



Northern Ireland
Assembly

Committee for Education

OFFICIAL REPORT (Hansard)

Eating Disorders in the School Community:
Eating Disorders Association NI

15 September 2021

delivered with our volunteer ambassador team, who all have lived experience of eating disorders in one way or another.

Lastly, we carry out advocacy and campaigning work to try to improve the eating disorder service in Northern Ireland. We are a member of the Regional Eating Disorders Network Group (REDNG) group in the Public Health Agency and the Eating Disorder Forum of Northern Ireland. I also sit as the Northern Ireland rep on the Regional Eating Disorder Charity Alliance and Network (REDCAN), which is a UK-wide group of smaller regional eating disorder charities that aim to share best practice and shape policy. We work with government bodies, the Department of Health and those in politics like yourselves to improve services here. That is our service.

I am aware that the Committee is particularly interested in the experience of school-age children, how lockdown has impacted on their mental health and how, we think, services could be improved for them. To give you a bit of context of what we are dealing with, last month, 23% of our emails were about children under the age of 18. Usually, it is parents getting in touch to discuss their children, but sometimes we have the children themselves reaching out. Also, the age of the children contacting us is much lower than we have previously experienced. Several are as young as 13 and 14.

The most common presentation is anorexia-type symptoms. However, since the beginning of summer 2021, we have seen an increase in children contacting us who are experiencing other eating disorders, such as bulimia, binge eating disorder, other specified feeding or eating disorder (OSFED) or avoidant/restrictive food intake disorder (ARFID). The people who are contacting us at the moment are a lot more unwell than we have previously experienced. Some common themes in our conversations with children and young people include dealing with stressful life transitions — for example, starting a new college or school or being in and out of school with lockdowns or being unwell — and feeling frustrated and isolated by a lack of understanding of eating disorders from family or peers. A lot are having poor experiences and feeling dismissed by professionals, especially children with binge eating disorder or ARFID. That means that vital early intervention opportunities are being missed. I recognise completely that we may get more of these cases, because often young people contact us if they have had that negative experience, and those with good experiences may just proceed with the service that they have got. Some are worried about the future on both a micro level and a macro level, from how they will afford things to climate change. There is a sense of nihilism among some of the young people who call us, especially those who have been through the system or been knocked back by the system in some way. Many struggle to label, integrate and regulate their emotions. There is also an undercurrent of adverse childhood experiences or trauma.

How has the pandemic specifically affected children developing eating disorders? For us, the pandemic has meant that more children are being exposed to known eating disorder risk factors than before. The children and young people whom we speak to tend not to mention lockdowns or the pandemic directly, but they talk about the specific risk factors that occurred for the first time or got worse because of the pandemic. Some eating disorder risk factors that affected a lot of children as a result of the pandemic and lockdowns include those stressful life transitions, a lack of social support and, very possibly, facing those traumatic events, bereavements and all that sort of thing. Additionally, the pressure on services has reduced access to a system that already struggled to meet demand. Many people had no access to appropriate healthcare. We heard of a child who was deemed an emergency being told that they had to wait 26 weeks before they would be seen. Early intervention is so important to eating disorder recovery, so that is not what we want to hear.

That leads us nicely on to the main concerns that we have about children in relation to eating disorders and how, we think, the services could be improved for them. I could talk about that all day but will touch on just the main points that the kids themselves have made. We need to be better at early intervention. I understand that there is talk of a workforce review in the mental health strategy, which I would welcome. I would hope that that would lead to increased capacity. We could also provide some sort of primary care for people, maybe within the talking therapy hubs that are also discussed in the mental health strategy. Also, improving awareness would help everyone to recognise the early signs of an eating disorder.

That leads us on to concern number two. There is a lack of awareness, understanding and, consequently, social support for children with eating disorders. That particularly affects boys. One in five of our calls from children is from boys, racial minorities, LGBTQ+ people and those with disabilities, to name just a few. Some suggestions to tackle that include a public health awareness campaign, providing more clinical experience on eating disorders for trainee health professionals and sustainably funding psycho-educational training and prevention workshops. We receive a small amount of funding from the Department, for which we are immensely grateful, but most of our staff

work part-time and are on temporary grant fundings. We are a really small organisation. There are three of us, so we have more training requests than we have capacity for, and we always prioritise our support work. It would be great if we were able to have someone whose sole role was to facilitate training or if the Department of Health or the Department of Education contracted that out in some fashion. There really is a large need and demand for that service.

Lastly, we are really concerned about the inflexibility of the system, the silos that are present, and the people who then fall between those cracks. We would like to see more flexibility and choice that empowers people in their recovery rather than forcing them to be compliant. We would like to see improved transitions from child and adolescent mental health services (CAMHS) to adult services and between trusts. Lastly, we would like to see better services for children with autism and ADHD. We see young people who are not getting help to manage their autism or ADHD symptoms who go on to develop eating disorders as they struggle to cope without the appropriate support.

That is us. Our last slide contains our contact information, should anybody want to get in touch. I really appreciate the opportunity to speak. It is great to see people taking an interest in eating disorders.

The Chairperson (Mr Lyttle): Thank you so much for your presentation, Sian, and for all the work that you do in this important area. I will be glad to bring members in for some questions to draw out the issues a bit further and to see what action we can take, if any, to support your work.

You touched on this a couple of times: are there particular gender or age profiles that have relevance to eating disorders in school-age children?

Ms Ogle: To be honest, Chris, it is a pretty mixed bag. We normally see a ratio of one boy to four girls, but we increasingly see young boys. It is the severity of the illness in children who are so young that we have not seen before. Generally, the children are from different backgrounds, schools and ages. It really seems to be a broad mix.

The Chairperson (Mr Lyttle): OK. Can you tell us a bit about the prevalence and the severity of the conditions? How prevalent are they, and how severe are some of the conditions?

Ms Ogle: Our numbers show that we had 2,000 support requests last year, but the data for Northern Ireland's prevalence figures for eating disorders is very loose on the ground. The reason for that is that the data captures only people who are in the trusts' care system and not people at a primary care level. I am passionate about improving our understanding of how many people are unwell. I can tell you who reaches out to us, but that is only the tip of the iceberg of who is out there. We can go through the Assembly questions and find out how many were in the trusts, but we have no idea how many people reach out to GPs. I would say that it is a significant amount, if we are getting 2,000 support requests in a year.

The Chairperson (Mr Lyttle): Maybe we can work with you on that to try to ensure that the data is enhanced.

You also touched on some of the causes. Does research suggest that self-esteem, cultural pressure or bullying are some of the causes of or factors in the disorders?

Ms Ogle: Absolutely. As you mentioned, there is not one causal factor but a multitude of things. We agree with the biopsychosocial model of eating disorder cause. There are biological factors. There may be an increased risk when someone in the family has had a mental illness. There are social factors of self-esteem, lack of support and all those things. There are cultural factors, such as the emphasis that we put on weight and the morality that we attach to weight, particularly in the media and that sort of thing. There are myriad factors, and, as you can understand, a lot of things around trauma, social support, bullying and loneliness have, no doubt, got worse during the pandemic. Those are the things that we hear when people call us.

The Chairperson (Mr Lyttle): It is easy for Education Committee members to think that this is a health issue, but, considering some of those impacts and causes, particularly in relation to bullying, there are significant responsibilities for the Department of Education in relation to anti-bullying and particularly around self-esteem, body image and our collective responsibility to make sure that people do not experience those causal factors and get the support that they need to combat them.

The Assembly Research and Information Service (RaISe) provided us with a research paper for today. Perhaps we can share that with you and home in on some of those questions and on the actions that we can take to support the excellent work that you do.

Ms Ogle: That would be super, thank you.

The Chairperson (Mr Lyttle): Thank you very much, Sian.

Mr Sheehan: Sian, thanks for your presentation. The Committee has devoted significant time to emotional health and well-being issues; indeed, when the mental health champion, Siobhan O'Neill, was with us a few months back, she agreed with my assessment that there would be a tsunami of emotional and well-being issues coming out of the pandemic, the lockdowns and so on. Although you mentioned in your presentation that young people who contacted your organisation did not reference the lockdowns or the pandemic as the cause of their eating disorders, they are certainly the backcloth to a lot of those situations. What is your assessment of all of that?

Ms Ogle: Yes, I agree with you, Pat. The children are maybe not able — they do not tie it back or say to me, "Oh, I feel this way because I was locked down for six weeks"; what they say is, "I feel this way because I have been unable to see anyone". They name the specific factors in their environment and the lack of social opportunities — all of the things that, we know, are more prevalent because of the pandemic. Indirectly, I definitely agree with you. That is what I hear on the ground.

Mr Sheehan: Do you expect the situation to continue over the period ahead? We are being warned that things will get worse with the pandemic over the autumn and winter, and the British Prime Minister warned yesterday of the potential for more lockdowns in the future, just as everybody thought that we were coming out of them completely. Do you expect that to throw up further problems and difficulties for young people's emotional health and well-being?

Ms Ogle: Yes. I have concerns on multiple levels. The primary one that I think about is that the strain on services was obviously already there before the pandemic. With so many more young people becoming unwell and more people being exposed to those risk factors, we are adding more and more people to longer waiting lists. An example is that poor child I mentioned who had to wait 26 weeks with an emergency case. With all due respect, a child with anorexia could be dead within 26 weeks, so that is really concerning. I am also concerned that, although I completely support lockdowns, the more we are in and out of them, the more we create stressful life transitions for children who are maybe in and out of school or their mums and dads are in and out of work. All those life upsets obviously increase the risks for us. On the basis of our figures, our calls and support requests remained constant between July 2020 and July 2021. We saw that similar level. It goes up and down month by month, but we saw a pretty consistent level of need throughout the pandemic. We have not seen any lull; that is for sure. I expect that to continue.

Mr Sheehan: OK. Thanks for that, Sian. In your presentation, you referenced your organisation being a charity. Do you receive any support from the Education Department or the Health Department?

Ms Ogle: Yes, we do. We are fortunate to receive a small grant from the Department of Health. I think that there is one from the Health and Social Care Board (HSCB), although I am not sure whether those will be amalgamated in the future. My position has been funded for a number of years through Halifax funding. That is all that we have at the minute, but we are grateful for it.

Mr Sheehan: Absolutely. It is good that you get that support. You said that your organisation consists of three people. Do you have sufficient capacity to deal with all the contacts that you receive?

Ms Ogle: I could have another five people and still have work enough for everybody. We are definitely under significant pressure and find that we have to prioritise our work. I will always prioritise speaking to and supporting people, because that is the primary aim of our organisation. Ultimately, I would like to focus a lot of my time on early intervention and prevention. However, as there are only three of us and we receive all those support requests, which we must prioritise, our training and prevention workshops are deprioritised a lot of the time.

Mr Sheehan: OK. Thanks for that, Sian.

Mrs Dodds: Hi, everyone, and good morning, Sian. Thank you for the presentation. Your last comments lead very well into the question that I wanted to ask. Teachers and school leaders spend an enormous amount of time with young people; they see them every day. What is your assessment of how teachers are trained in and have knowledge of these issues so that, if they are concerned, they have a way of taking it forward?

Ms Ogle: Many teachers and pastoral care heads in particular are amazing. I have had calls from pastoral care heads, and you can tell how much they care about their young people. However, when I have been doing the training with organisations, charities and schools — I sometimes help out with safeguarding training — I have also found that there is a general lack of understanding among many people about what eating disorders are as a coping mechanism for difficult emotions. An increase in understanding would really benefit pupils, and I would love to work more with teachers, perhaps in our teaching colleges, to integrate that learning so that they feel prepared. A lot of the teachers that I speak to lack confidence in dealing with eating disorders because they are so worried about saying the wrong thing and possibly making someone worse. I completely understand that, and we would love to be able to support teachers to develop that skill.

Mrs Dodds: Thank you. On the same theme, I recognise that teachers care a lot about their pupils and will try to help wherever possible. Is there anything that you would recommend that the Committee should do, ask for or campaign for that would improve the ability of teachers to recognise a problem and have a clear route to dealing with it? That would help young people, but it would also help teachers who may be anxious about a pupil or young person. Having clear pathways and understanding of how to do something is massively important. What are your recommendations on that one?

Ms Ogle: I would include a degree of eating disorder awareness training, either at the stage of training to become a teacher or routinely, which would be great, certainly every so many years. I already do that as part of that safeguarding training. That would give teachers a basic understanding of eating disorders across the board.

When it comes to pathways, we often discuss the need for proper safeguarding and proper safeguarding policies and approaches for teachers. It can be a safeguarding issue at times. Most of the time, teachers will have that end of things covered and well resourced and all that sort of thing. The only routes for eating disorder support at the moment are through our organisation or the trusts and the services. I would be more than happy for the Committee to ask teachers to speak to us. We would be more than happy to take those calls. What could really help everybody is actual improvements to the services so that young people are not sitting for months and months and teachers do not know what to do. Effectively, those young people are in limbo, and there is a limit to what teachers can do, other than be emotionally supportive, which we would love to help with.

Mrs Dodds: Thanks.

Mr McCrossan: Thank you very much for the presentation. You raised a concern about a lack of early intervention. I want to make a number of points about that. Why do we not have the capacity to intervene early? What are the consequences of a lack of early intervention? How can that be fixed and at what cost?

Ms Ogle: The big word there is "cost". One of the big things about early intervention is that eating disorders are a secretive illness, partly because of the shame and stigma that are still attached to them. A large part of raising awareness is tackling the myths and misconceptions about eating disorders, because those myths and misconceptions directly lead to people not going to receive help and to things getting to crisis point. Tackling stigma is a big one. Another one is ensuring that medical doctors and GPs have the appropriate knowledge of and training on eating disorders. In the rest of the UK, 1.8 hours of a foundation doctor's training is dedicated to all eating disorders: we do not think that that is enough. We work with Beat in the UK to increase that training, and we are working with Queen's to increase the training for health professionals that I mentioned in my presentation, to get in there and recognise the signs earlier.

The importance of early intervention is shown by the fact that every research article indicates that the earlier you intervene, the less chance someone has of becoming really or chronically unwell. If you can get in and provide someone with appropriate eating disorder-specific support early on — it is a highly complex psychiatric illness that requires specialist treatment — the chances of someone being very unwell for a long time are much lower. That is why we prioritise it so much.

Mr McCrossan: Thank you. Do you believe that there is a skills gap amongst professionals who support children with eating disorders? Which professional groups could benefit most from upskilling in that regard?

Ms Ogle: Yes, massively so. I was thinking about that when I touched on how much we welcome the workforce review that is proposed in the mental health strategy. We know that there is a skills gap here. Northern Ireland does not have an inpatient centre for children or anybody with an eating disorder. Anybody who becomes very unwell is sent across to the UK. The workforce review will highlight the need for appropriate eating disorder specialists. We often have to bring people over from England, Scotland and Wales.

The area that requires the most development — I have seen some moves towards this, but I would like to see more — is therapeutic interventions. Eating disorders are fundamentally a mental illness. I certainly welcome intervention from dieticians, occupational therapists and social workers. Whilst those numbers are low, they are not quite as bad as the likes of clinical psychologists, CBT therapists or things like that. I am absolutely happy to disclose that we are a peer-based organisation and that I have had eating disorders myself. I went through the service, and I did not get any therapeutic intervention from a clinical psychologist or a CBT practitioner for the entire time that I was in the service. There is a dire need for therapeutic intervention for what is a distressing mental illness.

Mr McCrossan: Related to that, do we have experts here who can upskill the professionals who have a remit to help children with eating disorders?

Ms Ogle: That would need to be identified by the workforce review. From what I have heard on the ground, there is not as much of a developed service in eating disorders as there is in other areas — I could be wrong in this, but it is my understanding — and the career progression prospects are not the same. Often, someone will come in to take a band 6 post and then move back out. It is maybe a case not of reskilling people who are already there but, for the people who are coming up, of developing the facilities and funds for those people to want to develop a skill set in eating disorder work. That is my understanding, but it would be great to see the outcome of a proper review.

Mr McCrossan: That is great. Thank you very much. That is helpful.

Mr Butler: Thanks for your presentation, Sian, and thanks for sharing your own journey when you were speaking to Daniel.

I will start there, if that is OK, and ask two questions in one so that I am not repeating. First, where do you see peer support and peer advocacy coming in? You talked a bit about the need for specialist intervention, which, I am sure, we all agree with, but I know that peer advocacy and peer support are almost invaluable when we talk about mental health services. Will you also give us more information on the life impacts of untreated or undiagnosed eating disorders? I know a bit about them, but I want you to talk about them and let people know what the impacts on people's lives will be if we do not do something about the issue.

Ms Ogle: Yes, 100%. Thanks very much for your questions. Peer support has an invaluable role in supporting people with mental illness in general and with eating disorders in particular, because it is such an isolating and secretive illness. When we speak to people on the phone, we often do not disclose the fact that it is a peer support agency, but they know that it is. Just knowing that fact gives people a level of trust in us. They know that we get it and have lived through it, and they do not have to worry about being misunderstood or misconstrued in any way. Often, people just want to be understood; they want to be heard, and that is a significant part of our work. Peer support is not a replacement — I am sure that you know that — but I certainly advocate working alongside the eating disorder team. My absolute dream is to see those peer support workers, who have lived experience of eating disorders, working alongside and helping psychiatrists and clinical psychologists and adding to the skills mix.

I cost the NHS a lot of money because of my eating disorder. My personal circumstances are that I had ME or chronic fatigue syndrome, for which there is no service in Northern Ireland. The lack of support for my ME and the fact that, basically, I was left to educate myself meant that I developed binge-eating disorder. That was not caught, which meant that I developed bulimia. From bulimia, which also was not caught, I went on to develop anorexia. All those things had massive impacts on my health: I have osteoporosis, a damaged heart and ongoing health issues outside of that. They also affected my career: I finished my GCSEs and graduated later in life. Moreover, as I said, I probably

cost the NHS a lot of money. It really is a moral duty to intervene early, but it is also cost-effective. If someone had been able to catch things earlier for me, it would have saved a lot of money for services. I preach about those things a lot when I talk to people about the importance of early intervention on the basis of my own experience.

Mr Butler: Thank you, Sian. Chair, I missed a little of what Sian said. I got 90% of it. I do not know if anybody else is experiencing difficulties with screens freezing and so on, but I want to put a marker down for the Clerk to look into it. It has been raised a number of times with me in the past couple of weeks.

Sian, thank you so much. It is important that people are made aware not only of what people are living through in the moment but of the life impacts and what happens to your health, employment opportunities and relationships. As you said, the problem that people live with is secret, so people are kind of hidden.

I was interested in the gender breakdown. You said that one in five reported cases is a male. Is that statement an accurate reflection of reality, or, because boys, traditionally, are less likely to talk out their problems, might the reality be slightly different from what we see?

Ms Ogle: Yes, 100%. I think that the situation with men and boys is a lot more severe than we understand. We talk about eating disorders and disordered eating as being a spectrum, with clinical eating disorders at the more severe end and going down the line to disordered eating. A lot of men hover around that line and may not think of their behaviours as eating disorders or disordered eating. They tend to say things such as, "Oh, I only do that to make the right weight for my boxing". An awful lot of societal rationalisation comes out when you are speaking with men. I definitely think that the stigma affects men particularly badly. We really try our best to reach out to men and to make our service as gender-inclusive as possible for all people, but I certainly agree.

Any research by Beat, Bodywhys, down South, or by any of the main organisations agrees that we massively underestimate the number of men who struggle. From our service's perspective, we find that more men come to us about binge-eating disorder, but we also see an increasing number of young boys with anorexia. There are a couple that I am supporting at the minute. There are more under there than is realised, for sure.

Mr Butler: My final question is not a question. I really enjoyed your presentation. Obviously, the voice of young people is really important in what you are doing. Coming to us is brilliant, because we will be able to push an education piece, particularly around prevention and awareness. There are two fabulous groups that you may want to tap into in order to raise awareness among young people. One is Pure Mental NI. It is incredibly engaged and a great platform to work with. There is also the Secondary Students' Union of Northern Ireland. It has 25,000 members, which could help with identifying people who are hidden and with raising awareness in the meantime.

I thank you for your presentation. I am sure that, as a Committee, we will do what we can to assist you.

Ms Ogle: Super. Thank you.

The Chairperson (Mr Lyttle): Thank you, Robbie, and thank you, Sian. As Robbie said, Sian, thank you so much for your brave and powerful testimony and the work that you do. If the health service were to listen to you, it could save a lot of money. Hopefully, that will be the case.

Ms Brogan: Thank you, Sian. I am glad that you have had the opportunity to present to the Committee. It is such an important issue that could be overlooked. With all that is going on with the pandemic, it would be easy to overlook it, but it is such an important issue. I am glad that you have had the opportunity to present to the Committee, and I echo Chris and Robbie in saying, "Thank you so much" for sharing your personal experience with us, especially for highlighting the long-lasting effects that an eating disorder can have. It brings it home to everybody.

From the Committee side of things, I am interested in what teachers can bring to the table. I know that you touched on it when you spoke to Diane. Teacher training could be a really good way of bringing in some sort of early intervention for young people who are suffering with eating disorders. Can you be more specific about what kind of teacher training you think would be beneficial for teachers and teaching staff such as classroom assistants?

Ms Ogle: No problem at all. Thank you for your question. I may be biased, but I think that the things that we deliver in our psycho-educational training would be beneficial. I have delivered those workshops to teachers, and I have certainly had positive feedback about them.

The main things that teachers come to us and ask about specifically are about how to support someone, the things to say or not say, what the care pathways for eating disorders in Northern Ireland are and what the young person is going through. A lot of the time, the eating disorders that people deal with are not anorexia, bulimia or binge-eating disorder. There is other specified feeding or eating disorder or ARFED, avoidant/restrictive food intake disorder. A lot of the time, with those lesser-known eating disorders, people do not understand what the person is going through. We touch on that big mix, as well as safeguarding issues such as when to call parents or what we say about safeguarding and things like that. Those are some key areas that, certainly, on the basis of what teachers ask me, would be helpful.

Ms Brogan: That makes some sense, Sian, and I can imagine anybody not knowing what to say or being afraid of inflicting more shame on the child and the consequences of that.

The other thing I want to ask you about is social media. Has it a big influence on eating disorders, through body image? If that is the case, is there scope to address those issues through an e-safety strategy?

Ms Ogle: Social media has a big effect on young people. You are effectively creating a numbered value on attractiveness for young people, with how many "likes" you get or whatever. Often, that is a specific kind of attractiveness. We hear young people talk about the pressures and anxieties created by social media. A poor body image and low self-esteem are both linked to eating disorder risk. Those are definitely things that we touch on in our prevention programmes.

Social media is a problem, but I sometimes feel conflicted about what we should do about it. Social media is here to stay. The best approach that I have come up with so far is to try to get those children to have as much media literacy skill as possible. Part of our prevention programme is going through media literacy. One thing that I found incredibly helpful, and I know that other people have as well, is realising how much effort goes into producing that wonderful, perfect picture that someone has put on social media. How long have they spent setting up the lighting, editing the picture and putting their plants up in the background? Knowing the effort taken to achieve that makes it seem more unrealistic to young people. Producing film and media content yourself makes you realise that you have to set cameras in a certain way and all that sort of stuff. I have found it to be really beneficial for young people.

Ms Brogan: It backs up the old saying that it is about what you see versus reality. We should explain that to younger people so that they are all aware of that. That would be good on a wide range of issues. Sian, thank you so much. We really appreciate you attending. I enjoyed listening to you.

The Chairperson (Mr Lyttle): Thanks very much indeed, Nicola. We appreciate that.

Mr McNulty: Hi Sian, how are you? Thank you very much for your powerful evidence. Well done. You are a powerful, positive example of somebody who has come through this complex, psychological, traumatic illness, and you have come out shining. You have bounced back, thriving and blossoming. You are a brilliant example to young people of how you can come through that, so well done. Be proud of what a powerful and strong advocate you are for children and young people and people in general who suffer from this illness. You are literally saving lives. You are articulate and an authority on this issue. You are not as detached from the issue as so many experts are. You have powerful credibility, so well done, Sian. I cannot emphasise that enough.

You mentioned that those in the real depths of this illness have to travel across the water. How many children or young people have to do that every year?

Ms Ogle: I appreciate your kind words. It is a long slog, and I really appreciate that, Mr McNulty.

I do not have the exact figure of the numbers who travel to England, but I know that it is a not insignificant number. Frankly, it is immoral for a single child to be sent away from their family, regardless of how many it is. I will try to find out that number and get back to the Committee with it. However, it is not moral or right for parents to have to fund flights, boat tickets, hotels and all the costs of going to see a child in treatment. Often, the difficulty is that the child is very unwell in a unit in

England, Scotland or Wales. They might not even be pleased to see the parent. They are often very unwell, angry and upset that they have been pulled out of their home. That is such a distressing experience for parents and families.

I know that an options paper has been created. I do not know whether that is in the public domain yet, but I know that it has been written. It is about whether Northern Ireland should have its own inpatient unit for eating disorders and whether that should be focused more at a community level to prevent people from becoming so unwell. Certainly, I would not mind which way they ended up doing it, as long as there was some provision for people who required inpatient care here. I know that some people have passed away while over in mainland UK. For parents, that is horrendously traumatic. That is not an appropriate way to care for people in this day and age.

Mr McNulty: Absolutely. I could not agree more, Sian. When you put yourself in the position of a person experiencing that trauma, you realise that having to travel to the UK for treatment would only exacerbate your despair.

I go back to what was asked previously: what is the number-one ask of us, Sian?

Ms Ogle: An increase in awareness — I understand that your priority is the school-age group — be it through schools' campaigns, public health campaigns or teacher training. I am up for anything that increases awareness about eating disorders and the signs and starts to cancel out those myths, if possible. In addition, I ask that schools be able to access the appropriate psycho-educational training and prevention workshops. I could have a full-time member of staff doing that training, and I could fill up my calendar from now to Christmas with it, because there really is a demand out there. It is wanted, and people want to learn to do better. However, the issue is capacity.

Certainly, the dream for me is to have increased awareness, psycho-educational training and prevention and some of sort of service for children with autism and ADHD, because that area is often really overlooked. There is such a crossover between issues with food, disordered eating and eating disorders and children who have autism and ADHD. We get calls from parents who have been passed around the houses, from GP to dietician to mental health practitioner and then back to the dietician and the GP, before being discharged with nothing. There needs to be some sort of integrated system. Greater support for children with ADHD and autism is a big priority for me.

Mr McNulty: Do you feel that the prevalence of the condition is greater among children with autism/ADHD?

Ms Ogle: It is under-researched, to be honest, on an academic level and a prevalence level. It is starting to come out now that there are links between autism and anorexia nervosa. We see quite a bit of that. There are also issues with avoidant/restrictive food intake disorder, which is an eating disorder whereby someone restricts their intake for reasons other than body image or self-esteem. It might be to do with the sensory aspects of food, fear of choking or fear of abdominal pain. We tend to see that quite a lot in children with autism and ADHD. There are particular needs in that population group. We vastly underestimate how much people struggle with that. I know that there is a parent group or a WhatsApp/Facebook group of parents in Northern Ireland who are dealing with the issue and are supporting each other because they cannot access any services.

Mr McNulty: That is sad.

Ms Ogle: Very. God love them.

Mr McNulty: Absolutely. Sian, thanks very much for your evidence.

Ms Ogle: Thank you.

Mr Harvey: Thank you, Sian. First, I really appreciate what you are doing and what you have done. We are mindful of what you have been through. At the minute, it is a serious concern. A lot more people are unwell. A lot of it boils down to the fact that there is increased pressure on our youth, and that is sometimes because there is more pressure on the parents. At this time, there is also a lot more pressure on teachers, which we are trying to deal with. A lot of questions have been asked, and a lot of mine have been answered, which is grand.

Early intervention is key, as is the role that schools and teachers play in that. I was going to ask about training and advice, but you have all that well answered and covered, which I really appreciate. Several disorders were outlined. What is the most common among young people at present? Is it the same for all age groups, or do different forms present more often in younger people than older people?

Ms Ogle: Most commonly, about two thirds of our calls from young people are about anorexia-type symptoms. Not everybody has a diagnosis yet because of the access issues, but it is those type of restrictive eating disorder symptoms. The one that would follow that in young people is binge-eating disorder, which, for the Committee to understand, is not just overeating occasionally, as, I am sure, you know. It is extremely distressing and compulsive, and those young people feel that they are unable to stop. They are completely out of control with their food and their weight. It is almost like a compulsion or an intrusive thought, and it is very distressing for them. About 25% of our calls are related to binge-eating disorder, 20% are related to bulimia, and the rest are unspecified and come under the umbrella term of OSFED or ARFID in maybe about 5% of cases.

Mr Harvey: While they are all equally important, anorexia seems to be the most life-threatening one in the end.

Ms Ogle: To be honest, they all are. In my personal testimony, I was initially in hospital because of bulimia. When you are being sick, you disturb the electrolyte imbalances in your body, and that can lead to sudden death. I have friends who have died because of that. With binge-eating disorder, there are risks of heart disease, obesity and diabetes, which, in themselves, can be lethal, so we try to take the approach that they are all potentially lethal illnesses.

Eating disorders as a general theme have the highest mortality of any psychiatric illness if you do not include addiction, in which case they are second. We take the approach that it is crisis levels at all fronts if someone is seriously unwell with any eating disorder. It is the level of unwellness that we try to focus on most of all.

At the moment, we are seeing, and I have heard through services, that people with anorexia are being prioritised in care here because of the immediate medical risk and stuff like that. I also know of people who are bulimic who are suicidal and are self-harming to a degree, and they are being deprioritised. It is a concern for us that we see a bit of inequality even within eating disorders.

A final point that I would like to make is that, at the moment, if someone goes to their GP and goes down the eating disorder care pathway, if they are deemed to have anorexia or bulimia, they are referred to the eating disorder service here, but, if they have one of those other eating disorders — binge-eating disorder, OSFED or ARFID — they are referred back to general mental health services. That is not appropriate. It is such a skilled job to improve the life of someone with an eating disorder, and I would like to see all eating disorders treated equally in the service. That is my personal rant for the day.

Mr Harvey: Thank you very much. I hope that the Committee will be of some help to you. Take care.

The Chairperson (Mr Lyttle): Thanks to all members for your questions. Sian, thanks for your really powerful and informative evidence presented to the Committee today. We are really grateful for it. We will consider what we can best do to support the work that you do to support school-age children with eating disorders. Thanks so much, Sian.

Ms Ogle: Thanks for having me. I really appreciate it.