Community Service Models for Personality Disorder - the Role of PPI and Design Thinking

PLAN/HTAS Special Interest Day on Personality Disorder
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Background: Mental Health Policy Research Unit

- On 22nd January 2019, Mental Health PRU (KCL & UCL) hosted a Research Planning Event on Community Personality Disorder Services
- The aim of the event was to **inform** a **future policy research project** which aimed to review typologies of community personality disorder services and assess financial costs related to treatment pathways and services.

Some key questions that we explored during the event were:

- How should we define personality disorder?
- Is the term personality disorder a useful category for service delivery? - Perhaps the biggest problem with the PD label is 'disorder' and we should be referring to 'Personality and Mental Health' services
- What current methods exist for treating PD in the community?
- Considering service models: what are the **key desirable elements** for a service for this group? How would we define success of a service?

What Do Service Users Need from Community PD Services?

There is **significant heterogeneity** in symptom presentation within the construct of personality disorders:

- irrational suspicion, mistrust, apathy, restricted emotional expression, detachment from social relationships, distorted cognitions and perceptions
- disregard for others, lack of empathy, manipulative and impulsive behaviour, abrupt mood swings, self-harm and impulsivity, attention-seeking behaviour, grandiosity, excessive need for admiration
- social inhibition, self-inadequacy, extreme sensitivity to negative evaluation, rigid conformity to rules, perfectionism

Common Factors to Inform Service Provision

Personality disorders (PD) are a class of mental disorders characterized by **enduring maladaptive patterns** of behaviour, **cognition**, and **inner experience**, exhibited across many contexts and deviating from those accepted by the individual's culture.

These **patterns of behaviour** may develop early, are inflexible, and are associated with significant distress or disability.

These behaviours may be **ego-syntonic** (i.e. the **patterns are consistent with the ego integrity of the individual**) and are therefore perceived to be **appropriate by that individual**. This behaviour can present as maladaptive coping skills and may lead to personal problems that induce extreme anxiety, distress, or depression.

Ego-Syntonic v. Ego-Dystonic

- Mental Illness v. Personality Disorder, for example OCD v. Anankastic (**OCPD)**
- Principal Difference: OCD is **ego-dystonic** and OCPD is **ego-syntonic.**
- On an experiential and clinical level, this means the person with OCD will be **(painfully) aware that what they are experiencing is a disproportionate degree of anxiety in response to certain triggers or concerns**, for instance whether or not a tap or cooker has been turned off. (Much to their possible frustration) they will also find that grounded insight and rational thinking are insufficient to defeat or dispel the anxiety, and may be drawn into obsessive-compulsive (checking/cleaning, etc.) behaviours which will temporarily serve to remove the anxiety.
- In **contrast** with OCPD the problem or difficulty may be experienced as stemming from dominant personality traits. The person with OCPD may **feel that their personality traits are positive and appropriate**, **regardless of the difficulties** they cause the individual.

Caring for Someone with Borderline Personality Disorder

- **Borderline Personality Disorder** is a condition in which **individuals fear abandonment** and **respond in emotionally reactive ways.** It may **seem** as if the person with this disorder is **looking for conflict**, at times, but this is a **conditioned response to their internal dialogue** which **anticipates abandonment and judgment** at every turn.
- Some of the **more trying aspects of BPD** are based on the emotional and psychological pain that stems from **deeply-seated feelings of shame and low self-worth.**
- Explain **ground rules** to the individual (**when they are in a good space**) so that **they know how you will respond** to certain situations ahead of time.
- It might help to **think of yourself as the counterbalance to the erratic feelings or behaviours** of the individual when they are experiencing a flare up, and to **maintain a level, calm presentation** and to step away from situations that feel amped up and harmful to you or them.
- Create a **crisis plan**: Sometimes with Borderline Personality Disorder, difficult and distressing emotions and behaviours can escalate quickly. Be sure to include the local **crisis hotline number** in the case of the individual becoming **suicidal** or **self-injurious**.

#MentalHealthPRU: What we Learned from Twitter

- Knowledge & Understanding Framework (KUF): national bespoke training programme was **formerly** delivered (by Emergence, a user-led organisation) to a cross section of organisations in a bid to provide the knowledge, skills and competencies required to work with the challenges of PD.
- Croydon Service User Network (SUN): community based support service which aims to help people better manage the difficulties associated with having a personality disorder. No formal assessment process, but membership is dependent on the completion of a Crisis and Support Plan (CASP) which takes place at the first meeting with support from other group members and facilitators. All work is carried out in the groups, and there is no care coordination or any One to One appointments.

#MentalHealthPRU: More Contributions from Twitter

- Trauma-Informed Approaches (TIA): TIAs for mental health services are strengths-based and reframe complex maladaptive behaviour in terms of a response to situational or relational triggers.
- individuals treated as ‘survivors in crisis’ who are (maladaptively) trying to cope in the present moment using any available resource.
- Stepped-Care Approach: improve the care that people currently receive - personality problems are recognised in general services - low intensity interventions are offered to those who want them - high intensity treatments are reserved for those with more severe problems
- IAPT- Gary Lamph (UCLan): people in receipt of a high intensity interventions had a better treatment experience than those receiving CBT who often felt that emotional and interpersonal difficulties were overlooked. Flexible, individualised, personalised approaches were well received.

Research Findings

Personality disorder service provision: a review of the recent literature (2017) by Sacha Evans, found (in short) that there are **therapeutic interventions which work**, but the **implementation is fragmented**.

- The **policy literature** **supports** the available **clinical evidence**, but current practice and what patients and carers can expect from services remains at odds.

Personality disorder services in England: Findings from a national survey (2017) by Oliver Dale et al. was an evaluation of the availability and nature of services for people affected by personality disorder in England (both NHS mental health trusts and independent organisations).

- In England**, 84% of organisations reported having at least one dedicated personality disorder service**. This represents a fivefold increase compared with a 2002 survey.
- However, **only 55%** of organisations reported that patients had **equal access across localities** to these dedicated services.
- Dedicated services commonly had **good levels of service use** and **carer involvement**, and engagement in education, research and training.
- A **wider multidisciplinary team** and a greater number of **biopsychosocial interventions** were available through **generic services**.

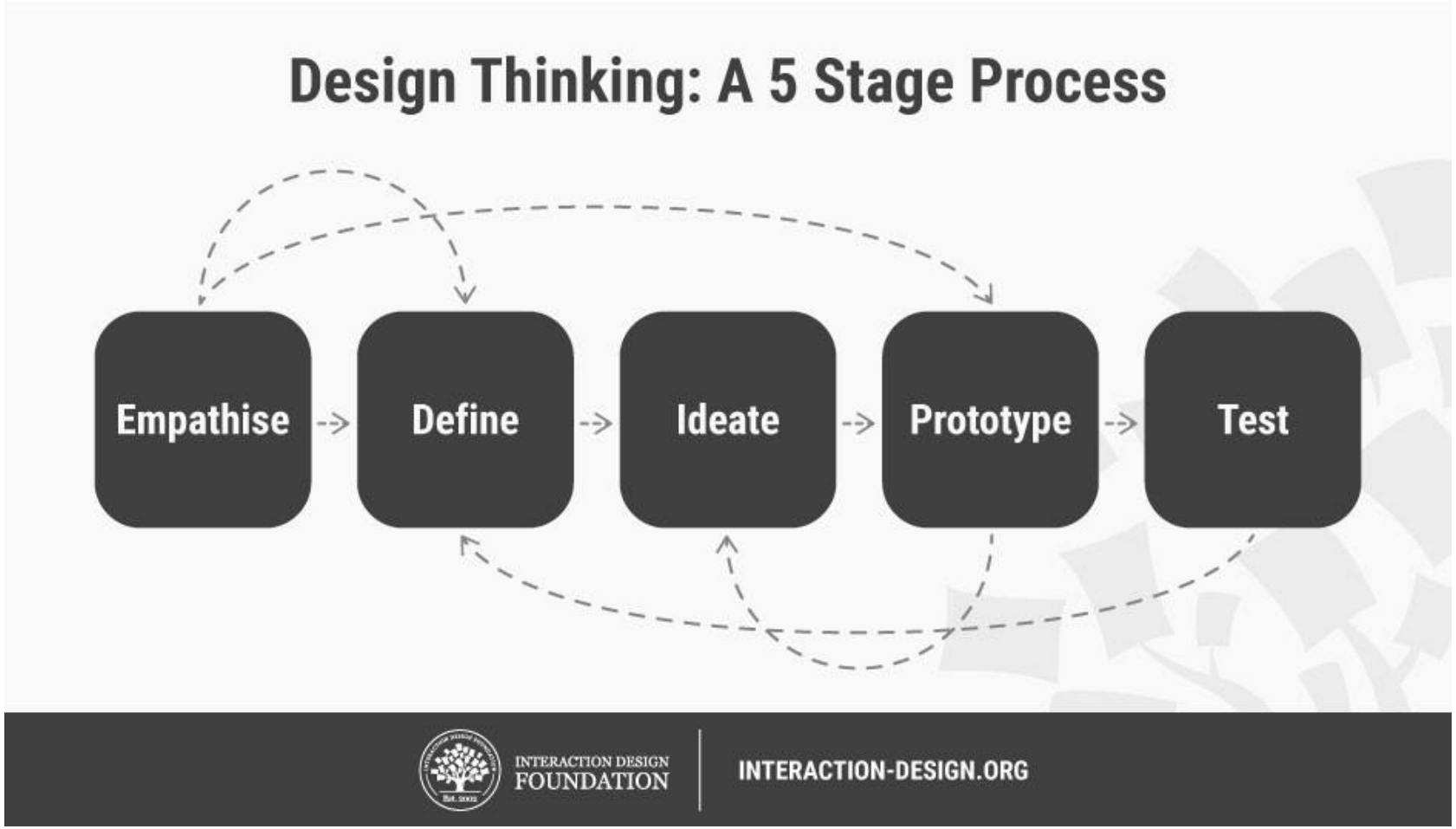
What does this mean for PD Service Typology?

- A dimensional approach to Personality Disorder service modelling?
- Or should a dimensional approach be applied to patients at an individual level?

When in doubt…Ask the Patient!

- **Person-centred practice** – what does the **patient need and want**?
  - how can they be **helped to understand their condition better**, and thereby their needs and possible solutions.
- **Psychological therapies**, for example psychodynamic therapy in which the psychologist supports the client to **understand their personality and behaviour** in terms of conscious and semi-conscious influences such as desires and emotions.
- **Determine with the patient** what **works best for them**.
- **Designing Services** via **Design Thinking Methodology** – as is currently being put into practice by NHS England secure services in developing the **new community model**.

Design Thinking Methodology



5 Stages in the Design Thinking Process

1. **Empathise**-gain an **empathic understanding** of the problem you are trying to solve. This involves **consulting experts (by experience)** to **find out more** about the **area of concern** through **observing**, **engaging** and **empathizing** with people to understand their experiences and motivations.

2. Define (the Problem)-analyse the information you have created and gathered during the **Empathise stage,** to define the **core problems** in a **human-centred manner.**

3.Ideate-start **generating ideas-**"think outside the box" to identify new solutions by looking for **alternative ways of viewing the problem**.

4. Prototype (experimental phase)- identify the **best possible solution** for each of the identified core problems. Implement and investigate the solutions on the **basis of the users' experiences**.

5. **Test** the **complete product** using the **best solutions identified during the prototyping phase.**

Design Thinking –In Practice

- The **NHS England Mental Health Secure Care programme** adopted a **Design Thinking methodology** to identify **priorities for action** and **potential solutions** through **forensic community services.**
- Between **December 2016 - February 2017**, the programme convened a **working group** of 50 participants including **experts by experience**, **carers**, clinicians, service providers and community organisations to collaborate in a series of **Design Thinking Workshops**.
- The **Design Thinking process** began by asking the working group to **consider and work with** the **experiences of people accessing secure care**, together with the **service data** and a **literature review of patient experience and needs**.
- The **working group concluded** early on that aims for transformation must include: **reducing length of stay**, supporting **step-down and recovery** in the **community** at the **earliest appropriate opportunity** and **preventing admissions and re-admissions** where possible.
- **Over the course of four workshops**, the working group **developed a number of 'prototypes' - or priorities** - to transform the secure care pathway.
- Working with the **programme's multi-disciplinary Steering Group**, **NHS England** has **drawn the prototypes together** into a **model** for a **new Forensic Mental Health Community Service**.

Pilot Site Go Live!

- **NHS England** has established **17 pilot sites** across the country which are currently **testing new ways of delivering specialist mental health services.**
- The **total budget** of the programme across **two waves** is approximately **£650 million**. All selected sites focus on **admission avoidance**, **shorter lengths of stay** and **repatriating patients** from out of area placements.
- The **six sites** in the **first wave** of the programme went live in **April 2017**. The **wave two sites** were launched gradually from October 2017 and at 1 October 2018 nine of the 11 wave two sites were live, giving a total of 15.
- A **full evaluation** of the programme is underway and will report early in 2019. **Feedback** from the sites has been **really promising**, with over 150 people brought **back into care in their area** in the first six months. In the same period **overall in-patient bed-days fell** by 2.6 per cent.

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The Sense of Self in Personality Disorder

Envel Tulving has claimed **that memory is underwritten by three types of memory systems:**

- Procedural
- Semantic - enables the preservation (in memory) of character traits and factual information, including self-knowledge.
- Episodic – retrieval of **an experience (or episode)** reliving it by **relocating herself in subjective time.**
- The capacity to and process of mentally travel through time, both to the past and the future is associated with action and decision-making, via insight and learning.

Nosology: Personality Disorder Clusters

Cluster A (odd or eccentric disorders): **Paranoid** PD, **Schizoid** PD, **Schizotypal** PD.

Cluster B (dramatic, emotional or erratic disorders): **Antisocial** PD, **Borderline** PD **Histrionic** PD, **Narcissistic** PD**.**

Cluster C (anxious or fearful disorders): **Avoidant** PD, **Dependent** PD, **Obsessive-compulsive** PD.

There is **no clinical evidence** supporting the **hypotheses** that personality disorders are **categorical** or that there are 10 (or any other number of) **discrete types** of personality disorder.

Well-established problems with **categorical** personality disorder diagnosis include:

- low reliability
- diagnostic comorbidity
- within-disorder heterogeneity

The **categorical model** of **personality disorder types** has proven to be **empirically problematic** and to **complicate research** and **treatment.**

Dimensional Approaches to Personality Disorder Nosology

- There are **no validated interventions** for most of the **categorical personality disorders**, and although several psychotherapies from different theoretical perspectives have been developed for borderline personality disorder that have evidence of only **moderate efficacy**.
- **Evidence for treatment mechanisms is sparse**, and there is no evidence that existing approaches have **specific efficacy** for borderline personality disorder as opposed to **general efficacy** for a variety of psychiatric difficulties.
- In contrast, there is a **vast body of empirical literature** supporting **dimensional approaches** to the diagnosis of personality disorder.

Alternate Approaches to Personality Disorder (Diagnosis & Treatment)

- The **categorical approach** is **binary** considering **illness** as either **present** or **absent**, and **similarity with prototypical description** of a disorder is taken as a marker of **severity**.
- The **dimensional approach** regards that **symptoms of disorder** exist on a **continuum** from **normal to severely ill**.
- The **hybrid approach** combines categorical and dimensional approaches, with **categorical diagnosis** for **broad diagnostic group** and **dimensional indicator** for severity.
- The **etiological approach** examines possible **biopsychosocial** causes for symptoms.
- **Conclusion:** psychiatric nosology may evolve through **epistemic iteration leading to successive changes**. This may lead to a more refined and useful system with time.

Nosology: Need for an Ontological Approach

- An **evidence-based framework** for diagnosing personality disorders has significant potential to **stimulate research** that can lead to **new treatments** and **aetiological models** that will ultimately reduce the burden of personality disorders on patients, families and society.
- An **ontological approach** may provide a **generative model** for conceptualizing the meta-structure of psychopathology.
- **Knowledge representation** and machine learning methods may be applied to formulate an **explicit data-based approach** to the diagnosis and treatment of personality disorders.