



# SAFE SPACE FOR MAKING SENSE OF EATING DISTRESS

Eating Distress North East: Evaluation Report  
June 2022

In the report:

- Eating Distress North East is generally abbreviated to EDNE.
- Quotes are indented.
- Most quotes are from people who have used EDNE services, and they are not labelled. Quotes from partner organisations are followed by (Partner); (EDNE) identifies quotes from people who are part of the team; quotes from archive materials are shown by (Archive).
- Literature references are presented in footnotes.
- Footnotes are used to explain and/or expand, outside of the main text.
- Report sections can be read in any order. Each of the five main sections starts on a new page.

Thank you to everyone who took part in the evaluation, giving generously of their time.

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## 1. Summary

Voices of people with experience of eating distress are foregrounded in the report. Their words show the value of having space to make sense of what they do with food, as a first step in getting on with their lives.

Eating Distress North East<sup>1</sup> offers empowering support around eating distress. Some participants described it as: 'life-changing'; 'a big turning point'; 'a lifeline'; 'support that kept me alive'; focusing on 'wellness and hopefulness, and a sense of being able to live your life'.

EDNE has sustained and developed specialist provision for more than thirty years. Set up at the end of the 1980s, it was promptly recognised as an example of good practice<sup>2</sup>. EDNE's overarching achievement through the evaluation period is its provision of safe, effective services during a global pandemic. It met all targets that were achievable in this crisis situation.

The introduction to this report is followed by a second section which draws extensively on the words of service users, showing the value of EDNE's provision for people experiencing eating distress, and those supporting them in a personal or professional capacity. People's accounts illustrate the process of making sense of eating distress, and the difference this makes in their lives. Section 3 situates EDNE in the national health policy context, as an invaluable partner in the current collaborative approach to transforming mental health care. Section 4 is the final part of the report and discusses EDNE's next steps.

Appendix 1 is an example of EDNE feedback on outcomes, for funders.

Appendix 2 outlines the evaluation process.

Appendix 3 is an overview of the organisation's beginnings, 1988 to 1995.

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<sup>1</sup> EDNE is a registered charity and company limited by guarantee, with an office, counselling room and use of a group/training room in a base in Newcastle city centre. People experiencing eating distress, over the age of sixteen and living in Tyne and Wear, County Durham or Northumberland, can contact EDNE directly by telephone, text, email, letter or Facebook. The team includes part-time employees: Chief Executive; Counselling Lead; Training Officer; Admin/media assistant; Office Manager; sessional counsellors; Mindfulness trainer. EDNE's organisational governance is overseen by a board of volunteer trustees who bring a wealth of experience from their professional roles across sectors.

<sup>2</sup> EDNE is referred to in: Good Practices in Mental Health, 1994, Women and Mental Health Pamphlet 8: Services for women who self-harm or misuse food, alcohol or drugs, pp.8-9, GPMH in collaboration with the European Regional Council of the World Federation for Mental Health, supported by Joseph Rowntree Foundation. In 1995 EDNE (under its original name of NIWE) received the mental health section Health Alliance award from the Northern and Yorkshire Regional Health Authority.

## 2. Introduction

People with eating distress are part of the national statistic of one in four with a mental health problem in any year<sup>3</sup>. Though experience of mental ill-health is widespread, it is often hidden because of stigma<sup>4</sup>, and people can struggle to find help when they need it<sup>5</sup>.

EDNE began as a specialist service in 1988, as UK media were starting to cover eating distress<sup>6</sup>, a subject that continues to feature. In a 2019 Guardian article actor Christopher Eccleston discussed his autobiography, *I love the bones of you*, in which he wrote that he had not previously revealed his eating distress because “I always thought of it as a filthy secret, because I’m northern, because I’m male and because I’m working class”. Singer Taylor Swift explored her eating difficulties in a documentary, January 2020. In March 2021 a Guardian article discussed several music artists’ experience of eating distress, and in April of that year the media reported the deaths from eating distress complications of celebrity Nicki Grahame and journalist Sushila Phillips. In a 2021 BBC radio programme<sup>7</sup>, Richard Osman, author and television presenter, talked about having professional help to understand connections between his issues with food and his having shut down feelings in response to a family crisis that happened when he was young. He said: “I’m either controlling it (ie what he refers to as over-eating) or not controlling it at any given time, and these days I control it more often than I don’t, but it’s actually quite hard and sometimes you do slip, but I try my best and I certainly have no shame about it now”.

EDNE’s theoretical base is that people who damage themselves do so for a reason. Some service users have a diagnosed eating disorder, and some feel they do not easily fit diagnostic criteria. Since the 1980s EDNE has provided a service for anyone experiencing extreme anxiety around food and eating. In the words of evaluation participants:

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<sup>3</sup> The section of the NHS England and NHS Improvement website on adult and older adult mental health highlights that people ‘in all walks of life can be affected, and at any point in their lives’, and that problems with mental health represent the largest single cause of disability in the UK, accessed 1 February 2022.

<sup>4</sup> NICE guidance highlights the need for awareness that eating distress might be a difficult thing to discuss because of feelings of stigma and shame, National Institute for Health and Care Excellence, 2017, Eating Disorders: Recognition and treatment, Guideline NG69, last updated 16 December 2020.

<sup>5</sup> Mental Health Taskforce, 2016, The Five Year Forward View for Mental Health: A report from the Independent Mental Health Taskforce to the NHS in England.

<sup>6</sup> In a 1992 Guardian article, *Hunger without a name*, Susie Orbach referred to food and body image as “a central issue in many women’s lives”.

<sup>7</sup> The programme, *Desert Island Discs*, broadcast 26 December 2021, is available on BBC Sounds.

This organisation is specialist. They ‘get’ this subject. They do it day in and day out, and this is where you should go.

They complement statutory service provision. They support people to become independent from services, engaging them in different ways and moving them on. (Partner)

Currently, EDNE:

- offers one to one counselling, and wellbeing sessions<sup>8</sup>, to adults with eating distress;
- provides counselling for students, in partnership with Newcastle University<sup>9</sup>;
- supports family members and friends with information, signposting, bespoke training, and group sessions;
- facilitates awareness-raising sessions with young people, focussing on early intervention and prevention<sup>10</sup>;
- builds professionals’ awareness and understanding of eating distress, and confidence and capacity to offer appropriate support, eg EDNE developed a training programme for physician associates in partnership with Newcastle University<sup>11</sup>;
- is an influential strategic partner in developing and improving services.

Eating distress is an area of mental health with particular challenges, as highlighted in the most recent guidance from the National Institute for Health and Care Excellence<sup>12</sup> and in recent research<sup>13</sup>. Successive EDNE reports and external evaluations have recorded the outputs and outcomes achieved.<sup>14</sup>

It’s a difficult area of work and hard to measure achievement. The team

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<sup>8</sup> At the point of the evaluation report being completed, EDNE wellbeing workshops had been suspended due to funding constraints.

<sup>9</sup> Students experiencing eating distress can access up to twenty counselling sessions after assessment within the university. They can also take part in health and wellbeing workshops.

<sup>10</sup> EDNE has developed resources with young people, for example a series of videos accessible via the EDNE website, [edne.org.uk](https://edne.org.uk).

<sup>11</sup> Physician associates are trained to a higher level than nurse practitioners.

<sup>12</sup> NICE guideline NG69, Eating disorders: Recognition and treatment, published 23 May 2017 and last updated 16 December 2020.

<sup>13</sup> Esmaeil Mousavi Asl and colleagues describe eating disorders as posing a serious challenge for mental health services, Mousavi Asl et al, 2021, Assessment of eating disorder psychopathology, Journal of Research in Medical Sciences, 26:71; Antoni Grau and colleagues similarly refer to the complexity of eating disorders, Grau et al, 2020, Using routine outcome monitoring in eating disorders, Conference, 28th European Congress of Psychiatry.

<sup>14</sup> Targets specific to different funders are not discussed in this report.

understands that and still tries to find ways of showing recovery. (EDNE)

EDNE uses a validated scale to measure pre-and post-counselling levels of mental health. In summer 2019 trustees wanted to know more about the difference the service makes, and commissioned an evaluation. Themes that emerged from analysis of the data produced by one hundred and one participants, show how EDNE supports positive change.

### **EDNE's achievements in context**

The following quotes illustrate EDNE's achievement in sustaining and developing service provision in a complex area of mental health, against a backdrop of insecure funding and repeated reorganisation of the NHS and commissioning.

Shortly after EDNE began, Youth Clubs UK published The Food Mood Guide in the 1990s. The introduction explained:

... the food is not the problem in itself. It is being used to mask a range of emotional problems. The key is to continue to make links between food and feelings, raising awareness about the difficult feelings which are being played out through food. (Archive)

The following excerpt from the minutes of EDNE's 1995 Annual General Meeting describes the address given by a local person, Denise Robertson, national writer and broadcaster<sup>15</sup>:

She spoke of how food had dominated her life, a hatred of food, feeling that she wanted to divorce herself from eating. She had never, as an adult, put food into her mouth without hating it, feeling guilty about it. Denise now thinks about food a lot less and still resents it being a constant theme, but she is not frightened or angry any more and is a great deal closer to understanding why food is in so many of the letters she receives. (Archive)

The foreword to the 1998 Staff Handbook by Jan McGregor Hepburn, a psychoanalytic psychotherapist who supervised workers and consulted with the whole team from 1989 to 1993, shows the complex issues with which EDNE works:

Organisations reflect the dynamics and motifs of the dominant issue in their work, driven by the difficult and painful feelings evoked by the issue. This organisation has a very problematic set of feelings and dynamics to contend with: anger and fear, covered by guilt and shame, which is then

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<sup>15</sup> Denise Robertson was part of the [ITV](#) show This Morning team from 1988 until her death in 2016.

covered by more ‘civilised’ or ‘professional’ attitudes. Feelings within the organisation are likely to be very powerful, with a lot of anger and fear being evoked from time to time. The team has always held on to the understanding of the processes I have just described, although at times it is extremely difficult, and has held on to the core belief that the use of food has internal meaning, and this can be understood ... users are treated with respect while being offered help to understand their own use of food. (Archive)

Along with the level of complexity inherent in the work, the EDNE team has recently had to respond to additional layers of challenge. During the first months of the evaluation trustees and team members talked about having just come through a period of change, with people leaving and joining, responsibilities shifting, and new systems being introduced. Six months into the evaluation, the World Health Organisation announced a global pandemic.

A body of evidence shows how the pandemic has: exacerbated existing inequalities<sup>16</sup>; significantly affected those already living with mental illness<sup>17</sup>; and made day to day life more difficult for people with problems around eating as they have negotiated restriction of movement and social contact, food insecurity, and reduced access to support<sup>18</sup>. Issues for young people have been highlighted<sup>19</sup>. Many family members and friends have faced increased demands, and/or new challenges<sup>20</sup>:

People working from home during the pandemic have seen more of what’s happening in their families than ever before and they’ve seen it close-up, including eating distress and other self-harming behaviour. They need specific support. (Partner)

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<sup>16</sup> For example: Clare Bambra et al, 2020, The COVID-19 pandemic and health inequalities, *Journal of Epidemiology and Community Health*; Richard Blundell et al, 2020, COVID-19 and inequalities, Institute for Fiscal Studies and Nuffield Foundation; Michael Marmot et al, 2020, Build Back Fairer: COVID-19 Marmot Review, The Pandemic, Socioeconomic and Health Inequalities in England, Institute of Health Equity.

<sup>17</sup> British Medical Association, 2020, The impact of COVID-19 on mental health in England: Supporting services to go beyond parity of esteem, <https://www.bma.org.uk/media/2750/bma-the-impact-of-covid-19-on-mental-health-in-england.pdf>.

<sup>18</sup> Dawn Branley-Bell and Catherine Talbot, 2020, Exploring the impact of the COVID-19 pandemic and UK lockdown on individuals with experience of eating disorders, *Journal of Eating Disorders* 8:44.

<sup>19</sup> A government study found that the proportion of children and young people with possible eating problems increased between 2017 and 2021. Rates were gender related, with girls and young women having higher rates across all age ranges., NHS Digital, Mental Health of Children and Young People in England 2021, wave 2 follow-up to the 2017 survey, p.20.

<sup>20</sup> Fernando Fernandez-Aranda et al, 2020, COVID-19 and implications for eating disorders, *European Eating Disorders Review* Vol 28 Issue 3, <https://doi.org/10.1002/erv.2738>.

EDNE's overarching achievement over the last two years is to have continued safe and effective service provision. The team did this while every client and everyone working with the organisation was experiencing disruption, restriction, and uncertainty<sup>21</sup>, and many people 'dropped off the radar' of their support provider organisations<sup>22</sup>.

A British Medical Journal article<sup>23</sup> published as the pandemic emerged, referred to some primary care teams being anxious about what might happen, and others being fired up. In EDNE evaluation interviews people working in partner organisations mirrored this range of response. They talked about an abrupt shift in ways of working, with effects including a positive curve of "learning through having to do", together with increased anxiety, and amplification of existing tensions within teams. Against this background EDNE has kept on providing an effective service, in and out of national closedowns:

Not one of the counsellors is responding to the continuing pandemic by saying: "I can't do that". They are always looking for solutions. We have great potential within the team. (EDNE)

It is admirable the way EDNE has managed the contract and has stepped up. It moved quickly as an organisation in response to the global pandemic. (Partner)

The team met all targets, apart from those that could not be achieved because of pandemic measures, eg some work planned with young people had to be postponed. The Training Officer arranged and facilitated on-screen awareness raising sessions for students in school/college/university settings, and training sessions for professionals. EDNE welcomed new trustees, expanding the board's range of professional experience. The trustees managed changes within the team and recruited to several posts, widening the spectrum of worker experience and bringing in new energy and ideas.

During an unprecedented time of crisis EDNE has continued to work in partnership to develop understanding of eating distress and improve service provision, including:

- collaboration with the NHS and the Children's Society to develop work in schools;
- production of eating distress resource packs for teachers;

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<sup>21</sup> Public Health England, 2021, Guidance for the public on the mental health and wellbeing aspects of coronavirus (COVID-19).

<sup>22</sup> Chris Pascal et al, 2020, COVID-19 and Social Mobility Impact, Research Brief 4, Sutton Trust.

<sup>23</sup> Jacqui Thornton, 2020, Covid-19: How coronavirus will change the face of general practice forever, BMJ 2020;368:m1279, published 30 March 2020.

- expansion of counselling provision, including introduction of sessions over the summer, with Newcastle University;
- collaboration with Northumbria University in eating distress research.

**Participants in the evaluation:** One hundred and one people took part.

- Thirty-eight people, each with experience of a range of difficulties with food and eating, participated: thirty-six women and two men
- Thirty participated in an interview, with most interviews being in-depth in terms of how people spoke about their experience of eating distress and support they have received
- Eight gave feedback in group sessions that were observed by the evaluator
- Participants' ages ranged from early 20s to 70s
- Participants live across postcode areas of Newcastle, North Tyneside, Gateshead and Northumberland, including some of the most economically disadvantaged parts of the north-east
- This self selected group reflects the demographics of EDNE users, ie mainly white women<sup>24</sup> across a broad range of age and postcode.

Participants also included:

- Six in the family/friends category, describing the difference EDNE has made for them
- Thirty people who gave feedback about training/awareness-raising sessions
- Ten professionals in partner organisations who gave their views of the value of EDNE's service provision
- Seventeen who have been/are part of EDNE management and staff teams.

Participants who work/have worked in partnership with EDNE, and participants who have commissioned training and awareness-raising sessions, represent a wide range of organisations across NHS, community and voluntary, education, and local authority sectors, including:

- General Practice
- Clinical commissioning
- Primary care management
- Mental health transformation management
- North-east clinical network management
- Public health
- Health visiting

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<sup>24</sup> It is important to note that people in ethnically minoritised groups experience disparities in accessing all mental health services, MIND, 2020, Briefing on inequalities for Black, Asian and Minority Ethnic communities in NHS mental health services in England. EDNE works with statutory and third sector partners to improve information about services and access pathways for people across majority and minority communities. One example of EDNE's development work: Greggs Trust funded outreach to raise awareness of eating distress among women in ethnically minoritised communities. The focus was in west Newcastle, which has some of the city's most economically disadvantaged wards. Sessional workers brought diverse language skills, including in Urdu, Farsi, Mirpuri and Punjabi. They worked to break down barriers to accessing services. Outreach has continued with women via existing groups, for exploration of eating issues in safe environments.

- School nursing
- Public services audit
- Community development
- Social prescribing
- Counselling
- Mental health support
- Occupational health
- Children's and young people's emotional health and resilience support
- Nursing
- Early help for children
- Youth work
- Support for families affected by domestic abuse
- Support for women affected by sexual violence
- Support for carers, including young carers
- Human resources
- Schools
- Colleges
- Universities.

### **Evaluation questions**

The research questions did not introduce any of the words that people used to describe their experience with EDNE.

Questioning was open and, depending on the participant, began with:

- How did it happen that you got in touch with the organisation
- How did you come to work here
- How did it happen that you came to commission a training session.

Further questions included:

- Could you tell me about the sort of support you have had from EDNE, and any difference it has made
- Is there anything that could be improved.

### 3. Safe space for making sense of eating distress: People's voices

This section includes quotes from people with experience of eating distress, and from those supporting them in a personal or professional capacity. It was difficult to decide which quotes to select from so many powerful accounts.

The voices represented in this section mirror key statements below, from the introduction to 2019 NHS guidance for commissioners and providers of services for adults with eating distress<sup>25</sup>. The guidance was developed with people with experience of receiving treatment for an eating disorder, and reflects what they need from services:

I want professionals to show compassion, understanding and trust.

Professionals who are working with me will understand how eating disorders can affect people differently.

I will receive collaborative, person-centred treatment that is focused on my needs and not just my weight or BMI, to help me recover mentally as well as physically.

I will not have to feel like I have to become worse to be seen.

Services will understand the distress we (families and friends) can experience and will help us to get support for our own mental and physical health.

EDNE has been providing this level of quality of service since it began in the 1980s. In the first organisational progress report, 1989-1993, service users identified the importance of being supported by professionals who understand the complexity of eating distress:

It's good to be able to talk about my eating and know I'll be understood and not judged. (Archive)

Talking about my difficulties with food has opened up many areas of thought and I feel I'm beginning to be able to deal with things hidden behind the eating problems. (Archive)

A 1994 Good Practice in Mental Health resource highlighted EDNE's non-judgmental, respectful and thoughtful approach. Service users said that they felt they were seen as people, not problems.

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<sup>25</sup> NHS, 2019, Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care: Guidance for commissioners and providers, published by the NHS, the National Institute for Health and Care Excellence (NICE), and the National Collaborating Centre for Mental Health, p.4.

## **Voices of people experiencing eating distress**

The adjectives 'safe', 'non-judgmental' and 'comfortable' were used consistently across interviews, as people described the EDNE environment:

I rang up crying and said I needed some help, and they took that at face value. It's a safe space to talk at your own pace. I felt comfortable.

I remember how comfortable I felt when I came here. There was dignity. They don't judge you, which is very important because you've already got a downer on yourself and you don't look at yourself in a good light. They say that you're worth it and then there's light at the end of the tunnel.

I talked more about the eating problem to the person who did the assessment than I've talked to anyone in the last twenty years. The environment was lovely and calm, and it was a really comfortable experience.

The counsellor made me feel very comfortable and I felt safe. I certainly wasn't judged.

I found the counselling sessions really helpful and felt comfortable there, even though it was difficult.

It gave me safe space that was non-judgmental, to make sense of it<sup>26</sup>.

Participants referred to particular aspects of service provision that have helped them feel confident in using it, including prompt response:

I realised I didn't have a healthy relationship with food ... one day I felt the need to sort it out because it had been going on for a few years. I'm a student in Newcastle and I searched online and found them. I emailed and they replied quickly. I filled out an online form and got another quick reply. The process was very clear.

I made an online referral for myself after a workshop they did where I was studying. There was a quick response and assessment appointment.

I rang and left a message, and someone phoned back quickly and discussed what was available.

There was appreciation of the clarity of EDNE's information about what is on offer:

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<sup>26</sup> The report tile was taken from this quote.

They are very clear about what they do and what they cannot do, and what their limits are. They emailed me some information so I could make sure the service was for me. I felt I could trust them.

Everything was discussed and laid on the table. I knew the limits. I knew there was a wait but it didn't feel too long, and they were calming and completely honest, not promising anything they weren't going to give me.

Some interviewees highlighted the flexibility of provision. Others commented on the competence and compassion of people in the team:

They were flexible with appointments where they could be. So I could arrange counselling sessions on my way to work.

I went to a wellbeing workshop. I was anxious beforehand and went along thinking: "Who is it who's leading this session, is it someone with just a bit of experience". I was blown away by the professionalism and the level of expertise.

It was a safe space for me to comfortably explore my relationship with food. It's an important organisation that has compassion, and understands the severity of eating distress, that it's potentially life-ruining.

Participants talked about the value of EDNE support in reducing isolation, providing opportunities for trying things out, and building a sense of hope:

I think a big thing about eating distress is it's such a secretive thing. This has been the first time I didn't feel alone with it. It has literally changed the quality of my life.

I was first in touch when it was set up in the late 1980s. I liked to be in the loop of what they were doing but I didn't use the service. Then I got poorly. Now I'm back in touch and I've been going to group sessions. Knowing you're in a group, even online, helps.

I think one of the things that changed me was the counsellor making me feel that I wasn't alone. I was feeling lonely, and it was fairly dark. The counsellor reassured me that there are other people in this situation.

Eating disorders are very isolating and they limit your social opportunities. In all the groups the focus is on wellness and hopefulness, and a sense of being able to live your life. Some of the activities give you the rare

experience of sitting still and concentrating and producing something. It was something I'd never done before. I went to a dance session and that was a way of connecting with my body, feeling better and better in it, and enjoying it and having fun. It was good to do that in a safe environment. For someone like me, who struggles to put things into words, it was good to do it through moving around. You're not getting that anywhere else.

EDNE offers intervention at the earliest possible point for people who feel they are affected by their relationship with food, and at the same time it has clearly defined parameters in relation to access to service provision. This adds value in the context of people with eating distress having to wait a long time for statutory sector treatment<sup>27</sup>, and/or not fitting criteria:

I don't meet the requirement for the NHS. You have to meet criteria like low BMI and being very unwell.

With the NHS, I had already done a lot of thinking about things and was feeling anxious about going to see my GP, and when I went and said: "I think I have an eating problem and I think I need help", they said: "We don't think you do". I felt crushed and I was so exhausted. When I got in touch with them (EDNE) they said I could have an initial assessment, and it happened quickly. That felt open and approachable. If this service wasn't here I don't know where I'd be.

You feel you have to be more ill to get NHS treatment. Here (EDNE) if your BMI isn't high enough you can't access help, and that's an incentive to take some responsibility for yourself if you can.

Interviewees expressed appreciation for EDNE's service provision as part of a locally joined-up approach:

I'm still under (NHS service) and this (EDNE) is a lifeline now. I'm due to have some counselling here soon.

It feels like joined-up help, the GP and what I get here (EDNE). It got so bad, it was affecting everything I did. Now I'm doing things myself. I'm thinking about what I'm eating. In the last month I haven't made myself sick or taken laxatives. I see my GP every month because of depression and I can get an emergency appointment if I need one.

Some participants described being held by EDNE support in ways that prevent crisis:

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<sup>27</sup> Royal College of Psychiatrists, 2020, Two-fifths of patients waiting for mental health treatment forced to resort to emergency or crisis services. One of the findings of the UK survey reported on in this briefing is that respondents with severe mental illness, including eating disorders, are waiting up to two years for treatment.

For this year they've set out a map of group sessions every two weeks. That is very helpful, that things are all arranged, it's a lifeline. Getting that regular support, I'm hoping it will chip away at how I'm feeling.

It's helped me concentrate on what's happening now, and on going forward. It's maintained me. It has helped me not to go down that awful hole.

The sessions keep me balanced. The service stops you falling through the cracks.

There was exclusively positive reference to digital access to EDNE service provision, although several people expressed initial reservation because of unfamiliarity. This feedback highlights the opportunities that remote provision can open up for some people to connect with the support they need:

Everything was online and I don't like that, but actually they managed it very well.

The option for texting is very useful when you don't feel you can speak with anyone.

I've had weekly sessions via Zoom. I know how to manage my stress more now, and the big high walls have come down. I don't hide away as much and I'll show my emotions. If I'm feeling emotional I can show that. It was a bit strange at first on Zoom and now it's normal. They made everything as good as it could have been done. They set up online counselling very quickly so that people weren't on their own. Then I had counselling, face to face first and then a seamless shift to online. Online sessions worked well. Sometimes my internet connection didn't work well and there was no problem going over to a phone call.

Before the pandemic I'd never used online. What's good is knowing you can switch yourself out for a bit.

The online group sessions felt like a lifeline. I'm out and about travelling for my job, so I can do them from my hotel room. One of the main things I get from them is mental wellbeing and relaxation.

### **Making sense and making changes**

Words of people with experience of eating distress are quoted extensively in this section to illustrate the process of making sense and making changes.

One of the EDNE counsellors emphasised that steps that might seem small are actually huge ones for the people who are taking them. An important step

described by participants was getting support to think about the meaning of their relationship with food, enabling them to move forward in positive ways:

It's been life changing. I can't describe how it feels to have switched mindset to: "I'm worth it" at my age (over 50). Food used to be a reward for being good when I was little, and it's what I would always turn to. My whole world started to revolve around food. I would go to food and grab it, and now I say to myself: "Do you really want it?". Coming here was not just like putting a plaster over something, it was about healing it. I have a deeper understanding of things and I enjoy food now. To be able to change fifty years of thinking is mind-blowing.

The counsellor's been helping me to get to the bottom of why, and helping me to process it. Something has just clicked and I'm so much better now than I was. For me it was a space to talk about myself and be a bit selfish. One really good thing I got was verification: "Yes, it makes sense that you feel like that". I think I was taught to manage stress with food. The counselling helped me recognise I had a problem, and that happened in a short space of time. I never expected that. If I don't eat much now, I ask myself: "What's going on?".

They don't delve in, they say: "You talk about what's going on", and it's like peeling an onion. It's about working on thoughts, not on food itself. In the sessions there was a sense of getting things out and leaving them behind. I am starting to enjoy food now and I feel like I am on track. I couldn't have managed without coming here. It gave me a way to talk about things with my family. I genuinely think this place has kept me alive. I have a sense of hope now.

Several people described the process of being supported to make sense of their eating distress as untangling and unravelling, developing their understanding of connections between feelings and using food in particular ways:

They said: "Let's step back and look at the big picture". They bring you out of yourself, which is massive, because you tend to get insular in your own head. It felt as though the counsellor helped me to uncomplicate things, then it's little bits that can be dealt with easier. They know how to unravel us. This literally has been a lifeline. They work around: "Why?". They don't focus on the eating. It's why you're doing what you're doing. I recognise now that it's about control.

The counsellor left silence at the right times so I could manage to unravel my own thoughts.

I was worried when I first went that everything would be restricted to talking about food and eating, but it was somewhere to explore

connections. It helped me understand what was going on.

I used to struggle to know what a feeling was, and to feel things. Understanding that was the big thing, understanding how I'd got to where I was. It's got nothing to do with food, but that's how it's been coming out. Instead of being a person with an eating disorder, I was a person who could feel feelings.

The main thing for me was that they helped me with what to do with my feelings, acknowledging them and talking about them. I felt more able to talk with friends and with my parents. I didn't talk about it before. Things aren't building up as much and I'm not getting to the point where it would be too much.

I'm shocked at what a difference counselling has made, talking about things that have happened to me. I feel much more in control, more confident in myself to say no to people, and being kinder to myself, which is making a massive difference. There's a feeling of less guilt and a lifting of a massive burden. I am thinking differently about food and don't feel I need to eat if I'm not hungry. There are some big changes. I am able to think to myself: "Food isn't going to make you feel better. It's not going to fix things". Having someone else to say: "It's not your fault that that happened. It's OK to feel like that. Your life is tough". The untangling of your thoughts is invaluable. I am finding some fun and starting to enjoy life again.

Interview data give insight into EDNE's person-centred approach, that supports people to work at their own pace, do things for themselves, and get on with their lives:

At the start I wouldn't talk. I just used to not talk. The counsellor gave me space. They started talking about things I'm interested in. I think they were doing that so I felt comfortable. I felt like I could trust them and so I could open a bit more. They didn't like push, didn't say: "Howay, you have to do this".

I was worried every time I went that I would run out of things to say. If that happened we brought the session to an end together. I felt clear that the counsellor was there to listen to me. They helped me to decide what might be helpful for me. They used language very cleverly. There was definitely a shift for me. It gave me some impetus to try things to help myself.

When I talked about my rituals, the counsellor didn't say to stop them completely, they suggested I try and reduce them. It was small steps. I was able to stop bingeing.

I had had months off work. I was waking up in the middle of the night and I'd got to breaking point. I felt scared. They got me to talk, with direction. They asked some core questions, which was good because we branched out from there. It never felt like it was a script from them and it never felt like they were pushing too much. They would always get me to come up with what I needed to do. I have been able to talk with my partner and tell them how I'm feeling. I am getting back into work, and I can feel pleasure now in what I do, and I feel like I can get on with my life.

I feel more secure in myself and can say to myself: "It's OK, it's just a bad day, go with what's right at this point". It's opened my eyes and given me hope.

It has totally changed my life. I've struggled with food for years. It was so person-led and such a safe space. I could take the counselling wherever I needed it to go. That made it safe. There were no expectations of us having to talk about eating. It was such a transformative experience. It has totally changed my eating behaviours. Now if I get a thought like: "I shouldn't eat that", I am more easily able to catch myself. I can do that now. It prevents my spiral down.

Interviewees highlighted the value of support that equips people with resources to take into their day to day lives.

There was follow-up communication (after counselling), with ongoing activities on offer, including yoga. There was a range of things. I got emails about groups, and although I couldn't attend, it planted a seed and I watched TED talks on self-compassion.

We talked about strategies for me to be able to notice when I'm getting bad, and that has worked really, really well. I had had an eating disorder for quite a few years. This counselling has been a big turning point.

The counsellor gave me a list of body positive influencers I could follow on Instagram.

As we got to the end of the counselling we talked about things I could do if I started going backwards. I wouldn't have had those strategies without coming here.

**EDNE's response to feedback:** Several people made suggestions about things that could be improved. These were passed on to the EDNE team:

Suggestion: It would be useful to have a map showing where EDNE is.

Action: Everyone who registers is sent a map and description of how to find EDNE.

Suggestion: It would be good to have more information about what it's like to come along to EDNE because the hardest thing can be to get through the door. Think about reassuring people about their first visit, for example by describing the door and where the buzzer is, and saying that someone will come to let you in. There could be a person's story on the website: "This is what happened and this is what I got out of it..."

Action: When people are invited to their first face to face appointment they are sent information about what they can expect, including about someone coming to meet them at the door. There is a photograph, of the building in which EDNE is based, in the information sent with acknowledgement of registration.

Suggestion: More information before joining a group session, including an outline of the format and content, and expectation about how people will look after themselves and each other.

Action: A full description of the outline and format of groups is posted on the new EDNE website. Everyone who signs up for a group is sent information about that particular group. For each Mindfulness course and Friends and Family Group the facilitator calls the people who have registered, to explain how the group works and describe what will happen in the sessions.

Suggestion: More information to GPs. One person fed back that their GP said everything she'd heard about EDNE had been excellent. Several people suggested that some service users might want to highlight EDNE service provision with their own GP practices.

Action: Where people who have used EDNE want to do this, it is encouraged and supported. EDNE is promoting its services through regular local GP practice newsletters.

### **Support for family and friends**

A small number of family members and friends shared their experience of EDNE. Group support was rated as particularly valuable in reducing people's feeling of being on their own, and reminding them of their identity apart from being a supporter of someone experiencing eating distress:

It's about you. You're not just a parent. You can get stressed, you can be embarrassed. Before, I didn't realise the impact it has. I can talk in here and I don't feel bad. Every week there's a different focus, like doing creative writing.

You know you're not alone. That's important ... because you feel every door closes.

Sometimes if they (family member) are quiet, you think to yourself: "Are they still alive?". You've got nowhere else to go with that. I've found it really helpful to have people here who understand how you feel.

It went on for quite a long time before anyone acknowledged they (family member) have a problem. Coming here has meant I've been able to talk about it, then talk about it in the family.

I only found out about the groups here because I got in touch with the school counsellor. I'd gone to see her in desperation. Then I went online to look up the Maudsley programme.

This person went on to talk about their experience of taking part in an online two-day course designed by the Maudsley Hospital<sup>28</sup> and offered by EDNE:

It was brilliant. It was good to share your story with others who are going through similar things. We were able to learn how to empathise, and that makes you feel more confident about what to say, like: "I've noticed that you're eating better" or: "I've noticed that you're exercising more this week". There was a series of workshops with very practical activities. It has given me more confidence. I can work out beforehand what to say, trying to see it from (family member)'s point of view. I've learnt to address them and not the illness. Before the course we got some theory, and afterwards we got a record of our work, with links to lots of resources. I really felt supported and now I feel better equipped. The facilitator's warmth still came across and that helped us all to feel at ease in the online workshops.

### **Effective learning environment**

Thirty professionals took part in interviews, having commissioned and/or taken part in training or awareness-raising sessions.

Some participants work with young people in educational and other settings, and some with adults. Some EDNE sessions were with groups of young people and the professional(s) working with them.

The interview participants represent a wide range of areas across education, NHS, community and voluntary, and local authority sectors, including:

- community development
- social prescribing

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<sup>28</sup> The aim of the course is to support people to feel more confident in supporting someone with eating distress towards recovery. EDNE offers this free two-day course twice a year.

- counselling
- mental health support
- occupational health
- children's emotional health and resilience
- nursing
- youth work
- human resources
- school and college settings
- nursing and medical training.

At a time of national crisis and increased work pressure, an interesting initial finding was people's willingness to give time to feeding back. The level of recall, after what was for many a long gap between the session(s) and interview, strengthens the theme of EDNE's effective learning environment that was identified in data analysis:

The session does come back to me, even two years down the line, because of the quality of the training. That's the type of training we should have for everything. I won't forget it.

All feedback about the overall quality and effectiveness of sessions was excellent, as illustrated by the selection below:

The session was one of the best the team has ever had, due to (the facilitator's) style, and the content.

Feedback from the people who took part was amazing. It was one of the best sessions.

This service is second to none, very high quality.

It was absolutely fantastic, the best training we've ever had. We all still talk now about how good it was.

I'd put the session at the top of all the training we've had from the statutory and voluntary sectors. This was the best, and made the most difference in our working knowledge.

There was positive feedback about the experience of contacting EDNE and arranging a session.

The experience of arranging it was really positive. The person was accommodating in terms of timing and the content was just what we needed.

The session was easy to organise with the facilitator, all by email.

Designing the session with them was brilliant, because we have a learning focused curriculum and (the facilitator) sent suggestions for content in line with the learning outcomes. We did some refining together to avoid any confusion for students about the learning outcomes.

Certain words and phrases were used consistently across interviews when people were asked what they could remember about their session, and the difference it made for participants. The most frequent were:

- informative
- interactive/engaging
- (developing) understanding and empathy.

Feedback conveyed a strong sense of EDNE training building professionals' awareness and understanding of eating distress, and confidence to offer an appropriate level of support.

Everyone learnt a lot. (The facilitator) was engaging and humorous, and brought in personal stories. It meant that the team was equipped with what to be aware of when speaking with people and with families. They now know where to signpost.

The content was of direct relevance to staff, and the whole session was genuinely informative and useful. Before the session people weren't really aware, they had a narrow view of eating disorders.

The team developed a broader, nuanced understanding, and an ability to relate what they were learning about to themselves and to the people they work with and the communities they're working in.

The session made us think about how to approach some of the people we work with. We might have thought beforehand that we knew about this, yet everyone came out of the session having learnt things.

There was a lot that we didn't know and it was useful and informative. It was very engaging, I can remember that very clearly. We learnt about different triggers, for example some people eating because of stress, and then strategies for doing something other than eating. I have shared some of the things we covered with people I've worked with. There was good content, and I came out thinking it was an excellent session. Everything the facilitator said was understandable, and I remember thinking: "I've never thought of it like that".

It gave us a broader mindset, that it might not be what you expect. I always thought of it affecting people thirty and under, and then in the session there was discussion of older people. It can be anyone.

It gave us confidence to talk with the people we work with who are carers of someone with an eating problem. We all feel more confident.

The training put us in the frame of mind of people with eating disorders, and we looked at our own relationship with food. It gave us a point of reference to work from. It was an excellent mix of theory and information, and the trainer got us to think and discuss. Everyone had that sort of moment where you think: "I hadn't thought about that".

People involved in education in school, college and university settings referred to learning new things alongside their students.

It was very useful because they (students) discussed things that they hadn't thought of as being eating disorders. That took them by surprise, that people of all ages can have an eating disorder. It gave them a wider understanding and they'll take that into their professional practice. It's not something we've had in the curriculum before. I've worked in health care since the 1980s, which was when I started training, and I didn't know about the huge range of other issues.

It was a brilliant session. We were all teachers in the session and we all got so much out of it. We feel we can broach the subject more easily. The trainer was able to break things down for us, saying: "This is what it looks like and this is what you can do". It increased our confidence to support young people and parents.

It was engaging and interactive. The outcomes for students were: interesting discussion, breaking down preconceptions, moving people to becoming non-judgmental, and signs of eating distress. I have been a health professional for twenty years and I learned something in this session.

The interactive design of sessions was rated as particularly effective:

There was a real buzz around the session, even though it was a hard subject. There was a lot of interaction and people were incredibly engaged.

There was an interactive element, giving context and using people's stories. There were amazing videos, and there were exercises that got people to put themselves in the place of people with eating disorders, so they could empathise. There was engagement.

It was interactive throughout, which was different to usual training. I thought it was a brilliant start to learning about eating disorders, an all-inclusive and meaningful discussion.

The session was with a whole year group, and it was very interactive. The facilitator has a fabulous style, and encouraged the students to ask lots of questions.

It was so interactive. The facilitator had us up doing lots of things, including role plays. At the end we thought: “Wow”. It had helped us to feel the feelings. The content was fabulous. It’s the only training I’ve been on where we learnt from what we did, not the notes that we took.

It was interactive, with pair work and discussion. I remember there was an exercise where you had to say how you thought you might feel in this scenario. That helped us get insight into how people with eating disorders might feel. People were encouraged to think about examples from practice, and to discuss how they would support people and where they would signpost and what resources they’d use.

Participants appreciated the skilled facilitation, including clarity, competence, and ability to create a comfortable learning environment:

It was really honest and straightforward and clear, and smoothly managed. It created conversations with some young people. Some young people felt uncomfortable with some of it, and that was to do with their own experiences, and there were measures in place for that.

They (facilitator) used humour quite a lot and, though we didn’t all know each other in the session, we felt comfortable discussing things and we weren’t frightened to ask questions. The facilitator opened up the group, asking us: “What do you think?” and “How would you approach this?”.

The trainer immediately put everyone at ease. They made sure everyone took care of themselves in the session. The way they approached it was down to earth. They were really good at the difficult stuff and held the times when the room felt heavy.

The facilitator knew about the local area and the community here. The session was really down to earth, and it was a very skilled delivery. The facilitator got them relaxed. We were a bit nervous because of the subject. When you get external people coming in you are anxious because you don’t know how it’s going to go. The facilitator was professional and there was good preparation. The facilitator reassured students at the beginning. At the end there were some students who stayed back afterwards, including some young men.

Some participants referred to the training leading to them linking people to support:

We have made referrals as a direct result of the training, because the session gave us a connection to the service and confidence in it. We understand what people will get.

Many interviewees expressed interest in further sessions, as here :

We like to think people move on to other jobs with more than they came with, and that's why we invest in training. We've got a number of new workers and it would be good to get in touch with EDNE again to arrange more training. It's an excellent organisation.

**EDNE's response to feedback:** One person made a suggestion about something that could be improved, and this was passed on to the EDNE team:

Suggestion: The only way it could be improved would be to include some people who could speak about personal experience of an eating disorder, maybe through pre-recorded videos.

Action: The person responsible for developing and facilitating training and awareness-raising sessions involves people with lived experience in ways that work for them, for example in the development and production of the series of videos for young people. Someone who is currently contributing in sessions, describes their motivation as wanting to do something to help people avoid missing out on years of their lives, and supporting them to make changes and live their lives away from eating problems.

## 4. EDNE adding value as a partner in transforming services

This section presents evidence of the value EDNE adds as a partner in developing an integrated approach to transforming services<sup>29</sup>. Research suggests greater need for services for people experiencing eating distress, following the shock of the pandemic<sup>30</sup>. Local level collaboration is a central feature of current health policy<sup>31</sup>, and will be particularly important in relation to supporting people already disadvantaged by health inequalities<sup>32</sup>.

### EDNE's capacity to develop

EDNE's existence for more than thirty years reflects capacity to listen to people who need the service, manage challenge and change, and develop cost-effective provision. The organisation has always been open to people bringing a wide range of work experience and skills to paid and voluntary positions, shaping what EDNE does. Interviews with the management and staff teams identified expertise in: counselling; community development; training; group facilitation; health improvement; project management; business development; accountancy; organisational administration.

One team member commented that they like the fact that there are always things to work on and improve. The following is a selection of developments that have been completed during the course of the evaluation:

- Production of four videos, each with a message about the importance of taking steps to get help around eating distress, in collaboration with younger service users. One worked as illustrator, with collective storyboard work. Co-producers were paid at a professional rate and gave feedback that the experience has developed their confidence and skills.
- Introduction of an appointments-only email slot, to make booking as efficient as possible, avoid wasted appointments, and save on administrative time.
- Introduction of SharePoint Online platform to enable the team to share/store information and work on documents together.
- New user feedback system in response to identified data gaps.
- Launch of a new name, EDNE, in autumn 2021, together with a new website offering improved access to EDNE and other service provision.

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<sup>29</sup> Francesca Solmi et al, 2021, COVID-19 and eating disorders in young people, [www.thelancet.com/child-adolescent](http://www.thelancet.com/child-adolescent), Vol 5, accessed 1 February 2022.

<sup>30</sup> Catherine McCombie et al, 2020, "Now It's Just Old Habits and Misery" - Understanding the impact of the Covid-19 pandemic on people with current or life-time eating disorders: A qualitative study, Brief Research Report, Frontiers in Psychiatry, Vol 11, Article 589225.

<sup>31</sup> The King's Fund, Leadership development programmes information: Building collaborative leadership across health and care organisations, accessed 1 Feb 2022.

<sup>32</sup> HM Government Mental Health and Disabilities Directorate, 2021, COVID-19 mental health and wellbeing recovery action plan.

## **EDNE's capacity to collaborate**

The government's proposals for health and care integration<sup>33</sup> are set out in the 2022 White Paper, *Joining up care for people, places and populations*. The document describes successful integration as:

... the planning, commissioning and delivery of co-ordinated, joined up and seamless services to support people to live healthy, independent and dignified lives and which improves outcomes for the population as a whole. Everyone should have the right care, in the right place, at the right time<sup>34</sup>.

Collaboration, 'as close to where people live as possible', is seen as essential for building effective integrated care systems<sup>35</sup>. The value of multi-sector partnership involving the community and voluntary sector is highlighted in the *Mental Health Implementation Plan 2019/20-2023/24*, which sits within the overall ten year strategy for transforming the NHS in England<sup>36</sup>:

VCSE (voluntary, community and social enterprise) organisations will often hold detailed knowledge of the existing infrastructure, assets and support communities access, and can help ensure new services are designed in a way that recognises this existing local context. A localised and community focus is invaluable when considering Multi-Disciplinary Teams and pathway local design<sup>37</sup>.

Local community mental health transformation is funded from the national NHS Long Term Plan. We are looking at how services can better connect. Eating disorders is one of the key areas identified for a place-based approach, connecting up the voluntary sector with primary and secondary care, so that everyone knows what's there and how to refer in, and there are no cracks that people can fall through. (Partner)

Collaboration has always been central to EDNE's way of working. EDNE was set up through partnership (see Appendix 1), and has continued to work

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<sup>33</sup> The Health and Care Bill 2021/22 sets out plans for health service reform through integrated care systems that bring organisations together at place level, NHS Confederation, 2021, Briefing: The health and care bill.

<sup>34</sup> Department of Health and Social Care, 2022, *Joining up care for people, places and populations*, The government's proposals for health and care integration, p.8.

<sup>35</sup> NHS England and NHS Improvement, 2020, *Integrating care: Next steps to building strong and effective integrated care systems*, p.13.

<sup>36</sup> NHS, 2019, *The NHS Long Term Plan*.

<sup>37</sup> NHS Mental Health Implementation Plan 2019/20-2023/24, p.15. This transformative plan builds on progress already made in relation to recommendations of the Five Year Forward View for Mental Health which outlined priority actions for the NHS by 2020/21.

collaboratively, as shown by following examples of strategic partnership:

- Member of local multi-agency group for transforming mental health care
- Member of the NHS Eating Disorders Educational Forum led by Cumbria, Northumberland, Tyne and Wear NHS Trust, for discussion of research and approaches to recovery
- Collaborator with Northumbria University on eating distress research
- Member of steering group for NHS England sponsored Trailblazer mental health work into schools in Newcastle and Gateshead
- Member of NHS England North East and Cumbria Eating Disorders Forum, until it came to an end in 2019
- Member of Gateshead and Newcastle CCG Mental Health Programme Board 2015-2019
- Contributor to Health Care Needs Assessment coordinated by North East and Cumbria Eating Disorder Services (NHS England Specialist Commissioned Services), and member of the planning/steering group from 2011 to 2019, through all stages of service development and implementation.

EDNE is held in high regard as a strategic partner, as well as service provider. The following quotes are from people who have or have had commissioning responsibility;

As an organisation they are very important strategically. They have helped shape the regional collaborative pathway for eating disorders, making sure that people with lived experience have input. Their community intelligence is so valuable, especially for the system transformation that's happening. (Partner)

EDNE's developing all the time to respond to unmet need. They are seen as an integral part of the pathway. (Partner)

They're a strong local presence and the length of time they've existed speaks to the value of what they do. The pandemic has presented a lot of additional issues, and one of their real strengths is their experience and knowledge of what has worked well and what has not. (Partner)

## 5. Next steps

### **Widening and improving access**

EDNE has always worked to broaden access to its provision, including for people in groups with protected characteristics, and for those with low levels of income. EDNE will continue with outreach work. There will be a particular focus now, given the disproportionate effects of the pandemic on people in some ethnically minoritised communities<sup>38</sup>

Studies have identified positive aspects to remote provision, promoting self-efficacy<sup>39</sup> via strategies for managing feelings and stress. In the evaluation feedback there was exclusively positive reference to digital access to EDNE service provision (see p.16), although several people expressed initial reservation because of unfamiliarity. This feedback highlights opportunities that remote provision can open up for some people to connect with the support they need. With a history of adapting safely/effectively in the short and longer term, EDNE is well-placed to respond. This is in line with its aim to develop capacity to provide a service for more people, including reaching into disadvantaged communities.

### **Further collaboration to transform services**

Government policy emphasises the need for preventive approaches that help people avoid developing eating difficulties that seriously affect their health, work, relationships and day to day lives. EDNE is already a valuable partner in transforming mental health service provision (see quotes on p.29). EDNE will work with partners, including the North-East/North Cumbria Integrated Care System Population Health and Prevention Programme, to develop service provision, including local early intervention.

### **Organisational development**

People in the EDNE team expressed their appreciation of the organisational environment, and a sense of being part of a team:

It has been good to join a place like EDNE. It has been a good transition for me. There are whole team meetings now, and I get the sense that there's a lot of potential to develop what is an already established organisation. I have lots of ideas for wellbeing sessions.

It's a very welcoming organisation. There's lots of humour and I feel comfortable.

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<sup>38</sup> MIND, 2020, Briefing on inequalities for Black, Asian and Minority Ethnic communities in NHS mental health services in England.

<sup>39</sup> Danielle Clark Bryan et al, 2020, Exploring the ways in which COVID-19 and lockdown has affected the lives of adult patients with anorexia nervosa and their carers, <https://doi.org/10.1002/erv.2762>.


It's good to be included in discussion, and I feel that they value what I bring. I haven't felt that when I've been working with other charities.

In interviews, members of the team covered general issues related to part-time and sessional work, and the particular challenges of remote connection because of the pandemic:

Everyone's in team meetings now, though it can be hard to get the team together because of people being part-time. It's a great charity to work for.

**Potential action in response to a suggestion from within the team:** There was discussion of a formal two-way communication channel between staff and trustees, to make sure the wide range of worker experience is fully used. The Office Manager could administer an online ideas/feedback link between workers and trustees.

## Appendix 1: Example of EDNE Outcomes

|    | <b>Outcomes</b><br><br><b>January 2019 to March 2022</b> |   |   |
|---|--|---|---|
| Workstream: Prevention and early intervention   | Number of young people participating                     | Number of participants who work with young people at risk | Outcomes for participants   |
| Educational sessions and training courses   | 3562   | 1108  | 97% reported increased knowledge and understanding of eating distress.  |
|   |  |   | 94% felt more confident about supporting someone experiencing eating distress.  |
|   |  |   | 95% said they had greater awareness of how to access support.   |
| Mental Health First Aid Training (2 courses in year 1)  |  | 2   | 88% reported increased awareness of mental ill-health, including signs/symptoms, and better understanding of how best to support others with a mental health issue. |
| Educational films x 4 shown in sessions:<br>Kayla's Story - <a href="https://vimeo.com/383501047">https://vimeo.com/383501047</a><br>Tommy's Story - <a href="https://vimeo.com/385450327">https://vimeo.com/385450327</a><br>Liam's Story - <a href="https://vimeo.com/356359201">https://vimeo.com/356359201</a><br>Amy's Story - <a href="https://vimeo.com/354255812">https://vimeo.com/354255812</a> | 2779   |   | 100% reported increased knowledge/ understanding of eating distress.  |

| Workstream:<br>Towards Recovery                        | Beneficiaries | Number of sessions  | Outcomes   |
|--|---------------|---|--|
| Counselling  | 526           | 4307  | 89% reported positive change in terms of being able to move on with their lives.   |
|  |               |   | 95% said they had increased skills and ability to deal with eating distress and/or life.   |
|  |               |   | 78% reported improved self-confidence and self-esteem.   |
| Initial registrations                                  | 573           | 573   | 100% said they had better access to services.  |
| Mindfulness courses                                    |               | 26  | 96% reported feeling able to make positive changes for their mental health.  |
|  |               |   | 88% said they felt less isolated.  |
|  |               |   | 88% described positive self-worth.   |
| Mindfulness workshops and self-help resource programme | 27            | 2 x resource pack sent out to 25 people                                       | Not formally evaluated due to last minute cancellation because of the pandemic and pivot to online delivery and packs for users. |
| Psycho-education workshops                             |               | 50<br><br>*Additional online sessions to address loss of HOPE group sessions, | 92% reported having improved mental health.  |
|  |               |   | 88% said their self-confidence had improved.   |
|  |               |   | 94% felt better able to deal with their mental health issues.  |
| HOPE recovery group sessions                           | 26            | 17<br>*Suspended in 2020 due to the pandemic.                                 | 95% felt supported with their eating distress and mental health.   |
|  |               |   | 95% reported increased ability to cope.  |
| Nutrition advice (pilot session)                       | 10            | 20  | 90% said they had improved their understanding of essential nutrition for people experiencing eating distress.                   |

| Workstream:<br>Carers' Support                                   | Participants | Number of<br>sessions | Outcomes   |
|--|--------------|-----------------------|--|
| Friends and Family<br>Support Group                              | 21           | 33                    | 90% found group sessions very useful.  |
|  |              |                       | 85% said the group made them feel more supported.  |
|  |              |                       | 99% said the group helped them feel better.  |
|  |              |                       | 97% said the group helped them improve their relationships.  |
| Friends and Family<br>Maudsley Training<br>course                | 37           | 8 (days)              | 100% felt more supported.  |
|  |              |                       | 96% reported learning ways to help them manage and improve relationships.  |
|  |              |                       | 88% reported improved mental health.   |
| Friends & Family<br>Mindfulness<br>course<br>(8 weeks) Y. 1 only | 6            | 8                     | 84% said they had improved their understanding of a healthy mind, and felt better able to develop more positive relationships. |
|  |              |                       | 67% said they felt they had support to help them cope.   |
|  |              |                       | 67% felt better connected to other people.   |

## **Appendix 2: The evaluation process**

EDNE commissioned an evaluation of its service provision from September 2019 to March 2022.

Data production methods comprised:

- interviews with people with experience of eating distress, starting with an open question: How did it happen that you got in contact with the organisation. This approach was used to avoid intrusive exploration of the reasons for people connecting with the service, using people's own words, going at their pace, and moving on to ask them to talk about their experience of service use and any difference it made for them;
- interviews with professionals;
- interviews with the EDNE team, including trustees;
- evaluator participation in group sessions;
- literature search relating to national and local mental health policy direction;
- review of organisational archives in Tyne and Wear Discovery Museum.

The first step in the evaluation was piloting the interview approach. This involved the Office Manager sending out an invitation to people on the EDNE circulation list, asking them to think about taking part in an interview. The invitation included an introduction to the evaluator and reassurance that they would be working in line with the organisation's confidentiality code. There was reference to safeguarding policy and procedure. The email invitation emphasised that expression of interest in taking part in an interview would not mean having to follow through with that. Anyone taking part in an interview would be able to change their mind about their information being included in the interim and final reports.

The interview approach used in pilot interviews produced information relevant to the evaluation and was further employed. From February 2020 there was repeated rescheduling and/or postponement of interviews. This was initially in response to the emerging global pandemic, and subsequently because of restrictions introduced by the UK government, as well as time pressure on interviewees employed in NHS, local authority, and educational settings.

Access to EDNE archives held at the Tyne and Wear Discovery Museum was similarly postponed because of the building being closed to the public. The evaluator was able to view files towards the end of 2021.

The evaluator was in regular contact with the EDNE board throughout, feeding back data at points at which they were useful. Two interim reports were written, in March 2020 and April 2021. Anonymised quotes were used for the re-launched EDNE website in autumn 2021. The evaluator collated information relating to government policy context, for funding applications.

### **Appendix 3: The beginnings of EDNE: 1988-1995**

EDNE began at the end of the 1980s as Northern Initiative on Women and Eating, with roots in women's self-organising on Tyneside. A 1993 publication on purchasing effective mental health services for women refers to service developments happening mainly through women working together<sup>40</sup>. The following quote is applicable to EDNE's early years: The knowledge they provide is hard won and based on attempts to develop and deliver services, usually on low and insecure budgets, that women actually want.

A multi-disciplinary group of professionals from community mental health, social work, and community development teams responded to what women were saying at health days in the east Newcastle areas of Walker and Byker. The women were expressing the sort of distress around body image and food that was being discussed in UK media<sup>41</sup>, and that Susie Orbach had written about in *Fat is a Feminist Issue*, published in 1978. Supported by their respective managers, the group of professionals formed a steering group and organised an open meeting<sup>42</sup>, which confirmed the need for development of local support around difficulties with food and eating. The steering group applied for funding from Tyne and Wear Foundation, now Community Foundation. The Foundation recognised that eating problems had received comparatively little attention and gave a start-up grant of £7900. This funded a telephone helpline and part-time coordinator<sup>43</sup> for eight hours a week. Health Action<sup>44</sup>, a Newcastle community health project, offered space in its office in the Shieldfield area of Newcastle upon Tyne.

During its first years the organisation received funding from the Mental Health Foundation, Newcastle Social Services, and Newcastle Health Authority. Reconfiguration of health authorities, the purchaser/provider split, and subsequent NHS reorganisations have mitigated against strategic long term funding arrangements with third sector organisations<sup>45</sup>

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<sup>40</sup> The 1993 guidance for mental health purchasers/providers presented a review of evidence showing how services were not meeting women's needs, Jennie Williams et al, 1993, *Purchasing Effective Mental Health Service for Women: A Framework for Action*, MIND Publications. p.8.

<sup>41</sup> Guardian newspaper article: *Hunger without a name*, Susie Orbach, June 13 1992, pp.8-9.

<sup>42</sup> The open meeting was held in central Newcastle in MEA House, a building with space for use by charities, community interest companies, and other forms of social enterprise.

<sup>43</sup> Tyne and Wear Foundation, 1989, *Investing in our future: First annual report*, p.9.

<sup>44</sup> Health Action, previously the Community Health Information Project under the umbrella of the CHC, worked closely with other Tyneside community health projects. The first worker was recruited in 1983.

<sup>45</sup> Department of Health, 2009, *Tackling Health Inequalities: 10 Years On*, London: The Stationery Office.