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The Unicorn Riding Mermaid is 16

She's no typical neurodivergent 🦄 🦄 🦄

Rebekah Corlett MNZM

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READ IN APP 7

"The bad news is, she's autistic. The good news is, you'll never meet anyone as interesting as your daughter."

That was how the developmental paediatrician broke the news to my husband and I way back when I was clinging to gateway diagnoses like global developmental delay and dyspraxia for dear life.

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Thirteen years later, and the 'bad news' isn't that bad after all. Though it felt like a terminal illness of the ego way back then. The good news still holds true, there's nobody like my girl, she is magical like a unicorn riding mermaid from Xanadu.



Thanks heaps AI for this creepy interpretation of 'maori mermaid riding a unicorn'

The way she moves, the way she talks, the way she sees the world are completely unique to her. I haven't seen an autistic person exactly the same as her. That's why I always laugh at the concept of autistic tick box style checklists because my girl broke the mold when it comes to (insert massive air quotes here) **typical neurodivergence**.

That's not to say that she is at a better end of the spectrum, less severe, more mild, tik tok trending, less disabled-more neuro-something, none of that - she is simply herself.

Her stims are like continuations of unseen currents of energy around her. Sometimes they are like car revs, <u>connecting her to a higher level of herself</u>. Sometimes they are beautiful and scary all in one tic/flap/stim.

Her voice is uncolonised. She's lingual, but simply not prescribed to any one language. Sometimes you hear syllables or shapes of words, but you seldom hear a word in its entirety. When she was little I used to call it 'Pinguese' as she sounded a bit more like the plasticine penguin Pingu than anything else. Nowadays she is just Sophia, she has her talker, that's her big voice, her colonised English voice. But she can use it well enough to make the people around her to understand her needs.



Not Pingu, but a non-licensed run of the mill Penguin. Mwop Mwop!!

The other day I was waiting for a train and heard a similar collection of clicks, squeals and mumbles. It was Sophia's language but coming from the voice of a young man, who was pacing up and down waiting for his train on the opposite platform.

WHOA!!! I've never heard anyone sound remotely similar to my daughter.

Without staring (because even excited staring is rude) I glanced at him making his way up and down the platform, taking care to stay behind the yellow safety barrier. He excitedly squealed when the signals changed colour. He stopped and smiled as the barriers at the crossing lowered, and made familiar Pingu noises as the train came closer to the station.

After he had boarded the train, I was left, deeply submerged in my own thoughts. On the surface, it was waves of pure joy to hear someone else with the sound dialect of awesome as my girl. Below the surface, was bubbling up thoughts of

Who is he? what's his diagnosis? where is he going? are there more like him somewhere?

Deep diving into my thoughts will eventually bring you to the dark ocean floor where scary sea creatures pop their head out of shipwrecks with intrusive thoughts like

Is he safe? who cares for him? are those other people on that side of the platform going to treat him with kindness?

Is his disability funding at risk? Will people expect Sophia to catch public transport on her own? Am I holding her back?

Diagnose my teenage rebellion here:

My daughter turns 16 this week. I couldn't imagine her catching a bus or train, or going anywhere independently. Everything is dependent on support for her.

SHIT what if it's my low expectations that stop her from being similarly independent. Maybe this was a glimpse into her future. Cool! Yikes!!

I like to think I am empowering my daughter to be strong and independent. But the world is not always safe or welcoming of difference. That's the juxtaposition for parents like me. Keeping them safe, while encouraging them to spread their wings. It's a constant juggle/struggle/

When I was 16, I felt invincible, like I could do a n y t h i n g, with no repercussions. Ironically, I *chose* not to rebel - but that was my own weird rebellion of peoples expectations of my wild teenage years. People expected me to rebel, so I didn't (diagnoses welcome, folks 😂) I spent lots of Saturday nights at home reading thick books on historical events, while my friends went to parties, and that was me living the teenage dream.

Sixteen year old me wanted a surf label hoody and a CD player for my birthday.

It's a milestone birthday, I thought about getting her a signet ring like I got as a teen. But she hates jewellery, and we struggle to get her to even wear her medic alert pendant. I thought about a korowai, or pounamu for such a special birthday, but my heart couldn't take it if she turned her nose up at it like she has done to every other neurotypical, age-appropriate present I've attempted to give her in years gone by! I'll keep those taonga for another year.



Instead, this year my daughter is getting a new makka pakka toy to (hopefully) replace the ripped and worn toy she has loved every day since her 3rd birthday. Makka Pakka has seen a lot, long after its eyes have been worn away. Makka Pakka (pronouns she/they) appears in every family photo, nestled into my daughters arm or pressed to her chin. She will wake up to a Peppa pig helium balloon at the end of her bed, like she had on her 4th, 5th and 8th birthday. On her 10th birthday she had pizza and an iggle piggle cake, which she has wanted every year since.

These are the things she loves, that are important to her - so thats what she shall get.

With everything going on with disability funding and support in Aotearoa right now, I'm constantly triggered by things happening to/around us. The young man at the train made me panic about expectations of autistic adults, and the opportunistic slashing of support for those whose lives are (too) good and (too) full.

We all want our young people to be self-sufficient and do the things they enjoy like catching a train. But is displaying independence a precursor for funding cuts? Are we expected to clip their wings to keep them safe?

I worry about scenarios like this constantly at the moment. Maybe it's another same-but-different scenario for other parents of 16 year olds.

I played a short sound recording of the young man's sounds for Sophia and she smiled, like she understood what he was saying, and who he was. That soothed my wairua more than you can imagine. I deleted the recording, partly for the man's privacy - but also because I felt vindicated - safe in the knowledge that none of us are ever really alone in the world, there's always someone who lives, thinks and sounds a bit like us out there somewhere.

We all deserve the right to be who we are, and able to get where we need to be, with access to the same supports as anybody else.

Disability rights issues are never far from my thoughts these days, and as my beautiful, wild and completely original girl turns 16 this week, I'm thinking about her rights to live a full and joyful life... Just like that young man at the train station.

The greatest gift I can give her is the space and freedom to be simply herself.

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