Transforming mental health research

T: 020 7922 7877   E: contact@mcpin.org   www.mcpin.org

Welcome to the fourth edition of our newsletter. This is a busy time of year for everyone and at the McPin Foundation we are planning our first communications campaign to raise awareness of our work and more importantly the central place of mental health in our society. It will be a twitter based campaign so if you use that platform and don't currently follow us, do sign up: @mcpinfoundation. In our newsletter we have an article about genetics research, an introduction to a new report from the British Psychological Society on understanding schizophrenia and psychosis as well as a review of new projects and introduction to new staff. We would also like to wish everyone "Seasons Greetings and our best wishes for 2015".

Our news

The **Alliance of Mental Health Research Funders**, chaired by the McPin Foundation, launched its own web site in October and has produced a **manifesto** calling all political parties to pledge support for mental health research. This is an important coalition of mental health charities, 13 in all, that come together to support the shared goal of improving mental health research. Why? As one carer, Gill Grimshaw, told us: "I cannot make my son better but boosting mental health research would give us both some hope for the future. My son has had severe mental health problems for over ten years and spends several months in hospital most years. We can see that his disease impacts on his physical as well as his mental health. We can also see how much it costs to treat his disease. Since he became ill we have met so many people who have been pushed to the margins of society by mental ill health, trapped at home unable to be economically active, ending up in the criminal justice system or on the streets. Not only are the services my son uses under-resourced but precious little new knowledge and data is being developed

to help us understand how money could be best spent on him. How soon can I expect priority to be given to mental health research?"

We have identified three priorities and call on all political parties to:

- Champion mental health research funding, influencing other funders and leading the way to combating mental health stigma that impacts not only on understanding of mental ill-health but the funding of research that can provide breakthroughs to transform people's lives and enhance wellbeing.
- Remove blockages to mental health research. We cannot improve mental health and wellbeing without better quality data and information, improved coordination of data sharing between government departments and more mental health knowledge among the wider public service workforce.
- Give priority to research that will make the biggest difference to people's lives including research into children's mental health, prevention and promotion of mental wellbeing and the links between mental and physical health. Setting research priorities should begin with the knowledge and experience of people with mental health problems

So what are the McPin Foundation doing to progress this agenda? We are delivering some research studies which will add to the evidence base on why lived experience perspectives are important in mental health research and how to work in this way. We are engaged in a new project making use of a research study on wellbeing networks to inform commissioning of a new service model for people with psychosis. We are part of a steering group looking at improving data capture and data use to support the commissioning of public health programmes as well as mental health services. And we are keen to develop new projects building on the children and young people studies that we will complete in 2015. There is much to do, and we look forward to working with members of the Alliance to create a greater presence for mental health research in health and social care policy circles.

Shaping McPin

Over the last three months the McPin Foundation has been very busy developing new projects and welcoming new team members on board. Back in the summer, we said goodbye to Paulina, one of our senior researchers, as she went on to start a PhD at Queen Mary's University. We will also be saying goodbye to Jessica in December, as she also goes off to start a PhD, this time at the University of Sussex. However, we are pleased to welcome three new members to the team: Agnes, Karen and Laura. You can find out more about them on our **website**.

As well as new team members, we have taken on a number of new projects which provide some exciting new opportunities for us. In October we started working with **My Support Broker** to evaluate their work providing peer brokerage and support to people with various social care needs. The importance they place on peer-to-peer working fits closely with our own commitment to peer involvement in research. We have brought on a new peer researcher who will be leading this work and bringing her own experience to the research.

We have also been commissioned to carry out a service user-focused evaluation of six demonstration sites delivering Improving Access to Psychological Therapy (IAPT) for people with schizophrenia, bipolar disorder and borderline personality disorder. This work will form part of the overall evaluation of IAPT for people with severe mental illness, providing a specific focus on the experience of using the service. Again, the research will be led by three peer researchers.

Over the next six months we will be building on the work we carried out in the **Community Health Networks study** and working with one site in West London to see how this work can be used directly as part of the support offered to people in mental health services. We hope to use this as an opportunity to do more work in this important area in the future.

We will be working with the **Centre for Mental Health** and with two employment support providers to evaluate a new approach to supporting people with schizophrenia, bi-polar and other severe mental health diagnoses, to get into employment. The project aims to support 100 people into a job that is suitable for them. We will be speaking to the people who go through this programme to understand whether this approach works for them, and how it can be improved. This project addresses a number of issues that we know are important to so many people living with a mental health diagnosis, including ensuring that people get the best possible support through Job Centre Plus and other employment support organisations, reducing stigma among employers, and finding suitable, supportive work that has a positive effect on people's health and wellbeing.

And finally, we have been commissioned to evaluate a large programme run by Kent County Council to improve the mental wellbeing of the public. This is a chance to extend our work to look at how wellbeing, and preventing the need for intensive mental health support, can be achieved through public health programmes. The work draws on the **Wheel of Wellbeing**, which suggests six ways to improve mental wellbeing – connect, stay active, keep learning, take notice, give and care for the planet.

So, it's an exciting time for research at the McPin Foundation. The new projects give us some exciting opportunities to address issues that we believe are important to improving the lives of people with living with mental health problems, as well as to work closely with peer researchers to improve practice.If you would like to know more about any of these projects, or would be interested in any opportunities to get involved, please email **contact@mcpin.org**. And keep an eye on our website for updates on progress.

Research in the news

To say that schizophrenia is a controversial diagnosis would be putting it mildly. Almost everything relating to schizophrenia has been contested, often ferociously. Putting that to one side, there is a lot of research into schizophrenia particularly to understand causation and treatments. We have known for a while that there is some evidence that schizophrenia **runs in families**. We have just got a bit closer to perhaps finding out why. In July 2014 the results of some research led by researchers at the University of Cardiff was published in the journal **Nature**. The research is part of a larger programme of work being carried out by the Psychiatric Genome Consortium.

The research was reported on in most of the daily newspapers such as the Independent ('DNA hope on schizophrenia: Research breakthrough points at over 100 genes'). The paper got quite a bit of attention in the news too with the **BBC** reporting on it as well as other broadcasters over the world.

So what was so exciting? Well the paper looked at the DNA of 37,000 people with schizophrenia in 35 different countries. These people's DNA was then compared to 110,000 people who did not have schizophrenia. The researchers found around 108 'points' across around 80 genes where there were significant differences.

In the world of psychiatric genetics this is a breakthrough -check out this **chart**. The 2014 study means that we now know of five times the number of genetic differences between people who do and do not have schizophrenia

compared with 2013. To find out more about what exactly a gene is please click **here**. If you would like to find out more about the actual study then please, please, (I beg you!) read this great **summary** of the paper on the NHS Choices website.

Aside from this it is important to note that all human beings pretty much have the same set of around 24,000 genes. There are some **differences** between men and women but these not large. So if we all pretty much have the same genes how come we all look so different? Good question. It's complicated. It's partly genetics and partly the environment. Genes come in lots of varieties. It's a bit like hair colours. Within any one colour there are thousands of different shades. And so it is with genes. There are many different versions of the same gene. This is why one person may be blonde but another brunette.

The environment obviously plays a big part too. If you grow up in the vicinity of a nuclear disaster zone without much food then you are likely to turn out a bit differently to someone raised in a very unpolluted and affluent area.

When scientists speak of finding a 'new' gene for something (say schizophrenia) they do not usually mean that they have discovered an entirely new gene. Usually they mean that they have discovered a particular **version** of a gene that has identified as having a role to play in something. In this context the bottom line is that the researchers from the consortium led by Cardiff University have found around eighty particular versions of genes that are more commonly found in people with schizophrenia. There is no such thing as a "gene for X, Y, or Z" as we all pretty much have the same set of genes. What is actually often meant is that "if you have this particular version of a gene then it may increase your likelihood of having X, Y or Z".

But why is this research important? Well nobody is claiming that this research is going to lead to a better way of helping people with schizophrenia anytime soon. But finding differences between someone with a health condition and those that don't is very often the first step towards developing new ways of managing and treating people.

Take breast cancer as an example. Two **genes** have been discovered called BRACA1 and BRACA2. If you have these genes you are at a higher risk of developing breast cancer compared with the general population. Once these genes were discovered, a way of testing if people had them was quickly found. Testing people for these two genes together with other advances has meant that survival rates for people with breast cancer have **improved significantly**.

There are significant ethical issues that arise from genetic research. Could people who test positive for genes that might cause disease be discriminated against? Could people refuse to employ you based on your genes? What do you do if you want to have a family? There are so many ethical issues that arise from the genetics of mental health conditions. If you would like to know more please do read this 1998 **report** from the Nuffield Foundation.

There are other problems too. Genetics is **massively** complicated. Even if you do test positive for a disease linked gene, all it does is increase the chance that you might get the illness. In fact there is only one condition (**Huntingdon's disease**) where if you test positive for the gene you will get the disease. It's a numbers game. Genetic testing only tells you something about your 'risk' of developing an illness or disease. Aside from this it's clear that genetics is not the whole answer. What happens to you in your life also has a big effect. Needless to say this is particularly the case in mental health.

The genetics of mental health is not well understood. In fact we are probably behind many other areas of health here. This could be for two reasons. 1. Mental health problems don't have a strong genetic component. 2. Not enough research has been done into the genetics of mental health. Things are changing though and the Nature paper should be welcomed.

What is a bit worrying is the lack of lived experience in genetic research. From what I have seen, service user and carer involvement in mental health genetics is relatively underdeveloped. I wouldn't say that there is **no** involvement in research into the genetics of mental health, I just don't see very much. And given the complexity of

genetics research and the issues that it raises, we probably need quite a bit more service user and carer involvement not less.

A number of articles were published about the research in the July 24th 2014 edition of Nature to accompany the research paper itself. Whilst one of the articles did include a very brief account of someone who had schizophrenia there was little direct focus on who's surely most important here: people with schizophrenia. To their credit, the following week Nature published an **article** entitled 'cause is not everything in mental health', by someone with lived experience of mental illness in response to the research published in the July 24th edition.

On the other hand there is no lack of goodwill or of people trying to explain what genetic research means. In fact there are some wonderful and innovative resources available (for example: **http://www.geneticseducation.nhs.uk/**)

But history teaches us that we that we need to be very careful. For example, there have been suggestions in the past that people with 'undesirable or defective' traits should be sterilised to prevent them from passing these on to future generations. A whole field of study developed around this called **eugenics**. And we aren't simply talking about the Nazi's here. Winston Churchill was in favour of "the confinement, segregation, and sterilization of a class of persons contemporarily described as the "feeble minded." . If you don't believe me click **here**

There is massive scope for the findings of genetics research to be badly communicated. Both geneticists and the press have probably been guilty of this in the past. The results of the ensuing misunderstandings can be severe. There are certainly people who have made bad choices or decided not to have children based on newspaper headlines or a false interpretation of genetic tests. Many of these issues have been tackled admirably in areas of health, such as cancer, but not so much in mental health. We would do well to actively involve people with lived experience of mental illness very early on in genetic research studies to proactively work through all of the issues that I have raised in this article, and more. Indeed a **report** from INVOLVE shows that "public involvement throughout a study can help to make research more ethical".

Doing this would ensure that we have some worked out solutions and approaches to the particular issues that genetics research into mental health raises. Who could be better placed to help develop these solutions and approaches than people with actual lived experience of mental illness?

Many abuses in medical research have happened when things are 'done to' rather than 'done with' people. I would never ever want to imply or suggest that the researchers from the Psychiatric Genome Consortium have done anything wrong -far from it, but we need more involvement of people with lived experience of mental illness involved in genetic research and we need it soon.

I don't want to end on a downbeat note. We need to understand mental illness better. The paper published in Nature potentially brings us one step closer to understanding what part genetics plays in schizophrenia. To all the researchers of the Psychiatric Genome Consortium I say 'thank you'!

Dr Thomas Kabir – Public Involvement in Research manager.

Further resources
To listen to a great Naked Genetics podcast on recent advances in psychiatric genetics please click **here**.
http://www.thenakedscientists.com/HTML/podcasts/genetics
OMIM (**www.omim.org**). OMIM is a database of all genes known to play a part in any illness or disease. To have a look at a full lust of genes sorted by illness or disease click **here**.
'Mental health: Depression needs large human-genetics' studies by Steven Hyman. Nature, November 2014. Volume 515 p189-191. Please click **here** to read the full article.
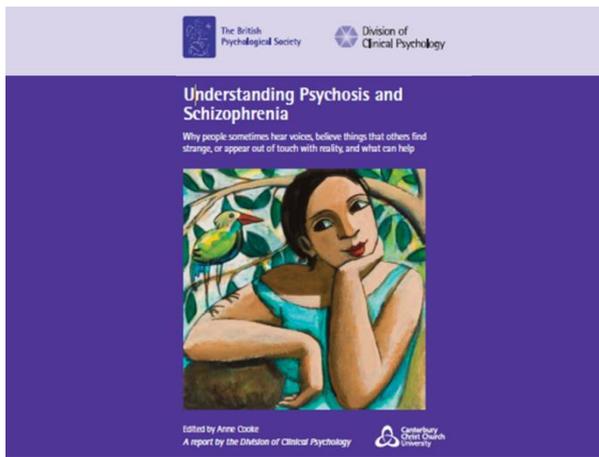
Hot off the press

The end of November saw the launch of a **new report** by the, **British Psychology Society** (BPS) with the aim of challenging stereotypes of schizophrenia and psychosis. This is 14 years on from the publication of the first edition "Recent Advances in Understanding Mental Illness and Psychotic Experiences" which was a really useful overview emphasising the contribution of a psychological perspective to making sense of 'serious mental illness'. In that time the National Institute for Health and care Excellence (NICE) guidelines have introduced recommendations that everyone experiencing distressing psychosis be offered talking based treatments – real progress indeed even if not everyone receives them. It is really worth a read, although at 176 pages you might need to choose which sections to dive into first. Unsurprisingly, the emphasis in the report is exploring the role of psychology in understanding and responding to distress but the authors do this by stressing that their aim is to look at both the psychological and the social aspects of recovery. We need more recognition of social aspects of everyday living for managing mental health so I welcome this emphasis.

At the beginning of the report the authors address the importance of language.

"Throughout this report we have attempted to use terms which are as neutral as possible, and which do not imply that there is only one correct way of understanding these experiences".

Language, for me personally, is the first challenge when working in mental health attempting to write in a person centred, recovery focussed framework that is sensitive to how one describes people's experiences of distress. Individuals choose their own language, but how does the author of a research report generalise? The full title of the report is: Understanding psychosis and schizophrenia - things that others find strange, or appear out of touch with reality, and what can help. I note with interest that the title of the new report is hedging its bets including a diagnostic label and non-judgemental descriptions.

The report uses case studies from a wide variety of contributors to take the reader through a detailed landscape of lived experience expertise, research insights and clinical work. In conclusion, the report emphasises what I heard psychiatrists also talk about at a conference in London recently – that globally our actions must focus on prevention by taking measures to reduce abuse, deprivation and inequality. These are massive tasks, involving cross sector working well beyond health, but central to the goal of improving the mental health of everyone in communities across the world.

Linked to another article in this newsletter the BPS report summarises what we can learn from genetics. Our conclusions are similar – genetics plays a part but it is absolutely clear that it is not the whole answer. Leaping forward in the report to what mental health services need to do differently I found myself nodding at the computer screen in agreement as I read the report. The authors say:

- Fundamental changes are required in how we plan, commission and organise mental health services.
- The starting point in services should be an acknowledgement that mental health is a contested area and there is no one framework to understand it – finding the framework that helps the individual in front of you understand and make sense of their experiences and manage their distress is the key.
- Practitioner's roles need to shift from delivering treatment to using their professional skills gained through education, training and clinical experience to offer help and support so that individuals can better manage their problems.
- Service structures need to allow practitioners to offer flexible support – not a standardised "package of care".

At the McPin Foundation we are just about to get involved in a co-production service design process within a Clinical Commissioning Group (CCG) to support the development of an innovative new model of care for people with psychosis based in primary care. We hope it will deliver all of the above – watch this space! However, achieving this in practice will require lots of organisations and stakeholders applying pressure to "systems" and the creation of a driving wind of innovation because the default position is usual practice. The BPS report does not end on a pessimistic note. It's up beat and inspiring focused upon prevention - safety, equality, non-discriminatory and oppressive practices, reducing harmful drug use and protecting our mental health. You can access a full copy **here**.

Reviewed by Vanessa Pinfold, Research Director.

Opportunities

We have a **crisis care concordat survey** that needs your response by 6th December 2014. Please do pass on the link to others who may have experiences to share. It can be filled out by people who have sought help in a crisis or mental health carers who have been involved in the process. ENRICH is a new research programme on peer support based at St George's University of London advertising two posts for a programme manager and peer research – but the **deadline** is 30th November so please apply quickly! Finally we have places for a charity bike ride on 2nd August next year. New year resolution - **ride for mental health**?

Thank you

We want to say a big thank you firstly to staff leaving us in December and also to all our volunteers who have helped this year. We organised our first fundraising challenges in 2014 and thank you to everyone who participated and donated; we raised over £4000 for mental health research which we are putting to good use resourcing peer researcher input into projects. Sarah walked 100km in just over 23 hours for the **Thames Walking Challenge** and there are 100km challenges in different parts of Britain in 2015 which you can sign up for and support any charity of your choice. Talking of fundraising, if you shop online you can support us, or any other charity, at no cost to yourself through **easyfundraising**. Give it a try! Finally as 2014 draws to a close – we wish all of you very best wishes for December and we look forward to sharing more of our updates in 2015.

Follow us on twitter
@mcpinfoundation – and look out for
our new campaign in December!