

World Autism Day Parliamentary Breakfast



Joanne Dacombe

Speech transcript

On behalf of people here today I thank you for taking the time out of your busy schedule with significant portfolios to host us this morning.

Thank you for touching on the importance of moving from awareness to acceptance, amplifying Autistic voices, working across government agencies, and acknowledging the significant need for improvement of Disability Support Services.

Before we hear from our next speaker, I'd like to take a moment to share some thoughts on behalf of the Board. I want to touch on two critical issues that affect many in the Autistic community: unmet need and the importance of inclusive practices in all facets of life which is part of the UN theme for World Autism Day 2025.

Many of you will have read the Stats NZ announcement of the Disability Survey results from 2023. That survey is highly likely to have undercounted Autistics and other people with different neurodiverse conditions because of the methodology used. It is significant that 62% of those counted in the Disability Survey had unmet need. This high rate of unmet need directly affects the wellbeing and potential of Autistic individuals, limiting their ability to participate and contribute fully in society.

It's far too common for people to make assumptions about Autistics like me, that we have little or no needs – but you'd be wrong. Or you could assume that I have access to natural supports but in fact, I provide natural supports to my Autistic adult son and even my Autistic grandson.

However, I am used to a lifetime of unmet need and accommodations. For too many of us a lifetime of unmet needs has been the norm. But that doesn't make it right and I want better for others, so they don't have to deal with the challenges I have faced, some of which have been life threatening.

I think about the lack of a pathway for many Autistics and their whānau and caregivers. The system is complex, fragmented, and often requires navigating multiple agencies, many of which fail to communicate with each other let alone us.

Privilege may help get a diagnosis but still provides little access to assessments or interventions such as speech language and occupational therapy. I would be remiss not to mention that access to assessment and some interventions has become harder with the DSS changes over the past year.

I think of the 51% (again likely higher for Autistics and those not counted in the disability survey) who lack support or accommodations in education. Even those with low support needs may struggle with being taught in a way that doesn't work for them, struggle with a curriculum that isn't inclusive or adapted for them, struggle with being understood,

struggle to gain access to speech language therapy or Augmentative and alternative communication (AAC). AAC tools help non-verbal individuals communicate, but access to them is often limited.

We also often risk being misunderstood in the health system. It's not uncommon for Autistics to have to educate those who support them – this includes a range of health professionals not just support workers or teacher assistants.

We face terrible circumstances and some of you may recall a recent case involving an 11-year-old non-verbal Autistic girl, who was misidentified twice and subjected to inappropriate treatment. This incident reflects the real fear experienced by those of us who are Autistic or who have Autistic children or grandchildren.

To address these unmet needs, we must focus on building inclusive environments and policies. This is a call to action for everyone – not just Government, not just Government agencies but local councils, businesses, not-for-profits, and local communities where people live, work and play. It drives much of my personal advocacy which is wide ranging.

The aim of inclusive practices and policies around autism is to create environments where Autistics and their families feel welcome, respected, and able to participate fully. These policies and practices should address barriers to ensure equitable access to opportunities, engagement and participation.

I'm going to touch on just 3 principles of Inclusive Practices and Policies around Autism:

Firstly, recognizing and valuing the unique characteristics, cultures, and experiences of Autistics. I want to emphasise the word value because many Autistics are made to feel like a burden because we get associated with costs – costs in DSS, costs to the economy, costs in time and effort, costs in lost income for families. Seeing our value, investing in that time and effort is worth it for the outcomes and I can testify personally to that.

Secondly, ensuring that everyone has equal access to resources, opportunities, and support so Autistics can thrive in participation and engagement across different settings, social activities, or decision making. Unfortunately, Autistics have a long way to go to get access to all of these be it in health, education, or employment or even community participation. And it also means creating safety for Autistics – recognising we are often targets for bullying in educational and workplace settings.

And finally, removing barriers to equity. Barriers are not always fences. They can take the form of budgets, siloed ministries, or a lack of training and understanding. It can look like trying to mould a person's needs into a shape that fits a specific set of guidelines that mean it's someone else's problem and someone else's purse strings. Sometimes barriers look like a lack of training. It would be great to see mandatory training for educators, health professionals, the police, the courts, and others on how to better support Autistic individuals. This could include practical strategies for supporting Autistics, recognition of sensory needs, and using a range of clear communication methods.

Here's the rub. I acknowledge it can be expensive in time and money. But investing in the right supports at the right time is way cheaper than managing a crisis or trying to fix things when they have gone terribly wrong. I think of families reaching breaking point before they get help, I think of Autistics who have ended up in the welfare or criminal justice system because of the lack of early supports. I think of the ongoing ramifications of not helping Autistics and their families thrive.

It's not enough to be aware of the challenges; we must act to remove barriers. I urge you to think about how you can make a tangible difference in creating more inclusive spaces for Autistics in every community. I believe everyone can play a part in driving change—whether they're a lawmaker, policymaker, service provider, or an individual advocate. Imagine a world where every Autistic individual has access to the resources they need, feels safe in their community, and is empowered to thrive. We can make this happen, if we work together. Together, we can ensure that World Autism Day is not just a day of awareness and acceptance, but the start of more action that leads to lasting change for Autistic people and their families.

I acknowledge the many families here today who have invested in their families – at huge personal cost, not just financial – and I thank you. I thank those who have funded our work at Autism NZ and provided support to Autistics in a variety of settings. And I acknowledge and thank my fellow board members and our Chief Executive Dane for their commitment, vision, sacrifice, and support of the organisation and of Autistics and their families.

And of course, I need to acknowledge Autism NZ staff who have done a lot of work around the social investment required to give Autistics a good life, an equitable life, the opportunity to thrive in society and who have a vision for more that can be done.

At the end of our event there will be an opportunity to mix and mingle and we encourage you to talk with us about our vision and the opportunities.

Anyway, that is enough from me. I'd like to introduce Beth Noble. Beth has a Master's degree in building science, and a second Masters in Architecture.

She runs her own consultancy business Access Insights which offers architectural design reviews, onsite assessments, research advisory services, and neurodiversity workshops to improve inclusivity in buildings and public spaces.

Beth and I are both involved in the Autism Research Clinic run by Canterbury University.

Beth is going to share a little of her personal Autistic journey with us and we thank her for her courage and vulnerability in doing so.



Beth Noble

Speech transcript

As part of your morning routine this morning, how many people brushed their teeth?

Did you have to think about it at all?

Did you have any stress or anxiety over doing it while you were brushing your teeth?

Did you notice things?

Did you notice the feel of the brush in your mouth?

The vibrations if you use an electric toothbrush?

The sound of the bristles in your mouth?

The coordinating your limbs and gripping the toothbrush?

Figuring out what on Earth does the dentist mean when they say circles?

The length of time. What is 2 minutes? How long? How long do I have to be doing this for?

The taste of the toothpaste. Why is it always mint?

The chalky, gritty texture left in your mouth afterwards?

It is a task that most people don't think twice about. But as an autistic person, brushing my teeth is a mountainous task.

All of those things are cliffs to scale each and every day.

I don't need support to stand and brush my teeth for me. Some disabled people do need this, but as an autistic person it's it's more complex than that.

And I know I have to right? I am well aware of the consequences. I'm using this as an example because in five days time, I go into Wellington hospital to go under a general anesthetic through the special needs clinic to have dental work done.

But that's because while I'm in a better space with brushing my teeth now, we're still working on catching up on 15 years worth of neglect from the point that my parents could no longer force me to brush my teeth. Like past a certain point, they can't, like, hold you down. And the point at which the support around me was in a place to enable me to do it.

Three years ago, I moved into an apartment that was built specifically for me underneath my family home, and in that opportunity and moving to a new space, I worked with my support workers to form better good routines.

So each night before I go to bed - Dishes, Door, Teeth, Tablets, Test.

- Wash my dishes (or at the very least rinse them and put them in the dishwasher).
- Lock my door
- Take my nightly tablets
- Brush my teeth

- And test my blood sugars because not only am I autistic, I am also a type 1 diabetic. Like most of us, we have multifaceted health conditions.

Yes. OK. Having a plan is good. But my support workers aren't there at night to remind me to do that.

So a big support for me is visual reminders and that looks like the new smart lighting system that we installed in my apartment, based on the research that I did for my Masters.

Sensory items don't only look like small portable handheld objects. Sometimes they are big, sometimes they are static.

Because not only do those lights visually remind me to brush my teeth at night, by dimming, so they dim at night.

They're also part of the support that helps me make the climb every night.

Being able to climb those cliffs, to brush my teeth isn't only a matter of remembering. It's about being in a space to mentally convince myself each night to pick up the toothbrush and do it.

Things that help me brush my teeth, cross all parts of my life. Support to do this looks like so many different things.

Support looks like sleeping well, so again my light system works on a circadian rhythm in the morning it's brighter and cooler like the sun, and in the evening it warms and dims. To get your brain and your body ready for bed.

It means eating well. So making a meal plan and doing grocery shopping with my support workers because I need help with that.

It means keeping physically active again, one of my support workers and I go to the pool and again I don't physically need a support worker

to help me get into the pool, but what I do need is like 2 weeks ago, actually no last week when my support worker and I were at the pool and an Intermediate School classroom full of children came in and started screaming at the top of their lungs. And I had a meltdown right in the middle of the pool. And so, my support worker needed to bundle me up and Get Me Out of the pool and help me manage this change of plans and sensory overwhelm.

It means having a clean and tidy house. Again, having support workers to come and keep me on track while I tidy having cleaners come in to do the tasks that I can't do like vacuuming and cleaning with chemicals in the kitchen and bathroom.

It also means having healthier relationships with my family because when I have support workers to help me do all those tasks, it means that I'm now less dependent on my family and as a 30 year old, I can have an adult relationship with my parents as opposed to very much a child dependence style relationship.

Ideally, support would also look like being supported, more engaged in the community, filling my time with things that are good for my brain and my body.

Previously, it included more flexible things like the ability to go to a sewing class to get out of the house to meet new people, but also learn skills like how to make foods out of fabrics that. Sensory friendly like the dress I'm wearing today.

Support also used to look like me having access to technology that helped me manage my diabetes because while autism and diabetes are not epidemiologically related in any way, autism means I forget my insulin. Forgetting my insulin means that my blood sugars run high. My blood sugars run high which affects my emotional regulation and then I get irritable and forgettable, and then the world just becomes worse.

For most people, the ability to brush your teeth does not depend on every other facet of your life. It is a task that most people don't give a second thought to.

But for an autistic person like me, it is an enormous task, and having support in place, investing in all of those types of support, that will help keep me out of hospital in the future.

I am an expensive person to keep alive. I fully acknowledge that!

Between health and welfare and disability support, I am and always will be "in the red". But is that all that I am?

An expensive person still has value.

It is easy to look at us as numbers on a spreadsheet, but we are more than that.

I am the very personally the very definition of autistic splinter skills.

I can't brush my teeth, but I can stand up and hear and talk to you today. Admittedly, the rest of the day is a write off, but I'm still here.

I get stuck planning meals and doing my grocery shopping. But I have two masters degrees.

I can't work in regular open employment, but I do some work as a consultant running my own business as a contractor where I can control everything to fit my needs. Though unfortunately at the moment contractors and consultants are a bit of a bad word.

I have to carefully manage my mental and sense mental energy and sensory needs. But I use what I can to give back to my community. I'm a girl, guide leader and I sew quilt incubator covers for babies in the hospital.

All of these things are part of my life. And all of those things require support in the day-to-day stuff to mean that I can do more with my time.

Support isn't just an expense, it is also an investment. We all have value and things to bring society more than just the costs that we take to keep alive.

There is a big push at the moment to about supporting those with the highest need and prioritising the highest need, but need is need regardless of how big or small it is.

That list of things that I can do and only with support shouldn't be used against me as a reason to not give support. It is not an either or situation for so many autistic people.

So what else did it take for you to get here this morning?

You brushed your teeth and all likelihood you probably set an alarm.

You woke up, you got up, you got dressed and maybe had a shower.

You figured out your transport, packed a bag, planned the rest of your day (for those of us who are capable of having a rest of the day).

Maybe you looked at the information document.

Once you got here, you found the entrance.

You went through security.

You have found a seat, had breakfast, chatted to some people.

Imagine if each one of those tasks had as many things to consider as the brushing the teeth example.

Because something that is a single task to most people have 5/10/15 considerations for us.

So if all of those seemingly simple everyday tasks were as complex as that for you...

Don't you think you would want, don't you think you would need support?

You can also listen to Beth's speech here: https://youtu.be/UFBJDjAt4pE?si=c0nwtYJQG7_2YeVk



What does support mean to you?

Watch the video here or read the transcript below:
<https://youtu.be/cc566m5JJ48>



Support means acceptance...

building from strengths to address challenges

shifting the lens from a deficit to a strengths based focus

Support means having somewhere he can feel safe and enjoy life without judgement

Support means having peace of mind and an ease of pressure and anxiety.

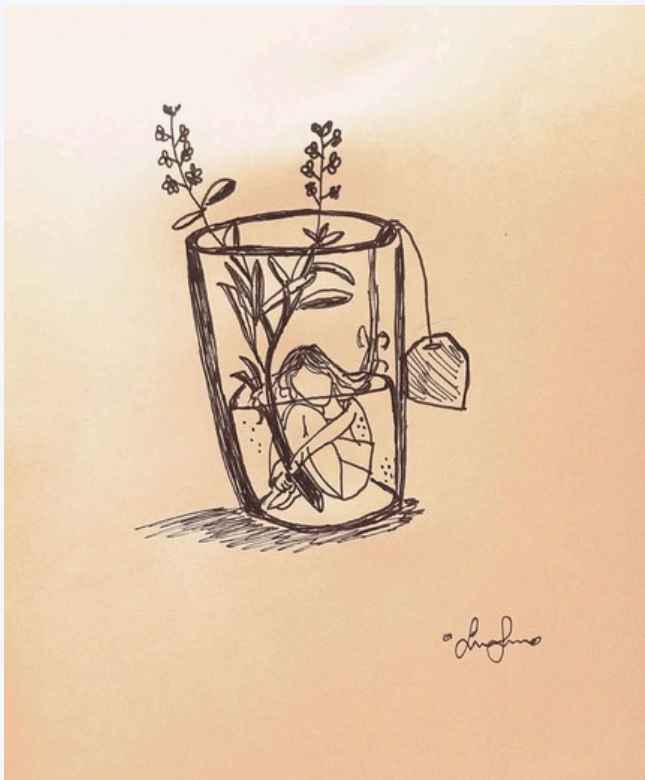


Support means having someone who understands

Support means we all stick together

Support means ensuring you live a valuable and purposeful life

Support means flexibility to meet individual needs



Support means enabling learning and independence

Support is the difference between feeling isolated and feeling empowered

Support means having rights to education and inclusion

Support means I get to live my life with autonomy, freedom, community, safety, and hope that I may thrive.

Support means the world to us

So, what does support mean to you?