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Self-harm and autism: an interview with Lucy Sanctuary

Can you tell us how you first became interested in autism?

So, I used to work with a child who was on the spectrum before I trained to be a therapist, and then, once I trained, I worked in a special school, to begin with, so I always had children who were on the spectrum on my caseload. But I was interested in lots of areas, not just autism at that stage.

And then I think that when I decided to leave the NHS, I was so surprised by the number of families who contacted me, who had children on the spectrum, who had slipped through all services. I thought I would have people contacting me to say "Oh, my child can't say...", I thought I'd have things like that, which I'm not...that's very important, but it's not my main area of interest, and I was absolutely amazed at...it was all autism work, there were so many families who I kind of saw the other side, so suddenly I heard all these stories about families that hadn't made it onto anyone's caseload, had had no help, didn't know what to do in very, very challenging situations, and yet there was no help there for them.

So that was one thing that started to turn it into more than just, you know, it became then a really strong interest, but also my daughter was diagnosed with being on the spectrum as well, and that also was very, very life-changing, so I think those two events changed everything for me, because when I worked at the NHS, and I do still work for the NHS, and the NHS is fantastic, but you very much are ring-fenced, but if you start to work independently, you take away that fence and I found it shocking, having a look at the world outside of that fence, and very life-changing.

Can you tell us about your current work?

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So, I work part-time for Kent Community Healthcare Trust, I went back into the NHS having said I left it; I do really believe in the NHS and I do the ADOS, so I have a very ring-fenced role by choice there, which is where I assess for autism using the Autism Diagnostic Observation Schedule with a consultant who is fantastic, so we do them, we do all ages, so, the youngest we've done is probably...we don't like to do under the age of three, but every now and again it happens if it's very obvious that that child is on the spectrum, and then I go up to 18, because I've also started to assess for CAMHS too, so I do early years, school age and up to 18, as I said.

And I also train for them, so I go and train some schools and with specialist teachers for early years, so that's my role for them, and then I work for a cluster of schools near Brighton and that's really fantastic because we do a lot of social communication stuff, so we are in the process of setting up long-running social communication groups, so I went to some training that said that courses like that have to run for three years to be truly effective, so we're trying to start it in Year 5, so that it will run for Year 5, Year 6, before the children go on to secondary school, so I'm lucky to work with a wonderful team and me and a specialist teacher set them up in the school, we spend a term, two terms working with teaching assistants from that school, setting it up, and then we hand it over, so we're embedding it through six different schools, which is just, it's really exciting, it's really fantastic, and we involve the families in that, and we try to take everything as wide in the school as we can, so resources in the classroom, in the playground, just to try to help transfer those skills that they're learning, so I do that, and then I have a very small caseload which I see privately, so that tends to be either children at the very, the lower end of the spectrum, so non-verbal or not much language, and working very closely with those families and that child to enable communication, which is great, and otherwise it tends to be the other end, very high functioning children and young people who have lots of problems with social communication and anxiety, so I don't tend to get so much in the middle actually, it tends to be those two, the two ends of the spectrum.

And I also am doing a Master's on top of that, so I have a case study, eight weeks of a case study and then I change, and those case studies are always on the spectrum because my Master's is in CBT for children and young people specialising in autism, so I'm not really interested in doing CBT with any other group of people, so, it's quite busy.

What factors might lead a young autistic person to harm themselves or others?

So, really complex question, and there's many, many, many. I think that it's unlikely to ever be just one factor; there's many elements involved, but I think that sensory factors can be a great area of difficulty and can lead to someone feeling absolutely so overwhelmed that they can then self-harm as a response to very unbearable feelings, so maybe that is to do with, you know, noise, to do with light, to do with textures, to do with all of those things, emotional regulation is a really big one, so recognising how you're feeling, recognising when that feeling is starting to increase and executive function difficulties are involved in that as well, because it's not just a matter of being aware of how you're feeling and being aware of the fact that it's increasing, but

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it's also being able to say "Stop, oh my goodness, I'm becoming more agitated, what could I do? Oh, well I could do this, and what might be the result of doing that? Or maybe I could do this and what would the..." you know, that sort of problem-solving thinking is also an area of difficulty so, they're all sort of linked together, so executive function difficulties, recognising emotions and realising when they are increasing, being able to bring yourself back down to an emotional state which you can function at, an emotional regulation, those are all biggies, communication is a massive one as well, being...a lot of communication is very, very stressful for a whole range of different reasons that I could spend a very long time going on about, but won't!

But you know, all those areas are big, big areas, and it's very hard to have one of those in isolation, and I think that, you know, you can talk about those factors in relation to a child or a young person, but you've got to go a bit wider than that as well, and talk about those factors as they are in the environment around that child or young person. So it's not just about them, it's about what they're interacting with and what is around them as well.

How can professionals support families and young autistic people to prevent harmful behaviour?

The first place that I always start is reducing the triggers, so, reducing the anxieties, reducing the pressure, reducing the stress, taking away as much as you can of things that just add and cause and create stress and pressure for a child or a young person, and that is very difficult as well, because that involves everybody becoming much more aware about the language that they're using with those children and young people, how much language they're using, what kind of language they're using, it involves everybody else looking at their communication to see whether actually they can help that child or young person more by adapting their communication and that is very often the case, and I think that sometimes, in fact very often, people use much too much language and ask too many questions and, you know, they're doing things that they expect to be able to do with someone of that age, but we're not talking about a situation like that, we're talking about a situation where actually, you do need to adapt. You might, that might be what you expect to be able to do, but that is not what you can do, and you need to adapt, how you are communicating, so I think that we all have to look at our own communication and we have to think, reflect on it and think what we need to do in order to make that less stressful, so that's one thing, you need to look at the environment, you need to look at, is it very noisy? Is it very bright? Are there lots of distractions here which are causing stress? You need to look at the routine; is it very unpredictable? Can we make it more manageable? Can we help the child or young person to give them, can we give them more control? You know, I think all these are really big areas and they're not easy to work on, it's, I find often that you know, when you start to get families to look at what is happening and what the triggers are, it's quite difficult to start off thinking like that, but that is definitely, to my mind, the way forward, to look at everybody around that child and young person, the profile of that child and young person, everyone around them, the environment, and then look at what it is you have to adapt in order to reduce those pressures, reduce those stresses and to enter the

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world of that child or young person rather than dragging them out to be in a very difficult situation.

So that is one area that I always start with but also, it's about understanding yourself and others, so you have to be able to recognise emotions, to understand those emotions, not just in yourself, but the impact of those, of things on other people and how that makes them feel; you have to be able to see as your emotions are increasing, so you need to work on emotional literacy, I suppose, and emotional regulation, and you also need to work on all the thinking skills, so there's a lot of areas there, this is something which cuts across many, many, many different areas, it's not a linear path. And everyone is an individual and will have a different degree or amount of difficulties in each of those parts, so I think it's got to be very bespoke as well.

What are the benefits of using speech and language therapy with autistic children and young people?

I've got to really big up speech and language therapy now, I think it is really, I think that speech and language therapy has so much to offer for children and young people on the spectrum and their families and I think that we are often a little tiny voice, which is a real shame because those things that I've just been talking to you about, they are all us, we are all about communication and enabling communication and we are, you know, really very finely-tuned into how to do that and how to help others to do that, and that is a large part of this: enabling people to communicate in the right way, in a way that opens doors, which enables functioning for children and young people, and that is what we are specialists in.

But I think because our profession has been cut back so much, and our role has been reduced so much in lots of ways, I think people perhaps don't know that that's what we do, which is a shame. I think we have a huge amount to, social communication as well as just sort of communication full stop, the whole sort of social interaction side of this as well, that is something which a speech and language therapist very much can help and support with.

How do you feel Cognitive Behavioural Therapy can support autistic children and young people?

Yeah, that for me is the missing part of the jigsaw in a way, so I mean I've only just started that course so I've got to say: I really don't know that much about it yet, but already, what I have been doing and experiencing and reading about is very, very, very helpful, because it deals with the psychological aspects, obviously, more than my own profession does.

So, Tony Attwood is the real master of this, so he writes about adapting CBT for autism, so it has to be adapted, you can't just use regular CBT for children who are on the spectrum. So what it has to offer is it has to offer...in fact, it's very, very similar to the things that I've been saying in that, you know, Tony Attwood says you should always work on emotions and also on social

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interaction skills within that context of cognitive behavioural therapy, and what cognitive behavioural therapy does is it enables a child or young person on the spectrum to be, to have more understanding of their emotional state and of other people's emotional states, so the whole area of emotions and emotional regulation, it does work on, I would say, in a deeper way than speech and language therapy, not to diss my own profession but I think it's...yes, a bit deeper than what I do as a speech and language therapist, and then it also helps them to become more aware of the link between their thoughts and their feelings and their actions, and that's not easy, that's very, very, very difficult for children and young people on the spectrum, but it does help them with that, and that obviously gives them more control, if they can understand emotions more and feelings then they can understand that link between emotions and feelings and behaviour then they have more control over what they do and their lives, so I think it has masses to offer.

I think that it can be very life-changing, and I've seen that already in, I'm on my third case study, but my second case study, it was amazing, absolutely amazing, he, I mean I don't, I was able to discharge him and I can say it was life-changing for him and for his family, because it's much more targeted than what I have been doing as a speech and language therapist as well.