



THE POWER OF LIVED EXPERIENCE

the production of a report on the needs of those affected by BPD in Derbyshire
to encourage the development of a PD pathway

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BACKGROUND AND OBJECTIVES

The Derbyshire Borderline Personality Disorder (BPD) Support Groups were established in October 2017. They are run by five people with lived experience of either having BPD or living with someone who does.

It soon became evident that much of the stress and distress, experienced by our members was caused by stigma, and the lack of help from mental health services. There were no real services in Derbyshire for any kind of personality disorder (PD). Too often, people are told 'there is nothing we can do because there is no pathway'. Our objective, then, was the establishment of such a pathway.

METHOD

After much research and many groups discussions, we came up with the following:



Each category was broken down with specific problems and solutions, and was presented to NHS and local authority commissioners, and a range of health professionals, at a workshop in October 2018.

The presentation brought much interest, but no action. We needed to do more and it had to be something that we could disseminate to a much wider audience. We decided that an in-in-depth study was needed, to be presented as a report.

It was already evident from working on the pathway, that the lack of education and training of certain professionals, along with a negative attitude and lack of compassion, was what we wanted to highlight the most.

Education
&
Training

1. Experts by experience MUST be involved.
2. Work to reduce stigma among professionals and the general public.
3. Personality disorders to be included in all mental health courses.
4. Education in schools and training for employers.
5. Zero-tolerance on inappropriate and offensive language (i.e., attention-seeker).
6. Help for carers and families to understand the disorder and know what to do in an emergency.
7. Training for police, probation and prison

Being a relatively small study, it was necessary to restrict the subject to BPD, rather than all PDs. Forty members of our support groups contributed their experiences of services within Derbyshire. All allowed us to use their narratives and direct quotations; seventeen elected to remain anonymous, the remaining twenty-three have chosen to be identified by their first name only. We are extremely grateful to each one.

Analysis was done to show the extent to which the complaints we had been hearing were commonplace and part of a theme. We have tried to present a balanced account but there were more negative comments than positive.

THE REPORT

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1. Executive Summary
2. Introduction
3. Personality Disorders
4. Definitions and Symptoms of BPD
5. Government (NICE) Guidelines
6. Stigma and Misconceptions
7. Members' Experiences of Services
8. What is it really like to live with BPD?
9. What is Needed
10. Other Counties
11. One Member's Journey
12. Summary

The first part of the report concentrates on the facts surrounding personality disorders and, specifically, BPD. There is also an excerpt from the NICE guidelines, which shows an insight into the needs of those with BPD, that is rare in some services. We asked for the pathway to adhere to these guidelines.

The rest of the document is dedicated to the members of our BPD support groups so that they can explain the realities of living with the condition, in their own words. This section is split into themes that reflect experiences of stigma and misconceptions, statutory personnel and systems and, finally, what it really feels like to live with BPD.

The *Report on the needs of those with BPD in Derbyshire* was published in July 2019 and disseminated widely within both statutory services and the voluntary sector. Towards the end of 2019, Psychologist DW, attended our group meeting to announce the forthcoming pathway for those with a PD.

Lived experience of services in Derbyshire

When I asked my mental health worker what to do, he said I am already doing what he would have suggested, coming to this group. Nothing else has been put in place for people with BPD. (Jodie)

I got arrested and the police didn't give me my medication. They knew I was a risk to myself so gave me special clothes. I made a whole in the shorts because I was anxious, and was charged with criminal damage. (Dan, age 19)

The approach seems to be that if you don't get on with one treatment, you are deemed to be not engaging. They will not offer alternative treatment and you may even be black-listed for refusing to engage.

I have been a patient of a CPN from Erewash Mental Health. He was very easy to get on with and work with.

I rate both Derbyshire and Nottinghamshire street triage teams highly. They have both helped me when I have been in crisis.

I always accept help/support because I'm afraid of being told I'm not engaging, and then not offered anything else. So, I feel I have to give everything a go, even if it's not suitable for me.

My counsellor wants to put me into secondary care, but the doctors say it is a waste of time.

I saw two therapists. Both discharged me because I was too much in a bad place.

I am alone with it, and I have no treatment because they don't know what to do with me, and so I feel like I am being made to feel isolated and attention-seeking, which reflects the reaction of my family. This, from the medical profession, does not help. (Ruth)

My psychiatrist is fantastic. He's always supportive and helpful. He always has solutions and options, and ensures that I see him every four months. (Amy)

I was told to ring the crisis centre but the duty worker put the phone down on me. He rang me back later and said my regular CPN would be ringing me, but he didn't. I complained, then got a discharge letter.

The GPs need to be more open-minded in their diagnosis. I feel I was 'pigeon-holed' with depression for 10 years, which led to feeling misunderstood, isolated and hopeless.

They just increase medication and pass the buck, rather than finding out the reason why. (Clare)

OUTCOMES

The *Derbyshire Emotion Regulation Pathway* was established in January 2020, with DW as the lead. The aim was 'to have a clear structured pathway with a choice of NICE approved evidenced-based treatments', 'to improve peoples' experiences and their outcomes by providing high quality interventions delivered by highly trained and well-supported staff', and 'to include existing Dialectical Behaviour Therapy (DBT) individual and groupwork and a new Structured Clinical Management (SCM) offer delivered within each CMHT'.

Whilst obviously delighted with this news we, as a group, were concerned with some aspects of the Pathway. For example, the criteria was quite strict, with exclusions. Fortunately, we were advised that our input would be required just as much as the Pathway progressed.

Due to the COVID-19 pandemic, it has been difficult to assess how effective the Pathway has been. Some work has been undertaken online and we look forward to seeing how it develops in the future.

For a copy of the report or to find out more about the groups, please contact
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