CHAPTER 11: REFLECTIONS ON THE WAY FORWARD FOR MENTAL HEALTH

Introduction

In this thesis so far, we have explored the need for integrated services (Chapter 10), the potential for using existing resources and building on existing capabilities to enhance access (Chapter 9), and promotion of rights for persons with mental illness (Chapter 5-8). Based on the results thus far, it is unclear whether a transition towards an accessible integrated and rights-based system is likely to occur. Such a transition may involve the input and influence of many actors – particularly their input on whether integration is a means to lead to a more accessible, rights-based system. To obtain more insight on this, we interviewed key stakeholders in health and development on two main topics: first, to reflect on the research findings presented in this thesis, and second, to discuss whether there is a need to focus on strategies for integration in the mental health system, and if so, a) what are these strategies and b) where should integration strategies be targeted?

Methods

Seven semi-structured interviews were conducted in the cities of Mumbai, Pune and Chennai in July 2013 with key players in mental health in India (n=3 clinicians, n=1 head of a mental health research unit, n=1 management official of a non-profit mental health services organization, n=1 professor and dean, n=1 founder of a non-profit mental health services organization). Interviews were carried out in English by the author of this thesis, together with a health systems researcher, and lasted on average 45 minutes. The primary author works in mental health and India, and key players were identified through convenience sampling based on the network of the author.

Using the conceptual framework for integrated care (Valentijn et al., 2013), originally used for modelling primary care, we structured the interviews according to integration occurring at the macro level, meso level and micro level. Within these three levels, integration could occur on three dimensions: aligning policies and regulations (macro level), professional and organisational/institutional integration (meso level), and clinical/services integration (micro) level. When all the macro, meso and micro levels are linked together, this results in functional and normative integration (See Chapter 2, Figure 3). It should be noted that the classifications of integration presented here are artificial, and in reality, integration often involves engaging multiple levels at the same time in a
complex multi-level process. However, from an analytical point of view, it was thought to be beneficial to structure results by level of integration to provide clarity.

Data Analysis

After familiarization with the interviews, deductive coding was used according to a pre-defined set of codes guiding the interviews. Inductive coding was used for any emergent sub-themes arising out of these broad pre-defined themes. We used a thematic analysis approach to analyzing the qualitative data. All interviews were analysed in the qualitative software MAXQDA (MAXQDA, 2001).

Results

The results emerging from the interviews were broadly categorised into the following four themes: definitions of integration, and the potential for integration at the macro level, meso level and micro level.

Defining integration

Across key stakeholders, the definitions of integration varied, however they all converged on several key points: considering the broader social, economic and political realities that may impact a client’s health, and being in a position as an organisation, service, or service provider to provide a basket of services or interventions that cater to a broad spectrum of medical and non-medical needs, all with the aim of promoting well-being:

“…The problem we are dealing with is increasing competition, increasing pressure to succeed, increasing pressure being able to retain jobs and able to get a new job, parental pressure, pressure from spouses… I think there are far more complications in society that we are facing… So it’s about understanding those underlying factors and integrating it with other sectors where it might have an impact” (ID 6, Professor)

“If I find a client living in very bad housing conditions, which he has not brought up in any of his sessions, as a service provider, I feel if you’re able to identify the people most impoverished, and help with their housing situation or child’s education or livelihood, we’ve done better justice in terms of serving their mental health needs. So through a home visit or a follow-up I may discuss and say ‘I think this [intervention or approach] may make an impact on your life.. do you think this would be useful?’ The therapeutic alliance is very important, openly discussing some ideas that you have, ideas the client has, and see if there is some meaning that they experience at the end of the day through it. so I would say that integration is possibly that. Integration is recognizing the basket of needs that one
can gauge through a therapeutic alliance (ID 2, Head, Mental Health Research Unit)

Integration at the Macro level (aligning policies and regulations)

Barriers to integration at the macro level

At the health systems level, integration was felt to be a difficult task to achieve due to several reasons: the first is the dichotomy between the public and private systems, which have differing client bases, services, and perhaps most importantly, differing driving forces (i.e. market forces drive the private sector, so outcomes of the health system differ). The second challenge to integration at this level was fragmentation, described as the lack of inter-sectoral communication and coordination, the increasing compartmentalisation of sectors, and the short-sightedness on behalf of sectors and policymakers to link relevant domains together and realising that this could yield a greater impact for the population:

“The policymakers ... if you talk to them they’re aware of it [non-integration]..somehow our systems are not designed in a way to address these problems in a holistic manner. There’s lots of initiatives on nutrition and sanitation, clean drinking water and all. But they don’t link in with the health team. They just say its’ good to have clean drinking water. They don’t make the link that clean drinking water means better health.” (ID 1, Psychiatrist)

“The bigger non-integration is the separation between health and social care. We don’t integrate this either and that’s where some of these problems start off. So a doctor will say ‘yes I know her husband beats her[client] up, and is an alcoholic, but what can I do about it, best I can do is write an antidepressant’. Very often, at the community level there is nothing available, so the doctor will say I can’t really do anything and the community will not accept me intervening in social issues” (ID 1, Psychiatrist)

Vertical programmes initiated at the government level were viewed as particularly problematic due to the fragmentation resulting from focusing only on one particular issue without considering the broader contextual factors:

“Our health system has always been vertical –dealing with a particular health issue as if it is a stand alone problem. And we never ever try to integrate very basic things like water and sanitation, link up with nutrition.. now you can’t deal with nutrition without dealing with water and sanitation and make any impact on morbidity and mortality among children,... If a child is malnourished we focus on that. We don’t deal with where the child is going home, what is in their environment... so this is the problem actually. At least in mental health what we should do is let us bring in a protocol that when you check people for any of these problems, then better check for the mental health problems. (ID 6, Professor)
Finally, one stakeholder expressed concern about embarking on the shift to integration when certain regions of the country did not even have the ‘basics’ (i.e. basic access to care):

"Resource deficits are a huge barrier, huge barrier... our state is okay, but there are places where the basic isn’t even there. So how do you talk about integration when they basics aren’t even there? How do you work in these places on integrated care?" Head, Mental Health Research Unit)

Opportunities for integration at the macro level

Several opportunities for systems integration were highlighted by stakeholders: the first is by showing the importance of linking between sectors, so that this may lead to inter-sectoral coordination or collaboration (to begin with), aligning health policies with broader policies in a given country (e.g. economic) to ensure that objectives and priorities are coherence across sectors, establishing public-private partnerships to streamline objectives and tasks, and finally, focusing on changing the education and training sector for health to encourage more ‘integrative thinking’ for new trainees.

Strengthening linkages between sectors

All stakeholders highlighted the importance of strengthening linkages between sectors (especially health and non-health sectors) as the formative step to moving towards a more integrated system:

"I think one needs to intervene at different levels: with clinicians, so they know how to treat depression (and mental illness), with the primary care people, with the social care people to deal with social care issues, and beyond social care, like nutrition and sanitation. If you did that, it links the whole thing. I mean, the public health sector does try to do that, there are some attempts like the NRHM\textsuperscript{10}, with village sanitation and nutrition committees - so they’ve made a link with health and sanitation, which is a great idea. But this is the first attempt at linking health and sanitation, so we need to do that at the top level too. From the government point of view, we have separate departments which function in their own independent silos..you need to talk about inter-sectoral collaboration.. getting this is really hard." (ID 1, Psychiatrist)

Related to strengthening partnerships between sectors was the importance of aligning policies and objectives across different sectors. Without policy alignment, it was felt that

\textsuperscript{10} NRHM: National Rural Health Mission, a flagship programme initiated by the Central Government of India. For more details, refer to \textit{Coordination} in Chapter 4.
efforts in one particular area (e.g. mental health) might be futile, without complementary objectives present in economic, education, or public health policies, for instance.

“You see, if we have such a [progressive public] policy then you need to have other policies consistent with that. When your economic policy is moving in one direction, you cannot have a public policy moving in another. Your public policy always is derived from your economic policy. So if you locate your economic policy in a particular manner, your public policy can only reflect this. You may say you have universal health care, but if your economic policy is such that it wants to create business opportunities for the private sector, then they are not consistent. The approach to deal with this problem is integration...you need to integrate. You cannot have health that is vertical and truncated and unintegrated” (ID 6, Professor)

Three additional ways forward were highlighted by stakeholders: creating new system-level partnerships (i.e. public-private partnerships), modifying existing training programmes to attach value to the idea of integration, and enshrining human rights and a right to comprehensive care within the system:

“The way the medical system and medical infrastructure is evolving, it is likely to become highly compartmentalised and specialised. This can make care very very complicated...Value systems, families, socioeconomic realities, technology, sophistication all may change, but problems facing humans will remain the same even after 100 years. So therefore it is important to strengthen the medical training... Its just not giving knowledge or skills, but its’ important for us to think of comprehensive care as being important - But how do we do it? That will remain a challenge. Whether it is possible for us to build it in training, strengthening, or we will have to enforce by laws and regulations that every person has a right...we will have to move to a political situation where people recognise that things cannot be compromised -These are individual rights.” (ID 3, Psychiatrist)

Integration at the meso level (institutions, professionals)

Integration at the meso level includes integration between professionals and between organisations/institutions. Stakeholders described two pathways to achieving integration at this level: working with community mobilisers, and strengthening the role between professionals and families in mental health care.

Opportunities for integration at the meso level

Working with community mobilisers

Stakeholders identified that working with non-professionals (i.e. lay community workers) at the village and community level is one of the few ‘rays of hope’ if the Indian public
health system is to transition into a more integrated one. This was attributed to the fact that existing community members are ‘change agents’ and hold far more community knowledge compared to professionals, thus offering a unique opportunity to identify undetected cases of mental illness, and bolster access to care by providing these lay community members with skills to facilitate needs related to mental ill-health and distress, as well as encouraging self-management in the community:

“The Indian health care system is physician focused – it is never ever a holistic approach of assessing individual’s characteristics, and trying to find what the individual needs... that luxury doesn’t exist for majority of Indians... if you have the village health workers looking at issues of mental health, they have much better understanding of who the individual is, what are the problems.. I tell you they have amazing insight about people and way, and mental health. We can build from there..But we need to create a protocol for that and we need to create people for that.” (ID 6, Professor)

In addition, it was felt that families are key players in providing and maintaining care, although it was perceived that skills transfer or task shifting roles from clinicians to families would be met with substantial resistance from clinicians who fear their autonomy and power status would be compromised. It was therefore important, as one stakeholder described, to ensure that the role for clinicians is etched out in the integration process so that they understand that, despite task shifting to different cadres of health workers and community members, they still hold value in the care process for clients:

“Ultimately, for care to become more comprehensive... we should empower families in caring responsibilities. Today, families have the role of passive partners in liaising with doctors...we have not thought of transferring technology to the family for mental illness. So that continuity of care could be maintained. Family empowerment, transferring some elements of care to families in the context of chronic illnesses is a certain way to reduce cost, reduce burden, reduce disability, move forward, comprehensively. Will doctors accept it? They’ll say, this is foolish, this is stupid. How can families take care of the severely mentally ill? Why are we [doctors] here? Why do we need medical training? Why do we need postgraduate training? Why do we require psychiatric training for nurses? Psychologists? Social workers? Now many people will feel threatened by this radically different thought..you’ll have to demonstrate that professional role still exists” (ID 3, Psychiatrist)
Integration at the micro level (services, clinical)

Barriers to micro level integration

One barrier to services integration was the difficulty in scaling up effective niche experiments or innovative services to the broader population in India. This was perceived as difficult as it was felt there were no models in place to guide this, nor any existing examples of how services could be scaled up for mental health in a horizontal, integrated way. One stakeholder referred to the success of the Polio programme in India, attributing its success to its simple formula and the fact that it was a vertical programme, which is not conducive to integration or in capturing the multiple, sometimes chronic care needs that persons with mental illness may have:

“I think we need to understand the scale of the problem and why some of these problems appear to have easy solutions. You can make it work in a small experimental model, but if you want to scale it up to the population, then the problems are completely different. So a lay counselor model in a district will work in an experimental setting, but, can you scale this up across the country? Then a whole new set of problems appear.. so it’s the scale up of these services that’s a huge problem, moving from small demonstrations to large size projects” (ID 1, Psychiatrist)

Despite this barrier, stakeholders had a clear view as to how the system could move forward to integrated care at the services level. It was felt that the client should be at the heart of the integration process, as the client needs to demand for integrated services and be driving this process (as opposed to other actors, such as practitioners):

“Integration has to be between different sectors and has to primarily be with the people you serve. Because the people you care for, the people you serve, they are your primary constituents. And if they are not leading the integration process, or they don’t have a buy into it, or they don’t believe that it will lead to greater wellbeing, then there won’t be significant public demand to press for integration. And if you don’t press for integration, we’re not going to see it” (ID 5, Founder of a non-profit organisation)

One way to include clients in the integration process is to ensure that they are co-creators in their own services. It was felt that, from the provider perspective, this could be achieved by balancing what the client perceives as important (expectations), versus what they actually need (needs assessment).

Rooting the integration process in primary care was mentioned as another important consideration, as the concept of integration is more in line with the fundamental principles of primary care (that is, a public health approach espousing a social model of
health, where services are equitably distributed at the community level, closest to peoples homes). Stakeholders felt that achieving integrated care in a specialist setting would be far more difficult than in primary care, thus it was better to anchor the integration process in primary care and focus on strengthening coordination between specialists and generalists instead:

“I am strongly convinced that [comprehensive care] can be formalised, validated, if we use primary health care as the platform. The more sophisticated more specialised it becomes, the more difficult it is to conceptualise comprehensive care because it becomes highly compartmentalised, highly specialised, and there becomes no vertical spread. On the other hand, in primary care, it can have a very good influence on horizontal spread. However, this kind of a philosophy is slowly fading away. We are moving toward specialisation. We don’t seem to worry or bother about generalists. So the generalists and specialists are very clearly divided, while they have to co-exist with a meaningful relationship. You cannot have a situation where there are only specialists, or only generalists, you should have a healthy proportion. Care can be continued by a generalist, after the work a specialist as done.. we need to strengthen this” (ID 3, Psychiatrist)

Linking the macro, meso and micro levels: Functional and normative integration

Functional integration argues for a flexible approach to integration; such that integration evolves and takes into account the changing needs and environment of the client. Arguing from this perspective, one stakeholder felt that reflexivity and reflection were important processes to embody as a provider, in order to be able to adapt to the constantly evolving nature of services provided to clients. In practice, this was described as the sudden change in user needs. A intervention that was once perceived as meaningful may no longer be meaningful or perceived as useful by clients, thus the need for adaptation and flexibility in re-assessing needs and responding to those needs by provision of different, more suitable services at that particular point in time. Consequently, this particular stakeholder was very hesitant about the use of rigid, prescriptive models about how integrated care ‘should’ be provided, as rigidity does not allow for flexibility and adaptation:

“I think there are significant barriers one needs to understand in terms of integrating care, how are you going to place your model? A model tonight is not necessarily a model for the future. It will keep changing as one gets more comfortable, so let’s say there’s a specialist who is providing a mental health service in a GP clinic and who is not just facilitating but also doing the service along with the GP.. maybe over time the GP becomes more confident with doing it. So I think flexibility is required for allowing this model to progress from point A to point B.. and it needs to evolve, maybe at a future point in time you’ll have a lot of specialists. And maybe a specialist in a PHC is more amendable to mental
health care - one needs to be open to those sort of formulations.” (ID 2, Head, Mental Health Research Unit)

Aligning value systems with integration

Four stakeholders described the importance of having a value system, or a shared set of core values among health workers in line with the principles of integrated care. It was stressed that this value system should evolve and change over time, and that both a shared definition of integration and an action plan outlining the process were important.

“How do you apply a changing sort of framework and value system? I think that’s a challenge. I think a barrier possibly is looking at value system and internalizing this value system...because unless everybody is on the same page, you don’t have an alliance and” (ID 2, Head, Mental Health Research Unit)

Health care workers described their own process of reflection – particularly reflecting on whether the care they provide is meaningful for clients. This was seen as one way to internalise the aforementioned value system. Another way to adopt this value system was to be proactive as a health professional to actively engage with clients to both look for and address needs. If identified needs fall beyond the scope of one health worker’s role, one stakeholder stressed the importance of liaising and networking with professionals working in both health and non-health sectors. This was highlighted as particularly important in isolated service settings (such as a rural primary care centre):

“I think it boils down to personal motivation and certain core values that individuals need to subscribe to if you want your health system to work...you need to believe in it, therefore you do it. You need to believe in the value that, I am assessing someone for fever, or for diabetes, but I also look at their mental health problems. It’s the act of an individual to understand the health system in a certain way and internalize these core values. I think that’s key, because with some practitioners, you don’t find this” (ID 2, Psychiatric Social Worker)

It was felt among stakeholders that this value system had to be cultivated early in one’s career, when enrolled in training and education. Stakeholders described that curricula for health care workers and medical doctors in India should embed the urgency for integrated services, and inheriting a value system that emphasises addressing a broad spectrum of client needs.
Conclusions

In conclusion, stakeholders placed considerable emphasis on the importance of integration at different levels (macro, meso, and micro) and on many dimensions (systems, professional, institutional, clinical, services) as well as spread of integration (emphasising horizontal rather than vertical approaches and programmes). Synthesised, their visions on the way forward for the mental health system show that working towards integration is needed in order to enhance access to mental health care, empower the service user to exercise their rights, and to make use of existing financial and human resources to build capacity. The strategies suggested by stakeholders could form the basis for an agenda setting exercise for mental health system strengthening in India.
CONCLUSIONS AND DISCUSSION
CHAPTER 12: CONCLUSIONS AND DISCUSSION

“So even if you look at the body – how does the body work? It works because different organs come together to make the body function. Similarly, if a state or a health system is to operate, then it has to be sectors which all come together. It obviously isn’t working that way, which is why you see one leg pulling backward and one arm pulling forward, so movement and mobility is constricted”

- Vandana Gopikumar, Co-Founder of The Banyan, July 2013

This chapter presents the conclusions of my research, guided by 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?

To answer this question, this thesis begins with a comprehensive exploration of mental health in India by means of a situational analysis. This analysis sets the stage for the research articles that follow from Chapters 5-11. Part 2 endeavoured to explore the challenges and opportunities in legislation, policy and human rights in India and describe how the disconnect between law and practice might be reduced. Part 3 presents a case study of a collaboration between faith-based and allopathic institutions, with the aim to bridge the service gap by providing more accessible, integrated care for clients at the community level, where services are most scarce. This collaboration demonstrates the possibility of reducing fragmentation in services while simultaneously promoting the rights of persons with mental illness. Part 4 explored whether comorbidities are recognized as a problem at the regime level and, the extent to which comorbidities pose a problem in practice. This was done through an empirical study that assessed the prevalence of depression among clients with diabetes in Pune, India. In Part 5, I interviewed key stakeholders to reflect on whether a transition is likely to occur in the mental health system in India, and the barriers and strategies to realising this change. This thesis begins on the path to addressing some relevant questions at the interface of health systems and mental health, which raise a number of points for discussion, covered by below, structured by sub-question.
**What are the persistent problems in the mental health system in India?**

A number of persistent problems emerged from the analysis relevant for this thesis. The first issue was poor access to care and services across the country, evidenced by the enormous treatment gap (47% for severe mental illness and 82% for common mental health disorders), the limited (and unequal) distribution of services, and the dearth of human resources to deliver these services. This demonstrates that indeed, India’s mental health system struggles to achieve its intermediary goal of providing access to care. To complement government efforts, a number of pilot programmes and initiatives are developing across the country to bridge the service gap, especially in tribal and rural areas. This gap is being filled primarily by non-governmental organisations and public-private partnerships (Chapter 9). Although these pilot programmes are receiving increased recognition from their efforts at the national level, they have not yet substantially influenced the regime, or the mental health system as a whole.

The second emergent issue is the transition in epidemiological patterns, which has shifted the burden of disease from communicable to non-communicable diseases (NCDs). However, there is still a high prevalence of communicable diseases, an alarming rate of accidents and injuries (including suicide) and rising rates of NCDs – referred to as the triple threat of disease. This triple threat is an issue afflicting both the private and public health systems in India. These disease groups, particularly communicable diseases, are often treated in isolation through centrally-driven, vertical programmes (e.g. eradicating polio, or the implementation of the DOTS programme for tuberculosis). Despite this fragmented way of addressing these diseases, there is increased evidence that multimorbidity (the presence of multiple conditions simultaneously) is an emerging problem in India. The presence of diabetes and co-existing depression, or anaemia and depression are both prevalent examples. If we relate this back to the multi-phase concept outlined in chapter 2, multimorbidity is a persistent problem that the mental health system (which is nested in the broader health system) which appears to not have been effectively dealt with, potentially due to the systemic issues of specialisation, leading to fragmentation.

Third, in terms of policy, laws and programmes, although there is demonstrated leadership and commitment at the policy and legislative level (landscape level, referring to Transition Theory) it is unclear whether these developments will exert any influence on the regime (mental health system). The formulation of the new Mental Health Care Bill and India’s first National Mental Health Policy appear promising, however these have yet to be formally approved by Parliament and have thus not yet been implemented. These documents mandate access to mental health care as well as introduce a rights-based approach to care, both of which are unprecedented in India. Thus, changes are occurring at the landscape level, and although it is unclear how the introduction of these two
documents will challenge the incumbent regime of the mental health system, it is possible that they will enable the emergence of new cultures, structures and practices in the mental health system more in line with those needed for a more accessible and integrated care.

In sum, conducting an assessment of the mental health system in India proved to be a useful exercise as it enabled us to map out where change is happening, in what capacity, and which problems persistently re-occur and press the need for change.

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?

In order to obtain a better understanding of the influence of leadership and governance on the mental health system in India, we looked at developments at the policy and legislation level both globally (Chapter 5-7) and locally (Chapter 8). At the international level, there is increasing pressure from regional, national and global actors to reform mental health legislation, particularly in shifting from models of guardianship, institutionalisation and protectionism to models of supported decision-making, community-based care, and promotion of human rights. Despite this pressure, results from Chapter 5 revealed that when countries were compared against UNCRPD provisions, many countries were non-compliant with the CRPD and had outdated laws. In fact, a number of countries had components of their mental health legislation reinforcing stigma, discrimination and protectionism. We found that many laws did not address access to care; without a focus on access, there is likely to be little motivation at the regime level to change services and approaches in order to enhance accessibility, as there are no accountability structures in place to enforce improvement in services/approaches. We also found that substantive and procedural provisions related to guardianship in mental health laws are particularly prevalent in Commonwealth countries and call for a shift to supported decision-making provisions. This raises the question as to why, despite ratifying the CRPD, countries remain hesitant to undergo legislative reforms to align with CRPD provisions and implement these provisions on the ground.

This question led us to explore whether any particular CRPD provisions had been implemented into domestic legislation and into practice. We chose to look at Article 12 of

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the CRPD (Equal Recognition before the Law), which states that persons with disabilities (including persons with mental illness) should have the right to exercise legal capacity (Chapter 6). One way to exercise legal capacity is through supported decision-making, where support is offered to persons with disabilities to make decisions. Our review found that internationally, there is a complete absence of evidence on initiatives focused on supported decision making. As there was limited research evidence on supported decision-making (two pilot studies in Ireland and Australia), we resorted to reviewing the evidence for shared decision-making which shares some commonalities with supported decision-making, such as an attempt to actively engage the service user in participating in care-related decision-making processes. The evidence showed that service users wanted more involvement in decision-making, and this desire was greatest among those with mental illness compared to service users with other health conditions. A number of studies also found that health practitioners were reluctant to change their attitudes and practices towards care consultations – an evident hindrance to ingraining shared decision-making in practice.

The legislative part of the review found that several high-income countries (e.g. Sweden, Scotland) offer provisions for certain degrees of supported decision-making, and a greater number of countries had substantial advocacy initiatives pushing for the introduction of the paradigm of supported decision-making, but without legislation backing up these advocacy measures. This serves as an example where niche level initiatives (advocacy groups and coalitions) wish to change the system, towards more legal recognition that service users with mental illness should be supported (if and when necessary) to make their own decisions, but does not build up enough momentum for change to challenge the regime or landscape level.

Despite these more progressive countries acting as examples for supported decision-making, a number of countries still had provisions for plenary guardianship, which contrasts with the aims of Article 12 of the CRPD. Plenary guardianship (particularly guardianship orders without procedural mechanisms for appeal/review) does not offer persons with mental illness to make decisions independently. Laws that did encourage service user autonomy often expressed this through provisions for psychiatric advance directives (PADs), a tool enabling supported decision-making.
In light of discovering that many countries made provisions for PADs, we wanted to find out what the barriers to uptake of PADs were in these countries (Chapter 7). While a number of reviews have been conducted on PADs (Campbell & Kisely, 2009; Henderson et al., 2008), none specifically assessed barriers at the system, professional and service user level. We found ample barriers to PAD uptake and implementation, hampering their use in practice. Barriers were found in 6 countries across 30 research studies, showing that regardless of the strength of their health system or the presence of a law offering the right for service users to choose to complete a PAD, barriers are frequently encountered. The research continuously found that addressing the attitudinal barriers that stakeholders hold to using PADs has yet to be fully addressed. This shows the stronghold that cultures (attitudes, perceptions) have on the introduction of an innovative tool in practice.

Several cross-cutting themes emerged from these three reviews, the first of which was the dissonance (or vertical fragmentation) between legislation, policy and practice, however this is a problem facing all countries, including India. Considering this, the question remains as to how fragmentation can be reduced between policy and law development and implementation, referred to as the ‘implementation gap’ (Lang, Kett, Groce, & Trani, 2011). Using the example of PADs, one could envision two routes to reducing this implementation gap. The first route could have entailed conducting formative research on the feasibility and usefulness of the PAD in communities throughout India, prior to its introduction as a provision in the new draft legislation. An alternative route, the one taken currently (Chapter 8) is to first introduce the provision on PADs, as it is in line with the CRPD and in light with the promotion of human rights, and conduct post-hoc exploratory research as to a) PADs are feasible and useful for service users and b) if not, how can the tool be adapted into a locally meaningful and relevant tool?

The second cross-cutting theme concerns attitudinal barriers, primarily from professionals in the existing regime (mental health system) working in institutions and organisations. Attitudinal barriers in this context refers to the resistance from professionals to adapt to a new way of providing care that may be more service-user centric (thus shifting more power to service users), or adapting to a new way of interacting with service users and family, where the professional’s knowledge and expertise is not necessarily the only valid form of knowledge in the dialogue. In Chapter 6 and 7, we found evidence of this reluctance to change from professionals, 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, by introducing PADs to service users at a non-profit organisation in Chennai. This was a niche experiment exploring factors influencing implementation of PADs. The 51 semi-structured interviews conducted in 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 (e.g. they felt it did not add any additional value to their lives), or they had difficulty in relating to a number of PAD-related concepts, such as autonomy, empowerment, quality of life, and decisional control. This finding highlights the significance of translating these tools to the context they are being implemented in. In order for the PAD to be truly appreciated by service users and generate demand for its usage, PADs need to be adapted in such a way that they are meaningful for service uses to complete. Thus, conceptual translation is required, both in terms of translating PAD-related concepts and outcomes. Doing this may change the entire PAD approach, however the essence of encouraging a voice in care and decision-making, remains central. Thus, perhaps formative research conducted prior to the introduction of new tools (developed in another context than where it is implemented) is an important step to ensure that the tool remains meaningful to its end user. Without this buy-in from service users, this innovation is unlikely to scale up from the niche level and remain in the pre-development phase.

In all, the findings from Part 2 allow for three overarching conclusions. First, in India there is leadership and governance at the national level in terms of commitment to develop a progressive mental health law as well as the country’s first National Mental Health Policy, which is the first step to mandating both access to care as well as recognising the rights of persons with mental illness. Second, the absence of evidence in implementing human rights principles, or tools, into practice highlights the dissonance between policy and legislation with practice. Third, there is a need for concept translation of these tools in order to reflect the local context, so that concepts hold meaning and value for the service user. Fourth, there is pressure from the landscape level on the regime to change by introducing the new legislation and policy into mental health care. That being said, there are currently limited initiatives relating to law, policy and human rights implementation at the niche level. This means that while pressure is exerted from the landscape level, there is limited pressure from the niche level, thus it is unclear whether this top-down pressure is enough to challenge the regime. Therefore, local initiatives are needed at the niche level, particularly projects/pilots that utilise existing resources to circumvent complete reliance on already scarce funding from the government.
Embedding human rights across multiple systems in India could take on several forms. The first avenue may be to embed the recognition of human rights beyond the health domain, such as in the economic domain. This could involve encouraging businesses and corporate companies to realise rights in practice throughout their organisations. In select high-income countries, this is regulated and monitored via the OECD guidelines; however India is not yet part of the OECD country network, therefore more thought should be devoted to communicating the added value for companies to adopt a more rights-based approach and change their existing cultures and practices. The second is to create awareness and ‘rights literacy’ among service users and their carers in order to generate demand from service users to exercise their rights (e.g. to exercise their legal capacity, to exercise their right to quality care, etc.). The difficulty here is determining a mechanism that gives a voice to all groups and members of society, which is particularly difficult in India given the social and economic inequalities, thus presenting limited opportunities to make their voice heard (Lang et al., 2011). The risk is that policymakers and professionals may be reluctant to acknowledge the rights of persons with mental illness, as they might feel that enabling persons with mental illness to enjoy a fulfilled life and participate on par with others in society would translate into additional resources needing to be dedicated in an already resource-constrained environment (Lang et al., 2011).

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

Initiatives to realize collaboration between professionals working in different healing systems (e.g. public and private, allopathic and alternative), if described and evaluated, can serve as important learning opportunities for other actors in the mental health system. The specific case study, the Dava Dua programme (Chapter 9) promotes a rights-based approach to community mental health via a collaboration consisting of faith-based and allopathic practitioners in the state of Gujarat. One unique aspect of the programme is the emphasis on joint coordination roles among practitioners from both systems, as well as a shared responsibility to take into account the broad needs (spiritual, medical, socio-economic) of the client while ensuring that no human rights violations occur (for example, ensuring there is no restraint or chaining in facilities, ensuring conditions in facilities are hygienic and offer areas for private consultations with practitioners). Interviews with the innovators behind the programme revealed that the start-up of the programme was allopathic practitioner driven, and arose out of the innovative idea to support faith-based practitioners rather than condemn them. After overcoming the initial apprehension from faith-based practitioners, important steps to reach collaboration included a gradual process of building trust, openness and learning of each other’s approaches to healing, mutual respect, training, and re-defining roles. When considering replication of this niche
experiment in other contexts in India (or even in other low and middle-income countries) it is important to take into account this gradual process of reducing mistrust and discovering mutual ways of working together. This trust-building process is not a new idea, but its process has rarely been documented in India for collaborations focusing on mental health.

When evaluating the programme, we found that clients and families felt that this unique programme contributed to improved wellbeing, as well as new or restored livelihoods (through free care and recovery achieved through treatment, service user and families could resume work, or save the money that they would have normally incurred from high treatment costs when seeking care elsewhere). Improvement on these outcomes was important for clients and carers for two reasons: first, many had endured a long trajectory of service utilization prior to receiving appropriate care at the Dava Dua programme (and incurring substantial debt due to out of pocket payments for consultations); second, this programme caters to particularly impoverished rural communities where help-seeking and access to care is poor. Thus, this programme resulted in a number of benefits for clients and carers.

This initiative is unique as a niche experiment for several reasons. First, it involves professionals from different domains/sectors/care systems to integrate and work together, for separate organisations (private trust, government, and private non-profit organisation) to interact for a common goal, and for separate care approaches (faith-based and biomedical) to be included in the same package of care. Thus, this niche experiment shows evidence of professional, organization, and clinical/services integration at the meso and micro level, respectively; which likely reduces fragmentation at all of these levels. Second, it is representative of niche experiments taken on by actors from the regime, as the partnership running the programme consisted of government mental health professionals. Third, the programme responds to calls to bridge the treatment gap by providing services in a rural part of the country where there are limited district-level services for persons with mental illness (Patel, 2011). It does this by using existing community resources (faith-healing sites) and by working together with existing community mobilisers (faith-based practitioners) in order to increase access to care for people who require it. The lack of services available at the village and community level is evidence of the fragmentation within the public health system, wherein public health services are often located in urban areas and tertiary care services are more accessible than primary care services. To illustrate, only 123 of 640 districts have district-level mental health facilities and/or care. Quack (2013) critiques this approach to utilizing community resources, stating that such an approach is evident of ‘utilisation’ of faith-based practitioners rather than collaboration (Quack, 2013). To some extent, indeed this
programme could be viewed as one-sided, with allopathic mental health practitioners ‘using’ faith-based practitioners to facilitate access to care; however, it is difficult to determine the extent to which a ‘true’ collaboration is achieved at the professional or organisational (meso) level. In order for this niche experiment to move to the take-off phase (in terms of the Transition theory), it needs to be ‘broadened’ (or replicated in other contexts). However forging collaboration between two separate healing systems is not a simple task – and this approach is difficult for one system alone to achieve (King & Balaba, 2009), thus highlighting the importance of building sustainable collaborations when considering replication such a community-based service delivery model in other parts of the country. In sum, the primary lesson learned from this case study is that divergent disciplines and practices should not exclude the possibility of collaboration, with the aim to address the needs of the client and improve wellbeing.

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

Multimorbidity has emerged as a persistent problem globally; however, the magnitude of the problem in India was unclear, with only small cross-sectional studies providing clinical data without detailing potential implications for stakeholders. We found that among clients with type-2 diabetes, 29.4% of our sample had depressive symptoms, irrespective of severity. We also found that the odds of depression were significantly associated with being young, female, unmarried, a lower level of education and socioeconomic status, living with diabetes for longer, having multiple diabetes-related complications, hypertension and a lack of daily exercise. Our findings were in line with previous studies in Northern and Southern India (Poongothai et al., 2011; Raval et al., 2010). The findings show that multiple care needs are a problem in the Indian context; however services and professionals do not often treat these conditions as inter-related, but rather in isolation. Thus, the findings could serve as an advocacy tool to further increase the evidence base so that the medical community (as well as policymakers) take action to provide quality care that really addresses these multiple needs of the client, which could be addressed potentially through integration at clinical and services level (meso level). Some scholars have argued that the best way to address depression and co-existing diabetes is to adopt an ecological approach; that is, encouraging integration of the clinical with social, organizational, and community approaches (Fisher et al., 2012). Comorbidities like diabetes and depression can be considered a problem at the regime level; however dealing with this problem at the regime level is difficult as health professionals all have their demarcations (especially specialists). Solutions to address this problem could therefore come either from a niche experiment in the community (bottom up change), such as health care workers mobilised together to adopt a different care approach at the
primary care level, or through priorities outlined in a policy at the national level stressing the need to tackle comorbidities (top down change).

Referring to transition pathways, as described by previous scholars, top down change typically entails changes in structures established by government; however these changes usually do not have an impact on the cultures within the regime and are thus not effective in actually changing practices (Essink, 2012; Van Raak, 2010). Conversely, bottom up changes entail experiments at the niche level with new structures, cultures, and practices emerging from actors. These changes often fail to scale up, and thus also do not have an impact on structures, cultures and practices of the regime. Therefore, solutions exist to address the problem of comorbidities, but currently due to the structures, cultures and practices of the incumbent regime that resist change, this problem will not be addressed effectively within a short timeframe.

*How likely is it that a transition towards accessible, integrated and rights-based care will occur in the mental health system in India?*

*To what extent can these initiatives and strategies at the niche level be characterized by more broadening and scaling up strategies, in relation to the Transition theory?*

*How likely are actors at the regime level to change their practices once introduced to these strategies?*

Reflecting on the findings of the preceding articles covered in this thesis, we spoke with key players in mental health in India to get their view on the research findings and the direction in which they see the mental health system heading in. Although a number of key players held a bleak picture of the future of the mental health system in India, they also countered these views by suggesting some tangible ways forward, via integration at various levels (macro, meso, micro). Furthermore, all stakeholders stressed that one needs to go beyond the health sector and form linkages and plans for integration with other sectors (for e.g. the sanitation sector, water management sector, education sector). In addition, all stakeholders emphasised the need for policies, organisations, professionals, and services to be more integrated to be able to address multiple client needs comprehensively in order to structurally improve the wellbeing of the client. Some examples of methods of integration provided by stakeholders included ensuring that mental health is incorporated into policy priorities in non-health policies (e.g. economic, education), modifying health-related educational curricula to focus on the importance of addressing the spectrum of client needs rather than narrowly focusing on one need, and enshrining a different value system for future doctors and health care workers.
In sum, Part 5 brings the complexities of addressing mental health issues to the forefront (in light of its relationships with poverty, housing, employment, comorbidities) in relation to the many layers of fragmentation that exist within and between systems.

From the interviews, it appears that achieving a transition in the mental health system will require long-term commitment and a fundamental overhaul as to the main platform where niche experiments are tested and implemented. Integration of mental health at different levels of the system is important, as currently it is largely based in tertiary care, thus care is specialist-driven. This is not feasible, given the fact that there are only 3500 and 5000 psychiatrists in India (V Patel, 2009) who are expected to meet the mental health needs of the entire population. Primary care is more accessible for service users, and due to the health care workers being more generalist than specialist driven and more rooted in the communities potentially can provide more comprehensive care to service users. That being said, the situational analysis in Chapter 4 showed that despite the focus on integrating mental health into primary care, the initial pilot experiments in the Bellary District in Southern India failed (thus representing a failed innovation). A more critical exploration as to how such niche experiments at the primary care level can be successful is warranted. If this risk of failure is instead turned into a learning opportunity, then perhaps the primary care platform can be used as a platform to test the extent to which integrative care be engrained in the system, and, whether this indeed has impact on accessibility, affordability of care as well as on the wellbeing of the service users.

Returning back to the idea that health systems strive to provide high-quality care, it appears that there is still substantial work to be done in this area. The immediate question that comes to mind is - what is quality care in the Indian context? Several niche-level initiatives outlined in Chapter 4 tell us that achieving quality of care is possible. One example is in the state hospital in Ahmedabad, Gujarat, and the psychiatric hospital which received some of the worst ratings from the audit taken of mental health facilities commissioned by the National Human Rights Commission after the Erwadi tragedy discussed in Chapter 4 and 9. This event urged stakeholders to change (according to Loorbach (2007), often in light of an urgent event or problem, change occurs). Several years later, the hospital has transformed (for example, through open wards, clean and private living conditions) and is now one of the only accredited psychiatric hospitals in the country. This was largely due to leadership at the top level. It shows that a transition, in terms of moving towards provision of quality care, is possible provided that enough pressure is exerted to change. Achieving a large-scale transition like this across India is very unlikely; rather, small incremental changes in the system are more feasible, and over time, pressure exerted on the regime level may be enough to catalyse the system to move.
towards accessible, rights-based, more integrated care, or at least some form of it. This would ensure better access to care, as well as a more equitable distribution of resources.

**Making separate parts into a whole: conclusions**

This thesis provided an overview of 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. This analysis is timely, with the introduction of the new draft mental health law before Parliament, as well as with the introduction of the first National Mental Health Policy, both of which are expected to come into effect later this year. Aside from the leadership and governance exuded through the policy and legislative developments in the country, there are a number of interesting niche-level developments throughout the country. This includes implementing psychiatric advance directives into the local context (Chapter 8), and public-private partnerships aiming to provide integrated care through collaboration between practitioners providing care in different systems (Chapter 9). Now is the time to conduct additional niche experiments throughout the system in India, particularly since the status quo (current regime) is not able to meet the needs of the population. New experience is needed to build on what has become an 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.

Looking back at the move towards a more integrated mental health system, the findings of this thesis show that there are limited (visible) attempts to move towards integrated care at the macro, meso, or micro level. We see some attempts to integrate mental health law and policy, aligning them with national plans and programmes (for example, the District Mental Health Programme), but two challenges remain: one is to integrate these priorities outlined in the mental health law and policy, including the rights-based approach that they adopt, and align them with existing policies in other sectors. The second challenge concerns reducing the implementation gap and ensuring that the ideals specified in the law and policy reach those who could benefit from using and living these ideals the most. Attempts at integration at the meso and micro level were observed in pockets throughout the country, such as the innovative Dava Dua Programme which integrates services as well as professionals and institutions. However that same attempt is not applied to other persistent problems in India, such as the issue of comorbidity, where very limited attention has been paid to integrate services to provide care that address simultaneous needs.
There are a number of niche experiments beyond the case studies presented in this thesis aiming to improve accessibility to mental health care, advocate for the rights of persons with mental illness, and integrate care. The presence of these niche experiments is an important prerequisite for a transition to occur. Stakeholder perspectives (Chapter 11), although divergent, all point towards the need for integration to reduce fragmentation that hampers the mental health system from carrying out its functions effectively. These stakeholders also stressed that, in order to ensure the wellbeing of the population, it is important to expand horizons and go beyond mental health to synergise new collaborations, partnerships, linkages, and coalitions. In addition, despite all these developments at the macro level and micro level, it is important that the service user’s wellbeing remains the central aim.

As for the direction of these developments at the macro and micro level, we anticipate that more initiatives will arise and require deepening, broadening and scaling up. We also expect that the changes at the landscape and niche level will put pressure on the regime of the mental health system to change, resulting in tensions in dominant structures, cultures, and practices. In practice, this translates to institutionalisation, attitudes of practitioners and the doctor-patient hierarchy, and masking the voice of the service user - all will need to be challenged in order to really lead to a transition of the mental health system. When looking at transition pathways, top down and bottom-up approaches both must be developed to put pressure on the existing regime (the current mental health system, or the status quo). If structures, cultures and practices are able to adapt, then this is likely to lead to change the regime of the system (which would mean new structures, culture and practices that support a more accessible, rights-based, integrated mental health system). However, not all transition processes in the take-off phase will progress to the acceleration phase. In the event that the transition to a more accessible, rights-based integrated system does not progress to the acceleration phase, change may slow down and stabilise, referred to as a ‘lock-in’ (Rotmans et al., 2000). Conversely, if these dominant parts of the regime are unable to adapt to the required structure, culture and practices, then a backlash may occur and the mental health system may retreat back to how it used to be prior to these innovations and developments; it is ‘business as usual’.

The variation between and within states (in terms of health indicators, resource availability, strength of the health system) is so vast and heterogeneous that it is unwise to put forth a ‘cure-all’ solution for the mental health system in India. The case studies presented in this thesis are context-specific, and substantiate the need to look at solutions that are specific to different conditions across India, that address various levels of the mental health system. Building up a basket of experiments that explore and demonstrate what works, what doesn’t, and under what conditions would be helpful. In light of this,
there are some ‘key ingredients’ for moving the mental health system towards a more accessible, rights-based and integrated one, which could be disseminated for the mental health system moving forward, and taking into consideration the variation within the country. The first ingredient is that collaboration is necessary, especially collaborations which build on existing actors and/or resources, given that resources, especially for mental health, are scarce in India. That is, finding ways to engage with local advocacy groups, building coalitions to share experiences and lessons learned in service delivery in different pockets of the country, and understanding and finding ways for cooperation with practitioners from other healing systems. The second ingredient is that reflexivity and flexibility in strategies developed and adopted is necessary. This is so that they can evolve and reflect the changing patterns both at the individual level and population level, as well as reflect the changing dynamics of the health system. Finding ways for actors to embody this reflexivity and flexibility is particularly important.

Validity of the findings

Overall, the validity of the research findings presented in this thesis was enhanced by triangulation of multiple methods and data sources, of conducting research in multiple settings (rural and urban settings, private clinics and public-private clinics, religious sites, tertiary care and primary care clinics) from three different regions of India (Tamil Nadu, Gujarat, and Maharashtra, respectively) in order to reflect the heterogeneity in India of health status, services, and resource availability. The validity of the findings specific to the type of methodology employed is described below.

Internal validity

We implemented several measures to enhance the internal validity of the research presented in this thesis. The first issue arising when reflecting on internal validity is the role of the researcher across the two case studies (Chapter 8 and 9). It may be that the author of this thesis had an increased sensitivity or attention paid to the issues of interest while conducting the research, which could have impacted the credibility of the qualitative data. However, to minimize this potential for this bias, the author of this thesis was not part of the implementation team (thus holding a more distant role). Instead, the author reflected with the implementation team on developments, setbacks, and concerns, and received helpful feedback as to processes occurring on the ground, which could help inform the research.

A second check to reduce researcher bias and maintain objectivity was to have the qualitative data analysed by multiple researchers (three researchers in Chapter 8, two researchers in Chapter 9). In addition, there were regular reflection sessions with
colleagues and peers not directly involved in the projects, which helped to strengthen the internal validity of the data as well as contextualised findings.

As the author of this thesis is not from India and did not speak any of the local languages used in interviews in this study (Gujarati, Tamil or Marathi), it was difficult at times to obtain rich data from the interviews due to the language and time constraints. However, maximum effort was made to probe with relevant questions for more information, field notes and observations were collected, and member checks were conducted with interviewees for accuracy and retained meaning of concepts which were translated. The involvement of stakeholders who reflected on the findings presented in this thesis in Chapter 11 was helpful in confirming and validating the findings. Obtaining rich accounts for Chapter 11 was possible as the interviews were conducted in a quiet location, and carried out in English, one of the native languages of the author of this thesis.

Finally, methodological and investigator triangulation (field notes, observations, checking with literature, interviews and multiple researchers involved in data collection and analysis) helped to ensure that bias from self-evaluation was minimal.

An element of selection bias may have been present in this thesis, as convenience sampling was used for the studies in Chapter 8, 9, and 11. Simple random sampling methods could have helped with minimizing selection bias. However due to time constraints and logistical difficulties (i.e. all three studies using samples of service users were derived from busy outpatient clinics with a substantial clinical load). Thus, service users were often rushed, and there was a limited window of opportunity to conduct interviews or collect data.

For our quantitative data, we piloted our questionnaire prior to commencing the study to ensure items were suitable for our population with diabetes. Second, we used a validated tool to assess the presence of depressive symptoms (The Beck Depression Inventory-II). In India, this tool has not been compared to a gold standard, to the best of our knowledge, however it has been in other countries and its assessment has been said to be consistent with a structured, clinician-led interview.

One threat to internal validity (both for quantitative and qualitative data) in this thesis was the presence of the researcher, a foreigner, in India. This means the researcher had different knowledge and perceptions about topics that could have influenced the interviews, and in addition, at times it was possible that the researcher just being present in that particular setting could have influenced responses from respondents (e.g. in order to appear more socially desirable, or shy/uncomfortable to talk). Aware of this in advance, we spent considerable time prior to commencing interviews to get to know the
interviewees to make them feel at ease, and to explain to interviewees the role of the researcher (and explain that the researcher resided in India and not just ‘passing through’ India). In all cases, a translator, who was often part of the clinic/project team and who already had rapport with interviewees, facilitated this.

External validity

To ensure the external validity of the findings presented in this thesis, a number of checks were built in. To enhance generalisability of the qualitative findings, we conducted interviews with a number of stakeholders to get a comprehensive view on the particular processes being studied (service users, carers, physicians, mental health professionals, faith-based practitioners, professors). In addition, a number of informal conversations were held with academic and non-academic peers in both India and the Netherlands to help in contextualizing the findings of this thesis to a broader context. I also attended and participated in many policy-related meetings, seminars, home visits, outpatient clinic times, and spent additional time beyond the research requirements on the ground in India where the three empirical case studies were conducted (outpatient urban and rural clinics clinic and a dargah12, respectively). This helped me to grasp the emerging needs from the demand side (clients and their family members) as well as the supply side (providers and policymakers).

For quantitative data (Chapter 10) the findings of our study on diabetes and depression could be applicable to other populations with comorbidities in India, and our findings are in line with similar research in India, Bangladesh and Pakistan. Furthermore, we felt that the conditions under which we ran this study (in an urban outpatient clinic) is representative of a typical outpatient clinic in urban India. Although this study was conducted in three private clinics, we feel that this study could be replicated in a different system as well, i.e. the public health system. We were able to have equal representation of some demographic characteristics in our sample (i.e. age, sex) however we struggled to have equal representation of socio-economic strata (education and socioeconomic status), with the inability to recruit enough participants from the lower strata. This was likely attributed to the study setting (private sector clinics), which often have an entirely different client base than the public health system, often those are who more educated and have a higher socioeconomic status. Thus it would be recommended to explore whether results differ when this study is conducted in a public health setting, or in a rural setting.

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We attempted to ensure the validity of the findings in the three reviews conducted in Part 2 of this thesis by selecting specific review questions (i.e. reviewing the barriers to PADs in clinical practice, as opposed to just reviewing the evidence on PADs), by selecting specific paradigms or concepts to review (i.e. supported decision-making and shared decision-making for mental illness), and by selecting specific contexts and countries (i.e. reviewing mental health legislation in Commonwealth countries). We also were careful to tailor our review questions to the specific audience (e.g. Commonwealth review for ministers and policymakers, supported decision-making review for policymakers and advocates, and the PAD review for practitioners). Furthermore, we took into account that our search strategies may have missed additional articles that could have been used for the review; therefore we scanned the references of articles for additional references that we could include. We also extensively documented our search strategy and list for inclusion of studies, through creating a sifting strategy, to avoid arbitrarily selecting studies for review.

For case studies in Chapter 8 and 9, it was also important to consider the extent of the role that intermediaries played, and the impact that this had on the positive findings/success of the programmes. For example, the intermediary role that the mental health professionals who initially started the Dava Dua programme (Chapter 9) without a doubt played a role in the continuation of this collaboration and the determination to continuously improve and evolve the programme. Locating and having such an intermediary when scaling up this collaboration to another context could prove to be difficult. Furthermore, the intermediaries involved in the mental health legislative reform in India have made such that the new draft Bill is currently the most progressive mental health laws in low and middle-income countries, which is positive but also attributed to the dedication and commitment of key policymakers who saw this process through. Aware of this, the author of this thesis drafted all the articles independently first, and once a final draft of the manuscript was prepared, it was sent to a number of scientists and researchers who were not affiliated with the programmes and/or policy progress to comment on the findings in the review, paying particular attention to generalisability of our results and discussion.

The question that remains is how applicable the findings are from this thesis to the broader Indian context and other countries. Given that nearly 20% of the world’s population lives in India, it is difficult to generalise even to the broader Indian context given the substantial variation between states in health outcomes, resource availability, and governance structures. To account for this, we sampled a diverse population, consisting of different cadres of professionals, clients, and families, who interact with both the public and private systems of healing. The researcher was particularly mindful of interviewing clients and families who often do not have their voice heard – those afflicted
with poverty and facing harsh socioeconomic realities. This was ascertained by conducting formative research prior to the studies to better understand the profile of clients and carers I would be working with. It was also important for my research to reflect the diversities of typical ‘care seeking’ or service utilisation patterns in India. To do this, I interviewed two sets of service users: those who have consulted many different services during their care trajectories and those who had only ever consulted one service or organisation (e.g. have always been a client at one non-profit organisation). The desire to reflect the spectrum of mental health problems was also reflected in my interviews (thus service users with both severe mental illness and common mental health disorders). Despite these measures in place, the substantial heterogeneity between states means that recommendations for ‘India’, or even for a cluster of states, run the risk of oversimplification (Peters et al., 2002). It should also be noted that the three states selected as the site of the case studies (Gujarat, Tamil Nadu and Maharashtra) are comparatively some of the most progressive states, especially when it comes to health care, so it is difficult to generalise to ‘weaker’ states (in terms of infrastructure, resources, governance), which may have different needs as their health system may be at a different maturity level.

In spite of this, we argue that the broad themes elucidated in this thesis (need for contextualizing and translating concepts related to rights, need for access to community-based and integrated care, and addressing complex care needs) reflect issues faced by the general population in India. Furthermore, inevitably every mental health system faces similar issues to the Indian mental health system: issues of resource constraints, pressure to improve access, quality and distribute care equitably, and adapt to changing epidemiological patterns and economic fluctuations which impact the economic realities of clients seeking care. Thus, many of the persistent problems and solutions outlined would be applicable or found to be similar in other countries.

**Mapping the future research agenda**

As this thesis lies at the interface of health systems and mental health, there are a number of avenues for future research.

**Addressing complexities in mental health systems**

As a whole, looking at the mental health system in India (or mental health systems in LMICs) could benefit from a transdisciplinary research approach for several reasons. First, mental health systems are complex adaptive systems that cannot be understood merely from one discipline or from one stakeholder perspective. Robust methodology must therefore be applied to include the voices of all those who have a stake in the health
system on what their needs and visions are for the future when it comes to mental health. Participatory research methods, agenda setting, and emphasizing learning cycles and reflection would all be beneficial in this regard. Second, it is key that processes and initiatives, and even more fundamentally, research questions, include service users; that is, the service user participates in every stage of the research from inception to dissemination. Such processes are uncommon in India, and it would be important for initiatives conducting research in this way to document these processes to generate learning opportunities for others. It would be important to explore the transformative processes that service users experience, in applying their experiential knowledge to developing strategies that could shape the mental health systems that they themselves are stakeholders in.

Throughout this thesis, we have consistently seen that is it important to address the underlying determinants of health when talking about promoting positive mental health or recovery from mental illness. Taking these other areas into account requires a better understanding of how these determinants of health affect service users and communities in different regional settings in India, and how interventions that integrate elements from different sectors could impact wellbeing and improved mental health. This could be explored in several forms. For example, do entrepreneurship opportunities enhance wellbeing and recovery from mental illness? If so, what are the elements contributing to this? How does integration of mental health and social care impact service users, and more broadly, the communities they live in? What does this process of integration look like?

The situational analysis in Chapter 4 provided some examples of niche experiments in mental health across the country, and this is only the tip of the iceberg - there are many more. This provides an excellent platform for research to learn from these niche experiments and move towards the process of scaling up to the regime level. Doing this also requires a greater understanding of the cultures, structures and practices in place that constrain or enable actors to make certain decisions at the health system level in India. For example, it would be interesting to know how perceptions that health professionals at the primary care level hold about mental illness impact the way in which they deliver services, which may affect integration of mental health into primary care.

Referring back to the Transition theory, in order to have enough critical mass to challenge the status quo (that is, the current structure, culture and practice of the mental health system) to move it to a new state (e.g. a mental health system capable of providing better access, integrated, and rights-oriented care), more niche-level experiments and initiatives are needed, diverse in both their approaches and levels of the mental health system that
they target, with specific attention to strategies for, not only deepening, but also broadening and scaling up.

**Setting priorities straight**

Part 5 of this thesis highlighted the need for priority-setting in India, not only concentrating on mental health, but more broadly on the intersection between mental health and other domains (e.g. livelihood, employment, social care, other non-communicable diseases, comorbidities). If a priority setting exercise is carried out in India, it should involve first and foremost those who have the biggest stake in a mental health system – service users and their families. The priority-setting agenda should therefore be driven by service users, and include actors at all levels (macro, meso, micro) and cut across sectors as well as systems (i.e. public and private). Including so many actors in priority setting of course results in a multiplicity of interests. However, this might be one step forward to developing a shared vision, and subsequently, a shared agenda, of where the health system wants to head to, can head to, and in what way.

**How do we address the implementation gap?**

In this thesis, the implementation gap has been referred to in the context of the dissonance between law/policy and practice; however, this gap is observed in many other areas beyond policy and practice. From this thesis (Chapter 7 and 8) and from other research, we are cognisant of the barriers to implementation; research is now needed on how actors, institutions and systems can overcome these barriers to implementation. In order to do that, we need to conduct formative research to better understand community-level influences, interests among actors (especially health care providers), and how informal relationships between actors influence programme implementation (Balabanova, McKee, Mills, Walt, & Haines, 2010).

Translational research would also be a welcome approach to addressing the implementation gap, or so called ‘bench-to-bedside’ approach (Woolf, 2008) to understand how tools, interventions, and perhaps most importantly concepts, can be translated to reflect the local context in India. This local context needs to be further broken down to reflect state-level, regional, and even local realities, as the “Indian context” is an oversimplified term given the diversity and variation in the country. Translational research approaches could also provide insight into strategies that could reduce fragmentation between sectors (for example, between mental health and social care), an area where fusion is needed in order to have innovative service delivery models that can facilitate access to both social and mental health care and yield a greater sense of wellbeing among the population.
If applying translational research and/or implementation science to the strategies and concepts covered in this thesis, it would be relevant to more closely examine the implementation of the CRPD in practice in order to outline ways of really enshrining human rights for persons with mental illness on the ground. Thus, research on how the CRPD can be expanded and linked to existing discourses on human rights (Lang, 2011) would be one important research topic. Relevant to the introduction of tools like psychiatric advance directives, translational research would be useful in detailing the process of contextualizing concepts so that they hold more relevance and meaning for its end users (persons with mental illness). In Tamil Nadu, where the research in Chapter 8 was carried out, concepts which seemingly are overused in Western contexts or by scholars and professionals, such as wellbeing, autonomy, quality of life, rights, and empowerment, did not appear to resonate with the service users and carers we were speaking with. Without grasping the locally important concepts and framing the tool according to these concepts, the tool is unlikely to hold value for service users. A similar process to translating concepts and local cultural idioms of distress has been carried out in mental health in Cambodia, for example (Hinton & Lewis-Fernández, 2011; Hinton & Otto, 2006; Lewis-Fernández et al., 2010). More broadly, conceptual formulations in questionnaires have been well documented.

Making blind spots visible

One theme throughout this thesis as well as in the broader discourses on the Indian health care system (Peters, 2003; Peters et al., 2002) is the relative disconnect between the public and private sectors and the over-emphasis on the public health system when envisioning the future of health in India. Ignoring key players in current service delivery in India threatens the transition to an accessible, rights-based integrated system. In practice, this means that ignoring the role of carers/families, of Indian systems of medicine, and of the private sector (more broadly), will likely result in further fragmentation and stagnation in the transition process. In light of this, there are two interesting branches for explorative research here: the first is documentation and descriptions of successful existing public-private partnership initiatives to enable learning and reflection opportunities for others (as has been done in Chapter 9 and 10); and second, to start priority-setting sessions between the public and private sectors to come up with potential areas for integration (e.g. service delivery).

Broadening the scope of mental health innovations

Finally, proof of principle of working with existing community resources and community mobilisers to bridge the gap of human resources and optimise the use of scarce financial resources for mental health and reduce stigma, is a welcome research area to explore in
the Indian context. Perhaps the more significant struggle is not the proof of principle, but the process of broadening and scaling up these niche experiments so that they can have broader coverage for the Indian population. Rather than prescriptive models for scaling up, perhaps distilling the core components or steps to scaling up (i.e. extracting the ‘DNA’ or code from successful pilot or niche experiments would be more useful so that tailoring interventions to the specific context is possible.

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“If change is to be for the better, it should be based on an understanding of why things are the way they are” (Fuchs, 1974) as cited in (Elhauge, 2010)