

## **London Complex Emotional Needs (Personality Disorder) Programme Access Statement, February 2022**

### **Background**

The Access, Delivery and Outcomes Task and Finish group preparing this report was part of a larger Clinical reference Group originally set up by HLP in Nov 2020 to contribute to the Long-Term Plan aims to increase recognition and treatment of people with a Personality Disorder. The group includes Clinicians, Lived Experience Practitioners and Charities from the London area.

### **Executive Summary**

This document has been created to inform conversations between clinicians, commissioners, and leaders within organisations and systems such as Integrated Care Systems (ICS), with the purpose of highlighting key considerations and priorities to shape improvements in access to care and support. It has been created using the knowledge and experience of all the varied membership of the CRG to drive forward change that offers long term benefits to those who may attract or have a diagnosis of Complex Emotional Needs/ Personality Disorder.

- the term 'personality disorder' is a necessary compromise that can still be stigmatising and limit the development and provision of adequate help for a broad and complex population.
- Access this population involves an understanding of the basic emotional struggle with trust in relationships and engagement in this complex population
- Clear, inclusive criteria for specific services and an open, flexible matrix of interventions aimed at engagement and coproduction of clients and their carers should coexist.
- A consistent, ongoing practice of training and clinical reflection for clinicians and practitioners is necessary for rewarding integrated experience of smooth transitions in, between and out of care.

### **Language**

The terms used have historically been fraught with controversy and agreement on one set term seems unlikely. From the beginning, the group adopted a broader term, 'Complex Emotional Needs' (CENs) to reflect the variety of presentations and acknowledge the problems and stigma associated with the diagnostic term 'Personality disorder' or 'Borderline'.

The group recognises that all terms have limitations, we therefore preferred to describe important aspects of lived experience of adversity, trauma and neglect, including:

- Stress response that involves powerful emotions or dissociation.
- A sense of self that becomes unstable.
- Intimate relationships can be difficult, confusing, or turbulent; this also affects help seeking behaviours.

This may variously be titled by different people involved as: complex emotional needs; complex trauma; personality disorder; or with no label at all. The overriding point is that the

name has less importance than the fact that clinical services do not always account for this widespread yet treatable pattern of issues and difficulties.

## Clinical population



## Key Data

The December 2021 NHS Benchmarking Report captured services existing at 31st January 2020 in all 53 MH Trusts in England. It indicates 75% of Mental Health Trusts had at least one dedicated PD service in their catchment area, and 64% of nationwide Trusts provided a dedicated 'PD' Community service treating 6,479 patients. 91% of Trusts provided some form of services for people with PD in generic community teams. High levels of people with a Cluster 8 classification – broadly including Borderline Personality Disorders - constituted 7 to 17 % of the caseloads. Most of these patients were being treated by non-dedicated services such as Generic CMHTS Adult Eating Disorder or Perinatal Mental Health services. Workforce include a diverse skilled mix.

This highlights the importance of understanding the needs of this group when accessing care, because of the differing access points and the need for clear, consistent approaches between services to assess and manage the psychological effect of rejection or “bouncing between teams”. The report also highlights issues around exclusion criteria, with substance misuse and risk to others continuing to be reasons for services not accepting people, yet these can be features of an emerging diagnosis. ('Services for people diagnosable with 'personality disorder', December 21).

The long-term plan implementation aims to change that through the development of Integrated Care System giving people choice and control over care including dedicated provision for groups with specific needs, such as adults with eating disorders or a 'personality disorder' diagnosis. The entry point to these ICS is broadly where people's 'access' to care starts. The specific needs around access of the 'personality disorder' population are the focus of this statement.

## Definitions of Access and evidence

A definition of Access includes the task of enabling people to get adequate resources (and health care) with the scope of improving their wellbeing (Guildford et al., 2002). More specifically, access to mental health care in Europe has been divided into three areas (Barbato et al, 2016):

- *Physical accessibility: geographical proximity, opening hours, waiting times, referral systems.*
- *Financial affordability: the price of the health services, as well as indirect and opportunity costs (e.g., the costs of transportation to and from facilities and of taking time away from work).*

- *Acceptability: psychological, social and cultural factors that may foster or hinder people's willingness to seek services, e.g. personal characteristics of providers, illness models, service organizational rules, provider perceptions of patients' needs, stigma.*

**Key elements of the Transformation Programme (NHS, 2019) in relation to access and access crisis intervention**

**Standards of access recently published by NHS England (2021), is to:**



**Access to 24/7 Crisis Resolution Home Treatment (CRHT) functions for:**



**Access to alternatives - a range of complementary and alternative crisis services to A&E:**



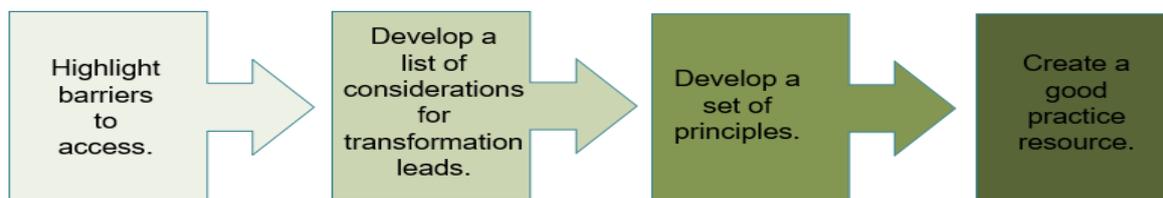
**London Community Transformation Plans as part of the LTP**

London ICS have plans to improve access to all mental health services. In order to understand what good "Access" needs to consider the Access Task and Finish carried out the following actions:

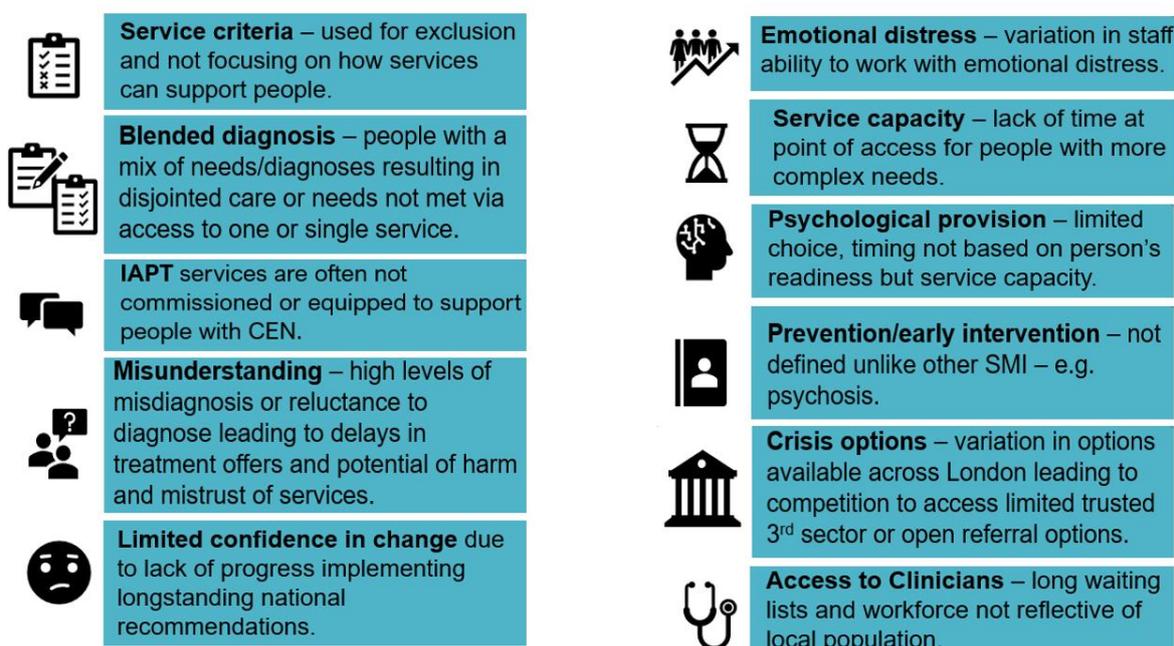
Actions
1. Discussed the current different models.
2. Reviewed recent literature and the early plans for transformation by different London NHS Trusts.
3. Listened to people's experiences of seeking help.
4. Agreed risk points in stepped care approaches and community-based services.
5. Developed addition considerations to the general needs of those accessing mental health support.
6. Identified examples of good local practice.

## Outcome

The result of the actions of the Task and Finish group has been:



## Barriers to Access:



## List of considerations and questions to explore

Consideration	Questions for Trust/Actions
Provide flexible and all age whole person system approach.	What are your trusts plans regarding 0-25 transformation? Highlight the opportunities of addressing a key point of transition from CAMHS to Adult services. What are the opportunities for early intervention? What is the offer for those with CEN within Older Adult services?
Provide training to staff to expand their knowledge about cultural sensitivity.	Do all London Trusts have a KUF training programme? ICS presentation at National level all Trusts are represented.

	How will London know how this programme is working CRG links with National Team? Does each Trust have a CEN programme as part of their recovery college programme?
Offer self-referral option to MH services.	London services agree what elements of the matrix/pathway are open to self-referral. What are single points of access offering as outcomes to those with CEN?
How can access to Tier 3 services be offered in line with the waiting time standard?	Provide specific time frames for response and assessments including patients on waiting lists.
Involve LXPs to act as models of 'connectors' that would provide local support, supervision and link to MH services.	Clear understanding of Peer Support/Community Connector/Lived Experience/social prescribing involvement as part of ICS plans.
What will the impact of the Transformation plans have on Tier 1-6 services?	How can the whole pathway be represented and improved? What are the ICS involvement with Tiers 4-6?
Develop principles for whole system access that support removal of rejection points in transitions and provide priority access points in services.	Local ICS adopt the principles outlined in this document.
Share good practice, along with lived experience, which do adhere to developed principles and explore for their potential to be scaled-up.	Local ICS use the good practice highlighted within this statement to inform improvements in CEN provision.

## A set of Access – Principles

**Principle 1:** *In London, front door services should be committed to working in a way that avoids further harm and rejection to people with Complex Emotional Needs. This includes those in services receiving access to other interventions “don’t shut the door” and those accessing services are not turned away “no wrong door”.*

 Challenges	<ol style="list-style-type: none"> <li>1. Service criteria leads to exclusion.</li> <li>2. Front door services have a responsibility to be aware of options within local communities.</li> <li>3. Trauma informed screening and initial assessment.</li> <li>4. Expectations of swift management of referrals leading to uniformed decisions.</li> </ol>
 Solutions	<ol style="list-style-type: none"> <li>1. Offer an outcome for each person based on need not limited to what is available within the immediate service.</li> <li>2. Directory of local services is owned by the ICS.</li> <li>3. Assessment and outcome not time limited.</li> <li>4. Frontline staff have received trauma informed approaches.</li> </ol>
 Examples	<ol style="list-style-type: none"> <li>1. The Offender Pathway uses the term “may have” rather than has a clear symptoms or diagnosis which is more inclusive reducing rejection.</li> </ol>

	<ol style="list-style-type: none"> <li>2. Forensic inpatient wards accept people with primary diagnosis of PD.</li> <li>3. SEL have a dedicated CEN steering group.</li> <li>4. Health Education England are developing Trauma Informed Training- CEN programme linked in.</li> </ol>
--	---

**Principle 2:** *Service providers to work on matrix model of care – Matrix is defined as a model that allows the person to access a range of interventions dependent on need is personalized and is not limited to one organisation offer.*

 Challenges	<ol style="list-style-type: none"> <li>1. Lack of a needs lead model.</li> <li>2. Medical vs psychological and social approaches.</li> <li>3. Comorbidity.</li> <li>4. Unwarranted variations across London teams, offering both evidence and non-evidence based approaches.</li> <li>5. Limited models of working across services and co-working.</li> <li>6. Ability of teams to offer timely access to interventions.</li> <li>7. Lack of diversity/services not designed to meet the needs of local population.</li> </ol>
 Solutions	<ol style="list-style-type: none"> <li>1. Testing ICS models with examples of real experiences to be assured that the transformation plans will result in improved access and care.</li> <li>2. Support offer for those on waiting lists.</li> <li>3. Highlight how the changes will result in people accessing different interventions addressing clinical governance issues.</li> <li>4. Use the NHS Benchmarking Report to highlight gaps in NICE recommended interventions/ non-evidence-based interventions and LXP reported good practice.</li> <li>5. Social Prescribing.</li> </ol>
 Examples	<ol style="list-style-type: none"> <li>1. SUN project model – appendix.</li> <li>2. Trusted Assessor – reduces the retelling of story.</li> <li>3. Tower Hamlets Primary Care social prescribing initiative.</li> </ol>

**Principle 3:** *Staff working in MH and other services understand strong emotional reactions are an intrinsic part of presentations that to inform care planning, rather than being viewed as “non-compliance” and forming exclusion criteria for services.*

 Challenges	<ol style="list-style-type: none"> <li>1. Low levels of training aimed at better understanding of the experience and psychological states that lie behind strong emotional reactions.</li> <li>2. Staff experiencing lack of support, highly-pressurised environments, and acute anxieties relating to assessment of risk leading to poorly formulated understandings of difficulties and then reactive responses from services.</li> <li>3. Spaces for reflection are either absent, irregular, or not operationally valued, leading to haphazard take-up from staff.</li> </ol>
 Solutions	<ol style="list-style-type: none"> <li>1. Trusts/Primary Care and other front line services to develop a brief communications training to encourage taking a validating and curious stance, to encourage authenticity and openness.</li> <li>2. Trauma-informed care (TIC) should form the backbone of services, to instil hope and optimism for change into staff interactions with service users and that every new interaction is a chance to change</li> </ol>

	<p>and enhance service user experiences of services.</p> <p>3. Brief training for front-line staff e.g. in primary care on 'distressed and angry people'.</p> <p>4. Trusts to promote a rolling programme of KUF trainings as part of their core training offer to front-line staff.</p> <p>5. To build into services reflective practice spaces to promote psychological understanding (evidence-based supervision groups within specific psychological models) of strong emotions and enhance staff understanding of their own emotional responses and reactions.</p> <p>5. Consistency of approach in terms of regularity of meetings and communications according to best practice guidelines (NICE).</p>
 Examples	<p>1. ELFT and C&amp;I have developed local Trauma-Informed Care (TIC) trainings which all staff can access to best understand service user experience and difficulties, and begin to structure operational response.</p> <p>2. CUSP Training Pack in development as part of CRG.</p> <p>3. Establishment of Senior Lived Experience posts to co-ordinate local programmes of KUF Training in close liaison with the national KUF Hub and local training leads.</p> <p>4. NWL Structured Clinical Management model.</p>

**Principle 4: Access to support crisis.**

 Challenges	<p>1. The timescales for the escalation of a CEN crisis can be fast: many services are not structured to meet that feature and use multiple assessments which miss the window for effective early intervention and so increase risk and limit options.</p> <p>2. Despite significant presentations at services such as A&amp;E, not all crisis services have resource parity between physical health and conditions which are driven by emotional distress.</p> <p>3. Delays in responding or referring to other services in crisis response create rejection points which have high potential for direct iatrogenic harm in CEN.</p> <p>4. Admission avoidance.</p> <p>5. Problem viewed as chronic and short term interventions not offered.</p> <p>6. Limited effective 3<sup>rd</sup> sector access to crisis houses/cafes.</p>
 Solutions	<p>1. Crisis service should work to the evidence base for effective, non-harmful interventions for CEN.</p> <p>2. Early identification of CEN can be used to create clinical passports which help services provide the early crisis intervention the CEN population requires.</p> <p>3. The role of compassionate human understanding should be viewed as the first line of intervention for CEN prior to attempting more technical solutions (such as diagnosis or medication reviews).</p>
 Examples	<p>1. The SUN (service user network) model provides open access, with the use of crisis action plans (formulations) and light touch escalation to NHS Home Treatment teams, demonstrating that “membership” models can meet and contain high levels of risk effectively. Such models are cost efficient and do not require high levels of professional input.</p> <p>2. The Sunshine Cafe Wimbledon: A recovery cafe offers quick access to peer support, a range of activities which effectively works to</p>

	<p>help attendees prevent crises. The cafe acts as a hub for increased access to social inclusion through volunteering activities. The local Home Treatment Team “pop in” and this light touch approach avoids many aspects of stigma which can increase risk.</p> <p>3. Greenwich Accident and Emergency project employed trained Lived Experience Practitioners alongside medical and nursing staff. Quick access to human understanding from Lived Experience Practitioners prior to more technical/medical interventions had a powerful effect on reducing emotional distress in those presenting with CEN and aided subsequent professional inputs where required.</p> <p>4. The use of advanced directives, such as the crisis and action plan (CASP) in the SUN groups has been effective for people. The principle here is that wherever possible, a what to do in crisis plan is made collaboratively between service user and professionals during a moment of calm. Such directives highlight:</p> <ul style="list-style-type: none"> <li>• What kind of approaches and phrasing from professionals helps.</li> <li>• How the service user feels they can help themselves.</li> <li>• What kind of experiences require help from others.</li> <li>• The service user and professionals both hold copies, and this is used in crisis events.</li> </ul> <p>5. Maytree.</p>
--	--

**Principle 5: Genuine Lived Experience Involvement including formal Peer Roles in services and commissioning.**

 <p>Challenges</p>	<ol style="list-style-type: none"> <li>1. How teams achieve genuine co-production in services and commissioning, rather than tokenistic consultation.</li> <li>2. Ensuring a diverse range of individuals with lived experience.</li> <li>3. The changeability of mental health / challenges resulting from having direct lived experience lack of understanding from HR and inconsistent approaches.</li> <li>4. Variations LXP/Peer career progression and structures.</li> <li>5. Confusion over paid and unpaid roles, Peer and LXP terms expectations and roles.</li> <li>6. Do Trusts have a clear strategy to support the expansion of Peer Roles?</li> <li>7. Creating a consistent approach to Trust and VSO approaches/relationships (also a solution).</li> </ol>
 <p>Solutions</p>	<ol style="list-style-type: none"> <li>1. Allocation of resource (both staff time and budget) to LXP involvement. Coproduction training. Services and commissioners sign commitment to LXP involvement so can be held accountable, etc.</li> <li>2. Flexible approach to participation / ability to flex work or projects based on individual's mental health needs at the time. Have compassion. Non-punitive, no disciplinary measures for being unwell. Play to people's strengths.</li> <li>3. Strategy to include, proactive recruitment of LXPs to projects, rather than an expectation that people put themselves forward. Peer/LXPs reflect local population. Leaders highlighting the benefits of involvement for potential LXP. Services accepting of and develop a culture where being challenged or hearing uncomfortable truths drives improvement. Provision of peer and professional support. Fair payment and reimbursement policies for time and expertise.</li> </ol>

 <b>Examples</b>	<ol style="list-style-type: none"> <li>1. CNWL Peer Support strategy and department.</li> <li>2. KUF training preparation for teams to embrace LXP roles.</li> <li>3. C&amp;I Peer Coaching Team.</li> <li>4. The Dragon Café.</li> </ol>
---	---

**Principle 6:** *Trusts offer culturally sensitive, diverse teams (for example, responsive to local reality survey), can help address wider inequalities.*

 <b>Challenges</b>	<ol style="list-style-type: none"> <li>1. Lack of a diverse workforce in professional groups.</li> <li>2. London is a highly culturally diverse city. Improvement needed in understanding cultural factors significantly affect how emotional distress is expressed.</li> <li>3. Organisations often lack skills and resources to link and create understanding with their local populations and partner organisations.</li> <li>4. Many professional clinical trainings are lengthy and can exclude those from local communities. Over reliance on traditional professions in service provision can reduce representation from local communities, which can create barriers to access.</li> </ol>
 <b>Solutions</b>	<ol style="list-style-type: none"> <li>1. Services evidence that they offer culturally sensitive training that is mandatory.</li> <li>2. Organisations which invest in building partnerships with local communities and related organisations reduce systemic duplication and friction, thereby increasing effectiveness and reducing cost.</li> <li>3. Diversifying the workforce through new roles (clinical assistant psychologists, lived experience practitioners, apprenticeships etc) can increase representation from local communities.</li> <li>4. Fostering cultural competence within services through training, staff assemblies and active contact with local communities can increase access, efficiency and reduce harm.</li> </ol>
 <b>Examples</b>	<ol style="list-style-type: none"> <li>1. Oxleas, like many London organisations, is meeting the current staff recruitment crisis by advertising for roles, rather than specific professions. This opens a number of roles to a wider set of potential candidates, such as lived experience practitioners, which diversifies the composition of community mental health teams to be more representative of local populations.</li> <li>2. Bromley One is a multi-agency collaborative that brings together third sector, statutory services, Healthwatch to understand and serve the specific needs of the local population. Streamlining resources and creating single access points reduces risk and waste.</li> <li>3. Following engagement with local community and faith leaders, St Georges increased access to Muslim populations (who otherwise found NHS settings inaccessible) by offering primary care psychological therapy sessions from a local Mosque.</li> </ol>

**Principle 7:** *Facilitate smooth, effective transitions developing transition workers and peer roles.*

 <b>Challenges</b>	<ol style="list-style-type: none"> <li>1. Many possible transitions – CYP- Adults and between Tiers 1-6 which work both stepping up, stepping down, stepping out. Increased risk of disengagement.</li> <li>2. Commissioning of services barrier to cross working.</li> </ol>
---	---

	3. Waiting times between interventions.
 Solutions	<ol style="list-style-type: none"> <li>1. LTP plans re 0-25 how may this help with the CYP/Adult interface.</li> <li>2. Peer support roles to include a transition role.</li> <li>3. Learning from EIP Transition posts.</li> <li>4. Personalised care folders.</li> <li>5. Opportunities with Provider Collaboratives.</li> </ol>
 Examples	<ol style="list-style-type: none"> <li>1. SLAM and Oxleas EIP transition workers.</li> <li>2. Peer Coaches in C&amp;I.</li> </ol>

**Principle 8:** *Comorbidities - management and support for patients with PD/CEN and other co-morbidities (physical, psychological e.g. eating disorders etc) should be coordinated throughout their treatment programme, regardless of where this is taking place.*

 Challenges	<ol style="list-style-type: none"> <li>1. Co-working to address co-morbidities is limited leading to only one need being met and clinical priority lead by service rather than person.</li> <li>2. Physical health of clients not met due to lack of the inclusion as an SMI.</li> </ol>
 Solutions	<ol style="list-style-type: none"> <li>1. ICS plans being explicit as to how co-morbidities will be addressed.</li> <li>2. Learning from dual diagnosis roles.</li> <li>3. CRG involvement in Physical Health London forums.</li> <li>4. Build a case for change for including CEN/PD into the Health Targets and incentives for Primary Care.</li> </ol>
 Examples	<ol style="list-style-type: none"> <li>1. Project in SEL focused on service offer for those with CEN/PD and addictions.</li> <li>2. CRG ambition for CEN/PD to gain equal status and access to physical health checks as other SMI's.</li> </ol>

**Principle 9:** *Engagement with those in a carer role is inconsistent which results in Carers feeling excluded, ill-informed, and unsupported.*

 Challenges	<ol style="list-style-type: none"> <li>1. Attitudes of professionals towards care givers for those with PD/CEN are not in line with Trust Policy or Strategies.</li> <li>2. Family dynamics, focus often on the person not family and wider understanding of how the family/carers can be involved or helped to understand behaviours and diagnose even if not directly involved.</li> </ol>
 Solutions	<ol style="list-style-type: none"> <li>1. Guidance specific for CEN/PD.</li> <li>2. Engagement by ICS with Carer groups.</li> <li>3. CEN/PD carer groups commissioned across London/collaboration with VSO.</li> <li>4. KUF Training for Carer.</li> <li>5. Recovery College courses.</li> </ol>
 Examples	<ol style="list-style-type: none"> <li>1. Guidance being developed by Carers/LXP's with the PD programme.</li> <li>2. Examples of carer groups supported by MH Trust.</li> <li>3. CNWL Recovery College courses for Carers and Mentalisation.</li> </ol>

## Conclusion

Co-production is at the centre of the NHS Long Term plan and local transformation and it is an expectation in all clinical services. This is even more the case in Complex Emotional Needs whereby it increases effectiveness, reduces harmful incidents, and improves both service user and staff experience. The CRG has aimed to embed co-production into the programme with our dedicated paid team of eight lived experience practitioners. The investment to realise the gains and support the system, a new paradigm for many organisations and their employees, in order to realise the gains and support the system, investment has been made in London, via funding, innovation, commitment, and resource. Good practice models are emerging, and these include our CRG as a unique breeding ground for growing ideas and disseminating such practice. The answers are within us, as articulated by one of the CRG LXP members.

*“Access to support should be improved and self-referral to services is so important with an open door policy and no rejection points or gaps in services. Recovery is possible and therapeutic optimism should be employed with an understanding of Trauma Informed Care and a less diagnostic approach treating the presentation of distress in a holistic person-centred way. Long term relationships with staff are so important to foster healthy patterns of behaviour in the long term with friends and family.”*

The current Access statement was made to capture the high consensus within the CRG around the specific challenges and solutions to the CEN issues. Most services were historically not set up to accommodate this important and sizable population.

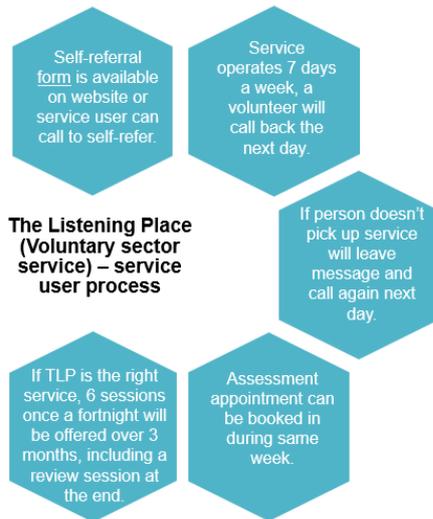
Our conclusions were like the findings of the benchmarking document ‘Services for people diagnosable with Personality disorder’ published in December 21. Where good practice models were identified they tended to be islets of innovations and exceptional examples and did not form part of the mainstream offer.

Therefore, the overarching challenge is that those innovations now need to inform how more widespread, significant changes to the way services are currently structured are made in the area.

Our work led to a widespread sharing of experience and good practice in London beyond the constrictions of local reality. We hope that the learning and toolkit in these documents support discussion groups and empower clinicians and those with lived experience and carers to review and discuss what access is, how it meets all needs, and informs positive action and local planning.

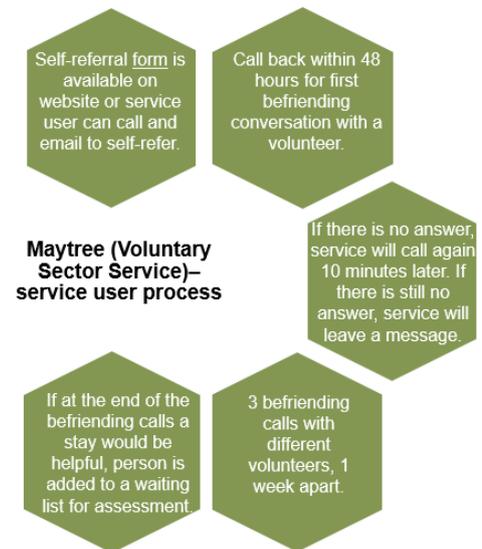
## Good practice resources and examples

### Voluntary Sector offer



**Fig. 1**

[https://referrals.listeningplace.org.uk/self\\_referral\\_form/](https://referrals.listeningplace.org.uk/self_referral_form/)



**Fig. 2**

<https://www.maytree.org.uk/im-feeling-suicidal/how-contact-us/please-complete-our-form#block-views-block-header-image-block-1>

### Drayton Park Crisis House (NHS service – Camden and Islington)

Info taken from: <https://www.cambridge.org/core/journals/psychiatric-bulletin/article/drayton-park-an-alternative-to-hospital-admission-for-women-in-acute-mental-health-crisis/ED3061DF542E46D3F1CA980A9C1188F8>

Referrals are taken by telephone from the women themselves, GPs, mental health professionals and carers. Following referral a decision is made as to whether to proceed to assessment and this takes place at Drayton Park and is carried out by a project worker. At assessment there is a thorough exploration of the current situation, the woman's mental state and her level of risk. Women who are considered to be at current risk of violent behaviour, who are misusing drugs or alcohol such that they require detoxification under medical supervision or who are unable to engage in a safety plan and therefore need constant supervision are not offered a place. On admission every woman is allocated two named workers with whom she will plan her care within the framework of the Care Programme Approach. Some women are already known to mental health services and will have community-based keyworkers who remain involved with their care. If women are new to the service then a decision is made as to whether a community-based keyworker needs to be allocated, in which case a referral is made to the sector community mental health team.

The women admitted to the project are temporarily registered at a local general practice which provides a 24-hour medical cover, and a sessional GP visits the project three times a week to see women at the staff's request. Any change in medication can be discussed with the women's own GP or psychiatrist and psychiatric advice and assessment is provided by the women's own sector community mental health team if required. The project has a target of a maximum stay of 28 days. The work done at the house is focused on identifying and resolving the triggers to crisis using a systemic approach based on the model used in family therapy. A variety of interventions are used, involving group and individual work, medication and various

complementary therapies including homeopathy, acupuncture and massage. Particular efforts are made to maintain supportive community links where they exist and to identify and strengthen the woman's own coping strategies. Throughout their stay women are encouraged to take an active part in resolving their situation including self-medication as soon as possible. The ethos of the project is to reduce unnecessary reliance on staff.

## The SUN-project

The service Users Network (SUN) (Miller, Jones and Warren, 2011) is a well-tested approach to open access services for people diagnosed with a personality disorder. It uses a membership model with more options and choice of when and how you engage (see table below).

We considered that the principles of such a membership model could be expanded to include other psycho-social offers (crisis cafes, stepped-care/psychoeducation) which may compliment psychological therapy. The groups have a light touch risk mitigation process and are compatible with, yet distinct from, primary care. Crucially, by removing scarcity through opening access, SUN projects have shown that their services do not get over-subscribed and have a numerical homeostasis in attendance.

### Membership model can be differentiated from patient model as below:

Domain	Patient	Membership
Access	Multiple points creates friction and exacerbates the difficulties associated with CEN.	Single point (no wrong door; collaborative understanding of ongoing needs).
Discharge	Multiple points increase anxiety and exacerbates CEN traits.	None, to mitigate for anxiety and feelings of rejection or abandonment. Open access approach.
Responsibility and accountability (including perceived risk)	Binary - assumed by services and divested at discharge.	Shared, includes member choice and a discussion around what risk means to them, as well as how this should be responded to.
Stigma	Remains High.	Lower (includes self-stigma).
System working with shared model	Clinical/health focus = some incompatibility with 3rd Sector/recovery model.	Relies on shared model and compatibility.
Democratic potential	Clinical governance can act against. Patient experience.	High control by members, AGM, co-production.
Implementation	Smaller systems, easier to run.	Resources/leadership needed to maintain system collaboration.
CEN Iatrogenesis	Multiple rejection points at referral: refusal; waitlist; discharge; scarcity; skill mix of staff. Risk of harm through inappropriate therapy offer (Barnicot, 2020).	Reduced scarcity and stigma.
Access to peer support	Developing, but limited to stay in service.	High.
Approach: choice and control	Medical model; restricted choice and control over care	Holistic and flexible; drop-in. Possibility of more than one group

	options; required to attend most set appointments at a specific time.	per week increases choice and control. May also offer evening rather than 9-5.
Comorbidities	Exclusion criteria is high; unable to work with substance misuse. Often have siloed thinking which is limited to considering alternatives.	Would assess options and suitability; substance misuse more likely to be included where agreement is to only attend when psychologically available.

### **CEN Passports –Oxleas Trust**

CEN can be identified through matching early adverse experience with pervasive and persistent emotional and relational responses to current stressors, which can be problematic to quality of life (e.g., interpersonal rejection, social-misunderstandings, isolation etc.). The use of a trusted assessor process could provide CEN passports between points an open access system.

## **Appendix: Access: A personal history from Lived Experience Practitioner**

### **Bad Practise: The Window- CATASTROPHY**

This was when I was in a pattern of self-destructive behaviour – impulsivity and aggression to others, limited emotional insight causing disruption to where I was living and no academic or employment achievements. I was in my late twenties and after dropping out of my third attempt at a degree I became ill and had to move back home to my parents who were emotionally and physically violent and abusive towards me. In the rush to pack my belongings my medication had been left behind. I spiralled into a psychosis as a result of the lack of meds and the resulting chemical imbalance in my brain. After a bitter argument I left the “family” home after my parents had called for an ambulance to admit me yet again. I was so reluctant to be admitted to the local psychiatric ward yet again and felt a failure in life- facing the rolling eyes and disparaging looks from the staff. So I grabbed my bags and ran away in the night to a local hotel and went from there to a hotel in another county.

I was so desperate to get help on my terms I communicated with a local psychiatric Women’s Service nearby to my parents address where I had had a short term but positive experience of care. They would not accept my request of admission despite being open to self-referral maybe because of a bed shortage. They did not take my increasingly desperate calls and did not find out where I was staying and no responsibility was taken for my care and I deteriorated into a very vulnerable position.

I called the police late that night who came to my hotel room and were obviously not trained in PD or MH or Trauma Informed Care. I was ill and in distress and believed people were coming to murder me. It was clear I needed an admission and an assessment and that I was in distress and had lost touch with reality. After a short time, the police left and I became increasingly upset – I had tried repeatedly to get help and no help was forthcoming. Half an hour later I was convinced that people were coming to the hotel room to murder me – I tried to escape this fate by sitting on the outside of the sash window and by then found it impossible to get back into the room. A crowd had gathered outside and no fire engine or police were called but there was an ambulance waiting. I remember falling, hitting the ground and being in excruciating pain. I was taken to hospital and had broken my lower back in three places. I had been a whisper away from paralysis. In the hospital I did not receive the anti- psychotic medication or the pain relief I needed. After some days I was thankfully transferred to a hospital in my home county and needed 12 weeks of bedrest. I still didn’t have a dedicated care team or therapist and was discharged again from this physical hospital with no correct support and from there was admitted to psychiatric hospital yet again.

I felt so let down- repeatedly. There had been so many exit points along the way. So many opportunities for people to have stepped in and helped me. It had all nearly led to a permanent paralysis – and how close I was to losing the use of my legs still haunts me to this day. Ironically I think it took this dramatic incident to flag up my dislocation and distress and from there after another admission- this time for two years – I was granted the help I needed- therapy, correct meds, a social structure and bespoke rehab.

### **Bad Practice and Good Practice: Self- Referral**

Self-referral is so important particularly if you are distrustful or dislocated from services and you cannot rely on inclusive or adequate care from your team. It can mean you yourself are taking responsibility for your ill health/ condition / MH and recognise that you need help from that service. It can mean you get the help needed at the most risky destructive time and avoid

damage from dangerous behaviour / self-harm to yourself or others. It can be a timely and relevant intervention. This can be demonstrated by the success of Recovery Spaces or Crisis Cafes and previously the Women's Service in South East London. You are then in charge of what you demonstrate to the team and from there a team and a plan can be built around you.

An organisation specifically for PD and that offers a self-referral system is the Service Users Network in South London (SUN) and this offers group therapy facilitated by psychotherapists and you can present yourself at one of the meetings and they ask you to fill in a Wellness Action Plan with insights as to what helps and what doesn't, any medication you are taking and who your next of kin is and if you have a care team. You are then placed in a position of taking responsibility for your own MH and the group is a safe space to bring any distress or issues to light and you are aided by the facilitators and your peers as to what might help and others will naturally understand you as they have been there (informal Lived Experience Experts). The group is advertised as appropriate for any one in emotional distress not specifically PD and as a result does not attach the stigma of the PD label.

Another advantage of Self-Referral is when individuals fall through the cracks of services not taking responsibility for their care- for example when a dislocated client moves from one area to another and the previous care team and the team in the new area do not take responsibility for the care of that client (particularly common in Out of Area Placements). Then that individual has to wait for a psychiatry appointment /assessment for 6 months leading to increasingly desperate and ill presentations in order to get the help they need and an increased risk in the wellbeing of that client and others they are in contact with.

### **Good Practice: Joined Up Care**

I have really benefited from Joined Up Care- All my MH professionals have been on the same page with my GP ( and Doctors receptionist) , dentist, physical health for my Long Term Health Condition (LTHC). Communication between all professionals (physical and MH Care) has been connected – especially around blood tests and medications so meds don't conflict with one another. There has been excellent communication between everyone on the MH team- Consultant Psychiatrist, Psychiatrist, Care Coordinator, Therapist. Any medication issues have been discussed with an expert at a London Hospital.

Communication with myself has been outstanding- with doctors able to see me and fit me in short notice about my care. When moving to a different team/ care worker I am prepared in advance with a combined transfer approach- able to speak to the old team /old worker whilst adjusting to the new worker/ new service.

Slow but sure step downs over a number of years to increasingly independent settings has been the key to recovery. Therapy has been offered and gratefully accepted and increased when needed (when more anxious or in a low mood). Good communication between the therapist and the team (even when working with a private therapist.)

Consistent help with blood tests and medication, help with therapy and anxiety relapses, support with letters for benefit applications. My doctor wrote a letter informing a prospective employer that I had wage restrictions and could not do night shifts. A professional on the team recommended I become a Patient Representative for the RCPsych. I have been encouraged to tell my story to Rethink and NHS Digital. I offer an understanding of my progress but also of my long- standing MH issues.

My team has shown faith in my ability to recover- a desired therapeutic optimism- a fixed hopeful, positive opinion of me as a person and my strengths and that I was a good person and deserved happiness and stability.

## **TOUCHSTONE Personality Disorder Team Based at Bethlem Royal Hospital – Lived Experience Practitioner Reflection**

This service is not Self-Referred. One has to be referred by their CMHT/ Secondary Care Service. It offers intensive MBT for a period of 18 months. Initially there is an assessment, if suitable the client is offered an introductory group for 1 hour a week for 10 weeks. Then there is a 3- day programme- 'Day Treatment Services' and a 2 -day programme called 'Intensive Outpatients programme'. These programmes run all day on the allocated days.

I have not experienced the Programme myself but I have heard excellent things about it. The one drawback maybe that some people cannot commit to the 2-day or 3- day a week therapy and cannot then benefit from the service. Therefore clients with additional needs, such as co-morbidity (physical and mental problems), drug and alcohol/substance abuse, severe anxiety or depression or psychosis and learning disabilities or learning difficulties will be excluded from the service.

The Touchstone Service is connected to the SUN Service.

Under Touchstone there is 1-1 sessions with an Individual Therapist but most sessions are in groups. Socially these groups may be stressful but are facilitated by a professional and are meant to be safe spaces.

## References

- American Psychiatric Association. American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders Fifth Edition. 5th ed. APA. Arlington, VA: American Psychiatric Association; 2013.
- Barbato, A., Vallarino, M., Rapisarda, F., Lora, A., and Almeida, J. M. C. (2016). Access to Mental Healthcare in Europe. Available online at: [https://ec.europa.eu/health/sites/health/files/mental\\_health/docs/ev\\_20161006\\_co02\\_en.pdf](https://ec.europa.eu/health/sites/health/files/mental_health/docs/ev_20161006_co02_en.pdf) (accessed September, 2021).
- Barnicot, K. (2020): Evidence-based psychological interventions for borderline personality disorder in the United Kingdom. Who falls through the gaps? *Journal of Psychological Therapies*, 5, (2), 148-167. Accessed via: <https://openaccess.city.ac.uk/id/eprint/24556/>
- Botham et al. (2021) <https://www.medrxiv.org/content/10.1101/2020.11.03.20225078v1>
- Dale, O., Sethi, F., Stanton, C., Evans, S., Barnicot, K., Sedgwick, R., Goldsack, S., Doran, M., Shoolbred, L., Samele, C., Urquia, N., Haigh, R., & Moran, P. (2017). Personality disorder services in England: findings from a national survey. *BJPsych bulletin*, 41(5), 247–253. <https://doi.org/10.1192/pb.bp.116.055251>
- Gulliford, M., Figueroa-Munoz, J., Morgan, M., Hughes, D., Gibson, B., Beech, R., & Hudson, M. (2002). What does 'access to health care' mean?. *Journal of health services research & policy*, 7(3), 186–188. <https://doi.org/10.1258/135581902760082517>
- Miller, S., Jones, B. & Warren, F. (2011). The SUN Project: Open access community-based support groups for people with personality disorder description of the service model and theoretical foundations. *Therapeutic Communities: the International Journal for Therapeutic and Supportive Organizations*, 32(2), 108-124.
- National Institute for Mental Health in England (NIMHE, 2003). Personality disorder: no longer a diagnosis of exclusion.
- National Institute for Mental Health in England (NIMHE, 2003a). Breaking the cycle of rejection: The personality disorder capabilities framework. Accessed via: <http://personalitydisorder.org.uk/wp-content/uploads/2015/06/personalitydisorders-capabilities-framework.pdf>
- NICE. Borderline personality disorder: recognition and management. CG78. 2009.
- NHS (2019) Community Framework for Adults and Older Adults. Available from: <https://www.england.nhs.uk/publication/the-community-mental-health-framework-for-adults-and-older-adults/>
- NHS <https://www.england.nhs.uk/2021/07/nhs-england-proposes-new-mental-health-access-standards/>
- Sheridan Rains L, Echave A, Rees J, Scott HR, Lever Taylor B, Broeckelmann E, et al. (2021) Service user experiences of community services for complex emotional needs: A qualitative thematic synthesis. *PLoS ONE* 16(4): e0248316. <https://doi.org/10.1371/journal.pone.0248316>
- Troupe, J. et al. (in press). Clinician perspectives on what constitutes good practice in community services for people with Complex Emotional Needs: A qualitative thematic meta-synthesis. *MedRxiv*, pre-print. doi: <https://doi.org/10.1101/2020.12.15.20248267>