SUMMARY

A responsive and integrated public health system is necessary for an effective mental health care system. Integrated health systems have been discussed as one way of improving access and continuity of care, particularly for people with complex and chronic needs such as those with mental illness. Systemic constraints, such as resource constraints (both human and financial) governance constraints and policy constraints and the dominant myopic allopathic approach to treating mental illness, create fragmentation both within the mental health system and between it and the overall health system. Fragmentation reduces the ability of the mental health system to achieve its primary goal (improved health status) and intermediary goal (accessibility) without compromising safety and quality.

This thesis focuses on the mental health system in India where mental illness affects approximately 55-70 million people and the treatment gap is estimated to be approximately 90%. Current efforts to improve the mental health system are hindered by the lack of an overview of the system, and the processes and dynamics shaping it. As a consequence, actors are unable to understand the direction in which the mental health system is changing, and cannot identify barriers and drivers for change. An understanding of the current mental health system, as well as the broader contextual factors influencing it, is required for the identification of strategies that could potentially result in a paradigm shift. Ultimately, understanding of the dynamics of the mental health system requires analysis of different elements. In this thesis, I focus on two elements of the mental health system, namely service delivery and governance/leadership.

An overview of the literature reveals that there is limited knowledge of mental health systems in low and middle-income countries, such as India. This thesis aims to contribute to the body of knowledge on the mental health system in India by answering the following research question:

*How can the mental health system in India be further described and understood, and what opportunities and strategies can be identified to move towards a more accessible, integrated, rights-based system?*

In India’s pluralistic health context, a series of separate systems of medicine provide care for mental health problems in isolation from one another.Persons with mental illness often consult practitioners from different systems simultaneously, illustrating the fact that the mental health system is composed of a series of independent, related health systems that share common elements. The complexities of care for many chronic conditions
(including mental illness) requires a service delivery that involves coordinated inputs from diverse actors, placing service users at the centre as co-producers of care. Despite this call for more integrated care, services are often fragmented. In India’s pluralistic system, fragmentation between systems, services, and professionals is often evident, creating substantial barriers to achieving an integrated health system that can provide accessible mental health care. Many countries try to move away from fragmentation by attempting to bridge the gaps between professionals, services, and institutions through integration.

This thesis draws on a number of conceptual frameworks and concepts: health system building blocks and health systems strengthening, integration of mental health care, and transitions in mental health systems using multi-level perspective and multi-phase concept. Effectively addressing persistent problems in health necessitates structural system-level changes; also referred to as a transition. Structural systems change is a complex, long-term, non-linear, multi-level process, involving multiple actors aiming to solve persistent problems and transform the system. Reductionist approaches to improving health systems (including mental health systems) have not been able to address persistent problems or to anticipate future challenges. To understand transitions within health system innovation, the multi-level perspective was applied throughout this thesis to understand where transitions occur, and at what level. The multi-phase concept has been applied to understand the development of a transition over time.

In order to answer the central research question, the main research question is further specified in 7 sub-questions that are addressed through the research presented in separate chapters in this thesis:

**What are the persistent problems in the mental health system in India?**

**What are the main issues at the mental health law and policy level, both internationally and in India?**

**To what extent are human rights integrated in legislation and policies, both internationally and in India?**

**Which obstacles hamper implementation of human rights for persons with mental illness in practice in India?**

**How can collaboration between professionals and institutions reduce fragmentation of the mental health system in India?**

**Are comorbidities a problem at the professional and organizational level in India? If so, to what extent are they recognized and acted upon?**

**What do stakeholders view as options for changing the mental health system in India?**
In order to address these sub-questions, this thesis employed a mixed-methods approach, combining a situational analysis of the mental health context in India, an analytical review on mental health legislation in Commonwealth countries, and two systematic narrative reviews on supported decision-making for persons with mental illness and barriers to using psychiatric advance directives in practice. This is followed by two case studies: an exploratory qualitative study on the introduction of psychiatric advance directives to clients at a non-profit organization in Chennai, India, and a mixed-methods study on collaboration between allopathic (biomedical) practitioners and faith-based practitioners in Gujarat, India. Subsequently, a quantitative screening study on the prevalence of depression among service users with type-2 diabetes was conducted, as well as a reflective study with key stakeholders in India on future directions for the mental health system. Data collection for these different methodologies included desk study, semi-structured interviews, and administering questionnaires.

**Part 1** identifies the many contextual factors (such as burden of disease, cultural attitudes to mental health, paucity of services and human resources) influencing the mental health system in India. In **Part 2**, we consider developments at the policy and legislation level both globally (Chapter 5-7) and locally (Chapter 8). From the three reviews (Chapter 5-7), it is clear that mental health legislation globally is outdated, and that there is a need for reform, particularly to promote entitlement of rights for persons with mental illness. Several cross-cutting themes emerged, the first of which was the dissonance between legislation and policy and practice, also known as the implementation gap. The second cross-cutting theme concerns attitudinal barriers, primarily from professionals in the existing regime (mental health system) working in institutions and organisations. In Chapters 6 and 7, we found evidence of professionals’ reluctance to change, underscoring the power differentials between health care professionals and service users. After completing these reviews, potential mechanisms for reducing the implementation gap were explored in Chapter 8, focusing on the introduction of psychiatric advance directives (PADs) to service users. The case study of the introduction of PADs by a non-profit organisation in Chennai explored the factors influencing implementation of PADs. The 51 semi-structured interviews conducted as part of this case study provided preliminary evidence that PADs may be useful for some persons with mental illness, particularly in enhancing self-efficacy and motivation to make decisions. However, many clients and their carers did not see the utility of the PAD and had difficulty in relating to a number of PAD-related concepts, such as autonomy, empowerment, quality of life, and decisional control. If PADs are to be appreciated by service users and to generate demand, they need to be adapted to the needs of service uses, requiring conceptual translation.
Findings from Part 2 lead to three overarching conclusions. First, there is leadership and governance at the national level in India in terms of commitment to developing a progressive mental health law as well as the country’s first National Mental Health Policy. The policy represents the first step in creating a mandate for access to care and recognising the rights of persons with mental illness. Second, the absence of evidence of the implementation of the principles of human rights into practice highlights the dissonance between policy and legislation with practice. Third, concepts and tools need to be translated to reflect the local context to ensure that they hold meaning and value for the service user.

**Part 3** presents a case study using a mixed-methods design (Chapter 9) which focuses on collaboration between professionals and organizations from faith-based and allopathic-biomedical mental health systems in the Dava Dua Programme. It highlights different experiences of the programme from the perspective of various stakeholders: practitioners, carers, and clients. Results reveal that the start-up of the programme was allopathic practitioner-driven and necessitated overcoming apprehension from the faith-based practitioners. Important steps to collaboration included building trust, openness, learning of each other’s approaches to healing, mutual respect, training and re-defining roles. Clients and families felt that this programme contributed to improved health and wellbeing, and restored livelihoods. Improvement on these outcomes was beneficial for clients and carers for two reasons: many had endured long periods of service utilization prior to receiving appropriate care at the Dava Dua programme; second, this programme caters, in particular, to the needs of impoverished rural communities, characterized by limited help-seeking and poor access to care. This niche experiment combines different forms of integration: professional integration and organizational integration at the meso level; and clinical and service integration at the micro level. The multiple forms of simultaneous integration probably reduce fragmentation at the micro and meso levels, enabling the programme to address a broad spectrum of service user needs. The programme represents a response to the treatment gap by providing services to rural areas with limited district-level services for persons with mental illness. It does this by using existing community resources (faith-healing sites) and working with existing community activists (faith-based practitioners) to increase access to care. The primary lesson learned from this case study is that divergent disciplines and practices do not preclude collaboration to address the needs of the client and improve wellbeing.

**Part 4** explores the challenges of addressing complex care needs in the mental health system, based on a public health study to screen for the prevalence of depression among 658 service users with type-2 diabetes in Pune, Maharashtra, India. Some 29.4% of the sample population exhibited depressive symptoms, irrespective of severity. The
occurrence of depression was significantly associated with being young, female, unmarried, with a lower level of education and socioeconomic status, living with diabetes for longer, having multiple diabetes-related complications or hypertension, and a lack of daily exercise. The findings show that multiple care needs are a problem in the Indian context while services and professionals generally treat these conditions in isolation. These findings are part of a growing body of evidence to try to convince the medical community and policymakers that care should address the multiple needs of the client. Such care could potentially be developed by the integration at clinical and service level (meso level) with the adoption of an ecological approach.

Part 5 reflects on the findings of the preceding articles with key actors in the Indian mental health system. Although a number of actors predict a bleak future for the mental health system in India, they also propose some tangible ways forward in terms of integration at various levels (macro, meso, micro). All respondents highlight the need to go beyond the health sector and to learn from other sectors. Part 5 highlights the complexities of addressing mental health issues, given their link to poverty, housing, employment and comorbidities, and given the many layers of fragmentation within and between the health and mental health systems.

This thesis provides an overview on the current state of the mental health system in India. Looking at a transition towards an accessible, rights-based and integrated health system through a mental health lens has enabled the identification of a number of strategies and mechanisms that could potentially help strengthen the mental health system in India. Additional niche experiments throughout the system in India are now important, particularly since the status quo (current regime) is not able to meet the needs of the population. New experience is needed to amend the ineffective mental health system, and these new experiments need flexibility if they are to deal with the fluctuations and diversity of conditions encountered in India. There are currently few attempts to move towards integrated care at the macro, meso, or micro levels. We see some attempts to integrate mental health law and policy, aligning them with national plans and programmes, but two challenges remain: one is to integrate these priorities outlined in the mental health law and policy, and embed them into existing policies in other sectors, aligning priorities. The second challenge concerns reducing the implementation gap and ensuring that the ideals specified in the law and policy reach those who could benefit most. Attempts at integration at the meso and micro level were observed in Chapter 9, which integrates services as well as professionals and institutions. However, this approach has not been applied to other persistent problems in India, (e.g. comorbidity), thus highlighting the importance of synergies with new collaborations, partnerships, linkages, and coalitions beyond mental health.
The variation between and within states is so vast that it would be unwise to apply a ‘cure-all’ solution for the mental health system in India. The case studies presented in this thesis are context-specific, contributing to a group of experiments that explore and demonstrate what works, what does not work, and under what conditions. In spite of this complexity and context-specificity, some key ingredients for a more accessible, rights-based and integrated mental health system can be identified. The first ingredient is collaboration, particularly collaborations which involve existing actors and resources. The second ingredient is reflexivity: strategies developed and adopted should be developed in a reflexive, flexible manner. Reflexivity is needed so that strategies can evolve over time and respond to changing patterns at both individual and population level, as well as reflecting the changing dynamics of the health system.