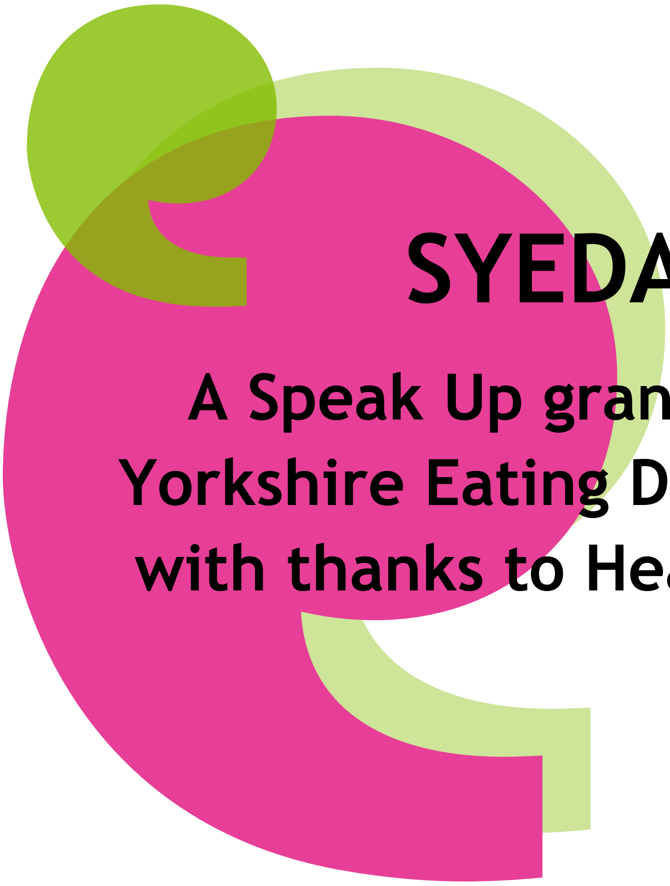
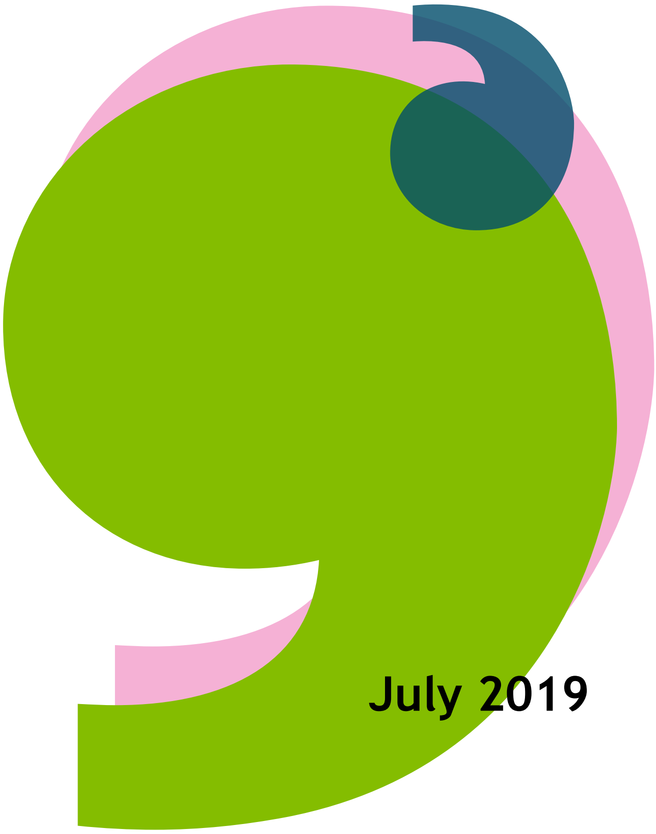


SYEDA Voice:

A Speak Up grant project by South Yorkshire Eating Disorders Association, with thanks to Healthwatch Sheffield.



July 2019

Introduction

South Yorkshire Eating Disorder Association (SYEDA) is a registered, independent charity offering help to people with eating disorders and their supporters. SYEDA is a non-judgemental service supporting those with a wide range of eating disorders, including Anorexia Nervosa, Bulimia Nervosa, EDNOS (Eating Disorders Not Otherwise Specified) and Binge Eating Disorder. SYEDA is Sheffield-based and offers services across South Yorkshire.

SYEDA offers support to people of all ages, genders and backgrounds. Our services include one-to-one therapeutic support, support groups, Cognitive Behavioural Therapy Ten (CBT-T), training programmes for schools and professionals, support for carers, and more. We have a focus on prevention and early intervention to support those at risk of developing eating disorders. We also deliver our “Treading on Eggshells” course, which provides support for family and friends of those with an eating disorder.

In Spring 2019, SYEDA received a #SpeakUp small grant worth £500 from Healthwatch Sheffield to enable us to pilot and develop “SYEDA Voice”, our new service-user voice initiative. SYEDA Voice is open to anybody who has used SYEDA’s services, past or present, whether they have experienced an eating disorder themselves or are a friend of family member who has accessed our services. SYEDA Voice’s long-term mission is to embed the views, experiences and ideas of our clients into our operational and strategic practice. Our immediate goals as described in our bid to Healthwatch Sheffield were as follows:

- Develop SYEDA Voice through a range of workshops, face-to-face meetings, online discussions, etc., to support people to share their views.
- Work with the newly formed group to share experiences of eating disorders services across the city, and collate these findings into a report.
- Focus on the Healthwatch Sheffield aims and priorities: “supporting local people to have their say” and “building capability and capacity across local health & care services to effectively involve local people”.

Our key outcomes from our activities funded by the grant include:

- Learning more about what enables and encourages clients to participate in a voice initiative, and how to make participation meaningful.
- Gathering recommendations, questions and concerns about the new eating disorders pathway in Sheffield which we intend to feed into the groups responsible for its development.
- Empowering the voices of groups who are underrepresented in the development of eating disorders support, including men, carers, and those with non-restrictive eating disorders.

What we did

We hosted three workshops in June and July 2019. Our workshops were attended by clients who have personally experienced eating disorders, and friends and family members who have used our services. We had an even amount of men and women attending our workshops. The workshops were broken down into the following themes:

- **Your general experience:** An open-ended section which allowed client-led discussion and ensured the topics close to them were raised.
- **Prevention and Early Intervention:** Exploring measures and initiatives which our client base feel would either have helped them, or could help those in the future who have a similar experience. This links heavily into our prevention work, but also provides valuable insight into what other community stakeholders, including schools and the NHS, could do to encourage prevention and early intervention.
- **Barriers to accessing support:** We wanted to better understand the reasons why a client would not access our service or other eating disorders services in general. This provides vital insight to us as to considerations we can make to maximise retention and the completion of support programmes, and also facilitates the access of new clients to our services.
- **The Sheffield Eating Disorders pathway:** The eating disorders pathway in Sheffield is currently under review, with the aim of developing a “single point of access” for those with eating disorders in Sheffield. Most of our service users and workshop attendees have used multiple eating disorders services within Sheffield and beyond, and this topic was of significant interest to our participants. We hope that our findings from SYEDA Voice, achieved thanks to the #SpeakUp grant, will be implemented into a review of the eating disorders pathway, to ensure it is effective for those with eating disorders.

We gathered approximately 150 unique insights, thoughts and recommendations from our participants. From this evidence base, we have been able to identify key recommendations and concerns which we believe will be invaluable for ourselves and any group evaluating eating disorders support in Sheffield. While the findings have been sorted into the above categories for our data-collection purposes, we found that issues such as comorbidity and Body Mass Index (BMI) spanned multiple categories. As such, we have structured this report to address insights based on issue, rather than category listed above.

Establishing a group such as “SYEDA Voice” can be challenging, and we noted several barriers to participation in SYEDA Voice itself through the experience of hosting our workshops. Experiencing an eating disorder, or supporting a loved one who does, can be a challenging and marginalising experience, and eating disorders are widely misunderstood. We had eight participants in these sessions, including staff representation, which was a lower level engagement than we had hoped. We hope to take our learnings from our experience of running SYEDA Voice to not only improve eating disorders support in Sheffield, but to improve access to SYEDA Voice itself. Working with clients and giving clients a meaningful say in our work is core to SYEDA's vision, and this activity will have a long-standing impact on how we conduct voice work in the future.

What we've learnt

The perception of different services

The perception of different eating disorders services across Sheffield was deeply significant to our participants, whether they experienced an eating disorder themselves or were supporters of loved ones who had. Some participants found the separation and distinct identity of services helpful, noting that a particular service's vision and values made it more appealing to them, thus positively influencing their view of the service.

"SYEDA's charity status makes it feel different. It isn't part of the NHS, which means if you have had a bad experience with NHS services, you might be less apprehensive about SYEDA, as it's separate. I think this is really important and it would be a shame for services to lose their distinct identity under a new pathway."

"You feel like SYEDA cares, like they really have time for you. When I think of SYEDA, I think of somebody who will always pick up the phone."

Others, however, perceived a "hierarchy" of services, meaning that if they got referred to a service they didn't view in a positive light, they would feel like they were being "brushed off".

"No offense, but when I first got referred to SYEDA I thought they were saying my disease wasn't serious enough, as if I wasn't having a bad enough time to get proper treatment. I know that SYEDA is aimed at milder sufferers and so it felt like a punch in the stomach."

Comorbidity

Multiple participants, both supporters and those with an eating disorder themselves, highlighted the problem of comorbidity and described concerns about the current support provision in Sheffield not being able to cope. Participants described being "bounced around" between services, and services being reticent or even refusing to provide them help if they experienced another diagnosis.

"The truth is, if your loved one experienced more than one psychiatric problem and were comorbid, it felt like none of the services wanted anything to do with you. Perhaps it was budget constraints, perhaps it was them feeling ill-equipped to deal with something more 'complex' or 'atypical'. Either way, the real-life consequence of this was that our child fell through the cracks because of this; nobody wanted to take them on. This meant their mental wellbeing just got worse and worse."

55%-97% of people with eating disorders are estimated to have at least one other psychiatric diagnosis[1], meaning that more people with eating disorders experience comorbidity than not. This highlights a serious problem within the current structure of care, where service users feel like their other diagnosis is a barrier to them getting help. One participant described feeling that clinical staff were not listening to them when they discussed their comorbid conditions:

"It was frustrating, when I'd try to get help for my panic attacks, they'd blame it on my eating disorder. They'd say 'no', that they somehow had to be linked, even though I told them my feelings about food and my triggers for my panic attacks were completely different. Then I'd go to get help for my eating disorder and it would be the same thing. They wouldn't want to help me until I learnt to cope with my panic attacks, but I couldn't get help for my panic attacks because the people who were supposed to help me with that wouldn't do it because they were insistent we needed to 'fix' my eating disorder first!"

These insights are crucial, particularly in the context of the new eating disorders pathway currently in development for Sheffield. Given that over half of those with eating disorders have a comorbid diagnosis, the consensus from participants was that such considerations should absolutely be built into the pathway to ensure both that nobody "slips through the cracks", and that users of such services should feel empowered to comment on the relationship between their comorbid diagnoses.

Body Mass Index (BMI)

Universally, participants criticised the use of Body Mass Index (otherwise known as "BMI") as a means of assessing the health of those with eating disorders, and thus gatekeeping access to support. Participants had an extremely negative perception of the usage of BMI, and were able to recount multiple ways in which it served as a barrier to accessing support. The harms caused by BMI were multi-faceted, and concerns participants raised included:

- That it encourages/triggers those with eating disorders to restrict in order to reach a diagnostic threshold for getting help. This was believed to be counter-intuitive as it effectively encouraged harmful behaviour, thus worsening the eating disorder and physiological health of the client.
- That it is additionally harmful for male clients. One participant noted how the BMI thresholds used in diagnostic criteria were based on female physiology. As men typically have lower body fat percentages than women, a man with a BMI of 15 was perceived to be in far greater danger than a woman with a BMI of 15.
- That it bars those who experience significant psychological distress as a consequence of their eating disorder from accessing help, just because they do not meet the weight criteria.

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[1] https://www.nedc.com.au/eating-disorders/eating-disorders-explained/types/comorbidity/

Furthermore, there was a general perception of arbitrariness surrounding the BMI, where participants felt like it was a case of “having to draw a line somewhere” in order to cope with low resources. It was clear that the use of BMI as a criteria for accessing support made clients feel invalidated, encouraged unhealthy behaviours, and seemed scientifically crude and ill-suited.

“BMI - well, put it this way, if you’re on the borderline then you’re considered ‘safe’, even if you’re a kilogram above being considered to be in serious danger. How does that make sense?”

“You can be very mentally unwell at any weight. I felt better, psychologically I mean, when I had a bit of a lower weight but I was in a recovery programme and wanted to get better. Some of the times I’ve felt my worst, I haven’t necessarily weighed my lowest. I mean of course, you can be very underweight and very unwell, but you can also be what is perceived to be a healthy weight and still be, you know, still have an eating disorder. I don’t think BMI helps this at all.”

“I hate having my BMI taken because I’m always worried I’m going to be told I’m not ill enough. I feel like my doctor is basically telling me to get worse.”

“The over-focus on BMI is crude, and frankly, dangerous. I can’t stress this enough. It’s even worse for men. Men have different physiological builds for women, and the BMI criterion is based on women and what’s a healthy body fat percentage and weight for them. This is just one of the many reasons BMI has to go.”

Part of SYEDA’s ethos is to support clients at any weight, which should notionally render BMI irrelevant for the purposes of accessing support in the first instance, however it was not clear that participants knew and believed this to be the case. It should also be noted that no participants explicitly stated that they experienced EDNOS or Binge-Eating Disorder, nor were any of our participants supporters of those with either of those diagnoses. It could be possible that those with such diagnoses might have a different experience with the Body Mass Index, however the perception of the use of BMI amongst our specific participants was universally negative.

Experiences in treatment

Participants with eating disorders and carers alike expressed difficulties in communication when accessing support.

“There were times where the staff member would come back with a diagnosis and I’d think, ‘where on earth did you get that from?’. It didn’t match my experience at all. I mean, I know they’re the expert but we never got a chance to talk about why. I kind of felt from then onwards that they didn’t get me and so their advice wouldn’t be useful for me.”

“I really don’t feel like I can challenge my therapist or whoever when they make a judgement

about me. I mean, I know they're the expert, but sometimes it feels like they make their mind up and it doesn't matter then what else I come out with."

"Sometimes I'd feel like I was being asked to do counter-intuitive stuff, you know, stuff which encourages the eating disorder, like counting calories or keeping a food diary, and I never got an explanation why. All I'm saying is this is the kind of stuff I did when I was really unwell, and I never felt like I had a chance to understand why we were suddenly doing what I thought I wasn't supposed to."

Further investigation into how communication can be improved could have a strong positive impact on treatment programme completion and engagement, and so we would recommend that any further SYEDA Voice work explores this. We were not able to have a member of clinical staff in attendance at all workshops, so we believe exploring communication from a clinician's perspective would ensure we develop a rounded and fair approach to improving it. In the spirit of co-production, we believe that facilitating open and honest conversations between clients and clinicians can clear up misconceptions and build trust.

Participants also discussed the experience of being referred between different support services, and the impact it had on them.

"Getting referred from one service to another, one waiting list to another… After a while, you get demoralised, you get really fed up, and that's just me as a [carer], I can't even imagine how that felt for our child."

"It was just the worst to go through the whole referral process - to get to the point they test you and diagnose you - just to be told you're not ill enough, or not well enough, and effectively you're back to square one. Those times were the darkest times and the times I felt closest to giving up."

However, participants from supporting backgrounds, as well as those with experience of an eating disorder themselves, discussed the value of being provided with literature and resources to take away and help them understand treatment. The general consensus was that being able to learn about different treatment options, and about eating disorders more generally, gave supporters and those with eating disorders a sense of hope and that they had the ability to change. It also made them feel "listened to" and supported by clinical staff, and that they were being given something meaningful to work with. It is possible that the development of further printed resources could supplement support and treatment while awaiting a referral or the outcome of a referral.

Despite this, some participants raised a counter-argument that "overloading" clients with information about eating disorders and their treatment might feed into it or make it worse. Any changes to the amount of information and insight shared between a client and a clinician should be carefully considered by experts and clients alike.

Participants who experienced an eating disorder themselves also described a sense that they were not able to be entirely truthful to clinical staff and therapists, as they felt that their answers would influence the access to their treatment.

"When I'm talking to my therapist, I feel like I have to be perfect, or kind of like I want to be perfect, too. I want to be the best patient and I don't want to fail. Sometimes I don't feel like I can tell them if things go wrong because I'm worried they'll be disappointed. Other times I'm worried that if I don't say the right thing, they'll not be able to help me anymore."

"I know it's bad, but sometimes I just lied on my forms. I just know from my friends' experiences that there's things you say which will get you better help, and I just want help."

This is highly worrisome and a likely barrier to accessing the appropriate support. Feedback suggests that participants did not feel like they could trust their therapists, or clinical staff more broadly. It would be worth taking the time to understand what could be done to improve trust between practitioners and clients, and how an environment can be fostered where clients feel more empowered to be honest about their experience in a clinical setting.

Increasing participation in SYEDA Voice

While we gained significant initial interest in SYEDA Voice, with 30 respondents to our scoping questionnaire, we found it challenging to translate this interest into participation in workshops. We would ask attendees to confirm their participation prior to workshop events, and for each workshop, two or three participants dropped out. The founding principle of SYEDA Voice is that it is co-owned by clients and as such, understanding barriers to participation in SYEDA Voice or similar activities is absolutely crucial. The majority of those who dropped out were mainly due to the following reasons:

1. Due to their illness, they were unable to travel to attend the sessions.
2. They were having a difficult day and did not feel able to participate.
3. They could no longer make the specific workshop date/time for logistical reasons.

While we conducted initial digital surveys and work to establish SYEDA Voice, in line with our grant application, we believe that further developing digital means of participation will mean that the barriers described above would be mostly removed. Using means such as surveys and discussion forums allows clients to participate at a time and from a location that suits them.

Digital workshops through Skype or similar can provide live, interactive opportunities to participate from the location of one's choice. We also believe that the particular nature of eating disorders, which we explore further in the "barriers to access" section, can make clients uncomfortable with being physically present in a workshop setting. This again shows the value of digital modes of participation, and also demonstrates a need for initiatives such as SYEDA Voice to be further developed in collaboration with clients and clinical staff. We are addressing this challenge and enhancing our digital engagement by partnering with Sheffield Flourish[2] as part of their "Digital Champions" initiative. Through Digital Champions, we aim to train service users in various media skills to improve digital voice and inclusion.

Finally, we unfortunately did not have any participants who experienced Binge Eating Disorder, nor supporters of those who experienced Binge Eating Disorder. Binge Eating Disorder is the most common specified eating disorder in the United Kingdom[3], and people with Binge Eating Disorders make up the largest portion of our clientele. Thus, we ought to consider targeted efforts to empower and enable such people to participate, and to understand what they would like to get out of a group such as SYEDA Voice.

Summary of recommendations

Comorbidity:

Even the most conservative estimates suggest over half of those with eating disorders have at least one other psychiatric diagnosis. Participants raised experiences where they felt that they were referred away from support due to their other diagnosis, potentially because clinical staff would not feel resourced or supported to help them with their comorbid condition in mind. We found the notion that some participants were unable to access support due to an additional diagnosis particularly troubling.

- **We suggest further investigation into the impact of comorbidity on one's experience of mental health support services in Sheffield, including amongst eating disorders services. Furthermore, we recommend that policies and procedures regarding comorbidity are built into the new eating disorders pathway, including an agreement as to which service can help clients under which circumstances. We believe it is crucial that gaps between services are "filled" so that clients are not able to fall between the remits of services.**

Body Mass Index (BMI):

Our participants unequivocally rejected the use of the Body Mass Index (BMI) as a tool for referrals, diagnosis, and for use in a treatment programme. Participants felt that their BMI score or current weight would not neatly correlate with their psychological well-being, meaning that they could feel at their lowest but appear "healthy", or have a positive attitude to recovery but be "dangerously" underweight. Clients also discussed how they found the use of BMI triggered their symptoms and made them dread accessing support.

- **We recommend that alternate diagnostic tools are used to assess the support needs of clients. Clients need appropriate support to prevent the triggering function of BMI creating a barrier to accessing support. Particularly in the case of men, our**

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[2] https://sheffieldflourish.co.uk/

[3] https://www.beateatingdisorders.org.uk/media-centre/eating-disorder-statistics

participants felt the suitability of BMI in assessing risk of physical harm should be reassessed. Finally, we recommend that when assessing suitability for support plans, greater account of psychological well-being and attitude towards recovery is taken.

Experiences in treatment:

Participants described difficulties in communicating with clinical staff, feeling a lack of confidence when they believed they had been misunderstood, or did not understand a decision themselves. Clients also described not being entirely truthful and omitting aspects of their story in order to achieve a favourable response. This being so, we did not have staff representation in all of our workshops, and so believe getting their perspective is essential, and fully in the spirit of co-production, in order to understand how to avoid miscommunication and build trust.

- **We recommend further dialogue between clients and clinical staff to help iron out misunderstandings, to empower clients to ask questions, and to build trust. We also recommend challenging the notion that clients ought to present their experience in a certain way to access a particular treatment programme. This could be achieved by building trust in a variety of treatment programmes, and empowering clients to feel that they can seek clarification regarding clinical decisions.**

Increasing participation in SYEDA Voice:

Various barriers prevented interested clients from participating in this initial pilot of SYEDA Voice, including distance, discomfort being observed by others with eating disorders, and workshop timings.

- **We want to bolster our digital work, which we have already commenced through our Digital Champions partnership, so that SYEDA Voice is accessible to all**.

While we were proud of the even gender split we achieved between participants, in line with our original bid goals, we did not have any participants who disclosed a background of Binge Eating Disorder.

- **We recommend specific resources are put into reaching participants who have been affected by Binge Eating Disorder. It is possible that the nature of Binge Eating Disorder would warrant separate workshops - this is something we recommend scoping out in further depth to ensure all SYEDA clients and their loved ones feel represented.**

About Healthwatch Sheffield

Healthwatch Sheffield is the city's local consumer watchdog for health and social care services. The organisation exists to help adults, children and young people to influence and improve the way health and social care services are designed and run in the city. Healthwatch Sheffield is completely independent from the NHS and Sheffield City Council.

About the #SpeakUp grants

In 2018/19 Healthwatch Sheffield ran a small grants programme called 'Speak Up'. Sheffield-based voluntary and community sector organisations were invited to apply for a small grant of up to £1,000 to run consultation and engagement activities. Organisations were asked to relate their projects to one of the aims and priorities in the 2018 – 2020 Healthwatch Sheffield 'Together for Good' Strategy.

The programme was designed to enable local organisations and community groups to gather views and experiences of health and social care services from Sheffield residents, especially from those who do not traditionally have a voice. The aim is to ensure that health and social care decision makers in the city hear from a diverse range of people about their experiences of services.

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