Eating Distress North East

Eating distress and VCSE sector project completion report
April 2024

Introduction

Through whole eating distress (ED) pathway development work, consistent voluntary, community and social enterprise sector (VCSE) capacity has been recognised as a gap. A small number of Integrated Care Boards (ICBs) commission additional capacity directly with Eating Distress North East (EDNE) at place level linked to community mental health transformation, but at best this has been inconsistent. There are some areas of the geography where there is no experience of direct engagement with the VCSE in pathway delivery.

The Adult Eating Disorder Provider Collaborative (AED PC) allocated non-recurrent monies to assess and test where the most meaningful added value from the VCSE might be in specialist ED pathways, and to help inform possible commissioning intentions both across the provider collaborative and at place to move towards delivery of the full clinical model.

The project aims were to:

1. Lead work to draw existing VCSE/community-based groups for AED (commissioned and non-commissioned) across the North East North Cumbria (NENC) region into an AED network.
2. Test how we can best expand the role of the VCSE in the AED pathway across the NENC.

Between April 2023 – April 2024 Eating Distress North East (EDNE) employed a Network and Development Officer to undertake this work, drawing on the combined expertise and insights of the EDNE staff team.

Definitions

For the purposes of this report, we use the following terminology.

Eating Disorder - An eating disorder is a medical diagnosis based on an individual's eating patterns, the effects these have on their body, and the psychological factors connected with this.

Disordered Eating - Disordered eating is used to describe a range of irregular eating behaviors that may or may not warrant a diagnosis of a specific eating disorder. The term "disordered eating" is a descriptive phrase, not a diagnosis.

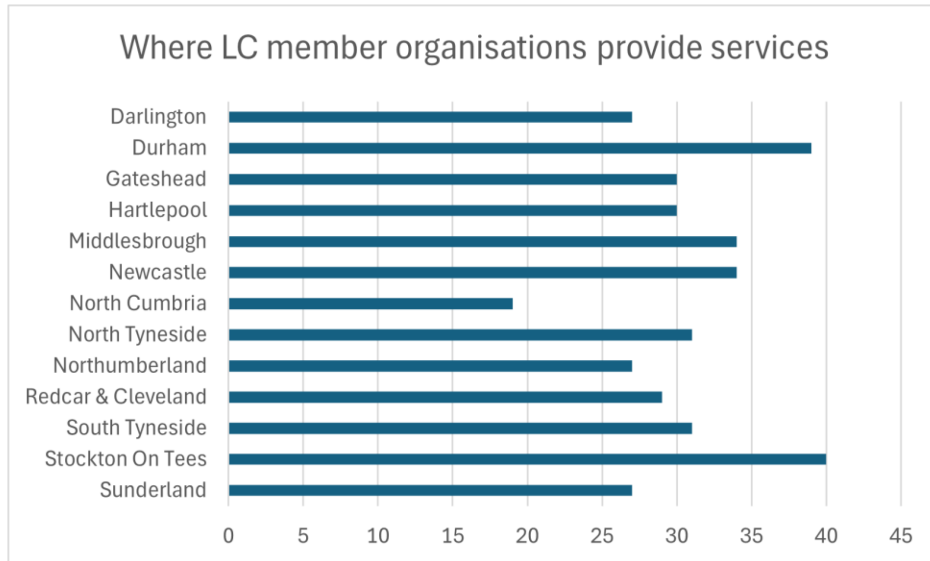
Eating Distress – Eating distress is any relationship with food which an individual may find difficult. EDNE use the term ‘eating distress’ as they provide support to individuals without the need for a diagnosis if the individual feels they are affected negatively by their relationship with food.

We will also use the terminology given by the NHS to describe the various levels at which decisions might be made or health and care services delivered, for example at Integrated Care System, Integrated Care Board, Place, or Neighbourhood level.

Project Aim One: Draw existing VCSE/community-based groups for AED (commissioned and non-commissioned) across the NENC into an AED network.

Membership of the Eating Distress Learning Community

At the point of authoring this report we have reached 147 individual members, which is a much greater number than expected when we embarked on this piece of work, made up of representatives from many different voluntary, community, and social enterprise (VCSE) organisations (77), plus staff who are employed within 18 other bodies, including Tees, Esk & Wear Valleys NHS Trust (TEWV), Cumbria, Northumberland & Tyne & Wear NHS Trust (CNTW), Primary Care Networks (PCNs), Durham Police & Crime Commissioners, Healthwatch teams, and universities and colleges. This interest demonstrates the unmet demand for eating distress specific education and training in health, education, and other public sector bodies. The geographical spread of member organisations is illustrated in the chart below (responses recorded are from individuals).



Engagement

Members have received seven monthly email bulletins between September 2023 and March 2024 which have included seasonal news and ED campaigns, events, and advice for those supporting people living with ED, information about EDNE services, support, and referrals, bookings links for learning community sessions and access to post-session recordings, plus the dissemination of relevant NHS resources where appropriate.

Member data has been collated using Airtable, an online platform for creating and sharing relational databases. This platform has provided a way to view and manage membership data and log engagement and attendance at learning sessions whilst also allowing interrogation and categorisation of members and organisations, which has been used to target work around particular geographical places or communities of interest.

Delivery of Online Learning Activities

The content of our online learning sessions was developed based on the learning and development needs identified through three focus groups which were held in summer 2023. Whatever the baseline knowledge of each member, we have provided opportunities to refresh existing knowledge, increase knowledge, and learn new skills and techniques which can be applied in a variety of different organisational settings. A summary of the online learning activities delivered alongside learning outcomes and views is available in the table below.

Session Name and Date	Learning Outcomes	Live attendee views	Recording views	Total views
1. Understanding Eating Distress: An Introduction, 23/10/23	• Increase knowledge, awareness and understanding of eating disorders. • Recognize signs, symptoms, and potential triggers of an eating disorder. • Increased confidence to talk about eating disorders. • Identify practical strategies for working with people with eating disorders. • Increase knowledge of local support services.	37	53	**90**
2.Cultivating Confidence 11/12/23	• To explore messages about body weight/image and shape in our families, schools, culture, and society. • To understand the impact of these messages on self-esteem and the development of eating distress. • To raise awareness of our own biases regarding weight, shape, and image, and how this may impact our work with others living with eating distress. • Identify ways to work with people and encourage them to engage by reducing stigma and judgement.	13	31	**44**
3. Creating Calm 31/01/24	• To increase our understanding and empathy for what it may be like to have an eating disorder.	6	5	**11**

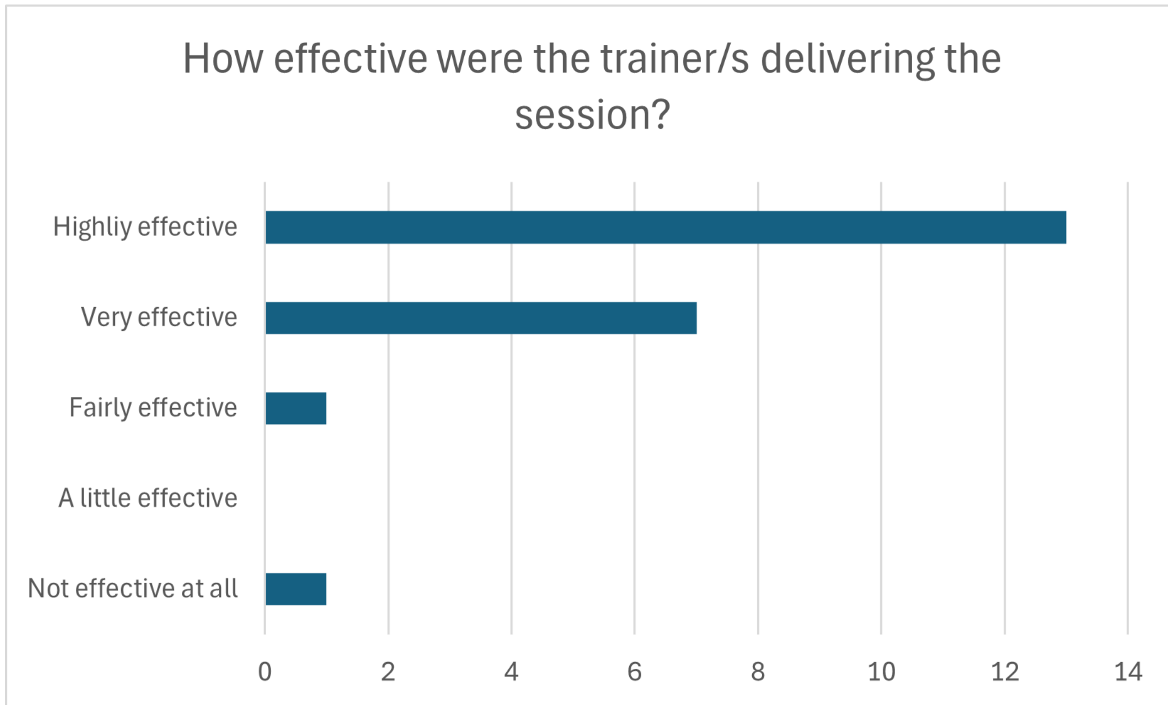
	• To increase our knowledge of thinking styles and how we all manage our emotions. • To raise awareness of our own reactions to working with anxiety and eating distress. • Explore strategies to help both the clients, and ourselves, self-soothe and regulate our emotions.			
4. Encouraging Change 26/03/24	• To increase our understanding of the process of change and how difficult that might be. • To explore person-centered approaches to encouraging change. • Exploring ideas and practical strategies. • Creating a ‘toolkit’ of ideas and resources for future reference.	16	0*	**16**

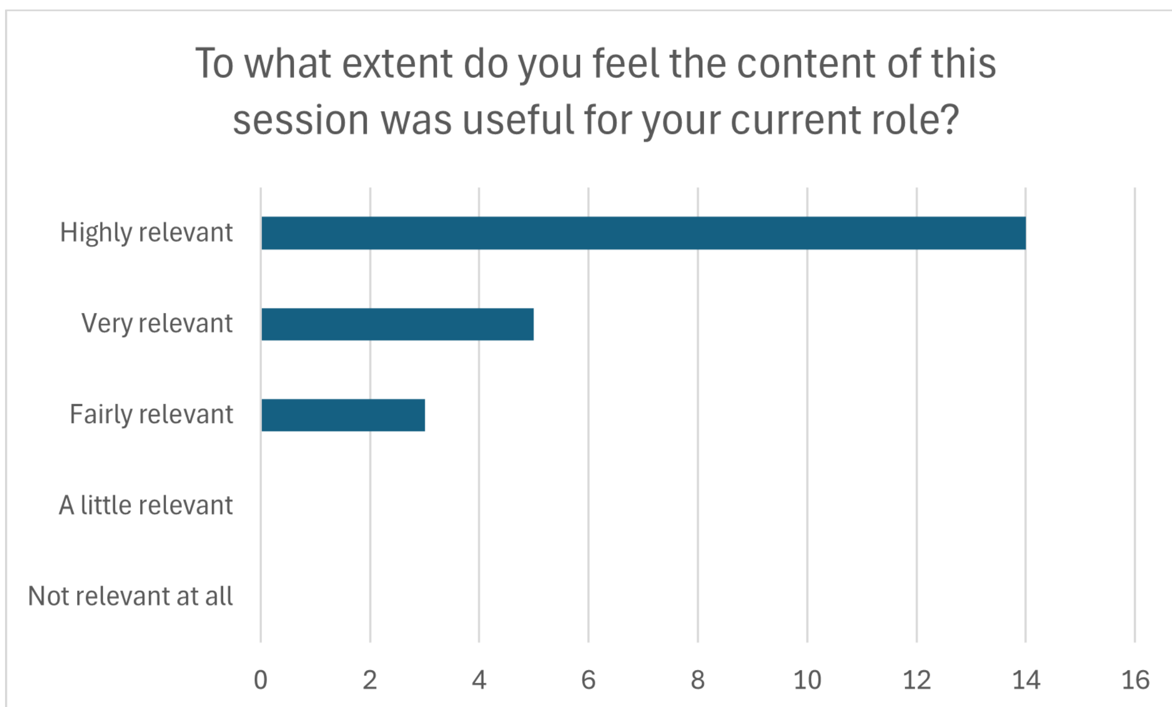
**The link to this recording has not yet been shared*.

EDNE has committed to ensuring these four session recordings are accessible to existing and new VCSE members of the Learning Community over the next 12 months.

Evaluation

The following graphs represent the feedback we have collated from participants via our online learning session evaluation.


How effective were the trainer/s delivering the session?
Highliy effective
Very effective
Fairly effective
A little effective
Not effective at all
0
2
4
6
8
10
12
14


To what extent do you feel the content of this session was useful for your current role?
Highly relevant
Very relevant
Fairly relevant
A little relevant
Not relevant at all
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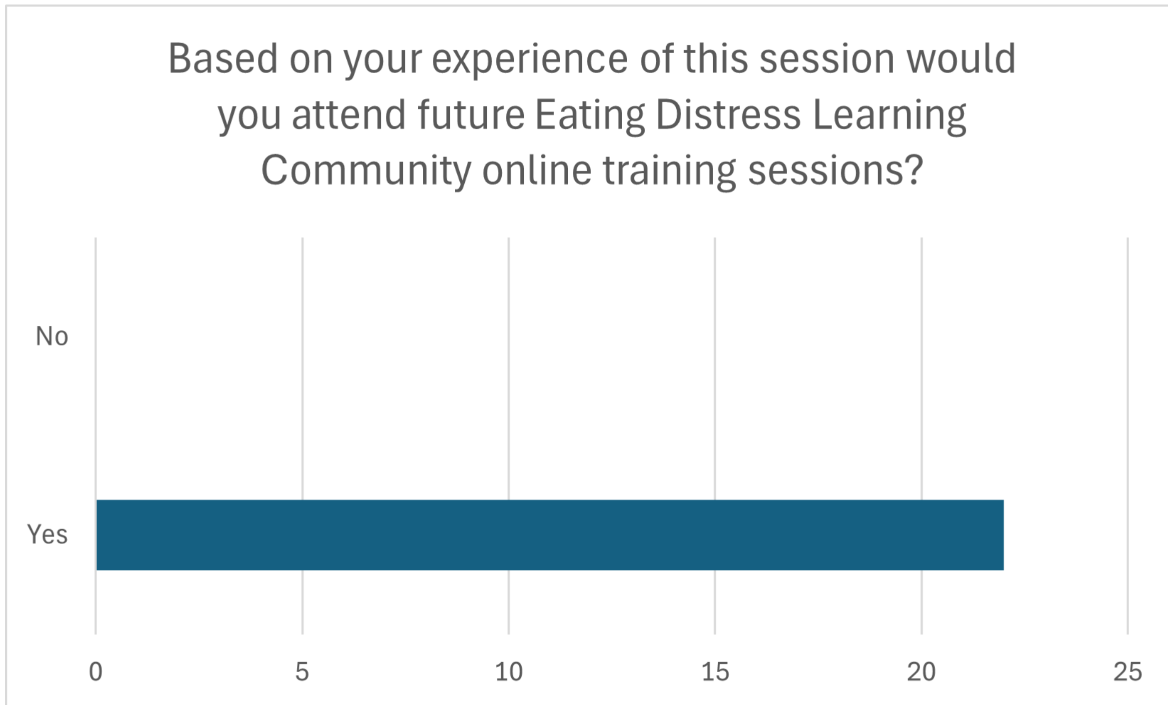

We also gathered qualitative data on how we could improve the sessions, and any final comments. Not all respondents completed this section, but 40% of those that did state that they were completely satisfied with the sessions. 26% suggest longer breakout sessions, and each of the following suggestions were made by one individual only:

- Clarity on participant group tasks during session.
- More information about local and UK-based support.
- Longer sessions.
- More practical advice for working with patients.
- Smoother use of technology.

Participant quotes

I have found it very thought provoking and informative. Thank you very much for the information that has been shared at a level that was just right for me.

Good reminder of skills I have that can be used with eating distress, taking the fear out of it. Some really good practical advice for example, reminder that coping strategies are good. Working with GP helpful, so is importance of signposting. Not focus on how they look, etc. Too much to say! Brought hope and took some of the fear out of it.

> Very informative, such important information and discussions that need to be had thank you!

> I felt a learnt a lot that I will carry forward into my role.

> Very informative and interesting session.

> Training was very interesting and useful for my role.

> I thought the session was really well facilitated.

Wider impact and outcomes

Undoubtedly the EDLC project has provided EDNE with a platform to promote its vision, mission, and services, and added capacity to the organisation in terms of development opportunities and building relationships. Although this was not the primary purpose of the project it has led to the charity making closer connections with health professionals and other commissioned services, such as NHS Talking Therapies, and VCSE health alliances such as Stockton Mental Health Forum, Middlesbrough Mental Health Partnership, Hartlepool Health and Wellbeing Alliance, Northumberland Health and Wellbeing Network, and ReCoCo in South Tyneside.

EDNE has also connected with Diabetes UK, National Childbirth Trust, and Darlington Healthwatch, amongst others as a direct result of the networking associated with the EDLC.

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Project Aim Two: Test how we can best expand the role of the VCSE in the AED pathway across the North East and North Cumbria (NENC)

Summary of Recommendations

1	Create collaborative pathways: Undertake mapping of the AED pathways with all partners and incorporate EDNE into AED care pathway.
2	Build an AED VCSE commissioning model based on collaboration and partnership, with appropriate investment and resources
3	Tackle place-based disparities in access to eating disorder/distress services across NHS and VCSE
4	Invest in education: Sustainable training and education in eating distress/disorder is needed by a wide range of organisations across the NENC ICS area.
5	Work towards implementing the Universal Personalised Care Model within AED pathway.
6	Embed VCSE community-based support into all Individual Care Plans, and allocate resources to establish a VCSE AED commissioning fund, ensuring this includes provision for micro commissioning.

The Brief

At the outset of this project the North East and North Cumbria Adult Eating Disorder Provider Collaborative (NENC AED) and EDNE agreed a workplan which formed the basis for project delivery. The workplan included a set of key questions around aspects of VCSE involvement that the Provider Collaborative would like insight into, and recommendations on.

Alongside the data collected during Learning Community registration and from extensive conversations with members, the Network and Development Officer has connected with:

- Four other Provider Collaboratives
- Four voluntary sector specialist support organisations across the UK who are also members of REDCAN
- A representative of the NENC Lived Experience Advisory Group
- Two other health professionals to inform the commissioning and good practice recommendations

A full list of the individuals interviewed is included as Appendix 1.

What role does the VCSE sector play in Adult Eating Disorder (AED) support in the region?

We have an extremely diverse voluntary sector in the region representing organisations of all sizes and causes, from large, registered charities to micro not-for-profits. Voluntary Organisations Network North East (VONNE), the regional VCSE infrastructure organisation, supports over 1400 member organisations, and place-based infrastructure organisations will be supporting many more who are not VONNE members.

These organisations are each delivering on their own charitable objects, however much of their work directly (but informally) supports people within our region who are experiencing eating distress, including a considerable proportion of those who may be undiagnosed/untreated. Most of the work of the VCSE sector is happening under the radar as these organisations are in the main not commissioned by the NHS, but our data highlights that 75% of members say their organisation is currently supporting (or has previously supported) service users with eating distress.

It is worth noting however that there are also several VCSE organisations working on a formal and commissioned basis around mental health, for example those organisations that hold contracts to deliver NHS Talking Therapies for anxiety and depression, that are seeing referrals of people with eating distress or eating disorders as a primary or secondary diagnosis, but most feel unable to work with these individuals due to lack of knowledge, training and issues around risk.

The NHS has long been aware that working in partnership with the VCSE sector can provide clear benefits, including direct access into communities that they may find more challenging to reach. Many VCSE organisations are working on a neighbourhood, or place-based level, and many are supporting communities living with the greatest health inequalities in our region. These organisations are each a specialist in their own field, and they possess expertise which can and should be harnessed, plus they have trusted relationships within their communities.

The region has only one local specialist eating distress charity, EDNE, which supports people with mild to moderate eating distress without the need for a diagnosis. EDNE delivers one to one psychotherapeutic counselling, peer support, and psycho educational workshops; support for loved ones of those in eating distress through the New Maudsley Model Training course; and the delivery of a training and education

programme to raise awareness of eating distress and eating disorders, supporting early identification and intervention and improving recovery chances.

Currently EDNE are commissioned to deliver one to one counselling for service users in several places in the North East region, however the way in which these services have been commissioned have exacerbated health inequalities and limited the potential impact of their work.

Evaluation of EDNE's services is done through regular reporting and contract review meetings with contract managers within the ICB and AED PC. All reporting contains data relating to the number of people engaged and outcome measures and is available on request.

In addition to EDNEs local support, the national charity BEAT provides a range of services for those experiencing eating distress and their carers, all of which are delivered remotely. BEAT provides a helpline, chatrooms, online and hard copy resources. They also deliver a programme of interventions and training, some of which can be provided free of charge and others at a cost.

Their public sector offer is summarised on their 'Commission Us' page. Their resources area includes literature to support with contacting GPs, Binge Eating Disorder, BLAST Distraction Techniques, guides for family and friends, how to spot the first signs, and how to support a loved one to recover. There is also a reading list which includes both self-help books and books aimed at empowering those in the parent and carer roles.

What role could the VCSE sector play?

According to a 2020 paper by the NHS Confederation [1] the key considerations for working with the VCSE are:

- VCSE organisations are essential to the planning of care and supporting a greater shift towards prevention and self-care. They are key system transformation, innovation, and integration partners.
- Organisations across the VCSE sector are uniquely placed to support people and communities and are vitally important to COVID-19 recovery planning, supporting population health and reducing health

[1] www.nhsconfed.org. (n.d.). *How health and care systems can work better with VCSE partners | NHS Confederation*. [online] Available at: https://www.nhsconfed.org/publications/how-health-and-care-systems-can-work-better-vcse-partners.

inequalities. Deepening partnerships with VCSE organisations will be essential in supporting communities to rebuild and recover following the coronavirus outbreak.
- NHS organisations should maximise the social value they generate by working more closely in partnership with the VCSE sector.
- Local VCSE organisations need to be included in health and care pathways and service redesign planning across systems, including population health management and social prescribing in primary care networks.

Although the report focused on rebuilding and recovering from the COVID-19 pandemic, the key points are still highly relevant in relation to the role of the VCSE within Integrated Care Systems.

According to National Association of Voluntary and Community Action (NAVCA) [2] 'understanding the full value of the VCSE sector in improving health and wellbeing and harnessing it within ICSs alongside the NHS and local government, will help create the personalised, holistic, community-based and preventative health and care system envisaged in the Health and Care Act (2022)'.

Across England there are many examples within other health and care workstreams where the commissioning of VCSE organisations is playing a pivotal role in reducing pressures and costs for the NHS and Social Services.

There are many examples in the hospital discharge field, where VCSE input is reducing bed blocking and helping to move people back into the community with the correct support to be cared for at home. Two examples of these types of schemes are the delivery of the Yorkshire Home from Hospital service by Carers Plus, and the Healthy and Home project in Warrington and Halton. Both support in the step-down of patients who were previously taking up a hospital bed, ensuring they receive the right levels of support to enable the individuals to recover in their communities, and thus reducing the likelihood of re-admission. Initiatives such as this embed VCSE staff within multi-disciplinary discharge teams, with access to IT and shared data to ensure maximum effectiveness.

A local example of commissioning of the VCSE is through the Waiting Well programme, one of the healthcare inequalities programmes commissioned by the NENC Healthier and Fairer workstream. Waiting Well is a

[2] NAVCA (n.d.). *NAVCA*. [online] NAVCA. Available at: https://navca.org.uk/embedding-vcse-in-ics-1-1 [Accessed 3 Apr. 2024].

programme offering targeted support to certain groups of patients waiting for surgery in the North East and North Cumbria ICS. There is significant evidence to show that by taking some simple steps before surgery or treatment to improve fitness, diet, and mental health this helps patients make a better and quicker recovery post operatively. It also reduces the risk of their treatment being cancelled because of them not being well or fit enough to have the operation.

Funding was allocated by NENC ICS in 2023 to support the VCSE to deliver Waiting Well interventions to specific groups across the NENC region. The accountable body for this funding was Cumbria Community Foundation (CCF), who administered an open grants scheme for the VCSE sector, and CCF also sub-contracted all other Community Foundations in the region to support the delivery of the project. By utilising existing, well respected grant making bodies in the region, the ICS reduces the complexity of contracting many smaller VCSE organisations, and places the burden of due diligence onto the accountable body.

When speaking with Clare Edwards from Cumbria Council for Voluntary Service (CCVS) regarding how this project progressed, we heard there was 'significant learning' and a report by J Harvey Research Ltd [3] highlights the findings around engagement. Clare also highlighted how the same model has been used extensively within NENC ICS to deliver on other workstreams such as Suicide Prevention and Awareness, and Winter Pressures. These examples illustrate how investing resources in the VCSE can be streamlined to support better patient outcomes and can reduce pressures on the NHS whilst addressing specific workstream priorities. Within NENC ICS there are also several examples of similar programmes, managed by Community Foundations, funding the work of the VCSE.

NICE guidance [4] highlights the need for health and social care professionals to be trained and skilled in 'negotiating and working with family members and carers, managing issues around information sharing and confidentiality, safeguarding, and working with multidisciplinary teams.' Section 1.11.8 also refers to the need for inpatient or day patient services to collaborate with other teams (including the community team) and the person's family members or carers (as appropriate), to help with treatment and transition.

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[3] Waiting Well across the North East and North Cumbria Engagement Findings Report FINAL. (2023). Available at: https://northeastnorthcumbria.nhs.uk/media/c4xldnml/waiting-well-engagement-findings-report-final.pdf [Accessed 3 Apr. 2024].
[4] NICE (2017). *Overview | Eating disorders: Recognition and Treatment | Guidance | NICE*. [online] Nice.org.uk. Available at: https://www.nice.org.uk/guidance/ng69.

In the North East EDNE could add significant value and provide additional insight and skills in terms of multi-disciplinary teams. EDNE's future strategy contains key strategic objectives including the development of new services and working with children and young people (below the current age range of 16+). Services which could be delivered in partnership include:

- Peer support/mental health support workers for non-therapeutic one to one support including with social, volunteering and employment related needs.
- Workforce development pathway for professionals including Occupational Therapists, Dieticians, Psychologists, etc., offering placements and learning and development opportunities in working with people with mild to moderate eating distress.
- Counselling pathway specifically designed for family and friends of a loved one with eating distress.
- Holding onto Hope workshops for family and friends (EDNE's version of Maudsley).

In the process of speaking to colleagues from Provider Collaboratives across the country, it has become apparent that the 'good practice' examples regarding the commissioning of the wider VCSE (outside ED specific organisations) that we had hoped to highlight do not exist. All the Provider Collaborative contacts interviewed were intrigued by the Learning Community project and this research and recommendations. Most expressed their desire to have access to this report for shared learning purposes and felt that our conversation had provided them with ideas and a desire to undertake local research to inform how they might utilise their VCSE to a greater extent within the eating disorder pathway in future. We suggest that (based on the Provider Collaboratives that responded to our request) the NENC AED PC leads the field. Commissioning EDNE in 2023 to deliver this piece of work in addition to our main therapeutic services illustrates a progressive approach and we hope that this report affirms the importance of maintaining and growing the existing VCSE network, and capitalising on the connections and momentum built over the last twelve months to integrate the VCSE into the AED pathway.

The commitment by the NENC AED PC to invest in a project which supports the VCSE, helps to identify how their value can be maximised with a view to future commissioning is an example of good practice. We heard from Gary Sainty, Head of VCSE at Humber & North Yorkshire Care Partnership, that this is not always the case across the health system. He sees a difference between the ICS top-tier managers and those working within specific workstreams. "The executive team are fully supportive of the VCSE and have recently recruited more

staff to my team, all on permanent contracts, but then the heads of workstreams can take more convincing of the value and contribution of the VCSE."

An example of a Provider Collaborative struggling to know where to start is CONNECT: the West Yorkshire AED service. Beth Gripton, Clinical Lead and Lead Dietitian said that "CONNECT are this tier 4 gatekeeping service that is really hard to get into, or that's how it's seen. It has to be that way because we are only seeing the tip of the iceberg in terms of eating disorders, as that's the eligibility criteria that we have got. We haven't got the resource, I suppose, to see everybody, so we are trying to think about what could be available at lower levels across the system, and obviously we are thinking about what the VCSE could look like, but it's really difficult as we haven't got anything to build from at the moment."

NICE guidelines section 1.1.8 set a clear expectation that effective treatment for patients should address not just weight restoration, but all their recovery needs, and states that treatment should 'address their emotional, education, employment and social needs throughout treatment.' According to Sarah Burford, Clinical Lead for Adult Eating Disorders at the South West Provider Collaborative, most eating disorder treatment units historically have been focused on supporting people with Anorexia Nervosa (AN) with a focus on weight restoration. The wide range of organisations that make up the NENC VCSE Learning Community provide an opportunity for the Provider Collaborative to harness the skills of the sector to support patients throughout their recovery journey. There are organisations that can provide friendship and support, social activities, employment support, mindfulness and wellbeing sessions, cooking and nutrition, assistance with housing, support with benefits and finances, access to further education, and much more, all of which contribute to supporting the patient to lead a fulfilling and purposeful life. When speaking with Tom Capeling, then Chair of the NENC Lived Experience Advisory Group, he explained that he feels the focus of the Provider Collaborative moving forward should be to be on what is most efficient and effective for the individual. When considering the scope and capabilities of the VCSE sector it makes sense to harness the skills, knowledge, and capabilities of the sector to ensure that patients do receive community-based support with all their recovery needs.

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Key Issues and Recommendations

We have identified what we believe are the priorities for Adult Eating Disorder care, along with the relevant insights. For each priority, there is one key recommendation for consideration by the Provider Collaborative which we hope will be incorporated into the workplan moving forward.

Recommendation 1: Create collaborative pathways

Undertake mapping of the AED pathways with all partners and incorporate EDNE into AED care pathway.

From interviewing other VCSE specialist eating distress organisations we know that integrating the VCSE provider into the pathway can work well. Nerissa Shaw, Clinical Lead at South and West Eating Disorders Association (SWEDA) outlined that her clinical staff work with both CAHMS and adult mental health services and have good relationships with their Community Teams. They are invited to attend regular weekly case meetings to determine the best course of treatment for each patient and are “treated as an important part of the wider team.”

Kevin Parkinson, Chief Executive of First Steps ED said that where they have experience of being integrated with primary and secondary care pathways that “works really well, especially in early intervention and prevention, and particularly with children and their care givers.”

As the only specialist NENC charity, EDNE’s Counselling Lead Rachel Cowey was interviewed to provide insights into the experiences of their team. We can summarise what’s working well and challenges as:

What’s working well:

- It is recognised by system partners that EDNE can work with people unable to access other services due to criteria/commissioning arrangements, for example people with mild to moderate eating distress, binge eating and low risk Avoidant Restrictive Food Intake Disorder (ARFID).
- EDNE is invited to attend AED PC meetings and task and finish groups so the voice of the VCSE sector, and the people who use our services, are heard.

- Where EDNE has been copied into assessment appointment letters to service users from Community Adult Eating Disorder Services (CAEDS) when EDNE made the referral this has been helpful in supporting the client.
- When professionals within CAEDS spend time explaining why a referral has not been accepted and advising what information would be useful to put in referrals this leads to improved outcomes for people and collaboration across services.
- Good experiences of primary care include some GPs being very engaged and collaborative.

Challenges identified were:

- **Difference in referral procedures in CNTW and TEWV.** Within Durham & Tees Valley EDNE can refer straight into the AED service, but in CNTW EDNE must go through the local Community Treatment team. This can cause delays and issues with referrals being rejected with little detail.
- **Variable experiences of working with primary care including**
    - Being asked for advice on what kind of tests are required for physical monitoring and how often, or GPs/Nurses being confused about which blood tests to run.
    - Not responding to referrals from EDNE for physical monitoring or lack of communication regarding whether physical monitoring has started.

This results in EDNE counselling staff time being taken up with advocacy/admin work which impacts on clients. Where GPs can monitor physical health and work in partnership with EDNE, people can be supported within the VCSE sector when their eating distress is mild to moderate, which may prevent deterioration of eating distress behaviours.

A multi-agency approach, bringing the VCSE and NHS teams closer together, including EDNE attending MDT/regular meetings where relevant, would mean more background information could be provided (providing consent is given) and a discussion about how to provide the best care for individuals can take place.

This could also extend to step down pathways. Whilst sometimes a therapy break is important, when people are discharged, some people may benefit from pro-recovery counselling focusing on relapse management. In some cases, EDNE finds out that people have been in CAEDS, but they seek EDNE out themselves because they have had a relapse. A supported step-down process could minimise these occurrences.

VCSE involvement in step-down pathways was something identified by LEAG as potentially offering complementary support to IDS or IDS at home and could include:

- Services from EDNE
- Other VCSE support around dealing with stress, body image, cooking/nutrition, developing relationships, aspirations/employment, etc. (whatever is of most relevance/interest to the patient).

This was echoed by Beth Gripton from CONNECT in West Yorkshire. She said it is common for those discharged to be weight restored, but that the treatment hasn't addressed what it feels like to live in a bigger body and further body image work would be beneficial.

Mapping of all services across the AED pathway would also bring into focus gaps between services, which we know anecdotally exist, and support system partners to think about what needs to happen to meet the needs of everyone with eating distress/disorders.

Recommendation 2

Build an AED VCSE commissioning model based on collaboration and partnership, with appropriate investment and resources.

In November 2023, the National Council for Voluntary Organisations (NCVO) published the results of a survey entitled 'What is the true cost of giving to public services?' The survey revealed that with the funding they receive, 73% of charities cannot meet current demand for the public services they deliver. Whilst underfunding is not a new problem, the impact of continued high inflation has put charities delivering public service contracts at crisis point.

Speaking to Nerissa Shaw, Clinical Lead at South & West Eating Disorder Association (SWEDA) she echoed these concerns citing years of piecemeal and short-term funding and highlighting a Guardian article from

November 2023[5] which highlights how the built-in assumption that voluntary sector will deliver 'on the cheap' is placing the burden of funding on the VCSE.

We hope that the AED PC will work with the VCSE to support a new commissioning model. The Centre for Charity Effectiveness has undertaken research evaluating the vital relationship between health and care commissioners and VCSEs. The research explores VCSE sector and health and care commissioning relationships, practices, and experiences to better understand the realities of commissioning and where improvements could be made and how they can collaborate better. The results of this research are available as a series of briefings.

Briefing 1[6] highlights that 'some areas had fought to protect funding to VCSEs and commit resources, including time, to building and strengthening relationships with VCSEs. Financial 'investment' took many different forms from ongoing investment in local VCSE infrastructure, full-cost recovery, and longer-term multi-year contracts for VCSEs, to re-imbursing the costs of VCSEs participating in planning or co-commissioning activities.' Resources and investments were however only one of the enablers they identified, with much emphasis also being placed on leadership; shared agendas; organisational skills, capabilities, and cultures; proportionate rules; shared spaces and structures; networks; trust; transparency; interdependency; distributed powers; and wider influencing factors. Figure 3 within this briefing is particularly helpful in going into more detail on each of these enablers and outlining the implications for practice.

Real contract value commissioning, ensuring full cost recovery, over meaningful periods of time regarding outcomes (three to five years) need to be the norm, not twelve-month contracts which exacerbate insecurity in the sector and lead to staffing issues. Several contacts we have spoken to, including Gary Sainty, Head of VCSE for Humber & North Yorkshire Health and Care Partnership say that where connecting to the VCSE is working well is where they have set up VCSE Place Assemblies, which take place in all six places within Humber and North Yorkshire. Eating distress is part of the remit and local providers such as SEED (a specialist VCSE organisation based in Hull) sit around the table, plus other wrap around services, and work closely together.

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[5] Butler, P. (2023). English charities 'near insolvency' after subsidising public sector contracts. *The Guardian*. [online] 13 Nov. Available at: https://www.theguardian.com/society/2023/nov/13/charities-near-insolvency-after-subsidising-public-sector-contracts.
[6] https://www.bayes.city.ac.uk. (1AD). *Towards Collaboration: VCSE and health and care commissioning relationships*. [online] Available at: https://www.bayes.city.ac.uk/__data/assets/pdf_file/0006/761325/Health-and-care-commissioning-and-the-VCSE-sector-research-briefing-1-October-2023.pdf [Accessed Apr. 3AD].

The need for full cost recovery for commissioned VCSE organisations and longer multi-year contracts have arisen in many of the conversations we have with VCSE eating distress specialist organisations. All those who currently provide commissioned services have raised how much more sustainable and effective their organisations could become if these became the norm, especially in terms of recruitment and retention of staff.

Recommendation 3

Tackle place-based disparities in access to eating disorder/distress services across NHS and VCSE

NICE guidelines section 1.1.2. state that the NHS should 'Ensure that all people with an eating disorder and their parents or carers (as appropriate) have equal access to treatments (including through self-referral) for eating disorders, regardless of: age, gender or gender identity (including people who are transgender), sexual orientation, socio-economic status, religion, belief, culture, family origin or ethnicity, where they live and who they live with, and any physical or other mental health problems or disabilities.'

Our conversations within and outside of the region have highlighted that despite this guidance geographical disparity in access to treatment is widespread and not all communities are represented within services.

EDNE provides services to individuals and families across the North East, however we are not currently commissioned to deliver our services in Northumberland, South Tyneside, or Sunderland. This directly contributes to health inequalities in these locations where waiting lists are significantly longer.

Most of the Provider Collaboratives and VCSE specialist organisations we have interviewed have highlighted this issue. Beth Gripton at CONNECT highlighted that operating underneath the West Yorkshire AED PC are Bradford, Wakefield, Leeds, Kirklees, and Calderdale which all have their own place-based funding as well.

"There are variants in what is available depending on where you live, which is a shame. One of the consistent offers is Recovery College, which is free, and CONNECT do offer some support with the nutrition side of that for eating disorders, but again that's something that we are working on. Because we are based in Leeds and the original service evolved in Leeds then we can be quite criticised for being too Leeds-centric and not

offering an equitable service across the region, so we need to be careful and make sure the support we are offering to the Leeds Recovery College we are offering within all places."

During 2022 the NENC ICS allocated funding through the Healthy Communities and Social Prescribing workstream (part of the Healthier and Fairer sub-committee) to support the development of social prescribing infrastructure and support at a place-based level. The fund was administered through VONNE and was bid for and allocated to Local Infrastructure Organisations (LIOs). To ensure the fairest distribution of resources the funding was allocated using a formula which was developed by VONNE based on the health inequalities index and weighted by population of each local authority area. The development of a similar formula to help inform the commissioning and funding of EDNE counselling services could be an option but would require additional thought and data analysis to help determine how to ensure resources are allocated where the need is greatest, but this type of approach could address some of the sustainability and waiting times issues.

Recommendation 4 - Invest in education.

Sustainable training and education in eating distress/disorder is needed by a wide range of organisations across the NENC ICS area.

75% of learning community members stated that the organisations they are employed by are currently, or have previously supported, service users with eating distress, which indicates that the prevalence of eating distress and disordered eating in the general population is likely to be higher than previous estimates have suggested.

There appears to be a disconnect between EDNE's waiting lists for services and the lack of waiting lists for Intensive Day Services and inpatient beds. The eligibility criteria for NHS treatment means that substantial numbers of people living with mild to moderate eating distress are either not being supported at all or are being supported by/held within the VCSE and it is crucial that staff within these services understand how to recognise and respond to eating distress/disorders.

Early intervention aims to reach people whilst their illness is still in its early stages, providing interventions which could prevent deterioration, however if the resources allocated to early intervention programmes are insufficient, capacity within the sector cannot keep up with demand, and there is a higher risk that these

individuals will start to deteriorate. This could create a future surge in demand/need for NHS Intensive Day Services and inpatient beds, which are incredibly costly to the NHS and comes at the cost of people suffering from their illnesses.

During the delivery of this 12 month project, EDNE has increased the number of staff and volunteers employed within the VCSE with adequate training around eating distress, and as a result the sector is now better able to support those individuals within their settings, however with staff turnover in the sector being high due to short term contracts, relatively low pay, and financial insecurity, it is necessary to continue to provide free VCSE training to staff within the sector, to ensure that VCSE organisations can continue to improve their understanding and provide better person-centred care and support which will assist with early intervention and prevention.

EDNE have already identified they can continue to deliver to VCSE organisations for 2024/25 after which there is no identified funding for this recommendation.

From the number of non-VCSE individuals registering for the Learning Community we can conclude that regionally there is also a demand for access to training on eating distress/ disorders from other settings. There is significant demand from educational establishments such as schools, colleges, universities, and youth services. Although EDNE recognise that the Provider Collaborative only commission adult services, funding free and accessible eating distress training to staff within these settings will lead to greater awareness and confidence in staff, and is likely to result in children and young people with eating distress being identified and supported appropriately at a much earlier stage in their illness, potentially shortening the length of illness/treatment, and reducing the need for potential day treatments or hospitalisation.

In addition, those working in NHS personalised care roles, such as Social Prescribing Link Workers, Health and Wellbeing Coaches, and Care Co-ordinators, some of whom have joined the Learning Community, could benefit from access to free training on eating distress. This would assist in ensuring that more adults with eating distress are recognised and supported within the community at the earliest stage.

It is also interesting that staff working within eating disorder services in the NHS have joined the Learning Community. Four staff employed within CNTW already in eating disorder support roles joined the Learning Community, including a Psychologist, an Acting Specialist Nurse, and two Nursing Assistants. Another potential

target could be those providing prenatal and perinatal NHS services as Learning Community training and resources have also been accessed by staff working in this field within TEWV, evidencing the demand within health and care roles for specialist training.

During the project we also connected with most of the NHS Talking Therapies commissioned services in the North East. We believe that tailored training could support more NHS Talking Therapies services to work with people with non-medically risky eating distress/disorders, creating stronger referral pathways across to EDNE or stepping up to NHS services.

Primary care has been identified as having variable levels of awareness of eating distress/disorders. This has been highlighted by BEAT previously and EDNE has reported several challenges working with GPs, alongside examples of good practice.

Across the country we have found several Provider Collaboratives that have used specialist VCSE organisations to deliver training on eating distress. Lindsey Taylor-Crossley, Recovery College Principal and Carers Lead for Wakefield, highlighted that Battle Scars, a self-harm charity based in Leeds, used to deliver an eating distress training course through some of their Recovery Colleges on a voluntary basis, however unfortunately their capacity meant they could no longer offer this, so the Recovery College has not run these sessions for a couple of years. Hannah Kent, Clinical Manager for the West Midlands Adult Eating Disorders Provider Collaborative also explained that First Steps ED were commissioned to provide training for both their inpatient and outpatient workforces in the West Midlands.

Recommendation 5

Work towards implementing the Universal Personalised Care Model within AED pathway.

If resources were invested in providing a holistic package of support for people with eating distress/disorders, it would propel the region to the forefront of treatment.

People could choose from a menu of complimentary activities as part of their step-down, and with continued investment in CPD training all VCSE organisations providing services would be trained to an agreed level, and

with a move towards collaborative commissioning of the wider VCSE sector to deliver these services this would result in a more sustainable recovery journey for people.

A pathway would be based on individual interests, needs and goals, which is one of the key principles of personalised care. The Comprehensive Model of Personalised Care[7] has six key components.

1. Shared decision making.
2. Personalised care and support planning.
3. Enabling choice, including legal rights to choice.
4. Social prescribing and community-based support.
5. Supported self-management.
6. Personal health budgets and integrated personal budgets.

This document[8] outlines how the model is intended to be used. According to the report 'a total of 2.5 million people will benefit from personalised care by 2023/24, aiming to double this to five million people within a decade (2028/29).' The document states that PCNs will be a key delivery mechanism for this expansion, where social prescribing and shared decision making will be mainstreamed, but the NHS Long Term Plan made a clear commitment to expand personalised care and personal health budgets, with a specific expectation that personal health budgets will be offered within mental health services as part of plans for up to 200,000 people to benefit by 2023/24.

Guidance on the legal rights to have PHBs[9] listed four categories of patients who have a legal right to a PHB, which are as follows:

- Adult NHS continuing healthcare (NHS CHC)
- After-care services under section 117 of the Mental Health Act (1983)
- People in receipt of NHS wheelchairs

[7] www.england.nhs.uk. (n.d.). *NHS England» Universal Personalised Care: Implementing the Comprehensive Model*. [online] Available at: https://www.england.nhs.uk/personalisedcare/comprehensive-model/.
[8] NHS England (2019). *Universal Personalised Care: Implementing the Comprehensive Model*. [online] England.nhs.uk. Available at: https://www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model/.
[9] Guidance on the legal rights to have personal health budgets and personal wheelchair budgets. (2019). Available at: https://www.england.nhs.uk/wp-content/uploads/2014/09/Guidance-on-legal-rights-to-have-personal-health-budgets-or-personal-wheelchair-budgets.pdf.

- Children and young people's continuing care.

This suggests that any patients who have been through compulsory admission (under section 117 of the Mental Health Act, 1983) into NHS treatment are legally entitled to a PHB, but we have been unable to find any specific examples of the use of PHBs with ED patients during our research. All areas across England are expected to offer personal health budgets to additional groups of people, based on local need, including people with a learning disability and/or autism. Decisions about who can have a personal health budget outside of the legal rights are made by ICBs. Every ICB should have information made publicly available about who is able to access a personal health budget locally. The immediate challenges with embedding this approach would be:

1. Potential changes to way clinicians work with patients, ensuring incorporation of PC components 1,2,3 and 5 into the AED care pathway.
2. How to ensure provision of component 3, Social prescribing and community-based support within the AED pathway.
3. The financing of PHBs.

Personal health budgets (PHBs) are closely aligned to one of the central strands of service transformation in mental health: recovery and as such they present an interesting opportunity. As a highly personal journey, recovery depends on services being able to develop individually tailored approaches. PHBs are one component of the model that could be harnessed (in addition to commissioning) to enable patient choice and provide additional resources to fund access to holistic services delivered by VCSE organisations.

An example of how this could run in practice is the care farming sector. Care farms often provide services for:

- People with mental ill-health
- Young people excluded from school or on Alternative Provision
- Adults, young people, or children with learning disabilities or with ASD
- People living with dementia
- Ex-service personnel with PTSD (Post Traumatic Stress Disorder)
- People with a drug or alcohol addiction history

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Growing Well is based in North Cumbria and is a member of the Learning Community, benefiting from the support and online training that has been provided. Green care and care farming is one of the sectors where Personalised Budgets (the social care equivalent of PHBs) are utilised to pay for services delivered by VCSE organisations. The most recent care farming and green care annual report [10] states that 61% of care farms cater for service users with mental ill health. Figure 2.7 in this report, 'Referrals with (and without) associated funding', shows that referrals from social care and education seem to be better funded than those from health. Over 80% of referrals from i) Local Authority social services; ii) self-referrals via personal social care budgets; iii) Local Authority schools; and iv) SEN services, come with associated funding to pay for the service provision, compared to 30% or less from social prescribing and other health referrals. Although this option may not work for all VCSE organisations due to administrative burden of invoicing service users, it could be part of the solution if the Universal Model of Personalised Care was implemented in eating disorders services, facilitating access to PHBs for more people upon discharge.

Recommendation 6

Embed VCSE community-based support into all Individual Care Plans, and allocate resources to establish a VCSE AED commissioning fund, ensuring this includes provision for micro commissioning.

With relation to care planning and discharge from inpatient care, NICE guidelines section 1.11.11. suggest clinicians should 'develop a care plan for each person with an eating disorder who is admitted to inpatient care. The care plan should: give clear objectives and outcomes for the admission, be developed in collaboration with the person, their family members, or carers (as appropriate), and the community-based eating disorder service, set out how they will be discharged, how they will move back to community-based care, and what this care should be'.

Tom Capeling reinforced that LEAG very much advocates an integrated approach, blending NHS and VCSE services to provide for the needs of each individual.

[10] Bragg, R. (2022). *Annual care farming and green care survey 2021: Full report*. [online] Available at: https://www.farmgarden.org.uk/sites/farmgarden.org.uk/files/annual_care_farming_and_gc_survey_2021_-_full_report_final.pdf.

VCSE community-based support should be a fundamental part of each patient's recovery journey, and could provide both eating disorder unit teams and Community Teams with a much more interesting and varied menu of support than they can offer patients on their recovery journey, but until this principle is embedded as a formal part of the care planning process it is unlikely to happen because our research suggests the VCSE is not currently seen as part of the that pathway.

Beth Gripton explained that in West Yorkshire "when people go into the community from in-patient, they are very reliant on the Community Team to help them get back on their feet in life, and it's the Peer Support Workers who would be doing a lot of that social prescribing. We have two posts, and their role is very much around identifying what people might like to do outside of their ED identity and helping them test things out, like arts and crafts sessions."

Within Kent & Sussex they still have the very traditional model of care explained Sinead Wileman.

"When people are leaving hospital we would just expect them to be within their eating disorder Community Team and receive all of their eating disorder services from them, and then it may well be that they would have a referral to a mental health team or Community Mental Health Transformation (CMHT) or whatever if they have dual diagnoses, which 9 times out of 10 people do, or that they would go to an autism team, i.e. they would sit across a couple of teams who would come to their Care Programme Approach ready for their discharge from hospital".

She highlighted that the Community Teams prefer to keep services in-house and have never suggested working more closely with the VCSE, but:

"I am wondering now, at the time that we were talking about transformation, prior to commissioning Orri… whether or not that was just considered something that wasn't relevant to us in some way, because I do think the Community Teams see us as commissioning Tier 4 beds and that's it, and I don't know how far reaching it would be understood that we could have an impact commissioning wise…But in terms of prevention, it's definitely something I will think about."

Sinead also described how they rarely see patients now with only one diagnosis.

"It's unusual to have someone that has an eating disorder that isn't autistic or that doesn't have some other mental health condition. The idea that there is this traditional stand-alone eating disorder presentation is dwindling, so it's definitely becoming something more of a picture that it's sitting within trauma, sitting within these other things I think, and is part of a bigger picture, and that's why it's important to think of things the way you are, because it can feel like sometimes our patients sit within a bit of a vacuum, and their other needs aren't recognised".

With the recognition of the traditional stand-alone eating disorder being less common, there is an opportunity to recognise and engage the specialist support and additional capacity that VCSE organisations working within mental health and learning disability and autism can potentially provide.

There is an emerging discussion about whether services should have separate pathways for people with ED and autism and this is something which needs further exploration, and the VCSE sector can be part of.

One of the questions the Provider Collaborative asked was around how they can better support and engage local AED support groups and networks that may not be formally connected to part of a VCSE organisation. EDNE has engaged with very few ED specific peer support groups in the region, demonstrating that there is a gap in this area of AED support. Making provision for a VCSE AED fund for simple applications to support the establishment, running costs, and promotion of new or existing support groups should be a priority.

One member of the Learning Community is Katherine Jones from Teesside ARFID Parent & Carer Support Group. This is an example of an informal organisation borne out of one parent's desire to support others as there is no clear ARFID support/pathway, so many parents are desperate for help. Katherine has been doing a fantastic job of supporting parents from across the NENC region who are willing to travel some distance to the messy play sessions the group hosts monthly on the premises of, and in partnership with, Hartlepool based organisation Make Believe. The cost of buying food and resources is significant so they currently charge families per child which means some families struggle to afford the session, especially when they must bring siblings with them too.

Funding to support this vital work would be hugely impactful for those children and families. Katherine is working towards formalising the organisation with charitable aims to potentially access funding to sustain and grow their services. We appreciate that this organisation is not currently supporting adults however the

Learning Community provided a mechanism for them to access free training and support, and as the children using these services grow older, they may be the AED patients of tomorrow, so it really is an opportunity for early intervention.

Kerry Carruthers runs West Cumbria Eating Disorder Parent and Carer Support Group. Kerry feeds into CNTW involvement bank, the Children and Young People's Lived Experience Advisory Group, and Provider Collaboratives. Although Kerry does not reside in the NENC region, she provides virtual support to anyone who wants to join their group, including people from within the NENC region. Kerry, like many parents who set up a support group, was initially seeking help herself when her daughter developed an eating disorder but found nothing suitable. She decided to establish a group herself to try to be a lifeline for other parents going through the same as her. Kerry runs a Zoom support group on the second Wednesday of every month, but said she has capacity for more frequent meetings. Kerry currently receives no funding for this group but has borne the costs herself and has won recognition locally with a volunteering award for the work she does. Providing accessible micrograms for these types of informal organisations would be a step forward and encourage more people with lived experience to develop this community and support others.

We have also supported six formal recovery organisations including Overeaters Anonymous (OA), Recovery Connections, Change Grow Live (CGL), Changing Lives, ReCoCo, and more recently SMART Recovery. Recovery Connections, CGL and Changing Lives are larger regional players focusing on recovery from drugs and alcohol, and all three benefitted from free training through the Learning Community and were interested in being part of the AED pathway in the future.

OA is an international organisation which runs a twelve-step programme like that of Alcoholics Anonymous based on abstinence. They were happy for AED services in NENC to signpost individuals to them for meetings and their online resources, which include resources for health professionals with evidence-based information. SMART Recovery is also an international charity that works closely with organisations such as CGL, Changing Lives and the Prison Service. SMART Recovery can support anyone with any type of addictive behaviour, and their content is not split by subject. People can self-refer, and they provide a programme of abstinence orientated self-study and mutual aid meetings.

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Appendices

Appendix 1 – List of external contacts

Name	Job title	Organisation
Dr. Rachel Bryant-Waugh	ARFID Clinic Lead/Consultant Clinical Psychologist	Maudesley Centre for Child & Adolescent Eating Disorders, South London & Maudesley NHS Trust
Sarah Burford	Clinical Lead, South West Adult Eating Disorder Provider Collaborative	Devon Partnership NHS Trust
Tom Capeling	Chair, NENC Lived Experience Advisory Group	LEAG
Clare Edwards	Health Partnerships Manager	Cumbria CVS
Beth Gripton	Clinical Lead and Lead Dietitian for CONNECT: The West Yorkshire Adult Eating Disorders Service	Leeds and York Partnership NHS Foundation Trust
Hannah Kent	Clinical Manager	West Midlands Adult Eating Disorders & Perinatal MH Provider Collaboratives
Iona MacTaggart	Community Engagement Co-ordinator (not quoted in report, no consent requested)	SupportED
Kevin Parkinson	Chief Executive	First Steps ED
Gary Sainty	VCSE Programme Manager	Humber & North Yorkshire Health & Care Partnership
Nerissa Shaw	Clinical Lead	South & West Eating Disorders Association (SWEDA)
Lindsey Taylor-Crossley	Recovery College Principal and Carers Lead for Wakefield	South West Yorkshire Partnership NHS Foundation Trust
Sinead Wileman	Quality & Safeguarding Lead, Provider Collaborative for Kent and Sussex Adults Eating Disorder	Sussex NHS Foundation Trust