December 2015

Transforming mental health research

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Welcome to our last newsletter of 2015. We end the year in anticipation of the NHS England commissioned **Mental Health Taskforce report** which will spell out the five year forward plan for our sector, including recommendations for mental health research. In the last few months we have hosted an **event to talk about the role of the RCT** (randomised controlled trial) in mental health research, started a new oral history project on psychosis, recruited our **first ever marathon runner** and joined the Personality Disorder commission chaired by Norman Lamb MP. We are busy – yes. We are looking forward to 2016 – definitely. **Thank you** for all your support and we wish everyone a restful and peaceful festive season.

Our news

Earlier this year, we completed the first phase of our evaluation of **Kent County Council's Mental Wellbeing Programme.** This involved developing a series of concept maps which was a new approach for us but is becoming more common in evaluation studies. We asked Ivan Rudd, Public Health Specialist at Kent County Council, to tell us a

bit more about the programme and why evaluation is central to its success.

One of our evaluation studies – The Kent Wellbeing Programme Evaluation – has been developing concept maps, also known as a Theory of Change approach to evaluation that New Philanthropy Capital describe well. Concept maps have been produced for the Kent County Council Public Health's Mental Wellbeing Programme, consisting of eight wellbeing interventions.

You can read the summary report from September here, or our full report which was published in April.

We also asked the commissioner in Kent – Ivan Rudd – to provide feedback on our reports, and to explain how they will be used in planning further work. Ivan agreed to write his own blog for us:

Ivan Rudd, Public Health Specialist at Kent County Council

We (Kent County Council Public Health) commissioned The McPin Foundation to evaluate our Kent Mental Health and Wellbeing programme. The first phase of the evaluation has involved developing a Theory of Change summary and interim report, which are now available. We welcome McPin's insight and support, and look forward to their final report on the programme in March 2016.

The cost of mental illness and the benefits of prevention are high, and our business model has piloted interventions that seek to raise self-esteem and strengthen individuals' coping skills as well as emotional resilience. Working with partners across Kent, we aim to grow positive mental health, which will also support good physical health, as well as better outcomes in educational performance, employability and earnings. These are all areas that are foundations for improved wellbeing.

Our programme includes interventions for building emotional resilience as well as raising mental health awareness – both at individual and community level. We are committed to working with communities through co-production with all our partners to improve health and reduce health inequalities. We can achieve this by mapping and developing the assets and strengths that exist in our communities and commissioning wisely with their strengths in mind. This is well articulated in both NICE guidance and in Public Health England's Community-centred approaches for health and wellbeing report.

We needed an evaluation partner, and the commission of McPin is helping us understand further the impact of our community-centred approaches such as the Kent Sheds programme and the Primary Care Link Worker Service. We believe mental health and wellbeing are priorities for good health and we want to evidence this and learn how best to achieve our strategic public health goals. McPin's service user focused evaluation provides insight and information to guide our planning and commissioning decisions. We know that while many citizens already make a contribution to community health, more could be done to realise the full potential of communities to address common health inequalities. We are building on the existing range of practical, evidence-based approaches that are used by local leaders, commissioners and service providers in Kent to work with our communities. The concept maps McPin have produced offer a valuable, visually accessible, resource to support our logic modelling. We welcome feedback on these reports from other councils and stakeholders working to deliver changes for their local populations.

Research in the news

In recent months, the mental health of children and young people has hit the headlines. It is well established that most mental health problems begin during adolescence, with [1 in 10] young people (aged 11-16) thought to experience a diagnosable mental health problem. Such problems have profound effects on young people's social development and educational attainment – effects that often extend into adulthood. In this respect, mental health problems during these crucial years are a major public health issue. So, whilst growing concern for the mental health of our future generations has seen renewed political commitment to [challenging stigma] and improving services, what does it mean for research in this area?

The official national data we have on children and young people's mental health is now over ten years old; a point made by the House of Commons Health Committee in its 2014 [report] into children and adolescent mental health services. The first national child and adolescent mental health survey was conducted in 1999[1] and was repeated in 2004[2]. A follow-up survey in 2007 found the prevalence was stable at 10%[3]. These surveys had robust methodologies and collected data from large, community based samples. In this respect, they are reliable indicators of prevalence at the local level. However, a lot has happened since 2004. How can we reliably commission services on this basis? There have been notable social and economic changes in the intervening years that may have a marked impact on the prevalence of mental health problems among young people. For instance, we do not know how economic [recession] and prolonged austerity, or the explosion in the use of [social media and digital technologies], has impacted on children and young people's mental health. Though we can speculate.

It was encouraging therefore that in a recent [speech], Alistair Burt, Minister for Community and Social Care, announced that with the Health and Social Care Information Centre, the government are commissioning the first national survey of child and young people's mental health since 2004. The survey, conducted by a consortium of NatCen and the Office for National Statistics, will be much wider in scope than in previous years – involving up to 10,000 young people aged between 2-19 years old, their families, carers, and teachers. It will also examine some of the issues linked to mental ill health, like [bullying] and other social pressures. This data will allow us to estimate how many children and young people in the population are currently living with a mental disorder. It is also hoped it will allow us to improve community based services, so that young people are helped earlier, and are therefore less likely to need to go into hospital.

So, arguably, better data is a positive first step. But does it go far enough? Large cohort studies are extremely important in improving our understanding of the epidemiology of mental health problems in children and young people. We need to know a lot more about why people develop mental health problems,

and the resources in people's lives that can help and hinder good mental health. However, if we are missing important data – or particularly groups are underrepresented – we may not have the full picture. Here we need to understand the social factors involved; we need to ensure the active involvement of young people and their communities, to ensure that data is representative and serves the population it aims to. We must engage communities in the design, delivery and dissemination of mental health research, in order to gather representative data on the most important factors. Increasingly, the voice of young people themselves is being recognised in these conversations. The Clinical Research Network Young People's Mental Health Advisory Group, for example, have been supporting academics to develop new studies over the past few years, and lobbying for change at a national level to improve mental health research. Likewise, earlier this month the Youth Select Committee, part of the British Youth Council, published its report on 'Young People's Mental Health' today, with recommendations across three key areas: funding and the state of service, the role of education; awareness, stigma and digital culture. This inquiry came in response to more than 90,540 young people voting specifically for mental health services as their number one issue of concern in the 2014 UK-wide 'Make Your Mark' ballot.

So, how is McPin involved in exploring these issues? The public involvement team is currently supporting the development of an exciting new research study, led by researchers from the Society and Mental Health Research Group at King's College London. The five-year REACH(Resilience, Ethnicity and AdolesCent Mental) study, funded by the European Union, will look at risk and resilience factors among young people. The REACH study is being conducted in schools in South London, and over 2,700 young people aged 11-14 will be invited to take part. The study will use questionnaires to tracks cohorts of young people, in terms of both their positive and negative life experiences, over a four-year period. It is hoped that REACH will help us to understand the best ways to promote good mental health in young people from a range of backgrounds. Cohort studies like REACH can collect data sets which when combined with other information are extremely helpful in taking our knowledge forward. This knowledge can help us in shaping innovations to improve responses to distress in a range of settings, from mental health services to schools and the community, and in identifying preventative strategies. To date, we have been consulting with young people aged 11-25 to help develop the study protocol and materials. This preliminary work will support the development of a stakeholder engagement programme to underpin the study, involving young people, parents and local communities. The stakeholder engagement programme aspires to leave its mark locally, using the research study as a community development project to leave a legacy of positive involvement in research and engagement with research experiences, as well as increasing awareness of mental health.

So what next for children and young people's mental health? It is clear that young people are best placed to understand the issues that affect their mental wellbeing: bullying, exam stress, relationships, issues of unemployment, and more recently, the impact of social media. Community development approaches may have a key role to play in sustaining this dialogue. Large cohort studies involving children and young people are important, but they need to be part of a wider conversation. Only a collaborative approach, with young people, teachers, parents, mental health professionals, community groups and the government working together can this progress be maintained. So while it is clear that children and young people's mental health is now on the agenda, we still have a lot to learn.

[1] *Meltzer, H. et al. (2000)* [The mental health of children and young people in Great Britain](#). *London: The Stationery Office.*

[2] *Green, H.,* et al. *(2005).* [Mental Health of Children and Young people in Great Britain 2004](#). *London: Palgrave.*

[3] *Parry-Langdon, N. (eds) (2008)* [Three years on: survey of the development and emotional well-being of children and young people](#). *London: Office for National Statistics.*

Hot off the press

How to reduce mental health related stigma and discrimination? This is topic that we have been doing research on for several years, most recently working in schools to evaluate the [Time to Change](#) children and young people pilot campaign. Time to Change have just released the next phase of their campaign targeting young people and parents in particular, building on the message ['small things can make a big difference'](#). The latest campaign message is ['be ready to talk about mental health with your family'](#). You can sign up at www.time-tochange.org.uk to get alerts and news of forthcoming activities. Much of the campaign puts people with lived experience centre stage, delivering the message and leading programmes to end discrimination. This is an approach that is very much at the heart of the way we work at the McPin Foundation; working directly with people experiencing mental health problems, their families and friends to improve mental health research. Lots has been written about this approach, also known as 'social contact', in the world of stigma research. In 2005 the New Zealand 'Like Minds, Like Mine' programme defined key conditions for effective change in their report entitled ['the power of social contact'](#):

- Equal status
- The opportunity for individuals to get to know each other
- Information which challenges negative stereotypes
- Active co-operation
- Pursuit of a mutual goal

Broadly, social contact is an approach that underpins anti-stigma and discrimination programmes across the world from Canada to South Africa and India. It has seen the development of programmes to help people ['come out loud and proud'](#) which Prof Pat Corrigan speaks about and anyone interested you can hear him talk in [Manchester on 3rd and 4th March 2016](#). It has seen research studies evaluate the impact of social contact interventions with school children, police officers, medical school students and the general public. It is an approach that has contributed to books such as "Shunned: Discrimination against people with mental illness" by Professor Graham Thornicroft.

So, when a systematic review was published in the November edition of British Journal of Psychiatry by a group we know well at the IOPPN (Institute of Psychiatry, Psychology and Neuroscience), on 'how to reduce mental health related stigma and discrimination?' we were very interested. The review had two aims:

- Synthesise evidence of what is known globally in relation to effectiveness in medium and long term outcomes for interventions addressing mental-ill based stigma and discrimination.
- Synthesise evidence of what is known globally abut interventions delivered in low and middle income countries.

The report authors led by Nisha Mehta provided a summary of their findings and conclusion:

Eighty studies (total number of participants = 422 653) were included in the review. For studies with medium or long-term follow-up those containing social contact (direct or indirect) were not more effective than those without. No studies from low income countries were found.

They concluded: there is modest evidence for the effectiveness of anti-stigma interventions beyond 4 weeks follow-up in terms of increasing knowledge and reducing stigmatising attitudes. Evidence does not support the view that social contact is the more effective type of intervention for improving attitudes in the medium to long term. Methodologically strong research is needed on which to base decisions on investment in stigma-reducing interventions.

(Mehta et al (2015) Evidence for effective interventions to reduce mental health-related stigma and discrimination in the medium and long term: systematic review The British Journal of Psychiatry, 207, 377–384. Extract from page 377).

On scanning the abstract a very familiar feeling came over us; disappointment, and yes, a little despair. Our intuition and experience told us that social contact is a powerful way to reduce stigma and discrimination, however this review suggests otherwise. But is this actually the case? Do we have a lack of evidence into the effectiveness of social contact because of limitations in current research, or because it is actually not more effective in the long term than other interventions?

How to reduce mental health related stigma and discrimination is a pressing question for researchers to help answer because the impact of public attitudes and behaviours are bearing heavily down on people with mental health problems. Recent work by four peer researchers and McPin Foundation staff interviewing 85 people about their experience of mental health related stigma and discrimination identified a framework for how mental health service users appraised whether they were being discriminated against. We found people weighed up their expectations of the situation, the behaviours encountered, the perceived rationale for the person's response and the impact on them before passing judgement on whether it was discrimination.

The systematic review paper in the British Journal of Psychiatry is an interesting read. It looked at studies across the globe as well as focusing in particular on interventions delivered in low and middle income countries. Social contact tends to be a cost effective intervention model when used well, because there are reservoirs of mental health experience in the community to tap into. However, this is where the conditions for social contact the 'Like Minds, Like Mine' project developed are so important. Might some of the studies reviewed being delivering low grade social contact that was not equal status or involved in active co-operation? Having a talk by someone about their health experiences may not be enough.

The authors considered 80 studies and assessed for research quality – including the risk of bias, and use of validated outcome instruments with sound psychometric properties. They concluded that for studies with a follow-up beyond 4 weeks:

Interventions aimed at reducing mental health-related stigma typically had a medium-sized effect on knowledge outcomes and a small effect on attitudinal outcomes, although for both types of outcome statistically non-significant findings were as common as significant ones. There were insufficient data on behavioural outcomes to draw any conclusions on the medium- or long-term effectiveness of interventions to reduce discrimination.
(Extract from page 380)

So where does this leave us? The authors suggest that evidence for social contact is stronger than any other anti-stigma intervention, having a small but positive impact in the short term, but most research is of poor quality. A key challenge is studies are hard to compare because many use bespoke questionnaires rather than validated assessment tools making it harder to compare findings.

Other systematic reviews also draw similar conclusions. So campaigns like Time to Change should continue their current strategies using social contact and help build an evidence base around how to reduce discriminatory behaviours among specific groups such as employers or family members. Our research indicates that we do need different solutions as the responses from for example a parent and a line manager to a person displaying signs of mental health crisis are different, as is the context in which they are experienced. We produced a poster summarising some of this work which you can read here.

Another strategy we have supported recently is the use of autobiographical books to communicate about mental health and mental distress. Attempting to displace myths and provide honest accounts of living with mental health problems. Linda Gask's book – The other side of silence – is a recommended read. We have written a blog which you can access and there is an interview with Linda too. Professor Linda Gask – psychiatrist, academic and person living with depression – wrote the book in part to educate others and tackle stigma. We don't know of a research study that has looked at the impact of memoirs on public attitudes to mental health problems but intuitively it feels useful and we encourage new staff to read personal narratives.

The field of mental health related stigma and discrimination research has grown in the past 10 years. As the Mehta et al 2015 review shows, there is still a lot more to find out if we are to achieve lasting change in public mental health knowledge, attitudes and behaviours. We must keep on trying, and sharing our learning.

Opportunities

How should we measure the quality of psychosis services? Have your say!

How do we know that a psychosis service is high quality? What should we be looking for? We would like to invite people with a lived experience of psychosis or carers of someone who has experienced psychosis to help us answer these questions. We will be holding two

workshops to discuss these issues and identify suitable quality measures for psychosis services: One in Leeds on Monday 25th January 2016 and one in London on Friday 29th January 2016.

This project forms part of NHS England's Clinical Service Quality Measure for Psychosis Programme. The programme is working towards the goal of ensuring that NHS England can tell the public how well services are performing and meeting their needs.

Download the flyer and more information here: CSQM for psychosis workshops flyer

We will cover travel expenses, lunch will be provided and anyone attending will receive a £20 a shopping voucher as a thank you for their time.

If you would like to join us, we would love to hear from you. Get in touch at: contact@mcpin.org or call us on 020 7922 7877.

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Take part in a study about diabetes and severe mental illness

Researchers at City University London would like to recruit people with type 2 diabetes who are aged 18 or over and have a severe mental illness (psychosis, schizophrenia, schizoaffective disorder or bipolar disorder) to take part in a short survey to find out about the diabetes care they receive and their experiences: https://goo.gl/ghxi7q

For more information please contact Frederique: Frederique.lamontagne-godwin.1@city.ac.uk

Prudential RideLondon-Surrey100

We're now looking for a team of people to take part in the Prudential RideLondon-Surrey100 cycle ride, on **Sunday 31st July 2016** and raise money to help transform mental health research! If you are a keen cyclist, have been personally affected by mental health problems, and have a passion to see people's mental health improved in communities everywhere then we'd love you to apply NOW!

Please download and complete our riders application form here and return to **contact@mcpin.org**, to be in with a chance of securing a charity place with McPin. Please note: there are limited spaces and demand is high, so we will choose who is successful based on the strength of your application, as well as a commitment to raise a minimum sponsorship of £500, so please be as detailed as possible in your application. Good luck!

Thank you

We'd like to say a huge Thank You to **Core Arts** for providing us with a great design for our Christmas Cards this year. Core Arts is a registered charity that promotes positive mental health and wellbeing through creative learning. In the autumn they ran a competition among their membership to produce a seasonal Christmas card design for us here at McPin with 14 entries. The winner of the competition was Ben Gooch with this Robin design. We have been selling our cards this year and the feedback has been great.

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