Greater Manchester
Adult Mental Health Service User Network Launch
Monday 16th July 2018
Conference Report
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Introduction

Julie Cheetham, Associate Director for the Health and Social Care Partnership Strategic Clinical Networks welcomed everyone to the launch and went through the aims of the day prior to introducing the Chair, Marsha McAdam.

Marsha McAdam, Shadow Chair for the Network.

Marsha thanked everyone for attending and explained what had inspired the establishment of the group.

She said she had been reading tweets sent by Jon Rouse, Chief Officer at the Greater Manchester Health and Social Care Partnership (GMHSCP Partnership) about mental health services, and replied, asking “where is your true service user involvement”?

This led to meetings between herself, Jon, and Warren Heppolette, Executive Lead at the Partnership, Strategy and System Development, and the agreement to form the new network.

She said the aim of the network was for it to be inclusive, with 100-120 people involved from across the 10 GM boroughs.

She said the future would be “challenging, but exciting”.

Tina Wardle, a Personal Perspective.

Tina spoke honestly and movingly about how she was badly affected by depression following the death of her father.

She said she didn’t realise at first how much it had affected her, but six months later went to see her GP.

She said the anti-depressants worked well at first, but it quickly became apparent there was a lack of support from counsellors. She said she had to proactively approach them for help, rather than them approaching you. She eventually attempted suicide.
She said health professionals need to know what people want and that at the moment chances to help people and make a difference are missed.

“We all need to work together as equal partners,” she said.

**Jon Rouse, Chief Officer, GMHSC Partnership**

Jon began his speech by telling a story about how the suicide of a close friend had affected him and put him on a path to do what he could to improve mental health services.

He stressed the importance of mental health by saying “there is no health without mental health” and it was “absolutely critical” people had access to the right services.

Jon highlighted the fact that adverse events in our past can cause damage to our mental health and that we are all fragile.

He said this was why the Partnership wanted to tackle mental health from the view of a lifelong journey. Positive action will now be taken even before a child is born, with a specialist in mental health on every maternity service.

Mental health programmes were also being introduced at schools, which was another positive step, although for some young people education wasn’t the right route for accessing these services and alternative routes were being set-up.

He said iThrive was being established in Greater Manchester, changing the statutory framework to help bring flexible support to young people. He said support shouldn’t be a drawbridge which is lowered only when it is needed, but something which is always there. And the support would be more based around someone’s existing peer support, more agile and flexible.

Future work would also look at vulnerable groups such as the homeless and care leavers and how they access help for their mental health.
problems. Jon said young people often talk about standing “on a cliff edge” when moving from child to adult care and more work needed to be done on managing the support they receive.

He said pathways needed to be defined for people living with borderline personality disorder, but this would have to be in a phased approach to manage the work. He said the network and Marsha would play a key role in defining the pathway.

Jon went on to discuss how young people are underrepresented in the system, but that the GMHSC Partnership was tackling this with the formation of the Children and Young People Health and Wellbeing Board.

He said he treated dementia as a separate issue to depression because, in his view, they were different, with dementia being a physical disease which has mental health implications.

Concluding his speech, Jon said none of the GMHSC Partnership’s plans would be successful if users were not involved and led on the improvements.

“We need to do it properly,” he said, “and that’s why we are here today.”

He said the approach to the network spelt out SPAR:

Service design – what improvements should be taking place?
Prioritisation – which areas need to be tackled first?
Advocacy – for people who are not heard
Review – scrutiny and challenge. Is it doing what it should do?

**Andy Burnham, Mayor of Greater Manchester**

The Mayor started his speech by echoing the words of Aneurin Bevan, founder of the NHS, who said it should be as easy to get help for a mental health disorder as for a corn on your foot.

Andy said unfortunately this had not been the case and the NHS had been “a medical treatment service, treating physical ill health”. He said he believed now was the time to fulfil Bevan’s original vision of putting mental health on an equal footing
with physical health.

He said modern life was shifting the focus onto mental health as people felt far more pressure and stress than their parents or grandparents did.

He said education wasn’t preparing children and young people for dealing with the stress of modern life, but was piling more pressure on them.

And he added that for adults there was “an epidemic of insecurity” with people on zero hour or short-term contracts unable to plan for the future and often left unsure if they would be able to pay the rent. He said this lack of security over housing was a big issue.

“It eats into our lives,” he said.

The Mayor said his father had worked in Manchester city centre for many years in the same job and that security in work had helped his family.

He said modern life means everyone is having to absorb higher levels of stress and support was growing all the time for both mental health and physical health to be at the heart of the NHS.

He said more money was now being spent on mental health, but only a fraction of this money nationally was being spent on services for children and young people.

In Greater Manchester, he said this was changing and pilot programmes were underway in schools to tackle it, which he thought was “fantastic”.

Panel: Questions and answers

- A question was asked about the lack of high quality dementia services for people in the BME community and Jon Rouse replied that the Partnership was working with each of the 10 boroughs to improve services in these communities.
Maqsood Ahmad said there were “pockets of success” across GM, but they had to work out how they could make this success consistent across the city region.

Manchester mental health user group said they feared their group could suffer because of the formation of the new Network which has a similar name to theirs. This issue will be resolved by the Steering Group moving forward.

Issues regarding Harpurhey were also highlighted by participants and Andy Burnham said he was not aware of the issue but would be happy to visit them and talk about their concerns.

A guest asked a question about zero hours, saying this put immense pressure on people’s mental health.

The Mayor said he agreed about zero hours contracts and wanted them banned.

A question was asked about suicide prevention and what was being done to help prisoners suffering from mental health

Andy said he thought counselling in general was not good enough at the moment, but now was an opportunity for GM to improve it.

Also, as a general comment to guests complaining about the current state of mental health services, he said “we are not saying it is good enough. In GM, mental health services have not been good enough.”

The morning session provided delegates with the opportunity to voice their concerns around the mental health services provided in their area, and also provided the opportunity for the Partnership to get feedback on what involvement delegates have already had with
their local care providers, CCGs, and local authorities.

**Maqsood Ahmad** facilitated the roundtable discussions during the morning session. The topics raised and the discussions had have been summarised below:

**Question 1**  
**What particular issues relating to mental health services are most pressing to yourself and the communities you represent?**

**Variation of services**  
Delegates spoke of a postcode lottery in GM, with only some areas having access to specialist services such as; mental health and learning disabilities, crisis care, Personality Disorder (PD) services, LGBT services, autism, ADHD and dementia. Patients want to be seen by multiple professions in one place. They also voiced their concerns on the lack of service provision for hard to reach groups such as the homeless, refugees and asylum seekers.

**Access and waiting times**  
In some cases, service users have had a good experience of this. However, this was also a common issue discussed by the delegates in terms of long waiting times, patients suffering during that time with nowhere to turn, and patients’ experiences of being bounced from service to service with nobody wanting to take responsibility for them. People want easier access to services and other routes into services other than referral by GPs.

**Lack of support for carers**  
Carers are at increased risk of suffering mental ill health. People want to see more support in place for carers and their families in terms of accessible mental health services.

**Voluntary, Community and Social Enterprise Sector (VCSE)**  
The VCSE sector was described as fundamental to supporting communities and in bridging the gap between NHS services. People want to see more funding channelled into VCSE services and for them to be recognised for the invaluable contribution they make to mental health patients and their recovery.
Training
There was a feeling of doubt amongst delegates that professionals across health and social care were adequately trained to deal with mental health patients.

There was a call for training and awareness of mental health issues for staff in care homes, education settings, housing providers, and generally across the board. Users want to feel that anybody they come in to contact with due to their mental health problem will have understanding and knowledge of the problems they face and how to deal with them appropriately. Furthermore, delegates wanted to see mental health professionals trained in specialist subjects such as suicide bereavement.

Cultural awareness
Commonly mentioned across all tables was that there was a lack of cultural awareness in mental health services across GM, in particular a lack of services for the Black, Asian and Minority Ethnic (BAME) population. It was stated that across GM there are 136 languages spoken; where is the support for non-English speaking patients? Information should be accessible in a range of languages, written and audio, to account for the diverse population.

There are also cultural barriers to accessing services due to the stigma attached to mental health in some cultures.

Further work needs to be done to reduce the stigma around mental health, including the implementation of more culture-specific services and support groups e.g. for Asian women.

Communication
Generally, people want to see improvements in communication, internally between services, and externally to service users.

Internally - patient information transferring between services, mental health records being accessible to A&E departments, the police and local authorities.
Externally - language used is too medicalised, it needs simplifying and should be more person-centred. People expressed that they don’t feel like there is enough information out there or at least in the right places, for people in crisis or just looking for their local services; signposting exists but could be better. People were also commonly unaware of their rights to complain and who to complain to. The information that currently exists is too confusing and full of jargon.

**Question 2**
*What involvement have you had already with local authorities, CCGs, NHS, service providers, in relation to mental health services?*

Delegates had previously had some meaningful engagement with various organisations including MIND and local GP practices and the VCSE sector. We also had delegates who had been heavily involved in co-designing and delivering specialist mental health training packages in Wigan. It was clear that there had been some good engagements so far with various organisations, but the GM AMH SUN would be a good way to connect these dots.

Discussions also highlighted some areas requiring improvement:

**CCG engagement**
A common theme amongst all discussions was lack of engagement with CCGs. Service users feel pushed out and devalued by CCGs, and found that they were the most difficult group to get in contact with. Those who had experienced service user engagement with CCGs said they felt like it was a tick box exercise and that their opinions didn’t really count.

People spoke negatively of the CCGs in that they are “stuck in their ways”, “rigid”, “not willing to listen” and “do not like to be challenged”. Some argued that commissioners should be more aware of the needs of the communities that they serve e.g. cultural diversity.
Service user engagement not meaningful
In general, delegates spoke about the service user engagement that they had been a part of, having felt meaningless; organisations cannot expect one service user to represent a whole community. Engagement feels tokenistic and not person centred. Service users who are on the boards are often excluded from meetings and feel that they are not taken seriously.

Javed Rehman, a personal perspective
Javed started the afternoon session with a powerful account of living with challenging mental health issues.

He said he had suffered from mental health difficulties for several years, but found he had no support from GPs. He said the only action they took was to give him medication.

He said the low point came three years ago when he had a breakdown and had to finish work.

He said medical professionals did not understand the cultural background to his problem; there was a “huge stigma” regarding mental health in his community, where they don’t discuss these issues.

He said he was “disgusted” with the psychological support he received after being accused of being a terrorist because his mental health difficulties had led to him stop grooming and he had grown a long beard. He said he felt persecuted by people who were meant to be helping him. Javed said in his view one of the biggest problems was the NHS/CCG procurement process and spending too much on services and equipment.

He said he was also annoyed at how the wrong decisions were often made. He said in Rochdale mental health services were recently located in a hospital, even though many in the BAME community would not go there because of the stigma attached to mental health. He said they are now looking
to move the services elsewhere.

Javed finished his speech by saying he had experienced a very unpleasant journey and he would fight to make sure it didn’t happen to anybody else.

Implementing the Greater Manchester Mental Health and Wellbeing Strategy: Progress so far

Jordan Fahy, Chief Officer, Bury Involvement Group (BIG) in Mental Health
Neil Thwaite, Chief Executive, Greater Manchester Mental Health NHS FT
Dr Henry Ticehurst, Medical Director, Pennine Care NHS FT

After an introduction by Jordan, Neil spoke to the audience about recently becoming chief executive and working to make the strategy a success.

He said the strategy aimed to narrow the gap in life expectancy, ensure parity of esteem with physical health and shift the focus to prevention.

He said there was a need to take the strategy and work closer with employers and the third sector to make it successful. He also said a pilot would soon be underway to work in partnership with a housing group to help reach people who need support.

Henry explained how the GM Mental Health Programme was being implemented via the approval of numerous boards and explained the structure.

He spoke about the different areas the strategy was focused on, such as suicide prevention, physical health of people with severe mental illness and increasing access to psychological treatments and said although there were still gaps, it was unrealistic to tackle everything at once.

He said out of area placements was one area which needed improvement. He explained he had taken a call on Saturday which highlighted only one bed was available for someone to receive treatment and it was in Bournemouth.
“This is an area we really need to work on,” he said.

Q&A with Neil, Henry and Warren

Afternoon discussions
The Greater Manchester Adult Mental Health Steering Group

Guests were presented with a draft Terms of Reference (TOR) and Code of Conduct (CoC) for discussion and feedback. They were also asked for their thoughts on how the Service User Network should be established.

Feedback - Terms of Reference and Code of Conduct

Common themes during the feedback session are listed below:

Language

Delegates felt that the documents contained too many acronyms, too much corporate language and ‘dry professional jargon’. A suggestion was to re-write the documents in plain English service user format and to include a glossary of unfamiliar words. Delegates also wanted to see a rationale in the introduction as to why this network has been set up.

Process

There was a general feeling across the room that the process for writing the TOR and CoC was the wrong way round. People would have preferred to have been consulted first, and the TOR and CoC to have been informed by those discussions. In terms of engaging locally, people also questioned how this would be feasible in each locality where service providers work across borders.

Marsha explained that the TOR was drafted by the Sounding Board members, who are all users of mental health services.

Representation
The TOR recommends that there are 12 people on the steering group, but people felt that this wasn’t enough as 12 people could not possibly represent the population of Greater Manchester. At the very least, they thought that there should be 12 people, with a deputy for each. The groups also discussed GM having a diverse population, and that there needs to be a good representation of this on the steering group, to ensure that all voices are heard. The documents do not mention carers or families and this should also be considered.

Communication
Some common feedback was around the flexibility of the network. People felt that in order to get a greater attendance and involvement, we should consider utilising other options such as email, Skype and teleconference for meetings.

Roles and responsibilities
People also commented on the specific roles of the chair and co-chair in that they appear to have too much responsibility. More clarity needs to be provided around the resource required for these roles and a full role description.

Concluding Remarks
Warren Heppolette, Executive Lead, Strategy and System Development
Marsha McAdam, Shadow Chair for the Network

Marsha and Warren spoke about how the idea of the network had grown over the past few months into a reality. Marsha thanked Warren, Maqsood and Health and Social Care Partnership Team for their support and said the network would not have happened without them.

The guests were thanked for giving their time and asked to give their feedback on the event.

Special Thanks
A special thanks to Javed Rehman for photographing the day, as well as all of our stall holders.