



“PD & Me”: What mental health services need to know about personality disorder

Dr Adrian Hayes¹, Stephanie Hares¹, Tori Otero²

Introduction

People diagnosed with a Personality Disorder can be maligned and disliked within mental health services. Their experiences in services can be re-traumatising, re-enacting difficult relationship styles from their past. We aimed to give a voice to people with this diagnosis, to share their experiences, be heard, and make recommendations for change. The project was fully coproduced from funding application through to dissemination.

Results

Nineteen current or recent service users took part either in workshops or fed back. A total of 72 staff attended the feedback session, including psychiatrists, psychologists, board members, care coordinators, police, GPs, hospital liaison, and AMHPs. At this event there were 12 contributions of presentations, videos, collage, artwork and poetry.

Method

We ran face to face and online workshops for people with a PD diagnosis, or related to parts of the diagnosis. In semi-structured focus groups, they described their experiences and the effects of these. They went on to feed back individually and in groups using creative means. We convened a feedback session for staff to hear and see their work.

Workshop Themes

- I am treated differently by services because of my diagnosis of PD
- I need staff to know more about the condition and how it affects me
- Services are not available when I need them
- What is important? Individual care, consistency, understanding of trauma, listening, and connection



The Inhuman Assessment

Assessors it seems are the bouncers of services,
Guarding access to a fortress they must blockage,
My frustration spills out like 100 overheated furnaces,
We are more than a tick box, pass, fail type of grade.

Our pain you see is very real,
We deserve a god damn chance,
Don't you dare shrug and say it's no big deal,
We warrant more than a rushed, quick glance.

Too many are told they're not sick enough,
How harsh can you get, when we've given up,
Dude, there is no need to be so heartless and rough,
Our emotions are already over flowing from this tiny cup.

Our health, our rights you dismiss and mishandle,
Please help us, we're human we cry,
Our lives are not something to gamble,
You leave our hope a desert landscape, empty and dry,

I cry,
I cry,
I cry.



In hospital

I overheard staff talking about an incoming admission. One of them said "not another fucking BPD-er". It reinforced the feeling that I have that I am unacceptable, and do not belong.

I have a personality disorder, but I am human.

I'm a woman.
I'm a partner, a mother, a daughter.
I'm a sister.
I'm a friend.

I am human.



Discussion and Next Steps

Feedback about the project was uniformly positive from service users and staff. Service users reported feeling heard and having a purpose, whilst staff described the material as powerful and moving. Contributors continue to work on projects including producing a leaflet 'What my Care Coordinator needs to know about Personality Disorder', artwork will be published in the Trust art magazine, and the group has been asked to contribute to further work by the Executive Board as well as research priorities and future service developments.

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