

## Personality Disorder and Complex Needs Service User Network - Information for Professionals

### Introduction

This document outlines the aims and objectives of the Personality Disorder and Complex Needs Groups, run by the Specialist Personality Disorder and Complex Needs Service User Network (SUN) Team within EPUT.

The overarching aim of the SUN is to facilitate the delivery of peer led support, promote staying well in the community and collaboration with service users and carers. The SUN is accessed on a **voluntary basis** and members can engage as much or as little as they would like. Groups are designed to:

- ☀ Offer a space for learning and growth
- ☀ Foster connection with peers who may be in a similar position to offer and receive peer led support
- ☀ Facilitate understanding of Personality Disorder and associated difficulties
- ☀ Create opportunities for supported engagement and meaningful involvement

The SUN is open to service users aged **18+** within Essex who have a formal diagnosis of Personality Disorder **and/or** have complex emotional needs that **may** meet diagnostic criteria. If they don't hold a diagnosis, service users must display at least 4-5 traits of personality disorder, which may include:

- ☀ Intense anger and difficulty managing this
- ☀ Mood instability (rapid mood changes, intensity of emotion disproportionate to trigger)
- ☀ Feelings of emptiness
- ☀ Lack of identity (confusion as to who they are, goal, beliefs etc., or these change suddenly)
- ☀ Dissociation, or paranoia when stressed (feelings of unreality and/or detachment; paranoid thoughts when stressed)
- ☀ Frantic efforts to avoid abandonment (behaviours to avoid abandonment, often without evidence)
- ☀ Thoughts of self-harm and/or suicide – (*however they must not be in active crisis and if current self-harm or suicidal behaviour is present they must be under the care of a service which can support risk management*)
- ☀ Impulsivity in other areas
- ☀ Unstable and intense relationships (often alternating between love and hate)

SUN groups run on MS Teams, on an **invite-only** basis. We currently offer 6 groups (more information below):

1. Personality Disorder and Complex Needs Awareness and Support Group (21+)
2. Young Adult Awareness and Support Group for Complex Emotional Needs (18 – approx. 27 years old)
3. 2 X Personality Disorder and Complex Needs Peer Support Groups
4. I care: Supporting Carers of Loved Ones living with Personality Disorder and Complex Emotional Needs (information below not applicable to carer group)
5. Personality Disorder and Complex Needs Service Development Collaborative (SDC)

**SUN groups are not clinical or therapy groups. Care co-ordination, risk management and 1:1 support are not part of the SUN provision.** Expressions of interest, rather than referrals, are invited to reflect this. Groups are **not a substitute for clinical intervention**.

Regretfully, the SUN Groups are not available to service users who are also employed by EPUT.

### Expressions of Interest Forms

Groups are accessed by a raised expression of interest form (apart from the SDC), to ensure that the group's function will match a service user's presentation and individual needs. For the Awareness and Support Groups, this must be completed by a professional. For the Peer Support Group and Carer Support Group this must be completed by the individual wanting to join. For the SDC, there is no form.

We use the terminology 'expression of interest' because **service users cannot be 'referred on' or 'into' the SUN**; it is intended to compliment and be an additional offer for service users who are receiving more tailored support elsewhere or who could benefit from light touch support (e.g. they are generally coping but would like to learn more about their diagnosis and skills to manage).

**Expressions of interest to the groups may be indicated:**

- ☀ Following a recent Personality Disorder diagnosis or undergoing assessment for a potential diagnosis (i.e., a service user may have 'traits of').
- ☀ When a service user is exploring a potential diagnosis and is 'working out' what is going on for them.
- ☀ When a service user has come to the end of a tailored intervention (e.g. STEPPS/DBT).
- ☀ When a service user is in receipt of 1:1 therapy and/or they have been accessing secondary mental health services for a period of time and their risk is being managed within these teams.
- ☀ When a service user no longer requires secondary mental health services but would benefit from light touch continued support, in addition to that which is offered by their GP/PCN.

The group might be considered inappropriate when:

- ☀ The service user would not meet diagnostic criteria for Personality Disorder.
- ☀ The service user is experiencing active psychosis and/or another psychotic disorder.
- ☀ The service user expresses risk which is not being managed within community mental health services.
- ☀ The service user is currently an inpatient.
- ☀ The service user does not reside within Essex.
- ☀ A life event is influencing the current presentation, e.g. loss, divorce, parenting challenge, etc., and the service user would benefit from a service aligned with those specific challenges.

For professionals raising an expression of interest, they must provide the following information **(ALL fields are mandatory and must be filled out for a request to be actioned)**:

- ☀ Full Name
- ☀ NHS number
- ☀ Locality/Area
- ☀ Service User's Email Address
- ☀ Service User's Telephone Number
- ☀ Date of Birth
- ☀ Service Currently under
- ☀ Named involved person (e.g. care coordinator, assessor, support worker, gp).
- ☀ Full Consent from the service user for the expression of interest

There are also a few questions we ask on the expression of interest form that must be completed:

- ☀ **Based on the service user's presentation of Personality Disorder, why do you think they will benefit from the SUN groups?:** We are looking for why this service user might benefit from the SUN groups based on their presentation of Personality Disorder. We do not require whole assessments but just need to understand why the service user may find our group helpful.

*E.g. "Kerry has a diagnosis of Personality Disorder. Kerry has a background of trauma from childhood and more recent experiences with a family member in adulthood. Kerry currently experiences long periods of anxiety and will avoid going out. Kerry has low self-esteem and has a strong sense of not being good enough in her relationships; she feels anger towards how she has been treated in life and has a sense of emptiness. Kerry has urges to self-harm but has managed the urges with coping skills. Kerry reports suicidal thoughts, but no current plan or intent to act on them."*

- ☀ **What the service user hopes to gain from attending the group? Do they have any particular strengths/interests:** We ask this because the groups we run are strengths-based and recovery-focused. It is helpful to know that a conversation has been had with a service user about the group and therefore having some awareness of their

understanding of the group. If a service user is currently high risk and seeking trauma work for example, it is unlikely the SUN will meet their needs.

E.g. *“Kerry is motivated to attend the group and this would be helpful alongside care coordination and her therapy plan. Kerry would like to attend the group for the peer support aspect. Kerry is interested in animals, and likes art activities and crafts.”*

☀ **Any other information:** Here, let us know if there is any other key things we should be aware of:

E.g. *“Kerry has recently been allocated a care coordinator in her local CMHT. Kerry is partially sighted.”*

If we are unsure, we will always seek clarification and ask questions around the appropriateness of a service user joining the SUN. Where the group is not indicated to meet the needs, we are able to support signposting and advice. It is important that we manage a service user’s expectation of what the SUN can offer and reasonably achieve.

### **Once a service user has been identified as potentially benefitting from the SUN:**

If we agree that the service user may benefit from being invited to the SUN Groups, we send them an invitation email but they are required to **opt-in**. This means that even if we have invited someone, they may choose to not join us. If they do opt-in, we will add them to the mailing list for the relevant group.

We hold a database of service user information based on the expression of interest form, if they opt in, we keep a register of attendance. We contact a service user after 3 missed sessions to check whether they would like to be involved, and will give them the opportunity to remain on our mailing list if they would like. Here we check in with them about any barriers they may be experiencing to taking part in groups and whether we can support these. If they do not respond after 2 weeks and/or say no, we remove their data. Service users have the option to opt back in at any point after they have been removed without completing a new form.

**Please note:** We do not routinely add notes to clinical records due to the nature of the groups. If we have a significant concern about an individual, we raise this with the necessary individuals. We encourage all members to refer to support available from GPs, local crisis services, 111 as well as resources listed on our group forum; this includes a wide range of support services and resources that others have found to be useful.

Please direct any questions or queries to [epunft.pd.cnsun@nhs.net](mailto:epunft.pd.cnsun@nhs.net)

## Each of the Groups



### Personality Disorder and Complex Needs Awareness & Support Group (21+) Young Adult Complex Emotional Needs Awareness & Support Group (18+)

*These groups are accessed via an expression of interest form completed by a professional.*

These groups run fortnightly. The group is facilitated by the SUN team and guest speakers who deliver talks on different topics such as services available within the community, benefits and employment, emotions, advocacy, sleep hygiene, practical activities, etc. Generally the topics have been specifically requested by members and sessions are tailored to the needs of its participants at the time. We actively encourage peer support, and empower our participants to offer their own experience and knowledge into sessions. We endeavour to provide a 4-week timetable, in advance, so that our service users can arrange to attend the sessions that will be most helpful to them. The young adult group is generally accessed until 21, where the individual can attend the adult group, however moving is on a case by case basis and up to the individual should they feel the young adult group better meets their circumstances (e.g. attending university), up until the age of 25.



### Peer Support Groups (18+)

*These groups are accessed via a self-expression of interest route by the service user completing a form.*

These groups run weekly. The groups are a 1 ½ hour session, facilitated by the peers that attend. Peers are invited to share how they are feeling and support each other through their lived and learned experience. This group has a time cap of 12 months and a cap of 12 service users; this means that at times there may be a wait list.



### Personality Disorder and Complex Needs Service Development Collaborative (SDC) (18+)

*Expressions of interest to the group can be made directly from a service user, or through a professional at service users' request. There is no form for this group and it is accessed via emailing the SUN inbox.*

Here, we offer people the opportunity to be more dynamically involved in shaping and developing services, using our lived experiences to inform positive change. There are various levels of engagement. These range from contributing our thoughts and ideas to a specific project, to participating in interview panels, co-delivering training and being Peer Support Workers. We work using a model of Co-Production, with service users working alongside staff, bringing together our experiences/journeys and using them in a meaningful and proactive way.



### I care: Supporting Carers of Loved Ones living with Personality Disorder and Complex Emotional Needs (Adult Carers)

*The group is accessed via a self-expression of interest route by the carer completing a form.*

The purpose of this peer support group is to bring together carers and loved ones of individuals living with Personality Disorder, who are over the age of 18, offering members the opportunity to make contact with others in a similar situation, help individuals to gain support and know that they are not alone. The aim is to support members in the form of conversation and sharing experiences, resource sharing and by simply listening. The Carer Support Group is open to any carer who resides in Essex (Essex registered GP) who is caring for a loved one who has a formal diagnosis of Personality Disorder and/or have complex emotional needs that meet diagnostic criteria for a Personality Disorder.



### Coffee and Connect Social Group

Coffee and Connect is a new community coffee group for those with Personality Disorder and Complex Needs. **Only members of SUN groups can attend these groups (e.g they must be a member of an existing SUN group such as the Peer Support Group).** Developed in response to feedback from SUN members, the groups offer a welcoming space for informal, supportive conversations with others who share similar diagnoses and experiences. The goal is to foster a sense of community and support among service users, helping them to feel less isolated.

Currently coffee groups have been held in some localities with plans to spread across the county in the future.