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communication matters

Creating something special with Kimi Ora Choir

Takiwātanga: Na Keri Opai • Diversity and inclusion in the our workplace • 25 years of START

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Rārangi upoko kōrero

Cover: Kimi Ora School Choir rehearsal. L–R: Te Au Mārire Madams, Himanthi Gunawardana, (Teacher-aide) and Aydin Taing.
Photo credit: Kimi Ora School

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

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From the president

Nā te tumuaki

Annette Rotherham president@speechtherapy.org.nz

The days are getting shorter but that does not mean we are doing any less in our daily lives. 2021 has been full of activity for myself and the NZSTA board and we hope you all managed to connect with some of our newer board members, Emma and Akshat at the recent area meetings. We hope to keep circulating attending the meetings to allow more connection and kōrero between us all.

Something that is top of mind for me at present is advocacy. Being heard in government is a vital strategic goal but requires specific skills and planning to ensure we achieve the desired outcome. We have been working with Deborah Hart, a specialist in public and government relations to assist us to develop our strategy for lobbying and advocacy. She is focussing on some vital areas such as our self-regulation model and the service gaps. When the leaders from all sectors of the profession met in 2019, we identified key national issues 1) there is still much unmet need out there for people with communication and swallowing disabilities 2) We are thin on the ground, only 19: 100000 SLTs in Aotearoa, lower than all our MRA partner countries.

We took a basic SLT to population ratio and came up with the following.

- 50 ASHA SLP members per 100,000
- 35 SPA members per 100,000
- 26 RCSLT members per 100,000
- 26 Canadian SLTs per 100,000
- 23 Irish SLTs per 100,000
- 19 NZSTA members per 100,000

The consequences of unmet need are the growing inequity in health and education systems, and a pressing need to address the support and services required for youth and adults who have been let down by the systems during their lives. I wish to applaud and Tautoko Sally Kedge from Talking Trouble for her stunning oral submission to the select committee in February in response to the Oranga Tamariki (Youth Justice Demerit Points) Amendment Bill – hearing of evidence (17 March 2021). You can read about this exceptional mahi from the Talking Trouble team on page 6. Thank you for portraying your message so clearly and simply but with strength and integrity. Ngā mihi nui.

NZSTA have benefited greatly from bringing Siobhan Molloy onboard in February. NZSTA is experiencing significant growth and needs to perform at a high level alongside other allied associations both nationally and internationally. The board has unanimously agreed that we want to be a governance board not a management board and we have explored how this will occur with the help of Siobhan, who brings not only her knowledge of the profession of SLT but also 16 years of association management. A full report will be shared with members soon to demonstrate the benefits from identifying our gaps in skill and policy and learning how to take the association to a more strategic and higher functioning level. I am thrilled to be able to offer a 12 month trial contract to Siobhan as the NZSTA Executive Director and I am sure you will all see some significant changes and progress with this milestone position for the association.

I hope you enjoy this edition of *Communication Matters*, please feel free to be in touch with myself, Siobhan and the rest of the board as well as Loreen our secretariat.

Hei konā mai
Annette

NZSTA happenings

Some of our recent Association happenings at a glance…

MARCH

AHANZ AGM attended by Annette, Rukingi. AHANZ cultural safety workshop attended by Annette, Katrina and Rukingi in Wellington.

MARCH

ICP – Annette reviewing the strategic goals of the ICP with partner organisations ASHA, SAC, RCSL, IASLT and SPA.

APRIL

Website survey to members – Members have their say about what is working and improvements they would like to see.

19 APRIL

Board meeting

Left: February NZSTA Board meeting.

20 APRIL

SLT Leaders summit include:

- NZSTA advocacy plan
- Cultural safety and building diversity into the workforce
- NZSTA CPD project
- Updates from the sectors

MAY

Call for nominations for the NZSTA Board – great opportunity.

"Joining the board of the NZSTA has been an opportunity to truly make a difference and have a voice for the profession both nationally and internationally."
– Annette Rotherham, President

MAY

Siobhan Molloy, project manager reports to the NZSTA Board with a nine step plan to effective governance for the NZSTA.

75th Anniversary of NZSTA

Siobhan Molloy, NZSTA Project Manager

This year, NZSTA celebrates 75 years as the pre-eminent association for speech-language professionals.

It is an opportunity to remember the instrumental role members have played in the past, and continue to play now and into the future. So many of you have contributed to our story, helping to build the future of speech-language therapy.

Why is the 70th annual general meeting coming up?

Each (annual) general meeting has been labelled with the date and sequential number – this year is the 70th (annual) general meeting. NZSTA project manager, Siobhan Molloy was curious as she came across contradictory information on our website which suggested that NZSTA might be older than 70 years.

A bit of sleuthing and a morning at the National Library, Wellington and the Alexander Turnbull Library unearthed some public and private collections of historical Association information.

The records are clear – the Association was formed in 1946 – making this year our 75th anniversary. Curiously though in 1954 there was a decade of biennial general meetings instead of annual meetings – thus this year marks the 70th (annual) general meeting and our 75th anniversary.

In the beginning

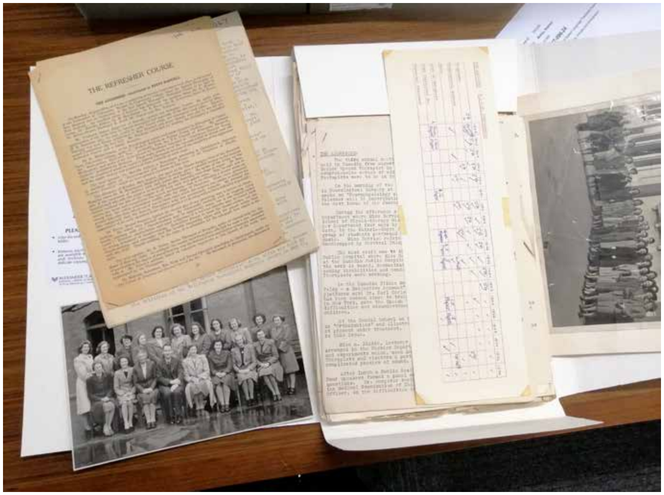
On 28 August, 1946 the first annual general meeting was held in Christchurch during the first annual conference. Those present elected an executive to 'control the organisation of the Association.'

They were:

- President – Miss. M.E. Saunders
- Vice-Presidents – Mrs. Roberts and Mr. Dunne
- Secretary and Treasurer – Miss. C. Justin
- Members – Mrs. Craw and Seabrook

The meeting agreed that a membership fee for practising therapists should be £1 while students were to be charged 5/-.

While no motion was passed, the members also agreed to sanction the charging of two guineas for 10–12 private lessons – something with today's Commerce Act, NZSTA would have found itself in serious hot water. ●



Left:
Siobhan uncovers SLT treasures in the Alexander Turnbull Library.

Photo credit: Siobhan Molloy

Expert Advisor recommendations

Members reported that they enjoyed the Autumn issue's array of suggestions from our Expert Advisors, for interesting and captivating media, which align and celebrate some of the areas which SLTs are passionate about.

We would like to hear yours! Please email **editor@speechtherapy.org.nz** about books, films, podcasts, blogs, pinterests; any media which you feel speaks to speech-language therapy and the people we care for.

You can find details of NZSTA's Expert Advisors, and how to contact them, on the back of *Communication Matters*, or on the website. Expert Advisors are approachable for queries about complex cases you are experiencing, and also contribute, on members' behalf, to national health and education strategy when needed.

Carlene Perris, Voice has a number of recommendations, inspired by her specialism in voice:

- Movie: Do I sound gay? Watch the trailer at **youtube.com/watch?v=R21Fd8-Apf0**
- TED talk: Vocal Branding Beyond Words **ted.com/talks/wendy_leborgne_vocal_branding_beyond_words_how_your_voice_shapes_your_communication_image**
- Website: Voice Medicine Australia **voicemedicineaustralia.com**

Liz Fairgray, Hearing Impairment and Cochlear Implant highly recommends this resource: **Facilitating Hearing And Listening In Young Children** by Carol Flexer.

This text is straightforward and easy to read, filled with practical information and suggestions for SLTS and all people working with children who have hearing loss. (CWHL). Many parents would find this useful as she explains many complex concepts in a simple format; emphasizing key ideas and omitting unnecessary detail. Examples include audiograms, different types of hearing aids, cochlear implants, FM systems, sating, background noise etc. This book truly shares great realistic techniques to facilitate hearing and listening in young children.

Maegan VanSolkema, Traumatic Brain Injury acknowledges the challenges of working as an SLT and needing to focus on "shadow work" in order to be the best for our clients and ourselves.

Maegan recommends: **Dare To Lead** and **Unlocking Us**: two fantastic podcasts by Brene Brown.

These have both provided an abundance of amazing books to read about emotional intelligence, counselling skills, becoming good leaders, but also books for our souls.

Selena Donaldson (editor) recommends: **Ngā Kete Mātauranga: Māori Scholars at the Research Interface** edited by Jacinta Ruru and Linda Waimarie Nikora.

As news emerged of Professor Gail Gillon… (page 6) I was enjoying dipping in and out of this exquisite volume. Providing rich narratives of Aotearoa's advancement of Māori academic excellence, there is so much to be learned for our profession, across it's many specialisms, from this book. ●

Recount and review

Thank you to the members who contacted us about our Ngāhuru issue. It is available on the **NZSTA website**.

Apologies to Nicole Kornelson, NZSTA Member currently working on Vancouver Island, Canada for not including her title in her interesting article about preserving language and dialect. Many members commented on the interest of this piece, and we send our warmest Aotearoa greetings to Nicole, remaining connected with NZSTA from afar.

Please contact Selena Donaldson **editor@speechtherapy.org.nz** with any contributions for *Communication Matters*. Large or small, written or pictorial, members' input for our association's magazine is vital. ●

ICP update

Annette Rotherham

Communication is a human right continues to be the message on an international level and I continue to meet with the International Communication Project strategic committee monthly.

The International Communication Project (ICP) aims to be an advocate for those with communication disabilities, their families, caregivers and communication professionals. The ICP highlights the importance of human communication and how communication disabilities significantly impact every aspect of life. Established in 2014, the ICP is built on the premise that communication is vital to life; yet is often ignored as a disability. The ICP joins organisations from around the world in advocating for people with communication disorders and raising the profile of communication disabilities.

NZSTA hosted the meetings from Dec–February and we are revising the ICP website information and planning 2021 activities with key focus areas. The UN Convention of State Parties will occur virtually in June 2021, so we hope to take this opportunity to plan a side event. I want to thank Ann Smaill for her continued representation of NZSTA on the advocacy ICP group. In the meantime, the ICP mission is:

- Include people with communication disabilities in international policy.
- Raise the profile and status of communication disabilities with international health bodies and policy makers.
- Increase public awareness of communication disabilities and the significant impact they have on people's lives. ●

Members in the media

11 March 2021

NZSTA were very proud to see **Professor Gail Gillon** (Ngāi Tahu) amongst the impressive line-up of Ngā Ahurei a Te Apārangi Fellows and Ngā Ahurei Honore a Te Apārangi Honorary Fellows elected to the Academy of the Royal Society Te Apārangi.

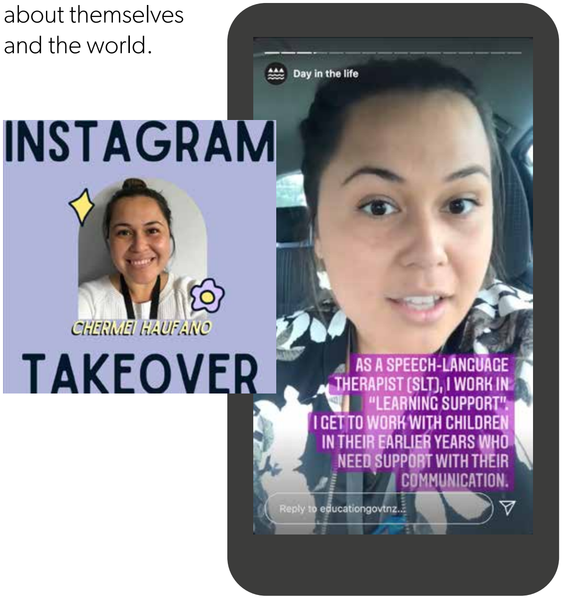
This award acknowledges Professor Gillon's enduring contribution to transforming speech language therapy and teaching practice in Aotearoa and across the globe, as a world expert in spoken and written language development.

The Better Start Literacy Approach, Te Ara Reo Matatini, the mahi of Professor Gillon and colleagues, is currently implemented by the Ministry of Education in new entrant and year one classes. There is an extensive and feature in Issue 2, Pages 42–48, (March), Tukutuku Kōrero Education Gazette, I about the Better Start Literacy Approach, the evidence behind it, and accompanying resources Ready to Read Phonics Plus.

21 March 2021

The Ministry of Education recently staged an Instagram take over to promote SLT as a career and highlight the scholarships they have available to support students. They followed **Chermei Haufano**, SLT, through a day's work supporting tamariki and whānau.

Chermei talked about why she chose the active, dynamic profession of SLT and what she enjoys about her daily working life. She profiled the difference SLTs can make for children with communication difficulties, their learning, interactions, relationships and how they feel about themselves and the world.



AS A SPEECH-LANGUAGE THERAPIST (SLT), I WORK IN "LEARNING SUPPORT". I GET TO WORK WITH CHILDREN IN THEIR EARLIER YEARS WHO NEED SUPPORT WITH THEIR COMMUNICATION.

17 March 2021

Sally Kedge, Talking Trouble Aotearoa, made an oral submission to the Social Services and Community Committee of New Zealand Parliament, for the Oranga Tamariki (Youth Justice Demerit Points) Amendment Bill. This was accompanied by an extensive written submission from Alayne McKee, Sally Kedge and Alison Paulin. The team made clear that they did not support this legislation being passed. Their submission discussed the language and communication needs of young people who might be involved, and how those might prevent the intention of the Bill being successful. Sally also talked to the Committee about the missed opportunities for addressing language, learning and other well-being needs much, much earlier in children's lives. She urged the MPs to consider how speech-language therapists and others could be utilised to bring about better outcomes for children.

Sally used innovation in her submission, abandoning the traditional 'oral' presentation and employing some effective visual aids to enhance her message. These were:

- A 'Bla-ometer' to help the Committee consider the level of 'blablabla' within the legislation and the interactions that it would involve for young people.
- A set of 'Communication Glasses' to allow the Committee to consider the communication skills of the youth population the legislation was going to apply to.
- A timeline to show options for providing interventions for children and young people.

The visuals were on the low-tech end of visual support – involving classic SLT creativity – laminated paper, white board markers and blutack!

Sally Kedge's oral submission is available to view on the Talking Trouble Facebook page **facebook.com/talkingtroubleaotearoanz/posts/2789407301327574**

The written submissions from all submitters (including the Talking Trouble team) and information about the proposed legislation are available here: **www.parliament.nz/en/pb/bills-and-laws/bills-proposed-laws/document/BILL_96165/tab/submissionsandadvice** •

Image credits: Carol Green

Te reo o te Kaumatua
Nā Rukingi Haupapa

Rukingi Haupapa, Kaumatua

Ngā mihi o te wā e koutou mā.

The University of Auckland Orientation

It was awesome to be invited to the School of Psychology orientation in February. Bumping into NZ Police and Iwi leaders before the welcome, and then having time to wait and talk with the new students and staff could not have been better planned. It was a great opportunity to let them know who I am as NZSTA kaumatua and to wish them all the best stepping into SLT study and their new careers. The excitement was building and it was great to also have time to talk a little about the pōhiri process and even practise our waiata.

The rest of the day involved meeting different staff and students spread across the various groups within the School of Psychology, and especially those in the SLT programme.

To see and hear the Doctorate in Clinical Psychology, the Applied Behavioural Analysis programme and of course Speech Science introduce themselves and their area of specialism, and then close with a waiata was awesome, (in fact it was almost a karaoke competition!) Thank you to The University of Auckland for your invitation and support.

Cultural Safety

Since I began as kaumatua in 2019, Cultural Safety has been a topic that many SLTs raised and continue to see as an issue. Stress and the anxiety of saying or doing 'the wrong thing' is affecting SLTs in their work. Unfortunately, I never really had the opportunity to specifically learn or train about cultural safety, so it was great in March when three of us from the NZSTA Board attended an Allied Health Association training session.

It was well attended by a number of health associations and with presentations from member organizations including Ngā Pou Mana, Māori Doctors, and the NZ Dietician Association. All impressed and informed me about where you and I sit and when we engage with others, particularly in regard to the culture, beliefs and knowledge that each has.

The NZSTA are holding their Summit later this month, with representatives of the various areas of our membership. During this we will be discussing Cultural Safety. I'm hopeful that we can contribute to the discussions that hopefully lead to clear step forwards with this kaupapa. Below is a well known whakataukī that applies.

Mā te mahi ka mōhio
Hard work leads to knowledge

Mā te mōhio ka mārama
Knowledge leads to understanding

Mā te mārama ka tau
Understanding concludes with
acceptance and completion

Ngā mihi ki a koutou katoa.

Nākū noa.
Rukingi

Remembering Marie Elizabeth Ellis

25 April 1939 – 27 December 2020

Christine Musgrave, Margaret Maclagan and Paul Ellis

Marie was born in Newcastle NSW in 1939 so technically she was an Australian. At 3 months, she travelled to the UK with her parents via New Zealand. Her war years were spent in Chatham and Crewe. She never forgot the sound of the air raid sirens.

She moved to NZ in 1953 and attended St. Margaret's College in Christchurch and then undertook Teacher Training, gaining a Teacher's Certificate with special qualification in Speech Therapy. Marie's first postings were in Motueka and Nelson Central which included working for the Education Board, visiting a multitude of schools in the Nelson region.

She moved to Australia, gaining the Australian Diploma in speech and language therapy (L.A.C.S.T.). She worked at Northern Districts Spastic Centre in Melbourne and The Royal Perth Rehab Hospital in Perth. It was heart-warming to see the many letters and cards Marie received from grateful patients after only two years in Australia. She returned as SLT at Christchurch Hospital in 1970. It was a fledgling department then. She established a strong department and championed the breadth and depth of SLT involvement in the medical world. After 10 years she returned to Nelson Hospital Board for 19 years, retiring in 1999.

She was a true professional and let nothing get in the way of her vocation and her commitment to her clients; a strong and tender-hearted advocate for them. One past colleague described Marie as being no 'fuddy-duddy' but being right up there with all the developments in speech therapy. She was always involved in NZSTA and regularly upskilled with Australasian opportunities. Her ability to deal with bureaucracy was legendary and she did not appreciate change for the sake of change. Management once asked her to write down what she did every fifteen minutes. She responded in the nicest possible way that she was very happy to do this as long as they supplied someone to follow her around.

Photo supplied

The epitome of her moral strength and disarming sincerity was demonstrated in a confrontation by a manager. For obvious reasons, we are not identifying you who it was or where and when this happened!

Manager: I am afraid we have to reduce your hours

Marie: I am usually fully booked for the week

Manager: We have to reduce our costs, you know.

Marie: How much do you intend to save on Speech Therapy?

Manager: Oh, about $18 000

Marie: If I write you a cheque for $18 000 will that make it all right?

Manager: I think we will be able to find the funding Miss Ellis.

Marie was a very private person. She was a much-loved member of St Barnabas Stoke, and a valued member of the NZ SLT profession although due to her humility she probably didn't appreciate the fact. Marie's life revolved around her work, the church and caring for people, including her mother. She was a deeply committed Christian and her whole life of dedicated service reflected her beliefs. She was described as an engaging colleague with a delicious sense of humour. ●

Takiwātanga: Na Keri Opai

Tōku/Tōna anō takiwā

In his/her own space and time

Nicky-Marie Kohere-Smiler, Te Aitangi-a-Mahaki; Ngati Porou; Tuhoe; Ngati Tuwharetoa; of Piki Kotuku Speech Language Therapy, recently joined a team of Māori and Pasifika speakers, in a wānanga exploring takiwātanga (autism) from a Māori world view.

Acknowledging that our Māori whānau have had no choice but to receive a support service that predominantly caters to a mainstream lifestyle and education system, this wānanga aimed to build awareness of what takiwātanga looks like from a Māori/Indigenous perspective. Nicky-Marie explains that it is important that whānau with tamariki with autism are nurtured acknowledging the strengths they bring with them. Kaiako are key to enhancing this kōrero as they are often the early identifiers of autism in Te Kohanga Reo and te Kura Kaupapa.

"Be confident in your own song" was one of Nicky-Marie's messages. The wānanga brought together whānau in the morning and then focussed the afternoon's sessions on messaging for service providers. Whakaaro with Liz and Dennis Makaleno of Porirua challenged the attitudes of services going into homes, including those of gang members. For Nicky-Marie, the day was an opportunity to embrace how her own practice has undergone decolonisation in her years in the field. Reflecting a series of whakatauki, Nicky-Marie provided a presentation about the role of SLT, what communication is, and how acknowledging the whakapapa and all that surrounds the child will enhance maramatanga (come into the light).

Nicky-Marie explains that this is about transformation and getting that kōrero started. ●

> "It is important that whānau with tamariki with autism are nurtured acknowledging the strengths they bring with them. – **Nicky-Marie**

Above: Piki Kotuku at Mareikura Expo.

Photo credit: Nicky-Marie Kohere-Smiler

Creating something special with Kimi Ora Choir

Cat MacKenzie, Kimi Ora School

One of the best parts of our job is having a cool idea, and then having it actually work. When our music therapist, Hazel, approached me about starting a choir we had no idea where it would lead, but we were excited to try.

Above: Kimi Ora School Choir on stage at Te Papa.

Kimi Ora School is a school for students aged 5 to 21 with high and complex needs. Many of our students are non-verbal, which some would see as a barrier to a choir. However, like most young people, our students love music. Heated class discussion around music choice is common, and picking Justin Bieber is always a divisive choice.

Kimi Choir takes our students love for music and their individual voices and combines them into something really special. Our choir is made up of ten students, all of whom use Pragmatically Organised Dynamic Display books (PODD) as their main form of communication. To access the PODD, many of these students use switches to tell us yes or no, or that they have something to say. The switches are placed wherever our students can best access them – head, chin, leg, hand – whatever works for them. These switches are big buttons that can have any message recorded onto them. By recording a line of music onto the switch, our students can also use these to sing in our choir. Our students pick which line they want and where in the song they want to put it. They are in charge of deciding if the song sounds better if they sing their part twice or twenty times. Hazel has been very clever in picking songs that sound great no matter when the line is sung. This way the focus is not timing but celebrating the students' individual voice.

We were so proud of how our students took to this new activity and made it sound beautiful. We were invited to perform at the Wellington Regional Primary Principals' Association Conference at Te Papa, after only a few weeks rehearsing. The whole team, staff and students, worked really hard to make it happen. We sang two songs – Bella Mama and Te Aroha, and received a standing ovation. Our students were so proud of themselves, and it was great to see others being proud of them too. This was a massive moment; performing for the first time, working together to make something beautiful and inspiring other people. We are already eagerly looking forward to our next opportunity to perform.

I'll leave you with what some students have said about Kimi Choir using their PODDs:

"I think that's – beautiful – nice."

"I think that's – not – yucky"

"I think that's – great – funny – handsome – nice – red – pink"

"Come see us." ●

Photo credit: Kimi Ora School

Diverse, included and supported in our workplace

Robyn Gibson, Speech-language therapist

It is estimated that 1 in 4 New Zealanders identify as disabled[1]. Of those, over half have more than one disability. Based on those statistics, there are likely to be over 200 SLTs in New Zealand who identify as disabled. I will admit now that I can count on one hand the number of SLTs who I know have a disability, when I probably know dozens. Why is this?

We work with people with a wide variety of disabilities from transient to life-long. We talk to them, their families, their caregivers, and their communities about living with disability and about being self-advocates – proud of who they are, what their dreams and goals are, and developing strategies to help them get there. We consider ourselves staunch allies of many different communities of disabled people. And yet I wonder how many of us are hiding our own lived experience.

There are many reasons for this including fear of being seen as unable to do our jobs, fear of having our competence questioned, and fear of how we will be perceived by colleagues and managers, families and those we are working with, particularly if our needs fluctuate. There seems to be a division between those who are 'professionals' and those who are 'patients', with the expectation that you can't be both at the same time. I recognise all of this: this is the way I have felt for much of my career.

I have multiple reasons for being able to identify as disabled. I live with chronic pain, and I have at least three diagnoses which fit under the umbrella of neurodivergent. I can't say I've always been proud to identify as either neurodivergent or disabled – it's been a struggle over many years to learn about what this means, and to reconcile the conflict between who I am and who I thought I should be. But over the years as it's become harder to hide some aspects of my difficulties, and as I met more colleagues who share my experiences over social media, I've become more comfortable with this aspect of myself. I've realised how much I've ignored the challenges at work, including the relentless pain and exhaustion, and the tears when it's overwhelming.

Above: **Robyn Gibson and family.**

My colleagues noticed at one point that I had stopped baking and bringing plates of cakes and cookies. I didn't mention that it's because baking hurt too much. At a conference I had to ask for help getting up to the speakers podium. At the next conference, the venue was so big and I was in so much pain that I needed a walking stick to get from one end to the other. I've been told to 'leave my baggage at the door', perhaps with good intentions of teaching me to hide my personal problems so that they don't complicate or impact my working day. However, I have found that accepting and learning how to accommodate my disabilities has been far more constructive

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[1] stats.govt.nz

Photo credit: Alistair Gibson

than masking and pretending that they don't have an effect on me.

I have now been involved in the SLT world for more than 20 years. In that time, I've had the good fortune to meet a couple of SLT students who have been open about their disabilities. It pains me that my reaction at the beginning of my career was to help them to learn to mask better. My own mask is so highly developed that sometimes even I forget that it's a mask until I burn out. However, there is inherent value in members of the health and education workforce who have lived experience of the challenges faced by those they are working with. Who better to understand about life as a wheelchair user than a wheelchair user? Who better to understand the challenges of living with chronic health conditions? And who better to understand what it means to manage life with sensory challenges and executive dysfunction? I don't share this with my patients explicitly, but my lived experience has shaped who I am as a clinician, how I interact with patients and their whānau, and the nature of my work with them.

It's been a hard journey at times, and there will be new challenges in the future.

I've been lucky to have wonderful colleagues and the best Professional Leader I could have hoped for. But now, by being open and honest about my own situation, I hope that others may feel safer so that we can be the truly supportive, diverse and inclusive profession that we all strive for. ●

For more reading, you may like to go to **therapistndc.org**. For more on the concept of masking, I recommend **theautisticadvocate.com**.

A word from Shannon Hennig, NZSTA's neurodisability and autism expert advisor

As the neurodiversity and autism expert adviser for the NZSTA, I am hearing more and more from neurodivergent professionals in Aotearoa – but only privately. I love that people are feeling safe to reach out and chat.

There remains a sense that it isn't safe yet to be openly neurodivergent in many of our professional spaces.

While the individuals have asked for confidentiality, the themes of these conversations are the same:

- a pressure to mask during training programmes and (often unintentional) messages that neurodivergent people don't have the dispositions to become/ be good therapists
- pressures to mask and not disclose at work, let alone ask for accommodations
- limited pathways for accurate adult diagnosis in parts of New Zealand, and subsequent concerns about whether you can identify as autistic (or dyslexic or living with ADHD etc) without a formal diagnosis
- worries that the anticipated benefits of disclosing professionally are not greater than the potential risks.

Last April, Autism Awareness/ Acceptance Month, I challenged everyone in our profession to do a spot check for systemic, inadvertent, and/or subtle forms of ableism in our professional spaces. And also, try to follow some openly neurodivergent people on social media. There are lots of people sharing their experiences with the tags #actuallyAutistic and #AutChat

Neurodiversity in our profession matters.

Let's keep growing and evolving together!–

Shannon

Why Can't You Learn a Bit of Autism? The Benefits of Peer Support Groups for Autistic Adults from the Perspective of Participants

Simone Horrocks, Court-appointed Communication Assistant, Talking Trouble Aotearoa NZ

A growing number of scientific and academic research studies are reporting that adults on the autism spectrum have difficulties with communication, social interaction and social inclusion throughout their lifetimes, higher rates of unemployment (or under-employment) than their peers, and higher rates of suicide and mental health problems such as anxiety and depression. The question of what support is needed for Autistic adults is recognised to be an important area of concern, but to date, has been relatively neglected.

In my role as an SLT, but also as a teacher aide and voluntary buddy in the community, I have met and worked with children and young people on the autism spectrum, with a wide range of abilities. Many of these young people have experienced bullying, exclusion and social rejection, and I have seen how their response is often to 'act up' or 'shut down'. I have also met parents who report feelings of frustration at not being able to get their teens "out of their bedrooms", and have expressed fears about how they will fare in adult life without them.

To learn more about how SLTs might better support these families and young people into adulthood, I attended the 2017 "Transitions Altogether Autism Conference". Altogether Autism is an information and advisory service that, along with Autism New Zealand, is one of the largest charity organisations providing education for families and community members nationwide.

I was to learn a lot over my two days at the conference, but two things struck me straight away. Firstly, I found myself surprised to see the number of adults on the autism spectrum, who were hosting presentations and workshops. Nine of these presentations concerned peer support initiatives set up by and for Autistic people, in the United Kingdom and Australia, as well as here in New Zealand. This was something that, until then, I had heard little about. Secondly, I noted that while some people were using the person-first language I was used to hearing in my professional work (i.e. 'person with autism'), many others – notably those speaking from the point-of-view of lived experience – were using identity-first language (i.e. 'autistic person'). The language we use to describe ourselves and others is important, as it embodies our

Above: **A lot of time spent at the desk.**

Photo: Simone Horrocks

> This is the first generation that we’ve ever had, of adults that can actually turn round and say ‘I’m Autistic and this is what it’s like for me, this is what it’s like, this is what I have come through in the services, et cetera, et cetera, and this is, you know.’ We can now say what it’s like, and [exhales] it’s really interesting what’s coming out.. – **Margaret, Research participant**

sense of identity, but also reflects and helps change societal attitudes and stereotypes, so I was curious about what had prompted this ‘divide’.

I reflected that a much wider discussion was taking place about autism in my own community than I had previously been a part of, and that in order to better understand the position Autistic adults find themselves in, I needed to better understand the issues they face, from their point of view. By chance I met a person wearing a badge that read: “Ask me about my autism”, and so I did. They told me about a cluster of local peer support initiatives, one of which was a social group that had been meeting for almost 10 years, and has grown from six participants to nearly 100. The group is now forming a trust to advance pilot schemes around work, housing and advocacy.

Following this experience, I decided to commit to a one year research only Master of Science in Speech Science, at The University of Auckland. The primary aim of the research was to learn more about how – and why – Autistic adults were coming together to support each other as peers and the benefits of this from their perspective. The secondary aim was to consider how this knowledge might inform the way we develop services for current and future generations. To date, there is very little research that specifically includes the perspectives of Autistic adults, and almost no research in our local context. The final research report was submitted and accepted in 2019. ●

The full thesis report from this research project is available free to all on Creative Commons from The University of Auckland library, theses and research essays: hdl.handle.net/2292/47453

Study results underlined the importance of:

- Recognising the value of expertise from experience
- Including the perspectives of Autistic people in research and practice
- Recognising the call for acceptance of neurodiversity
- Considering autism in the context of culture and society
- Questioning the ethics and appropriateness of “intervention” or “behavioural modification”
- Considering the value of consulting with the Autistic community to determine how professionals might best utilise their skills to support grass roots initiatives
- Ensuring professionals working with, and alongside, people in the Autistic community are well-informed about autism as those they seek to help.

25 years of Stuttering Treatment and Research Trust (START)

After a couple of false starts in 2020 due to COVID-19, START and their community of supporters, came together on 10 March, to celebrate the now 26 years of this specialist centre for excellence for New Zealanders who stutter.

This occasion provided a chance to reflect on START's many achievements as the only organisation in Aotearoa specialising in stuttering, and to celebrate some exciting innovations and developments in START's story. With an inspiring address from Judge Andrew Becroft, Children's Commissioner and Ambassador for START, the many people who have given their time and energy for START to flourish were acknowledged. ●

Mā te huruhuru
ka rere te manu

Adorn the bird with feathers
so it may soar

START: The story so far

Dr Aroha Harris of The University of Auckland supervised students from her Honours level oral history class, to collect the narratives underpinning START's 25 years. This illuminated how START was established, the changes in society behind this, and the many changes in the way START has delivered its services over time in response to evidence based practice. Meghan Williams (PhD student) undertook extensive additional research, and edited the book with sincere care and collaboration for the many stories within. With a foreword from Judge Andrew Becroft, Children's Commissioner and Ambassador of START, this superb volume spans 25 years of both stories of people who stutter and of speech language therapy within the specialism of stuttering, in Aotearoa.

START :The story so far
Edited by Meghan Williams

Mā te huruhuru
ka rere te manu

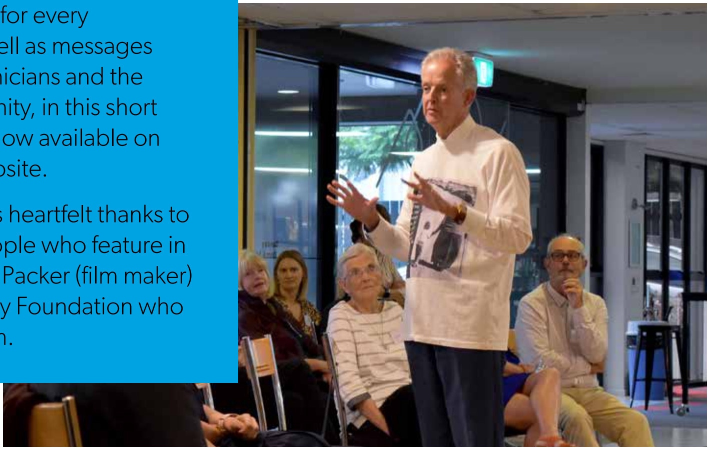
Adorn the bird with feathers,
so it may soar

Photo credits: START

Stuttering: Young Kiwis share their stories

Launched on TV3: Newshub on Sunday 14 March, Mike McRoberts (himself a person who stuttered as a teen), fronts this extraordinary film in which young New Zealanders share their experiences with the goal of making the world an easier place for people who stutter. The young people, ranging in age from 9 to 18 years, provide frank ideas about their experiences at school. Their insight is remarkable and there is sage advice for every educator as well as messages for us all as clinicians and the wider community, in this short film, which is now available on the START website.

START extends heartfelt thanks to the young people who feature in the film, Cody Packer (film maker) and the Lindsay Foundation who funded the film.



Top left:
Nigel Whiteman cutting cake.

Top right:
START's 25th year celebrations.

Left:
START's 25th year celebrations.

Above:
Judge Andrew Becroft.

Teacher's Guide to Working with Young People Who Stutter

Last issue we profiled the Teacher's Guide to Working with Young People Who Stutter which START has developed in collaboration with Massey University and University of Auckland speech language therapy students. This resource provides information about stuttering, reflections from young New Zealanders who stutter and their teachers, and strategies from young people who stutter about what is most helpful for them to be able to thrive in the classroom. It is both practical and thought-provoking, and is available on the START website.

AphasiaNZ Kōrero Clubs – the value of peer support

Kate Milford, AphasiaNZ CAA Practice Supervisor

AphasiaNZ has moved away from holding biennial conferences to focus more on the Community Aphasia Advisor (CAA) service, and the number of groups that we hold around the country has steadily expanded.

Aphasia New Zealand Charitable Trust
mate ngaronga reo

Our Kōrero Clubs are intended to provide the opportunity for people with aphasia to communicate in a relaxed supportive environment. The groups are not a replacement for speech language therapy but aim to complement therapy provision and help people with aphasia with the transition from participating in formal rehabilitation into feeling confident in their everyday lives and having greater independence.

There are currently over a dozen groups with Kōrero Clubs in Auckland, Hamilton, Tauranga, Rotorua, Taupō, Wellington, Christchurch and Dunedin. In addition, we have an online Kōrero Club held via Zoom for people who cannot physically attend a group.

Left:
Aphasia NZ 2019 Christmas lunch.

In a busy month, the CAA team facilitate over 30 meetings. Group frequency varies depending on the CAA time available and the preferences of group members. Many people with aphasia attend the group for years. We feel that it is important that people can attend for as long as they want so there is no time limit on group membership (or indeed on how long people can receive individual support).

Over time, nearly all the groups have become less formal, although most still have some structure to the meetings with members taking responsibility for various roles and aspects of the meetings. The aim is for the CAA to be present to support and facilitate if required, but for group members to feel able to lead and be independent. The majority of the groups meet for 2 hours, with a tea break in the middle. This allows enough time for all members to participate and also for a range of activities such as conversation topics, short speeches, joke-telling and games. In most groups, there is an expectation that members will do some preparation before each meeting.

Group members are really good at welcoming new people. People who have lived with aphasia for a number of years offer support and encouragement to those who are still coming to terms with their aphasia, and from a CAA perspective,

Photo credit: Aphasia NZ

it is wonderful to see ongoing improvement in people's communication abilities even many years post-stroke.

We have recently sought feedback from group members to find out what they like best about the group they attend, and also asked the CAAs what they like about their group(s). There was universal agreement that meeting other people with aphasia and sharing experiences was valuable. For most, the challenge of speaking in a group is positive, but a few prefer to be quieter and not pressured to participate. Feedback has been very positive about the current way groups are run. ●

"My favourite thing about the Kōrero Clubs is the relationships that the members build with each other through their unique shared experience of aphasia. Each person experiences their aphasia differently, yet they understand each other's struggles and support each other through life's challenges. As the CAA, I love to see the members confidence grow as time goes by and the way the group as a whole becomes like a family. It is a safe place for emotions, frustrations, laughter and celebration."
– CAA

"I am surprised by how little my group now talks about aphasia. Only if someone has an issue they want support with, does the topic come up. It feels as though because aphasia is the norm, it isn't as important. There is empathy when someone gets stuck, but very little stress around it. The group laugh a lot and tease each other. But they are totally supportive too. Lots of important discussions take place and the group feels really safe. I really enjoy facilitating Kōrero Club – it's a high point of my week."
– CAA

"Aphasia has taught me to listen. I wish I had aphasia years ago. I have a lot of time to think. I'm interested in other people's stories."
– Ron

"Kōrero Club meetings start with introductions and short speeches for 30 minutes, an hour-long coffee break, then back for half an hour of games, jokes and planning for the next meeting. Aphasia is the central theme of our meetings and members enjoy talking to an understanding audience about the realities and challenges of living with aphasia day to day. Our members really love our group and speak fondly of the friendship and support they feel as well as the improvements they see. They say what they enjoy most is meeting others with aphasia and having time to share stories about the realities of life with aphasia. Members are quick to congratulate each other as they improve."
– CAA

AphasiaNZ in 2021

Kate Milford, AphasiaNZ CAA Practice Supervisor

The past year has been challenging for the not-for-profit sector, with many of our usual activities cancelled due to COVID restrictions. Funding has been affected also, although the Ministry for Social Development created a number of new funding opportunities for innovative projects.

Lockdown provided us with one benefit – time to focus on new projects! As a result, AphasiaNZ is now offering a number of new services:

- An online Kōrero Club for those people who cannot attend a regular club due to their location or because they cannot get out.
- Introductory Training in Supported Conversation (IT'S Conversation). This has been designed to be delivered online but can also be done face-to-face. The package consists of 3–4 sessions delivered by a Community Aphasia Advisor working with a person with aphasia and their conversation partner. Supported conversation techniques are explained, and the couple choose one or two to focus on. The CAA then helps them to integrate these into their conversations and reflect on how these techniques can make conversations more successful and enjoyable.
- An online Mindfulness Course for Carers – this is delivered by a registered SLT, Melissa Delaux, who is also an accredited Mindfulness Teacher.
- An online carers support group, facilitated by a CAA.
- Some CAAs are now running support groups for people affected by progressive aphasia (including for family members).

We have also translated our most popular resource, the Aphasia? Booklet, into 5 different languages – Te Reo, Samoan, Tongan, Hindi and Chinese.

Our website has been updated so do have a look – **aphasia.org.nz**

Our normal CAA services are running as far as possible with groups/Kōrero Clubs and home visits. We have CAA cover across Auckland, central and western areas of Waikato, the Western Bay of Plenty, Rotorua, Taupō, Wellington, Christchurch and Otago and Southland.

Above:
AphasiaNZ team. Front row L–R: Jan Wanless, Kate Milford, Mel Dakin, Christa Grbin, Nicole Zwarts, Eleanor Maxwell. Back row: Chris Lawson, Abbey Jacobson, Lauren Morrison, Fiona Couldstone, Kirsten Drayton.

We welcome referrals at any time. CAAs do not usually visit in hospital but can support family while the person with aphasia is still in hospital. Our Stroke and Aphasia Handbook can be a great source of information for family at the acute stage, and this is free when people become Friends of AphasiaNZ. Being a Friend also provides access to our iPad loaning scheme for therapy support. Please note that iPad loaning is not available for people still in hospital.

Please do not hesitate to contact your local CAA for more information or get in touch with Emma (Executive Officer) or Nicole (Administrator) at the office on 0508 274 274 or via email at **info@aphasia.org.nz** or **admin@aphasia.org.nz**

With best wishes to you all,
Kate Milford

Photo credit: Aphasia NZ

Diversifying in the COVID-19 response

Grace Combellack, Locality Care Coordinator – Victory (Nelson)

All around the world we have been observing how health professionals have adjusted their roles in response to COVID-19. Particularly in my birth place of the UK, it has been terrifying and absolutely incredible to see and hear how my friends and former colleagues have had to adapt and often take on such an expansion of their roles to support patients and the NHS.

Here in Aotearoa it has obviously and fortunately been quite a different situation. It's left me questioning and reflecting on how well I would have been able to adjust to new working ways and new roles – I suspect like others, I wouldn't really have had much choice.

Partly because of this, when an email appeared in my inbox asking if I would consider taking on some extra work to support the COVID Immunisation Team, I decided I'd enquire and see if I could offer anything of value. Although I'd completed the training for 'COVID swabbing' shifts a few months back (with guidance from the NZSTA & local DHB), the thought of injecting people felt like a completely different ball game! Only a day later I was called and asked to complete some training on the 'COVID Immunisation Register', and a day after that, I was part of the team.

Thankfully, there was no request or expectation to complete 'vaccinator training'! This is left to those wonderful nurses who are a dab hand at it. My role has been mostly with the COVID Booking Team. A large part has been taking what feels like hundreds of calls and booking people in as quickly and efficiently as possible. Increasingly it is about liaising with those working at the clinics, working together to ensure the amount of people booked, matches the amount of vaccinations expected to be available from the Ministry of Health. It sounds a lot easier than it is! Wastage is not taken lightly, so if there's a sniff of a vaccination is going spare… every effort is made to find someone eligible to receive it before time runs out.

As the vaccination is made available to more of those in the 'general' public (and the 0800 booking number spreads across the community!) calls are taking longer & becoming more complex. Which vaccine? Will it hurt? When can I have my flu jab? Can I forfeit my vaccination for my loved one? All we can do is try to calm those on the phone, answer questions we're equipped to answer, and signpost them to information when we aren't. As always, the communication skills we develop as speech-language therapists, our ability to have patience and build rapport definitely go a long way. It's also still really gratifying to have a good kōrero with someone who's so very grateful for the work we all do. ●

Contact details
Whakapā tangata

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

NZSTA Board Members

President • Annette Rotherham
president@speechtherapy.org.nz

Communications • Emma Quigan
communications@speechtherapy.org.nz

Member networks • Akshat Shah
membernetworks@speechtherapy.org.nz

Professional development • Claire Winward
professionaldevelopment@speechtherapy.org.nz

Professional standards • Anna Miles
professionalstandards@speechtherapy.org.nz

Māori and cultural development
Katrina McGarr
culturaldevelopment@speechtherapy.org.nz

Other contacts

National private practitioner members' representative
Ashleigh Neumann
privatepractice@speechtherapy.org.nz

Administrator • ONZL Limited
admin@speechtherapy.org.nz
+64 9 475 0214

***Speech, Language and Hearing* Journal of APSSLH, HKAST & NZSTA**
Editor: Anna Miles
professionalstandards@speechtherapy.org.nz

New Zealand Speech-language Therapists' Association NZSTA
www.speechtherapy.org.nz
admin@speechtherapy.org.nz
PO Box 65503, Mairangi Bay, Auckland 0754

***Communication Matters* editor**
Selena Donaldson
editor@speechtherapy.org.nz

Expert adviser contacts

Ann Smaill
Alternative and Augmentative Communication
ann.smaill@talklink.org.nz

Anna Miles • Adult Dysphagia
a.miles@auckland.ac.nz

Annabel Grant • Dementia
a.grant@massey.ac.nz

Carlene Perris • Voice
cperris@adhb.govt.nz

Emily Jones
Paediatric Feeding and Swallowing
E.Jones@massey.ac.nz

Fiona Hewerdine
Adult Neurodegenerative Conditions and Palliative Care
fiona.hewerdine@bopdhb.govt.nz

Jayne Newbury • Child Language
jayne.newbury@canterbury.ac.nz

Liz Fairgray & Megan Lewis
Hearing Impairment and Cochlear Implant
l.fairgray@auckland.ac.nz
megan@talktogether.co.nz

Maegan VanSolkema • Traumatic Brain Injury
maegan.vansolkema@abi-rehab.co.nz

Sally Kedge • Vulnerable Children and Youth
sallykedge@gmail.com

Sarah Spence
Paediatric Complex Communication Needs
sarspen@gmail.com

Shannon Hennig • Autism and Neurodiversity
shannon@inclusive-communication.co.nz

Alison Zani • Aphasia
aphasiaadviser@gmail.com

Area representatives

Te Tai Tokerau • Suanna Smith & Denise Poole
ar.northland@speechtherapy.org.nz

Auckland • Tessa Livingston & Hannah Barnes
ar.auckland@speechtherapy.org.nz

Waikato/Bay of Plenty • Gwen Kerrison
ar.waikato.bop@speechtherapy.org.nz

Central • Elisa Mynen
ar.central@speechtherapy.org.nz

Wellington/Nelson • Polly Newton & Emily King
ar.wellington@speechtherapy.org.nz

Canterbury/Westland
Kate Cook & Ruth Ramsay
ar.canterbury@speechtherapy.org.nz

Otago/Southland • Meryl Jones
ar.otago.southland@speechtherapy.org.nz

Student representatives

Massey University • Jacqui Morgan, Brianna Oosterbroek & Bo Young Choi
sr.massey@speechtherapy.org.nz

University of Auckland
Crystal Aranha & Ella-Rose Meagher
sr.auckland@speechtherapy.org.nz

University of Canterbury
Emma Barbafiera, Jessica Eagle & Livvy Pride
sr.canterbury@speechtherapy.org.nz

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