilitate recovery and rehabilitation. This requires collaboration from a complex team of professionals including psychiatrists, psychologists, social workers and occupational therapists. The quality of life of people with schizophrenia is highly dependent on the quality of services made available to them.

As a severe and enduring condition, schizophrenia is considered to be one of the most stigmatized mental disorders. The World Psychiatric Association made one of its priorities to tackle stigma faced by people with schizophrenia from the population as well as by health professionals (215-217). All this makes schizophrenia a good choice given the aims of this research, as it is a highly stigmatised chronic condition.

Why type 1 diabetes?

The comparator condition employed in this thesis is type 1 diabetes. This is a chronic disease that occurs when the pancreas does not produce enough insulin, or alternatively, when the body cannot effectively use the insulin it produces. It is a life-long condition and requires daily treatment with insulin, coupled with careful management of diet (with both having to be adjusted to take account of, for example, exercise and intercurrent illness). Diabetes often results in a series of complications affecting, among others, the cardiovascular, renal and nervous systems and eyes. It can also cause acute emergencies due to high or low blood glucose levels (218). The onset of type 1 diabetes is typically in childhood.

Diabetes has been used as a tracer condition that allows the identification of weaknesses within the health care system, offering insights into its performance (219), for several reasons. Firstly, type 1 diabetes is a distinct condition that is rapidly diagnosed; there is no large pool of undiagnosed sufferers and those affected can be easily identified from health professionals. Secondly, prognosis of patients with diabetes is directly linked to the quality of the health care they receive. If inadequately treated, in time diabetes can lead to a variety of health problems affecting the heart, blood vessels, eyes, kidneys and nerves. To prevent the onset of these complications it is necessary that the patient have access to a well-functioning health care system, where different segments of care are well-coordinated. Therefore, the better the health care system, the better the chance that someone with diabetes is able to live a long and relatively normal life, being able to manage his/her health problems efficiently.

Type 1 diabetes thus represents a common chronic physical condition whose management has much in common with schizophrenia, a chronic mental condition. First, the point prevalence in Europe of type 1 diabetes (about 4.8 million people) is comparable with that of schizophrenia (4.3 million people) (2). Also, the twentieth century saw enormous changes in the management of both conditions. In 1921, the discovery of insulin by Banting and Best transformed type 1 diabetes from a rapidly fatal disease of childhood to one compatible with a normal life expectancy, albeit one requiring a complex package of multi-disciplinary care as well as an active role of the patient in self-management (220). The discovery, in the 1960s, of neuroleptics (221), similarly transformed the clinical management of schizophrenia (222).

While there are obviously many specific aspects of treatment that are different, such as the medications used, the key elements of care are functionally the same both for schizophrenia and type 1 diabetes. Thus, optimal management of both diseases requires ready access to appropriately equipped facilities, staffed by appropriately qualified health professionals. Both require the integrated efforts of a team of health professionals. In the case of diabetes this includes some that are medically qualified, such as endocrinologists, some with specialist nursing training and some from other professions, such as dieticians and chiropodists. In the case of schizophrenia the same broad categories are required but the details differ. In this case the physicians are psychiatrists, the nurses have specialist qualifications in mental health, and the other professionals include psychologists, psychiatric social workers and occupational therapists.

Choice of health care settings

The next question relates to the settings in which to undertake the research. Evidence from many European countries indicates that those with severe and enduring mental health problems do not receive the specific treatment for their condition in primary care (223). While in some countries, general practitioners do identify, diagnose and, in mild cases, treat people with diabetes and common mental health problems, in Romania most treatment for severe disorders is undertaken by specialists, with GPs playing at most a supportive role. For this reason, the research will be undertaken in facilities providing specialist services.

Rationale for selecting Romania as research setting

The country in which this research is undertaken is Romania, a transitional country that joined the European Union in January 2007. It still relies heavily on traditional systems of treatment and care for people with mental health problems, and is struggling to introduce nationwide reform. A former communist country, it endured arguably one of the harshest dictatorial regimes during the 1970s and 1980s. It was also among the most isolated of the eastern European countries, with very limited access to international literature and thinking. After the political changes at the end of the 1980s, the country went through a process of transition that proceeded much more slowly than in its neighbours and which was characterised by widespread corruption.

Like many of the former communist countries of Eastern Europe and the former Soviet Union, Romania is engaged in a process of reforming its mental health systems, looking to Western countries for models of good practice. In spite of sustained international support (e.g. through its participation in the Stability Pact, a sub-regional initiative sponsored by the WHO, the Council of Europe and a number of Western European governments) little had been done by the time this research was initiated. At that point Romania was in the process of acceding to the European Union and was subject to a specific requirement to tackle the poor quality of care for people with mental health problems, many of whom experienced grave human rights abuses. In 2006, a WHO report of an assessment mission to Romania, identified discrimination as one of the key reasons for the poor conditions of people with mental disorders in Romania, compared with others interacting with the health system (224). In 2000, Romania adopted anti-discrimination legislation that protects people from vulnerable and marginalised groups against direct and indirect discrimination in a number of areas, including health care (225). Among these groups, the legislation includes people with chronic non-communicable diseases and people with disabilities, both encompassing people with schizophrenia.

Criteria for assessing inequity and stigma

A framework for assessing quality of care for patients with complex chronic disorders

The classic starting point for assessing quality of care is Donabedian's structure-process-outcome framework (226). This is readily applicable to the current research.

Structure designates the conditions under which care is provided (the way in which the health system is set up) and includes:

1) material resources (e.g. facilities and equipment);
2) human resources (numbers, variety, qualifications);
3) organisational characteristics (the organisation of medical and nursing staff, kinds of supervision and performance reviews, methods of paying for care).

Process refers to activities that constitute health care including diagnosis, treatment, rehabilitation, prevention, patient education. This is usually carried out by professionals but also includes service users and carers. It also refers to such factors as what was done to a patient, how the health team operates, how clinical guidelines are used, measures of waiting time, and quality of record keeping and communication.

Outcomes refer to the change in the parameter being measured, most often health status. This is, however, beyond the scope of this project given the time frame, the challenges in applying validated measures, and the many potential confounding factors.

However, while this model is helpful in thinking through the scope of what needs to be included, it should not be seen as a rigid blueprint for assessment. Consequently, I have grouped them into meaningful categories for use in the research. In doing so, I have drawn upon a large number of international guidelines and recommendations. These are listed in Annex 2.

There is a striking difference between documents setting out standards for the care of schizophrenia and diabetes. Much of the guidance and recommendations on mental illness begin from an implicit assumption that those suffering from these disorders will be disadvantaged in many different ways. Consequently, they set out in considerable detail the basic elements of treatment that many would expect for someone with any disorder, whether mental or physical. These include, even if not always explicit, beneficence (doing good), non-malificence (not doing harm), dignity, and autonomy. These have often been operationalized in guidance on mental health, for example, by specifying that people will be treated in decent facilities by trained staff who respect their human rights. In contrast, guidance on diabetes simply takes this for granted, perhaps because such considerations can be found in many generic charters of patient rights and similar documents.

Another implicit assumption is that mental illness will be accorded a very low priority, especially compared with physical illness. Consequently, they typically include preambles setting out the burden of disease attributable to mental illness and evidence that the response is inadequate. In contrast, guidance on diabetes, with the singular exception of the St. Vincent Declaration, simply assumes that policy makers will recognise the importance of putting in place systems to respond to diabetes.

A further difference, reflecting the different emphasis of the two types of guidance, is that recommendations on diabetes contain much more content that is specific to diabetes, such as the detail of insulin regimes. There is also a difference in the extent to which each type of guidance uses evidence, which is generally much more explicit for diabetes, whereas that for mental illness more often appeals to values. Finally, there is a high degree of consensus (indeed virtual unanimity, after taking account of the timing of guidance in the light of emerging evidence) on the management of diabetes, while this is not the case for mental illness. Thus, not all of the policies of international bodies are endorsed by organisations representing users and carers. For example, the UN Principles of the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (MI Principles) have been criticised heavily in a Position Paper issued by the World Network of Users and Survivors of Psychiatry (WNUSP), which rejects the MI Principles and even called for their revocation on the basis that, in their (WNUSP) view, they promote the dominance of the medical model (by using the term "patient" and by specifying medication as the only type of treatment), that they endorse involuntary detention and treatment, contravening thus the Universal Declaration of Human Rights, and that they fail to take adequate account of citizen's rights.

The following sections represent the distillation of what emerge as key themes from this guidance. For the reasons set out in the previous paragraphs, most are stated explicitly in the guidance on the management of mental illness, but are implied from the guidance on diabetes. Clearly, the relative importance of each theme may differ for the two conditions but those selected are, to some extent, applicable to both. These issues have been operationalized to produce a set of criteria for assessing those aspects of the care of patients attending specialist facilities in Romania who have diabetes or schizophrenia (Box 4). The criteria that will be used in the research are as follows. Each of these will then be expanded on in the subsequent paragraphs.

Box 4 Criteria for assessing aspects of care that are equally applicable to the management of schizophrenia and diabetes

1. **Accessibility of specialist services**
    - 1.1. Access to care in the least restrictive environment/ community-based settings (S)
    - 1.2. Geographical accessibility of services (S)
    - 1.3. Access to services when needed (opening hours/ out of hours staffing) (S/P)
    - 1.4. Access to different parts of the system, as needed (Referral system) (P)
    - 1.5. Financial access to services (financial affordability) (S/P)

2. **Availability of evidence-based treatment and care**
    - 2.1. Availability of medication (S/P)
    - 2.2. Availability of other evidence-based interventions (P)
    - 2.3. Social care (P)
    - 2.4. Physical health (P)
    - 2.5. Availability of enough staff in all settings (S)
    - 2.6. Availability of multidisciplinary teams with good representation of each professional category (S)

3. **Delivery of care**
    - 3.1. Individual treatment plan developed for each patient, in the basis of a holistic assessment, service users participate in the development of the treatment plan and are given a choice of treatment when appropriate (P)
    - 3.2. Presence of discharge procedures (P)
    - 3.3. Continuity of care (P)
    - 3.4. Staff has the appropriate competencies and skills (S)
    - 3.5. Empowered to care for themselves and live an as independent life as possible/ Personal autonomy (P)
    - 3.6. Involvement of service users in shaping the services (P)
    - 3.7. Involvement of families and carers (P)

4. **Quality of facilities**
    - 4.1. Protection of patient's privacy and safety, decent living environment (S)
    - 4.2. Presence of appropriate treatment facilities (S)
    - 4.3. Hygiene (S/P)
    - 4.4. Food and drinks (S)

5. **Protection of human and civil rights**
    - 5.1. Right to respect of all human and civil rights on mental health facilities (P)
    - 5.2. Right to informed consent to treatment (P)
    - 5.3. Right to confidentiality (P)
    - 5.4. Right to information (P)
    - 5.5. Right to access to personal information (P)
    - 5.6. Right to notice of rights (P)
    - 5.7. Treatment sensitive to needs of minorities and those with different cultural and religious backgrounds (P)

Note: S = structure; P = process measures.

Patients should have access to relevant services and treatment. Neither should find their access to care limited by financial factors (1.5) physical distance (1.2) or opening hours (1.3) from services. Their treatment should restrict them as little as possible from leading a normal life (1.1, 3.6). Thus, where possible, those with schizophrenia should be managed in the community while those with diabetes should not be required to spend periods in hospital to undergo annual assessments, as happens in some former Soviet countries (227). Similarly, diabetes treatment regimes should enable patients to adapt their diets and insulin to accommodate a varied lifestyle.

Treatment should be based on the best available evidence (2). This means that patients with schizophrenia should have access to a range of medical and psychosocial interventions; those with diabetes should have access not only to insulin but also to the testing equipment that allows them to monitor their condition (2.1 and 2.2). There should be an adequate supply of essential drugs (2.1), appropriate to the patients being treated, and there should be scope to manage co-morbid conditions (2.4).

Patients with chronic disorders should also benefit from adequate social protection (2.3), which should, ideally, be integrated with the health care system. The precise nature of these arrangements is not, however, specified in international guidance. However, some broad recommendations exist. For example, disability benefits should be provided for persons with mental disorders at similar rates to those granted to people with physical disabilities, and in countries that have public or private health insurance schemes (2.3), legislation should ensure that people with mental disorders are able to obtain adequate insurance coverage for the treatment of both mental and physical conditions (1.5).

Guidance on both conditions identifies the importance of sufficient well trained, multidisciplinary staff (2.5), evenly distributed across different levels of services and across geographical areas. They should have the relevant competencies to cope with changing demands and adopt new models of service delivery that facilitate integration of services, multidisciplinary approaches (2.6) and inter-sectoral collaboration. To ensure that this occurs, staff should be provided with training that matches the required competencies, adapted to the context in which they are working (3.4).

Patients are expected to benefit from holistic (3.1) and sufficiently frequent assessments, to participate in the development of their treatment plans and only receive treatment following their informed consent (5.2).

Although equally applicable to diabetes and schizophrenia, guidance on diabetes has placed greater emphasis on continuity of care (3.3) across all tiers of the health system (1.4) and bridging the gap between episodes of care (3.2). This is exemplified by the Chronic Care Model, initially developed for the management of diabetes, which now underpins various models of long-term care (228-230).

Service users should be involved in shaping the services they receive (3.6), which should also take account of the needs of their families and carers (3.7).

Health facilities should comply with certain criteria (4), which are more commonly found in guidance on the management of mental illness. The physical environment should be structured so that patient's privacy is protected as far as possible: there should be sufficient space for the number of patients being treated; there should be reasonable space for receiving visitors; and adequate space should be provided for patients to store their personal belongings (4.1). In-patient facilities should be arranged in such a way that each patient has a small piece of territory which is seen as his or hers, large-capacity dormitories depriving patients of all privacy should be avoided and there should be reasonable privacy for bodily functions. Bedside tables, wardrobes, and individual clothing should be made available. There should be reasonable space for specific treatment procedures (including psychotherapies). Facilities should have available necessary rooms for vocational rehabilitation, facilities for leisure, recreation, education and religious practice (4.2). Patients should be allowed access to their room during the day rather than being obliged to remain with other patients in communal areas. Patients' rooms and recreation areas should be adequately decorated.

Facilities should provide a safe and hygienic environment (4.3); adequate sanitary conditions should be maintained in the facilities, and toilets should be in good working order for all patients. Catering arrangements should also take into account patients' customs and beliefs and the needs of those with disabilities, meals served to patients should meet recommended minimum nutritional requirements (4.4), suitable food should be provided to those with special nutritional needs. Facility kitchens should comply with agreed standards for hygiene and food service, sufficient and appropriate eating utensils should be available for use by patients, and an adequate supply of water should be available for patients.

Finally, as already noted, guidance in the field of mental illness places considerable emphasis on the rights of patients, while this tends to be implicit in relation to diabetes. Examples include the right not to be subjected to unauthorised, experimental treatment (5.2), the right to confidentiality (5.3), to information (5.4, 5.5), to access to personal information (for example by specifying that people with mental disorders have the right to free and full access to their clinical records), the right to be made aware of their rights (informing patients of their rights at the earliest possible time (5.6)) and the right to respect of all human and civil rights within health facilities (5.1). Services should also be acceptable to all users, for example through sensitivity to cultural, religious, and related dietary considerations (5.7).

These criteria have been selected to capture aspects of treatment that should be similar for both types of patients. Thus, if I find evidence that the care provided in Romania to patients with schizophrenia is systematically worse than that to those with diabetes, then I will be able to conclude that there is horizontal inequity in their management. The next step is to assess whether such inequity has arisen because of stigmatization of mental illness.

Criteria for assessing the presence of stigma

According to the definition of stigma discussed earlier, those in a position of power and influence stigmatize individuals and groups if they consider the characteristics, or "marks" (such as the diagnosis of schizophrenia) of those with a disability to be in some way disgraceful and signalling their flawed nature. This will lead them to view such individuals and groups as less worthy, degraded or devalued.

There are a number of instruments that have been developed to determine the existence of stigma, including questionnaires and interview guides for different target groups (examples are included in Annex 3). A review of these tools identified certain common themes identified as characterising stigmatization by health professionals and others involved in the treatment and care of people with mental health problems. For example, stigmatization by health care providers occurs when patronizing attitudes and beliefs are expressed such that the diagnosis of a particular disorder or type of disorders should, by virtue of the judgements associated with the disorder, result in the provider failing to uphold the rights of the individual concerned. This can be demonstrated by:

- Not informing patients about their diagnosis;
- Not providing comprehensive information about the cause or origin, risk factors and treatment of a disorder in a friendly, easy to understand manner;

- Believing that people with mental illnesses cannot comprehend nor apply suggested treatment;
- Not explaining to patients the impact of the disease on their everyday life, what they can do, and what they cannot (e.g. they can drink coffee and have children);
- Having a negative attitude about prognosis and the possibilities for rehabilitation and recovery;
- Believing that people with mental illnesses are incapable of independent living or real work and are not able to lead a 'normal' life;
- Failing to consider confidentiality of information, diagnosis and health status;
- Considering that a diagnosis of a severe mental disorder should result in discarding certain rights of service users:
    - to self-determination, e.g. a woman who had suffered severely from a mental illness should have an abortion in the case of a pregnancy;
    - to treatment options. This belief holds that service users should be treated against their will, even when they are not a danger to themselves or others;
- Physically threatening or attacking service users because of the diagnosis of a mental disorder.

Stigmatization is also reflected in the language used towards people with mental health problems:

- Negative stereotypes about people with mental health problems are reflected by words such as: "dangerous", "violent/aggressive", "unpredictable", "stupid/of little intelligence", "less skilled", "bedraggled", "abnormal", "unreliable", "untrustworthy", "weird", "unpredictable", "unreasonable", "lacking in self-control", "lazy", "lacking in personal hygiene";
- Labelling behaviour with a psychiatric diagnosis (e.g. the tendency to view one's caseload as full of "schizophrenics", "bipolars", "psychotics" or labelling negative behaviour as, for example, "crazy").

Finally, stigmatization can also be recognised in the provision of treatment in the following circumstances:

- Underestimating the effectiveness of psychosocial treatments in the belief that people with mental health problems cannot be successfully treated without drugs;
- Believing that people with severe mental disorders should be kept in hospitals as they cannot be successfully treated outside the hospital in the community;

- Believing that all people with mental health problems need prescription drugs to control their symptoms (this is, however, clearly appropriate for schizophrenia so this criterion will not be used in this research);
- Displaying of a lack of interest in the person suffering the mental illness and the history of their mental health problem;
- Not taking seriously complaints about somatic health problems, being ridiculed, or facing the suspicion that their physical complaints may only be imaginary;
- Blaming the patients for having the disease, placing the responsibility for the onset and continuation of their disorders on a weakness of character, implying that people are themselves to blame for their own mental illness and that they do not have a real illness and could "snap out of it" (this was not applicable to schizophrenia so this criterion will not be used in this research).

These criteria will inform the detailed methods that will be set out in the next chapter. They will be used to ascertain whether those in a position of authority and influence over the treatment of patients manifest stigmatization through their expression of attitudes and beliefs, their language and their approaches to treatment. In the event that the research findings show that stigmatization occurs, conclusions will be drawn with regard to direct institutional discrimination. However, this is dependent on findings evidence of horizontal inequity.

Summary

This chapter has provided a conceptual background to the methods that will be employed in this thesis. It has defined discrimination as harm that is caused to individuals or groups on the basis of their identifiable characteristics. For the purposes of this thesis, it has further defined that harm is the receipt of care that is less good than that received by others with similar needs, here differentiated by having a physical rather than a mental illness, and has shown why this is a manifestation of horizontal inequity. It has then examined why such inequity might exist and has identified the potential importance of stigma, in which certain characteristics, in this case, mental illness, mark out groups and individuals as less deserving than others. The next chapter will describe the detailed methods that will be used to test the hypothesis that those suffering from mental illness in Romania are discriminated against in comparison with their counterparts whose illness is physical.

Chapter 4 Research design and methods

This chapter sets out the aims and objectives of the thesis and describes the research methods that will be used to achieve them.

Aims and objectives

Aim

The aim of this thesis is to ascertain whether people with mental health problems are discriminated against in specialist mental health services in Romania.

Objectives

This aim will be pursued through a series of interlinked objectives, each generating a number of questions.

1. To determine whether people with chronic mental health problems (exemplified by schizophrenia) are treated equitably (horizontal equity) in specialist services in Romania, as compared to people with chronic somatic problems (exemplified by type 1 diabetes).

1.1. Do policy and legislation that apply to specialist health care of people with chronic mental health problems (exemplified by schizophrenia), and with chronic somatic problems (exemplified by type 1 diabetes) provide for comparable treatment for their comparable needs?

1.2. Do people with schizophrenia experience equitable treatment in specialist services as compared to people with type 1 diabetes, i.e. do they have comparable:

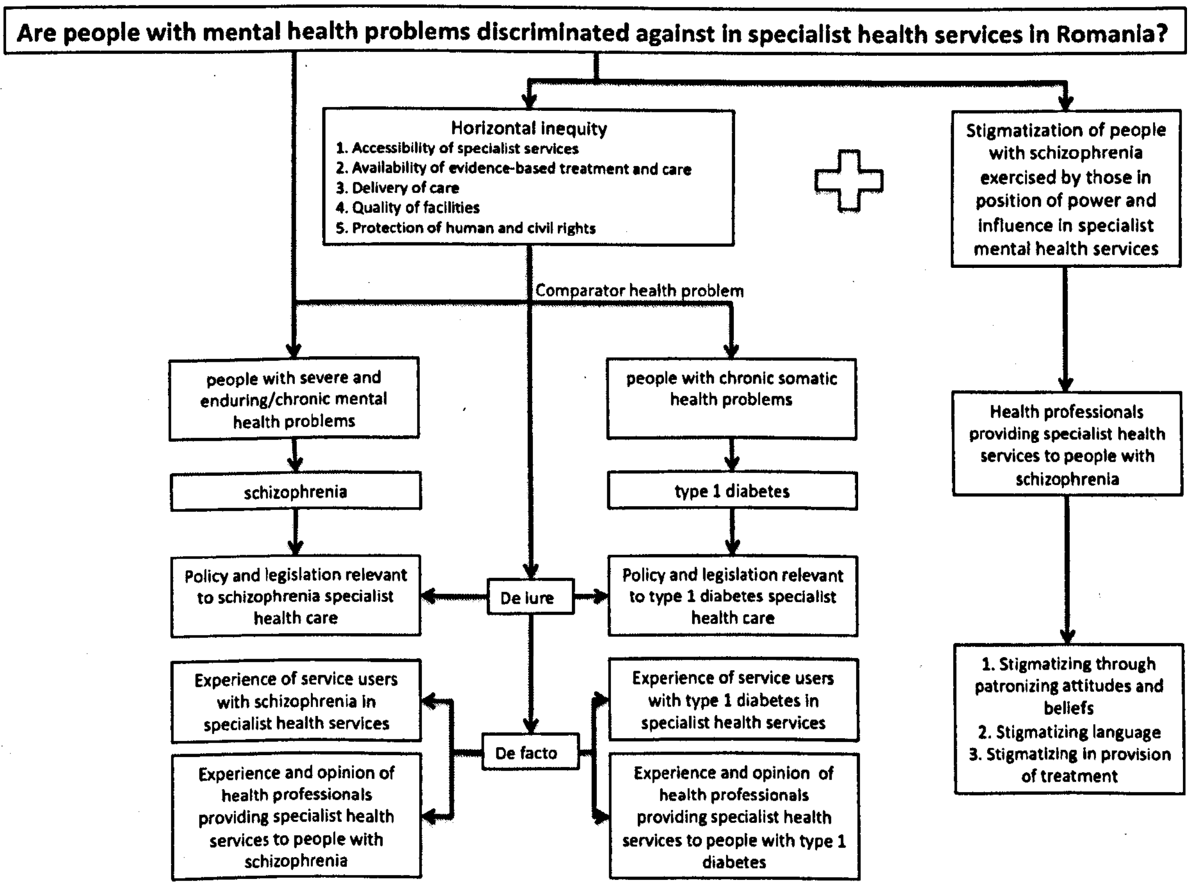
- access to specialist services?
- availability of evidence-based treatment and care?
- delivery of care?
- quality of facilities?
- protection of human and civil rights?

2. If evidence of worse treatment of those with schizophrenia is found (horizontal inequity), to determine whether this is the result of stigma against people with severe mental health problems, or is it benign neglect.

2.1. Do people in a position of authority and influence in specialist mental health services (namely the health professionals) stigmatise people with schizophrenia (exemplifying people with chronic mental health problems), i.e. display stigmatising attitudes and beliefs, language or approaches to treatment?

These objectives are set out diagrammatically in Figure 9.

Figure 9 Diagrammatic representation of the thesis objectives and research design



Research method – Rapid Assessment and Response (RAR)

This chapter outlines the research method chosen, Rapid Assessment and Response, including its theoretical underpinning and relevant methodological issues, the strengths and weaknesses of the research methods, methods of data analysis and ethical considerations.

What is a rapid assessment?

When selecting the research methods, several options were considered: the Rapid Assessment and Response, the Ethnographic Technique and the Nominal Group Process (231-237).

Ethnographic studies involve collection of very detailed information over prolonged periods of time, posing high demands on both time and financial resources (237). Ethnographic studies also require that the researcher will undertake observations of the social and natural environment of the informants. Such observations would go beyond the scope of this research, which targets specifically the health system. Rapid Assessment and Response methods are considered an effective alternative to detailed ethnographic studies in many circumstances, especially where time and resources are limited, but also because they incorporate a wider body of evidence than ethnographic studies. Consequently, they have been used extensively to assess the performance of health care systems. There were other reasons for rejecting an ethnographic study: this included the difficulty of including so broad a range of key informants, the unstructured approach to data collection, and the potential need for participant observation, which would be extremely difficult in the circumstances being studied.

Another possibility was the Nominal Group Process, as a means to provide qualitative insights into health care issues. It would have offered a structured approach to understanding the issues faced by the two patient populations but is best suited to exploratory research designed to identify problems faced by a group or community. Since this research was based on a defined conceptual framework and targeted a specific issue, namely institutional discrimination, this methodology was deemed to be unsuitable. The method of data collection is also unfeasible with the groups that are the subject of this research, as it would not have been possible to bring the participants together in one place, divide them into groups, and give them assignments (such as silent generation of ideas in writing), albeit for different reasons dependning on whether they were patients or health professionals. In addition, it was not feasible to conduct this work as an individual researcher. Consequently, it was not an ideal option for PhD research.

The rapid assessment/ appraisal family of social research methodologies includes Rapid Rural Assessment, Rapid Appraisal, Participatory Rural Assessment or Rapid Assessment and Response (238-245). The last of these has been tailored specifically for use in the area of health, which makes it most suitable for the purpose of this research.

Rapid Assessment and Response (RAR) is defined as "a means for undertaking a comprehensive assessment of a public health issue in a particular study area, including characteristics of the health problem, population group affected, settings and context, health and risk behaviours, and social consequences. It identifies existing resources and opportunities for intervention, and helps plan, develop and implement interventions. RAR draws from the experience of community development, participatory approaches and learning and rapid rural appraisal" (243). RAR is typically used in situations where organisations require contemporary, relevant data to develop, implement, monitor or evaluate health programmes, and where data are needed quickly and time and cost constraints rule out other, more conventional, research techniques.

The RAR includes a set of key features whose applicability to the current research is described in Table 1.

Table 1 Features of the Rapid Assessment

RAR Features	**Implementation**
Speed: typically completed within 12 weeks;	Implementation took place between 19 September 2007 and 7 January 2008.
Cost-effectiveness: uses techniques that have a high output of information in relation to input of research efforts;	By employing different techniques for each target group, this RA aims to obtain an optimum of information with minimum resources.
Practical relevance to interventions: its utility may be better judged by its adequacy for decision makers than increasing scientific knowledge for academic purposes;	The research is aimed at and designed to provide concrete information on the current status of discrimination against people with mental health problems. Relevant findings have already been shared with and used by key stakeholders in Romania (as detailed in the Chapter on Conclusions and Next steps).
Use of existing information: new data gathering exercises, such as surveys, are undertaken only where existing sources of information are inadequate. The aim is to verify information, reveal different aspects of the topic under investigation, challenge the interpretation of evidence, increase the validity and reliability of the rapid appraisal findings as well as the quality of interventions developed;	Information from a variety of source has been reviewed in the policy and legislation review, as described in Chapters 6 and 7 of the thesis.

RAR Features	Implementation
Multiple methods and data sources: it combines methods and sources of data to encompass all relevant aspects. Triangulation between multiple methods and data sources (e.g. between existing data reports, key informants interviews, focus groups, observations, mapping techniques, and community surveys) allows findings to be crosschecked and validated throughout. Different methods reveal different perspectives and conceal different aspects of the topic, allowing an insight into the scope and depth of the issue addressed. The chances that important conclusions are missed are decreased significantly (which increases accuracy);	The Rapid Assessment was implemented by triangulating data gathered using the following methods: 1) systematic review of policy and legislation; 2) focus group; 3) semi-structured interviews; 4) group interviews. The data was retrieved from the following sources: 1) policies and legislation; 2) existing literature (including published or unpublished reports and other documents); 3) services users; 4) health professionals.
Inductive approach: defined as the process of drawing conclusions and developing hypotheses from the data collected, and then searching for information that confirms, denies or modifies these conclusions and hypotheses. During the rapid appraisal questions and hypotheses will be investigated as they emerge during the data collection. Flexibility through induction is a vital part of the process;	The rapid appraisal is based on the criteria for assessing aspects of care that are equally applicable to the management of schizophrenia and diabetes, as identified in the Conceptual Frameworks. Additionally, information the on current status of policies and legislation was used in the direct data collected from the selected target groups.
Multi-level analysis: analysis commonly moves across several levels of investigation (individual, community, structural) in order to identify different levels for the intervention;	The investigation will take place at two levels: 1) at the level of service users; and 2) at the level of health professionals.
Adequacy of the public health response: the purpose of RAR is to gather information that can be used for further action;	The research will be fed back to policy makers in Romania.
Practical adequacy: optimal ignorance (to neglect irrelevant information) and proportionate accuracy (to prioritise practical adequacy over scientific perfection – especially with regard to surveys in which much of the data collected has a degree of accuracy that is unnecessary – ensure precise quantitative data are collected only when needed, and that other methods that are more appropriate are used when appropriate);	This principle is central to the implementation of this Rapid Assessment and was reflected in the way the research was conducted.
Pragmatism: Social research is rarely possible in ideal conditions. It implies having a pragmatic approach to the situation, adapting to different situations. This is essential.	The selection of service users and professionals will be done through opportunistic and prospective sampling. Cultural variations across sub-regions of Romania have been discussed in the RA Module 2 on Study Area Profile and limitations of findings are specified in relevant sections of the results (i.e. section on care for ethnic and religious minorities).
Opportunism: it is important to use any data chanced upon and make the most of any research opportunity that presents itself;	This principle will be used in the search for existing documents. Opportunities such as meetings and conferences, etc. will be used to discuss findings with key informants and identify relevant materials. Also, such opportunities have also been used for the initial consultation phase of the Rapid Assessment.

RAR Features	Implementation
Stop at the point of saturation: the point of saturation is where the team is no longer getting any new data or information on a particular topic that would refine or challenge their hypotheses and interpretations. At this point the team should move on to a new topic.	This principle will be applied in data collection.
Ethics: neutrality, confidentiality, informed consent, feedback, consequences of one's actions;	All these principles will be respected in the implementation of the research.
Cost: low to medium, depending on the methods selected;	The methods selected and the sample size require minimal financial resources for an optimum result.
Skills required: non-directive interviewing, group facilitation, field observation, note-taking, and basic statistical skills.	I have previous experience with facilitating focus groups, managing implementation of surveys and note-taking.

The WHO Guide for RAR makes the point that "RAR methods are arguably more rigorous, reliable and valid than investigations that use a single research method or data source" (246) (p.8). They give a relatively accurate picture of the prevalence of a phenomenon, attitude, perception, or behaviour pattern, but not of its extent or incidence. Findings usually relate to specific communities or localities and can be difficult to generalise. However, this approach has an added value when studying complex socio-economic changes, highly interactive situations, or people's underlying motivations, beliefs and value systems in project and programme settings. At the same time, the implementation of a RAR can bridge gaps among the communities concerned, the affected populations and other stakeholders with regard to the policy-makers. It can facilitate the translation of findings from the assessment process into a public health response. It produces rapid results at a lower cost than more formal methods and gives the investigator flexibility to explore new ideas and issues that may not have been anticipated when planning the study, but that are relevant to its purpose.

Limitations of the RAR

At the same time, undertaking a RAR poses a set of challenges for the researcher and their team. During the data collection stage, individual preferences, judgements and views of the interviewer may significantly affect the conduct of inquiry. The flexibility given to the interviewer contributes to more in-depth discussion but also leads to an increased probability of the introduction of biases and distortions (such that the investigator hears what they want to hear and ignores what they don't want to hear, or worse, is not even aware of the problem of possible distortions). This problem is compounded by using multiple interviewers. This problem is addressed in this research by having one person, the author of this thesis, conduct all interviews and focus groups.

Another challenge faced by researchers undertaking this method is recording, coding and analysing the data collected. This requires appropriate use of techniques for recording and analysing qualitative data. Strategies employed to minimize any element of bias during collecting and analysing data will be discussed in respective sections.

Structure of rapid assessment

Rapid Assessment and Response is a mixture of different modules that can include: initial consultation; generation of a study area profile; contextual assessment; population and setting assessment; health issues assessment; health and risk behaviour assessment; social consequences assessment; and intervention assessment. Assessment grids can be used to structure the inquiry, and in planning, fieldwork and summarising of the findings.

For each RAR relevant types of assessments are selected as appropriate; the first three (initial consultation, generation of a study area profile and contextual assessment) are used in almost all RARs and the last one (intervention assessment) is used in all RARs. Since this is a research project is not embedded in an ongoing process of policy design and implementation, and given the complexity of mental health systems this research implemented only the four key modules of the RAR methodology, as follows.

Module 1: Initial consultation

This module aims to support the initial judgements regarding the practical aspects that will be involved in implementing the assessment.

Decision on the services to be included in the research

In Romania, people with schizophrenia receive specialist care in 3 main settings: acute inpatient mental hospitals, long-term inpatient mental hospitals and outpatient mental health dispensaries. Specialist services for people with type 1 diabetes offer outpatient care in dispensaries and acute inpatient care in hospitals, but there are no long-term care institutions. During this stage of the research I discussed with relevant in-country specialists which of these services should be included in the research and to what degree, in order to allow for a meaningful comparative analysis of experiences with specialist services for the two conditions. The structure of outpatient services is similar for both disorders. At the same time, inpatient mental health care, unlike inpatient care for diabetes, is split between acute and long-term services. This complicates direct comparison. Based on my previous knowledge of the system and on consultations with national partners, my supervisor and advisory committees, I decided to include both types of inpatient mental health services in the research, to ensure that I would capture a fair and comprehensive picture of the mental health inpatient care, in the same way that all specialist diabetes services are covered.

The capital city Bucharest and some other large cities have mental hospitals that provide acute specialist care. In the rest of the country, acute cases are dealt with in psychiatric wards within district general hospitals. In order to take into account the differences in resources and practices in these two models, the research includes both a mental health hospital placed in a major city and a psychiatric ward in a district general hospital.

Long-term care is mainly provided in mental hospitals placed in villages on the outskirts of cities and towns. Due to some major media scandals reporting appalling conditions in some of these establishments, such as the Poiana Mare case in 2004 (247, 248) investments have been made in upgrading these services. However, the wave of reform has reached only a limited number of hospitals. Based on discussions with specialists at the National Centre for Mental Health, I have decided to include one hospital that underwent extensive changes in the research and one that did not.

Finally, outpatient mental health services are provided by dispensaries that were, until recently, called mental health laboratories. According to legislation adopted in 2006, these services are currently being upgraded to community mental health centres. They are typically tied, administratively, to inpatient mental health services. They sometimes consist of small offices run by one or two psychiatrists. Others are larger units employing teams. As part of this initial consultation, I have decided to study both types of outpatient services to provide a comprehensive picture.

Both inpatient and outpatient specialist services for people with type 1 diabetes are provided by district general hospitals. In most districts they have a ward specialising in the care of patients with diabetes and provide outpatient care in the outpatient clinic of the hospital which typically has offices specialised in diabetes.

Bucharest is different. It hosts the National Institute for Diabetes, a large institution offering a complex range of inpatient services for people with diabetes. Linked to it (though at different locations) there is also an outpatient clinic specialised in diabetes care. These facilities can easily be compared to the acute mental hospital in Bucharest and the mental health outpatient dispensary linked to it. As such, I have decided to include the Institute in Bucharest and its outpatient clinic, as well as a diabetes ward and an outpatient office in a district general hospital in a provincial town.

Selection of sites in Romania

Based on my previous experience in Romania with the planning and implementing of a rapid assessment project focused on injectable drugs use (IDU), and taking into account the aim, timeframe and resources necessary for this research, as well as the recommendations of the upgrading review, it was agreed that 2 districts would be sufficient to offer an accurate picture of the situation in the country.

The first site selected was the capital city, Bucharest, which has a large acute inpatient mental hospital, a long-term care mental hospital in a neighbouring village that had only recently started to upgrade its infrastructure and a larger outpatient mental health dispensary. Diabetes services are also well represented, Bucharest hosting the National Institute (designated the "N. Paulescu Institute") for Diabetes, Nutrition and Metabolic Diseases and its outpatient dispensary, as described above.

The second site selected was a middle-size provincial town (Figure 10). Though there are cultural differences across regions of the country, there is no evidence that these differences impact on the organization of services or on how treatment and care are delivered. Therefore, for convenience, the provincial town was selected from Oltenia region. The town, Slatina, is 2 hours away from Bucharest. Slatina had in place the relevant health services required for the study: a psychiatric inpatient ward in the district general hospital, a well-renovated and upgraded long-term mental hospital and a small outpatient psychiatric office as part of the outpatient clinic of the district general hospital. For diabetes care, the district general hospital has a specialised diabetes ward and a small outpatient diabetes office.

Figure 10 **Map of Romania**

Study sites

Source: World Sites Atlas (249)

Agreements with management of services included in the research

Following the selection of the settings and the sites for the research, managers of these institutions were contacted to determine whether they would agree to their services being included in the research. In most cases, verbal agreements were made, in others, written agreements were signed.

Logistic arrangements

To ensure the successful implementation of the research, I established a partnership with the National Centre for Mental Health based, at the time of the research, within the National School of Public Health. The Centre has facilitated contact with the local health authorities and the directors of the health settings selected for the research. They also provided logistical assistance (travel arrangements, setting up meetings, etc.) in organising fieldwork.

Module 2: Study area profile

- This module aims to provide a brief description of the main structural features (environmental, political, legal and economic) of the study area, in this case Romania. In so doing, the profile attempts to identify and understand the impact of each structural feature on the issues investigated. This is undertaken using information available from a variety of sources, mainly internet-based.

Module 3: Context assessment

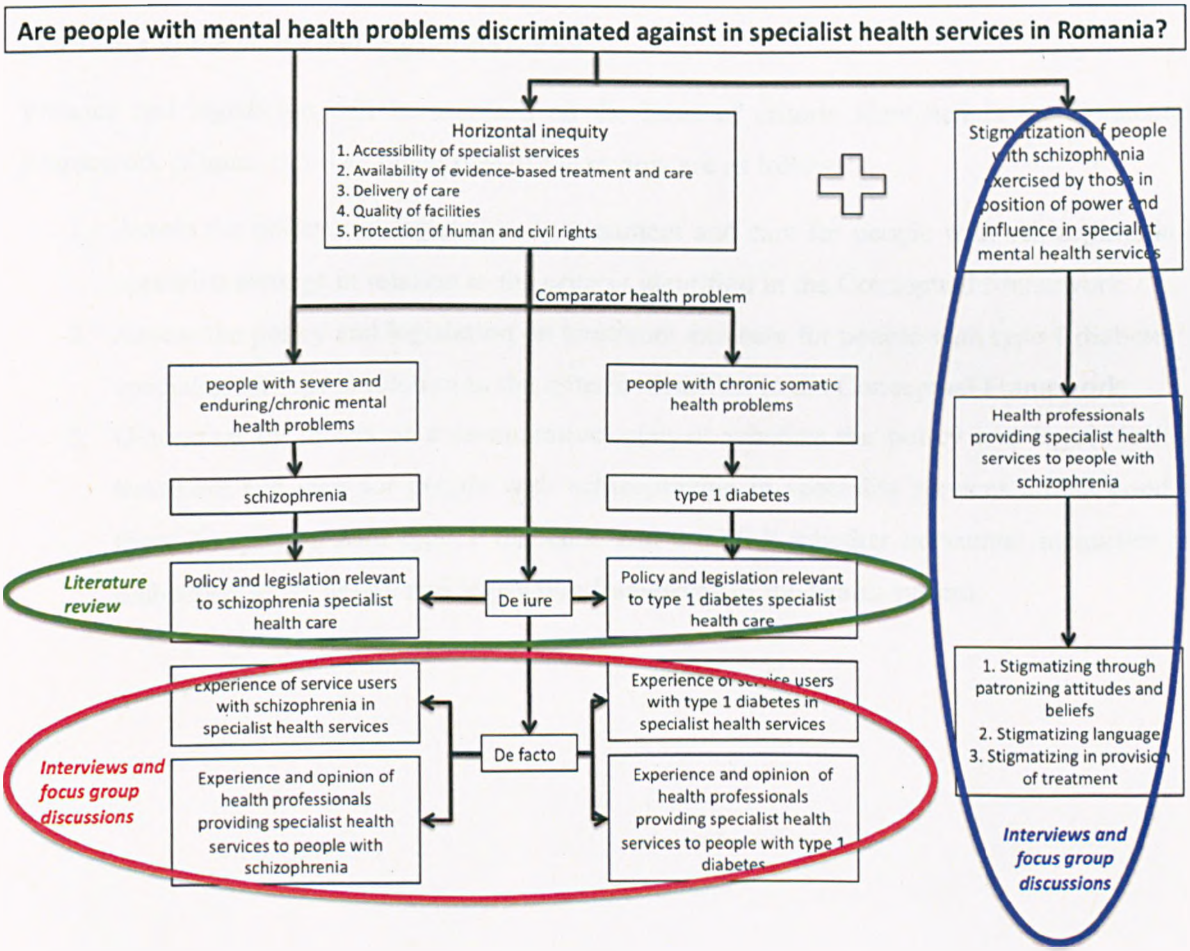
This module aims to create an understanding of the context within which the issues addressed in the study occur and to identify the factors that have an impact or influence on the issues addressed, so as to facilitate swift introduction of appropriate and feasible responses. The context of this research is the Romanian health system, with particular focus on the systems for caring for people with mental illness and diabetes. The main source of information for this section will be the review of policy and legislation undertaken in the first part of the research. Information relevant to the contextual assessment will be extracted and presented. A limited number of other sources will also be used, such as the 2008 review of the Romanian health care system produced by the European Observatory on Health Systems and Policies (250) and the WHO report of Mental Health Policies and Practices for Europe (written by the author of this thesis, based on data provided by national experts) (223, 250).

Module 4: Health intervention assessment:

This module aims to assess the intervention or health issue being investigated by the RAR. The intervention assessed in this research is specialist treatment and care for people with mental disorders, namely schizophrenia. As set out in the objectives, the research has two parts. In the first part, I seek to determine whether people with chronic mental health problems (exemplified by schizophrenia) are treated equitably in specialist services in Romania, as compared to people with chronic somatic problems (exemplified by type 1 diabetes). This component triangulated data from a wide range of methods that include critical analysis of laws, policy documents and other literature, observations of practice, interviews, and focus group discussions (Figure 11).

In the event that horizontal inequities are found in the policies and practices of the health system, and the first hypothesis of the research is confirmed, the second part of the research seeks to explain why any inequity exists, with a particular focus on the presence of stigma. This will be done through secondary analysis of the data collected from those who are in a position of authority and influence versus people with mental health problems in the context of the specialist mental health services, namely the health professionals. Their statements will be probed to determine whether they display stigmatising attitudes and beliefs, language or approaches to treatment, as defined in the chapter regarding Conceptual Framework.

Figure 11 **Rapid assessment methods (Module 4: Health intervention assessment)**



Policy and legislation review – analysing de jure equity

Aim

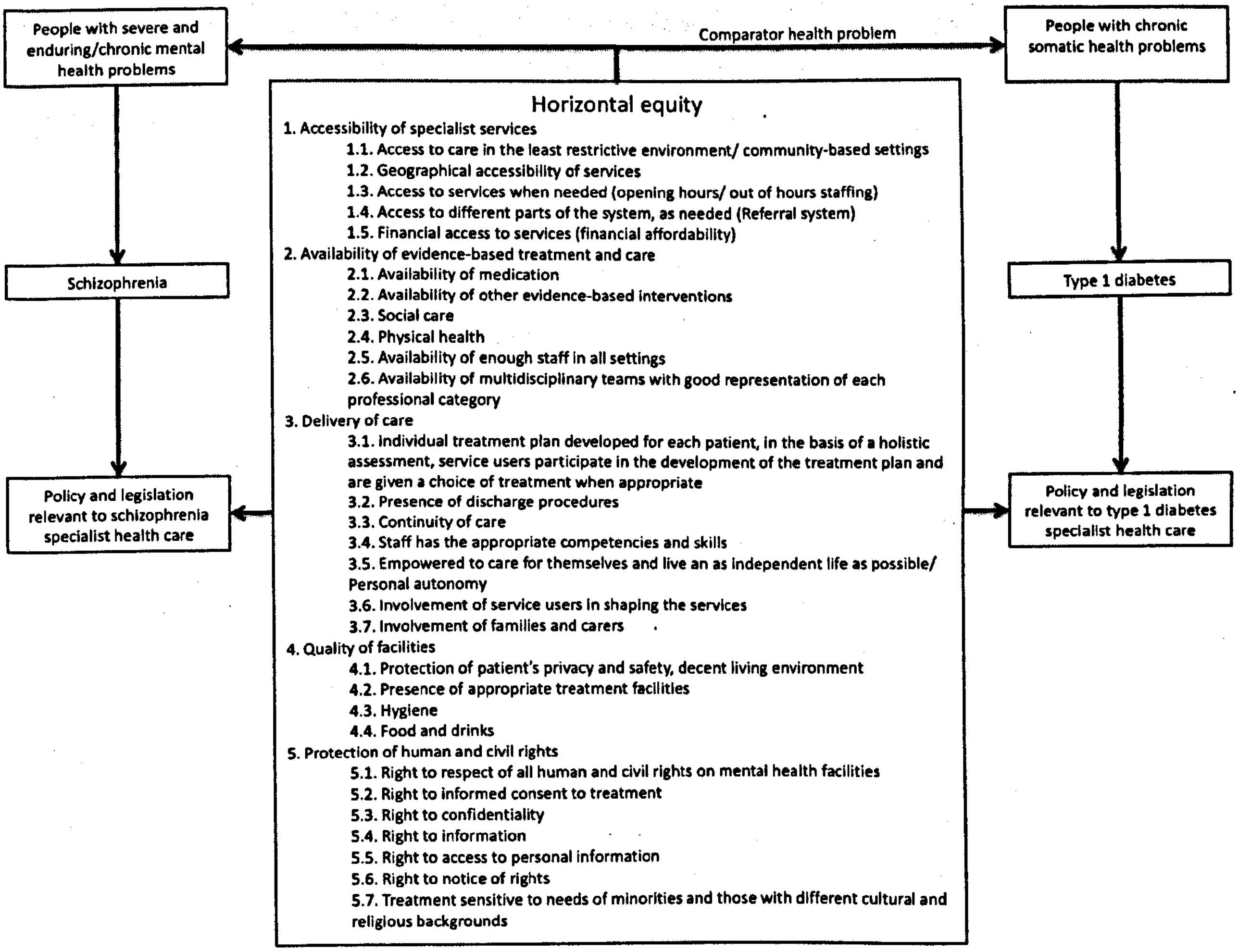
The review aims to assess whether the stated Romanian mental health legislation and policy provides for specialist services for people with severe mental disorders that are as good as those relevant to the management of chronic physical illness, specially type 1 diabetes.

Objectives of the policy and legislation review

Policies and legislation will be assessed on the basis of criteria identified in the Conceptual Framework (Figure 12). The objectives of the review are as follows:

1. Assess the policy and legislation on treatment and care for people with schizophrenia in specialist settings in relation to the criteria identified in the Conceptual Framework
2. Assess the policy and legislation on treatment and care for people with type 1 diabetes in specialist settings in relation to the criteria identified in the Conceptual Framework
3. Determine by means of a comparative analysis whether the policy and legislation for treatment and care for people with schizophrenia in specialist services are as good as those for people with type 1 diabetes, and establish whether horizontal inequities are embedded in the policy and legislative framework of the health system.

Figure 12 Structure of the policy and legislation review



Horizontal equity

1. Accessibility of specialist services
    - 1.1. Access to care in the least restrictive environment/ community-based settings
    - 1.2. Geographical accessibility of services
    - 1.3. Access to services when needed (opening hours/ out of hours staffing)
    - 1.4. Access to different parts of the system, as needed (Referral system)
    - 1.5. Financial access to services (financial affordability)
2. Availability of evidence-based treatment and care
    - 2.1. Availability of medication
    - 2.2. Availability of other evidence-based interventions
    - 2.3. Social care
    - 2.4. Physical health
    - 2.5. Availability of enough staff in all settings
    - 2.6. Availability of multidisciplinary teams with good representation of each professional category
3. Delivery of care
    - 3.1. Individual treatment plan developed for each patient, in the basis of a holistic assessment, service users participate in the development of the treatment plan and are given a choice of treatment when appropriate
    - 3.2. Presence of discharge procedures
    - 3.3. Continuity of care
    - 3.4. Staff has the appropriate competencies and skills
    - 3.5. Empowered to care for themselves and live an as independent life as possible/ Personal autonomy
    - 3.6. Involvement of service users in shaping the services
    - 3.7. Involvement of families and carers
4. Quality of facilities
    - 4.1. Protection of patient's privacy and safety, decent living environment
    - 4.2. Presence of appropriate treatment facilities
    - 4.3. Hygiene
    - 4.4. Food and drinks
5. Protection of human and civil rights
    - 5.1. Right to respect of all human and civil rights on mental health facilities
    - 5.2. Right to informed consent to treatment
    - 5.3. Right to confidentiality
    - 5.4. Right to information
    - 5.5. Right to access to personal information
    - 5.6. Right to notice of rights
    - 5.7. Treatment sensitive to needs of minorities and those with different cultural and religious backgrounds

Methods

Inclusion criteria. The review will cover primary and secondary legislation and policies that apply to the treatment and care of people with mental health problems, in particular schizophrenia, and of diabetes, regardless of which governmental institution initiated or adopted the instrument. The review will be limited to adults of working age, recognising that the specific needs of children and elderly people differ but are outside the scope of this thesis. I will use both primary sources (the actual policies and legislation) and secondary sources (including reports and assessments), as relevant.

Exclusion criteria. The review will exclude policies and legislation that: a) refer to non-specialist mental health or diabetes care or health care services other than mental health and diabetes; b) refer to the treatment and care of people with mental health problems other than severe and persistent concerns, as well as the treatment and care of type 2 diabetes; and c) refer to the treatment and care of people with mental health problems and diabetes other than those of working age.

Search strategy. I used three main approaches. In Romania, the main actors that initiate and/or adopt health-related legislation and policies relevant to health care of people with chronic conditions are the Parliament, the Ministry of Health, the National Health Insurance Fund and the Ministry of Work and Social Welfare with its National Authority for People with Disabilities. Therefore, my first approach will be to make a systematic search on relevant websites and libraries of the ministry of these bodies.

However, the websites of most of these institutions provide only limited information using the "Search" function. Instead, most of them have a webpage on current and draft legislation and policies, with most documents only in Romanian. Therefore, the second approach uses the "snow-ball" method for identifying other relevant documents on these websites.

Thirdly, I will consult with national experts who have a good knowledge of the national policies and legislation to ensure that no relevant document has been omitted.

As indicated above, the mental health services in Romania are regulated by a mixture of primary and secondary legislation and policies produced by the Government, the Ministry of Health (MoH), the National Authority for People with Disabilities (ANPH), the National Health Insurance Fund (NHIF) and the Parliament.

Search outcome

The websites of the official bodies were examined using the following search words: "health services"(servicii de sanatate), spital (hospital), “handicap”, “disabilitate”, "health insurance" (asigurare de sanatate) “sanatate mintala” (mental health), “psihiatr*” (psychiatr*), “psiholog*” (psyholog*), "diabet*" (diabet*). The findings were a follows.

- The Ministry of Health website/Legislation/Current legislation, I found seven documents relevant to mental health care (251-257) and one document relevant to diabetes care (258);
- Romanian Parliament website - contains a database of all current legislation under the *Chamber of Deputies/Legislation package of the Legislative Council.* The presentation of each legislative document contains information on all amendments made to the law (without incorporating them into a final version), as well as on all related legislation. I found nine documents relevant to both mental health and diabetes (259-267) and three documents relevant only to mental health care (268-270);
- The National Heath Insurance Fund website - I found three documents that were relevant to both mental health and diabetes care (271-273);
- The National Authority for People with Disabilities - I found eight documents that were relevant to both mental health and diabetes care (274-281).
- The Romanian College of Psychologists, - I found one additional document that was relevant to mental health care (282)

To ensure that all the relevant policy and legislation documents had been included, the information obtained was cross-checked by making another three searches that did not yield any new relevant documents. These additional searches were:

- The library of the Mental Health Programme of the WHO Regional Office for Europe (my employer at the time of the research);
- The WHO Regional Office for Europe website under the Country Information/Romania/Health care systems in transition and the Stability Pact web pages;
- The WHO on-line database Mental Health Atlas-2005 (283).

No additional findings were identified.

Finally, to ensure I had included all relevant legislation on the list I consulted the following national experts:

- Dr Florin Sologiuc, General Director of the National School of Public Health at the time of the research. Dr Sologiuc provided me with three additional legislative documents relevant to both schizophrenia and diabetes that were not available online (284-286);
- Dr Dan Ghenea, expert at the National Centre for Mental health at the time of the research, whom I have also consulted to clarify some legislative documents that leave room for interpretation (e.g. criteria for establishing the level of disability, structure on proposed model on mental health services);
- Dr Bogdana Tudorache, WHO National Counterpart for Mental Health at the time of the research;
- Prof. Constantin Ionescu Târgovişte, President of the Expert commission for diabetes of the Ministry of Health at the time of the research;
- Prof. Dan Mircea Cheta, Research Director of the National Institute for Diabetes, Nutrition and Metabolic Diseases "Prof. Dr. N. Paulescu" at the time of the research.

During the search, two main challenges were encountered, besides difficulties in identifying the relevant documents. The first challenge was in obtaining copies of these documents as the text of the law was not always included in the database. In these cases I made searches on Google using as search words the titles of the documents (entire title or just some key words) and managed to find the some of the documents on different websites, e.g. Legislaţie (former Superlex) (287). When I was not able to find the text online, I contacted experts in Romania (e.g. Dr Florin Sologiuc) who provided me with hard copies of the documents (by fax or by mail).

The second challenge that I encountered was that Romanian legislation is amended very often (one piece of legislation reviewed had 46 amendments by the time of the field work of this research (Annex 4)). This is problematic as the amendments are not incorporated into the text of the documents but published separately. Therefore, a key task was to ensure that I had the latest version of the documents that I reviewed. For this purpose I consulted the database recommended and approved by the Ministry of Justice which was developed by the Indaco Company. This provides updated versions of legislative documents (287). Where final versions were not available, I reviewed all amendments and identified relevant new provisions.

Analysis and synthesis of findings. The national policy and legislation will be scrutinized and assessed using as criteria identified in the Conceptual Framework. Afterwards, based on the findings of this assessment, a comparative analysis will be made with the aim of determining whether the policy and legislation relevant to the management of schizophrenia ensures that treatment and care of people with schizophrenia is as good as that for people with type 1 diabetes. The comparative analysis will therefore establish whether or not these instruments meet the requirements of horizontal equity.

Critical appraisal of documents reviewed. Relevant policy and legislation is critically reviewed in the introductory part of Chapter 6.

Implementation of policy and legislation – de facto equity

Aim

The review of policy and legislation will provide an assessment of the *de jure* situation facing patients with schizophrenia and type 1 diabetes in Romania, contrasting it with the criteria identified in the Conceptual Framework. However, it is clear that the *de facto* situation may well be different. This assessment aims to provide a description of the situation on the ground in relation to schizophrenia and type 1 diabetes in Romania. In this way it endeavours to determine whether experience of specialist treatment and care by people with schizophrenia is as good as that received by people with type 1 diabetes, or whether people with schizophrenia experience *de facto* horizontal inequities within the health care system. For this purpose, the experiences of people with schizophrenia and type 1 diabetes as well as the views of specialist health professionals on the experience of people with these conditions will be assessed using the criteria identified in the Conceptual Framework.

Target groups:

The research will focus on four target groups: a) people with schizophrenia who are users of inpatient and outpatient specialist mental health services; b) people with type 1 diabetes who are users of inpatient and outpatient diabetes specialist services; c) relevant mental health professionals working in inpatient and outpatient specialist settings; and d) relevant health professionals working in specialist settings caring for patients with diabetes.

Methods used

Interview strategies used in this research include focus groups, group interviews and semi-structured interviews. Interviews are economical in terms of time and resources and are traditionally used to explore the 'voices and experiences' of marginalized, vulnerable groups. In this research they provide an account of the experiences and views of service users and health professionals. As described below, each of these interview strategies was used with different target groups. Although the precise methods differed, (e.g. focus group discussions use the dynamic between members of the group to extract more in-depth and accurate information, while group interviews seek the point of view on each issue addressed from each participant, counting less on the group dynamic), for the purposes of this research, the information obtained could be combined to provide a meaningful picture. The choice of method was determined by the specificities of each target group and by practical considerations. Consequently, because of their self-perceived status and their time constraints, it would have been unrealistic and unfeasible to organise focus groups with medical doctors. In contrast, discussions with both patients groups and nurses benefited from group approaches that allowed more shy participants to open up and express views, and more vocal participants, and those inclined to put forward self-interested views to be balanced by other members of the group. While it is likely that psychologists and social workers would have been open to group approaches, due to their professionalexperiences with such research techniques, their small number made it impractical. The small number of group interviews (as compared to focus groups) thus reflected practical considerations, due to small numbers of staff in specific services, as described below. Despite differences in the means used to collect data from different target groups, the material obtained was consistent, reflecting the use of comparable interview guides for discussions with service users and health professionals, even though they were adapted to each target group. Following the Conceptual Framework, they covered: 1) accessibility of specialist services; 2) availability of evidence-based treatment and care; 3) quality of treatment and care; 4) quality of facilities; 5) protection of human and civil rights.

Interviews were semi-structured, using guidelines that followed the criteria set out previously and were pre-tested. The pre-testing involved one group interview with diabetes patients, one group interview with patients with schizophrenia, and two interviews each with the following health professionals: psychiatrists, psychologists, physicians specialised in diabetes, cardiologists, nurses working in mental health services and nurses working in diabetes wards.

Service users were asked to discuss their experiences of specialist services according to the same criteria. Health professionals who participated in the study were asked to express their opinions and discuss the experience of people with schizophrenia and type 1 diabetes in specialist settings where they worked. The interviews were flexible, allowing for open discussions around topics that aroused the interest of the participants.

Semi-structured interviews. The semi-structured interviews conducted with health professionals included: a) mental health practitioners (psychiatrists, psychologists, social workers); b) diabetes specialists: diabetologists/nutritionists (a mixed medical speciality in Romania), nephrologists, cardiologists, ophthalmologists, orthopaedists (in Romania, the physicians specialising in treating foot-related problems of diabetes patients).

The initial plan was to organise interviews with 3 professionals from each category in each facility included in the research. However, the number of staff employed, particularly psychologists, social workers and other specialist physicians involved in treatment and care of other body systems affected by diabetes did not allow for this, so a smaller number of interviews were conducted (see below).

Focus groups were conducted with relevant service users, as follows: a) people with a history of schizophrenia, in remission, with previous experience in specialist outpatient services and in acute and chronic inpatient services; and b) people with type 1 diabetes that have been previously admitted to specialist outpatient and inpatient facilities.

Eight sessions of 1-2 hours each were held with different participants from the selected districts in Romania: Bucharest (two sessions with people with schizophrenia and two sessions with people with type 1 diabetes) and Slatina (two sessions with people with schizophrenia and two sessions with people with type 1 diabetes).

Focus groups were held in as neutral a location as possible so to minimise any bias. Focus groups with people with schizophrenia were held in a relaxation room (used by patients and not used for treatment) within the "Balaceanca" Mental Hospital in Bucharest, and in the garden on the large grounds of "Schitu Greci" Mental Hospital in Slatina. Focus groups with people with type 1 diabetes were held in a classroom used for discussions with patients and courses by the National School of Public Health in Bucharest and in a rented venue within a hotel located in central Slatina.

Focus groups were also conducted with nurses working in mental health and diabetes specialist services, ten sessions of 1-2 hours with 6-12 participants each from the 2 selected districts in Romania.

In Bucharest five focus groups were organised altogether with: a) nurses working in the "Al. Obrejia" Mental Hospital which provides acute inpatient care; b) nurses working in the mental health outpatient dispensary, CSM 4, linked to "Al. Obrejia" Mental Hospital; c) nurses working in the "Balaceanca" Mental Hospital that provides long-term inpatient care; d) nurses working in the National Institute "N. Paulescu" for Diabetes, Nutrition and Metabolic Diseases that provides inpatient care for people with type 1 diabetes; e) nurses working in the diabetes outpatient dispensary "IL Caragiale", linked to the Institute.

In Slatina only three focus groups were organised, with: a) nurses working in the psychiatric ward of the District General Hospital that provides acute inpatient care; b) nurses working in the "Schitu Greci" Mental Hospital that provides long-term inpatient care; c) nurses working in the diabetes ward of the District General Hospital that provides inpatient care for people with type 1 diabetes.

Group interviews. In two settings in Slatina, the small number of staff employed precluded the organization of a focus group, so group interviews were conducted instead. These included: a) nurses working in the mental health outpatient office based within the outpatient clinic of the District General Hospital; b) nurses working in the diabetes outpatient office based within the outpatient clinic of the District General Hospital.

Group interviews were also conducted with auxiliaries working in specialist inpatient services, one in each inpatient facility included in this research. This category of staff was not initially included in the target group. During discussions with others, particularly with nurses, it became apparent that the roles of auxiliaries are expanding beyond their training and professional capacity within Romanian inpatient services, and that they now undertake a significant number of tasks traditionally done by nurses. For convenience, I organised group interviews rather than focus groups with these staff.

Sampling

Sampling methods

Multi-stage sampling was undertaken. In the first stage, one setting from each category was identified on a non-random basis, following consultations with national experts. The criteria of convenience and relevance were utilised, as explained in the section on Initial Consultation. In the second stage, a mixture of sampling methods was used. The rationale is detailed below and basic information on the facilities included in the research is in Annex 5.

Sampling was not stratified by gender. Service users were adults (over 18 years of age).

Target Group 1: Service Users

In Romania, health facilities keep poor or no record of patients' contact details, whether in inpatient or outpatient services. For this reason, a selection based on a list of patients from the facilities is not possible.

a) Service users with schizophrenia

People with schizophrenia were selected randomly from the list of patients admitted at the time of the research to chronic mental hospitals in the 2 locations (Bucharest and Slatina). The advantage of this approach is that it ensures that all patients included in focus groups have a combination of experience in outpatient services as well as acute and chronic inpatient services, as all patients admitted to long-term inpatient services have already been through acute inpatient and outpatient services, and are familiar with these services.

It should be noted that patients admitted to these facilities were chronic patients, many having recurrent admissions to chronic mental hospitals, though they also lived at home during which time they were treated in outpatient services and acute inpatient units. As such, they were unlike other chronic patients that are permanently admitted to chronic social institutions managed by social welfare authorities.

A list of all patients in hospital at the time of the study was prepared by the management of services included in the research. Patients who, based on the assessment of their psychiatrists, were not in remission at the time of the research were excluded from the list, based on consultations with psychiatrists. Lists were exported to Excel and random samples were drawn using the RAND function. About 8-12 patients were selected randomly for invitation to participate in each focus group, with random substitution to replace those unable or unwilling to participate.

To ensure that patients felt free both to accept the invitation to participate in the focus group and to freely express their opinions during discussions, no staff member was involved in the process of selecting patients and inviting them to focus groups. I went go to great lengths to avoid any form of real or perceived coercion.

b) Service users with type 1 diabetes

Since only a small number of patients with type 1 diabetes are admitted at one time in inpatient facilities, the selection of this group of patients had to be done differently. As none of the facilities have patients' list with contact details, I asked nurses in outpatient facilities to make a list of all the patients visiting the facilities during 2 months prior to implementation of the research. Patients were asked if they agreed to being contacted to participate in research. In order to avoid pre-selection of patients by nurses, patients were not actually invited to participate by the nurses but rather asked if they consented to being contacted. The list assembled in outpatient facilities was exported to Excel and random samples were drawn using the RAND function. About 8-12 patients were selected randomly for each focus group, again with random substitution of those unable or unwilling to participate. All patients with type 1 diabetes are admitted to inpatient facilities regularly (at least once a year). Therefore, as with schizophrenia, patients attending outpatient facilities had previous inpatient experience.

Target Group 2: Health Professionals

Lists of staff are available at health care facilities. These were obtained from the management of the facility. Lists were exported to Excel and random samples were drawn using the RAND function. Specific considerations were as follows:

a) Psychiatrists

Random sampling was employed to select 3 psychiatrists in each mental health service. In some cases, where the facility provided care for both people with mental health problems and for people with alcoholism and drug addictions, the psychiatrists assigned exclusively to the care of the latter group were excluded from the list of staff before the samples were drawn.

b) Other mental health professionals

The initial plan was to conduct the same number of interviews undertaken with psychiatrists (3) with other mental health professionals (psychologists, social workers). However, the employment practices in the Romanian health system are still traditional and mental health teams are largely limited to psychiatrists and nurses. Only a few psychologists and social workers were employed, so they were all approached and invited to participate in the research. Despite only one refusal of participation, the number of interviews with this staff category was smaller than was obtained with psychiatrists.

c) Nurses working in mental health services

Random sampling was employed to select 8-12 nurses working in each mental health facility utilised in the study. In cases where the facility provided care for both people with mental health problems and for people with alcoholism and drug addictions, the same approach was used as for psychologists.

The mental health outpatient office based within the outpatient clinic of the District General Hospital in Slatina employs a small number of nursing staff, only 5 at the time of the research. All were invited and all participated in a group interview.

d) Physicians specialising in diabetes

Random sampling was employed to select 3 physicians specialising in diabetes in each facility in Bucharest. In Slatina, there was only one such physician covering the whole district, for both inpatient and outpatient services. She was interviewed.

e) Nurses working in services providing care for type 1 diabetes

Random sampling was employed to select 8-12 nurses working in each facility providing care for people with diabetes. An exception was made regarding the diabetes outpatient office based within the outpatient clinic of the District General Hospital in Slatina as this facility had only 2 nursing staff assigned to this service at the time of the research. Both of them were invited to, and participated in, a group interview.

f) Other physicians involved in the treatment and care of diabetes patients

The initial plan was to conduct the same number of interviews (3) with other physicians involved in treatment and care for diabetes patients as those specialising in diabetes. However, since the services for people with diabetes are within general hospitals, these other professionals are not particularly associated with diabetes services. They were more reticent to participate in the research, citing their limited knowledge of diabetes. They further indicated that they are dealing with the particular health problems relevant to their specialty and that all diabetes related problems were dealt with by the physicians specialising in diabetes care who were being interviewed already. Consequently, the number of interviews was smaller than initially planned.

g) *Auxiliaries*

As already noted, the auxiliaries were not included in the initial design of the research. The decision to include them was taken during the implementation of the research so procedures similar to those with nurses were not possible. Instead, they were sampled opportunistically, to include those on duty at the time the focus groups or interviews with other staff were being undertaken. All auxiliary staff that were invited to participate in the research accepted the invitation.

Table 2 describes the distribution of focus groups and interviews by setting, target group and district selected for implementation.

Table 2 Summary of focus groups and interviews

Target group			**Bucharest**	**Slatina**
Service users	**Mental health service users** (based in long-term care mental hospitals, but with experience in acute inpatient and outpatient services)		2 focus groups	2 focus groups
	Type 1 diabetes service users (with experience in inpatient and outpatient services)		2 focus groups	2 focus groups
Mental health professionals	**Outpatient services**	Psychiatrists	3 interviews	1 interview
		Other health professionals	2 interviews	2 interviews
		Nurses	1 focus group	1 group interview
	Acute inpatient services	Psychiatrists	3 interviews	3 interviews
		Other health professionals	3 interviews	1 interview
		Nurses	1 focus group	1 focus group
		Auxiliaries	1 group interview	1 group interview
	Long-term inpatient services	Psychiatrists	3 interviews	3 interviews
		Other health professionals	3 interviews	1 interview
		Nurses	1 focus group	1 focus group
		Auxiliaries	1 group interview	1 group interview

Target group			**Bucharest**	**Slatina**
Type 1 diabetes professionals	**Outpatient services**	Diabetologist physician	3 interviews	1 interview
		Other health professionals	1 interview	-
		Nurses	1 focus group	1 group interview
	Acute inpatient services	Diabetologist physician	3 interviews	1 interview
		Other health professionals	3 interviews	1 interview
		Nurses	1 focus group	1 focus group
		Auxiliaries	1 group interview	1 group interview

In summary, the focus groups included:

- 78 users of either mental health or type 1 diabetes specialist services.
- 91 health professionals (nurses working in mental health or diabetes specialist services)

The group interviews included:

- 13 auxiliaries working in either mental health or diabetes specialist services
- 4 nurses working in the mental health outpatient ward and 2 nurses working in the diabetes outpatient office, all based within the outpatient clinic of the Slatina District General Hospital;

The semi-structured interviews included:

- 40 health professionals (specialist physicians, psychologists, social workers).

In total, there were 228 participants. They covered each condition in each specialist setting (mental health acute and chronic inpatient services and outpatient services as well as inpatient and outpatient services for type 1 diabetes) in the two locations, Bucharest and Slatina.

Data collection took place between October 2007 and January 2008.

Data analysis (1)

As described in the section on data collection methods, the interview strategies employed with different groups were designed to be interchangeable, with any differences in interview techniques addressed by the similar semi-structured nature of the interview guides, which followed the conceptual framework. This enabled data collection that took account of the characteristics of each target group. As such, findings could be pooled across target groups, regardless of the interview strategies employed.

Analysis of the data involved two methods: content analysis and narrative structure analysis. The content analysis method involves establishing a set of categories and coding frames that fit both the theoretical background of the research and the materials available for analysis. It allows for the simplification and reduction of large datasets into organized segments (288, 289).

While this method of data analysis has been criticized for shaping the analysis around a firm conceptual grid and excluding uncategorised findings, this is irrelevant to the current research as it is based on a conceptual grid that seeks to facilitate comparison of findings from some target groups (service users and health professionals from specialised mental health services) with those from other target groups (service users and health professionals from specialised services for type 1 diabetes) on the basis of the selected variables. For this reason the research used semi-structured interview guides to collect data. The merit of this research will not reside in the identification of categories emerging from the findings of fieldwork but, rather, on the manner by which the findings within each category compare across different target groups.

Categorisation of the primary data was based on the list of variables emerging from the Conceptual Framework, around which the interview guides were developed. In this regard, the interview guides were instrumental. Sub-variables were used to define the coding frame and rules. The initial coding was piloted on a number of interview transcripts with different target groups and adjusted as needed.

Data collected were transcribed in Romanian. Then, findings from each transcript were categorised by variables and sub-variables, according to the conceptual framework. They were thencompiled into tables with for: variable, sub-variable, condition (schizophrenia or type 1 diabetes), type of setting (outpatient, acute inpatient, and chronic inpatient), target group (service user, main medical doctor, other health professionals and medical doctors by categories, nurses, and auxiliaries), location (Bucharest or Slatina), participant code (see section on coding) and relevant text in Romanian. Findings were synthesised in English first by variable, sub-variable, condition, facility, target group, and location (e.g. synthesis of what mental health nurses from the acute inpatient unit in Bucharest said that is relevant to *Accessibility of specialist services/ Financial access to services*). Second, this synthesis findings were compared between the 2 locations, to observe differences in findings for the same variable and sub-variable between locations for the relevant` condition, type of setting and target group. When differences were found, they were noted. Third, comparison was made between different target groups, for the same variable and sub-variable, condition and type of setting and differences were noted. Fourth, comparison was made between different types of settings for the same variable and sub-variable and condition. The differences were noted. The following 2 chapters present the findings of both the synthesis and the three comparisons. These were used for the description of the *de facto* situation, as experienced by people with schizophrenia and type 1 diabetes, as well as by the health professionals providing them with treatment and care in specialist settings. Finally, the synthesised findings for the same variable and sub-variable were compared, differences noted and conclusions on *de facto* equity drawn, as presented in chapter 11. Due to the volume of the material that was synthesised and the multi-layered analysis done, which amounted to hundreds of pages of tabulated data, it was necessary to be selective in deciding what to include in either the body of the text or the annex.

One of the limitations of the content analysis method is that it can miss out on the interactions between participants in the research. To compensate for this limitation, content analysis was used in combination with the narrative structure analysis method.

In the narrative structure analysis, findings are analysed through the lens of those in different roles. As these roles are represented in both the mental health and somatic health sectors, even though they may be occupied by people with different titles, this allowed for a comparative analysis. Care was taken not to construct the narrative of the analysis from one particular perspective. The information from each target group was triangulated to limit the scope for bias.

Although the research was categorised by a single researcher (the author), so precluding formal assessment of overall reliability, a sample of material on each target group and setting was additionally categorised by another researcher and no problems were identified.

To satisfy the criterion of low-inference descriptors, interviews were tape-recorded except for a small number of interviewees who did not consent to recordings (3 interviews, 2 focus groups and a group interview). In this case, a note-taker was used to record the discussion. The tapes were carefully transcribed, including information on body language (when appropriate), silences and overlaps during discussions.

In addition to the actions indicated above which were employed to address concerns of validity, I would like to mention the following:

Impact of the researcher on the setting. Considering I am a native-born Romanian and have worked in the Romanian health system and have a good understanding of it, I consider that I will have minimal impact on those being studied.

Values of the researcher. I was constantly careful to maintain my neutrality during discussions and avoided expressing any personal views. It was notable that participants who expressed views to which I personally do not adhere (such as an expression of contempt and condescension towards health professionals that are not physicians, such as social workers or psychologists) felt quite relaxed about expressing them during our discussion and even felt comfortable enough to elaborate on these views.

The truth status of respondents' accounts. I believe that being acknowledged by research participants as being "one of them", as a fellow Romanian, while not living in the country, resulted in openness by participants in expressing opinions, without fear of negative consequences for any criticism expressed. At the same time, since I was not linked to the decision-makers in the country and constantly expressed my neutrality and the limitations of the research (the research in and of itself does not guarantee change), participants showed moderation in expressing their views. Indeed, they were not encouraged to express complaints as if it was to someone who could solve those complaints.

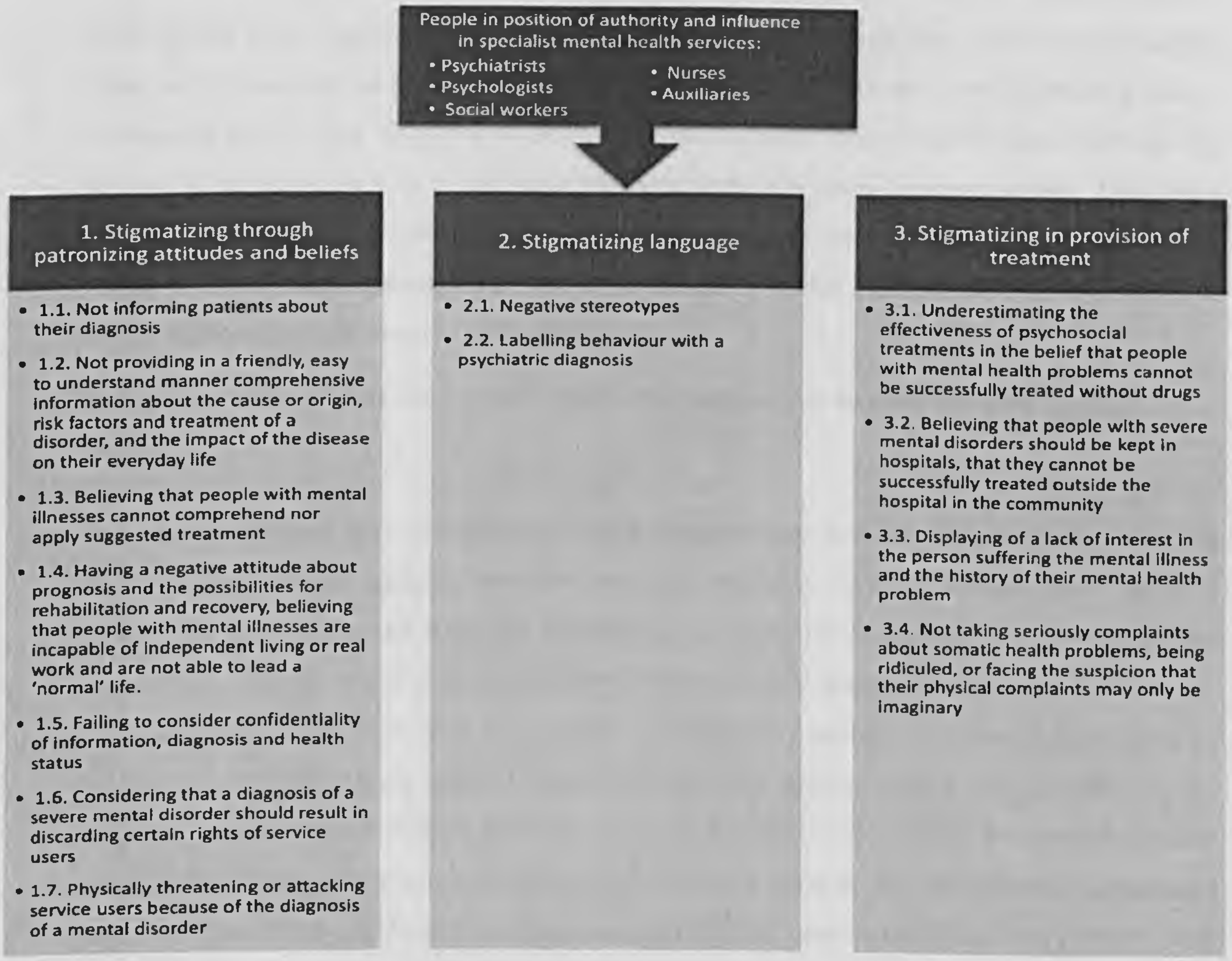
Comprehensive data treatment. Generalisations and conclusions regarding research findings were based on careful analysis of all cases of data collected and application to all relevant data collected.

Determining the presence of stigma

Aim

Following the implementation of the policy and legislation review and the field work, conclusions will be drawn as to whether horizontal inequities are present in the structures of specialist mental health services. In the event that such inequities are found, confirming the first hypothesis, the second part of this research aims to determine whether these inequities are due to stigma against people with severe mental health problems, or are the outcome of benign neglect. This will be done by ascertaining whether those in a position of authority and influence, namely the health professionals interviewed during the field work, display stigmatising of attitudes and beliefs, language or approaches to treatment, as defined in the chapter on the Conceptual Framework (Figure 13).

Figure 13 **Assessment of stigma**



People in position of authority and influence in specialist mental health services:

- Psychiatrists
- Psychologists
- Social workers
- Nurses
- Auxiliaries

1. Stigmatizing through patronizing attitudes and beliefs

- 1.1. Not informing patients about their diagnosis
- 1.2. Not providing in a friendly, easy to understand manner comprehensive information about the cause or origin, risk factors and treatment of a disorder, and the impact of the disease on their everyday life
- 1.3. Believing that people with mental illnesses cannot comprehend nor apply suggested treatment
- 1.4. Having a negative attitude about prognosis and the possibilities for rehabilitation and recovery, believing that people with mental illnesses are incapable of independent living or real work and are not able to lead a 'normal' life.
- 1.5. Failing to consider confidentiality of information, diagnosis and health status
- 1.6. Considering that a diagnosis of a severe mental disorder should result in discarding certain rights of service users
- 1.7. Physically threatening or attacking service users because of the diagnosis of a mental disorder

2. Stigmatizing language

- 2.1. Negative stereotypes
- 2.2. Labelling behaviour with a psychiatric diagnosis

3. Stigmatizing in provision of treatment

- 3.1. Underestimating the effectiveness of psychosocial treatments in the belief that people with mental health problems cannot be successfully treated without drugs
- 3.2. Believing that people with severe mental disorders should be kept in hospitals, that they cannot be successfully treated outside the hospital in the community
- 3.3. Displaying of a lack of interest in the person suffering the mental illness and the history of their mental health problem
- 3.4. Not taking seriously complaints about somatic health problems, being ridiculed, or facing the suspicion that their physical complaints may only be imaginary

Data analysis (2)

The data were analysed using the content analysis method, as described in the previous section. The categorisation and coding were based on criteria for stigma identified in the Conceptual Framework. The relevant findings were compiled in tables that contained columns for: variable, sub-variable (Figure 13), type of setting (outpatient, acute inpatient, chronic inpatient), target group (psychiatrists, psychologists, social workers, nurses, auxiliaries), location (Bucharest or Slatina), participant code (see section on coding) and relevant text in Romanian. Synthesis and relevant quotes were translated into English, as presented in Chapter 12, with differences between type of setting, target group and location noted. Again, due limited space, the tables with the syntheses and quotes were not included either in the body of the text or in the annex.

Ethical considerations

The research was approved by the ethics committees of the Romanian Ministry of Health and the LSHTM. All those interviewed had the study explained to them and were given an information sheet on the research, including a summary of their rights and the authority by which I was to conduct the study. They were free to decline to participate and were asked to sign a form giving consent to be interviewed or to have any views expressed in focus groups recorded. They were assured of confidentiality. Recognising that additional steps were required when interviewing people suffering from schizophrenia, advice was sought from the ethics committees concerned to ensure appropriate measures are put in place.

Precautions taken to limit the exposure of research participants to potential discomfort or distress

The obvious concern was that users of health services may feel uncomfortable or concerned about speaking freely regarding the care they have received. Strenuous efforts were taken to ensure that their comments were not attributable to them and, in particular, were not in any manner shared with service providers. None of the data were stored at the health facilities. For example, focus groups were held in as neutral a location as possible, as indicated above, and no health care providers were present. The subjects were drawn from a list provided to the researcher and the names of those participating were not disclosed to staff. The list of those who participated, along with the working notes of the focus groups, was maintained in password protected files. One additional concern was that fellow participants of focus groups could disclose what has been said but the unacceptability of this behaviour was stressed during the discussions.

Staff participating in interviews and focus groups were given similar reassurances, with the exception that most interviews of this category were held in the individuals' offices at their place of work within these facilities. This facilitated further privacy.

Ensuring confidentiality with regard to collected data

The data collected for this research from each focus group and interview that was conducted were coded using indicators of the type of service investigated (inpatient-acute, inpatient-chronic or outpatient) and the district (Bucharest or Slatina). All participants from Bucharest were coded "1" and all participants from Slatina were coded "2".

- Patients: Service users were coded with the letter "U". Additionally, depending on the disease from which they suffered, each was coded with either the letter "M" (for mental disorders) or the letter "D" (for type 1 diabetes). Users were included in the study if they had previous experience with both inpatient and outpatient services. Therefore, all patients were also coded with "I" (for inpatient) and with "O" (for outpatient). For example, patients with schizophrenia were coded as "UMIO" and patients with type 1 diabetes will be coded "UDIO".
- Health professionals: Information collected from health professionals was coded by the respective profession of the person: "P" (for psychiatrists), "G" (for psychologists), "S" (for social workers), "N" (for nurse), "A" (for auxiliaries), "E" (for physicians specialised in diabetes care), "F" (for dermatologist specialised in foot care), "H" (for ophthalmologists), "R" (for nephrologists) and "C" (for cardiologists). Additionally, they were coded with either the letter "M" (for mental disorders) or the letter "D" (for type 1 diabetes). Professionals were also coded with "I" (for inpatient) and with "O" (for outpatient). Inpatient services based in mental hospitals were either coded "a" for acute inpatient mental hospitals or "b" for long-term inpatient mental hospitals. For example, a psychiatrist working in the long-term inpatient mental hospital in Bucharest was coded as "1_PMI_b_1", while a nurse working in diabetes outpatient services in Slatina was coded as "2_NDO_1".

The coding minimised the potential to identify participants involved in the research and ensured the confidentiality of the information provided by participants. All abbreviations are listed in Annex 6 of the thesis.

The only record of the name of persons participating in focus groups and interviews was the tape taken during the discussions, in cases where participants agreed to have their discussion recorded. However, none of the persons who assisted me with the recording of data (e.g. note takers) were involved in the health services or institutions included in the research. Therefore, the confidentiality of the information collected was maintained.

Keeping the recordings of interviews safe

During the implementation of the Rapid Assessment and subsequently, no-one other than me and, in few cases, my assistant who helped with logistical arrangements, could link anything said during the discussions back to particular participants. No permanent record of the actual list of participants exists in Romania.

All participants were asked if they agreed to the audio recording of discussions (this was indicated in the Consent form). If they agreed, I recorded the discussions on my personal recorder. Each target group was coded (as indicated above) and the electronic recording was filed as such. No names were mentioned during discussions. Nobody except me has access to these recordings. They were saved on my personal computer in an encrypted directory (using the Safe function) and no copy has been made available to anyone else. The computer is, of course, password protected. In the event that participants did not agree to record the discussion, 2 note-takers took detailed notes of the discussions and these files were passed over to me as soon as they were finalised. Note-takers were required to destroy their recordings. Audio recordings were transcribed and the files password protected. Neither of the note takers used in this research have any connection with the health services or the institutions included in the research. Again, no person other than myself and the note-taker had access to these files. Neither the recordings nor the Word files were left in Romania. No permanent data record exists in Romania, except as anonymous summaries. Research collaborators in Romania (the National Centre for Mental Health and the Institute for Diabetes) were able to access anonymous summaries for research purposes (as approved by the Romanian ethics committee).

As noted above, all data is maintained in password protected files.

Consent obtained from participants

Prior to each focus group and interview, each individual who met the inclusion criteria was asked if they were willing to participate in the research. The purpose and nature of the study was then explained to them and they were asked to read an information sheet that they retained. If the individual consented, they signed a second consent form (Annex 7) (which I keep on record). Some subjects preferred not to give their real name in the interests of remaining anonymous (this falls within the exemption covering the situation when, as here, the only information connecting the subject to the research is the consent form, and the only risk from the research to the subjects arises from the potential for loss of confidentiality). This possibility was discussed on the information sheet. In all cases where this happened, the circumstances were noted and retained by me alone in a safe place. Potential participants were asked about a convenient date for them to participate in the focus group or interview and a timetable was organised.

At the time set for the focus group or interview, the researcher (myself) introduced myself and thanked the participants for agreeing to contribute to this research.. Participants were given the consent forms if the original ones had been forgotten, so as all participants were in possession of a written consent form. I personally witnessed the signing of the consent forms and answered all questions from participants. Participants were assured that their participation in the discussion would not in any way affect their health care or their current work.

The information sheet (see Annex 8) contains a number of alternative formulations, listed as bullet points, for the different types of participants: service users; health professionals who are nurses, psychologists, social workers or occupational therapists; health professionals who are physicians; decision makers, and other key stakeholders. The forms were individualised for each group and the appropriate bullet point inserted.

Quoting

In this thesis, when comparing data from different institutions there was no direct referral to the name of the institution but, rather, to the type of institution and its location. The managers of the institutions were asked for their consent to mention the name of their institution and this was obtained for all managers. In no place in this research is there any mention whatsoever of the names of the service users or health professionals included in the research.

No quotes or other results arising from participation in this study are included in any reports unless quoted anonymously. No participant was unwilling to be quoted anonymously.

Feedback to participants regarding research findings

Participants were asked in the consent form if they wished to receive feedback on the results of the study. Based on this expression of interest, a summary of the final thesis will be disseminated in Romanian to participants in the research.

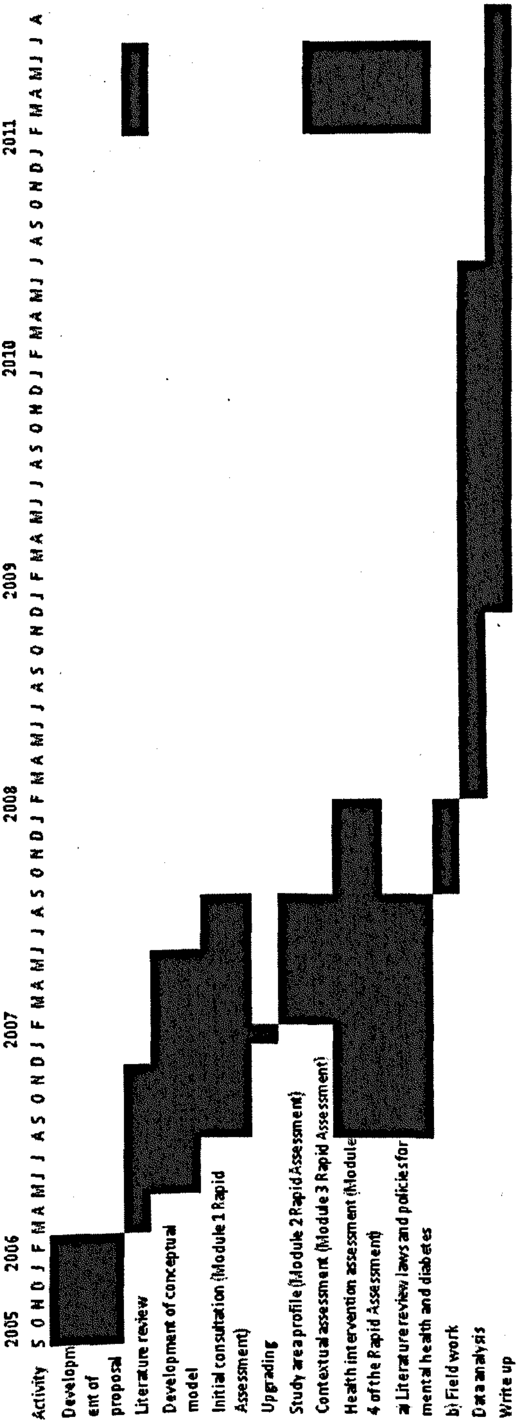
Payments made to participants

Symbolic remuneration was offered to nurses and auxiliaries (Romanian New Lei 30 = £6.30 for nurses) who took part in the study. Small gifts (such as T-shirts, badges or cups) were offered to the other health professionals and to service users. Travel expenses were covered for some service users with diabetes (upon request) (service users with schizophrenia did not have travel costs).

Timeline

A summary of the timeline of the research is in Figure 14.

Figure 14 Gantt chart showing the timeline of the research



Chapter 5 Understanding the national context

This chapter provides information on the setting of the research, describing Romania, its health system, and specific issues related to the systems for management of mental health and diabetes care. This is designed to give the reader sufficient understanding of the context of the research. The structure used maps on to that set out in the framework for rapid appraisal, as indicated in the section headings.

Main structural features of the study area (RA Module 2: Study area profile)

In this section I present some basic facts about Romania. I describe its territory, physical features, climate, socio-economic and demographic factors as well as basic information on the system of government of the country and the health status of the population. As will be shown, this contributes to the rationale for various decisions about how and where to undertake the research.

Romania is the second largest country in Central and Eastern Europe and the seventh largest among the 27 current member states of the European Union (EU), having an area of 238,391 km^2, just under half the area of Spain (290). It is situated in the South Eastern part of Central Europe between latitudes 43°37'07" and 48°15'06" North and longitudes 20°15'44" and 29°41'24" East and shares borders with Hungary to the northwest, Serbia to the southwest and Bulgaria to the south. The Black Sea and Ukraine are located to the nation's southeast and north respectively while the Republic of Moldova is to the country's east.

Physical conditions across the country are quite diverse. About 31% of Romania's territory is covered by mountains, about 36% by hills and orchards, and 33% by plains, rivers and lakes cover around 3.7 % of the country's area (290). The climate is also varies by season, latitude and altitude. As a country with temperate climate, the median temperatures during summertime are between 22°C and 24°C and during wintertime between -3°C and -5°C. However, there are noticeable difference in temperature between mountains and plains. For example, extreme low temperatures of -38.5°C have been recorded in town of Bod, in Brasov valley (in the mountains), and extreme high temperatures of +44.5°C have been recorded in Ion Sion town in Bărăgan plain. Variations in temperature impact on the needs of people with mental health problem, in particular in housing, living conditions in inpatient settings, as well as access to food and transportation for visits to health facilities. Heat waves and frequent floods in the summer can be as challenging as the heavy and prolonged snow falls in the winter.

The country was historically divided into three provinces, Moldavia, Transylvania and Walachia, and a number of smaller regions: Dobrogea, Oltenia, Banat (part of Walachia), Maramures (part of Transylvania), and Bucovina (part of Moldova). The three provinces were separate entities since the time of the Roman conquest in 105 AD, sometimes independent, sometimes annexed (in parts or entirely) by, or as vassals of the 3 neighbouring empires (Ottoman, Russian, and Turkish). There are some cultural differences between provinces and regions, reflected in variations in cooking, folklore, and accent. However, despite having a fairly large and physically diverse territory, and distinctive provincial cultures, the 21,584,365 population of Romania is largely homogenous. The ethnic composition is 89.5% Romanian, 7.1% Hungarian, 1.8% Roma and 1.6% other ethnic groups. The majority of the population (86.7%) have declared their religious identity as Romanian Orthodox. Other religious groups are: 5.1% Roman Catholic, 3.5% Protestant, 1% Greek-Catholic and 3.7% other religious affiliations (2). The Romanian language spoken on the territory of Romania (as compared to the Republic of Moldova) does not have any dialects, despite some regional differences in accents and some slight variation in vocabulary. Consequently, it is not necessary to seek to capture regional, ethnic, or religious differences when undertaking the Rapid Assessment, but discussions with participants will enquire about the treatment of ethnic and religious minorities.

About 55% of the population live in urban areas. The country is divided administratively into 41 counties, with 263 towns, 2,868 communes and 13,285 villages. The capital city, Bucharest, has the status of a county and a population of more than 2,200,000 (291). Large cities tend to be wealthier, with better public services but less community cohesion than provincial towns. Hence, the research will be undertaken in two locations, one large city and one provincial town.

Governance

Understanding the system of government in a country is important when it comes to making recommendations for action. Romania is a semi-presidential democratic republic where executive functions are shared between the President and the Prime Minister. The President is elected by popular vote for a five-year term. The Prime Minister is appointed by the President. S/he heads the government and appoints the members of his/her Cabinet. The legislative branch of government, the Parliament, consists of two chambers, the Senate (137 seats) and the Chamber of Representatives (334 seats). The members of both chambers are elected for a four-year term.

Corruption

The Romanian health system cannot be understood without considering the role of corruption. Romania was ranked number 69 out of 180 countries (last of all EU counties) in the 2007 Corruption Perceptions Index. This index ranks countries in terms of the degree to which corruption is perceived to exist among public officials and politicians (292).

33% of respondents to the Transparency International Global Corruption Barometer 2007 reported paying a bribe to obtain services. This is the highest rate in the EU. The impact of corruption on different sectors and institutions in a country were ranked on a 1 to 5 scale (where 1 was "not at all corrupt" and 5 was "extremely corrupt"). In Romania, political parties and parliament scored 3.9, the legislative system/judiciary scored 3.8 and medical services scored 3.7 (293). Later on in this chapter I will discuss the impact of corruption on the health care sector, as expressed in unofficial out-of-pocket payments made by patients. Furthermore, the participants to the research will be asked about their own experience with corruption and how (if) it limits their access to specialist health care.

Economy

Romania is a middle-income country with a GDP of US$ 169 billion and a GNI per capita of US$ 6,430 in 2007 (294) and 13.8% of the population living below the poverty line (295). The gross monthly income was 1522 Romanian New Leu (RON) (€370) in November 2007, and the net was 1121 RON (€273) (296), while the unemployment rate was 6.4% (7.2% for men and 5.4% for women) (297). The country ranked number 60 in the 2007 Human Development Index (298). In the World Bank 2007 Doing Business report (299), Romania was ranked as the top economic reformer in Europe and the second in the world for the period 2005-2006, the years before the current research was carried out. The economic situation of the country clearly impacts on the funds available for the health sector.

Key partners

Romania is a member of the United Nations (as of 1955), the Council of Europe (as of 1993), NATO (as of 2003) and the European Union (as of January 2007). As such, policy and legislation adopted by these international organizations, as presented in Chapter 3, are applicable to Romania.

Health status of the population

Life expectancy among Romanians is lower than the EU average, though it has increased slightly over the last 20 years, reaching 69.7 for men and 76.9 for women in 2007. The leading causes of death remain cardiovascular diseases (62.1%) and malignant tumours (17.6%). Romania remains the country with the highest infant mortality in the EU (300). However, mortality data provide only a partial picture. The greatest contributors to the overall burden of disease are cardiovascular diseases (27% of all DALYs), followed by neuropsychiatric disorders (18% of all DALYs) and malignant neoplasms (12% of all DALYs) (2).

Age-standardized DALYs estimates for 2004 indicate that the burden of diabetes mellitus accounted for 1.5% of the total and schizophrenia for 1.3% (2). According to WHO Health for All Database, the prevalence of diabetes mellitus was 2.73 in Romania in 2009 (301). There are no prevalence data for schizophrenia in Romania.

Romanian Health System (RA Module 3: Contextual assessment)

The health system is an important part of the context in which the research in embedded. The following section will present an overview of the Romanian system, covering key aspects of governance, service delivery, human resources and financing. This information will inform the conclusions drawn from the research.

Governance

At the national level, the lead institutions in the Romanian Health System are the Ministry of Health, the National Health Insurance Fund and the Romanian College of Physicians (250). Each of these institutions has responsibilities in the development of policies in their respective fields, which they implement through their branches at district level.

The Ministry of Health (MoH) is responsible for developing and implementing the government's health policy. Its stated aims are to ensure the health of the population and the implementation of health systems reform. It states that it leads, coordinates and organises all the activities necessary to secure the health of the population, the prevention of diseases (302).

The official priorities of the Ministry of Health at the time of the research (302) were to increase accessibility to health services and improve the quality of these services, to strengthen health system financing, as well as to decentralize the health system and coordinate institutional reorganisation of the Ministry, its arms-length agencies and health care providers.

At the district level, the Ministry of Health has a network of offices that are in charge of coordinating and monitoring the local implementation of national policy and health programmes and all health care services. Additionally, the Ministry of Health coordinates activities of a number of arms-length research and specialist institutes in charge of delivering on different health agendas (e.g. the National Institute of Public Health, and the National Centre for Mental Health).

The Ministry is responsible for the legal and regulatory framework of the health care system. This includes the development and approval of the Framework Contract on the Conditions of Providing Health Care within the Health Insurance System (hereafter Framework Contract) (271, 272), that defines the package of services covered by the National Health Insurance Fund (NHIF). It is also responsible for policies and regulations on public health policies and services, regulation of the pharmaceutical sector and regulation of sanitary inspections. It is responsible for developing the country's human resources policy and for building capacity for policy analysis and management of the health care system. It is responsible for monitoring the impact of financing reforms and assessing the need for capital investment.

The **National Health Insurance Fund** (NHIF) is an autonomous public institution whose president is appointed by the Prime Minister. Its main responsibilities are three-fold. Firstly, it develops a strategy for the health insurance system, which it administers and regulates. Secondly, based on the annual Framework Contract, it implements the benefit package to which the insured are entitled. Thirdly, it oversees provider payment mechanisms. The NHIF decides on the distribution of resources among different types of care and districts. It operates through district branches, whose activity it coordinates and supervises.

The **College of Physicians** (CoPh) is responsible for regulating the medical profession, including training and accreditation.

Health Priorities

The national health priorities are established though two main mechanisms of the MoH: the national strategy and a series of National Health Programmes. The first document describes the general and specific objectives of the MoH over a specified period of time. Its impact is, however, questionable as it has no funds, no monitoring mechanisms, and no system of accountability. In contrast, the National Health Programmes (such as the National Programme for Mental Health (254)) are updated annually and are funded. The responsible agency is clearly identified and is required to report on implementation each year. While most health services are covered by social insurance, these national health programmes allow for additional investments in areas that are considered a priority by the MoH.

Service delivery

Health basket

The Ministry of Health (MoH) and the National Health Insurance Fund (NHIF) develop, in partnership, a health basket for insured people. The Ministry of Health establishes standards of care and draws up clinical guidelines, while the NHIF is responsible for developing payment mechanisms for providers. A Framework Contract (271, 272) is negotiated and approved annually between the MoH and the NHIF.

Health insurance covers the whole range of services from primary care to specialist inpatient and outpatient care, as well as preventive health, dentistry, medical emergencies, medical rehabilitation, home nursing, medication, health care supplies and medical devices (259).

The system has gatekeepers in primary and ambulatory care. Those insured also have free choice of any health care provider (ambulatory specialists, hospital, etc.). However, if a person chooses a provider located in another locality, they must cover their own travel costs. All services included in the benefits package are free at the point of use, with entitlement indicated by a NHIF membership card.

Service providers

According to National Institute of Statistics (303), in 2007 health care was provided in 448 general hospitals, 400 specialised hospitals and ambulatories, 263 polyclinics, 206 dispensaries, 46 health care centres, 5 tuberculosis sanatoria, 67 health and social care units, 27 diagnosis and treatment centres, 135 specialised health care centres, 8370 specialised health care offices, and 12084 GPs offices. In 2007, the hospital admission rate was 24.2 per 100,000 population and the average length of stay in hospital is 7.6 days (301). In the same year, reported outpatient contacts with health services were 5.6 per person per year.

Quality assurance

At the time of the research, there were no specific systems for quality assurance of health services. While the Framework Contract (271, 272) indicated that health services would only be paid for by the NHIF if they meet certain standards, there is no enforcement mechanism in place. However, a Commission for Accreditation of Hospitals has recently become operational and is developing an accreditation system began to be implemented in 2010 (304).

Human resources

In Romania there are five recognised categories of staff working in health services: medical doctors, nurses, pharmacists, auxiliary staff (264) and other professionals contributing to health care (e.g. psychologists, laboratory staff or physiotherapists) (265).

According to the WHO Health for All database (301), in 2007 there were 212.2 physicians and 563.2 nurses per 100,000 population. Almost half of the physicians (49.1%) and the majority of the nurses (59.2 %) work in hospitals. There were 122.5 general practitioners per 100,000 population.

In spite of a reported shortage of staff in all categories, the Ministry of Health has no needs-based workforce strategy. Rather, the figure is mainly linked to the training capacity of universities and other educational institutions and there is no system to feed back evidence of shortages or surpluses.

The Romanian health system has faced shortages of trained staff in recent years as a consequence of migration. At the time of the research, there was no adequate system in place to monitor how many health workers leave Romania each year for other countries. The Ministry of

Health only records those who seek confirmation of their qualifications before migrating. A recent study showed that a high proportion of personnel who still work in the system report that they would like to leave (305).

Financing

Population coverage

The Romanian Constitution guarantees the right to health care for all Romanian citizens (306). Health insurance coverage is compulsory for all citizens, as long as they can provide valid identity documents, which in effect does tend to exclude some groups such as Roma (259). Persons with disabilities, war veterans, pregnant women, and children are exempt from paying contributions, which are funded from national health programmes (250, 273).

By law, health care services and medication are to be provided to all those covered by insurance, without discrimination. However, in order to maintain their entitlement to health care, the insured persons are obliged to follow strictly the treatment regimen prescribed by a doctor.

Revenue collection

Total health expenditure as a proportion of gross domestic product (GDP) in Romania was 4.7 in 2007 (301). The NHIF is the main vehicle for health spending; in 2007 it was estimated to have contributed around 75% of all health spending (250). However the NHIF faces a major challenge in that while its main source of income is contributions by insured people (up to 98% of all its revenue in 2004), only 5 million people of the over 21 million people entitled to benefits were paying contributions in 2005. Contributions are collected by the Fiscal Administration National Agency of the Ministry of Finance, or in the case of the self-employed, by the district offices of the Health Insurance Fund. Contributions for people receiving unemployment or other social benefits are paid by the Ministry of Labour and Social Solidarity and Family.

Taxation is the second source of health spending, accounting for 13.5% of overall health spending in 2003 (250). The Ministry of Finance allocates funds from general taxation to the Ministry of Public Health, which then funds the District Public Health Authorities. These funds are used to finance the National Health Programmes of the MoH, capital investment, high-technology medical procurement and support for certain arms-length bodies accountable to the Ministry of Health. The funds from taxation are variable and vulnerable to changing political priorities. For example, in 2007, the contribution of taxation to health spending increased as taxes on alcohol and tobacco were allocated to the health budget to cover certain National Health Programmes considered priorities at the time (e.g. the programme for people with mental health problems). This was due to pressure from the European Commission to speed up mental health reform at the time of EU accession. The fluctuating nature of these funds makes it difficult to use them for implementation of sustainable reforms.

The other source of health spending is out-of-pocket payments (250). These take different forms. Direct payments may be made either to private health care providers or for goods and services that are not covered by insurance or National Health Programmes. Co-payments and gap payments (between the actual and reference price) may also be paid for services and drugs respectively. Additionally, persons who obtain specialist health services without referral have to pay fees, other than in an emergency or where they already a confirmed diagnosis which requires regular specialist care.

Lastly, informal payments for medical services are another form of out-of-pocket payment that may be incurred. While those covered by insurance should have free access to health care, according to a World Bank study, in 2004 "Romanians paid about USD 1 million a day in bribes for medical staff", because "they felt the need to hand over cash to guarantee [a] basic standard of service"((307), p. 1515). The study found this practice to exist across all levels and areas of the health system and is acknowledged by health authorities in Romania (especially the Ministry of Health and College of Physicians) as a major challenge.

Commissioning

The National Health Insurance Fund (NHIF) is the main commissioner of health services in Romania. The NHIF decides on the distribution of resources to different types of care and to each of its district offices. Both public and private service providers (e.g. hospitals, ambulatory care and primary care) are contracted on the basis of the yearly Framework Contract (271, 272) by the District Health Insurance Funds. The NHIF also contracts with institutions providing long-term medical care.

The majority of health care providers in the outpatient sector are no longer state employees but instead are paid through a variety of contractual arrangements by district offices of the NHIF. Thus, the former polyclinics have been turned into independent outpatient health facilities and specialists working in these facilities are paid on a fee-for-service basis.

Hospitals are paid prospectively using a mixture of methods. Payment for medical personnel working in hospitals is still based on salary. However, hospital boards can set salaries according to individual competency and workload (within some limits). Most hospitals are publicly owned, with only limited private involvement.

Health system reform

Romania has lagged behind most of the Central and Eastern European countries in its implementation of health system reforms. The two main reforms introduced in post-communist Romania were, firstly, the establishment of primary health care that established the speciality of General Practice (GP), with creation of general practices covering the entire insured population and, secondly, the reform of the health financing system, which introduced health insurance.

Mental health and diabetes care

Governance

While there is considerable overlap, there are different organisational structures for the delivery of care for those with mental illness and diabetes. These can be divided into: policy development, definition of package of services, service delivery, responsibility for those registered with disabilities, and professional regulation (Figures 15-18). The main difference between the two systems is that, in the case of diabetes, there is no a separate institution assigned the responsibility for coordination of diabetes care nationally that corresponds functionally to the National Centre for Mental Health. Instead, the main service provider in the country, the National Institute for Diabetes, Nutrition and Metabolic Diseases "Prof. Dr. N. Paulescu" in Bucharest, also plays a policy and coordinating role.

Figure 15 **Policy development**

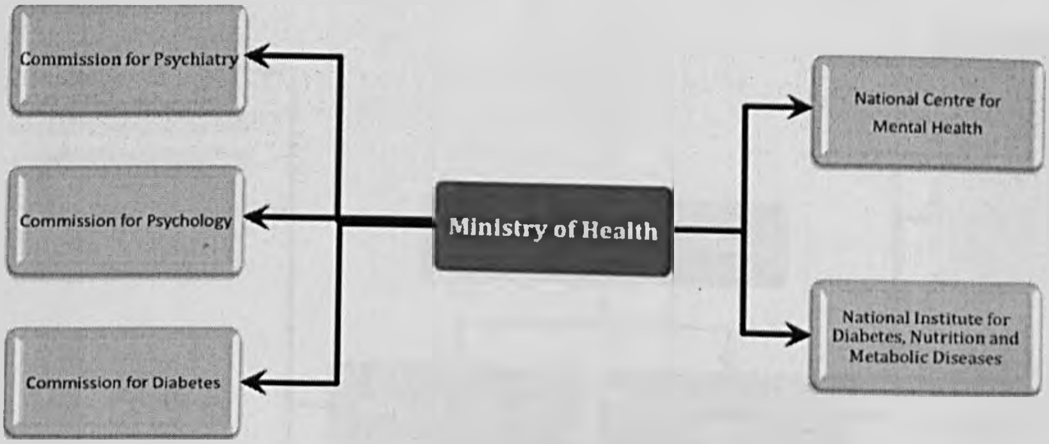


Figure 16 **Specialist health service delivery**

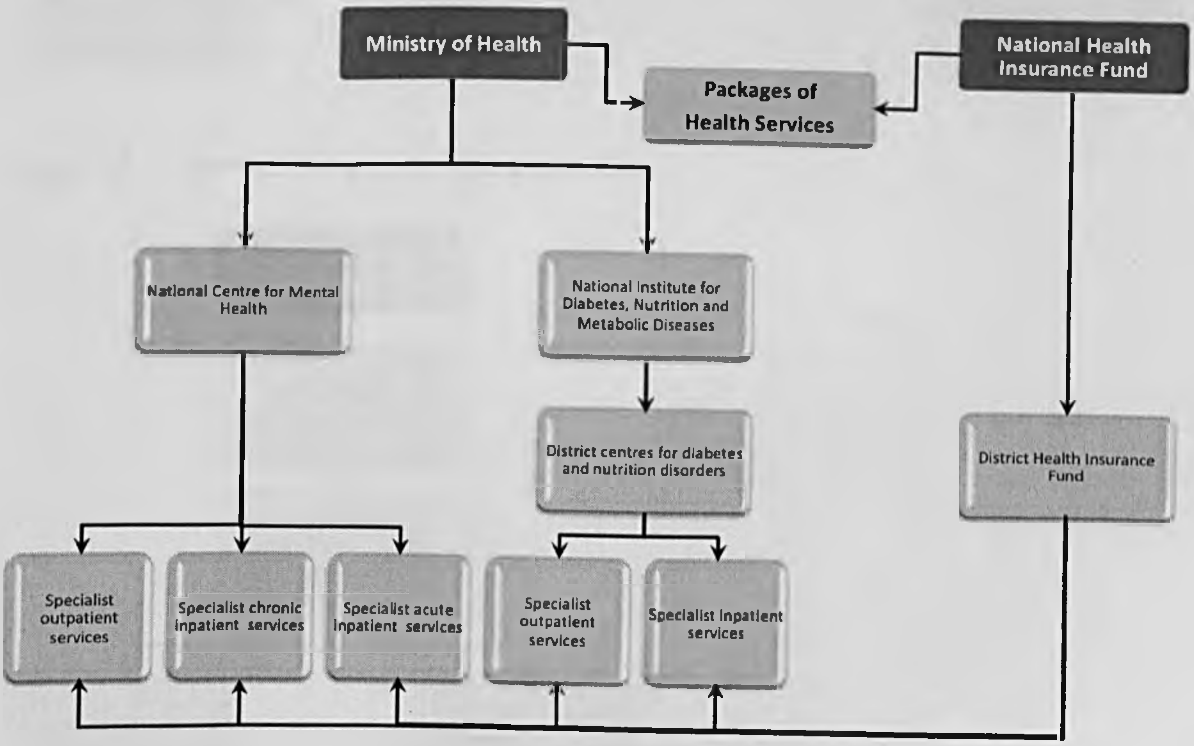


Figure 17 Professional bodies

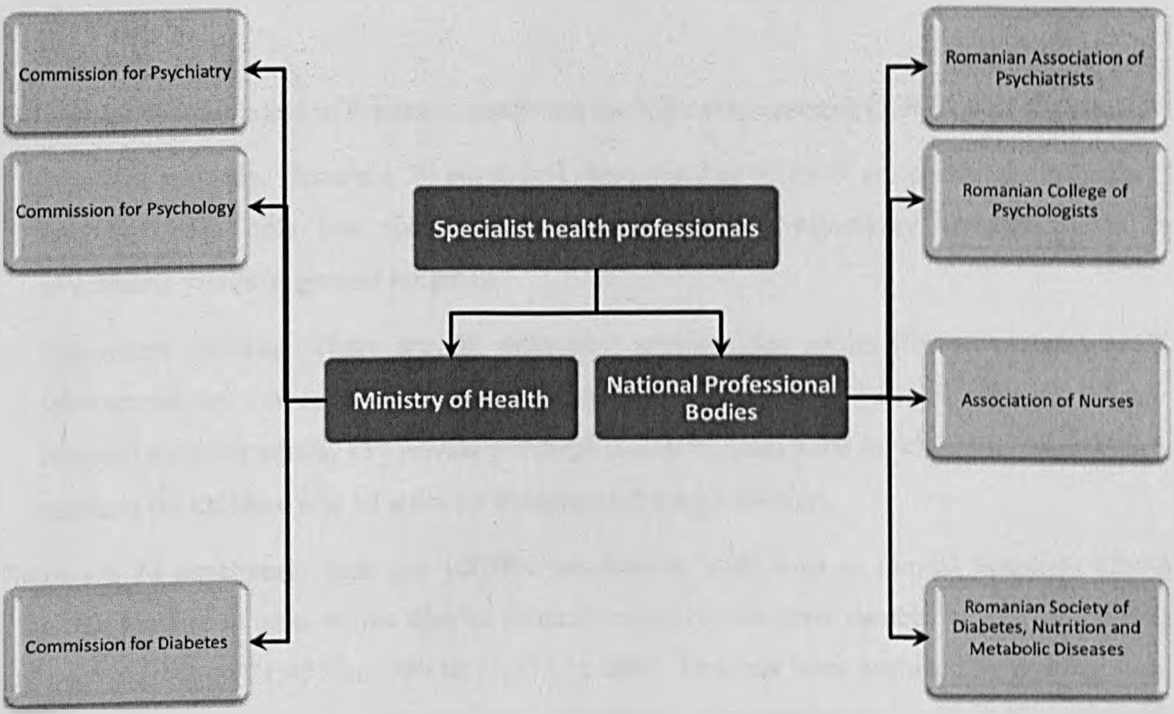
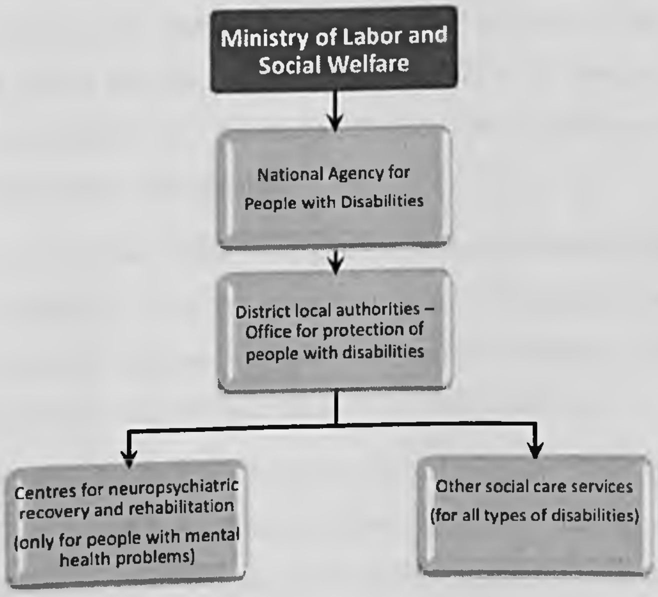


Figure 18 Services for people with disabilities



At the time of the research, inpatient services were provided by 24 hospital sections with a total of 732 beds and by 24 wards with a total of 249 beds. Data on outpatient services, private practices, admissions and visits and comparison with European services are not available.

Primary care plays little role in the treatment of people with type 1 diabetes, who are managed primarily by specialist physicians. At the time of the research, GPs did manage people with type 2 diabetes, but this is outside the scope of the current research.

Human resources

Romania has among the lowest densities of psychiatrists in Europe (at 4.7 per 100,000 population) but the density of nurses working in mental health settings, at 22.4 per 100,000 population, is comparable with the European median (223). The ratio of psychiatrists to nurses in Romania is 1 to 5, while the median in Europe is 1 to 2.4.

At the time the research, there were 98 diabetes physicians with the highest level of specialisation (primari), 95 diabetes specialist physicians, 29 physicians with competency in diabetes, nutrition and metabolic disorders, and 121 diabetes resident physicians in the country. The number of nurses working in diabetes care was not available.

Most nurses currently working in mental health and diabetes care have only generalist training. However, special courses to train mental health nurses and courses in dietetics for nurses working in diabetes care have been organised in recent years, with some specialised nurses already entering the workforce.

The number of other health professionals treating patients with severe mental illness or diabetes, such as psychologists, social workers, dieticians, or occupational therapists, is not recorded. The mental health team is led by a psychiatrist and the diabetes care team by a diabetes physician.

Financing

In 2006, mental health accounted for 3% of the total health budget, placing Romania 3rd lowest among the 34 European countries for which data are available (223). However, this excludes Ministry of Health funds for improvements in hospital infrastructure and community based services. These amounted to €25 million between 2006 and 2008 (308) but were only temporary. There are no comparable data for diabetes but one study has estimated the mean health

Service delivery

The mental health system in Romania comprises the following services (308):

- Inpatient services. There are 39 psychiatric hospitals, of which 9 are specialist hospitals (5 hospitals have only one speciality, and 4 are forensic psychiatry hospitals), and 75 psychiatric wards in general hospitals.
- Outpatient services. There are 36 outpatient services for adults (former mental health laboratories are currently being upgraded into community mental health centres), 20 day-hospital units for adults, 137 private practices, 8 day-hospital units for children, 14 outpatient services for children and 10 units for treatment of drug addiction.

There are 74 psychiatric beds per 100,000 population, with most in mental hospitals (75%), while the rest are in units within district general hospitals. The total number of psychiatric beds has decreased from 21,477 in 1990 to 15,959 in 2008. This has been achieved by closing many of the large isolated psychiatric hospitals, so that the number of beds has halved, from 9,442 in 1990 to 4,926 in 2008. In contrast, there has been little change in urban areas, from 12,035 in 1990 to 11,033 in 2008. However, the admission rate, which is more than double the European mean (1,301 versus 568 per 100,000 population) has remained almost constant in rural areas (39,415 admissions in 1990 and 40,672 admissions in 2008) and in urban facilities has actually increased, from 139,123 to 221,435. This has led to severe overcrowding in some facilities, often resulting in bed sharing.

Primary care plays a marginal role in the treatment and care of people with severe mental health problems. They are usually referred to specialist settings (223). This is one reason that this research focuses on specialist services. Further, there are no formal partnerships between primary care and specialist mental health services.

Diabetes care has a long history in Romania (309). The first diabetes ward was opened in 1934, and in 1942 the first Anti-diabetes Centre was open in Bucharest, an outpatient unit where patients were monitored. The first specialist physicians in diabetes, nutrition and metabolic disorders graduated in 1976. In 1993 the Institute for Nutrition and Metabolic Diseases was established.

expenditure per person with diabetes at US$ 149.3 in 2007, placing Romania 39th out of 51 countries in WHO Europe, and last of all EU countries.

The 2007 National Programme for Mental Health (254) had a total budget of 46.3 mil RON (about €11 million), while the National Programme for Prevention and Control of Diabetes (258) had a total budget of 303 mil. RON (about €72 million).

Summary

This chapter provides an overview of setting of the research, and gives insight into the Romanian health system. It shows the framework within which the mental health and diabetes services operate. It shows how the Romanian health system faces many challenges. This provides the context for the findings of the *de jure* and the *de facto* assessments described in the following chapters.

Chapter 6 Findings of the review of mental health policy and legislation (RA Module 4: Health intervention assessment)

We now move to the empirical part of the thesis. The first task is to assess whether the Romanian health system responds in a comparable manner to the needs of those with severe and enduring mental health problems (exemplified by schizophrenia) and those with a chronic physical illness (exemplified by type 1 diabetes). The assessment is based on the criteria set out previously that operationalize the elements of the Conceptual Framework (271, 272). In this, and the subsequent two chapters, I look at the *de jure* situation, asking what provisions are enshrined in the laws and policies that relate to the care of those with the two disorders. In this chapter I look at how these provisions relate to mental health. In the subsequent chapter, I look at how they relate to diabetes and then, in a third chapter, I compare the two.

Before doing so, it is necessary to be familiar with the legislative process in Romania and the resulting limitations of the documentation resulting from it. In theory, primary legislation should be presented to parliament, often after input from relevant agencies and following discussion in cabinet. It should then be scrutinised by both houses of parliament and, after successful passage, signed by the president. In reality, there are two more common approaches.

The first, which is now common, is to adopt ordinances (regular or emergency), which have the status of primary legislation. This is justified by the government as a means to speed up the legislative process.

The second approach is often used when primary legislation is adopted by the parliament but crucial provisions are omitted from the text. This has the benefit, for the government, of avoiding a lengthy and difficult process of negotiation that would put the passage of the law at risk. Instead, the missing provisions are left for secondary legislation (in the form of ministerial orders or regulations). The task of developing this secondary legislation is delegated to relevant ministries. In both these ways, the executive assumes a quasi-legislative role, circumventing the role of Parliament.

One disadvantage is that the quality of the drafting is often poor and related items of legislation are poorly co-ordinated. A second is that the absence of parliamentary scrutiny means that legislation can be easily amended by the executive. Indeed, one of the legislative acts examined here has been amended as many as 46 times, often in response to short-term political interests (Annex 4). The legislation is not consolidated after each amendment so it is necessary for those seeking to understand the current situation to read through each of the amendments listed in legislative register. This requires substantial effort and is extremely challenging.

Unfortunately, even those items of primary legislation that have undergone the full parliamentary process may also exclude detailed provisions on implementation and accountability mechanisms, making it difficult to understand the actual implications of the legislation, or even whether any implications arise at all.

The situation is complicated further by the existence of policies, many of which seem to have been developed to demonstrate to the international community that issues have been considered but which are non-binding and have no mechanisms for monitoring or enforcement.

A consequence of this legislative and regulatory muddle is that people with schizophrenia and type 1diabetes are subject to different areas of legislation that are neither coordinated nor coherent. The relevant measures arise from legislation developed by different ministries, singly or in combination. Thus the Ministry of Health is responsible for legislation on health care in general and on mental health in particular and the Ministry of Social Welfare is responsible for legislation on disability. The Ministries of Social Welfare and Finance come together to agree the legislation on social welfare. The Ministry of Health and the National Health Insurance Fund (NHIF) agree a Framework Contract (271, 272) that sets out the entitlements for care paid for by the health insurance fund. The National Authority for People with Disabilities (ANPH) is an arms-length body accountable to the Ministry of Social Welfare and can propose legislation to the ministry and enact non-binding policies. Unfortunately, it is not obvious which legislation has primacy when there are contradictions.

The most important practical implication is that the Framework Contract (271, 272), agreed between the Ministry of Health and the Insurance Fund, establishes in detail the standards that apply in health facilities of all types as well as what types of care the insurance fund will pay for. However, the Framework Contract is not aligned with the mental health legislation, so that certain of its provisions for people with mental health are not matched by a funding stream from the insurance fund. This has, in practice, provided a means for the government to adopt international standards in its mental health legislation while not making any provision to implement them. The same is true of *much of its legislation on disability, to the extent that it* interacts with the health system.

To whom do these laws refer

People with severe and persistent mental health problems are defined differently in the various pieces of legislation that exist, as well as in the regulations that arise from them. One definition appears in the mental health legislation (256). This identifies people with severe mental health problems as those who cannot understand the meaning and consequences of their behaviour and, therefore, need immediate psychiatric care. This will obviously include those who are actively psychotic. However its application to those with severe mental health problems who retain their mental capacity is less clear and it conflates people with learning disabilities and those with severe mental health problems.

The second definition appears in the policy and legislation on disability. The National Strategy for the Protection, Integration and Social Inclusion of Persons with a Disability, which covers the period 2006 to 2013 (276) defines disability as the loss of or limitation in a person's opportunities to participate in the life of the community at a comparable level to all other members of the community on account of their so-called "deficiencies" (physical, sensorial, psychological, mental and\or combined). This definition contains an explicit value judgement that people with disabilities are somehow deficient. This includes persons "with a mental or psychiatric disability due to underdevelopment or regression, or as a result of psychiatric deficiencies due to severe and pronounced neuropsychiatric diseases". It refers to persons in need of special protection; those with psychosis and/or with severe and pronounced behavioural problems, starting in early life (childhood or adolescence) or affecting the capacity for integration and performing organised activities. It also includes persons with autism, schizophrenia and dementia due to acquired cerebral damage, with or without personality disorders. The legislation is more detailed (274, 275, 281, 284, 286). In it, people are categorised as having a severe or pronounced disability according to the intensity of problems, the need for constant supervision and the capacity to perform daily activities independently. People with schizophrenia are categorised as severe if they have lost the capacity for self-determination, independent functioning and self-care. Those who partially retain their capacity for self-determination or independent functioning or who do not need continuous supervision are classified as having a pronounced disability if they can work in protected workshops but cannot retain any other employment. This is regardless of how demanding the job is. People with type 1 diabetes are classified as having a severe disability when they suffer from typical complications affecting one or more systems (have severe disability affecting sight, mobility, locomotion, postural or urological function), or when they suffer from severe functional problems due to Charcot Arthropathy of the feet. Pronounced disability resulting from type 1 diabetes is deemed to exist when the individual has unstable metabolic function, with or without metabolic decompensation. Persons with physical or mental handicap resulting from voluntary action (self-harm) are not eligible to be certified as disabled.

The current legislation and related policy on people with disabilities is, in general, in accordance with international standards, largely as a consequence of international reports on human rights abuses in Romanian institutions. However, the narrow and imprecise definitions of disability mean that these standards do not, in reality, apply to most people with severe mental health problems.

The third definition is in social welfare legislation (266, 286). It considers people with severe and persistent mental health problems from a different perspective. They are considered to be "invalids" (referring mainly to their incapacity to work), with very few specific rights regardless of the severity of the disease. The legislation recognises three levels of invalidity: invalidity of the 1st degree (total loss of the capacity to work or to manage on their own and of movement or spatial orientation such that the person needs constant care and supervision), invalidity of the 2nd degree (total loss of the capacity to work but the person still has the capacity to manage on his/her own and has movement and spatial orientation, without the help of another person), and invalidity of the 3rd degree (partial (at least half) loss of the capacity to work such that when the person can work partially). The severity of invalidity is established by doctors working for the social insurance system, specialised in medical assessment. This process is undertaken mainly for health insurance purposes.

Fourth, and finally, the regulations for the NHIF include people diagnosed by specialist physicians with severe and persistent mental health problems within the category of patients with chronic disorders who are entitled to direct access to specialists (271, 272).

The remainder of this chapter assesses the different pieces of legislation against the criteria set out earlier.

1. Accessibility of specialist services

1.1. Access to care in the least restrictive environment/community-based settings

The analysis of policy and legislation paints an ambiguous picture regarding access to care in the least restrictive or in community-based settings. Indeed, it is unclear as to whether or not people with mental health problems have any guarantee of access to specialist services in the least restrictive settings. On the one hand, the Mental Health Law (256) requires that services be provided where people with mental health problems live. According to it, the package of services that should be made available include: a) mental health centres; b) psychiatric offices and offices for assessment, therapy, psychological counselling and psychotherapy as well as assessment and therapy for speech disorders; c) crisis intervention centres; d) home treatment; e) psychiatric hospitals; f) day centres (i.e. small specialist centres administratively linked to district general hospitals); g) psychiatric wards or departments in general hospitals; h) psychiatric centres connected to general hospitals; i) centres for recovery and social reintegration; j) protected workshops and homes; k) centres for counselling for domestic violence.

The Implementation Rules (257) that accompany the Mental Health Law specify that services should be available in sectors with a population of 100,000 to 150,000 to ensure that those in need can access services where they live. This secondary legislation requires a slightly different structure of services than the primary legislation: a) a mental health centre (with mobile units, a centre for crisis intervention and a day centre); b) a stationary day unit, c) psychiatric offices; d) facilities with beds which may or may not be used for legal detention; and e) units with a maximum of 40 beds for the long-term care of people with severe and persistent mental health problems. In addition, they state that each psychiatric sector should provide the following types of services: a) psychiatric ambulatory services; b) mobile assistance services (for patients that are difficult to treat or who refuse to access health structures/services but who accept treatment, or for addressing various psychosocial needs that require presence of therapeutic teams at a community location); c) psychiatric day services (occupational therapy, individual or group psychotherapy, specialised rehabilitation programmes – this is available for patients admitted to day-time stationary units for a maximum period of 2 months, after which period they are referred to rehabilitation centres or primary care services); d) rehabilitation services (occupational therapy programmes, vocational rehabilitation programmes, leisure-time programmes or psycho-educational programmes); e) hospital services; and f) home care.

Further details on how these services should be provided to the target population are provided in another piece of secondary legislation published since the Mental Health Law (253), providing a framework for creating the mental health centres referred to in the Law. These centres should develop from existing outpatient services (known as Mental Health Laboratories). Most outpatient services are linked to mental hospitals or psychiatric departments in general hospitals. Services to be provided by the new mental health centres, according to this piece of secondary legislation, are very similar to the ones listed in the Implementation Rules and include: crisis interventions; mobile services; and rehabilitation services providing vocational and leisure/recreational rehabilitation programmes as well as counselling for patients and families.

The National Mental Health Strategy (251) also requires that specialist services be provided in community-based mental health centres, psychiatric hospitals, psychiatric wards in general hospitals, day-care services, crisis intervention centres and networks specialised in addiction, mental health of older people and others, etc *(sic)*. The document stresses the centrality of the community-based mental health centre, envisaged as becoming the main provider of mental health services. The Mental Health Action Plan (252) which, at the time of the research was in draft form, reinforces this point while adding that there is an acute need to improve the quality of psychiatric hospitals (currently the main providers of mental health services) and decrease the number of admissions by providing alternatives outside the hospital. The (draft) Action Plan also mentions that the community-based mental health centres should offer vocational rehabilitation, leisure and education and provides a detailed description of the services included in the law.

However, the model of care promoted by the mental health legislation and strategy is not reflected in the legislation that establishes the overall healthcare basket, namely the Framework Contract (271, 272). According to this document, specialist mental health services should be available in psychiatric offices, specialist outpatient services linked to mental hospitals, and in psychiatric hospitals. Emergency care provided in emergency rooms of health facilities is also covered by insurance. The Framework Contract classifies patients presenting with hallucinations or in a state of confusion as major emergencies, for which emergency treatment should be available. The document does not indicate, however, in which settings these emergencies are to be dealt with.

In the Framework Contract, specified hospital services include continuous hospitalisation (for the entire duration of treatment), hospitalisation for one day (maximum 24 hours), and day services (maximum 12 hours). The document sets out criteria for admission to hospital. These are: a) for medical emergencies, when the patient's life is at risk or when the patient needs continuous medical supervision; b) when the diagnosis cannot be established in outpatient units; c) when the treatment cannot be provided in outpatient units or when the patient cannot be moved; d) other circumstances documented by the physician in charge and approved by the head of section.

The optimal period of hospitalisation, as established by the specialised commissions of the Ministry of Health, and included in the Framework Contract (271, 272), is 17 days for acute psychiatric problems and 50 days for chronic psychiatric disorders. For chronic psychiatric patients who require long-term medical care, the average period of hospitalisation is the actual period of hospital stay during the previous year, rather than the recommended optimal period of hospitalisation.

Services that are usually provided in inpatient units can also be offered in outpatient units that have been authorised by the Ministry of Health in the event that admission is not strictly necessary (261). These services are covered by funds to hospitals. Hospitals are required to prepare a list of services that cannot be provided in outpatient services and require hospitalisation. These lists are included in the contracts between hospitals and the National Health Insurance Fund.

Finally, people deemed by law to be disabled should also have access to monitoring of their medical treatment within the framework of the social care to which they are entitled at home, in the community, or in the day centres and residential centres (such as centres for assistance and care, centres for recovery and rehabilitation, residential centres for people with disability or protected homes). This is based on individual needs, as defined by the criteria in the legislation for establishing the degree of disability (274, 281, 284). Thus, people with schizophrenia who are classified as severely disabled are entitled to continuous home-based medical, psychological and social monitoring, to a personal carer, and to specialist services. People with schizophrenia who are classified as having pronounced disabilities are entitled to a limited level of support. Home treatment is not available to them and the legislation places the responsibility for overseeing their care with the family (280). They are, however, entitled to regular check-ups to prevent complications arising. According to Government Decision 268/2007 (275), the social worker employed by the relevant local authority has a duty to check that these rights are upheld by the family or by the legal representative of the disabled person. Where they cannot ensure these rights, the local authorities must assume responsibility for them.

1.2. Geographical accessibility of services

The approach taken by mental health legislation on geographical distribution and availability of services is different from that of the overall health and insurance legislation. The Implementation Rules of the Mental Health Law (257) stress the importance of an equitable geographical distribution of services and require the organisation of specialised mental health services in sectors covering 100,000 to 150,000 population. Sectorisation is also reflected in the Mental Health Strategy (251) and the (draft) Action Plan (252). However, medication for people with mental health problems can be collected from pharmacies in other locations provided that they have been designated by the NHIF, based on VAT registration (271, 272).

The general health legislation requires a geographic distribution of human resources (at district, urban and rural level) (264), as described below (point 2.5.). The Framework Contract (271, 272) does pay for this but it is not coordinated with the mental health legislation on the distribution of services by catchment area.

1.3. Access to services when needed (temporal access)

The times when specialist services are available for people with schizophrenia are also inconsistent. The mental health legislation (253, 256, 257, 310) and related policy documents (251, 252) require that specialist services (including community-based crisis care, home treatment and assertive outreach) are available to people with severe and enduring mental disorders whenever needed.

At the same time, the Framework Contract (271, 272) requires that the outpatient specialist offices/practices should be open a minimum of 35 hours and a maximum of 52.5 hours per week. The inpatient specialist services follow a normal hospital programme, with emergency rooms available 24 hours a day, 7 days a week. Conversely, people with schizophrenia who are classified as severely disabled and qualify for home care should receive home services on the basis of a schedule agreed upon with the service provider Order 175/2006 (280).

1.4. Access to different parts of the system, as needed (Referral system)

Procedures for referral are established primarily by the insurance legislation. Once diagnosed, people with schizophrenia can, according to the Framework Contract (271, 272), access specialist outpatient services directly, subject to the agreement of the specialist physician in charge or whenever complications arise. The conditions for access to these services are: a) that persons with schizophrenia are registered with a GP but need services other than those which their GP can provide; b) that the therapeutic plan needs to be modified. The specialist physician is required to inform the GP if there are changes in the evolution of the disease or in the therapeutic plan and has to submit a monitoring plan for each patient to the National Health Insurance Fund. Patients with chronic disorders such as schizophrenia and diabetes can access specialised outpatient services without referral from the GP once the diagnosis is established. They may do so as often the specialist doctor in charge agrees or whenever there are complications.

Hospital services are available following referral by a GP, a specialist outpatient doctor, or a doctor working in medico-social institutions that have contractual relationships with the National Health Insurance Fund.

1.5. Financial access to services (financial affordability)

Insured people have free access to specialist mental health services. The Framework Contract (271, 272) specifies the services that are available within the national insurance system to people with severe and persistent mental health problems (as described in the previous section).

With regard to outpatient services, insured persons are entitled to 3 consultations (with an average duration of 30 minutes) to establish the diagnosis and the treatment plan, revise the plan or monitor its progress. These services are covered by insurance only when performed by the specialist doctor in his/her office/practice. When, at the request of the physician in charge, consultations are provided by other professionals such as psychologists or social workers (classified by the Ministry of Health as professions connected to medical practice (265, 311)), payments can only be claimed through the physician, conditional on the services being considered strictly necessary for establishing the diagnosis or treatment plan.

Hospital care is covered for insured people, while emergency care is provided free of charge to all patients (there are some Romanians who have been unable to obtain insurance, usually because they lack the necessary documents). Medication prescribed in outpatient services is either 100% free or with an out-of-pocket co-payment. Medication prescribed in hospital is entirely free. The list of drugs covered by the insurance fund is negotiated annually and specified in secondary legislation. The Framework Contract (271, 272) indicates that medication for conditions covered by National Health Programmes (such as schizophrenia) (254) should be covered in quantities required by therapeutic guidelines.

Legal mechanisms are in place to ensure that all people with severe and persistent mental health problems benefit from the same package of healthcare, even if they do not contribute to the National Health Insurance Fund. Thus, people that are registered with the National Authority for People with Disabilities as disabled have the right to health insurance without paying a contribution (274). Specialised services are provided following referral from physicians in social institutions or from GPs; persons utilising this system have the same access to medicines as insured people. Additionally, people benefiting from social pensions (including invalidity pension) also have their insurance contributions paid (286).

There is a final safety net in that the National Programme for Mental Health of the Ministry of Health (254) requires that people with severe and persistent mental health problems who do not contribute to the insurance system and are not insured or are not classified as disabled, should benefit from the same package of as insured people, once diagnosed.

In conclusion, by law, all people with severe and persistent mental health problems, be they insured, registered as disabled, on social welfare, or just diagnosed with schizophrenia by specialists in health services, should have financial access to specialist services included in the health basket.

2. Availability of evidence-based treatment and care

2.1. Availability of medication

Both the Mental Health Law (256) and the Framework Contract (271, 272) require that medication be available to people with severe and enduring mental health problems. The Law on Rights of Patients (260) also requires that hospitals have adequate medical supplies for patients. In fact, in the preamble of the Mental Health Strategy (251) it is noted that medication is the main and almost sole form of treatment provided by mental health hospitals.

In specialist outpatient services, people with schizophrenia can be prescribed medication for up to 30 days. When discharged they should receive a prescription to last 30 days.

Disability legislation (280) takes a similar approach to the mental health and insurance legislation and requires that those people with schizophrenia who are classified as severely disabled and qualify for home care should receive any necessary support when taking medication (in forms of pills, injection, etc.) and necessary related interventions. All interventions should be recorded in the patient's file. Details to be recorded are: the type of intervention, the time, date and duration of the intervention and the health status of the patient.

2.2. Availability of other evidence-based interventions

a) Psychosocial interventions

The psychosocial interventions guaranteed by the mental health legislation are different from those specified in the health insurance legislation.

The Mental Health Law (256) indicates the types of mental health services that should be available for people with mental health problems. These include: psychological counselling, psychotherapy and assessment and therapy for speech disorders. The Rules of Implementation of the Mental Health Law (257) state that therapeutic teams in the community and mobile assistance services should be available to meet the various psychosocial needs of persons with mental illnesses adequately. Individual or group psychotherapy should also be available for patients admitted to day units for a maximum period of 2 months, after which time they are referred to rehabilitation centres or primary care services. Psycho-educational programmes should also be provided by rehabilitation services, commensurate with local resources.

Similarly, another piece of secondary legislation (253) requires that community-based mental health centres (former mental health laboratories) provide treatment such as psychotropic medication and psychotherapeutic interventions, that mobile assistance services attend to various psychosocial needs, and that rehabilitation services offer counselling for patients and families.

At the same time, the Framework Contract (271, 272) establishes that existing outpatient mental health services are to be reimbursed for the following psychosocial interventions: a) an initial consultation that includes: anamnesis, psychological evaluation, establishing the psychotherapeutic objectives and the methods of treatment (with an average duration of 40 minutes); b) a check-up consultation that includes: performing and interpreting additional tests, conducting specialised tests (psychological test; IQ, social investigation, clinical tests and scales), undertaking re-evaluations, individual or family psycho-education, educational therapy (with an average duration of 30 minutes); c) individual and group psychotherapy (to treat psychosis, obsessive-compulsive disorders, phobic disorders, anxiety disorders, depression, addictions); d) individual non-specific psychiatric counselling; e) psycho-diagnosis (by a psychologist).

b) Rehabilitation and reintegration

Both the mental health and the disability legislation require that rehabilitation and reintegration services are made available to people with schizophrenia.

The Mental Health legislation (256) indicates the types of mental health facilities that should be available for people with mental health problems, including centres for recovery and social reintegration and protected workshops and homes. Its Implementation Rules (257) require that day-time psychiatric services offer occupational therapy and specialised rehabilitation programmes for patients admitted to day-time stationary units for a period of maximum of 2 months. After this period patients are referred to rehabilitation centres or primary care services. Also, the rehabilitation services are required to provide occupational therapy programmes, vocational rehabilitation programmes and leisure-time programmes based on resources at the local level. However, the Implementation Rules do not clarify which patients should receive these services. This is because people in need of long-term treatment should be referred to neuro-psychiatric recovery and rehabilitation centres or to protected homes that are the responsibility of the National Authority for People with Disabilities. The disability legislation (274, 275) provides no further details on this. It requires that people admitted to these institutions should receive therapy and rehabilitation based on individual assessment of needs.

The previously mentioned Order on Mental Health Centres (253) establishes that rehabilitation services should provide specialised rehabilitation programmes such as vocational rehabilitation programmes, leisure/recreational rehabilitation programmes and counselling for patients and families. It also requires that community-based mental health centres collaborate with services provided by other sectors (such as temporary or protected shelters, protected workshops, expertise commissions for the capacity to work and education centres) to meet the needs of patients with mental health problems. The (draft) Action Plan (252) also states that the community mental health centres should offer rehabilitation services and provides a detailed description of what should be provided.

The disability legislation goes beyond the mental health legislation and entitles those people with schizophrenia who are classified as severely disabled and qualify for home care to receive home-based recovery and rehabilitation services (280). The Framework Contract (271, 272) does not specify inclusion of any outpatient rehabilitation or reintegration services for people with schizophrenia. It does, however, include hospitalisation for people with severe and enduring mental health problems that require long-term medical care (deemed as chronic).

2.3. Social care

The social welfare legislation (266) states that social services should be provided to all those in need and those who are vulnerable and dependent on others, so as to increase their quality of life and promote social cohesion. These services should be provided in the community, at home, in day centres or residential centres. Entitlements vary according to whether individuals are considered "disabled" or "invalids".

a) Rights and entitlements for people with severe and persistent mental health problems, deemed as disabled by law

The disability legislation (274, 275) entitles those covered to a range of services including education and professional development, employment, supported employment and professional training, social care, housing, support with decorating their homes, transportation, access to the physical environment, information and communication, leisure time, access to culture, sport and tourism, legal assistance, fiscal facilities and regular (every 2 years) assessments of their health and social status. People with schizophrenia who are classified as severely disabled are entitled to a paid personal carer and relevant social services.

Disabled status entitles affected individuals to apply for early retirement, if they satisfy certain conditions related to duration of contributions (267, 286). Others not meeting these criteria can apply for an invalidity pension. These are granted on the authority of a doctor in the social insurance institution.

People with disabilities residing in certain institutional settings, specified in the legislation, are entitled to certain social services. These include centres for neuropsychiatric recovery and rehabilitation that accommodate people with learning disabilities and with mental health problems. These institutions receive funds from a variety of sources including local authorities, central government, and personal contributions by residents and their carers.

An order (278) entitles persons with disability, their families, and carers access to information about their rights and entitlements. However, the complicated legislative framework, with its frequent modifications, makes this difficult.

b) Benefits and entitlement of people with mental health persons that are considered, according to the law, to be invalids (permanent or temporary)

Those with severe mental health disorders not reaching the threshold to be considered disabled may qualify as invalids but benefit from far fewer entitlements than those who are disabled (267, 286). Invalidity allowances are based on previous earnings but the system is more complex. The basic invalidity allowance is only paid in respect of working days and official holidays. The cost is born by employers. After the 90th day, approval by a physician working in the social insurance system is required to extend it to 180 days. At that point, the physician can discontinue it, extend it for a single additional period of up to 90 days, or refer the patient for an invalidity pension. Following a period of leave on grounds of invalidity, the patient may return temporarily to work in a different job or return on a part-time basis. They may also be eligible for rehabilitation services.

2.4. Physical health

Physical health care for people with schizophrenia is primarily regulated through health insurance legislation, according to which they should benefit from the full package of care covered by the insurance system (259). An additional entitlement for people with schizophrenia admitted to mental health services is that they can benefit from some dental care free of charge.

Under disability legislation (274), the organisation providing social services should facilitate access to all relevant health services (including ophthalmology and dentistry). Additionally, those people with schizophrenia who are classified as severely disabled and qualify for home care should have regular check-ups at home.

2.5. Availability of enough staff in all settings

The requirements for staffing mental health services differ in various pieces of legislation. The Implementation Rules of the Mental Health Law (257) establish a system of psychiatric sectors, based on population numbers. Each psychiatric sector should cover 100,000 to 150,000 people and should have mental health teams composed of 8 full-time psychiatrists, 40 full-time registered psychiatric nurses, 4 full-time clinical psychologists, 5 full-time social workers and other staff members.

Conversely, the (draft) Action Plan (252) is based on hospitals. Mental health departments within general district hospitals should have three full time psychiatrists, 14 psychiatric nurses, one social worker, and one part-time psychologist. The document notes that there is a need for more psychiatrists at the national level and that the geographical distribution as well as the balance between inpatient (hospital) and outpatient services should be improved. The general health legislation (264), in contrast, bases its norms largely on bed numbers (Table 3).

Table 3 **Mental health staff in inpatient services**

	Inpatient services				
Staff categories	- Institutes and centres of speciality - Clinical hospitals - Regional emergency hospitals - District hospitals from university centres - Emergency hospitals	Units, sections and wards for chronic patients	District hospitals and hospitals with one speciality	Municipal and town hospitals	Rural hospitals
Psychiatrists	1 physician for 12 beds	1 physician for 20 beds	1 physician for 16 beds	1 physician for 20 beds	1 physician for 20 beds
Nurses	1 nurse for 10 beds per shift	1 nurse for 18 beds per shift	1 nurse for 14 beds per shift	1 nurse for 15 beds per shift	1 nurse for 18 beds per shift
Psychologists	1 psychologist per 80 beds in the psychiatric departments	1 psychologist per institution	1 psychologist per 90 beds in the psychiatric departments	1 psychologist per 100 beds in the psychiatric departments	-
Pharmacists	1 pharmacist per shift	1 pharmacist per shift	1 pharmacist per shift	1 pharmacist per shift	-
Auxiliaries	1 auxiliary per 23 beds per shift	1 auxiliary per 10 beds per shift	1 auxiliary per 25 beds per shift	1 auxiliary per 25 beds per shift	1 auxiliary per 26 beds per shift
Cleaners	1 cleaner per 225 square meters per shift	1 cleaner per 250 square meters per shift	1 cleaner per 225 square meters per shift	1 cleaner per 250 square meters per shift	1 cleaner per 250 square meters per shift
Social workers	-	1 social worker per unit	-	-	-

However, they further specify that staffing levels for mental health outpatient services are contained in secondary mental health legislation (253). This Order requires that each mental health centre (outpatient service) covering 150,000-300,000 population has, at a minimum, staff that include: 1 psychiatrist, 5 psychiatric nurses, 2 clinical psychologists, 2 social workers and 1 occupational therapist. This is one of the few occasions where the general health legislation integrates requirements of the mental health legislation (be it primary or secondary).

Finally, the disability legislation (280) requires that all patients who are provided with home-based social services should have access to one case manager (with each case manager coordinating 16-20 service users) and at least three specialists in fields such as medicine, social care, psychology and psycho-education.

2.6. Availability of multidisciplinary teams with good representation of each professional category

The Mental Health Law (256) identifies availability of both medical and non-medical staff as a measure of quality. The therapeutic team, set out in secondary legislation (253) comprises psychiatric doctors, psychologists, social workers, psychiatric nurse and other staff required by the specific characteristics of the sector. The team is lead by a psychiatrist. Another piece of secondary legislation (255) obliges medical units to employ social assistants.

The overall health care legislation requires that the mental health care is provided by psychiatrists, nurses, auxiliaries and cleaners at all levels of care, and psychologists, social workers and pharmacists in specified settings. The precise staff numbers are indicated in the section above. However, the general health legislation does not require that they work as a team, but rather lists the professional groups that provide services to people with mental health problems. This is reflected in the decision of the Ministry of Health to recognise only medical doctors and nurses as health care providers. None of the other professionals (psychologists, social workers, occupational therapists) are recognised as full or equal members of the mental health team, but rather as professionals that are connected to health care (265).

Similar to the mental health legislation, the disability legislation (280) requires that all patients who are provided with home-based social services should have access to a multidisciplinary team.

3. Quality of treatment and care

3.1. Individual treatment plans developed for each patient, on the basis of a holistic assessment. Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

a) Holistic assessment as a pre-requisite of the treatment plan

Different streams of policy and legislation specify the manner by which people with schizophrenia are to be assessed.

The Mental Health Law (256) indicates that the assessment of mental health status should only take place in a consultation with a psychiatrist. Except where treatment is involuntary, the assessment should be done at the request of, and with the informed consent of the person with mental health problems. Consent for assessment can also be given by their legal or personal representative if they are incapable of making the decision. The assessment should be non–discriminatory in terms of political, economic, social, racial and religious grounds, and irrespective of any lack of conformity to generally accepted moral, social, cultural, political or religious values held by the person being examined. Also, the fact that somebody had at one time received a mental health diagnosis should not lead in itself to another mental health diagnosis. The diagnosis can be contested by the person with mental health problems or by their legal or personal representative. In this case, another evaluation may be required.

The Rules for Implementation of the Mental Health Law (257) require that people with severe and persistent mental health problems who are deemed disabled by law and are cared for in Neuro-psychiatric Recovery and Rehabilitation Centres (which are coordinated by the National Authority for People with Disabilities) are evaluated by a psychiatrist at least twice a year.

The Framework Contract (271, 272) entitles people with mental health problems to certain outpatient examinations, many of which are obsolete or inappropriate. These include ultra-sonographic extracranial cervical-cerebral examination; b) standard electrocephalography; c) electrocephalography examination with stimulation tests; d) electrocephalography with mapping; e) a video- electrocephalography. However, it does not confirm entitlement to the assessments set out in the mental health legislation.

On the other side, the disability legislation (274) goes beyond the requirements of the mental health legislation for people with mental health problems who are deemed to be disabled. Here, the access to protective measures in medico-social institutions depends on the findings of the assessment. The assessment is holistic and includes proving the level of disability, medical condition, a functional evaluation to determine capacity for self-care (an evaluations of the level of autonomy of the person), an evaluation of the individual's social-economic situation, (even specifying that assessment should cover the level of income earned, availability of housing, levels of hygiene, the heating, lighting, humidity and electrical fittings available to the place of residence), an evaluation of the family and social (friends and neighbours) network, an evaluation of any risk of neglect, as well as the level of contact with the health and social system, and the need for home treatment and care. The assessment also asks the individual's views on the fairness of the assessment and whether they wish to be hospitalised in such an institution (285).

Besides the primary disability legislation, further assessment requirements are set out in legislation on access to home-based social services (including health care, as described above, but also looks into personal interests, hobbies, cultural and spiritual need) for people deemed to have a disability (280). Service providers are required to perform an initial evaluation of the person with the disability. Based on the findings of the evaluation, they are to develop an individualised package of home services. The evaluation should be by a multidisciplinary team. The person with the disability and their legal representative (where applicable) should be involved in the evaluation. The results of the evaluation should be recorded in the individual's file which should be kept confidential. Both the disabled person and his/her legal representative have full access to this file. Whenever significant changes take place the disabled person is to be re-evaluated (280).

Finally, persons benefiting from an invalidity pension are subject to a medical assessment every 6 to 12 months, depending on the disease, until they reach the age of retirement (267, 286). After each assessment, the medical doctor, an expert from the social insurance system, issues a new certificate that either confirms the previous diagnosis or notes any changes in the status of the disability. Their pension can be lost if the person fails to attend the assessment without a good excuse. These provisions do not apply to those whose disability is permanent, who have reached retirement age, or are within 5 years of retiring and have made sufficient contributions to the social insurance system.

b) Individual treatment plan developed for each patient

All streams of legislation require people with schizophrenia to have a treatment plan, though they define it differently.

The Mental Health Law (256) and subsequent secondary legislation require that each patient has an individual treatment plan that is updated regularly. The Implementation Rules (257) specify that the individual treatment plan should include a description of the nature of the patient's specific problems and needs, a description of the least restrictive treatment options that would also meet the patients' health care needs, a description of the objectives of treatment and the specifications of staff responsibilities. The psychiatrist is responsible for monitoring the implementation of the treatment plan. The same document requires that a therapeutic plan be developed based on the results of the psychiatric evaluation for people deemed disabled and cared for in Neuro-psychiatric Recovery and Rehabilitation Centres. The plan should be sent to relevant services and the GP on whose list the person is registered should be informed.

The Framework Contract (271, 272) does not prioritise the adoption of individual treatment plans, thought it implies that patients should have a treatment plan, while it requires specialist outpatient physicians to inform GPs about the treatment plan every 3-6 months, as appropriate, but it gives no details about what the plan should contain.

The disability legislation (274, 275) at the time of the research backed up the model of care covered by the Framework Contract (271, 272). The secondary legislation at the time of the research (Order 205/2005 (279) was cancelled and superseded by Order 559/2008 (312)) does not make any reference to a treatment plan for people with schizophrenia deemed to be disabled who were admitted to residential centres, day centres, or protected homes. However, other secondary legislation (280) makes special requirements for people with a severe disability who are entitled to home-based social services. This particular group should have an individual plan based on the initial multi-disciplinary assessment that should cover all services they receive. The plan should be revised every 6 months or whenever deemed necessary.

Finally, the social welfare legislation requires that people with schizophrenia have a recovery plan to support social and professional reintegration as a precondition for accessing social benefits and entitlements. The physician involved works for the insurance system.

c) Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

One section of the Mental Health Law (256) mentions that the treatment plan should be developed by the psychiatrist in charge after a diagnosis is established. Later in the same legislation it states that the treatment plan should be developed based on consultations with the service user, that it should be revised regularly, and that professionals who do not follow this procedure will be sanctioned. The Implementation Rules of the Mental Health Law (257) require that an individual treatment plan be established for each user of mental health services by the therapeutic team, with patient's consent. The Implementation Rules are not however clear as to whether these provisions also apply to people with mental health problems who are classified as being disabled and are being treated outside the health system (i.e. in social institutions).

The corresponding secondary legislation (Order 205/2005 (279)) was, however, cancelled and superseded by Order 559/2008, and did not, at the time of research, make any provisions for the involvement of service users with schizophrenia who are deemed to be disabled in developing their treatment plan. As in the previous section, special requirements are made for patients deemed severely disabled who are entitled to home-based social services. Relevant secondary legislation requires that they are involved, with their legal representative, in the development of their individual plan, which they should receive in a user-friendly form (280).

The approach taken in social benefits and entitlements legislation towards people with mental health problems is rather different. There is no indication that people with mental health problems should be involved in the development of their own treatment plan. Rather, according to this legislation, they should comply strictly with the plan made for them. If they do not or cannot comply, they lose their benefits and entitlements. The language of the document is relatively tough towards the user. This legislation contains almost no reference to the possibility of service users' having the right or the opportunity to make choices about the treatment they receive. Their input is only mentioned in the context of consent to treatment but neither the legal nor policy documents reviewed indicate where patients may be able to make choices (e.g. selecting the form of talking therapy they receive). The only choice patients can make is that of the service provider and treating physician.

3.2. Presence of discharge procedures

There are no special provisions with regard to discharge from specialist mental health services.

3.3. Continuity of care

The Mental Health Law (256) indicates that one of the criteria of quality in mental health services is continuity of care across different services. Its secondary legislation (253) requires that community-based mental health centres are to ensure collaboration with other sectors such as forensic medicine, temporary or protected shelters, protected workshops, social services, and education.

The National Mental Health Strategy (251) defines continuity of care as patients being cared for by the same professional, a case manager, throughout the pathway of care. It also specifies that medical records are shared among services as required.

The Law on the Rights of Patients (260) also calls for continuity of care, through partnerships within and outside the health sector.

The health insurance legislation, however, does not endorse the concept of continuity of care and the care coordinator approach. The Framework Contract (271, 272) only requires specialists in hospitals to communicate with specialists in outpatient services or GPs about the patient's treatment plan and follow-up requirements. Physicians in specialist outpatient services are also required to follow up patients with GPs and other relevant specialist physicians and inform them about the results of tests and other relevant information. The patient is given a written form containing this information and is expected to present it to the GP or specialist physician involved.

Finally, the disability legislation does not make any requirements for continuity of care of people with disability in general, only for those who are classified as severely disabled and qualify for home care. In their case, legislation requires that all medical interventions provided are recorded in the patient's file and communicated to the GP and relevant specialist services (280). This information includes the type of intervention, time, date and duration of the intervention and the health status of the patient.

3.4. Staff have the appropriate competencies and skills

Requirements for staff competencies and skills reflect the differences in requirements for availability of multidisciplinary teams.

The Mental Health Strategy (251) notes that appropriate training programmes should be developed in mental health for medical students, psychiatrists, psychologists, nurses, social workers and other staff. The (draft) Action Plan (252) also recognises the need to upgrade staff qualifications to support the proposed mental health reform. It notes how the health and educational systems need to recognise some new specialities (such as community psychiatry). The document also underlines the need for qualifications in management of services, which is almost completely absent at present. According to a national report quoted in the (draft) Action Plan, postgraduate training does not include psychotherapy or rehabilitation therapy. Secondary legislation (255) requires social workers to receive training specific to mental health and patients' rights.

In the general health legislation there are only limited remarks about competencies and skills of mental health staff. Its main requirement is that all health care staff allocate yearly a certain number of hours to continuing education, However, the type of skills and competencies expected to be achieved are not specified Except for specialist psychiatric nursing, who since 2002 must have completed a 1-year course. The profession of psychiatric nursing was officially recognised by the Ministry of Health in June 2003.

The disability legislation takes a different approach and stresses the importance of skills and competencies as employment criteria (274, 275). Each institution is required to produce annually a professional development plan for each member of staff, including internal and external training. In 2005 a National Plan for Staff Development was adopted for those providing health care for people with disabilities (277).

3.5. Empowerment of service users to care for themselves and live as independent a life as possible (Personal autonomy)

The Mental Health Law (256) notes that the aim of all treatment and care is to protect and strengthen the personal autonomy of people with mental health problems. The legislation requires that the quality of care be measured by the degree to which it empowers people with mental health problems to live independently and manage their disease. However, this Law does not specify any tools for measurement of these goals. Additionally, those people with schizophrenia who are classified as severely disabled and qualify for home care, are entitled to support in developing self-care, self-management, and skills to function independently (280). None of the other streams of legislation make any requirements for empowerment of service users.

3.6. Involvement of service users in shaping the services

There are no legal provisions for mental health users to be included in any management or decision-making structures in the health sector.

There is almost no reference in any policy document to user involvement. Only the (draft) Action Plan (252) mentions the need for involving users in the process of development of mental health services, as well as the need to train and support them (including financially). The (draft) Action Plan suggests that these are rights that should be formalised through secondary legislation initiated by the Ministry of Health.

3.7. Involvement of families and carers

Neither the mental health nor the general health legislation makes clear requirements for involving families and carers of people with schizophrenia. Thus, the only requirement in the mental health legislation is that community-based mental health centres provide family counselling (256). The legislation on patient rights (260) notes that the patient can benefit from family support, support from friends, material support as well as advice on health-related decisions. However, the general health policy and legislation make no reference to the involvement of families and carers of health care service users, except that they can be informed about the diagnosis and health status of the service user with their consent.

The disability legislation makes the most comprehensive provisions on this issue. It requires that those people with schizophrenia who are classified as being severely disabled and who qualify for home care, should receive support to maintain and develop relationships with their families, legal representative and friends (280). Families should be consulted in connection with any major decision regarding the person with the severe disability, and where necessary, family counselling should be offered by the service provider of home-based social service.

4. Quality of facilities

4.1. Protection of service users' privacy and safety, decent living environment

The Mental Health Law (256) states that mental health services should offer inpatient accommodation in an appropriate environment, similar to outside living conditions. Service users should be able to buy or receive personal possessions and be able to engage in activities that facilitate their social and professional reintegration.

The secondary mental health legislation on the establishment of community-based mental health centres specifies minimum items of furniture (2-4 desks, 30 chairs, 4 comfortable chairs and one reception table) and equipment (1 computer with internet connection, 1 printer, 1 photocopying machine, 1 TV, 5 writing boards, 1 clipboard, 1 fax machine, 5 landline telephones, 1 mini-telephone exchange and 1 heating station) for each community mental health centre.

Besides this, the general health legislation provides rather detailed quality standards for all hospitals and outpatient services, regardless of their clinical speciality (262). The legislation requires that a statement of patient rights and obligations be clearly posted in each ward. Wards are to ensure some level of privacy to patients. Specifically, regular wards should contain between three and six beds, with seven square metres provided for each bed, which should be separated by at least 70 cm. It also mentions that there should be a room for isolation of patients but it is not clear if this is for the benefit of patients, so as to offer them privacy if and when they wish, or if it is a seclusion ward. There should also be a light, a socket and an alarm bell by each bed. Standards for the safety of wards (electricity, ventilation, windows) are also set. Thus, in wards without air conditioning, windows should be placed in a south-east, south or north-west direction, or west and south-west if windows are properly protected from the sun. Windows in non air conditioned rooms are not to be in a north or north-west direction (due to cold winds).

The Framework Contract (271, 272) also makes specific requirements for inpatient and outpatient services. It indicates that outpatient services must provide an adequate physical environment including chairs/couch, table, information materials, equipment and furniture. In inpatient services, standard accommodation covered by insurance includes: a ward with a minimum of 3 beds, with one toilet per ward and with hygiene standards in place. It does not include TV, radio, telephone, fridge, air conditioning, and other technical equipment.

In addition to all these requirements regarding physical conditions, the Law on the Rights of Patients (260) sets out patients' rights within health care facilities that should be respected by staff. Patients should be treated with respect, always be addressed politely and they and their visitors should be greeted appropriately. They should not be pressured to pay for care to which they are entitled. Also, they have the right to a quiet environment.

4.2. Presence of appropriate treatment facilities

Both the mental health and the general health legislation set standards for treatment facilities. On one hand, the Mental Health Law (256) requires that specialist mental health settings have all the necessary facilities to enable the assessment and treatment of people with mental health problems at an international standard. It also mentions that patients should have access to education facilities. The secondary legislation on community-based mental health centres requires that each centre have 2-4 individual offices for relevant interventions, 1 room for group psychotherapy (for 15-20 persons), one reception hallway and 1 room for rehabilitation activities. In addition, the (draft) Action Plan (252) requires that all psychiatric hospitals should have a designated area for receiving guests in acute wards and in wards for long-term patients.

On the other hand, the general health legislation also sets standards of quality of all hospitals and outpatient services, regardless of their clinical speciality and requires that facilities have an entry hall and areas for waiting, visitors, and day activities. These are dependent on available space in the facility. There are also standards for treatment areas (size, furniture, equipment). Thus, the treatment rooms should have a surface area of 16-18 square meters and the offices for consultations should be 12-14 square meters. In day-care services there should be offices for consultation and treatment and an area for nurses. In outpatient services there should be offices for consultation and treatment which are equipped for each speciality, waiting areas, offices for making appointments and keeping patients' records, a pharmacy with relevant medication, and annexes for medical staff.

4.3. Hygiene

Requirements for hygiene emerge only from general health and insurance legislation. The general health legislation requires that all hospitals and outpatient services, regardless of their clinical speciality must comply with hygiene standards (toilets, showers, laundry). Thus, in inpatient units, each room with 1-2 beds or 3-4 beds should have either a separate or common toilet room with shower, toilet and sink. Rooms with 5-6 beds should have their own separate toilet room with shower, toilet and sink. Also, there should be 1 shower per 15 people where wards do not have showers assigned to specific rooms. In day-care centres and outpatient facilities, toilets and rooms with cleaning products should be available.

The Framework Contract (271, 272) indicates that there should be one toilet per hospital ward, with hygiene standards in place. It requires that, upon admission, all patients be cleaned before being taken to their ward. Additionally, people with schizophrenia that are classified as being severely disabled and who qualify for home care are entitled to support for bodily hygiene, dressing and undressing and for home cleaning (280). The Law on the Rights of Patients (260) also indicates that service users have the right to clean facilities.

4.4. Food and drinks

The Framework Contract (271, 272) indicates that the food provided to patients is to be based on the food allowance established by law. If patients wish to increase the standard of the accommodation or food, they are to bear these costs themselves. Assistant dieticians are in charge with calculating the quantity and the caloric value of the menus.

A similar approach is taken by the Law on the Rights of Patients (260), which indicates that hospitals have the obligation to ensure food of an appropriate quality and quantity, based on the legal standards for daily intake.

An additional interesting requirement set out in the disability legislation for those who are classified as being severely disabled and who qualify for home care. They are entitled to support with food shopping and cooking at home (280, 281).

5. Protection of human and civil rights

5.1. Right to respect of all human and civil rights on mental health facilities

Human and civil rights issues are primarily addressed by the mental health legislation but only briefly covered by the health and disability legislation.

The health legislation does not make explicit reference to the human rights of patients. However, all constitutional rights apply to all citizens equally, regardless of their health status. Direct reference is made only to some specific rights, such as the right to information and confidentiality (see below).

The disability legislation (274, 275) and the National Strategy on Disabilities (276) requires that all the human rights and freedoms recognised by law (political, economic, social, cultural, or any other right or freedom related to public life) should be respected for people with disabilities, without any form of discrimination.

At the same time, the mental health legislation stresses the importance of respecting the human and civil rights of people with mental health problems and requires that all civil, political, economic, social and cultural rights recognised by the Universal Declaration of Human Rights and other international human rights legislation ratified by Romania are observed. All people with mental health problems should be treated humanely and in a dignified manner, protected against all forms of exploitation (economic, sexual or other) and against harmful and degrading treatment. All people with mental health problems should enjoy full recognition as equal citizens. The Mental Health Law (256) guarantees their right to a private life, freedom of uncensored communication, through all means and with all people, and freedom of religion. In addition, it guarantees their right not to be subjected to experimental treatment without their informed consent and with approval of an ethics committee. People with mental health problems should not be coerced to work, and if they choose to work they should be paid accordingly. All contraventions are subject to disciplinary action and, potentially, criminal charges. The Implementation Rules (257) specify situations where it is permitted to limit freedom of movement of a patient with mental health problems so as to prevent any harm to himself/herself or others. It authorises physical restraint and isolation but it makes no reference to chemical restraint.

5.2. Right to informed consent to treatment

The right to informed consent is clearly guaranteed by the overall health and mental health legislation. The disability legislation provides weaker guarantees, while the insurance legislation and the social legislation focus on the duty of patients to comply with treatment, rather than on their entitlement to refuse it.

The Mental Health Law (256) states that, with the exception of involuntary admission in circumstances specified by law, the treatment plan can only be implemented if the psychiatrist has obtained the informed consent of their patient. Contraventions should be penalised.

Similarly, the Law on the Rights of Patients (260) notes that medical personnel have a duty to inform patients about possible risks associated with non-compliance. They must also inform patients how to get help in case of relapse and the conditions that need to be met for further admissions. If patients refuse treatment, they should sign a statement that he/she takes responsibility for this action.

Along the same lines, the Law on the Reform of the Health System (259) stresses that all patients should be offered the opportunity to give their informed consent before receiving any intervention. The physician or nurse in charge should inform the patient about their diagnosis, the nature and scope of the treatment, the risks and consequences of the proposed treatment and any alternatives. Patient consent should be written and should contain the name of the patient, home address, the medical intervention the patient is to receive, a brief description of the information provided by the physician or nurse, the unequivocal consent to intervention, the signature and the date of consent. Treatment is not to be given without such consent. The only exception is where the patient cannot give consent, for example where delaying the intervention would risk the health of the patient, and a legal representative or close relative cannot be contacted urgently (263).

At the same time, the legislation for people with disabilities requires that service providers obtain consent of patients for interventions but also imposes a duty on those with the disability to adhere to their individual plan (274, 275). A different approach is taken only for people who are classified as being severely disabled and qualify for home care. In their case, secondary legislation (280) requires that they should receive services only if they consent and on the basis of a written contract between them (or their legal representative) and the service provider.

The right to informed consent does not, however, apply to people who want invalidity benefits (286). These individuals are obliged to comply with the recovery plans for social and professional reintegration which have been developed by the social insurance physician and who issued the certification of invalidity. If they do not comply with this plan, he/she looses the right to the invalidity pension until they do so.

A similar approach is taken by the insurance legislation, which stresses that in order to maintain their entitlement to health care, the insured persons are obliged to follow strictly the treatment regimen prescribed by a doctor. This contradicts the general health and the mental health legislation.

5.3. Right to confidentiality

Confidentiality of personal information and files of patients is guaranteed by different legal documents but in a similar manner.

The Mental Health Law (256) requires that all patient information be kept confidentially except when the patient explicitly allows information to be given to someone else, or where other circumstances, described by law, are met.

The Law on the Rights of Patients (260) notes that all information regarding a patient's health status, diagnosis, prognosis, treatment and personal data are confidential, even after death, except for situations where the patient gives his\her consent to share this information or where the law requires it.

The law on health system reform (259) requires that confidentiality of patient data on diagnosis and treatment should be respected by health inspectors and health staff, whether directly or indirectly involved in their treatment and care. The exception is in situations where these patients represent a risk to public health. All contraventions should be sanctioned according to the law.

Disability legislation (274, 275) also guarantees the right to confidentiality for all people with schizophrenia deemed to be disabled.

5.4. Right to information

The Rules of Implementation of the Mental Health Law (257) have the same provisions as the Law on the Rights of Patients (260). These provisions state that service users have the right to be informed about medical services available and how they can use them, about the identity and professional status of the health care provider and about the rules and regulations they should respect during hospitalisation. They also have the right to be informed about the proposed medical interventions for their condition, and the alternative treatments available as well as the potential risks and side effects of all forms of treatment proposed including the risks of disregarding the medical advice and non-adherence to treatment. Patients have the right to request a second medical opinion. All this information should be provided to patients in a respectful manner, in user-friendly, non-medical language.

Additionally the Rules of Implementation of the Mental Health Law require that the patient is provided with descriptions of the nature of their problems and special needs, the least restrictive setting necessary for treatment, the goals of the treatment, and the responsibilities of the staff.

The Law on Promotion and Protection of The Rights of Disabled Persons (274) guarantees the right of all persons with disabilities and their family or legal representative to be informed about all the services and programmes available to them in all phases of treatment.

5.5. Right of access to personal information

The right to access personal information is guaranteed by overall health, mental health and disability legislation. While the overall health and disability legislation guarantee this right without exception, the mental health legislation provides the weakest guarantees to people with schizophrenia.

Thus, the Law on the Rights of Patients (260) clearly states that all patients should have access to their personal information and only at his/her express request will he/she stop being informed about his/her health status. They have the right to request and receive, when discharged, a written summary of all medical examinations, diagnoses, treatment and care provided during hospitalisation. Patients can choose to designate another person to be informed in his/her stead.

Similarly, the Law on promotion and protection of the rights of disabled persons (274, 275) guarantees the right of all disabled persons and their family or legal representative to all information related to their diagnosis and rehabilitation prospects.

The Mental Health Law (256) does guarantee the right of people with mental health problems to have access to their personal information, namely they have the right to receive, in written form upon discharge from a health service, their diagnosis and information on treatment and care. However, this right can be waived if the physician in charge considers that providing this information might affect the mental state of the patient.

5.6. Right to notification of rights

The right to notification of rights is specified only in the mental health and disability legislation, and not in the general health or insurance legislation.

The notification of patients' rights is guaranteed by the Mental Health Law (256), which requires that people with mental health problems are notified of their rights as soon as they are admitted to mental health services. In the case the patient does not have the capacity to understand his/her rights, their personal legal representative should be informed instead.

Similarly, the Law on the promotion and protection of the rights of disabled persons guarantees that all disabled persons and their family or legal representative have the right to be informed about their rights (274, 275, 278). The legislation requires that the rights and obligations of the patients need to be posted clearly in each ward.

5.7. Right to treatment sensitive to needs of minorities (with different cultural and religious background)

The right to treatment sensitive to needs of minorities is guaranteed by mental health, health insurance and general health legislation in a similar manner.

Thus, the Mental Health Law (256) mentions in broad terms that mental health services should respect the religious and cultural needs of the users. It specifies that services should be provided in the least restrictive settings based on the patient's health needs and their need for their physical and psychological integrity to be respected while ensuring, at the same time, their protection and the protection of the public.

The Framework Contract (271, 272) requires that the providers of health services, including mental health services, offer the most efficient form of treatment without discrimination.

Finally, the law on health system reform (259) indicates that the treating physician and nurse cannot deny health care on the grounds of ethnicity, religious affiliation or sexual orientation.

Conclusions

As I indicated at the beginning of this chapter, the assessment of mental health legislation and policy shows that the requirements for specialist care of people with schizophrenia emerging from each legislative stream (i.e. mental health, health insurance and overall health, disability and social welfare) are different in most of the areas examined. Sometimes the mental health and the disability legislation have similar requirements, (e.g. regarding availability of other evidence-based interventions), but they differ from the insurance legislation. Similar approaches were found only in relation to availability of medication, physical health care, protection of human rights (right to respect of all human and civil rights on mental health facilities, the right to confidentiality, the right to information, and the right to notice of rights) and provision of treatment sensitive to needs of minorities and those with different cultural and religious backgrounds.

In most cases, the mental health legislation and related policy were more comprehensive, with provisions that go beyond those in other legislation, with respect to the particular needs of people with schizophrenia. An exception is the weak legal provisions for access to personal information. The provisions in general health and disability legislation are significantly stronger guarantees on this issue.

The disability legislation went beyond the requirements of the mental health legislation in some areas, such as the holistic assessment of patients before the development of treatment plans, the support some patients can receive with cooking at home and the involvement of families and carers.

The insurance legislation was in most cases the most restrictive and least generous, often failing to incorporate the package of services specified by the mental health legislation.

Not all streams of legislation covered all of the areas assessed in this thesis. For example, insurance legislation is the only one that regulates the access to different parts of the health care system. Similarly, entitlements for social welfare were covered only by the social welfare legislation.

Finally, there were no legal provisions in any legislative stream on two of the areas assessed, namely discharge procedures and involvement of service users in shaping the services.

To conclude, the wide variety of approaches and entitlements offered by each legislative stream makes it difficult to determine what rights and entitlements people with schizophrenia are actually able to claim.

Chapter 7 Findings of the review of type 1 diabetes policy and legislation

This chapter will review legislation and policy applicable to people with type 1 diabetes in specialist settings in Romania. As with the review of provisions for people with schizophrenia, it will follow the Conceptual Framework set out previously. This review is, inevitably, more limited as it is covered by the same general health legislation as schizophrenia but, unlike schizophrenia, is not subject to any specific legislation. However, it adopts the same structure as the previous chapter to facilitate comparison, albeit somewhat abbreviated to avoid unnecessary repetition. Each section falls into one of three categories. In some areas of assessment, the same general health, health insurance and disability laws and policies provisions are applicable for the treatment of people with type 1 diabetes as they are for the treatment of people with schizophrenia. In other areas, while treatment of people with schizophrenia was shaped by a combination of specific mental health legislation and general health, health insurance and disability legislative and policy provisions, the treatment of people with type 1 diabetes was shaped only by general health, health insurance and disability laws and policies. In one area, relevant legislative and policy provisions are specific only to diabetes treatment. Finally, in other cases, in addition to general health, health insurance and disability legislative and policy provisions, treatment of people with type 1 diabetes was also regulated by specific diabetes legislation and general health provisions (Table 4).

Table 4 Correspondence between legislation and policy for mental health and that for diabetes

Correspondence	Areas of assessment
Provisions are the same for diabetes and schizophrenia.	1.4. Access to different parts of the system, as needed (Referral system)
	2.3. Social care
	2.4. Physical health
	3.2. Presence of discharge procedures
	4.3. Hygiene
	4.4. Food and drinks
Some of the general health legislation applicable to mental health, also apply to diabetes	1.3. Access to services when needed (temporal access)
	3.1. c) Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate
	3.3. Continuity of care
	4.1. Protection of service users' privacy and safety, decent living environment
	4.2. Presence of appropriate treatment facilities
	5.1. Right to respect of all human and civil rights on health facilities
	5.2. Right to informed consent to treatment
	5.3. Right to confidentiality
	5.4. Right to information
	5.5. Right of access to personal information
	5.6. Right to notification of rights
	5.7. Right to treatment sensitive to needs of minorities (with different cultural and religious background)
Some provision specific to diabetes, combined with some of the general health legislation applicable to mental health, also apply to diabetes	1.1. Access to care in the least restrictive environment/community-based settings
	1.2. Geographical accessibility of services
	1.5. Financial access to services (financial affordability)
	2.1. Availability of medication
	2.5. Availability of enough staff in all settings
	2.6. Availability of multidisciplinary teams with good representation of each professional category
	3.1. a) Holistic assessment as pre-requisite of the treatment plan
	3.1. b) Individual treatment plan developed for each patient
	3.4. Staff have the appropriate competencies and skills
	3.5. Empowerment of service users to care for themselves and live as independent a life as possible (Personal autonomy)
Provisions specific to diabetes only	2.2. Availability of other evidence-based interventions
No relevant policy	3.6. Involvement of service users in shaping the services
	3.7. Involvement of families and carers

To whom do these laws refer

This chapter considers legislation and policy that relates to the management of people with severe and persistent somatic health problems. The legislative provisions on disability and invalidity were discussed in detail in the previous chapter. For the present purposes, what is important is that people with type 1 diabetes are classified as having a severe disability when they suffer from diabetic complications affecting one or more organs (e.g. have severe disability of the sight, mobility, locomotion, postural or urological function) or when they suffer from Charcot Arthropathy of the feet, depending on the severity of the ensuing morphological-functional problems. Pronounced disability is recognised in cases where people with type 1 diabetes do not have stable metabolic function, with or without metabolic decompensation.

1. Accessibility of specialist services

1.1. Access to care in the least restrictive environment/community-based settings

Patients with type 1 diabetes can access services in hospitals (continuous or, for patients that do not need medical monitoring for more than 12 hours, day admission) and specialist outpatient medical offices linked to hospitals. The Framework Contract (271, 272) does not detail the medical services provided in these settings. Crisis care is covered by insurance for decompensated diabetes, which is classified as a 2nd degree emergency. The Framework Contract notes that in the majority of diabetes-related 2nd degree emergencies, there is probably no need to take the patient to a health facility and that local health insurance companies can contract private providers to deliver emergency home treatment. However, home treatment on a regular basis is not covered by insurance for people with diabetes. The Framework Contract also indicates that the optimal length of stay in hospitals is 6.5 days for patients with diabetes.

Additionally, provisions on types of hospital service (insurance legislation), the inpatient services that can be transferred to outpatient settings (in the general health legislation) and the range of services covered (disability legislation) are equally applicable to diabetes and schizophrenia.

1.2. Geographical accessibility of services

People with diabetes can collect their medication from *any pharmacy* that has a contract with the NHIF with regard to distribution of medication free of charge or with co-payment.

The general health legislation sets out a geographic distribution of human resources for diabetes care (at district, urban and rural level) (264), as described below (point 2.5.).

Provisions of overall health and insurance legislation are equally applicable to diabetes and schizophrenia.

1.3. Access to services when needed (temporal access)

Provisions on temporal access to services set by insurance and disability legislation for people deemed severely disabled are equally applicable to diabetes and schizophrenia.

1.4. Access to different parts of the system, as needed (Referral system)

The provisions are the same for diabetes and schizophrenia.

1.5. Financial access to services (financial affordability)

Akin to the requirements related to treatment and care of schizophrenia, financial access to health services for people with type 1 diabetes is ensured by different pieces of legislation and policy. Thus, insured people have free access to health services. The Framework Contract (271, 272) lists the following services that are covered for diabetes care: consultations, tests, diagnostic processes, medical or surgical treatments, care and recovery services, medication, medical appliances, accommodation and meals. Additionally, provisions on health insurance coverage by the National Health Insurance Fund and alternative mechanisms, such as national programmes of the Ministry of Health, setting out financial benefits for people with disabilities and pensions for people with invalidities are equally applicable to diabetes and schizophrenia.

2. Availability of evidence-based treatment and care

2.1. Availability of medication

In outpatient services, patients with diabetes can be prescribed medication for up to 90 days and can receive intra-venous administration of medication when necessary. Prescriptions can be made by the GP, based on the written recommendation of a specialist physician (be it a physician specialist in diabetes, nutrition and metabolic disorders, or a physician of another speciality contracted by the NHIF to provide diabetes care). When discharged from inpatient services, patients should receive a prescription for 30 days (271, 272).

The MoH approves the list of medication that should be covered by the National Programme for Diabetes (258). Also, one of the features of the 2007 National Programme for Diabetes was to ensure access to certain treatments such as insulin pumps and special shoes. As indicators for evaluation of the implementation of the Programme, it is required that levels of glycosylated haemoglobin are monitored and that eligible patients receive subcutaneous injections using pumps. Treatment with insulin analogue with or without tiazolidindione can be initiated only upon approval by the management of the district diabetes section. The Law on the Rights of Patients (260) indicates that hospitals should have enough supplies of medicines for patients. Additionally, people with type 1 diabetes deemed severely disabled benefit from the same entitlements guaranteed by disability legislation as do those with schizophrenia.

2.2. Availability of other evidence-based interventions

The basic package of interventions provided in specialist outpatient services includes dietary advice, foot care, and cardiac investigation.

2.3. Social care

The provisions are the same for diabetes and schizophrenia.

2.4. Physical health

The provisions are the same for diabetes and schizophrenia.

2.5. Availability of enough staff in all settings

The Regulations for health care staff (264), requires the same levels of health care staff (specialist physicians, nurses, pharmacists, auxiliaries and cleaners) in diabetes inpatient services as in mental health inpatient settings (Table 3). Exceptions are the number of psychologists, which are required in smaller numbers in non-psychiatric services, and social workers, which are only required in psychiatric units, sections and wards for chronic patients.

In case there are not enough physicians specialised in diabetes, nutrition and metabolic disorders, physicians of other specialities can be assigned to monitor patients with diabetes, under the supervision of the physicians specialised in diabetes, nutrition and metabolic disorders.

Additionally, inpatient services can employ other staff groups for different activities and to work in different units, such as staff working in laboratories and dietary care (Table 5). The legislation sets an upper limit for staff in this group. Each of the inpatient services may therefore employ dieticians that can be either medical doctors or nurses.

Table 5 **Maximum number of other staff groups per inpatient service**

	Inpatient services				
Other staff categories, among which dieticians	- Institutes and centres of speciality - Clinical hospitals - Regional emergency hospitals - District hospitals from university centres - Emergency hospitals	Units, sections and wards for chronic patients	District hospitals and hospitals with one speciality	Municipal and town hospitals	Rural hospitals
Hospitals with less than 400 beds:	- 1 physician for 20 beds - 1 nurse for 22 beds per shift	- 2 physician per unit - 2 nurse for 22 beds per shift	- 1 physician for 40 beds - 1 nurse for 30 beds per shift	-1 physician for 50 beds - 1 nurse for 35 beds per shift	- 1 physician per unit - 1 nurse per unit
Hospitals with more than 400 beds:	- 1 physician for 20 beds - 1 nurse for 22 beds per shift		- 1 physician for 60 beds - 1 nurse for 18 beds per shift	- 1 physician for 70 beds - 1 nurse for 18 beds per shift	

In addition, the legislation requires that specialist outpatient units have 1 doctor and 1 nurse per office for 2 shifts. Furthermore, Order 175/2006 (280) requires that all patients who are provided with home-based social services should have available one case manager (with each case manager coordinating 16-20 service users) and at least three specialists in fields such as medicine, social care, psychology or psycho-education.

2.6. Availability of multidisciplinary teams with good representation of each professional category

As was illustrated above, the overall health care legislation also requires that people with type 1 diabetes should receive health care from a team composed of physicians specialised in diabetes, nutrition and metabolic disorders (the main speciality providing diabetes care), physicians in other specialities contracted by the NHIF to provide diabetes care (including cardiologists, ophthalmologists, nephrologists), nurses, psychologists, pharmacists, auxiliary staff and cleaners. Hospitals also have the option of employing dieticians (who may be either doctors or nurses by training), among the general health staff.

Physicians specialising in diabetes, nutrition and metabolic disorders are responsible for establishing diagnosis, treatment and monitoring plans, regularly (every semester) confirming the treatment plan, carrying out the initial consultation (and determining who should be included in the National Programme for Diabetes (258)), check-up consultations, and writing medical letters to include all relevant information to GPs and the other specialist physicians providing diabetes care.

Physicians from other specialities contracted by the NHIF to provide diabetes care are responsible for recording in the patient's file any information provided by diabetes, nutrition and metabolic disorders specialists, including the complete diagnosis, the diet, activity, treatment and monitoring plans as well as the date and time of future medical examinations. Additionally, people with type 1 diabetes deemed severely disabled benefit from the same entitlements to multidisciplinary teams guaranteed by disability legislation as those with schizophrenia.

3. Delivery of care

3.1. Individual treatment plans developed for each patient, on the basis of a holistic assessment. Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

a) Holistic assessment as pre-requisite of the treatment plan

Different streams of policy and legislation require assessment of people with type 1 diabetes. These are as follows.

The National Programme for Diabetes (258) requires that people with type 1 diabetes benefit from a comprehensive annual check-up (glycosylated haemoglobin and detection of micro- and macro vascular complications). This assessment is one of the indicators for evaluating the success of the Programme.

In outpatient services people with type 1 diabetes benefit from an initial consultation which includes a medical history and general clinical assessment (which decides whether the patient will be enrolled in the National Programme for Diabetes), the specialist clinical assessment and the development of a protocol for investigations and other tests as necessary (this is decided by a specialist physician). The Framework Contract (271, 272) mentions that physicians specialised in diabetes can take samples for biopsies and refer patients for X-ray but does not provide any further details. Requirements for assessment in disability and in social care legislation for people deemed disabled, and in legislation on invalidity benefits, apply in the same way to people with diabetes and schizophrenia.

b) Individual treatment plan developed for each patient

The National Programme for Diabetes (258) requires that physicians specialised in diabetes, nutrition and metabolic disorders are responsible for preparing treatment and monitoring plans for patients. The physicians from other specialities who are contracted by the NHIF to provide diabetes care (when insufficient specialists are available), are in charge of monitoring the implementation of the treatment plan. The patient is responsible for communicating the treatment plan developed by the specialist physicians to the physicians of other specialities providing diabetes care and to any other relevant medical professionals. Patients who do not meet the objectives set out in the treatment plan, or who develop chronic complications (such as ophthalmological, nephrological, neurological, cardiac complications) should be monitored more closely.

Requirements for individual treatment plans guaranteed by health insurance legislation, disability legislation and social welfare legislation apply in the same way to people with diabetes and schizophrenia.

c) Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

Provisions for participation of service users in the development of their treatment plans guaranteed by disability legislation and social welfare legislation apply in the same way to people with diabetes and schizophrenia.

3.2. Presence of discharge procedures

The provisions are the same for diabetes and schizophrenia.

3.3. Continuity of care

Provisions for continuity of care guaranteed by general health legislation, patients' rights legislation and disability legislation for people deemed severely disabled apply in the same way to people with diabetes and schizophrenia.

3.4. Staff have the appropriate competencies and skills

The information, training and continuing education of staff working with people with type 1 diabetes are set out in the National Programme for Diabetes (258). Physicians from other specialities contracted by NHIF to provide diabetes care are required to take the training courses in diabetes, nutrition and metabolic diseases offered by the MoH. Additionally, disability legislation requirements apply in the same way to staff working with people with diabetes and schizophrenia.

3.5. Empowerment of service users to care for themselves and live as independent a life as possible (Personal autonomy)

The importance of empowering people with type 1 diabetes to care for themselves and thus live their life with as little as possible contact with services is stressed by the National Programme for Diabetes (258). Indeed, this Programme sets the self-monitoring of people with type 1 diabetes as one of its activities and as an indicator for the successful implementation of the Programme. Additionally, people with type 1 diabetes deemed severely disabled benefit from the same entitlements guaranteed by disability legislation as those with schizophrenia.

3.6. Involvement of service users in shaping the services

There is no reference in any policy document to user involvement or user empowerment.

3.7. Involvement of families and carers

There are no legal provisions for mental health users to be included in any management or decision-making structures in the health sector.

4. Quality of facilities

4.1. Protection of service users' privacy and safety, decent living environment

Standards of quality for inpatient and outpatient facilities set out in general health legislation and health insurance legislation apply in the same way to people with diabetes and schizophrenia.

4.2. Presence of appropriate treatment facilities

Requirements for availability of treatment facilities set out in general health legislation apply in the same way to people with diabetes and schizophrenia.

4.3. Hygiene

The provisions are the same for diabetes and schizophrenia.

4.4. Food and drinks

The provisions are the same for diabetes and schizophrenia.

5. Protection of human and civil rights

5.1. Right to respect of all human and civil rights on health facilities

While the health and disability legislation address the human and civil rights of people admitted to health facilities only briefly, their provisions apply in the same way to people with diabetes and schizophrenia.

5.2. Right to informed consent to treatment

Requirements regarding informed consent to treatment guaranteed by general health legislation, patients' rights legislation, disability and invalidity benefits legislation apply in the same way to people with diabetes and schizophrenia.

5.3. Right to confidentiality

Rights to confidentiality guaranteed by general health legislation, patients' rights legislation, and disability legislation apply in the same way to people with diabetes and schizophrenia.

5.4. Right to information

Rights to information guaranteed by legislation on patients' rights and disability apply in the same way to people with diabetes and schizophrenia.

5.5. Right of access to personal information

Rights to information guaranteed by patients' rights legislation and disability legislation apply in the same way to people with diabetes and schizophrenia.

5.6. Right to notification of rights

While the general health and insurance legislation do not guarantee patients that they will be notified of their rights, the provisions in disability legislation apply in the same way to people with diabetes and schizophrenia.

5.7. Right to treatment sensitive to needs of minorities (with different cultural and religious background)

People with type 1 diabetes from minority groups or with different cultural and religious background have the same rights guaranteed by health insurance and general health legislation to treatment sensitive to their needs as do people with schizophrenia.

Conclusions

The review of legislation and policy relevant to treatment and care for people with type 1 diabetes shows that specialist services for these patients are mostly mainstreamed into general legislation, whether health, insurance or disability legislation. Only a limited number of provisions are specific to diabetes care, except for those in the National Plan for Diabetes (258) and even these provisions are included in general documents, such as the Framework Contract (271, 272). The outcome is that, unlike in mental health care, there are no discrepancies between the general health and the insurance legislation, formally guaranteeing people with diabetes that they will be able to access their entitlements. Discrepancies remain between general health and insurance legislation on one hand, and the disability legislation on the other hand, with the challenges outlined in the previous chapter.

In order to draw concrete conclusion on how legislation and policy for diabetes compares with that for schizophrenia, a comparative analysis of the two is necessary and will be presented in the following chapter.

Chapter 8 The *de jure* situation: inbuilt inequities in policy and legislation

The overall aim of the reviews presented in the previous two chapters was to assess whether Romanian mental health legislation and policies lead to specialist services for people with severe mental disorders that are as good as those for management of chronic physical illness, specifically type 1 diabetes. In this chapter, policy and legislation related to these two chronic conditions will be contrasted and compared, using the Conceptual Framework set out previously. Based on this analysis, this chapter aims to determine whether the policy and legislation relevant to the management of schizophrenia ensures that treatment and care of people with schizophrenia is as good as that for people with type 1 diabetes and establish whether or not policy and legislation meet the requirements of horizontal equity.

1. Accessibility of specialist services

1.1. Access to care in the least restrictive environment/community-based settings

Here the main difference is that while the mental health legislation sets out a vision in which there is extensive community-based care, based on international norms, this is not included in the health insurance package which instead emphasises institutional care. Specifically, it excludes mobile teams, home treatment, crisis care (in the modern sense, rather than the emergency rooms in hospitals), assertive outreach and small scale facilities providing long-term care in communities. There is some funding for community mental health care via the National Programme for Mental Health (254) but, as already noted, this is vulnerable to short-term budgetary fluctuations. The result is that people with schizophrenia do not seem to have access to an optimal package of services.

Conversely, the policy and legislation applicable to diabetes favours care outside hospitals, with admission only where this is deemed necessary. Although the insurance fund does not cover regular home care, it does fund crisis care at home.

There are also differences in the types of hospital where each patient is treated. Inpatient care for people with schizophrenia is available in two types of hospitals. Acute care is provided in psychiatric wards of general hospitals, except in a few large cities (Bucharest, Iasi) that have a mental hospital inside the city. However, those in need of long-term care are moved to mental hospitals in villages on the outskirts of towns and cities. These patients do not have access to care close to the communities in which they live and are effectively institutionalised. The insurance fund will pay for up to the total days the patient spent in hospital in the previous year and no home treatment is covered. Thus, what amounts to life-long admission comes about simply on the basis of what happened to the patient previously. There is no requirement for re-assessment of the patient's health or social circumstances or any onus on health professionals to find alternative care settings, even though this is encouraged in the mental health legislation.

Conversely, inpatient care for persons with diabetes is provided in diabetes wards in general hospitals (with the exception of Bucharest, where there is also an institute specialising in diabetes). There are no isolated inpatient services for people with diabetes. The optimal length of inpatient admissions stay for people with type 1 diabetes in the Framework Contract (271, 272) is 6.5 days. There is no provision for long-term admission.

1.2. Geographical accessibility of services

The mental health legislation makes provisions for a range of services to be distributed according to population throughout the country, based on geographically defined sectors. The Ministry of Health also produces a national plan that specifies the staffing levels of facilities, should they exist in a particular setting. The health insurance fund pays facilities according to their staffing levels, but pays no attention to the geographical distribution of services. Consequently, no-one with command over meaningful resources is taking a population-based approach to service planning, with potential consequences for mental health services that have suffered from historical under-investment and concentration of long-term care in remote and inaccessible locations.

A further issue is that people with diabetes can purchase their medication in any pharmacy, including those closest to where they live, while those with schizophrenia that can only get their medication in a limited number of designated pharmacies.

1.3. Access to services when needed (temporal access)

Timely access to care should be the same for both groups, as set out in the Framework Contract (271, 272). The disability legislation (274, 275, 280) entitles people to home care based on their degree of disability rather than its cause. In addition, however, the Mental Health Law (256) requires that people with mental health problems, regardless of whether they are classified as severely disabled or not, should have access to a flexible programme of care that meets their particular needs. This can take the form of regular home treatment, crisis care, and assertive outreach. However, this is not recognised by the Framework Contract, so what might appear to be better temporal access than those with diabetes may not be achieved in practice.

1.4. Access to different parts of the system, as needed (Referral system)

There are no differences in the system of referral for the two groups. Those diagnosed with a disease included in a National Programmes (254, 258), which include both diabetes and mental health, can access the corresponding specialist services directly, without referral. If they require referral to other health services, they should follow the same procedure as any other patient.

1.5. Financial access to services (financial affordability)

The Framework Contract (271, 272) guarantees people with schizophrenia and type 1 diabetes equal and free access to outpatient and inpatient services and medication. As both conditions have corresponding National Programmes (254, 258), those affected are entitled to free health care regardless of whether they contribute or not to the insurance fund, whether or not they are registered as disabled, or whether or not they are incapable of work.

There are, however, two essential differences between the two groups. The first refers to the interventions covered by insurance and the second to the options for reimbursement of different interventions.

First, while the mental health legislation requires that people with mental health problems receive a range of evidence-based psychosocial interventions, based on individual needs, the Framework Contract covers a limited number of talking therapies and only in inpatient settings. This puts people with schizophrenia at a disadvantage, compared to people with diabetes, since the latter have access to the full range of interventions recommended for their treatment.

Second, people with schizophrenia have limited financial access to professionals that provide psychosocial interventions. Thus, even in inpatient settings, where the Framework Contract covers some psychosocial interventions, these can only be accessed when they are performed by a psychiatrist or when another professional (psychologist or social worker) is requested by the psychiatrist to perform them. All interventions provided by psychologists or social workers can only be reimbursed through the psychiatrist. As a consequence, if the psychiatrist in charge is not trained in psychosocial interventions (as it is the case for most psychiatrists in Romania) and is not sympathetic towards such interventions (and therefore does not refer patients to psychologists or social workers), then people with schizophrenia do not have financial access to these interventions. In contrast, access to all health professionals relevant to the provision of diabetes care is covered by insurance.

2. Availability of evidence-based treatment and care

2.1. Availability of medication

The respective national plans set out which medication is available to patients without co-payment, as long as it has been prescribed as part of a treatment plan by a specialist physician. However, they must co-pay for prescribed drugs falling outside the relevant lists. Consistent with the goal of encouraging autonomy and reducing dependence on health professionals, patients with diabetes can be prescribed medication for up to 90 days. However, for those with schizophrenia, the corresponding period is only 30 days. This means that those with schizophrenia must collect their prescription every month from the outpatient service where they are registered. Additionally, people with schizophrenia are entitled to request a change of medication in the event of significant side effects or poor response to medication only after a month has passed treatment from being prescribed. This may have negative implications in terms of treatment outcomes and long-term adherence to treatment.

In addition to medication, people with type 1 diabetes also need relevant medical equipment (e.g. insulin pumps, glucometers). A glucometer is only provided to patients under 30 years of age. There are no age limitations on any aspect of mental health medical treatment.

2.2. Availability of other evidence-based interventions

The mental health legislation entitles people with schizophrenia to a range of psychosocial interventions, as described in Chapter 6. However, as noted above, only some are included in the insurance package. Specifically, the Framework Contract (271, 272) does not include outpatient rehabilitation or reintegration services for people with schizophrenia, although these are included in the mental health legislation. Inpatient rehabilitation services are covered for people with severe and enduring mental health problems that require long-term medical care (deemed as chronic). Some services are, however, provided in social care institutions, although not under the auspices of the Ministry of Health, and as such are beyond the scope of this research. Conversely, there are no discrepancies between the interventions recommended in policy and guidelines on diabetes and the package of services covered by insurance. It is, of course, a separate question as to whether the package of services offered to people with diabetes includes cover all evidence-based interventions, although again this is outside the scope of this research.

2.3. Social care

People with schizophrenia and type 1 diabetes are entitled to the same social care, according to the severity of their disability.

2.4. Physical health

There are no differences between the services that should be available to treat co-morbid somatic health problems in people with schizophrenia and type 1 diabetes.

2.5. Availability of enough staff in all settings

The standards for staffing of inpatient specialist services for people with schizophrenia and type 1 diabetes are the same. There are, however, significant differences arising from the dominance of diabetes management by physicians. Thus, when people with diabetes require foot or eye care, they can be referred to the relevant specialist physicians, such as orthopaedic surgeons, dermatologists, or ophthalmologists. There are staffing norms for these specialists. In addition, the norms make provision for employment of dietary specialists, both nurses and physicians. The psychologists and social workers required by people with schizophrenia are far fewer in number. Furthermore, their reimbursement is via a medical specialist who must refer the patient (so they are not independent practitioners). Social workers are not included in staffing of acute hospitals and there is no provision for occupational therapists at all. Once again, there is a mismatch between the more generous norms indicated in the mental health legislation and what is covered by health insurance.

Unlike with inpatient services, the general health legislation does recognise the staffing levels proposed in the mental health legislation for specialist outpatient services. Consequently, there should be no difference in staffing in outpatient facilities for the two groups.

The Ministry of Health's staffing plan makes provision for the provision of short courses to train other physicians to fill gaps in diabetes care but there is no comparable provision for mental health.

Finally, the health system in Romania has not yet adopted international concepts of chronic care so neither group has access to care coordinators, even though the mental health legislation requires that people with severe and persistent mental health problems are assigned one, as does the disability legislation in respect of anyone deemed severely disabled, regardless of the cause of disability, paid from social care funds.

2.6. Availability of multidisciplinary teams with good representation of each professional category

By law, health care teams managing schizophrenia and diabetes must include physicians specialised in each condition; psychiatrists and specialists physicians in diabetes, nutrition and metabolic disorders (the main speciality providing diabetes care in Romania) respectively. In addition, both teams include a mixture of general nurses and nurses specialised in each condition. Pharmacists, auxiliary staff and cleaners are also present in both teams. However, as already noted, there are differences in the other team members providing interventions relevant to each condition.

The multidisciplinary approach to care for people with diabetes is apparent from the many professional categories included in the team. Besides the core staff mentioned above, patients with diabetes are also supported by teams which include physicians of other relevant clinical specialisations (cardiologists, ophthalmologists, nephrologists etc.), psychologists, and sometimes dieticians (at the discretion of the hospital manager). Similarly, a multidisciplinary team is required by both general and mental health legislation for specialist outpatient services supporting persons with schizophrenia, including psychiatrists, nurses, psychologists, social workers, occupational therapists and care coordinators.

On the other hand, the composition of the mental health team in specialist inpatient facilities is unclear given the contradiction between the mental health and general health legislation. The human resources plan arising from the mental health legislation is not recognised in the general health legislation and anyway would be difficult to implement in the current circumstances. Thus, although the staffing schemes proposed in both the mental health legislation and the general health legislation require the presence of psychologists in the mental health team, the difference is that the former recognises psychologists as full members of the team but the latter does not. Specifically, the MoH does not recognise psychology as a health profession but rather a profession connected to health, so that psychologists cannot be contracted by the insurance fund for any of the services they provide. This situation persists even though the Law on Psychologists (268, 269) stipulates that clinical psychologists can perform psychological testing, prevention and psychotherapy for personality and emotional disorders. Yet, as noted above, psychotherapy is covered by the insurance fund only when performed by psychiatrists or at the request of psychiatrists, who are themselves paid by the insurance fund. The position of psychologists outside the mainstream healthcare professions gives them a low status. The salary of a psychologist is significantly lower than that of a nurse, even though the duration and level of training of the latter is considerably less.

While it may appear that the diabetes team is too "medicalised", the fact that all members of the team are either doctors or nurses has significant advantages in the Romanian context. Firstly, it ensures that each team member is available to patients with diabetes. Secondly, all health professionals within the diabetes team enjoy full recognition, in terms of appropriate status and salary scale.

In conclusion, multidisciplinary teams are guaranteed by legislation for people with diabetes at all levels of specialist care, while people with schizophrenia benefit from effective multidisciplinary teams only in outpatient services.

3. Quality of treatment and care

3.1. Individual treatment plans developed for each patient, on the basis of a holistic assessment. Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

a) Holistic assessment as a pre-requisite of the treatment plan

People with schizophrenia and diabetes should benefit from the same procedures for assessing whether they are sufficiently disabled to obtain the various benefits described earlier. There are, however, differences in their entitlements arising from the respective National Programmes (254, 258). Thus, the National Programme for Diabetes (258), which is consistent with the Framework Contract (271, 272), provides comprehensive and detailed annual check-ups, focused on early detection of complications, that are monitored as a measure of performance. The Framework Contract also sets out the assessments to which people with schizophrenia are entitled but in much less detail. Furthermore, there is no requirement that they be done annually.

Once again there is a mismatch between the mental health legislation and the insurance coverage. The former provides for people with schizophrenia placed in residential care outside the health system to be assessed at least twice a year but the latter makes no mention of this, raising the question of whether it actually happens.

b) Individual treatment plan developed for each patient

The package of services covered by insurance does not specifically include a treatment plan for people with either diabetes or schizophrenia. The Framework Contract (271, 272) only refers to continuity of care with primary care services. At the time of the research, the disability legislation took the same approach, except in relation to those with a severe disability who are entitled to an individual treatment plan that addresses all their care needs. In addition, under social welfare legislation, those covered are supposed to have a recovery plan aimed at their social and professional reintegration.

The National Programme for Diabetes (258) requires that all people with type 1 diabetes have an individual treatment and monitoring plan. The mental health legislation also requires that all people with schizophrenia have an individual treatment plan, specifying what it should contain, regardless of whether the individual is cared for in the health care or social care system.

However, as noted above, neither of these requirements is endorsed by the Framework Contract so it is unclear whether service users actually benefit from them.

c) Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

While entitlements to participate in the development of their own treatment plan guaranteed by the insurance legislation, disability legislation and social welfare legislation differ, these three streams of legislation treat people with schizophrenia and type 1 diabetes similarly. Thus, the overall health regulations (including the Framework Contract (271, 272) and the National Programmes (254, 258)) make no requirement for the involvement of any of these service users in the development of their treatment plan. The disability legislation guarantees the right of all those deemed to have a severe disability to play an active part in the process of development of their individual treatment plan. Finally, the social welfare legislation requires that treatment plan are developed unilaterally by relevant health professionals. Service users are not expected to participate in developing their treatment plans, but are expected to comply to them if they wish to receive benefits. Current legislation makes no reference to patients being given a choice of treatment, except in relation to consent, although they can choose between different service providers.

The only difference is in the mental health legislation, which requires that people with mental health problems are involved in the development of their treatment plan. However, the legislation does not create any accountability mechanisms and the health insurance legislation does not support this approach.

3.2. Presence of discharge procedures

None of the documents reviewed address discharge from specialist services, except to oblige specialists to communicate information on diagnosis and treatment to general practitioners.

3.3. Continuity of care

The mental health legislation apparently places people with schizophrenia at an advantage in comparison with people with diabetes by placing continuity of care at the core of the new model of mental health services. Furthermore, the Mental Health Strategy (251) requires that people with mental health problems, including those with schizophrenia, are assigned a care coordinator.

This is an innovative approach in the Romanian health system, which, if implemented, could become a model that could be replicated for patients with other chronic disorders. The general health legislation, applicable to people with diabetes, does discuss partnership between elements within the health sector and with other sectors, but no mechanisms exist to do so. However, despite these provisions, the Framework Contract (271, 272) does not specify any particular approach to care management and it addresses continuity of care only in terms of maintaining psychotropic drug administration. Given the disconnect with funding, the degree to which people with mental health problems can actually benefit from the provisions of the mental health legislation is questionable.

The disability legislation, which applies to both groups, takes a similar approach to the general health legislation and focuses on recording and communication of information, rather than on coordination of care and supporting the patient.

3.4. Staff have the appropriate competencies and skills

According to the mental health legislation, the mental health team comprises of a variety of professional categories and recognises the training needs of all these categories. Similarly, the diabetes policy makes specific requirements for training of staff working with people with diabetes, in particular physicians from other clinical specialities that provide cover in the absence of those specialised in diabetes, nutrition and metabolic disorders.

The differences in the composition of the teams managing the two conditions have been described above. All professionals in the diabetes team are either doctors or nurses, and as such are subject to standardised training and continuing educational requirements defined by the MoH. In mental health, these requirements only apply to psychiatrists and nurses. The legislation that regulates other professions is unhelpful. Indeed, the legislation on the psychological profession (268, 269, 311, 313) excludes the MoH from the process of registration and accreditation of clinical psychologists, though the MoH is their main employer. While a limited number of bilateral agreements exist between universities and hospitals, the training of clinical psychologists is, by law, exclusively university-based. As a result, there are few opportunities for clinical training similar to the residencies undertaken by psychiatrists. This difference also exists for continuing education. Thus, there are no obvious mechanisms to assure the quality of interventions provided by psychologists, potentially putting people with schizophrenia at a significant disadvantage.

The level of training of nurses is similar in both sectors. Most nurses in Romania undergo a general nursing training and afterwards get on-the-job training in the specific areas to which they are assigned. Recently, efforts have been made to set up specialist training for nurses in both mental health and diabetes care. Regardless of where they work, all nurses employed in the health sectors must undergo compulsory continuing education every year. There are no requirements as to the type of courses they must undertake to attain the necessary skills and competencies for the areas to which they are assigned.

3.5. Empowerment of service users to care for themselves and live as independent a life as possible (Personal autonomy)

Mental health legislation states the importance of empowering patients. It even designates the degree to which service users are supported in achieving personal autonomy as a measure of the quality of services provided. However, neither the legislation (primary or secondary) nor supporting policy documents identify any measures to achieve this.

Diabetes policy also requires that patients be empowered to live as independent a life as possible. Minimising their contact with health services to only those occasions where it is necessary is listed as an *indicator of quality* in the National Programme for Diabetes (258). This document includes mechanisms that should, in theory, hold providers to account. Yet, as with mental health, there is no system to assess whether this has been achieved.

Conversely, policy and legislation are sometimes formulated in manners that impinge on the personal autonomy of people with schizophrenia. People with schizophrenia are not entitled to any home treatment and they must contact specialist providers for all of their mental health care needs. They are required to attend the outpatient services monthly if they want to receive prescriptions.

The only legislation specifying measurement of the extent to which people have achieved autonomy is contained in the disability legislation, which applies to those in both groups who are registered as having a severe disability.

3.6. Involvement of service users in shaping the services

The current policy and legislation does not make any provisions for the involvement of service users in shaping the services with which they are provided. The (draft) Mental Health Action Plan (252) indicated an intention to include some provisions but, as the document was not adopted at the time of the research, people with schizophrenia remained in the same situation as those with diabetes.

3.7. Involvement of families and carers

Policies and legislation make the same provisions for the involvement of families and carers for both groups of service users.

4. Quality of facilities

4.1. Protection of service users' privacy and safety, decent living environment

The legislative standards for living conditions in inpatient units providing healthcare covered by insurance are the same for all patients, regardless of the disease for which they were admitted. It should be noted that the legislation does not envisage single accommodation for any category of patient, regardless of the duration of the stay. The health legislation requires that an isolation room be available in the facility. It does not, however, specify the purpose of such a room and, in particular, whether is meant to give patients an option to be by themselves or whether it functions to isolate individual patients, for a variety of reasons (e.g. communicable diseases, violence).

For outpatient facilities, the Framework Contract (271, 272) requires that appropriate furniture and equipment be available but it does not differentiate clinical specialities. The health mental health legislation, however, is very specific about how the setting should be arranged, even indicating the number of furniture items (e.g. number of chairs and desks). The intention is to offer service users friendly conditions and an environment that is as unrestrictive as possible.

The health legislation requires that all service users, regardless of their disease, are treated with respect and consideration and that staff not complying with this requirement should be penalised.

4.2. Presence of appropriate treatment facilities

The legislation sets the same specific standards for rooms in inpatient and outpatient facilities for each condition. In addition, the mental health legislation specifies appropriate space for a range of interventions (such as individual therapy, group therapy and rehabilitation activities). There are no such detailed provisions related to diabetes services. The logistic arrangements for facilities used to treat patients with diabetes are at the discretion of the facility manager.

4.3. Hygiene

There are no measures specific to either group. There is, however, a difference between those, whether suffering from schizophrenia or diabetes, who use the health care system only and those who are entitled to additional support from the social care system (those classified as having a severe disability). The latter, if deemed severely disabled, are entitled to support under disability legislation for the maintenance of personal hygiene and house cleaning.

4.4. Food and drinks

The same legislation applies to both groups. Those people who are registered as having a severe disability (regardless of the cause of the disability) are entitled to support with shopping for food and cooking. No other people with schizophrenia or diabetes are entitled to this service.

5. Protection of human and civil rights

5.1. Right to respect of all human and civil rights on mental health facilities

The Romanian Constitution (306) guarantees respect of human rights to all citizens, regardless of their health status. Consequently, the health legislation only details a number of specific rights that are particularly relevant to health care, which are presented below. The mental health legislation does, however, re-affirm a number of human and civil rights enacted in response historical violations. There were no comparable violations related to diabetes. Among the specific provisions of the mental health legislation are the right to be treated humanely, to be respected and to be treated in a dignified manner, to be protected against all forms of exploitation and against harmful and degrading treatment, the right to a private life, the freedom of uncensored communication using all means and with all people and the right not to be subjected to experimental treatment without giving informed consent. The legislation also specifies the procedures and protections in the event of involuntary treatment, restraint and isolation. However, these issues are beyond the scope of this thesis. Similarly, the disability legislation stresses the entitlement of all people with disabilities, regardless of the type of disability, to all constitutional human and civil rights. In particular, it stresses the right to non-discrimination on any grounds.

5.2. Right to informed consent to treatment

The right to consent to treatment is guaranteed for all users of health services. The general health legislation specifies what constitutes consent, conditions which need to be met for the consent to be valid (including provision of information) and procedures for recording consent. Under the mental health legislation, people with mental health problems may lose this right in some circumstances. The legislation does not, however, make any provisions for the protection of voluntary patients against coercion, so leaving room for abuses. Conversely, people with diabetes cannot lose their right to informed consent under any circumstances.

5.3. Right to confidentiality

The right to confidentiality of all information related to the health of all service users is guaranteed by both health and disability legislation. The mental health legislation repeats the provisions of the health legislation, without any additions.

5.4. Right to information

All users of health services are guaranteed the right to information by the Law on the Rights of Patients (260), which is applicable both to people with schizophrenia and with diabetes. In addition, the mental health legislation requires that people with mental health problems are provided with a description of the nature of their problems, the least restrictive setting necessary for treatment, the goals of the treatment and the responsibilities of staff.

The disability legislation also affirms the right of all people with disabilities to information. In addition, it specifies that information tailored to the individual's situation should be provided to the service user, his or her legal representative, and the family.

5.5. Right of access to personal information

By law, all users of health services are entitled to access to their personal information. The Mental Health Law (256) specifies that people with mental health problems have the right, upon discharge, to receive a written copy of their diagnosis and information on treatment and care. However, this right can be waived if the physician in charge considers that providing this information might affect their mental state. However, the existing arrangements give the physician great discretion about whether to do so, with no system of oversight. This places patients with schizophrenia at a disadvantage to those with diabetes and contradicts to the Law on the Rights of Patients (260), which clearly states that all patients should have access to their personal information. According to this law, the only exception from the duty to provide access to personal information is when the service user states his or her express request that he or she wishes no longer to be informed about his or her health status.

5.6. Right to notification of rights

The mental health legislation guarantees people with schizophrenia the right to be notified of their rights. While the health legislation does not specify such an entitlement to all health service users, people with diabetes who are registered as having a disability are also guaranteed this right by disability legislation (274). The legislation requires that the rights and obligations of patients need to be clearly posted in all wards, regardless of speciality.

5.7. Right to treatment sensitive to needs of minorities (with different cultural and religious background)

Protection from discrimination on cultural and religious grounds is guaranteed for all people by health (general and mental), disability legislation.

Conclusions

It can be seen that policy and legislation are broadly equitable for people with schizophrenia and type 1 diabetes in the areas set out in Table 6.

Table 6 Areas where policies and legislation are essentially the same for people with schizophrenia and diabetes

1.4	Access to different parts of the system, as needed (Referral system)
2.3	Social care
2.4	Physical health
3.2	Presence of discharge procedures
3.4	Satisfaction with the quality of treatment provided
3.7	Involvement of service users in shaping the services
3.8	Involvement of families and carers
4.1	Protection of service users' privacy and safety, decent living environment, *just that mental health* legislation provides more details
4.2	Presence of appropriate treatment facilities, just that mental health legislation provides more details
4.3	Hygiene
4.4	Food and drinks
5.1	Right to respect of all human and civil rights on mental health facilities, just that mental health legislation provides more details
5.3	Right to confidentiality
5.4	Right to information, just that mental health legislation provides more details on the kind of information mental health services users should have access to
5.7	Right to treatment sensitive to needs of minorities (with different cultural and religious background).

In some areas, the policy and legislation puts people with mental health problems at an advantage as compared to people with type 1 diabetes:

- *1.3. Access to services when needed (temporal access).* The mental health legislation requires timely access to specialist services and a complex range of community-based interventions, which can potentially be considered better that that for people with type 1 diabetes. However, this is not recognised in the Framework Contract (271, 272) so it is not paid for.
- *2.1. Availability of medication.* People with diabetes aged over 30 years old are not provided with a glucometer. There are no age limitations for any aspect of mental health medical treatment.
- *5.6. The right to notification of rights.* Policy and legislation for people with mental health problems establish specific legal requirements on notification of rights that are not reflected in general health legislation applicable to people with diabetes. This does not necessarily

imply an advantage for people with mental health problems but it is an extra legal protection. At the same time, the disability legislation, does guarantee this right for people with diabetes if they are registered as having a disability.

- *3.1.c) Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate.* Under the mental health legislation, people with mental health problems are explicitly required to be involved in the development of their treatment plan, although there is no means of ensuring that this happens and the insurance fund does not require it.
- *3.3. Continuity of care.* People with schizophrenia are at an apparent advantage in comparison with people with diabetes, as mental health legislation requires that people with schizophrenia be assigned a care coordinator. However, this model is not included in the package of services covered by insurance, or in disability legislation, or by other funding schemes. As such, it is not evident people with schizophrenia can realise this theoretical advantage.

In many areas, however, the policy and legislation put people with mental health problems at a disadvantage as compared to people with diabetes:

- *1.1. Access to care in the least restrictive environment/community-based settings.* People with mental health problems have significantly less easy access to inpatient care and they cannot access long-term inpatient care in the least restrictive environment, close to where they live.
- *1.5. Financial access to services (financial affordability).* People with schizophrenia face greater financial barriers to the full range of interventions recommended, specifically psycho-social interventions.
- *2.1. Availability of medication.* People with mental health problems cannot have their treatment changed in less than a month, no matter how bad their side effects.
- *5.5. Right of access to personal information.* People with schizophrenia are at disadvantage. As subjects of the mental health legislation, they can lose their right to personal information based on the decision of a single health professional (the psychiatrist in charge). There are no safeguards against abuses. This is in contradiction to the Law on the Rights of Patients, and singles out people with mental health problems.

- *5.2. Right to informed consent to treatment.* Being subject to the mental health legislation, people with mental health problems can lose this right under some circumstances. Additionally, they have no legal protection from coercive treatment while voluntarily admitted to specialist services. This places them at disadvantage with people with type 1 diabetes who never lose this right.
- *2.2. Availability of other evidence-based interventions.* Specific psychosocial interventions and rehabilitation and reintegration services required by the mental health legislation are not included in the package covered by insurance. This potentially puts people with schizophrenia at a disadvantage to people with diabetes, who are entitled to all the interventions recommended by the national diabetes policy.
- *3.6. Empowerment of service users to care for themselves and live as independent a life as possible (Personal autonomy).* While policy and legislation for mental health and diabetes stress the importance of empowerment and personal autonomy, the mental health legislation limits these indirectly, for example by requiring people with mental health problems to report once a month if they want to receive a prescription. It also limits the ability of those with mental health problems to self-manage their condition and they are not eligible for home treatment, unlike those with diabetes.
- *3.5. Staff have the appropriate competencies and skills.* People with schizophrenia have significantly less access to qualified specialists. Of the entire mental health team, only psychiatrists and nurses have competencies and skills comparable with diabetes physicians and nurses. Other professionals are not recognised as members of the mental health team and there is no provision for their training or any feasible mechanisms for quality assurance of the interventions they provide.
- *3.1.b) Individual treatment plan developed for each patient.* While people with diabetes are guaranteed an individual treatment plan, people with schizophrenia are not, even though the mental health legislation requires they should have it, as a consequence of the absence of a funding mechanism and accountability.
- *3.1.a) Holistic assessment as a pre-requisite of the treatment plan.* While both the diabetes policy and the health insurance legislation require that people with diabetes receive a comprehensive assessment annually, similar requirements arising from mental health legislation are only partly supported by the health insurance scheme.

- *2.6. Availability of multidisciplinary teams with good representation of each professional category.* Multidisciplinary teams are included in legislation for people with diabetes at all levels of specialist care, but those with schizophrenia benefit from only limited teams except in outpatient services.
- *2.5. Availability of enough staff in all settings.* There are two main differences. First, neither policy nor legislation guarantee availability of enough specialist staff relevant appropriate for the care of people with schizophrenia, while they do for people with diabetes. Second, contingency plans for shortages of specialists in diabetes are not matched by plans in respect of psychiatrists.

In summary, there are many weaknesses, inconsistencies, and contradictions in the Romanian legislation and related regulations and policies in respect of diabetes and mental illness. Yet, the process of elucidating what measures are in place was a major task, involving a lengthy process of extracting, analysing, and comparing documents arising from different sectors, many of which had been amended on numerous occasions, often with the result that they obscured rather than clarified what was meant. It is reasonable to assume that the challenges faced when compiling this information for the thesis will, in practice, be viewed as insurmountable by many health care providers, patients, their carers, and even their legal representatives.

The review of the *de jure* system does, however, provide clear evidence that patients with severe mental health problems are, in some respects, disadvantaged compared to those with a complex chronic physical disorder, diabetes. The next step is to assess what this means in reality for those with the two conditions. This will be examined in the subsequent chapters.

Chapter 9 Experience of people with schizophrenia - Findings of the Rapid Assessment

This chapter will present the *de facto* situation in mental health specialist services, as experienced by people with schizophrenia and by the health professionals providing them with treatment and care.

This chapter presents the synthesis of findings for the first condition studied (schizophrenia) by variable, sub-variable, type of setting (outpatient, acute inpatient, chronic inpatient), target group (service user, psychiatrists, psychologists, social workers, nurses, auxiliaries) and location (Bucharest or Slatina). General assertions/descriptions of findings represent combined findings from all target groups, regardless of the type of setting, location, and interview strategies employed. Differences between target groups, locations and type of settings are noted and discussed.

1. Accessibility of specialist services

1.1. Access to care in the least restrictive settings

There was widespread knowledge among patients and professionals of the services that are available for those with schizophrenia. In general, patients must obtain outpatient and acute inpatient care in a facility within whose catchment area they reside; an exception is the acute mental hospital in Bucharest which takes patients from anywhere in the country. Long term residential care is provided in facilities on the outskirts of cities and although these have, in theory, larger catchment areas, these are poorly defined and enforced. Individual patients were very familiar with the means of accessing care in a crisis. There was a consensus that few patients with established mental illness would consult their general practitioners, instead going directly to mental health facilities.

Interviewees described the common reasons for hospitalisation. As expected, one was the severity of the illness. However, there was also consensus among patients and professionals that many patients were admitted to both acute and long-term facilities because they had nowhere else to live. Interviewees described how this often arose because family members persuaded them to transfer ownership of their accommodation to them, often while not fully aware of the consequences, and then refused them permission to return, or because they had no remaining family.

Many such patients are in long-term facilities. Those in Slatina described their environment very favourably, commenting on the cleanliness of the accommodation, the quality of the food, and the acceptance of their condition. Indeed, it seemed that this hospital was viewed by many patients as a desirable place in which to spend the rest of their lives, especially when the alternative was very uncertain. However those in Bucharest were much less positive, reporting their dissatisfaction with the accommodation. Others are in acute facilities, some for many years, even though the new payment system provides a strong disincentive to care for long-term patients there. A related reason is that some patients are considered disruptive by their families and neighbours. There was some sympathy among psychiatrists with those living near such patients but patients argued that others had a low threshold for irritation "*Often (admissions) are due to a purely social interest, the family wants to get rid of them, neighbours put pressure because it's inconvenient for them to have a schizophrenic in their building, he makes noise, or is weird and they prefer not to have him around. It's normal*".

There was a widely held view among patients in acute and long-term hospitals that many of those hospitalised but who have alternative accommodation could live at home. However, the crucial requirement was for a system by which health workers could supervise their medication, as they had concerns about their ability to adhere to treatment and to provide other forms of general support. This, they felt, would help them to obtain employment and lead a more normal life. However, such support does not exist at present. They are entitled to support from social workers but many expressed anxiety about contacting them. In particular, there were widespread stories of social workers mistreating patients with mental illness who experienced crises, often with the involvement of the police. Examples included breaking down doors and violent restraint.

Many health professionals were also supportive of the principle of greater domiciliary care, although to varying degrees. Psychiatrists were the most supportive and, on occasions, those based in the acute hospitals would go to patients' homes, especially outside Bucharest, particularly if the patient was a member of a high status family or if they were violent. They felt that it should be possible to manage some patients in crisis at home, rather than admitting them all as at present. However, they expressed concern that these visits were time consuming and that they were not compensated for them. Psychologists working in outpatient facilities were also supportive of home visits but reported that they undertook them only rarely, again for patients in high status families. In contrast, one psychologist in an inpatient facility in Bucharest viewed home visits as unethical and potentially illegal, raising concerns about the consequences if something went wrong. Nurses in all facilities except in the acute hospital in Slatina were unenthusiastic about taking part in home visits. Those in Slatina would be willing to do so, as long as they were paid for visits. Social workers attached to health facilities already do make some home visits, to make contact with families, to assess the degree of support patients will receive on discharge, and to help patients obtain benefits. Overall, the greatest barrier to home visits was the logistical difficulty as they are time consuming, and the lack of a system of paying for them.

In summary, there is widespread agreement that too many patients with schizophrenia are hospitalised. However, to reduce this number, attention needs to be paid to securing alternative accommodation, in particular by finding ways to achieve redress when they are deprived of their homes by exploitative relatives, and to support their adherence to medication regimes.

1.2. Geographical accessibility of services

Patients had to collect their medication from outpatient facilities they were registered with. In principle patients had an option between registering with the specialist mental health outpatient unit linked to a mental hospital or going to other specialist offices linked to general health services. In Bucharest, some patients would opt for the latter. Others, however, preferred to go to the specialist outpatient unit, even when it took them as much as 2 hours by public transport each way. Patients living in rural areas or small towns surrounding larger towns did not have any option other than to go to a specialist outpatient unit linked to an inpatient facility, since psychiatrists were not available where they lived. Once they obtained their monthly prescription they could however collect their medication at any pharmacy in the area where they lived. Access to talking therapies was limited to a few locations in Bucharest and only one in Slatina. Many patients found the trip too long and gave up. Access to rehabilitation services was even worse.

Interestingly, patients had no complaints about the location of hospitals and the distance from their home, as they were not aware of alternative solutions and took for granted that these were their only choices. Few professionals, psychologists or psychiatrists thought that inpatient services could be brought closer to the communities in which people live.

1.3. Access to services when needed (opening hours/ out of hours staffing)

Access to services after working hours

People with schizophrenia primarily had access to outpatient specialist care during official working hours. Outside working hours, some were able to contact their psychiatrists and occasionally psychologists in both outpatient and inpatient services on their private mobile phones, and receive brief consultations or be directed to the emergency services in mental hospital. A psychiatrist from acute inpatient hospital in Bucharest noted: "*Many times I was the one calling the ambulance*".

Psychiatrists who also had private practices provided crisis care at their offices. Not all professionals were open to being contacted privately. Psychiatrists from chronic hospitals and some from the other services and most psychologists, social workers and nurses were not.

When admitted to inpatient care, patients would have access to the full range of services offered in each setting only during the day time. During evenings and nights they would have access only to a reduced number of auxiliaries, nurses and psychiatrists. In the chronic hospital in Slatina, psychiatrists were not available during night shifts due to the scarcity of staff. One psychiatrist from this facility noted: "*We have only 2 full time psychiatrists, and with 25 working days per month, there is no way!*"

Psychologists in the chronic hospital in Bucharest made regular requests to increase their working hours, but were constantly refused. In their view, the needs of patients were not met during the official working hours, but decisions on working hours were made for administrative and financial reasons and not according to the needs of patients.

Waiting time

The waiting time for outpatient mental health specialist services was usually 1-2 hours, but sometimes it could be as long as 3-4 hours.

1.4. Access to different parts of the system, as needed (Referral system)

Patients diagnosed with schizophrenia cannot access long-term care without a referral from their GP or a psychiatrist working in acute or outpatient services. Within the mental health system, psychiatrists could refer patients to other professionals (psychologists and social workers), but not the other way around. Psychiatrists in outpatient and acute care services could refer patients between each other. They could also refer patients to somatic services, as needed. However, patients were not always accepted in somatic services (see below). Physicians in other specialities could also refer patients to psychiatrists. Welfare services could also refer patients to mental health professionals for assessment.

1.5. Financial access to services (financial affordability)

People with schizophrenia have free access to psychotropic medication, but access to medication for co-morbid conditions, whether mental or somatic disorders, was limited. Many patients reported that they struggled to cover the co-payments, which were often more than they could afford on their low incomes. Some said they refuse partially funded prescriptions, saying *"Don't bother, I cannot afford it anyway"*. Psychiatrists in outpatient services highlighted how they were not allowed by the insurance company to change medication more than once a month, even if the patient experienced significant side effects.

Mental health services were free-of-charge in public institutions, but psychotherapies were only covered when performed by psychiatrists or, following referral, by psychologists. Even under those circumstances, only few sessions were covered. Patients requiring additional psychotherapy sessions had to pay out-of-pocket. The great majority of patients could not afford the cost so did not have access to psychotherapies.

Unofficial out-of-pocket payments were common in outpatient services, but not so much in inpatient services, mainly because the patients could not afford it. Patients from the chronic inpatient hospital in Bucharest noted that patients from better-off families could afford better conditions in the chronic hospital by bribing staff or making direct payments to renovate their rooms. Most patients reported how falling ill with schizophrenia led to job loss and a significant reduction in income. For most, pensions and social benefits were far lower than their salaries prior to the illness. For some patients, loss of employment also led to difficulties in accessing insurance, despite the fact that a diagnosis of schizophrenia should automatically lead to coverage. Bureaucratic procedures, for insurance, for registration as disabled and for welfare pensions and other benefits, were often too difficult for people with schizophrenia. Many only managed to obtain part of the benefits they were entitled to. Those without pensions could not access chronic hospitals, which were in some cases the only alternative to homelessness. Informal solutions used by psychiatrists included prescribing medication under another patient's name, or claiming falsely that an admission was involuntary and so covered by insurance. A psychiatrist in Bucharest acute inpatient hospital noted: "*We used another subterfuge, since they don't have insurance, we admit them as involuntary patients, the law on involuntary care allows free treatment, with everything we have available in the hospital*".

Another challenge arising in acute inpatient services was that the DRG system created a financial incentive for early discharge. Psychiatrists in Slatina's acute inpatient unit admitted that when a patient clearly needed longer treatment an informal solution was adopted whereby a patient would officially be discharged, only to be readmitted some days later, even though, in reality, the patient remained in the hospital. These perverse incentives are likely to contribute to the high admission rate reported in Romanian hospitals.

2. Availability of evidence-based treatment and care

2.1. Availability of medication

There was a general agreement that availability of psychotropic medication (both new and old) in pharmacies had improved dramatically since the 1990s. However, the communist era ceiling of drug sales is still in place whereby pharmacies have a fixed monthly allocation for certain drugs. Thus, patients may not be able to obtain any after the beginning of the month. Psychiatrists often help patients to identify pharmacies with a higher ceiling. Alternatively, patients are prescribed another medication. Some psychiatrists were keen on ensuring patients get the ideal medication for them, so where pharmacies ran out they would broker arrangements with other patients to borrow some of their medication until it becomes available again. Some patients lend to one another as well. Another unofficial solution found by some psychiatrists was to anticipate shortages and keep some supplies in the office.

The situation was similar in inpatient settings where, although medication was largely available, there were sometimes shortages of a particular product so some psychiatrists found similar creative solutions. Their main motivation was to ensure that patients could get the medication with least side-effects, to enhance adherence. An additional solution in inpatient settings was to discharge patients officially (even though they remained in hospital), so that they can collect medication from pharmacies in town and then be "readmitted" formally after a few days. Alternatively, families are asked by psychiatrists to buy medications at community pharmacies, paying directly, until the product becomes available at the hospital pharmacy.

2.2. Availability of other evidence-based interventions

a) Psychosocial interventions

Psychosocial interventions were available only to a minority of patients as there were few staff qualified to provide such interventions (see below). In outpatient units, some patients received counselling and talking therapies, mainly with psychologists, but in Bucharest psychiatrists also provided this service. So did some of the patients in inpatient units, more so in chronic than in acute services. However, patients did not know much about what psychotherapies are, what they actually entail, or what outcome they should expect. They just knew that they *"talked"* to psychologists or psychiatrists. Due to time limitations, they were often offered group therapies rather than individual therapies which patients indicated that they preferred. Even then, only a minority of patients had access to them. The rest of the patients in hospital felt left out, creating tensions.

It was not evident that the talking therapies available to patients were of good quality. Some psychiatrists who had training in psychotherapies provided CBT, family therapy, existential therapy and Jungian therapy. Some psychiatrists (trained in CBT) were of the opinion that psychotherapies were not appropriate for people with schizophrenia; they found the benefits are marginal, saying *"let's get real"*, and not worth the effort. Others reported successful outcomes and rated talking therapies as essential components of treatment. Not all psychiatrists understood what talking therapies were. Some thought that they could provide them without any training, simply based on their life experience. At the same time, there was no system of quality control for talking therapies, regardless of how well qualified or otherwise the providers were.

Some psychiatrists, particularly in Slatina and in the chronic hospital in Bucharest, considered that talking therapies should be carried out by psychologists, not psychiatrists, though the insurance system did not recognise psychologists as competent to provide this service. Consequently, in practice, psychologists did provide counselling and psychotherapies, as well as psychological testing, depending on their qualifications, but with payment channelled via the psychiatrists. Psychologists were trained in a variety of psychotherapies: CBT, existential therapy, experiential therapy, family therapy and even hypnosis. Like most psychiatrists, they showed little appreciation of what evidence-based talking therapies to use with a particular disorder such as schizophrenia. In these circumstances, the poor understanding among patients of what talking therapies are is understandable.

b) Rehabilitation and reintegration

There were only few rehabilitation and reintegration activities available to people with schizophrenia, most of them in Bucharest. The acute hospital there ran a pilot unit for rehabilitation and reintegration of patients, where the only social worker in the hospital was based. Here, most of the efforts were concentrated on acquisition of practical skills, and very little is done to reintegrate people in the workforce, which was perceived by most health professionals as an unrealistic goal for most patients. Many psychiatrists sympathised with employers who refused to employ people with schizophrenia, admitting that *"nobody wants to take the risk"*.

In the past, chronic hospitals did organize a variety of occupational therapy activities, but they were shut down in the early 1990s amid allegations they were in fact forced, unpaid labour. Yet some patients in the chronic hospital in Bucharest reported that they were still pressured, if not forced, to work by auxiliaries who require them to help with cleaning the wards, washing floors, and doing laundry.

At the time of the research, some facilities organized small-scale painting, gardening, and sewing activities. Chronic hospitals planned to develop more in the future. One challenge however, was the lack of occupational therapists and poor definition of the roles of social workers and psychologists in these activities, which further limited the scope to make these interventions available to people with schizophrenia.

2.3. Social care

Many patients were unaware of the social care they are entitled to by law. For many, it was limited to receiving their pension. Despite legislation guaranteeing their entitlement to social care and disability benefits, even those who were aware of their rights struggled to claim them. With few social workers in mental health services, they depended on help from social workers in local authorities. However, these social workers had little interest or sympathy for people with schizophrenia who *"begged"* for their help with paper work needed to access their benefits but were refused. Some also asked for support with housing, facilitation of difficult family situations, and employment. Yet despite getting little or no support, those living at home who failed to take their treatment would lose even those few benefits they managed to claim.

Patients admitted to facilities that employed social workers could ask for some support, but the scarcity of social workers meant they could only focus on the most difficult cases and on ascertaining the identity and locating family members of those who did not know their name.

For many patients who had no home, most health professionals agreed that the most important social support available was to be admitted to a chronic hospital with good living conditions, like the hospital in Slatina.

2.4. Physical health

Patients living at home and registered with outpatient services attended somatic facilities like any other person. However, they were not always believed when complaining of somatic problems. Somatic physicians often felt insecure and uncomfortable around people with mental health problems. A psychiatrist in Bucharest acute inpatient unit noted: *"When they first make contact (with people with schizophrenia) they don't know if they're psychotic or not, and they are afraid of psychotic crisis on their ward and that they are not competent enough to cope with it."*. Patients and psychiatrists preferred that referrals to somatic services were made by GPs, who would avoid indicating that they had schizophrenia. However these patients struggled to cover the co-payments for their somatic conditions, as noted above, and were rarely able to bribe somatic health professionals, which often led to significantly less good care as bribery is common practice in these services.

Disclosure of their diagnosis could not be avoided for patients admitted to inpatient facilities. Many difficulties were reported in getting patients with schizophrenia accepted and treated promptly in somatic hospitals. The worst reports were from the acute hospital in Bucharest, even when the patients were in dire need of health care. Some facilities produced fewer problems, reflecting good relations established over time with somatic services. Some somatic physicians refused to treat people with schizophrenia primarily out of fear that they would not be able to cope due to their poor training in mental health. At the same time, many patients with schizophrenia found that patients with only somatic disorders often refused to be in the same room as them. Patients receiving inpatient care would receive their somatic treatment together with their psychiatric treatment.

2.5. Availability of enough staff in all settings

There were insufficient professionals of all types in almost all settings. The exceptions were psychiatrists in the acute inpatient hospital in Bucharest, possibly the most attractive service in the country, and nurses in the outpatient service in Bucharest, who complained about the tasks they were asked to do rather than the number of nurses. There were several implications of staff shortages. In outpatient services, psychiatrists stated that they would have consultations with as many as 60 patients per day. Psychologists found it more difficult to shorten sessions with patients and so had to turn down patients. Nurses and auxiliaries struggled in all inpatient facilities, particularly at night. In acute facilities, particularly in Bucharest, they felt overwhelmed by the demands on them; there was one nurse and one auxiliary per 100 beds in Bucharest and in Slatina. Psychiatrists noted that the low number of staff indirectly shapes the services they are providing. The shortage of psychiatrists in Slatina led to night shifts being cancelled. Managerial efforts to employ additional psychiatrists and social workers failed, due to the unattractiveness of the hospital and its remote location. Similar problems were encountered by the chronic hospital in Bucharest when it tried to employ additional nurses. Legislation norms for numbers of psychologists were achieved in inpatient facilities but staff complained that the norms were insufficient to treat all patients requiring their care. Consequently they were forced to select a small group of patients to work with. While this was considered the only feasible approach, it led to problems between patients. Those selected were seen by the rest as *"favourites"* of professionals.

2.6. Availability of multidisciplinary teams with good representation of each professional category

Representation of some professional categories was less good than others, as noted above. However, a major problem, as identified by health personnel, was that the staff in post did not operate as members of a team.

Relationships between psychiatrists and psychologists were unequal and in many cases tense. With few exceptions in settings where respectful relations had been established on an individual basis, the relationship was defined by psychologists as *"complete and utter subordination,* *humiliating for psychologists"*. Many psychiatrists reported that they work well with psychologists, but psychologists described how they are rarely consulted or taken seriously by psychiatrists except in their role in psychological testing. Their status was low, as reflected in their poor salaries, which were sometimes lower than nurses. Some psychologists openly linked their status with the poor quality of academic and clinical training of psychologists (see below).

The relationship of psychiatrists with nurses was rated better. In most facilities they worked as a team, particularly in inpatient facilities where psychiatrists depended on input from nurses on the status of patients as they actually spent little time with them. However, reports from nurses and psychiatrists were sometimes inconsistent. Thus, psychiatrists in the acute inpatient hospital in Bucharest thought their relationship with nurses was good and they relied on them. Nurses, however, reported that psychiatrists do not respect them; they blame them for problems that occur with patients even when that was not the case. In addition, personal interactions were marked not only by hierarchy, but by disrespect. Nurses minded that psychiatrists took liberty to address them with the informal "tu" while they were invariably required to address them with the polite "d-voastra".

Social workers reported similar relations with psychiatrists. While psychiatrists would refer patients to them, and in this way work together, the relationship was hierarchical and disrespectful. During the research I witnessed one illustrative scene. I was invited to lunch by the hospital manager, together with psychiatrists. When I asked whether other professionals would also join us, one psychiatrist mockingly told me *"Sure, there they are"* pointing towards the waitresses, whom I then noticed were actually the social worker and the nurses.

Psychiatrists had almost no relationship with auxiliaries, though they were actually the ones spending most time with patients. Instead, nurses worked closely with auxiliaries in all settings. Psychologists had limited interactions with nurses and social workers.

To conclude, while different professions were represented in the services studied, they did not work as a multi-disciplinary team.

3. Delivery of care

3.1. Individual treatment plan developed for each patient, in the basis of a holistic assessment, service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

a) Holistic assessment as pre-requisite of the treatment plan

People with schizophrenia were assessed on a number of occasions. When admitted in a crisis outside regular working hours, psychiatrists on call make a brief assessment to decide whether to initiate crisis treatment. This assessment is followed the next day by an extensive psychiatric and somatic assessment carried out by the psychiatrist assigned to the case. The somatic component, done together with nurses, includes blood pressure, heart, lungs, and reflexes, etc. Some patients are referred by psychiatrists to psychologists for psychological tests, and to social workers, where available, for assessment of their family and social situation. Families are also asked by psychiatrists to provide additional information on the patients' history and health status. Some psychiatrists assessed the risk of harm and self-harm, but they acknowledged that they had few tools to do so and no evidence of whether their assessments were effective. Patients identified as at risk would be placed in isolation. Other psychiatrists did not do such assessments.

Once admitted, patients were monitored regularly. The frequency of assessment varied with the number of psychiatrists available – in acute hospitals daily, in the chronic hospital in Bucharest every other day, and in the chronic hospital in Slatina sometimes every couple of weeks. When a patient is admitted in a crisis at night, patients receive a brief assessment by the psychiatrist on call. When no psychiatrist is on call overnight (as in the Slatina chronic hospital), nurses make the assessment and, when deemed necessary, would call a psychiatrist at home to agree to a course of action.

In outpatient services, patients are assessed at first attendance, making use of the notes from the inpatient services. The assessment covers the same components as in inpatient services. Once registered with an outpatient service, patients should be assessed each month when they visit for their prescription. However, in practice, patients are rarely re-assessed since psychiatrists have very little time for each patient. Discussions are focused on the new prescription and any need to adjust it.

Overall, the assessment of patients is limited and is dominated by the psychiatric assessment. Only a few patients receive psychological assessments or assessment of their social and family situation.

b) Individual treatment plan developed for each patient

All patients had an individual treatment plan which consisted almost exclusively of medication. Some patients received psychological counselling and talking therapies, but that did not really amount to a treatment plan. Only a limited number of patients in any setting, inpatient or outpatient, had access to talking therapies. While social workers were rarely available, most patients' treatment plans had no social component. Some facilities organized a number of activities such as group painting, gardening, etc, but they were not included in a treatment plan but rather were separate activities.

c) Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

To the extent that patients were involved at all in treatment decisions, it was limited largely to discussion of previously prescribed medication, with a focus on benefits and side effects. Most psychiatrists would take the patients' views into account when writing new prescriptions, particularly patients under long-term treatment as they saw it as a means to improve treatment adherence. Some psychiatrists in outpatient units noted they were more inclined to discuss treatment plans with better educated patients and those who managed to retain jobs, helping them to manage their treatment while at work. Some psychiatrists admitted that they would agree to change medication out of fear of patients. Others noted that the standing of psychiatrists in Romanian society is so high that the patients would not dare object to the treatment plan they propose. One psychiatrist even said *"the psychiatrist is the law"* and that *"the schizophrenics are nuts, no point in asking their opinion, if they make trouble just give them an injection"*.

Nurses were far less sympathetic to input from patients. Nurses from the chronic hospital in Bucharest thought that patients were unreliable and that *"one cannot just change the treatment because patients say they don't feel well, or has dizziness, or couldn't sleep, or slept too much."*

Patients were not able to participate genuinely in decisions on the talking therapies they might receive, since they knew very little about different types. Many psychologists recognised this challenge and the implicit limitations to their collaboration with patients. Others, however, had patronizing attitudes and thought that patients should tell psychologists about their problems and psychologists should tell patients what they should do.

3.2. Presence of discharge procedures

There were no discharge procedures in place at any level of the system. At discharge, patients would simply be give a hand-written note with brief information on their health status, the treatment they should follow, and a prescription for 30 days of treatment. However, many psychiatrists were dissatisfied with this, which they identified as a factor in the high rate of readmissions (Romania had at that time the highest admission rate in Europe (223)). Some gave patients and families their private phone number for crisis situations. Some psychiatrists in acute inpatient facilities took advantage of possibilities offered by the insurance system to operate private practice in parallel to their work in the hospital. Thus, they could continue to provide care after discharge and could focus on interventions other than medication, particularly talking therapies.

3.3. Continuity of care

Continuity of specialist health professionals

At the time of the research, the concept of care coordinator for management of chronic condition had not been introduced in Romania. Continuity of care was primarily left to informal processes and was seen as the responsibility of patients. Thus, there was an informal, yet well established procedure that patients returning to the same facility would be treated by the same psychiatrist. Patients indicated a preference for working with the same specialist, and psychiatrists largely considered this was a helpful approach. It was *"like an unwritten law"* recognised both by health professionals and by patients. Some psychiatrists argued that patients would feel rejected if psychiatrists would turn them down, and some argued that patients came to them *"as if they went to their parents, they love us"*. Patients indicated that they felt more secure discussing their condition with the same psychiatrist who knew their history and health status.

This practice also applied to psychologists, but some noted that, in many settings, the limited number of psychologists meant that patients do not actually have a choice.

While nurses tended to work in the same wards or facilities for longer periods, and consequently would deal with the same patients, there was no particular interest either from patients or nurses to ensure continuity. In fact some nurses even thought that too much familiarity with patients makes their interactions less therapeutic.

Input from previous specialist services

At entry to both inpatient and outpatient facilities, psychiatrists received the discharge note from the previous provider. While they took account of the information they received, they would, however, redo the tests and decide on the course of treatment, irrespective of previous recommendations.

Feedback to GPs and other health services

Contact between specialist and primary care services was limited. GPs in Romania had little involvement in the treatment of people with schizophrenia, who were expected to be treated almost exclusively in specialist services. Psychiatrists are required to send information to the patient's GP, but in practice this did not always happen.

Psychiatrists exchanged brief notes with specialist physicians from other health services when patients had somatic health problems. Besides these notes, often sent through patients, more substantive communication took place on a private basis among some specialists. There were no procedures to ensure continuity of care embedded in the system.

Communication with other relevant sectors

Psychiatrists prepared regular reports for authorities responsible for awarding disability and invalidity benefits when requested by patients. Beyond this, social workers noted the absence of connections that would enable exchange of information between different services. Such exchanges took place only occasionally, when there were special problems with a particular patient. Social workers in the mental health system did not collaborate with their counterparts in the local authorities, who were responsible for assisting people with schizophrenia with the formalities involved in obtaining disability pension and other entitlements. Psychologists and nurses had little or no interaction with other sectors, such as police or social care agencies.

3.4. Staff have the appropriate competencies and skills

Psychiatrists

Patients were largely satisfied with the quality of their psychiatrists, with the exception of the psychiatrists in the chronic hospital in Bucharest where they said that they *"clearly didn't take top marks in school"*. Psychiatrists in all settings rated their own competencies to be as good as in any other European country. All psychiatrists undertook yearly continuing education activities, often in national and international conferences, mostly sponsored by pharmaceutical companies. In addition, psychiatrists kept up to date with new developments by reading specialist journals and other materials over the internet. Most psychiatrists were not qualified to provide psychotherapy. The exceptions were the psychiatrists in Bucharest in the outpatient and acute inpatient services. Psychiatrists in these settings had competencies in a variety of psychotherapies including CBT, family therapy, existentialism, and Jungian therapy. Only some psychiatrists providing psychotherapy to patients showed concern whether the psychotherapy they provided was effective treatment of schizophrenia. One psychiatrist even admitted practicing a *"personal melange"* of psychotherapy, despite having no training in any form of talking therapy.

Psychologists

It was widely recognised that psychologists working in mental services had inadequate clinical training and lacked essential competencies. The reasons were complex. First, since the MoH did not recognise psychologists as health professionals, it took no responsibility for their clinical training and had no mechanisms for certifying or monitoring their quality. At the same time, the main competence required from them was to apply psychological tests. Counselling and talking therapies that they undertook were not reimbursed by the insurance system. In practice, however, psychologists were expected by psychiatrists to provide therapies on their behalf, for which the former could be reimbursed by the insurance scheme. Secondly, the degree in psychology, while it became very popular, also became increasingly easy to obtain, including through on line courses. Students were required to have placements in mental services, but they were not arranged through the MoH. Instead, arrangements were largely the responsibility of students, though some faculties would also make bilateral arrangements with hospitals. The lack of recognition from the MoH was matched by the disregard by psychologists' associations of the health care system. Regulations for competencies set out in the Law of Psychologists expressly exclude any input or influence of the MoH. Besides testing, the main competence psychologists should acquire was in psychotherapy. However, most psychologists could not afford to acquire it, since such training was not covered either by employers or universities. Continuous education was also not covered for psychologists, though it was covered for other health professionals. Another difference between training of psychologists and that of psychiatrists was the low priority given to ensuring interventions provided were evidence based.

All these factors led to low status and salaries for clinical psychologists (lower than nurses), which in turn led to difficulties in attracting the most competent and qualified psychologists into the public sector.

Social workers

Social workers reported that continuing education courses are scarce. They described participating in specialist conferences but very few are focused on mental health issues. They reported searching for information on the internet or reading materials brought by colleagues from specialist conferences.

Nurses

Nurses working in mental health had general nursing training with on-the-job training in mental health. Like psychiatrists, nurses rated their own qualifications and competencies highly. Psychiatrists and psychologists, however, often rated nurses' communication skills and patient handling poorly. The only challenge nurses admitted to was that they had difficulties in handling violent incidents. Most nurses were keen on getting training on this topic, but only a few, primarily from the acute inpatient hospital in Bucharest, had received it as part of their continuing education. All nurses were required to undertake annual continuing education, most of which was funded by the health service or by the pharmaceutical industry. Many took courses relevant to treatment of mental disorders and addiction, and on communication skills, but most nurses felt that they knew enough about mental health and actually took courses in other specialities, e.g. infectious diseases and cardiovascular disorders. The best qualified nurses complained that they were misused by psychiatrists, being asked to do paper work and secretarial tasks, and are able to spend little time with patients.

Auxiliaries

Although they are delegated many tasks that have traditionally been done by nursing staff, auxiliaries were mostly unqualified, particularly in the chronic hospitals where they were employed primarily on the basis of living close to the hospital. In most settings they had on-the-job training; some took a formal 6-month training for auxiliaries. Patients and most other professionals rated their competencies as poor, particularly their communication skills and patient handling skills. These views were not shared by auxiliaries, who rated themselves highly. Unlike nurses, while not trained in violence management, they reported they can handle situations they were confronted with, though they sometimes are aggressive themselves. The worst complaints about the competencies of auxiliaries were in the chronic hospital in Bucharest, where patients reported how they behaved in an authoritarian and abusive way, exhibiting behaviour that psychiatrists and nurses turned a blind eye to.

3.5. Empowered to care for themselves and live an as independent life as possible/ Personal autonomy

Services provided to people with schizophrenia did not seek to empower them to live independently and autonomously. While the insurance system tried to discourage long term admissions by limiting the number of paid hospitalization days in acute settings, in long term settings it allowed for patients, in practice, to remain until the end of their life. Efforts concentrated on improving living conditions there, rather than on supporting patients to live at home. In fact, nursing staff in long-term institutions reported that they supported families in completing procedures for patients with schizophrenia to be admitted permanently to institutions for people with disabilities.

Patients received little or no support with housing and employment. They did not get any support for self-management at home but were simply expected to comply with treatment. Instead, professionals expected and encouraged families to take responsibility for these tasks. At the same time, patients in long-term institutions that offered good living conditions (such as the Slatina chronic hospital) preferred living there than at home, where they often faced precarious conditions, were stigmatized by neighbours, and were rejected by their families.

3.6. Involvement of service users in shaping the services

Both patients and professionals found questions on involvement of service users in shaping services redundant, since the concept of patient involvement was new to them, and indeed to health care workers in Romania in general. Patients were hardly ever asked for feedback on the quality of existing services.

3.7. Involvement of families and carers

It was widely recognised that families play a key role in treatment and care of people with schizophrenia. At admission, they are asked about the patients' history, at discharge they are asked to monitor patients' adherence to treatment. When patients are considered at risk of suicide they are asked to manage their medication, when physically ill, they are asked to accompany them to somatic services. In addition, they are expected to provide for them and take care of all necessary formalities for their social benefits and pensions. Many families struggle. Some are keen to do their utmost to meet all these expectations. Patients in these families reported they comply with treatment and do all they are asked by health professionals to enable them to return home and be with their families. Others cannot cope. With poor information about the disease, and with little or no support from the system, they give up on their family members. They do not know how to cope with a crisis situation and often they are the ones calling the police and emergency services to arrange acute admissions. Some even actively contribute to their institutionalization. Health professionals often blamed these families for the frequent readmissions, believing that they could have been avoided if patients were cared for better at home. However, rather than just blaming them, some psychologists thought that the families themselves required counselling and support. At the same time, both patients and professionals reported that some families are sabotaging their relative's recovery to *"get rid"* of them. They try, and often succeed, to take away their property and collect and spend their social benefits and pension. These patients are in open conflict with their families and often try to claim their property back. They are rarely successful. It is up to professionals to decide how much they involve these families in the treatment of patients. Sometimes they take the side of families, other times they believe patients' complaints about families. Given the many limitations of the health system, professionals often believe that they have little choice.

4. Quality of facilities

4.1. Protection of service users' privacy and safety, decent living environment

Access and safety of personal belongings

Patients in inpatient facilities did not have storage secure space for personal belongings and they regularly suffered from thefts. One patient said "*if you leave your radio on the table in the evening, in the morning is gone.*" An exception was the chronic hospital in Slatina, probably due to the video surveillance system installed throughout the hospital, including in patients' rooms. An absence of locks was justified because, it was argued by nurses and auxiliaries, patients would not keep their lockers clean, would store old food in them, and would be likely to hide sharp and potentially dangerous objects.

While health professionals generally were aware of the fears of patients, not all of them believed patients when they complained of thefts and some argued that they exaggerate or imagine things, because *"they are hallucinating and imagining things in general"*.

Privacy and personal space

Facilities differed greatly in relation to patients' privacy and personal space. The acute mental hospital in Bucharest and the chronic mental hospital in Slatina were reported to be the best in this regard. Both had been renovated recently and most rooms in the hospital in Bucharest had only 2 beds per room. With cameras installed in their rooms, patients in Slatina did not have privacy but they saw it as a trade-off offering safety and the ability to monitor the quality of care.

The worst conditions were, once again, recorded in the chronic mental hospital in Bucharest. Women's wards were the most crowded, with up to 16 women per room, while most shared a bed with one other patient (double bed occupancy). Not all professionals saw bed-sharing as a problem and some thought that patients liked it as it makes them feel safer and less alone. Patients however found it stressful and uncomfortable. At the same time, some women commented that when *"you are as drugged as we are sometimes, you might as well be 4 in the same bed"*.

Patients also shared beds in the acute inpatient unit in Slatina, but professionals there are unhappy about it. They blame it on the policy of cutting beds in psychiatric units without offering alternative outpatient services.

Patients' violent and aggressive behaviour

Aggressive and violent behaviour by some patients put other patients at risk in all locations, though fewer problems were reported in the Slatina chronic hospital. While no fatality or life-threatening injury had occurred in any of the facilities for many years, sometimes patients would get hurt and require medical attention. The worst cases involved destruction of beds, walls, and locks. Patients were not allowed access to knives and forks, only spoons, nor any potentially dangerous sharp objects. Nurses and auxiliaries complained that they are more at risk of both physical and verbal violence than are patients, but psychiatrists were less aware of their concerns since they spent little time with patients, particularly at night when most incidents took place. The capacity of staff to contain incidents was limited due to low staffing at night and their limited competence in violence management.

Women's safety

In most settings, women patients were safe, with very few incidents being recorded. In the Slatina chronic hospital, the management acknowledged that some patients do begin consensual relations with other patients and some even asked the management to establish a room for couples. However intimate relations were not allowed in health facilities.

Women were reported to be at high risk only in the Bucharest chronic hospital, where male patients reported that women patients are pimped, primarily by male patients. Women patients confirmed this was indeed the case. There were allegations that pimps also came from outside the hospital, acquiescing with the hospital guards. Male patients thought that women consented to sex for relatively small price, sometimes just for supplies of cigarettes. Health professionals mostly denied there were any problems; one psychiatrist said *"officially, we don't have incidents"*. Though he refused to comment further, off the record he admitted there are problems, without giving any details.

Decent living environment

The quality of inpatient facilities varied greatly. The acute inpatient hospital in Bucharest and the chronic hospital in Slatina offered the friendliest living conditions. These facilities were recently renovated, with good heating and air conditioning in the summer, and had facilities for visitors. Conditions were not as good in the acute inpatient unit in Slatina. Psychiatrists there were not satisfied with conditions, but nurses considered that *"Conditions are fine, considering how patients behave"*, noting that they *"destroy everything"*. Outpatient facilities in Bucharest were also renovated, but patients complained about the heat in summer as no air conditioning was available. In Slatina, outpatient facilities were small, and though patients spent little time there, patients and some professionals (nurses) found them inappropriate. In both locations, patients queue for hours, often standing in the hallways and staircases.

The worst conditions were reported in the chronic hospital in Bucharest. Here rooms were overcrowded, and as noted above, some were in very bad condition with no paint or door handles, the heating was not always adequate, particularly in the women's wards, and there was no air conditioning in summer. Families of wealthier patients renovated the rooms of their family members and managed to obtain rooms with fewer beds (3-4 beds). Access to TV, one of the few leisure activities available in the hospital, was limited by auxiliaries. Men would have been happy to see a movie two-three times a week, but they only had access to one channel, while women had access to 4 channels. Male patients saw it as a form of passive aggression by auxiliaries. Both male and female patients also had no access to a telephone to talk to their families and some patients found this very hard. Renovations had been started, but the first areas to be redone were the management offices, not the patients' rooms.

4.2. Presence of appropriate treatment facilities

Health professionals interviewed painted a mixed picture of treatment facilities, reflecting differences in the facilities available to different professionals. Thus, psychiatrists in all settings had their own offices, but psychologists often shared their office and could not conduct either tests or talking therapies in appropriate conditions. Psychiatrists in outpatient services did not have conditions for talking therapies either, while the walls of their offices were thin with no phonic insulation, and discussions could be overheard by patients waiting their turn in the corridor. Social workers in the chronic hospital in Bucharest also shared offices and had no access to basic means of communication, such as a telephone, or PC with internet access, which are now essential for social work.

4.3. Hygiene

Standards of hygiene in facilities and the ability of patients to maintain personal hygiene also varied. The acute inpatient hospital and outpatient unit in Bucharest and in the chronic hospital in Slatina they were considered fully satisfactory both by patients and professionals. Patients in Slatina said *"It's clean, they change bed sheets every 3 days, it's pharmacy clean"*.

Patients in Slatina reported that the toilets in the outpatient unit were almost always locked. Conditions in acute inpatient facilities in Slatina were not very good. While showers with hot water were available at all times, and auxiliaries cleaned rooms and changed bed sheets regularly, the bed mattresses were dirty and smelly (due to a lack of pads for patients with urinary incontinence). Moreover, sometimes there were cockroaches in patients' rooms and hallways.

Again, the worst conditions were in the chronic hospital in Bucharest. Patients stressed how hygiene is substantially better in open wards than in involuntary wards, but the latter are outside the scope of this research. When admitted, patients were washed and disinfected, shaved, and given clean clothes, a practice common to all inpatient facilities. But patients here complained that initial check-ups are inadequate and that some patients have lice. Availability of hot water for showers varied from ward to ward. Women' wards had less access to hot water than men's wards. Patients receive help with personal hygiene, when needed. Others are monitored to ensure they shower at least 2-3 times a week. Women had no privacy in the shower, while shower cabins had no curtains or dividers. A hairdresser comes weekly and cuts their hair and shaves the men, but patients expressed dissatisfaction with the quality of haircuts they get. Bed sheets were changed every few days or whenever needed. Auxiliaries are in charge of cleaning, but they require patients to help them clean and do laundry. Patients reported occasionally seeing cockroaches.

4.4. Food and drinks

Both patients and professionals in the acute hospital in Bucharest and the chronic hospital in Slatina reported the food is very good and some even said that *"we don't eat at home what we eat here..."*. Meals included meat almost every day and included desert and fruits. Running water was reported to be good and patients often get juice and extra food. An interesting observation was made by one patient in Slatina regarding the fair distribution of food by staff. While most patients were keen to stress that they all receive equal portions, one patient discretely noted that this was not always the case and staff favoured patients who tipped or bribed them, giving them more meat.

Service users in the Bucharest chronic hospital could not agree among themselves on the quality of the food they received. Some thought it was bad, that they receive meat rarely, and have lots of beans, and pasta. Others thought it was fine, and acknowledged that it had improved significantly recently. Men tended to be more dissatisfied with their food. Patients noted that what they missed most were cigarettes and they would trade some of their food for them. Most professionals (psychiatrists and nurses) thought the food was very good, but psychologists were aware that some patients were not satisfied and complained regularly.

The acute ward in Slatina was the only setting where both patients and professionals reported that the food was not good. They previously had their own kitchen but now they had central catering in the hospital. Families who could afford it supplemented the diets. Otherwise, both patients and health professionals reported that patients steal from each other. Nurses noted that they would bring traditional cakes from home on national celebrations (e.g. Christmas, Easter) and they would also share some of their own food on a regular basis if patients asked them.

In all facilities meals were served 3 times a day in the canteen. Older patients and those with mobility problems are served in bed. Auxiliaries keep food and milk or tea for night time, because some patients get hungry and thirsty during the night. In all facilities, both patients and professionals noted that the biggest difficulty is to get cigarettes. Patients have no money so they often beg in the hospital courtyard to buy cigarettes.

5. Protection of human and civil rights

5.1. Right to respect of all human and civil rights on mental health facilities

Interviews with people with schizophrenia showed that while they largely thought their human and civil rights were respected, they had poor knowledge of what these rights are. The main complaints related to loss of property as a result of scheming by family and carers and poor access to legal support to claim back their houses. In the chronic hospital in Bucharest, there were reports of abuse by staff, particularly auxiliaries and nurses, who would pressure patients into helping them to clean the wards and wash the floors, under threat of having them moved to less good rooms in the hospital or simply making their life difficult. Women patients were more vulnerable to such requests. Other problems reported related to consent to treatment, women's safety and living conditions; these are discussed in the relevant sections of this chapter. All professionals in all settings reported that they respect the human and civil rights of patients, but some of them, and particularly psychologists in both locations and psychiatrists in Slatina, admitted that attitudes of nurses and auxiliaries are often inappropriate, but at the same time hard to correct or control. One grey area for professionals in all settings was management of violent incidents. Nurses in Bucharest reported being particularly challenged and struggled with how to respect the rights of patients while ensuring their own safety. Sometimes applying the rules seemed to the nurses in Bucharest to be unfeasible: *"If you want to do everything legal, you don't get anywhere"*.

5.2. Right to informed consent to treatment

Formal procedures were in place in all facilities requiring that patients be informed of their rights and give their written consent before admission. However, the consent given by patients was, on most occasions, not genuine. An exception was in the Slatina chronic hospital where most patients gave their informed consent and showed a strong motivation to remain in hospital. Patients reported that they largely agree to treatment for three main reasons. First, in outpatient settings, they would otherwise loose the social benefits they are entitled to as a consequence of their diagnosis. Second, they feared being involuntarily admitted to hospital and handled with force and brutality. There was a widespread recognition of this practice, which involved police *"storming"* patients' homes and taking them by force to acute inpatient units where they were admitted involuntarily. Some patients eventually consented to treatment, and patients accepted that this was a consequence of an improvement in their condition. Others did not and in some cases psychiatrists from the acute hospital would send patients who refuse treatment to the chronic hospital as involuntary patients, after their condition stabilizes, so that they can continue to be on medication, in spite of their lack of consent. Thirdly, in the chronic hospital Bucharest, where conditions in involuntary wards were appalling, consent to treatment was considered by patients to be the only way to avoid abuse and misery.

A particularly touching report was given by a middle-aged man, who was initially admitted to the involuntary ward, where he said he would *"beg for a glass of water, for food."* Access to toilets was restricted *"I wasn't allowed to the toilet, I'd hold it as long as I could"*. Conditions were so challenging that he cried all the time, felt terrified and thought he wouldn't make it. Staff paid no attention to his suffering. The only way to survive this situation was to consent to treatment. Since then he never dared not to consent. One can hardly qualify his consent, and that of all others in his situation, as a genuinely informed.

Some psychiatrists, in both inpatient and outpatient facilities in Bucharest and in the acute unit in Slatina, saw refusal to consent to treatment *"in itself, an expression of the illness"*, caused by the fact that patients cannot accept their diagnosis. Some psychologists agreed with this opinion, seeing refusal to undergo psychological tests as another manifestation of illness. Nurses in the outpatient facility in Bucharest shared the same view and they found patients who refused to consent as *"disobedient"* and *"stubborn"*, and as a consequence they deserved to be *"locked-up"* in hospital. Some patients, but not as many as psychiatrists expect, refuse to take medication because of side effects. Most psychiatrists insisted that if lack of consent is due to side effects, they would definitely try to change to medication with fewer side effects.

Two reports of gross violations of patients' rights to informed consent were made by psychiatrists in Bucharest. In the outpatient unit, one psychiatrist openly admitted lying to female patients who were very keen to become pregnant about the side effects of medication on fertility. Moreover, one described a female patient who was subjected to tubectomy after her last birth, at the request of the family, without even being informed, let alone being asked for consent. Everybody, health professionals and her family were lying to her, while she desperately kept on trying to get pregnant.

Another psychiatrist, from the chronic hospital in Bucharest, when asked about the procedure where a patient refused treatment, simply said *"No, (it does not happen that patients refuse treatment), because you just push him (the patient) down/to the ground and inject him"*, after which *"in 2-3 days he will want to take the treatment"*. The psychiatrist noted that this is a method that has been used in the hospital for 30 years. Nurses and auxiliaries also confirmed that if a patient refuses treatment the patient is injected, with the implicit agreement of the psychiatrist on call, even though they had not specifically ordered the procedure.

5.3. Right to confidentiality

Staff showed awareness of their duty to protect the confidentiality of patients. However, the great majority thought that this did not extend to communications with families, employers and public authorities and felt free to share this information with them. Most patients did not mind that their families were informed, but many were upset that their employers were also informed, which inevitably led to job loss. Some psychiatrists felt strongly about informing employers "*Of course the employer should be informed, we cannot be responsible of creating a risky situation, they [people with schizophrenia] are unpredictable*". While frustrated by the *status quo*, patients admitted it was very hard to keep their health status confidential when their diagnosis would be stated on all their medical papers, including medical examinations required by employers.

Psychologists in all facilities reported that they hold in confidence information obtained in talking therapies. They communicate to the psychiatrists only that information strictly relevant to the medical treatment. However, the results of the psychological tests are less confidential; they can be shared with various authorities upon request (e.g. disability authorities, pension authorities).

5.4. Right to information

People with schizophrenia received very limited information about their condition, its implications and the prospects for treatment or recovery. Often they were told by health professionals that schizophrenia is *"a disease of the soul"*, a terrible disease they will never recover from, which implies they will always be under treatment and they will never have a *"normal"* life again. That view was confirmed by their own experience since the onset of disease. Only a few patients, who worked with psychologists, reported obtaining information about the nature of the disease. Requests for information on their disease were always answered by information on what treatment they should take, which was viewed by many psychiatrists as an indirect and appropriate manner of providing information. Information was seen as a mean to convince them to comply with treatment. Other professionals, both psychiatrists and psychologists, admitted that there is little information available about their condition to patients. Nurses in all facilities believed that they were not supposed, or even allowed, to provide information to patients; that was the job of psychiatrists. Social workers would provide patients with information on entitlements to welfare benefits.

Patients with higher education were able to seek information by themselves, but internet access was not easily available to most patients. Psychiatrists were open to answering questions from these patients, including the potential impact of medication on sexual and social life.

Few reasons for not informing patients emerged from discussions with psychiatrists, in any facility. On the one hand they blamed patients for lack of interest. On the other hand they thought that comprehensive information on the severe and enduring nature of schizophrenia would lead many patients to commit suicide. Of all interviewees, only one psychiatrist noted that the new mental health law actually requires them to provide information about their disease, prospects, and medication, etc.

5.5. Right of access to personal information

Information on diagnosis

Most patients who were admitted on a long-term basis were aware of their diagnosis, but not all. Many found out after years of being ill, most often indirectly, and not from their psychiatrists. Many psychiatrists and nurses thought that patients should not be informed about their diagnosis, because *"it's not good for them"*, it would be upsetting, and they did not think it was up to patients to decide what they should or should not know about their own health status. However, most professionals were aware of the legal right of patients to know their diagnosis; it was just that they chose to implement it on a case by case basis. They would often use a pseudonym for schizophrenia, calling it *"sindrom discordant"*. Many patients found out they had schizophrenia from other patients once they told them they had *"sindrom discordant"*. Some psychiatrists were so determined that patients should not know their diagnosis that they argued that medication prescribed to people with schizophrenia should be given to them without the information sheet that usually accompanies it. They considered that such information would be *"disturbing"* for patients as they may indirectly discover that they have schizophrenia.

Another motivation, mentioned only by one psychiatrist in Bucharest, was that once knowing they have schizophrenia they would become dangerous since *"they know they can do anything with no legal consequences, hiding behind the diagnosis"*.

Access to personal file

It was generally accepted that patients did not have access to their personal files; they were given access only to the discharge note that contained very brief information such as duration of admission, notes on their behaviour, and any prescribed treatment. Patients admitted that they struggled to understand even these brief notes, written in difficult language and hard-to-read hand-writing. Most professionals were not aware of the legal requirement to provide access to personal files upon request, nor were patients aware they had this right. Only few of them asked to see their files, and even fewer were granted access to them.

Information on results of tests

Professionals took different views on informing patients about their test results. Some did not think patients were actually interested in knowing; others thought that patients would be troubled by findings and that they are better off not knowing. Only few were open to share the results with patients.

5.6. Right to notification of rights

While psychiatrists and nurses largely reported that patients are notified of their rights in an appropriate manner, most patients, psychologists and social workers disagreed. The latter contended that the information sheet, in small script, handed out on admission for the purposes of obtaining informed consent did not mean that the patient was properly informed in a language and manner that was accessible to them. Social workers, where available, did try to provide some information, but they could only reach a small number of patients. Some psychologists noted that these information sheets include procedures for organ harvesting from donors, meant for patients in somatic hospitals. This is often misunderstood by patients with schizophrenia and leads to unnecessary anxiety that they would be subjected to dangerous surgery.

5.7. Right to treatment sensitive to needs of minorities (with different cultural and religious background)

Both professionals and patients down-played the special needs of people with different ethnic, cultural and religious backgrounds. While recognising that some patients are Roma or of Hungarian nationality, they largely reported there were no language difficulties. Similarly, they argued that the religious background of patients was irrelevant as they were free to practice whatever they believed in.

The only challenges recognised were linked to the Roma. Patients and nurses reported that Roma patients steal from other patients and conceded that they are the first to be suspected in case of thefts. Psychiatrists and nurses in inpatient facilities outside Bucharest reported problems with Roma families, who were seen as very large and noisy when they visited. Nurses in outpatient units admitted that they would give Roma patients priority if in a queue to avoid problems. One psychiatrist in the chronic hospital in Bucharest also believed that Roma patients are less tolerant to pain and their symptoms can appear exaggerated.

Conclusions

This assessment demonstrates the different challenges faced by people with schizophrenia within the health care system. Some are a reflection of the overall organization of the system, such as the geographical distribution of staff, the poor quality of health facilities, financial difficulties arising from co-payments, or poor connections between the health system and the social care system leading to inadequate support to those in need. Others seem specific to mental health, such as the competencies of health professionals of different relevant specialities, the gaps in availability and coverage by insurance of some evidence-based interventions and violations of human and civil rights. However, in order to conclude on how equitable or not mental health services are, it is necessary to review the status of comparative specialist services for a chronic somatic disorder. For this purpose, the following chapter will describe the experience of patients with type 1 diabetes and the views of their health professionals.

Chapter 10 Experience of people with type 1 diabetes - Findings of the Rapid Assessment

This chapter will follow the same structure as the previous one, presenting the *de facto* situation in specialist services as experienced by people with type 1 diabetes and by the health professionals providing them with treatment and care.

This chapter presents the synthesis of findings for the comparator condition studied in this research (type 1 diabetes) by variable, sub-variable, type of setting (outpatient, acute inpatient), target group (service user, physicians specialised in diabetes, other physicians involved in the treatment and care of diabetes patients, nurses, auxiliaries) and location (Bucharest or Slatina). General assertions/descriptions of findings represent shared findings from all target groups, regardless of the type of setting, location, and interview strategies employed. Differences between target groups, locations and type of settings are noted and discussed.

1. Accessibility of specialist services

1.1. Access to care in the least restrictive settings

People with type 1 diabetes received regular treatment in specialist outpatient services, which are available in all districts in the country. Check-ups and acute care were provided in diabetes wards of general hospitals. The exception was the National Institute for Diabetes in Bucharest (one of the settings of this research), a hospital specialising in diabetes. Both patients and professionals agreed that diabetes care was well organized.

In Slatina, patients used the outpatient unit only to collect their prescriptions. Since the only physician in town was rarely available for consultations there, they had to go to the inpatient diabetes ward, located in the same building, for consultations.

Access to services close to where they lived was not a key priority for every patient. A small group of better-off patients from Slatina chose to attend services in Bucharest, despite the considerable cost and effort involved, as they believed that they would receive care of significantly better quality.

Patients were encouraged to self-manage as much as possible and to have as little contact with services as possible. They could receive prescriptions for courses of treatment lasting up to 3 months. Patients who had complications or co-morbid conditions, or who failed to manage their illness well, were encouraged to return for check-ups more frequently. Hospital admissions were not always for medical reasons. Poorer patients often chose to be admitted for regular short periods (as often as 7 days every 2 weeks) to obtain food and shelter unavailable elsewhere.

Home treatment, either in a crisis or otherwise, was largely unavailable, even for patients with mobility problems. Patients believed that while tests and check-ups should be done in health facilities, most of their care would best be provided at home. Nurses were adequately trained to provide home treatment, including crisis care, diet and lifestyle advice. Physicians noted that home services have been provided for some time by the non-governmental sector, but these services were not reimbursed by the insurance scheme and they were unsustainable. If the official package of services covered by insurance would include home treatment it would decrease the cost of care, since hospital care was the most expensive modality.

In a crisis, patients had only one formal option: the hospital emergency room. Some informal alternatives were employed on an individual basis: physicians allowed patients to contact them on private mobile phones or patients arranged either with physicians or nurses to provide a home visit, paid for privately. Both patients and most physicians and nurses agreed that home treatment would facilitate prompt interventions, which could help prevent hospital admission and more serious outcomes. That was particularly important since the paramedic services were notoriously slow.

Some physicians commented that they had expected diabetic patients' organizations, which are quite influential, to lobby more effectively for such services. Professionals stated that should patients' organisations take this initiative they would definitely support them, and it was believed that the Ministry of Health would be sympathetic, *"but someone has to take the initiative and push for it!"*.

1.2. Geographical accessibility of services

Access to outpatient services was more difficult for patients from Bucharest than for those in Slatina. In Bucharest, some patients had to travel up to 2 hours to get to the outpatient unit or the diabetes hospital, taking 2 or 3 separate buses and trams. That is especially problematic when patients need to go for tests, when they must be at the hospital before 8.30 am. There are medical centres closer to where they live, but they are private and not all patients can afford treatment there. Moreover, patients often needed to go to different places for tests, depending on the health problem they have (e.g. kidney, heart). In Slatina, patients who lived in town had easy access to the hospital and the outpatient unit located in the same place. Patient who lived on the outskirts of the town or in the surrounding villages took longer (about 30 minutes). Those with mobility problems, which were commonly due to foot complications, found the journey challenging.

1.3. Access to services when needed (opening hours/ out of hours staffing)

Access to services after working hours

Most professionals in Bucharest and nurses in the Slatina inpatient facility reported working extra hours to accommodate patients' needs. Additionally, most physicians in both locations shared their private mobile numbers with their patients and were regularly contacted by patients after working hours when in crisis. Patients would describe their symptoms and inform physicians about their degree of glycaemia. Depending on the severity of their condition, physicians would recommend them either to make a prompt change to their treatment plan, attend for consultation the next day at the hospital to have further tests, or seek immediate admission to the hospital's emergency room. Many physicians were rather positive about patients calling them after working hours, and acknowledged that it was not possible to deny help because it is at the end of the working day. Hospital services were available round the clock. Thus, in practice, patients had access to all services whenever they needed them and reported no difficulties in this regard.

Patients noted that while some diabetes physicians and physicians in other specialities were willing to provide home visits after working hours, they required private payment for their services, and as such this was not an option for many patients.

Waiting time

In Bucharest, patients' experiences with waiting time were different from one service to another. Patients were satisfied with the schedule of the diabetes outpatient clinic during the week (from 8 am to 6 pm), but complained that there were no services during the weekend. Patients faced more problems in accessing other health services for co-morbid conditions. For eye care, for example, they could be asked to wait for an appointment for weeks. Even with an appointment, some patients reported that they would start queuing as early as 4 am. If they came as late at 7 am, they did not have their consultation before the end of working hours.

In Slatina, patients complained that when they went to collect their medication they queued for up to 2 hours. There is little possibility to make an appointment to decrease the waiting time and, even when appointments were made, they were not kept by the physician. Patients were unhappy that the physician did not have a public working schedule and did not use appointments, particularly since she did so at her private clinic.

Another difficulty faced by patients both in Bucharest and in Slatina was that the waiting time for laboratory tests in the hospital was very long. Patients had to wait until 1-2 pm for the results, which was particularly hard for patients with diabetes who must fast until then, and so felt pushed to attend private laboratories instead if they were to avoid hypoglycaemia.

1.4. Access to different parts of the system, as needed (Referral system)

Patients needed an initial referral from their family physician to specialist diabetes services. Once diagnosed they did not need re-referral. In theory, patients needed to be referred by their family physician or other specialist physician for admission to hospital, except in emergencies. However, in reality, patients without a referral were admitted. Patients reported that they could access all the services they wanted, not only in their home town, but also in other cities such as Bucharest. Access to other somatic services was based on referral either from the diabetes specialist, from their family physician, or from other specialists dealing with their diabetes-related and other somatic conditions. Patients needed referral for laboratory tests.

When admitted to hospital, they could be referred to different departments by the diabetes physician. However, patients reported that physicians and nurses from specialities unrelated to diabetes were hesitant to treat them (see below). Therefore, in Bucharest in particular, patients with type 1 diabetes are often referred to the diabetes hospital from other hospitals, even if the health problem in question is unrelated to diabetes (e.g. a stomach ulcer). However, since the diabetes hospital did not have the capacity to manage these health problems, the patient would be admitted only for emergency care, if necessary, and was then referred back to the relevant hospital. Obstacles to admission were usually overcome using the personal connections of the physicians who made the referral (i.e. they would call a personal acquaintance or friend and ask for timely admission of the patient).

1.5. Financial access to services (financial affordability)

Once diagnosed and registered with the insurance system, people with type 1 diabetes had free access to specialist treatment. Nurses reported that some Roma patients were not registered with the health insurance system and so could not access free health care, even if diagnosed with type 1 diabetes. This problem is well known, as many Roma do not have the documents required for registration with the insurance system (314). Patients confirmed that insurance gave them free access to consultations in outpatient services, to hospital treatment, and free diabetes medication. People younger than 30 years of age had free access to glucometers and test equipment. However, older patients have to purchase this equipment out-of-pocket. Older people were at a further disadvantage since their disability pensions were lower than those of younger people, despite having the same diagnosis and, usually, more co-morbid conditions.

All patients had to co-pay for laboratory tests in outpatient settings. Additionally, they had to pay out-of-pocket for any special shoes they needed because of foot problems, a cost many patients complained they could not afford.

Financial access to many services and medications requiring co-payments was better for people who were registered as disabled. However, many people with diabetes found the process of registration difficult. As indicated in the review of legislation, the level of entitlements increased with the degree of disability. Many patients reported that they were not able to claim the level of disability benefit they were entitled to. Patients noted that *"It's easier to get social welfare benefits for eye disability than for diabetes"*. Those with other serious conditions that also entitled them to disability benefits registered that disability.

Cost of diet

While patients were often accused by health staff of being complacent and not persevering enough with their diet, patients reported they both knew how to keep to their diet and wanted to do so but were unable to due to financial constraints to purchasing necessary food. Most physicians, in both Bucharest and Slatina, displayed a lack of understanding of patients' financial difficulties. Some physicians believed that patients were insufficiently motivated to comply with their prescribed diets. Some believed that they should be required to co-pay for their medication, since diabetes treatment incurred substantial costs for the health system which they viewed as wasted if patients did not comply with their diet. Yet patients reported that they did take their free medication.

Unlike physicians, nurses in both locations were aware of the financial challenges facing patients. Some estimated that as many as 80% of patients cannot afford to buy food prescribed for them. Patients with co-morbid conditions had an even harder time as their diet was often more complex and expensive. According to nurses, many patients were admitted to hospital for regular periods of about 7 days, not because they actually need inpatient treatment, but because they could not afford to pay for their diet so they used the hospital for respite. Some patients would come as often as once or twice a month.

Cost of treatment of co-morbid conditions linked to diabetes

Patients reported that while they benefited from free diabetes medication, they did have to co-pay (between 10 and 50% of the costs) for medication for all their co-morbid conditions. Many could not afford the co-payment and as a consequence they sometimes skipped treatment. Physicians in other specialities, such as ophthalmologists, dermatologists, cardiologists, and nephrologists, were all well aware of patients' financial difficulties. Therefore, in consultation with patients, they often prescribed the cheapest medication, even if this was less effective and sometimes not ideal for that particular patient but was the only one affordable to him or her. Physicians admitted that *"This is a common practice"* and that that the financial means of the patient were the main determining factor in deciding on the treatment prescribed.

When admitted to inpatient facilities, patients were provided with medication for co-morbid conditions for free, but pharmacies sometimes lacked medication. In those cases, families of patients are asked to cover the costs until it becomes available again in the hospital. Alternatively, patients were officially discharged so that they can obtain a prescription from a community pharmacy, for which they co-paid, while in reality they remained admitted to the inpatient unit. Physicians in other specialities also noted that as public facilities lack advanced equipment, patients are pressured to either go to leading specialist hospitals (like the ones in Bucharest) or private health clinics. Many patients could not afford either option, and as such were unable to obtain specialist treatment.

Unofficial out-of-pocket payments

Patients spoke openly about bribing health workers, which was, in their experience, a common practice, particularly in inpatient units. People who did not bribe would be rushed through and would receive distinctly worse care. They noted "*One cannot even say Hello without giving* *something"*. Patients noted that bribery was less prevalent in diabetes that in other somatic services. In their view the frequency of bribing was linked to the dependency of a patient on health professionals and the level of scrutiny a certain service is under. For example, people undergoing surgery would even have to bribe the anaesthetist if they wanted to get effective anaesthesia. In the outpatient unit in Bucharest it was less common to bribe. In contrast, on admission to inpatient units, some patients were actually given an unofficial price list, per service and per health worker (from physicians to auxiliaries). Patients from Slatina who also used facilities in Bucharest noted that prices are higher in the latter. However, even in Slatina the amounts were significant.

While acknowledging that physicians have relatively small salaries, patients were appalled by demands of some (though not all) physicians for bribes from people who were clearly poor, living on pensions less than a twentieth of physicians' salaries. Patients were also upset about nurses, who *"chose this job to rip people off "*.

Unofficial payments were also necessary if patients needed home treatment, which was not covered by insurance. Though, by law, people with mobility problems were entitled to some support at home, most struggled to claim this right. Prices were lower for nurses than for physicians. A typical amount for a visit by physician was around 1 mil. RON (about 22 GBP), an amount representing a quarter of many disabled people's monthly pension.

Indirect cost of illness through loss of income

While many patients managed to remain employed, older patients with severe co-morbid conditions were unable to do so. Some younger patients reported that they experienced discrimination from employers who refused to employ them after finding out they had diabetes. That applied even for jobs that involved no physical hardship. Other patients noted that, as they became more unwell, they could not cope with the requirements of their jobs and either chose less demanding jobs or gave up working altogether. These patients struggled with the cost of health care, as noted above. However, some patients had successful careers, holding well-paid managerial positions. They described getting full support from their employers and were able to balance their need for health care with a fairly normal life.

2. Availability of evidence-based treatment and care

2.1. Availability of medication

Medication directly related to diabetes (e.g. insulin) was widely available in pharmacies and in hospitals, both in Bucharest and Slatina. Physicians were able to write prescriptions based on patients' needs. Price and availability of the medication were not factors in deciding the treatment. The only complaint from some patients in Slatina was that they were not always aware of new medications available in pharmacies as part of the insurance package.

In inpatient units, physicians sometimes noted shortages of other medications for co-morbid conditions and, sometimes, of cheap drugs, which were probably bought in too small amounts to make stocks viable. In the district general hospital in Slatina, both physicians and patients complained that equipment was of poorer quality than in Bucharest.

Besides medications, patients had access to testing equipment for glycaemia. As mentioned above, patients younger than 30 years of age were entitled to glucometers and test strips. Diabetes physicians estimated that about 40% of patients had their own glucometer. However patients complained they did not always have test strips, which prevented them from adjusting their doses.

2.2. Availability of other evidence-based interventions

a) Foot care

People with type 1 diabetes had regular foot check-ups as part of their annual assessments. Foot care was primarily provided in general health services, such as policlinics or general hospitals, and in specialist departments for dermatology, orthopaedics, surgery, etc., depending on the health problem they had. The only diabetes unit that also provided foot care was the outpatient unit in Bucharest. Patients chose the services of the foot specialist in the outpatient unit in Bucharest for less severe problems. When they had a more serious foot problem, patients went to the hospital. However, some patients expressed concerns about the attitude of some physicians in hospital towards amputations. Patients were afraid to go to hospital because the decision to amputate limbs was sometimes taken very quickly, with insufficient effort to save them. Diabetes physicians and physicians of other specialities worked closely together: the specialist physician established the diagnosis and proposed a course of treatment, while the diabetes physician gave patients prescriptions and monitored them.

Patients who had serious complications complained that after surgery they received little or no home care. Some patients had to travel to the hospital to have bandages changed. Patients received information in the forms of leaflets or directly from physicians or nurses about the type of shoes they should use and how to self-care for wounds, lacerations, and infected nails, etc.

b) Dietary management

Physicians strongly promoted awareness among patients of the role of diet in the management of diabetes. They said that *"medication represents 50% of the treatment, while the diet represents the other 50%"*. People with type 1 diabetes received information in forms of flyers, books and face-to-face training. The aim of the courses was to ensure that, once discharged, patients would be able to maintain a diet appropriate to their health status that would help rather than hinder their efforts to keep their blood glucose levels under control. Dietary advice included the amount of calories in different foods, principles of mixing different foods, and distribution of meals during the day. Newly diagnosed patients receive diet classes for about a week. Older patients also attend these classes once in a while. Patients from Slatina who had also attended courses in Bucharest thought that the quality of the courses is significantly lower in Slatina. Here, courses were only theoretical, while in Bucharest they could actually practice preparing their meals.

Patients felt confident in their knowledge of how to maintain their diet when they lived at home, how to combine foods correctly and adjust their diet to physical activity or eating sweets, etc. However, as described in the section on Funding, they complained that they cannot afford to buy appropriate food. Some patients weighed their food daily, others admitted they never do. Some patients said they often had hypoglycaemia because they found it expensive to buy food. Patients also complained that it is difficult to cook as a family because of their diet as others would eat normal food. They said that some days they simply find it hard to eat as they should, but that they know how to adjust their insulin intake. Many patients are tempted to eat sweets, though they know they are detrimental to their health. Special sweets for diabetes patients were available on the market, but they were very expensive and unaffordable for most patients. Some physicians estimated that only a third of patients maintain an appropriate diet on regular basis, another third on occasional basis and the rest not at all. Of the challenges faced by patients, physicians accepted that maintaining normoglycaemia was more difficult for patients who did not have their own glucometer and could not monitor the impact of different foods. Otherwise, physicians blamed patients for not complying with their diets.

When admitted to hospital patients are given food appropriate to their diet. The hospital kitchens had dietician nurses who prepared the diet. Meals are prepared daily (including during the weekend) based on each patient's health needs.

c) Eye care

Eye problems were, for some of the patients, even more disabling than diabetes itself, requiring intensive management, and preventing them from obtaining or retaining employment. People with type 1 diabetes received regular eye check-ups once or twice a year. People with eye problems go for check-ups every 3 months. Retinal screening was freely available only in the diabetes institute in Bucharest, but not in the outpatient service. In Slatina, the ophthalmologist reported that equipment was unavailable. At the same time, the only diabetes doctor in town refers patients to her own private clinic for these checkups – of course for a fee. Private clinics in Bucharest also offered eye screening. Where problems are found, patients are referred to specialist services. The screening equipment did not allow for photographic recording. Patients complained that records are not retained and test results are not communicated from one check-up to the next. They felt the need to have someone following up on their progress and coordinating their care.

Eye care was provided by ophthalmologists in specialist inpatient and outpatient facilities. Their task was to detect as early as possible retinopathies and to provide treatment for them to mitigate damage to the eye. Patients could access these services via referrals from diabetes and family physicians. When eye complications required surgical interventions, patients were admitted to hospitals. Some patients who underwent surgery were dissatisfied with the follow-up. Other patients expressed discontent about their care because of limited availability of screening equipment and of laser treatment in the public sector. They also felt that ophthalmologists knew too little about diabetes and were unable to diagnose and treat them adequately.

At the same time, the ophthalmologist in the provincial town noted that some patients are not aware of the connection between levels of glycaemia and eye health and they are at high risk of serious eye conditions. Diabetes physicians play an important role in explaining all this to patients and ophthalmologists feel they cannot get involved.

2.3. Social care

People with type 1 diabetes complained that they were not informed about the social benefits they were entitled to. Some patients know the legislation very well, others, and the majority, had a vague notion of their entitlements and how to access them. For example, it took some of them years to find out that they were exempt from some taxes. They kept on paying them until they found out by chance that they need not have to; afterwards, they could not claim back the amounts paid.

Even when patients knew their rights, they still faced many difficulties in realising them. Patients believed that authorities hindered their efforts and *"make the process so painful, until people give up"*. Some actually do give up, or because of their limited knowledge of their entitlements, they end up receiving only part of them. People with type 1 diabetes complained that procedures to register as disabled were complicated and that staff in the disability authority were unhelpful and rude. They openly accused patients of trying to cheat the system by claiming benefits beyond their rightful entitlements. Patients brought documentation on their health status to support their case, but these staff often disregarded it saying simply *"you don't look that sick!"*. Patients were revolted by this attitude, and many were determined to challenge it and pursue their rights although some were too unwell to do so. Moreover, even when they are registered are disabled, it is not evident that they get all their entitlements. One example concerned transportation allowance. Although entitled to cards that can be used for free public transport, it is very hard to get them and there are very long queues. Since patients are often sick they often cannot stand in line and are left without them.

Patients also complained about requirements by the disability authority to re-confirm the presence of their disability to ensure that they did not cheat the system. For example, a patient with amputated legs was still asked to undertake checkups to confirm his disability remained. He told doctors *"my legs won't grow back again"*, but he still had to attend regularly to maintain his entitlements.

Patients felt that the system created incentives to give up working and that they were strongly encouraged to do so by most health personnel. Those patients who continue to work are disqualified from some benefits given to those who are registered as disabled. Other patients had problems at work when applying for benefits as the social care authorities sent all the paperwork to their employer. Some eventually gave up seeking their entitlements so as not to jeopardise their job. These patients were very resentful about losing what they were entitled to.

2.4. Physical health

Diabetes physicians estimated that about 40% of people with type 1 diabetes had complications, including serious problems with their eyes, mobility, hearts and kidneys. They complained that other health conditions impact especially severely on them because they also have diabetes. For example, they felt that pain or emotional distress affected their glucose level.

Most patients had regular checkups for other somatic conditions. An ECG is done once a year and kidney examinations twice a year, while weight is checked at every visit to the outpatient service. A diabetes specialist noted that younger patients tended to have far fewer complications because they self-managed better, so they could live a relatively normal life. However, they represented only about a third of all patients.

In outpatient services, people with co-morbid conditions were referred to relevant specialists by their diabetes or family physicians. Patients noted that while physicians of other specialities accepted them, they knew very little about diabetes. A common practice is that when a diabetes patient attends another specialist, that specialist consults the diabetes physicians before they proceed with treatment, particularly if the patient has hyperglycaemia.

In inpatient facilities, access to other somatic services was easy. The diabetes hospital in Bucharest had small units caring for those with common complications of diabetes, employing relevant specialists (cardiologist, nephrologists, ophthalmologist, etc), and it collaborated closely with other general hospitals. In Slatina, patients had access to all the other departments of the district general hospital. Nurses noted that relations with the other departments are close and they are consulted when patients with diabetes have complications or co-morbid illnesses. With an appointment the waiting time is minimal.

While acknowledging that people with type 1 diabetes were prone to many complications, and could be difficult cases, diabetes physicians noted that other specialists may exaggerate the importance of diabetes when managing coincident conditions. This is complicated by the poor quality of many laboratories, which give contradictory results, so the other specialists may be unsure of the correct course of treatment. They identified this as one of the reasons diabetes physicians are always consulted by other specialists, because they can give an insight into the test results.

Patients reported that health professionals treated them well, but complained that the waiting time is often long, which is tough on them. Patients who had co-morbid conditions also complained they could not always afford the treatment received (as explained above).

2.5. Availability of enough staff in all settings

There were enough diabetes physicians in Bucharest, both in inpatient and in outpatient facilities. However, patients would still have to queue, mainly because not all patients respected appointments. Physicians found it hard to impose strict order, which in the past led to vocal complaints from patients. At the same time, physicians did take all the time they needed with all patients during consultations.

In Slatina, with only one diabetes physician, it was evident that there was a lack of specialist physicians. The hospital employed 2 other physicians, but they were both on maternity leave at the time of the research. Some patients blamed the hospital for not employing more physicians *"while young specialists in the country are looking for jobs"*. Some blamed the current physician, who, in their view, took advantage of the situation and steered patients towards her private practice. Patients who could not afford this would end up waiting in line for a long time to get their prescriptions. Moreover, the physician was rarely available in the outpatient unit so, on most occasions, patients would receive prescriptions from nurses, based on the previous prescriptions. Patients had to go to the inpatient diabetes ward for consultations.

Patients with type 1 diabetes had access to physicians in all specialities involved in diabetes care in the health system. They could access both physicians in the diabetes services they were registered with, or get a referral from their family physicians to any other specialists in their catchment area. It was outside the scope of this research to assess the availability of specialists in other health settings, but patients noted that it was fair to say they had *"as good an access to them as anyone else"*.

Outpatient units in both locations had enough nurses, as appreciated both by physicians, nurses themselves and patients. However, more nurses were needed in inpatient facilities, particularly where physicians wanted to delegate more tasks to them. With 1-2 nurses per 30-40 patients, they felt pressured to spend less time with patients than they would consider necessary.

Physicians also stressed the need to increase the number of nutritionists, many of whom have a nursing background.

Physicians and nurses both in Bucharest and Slatina complained there were not enough auxiliaries in inpatient facilities, particularly since they took over many nursing tasks. Auxiliaries in Bucharest reported that they could generally cope with the workload and do good quality work but the workload is high. Auxiliaries in Slatina, however, complained that they could not cope with the demands on them, with only one auxiliary per shift for the entire diabetes ward, which had 25 beds, with 6-7 per room.

2.6. Availability of multidisciplinary teams with good representation of each professional category

According to a diabetes physician, health professionals providing care to people with type 1 diabetes worked as a team, with each member's role well defined and reflected in their training. Other members of the team, such as nurses and auxiliaries, while acknowledging that they worked well together, saw the relationship as very hierarchical. Physicians delegated tasks to nurses whenever appropriate, and nurses to auxiliaries. Diabetes physicians in all settings noted that certain staff groups, such as nurses, dieticians and auxiliaries, needed to be better represented in the team.

While nurses in the outpatient facility in Bucharest agreed that they worked as a team with physicians, those nurses in the hospital reported that relationships with diabetes physicians varied. According to the nurses in the hospital, the large number of resident physicians sometimes made it difficult for nurses to do their work, residents got in the way, and could make conflicting demands on nurses. Nurses in Slatina reported that their relationship with the physician was clearly hierarchical, but that they are given more responsibilities, such as training patients how to self manage.

Relations between nurses and auxiliaries followed a similar pattern. In Bucharest, while nurses reported they had good relationships with auxiliaries, illustrated by instances when they would help out auxiliaries when needed, auxiliaries in Bucharest reported that nurses would not help them, even when they were overworked and could use some help. At the same time, the auxiliaries help the nurses with anything they needed. Auxiliaries here had little interaction with the physicians and worked mainly with the nurses and the cleaners. In contrast, auxiliaries in Slatina reported good teamwork with nurses. They help each other when needed. They felt respected by the other staff, but noted that respect for their work was not reflected in their salaries.

Diabetes physicians reported that they work closely with physicians of other specialties, such as endocrinologists, neurologists, cardiologists, and nephrologists, although they were not part of the same team. The dermatologist who provided foot care in the outpatient unit in Bucharest reported working with physicians of other specialties when needed, e.g. surgeons and nephrologists from the hospital. Additionally, when a patient with diabetes is admitted to another department, the specialist physicians in that department (e.g. gynaecology) always consult the diabetes physicians.

3. Delivery of care

3.1. Individual treatment plan developed for each patient, in the basis of a holistic assessment, service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

a) Holistic assessment as pre-requisite of the treatment plan

Assessment both in inpatient and outpatient facilities are made by multi-disciplinary teams of physicians and nurses. Patients registered with the outpatient service were assessed there, comprising a general examination, eye tests (though there is no equipment to make a photographic record), urine test, ECG, and foot checks. Not all tests were available in public facilities due to lack of equipment. Some are offered in private clinics, which are free at point of access for insured people attending clinics contracted by the NHIF. Most patients were able to monitor their glycaemia level by themselves.

People with diabetes are admitted once or twice a year for regular check-ups, including for complications: heart, eyes, feet, kidney, etc. Patients can also ask for specific tests. Blood glucose tests are done about three times a year. Tests are not repeated when patients have frequent readmissions. Physicians estimated that many patients are admitted three to four times per year. Patients admitted as emergencies receive a holistic assessment lasting one to two days, covering diabetes and other conditions.

b) Individual treatment plan developed for each patient

All patients had an individual treatment plan covering diabetes, its complications, and co-morbid conditions.

c) Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

People with type 1 diabetes felt they participated in the development of their treatment plans, and that their views are taken into account. Physicians consulted them on the choice of medication, considering effectiveness and side-effects. Physicians treating co-morbid conditions that are only partly covered by insurance checked patients' ability to pay for medication before prescribing it. Patients were also closely involved in the development of their diet plan.

3.2. Presence of discharge procedures

There were no discharge procedures in place and no support system for those patients who needed help at home. Although patients received comprehensive instructions on how to self-manage after discharge, health professionals expressed dissatisfaction with the current situation. Many saw it as a regression, since in the past follow-up procedures were better embedded in the system. Of particular concern to health professionals was the situation of patients who failed to attend planned check-ups. One approach was to offer patients who did not own a glucometer (older patients) the possibility of being tested at the outpatient unit every 2-3 days. In Slatina, the diabetes physician offered patients follow-up after discharge at her private clinic – but only a few patients could afford it.

3.3. Continuity of care

Continuity of specialist health professionals

As indicated in the previous chapter, no system of care coordinators, such as that envisaged in the chronic care model, has been introduced in Romania at the time of this research. Patients registered with outpatient services in Bucharest attended the same diabetes physician and often the same nurses. However, those admitted infrequently to hospital would inevitably see different staff. Patients with frequent admissions usually saw the same physicians for their diabetes and other conditions. In Slatina, since there was only one diabetes physician, all patients attended her. In inpatient facilities, nurses tended to change frequently.

Input from previous specialist services

The creation of a new information system, with unique personal identifiers, meant that information on patients was communicated within the diabetes network. However, since the system had only recently been implemented at the time of the research, it was not working well in all services, particularly between inpatient and outpatient facilities in Bucharest. These diabetes physicians would communicate directly when needed. In Slatina this was not necessary since there was only one physician in the entire town.

Feedback to GPs and other health services

Communication with other health services, whether in primary care or in specialist facilities, was significantly worse, since the information system only covered diabetes services. Responsibility for transfer of medical files is left to the patients. However, diabetes physicians reported that when they refer a patient to other specialists they follow up on the outcome of the consultation, the tests done, their results, and the proposed treatment. They described how, based on these findings, they would adjust the treatment plan they prepare for patients. When patients were admitted to hospital for another health condition, diabetes physicians were called in to assist if there were complications.

Communication with other relevant sectors

There were no mechanisms for coordination with disability and social welfare sectors, which led to significant difficulties for people with diabetes.

3.4. Staff have the appropriate competencies and skills

People with type 1 diabetes believed that health personnel had the necessary skills and competencies needed to provide good care.

Diabetes physicians

Diabetes physicians felt confident in their level of knowledge, skills and expertise, reflecting both their initial medical training and continuing education. Each year they must attend educational events, although these are mostly sponsored by pharmaceutical companies. These companies also pay their subscriptions to specialist journals.

Physicians of other specialities

The other physicians involved in treatment of people with diabetes were also well trained and kept up to date in the same manner, again benefiting from sponsorships from pharmaceutical companies. However, patients in Slatina complained that physicians in other specialties had little knowledge or understanding of the needs of patients with diabetes, which is why they were keen on involving the specialist diabetes physicians in the treatment plan.

Physicians considered that tasks such as those involved in foot care must be undertaken by physicians rather than nurses, whom they viewed as having inadequate skills. Only dietary care was delegated to nurses.

Nurses

Like the physicians, nurses working with diabetes patients in inpatient and outpatient units felt well trained and able to cope with the demands of their jobs. They were competent in giving medication, injections and checking blood glucose. Some of them, particularly in Bucharest, were trained in nutrition and dietetics and were able to train and advise patients on self-management. Interestingly, nurses and the physician in Slatina reported they are competent in providing dietary advice to patients, but patients did not recall receiving such advice from nurses, a task they associated with the physician. All nurses attended continuing education courses funded by the health services, some linked to diabetes care, but most on other health issues. Diabetes nurses also attended courses on medication organised by pharmaceutical companies, and had access to specialist journals, also funded by them. Additionally, nurses were briefed by physicians on new developments.

Auxiliaries

All auxiliaries had completed 6-month courses and had further on the job training. In Slatina, some auxiliaries only underwent initial training after they started to work, while in Bucharest it was a precondition for employment.

3.5. Empowered to care for themselves and live an as independent life as possible/ Personal autonomy

Patients and health professionals shared a common goal to empower patients to take care of themselves, and to live as normal lives as possible. Physicians said they *"impress on the patients that they have to take responsibility over their own treatment and self-manage – it is up to them how good a life they live"*. Patients were keen on being able to self-manage, saying *"I would find it unmanageable to have to consult physicians all the time"* and physicians encouraged them to *"be their own physician"*.

Patients receive training in how to inject and adjust their insulin level and diet to various circumstances. As noted above, physicians estimated that about 40% of patients have their own glucometers and self-monitor their glucose levels. Patients often knew how to manage their illness, but they nonetheless found it challenging, and many did not succeed in implementing what they knew, partly due to financial and social pressures.

Younger patients and those of higher socio-economical status showed a greater ability to manage their condition. They had little contact with health services and lived a fairly normal life. While some patients found it difficult to integrate into working life, most patients did have jobs and some had good careers.

Physicians blamed patients for not taking enough effort to implement all that they knew and estimated that only about one third of patients managed well, another third adjusted their diet occasionally, and one third do not manage at all well.

3.6. Involvement of service users in shaping the services

Patients reported no role in shaping health services. However, as noted above, some diabetes physicians stated that they would welcome patient groups to be more active in doing so and were disappointed that these groups did not lobby relevant authorities (e.g. the Ministry of Health) to improve those aspects of service organization that dissatisfy them, concluding *"we would back them up"*.

3.7. Involvement of families and carers

Both patients and health professionals agreed on the important role played by families, most of whom were heavily involved with the treatment and care of their relatives with type 1 diabetes.

For men, it was important that spouses get access to information and training on diet. For women, it was important to have the support of their spouses and family for keeping their own special diet. Older patients needed support from their family for insulin injections. When patients struggled with treatment, physicians tried to get families to support them. Sometimes, families collected prescriptions on behalf of patients from outpatient services.

4. Quality of facilities

4.1. Protection of service users' privacy and safety, decent living environment

Access and safety of personal belongings

In the hospital, patients had a personal drawer for their belongings. It was not very big and there was no key, but thefts were rare. Patients had easy access to their personal belongings.

Privacy and personal space

Living conditions were good in the hospital in Bucharest, where most rooms had 3-4 beds, with only one room of 8 beds. Some patients who needed help with changing and personal hygiene were dissatisfied with the level of privacy. Sometimes the door to their room would be open while they were getting changed, making them feel uncomfortable. Patients were rarely asked to share their bed when there were emergency admissions and, if so, only for one night. Health professionals claimed that patients are demanding and assertive, openly complaining and, in some cases, reporting them to the media.

In Slatina, conditions were significantly worse. Rooms had 8 beds, and double-occupancy was a frequent occurrence. An informal solution found by physicians was to send the patients home overnight, while they remained formally admitted. Patients complained that the allocation of beds for diabetes care did not properly take into account its increasing prevalence. Indeed, they are decreasing as a consequence of the health care reforms. However, no-one questioned the appropriateness of admission.

Patients' violent and aggressive behaviour

No instances of violence were reported in any setting.

Women's safety

Women reported they felt safe when admitted to inpatient facilities. No untoward incidents were reported between men and women.

Decent living environment

As indicated above, patients in Slatina were less satisfied with living conditions in hospital. In Bucharest rooms were newly renovated and equipped with a television and refrigerator. Most rooms had air conditioning and heating in winter was good. In Slatina, the hospital was in the process of being renovated, with new windows and air conditioning being introduced. However, the diabetes ward was not yet renovated, so conditions were not good.

4.2. Presence of appropriate treatment facilities

All services had adequate treatment facilities, although many professionals complained they lacked adequate equipment, particularly in Slatina. They noted *"people with type 1 diabetes are very demanding, they blame us for lack of equipment."* Patients from Slatina who could afford it sought care in other cities, either in Bucharest or in Craiova (the closest large city to Slatina).

4.3. Hygiene

Both patients and professionals in Bucharest agreed that conditions in hospital are good. They reported that bed sheets are changed regularly and rooms are cleaned 3 times a day. Toilets are generally clean, particularly when compared to other diabetes wards in general hospitals in Bucharest, but they could be better. Some physicians noted that toilets are often left without soap or toilet paper, even if only for short periods. Nurses and auxiliaries contended that more staff were needed to ensure a higher standard of cleanliness. Patients had showers almost daily and received assistance with personal hygiene if they had mobility problems.

In contrast, both health professionals and patients in Slatina agreed that the conditions in the district general hospital were poor. Patients noted that the *"toilets are horrible"*. There were not enough toilets on the diabetes ward so patients often had to queue. Men often used women's facilities due to the remote location of their toilets. Moreover, nurses noted *"beds and mattresses are awful, they have stain and smell of urine and blood. We have to put clean bed sheets over miserable beds"*. Maintaining personal hygiene of patient was difficult. One nurse said *"In the 10 years I worked here, I never found hot water in the showers"*.

4.4. Food and drinks

Experiences of patients with hospital food in Bucharest and Slatina differed. Patients in Bucharest were satisfied with the quality of food received, while those in Slatina reported that *"food is very bad"*. All patients could bring food from home, but in Slatina, patients deemed that it was a necessity. However, health professionals in Slatina hospital did not share their patients' opinions and thought that they received food that was most likely better than what they can afford at home. In hospital, auxiliaries brought meals to the beds for patients with mobility problems.

Patients in Bucharest complained that when they went for tests in the outpatient clinic, where they often had to wait for the results until 3 pm, they did not receive any food, so they had to bring it from at home.

As mentioned in the section on Financial Access, many patients complained that their meagre financial means does not allow them to purchase good quality food, as required in their dietary plans. That was identified as a major obstacle in managing their disorder when living at home.

5. Protection of human and civil rights

5.1. Right to respect of all human and civil rights on mental health facilities

People with type 1 diabetes found questions on human and civil rights on health facilities redundant, and felt their rights were respected.

5.2. Right to informed consent to treatment

Patients were rather surprised when asked whether professionals asked their informed consent to treatment prior to initiating it. They expressed their keenness to take treatment that makes them get better, and were only concerned with the possibility of accessing it. Some physicians were very unhappy with the lack of compliance with treatment rather than the issue of consent. In some cases, patients are reticent to take new treatments for complications (e.g. cardiovascular, nephrological). Physicians try to convince them, but respect their decision. In most cases, when their health status has deteriorated they end up consenting to it.

5.3. Right to confidentiality

Health professionals largely kept information on patients' health status confidential although while some insisted on patients' express consent to inform families, others assumed that patients' families were entitled to information.

Patients with diabetes had different opinions about the right of employers to know about their diagnosis. Some thought that employers are not entitled to this information; others noted that family physicians provide this information anyway when they fill in the medical forms for employment. Not all patients agreed that information on their diabetes should be kept confidential. Some thought that it did not make any difference if the employers knew; others felt strongly about their right to confidentiality. Some patients had experienced discrimination in employment, their applications being rejected once their health status was disclosed. Physicians acknowledged that information that a person has diabetes compromises their employment opportunities. They did not think employers were allowed to ask for such information legally, which can lead to discriminatory practice, and as such, most physicians kept patients' information confidential, other than in relation to employment medical examinations. Information was shared with other public authorities only with the patients' consent.

5.4. Right to information

Patients expressed satisfaction with the information they received, which covered treatment elements and instructions on how to administer it, diet, implications of the disease for other aspects of life, and how to monitor their health status. Some patients from Slatina rated the courses in Bucharest higher, others were satisfied with the information they received in Slatina too. All patients received training upon being diagnosed. In Bucharest, patients were required to attend a week-long course and were actually examined on it after completion. Updating courses were provided on regular basis, and patients received additional information upon request. Information flyers and brochures were also available in health facilities. Both patients and some professionals suggested that media awareness campaigns would be helpful. An ophthalmologist argued that patients would benefit from additional information on the complications of diabetes. Some patients were keen on getting access to the latest scientific discoveries and innovative treatments, though others were sceptical about their possibilities to pay for such treatments, even if they knew about them.

5.5. Right of access to personal information

Information on diagnosis

All patients reported that they knew their diagnosis.

Access to personal files

The large majority of patients had access to their personal file. Only one interviewee reported being refused access to it. Sometimes patients had access to it upon request, other times they accessed it while carrying it from one physician to another. Though some physicians thought the latter practice was not fully legal, they admitted it was hard to avoid. Unlike physicians, nurses largely thought that patients should not have access to their files, but admitted that in practice most patients do. Many nurses thought that patients were not able to understand information written in the files and that they can be better informed about their health status directly by doctors and nurses.

Information on results of tests

Patients reported they had full access to their test results, though some older patients noted they did not always understand them. All physicians were in favour of patients being well informed and some stressed *"it is very important that patients are fully aware of their health status"*.

5.6. Right to notification of rights

People with type 1 diabetes were well aware of their health rights. Some patients with diabetes were very knowledgeable about their rights and entitlements to social benefits, others less so. Many reported that they were poorly informed by health and social authorities. Sometimes staff purposely withheld relevant information on entitlements, but most patients were able to find out eventually. Some were able to read about rights on the internet but found it difficult to navigate the very complex legal system.

5.7. Right to treatment sensitive to needs of minorities (with different cultural and religious background)

Difficulties were reported by health professionals in communication with Roma patients. Romanian patients thought that health professionals treat these patients better, giving them priority when they are in line in the outpatient service. They suspected that physicians and nurses are motivated by fear. These suspicions were confirmed by health professionals. They found Roma patients to be the most difficult patients, more aggressive and revengeful. Some patients thought that Roma patients bribe physicians large sums, and in return expect the best possible health outcomes. Physicians denied taking bribes but some reported being threatened by family members, even at knife-point, when a family member was at risk. At the same time, physicians thought Roma patients were less likely to adhere to treatment. Health professionals of all types also reported frequently being insulted by Roma patients when these patients were in inconvenient situations (having to wait their turn in line, etc). Differences in religious background were reported by patients and health professionals to be irrelevant.

Conclusions

This assessment of specialist treatment and care available to people with type 1 diabetes shows that this group of patients receive a complex range of interventions from a variety of health professionals. They faced a number of challenges, particularly in care for any complications or co-morbidities and in access to social welfare benefits. Some challenges were greater in Slatina, where at the time of the research there was only one physician specialising in diabetes, and the quality of some interventions was worse than in Bucharest. However, the experience of people with diabetes needs to be compared systematically to that of people with schizophrenia in order to draw conclusions on how equitable treatment and care is for these two chronic conditions. This will be done in the next chapter.

Chapter 11 The *de facto* situation: differences in the care of people with diabetes and schizophrenia

The previous chapters have described, separately, the experiences of those with schizophrenia and diabetes and of those who care for them. However, the questions that this thesis asks are, do they differ systematically and what does this mean? This chapter will compare these experiences.

1. Accessibility of specialist services

1.1. Access to care in the least restrictive environment/community-based settings

People with schizophrenia and type 1 diabetes both had access to outpatient and acute care, and in similar settings in both Bucharest and Slatina. However, inpatient care differed markedly. People with schizophrenia, were often hospitalized in chronic mental hospitals in remote areas or on the outskirts of towns. There, they were isolated from the communities where they lived.

While none of these patients had routine access to home treatment, the implications for people with schizophrenia were far more severe. In seeking home treatment, people with type 1 diabetes aimed primarily to decrease their visits to outpatient services. Those with complications who had more frequent, but brief, inpatient admissions hoped that access to home treatment would further decrease these admissions. People with schizophrenia, however, had frequent long-term admissions to both chronic and acute hospitals. For them access to home treatment was a means to avoid the violence usually associated with acute admissions, and for many it was the only way they could continue to live at home (rather than being institutionalized).

1.2. Geographical accessibility of services

Patients with either diagnosis who lived in Bucharest complained about the long distances to specialist outpatient services. People with diabetes were especially affected by distance to facilities treating complications. The experiences of people with either diagnosis in Slatina were similar as the acute mental health ward, the outpatient mental health unit, the diabetes inpatient ward and the diabetes outpatient unit were co-located.

The only difference between these two groups related to the distance to chronic mental hospitals, which were placed in rural areas outside towns. It is interesting to note that patients were not especially bothered by this, mainly because they had not conceived that provision in the community where they lived would ever be possible.

1.3. Access to services when needed (temporal access)

Access to services after working hours

Access to specialist services during and after working hours was similar for both groups. Physicians in both specialties used similar informal means to provide support and care to patients living at home outside official working hours.

When in hospital, people with schizophrenia were at a disadvantage as compared to people with diabetes. There were few nurses or auxiliaries on duty at night, something both patients and professionals complained about. In the chronic mental hospital, patients also faced major difficulties in seeing a physician at night. In contrast, general hospitals were seen as having adequate staffing throughout the 24 hour period.

Waiting time

The waiting time for outpatient mental health services in Bucharest was significantly longer than for the diabetes services. In Slatina, however, the waiting time was similar for both. In addition, people with diabetes reported long waiting times for treatment of complications. However, this would equally apply to people with schizophrenia if they sought to obtain those services for similar conditions.

1.4. Access to different parts of the system, as needed (Referral system)

Referral procedures from the corresponding specialist physicians were similar for both groups of patients. However, while physicians in other specialities involved in diabetes care could refer patients to diabetes physicians, psychologists and social workers were not allowed to do so. They could only report to the psychiatrist leading their team.

Both groups of patients faced similar difficulties in referrals to other somatic services, due to the limited knowledge of other physicians about schizophrenia and diabetes. However, the difficulties faced by people with schizophrenia seemed more difficult to overcome.

1.5. Financial access to services (financial affordability)

While both groups of patients had the right to free health insurance, some people with schizophrenia were unable to take advantage of it as the registration procedures were too complicated. People with diabetes had coverage for care in all specialist settings relevant to diabetes, but people with schizophrenia needed a pension to be admitted to long-term inpatient facilities. Moreover, access to all specialist treatment was free for people with type 1 diabetes. However, people with schizophrenia had very limited access to talking therapies. Evidence-based treatments, such as cognitive-behavioural therapy (CBT) or family and supportive therapy, were only occasionally provided by psychiatrists. Since the package of services did not include talking therapies provided by psychologists, unless psychiatrists delegated the task (and transferred the money informally), patients had to pay out-of-pocket.

Both groups of patients struggled to pay for medication for co-morbid conditions and complications. The difference was that while people with schizophrenia were largely resigned to the situation, people with diabetes vocally and assertively complained about it. The same applies to the other financial challenges identified by people with diabetes when using the health system, such as payment for laboratory tests, or pressure to attend private practice for treatment not available in public facilities.

People with diabetes also struggled to pay for their diet due to their low incomes. While diet was effectively part of their treatment, and patients were clearly affected by their limited ability to purchase appropriate food, people with schizophrenia had even worse economic status.

2. Availability of evidence-based treatment and care

2.1. Availability of medication

While both psychotropic and diabetes medications were largely available, people with schizophrenia sometimes struggled to find the exact medication they were prescribed in public pharmacies and hospitals. In such circumstances they would either find informal solutions, often with the support of psychiatrists or by themselves, frequently borrowing from other patients. On the other hand, people with diabetes, particularly older ones, lacked personal glucometers and test strips for self-monitoring.

2.2. Availability of other evidence-based interventions

People with schizophrenia had poor access to other evidence-based interventions besides medication. Psychosocial interventions were rarely available. Even when psychiatrists or psychologists did offer talking therapies, the quality was often poor. Rehabilitation and reintegration activities were even more rarely available. In contrast, people with diabetes did have access to dietary advice and foot and eye care. They were regularly monitored. While treatment was not always ideal, patients recognised that they received care from qualified professionals and that treatment was as good as anyone would get within the Romanian health system. People with diabetes were knowledgeable about their treatment and had clear expectations of what it should comprise, and as such were critical and assertive. In contrast, people with schizophrenia had little or no understanding of what psychosocial, rehabilitation and reintegration interventions they should receive and, as such, had low expectations and few criticisms, despite the evident lapses in these areas of their care.

2.3. Social care

People with schizophrenia and with diabetes both faced many difficulties in social benefits. However, the level of awareness and assertiveness of people with diabetes was significantly better. The level of need was also very different. While people with diabetes struggled to claim tax waivers, fare reductions in public transport and the pension to which they were entitled, people with schizophrenia needed a place to live outside hospital or a decent institution to stay in when they had nowhere else to go. People with diabetes would struggle to retain social benefits while employed. At the same time, people with schizophrenia were almost inevitably refused employment and needed help from the social care system to find the very few jobs available to them.

2.4. Physical health

For people with schizophrenia, poor somatic health care was a direct consequence of their diagnosis. This reflected prejudices among somatic physicians against people with mental illness: they often did not believe patients when they had somatic complaints. Another factor was that these physicians had limited knowledge of mental illness and felt inadequately prepared to treat patients so afflicted, especially those at risk of an acute psychotic episode while admitted to a somatic facility. Physicians of other specialities also had limited knowledge about diabetes, but rather than deny patients care, they insisted that the diabetes physician get involved in the treatment plan.

People with either condition faced similar financial challenges in somatic health facilities when they had to bribe health professionals. Both groups of patients complained they could not afford to do so. At the same time, reflecting differences in economic status, most of those with diabetes reported that they did in fact pay bribes to ensure good quality care, while people with schizophrenia did not, simply because they really could not afford it, even though they knew they would get less good care.

2.5. Availability of enough staff in all settings

Staff shortages were reported both in mental health and diabetes facilities. A common complaint related to scarcity of nurses and auxiliaries. However, it is important to note the different standards eliciting complaints. Thus, in mental hospitals, staff complained that 1 nurse and 1 auxiliary would cover 100 patients at night, while in the diabetes institute, staff complained that 1-2 nurses would cover 30-40 patients. Moreover, there were considerable shortages in psychologists and social workers to provide care for people with schizophrenia. Occupational therapists were not employed in any of the mental health facilities studied. In contrast, people with diabetes acknowledged they had *"as good an access to them [diabetes specialists] as anyone else"*.

Staffing levels of psychiatrists and diabetes physicians were similar in Bucharest, in both outpatient and inpatient services. People with diabetes in Slatina were, however, at a disadvantage compared to those with schizophrenia, as they had access to only one diabetes physician for both inpatient and outpatient services. While this situation was temporary, due to two other diabetes physicians being on maternity leave at the time, people with diabetes were adversely affected by it.

2.6. Availability of multidisciplinary teams with good representation of each professional category

Strict hierarchical lines between physicians, nurses and auxiliaries were common among both mental health and diabetes professionals. However, the relationship between all physicians providing care to people with diabetes was good. They worked together and consulted regularly. In contrast, the relationship between psychiatrists, on the one hand, and psychologists and social workers on the other, was in many instances marked by disrespect and an expectation that psychologists would be subordinate to psychiatrists. The substantial differences in competencies, status and income between these groups led to poor teamwork. People with schizophrenia were the main losers in this situation. In addition, psychiatrists were less able than their diabetes counterparts to engage with physicians of other specialities when their patients with schizophrenia suffered from somatic conditions.

3. Delivery of care

3.1. Individual treatment plans developed for each patient, on the basis of a holistic assessment. Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

a) Holistic assessment as a pre-requisite of the treatment plan

In inpatient facilities, both groups of patients received regular assessments. Though people with schizophrenia were assessed for other health problems at admission, their hospital stay was dominated by psychiatric assessment. Similarly, in outpatient facilities, people with schizophrenia were hardly ever assessed for other conditions. Only a few received a psychological assessment or an assessment of their social situation.

In contrast, people with diabetes had holistic assessments both in inpatient and outpatient settings. The exception was the outpatient service in Slatina, where patients were rarely assessed.

b) Individual treatment plan developed for each patient

All people with schizophrenia and diabetes had an individual treatment plan. The latter had a comprehensive plan covering both diabetes and co-morbid conditions and complications. In contrast, treatment plans for people with schizophrenia failed to cover important elements, such as talking therapies and occupational health and social care, instead focusing primarily on anti-psychotic medication.

c) Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate

Most mental health professionals displayed a paternalistic attitude towards people with schizophrenia, reflected in the lack of involvement of patients in the development of their own treatment plan. The patient's primary contribution was to alert the physician to side-effects of medication, which hardly amounts to participation. In contrast, people with diabetes were consulted about various components of their treatment. While the decision on what medication to prescribe lay ultimately with the physician, patients felt they participated in the development of their treatment plans and that their views are taken into account.

3.2. Presence of discharge procedures

There were no effective discharge procedures for either group of patients. Both mental health and diabetes professionals expressed dissatisfaction with the current system and attempted to find informal solutions to ensure follow-up after discharge.

3.3. Continuity of care

Continuity of specialist health professionals

The chronic care model, with care coordinators for management of chronic conditions has not been introduced in Romania, affecting both groups. A common practice in mental health and diabetes care was that the same specialist physicians would attend patients over the years in outpatient or inpatient services. This was not possible in the inpatient setting for those with diabetes who had infrequent admissions. In Slatina, it was anyway only relevant for treatment of co-morbid conditions and complications, given the presence of only one diabetes physician in town. The same applied to psychologists and social workers in settings where there was only one available.

Input from previous specialist services

The inputs to different specialist services were comparable at the time of the research. The diabetes service was introducing an information system at the time of the research, but it was only partly operational then. Feedback to general practitioners was also comparable.

Communication with other relevant sectors

Communication between mental health and diabetes services and the disability and social welfare sectors was uniformly poor.

3.4. Staff have the appropriate competencies and skills

Specialist physicians

Specialist physicians felt confident in their training, their competencies and skills. Both psychiatrists and diabetes physicians underwent continuing education. However, while diabetes patients had faith in their physicians, not all people with schizophrenia had confidence in psychiatrists. They were well aware of the low status of psychiatry among medical specialities and, drawing on their own experiences, rated psychiatrists as less skilled than other physicians.

A particular problem was the limited ability of psychiatrists to deliver talking therapies, even though they were the only professionals formally allowed to be paid for doing so. In practice, many delegated this activity to psychologists. However, some did insist on delivering talking therapies despite their lack of training, while some also employed therapies for which there was no evidence of efficacy in schizophrenia. In contrast, diabetes physicians had at least basic competence in all tasks assigned to them, drawing extensively on evidence-based interventions.

Other specialists

Significant differences were found between the training, competencies and skills of other health professionals treating schizophrenia and diabetes. Physicians from other specialities treating people with diabetes were well trained in their speciality, though their limited expertise in diabetes led some to involve diabetes physicians extensively in treatment decisions. That made the process slower but it did not seem to give rise to negative outcomes for patients.

Nurses

The level of initial and continuing education of nurses working in mental health and diabetes services was similar. Both groups rated their own competencies and skills highly and considered that they are well trained to cope with all requirements of the job. The exception was when nurses in inpatient mental health facilities were confronted with violence and aggression by patients. They felt that had inadequate skills to cope with these incidents.

However, not all psychiatrists shared this high opinion of nurses working in mental health services, and some complained that nurses did not have the necessary competencies and skills and nor could they rely on them. That was not the case for nurses working in diabetes services, who were well appreciated by diabetes physicians and patients. Physicians felt confident enough in their competencies to delegate to them responsibility for dietary and self-management advice.

Auxiliaries

Auxiliaries working in diabetes services were better trained that those in mental health services. They were all required to complete 6-month training course for auxiliaries, while in mental health services, some only had on-the-job training. The high volume of complaints made by people with schizophrenia against auxiliaries reflected their poor training and limited competencies and skills. In contrast, people with diabetes appreciated auxiliaries, who provided a significant amount of their daily care.

3.5. Empowerment of service users to care for themselves and live as independent a life as possible (Personal autonomy)

The approach towards empowerment of patients to care for themselves and live an as independent life as possible was fundamentally different in the two areas. Patient with diabetes were trained, strongly supported and even pressured by health professionals to self-manage. A low level of interaction with health services was seen as a measure of successful treatment. In contrast, mental health services cultivated a relationship of dependency of patients with health services. Confidence in people's ability to live autonomously was virtually non-existent, and staff (particularly nurses) often facilitated the process of admission of patients to institutions providing life-long care.

3.6. Involvement of service users in shaping the services

While neither groups of patients were involved in shaping specialist services, as already noted, diabetes physicians were keen on patients lobbying health authorities to improve services.

3.7. Involvement of families and carers

Involvement of families was recognised as an important factor in successful treatment of both groups of patients. In both cases, families bore a significant share of the burden of care and they struggled with it.

One important difference between families of people with mental health problems and those with diabetes was that the former were sometimes blamed by patients and professionals for sabotaging treatment and playing an active role in the institutionalization of patients.

4. Quality of facilities

4.1. Protection of service users' privacy and safety, decent living environment

Access and safety of personal belongings

The experience of people with schizophrenia was significantly worse. While people with diabetes had easy access to their personal belongings, which were at all times safe, people with schizophrenia had limited access to their belongings which were constantly at risk of theft.

Privacy and personal space

In Bucharest, conditions in the acute mental hospital were comparable with those in the diabetes institute, where people benefited from a safe and decent living environment. The number of beds per room was actually less in the mental hospital. In the diabetes institute there were some complaints about privacy. Patients also enjoyed less privacy in the chronic hospital in Slatina, where otherwise living conditions were good. In the Slatina general hospital, while conditions were not ideal in the diabetes ward, they were similar to those in the mental health ward. However, conditions were significantly worse in the Bucharest chronic hospital, where patients were forced to share beds on permanent basis. The poor economic status of patients and their families was a factor in the quality of their living conditions. Frustration with poor living conditions led families of some people with schizophrenia to invest personal money in renovating their rooms.

Patients' violent and aggressive behaviour

Some patients were exposed to aggression and violent behaviour by other patients but exclusively in mental health facilities.

Women safety

In most mental health and diabetes facilities, women reported that they felt safe and experienced no incidents with male patients. However, a shocking finding from this research was that women in the chronic mental hospital in Bucharest were at high risk of being prostituted by male patients. Health professionals claimed to be unaware of the problem, and did nothing to protect these women.

4.2. Presence of appropriate treatment facilities

People with diabetes had good access to appropriate facilities. In contrast, people with schizophrenia lacked access to appropriate facilities for talking therapies, both in inpatient and outpatient settings. In the Bucharest chronic hospital, facilities were also not appropriate for social care consultations.

4.3. Hygiene

In Bucharest, hygiene standards were found fully satisfactory in the acute mental hospital and mental health outpatient unit, as well as in the diabetes institute and the diabetes outpatient unit. In Slatina, conditions were good in the chronic mental hospital, contrasting with poor hygiene conditions found in the chronic mental hospital in Bucharest. Conditions in acute inpatient and outpatient facilities in Slatina, while not good, were similar for both patient groups.

4.4. Food and drinks

Experiences of both groups of patient were similar. In Bucharest, patients were equally content with the food they received, while in Slatina they were all unhappy with the food provided in the district general hospital.

5. Protection of human and civil rights

5.1. Right to respect of all human and civil rights on mental health facilities

While various violations of fundamental human and civil rights were reported by people with schizophrenia, people with diabetes unanimously reported that their rights were fully respected.

5.2. Right to informed consent to treatment

Informed consent was a *sine qua non* for all treatment provided to people with diabetes. In contrast, experiences of people with schizophrenia were marked by cruel disrespect of their right to consent to treatment. Consenting to treatment was for many patients the only alternative to being submitted to humiliating and sometimes inhumane treatment.

5.3. Right to confidentiality

Health professionals caring for both groups of patients shared information on their patients' health status with families. Both groups of patients expressed dissatisfaction with the difficulties they faced in maintaining confidentiality with employers, though the implications for people with diabetes were less severe.

5.4. Right to information

While people with diabetes received comprehensive information about their condition and its implications for their everyday life, people with schizophrenia rarely received any. Mental health professionals, unlike their diabetes counterparts, had a negative attitude towards sharing information with patients and were largely unaware that they were required by law to do so.

5.5. Right of access to personal information

Information on diagnosis

People with schizophrenia were at a clear disadvantage as they were largely lied to about their diagnosis. Some eventually discovered it in time. In contrast, all people with diabetes knew their diagnosis.

Access to personal file

People with schizophrenia were denied access to their personal files, while people with diabetes largely had access to them. The attitude of mental health professionals was significantly worse: they denied patients this right, even when they knew they were wrong, while diabetes professionals offered patients extensive access to their files even beyond legal requirements.

Information on results of tests

People with schizophrenia were at a clear disadvantage compared with people with diabetes. The former were rarely informed about their test results, while the latter were always informed.

5.6. Right to notification of rights

People with schizophrenia had worse access to information on their rights, which often led to a negative attitude towards the treatment they received. People with diabetes were primarily preoccupied with entitlements for social welfare, while their health rights were clear to them.

5.7. Right to treatment sensitive to needs of minorities (with different cultural and religious background)

Difficulties were reported both in mental health and diabetes services in the treatment of Roma. Roma patients were blamed for thefts by other patients, and were feared by professionals. Families of Roma patients were blamed for being verbally and physically aggressive. Otherwise, both groups reported that ethnic, cultural and religious differences have no impact on health care.

Conclusions

The findings of the rapid assessment show that treatment and care provided to people with schizophrenia was systematically worse than for people with diabetes in many of the areas assessed (Table 7), providing evidence of substantial inequity.

Table 7 Areas where treatment and care for people with schizophrenia was worse

2.2.	Availability of other evidence-based interventions
2.4.	Physical health
2.6.	Availability of multidisciplinary teams with good representation of each professional category
3.1.	Individual treatment plans developed for each patient, on the basis of a holistic assessment. Service users participate in the development of the treatment plan and are given a choice of treatment when appropriate (a,b,c)
3.4.	Staff have the appropriate competencies and skills
3.5.	Empowerment of service users to care for themselves and live as independent a life as possible (Personal autonomy)
4.2.	Presence of appropriate treatment facilities
5.1.	Right to respect of all human and civil rights on mental health facilities

5.2.	Right to informed consent to treatment
5.4.	Right to information
5.5.	Right of access to personal information
5.6.	Right to notification of rights

In some areas, while some aspects of care were similar, people with schizophrenia did suffer from significant disadvantages, again indicating a degree of inequity (Table 8).

Table 8 **Areas where treatment and care for people with schizophrenia was worse generally, though some aspects were equitable**

1.1.	Access to care in the least restrictive environment/community-based settings.
1.2.	Geographical accessibility of services.
1.3.	Access to services when needed (temporal access).
1.4.	Access to different parts of the system, as needed (Referral system).
1.5.	Financial access to services (financial affordability).
2.3.	Social care.
2.5.	Availability of enough staff in all settings.
3.6.	Involvement of service users in shaping the services.
3.7.	Involvement of families and carers.
4.1.	Protection of service users' privacy and safety, decent living environment.
4.3.	Hygiene.

Treatment and care for people with schizophrenia was comparable to that for people with diabetes in only six areas of assessment (Table 9).

Table 9 **Areas where treatment and care for people with schizophrenia was comparable to that for people with diabetes**

2.1.	Availability of medication
3.2.	Presence of discharge procedures
3.3.	Continuity of care
4.4.	Food and drinks
5.3.	Right to confidentiality
5.7.	Right to treatment sensitive to needs of minorities (with different cultural and religious background)

Returning to the first objective of this thesis, the assessment of the *de jure* and the *de facto* situation has showed that people with chronic mental health problems (exemplified by schizophrenia) are treated worse (horizontal inequity) in specialist services in Romania than people with chronic somatic problems (exemplified by diabetes). First, inequities were embedded in policy and legislation regulating the treatment and care for schizophrenia and diabetes, as demonstrated in Chapter 8. Second, the rapid assessment revealed that people with schizophrenia are, in practice, treated systematically worse in most of the areas of assessment, as summarised above.

It is not, however, yet clear whether these inequities are the outcome of benign neglect or whether they occur in a context of stigmatising attitudes and beliefs among health professionals and others in position of authority and influence over specialist health services. This will be examined in the following chapter.

Chapter 12 Searching for evidence of stigma

The Romanian mental health system was shaken to its roots in 2004 by publication of human rights abuse in Poiana Mare, a long-term mental hospital, where patients died of starvation. Reports of abuse and violence against people in other mental hospitals soon emerged. International media coverage and a strong response from the European Commission stimulated wide-ranging reforms of mental health services, as was shown in previous chapters, and mental health workers were placed under intense scrutiny.

This is the background against which the research reported in this thesis was undertaken. Mental health staff were cautious about displaying ill-will or negative attitudes towards people with mental health problems. This makes it especially difficult to identify the presence of stigma from the accounts of subjects. It would be pointless to ask whether individuals with mental health problems are stigmatised given the high political priority to overcoming it. Instead, it is necessary to look at the evidence obtained as a whole and infer the presence or absence of stigma from it.

To a large extent, this inference can only come from the language used by the participants. However, any inference must also be tempered by the recognition that those interviewed are likely to be, to some degree, on their guard about what they say. Consequently, the research is, almost inevitably, likely to underestimate the extent to which these patients are stigmatised, if indeed they are.

Notwithstanding this important limitation, as the following sections will show, there was indeed compelling evidence that patients with schizophrenia were stigmatised, with this phenomenon apparent among all professional groups and in all settings, though the degree and nature of stigmatisation varied. With some individuals it was quite obvious while others were more subtle.

1. Stigmatizing through patronizing attitudes and beliefs

Stigmatization by healthcare providers is present where there is expression of patronizing attitudes and beliefs that the diagnosis of a particular disorder or type of disorders should, on the basis of judgements of the nature of the disorder, result in the provider failing to uphold the rights of the individual concerned. This can be demonstrated in a number of ways.

1.1. Not informing patients about their diagnosis

Chapter 9, point 5.5, on the *right to access to personal information* showed how people with schizophrenia were often not informed about their diagnosis. Professionals in both locations and all settings, whether psychiatrists, psychologists or nurses, intentionally misinformed patients, underestimating their capacity to understand their diagnosis. Yet most professionals were aware of their patients' legal right to information about their diagnosis. Patients often took years to discover their diagnosis, and some of those interviewed were still not fully aware of their actual diagnosis. Some psychiatrists justified their decision not to tell patients by concerns about their health, by saying *"it's not good for them"*. One psychiatrist said that *"it is not good to tell them"* while admitting that *"though theoretically one must tell them"*. Other psychiatrists thought that people with schizophrenia could become dangerous if they knew their diagnosis because *"they know they can do anything with no legal consequences, hiding behind the diagnosis"*.

Some psychologists said that patients should not be informed since they were *"interpretative, vulnerable and suspicious"*. Other psychologists did not think that patients should be told their diagnosis because *"they get ideas."* While they thought it was good for patients to understand they had a mental health problem, some psychologists suggested that psychiatrists should *give them a decent diagnosis"*, i.e. instead of telling patients their actual diagnosis, to tell them a made-up name for schizophrenia, such as *"sindrom discordant"* and *"Thus, the patient will not know he is schizophrenic"*.

While nurses did not have responsibilities to inform patients about their diagnosis, they supported the decision not to inform patients. Some nurses noted that most patients with schizophrenia are not aware of their diagnosis, mainly because they *"don't understand"*. Others thought that patients were not interested in information about their disease or their treatment and *"they prefer to be lied to"*.

1.2. Not providing in a friendly, easy to understand manner comprehensive information about the cause or origin, risk factors and treatment of a disorder, and the impact of the disease on their everyday life

As was shown in Chapter 9 point 5.4 on *Right to information*, people with schizophrenia were poorly informed about their illness and its impact on their everyday life. While some psychiatrists reported being willing to answer any questions that patients may have about their illness, others had a very different attitude. One psychiatrist in the outpatient service in Bucharest described how they do not inform patients about their results because *"they are not open to them"*. This psychiatrist also noted that *"patients don't ask for information, they are generally not interested"*. A psychologist in the same facility said that patients did not receive any brochures because *"they don't have the patience to read them and they don't always understand"*. This psychologist also noted that *"for patients with schizophrenia it is not beneficial to get more information about their disease", "because they are in denial of their condition and are likely to worsen their condition"* though they admitted that a patient could seek information by themselves online.

Another psychologist in the acute mental hospital in Bucharest thought that patients have little information because *"their cognition is not sufficiently developed"* to ask the psychiatrist for such information (*"nu e sufficient de mobilat cognitiv"*). Psychologists in Slatina reported that patients are told *"they have a difficult disease. But they don't really understand"*. At the same time, they admitted that only broad and superficial information is provided to them.

1.3. Believing that people with mental illnesses cannot comprehend nor apply suggested treatment

Many of the health professionals interviewed did not believe that people with schizophrenia could comprehend or apply the treatment they need. Psychiatrists in outpatient services in Bucharest noted *"the first condition is that they (patients) are aware of their illness, which in most cases is very difficult"*.

Many psychiatrists reported that they try to negotiate with patients the course of treatment to ensure greater adherence. These psychiatrists considered that patients are more likely to adhere to treatment if their views are taken into account. At the same time, they recognized that many other mental health professionals are of the opinion that *"the schizophrenics are nuts, no point in asking their opinion, if they make trouble just give them an injection"*.

Patients' ability to understand their treatment was also underestimated by psychologists. One psychologist in an outpatient facility in Bucharest said patients *"expect magical pills"* to make them feel better. Psychologists in the acute mental hospital in Bucharest noted how people with schizophrenia often interrupt their medication after discharge because they fail to understand the chronic nature of their condition, *"they think it's like flu, one takes the medication for a certain period, and then finishes the treatment"*. Of all those interviewed, only one psychologist reported informing patients who know they have schizophrenia about their symptoms, their possible prognosis and treatment, what can be the expected of treatment, and what happens if they do not take treatment.

Refusal to comply with treatment was largely seen as a symptom of their illness. One psychiatrist in the acute hospital in Bucharest also noted that *"patients do not consent to treatment because they lack their mental capacity"*. Some psychologists in the same hospital saw refusal to undergo psychological tests as a manifestation of acute mental illness. Some psychologists noted that patients who refuse treatment have refused to accept that they have a mental illness. A psychiatrist from the acute facility in Slatina said that some patients need medication, but *"they don't really know what is good for them"*.

Similarly, one psychiatrist in the chronic mental hospital in Slatina said *"the majority of people with schizophrenia are not in touch with the reality, and cannot acknowledge they are ill, which is why they refuse treatment"*.

1.4. Having a negative attitude about prognosis and the possibilities for rehabilitation and recovery, believing that people with mental illnesses are incapable of independent living or real work and are not able to lead a 'normal' life

This research shows that mental health professionals had little confidence in the possibility that people with schizophrenia might recover from their illness and reintegrate into society. Neither did they think they could retain their job after they became ill or find skilled jobs and they actively discouraged patients from seeking jobs that matched their qualifications and competencies. For example a psychologist in the Bucharest outpatient unit considered that patients were unrealistic in their searches for jobs, saying disapprovingly *"they think they can do anything"*.

Many psychiatrists expressed strong concerns about the ability of people with schizophrenia to integrate into the workplace. Other psychiatrists in an outpatient facility in Bucharest noted that *"even when patients are given a chance to work, part time, they in fact cannot cope for long"*. Psychiatrists in the chronic hospital in Slatina encouraged patients to do gardening in the hospital grounds, even though they thought that patients were unlikely to get paid jobs after discharge since *"nobody wants to take the risk"*. When prompted about the choice of jobs that patients might get, a psychologist from the Bucharest acute mental hospital suggested street cleaning, commenting that *"Patients understood they are sick"* and that these are their only jobs they can hope for. Nurses in the Bucharest chronic mental hospital thought that some people with schizophrenia do manage to retain employment. However, when asked about the kind of jobs they thought they might get, they all agreed that patients should be happy to be employed as night guards, regardless of their actual qualifications. Psychiatrists often impress on patients that their life will never be "normal" again, and encourage them to reduce their expectations radically.

Psychiatrists shared an opinion that they attributed to the general population that people with schizophrenia were a nuisance and hard to integrate into society. One psychiatrist in an outpatient facility in Bucharest noted that *"the family wants to get rid of them, or neighbours are putting pressures because they don't like having a schizophrenic in their building, because it is noisy, or weird, and they prefer not to mix with them. It's normal. "*

Psychologists in the outpatient unit in Slatina argued that they were empowering patients to live as independent a life as possible. However, when prompted to describe how patients actually carried on with their life after being diagnosed, one could only name one patient who managed to keep his job and his family, even though she noted that this individual was *"exceptional"*. This manner of reporting was also encountered in other interviews. When asked to cite concrete examples of positive developments, many interviewees would start with *"Once I had a patient..."*. Successful cases were described on a tone of surprise *"I once had a patient who was able to pursue his education"*, or *"I once had a patient who was a good mother"*.

1.5. Failing to consider confidentiality of information, diagnosis and health status

Confidentiality of personal information on people with schizophrenia was maintained to varying degrees, as shown in Chapter 9, point 5.3. on *Right to confidentiality*. All professional groups reported being aware of patients' rights to confidentiality. However, the manner in which they observed these rights was far from perfect. The main complaint from patients was that psychiatrists regularly disclosed confidential information on their health status to current or prospective employers, which hampered their chances of employment. However, many psychiatrists considered that they have a greater duty to *"protect"* employers and other employees against people with schizophrenia who were deemed *"unpredictable"* and *"potentially dangerous"*. Less disturbing for some patients, but still illegal, health professionals considered they were entitled to share all information about patients with their families, without asking the patients' consent. That was despite many patients having long-standing conflicts with family members who took their money and, sometimes, manoeuvred to obtain their property.

1.6. Considering that a diagnosis of a severe mental disorder should lead to discarding certain rights of service users

1.6.1. The right to self-determination, e.g. a woman who had suffered a severe mental illness should have an abortion in the case of a pregnancy

The right to self-determination by patients was defined only vaguely by health professionals. Professionals showed little confidence in patients' abilities to live independent, autonomous lives, as indicated in Chapter 9, point 3.5 on *Empowerment of service users to care for themselves and live as independent a life as possible (Personal autonomy).*

The most extreme illustration, also presented in Chapter 9, was provided by a psychiatrist in a Bucharest outpatient unit, who talked about women with schizophrenia and their desire to have normal lives, with families, and children. However the psychiatrist did not think this was realistic. The psychiatrist described a woman who was very keen to have children, and eventually managed to get married and have two children. Since she wanted more children, her family conspired with health professionals to carry out a tubal ligation, without informing the patient. The psychiatrist considered this to be completely acceptable and, although knowing about it, chose not to inform the patient, who continued to seek fertility treatment in her desire for more children.

While no other professional reported such abusive situations, it was widely agreed that people with schizophrenia cannot make good parents and that they need to be cared for rather than provide care to others.

1.6.2. The right to chose treatment; this belief holds that service users should be treated against their will, even when they are not a danger to themselves or others

This thesis did not explicitly address the issue of involuntary treatment, but findings arising from the fieldwork, presented in Chapter 9, point 5.2 on the *Right to informed consent to treatment* showed that patients were forced to consent to treatment. Some psychiatrists said that they would respect the wishes of the patients who refuse treatment, if they were deemed to be of no threat to themselves or others. At the same time, patients reported being heavily pressured to consent. Access to decent living conditions, freedom from abuse, and access to social welfare benefits were seen by professionals as conditional on patients' consent to treatment. As such, professionals demonstrated that they did not genuinely believe that patients should be allowed to refuse treatment. Many in fact saw refusal to comply with treatment as a symptom of their illness.

1.7. Physically threatening or attacking service users because of the diagnosis of a mental disorder

Abuses were obviously not easy to uncover during the research, which did seek to be an inspection, but rather an assessment of mental health services. However, instances of abusive behaviour of staff, particularly auxiliaries and nurses, were reported in the Bucharest chronic mental hospital. It is here that a psychiatrist admitted pushing patients to the floor and injecting them when in crisis if they refused treatment.

In Slatina acute unit, psychiatrists complained about the nurses' behaviour. In the psychiatrists' opinion they did not treat patients well and were at least verbally abusive towards patients when not supervised by psychiatrists.

Aggression against people with schizophrenia was justified by reports of aggressive behaviour by patients. Nurses in the acute mental hospital in Bucharest openly admitted to handling patients roughly, which they saw as the only way to handle patients they considered *"vicious"* and *"like possessed"*.

In addition, it was widely reported by patients and acknowledged by all groups of professionals that people with schizophrenia were the subject of routine aggression and roughly handled during emergency admissions.

2. Stigmatizing language

Stigmatization was also reflected in the language used towards people with mental health problems, as is apparent in the next section.

2.1. Negative stereotypes

While often guarded in the language they used, mental health professionals did, however, demonstrate negative stereotypes about people with mental health problems, as reflected in their language. Although they did not say directly that people with schizophrenia are "dangerous", "violent/aggressive", they did say it indirectly, using the terms "nobody wants to take the risk" to employ them, or that "they know they can do anything with no legal consequences, hiding behind the diagnosis", or that "it's only normal" for physicians of other specialities to be afraid of them.

Health professionals also showed they found people with schizophrenia to be "stupid/of little intelligence", though again, using indirect language:

> "*They have a difficult disease. But they don't really understand.*"
>
> They are not aware of their diagnosis because they "*don't understand*".
>
> They "*expect magical pills*", instead of medical treatment.
>
> "*They don't really know what is good for them.*"
>
> "*Their cognition is not sufficiently developed to ask the psychiatrist*" about their illness.
>
> "*They don't even have the intellectual capacity to understand what it means to have schizophrenia.*"

They also found people with schizophrenia to be "untrustworthy":

> A patient "*needs to be quite well to take seriously what they say*".
>
> "*Schizophrenia is a really weird disease.*"
>
> Some patients are "*incorrigibly violent*".
>
> "*Whoever would see one of our patients would think he's possessed*".

2.2. Labels applied to psychiatric diagnosis

People with schizophrenia were referred to by some health professionals as "*schizophrenics*", or "*psychotics*". Nursing and auxiliary staff also referred to them as "*crazy*" and "*nutters*".

3. Stigmatizing in provision of treatment

Finally, stigmatization can also be recognised in the provision of treatment in the following ways.

3.1. Underestimating the effectiveness of psychosocial treatments in the belief that people with mental health problems cannot be successfully treated without drugs

The package of services covered by health insurance at the time of the research allowed only limited access to psychosocial interventions. But poor access to talking therapies and other psychosocial interventions was not only due to limitations imposed by the system. Health professionals largely underestimated their effectiveness in the treatment of people of schizophrenia. Very few psychiatrists and psychologists had appropriate training in evidence-based talking therapies, as was shown in Chapter 9. Even those who were well trained rarely used these therapies on this group of patients, since they did not believe they can be helped by them. One psychiatrist from a Bucharest outpatient facility said *"let's get real"* when asked about the potential value of offering cognitive behavioural therapy to people with schizophrenia. A few psychiatrists and psychologists did provide talking therapies but those keen on doing so lacked the necessary competencies. Treatment plans rarely included talking therapies and there was no expectation of improved outcomes resulting. Both psychiatrists and psychologists considered improvements in health status most likely to be due to medication.

3.2. Believing that people with severe mental disorders should be kept in hospitals, that they cannot be successfully treated outside the hospital in the community

Admissions as inpatients to acute or chronic mental health facilities were seen as a primary form of treatment and Romania was, at the time of the research, the country with the highest admission rate to mental health facilities in Europe. At the same time, psychiatrists and psychologists supported the idea of creating alternative community-based care. Despite this support, in practical terms they expected such options to be of use only for people who hardly needed hardly any health care and who were only admitted in hospitals because they had nowhere else to go (social cases). They did not expect such solutions to be applicable to many of the long-term residents in chronic mental hospitals. While efforts were made to improve living conditions in hospitals, neither psychiatrists nor psychologists envisaged any possibility to shift long-term care in mental hospitals to community-based facilities. Similarly, while they said that they considered home treatment should be made available to people with schizophrenia, they expressed sympathy with families and neighbours who tried to institutionalise patients because they were difficult to be around.

Most nurses and auxiliaries however, did not think people with schizophrenia could be treated successfully at home. Those working in outpatient services noted that most of their patients required frequent admissions. Nurses in inpatient facilities described actively helping people to complete the procedures to have family members with schizophrenia admitted permanently to mental hospitals.

3.3. Displaying of a lack of interest in the person suffering the mental illness and the history of their mental health problem

This was not found with respect to schizophrenia.

3.4. Not taking seriously complaints about somatic health problems, being ridiculed, or facing the suspicion that their physical complaints may only be imaginary

People with schizophrenia encountered many challenges in accessing services for their somatic health conditions. Psychiatrists complained that their colleagues often refused to treat them, out of fear and because they failed to believe they were really ill. Nurses reported that health professionals working in somatic facilities are keen to *"get[ting] rid of the patients with mental health problems"*, even when they have serious, life-endangering problems.

Not all mental health professionals believed patients who complained of somatic health problem. Nurses in outpatient facilities in Bucharest thought that some patients *"complain of diseases they have heard of from other patients, but they don't actually have those diseases"*. Some psychologists reported how, when patients did complain to them about somatic health problems, they would first *"try to see whether the patient is delirious"* or *"whether complaints have any real grounds"*.

At the same time, it should be noted that most psychiatrists expressed concern at the poor response of somatic services to people with schizophrenia.

Conclusions

To conclude, this assessment of stigmatising attitudes, beliefs and practices and behaviour indicates that people with schizophrenia are stigmatised in mental health services, whether through patronizing attitudes and beliefs, through stigmatizing language or through stigmatizing approaches to provision of treatment.

Chapter 13 Conclusions and recommendations

Introduction

The final chapter of this thesis begins by revisiting the initial hypothesis; that there is direct institutional discrimination against people with mental illness exists in specialist health care settings in Romania. In summary, as shown in chapters 9-11, horizontal inequity is embedded in policy and legislation and in the structures and processes of specialist health care settings, to the disadvantage of patients with schizophrenia. Furthermore, as shown in chapter 12, this is at least in part a reflection of the stigmatising attitudes of those in positions of power and influence in health facilities. However, before examining this summary conclusion in more detail, it is necessary to consider the limitations that were faced in conducting and interpreting the research.

Limitations

Limitations related to sampling

The challenge, in any observational research, is to ensure that those sampled are representative of the population to whom the results will be generalised, in this case the total population of individuals with schizophrenia and diabetes in Romania. It was obvious that, with the resources (both time, human, and financial) it would be necessary to be selective in sampling subjects. Ideally, a comprehensive sampling frame would be used. However, such a sampling frame does not exist in Romania for either group. It was not possible to find any comprehensive records with contact details of people admitted to the services being studied.

As set out in Chapter 4, sampling of the two target groups had to be done in different ways. People with schizophrenia were selected randomly from the list of patients admitted at the time of the research to chronic mental hospitals in the two locations (Bucharest and Slatina). While this approach ensured that all participants had experience in all type of settings included in this research, there is a risk that the sample may be biased in favour of those with less functionality or less social and family support who would be more likely to be admitted to hospital.

Sampling of patients with type 1 diabetes was based on a list of patients visiting the facilities during 2 months prior to implementation of the research who also had experience in inpatient specialist services. This was compiled by nurses working in the facilities. Although this was carefully checked, it is not possible to verify with certainty that this included all such patients. However, it is not clear how any omissions might bias the sample.

Another limitation relates to the sampling of auxiliaries. These health workers were not initially intended to be included in the research but the initial findings from the first focus groups and interviews showed clearly that they should be. However, this meant that there was insufficient time to compile a full staffing list in each service from which to draw a random sample. Consequently, opportunistic sampling had to be used. However, again, it is not obvious that this would introduce any significant bias.

Limitations related to data collection

Unfortunately, not all participants selected by random sampling agreed to participate. While patients who declined to participate were replaced by other patients, in the order indicated during sampling, some of the health professionals could not be replaced to the small number of staff in some settings. Specifically, the ophthalmologist in the diabetes inpatient services in Bucharest, the social worker in the mental health outpatient service in Bucharest could not be replaced. However, professionals from other specialities, with similar status and involvement with patients, agreed to participate (such as the cardiologist in the diabetes inpatient services in Bucharest and the social worker in the acute inpatient service in Bucharest).

Another potential limitation is that participants, particularly service users, could have exaggerated the short-comings of the health services. However, I was very much aware of the risk of this happening and, as far as possible, claims were checked, accounts from different people were compared, and in the analysis the data were carefully triangulated. On the other hand, it was clear that mental health professionals were guarded in the language they used and, while there were some slips of the tongue, it is likely that my encounters included somewhat less name calling and pejorative terminology than would be normal (and which, in my previous experience with these professionals, was far more pronounced). This almost certainly reflects their awareness of public and political concern about abuses in mental health services and the administrative consequences for staff found to be involved in them.

Another limitation is that data collection lasted longer than 12 weeks, the usual duration of a Rapid Assessment, due to the winter holidays, and heavy snowing which limited travelling. As such, field work was finalised in 16 weeks. However, this should not influence the validity of the data.

Other limitations and challenges faced by the researcher

The main challenge in carrying out this PhD was finding a balance between my full-time work at WHO and concentrating on the thesis. Continuing to work while doing the PhD was not easy, but it was both necessary (i.e. I self-funded the field work) and helpful. It was good for my professional development to continue my carrier in WHO, and later on at the Trimbos Institute, but in the last two years it became increasingly difficult to find time for working on the thesis. As I was based in Copenhagen and then in Amsterdam, I also missed the regular interactions with colleagues at LSHTM and the important peer support I enjoyed during the first phase of the PhD when I was based in London. Organising the field work was not challenging in its own right, as I had substantial previous experience with project management and I knew the system very well. I had contingencies for eventual difficulties, and overall it went quite smoothly, with the excellent support I got from my colleagues at the Romanian National Centre for Mental Health. The main frustration linked to field work was the difficulties encountered in accessing the diabetes services, as I describe below. At a personal level, I had to use my holidays for the field work as well as for doing much of the writing, and I had very long working days in Romania. One advantage was that in Romania it is acceptable to schedule meetings very early in the morning, and quite late in the day.

What this thesis adds

The literature review

Evidence on discrimination in health care of grounds of mental illness

This thesis reveals a significant, yet neglected, gap in the current literature on discrimination against people with mental illness. This relates to discriminatory practices in provision of health care on grounds of mental illness. While there is extensive literature on discrimination on grounds of gender, race, sexual orientation, and immigrant status, etc., there is hardly any literature on discrimination exclusively on grounds of mental illness in health care provision. The implication is that discrimination of mental health services within the health system is neither recognised nor addressed (you cannot fix a problem if you don't know you have it).

What literature does exist on discrimination against those who are mentally ill, along with the legislative and policy responses, is focused on other sectors, such as employment, housing, or education. While measures taken in these sectors are important in their own right, this deprives people with mental illness from holding accountable those who make decisions on their behalf in the health sector. Moreover, it could be argued that the limited success in tackling discrimination in other sectors could be rooted in the low credibility of health sector advocates, who fail to address this problem 'in their own courtyard", as it is well known that mental health services are of lower quality than somatic health services.

Clarifications on the concept of "discrimination"

When I started to prepare this thesis, I had not anticipated the conceptual difficulties in measuring institutional discrimination. The substantial work carried out in the section on the Conceptual Framework, which may go beyond what a PhD thesis is expected to do, is the result of failed attempts to identify existing conceptual frameworks that would have allowed the assessment required by the objectives of the thesis. That said, the conceptual clarifications presented in Chapter 3 do contribute to discussions on measurement of discrimination. Building on the European Commission's definitions of direct and indirect discrimination, this thesis addresses their recognised weaknesses in the ability to demonstrate harm and assess causation of discrimination in court cases. Thus, this thesis proposes that the presence of harm can be demonstrated by identifying either horizontal inequity, whereby individuals are treated differently from others who have the same needs, or vertical inequity, whereby the different needs of individuals are not recognised, causing some of them to be disadvantaged. Furthermore, it proposes that people are discriminated against because they bear a particular stigma, or visible sign that differentiates them from others. By employing the concepts of inequity and stigma, respectively, to demonstrate harm and assess causation of discrimination, the presence of discrimination can easier be ascertained.

The Rapid Assessment

The review of mental health policy and legislation is the most substantial review done so far in Romania, as confirmed by the experts from the Romanian National Centre for Mental Health. As such, it was used by the experts involved in a Twinning Project on Mental Health Reform Romania (2007-2009) (315). This project, implemented in partnership with Austria and the Netherlands, proposed changes to the legal and financial mechanisms that impact on community-based mental health care. It also produced four training manuals for multidisciplinary mental health teams and GPs, which were used to train over 700 professionals. What is unique about the policy and legislation review in this thesis is the presentation of rights and entitlements on each topic, taking account of all relevant legislative streams, while highlighting similarities and differences between them. This review shows how current policies and legislation make it almost impossible for service users to be fully aware of their rights to mental health care.

The field work and subsequent analysis contributes to the evidence of observed institutional discrimination in health care provision against people with mental health problems (in this case, schizophrenia), on grounds of their mental illness. Unlike studies on self-reported discrimination using cross-sectional surveys or other qualitative research methods, the findings of this study provide objective evidence that specialist services for people with mental health problems are indeed less good than specialist somatic services Romania. It also shows that inequities in mental health care are coupled with stigmatising of people with schizophrenia by the health professionals, who are in a position of power and influence in mental health system.

What are the implications for further research

Future research that emerges from this thesis

Inevitably, this thesis has generated ideas for further research. Here I present two projects that arise from the work that I have done. The first draws on the recognition that, although people with mental illness do suffer from discrimination, they are not among the groups that are specifically recognised in legislation that applies to health care, at least in Romania and at a European level. The second builds on the growing recognition of the value of talking therapies and the role that psychologists play in providing it in many countries. Yet in Romania psychologists are clearly undervalued and lack formal recognition. Both projects take an explicitly comparative approach, seeking to draw upon the opportunities to learn from experience across Europe.

Testing the current European anti-discrimination legislation applicability for the protection of people with mental health problems

Aim:

To determine whether the current anti-discrimination legislation in 3 countries (UK, Denmark and France), with a strong tradition of protection of human rights and with comprehensive national anti-discrimination legislation, guarantees protection of people with mental health problems against discrimination in mental health care, on grounds of mental illness.

Objectives:

1. Review the current national anti-discrimination legislation to determine its scope and relevance to protection of people with mental illness.

2. Determine the presence of discriminatory practices in mental health settings against people with mental health problems, exclusively on grounds of mental illness, by employing the framework for assessing discrimination described in this thesis (see Chapter 3 on Conceptual Framework).

3. Draw conclusions on efficiency of national anti-discrimination legislation in protecting people with mental health problems in provision of mental health care.

Settings: The proposed countries for implementation of this research are UK, Denmark and France. All these countries have national anti-discrimination legislation, which they successfully apply in other sectors.

Methods:

1. Legislative review (Objective 1)

2. Rapid Assessment (Objective 2)

Competencies of psychologists across Eastern Europe.

The profession of psychologist is fairly new in all post-communist countries. The findings of this research show that while it is a very popular profession in Romania, it does not make the expected contribution to mental health care provision. Their recognised competencies and standards of training, in particular clinical training, are below those in other European countries. Since they are a key profession in the process of change of mental health services, it will be important to assess to what degree this professional group can meet the expectations that come with restructuring of mental health services and the development of community-based services.

Aim

Assess the level of readiness of psychologists to contribute to the process of reforms of mental health systems in Central and Eastern European countries.

Objectives

1. Determine the roles and responsibilities of psychologists in mental health services in Central and Eastern European countries;
2. Determine the necessary competencies and skills for clinical psychologists working in modern mental health care services;
3. Assess the current status in Central and Eastern European countries and establish to what extent the current education and training systems in these countries enable clinical psychologists to acquire these competencies and skills;

Settings

The proposed setting for this research is the Central and Eastern European countries. While the objectives are equally relevant to the former Soviet Union countries, due to low numbers of clinical psychologists there, such research might be less relevant for now.

Methods

1. Literature review (Objective 1 and 2);
2. Cross-sectional survey of key stakeholders in Central and Eastern European countries (Objectives 1 and 3).

Implications for practice for Romanian authorities

The findings of this research have already been fed back to the Romanian authorities and have been used by them. As noted above, they were used by the experts involved in a 2007-2009 twinning project to inform the component dealing with legislative analysis. Furthermore, the findings of the review of policy and legislation and of the assessment carried out in mental health services have been used in the preparation of a 2009 WHO meeting with managers of mental health services in Romania (316).

During the preparatory work to develop the field work, one of the stakeholders I met with was the president of the National Centre for Fighting Discrimination. The centre has expressed great interest in the findings, which will be used to begin to address the so far largely ignored issue of discrimination in the Romanian health system against people with mental illness.

Personal reflections on doing research in Romania

Having lived abroad, in Denmark, one of the countries with the highest standard of living in Europe, since 2001, returning to Romania to carry out the research has been at time a challenging experience.

On one hand, it was very good to see the progress that was beginning to be achieved in mental health, even if this was not because of any genuine interest in mental health by decision makers, but rather due to the demands by the European Union to strengthen the human rights of people receiving mental health services as a condition of Romania's accession in 2007. I was encouraged by the visible transformation in the Schitu Greci hospital, formerly a notorious and terrible asylum. At the same time, the visit to "Domnita Balasa" hospital on the outskirts of Bucharest, where I was confronted by the very difficult living conditions of voluntary patients, not to mention the horrible conditions in the involuntary wards and the stories of female patients' pimping inside the hospital was heart breaking. There was still so much to be done to bring mental health services to a level where patients could claim basic human dignity. But I knew the system, and while hard to see, it was not surprising.

The most surprising findings, personally, were my experiences with the diabetes services. As a Romanian, I was obviously aware that bribery was a common practice in health care. However, since I worked in the Ministry of Health before I left Romania, I was used to being perceived as coming from a position of authority, and requests for bribes were unimaginable. I wrongly assumed that working for the World Health Organization (my employer at the time of the research) or carrying out my research within such a well-known university as the LSHTM, I would be given a similar level of authority and respect. Apparently, living abroad for so long made me "regress" to naivety. In both locations, the first interaction with those in a position of allowing me access to inpatient diabetes services was dominated by one openly formulated, and repeatedly asked question: "What's in it for me?". In my newly acquired naivety, I kept on suggesting production of different exciting publications, joint research projects with international partners, opportunities to present research findings to international conferences. Then there was the opportunity I was giving them to work with a leading international expert in this field, my supervisor, Professor McKee. A contributory factor, in one mental health facility, was the reluctance of physicians to get involved in any research whatsoever. Discussions revealed that their prejudice against research was due to bad experiences with some pharmaceutical companies. While well paid, these initiatives were also highly demanding. The terms of participation in these research initiatives were not completely clear from the beginning, and they faced difficulties in cancelling their participation.

Since the question kept on being repeated, I clearly was not providing the answer they were looking for. As far as they were concerned, since neither LHSTM nor WHO had any direct impact on their financing, employment or working conditions, they assumed a position of authority in relation to me, which meant that I was at their mercy. Eventually I was granted permission, partly due to intervention of colleagues in the National Centre for Mental Health, partly due to accidently emailing one of these decision makers my confidential notes in which I was sharing with my supervisor my concerns about their delay in replying to our request for collaboration and about their repetitive question on benefits, and my decision to seek another location (city) for the research, in case the situation was not rapidly clarified. Yet despite initial difficulties with these decision makers, I would also like to note the positive experience I had with most health professionals interviewed in these settings. Most of them were open and helpful, and, as the research findings show, genuinely interested in the well-being of their patients.

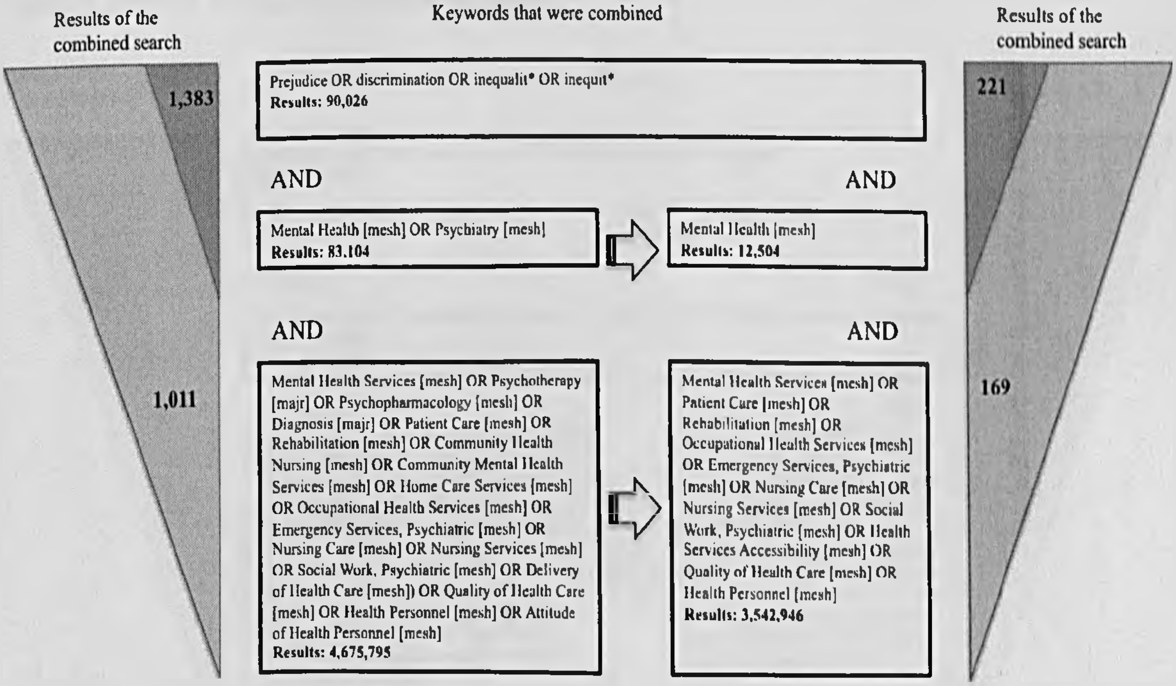
Annexes

Annex 1. Search strategies employed for the 2006 systematic review of literature

Search strategy:

Search strategy and findings. The initial search was conducted in August 2006, for the upgrading thesis. The following databases were used: Pubmed, PsycINFO, Embase and Web of Knowledge, using and relating the key-words for the entire time period covered by each database. The search strategy was customized to each database (Figures 1 - 4). Total number of documents found was 1878.

Figure 1. Search strategy on Pubmed database



Prejudice OR discrimination OR inequalit* OR inequit*
Results: 90,026

Mental Health [mesh] OR Psychiatry [mesh]
Results: 83.104

Mental Health [mesh]
Results: 12,504

Mental Health Services [mesh] OR Psychotherapy [majr] OR Psychopharmacology [mesh] OR Diagnosis [majr] OR Patient Care [mesh] OR Rehabilitation [mesh] OR Community Health Nursing [mesh] OR Community Mental Health Services [mesh] OR Home Care Services [mesh] OR Occupational Health Services [mesh] OR Emergency Services, Psychiatric [mesh] OR Nursing Care [mesh] OR Nursing Services [mesh] OR Social Work, Psychiatric [mesh] OR Delivery of Health Care [mesh]) OR Quality of Health Care [mesh] OR Health Personnel [mesh] OR Attitude of Health Personnel [mesh]
Results: 4,675,795

Mental Health Services [mesh] OR Patient Care [mesh] OR Rehabilitation [mesh] OR Occupational Health Services [mesh] OR Emergency Services, Psychiatric [mesh] OR Nursing Care [mesh] OR Nursing Services [mesh] OR Social Work, Psychiatric [mesh] OR Health Services Accessibility [mesh] OR Quality of Health Care [mesh] OR Health Personnel [mesh]
Results: 3,542,946

Figure 2. Search strategy on PsychInfo database

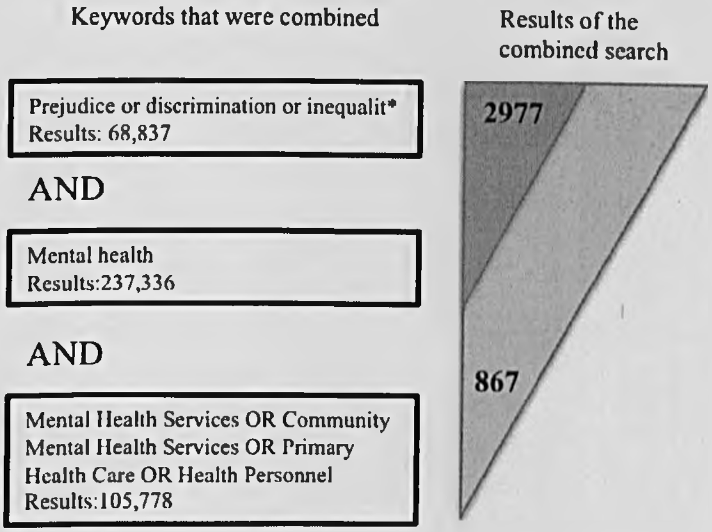


Figure 3. Search strategy on Embase database

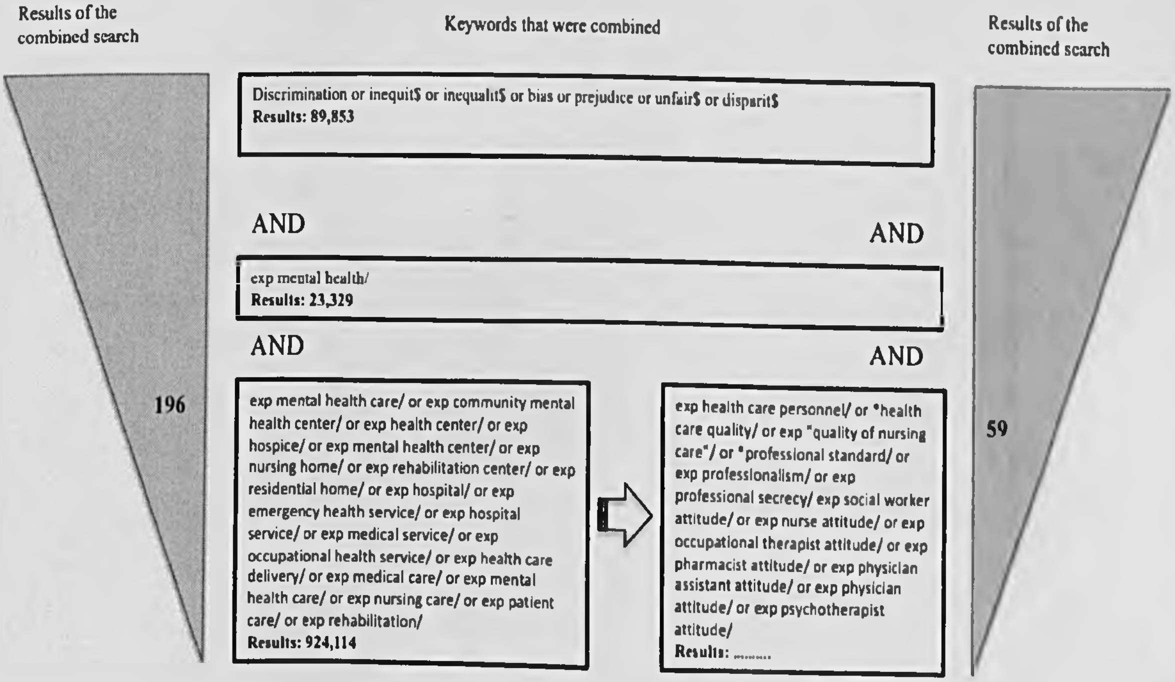
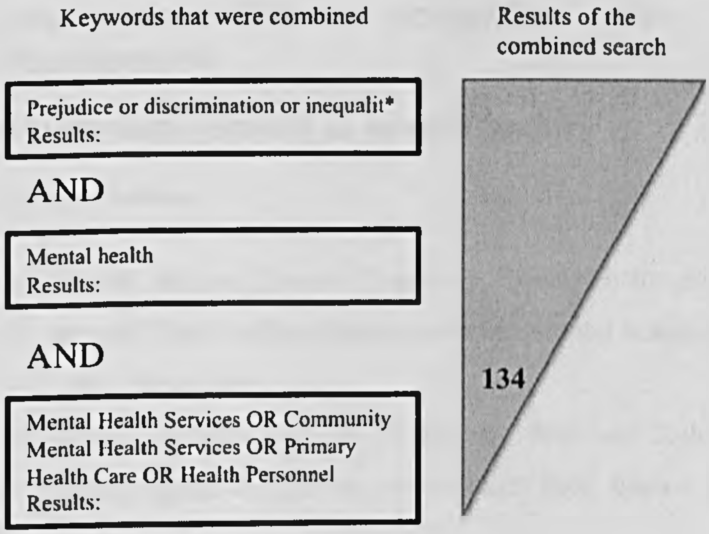


Figure 4. Search strategy on Web of Knowledge database



Annex 2. List of international guidelines and recommendations consulted for the Conceptual Framework

Documents relevant to mental health

United Nations

- United Nations General Assembly, Principles for the protection of persons with mental illness and the improvement of mental health care, United Nations, Editor. 1991: New York.
- United Nations General Assembly, Standard Rules on the Equalizations of Opportunities for Persons with Disabilities, United Nations, Editor. 1993: New York.
- United Nations General Assembly, Declaration on the Rights of Disabled Persons, United Nations, Editor. 1975: New York.
- United Nations General Assembly, Convention on the Rights of Persons with Disabilities, United Nations, Editor. 2006: New York.

World Health Organization

- World Health Organization, The World Health Report 2001 - Mental health: New Understanding, New Hope. 2001, Geneva: World Health Organization.
- WHO Regional Office for Europe, Mental Health Action Plan for Europe. Facing the challenges, building solutions. 2005, Copenhagen: WHO Regional Office for Europe.
- World Health Organization, The mental health context. WHO mental health policy and service guidance package - module 6. 2003, Geneva: World Health Organization.
- World Health Organization, Organization of services for mental health. WHO mental health policy and service guidance package. 2003, Geneva: World Health Organization.

- World Health Organization, Quality improvement for mental health. WHO mental health policy and service guidance package - module 8. 2003, Geneva: World Health Organization.
- World Health Organization, Human resources and training in mental health. WHO mental health policy and service guidance package - module 9. 2003, Geneva: World Health Organization.
- World Health Organization, Mental health legislation & human rights. WHO mental health policy and service guidance package. 2003, Geneva: World Health Organization.
- World Health Organization, Quality assurance in mental health care. Check-lists & Glossaries, ed. B. J.M. 1994, Geneva: World Health Organization.
- World Health Organization, WHO Resource book on mental health, human rights and legislation. 2005, Geneva: World Health Organization. 181.
- World Health Organization, World Health Organization Assessment Instrument for Mental Health Systems. WHO-AIMS Version 2.2. 2005, Geneva: World Health Organization.
- World Health Organization, Essential treatments in psychiatry. 1993, Geneva: World Health Organization.

Council of Europe

- Parliamentary Assembly of the Council of Europe, Recommendation 1235 on psychiatry and human rights, Council of Europe, Editor. 1994.
- Committee of Ministers of the Council of Europe, Recommendation 10 concerning the protection of the human rights and dignity of persons with mental disorder, Council of Europe, Editor. 2004.

Mental health service users organisations

- World Network of Users and Survivors of Psychiatry General Assembly Human Rights Position Paper. 2001, Vancouver: World Network of Users and Survivors of Psychiatry.

- European Network of (Ex-) Users and Survivors of Psychiatry, Vejle Declaration. 2004, Vejle: European Network of (Ex-) Users and Survivors of Psychiatry.
- European Network of (Ex-) Users and Survivors of Psychiatry, Zandvoort Declaration 1991, Zandvoort European Network of (Ex-) Users and Survivors of Psychiatry.

Professional Organisations - World Psychiatric Association

- World Psychiatric Association General Assembly, Hawaii Declaration 1977, amended in 1983, Hawaii, Vienna: World Psychiatric Association
- World Psychiatric Association General Assembly, Madrid Declaration 1996, amended in 2005, Madrid, Cairo: World Psychiatric Association
- World Psychiatric Association General Assembly, WPA Statement and Viewpoints on the Rights and Legal Safeguards of the Mentally Ill 1989, Athens: World Psychiatric Association

Documents relevant to diabetes

- WHO Regional Office for Europe and International Diabetes Federation, *Diabetes Care and Research in Europe: The St Vincent Declaration*. 1989, St Vincent WHO Regional Office for Europe and International Diabetes Federation.
- World Health Organization, *General Principles of Good Chronic Care. Integrated management of adolescent and adult illness*. 2004, Geneva: World Health Organization.
- American Diabetes Association (2003). Standards of Medical Care for Patients with Diabetes Mellitus. Diabetes Care, Vol.26, suppl.1, pp.33-50
- Austin, B., Wagner, E., Hindmarsh, M., Davis, C. (2000). Elements of Effective Chronic Care: A Model for Optimizing Outcomes for the Chronically Ill. Epilepsy Behav. Vol., n. 4, S15-S20.
- Bodenheimer, T., Wagner, E., Grumbach, K. (2002). Improving primary care for patients with chronic illness. JAMA. Vol. 288, n.14, pp.1775-9.(a)

- Bodenheimer, T., Wagner, E., Grumbach, K. (2002). Improving primary care for patients with chronic illness: the chronic care model, Part 2. JAMA. Vol. 288, n. 15, pp.1909-14. (b)
- World Health Organization (2002).Innovative care for chronic conditions: building blocks for action: global report. Geneva. Non-communicable Diseases and Mental Health.
- Singh, D. (2005). Transforming Chronic Care. Evidence about Improving Care for people with long-term conditions. HSMC, The University of Birmingham, & NHS Surrey and Sussex PCT Alliance.
- Tsai, A., Morton, S., Mangione, C., Keeler, E. (2005). A Meta-analysis of interventions to improve care for chronic illnesses. The American Journal of Managed Care. Vol.11, n. 8, pp.478-488.
- Wagner, EH. (1998). Chronic disease management: what will it take to improve care for chronic illness? Effective Clin Pract. n. 1, pp. 2-4
- Wagner, EH., Davis, C., Schaefer, J., Von Korff, M., Austin, B (1999). A survey of leading chronic disease management programs: are they consistent with the literature? Managed Care Quart. n. 7, pp. 56-66.
- World Health Organisation. WHO STEPS instrument (core and expanded). Department of Chronic Diseases and Health Promotion. http://www.who.int/chp/steps/Instrument.pdf (accessed 10 April 2006)
- World Health Organisation (2005). Preventing Chronic Diseases: A vital investment.

Annex 3. Instruments developed to determine the existence of stigma

The criteria for assessing the presence of stigma described in the Conceptual Framework of the thesis were drawn from a number of instruments that have been developed by different research groups to determine the existence of stigma, including questionnaires and interview guides for different target groups (see bellow). A review of these tools identified certain common themes identified as characterising stigmatization by health professionals and others involved in the treatment and care of people with mental health problems.

1. Heather Stuart, M.K.a.R.M., Inventories to measure the scope and impact of stigma experiences from the perspective of those who are stigmatized – consumer and family versions., in Understanding the stigma of mental illness: theory and interventions. , J.A.-F.a.N. Sartorius, Editor. 2008, John Wiley & Sons, Ltd.: West Sussex.

Stigma experiences scale – consumer version:

- Do you think that people think less of you if they know you have a mental illness?
- Do you think that the average person is afraid of someone with a serious mental illness?
- Have you ever been teased, bullied or harassed because you have a mental illness?
- Have you felt that you have been treated unfairly or that your rights have been denied because you have a mental illness?
- Have your experiences of stigma affected your recovery?
- Have your experiences your experiences with stigma caused you to think less about yourself and your abilities?
- Have your experiences with stigma affected your ability to make or keep friends?
- Have your experiences with stigma affected your ability to interact with your family?
- Have your experiences with stigma affected your satisfaction or quality of life?
- Do you avoid situations that may be stigmatizing to you?

2. Lauber, C., et al., Do mental health professionals stigmatize their patients? Acta Psychiatr Scand Suppl, 2006(429): p. 51-9.

Table 2. **Positive and negative stereotypes held by mental health professionals**

- Negative stereotypes: Unpredictable, Bedraggled, Mad, Distanceless, Weird, Threatening, Unreliable, Dangerous, Abnormal, Delinquent, Stupid
- Positive stereotypes: Creative, Highly skilled, Sympathetic, Clever, Charming, Sociable, Reasonable, Responsible, Self-controlled, Autonomous, Healthy

3. Ucok, A., et al., The impact of antistigma education on the attitudes of general practitioners regarding schizophrenia. Psychiatry Clin Neurosci, 2006. **60**(4): p. 439-43.

1. Patients with schizophrenia can work
2. Would oppose if one of his/her relative would like to marry someone who has schizophrenia
3. Schizophrenia patients could be recognized by his/her appearance
4. Schizophrenia patients are dangerous
5. Would not like to have a neighbor with schizophrenia
6. Schizophrenia patients are untrustworthy
7. Schizophrenia patients could harm children
8. Schizophrenia patients should be kept in hospitals
9. I don't worry about examining a person who is diagnosed with schizophrenia
10. Would a patient with schizophrenia be treated in the appropriate department of the general hospital
11. Schizophrenia could be treated
12. Patients with schizophrenia could not comprehend nor apply suggested treatment
13. Schizophrenia has the chance of recovery

4. Nordt, C., W. Rossler, and C. Lauber, Attitudes of mental health professionals toward people with schizophrenia and major depression. Schizophr Bull, 2006. **32**(4): p. 709-14.

To assess attitudes we used questions on stereotypes, restrictions, and social distance toward people with mental illness. To measure knowledge, we asked the respondents whether the person who was depicted in a short vignette was suffering from a mental illness.

- Stereotypes. The first part of the questionnaire assessed professionals' attitudes toward stereotypes of mental illness or psychiatric institutions. 5-point Likert scale to what extent people with mental illness differ from the general public with respect to 12 stereotypes (''dangerous'', ''unpredictable'', ''stupid,'' ''bedraggled,'',''abnormal,'' ''unreliable,'' ''weird,'' ''reasonable,'' ''selfcontrolled,'' and ''healthy'')
- Restrictions. To assess the willingness to restrict the individual rights of people who are mentally ill:
  - ''What do you think: should a woman who had suffered severely from a mental illness have an abortion in the case of a pregnancy?'';
  - ''Do you approve of the right to vote and to run for office for somebody who had suffered severely from a mental illness?'';
  - ''What do you think: should somebody who is severely mentally ill have her/his driver's license revoked?''; and
  - ''What do you think: should somebody be admitted to a psychiatric hospital even against his/her will and if needed retained, or should a person under no circumstances be compulsorily admitted to a psychiatric hospital?''

5. Schulze, B. and M.C. Angermeyer, Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. Social Science & Medicine, 2003. 56(2): p. 299-312.

Table 1. **Focus group guidelines for exploring the stigmatisation experiences of people with schizophrenia**

Opening question:

- What has changed for you after you first developed schizophrenia? Tell me concrete incidences and stories that you experienced! [if nec., probe: work, family, friends, education, everyday life]

Further questions (alternative):

- Were there situations in which you felt excluded or misunderstood? [if nec., probe: when? where? can you describe? other situations than you already described?]
- Did you tell other people that you had schizophrenia? [if nec., probe: whom? when? why? why not?]
- How did people around you react when they found out you had schizophrenia? [if nec., probe: withdrawal, interest, gossip, support?]

6. King, M., et al., The Stigma Scale: Development of a standardised measure of the stigma of mental illness. British Journal of Psychiatry, 2007. **190**(3): p. 248-254.

Stigma Scale. Forty-two questions on the stigma of mental illness were developed from the detailed, qualitative accounts of 46 mental health service users recruited in an earlier study (Dinos et al, 2004).

Table 2. **Test-retest reliability of all 42 statements**

1 The general public is understanding of people with mental health problems

2 Other people have mademe feel ashamed of myself because of my mental health problems

3 The way people have treated me upsets me

4 I have been discriminated against by housing departments/landlords because of my mental health problems

5 I have been discriminated against in education because of my mental health problems

6 Sometimes I feel that I am being talked down to because of my mental health problems

7 Having had mental health problems has made me amore understanding person
8 I am to blame for my mental health problems
9 I feel ashamed of myself that I have had mental health problems
10 I do not feel bad about having had mental health problems
11 Other people think less of me because I have had mental health problems
12 Newspapers/television take a balanced view about mental health problems
13 I am open to my family about my mental health problems
14 I worry about telling people I receive psychological treatment
15 Some people with mental health problems are dangerous
16 Other people have never made me feel embarrassed because of my mental health problems
17 People have been understanding of my mental health problems
18 I have been discriminated against by police because of my mental health problems
19 I have been discriminated against by employers because of my mental health problems
20 I have been physically threatened or attacked because of my mental health problems
21 My mental health problems have made me more accepting of other people
22 Very often I feel alone because of my mental health problems
23 I am scared of how other people will react if they find out about my mental health problems
24 I would have had better chances in life if I had not had mental health problems
25 I am as good as other people, even though I have had mental health problems
26 I do not mind people in my neighbourhood knowing I have had mental health problems
27 I would say I have had mental health problems if I was applying for a job
28 I worry about telling people that I take medicines/tablets for mental health problems
29 People's reactions to my mental health problems make me keep myself to myself
30 I am angry with the way people have reacted to my mental health problems

31 I have not had any trouble from people because of my mental health problems
32 I have been discriminated against by health professionals because of my mental health problems
33 People have avoided me because of my mental health problems
34 People have insulted me because of my mental health problems
35 Having had mental health problems has made me a stronger person
36 I do not feel embarrassed because of my mental health problems
37 I avoid telling people about my mental health problems
38 Having had mental health problems makes me feel that life is unfair
39 When I see or read something about mental health in the papers or television, it makes me feel bad about myself
40 I feel the need to hide my mental health problems from my friends
41 I find it hard telling people I have mental health problems
42 I do not understand the diagnosis I have been given

The authors indicate this scale is similar in content to that the Internalised Stigma of Mental Illness scale developed by Ritsher et al (2003).

7. Ritsher, J.B., P.G. Otilingam, and M. Grajales, Internalized stigma of mental illness: psychometric properties of a new measure. Psychiatry Res, 2003. **121(1)**: p. 31-49.

Item-level Statistics for the Internalized Stigma of Mental Illness (ISMI) scale (N=127)

Alienation

I feel out of place in the world because I have a mental illness
Having a mental illness has spoiled my life
People without mental illness could not possibly understand me.
I am embarrassed or ashamed that I have a mental illness
I am disappointed in myself for having a mental illness.
I feel inferior to others who don't have a mental illness

Stereotype Endorsement

Stereotypes about the mentally ill apply to me.

People can tell that I have a mental illness by the way I look.

Mentally ill people tend to be violent.

Because I have a mental illness, I need others to make most decisions for me.

People with mental illness cannot live a good, rewarding life.

Mentally ill people shouldn't get married.

I can't contribute anything to society because I have a mental illness

Discrimination Experience

People discriminate against me because I have a mental illness

Others think that I can't achieve much in life because I have a mental illness.

People ignore me or take me less seriously just because I have a mental illness.

People often patronize me, or treat me like a child, just because I have a mental illness.

Nobody would be interested in getting close to me because I have a mental illness

Social Withdrawal

I don't talk about myself much because I don't want to burden others with my mental illness.

I don't socialize as much as I used to because my mental illness might make me look or behave "weird".

Negative stereotypes about mental illness keep me isolated from the "normal" world.

I stay away from social situations in order to protect my family or friends from embarrassment.

Being around people who don't have a mental illness makes me feel out of place or inadequate.

I avoid getting close to people who don't have a mental illness to avoid rejection

Stigma Resistance (reverse-coded items)

I feel comfortable being seen in public with an obviously mentally ill person.

In general, I am able to live life the way I want to.

I can have a good, fulfilling life, despite my mental illness.
People with mental illness make important contributions to society.
Living with mental illness has made me a tough survivor.

8. Economou M, K.A., Gramandani C, Leontiadou A, Louki E, Stefanis C., *Mental disorder and mental health representations in Greek newspapers and magazines.* World Psychiatry, 2005. 4(45-49).

Reproduction, challenge or absence of the following stereotypes was measured: a) people with mental illness are violent and dangerous; b) parents are to be blamed for mental illness; c) mentally ill people cannot work; d) mental illness is incurable; e) people are themselves to blame for their own mental illness, i.e. they do not have a real illness, and could "snap out of it"; f) people with mental illness cannot make logical decisions. The stereotypes were selected from grouping the World Psychiatric Association's reviews on commonly held misconceptions about schizophrenia (World Psychiatric Association. Fighting stigma and discrimination because of schizophrenia. World Psychiatric Association, 1998.).

9. Lasalvia, A. and M. Tansella, *Fighting discrimination and stigma against people with mental disorders.* Epidemiol Psichiatr Soc, 2008. **17**(1): p. 1-9.

The concept of stigma was originally developed in social sciences research to define an "attribute that was deeply discrediting". This term was subsequently adopted by social psychiatry to indicate the series of prejudices and negative connotations ascribed to persons with psychiatric problems.

Professionals - *Stigma present among the structures assessed*

- Tell the diagnosis or not
- Provide best possible treatment
- Opinion about prognosis
- Training of staff
- Usefulness of the patient for the society

Annex 4. List of relevant Romanian legislation with amendments

Legislation	**Amendments**
Ministry of Health, *Strategia în domeniul sănătăţii mintale a Ministerului Sănătăţii din România.* 2001, Bucharest: Ministry of Health.	No amendments
Ministry of Health, *Plan de acţiune pentru implementarea Strategiei de sanatate mintala a Ministerului Sanatatii* 2005, Bucharest: Ministry of Health.	No amendments
Ministry of Health, *Ordin nr.375 din 10 aprilie 2006 privind înfiinţarea, organizarea şi funcţionarea centrelor de sănătate mintală.* 2006, Bucharest: Ministry of Health.	No amendments
Ministry of Public Health, *Programul Naţional de Sănătate Mintală.* 2007, Bucharest: Ministry of Public Health.	No amendments
Ministry of Health, *Ordinul pentru eficientizarea activitatii de asistenta sociala si respectarea drepturilor omului in unitatile sanitare cu profil de psihiatrie sau alte unitati sanitare care au in structura sectii si compartimente de psihiatrie.* 2007, Bucharest: Ministry of Health.	No amendments
Parliament of Romania, *Legea sanatatii mintale si a protectiei persoanelor cu tulburari psihice nr. 487 din 2002.* 2002, Bucharest: Parliament of Romania.	*Promulgated by:* D. nr.664/2002 pentru promulgarea Legii sănătăţii mintale şi a protecţiei persoanelor cu tulburări psihice *Amended by:* **Before 2008** 1. L. nr.600/2004 pentru completarea Legii sănătăţii mintale şi a protecţiei persoanelor cu tulburări psihice nr. 487/2002 introduce alin. (2) la art.63 **After 2008** - No amendments
Ministry of Public Health, *Ordin 372 din 10/12/2006 privind normele de implementare a legii sănătăţii mintale şi a protecţiei persoanelor cu tulburări psihice nr. 487 din 11 iulie 2002.* 2006, Bucharest: Ministry of Public Health,.	No amendments
Ministry of Public Health, *Programul Naţional de diabet zaharat şi alte boli de nutriţie.* 2007, Bucharest: Ministry of Public Health.	

Parliament of Romania, *Legea nr 95 din 2006 Privind reforma în domeniul sănătății*. 2006, Bucharest: Parliament of Romania.	*Promulgated by:* D. nr.418/2006 pentru promulgarea Legii privind reforma în domeniul sănătății *Amended by:* **Before 2008** 1. O.G. nr.35/2006 pentru modificarea şi completarea Ordonanței Guvernului nr. 92/2003 privind Codul de procedură fiscală - abrogă art.261 alin.(3) 2. O.U.G. nr.72/2006 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătății şi pentru abrogarea unor dispoziții din alte acte normative în domeniul sanitar - modifică art.14, art.16 lit.e), art.48, art.50 lit.d), art.52, art.54 alin.(1), art.60 lit.f), art.80 lit.a), b) şi d), art.81, art.93 alin.(5), art.110 alin.(2), art.153 partea introductivă şi lit.b), art.192, art.213 alin.(1) lit.b), art.223 alin.(2) lit.e), art.237 partea introductivă a alin.(1) şi lit.i) şi o), art.256 alin.(3), art.257 alin.(3), art.262 alin.(1) lit.b), art.285 alin.(3), art.298 alin.(4), art.299 alin.(1), art.306 lit.a) şi b), art.313, art.339 lit.c), art.359, art.362, art.863 lit.e); introduce lit.x) şi alin.(2) la art.16, alin.(11) la art.54, lit.r), s), t) şi u) la alin.(1) al art.237 şi alin.(3), lit.d) la alin.(1) al art.256, alin.(21) la art.265, alin.(2) la art.367; abrogă art.272 alin. (2) lit. d), art.350 alin.(3) 3. O.U.G. nr.88/2006 pentru modificarea şi completarea unor acte normative prin care se acordă drepturi sociale, precum şi unele măsuri în domeniul cheltuielilor de personal - modifică art.259 alin.(3), art. 260 alin.(1) lit.a); introduce art.2581 4. O.U.G. nr.104/2006 pentru modificarea alin. (3) al art. 190 din Legea nr. 95/2006 privind reforma în domeniul sănătății - modifică art. 190 alin.(3) 5. L. nr.34/2007 privind aprobarea Ordonanței de urgență a Guvernului nr. 72/2006 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătății şi pentru abrogarea unor dispoziții din alte acte normative în domeniul sanitar - modifică art.45 alin.(1), art.48, art.50, art.52, art.54 alin.(1), art.93 alin.(5), art.190 alin.(2) lit.g) şi alin.(3), art.192 alin.(2), art.229, art.237 alin.(1) lit.s) şi t), art.285 alin.(3), art.385 alin.(2),art.441 alin.(3), art.519 alin.(5) şi art.612 alin.(3) ; introduce lit.o) la art.17 alin.(2), alin.(11) la art.45, alin.(6) la art.93, alin.(4) şi (5) la art.189, alin.(3) şi (4) la art.237 6. O.U.G. nr.20/2007 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătății - modifică art. 48 alin. (1) şi (2), art. 50 lit. d); introduce alin. (11), (12) şi (4) la art. 48, alin. (6) la art. 233 7. L. nr.120/2007 privind aprobarea Ordonanței de urgență a Guvernului nr. 88/2006 pentru modificarea şi completarea unor acte normative prin care se acordă drepturi sociale, precum şi unele măsuri în domeniul cheltuielilor de personal - aprobă cu completări O.U.G. nr. 88/2006 8. L. nr.264/2007 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătății - modifică art.52 lit.a), art.93 alin.(6), art.111, art.174 alin.(3), art.178 alin.(3), art.180 alin.(1) lit.a), art.184 alin.(4) şi (10), art.190 alin.(3), art.217 alin.(2) şi (5),

	art.259 alin.(7) şi (8), art.268, art.321 alin.(1), art.338, art.385, art.484, art.565, art.684 alin.(5); introduce alin.(3) la art.17, alin.(11) la art.40, alin.(7) la art.93, alin.(31) la art.174, alin.(5) şi (6) la art.178, alin.(5) la art.179, alin.(5)-(8) la art.183, art.1831 - 1833, alin.(21) la art.190, alin.(11) la art.211, lit.h) la art.411, lit.h) la art.507dispune republicarea
	9. O.U.G. nr.90/2007 privind unele măsuri financiar-fiscale în domeniul asigurărilor sociale de sănătate şi reglementări în domeniul cheltuielilor de personal - modifică art. 259 alin. (3), art.260 alin. (1) lit. a)
	10. L. nr.281/2007 pentru modificarea alin. (3) al art. 17 din Legea nr. 95/2006 privind reforma în domeniul sănătăţii - modifică art. 17 alin. (3)
	11. O.U.G. nr.93/2008 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătăţii - modifică art. 4 alin. (1) lit. e), art. 8 lit. b), art. 11, art. 15, art. 16, denumirea cap. IV din titlul I, art. 25, art.26, art. 45 alin. (1) şi (2), art.48 alin. (11) şi (12), art. 49, art. 50 lit. d), art. 54 alin. (1), art. 60 lit d) şi f), art. 69, art. 93 alin. (5), art. 136 alin. (2), art. 174 alin. (31), art.178 alin. (3), art. 180 alin. (5), art. 183 alin. (5), art. 184 alin. (4), (5), (6), (8), (9) şi (12), art. 186 alin. (7), art. 190 alin. (21) lit a), art. 200 alin. (2) şi (3), art. 209 alin. (3), art. 210 alin. (1) lit. k), art. 233 alin. (6), art. 244 alin. (7), art. 246 alin. (1), art.247, art.249 alin. (1), art. 252 alin. (1), art.257 alin. (2) lit. e) şi f), art. 257 alin. (3), art. 257 alin. (5) lit. c) şi alin. (7), art. 260 alin. (1) lit. b), art. 266 alin. (2) şi (3), art. 288 alin. (4), art. 317 alin. (1) şi (2), art. 362, art. 385 alin. (5), (6) şi (8), art. 484 alin. (2)-(5), art. 565 alin. (2), (3) şi (4), art. 566, art. 661 alin. (1), art. 695 pct. 16 şi 34, art. 756, denumirea cap. VII al titlului XVII, art.787, art.788, art.789, art. 790 lit. a) şi b), art. 791 lit. c), d), f) şi g), art. 792 alin. (1) şi (2), art. 793 alin. (2), art. 794, art. 795, art. 836, art. 848, art. 851, art. 856, art. 858; introduce alin. (5) şi (6) la art. 48, lit. m) la art. 60, art. 691, art. 811, alin. (3) la art. 86, alin. (11) la art. 93, alin. (51) şi (52) la art. 93, alin. (32) la art. 174, alin. (2) la art. 182, alin. (9) la art. 183, lit. b1) şi m) la art. 1833, alin. (4) la art. 227, alin. (7) la art. 233, alin. (61) la art. 244, alin. (21) la art. 257, lit. g), h) şi i) la art. 281 alin. (1), alin. (11) la art. 288, lit. a1) la art. 305 alin. (1), lit. b1) la art. 306, alin. (11) la art. 317, alin. (11) la art. 388, alin. (31) la art. 484, alin. (11) la art. 485, alin. (31) şi (6) la art. 565, alin. (11) la art. 569, pct. 36 la art. 695, lit. g) la art. 697 alin. (1), alin. (2) la art. 697; abrogă art. 54 alin. (11), art. 200 alin. (4), art. 213 alin. (2) lit. a); înlocuieşte sintagma "inspecţia sanitară de stat" cu sintagma "control în sănătatea publică", în tot cuprinsul titlului II sintagmele " Agenţia Naţională de Programe" şi " Agenţia Naţională pentru Programe de Sănătate" se înlocuiesc cu sintagma "structură cu atribuţii în elaborarea şi coordonarea programelor naţionale de sănătate"; la data intrării în vigoare a hotărârilor Guvernului prin care instituţiile prevăzute la art. III alin. (1) încep să funcţioneze, se abrogă art. 12, art.13 alin. (1), art. 17 alin. (1) şi (2), art.

	18 - 23 şi art. 24 alin. (2); la aceeaşi dată la care instituţiile prevăzute la art. III alin. (1) încep să funcţioneze, sintagmele „autorităţi de sănătate publică judeţene şi a municipiului Bucureşti" şi „autorităţi de sănătate publică teritoriale" se înlocuiesc cu expresia „instituţii care desfăşoară activităţi în domeniul sănătăţii publice care preiau atribuţiile acestora" **After 2008** 12. L. nr.157/2008 pentru completarea alin. (2) al art. 218 din Legea nr. 95/2006 privind reforma în domeniul sănătăţii - introduce lit. d1) la art. 218 alin. (2) 13. O.U.G. nr.162/2008 privind transferul ansamblului de atribuţii şi competenţe exercitate de Ministerul Sănătăţii Publice către autorităţile administraţiei publice locale - abrogă titlul V cu art. 126 - 140 14. O.U.G. nr.170/2008 pentru modificarea Legii nr. 51/1993 privind acordarea unor drepturi magistraţilor care au fost înlăturaţi din justiţie pentru considerente politice în perioada anilor 1945-1952, precum şi pentru modificarea art. 213 alin. (1) lit. c) din Legea nr. 95/2006 privind reforma în domeniul sănătăţii - modifică art. 213 alin. (1) lit. c) 15. O.U.G. nr.192/2008 privind aprobarea unor măsuri de relaxare fiscală în vederea creşterii economice şi a numărului locurilor de muncă (abrogata prin O.U.G. nr.226/2008) - modifică art. 259 alin. (3), art. 260 alin. (1) lit. a) 16. O.U.G. nr.197/2008 pentru modificarea şi completarea unor acte normative din domeniul sănătăţii - modifică art. 260 alin. (1) lit. a) şi alin. (2); introduce lit. j) la art. 213 alin. (2) 17. O.U.G. nr.226/2008 privind unele măsuri financiar-bugetare - abrogă O.U.G. nr. 192/2008 şi modifică art. 259 alin. (3) 18. O.U.G. nr.227/2008 pentru modificarea art. 12 din Legea nr. 95/2006 privind reforma în domeniul sănătăţii - modifică art. 12 19. O.U.G. nr.69/2009 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătăţii - modifică art. 178 alin. (2) şi (5), art. 180 alin. (1) lit. a) şi alin. (5), art. 183 alin. (6); introduce alin. (21) la art. 178, lit. n) şi o) la art. 1833 20. O.U.G. nr.88/2009 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătăţii - modifică art. 406 alin. (1) lit. g), art. 431 lit. h), art. 470 alin. (2) lit. b), art. 477 alin. (1), art. 502 alin. (1) lit. g); introduce lit. g) la art. 16 alin. (1); abrogă art. 655 alin. (2) dispune republicarea 21. O.U.G. nr.104/2009 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătăţii - modifică art. 362, art. 366 alin. (1); introduce art. 171, alin. (11) şi (12) la art. 246, lit. x) la art. 270 alin. (1), art. 3631, alin. (11)-(13) la art. 365, anexa nr. 14 22. L. nr.329/2009 privind reorganizarea unor autorităţi şi

	instituții publice, raționalizarea cheltuielilor publice, susținerea mediului de afaceri și respectarea acordurilor-cadru cu Comisia Europeană și Fondul Monetar Internațional - abrogă, la data intrării în vigoare a hotărârilor Guvernului privind înființarea, organizarea și funcționarea noilor entități rezultate din reorganizarea autorităților și instituțiilor publice prevăzute în anexele nr. 1 și 2, art. 682, art. 683 alin. (1) și alin. (6)-(8), art. 684-687, art. 688 alin. (1) teza a 2-a și alin. (3), art. 689, art. 690, art. 692 alin. (1) 23. O.U.G. nr.114/2009 privind unele măsuri financiar-bugetare - modifică art. 259 alin. (3), art. 260 alin. (1) lit. a) 24. O.U.G. nr.1/2010 privind unele măsuri de reîncadrare în funcții a unor categorii de personal din sectorul bugetar și stabilirea salariilor acestora, precum și alte măsuri în domeniul bugetar - abrogă art. 688 alin. (3) 25. L. nr.91/2010 privind aprobarea Ordonanței de urgență a Guvernului nr. 69/2009 pentru modificarea și completarea Legii nr. 95/2006 privind reforma în domeniul sănătății - modifică art. 111 alin. (15) lit. a), art. 178 alin. (2), art. 180 alin. (1) lit. a) 26. O.U.G. nr.48/2010 pentru modificarea și completarea unor acte normative din domeniul sănătății în vederea descentralizării - modifică art. 4 alin. (2), art. 13 alin. (2), art. 17 alin. (2) lit. o), art. 19, art. 93 alin. (1) și (5), art. 170 alin. (3), art. 174, art. 178 alin. (3), art. 178 alin. (4), art. 179 alin. (1), (2) și (5), art. 180 alin. (4), art. 182 alin. (1) lit. d) și e), art. 183, art. 1832, art. 184 alin. (4), (6) și (7), art. 185 alin. (1) și (2), art. 185 alin. (4) lit. c) și d), art. 186, art. 189, art. 190, art. 191, art. 196, art. 197, art. 198 alin. (1) și (2), art. 200, art. 204, art. 362; introduce alin. (21) la art. 17, alin. (4)-(6) la art. 49, art. 491, alin. (53) și (54) la art. 93, alin. (5) la art. 171, alin. (31) la art. 178, alin. (6) la art. 179, alin. (11) la art. 182, alin. (2) la art. 1833, alin. (81) la art. 184, alin. (91) la art. 184, lit. e) la art. 185 alin. (4), art. 1871, art. 1901-1907, art. 1981, alin. (41) la art. 256; abrogă art. 93 alin. (6), art. 202; înlocuiește, în tot cuprinsul legii, sintagma "consiliu consultativ" cu sintagma "consiliu de administrație" 27. O.U.G. nr.72/2010 privind reorganizarea unor instituții din domeniul sanitar, precum și pentru modificarea unor acte normative din domeniul sănătății - modifică art. 14, art. 695 pct. 27; înlocuiește, în tot cuprinsul legii, sintagma "Agenția Națională a Medicamentului (ANM)" cu sintagma "Agenția Națională a Medicamentului și a Dispozitivelor Medicale" 28. D.C.C. nr.1.394/2010 referitoare la excepția de neconstituționalitate a dispozițiilor art. 257 alin. (2) lit. f) teza finală din Legea nr. 95/2006 privind reforma în domeniul sănătății - suspendă pentru o perioadă de 45 zile dispozițiile art. 257 alin. (2) lit. f) teza finală (termenul se împlinește la 6 februarie 2011) după care operează dispozițiile art. 147 din Constituție 29. Vezi si: D.C.C. nr.1.394/2010 referitoare la excepția de neconstituționalitate a dispozițiilor art. 257 alin. (2) lit. f) teza finală din Legea nr. 95/2006 privind reforma în

	domeniul sănătăţii - art. 257 alin. (2) lit. f) teza finală
	30. Modificată: O.U.G. nr.107/2010 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătăţii - modifică art. 213 alin. (1) lit. c) şi alin. (2) lit. h), art. 257 alin. (2) lit. f) şi alin. (3), art. 259 alin. (2), art. 260 alin. (1) lit. a); introduce alin. (22) la art. 257, lit. a1) la art. 260 alin. (1); abrogă art. 257 alin. (2) lit. e), art. 259 alin. (3), art. 260 alin. (1) lit. d)
	31. O.U.G. nr.117/2010 pentru modificarea şi completarea Legii nr. 571/2003 privind Codul fiscal şi reglementarea unor măsuri financiar-fiscale - modifică art. 213 alin. (2) lit. c), d), f), i) şi j), art. 215, art. 257 alin. (2) lit. a), art. 257 alin. (5) lit. a), art. 258; abrogă art. 257 alin. (21)
	32. L. nr.276/2010 pentru modificarea şi completarea Legii nr. 416/2001 privind venitul minim garantat - modifică în mod corespunzător art. 260 alin. (1) lit. a) şi d)
	33. O.U.G. nr.133/2010 pentru modificarea şi completarea Legii nr. 95/2006 privind reforma în domeniul sănătăţii, în vederea eficientizării unor instituţii şi activităţi în acest domeniu - modifică art. 48 alin. (2), art. 54 alin. (2), art. 212 alin. (1), art. 217 alin. (2), art. 244 alin. (1), art. 245 partea introductivă, art. 256 alin. (3), art. 262 alin. (1), art. 265 alin. (2), art. 268 alin. (2), art. 276 alin. (1), art. 277 alin. (2), art. 278 alin. (1), art. 282 alin. (5), art. 287 alin. (2), art. 312, art. 331, art. 332, art. 333, art. 335, art. 336, art. 338; introduce art. 1891, alin. (11) şi (12) la art. 262, alin. (3) la art. 276, alin. (2) la art. 330, art. 3381, alin. (11) la art. 683; abrogă art. 217 alin. (6); înlocuieşte, în cuprinsul titlului VIII, cuvântul "vicepreşedinţi" cu cuvântul "vicepreşedinte" şi în cuprinsul titlului XVI, sintagma "Şcoala Naţională de Sănătate Publică şi Management Sanitar" cu sintagma "Şcoala Naţională de Sănătate Publică, Management şi Perfecţionare în Domeniul Sanitar Bucureşti" dispune republicarea
	34. D.C.C. nr.335/2011 referitoare la excepţia de neconstituţionalitate a dispoziţiilor art. 208 alin. (3) lit. b) şi e) şi a dispoziţiilor art. 257 din Legea nr. 95/2006 privind reforma în domeniul sănătăţii - suspendă pentru o perioadă de 45 zile dispoziţiile art. 257 alin. (2) lit. f) teza finală în măsura în care se interpretează că valoarea contribuţiei minime la fondul de asigurări sociale de sănătate, datorată de persoanele care realizează venituri din cedarea folosinţei bunurilor, venituri din dividende şi dobânzi, venituri din drepturi de proprietate intelectuală realizate în mod individual şi/sau într-o formă de asociere şi alte venituri care se supun impozitului pe venit, nu poate fi mai mică decât cuantumul unui salariu de bază minim brut pe ţară, lunar.(termenul se împlineşte la 6 iulie 2011), după care operează dispoziţiile art. 147 din Constituţie
	35. D.C.C. nr.335/2011 referitoare la excepţia de neconstituţionalitate a dispoziţiilor art. 208 alin. (3) lit. b) şi e) şi a dispoziţiilor art. 257 din Legea nr. 95/2006 privind reforma în domeniul sănătăţii - art. 257 alin. (2) lit. f) teza finală
	36. O.U.G. nr.32/2011 pentru modificarea şi completarea unor acte normative din domeniul sănătăţii - modifică art.

	245; introduce alin. (9) la art. 191 37. L. nr.71/2011 pentru punerea în aplicare a Legii nr. 287/2009 privind Codul civil - modifică, la data de 1 oct. 2011, art. 144 lit. a), art. 147 pct. 4
Parliament of Romania, *Legea drepturilor pacientului nr. 46 din 21 ianuarie 2003*. 2003, Bucharest: Parliament of Romania.	*Promulgated by*: D. nr.60/2003 pentru promulgarea Legii drepturilor pacientului No amendments
Parliament of Romania, *Legea spitalelor nr. 270 din 18 iunie 2003*. 2003, Bucharest: Parliament of Romania.	*Promulgated by*: D. nr.388/2003 pentru promulgarea Legii spitalelor *Amended by:* **Before 2008** 1. O.G. nr.57/2003 pentru prorogarea termenului de intrare în vigoare a Legii spitalelor nr. 270/2003 prorogă termenul de intrare în vigoare până la data de 1 ianuarie 2004. 2. O.G. nr.94/2003 pentru prorogarea termenului de intrare în vigoare a Legii spitalelor nr. 270/2003 (abrogata prin L. nr.95/2006) proroga termenul de intrare în vigoare pâna la 1 martie 2004 3. O.G. nr.40/2004 pentru modificarea şi completarea Legii spitalelor nr. 270/2003 (abrogata prin L. nr.95/2006) modifică art.1 alin.(3), art.7, art.8, art.13 alin.(8), art.15, art.23, art.24 lit.c) si e), art.25 alin.(2), (3) si (5), art.26, art.30, art.32, art.35, art.36 alin.(1) si (3), art.36 alin.(2) lit.e) , art.38 alin.(2), art.39, art.43, art.47 alin.(1) si (3); abrogă art.10 alin.(2), art.25 alin.(7), art.27, art.41 dispune republicarea 4. O.G. nr.68/200 pentru modificarea şi completarea Legii spitalelor nr. 270/2003 (abrogata prin L. nr.95/2006) modifică art.1 alin.(1), art.6 alin.(3), art.19 alin.(2) si (4), art.45 alin.(2); introduce alin.(5) la art.19, art.201, alin.(10) si (11) la art.23, alin.(41) la art.25, alin.(11) la art.29, alin.(11) la art.45, art.471 5. L. nr.523/2004 privind aprobarea Ordonanţei Guvernului nr. 68/2004 pentru modificarea şi completarea Legii spitalelor nr. 270/2003 (abrogata prin L. nr.95/2006) aprobă O.G. nr. 68/2004 si modifică art.1 alin. (1), art.201, art.23 alin. (10), art.25 alin. (41), art.29 alin. (11), art.34 alin. (2), art.45 alin. (2); abrogă art.6 alin. (3) lit. c), art.45 alin. (11) 6. O.U.G. nr.206/2005 pentru modificarea şi completarea Legii spitalelor nr. 270/2003 (abrogata prin L. nr.95/2006) 7. Abrogată: L. nr.95/2006 privind reforma în domeniul sănătăţii - la data de 28 mai 2006 **After 2008** – No amendments
Ministry of Health, *Ordin nr. 713 din 8 iunie 2004 Privind aprobarea normelor de autorizare sanitară a unităţilor sanitare cu paturi*. 2004, Bucharest: Ministry of Health.	No amendments
Ministry of Public Health, *Ordin nr. 482 din 14 martie 2007 Privind*	No amendments

aprobarea normelor metodologice de aplicare a titlului xv "răspunderea civilă a personalului medical şi a furnizorului de produse şi servicii medicale, sanitare şi farmaceutice" din legea nr. 95/2006 privind reforma în domeniul sănătăţii. 2007, Bucharest: Ministry of Public Health.	
Ministry of Public Health, *Ordin nr.1.778 din 28 decembrie 2006 privind aprobarea normativelor de personal.* 2006, Bucharest: Ministry of Public Health,.	*Amended by:* **Before 2008** – No amendments **After 2008** 1. Modificat: O. nr.2.099/2007 al ministrului sănătăţii publice pentru modificarea Ordinului ministrului sănătăţii publice nr. 1.778/2006 privind aprobarea normativelor de personal 2. O. nr.1.224/2010 al ministrului sănătăţii privind aprobarea normativelor de personal pentru asistenţa medicală spitalicească, precum şi pentru modificarea şi completarea Ordinului ministrului sănătăţii publice nr. 1.778/2006 privind aprobarea normativelor de personal
Ministry of Health, *Ordin nr. 527 din 29 iulie 1999 pentru stabilirea activităţilor conexe serviciilor medicale.* 1999, Bucharest: Ministry of Health.	*Amended by:* **Before 2008** 1. O. nr.612/2003 al ministrului sănătăţii şi familiei privind completarea Ordinului ministrului sănătăţii nr. 527/1999 pentru stabilirea activităţilor conexe serviciilor medicale **After 2008** – No amendments
Parliament of Romania, *Legea nr. 47 din 2006 Privind sistemul naţional de asistenţă socială.* 2006, Bucharest: Parliament of Romania.	*Promulgated by:* D. nr.302/2006 pentru promulgarea Legii privind sistemul naţional de asistenţă socială No amendments
Parliament of Romania, *Legea nr.19 din 17 martie 2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale.* 2000, Bucharest: Parliament of Romania.	*Promulgated by:* D. nr.65/2000 pentru promulgarea Legii privind sistemul public de pensii şi alte drepturi de asigurări sociale *Amended by:* **Before 2008** 1. O.U.G. nr.41/2000 pentru modificarea şi completarea Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art. 80, art. 81, secţiunea a 8-a devine secţiunea a 7-a, art. 108 alin. (2), art. 177 alin. (1) lit. c; elimină titlul secţiunii a 7-a. Rectificare: M.Of. nr. 183/27 apr. 2000 2. O.U.G. nr.171/2000 pentru modificarea Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art. 140 alin. (4) 3. O.U.G. nr.294/2000 pentru modificarea şi completarea Legii nr.145/1998 privind înfiinţarea, organizarea şi funcţionarea Agenţiei Naţionale pentru Ocupare şi Formare Profesională, precum şi a Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de

	asigurări sociale modifică art. 140 alin. (2)-(6) şi (8), art. 143, art. 177 alin. (1) şi (3); completează art. 140 cu alin. (9); înlocuieşte denumirea "Ministerul Muncii şi Protecţiei Sociale" cu denumirea "Ministerul Muncii şi Solidarităţii Sociale", denumirea "Agenţia Naţională pentru Ocupare şi Formare Profesională" cu denumirea "Agenţia Naţională pentru Ocuparea Forţei de Muncă" iar denumirea "agenţiile de ocupare şi formare profesională judeţene şi a municipiului Bucureşti" cu denumirea "agenţiile judeţene pentru ocuparea forţei de muncă şi a municipiului Bucureşti" 4. O.U.G. nr.49/2001 pentru modificarea şi completarea Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art. 5 alin. (1) pct. I, pct. III, pct. IV lit. f şi pct. VI, art. 5 alin. (2), art. 6 alin. (3), art. 17 alin. (2), art. 21 alin. (5), art. 23 alin. (1) lit. a, art. 25, art. 26 alin. (1) lit. b, c şi d, art. 29 lit. c, art. 37, art. 38 alin. (1) lit. b, art. 38 alin. (3), art. 42 alin. (1), art. 43 alin. (1), art. 44, art. 49, art. 52, art. 56 alin. (4), art. 59 alin. (3), art. 68 alin. (2), art. 69, art. 70, art. 71 alin. (2), art. 76, art. 77, art. 78 alin. (8), art. 80 alin. (1), art. 81, art. 83, art. 86 alin. (3), art. 87, art. 88, art. 92 alin. (1) lit. b şi d, art. 94 alin. (2), art. 95 alin. (1), art. 99 alin. (1) şi (2), art. 101 alin. (1) lit. B, lit. a, art. 102 lit. d, art. 104 alin. (1), art. 111, art. 117 alin. (4), art. 121 alin. (1) lit. a şi b, art. 123 alin. (1) şi (2), art. 127 alin. (2) lit. b, art. 129, art. 133 alin. (2) lit. c, art. 135 lit. c, art. 141 alin. (2), art. 142, art. 148 lit. l, art. 162 alin. (2), art. 180, art. 193, art. 195, art. 198 penult Referită de: H.G. nr.403/2001 pentru aprobarea Normelor metodologice de aplicare a prevederilor art. 183 din Legea nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale (abrogat prin H.G. nr.687/2005) prevederile art. 183 5. O. nr.340/2001 al ministrului muncii şi solidarităţii sociale pentru aprobarea Normelor de aplicare a prevederilor Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale, cu modificările şi completările ulterioare (abrogat prin H.G. nr.257/2011) 6. O. nr.364/2001 al ministrului muncii şi solidarităţii sociale privind modificarea Ordinului ministrului muncii şi solidarităţii sociale nr.340/2001 pentru aprobarea Normelor de aplicare a prevederilor Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale, cu modificările şi completările ulterioare (abrogat prin H.G. nr.257/2011) 7. O.U.G. nr.107/2001 pentru modificarea şi completarea Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art. 21 alin. (51), art. 23 alin. (1) lit. a, art. 37 alin. (2), art. 41 alin. (5), art. 43 alin. (4), art. 45, art. 781, art. 80 alin. (1), art. 101, art. 104, art. 144 lit. f, art. 148 lit. k, art. 149, art. 151; introduce alin. (11) la art. 6, alin. (52) la art. 21, alin. (6) şi (7) la art. 31, alin. (21) şi (22) la art. 37, alin. (21) la art. 99, lit. k1 la art. 148, alin. (4) la art. 1671 8. L. nr.340/2001 privind aprobarea Ordonanţei de urgenţă a Guvernului nr.294/2000 pentru modificarea şi

	completarea Legii nr.145/1998 privind înfiinţarea, organizarea şi funcţionarea Agenţiei Naţionale pentru Ocupare şi Formare Profesională, precum şi a Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art. 140 alin. (9) 9. O. nr.518/2001 al ministrului muncii şi solidarităţii sociale privind modificarea şi completarea Ordinului ministrului muncii şi solidarităţii sociale nr. 340/2001 pentru aprobarea Normelor de aplicare a prevederilor Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale, cu modificările şi completările ulterioare (abrogat prin H.G. nr.257/2011) 10. O. nr.718/2001 al ministrului muncii şi solidarităţii sociale privind modificarea Ordinului ministrului muncii şi solidarităţii sociale nr.340/2001 pentru aprobarea Normelor de aplicare a prevederilor Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale, cu modificările şi completările ulterioare (abrogat prin H.G. nr.257/2011) 11. L. nr.16/2002 privind respingerea Ordonanţei de urgenţă a Guvernului nr.171/2000 pentru modificarea Legii nr.19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale (scoasa din evidenta) respinge O.U.G. nr. 171/2000 12. L. nr.338/2002 privind aprobarea Ordonanţei de urgenţă a Guvernului nr. 49/2001 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art. 9, art. 20, art. 21 alin. (5), art. 23 alin. (1) lit. a, art. 26, art. 37, art. 38, art. 41 alin. (5), art. 43 alin. (2) şi (3), art. 43 alin. (4), art. 44, art. 45, art. 51, art. 56 alin. (1), art. 59, art. 61, art. 64 alin. (1), art. 71, art. 78 alin. (7) şi (8), art. 781, art. 80 alin. (1), art. 84 alin. (2), art. 98, art. 99, art. 101, art. 104, art. 109 alin. (1) lit. g, art. 126 alin. (1), art. 138 alin. (2), art. 144 lit. a şi f, art. 148 lit. k şi l, art. 149, art. 151, art. 160 alin. (4), art. 164, art. 1671, art. 1672, art. 174 alin. (3), (4) şi (5), art. 180, art. 187 alin. (4), art. 193 alin. (1) şi (3), art. 194; introduce alin. (11) la art. 6, alin. (51) şi (52) la art. 21, alin. (6)-(8) la art. 31, alin. (6) la art. 41, art. 481 şi 482, art. 1331, alin. (4) la art. 138, lit. kl la art. 148; abrogă modificările efectuate la art. 43 alin. (1) şi la art. 99 alin. (5) prin O.U.G. nr. 49/2001, art. 178, art. 181 13. L. nr.341/2002 privind respingerea Ordonanţei de urgenţă a Guvernului nr. 107/2001 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale (scoasa din evidenta) respinge O.U.G. nr. 107/2001 14. L. nr.346/2002 privind asigurarea pentru accidente de muncă şi boli profesionale începând cu data de 1 ian 2004 dispoziţiile art. 98 alin. (1) lit. a, b şi e şi alin. (4), art. 104, art. 108 alin. (2), art. 109 alin. (1) lit. a, b, d, e, f şi alin. (2), ale art. 111, 112, 114 şi 115 îşi menţin aplicabilitatea pentru toate situaţiile prevăzute în legea sus-menţionată, cu excepţia celor generate de accidente de muncă şi boli profesionale, care sunt preluate prin L. nr. 346/2002; abrogă art. 100 alin. (2), art. 102 şi art. 110. Rectificare: M.Of. nr. 580/6 aug. 2002

	15. O.G. nr.61/2002 privind colectarea creanţelor bugetare (abrogata prin O.G. nr.92/2003) înlocuieşte începând cu data de 1 ian 2003 noţiunea de "majorări de întârziere, majorări" cu noţiunea de "dobânzi"
	16. O.U.G. nr.147/2002 pentru reglementarea unor probleme financiare şi pentru modificarea unor acte normative modifică, începând cu luna ian 2003, art. 21 alin. (2) şi (4), art. 23, art. 24, art. 78 alin. (4), art. 109 alin. (1) lit. g
	17. O.U.G. nr.9/2003 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art.5, art.6 alin. (1), art.18 alin. (1),art. 21, art.22, art.23, art.24 alin. (1) si (3), art.26, art.28 alin. (1), art.29, art.37 alin.(2), art.78 alin. (4) si (7), art.781alin. (2), art.83, art.84 alin. (2), art.92 alin. (1) lit. b), art.98, art.99, art.102, art.108, art.112 alin. (2), art.113 alin. (2), art.120 alin. (1), art.122, art.125, art.129, art.133, art.135 lit.a, art.1672 alin. (2); introduce alin. (4) la art.85, alin. (21) la art. 194; înlocuieşte sintagma „ salariul mediu brut pe economie" de la art.80 alin.(1)cu „ salariul mediu brut"; abrogă art.6 alin. (4), art.138 alin. (4) dispune republicarea
	18. O.U.G. nr.23/2003 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale şi pentru modificarea art. II şi III din Ordonanţa de urgenţă a Guvernului nr. 9/2003 modifică art. 98 alin. (4), art. 125, art. 133; introduce alin. (41) la art. 98, alin.(21) la art. 99; abrogă art. 21 alin. (7)
	19. L. nr.232/2003 pentru aprobarea Ordonanţei Guvernului nr. 36/2003 privind corelarea unor dispoziţii din legislaţia financiar-fiscală abrogă la 1 ianuarie 2004 art. 30 alin. 2, art.31 alin. 5, art.36 alin. 1, art.144 lit e) si f), art. 148 lit. l).
	20. O.G. nr.86/2003 privind reglementarea unor măsuri în materie financiar-fiscală repune în vigoare prevederile art. 30 alin. (2), art.31 alin. (5), art. 36 alin. (1), art. 144 lit. e) si f) si art. 148 lit. l) ca urmare a abrogării art. IV lit a) din L. nr. 232/2003
	21. O.U.G. nr.107/2003 pentru modificarea şi completarea Legii nr. 346/2002 privind asigurarea pentru accidente de muncă şi boli profesionale abrogă prevederile referitoare la accidente de muncă şi boli profesionale din cap. V "Alte drepturi de asigurări sociale" la 1 ianuarie 2005
	22. L. nr.276/2004 pentru completarea art. 169 din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale introduce alin.(11) la art.169
	23. L. nr.352/2004 pentru completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale introduce art. 1921
	24. O.U.G. nr.59/2004 pentru modificarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art. 80 si art. 81
	25. O.U.G. nr.67/2004 pentru modificarea art. 80 alin. (2) din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art. 80 alin. (2)
	26. L. nr.534/2004 privind aprobarea Ordonanţei de urgenţă a Guvernului nr. 59/2004 pentru modificarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi

	de asigurări sociale aprobă O.U.G. nr. 59/2004 si modifică art. 81 27. O.U.G. nr.129/2004 pentru modificarea Legii nr. 346/2002 privind asigurarea pentru accidente de muncă şi boli profesionale abrogă art. 100 alin. (2) precum si orice alte dispozitii contrare prezentei legi. Dispozitiile art. 98 alin. (1) lit. a) si b) si alin. (3),art. 102, 104, art. 108 alin. (2), art. 109 alin. (1) lit. a), b),d), e) si f) si alin. (2), art. 111, 112, 114 si 115, îsi vor mentine aplicabilitatea pentru toate situatiile prevăzute, cu exceptia celor generate de accidente de muncă si boli profesionale, asigurate în conformitate cu prevederile prezentei legi 28. L. nr.57/2005 privind aprobarea Ordonanţei de urgenţă a Guvernului nr. 129/2004 pentru modificarea Legii nr. 346/2002 privind asigurarea pentru accidente de muncă şi boli profesionale aprobă O.U.G.nr. 129/2004 29. L. nr.91/2005 privind aprobarea Ordonanţei de urgenţă a Guvernului nr. 67/2004 pentru modificarea art. 80 alin. (2) din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale aprobă O.U.G.nr. 67/2004 30. H.G. nr.687/2005 privind abrogarea Hotărârii Guvernului nr. 403/2001 pentru aprobarea Normelor metodologice de aplicare a prevederilor art. 183 din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale abrogă HG nr.403/2001 31. O.U.G. nr.98/2005 pentru modificarea art. 81 din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifica art. 81 32. O.U.G. nr.148/2005 privind susţinerea familiei în vederea creşterii copilului abrogă prevederile referitoare la concediul şi indemnizaţia pentru creşterea copilului, cuprinse la art. 98, 99, 121, 122, 123, 125, 1251, 129 şi 138 33. L. nr.321/2005 privind aprobarea Ordonanţei de urgenţă a Guvernului nr. 98/2005 pentru modificarea art. 81 din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - aprobă cu modificări O.U.G. nr. 98/2005 şi modifică art. 81 34. O.U.G. nr.158/2005 privind concediile şi indemnizaţiile de asigurări sociale de sănătate abrogă art.7, 26, 27, 35, art.98-101, art.103-125, art.129-134 şi la art.136-138 35. L. nr.44/2006 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 149 lit. a); introduce lit. m) la art. 148 şi alin. (7) la art. 160 36. O.U.G. nr.24/2006 pentru prelungirea aplicării prevederilor art. 1671 din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - prelungeşte, până la data de 31 dec. 2008, aplicarea prevederilor art. 1671 37. O.U.G. nr.46/2006 pentru modificarea art. 80 alin. (1) şi (2) din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale modifică art.80 alin.(1) şi (2). 38. O.U.G. nr.69/2006 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte

	drepturi de asigurări sociale - modifică art.90, art.140 alin.(2), alin.(8) şi alin.(9), art.193 alin.(3); introduce art.921, art.931 şi 932, alin.(21) şi (22) la art.140 39. D.C.C. nr.264/2007 referitoare la excepţia de neconstituţionalitate a dispoziţiilor art. 95 alin. (1) din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - suspendă pentru o periadă de 45 zile prevederile art. 95 alin. (1) (termenul se împlineşte la 11 iun. 2007, după care operează prevederile art. 147 alin. (1) din Constituţie) 40. D.C.C. nr.264/2007 referitoare la excepţia de neconstituţionalitate a dispoziţiilor art. 95 alin. (1) din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale art. 95 alin. (1) 41. O.U.G. nr.19/2007 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 161 alin. (2); introduce alin. (3) la art. 91, alin. (3), (4) şi (5) la art. 161; abrogă art. 921, art. 931 şi art. 932 42. L. nr.250/2007 pentru modificarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 5 alin. (1) pct. IV partea introductivă şi alin. (2), art. 23 alin. (3), art. 49 alin. (4), art. 52, art. 78 alin. (4), art. 80 alin. (3), art. 86 alin. (1), art. 162 alin. (2), art. 1671 alin. (1) 43. O.G. nr.40/2007 cu privire la rectificarea bugetului asigurărilor sociale de stat pe anul 2007 - majorează valoarea punctului de pensie începând cu 1 sept. 2007 44. O.U.G. nr.91/2007 pentru modificarea şi completarea unor acte normative din domeniul protecţiei sociale - modifică art.5 alin.(1) punctul V, art.5 alin.(2), art.6 alin.(2) şi (3), art.7 alin.(1) şi (2), art.23 alin.(1), art.24 alin.(1), art.24 alin.(5), art.26, art.28 alin.(1) şi (2), art.33, art.142; introduce art.61, art.131, alin.(4), (5), (6) şi (7) la art.28; abrogă alin.(11) al art.6, alin.(3) al art.7, art.10, alin.(3) al art.23, alin.(3) şi (4) ale art.24, alin.(4) al art.35 45. O.U.G. nr.111/2007 pentru rectificarea bugetului asigurărilor sociale de stat pe anul 2007, aprobat prin Legea nr. 487/2006 - majorează valoarea punctului de pensie începând cu 1 nov. 2007 46. L. nr.387/2007 Legea bugetului asigurărilor sociale de stat pe anul 2008 - majorează valoarea punctului de pensie începând cu 1 ian. 2008 **After 2008** 47. L. nr.11/2008 pentru modificarea art. 58 din Legea nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 58 48. O.U.G. nr.83/2008 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 9 alin. (2); introduce alin. (3) şi (4) la art. 9 49. O.G. nr.26/2008 cu privire la rectificarea bugetului asigurărilor sociale de stat pe anul 2008, aprobat prin Legea nr. 387/2007 - majorează valoarea punctului de pensie 50. O.U.G. nr.100/2008 pentru completarea Legii nr. 19/2000

	privind sistemul public de pensii şi alte drepturi de asigurări sociale - introduce art. 782 la 1 oct. 2008 51. O.U.G. nr.108/2008 pentru modificarea unor acte normative din domeniul social - modifică art. 61 alin. (2); abrogă art. 61 alin. (3) 52. Decizie nr.40/2008 DECIZIA nr. 40 din 22 septembrie 2008 - art. 43 alin. (1) şi (2), art. 77 alin. (2) 53. L. nr.200/2008 privind aprobarea Ordonanţei de urgenţă a Guvernului nr. 91/2007 pentru modificarea şi completarea unor acte normative din domeniul protecţiei sociale - aprobă cu modificări O.U.G. nr.91/2007 şi modifică art.26 şi art.142 alin.(1) 54. L. nr.218/2008 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 12; introduce art. 782, art. 1651 55. O.U.G. nr.209/2008 pentru modificarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 12 lit. b), art. 782 şi art. 1651 la data de 1 ian. 2010 56. O.U.G. nr.230/2008 pentru modificarea unor acte normative în domeniul pensiilor din sistemul public, pensiilor de stat şi al celor de serviciu - modifică art. 94; introduce lit. g) la art. 92 alin. (1) 57. O.U.G. nr.4/2009 privind reglementarea unor măsuri în domeniul bugetar - prevederile art. 80 alin. (3) nu se aplică în anul 2009 58. L. nr.19/2009 Legea bugetului asigurărilor sociale de stat pe anul 2009 - majorează valoarea punctului de pensie începând cu 1 apr. 2009 şi 1 oct. 2009 59. L. nr.39/2009 privind aprobarea Ordonanţei de urgenţă a Guvernului nr. 83/2008 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 9 alin. (2) 60. L. nr.209/2009 pentru modificarea şi completarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 26 alin. (2), art. 92 alin. (1) lit. b); introduce lit. d) la art. 26 alin. (1), alin. (2) la art. 87, lit. g) la art. 92 alin. (1), alin. (3) la art. 92, alin. (4) la art. 93, lit. e) şi f) la art. 94 alin. (1) 61. L. nr.273/2009 pentru modificarea Legii nr. 19/2000 privind sistemul public de pensii şi alte drepturi de asigurări sociale - modifică art. 49 alin. (4), art. 52 62. O.U.G. nr.114/2009 privind unele măsuri financiar-bugetare - prevederile art. 80 alin. (1) şi (3) nu se aplică în anul 2010 63. L. nr.49/2010 privind unele măsuri în domeniul muncii şi asigurărilor sociale - modifică art. 41 alin. (5), art. 82 alin. (2), art. 83, art. 86, art. 1672 64. L. nr.118/2010 privind unele măsuri necesare în vederea restabilirii echilibrului bugetar - dispoziţiile legale privind înscrierea la pensie anticipată şi pensie anticipată parţială nu se mai aplică _Cancelled by_: L. nr.263/2010 privind sistemul unitar de pensii publice

Parliament of Romania, *Legea nr. 213 din 27 mai 2004 privind exercitarea profesiei de psiholog cu drept de liberă practică, înfiinţarea, organizarea şi funcţionarea Colegiului Psihologilor din România* 2004, Bucharest: Parliament of Romania.	*Promulgated by:* D. nr.378/2004 pentru promulgarea Legii privind exercitarea profesiei de psiholog cu drept de liberă practică, înfiinţarea, organizarea şi funcţionarea Colegiului Psihologilor din România No amendments
Government of Romania, *Hotărâre nr.788 din 14 july 2005 pentru aprobarea Normelor metodologice de aplicare a Legii nr. 213/2004 privind exercitarea profesiei de psiholog cu drept de liberă practică, înfiinţarea, organizarea şi funcţionarea Colegiului Psihologilor din România.* 2005, Bucharest: Government of Romania.	No amendments
Romanian College of Psychologists, *Hotărâre nr.1/2006 din 10 martie 2006 privind constituirea, declararea, înregistrarea şi funcţionarea cabinetelor individuale, cabinetelor asociate, societăţilor civile profesionale de psihologie, precum şi exercitarea profesiei de psiholog cu drept de liberă practică în sectorul public sau privat, în regim salarial.* 2006, Bucharest: Romanian College of Psychologists.	No amendments
Government of Romania, *Hotararea nr. 1.842 din 21 decembrie 2006-partea ii Pentru aprobarea contractului-cadru privind conditiile acordarii asistentei medicale in cadrul sistemului de asigurari sociale de sanatate pentru anul 2007* 2006, Bucuresti: Government of Romania.	*Amended by:* **Before 2008** 1. H.G. nr.364/2007 pentru modificarea şi completarea prevederilor Contractului-cadru privind condiţiile acordării asistenţei medicale în cadrul sistemului de asigurări sociale de sănătate pentru anul 2007, aprobat prin Hotărârea Guvernului nr. 1.842/2006 (abrogat prin H.G. nr.324/2008) - modifică şi completează anexa dispune republicarea 2. H.G. nr.1.534/2007 privind modificarea şi completarea Hotărârii Guvernului nr. 1.842/2006 pentru aprobarea Contractului-cadru privind condiţiile acordării asistenţei medicale în cadrul sistemului de asigurări sociale de sănătate pentru anul 2007 (abrogat prin H.G. nr.324/2008) - modifică art. 5 lit. c); modifică şi completează anexa; prelungeşte aplicarea hotărârii până la 31 martie 2008 **After 2008** – No amendments *Cancelled by*: H.G. nr.324/2008 pentru aprobarea Contractului-cadru privind condiţiile acordării asistenţei medicale în cadrul sistemului de asigurări sociale de sănătate pentru anul 2008

Ministry of Public Health; National House of Social Insurance for Health, *Ordin nr.1.781/CV 558 din 2006 pentru aprobarea Normelor metodologice de aplicare a Contractului-cadru privind condiţiile acordării asistenţei medicale în cadrul sistemului de asigurări sociale de sănătate pentru anul 2007*. 2006, Bucharest: Ministry of Public Health; National House of Social Insurance for Health.	<u>*Amended by:*</u> **Before 2008** 1. O. nr.727/2007 al ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate privind modificarea şi completarea Ordinului ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate nr. 1.781/CV 558/2006 pentru aprobarea Normelor metodologice de aplicare a Contractuluicadru privind condiţiile acordării asistenţei medicale în cadrul sistemului de asigurări sociale de sănătate pentru anul 2007 2. O. nr.1.166/2007 al ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate privind modificarea şi completarea Ordinului ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate nr. 1.781/CV 558/2006 pentru aprobarea Normelor metodologice de aplicare a Contractului-cadru privind condiţiile acordării asistenţei medicale în cadrul sistemului de asigurări sociale de sănătate pentru anul 2007 3. O. nr.1.576/2007 al ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate privind modificarea şi completarea Ordinului ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate nr. 1.781/CV 558/2006 pentru aprobarea Normelor metodologice de aplicare a Contractului-cadru privind condiţiile acordării asistenţei medicale în cadrul sistemului de asigurări sociale de sănătate pentru anul 2007 4. O. nr.2.071/2007 al ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate privind modificarea Ordinului ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate nr. 1.781/CV 558/2006 pentru aprobarea Normelor metodologice de aplicare a Contractuluicadru privind condiţiile acordării asistenţei medicale în cadrul sistemului de asigurări sociale de sănătate pentru anul 2007 5. O. nr.2.144/2007 al ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate privind modificarea şi completarea Ordinului ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate nr. 1.781/CV 558/2006 pentru aprobarea Normelor metodologice de aplicare a Contractului-cadru privind condiţiile acordării asistenţei medicale "n cadrul sistemului de asigurări sociale de sănătate pentru anul 2007 **After 2008** – No amendments <u>*Cancelled by*</u>: O. nr.522/2008 al ministrului sănătăţii publice şi al preşedintelui Casei Naţionale de Asigurări de Sănătate pentru aprobarea Normelor metodologice de aplicare a Contractului-cadru privind condiţiile acordării asistenţei medicale în cadrul sistemului de asigurări sociale de sănătate pe anul 2008

Ministry of Health and of the Family; National House of Social Insurance for Health, *Ordin nr.706/262 din 2002 privind acordarea asistenței medicale pentru persoanele încadrate într-un grad de handicap și aprobarea modalităților de decontare a cheltuielilor aferente.* 2002, Bucharest: Ministry of Health and of the Family; National House of Social Insurance for Health.	No amendments
Parliament of Romania, *Legea nr. 448 din 06 decembrie 2006 Privind protecția și promovarea drepturilor persoanelor cu handicap.* 2006, Bucharest: Parliament of Romania.	*Promulgated by:* D. nr.1.342/2006 pentru promulgarea Legii privind protecția și promovarea drepturilor persoanelor cu handicap *Amended by:* **Before 2008** 1. O.U.G. nr.14/2007 pentru modificarea și completarea Legii nr. 448/2006 privind protecția și promovarea drepturilor persoanelor cu handicap - modifică art. 10, art. 11 alin. (1) lit. a), art. 12, art. 21 alin. (3), art. 22 alin. (1), (3), (5) și (8), art. 42 alin. (4) lit. c), art. 50 alin. (5), art. 53, alin. (2), art. 55 alin. (2), art. 57 alin. (6) lit. b); introduce art. 121, alin. (4) la art. 38, alin. (6) la art. 50, alin. (101), (102) și (12) la art. 57 dispune republicarea 2. L. nr.241/2007 pentru abrogarea unor reglementări prin care sunt acordate scutiri sau exonerări de la plata taxelor vamale ale unor bunuri - abrogă art.26 3. L. nr.275/2007 privind aprobarea Ordonanței de urgență a Guvernului nr. 14/2007 pentru modificarea și completarea Legii nr. 448/2006 privind protecția și promovarea drepturilor persoanelor cu handicap - aprobă cu modificări și completări O.U.G. nr. 14/2007 și modifică art. 12 alin. (3), (4) și (6), art. 121 alin. (3), art. 24 lit. a), art. 50 alin. (5), art. 57 alin. (11), art. 84 alin. (5); introduce alin. (41) la art. 12, art. 122, alin. (21) la art. 41 **After 2008** 4. H.G. nr.10/2008 privind indexarea cuantumului prestațiilor sociale prevăzute la art. 58 alin. (4) din Legea nr. 448/2006 privind protecția și promovarea drepturilor persoanelor cu handicap - indexează cuantumul prestațiilor sociale prevăzute la art. 58 alin. (4) 5. O.U.G. nr.86/2008 pentru modificarea Legii nr. 448/2006 privind protecția și promovarea drepturilor persoanelor cu handicap - modifică art. 27 alin. (1), art. 51 alin. (6), art. 78 alin. (3) lit. b) 6. O.U.G. nr.118/2008 privind modificarea și completarea unor acte normative în vederea eliminării legăturilor dintre nivelul unor drepturi de asistență socială și nivelul salariului de bază minim brut pe țară garantat în plată - modifică art. 13 7. L. nr.207/2009 privind aprobarea Ordonanței de urgență a Guvernului nr. 86/2008 pentru modificarea Legii nr. 448/2006 privind protecția și promovarea drepturilor

	persoanelor cu handicap - aprobă cu modificări şi completări O.U.G. nr. 86/2008 şi modifică art. 27 alin. (1); introduce alin. (11) şi alin. (3) la art. 27, alin. (41) la art. 78 8. O.U.G. nr.109/2009 pentru modificarea şi completarea Legii nr. 571/2003 privind Codul fiscal abrogă art. 26 lit. a), art. 83 lit. g), la data de 1 ian. 2010 9. L. nr.359/2009 pentru modificarea art. 20 alin. (2) lit. b) din Legea nr. 448/2006 privind protecţia şi promovarea drepturilor persoanelor cu handicap - art. 20 alin. (2) lit. b) 10. L. nr.360/2009 pentru modificarea lit. a) a art. 26 din Legea nr. 448/2006 privind protecţia şi promovarea drepturilor persoanelor cu handicap - modifică art. 26 lit. a) 11. O.U.G. nr.84/2010 pentru modificarea şi completarea Legii nr. 448/2006 privind protecţia şi promovarea drepturilor persoanelor cu handicap - modifică art. 2 alin. (1), art. 37 alin. (2) şi (3), art. 44 partea introductivă şi lit. a), art. 59, art. 85, art. 87 alin. (1), art. 100; introduce alin. (7) la art. 42, alin. (4) - (6) la art. 87, art. 901 - 905; abrogă art. 90
Government of Romania, *Hotărâre nr. 268 din 14 martie 2007 Pentru aprobarea normelor metodologice de aplicare a prevederilor legii nr. 448/2006 privind protecţia şi promovarea drepturilor persoanelor cu handicap*. 2007, Bucharest: Government of Romania.	*Amended by:* **Before 2008** - No amendments **After 2008** 1. H.G. nr.89/2010 pentru modificarea şi completarea Normelor metodologice de aplicare a prevederilor Legii nr. 448/2006 privind protecţia şi promovarea drepturilor persoanelor cu handicap, aprobate prin Hotărârea Guvernului nr. 268/2007 - modifică şi completează anexa dispune republicarea
Government of Romania, *Hotarâre nr. 1175 din 29 septembrie 2005 privind aprobarea Strategiei naţionale pentru protecţia, integrarea şi incluziunea socială a persoanelor cu handicap în perioada 2006-2013*. 2005, Bucharest: Government of Romania.	*Amended by:* **Before 2008** 1. H.G. nr.676/2007 privind domeniile de studii universitare de licenţă, structurile instituţiilor de învăţământ superior şi specializările organizate de acestea (abrogat prin H.G. nr.635/2008) - abrogă anexa **After 2008** – No amendments
Autoritatea Naţionala pentru Persoanele cu Handicap, *ORDIN nr.363 din 23 noiembrie 2005 pentru aprobarea Planului naţional privind formarea personalului din sistemul de protecţie a persoanelor cu handicap pentru perioada 2006-2008 şi a Programei-cadru de instruire specifică a personalului implicat în protecţia şi îngrijirea persoanei adulte cu handicap*. 2005, Bucharest: Autoritatea Naţionala pentru Persoanele cu Handicap.	No amendments
National Authority for People with Disabilities, *Ordin nr.162 din 16*	No amendments

decembrie 2002 pentru aprobarea Normelor privind desfăşurarea activităţii de informare şi consiliere pentru persoanele cu handicap. 2002, Bucharest: National Authority for People with Disabilities.	
National Authority for People with Disabilities, *Ordin nr. 205 din 17 iunie 2005 Privind aprobarea standardelor minime de calitate pentru centre rezidenţiale pentru persoane adulte cu handicap, centre de zi pentru persoane adulte cu handicap şi locuinţe protejate pentru persoane adulte cu handicap*. 2005, Bucharest: National Authority for People with Disabilities.	No amendments *Cancelled by*: O. nr.559/2008 al preşedintelui Autorităţii Naţionale pentru Persoanele cu Handicap privind aprobarea Standardelor specifice de calitate pentru centrele rezidenţiale, centrele de zi şi locuinţele protejate pentru persoane adulte cu handicap
National Authority for People with Disabilities, *Ordin nr. 175 din 12 iulie 2006 privind aprobarea standardelor minime de calitate pentru serviciile sociale la domiciliu pentru persoane adulte cu handicap*. 2006, Bucharest: National Authority for People with Disabilities.	No amendments
Ministry of Labour Family and Equal Opportunities; Ministry of Public Health, *Ordin nr.762/1.992 din 31 august 2007 pentru aprobarea criteriilor medico-psihosociale pe baza cărora se stabileşte încadrarea în grad de handicap* 2007, Bucharest: Ministry of Labour Family and Equal Opportunities; Ministry of Public Health.	*Amended by:* **Before 2008** No amendments **After 2008** 1. O. nr.124/2008 al ministrului muncii, familiei şi egalităţii de şanse şi al ministrului sănătăţii publice pentru modificarea art. 2 din Ordinul ministrului muncii, familiei şi egalităţii de şanse şi al ministrului sănătăţii publice nr. 762/1.992/2007 pentru aprobarea criteriilor medico-psihosociale pe baza cărora se stabileşte încadrarea în grad de handicap
Commission for Clinical Psychology and Psychotherapy of the Romanian College of Psychologists, *Proceduri de atestare, acreditare şi certificare în domeniul clinic*, Commision for Clinical Psychology and Psychotherapy of the Romanian College of Psychologists,: Bucharest.	No amendments
Ministry of Health and of the Family, *Ordin nr.726 din 1 octombrie 2002 privind criteriile pe baza cărora se stabileşte gradul de handicap pentru adulţi şi se aplică măsurile de protecţie specială a acestora*. 2002, Bucharest: Ministry of Health and of the Family.	*Amended by:* **Before 2008** 1. O. nr.277/2003 al ministrului sănătăţii şi familiei pentru modificarea anexei la Ordinul ministrului sănătăţii şi familiei nr. 726/2002 privind criteriile pe baza cărora se stabileşte gradul de handicap pentru adulţi şi se aplică măsurile de protecţie specială a acestora (abrogat prin O. nr.124/2008) modifică anexa **After 2008** – No amendments

	Cancelled by: O. nr.124/2008 al ministrului muncii, familiei şi egalităţii de şanse şi al ministrului sănătăţii publice pentru modificarea art. 2 din Ordinul ministrului muncii, familiei şi egalităţii de şanse şi al ministrului sănătăţii publice nr. 762/1.992/2007 pentru aprobarea criteriilor medico-psihosociale pe baza cărora se stabileşte încadrarea în grad de handicap
Ministry of Health and of the Family; Ministry of Labour and Social Solidarity, *Ordinul nr.491 din 23 mai 2003 Pentru aprobarea scalei de evaluare medico-socială a persoanelor care vor trăi în instituţiile medico-sociale*. 2003, Bucharest: Ministry of Health and of the Family; Ministry of Labour and Social Solidarity.	No amendments
Government of Romania, *Hotărâre nr. 400 din 19 aprilie 2001 pentru aprobarea criteriilor şi normelor de diagnostic clinic, diagnostic funcţional şi de evaluare a capacităţii de muncă pe baza cărora se face încadrarea în gradele I, II şi III de invaliditate*. 2001, Bucharest: Government of Romania.	No amendments Cancelled by: H.G. nr.155/2011 pentru aprobarea criteriilor şi normelor de diagnostic clinic, diagnostic funcţional şi de evaluare a capacităţii de muncă pe baza cărora se face încadrarea în gradele I, II şi III de invaliditate

Annex 5. Facilities included in the Rapid Assessment

Specialist facilities included in the research	**Location**	**Type of services**	**Name of the facilities**	**Staffing levels**	**Number of beds**
Mental health	**Bucharest**	**Outpatient services**	Mental Health Centre of the Clinical Mental Hospital "Prof. Dr. Al. Obregia"	8 Psychiatrists 3 Psychologists 1 Social workers 18 Nurses	Not applicable*
		Acute inpatient services	Clinical Mental Hospital "Prof. Dr. Al. Obregia"	86 Psychiatrists 27 Psychologists 1 Social workers 461 Nurses Auxiliaries	1,229
		Long-term inpatient services	Mental Hospital "Domnita Balasa"	7 Psychiatrists 2 Psychologists 1 Social workers 38 Nurses 1 Auxiliary during day shifts and 2 during night shifts per ward	341
	Slatina	**Outpatient services**	Mental Health Laboratory in the Slatina District Emergency Hospital	1 Psychiatrist 2 Psychologists 5 Nurses	Not applicable*
		Acute inpatient services	Psychiatric ward in the Slatina District Emergency Hospital	3 Psychiatrists 1 Psychologist 17 Nurses 1 Auxiliary during day shifts and 2 during night shifts per ward	75
		Long-term inpatient services	Mental hospital for chronic patients "Schitu Greci"	2 ½ Psychiatrists 1 Psychologist 21 Nurses 2-3 Auxiliaries during day shifts and 1 during night shifts per ward of 40 beds	160
Diabetes	**Bucharest**	**Outpatient services**	Diabetes outpatient unit of the National Institute for Diabetes "Prof. Dr. N. Paulescu"	18 Diabetologist physicians 1 Dermatologist specialised in foot care Nurses	Not applicable*
		Acute inpatient services	National Institute for Diabetes "Prof. Dr. N. Paulescu"	12 Diabetologist physicians 1 Cardiologist 1 Ophthalmologist 1 Nephrologists Nurses 2-3 Auxiliaries during day shifts and 1 during night shifts per ward of 58 beds	142

Specialist facilities included in the research	**Location**	**Type of services**	**Name of the facilities**	**Staffing levels**	**Number of beds**
	Slatina	**Outpatient services**	Diabetes outpatient unit in the Slatina District Emergency Hospital	1 Diabetologist physician 2 Nurses	Not applicable*
		Acute inpatient services	Diabetes ward in the Slatina District Emergency Hospital	1 Diabetologist physician 8 Nurses 2 Auxiliaries during day shifts and 1 during night shifts per ward of 25 beds In other wards of the DGH: 4 Cardiologist 2 Ophthalmologist 1 Nephrologists	20

* Number of visitors was not recorded

Annex 6. Coding system for participants to the Rapid Assessment

Target group			**Bucharest**	**Slatina**
Service users	**Mental health service users** (based in long-term care Mental Hospitals, but with experience in acute care mental hospital/ward and mental health outpatient dispensary)		1_UMIO	2_UMIO
	Type I diabetes service users (attending outpatient diabetes services, but with experience in both inpatient and outpatient services)		1_UDIO	2_UDIO
Mental health professionals	**Outpatient services**	Psychiatrists	1_PMO	2_PMO
		Psychologists	1_GMO	2_GMO
		Social workers	-	-
		Nurses	1_NMO	2_NMO
	Acute inpatient services	Psychiatrists	1_PMI_a	2_PMI_a
		Psychologists	1_GMI_a	2_GMI_a
		Social workers	1_SMI_a	-
		Nurses	1_NMI_a	2_NMI_a
		Auxiliaries	1_AMI_a	2_AMI_a
	Long-term inpatient services	Psychiatrists	1_PMI_b	2_PMI_b
		Psychologists	1_GMI_b	2_GMI_b
		Social workers	1_SMI_b	-
		Nurses	1_NMI_b	2_NMI_b
		Auxiliaries	1_AMI_b	2_AMI_b
Type I diabetes professionals	**Outpatient services**	Diabetologist physician	1_EDO	2_EDIO
		Dermatologist specialised in foot care	1_FDO	-
		Nurses	1_NDO	2_NDO
		Auxiliaries	1_ADI	2_ADI
	Acute inpatient services	Diabetologist physician	1_EDI	2_EDIO
		Other health professionals	1_RDI 1_CDI	2_HDI
		Nurses	1_NDI	2_NDI
		Auxiliaries	1_ADI	2_ADI

Annex 7. Consent forms for participants to the Rapid Assessment

Participant Consent Form

Study title: *Mental illness and diabetes in Romania in an international context - is there evidence of discrimination?*
Investigator's name and contact details: Ionela Petrea, HSRU, PHP, LSHTM, Keppel St, London, Ionela.Petrea@lshtm.ac.uk

1. I confirm that I have read and understood the information sheet (or have understood the verbal explanation) for the above study.
2. I have had the opportunity to ask questions concerning this study and have received answers from the researcher in charge.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my normal care and management being affected.
4. I do / do not agree to quotes or other results arising from my participation in the study being included, even anonymously in any reports about the study.
5. I agree to take part in this study.

Name of the Participant: ………….. Date: ………… Signature: ………………

Researcher: ………………….. Date: ………… Signature: ………………

Annex 8. Information sheets for the Rapid Assessment

INFORMATION SHEET

Research title: *Mental illness and diabetes in Romania in an international context - is there evidence of discrimination?*

What is this study about?

The project is examining the possible phenomenon of discrimination in provision of care delivered to people with severe and persistent mental disorders. The research aims to investigate whether the organization, provision and delivery of care for patients with a severe mental disease (exemplified by schizophrenia), is systematically worse than that for a severe physical disease (exemplified by type I diabetes) and if that is the case, determine whether this is due to discrimination against those suffering from mental health problems.

Who is organizing this study?

The study is being organized by a research team, representing two institutions: the National Centre for Mental Health and the London School of Hygiene and Tropical Medicine (LSHTM), based in the U.K. Ionela Petrea from the LSHTM is the overall co-ordinator of the study.

Where is this study going to take place?

The study is going to take place in a selected number of inpatient and outpatient services specialised in mental health and in diabetes type 1 from 2 districts in Romania: Bucharest and Slatina.

Who else is involved in the study?

This study has been approved by the Bio-ethical Commission of the Ministry of Health. Additionally, the directors of the institutions where the research is organized have also agreed to allow the research team to implement the research in their institutions.

During this research we will be talking to service users, health care workers, decision makers and other key stakeholders.

What happens if I agree to participate?

In the first part of the research, the existing policies and legislation relevant to mental health and diabetes have been analysed.

- Service users: Now, in the last part of the research we would like to see what is your direct experience, as service users of inpatient and outpatient services. We would like to discuss with you a number of issues related to your access to services, availability of treatment and care, and quality of the services you receive. We would like to talk to you for about 1 hour.

  If you agree to participate in the research, we will invite you to join us in the location in town selected for the focus group. Based on the preferences of most participants, we will then prepare a time schedule and we will afterwards contact you and inform you about the time and location of the focus group you will participate in.

- Health professions who are nurses, psychologists, social workers or OTs: Now, in the last part of the research we would like to see what is your opinion as health professionals working in inpatient/outpatient services and discuss with you a number of issues related to your access to services, availability of treatment and care, and quality of the services provided. We would like to talk to you for about 1 hour.

  If you agree to participate in the research, we will ask you to indicate a date and a time within the period selected for the research in your institution when it would be convenient for you to participate in the focus group discussions. Based on the preferences of most participants, we will then prepare a time schedule and we will afterwards contact you and inform you about the time and location of the focus group you will participate in.

- Health professionals who are MDs: Now, in the last part of the research we would like to see what is your opinion as health professionals working in inpatient/outpatient services and discuss with you a number of issues related to your access to services, availability of treatment and care, and quality of the services provided. We would like to talk to you for about 1 hour.

  If you agree to participate in the research, we will ask you to indicate a date and a time within the period selected for the research in your institution when we can come over to your office and interview you. Based on your preferences and the distribution of other interviews and focus groups, we will then prepare a time schedule and we will afterwards contact you and inform you about the final time of the interview.

- Decision maker: Now, in the last part of the research we would like to see what is your opinion as decision makers in this area and discuss with you a number of issues related to your access to services, availability of treatment and care, and quality of the services provided. We would like to talk to you for about 1 hour.

  If you agree to participate in the research, we will ask you to indicate a date and a time within the period selected for the research in your institution when we can come over to your office and interview you. Based on your preferences and the distribution of other interviews and focus groups, we will then prepare a time schedule and we will afterwards contact you and inform you about the final time of the interview.

- Other key stakeholder: Now, in the last part of the research we would like to see what is your opinion as key stakeholders in this area and discuss with you a number of issues related to your access to services, availability of treatment and care, and quality of the services provided. We would like to talk to you for about 1 hour.

  If you agree to participate in the research, we will ask you to indicate a date and a time within the period selected for the research in your institution when we can come over to your office and interview you. Based on your preferences and the distribution of other interviews and focus groups, we will then prepare a time schedule and we will afterwards contact you and inform you about the final time of the interview.

No quotes or other results arising from my participation in this study will be included in any reports, even anonymously, without your agreement.
You do not have to participate in this study and you can stop at any time without having to give a reason.

Any expenses involved in your participation will be reimbursed to you: there should be no expenses involved. (for nurses) A small cash payment will be made of Romanian New Lei 24.

If you do agree to participate, we would ask you to sign a form to confirm that you do. Please could you sign the form - it does not have to be with your own name if you would rather not leave a named record of this interview.

What will happen to the information I give to the interviewer?

At the beginning of the focus group/interview you will be asked if you agree to record the discussions on an audio tape. This procedure will only help us to better remember the conversation. You will be free to reject this procedure, as well as to refuse to answer to some questions or to stop the interview at any time. You can ask that anything you say that you feel uncomfortable about is not recorded. However, if all participants agree, then the discussions will be recorded.

Any sensitive data will be kept confidential by the research team. The data collected will be held at the National Centre for Mental Health but it will not be possible for anyone other than Ms Petrea to link anything said back to you. No permanent data record will exist in Romania, except as anonymous summaries.

The information received during the interviews (including the tapes) will be collected by Ionela Petrea and stored securely. Each focus group/interview will be given a number and each individual in the group interviews will be given a code to identify them in the final report produced. These numbers and codes will be used for the analysis. No one from outside the research team will have access to any personal information.

Will I be able to see the results of this study?

The report will be written in English and then translated into Romanian. This procedure will take some time. A summary of the most important results will be provided to you in Romanian, upon request, by mid 2007. You will be asked during the interviews if you would like a summary of the written report.

For further information

We have a major concern in avoiding to make people feel uncomfortable during the whole research process, therefore all questions, comments or suggestions that might arise are very welcome. You are kindly requested to address them to the following contact person:

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London School of Hygiene and Tropical Medicine
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Thank you very much for your time and help!

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