StrongVoices

EMPOWERED LIVES

Spring 2022

Worth a thousand words

Shelby's magic moment

Parenting at 3am

ihc
IN YOUR COMMUNITY

Kōrero

Where would we be without the internet?

Freedom of speech and access to information, awareness-raising, being part of political life, and accessibility, are all articles within the United Nations Convention on the Rights of Persons with Disabilities. Because so much of that information and connection happens online, it stands to reason that digital connection is key to people with intellectual disabilities living lives just like everyone else.

A recent Digital Skills Report from BNZ estimated that 20 percent of New Zealand adults do not have the digital skills deemed essential for modern life, and that rises to 30 percent for people with low education or low incomes and 42 percent for those living with a disability.

Over the past two years – with us being more isolated and locked away with COVID – that connection and access have been even more important.

Thanks to donations and support from members of the public during the lockdowns, we were able to provide people with devices to keep them connected with family and friends and to keep up to date with information and entertainment. Those devices were sent to people living in IHC's IDEA Services homes as well as people living alone, with family or flatting. We also connected houses with Netflix.

Just before Christmas we tested some online art and music sessions called 'Let's Give it a Go'. These were popular and they got us thinking. So later this year we are going to launch a new IHC media platform with content for and by people with intellectual disabilities. We will have more of the online sessions and we are gathering information about the kind of sessions you would like to see; you can expect tips on how to use a phone or tablet as part of it. We are also hoping to provide links to some useful information and learning modules and we will be looking for some stars to create and present some content.

We'll keep you posted.

Gina Rogers
Editor

CONTENTS

KEEP UP WITH WHAT IHC IS DOING – FOLLOW OUR CAMPAIGNS AND BE THE FIRST TO READ OUR STORIES AND SEE OUR VIDEOS.

WE'LL KEEP YOU POSTED WITH NEWS AND VIEWS ACROSS THE IHC GROUP AND THE DISABILITY SECTOR.

WE'D LOVE TO HEAR FROM YOU.

SO JOIN THE CONVERSATION.
FACEBOOK.COM/IHCNEWZEALAND
READ THE STRONG VOICES BLOG
IHC.ORG.NZ/STRONG-VOICES

COVER IMAGE:

Lucy White, who has Williams syndrome, gives most things her best shot. See the story on research on young children with Williams syndrome on the opposite page.

Kiwi kids catch up with Williams syndrome research

RESEARCH

Researchers tracking the development of young children in Australia and New Zealand with Williams syndrome are returning to New Zealand to catch up on lost COVID time with Kiwi kids.

The research is being led by Associate Professor Melanie Porter, a senior clinical neuropsychologist, and clinical neuropsychology intern and PhD candidate Jessica Reeve from Macquarie University in Sydney. Jessica recently submitted her PhD study on Williams syndrome.

While the pandemic prevented Melanie and Jessica from following up Kiwi participants, the pair have criss-crossed Australia testing and interviewing children and families in most states.

“Some of the Australian children we have actually seen three times now,” says Jessica. But the study is designed in a way that Kiwi participants are not left behind.

“Even though we have only seen a few in New Zealand, it’s a staggered design,” Melanie says. This allows them to recruit more participants as they go.

Melanie and Jessica came to the New Zealand Williams Syndrome Association camp in Christchurch in January 2019, where they discussed the research project and conducted interviews with parents and assessments of children.

Five New Zealand children are participating in the study and the researchers are hoping to recruit more families when they return to New Zealand in January 2023 for the next camp. There are 46 Australian participants so far.

The research is a longitudinal study in which families can participate over a long period of time to allow researchers to gather as much information as possible about the rare genetic condition and its impact on a child’s development. It also looks at the experiences of families – such as parent coping, parent mental health and parental attitudes.

They hope to track the children over two, five, 10 and perhaps 20 years. Jessica says the study has now reached its seven-year mark and is confirming trends seen in older people with Williams syndrome, particularly the huge variation in how the condition impacts individuals.

She says it’s about knowing the children’s strengths and building on them, and supporting their weaknesses.

Melanie says there is hardly any research on young children with Williams syndrome. Knowing more about younger children will help to predict later development and allow for the development of interventions for both children and their parents.

Above: Lucy White (right) and Amelie Miller, her great friend from next door.

Continues page 4.

Continued from page 3.

She says those with Williams syndrome often have strengths that support literacy rather than numeracy, so typically find maths more difficult than reading. “They tend to have a weakness in non-verbal and motor skills.”

The first time-point of the study focuses on children between the ages of two and seven years. It involves a face-to-face assessment with each child, as well as parent interviews and questionnaires. It looks at how early thinking and learning processes contribute to later intellectual, adaptive (daily living skills), academic and mental health outcomes for children with Williams syndrome.

Melanie says many see the high sociability of people with Williams syndrome as a positive thing in aiding social connection. But there are drawbacks. Over-friendliness brings dangers too. As the children get older it is harder for them to maintain their friendships as they struggle with social reasoning, and their extreme social trust brings some vulnerabilities.

“The big take-home message is early intervention,” Melanie says.

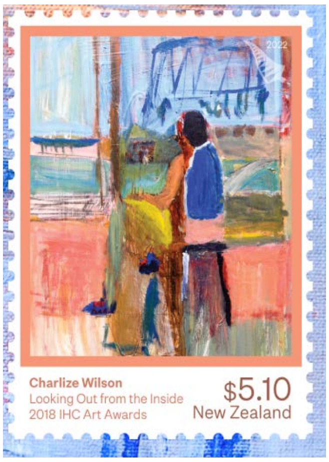
Williams syndrome is most commonly caused by a deletion of 26 to 28 genes on chromosome 7. This missing genetic material can cause a wide range of symptoms.

To know more about the research, or to participate, please contact Jessica Reeve at jessica.reeve@mq.edu.au and Melanie Porter at melanie.porter@mq.edu.au

Above: Bob Hastie dressed as a mariachi Wiggle at the last New Zealand Williams Syndrome Association talent quest.

Above right: Associate Professor Melanie Porter at the New Zealand Williams Syndrome Association camp in Christchurch.

Right: Clinical neuropsychology intern and PhD candidate Jessica Reeve.



Popular winners picked for new stamp designs

IHC

Four art works – all winners of the IHC Art Awards L'affare People's Choice Award – have been chosen as the designs for new NZ Post stamps.

The IHC Art Awards showcase the creativity of hundreds of Kiwi artists with intellectual disabilities. The winners of the top prizes are selected by a panel of judges. Since 2013, members of the public have been able to cast their votes to choose a popular winner.

The four artworks used by NZ Post are the winners selected by public voting for the past four years. The works are by Matthew Tonkin, Katie McMillan, Malachi Oldridge and Charlize Wilson. This award is sponsored by Wellington coffee pioneer L'affare.

"Together the artworks make a wonderfully vibrant, colourful and dynamic set of stamps. We are very proud to be showcasing such high-quality works from the IHC community," says Lynette Townsend, Programme and Content Manager for NZ Post Collectables. She says when NZ Post releases new stamps it looks for themes and designs that represent Aotearoa New Zealand and the stories of the people and communities of this country.

Importantly, the designs put forward by IHC were the ones chosen by members of the public. "We were really happy with what was selected and the rationale for selecting them."

The winner of the L'affare People's Choice Award 2021, Matthew Tonkin from Auckland, created his screen print *Aeroplane* at Two4nine art studio in Waitakere. Matthew's work, and much subsequent work during the lockdowns, was inspired by a trip to Los Angeles in 2019 where he visited Disneyland and other theme parks with a group from disability service A Supported Life. Matthew loves air travel. "I like it when the plane takes off. It's quite bumpy." Asked if he was going to collect some of the $1.70 stamps bearing his design, he said, "Of course I will".

The 2020 winner, Katie McMillan, made her *Colourful Unicorn* from coloured acrylic pompoms over a papier-mâché support, mounted on a shield. "I love all the bright colours and making this. I hope when people see it, they are happy," she said.

Palmerston North artist Malachi Oldridge won in 2019 for his work, *My Nani as a Māori Girl*. The pencil drawing on paper is a tribute to Malachi's grandmother. She has been a recurring inspiration for Malachi. *My Nani as a Māori Girl* is influenced by the late E. Mervyn Taylor's artwork, *Māori Girl (Hina)*.

Manukau City artist Charlize Wilson was a winner in 2018 for her painting, *Looking Out from the Inside*. Charlize was 13 at the time and a student at South Auckland Middle School. After winning she said, "The art is just a person looking outside. She is happy, she likes the view a lot."

The 2022 IHC Art Awards have attracted entries from 412 artists from all over New Zealand. The Top 100 selected by our judges are being exhibited for a month in a pop-up gallery in central Wellington.

The 30 finalists, including the major prize-winners, have been chosen from these Top 100 by a judging panel of actor Libby Hunsdale, artist and sculptor Simon Lewis Wards and Student Volunteer Army CEO Sam Johnson. Winners will be announced on 28 July 2022.

Last year the IHC Art Awards introduced a new category for young artists. The winner of the Youth Award and a cash prize of $1500 is selected from entrants between the ages of 13 and 17 and drawn from the top 100 artworks. They are also eligible to win the L'affare People's Choice Award ($2000) and first ($5000), second ($3000) or third place ($2000) overall. This year there has been a surge in the number of entries from young people still at school, from nine last year to 27 this year.

You be the judge. Keep an eye on our website – ihc.org.nz/art-awards-2022 – for details of when voting opens for the L'affare People's Choice Award. This year for the first time, people can also vote in person at the gallery. Artworks can be purchased from the pop-up gallery.

Bulletin

IHC says law changes undermine child protection

IHC says proposed law changes designed to protect children have the potential to do them harm by making it difficult to raise concerns or make complaints. IHC Director of Advocacy Tania Thomas says the Oversight of Oranga Tamariki System and Children and Young People's Commission Bill undermines the protection of children, particularly intellectually disabled and Māori children. She says the Bill must be withdrawn and redrafted to ensure children's rights are paramount. "This includes partnering with Māori and consulting with intellectually disabled children and their whānau who are also disproportionally affected by the child protection system. Any redrafting of the Bill should only occur after the Royal Commission into Abuse in Care has handed down its final report."

IHC volunteers honoured

New Zealand communities honoured IHC volunteers during National Volunteer Week in June. Tricia De Haan (North Canterbury) and Rachel Bird (Wellington) received Volunteer Centre awards for their service. Rachel, who is involved in i-Volunteering, was runner-up in the Volunteer of the Year category. Two Dunedin volunteers, Georgia Levey and Tony Watts, were named Volunteers of the Month for April and May respectively. IHC volunteers give their time to support more than 600 friendships annually. National Volunteer Week celebrates the amazing work of volunteers around Aotearoa New Zealand.

Hamish is presented with his gold award

Hamish Gilbert, a former Havelock North High School student has received his gold Duke of Edinburgh's Hillary Award from Governor-General Dame Cindy Kiro. Hamish finished at Havelock North High School last year having completed his Duke of Edinburgh gold – one of only two students at his school to achieve it in 2020. His achievement is all the more remarkable because he did the challenges solo rather than as part of a school group. He started in 2016 and it took him four years. Hamish is a passionate environmentalist, and for the service components of the bronze, silver and gold awards he collected scrap metal to raise funds for Special Olympics.

New disability housing and health research is grim reading

RESEARCH

Three new research reports on housing and health affecting disabled people have been released without any public launch, despite the wishes of the disabled people's organisations involved.

They are grim reading, revealing a level of desperation that will be uncomfortable for many because the issues they raise, many of them tangled together, aren't easy to fix.

The reports are part of monitoring under the United Nations Convention on the Rights of Persons with Disabilities to make sure disabled people have the same rights as everyone else. The New Zealand Government gets copies of these reports and so does the United Nations.

Leo McIntyre, spokesperson for the Disabled Persons Organisation Coalition (DPO Coalition), says the reports make for uncomfortable reading, but they provide plenty of evidence to be used by disability organisations and the Government to guide reform.

Case studies reveal disabled people living in houses where they cannot access their bathrooms and toilets, where older parents struggle to bath adult children in bathrooms without hoists, where a disabled family member is bathed outside in summer.

"The only time we give him a shower outside is when it is nice and hot … because we don't want him to get sick. So, wintertime is just sponge wipe, the whole winter," said one family-whānau interviewee.

Some disabled people were or had been homeless, and one young person was living in a rest home. One interviewee described living in a tent and some days being in too much pain to access the shared toilet block easily.

Because of hardened attitudes to disabled renters among some landlords and agents, some disabled people send others to viewings for them, so as not to be ruled out from the start.

One interviewee said: … "Landlords are getting very choosy. Even people with children, they're sending them away, they don't want children in the house. They don't want unemployed in the house. They don't want disabled in the house. They want these high professionals in the house and that's about it. They can afford to be really choosy, and they are. So, a lot of extremely good tenants who would really look after the place are just being turned away. They go for what society values the most and that's certainly not disabled."

Leo says the Coalition is looking for a response from the Government on the reports and it is hopeful that the creation of Whaikaha – Ministry of Disabled People, along with the health system reforms, will see progress. He urges the Government to employ disabled people and use their experience to guide the change that is needed in every sector to improve the lives of disabled people.

The health report recommends the removal of the two-tiered funding system (ACC and Ministry of Health) and an equitable funding and support system for everyone regardless of the cause of their disability.

"I think one of the big things would be combining the ACC model and the DHB model so that everyone is entitled to the same services regardless of how they acquired the disability," said an interviewee.

The report describes the case of a mother denied ACC for a severe birth injury, who was moved from an intensive rehabilitation facility to an aged care facility where she received minimal support and was separated from her child and family.

The report also recommends free primary health care and better health screening of disabled people. This was echoed by an interviewee.

"So, I would love there to be, even if it was every five years you could get a dental check-up or a health check-up. That's gotta be better than what it is now. If people haven't been to the dentist for 40 years. People haven't had a cervical smear or mammogram, or they've got this huge lump on their arm which is a melanoma, and they don't know."

The Donald Beasley Institute was appointed by the DPO Coalition and the New Zealand Government as the research partner to carry out the monitoring research. The research is led by disabled people.

The reports are available at donaldbeasley.org.nz/projects

New Advocacy Director impatient to see sector changes

IHC

New IHC Director of Advocacy Tania Thomas has waited too long to see positive changes happening for people with intellectual disabilities.

“We have spent a great deal of time defining the problems and issues in the disability sector. It’s time to find the solutions and to start implementing them. We have to think about different strategies.”

With the launch of the new Whaikaha – Ministry of Disabled People, she sees an opportunity to make progress.

Tania says the Government needs to prioritise a means to measure improvements happening in the lives of disabled people. “How do we know what is working if we don’t measure it? The basic statistics are missing,” she says.

Tania believes the answer is to create a movement of whānau, friends and communities to improve lives for disabled people.

“Together we can achieve more, and everyone has a role to play. We need to proactively make space for the voices of people with disabilities and their whānau. Imagine the positive change if people not used to being heard were heard by the people not used to listening.”

Tania has spent the past seven years as Manawhakahaere/Chief Executive of Kaupapa Māori disability support service Te Roopu Taurima. She is Ngāti Kahu on her father’s side and Scottish and Ngāti Mahurehure on her mother’s side. Based in Auckland, she is the mother of three adult daughters, one a midwife, one an early childhood educator and the third a customs officer. She has four grandchildren – all in Auckland.

She holds governance roles within her iwi authority and marae. Tania has also held leadership roles within the sector, including Deputy Health and Disability Commissioner and Director of the Centre for Family and Whānau Knowledge in the Social Policy Evaluation and Research Unit of the Families Commission.

She is now relishing the opportunity to get back to pure advocacy. “When you get to my age – I get my gold card later this year – you get to think how can my skills and experience make a difference?

“Promoting inclusion for people with disabilities in all areas of life and upholding human rights is at the core of advocacy. I have an opportunity to hold those with power to account and to push for more positive change in the disability sector.

“Things are better than they were 40 years ago when I first entered the sector but there is still a long way to go if we as a society are truly going to accept that diversity, equity, inclusion and a good life is for everyone.”

Tania says over the years she has watched as IHC has supported other disability organisations, including Te Roopu Taurima, and acted with generosity.

“I really like the opportunity to work with my peers, who I respect a great deal.” She says that has been reinforced in her early weeks at IHC. “Everyone I have met as part of my induction is on the same page. The people have got the same ethos, belief and the desire for people to have a better life. Everybody was telling me the same story. Everybody can tell you the whakapapa of where their job and their department came from.

“For me it’s about fit-for-purpose support and housing, health, education, vocation and living the principles of enabling good lives. I have come with some ideas already, but I have got a lot of questioning, thinking and listening to do.”

Above: Director of Advocacy Tania Thomas (left) with IHC Advocate Shara Turner.


CALIFORNIA

Shelby’s magic moment

SECTOR

This was his magic moment. The korowai came down off the wall and was draped around Shelby Porowini’s shoulders. It meant he was now one of the big kids and was going to school.

Shelby didn’t know what was happening, says his mum Stephanie Porowini. “He just thought he was having a party and he had seen the other kids doing it and thought, this is cool. It’s my turn now.”

Stephanie, on the other hand, was feeling emotional at the thought that Shelby was leaving Kind Hands, the early childhood education centre and respite facility in Whangārei where he had been since he was 18 months old.

“It was actually very sad because I didn’t want him to leave Kind Hands,” she says. “That has been his safety net since it opened.”

Shelby is the youngest of Stephanie’s five children and was born with a range of health conditions that makes her want a safety net. He has Down syndrome and autism and was born with a cleft palate and holes in his heart. He is at risk of choking, and is non-verbal and not toilet-trained, and Stephanie worried about how well he would be looked after at school.

“The only reason we let him go now was that Sharlene [Sharlene Clements, the owner of Kind Hands] said he was ready.”

Wearing the korowai was special, not just because the names and dates of all the children who have left Kind Hands are stitched on to the back, but because it was one of two funded by his mother. Stephanie, who owns a real estate agency in Whangārei, donates a percentage of every sale to the centre.

Just after his fifth birthday Shelby started at the small Whangarei Adventist Christian School, which has a roll of 30 children from primary to Year 8. Taine, 10, his older brother, moved from the much larger Whangārei Primary School so they could go together.

“He liked his school, but we explained that it would help Shelby to have his brother there,” Stephanie says. “We have an agreement that he helps by taking him in the morning. They get out of the car, and they get on the scooter together and go in.”

Shelby started school in April. “He does love school. He has not once, touch wood, whinged about school. He has made some little friends.”

He has a teacher aide for 13 hours a week paid for by Ongoing Resourcing Scheme (ORS) funding, but Stephanie is challenging that with the Ministry of Education. She says he needs high ORS funding of 20 hours. “Someone needs to be with him 100 percent of the time.”

Sharlene, who opened Kind Hands in July 2018, has known Shelby since he was born. She was the family’s community outreach nurse. “He was one of the first kids that we had when we opened Kind Hands.” But she says he had outgrown the centre.

“He was looking around for more challenges and more activities than we could offer him.”

And Sharlene did what she could to make the move to school a success. “I took him for transition visits myself.” She says there were three visits which gave the school the opportunity to ask her questions.

Kind Hands caters for children with disabilities and medical conditions who are unable to attend mainstream pre-schools. It employs registered ECE teachers and registered nurses. Kind Hands has a high ratio of four staff to four children, including a nurse, a teacher and caregivers.

Sharlene, a former paediatric nurse and a registered ECE teacher, says Kind Hands is rare in that it has nurses and teachers working together. It also offers respite care at weekends. Parents pay through various means – including whatever funding they receive. A child does not have to have ORS funding to go to the centre. The Kind Hands Trust can offer support in some circumstances.

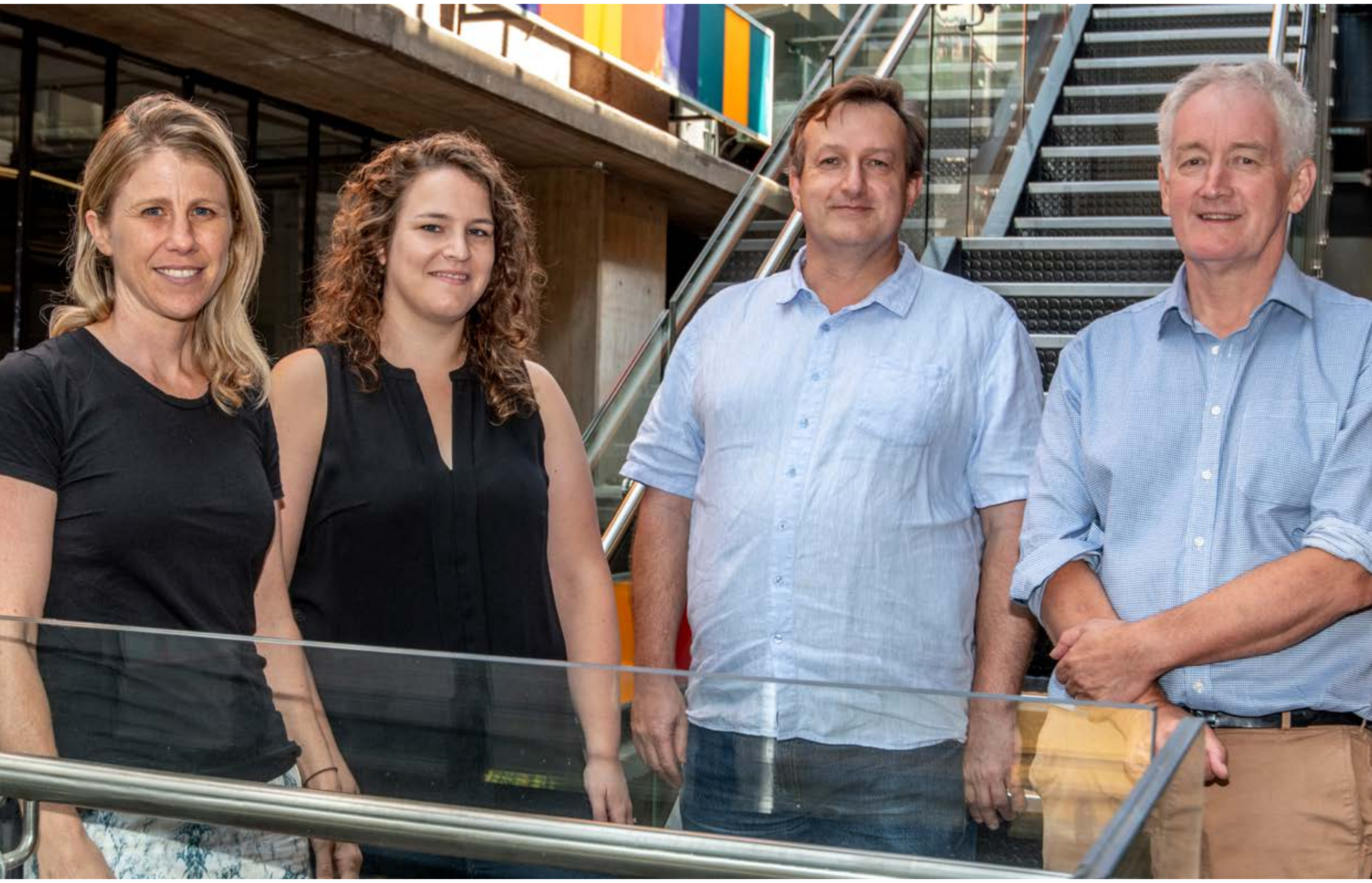
There is a story behind the name. Sharlene’s son Luke, who is on the spectrum, was supported by a teacher aide at his kindergarten. “She would say to him, ‘You need to use your kind hands Luke’.”

Sharlene says the phrase stuck with her and years later she reconnected with the woman and told her about the impact of her words. Luke is now 18 and a champion runner.

Sharlene is now expanding Kind Hands with a new building that will increase the centre’s capacity from 10 children to 22 children and reduce the waiting list for places.

Left: Shelby Porowini graduated from his Kind Hands early childhood education centre in April with a farewell hug from Kind Hands owner Sharlene Clements.

Above: Shelby wears the special korowai for his graduation. The korowai has the names and dates of all the children who have left Kind Hands stitched on to the back.



RESEARCH

New technology gets closer to the causes of genetic disorders

Eight families have diagnoses for rare genetic disorders thanks to the latest work by a team of researchers at the University of Auckland.

The DNA of 25 people with undiagnosed intellectual disability from 19 families was studied using advanced genome sequencing and analytical methods. The project aimed to uncover the genetic causes of the neurodevelopmental conditions and improve the health of these individuals. The study was funded by the IHC Foundation.

Genome sequencing is a laboratory method of studying the genetic makeup of cells. The human genome contains a person's complete set of genetic instructions.

As well as finding answers for eight families (12 individuals), the team believes it has broken new ground in a further four cases by identifying potentially novel genes or translocations involved in developmental delay. A translocation happens when a chromosome breaks, and the fragmented pieces reattach to different chromosomes.

No genetic diagnosis was found for seven of the 19 families, but analysis will continue in the hope of finding an answer for them.

The researchers from the University of Auckland's School of Biological Sciences; Dr Jessie Jacobsen, Professor Russell Snell, Associate Professor Klaus Lehnert, Dr Whitney Whitford and PhD student Chris Samson, use whole genome sequencing to find a variety of genetic variations, including those that are complex – such as changes in the DNA that involve combinations of deletions, duplications or translocations of genetic material. The team worked with colleagues at Harvard Medical School and Massachusetts General Hospital in the United States to sequence and analyse the complex cases.

Whitney, who participated in the project on a post-doctoral fellowship funded by the IHC Foundation, developed a 'bioinformatic pipeline' (software to process the DNA sequences) to detect large deletions and duplications of DNA. She worked alongside Chris to validate and confirm the cases with deletions, duplications or translocations of genetic material.

Everyone inherits genetic variations that cause no difficulties. But when they do cause problems, the results can be devastating for the individuals and for the families affected.

Jessie is thrilled that the study has provided a potential answer for more than 50 percent of the families. "The research funded by the Foundation has been a huge success. Compared to much of the international literature, it's a lovely statistic."

Jessie says in two or three cases they discovered a new role being played by structural variants, where they don't disrupt the gene itself but instead disrupt the non-coding regions nearby that interact with the key gene involved in the condition.

"Importantly, these results are contributing to the translation of this technology for routine use. Currently, we are applying to funding bodies to support the trial of this sequencing technology in the clinic, together with clinicians from Auckland District Health Board and Diagnostic Genetics at Auckland City Hospital."

In 2015 the IHC Foundation funded the team's pilot research project using genome sequencing to find the causes of rare, undiagnosed neurodevelopmental disorders. This early study found the genes and mutations responsible for rare conditions in 14 children. Following the success of the pilot, the Foundation funded the study in 2019 that has looked at even more complex variations.

New sequencing technology makes it possible to rapidly study large amounts of DNA at once. This has dramatically cut the cost of genetic detective work.

In 2001, it took years and cost $US95 million to sequence the whole human genome. Now it takes only days to sequence a person's DNA and by 2021 the cost had been slashed to $US450, according to the US National Human Genome Research Institute.

"Now you can sequence the genome by chopping it up into small bits and sequencing them at the same time," Jessie says. In New Zealand dollars the cost of sequencing the whole human genome is now around $1500 and the cheaper alternative of sequencing the human exome is $450. The exome is the protein-coding region that, while representing less than 2 percent of the genome, contains around 85 percent of known disease-related variants.

Jessie says cost-effective sequencing makes it possible to make the move from the research laboratories into clinics as part of normal diagnostic testing. She says finding genetic answers for families has been a real privilege and hopes this will tailor long-term management for those families involved.

Left: Researchers from the University of Auckland's School of Biological Sciences (from left) Dr Jessie Jacobsen, Dr Whitney Whitford, Associate Professor Klaus Lehnert and Professor Russell Snell.

Right: Dr Whitney Whitford's doctoral research resulted in diagnoses for two families and life-saving treatment for a seven-year-old boy.

Whitney tracks the missing pieces

Scientist Dr Whitney Whitford is skilled at finding missing pieces of DNA.

Her complicated version of a jigsaw puzzle involves things called copy number variants (CNVs). They are responsible for the duplications and deletions of genes or parts of genes that cause neurodevelopmental disorders.

As a PhD student at the University of Auckland Whitney developed a filtering and annotation system – called a 'bioinformatic pipeline' – to find and track CNVs in individuals with neurodevelopmental conditions.

Her doctoral research resulted in diagnoses for two families and life-saving treatment for a seven-year-old boy.

Whitney says one of the families participating in her research had two brothers, both with the same disorder. They had inherited genetic variants from both parents that prevented vitamin B being transported into their brain cells. The vitamin B deficiency had caused lesions in part of their brains, causing seizures. The older brother died, but the younger brother survived after treatment.

She says the cause was very difficult to find, but the treatment was straightforward, using biotin and thiamine supplements. "It's just understanding the genetic basis of what caused this condition. Our research was translated to the clinic and contributed to saving the remaining brother's life."

In 2019, funded through an IHC Foundation post-doctoral fellowship, Whitney took her skills and her computer pipeline to join the team at the university's School of Biological Sciences on their project to find the causes of rare genetic conditions. Whitney's role was to liaise with the families involved in the study and their clinicians, extracting DNA, and processing and analysing data.

Whitney says being able to deliver a diagnosis for families was a great result. "Obviously we would always like more.

We would like to be able to give every family an answer," she says.

"We are as good as the best in the world." But she also says, "We are not here for the glory. I know that our research can have such a profound effect on people's lives."

This project provided a platform for Whitney to obtain a three-year postdoctoral fellowship from the Neurological Foundation of New Zealand to continue her research career and she is now investigating the genetic basis of Charcot-Marie-Tooth disease in New Zealand. This is a group of disorders that cause nerve damage, resulting in smaller, weaker muscles and sometimes loss of sensation and voluntary movement. In New Zealand, the underlying genetic cause has only been identified in 40 percent of cases.

Whitney will be using genetic sequencing to identify DNA variations that cause the disorder. She says while she may not be actively researching neurodevelopmental conditions for the next three years, she will still be part of the team. We are still connected."

IHC

Pop-up park for Tauranga a real asset for tenants

A cool morning didn't spoil the warmth of the welcome for Accessible Properties' tenants to a new pop-up park in Tauranga.

"It was brilliant to see the local community come out over Matariki and have some fun at 899 Cameron, our new pop-up-park," says Vicki McLaren, General Manager of Accessible Properties Tauranga.

The park is on a vacant section owned by the IHC community housing provider. "It will be developed into housing in the next year or so, but while it's empty we wanted to turn it into a real asset for the area.

"We were privileged to have local kaumātua Puhirake Ihaka lead a blessing for the park in the early hours of what was a pretty cool June morning, and we also had a fantastic hangi for our tenants."

The forecast was atrocious for the Matariki Whānau Day the following weekend, but the rain stayed away and lots of people turned out for kai and family activities.

"Accessible Properties' role goes well beyond putting a roof over people's heads. We are really invested in the communities we are part of," Vicki says.

"And that includes working with other organisations. We've had great support from Tauranga City Council, the Department of Internal Affairs, EmployNZ, Sport Bay of Plenty and Good Neighbour to help us make the park happen.

"It's been a team effort and it'll be great to see people enjoying our new green space."

Top: Ereti Williams, Tenancy Operations Manager with Accessible Properties in Tauranga, celebrates with tenants.

Above Right: The rain stayed away and tenants enjoyed kai and family activities for the Matariki Whānau day.

Parenting at 3am – you’re not alone

IHC

Awhi Ngā Mātua is a community of parents who Emily Writes wishes she had known in those long nights when she felt alone and overwhelmed with the responsibility of caring for a sick child.

Emily, a mother of two boys living in Wellington, is the author of best-selling parenting books *Rants in the Dark* and *Is it Bedtime Yet?* – with another, *Needs Adult Supervision*, just released.

She is also the Director of the ‘Awhi’ online community.

Awhi started as a Facebook group for parents at home supporting children with intellectual disabilities in the first lockdown in 2020. Cut off from all their usual supports, Awhi provided connection and online resources to get families through the long hours of isolation.

Emily started out advising and writing content for the group. “I came in as a contractor but fell in love with the Awhi kaupapa and felt like this was what I had wanted my whole parenting life.”

Awhi is now evolving from a platform offering resources and support to a collective where parents take the initiative to build a strong community for each other.

“It’s always in my mind,” Emily says. “I think, this would be good for the community, or that would be good for the community.” She says 90 percent of dialogue takes place in private discussions. “Often parents are not asking for advice. They just need someone to say, ‘That is really hard’.”

Emily says she recently had a call at 3am from a parent who has a child with autism and struggles to sleep. “It’s just about saying, ‘You are not alone in this’. Often I am awake at 3am because I have an autistic child and a child who needs testing every two hours in the night.”

Eddie has type 1 diabetes. “We are managing his levels every two hours, while we are managing his health needs.”

Emily and her husband also know what it’s like to be judged by health professionals. When Eddie became seriously unwell, and before his diagnosis, they were told by a doctor that it was what happened when people didn’t manage their children’s diabetes. “When we came in with an unconscious child, they clocked us as two irresponsible parents.” She recalls saying: “What? He has diabetes? How do we cure that?

“With Eddie’s diagnosis, I knew nothing about diabetes. We didn’t have diabetes on either side of the family.

“My husband and I didn’t finish high school, so going up against doctors we say what does this mean and what does that mean? It’s really hard,” she says.

“My husband is Māori and there are few parts of the system that follow tikanga. They look at my husband and I and they see tattoos and they think, low-class.”

Emily says Awhi tries to speak in the language of parents – “language that is culturally safe and culturally appropriate”.

Awhi Ngā Mātua is led by founder Elizabeth Goodwin and Emily, with IHC in a supporting role. it has recently received funding from Oranga Tamariki to develop the community which, Elizabeth says, is about creating parent champions.

Elizabeth says the parents who support children with disabilities and high health needs exist on the edges. “They become different when this happens – even from their family. If we can help parents deal with these day-to-day things, then we have done a really good thing. We want it to be as collective as it can be.”

Connect with Awhi Ngā Mātua at
https://awhingamatua.org.nz/ or on
https://www.facebook.com/awhiathome

Above: Emily Writes, with her son Eddie, was drawn to the kaupapa of Awhi Ngā Mātua – an online collective where parents are building a strong community for each other.

Pictures worth a thousand

IHC

Every person portrayed in this multimedia exhibition has a story to tell, but their pictures alone are worth a thousand words. More than a thousand.

'Take a moment with us' is an IHC travelling multimedia exhibition that has grown and evolved as it has moved around the country. This year it will open on 15 August at Waikato Museum Te Whare Taonga o Waikato in Hamilton.

The exhibition is a glimpse into the lives of people living with many challenges to daily living and barriers of access and understanding – all looking to be included in their communities.

Moana Parker is Māori and was born in Whanganui. She has lived a life separated from her family. At the age of 10, Moana went to live at Salisbury School in Nelson, a school for disabled girls. She remembers it as a hard time. "I didn't know any people." She stayed there until she was 16. Much of her working life has been spent in Wellington, working for IHC, or volunteering for other organisations. "It doesn't matter what you look like, where you come from – it's where your heart is," Moana says.

Tatiana and Lania Vaireka are passionate participants in kapa haka, competing and performing in the Wainuiomata High School kapa haka group Te Tira Whakaau. It's something the sisters take very seriously. Tatiana, who has the rare genetic disorder Williams syndrome, has been participating in kapa haka for six years. "It's a part of my culture – Māori language and music. It's about who you are and where you come from."

Take a moment with us features photographs by Christchurch documentary maker and photographer Bridgit Anderson and video footage shot and edited by Sam Morrison, Tania McKenzie Bellam and Jasper O'Donnell.

Bridgit, Sam and Tania filmed in Auckland, Christchurch, Waikato, Wellington and Manawatū – and the result is a showcase of people with intellectual disabilities from every walk of life.

Bridgit is a Christchurch-based documentary and portrait photographer. She specialises in human-interest stories and related educational projects and her work has been widely published and exhibited throughout New Zealand.

Sam was a former IHC National Self Advocacy Coordinator. He is an artist and has a Master of Visual Arts degree from Auckland University of Technology. Tania is a videographer and photographer and works as a digital media producer at IHC. Jasper is a Wellington videographer.

Take a moment with us is created, funded and managed by IHC New Zealand.

Left: Alexander Szydlowski with his brother and sister, seven-year-old twins Thomas and Sienna.

Above: Tatiana and Lania Vaireka take competing and performing in the Wainuiomata High School kapa haka group Te Tira Whakaau very seriously.

Below: Moana Parker is Māori and was born in Whanganui. She has lived a life separated from her family.

words

Alexander Szydlowski works hard to achieve things his mates at school take for granted. He has Down syndrome and low vision and he finds it tiring understanding and being understood. But Alexander seems to come alive when he is outside on the trampoline, or at the beach or nearby native botanic garden with his brother and sister, seven-year-old twins Thomas and Sienna. Mum Amalia says Alexander enjoys his life. "We love him to bits. There are times when, to me, he is perfect. His life absolutely has value."


TeTuhi

Tom puts out the call for a café stop

SECTOR

Tom Russell has just finished a day's work at the Te Tuhi Training Café in Pakuranga working at the till, taking orders and baking a batch of almond friands.

He loves it. He loves it so much he wants other people with disabilities to come to the café and ask him or the trainers about whether it's something they would like to do "because it's a very good opportunity".

Two years ago, Tom lost his job at Altus Enterprises in Auckland when the lockdowns did away with the need to refurbish Air New Zealand's headphones. He had worked there for five years.

It turned out the pandemic provided the opportunity for Pakuranga's contemporary art gallery Te Tuhi, Rescare Homes Trust and the University of Auckland's School of Psychology to do something they had all been wanting to do – start a training café for people with intellectual disabilities.

Te Tuhi Executive Director Hiraani Himona says training cafés work well overseas but have been slow to take off in New Zealand. Te Tuhi launched at the worst possible time with repeated closures and low customer traffic to the gallery. But she is positive about the project. "It's been a joy," she says. "It's hard, but this is what an art gallery should be doing. It's filled our foyer space with activity and life and joy."

She thinks many Aucklanders might see Pakuranga as being too far to go for coffee but, like Tom, she would love to see more of them in the café. The café is not making money and relying on grants and other funding to pay the staff – a cook and a barista – and the trainees. Te Tuhi received a recent grant from the IHC Foundation.

"I would love some more customers. We are 20 minutes by car [from central Auckland] and there is loads of parking." The café is open six days a week from 9am to 2pm.

Each partner plays a specific role. Rescare selects and oversees the trainees and covers pastoral care. Te Tuhi runs the café and employs the trainers and trainees. The university's School of Psychology staff have developed the training manual and troubleshoot where necessary, working out how to adapt training if someone is having trouble.

Dr Katrina Phillips, senior lecturer in the School of Psychology, says the project, Nga Mātauranga ōu Mahi, provides benefits all round – for the trainees, the community and for the university students involved in developing and studying the project.

"We used the idea or term ako – that idea of learning from each other. It's the idea that everyone has something to give," Katrina says.

Tom was one of the first trainees when the café opened in July 2020. He's been working there ever since. He does some baking but prefers the customer-facing roles.

"I am more confident, absolutely. I like the customers to feel good about what we do."

Today was the second time he had made almond friands. "It took a while to remember how to do it again," Tom says.

He's comfortable on the till. "I am really good at my counting and maths."

His skills have led to other work too. Tom is employed at the Better Way container café at Drury on Fridays.

He says he is thinking about long-term goals now – perhaps trying some other kind of employment and a future with his girlfriend. "I really want to be living independently with my partner. That is my long-term plan. She is my blessing and my heart."

Left: Tom Russell works at Te Tuhi Training Café on Wednesdays, loving the connection with customers and staff.

Above: Rachel Martin and Falefatu Carreras are building their skills at Te Tuhi. Rachel is aiming to be a barista.

Bruce and David have reached an understanding

IHC

David Snelgar doesn't say much when he's concentrating on art. But during the 10 years he has shared Bruce Maunder's art studio the men have come to an understanding about a few important things.

Art is one of those things. For both men the art session at Bruce's place every second Wednesday is a firm commitment.

David, 59, has autism. Art has always been central to his life, revealing the way he views the world. He covered the walls of his family home in his paintings, encouraged by his mother Hazel, who was an artist who worked in clay.

David uses acrylic paint to create the strong blocks of colour that feature in his work, and he loves circles. He uses smaller circles as building blocks to make pictures.

Bruce, 48, electronics engineer and CEO of computer consultancy Celsius IT, has been making more room in his life for art. He joined IHC's volunteer programme more than 10 years ago to get a better work/life balance. He met David, who had been working at a community art centre until the funding dried up and was looking for a place to do art. They started working in a studio on Bruce's lifestyle block at Karaka.

Bruce says the commitment to the fortnightly sessions keeps him going. "Knowing how much it means to David, it makes it a good motivation."

Bruce enjoys experimenting with different art forms and media – he's working on sculptures in Oamaru stone at present. "We have tried so many things over the years," he says. David, however, will always be drawn back to the acrylic paintings and oil pastels that he loves.

David likes to take home two or three oil pastels at the end of the evening to keep working on his art during the week.

Bruce says his business has often taken a lot of his energy and he has always been someone who has gone hard at it. But that is changing. "My interests are definitely more creative these days. I am cutting down work time."

The fortnightly sessions have become part of the Maunder family routine. In the early days Bruce and wife Sonya's pre-schoolers, Erin and Jeremy, would sometimes stay and do some art. Now they are teenagers, aged 13 and 14, and hang out occasionally. "The kids and my wife will often bring coffee up to the art room."

Bruce says the family's friendship with David has helped to build their insights into how he sees the world. Bruce says he believes art brings David much happiness.

"Something that surprises me is that David is regularly happy. I think sometimes people forget that happiness is an important part of life. The way he sees the world is just beautiful – sometimes it's very literal and it just makes you see the world," Bruce says.

"We work quite independently but he often tells me the story behind what he is doing."

The men don't exhibit their art. "We just enjoy it for ourselves."

They work with music playing and there are few words spoken. "But every now and then you get some good insights into what he is thinking. Especially on the ride home. He is just so happy after the art session.

Bruce says David seems to be noticing everything along the way; he will point out the rabbits at night, and other landmarks on the 14-kilometre journey home to Pukekohe from Bruce's place. He says sometimes on the way he will turn to look at David and be greeted with a huge smile.

Above: Bruce Maunder (left) and David Snelgar make their Wednesday art sessions a priority.

NOTICE OF 2022 ANNUAL GENERAL MEETING

Notice is hereby given of IHC New Zealand Incorporated’s Annual General Meeting to be held at

5 pm Friday 7 October 2022

Vela Room, DoubleTree by Hilton Karaka

8 Hinau Road, Auckland 2113

Draft Agenda

1. Calling of Meeting
2. Obituaries
3. Welcome
4. Apologies
5. Meeting Rules and Procedures
6. Confirmation of Minutes of the 2021 Annual General Meeting
7. Matters Arising from the Minutes of the 2021 Annual General Meeting
8. Presentation of Annual Report, including reports from the Board Chair, Group Chief Executive, Member Council and Board Committees
9. Board Appointments Committee - Appointment of Board Members
10. Election of Patron
11. Appointment of the Auditor
12. Annual Membership Subscription
13. General Business
14. Next Meeting
15. Thanks and Closing

2021/22 Annual Report

The 2021/22 Annual Report and financial statements will be available at the Annual General Meeting. They will also be available via the IHC website prior to the Annual General Meeting at www.ihc.org.nz

Ralph Jones

IHC Group Chief Executive

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Take a moment with us

Take a moment to get to know people with intellectual disabilities living in your community.

Multimedia exhibition of photographs and stories.
15 August – 10 October 2022
Waikato Museum Te Whare Taonga O Waikato,
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ihc.org.nz/take-moment-us