Welcome to the second edition of our newsletter. It has been a busy few months and we are expanding our team. People tell us they feel it is important to have a charity emphasising the importance of involving people with direct experience of mental health issues in the research process. That has been very good to hear as it is what we are all about at the McPin Foundation and we look forward to achieving far more and involving more people in our work over the next year. Having signed up to the newsletter you have shown your support for this cause and we very much appreciate that.

Our news

The McPin team have recently completed some global research involving user-led mental health non-governmental organisations (NGOs) around the world. We investigated the provision of mental health services by user-led organisations and the key challenges they face. Civil society has lots of good ideas for how to build mentally healthy communities. Change in mental health must be based on principles of human rights and social justice.

1. What was this research?

The McPin Foundation and Mind were invited to assist in the development of a global mental health policy report for WISH (World Innovation Summit for Health), which was held in Doha, Qatar in December 2013. The event was hosted by the Qatar Foundation and chaired by Professor the Lord Darzi of Denham from the Institute of Global Health Innovation at Imperial College London.

The inaugural Summit was held in London, August 2012, and brought together over 500 health leaders from over 40 countries, including many ministers, to discuss the innovations needed to meet health challenges of the future. The meeting in 2013 focused on eight themes, one of which was mental health.

We were keen to be involved in work that would make the voices of people directly affected by mental health problems heard by those considering the future of mental health support and care provision across the globe. We sought to engage with user- or family-led mental health NGOs in each continent and reach global networks and individual groups. We completed interviews with 16 representatives and collected case material on innovations from various projects.
“Mental health is a global concern whilst it still seems to be an abandoned and neglected topic, despite the detrimental effects on individuals, communities and the socio-economy of countries across all borders. The remedy lies in the unification of every role-player in life, from mental health professionals, researchers, community members to persons affected by mental health disorders – where each and every intervention approach, whether successful or not, is the basis of learning and gaining alternative approaches that can only lead to innovation, success and discovering the ‘remedies’”. Charlene Sunkel, Central Gauteng, Mental Health Society.

2. Why is this research important?

NGOs are an important part of the mental health sector driving local, national, and global change. Involving civil society in implementing changes to the way in which people with mental health problems are supported and treated has become an important objective of some of the key global health organisations.

An increasing number of mental health NGOs are user-led and make it their mission to represent the views of people affected by mental health problems. Given their proximity to the communities, they are well placed to empower individuals to defend their rights, collaborate with local stakeholders, create partnerships and use their personal experience to raise awareness and educate others.

“As a User-led and User-run NGO we hope that as consumers of mental health services our voices will be heard and our views will be considered in the planning and delivery of mental health services after all, we’re the most affected by the policies and legislation. We hope to see more inclusion and participation of the various user movements across the world to self-advocate and play their role in the multidisciplinary and intersectoral nature of mental health to create positive synergy with various professionals with greater impact especially at the community level as this is an essential package for health”. Kanyi Gikonyo, USP-Kenya.

3. What did we do?

We identified most MHNGOs using a ‘snowballing’ method by identifying potential organisations through initial informants and their networks. 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 approached 25 MHNGOs and completed interviews with 16.

We asked all interviewees about:

- The main issues their organisation was dealing with in developing mental health care
- The role of the NGO sector in developing global mental health policy in their country
- What would help the NGO sector develop further
- Examples of best practice
- Challenges and barriers to introducing innovations in mental health policy and practice
- What enables successful innovations in mental health policy and practice
- Recommendations to be communicated to the global mental health audience

4. What is the current status of the project?

We have completed the research and, together with Mind, produced a report with findings, which has received a seal of approval from Qatar Foundation.

The report focuses on innovations and best practice – sharing local or national initiatives that could be scaled up to benefit mental health provision across the globe.


We were also invited, together with some representatives from the NGOs that took part in your project, to attend the World Innovation Summit for Health:
“We attended WISH Doha 10th and 11th December 2013, as part of the mental health forum led by Professor Vikram Patel from the London School of Hygiene and Tropical Medicine and Dr Shekhar Saxena from the WHO where a comprehensive report on innovations in global mental health was launched. The McPin Foundation are really proud to be part of this forum and will be seeking to take this work forward to gain increased recognition for the vital role of NGOs in developing innovative mental health care”. Vanessa Pinfold, Research Director, McPin Foundation.

5. What next?

We are keen to progress the work presented in the report by building peer mental health research literacy to enable NGOs to drive innovation and change in mental health. We are currently working on some ideas!

6. Who do I contact for more information?

You can contact the team via contact@mcpin.org

---

Shaping McPin

Last year we asked people what they wanted us to achieve and how to do it. One recommendation was to develop a user-led work programme. That will begin this May headed by our new Public Involvement in Research Manager. We have also recruited a peer research review panel and want to create more opportunities for people to get involved.

The Peer research day report that we wrote based upon our consultation has just been finalised and outlines our approach to developing a collaborative research strategy. It’s really important that we keep engaging with people with lived experience and families and find ways to respond to what they tell us is most important to transform mental health research. We plan to hold more events later in the year to share learning from peer research and identify priorities for new mental health research studies, including developing social interventions as solutions to mental distress.

The McPin Foundation will have been a team for 12 months this April. We do not have a clear map of the road ahead but we do have ambition. A challenge in this first phase has been finding ways to work with everyone who would like to get on board with peer research. We are going to turn our attention to that in the coming months – so please be patient with us!

We have been busy and it’s rewarding for all the term working on a diverse range of projects. A few highlights in the past two months:

- We completed a 30 month study investigating community health networks of people with psychosis; work which will add to understanding of recovery in mental health emphasizing the importance of connectedness and meaning in life for wellbeing.
- We have been commissioned to work with an amazing charity called Birth Companions who provide support through childbirth and beyond to vulnerable women in London; we will be evaluating their community links programme.
- We have been busy collecting research data in schools for the Time to Change programme; working with young people to help us design our survey data collection tools.
- We have been working hard to recruit women to interview for our peer-led study on pregnancy and medication; we still need more people to interview.

The shaping of any organisation is an on-going process and in our case involves trustees, staff, volunteers and our large group of peer researchers – we work with over 50 service user and carer researchers currently. Partners and collaborators are crucial – the mental health sector is built on strong partnerships and we are always looking to forge new relationships to co-produce impactful mental health research that can directly impact on people’s lives – for the better. If you know of anyone you feel we should be talking to – do let us know.
Research in the news

There’s been coverage recently about academic students and mental health problems; a series of blog posts were published by the Guardian newspaper. We thought this looked interesting and asked our Research Manager Sarah Hamilton who has just completed her PhD to take a closer look.

The McPin Foundation’s vision is to ‘transform mental health research’ to ensure that lived experience is at the heart of all research affecting people with mental health problems. This means making research accessible at lots of different levels to allow people with different interests and skills to have their contribution valued in research. One important aspect of this is that people with personal experience of mental health problems who have the interest and ability also have the opportunity to work in academic research at universities, whether as students or researchers.

Universities are the main sites of research activity in the UK. Transforming mental health research must, therefore, focus on the practice and accessibility of research work in universities. However, a recent series of blogs in the Guardian have highlighted how poorly some universities are supporting PhD students’ to manage their mental health and the serious impact that can have for the students involved [http://www.theguardian.com/higher-education-network/2014/mar/06/mental-health-academics-growing-problem-pressure-university].

Working and studying in universities can be extremely stressful, as I know from experience. I have recently completed my PhD and know very well the danger of becoming isolated from others, the pressure of not knowing whether your work is good enough and whether you will be able to complete it, and the constant, nagging feeling that you should be doing more which makes quality relaxation time hard to find. But I was lucky; I had fantastic supervisors and doing my PhD part-time meant that I had regular contact with other people and ways to escape from the all-consuming nature of a PhD. For some people, the pressures of doing a PhD, and of working in an academic environment for the first time can be unbearable.

There is evidence that the incidence of suicide among students has risen in recent years. [1] In 2011, the Royal College of Psychiatrists published a report which argued that universities needed to expand their provision for supporting students’ mental health, and called for research into why more students didn’t take up opportunities for support. [2]

For those who go on to conduct research in academia, many continue to experience considerable stresses to their mental health and wellbeing. A survey of people working in academia [3], published in July 2013, found that two-thirds of respondents were working more than 50 hours a week, and one-third often or always experienced stress at levels they found unacceptable. At the same time, universities have not been adequately supportive of mental-wellbeing for those who work in them. The same survey found that 44% seldom or never received support through emotionally challenging work. Low job security, long hours, high work pressures and isolation all make academia a difficult place for people to manage their mental health. It should not be surprising, then, if people with an existing diagnosis or experience of mental health problems do not feel that this is a good environment for them.

This can have real consequences for involving people with mental health problems in research, from access to research training through academic study, to working as professional researchers in universities, and even for service user researchers getting involved academic-led work. The culture and expectations of academic research – whether supportive or stressful – can impact on all those who come into contact with it.

Despite this, thankfully, an increasing number of people with personal experience of mental illness are choosing to work and study in academia and to use their experiences in their research. At a recent Mental Health Research Network conference in Liverpool, two service user researchers who had undertaken PhDs and research roles in universities gave excellent presentations about their experiences and the challenges and benefits for them of doing post-graduate research. They demonstrated the potential for universities to be supportive and to demonstrate that they value their work.
There are, of course, places where well-being is taken seriously and support is in place to help students and staff. Pastoral care and wellbeing training is made available in many places. Specific programmes and organisations like Students Against Depression [http://studentsagainstdepression.org/] and StudentMinds [http://www.studentminds.org.uk/] offer support and information for people who may be struggling.

However, in many cases universities have to take this responsibility more seriously to ensure that they are not unfairly excluding people with mental health problems. Our Viewpoint survey [http://mcpin.org/our-work/current-research/viewpoint-survey/] found that in 2011, approximately 1 in 10 people had experienced discrimination in education. [4] Last year, when we asked participants to tell us more about their experiences, we heard examples of undergraduates and post-graduates becoming unwell and having to abandon their study because universities did not provide the support and flexibility that they needed to complete them. The Guardian series shows that the consequences of poor support can be even more severe for the health of PhD students [http://www.theguardian.com/higher-education-network/blog/2014/mar/01/mental-health-issue-phd-research-university].

The writers in the Guardian pieces call on universities to improve their support for staff and student wellbeing, for the sake of all those who work in academia. As service users are increasingly valued for their contribution to research, universities also need to reflect on whether the environment they provide is supportive and inclusive or whether it is discouraging or even preventing access by people with mental health problems.

This is an area of particular interest to the McPin Foundation. We would like to see more research into ways of supporting student mental health at university, both undergraduate and postgraduate levels, including self-management and peer support as well as through formal mental health services.

If you have experience of managing mental health as a student or working in academia, or if you have considered further study and are concerned about how you would manage this, we’d love to hear from you.

[4] Corker et al

Hot off the press

Research publications are one way of ensuring the work teams do can be disseminated so that others learn from their findings. This month we had a paper published from our Viewpoint Study. We have identified seven types of discrimination experienced by people with mental health problems. You can access the abstract here or contact us for a full copy of the article.
Opportunities

The McPin Foundation is taking part in Ride London on Sunday 10th August 2014, a race from following the Olympic course through London and Surrey. We have two places that need riders and we’d love you to join us and raise money for mental health research! If you are a keen cyclist – the route is 100 miles - and fancy getting involved

Cycling is great for your health and wellbeing - and on Sunday 10th August 2014 a team of cyclists will be riding for mental health research. We have 3 charity places in the race. We would love you to join us. We are a small family foundation with big ambitions. Help us make a difference by raising vital funds for an issue that affects us all. We put people with mental health problems and their families at the heart of research to ensure it’s focused on the issues that really matter to people. Raise funds to help us support people with mental health problems back into work. Raise funds to help us tackle the stigma of mental illness – so people are not afraid to seek help because of what others will say about them or how they will behave towards them. Raise funds to evaluate the impact of new ideas and solutions to help keep people well – we need better treatments and support for mental health.

Ride for us and we will:

- Provide you with a training pack – helping you to achieve the 100 mile cycle with ease.
- Help you with your fundraising
- Give you plenty of morale support – and a t-shirt!

If you are interested please contact us contact@mcpin.org or call 0207 9227877

Thank you

We would like to thank everyone who has supported us this year – our volunteers, our partners and everyone who has been in touch. We’ve been going a year and all your support has been vital in building our foundations. We’ve got big plans and our voice will only grow stronger and louder through the support of everyone interested in mental health and mental health research.