Self-Harm Community Consultation

Exploring experiences of support and care for people who self-harm in Torbay

Make Space Collective CIC

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About the report

This report collates contributions by people with experience of self-harm and their supporters. From November 2022 - March 2023, Make Space conducted a community consultation, seeking to understand more about the experiences of providing and receiving care around self-harm in Torbay (South Devon). Overall, we spoke to 29 people with various relationships to self-harm - some had direct experience of self-harm, whereas others were in supporting roles.

What's included?

- An overview of the academic literature
- Findings from a national consultation with third sector groups supporting people who self-harm
- An overview of the project, including study design and methods
- Verbatim quotes from participants
- Key findings including participants' experiences of self-harm and experiences of care across sectors
- 7 areas for change

The full report

This report is a shortened version of a longer (77-page) **full report**.

Our aim with this **shortened version** is to summarise key information for those who may not have time or capacity to read a more in-depth version. However, if a particular finding or theme interests you, we hope you'll visit the full version to find out more.

The full report includes a longer academic literature review, and offers greater detail on our methods (including recruitment, limitations, data analysis, and participant demographics). The full report also explores our findings in significantly more detail (including more quotes, topics for consideration, and references/wider reading).

You can find the full report at **makespaceco.org/communityconsultation**

Disclaimer

While funded by Torbay Public Health, this research project was conducted by and the report written by Make Space. The findings of the report therefore do not reflect the views of Torbay Public Health. Instead, this report represents Make Space's efforts to accurately and honestly reflect the views and experiences of those we spoke to as part of the project.

Introduction

Self-harm means different things to different people. Often, it means different things to the same person at different times. There is **no 'typical' act of self-harm or 'typical' person who self-harms**. Self-harm can be difficult to respond to; while many try their best to offer care, fear and frustration can lead to insufficient or even punitive and coercive responses [1,2]. This can lead people who self-harm to avoid seeking help. It is vital to take tangible steps to prevent punitive responses and provide people who self-harm with compassionate, appropriate care that respects their dignity and agency.

Considering the flaws in and often inaccessibility of care available to people who self-harm, it should be a public health priority to both improve and widen the accessibility of this care.

While many findings are specific to Torbay (South Devon), they are also congruent with the broader national picture and academic literature on self-harm. We hope this report may be a useful resource for public health, integrated care systems, and others seeking to improve care for people who self-harm across the UK.

Content Note

Throughout the report are mentions of methods of self-harm, discussion of suicide, and examples of inappropriate and punitive responses to self-harm. While we have tried to write the report in a way that does not replicate structures of harm, its contents are often painful. Whether you have a lot of experience of self-harm or none at all, we encourage you to go gently while reading this work.

Academic literature

In designing and conducting this project, we conducted a scoping review of academic literature to explore both the findings and limitations of what was already known. The literature review highlighted the complexity of defining self-harm, and the tendency for research into self-harm to rely on limited, often clinical, populations. The literature review highlighted the **complexity of defining self-harm, and the tendency for research into self-harm to rely on limited, often clinical, populations.**

Two recent Cochrane reviews [3] provide a helpful overview of clinical interventions regarding self-harm. Key findings highlight there is little evidence of beneficial effects of either pharmacological (drug) or natural product treatments. There is a greater evidence base assessing the effectiveness of psychosocial interventions; results suggest both Cognitive Behavioural Therapy (CBT or CBT-based psychotherapy) and Dialectical Behavioural Therapy (DBT) may reduce repetition of self-harm. However, in both cases the results are not definitive, and the exact impact of the therapies remains unclear. Conclusions are not generalisable.

While there is some evidence around non-clinical interventions, studies often do not report the precise details of the content and form of training, making interventions difficult to measure and hard to replicate. A key finding from the scoping review was the tendency for studies to use the reduction of self-harm as the primary outcome measure. However, a recent qualitative study [4] suggests reduction is not always the most important outcome to people who experience self-harm. Instead, they might prioritise improved accessibility of support around self-harm, more supportive environments, and improvements in their quality of life. It is vital to centre the experiences of people who self-harm in designing interventions and providing care.

Given the limitations of existing quantitative studies, it's valuable to draw on sociological literature, which emphasises aspects of self-harm which are crucial for developing local community interventions. We identified key themes of authenticity, privacy, control, and coping, all of which highlight the importance of awareness of social drivers behind self-harm, particularly marginalisation, deprivation, and inequality.

National consultation

Before we began speaking to participants, we spoke to three third-sector organisations providing support around self-harm. We spoke to the **National Suicide Prevention Alliance (NSPA)**, **Intercom Trust**, and **Self-Injury Support (SIS)**. The purpose of these conversations was to learn more about the national picture when it came to care around self-harm.

These organisations highlighted the **importance of taking intersectional approaches to self-harm**, noting that people experiencing difficulty in other areas of life — through homophobia, transphobia, racism, poverty, domestic violence, and more — are more likely to experience difficulty regarding self-harm and accessing care.

The organisations we spoke to highlighted a broad lack of understanding of self-harm, including **persistent misconceptions such as seeing self-harm as attention seeking.**

Project Design

Research questions

Based on our preparatory research and in collaboration with Torbay Public Health and their Suicide and Self-Harm Prevention Action Plan Group, we developed the following research questions:

- What are the experiences of support for self-harm in Torbay?
- Where are the gaps and challenges for service and/or support provision in Torbay?
- What would communities and services that support people who are self-harming look/feel/sound like?
- What are the opportunities and/or challenges to care for self-harm?

Methods

The project involved collating academic literature, speaking to national organisations supporting those who self-harm, and holding conversations with people with experience of self-harm and those who support them.

Participants were free to self-identify as to whether or not they had experience of self-harm. Nobody was asked about the current nature, history, or methods of their self-harm, but were free to talk about these things if they wanted to.

In total **we spoke to 29 people** - 11 were people with experience of self-harm; 18 were supporters including people in the third sector, psychiatric liaison team, social prescribing, teachers, parents, and those in strategic roles in the local mental health trust. Of those we spoke to, 19 were via 1:1 interview and 3 via written testimony. We also held one focus group for supporters of children and young people, attended by 7 people.

Participants were also invited to fill out an optional form about their demographics. All participants filled out the form, but not every participant filled out all sections. There were no pre-determined categories on the demographic form and participants were welcome to describe their identities in their own words rather than ticking boxes provided.

Of those who completed the demographic form the majority of participants were aged 25-50. 21% identified as disabled. 69% identified as female, 17% as male, and 13% as non-binary, genderqueer, or transgender. For race and/or ethnicity, 84% of participants identified as white, 7% as British, and 10% as dual-heritage. 69% of participants identified as heterosexual, and 20% as bisexual, lesbian, gay, or pansexual.

Limitations

While we recruited a broad range of participants, we were not able to recruit from Community Mental Health Teams, GPs, or A&E staff. All supporters worked in Torbay, whereas some service-users lived in Torbay and some in wider Devon - therefore, not all findings are Torbay specific. As is usual for in-depth qualitative research, this project draws on a small sample size, prioritising depth over breadth in data and analysis. Because of this, findings are specific and contextual, rather than generalisable.

Key findings

Experiences of self-harm

Across the project we found that, while there were several key themes to be drawn out about care that both is and could be available, **experiences of self-harm were extremely varied.** People started self-harming at different ages, the presence of self-harm in their lives followed different trajectories, self-harm took different forms, and self-harm had a different role or meaning for them

What is self-harm?

Self-harm **meant many things to many people**. For some, it was linked to caring for oneself, whereas for others it was a helpful warning sign that something was wrong. Almost all participants felt misunderstood in their self-harm and wished they had more people in their lives who were curious and accepting about what self-harm meant to them. Some professionals talked about deliberately trying to construct or work with self-harm as a broad category, to ensure people weren't excluded.

Many people had different understandings of self-harm and used different definitions. People were clear that acts such as self-cutting were self-harm, but were less certain if things like eating disorders, substance use, or self-neglect were considered self-harm.

Several participants noted that it was important to recognise that self-harm had a variety of meanings, roles, or functions in different people's lives. This included recognising there might be instances where individuals felt strongly that self-harm had been helpful, necessary, or even productive, that it enabled them to cope or survive in difficult situations. Participants felt approaches to self-harm were often dominated by concerns about risk and physical safety, which they didn't always find helpful.

> '[Self-harm] has and sometimes does still serve a really useful cathartic function for me, but it's actually very, very low risk. [...] Actually, it's been really sensible and helpful and risk free way of discharging some stress and distancing myself from suicidal ideation.'
>
> **Carys, service-user/third sector.**

Who self-harms?

Participants highlighted that self-harm is not limited to a particular demographic, emphasising the variety of people who self-harm and their significantly different experiences. Participants suggested it was **difficult to generalise about who self-harmed,** and therefore difficult to generalise what people need in terms of care. Some expressed concerns that different groups who self-harmed weren't equally supported or didn't have equal access to care. In particular, participants said services were less equipped to assess or enquire about self-harm in adults than children and young people.

Many, especially service users, felt it important that self-harm was understood in the context of people's lives. This could relate to factors they believed contributed to their self-harm. Several service-users talked about interrelations between self-harm and eating disorders. **Treatments tended to form silos;** people could receive treatment for eating disorders in complete isolation from experiences of self-harm.

Service-users also connected experiences of self-harm to experiences of abuse or relational dysfunction, as a child or in adult relationships. While abuse is widely recognised in academic literature as a risk or causal factor for self-harm, several participants felt their experiences were under-explored by healthcare professionals, or went unrecognised because they didn't fall within the bounds of what is typically thought of as 'abuse'.

Several participants connected self-harm with failures of care around autism, special educational needs, and neurodiversity, noting long waiting lists and trends around late diagnosis. Many connected self-harm with the diagnosis of Borderline Personality Disorder (BPD) or Emotionally Unstable Personality Disorder (EUPD), often **highlighting the widely-evidenced tendency for a personality disorder diagnosis to prompt stigmatising or discriminatory attitudes and behaviour,** although some hoped this was improving.

Participants felt people could 'misinterpret' self-harm as a suicide attempt or a sign a suicide attempt would immediately, inevitably follow, and felt strongly this was inaccurate and untrue. Alongside this, for some, ran a concern such misunderstandings could lead to unhelpful responses that might impede or undermine care for self-harm. However, one participant who was involved in commissioning noted it was only by associating self-harm with suicide that it was possible to make self-harm a policy priority and assign it funding.

Self-harm and 'recovery'

As self-harm meant different things to different people, so did recovery. For some, 'recovery' was about stopping or lessening self-harm, while for others it was about developing compassion and care for self-harm. Some felt their self-harm was dangerous and the best thing to do was stop; others felt self-harm was a useful indicator of wellbeing or helped keep them well. It was **important for people to be able to access services without being required to stop self-harm** immediately or as a condition of participation.

'[Recovery is] not wanting to self harm anymore, not just having the willpower to stop myself.'

Jess, service-user.

Experiences of care

Participants described a range of routes and services through which people might access support for self-harm. People talked about: attempting to access care themselves; professional involvement in services designed to provide mental health care; experiences of helping others access services, whether through referral or otherwise.

A&E and inpatient care

Crisis care was most often accessed through A&E, where individuals may come independently or be brought by family, friends, or emergency services. Participants didn't generally specify, or distinguish between, individual A&E departments, but the experiences described occurred both in Torbay and in Devon broadly. There seemed to be little difference between care provided in different locations.

Many described extremely poor experiences of care in A&E. These failures of care usually centred around **punitive attitudes, sometimes accompanied by the threat of staff neglect or the withdrawing of physical treatment.** Participants described feeling shamed and like their privacy was disregarded. Participants talked about a sense that staff disapproved of them: since they had harmed themselves, they were less deserving both of treatment for physical wounds and also of kindness or care. People often had to wait a long time to be seen in A&E and were often left without being updated or checked on - feeling abandoned at a frightening and vulnerable time.

'Going to A&E and being treated - if you excuse the crude way of putting it - like a lump of shit. [...] If I needed anything, and I rang the bell, nobody would come. I was supposed to have anti sickness medication before any food, but she refused to give it to me. But, you know, she said, *'Well, I've had a friend that has a really awful life because their partner suffered with mental health issues'*. And it was like she was punishing me for the distress.'

Louise, service-user/third sector.

Substandard or less-than-ideal care as a trend within A&E was acknowledged not only by patients but also by clinical and third-sector professionals. At times, acknowledgement was contextualised by discussion of pressures on A&E staff to meet targets for wait times, under-staffing, and a suggestion that A&E staff did not have appropriate training to understand the nuances of mental health and self-harm.

Following A&E assessment, calls to emergency services, or assessment in the community, people might receive inpatient treatment. Unfortunately, participants who spent time on inpatient wards also reported extremely concerning practices, poor treatment, and failures of care. People talked about stigma associated with diagnoses of Borderline Personality Disorder (BPD) or Emotionally Unstable Personality Disorder (EUPD), and stigmatising attitudes held by staff - including a perception that self-harm was attention seeking, people who self-harmed were manipulative, and people who self-harmed or had personality disorder diagnoses would cause trouble. Criticisms focused on **what appeared to be a policy wherein self-harm was 'banned' in wards;** anyone 'caught' self-harming was discharged. This was clearly experienced as punitive by participants.

One difficulty of inpatient and A&E care was the **little to no follow up or long-term care available**: participants described a sense of a 'void' or **being discharged to 'nothing'.** This is particularly concerning as interactions with services were often prompted by crises.

'So I went into hospital twice[...] I went into an inpatient facility. And there would be self-harm on the wards. And I would also self-harm on the ward. And it would just be completely... you'd be penalised for it, there would be no support in it whatsoever, you would just be sent home. So if they found you doing it, or you admitted to doing it, or they realise you're doing it, you'd be sent home for like a week out of treatment to think about it, to think about what you've done, like it was really like a naughty school child kind of thing'.

Bex, service-user/third sector.

General Practice (GPs) and Social Prescribing

Though people rarely received direct care from GPs, interactions with GPs were a crucial aspect of self-harm care. Several talked about difficulties with GPs, some relating to systemic difficulties such as short appointment times and the rarity of repeatedly seeing the same practitioner, being unable to build familiarity or shared understanding. In contrast, positive relationships with GPs could be transformative.

GPs might also refer people to social prescribers. This was a relatively new form of care, described only by two social prescribers, rather than any service-users. Social prescribers spoke about a lack of self-harm-specific resources, and being uncertain what onward referral was possible - meaning they felt underprepared to respond to self-harm.

'They're [GPs] like the front door - aren't they? - to you like accessing support [...] and I've had so many terrible again, experiences with GPs who just like don't understand it, they're just quick to throw you on, like, whatever medication is going to solve, like, you know, mask it. And just kind of forgetting like, you know, the whole bigger picture. It's a bit better now that I've moved surgeries and I feel like my GP like I've actually developed more of a relationship so he understands kind of my history and stuff, but it's quite difficult I found accessing support when for one, you're not seeing the same person every time so you always get like a different opinion.'

Lisa, service-user.

Psychotherapy: TALKWORKS and private therapy

GPs might refer people to TALKWORKS, the local IAPT service. Our participants - both service-users and supporters - reported that ongoing self-harm disqualified them from accessing support via TALKWORKS*. This feature is not unique to TALKWORKS, but is reported as common in IAPT programs. Consequently, it was almost impossible for people who were self-harming or had recent experience of self-harm to access talking therapy without paying for private care.

*Having reviewed the report, TALKWORKs wished to clarify their official criteria for acceptance into their service. TALKWORKs said that they will offer support when 'the patient has not made an attempt on their life, and has not demonstrated escalating or frequent deliberate self-harm, or actions which could have accidentally led to their death, within the last 4 weeks'.

For service-users, it could be **frustrating to be proactive in seeking support only to be excluded for the nature of their difficulties.** For some, this was exacerbated by exclusion from Community Mental Health Team care (CMHT) if they did not meet risk or intensity 'thresholds'. For those able to access therapy, they may have positive experiences, sometimes limited by the therapy's time-bounded nature, often limited to 6 or 12 weeks. For many, the only reliable way to access sustained therapeutic support in the context of TALKWORKS and extremely long NHS waiting times was through private therapy; however, this was a significant financial burden and not possible for everyone.

In discussing forms of therapy, **several mentioned finding Cognitive Behavioural Therapy (CBT) frustrating,** as its self-led, process/action-oriented approach could feel stilted, pointless, and lacking in the depth and nuance needed to address the complexities of their experiences and difficulties. Dialectical Behavioural Therapy, which participants emphasised often had a particularly long waiting list, was identified as more helpful. However, some participants mentioned limitations, while others suggested the value of DBT lay less in its therapeutic approach and more in the opportunity for **sustained care and meaningful connection with an individual therapist — this was a resource rarely available outside of private care.**

'I referred myself to Torbay TALKWORKS as a preventative measure when I became aware of experiencing a relapse in my mental health, however following my assessment I was deemed too high risk because of my past mental health experiences and treatment. I was referred at this point to the CMHT who, following assessment with them, did not see me 'high risk' enough to access their services and suggested I go back to TALKWORKS who would not take me until I had reduced the risk — this left me with nowhere to go.'

Alex, service-user.

Home Treatment Team/Community Mental Health Team (CMHT) and Social Care

Within a standard care pathway, individuals deemed to have more 'complex' needs or be at higher risk of harm were referred to the Home Treatment Team for more sustained care and regular contact. Only a small number of service-users participating in this study had contact with the team in Torbay or Devon. One participant described receiving social care support, following a referral from the Community Mental Health Team. She spoke positively of this, describing it as a care which was stable and reliable, yet flexible enough to respond to specific day-to-day needs.

NHS services: Overarching difficulties

There were several difficulties running across various NHS services, making good care hard to access. One key limitation was the length of waiting lists described by service users and healthcare supporters. People could wait over a year or even two; service-users described **frustration at spending seemingly endless amounts of time on a list, with little information about when they may access support.** Professionals were concerned patients might become more ill or despairing while waiting for treatment. Delays might increase the possibility of someone reaching crisis point or needing to access crisis care.

'There's a huge waiting list [for the CMHT], and we often see people that have self-harmed who are sat on a waiting list. And that's really sad and frustrating because they want help, that's why they come in. They wouldn't be coming to our department if they didn't want help. But unfortunately the help that we know that they need, they've got to sit on a waiting list and for some people that's like a good couple of years before they get to doing any work.'

Michelle, psychiatric liaison nurse.

Participants also described feeling that **care across statutory services was disjointed.** Different parts of the healthcare system failed to communicate with each other or offer consistency. This was intensified when accessing care out of hours. Furthermore, when care was disjointed and every interaction involved a different staff member, root causes of distress could go overlooked. Participants described **frustrating experiences of having to retell lengthy accounts of their history every time they accessed services,** alongside the confusion of accessing support at different points and receiving extremely varied responses or diagnoses.

'That's the main problem. There is no sustained care whatsoever. You never see one person more than once or the same person more than once. Ever. It's really bizarre. And I must have spoken and told my story to more than 10 people, you know, or 10 instances. [...] Obviously, it's quite difficult to talk about your traumatic events. And I kept coming away from those appointments and knowing nothing was really going to happen. And having you know, or knowing that they're going to refer me somewhere else and I was going to have to go through the whole thing again.'

Kai, service-user.

Third sector: Charities, not-for-profits, and peer-led groups

Several third sector organisations in Torbay provide care around self-harm - either directly or in relation to broader mental health support. In general, **service-users had more experiences seeking care from statutory services than the third sector.** However, it is unclear whether this is because they weren't aware of services or due to our limited sample size. However, healthcare professionals were often very aware of relevant third sector organisations. Significantly, it seems **third sector organisations are often the first point of referral following crisis care in A&E.**

Third sector groups offered a variety of care to support mental health - including online peer-support, and recovery-oriented activities for those who self-identified as having experience of mental illness, distress, or trauma - but none offered self-harm-specific support. Many groups **felt statutory services and local authorities relied on them to supplement their work.** Third sector professionals were highly motivated to provide appropriate care where possible, but faced difficulties realising this. For instance, it was **hard to achieve consistency or build skills in projects only funded for one or two years**[**]. This was linked to the difficulty of securing funding for core running costs.

'It's quite rare to have the luxury of secure funding, without targets to prove or meet. And that [core costs funding] is absolutely crucial to being able to be community-led because you can't be community-led if a commissioner has decided what they want to see, that makes sense?'

Carys, service-user/third sector.

[**]**Problems surrounding the lack of core cost funding and constraints imposed by funders' expectations of 'reporting' and 'impact' are noted in multiple recent reports from the **National Survivor User Network (NSUN)**, evaluating the funding and needs of user-led mental health groups: **Funding Grassroots Mental Health Work** (by White, Wells, and Hammou 2022) and **What do User-Led Groups Need?** (by Brown and Omerod, 2020).

Children and young people

We did not have the resources or capacity to interview children and young people directly, but found that supporters (such as parents, carers, teachers, friends, and other adults involved in supporting them with their self-harm) wanted to be involved in the project. We therefore ran a single focus group with people supporting young people with experience of self-harm.

While we spoke to adults supporting young people in a state school, we do not know how young people experienced this care, or if supporters' reports of their needs match the needs of young people themselves. **We strongly advise conducting further research to better understand the experiences of young people who are self-harming.** While our findings offer tentative themes in supporters' views of care for children and young people who are self-harming, they cannot and should not be taken as a full representation of young people's experiences of or needs around self-harm.

Generally, supporters felt young people's wellbeing - and their parents', which is understood as highly determinative of young people's wellbeing - had declined in recent years, exacerbated by the pandemic. The **impact of austerity on parental support facilities was repeatedly noted**, particularly the closure of Sure Start Centres and Family Units. Participants felt self-harm was prevalent in schools, but were underprepared to respond. Care provided was often ad hoc, with no coordinated protocol for responding to self-harm. Supporters felt they had little to no formal training. Almost all wanted training, including on why young people may self-harm and how best to support them.

Those working in schools tended to offer in-house support rather than referring young people elsewhere - not because it was the most appropriate place but because they felt despondent about the appropriateness or availability of support elsewhere. **Schools did not speak highly of CAMHS or GP support.**

'I just find CAMHS really quite patronising and not really that helpful. [...] Then you hit 18 and they're suddenly like, 'Okay, bye. Leave now, like you're an adult, go'. And it's just like, okay, well actually now I've got to try and get used to someone else. So at that point, I withdrew from it all.

Maya, service-user.

Primarily, participants felt **CAMHS had extremely long waiting lists and support was often mismatched to the needs of a young person.** Another key concern with CAMHS (and statutory services generally) was the transitional gap once they reach 18 years old, noted by supporters of young people who self-harm and people with lived experience reflecting on experiences of accessing support as a young person. Schools relied heavily on online tools like Kooth or Calm Harm, which they found helpful but limited.

Several noted **safeguarding often stood in the way of schools offering the support they wanted***. These processes often led to forms of care that breached confidentiality and undermined young people's autonomy. In some cases, safeguarding practices also created greater danger by removing a young person's control over their self-harm.

'So quite often, we have to actually remove their blades, which they hate, and they'll actually hide them in the most ingenious of places. But if we find them I'm afraid, we do have to remove them which is upsetting for the young person because quite often they've, you know, they've selected a blade which gives them the right amount of cut. And one girl said to me, 'Miss, that was my favourite blade.'

Nicky, children and young people: safeguarding officer.

One participant with expertise supporting young people with special educational needs and disabilities (SEND) noted high rates of self-harm among those they supported. This was understood primarily as communicative, with self-injurious behaviours (such as head banging and self-scratching) interpreted as demonstrating a young person's frustration. **The focus of support for children with SEND was not to stop self-harm but to understand what the young person needed and try to respond to this.** Responding to self-injurious behaviours requires creativity, trust, patience, and time - elements not always available in mainstream school environments. Even in specialist schools, supporters may not feel well-resourced to provide these.

***To learn more about alternative approaches to safeguarding, see Maslaha's **Radical Safeguarding - A Social Justice Workbook for Safeguarding Practitioners** (by Johnston and Akay, 2022).

Contexts and structures

Participants described systems as underfunded and lacking capacity, including healthcare, education, and the third sector. They noted the **impact of funding cuts and austerity budgets, nationally and locally.** There was a sense that the under-funding of a single element of the system had a knock-on effect on other areas: lack of capacity in one area could lead to greater burdens on others, which were also struggling with funding and capacity.

At all levels, **individuals were displaced from one struggling, over-capacity system to another**. Struggles around capacity contributed to and were exacerbated by the absence of out-of-hours support. This was discussed by participants as a key difficulty in accessing care, especially in crisis or intense distress. This was connected to Torbay's relatively isolated coastal location, making it difficult and time-consuming to access care.

> 'I can't access services when I'm working. How can I attend a GP appointment where I have to phone up on the day? I can't just phone up and call in sick to attend a doctor's appointment or, like, just leave work at 3pm that day. And sometimes - like living in Torquay working in Plymouth - like, I can't just go back for a doctor's appointment and get back to work. [...] My crises tend to be at night: at night, no one's around. I can't pick up the phone, whatever. Can't go around someone's house.'

Ash, service-user.

Several noted aspects of society or culture impacting experiences of self-harm or making it harder to access care. Many of these aspects were economic, regarding pressures caused by austerity, rising living costs, and deprivation. These created living conditions of misery and struggle, making it impossible for many to access private therapeutic care which was often their only option, given lengthy waiting lists. Simultaneously, participants noted economic stressors impacted the community resources, both in general opportunities for community connection and in the closure of community-based programs.

Torbay is a **coastal area in the South West of England,** with an industry highly dependent on seasonal tourism. A high proportion of property is holiday accommodation or second homes. This is accompanied by a lack of opportunities for economic growth or career development. Due to the area's coastal location, infrastructure is often insufficient, for instance regarding transport or telecommunications. There was a **perceived lack of investment and a lack of resources outside urban centres.** These contextual factors can create situations of extreme difficulty, which may lead to distress.

Areas for change

Below, we identify seven key areas for change. Our recommendations are based on the insight and experiences of participants in this study - speaking to a gap in the literature regarding social interventions, which may prove beneficial to outcomes beyond cessation and go beyond extending pre-existing services.

We recognise - in alignment with the work of groups across the mental health sector - **that experiences of mental distress and the care provided in response are inextricably linked to wider structures of support,** and the systems through which care is organised and provided.

We focus suggestions on targeted interventions which respond most directly to experiences described in this report. Such interventions could make meaningful improvements to care available to people who self-harm in Torbay, and might improve support for those providing that care. However, **this should be read alongside the need for widespread system change** in broader systems of care to radically reform experiences of providing and receiving care for self-harm.

1. Peer-support

Many participants discussed the potential benefits of peer support groups, where people with experience of self-harm could gather to share experiences and offer each other solidarity, advice, and encouragement. They felt knowing others with similar experiences may reduce isolation and offer chances for connection and learning.

Peer-support groups must:
- be well facilitated by people with significant training in group facilitation and safeguarding.
- run at various times, so people can access them around work hours or caring responsibilities.
- be specific to self-harm, or at least equipped to respond to it.

Participants felt peer support groups for parents, family members, and other carers of people who self-harm could be helpful. Specific recommendations for this include:
- establishing regular peer support groups not oriented towards cessation.
- increased support for and provision of peer support for mental health more broadly.
- training around self-harm for those who facilitate mental health support group.

2. Training and attitudes

One of the most notable findings was the language, treatment, and attitudes people who self-harmed experienced from healthcare professionals. Participants described upsetting examples of poor care. NICE guidelines state healthcare professionals should treat people who self-harm with *'respect, dignity and compassion, with an awareness of cultural sensitivity'* [5]. This is frequently not achieved. Participants recommended additional training for clinicians and service-providers. This could be supplemented by clear guidelines regarding (in)appropriate language or care.

Specifically, we recommend:
- mandatory user-led training for all NHS staff supporting people who self-harm.
- a clear guide to language and behaviour standards.
- improved reporting and accountability where care falls below acceptable standards.
- improved resources and leaflets to replace those in circulation in healthcare settings.

'It has been helpful when self-harm is addressed with curiosity and care, not scorn and judgement or seen as a form of getting attention which has been my experience from family/the community and care services [...] To know and trust there is someone that does not hold judgement, who is there alongside you to help manage the periods of self-harm but without fear of withdrawing care if you speak up about it.'

Alex, service-user.

3. Children and young people

Participants noted gaps in care for young people in Torbay, not just regarding self-harm but more broadly. For example, there is a lack of youth groups and community centres, a lack of support for drug and alcohol use, as well as other social and emotional health issues. To address this, participants noted the need for more joined-up support for young people across all sectors in Torbay, underpinned by training and resourcing for those supporting young people.

Due to safeguarding concerns, we could not speak to young people directly about their needs. Implementing these recommendations needs to be done in collaboration with the young people they are designed to support. As a result, our primary recommendation to replicate this consultation with young people.

Following this, further steps to support children and young people might include:

- introducing wellbeing 'hubs' in school which provide holistic, person-centred support.
- providing peer support for families and carers, as well as young people themselves.
- improved training and resourcing for people providing support for young people.

4. Joined up care

A key difficulty at all levels of care for people who self-harm was a lack of joined up care. This reflected the difficulty of establishing and communicating coordinated care plans between facets of the healthcare system, as well as low levels of resources and staffing.

However, it also reflects failures of technology where, for instance, out-of-hours staff could not access patient records and pre-agreed care plans. Similarly, it reflects the difficulty of navigating a complex health and social care system. Finally, it reflects how service-users on waiting lists or recently discharged from services were left without follow-up support, at times without any referral.

This might be addressed by:

- increased provision of care co-ordinators.
- introducing 'navigators' to help service-users understand local resources and services.
- technological improvements around record-sharing and repeat assessments.
- bridging support for people on long waiting lists.

5. Community resources

Participants identified a lack of central, accessible locations to access support, especially out of hours. Providing genuinely caring support in communities requires more consistent funding for services and a culture change in attitudes to self-harm. Participants explicitly stated that this must be led by the community and respond to their priorities, and not be imposed top-down by commissioners and public health.

Improving community resources might involve:

- providing core costs funding for local community groups.
- investing in physical community centres that can provide varied and holistic support.
- tackling misconceptions around self-harm amongst community groups.

[Describing an idea for a community centre with a range of options]:

'So if people are coming in and they're feeling quite well, they might do some self management stuff, they might help out with different stuff. They might do whatever they wanted to, but as people's distress increased, they could say what it was they needed at that point. So they might do more of something or less of something. [...] They might just want mindfulness meditation; they wanted to do some art therapy. There was a menu of stuff that people could come in and do, it didn't matter where they were.'

Mary, third sector: peer support.

6. A&E and aftercare

A&E departments were a key pathway to treatment. Multiple sources said it was standard practice for those deemed to meet a lower risk threshold to be discharged without referral to statutory services or follow-up beyond being placed on lengthy waiting lists. Given that A&E was often a place people attended at times of intense crisis and vulnerability, it was troubling to hear repeated poor experiences of care. Tackling issues around care for self-harm in A&E would significantly improve care available to people who self-harm.

This might include:
- mandatory user-led training for all A&E staff.
- providing follow-up support following A&E.
- advocates in A&E departments to support people attending due to self-harm.

'To have, like, a designated room where you could go and you know, that [there are people] trained in the recovery principles [...] the language to use, and being person centred, maybe even with lived experience themselves. That would mean more support for that staff member, which means more NHS resources, but somebody that would understand [and] knows that their experience isn't everybody's experience. So doesn't say 'this is what helped me' but, but can have empathy when people show up. So that when people do go to A&E, you're not, you're not, you're not scolded for it, you're not shamed.'

Bex, service-user/third sector.

7. Community of practice

Many in third-sector and educational organisations expressed a need for greater connection, communication, information, and support. Professionals are not always specialists in self-harm, or even mental health. While they may have access to mental health or self-harm-specific training, broader support in how they address self-harm in their work is valuable. Many expressed a desire for a community of practice focussed on self-harm. This would help supporters connect with others in their field and across Torbay to share advice, best practice, resources, and opportunities for collaboration.

Creating a community of practice might involve:

- building a cross-sector network of professionals to share practice.
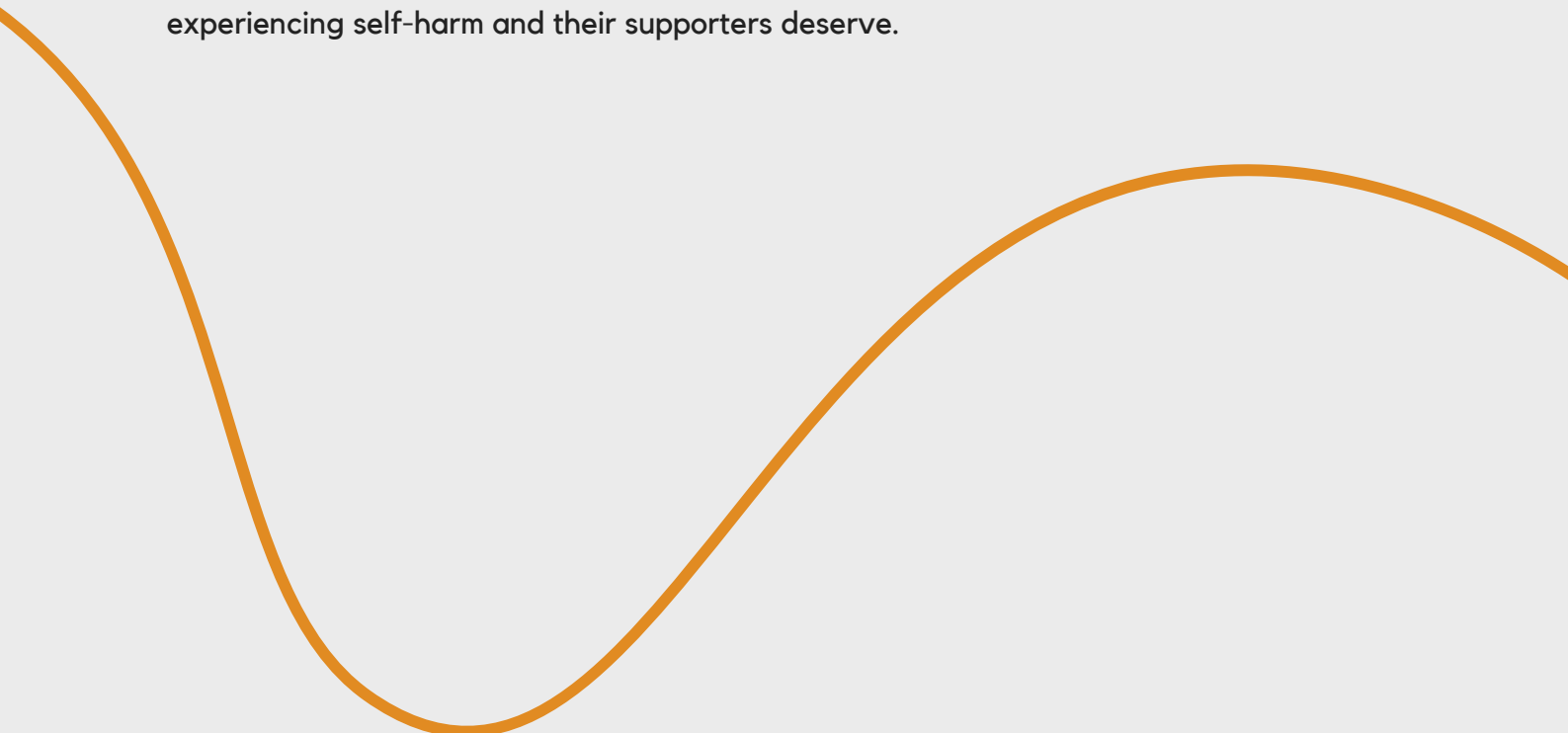- establishing a co-ordinator for this network within the Torbay public health team.

Conclusion

This report has detailed the findings of a year-long community consultation, conducted by Make Space and commissioned by Torbay Public Health. The purpose of the project was to learn more about the experiences of care for self-harm in Torbay and Devon more broadly.

The findings from the project were largely congruent with the academic literature scoping review and the national consultation - they were not 'unique' to the Torbay context but instead represent a broader picture, of **systemic underfunding of mental health care more broadly and widespread misunderstanding and misconception around self-harm.** They suggest that people had difficult experiences of both receiving and providing care around self-harm; this poor care was often connected to institutional policies or structural issues, including both the exclusion of people who self-harm from certain services and the scarcity of resources (such as understaffing and underfunding of NHS services).

Everyone experiencing self-harm deserves access to care that feels safe and affirming. That care should be able to meet a person in the entirety of their experience, including their history, identity, values, and hopes for the future. The care should be provided by people who feel they have the adequate resources to offer this care. While many reported instances of this kind of care, the majority of it was not so. We hope that by documenting the experiences of those we spoke to, we may help to bring about a world that people experiencing self-harm and their supporters deserve.

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About Make Space

Make Space is a user-led collective seeking to bring about a world in which all responses to self-harm are caring, just, and user-led. We do so through research, training, and peer-support. We are led by and for people with experience of self-harm.

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