

‘DIFFICULT TO ENGAGE’

Suffolk Barriers to Support – Is it the Service User or the
Service?

Live Case Study

- 13 years in the Mental Health System
- An experience of all pathways & apparent available options
- Access to the larger mental health community
- I am not a rarity regarding this – but an alarmingly typical representation – the things YP have told me are things I have said myself
- Co-Morbid Diagnosis
- Young Persons Mental Health Champion
- **‘Difficult To Engage’**



'The Facts' at surface level - Mental Health Concerns (In Suffolk)

- LGBTQ+
 - Bereavement from suicide
- Neurodevelopmental Conditions
 - Housing difficulties
 - Family mental illness
 - High self harm rates
- COVID-19
- Children in Care & Care Leavers

The Underlying issues – 3 E's of Engagement (in MH services)

- Empathy / Humility – Kindness in a crisis, patience, the ability to listen, a willingness admit to being wrong., **respect for their feelings**
- Education / Complex Understanding – Flexible thought, scientific capacity, ability to problem solve, **respect for the subject.**
- Each Other / Communication – Understanding of language, ability to relay messages with clarity, comprehension of conversation & **respect for the other person's viewpoint**

“If way to the better there be, it exacts a
full look at the worst”

-Thomas Hardy

Empathy & Humility

“Wisdom & Purpose can be too easily twisted to Pride & Desire” - DAI

- Quotes from young people;

“It just makes you feel like not a person.” “It’s like they want us to try and kill ourselves for them to take us seriously” “They don’t care if I die, they don’t care about me do they?”

- Every single YP that I’ve spoken to has ‘those stories’
- Hostility in a crisis – I’s situation
- ‘Attention Seeker’ and other negative labels
- Stigma/Judgement around MH in an apparent ‘safe place’
- Taught that vulnerability is weakness – or reaffirmed

Education & Broader Understanding

- Closed-mindedness – unwillingness to seek diagnosis – 3+ years waitlist
- Undiagnosed Impact – Education, Relationships, Work Life
- Offer of only limited CBT without understanding pitfalls e.g Dr Mike Lloyd on Dissociation – “don’t tell them to ‘relax’, have a bath’ mindfulness/meditation can be incredibly dangerous and do much more harm than good.”
- Trauma awareness – Retraumatizing practices – one size fits all approach
- No understanding of comorbidity – “You shouldn’t be thinking about your past, you have OCD, it’s bad for people like you.” “Your illness developed before your personality.” “That’s just how autistic people are.”
- Up to date understanding - e.g. DSM 4/5
- LGBTQ+ awareness or training = ‘you can choose to be whatever you want to be?’ ‘I’m a bit too tired for pronouns’
- “I’m still not backed up by a diagnosis – so I can’t really tell work, they don’t believe me. They understand a diagnosis.” “No-one will believe me. They just think I’m lazy, maybe they’re right.”

Each Other / Communication

- **Pillar to Post** – not talking to each other internally or externally – YP has to do the run around work if family won't or **aren't able** – then labelled 'difficult' if they get lost or overwhelmed.
- When you're out you're out – back to your GP **'if anything changes'** – More Wait Lists
- You wait month or years for an assessment and then they discharge you
- Language examples – **'Superficial Lacerations' 'Low Mood'**
- Misinformation – Not listening or hearing your side
- Jargon with **no explanation – even after complex diagnosis**
- Quotes – here are some things YP have heard from service providers in **CRISIS** situations;
"What do you expect us to do?" "That was silly wasn't it?" **"Are you feeling a bit blue?"**
"You're just too difficult." **"Have you split up with your boyfriend?"**
"I deal with really bad people, that can't control themselves. **You seem like you can handle it."**

Examples of Good Practice

- Care-Co Apologising – Humility
- First Response Line Suffolk – Empathy
- Home Treatment/Crisis Team in Bury St Edmunds – Respect
- Paramedics – Understanding
- Outliers – Teachers, Librarians, Nurses
- The MH Transformation in Suffolk
- Youth Panels
- Specialists – Autism Diagnostic Team

This should be the rule not the exception

Proposals/Recs for Change

- **More Specialist and Targeted Training** – FPP etc
- **More Therapeutic Pathways** – The offer informs the service, creates oversimplifying
- **Communication and Language Overhaul** – no more ‘difficult to engage’ or ‘what do you expect us to do?’
- **Culture shift** – rewarding and sharing good practise
- **More Peer Support** – lived experience
- **Service Users Of All Ages Involved in Recruitment & Training**
- **Ideal Worker focus**
- **Support Groups** -more targeted-
- **Definitions of Jargon** - openly available
- **Mental Health Awareness for GPs** – vital as they keep getting sent back there
- **Intro Packs** – Who is who? What does it mean to be in ‘Secondary Care’?

Conclusion

“These mixed messages breed mistrust”

Not engaging is not an ‘unwillingness’ to get better

People don’t reach out for a variety of reasons

Not usually is it the desire to stay sick

But because they’ve been taught not to trust

You are necessary – it should never be completely down to the sick person to have to be the expert, that should be a choice, not a necessity for survival.

This all seems complicated but on the ground people just want to be believed, listened to, and treated with respect.

‘Break The Vicious Cycle’