March 2022

New Ways of Supporting Child Abuse and Sexual Violence Survivors

a social justice call for an
innovative commissioning pathway

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Summary

Background/rationale

This report outlines the needs of child sexual abuse and sexual violence survivors in relation to the current conceptualisation and provision for 'personality disorder'. It has been collaboratively written by a socially diverse collective of survivors of child sexual abuse (CSA) and sexual violence (SV). Many of us have been forced to accept a personality disorder diagnosis and we wanted to come together to share our experiences and to propose less harmful approaches to future service provision for our population.

What we are asking for and why

We are asking for trauma-specific pathways, separate from personality disorder (or any re-named personality disorder) services. As a group, we have been profoundly harmed by both the application of the personality disorder construct, i.e. the ways in which services treat us as a result of the construct, and also by the treatment pathways which are harmful for our population.

As a group, we suffer from high levels of dissociation and trauma specifically related to our CSA/SV experiences. These have long been neglected because the only current provision for people like us sits within the personality disorder (PD) field.

In addition to this, we are bringing attention to the harm caused by current behaviourist approaches and systems that criminalise our distress rather than provide alternative support.

We explain how LGBTQ+ survivors are being doubly failed by services in that they are having their sexuality and gender identity understood and pathologised as a symptom of 'PD' leading to increased shame and self-hatred.

Conclusion

Ultimately, this report highlights how we have been failed and re-traumatised by state systems that are supposed to protect and support us when we were at our most vulnerable. It also shows how 'PD' has been used to silence and reframe our experiences. We finish by making recommendations for new trauma-specific pathways and services that are completely removed from a personality disorder frame of understanding.

Key Recommendations

Unless they explicitly ask, child sexual abuse and sexual violence survivors must not continue to be diagnosed as having a 'personality disorder', especially when there are less harmful alternatives that are more suitable and appropriate for this population. People must have the choice to not be subjected to this construct or treatment pathways.

In recognition of the harm caused, we request trauma-specific services, entirely **separate** from personality disorder pathways or services, to meet the current service gap for our population.

Personality disorder services that have changed their name to 'complex needs', 'complex emotional needs' and/or 'complex trauma' services are still inappropriate for our population. In fact, disguising these services makes them feel riskier and less safe for us.

Given our lived experience and the overwhelming research evidence, we ask that CSA/SV survivors never be sent on behaviour-based interventions such as DBT without first being offered a range of trauma-specific treatment options.

Anyone with mental health difficulties or in acute suicidal distress should be shown compassion, empathy and support. Punitive initiatives like Serenity Integrated management (SIM) that criminalise mental suffering must be immediately abandoned.

We call for the commissioning of innovative, survivor-designed, trauma, dissociation and complex-trauma specific pathways for survivor adults and children. These pathways and services should be informed by the [International Study of Trauma and Dissociation \(ISSTD\) guidelines](#).

Trauma-specific pathways need to be joined-up and holistic, offering a wide range of trauma-based interventions and support. Pathways should include NHS funded initiatives with the voluntary sector. Resources should be allocated to enable survivors to design, implement and support and evaluate the pathways we are requesting.

Any trauma-informed or trauma-specific initiative needs to first engage in a process of peace and reconciliation with harmed survivors and service-users. No healing relationships can be formed on a foundation of harm and mistrust.

A place to start...

This guidance document has been created specifically to address the needs of sexual violence (SV) and child sexual abuse (CSA) survivors. However, it is important to acknowledge that many people who have experienced other types of child abuse and neglect as well as people from other minoritised groups find their difficulties labelled as 'personality disorder'. This includes people who define as autistic, neurodivergent, from BME backgrounds as well as LGBTQ+ people. We have included a brief section regarding LGBTQ+ survivors, however, the overall focus of this document is on the needs of CSA/SV survivors, and it is hoped that other people will take up a similar approach, advocating for other minoritised groups as well as looking at other types of abuse that get pathologised.

We have chosen to focus on the specific trauma associated with CSA/SV but there are many other experiences that people find traumatic which are beyond the scope of this report. In advocating for our specific group, we in no way intend to position our experiences as any more or less traumatic than other people's. We believe that if someone feels traumatised by things that have happened to them in their life, then they deserve trauma-informed and trauma-specific therapy to support them to heal from those experiences.

Diagnosis and endless debates

The issues around the diagnosis of 'personality disorder' have been going on for over a century. Clinicians and researchers seem to spend time and money arguing about things like whether 'PD' should be classified on a spectrum or as discrete categories. The latest changes to the ICD-11 classification of 'personality disorder' now allow clinicians the option of 'rapid assessment of personality functioning'. [1] In reality, this means that more and more people are receiving this label. The expansion of the personality disorder construct has even led some clinicians to state that only 25% of the population have a normal personality. [2] Whilst these debates rage on, we as survivors are suffering. To our knowledge, there is no evidence to suggest that treating CSA/SV survivors using a personality disorder framework is useful. However, there is plenty of lived-experience evidence to show that this way of thinking about our distress is harmful. [3-6] The personality disorder diagnosis does not work for us. It does not inform helpful treatment pathways. It does not provide access to trauma-specific support and it actively harms our mental health. We argue that providing services for survivors of CSA and SV should not be about drawing on the limited and flawed evidence base, nor is it about the opinions of clinicians who are engaged in seemingly endless circular arguments about classification. It is about us, our lived experience, listening to our suffering and doing the right thing. It is about what is ethical. Ultimately, it is about commissioning services that will help rather than harm.

The Current Problem - Amy's Story

Amy is 34 years old. She has a history of being sexually abused by her step-father between the ages of five and twelve. Amy first entered mental health services when she was 17 after a long period of depression leading to a suicide attempt. Amy experiences memories and flashbacks of her abuse; to cope with these she self-harms. Often things are so bad that she thinks about suicide daily. Amy has struggled to feel connected to people around her and often feels ashamed and alone. When Amy first entered services no one asked her about her experiences of abuse. She was admitted to an inpatient unit for 5 days where staff spoke to her rudely or completely ignored her. Amy was discharged, despite telling the staff that she still felt suicidal. Staff explained that people with Amy's condition only get worse in hospital, so she needed to be discharged into the community and to learn to manage her emotions in a better way. Two weeks later Amy was copied in by accident to a letter from the hospital to the GP where they explained that Amy had been diagnosed with 'borderline personality disorder.' Amy didn't know what this meant so she googled it and found a lot of pages that described unstable identity, being manipulative and attention-seeking as part of the condition. She felt hurt, hopeless and ashamed that doctors had labelled her with this. She realised that this was perhaps the reason why nurses in the hospital had treated her so badly. She phoned the crisis team who told her to manage her own emotions with self-care techniques such as taking a bath or lighting a relaxing candle. Amy lives alone in social housing, does not have a bath and experiences frequent threats from her neighbours who have substance misuse issues. Over the years Amy has had many suicide attempts, sometimes she goes to A&E to try and get help. When she is in A&E she often waits over 12 hours to see the duty psychiatric liaison worker only to be told that they will not admit her to the hospital and she must phone the crisis team. Amy feels so hopeless she takes frequent overdoses, hoping that each time this might be the one that ends her misery. Hospital staff provide physical care for Amy at these times and then she is discharged back into the community and back into the same hopeless situation she was in before.

When she was 29, Amy was sent on a DBT course to stop her 'self harming behaviour'. The first session of the course was all about 'accepting your diagnosis'. Amy felt really angry about this because she didn't agree with her diagnosis and found it harmful. When she expressed this, the psychologist leading the course told Amy that she was resistant and not likely to improve whilst she remained in denial about her condition. This made Amy feel even more hopeless. Her self-harm became more frequent and she tried to call the psychologist to get help. The psychologist informed her that she would never speak to Amy or show warmth to her if she had self-harmed because she didn't want to reinforce any negative behaviours. On the fourth session, Amy took an overdose and missed three weeks of the course. She was discharged from the course for missing these sessions and was told she would have to wait two years until she could be put forward for the next one.

When Amy was 32 a friend of hers told her about a local charity service that had a counselling programme for rape survivors. Amy's friend told Amy not to tell them that she had been diagnosed with 'personality disorder' otherwise she wouldn't be eligible for counselling. Amy kept quiet about the diagnosis and was given a course of 12 sessions with a trauma-informed counsellor. Amy was asked for the first time about her experiences of sexual abuse. The counsellor was kind and empathic and understood the impact that CSA can have on mental health. The counsellor also helped Amy to identify that she suffered from a lot of dissociation and suggested that it would be a good idea to get some more specialist help for this. Amy felt relieved, listened to and validated by the counsellor but she also felt devastated that the therapy was only going to last for 12 sessions.

When she was 33, Amy found that she was in an area where a long-term NHS CSA support group has just been funded. She went through three assessments with different departments in order to finally get a referral to the service. She felt very hopeless and anxious when she was informed that the waiting list for this therapy was three years, the trauma-specialist therapist running the group recognised this and offered to see Amy immediately, once every month to make contact and to help Amy feel connected to some support system for her trauma. Amy is now in long term treatment for her dissociation, sexual abuse experiences and other childhood traumas. She is finding it very difficult but the therapist is compassionate, transparent and responsive, especially if Amy's self-harm or feelings of suicide increase. Because Amy has this support she no longer goes to A&E as often and she hasn't been admitted to the hospital for over a year. Amy feels very angry that she has had to wait for so long to get the trauma-specific help she needed and she feels that the label of personality disorder played a big role in preventing this from happening.

There are so many 'Amys' who don't make it. We often hear about these people in the news or in coroners' reports, people who have essentially been neglected to death because of a personality disorder label. Sometimes neglect and disbelief are embedded into treatment plans and framed as 'positive risk taking' or denying people support for fear of 'fostering dependency.' These ideas are deadly for some of us. We are writing this report to tell you about our needs but to also advocate for some of those people who are no longer with us.

Who we are

We are a socially diverse collective of survivors of child sexual abuse (CSA) and sexual violence (SV). We have either been forced to accept a personality disorder (PD) diagnosis or have been unable to access or engage with services because of the fear of this construct. Many of us have been failed and retraumatised by state systems that were supposed to protect and support us when we were at our most vulnerable.

Why our perspective is important

Whilst there are many people who identify with the diagnosis of 'PD', we are part of the sizable proportion of CSA/SV survivors who have found the diagnosis actively harmful. We believe that commissioning bodies need to hear from those of us who have been harmed by services. We have been excluded from consultation processes that do not allow space for the views of those of us who fundamentally disagree with the construct of 'personality disorder' (PD). Many of us are too traumatised by 'PD' services to give feedback about our experiences. Many of us are excluded from services because we are too fearful of having this label given to us in conflict with our own understanding of our difficulties. Many of us cannot contemplate involving ourselves in research or consultation around 'PD' because of how traumatising we find this construct. Those of us who are already in the mental health system are too scared to speak out or complain about the 'PD' construct because when we do we experience negative repercussions in terms of our care. This means that we have no way to express what we might need from services. Thus far, consultations on the future of 'PD' services recruit service-users who identify with the 'PD' diagnosis, or at least find it useful in some respects. These consultations often result in calls for reform of 'PD pathways' and for increased compassionate responses. However, our experiences and our aims are different. Therefore, as a seldom-heard population, we have collectively decided to write this statement to express our particular views and needs.

What we are asking for

We are asking for NHS-funded services that are specifically commissioned to support us as CSA and SV survivors. We ask for this support to be completely removed from the service provision and pathways of 'PD.' Whilst there is already some degree of commitment from the NHS to provide these types of services,[7] the current strategy does not fully consider the needs of our population. It is not possible for people in our situation to access trauma-based support via 'PD services' because of the retraumatizing impact on us as SV/CSA survivors. Service-users have been requesting separate complex trauma service provision since the late 1960s,[8] and in the last 10 years we have been able to collectively use the social media hashtag #TraumaNotPD [9] to try and get our message across. We want to make sure our experiences are heard and feel dismayed at the current and rapid expansion in 'PD' pathway provision,[10] particularly without a similar commitment to create and expand trauma specific support.

Why do we need this?

We have been retraumatized by being told our personalities are disordered. We have often been told by those who abused us, and sometimes by society, that we were in some way to blame for the abuse we experienced; this dynamic is then repeated when services tell us that the problem is located within the core of us, in our personalities. We have experienced iatrogenic harm from having our distress understood within this framework. This framework allows our every thought, feeling and action to be pathologised and our distress to be questioned, invalidated, and dismissed. This can and has led to long-term harm, suffering and death:

'In the vast majority of INQUEST's recent cases involving young women in mental health settings, those who died have been diagnosed with Emotionally Unstable Personality Disorder. National oversight on inquest findings is urgently needed to prevent repeated failings' [11]

In addition to ethical and moral duties, we feel it is financially wasteful to continue to fund services that harm so many of us. Many of us end up in services for years without the trauma-specific help we need. Many of us get significantly worse as a result of these interactions with services and we increasingly need to use crisis and emergency services.

As CSA and SV survivors we experience overwhelming levels of distress and despair specifically related to our life traumas. When we need NHS crisis services or secondary mental health care support, we are faced with a system that has no other framework with which to understand our distress other than to label it as 'PD', or the seemingly softer but equally damning 'personality traits'. This means that there is very little service provision within the NHS that can support us without forcing us to accept the 'PD' label. We are frequently seen as 'too complex' for the few trauma/PTSD services that exist because we have often experienced multiple, severe and/or relational traumas that these services are currently ill-equipped to respond to. This is also the case when we try to access support from the charity sector. Many charities that support CSA/SV survivors offer short-term interventions which are not sufficient to address the long-term mental health impact of complex trauma. They will frequently exclude anyone with a 'PD' diagnosis. This is especially harmful for those of us who are refugees and have sexual violence experiences related to war. As soon as we receive a diagnosis of 'PD' we are also excluded at policy level from many IAPT services. There is currently very little service provision within the NHS that can support us without forcing us to accept the 'PD' label.

"We cannot stress enough how damaging it is to tell a CSA/SV survivor that the issue resides within their personality. Our lives and identities have often been shaped by the horrific responses of services to us as personality disordered people."

We wish to raise serious concerns with regards to the diagnostic overshadowing that happens once this label has been applied. We are a population known to suffer from high rates of co-morbid health conditions, many of which are overlooked or dismissed once the PD label is on our records. [12,13]

Why we need this cont...

The construct of personality disorder encourages services to disregard what may have happened to us in our lives by focusing on what is wrong with us, essentially blaming us for our own distress. Pathologising survivors is nothing new, for example, women's attempts to resist domestic control have often be reframed as 'hysteria'. [14] In an era of #MeToo, the Independent Inquiry into Child Sexual Abuse (IICSA) [15] and increasing societal awareness of the impact of violence against women/people assigned female at birth, it is totally unacceptable that we are forced to either accept an intrinsically victim-blaming label or to stay silent about our experiences of abuse in order to access any support. It is iatrogenic and counterproductive to replicate the myth that we are challenging and complex due to our 'personality disorder' diagnosis rather than our traumatic life experiences and oppressive struggles or situations. The idea of 'personality disorder' as complex and difficult to treat often enables professionals to avoid providing empathic treatment and care. Whilst there may be some helpful aspects to dialectical behaviour therapy (DBT) and mentalization-based therapy (MBT) for us as CSA and SV survivors, because they are contextualised around 'personality disorder', many of us have found them to be pathologizing, blaming and harmful. Thus, we are left with no other therapeutic options because we have been labelled as 'PD'.

Traumatised children and young people

Given our experiences, we feel a deep sense of responsibility to speak out on behalf of young people and children who are increasingly being told that their personalities are disordered. No child should be seen through the lens of having a disordered personality and, specifically, no child who has experienced or is experiencing CSA should be labelled as having a personality disorder, emerging or otherwise. We believe this should be an ethical imperative for all healthcare professionals. We ask that the long-term impact of this current trend towards diagnosing children and young people is considered. The next generation of CSA and SV survivors deserve so much better than to be stuck in the cycle of harm and despair that many of us find ourselves within current mental health services. Early intervention initiatives should be created outside of the personality disorder construct to prevent this trajectory of harm and to avert years of unhelpful and prolonged service use.

'There is no early intervention argument for diagnosing 'personality disorder' in under 18s. You can intervene early for trauma, complex relational experiences, attachment difficulties, iatrogenic harm etc without using that label/conceptualisation' [16]

LGBTQ+ survivors

Prejudice against LGBTQ+ people is embedded within our society and institutions. LGBTQ+ people are significantly over-represented amongst those with a 'PD' diagnosis. Research has shown that LGBTQ+ people are more likely to be diagnosed with 'PD' (independent of any presenting pathology) than others presenting with the same symptoms. This is likely to be as a result of clinician bias which pathologises those who do not conform to gender and sexuality norms.[17] Indeed, our sexuality and identity is frequently framed as an 'intimate relationship choice' that can be seen as an 'important interpersonal symptom' in at least a third of us who meet the criteria for 'BPD.' [18] And of course, we are seen to meet the criteria because one of the diagnostic criteria is the presence of 'interpersonal issues'. Gay, cis-male survivors who are struggling with their sexual identity are especially at risk of being given a label of personality disorder. [19]

LGBTQ+ people are also significantly more likely to be survivors of CSA/SV. Studies suggest that around half of transgender people and bisexual women will experience sexual violence at some point in their lifetimes. A sizeable number of transgender individuals experience discrimination based on their gender expression or identity at rape crisis centres. [20] LGBTQ+ people face higher rates of poverty, stigma, and marginalisation, as well as higher rates of hate-motivated violence, which can often take the form of sexual assault. As a result, LGBTQ+ people are more likely to deal with complex trauma, contributing to their over-representation amongst those diagnosed with 'PD'.

Research shows that the way we are responded to when we decide to come 'out' as LGBTQ has a direct impact on the amount of so-called 'BPD traits' we are perceived to exhibit. [21] As LGBTQ+ survivors, we wouldn't conclude from this research that LGBTQ+ discrimination causes 'BPD', rather that discrimination of any kind is likely to induce mental distress, especially if someone is already dealing with the consequences of CSA and/or SV. It is possible that people who are having their discrimination experiences understood within a personality disorder framework, may increasingly do things like self-harm or feel suicidal to cope with this fact.

Once a 'PD' diagnosis is given, sexuality of any kind can become pathologised. This is even the case when someone has been the victim of a sexual assault; the implication is that they caused it to happen. As such, 'PD' services compound the trauma inflicted by CSA/SV, and LGBTQ+ people also face concrete discrimination within these services. For example, bisexual survivors within our collective have had their sexuality cited as evidence of an 'unstable sense of self' and of sexually promiscuous behaviour. One of our transgender survivors says:

'The gender incongruence and dysphoria, the trauma and distress caused by a lack of awareness, abuse, discrimination and exclusion by many in society (including family members), the psychiatric system and individuals within it simply because I'm transgender and my subsequent complaint to NHS mental health services were pathologised as so-called 'symptoms of BPD'. - Jee

The interpretation of our sexual preference and identity as somehow being evidence of PD pathology is not only unethical and harmful, it is also a violation of our basic human rights. People think that Psychiatry and Psychology's shameful history of pathologising gay and lesbian people is long gone but it isn't. It's just changed. Now it's become part of 'personality disorder'.

A justification for separate pathways and service provision

We have been harmed by the application of the 'PD' label. This harm comes from the construct itself, and the ideas that underpin it and then affect service delivery. We argue that it is semantically impossible to simultaneously convey the message to a CSA/SV survivor that our personalities are disordered and that the service is trauma-informed. To those of us who have been traumatised by the construct of 'PD', this would be like returning to an abuser who claims to have some method of healing.

As services are currently configured, we have no safe place to go to when we need support. We have been told that our ideas, our justifiable anger, our hyper-vigilance, nightmares, mistrust of people, sensory issues, low self-esteem, voice-hearing, dissociative experiences can all be simply seen as symptoms of our disordered personalities. NHS staff frequently see our distress as 'maladaptive coping' and 'behavioural problems' rather than as a consequence of trauma. This label and the ideas associated with it encourage NHS staff to believe we are responsible for our mental health crises. Many of us have internalised this message and we are now having to live with the daily consequences of believing that we are somehow responsible for our own ongoing mental suffering (as well as believing we are responsible for our own abuse).

Current 'PD' treatments decontextualise our experiences of CSA and SV. For example, some of us have been offered 'DBT' (discussed in the next section) which contains many components that directly contradict survivor-informed healing and empowerment principles. Many people who have experienced CSA or SV will avoid seeking help from mental health services because they know they are likely to be given this label. This means that many survivors are forced to try and find support outside of NHS services. Many survivors end up suffering and even dying because they are too frightened of this label to access the support they desperately need.

Punishment Rather than Care

Criminalising Suffering / Serenity Integrated Mentoring

Many of us cope with extreme distress by using self-harm to modulate our emotional states, end or initiate dissociation, provide a sense of control, self-punish, reduce suicidal feelings, or facilitate communication. We may frequently feel suicidal or experience suicidal feelings over a long period of time, sometimes making multiple suicide attempts.

Self-harm and suicide attempts are heavily associated with personality disorder, with NHS staff often giving out PD diagnoses solely based on a history of these. The PD construct is commonly understood by services to be a 'behavioural' problem. Self-harm and suicide attempts are subsequently viewed through this lens, as 'problem behaviours', rather than adaptive coping mechanisms or genuine attempts at suicide. Such an understanding has led to the creation and implementation of treatment pathways which, rather than supporting us with survivor-led, trauma-informed practices, heavily focus on modifying this apparent 'problem behaviour', with little to no consideration for our underlying emotional distress or trauma history.

One such intervention was the Serenity Integrated Mentoring (SIM) programme, run by the High-Intensity Network. Launched in 2013 on the Isle of Wight, SIM was a joint intervention between police and mental health services, which placed police officers into the mental health teams of patients at high risk of self-harm/suicide, who were also considered to be 'high-intensity users' of emergency services. [22] The SIM police officer existed to encourage emergency services to withhold crisis care from individuals under their management and to join mental health teams to place pressure on the patient to change their 'behaviour'. This pressure included intimidation within healthcare appointments, neglect under the guise of 'positive risk taking', threats of legal action, and support for conviction and imprisonment.

"Surely, services should not withhold support and care when I'm at serious risk of harm under the guise of it being in my best interests, to teach my badly behaved personality a lesson, as a way of tapering care to somehow facilitate resilience, or in a way to avoid blame. You're actually gambling with my life. It's scary! Positive risk taking – positive for who? It's no good promoting recovery if I'm dead!" [23]

In its pilot programme, all participants were survivors of sexual abuse and/or interpersonal violence, and all had been given a diagnosis of BPD/EUPD. [24] The subsequent literature described high-intensity service use as a "trauma driven problem" and linked this to PD. Between 2013-2021, over 20 NHS mental health trusts adopted the SIM programme, or created their own version, actively supporting the use of criminal sanctions to force traumatised people to stop using services. [25]

A recent presentation by SIM shows that the common characteristics of "high-intensity users" include a "history of sexual abuse and violence, a diagnosis of Personality Disorder, dissociative episodes, socially isolated and highly stigmatised people" [26]

As survivors of sexual abuse and violence, the threat or use of criminal sanctions to force us to 'take responsibility' for our distress is deeply traumatic. It strongly reinforces the belief that we are 'bad' people: to blame for the abuse we experienced and for our subsequent suffering. Such an intervention not only harms those of us within these programmes, but also places pressure on others in services not to 'misbehave', and actively discourages people from reaching out for support.

In 2021, an online campaign led by the #Stop Sim coalition of mental health service, survivors, neurodivergent people, and professional allies presented their concerns to NHS England in relation to data protection, human rights, lack of patient involvement and the absence of an evidence base. They called on NHS England to halt the SIM rollout and conduct an independent review and evaluation of the SIM model. In the same year and as a result of this activism, the High Intensity Network was shut down. [27] Despite this, some mental health trusts have continued to use SIM or their own punitive behaviour contracts for people who frequently seek help for self-harm and suicidality.

Punishing abuse survivors for experiencing distress is not compassionate, trauma-informed, or clinically effective. No evidence exists to support this type of intervention. Those of us treated within such frameworks commonly experience fear, re-traumatisation, and further distress. [28-29] Survivors of sexual abuse and violence deserve safe, caring, and evidence-based support, built on a foundation of trauma-informed and survivor-led practices.

Behavioural Approaches

The most common form of evidence-based treatment for 'personality disorder' is dialectical-behavioural therapy (DBT). DBT is a therapy system that combines cognitive-behavioural therapy (CBT) with Buddhist meditative practice. It was developed in the 1980s for the treatment of symptoms of Borderline Personality Disorder (BPD). It is incredibly popular in acute psychiatric care, outpatient settings and even in prisons. Whilst some people clearly get some benefit from behavioural-based interventions such as DBT, we want to raise awareness for survivors like us, who find DBT to be dismissive, silencing, patronising and victim-blaming. [30-31] Most of the current evidence base around DBT efficacy is flawed because it does not separate out the specific needs of our population. There is research to show that DBT is not a trauma-specific intervention and is actively harmful for people with unaddressed trauma needs. [32] There is also strong evidence to show that DBT increases self-harm for a significant percentage of people. [33] DBT practitioners themselves describe the intervention as "validation as sugar-coating so that the distasteful medicine of cognitive behavioural strategies go down". [34]

As the system is currently configured, diagnosis dictates treatment pathways and treatment for anyone who receives a personality disorder label will often include DBT. This is why we are making a plea to commissioners and service managers to think about the needs of our population. Not only is the diagnosis harmful for us but the treatment pathways we are then sent on are inappropriate and cause us further harm.

'What hasn't been helpful to me is this silencing of my own lived experiences that goes on in DBT because you label it as "therapy-interfering behaviours." It's traumatic. It feels as if you are taping my mouth shut, and I do not like it. I do not know all the stories of those given this label, but I can tell you every person I have ever met with this label was seriously abused.' [35]

'I was told 'just report it (CSA) to the police and then forget about it' and wasn't allowed to include anything about it in any of the homework set. The week I did, I was asked to leave.' [36]

'I had very upsetting experiences with DBT...some of the skills echo what an abuser would tell me, aside from the programme itself I also had bad experiences with the therapists so now I'm afraid to seek therapy.' [37]

'During my time in DBT, we weren't allowed to discuss any kind of trauma or abuse at all, in any detail. So I was implementing strategies that were 'inappropriate' but I wasn't allowed to talk about why I was doing what I was doing. just had to be trained out of them like a dog.' [38]

'...being told your emotions "don't fit the facts" by a therapist who hasn't experienced what you have and (in most cases) has no idea what your unique experiences of oppression have been, therapist refusing to talk about your trauma and instead insists you talk about your behaviour' [39]

Trauma services, C-PTSD and Dissociation

Dissociation is defined by the [NHS](#) as 'feeling disconnected from yourself and the world around you and forgetting about certain time periods, events and personal information'. During the traumatic incident(s), a person might enter an altered sense of reality, detached from the self and time. Dissociation is very common after CSA and SV experiences.

There is an acknowledgement that dissociation is often seen in those diagnosed with 'PD', [40] however this seems to be overlooked in most treatments on offer. Even highly specialist personality disorder services operating from a psychoanalytic approach fail to attend to dissociation; this may be because they view people's difficulties via a personality disorder lens. As the clinical lead for a specialist personality disorder recently explained:

'When you were talking about 'DID' and dissociation, for me, I was thinking how we don't, at the Cassel, really focus on or emphasize the sort of dissociative nature of presentations of our patients but obviously, we do have patients who suffer from dissociation' – Barlow, K [41]

For many of us survivors, dissociation is the root cause of our other difficulties and can frequently lead us into crisis. There is strong neurobiological evidence for the existence of dissociative states. [42-43] It is, therefore, unacceptable and unethical that we can spend so long in mental health services without being provided specialised support to directly address this highly disturbing trauma-based phenomenon. Unlike PD services, trauma services work with complex PTSD and dissociative disorders and therefore follow the International Society for the [Study of Trauma and Dissociation \(ISSTD\) guidelines](#), which recommend a phase-based approach. The first phase is stabilisation with a focus on safety, trust and trauma-focused psychoeducation. Trauma therapy then specifically focuses on assisting people to manage dissociation, triggers and hyperarousal states. Dissociation is often overlooked or unrecognised in PD services which means that someone who dissociates a lot may not be able to make use of therapy, even if they have agreed to attend a PD service. If grounding techniques and education around dissociation do not occur, then therapy may not be helpful as someone may not be truly present – rather they are outside of the "window of tolerance" and not available for the therapy or the therapist to reach them.

In addition to this, many PD services are not trained in or sometimes actively discourage the disclosure of sexual abuse. Without training in this, there is no recognition of the extent of people's trauma and survivors like us can feel even more silenced and ashamed. Shame is an integral part of dissociative states and can prevent disclosure of the amnesic episodes (lost time) and voice-hearing, which are often wrongly understood as 'pseudo-psychotic' if we have a PD label attached to us. On average people like us have endured eight years in the mental health system before anyone has recognised our dissociative specific difficulties.[44]

Personality disorder services are not trauma services

There have been recent moves to rename or rather to disguise 'PD' as 'complex emotional needs' or 'personality distress' or even 'complex trauma' or 'complex needs'. Renaming 'PD' services does **not** make them trauma-based or trauma-informed services. Any service or intervention commissioned for us needs to be informed by a deep knowledge and understanding of iatrogenic trauma; specifically, the iatrogenic trauma induced by 'treating' SV and CSA survivors using the 'PD' construct. Many of us have been so harmed that we could not contemplate receiving help from any service that was remotely connected to 'PD' services. Therefore we need separately funded services. This would enable us to heal from our original traumas and the trauma inflicted on us by the 'PD' construct. We believe that the services we need require a culture shift and a radically different, truly innovative approach to what current PD services offer.

PTSD, C-PTSD, Dissociative Disorder - a trauma pathway

Whilst many of us object to having our distress defined by a diagnosis, we recognise that often treatment pathways and commissioning processes require a diagnosis to organise funding streams. Therefore, if diagnosis is necessary for service model design then a diagnosis of PTSD, C-PTSD and/or Dissociative Disorder would more than adequately enable this to happen. Whilst there are many current academic debates about where the C-PTSD diagnosis should fit in terms of service provision, we would argue that this is the perfect opportunity to create innovative C-PTSD pathways and services that might sit alongside NHS trauma services currently catering for issues such as PTSD. Indeed, the emerging evidence supports our lived experience because existing trauma-based treatments appear to be showing promising results for our population.[45] There is further justification since C-PTSD has been evidenced as a separate disorder to EUPD, [46-47] and therefore requires different treatment pathways and approaches. Trauma approaches demand personalized care; this should consist of multiple modalities and a balance of top-down (talking therapies) and bottom-up (body-based therapies e.g. art therapy, yoga, dance, drama, gardening). The emerging evidence for psychedelic-assisted psychotherapy should be explored, [48] in addition to non-ordinary states of consciousness through breathwork. [49] This approach is very different to what is currently offered by PD services which is a one-size-fits-all approach with one or two behavioural based options (often MBT or DBT). Offering brief, time-limited interventions to severely traumatised individuals like us increase fragmentation, reduces trust and can re-traumatise. Treating those of us with dissociative disorders takes time and needs to be undertaken by appropriately trained therapists within specialist teams. For example, the [Clinic for Dissociative Studies](#) currently offers four years of twice-weekly therapy with a support worker.

15 Despite advocating for a trauma-specific pathway, our fear is that current conceptualisations of C-PTSD are too narrow. Some of us may be actively excluded from any C-PTSD treatment pathways that are created based on subjective issues around 'like-ability' or 'clinical perception of risk' or 'likelihood of successful service outcomes'. The eligibility for a C-PTSD type treatment pathway must not be so narrow that it excludes those of us who might attract a label of 'PD' simply because we are not traumatised in the 'right way' or that our traumas are somehow not seen as 'traumatic enough'. C-PTSD is a problematic diagnosis for many of us because what constitutes 'trauma' is so narrowly defined. Many of us have experienced seemingly more subtle abuse, socio-political oppression and betrayal that would be missed by the current diagnostic criteria. If services require a diagnosis it can become a form of gatekeeping and management of limited resources, with people like us left feeling as if we have "failed" an assessment. This often leads to people falling through various nets, meaning we end up with no support at all. This is one good reason to explore alternatives to diagnosis-led service provision but suggestions for this are beyond the scope of this report. What can be said is that we as patients must be able to choose which pathways and treatments we feel we will benefit from. Consent, choice and empowerment are the cornerstones of healing for those of us who have experienced CSA and SV.

Training and culture change

Trauma-specific pathways will also require trauma-specific training packages. The current rollout of personality disorder training has made some attempts to incorporate trauma-informed principles. However, for us, personality disorder training can never be trauma-informed. This is because the concept and industry themselves have caused us harm. One of the most popular PD training packages, known as the 'knowledge and understanding framework' (KUF training), has repeatedly sought to become more gender-informed, trauma-informed and is even delivered by people who identify as having received a personality disorder diagnosis. Yet, this training very clearly does not meet the needs of our particular population.

'I felt flattered and valued to be invited to deliver the training alongside qualified psychologists. However, it soon became clear to me that KUF did very little to challenge the validity of the diagnosis, nor indeed to convey the experiences of service users who had been utterly traumatised by their treatment because of this label. If anything, the KUF implicitly defended the legitimacy of the diagnosis, assimilated legitimate trauma narratives into the construct and inadvertently reinforced discrimination inducing stereotypes.' [50]

To keep us safe, trauma-specific training should be developed outside of the personality disorder construct. Training will need to incorporate information relating to iatrogenic harm, including the harm that may have been caused by the personality disorder construct. Managers and senior staff must understand that if they are providing services for people who have been sexually abused and violated, the last thing we need is to be told to take more responsibility, or that we have 'bad schemas' or to have our 'coping skills' punitively questioned. Trauma training should incorporate the latest neurobiological research around complex trauma and dissociation. It should also take into account the additional physical health needs of our population, for example, ongoing issues related to sexual violence induced dental phobia, high rates of brain injury associated with being a survivor of domestic violence, co-morbid chronic fatigue and fibromyalgia. Training should be explicitly named as trauma-specific and encourage a non-pathologising and compassionate response to us.

What Would Help?

The right to...

Express our needs and talk about our experiences of harm without being labelled as 'difficult', 'confrontational' or 'anti-psychiatry.' We deserve to be heard and listened to, to express our anger and hurt without people becoming defensive.

Access a range of treatments and therapies that are specific to individual distress, without having to be treated under a 'PD' service. This support should be compassionate, non-blaming, non-judgemental and based on individual choice.

Have treatment without the constant fear that what we say, think, feel, or do will be pathologised and labelled as a feature of our 'disordered personality' or associated with this construct.

Have appropriate help at times of distress, especially when that distress has led to self-harm. Self-harm should never be labelled as 'attention-seeking' or treated as 'another PD case' within primary and secondary services.

Appropriate, trauma-specific services and support offered to us even if we are engaged as witnesses in criminal justice proceedings or investigations against our perpetrators. (This includes incidences where perpetrators are located within the health Trust where we are patients.)

Specialist advocacy services trained in complex trauma and dissociation.

Trauma specific pathways and treatments

Pathways to be cohesively connected to existing sexual assault referral centres (SARCs). Almost two-thirds of SARC services report problems in referring on to mental health services. [51] Pathways must be joined up with other health and social care providers who work in the areas of SV and CSA.

Access to trauma-specific treatments and therapies such as EMDR, somatic therapy, long-term psychotherapy, medication, attachment-based therapies, specific interventions and support around self-harm, patient-led support groups, art and body therapies, narrative therapies, therapies that allow for the expression rather than suppression of shame and rage.

Informed by..

Models of racial and social oppression and intersectional disadvantage rather than psychological and psychiatric models only.

Feminist informed approaches and services influenced by the latest cultural knowledge about relevant societal issues such as victim-blaming, rape myths, rape culture, gender stereotyping, systemic misogyny as well as honor-based abuse.

An understanding of heteronormative privilege and identification of implicit or explicit bi-phobia, homophobia and transphobia.

Holistic, trauma-specific approaches, not just cognitive or behavioural models. There are a few good examples of this currently operating in the UK. [52]

A deep and comprehensive understanding of previous iatrogenic and relational harm that has occurred in healthcare systems.

Leadership and training

Complex trauma training for professionals outside of the 'PD' framework. This training would focus on enabling professionals to support people without replicating abusive practices.

Trauma specific training for professionals delivered and co-produced by a wide variety of people with lived experience, especially by those who have been iatrogenically harmed by previous service provision.

Innovative trauma services co-designed by those of us who have lived experience of being harmed by SV/CSA and past treatment within the NHS.

For professionals to be given ongoing trauma-informed supervision and reflective spaces so they are more able to notice and process the feelings that come up for them when working with traumatised clients.

A New Way Forward

1) Truth and Reconciliation

In addition to our experiences shared here, there is evidence to show that mental health services can be retraumatising for survivors. [53] The foundation of a trauma-informed approach must be built on a process of repair first. No healing relationships can be formed on a foundation of harm and mistrust. Therefore, we propose that a process of Truth and Reconciliation (T&R) be established and embedded into the creation of any new trauma-informed service. T&R processes are a form of 'transitional' justice aimed at forging newly respectful relations and restitution for harm and wrongdoing. These are based on an optimistic view of human relationships and the belief that social change is possible. [54] This process would not be about pointing fingers or blame. It would be about creating a space for survivors like us to come together with service managers and staff to authentically express the harm that has already occurred in services. It would be a space to have those experiences actively listened to and acknowledged. Then we would move on to dialogue about why these harms might have occurred and meaningfully explore the ways forward.

'Real reconciliation ... may only be possible once a line has been drawn, through the symbolism of an apology, which explicitly recognises the need for a new trajectory in the future.' [55]

2) Innovative Partnerships and Pathways

We would like commissioners to consider collaborative, NHS-funded, voluntary sector (VS) pathways and initiatives to meet our needs. We feel that the VS offers a distinctive approach and is better equipped than public sector services to support our needs. The VS is able to help groups that may be fearful of engagement with public sector services, [56] for example, people from BAME communities and specifically from African Caribbean communities (the [African Caribbean Community Initiative](#) provides an example of culturally appropriate support, underpinned by an African ethic of care); and people from specific communities such as victims of domestic abuse (e.g. the support provided by [Women's Aid](#)) and asylum seekers and refugees (e.g. [Freedom from Torture](#)). The unifying theme across these different types of VS organisations is the importance of peer support and the relatively flat hierarchies.

We would like a partnership model that considers a whole-systems approach to our health. This includes: thinking about preventing crisis, community-based pathways, as well as more intensive, therapeutic hospital type stays when we need them.

3) Survivor-designed, Survivor-evaluated Pathways

Any pathways or services created must be at least co-produced or, ideally, led by survivors and service-users. Co-commissioning models should be employed to make sure that new services are not replicating past cultures and practices that have previously been so harmful.

Once innovative pathways have been designed and established, there need to be safeguards to ensure that service specifications are adequately met. Survivor-led outcomes measures should be designed to monitor and evaluate services and support. If service users and survivors are truly at the heart of service design, then we should be the ones who evaluate if services are working effectively. Service-level outcome measures may sometimes be in line with survivor experiences and preferences but often this is not the case. For example, reduced hospital admissions or reduced A&E wait times can occur because we have silently withdrawn, deteriorated and given up hope and yet this would be recorded by traditional outcome measures as a 'success'. Survivors should be given the resources to design outcome tools and to carry out quality assurance inspections.

In Conclusion

As survivors, we have shared our experiences with you in this report in the hope that we will be listened to and that our needs will no longer be overlooked. We have explained how 'PD' pathways and services have failed to meet the needs of SV and CSA survivors. For many, these services have caused significant harm and suffering. We have discussed some of the ways in which we are currently being treated in mental health services and how some of the treatments on offer are actively harming us and making things worse.

Although we have explained how the current approach damages us as survivors, we have also provided suggestions and solutions to enable service provision to move forward for our population. No matter where you position yourself in terms of the current debates surrounding 'personality disorder', it is undeniable that what is currently being provided for us as CSA/SV survivors is either directly harming us or we can not engage with it. Therefore we need something totally new and innovative. Reforming current PD provision is not an option for us.

Rather than funding harmful services and training, we hereby make a heartfelt plea to commissioners and service managers/designers to invest in innovative trauma pathways, separate from the 'PD' construct, to enable people to access the support they desperately need and deserve. This is more than a social justice issue; funding separate services should save money by preventing the iatrogenic harm that keeps people trapped in mental health services.

We have shown how the introduction of the C-PTSD diagnosis and the increasing recognition of dissociative disorders, create the perfect mechanism and rationale to fund a trauma-specific pathway, separate to 'PD', to fix the current gap in service provision for our vulnerable and increasingly excluded population.

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