

Service user led research project

“Mental Health, Citizenship and Recovery”

Supported by:
The Centre for Citizenship and
community Mental Health

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Summary of Recommendations

BDCT should work to improve staff attitudes to those who use its services:

- Service users and carers should be involved in all aspects of staff appointment from writing job descriptions, through to the interview and selection process.
- Service users and carers should be involved with the induction of all new staff
- Service users and carers should be involved in the continuing professional development of all clinical staff.
- BDCT should work with CCCMH and service users and carer organisations to enable service users and carers to be involved in these activities
- BDCT should work with service users to engage with the media and promote positive stories around mental health issues.

Employment and Education

- BDCT should support the continued work of this group.
- BDCT should continue working to promote job applications from mental health service users and provide ongoing support for them once in post. To be done by funding a User Employment Program managed by an individual with service user experience.
- In particular in addition to existing programmes of work in this area, it should consider funding a service user development worker specifically dealing with employment.

Carers and Families

- BDCT should continue work with carers' organisations.
- BDCT should work closely with carers' organisations, service user groups and CCCMH to explore the complex issues involved in carer involvement in care plans, and see that this work influence CPA and CPD.

Rights, Information and Responsibilities.

- BDCT should work with CCCMH and service users and carer organisations to produce clear, informative information sheets about all aspects of care on offer.

User Involvement / having a voice.

- BDCT should engage service users in educating staff around issues of service user involvement and service user employment.
- Staff should be encouraged to use self disclosure of mental health problems when working with service users.

Independence and social involvement.

- BDCT should take all steps possible to increase the number of service users who receive funding to arrange their own care
- BDCT should work to reduce waiting times in all aspects of mental health services.

Recommendation for Taking this work further:

Primary Care Trust to develop performance management of the quality of mental health services by expanding the work that has been started with this project and fund an expanded level of service user research.

Bradford District Care Trust to employ several service user researchers to systematically interview other service users about their experiences of services.

To collate these on an ongoing basis to form a much bigger and more representative sample of views.

This could also be used to inform individual's Care Programme Approach with researcher possibly acting as advocate.

Service users could be interviewed each year and the changes analysed.

Ongoing service user led interviews could be used to implement real change in care and attitudes.

This could have a real impact on changing services and care.

Introduction

I was employed by Bradford District Care Trust as a service user research worker. This means that I have personal experience of using mental health services. This service user perspective has been essential to this research project.

I began by reading a lot of literature about service user involvement, previous service user research projects, Bradford District Care Trust's (BDCT) Citizenship Agenda and various papers from the Centre for Citizenship and Community Mental health (CCCMH).

I also attended an individual three day training course in qualitative research methods which was put on by The Nuffield Institute in the University of Leeds.

I attended various meetings and groups and visited various organisations in order to immerse myself in the mental health service user community within Bradford and Airedale to build up trust. I also familiarised myself with some of the important aspects of the Citizenship & Social Inclusion agenda, and spoke to key managers responsible for the agenda.

When I was known and accepted at these groups, I then started to speak at meetings and organisations about the research project I had been employed to carry out. I explained that I was doing a service user led research project looking broadly at service users' experience of mental health services, recovery and finding out people's views of Bradford District Care Trust's Citizenship Agenda. I invited anybody who wanted to get involved; either to be interviewed for the project, or to get involved in carrying out the research to get in touch with me. I had produced A5 flyers outlining this research and giving my contact details.

From this process I recruited 8 people who wanted to actively get involved in carrying out the research. This group have met regularly throughout the course of the research project and have been involved in every part of the research from that point on. We began by having general discussions about the citizenship agenda and people's experiences of mental health services. Together we compiled the following documents;

- Introduction to research project (to explain and introduce the research)
- Consent form
- Question sheet
- Feedback sheet

The introduction sheet explained the projects aims. It also gave three telephone phone numbers which people could use, in case they wanted extra support after they had been interviewed. By doing this we acknowledged

that talking about their experiences may be difficult for some people and raise issues they may not have thought about for a while.

In consultation with Maureen Goddard (who worked on the initial Citizenship Agenda Document), Colin Perry and Phil Thomas, I wrote a summary of the Citizenship Agenda document. The group gave feedback on this and changed various parts of it to ensure it was as jargon free and user friendly as possible (see appendix 1).

This group attended a two day training course in research methods and interviewing techniques to equip them to carry out peer interviews. This was run by myself and Phil Thomas. At the end of this training we carried out a pilot interview in front of the group using the previously compiled questions. This was done with myself as the interviewee and Phil Thomas as interviewer.

The majority of the group then interviewed one or two people who they already knew. Only one interview was carried out between people who did not previously know each other.

Throughout the time when the interviews were taking place the group continued to meet to offer peer support and talk about any ongoing issues. During this time we compiled the feedback sheet which was posted to people who had been interviewed along with the transcription of their interview.

The interviews were semi structured with main questions which were asked in every interview. It also included some prompt questions to be used if it was felt helpful. Interviewers were encouraged to not stick rigidly to the questions, but to feel free to discuss anything that the interviewee wanted to.

The interviews were audio recorded and transcribed externally. Both the interviewer and the person interviewed were then given a copy of the transcript along with a feedback sheet. This feedback sheet gave people the opportunity to say if anything had been transcribed incorrectly. They were also given space to add anything they had thought of since carrying out the interview; to say what the experience of being involved in the interview had been like, and to say what area of mental health they would like to see researched by service users.

The next stage involved me analysing the interviews by identifying the main themes in each interview. I paraphrased these in order to get the essence of what each person had said. These 'summaries' were then given back for further feedback.

From these summaries I then put all the main points made into groups, under main headings.

The process of sending transcripts and then summaries to everybody involved has been a very valuable process. It has given the research extra information

and has also enabled everybody involved to feel that they are truly a part of this project, rather than it being something that is 'done to them'. It increases the validity of these findings, in other words that the results really do represent how the people interviewed feel.

Who was Involved in the Project?

The team of researchers consisted of 8 people, all of whom had experience of using mental health services.

There were 7 female and 1 male.

There was a variety of ages taking part spanning from 23 years old to - 61 years young.

One researcher has physical disabilities.

One researcher identified as lesbian and one identified as bisexual.

6 of the researchers identified themselves as white.

One researcher identified them self as mixed race.

The research team members had a variety of experiences of using different services and for differing lengths of time from two years to over ten years.

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11 people were interviewed; 9 women and 2 men.

There were three focus groups held which consisted of a total of 8 men and 9 females.

## **Main Themes from The Research**

Analysis of the data from the interviews revealed 15 main themes (and 6 sub themes). These being

- Relationship with Mental health worker
- Attitudes of Mental health worker
  - Respect
- Prejudice
- Talking
- Mental Health Services General
- Recovery
  - Creative
  - Physical
  - Alternative Therapies
  - Hobbies
  - Spiritual
- Medication
- Diagnosis
- Information
- Waiting times
- Inpatient stay
- Power Imbalance
- Benefits System
- Voluntary work and Voluntary Organisations
- Employment

## **Relationship with Mental Health Worker**

The area that most people responded to and with the greatest number of comments was in respect to their relationships with mental health professionals. From the whole study, this was the area that seemed to generate the most passionate responses. 8 Individuals and two focus groups discussed this issue. There were 35 comments made. 34 of these could be categorised as either being about the continuity of relationship or the attitude of the professional. There were 16 comments about the continuity of the relationship and 18 about the quality of the relationship. The 16 comments about continuity were all about the importance of building up a relationship with one worker over time. Five different people made virtually identical comments about rarely seeing the same psychiatrist more than once; everybody who mentioned it saw this as negative. "Psychiatrists aren't helpful because they're always different, you can't build up a relationship with them. They don't know you". Another stated that its "easier to speak to someone you have some relationship with".

## **Attitudes of Mental Health Worker**

Clearly, developing a relationship with a worker depends on more than just contact with the same person. There were 19 comments about attitudes of workers. (These were made by 7 individuals as two comments from one focus group). The comments people made about attitudes of mental health workers commonly mentioned the importance of feeling their worker cared about them. Other aspects of the service user, worker relationship mentioned were; not being taken seriously, not being listened to, not feeling the worker was interested in them as a person, not feeling understood, the short amount of time spent with client. One person commented that "it's harder when you meet this attitude from somebody who's meant to be helping you." Comments such as "kindness and being treated like I was important; that mattered" and "what is needed is time and support" were common. Another aspect of this relationship that was seen as detrimental was lengthy delays in accessing mental health workers.

## **Respect from Mental Health Worker**

Four individuals and one group member commented on the importance of knowing about themselves and how this was often not respected by mental health workers. There was one positive comment "My GP believed my views of myself, this was important". But the rest were negative; "My GP doesn't recognise what I say impacts on my mental health"; "my consultant didn't value my decision about how to look after myself". It is clearly important to mental health service users that they have an expertise about themselves but that often this is not acknowledged.

## **Prejudice**

People also discussed the impact of other people's negative attitudes or prejudice towards them. One person said that the "disability employment advisor did not want to work with somebody with mental illness". Another said that the "Salvation Army didn't want to take anybody with mental illness because they were a suicide risk". Another stated that she had "been sacked because of a diagnosis of paranoid schizophrenia." There were also comments about people feeling stigmatised when they collected benefits from the post office; or psychiatric medication from the chemists.

Four people also mentioned the difficulty they felt in asking workers for help. Stating that they "felt guilty, others [were] more deserving of help".

Four people discussed portrayal of people suffering from emotional distress in the media. People felt that this was still mainly negative, with a focus on medication being the only solution for all.

## **Talking**

7 out of the ten individual interviewees said that talking was very important to them. Most people found that talking to another person who was known to them was helpful, and 3 people stated that talking to people who had been through similar experiences was the most helpful to them. There was a general sense of talking helping, as it was empowering, and stress relieving. It was felt that meeting and talking to people who had got through similar distressing experiences, gave hope and helped recovery. Four people said that their friends had been a good source of support. Interestingly, though, someone from one of the focus groups pointed out that "using friends and family for support leads to guilt and being a burden on people who should be your equals".

## **Mental Health Services Generally**

The general feedback about mental health services was quite negative. Four people said that they had not received any benefit from mental health services. The main criticism generally was the over emphasis on the medical model and medication. There were also strong feelings that actual recovery comes from within. One person commented that "Mental health services can act as a crutch, but recovery needs to come from within".

## **Recovery**

There was strong support for the idea that people's emotional distress / mental illness originated in aspects other than the medical. When asked what had helped their recovery, no-one mentioned mental health services or

medication. Social and personal aspects of people's experiences were stressed. One person summed up all the comments by stating that what helped her was "anything that boosts self confidence and self esteem". This was echoed by four other people. A couple of people spoke of the importance of taking charge of their own recovery: "It helped me when I took responsibility for my own care and my own decisions". "I need to know my own warning signs".

A large variety of things were mentioned in respect to people's recovery. They can be split into categories of: creative, physical, alternative therapies, Spiritual and other hobbies

### **Being Creative**

There were 5 people who mentioned creative outlets to help their recovery. These included expression through music, arts, poetry and writing.

### **Getting Physical**

The physical category consisted of 5 people who mentioned eating properly, getting enough rest and exercise. Four of these people mentioned exercising such as football, swimming and walking.

### **Alternative Therapies**

Under alternative therapies two individuals and two people from groups responded, mentioning a mixture of Bach flower remedies, omega oils, reflexology, Indian head massage, meditation, Tai Chi and relaxation. Two people mentioned that if they had been offered complementary therapies they would have liked to have tried them.

### **Hobbies**

A variety of hobbies were also mentioned by four people; two of which included learning something new.

Three people mentioned the importance of positive emotional states of mind such as "staying positive", "looking to the future and having goals".

### **Spirituality**

There were 7 comments about spirituality / culture. Two people responded by saying that spirituality had helped them recover. One person said, "My faith helped me to get through". Spirituality was also an issue in terms of people not having their spiritual / cultural needs met or recognised. Four comments referred to this. "Nurses didn't understand my cultural needs. I needed a scholar to help build my confidence. I needed verses to read". Another commented that forced medication went against his cultural beliefs and staff showed no understanding or respect for this.

## **Medication**

There was only one positive comment about an individual's experience of psychiatric medication compared to 18 negative comments from 8 different individuals and four negative comments from two focus groups. Most comments were about the bad side effects experienced, the loss of motivation due to medication and the difficulty in reducing or getting off medication. Comments such as "they made me feel like a zombie"; "my brain was really sedated; it was horrendous" and I felt such an "inner restlessness and bad anxiety", were very often repeated. People felt that the lack of motivation experienced whilst on medication meant that they could not do the things that made them feel better within themselves. On top of experiencing distress, people then had to contend with difficult side effects followed by the problems (emotional and physical) of withdrawing from the medication. It was usually people's experience that they had no support to withdraw from medication and had to do this alone. "I had to get off medication on my own. Now I'm in a cycle of getting zombified on meds. So coming off totally, and then getting afraid of what I'll do, so going back on them again".

There were also repeated comments about the lack of information people were given about medication. People had no prior information about effectiveness of medications, side effects or the addictive qualities. One person commented that "medication is always the first port of call.... It should be the last".

One lady who was interviewed manages her own medication, by taking it when she feels she needs it and then coming off it. "I find it helpful to manage off medication, but I take it for a while if I need it". She made a very interesting point; "Talking to my peers who do take medication ..... even they become unwell and go into hospital, even though they take their medication".

One person said that they felt they got more benefits from "Taking Omega oils instead of medication. My choice. More holistic. No side effects".

## **Diagnosis**

6 different people in the interviews and in one of the groups mentioned diagnosis (and/or labelling). There were a total of 12 negative comments and two positive ones. Interestingly, the positive comments were made by people who also gave negative comments. One of the negative aspects of diagnosis was being viewed through the window of that particular label. Three people made comments along these lines. One stated; "once you have a diagnosis; everything you do is seen as a symptom". Another commented "My wife thinks I'm manic whenever I'm angry with her".

Four people said that either their actual diagnosis or information about their diagnosis was not given to them. They found this unhelpful. The two

positive comments in respect of diagnosis were about individuals being able to go away and find out more about their diagnosis from different sources.

### **Information**

Information is a subject, which runs through many of the other sections of this report. As mentioned in the section on diagnosis and medication, there are clear comments about people not receiving information about the diagnosis which had been given to them nor about the medication they had been told to take. This clearly disempowers the service user and means that they are effectively unable to make informed decisions. One interviewee stated this clearly "it is disempowering to be given medication with no explanations". Another said "people need to be empowered with information to make choices".

Besides medication and diagnosis, there were comments from five individuals and four comments from focus groups about lack of information received by service users from mental health staff. This covered C.P.A. meetings, tests and results, other resources, treatment generally, roles of inpatient staff and discharge with all comments stating that there was a lack of information given to them. Two people commented on the need to educate the wider public about mental health issues. One person pointed out that "Schools teach us what our kidneys do, but not about our emotional health.

### **Waiting Times**

When asked about unhelpful aspects of mental health services, 9 people mentioned waiting times. There was one positive comment about a GP who returned the persons calls promptly. This led to the individual feeling valued and being able to access appropriate support when it was needed. However most people (the other 8 comments) mentioned long waits to get GP appointments, being left on wards for hours waiting to see a psychiatrist. "This was unhelpful, stressful and bad for self esteem". People wanted to be able to access help when they needed it.

### **Inpatient Stay**

7 individuals and all three groups had discussions about being inpatients. Two people said that they initially felt safe when they were admitted, that it gave "respite for a while". However, there were more comments about it being "traumatic being admitted" to hospital. One person stated; "I was afraid of the other patients". Another said that being an "inpatient increases stress".

Four comments were made about there being nothing to do on the wards. There were two comments that people found themselves using their time on

the wards helping other people; rather than focusing on themselves. There were no comments made about people's experience of being on the ward as helping their recovery. The only positives were about a safe place, or respite. As one person commented "managing people at home can involve taking a chance; but it can have positive outcomes".

### **Power Imbalance**

A sense of seeing mental health workers as a challenge or an added difficulty came across from a number of people. 5 people commented about feeling they had to get into a manipulative position when dealing with workers. They were afraid of the power workers hold, to give them an unwanted diagnosis, forced medication, or forced admittance. People did not feel safe or secure to talk about their difficulties. "I didn't tell mental health professionals that I heard voices because I was afraid of a diagnosis of schizophrenia". "I was threatened with sectioning, so I started to lie to them to get me out."

### **Benefits System**

6 people commented on difficulties from the benefits system. There were general comments about staff not having an understanding of mental health issues. Two people commented that signing on and attending appointments interferes with doing more positive things. It was thought that Job agencies deter people from voluntary work (due to extra paperwork and lack of understanding and that voluntary work can actually be very beneficial to people's emotional health.

### **Voluntary Work and Voluntary Organisations**

8 individuals and comments from two focus groups implied that people were engaged (or had been) in voluntary work or voluntary organisations. It seems clear that people got huge benefits from both volunteering and going to voluntary sector agencies. I have put these two together, as people were saying very similar things about both. Four comments were around the positive attitudes of staff, they included comments about caring, being made to feel normal, treating people as individuals and giving people space. People talked about re-engaging with people and the community. Enlarging on this, three people mentioned that their self-esteem or self-confidence had improved as a result of this. People also mentioned that being given responsibilities, helping others and learning new things all helped their emotional well being.

## **Employment**

There was an overriding feeling that getting back into the work force was a huge barrier to overcome for some people. One person commented "thinking about employment is distressing. Interviews would make me hysterical". Another person also mentioned that interviews knock her confidence. Others mentioned the stigma of having had emotional difficulties and one lady said that "I am desperate to work. I could only work in mental health services, because no one else would have me". Along side the difficulties of getting back to work; people discussed the benefits of working. People clearly gain a lot more than financial benefits, such as "feeling I belong" and "to feel I'm a person again".

## **Citizenship Agenda**

A lot of the areas already discussed can be categorised specifically in terms of the Citizenship & Social Inclusion Agenda. However, in order to relay individual perspectives as accurately as possible, this section of the report contains only comments that were made directly about each section of the Agenda

8 individuals and one group member made general comments about the Citizenship Agenda. 5 individuals and one group member made positive comments about the ideals and aims, either speaking in favour of its ideals or stating that they had noticed a difference in service provision. "It is relevant, but progress is going to be very slow".

On the other hand, 4 individuals made negative comments about its ideals or progress. "I don't see it making a difference". One person felt that the Citizenship Agenda actually "doesn't take people as individuals. Citizenship agenda and social inclusion is treating everybody the same".

### **1. Being included and accepted as full and equal members of society.**

3 people responded to this point. One person expressed doubt about whether this could be achieved. The other two both felt they weren't included and accepted as full and equal members of society. One because she was not receiving the treatment she requested and one because she was not in employment.

### **2. Being able to access public resources and community facilities like everyone else.**

One person commented that the key to this for them is "about having support, knowledge and more information". There was one comment that this hasn't happened and one comment that this was an achievable aim.

### **3. A meaningful role at home and in daytime activities.**

A couple of people commented that often activities could be very therapeutic but not necessarily meaningful. One person found colouring very beneficial to her emotional well being, but she didn't see it as meaningful at all. Meaningful occupation was clearly important to 2 other people who responded. One commended on the difficulty of keeping occupied after 5pm when day centres and services closed.

#### **4. Having a basic right to live my life as I wish, without infringing others by what I say or do.**

Two people agreed with this statement and one stated that she didn't feel she had this right at present due to not being able to access the help she wanted.

#### **5. Having a balance of meeting my needs with those of others.**

One person commented that this was a good aim. Another person said that this "sounds like, if my needs conflict with another's I'll be sectioned.

#### **6. Having the right to my own voice / opinions / feelings / beliefs being listened to and heard with out fear of penalty.**

From points 1 - 12 this is the point which generated the most feedback. 5 people responded with 9 comments.

There was a feeling that people were afraid to voice their opinions because of fear of a variety of penalties. "I felt that if I didn't go along with them, they would withhold support". "I'm afraid of getting medication or services withdrawn because of complaining or disagreeing". There were comments by 4 different people along these lines.

There were also comments by two different people about communicating with mental health professionals "you have to put your symptoms in the right sort of language for them to understand".

One comment sums up what being listened to means for one service user "it's more than being heard; it's the relationship with the psychiatrist. I need them to listen to my understanding."

#### **7. Having the right to my own understanding of my problems and difficulties recognised by other people.**

Two people stated that their experience was that this did not happen. One of these added that "sometimes mental health professionals don't have good spoken English, this leads to them using insensitive words."

#### **8. Influencing decision-making.**

There were three responses to this subject. All were negative, stating that this was "not happening".

### **9. Having choices in my life.**

Two people both responded the same way, by saying this is a "good idea, but its not going to happen".

### **10. Feeling safe and secure.**

The same two people answered that they did not feel they were getting the appropriate help to enable them to feel safe and secure.

### **11. Having the right to be kept fully informed with access to clear, jargon free information.**

People's experiences were that they did not get enough information. There was a comment that "all doctors speak jargon, you won't change that".

### **12. Having support and independent advocacy available when I need it.**

Support and advocacy were thought to be important by the three people who responded to this point. One person felt that this was already happening, whilst another thought that there was not enough funding provision for advocacy.

## **Citizenship Agenda KEY AREAS OF ACTION**

### **Attitudes and Stigma.**

One person commented that mental health staff need diversity training. Another stated that "Service users should be involved with all staff training". It was felt that "because we are stigmatised our voice isn't heard". Another suggested that "BDCT should challenge the media more about mental health articles".

BDCT should work to improve staff attitudes to those who use its services:

- Service users and carers should be involved in all aspects of staff appointment from writing job descriptions, through to the interview and selection process.
- Service users and carers should be involved with the induction of all new staff
- Service users and carers should be involved in the continuing professional development of all clinical staff.
- BDCT should work with CCCMH and service users and carer organisations to enable service users and carers to be involved in these activities
- BDCT should work with service users to engage with the media and promote positive stories around mental health issues.

### **Employment and Education**

Two people commented that service users should be supported to access all jobs; not just service user development posts or support workers. In this respect it is encouraging to see that the Citizenship & Social Inclusion Group is in the process of re-instituting the Service User Employment group

- BDCT should support the continued work of this group.
- BDCT should continue working to promote job applications from mental health service users and provide ongoing support for them once in post. To be done by funding a User Employment Program managed by an individual with service user experience.
- In particular in addition to existing programmes of work in this area, it should consider funding a service user development worker specifically dealing with employment.

### **Carers and Families**

Two people commented that their experience of carers being involved by services was very variable. Sometimes they are included and sometimes not.

- BDCT should continue work with carers' organisations.

- BDCT should work closely with carers' organisations, service user groups and CCCMH to explore the complex issues involved in carer involvement in care plans, and see that this work influence CPA and CPD.

### **Rights, Information and Responsibilities.**

It was suggested that "service users should be involved in written material, especially information about medication". It was felt helpful to have written information to be taken away and digested later.

- BDCT should work with CCCMH and service users and carer organisations to produce clear, informative information sheets about all aspects of care on offer.

### **User Involvement / having a voice.**

Two individuals and one group member believed that staff do not accept service users being employed within the trust. Another added, "some staff don't want service users to know their personal information".

Three people discussed the importance of having had similar experiences when supporting another. Typical comments were; "people are better able to help others if they've had similar experiences". "They can offer better understanding because they've been there".

One person noted that there has been a positive change around the area of service user development. However, another commented that BDCT do not fully take onboard findings from service users.

- BDCT should engage service users in educating staff around issues of service user involvement and service user employment.
- Staff should be encouraged to use self disclosure of mental health problems when working with service users.

### **Independence and social involvement.**

Five people discussed this. Two commented on direct payments; one stating that this isn't providing a service; the other commented that people would need a lot of support to use this method. Two other comments were about not being able to access help wanted quickly enough. The other comment was that "social issues are my main issues; but these are overlooked".

- BDCT should take all steps possible to increase the number of service users who receive funding to arrange their own care
- BDCT should work to reduce waiting times in all aspects of mental health services.

## **Recommendation for Taking this work further:**

Primary Care Trust to develop performance management of the quality of mental health services by expanding the work that has been started with this project and fund an expanded level of service user research.

Bradford District Care Trust to employ several service user researchers to systematically interview other service users about their experiences of services.

To collate these on an ongoing basis to form a much bigger and more representative sample of views.

This could also be used to inform individual's Care Programme Approach with researcher possibly acting as advocate.

Service users could be interviewed each year and the changes analysed.

**Ongoing service user led interviews could be used to implement real change in care and attitudes.**

**This could have a real impact on changing services and care.**

## Individual's Experiences of service user led research

"I found it a very rewarding experience".

**"I felt comfortable whilst taking part in the interview; it felt like someone was actually listening, although I felt quite anxious throughout".**

"Afterwards it did leave me feeling bewildered for quite a while as I'd never been given the opportunity to talk about these experiences before"

"I felt safe, especially with the knowledge that they were service users too".

"The whole experience of being an interviewer helped my self esteem"

**"I was pleased that someone was interested in me enough to do this and have my words transcribed in print, not just 'someone' listening and no trace of the interview".**

[The person I interviewed] "rang me up the following day to say how good it had been to get things off his chest".

## Testimonial One:

"The interview summary breakdown of my thoughts and feelings on mental health services were nothing but of benefit to me.

I myself wouldn't have been able to evaluate what has or hasn't been helpful in my various treatments as everything just appeared to be jumbled up and it just felt that I was a treadmill, not realising what was helping and what wasn't. I just went along with what ever treatment was suggested at the time!

From the main points that were expertly pulled out of the Interview summary; it clarified to me what treatments had / hadn't been helpful in my recovery.

Thanks to the research project I am now in a position to make an informed choice on future treatment i.e. medication and hospitalisation have hindered my recovery whereas being treated by the home care team i.e. G.P., C.P.N. and support groups have aided (possibly because it involves more one to one, is how I've evaluated this).

If I hadn't taken part in this project I wouldn't ever have questioned what treatment has / hasn't been helpful. For example, if I've experienced a time of crisis and a nurse or other professional suggested I went into hospital (this happened three times) I just went along with it. My interview has given me the proof and insight (so to speak) to challenge this and say "but look, that hasn't helped in the past, can I have home care".

Basically, what I'm trying to say is the project has been a form of treatment in itself for me. It has enabled me to recognise my own strengths and weaknesses, let alone those of the mental health system!

As for the Citizenship thing; I still stick to what I feel in that each and every one of us is unique in themselves and have their own individual needs. The Citizenship Agenda is in danger of putting everyone all in one box. Maybe it's too 'educated' for me to understand it properly; I wish I could get my head around the

philosophy of it, but the more I think about it, the more confusing it becomes!

Aside from that aspect, the research project as a whole has been an invaluable experience, certainly to me and I'm sure to all involved.

I would be very keen and willing to take part in any further future studies of this nature."

Testimonial two:

"Citizenship- what's that mean" We all chorused, it sounded like something from a Roman Senator.

"Well it's this and err that and errr this"

"Yes but what does it really mean"

Nobody knew, not 100% anyway, we all had an idea but weren't sure.

So what did we do?

We broke down the citizenship agenda and built it back up as something we could understand and ultimately work with.

We came up with our own definition of citizenship, and from that looked at what it meant to us and what we could give the research. We weren't just lab rats being prodded and poked for an end result. We were involved in every aspect of this research - it was ours!

We have been included, informed and kept up to date at every level and agreed who why and what the research should be.

It's been fun, at times it's been hard, I've met a lovely bunch of people and I've learnt new skills and a bit about myself.

Is "citizenship" just a buzz word, who knows - possibly!  
Has this experience been worthwhile - definitely!  
Will this research make a difference - it already has - to me!"

### Testimonial three:

" I became involved in the project because I think it is important for the future of Mental Health services in Bradford and Airedale.

I have attended most of the meetings in addition to the focus group preceding the launch of the project. However, I did not become involved in the interview stage because of personal circumstances.

I have thoroughly enjoyed taking part in this project; meeting new people from different backgrounds, but all with a specific interest in Mental Health.

I have learnt more about the Citizenship Agenda and its principals.

I have also completed a two day community research methods course which was offered to project members on community research methods in October 2005.

My personal experiences of Mental Health services have been within Lynfield Mount, Somerset House and Airedale General. Most experiences have been positive.

I think the Citizenship Agenda principals are very positive but I do wonder about the timescale within which these changes may take place e.g. changing people's attitudes, and stigma which is attached; both from a professional and service user angle.

I still think there are too many groups trying to work towards the same end. How about trying to work together more and duplicating less?

It would be a great stepping stone into the future for clients (service users) and professionals to share their combined knowledge and make a real difference for the future of mental health in Bradford and Airedale

Thank you to Sue for co-ordinating the project and carrying out such a professional job."

## Testimonial four:

“ I believe that mental health service users and survivors are the ultimate experts in mental health. In this area, text books and qualifications can never equate to the value of real experience of mental distress. Although painful, upsetting and impairing, these experiences are priceless in helping create services that can really help to make a difference in people’s lives. However, we struggle to be heard in both mental health services and society in general. I became involved in this project as I wanted to help to address this centuries old imbalance.

The project has been fascinating. By being service-user run, we negated the power issues that are often present with professional, and so I believe our results are truly congruent with service user views. That is not to say the project was easy. As you can imagine, the interviews we conducted brought up a lot of emotional issues. Again here, the project being service user run was helpful, as there was a deep empathy and understanding that is not often present in professionals.

The group itself has been fantastic to work with. Enthusiastic, committed and passionate about the research project, I think we have worked really hard to make it a success. Sue has been a great co-ordinator; both professional and down to earth. On reading the results I think it is clear that we covered a lot of relevant areas and uncovered some interesting results. Personally, I found a lot of new very valuable views and experiences that will be helpful in my work, studies and health, as well as meeting some really lovely and interesting people along the way. Overall, I’ve found the experience very empowering. I’d like this project to be the first of many, as I think there is still a lot of work to be done in this area.

I hope that everyone here today will be able to use the results and that the project will go some way to improving mental health services. I especially hope that all the professionals here today will be able to use it to help to improve upon their own practice. I will certainly be passing a copy on to my care team and be awaiting results!”

Appendix One:

## **Summary of The Citizenship Agenda and Key areas of Action**

As used for the purpose of this Service  
User Led Research Project.

**CITIZENSHIP** is about much more than holding a passport or being on the electoral roll of a particular country. Being a citizen means being regarded as a full human being, entitled to expect the same from life and the society in which one finds oneself as everyone else. On a basic level, it involves being free of discrimination, exclusion and oppression. On a more positive note, it means being able to try to understand yourself in your own way and to express that understanding in your personal way.

### **Summary of Citizenship Making it Real – Making it Happen**

Bradford District Care Trust has carried out some work into Citizenship. Various organisations, including service users (people who have used mental health services), carers and staff took part in workshops; the results identified ten common themes relating to citizenship and eight less common themes.

The ten most common themes;

|                             |                          |
|-----------------------------|--------------------------|
| Employment                  | Family and relationships |
| Attitudes                   | Information              |
| Rights and responsibilities | Service User Involvement |
| Independence                | Stigma                   |
| Choice and being heard      | Social involvement       |

From the ten most common themes, further workshops were held and finally a small group used that information to develop the following:

#### **Bradford District Care Trust’s Vision for Citizenship:**

“To create the conditions necessary for service users, carers and families to:

1. Influence the shape of service provision
2. Choose the type of help and support they receive
3. Choose where they live, learn, work and socialise without being singled out, stared at or rejected.

This will entail working with local communities to develop such opportunities”

#### **Bradford District Care Trust’s Principles of Citizenship:**

1. Being included and accepted as full and equal members of society.
2. Being able to access public resources and community facilities like everyone else.
3. Having a meaningful role at home and in daytime activities.
4. Having a basic right to live my life as I wish, without infringing others by what I say or do.
5. Having a balance of meeting my needs with those of others.
6. Having the right to my own voice / opinions / feelings / beliefs being listened to and heard without fear of penalty.
7. Having the right to have my own understanding of my problems and difficulties recognised by other people.
8. Influencing decision making.
9. Having choices in my life relating to:

- The decisions I take
  - Where I live
  - Who I socialise with
  - What care / treatment I receive
  - Who delivers my care /treatment and where
  - Where I work and what I do for meaningful occupation
10. Feeling safe and secure
  11. Having the right to be kept fully informed with access to clear, jargon free information.
  12. Having support and independent advocacy available when I need it.

### **Key Areas of Action:**

By 2008 Bradford District Care Trust plans to have a citizenship / inclusion model in place. In order to make this happen Bradford District Care Trust identified the following areas of action:

#### Employment and Education

Increase the numbers of service users who are employed by The Trust.  
Develop easier ways for service users to access employment and education.

#### Carers and Families

Carers (including young carers) to have clearly written care plans that include what to do in a crisis.  
Care and assessment to take account of family situations.  
Issues of domestic abuse to be included in care plans.  
Enable women using maternity services to access (other) mental health services quickly when needed.

#### Attitudes and Stigma

Involve service users in training for all staff.  
Work with service users to promote positive images in local press.

#### Rights, Information and Responsibilities

Provide clear, simple information about: treatments, alternative treatments, the effectiveness of treatments and individual's rights.

#### User Involvement / Having a Voice

To have a clearer way of involving service users in service development.  
To take on board the findings from service user work.  
Improve the experiences of service users from black and minority ethnic backgrounds.

#### Independence and social Involvement

Increase the number of service users who receive funding to arrange their own care.  
Ensure that people's care and assessment involves looking at their social issues.

## **Appendix 2.**

### **Work Produced by groups at the Dissemination Event:**

#### **1. Pros and Cons of Service User Led Research**

##### **Pros**

People interviewed feel more comfortable.  
Greater accuracy and empathy.  
Increased validity of research.  
Empowerment.  
Therapeutic sense of 'being heard'.  
Motivation.  
Transparency of interest.  
Being valued.  
Answers more likely to be open and honest.  
Benefits of getting involved in research (self esteem etc).  
More likely to ask the questions service users want asking.  
May be more likely to be read by staff because it's less academic.  
Kudos; being seen as a leader in this field  
Honest and open.  
Less guarded.  
Same wavelength.  
Relevant questions.  
Limitless  
Peer support  
Empowerment  
Only way to performance manage the organisation.

##### **Cons**

Representativeness.  
Who values it / how is it received.  
Poor literature.  
Low status of service users generally.  
Expertise or experience.  
Failed to engage BME communities.  
How to access users who aren't 'involved'  
Lots of effort for no pay!  
Discussion of past experience may bring up distressing things.  
User researchers may have vested interest in getting a certain slant to answers.  
May be ignored if care trust doesn't find anything that fits their priorities.  
Not taken seriously  
Not proper research  
Not getting access  
Shopping list  
Funding: on going.  
Not enough funding.

## **2. What Changes Could Mental Health Workers Make?**

Ensure accessible information i.e. language.

Flexible, go the extra step.

Take time to listen.

Non-hierarchical team work.

Involving and engaging carers / families / relevant others.

Clear communication and information sharing.

Employ more service users in all roles and levels.

Issue of psychiatrists separate training: how to target them.

Attitudes of workers is key.

Structure of medical training especially training in rights / power / recovery.

Nurse training just as bad.

Spend time listening.

Need to be less task orientated.

How can workers be trustworthy?

- Need to earn trust

- Doing what they say they will do

- Admitting when they don't know

Some people have positive experiences of psychiatrists.

Caring / listening / being with people is what counts NOT latest evidence based practice.

Treat people as individuals.

Hope is key.

The right to argue (decisions made / being made).

Be open minded and less fearful.

Remember everyone is an individual.

Relationship between two people.

Give choices / provide information.

Take time.

Listening / hearing: actively.

Freedom to be where they want to be.

Appointments / venues: be prompt.

Common courtesy.

### **3. What did you get from the Interview?**

Service users have voices.

They brought the research to life.

Highlights the lack of knowledge about:  
what works  
mental health issues e.g. benefits and employment.

Positive expressions about voluntary sectors, what can be learnt from voluntary services for those in statutory services.

In-depth answers.

How would I like to be treated by mental health services workers?

Open-mind is required.

Recovery is a way of life. Model it!

Identify good practice.

Questions could be too complex for some service users.

Lots of issues that have been around for a long time: answers were the same as five years ago.

Problem of targeting people who haven't got experience of going to user groups.

May be easier to talk about experience if some distance from it.

## Appendix 3

### **Feedback from the Dissemination Event**

The following three pages contains all the feedback comments that were given on the day of the dissemination event. All comments have been included and written exactly as they were. Nothing has been omitted, added or changed.

#### **Have you enjoyed this event?**

Very relaxed style.

Definitely.

Yes, very much.

Yes very much.

Very much. A good turn out: does need more 'professionals' to attend.

Yes!! It has been excellent well planned and well introduced. A good idea to give testimonials and demonstrate the interviews.

Varied. Thank you.

Yes, very much. Shame more people weren't here to share it.

Yes, very much so.

Yes, very honest, open and enlightening.

Yes very. Great to hear from the experts.

The sense of community and empowerment it created.

True role plays.

Sense of community.

#### **Do you think this project would have been different if it had not have been service user led?**

Yes, it would not have worked.

*Yes!!! It would not have represented what service users really feel.*

Completely different and far less interesting / valuable.

Yes – issues would have been modified.

No I don't think it would have been different at all.

*Yes of course it would, what a silly question!*

Yes, because it doesn't come with professional bias / involvement.

I believe it would have been difficult to obtain the same level of enrichment and learning among the interviewees.  
Yes and missed the benefits for the service user researchers too!

**What was the least interesting part of the day?**

Role play: felt rushed at times – less natural.

Role play seemed stilted

All good

**Which part did you find the most informative?**

Personal testimonies are very powerful.

Information about research.

Role Plays.

Personal experiences: people remain human beings with illness.

Personal testimonies.

Personal testimonials - very honest and open.

Personal testimonies

Testimonies.

**Have you learned anything new?**

Yes – I learnt that a number of service user led reports have been done – maybe these should be ‘pooled’ and a meta-analysis done.

*Yes, I learnt about a new research technique and that it has credibility.*

No not really because it hasn’t made sense to me.

Yes that this is a valuable contribution to the quality of research.

**Has it changed any of your views / opinions?**

*Sadly no – it confirms what users consistently say about services.*

Yes I agree.

To a certain extent.

No – it confirms my fears.

It has made me question current practice even further.

**What areas of research would you like to see carried out by service users?**

*1. Experiences of coercion. 2. The value of spirituality / creativity.*  
Service users and the benefits agency / social security attitudes and perceptions.

The impact on service users of forced treatment  
e.g. acuphase, rapid tranquilisation.

Local media's coverage of mental health.

Users of medical treatment - good / bad.

Experiences around voluntary work / employment.

Spiritual approaches to self – discovery and self-expression.

Service users experience of emergency respite, and planned respite.

What keeps you well?

Experience of counselling / therapy.

**How have you found the event overall?**

Great .

Glad that service users are taking ownership of difficulties and services required. Need more of these events.

The testimonials were brill, but the interview was a bit long.

Brilliant!

Very useful. Thought provoking.

Interesting.

Very good.

*Really well structured to maintain interest.*

Inspiring.

Very positive approach.

**Venue?**

Good.

*Good – bit noisy in corridor at times.*  
Poor acoustics.

### **Catering?**

Good.  
Good.  
Fab curry, plastic sandwiches.  
Very good.  
Not very healthy.  
Excellent.  
No brown bread sandwiches.  
Nourishing? But not healthy!

### **Any further comments?**

*May the “voice” become one. Build on this, keep momentum.*  
Find out more about those who work with us!  
More research on contemporary mental health issues and almost as important that the research has a material effect on service provision.  
It would be great if results can be shared with policy / decision makers at a national level.  
Skills of researchers need to be used by Bradford District Care Trust and others.  
It's a shame more senior managers from Bradford District Care Trust weren't at today's event – they might have learnt something.  
Empowerment leading to social action.

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