UCLouvain
Institut de recherche santé et société

Social integration of people with severe mental illness

A challenge for health care systems and policies

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Octobre 2021

Thèse présentée en vue de l’obtention du grade de
docteur en sciences de la santé publique

Secteur des sciences de la santé

Remerciements

“Une thèse c’est comme un voyage, et un bon voyageur doit parfois accepter de ne pas avoir de plan établi ou de destination. »

Citation largement détournée de Lao Tseu

Pour accomplir ce voyage j’ai été bien entouré,

Je voudrais tout d’abord remercier mon promoteur, le Prof. Vincent Lorant, pour l’impulsion qu’il m’a donné, sa disponibilité et ses conseils. Une thèse est un voyage à la fois personnel et professionnel et Vincent a été un compagnon de voyage de choix à pied comme en voiture de location.

Je remercie également les membres de mon jury pour l’accompagnement de mon travail scientifique et particulièrement le Dr. Pablo Nicaise, qui a accompagné et initié nombreux de mes voyages.

Merci à tous mes collègues et amis, pour leur support moral, intellectuel, et parfois même matériel. Les voyageurs sont par définition de passage, mais je suis convaincu que nous aurons encore l’occasion de planter notre tente dans le même camping. Après tout, les amitiés survivent aux voyages.

Enfin, mes remerciements vont aussi à ma famille et mes amis et particulièrement à mon épouse pour son soutien quotidien et indéfectible. Nous entamons avec le plus grand bonheur un nouveau voyage à trois.

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Chapter 1: Introduction

1.1 Definition and burden of severe mental illness

Mental health disorders are a global public health issue. Over a lifetime, nearly one in four people (IDR 25th - 75th = 18.1% -36.1%) will develop a mental health disorder [1]. In 2016, mental health disorders contribute over the world to 19% of the YLDs (Years Lived with Disability) and were the most common causes of the most severe disabilities [2].

There is heterogeneity in the diagnosis of mental health disorders, as their classification remains a controversial area with many nosological questions still outstanding [3]. The main reason is that the causes and mechanisms of mental health disorders remain poorly understood, with different etiological trends ranging from environmental to genetics and poly-causation hypotheses [4, 5]. Indeed, the causes of mental health disorders can be genetic, neurological, infectious, toxicological, psychological and social [6]. Therefore, the classification of mental health disorders results from a controversial consensus between these different etiological hypotheses. Following these classification issues, a method often used in psychiatric epidemiology is to combine mental health disorders distinguishing common and severe disorders [5, 7]. Common mental health disorders are high-prevalence mental disorders and include diagnostics of mood, anxiety and substance use disorders while people with severe mental illness (SMI) are a group of primarily non-organic psychotic and personality disorder with long-term and complex needs and serious functional impairment [7-9]. This distinction is all the more important as people with SMI have become a priority audience for mental health services in many countries for several reasons: (a) between 35% to 50% of people with SMI do not receive treatment in developed countries and 75% to 85% in less-developed countries [10]; b) the excess mortality and morbidity in people with SMI compared to other chronic disorders [11, 12]; and c) their high direct and indirect costs [13]. However, to date, there are still many definitions and criteria for defining a SMI and one study has shown that the criteria used vary the estimated prevalence considerably [14]. The definition that seems to have the most consensus is that of the National Institute of Mental Health (NIMH) [15] which categorises individuals as having a SMI if they met three criteria: (1) having a diagnosis of non-organic psychotic or personality disorders, (2) duration (i.e.

prolonged illness and long-term treatment), and (3) having disabilities as a result of the disease. Using this definition, it is estimated that people with SMI represent 2 to 5% of the general population [1, 16]. In Belgium, although it is difficult to obtain detailed figures on the prevalence of the population suffering from mental health disorders, the Belgian Health Interview Survey (HIS) estimated that in 2013, 32% of the population was suffering from psychological distress and 18% from a mental health disorders [17]. However, there are limited figures on the prevalence of people with SMI in Belgium.

People with SMI have long-term and complex needs and serious functional impairment. In addition to the clinical burden of their SMI, people with SMI are at risk of having comorbid diseases. The global burden of disease (GBD) studies have shown that compared to the general population and other chronic diseases, people with SMI have higher rates of comorbidities and excess mortality due to these underlying physical comorbidities (i.e. coronary heart disease, stroke, type II diabetes, respiratory diseases, and some cancers) [18-20]. However, people with SMI want and need more than just psychological and physical symptom relief [21]. Most people with SMI face social integration difficulties such as unemployment, homelessness, poor social capital, and little social participation in community life [22-24]. For example in OECD countries, people with SMI are six to seven times more likely to be unemployed than the general population [25] with an employment rate below 20% [26]. In terms of housing, the prevalence of homelessness among SMI patient is 15% [27]. Furthermore, the stigmatisation of and discrimination against people with psychiatric disorders have a negative impact on their self-esteem, social relationships and thus on their overall social integration [28, 29]. These few figures briefly illustrate the extent of the social exclusion of people with SMI and to quote Sir Graham Thornicroft: “European mental health policy: the key issue is social inclusion” [30]. It is therefore important to better understand the association between social exclusion and mental illness.

1.2 Social integration and mental health

1.2.1 Once upon a time: social exclusion in mental health and social sciences

The first study of the association between social integration and mental health was probably the sociological study of Emile Durkheim, *Suicide*, published in 1897 [31].

In this study, Durkheim analysed the association between the suicide rate in different European countries and the socio-demographic characteristics of the population of these countries. His hypothesis was that some social characteristics of individuals, such as their marital status, shape the likelihood of committing suicide. This study highlighted that individual with some social characteristics (i.e. married, with children, members of a religious group) were less likely to commit suicide. Durkheim's theories were subsequently tested and reinterpreted, for example with network theory. Indeed, the protective effect of religious affiliation on suicide is more complex than suggested because it operates through network mechanisms such as their structure and function [32]. Religious affiliation have an important role in organising an individual's network by ensuring strong and continuous social ties providing support and integration [32].

Another pioneer in the study of social exclusion is the Canadian Bruce K. Alexander with his series of studies undertaken in the late 1970s entitled "Rat Park" [33-36]. In these studies, Alexander and colleagues tested the association between opiate addiction problems of rats and their social environment. At that time, previous studies had shown that laboratory animals placed alone in cages favoured opiate drug solutions over water, and that they compulsively consumed this opioid solution until overdose and death despite the presence of alternative water solution [37, 38]. Subsequently, Alexander and colleagues wondered if this was related to the drug and the neurobiological affinity of mammals (i.e. tolerance, dependence, and overdose) or if it might be related to the environment and setting in which they were placed. Their hypothesis was that social isolation was associated with opiate addiction. To address this question, they built a rat park in which about fifteen female and male rats were free to socialise, play, eat, and mate (group condition) and they compared their consumption of opiate drug solution and water solution with that of rats housed in individual cages (isolated condition). The results of their studies showed that the rats in the group condition consumed significantly less opiate drug solution and more water inside the cage and that they showed fewer signs of dependence when outside the cage in comparison to rats in the isolated condition. Several variations of this experiment were carried out and highlighted constant differences between the two groups, even if the rats were pre-exposed to morphine or naïve to morphine, and if they had spent their early life in isolation or in a group [39]. Alexander and colleagues therefore concluded that the social environment is an important factor in the development and maintenance of addiction disorders.

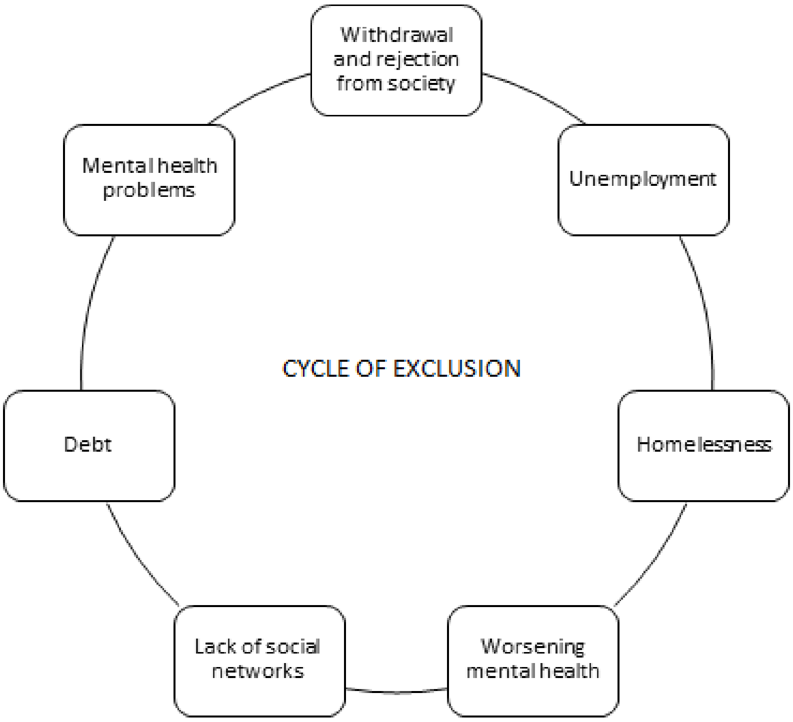
These two famous studies suggested that social exclusion and social integration of individuals are respectively a risk factor and a protective factor for mental health problems (i.e. suicide or addiction in these contexts). However, is the relationship between social exclusion and mental health so simple?

1.2.2 Social exclusion and mental health: The classic chicken-egg problem

In a way, the studies of Durkheim and Alexander supported the social causation hypothesis, stating that social exclusion increases the risk of poor mental health, addiction, or suicide through adverse social and economic conditions. Subsequently, the direction of this causality has often been questioned: does social exclusion cause poor mental health, or does poor mental health lead to social exclusion? These two hypotheses respectively illustrate the social causation hypothesis and the social selection/drift hypothesis [40]. The social selection hypothesis states that people with mental health problems drift into social exclusion during their illness due to increasing disability, discrimination and stigmatisation, and the decline in economic productivity caused by their illness. Several studies have supported either the social causation hypothesis [41-43] or the social selection hypothesis [44, 45]. However, as a result of recent and extensive research on the stigma of people with mental illness, health policies in many countries in the early 2000s have focused on the fight against social exclusion as a consequence rather than a as the cause of mental health problems [46, 47].

The causality and temporal relationship between social integration and mental health is complex for several reasons. The first reason is that social integration is a multidimensional concept and the association between some dimensions of social integration and mental health outcomes is clearly bidirectional. For example, having little social interaction, which is a dimension of social integration, can be a cause and a consequence of mental health problems [48, 49]. The second reason is the issue of temporality. Mental health disorders are often chronic and sometimes persistent and social exclusion evolves over the life course. Therefore, their association may vary over time depending on the evolution of the disease and the lives and social situation of individuals. Finally, there are many confounding factors of the association between social integration and mental health. For example, poverty can contribute to both social exclusion and mental health problems [46]. This complexity has led to the creation of models (see Figure 1) in which the causal association between social exclusion and mental health problems occurs in both directions in a dynamic cycle [46, 50]. In order to better grasp the complexity of this association, we must better understand the concept of social integration and investigate the association between the different dimensions of social integration and the mental health of individuals.

Figure 1: A cycle of exclusion – From Boardman & al., 2010 [46]



1.2.3 Social integration: key aspects

There are many definitions in the literature of the concept of social integration and its antonym, social exclusion [46, 51]. Social integration is a multidimensional concept and the Center for the Analysis of Social Exclusion (London School of Economics) has identified four main dimensions through the different existing definitions of social integration, lack of participation in one dimension being considered sufficient to constitute social exclusion [50]. The concept of participation in these different dimensions is transversal in the different definitions of social integration because *« an individual is socially excluded if he or she does not participate in key activities of the society in which he or she lives."* [50]. It is important to combine these different dimensions to have a comprehensive picture of social integration, e.g. not be limited to economic exclusion. In addition, it is possible to identify and measure indicators of each dimension and thus better grasp the social integration or exclusion of individuals. These four main dimensions are:

(a) *Consumption*: the capacity to purchase goods and services, the main indicator in this dimension through the literature is housing [46, 52].
(b) *Production*: participation in economically or socially valuable activities, the main indicator in this dimension through the literature is employment [46, 53]
(c) *Social interaction*: Social interaction with family, friends and community, the main indicators in this dimension through the literature are the social support and marital status [46, 51]
(d) *Social and political engagement*: This dimension has been less studied in the literature, the indicators used for this dimension are often proxies of how people engage and influence their environment, e.g. patient participation in decision-making, voting in general election, being a member of an association or commitment to daily life and cultural activities [46, 50].

The next chapter aims to study in more detail the four dimensions of social integration and the association between these dimensions and the mental health of individuals in order to produce a comprehensive update of the social integration of people with SMI at the international level and in Belgium. It is not always possible to obtain detailed and specific information for people with SMI. Therefore, in the following chapter, I have attempted to differentiate the evidence for people with SMI from those with mental health disorders that are more prevalent in the general population (common mental illness) and from all people with mental illness (regardless of the severity).

1.2.4 Dimensions of social integration: The Blind Men and the Elephant

Social integration is like an elephant. One day, six blind and curious men decided to precisely characterise an elephant to supplement their knowledge. The first blind man approached, his hands touched the elephant's body and he said "An elephant is like a large wall.". The second approached, touched one of the elephant's tusks and said "Fine and pointed, this elephant is like a spear". The third touched the animal's trunk and shouted, "To me, the elephant is like a snake.". The fourth touched the elephant's leg and compared it to a tree. After touching the elephant's ear and feeling the wind when it moved, the fifth said, "Even for the most blind of the blind, this elephant is like a fan!". Finally, the sixth grabbing the tail said "No, an elephant is like a rope! ". After long hours of discussion and disagreement between the six men, a wise man crossed their path and listened to each other's arguments. After listening to the six blind men, the wise man said, "You are all right! If you gather all your individual perceptions, you can have a representation of the animal as a whole.". This Indian fable illustrates that the truth or reality is not the result of a single point of view or a single perception but of a pooling of individual truths and realities.

To have a comprehensive and clearer picture of the social integration of people with SMI, it is therefore necessary to document, in different contexts, each dimension of their social integration and then to pool this knowledge. The first two dimensions of social integration, i.e. consumption and production, are related to the economic inclusion of individuals and the concept of socioeconomic inequality. Indeed, mental health problems are distributed unequally by socio-economic position in the general population and people with mental health problems are more likely than the general population to have low education status, to be unemployed and to live in material poverty and thus to be excluded from the dimensions of consumption and production [54-56]. The other two dimensions of social integration, i.e. social interaction and social and political engagement, are more related to how individuals interact with and influence their environment.

Consumption

This dimension refers to the capacity to purchase goods and services. Indicators in this dimension are, of course, indicators of economic inclusion or exclusion such as housing.

Housing

Housing is a fundamental right and is essential for stability, security and community integration [46, 57]. Several qualitative studies with people with mental illness have shown that having a safe and secure housing is for them the foundation of their social integration and journey into recovery [58-60]. Homeownership, independent housing, and good housing conditions improve self-esteem, perceived control and life satisfaction [61] and the majority of patients with SMI can and want to live in independent housing, without the need for on-site supervision and monitoring [62-64]. For example, a participant in a qualitative study [60] with people with mental illness reported: *"That's my ideal situation to actually be self-sustaining, a regular part of the community, you know. I want a part of the community. I just want a place to live that I have the keys to, I can open the door, I can shut the door, I can answer the bell, not answer the bell, little bit of my own."* $^{p.\ 385}$

However, people with mental illness are more likely than the general population to report uncertainty about the stability of their housing and to be dissatisfied with their housing conditions [65]. In addition, although there is no precise epidemiological data, people with SMI are more likely than the general population to live in social housing, supported housing or to be homeless [66]. Some studies have shown that between 25% and 30% of homeless people suffer from SMI [67, 68], but very few studies have quantified the prevalence of homelessness among people with SMI. A study conducted in the US on more than 10,000 people with SMI showed that the prevalence over one year of homelessness was 15%, which is much higher than in the general population [27].

The 2014 Belgian national evaluation "Towards Better Mental Health Care" revealed that in a non-randomised sample of 1,199 people with SMI, 9% were homeless or in a therapeutic community, 24% were in a supported housing, and 67% were in an independent housing [69]. However, there is no information on the housing status of people with SMI compared to the general Belgian population. In addition, the SMI patients included in the previously mentioned study may not be representative of the population of people with SMI as it was not a random sample. More information is given on residential services in Belgium in chapter 1.3.2.

Production

This dimension refers to the participation in economically or socially valuable activities and its main indicator is the employment status. Although research has mainly focused on the association between paid work and mental health, the employment status is not just an indicator of economic inclusion and there exist different forms of employment. Having a job, whether paid or unpaid, is considered good for the social integration (i.e. for identity, self-confidence and a sense of participation and belonging to society). However, paid employment can also have negative consequences on health and social outcomes. Therefore, this chapter is divided into three sections: unemployment, paid employment, and unpaid employment. Finally, integration to the labour market and access to certain types of jobs is directly linked to an individual's level of education. The last section will therefore be on education.

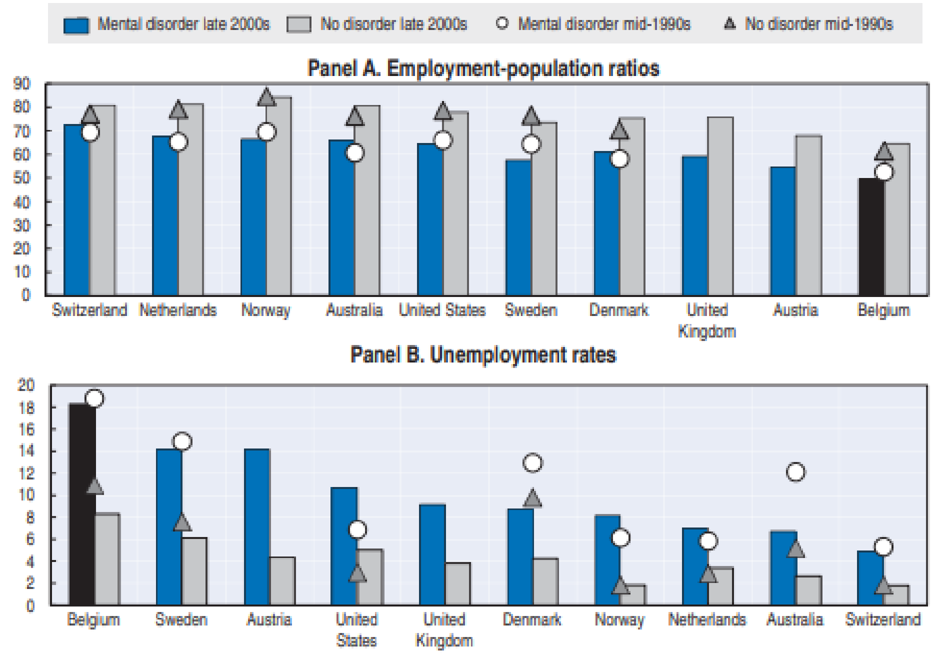
Unemployment

Unemployment of people with mental illness is probably the most studied indicator of their social exclusion. We spend a large part of our lives at work, so work is a crucial feature of mainstream life and social integration. The poor position of people with mental illness, especially those with SMI, in the labour market is now well established. Compared to the general population, the risk of being unemployed is two to three times higher for people with common mental illness and six to seven times higher for people with SMI in OECD countries [25]. Although between 70% and 90% of them want to work [70-73], people with SMI constitute one of the groups with the highest rates of unemployment as only 10 to 20% of them are in some form of employment [26, 74]. In addition, some studies suggested that the unemployment gap between people with and without mental illness is widening over time and that periods of economic hardship have intensified the economic exclusion of people with SMI, with a progressive drop in their employment rate [26, 75]. The main barrier to employment described in the literature is the stigmatisation of and discrimination against people with SMI [26, 76, 77]. Indeed, people with SMI commonly report being stigmatised in their workplace or during their job search [71, 78, 79]. On the employers' side, some studies have shown that employers often do not know about or understand severe mental illness [71]. Employers often believe that people with SMI are prone to violence and cannot perform complex tasks, and therefore are reluctant to hire them unless they have incentives from the state or a legal obligation [71, 80, 81].

While people with mental illness are less likely to find and keep a job, several studies have also shown that unemployment also has negative effects on mental health, i.e. increase depression and anxiety [82-84]. Unemployment can therefore be both a cause and a consequence of mental health problems. Employment status affects outcomes other than the mental health of individuals, as it is also a key area of their social integration [85, 86]. As previously explained, in addition to providing economic stability, going to work every day improves self-confidence, self-respect and allows people to interact with their colleagues and improve their social ties [80, 87]. Several qualitative studies with people with SMI highlighted that working makes them feel integrated into society, allows them to socialise, to have a meaningful social role and increases their self-esteem and independence [71, 88, 89]. Another study has shown that, for people with SMI, the most commonly sought role was that of a worker [90]. For these reasons, employment is considered as one of the main indicators of social integration and, conversely, unemployment as an indicator of social exclusion.

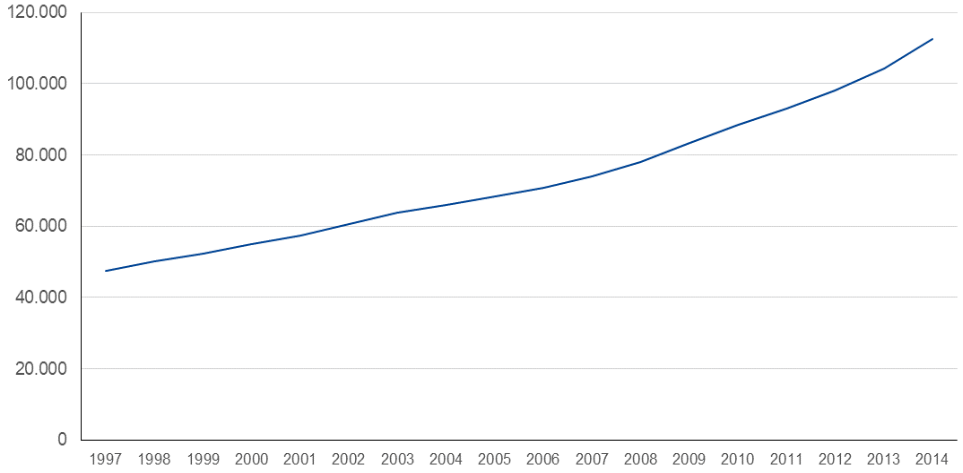
The employment rate of people with SMI varies between countries according to local social and economic contexts and to the labour market [91]. Figure 2 presents the employment and unemployment rates in OECD countries of people with mental illness compared to the general population [92]. Unfortunately, Belgium is not a very good student in terms of economic inclusion of people with mental illness: Belgium is one of the countries with the lowest rate of employment and the highest rate of unemployment among people with mental illness. In 2008 compared to the Belgian population without mental illness, the employment rate of people with mental illness was 15 percentage points lower (respectively 65% and 50%) and their unemployment rates was 10 percentage points higher (respectively 8% and 18%) [92]. In addition, it appears that the employment rate of people with a mental illness declined between 1997 and 2008, widening the employment gap compared to the general population from 9 to 15 percentage points [92]. The 2014 Belgian national evaluation "Towards Better Mental Health Care" revealed that in a non-randomised sample of 1199 people with SMI, only 14.5% had a paid job [69]. However, there is limited information on the employment status of people with SMI compared to the general Belgian population.

Figure 2: Employment and unemployment rates in OECD countries – From OECD, 2013 (Belgium: Health Interview Survey 1997 and 2008)



In 2015, the indirect costs of mental health problems on the labour market represented 2.30% of Belgium's gross domestic product (GDP), the highest percentage of OECD countries [93]. Mental health problems are a leading cause of sickness absenteeism in Belgium. In 2016, they were responsible for 35% of the sickness absenteeism of employees and 22% of the self-employed and these percentages are increasing over time [94, 95]. Figure 3 presents the number of invalid people because of mental health problems in Belgium between 1997 and 2014. We can observe that the number of disabled people due to mental health problems increased by 57% between 1997 and 2014 (from 45.507 to 112.648 invalid people), an increase far greater than the growth of the Belgian population [96].

Figure 3: Number of invalid people because of mental health problems in Belgium, 1997-2014. From the National Institute for Health and Disability Insurance



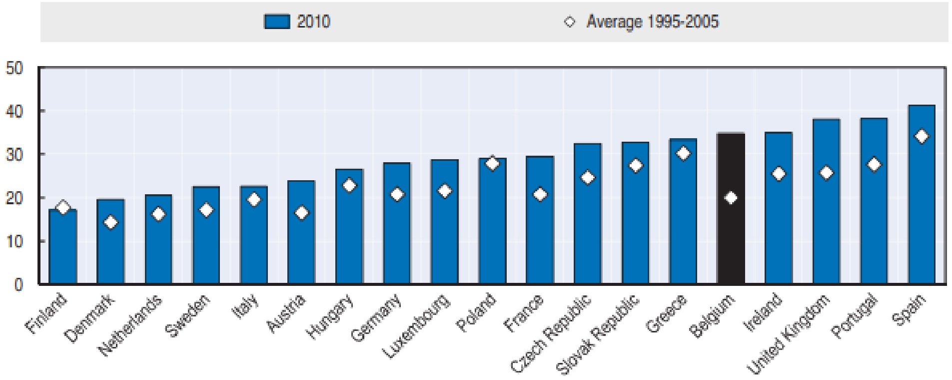
Paid employment

Is any job better than no job? Although paid employment is generally considered a protective factor for mental health problems and an indicator of social integration, paid employment can also have negative consequences. As the positive effects of paid employment on mental health and social integration are addressed indirectly in the previous chapter on unemployment, this section will focus on the negative effects of paid employment.

Several studies have shown that the health and social benefits of employment are moderate, if not reversed, by working conditions [97-102]. For example, one study found that compared to unemployed people, people working in poor conditions (i.e. low wages, high pressure, lack of support, job insecurity) had worse mental health outcomes [97]. A recent meta-analysis combining 20 cohort studies published between 2004 and 2014 compared the effect of unemployment and job insecurity on depressive symptoms in the general population and concluded that *"by comparing both stressors, job insecurity can pose a comparable (and even modestly increased) risk of subsequent depressive symptoms."* [101]. Even for PhD students, one study found that some of their working conditions such as high job demand, low job control, inspirational leadership style, and family-work conflicts were predictors of mental health problems [103]. Although there is no specific research on the working conditions of people with SMI, an international study has shown that they mainly access ‘elementary’ jobs such as cleaning, labouring, plumbing or metalwork [91], even if a SMI is not a bar to any king of work. Without generalising, elementary jobs may not always have good working conditions. Unfortunately for the moment, no study has described the distribution of job types among SMI. First, research on the effects of the employment status of people with mental illness on different outcomes should consider their working conditions. Second, policy efforts aimed at the social integration of people with SMI should also consider working conditions in conjunction with efforts to increase their employment rates in order to avoid “choisir entre la peste et le choléra”, i.e. being unemployed or working in poor conditions (see Chapter 3).

In the early 2000s in Belgium, people with poor working conditions (i.e. low job control, work-home conflicts or over-commitment) were 2 times more likely to have a depression [95]. In 2010, 67% of Belgian employees on sick leave reported experiencing work stress often to very often, compared to 48% of employees without sick leave [104]. In addition, the job strain (i.e. high degree of psychological demand and low decision latitude) increased between 1995 and 2010 in OECD countries and in particular in Belgium [92] (see Figure 4).

Figure 4: Proportion of job strain among workers in OECD countries – From OECD, 2013



Unpaid employment

The effects of paid employment on mental health and social integration are addressed indirectly in the previous chapter on unemployment so this short section will focus on the effects of unpaid employment. Unpaid employment such as volunteering or sheltered work and their association with the social integration and mental health of individuals are much less studied than paid employment. Although unpaid jobs do not contribute directly to the economic integration of individuals, this type of employment can contribute to their social integration as paid jobs do. Indeed, unpaid jobs such as volunteering improves social integration by giving people a feeling of worth, a sense of accomplishment, and improving their community engagement and social capital [105, 106]. In terms of mental health, a meta-analysis on 5 randomised controlled trials and 17 cohort studies found that volunteering had positive effects on depression, life satisfaction, and wellbeing [107]. Having unpaid jobs also increases paid employment opportunities [106]. For people with mental illness, unpaid jobs can be seen as an opportunity to improve their social integration and mental health, but also as an opportunity to improve their formal participation into the labour market.

However, unpaid jobs can also have negative consequences. Volunteering or sheltered employment can delay the search for paid work that matches people's professional skills and reduce their chances of finding employment in the competitive labour market [108]. A core principle of the Individual Placement and Support (IPS) model is the rapid search (i.e. by limiting as much as possible the preparation in a “place then train” logic) for employment in the competitive labour market [109, 110]. In addition, in Belgium, people in unpaid work do not pay social contributions and therefore do not have access to certain social rights (e.g.: family allowances). Although it is difficult to have precise estimates, the prevalence of adult volunteering in Europe is about 25%, with great differences between countries (e.g. around 40% in Austria, the Netherlands, Sweden and the UK and around 20% in Belgium, Ireland, Poland, Portugal, and Spain) [111]. However, there are limited data on the prevalence of volunteering among people with mental illness. The 2014 Belgian national evaluation "Towards Better Mental Health Care" revealed that in a non-randomised sample of 1199 people with SMI, 22% had a sheltered job or volunteering [69].

Education

Integration to the labour market is directly linked to an individual's level of education. However, the association between mental health problems and lower educational attainment has been known for many years in the field of social psychiatry and epidemiology [40, 112] and the debate between social causation and social selection remains lively. Several studies have supported the social causation hypothesis by demonstrating the effect of educational attainment on mental health (i.e. a low level of education leads to poor economic and social conditions which lead to poor mental health) [40, 113]. Other studies have supported the influence of poor mental health on educational attainment and hence the social selection hypothesis [114, 115]. Indeed, the age of onset of several mental illnesses and particularly severe mental illnesses such as psychosis and bipolar disorder is 15 to 25 years old, period corresponding to the end of secondary school and the start of higher education [19, 116]. As a result, the early onset of a mental health problem may have a negative impact on educational attainment and several studies have shown that mental health problems beginning in early life, adolescence, and young adults are associated with an increased risk of premature discontinuation of studies [117, 118]. For example, one study has shown that in people with early onset psychosis, more than half had no educational qualification [119].

The majority of epidemiological studies in this field have been performed on adults and there are few longitudinal and population-based studies on children and adolescents [120]. However, if there is a link between youth mental health on the one hand, and academic performance and educational attainment on the other hand, this reinforces the importance of early recognition and interventions. A systematic review on early school leaving among adolescents found that early school drop-out was associated with depression and substance abuse [121]. A longitudinal study of the health-related behaviours of adolescents and their outcomes in young adulthood found a negative relationship between depressive symptoms and years of schooling [115]. The key issue is that the lack of education increases the risk of social exclusion. Indeed, it reduces the chances of accessing a job [78], but it also leads to disadvantages in the acquisition of skills, a decrease in life chances in adulthood, and a loss of social capital [122]. In addition, low education attainment in childhood can be difficult to compensate for later in adulthood, especially as adults with mental health problems face barriers to participating in learning (i.e. lack of supported education interventions and services specific to adults with a mental health problem, see 1.3.8 supported education) [46, 123].

In Belgium, the health interview survey clearly illustrates the link between mental health and level of education, among adults and among young people and children [124]. In 2018 among Belgian adults, people with lower levels of education (primary or no diploma) were more likely to experience psychological distress (43.7%) and mental illness (26.1%) than those with a higher level of education (respectively 33.5% and 20.1%). This socio-economic gradient is all the more marked in depressive disorders, affecting 16.7% of adults with a lower level of education against 6.7% of adults with a higher level of education. This gradient is also present in youth and children. Indeed, young people and children from more educated families are less likely to present a potential mental illness (5.9%) than those from less educated families (between 11.5% and 13.4%).

Social interaction

Social interaction and social support have an important place in an individual's mental health and well-being. To quote the famous rock band R.E.M. and their song "Everybody Hurts" (1992):

« 'Cause everybody hurts

Take comfort in your friends

Everybody hurts

Don't throw your hand

Oh, no

Don't throw your hand

If you feel like you're alone

No, no, no, you're not alone”

Lack of social interaction is associated with poorer health, mental health, and increased mortality risk, while having social interactions is associated with better mental health outcomes. Indeed, having social interactions increase self-esteem, buffer the negative effects of socio-environmental stressors, enhance social integration by expanding access to opportunities and resources and increasing the levels of community tenure and functioning [125-129]. However, compared to the general population, people with mental illness are more likely to interact less with others, to be socially isolated, and thus to be socially excluded by having less access to opportunities and facilities in the community [46, 130]. Commonly used measures of social interaction in the literature are the social support network and marital status of individuals.

Social support network

The social support network (SSN) of an individual is the set of people (e.g. relatives, parents, friends, colleagues, care professionals and services) who interact with the individual and with each other to provide formal and informal emotional and material support to the individual during all kinds of life events [131, 132].

As previously explained, the SSN of individuals can have positive effects on their mental health and social integration [127-129]. However, the SSN of people with SMI differ from the SSN of the general population in terms size, composition, and structure. In the UK in the early 2000s, the proportion of people with moderate and severe mental illness reporting a severe lack of social support was respectively 17% and 33%, compared to 8% in the general population without mental illness [133]. Regarding the size and quality of the SSN, even though the most impaired patients are not completely isolated [134], many studies have shown that people with SMI have smaller and poorer quality networks compared to the general population [135-137]. Indeed, one study found that the SSN size of people with SMI was 2.5 times lower than the SSN size of the general population [138]. A recent systematic review on the SSN of people with psychosis estimated that the weighted mean size of their whole SSN was 11.7 members and 3.4 members for their friendship network [139]. The SSN of people with SMI also differs from that of the general population in terms of composition as they tend to include a larger proportion of family members ($\simeq$ 45% of their SSN), a smaller proportion of friends ($\simeq$ 25%), and a larger proportion of care professionals ($\simeq$ 15%) [139]. Finally, studies on the structural characteristics (e.g. density or centralisation) of the SSN of people with SMI and differences with the general population are limited and further research is needed on this topic.

In Belgium, although there is no specific figures on the social interaction of people with mental illness, in 2013, 9% of the general population reported being dissatisfied with their social contacts, 4% reported having less than one social contact per week, and 17% reported having a low perceived social support [140]. In addition, although the proportion of individuals reporting less than one social contact per week has decreased since 1997 (from 8% in 1997 to 4% in 2013), the proportion of individuals dissatisfied with their social contact has increased significantly (from 6% in 1997 to 9% in 2013) [140]. In terms of SSN of people with SMI, one study with 380 SMI patients recruited in in-and-outpatient mental health services in Belgium highlighted that their SSN was composed of a mean of 12 members (SD = 5), most whom were care professionals (mean = 7.4, SD = 3.4) [141]. The 2014 Belgian national evaluation "Towards Better Mental Health Care" found that of the 1199 people with SMI who participated in the study, 32% reported having no contact with a friend the previous week [69]. However, those studies do not provide a comparison with the SSN of the general Belgian population and the SMI patients included may not be representative of the population of people with SMI as it was not random samples.

Marital status

For many individuals, marital status is an important and stable source of social contact and support. Indeed, having a partner or a family generally provides continuous interpersonal closeness, emotional gratification, and support for coping with socio-environmental stressors [142, 143]. However, people with mental illness are more likely to be single, to live alone, or estranged from their families. In the UK in the early 2000s, 52% of people with psychoses were single, 22% were widowed, divorced or separated, and less than 40% lived in a family setting [119]. In Belgium, although there are limited data on the marital status of people with SMI, the 2014 national evaluation "Towards Better Mental Health Care" revealed that in a non-randomised sample of 1199 people with SMI, 36% lived with a partner or family while 64% lived alone [69]. However, there is no information on the marital status of people with SMI compared to the general Belgian population.

Social and political engagement

The social and political engagement (i.e. having a voice, choice, and control) of people with any sort of mental illnesses has been less studied in the literature. The main indicator of political engagement is voting. Indeed, voting is the foundation of the political commitment of individuals and an integral part of decision making within society. However, there is a paucity of literature regarding voting and mental illness. The capacity of people with SMI to vote, especially those under legal guardianship, has often been questioned and in many democracies, they do not have access to the ballot or are not informed of their right to vote [144, 145]. However, a study in Washington (2009) found that 92% of people with SMI had the capacity to vote in terms of reasoning and appreciation [146]. In Belgium, voting is compulsory for all Belgian citizens over the age of 18 who have their full civil and political rights. Voting is therefore accessible to all except if the person is declared incapable by a court decision (i.e. mentally ill offenders, some prisoners, and persons under prolonged minority) [147]. Like everyone else, people with SMI are therefore presumed capable of exercising their right and obligation to vote. However, there is limited information on access to voting for people with SMI in Belgium.

Another dimension of social engagement is the participation and engagement in leisure activities. A qualitative study with people with mental illness revealed that the majority of them felt dissatisfied with their leisure activities and that their activities during a ‘normal day’ circulate around meals and watching television, without going out or visiting family or friends [148]. In the UK in the early 2000s, 12% of people with SMI had fewer than three leisure activities and 29% more than ten, compared with 5% and 40% of the general population without mental illness [133]. The limited participation of people with SMI in leisure activities has been highlighted in other studies [149-151], and is not only related to the nature of these mental illnesses but also to barriers such as lack of opportunity, discrimination, and poor material circumstances [152-154]. There is no information on the extent of participation of people with SMI in leisure activities in Belgium.

1.3 Policies, systems reforms, and interventions to tackle social exclusion of people with severe mental illness

Now that the different dimension of social integration and the extent of the social exclusion of people with moderate and severe mental illness are clearer, this chapter looks at the policies, systems reforms, and interventions put in place to tackle their social exclusion. Mental health policies in many Western countries are pursuing this goal of social integration of people with mental illness with a focus on community inclusion, destigmatisation and helping people to obtain or retain employment and housing [30, 155-157]. Although there is no clear consensus on the definition of social integration, it is now considered as a key outcome for mental health systems and services [158-160] as "*numerous countries have policies and programmatic guidance that specifically mention social integration or inclusion as a goal of psychiatric services."* [161]. As shown in the previous chapter, the dimensions of social integration go beyond the health and social sectors, so social integration policies and interventions cover multiple areas such as employment, education, housing and justice. Therefore, this chapter does not claim to be exhaustive, but rather to provide an overview of the main policies, systems reforms, and interventions at the international level and in Belgium.

1.3.1 Global mental health movements and policies

For several decades, mental health systems in many Western countries have undergone reforms in terms of provision, coordination, and funding to provide effective, equitable and affordable mental health care [21, 155, 162, 163]. The second half of the 20th century was characterized by the decline of the asylums and the era of deinstitutionalisation, with public policies supporting the transition of resources from institutional psychiatric services to community-based services to provide long-term and continuous care within the community [155, 164]. Deinstitutionalisation and community care policies were supported by the failure of care in asylums, the development of new drugs, and the assumptions that community care was more related to the priorities of service users; was more consistent with the international conventions on human rights; and was cheaper than long-term institutionalised care [162, 164, 165]. The development of community mental health care foreshadowed the onset of consumer/ex-patient movements and the concept of recovery in the 1970s and 1980s [166, 167]. There are many definitions of the term recovery [168], but one agreed definition is that recovery is *"a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles"* and *"a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness."* [21]. A central idea of recovery is hope and building a life beyond illness without necessarily having a clinical recovery [21, 169]. By the end of the 1990s, the concept of recovery had become a guiding vision of international mental health policies, with the expectation that it would improve patient outcomes and result in cost-effective care [21, 170]. However, in practice, the concept of recovery has suffered from a lack of clear definition resulting in the lack of consensus and different appropriations of it. For example, one study have identified seven recurring misuses of the concept of recovery (labelled as "abuses" by the authors): (1) recovery is the latest model; (2) recovery does not apply to "my" patients; (3) services can make people recover through effective treatment; (4) compulsory detention and treatment aid recovery; (5) a recovery orientation means closing services; (6) recovery is about making people independent and normal; (7) and contributing to society happens only after the person is recovered [168].

Although the concept of social integration seems to have deep historical roots, it really appeared in national and international policies in the 2000s following the emergence of recovery in clinical practice and the changes in global human rights and mental health policies [161, 171]. Because of the multiple dimensions of social integration, it overlaps with dimensions and concepts of recovery. Indeed, *"recovery both requires and allows social inclusion and social inclusion helps to promote recovery"* [46]. For example, many outcomes associated with recovery are also indicators of social integration, e.g. having a job, living independently or socializing [85, 172, 173]. The main difference is that recovery emphasises a personal, and sometimes clinical process, that can be supported by recovery-oriented practices at the individual level while social integration places more emphasis on the effects of social and political processes on people and on the need for comprehensive health, social, and economic practices and policies [47, 174]. There have been many relevant international policies aimed at strengthening the social integration of people with mental illness. One of the main policies was the Convention on the Human rights of Persons with Disabilities adopted by the United Nations in 2006. This UN convention stated that people with mental illness have *"a right to full and effective participation and inclusion in society"*, with a focus on access to housing, employment, leisure activities and participation in political and public life [175]. Since 2004, the World Health Organization (WHO) published several reports with guidelines for countries to promote the social integration and reintegration of people with mental illness in the community [171, 176-178]. In addition, the WHO Mental Health Gap Action Programme (mhGAP) launched in 2010 promotes social integration interventions with a focus on community rehabilitation, inclusion in social activities, destigmatisation, employment and housing support, and emphasises the need for cross-collaboration between the health, labour, education, social and other relevant sectors [179]. In Europe, Mental Health Europe, with the support of the European Commission, performed in 2008 an analysis of national reports from 27 EU Member States on the promotion of social integration of people with mental illness [180]. Based on this policy analysis of the different Member States, they published recommendations aimed at promoting social integration at the level of health and social services, education and training, employment, housing, transports, leisure activities, and civil and human rights [180]. However, this report does not provide a state of the art of the social exclusion of people with mental illness in Europe nor an assessment of the evolution of their social integration following the implementation of these different policies in the EU Member States.

1.3.2 Community care

The social integration of people with mental illness was supported in many western countries by reforms in the organisation of mental health care with a transition from institutional psychiatric care to community care, a decrease in psychiatric hospital admissions and a reduction in the hospital length of stay in order to avoid the detrimental aspects of psychiatric hospitalisation on social integration [24, 181, 182]. Indeed, one of the consequences of excessive length of stay and readmissions in psychiatric hospital is the “social breakdown syndrome” in which people with mental illness experience community and social withdrawal, exclusion from typical social roles, and a decline in their social integration [183, 184]. Those deinstitutionalisation policies, which started in the 50s and are still in progress in many countries (e.g. in Belgium), have had unintended consequences for people with SMI. In many western countries, the closure of psychiatric hospital beds has not always been followed by an increase in the number of community alternatives [185, 186]. Community mental health services were mostly dealing with people with moderate mental illness and did not have the capacity to provide intensive care and support to people with SMI. In addition, this new community-based system included a large number of services, was complex and fragmented, and people with SMI had limited ability to navigate by themselves in this system and to coordinate their different providers [187, 188]. Therefore, in the 60s and 70s, deinstitutionalization policies led to perverse effects on people with SMI with an increase in homelessness and imprisonment, and the emergence in the remaining psychiatric hospital of a "revolving door" admission phenomenon and new "long stays" patients [185, 189-191]. In response, specific services and interventions were developed in the 70s to provide long-term assistance in the community for people with SMI and achieve their social integration (see 1.3.3 The Assertive Community Treatment model).

In Belgium, the process of deinstitutionalisation started around 1975 with the establishment of Community Mental Health Services and other alternatives to psychiatric hospitalisations (i.e. residential rehabilitation units, sheltered housing, and psychiatric nursing homes). However, this process of deinstitutionalisation was far from complete and in 2008, there were still 152 psychiatric beds per 100,000 inhabitants, the highest rate in Europe after Malta [178]. Since 2010, a reform in the organisation of mental health care has been under way with the objectives of "*further orient mental health care towards a reduction of residential hospital care in favour of patients' recovery and treatment in the community."* [192]. The basic funding mechanism of the reform was to convert part of the financial resources devoted to long-term psychiatric beds into means for developing mobile teams, working in a defined geographical area within a network of different services [192]. The networks of services were also developed during this reform and must provide five functions in their geographical area: prevention and early detection, outreach (mobile teams), recovery and social integration, intensive in-patient treatment, and specific housing and long-term facilities. The policy that underpins the reform has five main goals: (1) the recovery and social integration of people with mental health needs, (2) the shortening of hospital stays, (3) the implementation of community-based care system, (4) the establishment of collaborative procedures to improve continuity between the social and care sectors, and (5) the consolidation of previous community-based projects. The effectiveness of the Belgian reform in terms of social integration and other patient outcomes is addressed in Chapter 1.4.

1.3.3 The Assertive Community Treatment model

The main model developed to provide long-term assistance in the community for people with SMI was the Assertive Community Treatment (ACT) model developed in the US in 1973 [193, 194]. The ACT is an intensive mental health program for people with SMI in which a multidisciplinary team provide different services (e.g. helping with medication, housing, finance, etc.) in the community (at the patient’s home or in community settings) [193]. The goals of ACT is “*to ensure that the patient received all services needed to remain in the community and function optimally with the highest possible quality of life*” [188]. The ACT model spread throughout the world since the early 1990s, beginning with Australia, Canada, UK, and other European countries such as the Netherlands in 2002 [195-198]. In Belgium, the ACT model inspired the mobile teams implemented since 2010 as part of the national mental health care reform (see 1.3.2 Community care).

The effectiveness of the ACT model has been extensively studied over the past decades and several systematic reviews and meta-analyses have synthesised the studies on this model and concluded that the ACT model significantly improves community and social integration outcomes for people with SMI [199-202]. However, several studies have also highlighted contradictory findings depending on the context (e.g. the US versus Europe) partly related to variations in model fidelity and other organisational aspects of the implementation (e.g. multidisciplinary team, frequency of visits, etc.) [203-205].

1.3.4 Destigmatisation policies and interventions

This chapter could not end without mentioning the stigma of mental illness and destigmatisation policies and interventions. Indeed, one of the main barriers to the economic and social participation of people with mental illness is the stigma associated with their conditions. There is a great amount of literature on the subject of stigma of mental illness but this goes beyond the subject of this thesis and I can only advise to read Graham Thornicroft's book "Shunned" [206]. One thing to emphasise from this book is that the author argues that although the concept of stigma may be important to better understand the emergence and development of social exclusion, it tends to locate the problem within the individual rather than in the mainstream society. Thornicroft therefore proposes to break down the concept of stigma to consider three related issues: problems of knowledge (ignorance), problems of attitudes (prejudice), and problems of behaviour (discrimination) [206]. While anti-stigma campaigns were focused on individuals with mental health problems and learning disabilities to encourage them to engage in treatment, this shift to ignorance, prejudice and discrimination rather than on the individual highlighted the importance of destigmatisation policies and interventions at the level of knowledge, attitudes, and behaviours within the general society. Because of the complex multifaceted nature of stigma, actions must be taken in different sectors (e.g. justice, education, social, etc.) and at the international and national levels to reduce the stigma and discrimination of people with mental health problems [207, 208]. At the international level, the WHO published a resource book on mental health in 2005 entitled “Stop exclusion, dare to care” [209]. This book provided guidelines for countries to develop and revise mental health laws, including anti-discrimination legislation. However, in 2008, 25% of countries worldwide did not have mental health legislation, and of the 75% who did, half had not changed this legislation in the last 15 years [207]. In Europe, it was in 1997 that the first important step towards anti-discrimination legislation was taken when EU governments unanimously decided to introduce a new article (Article 13) into the EU Treaties. Anti-discrimination laws are now mandatory and the Article 13 remains the legal basis for any European anti-discrimination legislation [210]. In 2000, the EU directive on equal treatment in employment and occupation has been adopted on the basis of the Article 13 in order to protect the rights of persons with mental health problems and learning disabilities in the fields of employment and training [211]. Although disabled people are likely to be discriminated against in sectors other than employment (i.e. access to and supply of goods and services, education, housing, healthcare, social security and social assistance, and transport), these forms of discrimination are not yet addressed in EU legislation [212]. However, some countries have taken initiatives. Actions can obviously be put in place at the national level to improve the accessibility of disabled people to the different dimensions of society (e.g. access to education or housing), but also specific anti-discrimination programs and legislation. For example, one way to change knowledge (ignorance) and attitude (prejudice) and thus to fight discrimination is to set up mental health awareness campaigns targeting specific groups and fields (e.g. medical staff, journalists, school, police or employers) [213, 214]. A scoping review published in 2014 identified campaigns to reduce mental illness stigma in

21 European countries and regions[1], but none in Belgium, as well as a lack of evaluation and considerable variations in their content, delivery formats, duration and target groups [215]. The world's largest anti-stigma campaign is the “Open The Doors” program launched in 1996 by the World Psychiatric Association (WPA) aiming to fight stigma associated with schizophrenia [216]. In 2005, the program resulted in more than 200 projects in 20 countries around the world [217]. This program is different from the other because it is at the international level and not at the national level, it is conceive as a long-term program and not a one-time campaign, and specific target groups are selected in addition to the general public (i.e. health and social professionals, health authorities, and the media) [218]. After some evaluation of the program in Canada and Germany, there is evidence that it improve knowledge of mental illness and attitudes of specific target groups such as medical students or health professionals, however, there is limited evidence that it modify negative attitudes of the general population [219-222].

After some research, it seems that few national campaign against the stigma and discrimination of moderate (e.g. depression) or severe (e.g. schizophrenia) mental illness has been organised in Belgium in recent years. The "Te Gek" group organises awareness campaigns and events mainly at the initiative of Flanders, and some mental health services also organise local events. In Belgium, a law was promulgated in 2007 to prevent and fight against some forms of discrimination (on the grounds of the age, gender, race, sexual orientation, disability, etc.) [223].

1.3.5 Residential services

The international deinstitutionalisation movement in the 1950s introduced a paradigm shift in residential services for people with mental illness. The decrease in the number of psychiatric hospital beds and in the hospital length of stay has led to an increase in the number of patients with SMI and long-term needs being placed in the community and requiring housing alternatives. For example, in Germany, the number of psychiatric beds has been decreasing since 1990, and in Berlin, the number of places in supervised housing had already tripled in the early 2000s [224]. However, many countries struggled to provide a comprehensive and effective

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[1] Austria, Croatia, Czech Republic, Denmark, Germany, Greece, Hungary, Ireland, Italy, The Netherlands, Norway, Poland, Portugal, Romania, Scotland, Slovakia, Slovenia, Spain, Sweden, Turkey, and the UK.

range of housing alternatives [186, 225] and many patients found themselves simply discharged to their families, alone in the open housing market, in prison, homeless, or in a “revolving door” phenomenon within the remaining psychiatric hospitals [226, 227]. Subsequently, many residential interventions with and without support emerged [226], e.g. half-way houses [228], Fairweather Lodges program [229] or family foster care [230]. Despite the considerable diversity of residential interventions and the inconsistencies in their definitions [231], it is possible to identify in the literature two major models, i.e. the linear continuum model based on a transitional approach [226, 232] and the supported housing model based on a maintenance approach [233, 234]. In the linear continuum model, several housing services are provided with different levels of support, and patients are moving along the continuum from the most restrictive and intensively staffed service to less restrictive alternatives with the final goal of independent housing depending on the course of their illness [226]. The supported housing model is intended to be more based on patient preferences by giving them direct access to permanent (or at least long-term) independent housing combined with individualised and flexible community mental health and support services (e.g. case management or assertive community treatment team) [225, 231]. Both models still coexist and each one has advantages and disadvantages, however, there is little quality research evaluating their effectiveness. A Cochrane systematic review [235] aiming to determine the effects of supported housing interventions compared with 'standard residential services’ for people with SMI found that although 139 citations were obtained from the literature searches, no study met their inclusion criteria.

One specific housing intervention targeting chronically homeless people, who typically have a history of mental illness [66, 236], has received much attention in research and policy in recent years: the Housing First model. The housing first model was created based on the Pathway to Housing program developed in New York in 1992 [237]. The model is close to the supported housing model and is based on the belief that housing is a fundamental right and must respect consumer choices [237, 238]. The core principles of the housing first model are: (I) enable choice, (II) provide home support tailored to people's needs (mainly via assertive community treatment team), (III) target chronically homeless people, (IV) use a harm reduction framework, (V) have unrestricted and unlimited access to support services, and (VI) separate housing and care (i.e. access and retention of housing is not conditional on treatment compliance) [239]. In terms of effectiveness, one large study with 225 homeless people with dual diagnosis (mental and substance use disorders) randomly assigned to a housing first program or to a standard residential services (control) found that participants in the housing first program obtained housing earlier, remained stably housed, and reported higher perceived choice compared to the control group [63]. The Housing First model was quickly implemented in Canada and in various European countries (e.g. France, Denmark, and The Netherlands) with effective results similar to those reported in the United States [240-242].

There are different types of residential services in Belgium. A first way to identify them is to differentiate structures that are not accredited by the state from accredited structures. Non-accredited residential services, also called "pirate houses", are services that provide housing to people with difficulties to live autonomously, including people with mental illness. In 2011, it was estimated that there were 40 pirate houses in Wallonia, 20 in Brussels and none listed in Flanders, for about 3,000 people hosted [243]. Beside these structures, there are different types of accredited structures. Following the deinstitutionalization movement and the decline in the number of psychiatric hospital beds in the 1990s, two new types of residential services for people with mental illness were developed; sheltered accommodations (Initiatieven Beschut Wonen-IBW – Initiatives d'Habitations Protégées-IHP) and psychiatric care homes (Psychiatrisch Verzorgingstehuis-PVT – Maison de Soins Psychiatriques-MSP). These services were developed with a transitional approach with different level of support according to user needs, and therefore seem to be closer to the linear continuum model than to the supported housing model. Sheltered accommodations are short-term residential services for people with mental illness who do not need permanent follow-up but who must be assisted in their living environment to develop their social skills. The main purpose of these services is to support people with mental illness until they can live in independent housing. Psychiatric care homes are long-term residential services for people with mental illness who need permanent supervision by trained staff. These services specifically target people with SMI who do not require intensive in-hospital psychiatric care but are considered unable to live independently in the community or in other living communities. In 2017, there were 4247 places in sheltered accommodations and 2943 places in 40 psychiatric care homes [244]. In 2013, 5280 care periods were recorded in sheltered accommodations, 42% were patients with psychotic disorders, 18% with substance use disorders and 16% with mood disorders. In psychiatric care homes, 3841 care periods were recorded in 2013, 47% were patients with psychotic disorders, 9% with substance use disorders and 12% with mood disorders [245]. In terms of length of stay in sheltered accommodation, 27% of patients stay there between 1 and 3 years (16% in psychiatric care homes) and 20% more than three years (43% in psychiatric care homes) [245].

There are also specific interventions for homeless people. The Housing First model has been tested for 2 years between 2013 and 2015 in 11 experimental projects in Antwerp, Ghent, Hasselt, Brussels, Molenbeek, Liège, Charleroi and Namur. Through the different projects, 144 people found housing with the Housing First model and the rate of housing maintenance after 12 months was 93% [246]. The projects were extended, received an agreement in the different regions and there were 12 Housing First projects in Belgium in 2018 [243]. Unfortunately, these initiatives remain pilot projects which are not systematically implemented throughout the territory and are not systematically evaluated to show their effectiveness.

1.3.6 Labour market policies and reforms

As previously explained, being unemployed is probably the leading cause of the social exclusion of people with mental illness as their exclusion from the labour market is wide and associated with low income, social isolation, and low self-esteem [26, 87]. At international level, many countries signed in 2006 the United Nations Convention on the Rights of Persons with Disabilities, which entered into force in 2011 [175]. This convention was the foundation of the development of the European disability strategy 2010-2020 [247], which had as main objective to increase the participation of the people with disabilities, including with mental illness, in the labour market of the different member countries. In Belgium, a first reform started in the work incapacity insurance in 2006 with the aim of supporting the reintegration into the labour market of people with work incapacity (disability) but retaining part of their ability to get paid work. The main mechanism of this reform was to give the medical reviewer (médecin-conseil) the task of preparing their professional reintegration (i.e. suggest that a person be supported in vocational programs) in addition to the initial task of assessing their degree of incapacity [248]. This reform came into force in 2009 with the adoption of the Royal

Decree of 30 March 2009 amending, as regards professional reintegration, the application of the Federal law of 14 July 1994 on compulsory insurance and compensation [249]. Following this royal decree, the process of professional reintegration was individualised and proposed more systematically to people with disability [250]. In 2010, a declaration of intent was concluded between the National Institute for Health and Disability Insurance (INAMI-RIZIV), the national unions of the health insurers and vocational services in order to organise the professional reintegration of people with disability by signing agreements with the three regional employment services (agreements signed in 2012 in Flanders, 2013 in Wallonia, and 2014 in the Brussels-Capital Region) [250]. In 2011, the federal government launched its "Back to Work" program and improved access to professional reintegration by removing the need for authorization from a medical reviewer to begin the reintegration process and by making the combination of work income and partial disability benefit more attractive [250, 251]. In 2012, a new law was adopted to set up a financial incentive for professional reintegration, i.e. people with disability receive five euros instead of one per hour of training, supervision or apprenticeship and can double their allocation (from 250 to 500 euros) if the professional reintegration program is successfully completed [252]. In 2014, a law was adopted to establish an individual professional reintegration plan no later than 3 months after the beginning of the incapacity period of an individual and following a consultation with the medical reviewer [253]. Unfortunately, for people with mental illness, we had to wait until 2013 and the publication of an OECD report [92] highlighting that mental illnesses are one of the main causes of work incapacity in Belgium and the lack of a specific Belgian initiative to tackle this issue for their professional reintegration to be on the political agenda.

1.3.7 The Individual Placement and Support model

The low employment rate of people with SMI in Western countries can be partly explained by the inadequacy for this specific audience of the traditional "train-and-place" approach of vocational and employment services (i.e. support preparatory training prior to engagement) [254, 255]. Following the “recovery ideology” (people with SMI want and need more than just symptom relief) in the 90s in the US, the New Hampshire Division of Mental Health began to emphasise employment as a key outcome for mental health care [256]. Various vocational programs were then developed, with among them a model described by Deborah Becker that is now called Individual Placement and Support (IPS) [257]. The IPS model emphasise a “place-and-train” approach, i.e. rapid placement in competitive employment with support provided as needed, rather than the traditional "train-and-place" approach [70, 256]. The IPS model is based on several core principles [109, 110]: (I) Competitive employment is the goal, (II) zero exclusion policy, the only precondition is that the client wants to work; (III) rapid job search, (IV) integration of vocational rehabilitation and mental health services, (V) priority to client preferences, (VI) continuous and comprehensive assessment, (VII) time-unlimited support, and (VIII) benefits counselling. The IPS model has been widely developed and evaluated in the US through a large number of randomised controlled trials. Different meta-analyses highlighted that in comparison to people with SMI treated in traditional vocational programs, those treated in the IPS model were 2.4 times more likely to achieve competitive employment (RR = 2.40, 95%CI = 1.99 - 2.90) [258], 3.2 times more likely to find any employment (RR = 3.24, 95%CI = 2.17 - 4.82) [259], had shorter time to first competitive employment (d = -0.31, 95%CI = -0.46, -0.16), longer job tenure (d = 0.56, 95%CI = 0.33 - 0.79), longer duration of work (d = 0.46, 95%CI = 0.35 - 0.57), and higher total income (d = 0.48, 95%CI = 0.36 - 0.59) [260]. Subsequently, the IPS model was implemented and tested in Canada, the UK, the Nederlands, Germany, Italy, Bulgaria, and Switzerland, and the results of the different evaluations tended to confirm that the IPS model is more efficient than the other existing approaches in helping people with SMI to find and retain employment [72, 261-263]. However, as with many other evidence-based interventions [264], the IPS model is not consistently and widely implemented [109] (see Chapter 6).

In Belgium, following the publication in 2013 of the OECD report [92] highlighting the lack of a specific Belgian vocational programs for people with mental illness, the center of expertise on incapacity for work of the National Institute for Health and Disability Insurance (INAMI-RIZIV) launched in 2014 a first exploratory study entitled « Quelles perspectives de réinsertion professionnelle pour les assurés de l’INAMI souffrant de troubles mentaux ? » [250]. Subsequently, recommendations were made to improve the employability of people with a mental health problem in Belgium, in particular the implementation of IPS pilot projects in Belgium [250]. Finally, a randomised controlled trial (RCT) on the IPS model started in Belgium in 2017 and 1,200 vocational rehabilitation courses (600 in IPS and 600 in the traditional Belgian vocational program) of people with work incapacity who suffer from moderate to severe mental illness will be followed over a period of 5 years. The results of the RCT will be decisive for the implementation of the IPS model in Belgium.

1.3.8 Supported education

As previously explained, lack of education increases the risk of social exclusion as it reduces the chances of accessing a job [78], but it also leads to disadvantages in the acquisition of skills, a decrease in life chances in adulthood, and a loss of social capital [122]. Unfortunately, the age of onset of several mental illnesses and particularly severe mental illnesses such as psychosis and bipolar disorder is 15 to 25 years old, period corresponding to the end of secondary school and the start of higher education [19, 116]. As a result, this may have an impact on educational attainment and several studies have shown that mental health problems beginning in early life, adolescence, and young adults are associated with an increased risk of premature discontinuation of studies [117, 118]. For example, one study has shown that in people with early onset psychosis, more than half had no educational qualification [119]. Conversely, one study found that 50% of individuals with SMI want to pursue education [265]. Indeed, some studies have shown that people with IMS view post-secondary education as an opportunity for personal growth and for achieving recovery and social integration [266-268]. However, people with SMI who wish to pursue education face a multitude of barriers such as stigma from students and instructors [269, 270], lack of instructor empathy [271], lack of support from family and friends [272], and lack of access to general supported education services [271, 273]. There is therefore a need for specific supported education program and interventions to overcome these barriers.

Supported education is a practice delivered through community mental health or other mental health services in which supported educational workers help people with SMI to pursue and achieve their educational goals [274, 275]. There are three general models of supported education, depending on the degree of integration of the participants into the life of the school and of the service providing the support [276, 277]. First, the self-contained classroom model which offers a specialised program designed to help people with SMI acquire the basic academic skills needed to enter college or another school program of their choice. Second, the on-site model which offers the possibility for people with SMI to take integrated courses in a college or university while benefiting from the support of on-campus services for all students with disabilities. This model does not include preparatory coursework to improve academic and social skills before participants enter the school environment. Finally, in the mobile supported education model, supported educational workers travel to provide assistance at the facility where the person with SMI is attending classes. Supported education programs in many countries combine elements of these three general models.

Supported education programs for people with SMI have often been evaluated and various studies have shown that they increase enrolment in institutions and coursework [278, 279], course completion [280, 281], employment and or income [282, 283], and recovery [284, 285]. There is also some evidence that supported education can increase the positive effects of supported employment programs provided in mental health services [278, 286]. However, supported education programs are not widely implemented and therefore there is a lack of availability of these programs for the majority of people with SMI want to continue their education [287].

In Belgium it seems that there is no clearly defined and implemented supported education program for people with SMI. Some mental health services provide educational support and apart from these services, people with SMI benefit, like the general population, from general employment and training assistance services.

1.3.9 Voting rights policies for people with mental illness

There is no international or national legislation specific to the political participation of people with a mental illness; their status is often included in the legislation for people with a disability. The article 29 of the 2006 United Nations Convention on the Rights of Persons with Disabilities, ratified by Belgium, certifies that *"States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others"* including the right to vote and be elected [175]. Subsequently, the question of the capacity to vote was raised by many countries and in 2013, the United Nations Committee on the Rights of Persons with Disabilities ruled for a strict interpretation of article 29, regardless of the degree of capacity of individuals [288]. United Nations law therefore does not place any restrictions on the political participation of people with disabilities.

However, people with disabilities still have limited access to political participation and their political impact is less compared to their large number [289].

In Belgium, many efforts have been made to improve the political participation of people with disabilities. In 2013, the law on legal protection regimes has been amended with the “Loi du 17 mars 2013 réformant les régimes d'incapacité et instaurant un nouveau statut de protection conforme à la dignité humaine » [290]. The legal decision to put an individual under the status of legal protection no longer systematically deprives him of his right to vote, only a specific decision of the judge can. Other means to improve their political participation have been put in place, such as adapted transports on election days or the right for people with disabilities to be accompanied in the voting booth [291]. However, the participation in elections of people with a disability is not evaluated in Belgium as in many countries and there is therefore no data to assess the impact of these policies and interventions.

1.3.10 Interventions to support socialisation and community participation

As previously explained, people with SMI are more likely than people without mental illness to be socially isolated, they have a limited social support network (SSN), and less participation in community and cultural activities. However, these dimensions of social integration are not the most studied and interventions to strengthen the SSN and the community and social participation of people with SMI are limited. A systematic review published in 2015 assessed the effectiveness of interventions to strengthen the SSN of people with SMI and highlighted that although these interventions were effective (i.e. increase in the SSN size), only five studies met the inclusion criteria (n = 631 patients) [135]. The interventions identified as effective were guided peer support [292], volunteer partner scheme [293], supported engagement in social activity [294], dog-assisted integrative psychosocial therapy [295], and psychosocial skills training [296]. For more information on these interventions, I refer the reader to the cited references. Befriending is another intervention, mainly used in the UK, to help people with SMI to build and sustain social relationships. Befriending is mainly practiced in the voluntary sector, with volunteers supporting people in difficulty, including people suffering from mental illness, and providing *"companionship and support of a friend to a client especially in a lay capacity”* [297]. Unfortunately, there is moderate quality evidence to support the use of befriending to improve specific outcomes (i.e. severity of symptoms, quality of life, loneliness, social support) for people with mental illness [297].

However, these interventions are not widely implemented and practiced. In Belgium, there are few not-for-profit associations offering peer support and services aiming at community participation and socialisation. These services could be defined as "alternative services" (e.g. club house, café, peer-led services, etc.) and "*are note formally included within the mental health system, and were often created on the initiative of service users themselves and their relatives. They can be described as inclusive spaces which voluntary de-emphasize both social and diagnostic categories in every day interactions.*" [298]. The main objectives of these services are to integrate former and current mental health services users within mainstream society and to support and develop socialisation opportunities by organising collective activities in a local community [298].

Problematisation

1.4 Does the obligation of means lead to results?

What is the impact of these decades of changes in mental health systems, policies and interventions on the social integration of people with SMI? The purpose of this chapter was to address, and if possible to answer this question. There are many methods to assess the impact of a change at the system level (e.g. the establishment of a policy) on the health of a population (e.g. the social integration of people with SMI). One way to do this is to analyse changes over time in population health indicators. Therefore in this chapter, I reviewed and included systematic reviews and meta-analysis on social integration indicators of people with SMI, including their recovery rate because as previously explained, many outcomes associated with recovery are also indicators of social integration (e.g. having a job, living independently or socializing) [85, 172, 173].

It is widely accepted that a proportion of people with SMI have a favourable prognosis in terms of clinical and social functioning outcomes. However, the precise proportion of individuals and the evolution over time of this proportion are poorly understood. In addition, most epidemiological studies do not have a comprehensive approach of the social integration of mentally ill people. Large-scale surveys often focused on measures of economic exclusion, such as the unemployment rate [75, 299, 300] or income and debt [301-303].

To the best of my knowledge, only four systematic reviews and meta-analysis have assessed social integration-related outcomes among people with SMI and the evolution over time of the proportion of individual reported good outcomes [304-307]. The first meta-analysis published in 1994 by Hegarty and colleagues [304] was based on 320 cohort studies (311,400 person-years of follow-up) published between 1895 and 1992, “one hundred years of schizophrenia”. This study found that 40% of people with schizophrenia reported good outcomes and that this proportion did not improved over time. However, this meta-analysis combined studies using different definition of good outcomes, sometimes clinical and sometimes social functioning outcomes, thus making their comparison difficult and questionable. In 2004, Warner [306] analysed 114 follow-up studies published between 1904 and 2000 that used clear definitions of good clinical (loss of psychotic symptoms), functional (return to pre-illness level), and social (economic and residential independence and low social disruption) outcomes. This study estimated that 11% to 33% of people with schizophrenia reported both good clinical and functional outcomes and 22% to 53% reported good social outcomes. Consistent with the findings of Hegarty et al, this study highlighted no improvement over time in the proportion of individuals with schizophrenia reported good outcomes. In 2006, a systematic review by Menezes and colleagues [305] of longitudinal studies published between 1996 and 2003 found that 42% of people with first-episode psychosis reported good outcomes. However, as in the study of Hegarty et al, the 37 longitudinal studies included used widely different definition of good outcomes without clear criteria. More recently, Jääskeläinem and colleagues [307] conducted in 2013 a systematic review and meta-analysis of 50 longitudinal studies of people with schizophrenia. The included studies used criteria for defining good clinical (clinical remission) and social functioning (living independently, being employed or active, etc.) outcomes as well as a criteria for the persistence of good outcomes (lasting for at least two years). The proportion of people with schizophrenia reported both good clinical and social functioning outcomes for at least 2 years was 13.5% (25-75 quantiles = 8.1-20.0) and 19.0% (25-75 quantiles = 16.3–19.7) for social functioning outcomes only. These lower rates compared to other studies are probably related to more stringent criteria such as the persistence of good outcomes for at least two years. In addition, this study reported the first annual recovery rate for schizophrenia with a median estimate of 1.4% suggesting that *"for every 100 individuals with schizophrenia, 1 or 2 individuals per year would meet the recovery-related criteria, and approximately 14% would be expected to recover over 10 years"* [307]. Finally and consistently with the previous studies, this study highlighted no improvement over the last decades in the proportion of recovered cases.

In Belgium as previously explained, a reform in the organisation of mental health care has been under way since 2010 with the objective, among others, of strengthening the social integration of people with mental illness [192]. A recent case-control study assessed the effectiveness of this reform on continuity of care, quality of life, re-hospitalisation and social integration of people with SMI [308]. This study highlighted that greater exposure to the reform[2] was associated with a slight improvement in the perceived continuity of care of people with SMI ($\beta = 1.27$, $p < 0.01$), but not with their social integration ($\beta = 0.08$, $p < 0.20$) and other outcomes.

Taken together, these studies show that despite major reforms in mental health care and the implementation of policies and interventions to improve the social integration of people with SMI, their social integration-related outcomes, for example having a job and residential independence, have remained relatively low and have not improved over the past decades. How can we understand this remarkable but regretful finding?

1.5 Aim and backbone of the thesis

Why the social integration of people with severe mental illness is still lagging behind despite mental health reforms and the implementation of social integration policies and interventions to improve it? It is known that the health outcomes of the population are influenced by factors at the micro (i.e. direct care and support to users), meso (i.e. organisation of care and services), and macro (i.e. health systems

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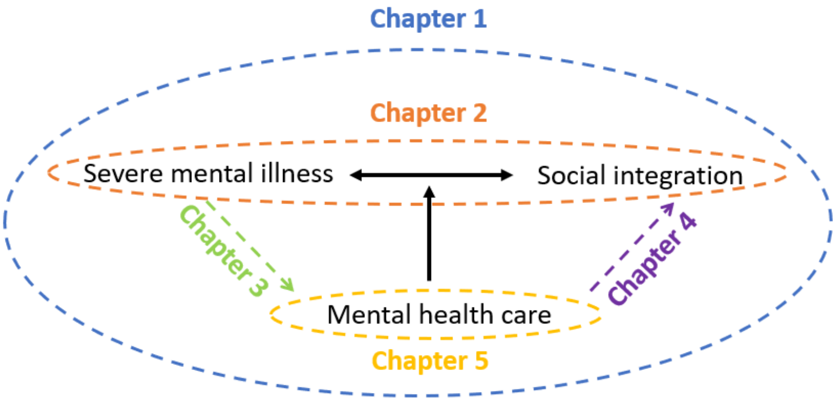
[2] In this study, a composite index of intensity of exposure to the reform was computed for each people with SMI with a total score ranging from 0 (lowest exposure) to 5 (highest exposure).

policies and reforms) levels [309, 310]. Much research has shown how the direct provision of care and support can influence the social integration of people with SMI and has developed socially inclusive evidence-based practices. However, social integration is by definition the result of collective mechanisms at the meso and macro level. Therefore, **the overall aim of this thesis was to shed light on how factors related to mental health services, systems and policies influence the social integration of people with SMI.** Figure 5 summarises the different hypotheses of this thesis as well as their articulation in the general structure of the thesis.

Figure 5: Structure of the thesis



Chapters	Perspectives / hypotheses	Aim
Ch. 1	Introduction of the thesis	Produce a comprehensive update of the different dimensions of the social integration of people with SMI and of policies, systems reforms and interventions to tackle their social exclusion, at the international level and in Belgium
Ch. 2 and 3	Previous population-level reviews had methodological limitations which may have hindered a proper assessment of the evolution over time of the social integration of people with SMI	Assess the evolution between 1997 and 2018 in Belgium of the social integration of people with SMI in comparison with the general population

Ch.4	There may be another dimension of social exclusion: services exclusion (i.e. not all people with SMI have access to adequate health services and interventions)	Identify which people with SMI are exposed to different care approaches and if this exposure is associated with the characteristics of individuals and/or health care systems
Ch.5	Psychiatric hospitalisations (widely used mental health care), may lead to some extent to social exclusion but the evidence is unclear	Assess the impact of the number of admission and the length of stay in psychiatric ward on the social integration of people with SMI
Ch.5	The social integration of people with SMI may not be a priority objective over the other objectives of mental health stakeholders	Identify the priority objectives of mental health stakeholders in Belgium

First, it is possible that the studies included in the previously mentioned systematic reviews and meta-analysis have samples, methods, contexts and criteria for the definition of good outcomes that are too heterogeneous to allow their comparison and a proper assessment of the evolution over time of the social integration of people with SMI. In addition, it should be noted that (1) these studies have focused on people with schizophrenia and (2) they did not systematically compare the indicators of social integration of SMI people with the general population. On the one hand, schizophrenia is a low prevalence disorder (below 1%) characterised by high levels of impairment and disability [19, 311, 312]. Therefore, it is unclear whether the lack of improvement over time in social integration is specific to people with schizophrenia and whether it has evolved differently for people with other severe and moderate mental illnesses. On the other hand, the social exclusion of an individual is directly related to the average level of social integration of the society in which he or she lives. Therefore, the analysis of the social exclusion of a very specific group such as severe mentally ill people should be settled in comparison with the general population. In view of the potential methodological limitations of the previous above-mentioned studies and to confirm or refute their results, the aim of the **second and third chapters** of this thesis was to assess the evolution between 1997 and 2018 in Belgium of the social integration of adults with moderate and severe mental illness in comparison with the general population.

Second, another hypothesis is that there could be a fifth dimension of social exclusion of people with SMI, namely services exclusion (i.e. not all people with SMI have access to adequate health services and interventions). For example, individuals with low socioeconomic status experience differential access to mental health care, as they are less likely to see a specialist [313, 314]. Therefore, even if evidence-based interventions are provided, they may not be accessible for all people with SMI and the expected outcomes will not be achieved. However, it is unclear which individuals have access to these different interventions because little research has been conducted to describe the characteristics of people with SMI who actually benefit from it. A key element of care for people with SMI is continuity of care and the interventions to guarantee and improve it. Indeed, mental health care systems in Western countries are complex and fragmented and people with SMI had limited ability to navigate by themselves in these systems and to coordinate their different providers [187, 188]. Therefore, they are more likely to experience fragmentation and lack of continuity of care as highlighted in the literature [315-317]. In Europe, at discharge from a psychiatric hospital, people with SMI may be exposed to one of two main models of continuity of care: personal continuity, where one clinician is responsible for in- and outpatient care, and specialisation, where various clinicians are responsible. However, specific needs of subgroups of patients, for example social integration needs, may be best met by either personal continuity or specialisation. Indeed, several studies suggested that specialisation would be more appropriate for patients with limited needs and moderate disease severity [317-319]. Conversely, vulnerable groups with more complex psychosocial needs might benefit more from having, a single clinician follow them up over time and across care settings [316, 320]. Although these two care approaches are more suitable for, and preferred by, particular subgroups of patients, they may not be accessible to or provided to those subgroups [321, 322]. However, there has been little research describing the characteristics of patients who actually benefit from each of these two care approaches. The aim of the **fourth chapter** of this thesis was to increase our understanding of the impact of the clinical and sociodemographic characteristics of people with SMI on the access to continuity of care models across five European countries (The UK, Italy, Germany, Poland, and Belgium) with different modes of organisation of care.

Third, despite a movement of deinstitutionalisation of mental health care has been in place in Western countries since the last decades to provide community care and promote the social integration of people with SMI, psychiatric hospital retains an important role in mental health care [323, 324]. Even today, people with SMI tend to experience long length of stays (LoS) in psychiatric hospitals and repeated admissions that may disrupt their social and professional life and may affect their social integration [182, 325]. As suggested by Goffman [326], Honigfeld [327], or Gruenberg [183], one of the consequences of excessive LoS and readmissions in psychiatric hospital is the "social breakdown syndrome" in which psychiatric patients experience community and social withdrawal, exclusion from typical social roles, and a decline in their social integration [183, 184]. For example, some patients fear that they will not be able to return to paid employment after a long hospital stay or repeated admissions [328]. So far, however, studies on the impact of hospitalisation in psychiatric ward on patients' social integration have been inconclusive [190, 329]. Therefore, the purpose of the **fifth chapter** was to assess the impact of the number of admission and LoS in psychiatric ward on the social integration of people with SMI in five European countries mentioned above.

Finally, although national and international bodies have advocated over the last decades for mental health care reforms to provide effective, equitable and affordable mental health care [330-332], the implementation of these reforms is often slow and inconsistent and the policy goals they aim for, such as the social integration of people with mental illness, are far from being achieved [264, 333]. One explanation for the slow and inconsistent pace of reforms is that they have been thwarted or reshaped because of resistance of stakeholders and inconsistency between their priorities and the policy priorities [168, 334-337]. For example, one study found that differences in the effectiveness of evidence-based supported employment interventions for people with SMI between the US, Canada, and Europe were related to implementation difficulties and to low fidelity of the implementation of the model due to resistance and barriers of stakeholders such as policymakers, program administrators, clinicians or the users themselves [109]. The effective implementation of health care reforms and interventions depends on the stakeholders' endorsement of their programs and goals, however, stakeholder priorities and oppositions around the main goals of mental health policies, including the social integration of people with mental illness, have received little attention. In the context of the ongoing nation-wide mental health care reform in Belgium, the objective of the **sixth chapter** was to identify and describe stakeholder coalitions formed around the mental health policy goals and highlight their core policy goals and oppositions.

Methods

Table 2 provides an overview of the data sources, setting, and methods used in the five empirical chapter of this thesis. This thesis is composed of quantitative studies using different methodologies. This whole thesis, as well as the literature review carried out in the introduction, is based on the postulate that can and should be measured by means of validated indicators or scales, ranging from exclusion to integration. This quantitative approach makes it possible to assess the social integration of one population in relation to another, to identify socially excluded sub-groups and to analyse the determinants, causes and effects of this exclusion. The main limitation of this choice is that social integration is also a subjective experience. For example, a person may have a job, housing, activities, family and friends but still feel socially excluded (See 7.3 Limitations of the thesis and perspectives).

The second particularity of this thesis is that it combines Belgian and international data. The studies in Chapter 2, 3, and 6 looked in more detail at the Belgian context and the studies in Chapters 4 and 5 used data from five European countries, including Belgium, and therefore identified elements applicable to Belgium but also to others international contexts. To ensure the coherence of the thesis, the social integration of people with SMI in Chapters 2, 3, 4 and 5 was measured with comparable economic (e.g. employment status) and social (e.g. friendship or marital status) indicators. This choice to combine Belgian and international data is mainly explained by two reasons. First of all, analysing the Belgian context requires putting it in perspective with other international contexts. This comparison of countries makes it possible to draw up recommendations for Belgium on the basis of the experience of other countries. Second, this choice is linked to my research questions. In some of my studies (e.g. Chapter 4), the question of the country effect arose and I therefore wanted to test the country effect and investigate the differences and similarities between Belgium and other countries. In other studies (e.g. Chapter 6), the research question was specific to the Belgian context and therefore required more detailed Belgian data and a more specific analysis of the Belgian context, without the possibility or utility of an international comparison.

The variety in the quantitative methods used is justified by the research question of each study. Large-scale surveys of people with SMI such as the COFI study used in Chapters 4 and 5 often do not allow comparison between people with SMI and the general population without mental illness. Therefore, in **Chapter 2 and 3** I used data from the Belgian Health Interview Survey to compare people with moderate or severe mental illness with the general population without mental illness and assess the evolution of their social integration over time using data from five cross-sectional waves (1997, 2001, 2004, 2008 and 2013, n ≈ 10,000 per wave). However, it should be noted that the prevalence of people with SMI as well as the severity of their condition are probably underestimated because data from health interview surveys do not cover the institutionalised population and an unknown proportion of people with more complex and severe mental illness are institutionalised.

In **Chapters 4** and **Chapter 5**, I used data from the COFI study to which I contributed from September 2016 to the end of the project in May 2018. As previously explained, people with SMI are a marginalised and often institutionalised population and it is therefore difficult to have detailed large-scale surveys with this specific group. Data from the COFI study are of rare quality as more than 7000 people with SMI (and more than 2000 in the more detailed subsample) were followed-up at one year in the UK, Germany, Poland, Italy, and Belgium. In addition, this study provides detailed data with sociodemographic, clinical, health and social measures of people with SMI, including on their social integration, as well as information on their use of care and services. The detailed protocol of the COFI study has already been published elsewhere [338].

Finally, social integration of people with SMI should be entrenched in the mental health policies. Thus, **Chapter 6** focused on mental health policy goals of the Belgian mental health care reform and on stakeholders in the organisation of mental health care. In this chapter, I collected data using a national online stakeholder survey as part of a general research project on mental health care and policy in Belgium, entitled KCE HSR52 (2017-2018) [243]. A stakeholder is a person or an organisation having an important stake in or influence on the solutions being considered [339, 340]. In this study, these included policymakers, public authorities, sickness funds, experts, professional associations, service managers and network coordinators, clinicians, and representatives of users and family associations (n = 469, online survey response rate = 40%). Data were collected on stakeholder policy priorities around the main mental health policy goals in Belgium (i.e. community care, continuity of care, recovery of users and the reduction of the resort to hospital).

Table 2: Overview of chapters and methodology

Chapters	Data sources	Methods	Settings
Chapter 2 and 3	Belgian Health Interview Survey	Quantitative, comparative cross-sectional population surveys (1997, 2001, 2004, 2008, 2013, 2018)	Belgium
Chapter 4	COFI survey data	Quantitative, prospective cohort study on 7302 patients consecutively admitted in 2014-2015 to inpatient psychiatric care and followed up at one year	Five European countries (The UK, Germany, Poland, Italy, Belgium)
Chapter 5	COFI survey data	Quantitative, prospective cohort study on a subsample of 2181 patients consecutively admitted in 2014-2015 to inpatient psychiatric care and followed up at one year	Five European countries (The UK, Germany, Poland, Italy, Belgium)
Chapter 6	KCE-HSR52 survey data	Quantitative, national online survey on 469 stakeholders of the Belgian mental health care organisation	Belgium

References Chapter 1

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Chapter 2

2

Chapter 2: Social exclusion of people with severe mental illness: The widening gap from 1997 to 2018 in the Belgian adult population

Since the early 2000s, the social integration of people with SMI has become a major objective of mental health and social welfare systems and many countries have developed specific social integration policies and interventions to achieve this objective [1]. However, four systematic reviews combining studies on different social integration indicators have shown that social integration outcomes of people with SMI, for example having a job and residential independence, had not improved in recent decades [2-5]. The studies included in these systematic reviews have samples, methods, contexts and criteria for the definition of good social integration outcomes that are too heterogeneous to allow their comparison and a proper assessment of the evolution over time of the social integration of people with SMI. In addition, these studies focused on people with schizophrenia, which is a low prevalence disorder (below 1%) characterised by high levels of impairment and disability [6-8]. Therefore, it is unclear whether the lack of improvement over time in social integration is (1) due to the potential methodological limitations of the aforementioned studies or (2) is specific to people with schizophrenia and whether it has evolved differently for people with other severe and moderate mental illnesses.

The aim of the **second chapter** of this thesis was to assess the evolution between 1997 and 2018 in Belgium of the social integration of adults with moderate and severe mental illness in comparison with the general population.

Chapter 2

Title: Social integration of people with mental illness: The widening gap from 1997 to 2018 in the Belgian adult population

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Status: Submitted to The British Journal of Psychiatry

Abstract

Background: People with mental illness (MI) struggle with poor social integration such as finding a job and maintaining social relationships. In the past decades, many countries have developed specific policies to address this issue. Yet, the improvement over time of the social integration of people with MI remains uncertain. This study aimed to assess the evolution between 1997 and 2018 of the social integration of adults with moderate and severe MI compared to the general population without MI, in a country, Belgium, which carried out important reform of mental health policies.

Methods: Data on the general adult population were retrieved from the Belgian Health Interview Survey in six cross-sectional waves (1997, 2001, 2004, 2008, 2013, and 2018). Three degrees of MI severity were compared using the 12-item General Health Questionnaire (GHQ-12): no MI, moderate MI, and severe MI (score < 4, 4-7, and > 7). Social integration was measured with employment status, income, social contacts, and partnership status. Adjusted prevalence and time-trend measures of social integration indicators were estimated for the different time periods. The association between social integration indicators, MI severity, and survey years was assessed with logistic regression models.

Results: Between 1997 and 2018, social integration increased for the general population without MI and for people with moderate MI, but it decreased for people with severe MI. Logistic regression analyses revealed that with 1997 as the reference year, the probability of being unemployed, of having low social contact, and of living on less than 60% of the median national income has increased over time for people with severe MI compared to the general population without MI.

Conclusions: The social integration gap between people with severe MI and people with moderate or without MI is widening over time. Social and economic policies and clinical practitioners should support the social integration of people with more severe MI, particularly their employability and social support. Introduction

Introduction

People with mental illness (MI) struggle with their social integration such as finding a job and maintaining social or intimate relationships. Although between 70% and 90% of people with MI want to work [9-12], they have lower employment rates than the general population without MI or than people with other chronic diseases. Compared to the general population, the risk of being unemployed is two to three times higher for people with moderate MI and six to seven times higher for people with severe MI [13]. Employment rates vary depending on the mental health disorder, with an employment rate of between 10% and 20% among people with schizophrenia [14, 15], between 40% and 60% among people with anxiety disorders [16], and up to 60% among people with mood disorders [17]. Global mental health movements and international bodies (e.g. WHO [18, 19], WPA [20]) have increasingly supported the goal of social integration of people with MI and many countries have developed interventions and policies that specifically targeted this goal, such as specific vocational programs and services for people with MI [21, 22]. However, there is limited comprehensive epidemiological data and figures on the extent of the social integration of people with MI. Therefore, social integration interventions and policies are not often based on empirical evidence on the needs and extent of the social integration of people with MI. In addition, the improvement of the social integration of people with MI over time since the implementation of these interventions and policies remains unsettled.

Social integration is a multidimensional concept that can be defined as the participation of an individual in the key activities of the society in which he or she lives (e.g. employment, social support, housing) [23, 24]. However, most epidemiological studies often focused on indicators of economic integration of people with MI, such as the employment rate [25-27] or income [28-30]. It is therefore difficult to have a comprehensive picture of the social integration of people with MI and its evolution over time. Four systematic reviews combined studies on different social integration indicators on people with severe MI. These reviews showed that social integration indicators of people with severe MI, for example having a job and independent housing, did not improve in the last decades [2-5]. However, the included studies have (1) focused on people with schizophrenia or with first episode psychosis, and (2) without systematic comparison with the general population without MI. First, psychotic disorders are low prevalence disorders (about 1%) characterised by high levels of impairment and disability [6-8]. Therefore, there is need to consider a larger spectrum of the wider population of people with MI and it is unclear whether the lack of improvement over time in social integration is specific to people with psychotic disorders and whether it has evolved differently for people with other severe or moderate MI. Second, the social integration of an individual is directly related to the average level of social integration of the society in which he or she lives [31]. Therefore, the analysis of the social integration of a group such as mentally ill people should be in comparison with the general population.

Therefore, the present study aimed to assess the evolution of the social integration of adults with moderate and severe MI in comparison with the general population between 1997 and 2018 in Belgium. To this end, we used sing data from six cross-sectional waves of the Belgian Health Interview Survey. This study aimed to obtain a more comprehensive picture of the social integration of mentally ill people using indicators in the following dimensions of social integration: employment, income, social contacts, and partnership status. In addition, Belgium has been through an important reform of his mental health care system to improve patient social integration since 2010. Our analysis will thus provide valuable insight into the achievement of this goal of social integration of people with MI.

Methods

Study population

Data were extracted from six successive cross-sectional waves of the Health Interview Survey (HIS) carried out in Belgium in 1997, 2001, 2004, 2008, 2013, and 2018. The Belgian HIS is a multistage stratified sampling of the non-institutionalised Belgian population aged over 15 years. The participation rate in the different waves of the survey is about 60% with on average 10,000 respondents per wave, the detailed methodology has been published elsewhere [32, 33]. We included only working age participants aged between 18 and 60 years old. The sample ranged from 4261 participants (in 2013) to 6497 (in 2001).

The mental health status of the participants was assessed in the different waves using the 12-items General health Questionnaire (GHQ-12). The GHQ-12 is a validated tool used to identify non-psychotic mental illness in the general population [34, 35]. The GHQ-12 range from 0 (no MI) to 12 (probable severe MI). A GHQ-12 score ≥ 4 was used as the cut-off point to identify the presence of a mental illness as in other studies [34, 36]. The upper scores were then categorized into two severity groups; moderate mental illness (score 4-7) and severe mental illness (score 8-12) [37]. Indeed, a high score of GHQ-12 is associated with a chronic course of severe mental illness [38]. Finally, we identified three groups; the general population without MI (GHQ score < 4), the population with moderate MI (GHQ score 4-7), and the population with severe MI (GHQ score 8-12).

Indicators of social integration

Four dichotomous indicators were chosen to capture key dimensions of social integration. The first dimension of social integration was the participation in economically or socially valuable activities and a widely used indicator is the employment status [31, 39]. In this study, the indicator used was whether the person had a paid job at the time of the interview. Indeed, having a paid job, regardless of the salary, can promote social integration because work allows people with MI to feel integrated into society, to socialise, and to have a meaningful social role [40, 41]. The economic integration and purchasing capacity (e.g. possibility of having independent housing) of people with MI are also directly related to their income. The income level is therefore additional information to the employment rate when studying the social integration of a population. Therefore, the second indicator used was whether or not the person lived on less than 60% of the median national income. The third dimension was the social contacts and support and an indicator often used is the frequency of social contacts [24, 42]. In this study, the indicator used was whether the person has at least one social contact per week. Finally, the last dimension was the partnership status and the indicator used was whether the person is married or live with his or her partner [31, 42]. Indeed, having a partner is an important and stable source of support as it provides continuous interpersonal closeness, emotional gratification, and support for coping with socio-environmental stressors [43, 44].

Data analysis

Descriptive statistics were computed for socio-demographic characteristics, mental health status and social integration indicators of the study population in each survey year. ANOVA and Chi-square tests were performed to assess the significance of the differences in the socio-demographic characteristics of the population between the six cohorts.

All the following statistical analyses have been adjusted for the age, gender and educational status of individuals. Adjusted prevalence rates of social integration indicators were computed by year for the three groups (people with severe MI, people with moderate MI, and the general population without MI) using direct standardisation with the 1997 Belgian population as the reference [45, 46]. In addition, absolute changes in prevalence rates between 1997 and 2018 were calculated. Trends between 1997 and 2018 of social integration indicators were also assessed in terms of Average Annual Percent Change (AAPC). AAPC is a single measure that describes the average change of prevalence rates over a period of several years [47]. The last stage aimed to quantify and test for the four indicators of social integration the change over time for people with moderate and people with severe MI compared to the general population without MI. Multivariate logistic regression models were used in order to test the association between each of the four social integration indicators and the mental health status (with the general population without MI as the reference group), year as a dummy variable (with 1997 as the reference year), and an interaction between mental health status and year. The interaction allows us to account for the differences in the distribution of mental health status between the six waves. Finally, the coefficients of the regressions were then used to compute the odds ratio of each social integration indicator, in each year compared to 1997, and for people with moderate and severe MI compared to the general population without MI.

Measures of average annual percent change were computed using the Joinpoint Regression Program. Other statistical analyses were performed using SAS 9.3.

Results

Study population characteristics

The six cohorts are presented in Table 3. Although the average age of the population was significantly different between the six cohorts (F = 15.8, $p < 0.01$), the distribution of the population between cohorts was comparable in terms of age and gender. The distribution of the population between the six cohorts was significantly different in terms of educational status ($\chi 2 = 73.3$, $p < 0.01$) and mental health status ($\chi 2 = 175.7$, $p < 0.001$). The proportion of the population with a higher educational status increased between 1997 (38.1%) and 2018 (44.8%). In terms of mental health status, the crude prevalence of moderate MI slightly decreased from 12.7% in 1997 to 9.2% in 2004, then gradually increased to 12.9% in 2018. Similarly, the crude prevalence of severe MI decreased from 6.1% in 1997 to 4.9% in 2001 and 2004, then gradually increased to 7.6% in 2018.

Regarding the evolution between 1997 and 2018 of the social integration of the general Belgian adult population, there was a significant decrease in the unemployment rate (from 31.3% to 25.8%, $\chi 2 = 81.5$, $p < 0.01$) and in the proportion of individuals with less than one social contact per week (from 8.2% to 3.9%, $\chi 2 = 168.2$, $p < 0.001$). However, the proportion of individuals living on less than 60% of the median national income significantly increased over time (from 18.4% to 26.5%, $\chi 2 = 291.6$, $p < 0.001$) as the proportion of single (from 14.5% to 17.9%, $\chi 2 = 71.4$, $p < 0.01$).

Table 3: Characteristic of samples in the six cross-sectional waves

Variables	1997 (n = 5867)	2001 (n = 6497)	2004 (n =5980)	2008 (n = 4906)	2013 (n = 4261)	2018 (n = 5185)	ANOVA / Khi2 (p-value)
Age (y.), mean (SD)	38.4 (11.6)	39.2 (11.5)	39.9 (11.8)	39.8 (12.1)	39.6 (11.7)	39.4 (11.8)	15.8 (<0.01)
Gender, male, n (%)	2908 (49.5)	2936 (49.1)	2931 (49.1)	2409 (49.1)	2059 (48.3)	2551 (49.2)	4.85 (0.30)
Educational status, n (%)							73.3 (<0.01)
- No/Primary	745 (12.7)	727 (11.2)	603 (10.1)	383 (7.8)	311 (7.3)	440 (8.5)	
- Secondary inferior	979 (16.7)	1111 (17.1)	998 (16.7)	677 (13.8)	515 (12.1)	731 (14.1)	
- Secondary superior	1906 (32.5)	2085 (32.1)	1901 (31.8)	1658 (33.8)	1440 (33.8)	1690 (32.6)	
- Higher	2235 (38.1)	2572 (39.6)	2475 (41.4)	2188 (44.6)	1994 (46.8)	2322 (44.8)	
Mental health status, n (%)							175.7 (<0.001)
- General population (GHQ < 4)	4763 (81.2)	5562 (85.6)	5138 (85.9)	4136 (84.3)	3395 (79.7)	4118 (79.4)	
- Moderate MI (GHQ 4 - 7)	747 (12.7)	620 (9.5)	550 (9.2)	509 (10.4)	549 (12.9)	669 (12.9)	
- Severe MI (GHQ > 7)	357 (6.1)	315 (4.9)	292 (4.9)	261 (5.3)	317 (7.4)	398 (7.6)	
Unemployment, n (%)	1700 (31.3)	1569 (26.3)	1487 (27.1)	1097 (25.0)	946 (24.1)	1312 (25.8)	81.5 (<0.01)
Living on less than 60% of the median national income, n (%)	1056 (18.4)	1559 (24.2)	1554 (26.6)	1520 (31.3)	1065 (25.4)	1348 (26.5)	291.6 (<0.001)
Less than one social contact a week, n (%)	480 (8.2)	458 (7.1)	401 (6.8)	163 (3.4)	155 (3.7)	200 (3.9)	168.2 (<0.001)
Partnership status, being single, n (%)	850 (14.5)	957 (14.7)	947 (15.8)	952 (19.4)	702 (16.5)	928 (17.9)	71.4 (<0.01)

Descriptive statistics were performed after exclusion of missing data

Trends of social integration indicators, 1997-2018

Table 4 presents summary measures from 1997 to 2018 of adjusted prevalence and odds ratios of social integration indicators of people with moderate and severe MI compared to the general population without MI. The evolution of the adjusted prevalence of the four social integration indicators over time is also illustrated in Figure 6.

In the different waves and for all four indicators, social exclusion decreased with the severity of the mental illness (i.e. the general population without MI is more socially integrated than people with moderate MI who are more so than people with severe MI). Overall, between 1997 and 2018, the social integration gap widened between people with severe MI on the one hand, and people with moderate or without MI on the other. The results on the adjusted prevalence of the four social integration indicators show two different trends in this widening gap: (1) the social integration indicator improved over time for the general population without MI and for people with moderate MI but not for people with severe MI (i.e. employment status and social contacts), (2) the social integration indicator remained relatively stable over time for the general population and for people with moderate MI but worsened for people with severe MI (i.e. income and partnership status).

Between 1997 and 2018, the unemployment rate decreased for the general population without MI (-12.6%) and for people with a moderate MI (-3.9%), but it increased for people with a severe MI (+5.2%). For the general population, the average annual percent change (AAPC) of the unemployment rate was significantly different from zero and showed an annual decrease of 0.90%. The AAPC of the unemployment rate of people with moderate and severe MI were not significantly different from 0.

Regarding social contacts, the proportion of individuals with less than one social contact per week decreased between 1997 and 2018 in the three groups (-4.5% in the general population, -7.2% among people with moderate MI, and -4.2% among people with severe MI). The decrease over time was more pronounced for the general population without MI, with an AAPC of -6.1% and significantly different from 0.

Conversely for income, the proportion of individuals living on less than 60% of the median national income increased between 1997 and 2018 in the three groups (+4.2% in the general population, +6.7% among people with moderate MI, and +11.0% among people with severe MI). This increase was significant only in people with severe MI, with a significant annual increase of 1.4% (AAPC).

Finally, in terms of partnership status, the proportion of single (i.e. not married or not living with his or her partner) was stable over time in the general population without MI, decreased by 1.1% among people with moderate MI and increased by 8.9% among people with severe MI. For people with severe MI, the increase over time of the proportion of single individuals was significantly different from 0, with an AAPC of 1.6%.

Table 4: Social integration indicators by mental health status and year, summary measures, Belgian adult population from 1997 to 2018

Summary measures		Years						Indicators	
		1997	2001	2004	2008	2013	2018	Absolute change[c] 1997 - 2018	AAPC [d]
Unemployment	Adjusted [a] prevalence (%), **Figure 1**								
	- General population without MI	34.5	31.1	30.4	28.6	24.3	21.9	- 12.6	-0.90*
	- Moderate mental illness	40.3	36.5	37.8	39.1	40.0	36.4	- 3.9	-0.05
	- Severe mental illness	50.4	38.6	42.7	51.7	55.9	55.6	5.2	0.55
	Adjusted [b] odds ratio (OR)								
	- General population without MI	REF	REF	REF	REF	REF	REF	/	/
	- Moderate mental illness	REF	1.30*	1.47**	1.72***	1.88***	2.46***	/	/
	- Severe mental illness	REF	1.52**	1.56**	2.86***	3.82***	5.37***	/	/
Less than 60% of the median income	Adjusted [a] prevalence (%), **Figure 1**								
	- General population without MI	16.6	22.2	23.7	26.8	22.3	20.8	4.2	-0.1
	- Moderate mental illness	18.5	20.5	22.5	28.5	26.1	25.2	6.7	1.2
	- Severe mental illness	19.6	24.8	26.0	32.6	28.1	30.6	11.0	1.4*
	Adjusted [b] odds ratio (OR)								
	- General population without MI	REF	REF	REF	REF	REF	REF	/	/
	- Moderate mental illness	REF	1.32*	1.21*	1.19*	1.48**	1.43**	/	/
	- Severe mental illness	REF	1.41**	1.22*	1.26*	2.15***	2.67***	/	/
Low social contact	Adjusted [a] prevalence (%), **Figure 1**								
	- General population without MI	7.1	6.3	5.9	2.9	2.7	2.6	- 4.5	-6.1*
	- Moderate mental illness	13.0	10.8	10.6	5.3	5.1	5.8	- 7.2	-5.2
	- Severe mental illness	14.3	14.1	15.5	7.2	9.4	10.1	- 4.2	-2.5
	Adjusted [b] odds ratio (OR)								
	- General population without MI	REF	REF	REF	REF	REF	REF	/	/
	- Moderate mental illness	REF	1.79***	1.83***	1.91**	1.96**	2.66***	/	/
	- Severe mental illness	REF	2.36***	2.91***	2.91***	3.58***	4.23***	/	/
Being single	Adjusted [a] prevalence (%), **Figure 1**								
	- General population without MI	13.5	13.8	14.8	15.0	14.6	13.9	0.4	1.1
	- Moderate mental illness	19.3	19.1	21.2	25.3	18.0	18.2	- 1.1	0.8
	- Severe mental illness	19.9	24.4	27.1	31.9	29.3	28.8	8.9	1.6*
	Adjusted [b] odds ratio (OR)								
	- General population without MI	REF	REF	REF	REF	REF	REF	/	/
	- Moderate mental illness	REF	1.44**	1.50**	1.55**	1.25*	1.63***	/	/
	- Severe mental illness	REF	1.88***	1.96***	1.92***	1.88***	1.87***	/	/

* p-value < 0.05, ** p-value <0.01, *** p-value <0.001

[a] Prevalence adjusted for age, gender and educational status

[b] Odds ratio from multivariate logistic regression models adjusted for age, gender and educational status with an interaction between mental health status and years (dummy)

[c] Absolute change = value in 2018 – value in 1997

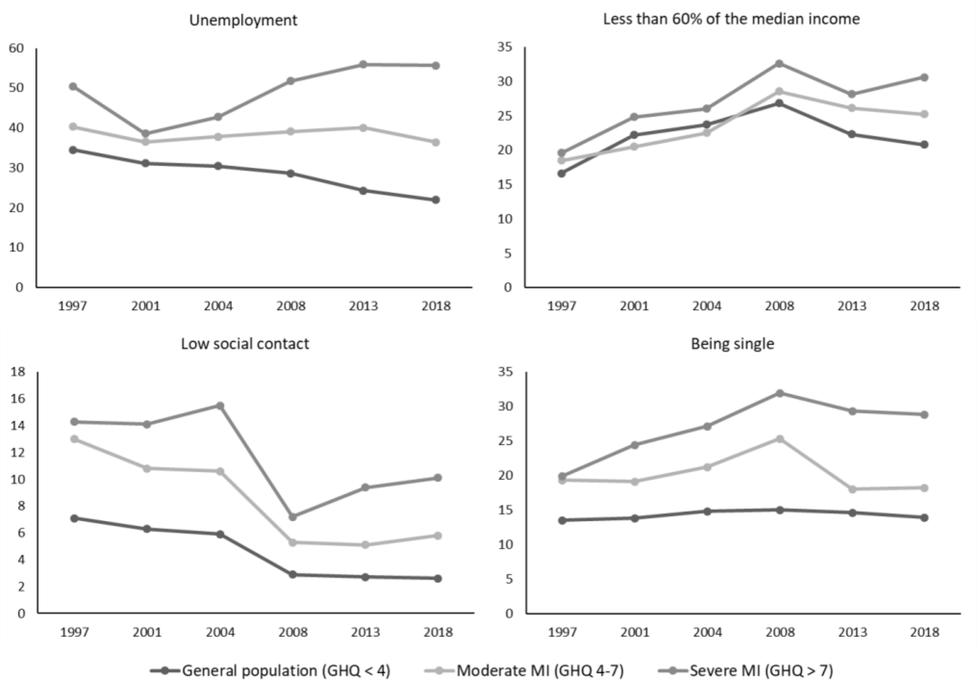
[d] Average Annual Percent Change = $\left\{exp\left(\frac{\sum w_i b_i}{\sum w_i}\right)-1\right\}\times 100$

[e] Multivariate logistic regression models, adjusted for age, gender and educational status, stratified by mental health status with 1997 as the reference year to test the evolution over time

Logistic regression analyses revealed that with 1997 as the reference year, the probability of being unemployed, of living on less than 60% of the median national income; and of having less than one social contact per week increased over time for people with moderate MI and severe MI compared to the general population without MI. With 1997 as the reference year, the probability of unemployment in 2001 was 1.30 ($p < 0.05$) for people with moderate MI and 1.52 ($p < 0.01$) for people with severe MI compared to the general population without MI and these probabilities increased respectively to 2.46 ($p < 0.001$) and 5.37 ($p < 0.001$) in 2018. Compared to the general population, the probability of living of living on less than 60% of the median national income was stable over time for people with moderate MI (from 1.32 in 2001 to 1.43 in 2018), and increased for people with severe MI (from 1.41 in 2001 to 2.67 in 2018). In 2001, the probability of having less than one social contact per week was 1.79 ($p < 0.001$) for people with moderate MI and 2.36 ($p < 0.001$) for people with severe MI and these probabilities increased respectively to 2.66 ($p < 0.001$) and 4.23 ($p < 0.001$) in 2018.

Finally, the probability of being single remained relatively stable over time for people with moderate MI and severe MI, although it remained significantly higher compared to the general population without MI.

Figure 6: Adjusted prevalence of social integration indicators by mental health status and year



Discussion

This study is in line with the results of previous studies that found a gradient of social integration according to the severity of mental illness (MI) [48, 49], people with severe MI are less socially integrated than people with moderate MI, who are less so than the general population without MI. This study shows that this pattern is worsening over time. Between 1997 and 2018, the social integration gap widened between people with severe MI on the one hand, and people with moderate or without MI on the other, with two different trends. First, for indicators of employment status and social contacts, this study highlights an improvement over time for the general population without MI and for people with moderate MI but not for people with severe MI. Second, for the income and partnership status indicators, this study shows that they are relatively stable over time (or an insignificant change) for the general population and for people with moderate MI, but worsen for people with severe MI.

Previous systematic reviews have shown that social integration outcomes of people with severe MI, for example having a job, had not improved in recent decades [2-

5]. However, the studies included in these systematic reviews did not systematically compare their social integration with the general population without MI. Our study in Belgium shows that by comparing the evolution over time of the social integration of people with severe MI with the general population without MI, and therefore considering the average level of social integration of the society in which they lived, we do not observe a lack of improvement of their social integration but a decrease.

The results of this study are linked to the Belgian context and are therefore influenced, among others, by national social integration policies, the mental health care system, the social welfare system, and the labour market. At the level of the Belgian mental health care system, a reform in the organisation of care has been under way since 2010 with the objectives of strengthening community mental health care in favour of users' personal recovery and social integration [50]. A recent case-control study assessed the effectiveness of this reform on continuity of care, quality of life, re-hospitalisation and social integration of people with severe MI [51]. This study highlighted that greater exposure to the reform was associated with a slight improvement in the perceived continuity of care of people with severe MI, but not with their social integration and other outcomes. The authors hypothesised that this low impact of the reform on the outcomes of people with severe MI is related to the lack of definition of target groups within the framework of the reform, leaving extensive autonomy to the different health services in selecting their patients, with a risk of excluding the most vulnerable patients such as people with complex and severe MI. Indeed, a previous study conducted with data from the first evaluation of the Belgian mental health care reform in 2010 had shown that patients with the lowest level of social integration were not the priority target of the services involved in the reform [52]. These results may explain the first trend of the widening social integration gap, i.e. the improvement over time in the social integration of people with moderate MI who benefit from the reform, the lack of improvement for people with severe MI who benefit less, and therefore the growing gap over time in social integration between these two groups. Taken together, these results may also highlight a potential new dimension of the social exclusion of people with severe MI, namely exclusion from services (i.e. not all people with severe MI may have access to adequate health and social services). Therefore, even if policies and interventions are implemented, they may not be accessible for all people with severe MI and the expected outcomes will not be achieved.

Regarding the Belgian labour market, the OECD highlighted in 2013 the lack of specific vocational programs for people with MI in Belgium [53]. This lack of specific vocational programs for people with MI may explain the high unemployment rates of people with MI in Belgium. However, this does not explain the increase over time in the unemployment rate of people with severe MI. A study in 27 European countries found that the period of macro-economic recession between 2006 and 2010 had intensified the economic exclusion and unemployment of people with MI compared to the general population [26]. Indeed, a period of economic recession is often followed by an increase of the competitiveness in the labour market, making it more difficult for people with MI to find and keep a job. Belgium like other countries in Europe was affected by the European economic crisis of 2008. The results of this study may show that this economic crisis has further reinforced the economic exclusion of people with severe MI compared to people with moderate MI. This may explain the second trend of the widening social integration gap, i.e. The stability or absence of significant change over time in the social integration of people with moderate MI but the worsening for people with severe MI.

Strengths and limitations

The main strength of this study is the use of nationally representative samples in six cross-sectional waves. These data allowed us both to compare people with moderate and severe MI with the general population without MI and to assess the evolution over time of their social integration. As previously explained, there is limited information on the evolution over time of the social integration of people with MI and many studies do not compare their social integration with the general population. However, the social integration of an individual is directly related to the average level of social integration of the society in which he or she lives [31]. The second strength of this study is the multidimensional approach of the social integration by combining indicators in the dimensions of employment, income, social contacts and partnership status. Indeed, large-scale epidemiological studies often focused on indicators of economic integration such as the employment rate or income of people with MI. This study also has some limitations. The first limitation is that the GHQ-12 is a validated tool used to identify non-psychotic mental illness in the general population. Although a high score of GHQ-12 is associated with a chronic course of severe mental illness [38], we cannot know if we have identified people with psychotic disorders in the samples of the six cross-sectional waves. Our additional analyses (see additional Table 1) of the socio-demographic characteristics of the 2018 sample put this limit into perspective by showing that our sample of people with a GHQ score greater than 7 do have characteristics of people with severe MI, with a majority of men, a lower level of education and a high proportion of psychotropic drug use compared to the other two groups. Another limitation is that the Belgian health interview survey does not cover the institutionalised population. However, a proportion of people with severe MI are institutionalised. A consequence of these first two limitations is that the social integration of people with severe MI is probably overestimated in this study because people with psychotic disorders and people institutionalised often have a lower degree of social integration. The lack of information on psychiatric diagnoses is also a limitation of this study. Indeed, several studies have established an association between the psychiatric diagnosis and the level of social integration [54, 55], with for example an employment rate of between 10% and 20% among people with schizophrenia [14], between 40% and 60% among people with anxiety disorders [16], and up to 60% among people with mood disorders [17]. Finally, this study covers only four dimensions of social integration, mainly because indicators of other dimensions were not available in the six cross-sectional waves of the Belgian health interview survey. Future studies should also cover two important dimensions of social integration, the dimension of consumption (i.e. the capacity to purchase goods and services, the main indicator in this dimension through the literature is the housing status) and he dimension of social and political engagement (i.e. patient participation in health care decision-making, voting in general election, being a member of an association or commitment to daily life and cultural activities).

Conclusion

Since the early 2000s, the social integration of people MI has become a major official objective of mental health and social welfare systems and many countries have developed specific social integration policies and interventions to achieve this objective [1]. This study highlighted that since 1997, in Belgium, despite the implementation of mental health care reforms and interventions to improve the social integration of people with MI, the social integration of people with severe MI has worsened compared to the general population but also compared to people with moderate MI. The results of this study also showed that this widening social integration gap can be explained by two trends. First, that the policies and reforms put in place between 1997 and 2018 in Belgium may have improved the social integration of people with moderate MI but not that of people with severe MI. Second, that certain contexts and events, such as periods of economic recession, may have a greater negative impact on the social integration of people with severe MI than on the social integration of people with moderate MI.

The social integration of people with a severe MI must therefore become a social, political and economic priority for various reasons. First, their widespread social exclusion is in conflict with international human rights conventions, especially the United Nations Convention on the Rights of People with Disabilities. Second, it is evident that social determinants play a major role in mental illnesses and in the personal recovery of those suffering from them. Indeed, mental illnesses may be both a cause and a consequence of social exclusion [24]. It therefore seems inconceivable to want to improve the personal recovery of people with severe MI without at the same time improving their social integration. Finally, the social exclusion of people with severe MI is costly for our societies. In 2015, the indirect costs of mental illnesses on the labour market represented 2.30% of Belgium's growth domestic product, the highest percentage of OECD countries [56].

The results of this study confirm the importance of interventions and policies aimed at bridging this growing social inclusion gap. This gap could be bridged by first avoiding the exclusion of people with severe MI from general mental health and social services and, second, by implementing specific interventions for people with severe MI, such as the Individual Placement and Support model of supported employment [57].

Funding: This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. The Belgian Health Interview Survey is financed by the Federal and Inter-Federated Belgian Public Health authorities

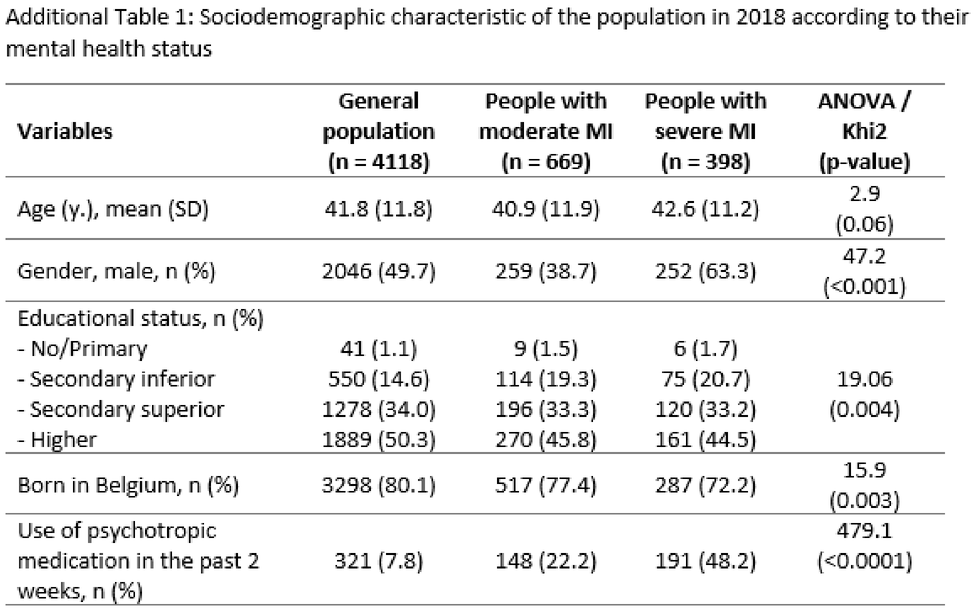
Acknowledgments: Data from the Belgian Health Interview survey used for the empirical part of this study were gathered by the Unit of Epidemiology, Scientific

Institute of Public Health “Sciensano”, in collaboration with Statbel (Directorate General Statistics—Statistics Belgium).

Compliance with Ethical Standards

Conflict of interest: The authors declare they have no conflict of interests.

Ethical Approval: Informed consent was obtained from all subjects involved in the study. The Belgian Health Interview Survey is carried out in line with the Belgian privacy legislation.



Additional Table 1: Sociodemographic characteristic of the population in 2018 according to their mental health status

Variables	General population (n = 4118)	People with moderate MI (n = 669)	People with severe MI (n = 398)	ANOVA / Khi2 (p-value)
Age (y.), mean (SD)	41.8 (11.8)	40.9 (11.9)	42.6 (11.2)	2.9 (0.06)
Gender, male, n (%)	2046 (49.7)	259 (38.7)	252 (63.3)	47.2 (<0.001)
Educational status, n (%)				
- No/Primary	41 (1.1)	9 (1.5)	6 (1.7)	19.06 (0.004)
- Secondary inferior	550 (14.6)	114 (19.3)	75 (20.7)	
- Secondary superior	1278 (34.0)	196 (33.3)	120 (33.2)	
- Higher	1889 (50.3)	270 (45.8)	161 (44.5)	
Born in Belgium, n (%)	3298 (80.1)	517 (77.4)	287 (72.2)	15.9 (0.003)
Use of psychotropic medication in the past 2 weeks, n (%)	321 (7.8)	148 (22.2)	191 (48.2)	479.1 (<0.0001)

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Chapter 3

3

Chapter 3: The Belgian labour market for people with moderate or severe mental illness: some additional figures from 1997 to 2018

Introduction

The previous chapter has shown an increase over time in Belgium in the social exclusion of people with severe mental illness (MI) compared to people with moderate MI and the general population without MI, especially in the employment dimension. Between 1997 and 2018, the unemployment rate decreased for the general population (-12.6%) and for people with moderate MI (-3.9%), but it increased for people with severe MI (+5.2%). However, three essential pieces of information are missing to allow a more detailed analysis of the dimension of employment, i.e. the types of job, the income level, and the level of education.

First, several studies have shown that the health and social benefits of employment are moderate, if not reversed, by poor working conditions [1-6]. However, there are limited studies on the types of jobs of people with severe MI and their working conditions. One study in the UK, France, and Germany has shown that they mainly have 'elementary' jobs such as cleaning, labouring, plumbing or metalwork [7], which do not always have good working conditions. The first objectives of this chapter were therefore to describe, in Belgium, the types of work of people with moderate and severe MI in comparison to the general population without MI and to compare the situation between 1997 and 2018.

Second, having a paid job, regardless of the salary, can promote social integration. As previously explained, the most commonly sought role of people with severe MI is that of a worker because working makes them feel integrated into society, allows them to socialise, to have a meaningful social role and increases their self-esteem and independence [8-10]. However, the economic integration and purchasing capacity (e.g. possibility of having independent housing) of people with severe MI are directly related to their income. The income level is therefore complementary information to the employment rate when studying the social integration of a population. Therefore, this chapter also aimed to study, in Belgium, the income level of people with moderate and severe MI in comparison to the general population without MI and to compare the situation between 1997 and 2018.

Third, integration to the labour market and access to certain types of jobs is directly linked to an individual's level of education. However, the age of onset of several mental illnesses and particularly severe mental illnesses such as psychosis and bipolar disorder is 15 to 25 years old, period corresponding to the end of secondary school and the start of higher education [11, 12]. As a result, this may have an impact on educational attainment and several studies have shown that mental health problems beginning in early life, adolescence, and young adults are associated with an increased risk of premature discontinuation of studies [13, 14]. School integration and supported education of people with moderate and severe mental illness is important because lack of education reduces the likelihood of attaining employment [15]. Therefore, this chapter also aimed to study, between 1997 and 2018 in Belgium, the level education of people with moderate and severe MI in comparison to the general population without MI.

Finally, in Belgium, employment policies are mainly regional and each region has a reference body for unemployment benefits, training and job search (i.e. Actiris for the Brussels-Capital region, VDAB for the Flemish region, and the Forem for the Walloon region). In addition, following the sixth state reform in 2011 and the transfer of competences from the federal state to federated entities (communities and regions), functional rehabilitation and social and professional reintegration services are mainly the responsibility of the regions. Education and teaching policies are linked to linguistic communities and therefore differ between Wallonia and Brussels on the one hand and Flanders on the other. Also, the three regions of Belgium have different political and economic contexts that may influence access to employment for people with MI. For these different reasons, the final objectives of this chapter were to study the regional differences in terms of unemployment rate, level of income, and level of education of people with moderate and severe MI and the evolution of these regional trends between 1997 and 2018.

Methods

As in Chapter 2, I used data from the Belgian Health Interview Survey (HIS). The mental health status of the participants was assessed using the 12-items General health Questionnaire (GHQ-12) [16, 17], ranging from 0 (no MI) to 12 (probable severe MI). The GHQ-12 score makes it possible to identify and compare three groups on the basis of validated cut-off points [16, 18, 19], i.e. the general population without MI (GHQ score < 4), the population with moderate MI (GHQ score 4-7), and the population with severe MI (GHQ score 8-12).

The types of work have been classified using the International Standard Classification of Occupations (ISCO-08) which organises jobs into a clearly defined set of groups according to the tasks and duties undertaken in the job [20]. There are ten types of work in this international classification; (1) managers, (2) professionals, (3) technicians and associate professionals, (4) clerical support workers, (5) service and sales workers, (6) skilled agricultural, forestry and fishery workers, (7) craft and related trades workers, (8) plant and machine operators, and assemblers, (9) Elementary occupations, and (10) armed forces occupations. The income level was estimated using the equivalent household income. The Belgian HIS computed 5 income quintiles based on the Belgian household population; Q1 (lowest), Q2, Q3, Q4 and Q5 (highest).

Descriptive statistics were performed to estimate the proportion of people with severe MI, with moderate MI, and of the general population without MI in the different types of work and in the different income quintiles in 1997 and 2018. Chi-square tests were performed to assess the significance of differences in the distribution of types of work and income quintiles in the three mental health groups in 1997 and 2018. Finally, descriptive analyses by region were performed to assess the difference in the trends in unemployment rate, income level, and level of education of the three mental health groups between regions.

It is important to note that these analyses do not make it possible to determine the direction of the association and to put forward a causality. For example, a high proportion of people with MI in one type of work may be linked to (1) a deliberate orientation of people with MI to that type of work or a lack of access to other types of work or (2) a negative impact of this type of work on the mental health of the people who work there.

Results

Types of work and level of income and education

Figure 9 presents the distribution of types of work among people with severe MI, people with moderate MI, and the general population without MI in 1997 and 2018. There was a significant difference in the distribution of the different types of work between the three mental health groups in 1997 ($\chi2 = 35.75$, $p < 0.01$) and in 2018 ($\chi2 = 70.05$, $p < 0.001$). Overall, it appears that the differences in types of work between mental health groups increased between 1997 and 2018.

We can observe two trends depending on the type of work. First, the categories of managers and professionals showed a negative trend with the severity of mental illness (i.e. these types of jobs were more common among the general population than among people with moderate and severe MI). Second, the categories of clerical support works, plant machine operators and assemblers, and elementary occupations showed a positive trend with the severity of mental illness (i.e. these types of jobs were more common among people with severe and moderate MI than among the general population). In addition, these negative and positive trends seem to strengthen over time. As an example of a negative trend, between 1997 and 2018, the proportion of professionals increased by 7% in the general population (from 19% to 26%) and by 3% in people with moderate MI (from 18% to 21%) but decreased by 2% in people with severe MI (from 19% to 17%). As an example of a positive trend, between 1997 and 2018, the proportion of elementary occupations decreased by 1% in the general population (from 9% to 8%) but increased by 3% in people with moderate MI (from 11% to 14%) and by 4% in people with severe MI (from 12% to 16%).

In 2018, the most common type of work in the three mental health groups was professional, although, as explained above, the distribution was different among the three groups. The second and third most common types of work in people with severe MI were respectively clerical support works (in 3rd place in the general population) and elementary occupations (in 5th place in the general population).

Figure 9: Distribution of types of work (ISCO classification) among people with severe MI, people with moderate MI, and the general population without MI in 1997 and 2018

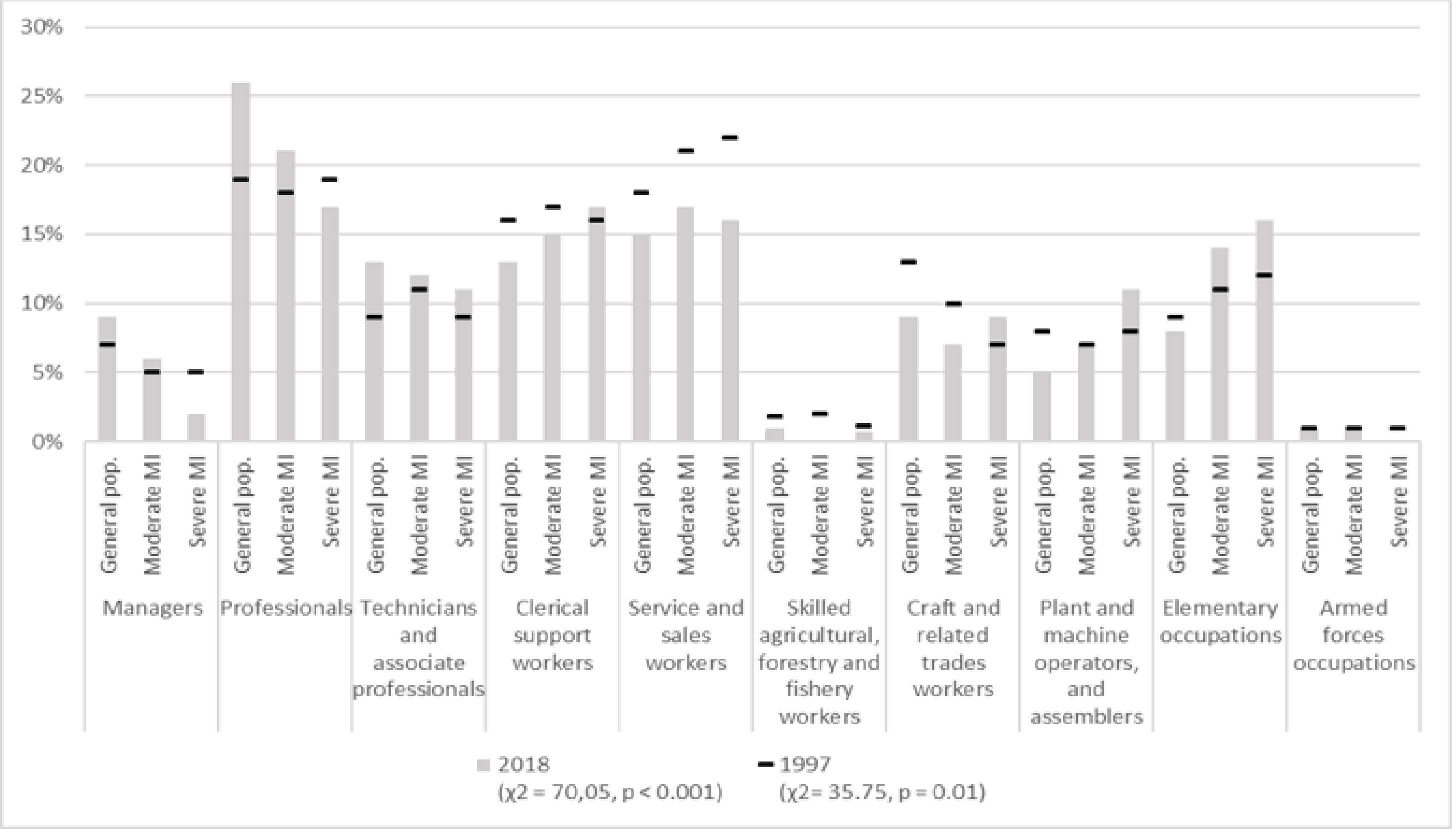


Figure 10.1 presents the distribution of the five household income quintiles by mental health groups in 1997 and 2018. There was a significant difference in the distribution of the five income quintiles between the three mental health groups in 1997 ($\chi2 = 32.25$, $p = 0.001$) and in 2018 ($\chi2 = 125.15$, $p <0.001$).

We can observe a negative trend between income quintiles and the severity of mental illness (i.e. the proportion of individuals in high quintiles decreases with the severity of MI). In 2018, the proportion of individuals in the fifth income quintile was 43% in the general population, 38% in people with moderate MI, and 27% in people with severe MI. Conversely, the proportion of individuals in the first income quintile was 4% in the general population, 8% in people with moderate MI, and 14% in people with severe MI.

Overall, it appears that this negative trend increased over time. Between 1997 and 2018, the proportion of individuals in the fifth quintile increased by 21% in the general population (from 22% to 43%) and by 20% in people with moderate MI (from 18% to 38%) but only by 11% in people with severe MI (from 16% to 27%). In the first income quintile, the proportion of individuals decreased by 10% in the general population (from 14% in 1997 to 4% in 2018) and by 11% in people with moderate MI (from 19% to 8%) but only by 1% in people with severe MI (from 15% to 14%).

Figure 10.1: Distribution of the five household income quintiles among people with severe MI, people with moderate MI, and the general population without MI in 1997 and 2018

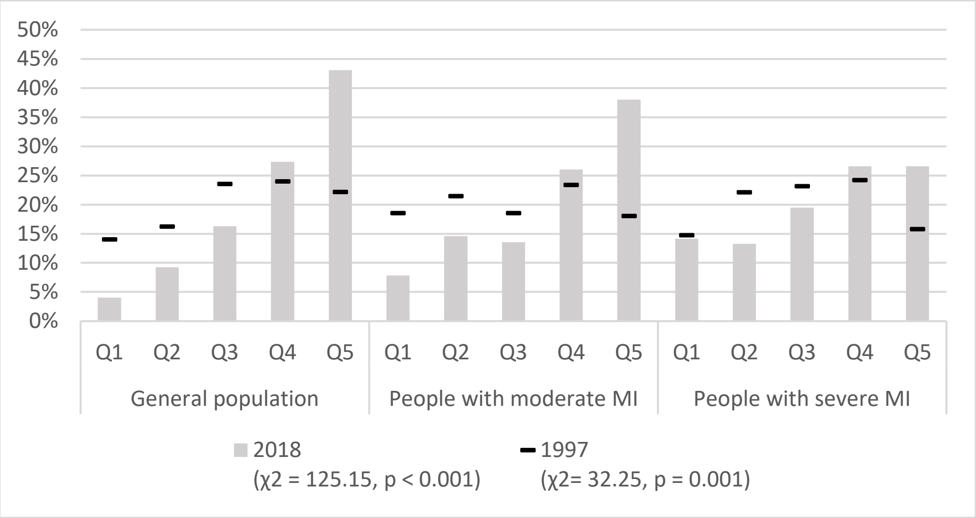
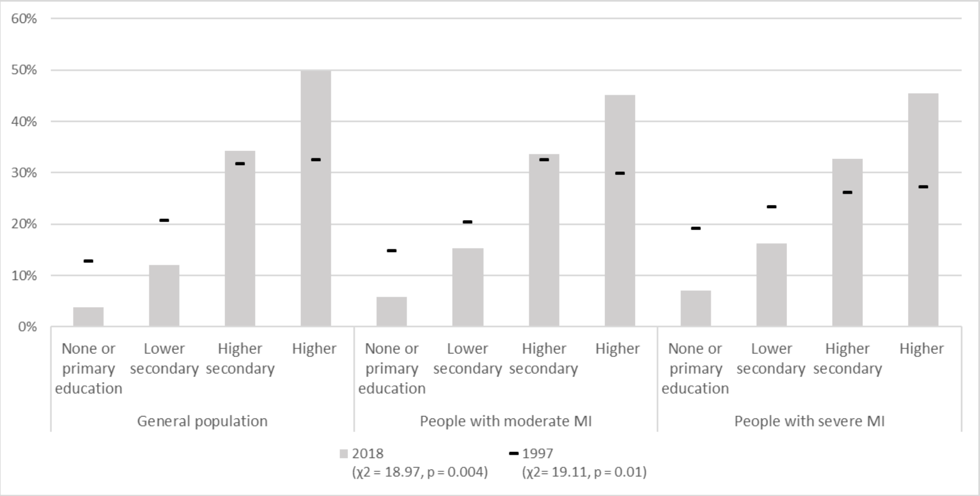


Figure 10.2 presents the distribution of education levels by mental health groups in 1997 and 2018. There was a significant difference in the distribution of education levels between the three mental health groups in 1997 (χ2 = 19.11, p = 0.01) and in 2018 (χ2 = 18.97, p = 0.004) and it appeared that this difference tends to decrease between 1997 and 2018.

In 1997, we can observe a negative trend between education levels and the severity of mental illness. The proportion of individuals with a higher level of education was 33% in the general population, 30% in people with moderate MI, and 27% in people with severe MI. Conversely, the proportion of individuals without a diploma or with a primary education was 13% in the general population, 15% in people with moderate MI, and 19% in people with severe MI.

In 2018, the level of education improved in the three mental health groups and this negative trend between education levels and the severity of mental illness tends to vanish. For example, the proportion of individuals without a diploma or with a primary education in the general population, in people with moderate MI, and in people with severe MI was respectively 4%, 6% and 7%.

Figure 10.2: Distribution of education levels among people with severe MI, people with moderate MI, and the general population without MI in 1997 and 2018



Regional trends

As previously explained, employment policies and reintegration services in Belgium are mainly the responsibility of the three regions and education and teaching policies are related to linguistic communities. It is therefore possible that differences exist between the three regions in terms of the economic integration of people with moderate or severe MI. In this chapter I describe (1) the regional differences in terms of unemployment rate, level of income, and level of education of people with moderate and severe MI and (2) the evolution of these regional trends between 1997 and 2018.

Unemployment rate

Table 6 presents summary measures of the unemployment rate in the three mental health groups by region and year. Overall, we can observe that in the three regions, the unemployment rate decreased between 1997 and 2018 for the general population and for people with moderate MI. For people with severe MI, the unemployment rate has slightly decreased in the Flemish Region (-1.5%) but increased in the Brussels-Capital region (+6.5%) and in the Walloon region (+3.3%). For the three mental health groups, the unemployment rate in 2018 was the lowest in the Flemish region, then in the Walloon region, then the highest in the Brussels-Capital region.

In 2018, the unemployment rate of people with severe MI reached 58.2% in the Brussels-Capital region compared to 55.2% in the Walloon Region and 39.3% in the Flemish Region. For people with moderate MI, the decrease over time was higher in the Brussels-Capital region (-10.9%) than in the two other regions (-5.8% in the Walloon region and -1.2% in the Flemish region). For the general population, the decrease over time in the unemployment rate was relatively identical between the three regions (around -12%).

As a result, the unemployment gap between the three mental health groups widened over time in the three regions, and more markedly in the Brussels-Capital region. In 1997 in the Brussels-Capital region, there was a difference in unemployment rate of 21.5% between the general population and people with severe MI and this difference increased to 39.3% in 2018.

Table 6: unemployment rate by region and mental health status, summary measures, Belgian adult population in 1997, 2001, 2004, 2008, 2013, and 2018

Unemployment rate		Years						Absolute change 1997-2018
		1997	2001	2004	2008	2013	2018	
Flemish Region	Prevalence (%)							
	- General population	25.1	21.4	21.2	18.2	14.6	11.3	-13.8
	- Moderate MI	26.7	37.1	30.6	31.5	25.0	25.5	-1.2
	- Severe MI	40.8	35.5	34.7	43.3	42.4	39.3	-1.5
	Absolute difference							
	- General population vs. severe MI	-15.8	-14.1	-13.5	-25.1	-27.8	-28.0	
	- Moderate MI vs. severe MI	-14.1	+1.6	-4.1	-11.8	-17.4	-13.8	
Brussels' Region	Prevalence (%)							
	- General population	30.9	23.9	29.0	23.8	22.5	19.6	-11.3
	- Moderate MI	39.5	30.5	35.7	28.5	37.4	28.6	-10.9
	- Severe MI	52.4	33.3	40.3	49.3	52.9	58.9	+6.5
	Absolute difference							
	- General population vs. severe MI	-21.5	-9.4	-11.3	-25.5	-30.4	-39.3	
	- Moderate MI vs. severe MI	-12.9	-2.8	-4.6	-20.8	-15.5	-31.1	
Walloon Region	Prevalence (%)							
	- General population	31.8	29.5	28.2	26.5	23.7	18.6	-13.2
	- Moderate MI	44.9	30.6	38.3	38.5	37.8	39.1	-5.8
	- Severe MI	51.9	34.1	39.4	52.2	53.8	55.2	+3.3
	Absolute difference							
	- General population vs. severe MI	-20.1	-4.6	-11.2	-25.7	-30.1	-35.6	
	- Moderate MI vs. severe MI	-7.0	-3.5	-1.1	-13.7	-16.0	-15.1	

Low income

Summary measures on the proportion of individuals in the first household income quintile in the three mental health groups by region and year are presented in Table 7. In 2018, the proportion of individuals in the first income quintile in the three mental health groups was the lowest in the Flemish region, then in the Walloon region, then the highest in the Brussels-Capital region. For the general population and for people with moderate MI, the proportion decreased between 1997 and 2018 in the three regions. For people with severe MI, the proportion increased between 1997 and 2018 in the Brussels-Capital (+5.3%) and Flemish (+2.7%) regions but decreased in the Walloon region (-2.7%). In 2018, 37.4% of people with severe MI were in the first income quintile in the Brussel-Capital region compared to 32.1% in the Walloon region and 21.2% in the Flemish region.

Regarding people with moderate MI, the decrease over time in the proportion in the first income quintile was higher in the Walloon region (-10.1%) than in the Brussels-Capital (-9.5%) and Flemish (-6.9%) regions. For the general population, the largest decrease over time was in the Brussels-Capital region (-16.6%), then in the Walloon region (-14.3%) and in the Flemish region (-9.9%).

Finally, the difference between the three mental health groups in the proportion of people in the first quintile increased over time in the three regions. For example, in 1997 in the Flemish region, there was a 3.8% difference between the general population and people with severe MI and this difference increased to 13.3% in 2018.

Table 7: proportion of individuals in the first household income quintile by region and mental health status, summary measures, Belgian adult population in 1997, 2001, 2004, 200n and 2013

Proportion in the first household income quintile		Years						Absolute change 1997-2018
		1997	2001	2004	2008	2013	2018	
Flemish Region	Prevalence (%)							
	- General population	14.0	13.9	12.8	12.5	8.9	4.1	-9.9
	- Moderate MI	14.7	13.7	12.4	17.8	10.9	7.8	-6.9
	- Severe MI	18.5	18.3	26.2	20.6	23.3	21.2	+2.7
	Absolute difference							
	- General population vs. severe MI	-4.5	-4.4	-13.4	-8.1	-14.4	-17.1	
	- Moderate MI vs. severe MI	-3.8	-4.6	-13.8	-2.8	-12.4	-13.3	
Brussels' Region	Prevalence (%)							
	- General population	28.5	22.5	25.5	25.9	21.1	11.9	-16.6
	- Moderate MI	34.0	27.7	31.0	39.8	29.2	24.5	-9.5
	- Severe MI	32.1	28.7	31.7	41.9	40.5	37.4	+5.3
	Absolute difference							
	- General population vs. severe MI	-3.6	-6.2	-6.2	-16.0	-19.4	-25.5	
	- Moderate MI vs. severe MI	+1.9	+1.0	-0.7	-2.1	-11.3	-12.9	
Walloon Region	Prevalence (%)							
	- General population	23.0	21.7	21.5	16.2	16.5	8.7	-14.3
	- Moderate MI	27.4	22.6	22.4	24.8	21.3	17.3	-10.1
	- Severe MI	34.8	27.2	30.9	29.7	33.6	32.1	-2.7
	Absolute difference							
	- General population vs. severe MI	-11.8	-5.5	-9.4	-13.5	-17.1	-23.4	
	- Moderate MI vs. severe MI	-7.4	-4.6	-8.5	-4.9	-12.3	-14.8	

Low level of education

Summary measures on the proportion of individuals with no diploma or primary education in the three mental health groups by region and year are presented in Table 7.2. In 2018, the proportion of individuals with a low level of education in the three mental health groups was the lowest in the Flemish region, then in the Walloon region, then the highest in the Brussels-Capital region. For the three mental health groups the proportion of individuals with no diploma or primary education decreased over time, especially in people with severe MI.

In the Brussels-Capital and Walloon regions, the decrease between 1997 and 2018 in the proportion of individuals with low education was most pronounced in people with severe MI (-14.4% and -10.2%) than in people with moderate MI (-10.0% and -8.6%) and in the general population (-9.6% and -10.9%). In the Flemish Region, the decrease was most pronounced in people with moderate MI (-12.6%) than in people with severe MI (-8.6%) and in the general population (-8.5%).

Finally, the difference between the general population and people with severe MI in the proportion of individuals with a low level of education decreased over time in the three regions. For example, in 1997 in the Brussels-Capital Region, there was a 8.6% difference between the general population and people with severe MI and this difference decreased to 4.5% in 2018.

Table 7.2: Proportion of individuals with no diploma or primary education by region and mental health status, summary measures, Belgian adult population in 1997, 2001, 2004, 2008, 2013, and 2018

Proportion with no diploma or primary education		Years						Absolute change 1997-2018
		1997	2001	2004	2008	2013	2018	
Flemish Region	Prevalence (%)							
	- General population	11.0	10.8	8.6	7.4	4.4	2.5	-8.5
	- Moderate MI	16.4	14.3	11.2	9.4	7.5	3.8	-12.6
	- Severe MI	15.5	15.1	12.4	10.2	7.6	6.9	-8.6
	Absolute difference							
	- General population vs. severe MI	-4.5	-4.3	-3.8	-2.8	-3.2	-4.4	
	- Moderate MI vs. severe MI	0.9	-0.8	-1.2	-0.8	-0.1	-3.1	
Brussels' Region	Prevalence (%)							
	- General population	15.4	12.6	10.1	5.7	4.7	4.5	-10.9
	- Moderate MI	16.7	13.2	11.2	6.3	6.9	6.7	-10.0
	- Severe MI	24.0	21.8	12.3	8.5	11.1	9.6	-14.4
	Absolute difference							
	- General population vs. severe MI	-8.6	-9.2	-2.2	-2.8	-6.4	-4.5	
	- Moderate MI vs. severe MI	-7.3	-8.6	-1.1	-2.2	-4.2	-2.9	
Walloon Region	Prevalence (%)							
	- General population	12.8	12.0	9.9	7.4	7.7	3.2	-9.6
	- Moderate MI	13.8	15.6	13.9	9.0	11.5	5.2	-8.6
	- Severe MI	17.8	16.4	17.3	16.9	17.4	7.6	-10.2
	Absolute difference							
	- General population vs. severe MI	-5.0	-4.4	-7.4	-9.5	-9.7	-4.4	
	- Moderate MI vs. severe MI	-4.0	-0.8	-3.4	-7.9	-5.9	-2.4	

Main results and discussion

This chapter provides interesting and complementary results to the study carried out in Chapter 2. As a reminder, the main result of the study performed in Chapter 2 was that between 1997 and 2018 in Belgium, the social integration improved in the general population and in people with moderate MI, but it deteriorated in people with severe MI, particularly on the dimension of employment. However, as explained in the introduction, having a job is a proxy but not a guarantee of economic and social integration and three other pieces of information are important: (1) type of job, (2) income, and (3) education.

The additional analyses performed in this chapter have shown that people with mental illness, especially those with severe MI, were more likely to have elementary jobs and to be in the lowest income quintiles compared to the general population and that these trends increased between 1997 and 2018. As previously explained, our data do not allow us to determine the direction of these associations and therefore these results can be interpreted in two ways, which does not diminish their importance. The first interpretation is guided by the social causation hypothesis, stating that poor economic and social conditions lead to poor mental health [21]. In this perspective, having an elementary job or having a low income seems to become, over time, an increasingly important factor of poor mental health in Belgium. Therefore, interventions should be put in place to improve the working conditions of people in elementary jobs as well as to support the production and purchasing capacity of people with low-income. The second interpretation is guided by the social selection hypothesis, stating that poor mental health leads to poor social and economic outcomes due to disability, discrimination and stigma associated with mental illness [21]. In this perspective, people with MI in Belgium seem to be increasingly exposed over time to elementary jobs and low income compared to the general population. This increasing exposure to elementary jobs is at odds with one of the founding principles of the Individual Placement and Support (IPS) model, « priority to client preferences », aiming that people with MI find the type of job they want. This result may be related to the lack of a specific vocational programs for people with MI in Belgium [22] and although a RCT started in 2017 and for 5 years on the IPS model, it will not be implemented routinely across the country before a few years. Finally, this higher proportion of elementary jobs and low income may be linked to the discrimination and stigmatisation of mental illnesses in the labour market, and to the absence in Belgium of specific policies or campaigns aimed at tackling the stigma of mental illnesses [23].

Our analyses have shown that the education level indicator had different results from the two indicators of the type of job and level of income. Although the proportion of individuals with a low level of education remains somewhat higher among those with severe MI, it is also among them that this proportion has decreased the most over time. By taking up the hypotheses of social causation and social selection, this result may indicate that the integration in school and in educational environments of people with severe MI has improved over time in Belgium, or that they tend to have less discontinuity and dropouts in their studies.

Although we cannot decide between the hypotheses of social causation and social selection, it is reasonable to think that the association occurs in both directions in a dynamic cycle, and that interventions are needed in the workplace and labour market (e.g. improving working conditions) as well as in the mental health field (e.g. implement the IPS model). In addition, in Belgium, it seems that some regions need more attention than others. Indeed, for people with a severe MI, it is in the Brussels-Capital region that there was the greatest increase between 1997 and 2018 in their unemployment rate (+6.5%) and in the proportion in the first income quintile (+5.3%). Finally, our results show that these regional differences seem to widen over time. These results show that in Belgium, it is important to analyse separately by region the social and economic integration of people with mental illness. As previously explained, successive state reforms have resulted in a transfer of competences in health but also in other areas such as employment, from the federal state to federated entities (i.e. regions and communities). In addition to other factors such as different socio-economic contexts between regions, it is possible that this transfer of competences is linked to the increase over time of regional differences. It is therefore important to assess the situation by region in order, if necessary, to develop local strategies and prevent inequalities between regions from widening.

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Chapter 4

4

Chapter 4: Predictors of exposure of people with severe mental illness to continuity of care approaches: A comparison across five European countries

Different evidence-based interventions for people with severe mental illness, such as the Individual Placement and Support (IPS) model, do not have the same effectiveness for all patients [1, 2]. Indeed, the IPS supported employment model do not appear to be as effective for older people or people with lower levels of education [2, 3]. One possible explanation for these disparities is that the different subgroups of patients do not have the same access to health care and interventions. For example, patients with low socioeconomic status experience differential access to mental health care as they are less likely to see a specialist [4-6].

In Europe, at discharge from a psychiatric hospital, people with SMI may be exposed to one of two main continuity of care models: personal continuity, where one clinician is responsible for in- and outpatient care, and specialisation, where various clinicians are. The objective of the COFI study was to compare in five European countries these two care approaches in terms of clinical outcomes over one year. The main findings of the COFI study were that there were no differences between personal continuity and specialisation in re-hospitalisation, inpatient bed days, untoward events and patients' social integration [7]. However, specific needs of subgroups of patients, for example social integration needs, may be best met by either personal continuity or specialisation. Indeed, several studies suggested that specialisation would be more appropriate for patients with limited needs and moderate disease severity [8-10]. Conversely, vulnerable groups with more complex psychosocial needs might benefit more from having, a single clinician follow them up over time and across care settings [11, 12]. However, it is unclear which individual actually benefit from each of these two care approaches. Therefore, the aim of this study was to identify predictors of patients' exposure to care approaches in different European countries.

This article was part of the COFI study (comparing policy framework, structure, effectiveness and cost-effectiveness of functional and integrated systems of mental health care) and was published in European Psychiatry in January 2019.

European Psychiatry 56 (2019) 69–74

Contents lists available at ScienceDirect

European Psychiatry

journal homepage: http://www.europsy-journal.com

Original article

Predictors of personal continuity of care of patients with severe mental illness: A comparison across five European countries

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Abstract

In Europe, at discharge from a psychiatric hospital, patients with severe mental illness may be exposed to one of two main care approaches: personal continuity, where one clinician is responsible for in- and outpatient care, and specialisation, where various clinicians are. Such exposure is decided through patient-clinician agreement or at the organisational level, depending on the country's health system. Since personal continuity would be more suitable for patients with complex psychosocial needs, the aim of this study was to identify predictors of patients' exposure to care approaches in different European countries. Data were collected on 7302 psychiatric hospitalised patients in 2015 in Germany, Poland, and Belgium (patient-level exposure); and in the UK and Italy (organisational-level exposure). At discharge, patients were exposed to one of the care approaches according to usual practice. Putative predictors of exposure at patients' discharge were assessed in both groups of countries. Socially disadvantaged were significantly more exposed to personal continuity. In all countries, the main predictor of exposure was the admission hospital, except in Germany, where having a diagnosis of psychosis and a higher education status were predictors of exposure to personal continuity. In the UK, hospitals practising personal continuity had a more socially disadvantaged patient population. Even in countries where exposure is decided through patient-clinician agreement, it was the admission hospital, not patient characteristics, that

predicted exposure to care approaches. Nevertheless, organisational decisions in hospitals tend to expose socially disadvantaged patients to personal continuity.

Introduction

The organisation of transitional care from in- to outpatient settings is a key issue in mental health care delivery [13-16]. At discharge from a psychiatric inpatient stay, the patient may be exposed to different ways of organising care with outpatient clinicians. Patients with severe mental illness (SMI) may be exposed to personal continuity, i.e. an approach in which the main inpatient clinician remains responsible for outpatient care; or to specialisation, i.e. an approach in which different, specialised clinicians are responsible for care in different settings [17-19]. These two care approaches coexist in different countries.

The literature comparing these two care approaches has shown a lower number of hospitalisations, shorter lengths of hospital stays, and higher satisfaction for patients treated in the personal continuity approach [20-22]. Several studies have also shown that personal continuity allows a faster and more flexible transition between services and that patients and clinicians prefer this care approach to specialisation [10, 18, 23-25]. However, the literature comparing these two care approaches in terms of other clinical, social, and cost-effectiveness outcomes for the general population has inconsistent findings [17]. Indeed, each care approach can have a specific clinical rationale, depending on patients' needs. Several studies have shown that specialisation is more appropriate for patients with limited needs, moderate disease severity, and the ability to navigate the multiple providers in mental health and social care [8-10, 15]. Vulnerable groups with more complex psychosocial needs (older, chronic condition, uninsured, etc.), however, prefer, and benefit more from having, a single clinician follow them up over time and across care settings [11, 12].

Although different care approaches are more suitable for, and preferred by, particular subgroups of patients, they may not be accessible to or provided to those subgroups [26, 27]. Indeed, socially deprived patients tend to have less access to specialised care than wealthier patients [4-6, 28]. Difference in accessibility is also explained by the severity of the illness, the complexity of the health and social situation, and the patient’s ability to state preferences and to negotiate with professionals [5, 29]. So far, there has been little research describing the characteristics of patients who actually benefit from each of these care approaches.

In addition, the accessibility of specialisation and personal continuity may also be influenced by health system characteristics such as gatekeeping across care lines and delimited catchment areas [4, 30]. For example, patients with a lower socio-economic status have less access to specialised care in the United States, while this association was not found in Ontario, which has universal health insurance coverage [4]. The different health systems can be categorised according to their characteristics [31-33]. In countries with a National Health System (NHS) type of system, care delivery is devolved to local health authorities, which are responsible for providing care within a delimited catchment area. In those countries, exposure to specialisation or personal continuity results from an organisational mechanism, i.e. the decision of the local health authority. In other European countries, care is delivered by multiple providers in a single catchment area and patients have more autonomy when it comes to choosing their care providers. In this second group of countries, exposure to specialisation or personal continuity generally results from a patient-clinician agreement at discharge from the hospital and the subsequent freedom of choice exercised by both clinicians and patients. We will refer to the systems of the second group of countries as regulated-market care systems (RMS) [31, 33]. However, the choice between personal continuity and specialisation after hospital discharge is likely to be influenced by multiple factors, e.g. the patient's individual characteristics and contextual factors related to the area and to hospital organisation.

The aim of this study was to identify the predictors of patients' exposure to care approaches, i.e. to either personal continuity or specialisation, at discharge from a psychiatric unit. Due to the difference in care organisation across countries, we hypothesised that patient characteristics would influence the exposure to care approaches in RMS countries but not in NHS countries. We expected that, in RMS countries, patients with more complex mental-health and social-care needs would be more exposed to personal continuity, as exposure is a shared clinical decision at hospital discharge. We also expected that, in NHS countries, exposure to care approaches would be determined by the hospital in which the patient is hospitalised, as the exposure results from an organisational mechanism.

Methods

Study design

This study is part of the “Comparing policy, framework, structure and effectiveness of Functional and Integrated systems of mental health care” project, COFI, funded by the European Commission (FP7) [34, 35]. In 2014-2015, data were collected on 7302 patients hospitalised in 57 psychiatric hospitals in the UK, Poland, Germany, Italy, and Belgium. After discharge, each patient was exposed to one of the two care approaches (personal continuity or specialisation) according to the usual local practice (natural experiment) [36]. In RMS countries, i.e. Germany, Poland, and Belgium, patients exposed to both care approaches were found in the same hospitals. The choice of one care approach was reported by the hospital’s clinician. In NHS countries, i.e. the UK and Italy, each geographic area had its preferred care approach and all the patients treated in a ward were exposed to the same approach. The care approach chosen was indicated in the clinical reports at the level of the organisation.

The inclusion criteria for patients were i) being 18 years old or older, ii) having a main diagnosis of psychotic, mood, or anxiety and somatoform disorder (F2, F3, and F4 according to the ICD-10 classification), iii) being hospitalised in a general adult psychiatric hospital unit, and iv) having the capacity to give signed informed consent [34]. Ethical committee approvals were obtained in each of the five countries that participated in the COFI project (ref: 14/NE/1017). The detailed protocol of the COFI project has already been published elsewhere [34].

Variables of interest

The outcome variable was the exposure to one of the two care approaches after hospital discharge, i.e. personal continuity or specialisation (intention to treat).

Predictors of exposure

Putative predictors of exposure to care approaches were selected, based on the existing literature [4, 5, 11, 26, 37]. The following socio-demographic and clinical characteristics of patients were included: age, gender, migrant status (whether born in the country of recruitment), homelessness, the main diagnosis category (ICD-10 classification), first admission versus repeated admission, and severity of symptoms. Severity was measured with the Clinical Global Impression Scale (CGI). The CGI is a scale from 1 (normal) to 7 (among the most severely ill patients), rated by clinicians [38]. The following socio-economic characteristics of patients were also included: employment status, educational status, receipt of state benefits, and social integration. Social integration was measured with the Objective Social Outcomes Index (SIX), which ranges from 0 (low social integration) to 6 (high social integration). The SIX includes four dimensions: employment, accommodation, living situation, and contacts with friends [39].

Admission hospital

Patients were exposed to one of the two care approaches at discharge from one of the 57 hospitals in the five countries. Hospitals were selected in different countries in order to have diversity in terms of urban, semi-urban, and rural areas. In addition, hospitals had to practice one of the two care approaches for at least a year [34]. In RMS countries, i.e. Germany, Poland, and Belgium, patients treated in the same hospital are likely to be exposed to one or the other care approach according to a shared decision between the patient and the clinician. The choice of one care approach was reported by the hospital clinician. In NHS countries, i.e. the UK and Italy, the care approach is an organisational decision and each geographic area has its preferred care approach. Therefore, patients treated in the same hospital are exposed to the same care approach. The care approach chosen was indicated in the clinical reports at the level of the organisation.

Data analysis

Descriptive statistics were calculated for the characteristics of patients exposed to personal continuity or specialisation. T-tests and Chi-square tests were performed to assess the significance of differences in the sample distribution between the two groups of patients.

Since the dependent variable is dichotomous, univariate and multivariate logistic regression models were performed to identify the predictors of exposure to personal continuity and specialisation in RMS and NHS countries. The multivariate logistic regression models were adjusted for country as a fixed factor, with the hospital of admission as a random intercept. Based on the multivariate logistic regression models, the proportion of variation in the models that was due to the hospital of admission was calculated for each country (covariance component). The multivariate logistic regression models were then stratified by country.

All the statistical analyses were performed using SAS 9.3.

Results

International sample characteristics

The socio-demographic, clinical, and socio-economic characteristics of patients exposed to personal continuity or specialisation are shown in Table 8. Patients' age and sex did not differ significantly between the two care approaches. The severity of the patients' symptoms was slightly but significantly higher in the personal continuity group than in the specialisation group (mean score 4.5/7 vs mean score 4.3/7, p = 0.02) and there was a higher proportion of patients with a main diagnosis of psychotic disorder in the personal continuity group than in the specialisation group (41.2% vs 37.2%, p < 0.01). In terms of socio-economic status, there was a significantly higher proportion of patients with primary education level (18.8% vs 16.8%, p < 0.01), who were unemployed (75.4% vs 70.4%, p < 0.01), or in receipt of state benefits (57.0% vs 49.3%, p < 0.01) in the personal continuity group than in the specialisation group. The patients' objective social outcomes index was significantly lower in the personal continuity group than in the specialisation group (mean score 3.63/6 vs mean score 3.76/6, p < 0.01). There was also a significantly higher proportion of patients with migrant status in the personal continuity group (15.5% vs 12.6%, p < 0.01).

Table 8: Socio-demographic and clinical characteristics of the sample

	Specialisation (n=4371)	Personal Continuity (n=2336)	T-test / Khi^2	P-value
	n/mean (%/SD)	n/mean (%/SD)		
Age (y.)	42.35 (14.50)	42.38 (13.90)	- 0.08	0.93
Gender (male)	2264 (51.81)	1260 (53.94)	2.77	0.09
Main diagnosis group (ICD-10)			12.26	<0.01
- Psychotic disorders (F2)	1627 (37.22)	962 (41.18)		
- Mood disorders (F3)	1840 (42.10)	953 (40.80)		
- Neurotic disorders (F4)	620 (14.18)	290 (12.41)		
- Others	284 (6.50)	131 (5.61)		
Severity of symptoms (CGI) (1 = low, 7 = high)	4.30 (1.10)	4.51 (1.16)	- 2.31	0.02
First admission (yes)	1496 (34.23)	749 (32.06)	3.19	0.07
Social integration (SIX score, 0 = low, 6 = high)	3.76 (1.40)	3.63 (1.39)	3.46	<0.01
Employment status (unemployed)	3078 (70.43)	1761 (75.42)	18.81	<0.01
Educational status			10.72	<0.01
- Primary	734 (16.80)	439 (18.80)		
- Secondary	1763 (40.34)	988 (42.31)		
- Higher	1873 (42.86)	908 (38.89)		
Receiving state benefits (yes)	2155 (49.32)	1331 (57.03)	36.15	<0.01
Homeless (yes)	199 (4.55)	128 (5.49)	2.87	0.09
Born in the country (no)	551 (12.61)	362 (15.50)	10.86	<0.01
Country			195.44	<0.01
- UK	1458 (33.36)	980 (41.95)		
- Germany	787 (18.01)	207 (8.86)		
- Italy	745 (14.04)	359 (15.37)		
- Poland	953 (21.80)	400 (17.12)		
- Belgium	428 (9.79)	390 (16.70)		

Descriptive statistics were performed after exclusion of missing data

Predictors of exposure to care approaches after hospital discharge

The association between patient characteristics and exposure to personal continuity in RMS and NHS countries is shown in Table 9.

In RMS countries, results of univariate regressions showed that having a main diagnosis of psychotic disorder, being hospitalised for the first time, being unemployed, having a lower level of education, and receiving state benefits were associated with being exposed to personal continuity. In NHS countries, being unemployed, having a lower level of education, and receiving state benefits were also associated with exposure to personal continuity, as were having a lower level of social integration and being a migrant. Age, gender, housing status, and severity of symptoms were not significantly associated with a specific care approach either in RMS or NHS countries. These variables were therefore not included in the multivariate logistic regression models.

The multivariate regression model showed that having a main diagnosis of psychotic disorder remained significantly associated with exposure to personal continuity in RMS countries. In both RMS and NHS countries, the other clinical and socio-economic indicators were no longer significantly associated with exposure to personal continuity. This result was mainly explained by the fact that the exposure to care approaches was associated, for 31% in RMS countries and 91% in NHS countries, with the hospital of admission.

Major differences in the proportion of variation explained by the hospital of admission were found between RMS and NHS countries and across countries (see Table 10). The hospital of admission explained a higher percentage of exposure to care approaches in NHS countries (UK, Italy) than in RMS countries (Germany, Poland, Belgium).

Table 9: Association between patient characteristics and exposure to personal continuity at discharge from psychiatric stay in regulated-market system and National Health System countries

	RMS countries (Poland, Germany, Belgium)						NHS countries (UK, Italy)					
	Univariate regression models			Multivariate regression Model *			Univariate regression models			Multivariate regression Model *		
	OR	CI 95	p-value	OR	CI 95	p-value	OR	CI 95	p-value	OR	CI 95	p-value
Age (y.)	1.01	0.99-1.10	0.11	1.01	0.99-1.11	0.15	0.99	0.98-1.10	0.13	0.99	0.98-1.01	0.26
Gender (male, ref = female)	1.06	0.91-1.23	0.42	1.03	0.85-1.24	0.75	1.07	0.93-1.23	0.29	1.15	0.84-1.56	0.36
Diagnosis of psychosis (yes, ref = no)	1.36	1.37-1.59	<0.01	1.38	1.13-1.68	<0.01	1.13	0.98-1.30	0.07	0.90	0.65-1.26	0.56
Severity of symptoms (CGI)	1.05	0.99-1.13	0.09	1.03	0.93-1.14	0.13	1.01	0.95-1.08	0.63	1.02	0.89-1.17	0.69
First admission (yes, ref = no)	0.79	0.67-0.93	<0.01	0.89	0.73-1.09	0.26	1.01	0.87-1.16	0.92	0.95	0.68-1.32	0.77
Social integration (SIX score, 0 = low, 6 = high)	0.95	0.90-1.01	0.09	1.06	0.87-1.30	0.33	0.94	0.90-0.99	0.02	0.93	0.81-1.10	0.21
Employed (yes, ref = no)	0.72	0.61-0.85	<0.01	1.02	0.83-1.27	0.37	0.85	0.72-0.99	0.04	0.96	0.66-1.41	0.86
Educational status												
- Primary	1.35	1.11-1.64	<0.01	1.12	0.92-1.36	0.10	1.37	1.08-1.72	<0.01	1.21	0.89-1.22	0.49
- Secondary	1.14	0.95-1.36	0.14	0.99	0.73-1.12	0.23	1.24	1.07-1.44	<0.01	1.08	0.79-1.49	0.61
- Higher	REF	REF	REF	REF	REF	REF	REF	REF	REF	REF	REF	REF
State benefits (yes, ref = no)	1.47	1.26-1.70	<0.01	1.04	0.85-1.28	0.69	1.24	1.08-1.42	0.002	1.10	0.76-1.58	0.60
Homeless (yes, ref = no)	1.05	0.70-1.57	0.80	0.93	0.52-1.63	0.78	0.76	0.57-1.01	0.05	0.63	0.43-1.19	0.15
Born in the country (no, ref = yes)	1.09	0.84-1.43	0.50	1.08	0.79-1.47	0.62	1.26	1.05-1.49	0.009	1.15	0.92-1.49	0.17

* Model adjusted for all variables in the model, for country as a fixed factor and hospital as a random intercept

Table 10: Hospital of admission and exposure to care approaches in the multivariate regression model: intra-class correlation coefficient

	RMS countries			NHS countries	
Intra-class correlation	31%			91%	
	Germany	Poland	Belgium	UK	Italy
	11%	44%	12%	92%	89%

Intra-class correlation is computed as: $\rho = \frac{\tau_0^2}{\tau_0^2+\frac{\pi^2}{3}}$

Predictors of exposure to care approaches in each country

The associations between patient characteristics and exposure to personal continuity per country are shown in Table 11.

In Germany, results showed that having a main diagnosis of psychotic disorder and having a higher education status were significantly associated with exposure to personal continuity. In Poland and Belgium, patients' clinical and socio-economic indicators were not significantly associated with exposure to personal continuity.

However, some associations were also significant in the NHS countries. In the UK, having a lower level of education and being a migrant were significantly associated with exposure to personal continuity. After conducting sensitivity analyses on these results, it turned out that the effect of patients' migrant status on exposure to care approaches was due to a Trust located in East London. However, the association between patients' socio-economic status and exposure to care approaches remains significant after sensitivity analyses. In Italy, patients' characteristics were not significantly associated with exposure to personal continuity.

Table 11: Association between patient characteristics and personal continuity in the five countries

	RMS countries (Poland, Germany, Belgium)						NHS countries (UK, Italy)					
	Univariate regression models			Multivariate regression Model *			Univariate regression models			Multivariate regression Model *		
	OR	CI 95	p-value	OR	CI 95	p-value	OR	CI 95	p-value	OR	CI 95	p-value
Age (y.)	1.01	0.99-1.10	0.11	1.01	0.99-1.11	0.15	0.99	0.98-1.10	0.13	0.99	0.98-1.01	0.26
Gender (male, ref = female)	1.06	0.91-1.23	0.42	1.03	0.85-1.24	0.75	1.07	0.93-1.23	0.29	1.15	0.84-1.56	0.36
Diagnosis of psychosis (yes, ref = no)	1.36	1.37-1.59	<0.01	1.38	1.13-1.68	<0.01	1.13	0.98-1.30	0.07	0.90	0.65-1.26	0.56
Severity of symptoms (CGI)	1.05	0.99-1.13	0.09	1.03	0.93-1.14	0.13	1.01	0.95-1.08	0.63	1.02	0.89-1.17	0.69
First admission (yes, ref = no)	0.79	0.67-0.93	<0.01	0.89	0.73-1.09	0.26	1.01	0.87-1.16	0.92	0.95	0.68-1.32	0.77
Social integration (SIX score, 0 = low, 6 = high)	0.95	0.90-1.01	0.09	1.06	0.87-1.30	0.33	0.94	0.90-0.99	0.02	0.93	0.81-1.10	0.21
Employed (yes, ref = no)	0.72	0.61-0.85	<0.01	1.02	0.83-1.27	0.37	0.85	0.72-0.99	0.04	0.96	0.66-1.41	0.86
Educational status												
- Primary	1.35	1.11-1.64	<0.01	1.12	0.92-1.36	0.10	1.37	1.08-1.72	<0.01	1.21	0.89-1.22	0.49
- Secondary	1.14	0.95-1.36	0.14	0.99	0.73-1.12	0.23	1.24	1.07-1.44	<0.01	1.08	0.79-1.49	0.61
- Higher	REF	REF	REF	REF	REF	REF	REF	REF	REF	REF	REF	REF
State benefits (yes, ref = no)	1.47	1.26-1.70	<0.01	1.04	0.85-1.28	0.69	1.24	1.08-1.42	0.002	1.10	0.76-1.58	0.60
Homeless (yes, ref = no)	1.05	0.70-1.57	0.80	0.93	0.52-1.63	0.78	0.76	0.57-1.01	0.05	0.63	0.43-1.19	0.15
Born in the country (no, ref = yes)	1.09	0.84-1.43	0.50	1.08	0.79-1.47	0.62	1.26	1.05-1.49	0.009	1.15	0.92-1.49	0.17

* Model adjusted for all variables in the model, for country as a fixed factor and hospital as a random intercept

Discussion

Main results

Across the five countries participating in the study, patients exposed to the personal continuity care approach after discharge from a psychiatric hospital were more socially disadvantaged (more unemployed, having a lower level of education, and receiving state benefits) than patients exposed to specialisation. However, these individual predictors of exposure to care approaches were factored out by the hospital where patients were admitted.

In regulated-market system countries, even if exposure to care approaches was decided by patient-clinician agreement, the stronger predictor of exposure was not patient characteristics but the hospital of admission – except in Germany, where having a main diagnosis of psychotic disorder and a higher education status were significantly associated with exposure to personal continuity.

In addition, the influence of the hospital of admission on exposure to care approaches was different across countries. In NHS countries, we expected that exposure to a specific care approach would only be influenced by the geographic area and the decision of the local health provider. As expected, the hospital of admission explained a greater share of exposure to care approaches in NHS countries than in RMS countries. However, in the UK, hospitals that practise personal continuity have a more socially disadvantaged patient population than hospitals that practise specialisation.

Interpretation of the findings

The model of personal continuity, in which the same clinician is responsible for care between in- and outpatient settings, is applied more to socially disadvantaged patients. These results are consistent with the literature, which suggests that having the same clinician following patients over time and between services is more suited for, and preferred by, vulnerable patients with complex health and social needs [11, 12], especially patients with psychosis. However, even in RMS countries where exposure to care approaches is decided through patient-clinician agreement, it is the hospital of admission, not patient characteristics, that predicts the care approach.

One study examined the determinants of primary clinicians' decisions on patient referral to the specialised sector [40]. The study concluded that such decisions were not based on the clinical status of patients only, but were influenced by a complex mix of patient, clinician, and health care structural characteristics. One systematic review also argued that studies exploring the influence of individual patient's characteristics on pathways to care had conflicting findings because of contextual differences across studies, e.g. the type of service and characteristics of the health care system [37]. These results underline the need for further analyses that will compare the outcomes of care approaches, i.e. personal continuity and specialisation, in different countries, taking into account local contexts. One possible explanation of these results is that exposure to care approaches in RMS countries is related to the care culture in different hospitals (care plan with gatekeeping arrangement, pilot project, care management, etc.) [37, 40]. For example, the speciality referral rate is higher in services with gatekeeping plans [41, 42]. In Belgium, some hospitals are linked to a mobile mental health team and have staff in common to follow the patient at discharge from the hospital [43].

In RMS countries, the exception to this finding is Germany, where two patient characteristics predict exposure to personal continuity: having a main diagnosis of psychotic disorder as a clinical predictor and a higher education level as a socio-economic predictor. This result may illustrate the influence of health system characteristics on patients' exposure. On the one hand, most patients exposed to personal continuity in Germany were included by means of specific pilot projects on integrated care [44], including the so-called "Hamburg Model", which was specifically designed for patients with psychotic disorders [44]. On the other hand, private health insurance companies take on an important role in care accessibility in Germany. These companies are given some flexibility to define the benefits that they cover, which may include access to an integrated care programme [33, 45]. This might be an explanation for the higher level of education found in patients exposed to personal continuity in Germany.

In the UK, hospitals that practise personal continuity have a more socially disadvantaged patient population than hospitals that practice specialisation. This result suggests that even if exposure to care approaches is organisational and decided at the geographical level, procedures for organising care from inpatient to outpatient settings also partly result from the type of patients cared for. Further research is needed to understand this result.

In terms of practical implications, this study highlights the importance of organisational decisions within hospitals, as these have a major impact on patients' exposure to care approaches, regardless of the type of health care system.

Strengths and limitations

This study is currently the largest study to have compared the exposure of patients to personal continuity and specialisation at discharge from psychiatric hospitals across different countries. Moreover, exposure to care approaches was assessed within routine care practice, thanks to a naturalistic study design, which made it possible to avoid the novelty effect of experimental interventions [17, 46]. With its large sample size of more than 7000 patients, the study provided a high statistical power that made possible accurate estimates of the predictors of exposure at the hospital, country, and cross-country levels. Another strength of this study is the multiplicity of contexts assessed: the total sample is spread over 57 hospitals across five European countries with different systems of care organisation. Finally, we had very few missing data on the care approaches at discharge (0.14%), thus limiting any selection bias related to missing values.

However, the present study also has some limitations. The first limitation is related to the naturalistic design, with potential confounding variables. This limit was partially overcome because analyses were controlled for patients' individual characteristics and adjusted with hospitals as a random intercept to account for the clustering effect of hospitals in each country. The second limitation is that the method of collecting data on exposure to care approaches was different between NHS and RMS countries. The choice of one care approach was reported by the hospital clinician in RMS countries and in the clinical reports at the level of the organisation in NHS countries. These two care approaches were the main exposure variable of the COFI project. Different procedures were used to ascertain the exposure to one or the other approach and misclassification bias is therefore unlikely [34]. Another limitation is that the size of the sample varies between countries. Countries were added in fixed effect in the multivariate analyses to partially overcome this limitation, and some analyses were stratified by country.

Another limitation concerns NHS countries, for which data on population characteristics and the socio-economic context of the regions where hospitals are located would have been useful for more detailed analysis of their influence on organisational choices within hospitals. Finally, a longitudinal design would have been relevant, to test the association between variations in patient characteristics and variations in care approaches over time.

Conclusion

Assessing the determinants of patients’ exposure to care approaches at discharge from hospital is important because some care approaches may be more suitable for, or preferred by, particular subgroups of patients with specific needs. Indeed, patients with complex psychosocial needs who have difficulties navigating between mental health and social services might benefit more from personal continuity than specialisation [11, 12]. Conversely, patients with limited needs and able to navigate in and between services might prefer to have the choice of different specialised clinicians [9, 15].

This study highlights the extent to which patient exposure to care approaches is hospital-dependent, even in countries where the care approach is decided through patient-clinician agreement. These results highlight a paradox because, in theory, models of care should stick to the needs of patients, but in practice, these models are mainly determined by the hospitals. This could highlight the difficulty of offering patients specific, individualised care pathways within the same hospital.

Future research should investigate what influences a hospital's decision on organising care from inpatient to outpatient settings. Indeed, even if the exposure is an organisational decision, it can reflect the needs of patients. This study suggests that organisational decisions in hospitals may be influenced by the socio-economic characteristics of their patient populations and are therefore not intended to address the needs and preferences of individuals but the needs of the population as a whole.

Acknowledgements

This study was funded by the European Commission’s 7th Framework Programme. The grant agreement number is 602645. The authors would like to gratefully acknowledge the 7302 participants and the 57 services that took part in the study, the wider COFI study group, and the support of the funders.

Conflict of interest

None.

References chapter 4

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Chapter 5

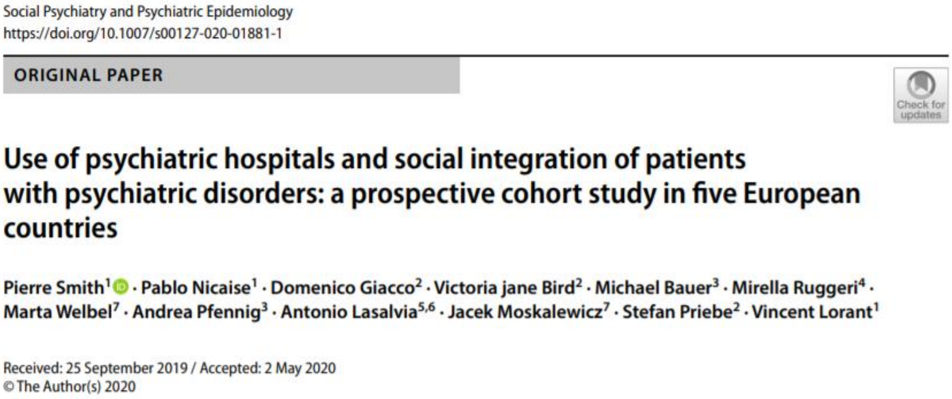
5

Chapter 5: Impact of psychiatric hospitalisations on the social integration of people with severe mental illness in five European country

The social integration of people with SMI is supported by deinstitutionalisation movement with a transition from institutional psychiatric care to community care, a decrease in psychiatric hospital admissions and a reduction in the hospital length of stay [1-3]. However, there are wide variations between countries in terms of deinstitutionalisation and hospitals still have a major role in mental health care as highlighted in the fourth chapter of this thesis [4, 5].

Although the length of stay (LoS) in psychiatric ward has decreased over the past decades with deinstitutionalization movement, it remains longer than for physical disorders and people with SMI still tend to undergo long and repeated hospitalisation [2, 3, 6, 7]. The impact of repeated or lengthy psychiatric hospitalisations on employment, housing, and other dimensions of patients' social integration remains, however, unclear. Few studies have explored the impact of psychiatric hospitalisations on the social integration of people with SMI and they had inconsistent results [8]. Therefore, the aim of this study was to assess the impact of psychiatric hospitalisations on the social integration of people with severe mental illness.

This article was published in Social Psychiatry and Psychiatric Epidemiology in May 2020.



Social Psychiatry and Psychiatric Epidemiology
https://doi.org/10.1007/s00127-020-01881-1

ORIGINAL PAPER

Use of psychiatric hospitals and social integration of patients with psychiatric disorders: a prospective cohort study in five European countries

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Received: 25 September 2019 / Accepted: 2 May 2020

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Chapter 5

Abstract

Purpose: Long lengths of stay (LoS) in psychiatric hospitals or repeated admission may affect the social integration of patients with psychiatric disorders. So far, however, studies have been inconclusive. This study aimed to analyse whether long LoS or repeated admissions in psychiatric wards were associated in different ways with changes in the social integration of patients.

Methods: Within a prospective cohort study, data were collected on 2181 patients with a main ICD-10 diagnosis of psychotic, affective, or anxiety disorder, hospitalised in the UK, Italy, Germany, Poland, and Belgium in 2015. Social integration was measured at baseline and one year after admission using the SIX index, which includes four dimensions: employment, housing, family situation, and friendship. Regression models were performed to test the association between LoS, the number of admissions, and the change in social integration over the study period, controlling for patients' characteristics (trial registration ISRCTN40256812).

Results: A longer LoS was significantly associated with a decrease in social integration (β=-0.23, 95%CI -0.32 to -0.14, p=0.03), particularly regarding employment (OR=2.21, 95%CI 1.18–3.24, p=0.02), housing (OR=3.45, 95%CI 1.74–5.16, p<0.001), and family situation (OR=1.94, 95%CI 1.10–2.78, p=0.04). By contrast, repeated admissions were only associated with a decrease in friendship contacts (OR=1.15, 95CI% 1.08-1.22, p=0.03).

Conclusions: Results suggest that a longer hospital LoS is more strongly associated with a decrease in patients' social integration than repeated admissions. Special attention should be paid to helping patients to find and retain housing and employment while hospitalised for long periods.

Keywords: Mental illness, Social integration, Length of hospital stay, Hospital readmissions, Employment

Introduction

Patients with psychiatric disorders need more than just symptom relief [9]. Most psychiatric patients face social integration difficulties such as unemployment, homelessness, poor social capital, and little social participation in community life [1, 10, 11]. There are different definitions of the concepts of social integration and social exclusion in the literature [12, 13]. Social integration is not limited to the economic participation (production and purchasing capacity) of individuals in society, but also includes dimensions relating to social engagement and social interaction [14, 15]. The social integration of an individual is, therefore, his/her participation in the key activities of the society in which he/she lives (e.g. employment, housing, friendship, etc.). Conversely, a lack of participation in such activities constitutes social exclusion [13, 16]. Over the past few decades, mental health care systems have increasingly considered the social integration of psychiatric patients a major objective and countries have developed policies and interventions aimed at achieving better social integration [1, 12, 17, 18]. However, these initiatives have had mixed results, and the social integration of psychiatric patients remains an issue in high-income countries. For example, in OECD countries, people with psychiatric disorders are still six to seven times more likely to be unemployed than the general population [19]. In regard to housing, the prevalence of homelessness among psychiatric patients is 15%, which is much higher than in the general adult population [20]. The extent to which social exclusion occurs is often greater among patients with more serious mental disorders [21, 22], but it also varies according to the patient's psychiatric diagnosis. For example, different studies have found an employment rate of between 10% and 20% among people with schizophrenia [23, 24], between 40% and 60% among people with anxiety disorders [25], and up to 60% among people with mood disorders [26].

One of the multiple factors that might hinder the social integration of psychiatric patients is the fact that most of them tend to experience long lengths of stay (LoS) in psychiatric hospitals and repeated admissions, which may disrupt their social and professional lives and affect their social integration, as suggested by Goffman [27], Honigfeld [28], and Gruenberg [29]. In fact, one of the consequences of excessive LoS in psychiatric hospital and psychiatric readmissions is the "social breakdown syndrome", whereby psychiatric patients experience community and social withdrawal, exclusion from typical social roles, and a decline in their social integration [29, 30]. For example, patients report that there is a stigma attached to psychiatric hospitalisations and fear that they will not be able to return to paid employment after long hospital stays or repeated admissions [8, 31]. Although the average LoS in psychiatric hospitals has decreased in recent decades due to deinstitutionalisation policies, it remains longer than for most physical disorders [2, 3, 6, 7]. Some patients with severe and chronic mental illness and complex health and social needs may require longer hospital stays to adapt to psychotropic medication, stabilise symptoms, manage suicidal ideation or aggressive behaviour, and plan hospital discharge and community follow-up [32, 33]. Indeed, some clinical and socio-demographic characteristics of patients, such as having a diagnosis of psychosis, the severity of the illness, or being homeless, have been associated with longer LoS in psychiatric hospitals [6, 34-38]. However, socio-demographic and clinical characteristics of patients predict only 15% of the variance of LoS in psychiatric hospitals [39]. Furthermore, LoS in psychiatric hospitals vary substantially across countries and across hospitals among patients with similar profiles, suggesting that LoS is also determined by features related to policies and practices, i.e. availability of psychiatric hospital beds, legal frameworks for involuntary hospital treatment, availability of alternatives to hospitalisation, funding mechanisms, and the culture of mental health care [34, 40, 41]. In one study, more than 500 long-stay patients (median continuous LoS of more than twenty years), who were discharged from two London psychiatric hospitals after their closure in the 1990s [42], were followed up within the community. The social and clinical outcomes of these patients were assessed during the five-year period following hospital discharge. The study concluded that there was no change in the severity of patients' symptoms or social behaviour problems and indicated that there was an improvement in their social capital and community and domestic skills. Taken together, these results indicate that LoS in psychiatric hospitals bears a weak relation to the clinical and social needs of patients at admission, that excessive LoS and repeated admissions may affect patients' social integration, and that being discharged from hospital may even be beneficial for long-stay patients.

However, the effect of LoS and readmissions on patients' social integration remains a controversial subject. Some argue that psychiatric hospitalisations should be dedicated to acute care only, should be as short as possible, and should be considered as a last care resort. Long stays in, and repeated admissions to hospital, according to them, disrupt the social and professional lives of patients, have a negative effect on social integration, and lead to institutionalisation [9, 43-45]. According to others, however, an excessive reduction of hospital LoS would lead to precipitous hospital discharge, increasing the likelihood of readmission and inducing a “revolving door” admission phenomenon, which would have adverse effects on patients’ social integration [46-48]. Furthermore, studies analysing the association between lengthy hospital stays or repeated hospitalisations and patients’ social and clinical status have been inconclusive, so it is unclear whether the impact of a long stay in hospital on patients' social integration would be similar to that of repeated, shorter stays. A systematic review showed that the few studies which have explored such associations have had inconsistent results [8]. Another more recent review of randomised controlled trials [46] comparing the effect of short and long psychiatric hospitalisations showed that patients with serious mental illness who were allocated to short hospital stay interventions had higher post-hospitalisation rates of employment and independent living than patients who were allocated to longer stay interventions. The trials were limited, however, and the quality of the evidence was poor [46]. Other studies showed no significant association between LoS in psychiatric hospitals and patients’ work attendance and employment status after discharge [49, 50].

Both in terms of clinical practice and in order to support recovery-oriented mental-health care, more research is needed on the association that may exist between the use of hospitals and changes in the social integration of psychiatric patients. Therefore, in this study, we examined (1) whether readmissions or LoS in psychiatric wards were associated in different ways with changes in the social integration of patients with psychiatric disorders, and (2) which dimensions of social integration were the most affected.

Methods

Study design

This study was part of the project “Comparing policy, framework, structure, and effectiveness of Functional and Integrated systems of mental health care” (COFI), funded by the European Commission (FP7) [51]. COFI was a prospective cohort study conducted in 57 psychiatric hospitals in the UK, Poland, Germany, Italy, and

Belgium. The inclusion criteria for patients were i) being 18 years old or older, ii) having a main diagnosis of psychotic (F20-29), mood (F30-39), or anxiety and somatoform disorder (F40-49), iii) being hospitalised in a general adult psychiatric hospital unit, and iv) having the ability and capacity to give informed consent. These diagnosis groups were selected as inclusion criteria in order to allow comparison between sites. Indeed, in the preparation of the study, we screened the diagnoses of the patients admitted to the inpatient wards and noted that these were the main diagnosis groups in all five countries. The point of entry of patients was hospitalisation from October 2014 to December 2015 in one of the 57 participating hospitals. Patients were followed up one year after their index admission. Twenty types of inpatient and outpatient services were defined using the Client Socio-Demographic and Service Receipt Inventory − European Version CSSRI-EU [52] and data were collected on their use during the follow-up period. Although the exact availability of the existing health and social services was not assessed for each of the 57 sites, the 20 service types that were assessed were systematically provided in the different sites [53]. As a natural experiment, the COFI study addressed psychiatric patients within their natural care pathway, i.e. as it is organised in the five countries. Obviously, there were some differences between countries in terms of the whole population admitted to hospital. However, the profile of the patients included in the study was similar in all countries.

The sample size was estimated to be 1200 patients per country with an overall sample size of 6000 patients, in order to detect a 5% difference in readmission rates, which was the primary outcome of the study, taking into account the possible clustering effect of recruitment sites and a 15% drop-out rate [51]. The final whole sample of the study included 7302 patients with baseline and follow-up measurements available, and a pre-planned subsample of 2181 patients with more detailed follow-up measurements. Baseline data were collected via routinely collected clinical records or through face-to-face interviews with trained researchers. Patients in the pre-planned subsample were selected randomly from the whole sample and stratified according to the patients’ diagnoses and type of index admission (first admission or previous admission). The stratified random sampling was used to decrease the variance of the sample estimates [54]. The pre-planned subsample was expected to include at least 360 patients per country and 1,800 patients overall [51]. The final subsample included 2,181 patients, with a distribution of baseline characteristics similar to that of patients in the whole sample. Detailed follow-up data on patients' social integration were collected from patients in the subsample via telephone contact or through face-to-face interviews one year after admission. This study used data from this pre-planned subsample. Ethical approvals were obtained in each of the five countries that participated in the COFI project (ref: 14/NE/1017). The detailed protocol of the COFI project has already been published elsewhere [51].

Measures

The outcome variable was the change, over one year, in the patients' level of social integration. Social integration was measured at baseline and one year after admission using the Objective Social Outcome Index (SIX) [55]. The SIX is a global index of social outcomes that combines different indicators of an individual's social situation in order to provide a brief, meaningful, and comprehensive overview in a single indicator. The SIX index has been tested and met the following quality criteria: having a sufficient distribution to identify differences between groups, capturing changes over time to assess the potential effect of interventions, and carrying a low risk of error in assessment and documentation so that scores remain stable in the absence of real change [55]. Furthermore, The SIX was used to test the concurrent and convergent validity of other measures and scales of social integration and met the validity criteria [56, 57]. An important feature of the SIX index for this study is that it captures relevant changes in the social situation of individuals over time [55]. The SIX index ranges from 0 (low social integration) to 6 (high social integration). It includes four dimensions: employment status (0 = none, 1 = voluntary⁄protected⁄sheltered work, hereafter "protected job", and 2 = regular employment), housing status (0 = homeless/24h-supervised accommodation, 1 = sheltered/supported accommodation, 2 = independent accommodation), family situation (0 = living alone, 1 = living with a partner/family), and friendship status (0 = did not meet a friend in the last week, 1 = met at least one friend in the last week). A change in the overall SIX score was calculated, based on the difference between the SIX score at baseline and at follow-up in order to measure the change in social integration one year after the index admission to the hospital. Thus, the change in the SIX score ranges from -6 (major decrease in social integration) to 6 (major increase in social integration). In addition, each of the four dimensions of social integration (employment, housing, partnership and family situation, and friendship) was assessed separately. A binary variable was calculated for each dimension according to whether the score in this dimension decreased or not during the follow-up period.

The main exposure variables were the total LoS in, and the number of admissions to a psychiatric ward in general and psychiatric hospitals (i.e. acute psychiatric and long-term hospitalisations) during the follow-up period. Length of stay in hospital is a variable that is known to have a positive skewed distribution [58, 59]. We therefore classified the LoS into four categories using a regression tree analysis with the LoS as the dependent and independent variable. The regression tree analysis is an appropriate method for identifying cut-off points that represent the distribution of the variable in the sample and it contributes to detect possible non-linear trends and risk groups. The four LoS categories were: less than 22 days, from 22 to 75 days, from 76 to 162 days, and more than 162 days.

Several baseline socio-demographic and clinical variables which were likely to influence both LoS and social integration were included in the analysis, in line with the existing literature [8, 14, 20, 42, 43, 46, 60-62]. These were: index of admission (first admission or not), involuntary admission (yes/no), age, gender, educational status, migrant status (born in the country of recruitment or not), psychiatric diagnoses (ICD-10 classification), having a comorbid diagnosis of substance misuse (yes/no), and severity of symptoms. Severity was measured using the Clinical Global Impression Scale (CGI). The CGI is a scale from 1 (normal) to 7 (among the most severely ill patients), rated by clinicians [63].

Data analysis

Descriptive statistics were computed for patients' socio-demographic and clinical characteristics and hospitalisation variables. Descriptive statistics were also computed according to patients' main diagnoses (see online Supplementary Table 1). Additional descriptive statistics were computed on patients' baseline and follow-up social integration scores in order to describe and model their evolution. The change in the overall SIX score had a normal distribution and met the normality criteria. Therefore, mixed-effects univariate and multivariate linear regression models were used to test the association between the change in patients' social integration one year after the index admission and the total LoS, number of psychiatric admissions, patients' characteristics, and other hospitalisation variables. As far as each social integration dimension was concerned, multivariate logistic regression models were used in order to test the association between each of the four dimensions of social integration and the total LoS, number of psychiatric admissions, patients' characteristics, and other hospitalisation variables. Finally, the association between LoS and social integration may differ depending on patient profiles and on some of their socio-demographic and clinical characteristics. For example, a low level of education and a diagnosis of psychosis are both predictors of long LoS in psychiatric wards [34, 39, 64] and risk factors for social exclusion, as people with a lower level of education are more likely to be excluded from the labour market and psychotic patients are at higher risk of having a precarious housing situation [14, 62, 65]. Interactions were therefore computed to assess whether the main socio-demographic and clinical characteristics of patients (i.e. educational status and psychiatric diagnosis) had a moderating effect on the association between psychiatric hospitalisations and social integration. Both linear and logistic models were adjusted for country as a fixed factor, and with the hospital of admission as a random intercept. The statistical analyses were performed using SAS 9.3.

Results

Sample characteristics and patients' social integration

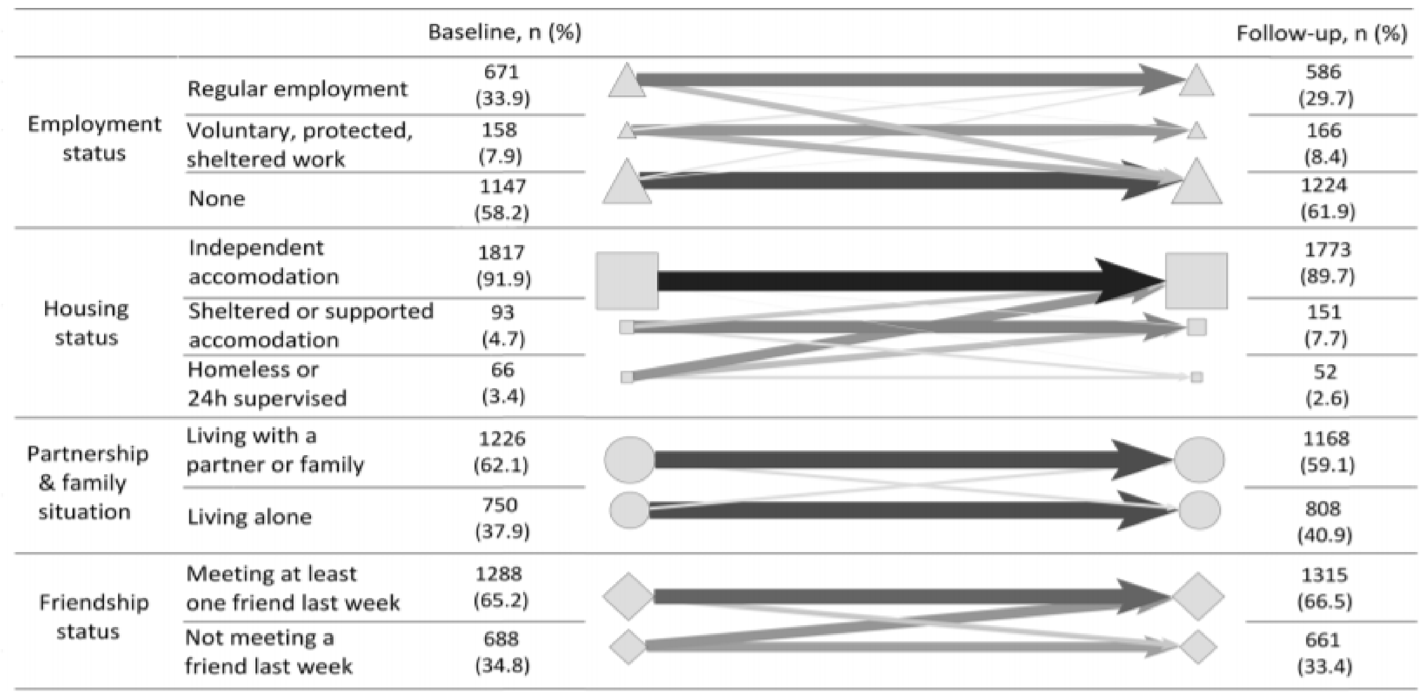
Patients' characteristics and variables on hospitalisation are shown in Table 12. Patients were 43 years old on average and 51% were male. The mean score of severity of patients' symptoms was 4.4 out of 7 (SD = 1.1). Thirty-six percent had a main diagnosis of psychotic disorder, 15% had a comorbid diagnosis of substance misuse, 45% had completed tertiary education, and 12% were migrants. The average total LoS in a psychiatric ward over the follow-up period was 55.6 days (SD = 62, median = 35) and the average number of psychiatric admissions was 1.6 (SD = 1.1). The index admission was the first admission for 36% of patients and 22% were admitted involuntarily at least once during the follow-up period.

Table 12: Study sample and characteristics

	Total sample **n = 2181**
Age, mean (SD)	43 (12)
Gender, male, n (%)	1114 (51)
Baseline SIX, mean (SD)	3.9 (1.4)
Follow-up SIX, mean (SD)	3.7 (1.3)
Decrease in employment status over a year, n (%)	283 (14)
Decrease in housing status over a year, n (%)	114 (6)
Decrease in family situation over a year, n (%)	182 (9)
Decrease in friendship status over a year, n (%)	335 (17)
Total length of stay in the year, mean (SD) median	55.6 (62) 35
- < 22 days, n (%)	719 (33)
- 22 – 75 days, n (%)	960 (44)
- 76 – 162 days, n (%)	371 (17)
- > 162, n (%)	131 (6)
Admissions in the year, mean (SD)	1.6 (1.1)
First admission, n (%)	783 (36)
At least one involuntary admission in the year, n (%)	445 (22)
Severity of symptoms (CGI), mean (SD) (1 = low, 7 = high)	4.4 (1.1)
Having a comorbid diagnosis of substance misuse, n (%)	289 (14.6)

At baseline, the average score for patients' social integration was 3.9/6 (SD = 1.4) and it decreased slightly but significantly one year later: 3.7/6 (SD = 1.3) (paired t test, t = 4.03, p < 0.001). After one year, 14% of patients had a less favourable employment status (i.e. had become unemployed or moved from a regular to a protected job) and 6% had a less favourable housing status (i.e. had become homeless or moved from independent accommodation to sheltered or supported accommodation). Among patients who reported at baseline that they lived with a partner or that they had had contact with a friend at least once in the last week, 9% no longer live with their partner and 17% reported no such contact with a friend at follow-up. The changes in social integration scores between baseline and follow-up are presented in detail in Figure 11. At baseline, 58.2% of patients were unemployed, 33.9% had a regular job, and 7.9% had a protected job. Between baseline and follow-up, the employment status of patients remained relatively stable, especially for unemployed patients. In terms of housing, 91.9% of patients had independent accommodation at baseline and the majority still did after one year. Moreover, the majority of patients who were homeless or in a 24h- supervised accommodation at baseline had independent accommodation at follow-up. The partnership and family situations of patients remained relatively stable. About 60% of patients reported living with a partner or family at baseline and at follow-up. In terms of friendship, about 65% of patients reported contact with a friend in the last week at baseline-and at follow-up. The social integration scores at baseline and follow-up are shown in detail in Table 2 of the online supplementary material.

Figure 11: Baseline and follow-up social integration scores and change over one year



		Baseline, n (%)	Follow-up, n (%)
Employment status	Regular employment	671 (33.9)	586 (29.7)
	Voluntary, protected, sheltered work	158 (7.9)	166 (8.4)
	None	1147 (58.2)	1224 (61.9)
Housing status	Independent accomodation	1817 (91.9)	1773 (89.7)
	Sheltered or supported accomodation	93 (4.7)	151 (7.7)
	Homeless or 24h supervised	66 (3.4)	52 (2.6)
Partnership & family situation	Living with a partner or family	1226 (62.1)	1168 (59.1)
	Living alone	750 (37.9)	808 (40.9)
Friendship status	Meeting at least one friend last week	1288 (65.2)	1315 (66.5)
	Not meeting a friend last week	688 (34.8)	661 (33.4)

Legend: Shapes represent the groups of patients with the different scores in each of the four dimensions of the SIX index at baseline in the left column and at follow-up in the right column. The size of the shape is proportional to the size of the group. Arrows represent the change of score. An arrow's width is proportional to the percentage of the group from the baseline sample. Arrows are also represented in greyscale according to the same proportions

Association between hospitalisations in psychiatric wards and the change in patients' level of social integration after one year

The associations between the change in patients' social integration over one year and variables of hospitalisation are shown in Table 13. In multivariate analysis, a longer total LoS in psychiatric wards was significantly associated with a decrease in the social integration score, but not the other hospitalisation variables. The negative association between LoS and patients' social integration scores was dose-response and significant for patients who were hospitalised for more than 162 days during the follow-up period (β = -0.23, p = 0.03).

In particular, employment, family, and housing status significantly decreased with a longer LoS. Compared to patients who were hospitalised for less than 22 days over the follow-up period, patients who were hospitalised for more than 162 days were more likely to become unemployed or to move from a regular to a protected job (OR = 2.21, p = 0.02) and more likely to no longer live with their partner or family (OR = 1.94, p = 0.04). Patients who stayed in hospital for between 76 and 162 days (OR = 2.34, p = 0.005) and for more than 162 days (OR = 3.45, p < 0.001) were also more likely to become homeless or to move from independent accommodation to sheltered or supported accommodation during the follow-up period than patients whose total Los was lower than 22 days.

There was no significant association between LoS and friendship status. However, friendship status significantly decreased with a higher number of admissions over the follow-up period (OR = 1.15, p = 0.03). In contrast, there was no association between the number of admissions and the other dimensions of social integration.

Finally, patients who had been hospitalised for the first time in a psychiatric ward were more likely to become unemployed or to move from a regular to a protected job (OR = 1.42, p = 0.01). They were, however, less likely to become homeless or to move from independent accommodation to sheltered or supported accommodation (OR = 0.52, p = 0.01) than patients who had been admitted previously.

Table 13: Association between hospitalisation in psychiatric inpatient units and the change in social integration, employment, housing, friendship status, and family situation of psychiatric patients over a year

	Change in social integration over a year		**Decrease in employment status over a year**		**Decrease in housing status over a year**		**Decrease in family situation over a year**		**Decrease in friendship status over a year**	
	β	p-value	OR	p-value	OR	p-value	OR	p-value	OR	p-value
Length of stay										
- < 22 days	REF	REF	REF	REF	REF	REF	REF	REF	REF	REF
- 22 – 75 days	-0.01	0.95	1.09	0.68	0.91	0.34	1.37	0.12	1.10	0.95
- 76 – 162 days	-0.12	0.07	1.41	0.06	2.34	0.005	1.57	0.08	1.008	0.61
- > 162 days	-0.23	0.03	2.21	0.02	3.45	<0.001	1.94	0.04	1.10	0.63
Number of admissions	-0.05	0.54	1.006	0.31	0.90	0.33	0.98	0.99	1.15	0.03
First admission (Yes)	-0.08	0.83	1.42	0.01	0.52	0.01	1.08	0.11	0.97	0.79
Involuntary admission (Yes)	0.03	0.50	0.99	0.97	1.02	0.92	0.75	0.33	0.96	0.62

Multivariate linear and logistic regression models adjusted for variables in the models and age, gender, severity of symptoms, psychiatric diagnosis, comorbid diagnosis of substance misuse, educational status, migrant status, and country as fixed factors and the admission hospital as a random intercept

The temporal relation between length of stay in psychiatric wards and the change in patients' level of social integration after one year

As the LoS in psychiatric wards and the patients' level of social integration are likely to affect each other, a sensitivity analysis was performed using the same statistical model as in Table 13, but including only the LoS of the index admission, instead of the total LoS during the follow-up period. The objective of this analysis was to gain more insight into the temporal relation between LoS and the change in social integration, as the LoS of the index admission occurred before the change in social integration over the follow-up period. The results showed a significant, negative association between the LoS of the index admission and the change in social integration over the follow-up period (β = -0.14, p = 0.03).

Socio-demographic and clinical moderators of the association between length of stay, number of admissions in a psychiatric ward, and the change in the patient's level of social integration after one year

The socio-demographic and clinical moderators are shown in Table 14. The patient's main psychiatric diagnosis and educational status were significant moderators of the association between LoS and the level of social integration in the multivariate analysis. Patients with a main diagnosis of mood disorder who were hospitalised for more than 76 days during the study period were significantly more likely to have a decrease in their social integration score (76-162 days, β = -0.52, p = 0.01; > 162 days, β -0.81, p = 0.004) than patients with a main diagnosis of psychotic disorder who had the same LoS. In particular, a decrease was found in their employment status (76-162 days, OR = 2.08, p = 0.04; > 162 days, OR = 4.13, p = 0.01). Patients with a mood disorder and a long LoS, however, were less likely to have their housing status decrease (76-162 days, OR = 0.45, p = 0.01; > 162 days, OR = 0.38, p = 0.008) than patients with a main diagnosis of psychotic disorder who had the same LoS. Patients who had a low level of education (i.e. primary education) who were hospitalised for between 76 and 162 days during the study period were less likely to experience a decrease in their employment status (OR = 0.65, p = 0.02) than patients with a higher level of education (i.e. tertiary education) with the same LoS. However, patients with a lower level of education who were hospitalised for more than 76 days were more likely to experience a decrease in their housing status (76-162 days, OR = 2.63, p = 0.03; > 162 days, OR = 4.76, p =

0.007) than patients with a higher level of education and the same LoS. The other socio-demographic and clinical characteristics were not significant moderators.

Table 14: Socio-demographic and clinical moderators of the association between length of stay, number of admissions in psychiatric wards, and changes in patients' social integration outcomes over the follow-up period

	Change in social integration over a year				Decrease in employment status over a year			
	Main effect B (p-value)	Interaction β (p-value)			Main effect OR (p-value)	Interaction OR (p-value)		
		Length of stay (days) [c]				Length of stay (days) [c]		
		22 – 75	76 – 162	> 162		22 – 75	76 – 162	> 162
Diagnosis ICD-10 [a]								
- Mood disorders	-0.17 (0.25)	-0.21 (0.65)	-0.52 (0.01)	-0.81 (0.004)	1.75 (0.02)	1.32 (0.19)	2.08 (0.04)	4.13 (0.01)
- Neurotic disorders	-0.05 (0.81)	-0.03 (0.54)	-0.17 (0.63)	-0.23 (0.29)	1.09 (0.52)	1.12 (0.53)	1.28 (0.16)	1.08 (0.79)
Educational status [b]								
- Primary	0.11 (0.59)	-0.08 (0.93)	0.09 (0.71)	0.007 (0.95)	0.78 (0.006)	0.92 (0.65)	0.65 (0.02)	0.78 (0.13)
- Secondary	0.09 (0.72)	0.04 (0.81)	-0.02 (0.79)	0.19 (0.31)	0.98 (0.93)	0.97 (0.83)	0.72 (0.53)	0.89 (0.68)
Length of stay (days) [c]								
- > 162	-0.20 (0.04)	/	/	/	2.11 (0.03)	/	/	/
- 76 - 162	-0.09 (0.52)	/	/	/	1.11 (0.08)	/	/	/
- 22 - 75	-0.02 (0.76)	/	/	/	1.01 (0.88)	/	/	/
Number of admissions	-0.02 (0.15)	/	/	/	0.89 (0.78)	/	/	/

Multivariate linear and logistic regression models adjusted for variables in the model and age, gender, severity of symptoms, comorbid diagnosis of substance misuse, migrant status, first admission, involuntary admission, country as fixed factors and the admission hospital as a random intercept

[a] Reference category = psychotic disorders, [b] Reference category = tertiary or further education, [c] Reference category = < 22 days

	Decrease in housing status over a year				Decrease in family situation over a year				Decrease in friendship status over a year	
	Main effect OR (p-value)	Interaction OR (p-value) Length of stay (days) [c]			Main effect OR (p-value)	Interaction OR (p-value) Length of stay (days) [c]			Main effect OR (p-value)	Interaction OR (p-value) No. of admissions
		22 – 75	76 – 162	> 162		22 – 75	76 – 162	> 162		
Diagnosis ICD-10 [a]										
- Mood disorders	0.41 (0.009)	0.71 (0.32)	0.45 (0.01)	0.38 (0.008)	1.02 (0.92)	0.47 (0.21)	0.51 (0.29)	0.89 (0.73)	0.89 (0.81)	1.02 (0.85)
- Neurotic disorders	0.82 (0.63)	0.71 (0.32)	1.13 (0.53)	0.59 (0.29)	2.04 (0.07)	0.89 (0.73)	1.12 (0.54)	1.81 (0.09)	0.78 (0.67)	1.05 (0.76)
Educational status [b]										
- Primary	1.42 (0.01)	0.97 (0.81)	2.63 (0.03)	4.76 (0.007)	1.71 (0.07)	1.47 (0.68)	1.68 (0.61)	1.76 (0.11)	1.43 (0.12)	1.35 (0.29)
- Secondary	1.02 (0.89)	1.05 (0.96)	1.22 (0.18)	1.38 (0.11)	0.96 (0.83)	0.91 (0.85)	0.98 (0.87)	0.61 (0.31)	0.98 (0.86)	0.89 (0.76)
Length of stay (days) [c]										
- > 162 days	1.82 (0.01)	/	/	/	1.76 (0.04)	/	/	/	/	/
- 76 – 162 days	1.59 (0.04)	/	/	/	1.31 (0.24)	/	/	/	/	/
- 22 – 75 days	1.03 (0.87)	/	/	/	1.14 (0.43)	/	/	/	/	/
Number of admissions	0.93 (0.89)	/	/	/	0.94 (0.85)	/	/	/	1.11 0.04	/

Multivariate logistic regression models adjusted for variables in the model and age, gender, severity of symptoms, comorbid diagnosis of substance misuse, migrant status, first admission, involuntary admission, country as fixed factors and the admission hospital as a random intercept

[a] Reference category = psychotic disorders, [b] Reference category = tertiary or further education, [c] Reference category = < 22 days

Discussion

Main findings

Having a long length of stay in a psychiatric ward was more strongly associated with a decrease in the social integration of psychiatric patients after one year than experiencing repeated admissions. The dimensions of social integration that were more strongly and negatively associated with longer lengths of stay were the patients' housing, employment, and household living situation. Psychiatric patients who experienced a total of more than 76 days of psychiatric hospitalisation in one year had a significantly higher probability of becoming homeless or moving from independent accommodation to sheltered or supported accommodation. Moreover, psychiatric patients who were hospitalised for more than 162 days in one year had a significantly higher probability of becoming unemployed or moving from a regular job to a form of protected job. There was also a higher probability that patients who were hospitalised for more than 162 days would no longer be living with their partner or family. By contrast, repeated admissions over one year was not associated with such a decrease in employment, accommodation, and family status, though it was negatively associated with friendship contact. In terms of housing, patients who were hospitalised for the first time were less likely to be affected than patients who had previously been admitted to hospital.

The main psychiatric diagnosis and the educational status of the patient were moderators of the association between LoS and the change in social integration, particularly in relation to employment and housing status. Among patients who have been staying in hospital for more than 76 days over one year, those with a main diagnosis of mood disorder and those with a higher level of education were more likely to experience a decrease in their employment status. By contrast, patients with a main diagnosis of psychotic disorder were more likely to experience a decrease in their housing status. Among patients who have been staying in hospital for more than 162 days, those with a lower level of education were more likely to experience a decrease in their housing status.

Interpretation of findings

So far, the literature on the association between hospitalisation in psychiatric wards and patients' social integration has been inconclusive [8, 49, 50]. The results of the present study are, however, consistent with the literature suggesting that a longer length of stay in a psychiatric ward is associated with a decrease in the social integration of psychiatric patients, in particular on dimensions such as employment and housing [46]. Obviously, the relationship between the LoS in hospital or hospital readmissions and patients' level of social integration is complex, as they are likely to affect each other. Given the design of the study, we cannot disentangle the temporal relation found between LoS and the change in the social integration of patients over the study period. A long LoS in a psychiatric ward might disrupt a patient's social and professional life and negatively affect his/her social integration, but a decrease in a patient's level of social integration might also cause a relapse and, consequently, a longer LoS in hospital. The latter interpretation, however, should not be overstated for two main reasons. Firstly, some studies have shown that patients' socio-demographic and clinical characteristics only weakly predict the LoS in psychiatric hospitals [34, 40]. A recent study found that patients' characteristics, including clinical status, predicted only 15% of the variance of LoS in psychiatric hospitals [39]. Authors have argued that, although poor social functioning may reflect the need for lengthy hospitalisation, the possibility that lengthy stays lead to poor social functioning should also be taken into account and have appealed for more research into these aspects. Secondly, the results of the sensitivity analysis of the association between the LoS of the index admission and the change in social integration showed that having a long length of stay during the index admission was significantly associated with a decrease in the social integration of psychiatric patients after one year. Taken together, these two arguments support the hypothesis that long LoS in psychiatric wards have an effect on patients' social integration.

The study also found that a long length of stay is more strongly associated with a decrease in the social integration of patients than repeated admissions. This finding has important practical implications for policies and interventions. To the best of our knowledge, this result has never been highlighted before. This finding suggests that a reduction of the length of hospital stays is consistent with policies and interventions aiming to strengthen patients' social integration. Some authors have argued that the process of deinstitutionalisation and the reduction of LoS in psychiatric hospitals have had adverse effects on patients' social integration with, for example, an increase in homelessness and social isolation [46, 66-68]. The results of the present study, however, indicate that the relationship between length of hospital stay and social integration is more complex and that, to a certain extent, long stays in psychiatric wards may also have adverse effects on social integration.

Patients' friendship was the only dimension of social integration that was negatively associated with repeated hospital admissions. Although further research would be needed to explore and understand this association more in detail, one possible interpretation is that creating and maintaining friendship ties takes time and is probably more difficult when a patient moves back and forth between hospital and the community. In addition, this finding is consistent with other studies examining the social support network of psychiatric patients [69].

This study also highlights some clinical and socio-demographic risk factors related to social exclusion and, more specifically, to job and housing loss during long stays in psychiatric wards, that care providers should consider more carefully. Patients with a main diagnosis of mood disorder who were hospitalised for a long period were more likely to experience a decrease in their overall social integration. People with mood disorders are known to have relatively better social integration than people with psychotic disorders [25, 26]. One possible interpretation of this result is that people with a diagnosis of mood disorder and a higher level of social integration at baseline are more likely to experience a decrease in social integration during a long hospitalisation than people with a lower level of social integration at baseline. Regarding job loss, being admitted for the first time, having a main diagnosis of mood disorder, and having a high level of education were risk factors. People with a high education status are more likely to work within a competitive environment. Experiencing their first, long psychiatric hospitalisation with a diagnosis of psychiatric disorder, therefore, has heavier consequences for their employment. By contrast, having had several previous hospitalisations, having a main diagnosis of psychotic disorder, and having a low level of education were risk factors in terms of housing loss. Patients with a lower educational status may have a more unstable housing situation and are therefore more likely to be affected by long hospital stays in terms of accommodation. Psychotic patients are at a high risk of homelessness or of having a precarious housing situation [20, 62]. However, if a longer stay in hospital may seem appropriate for psychotic patients in precarious housing situations and without accommodation, it can be detrimental for those who have an independent accommodation solution.

Strengths and limitations

In a review conducted in 2014 that compared the effects of short and long hospital stays on the social functioning and social integration of psychiatric patients, the most recent study included was from 1980 and the largest sample size was 1169 patients [46]. The main strength of this study is, therefore, its large sample of more than 2,000 patients recruited from 57 hospitals in five European countries. Because it is so large and diverse, that sample provides not only a high statistical power but also a strong external validity to different contexts and countries.

This study, however, also has some limitations. One major limitation is that the association between LoS and readmissions in a psychiatric ward and patients' social integration is likely to be affected by several other confounding and unobserved variables, the most important of which is probably the clinical status of the patient. Given the design of the study, i.e. a natural experiment, the inclusion of patients across the 57 hospitals was not random and there were potential confounding factors. A causal relationship between LoS or readmissions in psychiatric ward and a change in social integration cannot, therefore, be determined. Only a randomised clinical trial (RCT), in which the LoS and the frequency of hospitalisation were randomised would make it possible to establish causation. However, randomising the LoS and the frequency of hospitalisation entails other obstacles and may be clinically and ethically problematic. The few RCTs published in the second half of the twentieth century did not randomise the LoS, but randomly allocated patients to different types of hospitalisation, i.e. planned short-stay admission or brief hospitalisation versus long or standard stay [50, 70-74]. However, it is difficult to draw conclusions about the impact of LoS on the social integration of patients, because the results of these studies were inconsistent and because the definition of a short stay admission varied from one study to another. Moreover, the patients allocated to short-stay hospitalisations also received other treatments, such as discharge planning or intensive aftercare. By contrast, in our study, this risk of confounding bias was partially overcome because analyses were controlled for several baseline variables known to be associated with both LoS and readmissions and social integration, and were adjusted with the hospital as a random intercept in order to take into account a potential clustering effect. We cannot rule out, however, that other possible confounding and unobserved factors were not taken into account, e.g. the physical health status of patients and the evolution of the psychiatric disorder during the follow-up period. A sensitivity analysis was therefore performed in order to test the endogeneity of LoS in relation to social integration. The null hypothesis was not rejected (LR = 0.76, p = 0.38), indicating the absence of endogeneity of LoS to unobserved confounders affecting social integration [75, 76]. This result suggests that the variation of LoS is not likely to be related to unobserved confounders, e.g. unobserved clinical or socio-demographic characteristics of patients.

Another limitation is related to the sample selection. We cannot rule out a selection bias, as the study is based on data from a pre-planned subsample. To control for this potential bias, we examined the difference between the baseline social integration scores of patients in the subsample compared to the other patients in the whole sample. The mean score in the subsample was 3.87 / 6 (SD = 1.39), while it was 3.69 / 6 (SD = 1.43) for the other patients in the whole sample (t-test = 2.46, p = 0.01). Although the difference was statistically significant, it was very small and, therefore, very unlikely to have clinical or social significance. In addition, the risk of selection bias was minimised because the pre-planned subsample was randomly selected from the whole sample. Finally, social integration is a multidimensional concept. Although the SIX index has been validated [55], it aims to summarise a complex phenomenon using a limited number of dimensions. For example, information about social relationships and support is probably not entirely captured by a single question about the frequency of meeting a friend. Therefore, other dimensions of social integration might be worth studying in this context, e.g. social participation and political and community engagement.

Conclusion

The social integration of patients with psychiatric disorders is a major objective of mental health systems, policies, and services, both for clinicians and for patients themselves [1, 11, 18]. This study supports the importance of policies and interventions that aim to reduce the length of hospital stays for psychiatric patients in order to preserve their social integration. The results of this study suggest that shorter lengths of stay in hospitals should be favoured, especially for patients with mood disorders, not so much from a budgetary perspective, but in order to protect patients' employment, housing, and partnership-family situations, and that fewer hospital stays should be favoured in order to protect patients' friendships. In addition, special attention should be paid to helping psychiatric patients to find and retain their housing and employment while hospitalised. Therefore, the results of this study also support the importance of evidence-based employment and housing support interventions for psychiatric patients, e.g. Housing First and Individual Placement and Support [77-79].

The objective of this study was not to make cross-country comparisons. In view of the differences between countries in terms of length of stay, mental health care, and social integration policies, however, further research might compare the association between long LoS or readmissions in psychiatric wards and the social integration of psychiatric patients in different countries [4, 34, 80]. Finally, a one-year follow-up period is relatively short to detect significant and meaningful changes in the social integration of individuals. Further studies might use a comparable design with a longer follow-up period, especially since we know that psychiatric patients sometimes use psychiatric hospitals throughout their lifetime.

Acknowledgments

The authors would like to gratefully acknowledge the 2181 participants and the 57 services that took part in the study, the wider COFI study group, and the support of the funders.

Funding

This study was funded by the European Commission 7th Framework Programme. The Grant agreement number is 602645. The Polish part of this study was co-financed by the Polish Ministry of Science and Higher Education (agreement number 3153/7.PR/2014/2 to conduct a co-financed international project no. W112/7.PR/2014).

Compliance with ethical standards

Conflict of interest: The authors declare that they have no conflict of interest.

Ethical approval: The authors confirm that the study had been approved by the appropriate ethics committees in all five countries and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.

Ethical standards: The authors confirm that the ethical approval was obtained in all countries: England (NRES Committee North East – Newcastle & North Tyneside), Germany (Ethical Board, Technische Universität Dresden), Italy (Comitati Etici per la sperimentazione clinica – CESC), Poland (Komisja Bioetyczna przy Instytucie Psychiatrii i Neurologii w Warszawie), Belgium (Comité d'Ethique hospitalo-facultaire des Cliniques Saint-Luc).

References chapter 5

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Chapter 6

6

Chapter 6: Stakeholder coalitions and priorities around the policy goals of the Belgian mental health care reform

The social integration of people with mental illness has become one of the main goals of mental health policies, along with community care, continuity of care, and recovery [1-4]. To achieve these goals, mental health reforms have been implemented in recent decades in Western countries [5-8]. However, as previously explained, different systematic reviews and meta-analysis have shown that despite reforms in mental health care and the implementation of evidence-based interventions, the social integration of people with SMI have remained relatively low and have not improved over the past decades [9-12].

One explanation for this lack of improvement in the social integration of people with mental illness is the slow and inconsistent implementation of mental health care reforms. Indeed, the pace of reforms has been slow, efforts have been partially thwarted by the resistance of stakeholders, and initial goals, such as the social integration of people with mental illness, are not really achieved [13, 14]. The effective implementation of a reform depends, among other things, on the stakeholders' endorsement of its program and goals. However, stakeholder policy priorities and coalitions on the main goals of mental health reforms has received little attention.

In the context of the ongoing nation-wide mental health care reform in Belgium, the objective of this study was to identify and describe stakeholder coalitions around mental health policy goals and to highlight their core policy goals and oppositions.

This article was published in Administration and Policy in Mental Health and Mental Health Services Research in November 2020.

Administration and Policy in Mental Health and Mental Health Services Research
https://doi.org/10.1007/s10488-020-01100-8

ORIGINAL ARTICLE

Stakeholder Coalitions and Priorities Around the Policy Goals of a Nation-Wide Mental Health Care Reform

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Accepted: 24 November 2020

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Abstract

Purpose**:** The difficulty of implementing mental healthcare reforms owes much to the influence of stakeholders. So far, the endorsement of mental health policy reforms by stakeholder coalitions has received little attention. This study describes stakeholder coalitions formed around common mental health policy goals and highlights their central goals and oppositions.

Methods**:** Data were collected on the policy priorities of 469 stakeholders (policymakers, service managers, clinicians, and user representatives) involved in the Belgian mental healthcare reform. Four coalitions of stakeholders endorsing different mental health policy goals were identified using a hierarchical cluster analysis on stakeholders' policy priorities. A belief network analysis was performed to identify the central and peripheral policy goals within coalitions.

Results**:** Coalitions brought together stakeholders with similar professional functions. Disagreements were observed between service managers and policymakers around policy goals. The two coalitions composed of policymakers supported a comprehensive approach that combines the different goals and also supported the shortening of hospital stays, whereas the two coalitions composed of service managers emphasised the personal recovery of users and continuity of care. Regardless of the coalitions' differing policy priorities, strengthening community care was a central goal while patient-centred goals were peripheral.

Conclusions**:** The competing policy positions of the coalitions identified may explain the slow and inconsistent pace of the Belgian mental healthcare reform. Strengthening community care may be an essential part of reaching consensus across coalitions. Finally, special care must be taken to ensure that patient-centred policy goals, such as social integration, are not set aside in favour of other goals.

Background

In recent decades, mental health care systems in Western countries have undergone provision, coordination, and funding reforms [5-8]. The historical roots of mental health care and its evolution over time have led to numerous reforms with multiple policy goals [15]. Two important policy goals have been the deinstitutionalisation of mentally ill people, which started in the second half of the twentieth century [16, 17], and priority being given to the personal recovery of people living with mental illness, which has been a guiding principle of mental health care reforms since the early 2000s [6, 18, 19].

Mental health care reforms and policies have been driven by multiple demands that have emerged from the health and social sectors and also from society more generally [20-22]. For example, in the 1980s, the deinstitutionalisation of people who live with mental illness in Italy was rooted in a "democratic psychiatry" movement with a progressive view of the human capacity for resilience [23, 24]. In the UK, however, deinstitutionalisation has been driven by a neoliberal vision that has sought to reduce the costs related to the number of psychiatric beds in public hospitals [25, 26]. Demands have often been contradictory and mental health reforms and policies have continuously been subject to recurring tensions, ambiguities, and inconsistencies [15, 27]. Indeed, mental health policies, like other policies, are an attempt to balance technical demands (such as efficiency, cost control) and normative ones (such as human rights, quality of care) [20]. In addition, there may also be tensions between contradictory normative demands [20, 28]. An example of this is the tension between users' movements calling for more social inclusion and safety concerns raised by wider society, the former aiming to support the autonomy and inclusion of people living with mental illness in the community while the latter aims to separate individuals who are stigmatised as potentially dangerous (e.g. people living with severe mental illness) from the community.

Amid multiple, contradictory demands, the implementation of mental health care reforms is often slow and inconsistent, leaving policy goals unachieved. Thus, although national and international authorities have advocated deinstitutionalisation and the provision of effective community-based care over the last few decades [29, 30], an international comparison of the progress of deinstitutionalisation policies found that hospital closure was still in an early stage in 21 out of 30 European countries in 2016 [31]. Another study also drew attention to forms of reinstitutionalisation in some countries, i.e. an increase in the number of involuntary hospital admissions and places in forensic institutions and supported housing, to replace the beds that were closed in psychiatric hospitals [32]. In terms of recovery-oriented policy goals, four systematic reviews have shown that recovery outcomes of people who live with severe mental illness have not improved over recent decades, despite reforms and major changes in mental health care [9-12]. For example, employment is an important dimension of personal recovery and the integration of people with mental illnesses into the labour market has been on the political agenda of many OECD countries since the early 2000s, but the pace of policies and reforms to achieve it has been slow [33]. In 2010, in OECD countries, the risk of being unemployed was two to three times higher for people living with mental illness than for people without mental illness [34]. Furthermore, some studies have suggested that periods of economic hardship have intensified the economic exclusion of people living with mental illness and caused a progressive decline in their employment rate [35, 36].

Another key reason for the slow and inconsistent pace of reforms is that they can be thwarted or reshaped by inconsistencies between stakeholder and policy priorities [37-40]. In policy implementation research, disagreements within the policy community and between the policy community and other stakeholders have frequently been identified as a factor explaining failures in the implementation of public policies [41, 42]. Furthermore, recurrent tensions and ambiguities in mental health reforms have enabled the most powerful stakeholders to protect their particular interests [20], so that the effectiveness of a reform’s implementation is also related to the stakeholders' endorsement of its goals and programme [43, 44].

For example, it has been suggested that the difference in effectiveness between evidence-based supported employment interventions in the USA, Canada, and Europe result from their differing implementation strategies and low fidelity to the intervention programmes due to stakeholder resistance [45].
Although reform programmes are often devised by policymakers, their implementation is largely shaped by mid-level managers, who have the most influence in practice [46]. This is described by Lipsky [14] in policy implementation research as "street-level bureaucracy", emphasising the central role of frontline staff in putting policy into action. However, mid-level managers may have different priorities and interests to policymakers [47, 48]. The influence of service managers and other providers on the implementation of public policies is even greater in health care systems that are based on corporatist decision-making processes, with a weaker state authority and in which providers (e.g. private hospitals or private practitioners) have extensive autonomy. [49-52].

Finally, the mental health sector is characterised by a multitude of stakeholders with different professional profiles and there is little consensus among them on the etiology of mental illnesses, the definition of recovery, treatment approaches, and appropriate quality of mental health care [53]. This situation facilitates appropriation of and opposition to reform programmes and goals [54]. The reform process, therefore, requires gaining the support of these multiple stakeholders from different statutory frameworks and professional backgrounds, who form coalitions around common interests and priorities [4]. Coalitions may have a greater influence on policy-making and implementation than fragmented groups of stakeholders [55, 56]. The Advocacy Coalition Framework developed by Sabatier [57] analyses, among other things, the influence of coalitions whose beliefs differ about what constitutes good evidence and about what the priorities should be, and on the adoption and implementation of public policies [58]. Although research has started to address the influence of coalitions on health policy agenda setting and implementation [56, 59, 60], there has not been much research looking at coalitions of stakeholders in mental health policies. This is unfortunate given the heterogeneity of mental health policy goals and the diversity of the actors involved.

Identifying stakeholder coalitions and understanding the complex relationships between policy goals and stakeholders’ priorities would be useful in understanding why reforms are lagging behind and would help to coordinate policy implementation more effectively. In the context of an ongoing nation-wide mental health care reform in Belgium, we (1) identified coalitions of stakeholders around the policy goals of the reform, (2) highlighted the central policy goals of those coalitions, and (3) identified the most influential stakeholders in the organisation of mental health care.

Methods

Setting

The Belgian health care system is a regulated-market, social insurance-based system characterised by a substantial level of corporatism in policy decision-making. Although the provision, coordination, and funding of care are the responsibility of the political authorities, these responsibilities tend to be delegated to semi-public institutions in which stakeholders, such as sickness funds and representatives of professionals, have a high level of bargaining power and defend their particular interests [61].

In Belgium, the process of deinstitutionalisation started around 1975 with the establishment of community mental health services, followed in the 1990s by other alternatives to psychiatric hospitalisation (e.g. residential rehabilitation units, sheltered housing, and psychiatric nursing homes). That process of deinstitutionalisation is, however, still far from complete and long-term psychiatric hospitalisation remains an important part of the care supply for adults with mental health problems [62]. In 2008, the rate of psychiatric beds per 100,000 inhabitants was 153, one of the highest in OECD countries [63].

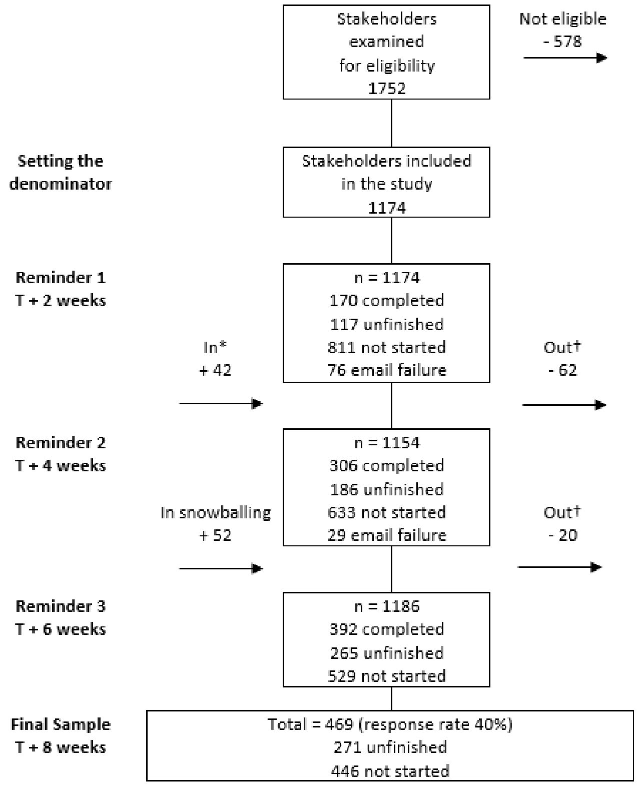
Belgium has been implementing a reform of its mental health care system since 2010. The policy underpinning the reform had various objectives, such as the personal recovery and social integration of people with mental health care needs, the improvement of continuity of care between the social and health care sectors, shorter and less frequent hospital stays, and the strengthening of the community-based care system. The reform mainly focuses on the establishment of networks of services that must cover all mental health care needs in a defined area and provide five care functions: (i) prevention and early detection, (ii) outreach, (iii) personal recovery and social integration, (iv) intensive inpatient treatment, and (v) specific housing and long-term facilities. The reform was implemented from the bottom up, leaving extensive autonomy to local care stakeholders in the development of their own networks of services and resulting in diversified projects [64]. The programme theory of the Belgian mental health care reform has been analysed in detail elsewhere [62].

All in all, these successive waves of reforms have pursued a wide range of international mental health policy goals, such as the deinstitutionalisation and personal recovery of people with mental health problems.

Design

A national stakeholder survey was conducted online in 2018 as part of a broader evaluation of the Belgian mental health care reform. A stakeholder is a person or an organisation that has an important stake in or influence on the solutions being considered [65]. In this study, stakeholders include policymakers, public authorities, sickness funds, experts (i.e. people working in academic or public mental health research centres and mental health expert committees from different ministries), professional associations, service managers and network coordinators, clinicians, and representatives of users and family associations. The stakeholders were selected from the databases of the Belgian Health Care Knowledge Centre (KCE) and from two academic mental health research institutes. The survey questionnaire was delivered via Qualtrics and the anonymity of respondents was ensured throughout the survey procedure. The survey was open for two months, during which participants received three reminders. The flowchart of the sampling process is presented in Table 15. After examination of their eligibility, 1174 stakeholders were contacted. Snowball sampling was used to improve the initial contact list of stakeholders. Initial respondents were asked to nominate up to five people whom they considered important in the organisation of mental health care to contact for the survey. We received 643 nominations regarding 391 different individuals. Of these, 75% were already on the initial contact list. For the remaining 96 people, eligibility was assessed, a contact email was sought, and 52 people were added to the list. In total, 469 stakeholders replied (response rate = 40%). The comparison of the characteristics of respondents and non-respondents is presented in Additional Table 1. The respondent group did not differ from the non-respondent group in terms of professional function (χ2 = 2.03, p = 0.31) and differed slightly in terms of language spoken (χ2 = 4.25, p < 0.05), with an overrepresentation of the Dutch-speaking stakeholders in the respondent group.

Table 15: Flowchart of the sampling process



* New contact persons (job change, resignation, or retired)
† Job change, resignation, retired, or email failure

Measures

Six generic mental health policy goals were identified and presented to respondents: (1) to ensure continuity between the social and care sectors, (2) to treat users in their community, (3) to provide short hospitalisations and three patient-centred goals: (4) to support users with their life goals, (5) to support users to connect with their community, and (6) to involve users in developing and offering new services. These different goals were based on those of the reform programme

[66]. The goal of continuity of care, referred to as “de-categorisation” in the reform programme, is to provide integrated care across the multiple care and welfare sectors. The goal of treating users in their community is derived from the “deinstitutionalisation” goal; it refers to providing care in the community and avoiding residential care as much as possible. The goal of shortening hospital stays is derived from the “intensification of care in hospitals” goal in the reform programme; the aim is to limit hospitalisations to acute, short care episodes. Finally, the "inclusion" goal refers to the social integration and personal recovery of users. We subdivided this broadly defined goal into three patient-oriented goals (i.e. to support users with their life goals, to support them to connect with their community, and to involve them in developing and offering new services), which were derived from previous analyses of the reform programme [62, 67]. A Budget Reduction Decision method was used to identify the respondents' explicit policy priorities [68, 69]. Each respondent was asked to indicate the level of priority they gave to the six goals presented by distributing 100 points across the goals. Respondents could give as many points as they wanted between 0 and 100 to one or more of the six goals according to the goal’s priority until they had given a total of 100 points. The order in which the six policy goals was presented in the online survey was randomised in order to avoid a possible design bias. The Budget Reduction Decision method was used instead of ranking or scoring to identify trade-offs between the different goals [69, 70]. Indeed, in the real world, stakeholders face choices that involve a trade-off between the different goals of health policies [71]. For example, stakeholders may acknowledge the need to improve care coordination but, at the same time, want to preserve the autonomy of providers [72]. There is, therefore, “*a need for methods that study the implementation decision in the context of the tradeoffs that influence real-world planning”* [44]. Information was also collected on respondents’ language, professional function, seniority, and self-perceived influence on the organisation of mental health care. The stakeholders’ self-perceived influence on the organisation of mental health care was measured using four criteria with 5-point Likert scales, returning a total score ranging between 0 (no influence) and 20 (strong influence). The four criteria were: influence of the institution on the organisation of mental health care, participation in recruitment or promotion of employees within the institution, participation in budget decisions within the institution, and participation in decisions on the adoption and implementation of new activities, policies, and

programmes within the institution. This score of influence has been used in previous studies [73, 74]. It measured both the influence of the respondent's institution and the respondent's influence within the institution.

Data analysis

The different statistical analyses that were carried out complemented each other and aimed to (1) identify the stakeholders' priority policy goals, (2) identify coalitions of stakeholders around those policy priorities, and (3) identify the central and peripheral policy goals of those coalitions.

First, descriptive statistics were computed for stakeholders' characteristics and priority scores of the six mental health policy goals. One-way analyses of variance (ANOVA) were performed to assess the significance of differences in stakeholders' self-perceived influence on mental health care organisation across professional functions and language groups.

Second, a cluster analysis was used to group those stakeholders who gave similar priority scores to the six policy goals of the reform. This method identifies potential advocacy coalitions and has been applied in other studies [75-77]. Indeed, the Advocacy Coalition Framework (ACF) suggests that policy subsystems are structured around competing coalitions that bring together stakeholders sharing similar policy viewpoints and priorities [78, 79]. We performed a hierarchical cluster analysis on the priority scores of the six policy goals using the Ward minimum variance method. The dendogram of the cluster analysis (see Additional Figure 1) was used to determine the optimal cut-off point for the number of clusters. We decided to proceed with four clusters that accounted for 34% of the variance. The four-cluster solution was chosen because the fifth cluster was a small subgroup of the first cluster (n = 26) and this small sample size reduced the value of additional subdivision. In addition, a limited number of clusters of comparable sizes also makes for better interpretability. Chi-square and ANOVA tests were performed to describe the composition of these clusters.

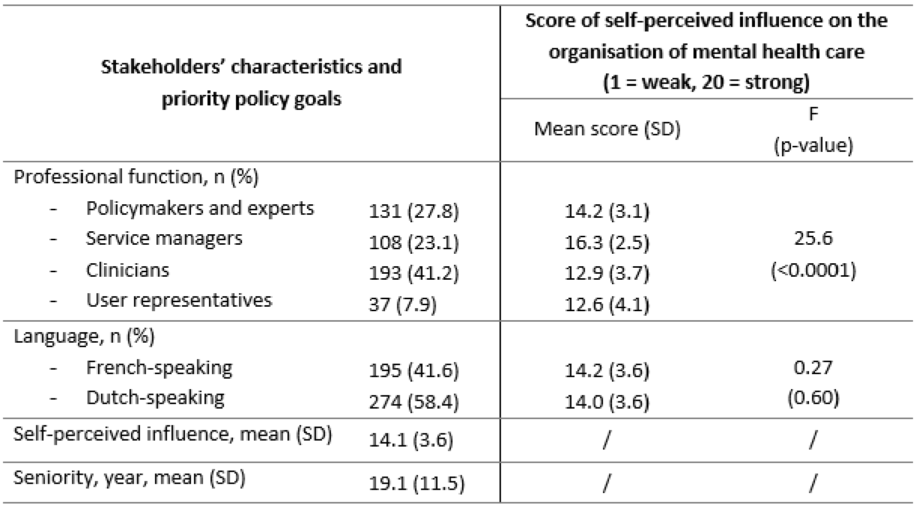
Finally, several theories suggest that policy preferences are structured as networks of interrelated policy positions, in which some are central and others are peripheral, the former making the backbone for the latter [80-82]. In the context of advocacy coalitions, some studies have supported the hypothesis that members of a coalition adhere to hierarchically structured policy positions in which a central policy priority constrains the peripheral ones and is related to political decision-making [57, 83, 84]. A policy goal may, therefore, be considered the lowest priority, but nonetheless be central. The priority and centrality of policy goals, therefore, constitute complementary information. For that reason, a belief network analysis was used to identify the central and peripheral policy goals of the different clusters of stakeholders [82]. This method uses weighted networks constructed from squared correlation between pairs of variables (e.g. a priority score of policy goals) to analyse the relationship between them and to identify central and peripheral variables [82]. A policy goal is considered central when it is strongly correlated, positively or negatively, with all the other policy goals. In this study, the method was applied to the priority scores of the six mental health policy goals. Since the priority scores were continuous, we performed squared Pearson's correlation for each pair of policy goals in order to construct the network of policy priorities of stakeholders for the four clusters and for the whole sample ($T = \sum \rho^2$). We also used a Quadratic Assignment Procedure (QAP) to test whether the network of policy priorities differed between the four clusters of stakeholders. QAP tests the correlation between pairs of networks. The Belief Network Analysis was performed using UCINET 6. Other statistical analyses were performed using SAS 9.3.

Results

Stakeholders' characteristics, priority policy goals, and self-perceived influence on the organisation of mental health care

Stakeholders' characteristics and self-perceived influence on the organisation of mental health care are presented in Table 16. The sample was well balanced between clinicians and non-clinicians and representative of the language groups in the Belgian population. The mean score of self-perceived influence on the organisation of mental health care was 14.1 on a maximum of 20 (SD = 3.6). Self-perceived influence differed significantly depending on stakeholders' professional function (F = 25.6, $p < 0.0001$). Service managers perceived themselves as more influential in the organisation of mental health care (16.3/20, SD = 2.5) than policymakers and experts (14.2/20, SD = 3.1) and clinicians (12.9/20, SD = 3.7). User representatives had the lowest self-perceived influence (12.6/20, SD = 4.1).

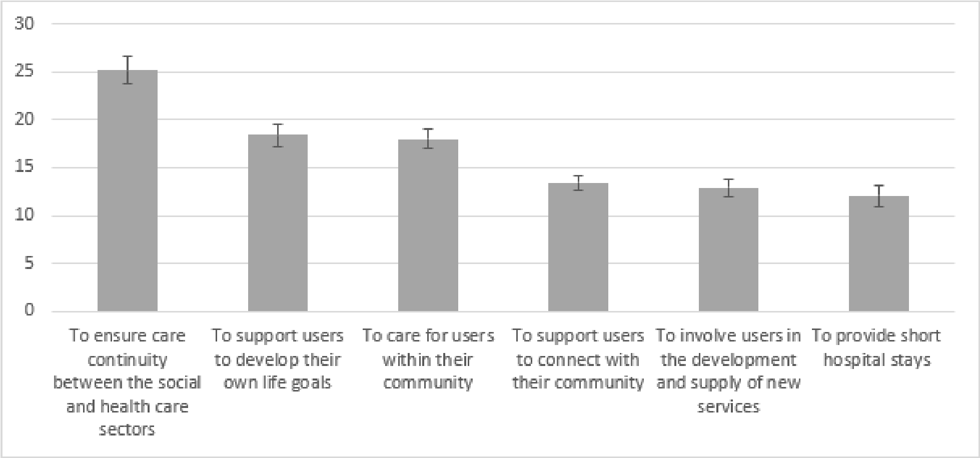
Table 16: Stakeholders' characteristics and self-perceived influence on the organisation of mental health care



Stakeholders' characteristics and priority policy goals		**Score of self-perceived influence on the organisation of mental health care (1 = weak, 20 = strong)**	
		Mean score (SD)	F (p-value)
Professional function, n (%)			
- Policymakers and experts	131 (27.8)	14.2 (3.1)	25.6 (<0.0001)
- Service managers	108 (23.1)	16.3 (2.5)	
- Clinicians	193 (41.2)	12.9 (3.7)	
- User representatives	37 (7.9)	12.6 (4.1)	
Language, n (%)			
- French-speaking	195 (41.6)	14.2 (3.6)	0.27 (0.60)
- Dutch-speaking	274 (58.4)	14.0 (3.6)	
Self-perceived influence, mean (SD)	14.1 (3.6)	/	/
Seniority, year, mean (SD)	19.1 (11.5)	/	/

Stakeholders' priority goals are presented in Figure 12. Ensuring care continuity between the social and health care sectors was the highest priority (25.1/100, SD = 14.6). Next in terms of priority were the goals of supporting users to develop their life goals (18.4/100, SD = 13.2) and treating them within their community (18/100, SD = 11.1). Finally, the lowest priority goal was the provision of short hospital stays (12.1/100, SD = 12.1).

Figure 12: Stakeholders' priority policy goals in relation to the mental health care reform (0 = low priority, 100 = high priority)



Note: mean 95% CI displayed on each bar

Stakeholder coalitions around policy goals

Table 17 presents the clusters of stakeholders who share similar mental health policy priorities and the characteristics of those who form the four coalitions identified.

The four coalitions were significantly different in terms of stakeholders' professional function ($\chi 2 = 43.9$, $p < 0.001$). The first coalition was the largest and included 161 stakeholders. In this coalition, stakeholders gave relatively equal priority to the different policy goals, so we labelled this coalition "everything is important". Compared to the other coalitions, there were more user representatives and policymakers or experts and fewer service managers in this coalition. Stakeholders in the second coalition (n = 101) favoured the policy goal of supporting users to develop their own life goals (32.7/100, SD = 14.8). We labelled this coalition "personal recovery". This coalition was composed of more clinicians and service managers and fewer policymakers or experts than the other coalitions. The third coalition (n = 97) favoured shortening hospital stays (28.6/100, SD = 13.5), so we labelled this coalition "deinstitutionalisation". The coalition was composed of more policymakers or experts and fewer service managers than the other coalitions. The second and third coalitions had opposing priority goals. The goal of shortening hospital stays was of the lowest priority (6.4 / 100, SD = 5.5) for stakeholders in the "personal recovery" coalition and the goal of supporting users to develop their own life goals was not a priority (11.4 / 100, SD = 9.4) for stakeholders in the "deinstitutionalisation" coalition. Finally, stakeholders in the fourth coalition (n = 94) favoured care continuity between the social and health care sectors (45.2/100, SD = 15.0). Compared to the other coalitions, there were more service managers and fewer policymakers and user representatives in this coalition. We labelled this coalition “continuity of care”.

The two policy goals on which coalitions differed the most were ensuring continuity of care (F = 169.3, p < 0.0001) and shortening hospital stays (F = 156.9, p < 0.0001). Conversely, the two policy goals on which coalitions differed the least were supporting users to connect with their community (F = 15.4, p < 0.001) and caring for users within their community (F = 6.1, p < 0.01).

Table 17: Composition of stakeholder clusters and priority policy goals

	Clusters*				
	"Everything is important" (n = 161)	"Personal recovery" (n = 101)	"Deinstitutionalisation" (n = 97)	"Continuity of care" (n = 97)	
Policy goals	Priority score (0-100), mean (SD)				F, (p-value)
Ensure continuity between the social and care sectors	19.1 (6.7)	17.4 (8.8)	23.6 (9.6)	45.2 (15.0)	169.3 (<0.0001)
Provide short hospitalisations	9.1 (6.5)	6.4 (5.5)	28.6 (13.5)	6.4 (7.6)	156.9 (<0.0001)
Support users to develop life goals	16.9 (7.3)	32.7 (14.8)	11.4 (9.4)	12.9 (10.9)	85.8 (<0.0001)
Involve users in developing and offering new services	19.1 (9.6)	9.1 (6.0)	10.4 (8.1)	9.3 (9.2)	44.1 (<0.001)
Support users to connect with their community	15.1 (7.6)	16.4 (9.5)	10.1 (7.6)	10.8 (8.3)	15.4 (<0.001)
Treat users in their community	20.7 (11.1)	17.9 (10.1)	15.9 (9.9)	15.5 (12.4)	6.1 (<0.01)
Stakeholders' characteristics					F / χ2 (p-value)
Professional function, n (%)					
- Policymakers and experts	47 (29.2)	18 (17.8)	42 (43.2)	20 (20.6)	43.9 (<0.001)
- Service managers	30 (18.6)	26 (25.7)	12 (12.4)	37 (38.1)	
- Clinicians	62 (38.5)	51 (50.5)	37 (38.1)	38 (39.2)	
- User representatives	22 (13.7)	6 (5.9)	6 (6.2)	2 (2.0)	
Language, n (%)					
- French-speaking	69 (42.8)	34 (33.6)	43 (44.3)	45 (46.4)	3.9 (0.27)
- Dutch-speaking	92 (57.2)	67 (66.4)	54 (55.7)	52 (53.6)	
Self-perceived influence, mean (SD)	14.2 (3.5)	13.5 (3.4)	14.4 (3.7)	14.6 (3.7)	1.27 (0.28)
Seniority, year, mean (SD)	17.3 (10.9)	20.1 (11.5)	21.1 (12.1)	18.7 (11.5)	2.7 (0.09)

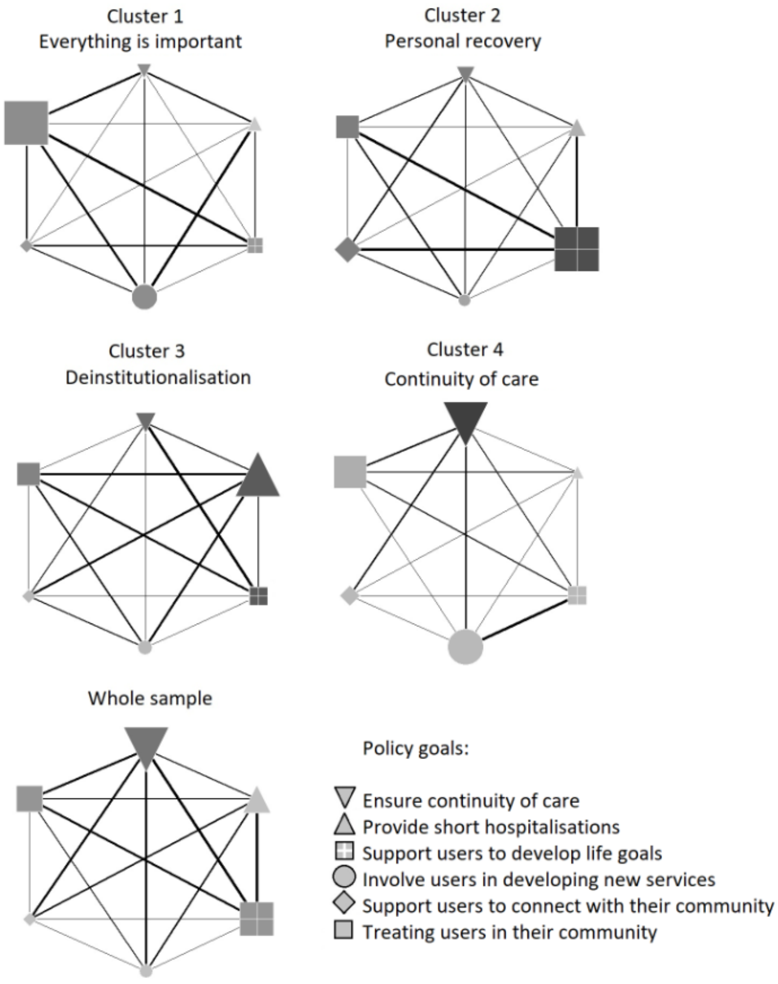
* Hierarchical cluster analysis with the Ward minimum variance method on the priority scores of the six policy goals with a cut-off point of four clusters accounting for 34% of the variance

Central and peripheral policy goals within the four coalitions of stakeholders

The networks of policy priorities of stakeholders are illustrated in Figure 13 for the whole sample and for each coalition. For the whole sample, the two policy goals that were considered priorities were also central, i.e. ensuring continuity of care and supporting users to develop their life goals. Providing short hospital stays, however, was also central, though it was the lowest priority. The peripheral goals for the whole sample were supporting users to connect with their community and involving them in developing new services. This pattern differed between coalitions. In the "everything is important” coalition, the different policy goals were all considered priorities, but we observed that the central goal was treating users in their community while the most peripheral goals were supporting users to connect with their community and providing short hospital stays. In the "personal recovery" coalition, the priority policy goal was supporting users in the development of their life goals, which was also the most central goal. The most peripheral goal in this coalition was involving users in developing new services. In the "deinstitutionalisation" coalition, providing short hospital stays was both the highest priority and the most central goal. The peripheral goals in this coalition were supporting users to connect with their community and involving them in developing new services. In the "continuity of care" coalition, three policy goals were central: ensuring continuity of care and treating users in their community, which were also the priority goals, and involving users in the development of new services, which was not, however, a priority goal. The peripheral goals in this coalition were providing short hospital stays and helping users to connect with their community.

Finally, across the four coalitions, we observed that the goal of treating users in their community was often central, while the goals of supporting users to connect with their community and of involving them in the development of new services were often peripheral.

Figure 13: Networks of policy priorities of the four coalitions of stakeholders



Legend:
Tie strength | Tij | = cor2 (xi, xj) is represented by the edge thickness
The size of the symbol = ∑ cor2 is proportional to policy goal centrality
The boldness of the symbol = xi is proportional to policy goal priority

Table 18 presents the correlation (quadratic assignment procedure) between the networks of policy priorities of the four coalitions. Overall, there was no significant correlation across the four coalition’s networks. The highest convergence was observed between the “personal recovery” and “everything is important” coalitions (r = 0.258, p = 0.15). The largest difference between networks was observed between the “deinstitutionalisation” coalition and two other coalitions, the “continuity of care” coalition (r = -0.260, p = 0.17) and the “personal recovery” coalition (r = -0.251, p = 0.18). The central goal in the “deinstitutionalisation” coalition, shortening hospital stays, was peripheral in the “continuity of care” and “personal recovery” coalitions. The central goals of the “continuity of care” and “personal recovery” coalitions respectively, ensuring continuity of care and supporting users in the development of their life goals, were peripheral in the “deinstitutionalisation” coalition.

Table 18: Correlation between networks of policy priorities

	Quadratic assignment procedure, r (p-value)			
	Cluster 1	Cluster 2	Cluster 3	Cluster 4
Cluster 1: Everything is important	1			
Cluster 2: Personal recovery	0.258 (0.15)	1		
Cluster 3: Deinstitutionalisation	-0.052 (0.42)	-0.251 (0.18)	1	
Cluster 4: Continuity of care	-0.235 (0.21)	-0.116 (0.40)	-0.260 (0.17)	1

Discussion

Main findings

This study found that mapping mental health policy goals enables us to identify different stakeholder coalitions that shared different policy priorities. This study highlighted four main stakeholder coalitions bringing together stakeholders with similar professional functions in the mental health care system, and revealed a divergence in priority policy goals between service managers and policymakers. The largest coalition was made up of a majority of policymakers and fewer service managers and supported all the policy goals with equal priority. The other three coalitions were each formed around one specific (and different) policy goal. One of those three coalitions prioritised deinstitutionalisation and was also made up of a majority of policymakers and fewer service managers. The other two coalitions were made up of a majority of service managers and fewer policymakers. One prioritised the personal recovery of users and the other prioritised continuity of care. Across coalitions, service managers considered themselves more influential in the organisation of mental health care than other stakeholders. As for the representatives of users and families, they considered themselves to be the least influential stakeholders in the organisation of mental health care and were mainly represented in the “everything is important” coalition, in which all the policy goals were considered priorities, and were poorly represented in the “continuity of care” coalition.

As well as each having a different priority goal, our results also showed that the structure of the network of policy priorities of each coalition was different. The largest difference was observed between the “deinstitutionalisation” coalition, on the one hand, and the “continuity of care” and “personal recovery” coalitions, on the other. Indeed, providing short hospitalisations was a central goal of the coalition in favour of “deinstitutionalisation”, but it was peripheral in the “continuity of care” and “personal recovery” coalitions. The central goals of the latter two coalitions (ensuring continuity of care and supporting users in the development of their life goals, respectively) were peripheral in the “deinstitutionalisation” coalition.

Finally, while the policy goal with the highest priority tends to be the most central of each coalition, the goal of treating users in their community was highly central across all coalitions, while two patient-centred policy goals, i.e. supporting users to connect with their community and involving them in the development of new services, were peripheral across all coalitions.

Interpretation of findings

So far, coalitions of stakeholders formed around mental health policy goals have received little attention. This study revealed four stakeholder coalitions, bringing together stakeholders with common professional functions in the organisation of mental health care that have significantly different policy priorities. This result indicates that there is a strong link between the professional functions of individuals and their policy priorities, and reveals differences in policy priorities between policymakers and service managers. The two coalitions mostly composed of policymakers supported a comprehensive approach to the different policy goals and the provision of short hospital stays while the two coalitions composed mainly of service managers emphasised the personal recovery of users and continuity of care. In addition, the “deinstitutionalisation” coalition (i.e. in favour of short hospital stays), which was mainly composed of policymakers, and the two coalitions mainly composed of managers were in opposition regarding the overall structure of their policy priorities, i.e. the central policy goals of the former were peripheral in the latter and vice versa. If these different policy goals aim at general interest, which can be shared by all stakeholders, i.e. to provide effective, equitable, and affordable mental health care, the specific functions of stakeholders may involve individual interests that influence their priorities. These cleavages and oppositions may, therefore, reflect the different relationships and interests that stakeholders have in relation to policy goals, depending on their function and position in the mental health care system. For instance, policymakers may support the shortening and intensification of hospital stays because of pressure from international organisations, e.g. the WHO [85-87], or to reduce public expenditure, whereas service managers are not so concerned by such demands. The WHO European Mental Health Action Plan 2013-2020 reinforced the focus on shortening and intensifying psychiatric hospital stays by stating that *"the commitment to deinstitutionalization and the development of community-based mental health services have continued, although progress is uneven across the Region. The consensus is that care and treatment should be provided in local settings, since large mental hospitals often lead to neglect and institutionalization"* [87]. By contrast, in Belgium, as in other regulated-market systems, hospitals are partly funded on a fee-for-service basis and, therefore, the reduction of the length of stay in hospitals may also reduce the hospital’s income, which is a concern of hospital managers. Conversely, the interests of service managers probably have more to do with the organisation of their services and care, e.g. ensuring continuity of care, and with patients, e.g. supporting users to develop their life goals. Some studies have shown that mid-level managers weigh the implementation of policies against their local management agenda (i.e. funding of their institution, staff management, organisation of activities, and performance) [88-90]. In other respects, while the goal of supporting users to develop their life goals was central in one of the two coalitions mostly made up of service managers, the goal of involving users in the supply and development of new services was the most peripheral. It is likely that, for service managers, involving users in the supply and development of services may induce organisational and management constraints, so that these considerations run counter to their central goal of patient personal recovery.

This study also found that service managers perceived themselves as the most influential stakeholders in the organisation of mental health care, particularly compared to policymakers. This supports the results of a previous study that found that the most influential stakeholders in the public health policy-making process in the UK were mid-level managers [46]. Although it has been observed in other countries, this result is probably reinforced by the Belgian context. As previously explained, the Belgian health care system is characterised by a substantial level of corporatism in policy decision-making and the mental health care reforms of recent decades have mainly been developed using a bottom-up approach [61, 64, 91], thus leaving extensive autonomy, bargaining power, and influence to stakeholders such as service managers [52]. This finding is important for policy development and implementation. Indeed, the frameworks and main goals of policies and reforms are often set by policymakers, but our results highlighted that the implementation of these frameworks and the achievement of initial goals relies heavily on mid-level managers and on the degree of convergence with their priorities and interests. This divergence in relation to policy priorities between policymakers and managers and the latter's perceived high level of influence could, therefore, explain the difficulty of implementing some policy goals of the reform, such as the deinstitutionalisation and personal recovery of people living with mental illness. In Belgium, the process of deinstitutionalisation began around 1975 but was far from being complete in the 2000s; in 2008, the per capita psychiatric bed rate per 100,000 population was the second highest in Europe (153/100,000) [63]. Since 2010, one of the goals of the reform has once again been the deinstitutionalisation and intensification of psychiatric hospitalisations (i.e. reduction of the number of beds, resort, and length of stay in psychiatric wards). Recent figures have shown, however, that this goal has not been achieved [92]. According to a report on the performance of the Belgian health system published in 2019, the number of days of psychiatric hospitalisation per inhabitant even increased between 2000 and 2016 (from 305 per 1000 inhabitants in 2000 to 351 in 2016) [93]. The employment rate of people living with mental illness as an indicator of their personal recovery. Compared to

other OECD countries, Belgium has one of the lowest rates of employment and one of the highest rates of unemployment among people living with mental illness [94]. Furthermore, the employment rate among Belgians living with mental illness declined between 1997 and 2008, widening the employment gap between them and people without mental illness [94].
In the context of a bottom-up reform, these results highlighted the importance of mobilising and bringing together policymakers, service managers, and other stakeholders in the different stages of policy development and implementation. For example, in Canada, Ontario's 2011 Mental Health and Addictions Strategy placed more emphasis on stakeholder engagement and established policy networks which brought together people from government ministries and stakeholders representing different individual and collective interests, such as researchers, service managers, professional associations, and consumer groups [95]. These policy networks were mobilised during the policy formulation phase (to provide overall direction and priorities for the strategy) and during the implementation phase. A policy analysis of this process has shown that *“continuing to mobilize policy network actors into the implementation stage significantly increases the prospects for reform by embedding changes across systems and developing shared ownership at the implementation level.”* [95].

Despite the competing policy positions of the coalitions, some policy goals could be a lever for consensus within and between coalitions. As previously explained, several theories suggest that policy priorities are structured as networks of interrelated policy positions, in which some are central and others are peripheral, central policy positions structuring the more peripheral and being strongly related to political decisions [80, 96, 97]. On the one hand, the political support and decisions of stakeholders in a specific coalition can therefore be fostered by identifying and then supporting the central goals of that coalition. On the other hand, identifying and supporting a policy goal that is central in all coalitions, such as the policy goal of treating users in their community, could be a lever for consensus between the coalitions.

Finally, representatives of users and families were mainly represented in the coalition that gave equal priority to all the policy goals, which may indicate their desire to have a comprehensive mental health policy and to prevent certain policy goals from taking precedence over others. This study, however, made it clear that, regardless of the goals around which the coalitions were formed and the structure of policy priorities of each coalition, two patient-centred policy goals were often peripheral policy goals, i.e. supporting users to connect with their community and involving them in the development of services. In addition, the descriptive results also showed that user and family representatives perceived themselves as the least influential stakeholders in the organisation of mental health care.

Although the participation of user and family representatives in policy and health care decision-making is on the political agenda in many countries [98, 99], several studies have shown that their full participation remains a challenge and that there is little consensus on their role, on the extent of their participation or even on the aims of such participation and the process for achieving it [100-102]. These results can be interpreted in two ways. First, they can be linked to the literature suggesting that Western health care systems tend to prioritise the needs of providers and society rather than those of patients [103] and that, as a result, policy goals oriented towards professionals and services, such as continuity of care or intensive psychiatric hospitalisation, can override patient-centred goals. Second, this result could be interpreted in relation to two notions of health economics: uncertainty and opportunity cost. On the one hand, there is more certainty about the return on an investment in policy goals such as the intensification of hospital stays than about patient-centred goals such as involving patients in the development of services. On the other hand, “to choose is to renounce”. Since health care systems have limited resources, it is necessary to choose one alternative (e.g. if there is more certainty about the return on investment) and forgo others (e.g. if the return on investment is less certain).

Strengths and limitations

The main strength of this stakeholder survey is the representativity of the sample. We started with a database of 1752 people. Their eligibility as stakeholders in the organisation of mental health care in Belgium was evaluated to arrive at a contact sample of 1174 stakeholders. This contact sample was representative of the diversity of the different services involved in the provision, organisation, and funding of mental health care, the different stakeholder profiles, and the different regions. As previously explained, stakeholders had the opportunity to nominate up to five people to contact to complete the survey and the analysis of the nominees showed that 75% were already in our starting sample. This result confirms the quality of our initial sample. The remaining 25% were contacted after their eligibility had been checked. Another strength of this online survey is the 40% response rate obtained. A response rate of 30% was expected, based on the literature [104, 105]. Finally, the Budget Reduction Decision method used to identify the policy priorities of stakeholders allowed us to replicate the trade-offs that stakeholders face in real life (e.g. if I choose to invest time and funds to achieve one policy goal, I will not invest that time and those funds to achieve another) and to identify central and peripheral policy objectives [70, 71]. This study also has some limitations. One limitation is that, although the 40% response rate is satisfactory for an online survey, we cannot rule out a selection bias. To control for this potential bias, we compared the main characteristics of respondents and non-respondents. The final sample of respondents did not differ from the non-respondents in terms of the stakeholders' professional function. There was a slight oversampling of Dutch-speaking stakeholders among the respondents. Another limitation of this study is that the belief network analysis was developed on the assumption that the relationships between policy positions are linear and can be captured by correlations. It is possible, however, that the relationships between policy positions are more complex (e.g. non-linear functional form or unobserved heterogeneity) [82]. Another limitation is that stakeholder coalitions and their policy priorities are context-dependent, even if the policy goals are international. These results are therefore linked to the Belgian context and are not intended to be extrapolated to other contexts. However, the question raised and the method used to answer it can be applied to other contexts, since the difficulty of implementing policies and reforms and the presence of competing advocacy coalitions is a feature of all health systems. Finally, although the cluster analysis provides a credible and realistic representation of the formation of potential advocacy coalitions, we cannot confirm the existence of these coalitions in real life. Indeed, we were able to identify potential advocacy coalitions based on the policy positions and priorities of stakeholders but we cannot prove that there was an interaction between the members of a coalition.

Conclusion

The first step in solving a problem is to identify it and ascertain its nature. Working with the different coalitions of stakeholders is essential in the context of mental health care reform as they have a strong influence on policy-making and implementation. This study showed that stakeholder coalitions favour different and conflicting mental health care policy priorities. These competing interests between coalitions may explain the slow and inconsistent pace of the Belgian mental health care reform and the difficulty of achieving some initial goals. Mapping policy priorities and identifying areas of agreement and disagreement may, therefore, be one of the first steps towards improving the implementation of health care policies and reforms. This is particularly true in a corporatist health care system in which some stakeholders, such as service managers, have a big say in the decision-making process.

This study found a divergence in relation to policy priorities between policymakers, i.e. those who often set policy programmes and goals, and service managers, i.e. those who have a strong influence on policy development and implementation. Since these different priorities can reflect the different relationships and interests that the stakeholders have in relation to the different policy goals, it seems important to find common interests and objectives. The results of this study showed that the policy goal of treating users in their community was a relatively central policy goal in the different coalitions. Since central goals are strongly related to political decision-making, this goal could, accordingly, be emphasised in order to reach consensus between coalitions. Finally, special care must be taken to prevent policy goals that are oriented towards professionals and services, such as improving continuity of care or intensifying psychiatric hospitalisations, from overriding patient-centred goals, such as their social integration and personal recovery.

Further research might study stakeholder coalitions and policy priorities in other countries. In this study, the mental health policy goals were international (e.g. recovery, continuity of care, or community care) but the influence of stakeholders and their explicit policy priorities were specific to the Belgian context. A common feature in all countries and contexts is the difficulty of implementing policies and reforms and the presence of competing advocacy coalitions. The methodology used in this study could, therefore, be replicated and improved in other contexts to achieve a better understanding of stakeholder policy priorities and coordinate policy implementation more effectively.

Funding: This study was funded by a grant from the Belgian Health Care Knowledge Centre (KCE).

Compliance with Ethical Standards

Conflict of interest: The authors declare they have no conflict of interests.

Ethical Approval: This study was in accordance with the ethical standards of the institutional and national research committee.

Informed Consent: Informed consent was obtained from all individual participants included in the study.

References chapter 6

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Chapter 7

7

Chapter 7: Discussion

Whether in the literature review that introduces this thesis or in the empirical chapters, the aim was to systematically put the Belgian context in perspective with other international contexts, and this discussion will not derogate from it. In this chapter, I wanted (1) to compare and interpret the results of this thesis with the international literature and (2) to identify specific elements that could be leveraged to improve the social integration of people with SMI.

In Chapter 8, the objective was to develop the discussion with elements that go beyond this thesis, and to develop concrete recommendations for Belgium. I want to point out that the recommendations for Belgium in Chapter 8 were developed on the basis of my research work even if they may go beyond the scope of this thesis. Indeed, these recommendations were also drawn from the report[3] to which I contributed as part of the 2019 evaluation of the organisation of mental health care for adults in Belgium led by the Belgian Health Care Knowledge Centre (KCE). The final recommendations (see 8.4 Summary of recommendations and avenues for action in Belgium: The Twelve Labours of Hercules) include a general orientation, the target audience and more operational avenues for action.

7.1 Summary and discussion of the main findings

People with severe mental illness (SMI) face issues of social integration such as finding a job and maintaining social or intimate relationships. In past decades, global mental health movements and international bodies have increasingly supported the goal of social integration of people with SMI [1, 2]. Their social integration remains high on the political agenda and many countries have developed policies and interventions that specifically targeted this goal since the early 2000s [3, 4]. The main result of the literature review performed in **Chapter 1** was that despite major reforms in mental health care and the implementation of

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[3] Smith P, Nicaise P, Neyens I, Hermans K, Thunus S, Walker C, Van Audenhove C, Lorant V. (2019). Values and sets of possible organisational solutions: a choice-based stakeholder analysis survey. In: Mistiaen P, Cornelis J, Detollenaere J, Devriese S, Farfan-Portet MI, Ricour C (Editors) Organisation of mental health care for adults in Belgium Health Services Research (HSR) Brussels: Belgian Health Care Knowledge Centre (KCE) KCE Reports 318 D/2019/10273/50.

policies and interventions to improve the social integration of people with SMI, their social integration has remained relatively low and has not much improved over the past decades. Much research focuses on socially inclusive evidence-based practices and interventions, but the general assumption of this thesis was that factors related to services, systems and policies also influence the improvement of the social integration of people with SMI. Therefore, the overall aim of this thesis was to shed light on how factors related to mental health services, systems and policies influence the social integration of people with SMI.

Another result of the literature review in Chapter 1 was that systematic reviews and meta-analysis on the evolution over time of social integration indicators of people with SMI combined studies with samples, methods, contexts and criteria for the definition of good social integration outcomes that are too heterogeneous to allow their comparison and a proper assessment of the evolution over time of the social integration of people with SMI. Furthermore, these studies did not systematically compare the social integration of people with SMI with the general population without mental illness (MI). However, the social exclusion of an individual is directly related to the average level of social integration of the society in which he or she lives. Therefore, the analysis of the social exclusion of a very specific group such as severe mentally ill people should be in comparison with the general population without MI.

Main findings Chapter 1

- Despite major reforms in mental health care and the implementation of policies and interventions to improve the social integration of people with SMI, their social integration has remained relatively low and has not improved over the past decades.
- Systematic reviews and meta-analysis on social integration indicators of people with SMI have methodological limitations that may hinder a proper assessment of the evolution over time of their social integration.

In view of the potential limitations of the previous above-mentioned studies, the aim of the study in **Chapter 2** was to assess the evolution between 1997 and 2018 in Belgium of the social integration of adults with moderate and severe MI in comparison with the general population without MI. The main result of this study was that between 1997 and 2018 in Belgium, the social integration of the general population without MI and of people with moderate MI improved, but the social exclusion of people with SMI increased, particularly on the two dimensions of employment and partnership situation. Therefore, the social exclusion gap between people with SMI and people with moderate or without MI is widening over time in Belgium. This study showed that by comparing the evolution over time of the social integration of people with SMI with the general population without MI, we do not observe a lack of improvement of their social integration but an increase of their social exclusion. Additional analyses presented in **Chapter 3** have shown that in Belgium, people with MI and especially those with SMI, were more likely to have elementary jobs (i.e. clerical support works, plant machine operators and assemblers, and elementary occupations) and to be in the lowest income quintile compared to the general population without MI and that these trends increased between 1997 and 2018.

The results presented in Chapters 2 and 3 are strongly linked to the Belgian context. First, they may be related to the lack of specific vocational programs for people with MI in Belgium, as the OECD pointed out in 2013 [5]. Although a randomised controlled trial on the Individual Placement and Support (IPS) model started in 2017 for a period of five year, we will only see the potential impact of this model on the employment rate and other job-related outcomes of people with MI if it is generalised across the country thereafter. In addition, the IPS model tends to develop specialised services with an individualised and relatively long-term support, so it is difficult to imagine this type of model for the entire population with SMI. Second, the increase over time in the social exclusion trends of people with SMI can be explained by the economic context in Belgium. For example, Belgium was affected by the European economic crisis of 2008 and a study carried out in 27 European countries found that the period of macroeconomic recession between 2006 and 2010 had intensified the economic exclusion and unemployment of people with MI [6]. Our results may show that periods of economic crisis reinforce the economic exclusion of people with SMI more than people with moderate MI. Third, the stigmatisation of and discrimination against people with SMI may also explain their social exclusion compared to people with moderate MI and the general population without MI. Indeed, the main barrier to the employment of people with SMI described in the literature is their stigmatisation during their job search and in the workplace [7, 8], and this stigmatisation may also affect the other dimensions of their social integration such as their social interactions and community engagement [9, 10]. However, a scoping review published in 2014 identified policies and campaigns to reduce mental illness stigma in 21 European countries and regions, but none in Belgium [11]. This lack of mental health anti-stigma policy and campaign shows on the one hand Belgium's low interest in issues of mental health stigmatisation, and on the other hand may partly explain the high prevalence of social exclusion of people with SMI. Finally, at the level of the Belgian mental health care system, a reform in the organisation of care has been under way since 2010 with the objectives of strengthening community mental health care in favour of patients' clinical recovery and social integration [12]. A recent case-control study assessed the effectiveness of this reform on continuity of care, quality of life, re-hospitalisation and social integration of people with SMI [13]. This study highlighted that greater exposure to the reform was associated with a slight improvement in the perceived continuity of care of people with SMI, but not with their social integration and other outcomes. The authors hypothesised that this low impact of the reform on the outcomes of people with SMI is related to the lack of definition of target groups within the framework of the reform, leaving extensive autonomy to the different services and providers in selecting their patients, with a risk of excluding the most vulnerable patients such as people with more complex needs and severe mental illness. In addition, a previous study conducted with data from the first evaluation of the Belgian mental health care reform in 2010 had shown that patients with the lowest level of social integration were not targeted for care by clinicians from different services [14].

Main findings Chapter 2 and 3

- Between 1997 and 2018 in Belgium, the social integration of the general population without MI and of people with moderate MI improved, but the social exclusion of people with SMI increased, particularly on the two dimensions of employment and partnership situation.
- In Belgium, people with MI and especially those with SMI, were more likely to have elementary jobs and to be in the lowest income quintile compared to the general population without MI and these trends increased between 1997 and 2018.

Taken together, the results of the study presented in Chapters 2 and 3 suggest that the policies and reforms put in place between 1997 and 2018 in Belgium improved the social integration of people with moderate MI but not that of people with SMI. This interesting result may shed light on a potential new dimension of the social exclusion of people with SMI, namely services exclusion (i.e. not all people with SMI may have access to adequate health and social services). For example, in several countries, people with low socioeconomic status experience differential access to mental health care, as they are less likely to see a specialist [15, 16]. Therefore, even if evidence-based interventions are implemented and provided, they may not be accessible for all people with SMI and the expected outcomes will not be achieved. However, it is unclear which individuals have access to these different interventions because little research has been conducted to describe the characteristics of people with SMI who actually benefit from it in routine practice. The study presented in **Chapter 4** was a natural experiment and used two routinely practiced continuity of care interventions for people with SMI as a case study. Indeed, continuity of care is a key element in the care of people with SMI because they have limited ability to navigate the health and social systems by themselves and to coordinate their different providers [17, 18]. They are therefore more likely to experience fragmentation of care and lack of continuity [19-21]. In Europe, at discharge from a psychiatric hospital, people with SMI may be exposed to one of two main models of continuity of care: personal continuity, where one clinician is responsible for in- and outpatient care, and specialisation, where various clinicians are. Depending on the country’s health system, such exposure is decided through patient-clinician agreement (i.e. regulated-market system countries such as Germany, Poland, and Belgium) or at the organisational level (i.e. national health system countries such as the UK and Italy). However, specific needs of subgroups of patients, for example social integration needs, may be best met by either personal continuity or specialisation. Indeed, patients with more severe mental illness and complex psychosocial needs might benefit more from personal continuity and having a single clinician follow them up over time and across care settings [20, 22]. Conversely, several studies suggested that specialisation would be more appropriate for patients with limited needs and moderate disease severity [21, 23, 24]. Although these two care approaches are more suitable for, and preferred by, particular subgroups of patients, they may not be accessible to or provided to those subgroups [25, 26]. Therefore, the aim of the study performed in

Chapter 4 was to determine whether patient characteristics and/or health systems influence patients' exposure to continuity of care approaches at discharge from a psychiatric hospital ward. The main result was that across the five countries participating in the study (i.e. the UK, Italy, Poland, Germany, and Belgium), the main predictor of exposure of people with SMI to continuity of care approaches was their hospital of admission, and not their clinical and socio-demographic characteristics. Even in regulated-market system countries (i.e. Poland, Germany, and Belgium) where exposure to care approaches was decided by patient-clinician agreement, the individual predictors of exposure were factored out by the psychiatric hospital where patients were admitted. Finally, as expected, the hospital of admission explained a greater share of exposure to care approaches in national health system countries (i.e. The UK and Italy) than in the three regulated-market system countries. One study examined the determinants of primary clinicians' decisions on patient referral to the specialised sector [27]. The study concluded that such decisions were not based on the clinical status of patients only, but were influenced by a complex mix of patient, clinician, and health care structural characteristics. One systematic review also argued that studies exploring the influence of individual patient's characteristics on pathways to care had conflicting findings because of contextual differences across studies, e.g. the type of service and characteristics of the health care system [28]. Taken together, these results show the extent to which patient care pathways and exposure to care approaches is hospital-dependent, even in countries where the care approach is decided through patient-clinician agreement. This finding highlights a paradox because, in theory, models of care should stick to the needs of patients (i.e. demand-side factors), but in practice, these models seem to be largely determined by the hospitals (i.e. supply-side factors).

Main findings Chapter 4

- The main predictor of exposure of people with SMI to continuity of care approaches was their hospital of admission, and not their clinical and socio-demographic characteristics.
- Patient care pathways and exposure to care approaches is hospital-dependent, even in countries where the care approach is decided through patient-clinician agreement.

The results of the study presented in Chapter 4 could also highlight the difficulty of offering patients specific, individualised care pathways within the same hospital. For example, socio-demographic and clinical characteristics of people with mental illness predict only 15% of the variance of their lengths of stay (LoS) in psychiatric hospitals [29]. Furthermore, LoS in psychiatric hospitals vary substantially across countries and across hospitals among patients with similar profiles [30-32], suggesting that LoS in psychiatric hospitals bears a weak relation to the clinical and social needs of patients at admission. Given the major role played by psychiatric hospitals in patient care pathways (particularly in Belgium), the objective of the study in **Chapter 5** was to assess the impact of psychiatric hospitalisations, i.e. the number of admission and LoS in psychiatric ward, on the social integration of people with SMI in the five European countries mentioned in Chapter 4. Indeed, despite a movement of deinstitutionalisation of mental health care has been in place in Western countries since the last decades, psychiatric hospital retains an important role in mental health care [33, 34]. In addition, people with SMI tend to experience long LoS and repeated admissions in psychiatric wards that may disrupt their social integration [35, 36]. As suggested by Goffman [37], Honigfeld [38], or Gruenberg [39], one of the consequences of excessive LoS and readmissions in psychiatric hospital is the "social breakdown syndrome" in which people with mental illness experience community and social withdrawal, exclusion from typical social roles, and a decline in their social integration [39, 40]. However, previous studies on the impact of hospitalisation in psychiatric ward on patients' social integration have been inconclusive [41, 42]. Chapter 5 found that long LoS in a psychiatric ward was associated with a decrease in the social integration of people with SMI after one year. Repeated admissions were weakly associated with changes in the social integration. The dimensions of social integration that were more strongly and negatively associated with longer LoS were the housing, employment, and household living situation. More precisely, people with SMI who experienced a total of more than 76 days of psychiatric hospitalisation in one year had a significantly higher probability of becoming homeless or moving from independent accommodation to sheltered or supported accommodation. Moreover, people with SMI who were hospitalised for more than 162 days in one year had a significantly higher probability of becoming unemployed or moving from a regular job to a form of protected job. Finally, there was also a higher probability that people who were hospitalised for more than 162 days would no longer be living with their partner or family. This study supports the importance of deinstitutionalisation policies and interventions that aim to reduce the length of hospital stays for people with mental illness in order to preserve their social integration. However, although the average LoS in psychiatric hospitals has decreased in recent decades due to deinstitutionalisation policies in Western countries, it remains longer than for most physical disorders [36, 43-45]. Furthermore, although national and international authorities have advocated deinstitutionalisation and the provision of effective community-based care over the last few decades [46, 47], an international comparison of the progress of deinstitutionalisation policies found that hospital closure was still in an early stage in 21 out of 30 European countries in 2016 [34]. Another study also drew attention to forms of reinstitutionalisation in some countries, i.e. an increase in the number of involuntary hospital admissions and places in forensic institutions and supported housing, to replace the beds that were closed in psychiatric hospitals [33].

Main findings Chapter 5

- After one year, a longer length of stay in psychiatric ward is more strongly associated with a decrease in patients' social integration than repeated admissions.
- The dimensions of social integration that were more strongly and negatively associated with longer lengths of stay were the housing, employment, and household living situation.
- This study supports the importance of deinstitutionalisation policies and interventions that aim to reduce the length of hospital stays for people with mental illness in order to preserve their social integration.

Chapter 5 leaves us with an outstanding question: The deinstitutionalisation of mental health care, such as the social integration and recovery of people with SMI, have been official policy goals for several decades and many Western countries have undergone successive mental health care reforms to achieve them, so why are they only partially met? One explanation for the slow and inconsistent pace of reforms is that they can be thwarted or reshaped by inconsistencies between stakeholder and policy priorities [48-52]. In policy implementation research, disagreements within the policy community and between the policy community and other stakeholders have frequently been identified as a factor explaining failures in the implementation of public policies [53, 54]. For example, one study found that differences in the effectiveness of evidence-based supported employment interventions for people with SMI between the US, Canada, and Europe were related to the low fidelity of the implementation of the model due to resistance of stakeholders such as policymakers, program administrators, clinicians or the users themselves [55]. Therefore, the effective implementation of health care reforms and interventions is related to the stakeholders' endorsement of their programs and goals. However, the mental health sector is characterised by a multitude of stakeholders with different professional profiles and there is little consensus among them on the etiology of mental illnesses, the definition of recovery, treatment approaches, and appropriate quality of mental health care [56]. This situation facilitates appropriation of and opposition to reform programmes and goals [57]. The implementation process, therefore, requires gaining the support of these multiple stakeholders from different statutory frameworks and professional backgrounds, who form coalitions around common interests and priorities [58]. Coalitions may have a greater influence on policy-making and implementation than fragmented groups of stakeholders [59, 60]. The Advocacy Coalition Framework developed by Sabatier [61] analyses, among other things, the influence of coalitions whose beliefs differ about what constitutes good evidence and about what the priorities should be, on the adoption and implementation of public policies [62]. Although research has started to address the influence of coalitions on health policy agenda setting and implementation [60, 63, 64], there has not been much research looking at stakeholders’ priorities and coalitions in mental health policies. In the context of the ongoing nation-wide mental health care reform in Belgium, the objective of the study in **Chapter 6** was to identify and describe stakeholder coalitions formed around the policy goals of the reform and highlight their central policy goals and oppositions. This study identified four main stakeholder coalitions bringing together stakeholders with similar professional functions in the mental health care system, and revealed a divergence in priority policy goals between service managers and policymakers. The largest coalition was made up of a majority of policymakers and fewer service managers and supported all the policy goals with equal priority. The other three coalitions were each formed around one specific (and different) policy goal. One of those three coalitions prioritised deinstitutionalisation (i.e. in favour of short hospital stays) and was also made up of a majority of policymakers and fewer service managers. The other two coalitions were made up of a majority of service managers and fewer policymakers. One prioritised the personal recovery of users and the other prioritised continuity of care. In addition, the “deinstitutionalisation” coalition, which was mainly composed of policymakers, and the two coalitions mainly composed of managers were in opposition regarding the overall structure of their policy priorities, i.e. the central policy goals of the former were peripheral in the latter and vice versa. These cleavages and oppositions may reflect the different relationships and interests that stakeholders have in relation to policy goals, depending on their function and position in the mental health care system. For instance, policymakers may support the shortening and intensification of hospital stays because of pressure from international organisations, e.g. the WHO [65-67], or to reduce public expenditure, whereas service managers are not so concerned by such demands. By contrast, in Belgium, as in other regulated-market systems, hospitals are partly funded on a fee-for-service basis and, therefore, the reduction of the length of stay in hospitals may also reduce the hospital’s revenue, which is a concern of hospital managers.

This study also found that service managers perceived themselves as the most influential stakeholders in the organisation of mental health care, particularly compared to policymakers. This supports the results of a previous study that found that the most influential stakeholders in the public health policy-making process in the UK were mid-level managers [68]. This is described by Lipsky [52] in policy implementation research as "street-level bureaucracy", emphasising the central role of frontline staff in putting policy into action. Although it has been observed in other countries, this result is probably reinforced by the Belgian context. Indeed, the Belgian health care system is characterised by a substantial level of corporatism in policy decision-making and the mental health care reforms of recent decades have mainly been developed using a bottom-up approach [69-71], thus leaving extensive autonomy, bargaining power, and influence to stakeholders such as service managers [72]. This finding is important for policy development and implementation. Indeed, the frameworks and main goals of policies and reforms are often set by policymakers, but our results highlighted that the implementation of these frameworks and the achievement of initial goals relies heavily on mid-level managers and on the degree of convergence with their priorities and interests. This divergence in relation to policy priorities between policymakers and managers and the latter's perceived high level of influence could, therefore, explain the difficulty of implementing some policy goals of the reform, such as the deinstitutionalisation of mental health care and the social integration of people living with mental illness.

Representatives of users and families were mainly represented in the coalition that gave equal priority to all the policy goals, which may indicate their desire to have a comprehensive mental health policy and to prevent certain policy goals from taking precedence over others. However, this study highlighted that, regardless of the goals around which the four coalitions were formed and the structure of policy priorities of each coalition, two patient-centred policy goals were often peripheral policy goals, i.e. supporting users to connect with their community and involving them in the development of services. In addition, the descriptive results also showed that user and family representatives perceived themselves as the least influential stakeholders in the organisation of mental health care. Although the participation of user and family representatives in policy and health care decision-making is on the political agenda in many countries [73, 74], several studies have shown that their full participation remains a challenge and that there is little consensus on their role, on the extent of their participation or even on the aims of such participation and the process for achieving it [75-77]. These results can be interpreted in two ways. First, they can be linked to the literature suggesting that Western health care systems tend to prioritise the needs of providers and society rather than those of patients [78] and that, as a result, policy goals oriented towards professionals and services, such as continuity of care or intensive psychiatric hospitalisation, can override patient-centred goals, such as their social integration and personal recovery. Second, this result could be interpreted in relation to two notions of health economics: uncertainty and opportunity cost. On the one hand, there is more certainty about the return on an investment in policy goals such as the intensification of hospital stays than about patient-centred goals such as involving patients in the development of services. On the other hand, "to choose is to renounce". Since health care systems have limited resources, it is necessary to choose one alternative (e.g. if there is more certainty about the return on investment) and forgo others (e.g. if the return on investment is less certain). Therefore, special care must be taken to reduce stakeholder uncertainty regarding the return on investment in patient-centred goals, such as their social integration and personal recovery, and to prevent policy goals that are oriented towards professionals and services, such as improving continuity of care, from overriding them.

Finally, despite the competing policy positions of the coalitions, some policy goals could be a lever for consensus within and between coalitions. Several theories suggest that policy priorities are structured as networks of interrelated policy positions, in which some are central and others are peripheral, central policy positions structuring the more peripheral and being strongly related to political decisions [79-81]. On the one hand, the political support and decisions of stakeholders in a specific coalition can therefore be fostered by identifying and then supporting the central goals of that coalition. On the other hand, identifying and supporting a policy goal that is central in all coalitions, could be a lever for consensus between the coalitions. This study showed that in Belgium, the policy goal of treating users in their community was a relatively central policy goal in the different coalitions and could, therefore, be supported and put forward in order to reach consensus between competing coalitions.

Main findings Chapter 6

- This study identified four main stakeholder coalitions endorsing different mental health policy goals and bringing together stakeholders with similar professional functions in the mental health care system.
- Disagreements around priority policy goals were observed between policymakers (i.e. those who devise reform programs and goals) and service managers (i.e. those who largely shape the implementation of the reform).
- Service managers perceived themselves as the most influential stakeholders in the organisation of mental health care, particularly compared to policymakers.
- This divergence in relation to policy priorities between policymakers and managers and the latter’s perceived high level of influence could, therefore, explain the difficulty of implementing some policy goals of the reform, such as the deinstitutionalisation of mental health care and the social integration of people with SMI.
- Regardless of the goals around which the four coalitions were formed and the structure of policy priorities of each coalition, two patient-centred policy goals were often peripheral policy goals, i.e. supporting users to connect with their community and involving them in the development of services.

- The policy goal of treating users in their community was a relatively central policy goal in the different coalitions. Since central goals are strongly related to political decision-making, this goal could, accordingly, be supported and put forward in order to reach consensus between competing coalitions.

7.2 General conclusion of the thesis

The conclusion of this thesis is articulated around the theoretical framework proposed by Shiffman and Smith for policy agenda setting [82], in order to synthesise the results and describe how factors related to mental health services, systems and policies influence the social integration of people with SMI. The policy agenda framework proposed by Shiffman and Smith highlighted four categories to explain how health matters are relevant for the policy agenda: (1) the intrinsic characteristics of the issue, (1) the power of the actors involved, (3) the political context, and (4) the power of the ideas used to describe the issue (i.e. how the issue is characterised and described in trying to draw attention to it). According to Schiffman and Smith, a health issue, policy or intervention is more likely to gain political support if it shares specific characteristics in these four categories.

The intrinsic characteristics of the social integration of people with SMI

According to Schiffman and Smith, a health issue is more likely to gain political support when it is deemed serious enough, compared to other issues deemed less serious. Two main elements come into consideration: (1) having credible indicators to assess it and to monitor the progress and magnitude of the burden of the health issue and (2) the existence of interventions that are feasible and effective in tackling it.

In terms of indicators and monitoring, a result of this thesis is that in a way, we do not properly assess social integration and therefore do not fully understand its nature and the burden of social exclusion.
First, the literature review in **Chapter 1** showed that systematic reviews and meta-analysis on the evolution over time of social integration indicators of people with SMI found that their social integration has remained relatively low and has not

much improved over the past decades. However, these studies did not systematically compare the social integration of people with SMI with the general population without mental illness. This finding is problematic because the social exclusion of an individual is directly related to the average level of social integration of the society in which he or she lives. Therefore, the analysis of the social exclusion of a very specific group such as severe mentally ill people should be in comparison with the general population. The studies in **Chapter 2 and 3** showed that by comparing the evolution over time of the social integration of people with SMI with the general population, and therefore considering the average level of social integration of the society in which they lived, we do not observe a lack of improvement of their social integration but an increase over time of their social exclusion. Therefore, failure to consider the level of social integration of the general population results in underestimating the burden of the social exclusion of people with SMI.

Second, social integration is a multidimensional concept. However, the literature review in **Chapter 1** also highlighted that the international scientific literature often focused on indicators of economic integration such as the employment rate or income of people with mental illness. This focus on economic integration may be linked to the high indirect costs of mental illness on the labour market of Western countries. For example, in 2015 in Belgium, the indirect costs of mental health problems on the labour market represented 2.30% of Belgium's gross domestic product (GDP), the highest percentage of OECD countries [83]. Employment is a key social determinant of the mental health and social integration of individuals, but it is not the only one. Therefore, efforts are needed to have a more holistic approach in the assessment of social integration by combining indicators capturing its different dimension.

This focus on the economic dimensions of social integration is also reflected in the research and implementation of policies and interventions aimed at tackling social exclusion. For example, mental health anti-stigma laws and policies primarily target the employment sector. However, the stigmatisation of and discrimination against people with mental illness is also a barrier to their participation in other dimensions of life in society such as housing, social relationships, etc. In addition, the literature review in **Chapter 1** found that there is limited research on interventions aimed at improving social support or community engagement of people with SMI compared to supported employment or housing interventions. In addition, the effectiveness of certain interventions on social integration remains controversial. For example, one of the multiple factors that might hinder the social integration of people with SMI is the fact that most of them tend to experience long lengths of stay (LoS) in psychiatric hospitals and repeated admissions, which disrupt their social and professional lives, as suggested by Goffman [37], Honigfeld [38], and Gruenberg [39]. However, the effect of LoS and readmissions in psychiatric wards on their social integration remains a controversial subject, probably because the few studies that have explored such associations have had inconsistent results [41, 42]. Therefore, some argue that psychiatric hospitalisations should be dedicated to acute care only, should be as short as possible, and should be considered as a last care resort. Long stays in, and repeated admissions to hospital, according to them, disrupt the social and professional lives of patients, have a negative effect on social integration, and lead to institutionalisation [84-87]. According to others, however, an excessive reduction of hospital LoS would lead to precipitous hospital discharge, increasing the likelihood of readmission and inducing a “revolving door” admission phenomenon, which would have adverse effects on patients’ social integration [41, 88, 89]. To shed light on this debate, the study in **Chapter 5** found that having a long stay in a psychiatric ward was associated with a decrease in the social integration of people with SMI. Therefore, this study supports the importance of policies and interventions that aim to reduce the length of hospital stays for people with SMI in order to preserve their social integration. However, the implementation of policies and interventions, such as the deinstitutionalisation of mental health care and the reduction of LoS in psychiatric ward, is also influenced by the power of the actors involved.

The power of the actors involved in the social integration of people with SMI

According to Schiffman and Smith, the policy agenda setting of a health issue is also determined by the power of actors involved with three key components: (1) the existence of strong leadership, (2) the mobilisation of civil society, and (3) have guiding institutions that could operate the initiatives.

In terms of leadership, the study in **Chapter 6** found that, in Belgium, user and family representatives perceived themselves as the least influential stakeholders in the organisation of mental health care. However, the central component of the social integration of people living with mental illness is their participation in society, and this participation also applies to policy and health care decision-making (e.g. user participation in the planning and delivery of services). Indeed, many authors suggest that a socially inclusive system requires greater involvement and participation of services users in decision-making, inducing a paradigm shift in the relationship between them and professionals [90-92]. Different approaches exist to increase this participation, such as the presence of user and family representatives in the administrative boards of services and in local and national decision-making bodies, and to involve them in decisions, recruitment and training of professionals, evaluation and research, etc. However, the study in Belgium presented in **Chapter 6** also showed that regardless of the mental health policy goals around which stakeholder coalitions were formed and the structure of policy priorities of each coalition, the policy goal of involving users in the development and provision of services was often peripheral. For example, while the policy goal of supporting users to develop their life goals was central in a coalition mostly made up of service managers, the goal of involving users in the development and provision of services was the most peripheral. Some studies have shown that mid-level managers weigh the implementation of policies against their local management agenda (i.e. funding of their institution, staff management, organisation of activities, and performance) [93-95]. Our interpretation is therefore that, for service managers, involving users in the development and provision of services may induce organisational and management constraints, so that these considerations run counter to their central goal of personal recovery and social integration of users. This interpretation is also supported by the results of our study in **Chapter 4** which showed that the main predictor of exposure of people with SMI to continuity of care approaches was their hospital of admission, and not their clinical and socio-demographic characteristics. These results highlight a paradox because, in theory, the organisation of care should be based on patient needs (i.e. demand side factors), but in practice it seems to be largely determined by services and providers (i.e. supply-side factors).

Mid-level managers have a strong influence on the implementation of policies and intervention, this is described by Lipksy as “street-level bureaucracy” [52]. Indeed, our study in **Chapter 6** also found that service managers perceived themselves as the most influential stakeholders in the organisation of mental health care. As previously explained, one of the goals of the mental health care reform in Belgium

is the intensification of psychiatric hospitalisations (i.e. reduction of admissions and length of stay in psychiatric wards), which is consistent with the results of **Chapter 5** and with a general objective of social integration of people with SMI. However, the study in **Chapter 6** highlighted that this goal was not supported by service managers, possibly because the reduction of the length of stay in hospitals may also reduce the hospital’s income, which is a concern of hospital managers. This opposition, combined with their high influence on the organisation of mental health care, may explain the difficulty of implementing some policy goals of the reform, such as the intensification of psychiatric hospitalisations.
The lack of power and participation of users in care decision-making as well as the competing policy priorities of service managers could explain the lack of leadership and cohesion around the goal of social integration of people with SMI. Therefore, these findings may highlight (1) the need to strengthen and define the participation and involvement of service users in policy and care decision-making, and (2) the importance of aligning the priorities of stakeholders, such as service managers, with the objectives of mental health policies (e.g. with the implementation of incentives).

In terms of mobilisation of civil society, there may be tensions between the demands of the general society and mental health policies [96, 97]. An example of this is the tension between mental health users' movements calling for more social integration and safety concerns raised by wider society, the former aiming to support the autonomy and inclusion of people living with mental illness in the community while the latter aims to separate individuals who are stigmatised as potentially dangerous (e.g. people living with severe mental illness) from the community.

Finally, it is difficult to have a guiding institution to operationalise the actions because the multidimensional character of social integration often induces a sharing of responsibilities between several health, mental health, and social institutions and at different levels of power. For example, in Belgium, the sixth reform of the Belgian state in 2011 led to a significant shift of competences from the federal state to federated authorities (communities and regions), particularly in the domain of mental health care. The mental health care reform process and the funding of the psychiatric inpatient facilities remain a federal competence whereas outpatient mental health and social services are now reporting to regional authorities. Employment policies are also mainly regional and each region has a reference body for unemployment benefits, training and job search (i.e. Actiris for the Brussels-Capital region, VDAB for the Flemish region, and the Forem for the Walloon region). Therefore, in Belgium, social integration mainly becomes a competence of the federated entities, however, several funding competences remain at the federal state which is the main funder. This division of political competences, combined with regional differences such as population density or economic growth, are likely to generate territorial inequalities in terms of social integration of people living with mental illness. Indeed, the study in **Chapter 3** highlighted differences in the social integration of people with mental illness between the three regions of Belgium and that these differences tend to increase over time, to the detriment of people living in the Brussels-Capital region compared to Wallonia and Flanders. These results show some local contexts may need different strategies for organising mental health and social care and autonomy to implement them in order to prevent social integration inequalities between regions from widening. In Belgium as in other countries, the social integration of people with SMI may therefore requires (1) coordination between local and national authorities responsible for (mental) health care, welfare and social affairs and (2) local autonomy and governance in the organisation of mental health care and policies.

The political context around the social integration of people with SMI

According to the framework of Shiffman and Smith, the political context is the environment in which stakeholders operate and it includes their ability to take advantage of policy windows (i.e. external conditions that are perceived as favourable for tackling the issue).

In Belgium, the 2010 reform in the organisation of mental health care was an important policy window for the social integration of people with SMI. Indeed, the social integration of people living with a mental health problem was one of the policy objectives underlying the reform [12]. However, the mental health sector is characterised by a multitude of stakeholders with different professional profiles, interests, and priorities [56]. This situation facilitates appropriation of and opposition to reform programmes and goals [57] and as explained in **Chapter 6**, disagreements within the policy community and between the policy community and other stakeholders have frequently been identified as a factor explaining failures in the implementation of public policies [53, 54]. The study in **Chapter 6** identified four main stakeholder coalitions endorsing different mental health policy goals of the Belgian reform and bringing together stakeholders with similar professional functions in the mental health care system. The modelling of these coalitions revealed a divergence in priority policy goals between service managers and policymakers. This finding is important for policy development and implementation because, although reform programmes and goals are often devised by policymakers, their implementation is largely shaped by mid-level managers, who have the most influence in practice [68]. It is therefore important to find a consensus and to align the priorities and objectives of policymakers and managers. In the context of a bottom-up policymaking, as in Belgium, these results may highlight the importance of mobilising and bringing together policymakers, service managers, and other stakeholders in the different stages of policy development and implementation. For example, in Canada, Ontario's 2011 Mental Health and Addictions Strategy placed more emphasis on stakeholder engagement and established policy networks which brought together people from government ministries and stakeholders representing different individual and collective interests, such as researchers, service managers, professional associations, and consumer groups [98]. Another result of the study in **Chapter 6** was that the policy goal of treating users in their community was a relatively central policy goal in the different stakeholder coalitions. Since central goals are strongly related to political decision-making, this goal could, accordingly, be emphasised in order to reach consensus between competing stakeholders coalitions. Stakeholder endorsement of policy goals relies on a common understanding of those goals, which brings us to the final section on the power of ideas.

The power of ideas around the social integration of people with SMI

Finally, the power of ideas in Shiffman and Smith’s theoretical framework refers to how the issue is characterised and described, and how the actors involved in the issue understand and portray it, in order to achieve consensus on the issue and potential measures to tackle it. This section will therefore be dedicated to ideas around the two main concepts of this thesis: (1) severe mental illness and (2) social integration.

Why define and identify a specific target group such as people with SMI? First, some specific services and interventions should have one or more target groups who are most likely to benefit from them. Second, the absence of target groups in the organisation of care may lead to the exclusion of the most vulnerable groups. The current Belgian mental health care reform targets mainly the whole population with mental health needs and does not propose different organisational mechanisms or services according to target groups, except for age groups (child and adolescent psychiatry, adult psychiatry, and elderly psychiatry) or for specific audiences such as mentally ill offenders. However, the lack of definition of target groups within the framework of the reform can leave an extensive autonomy to the different services and providers in selecting their patients, with a risk of excluding the most vulnerable patients such as people with more complex needs and severe mental illness. Indeed, the results of the study presented in **Chapters 2 and 3** suggest that the policies and reforms put in place between 1997 and 2018 in Belgium improved the social integration of people with moderate mental illness but not that of people with SMI. This highlights the need to define different target groups requiring specific care mechanisms and services within the framework of the organisation of mental health care to prevent people with SMI from being "forgotten".

However, the very definition of a severe mental illness remains disputed. As highlighted in the literature review in **Chapter 1**, the definition that seems to have the most consensus is that of the National Institute of Mental Health (NIMH) [99] which categorises individuals as having a SMI if they met three criteria: (1) having a diagnosis of non-organic psychotic or personality disorders, (2) duration (i.e. prolonged illness and long-term treatment), and (3) having disabilities as a result of the disease. This definition puts forward the psychiatric diagnosis, which would therefore be the entry point of a specific service or care circuit for people with SMI. However, the operationalisation in the organisation of mental health care of the previously mentioned NIMH definition proved to be controversial. Indeed, restricting the definition to diagnosis of non-organic psychotic or personality disorders is criticised because people with other psychiatric diagnoses may have severe forms and need care and services specific to people with SMI [100]. The long-term criterion is also criticised because in modern mental health care, people with moderate mental health disorders can also receive care for years without their illness having been in severe form at any time [100]. In the Netherlands, another definition has been developed in order to better organise the provision and funding of mental health care by developing specific care circuits for different target groups, including people with SMI [100]. This definition tends to place more emphasis on social and functional dysfunction and care needs, rather than on psychiatric diagnoses. In recently developed evidence-based interventions specifically for people with SMI, such as the Individual Placement and Support and the Housing First models, the entry point is their social exclusion (i.e. unemployment or homelessness), not their psychiatric diagnosis. It therefore seems relevant to recognise social exclusion as a main criterion in the definition of SMI, and therefore in the organisation of specific care services and circuits for people with SMI. This seems all the more important in the Belgian context because a study conducted with data from the first evaluation of the Belgian mental health care reform in 2010 had shown that people with SMI with the lowest level of social integration were not targeted for care by clinicians from different services [14].

Although social integration is now considered as a key outcome for mental health systems and services, the literature review in **Chapter 1** showed that there is no clear consensus on its definition [101-103]. This observation has also been made for other mental health policy goals. For example, although the concept of recovery is a central component of mental health practices and policies since the early 2000s, researchers have identified seven recurring misuses of the concept (labelled as “abuses” by the authors): (1) recovery is the latest model; (2) recovery does not apply to “my” patients; (3) services can make people recover through effective treatment; (4) compulsory detention and treatment aid recovery; (5) a recovery orientation means closing services; (6) recovery is about making people independent and normal; (7) and contributing to society happens only after the person is recovered [49]. As showed in **Chapter 1**, our approach to social integration in both research and practice is fragmented, with an emphasis on economic integration. There are growing global and national calls for adopting social integration as a key outcome for people with mental illness, however, efforts are still needed to provide a clear and comprehensive framework for this concept (see 8.2: Assessment of the social integration of people with severe mental illness: Let's visualise the elephant). Such a framework would allow consensus to be reached on this issue and on potential measures to address it. This comprehensive framework brings us back to the first section of this conclusion, on the intrinsic characteristics of the social integration of people with SMI, and the circle is now complete.

7.3 Limitations of the thesis and perspectives

Limitations and unaddressed issues

Like all research work, this thesis has limitations. The first limitation is linked to the quantitative orientation of this thesis and to the postulate that social integration is a measurable reality by means of validated indicators or scales, ranging from exclusion to integration. Social integration is also a subjective concept which cannot be fully captured with quantitative methods. Indeed, a person may have a job, housing, activities, family and friends but still feel socially excluded. This subjective dimension of social integration could have been investigated by means of qualitative methods. Rather than seeking to identify generalisable results in terms of groups at risk, determinants, causes and consequences of social exclusion using quantitative methods, qualitative methods can help disentangle some of the individual complexities of social exclusion and the causation and temporal relationship with mental health using a life course perspective (i.e. explore individual change over time). The second limitation of this thesis is linked to its "meso and macro" approach to social integration, leaving aside the micro level (except for the literature review in Chapter 1). Indeed, it is known that the health outcomes of the population are influenced by factors at the micro (i.e. direct care, interventions and other support provided to individuals), meso (i.e. organisation of care and services), and macro (i.e. health systems policies and reforms) levels [104, 105]. Much research has shown how the direct provision of care can influence the social integration of people with SMI and has developed socially inclusive evidence-based practices. However, working in a mental health services research (MHSR) group and doing a thesis in public health sciences, I chose to focus on the meso and macro levels and study how factors related to mental health services, systems and policies influence the social integration of people with SMI.

In terms of methodological limitations, I used different data and quantitative methods depending on the research questions addressed. The methodological limitations related to the data and methods used are therefore presented in each chapter individually. An important point is that I wanted to overcome some methodological limitations related to one chapter by varying the data or methods in the others. For example, specific surveys on people with SMI such as the COFI study used in Chapters 4 and 5 do not allow comparison between people with SMI and the general population. However, the social exclusion of an individual or a group is directly related to the average level of social integration of the society in which he or she lives. Therefore, in Chapter 2 and 3 I used data from the Belgian Health Interview Survey to compare the social integration of people with moderate or severe mental illness with the general population without mental illness. Conversely, individuals who experience one or more forms of exclusion (e.g. living in institution, homelessness, having poor literacy and language skills or having a severe mental illness) are difficult to include in large epidemiological studies such as health interview surveys and are therefore often under-represented or even excluded. This is called "the exclusion of the excluded", which can lead to an underestimation of the social exclusion of a group. In this perspective, data from the COFI study are of rare quality as more than 7000 people with SMI, institutionalised at inclusion in the study, were followed-up at one year in the UK, Germany, Poland, Italy, and Belgium.

Finally, since social integration is a multidimensional concept and the factors at the meso and macro level that can influence it are innumerable, this thesis also has unaddressed issues. The main one is that, apart from the literature review in Chapter 1, I did not study the dimension of social and political engagement (i.e. how people engage and influence their community and environment). However, this dimension is one of the four dimensions of the definition of social integration that I have chosen to use [106], along with the dimensions of consumption (i.e. the capacity to purchase goods and services), production (i.e. participation in economically or socially valuable activities, and social interaction (i.e. social interaction with family, friends and community). This dimension is probably the least studied in the scientific literature, and this thesis unfortunately contributes to this observation. For example, voting is an indicator of this dimension because it is an integral part of decision making within society, but there is a paucity of literature regarding voting and mental illness. The other indicators used in this dimension are often proxies of how people engage and influence their environment and are rarely collected routinely at the individual or societal level, e.g. patient participation in decision-making, being a member of an association, or commitment to daily life and cultural activities [106, 107]. Within the framework of this thesis, this dimension could have benefited from a collection of primary data (quantitative or qualitative).

Perspectives

The findings of this thesis have put forward some perspectives for further research and I would like to develop two that are important to me. The first relates to the results of the study in Chapter 5. The main finding of this study was that having a long length of stay (LoS) in a psychiatric hospital was more associated with a decrease in the social integration of people with SMI after one year than having repeated and shorter stays. To the best of our knowledge, this result has never been highlighted before. This finding has important practical implications for policies and care practices because despite a movement of deinstitutionalisation of mental health care, the psychiatric hospital retains an important role and people with SMI tend to still experience long LoS. Given the difficulty of reducing LoS for people with SMI, our results show that short and repeated admissions could be an alternative to long stays in order to preserve the social integration and possibly promote other outcomes of people with SMI. This hypothesis could be tested, for example by comparing the outcomes (e.g. social integration, severity of symptoms, patient satisfaction with care, etc.) of patients exposed to short and repeated admissions with those of patients exposed to long stays (usual care) in psychiatric hospitals. The best design to establish causation between types of hospitalisations and patient outcomes would be a randomised clinical trial in which patients are randomly assigned to both types of hospitalisation upon admission to hospital. However, randomising the LoS and the frequency of hospitalisation entails obstacles and may be clinically and ethically problematic. An alternative design would be a non-randomised trial in which the type of hospitalisation is chosen by the patient or by patient-clinician agreement. This type of design makes it more difficult to establish causation between types of hospitalisations and patient outcomes due to multiple confounding factors. Potential confounding factors can however be collected and included in models in order to partially overcome the risk of confounding bias. I had the opportunity to discuss the study of Chapter 5 with Prof. Philippe De Timary, psychiatrist and head of the department of adult psychiatry at the Cliniques universitaires Saint-Luc. He explained to me that for several months he had been providing short and repeated admissions in his department for patients with alcohol use disorder and that this type of hospitalisation seemed to be beneficial, even though he had not yet had the opportunity to assess it. A collaboration with Prof. De Timary would therefore be possible to make this perspective concrete.

The second perspective is part of the general continuity of my thesis and would be a research and development project. As underlined in my thesis, it is important for clinical practice but also for scientific research and the development of evidence-based policies and interventions to have quality data on the social integration of people living with mental illness (see 8.2 Assessment of the social integration of people with severe mental illness: let's visualise the elephant). A relevant research and development project would therefore be to implement a tool to assess and monitor the social integration of people with mental illness in routine clinical practice. Such a tool could be implemented in the current tool for collecting patient data in psychiatric hospitals and psychiatric wards in general hospitals (i.e. Résumé Psychiatrique Minimum), but also in outpatient services of a given territory (e.g. based on geographical territories defined during our mental health care reform). The data collected would be useful for care professionals and direct patient care, but also for scientific research and mental health policies. I would like to suggest three tools that each have advantages and disadvantages.

The first tool is the Objective Social Outcome Index (SIX) [108] that I used in the studies of Chapters 4 and 5. The SIX is a global index of social outcomes that combines different indicators of an individual's social situation in order to provide a brief, meaningful, and comprehensive overview in a single indicator. The SIX index has been tested and met the following quality criteria: having a sufficient distribution to identify differences between groups, capturing changes over time to assess the potential effect of interventions, and carrying a low risk of error in assessment and documentation so that scores remain stable in the absence of real change [108]. Furthermore, The SIX was used to test the concurrent and convergent validity of other measures and scales of social integration and met the validity criteria [109, 110]. The SIX index ranges from 0 (low social integration) to 6 (high social integration). It includes four dimensions: employment status (0 = none, 1 = voluntary⁄protected⁄sheltered work, hereafter “protected job”, and 2 = regular employment), housing status (0 = homeless/24h-supervised accommodation, 1 = sheltered/supported accommodation, 2 = independent accommodation), family situation (0 = living alone, 1 = living with a partner/family), and friendship status (0 = did not meet a friend in the last week, 1 = met at least one friend in the last week). The advantages of SIX are that it is very brief although it is multidimensional and that part of the data to compute it are already collected in clinical routine, so it should not add data collection burden on care professionals. This advantage is also its disadvantage because it aims to summarise a complex phenomenon using a limited number of indicators. For example, information about social relationships and support is probably not entirely captured by a single question about the frequency of meeting a friend.

The second tool is the Social Inclusion Questionnaire User Experience (SInQUE) [109]. The SInQue has construct and concurrent validity with measures of quality of life and unmet needs in people living with SMI. This tool is much more exhaustive than the SIX, its main drawback is therefore the time to collect it in clinical routine. Indeed, the SInQUE takes approximately 45 minutes to be completed because it was designed as a structured interview between the care professional and the patient rather than as a self-report measure. According to the authors, "a*lthough the questionnaire took about 45 minutes to administer, participants appeared to find it acceptable as only one individual failed to complete it* (out of 66). *This may be because participants perceived the questions as relevant and as addressing areas that may be overlooked in other mental health assessments. They appeared to value the opportunity to talk about matters unrelated to medication and symptom control."* [109]. In my opinion, the first strong point of this tool is that it was developed specifically for people with SMI who may have cognitive problems and difficulty completing non-specific tools. The second strong point is that it collects information on multiple dimensions of social integration, including the dimension of social and political engagement (e.g. voting, membership in campaigning), a dimension that is often overlooked in clinical practice as well as in research. The third strong point is that it collects information on the reasons why participation is not achieved in the different dimensions of social integration: lack of money, lack of transport, problems with location, no interest, not available, no time, lack of childcare, no one to do it, or "any other reason". This tool is therefore not limited to the assessment and monitoring of social integration because it opens the discussion between the care professional and the patient on the obstacles to social integration. The scoring system of the SInQue allows to compute a total score ranging from 0 (low social integration) to 93 (high social integration).

The third tool, which is the short version of the SCOPE, may seem like a consensus between the first two. The Social and Community Opportunities Profile (SCOPE) is an index allowing to grasp the subjective and objective life domains linked to social integration [111]. It was developed by the London School of Economics and Political Science for use in research and clinical settings. The original long version of SCOPE consisted of 121 questions covering eight specific areas of social integration: (1) leisure and participation, (2) housing and accommodation, (3) safety, (4) work, (5) financial situation, (6) self-reported health, (7) education, and (8) family and social relationships. Questions are asked to assess objective and subjective measures for availability, access, and participation in each area of social integration. Open questions are also present for each area in order to question the ways in which the individual would like to change his situation in the area concerned, thus opening the discussion with the clinician on potential changes and interventions. The scientific evaluation of the use of the tool in clinical practice has shown that the main complaint was that the SCOPE was too long and took too much time to complete [111]. A short version of the tool was therefore developed, reducing the number of items from 121 to 48. The test of this short version [111] showed that it retained good internal consistency, reliability over time, and good discriminant validity between the mental health groups. More importantly, the acceptability of the tool increased and 90% of users described the questions as relevant.

References chapter 7

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Chapter 8

8

Chapter 8: Social integration is not a clinical outcome, it’s a system outcome requiring a systematic approach: The Belgian case

8.1 Overview of the Belgian context

The aim of this chapter is to give a quick overview of the Belgian context and the social integration of people with severe mental illness (SMI) in Belgium.

The Belgian health care system is a regulated-market, social insurance-based system characterised by a substantial level of corporatism in policy decision-making. Although the provision, coordination, and funding of care are the responsibility of the political authorities, these responsibilities tend to be delegated to semi-public institutions in which stakeholders, such as sickness funds and representatives of professionals, have a high level of bargaining power and defend their particular interests [1].

In Belgium, the process of deinstitutionalisation started around 1975 with the establishment of Community Mental Health Services and other alternatives to psychiatric hospitalisations (i.e. residential rehabilitation units, sheltered housing, and psychiatric nursing homes). However, this process of deinstitutionalisation was far from complete and in 2008, there were still 152 psychiatric beds per 100,000 inhabitants, the highest rate in Europe after Malta [2]. Since 2010, a reform in the organisation of mental health care has been under way with the objectives of “*further orient mental health care towards a reduction of residential hospital care in favour of patients’ recovery and treatment in the community.*” [3]. The basic funding mechanism of the reform was to convert part of the financial resources devoted to long-term psychiatric beds into means for developing mobile teams, working in a defined geographical area within a network of different services [3]. The reform was implemented from the bottom up, leaving extensive autonomy to local care stakeholders in the development of their own networks of services and resulting in diversified projects [4]. The programme theory of the Belgian mental health care reform has been analysed in detail elsewhere [5]. The networks of services developed as part of this reform must provide five functions in their geographical area: (1) prevention and early detection, (2) outreach, (3) recovery and social integration, (4) intensive in-patient treatment, and (5) specific housing and long-term facilities. However, the types of services that must provide each of these five functions have not been systematically or clearly defined by the authorities and the bottom-up approach of the reform implementation left extensive autonomy to various services and providers in defining their missions and roles. The Belgian mental health system is therefore often put forward positively for its diversity and its many local experimental projects, on the one hand, and negatively for its gaps and overlaps in the provision of care as well as disparities in care practices, on the other.

The policy that underpins the Belgian reform has five main goals: (1) the recovery and social integration of people with mental health needs, (2) the shortening of hospital stays, (3) the implementation of community-based care system, (4) the establishment of collaborative procedures to improve continuity between the social and care sectors, and (5) the consolidation of previous community-based projects. A recent case-control study assessed the effectiveness of this reform on continuity of care, quality of life, re-hospitalisation and social integration of people with SMI [6]. This study highlighted that greater exposure to the reform[4] was associated with a slight improvement in the perceived continuity of care of people with SMI ($\beta = 1.27$, $p < 0.01$), but not with their social integration ($\beta = 0.08$, $p < 0.20$) and other outcomes. We will now develop in more detail the 4 dimensions of social integration with some key indicators: housing, employment, social interactions, and political participation.

Housing

The 2014 Belgian national evaluation "Towards Better Mental Health Care" revealed that in a non-randomised sample of 1,199 people with SMI, 9% were homeless or in a therapeutic community, 24% were in a supported housing, and 67% were in an independent housing [7]. However, there is no information on the housing status of people with SMI compared to the general Belgian population. In

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[4] In this study, a composite index of intensity of exposure to the reform was computed for each people with SMI with a total score ranging from 0 (lowest exposure) to 5 (highest exposure).

addition, the SMI patients included in the previously mentioned study may not be representative of the population of people with SMI as it was not a random sample.

There are different types of residential services in Belgium. A first way to identify them is to differentiate structures that are not accredited by the state from accredited structures. Non-accredited residential services, also called “pirate houses”, are services that provide housing to people with difficulties to live autonomously, including people with mental illness. In 2011, it was estimated that there were 40 pirate houses in Wallonia, 20 in Brussels and none listed in Flanders, for about 3,000 people hosted [8]. Beside these structures, there are different types of accredited structures. Following the deinstitutionalization movement and the decline in the number of psychiatric hospital beds in the 1990s, two new types of residential services for people with mental illness were developed; sheltered accommodations (Initiatieven Beschut Wonen-IBW – Initiatives d’Habitations Protégées-IHP) and psychiatric care homes (Psychiatrisch Verzorgingstehuis-PVT – Maison de Soins Psychiatriques-MSP). These services were developed with a transitional approach with different level of support according to user needs, and therefore seem to be closer to the linear continuum model than to the supported housing model. Sheltered accommodations are short-term residential services for people with mental illness who do not need permanent follow-up but who must be assisted in their living environment to develop their social skills. The main purpose of these services is to support people with mental illness until they can live in independent housing. Psychiatric care homes are long-term residential services for people with mental illness who need permanent supervision by trained staff. These services specifically target people with SMI who do not require intensive in-hospital psychiatric care but are considered unable to live independently in the community or in other living communities.

There are also specific interventions for homeless people. The Housing First model has been tested for 2 years between 2013 and 2015 in 11 experimental projects in Antwerp, Ghent, Hasselt, Brussels, Molenbeek, Liège, Charleroi and Namur. Through the different projects, 144 people found housing with the Housing First model and the rate of housing maintenance after 12 months was 93% [9]. The projects were extended, received an agreement in the different regions and there were 12 Housing First projects in Belgium in 2018 [8]. Unfortunately, these initiatives remain pilot projects which are not systematically implemented throughout the territory and are not systematically evaluated to show their effectiveness.

Employment

Unfortunately, Belgium is not a very good student in terms of economic inclusion of people with mental illness: Belgium is one of the countries with the lowest rate of employment and the highest rate of unemployment among people with mental illness. In 2008 compared to the Belgian population without mental illness, the employment rate of people with mental illness was 15 percentage points lower (respectively 65% and 50%) and their unemployment rates was 10 percentage points higher (respectively 8% and 18%) [10]. The analyses in **Chapter 2** showed that between 1997 and 2018, the unemployment rate decreased for the general population (-12.6%) and for people with moderate MI (-3.9%), but it increased for people with severe MI (+5.2%). Additional analyses presented in **Chapter 3** have shown that in Belgium, people with MI and especially those with SMI, were more likely to have elementary jobs (i.e. clerical support works, plant machine operators and assemblers, and elementary occupations) and to be in the lowest income quintile compared to the general population without MI and that these trends increased between 1997 and 2018. In 2015, the indirect costs of mental health problems on the labour market represented 2.30% of Belgium's gross domestic product (GDP), the highest percentage of OECD countries [11]. Mental health problems are a leading cause of sickness absenteeism in Belgium. In 2016, they were responsible for 35% of the sickness absenteeism of employees and 22% of the self-employed and these percentages are increasing over time [12, 13].

A first reform started in the work incapacity insurance in 2006 with the aim of supporting the reintegration into the labour market of people with work incapacity (disability) but retaining part of their ability to get paid work. The main mechanism of this reform was to give the medical reviewer (médecin-conseil) the task of preparing their professional reintegration (i.e. suggest that a person be supported in vocational programs) in addition to the initial task of assessing their degree of incapacity [14]. This reform came into force in 2009 with the adoption of the Royal Decree of 30 March 2009 amending, as regards professional reintegration, the application of the Federal law of 14 July 1994 on compulsory insurance and compensation [15]. Following this royal decree, the process of professional reintegration was individualised and proposed more systematically to people with disability [16]. In 2010, a declaration of intent was concluded between the National Institute for Health and Disability Insurance (INAMI-RIZIV), the national unions of the health insurers and vocational services in order to organise the professional reintegration of people with disability by signing agreements with the three regional employment services (agreements signed in 2012 in Flanders, 2013 in Wallonia, and 2014 in the Brussels-Capital Region) [16]. In 2011, the federal government launched its "Back to Work" program and improved access to professional reintegration by removing the need for authorization from a medical reviewer to begin the reintegration process and by making the combination of work income and partial disability benefit more attractive [16, 17]. In 2012, a new law was adopted to set up a financial incentive for professional reintegration, i.e. people with disability receive five euros instead of one per hour of training, supervision or apprenticeship and can double their allocation (from 250 to 500 euros) if the professional reintegration program is successfully completed [18]. In 2014, a law was adopted to establish an individual professional reintegration plan no later than 3 months after the beginning of the incapacity period of an individual and following a consultation with the medical reviewer [19]. Unfortunately, for people with mental illness, we had to wait until 2013 and the publication of an OECD report [10] highlighting that mental illnesses are one of the main causes of work incapacity in Belgium and the lack of a specific Belgian initiative to tackle this issue for their professional reintegration to be on the political agenda.

Following the publication in 2013 of the previously mentioned OECD report [10], the center of expertise on incapacity for work of the National Institute for Health and Disability Insurance (INAMI-RIZIV) launched in 2014 a first exploratory study entitled « Quelles perspectives de réinsertion professionnelle pour les assurés de l’INAMI souffrant de troubles mentaux ? » [16]. Subsequently, recommendations were made to improve the employability of people with a mental health problem in Belgium, in particular the implementation of IPS pilot projects in Belgium [16]. Finally, a randomised controlled trial (RCT) on the IPS model started in Belgium in 2017 and 1,200 vocational rehabilitation courses (600 in IPS and 600 in the traditional Belgian vocational program) of people with work incapacity who suffer from moderate to severe mental illness will be followed over a period of 5 years. The results of the RCT will be decisive for the implementation of the IPS model in Belgium.

Social interactions

The analyses in **Chapter 2** showed that in 2018 in Belgium, 10.1% of people with SMI had less than one social contact per week, compared to 5.8% and 2.6% among people with moderate MI and the general population. In addition, between 1997 and 2018 this proportion decreased by -7.2% for people with moderate MI but only -4.2% in people with SMI. In terms of “Social Support Network” SSN of people with SMI, one study with 380 SMI patients recruited in in-and-outpatient mental health services in Belgium highlighted that their SSN was composed of a mean of 12 members (SD = 5), most whom were care professionals (mean = 7.4, SD = 3.4) [20]. The 2014 Belgian national evaluation "Towards Better Mental Health Care" found that of the 1199 people with SMI who participated in the study, 32% reported having no contact with a friend the previous week [7]. However, those studies do not provide a comparison with the SSN of the general Belgian population and the SMI patients included may not be representative of the population of people with SMI as it was not random samples.

In Belgium, there are few not-for-profit associations offering peer support and services aiming at community participation and socialisation. These services could be defined as "alternative services" (e.g. club house, café, peer-led services, etc.) and “*are note formally included within the mental health system, and were often created on the initiative of service users themselves and their relatives. They can be described as inclusive spaces which voluntary de-emphasize both social and diagnostic categories in every day interactions.”* [21]. The main objectives of these services are to integrate former and current mental health services users within mainstream society and to support and develop socialisation opportunities by organising collective activities in a local community [21].

Political engagement

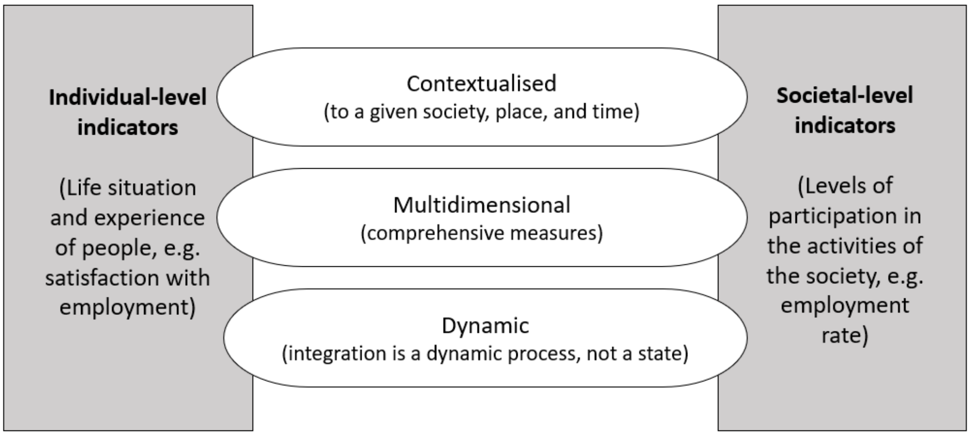
In Belgium, voting is compulsory for all Belgian citizens over the age of 18 who have their full civil and political rights. Voting is therefore accessible to all except if the person is declared incapable by a court decision (i.e. mentally ill offenders, some prisoners, and persons under prolonged minority) [22]. Like everyone else, people with SMI are therefore presumed capable of exercising their right and obligation to vote. However, there is limited information on access to voting for people with SMI in Belgium.

There is no international or national legislation specific to the political participation of people with a mental illness; their status is often included in the legislation for people with a disability. The article 29 of the 2006 United Nations Convention on the Rights of Persons with Disabilities, ratified by Belgium, certifies that *“States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others”* including the right to vote and be elected [23]. Subsequently, the question of the capacity to vote was raised by many countries and in 2013, the United Nations Committee on the Rights of Persons with Disabilities ruled for a strict interpretation of article 29, regardless of the degree of capacity of individuals [24]. United Nations law therefore does not place any restrictions on the political participation of people with disabilities. However, people with disabilities still have limited access to political participation and their political impact is less compared to their large number [25]. In Belgium, many efforts have been made to improve the political participation of people with disabilities. In 2013, the law on legal protection regimes has been amended with the “Loi du 17 mars 2013 réformant les régimes d'incapacité et instaurant un nouveau statut de protection conforme à la dignité humaine » [26]. The legal decision to put an individual under the status of legal protection no longer systematically deprives him of his right to vote, only a specific decision of the judge can. Other means to improve their political participation have been put in place, such as adapted transports on election days or the right for people with disabilities to be accompanied in the voting booth [27]. However, the participation in elections of people with a disability is not evaluated in Belgium as in many countries and there is therefore no data to assess the impact of these policies and interventions.

8.2 Assessment of the social integration of people with severe mental illness: Let's visualise the elephant

Remember, social integration is like an elephant (see 1.2.4 Dimensions of social integration: The Blind Men and the Elephant). The Indian fable “The Blind Men and the Elephant” illustrates that the truth or reality is not the result of a single point of view or a single perception but of a pooling of different truths and realities. As I said before, the first step in solving a problem is to identify it and ascertain its nature. However, what I would like to expand on in this chapter is that, in a way, we do not properly assess social integration and therefore do not fully understand its nature and extent. Figure 14 shows a theoretical framework developed as part of this thesis for the assessment of social integration.

Figure 14: A theoretical framework for the assessment of social integration



Developed on the basis of the results of this thesis as well as the research of Burchardt [28] and Berman and Phillips [29].

8.2.1 Individual and social-level indicators

First, a comprehensive assessment of the social integration of a group requires indicators at the individual and societal level. **Individual-level indicators** should capture the life experience of individuals and their perception/satisfaction of their participation in the different dimensions of life in society. These indicators are important because, for example, a person may have a job or a large social support network but not be satisfied with their job and social support and therefore feel socially excluded in both dimensions. These indicators are often of interest to clinicians and could therefore be collected in routine care practice. For example, the DIALOG + scale is an app-based intervention developed at the Unit for Social and Community Psychiatry (Queen Mary University of London) to assess, in routine mental health care practice, patient satisfaction with life domains (e.g. employment, accommodation, leisure activities, etc.) [30]. Since 2017, DIALOG+ has been implemented within the East London NHS Trust, on the one hand as a new care practice, and on the other hand to collect and centralise data on patient experience and satisfaction in the different dimensions of life in society. These centralised data therefore make it possible to describe the satisfaction of people attending one or more mental health services in a given territory with regard to their social participation and social integration. Such a tool could be implemented in Belgium, for example in the current tool for collecting patient data in psychiatric hospitals and psychiatric wards in general hospitals (i.e. Résumé Psychiatrique Minimum), but also in outpatient services of a given territory (e.g. based on geographical territories defined during our mental health care reform). The use of these individual-level indicators for research and evidence-informed policymaking requires a system to centralise and manage medico-administrative data of health care users. For example in Canada, the National Institute of Public Health of Quebec (INSPQ) has developed an integrated system for the surveillance of chronic diseases in Quebec called "SISMACQ" (Système intégré de surveillance des maladies chroniques du Québec) [31]. This database is the result of a pairing of five medico-administrative databases since 1996 with an annual update to obtain representative data of the population with information on the socio-demographic and clinical characteristics of individuals, on the burden of diseases and on the use of health care and services, including the consumption of medication under medical prescription. Unfortunately, in Belgium, the centralisation of the different sources of medico-administrative data seems to be lagging behind. In 2019, the Belgian Health Care Knowledge Centre (KCE) was commissioned to conduct a study on the organisation of mental health care for adults in Belgium in which our research team participated. After nearly 500 pages of scientific report, the main conclusion of the KCE [32] was that "The KCE was commissioned to map the current landscape of mental health care and identifying possible gaps and overlaps. But as the needs of the Belgian population are not known - for lack of reliable figures - the KCE was unable to verify whether the healthcare offer corresponded to these needs."[5]. Systematic recording of population health data and the establishment of a system to centralise them should therefore be a priority for Belgium. So far, In Belgium, it is difficult to recognise an elephant (which is a shame given the label of our famous Côte d'Or chocolate).

As previously explained, the social exclusion of an individual or a group is directly related to the average level of social integration of the society in which he or she lives. However, individual-level indicators seldom compare the situation of a specific group (e.g. people attending mental health services) to that of the general population, simply because these indicators are usually not collected outside that specific group. Therefore, **societal-level indicators** are needed to assess the social exclusion of a specific group, such as people with SMI, compared to the general population. Furthermore, not having a reference population can lead to a bias in the estimation of the social exclusion of a group. For example, the employment rate of people with SMI may be stable over time and alone indicate that their social integration has not changed. By cons, if we observe that the employment rate of the general population has improved over time (as it has over the last decades on Belgium), this means that the social exclusion of people with SMI has worsened, even if their employment rate has remained unchanged. Existing systematic reviews and meta-analysis have concluded that social integration outcomes of people with SMI, for example having a job and residential independence, had not improved in recent decades [33-36]. However, the studies included in these reviews did not systematically compare the social integration of people with SMI with the general population without mental illness. Our study in Belgium presented in **Chapter 2** showed that by comparing the evolution over time of the social integration of people with SMI with the general population, and therefore considering the average level of social integration of the society in which they lived, we do not observe a lack of improvement of their social integration but an increase of their social exclusion. Societal-level indicators such as the employment status, income level, housing situation or social capital could be collected through large-

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[5] Original quote in French : « *Le Centre fédéral d'expertise des soins de santé (KCE) a été chargé de cartographier le paysage actuel de ces soins et d'en identifier les lacunes et les possibles recoupements. Mais comme les besoins de la population belge ne sont pas connus – car il n'existe pas de chiffres fiables sur ce sujet – le KCE n'a pas été en mesure de vérifier si l'offre de soins correspond à ces besoins.* » *[32]*

scale surveys or population registers and censuses. An example in Belgium are the data collected in the successive cross-sectional waves of the Belgian Health Interview Survey (HIS) carried out by Sciensano that I used for my study in **Chapter 2 and 3**. The Belgian HIS is a multistage stratified sampling of the Belgian population aged over 15 years. Unfortunately, these data sources have one important limitation that should be taken into account: “the exclusion of the excluded” [37]. Indeed, individuals who experience one or more forms of exclusion (e.g. living in institution, homelessness, having poor literacy and language skills or having a severe mental illness) are difficult to contact and to recruit in large epidemiological studies and are therefore often excluded. Failure to assess their situation can therefore lead to an underestimation of social exclusion, but worse to inappropriate recommendations, the implementation of inadequate policies and interventions, and thus to an increase in the marginalisation of the most excluded. Therefore, in general population surveys, it may be necessary to supplement standard sample with additional subsamples composed of groups known to be under-represented. However*, “this represents a compromise between the desire for generalisability on the one hand, and the need to include specific, marginalised groups on the other”* [37].

8.2.2 Contextualised indicators

Indicators at the individual and societal level of social integration must be contextualised to a given society, place, and time. As explained above, the social exclusion of an individual or a group is directly related to the average level of social integration of the society in which he or she lives. Social integration indicators must therefore be socially contextualised.

The place is also important. Indeed, the social integration of a group of individuals can be assessed at the international level or at the level of a country, a region or even a neighbourhood. Assessments of social integration at these different levels are important because they may need different policies and interventions. For example, reducing the stigma and discrimination of mental illness requires different actions at the international, national, and local levels [38]. In addition, the collection of data at these different levels makes it possible to study the differences between countries or within a country and to assess territorial inequalities in terms of social integration. The study presented in **Chapter 3** of this thesis showed that there are inequalities in terms of social integration between the three regions of Belgium and that these equalities tend to increase over time. Indeed, for people with SMI, it is in the Brussels-Capital region that there was the greatest increase between 1997 and 2018 in their unemployment rate (+6.5%). As previously explained, successive state reforms in Belgium have resulted in a transfer of competences in health but also in other areas such as employment, from the federal state to federated entities (i.e. regions and communities). In addition to other factors such as different socio-economic contexts between regions, it is possible that this transfer of competences is linked to the increase over time of regional differences. It is therefore important to assess the situation by region in order, if necessary, to develop local strategies and prevent inequalities between regions from widening.

Finally, these results also show that the time dimension is important because the social integration of an individual or a group evolves in a dynamic process (see "*Dynamic*" below). It is therefore important to contextualise in time social integration measures. This contextualisation makes it possible to make the link between a social integration measure carried out at a time T, and the implementation of a policy or intervention at a time T-1. For example, the study performed in **Chapter 2** used social integration indicators collected between 1997 and 2018 in Belgium and highlighted that since 1997, despite the major 2010 reform of the organisation of mental health care, the social exclusion of people with SMI has worsened compared to the general population but also compared to people with moderate mental illness. These results allowed us to suggest that the policies and reforms put in place between 1997 and 2018 in Belgium improved the social integration of people with moderate mental illness but not that of people with SMI.

8.2.3 Multidimensional indicators

Repetition is the mother of learning: social integration is a multidimensional concept. There are several theoretical frameworks and definitions of social integration that identify different dimensions. In this thesis, I chose to work with four main dimensions identified on the basis of the literature by the Center for the Analysis of Social Exclusion (London School of Economics) [39]: 1) consumption (i.e. the capacity to purchase goods and services), 2) production (i.e. participation in economically or socially valuable activities, 3) social interaction (i.e. social interaction with family, friends and community), and 4) social and political engagement (i.e. how people engage and influence their community and environment). In addition, this thesis and particularly the studies in **Chapter 2 and 4** put forward a potential fifth dimension of the social exclusion of people with SMI, namely services exclusion (i.e. not all people with SMI may have access to adequate health and social services). In this perspective of services exclusion, even if policies or interventions are implemented and provided, they may not reach or be accessible for all people with SMI and the expected outcomes will not be achieved. The combination of these five main dimensions is therefore important to have a comprehensive picture of the social integration of an individual or a group. However, the literature review performed in **Chapter 1** highlighted that the international scientific literature often focused on indicators of economic integration such as the employment rate of people with mental illness and this orientation is also reflected in policies and interventions implemented. For example, mental health anti-stigma laws and policies primarily target the employment sector. However, the stigmatisation of and discrimination against people with mental illness is also a barrier to their participation in other dimensions of life in society such as housing, social relationships, etc. In addition, there is limited research on interventions aimed at improving social support or community engagement of people with SMI compared to supported employment or housing interventions. This focus on economic integration may be linked to the high indirect costs of mental illness on the labour market of Western countries. For example, in 2015 in Belgium, the indirect costs of mental health problems on the labour market represented 2.30% of Belgium's gross domestic product (GDP), the highest percentage of OECD countries [11]. Employment is a key social determinant of the mental health and social integration of individuals, but it is not the only one. Therefore, efforts are needed to have a more holistic approach in the assessment of social integration by combining indicators capturing its different dimensions. I must admit that this holistic approach is complex because it requires collecting data of very different natures. In this thesis, apart from the literature review in **Chapter 1**, I did not study the dimension of social and political engagement. This dimension is also one of the least studied in the scientific literature. The indicators used in this dimension are often proxies of how people engage and influence their environment and are rarely collected routinely at the individual or societal level, e.g. patient participation in decision-making, voting in general election, being a member of an association or commitment to daily life and cultural activities [37, 39].

In addition to a multidimensional approach, I would like to highlight the importance of using different indicators in each dimension as I did in **Chapter 3** for the "production" dimension. As explained in Chapter 3, having a job is an important indicator of social integration. However, the health and social benefits of employment are moderate, if not reversed, by poor working conditions [40-45]. It is therefore important to also have information on types of jobs and working conditions of individuals. In addition, having a paid job, regardless of the salary, can promote social integration. However, the economic integration and purchasing capacity (e.g. possibility of having independent housing) of individuals are directly related to their income. Income level is therefore additional information to employment status for the assessment of social integration. The importance of having a diversity of indicators also applies to the other dimensions of social integration. These different indicators can also measure the same concept but with different and complementary approaches. For example, the dimension of "consumption" can be measured with a housing indicator in a participation approach (e.g. having independent housing), a satisfaction approach (e.g. satisfaction with housing conditions), or a choice approach. (e.g. have the choice of accommodation).

8.2.4 Dynamic indicators

Social integration is a dynamic process, not a state. Indeed, the determinants of the social integration of people with SMI fluctuate over time (e.g. working and housing conditions) just like the conditions of mental illness (e.g. relapses). People with SMI, like everyone else, are therefore likely to move into and out social exclusion over time in a dynamic cycle. In addition, the fundamental nature of mental health symptoms is to be episodic. Finally, some determinants of social exclusion, such as early childhood events, can occur long before exclusion. Social integration must therefore be assessed from a life course and longitudinal perspective. This longitudinal perspective can be explored with data from population-based cohort studies (i.e. in which a defined population is followed up and observed longitudinally) or other longitudinal studies. For example, in the study in **Chapter 5**, I used data from a prospective cohort study in which people with SMI were followed up one year after their index admission which allowed me to assess the evolution, over one year, of their social integration and the associated factors. I must admit that a one-year follow-up period is relatively short to detect significant and meaningful changes in the social integration of individuals. However, longitudinal studies that follow individuals over long periods of time require significant resources. In another methodological approach, qualitative methods can facilitate, at the individual level, the study of social integration from a life course perspective (see 7.3 Limitations of the thesis and perspectives). It is also possible to study the evolution over time of the social integration of a population, rather than of a group of individuals. This evolution at the population level can be described using data from repeated cross-sectional studies such as the Belgian Health Interview Survey that I used for my studies in **Chapters 2 and 3**. This chapter on the assessment of the social integration of people with severe mental illness brings us to the first recommendation for Belgium.

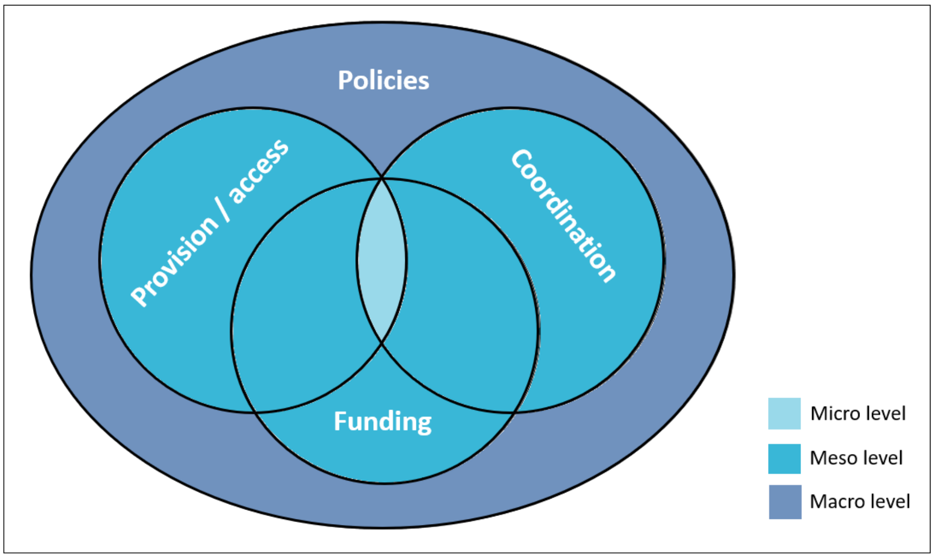
Recommendation 1: Improve the collection, encoding, and centralisation of data on mental health care

Targeted audiences: Federal and federated health authorities, federal centres of expertise (KCE, Sciensano), regional centres of expertise (CRESAM, VVGG - Vlaamse Vereniging voor Geestelijke Gezondheid, Observatoire de la Santé et du Social), and universities and research institutes

8.3 Social integration of people with severe mental illness: from the provision of services to policies

The social integration of people with SMI relies on the use of evidence-based socially inclusive practices and interventions, but also on factors related to services, systems and policies. In this chapter, I wanted to analyse the factors that influence the social integration of people with SMI using a system level approach (see Figure 15). The micro level represents the care, interventions and other support provided to individuals. This level is documented in the literature review in **Chapter 1** but was not in the scope of this thesis. The meso level represents factors related to the organisation of care and services. In this level, I chose to group the results of my thesis into three broad categories, i.e. (1) the provision and use of care and services, (2) the coordination of care and services, and (3) the funding of care and services. Finally, the macro level represents policies and reforms of our health systems. The analysis in different countries of the influence of the provision, coordination, funding of services and of health policies and reforms on the social integration of people with SMI would be nice but would deserve another thesis. Therefore, this chapter presents a more specific analysis of the Belgian context as well as comparisons with other international contexts.

Figure 15: The social integration of people with SMI, a system level approach



Developed for the purposes of this thesis.

8.3.1 Provision and use of care and services

Provision and use of services are two close but distinct concepts. The provision involves the large-scale implementation of evidence-based interventions and practices that support the social integration of people with SMI. Use implies making them accessible within a reasonable timeframe to the target audiences. It is important to take these two concepts into account together because, as previously explained, even if interventions are implemented and provided, they may not reach or be accessible for all people with SMI and the expected outcomes will not be achieved. Indeed, our studies in **Chapter 2 and 4** put forward a potential fifth dimension of the social exclusion of people with SMI, namely services exclusion (i.e. not all people with SMI may have access to adequate health and social services). In my opinion, ensuring adequate provision and use of services and interventions involves two main questions: for whom (for which target groups) and by whom (with what types of services)?

Target groups

The results of the study presented in **Chapters 2 and 3** suggest that the policies and reforms put in place between 1997 and 2018 in Belgium improved the social integration of people with moderate mental illness but not that of people with SMI. In addition, a recent case-control study on the effectiveness of the Belgian mental health care reform highlighted that greater exposure to the reform was associated with a slight improvement in the perceived continuity of care of people with SMI, but not with their social integration and other outcomes [6]. In my opinion, this may be linked to a process of selection or exclusion of certain patients in the Belgian context and with the absence of target groups in the organisation of mental health care. The current Belgian mental health care reform targets mainly the whole population with mental health needs and does not propose different organisational mechanisms or services according to target groups, except for age groups (child and adolescent psychiatry, adult psychiatry, and elderly psychiatry) or for specific audiences such as mentally ill offenders. However, the lack of definition of target groups within the framework of the reform can leave an extensive autonomy to the different services and providers in selecting their patients, with a risk of excluding the most vulnerable patients such as people with more complex needs and severe mental illness. We therefore face a paradox because the main argument put forward for not defining people with SMI as a specific target group requiring specific services and care circuits is the fear of reinforcing their social exclusion. However, this lack of a target group can actually reinforce their social exclusion.

Some specific services and interventions should have one or more target groups who are most likely to benefit from them. For example, a case-manager may be of interest for someone without sufficient capacity for navigating the care system, such as someone with a complex and severe mental illness, whereas it is a costly and counterproductive intervention for someone who is able to navigate the health care system on his own. Another example are the mobile teams implemented since 2010 as part of our mental health care reform and inspired by the Assertive Community Treatment (ACT) model. While the ACT model is a specific intervention for people with SMI [46], the Belgian mobile teams were developed as a generic service as part of a reform programme for the whole adult population with mental health needs [3]. However, moving from a specific service to a generic service can lead to the exclusion of the excluded. Indeed, a study conducted with data from the first evaluation of the Belgian mental health care reform in 2010 had shown that patients with the lowest level of social integration were not targeted for care by clinicians from different services, including mobile teams [47]. Another example of the impact of the lack of target groups is our use of psychiatric hospitalisations. In the European COFI research project I contributed to, the inclusion of patients in the study was performed in psychiatric hospitals in five countries (the UK, Poland, Germany, Italy, and Belgium) and one of the patient inclusion criteria was to have a main diagnosis of psychotic (F20-29), mood (F30-39), or anxiety and somatoform disorder (F40-49), according to the ICD-10 classification. These diagnostic categories were considered to be the most common severe psychiatric illnesses and therefore the most likely to be hospitalised in psychiatric wards. The inclusion results, which have not been published, were that only 38.3% of patients in psychiatric hospitals in Belgium had these diagnoses and were eligible for the research project, compared to 70.5% in Italy, 67.8% in the UK, 55.6% in Germany, and 50.3% in Poland. In addition, a study published with data from the COFI project showed that patients with these diagnostic categories and hospitalised in Belgium had on average a severity of psychiatric symptoms that was lower than in the other four countries [48]. These results suggest that in Belgium compared to other European countries, we tend to hospitalise in psychiatric wards patients with less severe symptoms and diagnosis who could possibly be cared for in the community.

Finally, the study we performed as part of the 2019 evaluation of the organisation of mental health care for adults in Belgium (KCE-HSR52 study) led by the Belgian Health Care Knowledge Centre highlighted that individuals with complex mental health and social issues were more likely to be "forgotten", have less access to some services such as employment support, low threshold services, affordable long-term housing facilities, and psychotherapy services [49].

Taken together, these results may highlight the need to rethink the priorities in terms of target groups in mental health care in Belgium. Indeed, another important result of the KCE-HSR52 study was that Belgian stakeholders supported a relatively different organisation of mental health care depending on the target group [49]. This is supported by Leutz's laws of care integration, the integration of care being a mechanism among others of the organisation of care: « *you can integrate all of the services for some people, some of the services for all of the people, but you can't integrate all the services for all of the people.* » [50]. According to this theory, a way of organising care can be adapted to a small number of services for the whole population, to all services for a specific target group, but not to all services for the whole population. The lack of target groups in the organisation of mental health care tends to be unfavourable for the most vulnerable and also has repercussions throughout the system. Indeed, defining target groups could allow a better use of the various services and thus prevent some services from being on waiting list because of over-consumption or misused.

However, the very definition of a severe mental illness remains disputed. As highlighted in the literature review in **Chapter 1**, the definition that seems to have the most consensus is that of the National Institute of Mental Health (NIMH) [51] which categorises individuals as having a SMI if they met three criteria: (1) having a diagnosis of non-organic psychotic or personality disorders, (2) duration (i.e. prolonged illness and long-term treatment), and (3) having disabilities as a result of the disease. This definition puts forward the psychiatric diagnosis, which would therefore be the entry point of a specific service or care circuit for people with SMI. From my point of view, the importance given to psychiatric diagnosis is also present in Belgium, however, the operationalisation in the organisation of mental health care of the previously mentioned NIMH definition of SMI proved to be controversial. Indeed, restricting the definition to diagnosis of non-organic psychotic or personality disorders is criticised because people with other psychiatric diagnoses may have severe forms and need care and services specific to people with SMI [52]. The long-term criterion is also criticised because in modern mental health care, people with moderate mental health disorders can also receive care for years without their illness having been in severe form at any time [52]. In the Netherlands, another definition has been developed in order to better organise the provision and funding of mental health care by developing specific care circuits for different target groups, including people with SMI [52]. Concretely, a person is included in the SMI group when: there is a psychiatric disorder (without restriction depending on the diagnosis) which is not in remission and therefore requires care; which is the cause or consequence of serious limitations in social functioning; is not transitory (at least a few years); and requires coordinated care with different providers. This definition tends to place more emphasis on social and functional dysfunction and care needs, rather than on psychiatric diagnoses. The basis of my motivation for doing this thesis was to highlight the importance of social integration, and therefore social determinants, in the care and recovery of people with SMI. The first step would therefore consist in recognising social exclusion as a main criterion in the definition of SMI, and therefore in the organisation of specific services and care circuits for people with SMI. Indeed, in recently developed evidence-based interventions specifically for people with SMI, such as the Individual Placement and Support and the Housing First models, the entry point is their social exclusion (i.e. unemployment or homelessness), not their psychiatric diagnosis.

Recommendation 2: Different target groups requiring specific care mechanisms and services must be defined within the framework of the organisation of mental health care in Belgium
Targeted audiences: Taskforce mental health, federal and federated health authorities

Types of services

What types of services should be provided for a socially inclusive mental health system? The social integration of people with mental illness was supported in many western countries by reforms in the organisation of mental health care with a transition from institutional psychiatric care to community care. Some people with severe and chronic mental illness and complex health and social needs may require longer hospital stays to adapt to psychotropic medication, stabilise symptoms, manage suicidal ideation or aggressive behaviour, and plan hospital discharge and community follow-up [53, 54]. However, one of the consequences of excessive length of stay and readmissions in psychiatric hospital is the “social breakdown syndrome” in which people with mental illness experience community and social withdrawal, exclusion from typical social roles, and a decline in their social integration [55, 56]. Indeed, the main finding of the study in **Chapter 5** was that having a long stay in a psychiatric ward was associated with a decrease in the social integration of people with SMI. Therefore, the approach taken in many countries has been to devote psychiatric hospitalisations to acute care only (i.e. as short as possible and as a last care resort) and to invest in and develop community services that can provide personalised support, minimise hospital use, and increase user access and participation in key activities of the society. Belgium is no exception to this trend because since 2010, the objectives of our mental health care reform were to further orient care towards the community with a reduction in hospital care to support patients' clinical recovery and social integration [3].

Put simply, a socially inclusive mental health system should both limit the use of hospitalisations and offer adequate community alternatives. However, the Belgian mental health care system tends to be hospital-centred. In Belgium, the process of deinstitutionalisation began around 1975 but was far from being complete in the 2000s; in 2008, the per capita psychiatric bed rate per 100,000 population was the second highest in Europe (153/100,000) [2]. Despite the reform that started in 2010, the number of days of psychiatric hospitalisation per inhabitant even increased between 2000 and 2016 (from 305 per 1000 inhabitants in 2000 to 351 in 2016) [57]. Another study published in 2018 based on data from the European COFI research project on which I worked showed that the average length of stay in psychiatric ward of a sample of 1043 Belgian adults with psychiatric disorders was 55 days (SD = 62.4, median = 36) and longer than for people with similar profiles in Italy, Germany, Poland, and the UK [48]. The difficulty of reducing the use of psychiatric hospitalisations is visible in other countries. An international comparison of the progress of deinstitutionalisation policies found that hospital closure was still in an early stage in 21 out of 30 European countries in 2016 [58]. Another study also drew attention to forms of reinstitutionalisation in some countries, i.e. an increase in the number of involuntary hospital admissions and places in forensic institutions and supported housing, to replace the beds that were closed in psychiatric hospitals [59]. As I explained previously, limiting the use of psychiatric hospitals requires that community alternatives be provided to meet the mental health needs of the population. However, a qualitative study conducted as part of the 2019 evaluation of the organisation of mental health care for adults in Belgium highlighted that Belgian stakeholders emphasised the lack of low-threshold services without admission criteria, limited access to psychotherapy services, and the inadequacy and insufficiency of housing facilities, especially for the most vulnerable and complex groups [60]. In Belgium, the difficulties in finding places within a reasonable timeframe in some community services may also explain the results previously mentioned showing that compared to other European countries, we tend to hospitalise in psychiatric wards patients with less severe symptoms and diagnosis who should be cared for in the community. I allow myself in this discussion to write a quote: *"If people perceive the psychiatric hospital as one of the only solutions to their problems, they are likely to seek the same solution to subsequent problems."*. In other countries, the closure of psychiatric hospital beds in a context of deinstitutionalisation has not always been followed by an increase in the number of community alternatives [61, 62] and some authors have explained that deinstitutionalisation policies have had perverse effects on people with SMI with an increase in homelessness and imprisonment, and the emergence in the remaining psychiatric hospital of a "revolving door" admission phenomenon and new "long stays" patients [61, 63-65]. These various observations lead us to recommendation 3.

Recommendation 3: Efforts to shift psychiatric hospitalisations to acute care should be continued and accompanied by a strengthening of the provision of community services and condition of access to care for people with more severe and complex mental health and social conditions
Targeted audiences: Federal and federated health authorities, mental health services networks, (mental) health and social care services

8.3.2 Coordination services and providers and continuity of care

The coordination of the various services and providers around people with SMI and the continuity of their care are also key elements to support their social integration. Indeed, the multidimensional nature of social integration implies that a comprehensive approach requires the involvement of multiple providers from the sectors of health, mental health, social, education, justice, etc. We could postulate that the way in which our health and social systems have evolved over the past decades, with the specialisation of different professionals and services, has fragmented our approach to patients and their social integration. While specialisation stimulates innovation and the development of cutting-edge practices and interventions, it may also be a vector of fragmentation. For example, I have often witnessed as a care professional that during a patient's stay in a psychiatric hospital, the dimensions of employment and housing concerned the social worker, the dimensions of leisure activities concerned occupational therapists, and clinical dimensions concerned mental health professionals (e.g. psychiatrists, psychologists, and psychiatric nurses). Whether within a service or between several services and providers, continuity of care is therefore important to avoid a fragmented approach to social integration. Continuity of care is all the more important for people with SMI as their clinical and social situation can limit their ability to coordinate their different providers [5, 66]. Indeed, people with SMI are more likely to experience fragmentation and lack of continuity of care as highlighted in the literature [50, 67, 68].

As explained in **Chapter 4** of this thesis, different approaches to improve the continuity of care for people with SMI have been developed in several countries, including Belgium. In Belgium, improving continuity of care is one of the objectives of the mental health care reform launched in 2010 and a study has shown that greater exposure to the reform was associated with a slight improvement in the perceived continuity of care of people with SMI ($\beta = 1.27$, $p < 0.01$) [6]. However, it seems that efforts should be continued. In 2019, the quantitative study that we conducted as part of the evaluation of the organisation of mental health care for adults in Belgium highlighted that the priority objective of the reform, according to the stakeholders of the three regions, was to ensure continuity between the different sectors and services (health, mental health, social). This paragraph brings us to recommendation 4.

Recommendation 4: The multidimensional nature of the social integration of people with SMI implies that it is based, among other things, on the continuity of care between the multiple services and providers involved in their care pathway. Therefore, continuity of care between sectors and services (health, mental health, social) should be considered as a priority in the organisation of mental health care for adults in Belgium

Targeted audiences: Mental health services networks, (mental) health and social care services

The coordination of the different services and providers around the patient also requires that their roles and missions be clearly defined. As explained in **Chapter 6** of this thesis, the Belgian health care system is a regulated-market, social insurance-based system characterised by a substantial level of corporatism in policy decision-making. Although the provision, coordination, and funding of care are the responsibility of the political authorities, these responsibilities tend to be delegated to semi-public institutions in which stakeholders, such as representatives of professionals and services, have a high level of bargaining power and can defend their particular interests [1]. One of the mechanisms of the 2010 mental health care reform was to develop, on a geographical basis, networks of services which must provide five care functions in their geographical area: (1) prevention and early detection, (2) outreach, (3) recovery and social integration, (4) intensive in-patient treatment, and (5) specific housing and long-term facilities. However, the types of services that must provide each of these five functions have not been systematically or clearly defined by the authorities and the bottom-up approach of the reform implementation left extensive autonomy to various services and providers in defining their missions and roles. The Belgian mental health system is therefore often put forward positively for its diversity and its many local experimental projects, on the one hand, and negatively for its gaps and overlaps in the provision of care as well as disparities in care practices, on the other. For example, although psychiatric hospitals are implicitly identified with function 4 “intensive in-patient treatment”, some hospitals identify their role and missions with other functions and have divergent care practices. In 2019, I had the opportunity to evaluate the work of a master's student in public health who aimed to analyse the care practices within a psychiatric hospital in Belgium. This student reported that this hospital identified primarily with a “recovery” mission and often provided long hospital stays during which they supported patients in the development of daily life skills such as shopping, cooking, managing their money, etc. To support this argument with a more empirical study, the qualitative study conducted as part of the 2019 evaluation of the organisation of mental health care for adults in Belgium showed that stakeholders reported a lack of clarity of the roles and missions of mental health providers, particularly community mental health centres and mobile teams [60]. According to stakeholders, this lack of clarity leads, on the side of services users and their relatives, to a difficulty of identification of the adequate providers according to their needs and, on the side of providers, to inappropriate patient referrals and coordination issues. A direct consequence on the overall mental health system being the over-consumption and misused of services. However, the quantitative and qualitative studies of this research project revealed results around the theme of coordination which may seem paradoxical. The quantitative study we conducted showed that the coordination between providers was considered by stakeholders as one of the most important dimensions of the organisation of mental health care in Belgium and that it was important to strengthen it [49]. However, the qualitative study highlighted that many stakeholders do not want to formalise and standardise their practice and collaboration, although they recognise the complexity of our mental health landscape and the lack of clarity of services’ missions and roles [60]. The more in-depth analysis of the qualitative material revealed that formalisation and standardisation are sometimes associated to the ongoing reforms and viewed as threatening individual creativity and autonomy. These observations lead us to two conclusions and to recommendations 5 and 6. First, such negative representations of tools for formalising and standardising coordination between providers are not shared by all stakeholders, therefore, these tools and their impact on practices and coordination between providers must be clarified. Second, Belgium is a country of compromise. It would therefore be possible to formalise the roles and missions of the various services and providers, while leaving them creativity and autonomy over the means to achieve them.

Recommendation 5: Tools and interventions to strengthen coordination between providers should be funded, implemented, and evaluated

Targeted audiences: Federal and federated health authorities, mental health services networks, (mental) health and social care services

Recommendation 6: The roles and missions of mental health services and providers should be clarified and formalised while leaving them creativity and autonomy over the means to achieve them

Targeted audiences: Mental health services network, federal and federated health authorities

8.3.3 Funding of care and services

Funding mechanisms are a key dimension of any (mental) health care system because they determine how resources are allocated between services and providers and can both facilitate or hinder the achievement of the policy goals pursued by the authorities, such as the social integration of people with SMI. For example, the overall funding mechanism to pay for psychiatric inpatient care in Belgium has not changed that much since the 2010 mental health care reform and remains, basically, a per diem system for inpatient services. As previously explained, one of the goals of the reform is the intensification of psychiatric hospitalisations (i.e. reduction of admissions and length of stay in psychiatric wards). This goal is consistent with the social integration of people with SMI, because as shown in **Chapter 5**, longer length of stay in psychiatric ward is associated with a decrease in their social integration. However, the study in **Chapter 6** highlighted that this goal was supported by policymakers but not by service managers, possibly because the reduction of the length of stay in hospitals may also reduce the hospital's income, which is a concern of hospital managers. In addition, our study found that service managers perceived themselves as the most influential stakeholders in the organisation of mental health care, particularly compared to policymakers. This divergence in relation to policy priorities between policymakers and managers and the latter's perceived high level of influence could, therefore, explain the difficulty of implementing some policy goals of the reform, such as the intensification of psychiatric hospitalisations. As a reminder, the number of days of psychiatric hospitalisation per inhabitant even increased between 2000 and 2016 (from 305 per 1000 inhabitants in 2000 to 351 in 2016) [57]. Taken together, these results indicate that our funding mechanism of inpatient care may lead to over-utilisation of and long lengths of stay in psychiatric hospitals, as well as difficulties in achieving the transition to community care. Thus, this funding mechanism may end up jeopardising the social integration of people with SMI.

The qualitative study conducted as part of the 2019 evaluation of the organisation of mental health care for adults in Belgium showed that stakeholders acknowledge that the ongoing shift toward community mental health care requires rethinking resources' allocations across the system and mechanisms of payment of providers [60]. Indeed, stakeholders raised the issue of the lack of resources of outpatient services and primary care providers compared to the inpatient sector. This goes against a general objective of social integration of people with SMI because as previously explained, a socially inclusive mental health system should both limit the use of hospitalisations and offer sufficient adequate community alternatives. For example, the shortage of psychiatrists and psychologists in outpatient services is worsening because of the disparities in remuneration, related to differences in payment mechanisms, of these professionals in outpatient services compared to the inpatient sector. Another important paradox highlighted by stakeholders is that, in a context of reform aimed at community care, the development and funding of mobile teams remains in the hands of the inpatient sector. Indeed, the basic funding mechanism of the reform was to convert part of the financial resources devoted to long-term psychiatric beds into means for developing mobile teams [3]. This paradox was already highlighted during the first evaluation of the reform program in 2010 [5].

There is room for change. The conjoint analysis we performed as part of the quantitative study revealed that stakeholders were ready to consider an episode-based payment of providers and a pooling of financial resources for a set of services at the network level [49]. These results indicate a major change in the Belgian context because the current dominant payment mechanism of providers is activity-based and the resources are mainly pooled at the level of each service or provider individually. The scientific literature emphasises that an activity-based payment of providers does not favour continuity within the network (patient retention) [69, 70]. However, the multidimensional nature of social integration implies that a comprehensive approach requires the involvement of multiple providers from the sectors of health, mental health, social, education, justice, etc. Stakeholders explained during the qualitative interviews that the pooling of financial resources at the local (network) or regional level would be more consistent with the current transitions in the organisation of mental health care in Belgium [60]. This chapter on funding and payment mechanisms brings us to recommendation 7.

Recommendation 7: The funding and payment mechanism of mental health care providers and services should be reviewed to align with the goals of the reform in the organisation of mental health care

Targeted audiences: Federal and federated health authorities

8.3.4 Policies

The central component of the social integration of people living with mental illness is their participation in society, and this participation also applies to policy and health care decision-making (e.g. user participation in the planning and delivery of services). Indeed, many authors suggest that a socially inclusive system requires greater involvement and participation of services users in decision-making, inducing a paradigm shift in the relationship between them and professionals [71-73]. Different approaches exist to increase this participation, such as the presence of user and family representatives in the administrative boards of services and in local and national decision-making bodies, and to involve them in decisions, recruitment and training of professionals, evaluation and research, etc. However, although the participation of user and family representatives in policy and health care decision-making is on the political agenda in many countries [74, 75], several studies have shown that their full participation remains a challenge and that there is little consensus on their role, on the extent of their participation or even on the aims of such participation and the process for achieving it [76-78]. The study presented in **Chapter 6** showed that, in Belgium, user and family representatives perceived themselves as the least influential stakeholders in the organisation of mental health care. In addition, regardless of the mental health policy goals around which stakeholder coalitions were formed and the structure of policy priorities of each coalition, the policy goal of involving users in the development and provision of services was often peripheral. For example, while the policy goal of supporting users to develop their life goals was central in a coalition mostly made up of service managers, the goal of involving users in the development and provision of services was the most peripheral. Some studies have shown that mid-level managers weigh the implementation of policies against their local management agenda (i.e. funding of their institution, staff management, organisation of activities, and performance) [79-81]. Our interpretation is therefore that, for service managers, involving users in the development and provision of services may induce organisational and management constraints, so that these considerations run counter to their central goal of personal recovery and social integration of users. This brings us to recommendation 8.

Recommendation 8: Strengthen and define the participation and involvement of service users and their families in policy and care decision-making

Targeted audiences: Federal and federated health authorities, Taskforce mental health, mental health services networks, (mental) health and social care services

As previously explained, the social integration of people with SMI relies, among other things, on the coordination of the multiple services and providers involved in their care pathway. This coordination is based on a common understanding of the objectives sought. However, the mental health sector is characterised by a multitude of stakeholders with different professional profiles and there is little consensus among them on the etiology of mental illnesses, the definition of recovery, treatment approaches, and appropriate quality of mental health care [82]. For example, although the concept of recovery is a central component of mental health practices and policies since the early 2000s, researchers have identified seven recurring misuses of the concept (labelled as “abuses” by the authors): (1) recovery is the latest model; (2) recovery does not apply to “my” patients; (3) services can make people recover through effective treatment; (4) compulsory detention and treatment aid recovery; (5) a recovery orientation means closing services; (6) recovery is about making people independent and normal; (7) and contributing to society happens only after the person is recovered

[83]. This observation can be made for other mental health policy goals than recovery. In Belgium, a content analysis of the policy blueprint of the 2010 mental health care reform noticed that the policy goals of the reform were quite broad and ambitious [5]. In addition, the qualitative study conducted as part of the 2019 evaluation of the organisation of mental health care for adults in Belgium highlighted a diversity of stakeholder reactions to a clinical vignette embodying two goals of the reform, individual autonomy and social integration of users, demonstrating considerable variation in the understanding of these goals [60]. This evaluation also concluded that the intensification of inpatient care (short psychiatric hospitalisation) has remained a controversial policy goal since the beginning of the reform in 2010 [84] and that many stakeholders do not perceive it as a goal to be achieved but rather as means to achieve the other policy goals of the reform (i.e. community care, users' social integration and personal recovery) [49]. We come to recommendation 9.

Recommendation 9: The objectives and underlying concepts of mental health policies in Belgium should be better defined and clarified by all the authority levels with responsibilities in mental health care

Targeted audiences: Taskforce mental health, federal and federated health authorities

One thing is understanding the policy goals, the other is their endorsement by stakeholders. As explained in **Chapter 6**, disagreements within the policy community and between the policy community and other stakeholders have frequently been identified as a factor explaining failures in the implementation of public policies [85, 86]. Furthermore, recurrent tensions and ambiguities in mental health reforms (see Chapter 6) have enabled the most powerful stakeholders to protect their particular interests [87], so that the effectiveness of a reform's implementation is also related to the stakeholders' endorsement of its goals and programme [88, 89]. The study in **Chapter 6** identified four main stakeholder coalitions endorsing different mental health policy goals of the Belgian reform and bringing together stakeholders with similar professional functions in the mental health care system. The modelling of these coalitions revealed a divergence in priority policy goals between service managers and policymakers. The two coalitions mostly composed of policymakers supported a comprehensive approach that combines the different policy goals and also supported the shortening of hospital stays, whereas the two coalitions mostly composed of service managers emphasised the personal recovery and social integration of users and continuity of care. This finding is important for policy development and implementation. Indeed, although reform programmes and goals are often devised by policymakers, their implementation is largely shaped by mid-level managers, who have the most influence in practice [90]. This is described by Lipsky [91] in policy implementation research as "street-level bureaucracy", emphasising the central role of frontline staff in putting policy into action. This is probably reinforced by the Belgian context because, as previously explained, the Belgian health care system is characterised by a substantial level of corporatism in policy decision-making and the mental health care reforms of recent decades have mainly been developed using a bottom-up approach [1, 4, 92], thus leaving extensive autonomy, bargaining power, and influence to stakeholders such as service managers. This divergence in relation to policy priorities between policymakers and managers could, therefore, explain the difficulty to implement the reform and achieve the expected policy goals. In the context of a bottom-up policymaking, as in Belgium, these results may highlight the importance of mobilising and bringing together policymakers, service managers, and other stakeholders in the different stages of policy development and implementation. For example, in Canada, Ontario's 2011 Mental Health and Addictions Strategy placed more emphasis on stakeholder engagement and established policy networks which brought together people from government ministries and stakeholders representing different individual and collective interests, such as researchers, service managers, professional associations, and consumer groups [93]. It is important to specify that the various stakeholders must be brought together to implement a common goal, but that it is up to parliamentarians to define it, because they are the only ones with democratic legitimacy. Another result of the study in **Chapter 6** was that the policy goal of treating users in their community was a relatively central policy goal in the different stakeholder coalitions. Since central goals are strongly related to political decision-making, this goal could, accordingly, be emphasised in order to reach consensus between competing stakeholders coalitions. These various observations lead us to recommendation 10.

Recommendation 10: In our context of bottom-up mental health policy, it is important to mobilise and bring together all stakeholders, particularly policymakers and service managers, in the various stages of the policy development and implementation in order to identify converging goals and interests

Targeted audiences: Federal and federated health authorities, Taskforce mental health, mental health services networks, (mental) health and social care services

Finally, in Belgium as in other countries, the social integration of people living with mental illness requires actions at the national and local levels and therefore political coordination between national and local authorities. One example among others is the fight against sigma and discrimination of mental illness which, according to Graham Thornicroft, requires actions at the local and national levels [38]. In Belgium, the sixth reform of the Belgian state in 2011 led to a significant shift of competences from the federal state to federated authorities (communities and regions), particularly in the domain of mental health care. The mental health care reform process and the funding of the psychiatric inpatient facilities remain a federal competence whereas outpatient mental health and social services are now reporting to regional authorities. Employment policies are also mainly regional and each region has a reference body for unemployment benefits, training and job search (i.e. Actiris for the Brussels-Capital region, VDAB for the Flemish region, and the Forem for the Walloon region). These local political competences, combined with regional differences such as population density or economic growth, are therefore likely to influence the social integration of people living with mental illness. The study in **Chapter 3** highlighted differences in the social integration of people with mental illness between the three regions of Belgium and that these differences tend to increase over time, to the detriment of people living in the Brussels-Capital region compared to Wallonia and Flanders. It is not excluded that the context of decentralisation and the transfer of competences to the federated authorities is linked to the increase over time of regional differences in terms of social integration. Some local contexts may therefore need different strategies for organising mental health and social care and autonomy to implement them in order to prevent inequalities between regions from widening. Indeed, the results of the quantitative stakeholder analysis that we performed as part of the 2019 evaluation of mental health care in Belgium revealed clear local differences regarding expectations and needs in the organisation of mental health care [49]. For example, stakeholders in Flanders favoured an integration at the network level both in term of provision, coordination and funding of services, while stakeholders in Wallonia wished to preserve the operating and funding autonomy for each service or provider individually. It is in this “local” logic that the 2010 reform was developed with a bottom-up approach, giving each geographical area the autonomy to set up a network of services considering the resources and services available in the area and the mental health needs of its population. However, the current governance of the networks may be too weak to be effective and allow local autonomy (e.g. no funding competence), as evidenced in the previous results of the reform evaluation [5, 94]. The context of decentralisation of mental health competences in Belgium therefore requires, on the one hand, coordination between local and national authorities and, on the other, local autonomy and governance in the organisation of mental health care. These observations bring us to the last two recommendations 11 and 12.

Recommendation 11: Federal and federal authorities responsible for (mental) health care, welfare and social affairs must coordinate and jointly pursue current mental health policies
Targeted audiences: Federal and federated health authorities, Taskforce mental health

Recommendation 12: In the current context of decentralisation of political competences, an organisational model allowing local autonomy and governance in the organisation of mental health care should be favoured
Targeted audiences: Federal and federated health authorities, mental health services networks

8.4 Summary of recommendations and avenues for action in Belgium: The Twelve Labours of Hercules

The aim of this chapter is to summarise the 12 recommendations developed within the framework of this thesis and to propose concrete avenues for action for Belgium. To find the scientific rationale for these recommendations, please read both sections **6.2** Assessment of the social integration of people with severe mental illness: let's visualise the elephant and **6.3** Social integration of people with severe mental illness: from the provision of services to policies.

Recommendation 1: Improve the collection, encoding, and centralisation of data on mental health care
Targeted audiences: Federal and federated health authorities, federal centres of expertise (KCE, Sciensano), regional centres of expertise (CRESAM, VVGG - Vlaamse Vereniging voor Geestelijke Gezondheid, Observatoire de la Santé et du Social), and universities and research institutes
Avenues for action: **(a)** The competent authorities must optimise the collection, encoding and centralisation of three different types of mental health data: 1) psychiatric epidemiology (distribution and determinants of mental health problems and disorders in the Belgian population), 2) mental health care use (use of services and providers and consumption of medication under medical prescription), and 3) provision of mental health services (up-to-date register of the mental and social health care offer with the nature of the care offer, target groups, admission criteria, availability and waiting time, contact details, etc.). This approach can be part of the Belgian e-health action plan[6]. **(b)** Implement a tool to assess and monitor the social integration of people with mental illness in routine clinical practice. Such a tool could be implemented in the current tool for collecting patient data in psychiatric hospitals and psychiatric wards in general hospitals (i.e. Résumé Psychiatrique Minimum), but also in outpatient services of a given territory (e.g. based on geographical territories defined during our mental health care reform). **(c)** Improving the collection, encoding, and

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[6] https://www.health.belgium.be/fr/plan-dactions-e-sante-2019-2021

centralisation of data on mental health care is also an opportunity to develop a comprehensive framework for evaluating and monitoring mental health services. Data on mental health care could help identify key evaluation indicators that are relevant and practical and meet the need for a rigorous evaluation framework for monitoring service performance and quality of care.

Recommendation 2: Different target groups requiring specific care mechanisms and services must be defined within the framework of the organisation of mental health care in Belgium

Targeted audiences: Taskforce mental health, federal and federated health authorities

Avenues for action: **(a)** There is a need to rethink the priorities in terms of target groups in mental health care in Belgium to prevent people with complex mental and social health problems from being “forgotten”. Some specific services and interventions should have one or more target groups who are most likely to benefit from them. For example, a case-manager may be of interest for someone without sufficient capacity for navigating the care system, whereas it is a costly and counterproductive intervention for a patient able to navigate the health care system on his own. **(b)** Social exclusion must be recognised as a main criterion in the definition of SMI, and therefore in the organisation of specific care services and circuits for people with SMI. Indeed, in recently developed evidence-based interventions specifically for people with SMI, such as the Individual Placement and Support and the Housing First models, the entry point is their social exclusion (i.e. unemployment or homelessness), not their psychiatric diagnosis. **(c)** More specifically, access to the following services should be strengthened for people with complex mental and social health problems: employment support, low threshold services, affordable long-term housing facilities, and psychotherapy services. Care circuits are an adequate tool to achieve this objective. A care circuit is as a specific organisational package available for a defined target-group of patients. It may include specific access criteria, information exchange tools, and specific mechanisms for allocating resources and financing interventions and services.

Recommendation 3: Efforts to shift psychiatric hospitalisations to acute care should be continued and accompanied by a strengthening of the provision of community services and condition of access to care for people with more severe and complex mental health and social conditions

Targeted audiences: Federal and federated health authorities, mental health services networks, (mental) health and social care services

Avenues for action: **(a)** The reduction in lengths of stay and admissions to psychiatric hospitals must be accompanied by an increase in community alternatives in order to avoid overuse of psychiatric emergency services and involuntary hospitalisations. The provision of community primary health and social care services (psychologists, psychiatrists, general practitioners, community mental health services, social assistance services, outreach teams, etc.) must be strengthened and be accessible and affordable. To this end, the competent authorities should strengthen legislation and funding for the development and accessibility of community mental health care and to improve the continuity between inpatient and outpatient treatment. **(b)** Institutional alternatives to psychiatric hospitalisations such as sheltered accommodations (Initiatieven Beschut Wonen-IBW – Initiatives d’Habitations Protégées-IHP) and psychiatric care homes (Psychiatrisch Verzorgingstehuis-PVT – Maison de Soins Psychiatriques-MSP) must also be strengthened (i.e. support and increase the supply of services). **(c)** Specific vocational and rehabilitation services for people with more severe and complex (mental) health and social issues should be supported, e.g. peer support, employment support (Individual Placement and Support - IPS), and housing support (Housing First).

Recommendation 4: The multidimensional nature of the social integration of people with SMI implies that it is based, among other things, on the continuity of care between the multiple services and providers involved in their care pathway. Therefore, continuity of care between sectors and services (health, mental health, social) should be considered as a priority in the organisation of mental health care for adults in Belgium

Targeted audiences: Mental health services networks, (mental) health and social care services

Avenues for action: **(a)** The decentralisation of several health and social competencies from the federal state to federated entities and the development of the mental health care reform with a bottom-up approach induces fragmentation both at the level of decision-makers and in mental health care. In this context, continuity of care across multiple services and providers must therefore be strengthened at the local level. For example, in each geographical territory defined during the mental health care reform, (1) having clear rules regulating referrals between services and a clear information about these rules provided to the patient, (2) having tools to share patient information between services, and (3) having a local care provider responsible for deciding which services are required. Indeed, the service networks that were established on a geographical basis by the Belgian reform offer an opportunity to strengthen the capacity for such regulation at the local level. **(b)** Local networks should include the whole range of (health and social) in-and-outpatient services, public and private, that are likely to be involved in the care pathway of patients. Particularly, primary care and social care services should not be left aloof.

Recommendation 5: Tools and interventions to strengthen coordination between providers should be funded, implemented, and evaluated

Targeted audiences: Federal and federated health authorities, mental health services networks, (mental) health and social care services

Avenues for action: **(a)** Formalisation and standardisation are sometimes associated to the ongoing mental health care reforms and considered by some stakeholders as a threat to the creativity and autonomy of services and providers. Such negative representations are not shared by all stakeholders, therefore, these tools and their impact on practice and coordination between providers must be clarified. **(b)** One of the main tools and prerequisite of collaboration-coordination between services and providers is the exchange of information. Previous research in Belgium has highlighted the willingness of stakeholders to set up a system for sharing information between (mental) health and social services as well as to work on existing procedures to standardise and simplify them [95]. However, issues of preserving the anonymity and confidentiality of user information and sharing care information between (mental) health care services and the patient should be discussed beforehand. An example among others of a system for recording and sharing clinical information between health and social services is the interRAI system and the Belgian version BelRAI[7]. **(c)** Another tool is the "access and referral services" which could be developed in Belgium or this mission could be entrusted to an existing type of service. These services are the entry point into care and aim to guide people with mental health needs to appropriate and timely services. These services allow better use of the various services according to user needs and thus prevent certain services from being on a waiting list due to overconsumption or misuse. **(d)** Federated entities, which are responsible for education, should consider the development of coordination-collaboration roles and tools into the framework of education programmes and training, e.g. in universities, high schools, and permanent training programmes, in particular in medicine and psychiatry, psychology, nursing, and social working teaching programmes.

Recommendation 6: The roles and missions of mental health services and providers should be clarified and formalised while leaving them creativity and autonomy over the means to achieve them

Targeted audiences: Mental health services network, federal and federated health authorities

Avenues for action: **a)** As previously explained, formalisation and standardisation are sometimes associated to the ongoing mental health care reforms and considered by some stakeholders as a threat to the creativity and autonomy of services and providers. However, formalisation is required to improve the visibility of the care supply at the local level (e.g. network level). In this context, the competent authorities should formalise the roles and missions of services and providers, particularly community mental health centres and

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[7] https://www.ehealth.fgov.be/fr/esante/professionnels-de-la-sante/belrai-20

mobile teams, while leaving them creativity and autonomy over the means to achieve them. **(b)** The formalisation of roles and missions must be accompanied by changes in the funding of the different services, in order to align the resources granted and the payment mechanism with the missions to be carried out. Indeed, some services, mainly in the outpatient sector, are currently underfunded (see recommendation 7).

Recommendation 7: The funding and payment mechanism of mental health care providers and services should be reviewed to align with the goals of the reform in the organisation of mental health care

Targeted audiences: Federal and federated health authorities

Avenues for action: **(a)** Belgian stakeholders acknowledge that the ongoing shift toward community mental health care requires rethinking resources' allocations across the system and mechanisms of payment of providers, so there is room for change. **(b)** In terms of resource allocation, there is a lack of resources of outpatient services and primary care providers compared to the inpatient sector. An important paradox highlighted is that, in a context of reform aimed at community care, the development and funding of mobile teams remains in the hands of the inpatient sector. The competent authorities must therefore review the allocation of resources between services in order to align them with the goals of the reform in the organisation of mental health care. **(c)** There may also be a conflict between the objectives to be achieved and the mechanisms of payment of providers and services. For example, the overall funding mechanism to pay for inpatient care has not changed that much since the 2010 reform and remains, basically, a per diem system for inpatient services. However, per diem system may lead to over-utilisation and long lengths of stay, beyond what is necessary. Another example is the shortage of psychiatrists and psychologists in outpatient services due to disparities in remuneration, related to differences in payment mechanisms of these professionals in outpatient services compared to the inpatient sector. Therefore, the payment mechanism of mental health care providers and services should also be reviewed to align with the goals of the reform in the organisation of mental health care. The experience of several OECD countries on episode-based payment mechanisms, rather than the activity-based payment mechanisms which are dominant in Belgium, deserves to be considered in this regard.

Recommendation 8: Strengthen and define the participation and involvement of service users and their families in policy and care decision-making

Targeted audiences: Federal and federated health authorities, mental health services networks, (mental) health and social care services

Avenues for action: **(a)** Different approaches can be put in place to strengthen the participation and involvement of service users and their families in policy and care decision-making, such as the presence of user and family representatives in the administrative boards of services or service networks and in local and national decision-making bodies **(b)** Before setting up such participation, it is necessary to clarify their role, the extent of their participation, the aims of such participation, and the process for achieving it.

Recommendation 9: The objectives and underlying concepts of mental health policies should be better defined and clarified by all the authority levels with responsibilities in mental health care

Targeted audiences: Taskforce mental health, federal and federated health authorities

Avenues for action: **(a)** Federal and federal authorities (mainly the regions) responsible for health care, welfare and social affairs must jointly clarify the policy goals of the mental health care reform and should determine priority public-health goals for the entire country, while leaving room to local entities as how to operationalise these goals (See recommendation 12). **(b)** The inter-ministerial health conference must be mobilised to bring together the different competent authorities and develop a national mental-health policy plan.

Recommendation 10: In our context of bottom-up mental health policy, it is important to mobilise and bring together all stakeholders, particularly policymakers and service managers, in the various stages of the policy development and implementation in order to identify converging goals and interests

Targeted audiences: Federal and federated health authorities, Taskforce mental health, mental health services networks, (mental) health and social care services

Avenues for action: **(a)** The Belgian mental health system is made up of competing coalitions of stakeholders supporting different priority mental health policy goals. The divergence on priority policy goals is particularly great between policymakers and service managers. Reform programmes and goals are mainly devised by policymakers, but in our context of bottom-up mental health policy, their implementation is largely shaped by service managers. The effective implementation of the reform therefore relies on the engagement of the various stakeholders and the ability to identify converging goals and interests. The Canadian experience shows that policy networks could be set up to bring together the different stakeholders and strengthen their engagement in the different phases of the policy development and implementation [93]. **(b)** Community care seems to be a central policy goal and shared by the different competing stakeholder coalitions. Since central goals are strongly related to political decision-making, this goal could, accordingly, be emphasised in order to reach consensus between stakeholders. For example, shortening hospital stays has remained a controversial policy goal since reform began in 2010, a priority for policymakers but the lowest priority for service managers. To overcome this controversy, shortening hospital stays could be presented not as a policy goal in itself, but as a means of achieving the goal of community care which is consensual.

Recommendation 11: Federal and federal authorities responsible for (mental) health care, welfare and social affairs must coordinate and jointly pursue current and future mental health policies

Targeted audiences: Federal and federated health authorities, Taskforce mental health

Avenues for action: **(a)** The inter-ministerial health conference must be mobilised to bring together the federal and federated authorities and develop current and future mental health policy. **(b)** Two important issues must come to the political agenda because they are currently too neglected in Belgian mental health policies: (1) the prevention of mental health problems and disorders and (2) the discrimination and stigma of mental illness.

Recommendation 12: In the current context of decentralisation of political competences, an organisational model allowing local autonomy and governance in the organisation of mental health care should be favoured

Targeted audiences: Federal and federated health authorities, mental health services networks

Avenues for action: **(a)** Each authority with responsibilities in mental-health care (mainly the federal authority and the regions) should develop its own mental-health policy that is integrated in the national mental-health policy plan. In 2017 in Flanders, the Policy Research Center Well-Being, Public Health and Family developed, in cooperation with the Agentschap Zorg & Gezondheid, an integrated mental health policy that resulted in several policy regulations that are included in a draft decree concerning mental health. **(b)** The current governance of service networks should be strengthened to allow local autonomy on each geographical area defined by the reform. For example, networks could become Network Administrative Organisation (NAO), with its own legal personality and be in charge of helping care coordination, funnelling the federal funding to the network, helping into the development of local information system and local evaluation procedures.

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Scientific Curriculum Vitae of the candidate

With a background in psychiatric and mental health nursing and a master in public health, I started working as a researcher at the Institute of Health and Society (IRSS) of the Université catholique de Louvain in 2016. In 2021, I continued my career at Sciensano, while being a scientific collaborator at the Université catholioque de Louvain. My research methods are mainly quantitative (research and statistics in health and social sciences and epidemiology). My research and teaching themes focus on the social determinants of health and mental health, the social and economic integration of vulnerable people, health and social policies as well as the organisation of health care and services.

Publications in peer-reviewed journals

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Mapping and Assessment of Developments for one of the sectoral professions under Directive 2005/36/EC – nurse responsible for general care, European Commission, 2019.

Organization of mental health care for adults in Belgium: benefits, barriers, gaps and overlaps in the current offer of mental health care (KCE-HSR-52), KCE project, 2017-2018.

Comparing policy framework, structure, effectiveness and cost-effectiveness of functional and integrated systems of mental health care (COFI) – European Union 7th framework, 2014-2018.

Feasibility study of Drug Consumption Rooms in Belgium (DRUGROOM), The Belgian Federal Science Policy Office (BELSPO), 2017.

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