

healthwatch

Blackburn with Darwen



Mental Health, Stigma &
Lived Experience

Your View Your Voice

A series of monthly workshops, each with a dedicated theme, giving residents the chance to share their views and experiences on a certain topic or theme. The workshops provide an environment for discussion, debate and information sharing whilst feedback gathered influences & contributes towards our future work priorities.

Introduction

1 in 4 people in the UK will experience negative Mental Health each year.

People with Learning Disabilities demonstrate the complete spectrum of negative mental health, with higher prevalence than found in those without learning disabilities.

Blackburn with Darwen has a significantly higher percentage of adults (18+) with depression than England, 13.99% of the population as compared to an average of 11.68% in England*.

*Community Mental Health Profiles 2013

Findings

It became apparent early on that just the term mental health was a difficult one for many. There was a general consensus that the term led to confusion and lack of clarity with many expressing how often it was directly linked with negative mental health rather than addressing the full spectrum. This in most cases led to stigma & discrimination throughout the health & social care journey. The difference in approach between physical & mental health was touched upon by a number of people.

We held two workshops to discuss Mental Health, Stigma & Lived Experience in which we engaged with 20 local residents.

Language & Terminology

It was apparent that the basic use of language & terminology directly impacted an individual's experience both throughout the health & social care journey & from within wider society.

Participants discussed which frequently used words associated with Mental Health had a positive & negative effect, here are some which received wide & popular consensus.

Positive

Expert by Experience:

people found this put them in control, treating each as an individual & tailoring support & services through one's lived experience. People also spoke of feeling equal & respected.

Support:

most found this positive although the support received wasn't always reflective of this.

Diagnosis:

receiving a diagnosis was a positive experience for most as it helped them better understand their Mental Health & Wellbeing. It also usually led to further services & support & also let people identify within a peer group.

Negative

Mental Health Problems:

This received wide consensus as a negative term. Those living with a lifetime condition didn't want to identify themselves as having a 'problem'. One participant related this to physical health saying 'you wouldn't say someone had a cancer problem'. If something is a 'problem' it creates the impression it's too hard to deal with, this was the experience many felt they had received. One participant said it felt like they were placed on a 'too hard to treat' pile.

Coping mechanism:

Although a number of participants did sometimes find this useful for lower level negative mental health & wellbeing experiences, a number thought this was insulting for those with chronic mental health conditions. Being told to 'cope' again placed a responsibility on the individual when sometimes it was too far out of their control. One participant recalled how he had been told 'we all have good & bad days' during Cognitive Behavioural Therapy (CBT). They found this inappropriate & unhelpful, again creating a sense of blame on the individual.

Service User:

This received mixed feedback but many found it impersonal & a little patronising. One participant mentioned how they associated it with drug user & felt it created a sense of neediness & over reliance.

Patients:

A number of participants thought this raised negative assumptions when associated with Mental Health. Those living with a lifetime condition or more lengthy negative experiences in regard to their mental health didn't want to be identified as a patient.

Mental Health Disorder:

Disorder creates the impression someone is purposely creating it & therefore feeds further stigma & discrimination.

“You wouldn't say someone had a cancer problem”



Challenges

Confidentiality:

Many participants raised concerns over GP receptionists asking inappropriate questions within public waiting rooms. People didn't want to discuss details regarding their mental health & found it intimidating. They also felt the worthiness of seeing a doctor was placed with a non medical professional. A number of people felt they couldn't trust those in authority & felt professionals talked behind their backs sharing confidential information. This led to further stigma and 'gossip' leading to mistrust and in two cases participants said they had stopped accessing services due to this.

Stigma:

Participants found there was widespread stigma in regards to mental health & wellbeing. People talked about how they had felt excluded & negative labels stuck with them throughout their health & social care journey & from within wider society. One participant recalled how they had been labelled an 'alcoholic' due to her mental health along with their physical symptoms. Jumping to conclusions to create a false sense of clarity was widespread, and people spoke of how they were often pressured or bullied into conforming.

Diagnosis & Medication:

People often felt rushed & placed on a 'too hard to treat' pile. This usually led to no action being taken, or the easiest option, being given medication without really looking at the underlying issues or taking time to reach a firm diagnosis. Participants found this inappropriate, a waste of time & money.

Communication:

Time isn't given to clearly communicate issues. Remembering what health professional have said is often difficult. One participant said how she had been told to go on the internet. They found this impersonal & placed too much responsibility on the individual whilst not being accessible for all. There was a general consensus that people wanted to speak to someone face to face, especially when experiencing negative mental health. The use of online resources could also lead to misinformation which could further hinder ones experience.

Short term approach:

Although sometimes there was positive support & services available often these were short term lasting a number of weeks. People didn't feel this helped in the long term in many cases.

Participants felt a stepped approach with continued support would be beneficial. A number of people raised their frustrations with pilot projects, project names & criteria regularly changing along with the professionals or organisations responsible. One participant said nothing seems to have changed in thirty years due to this short term flittered approach.

“Nothing seems to have changed in 30 years”

What can be done to overcome the challenges?

Residents were asked what could be done in Blackburn with Darwen to overcome challenges with mental health support and services.

- More education & training.
- A single point of access leading to a more holistic approach.
- Designated key workers.
- Improved communication & use of language.
- Removing negative language & terminology.
- Awareness raising of symptoms and where to get support.
- Awareness & understanding of resilience
- Celebrate those who may be experiencing difficulties with their mental health.
- Hearing their personal stories & showcasing the contribution they give back to society.

If you would like more information about Healthwatch BwD, a hard copy of the report, or to see how you can get involved in future work please get in touch.

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