The West Midlands Mental Health Commission Citizens Jury

WEST MIDLANDS
COMBINED AUTHORITY

About Shared Future

We are a community interest company primarily serving the North West of England, and with associates based across the UK.

Our aim is to provide an excellent service that makes a difference to communities and individuals and works towards a fairer, more equal society.

Our mission is to move those we engage with towards greater individual and collective authority and autonomy, by supporting their ability to act wisely, confidently and in community with others. Since setting up Shared Future in 2009, we've built a team of experienced consultants and practitioners with a diverse range of skills. We work together on worthwhile and stimulating projects that reflect our personal values.

www.sharedfuturecic.org.uk

Contents

Summary

In spring 2016, fifteen residents of the West Midlands, with lived experience of mental health problems, met for eight sessions of deliberation. Their task was to produce a set of recommendations for the West Midlands Mental Health Commission, whose function is to advise government and the West Midlands Combined Authority on how public services can be transformed in the context of a devolution deal for mental health and well-being.

Members of the diverse Citizens Jury shared their experiences and opinions in a highly participatory process before producing firstly a set of building blocks that should underpin any future mental health system and secondly a set of twenty recommendations illustrated by their own personal stories.

After meeting members of the jury the Commission has committed to take into careful consideration the detailed recommendations produced through this process.

1. Introduction

The importance of involving people with lived experience of mental health problems in well-being and mental health policy-making is undisputed. However, there are still seldom opportunities for this to happen in a way that reflects the challenges of enabling citizens to navigate their way through this complex issue and then write meaningful recommendations.

Devolution presents an opportunity for us to think again about what we want from a system that prioritises people's well-being and mental health. Our Citizens Jury is an attempt to enable a small, diverse group of people with lived experience from the West Midlands to deliberate over a period of three months culminating in the creation of a vision for the future which was subsequently presented to members of the West Midlands Mental Health Commission.

The task for the group of 15 local residents was to attempt to answer the following question:

'How can public services be transformed within current spending limits to build wellbeing, keep people mentally well and reduce the impact that poor mental health and wellbeing have on public services, the economy and communities in the West Midlands?'

This was achieved through the recruitment of a group of local residents that reflect the diversity of the area. Together they met for eight sessions, a total of some 24 hours, to share experiences and opinions, to listen to each other, to challenge each other, to deliberate.

This report summarises the process they went through and documents their deliberations and recommendations.

What is the West Midlands Mental Health Commission?

The West Midlands Combined Authority Commissioned research in to mental health and its impact on the public sector. The Commission is examining evidence from the West Midlands region and beyond including people with mental health experiences, as well as the professional mental health practitioners and mental health organisations.

The Commission is chaired by Norman Lamb MP, former minister of state for care and support. The Commission has identified the following key areas of enquiry: employment and housing, early intervention principles, criminal justice/troubled individuals, the role of employers and primary care.

The Commission will make recommendations to Government and Combined Authority on:
   a) How public services can be transformed to reduce impact of poor mental health and wellbeing, within resources.
   b) How resources currently spent on mental ill health can be re-directed to keep people mentally well and enable recovery.
   c) Potential for, and content of, a 'devo' deal for mental health and wellbeing.

The Commission aims to a) Assess the scale of mental health problems in the West Midlands and their cost and impact across the whole system, b) Examine best practice elsewhere nationally and internationally in both health and other service areas c) Establish the relative costs and benefits within the whole system of the application of this best practice to the West Midlands.

The Commission is expected to launch its final report and recommendations in September 2016. For more information visit

https://westmidlandscombinedauthority.org.uk /what-we-do/Commissions/mental-health /

Recruitment

The target group of Citizens Jury participants was those with current or previous lived experience and carers from the West Midlands. The second essential element was that participants should reflect the diversity of local populations. An effort was also made to try to recruit people that have no little previous experience of engaging in similar processes i.e. 'people that don't usually do this kind of thing'.

A profile of participants was agreed with the West Midlands Mental Health Commission steering group.

A recruitment letter was agreed with the Commissioners, outlining the aims of the jury and the payments of vouchers and expenses available. Recruitment was promoted through local agencies and members of the WMMHC steering group (see box).

To incentivise attendance participants were offered shopping vouchers at the end of the jury process (via a prize draw). There was also a budget for participant support costs (including transport and child care).

Those interested in taking part in the jury were invited to complete a very simple one page form to register their interest and express their preference for afternoon or evening sessions. Would-be participants were also offered the option of filling-in the form over the telephone. Freepost envelopes were also available. An online application process enabled potential applicants to submit their details via the West Midlands combined website.

After a three week period of promotion through targeted agencies and individuals and the local media, 115 local people made applications to take

What is the West Midlands Mental Health Commission Steering group?

The steering group was established to guide and support the work of the Commission. It consists of the following members:

- Lola Abudu
  (Public Health England),

- Sarah Barnes
  (Troubled Individuals Programme – Solihull MBC)

- Stephen Chandler
  (National ADASS Mental Health Lead)

- Dr Aquil Chaudary
  (Cross Birmingham CCG)

- Ruth Cooke
  (CEO Midland Heart)

- Dr Elizabeth England
  (Sandwell CCG/RCGP MH lead)

- Simon Gilby
  (Coventry & Warwickshire Mental Health Trust)

- Viv Griffin
  (Wolverhampton Council and West Mids ADASS and ADCS)

- Sarah Jury-Onen
  (DWP)

- Dr. Adrian Philips
  (DPH Birmingham)

- Sean Russell
  (West Midlands Police)

- Dr Paul Turner
  (Birmingham South Central CCG)

- Helen Wadley
  (Birmingham MIND)

- Shelley Ward
  (Prevention of Violence Against Vulnerable People Programme)

part in the Citizens Jury by the closing date of March 4th 2016.

This is an exceptionally high response rate for Citizens Jury recruitment. Applications were received via telephone, email, freepost return and online. The most popular time requested by the profile required was the afternoon.

The selection process worked as close as possible to the profile of jury participants agreed by the Steering Group. Inevitably it was difficult to recruit exactly to the profile agreed.

The twenty-one shortlisted applicants had the following diversity:

Citizens Jury profile

The diversity profile of the twenty one shortlisted applicants was as follows:

Females: 12,

Males: 9

Ages:

- 20 to 35: 6,
- 36 to 45: 5,
- 46 to 60: 6,
- 60+: 3

Geography:

- Birmingham: 15,
- Coventry: 2,
- Sutton Coldfield: 1,
- Walsall: 3

Ethnicity:

- White: 12,
- Asian British: 4,
- Black/Black British: 3,
- Chinese: 1,
- Mixed heritage: 1.

Participants had experiences of psychosis, bipolar, depression, schizophrenia, eating disorder, anxiety, borderline personality disorder, stress, FTSD.

Twenty-one people were offered places and all were contacted the week before the first session. Fourteen attended the first day and fourteen on the second, a total of fifteen different people. In the following week two additional people were recruited. Average attendance over the eight weeks was fourteen.

Our stories

Many of the participants of the Citizens Jury felt that the best way to illustrate the importance of the work of the Citizens Jury and the Commission was to offer personal stories. The following powerful pieces of writing are also an attempt to show how essential it is that people with lived experience are able to shape the policies that directly affect them and the communities of which they are part.

'I became unwell at 23 and was prescribed huge amounts of Valium for panic attacks. On stopping medication I suffered a breakdown at 29 and lost my memory for 12 months, unable to recognise my parents or my three children. I weighed only five stone. I have been sectioned over and over, spent time in police cells, hospital cells and been injected to put me out many times. Most recently I had a six-month section spent in the Priory at an expense to the NHS of £150,000, after losing my 42-year-old son to Heroin. Having a very supportive family and children and caring NHS and police service helped me to survive'.

'I was employed by a large local University. I was at the time suffering from anorexia nervosa and during my employment I was hospitalised several times. I was shown nothing but kindness, compassion and understanding by my boss. My colleagues followed his lead and were also very understanding. I was told frequently that I was a very conscientious and hardworking employee who more than made up for my absences. This human compassion allowed me to be a productive member of society and I stayed in this job until I left to have my first child. At one time it was even arranged for me to live in the hospital and attend work part time from there as a first step back.

I later returned to the University in a different role. I progressed to part time and then fulltime, earning a promotion and was even nominated for a best newcomer of the year award. After a while I began to have some breakthrough symptoms of

bipolar disorder (my primary diagnosis) so my psychiatrist initiated a change of medication.

Although this was a difficult time for me I continued to work throughout. I still did the jobs nobody else liked doing, and the shifts nobody else wanted. I was loyal and conscientious. My work did not suffer but my relationships with my colleagues became difficult because I was over sensitive and emotional. It was known that I had a mental illness but I received no support or kind words during this time. This episode culminated in my being taken to a performance management meeting with HR because my manager said I was causing the department stress by my 'behaviour'. This 'behaviour' was my being tearful, telling a colleague I felt suicidal. I also started to request my coffee breaks. It was the habit of the department to take our breaks on the job.

This wasn't a major relapse and would have required no time off if my manager had shown some kindness and understanding. She didn't. Instead I was subjected to a performance management meeting. This was one of the most humiliating and degrading experiences that I have ever experienced, causing a breakdown which destroyed my confidence, self-esteem and everything I had worked for. It culminated in my taking sick leave and not returning. I have not worked since'.

'I am a wheelchair user. Countless times I have been refused a bed at a mental health hospital or a respite bed because they did not have adequate accessible facilities. I've been left sleeping on the floor due to being unable to access a suitable room. I've been forced into unsuitable transport and injured when being transferred between hospitals. I've been left to shower on the floor in a mental health hospital because they couldn't source a shower chair.

I've been advised to do things by the mental health team that my physical health team say is actively harmful. I'm currently being denied

access to psychotherapy because there is no accessible transport available to take me there.

I cannot use the phone due to an auditory processing disorder. Countless times I've been told to ring a crisis access number. I can't. I have had multiple suicide attempts as I've been left with no accessible support.

There is no joined up accessible to all service. This needs to change. Urgently'.

'It came like a bolt from the blue. Things had happened in my life before and I'd always bounced back. Things far worse than a relationship break up. But this seemed to trigger something in my head. Within a week I was desperately and morbidly sad. I was paranoid, I believed everyone knew. I didn't know what they knew, they just knew. Everyone that saw me while I was out were communicating by thought to each other, or so I believed. I was scared, confused, lonely and yet didn't want company.

I found myself one day at my GPs surgery, crying like a baby. The next thing I know I'm in the doctors room trying to fill out a tick sheet of how I was feeling. My GP gave me a prescription for anti-depressants and told me to book an appointment for two weeks time. Somehow I cashed in my prescription and got back home. I spent the next two weeks in my bedroom with the curtains closed.

During these two weeks I stumbled across an American chatroom for those with mental health problems. I visited that chatroom every night for months. Thankfully America was open when my daemons came to visit as the UK was only ever open 9am to 5pm Monday to Friday. I had been back to visit my GP after the first two weeks and he said he would put me on a waiting list for some counselling. Counselling that had a ten week waiting list. He also gave me a helpline phone number, but like I've already said my daemons didn't conveniently visit me between 9 & 5 so it was useless. I still struggle sometimes. I've been on and off anti-depressants for five years. I don't have a 'label' from my GP, apparently my depression isn't serious enough for that. As a

result there are many services I have found that I can't access.

So I am left to look after myself and hope that when things get bad and I crawl into bed or don't even have the strength to get out of bed in the first place, that my daemons will eventually move on and I can try to live a life once more. The best advice I have ever been given was from an American man in the afore mentioned chatroom. He said " You're a nutter. Get on with it". He understood me, he 'got it'. I didn't have to explain what a panic attack felt like, what paranoia felt like or what dark dark depression felt like... Since then I have spoken to many young and not so young people about my depression and this has given them the chance and encouragement to open up about their mental health problems and so start their recovery journey. We all need someone to talk to, someone who...'Gets it'

'My lived in experience I believe started when I was three and a half. My first memory is of crying and trying to rub my tears away on a linoleum surface which even rejected my tears. I remember being afraid of having to leave the house I had been brought to. Another rejection, another loss. I was adopted, due to what I was told was neglect by my birth mother. I smelled , so all my belongings were burnt and apparently I was covered in bruises. The first grandson in the family was born on March 15th 1948 and I was adopted in July of that year. Again I felt rejected my adopted mum who idolised her first grandchild more especially as it was a boy. John Bowlby, Psychodynamic counsellor says loss in early childhood results in boys becoming angry and girls depressed, and in my case he sure was spot on. This depression lived with me till after three suicide attempts, I finally found someone who really listened , he was a consultant and it helped that he had ethnic origins too.

He said it was a wonder I had not turned to drugs as well as alcohol and ended up with a criminal record. I was wrongly diagnosed too as bi-polar but there is no evidence of this. I said that I did not need medication, he agreed and a talking therapy was arranged. I wanted a Psychodynamic

counsellor and a black one. I got a Spanish psychotherapist and CBT therapy.

I am very stubborn, and it was 68 years of baggage to wade through, but after a year there seemed nowhere else to go I felt ill equipped but I just needed hope, courage and opportunity to realise my talents. The greatest thing my Psychotherapist said was "If I do not get the help I need from someone I simply try somewhere else."

'I'm going to start off talking about my experience with services I've come across and then how I feel it could of been improved.

My first experience with mental health services was when I was 19. I had suffered from really bad depression from the age of 16, after someone close committed suicide. I didn't feel it was bad enough to get professional help, and to be honest, I didn't even know how to if it was. By 18 I was self medicating with alcohol and drinking every day. I had a good job managing a leisure centre and I was good at hiding it. Alcohol lead on to drugs, which helped numb the pain and allowed me to function as though nothing was wrong. At first I just smoked weed, it helped calm me down and hide my feelings of inadequacy and terror. I continued like this for a few years, balancing the use of drugs and alcohol with my full time job.

At 22, my relationship broke down, and I was sexually assaulted by one of my friends which left me feeling vulnerable and alone. I quit my job, not being able to handle the pressure and stress and later that week, took an overdose of pills. My flatmate found me, and I was rushed to the QE hospital. After 3 days in hospital I was released, and a letter was sent to my GP. During my stay I was assessed to see if I was a risk to myself, but I wasn't referred to anyone, and no one checked to see if I had a support network when I got home; which I didn't.

My self-medicating slowly got worse; by this time I was still drinking every day, and had moved on to sniffing drugs and taking pills. It seemed like the only escape from my world which was crashing down around me. To fund my habit, I started selling drugs from my flat, which caused

my habit to become worse; I felt like I was stuck in a world I couldn't escape from.

I ended up in a new relationship, but after a month it became obvious they also suffered from mental health issues, and were eventually diagnosed with borderline personality disorder. Trying to deal with this whilst also being ill myself was hard, and there was no support offered to me to try and help deal when there was a crisis. My partner's mental health slowly got worse and then after numerous overdoses, police call outs and violence towards me, it ended with me being stabbed in the back and strangled whilst I slept. I admitted to myself I couldn't cope, and we split up, but this just left me feeling more lonely and isolated.

My drug habit quickly developed and I ended up injecting, to try and numb the pain further. It worked to start with, so I continued; every day I would drink, inject, sell drugs and buy more. I didn't leave my house unless it was to buy alcohol or sell drugs. In August 2015, I was pulled over by the police, and whilst in the back of their car, they found my drugs in the glove box. I was arrested and taken to the police station, where I was honest about what was happening in my life. At the desk I was asked about my mental health, I explained why I ended up doing drugs, and that I had attempted suicide and self harm. I was classed as a suicide risk and a note was put on my cell door. I was seen by a nurse, who talked to me about my drug and alcohol use, and made sure I was comfortable and safe. The police officers themselves were wonderful, supportive and understanding, and I was released the next day, but again, no attempt was made to refer me to a mental health service or offer me any other support.

In October 2015, following another relationship breakup, I attempted suicide again, and once more ended up in the QE hospital. I was alone, and lying in the hospital I just felt lonely; like there was no way out. A trainee University doctor came to speak to me on the first day; we chatted for 20 minutes; which I have to say, was the best help and support I had received. He had the time to talk honestly with me, and actually listen, and even though he wasn't a mental health specialist; his empathy and understanding left me feeling a lot better. A mental health nurse came to see me the following day, and after completing her check

sheet, promptly told me that I didn't have any mental health issues, just a drug and alcohol addiction, and referred me to a drug and alcohol support service, though by this point even I understood that my addiction stemmed from my mental health issues. I felt like it was more about completing a check sheet and then passing me on, than offering actual help or support.

After 3 months, I was finally booked in to see someone from the drug and alcohol support service for the first time, and I felt like I might actually get somewhere; she said they could offer support groups for depression and mental health. However after this first meeting I heard nothing back, and my depression just got worse; most days I wouldn't even get out of bed. In the end, I was evicted from my house and had to give up my dog, a husky called Simba, who had been my main support and the thing that kept me going; since he made me feel like my life had a purpose, this was my rock bottom.

I managed to get clean myself and with the help of my friends and some brilliant self help books, stopped using and learnt to deal with the feelings that for so long, I couldn't cope with or understand.

I feel that, through my experience, there were so many opportunities for early intervention and services to help but because of the disjointed approach and lack of communication, I just fell through the cracks. If we can find a way to make sure that the police, criminal justice system, A and E, drug and alcohol services and GPs could communicate and work together to deliver a combined holistic service that aims to identify people in need early, then so many more people could be treated far quicker, and instead of problems spiralling out of control, we can be supported and access services in a way that keeps us active, employed and healthy; which as well as saving lives, will also reduce the long term cost of treatment'.

'It has been wonderful to be a part of the Citizens Jury. We believe that public funds are at stake. It is public funds and so we believe that the budget for mental health services and its sub services and the out goings to external and private services should be shown in its proportions annually. These statistics can be represented via pie charts and maps for which services overshadow which

regions. This would be entirely useful for service user groups such as ours to review services more accurately rather than clutch at straws and assume'.

'In September 2014, I just turned 21 years old and was about to begin life as a University student. Most students in my position as a 'fresher' would have been excited about going to all of the parties and getting drunk but for me? All I could think about was 'alcohol? Too many calories!' or 'gym is way more important than a party'. I went to University with an undiagnosed eating disorder which had been slowly developing over several months. I cannot pinpoint where it all began but a key aspect was from a depressive episode from a break up in November 2013, which affected my appetite.

As I began to lose weight I didn't realise until family and friends would comment on my appearance 'wow, have you lost weight? You look great?' 'What's your secret?' as this continued, I felt I was being validated and so I continued to lose weight. However, my mind started to change and I became anxious about regaining weight and so I began to restrict myself. At this point I was receiving help through a mental health support service and the only thing they could offer me at the time was online CBT therapy otherwise, I would have to be put on a waiting list to see a therapist. I gave it a chance but it wasn't beneficial for me and so I requested to be put on a waiting list (April 2014). During this waiting period, my eating habits had slightly improved but I had also started exercising by going to the gym or running.

As the month went on, I became more entrenched with calorie counting, macro-nutrition counting, weighing food and calories burned through exercising but no one picked up on it because they just thought I was 'super healthy'.

Finally, one week before I went to University, I got to see a therapist but after 5 months of waiting, I could only have one session with her because I was changing areas; this meant starting the whole waiting process all over again. During that session, I only had one hour to talk about all my feeling that I have been experiencing, including

my eating/exercise habits and when questioned about my weight, she just said 'oh you're still within a healthy BMI, there nothing to worry about' and just said that I'm mildly depressed. So I went to university, where my symptoms became worse and started to use other methods to lose weight, example: laxatives. I became more isolated and still no one picked up on this apart from parents when I would come home on weekends but like most people with an eating disorder, I just denied that there was nothing wrong.

I eventually told a friend at the beginning of November, who gradually encouraged me to seek help. We went to the University doctors and I gave them a letter of all things I had been doing to myself because I was ashamed. The doctor asked me what was my weight and I said a BMI of 15, to which she replied 'Hmmm that is low, why don't you drink a glass of milk?' where I clearly stated in the letter I was following a restricted vegan diet. Nevertheless, even though I was severely underweight, the doctor refused to get me referred because my weight was not low enough.

I had no choice but to go A&E who kindly passed me on to the mental health liaison team, who kept me in overnight to have a body check, blood test and to refer me to an eating disorder service. On December 1st 2014, 2 weeks after being referred I had an appointment with an eating disorder service at which point I had a BMI of 13 (from the beginning of November I had lost 17LBS) therefore, they had no choice but for me to be admitted to a psychiatric hospital. Once I was in the hospital, I was diagnosed with Anorexia Nervosa and I was a patient for 4 months.

When I was finally discharged, I was not recovered but I had a better understanding of my illness and ways on how to control it. I eventually went back to university to attempt my first year again but with a different perspective.

I study Creative Expressive Therapies, which involves using different art forms such as music, dance, drama and art, to help those with learning disabilities, mental health, etc. This type of therapy has worked effectively with numerous people for it gives them a chance to express themselves through creativity. What is most important about creative therapies is, it is not about the end product but about the process, example: a person is drawing a picture but it does not matter if it is perfect or not; if that person is feeling good while in the process of drawing, then it is working. The same method can be applied to alternative therapies too, such as gardening. By using this type of therapy it is giving that individual an opportunity to discover something new about themselves, as well as enjoying a new hobby.

I too have learnt new qualities about myself throughout my first year on the course which has enabled me to become empathetic and more engaged when interacting with people. One significant aspect I have learnt is to see the potential within myself and by seeking positive support you can achieve goals; I have just completed my first year of university with an 'upper 2:1'. Almost 3 years on (or more) since I began experiencing symptoms of an eating disorder and even though I'm in a better place, I've still got a long way until I'm recovered. Just like Creative Expressive Therapies, I'm not focused on the end product of becoming recovered but instead, the process of being happy again.

'Growing up my childhood was a unhappy and troubled place, my mother didn't want me and I was passed around the family until I ended up being raised by my Aunt and abusive Uncle, I started work at 16, the day after leaving school, to me at the time this was a escape from home life and gave me independence. I soon managed to move away from home but my problems and insecurities still haunted me, looking back now I realize that being in a job actually kept me focused, giving me a purpose in life and suppressed my mental health issues.

I was employed in my first job for 23 years until the company closed down but managed to find another job not too long after, which I was at for 8 years until being made redundant due to cost cuts. I now find myself, not far off 50 years old trying to find employment with no qualifications, hardly any computer skills and in an environment geared around school leavers. I signed on, which was soul destroying and the DWP staff were totally unhelpful, making me feel worthless, I carried on signing on as long as possible after my

6 months jobseekers allowance came to an end, but it all became too stressful and I had to sign off.

All of my confidence had gone, I cut myself off completely from friends, family and the outside world, not opening my mail or answering the phone, I'd lost interest in everything, spending all day ruminating about past events and hating myself for even being born, I'd started to make plans to end my life as I no longer wanted to carry on but thinking about the devastation it would cause my partner, I decide to see a doctor, he was more than supportive and I managed to get the help I needed.

My recovery has been a long process, I now feel ready to go back into employment but unfortunately I'm in a even worse situation as I now have to disclose a long break in my work history due to mental illness. This is why I feel so strongly about introducing support back into work schemes for all who want it, being in work is good for mental wellbeing, building confidence, combating isolation, the economy and so many other things'.

'I was born into mental troubles. When I was born after a few days I was taken from my mother as she suffered Post Natal Depression. I was farmed out to my nan. For a long time afterwards I believed her to be my real mother. After mom's subsequent multiple breakdowns and at times I witnessed her self harming and attempt suicide several times a child and into adulthood. It wasn't too long before the cracks began to appear within my own psyche. Through continual years of anxiety and depression, two attempts to block the pain of failed relationships using pills, then addiction to alcohol and tranquilisers for the rest of my pain I found the strength to over come my inheritance to a larger extent eventually.

There really wasn't much help out there. And the bits that worked and were on the NHS were difficult to find and short lived in provision leading to setbacks. Just when I thought I had found one person I could trust and rely on to be in the world to be a rock for the rest if my time, it was to my utmost horror and shock when I walked into their

flat and found that they had ended their own life tragically.

After hours of questioning by the police with a body of someone I cared for in the next room I was suddenly alone in the room where my 'rock' died, with their dog and nothing and no one there to help me. I honestly do not know how I am still on planet earth today. The only thing that saved me was the most wonderful doctor's practice and two GPs there...One of which I still see monthly. I managed to find a counselling service to support me for a few years but I had to find that myself as it was not offered and when I did it was by chance and out of desperation.

Seeing my wonderful GP over these last ten years has enabled me to survive. From time to time I am asked to give little talks to medical students about the events in my life through my GP as he wants these budding doctors to see the reality in people's lives and to make them more aware of how life can be sometimes. It's a positive way for me to give back to the practice I sought help from and to help the students in their medical journey. I can only live from day to day but at least more hopefully through my wonderful GP practice. I thank them from the bottom of my heart'.

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2. The Citizens Jury sessions

The 'Building Blocks'; sharing experiences and ideas: sessions one to four

The members of the Citizens Jury met for the first time on March 14th at a fully accessible room in the Library of Birmingham.

The group heard from WM Mental Health Commissioner Steve Gilbert and Steve Appleton (WMMHC secretariat), for a detailed explanation of the process and its context. The group then started to get to know each other through icebreaker activities.

Previous experience of such processes show the importance of creating the right atmosphere in the first session so that participants understand the philosophy underpinning the process and are encouraged to return for subsequent sessions.

Central to achieving this is a commitment to a participatory way of work; small group work, use of

Participatory tools

What helps and hinders?
Jury members used large trees drawn on flip charts to record on post its what helps, (in the branches) and what hinders, (in the roots) people's mental health. Facilitators encouraged the group to drill down and find the root causes of these positives and negatives.

Wellbeing Rivers
Participants drew rivers using river features to reflect on their different experiences of mental health/wellbeing throughout their lives (e.g. rapids, calm water etc). Marked on the rivers (on post its) were times when well-being/mental health was low and what helped and worked. On different coloured post its participants recorded what didn't work and why.

participatory tools, inclusivity and fun.

During the first session participants used a tree activity to explore the question *'What helps and hinders people's mental health'*?

In the second session participants shared the learning from the tree activity before choosing to either work on drawing wellbeing rivers, or continuing to develop the tree diagrams from session one.

These participatory tools enabled participants to start to get to know each other better and to hear

directly from each other their past experiences of mental health and well-being. Participants started to see connections and commonalities. Building on this period of reflection, participants were asked to identify what they felt are the themes of building blocks that need to be the foundations for a future mental health system.

In order to do this, participants worked in pairs during the first four sessions and in small groups, to produce a number of ideas. These were then grouped into themes as listed below.

The full version of the list of building blocks is in Appendix 2.

Facilitators were careful to use the term 'mental health system' to encourage participants to think beyond those services offered by traditional service providers and to consider the mental health system in its broadest form.
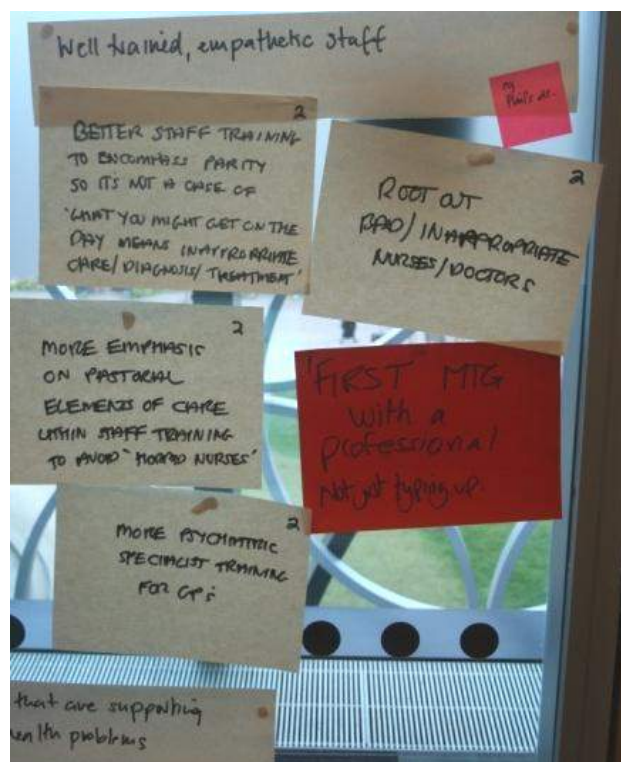
Building blocks for a future mental health system

- **a high quality system for diagnosis that is speedy, clear, where appropriate leads to correct medication and allows early self diagnosis**

- **Well trained, empathetic staff.**

- **24/7, quick access to support that is relevant and accessible for everyone**

- **Early intervention in schools that breaks down the prejudice and tackles stigma and educates them about mental health issues and supports those affected by it.**

- **Support for people that are supporting those with mental health problems**

- **Different options/alternatives for services and different ways of accessing them are widely promoted.**

- **Holistic services that take into account physical and mental health, provide continuity, stop people falling through the safety net and getting lost in the system, offer support for all, are local, joined up, quick to access and are focused on prevention**

- **Listened to: people with lived experience having a voice in their recovery and being actively involved in their recovery.**

- **Lots of opportunities for people with lived experience of mental health to support and help each other: peer support.**

- **Tackle stigma and increase awareness in society of mental health and what it is.**

- **A workplace that supports people's mental health with employers that have awareness and support people into employment.**

As part of this process, a number of commentators were invited to the first four sessions. Commentators are, in effect, the 'expert witnesses' called before the members of the jury to give their 'testimony'.

Each commentator was identified by the Shared Future team in conjunction with Steve Appleton (WMMHC secretariat). The commentators were briefed in advance to guide their contributions within the ethos of community-led deliberation

Each commentator was invited to talk for up to 15 minutes. In their presentations they were encouraged to include:

- Details of who they are (and their organisation)

- An explanation what they feel the problem / issues are

- An explanation of what they feel are some of the solutions.

Essential to the success of this process is the use of clear, simple, easy to understand language. A red card system was employed whereby members of the jury were encouraged to show the red card if they were having difficulty understanding what is being said. After each presentation, commentators were asked to leave the room to allow participants the space to talk with each other about their learning and to write any questions they may have.

The commentator is then invited back into the room and the questions are addressed to them (either by the person that wrote question or by the facilitator).

(All the questions asked of each commentator are listed in full in Appendix 1)

Finally, in the absence of the commentator, participants were asked to reflect on their learning and deliberate with each other.

In session three the commentator was Dr. Ian McPherson (Centre for Mental Health): building upon the reflections of the Citizens Jury members on what works and what doesn't from the first two sessions, Ian's presentation concentrated on 'How the mental health system tries to help now'. In session four, our second commentator was Karen Newbigging (Senior Lecturer in Healthcare Policy and Management: Birmingham University) who presented on '*Devolution: what is it and what does it mean for mental health*?'

In the light of the two commentator presentations, members of the jury reflected upon their building blocks a final time.

Open Space Listening Events

After the first four sessions, participants enjoyed a five week break before the second half of the programme began. This gave participants an opportunity to reflect upon their deliberations at the same time as allowing them time to attend the series of Open Space Listening Events organised as part of the process.

These events were an attempt to bring together 'stakeholders' from the mental health system to work together to produce their own recommendations for the Mental Health Commission. A total of ten of the Citizens Jury participants attended the three events which took place in Birmingham, Coventry and Dudley.

As part of the half day long events, the volunteers made a brief presentation of the work of the

Citizens Jury to date (including explaining the process and the building blocks) before joining the Open Space small group discussions which led to the production of some 100 recommendations.

219 people registered for the events and a total of 125 attended.

A full summary of the process followed and the recommendations produced during the events is available in the companion report to this document.

The recommendations produced during these three events were given to the members of the Citizens Jury at the end of the process in order for them to read and discuss them before prioritising them.

Deliberation and hearing from others: sessions five to seven

The group was anxious to ensure that their deliberations would serve to effectively influence those of the Mental Health Commission. The building blocks were an opportunity for the jury to decide what the principles should be that underpin a future mental health system.

So, the group agreed that some of the remaining sessions should be dedicated to in-depth

deliberation on the key issues which both jury members (through the building blocks) and members of the Mental Health Commission had identified as priorities. As a result sessions five, six and seven were dedicated to hearing from commentators on:

- Primary Care
- Employers/Employment
- Early Intervention

Prior to this the members requested a commentator session with Steve Appleton (MHC secretariat) in order to ask further questions about the role of the Commission.
The subsequent commentators were:

Dr Paul Turner (GP, clinical lead for mental health Birmingham South Central clinical commissioning group)**Nicola Oliver** (IPS employment services – Northamptonshire NHS Foundation Trust/Centre for Mental Health)

Dr David Shiers (Former GP North Staffordshire; former joint lead of National Early Intervention in Psychosis Programme; Honorary Reader in Early Psychosis: Manchester University.)

During these crucial sessions, the primary aim was to enable participants to spend time in deliberation with each other.

Such deliberation is about people sharing their opinions with each other, reacting to each other, trying to understand the opinions of each other, disagreeing, challenging and showing a willingness to be persuaded by other people's ideas.

This was achieved through careful facilitation using small groups and pairs and not treating participants merely as empty vessels waiting to be filled by the knowledge of outside 'experts.'

Deliberation

'Public deliberation is the 'process of exchanging reasons for the purpose of resolving problematic situations' (Bohman 1996) that require interpersonal coordination and cooperation.

The goal of deliberation is to make informed and reasoned decisions. In the context of public engagement activities, such decision-making may materialise in a range of activities, from reaching conclusions and producing a report, to making recommendations, shaping policy, or deciding how to spend a budget.

Ideally, deliberation aims to build consensus through a progressive communicative process that entails seeking information, evaluating alternatives, and making decisions after a substantial exchange of reasons.

During this process, participants are 'challenged to justify their decisions and opinions by appealing to common interests or by arguing in terms of reasons that "all could accept" in public debate.'

Escobar (2011) Public Dialogue and Deliberation

Preparing recommendations: session seven and eight

During session seven and eight participants were given space to deliberate and produce a set of recommendations.

This process started in session four as participants were put into groups to start to come up with preliminary recommendations (groups of 4/5).

In session eight, the ideas from the previous session were placed into themes and members of the jury worked in themed groups to remove duplicates and add detail to each idea.

People were encouraged to think about the recommendations in terms of their own personal experiences. All the way through the process, as conversations developed, it was still possible to add new recommendations. Participants moved from group to group to add to the conversations until a coherent set of recommendations had been produced.

These were displayed on the walls of the meeting room and participants were given time to read through them before a whole group session checked for clarity across all recommendations.

All recommendations were given a letter of the alphabet and every participant was given an individual alphabetised voting sheet to confidentially choose their top ten recommendations.

All recommendations irrespective of the number of votes received are listed in the following chapter.
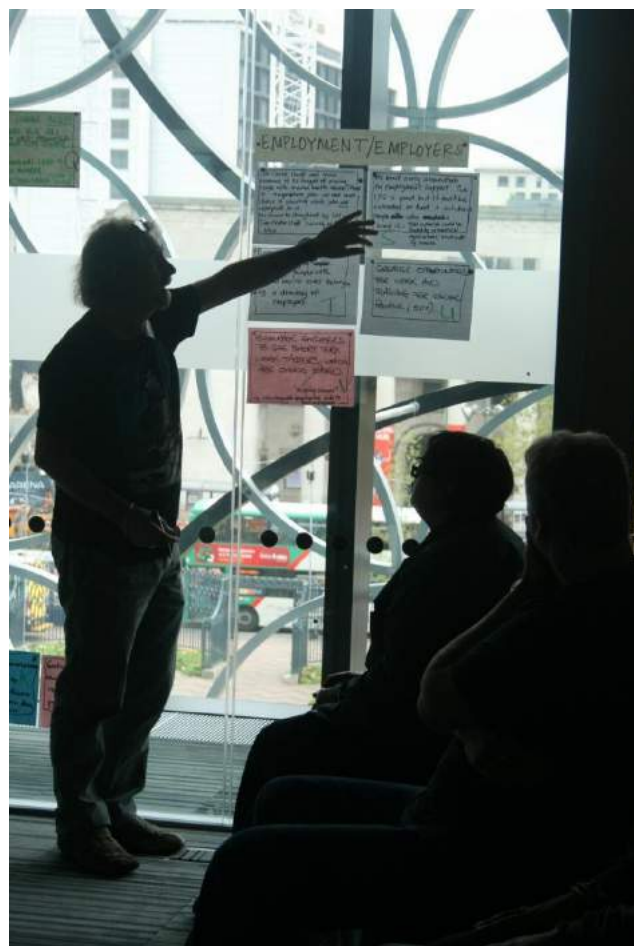
Citizens Jury recommendations

Members of the Citizens Jury deliberated over eight sessions to produce a set of prioritised recommendations that attempt to answer the question:

'How can public services be transformed within current spending limits to build well-being, keep people mentally well and reduce the impact that poor mental health and well-being have on public services, the economy and communities in the West Midlands?'

Each recommendation is listed below with the number of votes it achieved and the subsequent ranking. Some of the recommendations are illustrated with personal stories written and chosen by some members of the jury. These stories are in the yellow boxes.
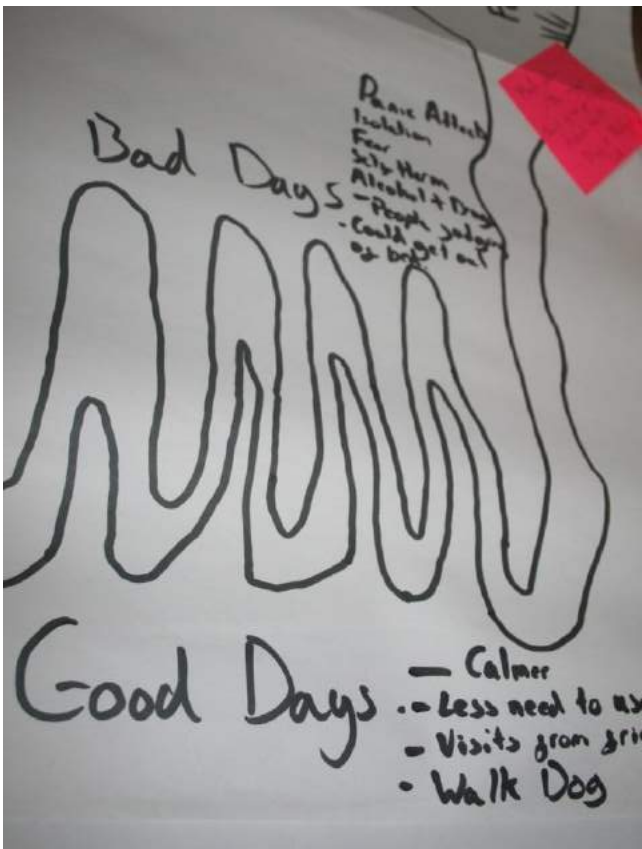
Recommendation 1

(joint first, 10 votes)
Providing free mental health first aid training to everyone in the West Midlands to create health champions in the community (schools businesses, librarians groups, A and E, police public services) to understand and support people to reduce the overall cost of sickness and care e.g. trained librarians to be aware of young people's mental health problems, to act upon a crisis situation with professional contacts at hand.
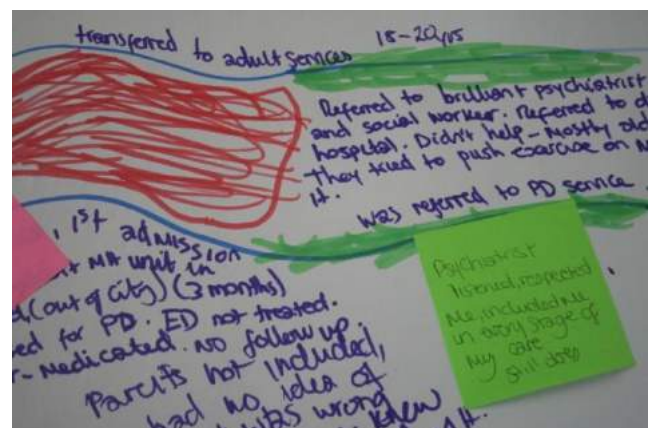
Recommendation 2

(joint first, 10 votes)
Create clearer access to services for all, which are well promoted e.g. 24-hour city centre drop in, e.g. one national logo and contact number, e.g. public safe spaces when in crisis.

Recommendation 3

(joint second, 8 votes)
Mental health staff attached to GP surgeries and other primary care and first contact settings to provide support to service users and assist professionals in better supporting their clients.

Recommendation 4

(joint second, 8 votes)
Early intervention services available at the first sign of mental illness to reduce cost of crisis based services.

'My lived in experience I believe started when I was three and a half. My first memory is of crying and trying to rub my tears away on a linoleum surface which even rejected my tears. I remember being afraid of having to leave the house I had been brought to. Another rejection, another loss. I was adopted, due to what I was told was neglect by my birth mother. I smelled , so all my belongings were burnt and apparently I was covered in bruises. The first grandson in the family was born on March 15th 1948 and I was adopted in July of that year. Again I felt rejected my Adopted mum who idolised her first grandchild more especially as it was a boy. John Bowlby Psychodynamic counsellor says loss in early childhood results in boys becoming angry and girls depressed, and in my case he sure was spot on. This depression lived with me till after three suicide attempts,

I finally found someone who really listened , he was a consultant and it helped that he had ethnic origins too. He said it was a wonder I had not turned to drugs as well as alcohol and ended up with a criminal record. I was wrongly diagnosed too as bi-polar but there is no evidence of this. I said that I did not need medication, he agreed and a talking therapy was arranged. I wanted a Psychodynamic counsellor and a black one. I got a Spanish psychotherapist and CBT therapy. I am a very stubborn, and it was 68 years of baggage to wade through, but after a year there seemed nowhere else to go I felt ill equipped but I just needed hope, courage and opportunity to realise my talents. The greatest thing my Psychotherapist said was "If I do not get the help I need from someone I simply try somewhere else."

'I eventually told a friend at the beginning of November, who gradually encouraged me to seek help. We went to the university doctors and I gave them a letter of all things I had been doing to myself because I was ashamed. The doctor asked me what was my weight and I said a BMI of 15, to which she replied 'Hmmm that is low, why don't you drink a glass of milk?' where I clearly stated in the letter I was following a restricted vegan diet. Nevertheless, even though I was severely underweight, the doctor refused to get me referred because my weight was not low enough. I had no choice but to go A&E who kindly passed me on to the mental health liaison team, who kept me in overnight to have a body check, blood test and to refer me to an eating disorder service. On December 1st 2014, 2 weeks after being referred I had an appointment with an eating disorder service at which point I had a BMI of 13 (from the beginning of November I had lost 17LBS) therefore, they had no choice but for me to be admitted to a psychiatric hospital. Once I was in the hospital, I was diagnosed with Anorexia Nervosa and I was a patient for 4 months.'

Recommendation 5

(joint third, 7 votes)
Mental health awareness studies for all children and young people e.g. in national curriculum at all ages e.g. options for compulsory e.g. Norwegian TIPS project.

Recommendation 6

(joint third, 7 votes)
Provide free spaces in community venues for self-help support meetings e.g. Fire service model.

Recommendation 7

(joint third, 7 votes)

In the West Midlands services need to be the same everywhere, for example level of service, access thresholds etc. these services need to be joined up (e.g. health, criminal justice and drug and alcohol services working together for holistic care), offer continuity of care and have more frontline staff.

Recommendation 8

(joint third, 7 votes)

We need early intervention for employment support. The IPS is great but it must be extended so that it includes people who need it. This expansion could be funded by

'I had been off work long term due to anxiety and depression, but when I found a window of stability, I decided I would try and return to work. It was a big thing for me to try after dealing with my issues. I had heard of a sheltered employment provider and made an appointment and started attending.
I asked my advisor what I should put on my CV. He told me to be honest. So I put on my CV that I had previous mental health issues and not been able to work for some time. When I applied for positions I did not get one single reply. It really sapped what little confidence I had left. I found the employment service virtually useless and so I drifted back into the benefit system with my self esteem lessened because of my experience. There is not much out there if you are an older person and when you have experienced mental health issues too, it seems it is nearly impossible to find suitable and/or supported suitable employment. I was told by employment agencies I tried to find work with, that if one has been out of work for two years then they will not employ you at all regardless. I feel that I am on the employment 'scrap heap'.

'I was employed in my first job for 23 years until the company closed down but managed to find another job not too long after, which I was at for 8 years until being made redundant due to cost cuts. I now find myself, not far off 50 years old trying to find employment with no qualifications, hardly any computer skills and in an environment geared around school leavers. I signed on, which was soul destroying and the DWP staff were totally unhelpful, making me feel worthless, I carried on signing on as long as possible after my 6 months jobseekers allowance came to an end, but it all became too stressful and I had to sign off.

All of my confidence had gone, I cut myself off completely from friends, family and the outside world, not opening my mail or answering the phone, I'd lost interest in everything, spending all day ruminating about past events and hating myself for even being born, I'd started to make plans to end my life as I no longer wanted to carry on but thinking about the devastation it would cause my partner, I decide to see a doctor, he was more than supportive and I managed to get the help I needed.

My recovery has been a long process, I now feel ready to go back into employment but unfortunately I'm in a even worse situation as I now have to disclose a long break in my work history due to mental illness. This is why I feel so strongly about introducing support back into work schemes for all who want it, being in work is good for mental wellbeing, building confidence, combating isolation, the economy and so many other things'.

commercial organisations/private-sector e.g. banks.

Recommendation 9

(joint fourth, 5 votes)

Trained students and people with lived experience giving talks in schools on mental health

Recommendation 10

(joint fourth, 5 votes)

Create an educational document that defines mental health to be used in schools, colleges, universities et cetera by champions, mentors, students etc.

Recommendation 11

(joint fourth, 5 votes)

Job Centre staff, need more awareness of the dangers of placing people with mental health issues/illness in inappropriate jobs. Read more choice in deciding which jobs are appropriate for us. This should be strengthened by GPs and Job Centre staff liaising with each other.

Recommendation 13

(joint fifth, 4 votes)

Services should be holistic (physical, mental and spiritual), accessible to everyone, and

'I am a wheelchair user. Countless times I have been refused a bed at a mental health hospital or a respite bed because they did not have adequate accessible facilities. I've been left sleeping on the floor due to being unable to access a suitable room. I've been forced into unsuitable transport and injured when being transferred between hospitals. I've been left to shower on the floor in a mental health hospital because they couldn't source a shower chair. I've been advised to do things by the mental health team that my physical health team say is actively harmful. I'm currently being denied access to psychotherapy because there is no accessible transport available to take me there. I cannot use the phone due to an auditory processing disorder. Countless times I've been told to ring a crisis access number. I can't. I have had multiple suicide attempts as I've been left with no accessible support. There is no joined up accessible to all service. This needs to change. Urgently'

'I study Creative Expressive Therapies, which involves using different art forms such as music, dance, drama and art, to help those with learning disabilities, mental health, etc. This type of therapy has worked effectively with numerous people for it gives them a chance to express themselves through creativity. What is most important about creative therapies is, it is not about the end product but about the process, example: a person is drawing a picture but it does not matter if it is perfect or not; if that person is feeling good while in the process of drawing, then it is working. The same method can be applied to alternative therapies too, such as gardening. By using this type of therapy it is giving that individual an opportunity to discover something new about themselves, as well as enjoying a new hobby.'

offer creative and alternative therapies e.g. qualified artists

Recommendation 14

(joint fifth, 4 votes)

Care plans need to be regularly updated and kept current

Recommendation 15

(joint fifth, four votes)

Make budgets transparent so we can

'It has been wonderful to be a part of the Citizens Jury. We believe that public funds are at stake. It is public funds and so we believe that the budget for mental health services and its sub services and the out goings to external and private services should be shown in its proportions annually. These statistics can be represented via pie charts and maps for which services overshadow which regions. This would be entirely useful for service user groups such as ours to review services more accurately rather than clutch at straws and assume."

understand where money is being spent e.g. on the trust website

Recommendation 16

(joint fifth, 4 votes)

Promote employers who have a history of supporting people with mental health issues through for example a directory of good employers

Recommendation 17

(joint fifth, 4 votes)

Encourage employers to give short-term work tasters 'stepping stones' e.g. voluntary work opportunities prior to paid employment, which are choice based

Recommendation 18

(joint sixth, 3 votes)

Raise awareness of mental health issues

'We need to train GP's to engage with patients more. For example, in the past I was refused Counselling by a GP, who refused to refer me for no reason at all.

A positive experience was when the police treated me with empathy when I was in a crisis situation, due to experiencing psychosis. They were at my wavelength. This is how it should be done!

The triggers of my psychosis were:- being treated like a criminal by security staff in a town centre (who followed me everywhere) and being bullied by my Landlord.

Professionals must apply empathy. Empathy is about caring and showing concern. It should be the driving force to reach out to vulnerable individuals. Professionals should therefore equip themselves with the knowledge of Mental Health illness and who to contact if witnessing a crisis situation or if someone is in need of advice. Delivering this knowledge to ordinary people, for example in the form of leaflets or training programmes is needed right now!'

amongst GPs, A and E, police and any first responders, to encourage empathy

Recommendation 19

(joint sixth, 3 votes)

Greater opportunities for work and training for older people (50+)

Recommendation 20

(seventh, two votes)

Provide more entry points into work for young people with mental health issues e.g. apprenticeships

The role of the Citizens Jury

1) **Continue to meet as a group once a month for coffee and to support/volunteer for any projects people are working on.**

2) **Feedback from Commissioners on the implementation of the Citizens Jury recommendations including reasons why something hasn't been done and implementation timescales**

Joint meeting with the Commissioners

Citizens Jury members presented their recommendations to members of the West Midlands Mental Health Commission at a joint session on May 25th at Birmingham Library.

Members of the jury met in advance of the session to plan the most effective way of using the time available to them. They discussed at length the purpose of the event, the roles needed to make the event a success and a structure for the gathering.

On the day the group presented a summary of the process before presenting the recommendations interspersed with personal stories that served to illustrate the importance of each recommendation

After the formal presentation, participants were invited to pick a theme they felt they could influence and were interested in. Each theme was allocated a meeting space, with pre-agreed jury members hosting each small group discussion.

The session finished with a vote of thanks and a commitment from the Commission to meet again with members of the Citizens Jury before the Commission's recommendations are written and launched.

Members of the Citizens Jury have agreed to continue meeting beyond the sessions described in this report.

Appendix 1: Questions for the commentators as asked by the Jury members

Questions for Ian McPherson (Centre for Mental Health)

- What works for who? Money goes to risk before prevention. Is prevention value for money?
- Is there any more cutbacks? Workforce, limited beds. Will the 6% change for the better/worse?
- What services are available after discharge from hospital beds? Especially care and support.
- What join up is there for physical and mental health services to provide holistic treatment?
- What one thing would you like to see changed?
- Could the NHS work with employers to create a support back into work scheme?
- How do we get a referral from a GP to mental health services and day centres? Why aren't we told that we are entitled to 2 hours per month from CPN's?
- What is the criteria for primary and secondary care?
- Will there be more specialist training for GPs?
- Why is there such a lack of beds?
- Why is the focus on crisis and not prevention?
- Are there any peer led services in Birmingham, if not why not?
- Why are there not more peer run support groups (peer led)?
- In services, why are academics more important than personal experience?
- Can you tell of any failings in the system that you are aware of and how you would change them as examples on new policy/ways forward?
- Will services be unified to avoid fragmentation/shortfall and failure?
- Will the value of service be at the expense of quality?
- Will things be localised with better facilities for each area or centralised?
- Why aren't there specialist A and E services?
- How can we stop private companies taking on mental health services?
- How can we improve standards in patient care?

- Why aren't services monitored closely?
- Who are services monitored by? Are they independent and objective or biased?
- Is it possible for the public to access monitoring reports? If not why not?
- Why are some areas better at delivering/combining services?

Questions for Dr Karen Newbigging, (Senior Lecturer in Health Policy and Management, The University of Birmingham.

- You said all these ideas of ours have been seen before, so what is different? I found this depressing and negative.
- Will one combined authority be a fair system as some areas have a higher percentage of people with mental health problems?
- What or when should we disclose mental history to employers? Would we be entitled to not disclose in order to gain employment?
- Which powers are being devolved?
- It's an optimistic timescale?
- Is the funding given to the local authority going to be protected re. Mental health?
- Who would regulate the quality of training to ensure standards were maintained right across each area/unit/provider?
- What can the combined authority do to actually get people into employment since the NHS has already said they want to extend the employment support programme?
- Is devolution actually going to be implemented?
- If these 'ideas' have been seen before why run this jury? It has costed £20,000. The idea of a Birmingham and Solihull mental health foundation trust running a family fun day is an

absurd waste of time money and resources. Who has sanctioned this? What will a fun day achieve? The money that went into this Inquiry how many psychiatrists could have been employed?

- I am not clear, what does the mental health commission do? Apart from NHS funding towards patients in secure units. How does the mental health commission fit in with the CQC?
- Does the mental health commission cover: learning disabilities, neurological disorders, age-related mental health issues, dementia, Alzheimer's, child and adolescent mental health services, substance misuse, alcoholism?
- Re. Devolution If the county council didn't work, what's the point in trying again? Won't we just scrap it in 10 years when it's decided there's too many layers of government?
- The five-year NHS mental plan already has focused on 24-hour service, employment et cetera so why are we repeating work that's already been done and not doing it?
- Why can't the DWP have a support back into work programme? For people with mental health problems?
- Vulnerable children in schools. What can be done to prevent bullying on Facebook to prevent children from self-harm?
- There is an age group between working adults and children/child rearing?
- How could mental health be incorporated into the national curriculum? Could there be a national diploma in mental health study?
- What about those who cannot work and have mental health problems?
- Do you have any examples of good employers?
- You mentioned children and employment issues. How about the elderly and those that fall within the gaps?
- What support is there for people of the retirement age with their mental health (there is a focus on employment and children both of which are vital but.......)
- Individual help was mentioned re. Getting back to work. Where and how may this be accessed?
- How can employers and staff force become more understanding and considerate to a vulnerable job applicant?
- Why would the government go to universities rather than the NHS for research and

information. Why aren't the better doctors working for us (NHS)

- The gap between physical and mental health services. What will be done?
  Why are some patients prescribed medication by GPs and other patients in the care of consultants?
- On what basis are people given a CPN?
- Would police/firemen etc have only basic psychiatric training?

Questions for Steve Appleton (secretariat W. Mids Mental health Commission)

- Please give a barebones explanation on how the West Midlands combined authority will work?
- Intervention could, or we feel it could, be introduced early re. Schools
- Paula Hampton is Birmingham's mental health champion. What is her role?
- As the Citizens Jury model been effective in other areas? Have other recommendations affected change?
- Steve, what do you hope the commission will achieve?
- If Karen said these ideas have been said before, why have they not been acted on?
- Is devolution a foregone situation? And we have no say in it and it's a done deal?
- If recommendations are accepted when will likely be implemented by?
- Are there votes in mental health provision?
- Will the West Midlands combined authority commission mental health services? Do they get the money?
- How can the system be changed when there is so much wrong with it? E.g. being refused psychiatric services because of waiting times even if suicidal.
- Resources. Money and services, are there areas that have been recognised that can be cut back or transferred to improve other services?

Questions for Nicola Oliver (IPS Employment Services Implementation - Regional Trainer, Northamptonshire NHS Foundation Trust /Centre for Mental Health

- Where does the funding come from?
- How can the Equality Act help employers become more empathetic?
- How can people be helped without being labelled?
- After being diagnosed by a GP, people can feel depressed because of the label. How can this be prevented?
- For people who have no family, friends et cetera who have grown up without love/affection how can they be helped to have a beneficial relationship?
- If a person has been out of work for so many years and doing volunteering how can this build his/her employment history to get back into work?
- Is there a charter of employers who work with IPS?
- Do you find jobs for people or is it just a support service?
- Do you work with the DWP or are you independent?
- Do you have to be on benefits or have to be referred to use the service?
- What work is being done to educate employers about mental health and illness?
- What about people who want to work but don't have the confidence to be able to do it? What support is there for them?
- How can IPS be introduced into the West Midlands without having a negative effect on existing local services?

Questions for Paul Turner GP (Birmingham South Central CCG, Steering Group member WMMHC)

- How would you recommend the commission improves mental health services?
- Arts on prescription. How widely available is it?
- How can primary care assist with treating people holistically? Learning disabilities/mental health. Physical disabilities/mental health.
- What training in recognising mental health issues do GP's receive?
- Who supports the mental health of GP's?
- Please define primary care mental health in lay man's terms?
- I know someone personally who is walking the streets, ranting and raving obviously insane, an ex-accountant. I tried to speak to see the CPN who said we will sort it a) how can this be allowed to happen? b) who should I call to help? Police? c) who is responsible for him?
- What determines a referral to psychiatric teams?
- Can more provision of mental health services be run from the GP surgery? Counselling etc.
- It sounds nice, but how are you going to fund it?
- How can we help people who are on the fringes of society and isolated from everyone?
- Has Birmingham South Central CCG commissioned a well-being hub similar to Birmingham cross city CCG?
- Are GPs in a position to recommend levels of medication?
- Would it be possible to see the same practitioner through the process as continuity can help with recovery?
- Can the timescale between diagnosis and start of therapy be shortened? Are GPs being trained to show more empathy to patients with mental health issues?
- How do we tackle systematic labelling e.g. 'bad' 'naughty'?

Questions for David Shiers (Former GP; former joint lead of National Early Intervention in Psychosis Programme)

- How would early intervention be delivered? Schools?
- What are the initial symptoms for early intervention?
- If you present yourself to A and E can they still link up with a NHS mental health service (e.g. RAID)?
- Would it be possible for GPs to have an early intervention service to assess your needs at first diagnosis?
- How can you complain about the service without the fear of being struck off the patient list?
- Who do you complain to if you feel you're not getting enough time with your CPN?

- How can we make the health system inclusive for all age groups?
- What one thing would you change about current early intervention services?
- 'Just depression'!! Need more help before it turns into something more. Where is the help!!
- Is there early training for teachers to pick up signals? If so, where do they refer children to?
- David, Staffordshire seems to have made good progress. Any idea regarding other areas of the UK?
- The emphasis of early intervention seems to have been placed from adolescence on, but we feel it occurs often much earlier. Do you agree?
- Is there a way of making budgets more transparent? E.g. a pie chart?
- Any plans to bring people with mental health experience to help children in schools understand mental health problems

Appendix 2: Building blocks

After the use of a series of participatory tools in sessions one and two, participants produced a set of building blocks that 'should form the foundation of a future mental health system'.

Participants worked in small groups and pairs to identify the building blocks (listed below as issues) before theming these as below

Theme	Issues
A high quality system for diagnosis that is speedy, clear, where appropriate leads to correct medication and allows early self diagnosis	More early self diagnosis information. If no diagnosis where do you go? Obtaining diagnosis from referral. Not sure how system works regarding CPN Diagnosis of mental health needs to speed up. Correct medication and dosage and dosage medication and dosage medication. Bad diagnosis can cause stress leading to suicides better training needed for doctors, psychiatrists nurses etc. people without diagnosis of mental health condition should access services
Well trained, empathetic staff.	Root out bad inappropriate nurses and doctors. Better staff training to encompass parity so it's not a case of 'what you might get on the day means inappropriate care, diagnosis, treatment'. More considerate language. More emphasis on pastoral elements of care within staff training to avoid 'horrid nurses'. More psychiatric specialist training for GPs
24/7, quick access to support that is relevant and accessible for everyone.	24/7 access to support
Early intervention in schools that breaks down the prejudice and tackles stigma and educates them about mental health issues and supports those affected by it.	People with lived experience or buddies to volunteer in schools to share their experiences. Mental health in schools. Formal education start young (primary school). Primary/secondary schools. Every child matters.

Support for people that are supporting those with mental health problems.	More support for siblings whose parents or both parents have suffered mental health issues since the birth of the child so it doesn't 'wear the illness' through exposure or mental osmosis. Good support network (friends, family, professionals etc.)
Different options/alternatives for services and different ways of accessing them are widely promoted.	Holistic and alternative treatments, not just medication. Different ways of accessing services. Free passes to social events etc. make community activity providers aware of their ability to help people in recovery and give support as they do this and resources to promote these opportunities. Creative support e.g. places of support to do relaxation, mindfulness. Signposting to groups by GP, holistic therapies, therapies – alternative. Birmingham and Solihull recovery College a place where people service users, carers, clinicians may learn to be creative. Self-assessment before the crisis. Quick access to CBT / talking therapy. Range of options to treat and recover.
Holistic services that take into account physical and mental health, provide continuity, stop people falling through the safety net and getting lost in the system, offer support for all, are local, joined up, quick to access and are focused on prevention.	Holistic services taking into account physical and mental health. Quick access to mental health services in the community. Prevention cheaper than cure, more time and cost effective. More frontline professionals to limit the number of inpatient admissions. Stop people falling through the safety net and being lost in the system. Effective joined up communication not fragmentation. Early intervention and local treatment. Support for all aspects of people: gay older people mental health etc and trans. Floating support workers actually do what they are supposed to and if they leave adequate crossover with new worker. Follow-up services (more in-depth and longer service). Awareness of people's different abilities to learn at different rates. Post crisis assessment should, self, professionals and others. Continuity of service (frequently a service starts and then ends - can cause collapse).

Being listened to: people with lived experience having a voice in their recovery and being actively involved in their recovery.	Individual care plans and relapse planning. Having a say in your treatment/recovery e.g. via creative support. Communication to improve between professionals and patients. Treat as an individual. I'm not a number! Care or control?
Lots of opportunities for people with lived experience of mental health to support and help each other: peer support.	Peer support creates greater feelings of being accepted, understood and liked compared to traditional mental health care. It allows participants to create relationships and practice a new identity in a safe and supportive environment. It promotes self acceptance and success that challenges the barriers created by self stigmatisation and anticipation of discrimination. Peer support creates a sense of hope a belief in a better future created through meeting people who are recovering, people who have found ways through the difficulties and challenges. People who have similar experiences can better relate and can consequently offer more authentic empathy and validation. Peer support promotes wellness, it focuses on strength and recovery: the positive aspects of people and their ability to function effectively and supportively rather than professionals who place emphasis on symptoms and problems of individuals. When engaging in peer support (the pier and supported) are exposed to differing perspectives and successful role models who may share problem-solving and coping skills and so improve social functioning. Peer support can improve self-esteem and confidence due to mutual development of solutions, shared exploration of feelings and the normalisation of emotional responses that are often discouraged and seen as crisis in traditional healthcare. Social isolation is often one of the most significant challenges based by individuals with mental health problems other than superficial social contact, shop assistant, hairdresser) many people have little social contact does not involve mental health staff or doctors. Peer support is about being an expert at not being an expert and that takes a lot of expertise. Peer support 1) informal, naturally occurring peer support 2) participating in peer run programmes, 3) employment of service users (peers) supporting within traditional services. Doing voluntary peer work. An expert at not being an expert. Access to support groups on a regular basis. I don't want to be diagnosed where can I go for a chat? At what stage do you use public services?

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Tackle stigma and increase Awareness in society of mental health and what it is.	Just say it be brave and explain KISS!
	We need more voices.
	Far more publicity and training for Joe public i.e. in schools etc it's better but far more needs to be done.
	Positive awareness through television rather than negative.
	Awareness education regarding stigma/understanding.
	Public aware of what are the warning signals? Triggers? Of mental health problems
A workplace that supports people's mental health with employers that have awareness and support people into employment.	Mental health 'champions', in schools and in the workplace and in society.
	Support into employment and more employer awareness of mental health needs.
	Awareness of benefits/awareness of entitlements.
	Support for mental health in the workplace

Appendix 3: River diagrams

Participants were asked to draw rivers using river features to reflect on their different experiences of mental health/wellbeing throughout their lives.

They then marked on the rivers times when well-being/mental health was low what helped them and what worked using green post-its.

On red post-its participants recorded what didn't work.

This appendix is made up of photographs of some of the river diagrams.
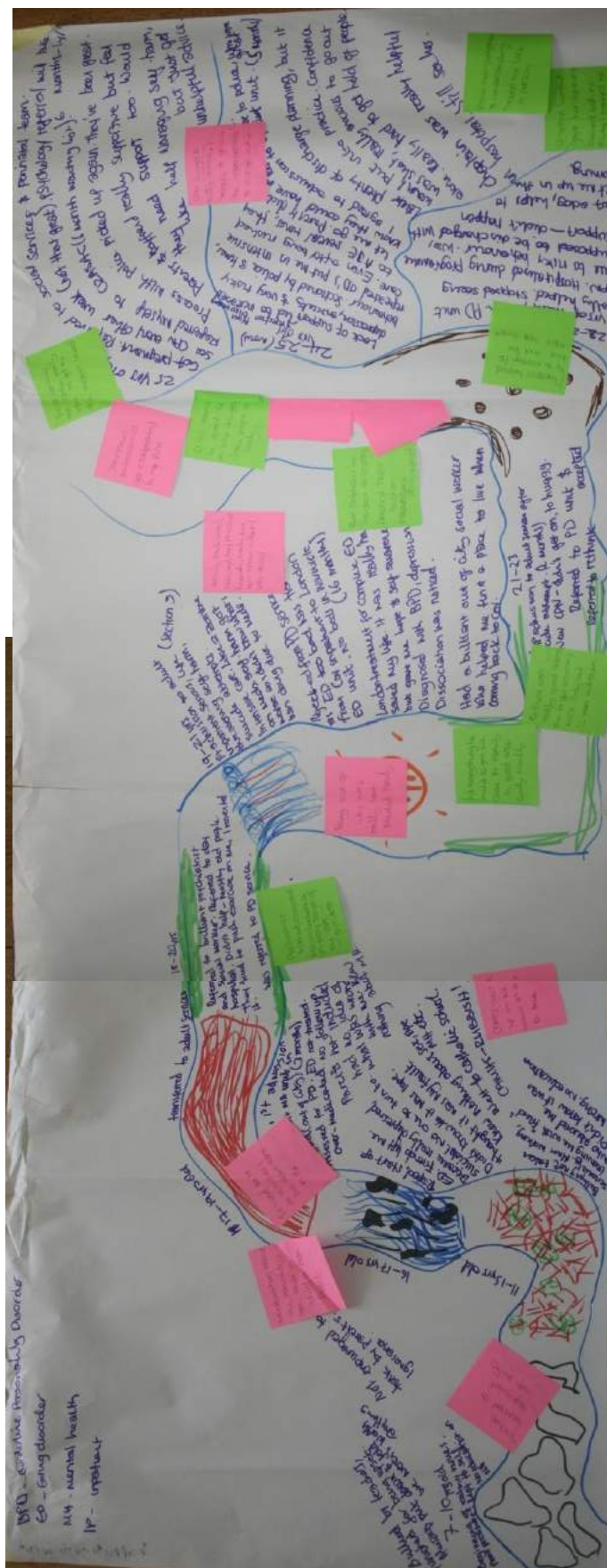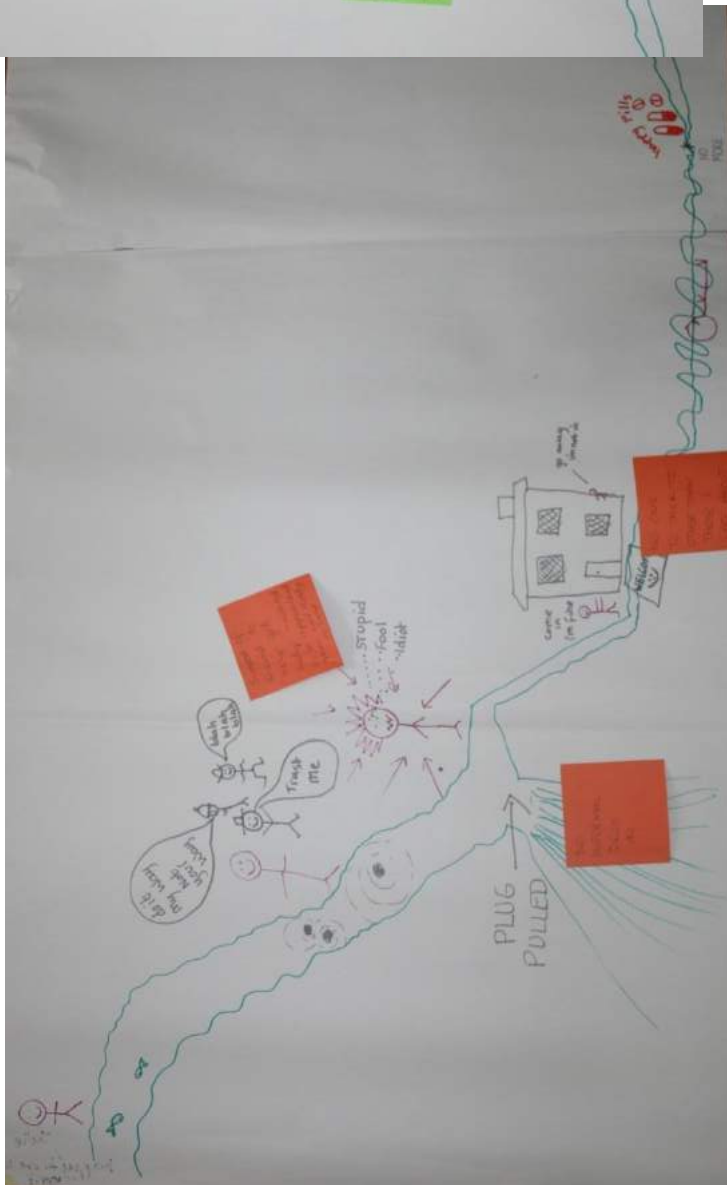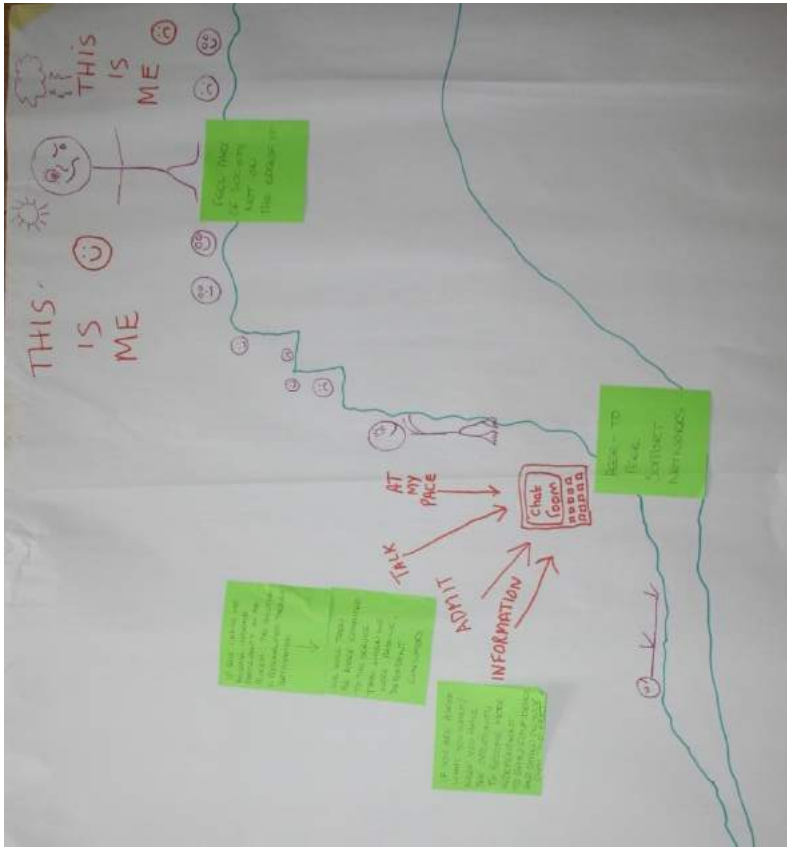
West Midlands Mental Health Commission: Citizens Jury 2016

This report summarises the deliberations of a group of people with lived experience of mental health problems from across the West Midlands in 2016 who took part in the West Midlands Mental Health Commission's Citizens

Shared Future
A Community Interest Company