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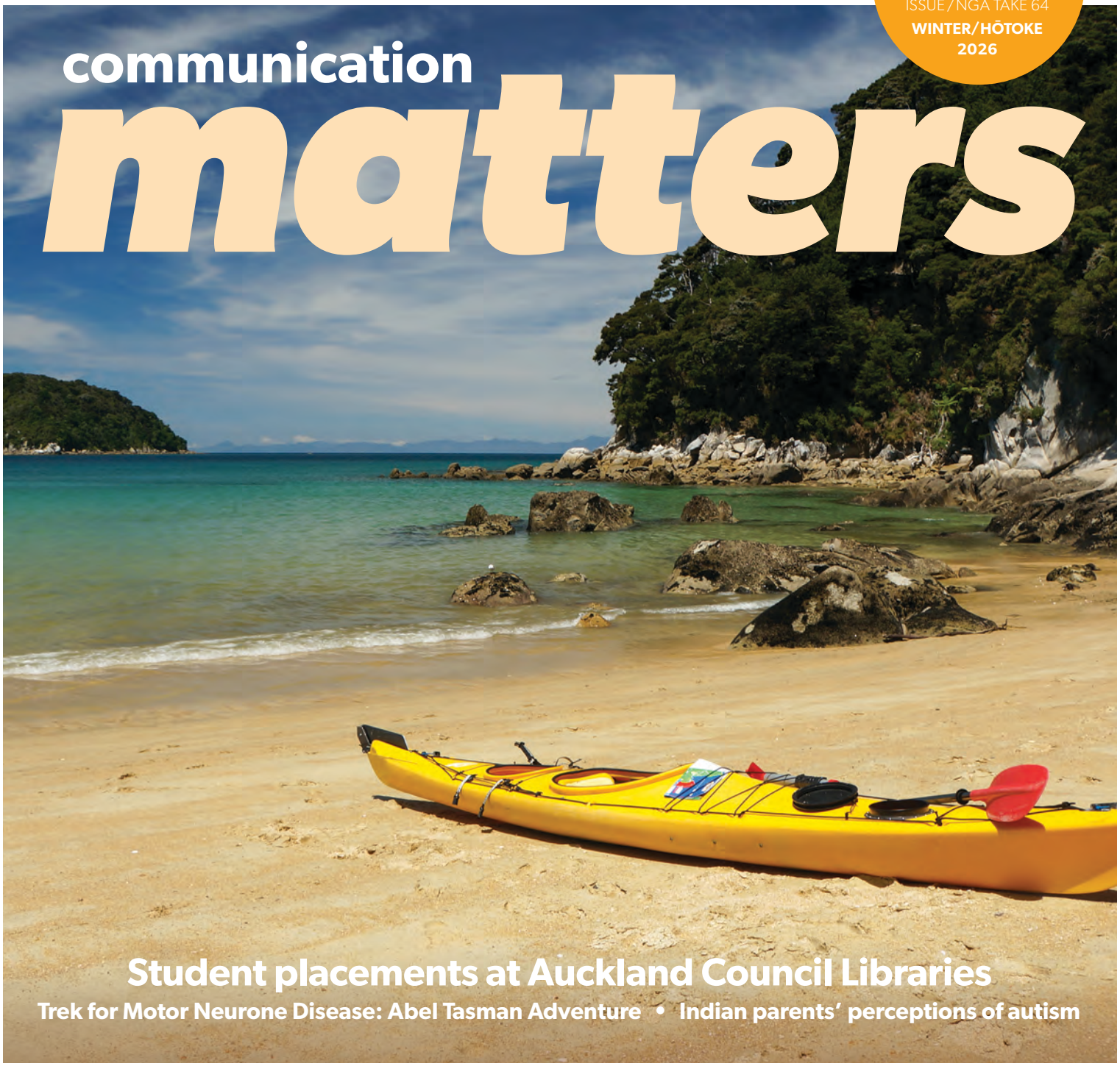
communication matters



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Please be aware that the articles on p.14 and p.16 of this edition of Communication Matters address topics of death, and contain images of people who are deceased.

Cover image: This year's Trek for Motor Neurone Disease will take place in the Abel Tasman National Park.

Please contact the editor with your ideas at any time: editor@speechtherapy.org.nz

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NZSTA upcoming events

Check out the Member Learning Hub, Bicultural Kete, and Online Continuing Professional Development sections of the NZSTA website for additional professional development opportunities!

Email **editor@speechtherapy.org.nz** to list your event on the NZSTA website in future issues.

JUNE

New Zealand Audiological Society Conference

Te Pae Christchurch Convention Centre
15–17 June

Theme: Audiology, Connection, and Clinical Excellence

More information and full conference programme available at
audiologyconference.org

JUN–JUL

Australian & New Zealand Association for Health Professional Educators Conference

Ōtautahi Christchurch
29 June–2 July

Theme: Weaving Connection – Nāku te rourou, nāu te rourou, ka ora ai te iwi

More information available at
anzahpe.org

JULY

Literacy Intervention for Older Kids

Online
7 July

Presented by Voon Pang

Tickets available at
events.humanitix.com/online-literacy-intervention-for-older-kids

AUG

Assistive Technology Alliance New Zealand: 2026 Coaching for Communication Partners

Jetpark Hotel Auckland Airport
Tāmaki Makaurau Auckland
10–11 August

Russley Golf Club
Ōtautahi Christchurch
20–21 August

Presented by Dr Sam Brydon

More information available at
atanz.org.nz/events

OCT

Talking Mats Foundation Training

Tāmaki Makaurau Auckland
23 October

To book a place, email
contact@talkingtroublenz.org

OCT

8th National Dyspraxia Conference

Ōtautahi Christchurch
2–3 October

Theme: Paving the way for success

More information available at
dyspraxia.org.nz

Speech-language therapy student placements at Auckland Council Libraries

Dr Prianka Parusnath • Lecturer, Te Kunenga ki Pūrehuroa Massey University

The thing I love about speech-language therapy is the breadth and depth of the profession, wide enough and open enough that one day you'll find a space that makes you come alive. For me, that place is the library.

This year, Massey University has started a community student placement with Auckland Council Libraries (ACL), facilitated by their Whānau Learning team. It's been one of the most joyful, liberating, soul-filling experiences I've had in my career thus far. I am honoured to have been the clinical educator to wonderful Speech Therapy students working within libraries.

The innovator behind this project is Emma Quigan. As the Work-Integrated Learning Coordinator, Emma holds the task of not only finding enough placements to meet the demands of a growing programme, but ensuring those placements stretch students in genuinely new directions.

Emma is always on the lookout for placements that grow the profession, not just the student. Emma and Alexis McCullough, Auckland Council Libraries Whānau Learning Specialist, go back a long way – old school friends whose paths had taken them into different corners of the community. A coffee catch-up turned into a conversation about mahi, and what started as two old friends catching up quickly became something much more exciting.

When Emma invited me on board, I was ecstatic. Meeting with the ACL Whānau Learning team was a gift. Here was this organisation, opening their arms to us, passionate about all the things we often have to fight so hard for: access, inclusion, participation, belonging. With Alexis on board as our field educator, we were all set to meet the teams at Mount Roskill and Mount Albert libraries.

Here we found buzzing communities. Librarians are community liaisons, story tellers, advocates, friends, and pillars of inclusion. We learnt about the work Mount Albert Library is doing to support the Deaf community and adults with disabilities through regular programmes and events, and the initiatives to foster digital literacy in an increasingly technological world. We learnt about the work Mount Roskill Library is doing to support its growing Farsi speaking population, and to invite students from their neighbouring special schools to come shelve books, learn about making sandwiches, to just come hang out and play table tennis. The libraries were nothing like the quiet, reverent, 'book houses' of my youth. They are vibrant, energetic, safe spaces alive with opportunity.

We stepped into a world where the often marginalised were welcome, where decolonisation was in action and at the forefront of the service. Children have access to toys and games, books are available in a multitude of languages across every topic, teenagers are hosted at badge making workshops, creatives are sewing in the corner.

People experiencing homelessness are free to close their eyes for a moment's rest, jobseekers have access to tech to write CVs and apply for jobs, and disability friendly story times are held in the middle of the library floor. Space is made here for people who are often told that there is none for them.

For our two final-year students on this placement, Mat Rope and Zara Sebi Mohamed, they echo that it's been a fascinating experience to enter libraries and find vibrant, community-centred

Bunny Elwell facilitating the Sing and Sign event at Mount Albert Library.
Image credit: Benj Brooking for Auckland Council Libraries

Students Mat and Zara with Alexis McCullough and Prianka Parusnath.

spaces where communication was already unfolding, but not in ways in which we would typically define therapy. The two said of their experience "The emphasis we have seen on participation, alignment of community goal setting towards Te Ao Māori, programmes catering to different linguistic backgrounds alongside the care and empathy of kaimahi has been a privilege to see kanohi ki te kanohi."

Our project focused on creating an accessible communication toolkit for library programming. What we discovered was how much libraries are already doing – and doing very well. We found a comfortable home in accessibility: The sweet spot between all the fantastic programmes that were already running at the library, with the opportunity to add our unique lens in a sustainable way.

The toolkit will include communication tips for people of all ages, including: access to AAC and how to use it, demonstration videos to implement language strategies, and session plans for any librarian to pick up. We're hoping that this toolkit will serve as a valuable and practical resource that will create inclusive environments in library programmes across the region. The focus isn't just on disability inclusion, but on language learning and communication development as well.

We're rolling this pilot out during the first half of 2026 and we're really excited

> "As far as we know, it's rare for a community, rather than an individual or whānau, to be the client in an SLT student placement. I really feel that our graduates need to be confident operating in spaces where SLT expertise has not traditionally been visible. Conventionally, placement learning consolidates what students already know, which is important too, but this felt like a chance to genuinely disrupt that and put tauira in an environment where they had to think differently about who they serve, how they share knowledge. It got them questioning what it means to be an SLT in a community context."
>
> **Emma Quigan**

Visiting the Heritage Collections at Auckland Council Libraries.

“We’re very excited about the opportunities to partner together with Massey on different initiatives, beginning with this first student placement. The Whānau Learning Team’s Literacy Plan 2025–2028 focuses on lifelong learning initiatives that foster communication and literacy in our community. This partnership with Massey University actively advances the team’s goals of early literacy development, oral language support, and family capability building by embedding SLT expertise directly into library environments.

Librarians and SLT practitioners share common goals around fostering communication, literacy and cognitive development in supportive, accessible ways, so there’s a solid foundation to build upon and a strong sense of reciprocal shared learning within the placement.”

Alexis McCullough

about it. We loved the community collaboration. We loved being active learners. We loved meeting new people and seeing the tiny books from the heritage collections held at the Central City Library (highly recommend booking an appointment at aucklandlibraries.govt.nz/en/heritage-and-research/research-services to see these if you’re a bibliophile or you just like cool things). We loved being humbled by the work that exists outside of our profession, and we felt privileged to be a part of the library team.

It’s our goal with this work to change the perception of speech-language therapy as being a service that’s needed when things go wrong, when things need correcting, when there is a deficit.

Students Mat and Zara with Karla Ramirez from the Whānau Learning team, Bunny Elwell from Mt Albert Library and their supervisor Prianka.

With the Mt Roskill Library team.

We want to promote a profession that is ever-present in our communities, that is available and accessible (despite the shortages we face). Often our intervention puts more responsibility on those who are already doing as much as they can: caregivers, teachers, and our clients themselves. Through this kind of innovation, we want to create a village that shares the load.

We see community placements like these as powerful tools toward decolonising the profession, creating responsive and reflective therapists in the students that pass through, and reimagining ways in which we can practise.

“From an SLT perspective our focus shifted from the individual to the environment; to see how participation is shaped by the space itself, through programmes, interactions, and the ways people are invited to engage. The library emerged as a powerful ‘third space’: one that fosters belonging, and celebrates diversity.

Our role has been one of collaboration rather than introducing something new. The focus of our mahi has been in supporting and extending the meaningful work already being done by kaimahi through small, intentional changes that enhance accessibility and participation in a universal manner. It’s been a significant shift from thinking about the individual versus the community as client, which has encouraged both of us to reconsider our scope, and the versatility of our role in our professional journey.”

Mat Rope and Zara Sebi Mohamed

What's your speech-language therapy legacy going to be?

Dr Philippa Friary • Expert advisor – supervision, New Zealand Speech-language Therapists' Association

Do you remember your first off-site student placement?

I bet you do. I clearly remember all my external placements vividly, which says a lot given they were a few haircuts ago now. I remember carpooling with my friend's cousin down to Wellington from New Plymouth. I remember staying at my flatmate's parents' place. I remember feeling unsure about what to wear on my first day and turning up to the placement office feeling pretty nervous. I remember my delight in having access to free Milo and I will never forget how I felt when I worked with a child on my own, without my supervisor observing! I am sure you will have similar memories – not always glowing, I'm sure. Yet that comes with the territory of being out of our comfort zones, extending ourselves and learning with some micro failures thrown in.

When I think back to all the supervisors who I connected with as a student, they taught me much more than how to do the technical parts of our job. I learnt about how to look after myself at work, and how to ensure a work-life balance. I learnt how to make staff feel welcome, necessary and connected. I learnt about how to advocate for the profession, clients and ourselves. And I learnt who I wanted to be as a speech-language therapist.

I also vividly remember the first student I supervised. I remember feeling nervous about not being good enough, not knowing enough, not being ready – and then feeling relieved when I discovered that I had many skills I could transfer into this new role as a field educator. While I did need to spend a bit more time initially planning and prepping, once our supervision relationship was up and running, it was fun, and I think I was pretty good at it.

With university programmes at Massey, Canterbury, and the University of Auckland training over 200 students at any time, a relationship with the sectors employing speech-language therapists is crucial to ensure that graduates reach the communities they need to serve, work-ready. This is where you come into the picture. Have you had a student join you and your team before? When was the last time? What capacity do you have to support the learning of a student? If you are new to supervision or someone who has not supported a student for a while, here are some tips to help you put up your hand to support a student placement:

- Reach out to your immediate or wider team. Who has experience in supporting student placements? Catch up with them for a coffee and chat to learn about what they do.
- Chat about your ideas with your supervisor and peer mentor. Reflect on your strengths you would bring to this new role and some areas for development.

> I remember feeling relieved when I discovered that I had skills I could transfer into a new role as a field educator."

- Reach out to the university programmes. We geek out on practice education, and have too many resources available to share with you.
- Consider sharing a student for your first placement.
- Find out what information your workplace has to support students orienting to the sector.
- If you are brand new to supervision and a colleague is supporting a student, could you have the student join you for a day here and there?
- Attend the Field Educator Modules.

Each year, the University programmes collaborate to bring you the Field Educator Modules. These are a series of live workshops with some pre-recorded content to work through in your own time. They are focused on those new to field education but can be good for those wanting a refresher. These modules cover the following topics:

A model for field education in Aotearoa

Ethics and field education

Culturally safe field education

Field educator tools: use of questions, feedback, and reflective practice

Getting the most out of COMPASS for learning and assessment

The field educator hui are also a time to meet other SLTs across the motu interested in student education. These hui create an opportunity to form new peer networks for ongoing support and information sharing.

If you are reading this and thinking, yeah, I think I have space to support a student, just reach out to any of the programmes for more information.

The opportunity to be part of the education and development of the speech-language therapy profession is yours to take, and a great way to give back to the community. What's your speech-language therapy legacy going to be? Field education is one way to make a memorable impact. •

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Understanding autism through culture: Indian parents' perceptions of autism in Aotearoa New Zealand

Shalini Devi Krishnan • Speech-language therapist, Ministry of Education Christchurch – Te Mahau Te Tai Runga

Autism is increasingly recognised in Aotearoa New Zealand, yet families' experiences of diagnosis and support are shaped not only by clinical knowledge but also by culture, beliefs, and migration histories. My research explored how Indian parents living in New Zealand understand autism, how they make sense of their child's diagnosis, and how cultural values influence family life, help-seeking, and engagement with services.

Why this research matters

The Indian community is one of the fastest-growing ethnic groups in New Zealand, yet little local research has focused on how Indian families perceive autism. As a speech-language therapist working with culturally diverse families, I observed that some Indian parents experienced delays in diagnosis or uncertainty around intervention, even when they were highly involved and motivated. This research aimed to understand ***why*** – not as a deficit in parenting, but as a reflection of cultural frameworks, expectations, and systemic barriers.

Using a qualitative, phenomenological approach, I conducted semi-structured interviews with four Indian parents of autistic children. Reflexive thematic analysis revealed five key themes that highlight the lived realities of these families.

Awareness and understanding of autism

Most parents reported limited awareness of autism prior to their child's diagnosis. Autism was not something they had encountered in their families or communities in India, and several described learning about autism only after professionals raised concerns.

Initially, many parents interpreted their child's differences as a developmental delay rather than a long-term neurodevelopmental difference. There was a strong belief that with time, exposure to peers, discipline, or effort, the child would "catch up." Some parents also wondered whether autism was caused by environmental factors such as migration stress, lack of extended family involvement, or reduced verbal interaction at home. These beliefs reflect common cultural explanations and highlight the importance of providing clear, culturally sensitive information at the time of diagnosis.

Identification and perceptions of autism

Across all families, communication differences were the earliest and most key concern. Parents noticed delays in speech, limited back-and-forth interaction, and challenges with social engagement. These communication difficulties caused significant worry, particularly as parents strongly associated spoken language with independence, academic success, and social inclusion.

At the same time, parents were quick to identify their children's strengths. Many described exceptional memory, strong numeracy skills, and the ability to learn quickly through repetition and visual input. Academic abilities were highly valued, reflecting cultural emphasis on education. This strengths-based recognition suggests an important opportunity for professionals to align intervention goals with family values.

Impact on family life

Parenting an autistic child had a profound impact on daily routines, emotional wellbeing, and social participation. Parents described constant supervision, difficulty with transitions, and limited opportunities for rest or personal time. Mothers, in particular, carried the primary caregiving role and reported emotional exhaustion, worry about the future, and reduced social connection.

Migration compounded these challenges. Parents frequently contrasted life in New Zealand with life in India, where extended family members, especially grandparents would typically provide practical and emotional support. The absence of this support network increased isolation and pressure on parents, particularly when both parents were working. Several families described placing plans for having additional children on hold in order to focus their time, energy, and resources on their autistic child.

Social perceptions and stigma

Stigma emerged as one of the most emotionally charged themes. Parents described repeated experiences of misunderstanding from relatives and community members, who often viewed autism as a temporary illness, poor behaviour, or something that could be "fixed" with medication or discipline.

Because explaining autism repeatedly was emotionally draining, some parents chose to avoid disclosure altogether. Many reported responding to questions with vague reassurances that their child was "fine" to avoid judgement or intrusive follow-up questions. This concealment highlights the invisible burden families carry and the powerful role of cultural stigma in shaping behaviour.

Navigating services and hopes for the future

Parents expressed mixed experiences with services in New Zealand. While appreciative of support from schools and speech-language therapists, some felt services were too indirect or parent-led and wanted more hands-on, individualised therapy. Several parents believed more intensive intervention was available overseas, particularly in India, and expressed interest in travelling there for treatment.

Despite uncertainty and fear about the future, parents' aspirations were clear. Communication, independence, and meaningful participation in society were consistently prioritised. Some parents became more open to alternative communication methods, such as sign language or assistive technology, reflecting gradual shifts in expectations over time.

Implications for practice

This research highlights that delays in diagnosis or hesitancy toward services are not due to lack of care, but to deeply rooted cultural beliefs, stigma, and systemic mismatches. For speech-language therapists and educators, it underscores the importance of culturally responsive, strengths-based practice.

Building trust, using accessible language, acknowledging cultural values, and focusing on functional goals rather than labels can support stronger partnership with Indian families. Community-based education and collaboration with cultural organisations may also help reduce stigma and improve early engagement.

Conclusion

Indian families raising autistic children in New Zealand navigate complex emotional, cultural, and systemic challenges. By listening to their voices and understanding autism through a cultural lens, professionals can better support families – not by asking them to change their values, but by working alongside them in respectful, collaborative ways. •

When health IT fails us

Callum McMenamin • Founder, OpenAccess

Kia ora – I'm Callum McMenamin. I run a consultancy called **OpenAccess**, which specialises in helping organisations to make their services more accessible for disabled people. I am dedicated to improving how our health system supports and includes disabled people.

Recent cybersecurity events

As you've likely seen in the media recently, important health systems like Manage My Health, and MediMap suffered severe cybersecurity breaches – where patient data was stolen by hackers and modified.

This strikes at the heart of patient trust in healthcare providers. If these breaches keep happening, the public will no longer trust that healthcare providers are able to keep them safe.

Health information technology (IT) systems provide a crucial non-speech communication pathway – where speech and hearing aren't required to interact with health systems. Because health IT provides a critical communication pathway for disabled people, we must ensure these systems remain accessible, and safe.

A failure of governance

I wanted to dig into the root cause of these breaches. What I discovered was that the entire healthcare system lacks appropriate IT security standards, and nobody monitors or enforces these standards across the health system.

The healthcare system comprises thousands of healthcare providers, all using thousands of different private health IT systems. Patient data is scattered across more systems than anyone realises. This means there are thousands of places for hackers to attack – a weak link in any of these systems will cause disasters.

The part I find most appalling is that Health NZ – Te Whatu Ora takes no responsibility for the security of the overall system: responsibility for security gets outsourced to the private sector. If a health IT system is hacked, Health NZ shrugs it off and points their finger to the private sector. This is not how a responsible government agency should behave.

When breaches happen, Health NZ and the Ministry of Health deny culpability for a system of which they are the architects. New Zealanders should be able to trust our government to be a responsible guardian of our health system – and we have been rudely awakened to the fact that the government was doing virtually nothing to keep our health data safe.

The Minister of Health refused to meet with me to discuss these issues.

An important area is breach notifications: when a data breach happens, we must ensure we tell patients what has happened. This needs to be done in a way that is accessible for all people, regardless of disability. Relying on phone calls excludes people who are Deaf or have speech impairments. Ensuring data breach responses are planned with disabled people in mind is essential.

How bad can it get?

In Finland, Vastaamo was a private psychotherapy service provider which received government funding.

In 2020, a hacker compromised Vastaamo's security and gained access to the entire patient database.

The patient database contained detailed therapy session notes for 36,000 patients – covering the most sensitive aspects of their lives, from affairs to suicide attempts.

The hacker attempted to extort the Vastaamo service, and individual patients, which was largely unsuccessful. 36,000 patients had their private therapy notes published on the public internet.

In some cases, victims of this data breach took their own life.

An organisation which was entrusted to improve the mental health of their patients, instead caused widespread psychological harm, all due to lax security measures.

This is the kind of scenario I fear New Zealand is walking into. This is a literal ticking time-bomb. The breaches of Manage My Health and MediMap were just warning shots: if we do not get immediate, and significant reform of cybersecurity in the health system, the next breach may have a measurable death toll.

Back-office roles are essential

Cutting back-office roles has a significant, and measurable impact on front-line services. If our government under-invests in cybersecurity, we will be guaranteed to encounter more frequent, and severe data breaches in the future.

The latest artificial intelligence systems are highly capable of designing and carrying out complex cyber-attacks. As each day passes, AI systems are becoming exponentially more intelligent and capable. We are not seeing appropriate increases in cybersecurity spending to combat this risk.

What can you do?

Cybersecurity needs all people involved to play their part.

Some tips to improve the security of your systems include:

- **Ensure multi-factor authentication is enabled on all systems.**
- **Use long, unique passwords on all systems.**
- **Pay for a cybersecurity consultant to audit your systems.**

On top of security, we also need to ensure healthcare is accessible – as in, it has no barriers that impact disabled people.

I recommend that all healthcare providers pay for periodic accessibility audits – these audits help to identify areas where disabled people might struggle to interact and participate in healthcare.

With some careful planning and auditing, we can achieve an inclusive, and secure health system for Aotearoa.

Trek for Motor Neurone Disease: Abel Tasman Adventure

Louise Blockley • Communications specialist, Motor Neurone Disease New Zealand

If you're looking for an exercise goal that truly makes a difference, Motor Neurone Disease NZ's **Trek for MND: Abel Tasman Adventure** is the perfect opportunity.

You'll boost your physical and mental wellbeing while helping support people living with a fatal, incurable disease – one that often affects speech and swallowing. Every step you take helps fund vital support and research for those impacted by MND.

The trek is five days, 55 kilometres of golden beaches, native forest, and rugged coastline, all to raise vital funds for support and research of those impacted by motor neurone disease (MND).

You can join a community of supporters on the Abel Tasman Coast Track to:

- Trek up to 55 km through diverse scenery: secluded bays, native forest, and sweeping headlands.
- Camp at stunning coastal sites and share stories around the campfire.
- Follow routes once trodden by miners and prospectors, linking history with purpose.

If you can't join the team on the trek, you can support those who have already committed to the trek, like the three sisters on a mission for MND, Lisa, Katrina and Veroncia. They're walking in memory of Lisa's husband Carl, who died of the disease in August 2025 aged 56.

Two days before Christmas in 2024, Lisa and Carl Cavanagh received the news that Carl had MND.

"For me, one of the things that hit hardest from the day we were diagnosed is the total lack of any hope of a cure right now. There's no real treatment, you're just totally at the whim of the disease… Carl passed away eight months after his diagnosis, in August 2025. He had quite an aggressive form of fast-progressing MND. It was a similar pathway to the actor Eric Dane, he was diagnosed not long after us," says Lisa.

Lisa has described how much it means to her to be helping other families by participating in the Abel Tasman Trek for MND with her sisters, and doing unique fundraising events together with her extended family. She is looking forward to five days on the beautiful trail in October.

Lisa and Carl were living their dream travelling around Australia in a caravan when they first noticed Carl's MND symptoms. They had sold their house and belongings in New Zealand, given up their jobs, and taken the leap to travel and work.

“

The support we got from MND NZ was just amazing. It’s important to me to give back and know that by raising money ourselves, we’ll be able to help another family in that situation.”

Lisa Cavanagh

Carl and Lisa Cavanagh

Carl stopped riding his mountain bike for a couple of months, partly due to weakness on his left side and several falls. He was struggling to get in and out of the caravan, needed help to get up off the ground, and was experiencing tingling sensations.

Medical specialists thought he had a pinched nerve, and sent him to a neurological surgeon for what should have been minor day surgery. However, the surgeon said he couldn’t help and got Carl fast-tracked to see a neurologist.

In December 2024, Carl fell badly and was going to the accident and emergency clinic when he happened to get a follow-up call from the surgeon. Carl explained that his symptoms were getting worse, he hadn’t heard from the neurologist, and he was now enroute to A&E after a fall.

“And that surgeon must have known what he thought it was. Because he rang the neurologist, got him off the golf course and made him come and meet us at A&E,” recalls Lisa.

They returned home to New Zealand to set up a home in Auckland again, with their caravan stored in Australia and their two dogs temporarily rehomed with Carl’s sister. They bought and set up a house from scratch while dealing with Carl’s deteriorating health. By February 2025, he was in a wheelchair, and he sadly passed away in August.

“By also supporting the research with our fundraising, hopefully we can give another family hope that someday MND is no longer a death sentence, but it’s something that is treatable,” says Lisa.

Motor Neurone Disease NZ (MND NZ) is the only organisation in Aotearoa solely dedicated to supporting people with motor neurone disease (MND) and their loved ones. From diagnosis through every stage, MND NZ offer tailored support, strong advocacy, practical education, and a clear voice for research and systemic change.

For more information on the Abel Tasman Trek for MND or to register for the walk go to the MND NZ website: **mnd.org.nz/abeltasman**

Support Miles for MND – 3 Sisters on a Mission here:

When we lose a child

Tracy Kendall • Speech-language therapist

This article is the first in a two-part series by Tracy about coping with the death of tamariki, a situation that many speech-language therapists have faced. Please note that this article deals with sensitive topics.

Daniel celebrating his birthday.

As speech-language therapists, parents, and grandparents, we struggle to imagine losing a child. Nasim, and her husband Arash, always knew that Daniel, who had a rare genetic condition, could die young.

Daniel was diagnosed soon after birth with CACTD, Carnitine Acyl Carnitine Translocate Deficiency. At the time, Daniel was the first known New Zealander to have this condition. As Nasim and Arash parented Daniel, dying young was never forefront in their minds. Instead, like any other parents, they got on with their lives as a family of three. In fact, they had big hopes for Daniel, because in their words

> “They thanked God he was doing so well.”

Daniel was mobile and could use the bathroom independently; he showed emotions, and while he was developmentally delayed, used a range of expressive language to communicate. He was artistic, meticulously cutting his drawings out. Daniel, diagnosed with autism at around five years old, was funny, and could masterfully apply the lines of a movie to his own life that made astonishing sense. He was also upfront with his honesty. Daniel loved the experience of buying an ice cream from a shop, or a fundraiser sausage. He didn’t actually eat the sausage, or the ice cream, because for all of his life most of his nutrition came via a MIC-KEY button in his stomach.

My lasting memory, one of imagery, is of Daniel aged around seven. His parents had brought him to me for his speech-language therapy session; following this, it was time for a feed before going back to his special class at school. Nasim and Arash were in the atrium next to my clinic, bent over their son. Like two devoted birds, they folded their protective wings over their fledgling, as they delivered the food into his stomach. It was an intensely private moment, in a very public space. People walked by oblivious to this ritual, that was repeated eight times, every 24 hours, for the 15 short years of his life. To observe their devotion was deeply touching.

Daniel was tube fed for the first eight years of his life, and then started drinking thick liquids during the daytime, after feeding interventions sessions with a behavioural psychologist.

Nasim usually did Daniel’s first morning feed. When Daniel suddenly died peacefully in his sleep one winter’s night a few years back, from a cardiac arrest connected to his genetic condition, Nasim had unusually slept in.

Nasim told me that people who believe in “something,” – not necessarily her Christian faith, but ‘anything,’ – do better in grief. Nasim also believes that while it’s different for everyone, it was grace that guided her through the first painful 18 months following Daniel’s death. Nasim’s son was the centre of her purpose and attention; everything she ever did was focused on him. Her weeks were full, and suddenly her sense of purpose vanished. She was lost. The thing is, Nasim told me,

> “You don’t enjoy the things you were doing before.”

Dr Lucy Hone is a resilience researcher, grief specialist, and author; in her 2020 Ted talk titled “The Three Secrets of Resilient People” she writes about why some people navigate uncertainty,

disruption, grief, loss, and change with clarity and confidence, while others feel overwhelmed or stuck.

Lucy, a parent who also had a child tragically die young, states three reasons why she believes resilient people manage:

- They get that s**t happens.
- They are really good at choosing carefully where they select their attention.
- They ask themselves: is what I'm doing (to cope) helping or harming me?

So how did Nasim manage?

Nasim's GP wanted her to go on anti-depressants. Despite the first very dark early months, she is glad that she chose not to do this. Around two years after Daniel's death, Nasim went out into her neglected garden, which she used to love caring for; on that day she found a glimmer of joy again. Out there in the garden, she recalled the feeling of excitement and called to Arash:

> "You know what? After so many months, this is the first time I have felt a little bit of hope and joy in the sun."

This was the beginning of learning how to live again, without their son, Daniel.

I asked Nasim what advice she would give to other parents who experience the loss of a child. Nasim told me:

> "Occupy yourself with something to help support your grief and emotions, such as I did in the gardening, and by doing a one-year course. These things helped me a lot."

Insightfully, Nasim also relayed that in a strange way, Daniel's death gave them release from the ever-present thinking that when Daniel was away from them both at school, he might need them; because as parents of a seriously health-compromised child, this responsibility was always with them.

Nasim also observed, and recognised the feelings of others close to Daniel:

> "Sometimes even the closest relatives and people don't understand what you are going through as parents who have lost a child. Sometimes they make comments in goodwill, but it doesn't sit right with your heart. We should remember that these people are grieving as well; they don't mean what they said, they just want to comfort us."

Nasim, who is a hairdresser, recently found something else to help her on this journey. She'd always felt drawn to working with children with special needs. One sleepless night at 2:00am, three and half years on from Daniel's death, the idea came to her, 'I can cut hair!' After a phone call to Daniel's school SENCO, she packed up her hairdressing tools and took them to his old classroom. She'd observed that parents of some special class children struggle to take their children to the hairdresser to have a decent haircut. In fact, many parents end up cutting their own children's hair, and, as Nasim observed, not very well! The SENCO was grateful, because after unsuccessfully calling ten separate hairdressers to come in and cut hair, Nasim arrived in the classroom.

> "It's going well. I am serving special needs children in this way. It makes me feel that I'm close to Daniel. I'm doing something positive; it's not just for the community; it's for my heart."

Nasim wanted to share with other parents who have lost a child:

> "We keep remembering our Daniel on a daily basis; this brings joy to our hearts, sometimes sadness, but mostly joy, like his words, and the funny comments he made. This keeps us going, because we still live on a daily basis, that's how we keep on living with this grief."

Written in loving memory of Daniel, with grateful thanks to Nasim for sharing.

For more information on Dr Lucy Hone's work: **drlucyhone.com**

Part 2: On losing a child: Hugo, will be published in a year's time

King's shout-out for aphasia

Kate Daellenbach • Community Aphasia Advisor, Aphasia New Zealand Charitable Trust

Kate Milford, a champion for aphasia in Aotearoa New Zealand, has been awarded a Member of the New Zealand Order of Merit, for her leadership in improving the lives of people with aphasia.

Originally a speech-language therapist in the United Kingdom, Kate moved to New Zealand in 2000. Working in the community in south and central Auckland, she became more aware of the long-term impact of aphasia and need for tailored on-going services.

Following the first aphasia conference organised by clinicians and academics in Auckland in 2005, Kate raised her hand (she says "*with trepidation*") to help set up an association and continue with biennial aphasia conferences. The first AphasiaNZ-run conference was held in 2007.

While this was a huge endeavour for all involved, Kate and colleague Emma Castle knew there was much more that needed to be done.

"It became much more apparent that while the conferences were valued, we were only supporting a small number of people with aphasia and we needed to do things differently," says Kate.

Transitioning AphasiaNZ from an incorporated society (supporting members only) into a charitable trust, Kate then led the development of a new community-based model of support, establishing aphasia advisors (all of whom are registered speech-language therapists) around the country to provide home visits, education, awareness-raising and communication groups. This innovative approach was unique

Kate Milford with Governor-General Dame Cindy Kiro

internationally, and has extended support to many more people with aphasia and their whānau, ensuring help is available closer to home and over the longer term.

Responding to the honour, Kate says:

> “I am deeply honoured to receive this award, and thankful for the opportunity to raise awareness of aphasia. I am privileged to work alongside people with aphasia and their whānau and am consistently impressed by their resilience and bravery.”

Kate is currently the Community Aphasia Advisor practice supervisor and a trustee.

From all of us, and people with aphasia and primary progressive aphasia, thank you Kate and well done!

Facts about AphasiaNZ

AphasiaNZ supports people with aphasia and their whānau throughout the country via 15 part-time Community Aphasia Advisors (all SLTs).

In 2025, AphasiaNZ ...

- held 456 home visits with people with aphasia, including 347 whānau members
- made nearly 700 phone calls to support people with aphasia and their whānau
- ran 20 regularly occurring conversation groups around the country, and a further 6 online
- made 5,346 contacts with people with aphasia at a total of 632 groups
- networked with other related organisations across Aotearoa
- provided 34 education sessions and participated in 8 events

At any one time AphasiaNZ supports around 1,100 people with aphasia plus whānau. On average a new referral is received every working day.

AphasiaNZ’s service is offered free of charge; funding relies on koha/donations and community grants.

Stop Shouting! A humorous grammar guide for speech-language therapists

Siobhan Molloy • Kaiwhakahaere Matua
Executive Director, NZSTA

Picture this: the NZSTA executive director sits at her desk, sifting through a mountain of reports and emails, each one a testament to the boldness of rogue capital letters. Her eye twitches yet again as she reads ***"Speech-Language Therapist,"*** with every word capitalised as if it's some grand title to be shouted from the rooftops. Help, next, they'll be capitalising ***comma***.

Determined to save the Association (and yes, that capital is used advisedly) from grammar chaos, she pens a memo on the importance of reserving capitals for proper nouns only. "Let's keep speech-language therapists down-to-earth, shall we?"

Ah, grammar – our old friend and occasional foe. As speech-language therapists (not Speech-Language Therapists or Speech-language Therapists, please!), we know that clarity in communication is key. So, let's dive into some grammatical gems and how to dodge common pitfalls.

Capital letters: not every word deserves a crown

Let's start with capitals. They're for proper nouns, the start of sentences, and that's it. While you might be tempted to Capitalise Every Important Word to make things look impressive, resist! Capital letters should be sparingly bestowed, much like the last slice of pavlova at a family dinner.

First, never capitalise "speech-language therapist" or "speech-language therapy" in the middle of a sentence. We're not a specific place or person (yet!), so we don't get the capital treatment.

Capitalisation is only appropriate and typically reserved for formal titles directly preceding someone's name (like Co-presidents Jane McKinnon and Emma Quigan). However, it is equally appropriate to write Jane McKinnon and Emma Quigan, co-presidents of NZSTA.

The same rule applies to membership language. In ordinary body text, write NZSTA registered member and NZSTA registered membership in lowercase. Save capitals for formal headings, form labels or official category names, such as NZSTA Registered Member or Registered Member Declaration.

Acronyms can also trick us into unnecessary capitals. Just because SIG is shouted in capital letters does not mean special interest group needs to arrive wearing a crown. The same goes for CPD – continuing professional development is perfectly happy in lowercase – and APC, which becomes annual practising certificate in ordinary body text. Save capitals for formal titles, headings and official form labels.

The apostrophe's wrath

Tiny yet powerful apostrophes are used primarily for two purposes: to indicate possession (e.g., ***the therapist's report***) and to form contractions by omitting letters (e.g., ***don't*** for ***do not***). It helps clarify meaning and denote plural forms for letters and numbers (e.g., ***Mind your p's and q's***). It's easy to misuse them, and you don't want to create confusion. For example, when writing about your client's progress, notice the neat little apostrophe. But don't overdo it. If you find yourself writing, "The SLT's are meeting today," stop right there. Apostrophes are not for plurals. Think of them as exclusive; they only show up when they want to, and it's usually not for numbers.

Pronouns and the mysterious case of "they"

While "they" as a singular pronoun might once have raised eyebrows, it's perfectly acceptable these days. As SLTs, embracing "they" can simplify discussions about clients without getting into the he/she business. It's a great way to avoid those awkward moments when you realise you've been using the wrong pronoun halfway through a sentence.

The Oxford comma – A great debate

Now, to comma or not to comma? The Oxford comma debate rages on, but here's a quick tip: use it if it clarifies meaning. "I love working with children, adults, and animals" is a very different statement from "I love working with children, adults and animals." You might just avoid a misunderstanding that could end with you delivering therapy to a very patient labrador.

The dreaded passive voice

Finally, a word on passive voice. Often seen lurking in scientific papers, it can sap the life from your sentences. Instead of "therapy goals were met by the client," try "the client met therapy goals." An active voice is direct and clear, making you sound like a go-getter.

So, remember these grammar basics the next time you're crafting a report or an email. With a bit of attention to detail, you'll communicate clearly – and avoid the wrath of grammarians everywhere. Go forth, speech-language therapist, and wield your words wisely!

Launching the TD Snap special interest group

Christina Doughty • Speech-language therapist and assistive technology consultant, Link Assistive New Zealand

The TD Snap special interest group (SIG) for speech-language therapists and educators has officially launched, creating a dedicated space for AAC practitioners across the motu to connect.

This group started as a response to the growing interest in TD Snap and a clear desire for peer connection. The SIG aims to provide a welcoming, practical, and collaborative space for therapists and educators who are using, or considering using, TD Snap with the people they support.

Our first session was a great success, with a strong turnout of attendees with ranging experience, reflecting the increasing awareness and presence of TD Snap across clinical, educational, and community settings. We spent time looking at recent software updates, various ways to access the app (including the TD Snap for Schools initiative), and useful tools like shortcuts and Boardmaker activities.

Looking ahead, future SIG sessions will continue to build on this strong foundation. We want these sessions to be grounded in the reality of clinical and educational work. Planned content will include:

- Latest updates from the TD Snap developers – ensuring members stay up to date with new features, improvements, and the rationales behind them.
- Pageset deep dives – exploring the structure and customisation of different pagesets to make the most of TD Snap's flexibility.
- Practical feature overviews – focusing on tools that simplify setup, support access, and enhance user experience.

While Link Assistive NZ is currently facilitating the SIG, the long-term vision is for this to be a shared space. We want to move away from a "one-way" presentation style and instead foster a community where we learn from one another. In future sessions, we'd love to see attendees take a more active lead. Members will be invited to bring case studies, challenges, and "what would you trial in this situation?" scenarios to the group. This collaborative problem-solving approach supports reflective practice and helps translate knowledge into meaningful outcomes for AAC users and their teams.

Supporting AAC effectively is about more than just knowing the tech; it's about confidence, creativity, and having a solid professional network. By meeting quarterly, we can stay connected, build our collective skills, and better support communication for tamariki, rangatahi, and adults throughout Aotearoa.

If you have an interest in TD Snap – at any level of experience – you are very welcome to join us. •

Sign up for future sessions at: bit.ly/TDSnapSIG

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Please consider contributing content to *Communication Matters* about any aspect of our profession. Feel free to discuss with Emma Wollum, Editor, any ideas you have. **editor@speechtherapy.org.nz**

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