



Research on knowledge about neurotypical people



IN COOPERATION WITH NEURORÓŻNORODNI



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GAM Research is a part of the Global Awareness Movement. It is an initiative that combines all of our research work in one place. You can find all data, statistics and knowledge we have gathered while working on our projects here. We believe it is extremely important to explore deeply what we are passionate about as it is the best way to learn. This whole process is done in collaboration with experts from different fields, which allows us to maintain professionalism while discovering new things in a creative way.

-Karolina Sosnowska



Report on the questionnaire about knowledge on neuroatypical people

by Karolina Sosnowska, Zuzanna Kotrych, Kaja Pośnik, Alicja Grzelak, Weronika Tomiak with mentorship of Dr Joanna Liliental, Stanford University



The goal of our project is to research the importance of communicating science and answer the question if it is needed in today's society. We are touching on many different aspects of this topic in our issue. We dedicated a part of our Special Edition to the topic of "Knowledge on neuroatypical people" by conducting a survey on this topic. We believe it will help to understand the levels of knowledge about neurodiversity in society. The survey shows us whether communicating science and spreading awareness in this area is as important as we would assume. We hope it sheds some light on the issue and provides neuroatypical (NA) and neurotypical (NT) people with the opportunity to articulate their opinions. Combining all data and conclusions from our responders shows us how significant this issue is and why we should pay more attention to it. Our main aim is to challenge the status quo on the awareness of neurodiversity. We are hoping that through

approaching this issue and conducting this report we managed to do it at least to some extent.

We have been collecting answers for the period of two months through an online survey. We were able to get more than 500 answers from all over the world and from different age groups. We have reached all of the continents with the most answers from Poland and the USA. We also gathered information from Germany, Canada, the Netherlands, Bangladesh, Malaysia, Australia, Mexico, Egypt, Nigeria, Scotland, and many other locations. Our responders were mainly between 19-25 years of age, however, there was also a significant number of responses from people above and below this age range. This allowed us to maintain diversity in our research and perspective of different nationalities and age groups. We acknowledge that the sample may not be entirely representative due to our sampling methods, however we are hoping that the large sample size can still provide a useful idea on the levels of neurodiversity awareness. One of our main goals was to recieve answers from many different perspectives, of which the most common were:

- a parent/family member of a neuroatypical person,
- an individual diagnosed as a neuroatypical person,
- somebody in a relationship with a neuroatypical person,
- a friend of a neuroatypical person,
- a colleague of a neuroatypical person.

Another question posed in the questionnaire concerned different types of neurodiversity. We received a variety of answers of which the most popular were the following:

- •ASD (autism spectrum disorder),
- •ADHD (attention-deficit hyperactivity disorder),
- •ADD (attention deficit disorder),
- •OCD (obsessive-compulsive disorder),
- Dyslexia,
- •Touurette syndrome,
- •Epilepsy.

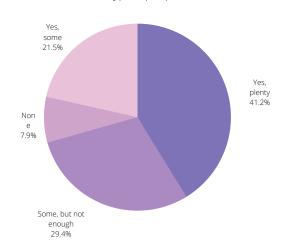
Subsequently, we asked about knowledge on and understanding of neuroatypical people. The majority of

Source: www.pinterest.com

respondents agreed that they would like to learn more about this topic. Another frequent response was "I don't feel confident with my knowledge". Some responders felt confident with

understanding neurodiversity but were eager to learn more. The least selected answer was with people who were satisfied with their awareness of the subject. These responses led us to the following conclusions. Firstly, the vast majority of survey participants did not feel fully educated on neurodiversity. Secondly, more than half of the responders were willing to learn more about neurodiversity and pursue their knowledge in this field. This is a positive aspect, as it shows a willingness to make a change in perceiving and understanding this complex topic.

Do you have access to resources that provide reliable knowledge on neuroatypical people?

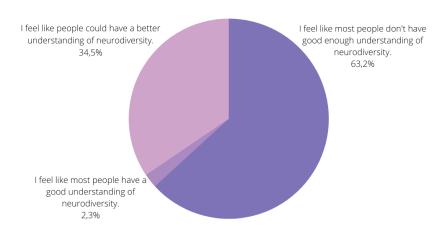


Furthermore, we asked about access to the resources that provide reliable knowledge on neuroatypical people. The most common answers were that there are some resources but not enough.

Considerably fewer responders suggested that they are satisfied with places where they could seek knowledge about neurodiversity. A small percentage of people said that they had not had any resources to get information on this topic. This could lead us to conclude that there are some reliable sources but they are not as well shared or popular as they should be.

Another question we posed concerned the level of awareness about neuroatypical people among the general public. The vast majority said, "I feel like most people don't have a good enough understanding of

How do you feel about the level of awareness about neuroatypical people among the general public?



neurodiversity". Slightly fewer people chose "I feel like people could have a better understanding of neurodiversity". This

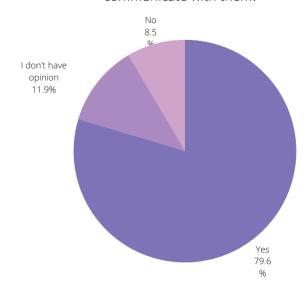
suggests a significant knowledge deficiency and lack of awareness among the general public. It is a rising problem that needs to be adressed and solved. This is one of the many reasons why we decided to run this project.

The next question we asked was "Do you think the level of awareness among the general public affects the way neuroatypical individuals are treated in our society and the way people communicate with them?". More than 70% of respondents answered "Yes", significantly less chose "No" and the least popular answer choice was "I don't have an opinion". Therefore, the majority of respondents agree that the view of a

group o f people 1 S affected by the general public's awareness. Our a i m therefore should be to educate the public and propagate reliable

information on

Do you think the level of awareness among the general public affects the way neuroatypical individuals are treated in our society and /the way people communicate with them?



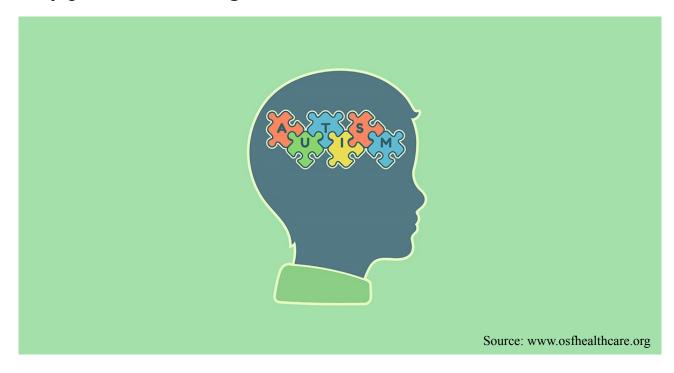
the matter. If getting informed and learning about it becomes more and more common, this problem could become less significant in a negative way. We believe it is a positive aspect that people are aware of this issue from the viewpoint of neuroatypical people. If they know about it, that's one step closer to success. The reason for this survey was to show the realities concerning this topic and show the viewpoint of people from all over the world. We hope that by reading this we gave you an idea of the current situation. We would like to mention that all responses in this survey were anonymous. The data represents our own interpretation of the answers we collected.

At the end of the survey, we gave our respondents a chance to share their stories about how they found out about their neurodivergence. They were able to share their experience or thoughts from the past or recent moment.

The question we asked was 'Do you want to share the story of how you've found out about and/or experienced your neurodivergence, either now and/or in the past?'. The answers we obtained have made an impact on the way we perceive the results of our survey and their possible implications in the future, as the personalized view on the topic allowed us to gain more insight into the perspective of our respondents.

Many of the answers mentioned the feeling of loneliness, misunderstanding and lack of support from the immediate environments. Statements such as 'I guess I still experience grief that no one listened to me when I was a child and spoke about my feelings.', 'Previously, I thought of it as character traits, shyness, indecision, lack of self-confidence.', 'I had to discover it myself, my parents didn't really want me associated with the stigma and so treatment as a child was basically non-existent. Learning about myself in my early twenties has helped me to live a somewhat normal life.', 'People around me also haven't been supportive and they always blame me for having bald spots as I can't stop pulling my hair. When the sad truth is I can't control it.' (when talking about anxious hair pulling classified as a disorder – Trichotillomania). These and

many other stories show how misundertood neurodivergent individuals feel and for their feelings to be considered as less important or simply a creation of their imagination. Moreover, we received answers such as "Previously, I thought of it as character traits, shyness, indecision, lack of self-confidence.', 'Soon enough, I was talking with my therapist and they told me I actually might be on the spectrum, and that a lot of my problems with understanding my peers, procrastination (I always thought I'm just lazy, I'd have never connected it with neurodivergence) or problems with focusing might be the direct result of me, being neuroatypical'. The problem of misconceptions and assumptions about neurodiversity becomes very prominent through these answers.



The problem of societal stigma has emerged as very significant. Some answers tackling it were as follows:

'My younger brother has been diagnosed as autistic (his school sent him to psychologists because there were big problems with his behaviour) and then my parents remarked that I am autistic too. At first, they didn't want me to be diagnosed because of fear that I could have more problems and

difficulties when I would be perceived as autistic, but later they have changed their minds and we went to a psychiatrist. I got the certificate of disability. For now, it is better for me to have that because till now I got a lot of help e.g. at school. (...)'.

Two answers, one from the perspective of a therapist, the other from the perspective of a person, who has experience with the lack of resources about neuroatypical people were important in highlighting the issues we raised through our survey. The previous answer reads 'I am a psychologist and I work with neuroatypical people. Also, I have always thought that I am different, even different among psychologists, this is why I went for my diagnosis. And now I am happy to be in this neurodiversity community;)'. The latter is 'When I was in pre-k and kindergarten with neuroatypical kids, the teachers had limited resources to help them.

There were no specific individual classes, games or exercises tailored towards those kids. Today I have a young cousin who is now in a private school that specializes in teaching and helping children on the autism spectrum. From a boy who could not talk, screamed at the slightest touch and had a



myriad of other early development problems he has grown into a talkative and communicative young boy with an incredible talent for programming. In fact, he has recently been able to discuss a number of topics with my husband who is a professional developer. I should mention that my cousin is only 9 and my husband commented that he could not understand everything my cousin was working on. I am amazed at how incredible his progress has been. I do not think the children I grew up with had the same chance to develop and I am so glad that we are now better at creating safe spaces and inclusive education, but we are still a long way from being done in terms of neurodiversity.'. The concluding sentence also constitutes part of our research conclusion and the aim of raising awareness about neurodiversity that we had set for ourselves.

Through writing 'I was fighting depression since I was fifteen, anxiety disorder since I was nineteen, and was diagnosed as autistic when I was 32 years old. Now I'm an autistic self-advocate and trainer for parents, teachers and specialists, social activist, but also scientist/researcher on the topic of autism' one person shared a very personal story with us and told us how they take from their experience to help others going through similar difficulties.

Several answers talked about the influence of social media on their perception of neurodiversity. Such answers included statements like 'Yes, after watching Netflix's show called "atypical" I realized that I don't really know much about people on the spectrum so I started doing research and now I think I know pretty much about them. I still read and study about autism and autistic people. It's fascinating.', 'Pandemic basically collapsed my life, and I started having problems with basic hygiene and problems I had before amplified making everything harder. I learned a lot from TikTok and started looking at more professional sources later. I can clearly see that I had many of those problems before but I had lots of coping mechanisms, and like reading, drawing, the crafts that allowed me to survive school with only small problems.', 'Last year I was watching "Queen's Gambit" on Netflix and I thought that I am similar to Beth. It sounds stupid, but then I was diagnosed