
Autism and kickboxing: Interview with Jo Luck

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Jo is one of the patrons of Anna Kennedy Online (AKO). She has diagnoses of Asperger syndrome and ADHD and is a multiple world champion in her sport of kickboxing. Jo is a resilient, strong woman who was diagnosed as an adult and subsequently has faced many challenges and battles around accessing support and in mental health. In spite of all the knockbacks she has had in recent years, she has not allowed these to defeat her and has in fact grown stronger and has become passionate about developing herself and supporting others, especially around changing views around disability and autism.

You were not diagnosed until you were an adult, what was it like to go through diagnosis and how do you feel this has impacted your life?

I was not diagnosed until 2010 when I was 23 and then I was diagnosed with ADHD in 2014 when I was 28 and it was a mental health crisis that led to my diagnosis. If it had not been for that I don't think I would have been diagnosed. It was actually quite difficult as on one hand it was relieving to know that there wasn't something majorly wrong with me and to know what I was dealing with. But it was also very hard to go through because it led to a lot of self-analysis and it was a lot to process and make sense. It was kind of like having a book that you can't read in a different language or with bits missing but then one day suddenly you can read it because all the information is there. There was a lot of reframing of experiences and things I did. But actually the self-understanding is probably one of the most helpful things in managing day to day life. I did feel sad and think about what might have been with a diagnosis at a younger age. I did have struggles in school, I wouldn't speak to anyone in playschool and then by secondary school I was going through whole days not speaking. I was very stressed and there were a lot of concerns about me, I fell asleep in classes. I couldn't structure my revision for my exams and basically did very little work in my exam year. I didn't reach my potential in my exams and didn't know what would be possible for me. With more support this might have been easier. I went under the radar in

school as I was very quiet. Accepting I was autistic was easy, it was the understanding and accepting what it meant for my life past, present and future that I found more of a challenge.

How did it feel to become a patron for AKO, can you tell us about your experience around being involved with AKO?

I first got involved with AKO after I spoke at Autism's Got Talent in 2013. It was just after I had won my world titles in kickboxing and I had started speaking to school assemblies and I just wanted to reach out and help others and give some hope. I felt privileged and honoured to be asked to become a patron. It was a big thing for me, it made me feel valued. I haven't been able to do as much as I would have liked with the charity as I have had a lot of difficulties over the last few years, but I have created a comic and spoken at a few events including the AKO Expo. I've also helped people that I have met through the charity. I like being involved with AKO, everyone is friendly and happy to see me when I am able to come to events. I have made friends and it has had a positive impact on my life.

You have been very successful in your sport of kickboxing winning three world titles, what made you start kickboxing?

I started kickboxing with my dad when I was 13; he thought it would be helpful for me in terms of my confidence. At first he took my little brother along and then I went too and I ended up sticking at it whereas my brother didn't. I just instantly loved it and although I didn't really speak to anyone there for like two years in the end it has been very helpful for me with my confidence and in teaching me how to work hard for things and be successful.

You have said before that kickboxing is really helpful in terms of managing your autism and ADHD, could you tell us how it helps?

Well, my psychologist actually said that having autism and ADHD can actually be a benefit to kickboxing because I am drawn to the repetitive nature and the structure of training sessions. I will practise the same technique until I perfect it and will pick out things to work on. The routine of practising is something I like. Then also the need to be reactive and alert really feeds into ADHD where I constantly need to move and be active. So sometimes I react quicker and notice the patterns of movement in others to anticipate what I need to do. The routine and structure helps a lot as does the inclusion of being part of a team. It has helped me socially and the pressure is off because everyone is there to do kickboxing, we all have a common interest and there is less conversation time. I'm valued for my talents.

I also find kickboxing helps me a lot with my regulation of sensory and stress. I have a lot of sensory issues, things like struggling with bright lights, loud noises, unexpected touch, crowds and visual stress. I struggle with balance too which is funny given I do kickboxing and kick people. When I get overloaded the first things I lose are my speech and balance so I can struggle to walk at those times. Kickboxing helps because when I spar I get a lot of proprioceptive input. Proprioception is one of the senses, it helps us to know where our body and joints are in time and space and it can be very calming. Proprioceptive input can include things like weighted blankets and deep pressure. So for me it is not the hitting people that helps but actually being hit. And you can tell how it calms me, I can turn up to training stressed, not able to have a conversation and within minutes of sparring I am visibly calmer and relaxed. Sensory issues and knowing what works to help can be difficult to work out and they can change in time. Things can become less effective so rotation of strategies is necessary. There are places that rent out weighted things for a trial before buying them. And there is also a really good book (i.e., Voss, 2011) that helps to unpick what certain behaviours might be seeking in terms of sensory input. This book has a contents page of behaviours so you can navigate it easily. Getting to know sensory needs can often depend on

watching behaviours and trying to find alternatives. A couple of years ago I was having meltdowns where I would stamp a lot and nearly fractured both feet doing so, so I got a fitness step with air pods on the bottom and would use this when I felt stressed and it would help me to regulate.

I know that you compete as part of the BCKA Kickboxing Team and have to travel abroad with them. How is it being part of a team, are your team mates supportive or understanding when you struggle?

I have been part of my team for a very long time, so there a lot of team mates who have been there for years and know me really well but some who are newer. I am accepted and my team is very much like a family. I have issues with travel and with sensory environments at competitions. It is something for people to adjust to but it is just part of me and my teammate knows when to leave me or speak to me. They are all really supportive, certain team mates will spar with me and adapt my training when I am going through a more stressful time to help me. When I was in Northern Ireland recently after the competition I was with my carer eating in a restaurant and it was very sensory it was dark but with spotlights, lots of noise, smells and sizzling. There were some small children running around my table and it was making me feel stressed especially after one touched me as they ran past. So then I was scared every time they ran past that they would touch me. I went from being able to be sat eating my dinner to being unable to eat or use my knife and fork properly. I couldn't speak or walk. My carer had to give me my PRN (pro re nata) medication as in this state I was unable to pick up the tablet as I couldn't judge where it was. And my carer knew that I needed to leave the environment but I couldn't balance enough to stand, luckily having team mates around they were there to help carry me out otherwise I'm not sure how my carer would have got me out. Then I was struggling in meltdown back in my room and my coach Alex came to help reassure me and give validation that I was strong. He knows well how to deal with my meltdowns; he calmly gives me instructions about what I need to do and what is happening.

Mental health issues occurring with autism has been something you have been quite vocal about in the past two years, do you mind telling us about some of your personal experiences?

Well last year was a very horrible year for me. I had a mental health crisis around this time last year after I had had to go through a tribunal for Personal Independence Payment and on top of a lot of difficulties I was already coping with. I ended up being away from home for several months, I was taken to A&E and there was nowhere for me to go. Professionals didn't know how to treat me. I was left in A&E for the whole day not knowing what was going on, I had no food, had no assessment; I was on my own and tried to leave but was prevented from doing so even though I had not been sectioned. I was overloaded by the sensory environment and was hiding under tables. Eventually I was put into a crisis house which you are supposed to be in for a maximum of seven days and I was there for 6-7 weeks because there was no service to support me. I was not assessed and I had no health input really and had to pay to see a psychologist privately at this time. The first two nights there I had to sleep on a chair as there was no bed available and there was nowhere else for me to go. In my county there is a protocol not to admit people autism or SEND to psychiatric hospital, however alternative facilities are not there. My psychiatrist reluctantly agreed to see me for 10 minutes and as I was unable to make a decision I had got stressed and the police had been called as I had left and was not safe to walk around. The police liaison officer shouted at me when I had laid on the floor and told me I was an adult not a child and to get up off the floor. I lay on the floor as a coping strategy as I lose my balance and to keep myself safe from self-injurious behaviours that would occur. The floor is hard so laying on my stomach gives me proprioceptive input which calms me down. I was told they would make a decision for me and I ended up back at the crisis house having a meltdown because my dog was not allowed to come back with me. I had been allowed my dog Oscar with me for the first night and then suddenly he wasn't allowed anymore. Oscar is helpful to me; he makes me feel safe and calmer. He knows how to respond to my meltdowns and will lay on me to calm me down. He is very in tune with me.

Because I had no health input when I went home from the crisis house with overnight care I still wasn't OK and was taken to A&E three nights in a row and on the third night I was kept in and admitted to the general ward. There was still nowhere for me to go and there were a lot of meetings about me. While in hospital I was not treated very well, it was very distressing. I was not assessed again; I had no food for two days as I could not make a decision. Nobody was aware of my needs and I had spent a whole day on my own in a room in A&E and then transferred to the ward and was being watched. I wasn't allowed to shut the door to go to the toilet which nobody explained to me. Nobody knew what medications I had to have, I was not given PRN. I hid behind a cupboard and was scared of the staff. I even heard nurses arguing with the mental health team over how to support me and saying they needed more training. I was told if I kept asking to go home I would be sectioned and if I shut the door to the toilet security would be called. In the end I was put into a care home for 7–10 days but ended up being here for 7 weeks. Nothing was communicated to me, my health was never monitored or followed up and I was put into a care home as an alternative to a psychiatric hospital. I only went because my dog could come with me and it was having him here that helped me the most.

So after all that you have been through, what do you think needs to change to support autistic individuals with mental health issues better?

More specific services are needed and definitely more training. I can relate to Oliver McGowan's story (Kennedy, 2019) some parts really resonated with me. Not to the same extent but things like people not understanding autism or my needs, not being listened to, environment not being adapted and communication not being adapted. I felt very much that I was not treated as a person and that my mental health is dismissed as being just due to my autism. More training needs to be led by those who are autistic and those who have had experiences with mental health. It took me four years to get funding for psychologist treatment because the psychology the mental health team could provide they said would not meet my needs, however I was denied numerous times funding for the specialist psychology they said I needed. It has added to the distress and problems and the lack of trust I have in people now has become a big issue for me. I have become involved with the local health service in training. I did my first training day with them recently which went really well, I try to give relatable experiences and examples instead of the more formal textbook style of training.

I know that day to day life can be difficult for you, are there any strategies and approaches that you use to make things easier?

I struggle with a lot of things day to day, it is very deceptive due to being articulate and intelligent. I can go from being like this to being unable to speak, stand or function and needing a lot of help. I need structure. I have visual systems at home, a picture board and each day broken down into tasks. Even if I don't follow the structure exactly, I have difficulty with this due to my ADHD, just knowing there is a plan and having that to follow if I can't decide helps me greatly. It gives me a sense of satisfaction to be able to cross off what I have completed. I have been developing my own strategies with my carer in response to the challenges that occur. Now that I understand my challenges it is easier to work out solutions to the problems. I have a folder to share information with my carer as I often struggle to direct and communicate what I need to get done in care sessions. So this will have my appointments and to do lists in it and also task progress sheets so we can keep on top of what is going on within outstanding issues. I also have been using google speakers to help me day to day as I live alone. I have set routines to give me verbal prompts to get ready for bed and get ready for appointments, etc. I needed more than a reminder; Google will tell me that I have to stop what I am doing and get ready for bed and to take medication. In the morning google will also tell me what I have on for the day and it can help me decide what to wear by the weather. If I say I am going out it will turn off the lights and turn down the heating and prompt me to take the things I need. I have also set commands for things like saying: 'I'm stressed,'

and Google will then remind me my stress is temporary and won't last and ask me if I need my PRN and prompt me to my strategies. I also get things ready the night before including the things I need for each task, as having to set up the task can sometimes mean I won't start it. It is a lot of hard work managing my life but the biggest help has been taking control and ownership of my challenges - this meant finding out more, learning what might help, understanding it and then looking how I could fill in where I struggled with something alternative. I have become very good at thinking outside of the box and being resourceful in managing my day.

What are the most important pieces of advice you could give to someone who is autistic and to a family member of or person working with an autistic person?

To someone who is autistic I would say the biggest thing is that it is ok to be you and it is OK to struggle. It will be frustrating and hard work but accepting this is better than being angry about it, which can just give you more barriers. Learning about autism and your difficulties is really important, if you can take control and ownership of that it will help you feel better about it and you might surprise yourself with the things and solutions you might be able to come up with. You have just as much to add to the world as anybody else and there is always more than one way or one path to accomplishing things. Finding your own way is absolutely fine if the 'usual' way doesn't work.

To family and those working with anyone autistic one of the more important things I think is to validate the experiences of the autistic person. That can be such a huge thing in making a difference. Often the experiences are negative and so much focus is on that and in how it is difficult to understand. Just validating it is ok to have a feeling; to be angry, upset or stressed is so important. You are communicating that you understand something is wrong, you are helping to give a feeling a name, you are acknowledging distress because if you think about it we all need that when we are upset and when our upset is not understood or acknowledged it increases. An autistic person may present this differently or in unexpected ways but fundamentally it is still distress. Even challenging or intimidating behaviours can be a communication of distress. Acknowledge and validate the feeling, even if you don't know what has caused it. Just saying you look very stressed, I don't know what has made you feel this way but I understand this is a very horrible feeling for you and I want to help you, I know this feeling is very scary but it won't last – that can make a huge difference. When I am distressed I can't explain it to people and I can't ever see it being different; that makes it even scarier.

Reference

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