

A long road to ...

The views of people with personality disorders about
their experiences of treatment and services
in Dorset, Hampshire and Isle of Wight

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Introduction

During the summer of 2019, Wessex Voices engaged with people who have been diagnosed with a borderline personality disorder (BPD) or emotionally unstable personality disorder (EUPD) and their carers to ask about their experiences of using mental health services.

Wessex Voices were asked to do this on behalf of the Wessex Clinical Network for Mental Health and Dementia Services, who are undertaking a review of personality disorders (PD) services with colleagues in Dorset, Hampshire and the Isle of Wight. For more detail about what we did and who we spoke to see Appendix A.

This report sets out our findings and makes a number of recommendations about both the approach taken to engaging with people in this exercise, as well as from listening to what people said.

Summary of what we were told

We interviewed 19 people, which gives a small snapshot of the views of people with PD from across Dorset and Hampshire about their treatment and care. Most of the people we talked with had recently received therapy or had been recently discharged from their therapy.

Their stories are about the treatment they have received over a period of years and they describe the frustrations they encountered in accessing support, information and treatment. They also talked about their difficulties in the early years trying manage symptoms without support or an understanding of what might be the cause.

Behavioural problems, anxiety, depression and sometimes substance and alcohol misuse were reported to be their early signs of poor mental health.

Very often people talked about finding it difficult to access an initial referral to a community mental health team (CMHT) or a psychiatric assessment without having it escalated by a crisis or serious incident or self-harm.

People said they were frustrated by a lack of coordination and felt they were not listened to, especially when making care plans and crisis care plans, as they say these are not respected and acted upon.

Prior to people accessing therapy, we heard about people being admitted to hospital on numerous occasions without a follow up.

There is a common lack of information about their illness at the point of diagnosis and people said they felt most isolated and unsupported after a diagnosis. People

said they cannot access Steps to Wellbeing in Dorset if they have a diagnosis of a personality disorder.

There is not equitable access to support and drop in services across the geography.

People ask for a courteous tone and manner to be used by all staff, and not a patronising or dismissive attitude when they are upset, especially from out of hours services. The group we spoke to who were not 'treatment ready' still have difficulty accessing basic services, such as a GP and feel easily dismissed.

The impact of treatment is positive. People report having more control of their lives. People who gone through talking therapy are optimistic about their future. Some people have requested refreshers and further follow up peer support. They would like to take part in peer group support schemes.

Carers say there is little support or information easily available for them to help them manage sometimes very challenging situations. They say they are not listened to and often ignored even when they are included as key people in care planning.

What people told us in detail

Services people have used

Most reported a childhood visit to a GP with concerns about feeling depressed, anxious or displaying behavioural problems but all respondents had experienced involvement from a range of services spanning several years, including:

GP	Children and family services	Drug and alcohol services
Schools	Community Mental Health Teams (CMHT)	Shelter
CAHMS	Samaritans	Alcoholics Anonymous
Police	Dorset Mental Health Forum	NHS 111
Social housing services	Steps to Wellbeing	Voluntary organisations
Local Authority social services	Stairways	Church projects supporting homeless and addictions
Psychiatric liaison services	SABP - Psychotherapy	Addaction
NHS Hospital admissions	STEPPS	Probation service
NHS Psychiatric Intensive Care Units	Solent Mind	HM Prison services
NHS General Hospital Admissions	Andover Mind	NHS Accident and emergency services
NHS Out of area placements for adolescents	Criminal justice system	The Retreat
	Universal Credit	NHS talking therapies services
	DWP	Autistic Society
	Eating Disorders Services	

As well as attending the Retreat, those in this group said they have regular and ongoing involvement with many of the services above, notably crisis out of hours services, the police, accident and emergency, and drug and alcohol services.

Most helpful aspects of services

All those who had experienced dialectical behavioural therapy service said that this had been the most useful for them. People had the most positive experiences of services when they were treated well, with kindness or were able to develop relationships with staff. Here are some of their comments/stories:

- One person who received radically open dialectical behavioural therapy (RODBT) in Dorset said it has been the most successful treatment for them and now runs a peer support group with a mailing list of up to 18.
- One person said that Anchor House, a CMHT in Totton, has a consultant with staff that responds to them individually as a whole team so everyone understands them.
- ‘New Road’ drug and alcohol services in Southampton worked well with one person alongside mental health services and this dual support has really helped.
- Bournemouth’s Retreat ‘drop in’ was praised for their support during a crisis because “being here can take away the hurt for a while.”
- “The Retreat because I have friends here.”
- One person said, “My support worker from the Austistic Society has given me above and beyond their contracted time to help me.”
- One person said, “Police can be very good, they come in, sit down and have a cup of tea with me when I am upset and just help me calm down.”
- Dorset Mental Health Forum’s Wellbeing Recovery College has been useful to understand symptoms but is only available during working hours.
- A carer and cared for person in Hampshire said, “Family Connections has been good for us” because they could work together there.

Information about diagnosis and support

There was no consistency about the information people were given at diagnosis. People described being given a diagnosis as helpful but little explanation or information was given to them of what that meant. People described being discharged from CMHTs shortly after a diagnosis and said they then felt they had no support. Most people said there was a long gap between a diagnosis and having a therapy to learn about what it meant.

- Most of the Retreat group said they had been given a diagnosis of a personality disorder but knew little or nothing about what it meant.
- Three people discovered their diagnosis by reading it on a GP monitor as part of their medical notes.
- One person said they felt relieved at the diagnosis as it “was probably the biggest step forward.”
- One person said “diagnosis was helpful - it helped me understand the reasons for my personality.”
- One carer said they have never received any information.
- One person had been misdiagnosed for a long time and now has a new diagnosis that fits their behaviours and feelings, which means managing and understanding their condition is much better.

Treatment options and choices

Most people said they were not aware or were not offer any options. Most said they were prescribed medication and were put on a waiting list for therapy. Most people said that it was at this point that they were discharged from their CMHT and said they felt there was little support for them.

- One carer said their cared for person had misheard and misunderstood their diagnosis and took medication on the grounds of the misheard illness.
- One person had an appointment but received the letter confirming date and details after the actual scheduled appointment. They were then told that because they had not attended the appointment, they were not engaging and were discharged from their CMHT.
- One person self-advocated for a talking therapy rather than strong prescribed medication on grounds of their former drug and alcohol use. This decision was respected by the prescriber.

Overall experience of treatment and care

Prior to their diagnosis and therapy, people experienced many different services and generally said they had poor experiences of these. At this point their care was uncoordinated. Crisis care plans were either not read or not available to read in out of hours services. People said that they were often misinformed about their care and treatment.

- “Being listened to is important when I am upset. I don’t want to be told I should breathe. I have been doing that for fifty years.”
- One person said his medical notes have not followed him when he moved from another part of the country. He is currently prescribed a lot of strong medication without reference to his previous history and is worried about it. He does not take every medication as he is homeless and feels some of the medication makes him less alert and it makes him more vulnerable on the street.

Once people were treatment ready and given access to therapy and ongoing support their experiences improved.

- “Both treatment and support are equally important.”
- “Devoted staff helped me through and through.”
- ‘STEPPS - I found the programme extremely helpful and beneficial for my recovery. Two trainers were very understanding, helpful and knowledgeable. I enjoyed going to these sessions.’
- “Realising other people felt the same way. I think I was diagnosed well before the DBT we all had the same diagnosis in the group. If this was by design, we all had a common factor. The fact we all had the same diagnosis was really helpful. It was probably hard to run the course, but it was helpful to know there was a sharing.”

What could improve treatment and care

People who have been treated and supported through therapy feel positive about those services. On discharge from therapy, people say they feel a lack of follow up support and some would welcome becoming peer supporters. Some people we spoke with are involved with peer support and talk positively about it.

Looking back over their experiences, people talked about the frustrations of their journey. Poor communication, a lack of understanding about their diagnosis, a lack of continuity of care and coordination, a lack of being listened to and being treated with respect contributed to these frustrations.

People want to be treated with courtesy and respect, including around their decisions and not having assumptions made about them:

- “I should be treated like a person not a number.”
- “I want to be liked and respected.”
- “Train people to have a good manner and tone as they can be so dismissive.”
- “There is an assumption from professionals that people with a personality disorder know about their emotions and know what they mean.”
- “Read care and crisis plans. My crisis care plan was not read. It said no admissions, but I was admitted. I could have been treated at home according to the plan.”

People - patients and carers - talked about feeling isolated without support after the person’s initial diagnosis and beyond.

- “Biggest problem is feeling isolated and having nothing but an out of hours telephone number to call.”
- “The out of hours answer phone was on and I had to ring sixty times before I could get through.”
- “More support at the beginning with better communication, to make sure they’re diagnosing people within the early stages and not fobbing them off. To discuss a recovery pathway too and go through the necessary steps to get the support that individual needs.”
- “One thing I found is a disappointment is the aftercare. Once you are discharged from CMHT there is very little to carry on with like refreshers. I was told there is a load of stuff online I can look at.”
- One person said, “Support groups for families/carers during the whole period of a patients mental health journey would help as I know it really affected my mother’s mental health.”

- Carers talked about being uninformed and unsupported and not being noted in care plans. Carers also talked about a lack of understanding about how mental health illness impacts on the family. One carer has been offered support and therapy for the first time to help them cope after many years of being emotionally abused by their relative with a personality disorder.

Final comments

People who were positive about their treatment were also aware that there is little follow up or ongoing support offered.

One carer whose relative waited a long time to see a psychiatrist, said she was disappointed that medication and concern about weight gain (the least of their problems) seemed more important than a conversation about therapy.

One carer who had no information or support said “I know he hasn’t chosen to be like this but neither have I. I want to know why. All I can say is that it is an ugly illness. It’s not cute and it’s certainly not cuddly.”

People reflecting on their treatment commented:

- “I have come a long way. I think I am at the beginning of my journey. I have gone back to work since 2011 and am now working with people who are still idiots etc. Before the therapy and diagnosis, I wouldn’t have the tools to work round them.”
- “My GP didn’t have anywhere to refer me, but I should not have had to attempt suicide to be picked up. Earlier prevention, aftercare peer support which I have volunteered to give and receive support, but it never gets off the ground. It gives you a space to talk about things in a safe place.”
- “I have a choice of what road to take, I can take stock and think.”

- “I know I will always have an underlying BPD and it will never go away or be cured and that it could resurface, but as I said I am more in control now and have learned how to handle situations which I couldn’t before.”
- “I think it would have been really beneficial to have someone attend a session to hear how they recovered and life doesn’t have to always be that way, as I used to always think I had no future and could never live a happy life.’

Conclusion

The conversations with this relatively small group of people have been rich and insightful. We learnt lessons from undertaking this patient engagement (Appendix B) and have made recommendations about future exercises below.

People who have been through talking therapy are positive about it and say how they are now able to live their lives feeling in more control. This type of treatment works. However, it is not to say that there are not other treatments and methods that are also successful in treating people with PDs.

Waiting times are lengthy for people to access treatment and the gap of support services either side of therapy is common. Many diagnosed people who are not ‘treatment ready’, remain vulnerable and there is a lack of clear information for them and their carers about their illness and treatment. As well as a lack of support, they are frustrated with poor coordination of care. Drop in support is not universal leaving people isolated. People say services can lack compassion, courtesy, respect and people don’t feel listened to. They will continue to access multiple services and continue living with poor mental health.

In conclusion, one person said a lot more people will be living with poor mental health if we do not develop better early interventions now.

Recommendations

From listening to people with PD and their carers, we have heard some consistent themes from which we would make the following recommendations:

- As part of the review of Personality Disorders, reflect on the positive experiences and outcomes of those who have been through talking therapies and consider whether treatments can be made more consistent across Dorset, Hampshire and the Isle of Wight.
- Ensure that people are given and understand their diagnosis of a personality disorder and help people make sense of it. Make clear what treatment options are available and set out a clear pathway at the point of diagnosis, including to carers. Make sure that clear information is available and provided about personality disorders, including to support carers, at the point of diagnosis and beyond.
- Provide better access to early support and accurate signposting for people and carers whether patients are treatment ready or not.
- Provide training to all staff, including those from out of hours services, about what it means to actively listen to people and their carers and how to treat them with dignity and respect.
- Ensure care plans and crisis care plans are made readily accessible and acted upon appropriately at any time.
- Review access to and the availability of drop in and support services throughout the area, including out of hours.

- Continue to develop and promote peer support specialist projects.
- Further explore people’s experiences of using multiple services before they are treated and at their most vulnerable, for example through ‘customer journey mapping’.

In terms of recommendations about how to engage with people with PDs, we set out some learning from our approach this time in Appendix B. Our recommendation from this would be:

- To plan this earlier to be able to consider the timing of when to engage and extend the recruitment and reach, as well as involve people with PDs in the process.
- Engage with Black and minority ethnic people with PDs about their experiences of treatment and care.

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Appendix A: What did we do?

We started this piece of work by looking for other evidence of patient and carer involvement, for which we found very little. Whilst there is public information from people talking about how their illness affects them, we could not find much about how patients experience treatment and care in these services, other than the [‘Safer Care for Patients with Personality Disorder’](#) report.

The themes from this were around:

- Poor communication with patients
- Lack of understanding of PD by staff
- Access to appropriate and timely care
- Lack of treatment options offered to patients
- PD is a diagnosis of exclusion

We met with clinical leads and service managers for mental health services across Dorset, Hampshire and Isle of Wight to explore current services for people with personality disorders. We also wanted to find out whether work had been undertaken in capturing patient experiences locally and what would be useful for them to understand from patients to inform the review. We also asked for help to identify individuals with the relevant diagnosis and who had been through treatment who may be willing to take part in interviews.

We worked with a specialist mental health worker and a researcher from Healthwatch Isle of Wight to develop seven questions set out below.

1. How many services have you had involvement from?
2. Which of those services were most helpful to you? What was it about that/those service(s) that was good?
3. What information were you given about your illness and when? How helpful was this?

4. Were you given options and choice in terms of your treatment?
5. How would you rate the treatment and care you have received? On a scale of 1-10 where 1 is very poor and 10 is very good.
6. How could services or things be done differently to improve the quality of care?
7. And finally, is there one last thing you would like to tell us about your treatment and care.

Once agreed, a letter of introduction and a comprehensive consent form (available on request) were designed for prospective interviewees. This pack was shared with potential participants and voluntary organisations across the area including Solent Mind, Dorset Mind and Dorset Mental Health Forum.

We arranged for one to one interviews to take place at times and places to suit the individual in discreet public settings to enable free flowing, confidential discussions to take place. Telephone interviews were offered as an alternative. We made it clear that what was said would be anonymous and information would be kept in accordance with data protection laws.

Who we spoke to

- 19 people took part overall
- 5 people with a personality disorder participated in one to one interviews and 3 parent carers. 4 were female and 4 were male
- In addition, 11 service users attended two discussions facilitated with a peer specialist from Dorset Mental Health Forum at The Retreat, Bournemouth. Most of the group have been diagnosed with BPD or EUPD. The group were predominately men
- 13 people interviewed live in Dorset and 6 people live in Hampshire
- The age range of those who took part was from 18 to 65 years old
- No one from a Black and minority ethnic community took part.

Appendix B: Learning from this approach

The time restraints for recruitment and engagement with people, with a specific diagnosis, across the area of Hampshire, Isle of Wight and Dorset were challenging and we would welcome more time to undertake engagement in the future.

In future we would hope to allow a longer lead in time for recruiting people to interview and be aware that some people who express an interest in taking part do not attend or respond to invitations to take part.

We would schedule the project for a different month from August as many partners are on leave at that time of year. This impacted on recruitment as we were reliant on several agencies to assist with recruiting.

It would be useful to capture experiences from people from all areas. We were unable to interview any people from the Isle of Wight and more rural parts of Hampshire and Dorset.

It would have been interesting to engage with and contrast the views of people accessing The Retreat drop in in Bournemouth with another similar drop in service elsewhere.

During interviews, people welcomed the invitation to talk openly and were honest and candid about their experiences. Some people, post treatment, had described the exercise as a helpful part of their process in reflecting their experiences with their carers and themselves.