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Transcription of interview on anorexia nervosa in autistic people with Mair Elliott and Dr William Mandy

Qu. Can you tell us about your current work and how autism has come to play a part in your life?

Dr William Mandy - So, I'm a Clinical Psychologist and a Researcher. For quite a few years, I've been studying Autism and fundamentally trying to find ways in which we can improve services and improve schools, and improve other ways to support Autistic people to lead more satisfying lives. And one of the things I have become interested in is this notion that there are gender differences in Autism, that women and girls on the Autism spectrum present somewhat differently to boys and men, and therefore need particular specialised support. And one of the areas that's led us into is an interesting in the overlap between Anorexia Nervosa and other restricted eating problems, and Autism.

Mair Elliot - I suppose my journey into Autism started from birth, so I'm diagnosed with Autism Spectrum Disorder, and I've also experienced Eating Disorder from the age of about 14. So, I'm 21 now, so it's something that's very personal to me.

Qu. What is the prevalence of anorexia nervosa in autistic people and do you feel this reflects an accurate picture?

Dr William Mandy - What we strongly suspect is that the prevalence of Anorexia Nervosa is higher amongst Autistic people than amongst non-Autistic people, and particularly higher amongst Autistic teenage girls and Autistic women. Funnily enough, we don't precisely know the size of that increased risk. What we know is, we know about this almost from the other side of the equation. So, we know that if you look at people who are diagnosed with Anorexia Nervosa, so people who are in various countries actually across Europe, who have been diagnosed with Anorexia Nervosa, who are receiving treatment, we find very, very high rates of undiagnosed Autism amongst those people. So, generally, 20 to 30 percent of people, of women in studies of Anorexia Nervosa, if you actually assess them and think carefully about their social

communication and their flexibility, you find that 20, 30 percent of those women meet the criteria for Autism.

Mair Elliot - I think it's important to say this is only just starting to be recognized, and so there's still a lot more work that needs to be done.

Qu. What can be some of the challenges of identifying anorexia nervosa in autistic people?

Dr William Mandy - I think one of the challenges that has really, sort of, I wouldn't say held back the field but has really represented a significant challenge to Clinicians and to Researchers is that, actually, the psychological effects of starvation can mimic, in some ways, the characteristics of Autism. So, people who are starved, you know, and almost by definition, people with clinically severe Anorexia who are experiencing starvation, tend to experience less social interest, become less empathetic and become more inflexible. So, one of the real challenges has been, if you like, to discriminate between symptoms that actually arise from starvation and those that reflect, that truly reflect, an underlying Autism Spectrum Disorder. And I think that's led people to miss Autism amongst people who are experiencing Anorexia 'cause they, if you like, dismiss their social difficulties as merely the result, a kind of side effect, of their Eating Disorder.

Mair Elliot - From a personal experience, I'd say, partly that, and also, I experienced my restrictive food problems in a different way to other women who don't necessarily have Autism but also have Anorexia. Mine is very much more revolved around the rituals and routines around food, and kind of the obsessive counting, rather than the preoccupation with size and body shape and weight. I still have that element of Anorexia but it's not as overpowering as maybe someone else who has just Anorexia and not Autism as well. So, there may, there theoretically may be differences in the presentation of AN comorbid with ASD.

Qu. Is the experience and presentation of anorexia nervosa different for autistic people compared to neurotypicals?

Mair Elliot - It's almost as if it becomes, food becomes a special interest. So, people with Autism will have special interests, which is one topic that they focus on to an extreme extent, and therefore be referred to as obsessions and things like that, and it's almost as if the special interest becomes food, and counting calories, and the rituals around food, which can start to become damaging in terms of restrictive eating. Like, for myself, I will get into a routine of rituals and rules around food, which result in me losing an extreme amount of body weight very quickly. And although I do have an altered sense of body image, it's not the main preoccupation when I'm struggling, it's more to do with the obsession and the rituals, and that may be similar for other people with ASD and Anorexia Nervosa.

Dr William Mandy - And I'll just add to that, I think that's really, really important in terms of the services that we offer Autistic people with Eating Disorders. So, you know, the classic formulation of Anorexia Nervosa that would be a nice guideline, and it will be used in Eating Disorder services across the UK and beyond, is that this is fundamentally a condition driven by weight and shape concerns, and so, inevitably, a lot of the treatments focus on that. So, there's

CBT that might address people's weight and shape concerns. Now, if you're giving that to somebody whose eating problems aren't actually driven by weight and shape concerns, that's a waste of resources. You know, it could actually be quite harmful for the person receiving it 'cause they're then taking a treatment where their difficulty is not really being understood. I mean, perhaps even somebody might be dismissed as being dishonest, you know, in these sort of services, because, oh, no, I don't have weight and shape concerns, you know, staff might think, well, actually that's just somebody in denial, whereas, actually, that's really not what the issue is. So, it's really important that we get an Autism-specific understanding of eating difficulties so that the large numbers of women presenting with those difficulties are actually listened to and treated effectively.

Mair Elliot - I think, from a personal experience, I've had extreme difficulty getting the right support, and I still haven't to this day, so I still get into loops of restrictive eating and becoming very unwell, because when I access the standard treatments and approaches that are available on the National Health Service, they're all focused around body image and body weight, and that's not the primary concern from my perspective in terms of my food problems. And so, what often happened is that I will start accessing some kind of support, it won't be relevant or appropriate to what I'm experiencing, I tend to feel like I'm not being listened to, and I also get accused of choosing to not engage, and then they withdraw the support, which then is a very frustrating situation to be in, especially when every time I've fallen unwell, I actually am asking for help, but that relevant or appropriate support isn't available. And also, professionals just don't have the awareness or the knowledge of what it is to have comorbid ASD with mental illness and Anorexia Nervosa, and they don't understand the interplay between the two diagnoses and what that can mean for someone living with the two diagnoses. It's very, very hard, currently, if you're in this situation that I am in, to get the appropriate support.

Qu. Can you tell us about your experience of trying to access support?

Mair Elliot - I have to say from the start that I have a really complex diagnosis history. So, I have had psychotic episodes, Dissociative Disorder. I've got a vast number of diagnoses. So, it's not just the Autism and Anorexia, it's an interplay between all of them, and it can be quite hard to separate out which is doing what and causing which behavior, et cetera, et cetera. But, in terms of the eating issues, I actually started to experience eating problems around the age of 14, and at the same time, I was developing depression and anxiety, I was self-harming, and it kind of snowballed into a far more serious situation. But the eating problems were actually the first thing that started to appear. But because I wasn't exhibiting concerns around my body shape, I wasn't restricting food to lose weight, it was more to do with that restricting food gave me a sense of control, it became, the maths around it, I loved doing maths, and the maths around restricting food was something that I could immerse myself in when everything else felt too much. And so, because it wasn't around body shape, or weight, professionals did not pick up on it as Anorexia Nervosa, and what that meant was I didn't get any support for my food intake or relationship with food. And so, it was allowed to just kind of carry on and become much worse. And it wasn't until, I was in a psychiatric ward for about four months, but I was in this psychiatric ward with girls with Anorexia Nervosa, and I kind of instinctively adapted myself, as Autistic women do, adapted myself to fit into the social situation, which meant that I was actually subconsciously picking up on the Anorexia Nervosa characteristics that these other girls were exhibiting. And it was only after that, then, that I officially got diagnosed with Anorexia Nervosa, and then I started to receive the support, although it wasn't appropriate or relevant support.

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And so, it's still a huge issue for me in day-to-day life, but by doing things like this, hopefully it'll change.

Qu. Can you explain some of the support options you might use for autistic people with anorexia nervosa?

Mair Elliot - The thing that's helped me most is having a bit of self-awareness, and that's not really come from services, that's come from my own research and my own, just, everyday living through it and starting to be able to recognize patterns and behaviors. So, the self-awareness is quite important. My family have been helpful, obviously. They're there day to day, so they're living through it with me. Unfortunately at the moment, as I said before, it's really hard getting the right kind of support, So, for about seven years now, I go through a cycle of becoming unwell, which often leads to all my other mental illnesses getting worse, which often leads to, then, having to go into hospital, and then coming out and not getting the right support, and then the whole cycle starts again. It's a very complex issue and I think we need to be doing the research to be able to build this model of what AN, or Anorexia Nervosa, looks like in Autistic women to be able to kind of adapt treatments and approaches that are available.