Torbay 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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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.

Executive Summary

About the project

This report collates the contributions provided 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.

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 are led by and for people with experience of self-harm. Our work is rooted in liberatory politics and mental health care as a political act.

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 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. In total we spoke to 29 people - 11 of whom were service-users with experience of self-harm, and 18 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.

We collected information through interviews, focus groups, and written testimony. All participants were paid for their time, and we provided the opportunity for all involved to have a 1:1 debrief with a therapist, free of charge.

Limitations

While we successfully recruited a broad range of participants, but were not able to recruit from Community Mental Health Teams, GPs, or A&E staff. Due to issues with recruitment, not all of our findings are Torbay specific. All supporters worked in Torbay, whereas some service-users lived in Torbay and some in Devon more widely.

As is usual in in-depth qualitative research, this project draws on a **small sample size**, and prioritises depth rather than breadth in data and analysis. Because of this **the findings are specific and contextual, rather than generalisable.**

Key Findings

What is self-harm?

Varied experiences of self-harm

Self-harm meant many things to many people. For some it was linked to caring for oneself, whereas for others it served as a helpful warning sign that something was wrong. Almost **all people felt misunderstood in their self-harm** and wished that they had more people in their lives who were curious and accepting about what self-harm meant to them.

Defining self-harm

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 would be considered self-harm. There was also a mixed discussion of the relationship between self-harm and suicide; for some people self-harm existed alongside thoughts of suicide, whereas for others self-harm was not linked to suicide, or helped them to prevent suicidal thoughts or acts.

'Recovery' as individual

Just as self-harm meant different things to different people, so did recovery. For some people 'recovery' was about stopping or lessening self-harm, while for others it was about **developing compassion and care around their self-harm.** Some people felt that their self-harm was dangerous and that the best thing they could do would be to stop, while other people felt that their self-harm was a useful indicator of their wellbeing or helped them to keep themselves well.

Experiences of care

Spaces and sources of care

Participants described seeking and receiving care from a variety of sources. In terms of healthcare, people who self-harmed often entered care pathways through a visit to A&E, which would be accompanied by assessment from a member of the psychiatric liaison team and might lead to an inpatient admission, referral to the home treatment team, or simply discharge.

People also described trying to access care through their GPs, who might refer them onwards to talking therapy through TALKWORKS (to which they could also self-refer), or to the social prescribing team. Young people often accessed care through the Child and Adolescent Mental Health team (CAMHS). People who were accessing multiple forms of care might have access to a care coordinator. Care was also available through a variety of third-sector or voluntary organisations, including Devon Recovery Learning Community and Recovery Devon.

Punitive and inappropriate care

Almost all people with experience of self-harm had one or more negative experiences of care. People spoke of punitive and care, especially in A&E departments and inpatient care. **People felt stigmatised, shamed, and punished for having self-harmed.** This included inappropriate language from supporters and withdrawal of care. People were often referred elsewhere or given leaflets/resources that felt insensitive or patronising.

The void

Most people discussed **long gaps in care, or no care at all**. For some 'the void' meant being on a long waiting list with no updates, whereas others had experiences of being discharged from services to nowhere. There was an awareness that resources were stretched across the healthcare system, with low rates of staffing and a lack of inpatient beds.

Simultaneously, there was a sense that self-harm could trigger safeguarding protocols which often felt at odds with people's needs and desires, or would mean people surpassed a 'risk' threshold for a particular service and they would be discharged. There was a persistent issue with being too 'high-risk' for some support and too 'low-risk' for others.

Appropriate care as case-by-case

People described many ways of experiencing care for self-harm. Some people found therapies such as Dialectical Behavioural Therapy (DBT) or Eye Movement Desensitization and Reprocessing (EMDR) helpful. Others preferred non-medicalised support such as peer-support. Many people felt a mixture of

mainstream and non-medicalised support was helpful. **There was no one-size-fits-all.**

Contexts and structures

Participants acknowledged that some aspects of Torbay's social and geographical context impacted experiences of self-harm, for instance failures in infrastructure, and difficulties of establishing community ties within a tourism-dependent seasonal economy. Broader national structures also had a significant impact, including austerity, the rising cost of living, and decades of cuts and systemic underfunding to community resources and healthcare services.

Areas for Change

As part of the report we identified seven key areas for change. These are developed in response to our findings and acknowledgement of national resourcing issues, especially within the NHS context. In the report we introduce each area for change, describe how it correlates to our findings, in some instances offer a case study, and then make a set of recommendations of how each area for change could be improved.

Peer-support

People spoke highly of peer-led work. People wanted **non-medicalised, self-referral spaces that were led by peers**. In the third sector, peer led work was threatened by lack of core costs funding.

Training and attitudes

Few supporters had self-harm-specific training. There was an overarching desire to know more about self-harm and how to respond to it. Those who found ways to support people with self-harm often learned 'on-the-job' and created solutions case-by-case. They lacked space, resources, and systems to support themselves. Lack of training or support was especially true for those working in schools.

Many people hoped for improvement to the way people responded to self-harm, so that punitive or shaming attitudes were no longer accepted. It was important that those providing support and care around self-harm understood self-harm, and were equipped to respond sensitively - this was not always the case.

Holistic support for children and young people

Young people need easily accessible support, beyond that provided by CAMHS and perhaps through hubs located in schools. This support must be provided by skilled professionals and led by the needs and preferences of young people.

Joined up care

Many **struggled to navigate a bewildering system** and find any form of consistent care, or even a consistent diagnosis. People were often discharged from statutory services without follow up. Finding ways to join up sources of care will be valuable.

Broader community resources

People felt it important to understand **self-harm in the broader context of people's lives and relationships**, and that valuable support might be possible through investing in general community resources. People especially talked about the possibility of community hubs and physical spaces for individuals to find connection and care.

A&E and aftercare

The A&E department was a key pathway to care, but also often a **site of poor care.** Increasing training for A&E staff, and providing opportunities for follow-up care, could significantly improve experiences of people who self-harm.

Community of practice

Professionals in non-healthcare roles (particularly education and third-sector organisations) wanted to provide support around self-harm but often didn't feel equipped to do so and weren't aware of resources or sources of support in Torbay. Creating connections and increasing awareness will be valuable.

Conclusion

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 and support to offer this kind of care. While many reported to us instances of this kind of care, the majority of it was not so. This is not unique to Torbay but instead a reflection of national issues relating to resourcing of mental health services and attitudes toward self-harm.

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Content Note

The focus of this report is self-harm. 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.

Terminology

Service-User

We use the term service-user to describe people with direct personal experience of self-harm. This term is not without flaws, as some feel it is disempowering or implies passivity - others prefer the term 'survivor'. You can read more about the term service-user here, and explore the use of different terminology <a href="here. We use it in this project specifically to reflect our focus on services and structures of care through which people might access support, rather than on experiences of self-harm more broadly.

Supporter

We use the term supporter as a catch-all term to describe those who find themselves supporting someone with experience of self-harm - whether as a friend or carer or in a more professionalised role such as a Doctor or teacher.

Self-harm

Self-harm is difficult to define. For the purpose of this report we began the project using a definition of self-harm as 'an act, normally a repeated, habitual act, which in some way causes direct harm to the body but one where the focus and purpose of the act is this harm itself and not some other goal'. For recruitment, we allowed people to self-identify as having self-harmed - this means we may have included experiences and perspectives that fall outside of this definition.

Non-Suicidal Self-Injury (NSSI)

NSSI is used in academic and public health literature. It is often used to mean the intentional destruction of one's own body tissue without suicidal intent and for purposes not socially sanctioned'². This is not a term we adopt ourselves and we instead prefer to use the term self-harm.

Acknowledgements

Our gratitude to all who supported us in this project. In particular, thank you to our participants who shared their experience, expertise, and insight with generosity and vulnerability. It is our hope that this report may help to make a difference.

¹ Steggals, P., 2015. Making Sense of Self-harm: The Cultural Meaning and Social Context of Nonsuicidal Self-injury. Springer. p. 9.

² Klonsky, E.D., Victor, S.E. and Saffer, B.Y., 2014. "Nonsuicidal self-injury: What we know, and what we need to know." *The Canadian Journal of Psychiatry*, 59(11), pp. 565-568.

Introduction

Everybody deserves access to safe and affirming care, whatever they are experiencing. Both the broader literature and this consultation suggest that when it comes to self-harm, safe and affirming care is often absent.³ Self-harm is a significant public health issue in Torbay and across the UK more broadly⁴ - a recent report suggested that non-suicidal self-harm increased from 2.4% of the population to 6.4% in 2014⁵. While statistics measuring rates of self-harm are difficult to verify or interpret, they point to a concerning prevalence of distress and difficulty. People experiencing distress need and deserve appropriate physical, psychological, and emotional care. Such care comes in a variety forms. While the 'success' of self-harm care is often measured by the extent to which people seek help, help-seeking is not always a reliable measure of care, especially when 'help' can be absent or inappropriate⁶. 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.

Self-harm means different things to different people. Often, it means different things to the same person, at different times in their life. **There is no 'typical' act of self-harm or 'typical' person who self-harms.** Self-harm can also be difficult to respond to; while many try their best to care for others, fear and frustration can lead to punitive or coercive responses. This can lead people who self-harm to avoid seeking help in general or from specific services. 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.

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https://www.nsun.org.uk/not-a-naughty-child-peoples-experiences-of-service-responses-to-self-injury/

³ Quinlivan, L., Gorman, L., Monaghan, E., Asmal, S., Webb, R.T. and Kapur, N., 2023. Accessing psychological therapies following self-harm: qualitative survey of patient experiences and views on improving practice. BJPsych open, 9(3), p.e62.

Quinlivan L, Gorman L, Littlewood DL, Monaghan E, Barlow SJ, Campbell S, Webb RT, Kapur N. 2022. 'Wasn't offered one, too poorly to ask for one' – Reasons why some patients do not receive a psychosocial assessment following self-harm: Qualitative patient and carer survey. *Aust N Z J Psychiatry*. 2022 Apr;56(4):398-407;

Mughal F, Troya MI, Dikomitis L, Chew-Graham CA, Corp N, Babatunde OO. Role of the GP in the management of patients with self-harm behaviour: a systematic review. *Br J Gen Pract*. 2020 Apr 30;70(694):e364-e373.

Faulkner, A, and Rowan Olive, R. 2022. Not a Naughty Child: People's experiences of service responses to self-injury, *National Survivor User Network Blog*. Available at:

⁴ Witt KG, Hetrick SE, Rajaram G, Hazell P, Taylor Salisbury TL, Townsend E, Hawton K. Pharmacological interventions for self-harm in adults. 2021b. *Cochrane Database of Systematic Reviews*, Issue 1.

⁵ McManus, S., Gunnell, D., Cooper, C., Bebbington, P.E., Howard, L.M., Brugha, T., Jenkins, R., Hassiotis, A., Weich, S. and Appleby, L., 2019. Prevalence of non-suicidal self-harm and service contact in England, 2000–14: repeated cross-sectional surveys of the general population. *The Lancet Psychiatry*, 6(7), pp.573-581. In the study, non-suicidal self-harm is taken as a synonym for non-suicidal self-injury, but including self-injury and -poisoning.

⁶ https://www.cost-ofliving.net/help-seeking-wheres-the-help/

This report details findings of a year-long community consultation undertaken by Make Space, a user-led collective that seeks to reimagine understanding of and care around self-harm. The report was commissioned by Torbay Public Health, who wanted to learn more about care for self-harm in Torbay (South Devon). As part of the consultation we looked at academic literature, spoke to national organisations, and held conversations with people in the community who had experience of self-harm. This included people who self-harmed and their friends and families, as well as supporters in the third and public sectors. The majority of our participants were based in Torbay, but some were working in or accessing care in Devon more broadly.

While many findings are specific to Torbay, they are also congruent with the broader national picture and academic literature on self-harm. Inappropriate and harmful care are not limited to Torbay, but reflect broader issues around self-harm: misunderstanding, stigma, and national cuts to public and third sector services. Moreover, this report reflects a picture of self-harm care in a difficult time for everybody, particularly in the midst of the pandemic and cost of living crisis. We believe this could be a useful resource for public health professionals, integrated care systems, and others seeking to improve care available for people who self-harm across the UK. By sharing the report, we hope to begin a conversation about what it means to be someone who is self-harming, and what it could look like or will take to ensure everyone has access to generous, life-affirming, and genuinely supportive care.

We encourage all readers to take their time to read and reflect upon what follows. Firstly, because its contents can be distressing and touch upon experiences in our own lives. Secondly, because care around self-harm involves complex and multifaceted issues - which to overcome require conversation, reflection, and time. You may like to read the report with a peer and create some time to reflect on it together.

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 are led by and for people with experience of self-harm. Our work is **rooted in liberatory politics and mental health care as a political act.**

Make Space centres lived experience as a valid and legitimate form of knowledge. We believe people with experience of self-harm have a right to share their experiences on their own terms, and that any **research practice should centre safety, care, and integrity over 'output'.**

1. Wider Context

This section provides background to the subsequent analysis and to the decisions made regarding project design. This included:

- A scoping review of relevant academic literature.
- National consultation with third-sector organisations providing support around self-harm.

1.1 Literature review

This section provides a summary of our full scoping review, which helped us to contextualise the findings of the project, and highlighting the complexities of conducting research in and establishing definitive conclusions in this area.

A key complexity of research in this area is in **defining self-harm** - and particularly establishing self-injury as a repeated practice distinct from any intent to fatally injure. Attempting such a distinction raises important questions around intentionality, whether it is possible to clearly distinguish between self-harm and suicide, and how much the location of studies or interventions (such as A&E departments or inpatient wards) impacts how self-harm is defined. Different research studies often use divergent definitions of self-harm, so it is important not to take for granted that conclusions regarding particular groupings or sub-sections of self-harm can be applied to the category more broadly. **Research into self-harm has frequently relied on limited, often clinical, populations** and conclusions should not necessarily be extended beyond such samples. This is particularly significant with relation to race and gender for example, a sample of primarily white women can't be assumed to reflect the broader population of those who self-harm.

Clinical interventions

Clinical interventions include both pharmacological (drug) interventions and psychosocial (predominantly therapy-based) interventions. These groupings form the basis for a pair of recent Cochrane reviews which provide the best summary of the current evidence base and were central to this project's literature review. The central conclusion on pharmacological interventions is: 'there is little evidence of beneficial effects of either pharmacological or natural product treatments' (Witt et al., 2021b, pg. 2). This reflects a paucity of relevant, high-quality evidence, and that the evidence available suggests the low effectiveness of such interventions in reducing repetition of self-harm. 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

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⁷ Witt KG, Hetrick SE, Rajaram G, Hazell P, Taylor Salisbury TL, Townsend E, Hawton K. Psychosocial interventions for self-harm in adults. 2021a. *Cochrane Database of Systematic Reviews*, Issue 4. Art. No.: CD013668.

Witt KG, Hetrick SE, Rajaram G, Hazell P, Taylor Salisbury TL, Townsend E, Hawton K. Pharmacological interventions for self-harm in adults. 2021b. *Cochrane Database of Systematic Reviews*, Issue 1.

self-harm. However, in both cases the results are not definitive, and **the exact impact** of the therapies remains unclear. There is moderate evidence that group-based emotion-relation psychotherapy may reduce repetition of self-harm, and a single study suggesting the efficacy of mentalisation-based therapy. However, across all interventions the evidence is weak both because the exact effect is unclear and hard to definitively state, and because the population under study do not represent the broader population of people who self-harm, and so **conclusions are not generalisable**.⁸

Non-clinical interventions

Given this uncertainty, non-clinical interventions remain vital to consider. Unfortunately, this literature is also not definitive; there is some evidence that interventions such as apps or training are helpful and acceptable. However, studies frequently do not report the precise details of the content and form of training, making it hard to replicate, and apps under study are often not widely available. **These interventions can be difficult to measure** – it is not straightforward to establish their effect, so conclusions regarding their efficacy remain uncertain.

Outcome measures

Almost all the studies discussed in the literature review used the reduction of self-harm as their primary outcome measure. However a recent qualitative study suggests that this **reduction is not always the outcome which is most important to people with experience of self-harm.** Instead they might prioritise greater ability to access support around self-harm, more supportive environments, and improvements in their quality of life. This introduces further uncertainty regarding the relevance of the available evidence-base for interventions, and suggests that in any future assessment of interventions outcome measures should be designed in collaboration with people with experience of self-harm.

Sociological literature

Given the limitations of existing quantitative assessments of intervention efficacy, considering other forms of evidence is particularly important. For this reason, we also explored sociological literature which provides insight into experiences of self-harm, particularly its social contexts and dynamics. We identified four key themes which might be relevant to developing local community interventions:

1. **Validation**: self-harm can both be a way of authenticating feelings which feel illegitimate or hard to express, while self-harm itself is often accused of being inauthentic, through charges of 'copying' or 'attention-seeking'.

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⁸ For instance, the Cochrane review into psychosocial interventions notes that 'there were a number of methodological limitations across the trials included in this review' (Witt et al, 2021a, pg. 3) and categorises the available evidence as 'moderate or very low quality' (Witt et al, 2021a, pg. 2).

⁹ To find out more about outcomes that matter to people with experience of self-harm, you can read the original paper: Owens C, Fox F, Redwood S, Davies R, Foote L, Salisbury N, Williams S, Biddle L, Thomas K. Measuring outcomes in trials of interventions for people who self-harm: qualitative study of service users' views. *BJPsych Open*. 2020 Feb 12;6(2):e22.

- 2. **Privacy or secrecy**: self-harm is often presented as 'real' (or reflecting real distress) when it remains secret, but becomes less credible and more liable to accusations of attention seeking when it is made public.
- 3. **Control:** self-harm can be experienced as a way of remaining 'in control' or exerting control over difficult emotions and feelings, while at the same time self-harm can feel addictive, or as if it can become 'out of control'.
- 4. **Coping:** we noted tension around whether self-harm is understood as a reasonable and understandable 'coping' mechanism and even productive and meaningful or as entirely pathological and reflective of mental illness.

Taken together, these themes highlight the importance of being aware of social drivers behind self-harm, particularly issues of marginalisation, deprivation, and inequality. They also highlight the **importance of being aware of how self-harm is understood and responded to by the general public and those providing care.** This is particularly urgent when such understandings seem to enable poor care, underpinned by stigma, ignorance, and avoidance. Understanding these social facets is vital to designing interventions and forms of care which are effective, implementable, and genuinely helpful to those who self-harm.

1.2 National consultation

In order to identify the national trends, barriers, and opportunities in regards to support for self-harm, and thus identify the alignments or discontinuities between Torbay and the rest of England, Make Space spoke to three organisations:

- National Suicide Prevention Alliance (NSPA): A collaboration of public, private, and volunteer organisations with the shared aims of suicide prevention and self-harm reduction.
- **Intercom Trust:** An LGBT+ charity covering the South West, supporting the wellbeing and inclusion of LGBT+ people in the region and working against homophobic and transphobic prejudice and discrimination.
- **Self-Injury Support (SIS):** An organisation running a UK-wide support service for women and girls who self-harm, promoting positive models of support through training, consultancy, and cross-organisation partnership.

These organisations were selected in order to connect both with organisations for whom self-harm was their primary focus, and with organisations who might focus on other issues, but who might regularly encounter or support people who self-harm. In our conversations, the organisations discussed the following key themes:

Intersections: Demographics and current events

Experiences of self-harm do not exist in a vacuum. People's **experiences intersect with factors relating to their identity and situation**, including: gender, sexuality, age, race, socio-economic background, and region. For example, the organisations we spoke to

felt that the rise in hate crimes since Brexit¹⁰ might have led to an increase in people accessing support for self-harm, as do the long waits for appointments at gender identity clinics. People experiencing difficulty in other areas of their lives - through homophobia, racism, poverty, domestic violence, and more - are more likely to be experiencing difficulty in terms of self-harm and therefore to be accessing services for this.

Lack of understanding

There is a lack of understanding around self-harm; training often aims to provide people with tools to offer care while neglecting the underlying perceptions of those providing this care. There is a need for more nuanced understandings of self-harm: the diverse forms of self-harm (not just physical injuries) and the diverse ways this intersects with other aspects of people's lives. Some **misconceptions are persistent**, such as seeing self-harm as attention seeking.

Misinformation around identities overlaps with misinformation around self-harm; some demographics are more likely to have their experiences misunderstood in multiple ways. For example, misinformation about trans identities or the communication needs of people with autism can compound the ways people find it hard to have their self-harm understood by those providing care.

Gaps in provision

There is a **lack of training** for statutory services to tackle underlying perceptions of self-harm. There is also a lack of training for those in other sectors supporting people who self-harm in other areas of life, such as housing or benefits workers.

There is a lack of free of cost, non-judgemental spaces for people to discuss self-harm without intervention; this is especially true for children and young people. The organisations we spoke to wanted more opportunities to speak about self-harm without risk management arising, in contexts not focused on cessation. These spaces should be specific to situations, for example: age, religion, sexuality.

What constitutes good care

All three organisations advocate for person-centred support that foregrounds people with lived experience. **Good care is nuanced and personal, not focused on cessation but responsive to people's individual needs and goals.** It involves awareness of diversity, both in people's experiences of self-harm and the diversity of cultural and social identities of those seeking support. Experiences of self-harm are individual and disparate - there should not be a one-size-fits-all approach.

Barriers to good care

Organisations noted both structural and sociocultural barriers to providing good care. Sociocultural barriers include:

• Fear of getting things wrong (compounded by intersections with other identities, such as race, gender, and sexuality)

¹⁰ Devine, D., 2021. Discrete events and hate crimes: The causal role of the Brexit referendum. Social Science Quarterly, 102(1), pp.374-386.

• Views of self-harm as solely a coping mechanism or cry for attention

Structural barriers include:

- Short-termism in the commissioning and funding of projects
- Focus on prevention and risk management
- Over-emphasis on a causal link between self-harm and suicide
- Costs of accessing private support
- Institutional barriers faced by women (also intersecting with experiences of sexism, assault, or domestic violence)
- Lack of privacy in institutional settings, especially in prisons (where there was also a lack of understanding of people's experiences of self-harm)

In this project, we identified similar themes. This suggests that Torbay is mostly consistent with the national picture, and highlights the importance of awareness of barriers to good care as widespread and systemic, and therefore requiring structural change on a national level.

2. Methods and Approach

The purpose of the project was to understand more about the needs, wants, and experiences of care among people in Torbay who have experience or self-harm or supporting someone else who does. 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?

We chose **qualitative methods**, reflecting a desire to prioritise and explore people's lived experiences and social contexts, opinions, and beliefs. Such methods allow for **detailed reflections and nuanced conclusions**, rather than more definitive but less particularised conclusions which might be drawn from large-scale, quantitative approaches.

We hoped to speak to as many people as possible to get a range of experiences and perspectives. Originally, we aimed to speak to people only in Torbay, almost exclusively via in-person focus groups. Most of Make Space's work has been in groups; we find this creates generative conversations that allow people to share and reflect on ideas and experiences together. However, recruitment was difficult for group work, so we ended up speaking to people 1:1, primarily online.

Recruitment was particularly difficult given the context of the work, many were overstretched as a result of the pandemic and had little appetite for more time spent on Zoom. As such, we widened our search parameters and were flexible in our approach as to how we conducted data analysis (e.g. various meeting options/formats, introducing written testimonies as an opportunity for involvement, and widening our parameters to include people not currently living in Torbay).

For service-user groups, we recruited via local charities and put posters across Torbay. For those speaking to us in their professional capacity, we drew on our networks and distributed adverts via mailing lists. All participants were paid for their time, and we provided optional post-sessional debrief support (described below). Interviews were conducted by a member of the Make Space team, who have experience holding conversations about self-harm. For people who could not participate in an interview but still wished to be involved, we offered the option to complete a written testimony.

Overall, we spoke to 29 people over three months. This included service-users, as well as supporters - including people in the third sector, psychiatric liaison team, social prescribing and those in strategic roles in the local mental health trust. We gathered information primarily through interviews, but also received written testimonies, and

held one focus group focusing on self-harm in children and young people (attended by teachers, pastoral teams, parents, and youth workers).

In total, we spoke to:

- 11 people with direct personal experience of self-harm (in Torbay and Devon more broadly)
 - o 9x 1:1 Interviews
 - 4 of these people also held roles in which they supported people with experience of self-harm
 - o 2x written testimonies
- 18 people who supported people with experience of self-harm (in Torbay)
 - o 10x 1:1 interviews
 - 1 written testimony
 - o 7 attended the supporters of children and young people focus group

2.1 Project Design

Consent and recruitment

Potential participants were invited to email us to take part in the project. Once they expressed interest, we sent them a detailed consent form and information sheet. The information sheet provided information on what participation would involve, how their data would be stored and for how long, their right and routes to withdraw from the project, and the support we would offer after participation. If we did not hear back from people, we only followed up once. Participants could withdraw from the project up until the point that this report was published.

Demographics

Participants were invited to fill out a demographic form asking them about their age, disability status, gender identity, race/ethnicity, and sexuality. We did not include pre-determined categories, instead these were open questions and participants were invited to fill out the form in their own words. Some people left some sections blank. We have explained the demographic makeup of our participants below, **using their own words.**

Categories and responses are listed alphabetically.

Age					
18-24 (3%) 1 participant	25-30 (14%) 4 participants	31-40 (31%) 9 Participants	41-50 (34%) 10 participants	51-60 (10%) 3 Participants	61-70 (7%) 2 participants

Disability				
Note: 3 Participants left this question blank (10%)				
Disabled (21%) 6 participants	No disability (65%) 19 participants			
1 person listed Bipolar Disorder (3%) 1 person listed Anxiety and Depression (3%) 1 person listed neurological disability				

Gender identity				
Female (69%) 20 participants	Genderqueer (3%) 1 participant	Male (17%) 5 participants	Non-binary (7%) 2 participants	Transgender (3%) 1 participant

Race/ethnicity				
Dual-Heritage (10%) 3 participants	British (7%) 2 participants	White (84%) 24 participants.		
1 as mixed-race Anglo Indian 2 as White British/Black Caribbean		16 as white British 1 as white Welsh 1 as white other 3 as white		

Sexuality				
Note: 3 Participants left this question blank (10%)				
Bisexual (7%) 2 participants	Gay (3%) 1 participant	Heterosexual (69%) 20 participants	Lesbian (3%) 1 participant	Pansexual (7%) 2 participants

Anonymity

All participants were given pseudonyms. Service-users were anonymous by default. Those attending in professional roles (supporters) were offered two levels of anonymity: anonymous but identifiable (i.e. referred to by specific job titles) or fully anonymous.

2.2 Analysis

All interviews and focus groups were audio recorded and transcribed. Throughout the process, Make Space went through each transcript looking for themes, at the same time identifying key quotes illustrative of those themes. In the social sciences this analytical approach is called Thematic Analysis¹¹.

Throughout the project we were guided by Grounded Theory¹². Grounded Theory is a popular inductive approach to research which uses reflective and iterative data collection and theory building to develop the outcomes of a project. This involves collecting data, identifying potential themes, and then collecting more information to try and 'test' the emerging themes.

We also drew on feminist research methods such as Institutional Ethnography¹³, which centre self-reflection as a key part of the research process. As a user-led group, we each had experiences of receiving (or not receiving) care around self-harm. This meant our findings felt incredibly 'close to home'. Throughout our analysis we reflected as a group on how findings aligned with our experiences. This group reflection allowed us to document findings we found personally difficult, challenging, or did not align with our experiences or those we had supported.

2.3 Safeguarding

Make Space has an internal safeguarding procedure which we followed throughout the project. In line with our legal responsibilities, we were obliged to breach confidentiality if we felt somebody's life was in immediate danger.

For Make Space, a disclosure of self-harm (whether past or ongoing) does not automatically trigger formal safeguarding processes - instead, we seek to hold people's disclosures in the context in which they were spoken, attending to the immediate needs of a situation. This criticality toward mainstream safeguarding practices is an ongoing, increasingly central question in the user-led movement¹⁴. Respecting people's autonomy and right to make decisions about their lives often involves going above and beyond what is usually understood as safeguarding.

Taking care of ourselves

This project was conducted by people with experience of self-harm. It involves, for each of us, hours of interviews about self-harm and/or suicidal crisis, as well as months of analysing the full data set. Seeing the scale of a crisis is emotionally taxing at any rate, and especially so when the work is intimately connected to our experiences. Many

¹¹ Braun, V. and Clarke, V., 2012. *Thematic analysis*. American Psychological Association.

¹² Glaser, B. and Strauss, A., 1967. "Grounded theory: The discovery of grounded theory." *The Journal Of The British Sociological Association*, 12, pp.27-49.

¹³ Smith, D.E., 2005. *Institutional Ethnography as Practice: A Sociology for People*. Altamira.

¹⁴ A primer on safeguarding issues can be found here: <u>Reimagining Safety beyond Safeguarding</u>. White, R. (2022). *National Survivor User Network*.

things people discussed, especially when it came to failings in care, spoke to our lived experience. This meant we had to take care of ourselves as we went through the project. We checked in with each other weekly on how we were finding the work, and took measures to respond to each of our needs. Each of the team was eligible to access the therapist debrief spaces outlined below.

Taking care of others

There has been an increased recognition and uptake of co-production practices in recent years - this is welcome. However, efforts to include people with lived experience in service design, evaluation, and delivery has not been without critique. Primary critiques of the co-production include: tokenistic involvement, poorly (if at all) remunerated work, insufficient (re)distribution of power, and involvement opportunities that are ostensibly open to all but in practice inaccessible to many (e.g. for financial reasons or physical/mental (dis)ability). 15

Throughout the project, we tried to be aware of these critiques, and ensure that our approach to co-production enabled participants to feel seen, cared for, and safe in the research. We drew on our experience in both academic research and facilitating user-led spaces, following established best practice in survivor-led research.¹⁶

Before participation

First, we gave participants a clear sense of what participation involved, including:

- An understanding of the expertise we were trying to draw on and the parts of the project that their involvement would influence.
- Clarity on what data we would hold about them, for how long, and how they could withdraw from the research if they so wished.
- The support that would be available to them after they had participated.
- Details of how much/by which means they would be paid for involvement.

We also felt it important that those who face additional barriers to participation knew we would make provision for their involvement. For example, this included offering to pay for childcare, travel costs, a contribution towards internet connection, and to speak to them by the means they wished - on the phone, on a video call, via written testimony, or in person.

During participation

Each interview or focus group was held by a member of the Make Space team, with each of us comfortable and experienced in holding conversations about self-harm with people who had direct or indirect lived experience of it.

¹⁵ An overview of issues relating to co-production can be found in a recent report by Shaping Our Lives: <u>Tickboxes and Tokenism: Service User Involvement Report.</u> Batty, Humphrey, and Meakin (2022). *Shaping Our Lives*.

An overview of best practice survivor-research is found in Alison Faulkner's report: "The ethics of survivor research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors" (2004).

www.jrf.org.uk/report/ethics-survivor-research-guidelines-ethical-conduct-research-carried-out-mental-health

Participants were made aware at the start that they could end the interaction at any time or decline to answer any given question. We let participants share as much or as little of their personal experience as they wished, and did not ask anyone to explicitly describe experiences of self-harm including histories, methods, or if they currently self-harmed; some participants chose to share this information with us. Participants were explicitly approached as experts on their own experience and in the kinds of care (un)available to themselves or those they supported.

After the focus group, we held a **30 minute debrief space**, inviting participants to stay on the call and ask questions, talk about content other than self-harm, and reflect on the process. It is a space to decompress after a difficult conversation and soften the edges of digital spaces where conversations open and end abruptly.

After each interview, participants could access a **1:1, 1hr debrief session** with a licensed psychotherapist who had their own lived-experience of self-harm. The therapist was independent of Make Space; we were not told who accessed sessions - something we made participants aware of. Participants were given the therapist's contact details and website, and were free to reach out after the session. We paid the therapist a retainer fee over the period we conducted interviews, for them to monitor emails throughout this time. The therapist invoiced us for each session held. The therapist followed their own safeguarding protocols and would only breach confidentiality to tell us who accessed a session if there was a serious safeguarding concern; this did not happen during the project. These sessions were available to everybody who participated in the project, including supporters.

Service-user feedback

All service-users involved in the project were invited to input on the final report. This was held through a single focus group in February 2023, and was attended by 6 people with experience of self-harm who we had interviewed as part of the project. Those who joined us were sent the report ahead of time. During the focus group we offered a short presentation on the findings and moved on to explore their reactions to and thoughts about the report. This also allowed participants to withdraw from the project if they wished, but nobody did so. All participants were paid to attend this meeting and were offered therapeutic debrief support, prepaid by Make Space.

The consensus among the group was that they felt seen and heard by the report, feeling as though it accurately represented their experiences and that they felt respected and valued in their involvement in the project. Some people had been seeking support for self-harm for many years, and felt that little had changed in that time. Participants welcomed the breadth of the report but also had concerns about the ability for single recommendations to bring about the scale of change required, reflecting that wider systemic change would also be required alongside the recommendations of the report. Participants were keen to see many of the recommendations implemented and hoped that the report may help to make tangible changes.

The report was also reviewed in more detail by a critical reviewer who had experience of self-harm as well as extensive experience working both within the NHS and in the third sector around mental health. The critical reviewer spoke highly of the report, and felt as though we had captured a lot of nuance. They also hoped that the recommendations would be implemented, recommending in particular group reading of the report as well as reflective sessions helping those with power to make changes to reflect upon and think about how they might implement its findings. This reviewer was also paid for their time and offered therapeutic debrief support.

2.4 Feedback

Through the project we received positive feedback about the user-led nature and the post-sessional support that was offered. One participant referred to the process as 'proper co-production basically, not just tokenism':

'It's really refreshing not to just be like, sponsored or like requested by a professional to like, tick a few boxes...like to actually have what you're doing with it, like anecdotal evidence and the way that you've gone about it with the support session, and paying people for their time when they've got like, valid, like really valid contributions. Because I really support that way of working. And it's not that common.'

- Ash, service-user.

Another person with experience of self-harm said statutory services fail to recognise the effort and emotional energy it takes for people to describe their experiences. They compared that process to being part of our project, and the support we put in place for participants:

'[Statutory services] need to recognise the level of detail they are asking people to describe and go in to about their mental health and experiences, and put in place an appropriate support package (like the one that is provided for completing this testimony, i.e access to one off counselling funded by the service) and/or care and sensitivity throughout the process.'

- Alex, service-user.

A third person spoke about the benefits of user-led coproduction. She said third sector and user-led groups specifically were best placed to do this work. Of their own user-led coproduction work, which is funded by the NHS, she said:

'People seem to trust us [user-led group] in a way that they might not trust the engagement officer from the NHS or the county council.'

- Carys, service-user/third sector.

2.5 Limitations

While we successfully recruited a broad range of participants, but were not able to recruit from Community Mental Health Teams, GPs, or A&E staff. Moreover, we found it difficult to recruit only within Torbay, so we widened our recruitment strategy to include people living and working in Devon more broadly. All the supporters we spoke to worked in Torbay. The majority of service-users we spoke to either lived in Torbay or discussed care they received when they did. However, some service-users lived in Devon more widely. Some of our findings, particularly those relating to experiences of care, are applicable to Devon rather than Torbay specifically.

As is usual in in-depth qualitative research, this project draws on a **small sample size**, and prioritises depth rather than breadth in data and analysis. While we talked to a range of people, we do not assume that the sample of participants is representative of the broader group of people with experience of self-harm or of providing care around self-harm. Rather we recognise that **these findings are specific and contextual**, **rather than generalisable.**

3. Findings: What have we learned?

This report draws together a range of findings from the research project, many of which align with research conducted elsewhere. While they offer a snapshot of a particular locality (Torbay, and also Devon more widely), the **findings are congruent with the broader academic literature and national situation regarding support for self-harm and mental health care more broadly.**

The project contributes both breadth and depth to the existing research: because we spoke with a range of stakeholders - including service users, healthcare professionals, and third sector organisations - we can present a rounded picture of the working of the entire system of care around self-harm. At the same time, by focusing primarily on services in Torbay, with some additional input from stakeholders in Devon more broadly, we gained an in-depth understanding of the organisations and practices most relevant and present in this particular location.

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, people's 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, their self-harm took different forms, and self-harm had a different role or meaning for them.

Through these experiences, people often sought out care, or were directed towards care by parents, teachers, or friends. There were **many reports of less-than-ideal care**, including examples in which people who self-harmed were treated as problems or as in some way disruptive by healthcare professionals. Participants also reported repeated examples of simply an absence of care: **over-long waiting lists, policies of exclusion, and a repeated sense of being discharged to nothing.** This is not to say that there were no positive experiences of care; participants reported some experiences of good care which prioritised openness to people's different needs and preferences, responded to people's different circumstances, and was coordinated across different organisations and sectors.

Professionals who sought to provide good and thoughtful care around self-harm also reported difficulties, not least of which was the **struggle of working within systems** which were often under-resourced or even pushed to breaking points. Professionals in services not directly aimed at responding to self-harm described feeling under-trained and not confident in their abilities and knowledge around providing an appropriate response. They also reported difficulties in coordinating across different organisations or areas, feeling they were unaware of work being carried out elsewhere in Torbay and Devon, or feeling that they didn't know where to turn for support, either for themselves or for those self-harming.

3.1 Understandings and experiences of self-harm

What is self-harm?

There was uncertainty - or simply breadth - in how self-harm was understood. Self-harm has traditionally been predominantly taken to refer to self-cutting or self-burning, or alternatively to mean all forms of self-harm including overdosing regardless of suicidal intent. However, in this project there was evidence of a growing sense that there might be benefits to interpreting the category of 'self-harm' more broadly, or at least acknowledging it as an uncertain grouping.

Some professionals talked about deliberately trying to construct or work with self-harm as a broad category, to ensure people weren't excluded. This was important to service users, who at times discussed the difficulty of self-harming in ways not typically recognised as such, and finding this impeded their ability to seek or access care. One service user in particular suggested this could be connected to the tendency for services to prioritise certain understandings of 'risk' which emphasised danger to an individual's life. Others spoke about trying to make connections between practices traditionally understood as self-harm and other potentially harmful acts, such as drinking or over-exercising. This was part of destigmatising self-harm, or encouraging other professionals or the general public to see it as more comprehensible, something that fell within the 'normal' range of human experiences or that might be easy to relate to.

'We try and keep it open, but I am aware of the NICE guidance and if we have to, we kind of come back to that. But we do try and, yeah, keep that quite open just so that we don't exclude anybody.'

- Claire, commissioner.

'My take on it is that everybody self harms - every person to a degree or to one degree or another.'

- Mary, third sector: peer support.

'So I have a history of self harming, but I didn't even recognise that it was actually self-harm until probably 5 years ago. [...] The language that's used around self-harm is so focused on risk. So things like cutting are high risk, because your life could be in danger. But if your life isn't necessarily in danger by it, it's not seen as risky. So it gets forgotten.'

- Carys, service-user/third sector.

Self-harm and suicide

One of the most important and contentious aspects of understanding or defining self-harm was its links with suicide. As discussed in the literature review, **the boundary between self-harm and suicide has long been open to question**, reflecting varied priorities around assessing the meanings, risks, and effects of acts and practices. In this study, both services users and professionals emphasised the distinction between self-harm and suicide, noting frustration that they were often grouped or treated as the

same thing. They felt people could 'misinterpret' self-harm as a suicide attempt or a sign a suicide attempt would immediately and inevitably follow, and felt strongly that this was inaccurate and untrue. Alongside this, for some, ran a concern that such misunderstandings could lead to unhelpful responses that might impede or undermine care for self-harm specifically.

However, one participant who was involved in commissioning noted that it was **only by** associating self-harm with suicide that it was possible to make self-harm a policy priority and thus assign funding to it. This reveals a complex tension: to claim care (or resources through which care is possible) self-harm must be associated with risk and thus with suicide or attempted suicide. However, in practice this sense of heightened risk or danger can be unhelpful and can impede attempts to provide open, person-centred care to the wide range of people for whom self-harm feels both distinct from suicide and, in many ways, low risk.

'We're very focused on long-term plan targets. [...] Within that there is a target around suicide, but there is nothing around self-harm. So the way that we managed to work on self-harm is to link it to suicide, so that it then becomes a priority.'

- Claire, commissioner.

'And I think there's a huge, it's all based on the misunderstanding that, you know, if you self-harm, you want to die, as well. So it's that education around the fact that actually, the majority potentially just do it as a coping mechanism. It's got nothing to do with suicide.'

- Megan, service-user/social prescriber.

'[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.

Self-harm and intersections

People we spoke to, especially service users, felt it important that self-harm was understood in the context of other aspects of their lives. This could relate to factors they believed contributed to their self-harm or their reasons for self-harming. It also included factors which changed or impacted the nature of their self-harm, what self-harm felt like, what it meant to them, or how it functioned in their lives. Further, it included aspects of their lives or their self-harm which they felt impacted the way services responded to them, or could limit the care and services available to them.

Several service-users talked about interrelations between self-harm and eating disorders. **Treatments tended to form silos,** so people would receive treatment for eating disorders in complete isolation from experiences of self-harm. Sometimes self-harm was minimised as 'superficial', dismissed as low risk, or completely ignored as an experience which professionals didn't have relevant experience in addressing.

Alternatively, professionals might insist that cessation of self-harm was prioritised, but without examining the underlying issues, which might involve disordered eating or body dysmorphia. For those who felt their self-harm and disordered eating were related, this felt counterproductive and frustrating.

'I was saying, 'I need to sort out the weight, the eating and the body dysmorphia. That is what is causing this, that is, that's the underlying thing', but they were like 'no self-harm is the risk, you need to stop doing it'.'

- Ash, Service-User.

Service-users also connected experiences of self-harm to experiences of abuse or relational dysfunction, whether as a child or in adult relationships. While this 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'. For one participant, this related to an experience of abuse within a queer relationship, which seemed to fall outside of the heteronormative paradigms that domestic violence services worked within – a significant failure on the part of services. Participants felt that understanding trauma they'd experienced and the coping mechanisms they'd developed as a result was vital to addressing their self-harm or to any form of recovery.

'It [experience of abuse] is probably, I don't know, like a root cause of the things but you don't I don't know it's yeah, it's quite a shame that like, like you say that I have had support for a lot of years, but it was never in all those years kind of even. Yeah, just very simple questions, even like on the basis of like abuse and things like that, that, that was never even asked to me.'

- Lisa, service-user.

Several participants connected self-harm with failures of care around autism, special educational needs, and neurodiversity more broadly, noting particularly the long waiting lists and trends around late diagnosis. Once again, there was a sense that services were unwilling or unable (due to lack of training) to consider how the two experiences might interact. Participants also commented on the lack of services or support around autism and special educational needs, not only in terms of accessing a diagnosis, but also in the lack of provision of appropriate resources both within and beyond schools.

'I have autism. I've had a screening but not yet a diagnosis due to the length of the waiting list. [...] I have spoken about autism and its effect on eating, but I feel it has been ignored and dismissed, which has been invalidating for me and an example of not being seen as all parts of me.'

- Alex, service-user.

Many participants connected self-harm with the diagnosis of Borderline Personality Disorder (BPD). It is perhaps worth noting that although Non-Suicidal Self-Injury (NSSI) now carries its own entry, self-injury first appeared in the Diagnostic and Statistical

Manual of Mental Disorders (DSM) in 1994 as one of nine diagnostic criteria for BPD. There is no doubt that BPD is a common diagnosis in people who self-harm, however, it is also a contentious diagnosis. **People who have been diagnosed with BPD, along with academics, have criticised it as individualising and pathologising responses to trauma.** Similar critiques have been applied to attempts to 'reformulate' the diagnosis, such as by shifting to instead using 'Emotionally Unstable Personality Disorder' (EUPD). Importantly, people diagnosed with BPD have reported experiencing discriminatory behaviour from healthcare professionals as a result of the diagnosis, and a recent review demonstrated that negative attitudes towards BPD continue to be a problem among clinical staff¹⁸. In our study, both service users and healthcare professionals described stigmatising or discriminatory attitudes and behaviour, although for some there was hope that this was changing for the better.

'It's especially bad, around as I said, you know, people with an emotionally unstable personality disorder, because they [clinical staff] are automatically like 'this one's going to be difficult.' [...] Either 'they're gonna kick off' or 'they're just attention seeking, they're manipulative'.

- Louise, 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 the likelihood of significantly different experiences. Participants suggested it was difficult to generalise about who self-harmed, and perhaps therefore also difficult to generalise what people who self-harm needed in terms of care. They also noted that self-harm was not static: it might recur and change over the course of people's lifetimes in ways that were not linear and couldn't be straightforwardly predicted.

'Everybody's different, aren't they? Every single human being is different. Every type of self-harm is different. They're doing it for different reasons, they're doing it... It's a different pattern. It's different. So it is difficult to have any kind of formal 'this is what we do'.'

- Sarah, third sector: suicide bereavement.

However, some participants did express concerns that different groups of people who self-harmed weren't equally supported or didn't have equivalent access to care. This was most commonly articulated with regards to age. Participants discussed that services were less well equipped to assess or to enquire about self-harm in adults than in children and young people. They also suggested that older adults specifically might

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¹⁷ Lewis, K. L., and Brin F.S. G. 2009. 'Borderline personality or complex post-traumatic stress disorder? An update on the controversy.' *Harvard Review of Psychiatry 17*, no. 5: 322-328. Shaw, C., and Proctor, G. 2005. 'Women at the margins: A critique of the diagnosis of Borderline

personality disorder.' Feminism & Psychology, 15, no. 4: 483-490.

Wirth-Cauchon, J. 'A dangerous symbolic mobility: Narratives of borderline personality disorder'. *Pathology and the postmodern: Mental illness as discourse and experience* (2000): 141-162.

¹⁸ Baker, J.; Beazley, P. I. Judging Personality Disorder: A Systematic Review of Clinician Attitudes and Responses to Borderline Personality Disorder. *Journal of Psychiatric Practice 28*(4): pp. 275-293, July 2022.

not have access to ways of understanding certain acts or practices as self-harm, and also (perhaps as a result) that there might not be appropriate support available to them around self-harm.¹⁹

'I remember one person saying 'sometimes I just do a few rounds with myself', and I said 'oh what does that mean'. And she eventually admitted over a few sessions that she would give herself a smack in the face and say 'oh, pull yourself together'. And I thought 'there's self-harm', but I think for the 65-70+ generation, they don't have the language around self-harm or support around it.'

- Carys, service-user/third sector.

What does self-harm mean to people?

Several people noted that it was important to recognise that self-harm had a **wide variety of meanings, roles, or functions** in different people's lives. Participants felt this was important for third sector and healthcare professionals to realise, so they could respond to the specific function or meaning of self-harm to an individual. This included recognising there might be instances where individuals felt strongly that self-harm had been a helpful, necessary, or even productive practice: that it had enabled them to cope or to survive in difficult situations. It was important for services to be able to validate and respond to this, rather than dismissing it.

'We recognize that [self-harm] is, it may be a helpful behaviour to them. At the same time [it] has been a harmful behaviour. [...] We look at the context as well. So we might, you know, we look at it within the context of what's going on in their lives.'

- Robert, third sector: children and young people.

'Trying to understand that distinction between well, actually was it, were they, in that moment in time, was it to manage a difficult situation? Or was it because they actually wanted to end their life? [...] What we're trying to push forward is, can we really start to now get alongside people and understand the different functions because you know, self-harm can be so individual, but even for that individual, there could possibly potentially be many, many different reasons to why they've done it.'

- Mark, Devon Partnership Trust.

Approaches to self-harm were often dominated by concerns about risk and physical safety. For several organisations it was clear that procedure around self-harm involved an initial assessment of safety, which sometimes involved people's immediate circumstances – that is to say whether their life was in immediate danger. However, a

¹⁹ There is very little research into the care available to older adults who self-harm. A recent study found that 36% of adults aged 60 years and older were referred back to their general practitioner after self-harm without onward referral to specialist services, contrary to NICE guidelines; however, this study did not distinguish self-harm from attempted suicide.

Murphy, E., Navneet, K., Roger, W., Nitin, P., Hawton, K., Bergen, H., Waters, K., & Cooper, J. 2012. 'Risk factors for repetition and suicide following self-harm in older adults: multicentre cohort study.' *The British Journal of Psychiatry*, 200, no. 5: 399-404.

broader approach was also described, which seemed more reminiscent of harm reductionist approaches, in which there was an emphasis on wound care and making sure any blades or other instruments were clean and therefore that the risk of infection was minimised.

'The first thing we would talk to them about is safety. Are you being safe? Do you know how to keep clean? Do you know how to deal with any wounds?'

- Sarah, third sector: suicide bereavement.

Participants also described attitudes towards and understandings of self-harm they felt were unhelpful. This included a sense that within the wider population there was a **high level of fear around self-harm,** and perhaps a tendency to overestimate the potential risks involved. At the same time several service-users talked about the widespread perception that self-harm was a form of attention seeking. This has long been an accusation levelled at people who self-harm. Sociological research has situated it in a broader tendency to question the authenticity of people who self-harm and their distress, along with associations of self-harm with youth, melodrama, and over-reaction. These framings undermine claims to care made by people who self-harm and contribute to a general sense that self-harm was stigmatised and misunderstood.

'Attention seeking isn't always negative. I hate the way we use the word attention seeking and I feel like that's linked a lot with self harm, especially in younger children... If someone's seeking attention, there's a reason why someone's seeking attention. There is a need that is not being met.'

- Bex, service-user/third sector.

Some commissioners and third sector professionals talked about prevention-first approaches, emphasising children and young people's mental health, early intervention, and proactive steps to support people and provide them with tools to manage what happens in their lives before it reaches crisis point.

'[It's all around] prevention, isn't it? So I think if children and young people are self-harming now, they're more likely to obviously carry on into adulthood and continue that behaviour if there isn't interventions. [...] Not only have you got the crisis support, but that... at that low-level support of what actually matters to them, what's going to help change them and change their ways day to day to help manage that problem.'

- Claire, commissioner.

Self-harm and recovery

Several participants talked about the importance of taking an open or spacious approach to self-harm, rather than rushing to 'fix' the problem. This often went hand-in-hand with a perception of the **value in not emphasising cessation.** Participants suggested that when services or professionals perceived stopping self-harm as the most urgent and desirable outcome, this devalued other, equally important, aspects of recovery or wellbeing. Conflating recovery with cessation could also create a perception that people who continued to self-harm had in some way

failed or contributed to a sense of shame around ongoing self-harm - a concern which is also reflected in the academic literature²⁰. It was important for people to have access to services without being required to stop self-harming immediately or as a condition of participation. Participants also discussed the fact that if self-harm was an important part of managing their life or emotions, then sudden cessation could leave them in a hard or even dangerous situation.

'I don't think it's for us to decide that nobody should be allowed to self-harm. [...] Really careful about our language around this, really careful with judgement, really careful with shame. Really careful not to be invested in the outcome [...] To not really massively celebrate the weeks where they don't self-harm, and be disappointed on the weeks where they do.'

- Sarah, third sector: suicide bereavement.

For some, it was valuable to recognise that self-harm may be a long-term part of some people's lives, but this didn't mean they were unable to live meaningfully or hopefully. Service-users offered a mixed picture of what recovery meant to them. Many people spoke about stopping self-harm, but cessation was often not an end goal in itself. More important was understanding the role self-harm played in people's lives and the reasons they were self-harming. These findings are consistent with academic literature, which shows that 'the relationship between self-harm and mental health was not straightforward and that it was wrong to assume that less frequent is necessarily better'²¹. Academic research suggests young people prioritise self-understanding and safe environments over cessation²².

'I think, for me it [recovery] means no longer relying on self harm as a tool to manage pain and emotions and recognising the warning signs when it does. I believe recovery is a journey that doesn't have an end and there will always be learning. It also means there might be times of lapse or relapse but each time learn something different to the point perhaps that self harm is no longer dominating and/or is no longer active. But it could also mean that someone may make that choice to self harm safely, but with the right harm reduction advice and support it can be managed and it is no longer out of someone's control or impacts their quality of life in the way it once would have.'

- Alex, service-user.

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²⁰ Chandler, A. 2015. 'Recovering the body: self-injury, scarring and recovery.' In *Recovery and Self-injury: exploring the evidence* (pp. 1-8). Chipmunka Press.

Lewis, S.P., Kenny, T.E., Whitfield, K. and Gomez, J., 2019. Understanding self-injury recovery: Views from individuals with lived experience. *Journal of clinical psychology*, 75(12), pp.2119-2139.

²¹ Owens C, Fox F, Redwood S, Davies R, Foote L, Salisbury N, Williams S, Biddle L, Thomas K. 2020. 'Measuring outcomes in trials of interventions for people who self-harm: qualitative study of service users' views.' *BJPsych Open*. 6(2):e22. P.2.

²² Knowles, S., Sharma, V., Fortune, S., Wadman, R., Churchill, R. and Hetrick, S., 2022. 'Adapting a codesign process with young people to prioritize outcomes for a systematic review of interventions to prevent self-harm and suicide.' *Health Expectations*.

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

- Jess, service-user.

3.2 Experiences of care

The following section collates what participants told us about experiences of care around self-harm - either their own or their observations as a supporter of somebody else. While the majority of participants were based in Torbay or discussed care they received/offered while living there, some of the findings apply to Devon more broadly. Given this, we have not implied or named particular hospitals, departments, or organisations in this section, unless they were specifically indicated by participants.

Participants described a range of routes and services through which people might access care or support for self-harm: people talked about attempting to access care themselves; professional involvement in services designed to provide mental health care; and experiences of trying to help others access services, whether through referral or other means. This allowed us to build up a rounded picture of the services and care available, of where those services were experienced positively or felt to work well, and of where there were gaps or other problems.

This section describes the specific places and services through which care was (or, at times, was not) available, after which we explore some broader issues and problems which affected care around self-harm across the board.

A&E and inpatient care

Crisis care was most often accessed through A&E departments - where individuals may come by themselves, or be brought by family, friends, or the emergency services. Participants didn't generally specify, or make distinctions between, individual A&E departments, but the experiences described here occurred both in Torbay and in Devon more broadly, and there seemed to be little difference between the care provided in different locations. Some individuals accessing A&E may primarily require immediate wound care, but people also talked about experiences of overdosing or other forms of self-harm which required more sustained physical care or complex interventions – this might result in initial experience in A&E followed by inpatient admission.

Many participants described extremely poor experiences of care in A&E. These failures of care usually centred around punitive attitudes sometimes accompanied by the threat of withdrawing physical treatment or that staff might neglect them. The attitudes described were hugely distressing, and represent a serious failure on the part of staff. Participants described feeling shamed and that their privacy was disregarded. Participants talked about a sense that staff disapproved of them, and felt that since they had harmed themselves they were less deserving both of treatment for their physical wounds and also kindness or care. Repeatedly, people who had self-harmed felt as though they were causing unnecessary problems for staff, rather than being a

patient seeking healthcare. One particularly disturbing report involved an individual being apparently 'banned' from their nearest A&E for too frequently seeking care as a result of self-harm, and so instead had to travel a great distance to access appropriate treatment.²³

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

Finally, one service user noted that - though experiences of A&E and emergency services were often mixed or poor - they did want to note that they were kept physically safe at times of crisis. They highlighted that physical care was available, in a way other forms of care (or care at times not characterised as crisis) were not.

'Going to A&E and being treated - if you excuse the crude way of putting it - like a lump of shit. Hearing what other people, other nurses, doctors, you'd come for help, and hearing what they said. And, you know, I've experienced this, and this was actually as a patient on the ward following the last overdose, when I talked to a nurse about my experiences and what had happened. 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.

'If they had to go and have dressings redone or sutures removed, there was often...my colleagues...would come back and report with a lot of tutting a lot of sighing, sometimes quite rough treatment....Not the thing that you would expect in terms of love, and care, and gentleness, and support. Occasionally, it would be that, but more often the sense was that... people were being frowned on,... or 'you're wasting my time'. 'This isn't a genuine injury', if you like.'

- Mary, third sector: peer support.

'They don't have the time and they also don't have the information like we do, about that person's mental health. [...] They just do the treatment and just want

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²³ There is an echo here of the Serenity Integrated Mentoring (SIM) Program, which was rolled out in many NHS Trusts across the UK following its initial piloting in 2018. The SIM model of care focused on people in frequent contact with emergency services as a result of their mental health, and advocated for police involvement in their care. In general, the model recommended cold or discouraging responses to help-seeking to deter reattendance. For more details, visit the StopSim Coalition website: https://stopsim.co.uk/

to get them through and get them out of A&E. Because they have so much pressure to get people out and not be keeping people in A&E.'

- Michelle, psychiatric liaison nurse.

Following A&E assessment, calls to Emergency Services, or assessment in the community, people might receive **inpatient treatment**. This might be for physical health complications following self-harm, or as part of a specialist mental health ward. 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 were likely to cause trouble.

Criticisms particularly focused around what appeared to be a policy wherein **self-harm** was essentially 'banned' in wards; anyone 'caught' self-harming would be discharged. This was very clearly experienced by participants as punitive. Although admission to an inpatient was the most intensive care available and intended to provide particular support to people who were really struggling, at least one participant discussed deliberately planning to avoid admission because it was felt to be so unhelpful.

One difficulty of both inpatient and A&E care was that there was **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 because interactions with these services were often prompted by crises. This was particularly clear in the tendency for discharge procedures to rely on third sector referrals (i.e. phone numbers for the Samaritans and other crisis lines or local community groups like Devon Recovery Learning Community) rather than directing people to NHS healthcare resources.

'They just discharge you. They just, like 'Oh yeah, you're not our problem, and you'll get picked up by Community Services.' [...] Thankfully I think most of the time I've had a care coordinator. So I've had someone there. But then they struggle because they're like 'What are we supposed to do? We only have a limited amount of resources in the community. What are we supposed to do if we think you're unsafe. We're going to admit you' but then if they say, 'well, we don't want you doing that here', they discharge you. So yeah, it can be quite difficult.'

- Hannah, service-user.

'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.

Outpatient care

It is possible that part of the difficulty of discharge procedures is linked to broader problems in outpatient care, encountered both by those moving from A&E or inpatient care to other services, and those attempting to access care and support without prior admission. As the discussion below explores, while some could access helpful and constructive care, particularly forms of therapy, people who self-harmed often struggled with both the *availability* and *forms* of care offered.

General Practice (GPs)

Though people rarely received direct care from GPs, their interactions with GPs were a crucial aspect of care around self-harm. Several people talked about difficulties regarding GPs, some of which related to systemic difficulties such as short appointment times and the rarity of repeatedly seeing the same practitioner, so being unable to build familiarity or shared understanding. This meant it was easy to feel as though GPs didn't comprehend the difficulties people faced, or even that simple things like records and care plans weren't accessible. In such a system it was easy to feel that things fell through the cracks or were brushed over in a search for quick fixes. People talked about avoiding GPs or trying to minimise contact with them. In contrast, positive relationships with GPs could be transformative. Being able to trust a GP and have a sense that they understood your history, the context of your life, and the nuances of your difficulties could make a huge difference to the care received – sometimes simply having a GP who was compassionate was enough to feel that genuine care had been offered.

'My next thing would be, like, support through the GP. Just because they're like the front door, aren't they to you like accessing support, like for mental health, 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, like, bigger picture. The potential other diagnosis that could be maybe coming into play or the past traumas that you know, you're not going to be able to, like, even delve into in like a five to 10 minute appointment like, people just don't even, like, touch the sides [...] With the GP as well, I found I feel like 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 like 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.

'Even though they couldn't do much, and they weren't obviously specialised in it, just the fact that they were there and able to listen, and be very clear, actually, there was a person who was the most clear of like, 'this is what I found, this is

what I can't do'. That was really helpful to have to feel held in that space, if I needed it.'

- Ash, service-user.

TALKWORKS (Increasing Access to Psychological Therapies - IAPT)

GPs might refer people to TALKWORKS, which is the local IAPT service. Our participants - both service-users and supporters - reported that **ongoing self-harm disqualified them from accessing support via TALKWORKS²⁴.** This is not unique to TALKWORKS, but has been reported as a common feature of IAPT programs.²⁵ TALKWORKS' exclusion of people who were currently self-harming was widely commented upon by participants across the board. This exclusion created many obvious difficulties, most notable of which was that it was almost impossible for people who were self-harming or who had particular recent experiences of self-harm to access talking therapy without paying for private care.

Service-users talked about the practical and emotional difficulty of attempting to access TALKWORKS, either through GPs or self-referral. It could feel **frustrating to take proactive action to find support only to be excluded for the nature of these difficulties**. For some, this was exacerbated by an accompanying exclusion from Community Mental Health Team care (CMHT) because they did not meet risk or intensity 'thresholds'. This was an incredibly difficult situation, in which the experiences of people who self-harmed were simultaneously deemed too serious or risky and also not serious or risky enough. For some, this meant they withheld information or curated answers to questionnaires to let them access services.

'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.

Professionals were aware of the difficulty this posed, and some spoke about frustrations with this process, or deliberate decisions not to refer people who were self-harming to TALKWORKS, to avoid the harm that might come to service-users from being excluded or 'passed around'.

'If someone came to A&E and they'd taken an overdose and it was their first time and it was due to them feeling a bit low and social stresses and stuff like that. We

²⁴ 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."

²⁵ For instance a similar problem is discussed in this report from the Samaritans: https://www.samaritans.org/news/mental-health-services-people-who-self-harm-england-are-inadequate-say-samaritans/

might think, for instance, TALKWORKS might call them as a talking therapy to start with. However, they can't be referred to TALKWORKS if they've self harmed, they have to be self-harm free for like six weeks.'

- Michelle, psychiatric liaison nurse.

'Our mental health referrals, we do tend to refer people then to TALKWORKS in Torquay, and Torbay and that's our kind of go to, but the second that people mention suicide or any type of risky behavior, like self harm, that's it, they're not part of the criteria list and they get booted out. So they usually get bounced back to us. [...] Having been on the receiving end of being bounced between pillar and post, I just don't, morally it doesn't sit right with me kind of sending this poor person to someone that's going to just say, 'Sorry, we can't help you'.'

- Megan, service-user/social prescriber.

For those able to access therapy, they may have positive, helpful experiences, though sometimes this was limited by the time-bounded nature of the therapy:

'My experience of TALKWORKS has been, apart from the waiting times, has been really good. I've gone three times for EMDR. And I've got EMDR all three times. And that was what I was hoping to get. That's why I made a referral, to process the trauma.'

- Ash, service-user.

'So I did have the - if they still do it - but like the group therapy through like TALKWORKS or adult services... Where like a few of you go and you've all you're all there for kind of similar but different reasons. And that was okay. But again, that's only like maybe like six weeks or something and then it's good, but then they're kind of like, 'okay, you've done your little course now and it's okay', but that doesn't, that doesn't solve anything. We've been, all of us, been living with this stuff for years and years. Like you just get one session a week. I just thought well, you kind of get going, you get a little bit of momentum, and then you stop.' - Maya, service-user.

Private therapy

As a result of difficulties with TALKWORKS, as well as extremely long waiting times (explored in more detail below), several participants discussed accessing private therapy. They acknowledged that this was a **significant financial burden and not possible for everyone;** even for those who did access therapy in this way it might involve financial sacrifices. However, they felt this was the only reliable way to access sustained therapeutic support, in the context of seemingly endless NHS waiting times and NHS support which might be substandard or where they might have had a bad previous experience.

'Now I just pay private [...] When I got my diagnosis...they were like oh, you know, 'we can signpost you to TALKWORKS' but I was like 'No, thank you.' And they were like 'Oh, but you know, they can do some trauma work.' I was like 'No thanks. I would rather just pay.' Because I've been burned too many times. [...]

Now I actually feel like I'm starting to make a bit of progress. So it's like, I'm not going to jeopardise that. I would rather just pay than be like, 'Oh, I can't see you anymore. I'm gonna go to this free service.' And then have to grovel my way back after a month. [...] I knew the waiting list for my assessment was so long, and I was like, 'right, I need to, I wasn't in a good place...I need to get something underway"

- Maya, service-user.

Cognitive Behavioural Therapy (CBT)

Some participants differentiated between types of talking therapy, though naturally the small numbers involved in this study discourage drawing general conclusions about effectiveness. However, the experiences are interesting and worth consideration. Several talked about Cognitive Behavioural Therapy. There was a sense that, if a therapy referral was made, CBT might be the initial option offered, before anything more sustained or in-depth was available. For some service-users, CBT was a somewhat frustrating experience, as its self-led, process/action-oriented approach could feel stilted, pointless, and lacking the depth and nuance required to address the complexities of people's experiences and difficulties.

'The first time they always do a round of CBT which is online, self-directed. Which I mean, might help some people but a lot of the time it feels you know, when I did it, I didn't even do it in the end. So you've really got to be determined in yourself to complete that. Because it doesn't feel that you have any support completing it; it feels like a completely pointless activity.'

- Kai, service-user.

'I know it [CBT] is actually not for everyone. It works for some people, that's fine. But for me personally, I find it very superficial. And to me, it's very much like you put a plaster on a scar and you just hope something happens, but it doesn't get rid of it [...] So the first time [...] It's not their fault, they were relatively new, but they, it was like they were following a script and they were like... 'Rate your mood one to ten blah, blah. And then just like ok, so how have you been this week?'. And then she gives you like a worksheet and I was just, I was in and out within like 20 or 30 minutes. And I was like it's actually taking me longer than that to get to and from the Torquay to Paignton on the bus. [...] CBT is not for me. I've not had a good experience.'

- Maya, service-user.

Dialectical Behavioural Therapy (DBT)

Other service-users described accessing Dialectical Behavioural Therapy: more specialist support which often involved longer waiting lists (discussed in detail below). Several service-users identified DBT as helpful, emphasising the provision of more intensive support and practical resources to help manage mental health:

'DBT was definitely the kind of cut through, like the real best treatment, really, for different bits, for anything really. With trauma, for any type of bits and pieces. I

think DBT is the way forward and it seemed to cut through.'

- Megan, service-user/social prescriber.

'DBT has been very helpful...in the sense of making me able to stop and think more before I act. It gives me those tools like the mindfulness tools, and distress tolerance, those kinds of skills. That's been really helpful.'

- Hannah, service-user.

Some participants mentioned potential limitations, while others suggested that the value of DBT lay less in its particular therapeutic approach and more in the **opportunity** for sustained care and meaningful connection with an individual therapist – this was a resource which was rarely available outside of private care.

'I'm not sure how much sort of support I really kind of got for that in terms of, like, things that I could put in place to help change my behaviour or things. It was more I think that I really connected with the person and was able to...go deep and like go through a lot of things. That was more helpful rather than, like, having techniques as such. I've not really had that kind of support, to be actually have things that I can implement, really, but yeah, that was that was quite useful.' - Lisa, service-user.

Home Treatment Team/Community Mental Health Team (CMHT)

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. This referral may be made by a GP or member of the psychiatric liaison team following an A&E visit. This team was sometimes referred to as the Community Mental Health Team, a name for the service in other areas of the UK. Professionals knew about the resource, but **only a small number of service-users participating in this study had contact with the team in Torbay or Devon.** As a result, we could gather little detailed data about how the resource worked or the difficulties in accessing support through it.

'We think about whether they need a referral to our home treatment team. We'd also consider whether they're already open to the CMHT. The problem with the CMHT and something that I've certainly noticed since working with the liaison team, there's a huge waiting list, and we often see people that have self harmed who are sat on a waiting list.'

- Michelle, psychiatric liaison nurse.

'Then the practice had like a mental health nurse that was attached to the practice. So I was referred to them who thought there's maybe more going on, and they referred me to CMHT. And they refer me to CMHT to get DBT.'

- Ash, service-user.

Social care

One participant described receiving social care support, following a referral from the Community Mental Health Team. As a result, funding from social care allowed her to

have support workers that visited her for a couple of hours, each weekday. She spoke very positively of this resource, describing it as a form of care which was **stable and reliable**, **yet also flexible enough to respond to specific day-to-day needs.** It seemed to be helpful both in providing support around practical tasks and emotional care or reducing isolation.

'They're really helpful because they can, if I go through a period where I'm feeling down and not feeling able to leave the house, them coming and they can encourage me to go out, they can help me with shopping, things. But sometimes we just come and don't leave the house and play games or something. It's just having that, that regular kind of contact, I suppose, is really helpful.'

- Hannah, service-user.

Social prescribing

Some people with experience of self-harm were referred to social prescribers. This was a relatively new form of care, and was described only by two social prescribing practitioners, rather than any service-users. Social prescribing is an approach which seeks to acknowledge and address the contextual and social aspects of wellbeing, and explore forms of care beyond the medical. People with experience of self-harm would be referred to social prescribers by GPs – there are currently no options for self-referral. The social prescribers we talked to described receiving a large number of mental health referrals, often involving self-harm, but feeling under-resourced and under-trained to respond appropriately. Social prescribing is intended as a form of support for proactively managing low-level health concerns rather than crisis care, so practitioners are not automatically trained in managing risk or responding to high levels of distress. Social prescribers told us about a lack of self-harm specific resources, and being uncertain about what sorts of onward referral might be possible.

Due to a lack of specific knowledge and training social prescribers often relied on external resources such as leaflets about self-harm. The **leaflets we were able to access as part of this research tended to be poorly designed, sometimes showing crude and stigmatised images of self-harm.** They focused heavily on cessation and distraction techniques, despite clear information that cessation is not the primary goal for all people who self-harm (see section on Recovery above). Leaflets we reviewed as part of this project relied on shame and stigma to try and dissuade people from self-harming - encouraging readers to think about the impact of living with scars or how others may feel about their self-harm. Moreover, leaflets also relied heavily on distraction techniques, which can miss the nuance of what it means to be self-harming. In particular, emphasis on distraction assumes that cessation is the primary goal, which is not substantiated in either the academic literature or by service users we spoke to (see 'self-harm and recovery' section above).

'The majority of our referrals for social prescribing are mental health related. It usually is at a crisis point because of the way that our systems are kind of governed at the moment and waitlists and just well, you know, probably more than most that they're not necessarily set up for getting people early. So we do

deal with a lot of crisis work, which isn't what social prescribing is meant to be about, but that's what we're dealing with. [...] There are team members that I kind of safeguard, there's two of us that kind of feel comfortable being able to deal with what we're dealing with, but then there's three of us that just can't, wouldn't be able to.'

- Megan, service-user/social prescriber.

'Because our self-harm sort of resources are so limited - we have, other than an app, we don't really have anything to send them to. We don't have anything in place or there isn't anything in place to help support those people. So at the moment, as it stands, till there's sort of, there is more support for people who self harm, then it doesn't sit comfortably with me receiving referrals for self harm when we actually can't really do anything for them - or much for them, should I say.'

- Lucy, social prescriber.

NHS services: Overarching difficulties

Waiting lists and resource shortages

One difficulty with several forms of care described above, was the length of waiting lists - particularly for CBT, DBT, and other psychotherapy. Both service users and healthcare professionals described extremely long waiting times before people could access support they might be referred to, either by their GP or specialist mental healthcare teams. People described waiting over a year or even for two years, especially for slightly more intensive forms of support like DBT.

Service users described the **frustration of spending seemingly endless amounts of time on a waiting list, with little information about when they may actually access support.** In such a situation it was easy to feel abandoned, or as though help would never arrive. Professionals expressed concern that patients might become more ill or more despairing while waiting for treatment, and that delays might increase the possibility of an individual reaching crisis point or needing to access crisis care. There was a sense of a system significantly overstretched and overburdened, and in which initial resource shortages led to the intensification of needs and thus even greater requirements for care and resources. This extended to inpatient care, regarding which some participants described a bed shortage.

One participant described an ideal situation of short-term planned admissions, through which participants might access intensive support prior to a crisis, thus avoiding the need for longer term admissions. This, however, was impossible to achieve due to a lack of beds. Resource shortages and waiting lists were problems which professionals we spoke to generally had no control over or ability to change: this was understood as a broader, system-wide problem, in the context of which it was very difficult to provide good, effective care.

'Our capacity to see people and treat people isn't great. So for example, looking at all those, looking at people that are sitting on our waiting list, you will see

people having to [attend] psych liaison several times while waiting to actually get a treatment for their self-harming.'

- Mark, Devon Partnership Trust.

'The problem with the CMHT [...] there's a huge waiting list, 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 and stuff [...] We often see people, lots of times you know, coming back very sadly and stuff and then they get really disheartened and sort of saying well 'what is the point?' and 'I'm never gonna get any help'.'

- Michelle, psychiatric liaison nurse.

'I'm on like this waiting list which I'm, I'm really grateful now that I'm on it. But it's yeah, it's another thing where you're just kind of on this road not knowing where you're kind of going, how long it's going to take. And yeah, just not feeling that confident, really, about what they're able to provide.'

- Lisa, service-user.

Disjointed care

A second difficulty across many experiences of statutory services was the feeling that care was disjointed, and that **different parts of the healthcare system failed to communicate with each other or offer consistency**. This related to the difficulty with out-of-hours care, which meant the person you talked to one day often wouldn't be there the next, and notes or records of your conversation wouldn't be passed on. Alternatively, it might mean phone numbers to call for support or at a time of crisis would cease to be relevant, and it would be unclear who to contact or how. It might also mean care plans, made in detail with trusted professionals, might be discarded, ignored, or simply inaccessible to/by a different set of professionals.

'The work that starts to get a bit more fractured, is then if you then turn up at liaison in the middle of the night, kind of that communication. The person that saw that, you know, the person who might have done the liaison assessment then isn't working the next day, so it's just a case of emailing over to a care coordinator, who might pick it up, because they might be going out to see different people.'

- Mark, Devon Partnership Trust.

'I can't remember if that was, if we tried to phone them on those contacts and we just went round in a circle. Because that happened a few times where you, they give you this number and you phone, and they're like 'oh no, that's the wrong number. We'll forward you on to this person I'll forward you on' and then it's like a dead line or something.'

- Kai, service-user.

Beyond immediate difficulties in accessing timely, appropriate, or agreed-upon care, service-users also identified broader complications. One of these was the sense that, when care was disjointed and every interaction involved a different staff member, **root causes of distress could go overlooked**. Participants suggested that if care was not sustained, then it often remained superficial, limiting its value.

Participants also described frustrating experiences of **having to re-tell a lengthy account of their history every time they accessed services.** This could be extremely painful, to the point of feeling re-traumatising. Finally, participants discussed the frustration of accessing support at different points and receiving extremely different responses or varied diagnoses. To receive completely divergent opinions from healthcare professionals was bewildering, and could cause service-users to lose faith in the system and individual professionals, and also to feel uncertain they were being understood or would receive care that might actually help.

'So 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. [...] Which 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 whole thing again.'

- Kai, service-user.

'When it's so inconsistent, that almost it's like, the polar opposite of what one person is saying. It's just like, yeah, it just makes it really quite hard for you as like a patient to kind of like, know where you're going with things and you do find yourself like withdrawing then because you're like, wow, like nobody understands me and then you just feel even more like weirded out because yeah, no one understands you and nobody kind of knows what's wrong.'

- Lisa, service-user.

In contrast, **joined-up care could be incredibly helpful**: one participant emphasised the importance of a good care coordinator and suggested this made all the difference in ensuring they could access appropriate, timely care. Working together over a long period meant a care coordinator knew a service user's needs and preferences, and understood what forms of care might be more effective. They could co-produce forms of care rather than enforcing or mandating them.

'So I suppose the best care is really good care coordinators. People who are able, I've had one, and because of having to go into AMU [Acute Medical Unit], and them not being very helpful, he's managed to liaise with them and put plans together so that it's easier and so that it's simple for me to go in and receive the treatment that I need. So that's been, that was, really helpful.'

- Hannah, 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 as something that comes up in relation to broader mental health support. In general, service-users we spoke to had more experiences of seeking care from statutory services than the third sector. However, it is not clear whether this is because they weren't aware of services available, or because in our limited sample we did not speak to people who sought support from non-statutory services. However, healthcare professionals were often very aware of relevant third sector organisations. Significantly, it seems that **third sector organisations are the first point of referral following crisis care in A&E.** One psychiatric liaison nurse said that if individuals seeking care were deemed not to require admission or referral to the Home Treatment Team, then they were referred to non-statutory services, including The Samaritans and Devon Recovery Learning Community.

'We'd also signpost them to the Samaritans as well, and I've sometimes made referrals to the Samaritans on their behalf so that Samaritans can ring them. [...] Also SHOUT - the text line - because some people find it easier to use text, especially these days, you know, people are more on their phones, aren't they? And find that more helpful. So we, we you know, signpost people to texts and stuff like that. Andy's Man Club, which I think is really great, especially for men, because there isn't lots and lots of stuff out there necessarily for men. And that's been really good having that as an option. I use Devon Recovery Learning [Community] quite a lot as well. There's lots of courses on there that people can do. So I signpost people to lots of that.'

- Michelle, psychiatric liaison nurse.

Third sector groups we spoke to offered a variety of care to people in support of their mental health, but none offered support specific to self-harm. Mostly, third sector groups felt they learned how to support people with experience of self-harm 'on the job' and felt comfortable doing so. However, they did not feel prepared to offer self-harm-specific support. Some said they felt comfortable offering self-harm support, but also questioned whether this was the best way to support service-users with experience of self-harm. In particular, they spoke about the benefit of **non-directional**, **open**, **recovery-oriented spaces that did not require people to use particular language or descriptors of their experience.**

Spaces provided included online peer-support, and also recovery-oriented activities to people who self-identified as having experience of mental illness, distress, or trauma. People we spoke to found that, in open spaces, many ended up disclosing self-harm. Sometimes, those they supported used the language of 'self-harm' to describe experiences, but for the most part they did not. Those offering these spaces felt that many they supported would not attend a self-harm specific space, because they did not understand their experience in that way. The third sector also appeared to have greater flexibility to respond directly to the needs of people who self-harmed, in part

because they could be less concerned with managing 'risk' and instead prioritise support, which service-users valued.

Third sector groups felt statutory services and local authorities relied upon them to supplement or support their work. For example, some groups spoke about delivering training to statutory organisations on how best to support others, and others supported/facilitated NHS co-production initiatives. While participants reflected that their involvement was good and that third sector groups may be best placed to do the work, sometimes this felt tokenistic or placed responsibility upon them that outweighed their funding or even qualifications to do so.

'Open meetings of the kind we have been doing, that bill themselves as being a place to talk about distress, but not asking people to select or self select out of whether its for them. Yeah, so we've made some inroads into doing that with our online open meetings. And our anxiety peer support, anxiety is such a broad term, you know, it doesn't matter what's causing it. But it's still anxiety. I think people might not even know that they're experiencing anxiety and self select out. So yeah, so really open meetings where people can talk about as loosely as the human experience or managing distress. And see that as a way for people to to start to make connections and be less alone'

- Carys, service-user/third sector.

'[In third sector groups] the systems are better because the systems are ones that they've created themselves, they have decided how they're going to work. And generally speaking, as charities are more localised, so they can make changes more quickly and more flexibly, they're much more aware of the people that they're serving, because that's the whole point of existence, whereas the NHS is this massive beast. [...] Charities, they tend to have more, more time for you.'

- Ash, service-user.

Some third sector groups saw their contributions to support for self-harm as **offering alternatives to medicalised and individualised forms of care.** Without the constraints of institutional regulations and guidelines, many organisations sought to be more explorative in the care they provided, focusing on transforming community perceptions rather than 'treating' individuals experiencing self-harm.

'Changing the culture by informing community organisations around their responsibility to support people in the community, in their community mental health. So it's not always a default to the mental health services, clinical services, clinical interventions. [...] There's so little understanding around mental health that some community organisations think that... Well, there's a lot of fear. [...] There needs to be more opportunity for people to interact with their community. And to bring their lives within what's happening in the community: to belong to community cafes, to be part of what's going on, to introduce, you know, opportunities for people to, you know, for their lived experience to be better

accepted in the workplace.'

- Charlie, third sector: community support.

Threats to the third sector

Professionals in this sector were highly motivated to provide appropriate care whenever possible, but faced difficulties in realising their ambitions. Some difficulties concerned structural aspects of the sector, related to the nature of funding for third sector organisations. For instance, it was hard to achieve consistency or build up skills because projects were often only funded for one or two years. It took time to build up resources or gain buy-in from stakeholders, and this careful, difficult work could be quickly undone when funding ran out. This made it difficult to recruit or retain staff; there could be a seemingly constant process of recruitment and training, wherein staff who built up skills around self-harm (as well as organisational and community knowledge) were lost at the end of a project, and new staff had to be brought in and trained from scratch. This was associated with the difficulty of securing funding for the organisation's core running costs. Therefore, it was extremely difficult to employ staff over long periods or cover expenses like insurance, software, subscriptions, accountants fees, and the work involved in managing these aspects of an organisation - this made it difficult for the third sector to innovate and create new interventions.

Staff in third sector groups connected this with an **increasingly scarce and competitive funding environment,** in which a lot of pressure was placed on organisations to prove the 'impact' of work. This could be difficult, especially in the clear-cut, outcome-oriented ways funders or commissioners looked for; this echoes the literature review findings on the importance of reconsidering what is taken for granted as a 'successful' intervention outcome and how such success is measured. These issues are not unique to Torbay and are seen across the sector²⁶.

'My staff, they've been on a journey. They've kind of learned a lot as we've gone along, and then come March, they haven't got jobs after that. So potentially what you're going to do, if there isn't more funding, is lose a cohort of people to other areas. And then people who come along later will have to start all over. [...] You want long- longevity, you want things to... you can't build on things. If everything is such short, short term.'

- Naomi, third sector: children and young people.

'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.

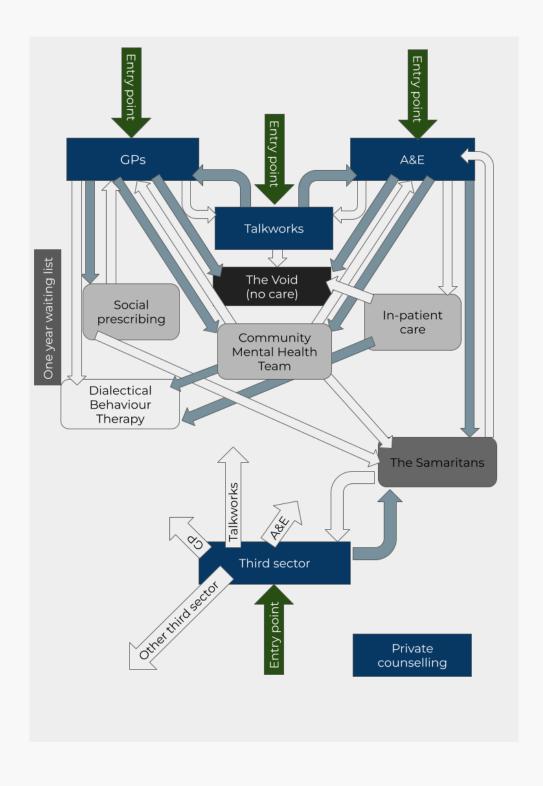
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²⁶ Problems surrounding the lack of core cost funding and constraints imposed by commissioners'/funders' expectations of 'reporting' and 'impact' were noted in multiple recent reports from the National Survivor User Network, evaluating funding and needs of user-led mental health groups: <u>Funding Grassroots Mental Health Work</u> (by White, Wells, and Hammou 2022) and <u>What do User-Led Groups Need?</u> (by Brown and Omerod, 2020).

Visual summary: Care pathways

This diagram provides a visual summary of the care people described to us. Rather than representing "official" or "intended" care pathways, this diagram **collates participants' experiences of accessing care, as they described it to us.**

The **complexity of the diagram illustrates the confusion of accessing care** - many people discussed contradictory or confusing paths to care, or instances in which they were passed back and forth between different services.



3.3 Children and young people

Scope and applicability of findings - Children and Young People

This project originally intended to understand adults' experiences of self-harm. However, as the project developed there was increasing interest in participation from those who supported children and young people. We did not have the resources or capacity to interview children and young people directly, but felt it would be beneficial to include their supporters in the project. For that reason, we ran a single focus group with people who supported young people with experience of self-harm. We also interviewed others who supported young people who could not attend the focus group. The focus group was attended primarily by pastoral leads and safeguarding officers at mainstream state secondary schools, but also included one parent, some who provided support for children in care, and a few who provided third sector support in a secondary school. Some people who spoke about supporting adults also discussed histories of self-harm beginning in childhood or adolescence.

While we spoke to people supporting young people in a state school, we do not know how young people experienced this care or whether supporters' reports of their needs match the needs of young people themselves. Moreover, all bar one of the people we spoke to supported those of secondary school age (11-18 years old). We cannot meaningfully comment on the needs of people younger than 11 or those who support them. While we are able to offer an analysis of young people's needs based on their supporters' perspectives, we strongly advise that further research is required to better understand the experiences of young people who are self-harming. This research should be co-produced by and with young people, exploring their experiences of self-harm and their priorities when it comes to care for self-harm.

Overview

Supporters reported a sense of high and increasing rates of self-harm among young people they supported.²⁷ In general, they experienced self-harm among young people

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²⁷ A recent NHS report into young people's mental health found self-harm was common among children with a 'probable mental disorder' - 28.3% of those aged 7-16, and 68.6% of those aged 17-22. These rates were higher than those not considered to have a 'probable mental disorder' -2.5% of those aged 7-16 and 17.8% of those aged 17-22. Whether self-harm is higher in these populations, or more likely to be visible or regarded as self-harm as young people get older or are identified as having a mental health disorder, is unclear. The dataset found girls were more likely to self-harm than boys. Rates of lifetime self-harm were 48.2% in young women compared to 23.3% in young men. The report did not consider self-harm rates in non-binary or gender non-conforming young people. The emphasis on binary gender in self-harm reporting is noted in academic literature, despite high rates of self-harm among transgender, non-binary and gender diverse groups: Witt KG, Hetrick SE, Rajaram G, Hazell P, Taylor Salisbury TL, Townsend E, Hawton K. Psychosocial interventions for self-harm in adults. 2021a. Cochrane Database of Systematic Reviews, Issue 4. Art. No.: CD013668. DOI: 10.1002/14651858.CD013668.pub2.; Newcomb, M. E., Hill, R., Buehler, K., Ryan, D. T., Whitton, S. W., & Mustanski, B. (2020). High burden of mental health problems, substance use, violence, and related psychosocial factors, in transgender, non-binary, and gender diverse youth and young adult.. Archives of Sexual Behavior, 49, 645–659.

as not notably different from adults. Participants reported small variations in methods across gender, but not enough to ascertain trends.

Methods of self-harm discussed included forms more commonly associated with 'self-harm', including cutting and ligatures²⁸, but also self-injurious or 'risky behaviours' that often fall outside conventional definitions - including organised fighting, disordered/restricted eating, and steroid use. Many observed that young people were operating at low capacity with many basic needs not met, though it was unclear whether this was 'self-induced' or otherwise - these specific issues primarily related to young people having eaten or slept enough/well²⁹.

Generally, supporters felt young people's wellbeing had declined in recent years, exacerbated by the pandemic - both their wellbeing and their parents' wellbeing, which was understood as highly determinative of young people's wellbeing.

Summary of key themes

- **Statutory support:** Long waiting lists, and support offered is often not in line with the needs or wants of young people.
- **Parental well being:** A key indicator of the mental health of young people interventions must also support their parents/carers.
- **Schools:** Overwhelmed, lacking training/confidence to respond to self-harm.
- **Safeguarding:** Protocols often lead to forms of care that undermine a young person's autonomy and does not respect their privacy.

Schools

Most people we spoke to about young people's self-harm worked in a school. Participants felt there was a high prevalence of self-harm in schools, but were under-resourced and underprepared to respond. Those working in schools learned 'on the job' how to offer care. Care was ad-hoc, with no coordinated or agreed protocol for responding to self-harm. Supporters felt they had little to no formal training. Almost all participants wanted training on self-harm, including why young people may self-harm and how best to support them. They also found a lack of places to refer young people to. Participants spoke about teachers and parents feeling 'anxious' about self-harm and that it was frightening to respond to, suggesting this may foster a reticence among adults to open conversations about self-harm.

Schools were overwhelmed by the number of young people needing support. They felt as though parents and statutory support systems expected them to offer care, though they felt unprepared to do so. Moreover, they were **expected to provide support for young people in a changing economic landscape in which schools had less funding and staff, and more students.**

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²⁸ A thing used for tying or binding something tightly.

²⁹ The link between mental and emotional distress and lack of sleep is highlighted by a 2022 NHS report, which found that 89.5% of young people with a 'probable mental disorder' had trouble sleeping, higher than their mentally 'healthy' peers: Mental Health of Children and Young People in England (2022, NHS Digital).

'People are still anxious about self-harm. I think it frightens people when young people are self-harming: they're not sure what to say. So therefore, they probably don't open up conversations always to get those young people to the right service in the first place... It's easier to say nothing or just to instantly refer someone on without properly talking to that young person about actually: did they want to be referred on and actually do they need to be referred on? Like I said, that young person who'd only cut once, that was a real knee-jerk reaction from everybody else. It wasn't actually listening to what the young person was saying. So I think it is confidence.'

- Naomi, third sector: children and young people.

Schools offered various forms of support to young people who were self-harming, including providing first aid items, holding space for them to disclose self-harm, and supporting them to tell their parents/carers that self-harm was happening. Schools also ended up offering a lot of support to parents who often felt scared when a young person disclosed that they were self-harming. Self-harm-specific support existed in the school that was part of the The Children's Society pilot (described in Section 4.3 below), but those who were not part of the pilot did not. Some schools offered young people support via an in-house counsellor, but this had limited capacity. Multiple schools discussed the use and utility of Thrive practitioners who worked more broadly on young people's wellbeing, though the implementation of the program was inconsistent across sites. One school was part of the Mental Health Support Team pilot, in which multiple mental health practitioners came into the school to provide additional support to students and staff members. This participant spoke highly of the pilot, especially in supporting people providing care, and felt the roll-out should be more widespread.

Those working in schools tended to offer in-house support rather than referring young people elsewhere, not because they felt it the most appropriate place but because they felt **despondent about the appropriateness or availability of support available elsewhere.** Schools did not speak highly of CAMHS (discussed below) or support from GPs. Schools relied heavily on online tools such as <u>Kooth</u> or <u>Calm Harm</u>, which they felt to be helpful but still limited.

Participants who offered support to young people in care spoke about having created a 'self-harm response box', which included various first-aid supplies, tools for distraction, and - in the case of one young person who self-harmed by cutting - they cleaned and returned blades. Those working in schools were curious and supportive of the self-harm response box but noted that, due to safeguarding, it was not something they could offer. Safeguarding protocols often stood in the way of schools offering the support they wanted. For example, many people in the focus group held nuanced and kind understandings of self-harm, but insisted blades must be confiscated and parents must be told if a young person was self-harming - even though in other moments they noted that these practices were often not what young people wanted or needed. Safeguarding processes often led to forms of care that breached confidentiality and undermined the autonomy and wishes of young people. Issues with safeguarding protocols tap into a broader national conversation about what it means to support young people on their own terms, and how safeguarding practices can lead to

'support' that causes more harm than good³⁰. These conversations occur across age groups but involve issues especially prevalent to children and young people.

'We do readily supply them [young people] with antiseptic wipes and bandages and plasters and anything else like that we need and we actually sort of almost push it on them and go, 'no, you will take some wipes'. Because you know, we want them to keep it, keep whatever they're doing clean. Obviously, blades are a different matter because we can't really have blades in school. 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.

Generally, schools were overwhelmed and under-resourced. One participant described the lack of time to support young people individually as 'heartbreaking'. The rest of the group agreed. There was little to no discussion in the group about the wellbeing of those offering support, though it was clear from conversations that they were also struggling.

'Within school, we are crazy busy. We are expected to do a lot at the moment. We become lead professionals, a lot of the time. We have so much that we are doing and having to also we are still catching up from the last two years. I mean, my year group, this is their first full year of secondary school, which has had a massive toll on them and things like that. And although we're very fortunate in the fact that we do have a pastoral lead for each year group, which I know a lot of schools potentially don't. I definitely know my school that I went to definitely did not have that. I mean, I wouldn't say we even had one for the whole school. So we are fortunate but we are still only one person, and I've got 244 students. And it is that moment of, you can see a child wants to talk to you. And you can imagine it's taken a lot for them to get there. And I don't have the time to do that. Which for us is heartbreaking as well because it feels like we can't, we can't do enough to support at the moment.'

- Anna, children and young people: pastoral support.

NHS support

Regarding support outside of school, the primary sources were through a young person's GP or through the Child and Adolescent Mental Health Service (CAMHS). Overall, schools had a despondent view of these services, particularly damning of long waiting lists and the expectation that if a statutory service could not support a young person, 'school would deal with it'. Participants mentioned parents taking young people to see their GP, but did not speak highly of the process. Largely, schools felt GPs

³⁰Johnston, A. & Akay, L. 2022. <u>Radical Safeguarding - A Social Justice Workbook for Safeguarding Practitioners</u> at <u>Maslaha</u>

would either refer a young person to CAMHS or send them back to school with the view that they were best placed to support a young person.

Participants raised multiple issues with CAMHS. Primarily, participants felt **CAMHS had** extremely long waiting lists and the support offered was often mismatched to the needs and wants of a young person. Participants were concerned that young people would seek support, potentially be offered it in a crisis, and then be left in a 'vacuum'. They observed that CAMHS offered only in-hours support that was not tailored to the specific needs of the young people seeking support.

'There's a huge gap between them talking to school or telling us about their self harming, between them getting any support. It's like a two year waiting list for CAMHS. And even if you're on the CAMHS waiting list. There's nothing available other than what school or Checkpoint can provide. There's just nothing out there. Sort of as a almost like a drop in or you know, or just something just to give them a small amount of support in between getting the treatment that the help they need.'

- Nicky, children and young people: safeguarding officer.

'I am working with young boys and men mostly and they often need more time to build trusting relationships where they can talk about self-harm. They also tend to have lifestyles that don't always fit around the appointment times they are given for support. My mentoring session slots have more flexibility, and this helps. I appreciate that services are stretched but often YP just need someone to talk with unless their self-harming needs specialist medical attention. I'm from a mixed heritage background (British and Caribbean) and it would be helpful to see more practitioners and support teams that represent ethnically diverse communities.'

- Desmond, third sector: youth mentor.

Another key concern with CAMHS (and statutory services generally) is the **transitional** gap once they reach 18 years old, noted by supporters of young people who self-harm and people with experience of self-harm reflecting on their experiences of accessing support as a young person.

'I think the bit I struggled the most were that sort of like the teenage years and also that gap where you're like, you're just coming out of being a child and going into like adulthood, it's almost like this like this gap where nobody really wants you. Well, that's how it feels. Kind of. Everyone's like, oh, yeah, that's kind of that, you know, they deal with this. But then you go to them, and they're like, Oh, well, you're not quite ready for this service. Kind of there's other people who, you know, is our priority. So you're kind of in a bit of a limbo. So I'd say that was quite a challenge.'

- Lisa, service-user.

'I just find CAMHS really quite patronising and not really that helpful. They do their best obviously. Like I said, think the bits for me, I don't know if I'm going too

far into it now but like so when I did this was kind of when I was about 17. So then obviously, I started to trust my counsellor, took a long time and 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.

Even when people could access CAMHS support, the services offered were not necessarily beneficial. Almost all participants spoke about negative feedback from young people who accessed CAMHS. Concerns ranged from CAMHS' emphasis on assessment rather than intervention, to the architectural layout of the spaces.

'I've had students talk about how horrible the rooms are. When they get to CAMHS. You know, they've said it's a room with a chair. That is it that I'm sat in this room with the chair, and I'm supposed to be talking about how I feel and my emotions and it's horrible. It's just like, almost imagine you're in an interview room at the police station.'

- Helen, children and young people: safeguarding officer.

CAMHS services relied upon young people's ability to attend appointments, which was sometimes about their own willingness to attend but was also determined by the extent to which parents/carers could take them to and from appointments. Young people were turned away if they arrived at the wrong time or previously missed an appointment. Participants who supported young people in care discussed a circumstance in which a young person did not want to attend their sessions with CAMHS. Instead of removing support, the CAMHS worker agreed to work with the young persons' support team instead. The participants who received support from CAMHS in this way noted that it was hugely beneficial for them and thought this should be standard practice.

Children with Special Educational Needs and Disabilities (SEND)

One participant with expertise supporting young people with SEND noted a high prevalence of self-harm among those they supported. However, 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 primary focus of support for children with SEND was not to stop the self-harm but instead 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 schooling environments and that even in specialist schools, supporters may not feel well-resourced to provide. It was in the specialist school setting that we heard the most positive examples of care. The participant we spoke to said the school could provide this care because they had the time to offer it, and spoke at length about the simplicity of care many young people need - if only staff had the space and confidence to offer. In this case, the key determinant of good care seemed to be supporters who had the time and confidence to listen to what a young person actually wanted or needed. Responding to self-harm with care sometimes

required hours or 1:1 support, working closely with parents/carers, the capacity to change approach, and a flexibility to break up or change the teaching schedule.

'That time to invest in that, that knowledge of each individual child. I mean, for me, that's the thing that we have permission to do in our school. Investing the time to try and understand and what is needed. I need as many really skilled staff who can who can work out is this a sensory need? Is this hunger is this thirst? Is this unwellness?'

- Tim, teacher at a SEND school.

Social media

Many who attended the focus group spoke about the role of the internet in the lives of young people they supported. In particular, they noted the role of social media in young people's lives. When it came to self-harm, the group offered a sensitive consideration of how social media platforms are used by young people to access support for their wellbeing, in general terms but also specifically in relation to self-harm. The group suggested there was an increased prevalence of young people sharing their self-harm on Snapchat in particular, for multiple reasons. Firstly, the group considered that Snapchat allows young people to share their experiences with peers in a way that is anonymous and non-permanent - in contrast to seeking support from adults which often triggered safeguarding processes that did not maintain confidentiality and felt as though they put a young person into a box of being a young person 'at risk'.

Secondly, social media offered young people instant feedback at all hours - in contrast to mainstream support with long waiting lists, available in working hours. The group observed that many young people are awake at night, with little support available at this time. While the group was sensitive and generous in their understanding of young people's use of social media, they were concerned that online spaces were unregulated and unobserved by adults. In particular, supporters were concerned that young people would offer informal peer-support without support for their own wellbeing. The focus group did not seem to want to 'get involved' in peer support, but instead ensure those supporting others knew where to turn if care they offered felt uncomfortable or outside their capacity.

'Being in school if you don't want to tell anyone that's permanent. So you tell one person in school, you're with them for the next five years. You tell a random stranger on Snapchat, you've got it out of your system in the moment and you know, they don't know you they don't go to your school'

- Steph, third sector: youth worker.

'Within my year group, I feel like I have quite a culture of: somebody who's self harmed, they will tell their friends, their friends then feel like it's their responsibility to deal with that. They don't tell an adult, they then take it upon themselves and then often you find that they will have self harmed as well as almost kind of like a unity thing that's going on like they do it together. So they're all in it together at the moment. So like, you were just saying if there was somebody completely separate, that they could speak to, I think that would

benefit kind of all of them, not just the one individual as well like it wouldn't have that knock on effect on others too.'

- Anna, children and young people: pastoral support.

Parent and carer wellbeing

Every participant we spoke to discussed parent/carer wellbeing as a key and often overlooked factor in the wellbeing of young people - including those who self-harmed. Parents were often afraid when they found out their child was self-harming and feared it may be linked to suicide. Those supporting young people often found themselves having to reassure and support parents also.

'There isn't enough support for parents who may have a child self-harming. I don't think there's enough, like, peer support for parents or professional support for parents as to what to do. And yeah, I have to wonder if there's enough, like, kind of the peer support stuff for young people. I think it's really important that they meet other people who may be experiencing the same thing in a safe way, not in a kind of contagion way, but in a, in a safe way, you know, and maybe meet people who've gone through that journey of finding other ways to cope with emotional difficulties.'

- Sarah, third sector: suicide bereavement.

'Something for parents and guardians, as well, on how to deal with it. [...] How you handle it in the moment is dependent on you and your situation. But maybe some guidance for parents to be like actually, if you find your child's been doing this, you've got concerns, you know, maybe don't just blow up and don't just be like oh my god, you can't do this. Take away all the stuff they're doing it with.'

- Maya, service-user.

Generally, participants felt **parents were unsupported and many were struggling,** especially after the pandemic, an observation supported by research literature³¹. The **impact of austerity on parental support facilities were repeatedly noted** - in particular the closure of Sure Start Centres and Family Units. They felt that closing these centres meant parents had little support; participants felt it important to recognise young people's mental health does not occur in a vacuum, and efforts to support them must also include care for the wellbeing of families and parents.

'There is a massive piece of work, before you even get there supporting a child]. The biggest bit of work for me would be around, around the education support for families. And that needs to start as early as possible. So I mean, there's possibly a correlation between the absence of organisations like Sure Start, and appropriate parenting skills. [...] If you're going to try and fix it, you can either do with the classic NHS or sticking plaster, or you go back to first principles and say,

³¹ For example, a 2022 NHS report found that 1 in 5 young people lived in a household that experienced a reduction in household income in the past year. The report also found 14.8% of 17-22 year olds experiencing mental and emotional distress reported living in a household that was not able to buy enough food or were using a food bank in the past year: Mental Health of Children and Young People in England (NHS Digital, 2022).

you know, what's happening in-utero (which is vital), what's happening, post birth, what's happening in the early years. And if that bit is right, not only for the child, but for the family, I would imagine that you can guarantee that there will be fewer, less than requirement for higher end organisations like CAMHS, which clearly can't cope with the load that they're facing.'

- Tim, teacher at a SEND school.

3.4 Contextual Factors: Structural issues and local context

Experiences of self-harm and seeking or receiving care were heavily influenced not only by specific services available (or not), but also by contextual factors. These included **broader structural failures or inequalities,** which determined how services ran and how self-harm existed in people's lives. Some are highlighted above, such as staffing in the NHS and underfunding of mental health services. These structural factors are not necessarily open to change at a local level, or without widespread, national change across a range or areas. Simultaneously, participants described both care and self-harm as impacted by specific aspects of Torbay's context, such as social deprivation. These, too, are not necessarily easy or possible to change quickly, but are important to be aware of in designing interventions.

Underfunding and lack of capacity

Participants described systems underfunded and lacking in capacity, including healthcare, education, and the third sector. They noted the **impact of successive funding cuts and austerity budgets on national and local levels.** As a result of stretched budgets, interventions often required economic justifications and evaluations emphasising economic outcomes, which were often difficult or even impossible to measure. There was a sense that **economics were prioritised above people's needs and wellbeing.** There was also 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 other areas, which were also struggling with funding and capacity. At all levels, individuals were displaced from one struggling, over-capacity system to another, struggling, over-capacity system.

"Can you demonstrate it, the economic impact of it, of stopping the self-harm?" And the, the truthful answer is no. [...] The problem then, then, obviously, it's about justification for services. So, you know, so that's why the CCG is pushing me, to say: 'Can you demonstrate the financial viability of this service? You know, how many times did they stop going to the doctor?' [...] There's little capacity in the system to do the stuff.'

- Robert, third sector: children and young people.

Lack of out-of-hours support

Struggles around service capacity both contributed to and were exacerbated by the absence of out-of-hours support. This was widely discussed by participants as a key difficulty in accessing care, especially in moments of crisis or intense distress. They noted such moments may be more likely to occur late at night or in the early morning,

when services were limited or inaccessible. This was especially the case of third-sector organisations, which were rarely open 24-hours, an unsurprising fact given the lack of funding available and financial cost of 24-hour access. Even beyond crisis, participants discussed the difficulty of accessing support while working a 9-5 job. As discussed further below, considering current economic difficulties and the rising cost of living, individuals were unlikely to be able to take unpaid sick leave or risk losing their job to access care. This was connected to Torbay's positioning as a 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.

'If I could make one thing change in the support that is available in my area it is that I'd make it available 24/7. I work currently 100% of the hours that most services are open. [...] I mean things other than crisis support. I know that logistically it's not really doable but it's sad that help is only available really to those who can afford time off.'

- Jess, service-user.

Social structures: Cost of living, deprivation, lack of resources

Several participants talked about aspects of society or culture which impacted people's experiences of self-harm or made it harder to access care for self-harm. Many were economic; people discussed pressures caused by austerity, rising living costs, and widespread 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 that economic stressors impacted the community resources available, both in general opportunities for community connection and belonging and in the closure of specific community-based programs. The latter was most frequently mentioned in relation to the closure of Sure Start centres; half of Sure Start centres have closed in the last 10 years. The lack of community resources and spaces could lead to loneliness or social alienation, and the abandonment of people who might benefit from early support and connection.

'In Devon we've got particularly deprived areas. They've got high rates of self-harm. So we know Torbay is obviously one of those; Plymouth is another one.' - Claire, commissioning.

'It's the access to, I don't know, maybe DBT or CBT that doesn't cost the world really. Because I've had to source private, you know, and not everybody's in the

position to be able to do that or have the knowledge or the gumption to do it.'

- Megan, service-user/social prescriber.

'The children that we work with generally, quite a few of them come from deprived wards and, you know, difficult things are happening in their lives. But I don't think that's different in Torbay than anywhere else, really.'

- Naomi, third sector: children and young people.

Local context: Geography, tourism, population

Several participants noticed Torbay-specific factors which impacted experiences of self-harm, the care it was possible to provide, and broader opportunities for community connection and support. Torbay is a coastal area in the South-West of England, with an industry highly dependent on seasonal tourism. This means, as is common across similar areas in the South-West and UK more broadly, the area sees an influx of wealthy tourists in summer and a high proportion of available property is holiday accommodation or second homes. This is accompanied by a lack of opportunities for economic growth or career development, for people who often live in deprivation and whose available housing is often severely limited.

Due to the area's geography, infrastructure is often insufficient, for instance regarding transport or telecommunications. There was a perceived lack of investment in the area and a lack of resources outside urban centres. These contextual factors create situations of extreme difficulty where it is not surprising individuals experience high levels of distress. In addition, the area's natural beauty makes it a popular location for retirees, which can leave individuals struggling with their health and displaced from previous support networks. This, too, can align with difficulties in creating connected, supportive communities.

'We do have in different areas high levels of poverty or, you know, socio-economic deprivation, coupled with, you know, areas where there is quite a bit of affluence. In, like in North Devon, you've also got a lot of second homes, holiday homes. So the community can be thriving for those, you know, busy things happening for those eight or more months that a lot of these places are open, but then it goes very quiet. [...] The internet connection just isn't that. [...] In the big, bigger cities, there's probably bigger range of support services. Because the money goes there, doesn't go to Devon. [...] I've heard before people say 'Oh well Lynton is only 24 miles away.' Yeah, but you try getting a bus there.'

- Louise, service-user/third-sector

Findings: Conclusion

People who self-harmed accessed care and support through numerous avenues - via GPs, in A&E, in schools, or through third sector groups. Participants mentioned instances of good and appropriate care where their needs and experiences were taken seriously, they felt listened to, there was flexibility to tailor responses to individuals, and there was access to tangible resources such as CBT, DBT, EMDR, or simply sustained contact with a trusted professional.

However, accessing such care was not guaranteed. People trying to access support around self-harm were hampered by the difficulty of both meeting and exceeding thresholds, of seeking care and finding none available, of fragmented care and difficult-to-navigate systems, and of seemingly endless waiting lists. Those attempting to provide sensitive, nuanced care around self-harm were often limited by under-funding, by difficulties in accessing appropriate training and expertise, and by risk-averse structures or rigid safeguarding procedures. There were concerning instances of significant failures of care, and punitive responses to self-harm, particularly within NHS services.

The vast majority of the difficulties and gaps regarding care around self-harm were not specific to Torbay, but instead reflect the broader national picture, and problems or failings across multiple systems (including health and social care, education, and the third sector). Having laid out the broad picture of care available in Torbay, we now focus on seven key areas for change, identified through analysis of the data as offering the greatest opportunity for positive change, perhaps because they were areas of considerable need or because they were areas where good care might be extended or augmented.

4. Areas for Change

Throughout the project people made several recommendations about how care could be improved - sometimes suggesting things that did not already exist, and sometimes highlighting the need to further resource/support pre-existing care. This section brings together suggestions into seven key recommendations. These are recommendations based on the insight and experiences of participants in this study. They speak to a gap in the literature regarding social interventions, which may prove beneficial to outcomes beyond cessation and go beyond extending pre-existing services.

Prompter and more widespread access to interventions such as CBT and DBT, greater access to inpatient or intensive CMHT care, and the ability to access less time-pressured GP appointments might all be beneficial. However, meaningful change in such areas requires a widespread shift in resourcing, management, and structuring mental health care in the NHS, and is unlikely to be achieved simply through initiatives in Torbay. Improving care around self-harm requires a radical shift in national approaches to social care, as well as structures that cause and sustain distress, including reform of the benefits system, housing provision, and school resourcing.

Our recommendations focus on targeted interventions which respond most directly to the experiences described in this report. However, **recommendations should be taken alongside the need for wider system change in both mental health care and the broader systems that create, exacerbate, and sustain distress.**

In our interviews and focus groups, a number of positive examples of support for self-harm were mentioned; we include these below as case studies. They reflect some of the key values and approaches participants felt were important, and are included as examples of approaches that address areas for change we identified. They demonstrate how people can be creative, careful, and supportive in systems that do not always provide the qualities or resources to implement such care.

While elements of the **case studies** could serve as inspiration for new approaches, they should not simply be replicated without careful thought and consideration as to how these can be implemented in practice. Though they reflect caring interventions from supporters, they often run without adequate funding and are not joined up to the rest of the system. This can lead to good care being pocketed or segmented, doing little to influence wider systems of care around self-harm. In short, they respond to rather than resolve harm within the system.

4.1 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 provide each other with solidarity, encouragement, and advice. They felt knowing others with similar experiences may reduce isolation and offer chances for connection and learning. Professionals discussed running such groups, or similar groups with different foci, and witnessing positive results and engagement; service-users described thinking such spaces would be helpful, or occasionally accessing such spaces, at times through formats such as online forums.

Peer-support groups must be well facilitated by people with significant training in group facilitation and safeguarding. They should run at various times, so people can access them around work hours or caring responsibilities.

Participants recommended having groups specific to people who self-harm and groups with a broader mental health remit that were equipped to respond to self-harm. Participants felt it could be helpful to have peer support groups for parents, family members, and other carers of people who self-harm.

'It did peer support for parents, but it also did group activities for the young people that were self-harming. And I always thought that was, you know, that kind of covered both bases, really. And then I think young people that went through it could come back and volunteer for the yeah, that's, that's lush. That's just perfect, I think.'

- Sarah, third sector: suicide bereavement.

'Access to peer support I think is vital, and having that well managed. Because I know as a professional, if I were to suggest getting a peer support group for self-harmers together, my manager would freak. There would be no way. [...] Peer support is just so, so important. And people on varied journeys as well, so people that have come out of it and had prolific kind of, you know, experience and kind of see people through it. Ideally, having really well-run, well-established peer support would be brilliant.'

- Megan, service-user/social prescriber.

Case study: Daybreak Learning Community

One participant talked about previous experience in working with a local service that emphasised peer support and peer learning. She emphasised the possibility for peer-led services to encourage open, important conversations, and that support could be open to people whose self-harm was ongoing. She described a structure in which individuals with experience of mental distress or mental ill health could be part of the peer-learning team, but could also, while going through difficult times, access the services themselves. She talked about having the freedom, in a non-medical service, to

take open, imaginative, personalised approaches to self-harm, which prioritised what worked for each person.

Key qualities of this service included:

- No referral needed: Self-harm groups were open to walk-ins and did not require referrals from healthcare professionals. It was important no one was ever turned away. The participant who described this mentioned people who were referred often arrived with a sense of being 'told' to attend; for her, it was important people felt this was something helpful for them.
- **No emphasis on cessation:** There was no requirement to stop self-harming to attend sessions, and there was a willingness to be with people as they self-harmed to try and break cycles of isolation and shame
- **Distinct from therapy:** Peer support sessions were not therapy or substitutes for this. There were difficulties with certain healthcare providers refusing to offer additional support if individuals also attended peer support groups; refusal was inappropriate and needed to be avoided.
- **Self-harm in context:** The groups noted the importance of viewing self-harm in the broader context of a person's life and the difficulties they were experiencing, whether that be trauma, low mood, bullying, or any other significant factor. This holistic approach was vital.

'Some of the groups that moved us the most were around supporting people who were self-harming because it's, it's very personal. It's very often very private. It's something that people don't necessarily easily share. And the other thing, I think that that was important, particularly for those groups was people didn't have to stop self harming to come along. [Yes, yeah.] Because as you may or may not know, a lot of services the emphasis is on: 'You need to stop that thing before you come and get support', rather than, 'well, we need support to stop that thing'.'

- Mary, third sector: peer support.

Peer Support: Recommendations

Regular self-harm peer support groups in and around Torbay

We recommend establishing regular peer support groups in and around Torbay. These should be held at various times, in various locations. The groups should be run by people with experience of self-harm who have training in group facilitation and are supported with significant supervision. Groups should not be outcome or cessation-oriented; they should aim to support those who self-harm and provide them with a space to discuss difficult aspects of their lives and experiences, rather than encouraging them to stop self-harming. They should be open, both to people who would like to self-refer, and to people whose self-harm is ongoing.

Increased support for/provision of peer support in and around mental health

It is valuable for people who self-harm to be able to attend general peer support groups. Self-harm rarely exists in isolation: people who self-harm may have much in common with people experiencing other mental distress or illness. While groups do exist in and around Torbay, they can be better resourced, more widely available, and better publicised so staff and service-users are aware of them.

<u>Training for pre-existing mental health groups</u>

In making broader mental health support available for people who self-harm, it is important to provide staff and facilitators with self-harm specific training. This is often not available, and staff may not feel they have the skills to give appropriate support. It would be particularly helpful if training could be available at a reduced cost, or free, for small user-led organisations which often receive minimal funding.

4.2 Attitudes and training

One of the most notable findings was the language, treatment, and attitudes people who self-harmed experienced from healthcare professionals. The incidents described to us were upsetting examples of poor care. NICE guidelines state that healthcare professionals should treat people who self-harm with 'respect, dignity and compassion, with an awareness of cultural sensitivity.¹³² This is frequently not achieved.

Participants recommended providing additional training for clinicians and service-providers. We suggest this could be supplemented by clear guidelines regarding (in)appropriate language or care. Repeatedly, participants emphasised the importance of kindness, and care which recognises the humanity and dignity of people who self-harm. Though a simple idea, in practice it seems difficult to achieve. This suggests in-depth training may be needed, or expansive approaches to widespread culture change in attitudes to self-harm in healthcare settings.

'I've sometimes had difficult attitudes from people if I've been on the acute wards because I self harm. So maybe better training for people on wards?' - Hannah, service-user.

'Maybe start with a bit more of an approach that does see past, like, a troubled individual that's causing you more paperwork. Because sometimes that's how it felt, you know, I, you know, I'd probably look at the language around it as well, because sometimes the language can be a bit more damaging. And then people realise, you know, like, the word superficial really stayed in my brain of, well, it's just superficial. Okay, well, what, what, what does it need to get to? To like to have some response where it's like, oh, this person does need a little bit more help.'

- Bex, service-user/third sector.

'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

The NICE quality standard of compassion, respect, and dignity can be found here: www.nice.org.uk/guidance/qs34/chapter/Quality-statement-1-Compassion-respect-and-dignity

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. Good care is like a parent who accepts their child and allows them to be who they are, allows them their emotions, but encourages them also to experience them in healthy ways.'

- Alex, service-user.

Attitudes around self-harm: Recommendations

Mandatory user-led training

Staff who provide support for people who self-harm - including GPs, Crisis Team members, staff on inpatient wards - should receive mandatory, user-led training on self-harm. This training should focus on improving or shifting understandings of self-harm, establishing (in)appropriate language and forms of care, and focussing on the difference between self-harm and suicide. It should be designed and led by people with experience of self-harm who are paid for their work and provided support while doing so.

This training could be integrated into educational programs and form part of professional development for staff who have already qualified. This training requires institutional support to ensure it is possible for already overburdened staff, supporting them to attend and integrate learning into work practices.

<u>Language and behaviour guide or standards</u>

Training should be supplemented with a clear resource, designed and led by people with experience of self-harm. Again, people should be paid and supported for their work. The resource should lay out appropriate versus inappropriate language/practices and set clear standards for care.

Guidelines would establish standards and provide service-users a point of contact to challenge unacceptable language or treatment. It would help for the resource to be available or prominently displayed in settings where people described poor care (such as A&E), so service-users can identify when care falls below acceptable standards. This may help ensure staff are widely aware of standards.

Improved modes of reporting and accountability

While training can improve understanding, it cannot on its own ensure standards are maintained. We recognise work within Healthcare Safety and Improvement research which encourages a move away from a 'blame culture' in healthcare settings. However, in the case of egregious failures of care described in this report, it is vital that forms of accountability are available. How to achieve this is an area of significant debate: significant further research with service-users and healthcare practitioners would help establish modes of accountability which are fair, practical, non-punitive, and effective and can enable improvements in practice.³³

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³³ In taking a holistic approach to this area of improvement, it may be valuable to draw on recent research on the interaction of training, culture, and standards in establishing safer maternity care. Detailed exploration of factors in creating a 'safety culture' is found here:

Improved information leaflets

As part of this research, we were shown Information Leaflets currently provided to people who seek care in healthcare settings, particularly GP practices and social prescribing centres. We found the leaflets patronising, inappropriate, and out-of-date; we strongly recommend those in circulation be removed and replaced by alternative existing user-led resources or new leaflets designed by people with experience of self-harm.

4.3 Holistic and accessible support for children and young people

Participants noted significant 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 far more joined-up support for young people across all sectors in Torbay, underpinned by training and resourcing for those supporting young people - families, friends, teachers, youth workers, mental health professionals.

Due to safeguarding concerns, we could not speak to young people directly about their needs and experiences. Implementing these recommendations would need to be done in collaboration with the young people they are designed to support.

'A question in my mind, I think, really is about how well equipped we are to deal with what we're seeing. [...] They [my team] feel comfortable dealing with it, but I think the reason they feel comfortable with it is because we got training, but we've also got sort of robust procedures. So it's a bit like when something comes up, we've dealt with it before, and we know and we've got our kind of procedure you can follow and that instils confidence.'

- Robert, third sector: children and young people.

'That seamless level of care, so they know that wherever they come in, they're going to be supported, and if they need different services they'll just, they'll just move between services and be supported and not: 'Oh, no, sorry. You're only 15, you know, you don't meet our threshold: please go somewhere else'.'

- Claire, commissioner.

www.thisinstitute.cam.ac.uk/research-articles/safe-maternity-unit-ethnographic-study/. refers to the PROMPT training package, developed to address obstetric emergencies and associated with improved outcomes: www.promptmaternity.org/prompt-uk-1. The academic research study above found that training itself was not solely responsible for improving practice; improvement occurred because training was implemented alongside clearly articulated and constantly reinforced standards of practice, behaviour, and ethics; monitoring multiple sources of intelligence about the unit's state of safety; a highly intentional approach to safety and improvement. We suggest, in the case of self-harm, safety might be taken to mean not only physical safety but also emotional, which may in part be enabled through the 'compassion, respect, and dignity' NICE guidelines require. Translating the approach described in the research from focus on physical safety to focus on emotional safety, compassion, respect, and dignity, may be a productive approach.

Case Study: The Children's Society Pilot Project at The Spires College

This is an **in-school service offering young people free, confidential support.** Hubs in schools, staffed by trained teams of youth workers, could ensure young people can access care quickly in a location familiar to them, whilst enabling those providing support to communicate effectively.

Particular positives noted are that this care is:

- **Person-centred:** Support only happens with a young person's consent and is responsive to their needs and preferences. There is no stock response, but a range of options that can be adapted to meet their needs.
- **Skilled:** The team is highly trained to provide this level of emotional support to students, providing a valuable resource for young people, parents, and teachers to call on with guestions/concerns about self-harm.
- **Embedded in a school:** Central, accessible location for young people and families, reducing barriers faced in referring young people to other services.

The Children's Society Pilot Programme is a positive example of what can happen in schools with the appropriate resourcing and time. However, the programme is not led by children and young people and its placement within a school leads to limitations on their ability to practise open and expansive forms of safeguarding.

'We've changed the culture of self-harm. So within that school now, I think it's much easier for the children that we're working with and the staff to have conversations around self-harm. I think they've stopped shaming children for self-harm or underestimating the impact of their self-harm. [...] [Teachers'] feedback to us has been: before, we could have referred them to various different places, but we didn't know which was the right place. We didn't know they'd get what they need. Whereas actually we know you're in school; we know we can trust you. We know that if there is a safeguarding issue, you're going to come and communicate with us.'

- Naomi, third sector: children and young people.

'Schools have valued having them [youth workers] and young people have valued having that level of support. [...] Some of the children that self-harm can be quite difficult to engage. So that's really good. I think that's where the voluntary sector are really good because they have different, different ways of working with young people.'

- Claire, commissioner.

Support for children and young people: Recommendations

Community consultation

Effective support for young people must reflect the needs and wants of young people. Action based on these findings without involving young people runs the risk of being top-down, paternalistic, and out of line with what young people require. The current community research project could be replicated, interviewing young people about their experiences of receiving support for self-harm in Torbay. This would foster more meaningful co-production with young people, meaning care could more accurately reflect young people's wants and needs.

In the absence of specific research into young people's perceptions, three key recommendations emerged from discussions with those who support them.

Hubs in schools

There must be joined-up communication between young people, teachers, families, and support workers. Rather than facing long waiting lists, difficult-to-navigate referrals, or miscommunications between professionals, 'hubs' similar to The Children's Society pilot can help ensure joined-up and immediate support.

Hubs should follow holistic, person-centred approaches. Every young person is different, and the care they need is different. While CBT may work for some, others prefer group sessions or craft therapy. Support must be offered with the young person's consent, and be responsive to their needs and preferences. Any service would benefit from engaging with critical safeguarding practices³⁴.

Furthermore, self-harm is not isolated from social issues, adverse childhood experiences, difficult familial circumstances, and more. Support for young people must be adaptive to specific needs and circumstances, with support workers equipped with training and resources to address self-harm in context.

It is crucial to take care to avoid punitive approaches which use support as a way of sanctioning negative behaviours in schools. For example, support should not be seen as a way of removing students exhibiting behaviours that are difficult to manage in a classroom, but instead as a way of helping to meet emotional needs.

Family and peer support

Supporting young people means caring for families too. Families or carers can find it difficult to know how to support a young person. They need spaces to talk to other families, information on how to support young people, and their own emotional care, so these networks are supported emotionally and practically too. Similarly, young people share experiences, information, and advice with others in schools already. They need space and resources to be equipped to offer effective informal peer support, in ways that protect their emotional wellbeing.

Resourcing and expertise

For a critical discussion on what radical safeguarding can look like in schools, see Mashala's workbook here: www.maslaha.org/Project/Radical-safeguarding

The above recommendations require time and expertise to implement effectively. There must be enough resourcing so there is the spaciousness for person-centred and encompassing support, and specific, quality training for supporters to implement this with nuance and care. This includes training for everyone involved in supporting young people: teachers, youth workers, CAMHS, peer supporters, and other professionals who work with young people in a pastoral capacity.

4.4 Joined up care

One key difficulty we identified at all levels of care for people who self-harm was a lack of joined up care. This in part reflected the difficulty of establishing and communicating coordinated care plans between different facets of the healthcare system, as well as low levels of resources and staffing. However, it also reflects failures of technology where, for instance, patient records and pre-agreed care plans seem impossible to access for out-of-hours staff. Similarly, it reflects the **difficulty of navigating a very complex health and social care system,** wherein people with complex needs often require support from multiple groups of staff.

This system can be bewildering, especially for people who are unwell or may benefit from someone with expertise and energy to advocate for them and help them move through it. Finally, it reflects a **tendency for service-users on waiting lists or recently discharged from services to be left without follow-up support,** at times without any referral. This can be disorienting and distressing.

'The best care is really good care co-ordinators. [...] I've had one, and because of having to go into AMU, and them not being very helpful, he's managed to liaise with them and put plans together so that it's easier and so that it's simple for me to go in and receive the treatment that I need.

[On what constitutes good care]: Knowing that there's someone there that has your back or is fighting your corner. And can communicate for you. [...] Joined up care, joined up systems, systems that work well together.'

- Hannah, service-user.

'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. [...] I was going in and saying the same stuff over and over and over again. Which 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 whole thing again.'

- Kai, service-user.

[On the Stoma Association]: 'They have a buddy scheme where you know people who are struggling with that, and they link them with others who also have a

stoma. So you know, sort of to link, someone who is self-harming with someone who has been self-harming or experience self-harming so that they can connect and have that sort of budding system that budding that friend, that person that point of contact, who will understand why they do it, what they're doing, and how you know how best to support them towards recovery.'

- Lucy, social prescriber.

Joined up care: Recommendations

<u>Increased provision of care coordinators</u>

Participants with experience of care coordinators identified them as key to receiving good, joined-up care. While the lack of care coordinators reflects a lack of staffing in the NHS, increasing their number would significantly improve many people's experience of care even within a system which is otherwise struggling.

Introduction of 'navigators'

While care-coordinators operate within the NHS and have the power to make referrals and bring services together, there may also be value in providing support beyond healthcare services. Participants discussed 'recovery navigators' or other similar instances of support which could be provided by and through third-sector groups. This would mean they wouldn't have equivalent influence in instigating care, but could provide low level advice, expertise, and support to people who self-harm who might struggle to understand different facets of care available to them. It would be helpful if these individuals had a high level of knowledge of the available local resources and services, and could inform people about thresholds and exclusion measures in various clinical services.

<u>Improvements to technological systems within NHS services</u>

Several participants described fractures of care which could be partially addressed by improved technology within the NHS. For example, it is counterproductive that an agreed-upon collaborative care plan is not easily available to out-of-hours staff or to emergency workers. Attention should be paid to how this could be resolved.

Many participants discussed the frustration and pain of repeated assessments, rarely leading to meaningful support and almost never follow-up care. It is unclear if assessments are stored in patients' records and what the rationale is to conduct new assessments at every interaction with services. It may be valuable to assess the system by which it is decided an assessment is required or consider how assessments are shared between services, updated rather than repeated.

Bridging support

Given the extreme length of current waiting lists and the complexity of thresholds for various services, it is worth considering how to provide support while people who self-harm are between services. This could be as simple as a fortnightly - or even monthly - 10-minute phone call, to check in on individuals and discuss whether their distress or ill-health is improving or deteriorating. This would help ensure individuals on

long waiting lists do not feel entirely abandoned, and enable the healthcare system to provide proactive support if things get worse.

4.5 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. This must be led by the community, not imposed top-down by funders, responding to community members' priorities.

'If I was really struggling with things, to be able to go to somewhere where there are staff there all the time that I can talk to. I managed to access it once and since then I haven't been able to access it, partly because I'm physically disabled and there just aren't places for people who are both physically [disabled] and [have] mental health problems.'

- Hannah, service-user.

'The Moorings, the Samaritans, Devon Recovery Learning [Community] - they're great and they're fantastic. But again, they only have so much capacity, and they're only open certain hours. It would be really lovely if there would be more 24-hour services. It'd be really great if there were services that ran groups and then drop-ins and stuff for people to go to. That would be really lovely. Unfortunately, it comes down to money, doesn't it, and resources.'

- Michelle, psychiatric liaison nurse.

'Describing an idea for a community centre with a wide 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. But actually, the expectation was that people would, 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.

Case study: Devon Recovery Learning Community (DRLC)

DRLC was highlighted as a positive example of support within a local community, expanding definitions of responsibility for self-harm to include the whole community. This incorporates aspects of belonging, self-expression, and engagement, as well as specific support for self-harm. A holistic, person-centred approach is taken, supporting people in all areas of life rather than isolating self-harm as disconnected from other experiences. This may mean signposting people to walking groups, taking them

cold-water swimming, visiting museums and art galleries. DRLC combines efforts to extend services with tackling underlying misconceptions of self-harm.

The caveat is that DRLC does not have a physical base. Many participants noted the importance of an accessible place they could go to, where they knew there would be someone to support them and that could be available out of hours.

Particular positive elements of DRLC include:

- Holistic, person-centred approaches: Community members are viewed as whole people. Self-harm is not taken in isolation, but viewed in combination with aspects of people's experiences, identity, and personality. Support responds to that person's individual needs, whether this is a need for social connection or to explore one of their personal interests.
- **Community responsibility:** DRLC expands definitions of support for self-harm, encouraging a range of community groups to recognise their role in supporting people who experience self-harm. This could include walking groups, museums and galleries, religious organisations, and more.
- **Challenging misconceptions:** DRLC is proactive in challenging misconceptions about risk, an issue which makes community groups resistant to welcoming and including those who experience self-harm.
- **Secure funding pathway:** being NHS funded allows the work to plan for longevity, raise awareness, and build community links.

'I see the role of the DRLC as supporting a little bit something of a change of culture and attitude around what, you know, around mental health and mental ill health and around self-harming, because I think people get very frightened when they see someone who has scars all over their arms or legs or face even and that can be very troubling for, you know, people who have no experience of mental health issues. [...] How do we, you know, just invite conversations with community people, you know, with community organisations who wouldn't otherwise have a lot of engagement with people who struggle with severe mental health issues or who, whose mental health - oh what's the word - that their mental health issues are expressed in a more visible way, like through self-harm, or addictions.'

- Charlie, third sector: community support.

Community resources: Recommendations

Core costs funding

Community groups cannot function without funding to cover core costs. For projects to last and have a meaningful impact, they need sustained funding (over several years) to cover costs related to staffing, overheads, and resources. Many groups felt limited by the need to report impact after relatively short periods of time, forcing them to neglect more important long-term goals and avoid experimenting with ideas possibly considered 'risky'. 'Impact' was often defined by commissioners and their agendas, not the needs and values of those accessing services. For community groups to flourish,

they need secure core-costs funding. Impact reporting must be re-evaluated to meet groups' needs and capacity³⁵.

Physical community centres

People need physical places to go for support, social groups, and connection. Bases must be distributed across Devon and physically accessible, so people can access them regardless of where they are or the physical access needs they have.

Support offered at community centres should be varied and holistic, providing people with a range of options rather than prescriptive, limited definitions of what support for self-harm means. This may include art therapy, walking groups, social cafes, mindfulness, meditation, and more. Many participants recommended an extension of crisis cafes for welcoming and inclusive out-of-hours support.

Tackling misconceptions

Many participants noted a reticence amongst community groups to include those who experience self-harm, partly because they did not necessarily see this as their purpose or responsibility and partly because of fear of risk. Efforts to extend care in local communities must actively address such misconceptions. Implementing this may include training or awareness-raising resources so people gain confidence talking about or supporting people with self-harm.

4.6 A&E and aftercare

A&E departments were a key pathway into treatment for people who self-harm. We heard from multiple sources that it was standard practice for people deemed to meet a lower risk threshold to be discharged from A&E without referral to care from 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 extremely troubling to hear repeated poor experiences of A&E care. Tackling issues around care for self-harm in A&E would significantly improve the care available to people who self-harm.

'To have, like, a designated room where you could go and you know, that the person won't say that to you, because they're, they're trained in [...] recovery principles, trained in the language to use, trained and being person centred, maybe even with lived experience themselves, you know, that would mean more support for that staff member, which means more NHS resources, but somebody that would understand and kind of know how to react to different people that 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, you're not, you're not, you're not scolded for it,

³⁵ The National Survivor User Network offers a detailed exploration of the issue of funding user-led groups: www.nsun.org.uk/news/new-nsun-podcast-funding-user-led-groups/

you're not shamed.'

- Bex, service-user/third sector.

'Obviously got taken to A&E, got that stitched up. I think that's a scar up here somewhere. Oh yeah. So that was one of my first trips to A&E and I can't remember if... I was 17 then so I got seen by CAMHS the next day. So obviously that was in the night and then in the morning, when I was a bit more lucid, CAMHS sat me down with a few, a few of them. I think there was two or three people...I think their goal was more to create a plan or something on how I was going to manage my feelings or something. I don't know, it wasn't very, there was only a short session like 30 minutes maybe. And then after that, but there was sort of just like, you know, 'off you go'.'

- Kai, service-user.

Case Study: A&E follow-up service from Self-Injury Support (SIS)

SIS (previously Bristol Crisis Service for Women) is a national charity which aims to improve support and knowledge around self-injury. They run a UK-wide multi-channel support service for women & girls affected by self-injury, trauma, and abuse, accessible by anyone via phone, text, or email. They were recently commissioned to run a regional peer-support service for people who have been to A&E or Urgent Care for self-harm treatment. Referrals are made by a member of NHS A&E or psychiatric liaison staff. The service aims to offer non-medical and non-judgmental support, giving individuals opportunities to talk through experiences of self-harm. Individuals are offered a one-off, 90-minute session, in which they are provided with resources they may find useful. Sessions are face-to-face, or via video or phone call. Support is tailored to the individual, recognising that while some might want to stop self-harm, others might not.

Positive elements of this service are:

- **Peer-led support:** Staff are recruited, trained, and managed directly through Self-Injury Support, rather than the NHS. This means staff are part of a broader experience-led team, with proactive policies and support practices around working with and through experiences of self-harm
- A non-directional service: Service-users set their priorities and aims for sessions, and can use the time however they wish. They can articulate their own support needs, and experience empathetic, non-judgemental listening and responses this may be a unique or new experience.
- **Immediate support:** People likely see someone in 7-14 days of an A&E visit, contrasting the waiting lists or void of care they experience otherwise.

The caveats and limitations to this service are as follows:

- **Shifting absence of care forward:** Though the one-off session can be extremely valuable, it is only a single instance of care and does not change the broader lack of care. It shifts the pressure of impossible referrals onto third sector staff: it is

- now their responsibility to manage the difficulty that there is little further support available to individuals attending the service.
- **Buy-in from clinical staff:** It can be difficult to spread knowledge of the service amongst busy and over-stretched clinical staff, and also to persuade clinicians or commissioners of the value of such a service.

A&E and aftercare: Recommendations

Mandatory training

It is urgent for A&E staff - who may not have specialised in mental health and therefore have received little information on self-harm - to receive mandatory, user-led training in self-harm. Training should emphasise non-punitive responses to self-harm, that punitive responses are contrary to NICE guidelines, and that punishment is an affront to the dignity of people who self-harm.

Post-A&E support

There is a concerning trend for people attending A&E to be discharged with little or no ongoing support. This reflects long waiting lists for statutory support, but represents an egregious failure of care. Ideally, this would be resolved through vastly improved provision. Until this is possible, we recommend implementing a similar program to that run by Self-Injury Support in Bristol, wherein third sector services are funded to offer follow-up appointments to people accessing A&E care for self-harm. This program would provide people with space and time to discuss the difficulties which led them to attend A&E, and let them explore opportunities for further support within or beyond statutory services. Third-sector professionals providing this service would need extensive training, supervision, and support.

Advocates or supporters in A&E

A&E was consistently a poor environment for people who self-harm, not only because of failures of care, but also because both the process and the physical space could be uncomfortable, intimidating, overwhelming, and even frightening. We suggest funding third-sector professionals who could attend A&E and be available to support and advocate for people attending due to self-harm³⁶. These advocates could provide a comforting presence at a difficult time and give information about the process and care patients were likely to experience.³⁷ This could be especially valuable for people attending A&E alone or for the first time.

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³⁶ A National Institute for Health and Care Research study explores experiences of patients, carers, and staff in A&E. They offer a new assessment, with rapid follow-up care, as a way for clinicians to provide empathetic, caring support to people attending A&E for self-harm: <a href="mailto:evidence.nihr.ac.uk/alert/what-help-do-people-who-self-harm-need-in-emergency-department-charm-need-in-emergency-department-charm-need-in-emergency-department-charm-need-in-emergency-department-charm-need-in-emergency-department-charm-need-in-emergency-department-charm-need-in-emergency-department-charm-need-in-emergency-department-charm-need-in-emergency-department-charm-need-in-emergency-department-characteristics."

³⁷ Recent research suggests people who attend A&E for self-harm value and need human connection to offer hope when life feels hopeless; however, clinical staff do not see this as part of their role or feel equipped to engage in such interactions: O'Keeffe, S., Suzuki, M., Ryan, M., Hunter, J., & McCabe, R. 202). Experiences of care for self-harm in the emergency department: Comparison of the perspectives of patients, carers and practitioners. BJPsych Open, 7(5), E175.

4.7 Community of practice

Many in third-sector and educational organisations expressed a desire and need for **greater connection, communication, information, and support.** Professionals in these roles are not always specialists in self-harm, or even mental health. While they may have access to mental health or self-harm specific training, it is valuable to have broader support in how they address self-harm through their work.

Many expressed a desire for a community of practice focussed on self-harm. This space would help supporters connect with others in their field and across Torbay to share advice, best practice, resources, and find opportunities for collaboration.

'I don't think organisations are very well networked. I think it's a bit hit and miss if you find something. I don't think everyone is aware of who's doing what and who's, who's got little pots of money for a bit of self-harm work or who's, you know... I just don't think we're very well hooked up. I think Devon's so sprawling, I think it's difficult.'

- Sarah, third sector: suicide bereavement.

Community of practice: Recommendations

Build a cross-sector network of professionals

We recommend establishing a cross-sector network of professionals interested in sharing practice around caring for people who self-harm. This network might involve establishing a mailing list, and holding monthly or bi-monthly drop-ins for people who want to discuss issues or seek recommendations. The network would benefit from a launch event to disseminate information on resources and services already established, which they or people who self-harm might find helpful.

Establish a coordinator within Public Health

It would be valuable to establish and publicise a key individual (within the public health team or a third sector group) to coordinate the network and act as a point of contact for queries regarding care for people who self-harm in Torbay. The individual must be well-informed about current resources and services available in Torbay, and therefore able to signpost attendees to relevant sources of support.

5. 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 staffing and underfunding of NHS services.

Participants did not seem to show that a particular treatment or intervention was better than another - more that **what made good care was its qualities**. Namely, non-stigmatising interactions focussed at supporting an individual's whole experience (rather than just their self-harm), a sense of being listened to for their genuine needs, and the ability of supporters to see an individual as a person needing support rather than a 'problem' or as a 'risk. Supporters across the board reported a lack of self-harm specific training and support. We did not speak to young people directly, but their supporters reported similar themes to those among our adult participants. It was felt that self-harm was highly prevalent in school settings, and schools struggled to support young people. In response to these experiences, we outlined a number of areas for potential change that participants highlighted, including increased peer support, better training and clearer standards, more joined-up care, and investment in community resources. However, we also highlighted that within an over-stretched and under-funded system, and a social context of inequality and austerity, even implementing these recommendations can only do so much.

Everyone experiencing self-harm deserves access to care that feels safe and affirming. 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 and support to offer this kind of care. While many reported to us instances of this kind of care, the majority of it was not so.

It is our hope that the findings of this report may help to improve care around self-harm - not just in Torbay but also more broadly. We have found many gaps, absences, or failings in care. For those of us with experience of self-harm, little of this comes as new information. However, we have also found instances of care, tenderness, and possibility. We hope that by documenting the experiences of those we spoke to, we may help to bring about a world that those experiencing self-harm and their supporters deserve.