

TILTING TOGETHER

The Tilting the Seesaw for Teams Newsletter

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NOT ALL HEROES WEAR CAPES

Let's see success!

This has been a busy month of programmes and we've been all over the country, from Auckland to Dunedin and many places in between!

One of the most important messages we hope we leave behind is to remember the bridge. Take small steps with the person you're supporting, and celebrate those successes. We need to recognise the heroic effort that goes into just being in the school environment for a lot of kids with autism, and give them the kudos they deserve.

In this issue, we'll be talking about diagnosis. From whether we should use the word 'autism' to pursuing a diagnosis as an adult, it's a topic that is raised often both in and outside of the course. Remember if you have any questions please reach out. Happy reading everyone!

FEAR OF A NAME

THE STIGMA CYCLE



If you've ever read any of the Harry Potter books, you might remember the moment when Harry first hears about the dark wizard Voldemort. No one will speak Voldemort's name, and if they do, it's with fear in their voices. It's the brave Dumbledore who tells Harry not to be afraid. "Always use the proper name," he says. "Fear of a name increases fear of the thing itself."

With our Tilting the Seesaw for Teams course, our job is to travel the country to talk about autism. But more than that, our job is to empower educators and parents to support young people with autism - to allow kids to learn, to grow and to achieve their potential. To feel safe, and to be happy.

Almost every week of the course we are asked a variation of the same question: should I tell my child they have autism? And should we call it by that name?

The decision of when to disclose an autism diagnosis to a child is a very personal one. There are many factors to consider, including whether they are at a stage when they will be able to take on the information in a way that is useful to them. It also often takes parents time to accept the diagnosis themselves, and then be able to discuss autism in a positive light.

But as for whether they should call the condition by its name — our answer is always yes.

Many people are afraid that by attaching a label to a person, the person will be stigmatised. But it's important to think about what a stigma really is. A stigma is a social construct, meaning that it's an idea that people have built, and therefore an idea that people can dismantle. Stigmas grow from misunderstanding and fear. And the unfortunate truth about stigmas is that they can become a vicious cycle: we fear that a word will cause discrimination, so we don't use it. By reducing its use we make the word less common; more unusual; something to fear.

Fear of a name only increases fear of the thing itself.

When we listen to autistic adults in the community, the most clear message is one of empowerment. So many adults are proud of their diagnosis, and entirely accepting. They would not want to be without their autism, even if that was an option. And they prefer the term 'autistic' to 'person with autism,' saying that autism is not additional to their personhood, but an intrinsic part of it.

We do not speak for autistic people. But it is our job to listen. And because we connect with so many people who are directly supporting autistic children, our role as allies to the autistic community is so important.

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FEAR OF A NAME CONT.

And so, our job is to build a community of autism champions. People who will say, loud and clear, that autism is absolutely OK. That there is nothing to lose - and so much to gain - from living in a neurodiverse world. That autism may present challenges, but it also presents super powers. It is part of some of the greatest thinkers, activists, revolutionaries and creators in human history. Autism is part of our schools and our communities. And we wouldn't change that for the world.

But we would change the world to make it a place where all people have the right and opportunity to thrive. And we still have changes to make to ensure that this is true for autistic people.

One of the changes we can make is to give the word 'autism' the power it deserves. To be unapologetic in its use. To speak it with positivity. And to say: people built a stigma around this word. So people can destroy that stigma.

And then, there is nothing left to fear.



Remember: We don't want to turn an autistic person into a non-autistic person.

We want to help an autistic person who struggles to become an autistic person who doesn't struggle.

Website Update

If you had issues logging into the website upon registration, these issues should now be resolved. You'll just need to follow your email link and create a password. If you're still having issues, please let us know by contacting:

training@autismnz.org.nz



Tell Us Your Success Stories!

We would love to hear if something you learned on one of our courses is going well. It also helps other participants with ideas and confidence to give things a go! If you've had a success, please tell us about it! You can email your story to:

training@autismnz.org.nz

RESOURCE BOX

If you'd like to find out a bit more about Circle of Friends, you can check out the YouTube video, shown below and found at <https://www.youtube.com/watch?v=7rsKqokxyxs>

You can also read more at Inclusive Solutions, <https://inclusive-solutions.com/>



Check out this TED Talk by Rosie King, a 16 year old autistic woman who speaks so well about her journey with autism, the uniqueness of every individual on the spectrum and the positivity it has brought to her life!

https://www.ted.com/talks/rosie_king_how_autism_freed_me_to_be_myself?language=en#t-108911

If there's one TED Talk to watch this year it might just be this: Letting Go of Control and Rethinking support for Autistic Individuals, by Amy Laurent.

"Autistic people are not a collection of behaviours to be modified, but rather individuals to support, so that we can use the strengths that they have to lead fulfilling and productive lives - and make that the rule, rather than the exception."

<https://www.uri.edu/tedx/talks/amy-laurent-rethinking-support-for-autistic-individuals/>



I THINK I MIGHT HAVE AUTISM

NOW WHAT??

Every now and again a parent comes along to our course and some of the material sounds strikingly familiar. Sometimes parents may begin to wonder if they, too might have autism, or if another family member or older child might. This might be something they've been wondering about for a while, or it might be something that strikes them out of the blue. It can be hard to figure out what the next steps are, so please read on for some more information:

1) You're still the same person

Autism is a lifelong condition, meaning that if you are autistic you have been and will be for your entire life. How autism affects you, however, may change across your lifetime. Having new information or considering a diagnosis can affect people in many ways, from being frightened and worried to feeling intrigued, empowered or excited. All of these reactions, or a mix of all and many more, are okay. Remember that you are still the same person that you have always been, and that learning about ourselves is lifelong – there might just be another aspect to you that you didn't previously consider.

2) We're here to help

If you think you may have autism and would like more information, you may wish to get in touch with one of Autism New Zealand's outreach coordinators. We have 16 branches nationwide, all of whom are staffed by one or more of our outreach team, and they are there to help to give guidance and support to anyone affected by autism. You do not need a diagnosis of autism to access our outreach services, and the service is completely free.

If you'd like to make contact with an outreach coordinator, the best way to do so would be to find your local branch on our website, here: <https://www.autismnz.org.nz/living-with-autism/support-from-us/>

3) What about a diagnosis?

If you would like to pursue a diagnosis of autism you do have options, although it can be difficult for adults in New Zealand. Your local outreach coordinator will be able to inform you of the diagnosis services in your area. For adults, this will generally be via a private service that must be paid for, for example a psychologist or psychiatrist who has experience in autism diagnosis.

To pursue a diagnosis of autism through the public health system, an adult in New Zealand generally must have an existing diagnosis of intellectual disability to be considered for a referral.

One thing to ask yourself before pursuing a diagnosis is: how will a diagnosis support me?

The potential benefits of receiving a diagnosis as an adult may include:

- Increased awareness or sense of self
- Increased understanding of yourself or your mind
- A feeling of connection to a community
- Confirmation of a suspicion
- Increased understanding from family, friends, workplace, etc.

The potential downsides or risks of receiving a diagnosis as an adult may include:

- A feeling of shock, grief or sadness
- The expense of the diagnosis
- A lack of support options once you have received a diagnosis

It's also important to note that you may pursue a diagnosis and find that you are not diagnosed with autism. For some people this can be frustrating or upsetting, or feel like a waste of time and money. For others, it is worth asking the question and finding an answer, regardless of what that answer is. If that might be the case for you, then give your local Autism NZ branch a call, as a place to start.

