

# ‘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’