Access to mental health services: informing efforts to close the mental health treatment gap

Analytical Commentary

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Declaration

I, Julian Eaton, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Most importantly, my family, who have been unendingly forgiving of my wide interests, overcommitment to work, and frequent absence.

List of acronyms

ARTEMIS	Adolescents' Resilience and Treatment nEeds for Mental Health in Indian Slums
DAH	Development Assistance for Health
DALY	Disability Adjusted Life Years
DHIS	District Health Information System
DSM	Diagnostic and Statistical Manual
GBD	Global Burden of Disease
GRADE	Grading of Recommendations, Assessment, Development, Evaluations
IAPT	Improving Availability of Psychological Treatment
ICD	International Classification of Disease
INDIGO	International Study of Discrimination and Stigma Outcomes
LAMIC	Low- and Middle-Income Countries
LSHTM	London School of Hygiene and Tropical Medicine
mhGAP	Mental Health Gap Action Programme (WHO)
mhLAP	Mental Health Leadership Programme
mhSUN	Mental Health Scale Up Nigeria
MHPSS	Mental Health and Psychosocial Support
MNS	Mental, Neurological and Substance-Use (conditions)
NCD	Non-Communicable Diseases
NTD	Neglected Tropical Diseases
ODA	Official Development Assistance
OPD	Organisation of People with Disabilities
PANPPD	Pan African Network of People with Psychosocial Disabilities, previously Pan African Network of Users and Survivors of Psychiatry
PPI	Patient and Public Involvement
PRIME	PRogramme for Improving Mental health CarE
RCT	Randomised Controlled Trial
RISE	Rehabilitation Intervention for People with Schizophrenia in Ethiopia
SDI	Socio-Demographic Index
SPARK	SuPporting African communities to increase the Resilience and mental health of Kids with developmental disorders and their caregivers

SUCCEED	Support, Comprehensive Care, and Empowerment for People with Psychosocial Disabilities
SDG	Sustainable Development Goals
UNCRPD	UN Convention on the Rights of Persons with Disabilities
WHO	World Health Organization
WNUSP	World Network of Users and Survivors of Psychiatry
YLD	Years Lived with a Disability
YLL	Years of Life Lost

Figures and Tables

Abstract

Addressing the mental health treatment gap

The Global Burden of Disease studies carried out in the late 1990s established for the first time that mental, neurological and substance-use (MNS) conditions were among the most significant of all disease categories in terms of global Disability Adjusted Life Years (DALYs), with depression, dementia, schizophrenia and alcohol use disorders among the top ten contributors to total global burden of disease. In 2016, the total proportion of global DALYs attributed to MNS conditions was 9.4% at a global level, and 4.3% in low-income countries.

Despite the high level of disability associated with mental ill health, around 35-50% of people with mental conditions in high income countries, and 76%-85% in low and middle income countries do not access mental health care. If the expected standard of care is defined as 'minimally adequate', then the treatment gap is even higher. A survey of 21 countries found that only 41% of people who attended services received adequate treatment for depression.

The first paper submitted with this analytical commentary ('*Interventions to increase use of services; mental health awareness in Nigeria'*) addresses one of the postulated reasons for low service use – lack of awareness about existence of services, and lay explanatory models of illness not lending themselves to help-seeking through health services. A campaign consisting of media appearances and targeted engagement with community groups in South Eastern Nigeria, led to a substantial increase in primary health care-based mental health service use. Subsequent work in stigma has emphasised contact interventions (direct or virtual engagement with people living with the stigmatised condition) as a key active ingredient, and there has been important evolution of measures to more accurately explore knowledge, attitudes and discrimination (referring specifically to the behavioural consequences of stigma), which we are now employing in subsequent iterations of this work.

Scaling up services

Addressing stigma is an example of one intervention component that contributes to closing the treatment gap, and the second paper submitted (*‘Scale up of services for mental health in low-income and middle-income countries’*) focuses on the question of measuring the extent to which implementation at scale has been achieved. This paper, part of the 2011 *Lancet* Series on Global Mental Health, found that despite an impressive number of rigorous studies that showed positive improvements in symptom and functioning outcomes, few governments have invested in applying this evidence at scale. These studies have led to an increasingly well-defined model for mental health service reform. However, there are important differences between how an intervention works as a pilot or in a trial, and when replication is attempted at scale. The barriers to scaling up mental health care essentially remain those that were identified in a key early paper by Saraceno et al in the first *Lancet* Global Mental Health series.

One significant challenge we highlighted was weak health information systems in mental health and poor epidemiological data, so that coverage could not be accurately calculated. Use of other information such as policy reform and investment in national services or Official Development Assistance for mental health, reinforced the conclusion that little concrete progress had been made towards closing the treatment gap.

Accountability to service users

In the *Lancet* Commission on Global Mental Health and Sustainable Development in 2018, I led the section on a ‘dimensional approach to mental health’, where we discussed reframing perspectives around mental health and illness, diagnosis, disability and the role of service users in their own recovery. To understand whether service users have influence in mental health service reform, we assessment objectively their participation in global accountability mechanisms (my third submission: *Accountability for the rights of people with psychosocial disabilities: an assessment of country reports for the convention on the rights of persons with disabilities’*). In the reports, we found outdated approaches, inappropriate language, and low levels of participation described, particularly in low income countries.

However, despite this, there is a significant move towards participation of service users and rights-based approaches as a basis for new international normative guidance development, and we describe the essential role of co-production in global mental health research moving forward.

Applying lessons learnt in different contexts and population groups

As in other low- and middle-income countries, while there has been progress on pilots evaluating decentralised services using task-sharing and collaborative stepped care, driving policy change with evidence, and gaining financial investment for scaling up in Nigeria has proved more challenging. The fourth submission (*'A structured approach to integrating mental health services into primary care: development of the Mental Health Scale Up Nigeria intervention (mhSUN)'*) outlines the development of an intervention and a plan for scaling up mental health services in Nigeria. The process was participatory, using Theory of Change methodology to ensure broad stakeholder participation in model development, while drawing on global guidance and research findings. Key methodological considerations in this work included a focus on process alongside outcome evaluation (on the basis that positive clinical and social outcomes are well documented, but the proof of application in Nigeria was of primary interest to policy makers).

Future contribution to the field

This learning around integration of mental health into primary care and community settings can be usefully applied to other target groups or sectors. One example of how this has been done is the field of neglected tropical diseases (NTDs). With a team at University of Jos in Nigeria, a number of studies were carried out to ascertain comorbidity and test an intervention for mental health integration in primary health care (PHC) to improve access for people with NTDs. I describe how research can contribute to building a case for application of these ideas in this new sector, resulting to date in a scoping review, a WHO Guide on Mental Health and NTDs and a forthcoming WHO Essential Care Package. I conclude that in this way, we can increase coverage (and reduce the treatment gap) by not only mental health service strengthening, but also mainstreaming mental health care into other sectors, using the lessons we have learnt in global mental health. More work is needed in health services research to understand how such normative guidance translates to adoption, embedding and sustaining change as we move to a new phase of scaling interventions and integrated services.

Analytical commentary

1 Introduction

In this analytical commentary, I will outline a body of research that contributes to our understanding of a key priority in the field of global mental health; to reduce the wide treatment gap that currently exists for mental health conditions, by improving access to mental health services. While my focus will be on research and evidence related to low and middle-income countries, in fact this treatment gap is high in all categories of national economic development using the World Bank's system.[1] As economic and social inequities are often as extreme within countries as across countries, the distinction of High-Income vs Low- and Middle-Income Country-focused (LAMIC) research is increasingly seen as arbitrary. However, it remains the case that there is far more research carried out in richer than in poorer parts of the world, despite this being where 90% of the world's population lives.[2]

I will review the evidence-base that has been developed since 2007 to address this stated goal of the global mental health field, including that to which I have contributed, and chart the different issues that have arisen to provide nuance and additional depth to this basic early aim – many of which touch on the research I have carried out. The decision to address a gap in access to mental health treatments was articulated in the final paper in the foundational first *Lancet* series on Global Mental Health in 2007.[3] Alongside addressing common and profound human rights abuses, reducing the treatment gap was identified as the major 'call to action' for not only an area of research, but also a wider 'movement'.[4] The arrival at this consensus (at least among a particular group of mainly researchers and clinicians) was reached despite a history in psychiatry of profound differences over some key issues that had resulted in a slower development of a 'global public mental health' compared to, for example, in global efforts to address infectious diseases, or maternal and child health.[5]

1.1 Major contested issues in global mental health

The most important issue has run through the development of the field, and that remains contested, is the degree to which mental health and ill health can be seen as a universal phenomenon.[6] It is only if there are sufficient similarities, can an assertion be defended that a global scientific endeavour could examine common phenomena, on the basis that there are common experiences of a person in Chad as in Chile, for there to be approaches that would alleviate these shared experiences of suffering.

Emil Kraeplin famously visited Java in 1904 to investigate the social, cultural and environmental factors associated with mental ill health, and arrived at the conclusion that there were sufficient similarities in phenomenological characteristics to warrant a common diagnostic framework. His categorisation of psychosis as either manic depression or dementia praecox (what we now call schizophrenia) has remained essentially what is still used in major classification systems. Transcultural psychiatry and related research continues to address the question of what is common, and what varies, across cultures in terms of expression of mental illness, and by extension, the degree to which treatment might or might not be appropriately utilised across cultures. Kraepelin's conclusions of the consistency of findings across cultures largely remain the basis of justifying the investment in common approaches to treatment and care in global mental health. It has been pointed out that in fact most of the early interest in cross-cultural psychiatry worked on the basis of seeking to fit behaviours observed in other cultures into the western classification systems, and where this was not possible, they were termed 'culture-bound syndromes.[7] Interestingly, the Indian psychiatrist, Ajitha Chakraborty made the case (in 1974) that transcultural psychiatry, in focusing on mental health in the global south was in fact not acknowledging culture in more economically developed countries.[8] A very similar charge has been made about global mental health today.

Evidence to support the idea of a universality of mental illness would include an observation of similar behavioural and described phenomena (symptoms and signs) across varying cultures. Clinical experience would seem to align with epidemiological findings, where prevalence of many conditions is perhaps surprisingly similar across cultures when using standardised instruments based on diagnostic categories – tools based on the WHO's International Classification of Disease (ICD) or American Psychiatric Association's Diagnostic and Statistical Manual (DSM) systems for example. However, this cannot be assumed to mean that there is a common aetiological basis, only that the instruments are eliciting similar behaviour or experiences. All psychiatric aetiology is a mixture of biological, social and psychological influences, so while similar prevalence may imply shared biological or environmental factors, it is challenging to tease out the extent of each. The more disabling conditions characterised by psychosis (sometimes called Severe Mental Illnesses) seem to have more similar prevalence rates across the world than Common Mental Conditions like depression and anxiety.[9] Psychotic conditions like schizophrenia and bipolar disorder have higher heritability (and concordance in twin studies) than depression or anxiety[10], which are also more influenced by extreme environmental conditions like conflict,[11] though differences in rates of psychosis among some sub-populations, of people who have migrated for example, are significant. While syndromes like schizophrenia have been recorded in similar rates in countries that had not been exposed to Western influence, eating disorders are recognised to be very dependent on exposure to influences like the media.[12] While we are not able to make causal inferences from similar prevalences or expressions of behaviour across cultures and geographies,[6] the field that I describe in this commentary is based on the premise that there are sufficient similarities across cultures to justify a global approach to the problem.

A second key issue, which is really a risk of unqualified universalism, is the question of which models of mental health and ill health become predominant. Critical voices in the transcultural psychiatry community argue that western-derived models of medical psychiatry cannot be universally applied to all cultures, and that there is significant risk of harm in attempting to do so, as this would inevitably usurp traditional means of providing support already in place.[13] Those seeking to set out the basis for a new field of global mental health did not deny this risk – after all, psychiatric institutions remaining in many countries as a legacy of colonialism are widely targeted for reform[14] – but argued that neglecting the application of appropriate scientific evidence would deny people in need the support they deserve.

Recent moves to ‘decolonise’ science and curriculums may provide the necessary check to the risk of historical European traditions and assumptions in science being unquestioningly applied.[15]

There is no question that most key thinkers in the emergence of the field in the early 2000’s were western-trained clinicians, even if from low- and middle-income countries.[16] While a broad public health approach was always proposed, there is the inevitable risk of an unquestioned application of western-derived models of ‘psychiatric illness’ in all countries. The fact that the WHO plays such a key role in the development and dissemination of normative guidance like the mental health Gap Action Programme (mhGAP) inevitably leads to criticism of a top-down influence and a ‘one size fits all’ approach.[17] Even when rigorous and structured approaches to generating guidance was used, like the GRADE methodology,[18] the dominance of evidence from high income countries was openly acknowledged as a weakness that had to be addressed.[19] The process of developing the latest version of the International Classification of Diseases (ICD-11) includes guidelines on the role of culture, which also added to their clinical utility.[20] It was judged to be important to have diverse representation in the technical committees developing the classification.[21] In the same way The mhGAP Guidelines Development Committee is deliberately chosen to be diverse, across scientific and clinical expertise, geographical and cultural representation, and increasingly, recognition of expertise by lived experience.[22] This latter consideration is a theme I have explored as an integral consideration in my implementation and research work.[16,23]

An importance counterbalance to this significant risk of dominance of western models of mental health care are efforts to promote locally-derived evidence and ideas, to address needs in a more contextually appropriate way. The question of the relationship between orthodox psychiatry and traditional and religious healers remains one of significant interest, and in recent years more concrete evidence has started to emerge to add to the experience of practitioners in navigating this relationship.[24,25] Over the past 20 years, ethnographic research, documenting local traditional practice as well as its intersection with modern psychiatric services, has moved beyond binary positions of criticism of the harm done by, versus defence of the use of, western models of care, to valuably informing how services can be more culturally appropriate, respectful, collaborative and effective.[26]

Another means of favouring less heard perspectives (or at least providing some balance) is by facilitating their exposure. The Mental Health Innovation Network, of which I am Principal Investigator, was established by London School of Hygiene and Tropical Medicine and the World Health Organization in 2013, to not only provide a forum for research translation, but to highlight innovative practice from the global south and enable useful ideas to grow.[27] It remains the biggest such network in global mental health, and has highlighted the possibility of innovations in mental health care provision in low income settings having the potential to bring learning from low- and middle-income countries to inform providers of services in resource-poor communities everywhere. One example of this 'south-north' transfer of innovation is the Friendship Bench, that was developed in Zimbabwe, and has informed practice in New York, London and a number of other settings.[28] While there are of course significant contextual differences across countries of different income levels, for example of culture or political and health system structures, there are often similarities in poorer communities in terms of social determinants, like the impact of poverty,[29] and in the challenges faced by poorly-funded service providers.

While these questions of universalism, culture and power have not gone away, the consensus around the need for urgent action on a global scale to respond to the suffering and disability caused by mental conditions, means that they have not derailed the growth of efforts to reduce disparities in access to mental health care in different countries – a state of affairs termed 'strategic universality'.[19] This need for urgent action was framed in explicitly moral terms by a key driver of the field, the anthropologist Arthur Kleinman, with a clear position that while cultural context is extremely important, it need not be in opposition to achieving the value of finding fundamental commonalities across countries. Solutions that are mutually acceptable to both the need to pay attention to unique cultural drivers of mental distress, and the understanding of the human condition that is relevant to people in multiple contexts, are possible by applying social science in a way that enables cultural validity to be valued alongside epidemiological methods that favour reliability.[30] The challenge for global mental health is to find these, even if mistakes are made on the way, because given the huge burden of mental conditions and associated social suffering,[31] inaction itself would be a failure of humanity.[32] This is the foundation of the field, providing a values-driven basis for the subsequent political buy-in, and growth in research and investment that has followed.[5] An important corollary that Kleinman insists upon, is the need to apply the same cultural analysis to (western) psychiatry as to the beliefs of indigenous populations.[30] Such reflection is an important counter to the risks of dominance of western psychiatry, and a prerequisite for any adaptation process, including Theory of Change, the application of which I discuss later.

1.2 Outline of this analytical commentary

A major Delphi exercise to gain consensus on priorities for global mental health research, published in *Nature*, raised identifying solutions for closing the treatment gap as a major focus.[33] I will outline the work that I have carried out in my particular areas of interest under this broad domain, with a specific focus on the main contributions I have made.

The four papers I am submitting to demonstrate this work are listed below[a].

Paper 1: Interventions to increase use of services; Mental Health Awareness in Nigeria. *International Journal of Mental Health Systems*, 2017; 11:1-6

Paper 2: Scale Up of Services for Mental Health in Low-Income and Middle-Income Countries. *Lancet*, 2011; 29:378(9802)

Paper 3: Accountability for the rights of people with psychosocial disabilities: an assessment of country reports for the Convention on the Rights of Persons with Disabilities. *Health and Human Rights Journal*, 2021; 23(1):175–189

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[a] My full publication record can be accessed on Google Scholar.

Paper 4: A structured approach to integrating mental health services into primary care: Development of the Mental Health Scale Up Nigeria intervention (mhSUN). *International Journal of Mental Health Systems,* 2018; 12:1

The overarching thread that links these papers is the exploration of the means by which we can reduce the gap in access to mental health services in low- and middle-income countries. The first paper examines factors that might influence help-seeking behaviour (namely cultural beliefs and stigma), and how we can design programme components to reduce these barriers and increase use of mental health services. The second paper was written as part of a major exercise undertaken to review what progress had been made in reducing the treatment gap for mental health, and I discuss some of the factors influencing progress of the field towards this goal, including issues related to measuring coverage. A key theme that is integral to all of my work, given its importance in global health, has been the essential consideration of how culture, colonial histories and power influence the way that evidence is generated and applied. The third paper examines the practical efficacy of one important global mechanism in place to promote better accountability to people affected by mental conditions and their representative organisations. The final paper is an example of the application of many of these ideas in a practical collaborative development and evaluation of an intervention to integrate mental health into primary care in Nigeria, where I have carried out much of my work, and continue to do so. This is a direct application of the core global guidance for health systems reform towards decentralization, task-shifting and stepped collaborative care. I have had the privilege of participating in several processes of reflection and consensus-building around the direction of the field, and the final section builds on the way that the field of global mental health has evolved in relation not only to participation of people using services, but also a shift towards an emphasis on social determinants, and away from vertical siloing to integration of mental health across sectors. I use one example that I am particularly engaged in, namely integrating consideration of wellbeing and mental health to the field of neglected tropical diseases (NTDs).

In this commentary, I will seek to cover in detail the issues addressed in my chosen papers. However, while the nature of the topic demands a broad overview of the key emergent themes that have shaped the field, like transcultural psychiatry, decolonizing mental health, and global health financing, it is not possible to explore all of these in great depth.

2 Addressing the mental health treatment gap

The Global Burden of Disease (GBD) studies carried out in the 1990s established for the first time that mental, neurological and substance-use (MNS) conditions[b] were among the most significant of all disease categories in terms of global Disability Adjusted Life Years (DALYs), with depression, dementia, schizophrenia and alcohol use disorders among the top ten contributors to total global burden of disease.[34] The use of the DALY metric itself was important in repositioning mental health, and other Non-Communicable Diseases (NCDs) as worthy of attention, because by combining Years of Life Lost (YLL) with Years Lived with a Disability (YLD), the main means by which different health conditions were compared acknowledged disability (of those living) in addition to only considering mortality. Mental conditions tend to start early (with a large upsurge in teenage years),[35] many are chronic, and have been allocated a high disability weighting.[36] Table 1 demonstrates the high levels of self-perceived functional loss associated with different physical and mental conditions in a Nigerian population (the Ibadan Study of Aging),[37] which is reflected in the results of the GBD studies. Disability weights are derived from brief standardised descriptions, following which people are asked to determine how disabling they feel the condition is. Although people rate mental conditions as very disabling, it has been argued that even this underestimates the true burden as the weightings are still limited to a focus on health loss, rather than including welfare loss, and the descriptions do not capture the multifaceted impacts of mental health conditions.[38]

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[b] I have used ‘conditions’ directly in place of ‘disorders’ throughout this paper, and the terms can be read as synonymous. This is preferred by the disability movement, and the convention is gradually being adopted through the field, including by the WHO.

Condition	Male	Female	Total
	%	%	%
Depression	58.0	39.7	47.2
Arthritis	18.5	22.6	20.6
Back Pain	23.1	25.0	24.2
High BP	31.2	16.7	25.0
Asthma	9.6	17.6	13.6
Diabetes	5.7	14.3	10.0

Table 1: Proportion of people by health condition self-defining their level of functioning as severely impacted, based on research in Nigeria (Global Disability Rating of 'Severe').[37]

The total proportion of global DALYs attributed to mental, neurological and substance-use (MNS) conditions is 9.4% at a global level, and 4.3% in countries with a low Socio-Demographic Index (Figure 1).[c,39] This is 2016 data, and a gradually increasing trend has been noted. In fact, between 1990 and 2019, a reduction in DALYs from communicable, maternal, neonatal, and nutritional diseases has been offset by an increase in burden due to non-communicable diseases, including mental conditions.[38] More recent estimates have suggested this is an underestimate, and MNS conditions make up around 13% of all health-related DALYs.[40] This places mental conditions as 'a distant first' in terms of YLDs, and equal to cardiovascular diseases in terms of DALYs. The authors of this paper make their case on the basis of some conditions not being seen as under the area of mental health (personality disorders, suicide and self-harm), a lack of recognition of the intersection of mental conditions with chronic pain, and the role of mental conditions in early mortality from other causes.

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[c] SocioDemographic Index (SDI) is a summary measure of sociodemographic development, based on average income, educational attainment, and total fertility rate.

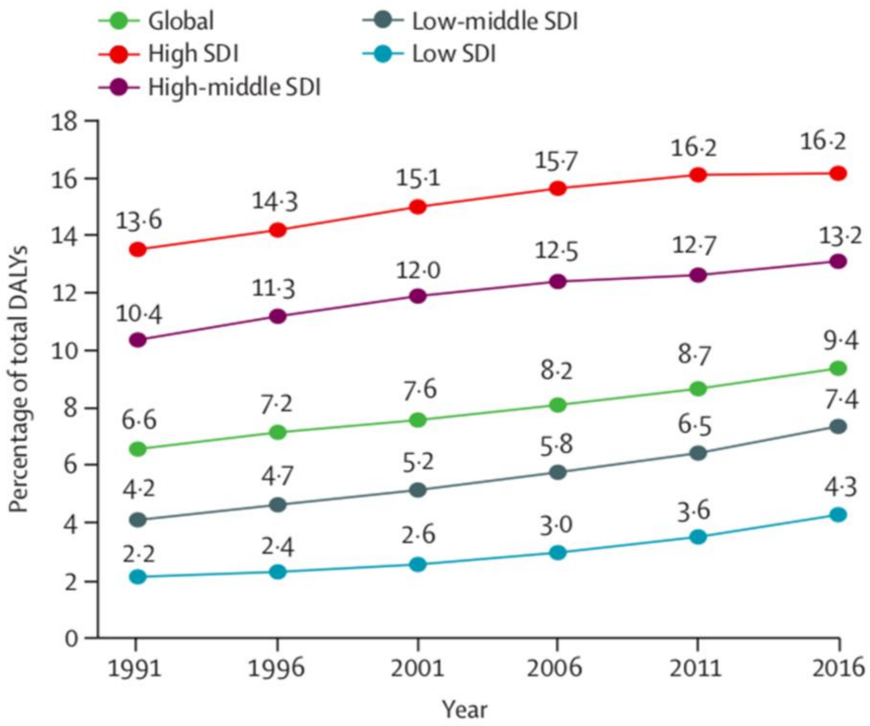


Figure 1: Burden of mental and substance use conditions, including dementia and suicide (self-harm) by Socio-Demographic Index (SDI) groups, 1991-2016 (from Lancet Commission on Global Mental Health and Sustainable Development[39]), using data from the Global Burden of Disease studies.

It is also worth noting that while mental conditions have historically not been considered to have high mortality, several mental conditions are associated with reduced life expectancy, for example people with schizophrenia have between 15 and 20 years of potential years of life lost compared to their peers, with the higher figures found in Africa.[41] Major reasons behind this are postulated to be exposure to many social risk factors and barriers to accessing health care (for example through diagnostic overshadowing, where physical conditions are overlooked due to a focus on a person's mental health condition[42]), metabolic impacts of antipsychotic medication, and social drift leading to increased risk of many physical health conditions. Eating disorders also have a high mortality,[43] and other conditions like depression and anxiety all have an associated increased mortality rate.[44] The differences in mortality in high versus low income country settings has been contested since the major International Pilot Study on Schizophrenia (IPSS) and International Study on Schizophrenia (ISOS) studies,[45] which showed better long-term outcomes for people with schizophrenia in low income countries where the studies were carried out (though this did not include analysis of the African site in

Ibadan), with these findings being questioned by some authors.[46] In a detailed review of longitudinal studies across 11 countries, they found significant variation in impact of mental conditions on mortality, but did not support the axiom that outcomes for people with schizophrenia are better in low income settings, and argued that they are almost certainly worse.[46]

In addition, suicide is now recognised as the fourth highest cause of death globally among young people (between the ages of 15 and 29).[47] This is in part a result of suicide data becoming more reliably collected, and probably reflects a real increase in successful suicide in young people globally (where historically older men were those at greatest risk). In many high income countries, suicide is the single highest cause of death,[47] and in countries of all income levels, this issue has captured the attention of politicians, health leaders, and the wider community to become a potent point of focus for advocacy to strengthen mental health care provision more broadly.[48] Reducing rates of suicide is also one of the few Sustainable Development Goal targets (Target 3.4) associated with mental health (though by no means directly). Ironically, better mental health treatment is only likely to have a relatively small impact on suicide rates, as social determinants and specific public health interventions like reducing access to means of self-harm are far more important factors.

It is increasingly well recognised, and to an extent measured, that mental distress (which when more severe can lead to symptoms amounting to a comorbid diagnosis) has a negative impact on outcomes of many physical conditions, including HIV/Aids and TB[49], non-communicable diseases (like diabetes and cardiovascular conditions), and neglected tropical diseases. In fact, it has been argued that disability weightings (used in calculating DALYs) for many of these conditions would be higher if the common comorbid mental conditions they are associated with were considered.[50] When associated mental health impacts are taken into account, the total Burden of Disease increases two-fold and ten-fold for lymphatic filariasis and cutaneous leishmaniasis respectively.[51]

Despite the high level of disability associated with mental ill health, around 76%-85% of people with the most severely disabling mental health conditions in the lowest income countries do not access mental health care in the 12 months prior to the survey.[52] If the expected standard of care is defined as 'minimally adequate', then the treatment gap is even higher. A survey of 21 countries found that only 41% of people who attended services received adequate treatment for depression.[53] As we will see later, measuring coverage (arguably the core metric for success in scaling up access to services), must include measures of quality and other qualifications beyond simply numbers of people using services.

What is surprising is that even in high income countries, 35-50% of people with these conditions do not access treatment. It is worth noting that in both higher-, and lower-income countries, severity of the condition, and perceived need, was most strongly correlated with increased help-seeking. This is well documented in high income countries,[54] and is certainly the experience in many implementation programmes in sub-Saharan Africa, where, despite depression and anxiety being much more common than psychoses or epilepsy, the latter make up the majority of cases attending services.[55] This is hardly surprising, but does imply a high threshold for people to attend services (or to be taken by their relatives). The reason why people do, or do not, access treatment is poorly studied in low income countries, but in a systematic review (where five out of 52 papers were from middle income countries, and only one was a low income country), positive associations were found with middle-age, female gender, higher educational level, and being in the dominant ethnic group.[56] Low income and poverty is more of a barrier in countries with little social protection or health insurance,[29] and stigma is a major factor.[57]

2.1 Mental health awareness raising in Nigeria

The first paper submitted ('Interventions to increase use of services; mental health awareness in Nigeria')[58] addresses one of the postulated reasons for low levels of service use – lack of awareness about existence of services, and lay explanatory models of illness not lending themselves to help-seeking through health services.[59] The relationship between belief systems, attribution of causation, and help-seeking decisions is complex. It is well recognised that in many countries, people will first seek treatment from traditional healers (including in sub-Saharan Africa where much of my work has taken place). However, even when people continue to hold these beliefs, they will often make use of orthodox psychiatric services at the same time as seeking support from traditional or religious options.[60]

While living in Nigeria (2003-2011), I had the role of coordinating a community mental health service, supporting psychiatric nurses who were based in state Primary Health Care (PHC) centres in the South Eastern Nigeria.[61] I carried out research with health service colleagues in primary care services, the State health ministries, and a local Federal Neuropsychiatric Hospital (Enugu), to examine the impact of community awareness-raising on attendance to services.

Mental health services in Nigeria are largely based in specialist tertiary hospitals (Federal Neuropsychiatric Hospitals, Federal Medical Centres, and some university teaching hospitals).[62] This centralisation of services (in a country of 200 million people) means that the treatment gap is estimated at 80% in Nigeria (in the mid-range for low- and middle-income countries, though it is worth noting that the definition of accessing care included traditional and religious healers, which is common).[63] At least 90% of the formal mental health budget in Nigeria is spent on these services, and there is little mental health care available at primary care level outside of pockets of often research-based pilots.[64] Lagos is a recent exception, where an externally funded pilot has been adopted more widely by State authorities.[65] Patients usually have to pay for services out of pocket, as only 5% of the population (civil servants) are part of the National Health Insurance Scheme (NHIS), and within this, mental health provision is weak.[66] This established pattern of service access, where people will tend to go straight to specialist services due to not historically having services of adequate quality provided at primary care goes beyond mental health. Any move towards the globally recognised ideal of decentralisation of services, to which Nigeria’s policy is aligned,[67] will require a change in population help-seeking behaviour.

In this study, we evaluated a programme designed to raise awareness about mental health, including existence of the primary care-based services in Abia, Imo and

Ebonyi States that we supported. We used service use data to measure the impact on service uptake of an intervention based on community health volunteers (Village Health Workers) receiving training and undergoing targeted engagement through existing community groups like churches, or women's and youth groups. This occurred alongside a campaign of media appearances, using radio appearances and jingles, and posters. Immediately after the intervention started there was aa five-fold increase in service use, which quickly dropped off, but remained at a statistically significant higher level for 10 months. It remained elevated until data collection stopped (month 48) but was no longer statistically significant..

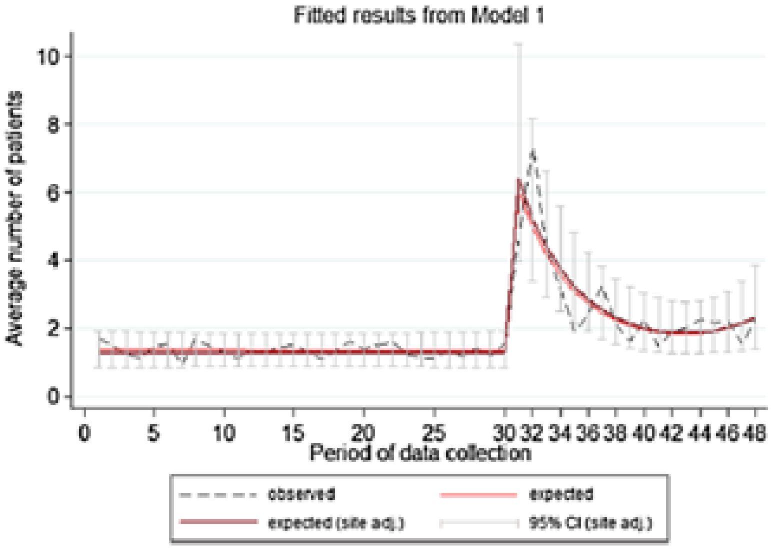


Figure 2: Fitted regression estimates of the incidence of new patients per month before and after an awareness-raising intervention in Imo State (intervention in month 30)

This paper replicated the results of a previous study we carried out in the same context,[68] but used a more rigorous methodology while trying to stay true to real-world circumstances in which we were working. While we wanted to use routinely collected data, we decided to more actively collect the data on a monthly basis from clinics ourselves, as previously we found information systems to be very weak when we relied only on the state system, with significant missing data. The major weakness was that because our comparator site (Anambra State) had a nurses strike during the period of the study, we were unable to directly compare our outcomes with a similar location that had not had the intervention. To account for this, we used a statistical method of comparing expected Incident Rate Ratios across time. A second weakness of this paper was that it presents only the combined total of people seen every month, masking a considerable variation in the number of people attending the clinics in each site. It would have been valuable to explore the reasons why some Village Health Workers were much more effective than others. This could have been done firstly by presenting more granular service use data (at an individual site level), and by following up with measurement of postulated factors that might influence this; location or reputation of the clinic or staff, ease of transport, population characteristics, or communication skills or competencies of the staff member involved.

The results demonstrated that population engagement using existing community health staff (in our case established volunteers) could significantly increase use of health services. We concluded that there would be benefit in occasional (eg 6-monthly) refresher sessions to maintain the effect, and that this type of intervention is valuable especially when new services are started. I used these results in later work when establishing a national network of mental health services in primary care in Sierra Leone,[69,70] and we are currently evaluating an anti-stigma intervention there.[71] Subsequent work in the field has continued to emphasise the importance of community engagement alongside establishment of new services to promote uptake, but has evolved to usually encompass a deliberate attempt to also address mental health-related stigma.

One significant development in these more recent approaches has been to emphasise contact interventions (direct or virtual engagement with people living with the stigmatised condition) as a key active ingredient alongside media campaigns and community engagement.[72] A personal connection, and seeing the person in their full humanity is seen as challenging the labelling and stereotyping that happens in the process of stigmatisation. ‘Champions’, who are willing to speak openly about their lived experience with mental conditions have become a hallmark of stigma-related work, from large national programmes to more localised campaigns. Time to Change, the official anti-stigma campaign that ran in England from 2007 to 2021 accrued a substantial amount of evidence that such interventions contribute to changed attitudes.[73] I worked on a project where the intervention was subsequently adapted and implemented in sites in five low- and middle-income countries (four in Africa, and one in India), using similar approaches.[74]

An international study of discrimination in severe mental illness found that 90% of people with schizophrenia reported discrimination, and over 70% sought to conceal their diagnosis.[75] Perhaps not surprisingly then, given the very real impact of discrimination on stigmatised people's lives, there are risks associated with publicly identifying oneself as part of anti-stigma work, and people risk losing their jobs and being excluded in other ways. If not well supported, champions or lived experience advocates risk being harmed by these intervention methods, and there are important ethical and practical considerations to consider. We will revisit these issues of how service users engage with programme development and research in Chapter 4 below. Similar considerations have to be taken into account when co-producing research, to ensure that the emotional labour of participation for people with lived experience is not over-burdensome.[76]

It is challenging to measure complex cognitive, social and behavioural factors associated with stigma,[77,78] with a variety of different models seeking to define in a structured and logical way cognitive processes, attitudes, emotional consequences and behaviours – at an individual and social level.[79] This structure of knowledge/attitudes/behaviour (discrimination), based largely on Corrigan's work, has become the dominant model that has been applied to mental health-related stigma research.[80] Complementary to this has been an emphasis on the importance of power dynamics and attribution of blame as enablers of stigma.[81] Consequently, in intervention research, local belief systems (especially related to causation and perceptions of blame) play an important role in practical design of anti-stigma campaigns, across a variety of cultural settings. I have routinely taken this approach in developing anti-stigma campaigns in my mental health and NTD interventions.[82,83] Recognising not only stereotype and labelling, but also power dynamics has contributed to the thinking of the movement of people with lived experience,[84] acting as a powerful counter to self-stigma. Placing people with lived experience at the centre of this work, often through self-help or peer groups, not only mobilises the effectiveness of contact interventions to influence potential stigmatisers, but also allows people affected to create a different narrative and more confidently assert their perspectives.

While on the one hand stigma is a universally well understood phenomenon of social exclusion at a popular level, there are some practical challenges to its measurement. For example social desirability is a major issue in such a socially taboo topic, and instruments must be administered carefully.[85] Despite this, there has been an important evolution of measures to more accurately explore the dimensions of knowledge, attitudes and negative behaviours (discrimination), described above. Measures like the Mental Health Knowledge Schedule (MAKS), the Discrimination and Stigma Scale (DISC), and the Reported and Intended Behaviour Scale (RIBS) have been found to have strong psychometric properties and good reliability and validity in comparison to other established stigma scales.[86] Discrimination (behavioural consequences of stigma) is particularly hard to measure in practice, hence RIBS relying on asking people what their intended behaviour might be, rather than measuring discriminator behaviour itself, though fundamentally, this is the most important outcome for people affected. These instruments are now being employed in subsequent iterations of this research work (for example under the International Study of Discrimination and Stigma Outcomes (INDIGO) project[86], with whom I collaborate. In a study in Sierra Leone, we applied these elements to an approach to engage communities and seek a better understanding of their perspectives and how they might provide support to people with mental conditions through Community Mental Health Forums (CMHF).[41] This CMHF intervention is also being used in the the Support, Comprehensive Care and Empowerment for People with Psychosocial Disabilities programme (SUCCEED Africa)[87], and is one of the elements of the complex intervention that we are evaluating in a process evaluation and Randomised Controlled Trial.[88] Stigma is also an important mechanism linking high rates of mental health conditions among people with physical conditions like neglected tropical diseases (Chapter 5).

2.2 The case for investment in mental health

There is no doubt that mental health is a neglected area when compared to other fields of global health. The simplest proxy for commitment to addressing the treatment gap is to compare the proportionate contribution of mental conditions to total global burden of disease, to the proportion of health budgets spent on mental health. This can be done at national level, for which burden of disease data is generally available, and budgets for mental health are often available as a part of total health budget. The quality of both these types of data is generally poor, with substantial extrapolation from generic prevalence data, despite prevalence varying across populations for both common mental health conditions[11] and 'severe mental conditions' like psychoses.[89] In general, national health budgets are better at documenting accurately the resources allocated to specialist services, than to mental health (or other services) that are incorporated into secondary or primary health services.[90] However, given that in many countries, the great majority of mental health care provided in government services is in specialist hospitals, this is not always a problem. In an example assessing financial allocation to mental health services in Nigeria,[91] the authors were able to identify the budget to specialist neuropsychiatric hospitals (3.3% of specialist hospital budget) and used this as a proxy for total mental health spending, as so little was thought to be spent elsewhere.

At national level, even in high income countries, which have typically undergone substantial reforms in mental health service provision in the last 20-30 years, mental health is almost always far less as a proportion of total health spend than the percentage burden of disease that it represents. In sub-Saharan Africa, less than 1% of the health budget is typically spent on mental health.[92] This small allocation is in countries where an already low proportion of national budget is spent on health. The African Union's Abuja declaration of 2001 recommended African countries spend 15% of their annual Gross Domestic Product (GDP) on improving health. This has never been achieved,[93] though it is important to recognise that the Abuja Declaration also reaffirmed the UN recommended level of 0.7% of High-Income Country (HIC) GDP to be devoted to international development, and this has also only been achieved by a handful of countries, with the UK stepping back from the commitment in 2021 after having previously achieved it since 2013. As we have seen above, funds that are spent on mental health are often spent inefficiently on centralised services with expensive 'hotel' costs of hospitals, and a small number of specialist clinicians.[94]

At the level of global health, international levels of Official Development Assistance (ODA) for mental health might similarly be seen as a barometer for commitment to mental health in international development. In 2013, less than 1% of Development Assistance for Health (DAH) from governments and private philanthropy was for mental health.[95] This amount is slowly increasing, but even this amount was largely devoted to emergency response, rather than development initiatives or health system strengthening. The shifting winds of political will and risk of a particular emergency no longer commanding sufficient attention or prioritisation means that such funding is not always reliable in the long-term. For example, during COVID-19, substantial funds were donated for MHPSS, mainly through bilateral donations, but in previous emergencies, such funding was short-lived and even here, funds were skewed towards certain populations, often not reaching people with pre-existing mental conditions,[96] though they were very seriously affected by the outbreak and its response.[97] There are also significant opportunities for funding mental health as a cross-cutting issue, for example with its recognition as a ‘fifth Non-Communicable Disease’,[98] or as a component of physical conditions like HIV, or in humanitarian response - a theme emphasised in the *Lancet* Commission on Global Mental Health and Sustainable Development (see Chapter 5).

Finally, outside of bilateral and multilateral finance mechanisms, there are other actors emerging in the finance landscape,[99] notably philanthropic organisations, whose giving has risen to a third of total Development Assistance for Mental Health (more than doubling over the 16 years of one analysis).[100] However, this form of funding also has inherent sustainability issues, as well as inequities in distribution. There is some evidence that such external funding can have a stimulant effect, leading to increased governmental investment, which is usually a preferred and more sustainable source.[101]

The stark contrast between a high demonstrated need, and low levels of investment, represents the clearest case for increasing attention to mental health as a global public health priority. As a complement to this case for equity, is the case for the positive contribution that mental health can make to international development.

Mental illness, through lost income from unemployment and high health care costs, exposes people to poverty.[102] Poverty is also a strong risk factor for mental illness in a reinforcing cyclical relationship.[29] These two directions of the cycle have been called the ‘social drift’ and ‘social causation’ hypotheses, and have formed a helpful basis for starting to examine the interventions that might have potential to break this cycle.[29] A systematic review and meta-analysis carried out in 2020 examined 39 mental health interventions from low- and middle-income countries to determine their economic outcomes, and found around half had demonstrated a significant impact on poverty.[103] There was a strong correlation between individual improvement in mental health outcomes and economic outcomes, and greater improvement when there was an explicit economic component to the intervention.

An important part of the case for the importance of improving population mental health is therefore that better mental health leads to a more productive workforce and might be less of a brake on economic development. This economic research is at a fairly early stage, but evidence around the economic value of investment in mental health has been generated, for example the cost-effectiveness of services for schizophrenia,[104] bipolar disorder,[105] and depression[106] in low income settings. An estimation of costs associated with scaling up a package of care to achieve basic coverage was carried out for Nigeria,[107] and a global return on investment (ROI) analysis found a ROI of 3-5 dollars for every dollar spent on services for depression and anxiety.[108] Since 2019, a series of investment cases have been drawn up for Liberia, Ghana, South Africa and other countries, with the methodology recently documented in a WHO Guidance Note.[109] The methods used in these analyses tend to be based around modelling, the results of which is only as strong as the source data used, the degree of extrapolation needed in interpretation for their use, and accuracy of assumptions made.

Despite these methodological and data challenges, these studies have made valuable contributions to advocacy for increased investment in mental health, but it will be once larger scale programmes are evaluated that more accurate real-world data will be available. A final point is that while an increase in resources is essential, the way that these resources is used is key, with a paper in the *Lancet* 2011 Global

Mental Health Series pointing out that inefficiency and inequity also had to be addressed alongside scarcity.[94]

Mental health was not mentioned in the Millennium Development Goals (MDGs) specifically at all, but was included after more vocal and effective advocacy during negotiations for the post-2015 Sustainable Development Goals,[110,111] including in Africa.[112] Since then, the role of mental health in major health developments at a global level, like Universal Health Coverage[113] or the response to the COVID-19 pandemic,[114] have become much more routinely accepted as a core component. The COVID-19 pandemic also reinforced a trend (at least in high income countries) of a wider popular discourse around mental health and wellbeing, for example as a part of business considerations and workplace efficiency.[115] This recognition of mental health and wellbeing as an integral part of how society functions has probably served the cause of more formal investment in integration of mental health in wider health and development sectors well.

3 Scaling up services

The past 20 years have seen a mushrooming of research around mental health interventions, the second submitted paper focuses on the question of measuring whether this growth in evidence has translated to implementation at scale.[116] This paper, 'Scale up of services for mental health in low-income and middle-income countries', which I led as part of the 2011 *Lancet* Series on Global Mental Health,[117] sought to answer the major question of any action-orientated endeavour – '(to what extent) has success been achieved?'

3.1 Measuring service use; coverage

One significant challenge we highlighted was in measurement. The weak health information systems and poor availability of mental health and epidemiological data, meant that coverage (proportion of population whose identified needs are met - our main metric) could not be accurately calculated due to unavailability of reliable figures for both numerators (number of people with mental health needs met) and denominators (total number with needs).[118] Use of other information such as policy reform and investment in national services or Official Development Assistance for mental health, reinforced the conclusion that little concrete progress had been made towards closing the treatment gap.[119]

National and global work to strengthen health information systems has continued, seeking to more reliably measure mental health system indicators. For example, incorporation of mental health indicators into the District Health Information System (DHIS2) in many countries, including work I was involved with in Nigeria[120] and establishment of a global dashboard for mental health progress (Countdown 2030).[121]

Coverage is a central concept in scaling up services, and usually defined as the primary intended outcome. Most studies limit measurement to contact coverage (numbers attending services/population in need), but De Silva, in her 2014 systematic review of measurement of coverage in mental health,[118] describes stages of a service being (i) physically available; (ii) financially and geographically accessible; (iii) acceptable; (iv) used; and (v) delivered appropriately and effectively. While effective coverage (those responding adequately/population in need) can been seen as the strongest measurement,[122] in fact, De Silva found in her review that only one mental health programme (Improving Availability of Psychological Treatment, IAPT, in the UK[123]) had measured effective coverage.

Equity is also an important consideration in coverage, and there are several intersectional ways that equity must be considered in scaling up. Characteristics such as gender, age, ethnicity, disability, literacy and sexual orientation often lead to exclusion and under-representation in service use. Awareness-raising and other means of identification, screening or reducing barriers to care must be deliberately targeted at marginalised communities so that they are accessible to all. Recent work in MHPSS has included guidelines for improving inclusion of persons with disabilities,[124] and addressing specific needs of different populations for COVID-19 response.[125] There is good evidence that perceived discrimination and mistrust not only results in reduced service use, but worse mental health outcomes,[126] though there are many intersecting mechanisms, and social and structural determinants are likely to intersect with psychological reactions to stress and exclusion.[127]

3.2 Progress in improving coverage

The 2001 WHO World Health Report; ‘New Understanding, New Hope’[128] – the first focused on mental health – reinforced the importance of mental health in overall health (established in the WHO constitution’s definition of health; ‘… a state of complete physical and mental wellbeing…’). The report laid out clear actions, and a platform for research, based largely on consensus and extrapolations of evidence from high income countries, as there was very little published from low income settings. Prompted by the recognition of the mental health treatment gap described above, there has been a significant increase in research, often with an explicit aim of addressing this gap, for example the ‘call to action’ that followed the foundational *Lancet* 2007 Series on Global Mental Health,[129] followed by a subsequent 2011 series, which included this paper on scaling up mental health services as an explicit recognition of the need to measure progress.[116]

The impressive growth in research evaluating mental health interventions that we found, was almost entirely made of relatively small scale pilot studies.[130] These key individual trials vary in quality, but many are methodologically rigorous (often using mixed methods, and Randomised Controlled Trials, RCTs), and tend to show both statistically significant and meaningful improvements in clinical and social functioning. The advantage of RCTs in addressing problems of confounding and bias has been criticised as limited, however, by their inability to unpick the mechanisms of action that might enable more comprehensive learning about complex interventions.[131] The focus on demonstrating overall effect sizes may be of use for decision-makers, including by using such results as a basis for economic evaluation, but this approach is generally poor at understanding the way that context or personal characteristics influence individual or group outcomes. Effective mental health care is inherently dependent on interpersonal therapeutic factors that lend themselves less well to manualisation than in physical care, and statistical methods like sub-group analysis often lack statistical power, hence are not ideal for subtle analysis of the many factors known to influence causation and outcome.[132]

Mixed methods approaches, which complement the strengths of RCTs, are therefore commonly used in the global mental health field, systematically applied to understand process as well as outcomes. Consensus recommendations for process evaluation such as the MRC Guidelines[133] have been widely used, often in combination with Theory of Change,[134,135] which has gained particular traction in the mental health field.[136-138]

In recognition of the so-called 10/90 research imbalance, where less than 10% of research is carried out in the countries where 90% of the world's population lives[2], many researchers have followed a commitment to evaluate interventions through implementation in low resource settings with weak service infrastructure, and among populations facing multiple risk factors for poor mental health. Such a commitment to realist methodologies promotes evidence that is potentially more valuable for policy- and decision-makers.[139,140] It is worth noting that despite an increase in the amount of evidence drawn from the global south, mental health research infrastructure remains unbalanced through research partnerships that are inherently reflective of established (colonial) relationships, with consortiums that are more likely to have funding channelled through a lead in a high income country etc. However, new models of addressing such imbalances have been proposed – usually drawing on now long-standing collaborations.[141,142]

Specific examples of influential studies include COPSI (Community-based intervention for People with Schizophrenia and their caregivers in India),[143,144] which demonstrated improvements in functioning with a WHO disability scale (WHO-DAS) using a community based approach addressing needs of people with schizophrenia. Similarly, RISE[145] (Rehabilitation Intervention for People with Schizophrenia in Ethiopia) found improvements in clinical and functional outcomes for people with schizophrenia using a community approach. MANAS (MANashanti Sudhar Shodh, or 'project to promote mental health' in the local Konkani language),[146] focused on use of lay counsellors in primary care settings for common mental conditions (depression and anxiety) and found improved clinical outcomes in the intervention arm of the cluster RCT. Other, more recent interventions, like The Friendship Bench,[147] have applied many of these learnings while adding new elements like problem solving therapy, or have been directed towards different target groups, like adolescents, eg Early Adolescent Skills for Emotions (EASE),[148] or Helping Adolescents Thrive (HAT).[149] The WHO has invested heavily in so-called 'transdiagnostic psychological interventions' (like Problem Management Plus, PM+),[150] in recognition of the major gap in evidence for non-pharmacological interventions identified during the development of mhGAP Intervention Guide.[151] These are specifically designed to be of practical feasibility in low resourced settings, seeking to overcome some of the challenges of the delivery of talking therapies at scale. In fact, the WHO has now renamed these interventions 'scalable low-intensity psychosocial interventions' and have also explored options for their delivery using digital platforms.[152]

Beyond outcome evaluation of specific interventions, several key research projects have focused more on *how* these can be delivered at a wider scale leading to sustained service reform. The PRogramme for Improving Mental health CarE (PRIME)[153] was a partnership across five low- and middle-income countries that developed, implemented, and evaluated district mental health care plans in an effort to better understand how to expand coverage of mental health care through state services. Using process evaluation methods, they found that it was feasible to integrate mental health into primary care in low resource settings, though success in increasing treatment coverage varied significantly. The Emerald programme grew out of PRIME, and sought to enhance health system performance, directly addressing factors that led to PRIME's variable success, like human resource capacity, financing, health information and other health system processes.[154]

In the next section, I will summarise consensus on the main health system reforms that might achieve sustainable improvements in mental health care coverage.

3.2.1 Deinstitutionalisation and decentralisation

Human rights concerns, coupled with advances in medication (like the discovery of chlorpromazine in 1951 for the treatment of schizophrenia) and social interventions (like Assertive Community Treatment) ,[155] alongside financial incentives, were a driver of reform starting in the 1980s, when many high income countries shifted from long-stay hospitals or asylums towards community-based mental health services. The United Kingdom is a well-documented example,[156] as well as the more radical Trieste model in Italy,[157] where all specialist hospitals were closed as a first step. Deinstitutionalisation, or closure of long-stay residential hospitals was the central pillar of these reforms, with most people moving towards independent living in the community, and a limited number living in small group homes. However, despite a recognition that institutional care has many inherent weaknesses, this model remains stubbornly resistant to change in many countries, including in Eastern Europe[158] and the Eastern Mediterranean.[159] In many previously colonised countries, asylum-based system continue to be reflected in the structure of services to this day.[14] Reasons for the slow pace of reform include government inertia, discrimination in the community, lack of public mental health expertise and community alternatives for long-stay patients, and resistance from entrenched interests.[160] These overlap with the barriers to scaling up mental health care that were identified in a key early paper by Saraceno et al in the first (2007) *Lancet* Global Mental Health series.[161] These included weak political will, lack of investment, low human resource capacity and a lack of understanding of public mental health.

Learning from high income country settings has been applied theoretically to advocate for ‘balanced care’ models, shifting from the dominance of large institutions towards a mix of services to meet varied needs. Community mental health services have been shown to not only improve access to care and clinical outcomes,[162,163] but also the risks of neglect and abuse.[164] In addition, effective treatment for mental ill health is associated with better economic outcomes and improved economic status.[104] As with all aspects of reform, greater progress has been made in terms of *policies and plans* for reform for such deinstitutionalisation and balanced care,[165] than *investment*, due to the reasons above. When deinstitutionalisation does occur, it must be done well, with readiness of a balance of appropriate health and community resources[166] being the key factor in protecting past patients.[160] Otherwise there are risks of failure of continuity of care, particularly when arguments for greater efficiency underly advocacy for reform, and there is insufficient investment in community alternatives. In the UK reforms of the 1980s, it was argued that a shift to a community model of care would save money. This did not turn out to be the case, and costs were roughly equal.[156] Closure of state psychiatric hospitals in the USA in the 1970s (favoured both by fiscal conservatives and advocates for human rights) has been associated with a massive increase in mentally ill people in prison or becoming street homeless.[167] In South Africa, a decision to close an institution (Life Esidimeni in Gauteng Province) in 2015/16 was carried out in a rushed way, with inadequate preparation of community placements, leading to 144 people dying, with the whereabouts of another 44 remaining unknown.[168]

3.2.2 Integration into existing services, particularly primary care

Established service infrastructure offers the opportunity for mental health care to be integrated into existing services, with parity between mental and physical health.[169] In addition there are clear potential benefits of reducing stigma, efficiencies of using existing infrastructure, and making care more accessible.[170] However, general health systems are typically extremely weak in low income countries (especially at the primary care level), and infrastructure and personnel struggle to cope with the extra burden that introducing new work brings where services are poorly resourced.[171,172] There has been significant research exploring this issue, reflecting its practical pertinence and degree of focus as a means of improving coverage.[173,174,175] This builds on a well-established tradition of research in low income settings, though most, like the Bamako Initiative, have not included mental health, so lessons must be adopted with care.[176] Policy in many countries already identifies primary care as the site for first line care, reinforced by WHO recommendations since Alma Ata, reinforced by the Astana Declaration of 2018. This represented an important reassertion by WHO of primary care as the foundation of health systems, and mental health is mentioned alongside physical conditions. The WHO framework of health system building blocks describes the health system in terms of seven building blocks—governance, human resources, financing, medicines and technologies, service delivery, information, and infrastructure,[177] that respond to the needs of the population in a given context. This framework is able to incorporate mental health service provision well, and has been revised specifically for the Africa region.[178] The mhGAP programme was designed to provide appropriate guidance on clinical interventions in primary and secondary care settings, and remains the major evidence-based vehicle for WHO in translating advice for frontline clinicians.[179]

However it has been noted that simply training more staff is not sufficient, but understanding, and utilising existing health system processes (especially for chronic care) is essential,[180] and subsequent operational guidance incorporates attention to addressing the relevant health system building blocks as a support to improving staff competencies alone.[181]

3.2.3 Task sharing

A major review of human resources in low income health settings found that replicating a high income country model of professionally-delivered mental health services is impossible to achieve.[182] Instead, use of less highly trained general health and social care staff to deliver defined tasks is proposed; a process termed ‘task sharing’ (or originally ‘task shifting’).[183,184] The implication is that this might address not only staff shortages, but is more cost-effective.[185,185] It has also been shown to be acceptable to service users and staff.[173,186] If this model is to be supported, however, the question of maintaining quality service provision is key. If assessed based on outcomes, a number of trials have established this for different conditions, for example in dementia (the Home Care Trial[187]), in schizophrenia (the COPSI trial[188]), in epilepsy (China[189]) and in common mental conditions like depression and anxiety (the MANAS trial).[146] These trials demonstrate significant clinical benefit, and reduction in disability, implying quality could be maintained.

The term ‘competencies’ has come to be used for the skills expected of different actors in a reformed system. These are commonly defined within individual countries or programmes, and more generic versions have been proposed, for example for Africa.[190] One approach extended beyond health services to define community competencies.[191] Even if staff with only relatively brief training in mental health can achieve the necessary competencies to provide safe and effective care, then they require ongoing support. In fact, the provision of training without sufficient support has been identified as one of the major reasons for failure in efforts to integrate mental health into primary care historically.[192,193] Successful methods of providing adequate support include;

- *Stepped care*, where clear treatment protocols are given, within which are clear points for referral. A well-described stepped care model is of depression in Chile, which was scaled up to national level,[130] and a similar approach has also been evaluated in Nigeria (STEPCARE).[194]
- *Collaborative care,* where primary care staff have routine access to specialist advice (eg regular visits by specialists to primary setting) or are easily able to reach such expertise when necessary.[195] This term is often also used to refer to engagement with non-formal health care providers (which I discuss below).

In practice, these two methods are often combined (‘collaborative stepped care’) and integrated into established processes including referral mechanisms, and supervision. Referral mechanisms are integral to the three level structure of care (which is very strong in Nigeria), and understood as a way of supporting primary care since Alma Ata, which states that primary care ‘should be sustained by integrated, functional and mutually supportive referral systems’.[196] However, in many cases it does not work well, with patients being unable to afford to attend secondary or tertiary care.[161]

3.2.4 Peer support

A specific case in the enrolment of lay people in provision of mental health care is the unique contribution that can be made by people who have themselves had experience of mental health conditions.[197] The WHO has promoted peer support as a component of task sharing,[198] and the case has been made that peer support might be particularly well suited to low income settings where few mental health services exist, either at an individual level of in user-led groups.[199] There is a risk of exploitation of peers supporters either by not properly compensating them for their time, or seeking to give them tasks that are not appropriate and conflating the added value of lived experience with provision of clinical care.

The deep understanding of local culture, stressors and resources can provide practical insights from a person who had previously navigated both the experience itself, and the health and support services available. Peers are more likely to promote a person-centred recovery model, reducing the risk of a dominant focus on biomedical priorities.[200] In high income countries, there is little strong evidence for clinical improvement (hospital readmission rates for example),[201] but peer support group members report positive effects in personal recovery.[202] There is very little evidence generated in low income settings related to peer support,[191] though a large multi-site trial (UPSIDES) which includes low- and middle-income countries (India, Tanzania, Uganda) is soon to report.[203]

3.2.5 Engagement with families and the community

One of the associated benefits of task sharing is that the important role of the family and other community members is recognised and legitimised.[204] Families and lay carers play a crucial role in chronic conditions such as schizophrenia, and family interventions have been shown to positively or negatively affect outcomes in foundational work related to ‘expressed emotion’ in high income settings,[205] and more recently in low and middle income settings such as China.[163]

Communities can either promote or limit social inclusion, or degree of psychosocial disabilities, based on social theories of disability.[206,207] Stigma and discrimination also provide a useful theoretical framework for the mechanisms of social exclusion and the double burden of suffering associated with mental illness.[77] Interventions that improve knowledge about services and increase service uptake have been documented as described above, but the evidence for changing community attitudes is mixed, even in extensive media campaigns in high income settings.[208,209] Mobilisation of local actors, including service users and carers, in effective coalitions can facilitate change in leaders’ attitudes.[210]

3.3 Scaling up consensus models

Many of these ideas are now starting to be systematised in overarching models[211] and summary resources (like a PLoS Series on mental health packages of care in low-income settings[212]) and WHO normative guidance,[213] as well as reports of several major global meetings.[214] Despite this, a landmark Lancet Commission on Global Mental Health and Sustainable Development in 2018 came to broadly similar conclusion as the 2011 Lancet paper; that the evidence for effective mental health reforms was strong, but this was yet to be reflected in national-scale investment.[39]

The term ‘scaling up’ can refer to increasing coverage of services, or provision of a wider range of services to the same population or geographic area.[116] The ambition to scale up services (and hence reduce the treatment gap) is clearly the basis for much services research, and strongly aligned to the Universal Health Coverage agenda. ‘Scaling up’ has also been applied to the financial, human and capital resources required to expand coverage.[215] There are important differences between how an intervention works as a pilot or in a trial, and when replication is attempted at scale.[153,216] For example, carefully managed trials inevitably have close attention paid to every detail of implementation in a way that cannot be replicated with less motivated, personally committed, and trained individuals.[215] Additional contextual issues to be considered in scale-up processes include political support, organisational structure and governance, logistics, human resource allocation and financing.[133]

3.4 Progress in increasing coverage since 2011

While absolute measurement of coverage remains challenging in the context of weak information systems, using some of these broader metrics, there is some evidence of more significant development since the 2011 paper. Probably most significant is the wider adoption of updated mental health policy and legislation. For example, 2011 WHO Mental Health Atlas data recorded 59.2% of countries as having stand-alone mental health legislation and 76% had policies or plans.[217] By the publication of the 2020 Atlas, this had risen to 65% and 86% respectively.[218] By 2020, it is also notable that the existence of specific policy on child and adolescent mental health was being measured, as was detail about level of compliance with human rights instruments.

Unfortunately, success in driving policy change has not led to significant financial investment for scaling up, especially in primary care.[219] In 2020, mental health as a percentage of Domestic General Government Health Expenditure remained stubbornly low at 2.13% (1.05% in LAMICs to 3.8% in HICs).[218] This is in part a question of political will – long recognised as a barrier to reform[161] – and hence investment – particularly for an area in health that has long been neglected and a low priority.[220] A number of efforts to bridge this gap have been made, for example with a World Bank meeting on mental health in 2016,[221] a series of Ministerial Global

Mental Health meetings between 2018 and 2023, and the launch of a WHO programme specifically aiming to achieve comprehensive national-level reform in a number of target countries, under the banner of Universal Health Coverage; the Special Initiative for Mental Health.[222]

Finally, there has been some nuanced development in concepts of task shifting. Now widely acknowledged and practiced as an important mechanism, there is greater clarity on the core competencies of different actors at different levels in the system[190,211] and a more confident assertion of the added value that these new roles can play, beyond replacing traditional doctors, nurses and psychologists. The unique role of peer support workers is a good example,[202] as well as the widespread adoption of psychological first aid among front-line emergency workers.[223] While task shifting can go some way to improving care and addressing human resource gaps, the last decade has seen a huge increase in already high rates of health professional migration away from Africa and Asia.[224] This negative trend probably serves as a barometer for the underlying levels of motivation of health personnel, whether related to the working conditions specifically, or wider social and economic factors.

If the 2011 Lancet paper were to be repeated now, there is no doubt that there is far more information available about some of these contextual factors, and system components that contribute to improving coverage. This would help to provide a fuller picture of overall progress, but unfortunately, on the core metric of coverage itself, a similar conclusion would still have to be reached; that it remains very difficult to measure coverage accurately from routinely collected date, but there is little evidence of more people accessing services, even if some progress has been made in policy terms and in attention paid to the experience of using services.

4 Accountability to service users

4.1 Evolving ideas and terminology

The 2007 *Lancet* series ‘Call for Action’ refers to two main ambitions; scaling up services to close the treatment gap (the topic of the sections above), and addressing human rights abuses experienced by people with mental health conditions. A branch of research work and civil society activities has subsequently followed this second theme, building on a long tradition of service user activism that itself grew from the critical and transcultural psychiatry fields mentioned above. The different traditions in this area are reflected in the terminology used (in italics below), which I will use as a basis for exploring each.

The term ‘*users and survivors of psychiatry*’ refers to the assertion that much of the suffering associated with the experience of having a mental health condition (as defined by a medical diagnosis, but also in expressing socially non-conforming behaviour) is associated with the systems in place to control such behaviour, rather than the experience itself – hence survivors of psychiatry.[225]

The World Network of Users and Survivors of Psychiatry (WNUSP, based in the USA) were active in negotiations around the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and the result was a strong position on equivalence of psychosocial disabilities to other disabilities.[226] The ramifications of this are profound, and have been the cause of important debates. For example, Article 12 (Equal recognition before the law) and Article 14 (Liberty and security of the person), which have been challenged, for example by countries in defending their existing laws, on the basis that there is a material difference in decision-making by people with mental health-related impairments (using social model terminology) compared with physical disabilities. The clear distinction between ‘mental capacity’ (the basis of justification for the medical profession and the state avoiding the usual rights to self-determination) and ‘legal capacity’ (inherent rights to equal recognition before the law, whatever the status of a person’s decision-making, or mental capacity)[227] was established in the UNCRPD. The UNCRPD Committee issued a General Comment on Article 12 in 2014 (number 1), which was a firm reassertion that countries should indeed provide equal treatment on the basis of legal capacity.[228] In relation to decision-making the UNCRPD and the General Comment articulate a move from ‘substitute decision-making’ to ‘supportive decision-making’, where traditional ‘best interest’ perspectives of family members or professionals should be replaced by efforts to understand a person’s own ‘will and preference’ (by implication accepting that people have the right to make decisions perceived as illogical or even harmful). It has been argued that if taken too far, this right to self-determination can lead to an erosion of other rights like a right to health or to life itself,[229] and hence the risk of an abdication of responsibility by professionals, services and governments (‘duty-bearers’).

A widespread acceptance by activists that alignment to the disability movement, with an adoption of social and human rights models of disability (the basis of, and underpinned by the UNCRPD) offered not only an emancipatory vision, but also allowed for solidarity with a large movement, and the ability to draw on the very strong accountability mechanisms offered by UNCRPD (especially its Option Protocol). As even social and human rights models of disability accept the reality of an impairment (that intersects with social determinants and barriers to participation),[230] this did involve leaving behind the social constructionist traditions of Thomas Szasz[231] (The Myth of Mental Illness), Foucault[232] (The History of Madness) and an article of faith of subsequent threads of critical psychiatry.[233,234] This tradition of course continues as an important critique of global mental health,[13] but the International Disability Alliance, as the formally recognised representative voice of the disability movement (which has WNUSP as a founder member) has moved strongly in this direction. The clear change in terminology that accompanied this was the widespread adoption of the term ‘*psychosocial disabilities*’ which highlights the social exclusion associated with stigma linked to mental conditions or socially unacceptable behaviour, equating this to the barriers to participation people with all disabilities face.

Interestingly, as nascent representative organisations in Africa, Asia and Latin America have often been fostered by the older established organisations in Europe and North America, many of these traditions were carried over in the early years. For example, with the foundation of the Pan Africa Network of Users and Survivors of

Psychiatry (PANUSP) out of the WNUSP in 2005. However, in 2011, PANUSP chose to change its name to the Pan African Network of Persons with Psychosocial Disabilities, partly due to a desire to adopt the terminology of psychosocial disabilities, but largely, as noted at the time, that the vast majority of people with mental health needs on the continent are not accessing services, and therefore could not be defined as 'users of psychiatry'.[84] Underlying this change is also an increasingly strong assertion of the different priorities of a local movement, one that did not emerge from a position of services being assumed to be available (and often forcibly intruding on personal freedom). The movement in Africa has tended to be more likely to prioritise the right to access services (of good quality and offering choice and dignity),[235] rather than focusing on the need to resist over-reach of psychiatry.

The most commonly used term in recent years has become *'(person with) lived experience*', which emphasises the complementary value of 'expertise by experience' alongside expertise by profession, whether this is in services development and provider accountability, or in research. The term lived experience is now widely used, especially in relation to efforts to bring representation of user voice into policy, normative guidance or research processes, fulfilling the principle of the disability movement: 'nothing about us without us'.

A related term which emphasises the value of mutual understanding and solidarity between people sharing similar experiences is '*peers/peer support/peer networks*'. There is important emerging evidence around peer support as a component of task-sharing and provision of care in a comprehensive system, as I have described above in relation to service delivery by people with a lived experience.

One key organisation that emerged from the 2007 'Call for Action' was the Movement for Global Mental Health.[236] While initially established by professionals involved in the *Lancet* series, the aim was to stimulate a broad-based movement to catalyse change (with the (HIV) Treatment Action Campaign used consciously as a blueprint). The membership of the Movement has always deliberately included people with lived experience of mental health conditions, who have often chaired the

Movement, but a new group was established in 2011 – the Global Mental Health Peer Network – whose stated aim is ‘towards enhancing the “voices” of people with lived experience through creating a platform where their needs, challenges, views, opinions, and perspectives are raised and incorporated into policy and plans for mental health’.[237] It is worth noting that the Movement for Global Mental Health has sometimes been conflated with the wider field (especially in critical literature), but is itself quite small and does not have a wide reach or represent wider global mental health.

In the *Lancet* Commission on Global Mental Health and Sustainable Development in 2018,[39] I led the section on a ‘dimensional approach to mental health’, where we discussed reframing perspectives around mental health and illness, diagnosis, disability and the role of service users in their own recovery. The largest research programme I am currently working on as CEO (Support, Comprehensive Care and Empowerment for People with Psychosocial Disabilities, SUCCEED) is focused on these issues, developing and evaluating a community intervention to provide support for people with psychoses.[238] The strong focus on participatory methods builds on this *Lancet* Commission work, and I have also worked with WHO on a process of establishing minimum standards for patient care and service quality (QualityRights)[239] and new policy guidance,[240] focused on reducing coercive treatment[241] and improving accountability to service users.

To inform this, we published an assessment of the effectiveness of service user voices in holding governments to account under processes of the Convention on the Rights of Persons with Disabilities (my third submission).[23] In this paper, we sought to examine the degree to which organisations of people with psychosocial disabilities had been able to make use of the provisions of the CRPD – the requirement for countries who have ratified the Convention to submit a progress report every two years. The CRPD states that people with disabilities must be involved in the process of developing this official report submitted by the State Party (countries), but they also have the right to develop parallel or shadow reports independently. We used a co-production approach, which in our case meant establishing a Steering Committee of people with lived experience of psychosocial disabilities, who met regularly and oversaw the whole process. We assessed a selection of the reports submitted by States Parties as part of the compliance review process for CRDP. We selected 19 countries, based on the most recently available reports, while ensuring they also covered the range from low- to high-income countries, from all regions of the world.

We used content analysis to review the extent and quality of the reports' documentation of issues related to mental health and psychosocial disabilities across the selected countries. The criteria used for the analysis were identified by the Steering Committee. These included the extent of discussion in the report regarding psychosocial disability (Variable 1), theoretical approaches informing the report's discussion of psychosocial disability(Variable 2), the extent to which the report distinguishes psychosocial disability from intellectual disability (Variable 3), and the extent to which the report addresses CRPD articles considered highly relevant to people with psychosocial disabilities (Variable 4), and the extent to which the report's discussion of accessibility initiatives (such as reasonable accommodation) addresses psychosocial disabilities compared to other disability types. The CRPD articles particularly pertinent to psychosocial disability included were Article 4 (equal recognition before the law), Articles 14 (Liberty and security of the person), Article 17 (Protecting the integrity of the person), Article 19 (Living independently and being included in the community) and Article 29 (Participation in political and public life). These variables sought to tease out whether there was a recognition of the specific issues pertinent to the needs of people with psychosocial disabilities were appropriately addressed in the report. We also directly sought information about who had been invited to participate in the report writing.

There was a wide variation in the reporting, with less economically developed countries tending to report less in terms of content amount, and in a way that was aligned less to CRPD and user priorities. While there has been progress in representation of people with lived experience at the global level, our findings suggested low levels of participation in CRPD processes at the national level in many countries. The weakness of national representative organisations (even compared to other disability groups) means that governments, services and advocacy by wider disability federations are not significantly influenced by the voice of people with mental health conditions. Subsequent work we carried out on the process of legal reform in Nepal confirmed this finding.[242]

4.2 Participation of service users in global mental health research

While progress has been slow in meaningful participation in national policy and legislation reform and accountability, assessment of priorities of people for whom interventions are intended has been a consistent part of a formative phase of intervention development in global mental health research. For example in Ethiopia,[243] this has led to a set of priorities being identified that includes the ability to work and be economically active, fulfilling social roles, being valued, and being free from the suffering of mental health conditions.[244] PRIME, RISE[245], mhSUN[82] and SUCCEED[88] have all had similar exercises underpinning intervention development, often as part of Theory of Change processes.

Despite this consultation of users to understand their priorities for intervention development, the active participation of people with lived experience in generating and carrying out research is far more limited. Co-production of research is founded on the tenet that expertise of lived experience has a key role in contributing to all parts of the research process. This requires more than simply consultation, and while there are recognised challenges in power imbalances and communicating across different types of language and knowledge sets,[246] with planning and acknowledgement of group dynamics, the result can be a richer and better informed research, reflecting the contribution of a wider range of perspectives.[247]
While co-production is fairly well established in mental health research and service provision in high income countries,[248] the proportion of global mental health research that actively engages with people with lived experience in its generation is extremely low. A 2016 systematic review identified only one example where meaningful participation in global mental health research was documented,[249] though by 2018, a similar review found ten examples using similar criteria for participation of people with lived experience.[250]

There is a clearly stated aim by many global organisations to have participation of people with lived experience in their work. For example the WHO’s Comprehensive

Global Mental Health Action Plan included such representation in its development, and has service user participation in all elements of systems reform as one of its key underlying principles,[198] as does the new WHO/UNHCHR guidance on mental health legislation development.[240] While the first edition of mhGAP (published in 2010) did not include identified representation, subsequent editions do – both of people with lived experience, and an attempt at better global representation (though all within the predominant psychiatry/global mental health tradition).[16] The *Lancet* Commission on Global Mental Health and Sustainable Development deliberately stated this approach also, and the *Lancet* Commission on Stigma was co-chaired by the founder of the Global Mental Health Peer Network,[251] who now also co-edits a major new global mental health journal (PLOS Mental Health) which seeks to address challenges and gaps 'in ways that put the lived experience of individuals and communities first'.[252] The Wellcome Trust – the world's biggest private research funder – has a strong philosophy of lived experience guiding funding decisions and prioritisation in their investments in mental health research, and 'patient and public involvement' (PPI) is a required criteria for applicants to NIHR research grants, as it is for many other funders.[253]

In all these welcome changes in policies and documented approaches, there remains a significant risk of tokenism. Long-established relationships associated with traditional roles of service users and clinicians, or research subjects and researchers, take time to change. Despite more often being invited to participate in mental health research, for example, collaborations can still be frustrating even for well established lived experience researchers.[246] Power imbalances, especially when dynamics of seniority, international vs local, ethnicity and wealth are laid on top of lived experience mean that it can be challenging to promote genuine meaningful participation. Tools like Theory of Change and others, must be used while reflecting on positionality and power dynamics, otherwise without acknowledging and deliberately surfacing and addressing these factors, efforts at coproduction will remain superficial, to the detriment not only of the values associated with co-production, but also the quality of research.

While there is far to go, there is some evidence of early steps in the ‘transformational shift’ towards meaningful participation by people with lived experience that the *Lancet* Commission on Global Mental Health[39] and the PANPPD’s Cape Town Declaration[84] aspired to for the field. This co-production approach has informed much of the work I will outline in the next chapters of this commentary.

5 Applying lessons learnt in different contexts using participatory approaches

My fourth submission is a paper that outlines the development of an intervention for scaling up mental health services in Nigeria.[82] As I have outlined, outcome studies have been a strong thread of research in global mental health, but the purpose of this research is to explore in more depth the processes through which implementation of such interventions can be made to be as effective and sustained as possible. As a country with a vibrant research community in mental health, Nigeria has been the location of several pilots and trials evaluating decentralised services using task-sharing, collaborative stepped care, supervision etc. Despite some recent success in policy and law reform,[254] there has been little evidence of major investment or implementation progress.

With this in mind, and a clear eye on advocacy for change by engaging with government, a project was designed, seeking to use research from across Nigeria to inform a common set of interventions, demonstrated as effective in Nigeria, that might positively influence government. The mental health Scale Up Nigeria (mhSUN) programme sought to evaluate implementation of a model in two sites (Calabar and Kaduna), and was coordinated by Professor Oye Gureje at the University of Ibadan. These sites were chosen to represent the north and south of the country – a recognition of the political importance of ‘national character’ in any advocacy with government. The first step was to carry out a situation analysis of needs and available resources, as well as social determinants related to mental health in each state. We then reviewed the extensive literature around mental health service reform from Nigeria and other African countries. Over the course of 4 days, we drew on this information, alongside a broad group of stakeholders, and incorporated this information in the design of a Theory of Change. [255] Participants included traditional leaders, health system leaders, mental health experts, and people with lived experience, alongside the research team.

This paper focuses on the process of participatory intervention development, from which we subsequently developed the proposal and research protocol for intervention evaluation.[256] The final results are due to be published. Key methodological considerations in this protocol include a process alongside an outcome evaluation (on the basis that positive clinical and social outcomes are well documented, but the proof of application in Nigeria was of primary interest to policy makers). Similarly, we used realist approaches to add to the much more tightly managed RCT methods in these trials. Government participation was integral from the start, and in addition, a policy engagement component of the programme was also put in place, supporting regular meetings of the National Mental Health Action Committee as well as engagement at individual state level. During this time policy and legislation was reviewed, though it was not until 2023 that there was successful passage of a National Mental Health Act (2021),[257] replacing the 1956 colonial-era ‘lunacy ordinance’.[258] Subsequent establishment of an effective National Mental Health Programme has created a new momentum in this previously neglected field at the Federal Ministry of Health and Social Welfare.

The mhSUN programme emerged from a collaboration focused on strengthening the expertise in public mental health in the West Africa region – the mental health Leadership and Advocacy Programme (mhLAP).[259] The lack of public health knowledge among mental health experts, and conversely, a lack of mental health knowledge among public health experts, has long been cited as one reason for the lack of political buy-in for mental health.[161] The role of effective public mental health leaders – not just senior clinicians – is crucial then, in generating and disseminating evidence, and making a case for services reform, including integration of mental health. A recently launched Africa CDC continental Mental Health Leadership Programme, which I co-developed, builds on the mhLAP programme, scaling up to establish a similar short course in five African regions, as well as integrating a mental health track into the prestigious Kofi Annan Fellowship and Field Epidemiology Training Programmes (FETP).[260]

The historical lack of progress in achieving global and national scale-up of services can be partly seen as a failure of policy uptake, but it has also been noted that even a substantial increase in investment and major reform of service structures can only address the needs of those people already affected by mental conditions, but will never reduce the actual incidence of mental conditions, and have little effect on prevalence. It is public health measures that address social determinants of poor mental health, that will reduce prevalence.[39] Mental, neurological, developmental and substance use disorders are now included in the influential World Bank Disease Control Priorities (DCP) publication (since the third edition), which identifies the 'best buy' public health interventions across the life course for mental health.[261] It is beyond the scope of this commentary to extensively review these, but as is often the case in public health, investment can be even more difficult to mobilise for such population-wide measures, despite the strong economic case that can be made. Logistical and political complexities of protecting mental health through other sectoral investment can add to this reluctance to focus on these more up-stream efforts, though there have been a number of efforts to provide guidance on how this can be done.[262]

Similarly, for the many people whose primary driver for mental distress is physical ill health and disability, support through the other medical services they access is often more acceptable, less stigmatising and more efficient than accessing separate mental health services.[263] There is a well documented increase in prevalence of mental conditions among people with other health conditions, particularly chronic, painful or disabling conditions.[264] Co-morbidity with HIV is well studied, and relevant for the settings that are the focus of global mental health research.[49] Progress has been made in not only outlining effective models of prevention and treatment in HIV services, but in policy terms. A positive example is of international funding being made available for mental health under the Global Fund To Fight AIDS, Tuberculosis and Malaria in the Global Fund Strategy (2023-2028).[265] In the next section I will outline the ways in which these lessons are being applied to an area of intersection with mental health that I have been particularly involved in; neglected tropical diseases.

6 Future contribution to the field; application to other sectoral integration

Our learning around strengthening mental health service provision is being applied to other target groups, taking forward the aim of integrating mental health horizontally into other sectors. In many cases, it is clear that mental health can most effectively be protected and promoted through other sectoral activities. For example in the case of the intersection of homelessness and mental ill health/substance use, it is provision of housing that is the priority (‘housing first’).[266] Similarly, addressing poverty through cash transfers,[267] or reducing carbon emissions to counter the huge likely impact on mental health of climate change.[268] I support several projects, either as co-investigator or on advisory committees, for example in services for children with intellectual disabilities in Kenya (SPARK),[269] deaf children in emergency settings,[270,271] or young people in slums in India (ARTEMIS).[138] The common element of all these projects is that they largely take place within other sectors – education, disability or development – whose processes and priorities need to be taken into account.

A particularly high prevalence of common mental health conditions has been noted among people affected by neglected tropical diseases. We carried out a systematic mapping of the evidence, and noted that at present, epidemiological evidence of this intersection is weak, characterised by small, heterogenous studies.[272] This review was carried out as part of systematic process of building a case for a more holistic approach to supporting people with NTDs, specifically the incorporation of prevention and treatment of mental conditions. There are a number of mechanisms through which NTDs can have mental and neurological impacts; direct effects of causative agents, as with neurocysticercosis (a common cause of epilepsy), or the coma of human African trypanosomiasis (sleeping sickness); and the psychological impact of physical symptoms like chronic pain or urticaria (itch) of onchocerciasis, or blindness in onchocerciasis or trachoma. However, there is strong evidence to show that it is the impact of stigma and social exclusion that is the main driver of mental distress, development of conditions like depression and anxiety, and suicidal ideation.[273] As is often the case in relation to intersecting models of social determinants, this is a mutually reinforcing cycle,[274] with social exclusion associated with a stigmatising condition leading to poor mental health outcomes, and other mediating factors like poverty reinforcing challenges in breaking this cycle.

We proposed a theoretical model to help in designing research and interventions, partly as a means of more effectively communicating our findings, but also as a way of proposing appropriate interventions and informing a research agenda (Figure 3). This model draws on a large body of evidence related to mental health, stigma and NTDs, including a major systematic mapping of evidence.[272] This was reinforced by a number of Theory of Change exercises held as part of intervention development processes.[83] The arrival at this point in translating evidence to guidance is in line with a previous research prioritisation exercise we had carried out.[275]

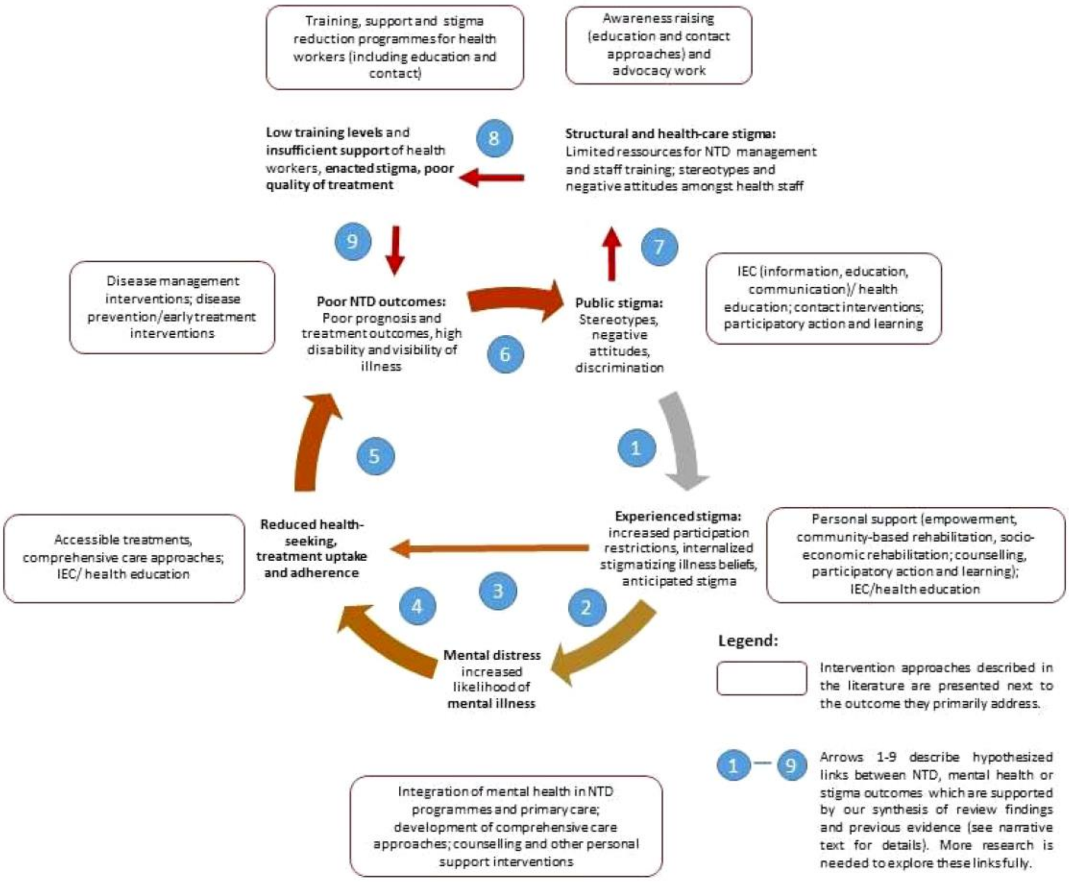


Figure 3: Theoretical model linking mental health, stigma and NTDs[272]

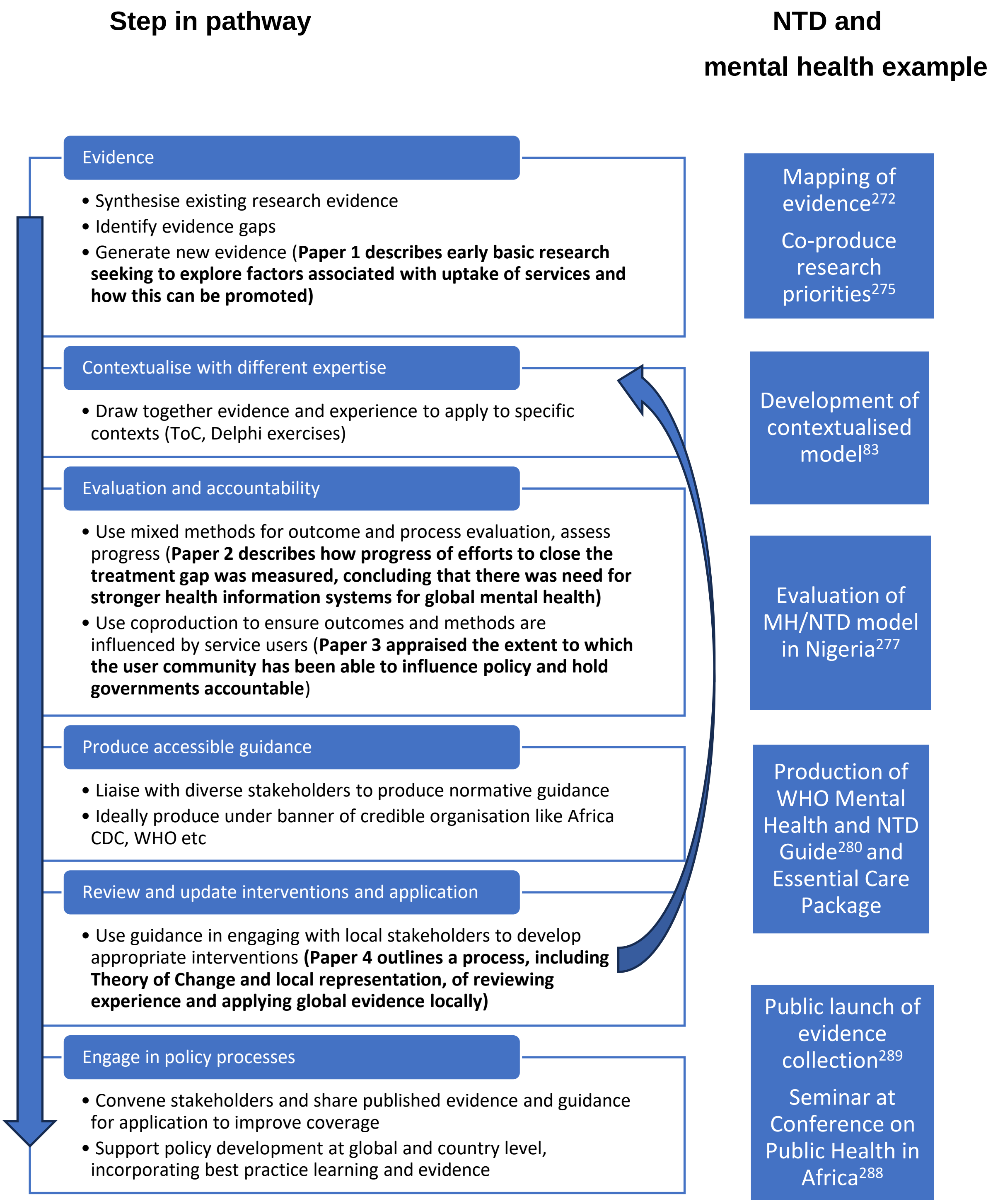
This formative research was the basis for a number of studies I have now carried out with a team at University of Jos in Nigeria, measuring prevalence of mental conditions among people with visible signs of leprosy and lymphatic filariasis (elephantiasis),[276] and developing an intervention for mental health integration in primary health care (PHC) to improve access for people with NTDs,[83] which we have tested for feasibility and acceptability.[277] Again, engagement with health leaders in the Nigerian Federal Ministry of Health and Social Welfare across the Mental Health and NTD Programmes led to successful integration, for the first time, of a pillar dedicated to mental health and psychosocial support in the Nigerian NTD Masterplan (2023-2027).[278]

The catalyst for much of this work was the incorporation for the first time of mental health into the WHO NTD Roadmap 2021-2030,[279] which made a paradigm shift from a purely preventive/eradication agenda to recognising the wider needs of people already affected by NTDs. While difficult to attribute causation, consistent advocacy based on relevant research, including in relation to the likely impact of mental health on the burden of disease attributable to NTDs, may have influenced this shift.[51] As part of a consortium addressing these issues, we have contributed to a WHO Guide on Mental Health and NTDs[280] – importantly, this was the first time that the WHO departments of Mental Health and Substance Use, and of NTDs had collaborated. Similarly (arising from our collaboration with the University of Jos), we have facilitated a forthcoming WHO Essential Care Package (intended to act as the evidence resource for this sector in the WHO Universal Health Coverage Compendium). This increased interest in mental health and NTDs has resulted in a growth of research in the field, and I proposed and guest-edited (with Laura Dean at Liverpool School of Tropical Medicine) a Supplement of *International Health* journal on Mental Health, Stigma and NTDs, which brought together a range of related research in his area, much of it rooted in practical field programmes.[281] We made a deliberate effort to include perspectives of people with lived experience[282] and to facilitate submissions from French- and Spanish-speaking researchers.[283]

The papers I have chosen to link in this analytical commentary bring together the experience of generating and synthesising evidence, participatory processes of developing consensus models, their evaluation, and co-producing accessible versions of guidance (ideally endorsed by WHO or a similar authority), to engage with policy actors to promote their uptake.

These approaches were applied to the field of NTDs to take this specific space forward in a relatively short time-frame of 10-15 years. In the diagram below, I have sought to show this process, and where my work aligns using this example. Such processes are not linear, but tend to follow a roughly sequential approach as principles and interventions progress from conceptualisation to application and replication,[284] with repeated cycles of evaluation and adaptation. This process is equally applicable to both use of established evidence to a new field (as in the example of NTDs in figure 4), and adaptation of innovations from one context to another, as described in paper 4 using the example of the mhSUN programme in Nigeria.[82]

I would also note here the essential role of experts in communication and advocacy, whose collaboration with those generating evidence and implementing in the field have been instrumental in many successes in moving forward the agenda. I have not attempted to explore this crucial work in this commentary, though I have had the privilege of working closely with such advocacy experts, for example in the period of engagement with the UN around the Sustainable Development Goals.[285] Neither have I described in detail the related body of research exploring research translation, ‘diffusion of innovations’,[286] and processes involved in embedding reform.[287]



Step in pathway

NTD and mental health example

Evidence

- Synthesise existing research evidence
- Identify evidence gaps
- Generate new evidence (**Paper 1 describes early basic research seeking to explore factors associated with uptake of services and how this can be promoted)**

Contextualise with different expertise

- Draw together evidence and experience to apply to specific contexts (ToC, Delphi exercises)

Evaluation and accountability

- Use mixed methods for outcome and process evaluation, assess progress (**Paper 2 describes how progress of efforts to close the treatment gap was measured, concluding that there was need for stronger health information systems for global mental health)**
- Use coproduction to ensure outcomes and methods are influenced by service users (**Paper 3 appraised the extent to which the user community has been able to influence policy and hold governments accountable**)

Produce accessible guidance

- Liaise with diverse stakeholders to produce normative guidance
- Ideally produce under banner of credible organisation like Africa CDC, WHO etc

Review and update interventions and application

- Use guidance in engaging with local stakeholders to develop appropriate interventions **(Paper 4 outlines a process, including Theory of Change and local representation, of reviewing experience and applying global evidence locally)**

Engage in policy processes

- Convene stakeholders and share published evidence and guidance for application to improve coverage
- Support policy development at global and country level, incorporating best practice learning and evidence

Mapping of evidence[272]

Co-produce research priorities[275]

Development of contextualised model[83]

Evaluation of MH/NTD model in Nigeria[277]

Production of WHO Mental Health and NTD Guide[280] and Essential Care Package

Public launch of evidence collection[289]

Seminar at Conference on Public Health in Africa[288]

Figure 4: Evidence to policy and practice pathway. The example of mental health and NTDs

7 Conclusion

The narrative at the outset of the modern field of global mental health is of a values-driven agenda, with research guiding its effective implementation. In this commentary, I have attempted to show the way that the sense of urgency in addressing a failure of care prompted an emergent research community to define initial priorities of increased coverage of mental health services, based on equity and access considerations.

The solutions to these public health challenges, have often been characterised as ‘innovations’,[214] drawing from a set of ideas around investment in targeted ‘big-idea’ solutions to the world’s biggest problems (or ‘grand challenges’’).[290] When moving to implementation and evaluation, the terminology has been of ‘interventions’, or more often ‘complex interventions’. There are various definitions of complexity, but the aim is usually to convey multiple interacting active ingredients or components of an intervention, delivered by multiple agents at different organisational levels, and often with a number and variety of outcomes.[291]

The research I have presented in this commentary sits within this endeavour of finding effective means of delivering the aspirations of the field; I have started by teasing out some of the factors that influence the behaviours of potential service users. In doing so we learnt the need to respect the necessity of allowing flexibility or tailoring in implementation of an intervention to account for different contexts, while still adhering to an underlying theoretical model or set of core components.[292] In the case of what was then conceived of as ‘awareness raising’, subsequent learning has led to a much more nuanced appreciation of the importance of using explanatory models relevant to community beliefs to shape anti-stigma messaging, while building in what seems like a common active ingredient of lived experience voice in delivery of messages.

A tension between the simplicity of a single intervention versus the reality of a need for more comprehensive and multifaceted approaches necessary for mental health has been cited as a key issue that differentiated mental health from some fields like eradication of infectious disease for example. There is no ‘mosquito net for mental health’.[293] At the level of advocacy (for investment), the same tension exists in seeking to maintain a single and simple priority message like ‘increase coverage of services’, while also needing to be true to the evidence for a range of simultaneous approaches being necessary for meaningful impact either at a systems level (needing all building blocks to be in place) or for individuals (requiring both medical and social aspects of recovery to be addressed). Of course, delivery of similar interventions will also need to be influenced also by the different context in which it is delivered.

As documented in the second paper on assessing success in scaling up services, we remain in a transition between evidence building at a piloting scale, and the kinds of investment needed to make a genuine difference either to *treatment coverage* or to reducing *prevalence* of mental conditions through public health measures aimed at addressing social determinants. This paper did, however, show some success at a policy level, demonstrated by the fact that the Sustainable Development Goal 3 has wellbeing in its title (‘ensure healthy lives and promote wellbeing’), and Universal Health Coverage includes mental health. Despite this, only a few targets directly relate to mental health: target 3.4; ‘reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and wellbeing’, and target 3.5; ‘strengthen the prevention and treatment of substance abuse’.[294] As with the limited success in increasing coverage, neither of these goals will be met by 2030 without scaling up relevant services and interventions in a way that there appears little chance of achieving. Other Goals (like 4 (education), 8 (work and economic growth), 10 (reduced inequalities), and 11 (sustainable cities)) include specific references to inclusion of people with disabilities, including with mental, intellectual, and psychosocial disabilities, and it has been argued that almost all goals will be furthered by addressing mental health.[277]

Progress in this agenda of ‘mental health in all sectors’ is even harder to measure, but this is an important new front in efforts to reduce mental distress and diagnosable conditions. I hope I have shown that the lessons learnt, and research methods used, in mental health-specific services reform can be applied to these intersections with other sectors to accelerate integration of mental health. HIV, TB and NTDs are an examples of this, but mental health has become a topic of research and practice in many other fields that can effectively contribute to wellbeing and wider human development.

The initial focus on closing the treatment gap has subsequently been shaped by a number of additional considerations, argued for by different stakeholder groups. While each of these groups – psychiatrists, psychologists (in both cases often with a social focus), health system actors and multilateral health organisations, service user and caregiver groups and human rights advocates etc, has agency, their degrees of influence vary, and the changes seen in the field are a product of their relative resources, constraints and effectiveness in furthering their ideas.[242] The Convention on the Rights of Persons with Disabilities serves as an important tool for holding service providers to account, and is regularly cited by service user groups. However, we found in our work analysing the country reports on government progress that the level of familiarity with, and effective use of, the Convention by the psychosocial disability movement in low-income countries was not as high as in wealthier countries. It is essential in a field focused on these low resource settings that we proactively build this movement id we are to achieve meaningful co-production.

Some priorities that have emerged in the field, like a greater emphasis on prevention and promotion interventions to address social determinants, are deeply rooted in established traditions of public health that the mental health field has again borrowed from. Some, like responding to the critiques of global mental health related to cultural imperialism, medicalisation and empowerment of user voices, come from newer centres of influence, like the disability movement. The field has incorporated many of these ideas, while there remain open debates around some issues like coercion and medical power. Interestingly, the concept of Universal Health Coverage, central to the Sustainable Development Goals, has similarly expanded a traditional remit to an extent by incorporating dimensions of not only population covered (equitably), but also financial access/costs, and range of services covered.[295]

The past 20 years have been a period of great learning and consolidation of some clear positions in relation to global public mental health around intervention development, participation, evaluation and scaling up. In the papers I present, I was able to touch on some of the steps in this process – exploring what influences uptake of services (paper 1), how we can effectively measure population coverage of services (paper 2), properly acknowledging and enabling accountability to service users and historically under-represented groups (paper 3) and formulating standardised approaches to bringing together published research evidence with needs and realities of local contexts (paper 4). The fact that this research has been carried out in a variety of contexts has established principles and honed skills (described in my fourth paper on intervention development, and in Figure 4 above), to approach application of services models developed in one context to another in a structured and efficient way. These approaches should be applicable as flexible tools to efficiently move towards reducing the treatment gap in a way that pays sufficient heed to the need for locally-appropriate solutions. I chose these four papers because they illustrate key issues that need to be addressed by the research community, in an emerging field driven by a strong values-based agenda, but constrained by practical limitations, and needing to navigate sometimes competing priorities. I hope that the key message though, is that taking diverse and critical voices seriously can indeed spur rigorous and impactful research, that if underpinned by commitment to a common aim (even if complex in its subtleties), leads to a science that more effectively addresses global challenges.

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Annex 1: Papers for analytical commentary
Preceded by statement of contribution.

Paper 1

Eaton J, Nwefoh E, Okafor GOC, Onyeonoro U, Nwaubani K, Henderson C.

Interventions to increase use of services; Mental Health Awareness in Nigeria. *International Journal of Mental Health Systems* 2017; 11:1-6

https://link.springer.com/article/10.1186/s13033-017-0173-z

This research explored the impact of an intervention combining community engagement activities and mass media (radio, posters) in an effort to reduce stigma, and increase attendance at primary care centres where we were establishing a mental health service in south-eastern Nigeria.

The methods involved drawing on routine health information system data collected from the service and comparing levels of service use by time. We found statistically significant impacts on the levels of people attending services during the time of the awareness-raising exercises. Since this research, we have carried out further research that has developed these initial models of anti-stigma intervention components that adopt a more targeted approach to community attitudinal change, and adding key ingredients (for example contact interventions). Means of measurement of knowledge, attitude and population behaviour change has also developed significantly since this research was carried out.

My contribution to the research was as programme lead for the Amaudo Community Mental Health Programme in Abia, Ebonyi and Imo States (the programme carrying out the intervention under investigation), instigator of the research, coordination of data collection, and lead author.

Confirm role: Julian Eaton Signature: J Eaton Date: 15/11/23

Confirm role: Prof C Henderson, King's College London Signature: C Henderson Date: 9/11/23

Eaton *et al. Int J Ment Health Syst (2017) 11:66*
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RESEARCH **Open Access**

Interventions to increase use of services; Mental Health Awareness in Nigeria

Julian Eaton[1*], Emeka Nwefoh[2], Godwin Okafor[3], Ugochukwu Onyeonoro[3], Kenneth Nwaubani[4] and Claire Henderson[5]

Abstract

Background: Mental health services in Nigeria consist mainly of large government psychiatric hospitals and there are very few mental health professionals to serve the large population of the country. However, more recently, community mental health services, which have been shown to improve access to care and clinical outcomes are beginning to develop in some locations. Despite efforts to promote more accessible services, low levels of knowledge about effective treatment of mental disorders means that even where these services are available, a very small proportion of people utilise these services. Therefore interventions to increase service use are an essential component of health system.

Methods: This intervention was designed to increase use of a mental health services through the work of community-based Village Health Workers. Fifteen Village Health Workers in each Local Government Area (district) were selected and trained to create mental health awareness in communities. Their function also include identification and referral of persons with mental illness to trained mental health nurses in the clinics. Attendance data prior to and after intervention were collected and compared.

Results: The incident rate for initial period of intervention is five times higher than the baseline rate (95% CI; 3.42–7.56; $p < 0.001$) though this diminished in the long term, levelling off above initial baseline.

Conclusions: This study demonstrated that addition of awareness raising using volunteers in communities as part of health programme implementation can increase services use by a population. Mechanisms such as informing populations of the existence of a service which they were previously lacking; explanation of causation of mental illness and achieving community leaders' support for a new service can make investment in services more efficient by increasing attendance.

Keywords: Community Mental Health, Village Health Workers, Psychiatry, Mental Health Awareness, Programme, Nigeria, Primary care, Help seeking behaviour

Background—services for people with mental illness

In Nigeria less than 15% of people with severe mental illness access mental health care services [1]. As with other countries in sub-Saharan Africa, mental health care is neglected, and neuropsychiatric services receive low priority in national budget allocations [2], with only around 1% of the health budget spent on mental health [3], whereas the proportion of the burden of disease attributable to mental illness is around 8% in the same region [4]. These funds are also spent inefficiently; mental health services in Nigeria consist mainly of large government psychiatric hospitals. There are eight Federal Neuro-Psychiatric Hospitals and a similar number of university teaching hospital psychiatric departments, for a population of 170 million people. Nigeria has around one psychiatrist per 1 million population and four psychiatric nurses per 100,000 people [5]. However, the country is starting to develop community mental health services, which have been shown to improve access to care and

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clinical outcomes [6–8]. Theoretical models related to stigma imply that reduction in florid symptoms, that lead others to label a person as having a mental illness and hence stereotype them as being unpredictable and dangerous, would reduce their experience of stigma and discrimination [9]. Despite recent efforts to promote more accessible services, low levels of knowledge about effective treatment of mental disorders means that even where it is available, a very small proportion of people receive appropriate care [10]. Interventions to increase service use are therefore an essential component of the health systems approach to reducing the treatment gap for mental illness.

Effective techniques to improve knowledge about, and attitudes towards, people with mental illness include educating key influential groups and those with frequent contact with people with mental illness [11, 12]. Most work to date has been concentrated on experience in high income settings, but there are increasing examples in low income setting of interventions to address knowledge and stigma associated with mental illness [13, 14], In addition, studies on combating the stigma associated with leprosy and HIV/AIDS suggest that interventions based in such settings can be effective [15, 16].

A previous programme in this part of Nigeria found that a community awareness programme resulted in significantly increased clinic attendance [17]. In this programme, community-based volunteers underwent a week long course to gain a basic understanding of mental health, and training in which they were taught to share key messages, and identify and refer people in the community with mental health problems. The intervention resulted in a significant increase in referral rates. This study aimed to replicate this work, and add rigour by including a comparison site in the study design. Our primary hypothesis was that; compared to the control State, the intervention State would show a significant increase in presentation rates to Community Mental Health Programme (CMHP) clinics.

Study design and methods

The Mental Health Awareness Programme intervention

The Mental Health Awareness Programme (MHAP) was an initiative of a local Non-Governmental Organisation (NGO) in South East Nigeria called Amaudo (or Village of Peace in the local Igbo language). Amaudo was initially established in 1990 to support homeless people with severe mental illness, and the Community Mental Health Programme was added to this work 10 years later [18]. The services are provided as a partnership with the State and Local Governments in South-East Nigeria. Nigeria's health system reflects its Federal structure of governance, with specialist tertiary services being largely the mandate of Federal Government, each of the 36 States running secondary hospital services, and Local Government Areas (LGAs) running primary care. Local Government Areas are a legislative level that may be considered equivalent to a large health district, under which there are usually many primary care centres of different sizes, organised under health wards. Under CMHP then, LGAs were identified as the unit under which the services would be organised. Services are run by a psychiatric nurse placed in one primary care clinic—usually the largest—in each LGA in the State. This nurse provides outpatient services, and also makes domiciliary visits and acts as a point of referral for other health workers. The awareness programme was specifically designed to strengthen this service and used the network of CMHP clinics (and psychiatric nurses) in its three States of operation in Nigeria (Abia, Imo and Ebonyi States) as well as in Anambra and Enugu States where the CMHP planned to expand. Its aims were to increase awareness about human rights of people with mental illness (and epilepsy); to change attitudes and reduce discrimination; and to increase the number of people using primary health care for mental/neurological illness, in line with the Nigerian National Policy for Mental Health [19].

The MHAP intervention was designed to increase use of a mental health service in Nigeria, by utilising Village Health Workers (VHWs), who work in communities, usually in a health promotion role such as vaccination programmes or HIV/AIDS awareness. As local volunteers linked to health services, they have a unique engagement with members of communities, including people with mental health conditions, and their carers [20]. 15 VHWs in each Local Government Area were identified using clear criteria designed to engage those who were motivated to work in mental health, and were likely to remain in the community and role for some time. A total of 315 VHW were identified and each group of 15 received a 5 day training by the psychiatric nurse in their local clinic, using a package that had been previously developed and tested by Amaudo. The content focused on gaining knowledge about mental illness, promoting human rights and dignity, and sharing practical ways of supporting social integration. The fact that the nurse provided the training reinforced relationships for ongoing work between the nurse and the VHWs. In addition, key local actors such as Primary Health Care Coordinators and other local health leaders were invited to supervise the training, and local community leaders participated in opening ceremonies. Further details are available from http://www.amaudouk.org. Following the training, they were then expected to visit each village in their catchment area, share information using the provided materials, and encourage people identified as having mental health problems to attend the clinic. The awareness-raising activities in communities involved speaking to community leaders, at community gatherings (including women's and youth meetings), and in church meetings. At the same time, a media campaign was run involving brief messages on the radio, and use of posters and leaflets. VHWs received a 1 day refresher training 6 months after the initial training, and maintained a relationship with the psychiatric nurse. This intervention has been described previously in previous published work [17] and a programme report [21].

The study used the phased roll-out of the programme to measure impact during the MHAP implementation in Imo State (intervention), and used Anambra States as a control during the year prior to implementation there. We selected Imo as the intervention state (population 3.9 million, 21 active clinics) and Anambra State (population 4.2 million, 21 clinics) as the control because they have similar demography and health systems, and the CMHP services were identical, including VHW presence.

Routinely available attendance data from all clinics in the service in the intervention and control state were collected (42 in total). Unfortunately, there was a nurse strike in our control state (Anambra) during the period where we needed to collect service use data, so we were unable to compare concurrent data using comparison of mean attendance with the t test. We adjusted the analysis instead to rely on a comparison with data from Imo prior to the intervention.

Results

Change in number of new patients using clinics

The statistical analysis had to be adjusted to take account of the lack of a control site. The negative binomial model used is an extension to the Poisson model for analyzing count data in that it allows for the over-dispersion of zeros that would be uncharacteristic of the more familiar Poisson distribution. The results however can be interpreted in the normal fashion in the form of incident rate ratios (IRR). In the context of the model above, IRRs higher than 1 indicate an increased risk of the event occurring (i.e. higher number of new patients) and IRRs lower than 1 indicates a lower rate of new patients.

The model is adjusted for an underlying baseline risk that has been tested for non-linearity but appears to be linear in nature (i.e. constant). With increasing months, the risk of increased number of new patients is 1.000 indicating that the risk does not change with time (i.e. the gradient of the slope is 0, flat). Thus there was no significant trend for the number of new patients seen from beginning of the data collection up to and including June 2011.

The incident rate for the initial period of the intervention was 5.1 times higher than the incident rate for the baseline rate (which we have shown to be a flat trend) and this increase was highly statistically significant (95% CI 3.42–7.56, p < 0.001).

The long-term effect of the intervention

This initial significant effect quickly diminished, and the intervention effect reduced before leveling off above the initial baseline (see Fig. 1).

Figure 1 shows the expected results calculated from the first model above. The fitted regression line (maroon) closely fits the observed data (black dash line) that was seen previously in Fig. 2, and closely describes the change in the number of new patients seen each month. The red line shows fitted results unadjusted by site for reference.

This shape of curve is seen frequently following an intervention whereby the initial effect is not sustained

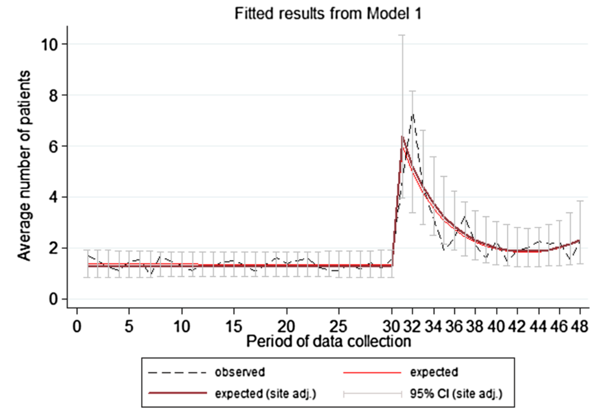

Fig. 1 Fitted regression estimates for the incidence of new patients per month

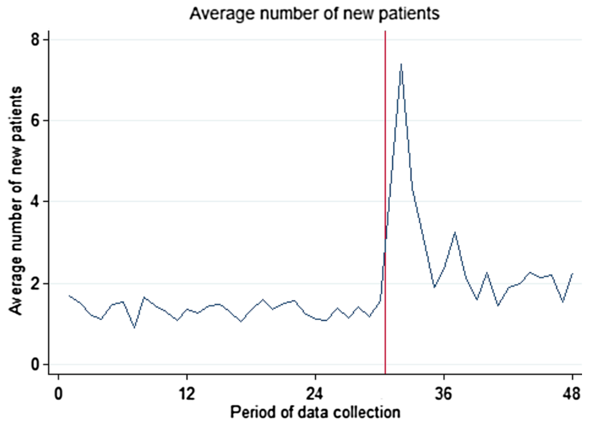

Fig. 2 Mean number of new patients seen per month

and eventually levels at a smaller effect or returns to the baseline. Unfortunately we do not have enough points of data collection after the intervention to estimate the stable intervention effect as the rate of new patients seen each month may or may not be changing by the end of data collection. Also, local fluctuations towards the end of the data collection appear slightly increased, but the figures fall within the range of fluctuations seen in the data.

Another way of describing the intervention effect is to use this regression equation to see at which points following the intervention is the rate of new patients seen higher than the baseline rate. See Table 1.

Table 1 compares the intervention effect at each time-point and compares it to the baseline rate of new patients seen per month. As described previously, the rate of new patients seen in the initial intervention was 5.09 times higher than the baseline. By the following month, the number of new patients seen per month was 4.18 times higher than the baseline ($p < 0.001$). Up to and including the 10th month following the intervention, the number of new patients seen per month was higher than the baseline rate. Following this, the rate of new patients seen each month remains above baseline until the end of data collection, but the results are not statistically significant for a period, before tending in this direction again.

Table 1 Treatment effect with time

Treatment effect with time	IRR	95% CI (LL–UL)	p value
0—initial intervention effect (July 2011)	5.09	(3.42–7.56)	< 0.001
1st period after the intervention (August 2011)	4.18	(2.94–5.93)	< 0.001
2nd period after the intervention (September 2011)	3.49	(2.52–4.84)	< 0.001
3rd (October 2011)	2.97	(2.15–4.09)	< 0.001
4th (November 2011)	2.56	(1.84–3.56)	< 0.001
5th (December 2011)	2.25	(1.60–3.17)	< 0.001
6th (January (2012)	2.02	(1.41–2.89)	< 0.001
7th (February 2012)	1.83	(1.26–2.66)	0.001
8th (March 2012)	1.70	(1.15–2.50)	0.007
9th (April 2012)	1.60	(1.08–2.38)	0.020
10th (May 2012)	1.53	(1.02–2.30)	0.038
11th (June 2012)	1.49	(0.99–2.25)	0.056
12th (July 2012)	1.48	(0.97–2.25)	0.066
13th (August 2012)	1.49	(0.97–2.30)	0.067
14th (September 2012)	1.53	(0.98–2.40)	0.062
15th (October 2012)	1.60	(0.99–2.58)	0.053
16th (November 2012)	1.70	(1.01–2.85)	0.044
17th (December 2012)	1.84	(1.04–3.27)	0.037

Discussion

Carrying out implementation of innovative programmes is challenging in Nigeria, particularly in the public sector. This is in part due to the fact that systems of management and bureaucracy were not very efficient, and due to the frequency of disruptions in services. Despite the fact that political circumstances resulted in a change of available data, which required a different statistical analysis, we have been able to demonstrate that an awareness intervention can significantly increase service use (in this case a fivefold increase). These results show that addition of an awareness raising component, delivered by lay community workers, as part of health programme implementation can increase use of services by the target population.

Potential mechanisms for the increase in service use observed include simply informing populations of the existence of a service of which they were previously unaware (but that they would be inclined to use), to impacting on explanatory models of causation of mental illness (and challenging negative ideas of prognosis for example), or the effect of community leaders' endorsement of a new service.

The initial increase in service use may well have been in part due to large numbers of people making use of the service on discovering its availability (it was not a new service). The sharp reduction in new patients is not entirely justified by this, however, because the treatment gap far exceeds even the increased numbers accessing the service. The awareness intervention covered both common mental disorders, severe mental illness (especially psychosis) and epilepsy. It is worth noting that a high proportion of service users had epilepsy and severe mental illness, compared to local population prevalence. This is a common finding, representing pathways to care, identification of common mental disorders, and somatization issues.

Even interventions that are deliberately designed to penetrate the most remote communities will always first reach those who are closest to making use of the service, because they are able to reach it, to afford it, or would tend to use formal health services for mental health needs. Alternatively, those who have already used traditional options without satisfaction may be ready to try a new option available to them. Further qualitative research would shed light on which of these processes are relevant.

The up-turn in attendance at the end of data collection may have been due to the refresher training carried out on average 6 months after the initial training, though a longer data collection period would have made this clearer. A greater sustained effect might have been increased by more intense use (increasing the dose) of active elements of the intervention like VHW refresher training (which has a motivating effect in addition to reinforcing knowledge). In addition, other elements of a comprehensive intervention, like media campaigns, are recognised to contribute to the overall effect [22].

The lack of a control site was an important limitation in the study. While we can reasonably attribute the change to the intervention, this would have been more appropriately tested with the control group as originally planned. In addition, while an increase in service use was demonstrated, it is not possible to know what element of the intervention was responsible for this effect, as the study did not explore this a methodology that allowed such analysis.

Conclusions

Our results imply that targeting key community actors is an effective way of improving help-seeking in areas where formal health services are not necessarily seen within local belief systems as the obvious place to seek treatment for mental illness. Further research might explore potential mechanisms for change in attendance and service use behaviour using qualitative methods.

In this case, although the existing health intervention (a community mental health programme) did not change, there was a significant increase in use of the service following an awareness-raising intervention using village-based health workers. This was sustained for almost a year, but there was a clear reduction in the effect with time. This might be addressed by ensuring ongoing engagement and repetition of active ingredients of the intervention.

Abbreviations

CBM: formerly Christoffel Blindenmission; CMHP: Community Mental Health Programme; HIV/AIDS: Human Immunodeficiency Virus and Acquired Immunodeficiency Diseases; IRR: incident rate ratios; LAMICs: low and middle income countries; MHAP: Mental Health Awareness Programme; NGO: Non-Governmental Organisation; PHC: Primary Health Centre; VHWs: Village Health Workers.

Authors' contributions

JE, GO and UO wrote the proposal and protocol. JE, GO, UO and EN trained and retrained the service provider and field assistants. CH analysed the data set. JE drafted the manuscript. All authors read and approved the final manuscript.

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Competing interests

The authors declare that they have no competing interests.

Availability of data and materials

The data set used and analysed during the current study are available from the corresponding author on reasonable request.

Consent for publication

Not applicable.

Ethical approval and consent to participate

The study received ethical approval from the local Abia State University, where two of the co-authors were based (GO, UO). The project was managed by a Steering Committee comprised of local project staff, local researchers, a member of Amaudo staff, a service user, and a technical advisor from an international NGO (CBM; EN). Permission was sought from the health service authorities to use routine data for this study, and VHWs arriving for MHAP training were given verbal and written study information, and written informed consent was obtained.

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Paper 2

Eaton J, McCay L, Semrau M, Chatterjee S, Baingana F, Araya R, Thornicroft G, Saxena S.

Scale Up of Services for Mental Health in Low Income and Middle Income Countries. *The Lancet* 2011; 29:378(9802)

https://www.sciencedirect.com/science/article/pii/S014067361160891X?casa_token=q2ECujPWMUgAAAAA:0upSW3zE4Sj4mukWCSUHmc53_CZmIOxXvaezwtDX_8N8MWzA8TVP2NABAsa3zL2z7W69nHsYdNyC

The foundational 2007 Lancet Global Mental Health Series concluded with a ‘Call for Action’ for the emerging field of global mental health to close the mental health treatment gap and address human rights abuses. This paper sought to use a systematic approach to assess progress in scaling up mental health services globally (particularly in low- and middle-income countries that have the widest treatment gap). This was done using a systematic review and survey of key experts in the field.

Its conclusions were that while significant progress had been made in testing approaches that had shown significant promise in improved clinical and social outcomes at small scale (using very robust methods), there was no evidence that this research had been scaled in a way that had any impact on the treatment gap. This was likely to be a broadly accurate finding (based on our methods), but a major issue identified was the very weak data collected that would have enabled accurate measurement of coverage in most countries in the world (which would have been the most direct means of accurately assessing any change in the treatment gap).

My role in the research was to lead the conceptualisation and to coordinate and carry out many aspects of the systematic review and survey methodology that were undertaken, including analysis. I also lead the writing of the paper through to submission.

Confirm role: Julian Eaton Signature: J Eaton Date: 26.5.23

Confirm role: Prof S Saxena, last author: Signature: S Saxena Date: 26 may 2023

Global Mental Health 4

Scale up of services for mental health in low-income and middle-income countries

*Julian Eaton, Layla McCay, Maya Semrau, Sudipto Chatterjee, Florence Baingana, Ricardo Araya, Christina Ntulo, *Graham Thornicroft, *Shekhar Saxena*

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This is the fourth in a **Series** of six papers about global mental health

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Mental disorders constitute a huge global burden of disease, and there is a large treatment gap, particularly in low-income and middle-income countries. One response to this issue has been the call to scale up mental health services. We assess progress in scaling up such services worldwide using a systematic review of literature and a survey of key national stakeholders in mental health. The large number of programmes identified suggested that successful strategies can be adopted to overcome barriers to scaling up, such as the low priority accorded to mental health, scarcity of human and financial resources, and difficulties in changing poorly organised services. However, there was a lack of well documented examples of services that had been taken to scale that could guide how to replicate successful scaling up in other settings. Recommendations are made on the basis of available evidence for how to take forward the process of scaling up services globally.

Introduction

The past two decades have seen an unprecedented increase in efforts to address global inequalities in physical health care, particularly as part of the UN's Millennium Development Goals (MDGs) initiative. Resources targeting HIV/AIDS, tuberculosis, malaria, and maternal and child health have increased substantially. Development assistance for health grew from US\$5·6 billion in 1990 to \$21·8 billion in 2007,[1] and there have been similar increases in education and social development activities. Less progress has been seen in the response to mental, neurological, and substance misuse disorders, despite the identification of the large treatment gap[2,3] and a consensus that improved access to mental health care could provide new hope for people with these disorders, especially in the poorest countries of the world.[4,5]

In 2007, *The Lancet* presented a Series of papers on global mental health that reviewed the global state of mental health systems,[5,6] summarised the evidence for effective treatments,[7] identified barriers to service improvement,[8] and examined existing and required resources for mental health care.[9] The series concluded with a call for global action to increase access to mental health services—a process referred to as scaling up.[10] In this report, we assess global progress in scaling up of mental health care in low-income and middle-income countries since 2007.

Definitions of scaling up typically refer to an objective with several common components: an increase in the number of people receiving services (coverage); an increase in the range of services offered; services that are built on a scientific evidence base, usually with a service model that has been shown to be effective in a similar context; services made sustainable through policy formulation, implementation, and financing (strengthening of health systems).

Scaling up has also been used to refer to a process, which includes mobilisation of political will, human resource development, an increase in the availability of essential medicines, and monitoring and evaluation.[11] WHO has described scaling up as "deliberate efforts to increase the impact of health service innovations successfully tested in pilot or experimental projects so as to benefit more people and to foster policy and programme development on a lasting basis".[12]

Much research on scaling up focuses on resource availability, identification of barriers, and service delivery issues.[11] We have followed this outline in our report. Progress in scaling up of services could most accurately be measured by comparing change in effective coverage—ie, the proportion of people with a mental disorder who receive appropriate treatment.[13] However, such information

Key messages

- There are many examples of mental health initiatives being developed worldwide.
- There is a need to scale up such services in low-income and middle-income countries so that more people can benefit; however, thus far very few innovative services have achieved this goal.
- Barriers to the scaling up of services should be strategically and systematically considered and addressed. Key to this process is to involve all stakeholders, including decision makers to ensure their support and to facilitate sustainability of services, as well as people using mental health services.
- Services should be both evidence-based and locally relevant, ensuring that they take into account all aspects of existing systems.
- Assessment of examples of scaling up is important so that conclusions can be implemented in a practical way. These conclusions should be disseminated in a format that is accessible to implementers of services.

relating to coverage is not widely published in governmental or scientific literatures, particularly from low-income and middle-income countries.[14,15] The absence of available baseline prevalence and service use data in these countries makes accurate measurement of coverage impossible, although recent data suggest that across the range of mental disorders, only a third of people with mental health disorders are treated in high-resource countries, and as few as 2% of people with such conditions are treated in some low-income and middle-income countries.[16,17]

We therefore used a combination of a systematic review of published literature and a survey of key informants (panel 1). We aimed to gather as comprehensive and up-to-date a view as possible of the extent of scaling up of mental health services in countries with low and middle incomes. Additionally, we have been able to identify many programmes from which we drew out themes related to challenges and practical solutions for making progress in scaling up of services.

The literature review and survey identified many examples of services being scaled up (see webappendix pp 10–19), but few met all of our criteria. There were some published descriptions of services that were scaled up to cover increased population numbers (eg, in Brazil,[20] Chile,[21] and China[22]), but most reports described early stages of reorganisation of services[23–25] or preparation of policy and legislation.[26] This outcome could in part be attributable to the length of time needed to plan, implement, and evaluate programmes. Almost half the respondents to the survey reported that progress in

See Online for webappendix

Panel 1: Systematic review and survey

Methods

To capture a global perspective, we included English, Spanish, and French language publications in each of the literature searches. We were not able to include literature published exclusively in other languages, including Mandarin Chinese, Portuguese, or Russian, because of resource limitations. With the exception of global organisations (eg, WHO and the World Psychiatric Association), much of what is published is only in English. This factor constitutes a major barrier to sharing and accessing of information for people who are not fluent in English.

Systematic review

A systematic review of the published and grey literature was undertaken (by LM) to identify evidence of scaling up of mental health services in low-income and middle-income countries since 2007. "Scaling up" and "LAMIC" are not widely used terms, and so we used search terms that were deliberately broad, and information for each country was also searched for individually. Countries with low and middle incomes were defined with the World Bank classification (countries with low incomes, lower-middle incomes, and upper-middle incomes were included)[18]—144 countries in total.

Searches covered the period from January, 2007, to November, 2010, inclusive, and used Medline, Embase, Global Health, PsychExtra, PsycInfo, Cochrane Database and DARE, Africa-Wide Information, Index Medicus EMRO, Index Medicus South East Asia, LILACS, IndMed, KoreaMed, and WHOLIS. Search terms used are listed on webappendix p 1. The titles and abstracts of retrieved publications were screened for relevance to scaling up, to treated prevalence, or to the WHO Mental Health Global Action Programme initiative. Further, *International Psychiatry, World Psychiatry,* and *International Journal of Mental Health Systems* were hand-searched, since they were not fully indexed by these databases.

In addition to the scientific databases, we undertook a web search using Google for relevant papers using the terms "scaling up", "psychiatry", and "mental health". References of all relevant studies and publications were scanned to identify any further relevant publications. The Google search, but not references from it, was restricted to PDF articles. The WHO Assessment Instrument for Mental Health Systems[19] was also searched and all reports published from 2007–10 were retrieved (table 1).

Survey

To obtain additional unpublished information, we identified expert key informants with knowledge at the national level of mental health services in low-income and middle-income countries. To a list provided by the WHO Mental Health and Substance Abuse Department (Geneva, Switzerland), we added a wider range of relevant stakeholders including users of services. The very small number of people in many countries qualified to be included in the sample made random selection of people impossible. The web questionnaire (webappendix pp 2–9) included a brief introduction of its purpose, a definition of terms, and 15 questions on progress in scaling up services, resources available, new materials to support scaling up, new alliances for scaling up, and obstacles and lessons learnt.

Participants were emailed and asked to respond to the survey through the www.surveymonkey.com website, or by completing an attached version of the survey. The questionnaire was made available in English, French, and Spanish. Data were analysed (by JE and MS) by grouping free-text data and coding according to categories, with counts undertaken where relevant.

Of the 142 people contacted, 87 (61%) responded, and their characteristics are shown in table 2. Respondents were mainly senior figures at the country level who could reasonably be expected to know about activities beyond their own organisation. 59 countries were represented in the survey, of which 19 (32%) were in the WHO Africa region, 16 (27%) in the Americas region, eight (14%) in the eastern Mediterranean region, six (10%) in the western Pacific, five (8%) in southeast Asia, and five (8%) in Europe. Of these, 20 (34%) countries had low incomes, 20 (34%) lower-middle incomes, 16 (27%) upper-middle incomes, and three (5%) high incomes (figure 1).

	Total identified	Total relevant
Medline, Embase, Global Health, PsychExtra, PsycInfo	478	9
Cochrane Database and DARE	262	0
Africa-Wide Information	2452	41
Index Medicus EMRO	115	1
Index Medicus South East Asia	1235	0
LILACS	667	0
IndMed	4	0
KoreaMed	14	1
WHOLIS	18	5
International Psychiatry, World Psychiatry, and *International Journal of Mental Health Systems*	>28 editions	33
Google (restricted to PDFs)	>170 000 (400 screened)	9
Reference search	NA	8
WHO-AIMS	68	29
Total	..	136

NA=not applicable.

Table 1: **Reports identified, by source**

their country towards scaling up of services since 2007 had been “good” or “very good” (figure 2A).

Political will and the prioritisation of mental health

At the core of global[27,28] and national[29–31] efforts to scale up services is the need for decision makers and political leaders to understand the issues, recognise their importance, and prioritise action to address mental health needs.[32] Our survey identified some improvement in awareness of mental health issues among leaders during the past 3 years, with more than half of respondents reporting “more” or “much more” awareness (figure 2B). Yet about 40% of respondents, from 26 (44%) countries, identified continuing poor awareness and low priority or poor commitment by political leaders as major barriers to development of mental health services.

> “[There is a] lack of political will to provide a workable mental health policy, introduce reforms in health service delivery, and poor funding at all levels of government.” (Nigeria)

Survey respondents cited the absence of a national government mental health policy, strategy, or programme as a key barrier to implementation.[23,25,33,34] However, many countries are now updating their mental health policy or legislation (webappendix pp 20–25). Mental health policy is an important component of scale up of services,[35] although it is not in itself sufficient.[26] An analysis of mental health policies in Ghana, South Africa, Uganda, and Zambia, for example, found them to be weak (in draft form or unpublished) and inadequately implemented. They often lacked feasible plans and adequate resource commitments.[36] We also identified examples (see case study of Uganda, panel 2) in which significant progress was achieved without a recent or complete national policy.

> “There appears to be a disconnect in Government regarding expressed interest and support for mental health services and the lack of tangible expressions manifested by resource availability and policy implementation.” (Liberia)

	Survey respondents (n=87)
Sex	
Male	60 (69%)
Female	27 (31%)
WHO region of country for which survey answered	
Africa	46 (53%)
Americas	25 (29%)
Southeast Asia	16 (18%)
Eastern Mediterranean	9 (10%)
Western Pacific	8 (9%)
Europe	7 (8%)
Classification of country for which survey answered*	
Low-income country	45 (52%)
Lower middle-income country	40 (46%)
Upper middle-income country	23 (26%)
High-income country†	3 (3%)
Type of organisation worked for	
Non-governmental organisation	34 (39%)
Academic institution	33 (38%)
Government department	25 (29%)
Patient organisation	6 (7%)
Multilateral agency	4 (5%)
Other	1 (1%)
Role	
Academic (professor, lecturer, or researcher)	26 (30%)
Director or manager of mental health services or programmes	24 (28%)
Psychiatrist	21 (24%)
Programme advisor, consultant, or coordinator	15 (17%)
Other mental health clinician or specialist (not psychiatrist)	6 (7%)
Other	4 (5%)
Language in which survey completed	
English	69 (79%)
Spanish	13 (15%)
French	5 (6%)

Data are number (% of total). Numbers do not always add up to the total number of respondents (n=87), either because respondents were able to select more than one response, respondents answered questions for more than one country, or responses were missing. *According to the World Bank. †A small number of respondents currently reside in high-income countries although they responded to the survey on the basis of experience in low-income and middle-income countries.

Table 2: **Characteristics of survey respondents**

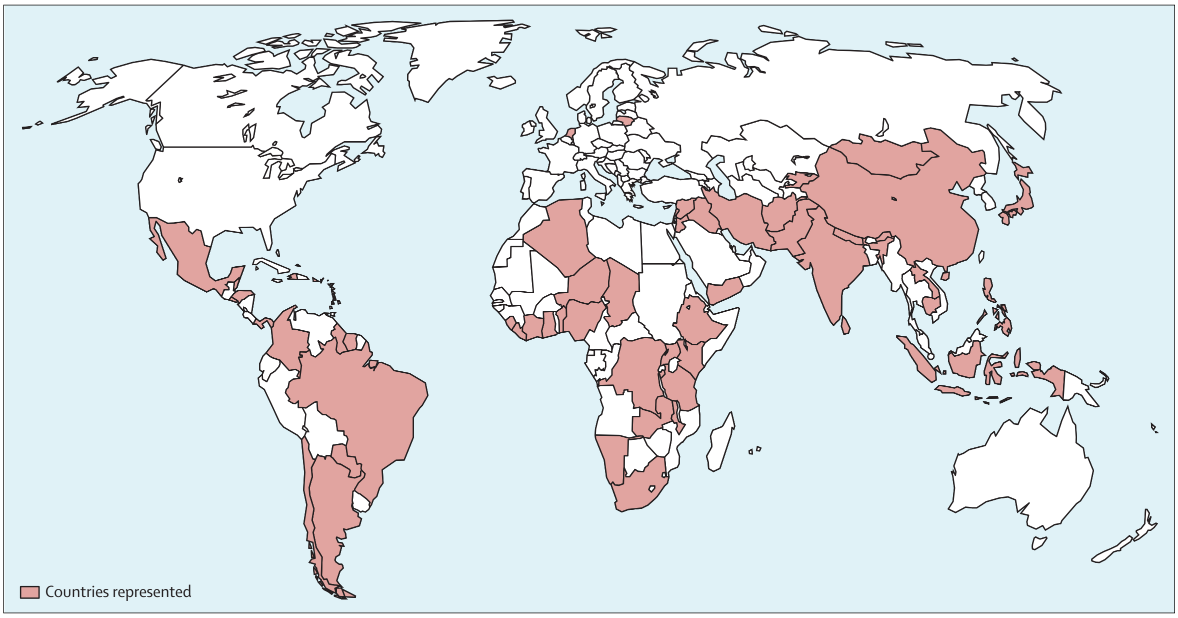

Figure 1: **Countries represented by respondents to the survey**

Legislation provides a clear legal framework that assures respect for human rights as a condition of care, and can also be a lever for change.[39] The UN Convention on the Rights of Persons with Disabilities specifically includes the rights of people with psychosocial disabilities,[40] but there was no evidence that this instrument has yet been effectively used in any country included in the survey.

The survey provided a wealth of recommendations to challenge poor government commitment. The main messages were to be persistent, use all relevant evidence of need and of effective interventions, respond pragmatically to opportunities as they arise, use strong stakeholder advocacy groups,[31,41] and clearly allocate responsibility for implementation of plans,[42] including through local management structures.[41]

Poor knowledge and stigmatising beliefs among the general population were also identified as key barriers, reducing willingness to seek help.[29,43,44] Key strategies to change attitudes and helpseeking behaviour were engagement of people using mental health services, their families, and the general community,[41] as well as specific target groups including respected leaders such as village elders[30,39] and traditional health-care providers.[45] Methods included protesting against misinformation and discrimination, sharing of information through direct contact, or use of media.[31] One service model in Nigeria, for example, included a mental health awareness campaign that led to increased use of community mental health services.[46]

At a global level, the central advocacy messages have been to draw attention to the mental health treatment gap,[47–50] reinforce the need to scale up services,[29,51] call for policy and legislation on mental health,[52] and show that evidence-based systems of care should be implemented in the community.[27,53] One initiative strengthening the case for prioritisation of mental health is Grand Challenges in Mental Health. This systematic identification of priorities in mental health is part of the Global Alliance for Chronic Disease. Availability of this kind of evidence has the potential to raise the profile of mental health on the global health and development agenda.[27]

Several new organisations have emerged at national, regional, and global levels whose stated aim is to enable scaling up of services (webappendix pp 26–27). These groups include academic or research bodies, advocacy organisations, and journals. Civil society and non-governmental organisations were repeatedly identified in the survey as playing a key part in strengthening capacity, mobilising funds, and facilitating the implementation of new programmes (figure 2C).

Several global programmes that aim to support efforts to scale up services were identified in the literature review and survey. The Mental Health Gap Action Programme (mhGAP) is the WHO's flagship project in mental health.[54] The objectives of the programme are to reinforce the commitment of stakeholders to increase the allocation of financial and human resources for the care of people with mental, neurological, or substance misuse disorders and to achieve increased coverage of evidence-based interventions, especially in countries with low and lower-middle incomes.[55]

The World Psychiatry Association (WPA) 2008–11 Action Plan is based on a systematic survey of international leaders in psychiatry from almost

For the **UN Convention on the Rights of Persons with Disabilities** see http://www.un.org/disabilities/convention/conventionfull.shtml

For more on **Grand Challenges in Mental Health** see http://grandchallengesgmh.nimh.nih.gov

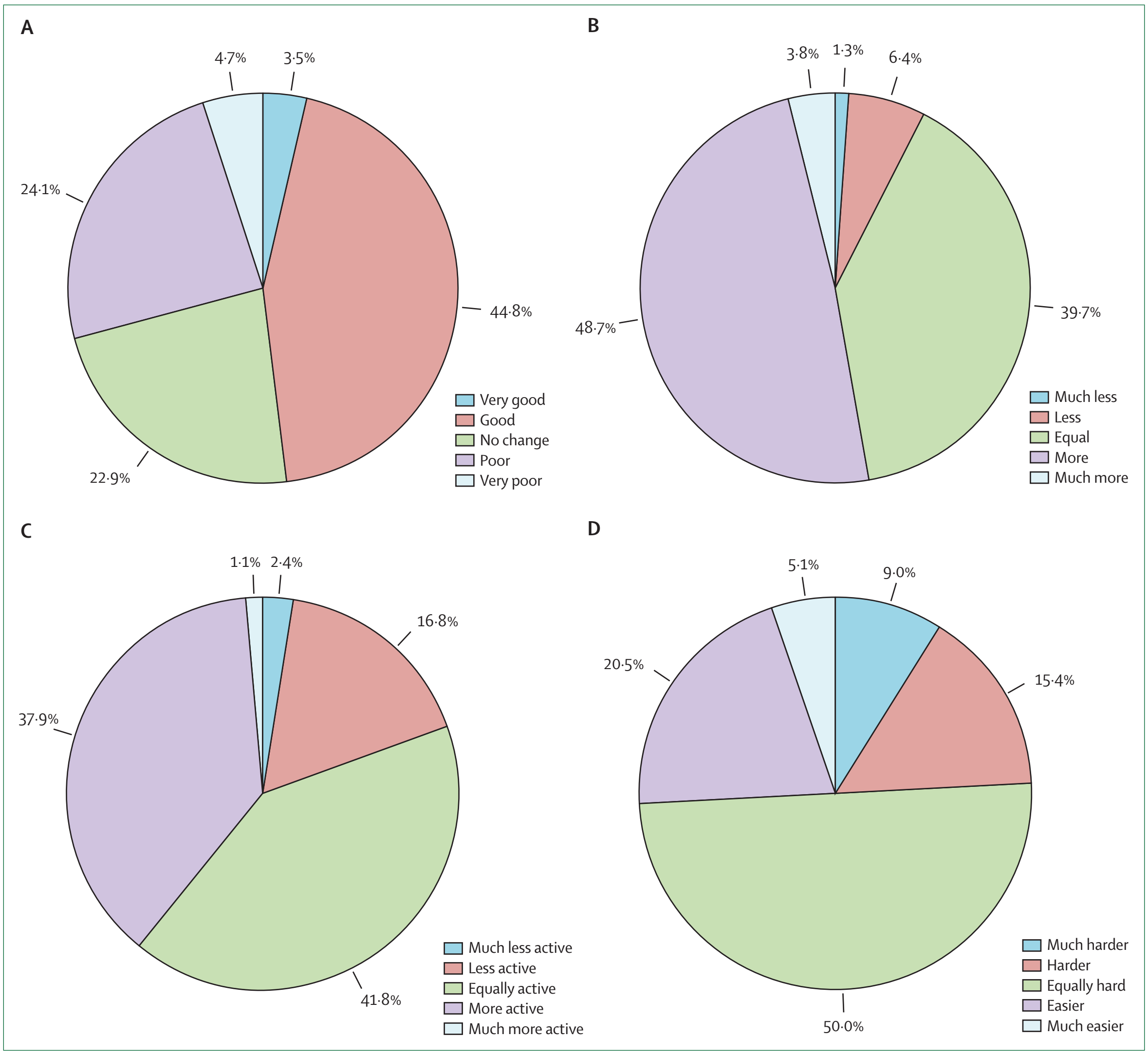

***Figure 2:* Survey results**

(A) Respondents' view of country-level progress in scaling up of mental health services since 2007. (B) "In my opinion, the level of awareness among health planners about the need to scale up services compared with 3 years ago is…". (C) "In my opinion, since 2007, in the area of scaling up mental health services, non-governmental organisations/civil sector have become…". (D) "In my opinion, over the past 3 years, mobilising funding for mental health related activities has become…".

60 countries, of which two-thirds have low and middle incomes.[39] The results emphasise strengthening of specialist care while also task sharing (also known as task shifting) in primary care to maximise coverage,[56] increasing access to psychological therapies and social interventions, and the active involvement of people using mental health services and their families. On the basis of these findings, the WPA is implementing a training programme in selected low-income countries.[57]

For the **Movement for Global Mental Health** see www.globalmentalhealth.org

The Movement for Global Mental Health emerged in 2008 after publication of *The Lancet*'s Series on global mental health.[53] This coalition includes people using mental health services, professionals, and institutions ranging from universities to non-governmental organisations. It aims to be a social movement advocating scale-up of mental health services and protection of human rights.

Organisation of services

Existing structures into which mental health services fit often do not facilitate evidence-based interventions. The continued dominance of large psychiatric hospitals in many countries is at odds with the evidence, which suggests that most services should be delivered in decentralised locations,[24,58] with deinstitutionalisation[39,47] and integration between the community and hospitals,[27,41] and appropriate referral systems incorporating secondary and tertiary care.[33,59,60] There still remains an important role for tertiary hospitals in provision of specialised beds (which remain in short supply compared with need).[30,61]

One model for decentralisation is in Ethiopia, where nurses are trained to assume a range of extended roles in district settings, from prescription of drugs to community mental health education.[62] Integration of mental health into primary care has commenced in five regions of Egypt as part of the country's Health Sector Reform Programme.[26] This programme includes staff training with follow-up, supervision, and a referral system to support primary care doctors. In Kenya, the mental health programme that was established in 2001 is now in its second phase involving training, supervision, and medicine supply.[35] Panel 3 shows a case study in the occupied Palestinian territory.

Poor knowledge of mental illnesses among primary health-care staff and scarcity of mental health specialists for liaison and supervision have been identified as key concerns.[25,32,45] Task sharing has proved to be an effective strategy in other areas of health, such as immunisation uptake and management of tuberculosis and HIV.[63] There is growing evidence that lay people and health workers can also provide care traditionally delivered by psychiatrists.[30,43,64–66] However, several of the respondents to the survey stated that unless staff receive ongoing training and supervision, motivation to undertake mental health work is lost. Some innovative approaches in India and Niger addressed the need for staff supervision by using telephones to facilitate communication.[30,67]

The difficulty of giving increased responsibilities to busy primary health-care staff is often cited.[27] A possible solution is the integration of mental health care with services for people with long-term (chronic) conditions,[68–70] since services for individuals with chronic conditions share many of the characteristics of services for people with mental and neurological disorders. There is also a strong consensus that mental health should be integrated with other systems, such as social care[71] and education.[60,72]

Task sharing always necessitates substantial training, but where there is high staff turnover, this investment might be wasted.[34] Some reports called for task sharing with families, carers, and volunteers, empowering them to play a more informed part in caring for people with mental illnesses in the community—a training investment less likely to risk so-called brain drain.[39,41] This peer support is also favoured by organisations of people using mental health services, families, and carers,[40] but this strategy should avoid reducing choice by replacing proper provision of professional services on which people also rely.

Many health information systems (which can include various population-based data sources [eg, censuses or household surveys] or health-facility based sources [eg, public health surveillance, health services data]) do not include mental, neurological, and substance misuse disorders.[73] This factor makes it more challenging for mental health to be regarded as an integral part of the overall health system, as well as jeopardising efficient mobilisation of essential drug supplies, and implying low demand for mental health services.[74]

Panel 2: Integration of services into primary health care in Uganda

Uganda is an east African country with a population of about 32 million people, of whom more than 80% live in rural areas and 31% live on less than US$1 a day.[37] The Uganda National Mental Health Programme was conceived of in 1999, after collaboration between WHO, non-governmental organisations, and the National Mental Health Programme. The subsequent Health Sector Strategic Plans included mental health for the first time. Key elements included staff training, strengthening of drug supply systems, guideline implementation, and public education. Initial reports described successful implementation,[24] but subsequent evaluations have been more mixed. One qualitative assessment[25] based on focus groups and interviews found that staff in the site studied did not focus on mental health, and psychotropic drugs were not available. Progress is more substantial in districts that have included mental health personnel as members of the District Technical Planning Committee. In 2001, there were few community-based services beyond those supported by non-governmental organisations. By 2010, the Annual Health Sector Performance Report[38] found nine functioning regional mental health units compared with four in 2001, a 75% increase in psychiatric nurses at district level (though some were deployed to other functions), and 80% of all health subdistricts had at least one antipsychotic, one antiepileptic, and one antidepressant drug.

In terms of funding, the first Strategic Plan indicated an allocation of 0·7% of the total health sector budget to mental health—the first time that mental health had a clear budget line. Mental health is now estimated to be allocated about 4% of the health sector budget. Before 2004, most community-based work was done by non-governmental organisations, but this contribution greatly reduced with the end of the Lord's Resistance Army and Karamajong wars.

There is a new Ugandan mental health policy in draft form, and Parliament has approved the drafting of legislation that will replace the Mental Health Act of 1964. These two draft documents are progressive in being rights-based, in promoting community mental health as the priority strategy for service provision, and in recognising the role of people using mental health services and non-governmental organisations in planning, implementing, and evaluating mental health services.

Even services based on simple packages of care need a sustainable supply of psychotropic drugs,[45,75] and the systems to provide this supply are often weak in low-income settings.[76] In the short term, non-governmental organisations can find innovative ways of ensuring a supply of drugs, but ultimately the solution is to strengthen systems for sustainable provision of essential drugs.[41,76] The availability of psychological therapies is even less than for pharmacological interventions,[34] and is an area with a weak evidence base in low-income and

Panel 3: Mental health and psychosocial services support project in the West Bank and Gaza

The European Union is financing a Mental Health and Psychosocial Services Support Project in the West Bank and Gaza, implemented by the WHO office in Jerusalem in collaboration with the Palestinian Ministry of Health. The goal of the project is to improve the quality, effectiveness, and sustainability of public mental health services through primary health-care services.

In the West Bank, extensive consultations led to a scaling up strategy using a stepped care model of treating common mental disorders in public primary care facilities. The Primary Health Care Directorate and the Mental Health Unit of the Ministry of Health agreed to implement the programme across the 12 health districts of the West Bank. Primary care doctors (GPs) and primary care nurses (PCNs) were trained to identify and treat common mental disorders, with antidepressant use in moderate-to-severe cases, referral to specialist care when indicated, adherence management, and trained PCNs to implement psychosocial interventions. To date, 535 staff in nine of the 12 West Bank districts have completed the necessary training. Ultimately, the programme will be rolled out across all districts, with training and ongoing supervision of the primary care team members.

In Gaza, the mental health care integration plans were preceded by a rapid situation analysis of the prevalence of common mental disorders. 500 randomly selected adults in five primary health-care centres around Gaza were screened with the General Health Questionnaire-12. More than a third (38%) of adult attendees were identified as having mental health problems. An assessment of the skills and attitudes of primary health-care staff showed poor recognition of common mental disorders, inappropriate treatments, and negative attitudes. Introductory courses were held for 200 GPs and PCNs. Additionally, 12 mental health specialists were trained in clinical supervision for primary health-care staff. At present, a pilot programme for integration of care for people with common mental disorders is underway in five primary health-care centres, with plans for further scaling up.

middle-income countries.[55,77] In Chile, scaling up of evidence-based depression care needed an increase in full-time psychologists in primary care centres of 344% from 2003 to 2008.[78]

Evaluation and effect

Although respondents accepted the importance of evaluation in principle, most programmes were not evaluated.[79–81] In a systematic review of community mental health services in Africa, only a fifth of relevant programmes included any evaluation,[59] and our findings accord with this assessment. Of the 56 respondents who described new mental health programmes in their countries, only 22 (39%) reported completed evaluations. Most research into scaling up of services emphasises two issues: first, there are gaps in metrics and evaluation along with inadequate and incomparable primary data sources and analyses;[82] and second, even well researched pilot projects are rarely scaled up. For example, two randomised controlled trials (in Pakistan and India) evaluated community workers in delivery of care for perinatal depression and dementia, respectively.[64,66] Despite being high-quality studies with positive results, there was not sustained success at integration of such services in health systems after the research trials. This finding emphasises that close collaboration between research groups, government, non-governmental organisations, and other stakeholders is essential from the outset, and that consideration of practical sustainability issues is vital for making services research influential in the real world.

Resources

Financial resource allocation

If services are to be scaled up, a substantial increase in resources and more efficient use of the resources that exist is needed.[9] Absence of funding remains the dominant reported impediment to programme implementation.[23,25,74,83] Tracking of financial resource allocation is one key way to judge political commitment to scaling up of mental health services (panel 4). In some cases, increased allocations of funds have been achieved, as in Chile[21] and Brazil.[20]

Access to evidence-based information: guidelines

The literature review and survey respondents identified several guidelines that have been produced to assist scale up of services (webappendix pp 28–29). Some cover incorporation of mental health interventions into other sectors, such as the Inter-agency Standing Committee guidelines on emergency interventions,[85] and the WHO Community-Based Rehabilitation Guidelines.[86] Others relate to a specific component of mental health work—eg, working with children in war-affected areas.[87]

One series covering treatment of a range of mental illnesses in low-income and middle-income countries was published in *PLoS Medicine* after consultation with more than 100 experts in 46 countries,[32] and describes how non-specialist health workers can deliver effective treatments for mental and neurological disorders in resource-poor settings, and how to integrate this approach into primary care settings with the treatment of other chronic disorders. The targeted disorders included attention-deficit hyperactivity disorder,[88] epilepsy,[89] depression,[90] schizophrenia,[91] alcohol misuse disorders,[92] and dementia.[93]

The mhGAP Intervention Guide for eight priority mental, neurological, and substance misuse disorders in non-specialised health settings[94] was published in October, 2010. These guidelines were the result of a systematic process of evidence collection and evaluation using the GRADE methodology.[55] The recommended interventions aim to be feasible and acceptable in low-income and middle-income countries, and should be integrated into existing systems. The mhGAP Intervention Guide is now available in English, French, and Spanish.

Staff training

In most low-income and middle-income countries, the ratio of people who need mental health care to the number of qualified psychiatrists is so disproportionate that there is no prospect of psychiatrists being able to deliver the care that is needed in the foreseeable future.[24,26,43] In India, if every psychiatrist worked full-time, they would succeed in treating less than 10% of people with mental health needs.[32] In countries with low and middle incomes, the psychiatrist should also be a public mental health practitioner,[43] influencing policy makers, overseeing training, and providing support, supervision, and expertise as needed. Shortage of these skills among mental health leaders has been identified as a major barrier to progress in mental health service reform.[8]

This deficit in leadership and public health skills among mental health professionals is addressed by emerging training options (webappendix pp 30–33). One example is the Sangath Leadership in Mental Health Course , and a similar course is run in Nigeria (University of Ibadan), with a focus on Africa. Related courses include the International Diploma in Mental Health Law and Human Rights run by the Indian Law Society, the International Masters in Mental Health Policy and Services run by the University of Lisbon in Portugal, and the Global Mental Health courses at the London School of Hygiene and Tropical Medicine, King's College London, and the University of Melbourne, Australia.

For more on the **Sangath course** see http://www.sangath.com

For more on the **University of Ibadan's course** see http://www.cbmnigeria.com/mh_ibadan.html

For more on the **Indian Law Society's course** see http://www.mentalhealthlaw.in

For more on the **University of Lisbon's course** see http://www.fcm.unl.pt/masterint

Challenges and lessons learned

Five major barriers to scaling up of mental health services in countries with low and middle incomes have been previously identified:[8] (1) absence of financial resources and government commitment; (2) overcentralisation; (3) challenges of integration of mental health care into primary care settings; (4) scarcity of trained mental health personnel; and (5) shortage of public health expertise among mental health leaders. We examine whether these barriers remain the crucial challenges, and summarise what progress has been made in scaling up.

The central message of the need to scale up evidence-based services in low-income and middle-income countries has been disseminated and has started to be translated into policy, legislation, strategies, and programmes. We found evidence that political leaders and decision makers are giving increased priority to mental health care in some countries, accompanied by an increase in funding by some international development and research agencies, although this change is not yet widespread.

Panel 4: Change in financial resources for scaling up of services

Although systems tracking Development Assistance for Health are becoming more sophisticated,[1] systematic measurement of financing for mental health remains difficult. Mental health is often not identified as a subcategory within non-communicable diseases (NCDs), a diverse category including tobacco control and injuries. Despite recognition of the growing relative effect of NCDs on disability and mortality,[70] less funds were given by government donors in 2008 than in 1995, and WHO spending on NCDs decreased by a third between 2002 and 2008.[84] Where NCD aid funds are intended for mental health activities, this information is rarely disaggregated in reports, although it can be found in the field.[73]

Overall, there is no evidence of a substantial shift in financial investment in mental health care in low-income and middle-income countries, since 50% of survey respondents felt that securing funds for mental health work was no easier than in 2007, with other respondents equally divided between reporting that it was easier or harder (figure 2D). Examples of funding for service implementation identified included national and local governmental agencies (for instance, in Indonesia, Ghana, Kenya, India, and Brazil) as well as UN agencies such as UNICEF and WHO (in particular, the WHO Mental Health Global Action Programme). Other sources included mental health projects funded by donor agencies such as the African Development Bank, African Medical and Research Foundation, Australian Aid Agency, UK Big Lottery Fund, European Commission for Humanitarian Aid and Civil Protection, and the EU Development Fund, as well as funds allocated through international non-governmental organisations such as BasicNeeds, CBM International, Comic Relief UK, and International Medical Corps.

Some new funding sources for research were identified, including from the Wellcome Trust, UK Medical Research Council, global mental health research programmes by the National Institute of Mental Health, as well as international research fellowships by the Fogarty Program at the US National Institutes of Health (NIH). Funding from NIH to mental health increased by 8% between 2007 and 2010, but we could not establish what proportion was devoted to low-income and middle-income countries.

There has been some progress in reorganisation of services by decentralisation and integration into primary health care, in standardisation of models of service delivery (including through an increasing number of well designed trials of complex interventions), and in understanding of the policy environment needed to make scaling up more feasible. There is now experience in several countries in engagement with the whole health system to ensure the necessary resources, such as personnel training and medicine supply, are widely available.

1. Situation analysis

Gather information about needs in defined population/area and identify priorities for scaled services to address

Engage with local stakeholders including patients and caregivers[30,45,59] to understand their needs and improve ownership and use of the services[41,46,63]
Review official policy, strategies in the country for compatibility of planned services[41,42]
Work with regional/local government and secure commitment to participation in process[31,42]
Find best available epidemiological data to understand needs[34]

Identify available resources:
- Human resources
- Strengths of existing health system
- Sustainable funding
- Map relevant local government, non-government, and private sector agencies in the area

Identify available human resources at different levels of existing health services[31,41,42]
Explore health system for task-sharing options[43,60]
Consider combination of government and external funding
Potential partnership with non-governmental organisations and other local helping agencies as a broad alliance for social inclusion and employment[41]

2. Planning

Define priority conditions for service provision
Review evidence for treatment that is appropriate for the local context (acceptable, affordable, feasible)

Develop consensus amongst key stakeholders about the priority conditions requiring services[94]
Use available evidence-based guidelines of relevance to low-income and middle-income settings[32,94]
Adapt guidelines as necessary to local culture, priorities, and resource availability[41]

Design a method of service delivery that fits in with existing health system

Develop a strong planning and implementation group with effective representation from all stakeholders and external experts as appropriate[31,35,41]
Develop linkages with existing community service resources (traditional healers, faith-based organisations, family and peer groups)[31,47,68,69]
Identify the methods of service provision for priority disorders largely through the existing health system
Develop locally relevant and clear referral systems between components of the services[60,65]
Consider partnering with maternal health[66] and chronic disease services[68,70] or other relevant services for children,[72] older people,[64] prisoners etc
Ensure essential medicine is available at service delivery level (strengthen existing systems and/or build alternative routes)[39,76]
Lobby for the inclusion of mental, neurological, and substance-use disorders in health financing systems
Reduce out-of-pocket payments[31,73]

Identify the barriers to scaling up and develop risk management plans

Identify a mental health focal person at national and district levels[59] with responsibility and mandate for seeing changes through
Create competent and representative local leadership and enhance public health and programme management skills[10,25,41]
Plan training/capacity building to fill gaps in human resources[33,39,47,69]
Systematically identify risks and manage on the basis of evidence and documented experience[31,59]

3. Implementation

Build coalition of stakeholders to oversee sustainable, long-term scaling up of balanced care

Strengthen management structures at national and district levels to implement and oversee scaling up[41]
Include advocacy for sustainable resources in their remit
Foster strong voice for advocacy by empowering patient organisations and civil society (eg, human rights)[31,41]
Engage with other relevant programmes (health and non-health) to integrate mental health in their activities (education, social welfare) for mental health promotion and service delivery[26,27]

Implement scaling up strategy according to evidence and results of situation analysis

Raise community awareness about mental health; identification, promotion, prevention, human rights/stigma, how to access services; include patients in this process[30,31,46,59]
Target community leaders, vulnerable groups, religious and other healers, and general population[31,46]
Deliver evidence-based medical, psychological, and social interventions that are accessible and affordable[23,31,39]
Ensure that relevant staff are appropriately trained and receive ongoing structured supervision[31]
Ensure good communication throughout referral system and that patients are followed up[31]

4. Evaluation

Monitor/evaluate the intervention
Modify strategy according to findings

Integrate mental health into existing health information systems[73]
Involve all stakeholders (government, staff, and patients) in evaluation, and planning of modifications to services that result[25,31,41]

Disseminate findings in relevant forums

Develop partnership with academic institutions for formal evaluation and research
Disseminate findings to all local stakeholders
Disseminate findings for advocacy at regional and national level
Disseminate findings in the public domain—scientific publications or reports on internet

Figure 3: **Important steps in strategic scaling up of mental health services in low-income and middle-income settings**

There are many examples of training of community and primary health-care staff to take on mental health activities, and even of new grades of staff or reallocation of roles. However, ensuring that trained personnel continue to devote time to mental health activities in the long term remains a challenge, although refresher training and robust supervision structures might improve this situation. Focal personnel dedicated to mental health or chronic diseases (for example, at the district level) might also improve the commitment to delivery of services in a sustainable way.

Although there are examples of services that are being taken to scale, few have been evaluated and shown to be delivering care of a consistent standard to increased numbers of people. Crucially, this finding means that the evidence base for proven strategies for scaling up that are replicable remains weak.

The way forward

A systemic and strategic approach to scaling up is needed (figure 3). Specific interventions to increase coverage of mental health services need to be part of a broader and integrated process. This approach will need strong advocacy for financial commitment and will need to ensure that relevant elements of health infrastructure are strengthened to allow services to be sustained in the long term.

Task sharing is the means to most efficiently use low numbers of trained personnel. A high proportion of need can be met with simple packages of care delivered in non-hospital settings by non-specialists. Primary health-level staff need to be better trained and supported to identify and manage mental disorders. The specific roles they should have, the training and supervision they need, and the way that they relate to the overall health system are important questions to be evaluated.

Specialist mental health staff are needed at the district level. The composition of personnel will vary depending on available resources, and preferably should consist of a multidisciplinary team, but at least a prescribing clinician. In many of the countries represented in our survey, the mere decentralisation of any mental health expertise to district level (rather than only the very largest cities) would have an enormous effect on access to care. Such staff would not only provide clinical services, training, and supervision for non-specialist staff in primary care, but also a managerial function to ensure that the health system facilitates integration of mental health services.

Mental health professionals and practitioners need to broaden their roles. Besides being traditional clinicians, specialist staff also need to accept responsibility for planning, training, supervision, and advocating with decision makers in their area of expertise. To achieve this goal, specialists themselves need access to relevant training in these skills.

Scaled up services need to be evaluated, and the lessons learnt from evaluation then generalised. The evaluation of innovative programmes can make an important contribution to the case for scaling up. Although contextually appropriate services will always differ, effective models will be those that show the best performance for relevant outcomes. To achieve this aim, the evaluation methods used need to be feasible in the context of low financial resources, and routine collection of relevant information is needed.[80] Many countries have used WHO-AIMS, for example, to make initial assessments of their mental health care systems.[10,61] Further refinement and repeated use of this system would add substantially to our ability to measure progress in scaling up. WHO should facilitate coordination of this process, drawing on a network of local experts at country level.

A new paradigm of public mental health is needed. Strong partnerships need to be built between well resourced research institutions and researchers and practitioners in low-income and middle-income countries. This approach should be based on the principles of local capacity building to ensure high scientific standards and participation by all stakeholders, including people using mental health services.

Since 2007, a substantial amount of evidence has shown how feasible and effective services for people with mental illness in low-income and middle-income countries can be. Scaling up of such services can be achieved by tackling, in an integrated way, poor political will, scarcity of resources, and inefficiently organised services, so that care is made available to people who were previously unable to access it. The challenge remains to scale up these services so that an increased number of people benefit, but we have moved a long way in a short time towards this end.

Contributors

JE conceptualised the paper with support from SS and GT. LM undertook the systematic literature review. JE and MS undertook the survey of key informants. FB drafted the panel on financial resources, CN drafted the case study on Uganda, and SC drafted the case study on Palestine. The final report was written by JE with input from all authors and particular editorial support from SS and GT. All authors have seen and approved the final version.

Conflicts of interest

We declare that we have no conflicts of interest.

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Paper 3

Eaton J, Carroll A, Scherer N, Hodson L, Njenga M, Sunkel C, Thompson K, Kingston D, Dryer S.

Accountability for the Rights of People with Psychosocial Disabilities: An Assessment of Country Reports for the Convention on the Rights of Persons with Disabilities. *Health and Human Rights Journal*, 2021; 23(1):175–189

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There has been a welcome move to hold as a principle, and document commitment to, inclusion of perspectives of people with mental health conditions due to their expertise by lived experience, in global guidance like the WHO Global Mental health Action Plan. This is also the case in the system of member state accountability under the Convention on the Rights of Persons with Disabilities, but there is concern that people with psychosocial disabilities are under-represented. In order to objectively examine the degree to which this is reflected in real-world practice for people with psychosocial disabilities, we examined the content of the required country reports submitted to the CRPD Committee, against standard criteria, using content analysis.

My contribution was as convener of the authors of the paper, and to chair a Steering Group which included several people with psychosocial disabilities, participating in what we sought to be a co-produced process. I initiated the research, supported the conceptualization of the aims and research questions, as well as the methods employed to find the results, working with co-authors in analysis and arriving at lessons learnt described in results and discussion. I wrote the main parts of the paper, and coordinated written input from other authors throughout the process.

Confirm role: Julian Eaton Signature: J Eaton Date: 2nd May 24

Confirm role: Sean Dryer, last author Signature: S Dryer Date: 2nd May 2024

HHR
Health and Human Rights Journal

Accountability for the Rights of People with Psychosocial Disabilities: An Assessment of Country Reports for the Convention on the Rights of Persons with Disabilities

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Abstract

The Convention on the Rights of Persons with Disabilities (CRPD) has been identified as a milestone in human rights protection, offering people with psychosocial disabilities the opportunity to hold their governments accountable for the realization of their rights. To facilitate such accountability, the country reports produced under the CRPD reporting process should adequately reflect these persons' experiences and relevant positive or negative developments in the country. Our study used content analysis to review the extent and quality of reporting related to mental health and psychosocial disabilities in 19 country

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reports. The criteria used were based on provisions of the CRPD and on priorities identified by a steering committee of people with psychosocial disabilities. We found a wide variation in the quantity and quality of states' reporting, with an indication that this variation relates to countries' economic development. Increasing the participation of representative organizations of people with psychosocial disabilities is needed for state parties to fulfill their reporting obligations. While there has been progress in improving organizations of persons with disabilities capacity to be heard at the global level, our findings suggest low levels of participation in CRPD processes at the national level in many countries. State parties must actively include these groups to ensure implementation of the CRPD principles.

Introduction

Around the world, people with mental conditions and associated psychosocial disabilities are among the most marginalized groups in society.[1] Psychosocial disabilities are those disabilities that arise from barriers to social participation experienced by people who have or who are perceived to have mental conditions or problems, and the term is now widely used within the disability movement.[2] While the form and extent of exclusion and abuse may differ from culture to culture, the problem is "near universal."[3] Since coming into force in 2008, the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) has been heralded as marking a paradigm shift in the way that disability is understood and responded to.[4] It moves away from the traditional perspective of persons with disabilities as "objects" of charity in need of "cure," to a human rights perspective that addresses the barriers experienced by people with psychosocial disabilities across all life domains.[5] This is the realization that people with disabilities are rights holders, who must be afforded agency to make their own decisions and to participate, on an equal basis with others, as active members of society.[6] In addition, a systematic review in 2016 found that consultations with mental health service users in policy formulation processes increased the likelihood of improved mental health services and outcomes.[7] The CRPD provides a clear articulation of the human rights of people with psychosocial disabilities in line with other impairment groups, and was drafted with the involvement of their representative organizations.[8]

The accountability mechanisms for monitoring and reviewing states' implementation of the CRPD are detailed in the UN Disability Inclusion Strategy.[9] The Optional Protocol to the CRPD includes further mechanisms for remedies and redress.[10] The Committee on the Rights of Persons with Disabilities (CRPD Committee), an independent "committee of experts"—also known as a human rights treaty body—conducts a constructive dialogue with countries that have ratified the treaty (state parties). Initially, countries must submit a report two years after formal ratification of the treaty, and then periodically every four years, outlining their progress in the realization of disability rights in domestic law, policy, and practice. Persons with disabilities are expected to be full participants in this process—based on clear recommendations in the CRPD Committee's General Comment 7, which includes a discussion of articles 4(3) and 33(3) concerning the meaningful participation of people with disabilities in decision-making and in providing input into national reporting by state parties.[11] Civil society organizations and national human rights institutions are encouraged to submit parallel, or "shadow," reports during the state's drafting process. Other aspects of this process also encourage meaningful participation—for example, the review of the country report by national human rights institutions must include the expectation of participation and must be attuned to the priorities of people with psychosocial disabilities as identified by their representative organizations.[12]

A member of the CRPD Committee volunteers to lead the report review and drafts a "list of issues" to be addressed by the country in its response. This "list of issues" is a list of themes or questions formulated by the treaty body on the basis of a state party's report and other available information (for example, information supplied by UN specialized agencies, national human rights institutions, civil society organizations, and other contributors), which is transmitted to the country government in advance of the session at which the treaty body will consider the country report. The list of issues provides the framework for a constructive dialogue with the government delegation. A good general understanding among actors in the process is essential if these issues are to be properly addressed in the "constructive dialogue" on the report at the CRPD Committee meeting.

Civil society organizations can access the committee's concluding observations or recommendations issued to a government after the constructive dialogue. The concluding observations or recommendations provide civil society with another mechanism to hold state parties accountable. In this way, civil society organizations can contact the Secretariat of the CRPD Committee and draw the committee's attention to inaction on the part of state parties. The CRPD Committee also has its own follow-up procedure whereby a dedicated member of the committee tracks the actions that state parties are undertaking or failing to undertake.[13]

Despite these formal procedures, throughout the world, it is unclear whether people with psychosocial disabilities are fully benefiting from the potential of the CRPD accountability mechanisms when it comes to the realization of their rights. There are a number of reasons why this may be the case. First, while at the global level national organizations of persons with psychosocial disabilities have been very influential, not least in the CRPD development process, these organizations may be newly formed or emerging, financially vulnerable, or nonexistent at the national level in many countries, particularly in lower-income countries.[14] Second, where such organizations do exist at the national level, there are barriers to their participation in the preparation of country reports, given that based on prejudice and exclusion, there is often no formal role for them to contribute to decision-making processes such as policy development. Such exclusion can also come from within the disability community itself, meaning that persons with psychosocial disabilities may be underrepresented in national disability federations. This exclusion undoubtedly results in members of organizations lacking the opportunity to advocate effectively as part of the reporting process.[15]

The aim of this research is to empirically assess these assumed limitations by measuring how psychosocial disabilities have been included in the reports submitted by state parties to date. By better understanding the content of these reports, it will be possible to gain insight into the inclusion of people with psychosocial disabilities in national policies and programs, as well as the success of their representative organizations in using the CRPD Committee as a mechanism to hold duty-bearers, including governments and the private sector, to account. We hope that these insights into the country reporting process will elucidate disparities in participation in the CRPD accountability process at the national level and inform the strengthening of this process going forward.

Methods

We reviewed 19 states parties' official reports submitted to the CRPD Committee to ascertain the quantity and quality of content related to psychosocial disabilities. These reports were purposively selected for representation across global regions and income levels (low-, lower-middle-, upper-middle-, and high-income countries using World Bank criteria) to ensure that a diverse range of national experiences were captured.

Overall, the review included three countries classified as low income, five of each other classification, and one unclassified (Figure 1). The East Asia and the Pacific region, the Latin America and the Caribbean region, and the Sub-Saharan Africa region were the most represented, at four countries each. Myanmar was the only country included that is classified under "fragile and conflict-affected situations" by the World Bank. Table 1 includes a list of the countries reviewed and their detailed classifications.

A review of the relevant literature did not identify an appropriate tool for analyzing the content of such reports. We therefore developed a framework for assessing the variables considered to be particularly pertinent to reporting on the realization of rights of persons with psychosocial disabilities and used content analysis of the reports' text to review them.[16]

At the start of the research, we established a steering committee to inform the process and guide decisions at various stages. This committee was made up of people who have personal experience living with psychosocial disabilities and working in this field, some of whom had participated in CRPD reporting processes, and who come from a range of countries, including those in our study.

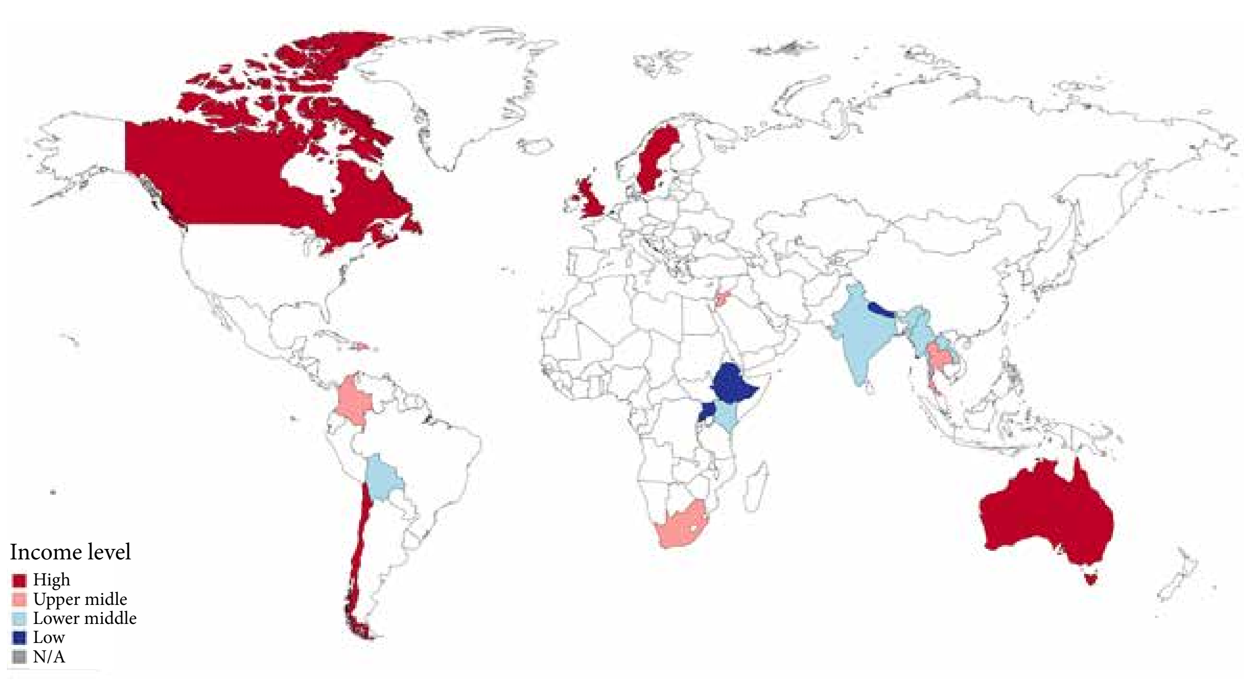
The steering committee (which included all of this paper's authors) developed, by consensus, five variables for judging the strengths of the country reports with respect to psychosocial disabilities. These variables were based on CRPD principles, common errors in understanding psychosocial disabilities, and priorities identified by organizations of people with psychosocial disabilities in the literature.

Variable 1: *The extent of discussion in the report regarding psychosocial disability*

Variable 2: *Theoretical approaches informing the report's discussion of psychosocial disability*

Variable 3: *The extent to which the report distin-*

FIGURE 1. World map showing countries included in the review and their classification by World Bank-defined income level (FY17 classifications)



guishes psychosocial disability from intellectual disability

Variable 4: *The extent to which the report addresses CRPD articles considered highly relevant to people with psychosocial disabilities*

Variable 5: *The extent to which the report's discussion of accessibility initiatives (such as reasonable accommodation) addresses psychosocial disabilities compared to other disability types*

This framework was developed into a psychosocial disability rights content analysis tool (PDR-CAT), establishing a coding guide for each variable, which we used to analyze the country reports and assign scores for the reports against each variable. The tool and coding guidance are available on the Mental Health Innovation Network's website. This process was repeated by a second independent reviewer using the same tool. We assessed inter-rater reliability using the Cohen's Kappa method.[17] Where there were discrepancies between the raters, reasons for this were discussed by the researchers and the steering committee to decide on clearer coding guidance to remove ambiguity, and with a view toward better reflecting the intended purpose of the variable. We then recoded the relevant variables according to these decisions. In addition, there is much detail in the reports that cannot be captured in dichotomous variables, even where some intermediate scores were used. Thus, throughout the results, we have included notes that attempt to describe these nuances. More details for each variable, along with the reconciled coding and notes of these additional details, are presented below.

Results

Variable 1: The extent of discussion regarding psychosocial disability

Variable 1 measured the extent of each report's discussion of psychosocial disability. We carried out a word search to identify paragraphs including "search terms" related to psychosocial disability (Table 3), which we identified through a literature review and review of a sample of country reports. We excluded paragraphs if they included the search terms but clearly did not refer to psychosocial disability. We then calculated the proportion of paragraphs in each report that included the search terms (see Figure 2).

Table 1. Countries included in the review

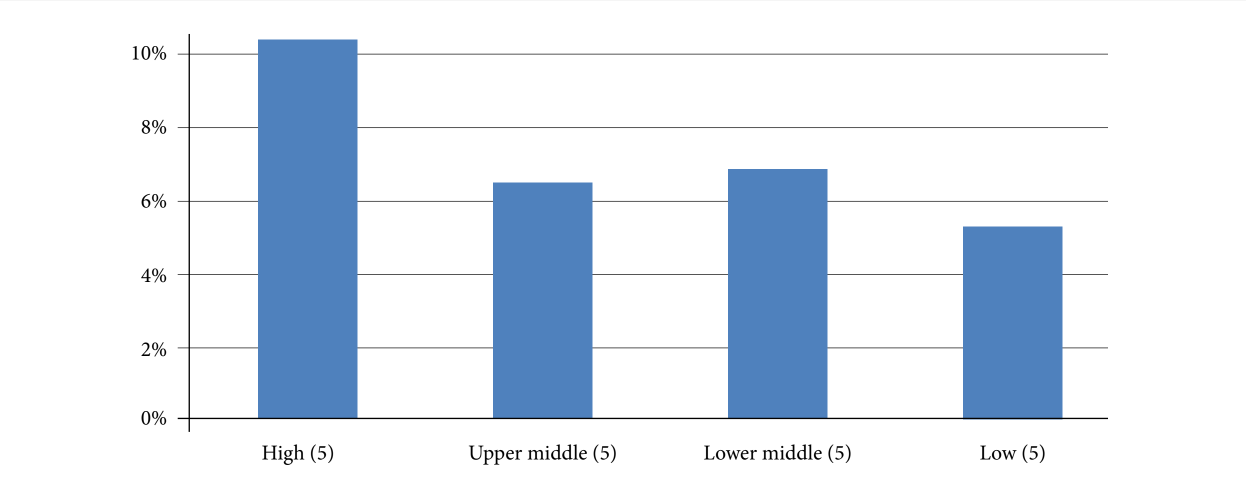
Country	Income	Region	Fragile or conflict affected
Australia	High	East Asia & Pacific	No
Bolivia	Lower middle	Latin America & Caribbean	No
Canada	High	North America	No
Chile	High	Latin America & Caribbean	No
Colombia	Upper middle	Latin America & Caribbean	No
Cook Islands	Unclassified	Western Pacific	No
Dominican Republic	Upper middle	Latin America & Caribbean	No
Ethiopia	Low	Sub-Saharan Africa	No
India	Lower middle	South Asia	No
Jordan	Upper middle	Middle East & North Africa	No
Kenya	Lower middle	Sub-Saharan Africa	No
Lao PDR	Lower middle	East Asia & Pacific	No
Myanmar	Lower middle	East Asia & Pacific	Yes
Nepal	Low	South Asia	No
South Africa	Upper middle	Sub-Saharan Africa	No
Sweden	High	Europe & Central Asia	No
Thailand	Upper middle	East Asia & Pacific	No
Uganda	Low	Sub-Saharan Africa	No
United Kingdom	High	Europe & Central Asia	No

TABLE 2. Summary of results for variables 1–3

	Variable 1: No. (%) of paragraphs containing search terms	Variable 1.2: Avg. rating among paragraphs mentioning search terms	Variable 1.2: No. (%) of paragraphs with high extent (3) of discussion of psychosocial disability	Variable 2: No. (%) of paragraphs using a human rights approach	Variable 3: No. (%) of times a term used clearly refers to psychosocial disability as distinct from intellectual disability
Australia	30 (14%)	2.3	17 (8%)	11 (37%)	62 (93%)
Bolivia	21 (6%)	2.1	9 (2%)	9 (43%)	24 (71%)
Canada	49 (13%)	2.2	27 (7%)	20 (41%)	67 (71%)
Chile	20 (8%)	1.8	6 (2%)	4 (57%)	20 (65%)
Colombia	13 (5%)	2.2	7 (3%)	5 (38%)	12 (55%)
Cook Islands	9 (4%)	2.0	4 (27%)	3 (33%)	4 (44%)
Dominican Republic	10 (6%)	1.8	4 (3%)	1 (10%)	12 (52%)
Ethiopia	5 (3%)	1.6	1 (1%)	1 (20%)	1 (13%)
India	40 (13%)	1.9	15 (5%)	17 (43%)	44 (59%)
Jordan	17 (6%)	2.1	9 (3%)	7 (41%)	25 (51%)
Kenya	15 (6%)	1.8	5 (2%)	7 (47%)	2 (11%)
Laos	4 (5%)	1.0	0 (0%)	1 (25%)	3 (60%)
Myanmar	5 (5%)	1.8	2 (2%)	4 (80%)	4 (57%)
Nepal	15 (5%)	1.4	2 (1%)	9 (60%)	18 (64%)
South Africa	52 (12%)	2.4	34 (8%)	28 (54%)	51 (53%)
Sweden	19 (6%)	2.1	10 (3%)	11 (58%)	24 (62%)
Thailand	7 (3%)	1.6	2 (1%)	4 (57%)	6 (86%)
Uganda	21 (8%)	2.1	10 (4%)	15 (71%)	14 (42%)
United Kingdom	37 (12%)	2.5	24 (7%)	14 (38%)	46 (61%)

Note: Full results are available on the Mental Health Innovation Network's website.

FIGURE 2. Average percentage of paragraphs referring to psychosocial disability, by income level classifications



Note: Cook Islands unclassified

Of the 19 country reports assessed, the total report lengths ranged between 88 paragraphs (Laos) and 426 paragraphs (South Africa), with a median of 265 paragraphs (Uganda). The percentage of paragraphs discussing psychosocial disability ranged between 3.3% (Thailand) and 13.9% (Australia), with a median of 5.6% (Nepal) (Table 2). Following recoding for differences, Cohen's Kappa for the inclusion/exclusion of paragraphs as discussing psychosocial disability was 0.91, "almost perfect" according to the guidelines proposed by J. Richard Landis and Charles Koch. While we cannot comment on the proportion of paragraphs deemed to be a good amount—as we would not expect to have specific impairment groups mentioned in some paragraphs—what is clear is that there is a wide variation among countries. In addition, the average proportion of paragraphs discussing psychosocial disabilities was twice as high in high-income countries compared to low-income ones (Figure 2).

The extent to which psychosocial disability is discussed in each paragraph

Variable 1.2 measured the extent to which psychosocial disability was discussed in each paragraph based on a set criteria and ordinal scale (1=low, 2=moderate, 3=high extent). The extent may be rated higher either because the search terms appeared in a large proportion of the paragraph's sentences or because one or more sentences focused on issues relevant to psychosocial disability in particular (as opposed to disability in general). These data inform several considerations:

- The total rating of all paragraphs mentioning the search terms, to give an overall summary of the amount of discussion of psychosocial disability in the report.
- The average rating among those paragraphs mentioning the search terms, to give a sense of the extent to which the discussion of psychosocial disability in the report focused specifically on psychosocial disability compared to including it in broader discussion.
- The average rating among all paragraphs, with paragraphs not mentioning the search terms rated as zero. This provides a composite between variables 1 and 1.2, providing an overall summary of the degree to which the report focused on psychosocial disability relative to other topics.

Key findings by country are given in Table 2. Of the 19 country reports assessed, the total scores for reports ranged between 4 (Laos) and 127 (South Africa), with a median of 36 (Chile). It should be noted that this is influenced in part by the overall length of the report (the South African report was long overall). The average score for paragraphs including search terms was 2.1, reflecting a range between 1.0 (Laos) and 2.5 (United Kingdom). The average score among all paragraphs was 0.16, reflecting a range

TABLE 3. Search terms for variable 1

Mental	Include mentions of words that are direct derivatives of "mental" (e.g., "mentally"). Exclude mentions of words that signify separate concepts (e.g., "governmental" or "fundamental"). Also exclude mentions of words that signify intellectual impairment, namely "mental developmental disability" and "mental retardation."
Psych*	Include mentions of words that are direct derivatives of "psych" (e.g., "psychosocial," "psychiatric," "psychological"). Exclude mentions of words that signify separate concepts.
Lunatic, lunacy, insane, insanity	These terms once held pseudo-scientific meanings but have been considered completely inappropriate and outside all formal classification systems for decades. Nonetheless, we considered it important to include these terms, as some reports may include them (for example, a number of countries still have "Lunacy Acts" in their legislation, even if outdated).
Unsound	This is intended to capture discussion of people with psychosocial disabilities as having "unsound" minds or "unsound" reasoning. Exclude mentions of the term "unsound" that clearly do not relate explicitly to people with psychosocial disabilities (e.g., exclude mentions of "unsound practices" if these do not refer explicitly to people with psychosocial disabilities).
Mind	Exclude mentions of the term "mind" that clearly do not relate explicitly to people with psychosocial disabilities.
Asylum	Exclude mentions of the term "asylum" that clearly do not relate explicitly to people with psychosocial disabilities (e.g., exclude mentions of asylum seekers, or asylums for children with physical disabilities).

between 0.05 (Thailand, Laos, Ethiopia) and 0.32 (Australia). Notably, the report from Laos was the only report with no paragraphs with a high extent of discussion of psychosocial disability. Weighted Cohen's Kappa was 0.57, rated as "moderate" according to the guidelines proposed by Landis and Koch. The relatively low agreement is due to the multiple pathways by which scores are assigned and by a decision by the steering committee to clarify the criteria after coding had been done, at which point the first coder was not available to recode. (See "Strengths and weaknesses" below.)

Variable 2: Theoretical approaches informing the discussion of psychosocial disability

Variable 2 assessed the theoretical approaches informing each report's understanding of psychosocial disability, rating each paragraph that mentioned psychosocial disability according to one of four categories based on recognized models and ways of thinking about disability: (1) human rights approach; (2) medical/charity/welfare approach; (3) discriminatory denial of legal capacity; and (4) unable to determine. The percentage of paragraphs in a report that took each approach serves as an indicator of the report's theoretical approach, and not any underlying policies it describes. Thus, a paragraph that described a discriminatory policy, but criticized it, was rated "human rights approach." Cohen's Kappa was 0.61, rated as "substantial." Reduction in concordance was driven mostly by the tool stating that where a country report's frame was both "discriminatory denial of legal capacity" and "medical/charity/welfare approach," then the overarching approach subsumed the "discriminatory denial," causing some confusion. In general, this highlights that there was little disagreement as to whether the "human rights" approach was taken.

Findings for countries' use of the "human rights" approach are presented in Table 2. A summary of findings for variable 2 is presented in Table 4.

Variable 3: The extent to which psychosocial disability is distinguished from intellectual disability

The degree to which each country report made a clear distinction between intellectual and psychosocial disability might be judged to be a sign of depth of understanding among the report writers. Confusion between these two types of disabilities is fairly common, though it should be noted that the CRPD does not itself provide a definition. We assessed each individual mention of a search term and coded whether the term clearly referred to psychosocial disability or possibly included intellectual disability. A list of classifications is provided in the guidance, indicating whether a given term indicates one or the other; however, coders could classify terms based on their judgment as to whether the rest of the paragraph gave greater clarity.

Findings are shown in Table 2. Across all reports, 61% of all relevant terms used clearly distinguished psychosocial disability from intellectual disability. Australia had the highest percentage (93%), while Kenya had the lowest percentage (11%). Cohen's Kappa (following a reconciliation after a coding clarification) was 0.83, "almost perfect" under Landis and Koch's guidelines.

Table 4. Summary of results for variable 2

Approach	Overall %	Highest %	Lowest %
Human rights	46%	80%, Myanmar*	10%, Dominican Republic
Medical/charity/welfare	9%	50%, Laos	0%, Bolivia, Colombia, Myanmar, Nepal, Uganda
Discriminatory denial of legal capacity	20%	38%, Colombia	0%, Cook Islands, Laos, Myanmar, Thailand
Unable to determine	25%	60%, Dominican Republic	16%, United Kingdom

* Relatively high scores were achieved where few paragraphs discussed psychosocial disabilities at all, but where those that did so used a particular approach (as was the case for Myanmar).

Variable 4: The extent to which CRPD articles considered highly relevant to people with psychosocial disabilities are discussed

Certain articles in the CRPD (12, 14, 17, 19, and 29) are considered to be highly relevant to people with psychosocial disabilities (as determined by the steering committee and the priorities of people with psychosocial disabilities identified in the literature). Where specific content for one of these articles was identified in the country report, we scored the report "yes" (1.0) for that article. If the phrasing in regard to the article was not consistent with the priorities of people with psychosocial disabilities, then we gave a score of "no" (0). Reports were rated 1.0 only if they described the issue specifically for people with psychosocial disabilities, as opposed to people with disabilities in general.

"Yes" ratings were rare for most topics. Following the initial round of coding, we modified this variable to allow for a score of 0.5 for articles with multiple criteria in which a report discussed some of those criteria but not all of them. We made this change to make the variable more sensitive, as initial ratings were extremely low. A summary of scores is presented in Table 5.

Out of a possible 10 points across all topics, South Africa had the highest total (5.5), while the Dominican Republic and Laos had the lowest (0.5). The median total score was 1.5—in other words, very low. Notably, no report discussed measures taken to protect all persons with disabilities from forced sterilization and girls and women from forced or coerced abortions or contraception. The

Table 5. Scores for each topic under variable 4

Topic	Mean score	Countries scoring 1.0 (specific content identified)
Article 12: Equal recognition before the law		
Discusses whether legislation does or does not exist which restricts the full legal capacity on the basis of psychosocial disability, as well as actions being taken toward conformity with article 12 of the convention	0.53	Bolivia, Colombia, Kenya, Nepal, South Africa, Uganda
Support available to persons with disabilities to exercise their legal capacity and manage their financial affairs	0.16	Canada, Colombia, South Africa
The existence of safeguards against abuse of supported decision-making models	0.05	United Kingdom
Article 14: Liberty and security of person*		
Measures taken by the state party to ensure that all persons with all forms of disabilities enjoy the right to liberty and security of person and that no person is deprived of their liberty on the basis of their disability	0.05	None
Actions being taken to abolish any legislation that permits the institutionalization or the deprivation of liberty of persons with any form of disability	0.16	Ethiopia, South Africa, Uganda
Legislative and other measures put in place to ensure that persons with disabilities who have been deprived of their liberty are provided with the required reasonable accommodation and benefit from the same procedural guarantees as all other persons to fully enjoy their human rights	0.16	None
Article 17: Protecting the integrity of the person		
Measures taken to protect persons with disabilities from medical (or other) treatment given without the free and informed consent of the person	0.11	Nepal, South Africa
Measures taken to protect all persons with disabilities from forced sterilization, and girls and women from forced abortions	0.0	None
Article 19: Living independently and being included in the community		
Measures taken to ensure the equal right of all persons with disabilities to live in the community (including access to support services) and to choose where they live	0.18	Canada
Article 29: Participation in political and public life		
Legislation and measures to guarantee political rights for persons with disabilities (in particular persons with mental or intellectual disabilities), and, if it is the case, existing limitations and actions taken to overcome them	0.53	Colombia, South Africa, Sweden, Thailand, Uganda

Note: Full results are available on the Mental Health Innovation Network's website.
* Under article 14, references to the deprivation of liberty exclude cases where people with psychosocial disabilities are subject to the same laws and due process as people without disability.

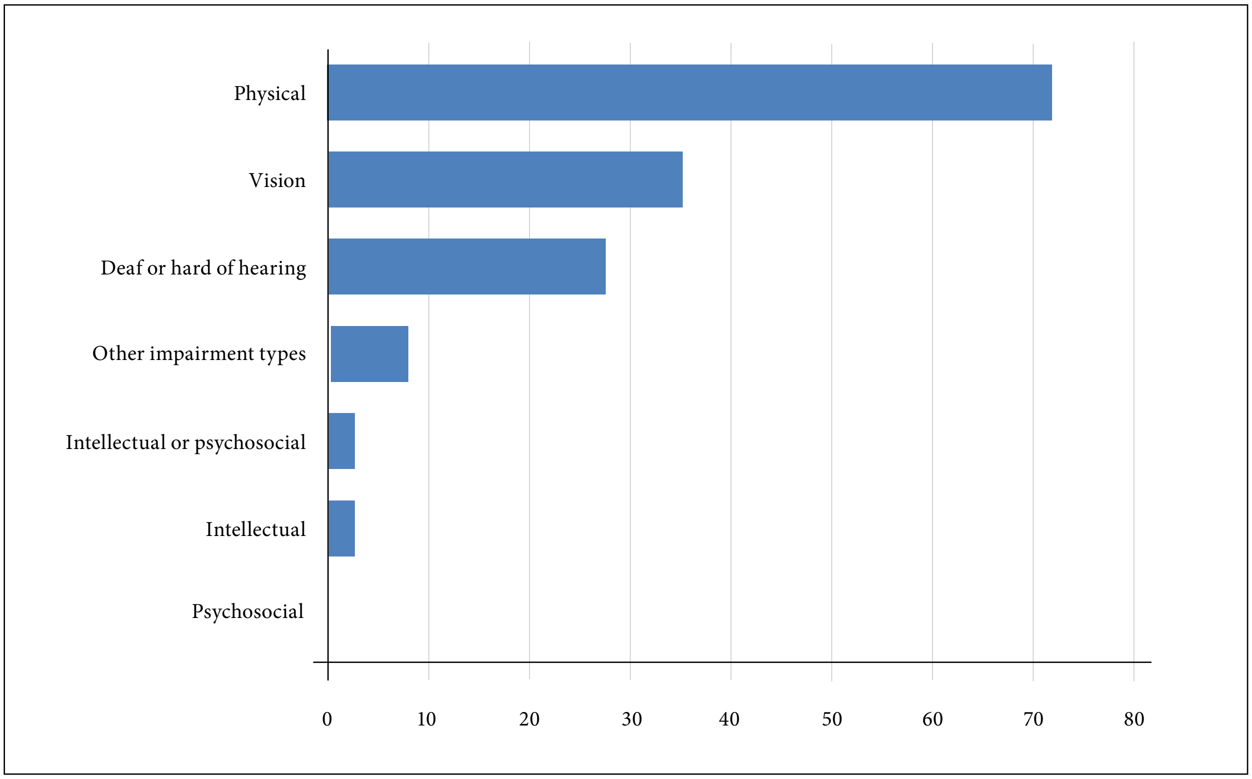
initial Cohen's Kappa for the entire data set (that is, analyzing all of the content pieces together) was 0.63, rated as "substantial" according to Landis and Koch's guidelines. After we recognized that all criteria for a "yes" were hard to meet, we introduced the 0.5 score and then recoded all reports using the new system.

Variable 5: The extent to which the discussion of accessibility initiatives addresses psychosocial disabilities compared to other disability types

While issues related to accessibility and reasonable accommodations are generally well understood for people with physical and sensory disabilities, the means of addressing exclusion in psychosocial disabilities are often not well understood or even considered. We therefore examined discussion of article 9 in each country report to explore reported initiatives to address accessibility and reasonable accommodation in relation to psychosocial disability compared to other disabilities. We used criteria to review this section of each report in full and identify any accessibility initiatives, coding each as "physical," "vision," "deaf or hard of hearing," "intellectual," "intellectual/psychosocial (unclear)," "psychosocial," "other impairments," or "unable to determine."

Our findings are shown in Figure 3. There was a dramatic lack of initiatives for psychosocial disabilities compared to every other group identified, except for intellectual disability. Across all reports, physical, vision, and deaf or hard of hearing had 71, 35, and 28 initiatives identified, respectively, compared to 0 for psychosocial disability and 2 for intellectual/psychosocial. The overall findings of the two coders were nearly identical. Due to the nature of coding this section, Cohen's Kappa could not be calculated on a pairwise comparison of specific initiatives and was instead calculated at the country level at 0.63, rated as "substantial" according to Landis and Koch's guidelines. This

FIGURE 3. Total initiatives identified to address reasonable accommodation and accessibility, by impairment type



Note: Results by country are available on the Mental Health Innovation Network's website excludes "unable to determine," which was much less consistent, but not considered important to the findings.

Discussion

There is substantial variability in the extent to which country reports discussed psychosocial disability (demonstrated by variable 1). Using the composite score, Australia's score of 0.32 indicates more than six times the proportion of discussion dedicated to psychosocial disability compared to Thailand, Laos, or Ethiopia. In gross terms, South Africa devoted more than 10 times as many paragraphs as Myanmar, Ethiopia, or Laos.

While some of this variation may be attributed to the length of each report in general, it could also be an indication of the wide variety of prioritization of psychosocial disability in countries' national disability agenda, as well as governments' competence and confidence in reporting on this issue.

An additional consideration is the tendency for more and better focus on psychosocial disability when relevant people were included in the writing process of the report, as stipulated in article 35(4) of the CRPD. People with psychosocial disabilities may not have been part of the writing group in all countries. Even where their input was invited, governments' decision whether to include their submissions in the final draft was ultimately outside the control of people with psychosocial disabilities. This was also reflected in the experience of our steering committee, whose members felt that where organizations of people with psychosocial disabilities were included from the start, their issues were covered better and more prominently.

The wide variation in the extent to which countries reported specifically on psychosocial disability—as opposed to integrating it into wider disability issues—should be taken into context. For example, the United Kingdom's high score on specific mention of psychosocial disability is in general a good thing (as a neglected area needs to be highlighted), but the state fell short in considering psychosocial disability across all life domains beyond health—for example, in relation to housing, education, community life, and so forth—and alongside other types of disability. Where reports discuss states' performance on disability in general, it is important for psychosocial disability to also be included, and not only in special sections (for example, by focusing only on specific rights like consent or access to mental health services). We believe that this would be reflected by a higher proportion of paragraphs including our search terms (variable 1) than the median of 5.6% found in this sample.

Variable 2 demonstrates that nearly half of the paragraphs discussing psychosocial disability appeared to use a theoretical approach grounded in human rights, although charity, medical, and discriminatory approaches were used in almost all country reports. This may be a reflection of levels of knowledge and attitudes about different models and approaches to disability in general rather than psychosocial disability in particular, which we would expect to be high among those writing the reports. That being said, in many countries (such as Australia, India, and South Africa), psychosocial disability and intellectual disabilities are treated distinctly from other types of disability, particularly in relation to autonomy and in relation to will and preference in decision-making, including for medical treatment. As noted in Australia's report:

> *Consent to medical treatment is regulated by policies and/or legislation in each jurisdiction. Australia considers that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental illness, where such treatment is necessary as a last resort and subject to safeguards.*[18]

With the introduction of the CRPD, the International Classification of Functioning, Disability and Health, and other disability models and frameworks, global actors are moving away from traditional medical and charity models. However, there needs to be a recognition that this process is more difficult for countries with limited resources or different cultural attitudes and beliefs. Such countries may need additional support, especially when cultivating cultural responsiveness toward and acceptability of a global movement.

Based on variable 3, it is clear that many country reports did not make a distinction between psychosocial and intellectual disability, although this varied substantially between countries. In some cases, this approach may be appropriate (such as mentions of "physical and mental disabilities"), and in other cases, it is difficult to determine whether it reflects a poor use of language or an underlying failure to distinguish the two in practice, especially for countries where English is not a national language. Examples of ambiguous and derogatory language include "mental disability," "mentally challenged," "unsound mind," and "mentally deranged." For such high-level reports to not be clear about the distinction implies a poor level of understanding among the authors. We would suggest that knowledge of the distinction between psychosocial and intellectual disabilities—and of the nuances of neurological (for example, migraine), behavioral (for example, autism or attention deficit disorder), and cognitive (for example, dementia) conditions—is essential for authors of CRPD country reports.

It is clear from variable 4 that country reports did not describe policies ensuring the prioritization of the rights of persons with psychosocial disabilities. By extension, this could mean that organizations of people with psychosocial disabilities are facing barriers to advocacy efforts in national CRPD accountability mechanisms. Further research is required to elucidate the experiences of people with psychosocial disabilities and their organizations when engaging with CRPD report-writing processes. National-specific assessment would need to be done to verify this in each case. Variable 5 strongly indicates that state parties are not implementing, or at least reporting, reasonable accommodations and accessibility initiatives for persons with psychosocial disabilities (or intellectual disabilities). This is one variable where a direct comparison with other disabilities was possible, and it is clear that there is a dramatic gap in progress for psychosocial disability compared with other areas of disability.

Our findings indicate that there is, in general, a poor level of reporting about psychosocial disabilities in country reports to the CRPD Committee. While there is need for further research to understand what the reasons for this might be, it is clear that states' reporting capacity needs to be addressed. This requires that national reporting processes better engage with people with psychosocial disabilities and their representative groups, empowering their input and advocacy. The results of our research may be a useful tool for the CRPD Committee, relevant UN agencies (particularly members of the UN Partnership on the Rights of Persons with Disabilities), and civil society groups seeking to advocate more effectively for a greater focus on rights-based approaches to psychosocial (and intellectual) disabilities in policy, and in CRPD reporting in particular.

Strengths and weaknesses

Content analysis proved a valuable way to objectively assess the content of the country reports for volume and quality of content related to psychosocial disability and to reveal disparities in the representation of different disabilities. The variables that were included in our tool were derived from a consensus among a group identified as experts and experienced in the field, with backgrounds in policy, the UN system, academia, and service user movements. We feel that these allow the reports' quality to be judged by how well they address issues that are relevant to psychosocial disabilities. What is harder to examine is the underlying reasons behind our findings. This question of the "why" would be best addressed through additional qualitative research. It would also be useful to analyze country reports in the context of shadow reports (where they exist). Although shadow reports may have no impact on a country's report, the representation of psychosocial disability in these shadow reports may indicate the level of participation of people with psychosocial disabilities in national disability movements, thus helping target capacity-building interventions. In addition, a review of subsequent country reports from the same countries could be used to gauge whether there is a trend of improvement in this area.

Our sampling frame was purposive, so we were able to compare results across, for example, income levels of countries, but we cannot claim that the countries chosen were representative of these income levels or that the political and policy environments are consistent across these countries.

The use of our tool raised some complex questions of interpretation, even though agreement was achieved between the independent reviewers. For example, Myanmar used the human rights approach in almost all cases where it mentioned psychosocial disabilities, meaning that it scored highly, despite mentioning such disabilities infrequently and without detail. The United Kingdom tended to write specifically about psychosocial disabilities in particular areas but did not address psychosocial disability across all life domains. While we feel we achieved a fair level of agreement about interpretation, there would be benefit to updating guidance for the tool for future use. There was great value in having a steering committee to guide the nuanced discussions that often arose, anchoring the final decisions in core approaches that we wished to reflect in the establishment of the criteria for the analysis. Inevitably, any element of change raises questions of replicability and consistency of method, requiring reflection in interpretation. The tool also relies on identifying relevant paragraphs through the use of a set of keywords associated with psychosocial disability, which may not be exhaustive. Some generic paragraphs not mentioning our search terms may theoretically be referring to psychosocial disabilities.

Variable 5 was our only variable that analyzed data for other disability types, and for this variable the difference was stark. However, while representation of psychosocial disability may appear low in other variables, we are unable to measure this against other types of disability. A version of the tool adapted for one or more other types of disability would allow this comparison in future analysis. In addition, this may highlight how strong the reports were for other disabilities and whether those that were weaker for psychosocial disabilities were also weaker overall.

Conclusion

There is considerable variability in the quality of states' reporting on psychosocial disabilities when following CRPD accountability processes, despite broad recognition of the importance of the full and meaningful participation of people with psychosocial disabilities.[19] We found a lower quality of reporting on psychosocial disabilities in low-income countries in particular, which may reflect the effects that limited resources have on reinforcing prejudicial social norms or a lack of exposure to contemporary debates around psychosocial disability in relation to CRPD compliance. While this research did not include information on the extent to which people with psychosocial disabilities participated in the reporting process, we recommend that the first step in addressing disparities in reporting be to improve engagement with representative organizations of people with psychosocial disabilities. International and national agencies working with government bodies can engage with government focal points to promote a more receptive environment for civil society participation.

Hand in hand with this recommendation is the recognition that meaningful engagement will require the empowerment of people with psychosocial disabilities by providing sufficient resourcing for existing and emerging organizations and building the capacity of national umbrella organizations. In all countries, organizations of people with disabilities would benefit from increased knowledge of UN reporting processes and the extent to which they should be included in reporting mechanisms. Though the evidence on what works to promote the leadership of people with psychosocial disabilities in low- and middle-income countries is still relatively limited, there are examples of success.[20] These examples usually point to organizations and movements with strong governance structures and clear values.[21] Integral to the realization of the rights enshrined in the CRPD for people with psychosocial disabilities is building their capacity and strengthening their voices at the national level, and improving their representation at the global level, so as to exploit fully CRPD processes for meaningful participation of people with disabilities.[22]

It is perhaps most helpful to use equivalence with other forms of disability as the best benchmark for expectations of levels of participation and quality of reporting. By this measure, there are particular gaps in understanding and reporting around reasonable accommodation and accessibility for persons with psychosocial disabilities. Specific efforts need to be made to improve understandings and attitudes around mental health and psychosocial disabilities. Epilepsy South Africa has developed good guidelines that could be used as an example for making similar information available for psychosocial disabilities.[23] There also exist accessible online resources that could be adapted for use in other countries.[24] In all areas of disability practice and research, attention should be paid to ensuring that this historically neglected area is now able to make full use of this essential global mechanism for accountability for the rights of people with disabilities. More broadly, strengthening procedures for the meaningful participation of people with disabilities is likely to lead to improved accountability for their rights at the national and international level.

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Paper 4

Eaton J, Gureje O, De Silva M, Sheikh TL, Ekpe E, Abdulaziz M, Muhammad A, Akande Y, Onukogu U, Onyuku T, Abdulmalik J, Fadahunsi W, Nwefoh E, Cohen A.

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The mental health Scale Up Nigeria (mhSUN) programme ran from 2015-2020. It sought to bring together many of the key learnings in global mental health around mental health service delivery integrated into decentralised state structures at primary and secondary care, while deliberately engaging with government leadership to advocate for translation of evidence into policy and legislation change. The project was implemented in two sites, building on the idea of Federal institutions providing technical support for primary care services, applying evidence under the WHO's mhGAP programme and evaluating using process and outcomes indicators.

With colleagues at the University of Ibadan and two implementing sites (Calabar and Kaduna), I wrote the successful funding proposal for the mhSUN programme, which included both implementation components and an evaluation methodology. This paper describes the intervention development through a Theory of Change process, drawing on best evidence and local technical and lived experience, resulting in a contextually adapted intervention.

My role was in conceptualising the project, co-facilitating the Theory of Change process, drawing together the results and leading on paper writing.

Confirm role: Julian Eaton Signature: J Eaton Date: 25.10.23

Confirm role: Dr A Cohen, last author Signature: A Cohen Date: 17 Oct 2023

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RESEARCH

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A structured approach to integrating mental health services into primary care: development of the Mental Health Scale Up Nigeria intervention (mhSUN)

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Abstract

Background: The treatment gap for mental illness in Nigeria, as in other sub-Saharan countries, is estimated to be around 85%. There is need to prioritise mental health care in low and middle income countries by providing a strong body of evidence for effective services, particularly with a view to increasing international and government confidence in investment in scaling up appropriate services. This paper lays out the processes by which a programme to integrate evidence-based mental health care into primary care services in Nigeria was designed, including a research framework to provide evidence from a robust evaluation.

Methods: This paper forms the first step in the overall process evaluation of the mhSUN intervention, where standard research practice indicates that the intervention, and its development, is clearly documented prior to subsequent evaluation. The report covers the period of programme development and evaluation design, and study site and design was chosen to allow generalisability and practical conclusions to be drawn for service development in Nigeria. In order to design an intervention that was informed by evidence and took into account local context and input of stakeholders, a structured process was followed, including: (1) Engagement of relevant stakeholders for information gathering and buy-in; (2) Literature review and gathering of pertinent evidence; (3) Situation analysis at a national and local level; (4) Model development (using Theory of Change); (5) Ongoing consultation, recognising the iterative nature of Theory of Change, and need for ongoing refinement of complex interventions.

Results: The different sections of the structured approach resulted in outputs that built the necessary components (literature review, situation analysis) for informing the Theory of Change. A Theory of Change map is presented, which includes transparent documentation of the assumptions and logic behind the activities to drive the desired change. In addition, it documents the indicators necessary to measure fidelity and draw conclusions as to hypothesised effects of different mechanisms of action in subsequent evaluation.

Conclusion: In addition to the details of ensuring robust evaluation design, there are a number of considerations that are particular to the context that must be taken into account in programme development, including the relationships between ultimate beneficiaries, implementers, host government and institutions, donors, and programme evaluators. Structured methods from existing frameworks can be drawn upon to use and collate relevant information to maximise the local applicability of a generic evidence base. Theory of Change, with its documented assumptions

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can form the basis of subsequent evaluation and iterative programme refinement, contributing to a more scientifically valid means of developing mental health programmes for scale up.

Keywords: Mental health, Community mental health services, Primary care, Scaling up, Integration, Low-and middle-income countries (LAMIC)

Background

Recent epidemiological work has demonstrated that the burden of disease associated with mental and neurological illness is among the highest for all disorders globally [1, 2]. Despite the high level of disability, more than 85% of people with severe mental illness in low and middle income countries do not receive the care they require [3]. In sub-Saharan Africa, less than 1% of the health budget is typically spent on mental health [4]. This small allocation is in countries where an already low proportion of national budget is spent on health, and is often spent inefficiently, with almost all resources used at tertiary hospital level services that are inaccessible to the majority of people [5].

Evidence for integration of mental health into health services

Integrating mental health into existing health infrastructure improves accessibility, encourages parity between mental and physical health [6], and reduces stigma associated with using services [7]. However, general health systems are typically extremely weak in low income countries. While a balanced approach to care at all levels is necessary [8], there are particular gaps in decentralised, primary level care. Policy in many countries identifies primary services as the site for first line mental health care, but this is often not implemented [4], and infrastructure and personnel struggle to cope with the extra burden that introducing new work brings [9].

The use of less specialised general health staff to deliver defined tasks such as identification, treatment, delivery of psychological therapies or family psychoeducation—termed 'task sharing' or 'task shifting'—has been demonstrated in several low income settings [10]. If this model is to be effective, the quality of service provision must be assured. Several means of achieving this have been proposed and tested, for example stepped care approaches, where patients are treated at the lowest appropriate tier of services using clear guidelines for intervention, and are referred for more specialist care if they meet certain thresholds, for example if they have complications or do not respond to treatment [11, 12]. In addition, the important role of ongoing collaboration between frontline workers and specialists, with supervision and ongoing support after training has been emphasised in many interventions that have used task sharing [13].

A number of trials have established positive results for these interventions in different contexts, and for a range of conditions: in dementia and schizophrenia [14, 15] and epilepsy [16]. For common mental disorders, systematic review has shown moderate to strong effect sizes for clinical benefit and reduction in disability, for low-cost brief psychological interventions delivered by general health workers [17], and stepped care approaches [18].

In recent years, evidence-based resources have become increasingly available to address historic disparities [19] in mental health delivery, for example WHO's mental health Gap Action Programme (mhGAP) Intervention Guide [20]. There is now good evidence to show effectiveness of increasingly well-defined intervention models, and in a small number of cases, these resources, and the global advocacy for increased investment in mental health are being adopted by national governments, for example in India, China [21] and Ethiopia [22]. However, the scientific underpinning for scale up of services that have been demonstrated at district or regional level remains relatively weak. Several large programmes are now under way to address this, for example through such multi-country programmes as PRIME [23] and Emerald [24].

Rationale, aims and objectives

Nigeria has been a site for ongoing research in this process, including by collaborators in the research outlined in this article, mainly focusing on system strengthening, and support for self-advocacy by service users [25–27]. Despite the relative volume of research in this field in Nigeria, to date, there has been little commitment to strengthen mental health services from the national (Federal) Government. This reflects well recognised challenges in changing political will in order to effect policy change and mobilise resources [28].

A decision was therefore taken by a number of actors in the country to develop a programme with the aim of contributing towards progressive reform by demonstrating efficacy of integrating mental health into primary care in Nigeria, and to produce results that would be generalizable for sub-Saharan Africa that share many of the structural and resource characteristics of Nigeria. The objectives of the Mental Health Scale Up Nigeria (mhSUN) programme were (1) to develop a model for integration of mental health into primary care in Nigeria that is evidence-based, appropriate to the local context, feasible, accessible, and acceptable to those using the service and providing the service (the focus of this paper); (2) to evaluate the service, focusing particularly on key processes for successful implementation, as well as broad outcomes such as coverage, efficacy and user acceptability, and; (3) to use the results to advocate for service reform and investment by presenting convincing evidence, in an accessible and persuasive format to key decision-makers.

The research associated with the programme aims to evaluate how evidence-based interventions might be utilised appropriately in a particular setting.

Methods

This paper focuses on the development of an intervention model for the mhSUN programme, which from the outset also sought to establish a suitable framework for evaluation and research. It describes the structured approach that was utilised, which was itself drawn from best practice in similar programmes.

The development of a suitable model for service integration involves a structured process of information gathering and consultation with partners and other stakeholders, in order to align international and local evidence with local needs. We followed a number of key sources for guidance in this process, including the MRC guidance on developing and evaluating complex interventions [29, 30]. In addition, there are a range of resources for project planning in the grey literature. In this case we used the CBM Inclusive Project Cycle Management and Multi-Year Planning tools [31], which have a particular focus on inclusion of people who will be using services. Within the field of Global Mental Health, there are a number of examples of such structured programme development, often as a precursor to trials [32, 33].

Several key issues emerged from this guidance and experience, which we incorporated into our methodology.

First It is important to emphasise local expertise and allow this to feed into local adaptation of a consensus (international) evidence base. Stakeholder consultation involved identifying relevant groups, including service users, and facilitating means of collating their perspectives, for example through questionnaires and workshops. Theory of Change was a useful means of documenting their perspectives.

Second Sustainability is often inadequately considered in research projects which tend to be shorter-term, and do not have ongoing service provision as their prime purpose. This is a key weakness in generalisability of much trial design. This means that while such models might be *replicated* in a similar context, there are additional factors that if not engineered into the model at an early stage, might render a model with demonstrated efficacy in a trial setting, difficult to *scale up*. This issue is well recognised as a key limit to the current evidence-base, and alongside the problem of funding tending to follow relatively short cycles, is one reason behind the fact that there are relatively few examples of interventions taken to scale. In this case, we adopted an approach which explicitly referenced this issue [34], emphasising engagement with key stakeholders, establishing buy-in at an early stage, and establishing systems of governance that fostered ongoing support.

A third weakness in traditional research trial design that also acts against generalisability and scalability is the degree to which the local environment is amended in order to facilitate fidelity to a model. The intense scrutiny, heavy personal and financial investment, and focus on outcomes, inherent in Randomised Controlled Trials tend to reduce relevance to real-world environments. More naturalistic research methods would be more likely to result in realistic results that can be replicated in less intensely managed and monitored settings. In addition, there is a need for application of implementation science methods alongside the effectiveness trials of which there are now a relatively large number. As a response to these issue, the mhSUN intervention, and its evaluation, was designed to focus on pragmatic, real-world evaluation methods while ensuring scientific rigour. This is in keeping with the objective to provide a model that is not only demonstrably effective, but that can be used practically in the field to meet the growing demand by governments and donors for quality but practical routine monitoring and evaluation, reflecting the available human and financial resources in implementation settings as opposed to research.

Based on these principles, the following stages were followed:

1. *Initial engagement* with partners to gain consensus on aims, scope of the project and desired outcomes. In addition to developing a fundable proposal and establishment of formal partnership structure and contracts, this is an opportunity to gain political buy-in and support [35, 36].
2. *Literature review* In order to understand potential components of an intervention model, and to describe Nigeria's health and mental health system, several sources were consulted, including:

- Systematic reviews of programme evaluations, and relevant review articles.
- Published evaluations of programmes providing mental health care in low income settings.

- Evidence-based guidelines related to service reform. WHO mhGAP materials were explicitly referenced as the Nigerian government has adopted these as part of national MH Strategy.
- Government and inter-governmental sources related to health services and governance.
- Unpublished programme evaluations, focusing on low income settings, particularly in Nigeria and West Africa, accessed online [6] and through links with implementers in Nigeria.

3. *Situation analysis* to understand the policy context and political environment to guide plans for advocacy towards replication of services, and information about the local population characteristics, resources available, and cultural beliefs. This was carried out using a template developed for the purpose, based on domains derived from the WHO Assessment Instrument for Mental Health Systems (AIMS) [37] (for national level factors like policy and legislation frameworks), the Case Study Methodology [38] field evaluation questionnaires, and PRIME Situation Analysis Tool [39] for a more fine-grained analysis of local health and other sector services.

   The templates were populated at national level using a variety of data sources, including the WHO Mental Health Atlas [4] for information on the mental health system, and online databases such as UNICEF UNDP, and DfID for basic population and demographic data. Nigeria is well served compared to many surrounding countries for national-level data, including epidemiological studies in mental health, and through the National Bureau of Statistics [40]. At State-level and Local Government Area (LGA) level (roughly equivalent to districts in other countries), local researchers completed the templates by accessing local information sources at state level, interviewing relevant experts, and visiting communities to meet with stakeholders. This allowed for documentation of government and civil society and informal services related to the variety of needs that people affected by mental conditions might have, and initial documenting of local beliefs and cultural practices related to mental health in the communities to be served. Such issues would be explored further during training, awareness-raising and other community and stakeholder engagement exercises during the programme.
4. *Model development workshop* with partners, stakeholders and invited experts, to develop a service model and research plan using literature review, situation analysis, and the experience of partners. This was done using Theory of Change (ToC), an increasingly respected method for exploring and documenting the factors that contribute to how and why an intervention achieves the desired impact [41]. ToC is a participatory process of exploring processes for change, which both develops an intervention using the experience and expertise of the participants (while promoting buy-in), and documents key indicators that allow systematic evaluation of processes and outcomes of the intervention. It is particularly suited to generating relevant process evaluation questions, as steps in the service process are clearly documented so assumptions about how one pre-condition leads to an expected outcome can be tested.
5. *Ongoing consultation* with relevant actors was built into the programme model that was developed, for example through State Steering Committees, which included relevant stakeholders in the programme, government health leadership, and service users and carers [42].

Study setting

As an extension of ongoing work between University of Ibadan and CBM International, a scoping exercise for work in integration of mental health into PHC was carried out. As a result, it was decided that the intervention should take place in two sites, one in the South of the country, and one in the North. The inclusion of a site in both settings is useful for generalisability and comparison of contexts, but also has important implications in a country where national unity and broad representation (locally referred to as National Character) are a key factor in any political decision. The States of Cross River and Kaduna were chosen as they represent typical, but distinct cultural, economic, geographical and political realities in Nigeria, allowing exploration of the alignment of the model to these settings, and increased generalisability within and beyond Nigeria. These particular states were also identified for pragmatic reasons as they included well-functioning Federal Psychiatric Hospitals with good expertise and teams who had expressed an interest in developing decentralised services. Each state identified candidate local government areas (3 in Kaduna, 2 in Cross River—based on resources for implementation, and agreement of local authorities), from which health system infrastructure and personnel could be utilised (Fig. 1).

Given the focus on integrating into government structures, local implementation would be overseen by the Federal Neuropsychiatric Hospitals in those two States. These tertiary centres contain sufficient expertise to support local implementation in primary care settings. They were themselves coordinated by the University of Ibadan, allowing a single point of programme management, and technical support for the research component

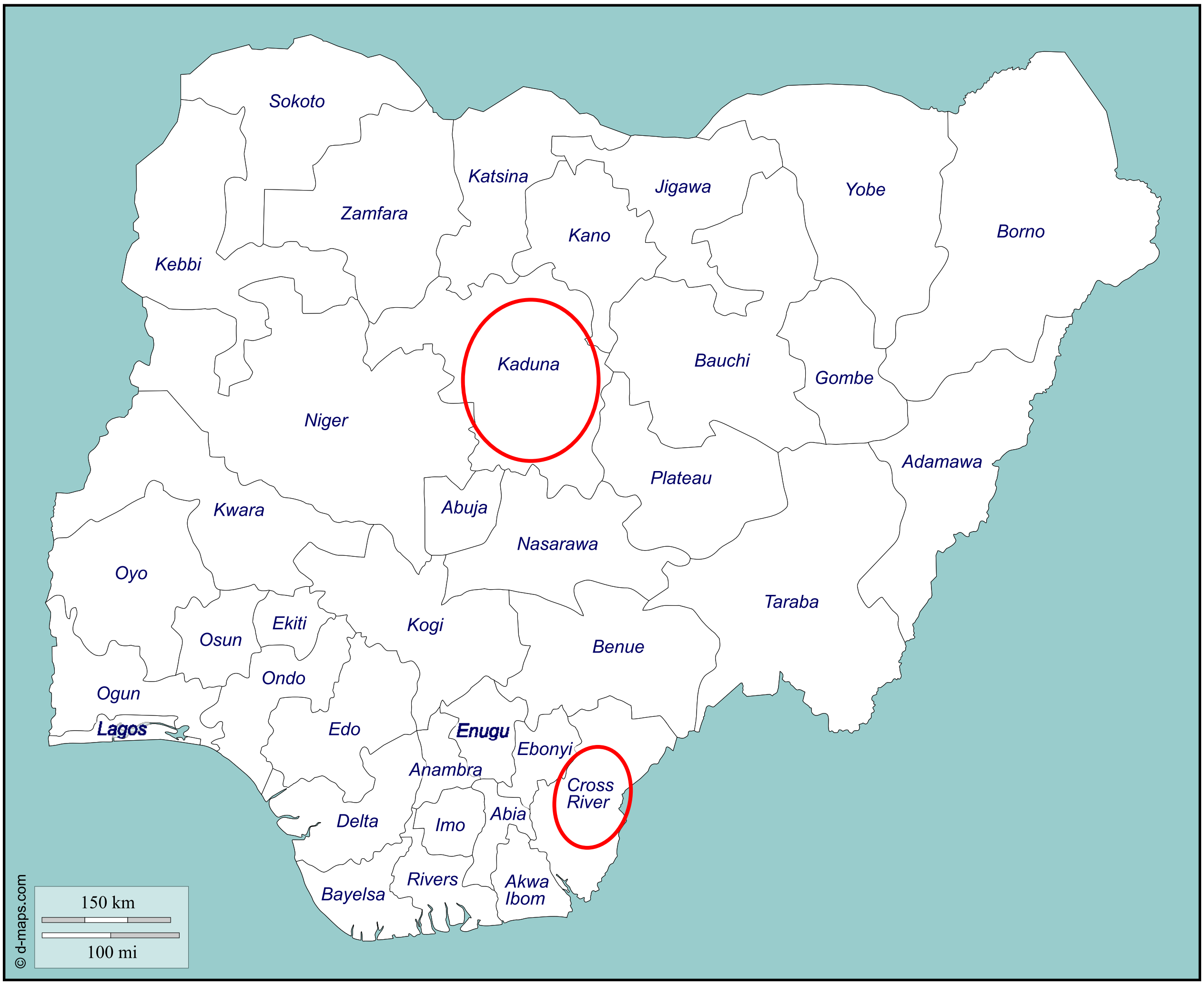


Fig. 1 Map of Nigeria, showing the two states of the mhSUN intervention

of the programme. PHC services are run through the local (LGA) tier of government in Nigeria, with oversight from State Governments, so it was important that each level was included in local management structures, and involved in planning.

The aim was to effect systems change within government services, so collaboration with government health providers at local and state level was essential. In addition, the Federal Ministry of Health was invited as a partner from the very beginning of the process, in order to foster their engagement (as an ultimate target for advocacy), and gain from their expertise and support.

The engagement and consultation process involved visits to key government and health system leaders in the identified states, as well as stakeholder meetings with service users, carers, health workers, NGO partners, and academics. These initial connections were reinforced in the field sites through establishment of local planning groups that subsequently made up the State Steering Committees overseeing programme implementation. An early consequence was that in Kaduna, this led to adoption of a mental health policy by the State Council on Health.

Initial meetings and scoping activities at state level provided a framework within which a funding proposal could be developed by the national partners. The proposal was subsequently funded by the Government of Australia through CBM Australia. See Additional file 1: Appendix S1 for the Organisational Chart of mhSUN Programme.

The literature review was carried out (by JE), drawing together relevant evidence for appropriate and effective services in Nigeria. This is summarised in the introduction above, and was presented at the model development/ToC workshop to inform the decisions about the intervention model contents and processes for implementation.

The situation analysis was carried out at State level by the local teams. Some information was available in publications or online, but much had to be found through interviews and travel to facilities. Specific information about mental health (prevalence, services, resources), was particularly weak, and either had to be sourced directly, or national data used.

See Additional file 2: Appendix S2 for completed Situation Analysis framework for the two sites, covering local political considerations, demographic situation, health system structure and available resources.

A model development and Theory of Change workshop was held in January 2015, to which the main implementing partners, experts in community mental health programme implementation in Nigeria, representatives from the Federal and State Ministries of Health, and international facilitators were invited (a total of 16 people). During the 4 day workshop, the results of the literature review, situation analysis, and interviews with key stakeholders in Nigeria, were presented.

The outputs of the model development process included:

1. A Theory of Change map, outlining the logical steps by which certain pre-conditions lead to outcomes and impacts (Figs. 2, 3). This included a more detailed description of each step in tabular form, and indicators to be used in the evaluation to determine whether each step was achieved. See Additional file 3: Appendix S3: Indicators for mhSUN Theory of Change evaluation.
2. A description of the proposed intervention, which was ultimately refined into a Manual of Operations. This is summarised in Box 1: The mhSUN Intervention, and Fig. 4: functions and tasks of different actors.

While a common Theory of Change was developed across both sites, it was decided that where

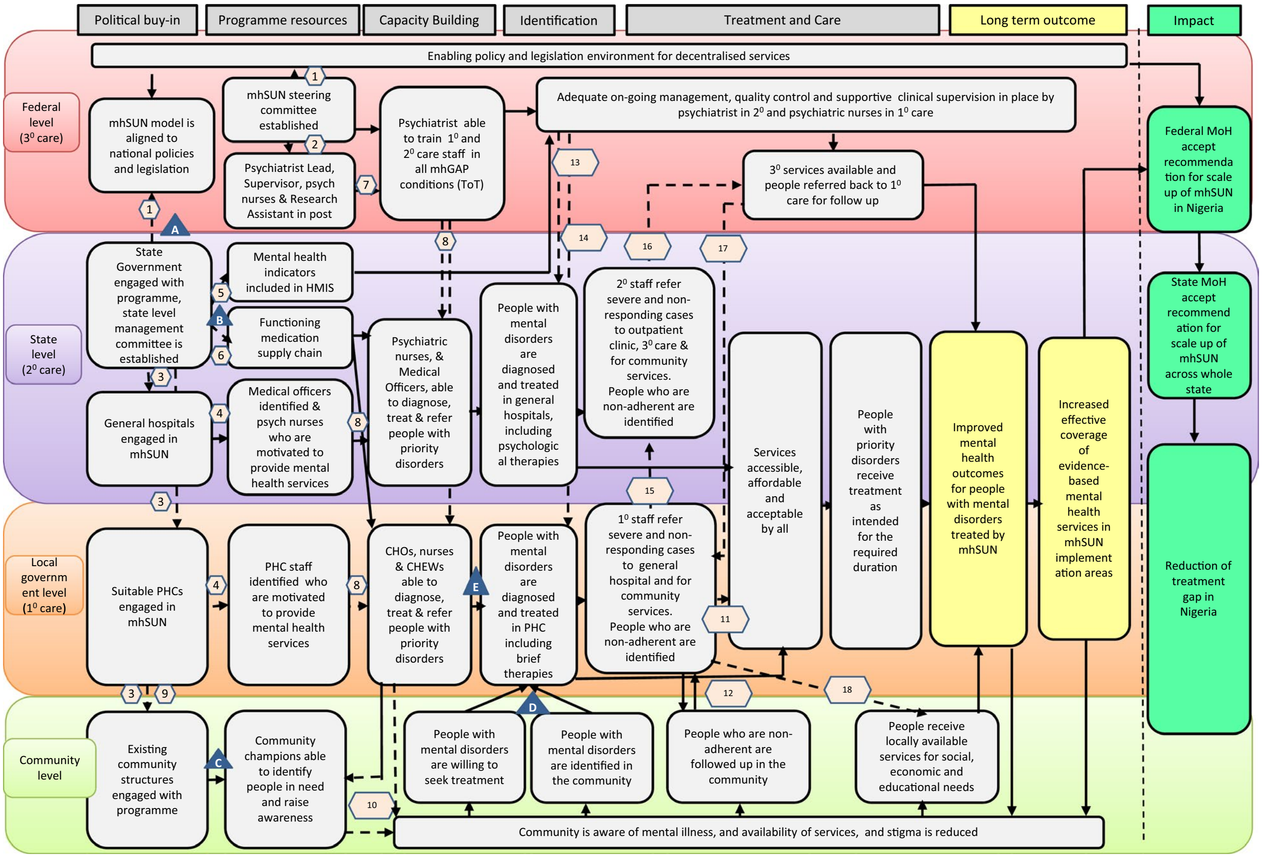
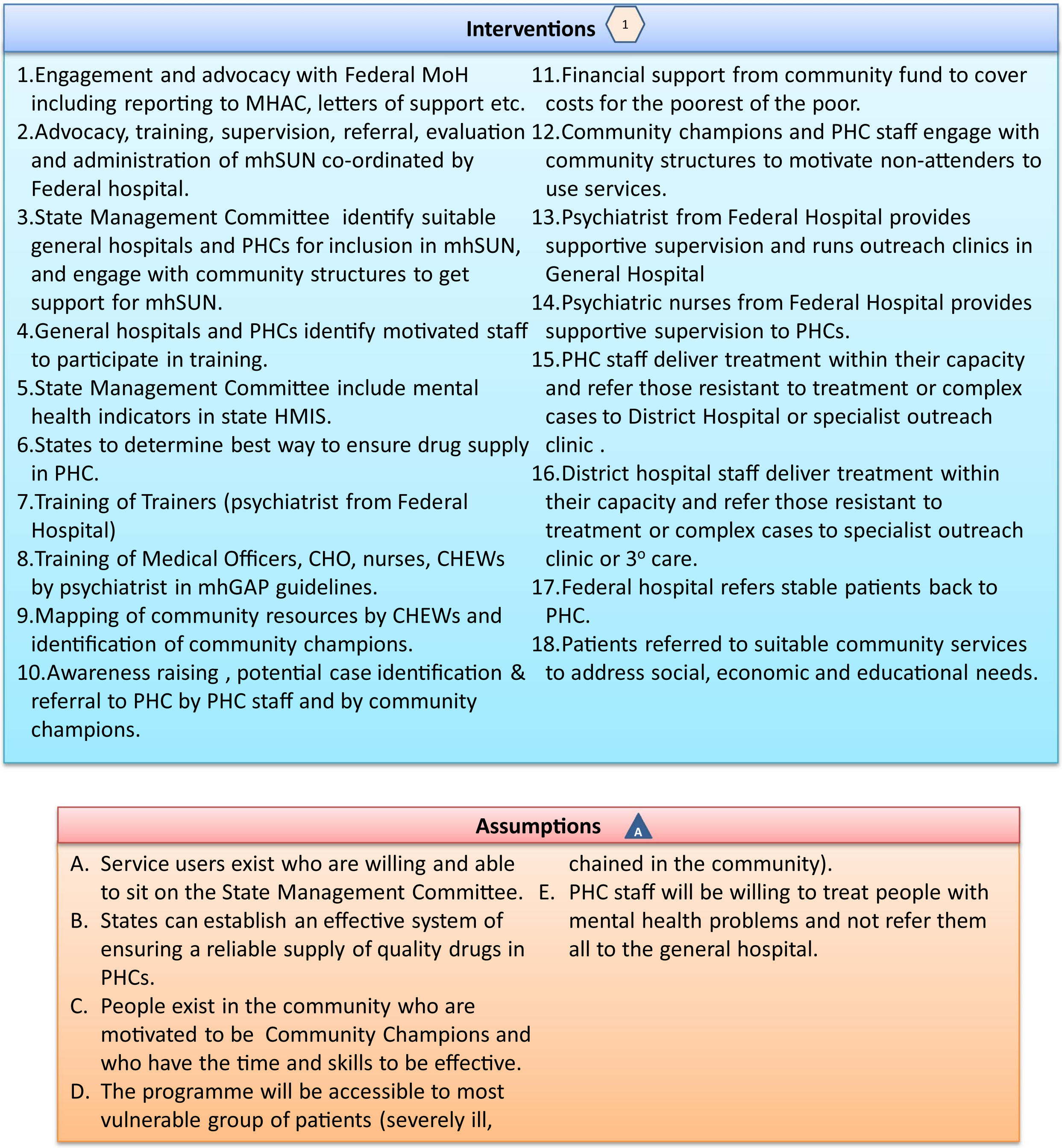


Fig. 2 Theory of Change map for mhSUN



Interventions 1

1. Engagement and advocacy with Federal MoH including reporting to MHAC, letters of support etc.
2. Advocacy, training, supervision, referral, evaluation and administration of mhSUN co-ordinated by Federal hospital.
3. State Management Committee identify suitable general hospitals and PHCs for inclusion in mhSUN, and engage with community structures to get support for mhSUN.
4. General hospitals and PHCs identify motivated staff to participate in training.
5. State Management Committee include mental health indicators in state HMIS.
6. States to determine best way to ensure drug supply in PHC.
7. Training of Trainers (psychiatrist from Federal Hospital)
8. Training of Medical Officers, CHO, nurses, CHEWs by psychiatrist in mhGAP guidelines.
9. Mapping of community resources by CHEWs and identification of community champions.
10. Awareness raising , potential case identification & referral to PHC by PHC staff and by community champions.
11. Financial support from community fund to cover costs for the poorest of the poor.
12. Community champions and PHC staff engage with community structures to motivate non-attenders to use services.
13. Psychiatrist from Federal Hospital provides supportive supervision and runs outreach clinics in General Hospital
14. Psychiatric nurses from Federal Hospital provides supportive supervision to PHCs.
15. PHC staff deliver treatment within their capacity and refer those resistant to treatment or complex cases to District Hospital or specialist outreach clinic .
16. District hospital staff deliver treatment within their capacity and refer those resistant to treatment or complex cases to specialist outreach clinic or 3° care.
17. Federal hospital refers stable patients back to PHC.
18. Patients referred to suitable community services to address social, economic and educational needs.

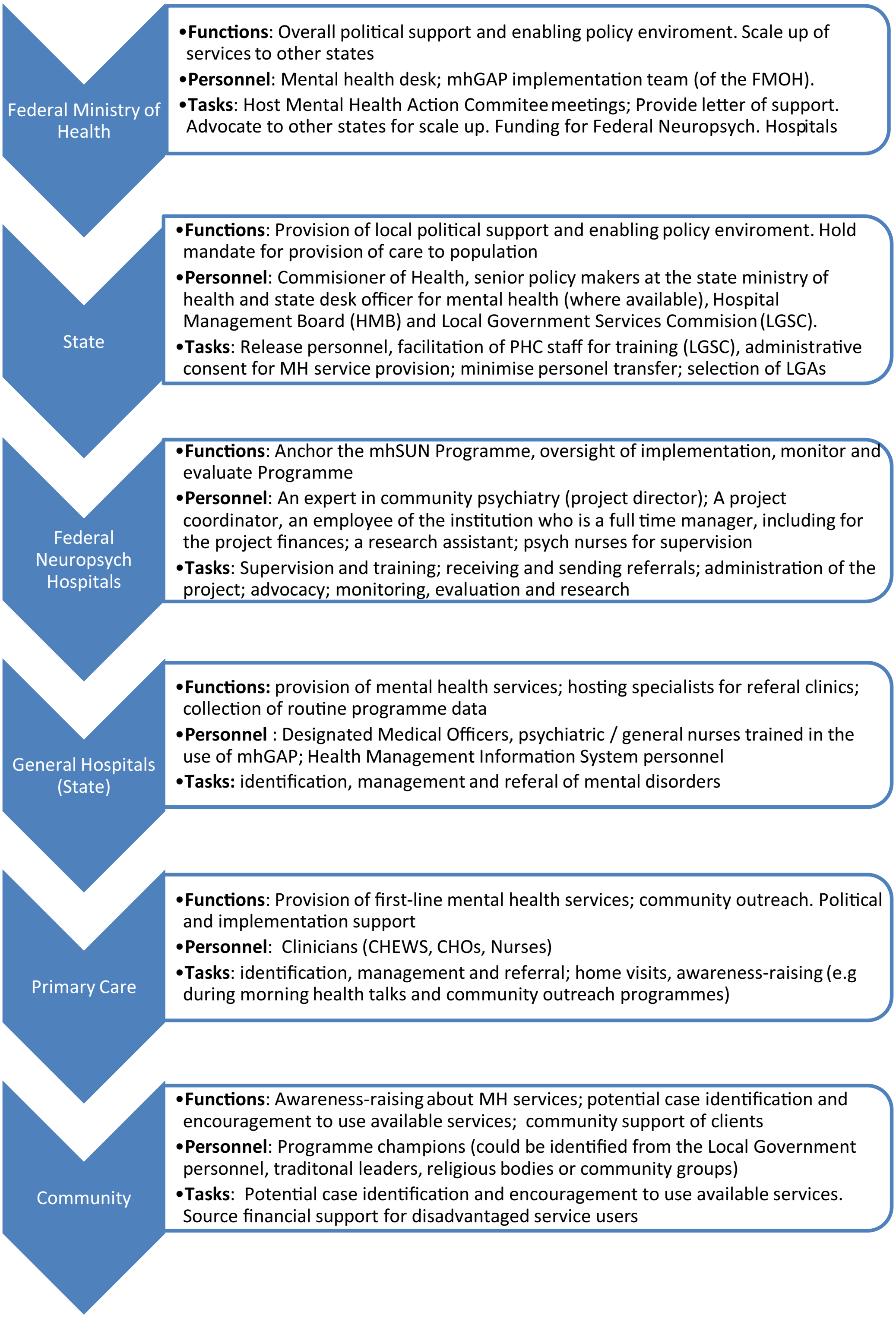
Assumptions A

A. Service users exist who are willing and able to sit on the State Management Committee.
B. States can establish an effective system of ensuring a reliable supply of quality drugs in PHCs.
C. People exist in the community who are motivated to be Community Champions and who have the time and skills to be effective.
D. The programme will be accessible to most vulnerable group of patients (severely ill, chained in the community).
E. PHC staff will be willing to treat people with mental health problems and not refer them all to the general hospital.

Fig. 3 Interventions and assumptions for theory of change

circumstances differed, some elements would be amenable to local adaptation. One example of this was ensuring availability of medication. The common problem of lack of effective systems for delivering medication within the state structures was addressed by one site by establishment of a drug revolving fund run by the project, while the other felt that this would not be an acceptable solution, and they would need to work through advocacy with the government to improve availability through the standard supply chains.

Ongoing consultation and refinement of the programme is integral to the complex nature of initiating and



Federal Ministry of Health

- **Functions**: Overall political support and enabling policy enviroment. Scale up of services to other states
- **Personnel**: Mental health desk; mhGAP implementation team (of the FMOH).
- **Tasks**: Host Mental Health Action Commitee meetings; Provide letter of support. Advocate to other states for scale up. Funding for Federal Neuropsych. Hospitals

State

- **Functions**: Provision of local political support and enabling policy enviroment. Hold mandate for provision of care to population
- **Personnel**: Commisioner of Health, senior policy makers at the state ministry of health and state desk officer for mental health (where available), Hospital Management Board (HMB) and Local Government Services Commision (LGSC).
- **Tasks**: Release personnel, facilitation of PHC staff for training (LGSC), administrative consent for MH service provision; minimise personel transfer; selection of LGAs

Federal Neuropsych Hospitals

- **Functions**: Anchor the mhSUN Programme, oversight of implementation, monitor and evaluate Programme
- **Personnel**: An expert in community psychiatry (project director); A project coordinator, an employee of the institution who is a full time manager, including for the project finances; a research assistant; psych nurses for supervision
- **Tasks**: Supervision and training; receiving and sending referrals; administration of the project; advocacy; monitoring, evaluation and research

General Hospitals (State)

- **Functions:** provision of mental health services; hosting specialists for referal clinics; collection of routine programme data
- **Personnel** : Designated Medical Officers, psychiatric / general nurses trained in the use of mhGAP; Health Management Information System personnel
- **Tasks:** identification, management and referal of mental disorders

Primary Care

- **Functions**: Provision of first-line mental health services; community outreach. Political and implementation support
- **Personnel**: Clinicians (CHEWS, CHOs, Nurses)
- **Tasks**: identification, management and referral; home visits, awareness-raising (e.g during morning health talks and community outreach programmes)

Community

- **Functions**: Awareness-raising about MH services; potential case identification and encouragement to use available services; community support of clients
- **Personnel**: Programme champions (could be identified from the Local Government personnel, traditonal leaders, religious bodies or community groups)
- **Tasks**: Potential case identification and encouragement to use available services. Source financial support for disadvantaged service users

Fig. 4 Functions and tasks of different actors integrating a new intervention into an existing system. Situation analysis, Theory of Change and intervention implementation are all iterative processes, so these are expected to be revised at key stages in the initial piloting (6 months) and ongoing implementation phases. Specific elements of the Manual of Operations for the service will be reviewed after piloting. For research, data collection, training and competencies of research assistants, data management and secure storage, recruitment issues, and logistics will be considered, and revisions made as appropriate. This period would also serve as an embedding period for the service prior to certain elements of evaluation.

Results

Overview of the mhSUN programme model

After following the structured development process as described, a programme model was developed, which was documented through the Theory of Change map, a model description and Manual of Operations. Alongside the implementation of the basic mhSUN intervention (see Box 1), was a deliberate process of engagement with government for advocacy (leading to dissemination of results), including through engagement with local leaders, and support for the National Mental Health Action Committee.

While developing the programme, particularly in the Theory of Change workshop, key areas of debate included:

Balance between fidelity to an evidence-based model, and resonance with local contexts

This is true on an international level, but in this case, was also an issue in terms of uniformity between sites. As described in the results, the Theory of Change was able to accommodate this. Such points of local divergence might be helpful points for comparison of different intervention components, and demonstrate the flexibility and adaptability of the approach, where ongoing adaptation is recognised as legitimate.

Engagement with traditional systems

There was consensus that local traditional healers and religious leaders who provided treatment for people who consult them with mental health problems were a key element of pathways to care. Their deep resonance with local explanatory models of mental illness was acknowledged, and a means of engaging with them was included, that would draw upon their experience of effectively addressing concerns of people who used their services, while also addressing concerns that harm is done by some providers, and some interventions used lack efficacy in some cases, resulting in neglect if not identified and alternatives offered.

Advocacy for resources from government systems

Given the issues of sustainability described above, a clear focus was put in place to not only engage with government early, but to continue effective communication, continuing advocacy at local, State and Federal Government levels, including through provision of accessible evidence from the project. While this remains a focus and commitment, there was a degree of scepticism as to the likelihood of investment in these services, based on past experience, particularly as the economy appeared to be entering challenging times.

Engaging with communities

It is clear that the health system plays only a small role in recovery and maintenance of mental health, and family and communities have huge impact. While health services have a limited mandate and resources, it was clear that community engagement, through both the existing means used by community mobilisation officers in PHC, and further outreach to communities, was necessary. It was hoped that this might be one means of improving the historically extremely low follow-up rates of patients after initial presentation (usually during crisis).

Box 1: The mhSUN programme model

Primary and secondary services will integrate a basic package of mental health care based on the mhGAP Intervention Guide. This has been previously adapted for the Nigerian context [43], and provides practical, evidence-based guidance for treatment of 8 priority conditions. Services will be provided by primary health care workers who are mainly nurses, community health officers (CHO) and community health extension workers (CHEWs). CHOs and CHEWs are non-physician health workers who have received 2–3 years of post-high school training specifically designed to prepare them for providing essential first-line health care service close to the community. This training will include a component teaching ‘standing orders’ for mental health, however this is very brief, and there is little follow-up or support resulting in a low level of confidence to use this training.

Capacity building of local health practitioners will be provided using the mhGAP-IG training package. Initially, master trainers from the University of Ibadan will train local mental health leaders (Training of Trainers). The Federal Neuropsychiatric Hospitals

(FNPH) will then be responsible for initial (base) training, and regular refresher training of personnel.

Ongoing support and skills development of practitioners included monthly supervision, and support for complex cases through outreach visits (collaborative care) to each clinic at least every month. A system of referral will be put in place (stepped care), including downward referral from specialist care to community follow-up.

Governance will be provided through the established health systems structures, with particular attention to mental health aspects through a Steering Committee, made up of government, health service leaders and staff, community leaders, service users, and programme personnel. In addition, the service is designed to comply with national and state legislation, policy and plans.

Health systems approach to ensure all relevant components that contribute to successful services will be addressed; negotiating use of appropriate physical infrastructure (access to a suitable private clinic room in each facility), health financing (including consideration of provider and service user costs), health information systems (integrating mental health indicators where they are absent), medication availability, and interaction between the different levels of service (referral and supervision). The need to travel large distances to see a specialist if referred would generally be avoided through monthly consultation in PHC clinics by visiting specialists, and follow-up improved with deliberate efforts to engage with people missing appointments. As far as is possible, established systems will be strengthened and integrated into, rather than duplicated.

Community engagement is essential for ensuring social integration, and providing social support. An awareness programme accompanies establishment of the service, including use of local means of sharing information through existing health system means, as well as use of media, and identification of local 'champions' for awareness-raising and community support of clients. In addition, community resources will be mapped to promote access to other sectors for social, livelihood and human rights interventions.

Discussion

This structured approach to using an international evidence base appropriately in a specific local context is central to Global Mental Health in general, and essential in application of global normative standards like mhGAP in diverse countries. We found that this can be done in a systematic way as has been documented in this paper, and demonstrated by some good practices described in published literature.

Since many of these projects have been rooted in research contexts, however, there are several key factors that we emphasised in the development of this project, namely:

Strong and meaningful participation at all levels to promote engagement and ensure good fit to the needs of users of services, and those working in them.

Respecting and integrating with governance structures and other local systems. While this tends to be a more challenging and longer process, it is likely to result in more sustained change.

Avoidance of excessive external resource or technical support that will not be realistically available after a short pilot or trial phase.

Analysing local context and organising these and other inputs in a structured way using a Theory of Change methodology, but one that is iterative should the initial experience of implementation demand adjustment.

Conclusion

Recent years have seen a significant increase in the number of interventions developed and implemented for priority mental disorders in low- and middle-income settings. There remain a number of criticisms related to the consistency of this process, and the degree to which it reflects good practice related to capturing relevant information, organising it in a structured and theoretically sound way, and paying attention to the expertise and experience of local actors. We have developed a comprehensive process for consolidating international and local evidence, adapting this to local needs through consultation with relevant actors, and designing an intervention rooted in a local context. This approach might be useful for those designing other interventions (including as part of evaluation research). The mhSUN programme itself is now proceeding with implementation of the intervention and evaluating it at scale.

There remains a significant degree of art in the science, however, and examination of the processes through which this implementation occurs should enrich our understanding of effective mental health service strengthening.

Additional files

Additional file 1: Appendix S1. Organisational chart of mhSUN programme.

Additional file 2: Appendix S2. Situation analysis of political, demographic and services context in Calabar and Kaduna States.

Additional file 3: Appendix S3. Indicators for mhSUN Theory of Change evaluation.

Authors' contributions

JE is Principle Investigator of mhSUN, and conceived of and drafted the article. All authors contributed to the design of the research, and to collection and analysis of results. All authors read and approved the final manuscript.

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Competing interests

All authors have participated in implementation of the mhSUN programme.

Availability of data and materials

All data is stored through the secure LSHTM data storage system and is available from the corresponding author on request.

Consent for publication

Obtained from each study participant as part of consent procedure.

Ethics approval and consent to participate

Ethical approval was sought and obtained for the Ethical Review Committees of the Federal Neuropsychiatric Hospitals at the two sites in Nigeria, and from the supporting institution in the UK (London School of Hygiene and Tropical Medicine). The project implementation in each state was overseen by a State Steering Committee, and the research teams meet monthly in telephone meetings, supported by an Advisory Committee for the associated PhD.

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