

# StrongVoices

EMPOWERED LIVES

Summer 2021

**We are warriors**

**A real 'tight five'**

**Find your bubble**



# Kōrero

The Government has announced the very welcome news that it will establish a new standalone Ministry for Disabled People.

This marks a fundamental change in the way people are viewed and valued as equal citizens. IHC has pushed for this change and for the Government to see individuals' lives in their entirety – their income, support, housing, transport and more – rather than defining people by health need and diagnosis.

As our Director of Advocacy, Trish Grant, said at the time of the announcement, "Disabled people have long called for a system that is joined up and responds in a holistic way to who they are and what they need for a great life."

More than half of the users of disability support services have intellectual disability as their primary diagnosis.

The new ministry, whose name is yet to be finalised, will be supported by the Ministry of Social Development.

The announcement comes alongside the Government's commitment to rolling out Enabling Good Lives throughout the country. We hope to see the combined developments put the purchasing power and choice – with support as needed – into the hands of people with disabilities.

Work continues in the fight to ensure all children get a fair chance to attend their local schools and set goals and achieve them. In the longer term we would also like to see education covered by the Ministry for Disabled People to make it easier to put in place holistic, wrap-around services across the disability sector. We watch with great interest.

We look back on another tough year. As we talk about traffic-light systems for living with COVID we note how hard the lockdowns and COVID cases rollercoaster have been.

We know they have been tough on people with intellectual disabilities, staff and families and whānau. It has been a complicated time of rapidly changing guidelines and expectations, with encouragement to vaccinate being replaced with mandatory Health Orders.

We hope that 2022 will bring new discussions and hope; new energy for new initiatives in our sector.

Many of us will keep working over the holiday period. From all of us here at IHC, we wish you some rest, recreation and fun with friends and family.

Meri Kirihimete and enjoy your raumati.

Merry Christmas and enjoy your summer.

**Gina Rogers**  
Editor

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

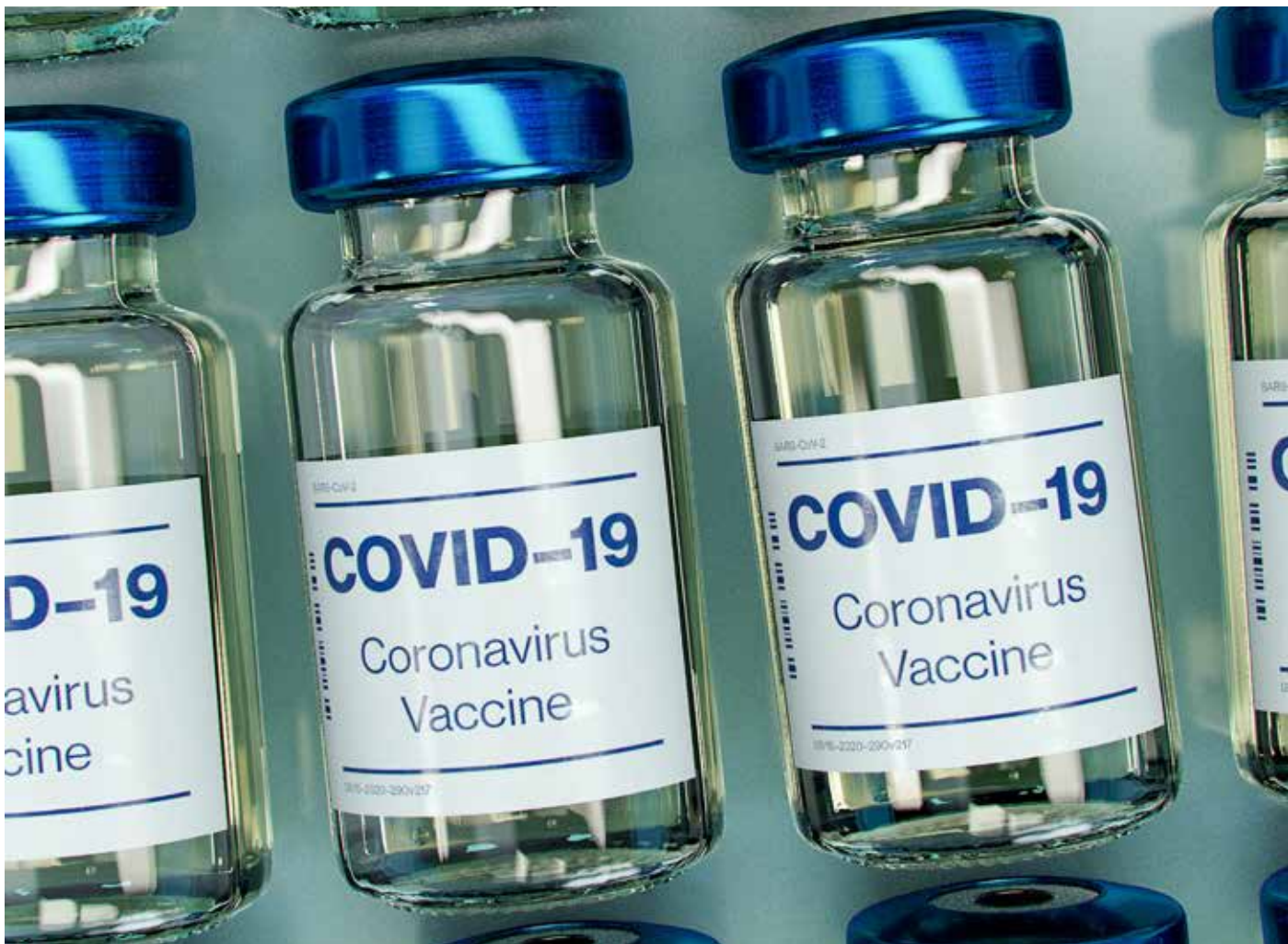
**WE'LL KEEP YOU POSTED WITH NEWS AND VIEWS ACROSS THE IHC GROUP AND THE DISABILITY SECTOR.**

**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:

Dunedin photographer and poet Carlos Biggemann is one of three people nominated for the Attitude Creative Award, with the winner to be announced in December. See story page 4



IHC

## Vaccinations mandatory for most staff

**Across the IHC Group, it's extremely important for us to protect our colleagues and the people we support from COVID-19.**

Since the beginning of the pandemic, particularly in our services, we have taken advice from the Ministry of Health as alert levels have changed on everything from social distancing and more stringent cleaning to mask use and more flexible work schedules.

In late October the Ministry of Health published a Health Order that made it mandatory for certain health and disability workers to be fully vaccinated.

In IDEA Services, this includes all support workers, service managers and area managers.

In Choices NZ, it covers all life coaches and facilitators.

In IHC, it applies to all family liaisons, volunteers (face-to-face) and volunteer coordinators.

At Accessible Properties, it includes all property managers.

And across the whole organisation, it includes those working in all National Support Services roles (Quality, Psychology, Clinical Health, Systems, Service Development and Health and Safety), administration roles (in local offices) and local office-based roles, and any other staff who conduct site visits to residential homes, day bases and other facilities where the people we support are present.

Deb Hammond, General Manager Group Health and Safety, says this is a hardline but welcome move from the Government to ensure we are doing the most we can to protect each other from the virus.

"While we know this may be tough for some people who either choose not to be vaccinated or are on the fence about it, we recognise that vaccinations are the best line of defence against COVID-19.

"We know that people with disabilities and other health conditions are more at risk of

the effects of COVID-19 and, if we can say with certainty that 100 percent of staff in those high-risk roles are vaccinated, that provides a level of assurance that we are doing the best we can to keep people safe."

Affected staff had to have their first vaccination by 11.59pm on 15 November 2021 and their second vaccination by 11.59pm on 1 January 2022.

Those who choose not to be vaccinated will not be allowed to work from those dates.

"We respect that people can decide to not be vaccinated, however this will have consequences for their employment," says Deb.

"We know this will be a difficult situation for some, but we need to comply with the legally binding order and continue to reduce the risk of COVID-19 in our workplaces."

**Above: The Health Order makes it mandatory for certain health and disability workers to be fully vaccinated. Photograph: Daniel Schludi – Unsplash**



## SECTOR

# We are warriors, we are resilient

**Ask Carlos Biggemann what needs to change in the world, and he starts with global issues – war, poverty and the destruction of the rainforests – before coming to his disability.**

This doesn't mean attitudes to disability are any less important to him. Carlos, a 30-year-old Dunedin photographer and poet, says he has to prove himself every day of his life.

Carlos' family came to New Zealand from La Paz, Bolivia, in 2006 in search of a better life and greater opportunities for him. Carlos

was born with Down syndrome and it wasn't long before doors started to close. "I was rejected from many schools," he says.

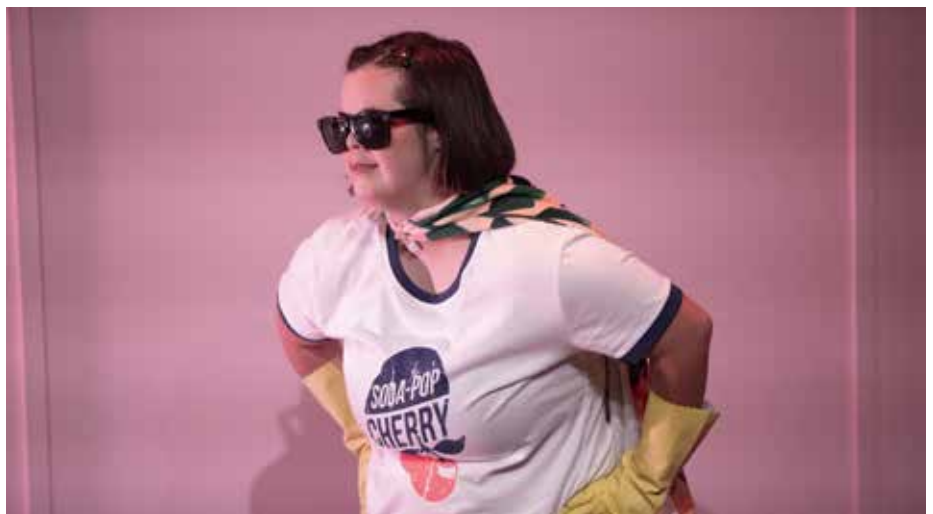
When his parents finally found a school for him, Carlos says he knew he would have to work very hard. "It was not going to be easy, but I do like challenges."

He graduated from Aoraki Polytechnic in 2012 with a certificate in digital photography. In 2013 he was awarded a New Zealand Down Syndrome Association National Achievement Award by Governor-General Sir Jerry Mateparae. In 2016 Carlos won the British Down's Syndrome Association

Stephen Thomas Award in its My Perspective international photography competition. Carlos has exhibited his work in New Zealand and Bolivia and has recently collaborated with 14 poets to create an e-book featuring his photographs of the sky.

The hard work is paying off in terms of recognition of his creativity, but not in terms of paid employment. He is looking for work.

"Oh yes, I know that people who have Down syndrome can do it as well. We have two hands and two feet, we can do extraordinary stuff," he says. "People like us who have Down syndrome, we should have this goal



in life for all of us. We can climb every mountain. We can swim every ocean ... and then we will rise up and be more powerful, stronger.

“We are just warriors. We are resilient. We have a voice to be heard,” he says.

“Through my art I want to celebrate happiness, joy, love, tranquility, humanity and to realise we are living in a world of love – love of almighty God.”

Carlos is just one of 24 impressive individuals selected as finalists in this year’s Attitude Awards. Competing against him for the Attitude Creative Award is actor Lily Harper from Palmerston North, fresh from a starring role in *Up Down Girl* and winner of an ‘emerging actor’ award, and Keegan Lewis, from Hikutaia in Waikato, who released his

first album *My Own Voice* in 2016 and has various singles available on Spotify, Apple Music and Amazon.

As a result of the Auckland lockdown, the Attitude Awards in December will move to Christchurch for the first time. The gala dinner and awards presentation will be held on 10 December at Christchurch Arena and hosted by TVNZ’s Simon Dallow. It will feature entertainers from the disability sector and the New Zealand Army Band.

The Attitude Awards celebrate excellence and achievements in the disability community, and recognise athletes, employers, employees, young people and other game-changers.

“We’re excited to be bringing the Attitude Awards to Christchurch, introducing Cantabrians to this truly one-of-a-kind event,” says Attitude’s CEO Dan Buckingham, a Paralympic gold medallist who uses a wheelchair after a spinal cord injury. “Audiences can expect a full range of emotions, from being entertained to inspired, to having their heart warmed.”

The eight categories for this year’s awards are: Attitude Impact Award, Attitude Youth Award, Attitude Creative Award, ACC Attitude Employer Award, Attitude

Community Champion Award, Sporting Endeavour Award, Attitude Enterprise Award and Spirit of Attitude Award.

The event will be recorded on the night and broadcast as an hour-long television special on TVNZ on Sunday, 18 December at 4pm.

“We have two hands and two feet, we can do extraordinary stuff.”

**Left: Carlos Biggemann photographed by the Attitude Awards filmmakers against a characteristic big Dunedin sky at the Royal Albatross Centre at Taiaroa Head on Otago Peninsula.**

**Above: Actor Lily Harper in the leading role of *Up Down Girl* and (top) musician Keegan Lewis. Both are competing with Carlos Biggemann for the Attitude Creative Award.**

### Changes to carer support

The Ministry of Health has announced changes to disability-funded carer support. Carer support claims are going online in December. This should make life easier and means claims will be processed faster. Families can still claim carer support using the present paper-based system. In another change, carers can regard their annual carer support as a budget and use this in whatever way works for the family (using the Purchasing Guidelines). The budget is designed for carers to get breaks in ways that suit them and their families.

### Companion Card trial

A trial Companion Card programme is enabling people with disabilities to take part more easily in activities in Palmerston North. The digital card is for people who are unable to access ticketed events and venues without a support person, which means paying the extra cost of a second ticket. The Companion Card programme was launched in August through a partnership between Mana Whaikaha, a government disability support system, and Palmerston North City Council. The trial will run for 12 months before being reviewed. People eligible for Companion Cards can apply for them online at [palmycompanioncard.co.nz](http://palmycompanioncard.co.nz).



### Poppy movie goes wider

The makers of *Poppy* have created a version of the movie with captions for people with hearing impairments, and can make the film available for cinemas to have private captioned screenings, says producer Robin Laing. After a successful 14-week run in New Zealand cinemas, *Poppy* is moving out into the wider world thanks to a range of international festival invitations. The film was selected for CinefestOz in Western Australia and screened in October at La Femme International, a Los Angeles-based festival for women filmmakers, and at Cinemagic Belfast, a festival of films for young people. A date for a television broadcast in New Zealand is still pending.

# Autism community has direct input into research

## Autistic people are participating in a University of Canterbury project to highlight their priorities for future autism research.

This year researchers have been talking directly to autistic people and the autism community to find out what is important to them.

Working with a \$29,000 grant from the Health Research Council, the research team ran a series of focus groups between May and July to gather views and is now casting the net more widely with a nationwide online survey.

“We want to enable as many autistic people to take part as possible. The survey has been designed with and for the autistic community. It is also open to members of the wider autism community. So we hope to gather multiple perspectives,” says University of Canterbury research lead Dr Lisa Emerson.

Lisa says there is no limit to the number of people who can participate. The team plans to release the findings in March or April 2022.

She says they have had a strong indication from the focus groups that people want research that is specific to Aotearoa New Zealand. “That preference cut across multiple groups – the need for New Zealand-specific research. That, for me, was a real stand out,” she says. “The project has gathered a lot of momentum and a lot of interest.”

Lisa is joined on the research team by fellow University of Canterbury researchers Associate Professor Laurie McLay and

Dr Ruth Monk, and Dr Larah van der Meer, Research and Advocacy Advisor at Autism New Zealand.

The project team is working with two advisory groups – an Autistic Adults Advisory Group and a Partnership Advisory Group made up of family-whānau, practitioners and researchers.

Ruth, who is autistic, says the research is being conducted not for the autism community but by the autism community. “By having an autistic researcher on the research team and by holding the views of the Autistic Advisory Group central to the design and conducting of the research, we’re trying to make sure that autistic people’s involvement in this research is safe, accessible, inclusive, and can actually translate back to our community.”

Lisa says the Health Research Council has a key role in research and the hope is that any autism research conducted in New Zealand in the future will reflect the research that autistic people here have identified as important to them.

The project has also been important in another sense. “It has provided a platform for autistic people to connect with researchers and practitioners to co-produce and conduct research with and for the autistic and wider autism communities. This connection and partnership is extremely valuable,” she says.

**Below: This symbol was designed to represent the vital partnership with the autistic community in this project. It was designed by autistic illustrator Chanelle Moriah in collaboration with the Autistic Advisory Group. To participate in the research survey, visit [canterbury.ac.nz](http://canterbury.ac.nz) and search for ‘autistic co-led research’.**





IHC

## David is finally on firmer ground

**David Simpson had the ground cut from beneath him when his Kaiapoi home was destroyed in the first Christchurch quake. Then the ground shifted again.**

Just over two years ago David's life started to unravel. He split up with his partner of 17 years, and in early 2020 he lost his job and his driver's licence after an accident in his truck.

Without the stability and support of a partner and a job, David found himself struggling to manage everyday life. A Christchurch community worker contacted IHC Family Liaison Sheridan Myall and asked her to get involved.

Sheridan says the huge life changes had severely affected David's independence, his participation in the community and his health.

Truck-driving had been David's life for more than 30 years. He had started out at a rental vehicle company, where he got his truck

licence, then moved on after 18 years to driving a truck for a recycling firm for another 14 years. "I have been a workaholic – worked seven days a week," David says.

But without the job and now living alone, David became very isolated. He could no longer drive to get his groceries, topping up his phone was in the too-hard basket and lockdowns made everything much worse. He has no contact with his family.

"It's hard to live on your own," he says. He has only the TV and the radio for company. "At the moment I watch the news and what's going on with Delta and that. I do a short walk. Whatever happens, happens. At the moment I just go day by day – just get on with it, take it as it comes."

For more than a year, Sheridan has worked with the community worker to help David get his life back on track. Believing David needed more assistance, they approached LifeLinks, the local Needs Assessment Service

Coordination organisation, for an assessment and David, 58, has been diagnosed with an intellectual disability. David had slipped through the support nets in the health and education systems, but now has a diagnosis that entitles him to the support he needs. That includes five hours a week help with housework and cooking and another five hours of supported living, covering budgeting and paying bills.

LifeLinks is also keen to get David help with technology and to reconnect him with his community.

David says he is happy to share his story to help anyone who might be in a similar situation. He says Sheridan is great. "She's my first port of call if anything goes wrong." And his advice to anyone who needs help? "Take whatever opportunities come to you. Take them with arms open."

**Above: David Simpson, with Sheridan Myall, is getting his life back on track.**



IHC

# Places in my mind, places of

**Two teenage high-school students have taken top prizes in the IHC Art Awards 2021 with works that give voice to their deepest feelings.**

Danni-Lee Kokiri, 18, from Lower Hutt, won first place in the IHC Art Awards for 2021 and a \$5000 prize for her mystical painting *The Chakra Forest*. Interviewed after her win, the Taita College student said the trees made her want to fly over them.

“My picture *The Chakra Forest* is my depiction of a scene from my favourite anime, *Naruto*. It has a spiritual energy that makes me feel like I’m actually in the Chakra Forest when I get up close to it,” Danni-Lee said in her artist statement.

In the Netflix anime series the orphan Naruto, guided by his spirit demon, learns to harness his powers as a ninja.

Lily Reardon, 15, a student at Papanui High School in Christchurch, won the Youth Award with a pen and watercolour drawing, *My Mind*, that illustrated the anxious thoughts racing through her mind at school. This was the first year the IHC Youth Award has been presented.

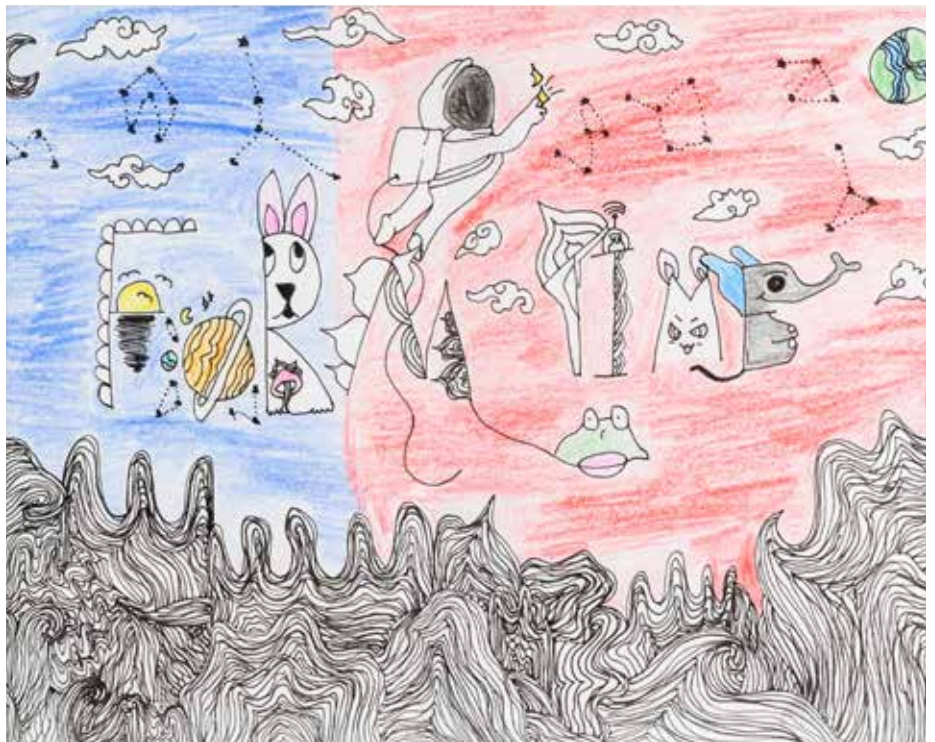
“Form time is my least favourite time at school. This picture represents my mind during this time, feeling calm (blue) and anxious (red). I have included some of my favourite things to help associate good thoughts with form time,” Lily said, describing her work.

Since 2004, the IHC Art Awards have given voice to thousands of artists with intellectual disabilities in New Zealand, many of whom struggle to express themselves in other ways. This year 356 artists entered the competition.

Deshan Walallavita from Hamilton won second prize of \$3000 for his acrylic painting, *Friesian Cow*.

Emma White from Hamilton came third with her acrylic painting, *Portrait of Amy Winehouse*. She won \$2000. Matthew Tonkin from Auckland won the L’affaire People’s Choice Award and a prize of \$2000 for his screen print *Aeroplane* after receiving more than 4500 votes.





# the heart

“This was another year of incredible art,” says IHC General Manager of Programmes Janine Stewart. “I’ve been involved with the awards since their establishment in 2004 and every year there’s something new, with an increase in alternative mediums this time around.”

The winners of the IHC Art Awards are selected by a judging panel of high-profile New Zealand artists. This year’s judges, Judy Darragh ONZM, Paul Hartigan and Otis Frizzell, completed the judging online due to the nationwide lockdown.

This was the second time the awards gala night had been cancelled because of COVID-19 restrictions. The top 85 artworks

were exhibited at the IHC Art Awards Pop-up Gallery at 69 Willis Street, Wellington. Many of the artworks were auctioned via Trade Me, with 100 percent of the sale price going directly to the artists.

The IHC Art Awards are open to New Zealanders aged 13 and over with an intellectual disability regardless of whether they use IHC, IDEA Services or Choices NZ services.

“IHC would like to say a huge thank you to our major sponsors, the Holdsworth Charitable Trust and William Robbins,” says Janine. “We’d also like to thank L’affaire for sponsoring the L’affaire People’s Choice Award and all those who went online to vote or buy a piece of extraordinary art.”

“Finally, thanks and congratulations to all the talented artists, and their supporters, from across the country who submitted artwork covering everything from sculptures, installations and textile art to painting and drawing.”

**Left:** Taita College student Danni-Lee Kokiri has taken home the top prize of \$5000 in the national IHC Art Awards. Photograph: Monique Ford/Stuff

**Top:** Danni-Lee’s winning painting, *The Chakra Forest*, was inspired by her favourite anime, *Naruto*.

**Above:** Lily Reardon’s work, *My Mind*, colour-coded her feelings about being in class.

# Family turns to life on the land with Ben

**This summer Trudy and Paul Masters are expecting their first banana harvest from their rural block near Whangārei. But there is more at stake for the couple than wanting to join Northland's recent enthusiasm for growing the fruit.**

The Masters moved north from Auckland in 2016 in search of an easier place to care for Ben.

Ben, 14, has the rare Nicolaiades Baraitser syndrome, which was only diagnosed four years ago after genetic testing as part of a

research project in Japan. He has very high needs, including intellectual disability and physical challenges, epilepsy and many allergies. As well, Ben is non-verbal and needs help with every aspect of daily living.

The family moved from Kaukapakapa, north-west of Auckland, when taking Ben to the specialist Wilson School in Takapuna each day was becoming too hard.

The move has meant a huge lifestyle change for them. "I love it, but it has taken an adjustment for Paul," Trudy says. They have found it hard to meet people when they

can't go out in the evenings and it's too difficult to take Ben. Their free time is during the day when Ben is at the Blomfield Special School in Whangārei.

The shortage of trained support staff and respite care in Northland is another major drawback. The couple, who manage Ben's individualised funding, qualify for respite care because of Ben's high needs. But they struggle to find ways to use it. There is only one respite facility in Whangārei for children of Ben's age, which they no longer use after differences earlier this year over how Ben's behaviour was managed. They are now trying to employ a support worker with the right training in complex needs. "We have just been managing ourselves," Trudy says. "There is the funding there, but there is just a shortage."

As Ben has got bigger and stronger, so have the challenges. "It was lucky that we were already in behavioural services," Trudy says. At the same time, she describes him as a happy boy. "He is very social and he's very nosy. He wants to be part of things."

When the family first moved to Whangārei, Trudy was able to work remotely, but she gave up her job in accounts and compliance two years ago when Ben's kneecap dislocated, a condition related to the syndrome. This resulted in him having a knee reconstruction. At the same time, Trudy and Paul were struggling to manage Ben's escalating and challenging behaviour – not helped by the pain.

"It just got too tiring," Trudy says. "Paul also gave up work – we started to think outside the square." Trudy and Paul also do small-scale property development, helped by an inheritance from Paul's father. "We only do one at a time."

Then Trudy hit on the idea of growing bananas. "We have got a whole lot of banana plantations up here." She has planted 100 misi luki (lady finger) and the more common supermarket offering dwarf cavendish. Both varieties do well in Northland. "We put them in in October last year. Hopefully this summer we will start getting fruit," she says. "I love growing things, and we have got the land here."

**Left: Ben Masters on the family's Whangārei farm.**



# The Wallaces are a real ‘tight five’

**The Wallaces’ five-week-old baby girl, Edin, was in Starship children’s hospital in Auckland with unexplained seizures. Her mother Karen was by her side.**

Edin’s father Rob was nearby in Ronald McDonald House with her two brothers, Ben, 6, and Ryan, 4. Whatever was going to happen to Edin, the Whangārei family was going to face it together.

“Life got flipped upside-down very quickly for us,” Rob says. Edin was in the grip of infantile spasms, or catastrophic childhood epilepsy, which is drug resistant and associated with a range of other conditions. Two years later Edin was diagnosed with the rare genetic disorder CDKL5 – a condition only discovered in 2004. To their knowledge she was the second child in New Zealand to be diagnosed.

“It took a long time to get the diagnosis because her bloodwork got sent off to Cardiff, in Wales,” Karen says. Karen, meanwhile, had been doing her own Google research after spotting a reference to CDKL5 that seemed to fit Edin’s symptoms. “By the time we got the confirmation I had already got my head around it.”

While the diagnosis didn’t make a difference to their everyday care for Edin, it was important for understanding her condition. “At the end of the day it’s only for the peace of mind – to find a reason as to why. It’s not a hereditary thing; it’s completely out of the blue,” Rob says.

Apart from her seizures, Edin cannot speak or walk. She has gastro-intestinal issues and is mostly fed through a tube in her stomach, and she has limited use of her hands. She needs 24-hour, seven-days-a-week care and the whole family pitches in.

The Wallaces’ instinctive reaction to form a tight circle around Edin has been their means of coping and their way of life for 10 years.

“I basically have done the nights and Karen has done the days,” Rob says. “Even on the nights that Edin will sleep through, I will wake up at 3am to see why she is so quiet.”

Karen says the tag-team works. “I am someone who needs my sleep and I can’t function without it. And Rob is a night owl.”

Ben and Ryan, now 17 and 15, are an essential part of the team. “The boys have been a great help. They have been extra eyes and ears,” Rob says. “Once we decided we had to take it on as a family unit, we did it.”



Edin attends the Blomfield Special School’s satellite class at Morningside Primary School. Aside from that, the family provides all her support. Karen acknowledges that they have been reluctant to hand over Edin’s care to others. “We would be more stressed and lose more sleep if she was with somebody else and we weren’t comfortable,” she says.

For 10 years, doctors have been trying to bring Edin’s seizures under control, trying one drug after the other. She is now on a medical ketogenic diet, a special high-fat, low-carbohydrate diet that is showing some success in limiting her seizures.

Financially, things have been extremely tough as neither Karen nor Rob is available for full-time employment. Rob, who has been on JobSeeker Support, has come under pressure to find a job – something he says is impossible when he is on nights with Edin. “It’s been 24/7 for 10 years. We have both had to give away our KiwiSavers.”

But Rob says their lives changed after an introduction to IHC Family Liaison Jim Callaghan. Jim arranged a face-to-face meeting with needs assessment agency NorthAble, and as a result the extent of Edin’s needs has been reassessed. The Wallaces have switched to individualised funding through Manawanui and now have a navigator to help them access the services they need. Manawanui is an organisation that manages self-directed funding for disability support services.

The financial pressure has now eased. Karen is classed as a full-time carer on a Supported Living Payment through Work and Income while she manages Edin’s funding. Rob will be an employee, paid through Edin’s funding package.

“It has changed our lives meeting Jim. It is a shame it didn’t happen 10 years ago,” Rob says. “There are not enough Jims out there.”

**Above: Edin Wallace has a strong team of supporters behind her.**



IHC

## The right time to make a change

### **It's hard to innovate in the middle of a pandemic.**

But it might also be exactly the right time to rethink how the lives of people we support can be more creative, be more fulfilling and have more freedom.

The North Otago town of Oamaru has two IDEA Services day bases. One is located at Severn Street, just off State Highway 1, the main road through town. The other is 500 metres away at Ribble Street on the other side of the highway.

Both day bases are open for now, but following the recent IDEA Services National

Services Review other options are being explored for both of them.

Otago Area Manager Tanya Povey says the Severn Street day base also serves as the IDEA Services office, so any future space will need room to accommodate staff and offices. "It's an awful building for a day base. It's not fit for purpose, but it's a great location."

Tanya says families are worried about the change and the kinds of service that will be on offer in the future. "The family engagement meeting in Oamaru was very challenging, but robust and honest."

She says one initiative from that meeting was a project to find a space that worked better for everyone, and Service Managers set up a focus group to define the things that people wanted to see. "We established a group made up of two people we support, two staff and two family representatives," she says. "It's their community, their futures and they also have the understanding locally."

The group wanted the space to be multi-functional, include outdoor space, and able to be used into the evenings and the weekends. That meant it had to have easy access for the community, regardless of whether the IDEA Services office was open.

It would be able to host a range of other activities, from coffee drop-ins to art classes.

On top of that it needed to work for the new Kai + Konnect evening social and dinner group that was just getting underway in Oamaru when the country went into lockdown.

A suitable building has been found, and IDEA Services is now in negotiations with the owner through IHC's property company Accessible Properties.

Tanya says the challenge for Oamaru, as it is for many communities outside the main centres, is that there are fewer things to do out of hours, especially opportunities for people with disabilities. She says the IHC North Otago Association has been supportive with funding for Kai + Konnect.

While the dinners have been kicked off by staff, it's an opportunity for staff, the people we support and families to all be in a room together. The plan is that the people we support will become progressively involved in meal preparation, and this will serve as a way of making social connections while people build essential skills.

"The Association and the families can see that we are trying to do something different," Tanya says.

As well, a fortnightly calendar is being put together and emailed out with the activities on offer from IDEA Services, and also those on offer in the community. Tanya says the aim has to be to deliver the right activities for the individuals. "We are saying, here are the programmes we run. Talk to us about what might work well for you and your loved one."

*"Talk to us about what might work well for you and your loved one."*

IDEA Services in Manawatū/Rangitīkei has started a seasonal activity programme offering a range of activities, events and trips over a block of four to six weeks that any of the people we support can join.

"We were lucky enough to complete our winter programme before lockdown and people took trips to destinations ranging from Paraparaumu to Ōhakune to the Hawke's Bay," says Area Manager Karen Wilton. "At home in Manawatū, activities ranged from Daytona car racing and pool at the pub to Matariki celebrations and indoor cricket."



Implementing programmes like this across the country has presented its own challenges as well as its successes.

In Tauranga, IDEA Services is cementing key community relationships, including participating in Good Neighbour. Through this, the people we support can contribute to the community through projects such as community gardens, delivering firewood and food rescue.

In another Tauranga initiative, an alliance with CCS Disability Action has resulted in several referrals, which have been successful in helping people to find work.

In Auckland and Northland, things have been made more complicated with longer lockdowns. According to Joan Cowan, IDEA Services' Chief Operating Officer, technology has been crucial.

"During the first lockdown last year we were able to introduce WhatsApp to the homes of the people we support, so they could connect with their loved ones," she says. "This proved to be really successful and we have begun using Zoom as a way for groups of people to connect for activities like kapa haka."

More recently we have begun rolling out Netflix, prioritising Northland and Auckland because of the lockdown.

Joan says it has been very important for each community around the country to develop its own plan.

"We weren't happy with the existing model and knew it was time for a change," she says. "We know people are keen for us to hit the ground running, and we're now at the stage where we're seeing these programmes introduced," she says. The extensive consultation and review period enabled IDEA Services to learn what people wanted from services – and mostly it was about disabled people being able to better connect with their communities.



The national team has been creating and distributing weekly activity calendars with a range of activities that people can undertake at home and out in the community.

Joan says she's seeing the benefits already, with more variety and purposeful activities.

"More flexibility and control during the day is what people have told us they want, and we're starting to deliver that," says Joan. "It's not about getting up and out of the door to head to a day base every morning, but to have a range of activities in the community throughout the week – from yoga and music therapy to movies and walks in the park, or just sharing a cup of tea with a friend online."

**Left: Stephen Stewart lines up the car of his choice at the Southward Car Museum in Paraparaumu.**

**Top: A trip for people we support in Manawatū/Rangitīkei to Ōhakune and the snow (from left to right) Hannah Janes, Tony Church, Barbara Price, Aron Rastrick, John Tawa, Antoni Brown and Cora-lee McKenna.**

**Above: Cora-lee McKenna feels a drop in temperature.**



## SECTOR

# Old laws on decision-making headed

**The Law Commission is reviewing the legal powers people are given to make decisions for others, something disability advocates say is well overdue.**

The main law covering adult decision-making is the Protection of Personal and Property Rights Act (PPP&R). It dates back to 1988 and affects many in New Zealand's disabled community. It is one of four laws that are coming under the spotlight.

The PPP&R has remained largely unchanged for decades, and disability advocates say it is outdated and leaves vulnerable people open to exploitation. Decisions can be made without consultation and people deprived of their rights and property.

And no-one is monitoring the behaviour of welfare guardians.

The Law Commission wants to know whether these laws strike the right balance between enabling people to make decisions about their own lives – with appropriate support from whānau, family, caregivers, professionals and the wider community – and safeguarding people from harm.

IHC Director of Advocacy Trish Grant is very keen to see the laws reviewed. IHC is New Zealand's leading provider of services for people with intellectual disabilities. "This is the demographic who have the least amount of freedom. Every part of their lives can be controlled," she says.

Trish and fellow IHC advocate Shara Turner

met the Law Commission as it was drafting the terms of reference for the review, and are keen to be involved at every stage of the process.

Trish says it's appalling that parties in Family Court proceedings can make guardianship orders without any understanding of disability rights – including GPs with no training in intellectual disability saying a person lacks the capacity to make decisions because they have Down syndrome.

"We have been disturbed by individual cases we have been involved with who have been subject to guardianship and property management orders. I think it's very timely for us as a country to have a new look at capacity and how that impacts on our laws."



towards disability have shifted, and Aotearoa New Zealand has committed to implementing the United Nations Convention on the Rights of Persons with Disabilities. In addition, as our population ages an increasing proportion of New Zealanders will require support to make decisions about their lives. Further, our law may not be compatible with perspectives in terms of te ao Māori [the Māori worldview], te Tiriti o Waitangi and the rights of tāngata whaikaha Māori [Māori disabled people] and their whānau, hapū and iwi.”

CCS Disability Action Midlands General Manager Colene Herbert has been dealing with these issues while working in the disability sector for more than 40 years – nine of them with IHC as Regional Manager of its former Family-Whānau services in Waikato and Bay of Plenty.

Colene says she has seen harm done. “Absolutely. I have seen families approach organisations wanting to take guardianship of people who have inherited land and property.”

She says sometimes there can also be a major conflict of interest when a family member who is a paid caregiver then also tries to seek control of the finances.

She is concerned that no one monitors the behaviour of welfare guardians. Each application for guardianship lasts three years and she says that is too long. The orders should be reviewed annually.

“There needs to be more checks and balances in place to determine the motives of the person seeking control.”

Colene hopes the Law Commission will recommend that an independent body be set up to monitor the situation. “They need to hear the stories of those who have lived with families and had their Eftpos cards taken from them and their benefits controlled.”

Her family made sure that her older brother Paddy Jones, who had an intellectual disability, was involved in the decisions that affected his life. “My brother passed away



in 2011, but he chose to go into residential care when my Mum passed away. That was his decision.

“Me and my sisters took him around all the residential services. He decided he wanted to go and live at Te Roopu Taurima. He spent the last five years of his life there.” Paddy died there, in Hamilton, at the age of 69.

The Law Commission will conduct public consultation in 2022. In addition, it will work with disabled people and their representative organisations on accessible consultation processes, and maximise the participation of those individuals and communities most directly affected by the law relating to adult decision-making capacity. The Commission intends to report to the Minister of Justice by the end of 2023.

**Left: Outdated laws governing decision-making leave vulnerable people open to exploitation. Photograph: Zach Vessels – Unsplash**

**Top left: IHC Director of Advocacy Trish Grant.**

**Top right: IHC Advocate Shara Turner.**

**Above: CCS Disability Action Midlands General Manager Colene Herbert. Photograph: Gisborne Herald**

## for overhaul

Shara Turner, who will lead IHC’s response to the review, says there needs to be more flexibility and the law must assume as a starting point that people are able to make decisions. “We need to ask what do they need to help them make a decision? We need structures in place that aren’t as formal and rigid as guardianship.”

Law Commissioner Geof Shirtcliffe says the law relating to adult decision-making capacity covers a wide variety of decisions people may face over the course of their lives. “This law affects a significant range of people, and particularly affects disabled communities,” he says.

“Key law in this area hasn’t been reviewed in decades. There have been significant developments in this time. Our attitudes

# Find your ‘bubble inside a bubble’

**Families shut inside in Auckland and Northland have had some online relief during their extended COVID-19 lockdown, with Auckland-based music therapist Ahjay Stelino taking his sounds and skills directly to families with disabled children.**

Ahjay Stelino works with IHC Programmes to offer music therapy. As lockdown dragged on in the north, IHC sent out an invitation to families in Auckland and Northland on the IHC Library database to participate in online music therapy with Ahjay. The sessions started in early September and the first one, for children under 12, was booked out within hours.

The online groups are kept small and children are grouped by age. Families are asked to have a few things handy (a musical instrument, plastic container, rice, dried lentils, silk scarf, bubbles) to use in the workshop.

This is familiar territory for Ahjay. He was online during lockdown 2020, providing free musical interaction for families struggling to entertain young children through a dedicated Facebook channel – now called Awahi Ngā Mātua. This is an online community for parents of tamariki with disabilities and high health needs, set up and supported by IHC Programmes.

Ahjay says nine online workshops have been held since June 2020 – “four of these workshops are in our new online workshop format”. These formats are specifically designed for up to five families and run for 90 minutes each, providing an in-depth and personalised approach to resourcing the families to do music at home with their young people.

He says the format has been particularly successful for children aged three to 10 years. “The workshops have been so successful that we had to add extra sessions to the original plan to cope with the demand.

“The workshops offer a great way to support families while they are at home. It also demonstrates that it is possible to engage children with disabilities and their families through an online medium.”

Ahjay, who has two boys aged five and nine, says listening to music together or playing music together can be a fun, relaxing family activity to add to the day.

“Listening to music individually can allow each person to have their own ‘bubble within a bubble’ where they can escape into the world created by the music they are listening to.”

Ahjay says these are one-off sessions, so the focus is on helping parents with ideas for using music at home, rather than on doing

music therapy sessions with the children.

“With both the in-person and online sessions, I like having the whole family involved,” he says. “Especially important are siblings, as I find that these younger persons are usually very enthusiastic and naturally inclined to want to do music with their brother or sister with disabilities.”

An important aim of the project is to make sure the families keep using music beyond the one-off sessions. The families all receive musical resource packs to help them continue to apply the ideas learnt in the sessions. The packs are handed out at the in-person sessions and mailed out for the online sessions.

The success of last year’s online sessions was the catalyst for the in-person sessions hosted by IHC this year and funded by Wellington Community Trust and Trust Waikato.

**Below: Ethan Wan-Zeng, encouraged by dad Caleb Wan-Zeng, shakes a shaker made at the Hamilton Central Library workshop in May, as Ahjay Stelino plays and sings. Ethan took part along with his twin brother Enoch.**

**Right: Ethan Wan-Zeng lets the music carry him away at the Hamilton workshop. The session was attended by six families, for children aged 12 and under.**









IHC

# New strategy to strengthen cultural opportunities

## A new Māori strategy is giving IDEA Services staff the confidence to explore cultural opportunities with the people we support.

Te Rautaki-Urupare Māori O IDEA Services 2020–2022 has been developed to increase the cultural capabilities of staff and improve the lives of Māori supported by IDEA Services.

The strategy was developed by Te Anga Pāua o Aotearoa, IDEA Services' Māori Advisory Group. Since its creation more than six years ago, the group has been committed to all kiritaki (people we support) and staff having the opportunities and resources they need to understand kaupapa Māori and include it in their day-to-day activities.

"While our mission to achieve best outcomes for kiritaki Māori and their whānau has not changed, our strategic priorities have shifted to give greater emphasis to the cultural capability of our workforce," says Vonny Davis, IDEA Services Regional Manager and Chair of Te Anga Pāua o Aotearoa.

"It's about improving our own cultural practice and promoting ways that staff can build their confidence and understanding of te ao Māori, benefiting the people we support."

Vonny says there are a number of ways we can do this. One way is to make the staff training package more accessible and to give staff more confidence in practising te reo and using their pepeha. She says the group is exploring how to increase cultural competency through recruitment. But most important is the need to encourage cultural practices such as pōwhiri and mihi whakatau to welcome staff, and karakia to open and close meetings. "That practice of karakia is permeating and being modelled by people in leadership positions."

Te Anga Pāua o Aotearoa has already had an impact, providing opportunities and resources. In 2019, an Easy Read book about the Treaty of Waitangi was developed by the group in partnership with Tangata Tiriti – Treaty People. The book is a valuable resource that is accessible to people with intellectual disabilities, created so that everyone can understand their rights, learn and live their tikanga, and advocate for themselves.

Te Anga Pāua o Aotearoa is also behind the widely celebrated regional and national IDEA Services kapa haka festivals, which showcase the talent and tenacity of performers and provide them with opportunities to increase their knowledge of, confidence in and

understanding of tikanga and te ao Māori.

Vonny says Te Anga Pāua o Aotearoa is looking at commissioning research that will identify and promote the benefits of kapa haka that we are already observing.

"The opportunity that has opened up for kiritaki in kapa haka has far exceeded our expectations in the personal growth of performers and in their whānau," says Te Atakura Ryan, IDEA Services Kaitakawaenga and Te Anga Pāua o Aotearoa member.

"It is not only a physical uplifting, moving your body in line with singing a waiata or haka, but it is also a mental and spiritual lifting of a person's wellbeing in every sense."

Looking forward, Te Anga Pāua o Aotearoa will be excited to implement the new strategy, increasing the opportunities for the people we support to learn and engage with te ao Māori, enriching their lives.

**Above: Te Anga Pāua o Aotearoa members and guests at the review of Te Rautaki-Urupare Māori O IDEA Services: (from left) Maia Renner, Keni Waikiri, Teena Harvey, Taki Peeke, Pam Houia-McGreevy, Waata Houia, Georgie Meadows, Lianne Bryers, Te Atakura Ryan, Jan Dowland, Frank Macskay, Stephen Hallet, Vonny Davis, Mary Bradford and Mike Galuszka.**

# Fun send-off for a tough year

**It has been another tough year of lockdowns. And that came as a real blow to those of us who had hoped the worst was behind us in 2020.**

At the start of November, with Auckland still in lockdown, the idea was born to run some online sessions in the lead-up to Christmas so that people could connect, try something new and have some fun.

'Let's give it a go', was launched very quickly says Janine Stewart, General Manager IHC Programmes.

"We had been running some sessions for young families and thought we could extend them out to adults too."

Throughout the past two years our generous donors, members and associations have funded technology in IDEA Services homes and for people living with families to help everyone be better connected during lockdowns.

But that tech also means we can run these online sessions.

"Right from the start there was a great turnout," says Gina Rogers, General Manager IHC Communications. "We had people joining us from school, from day-bases and from their homes, whether it was a group of people supported in IDEA Services or individuals living with their families."

The sessions include music, arts, exercise and drumming and all are relatively short – about 40 minutes – relaxed, informal and fun.

"It's been a win all round and great fun for all of us," says Janine. "The Programmes and Communications teams loved using their skills for this and our presenters are great – they clearly enjoy the sessions and make it easy for people of any ability to be involved."

You can read more about Let's give it a go at [ihc.org.nz/lets-give-it-go](http://ihc.org.nz/lets-give-it-go)

And then, give it a go.



[ihc.org.nz/lets-give-it-go](http://ihc.org.nz/lets-give-it-go)

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# It's your life



**IDEA Services will support you to live the life you want to live.**

To set goals and achieve them - to have great experiences.

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