

StrongVoices

EMPOWERED LIVES

Autumn 2021

**Girl who kicked the
door open**

The bike doctors

**Your child is
beautiful**



Kōrero

Guest editorial

I wish to pay tribute to our former IHC President, Chair and IHC New Zealand Life Member Donald Thompson, ONZM, who died early in February.

It was a great shock to lose Donald so suddenly. He made an enormous contribution to IHC and the lives of people with intellectual disabilities.

But most of all he was a husband, an incredible father and a friend to many of us.

Donald, a former Oamaru farmer, served at every voluntary level of the organisation over 35 years and was widely known and admired within IHC.

He became a member of IHC not long after his daughter, Karen, was born in 1981 with a rare genetic condition and needed significant support.

He was always ready to share their family's experiences with Karen. "It was difficult at the beginning because we had no-one to compare her with, we didn't know what she could achieve. Now we just accept Karen for who she is," he said in an interview in 2006.

Donald said society had to allow people, even with significant disabilities, the right to be heard. "I would encourage parents not to be the limiting factor in their children's development. I'm a great believer in stretching people's ability as much as you can."

Donald was Branch President of IHC for North Otago for 12 years. The branch committee gave many families with a new diagnosis of intellectual disability vital access to camaraderie and support. He remained Branch President until 2001 when the family sold the farm and moved to Wanaka.

Donald joined the IHC Board in 1998 and served on its New Zealand Council for 20 years. He was elected President and Board Chair in 2005.

He stepped down in 2017 and significant contribution was recognised with IHC New Zealand Life Membership. In 2019, he was made an Officer of the New Zealand Order of Merit in recognition of his long commitment to IHC.

He was a director of IHC subsidiaries IDEA Services and Accessible Properties, and a trustee of the Donald Beasley Institute, a disability research organisation. From 2007 until 2017 he was a trustee on the IHC Foundation Charitable Trust.

Donald will be deeply missed as a husband to Gaye, father to Nick, Hamish and Karen, grandfather to his four grandchildren and great friend to many of us. Our thoughts are particularly with his family.

I will miss a great friend who was as generous with his wise counsel as great company.

Ralph Jones
IHC Group Chief Executive

Above: IHC Board Chair Donald Thompson (left) with IHC Chief Executive Ralph Jones at the Annual General Meeting in 2015.

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COVER IMAGE:

Sarah Holten-Warren discovered her voice and opened the way for other young women with Rett syndrome to use eye-gaze technology.

The girl who kicked the door open

Sarah Holten-Warren is under attack from the degenerative neurological condition Rett syndrome and is fighting back using her eyes and her art to communicate.

Sarah, 27, a Māori mixed-media artist, was one of five artists in the Studio One Toi Tū Creative Studio Residency last year. Her exhibition 'Making My Mark', in October, is believed to be the first eye-gaze art exhibition to take place in Auckland.

The impact of her neurological condition means Sarah cannot speak or use her hands for everyday functions. Instead, she uses a head pointer on an adaptive headpiece to create her large-scale, expressive artworks.

Sarah uses a speech-generating device called a Tobii, which works by tracking her eyes. Her point of vision becomes a cursor or 'dwell' on the screen, which selects the language or pictures she wants to use. The Tobii device then speaks them out through voice generation.

"It was the eyes; the understanding was there."

Sarah's Mum Lisa Holten thinks back to how she watched her small daughter, who had learned to walk at nine months, to push a chair up to the bench at every opportunity and was expert in doing three-point turns on her bike, begin to change. She began to lose her language and struggled to hold a spoon. She developed gastric problems and obsessive hand movements.

When Sarah was aged two she started to bite her thumbs repeatedly, and when Lisa sought medical help Rett syndrome was diagnosed. Sarah lost a lot of her fine motor skills by the age of four but was able to walk and run until she was 10 or 11 years old.

Right: Sarah Holten-Warren reconnected with her world through technology and is making plans to develop a business based on her art.

Continues on page 4.



Continued from page 3.

As Sarah's condition progressed Lisa remained convinced that her daughter was still reachable. "It was the eyes; the understanding was there," she says. "There is so much behind them, there is so much expression."

She says for people with Rett syndrome the eyes remain the easiest part of the body to use. "There is a direct neural pathway to the brain."

Lisa says she struggled to have Sarah properly assessed. "They thought she couldn't comprehend." But Lisa believed new eye-gaze technology was a medical necessity for Sarah and convinced the health assessment service to let her try it. "I pleaded with them to give her a trial and they gave me two weeks." Lisa shot a lot of video in that fortnight and it convinced them. "They could see that she was having purposeful conversations and it really opened their eyes," Lisa says.

Sarah started trialling a Tobii device in 2013 and she was funded for her own device in 2014. "She was the first Rett girl in New Zealand to be funded for a Tobii device. Now there are heaps of girls who have followed through with that device. Sarah kicked the door open," Lisa says.

Finally, Sarah got her voice. Lisa discovered that her daughter had a sense of humour and could – and did – have her on. "She does have a lot to say." Lisa says the affirmation that Sarah could understand was a huge breakthrough. "It was concrete proof that I wasn't a 'hopeful mother'. She could say how she felt, if she was hungry or tired, or in pain, or where she wanted to go, or who she wanted to see. Now the locus of communication is under her control."

Becoming an artist

Lisa Holten didn't imagine that her daughter Sarah would, or could, become an artist.

Lisa was caught up in the grind of managing day-to-day services. Like many families dealing with disability funding, she had become focused on services – what was there and what wasn't there.

For the first four years Sarah's Very High Needs (VHN) funding had to be delivered by a Ministry of Social Development (MSD) contracted day programme provider. She could have an individualised activity plan, but it was problematic. Sarah needs continuity in her nursing-level care to manage restricted medications and medical equipment, and her very changeable symptoms.

"Her staff are highly trained. You can't have outside staff coming in for a few hours, a few times a week from a provider. We need her team who work with her the majority of the time," Lisa says.

These staff were already employed through Sarah's other health budgets, but in order to pay them from Sarah's VHN budget they would need to be employed by the provider. That would mean secondary tax, another employment agreement, and a far lower pay rate, which wasn't feasible.

Lisa says the situation with Sarah's provider became very frustrating and they moved her VHN funding under the same umbrella as her other budgets. They could now use the funds not only to pay for her programme costs but also to pay the staff.

"We are with Manawanui as a host. They are basically the middleman between me and MSD and me and MoH and me and the DHB for Sarah's budgets. They invoice the government department funders for our



submitted costs. I manage the budget and help employ the staff. Sarah is the employer and I am her agent," Lisa says.

"This is not for all people. There are a lot of people who can't do individualised funding as it doesn't work for them and what they are wanting in supports. But there has to be choice. There can't be a one-stop shop." Lisa says individualised funding works for them. "For Sarah, this has been the best thing."

Sarah goes to an art class at Māpura Studios every week, and this led to her art residency last year at Studio One Toi Tū. She also meets with a group of young adults at Peers, which offers creative projects, music and dance and living skills through the Physically Disabled and Able-Bodied (PHAB) organisation. She also loves to go swimming and to get out in the community to build relationships and resources and pursue the art and business projects she has in mind, including plans for a solo exhibition and adapting her art for use on textiles.

Above: Sarah Holten-Warren uses a head pointer to create her artworks.

IHC

Community workshops will develop local approach

Close to 50 community workshops will be held by May to develop local approaches to services around the country. This is part of the National Services Review by IDEA Services.

"We recognise that no two communities are the same, and so it is crucial that we understand what is important in your area. Our goal with these workshops is to develop a localised approach for people with intellectual disabilities," says IDEA Services Chief Operating Officer Joan Cowan.

"I'd like to thank everyone so far who has participated in the four workshops held towards the end of 2020 in South/East Auckland, North Canterbury, Hutt Valley, Tauranga/Mount Maunganui and Mana.

Joan says it has been a great opportunity to hear from families about their top priorities and how we can incorporate them into future plans. "We also intend to gather input from people we support and staff."

The groups so far have had the opportunity to create a vision for the future and to develop some goals, including quality of life, friendship, variety, safety and future growth. What has

also been a common theme is enabling people to do things they enjoy and to connect more with their communities.

Each workshop is facilitated by external consultants from Connect+Co and, in most situations, is co-hosted by the local Area Manager and Association Chair.

The ideas will be collected and themes identified, and IDEA Services will then provide feedback to families.

Along with collecting feedback from people we support and staff, we will be developing localised area plans.



We just inched a step closer

IHC

New Zealand just inched a step closer to fully inclusive education for disabled children.

In December the Human Rights Review Tribunal issued a decision – five and a half years late – that it would hear a complaint from IHC that our education system discriminates against disabled students.

The complaint has languished in a queue waiting for a ruling from the overloaded Human Rights Review Tribunal.

The decision was about the challenges to IHC’s claim brought by Crown Law on behalf of the Attorney-General and the Ministry of Education on the grounds of jurisdiction and ‘justiciability’ – in other words whether IHC’s

2014 amended claim was different from the original claim lodged in 2008 and whether the IHC legal action was aimed at increasing education funding.

IHC Director of Advocacy Trish Grant says the Tribunal’s decision to dismiss the Crown’s challenges is great news. “We can now let the human rights experts decide whether disabled students can exercise their right to education free from discrimination,” she says.

“This is a disabled children’s citizenship issue. They shouldn’t have to beg for what they deserve.”

IHC does not point the finger at schools or principals, saying instead that discrimination in the system means schools are not adequately resourced to respond to

individual learning and social support needs.

Now the hard work starts again. Trish will be updating the facts and gathering new evidence to refresh the claim in time for the hearing, which she hopes will be held this year.

IHC’s initial claim was supported by evidence from parents, teachers, principals and others in the education sector; evidence that is now more than five years old. Trish is planning a new survey to gather quantitative and qualitative evidence from students, families, principals, boards of trustees and learning support specialists.

“We will get some updated evidence about the discrimination that is being experienced. What we are saying is that the schools don’t have the capacity or resources to teach disabled students or to respond to disability-related behaviours.”

Trish says IHC’s education complaint may not have yet made it to a hearing, but it has already had an impact in terms of changes in education policy. A new learning support delivery model has been developed in place of the one we have complained about. The Ministry of Education has required schools to set up learning support registers, so it has a better idea of how many students need support. There is a planned review of Ongoing Resourcing Scheme funding, a new Education Support Agency is being developed to better support schools, and the teaching profession has a new Code, new graduating standards and a new focus on developing and supporting school leaders. School boards of trustees are now required by law to report on inclusion.

“The learning register is a positive step and could be an important lever. We will have a clear picture of how many students need support in the classroom. Whether the Ministry will use that data to review and adjust the resourcing framework is another thing,” she says.

“During the 12 years of IHC’s human rights legal action there has been undoubted progress in disabled students’ access to education.”

Despite this, Trish says IHC needs to pursue the legal action because, in 2021, disabled students still experience discrimination on a daily basis due to a flawed policy and resourcing framework and capacity issues across the education system.

“IHC’s founding families wanted their children to access education on the same basis as children without a disability. Seventy years on IHC continues to stand up for fairness and equity. We will not turn our backs on disabled children who are not getting a fair deal.”

Above: Schools are not adequately resourced to respond to individual learning and social support needs. Photo by Nathan Dumlao on Unsplash.

Schools to trial employment service

School leavers looking for work will have extra help this year thanks to a new scheme being trialled in a number of secondary schools.

The pilot Employment Service in Schools was launched on 1 February 2021 and will run until 30 June 2022. It is being managed by the Ministry of Social Development (MSD) and the Ministry of Health (MOH).

It will run in five Ministry of Education regions: Auckland, Waikato, Wellington, Canterbury and Otago/Southland. IHC's Choices NZ has been selected as a provider of the service in Canterbury and Otago/Southland.

Kelvin Moffatt, MSD General Manager Service and Contracts Management, says up to 1000 young people will be able to use the service. It is available to students in their final two years of school and targets those with high needs or very high needs funded through the Ongoing Resourcing Scheme (ORS). Students without ORS funding, but who need additional support to learn are also eligible. This includes students with disabilities, with health conditions or who are neuro-diverse.

The Employment Service in Schools is an alternative to the MSD-funded Transition Service. It is being provided in addition to other post-school services and options for disabled people, including MSD and MOH-funded community participation and day services, tertiary education and open employment opportunities.

Young people interested in participating in the service first need to check if their schools have chosen to be in the pilot. Around 50 schools are participating so far.

Pilot schools will connect young people with contracted providers.

“Work experience is important to help young people understand what will be expected of them in the workplace. Under the Education and Training Act 2020 young people are not entitled to be paid for work experience in school hours; however, employers may choose to pay them,” Kelvin Moffatt says. “If a young person is employed outside school hours, for example after school or at the weekend, it is expected they will be paid.”

The New Zealand Disability Support Network is holding workshops in the main centres for service providers, schools, students and families/whānau to explain how it works.



Schools taking part in the three areas covered by the Choices NZ contract are:

Canterbury – Christchurch Boys’ High School, Hornby High School, Kaiapoi High School, Lincoln High School, Linwood College, Middleton Grange School, Oxford Area School, Rangiora High School, Rolleston College, St Bede’s College, St Thomas of Canterbury College, Te Pā o Rākaihautū.

Otago and Southland – Aurora College, Bayfield High School, Blue Mountain College, James Hargest College, Kaikorai Valley High School, Otago Boys’ High School, South Otago High School, St Kevin’s College, Taieri College, Tokomairiro High School, Waitaki Girls’ High School, Wakatipu High School.

“Choices NZ looks forward to working with families, schools and communities to find employment and real opportunities for these young adults,” says Choices NZ National Manager Toni Griffiths.

Kelvin Moffatt says funding was approved as part of the COVID-19 Budget package. The goal is to increase expectations that young disabled people can and should be entering the labour market when they leave school. The service aims to:

- Promote employment or employment-related training as the first and best option for young disabled people when they leave school.
- Develop work confidence through work experience and paid part-time work outside school hours.
- Collaborate with the students’ existing schools and learning supports to ensure the students’ educational and employment goals are aligned.

Above: The Employment Service in Schools is an alternative pathway to employment. Photo by Clarisse Meyer on Unsplash.

Free ‘plus-one’ bus travel

Free bus travel for carers of people with accessibility concession cards is now available in the Waikato region. Around 2400 people hold concession cards for free bus travel in the area. The card was introduced in 2019 and is for people with permanent or short-term disabilities of longer than six months. Cardholders who need assistance to travel can now register their ‘plus ones’ with Waikato Regional Council.

Wellington Airport smooths the way

People with hidden disabilities such as autism, dementia and ADHD can now travel a little easier after Wellington Airport launched a new initiative to discreetly let staff know when a person might need extra help. Anyone travelling through the airport can now request a special green lanyard, which will help staff identify people who might need extra care. The lanyard is voluntary and will indicate that a passenger might need more time to process information or clear verbal instructions. It will help those who have trouble reading departure and boarding signs, and people who need to stick with family or friends.

Families to view IHC MySupport information

IDEA Services and Choices NZ are trialling an extension of the IHC MySupport database to allow the people we support and their families to view their information. It’s important for the people we support to have a good team around them. A big part of this is involving family members at the right time. At present, information such as support plans and goals can only be viewed by staff. We have asked 40–50 people to take part – a mix of people we support and their family members. The 12-week trial started at the end of January. When it ends we will ask people if they found it useful and whether it’s something they want to continue with. We will let you know the outcome.

New coordinator for i-Volunteering

Belinda Donaldson is our new IHC i-Volunteer coordinator. Her role is to implement an online/virtual volunteer programme to help link carers and people with intellectual disabilities with online friends. Belinda isn’t new to working with IHC Volunteering and for the past several years has been working behind the scenes on annual customer satisfaction surveys and updating the coordinator manual. IHC National Volunteering and Community Development Manager Sue Kobar says this will broaden the opportunities for IHC volunteers to support people with intellectual disabilities.



IHC

It's time for more 'pay experience'

Debbie Kennedy has done years of work experience in hospitality and customer service with little pay to show for it. She estimates half of the work she has done has been unpaid.

Work experience can be a trap for people with disabilities if it never leads to 'pay experience'.

IHC recently tried a new approach to see if Debbie Kennedy, a 24-year-old Dunedin woman, could finally break through the job barrier. Local IHC Volunteer Coordinator Dean Reed worked out a strategy with Choices NZ Facilitator Kaitlyn Brown to not only boost Debbie's employment skills but help her recognise and promote the many skills she already has.

In September, Debbie was introduced to Phoebe Hillyer-Brandt through the IHC skills-based volunteering programme. Phoebe was finishing a master's degree in psychology and looking for a short-term volunteering opportunity.

For four weeks they worked through a plan – money handling, going undercover as

'secret shoppers' to check customer service in retail stores, job interview skills, and visiting a job expo.

In week five there was a dress rehearsal for the job interview, conducted by Dean and Phoebe, and Debbie passed with flying colours. "I would give her a job for sure," Phoebe says. "We wrote some notes about what she did well and a few little things to work on."

Phoebe says Debbie knows her way around customer service, but she says it's one thing to have the theory, but another to be able to apply it in practice and to find the opportunity to talk about that experience with a prospective employer. "It's a matter of confidence."

Debbie says she found the mock interview difficult. "I was nervous on the day. There were hard questions."

She would like a job in retail – "somewhere that is a good environment" – and says she found the skills programme helpful. "It got my confidence back up."

Phoebe has now left Otago to return home to Wellington, but the pair plan to keep in touch. Debbie will now work with Kaitlyn to find work through Choices NZ and Kaitlyn is optimistic. "She will work well in a team – she is a team player," she says. "The plan is to keep applying and advocating for Debbie. Hospitality and retail jobs are no longer entry-level jobs in Dunedin, and it seems employers are only looking for people with paid experience and people without employment gaps."

Kaitlyn says Choices NZ can offer on-the-job support and training to employers who are prepared to invest in Debbie and other Choices NZ clients. It can also advise employers about the funding that is available through the Ministry of Social Development for job support and training.

For more information about how Choices NZ can work with job seekers and partner with employers, see choicesnz.org.nz/what-we-offer/job-seekers

Above: Debbie Kennedy and Phoebe Hillyer-Brandt end their working sessions with some time out.



RESEARCH

Early deaths must be better understood

Researcher Sharon Brandford is keenly aware of the outrage felt in the disability community over the way New Zealand treats the lives and premature deaths of people with intellectual disabilities.

It was her own outrage that led her to look at how we investigate their deaths.

Her report released late last year, 'Counting for Something', says life expectancy for New Zealanders with intellectual disabilities is between 18 and 23 years less than for the general population.

Sharon says she resisted the temptation to plunge straight into what she sees as contributing factors to those premature deaths – too much medication, too few

health checks, late diagnosis and treatment, poor awareness of health issues and failure to promote good health. Instead she wanted to look behind the deaths and suggest how a coordinated approach to recording them might make a difference.

"We've known about the poor health outcomes for years now. The agencies responsible for recording and investigating deaths must be supported to identify ways to improve life expectancy," she says.

"Bereaved families and friends want these premature deaths to count for something."

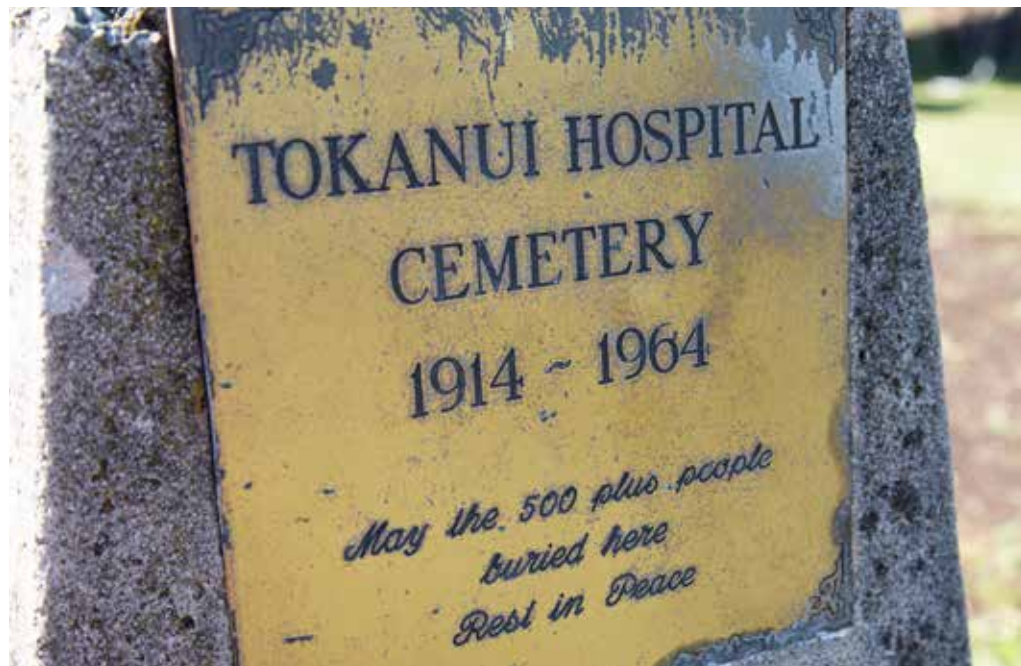
Underlying it all is a sense that the death of someone with an intellectual disability is not a tragedy but 'a release'. "It is just not seen to be a loss when someone with a disability

dies because there is an inherent lack of value," she says.

'Counting for Something' was the second report to come out in 2020 criticising the lack of information about the deaths of these disabled New Zealanders.

The report describes a piecemeal and uncoordinated approach by the Ministry of Health (MOH) and various mortality review bodies and suggests they work together to avoid these premature deaths.

An earlier investigation by the Chief Ombudsman, released in July last year, identified significant gaps in the MOH's collection and use of information about the deaths of people with intellectual disabilities in full-time residential care.



That investigation found that the MOH had not adequately dealt with deaths reported to it by disability service providers, despite its knowing through its own research that people with intellectual disabilities were high users of health services but still had poor health.

Sharon, who has more than 35 years' experience in the intellectual disability support sector, backed the Ombudsman's call for New Zealand to develop an independent national death review system.

She says she felt energised by the Chief Ombudsman's investigation. Her purpose in preparing her report was to increase the visibility of and responses to early deaths, and not just for those in full-time care. Her work has been funded by the IHC Foundation.

She says overseas research shows that people with intellectual disabilities too often die from conditions that can be treated and would not normally be fatal, or from conditions that are not recognised and poorly treated.

"New Zealanders with disabilities want and expect health services to treat them right when they are unwell. Like everyone else, they want to get on with living good and long lives."

She believes more progress will be made if the New Zealand health and disability sectors create a culture of openness rather than blame.

Sharon is keen to have a conversation with the MOH about how to make people with intellectual disabilities more visible in health records and public health data; to better inform families, friends and carers about their options for investigating a worrying death; and how to support the MOH to urgently lead a coordinated response to improve life expectancy. She wants to see action involving not only its Disability Directorate, but also health experts and policy makers in personal and public health.

"I would really like there to be some clearing house where we could put all the information that we have already, so it is more easily shared."

Sharon would also like disability providers to have a common approach to supporting access to health and to investigating death, and to commit to increasing the awareness and skills of the disability workforce.

"With better recording, reporting and investigation, families, people with disability and advocates can push for attention to those factors known to impact on health outcomes."

The IHC Foundation says it is pleased to contribute to this important debate – "in the hope that we will finally see concerted action to address the unacceptable fact that people with intellectual disability are dying younger than other New Zealanders".

IHC Director of Advocacy Trish Grant says the Government now has an opportunity to make this group of New Zealanders count for something after decades of "death by indifference".



"IHC calls on the new Minister of Health, Andrew Little, to ensure health 'justice'. This will require his officials in the Ministry of Health to lead the collaborative work required to stop people with intellectual disability dying too early. These are avoidable deaths in many cases," she says.

Dr Garth Bennie, Chief Executive of the New Zealand Disability Support Network, says this is an extremely timely piece of research highlighting the lack of progress in an area that should be receiving the utmost urgency. "A comprehensive and accessible report, 'Counting for Something', provides a clear pathway for substantial change that leaves no doubt about who should be doing what from this point forward."

Top: For years, the nearly 500 people buried at Tokanui Hospital Cemetery were remembered with a single headstone. Photo by Ascend Photography.

Top left: A memorial wall was finally built in 2016 to list the names of all those buried between 1914 and 1964 at the Tokanui Hospital Cemetery, in a field that lies south of the Waikato town of Te Awamutu. At one time 1000 patients, including many with intellectual disabilities, lived and worked in the hospital. It closed in March 1998.

Above: Researcher Sharon Brandford says a better understanding of premature deaths will help us avoid them.

Webb's Est. 1976



Disabled artists welcomed to the heart of the art scene



Disabled artists came out of lockdown and into the heart of the New Zealand art scene – selling more art than ever before.

Thanks to a brainwave of IHC Art Awards Ambassador Dame Denise L'Estrange Corbet, the three top works in the 2020 IHC Art Awards were auctioned live at Webb's art auctioneers in Auckland, in association with a WORLD Legacy Charity Project event called Artists 4 Artists.

Dame Denise approached 13 contemporary artists to donate works to be sold for the benefit of artists with disabilities. Renowned New Zealand artists Billy Apple, Judy Darragh, Dick Frizzell, Mike Weston and Otis Frizzell, Max Gimblett, Bill Hammond, Paul Hartigan, Gavin Hurley, Gregor Kregar, Judy Millar, John Reynolds, Greer Twiss and Pamela Wolfe all got involved. Their artworks raised nearly \$51,000, all of which goes towards the IHC Art Awards.

Dame Denise says that when all the art studios had to close when the country went into lockdown, she realised there would be no opportunity to access the wonderful works that are usually submitted and sold. She wanted to find another way of raising funds for the artists.

"The event way exceeded what I had hoped for," she says. "Webb's came on board and agreed to hold the event at their premises and auction the works on the last big art auction night of the year, which was just so tremendous, as their reputation put us on the map in terms of art; it gave the event enormous kudos.

"I am so grateful to all those involved – the artists who donated works, Webb's, and especially the public who buy the works."

The works of the three winners of the IHC Art Awards were sold first, ahead of the Artists 4 Artists auction. Palmerston North student Malachi Oldridge, who won the \$5000 first prize with his self-portrait *Malachi is a Māori Boy*, sold his work for \$1057. Michael Nathan won \$2000 for his work *Infinity Part 1*. It sold for \$1233. Gary Buchanan won \$1000 for his work *New Convention Centre of Christchurch*. It sold for \$470.

Most of the remaining entries in the Art Awards were sold on Trade Me. Sixty-nine of the top 89 artworks entered in the IHC Art Awards 2020 were sold to an online public audience.

"We sold a lot more artworks than we would normally," says IHC Art Awards Event Manager Danette Wilson. "We always sell

the 30 finalists' and winners' artworks at the gala event, but we don't sell that many at the national exhibition. So Trade Me definitely worked better. Some prices were high, some just over reserve or just met reserve."

During lockdown the artists couldn't work in their studios. Artworks that they planned to enter were not finished and no-one knew when they would be. But behind the scenes IHC Art Awards organisers were working on a plan to make sure the event went ahead in some form.

"Some of the artists had been working on their artworks for months, so it would have been a great disappointment not to have given people a competition," Danette says.

In 2019, 384 artists entered the national competition. But the impact of COVID-19 had her worried. "When we reached 279, it was a huge sigh of relief and we were really happy with that number," she says.

Left: IHC Art Awards winner Malachi Oldridge, with his self-portrait *Malachi is a Māori Boy*, at Webb's auctioneers.

Above left: Malachi Oldridge with IHC Art Awards Ambassador Dame Denise L'Estrange-Corbet, who arranged the art auction.

Above: Malachi and his family travelled from Palmerston North to the Auckland auction.



IHC

A place to call home for those hardest hit

Last year marked the 10th anniversary of the creation of IHC's property company, Accessible Properties.

Accessible Properties' first day of operation was 1 July 2010, and as IHC Chief Executive Ralph Jones put it at the time, it signalled "IHC's intention to increase its participation in the social housing market and provide accommodation for people who struggle to find somewhere to live because of health or disability issues".

Accessible Properties Chief Executive Greg Orchard says that vision is as true now as it was then. "Our goal, our belief, is to create thriving communities," he says. "Whether that is someone supported by IDEA Services or a family that's been through some tough times financially, we want to give people a place to belong and thrive."

Accessible Properties hit the ground running. From day one, the company

managed more than 1000 properties for IHC. These included – and still do – IHC's day bases and residential homes and units.

"The people IDEA Services supports are extremely important to us," says Greg. "We are very proud of our homes and facilities that keep people safe, happy and healthy."

Accessible Properties' growth has been spectacular. Support from the Government's Housing Innovation Fund in its first year



allowed Accessible Properties to build housing units in Hamilton.

The following year, Accessible Properties was the most successful applicant to the Social Housing Fund, allowing a \$23 million programme to build 67 new housing units for social housing in Auckland, Hamilton, Tauranga, Wellington and Christchurch.

Within three years Accessible Properties was managing the largest non-government housing portfolio in the country, with 870 homes. More than 4000 people with intellectual disabilities were using IHC premises.

In April 2014, Accessible Properties achieved Community Housing Provider registration, providing access to income-related rental subsidies. That meant the rent subsidies that used to be available only for Housing New Zealand properties now applied to homes provided by Accessible Properties.



Accessible Properties was the successful bidder for the purchase of the Hamilton City Council housing for older persons' portfolio and took possession of its 344 homes in March 2016.

In December that year, Accessible Properties entered into an agreement with the Government to provide 358 of the 508 social housing homes to be made available in South and West Auckland.

By the end of the 2016 financial year, the value of the property portfolio had grown rapidly to more than \$100 million.

Partnering with Lifemark Standards meant properties were adaptable for people with disabilities and situated and grouped in ways that fostered community inclusion.

But the biggest growth for Accessible Properties came in April 2017, when it formally acquired and began managing 1138 former Housing New Zealand homes.

In October, Associate Housing Minister Kris Faafoi opened the first development of six homes in Tauranga – part of Accessible Properties' plan to help address the chronic Tauranga housing shortage.

Accessible Properties wants to replace 140 former state homes in Tauranga with more than 400 new townhouses and apartments, as part of its Pukehinahina Project.

"The need for social housing is not going away – it's greater than ever. In Tauranga especially, there is immense pressure," says Greg.

"We know that places stress on older people, single-income households and poorer families. We are committed to working with Government to find solutions and homes."



To support tenants, Accessible Properties works closely with agencies, councils, New Zealand Police and iwi to ensure properties are safe and tenants well looked after.

That's reflected in annual tenancy surveys, which show overwhelming satisfaction among tenants.

Greg says: "Ten years is a significant milestone, but we are committed and looking forward to working with IDEA Services and the IHC Group for many more years to come."

Top left: Tenants, volunteers and Accessible Properties staff pitch in for Clean Up Week 2019. Keeping neighbourhoods safe and clean helps tenants and communities to flourish.

Top: Housing Minister at the time, Phil Twyford, attends the opening of five new homes for people with disabilities in Massey, Auckland in 2018.

Above: An upgrade at Peachgrove Road in Hamilton in 2016 gave tenants in the 22 units gardens, picnic tables, and a place for a barbeque.

Tenant Raymond Holloway poses for photos at his new home in Cameron Road, Tauranga, in 2019: "It's given me a new lease of life."

We're spending too long 'getting ready'

David Corner has spent 12 years representing people with intellectual disabilities internationally. He has spent 24 years promoting their rights in New Zealand.

But when the bathroom in the house he owns was renovated last year, he didn't get to choose the paint, or the vinyl that went on the floor.

David, IHC National Self-Advocacy Adviser, recently gave presentations about self-advocacy at Regional Focus Groups in Auckland, Hamilton, Kāpiti and Christchurch to encourage people with disabilities to speak up about how they want to live their lives.

This was the second round of Regional Focus Groups organised by the IDEA Services Quality Team.

"It's important to speak up about the things that are important to you," he told participants at the Kāpiti forum. "IDEA Services needs to hear back from you about what is working well for you in services and what needs to be improved. It is the staff's role to help you make the choices."

He fears that people's confidence can be easily eroded. "We don't give them confidence. We set them up to fail," he says. "There is a 'readiness trap' sometimes. 'You are not ready to go flatting. You are not ready to go and talk to such and such.'"

David asked those at the meeting whether they answered the phone in their homes and were able to choose what they ate or what television channel they watched.

He reminded them that it was their right to have support to make decisions, but people sometimes confused the line between acting in someone's best interests and allowing



them to exercise their will and preference, which was a right protected by the United Nations Convention on the Rights of Persons with Disabilities.

David, who lives at home supported by another service provider, told of the time a new team leader turned up at his house unannounced. "My support worker didn't let me know he was coming until two minutes before he turned up – and it was my house."

He said last year he was planning a party and saw emails between two people asking if his house was accessible. "It's my house, but no one asked me if my house was accessible."

As far as his bathroom renovation went, David acknowledged that he did get a photograph of the chosen vinyl sent to him, but said he had no opportunity to have input.

In November, David signed off from his job as Asia-Pacific Regional Representative for international disability organisation Inclusion International. At his final meeting he was awarded life membership for his service.

It was a role that took him around the

world – to Florida, Germany, Nepal, Washington, Portugal, Spain, Suva, Thailand, India and Australia.

At meetings and conferences David participated in brainstorming sessions about the issues facing people with intellectual disabilities in all parts of the globe and was able to contribute New Zealand's and his own experiences to the mix. "It's all about listening, including and respecting and valuing the people with intellectual disability," he says.

Helen Sinclair, IHC's National Manager Quality, says David delivered some important self-advocacy messages at the meetings. "His views prompted some great discussions with participants about what good support looks like and the ways people can speak up and be supported to raise issues that matter most to them." The Quality Team intends to share the views of the focus groups throughout the organisation and to get more people involved in 2021.

Above: David Corner, IHC National Self-Advocacy Adviser, says self-advocacy is about listening, including and respecting and valuing people with intellectual disabilities.



VOICES

Try this one at home

Just pull the curtains and your lounge becomes a stage. Tear an old white sheet into moonbeams. Then find a soft, fluffy jumper to be *The Badger*.

Now you are ready to hear, see, touch, taste and smell *The Badger Story*. This is new digital, multi-sensory theatre delivered online by the Glass Ceiling Arts Collective to people with profound and multiple learning disabilities.

It's a COVID-inspired, in-home theatre experience for families who supply their own props from the cupboard, supermarket or \$2 shop. It was developed with funding from the IHC Foundation.

The process of gathering the props is part of the whole experience. *The Badger Story* comes with instructions about how to get the best experience for participants as they use all their senses and involve all the family.

"For me, going out into the forest and finding leaves and playing with grass is an exciting thing in itself. Even my son, who has autism, it was an exciting process for him," says author Charlotte Nightingale. Charlotte, a teacher and actor, is Co-Founder and Artistic Director of the Glass Ceiling Arts Collective.

The crew ventured into the trees near Charlotte's home with a binaural microphone specially imported from Canada to record 3-D stereo audio for more lifelike sounds.

The Badger Story is an excerpt from Charlotte's play, *The Incredible and Glorious World According to The Fitzroys*, which won Best Performance (Ensemble) at Auckland Fringe last year.

It is the story of a teenager with autism who finds the outside world tricky, so he creates an incredible world at home. The Badger narrative is about navigating friendship. It is performed by an inclusive cast – of people and live action, animated characters and puppets. The giant badger was made by Tusk Puppets in Christchurch and Deaf actor Courtney Nairn is the screen goddess.

Co-founder and General Manager of Glass Ceiling, Mike Eaglesome, says *The Badger Story* was born out of COVID. He says those with high health needs were even more vulnerable during lockdown. Even at the best of times, going out to the theatre is beyond the reach of many. *The Badger Story* brings theatre into their world.

"*The Badger Story* was initially conceived to address the needs of a New Zealand audience. However, given that it is delivered as a digital experience, the audience can be anywhere." Mike says New Zealanders out and about on their summer holidays were not so much in need of an indoor theatre experience. "Meanwhile, in the United Kingdom it's winter and they're in COVID lockdown and the demand is much more apparent."

Mike says they have already had good feedback from Britain. A mother of twin daughters with a rare genetic condition and high needs, said she was working hard to find a variety of meaningful experiences for them while they were shut in.

"It wasn't too bad when the weather was nice during the summer and we could do



a lot outside, but during the winter any online-appropriate activities have been a godsend. The days are very long as the girls cannot easily occupy themselves. I am exhausted being entertainments manager.

"D... liked the dough, the foliage, the fur and the water spray. R... enjoyed each sensory experience but loved the lights and torch activities. We also used our bubble machine for the mist as the girls really love it and also had our light machine for the rave at the end."

Mike sees the theatre experience evolving as families join in. "It also makes me think about our next theatre experience for people with high health needs, and what we can do better/differently to make the user experience even better.

"If any of your IHC members/whānau are particularly keen to embrace *The Badger Story* and give detailed feedback, we'd be really interested to hear from them."

Top: Puppeteers Jon Coddington and Paul Lewis from Tusk Puppets.

Above: Writer of *The Badger Story*, Charlotte Nightingale, smells the fragrance of the forest floor. Photos: Tom Grut.

Bike repair shop has the answer

You can't get a greener, more sustainable scheme than the Bike Project, run by the bike repair guys at Mersey Street, Invercargill.

The team at the IDEA Services day base collect old bikes, fix them up and pass them on to people who need them.

They recycle and reuse bikes that would otherwise go to the landfill, encouraging people to use pedal power rather than motor vehicles. They also hope to gain skills that might lead to future employment.

Service Manager Jo Fredericks-Rizzi says the Bike Project started in 2011 as a joint venture between IDEA Services, Bike Doctor Tony Tresidder, who operated a voluntary bike repair and hire service in town, and the Invercargill Environment Centre. The most recent donation was 17 bicycles to pupils at Fernworth Primary School, just before Christmas.

Since 2011, around 450 bikes have been restored and donated to school children, local charities and support services, community groups, church groups, Workbridge clients and refugee families.

"IDEA Services developed the project as an opportunity for the people we support to learn to repair and maintain bikes with a view to using these skills to earn a wage," Jo says. "The project aims to build technical ability, teamwork skills and work confidence and to provide free recycled bikes to the local community."

Before lockdown the team worked for two days a week on the bikes. It's now operating one day a week, with up to six people working on the bikes. One of the team, Mark Cook says he enjoys taking the bikes apart and has become expert at stripping them down.

Tony says there are many tasks for people to get involved in. "They learn to use tools, strip bicycles, sand down bikes and paint them back up. We accept everything from wee bikes for kindy kids."

If a donated bicycle is too far gone, they cannibalise it to repair other bikes. "We have got plenty of boxes of parts and tyres and tubes and reflectors. I have got too many parts," he says.

Tony often puts on the finishing touches. "I have done it all my life. I have done bikes ever since I was a wee kid," he says.

Tony has plans for even bigger and better things this year, starting with a new name – Ride Again Cycles – and the launch of a website. "It's got to be done. Cycling is a big part of everything now – the way the world has gone."

Jo says as more schools become involved in learn-to-ride-a-bike programmes, they will get in touch to see if they can help with providing a pool of bikes for the children to use at the schools.

"We have been approached by agencies such as WINZ, Red Cross, Workbridge, local Māori support service providers, Family Works, and Women's Refuge on behalf of their clients, and also directly by some individuals who are experiencing periods of hardship and would benefit from a bike to get to work or a job interview.

Support worker Hayden Anderson-Brown says that after Fernworth Primary School made the local newspaper, four people got in touch offering bikes and another four asking for bikes.

Below: Bike repair man Mark Cook has become expert at stripping down old bicycles so the team can get to work on them.





‘Your child is beautiful’

Shelby is the youngest of the five Porowini kids and his arrival upended their family life. But being told he was beautiful made all the difference.

Stephanie Porowini and her husband Mark were living on the Gold Coast in Australia with their four children. She was selling real estate when she became pregnant with Shelby and they headed for home in Whāngārei. That was in 2016.

“He was unexpected, but he is a blessing and he is amazing,” Stephanie says. “We found out he had Down syndrome when he was first born. We knew he had a heart condition, but we did not know anything else.” Shelby was also born with a cleft palate and he has trouble with choking and keeping food down. A scan showed he had two holes in his heart – he has surgery scheduled at Starship Hospital in February for a repair.

“I had severe post-natal depression after he was born. I didn’t bond with him straight away. There were all these little complications that he had. It just became really overwhelming,” she says. “There was a lot to deal with, with my other four kids.”

Stephanie says she didn’t feel supported by health and disability professionals.

But when Shelby was three months old the family were assigned an outreach nurse who changed that. “She said, ‘Your child is beautiful’. She just clicked with us straightaway. Ever since then we just never looked back.”

Stephanie is now helping to make sure other families have a better experience. She is one of a group of mothers who meet in Whāngārei each month to offer each other support over coffee. “Sometimes we get mums who come along and tell their stories and sometimes they cry,” she says.

More recently they have been meeting representatives of the Child Health Centre at Whāngārei Hospital to identify gaps and ways to improve services to families, who experience long waits for assessment and treatment and poor communication.

The mums’ group was initiated by IHC Family Liaison Jim Callaghan to identify the needs of families. “All the stories were different and the pathway for all of them had been completely different,” he says. “The consistent thing was the lack of consistency.”

After an initial meeting late last year with a multi-disciplinary team from the Northland District Health Board’s Child Health Centre,

a follow-up meeting was held with the community nursing team. “Other health professionals will follow. It’s taken on a life of its own,” Jim says.

He says it’s important that outreach nurses are the right fit and parents aren’t overwhelmed with offers of services all at the beginning, but at different times as needed. “I am really happy that the families are being heard.”

Martina Ackermann, Quality Facilitator at the Child Health Centre, says the initial meeting was to get a parents’/patients’ perspective. “The feeling of not being listened to seems to be a common theme, also having to repeat themselves – every different health professional they come into contact with is asking them the same questions,” she says. “The aim of this is to have a consistent approach for all children who come through our service so everybody gets the same offering, the same support and the same information about where they can go to get support.”

Above: Shelby Porowini is going from strength to strength.



IHC

Charlie's lifetime crusade is over

Charlie Waigh was a lifetime crusader for his daughter Christine and for people with intellectual disabilities throughout the country.

Charlie died in Auckland on 9 November 2020 at the age of 96, after working for 50 years with IHC.

It was a personal crusade at first. Charlie and Mary's daughter Catherine was born in 1961 with Down syndrome. They were living in Takapau in southern Hawke's Bay when Catherine turned five, and there were no services for her. Charlie set out to change that.

Charlie's story traces the milestones of IHC – from the early pre-schools and occupational centres to special schools and institutions, then the closure of institutions.

He acknowledged that some of the changes were painful. In 1972, he and Mary were persuaded by a social worker that Catherine should leave Kingswood Special School and go to Mangere Hospital & Training School, which had recently opened. But Catherine struggled to adjust.

Charlie wasn't a person to sit back and wait for other people to help. He was one of a

breed of do-it-yourselfers in IHC who built our services from the ground up. In New Zealand's small towns in the 1960s there was little support for families who had a child with an intellectual disability so Charlie and others would get IHC branches going wherever they happened to be.

Charlie was a postmaster and moved towns with his family every couple of years. This meant the family often had to start from scratch to provide for Catherine. He helped to set up the Central Hawke's Bay sub-branch in 1966, the Pahiataua sub-branch in 1968 and the Manukau sub-branch in 1974. After their move to Auckland, most of his work for IHC was in Manukau, Papakura and Counties. He was chair in Manukau for six years and Branch President of Papakura for 16 years.

Charlie retired from the Post Office in 1980 at the age 56, after 43 years of service. He didn't retire from his voluntary role with IHC until 2016.

In a 2010 interview, a year before he was named a New Zealand Life Member of IHC, Charlie said he was only doing what many parents were doing throughout New Zealand at the time. "You might say I was in the right place at the right time. We had to do something to get those facilities."

When the role of IHC branch committees changed and they had less to do with property and services, Charlie saw a new important role in providing advocacy on behalf of people with disabilities both within IHC and in the community.

When Charlie eventually retired after 50 years of serving on IHC committees, he made one condition. If the IHC Counties Association was going to put on a lunch for him he didn't want any speeches. With characteristic humility, he said that he was just one of many people in many communities trying to improve services and lives for their children with disabilities.

His daughter Theresa says he was a gentle person with a deep faith, and Catherine enjoyed accompanying him to church each week. He loved talking with a friend over a glass of wine.

Mary died in 1998. There were five daughters: Theresa, Catherine (deceased), Jeannie, Mary and Linda (deceased). Catherine, who lived in IHC residential services for many years, died in 2013.

Above: Former IHC Board Member Michael Quigg (left) with New Zealand Life Member Charlie Waigh at the IHC Annual General Meeting in Wellington in 2015.



VOICES

Lily takes the lead

Actor Lily Harper is riding the wave of success in her first leading role and planning to do it all again in a Wellington season of *Up Down Girl* at Circa Theatre.

Up Down Girl is about a young woman with Down syndrome getting ready to leave home for the first time and her mother's hilarious perspective on bringing her up.

Its first season at Palmerston North's Globe Theatre last year sold out. "I felt great about that and I wanted to show the world that people with Down syndrome can do the same things that they can," Lily says.

Lily, from Palmerston North, has a passion for performance and she believes it's possible to change attitudes – "When you do something that you believe in, when you do a show and want to show people what you are capable of".

She works hard to live in the character of 19-year-old Mattie, who likes to escape into a world of fantasy and superheroes rather than concentrate on packing her bags. Lily and stage mum Trudy Pearson dominate the show. They have developed a strong relationship, and each has been nominated for Best Female Actor in the Regional Theatre Awards. Lily has also been nominated for Emerging Performer.

Producer/Director Nathan Mudge says Lily immerses herself in her character – to the extent of calling Trudy 'Mum' on and off stage – and this provides depth and understanding to the performance. "The work that Lily does on stage is absolutely

stunning because she will listen to songs that remind her of her character or watch DVDs that remind her of her character."

Up Down Girl was originally written as *Up Down Boy* by British writer Sue Shields. Nathan adapted the play for a New Zealand context and interlaced it with songs, dances and drama skits.

The Wellington production will be fully accessible with audio description, sign interpretation and relaxed performances.

Lily urges everyone to come – "Because this is a message for everyone who was born different. Parents will be interested in this play because it's a play about parents and a child".

Up Down Girl is on from 20 April to 1 May at Circa Theatre, during the school holidays. For more information see circa.co.nz.



Lily Harper and 'Mum' Trudy Pearson

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