

WELCOME TO EDITION 2 OF THE NEW AND EXCITING CONVERSATION SERIES FROM AUTISTICS ALOUD.

This edition is a Conversation with:

JAKE LEWIS



My name is Jake Lewis. I'm twenty years old, single, and live with my family in the community of Hantsport in the Annapolis Valley.

Over the last decade or so, I have been on a part-time mission to help promote equity, and awareness, for people on the autism spectrum.

I have travelled to schools across the Annapolis Valley, giving educational talks. I have had several articles pertaining to autism published in Autistics Aloud, interviewed a survivor of institutionalization, produced a video on the Red Instead movement, and even been interviewed on CBC a couple of times.

What's more, I recently graduated from NSCC Kingstec in June, having received my diploma in Disability Supports & Services. Currently, I'm working as a casual Residential Rehabilitation Worker at Quest Societies Residential Rehabilitation Centre. There I support adults of a variety of ages, who have complex needs and/or challenging behaviours.



When I'm not doing this, I'm usually painting models, or watching YouTube videos about the models I should probably be painting.



Autistics Aloud is so happy to present a Conversation with Jake Lewis! You may recognise Jake's name from being a contributor to Editions 1 - 4 of the LifeSpans Series.



QUESTION 1

Finding such personal satisfaction at a young age educating others about autism, can you share a specific moment or experience that inspired you to become an advocate, and how your personal experiences as an autistic individual have influenced your approach to advocacy?

Jake

"Well, I was never inspired to begin with, it was my mother who gave me that push. I was around ten years old, in the fifth grade. I didn't want to do it, but she and the EA who was with me at the time managed to make me go along - after much encouragement and prompting - and read off the script they provided. It wasn't until I was around fourteen that I began to truly understand what I was doing, and see the bigger picture of how important advocacy was. Before that realization, I did it because it got me out of class, and I enjoyed the compliments (I still do). Now, as I've gotten older, that random epiphany is what helped motivate me to learn from myself and others. From knowledge comes experience, and from experience comes examples. I can now use these examples, both from my life and the lives of others, to help emphasize and demonstrate the points I'm trying to make whenever I do a talk or write a piece. I believe people learn best when they have real world examples, especially ones they may have already seen, and when provided with those examples, what they learn sticks with them for longer. So, long story short, I became more inspired with age and experience."









As an autistic advocate, what do you see as the biggest challenges and opportunities in advocating for autism awareness and acceptance, and how do you use your personal experiences to address these issues?

"The biggest challenge is making sure people remember what they have learnt. A good chunk of the things I talk about are common sense, but unless the person consistently sees or hears about something related to autism, then I find that people tend to forget over time. Then of course you have the issue of ambivalence and/or people not really caring, due to not really being personally affected by autism or neurodivergence. I'd be lying, however, if I said I hadn't been guilty of this sort of thing myself. It's a common occurrence. It's talking like this that helps lessen the ignorance, and helps the knowledge last.

The main way I help boost understanding is by starting off my presentations by asking people what they know already. That sets the groundwork and helps people learn, and start thinking about what they know. Then, when I inevitably talk about sensory issues, I ask the audience what things they don't like to feel, and then I ask why. When they answer, that's when I can start talking about my own sensory issues, and how it affects me and how it can affect others on the spectrum. That helps them connect, and empathize, and once they can empathize they can truly begin to understand. As I suspect is going to be a running theme in this article, with experience comes knowledge, and through knowledge can come the kindness that is needed for true equity."



What are some common misconceptions about autism and autistic people that you've encountered in your personal life and while educating about autism, and what have you found that has been successful in getting people to be more educated about autism, especially from first-person experience.





"When I do a presentation at a school, especially when the audience is elementary school students, I do a true or false segment after a general explanation of what autism is. A good chunk of the questions pertain to what was already talked about and are mostly common sense, but some questions tend to catch the students off-guard. The more common ones tend to be the ones regarding why people get autism, and why researchers haven't found more concrete answers as to how. From there I'm typically able to try and have a discussion on what they themselves think might be the cause, and talk a little bit about some theories, before shifting the topic.

Another time was when I was doing my practicum in January of this year, in what is now my current workplace, where I questioned if this type of support, and to a certain degree the disability support field was quite right for me. This was due to my sensitivity to sounds, smells, and textures, and when you provide care you see all sorts of those things. But, in the three weeks I was there, I learnt to acclimate myself to the shouting, the smells, the textures. I proved to myself that I could do it, and make it in that environment. Could everyone on the spectrum do that? Maybe not, but I showed that it's possible."



Having recently graduated with a diploma in Disability Supports and Services and also thinking about your own personal experiences trying to navigate supports and services, in what ways do you think the field of disability support can evolve to better meet the needs of those it serves?







"As a support person, the main change I want to see is in regards to training. In Nova Scotia, the hiring process is unique to each organization. In most cases however, you do not need any prior experience. That means you can just walk off the street, apply to an organization, and have a genuine chance of being hired. Once you're hired, you receive training as you work. I personally do not agree with this, as training can often be very spread out and/or disorganized. This is how accidents happen. What's worse, due to frequent staffing shortages in places, people are often forced to do things they may not have training in. These are things like transferring a person from a wheelchair to a chair, personal care, controlling personal bias, et cetera. I wish we had a standard training program, where you get all your bases covered, receive all your certifications, and then at the end of it all receive a license to provide care.





continued...

Jake

I know something like this is possible, because otherwise the course I took at NSCC Kingstec would not exist. People who were enrolled in, or had graduated from, the program I was in were highly sought out. By the end of course, the and me my classmates all had job offers, or were already working in the field. I also wish we had a board, like what social workers or doctors have, that issues that license, but can also revoke it if necessary. Why we don't have something like this, I am unsure, as we play an immensely important role in our society; helping those unable to fully help themselves.



As who has someone been supported, over the last couple things years have become increasingly more expensive, and money is tighter and more needed. This is a harsh fact for many people who require support, as they can often fall through the cracks, and find themselves in poverty.

Another issue is lack of awareness of available resources. I wish the government, or some organization, would send out a monthly or biweekly newsletter with available resources that people may be able to apply for. I know that would have helped me, and would have helped a fair few of the people I've worked with."



Could you please share a few personal and professional goals you have for over the next 5 years, and what kinds of support do you feel will be the most effective in helping you to successfully achieve them.





"I have several things I would like to do, I would never call them goals, mind you. For personal things, I would like to go back to the UK to see family, and learn about the tabletop gaming culture over there, that I wasn't able to do during my trip with my family a couple of months prior. I would like to go to Rome, and get to actually see the temples and statues, and witness the ancient history firsthand.

In regards to more "professional" things, I would like to try and do more advocacy work in general, with a special interest in advocating for better public transit that does not cost a small fortune and can be prohibitive for those on low-income in rural areas of the province. I am also interested in potentially starting up a YouTube channel at some point in the near future; focused around model painting, and diorama building. I imagine the main thing that would support me in these things, especially in regard to my desire to do more advocacy work where possible, would be transit. Due to my vision impairment, without the aid of friends and family driving me around, I would not have accomplished what I have, and I think that a fair amount of people in Nova Scotia are in the same boat."