

2018-19 Impact Report

Bury Involvement Group

Charity No. 1166584

Mission:

To empower adults with mental health conditions towards recovery and improved quality of life by providing mutual support and hope.





PART I – Introduction

Purpose

Bury Involvement Group was set up by people with lived experience of mental distress due to a lack of support for people living with mental distress in Bury. Since 2007 we've worked with the ethos of 'recovering together' based on our understanding that people experiencing mental distress have strengths to draw on and these strengths are best realised within peer relationships, which remain hopeful about recovery, are mutual and share power.

The support we offer is led by peers who have a lived understanding of what living with mental distress means and can truly empathise and provide compassionate support. Peer support challenges the traditional dynamics of the expert and patient relationship. Effective peer support breaks down the crippling sense of aloneness, feelings of being uniquely ill, and allows people to connect within a community of people that understand.

Aims

- Provide mutual peer support for people with mental health conditions.
- Prevent and reduce the likelihood of crisis or the severity of an episode.
- Reduce social isolation.
- Raise awareness about and reduce stigma around mental health through outreach work in the community.
- Act as a strong independent voice for service users and represent their views to inform practice development and improve services.
- Increase the uptake of meaningful opportunities for service users to harness the power of their lived experience through volunteering and employment.
- Provide the people of Bury with a service which is responsive and needs led.

Activities:

Peer Support

We currently provide five groups in the community every week: two focused peer support groups; two peer social groups; and a peer discussion group with guest speakers. We also provide a weekly peer support group on the psychiatric ward at Fairfield Hospital in Bury. Our service model was designed by people with lived experience. The groups we hold are: free; open to anyone over 18; from any area; who self-identifies as needing support; requires no referral and has no waiting lists. All of our support is led by people with lived experience.

Involvement & Outreach Work

BIG is also a strong independent voice for the people who use mental health services in Bury and Greater Manchester. Our group advocates for the involvement of people with lived experience within the mental health economies, with the view that this involvement can challenge bad practice and support the improvement of services through co-design and co-production. We represent the

needs of people who use mental health services across Bury and Greater Manchester on strategic boards:

- GM Mental Health Programme Delivery Board,
- Acute Care Forum,
- Safe Haven Mobilisation Group,
- Bury Suicide Prevention Group.

In 2018 we worked with the Health and Social Care Partnership to establish the first Greater Manchester Adult Service User Network. We hold events in the community to educate people about mental health in a non-judgemental and supportive way, improving knowledge and reducing stigma, and raise awareness through outreach work with professionals, employers, and across social media.

Service Level Data

2018-19 financial year continued to be a busy year for BIG with our services in high demand. Across the year our Organisation delivered 243 group support sessions in the community and we supported 406 unique individuals experiencing mental distress.

Total Attendance 2018-19 Financial Year						
Number of	2018-19 Total					
Groups	60	65	57	61	243	
Unique people	185	178	166	174	406	
Total Attendance	986	1074	854	917	3831	
Average	16	17	15	15	16	

See Appendix 1 (Attendance Breakdown) for details of individual group attendance data.

PART II – Results

This section of the report details our achievements and the positive impact BIG has had over the 2018-19 financial year supporting people with mental distress.

Demonstrating our Impact

The Organisation has always had a strong record of the positive outcomes supporting people experiencing mental distress. We use a range of methods to identify the impact we have on people's mental health, including:

- Case Studies
- Testimonials
- Self-Evaluation forms
- Anonymous feedback forms
- Group consultations

Outcome Gathering Methodology

Our approach to gathering outcomes has been shaped by our ethos, the people who use our service designed what outcomes our Organisation should collect based on what they felt was most important to them. Because of this we look at:

- Their experiences within our Organisation;
- Feelings they would like to gain control of;
- Behaviours they would like to stop;
- Positive changes they wanted to make in their lives;
- Services they would like to no longer need.

The way we gather outcomes has also been influenced by the people using the service. We heard consistent reports from people about having to complete form after form every time they accessed a mental health service for support. With this in mind the Trustees decided to gather outcomes quarterly from the people accessing our service to ensure our focus remains where people wanted it to be, on delivering a high quality service.

Case Study

This was written by a young woman who has been accessing our service in the community for several years, the only details which have been changed are those which protect her anonymity.

My name is Maddie and when I was 10 years old I was sexually, physically and emotionally abused by a neighbour. A difficult childhood has shaped me to this day. My aunt committed suicide in her twenties and my mother attempted to kill herself, both while I was only a small child. My mum suffers from depression and she was never nurturing towards me. I still find it difficult to accept that I never got the love and support I needed from my mum when I was little. All my life I've been left feeling unloved, I struggle forming relationships to this day and I always feel like people will abandon and reject me.

I ended up developing severe anorexia, this meant a lot of bingeing, purging, laxative abuse and starving myself. I become desperate and feel I can't handle life, I self-harm as this is a release for my extreme emotional distress. This brings on feelings of hopelessness and never seeing an end to it. This causes anxiety and low mood leading to another bad episode which turns into risky behaviours. I have asphyxiated, ligatured and ran out in traffic. I restrict what I eat and drink which has led to health complications. It was like a vicious circle going round and round.

When I was 16 I was sexually assaulted again, I ended up taking an overdose and was hospitalised because I was so unwell. I was sectioned and put on an adult ward. I ended up being on suicide observations for nearly 9 months. My eating disorder became more severe and I lost more weight and became bed bound, I had pressure sores and I had to have bandages all over my body. I was sent to another ward 90 miles away from home so I rarely saw my family. From 2005 to 2016 I was moved from hospital to hospital.

These years were horrible. I was threatened by staff. Some of them would call me an 'attention seeker', 'selfish' and 'irresponsible'. This all made me feel ashamed and embarrassed. I didn't want to kill myself I just wanted the pain to stop, not to die. But it hurt so much that I didn't care if the harm I did to myself killed me. Whilst I was a patient in hospital one member of staff tried to sexually assault me. My rights were taken away from me, I had little input into my care and I was treated like I was nothing. Because of the self-harm and the suicide attempts I spent over 10 years in psychiatric hospitals all over the country. When I became better, I was assessed for supported accommodation in the community, but I had to stay in hospital for nearly another two years because I didn't fit their criteria, yet I was too well to be in hospital.

Coming out of hospital was difficult. I struggled with loneliness and developed agoraphobia. I was put under the mental health team in the community. I had more say in my care but received little support as there was such a high turnover of staff I had little consistency. I heard about BIG from my psychiatrist. The first time I went was daunting but from entering the door I was made to feel welcome and everyone was friendly.

Everyone at BIG shares similar experiences and we can help each other out. We can relate to each other, not through a text book but through our experiences. The support comes from the heart. I feel more understanding from the people at BIG than from the doctors.

Before BIG I couldn't go out on my own, or at all. Now when I go I feel understood and not alone. I feel part of a community. A "BIG family" we call it. I have gained confidence and made friends and I even joined a band with some people from BIG called 'Nearly Normal'.

I get out more instead of isolating myself which has a massive impact on my mental health. I have gained knowledge and skills which have helped me control my self-harm and risky behaviours. I still have difficult times but now I feel supported by BIG, it has stopped me from reaching crisis point on so many occasions.

BIG has changed my life. I now volunteer and help run a drop-in group for people so I get to make others feel welcome and supported when they come to BIG. I never thought I'd get this far. I would not be here today without the groups and support from BIG, I owe it my life.

Outcomes

BIG has a reputation in the area as a Charity led by people with lived experience providing people with a quality service. In 2014, BIG was awarded the Queen's Award for Voluntary Services. We specialise in delivering peer support, with demonstrable impact, supporting people towards recovery and improved quality of life. As one consultant psychiatrist from Bury said:

"BIG is the greatest mental health resource in Bury. It has helped many patients stay out of hospital and been the most important resource that has helped them. Peer support is very effective and I'm a witness to this." – Consultant Psychiatrist Dr. Nihal Fernando

Across 2018-19 we gathered outcomes from 107 individuals accessing our service. Of the 107 individuals who provided feedback on our self-reporting evaluation tool, all reported at least one positive outcome.

Their experiences within our Organisation:

- All 107 people said they would recommend our service to a friend or family member if they were struggling with their mental health.
- When asked how they would rate the support they received from BIG 82 people described it as *very helpful*, while 22 described it as *'helpful*.'
- 81 people said the service was meeting their needs very well.
- When asked how they felt when they accessed our service 100 people reported being
 listened to, 94 felt respected as a person, and another 94 people felt empathy and
 compassion.

"BIG is my lifeline. It is a place where I can feel safe. I can meet with people who understand how I feel, who do not judge me and make me feel accepted and valued. I have gained a lot of knowledge and made several friends attending BIG."

Feelings people have gained control of:

Because of coming to BIG out of the 107 people we gathered feedback from:

- 94 people reported they no longer feel alone;
- 76 people no longer feel hopeless, or despaired about their future;
- 70 people no longer feel shame about their mental health condition.

"Big has had a hugely positive effect on my life and I have achieved things I never thought I could. I have made a lot of new friends and if it were not for BIG, I doubt I would have made it half as far as I have in my recovery from my mental health illness."

Behaviours people have stopped:

Because of the support provided to them at BIG out of the 107 people we gathered feedback from:

- 56 people didn't act on suicidal feelings
- 50 didn't relapse into crisis
- 33 didn't stop taking their medication
- 32 people stopped using self-harm as a way to manage their distress
- 26 people no longer need to abuse alcohol or drugs to manage their mental distress
- 23 were able to stay in work.

"I wouldn't be here if it wasn't for BIG... I would be back in hospital or dead."

Positive changes they wanted to make in their lives:

Because of coming to BIG out of the 107 people we gathered feedback from:

- 87 people had increased their understanding of their mental distress
- 81 people reported feeling part of a community
- 80 people had increased their knowledge
- 76 people get out more into their community
- 71 people have made friends
- 69 people have improved their overall wellbeing
- 69 people feel more able to speak about their distress with family and friends

"I'm alive. It has helped dramatically, coming to terms and understanding my illness and having people understand what I am going through, it has given me a more positive outlook on life, support and enthusiasm. BIG is important to my mental health knowing when I am in crisis I am not alone and there are people who love and care for me within BIG."

- 66 now have improved coping skills
- 65 people feel more resilient
- 63 people had increased confidence

- 61 people feel more positive about the future
- 58 people have improved self-esteem
- 56 people have started something new in the community
- 54 have greatly increased their quality of life

"BIG is a safe place to be myself, chat with others and not feel judged, a place where I can ask for help and advice and feel that it's ok to be me, a safe place to learn from others in a relaxed, friendly environment. BIG is the difference between just dragging yourself through the day and actually being able to cope and manage the challenges of the day more effectively – the support groups are essential."

Services they would like to no longer need

Because of the support provided at BIG out of the 107 people we gathered feedback from:

- 70 people didn't need to access their GP
- 59 people didn't need to access A&E in crisis
- 46 people didn't need to access Healthy Minds
- 44 people didn't need to access their psychiatrist
- 44 people didn't need to access their social worker or CPN
- 39 people didn't need to access the Home Treatment Team

"Put simply, BIG has kept me well, it has kept me home, and for the first time in almost a decade I have stayed out of hospital this time. BIG has given me a real focus, a role in society where I know I can make a real difference to others. There are a lot of people out there who need peer support and help on their road to recovery. Through BIG, I've been given the opportunity to turn a negative into a positive. I want to be there and make a difference to people's lives, and to help other people to be survivors just like me. If I can help just one person, then it will be worth it. I can't thank BIG enough for how they have helped me to turn my life around."

PART III - Lessons Learned

Across 2018-19 our Organisation produced a new five year business plan. A central part of developing the Organisation's Business Plan was co-producing it with a range of stakeholders. The work was undertaken to develop the Organisation's strategy. Over 2018 we consulted with the people who use our service, our personnel and volunteers, and external stakeholders from varying sectors including health, social care, mental health commissioning, and the VCSE.

The initial focus of the feedback gathering was on gaging how the current BIG offer is meeting the needs of the people in Bury, to highlight strengths and weaknesses, with the view of building internal improvement work around this feedback. Feedback from the varied stakeholders was themed into three distinct categories:

- What currently works best about our service;
- What our Organisation could do to improve the current service;

What we learnt about our work:

What is working:

Themes from the stakeholder analysis identified two clear themes which people using our service defined as being most beneficial in supporting their recovery. These themes were, peer support and social contact, both of which confirmed what we already believed when we initially formed our group. That being, there was a strong need for: greater access to peer support and the benefits this has on people's recovery; and the need for a strong social network in the community for those living with a mental health condition.

Peer Support: reported by service users, this theme was described by one person as "understanding from people who've been in the same situation" which others went on to state resulted in "being able to be more open and not feel ashamed" and engendered a "feeling of community." Volunteers and staff noted peer support as the most important element of BIG, it was noted that what BIG offers is a "chance to talk things over with people who understand" and that this lead to more "honesty within relationships, greater connectedness and recovery based on hope." Professionals also mirrored this point, with one psychologist stating peer support led to service users "feeling understood, not judged and cared for by each other" with a psychiatrist adding this "validated their experiences" and "normalised their recovery."

Social Contact: people using our service noted the importance of the social contact BIG affords, with one person saying it "it gives me a reason to get out of the flat" and others noting coming they had "made very good friends" and were "less lonely". Volunteers and staff also noted that "meeting other who can understand" was a significant benefit to the service with social contact "preventing isolation" and "reducing loneliness". Professionals and external stakeholders recognised the importance that social contact at BIG plays in recovery with similar attention payed to reduced social isolation through "coming together socially to engage and build relationships" with one psychiatrist stating this was the "most important aspect" and a VCSE executive stating "having a strong network

of mental health support groups across Bury clearly plays a positive on going role in supporting people with mental health conditions."

What we need to improve:

A major part of the stakeholder analysis was undertaken with the view of building improvements in the future, with this in mind feedback was gathered to understand what currently requires improvements in our service. Three themes were raised by people which have identified areas of improvement for BIG.

Expand offer: the majority of people using the service reported the need for BIG to increase the current offer, with people asking for "more groups", "longer hours", "more daytime meetings" and more "evening social groups". Also noted by service users was improving the introduction to the service with some people expressing how "daunting" group work was initially and how this was a barrier to access the support offered by BIG.

Increasing awareness: a consistent theme from the feedback from service users, was the importance of increasing the profile of BIG, as people reported not knowing about the service before an inpatient stay, with people saying it "would have kept me out of hospital". Service users noted the importance of online presence, particularly on social media as a key way of reaching people who are isolated. This point was echoed by professionals with a VCSE executive stating a number of people reported only finding out about BIG "by word of mouth but that after attending, it had become a lifeline to them."

Improve accessibility: This point was compounded by a message from the service users that some groups were inaccessible as they were too large in size for them to engage with, there was a general perception of the demands of group work with initial contact with the organisation seen as "daunting", especially when distressed. Service users agreed that an optimal group size, particularly for focused support sessions, was between 10-12 people. The accessibility of the service was also seen by staff and volunteers as a barrier for certain people, with one person commenting "I feel the demand for some groups means others are unable to integrate and engage in the work meaning they drift away from the service."

How we are improving from what we learn

Our goal for the coming years is to improve service user experience of our current service, whilst we design and deliver new services to expand our comprehensive range of peer led interventions designed to address different mental health issues, preventing relapse and promoting recovery.

The work to produce the business plan has led to the creation of our five key objectives for the coming years:

- Ensure the sustainability of the current service, whilst we strengthen governance, and remain a financially viable charity.
- Attract retain and develop personnel and volunteers to deliver our services.

- To increase the effectiveness and accessibility of the current service.
- Acquire a building that will enable the expansion of our current offer to meet unmet need in the community.
- Increase the involvement of mental health service users and work towards co-producing services internally, and work with external stakeholders to evaluate existing services and co-produce and deliver new services based on unmet need.

The primary focus of the Organisation over the coming years will be to strengthen our current offer and increase accessibility to high quality peer support within the community. Central to achieving this objective is the acquisition of premises within Bury, which will allow the service to expand and provide a base for future activities. With the voice of those with lived experience at the heart of our plan we are confident as an Organisation we will continue to grow in a manner which best meets the needs of our beneficiaries.

Appendix 1: Individual Group Attendance Breakdown

Total Anxiety & Depression Group						
Number of Q1 Q2 Q3 Q4 2018-1						
Groups	10	12	12	12	46	
Unique people attending	51	52	49	58	131	
Total Attendance	143	195	150	190	678	
Average	14	16	13	16	15	

Total Recovery Group					
Number of Q1 Q2 Q3 Q4 2018-19 T					
Groups	13	13	12	12	50
Unique people attending	93	93	98	75	211
Total Attendance	315	333	280	281	1209
Average	24	26	23	23	24

Total Dual Recovery Group						
Number of	Q1	Q2	Q3	Q4	2018-19 Total	
Groups	13	13	10	12	48	
Unique people attending	28	24	20	17	51	
Total Attendance	99	98	72	80	349	
Average	8	8	7	7	7	

Total Dual Recovery Group					
Number of	Q1	Q2	Q3	Q4	2018-19 Total
Groups	12	13	12	13	50
Unique people attending	74	63	55	62	142
Total Attendance	278	286	239	237	1040
Average	23	22	20	18	21

Total Social Groups					
Number of	Q1	Q2	Q3	Q4	2018-19 Total
Groups	12	14	11	12	49
Unique people attending	35	40	30	32	74
Total Attendance	151	162	113	129	555
Average	13	12	10	11	11