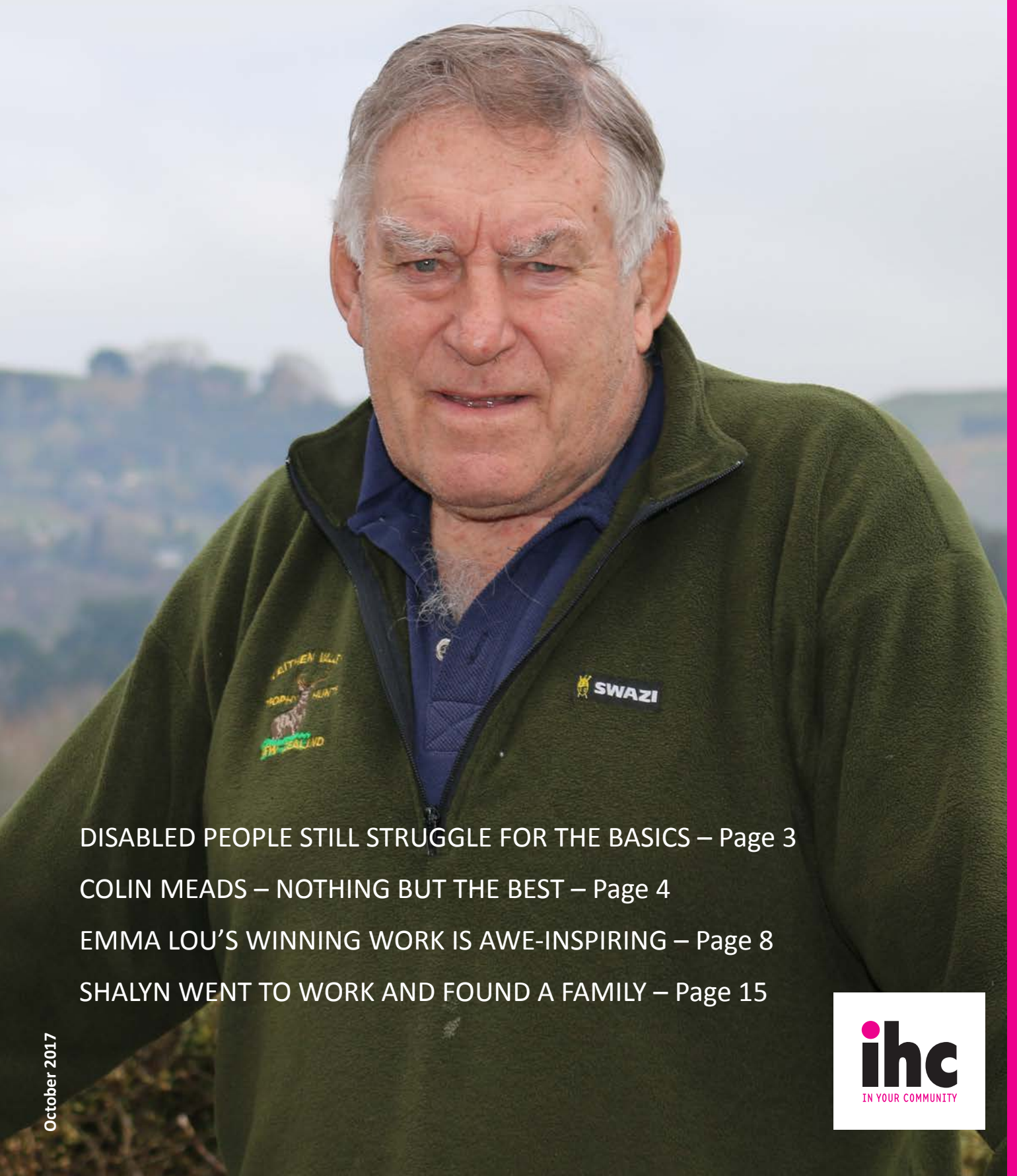


Community MOVES



DISABLED PEOPLE STILL STRUGGLE FOR THE BASICS – Page 3

COLIN MEADS – NOTHING BUT THE BEST – Page 4

EMMA LOU'S WINNING WORK IS AWE-INSPIRING – Page 8

SHALYN WENT TO WORK AND FOUND A FAMILY – Page 15

Personally speaking

Early in September we held our Annual General Meeting. This is always a great get together where we acknowledge the achievements and changes in the previous year and look ahead to the future.

This year saw a change to the Board Chair of IHC New Zealand. I'd like to take this opportunity to pay tribute to Donald Thompson who has held the roles of President or Chair since 2005. Donald has also served on a number of Board committees and associated Trust boards over the years.



I am delighted that Neil Taylor has been appointed as our new Board Chair. Like Donald, Neil has had a long commitment to IHC dating back to the '80s. Neil has served on our Board and Board committees for a number of years and has been active in the South Taranaki community. I invite you to read more about Neil on page 6.

We held a number of workshop sessions at the AGM around the changing funding environment with the Ministry of Health's 'systems transformation'. We also discussed the increasingly complex needs among the people we support. We do not believe government funding will be enough to give people with intellectual disabilities and autism the lives they deserve.

How do we fit into this? What support will people need? What services will they seek from IHC and how can our community programmes align even better to complement services? You can read more about these sessions on page 14.

Of course there will still be those who want or need support around the clock. We now support 600 people with a diagnosis of autism, many with mental health issues or addictions, many with significant physical health challenges, increasing numbers of people reaching older age, and more than 150 people who have intensive wraparound one-on-one services, sometimes with up to three staff.

Accordingly we are looking at the need for specialist clinical skills and greater support for frontline staff. We must still ensure people can grow old in the community, just as we expect to. We need to consider partnerships and make the most of our property expertise so that people can have the best.

We have a strong history of community support and our fundraising continues to bring in donations that allow us to go above and beyond what is possible through government funding.

We have some important conversations ahead of us – but I am reminded that these occasions also give us a chance to celebrate – to celebrate where we have come from, what we have achieved and that we are in a great position for what is to come.

Ralph Jones
Chief Executive

Disabled people still struggle for the basics

Having an intellectual disability leaves many Kiwis open to a life of struggle – for education, good health-care and above all the ability to earn money.

A major IHC survey in July has revealed that around 80 percent of disabled people and their families do not have enough money for food, clothing, bills and transport – let alone for going out, holidays, celebrations or paying for additional disability costs.

More than 650 people responded to the survey. They included disabled individuals, their families and supporters, and those who work in the sector. What they say paints a bleak picture of Kiwis battling for equal treatment with the rest of the community.

About three-quarters of respondents think students and adults with intellectual disabilities do not get the right support to enter the work force – 75 percent feel the country is stuck or going backwards in getting students into work and 80 percent think adults are being shut out of employment.

The Government's labour market statistics for the June 2017 quarter recorded that 11.4 percent of disabled people in the labour force were unemployed, compared with 4.5 percent of those without a disability. The employment rate for disabled people was 22.4 percent, while it was 69.3 percent for those who were not disabled.

This is the first time Statistics NZ has collected annual data for people's disability status in the Household Labour Force Survey.

"There is little real work on offer for people and so they are stuck on low incomes and all that it means in terms of housing and living options," said one person surveyed. Another commented: "Not all of them want to be trolley boys or girls. They want other meaningful work options and volunteer work options too."

Most people said New Zealand is regressing or stalled on education for people with intellectual disabilities. Education for adults was highlighted as a particular problem, with 74 percent saying New Zealand was stalled or the situation was getting worse. Sixty percent thought things were getting worse or stalled in children's education. "I constantly feel like I'm battling to get a good education for my child. My child goes to school to be educated not babysat," one parent said.

Nearly half of respondents told us healthcare for disabled children is making progress. But this is offset by more than half of respondents saying healthcare is stalled or worsening for adults.

IHC Director of Advocacy Trish Grant says opportunities for a good life – or even a fair life – are limited in a multitude of ways and government support is not responsive to individual circumstances and does not deliver fairly.

"It's nothing less than discrimination," Trish says. "People with intellectual disabilities continue to face unacceptable barriers undermining their quality of life and citizenship."

"Families feel worn down by the difficulties accessing support for their children and they worry that access to support will be even harder in the future," she says.

CONTENTS

- 3 Disabled people still struggle for the basics
- 4 Colin Meads – Nothing but the best
- 6 New IHC Chair continues longstanding support
- 7 I'm a citizen too, questioners tell candidates
- 8 Emma Lou's winning work is awe-inspiring
- 10 Inquiry into abuse is the best way forward
- 11 Friends break through the communication barrier
- 12 IHC Foundation funds new ASD research projects for children
- 14 Members discuss challenges facing services
- 15 Shalyn went to work and found a family

**CHECK US
OUT ON
FACEBOOK**



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, VIEWS AND BOOK REVIEWS FROM THE IHC LIBRARY.

WE'D LOVE TO HEAR FROM YOU.

**SO JOIN THE CONVERSATION.
FACEBOOK.COM/IHCNEWZEALAND**

COVER IMAGE:

Rugby great and King Country farmer Colin Meads was a firm friend and supporter of IHC and people with disabilities for more than 40 years. See story page 4.

Colin Meads – nothing but the best



Colin Meads with Isaac Lyons at the IHC Calf Scheme's 25th birthday at the Tarr Road Farm in Cambridge in 2009.

Colin Meads, who died on 20 August this year, never stopped looking for ways to make life better for people with intellectual disabilities.

IHC was privileged to have the support of the big man from 1974. He was a man who was generous with his name and his fame, driven by a strong belief that people with intellectual disabilities deserved the best. He believed that as a former All Black, with the opportunities he had been given, he had a responsibility to lend a hand where he could.

The legendary 'Pinetree' Meads played 133 matches for the All Blacks between 1957 and 1971. He was on our team for 43 years.

Colin threw his weight behind IHC after he stopped playing rugby. In 1974 he announced he was taking a two-year break to spend some time with his wife, Verna. An IHC delegation from IHC in Hamilton saw their chance and turned up to the Te Kuiti farm for tea and scones. By the time they left,

Colin had agreed to head up a newly formed King Country sub-branch.

"I said then I would give you two years. Within two years I was on the National Fundraising Committee," Colin said in his last interview with *Community Moves*. The two-year deadline came and went.

"We were going through the process of getting people away from the big institutions and out into the community," he says. Residential homes were soon established in Otorohanga, Taumarunui and Te Kuiti.

He often spoke about one young man from Kimberley Hospital in Levin who became his friend. "Dean Walker had been there since he was five." He was 15 or 16 when he left the institution to live in Te Kuiti and he became part of the community. "It was the greatest move. Deano became part of the Waitete Rugby Club, so one thing led to another."

Colin put his money where his

mouth was. Rugby in those days wasn't professional and there were rules around fees. So Colin and the IHC branch set up a special account into which he donated the proceeds from his many speaking engagements. In 1988 this money went towards buying a farm in Te Kuiti for people with intellectual disabilities. The idea was to provide employment and teach farming skills and it became home to Dean and other men with disabilities for many years. The 4-hectare smallholding called Pinetree Farm is still owned by IHC and used as accommodation for people with intellectual disabilities.

He remained concerned at the lack of employment opportunities for young people with disabilities and recalled the pride when someone got a job. "I can remember the thrill of some of them getting their first pay. That was theirs; they were going to bank it."

Lately Colin had suggested to the IHC King Country Association that

it might be time to move on, and arrangements are being made to sell the farm and reinvest the money in housing improvements in the King Country for people in IHC residential homes.

Colin was knighted in 2001, but didn't use the title 'Sir'. That would have set him apart. He was more comfortable kicking a ball around with a young disabled rugby player or standing for long hours at Mystery Creek Fieldays, whipping up support for IHC among his fellow farmers.

Colin was a natural fundraiser and backed a number of ingenious farm-based fundraising schemes. He bought a horse each year at the yearling sales, and he and IHC supporters sold raffle tickets around the district for \$10 a go. They raised between \$110,000 and \$120,000 a horse. Colin also supported farmers Norm Cashmore, from Taranaki, and Mick Murphy, from Marlborough, who started the IHC Calf Scheme in 1983. They encouraged dairy farmers to raise a calf and donate the proceeds to IHC in exchange for a pair of gumboots.

"I used to praise up the farmers. In those days you would get \$90 for a calf – you get a lot more than that now," Colin said.

When the farms got bigger, Colin told the large herd owners to think about donating even more

calves. The IHC Calf & Rural Scheme is still going 33 years later and it raises more than \$1 million annually for people with disabilities.

When Colin was made a Distinguished Companion of the New Zealand Order of Merit by Governor-General Dame Silvia Cartwright in 2001 "she said this is not just for your rugby, this is for your work with IHC also. I was quite proud of it to be honest".

In a 2008 interview with the Ministry of Social Development's *Rise* magazine, Colin argued for comprehensive IHC funding to provide services for people with intellectual disabilities.

"They're all our people. They should have the best of everything in life, rather than us. And it should be us that provide it for them."



Colin with Botting, first prize in the horse lottery 1983 – NZ Herald



Colin and Verna at home in Te Kuiti.

When Colin and Verna retired from their farm they moved to live in the Te Kuiti township, with three of their five children nearby. They have 14 grandchildren and four great-grandchildren. On his 81st birthday on 3 June 2017 Te Kuiti unveiled a statue to him.

Colin was a supporter of the IHC Calf Scheme from the start and its patron since 2002. He was also a New Zealand Life Member of IHC. "While Colin is best known for rugby, to us he is one of a small number of distinguished IHC New Zealand Life Members recognised for their significant support for people with intellectual disabilities," says IHC Chief Executive Ralph Jones.

"Colin and Verna have always worked as a team in their dedication to IHC's cause and accordingly have made a huge difference to the lives of so many people with intellectual disabilities and their families." IHC pays tribute to Colin – our friend and supporter for so many years. Our thoughts and the best wishes of the many people associated with IHC New Zealand are with Verna and their family.



Colin and Andrew Sirl at Pinetree Farm in Te Kuiti in 2012.

New IHC Chair continues longstanding support

Neil Taylor has taken over from Donald Thompson as Chair of the IHC Board, continuing his long commitment to this organisation.

Donald retired at the IHC Annual General Meeting in September, after nearly 20 years on the IHC Board, and has been awarded a NZ Life Membership.

When Neil became involved in IHC in the early '80s, he joined a team of parents in South Taranaki who raised money tirelessly to provide the services their disabled children were missing out on.

Neil did not have a child with a disability, but he joined forces with those who did to make lives better for families.

“Working in the field of intellectual disability as a volunteer has been incredibly rewarding for me and my family for the largest part of my working life,” Neil said last year when he was reappointed to the IHC Board. “Joining IHC was for me an opportunity to give something back to the community and to be part of an organisation that upholds strong values and a commitment to enhancing the lives of people with intellectual disability.”

Neil was South Taranaki Branch President from 1986 to 1996. He has also served as IHC Vice President, and on the Board of both IHC and Accessible Properties Ltd, chairing the Audit & Finance committees of both organisations. He is a Chartered Accountant and Fellow of Chartered Accountants Australia and New Zealand. In 1998 he was made a NZ Life Member of IHC.



From left: IHC Chair Neil Taylor and retiring Chair Donald Thompson.

"Joining IHC was for me an opportunity to give something back to the community."

The South Taranaki Branch, founded in 1959, went into recess this year finally acknowledging the fact that fewer people these days have the time or the inclination to serve on committees. Speaking at the time, Neil put it down to time-poor families, rather than lack of support for people with intellectual disabilities.

Most of the members of IHC in South Taranaki were parents of children with intellectual disabilities. “Their intellectually disabled children have become adults now and everybody just became too busy with their lives. What was happening was that new young parents of disabled children didn’t want to be on committees. I think it’s all about the two-income family. Everybody is working,” he said.

A challenge now facing the organisation is the future role of the IHC Associations. “The Member Council is very enthusiastic and it may give

people who want to get into governance an opportunity to do that,” he said.

Donald was first elected to the IHC Board in 1998 and was elected President in 2005. Since 1998, there have been a number of key changes to the organisation, including a change from a 52-member New Zealand Council to an 11-member IHC Board in 1998.

In 2008, after a drop in the number of branch committees and the difficulty in attracting new members, votes were assigned to individual members rather than branch delegates. Then in 2015 the IHC Board was reduced from 11 members to eight with the roles of President and Vice President disappearing. Donald remained as Board Chair. At the same time a Member Council was established to connect members more closely with the organisation.



People with disabilities make their presence felt at an IHC election forum in Wellington.

I'm a citizen too, questioners tell candidates

With the election over, people with disabilities are waiting to see if anything comes of the promises they were given during the campaign – promises to increase benefits, jobs, education opportunities and provide easier access to good housing and health care.

At an IHC election forum in Wellington, they were promised a culture change at Work and Income so they could be told about all their entitlements, did not have to keep proving that they still had a disability to keep their benefits, and didn't face losing their benefits if they moved in with a partner.

They were also promised better access to information and the places they needed to go.

Four candidates – Greens' disability spokesperson Mojo Mathers, Labour's finance spokesperson Grant Robertson, NZ First Rimutaka candidate Talani Meikle and National's Wellington Central candidate Nicola Willis – heard from people with disabilities that they were struggling in almost every area of life.

Disability advocacy group People First New Zealand, Nga Tāngata Tuatahi members kicked off the questioning by reminding candidates that they were citizens too.

"I'm a citizen too and I need money to live, just like everyone else," Ally Moore from People First told the candidates. "Many disabled people spend all their adult lives on a benefit and don't have enough money to live on. They have to choose between having food and going to the doctor."

"I am a citizen too and I want to get a job. Many workplaces will not give me a chance," Jenna Maguren told candidates.

Labour and the Greens told the audience they would increase supported living payments for disabled people and support accessibility legislation.

NZ First promised to extend the SuperGold Card scheme to people with disabilities so they would be able to access the same or similar transport benefits and other discounts.

National said its Employability Programme was

a success and promised to work alongside employers to provide job opportunities.

National's election policy put \$18 caps on GP visits for everyone with a Community Services card or receiving the accommodation supplement, as well as lifting the Accommodation Allowance and to raise the Supported Living Payments each April by CPI (Consumer Price Index).

Labour promised to cap GP visit costs for the same people as National at \$8 per visit for adults and \$2 for teenagers.

The Greens, Labour and NZ First all promised an inquiry into the historical abuse of disabled people in state care – and also a state apology. National said it had done a lot of work with individuals and in many cases had issued individual apologies.

People with disabilities have been promised a good life before. There is now an opportunity to deliver on the promises.



The panel of candidates, from left: Talani Meikle (NZ First), Nicola Willis (National), Grant Robertson (Labour), and Mojo Mathers (Green).

Emma Lou's winning work is

Wellington artist Emma Lou has won this year's IHC Art Awards with a finely detailed pastel drawing composed of figures and characters in Cantonese and English.

She worked on the self-titled work *Emma Lou* for almost a year. The large drawing features tiny pictures of animals and fish and human faces, which seem mysteriously submerged among floral symbols and very small lettering.

Support worker Brooke Clements says Emma's work is always stunning. Emma, who has been doing art at the Alpha Studio since 2010, favours pastel images and her human figures are always female. This gives her works a feminine and soft quality. "I always think they have an underwater feel about them," Brooke says. "It's quite whimsical as well – it's gorgeous."

Brooke says she would love to know what the words say. "It's a shame because no one here speaks Cantonese. It would be great to know what is being said in the works."

Emma's style is controlled. She uses calligraphy pens along with felt pens, pencil and ink pens to achieve the detail she wants.

There are many of Emma's works on the walls at Alpha Studio and Team Leader Andrew Grieve says she could have entered any one of a number of them. "Some of the other ones are just as beautiful.

"When we found out that she was a finalist I googled Cantonese and wrote 'Congratulations Emma Lou,'" Andrew says.

Emma Lou works most of the time on her art – three days at the IHC Alpha Studio in central Wellington and two days at the Aranui vocational base in Kilbirnie.

"*Emma Lou* is an extraordinary piece of work and a thoroughly worthy winner," says Wellington artist and Art Awards Judge Gina Matchitt. "The hours of work that have gone into the intricate details of the piece is simply awe-inspiring."

Second prize of \$2000 went to Wellington artist and 2016 winner Jo-Anne Tapiki and third prize of \$1000 was won by Cherie Mellsopp of Hamilton.



Wellington artist Emma Lou, with her winning work, celebrates at the IHC Art Awards.

Auckland-based Judges Tim Walker and Boh Runga said that the calibre of art produced by this year's 30 finalists was worthy of inclusion in any gallery. "The quality of work in 2017 was outstanding and covered a wide range of medium and subjects, which made the judging process very difficult," says Tim.

‘awe-inspiring’



(From left) judges Boh Runga, Tim Walker and Gina Matchitt with the top three artworks – *Kiwiana* by Jo-Anne Tapiki, *Emma Lou* by Emma Lou and *Jade on Black* by Cherie Mellsopp.



Art Awards finalist Nathan Child talks art with Master of Ceremonies Mark Sainsbury. Nathan’s painting, *American Chopper*, reflected his passion for motorbikes and engines. Guest Claire Stearn is on the left.

ds gala night.

“But the three winning pieces really stood out and each artist deserves to be recognised as a winner,” said Boh.

WORLD fashion director and IHC Art Awards Ambassador Denise L’Estrange-Corbet said art was a wonderful medium that elicits joy in artists and appreciators alike. “I think every artist with an

intellectual disability should be encouraged to enter the Awards and share in that joy.”

There were 394 entries in this year’s Awards, including sculptures, installations and textile art, painting and drawing. The IHC Art Awards are open to all New Zealanders with an intellectual disability, age 13 or over.

Inquiry into abuse is the best way forward

Disabled people who were abused in state institutions are still living with the consequences, says Dr Brigit Mirfin-Veitch, the co-author of research into abuse that happened between the 1950s and 1990s. She says an inquiry and an apology is the best way forward.

The research, *Institutions are places of abuse*, by Brigit, the director of the Donald Beasley Institute, and Dr Jenny Conder was released in July, along with a call from the then Disability Rights Commissioner Paul Gibson for an inquiry and apology. The research was carried out for the Human Rights Commission.

“What we did to disabled children and their families was wrong. The abuse each child experienced in being taken from their family was frequently compounded by physical, psychological and sexual abuse. Most staff were not abusers, however some staff were abusers who preyed on the vulnerable and voiceless, out of sight, out of mind,” Paul said in the foreword to the research report.

Brigit says some people want to draw a line under the abuses of the past, and are of the view that it was a product of a different time. But she says this is unfinished business for the people who suffered that abuse who, years later, keep telling their stories.

And, she says, abuse is abuse no matter when it happened or what the prevailing culture was. “What these individuals were describing, even at the time, was abusive. Sexual abuse is abusive, no matter when it happened. Physical abuse is abusive. Dunking people in pools when they are blind is



Brigit Mirfin-Veitch and Jenny Conder have researched the abuse that happened to disabled people in state institutions.

abusive. Abuse was going on in a multiplicity of ways. People with disabilities were abused by staff. They were also abused by their peers. Staff who knew what was occurring and did nothing, for whatever reason, could be seen as having been complicit in the abuse.”

The research is based on the experiences of 17 individuals – 12 men and five women – all of whom have published accounts of what happened to them. Brigit says while this is a small sample, she is convinced that what they have described is true for many thousands of people living in institutions at that time.

“The similarities are striking,” she says. “These were things that happened independently – done at different times by different people – and we are seeing similar stories.

“Even if people didn’t experience overt abuse on their person in some way, there was no question that they witnessed abuse – and that is also abusive.”

In 1981, 3754 people with intellectual disabilities lived in institutions in New Zealand – 1961 people lived in the four psychopaedic institutions (Braemar, Kimberley, Mangere and Templeton) while another 1793 lived alongside people with mental illnesses in 13 different psychiatric hospitals. Many more children and young people were in other forms of state care such as residential schools and foster care during this same period.

Brigit and Jenny have also called for further research into the experiences of disabled children in foster care.

Avis Hunter was put into foster care at three months old and institutionalised at the age of four. She remembered being tied to her bed in Templeton Hospital and being frequently scared and hiding. She spent over 50 years living in a range of institutions and only finally met her family in 1996.

Best friends, David Blackett and John Te Kiri, two blind men, both

described being locked up and frightened much of the time. Both men were left fearful of swimming after being thrown in pools.

Robert Martin was in and out of foster care and institutions from the age of 18 months until he was 15. “I was never loved as a child. Me and all those other kids ... Even today I find it hard to show affection to other people. I don’t trust easily,” he said in his biography *Becoming a Person*.

Brigit says an inquiry will require sensitive handling and it will need to involve families and staff, as well as those who lived in the institutions.

She says a comprehensive inquiry has to offer staff, who witnessed

abuse and now wished they had said something, the opportunity to do that now. She says it is important to remember the gender and power imbalance that would have existed in these institutions, which would have made it difficult for younger staff to speak out. She says we need to be sensitive to families who sought institutionalisation only to later hear that their child had been abused. Brigit says it was considered best practice at the time to care for disabled children in institutions, and families were frequently encouraged not to visit because of the distress and stress it caused to both the family and to the disabled child. This led to people losing the connection with

their families and helped to foster an environment where abuse could occur.

Without an inquiry, there couldn’t be any certainty that people weren’t still being abused.

“We need to remain vigilant to experiences of abuse in other contexts,” she says.

“What that will give people is the dignity of an acknowledgement that someone has believed that this has happened – and they deserve to have the state say sorry for that.”

In July, survivors of state abuse and supporters delivered an open letter and petition to Parliament calling for a public inquiry and a state apology.

Friends break through the communication barrier

Lauren Hilton, a volunteer in IHC’s Volunteering Friendship Programme, met Sharleen Monaghan in June, but at first they struggled to communicate.

Lauren soon realised that if they were going to get to know each other they needed to find a better way to communicate. So she started to learn sign language.

That was a breakthrough. Over the past few months the communication has got easier as trust developed. Now Lauren and Sharleen no longer need the signs. “It’s only been about three or four months, but I feel like we have a connection,” Lauren says. “She is not signing anymore. Now she is talking to me.”

Sharleen lives in a group home in Lyall Bay, Wellington, with housemates. She and Lauren meet on Sundays every fortnight. Lauren is from Cleveland, Ohio, and has been living in New Zealand for six



Sharleen Monaghan (left) and Lauren Hilton no longer need signs to communicate.

years. She says volunteering is an important part of her life. “It is important for me to contribute what I can,” she says. “It’s lovely for me to see how happy she gets.”

Volunteer Coordinator Tyler Wickham says their friendship

has grown with so much respect and joy. “It is so great to hear all about the things they do together – milkshakes in the sun, wandering along the nearby beach, heading to one of the many glorious cafés around Lyall Bay and buying stickers for Sharleen’s sticker chart.”

IHC Foundation funds new ASD research projects

Over the next two years, the IHC Foundation will invest \$140,000 in two autism research projects at Victoria University in Wellington.

Nearly \$100,000 will be spent funding a two-year project exploring the effectiveness of music therapy for children diagnosed with autism. Dr Daphne Rickson from Victoria's New Zealand School of Music: Te Kōkī is leading the project. Her goal is to provide evidence for the benefits of music therapy, so that more children can take advantage of it.

Across the campus in the Education Faculty, another team led by Dr Larah van der Meer plans to provide and evaluate a play-based therapy for children with autism, called the Early Start Denver Model. The team will introduce to New Zealand children a therapy that is changing lives for children elsewhere. The IHC Foundation will contribute \$42,600 towards the cost of this project.

Where's the proof?

Dr Daphne Rickson is set to tackle a major barrier preventing many children with ASD receiving music therapy. She plans to provide evidence that music therapy is effective in a way that will convince the Government that it is worth funding.

Funders look for consistency and hard evidence, but music therapists use an improvisational style that responds to the child in the moment. Each situation is unique, so controlled trials are difficult.

Daphne, a senior lecturer in music therapy at Victoria University, plans to evaluate the impact of music therapy on 10 children with ASD and has enlisted music therapists from across the country. She is pleased with the response to the study from families. "We had to limit our invitations to Christchurch, Wellington and Auckland families because that's where the music therapists were – so the response is excellent. It will be hard for families who miss out this time."



Daphne Rickson has enlisted music therapists from across the country for her research project. Photograph: Image Services, Victoria University of Wellington



(From left) ASD researchers Hannah Waddington, Larah van der Meer and Jessica Tu. Photograph: Image Services, Victoria University of Wellington

The study will include children from pre-schoolers to 18 years, who are enrolled at school, and each child will be offered up to 50 weekly sessions with a therapist from January to December 2018.

The progress of each child will be assessed by 10 evaluators, five who know the child, and five who don't. They will be asked to evaluate a case study provided by the music therapist. The evaluators who know the child will ideally include a parent and may also include a teacher, speech and language therapist, or psychologist. The evaluators who don't know the child will be specialists in ASD.

All the evaluators will be answering the same questions and, from the 100 total evaluations, statistical data will be provided for the effectiveness of music therapy generally. The evaluators will also write a short summary of the case, which might help with understanding how and why some approaches will work for some children and not others. Daphne is working with the university's Information Technology Services department to develop a purpose-built online platform for collecting the data.

Daphne says there is a need for hard evidence in New Zealand and overseas on how music therapy can influence a child's development of communication skills, including attention, imitation, initiation, turn-taking and emotional expression.

She believes the research is coming at the right time. "I am asking the Ministry of Education and others to accept different forms of evidence at a time when they themselves are saying that different forms of evidence are important," she says.

Projects for children



Tupou will offer play-based therapy to pre-school children.

To do this, Daphne is adapting one of the methods of assessment used already in schools by the Ministry of Education itself. “The way in which the case studies will come to us is called narrative assessment. It’s the way many schools report to parents and others in the

community about the way the child is performing,” she says.

“Researchers and funders usually value research which involves a consistent treatment approach. I am not saying that that is not important but what I am doing is leaning towards another way of assessing which is becoming more common, and which enables practitioners to work in the way they would normally work.”

At the end of next year, Daphne will be able to start analysing the data that will include written reports and videos to determine the impact of the therapy.

A first for New Zealand

In a first for New Zealand, Victoria University lecturer Dr Larah van der Meer and three other specially trained therapists plan to offer the play-based autism therapy, the Early Start Denver Model (ESDM), to pre-school children.

Larah and PhD researcher Hannah Waddington say international clinical trials of the therapy are showing dramatic results for children – including increased intelligence scores, improvement in language abilities and fewer autism symptoms. In some cases it led to a change in diagnosis.

The ESDM model, developed in the United States, focuses on relationship-building between families, the educational therapists and the children. It is about positive social interactions and shared engagement to build language and communication, as well as other important developmental

milestones. Parents are a key part of the therapy.

Hannah says the therapy is gentle and child-led and teaches through play. Its emphasis is on teaching through a parent’s ordinary routine and can be done throughout the day, for example at mealtimes and at bath-times, and is flexible to each child. “The great thing about this model is that it’s combining all these different areas of positive practice,” she says.

The model is based on intensive therapy of 15 or more hours a week, but recent research on using the model for fewer hours and in group settings is also showing positive results.

A clinical trial published in the international journal *Pediatrics* showed that children who received ESDM therapy for more than 30 hours a week – 15 hours by trained therapists and 16 hours by parents – over a two-year span showed greater improvement in cognitive and language abilities and adaptive behaviour and fewer autism symptoms than children referred for interventions commonly available.

Larah says that while these results are positive, most families do not have access to this level of intervention. “The aim of our project is to not only offer the ESDM therapy to children but conduct research into its impact when fewer hours of therapy are offered and in different formats. We hope to make early intervention more accessible for families.”

The families who participate in the project will be restricted to the Wellington region because of proximity to the university. The play-based therapy is designed for children up to five years of age.

Larah’s team is from the university’s Educational Psychology Clinic – a research-based clinic that provides services for children with developmental disabilities. They will work with the children and their families to develop language and communication, social interaction, imitation, cognitive play and daily living skills. Initially the project will recruit eight to 10 children and their parents early in 2018.

One of the team members, PhD student Jessica Tupou, will conduct research into its impact in inclusive early childhood centres. She will also be working with early childhood education providers in the Hutt Valley and training teachers in the therapy.

Larah is now recruiting the last member of the team – a Community Adviser who will work with families, the community and other associated organisations.

Members discuss challenges facing services



IHC Member Council Chair Barbara Rocco (left) and IDEA Services Chief Operating Officer Janine Stewart set the scene for the discussion.

IHC Association Chairs and members were briefed on the challenges facing services at a workshop held before the Annual General Meeting in September. The workshop was hosted by the IHC Member Council.

The workshop opened with some scene-setting presentations by Accessible Properties Chief Executive Greg Orchard and IDEA Services Chief Operating Officer Janine Stewart.

Ministry of Health Programme Leader Sacha O’Dea then spoke about the Ministry’s project to transform the way disability support services were delivered. She said the Ministry was working with people across the sector to change the system rather than adding something on top. She said families now had to coordinate their own support across a range of agencies. Her team wanted to give people a one-stop shop and to offer a range of ways that people can engage – from digital hubs, to email, phone calls and face to face.

John Taylor, Chief Executive of Community Connections, who is on the project team, said change could be scary, but if people were happy with the support they had, then they wouldn’t have to change. The team was looking at more flexibility in funding with the idea of a personal budget. This was quite different from individualised funding and was more about who governed the money. In future it would be more about “how do you want your life to look and can we make it happen”.

Consultant Adele Carpinter spoke about how families could be empowered by accessing their own support networks and she described some successful family collectives. She said the families who were flourishing were not necessarily those that were wealthy or received the most services – they were the ones that had connected with their communities and networks. She said when families were doing well, everybody benefited.

They were followed by IHC speakers giving first-hand accounts of their experiences providing support. IHC Board member Anne Gilbert spoke about supporting a young adult son and building natural support networks through friends. Barbara Rocco discussed being an older parent and her expectations of her son’s support service. IHC North Canterbury Association Chair Robyn Stark, who supports her daughter to purchase services through the Enabling Good Lives personal budget, challenged families to ‘dream big’. Janine Stewart discussed the difficulties of working as an agent to manage support staff for a woman with a disability.

Against that background, Association Chairs and members were then posed a series of questions asking what was important to families and what the changes were likely to mean to them and their disabled family member, and what they would mean for IHC. The discussions were captured in a series of workshops and will be reported back to the IHC Board.



Shalyn Kearns and Gareth Weeds at one of the folding machines at the Executive Laundry in Petone.

Shalyn went to work and found a family

The Executive Laundry in Petone works seven days a week, processing tonnes of dirty laundry for Wellington's hotels, motels, function centres and private hospitals.

The family business, purchased in 2009 by John and Pam Weeds, has expanded over that time from 17 to 64 fulltime staff and spread into adjoining buildings to accommodate the increasingly sophisticated washing/drying and folding machines needed to process the huge volumes of washing.

One of the 64 staff is Shalyn Kearns, a young woman with Down syndrome, who came to the laundry in 2012 for some work experience for a couple of half-days a week and found herself a family. She was taken on for a two-year contract in 2013. When the two years were up, Shalyn says she feared she would lose her job and her Mum, Mary Kearns, advised her to be ready with her CV so she could reapply. But she needn't have worried. "John said that Shalyn is part of the family and there is no way we are going to let her go," Mary says.

Shalyn now works three days a week. "She loves it; the staff absolutely love her," says Gareth Weeds, John's son. "She is one of the team."

Shalyn used to fold tea towels by hand, but now operates an ironing press for the towels and she has been trained to use the machine that automatically irons and folds the sheets.

"On any day we do between 11–14 tonnes and that will consist of 7500 sheets and 6000–7000 bath towels," says Gareth, who left work as a plumber five years ago to work in the business too.

He says the laundry used to run 24 hours a day to handle the volumes of washing, but decided the shift work wasn't ideal for staff. "Everyone wanted to do the day shift," he says. So the company bought two 35 kilo industrial CBWs – continuous batch washers – designed to handle heavy loads and all the staff went back to a 7am to 3.30pm day.

"I am loving it. I like the staff. I am making good friends," Shalyn says. "My best buddy I would like to say is John."

IHC NEW ZEALAND INCORPORATED ihc.org.nz

IHC BOARD

Neil Taylor, Chair
Anne Gilbert
Jason Hollingworth
Ralph Jones, Chief Executive
Shelley Payne
Michael Quigg
Barbara Rocco ONZM
Rob Steele

IHC MEMBER COUNCIL

Barbara Rocco, Chair, ONZM
Janet Derbyshire
Diane Mara
Scott Miller
Pip O'Connell
Kay Pearce
Sylvia Robertson
Danny Tauroa

PATRONS

Sir Roderick & Gillian, Lady Deane

NZ LIFE MEMBERS

Dr Donald Beasley CBE
Dr Terry Caseley
Sir Roderick Deane KNZM
Jan Dowland
John Hanning
John Holdsworth ONZM
JB Munro QSO
Lynne Renouf
Barbara Rocco ONZM
Tony Shaw
Neil Taylor
Donald Thompson
Charlie Waigh
Maureen Wood

IHC NATIONAL OFFICE

Level 15, 57 Willis Street,
Wellington 6011
PO Box 4155, Wellington 6140
Ph 04 472 2247, Fax 04 472 0429

EDITOR

Gina Rogers
Ph 04 495 2771
Email gina.rogers@ihc.org.nz

COPYRIGHT

Community Moves is published by IHC New Zealand Incorporated. The content of *Community Moves* is copyright. No part of this publication may be reproduced or transmitted in any form or by any means without the prior written permission of the publisher.

ISSN 1171-8587

