McPin Foundation

Driving Change

Experiences of non-governmental organizations in the provision of mental health services across the world

A report prepared for the World Innovation Summit for Health 2013

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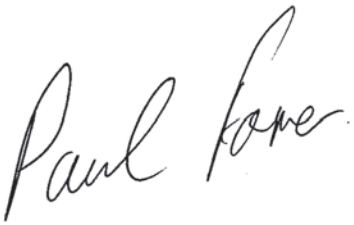
Foreword

Throughout generations, the voice of the individual and their experience has had the power to improve society. In many cases, this voice has been brought together by groups and associations of those individuals to make it stronger and easier to hear. The role of NGOs in delivering change across many health sectors is well-documented.

This report has been developed to give people with mental health problems and NGOs working in mental health a voice at the highest level. It reflects the experiences of NGOs from small, middle, and high income countries. It concludes that people with lived experiences of mental health problems, their families and wider civil society, alongside the NGOs, have a central role to play in transforming mental health services across the globe.

With the rapid advances of social media, we are already seeing the potential of that voice to have a local and global influence. Campaigns addressing stigma, human rights issues, and the improvement of care have already started to use new technologies to reach ever wider audiences.

Our report, *Driving Change,* should be read alongside the World Innovation Summit for Health (WISH) (2013) publication '*Transforming Lives, Enhancing Communities: Innovations in Mental Health*'[5]. It is only by partnership between policy-makers, system providers, clinical leaders, NGOs, and people who have lived experience of mental health problems that transformational change can happen.



Paul Farmer
Chief Executive, Mind

Introduction

Not for profit, voluntary, or charitable Non-Governmental Organizations (NGOs) are an important part of the mental health sector driving local, national, and global change. The World Bank[1] defines NGOs as "private organizations that pursue activities to relieve suffering, promote the interests of the poor, protect the environment, provide basic social services, or undertake community development". The global Mental Health Action Plan[2] developed by the World Health Organization (WHO) recognizes NGOs as key partners in implementing its objectives and highlights the importance of collaboration with civil society. The recent Grand Challenges program identified 25 top priorities for global mental health research, emphasizing the importance of co-ordinated actions to deliver progress, including the involvement of advocacy organizations[3]. However, a recent review article analyzing why global mental health does not get the attention it deserves, highlighted lack of civil society advocacy for change was a weakness[4]; too few Mental Health NGOs (MHNGOs) have substantive power at national and international levels. In this report we detail NGO contributions to the mental health sector, their ambitions, and what needs to change to support their work.

The MHNGO sector includes mental health and substance use specialist organizations, as well as those with broader social care or economic welfare remits. They vary in scale from international networks to local advocacy groups. Many are embracing technology, and in particular social media, to profile their work and strengthen their voice to raise the awareness of mental health as an issue for civil society to address urgently. MHNGO scope typically includes: campaigning and activism; promotion and prevention activities; empowerment, advocacy and education; provision of help and support; community development. An increasing number of MHNGOs are user-led and focus on representing the views of people affected by mental health problems. They are well placed to give a voice to people affected, empower individuals to defend their rights, develop innovative solutions based on need and experiences of people directly affected – and their families, deliver community education programmes to raise awareness and partner with other organizations to drive forward a values-based mental health system. The objective of these organizations is to protect human rights, place mental health on the public agenda, raise awareness and eradicate discrimination, and provide effective support for those affected and their families. Driven by a values-based strategy that places lived experience at the core of developing policy or delivering support, a perspective that is vital but often ignored, they offer the mental health sector multiple ways of addressing complex problems and empower individuals on a recovery journey.

In order to capture the knowledge and expertise of people with lived experience for the World Innovation Summit for Health (WISH) 2013, a number of MHNGOs were contacted to share their views on innovations in mental health care. The WISH mental health report titled "Transforming lives, enhancing communities: innovations in mental health" was led by Professor Vikram Patel from the Centre for Global Mental Health, London School of Hygiene and Tropical Medicine and Dr Shekhar Saxena from the WHO, funded by Qatar Foundation. Information from interviews with MHNGOs was shared with the WISH mental health report team[5]. In this separate report, a fuller account is provided of the MHNGO views shared.

Background

Mental Health NGO perspective

We spoke to 16 MHNGOs from low, middle, and high income countries over a four-week period. The organizations were run by, or focused on representing the views of people with mental health problems and their families. We acknowledge this is a small number of MHNGOs, from a limited number of countries but the consistency of emerging themes provides some confidence that what we found are core concerns of user and family-led NGOs working in mental health across the globe. We supplemented this with written information from three additional organizations and again the themes were consistent. We hope this report can provide a basis for further work, understanding the role of MHNGOs in global mental health care and their core concerns.

It is important to acknowledge how we chose the terminology to use in this report. How we describe people and their work matters but there is no consensus on which terms should be used in mental health to describe the health condition or the people affected. We have consumers, survivors, service users, people with psychosocial disabilities, lived experience experts and patients. We have families, care-givers and carers. There is mental disorder, mental illness, mental health problems, mental distress, and emotional health issues. In this report, we have adopted the terms most used among the MHNGOs we worked with: *people with mental health problems, families, and mental health problems*.

Our approach

We identified MHNGOs using a 'snowballing' method by identifying potential participants through initial informants and their networks. Invitations were sent out to user-led or family-led MHNGOs who were known to the members of the WISH Mental Health Forum. The McPin Foundation reviewed all suggestions and searched for further contacts using recommendations from experts working with the global mental health forum, literature searching and web-based information resources. Interviewees were also asked to identify any other user or family-led MHNGOs they were familiar with. We approached 25 MHNGOs and completed interviews with 16. This is a very small number compared to the size of the global NGO mental health sector. However, to date, there are no available statistics about the number of NGOs focused on mental health. We sought to engage with MHNGOs in each continent, include both family-led and user-led organizations, and reach global networks and individual groups. We were limited by a challenging timescale and were unsuccessful at including representation from some regions, including Eastern Europe, Middle East, and South America.

In addition we collected case material on innovations from projects beyond these initial contacts, attended a global mental health conference with NGO attendance, and searched published literature to capture the NGO view of global mental health care. An important omission is the voice of Community Based Organizations (CBOs) which do not have formal NGO status but deliver similar activities within localities; we only engaged with one mental health CBO.

Table 1: Locations of MHNGOs involved in the consultation

Country	Income status	Population (million)
Australia	High income	22.68
Costa Rica	Upper middle income	4.805
El Salvador	Lower middle income	6.297
Ghana	Lower middle income	25.37
Guatemala	Lower middle income	15.08
India	Lower middle income	1237.00
Indonesia	Lower middle income	246.9
Kenya	Low income	43.18
Mexico	Upper middle income	120.8
Nepal	Low income	27.47
Netherlands	High income	16.77
Panama	Upper middle income	3.802
South Africa	Upper middle income	51.19
Uganda	Low income	36.35
United Kingdom	High income	63.23
United States	High income	313.9

Source: The World Bank[6]

Table 2: MHNGO sample characteristics

Reach and focus of MHNGO operations:	Number in sample
Locality or region	2
National	10
Multinational	4

Table 3: MHNGO sample characteristics

Lived Experience within leadership roles:	Number in sample
User-led	8
Family-led	3
Lived experience within governance	5

Findings

1. The main issues and challenges facing MHNGOs

We asked MHNGO representatives to identify the most prominent issues that their organizations were addressing. Stigma and discrimination were central to a lot of topics discussed in the interviews, especially human rights violations. Another focal issue was limited resources that impact on the capacity of MHNGOs to achieve their mission.

1.1 Human rights violations

Human rights abuses of people with mental health problems are a fundamental challenge. Mental health problems leave individuals vulnerable to violations of human rights to the extent that the issue has been called 'an unresolved global crisis'[7]. Mental health human rights violations have been reported as a pertinent issue especially in low and middle-income countries; however no country is immune to these violations with social justice and human rights being central to the mission of MHNGOs across the globe.

International human rights standards including the United Nations Committee on the Rights of Persons with Disabilities (CRPD)[8] require governments not only to protect the rights of people with psychosocial disabilities, but also to empower them to be an equal partner in all aspects of community life and development efforts.

This is further emphasized in the Mental Health Action Plan developed by WHO[2], which features human rights as one of six cross-cutting principles and puts human rights at the heart of actions for different stakeholders. For example, the Mental Health Action Plan calls international and national partners to "Ensure that people with mental disorders and psychosocial disabilities are included in activities of the wider community, for example, when advocating for human rights and in processes for reporting on implementation of the Convention on the Rights of Persons with Disabilities and other international and regional human rights conventions." (p18)

MHNGOs' advocate for the rights of individuals with mental health problems and they work to influence relevant stakeholders. Our respondents talked about NGOs' responsibility for fighting for the rights of people who are marginalized and excluded:

"The NGO sector plays the role of a whistle blower in terms of fighting for the rights of the traditionally marginalized and excluded groups and individuals in the community."

Eddie Nkurunungi, Heartsounds Uganda

MHNGOs also facilitate service user participation in public affairs on an equal basis with others, in line with article 29 of the UN CRPD "Participation in political and public life"[7]. The voice of people with mental health problems was described in one of our interviews as the most powerful and effective factor in addressing issues related to the rights that they are often denied:

"There is no more powerful and effective method for delivering the message and understanding the need to address human rights violations, social exclusion, a lack of good mental healthcare than the direct voice of those who have personal experience."

Joel Corcoran, Clubhouse International, USA

The United Nations Convention on the Rights of Persons with Disabilities (2006) reaffirms the importance of human rights and fundamental freedoms for all people with disabilities. It provides a framework for making adaptations for people with disabilities, to exercise their rights and

reinforce protection of those rights within disability legislation. This participation is key to developing policy, legislation and practice that addresses the concerns and issues experienced by everyone affected by mental health issues including families. The World Psychiatric Association[9] emphasized the need for collaborative work between key stakeholders and recommended to the international mental health community that:

"Legislation, policy and clinical practice relevant to the lives and care of people with mental disorders need to be developed in collaboration between mental health practitioners, service users, and carers." (p234)

Our respondents talked about the issue of developing and implementing appropriate mental health laws and legislation. Some MHNGOs were involved in pressuring governments to address the abuses of human rights by repealing existing mental health laws and developing more appropriate legislation in line with the UN CRPD.

"We want the repeal of mental health laws that we believe serve to segregate people with psychosocial disabilities, that allow for involuntary committals and coercion of forced medical treatments. We believe good health legislation should comprehensively include people that choose to have medical treatments and Disability Legislation should ensure the protection of our rights."

Pan African Network of People with Psychosocial Disabilities (PANUSP)

Where appropriate legislation already existed, some organizations campaigned for its implementation as there were numerous barriers to applying it into practice.

"It is clear that the policy and legislation of laws concerning persons with disabilities are in place but implementation of these laws remains a hurdle that the stakeholders in the cross disability movement will need to address."

Kanyi Gikonyo, Users and Survivors of Psychiatry in Kenya

Our respondents described instances of human rights violations, such as chaining, shackling, starvation, treatment without consent, denying the right to access help, and rape. The urgency of these issues is often exacerbated by the limited access to appropriate support, which puts many people with mental health problems at risk of becoming homeless:

"From the government research, there is about 18,000 people in shackles [in Indonesia], so it's a very urgent situation. Thousands of people are at a risk of becoming homeless without any proper support from the government. Thousands of people also don't have any access to the mental health service. From 7,000 people accessing primary care, only 100 are offered mental health services in Indonesia. There are very limited facilities."

Bagus Utomo, Komunitas Peduli Skizofrenia Indonesia

Rally in South Africa highlighting human rights issues and mental health

Source: Central Gauteng Mental Health Society

Many individuals are subjected to abuse and discrimination and face rejection from their communities:

"In my country, for instance, people might have a disease and when they become aggressive they are accused of being bogey men. Some when they are in communities they are locked up, stoned and cannot walk about in the community. And then some of them are not given enough food to eat and menial jobs."

Dan Taylor, MindFreedom, Ghana

The role of families in managing mental health of their relatives was discussed in the context of abuse resulting from the lack of awareness and the lack of treatment options:

"A lot of families, when we get in touch with them for the first time, in innumerable occasions they chain this person. In the majority of the cases that is done not because they hate this person or just don't care about this person, but imagine if there is a person who is severely symptomatic for years on end. That person is not able to go out, get work and get on with every day. Then the immediate caregiver also cannot work. (...) part of the human rights abuse is because families have to survive. Sometimes this is their only way of doing it."

Shoba Raja, BasicNeeds

Despite the alarming situation of many people with mental health problems affected by human rights violations, it is important to emphasize that there is hope evidenced in the instances of addressing abuse and rebuilding lives.

Some of the human rights violations our MHNGO respondents talked about were closely connected to spirituality and religious beliefs. In many instances people subject themselves and/or their family members to cruel treatment in the name of the tradition or religion. Traditional healers often use brutal methods to "heal" in the absence of alternatives.

"...the church is chaining people with mental illness because they actually believe that by chaining them, they will release the demons. They believe that mental illness is demon possession."

Charlene Sunkel, Central Gauteng Mental Health Society, South Africa

"There are issues about cultural beliefs and superstitions that are really a problem. It's very difficult for people to actually accept the fact that mental disorders are caused by way of life and their lifestyles. Many times these are attributed to evil forms and spirit."

Dan Taylor, MindFreedom, Ghana

"In the community, there are traditional healers. And because there is no other treatment available, most families have been to the traditional healers. (...) There are cases where they have been abused in the name of treatment. They exercise exorcism and sometimes it involves physical abuse."

Shoba Raja, BasicNeeds

Because in many countries across the world there is no mental health care available, these techniques are widespread. These are not humane solutions to human suffering and distress. MHNGOs alongside other groups concerned with mental health, such as WHO, are active in campaigning to raise awareness and lobby governments to create laws that make such practices illegal. It is necessary for all sectors of the community to come together to offer better public education and treatment options in order to overcome those beliefs and prevent their devastating consequences.

This report provides some examples of good practice in raising mental health awareness, education and campaigning for the rights of people affected by mental health problems. Other research also emphasizes that for global mental health to achieve greater recognition as a key health challenge, solutions must be underpinned by a social justice and human rights approach[4].

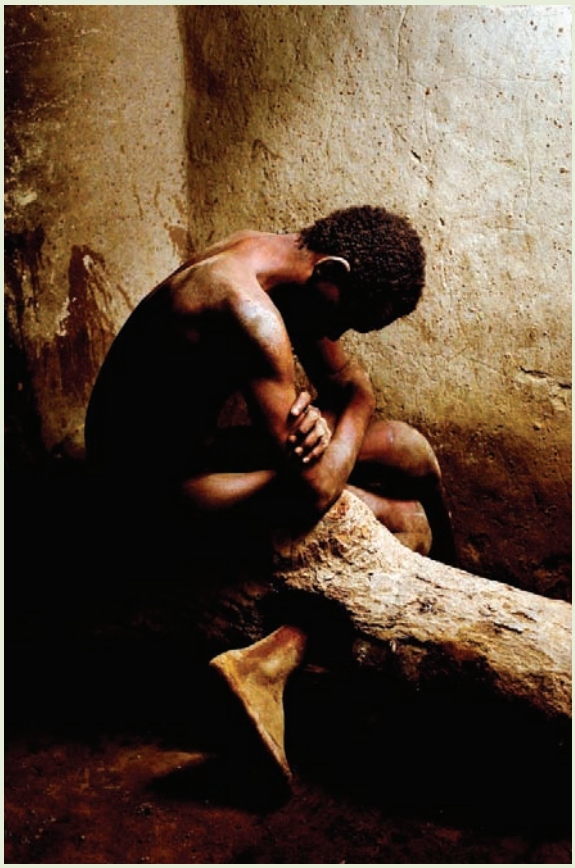
Francis' Story

Francis spent nearly one-and-a-half years bound to this log because of his mental health problems; a common practice in Ghana. This was partly because his family could not afford $17 for medication that would have stabilized his condition and enable him to be released.

Francis said: *"I felt very sad, neglected and abused, having my leg pinned to a log like an animal. It did not feel like home to me. I felt immeasurable pain from the weight of the log, especially whenever I wanted to reposition myself..."*

Following support from his friend Samuel, a Community Psychiatric Nurse, and BasicNeeds, Francis is well and teaching again.

Francis said: *"I am thankful to my friend Samuel, but it is BasicNeeds that brought me my transformation. But for you, I possibly would have been dead today."*



Source: BasicNeeds www.basicneeds.org
Photo: © Nyani Quarmyne for BasicNeeds. Reprinted with permission.

1.2 Discrimination and stigma

Stigma of mental illness has been defined as a negative attitude towards the person affected by the illness[10]. Some efforts have been made to replace the term 'stigma' with two other words: prejudice and discrimination. Increasingly, it is the term mental health discrimination rather than stigma that describes the key problems impacting on people affected by mental health problems[11]. Individuals may also experience self-stigma, internalizing societal views of mental health which impact on recovery. Mental health discrimination and stigma has been described as the second "illness", and equally, if not far more damaging because of the social barriers and abuse people face from being labelled "mentally ill"[12].

Article 5 of the CPRD[8] on – Equality and non-discrimination (2006) states that:

"States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law and that state parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds."

Mental health discrimination and stigma can result in reluctance to seek help and support as people do not want to be stereotyped and labeled[13]. Basic mental health awareness work increases public mental health literacy so that everyone knows the signs and symptoms of mental health issues, how to help someone in distress, and the options for early help seeking to prevent crisis interventions. A central mission of mental health awareness is spreading the word that the best way to help those in mental distress is to use common humanity principles.

A report to the Commonwealth Secretariat[14] called for anti-stigma campaigns building on the strength of communities and taking into account socio-cultural and economic factors. The report emphasizes the importance of involving people with mental health problems and their families in campaigns to promote awareness and understanding of mental health.

MHNGO representatives discussed the different ways in which stigma impacts on people's lives, including accessing adequate help and treatment, being part of the local community, pursuing interests, employment, family relations, and many others.

"They [family members] don't know anything about mental illness, they don't know how to handle somebody in crisis, they don't know whether it's devils or some physical problem. Then the person ends up in a psychiatric hospital and it's quite rare that people in society understand how bad the conditions are or how they could be improved."

Sam Nickels, Center for Health and Human Development, USA & Association for Training and Research in Mental Health), El Salvador

These issues might also stand as major barriers not only to existing treatment and services, but also to introducing new ideas and innovations. Tackling lack of awareness and stigma within families and communities is required in order to successfully introduce improvements in mental health care.

"Lack of public interest, the failure to understand the social, economic, and political dynamics of mental health issues aside from medical understanding, deep social stigmas are major challenges/barriers to introducing innovations in mental health policy and practice."

Jagannath Lamichhane, Nepal Mental Health Foundation

MHNGOs play an important function in raising mental health awareness among the public. Campaigns are often the most effective and efficient way of achieving that goal. User and family-led MHNGOs have an especially important role as they represent the views of the group affected by the issues that are the subject of a given campaign.

"Raising awareness, providing education, and demonstrating solutions to public policy opinion and decision makers is necessary. Creating an understanding that there are healthcare and social innovations that work is important in this endeavor. Organizing the resources needed to do

this advocacy in addition to acquiring funding and delivering mental health programming is a real challenge."

Joel Corcoran, Clubhouse International, USA

Our respondents provided numerous examples of the important work their organizations undertake in order to raise mental health awareness and campaign for people's rights. More examples of mental health education and training are provided in section 3.

Example: Provision of help and advocacy in Nepal

"Koshish's mission is to unite people living with mental health problems and their families, and empower them to advocate for their rights and achieve correct awareness about mental health in their communities. Koshish uses a rights-based approach with twin track: first taking the initiative to help persons living with mental health problems, and secondly advocating for mental health issues at the national policy level.

Koshish emphasizes a community mental health program model that applies a multidisciplinary approach and advocates such an approach as the best way to provide holistic mental health services."

Example: Raising human rights awareness among those we support in South Africa

"We empower service users not to accept any abuse inflicted on them, and make them aware that there are policies and legislations that could protect their rights. Then we've also got quite a bit of focus on human rights that involves access to health care and all kinds of life opportunities, like employment and education."

Charlene Sunkel, Central Gauteng Mental Health Society, South Africa

Example: Campaigning for more resources for mental health care

"In March 2006, as part of our advocacy work, we organized the first forum on mental health at the National House of Representatives, resulting in a budget increase for mental health from 0.75 percent to 1.30 percent of the total budget of health. Mental disorders are now in the Popular Social Security Cover. The disability of mental disorders is becoming recognized. The rights for people with mental disorders and their family are getting space."

Gabriela Camara, Voz Pro Salud Mental, Mexico

Use of appropriate and non-stigmatizing language was highlighted as an important challenge. The World Network of Users and Survivors of Psychiatry (WNUSP) advocates replacing the term 'mental disorders' with 'users and survivors of psychiatry'' or, where appropriate, 'people living with psychosocial disabilities' in order to promote equality and eradicate negative attitudes[15]. A representative from the Pan African Network of Users and Survivors of Psychiatry (PANUSP) explained the reasons for using appropriate terminology:

"We do not use terms such as "mental illness/ disorders or disease" but rather refer to people that identify as living with psychosocial disabilities, users, and survivors of psychiatry. Those [terms] that identify that their impairment interacts with barriers in society such as stigma and discrimination."

In addition, one interviewee identified stigma as a major barrier to more medical students choosing to pursue psychiatry. It can be a problem for other professions, such as nursing, social work, and occupational therapy, where a shortage of committed and talented people hinders the development of improvements in mental healthcare in the community as well as through institutions. This stigma among future health professionals may be one of the factors leading to issues with specialist capacity discussed in section 1.3 below.

"You don't find a lot of people interested in getting into the mental health sector. I can always say that's related to stigma and discrimination. (...) I get to see the medical students' perceptions of psychiatry and people with mental illness. About 95% or more of them say they don't want to go into mental health sector, they don't want to do psychiatry."

Charlene Sunkel, Central Gauteng Mental Health Society, South Africa

1.3 Limited resources

MHNGO representatives talked about the difficulties their organizations have to deal with in their work. The two most prominent issues linked to resources were shortages of mental health staff and low funding for mental health.

The worldwide shortage of mental health staff has been well documented[16] and reported as a significant barrier to treating and supporting people with mental health problems. Many MHNGO representatives identified the issue of having an inadequate number of specialists as a barrier to provision of mental health care.

"The main issue for my organization is, in Indonesia, there is a very limited number of psychiatrists and psychologists. There is only about 600+ psychiatrists, it means 1 for a couple hundred thousand people. Indonesia comprises a very vast archipelago, so geographical access to health service is very difficult."

Bagus Utomo, Komunitas Peduli Skizofrenia Indonesia

This finding confirms what previous research studies reported. Key reasons for the paucity of mental health staff that have been identified include: low professional status, poor incentives for mental health professionals to live in areas of greatest need, and lack of adequate training[17].

The mental health sector not only needs specialists, but a society that can respond to those in distress. Many programs in low and middle income countries are skilling up lay people to deliver support.

They may be members of the community or others with lived experience of mental health problems who can work as peers. We describe examples of peer support work from Kenya, Uganda and Australia in section 2.3.

Fundraising was discussed as a challenge in the majority of the interviews. Some MHNGOs accept support from government, but often they depend solely on private donors, members and grants. This means that they rarely have a stable income and need to actively seek opportunities to raise funds to continue their activities.

"NGO sector should lobby for more funding from governments and the donor community to promote mental health in the community in particular in low resourced settings of which Uganda is one."

Eddie Nkurunungi, Heartsounds Uganda

The lack of sufficient funding simply means that MHNGOs cannot provide the help and services needed by the local communities they serve. Our respondents from Indonesia and Australia both emphasized the need for MHNGOs to work together and learn from each other in order to build the capacity of the individual organizations and the whole sector:

"Funding is one of our big issues. (...) Without funding we cannot respond to people's aspirations from the local groups. We already have around 10 local groups in different cities but without support and capacity building from other organizations it's very hard to move to the next step."

Bagus Utomo, Komunitas Peduli Skizofrenia Indonesia

"In Australian context there has always been a challenge about how world health organizations can speak well together, have one voice. This could be due to insufficient funding, especially compared to physical disability. Mental health is about 10 years or so behind physical disability."

Jack Heath, SANE Australia

2. The role of the MHNGO sector in developing mental health policy and achieving change

MHNGOs are an important partner in the provision of mental health care, alongside public health services. They also play a significant role, often on par with public health initiatives, in developing mental health policy and improving mental health care.

The diversity of the MHNGOs' roles means they can achieve impact in a wide array of areas, including campaigning and providing services. With the growth of user and family-led MHNGOs, there is an increasing focus on meeting the needs of people with mental health problems as defined by them and their families. This focus is often reflected in the role of MHNGOs that aim to empower and engage people and make them an equal partner in mental health care development and provision.

"NGOs are basically active to fill the gaps where the government's resources and capacity are limited to serve the population."

Jagannath Lamichhane, Nepal Mental Health Foundation

This section outlines the core activities undertaken by MHNGOs who participated in our research and provides examples of specific programs and activities undertaken by these organizations.

2.1 Delivering help and services

Many MHNGOs are also service providers delivering help and support to address problems of poverty, social disadvantage and health issues. The benefit of MHNGOs providing services is that they are often closer to communities and therefore more accessible to people who might otherwise have limited access to health and social care. Another potential advantage of MHNGOs is the opportunity to be more creative as they are not necessarily bound down by large bureaucracies. This means that they can be more flexible and adaptable to the needs of the local population.

"Our approach is to enable people to engage in some economic activities that can uplift their lives to purchase medication, food, and shelter. We consider these as underlying determinants of health in the long term, as medication is not the only intervention needed for mental health."

Kanyi Gikonyo, Users and Survivors of Psychiatry, Kenya

The role of user or family-led MHNGOs is often to facilitate active engagement of community members in all aspects of mental health, ranging from influencing policy to delivering support services. The Mental Health Action Plan[2] talks about the role of people affected by mental health problems and NGOs in providing and evaluating community services:

"Objective 2: To provide comprehensive, integrated and responsive mental health and social care services in community-based settings: *More active involvement and support of service users in the reorganization, delivery, and evaluation and monitoring of services is required so that care and treatment become more responsive to their needs. Greater collaboration with "informal" mental health providers, including families, as well as religious leaders, faith healers, traditional healers, school teachers, police officers, and local nongovernmental organizations, is also needed."* (p14)

Our respondents described examples of psychosocial support and treatment they provide to individuals with mental health problems and/or their families:

Example: Psychosocial support groups in El Salvador

"Providing an educational class to family caregivers, and that quickly expanded to a monthly support group using a local psychiatrist to help us with family home visits for families who were in crisis and eventually the families wanted something for their mentally ill family members, so we created a psychosocial group on Saturdays. In the last few years they expanded and added a very small income-generation project."

Sam Nickels, Center for Health and Human Development, USA & Association for Training and Research in Mental Health, El Salvador

Example: Best practice standards model of psychosocial rehabilitation in USA

"Working across national, cultural and economic borders we have solidified a consistent approach to delivering necessary social and economic opportunities and the on-going support to people who have experienced mental health problems.

We have developed an approach that is user empowering, cost effective and that achieves practical and measurable results. We have a well-developed method for delivering training, quality assurance/improvement and a network of support providing consultation, technical assistance, and information dissemination at little or no cost."

Joel Corcoran, Clubhouse International, USA

2.2 Peer support and the delivery of mental health services

One of the most common ways of involving lived experience in direct provision of services is through peer support. Peer support is based on the idea of reciprocal support beneficial to both those who provide it and those who receive it. Peer support groups and programs aim to provide training to people with lived experience who can help their peers with their issues[18].

MHNGOs are well placed to develop and facilitate peer support, linking people with a lived experience of mental health problems who are willing to help others in a similar situation. Below we present examples from Kenya, Uganda, and Australia.

Heartwing Clubhouse Changsha, China

Source: Clubhouse International

Example: "The Personal Helpers and Mentors" (PHAMs) service in Australia

There are thousands of PHAMs workers around Australia. They work out of mental health teams, but most people who have been recruited as PHAMs workers are actually consumers themselves, they're peer workers, and what they will do is go and visit people who are referred to PHAMs support because they need help with daily living (...). These PHAMs workers would go and visit once or twice a week perhaps and help the person to work out the program for how to connect with life again. It really helps that PHAMs workers have a mental illness themselves, they can talk about it from first-hand experience, so it's very much a peer-to-peer "Come on, mate, I know where you're at, I've been there myself".

The service:

- aims to provide increased opportunities for recovery for people whose lives are severely affected by mental illness,
- takes a strengths-based, recovery approach. and
- assists people aged 16 years and over whose ability to manage their daily activities and to live independently in the community is impacted because of a severe mental illness.

Paul Morgan, SANE Australia

Example: Peer support groups in Kenya

"One of our newest peer support groups was born out of the issue of accessibility due to the long distances that had to be covered with implication of transport costs to the County Support group. That led also to a revelation that the extra cost on bus fare also impacted their already limited purchasing power to access hospital care, some for medical review or monthly injection and refilling of prescriptions at the hospital located in the town area far from their residences. They have also engaged their local county government to bring the health services to their locality.

USP Kenya's role is to provide technical support to enable the group to become a duly registered group in the respective community. The group could propose to the hospital to arrange clinical days that take medical services for mental health conditions closer to the locality of the persons who require the service.

From a policy perspective the hospital will only consider outreach programs in the respective communities having the requisite organization or other groups of the persons to justify bringing services closer to the people. They have done that for diabetes, hypertension, and other chronic and non-communicable diseases (NCD)."

Kanyi Gikonyo, Users and Survivors of Psychiatry, Kenya

Members of the Nakuru peer support group at the Langa Langa Health Centre

Source: USP Kenya

Peer support workers from Heartsounds Uganda

Source: Heartsounds Uganda

Example: Peer Support Work in Uganda

We have successfully completed an 18-month mental health Peer Support Work pilot project in urban Kampala that we would wish to scale-up and roll out across the country if we could secure further funding for this work.

Supervision and mutual support through regularly or routinely scheduled meetings is very important to keep peer support workers focused once in the community. Debriefs amongst peer support workers before and after visits are helpful. Having to prepare and submit periodic reports to funders also helps the organization have a sense of responsibility to keep an account of the expenditure of funds received.

Eddie Nkurunungi, Heartsounds Uganda

3. Improving information sharing, awareness raising and education

Many MHNGOs we spoke to made it their mission to provide information and education about mental health to all in society. Every man, woman and child across the world is affected by mental health issues[2,5]. Education was believed to be the key way of combating mental health discrimination and improving the quality of lives of people affected by mental health problems. We were provided with examples of different and often innovative ways of achieving that goal.

"At Clubhouse International we see raising general public awareness about mental health problems as a priority. Making it as "normal" and acceptable to talk about personal experience with mental health problems as it is to discuss diabetes or cancer is critical to reversing the prejudice and discrimination on the personal and public policy level."

Joel Corcoran, Clubhouse International, USA

"The best way to attack stigma is through education and knowledge, informing that a mental disorder is an illness, it is nobody's fault and there is a chance of a better life with proper treatment."

Gabriela Camara, Voz Pro Salud, Mexico

Example: Mental health training for frontline workers in Central America

"We provide mental health training to frontline workers in other institutions who have a lot of contact with people with mental illness, such as public health clinic workers and the national civilian police force, different units around the country. Last year we were invited to do our first psychosocial support and education group for police officers with mental illness."

Sam Nickels, Center for Health and Human Development, USA & Association for Training and Research in Mental Health), El Salvador

Source: USP Kenya

Workshop aimed at building human rights awareness among persons with psychosocial disabilities in Nairobi, Kenya

Example: Using a Facebook group as a communication tool in a rural area with good Internet access, Indonesia

Indonesia is very unique, we have over 1,000 islands, so the geographical spread problem is very real. The need for mental health information is huge here, but we are lucky that we have good mobile Internet access everywhere with various brands of mobile phones. It's very helpful for us in spreading the information to the consumer. Currently we're mainly using a Facebook group as a communication tool and to organize local gatherings every few months to share experience with other families.

We have had feedback from very remote places, from people using very simple mobile phones. It's an acceleration of technology that we're very lucky to have. We have already grown so much through Facebook and social media, we have around 1,000 members spread throughout Indonesia and many islands.

Bagus Utomo, Komunitas Peduli Skizofrenia, Indonesia

4. Strengthening consumer groups and advocacy

Most MHNGOs we interviewed were led by people with mental health problems, or focused on representing their views. Empowering individuals is often achieved by MHNGOs through establishing groups led by the people affected, or their families. By bringing people together and supporting their initiatives through advocacy, their voice can be strengthened to achieve specific goals. Some MHNGOs were involved in facilitating lived experience input into mental health policy-making.

"In terms of the involvement of users and the whole recovery movement they [policy-makers] need to understand that this is a civil rights, human rights issue and that we involve people not because it's the most economically efficient thing to do but because it is the right thing to do."

Sam Nickels, Center for Health and Human Development, USA & Association for Training and Research in Mental Health), El Salvador

One respondent pointed out that 'user movement' is much better developed in high-income countries compared to countries with low income, where there is a need for more innovative approaches to involving people with mental health problems:

Example: Achieving informed and equitable service user involvement

"One [best practice] is involvement of the directly affected people and their caregivers. I know that in developed countries, user movement is much stronger than it is in low-income countries. The innovation is getting informed and equitable involvement of affected people and their caregivers. They have a mental illness, but they are also poor, have low education, all the disempowering factors in life."

Shoba Raja, Basic Need

An example of a successful advocacy movement driven by people with mental health problems was provided by a respondent from South Africa:

Example: Advocacy movement In Gauteng

"Our role is to ensure that these people affected by mental health problems have the opportunity or must have the opportunity to provide their input as part of the process in developing mental health policies.

It's been very successful because it is a completely mental health user-driven movement. They completely run the thing. It's using mental health care users in raising awareness, providing emotional support to families and persons with mental health illness. It also looks at human rights violations.

A big part is also training mental health care users on their rights as well as on their mental health condition and other conditions, so they can better understand other people as well. Treatment, because we find that the more they know about their mental health condition, the better able they are to manage it."

Charlene Sunkel, Central Gauteng Mental Health Society, South Africa

Another example of advocacy was based on a medical model equipping families of people with mental health problems with key information about the condition:

Example: Medical advocacy project "Uthama Sahaya"

"The project activity consists of education and empowerment of families who are providing care for their family members afflicted by chronic mental illness. The empowerment component known as Kshema (designed and developed by ACMI) aims at promoting supportive family environment in a one to one session with the client family.

Uthama Sahaya, has a triple component or 3Es: empowerment, enablement, and enlightenment. Ranging from illness related information to treatment and side effects, deficits and special needs; this package empowers families to endure grief or guilt with coping skills and management.

The unique feature of this package is the verbal and written information provided to the care givers about the benefits available to the disabled persons under the Persons with Disability Act 1995. Such a package is empowering in more than one way. We found that it gives them a great sense of relief relatively more than the conventional packages on psycho social education."

Nirmala Srinivansan, Action for Mental Illness (ACMI), India

"I believe the best practice is to start with medical advocacy, and empower the family carers and users with knowledge of rights and entitlements. We were pioneers in this enablement, empowerment and enlightenment community mental health approach."

Nirmala Srinivasan, Action for Mental Illness, India

5. Working in partnership

It was clear that collaboration with other partners was key to the effectiveness of MHNGOs' work. Although some organizations wanted to stay independent of government bodies, they were still impacted by the policies and initiatives undertaken by their national and local governing authorities. Working in partnership with organizations sharing similar mission and goals was described as beneficial due to shared learning and opportunities for capacity building.

"Engaging and working with the broader civil society actors can be cited as one of the best practices we are doing in Nepal. It is vital for us to work directly with the political actors of every country."

Jagannath Lamichhane, Nepal Mental Health Foundation

"The lesson we learned from the process of introducing the 'Improved Access to Psychological Therapies' program is that there is a need for effective partnerships with a high intensity provider – local National Health Service Trust – and universities – for specific qualifications."

Richard Barritt, Solent Mind, UK

Our respondent from the USA talked about the need for advocacy groups to build partnerships in order to create a collective voice and achieve changes in mental health on a global scale:

"Clubhouse International sees building partnerships amongst national and international advocacy organizations as a necessary step in influencing positive change in mental health globally. The lack of unified goals, language, and campaigns is a perpetual issue."

Joel Corcoran, Clubhouse International, USA

An example of a successful collaboration between NGOs aimed at developing communications strategies for mental health came from South Africa:

Example: International collaboration on Mental Health Care Communications

"There is the Empower Project, of the Movement for Global Mental Health. That was a partnership between mental health care user groups from Nepal, India, Kenya, and Zambia working together with mental health professionals, including Professor Vikram Patel. It was developing mental health care communications strategies for these countries to ultimately upscale mental health services. The focus was on the partnership that was created to achieve that. Various methods of communication were chosen, for example there was theatre play that was done by Zambia, two songs done by Kenya, audio visual materials, and also a documentary."

Charlene Sunkel, Central Gauteng Mental Health Society, South Africa

Another example presents a partnership between a Ghanaian MHNGO, a large agency for international development and local government:

Example: Partnership between MHNGO, US AID and local government in Ghana

"Last year we did a project in the Western Region [of Ghana]. That project was funded by US AID. The focus of the project was awareness creation of mental health and then issues about advocacy. Some of the stakeholders in that project were the District Assemblies, the local government authorities in the area. We have the traditional authorities, we have the media, we have the people from the Christian community and the Muslim community. We took them through what mental health is, the causes of mental disorders, types of mental illness and all of that and then we went on to talk about superstition; this type of notion about mental health, and then about people who are really having big problems within the communities."

Dan Taylor, MindFreedom, Ghana

Medical Advocacy in India

Source: Action for Mental Illness

6. Help required by MHNGO sector to develop further

MHNGOs identified three main areas that require support to enable them to take their work further. We summarize these below.

6.1 Need for capacity building

The capacity of the MHNGO sector, and particularly the user and family-led MHNGO sector, needs to be built to play a greater role in fashioning mental health solutions for tomorrow. Our respondents suggested that this could be achieved by learning from other organizations, sharing advice, and receiving help with innovations that work in other geographical areas. Networking was mentioned as key to enabling MHNGOs to develop.

There are existing global and regional networks that bring together NGOs with similar goals; nonetheless, many interviewees highlighted an unmet need for working in partnership with other organizations.

"There is a lot of need for capacity building and a lot of need for folks to feel that they have an important role, that they feel empowered, and they actually have some access to funding."

Sam Nickels, Center for Health and Human Development, USA & Association for Training and Research in Mental Health, El Salvador

Access to funding for the MHNGO sector is variable. We have discussed the reliance on private donors, and there are challenges of accepting resources from local or national government. Consistent funding is required for MHNGOs to develop long-term plans and continue with their work that proves to be beneficial to people affected by mental health problems.

The need for funding is closely linked to capacity building, as pointed out by our respondents from Uganda and Indonesia:

"Funding is very important, however this should be coupled or accompanied with adequate capacity building through training and exposure like international conferences and fellowships."

Eddie Nkurununngi, Heartsounds Uganda

"Funding is one of our big issues. (...) Without funding we cannot respond to people's aspirations from the local groups. We already have around 10 local groups in different cities but without support and capacity building from other organizations it's very hard to move to the next step."

Bagus Utomo, Komunitas Peduli Skizofrenia Indonesia

6.2 Developing equal partnerships

Working in partnership with other stakeholders enables MHNGOs to reach more people, share resources and improve the quality of their work. When working with other organizations, it is important for MHNGOs to be recognized as an equal partner and for their contribution to be truly valued and acknowledged.

The first objective of the Mental Health Action Plan[2] highlights the importance of the relationship with NGOs and civil society:

> **"Objective 1: To strengthen effective leadership and governance for mental health**
>
> Governance is not just about government, but extends to its relationship with nongovernmental organizations and civil society, particularly organizations of people with mental disorders and psychosocial disabilities and families and carers, can help to create more effective and accountable policies, laws, and services for mental health in a manner consistent with international and regional human rights instruments." (p11)

The need for a strong collaboration between MHNGOs was frequently brought up in the interviews. Effective networking was argued to strengthen MHNGOs' voice, influence the sector, and benefit the people affected by their work.

"Ministers change a lot and political parties change and if they can have a vision and communicate a vision to the people that they work with who are long-term within their ministries of health, that goes beyond political party divisions, then I think we have some hope of really developing strong partnerships between users and families, civil groups, professionals, researchers, and government."

Sam Nickels, Center for Health and Human Development (USA) and Partner, Association for Training and Research in Mental Health, El Salvador

6.3 Improved access to research evidence

In order to be able to identify areas for improvement, make informed decisions, and apply them in practice, MHNGOs and other actors in the mental health arena need to have access to relevant research evidence of high quality. Our respondents highlighted lack of support for research activities and collaborations as one of the key barriers to improving mental health practice. Robust evidence is also needed when applying for grants and appealing to donors as it helps to back up the need for more funding and to show where and which MHNGOs' services are effective.

Many MHNGOs get involved in research studies as they can act as a gatekeeper to their service users and often facilitate their involvement. It is important for those organizations to be informed of the findings, so that they can learn from the process and develop their practice.

Our respondent from South Africa emphasized the need to support local research into mental health, which would help in equipping MHNGOs with evidence-based arguments they could present to the government:

"I don't think mental health research is very well supported. In South Africa we often work with global statistics, so my question is what happens with the local statistics and then how can we convince the government that mental health should be a priority? (...) I think research is also very important to indicate the problem, the impact that mental health has."

Charlene Sunkel, Central Gauteng Mental Health Society, South Africa

Another respondent involved in work in El Salvador talked about the need for practice-oriented research that could be achieved by creating partnerships between researchers and those delivering help and services:

"The researchers have to be involved in understanding and interacting with folks who are doing practice. Anything that we can do to bring those two areas of expertise together to work in a partnership will drive change"

Sam Nickels, Center for Health and Human Development (USA) and Partner, Association for Training and Research in Mental Health, El Salvador

7. Recommendations from MHNGOs

We asked our respondents to make recommendations for the global mental health policy and practice. Underpinning all recommendations were concerns about human rights violations.

"Human rights must be a bridge for us to transform our life from neglect to care, discrimination to dignity and non-human to human. Global mental health should serve as a catalyst for this transformation."

Jagannath Lamichhane, Nepal Mental Health Foundation

Specific priority actions are presented to the right – all within a framework of addressing human rights violations and promoting the rights of people with mental health problems.

These recommendations are linked to the material in this report and are based on MHNGOs experience of campaigning, educating, working in partnerships, delivering services that deliver values driven improvements in mental health care. The gap in what MHNGOs would like to see delivered and the experiences of current delivery across the globe is enormous.

Priority actions

1. To eradicate discrimination and stigma.
2. To develop and implement mental health legislation in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), that promotes and protects the rights and freedoms of people with psychosocial disabilities.
3. To recognize the critical importance of early help and invest in informal community care sector to ensure that people get help early on.
4. To improve active participation and contribution of people with mental health problems and psychosocial disabilities, carers and professionals in creating communities of inclusion and care in all aspects of mental health.
5. To recognize practical as well as therapeutic and holistic support, with peer-led support regarded as an ideal.
6. To increase funding to support advocacy efforts and ensure sufficient and appropriate manpower in mental health.
7. To support MHNGOs to work together and to share experiences and information.
8. To create real partnerships in doing research on the frontline.
9. To use technology to deliver services, share information, organize, engage, and build communities.
10. To integrate mental health with public health.

Our conclusion and recommendations

There are a lot of lessons to be learned both from the information provided by the MHNGOs, and from the process of collating the report. We would like to share some of our reflections and offer recommendations from our findings.

Firstly we endorse the recommendations put forward by the MHNGOs we consulted (see page 25). These all align with the WISH mental health report framework for action[5] which outlines the importance of policy actions underpinned by respect for human rights and inclusion. In the report foreword Lord Darzi and the Chairs, Professor Vikram Patel and Dr Shekhar Saxena emphasize "mental health is perhaps one of the most neglected of all global health concerns. A major reason for this neglect has been the lack of awareness of the burden mental health conditions impose on individuals, families, and societies. The stigma attached to mental health problems, which in some instances leads to the worst human rights violations of our times, is another major barrier which stalls action. Put simply, the vast majority of people affected by mental health problems do not receive the treatment and care that we know can transform their lives".

We recommend that MHNGOs should have an active role in shaping the future of global mental health care and need to be actively engaged in work to follow-up actions emerging from WISH 2013. A mechanism to support global MHNGO engagement in policy discussions, international research programs and best practice idea sharing is required, recognizing the differences between organizations as well as their common goals, to ensure this is an inclusive process.

Our report focused specifically on the views of MHNGOs run and governed by individuals with mental health problems and/or family members across the world. We discovered that this was difficult to achieve given the small number of organizations easily identifiable as such without an in-depth knowledge of their activities. There are different models of MHNGOs and in some regions of the world there are barriers to establishing any NGO sector; that means family – and user-led NGOs or other structures. Scale of operations varied in the group of MHNGOs interviewed. We spoke to organizations with only volunteers and others with one or two staff operating in a single locality. At the other end of the spectrum are large national or multi-national MHNGOs with complex staffing and governance arrangements. Both large and small MHNGOs play an important role in influencing the national and global agenda for mental health where they are increasingly described as representing 'civil society'. We found evidence for how MHNGOs are driving forward innovations in mental health care. How they are leading values based mental health provision. But they could achieve far more if given greater recognition for their work at international, national, regional, and local policy levels.

However, there are regions with very limited MHNGO presence. In some areas those working in government and in psychiatry do not believe that MHNGOs have an important and useful role. Here, more work is needed to show the role of MHNGOs and the importance of critical voices in driving change and stimulating ideas for innovative ways of addressing gaps in mental health support and services. Partnership working is believed to be crucial in supporting the work of those organizations and many MHNGOs have proven that they have a significant role to play in these collaborations. However, they are not always easy to establish and maintain. We heard from statutory services who would like to involve MHNGO partners more but struggle to do so.

We thus recommend more work needs to be done to build recognition of the different types of MHNGOs, how they can be built, and developed as well as understanding their models of operation; information that would help to promote their work and help develop the civil society sector. Research could help here – there are very few studies building an evidence base for MHNGO best practice.

We heard from respondents about the struggles of leading an MHNGO with a fragile funding base, multiple priorities and varying levels of engagement with governments, local services and other MHNGOs. We also found that many organizations are run by committed and passionate individuals with extensive lived experience and organizational expertise. When we invited organizations to take part in the research for this report we suggested the idea of an innovation network – bringing MHNGOs together in a network to support global mental health innovations. This received mixed reactions among those already within networks, those keen to establish new connections and those unsure they had the resources to engage in a global communications platform.

We recommend that an MHNGO innovation network would be a useful structure for helping to build a strong voice for civil society. This could be built using a current platform or a new network created to achieve this specific goal. Technology is helping improve global communications and a web based platform including discussion forums, online learning modules, shared resources could provide a useful medium to set up an MHNGO network for sharing expertise, experiences, support, passion, challenges, and progress.

Access to research evidence was described by our respondents as a key factor enabling informed decision-making and providing evidence of the needs of people affected by mental health problems and the role MHNGOs in meeting those needs. Doing research often provides an opportunity for partnership working between academics, people affected by mental health problems and family members, practitioners, the local community, and other MHNGOs, and contributes to an improved understanding of the perspectives and priorities of these different groups. This understanding can in turn help come up with solutions that improve mental health services and community responses to mental health and wellbeing.

The MHNGO sector requires improved access to research evidence, country and context specific as well as programs that have been scaled across nations. Research funding for studies incorporating greater levels of lived experience in the design and delivery of research, would help in developing innovative, evidence-based solutions to the challenges faced by people affected by mental health problems and support the work of MHNGOs.

There is no consensus on the use of terminology in mental health. Different stakeholders, even those sharing the same philosophy and mission, use different terms and have clear justification for their choices. Writing a report aimed at representing the views of multiple organizations is challenging when it comes to deciding use of language. MHNGOs tend to have similar objectives to reduce human rights violations and improve the responses to people in mental health crisis, but their solutions vary particularly over the appropriateness of the medical model. However, looking beyond language and approaches, our respondents, for the most part, expressed similar concerns and reported the same underlying principles of their work based upon empowerment, human rights, and social justice.

We recommend that it would be useful to continue the conversation with MHNGOs to explore further the reasons over choice of language within an organization, how this can change over time, and how to overcome barriers presented by terminology when working on global mental health projects. This approach would also help in building partnerships across the mental health sector and beyond.

Lastly, there is a recognition of the widespread impact of mental health problems on health systems resulting in calls for prevention and treatment to be made a public health priority[5,19]. We would like to emphasise that change in mental health must be based upon principles of human rights and social justice. Many parts of the world have very limited or no systems of support for people affected by mental health problems. Human rights violations are occurring in all countries and strong action is required to improve current practices for responding to people with mental health problems.

We recommend co-ordinated global action is needed to support local communities and MHNGOs in preventing and addressing human rights violations, for example through helping individual nations in making practices that violate human rights illegal. Building MHNGO presence in regions where this voice is absent is a particularly important part of this goal. Mental health and physical health parity "no health without mental health" and the pan-disability and participation slogan "nothing about us without us" should be combined to address global mental health inequalities with those people affected – family members and people with mental health problems – in leadership roles.

MindFreedom Ghana's training workshop, one of the activities of the US AID-sponsored project in the Western Region of Ghana

Source: MindFreedom Ghana

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http://d2qq2w1ozyf295.cloudfront.net/app/media/381

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About the authors

Vanessa Pinfold is the founder and Research Director of the McPin Foundation. Set up in the UK in 2007 as a small family grant giving charity, from April 2013, the Foundation has been staffed by a team of researchers dedicated to putting lived experience at the heart of the mental health research agenda. Vanessa has written both practical resources to support innovations in mental health care and published research on stigma and discrimination, social inclusion, and information sharing with families. Most recently Vanessa has led a project mapping the personal networks of people with severe mental health problems to understand the resources people use to manage well-being. Vanessa set up the McPin Foundation to contribute to global efforts to improve the quality of mental health research undertaken in order to provide better support to people in distress. This project has provided the first opportunity to work with global partners; something Vanessa hopes she can do more of in the future.

Paulina Szymczynska currently works as a Senior Researcher at the McPin Foundation based in London on a number of different projects concerned with service user involvement and mental health issues. She also teaches on a postgraduate Dementia Studies course for health and social care professionals in Scotland. Paulina decided to pursue a career in mental health research after gaining experience as a knowledge broker in rural Scotland, where she facilitated the appropriate use of the best available research evidence in improving services for people with dementia. Prior to that project, she worked in the area of organizational psychology research in Germany. Paulina's main research interests lie in the application of patient and public involvement to public health interventions at the national and global level. She is interested in the development and implementation of innovative research methodology and lived experience to improve mental health care and well-being.

About Mind

Every year, one in four of us will experience a mental health problem.

However, hundreds of thousands of people are still struggling to get the support they need. Still unable to access the services that could change their life. Still facing prejudice and misunderstanding.

Mind believes no one should have to face a mental health problem alone. We'll listen, give you support and advice, and fight your corner. And we'll push for a better deal and respect for everyone experiencing a mental health problem. Supportive and reliable information is vital. When experiencing a mental health problem, it can change your life.

We believe in empowering individuals to understand their condition and the choices available to them. We do this through:

- The Mind Infoline which offers callers confidential help for the price of a local call
- The Mind Legal Advice Service which provides information on mental health related law to the public, service users, family members/carers, mental health professionals, and mental health advocates
- Mind award-winning publications and website, now certified by the Information Standard.

Mind provides help and support directly to those who need it most. Our network of more than 150 local Minds offer specialized support and care based on the needs of the communities they support, providing over 1,300 local services in England and Wales, helping around 300,000 people every year.

We believe everyone with a mental health problem should be able to access excellent care and services. We also believe you should be treated fairly, positively and with respect.

We campaign on a range of issues that could affect anybody with a mental health problem. This includes health services, legislation, protection of legal rights, and employment. Mind is a partner in the Time to Change campaign, the biggest-ever campaign in England to tackle stigma and discrimination around mental health.

About McPin Foundation

We are a charity dedicated to improving the quality of mental health research by increasing involvement of people with lived experience of mental health problems. Set up in 2007, the charity expanded in 2013 to create a research unit staffed by people committed to:

- developing collaborative and user-focused mental health research with individuals, families, and carers who have experience of mental health problems.
- encouraging and supporting individuals, families, and carers who have experience of mental health problems to get involved in research.
- partnering with organizations to deliver public and patient involvement in research studies.
- collaborating widely with individuals and organizations to ensure our work benefits everyone affected by mental health problems particularly delivering practical resources based upon research insights.

Why is placing the voice of lived experience at the heart of research activities important in mental health and other health research? The evidence base for our approach is developing but the case for support is strong and reflected by the requirement from most UK health research funding bodies for applicants to provide evidence of stakeholder (including lived experience) participation in the shaping of research ideas and increasingly the delivery of projects. Mental health problems impact on the lives 10 percent of the population across the world and high-quality research is required to improve treatment and support. Investment in mental health research is small compared to other health areas, in the UK spend is 5.5 percent of health research budget compared to 12 percent health burden, which makes it even more important that it is good quality. We believe:

- The best quality research and services will emerge from combining high-quality research expertise with insight developed through first-hand experience of the subject being researched.
- People who access services should have the right to help shape the research that impacts on the treatments they receive.
- An effective mental health system should be user-focused, based on knowledge and science that intrinsically includes the voices and expertise of people affected by mental health problems.
- Involving people with mental health problems and their families in research can improve the quality of research by:
    - ensuring that research addresses relevant questions, those that have the greatest impact on people's lives.
    - helping researchers engage positively and ethically with participants.
    - challenging researchers' assumptions in their study design and data interpretation.
    - making study findings accessible and engaging for a wider variety of audiences.
    - Empowering people with mental health problems to use their expertise to make a difference.
    - Challenge stigma around perceptions of the ability of those with mental health problems to engage with and help shape research

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