

Community MOVES



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ihc
IN YOUR COMMUNITY

Personally speaking



In my last column I mentioned that the IHC Executive Group had presented several strategy discussion documents to the IHC Board. These documents included an analysis of the disability and housing sectors and identified opportunities for growth and new ways of supporting people.

In disability services we are keeping our focus on the experiences of individuals and on improving quality. In 2018 we increased our investment in frontline managers, increased our capacity and expertise in the areas of clinical support, quality, safety and risk and invested in our own model of respite (Take a break) through our charitable programmes.

In Strategy 2020 we identified a number of issues that we would track. In 2019 we are seeing:

- increased competition in the service delivery and charitable sectors
- changing consumer values and expectations
- a strong human rights agenda being pursued by disabled people and advocacy groups
- increasingly complex client needs
- low unemployment nationally
- a shrinking government role in funding support services and in its ownership and management of affordable housing
- growth in demand for individually tailored supports and self-managed funding arrangements
- ageing of baby boomers and difficulties filling traditional volunteer roles.

This year we are looking particularly at people's experiences during the day, the low rates of employment for people with intellectual disabilities and new models that encourage people to pick and choose their services. We want to make sure we are responding well to people's changing preferences.

We have established a new service delivery company, Choices. It is a subsidiary of the IHC Group sitting alongside IDEA Services, Accessible Properties and our charitable programmes. Choices will take advantage of new ways of working in response to more individualised funding models and we will also be increasing our employment support throughout the country.

We expect some new people to come to our organisation through Choices and accept that some people may also choose to move between Choices and IDEA Services. In IDEA Services we continue to strive to provide quality services and be an attractive option for many. The people we support are those who benefit from intensive support – that may be 24/7 and may include residential services, supported living, healthy ageing at home, specialist services or vocational services.

In this edition of *Community Moves* we have included a readership survey. I am assured by our editor that we get many emails and comments about the great stories we feature in this publication. But our readers are loyal and long-time readers – therefore we want to make sure you are getting content and information you value. Please take part in our survey.

Finally, our Annual General Meeting will be held on Friday 13 September in Wellington and I look forward to seeing those attending and updating those of you who will not be there.

Ralph Jones
IHC Group Chief Executive

Budget sets overdue pathway for disabled people

The Government’s announcement that benefit payments will rise in line with wages, not inflation, will make a huge difference to people with intellectual disabilities, says IHC.

The policy, highlighted in May’s Wellbeing Budget, is part of a broader welfare change package to stop struggling families falling further behind.

IHC Director of Advocacy Trish Grant says this policy sets a wellbeing pathway for people with intellectual disabilities that hasn’t been clear before.

“For the many people who haven’t experienced wellbeing in an equitable way, this is significant,” says Trish.

“Most people with intellectual disabilities are beneficiaries, and the Budget will be a welcome boost in allowing beneficiaries to work more hours by lifting abatement rates.”

Trish says the funding commitment to increased learning support in the classroom is also pleasing.

“We hope this will result in more children with disabilities being able to attend their local schools,” says Trish.

“We also hope the \$1.2 billion



IHC Director of Advocacy Trish Grant has high hopes for wellbeing.

earmarked for school property, which includes 150 more classrooms, will support more schools to become more welcoming to children with disabilities.”

Trish says there is a lot for people with intellectual disabilities, throughout all life stages, in the Budget – from extra investment in early childhood education to a sustained commitment to a better learning support and policy framework – but she is disappointed with some of the funding allocation.

“The spending on the Ministry of Health’s Disability Support Services is around \$7 million less than they estimated they actually spent last year, so they plan to cut \$7 million from actual spending.”

IHC will continue to monitor the Government’s commitment to better life outcomes for people with intellectual disabilities.

What makes a great read?

Tell us what you like, or don’t like, about *Community Moves* – and what you would like to see more of.

We are surveying readers in this issue about your preferences and would love to hear from as many of you as possible.

Please either fill in the survey form

inside the magazine and return it in the reply-paid envelope or, if you prefer, go to the online version at ihc.org.nz/CMsurvey. If we have your email address, we will also email it to you to make it easy.

We’re looking forward to hearing from you.

Gina Rogers
Editor

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COVER IMAGE:

Kevin Galbraith joined in with friends for some ground-breaking action at Dig This Invercargill, thanks to money raised at the latest Winton Lions IHC Charity Golf Tournament.
See story page 5

Queen's Birthday Honours richly deserved

Former IHC Chair Donald Thompson and former Chief Executive Jan Dowland have been recognised in the Queen's Birthday Honours for their work on behalf of people with intellectual disabilities.

Donald was made an Officer of the New Zealand Order of Merit and Jan a Member of the New Zealand Order of Merit. Donald and Jan are already held in the highest regard at IHC.

Former Chair of IHC subsidiary Accessible Properties New Zealand Ltd (APNZL) Sir Paul Adams also received a Knighthood for services to philanthropy and community. Sir Paul served as Chair from the establishment of the company in 2010 until last year, bringing insight and commitment to improving the lives of people in social housing.

Donald and Jan are two of just 13 IHC New Zealand Life Members – an honour bestowed by our organisation in recognition of their personally having made a difference to the lives of disabled people. Their contributions over many years are of such value that we can't quite let them go. Following his retirement as IHC Chair, Donald joined the Board of APNZL and has also served on the Board of the IHC Foundation. Jan works as a consultant for IHC, providing strategic advice on services and programmes. She is Executive Director of the IHC Foundation.

"The recognition of the contributions made by Jan and Donald are richly deserved," says IHC Group Chief Executive Ralph Jones. "Their decades of service mean they are personally known to thousands who, like me, will be feeling enormously proud at this news."



New Queen's Birthday Honours' recipients Jan Dowland and Donald Thompson are two of just 13 living IHC New Zealand Life Members.

Jan has dedicated her career and time to working for community and health organisations in paid and unpaid roles. She served as IHC's Chief Executive from 1998 to 2002 and was a panel member on the Confidential Forum for Former Inpatients of Psychiatric Hospitals from 2005 to 2007. She has served as a Trustee and Chair of the Wellington Community Trust and Chair of the Mental Health Commission.

"Jan is an extraordinarily professional operator," says Ralph. "But it is the contribution above and beyond the professional roles that we celebrate. She is committed to using her personal time, strategic leadership and influence to improving the lives of vulnerable people and to ensuring the arts are supported in Wellington and New Zealand."

"People with intellectual disabilities have received the lion's share of her voluntary time and Jan is professional and adds personal warmth to everything she does."

"As one colleague with an intellectual disability said, 'Me and my family, we trust Jan'."

Donald has given more than 35 years to ensuring people with intellectual disabilities in New Zealand have the right support to be included in their communities and live good lives. He's also been heavily involved in the Lions Club.

He has served at every voluntary level of IHC, as a member, a Branch President (running local fundraising programmes and events), a member of the IHC New Zealand Council, a Board Member, President and Chair. He has also been a director or Board Member of IHC subsidiaries IDEA Services and Accessible Properties and a trustee of the Donald Beasley Institute.

"Donald's leadership style is gentle and encouraging but firm. He is decisive and has a strong corporate focus that is grounded in the experience of being a family member of a daughter with an intellectual disability," Ralph says.

"His generosity in sharing his personal experience and time has made a real difference to people with intellectual disabilities and their families. He has made brave decisions, shared his story, and given others comfort to be able to do the same."

Earth-movers let it rip in a giant gravel pit



Anthony Doak takes the controls of a 1.7-tonne fixed-position excavator in the Dig This Invercargill gravel pit.

Eight enthusiastic earth-movers have been letting it rip in a giant gravel pit at the Dig This Invercargill fun park.

The tickets were paid for with money raised at the latest Winton Lions IHC Charity Golf Tournament for IHC in Southland.

Dig This Invercargill is a heavy-duty playground where the boys' toys are full-size for guys – and gals – keen for some ground-breaking action. Visitors can take control of bulldozers and excavators and move piles or rocks or tyres backwards and forwards, even crush a car.

Dig This has a variety of machines for people to choose from, including 15-tonne diggers, one 20-tonne digger (to smash cars), two 10-tonne bulldozers, two five-tonne diggers, two all-terrain skid-steer loaders and four two-tonne diggers. Players can take friends and family to watch them 'Dig and Destroy' or try a 'Big Push', a 'Big

Dig' or an 'Aggression Session'.

The total of \$5000 from the golf tournament has now been allocated to people with intellectual disabilities in Invercargill who are living independently. These recreation activities are usually beyond their budgets.

IHC Southland Association Chair Juli Marshall says the Winton Lions Club has been a strong supporter of IHC in Southland for many years. Club President Allan Wilson believes the tournament would have raised at least \$200,000 in the past 53 years. The first tournament was held at the Riverton Golf Course in 1966, then it was shifted to the 18-hole course in Winton in the 1970s to accommodate the increasing number of people who wanted to take part. This year the IHC Southland Association decided to allocate the money to benefit 29 people in our Supported Living Service.

"We were very aware that people

in Supported Living have the highest costs and the least money to spend on things," Juli says.

Pat Tauranga, Service Manager for IDEA Services, says the golf tournament money has paid for movie and theatre tickets, café visits and trampolining, as well as visits for eight men to Dig This. She says IDEA Services staff have volunteered their off-duty time to accompany service users on the visits.

Support Worker Melissa Beukes watched the Dig This action from the sidelines over several weekends. "All of the guys really did enjoy themselves," she says. "The girls weren't really too interested so we took them trampolining."

Juli says golf tournament money has paid for extra indoor and outdoor furniture at residential homes and contributed to a tunnel house where people with disabilities grow vegetables for the homes, and to music therapy and a bike recycling programme.

Whitney loves to talk about science

Whitney Whitford is a specialist in genetics – specifically copy number variants (CNVs) that are responsible for duplications and deletions of genes or parts of genes.

Having just completed her doctoral research at the University of Auckland she now has a new job, funded by the IHC Foundation, working with a team at the university's School of Biological Sciences and Centre for Brain Research to find the causes of rare genetic conditions.

Whitney's role is to liaise with the 20 families involved in the study and their clinicians – and it's the perfect role for her, because she loves to talk about science in a way that helps people to understand what is happening. She has a history of engaging with the community and runs the Minds for Minds website and email interface.

"I am really passionate about trying to accurately represent science and to increase science literacy. You can be there and doing the research, but if you can't connect and communicate the research to the people, then you miss out."

Whitney says to fully describe what she does without going into the jargon is almost impossible. She describes CNVs as being like sentences or paragraphs from a book that have been removed or duplicated, which can be responsible for causing rare genetic conditions. "Part of my PhD was creating a computer pipeline so I can find those variants and track them. They certainly have the potential to have some profound and severe effects," she says. "At the same time it is an area that has been



Whitney Whitford has been awarded an IHC Foundation Post-Doctoral Fellowship to work with the University of Auckland's gene team.

under-researched."

Whitney says there are huge genetic variations between people. "Everyone is walking around with over 1000 copy number variants which seemingly aren't causing any problems. That makes it harder to find those that are actually causing problems."

After the success of the genetics team's pilot project with an initial 20 families, researchers Dr Jessie Jacobsen, Professor Russell Snell and Associate Professor Klaus Lehnert are now recruiting families for their new study. In the pilot project, from 2016 to 2018, the team was able to find the genes and mutations responsible for

rare conditions in 14 children. Whitney's job is to extract DNA and process and analyse data. "I am in a unique position in terms of our team, being the one who is managing the emails with families."

Whitney says what help is on offer for these families is very dependent on the cases. "With a lot of families we are working with, there isn't necessarily going to be a fix." But she says knowing the cause of a genetic condition might guide treatment plans for a child and for some families knowing why is very helpful.

"They want to understand their loved ones, and finding genetic variants can help this," she says.

Strangers in a storm set Gary back on track



Runners in the Christchurch marathon raised more than \$8000 for the New Zealand Williams Syndrome Association.

A Queen's Birthday weekend storm lashing the South Island was turning Gary Braddock's dream of running in the Christchurch Marathon to mush.

The Wellington man had trained for weeks to run the half-marathon to raise money for the New Zealand Williams Syndrome Association. But late on Saturday afternoon in Kaikōura his bus driver announced that the road to Christchurch was blocked and the bus was returning to Picton.

Not Gary. "It was more than a run," he says. "It was the whole social side of it and meeting my friends again." He got off the bus but then wondered what on earth he was going to do in Kaikōura in a downpour.

"It was stormy. It was raining. It was blowing a gale," Gary says. "I walked a little way and found this store that was open." Rosella Wise was working in the Kaikōura Night 'N Day Food Centre when Gary walked in. "I told her, I have taken a bit of a risk here and I have nowhere to stay."

Rosella says Gary came in absolutely drenched and not sure what to do.



Gary, who has Williams Syndrome, runs in the Lower Hutt parkrun every Saturday.

"We let him dry off and made him a cup of coffee." She says the best thing seemed to be for him to go back to Picton because the roads were closed. She was on the lookout for a truckie who might offer Gary a lift.

Gary was messaging his friends in the Williams Syndrome Association about what was happening and Trish Hastie, who he was to stay with in Christchurch, jumped in her car to pick him up. Gary says she got within 56 kilometres of Kaikōura, but was turned back.

In the meantime Rosella's workmate at the Night 'N Day, Zac Murray, was at the back of the store. "Rosella told me that somebody was stuck and they needed a place to stay the night. I just took two minutes off work to take him back to my house."

Zac's flatmate Michael Bennett was determined to find a way to get Gary to Christchurch and the start line. "That was my mission. I said, 'I am going to take you to Christchurch and that's that,'" Michael says.

At 1am they started driving. Knowing the coastal road was closed, they headed south by the inland route and had a clear run. "I dropped him at Christchurch City Hall at 4am – and he was amped."

Gary completed his half-marathon on the Sunday, along with his team of 60 Williams syndrome runners. "It took me three hours and 12 minutes. It was my slowest by about 32 minutes."

The group run was organised by George Stilwell, whose younger brother has Williams syndrome. Five people ran the full marathon, while others ran the half-marathon or 10-kilometre run or walk. More than \$8000 was raised for the next Williams Syndrome Association camp.

The long and bumpy road to inc

It has been 30 years since children with disabilities were given the right to attend their local schools, but they are still waiting to be included on the same basis as their non-disabled peers in the classroom.

IHC has been asking these questions for many decades now: Do children and young people with disabilities get a fair deal in New Zealand's schools? And does the education system give schools what they need to do their best by all learners, including those with disabilities?

Unfortunately, the answer is categorically "no".

This has been backed up by a new report from the Independent Taskforce appointed to review Tomorrow's Schools, which has found that students with learning support requirements do not have the same access to education as other students.

In its submission to the Independent Taskforce, IHC Director of Advocacy Trish Grant agreed that nothing short of widespread transformation and increased investment in education will ensure better outcomes for all students, including those groups who are currently missing out – Māori and Pasifika students, refugee and migrant students, and disabled students.

Trish says more investment in the system is important, as well as more funding and access to specialist advice and support for students with disabilities and schools.

"These students, their families and their schools have been saying

for too long now that the support needed to learn and participate is unavailable, contestable, highly fragmented or almost non-existent. Even when approved, it takes far too long to arrive," says Trish.

"Our evidence shows children are being turned away at school doors, or they are told they can't complete a full day – disabled children experience discrimination on a daily basis and it is neither right nor fair.

"Schools are being put in untenable situations, with little financial assistance or access to the specialist supports need."

In addition to adopting the recommendations from the Independent Taskforce, Trish says, the Government must move to strengthen the rights of disabled children to education.

"The rights to inclusive education and reasonable accommodation need to be embedded in the Education Act," says Trish. "The 30-year history of struggle reflects a lack of an enforceable right to education.

"Disabled students, their families and their schools need to be able to access independent mechanisms that have the power to recognise and enforce rights to education.

"Relying on best endeavours with a luck-and-love approach isn't good enough anymore, and if we're serious about a quality public education for all children we need the Government to commit.

"The Independent Taskforce is calling for more robust initial teacher education, professional development and leadership development – IHC welcomes this recommendation.



When they saw Lucas struggling, his parents, Stephen saw that he was happy again.

"All teachers need to feel confident about teaching all children and have access to the right additional support when they need it," says Trish.

"IHC is calling for strong accountability within, and across, the system and we support the need for a mechanism to evaluate system performance so that it delivers equitable access and outcomes for all.

"It's time for the Government to show bravery and think beyond election cycles.

"The right to turn up to the local school gate should count as an explicit right to inclusive education in the classroom, and we need a system that works for all children."

Inclusive education



Broomfield and Pauline Leota, pulled him out of school and after a few months

Did you know that when students with learning support needs enrol in a school they aren't actually guaranteed to be in the classroom full-time?

At the same time as the Tomorrow's Schools review, the Ministry of Education is drafting a Bill aimed at improving education legislation. The proposals are intended to:

1. strengthen the provisions that give children and young people a right to education
2. prohibit, except in limited circumstances, the offshore awarding of the National Certificate of Educational Achievement (NCEA)
3. update the name of 'special schools' to 'specialist schools' and transfer the provisions regarding their establishment and disestablishment to a new Act in a way that does not affect existing obligations but removes outdated and unnecessary terms. This is a technical change that does not affect the number of specialist schools or their operation.

Home schooling a last resort

Some families in New Zealand choose to home school for philosophical reasons, but many others are home schooling because the education system cannot support them. There are no accurate statistics around this, and it needs to change, says Stephen Broomfield, dad to Lucas, eight.

"At kindy Lucas was a happy and relaxed child with good friends. He wasn't developing as fast as his peers, but he was curious and loved tactile, play-based learning so we weren't worried. He was just going at his own speed."

He started school at five and immediately struggled with the highly structured environment. Instead of being supported to learn at his own pace, the school reported back that he wasn't meeting expectations. Unable to keep up with the class, he disengaged from learning and was considered disruptive.

"The school felt he must be ASD or ADHD, and they pushed us to seek a diagnosis. They provided a speech therapist and some support with handwriting, but they told us without a formal diagnosis they couldn't do more. However, a paediatrician confirmed there was no diagnosis to be had, he was just developing more slowly. He began to be left to his own devices at school; he felt stigmatised, lonely and dejected.

"We're not hippy rejects, we home school because there was no other option."

"I was quite against home school, but we couldn't see any future at school either. We pulled him out and after a few months of loving care we started to see our happy-go-lucky little boy back again. My wife Pauline and I provide him with good structure and variety at home and, while I don't think he will be a rocket scientist, everyone has a little place in the world and Lucas will find his.

"Home school has been a good decision for us, but we didn't end up here by choice. We aren't troublemakers or hippy rejects; the system just wasn't able to support Lucas – and there are thousands of families like us. There are so few stats around home schoolers; how many are there because the system doesn't work for them? How many go to university? Why does home school work? Understanding this is key to getting better support in schools, and hopefully better support for those of us home schooling as well."

Continued on page 10



Felix, with mum Kerry Hodge, is enjoying school now that the issues have been ironed out.

Felix is now happy to be at school

Much of the current support offered to learning support pupils is focused on academic achievement, but good emotional health and wellbeing is vital for students to be raised to their version of success, says Kerry Hodge, mum to Felix, 9.

“Felix wants to be at school, but struggles to be there as well. The classroom is noisy, he feels overstimulated, or he experiences anxiety and runs away. This is obviously disruptive for the class, and dangerous for Felix.

“We’ve had Intensive Wraparound Service funding for a year, and it was hard won. We had a bumpy start but once early issues were ironed out we’ve seen a huge improvement in Felix’s ability to engage in school, and the joy he feels at being there.

“The main points for Felix to work on are emotional regulation and social skills. Monday and Tuesday he is supported full-time by a teacher aide. Wednesday and Thursday he is supported until 1pm and then leaves school. Fridays, he works alongside a specialist teacher. We’ve also got support from an occupational therapist and we are applying the techniques at home. It’s been fantastic.

“Felix is starting to understand his emotional responses. If he does feel the need to run, he can identify and acknowledge why. And he is learning strategies to deal with his emotions too, both at home and at school. We were introduced to the Zones of Regulation programme – it’s not only helped Felix with understanding his emotions, but our neurotypical child too. Every child needs to learn this in my opinion.

“We’ve seen a huge improvement in Felix’s ability to engage in school, and the joy he feels at being there.”

“The ultimate goal is for Felix to be able to self-regulate at school full-time. When the funding ends this year there will be limited support for him. If every classroom had a fully trained teacher aide to support the work of the teacher, Felix may not need specialised help. At the moment our system is the ambulance at the bottom of the cliff. We know there is a problem, the current system isn’t supporting our neuro-diverse kids, but services aren’t put in place until it’s almost too late.”

Learning support needs proper funding

Berhampore School in Wellington has prioritised learning support in a way that demonstrates how a well funded system could support all children to succeed, says Principal Mark Potter.

“The current system is financially deficient. For example, we have five ORS-funded [Ongoing Resourcing Scheme] students, but as a school we still need to find \$8000 per student per year so they can access meaningful education. We do this by making learning support a priority, and that means we have to let other things go, like building maintenance.

“Our philosophy is based around the child’s right to be here. Berhampore School is everyone’s school – we don’t turn people away. Instead, we ask what accommodations do we need to make so this child can access school like their peers?

“We employ 16 teacher aides because we believe a classroom teacher alone cannot support children with communication and behaviour challenges and still meet the needs of the whole class. We fund our own learning support coordinator to take the admin load off the teachers.

“Perhaps the biggest difference is the way we measure success. For some children it could be using the toilet independently or making a genuine friend in the playground.



Berhampore School Principal Mark Potter.

“The Tomorrow’s Schools review has some key concepts underlying it that will enable change, but it is lacking in financial resourcing. We can’t keep reducing money in comparison to what we need that money to do. We need a clearer idea of the need, and we need to fund it appropriately.”

Send us your calves

IHC is calling for people to donate their calves this year, after what was an incredibly challenging season for the rural sector because of *Mycoplasma bovis*.

IHC National Manager of Fundraising Greg Millar says the Calf and Rural Scheme will continue, and this year is more important than ever.

“Farmers still managed to raise nearly \$750,000 for people with intellectual disabilities – and despite falling short of our \$1 million target, it was great to see the rural community continue to support our cause,” says Greg.

“While some of the processes of the scheme have changed, its purpose has not – to make a real difference to the lives of people with intellectual disabilities, particularly those living in rural communities.”

Greg says that now more than ever IHC needs the support of farmers. “This year the scheme is off to a good start and we received just as many pledges of calves at Fielddays as we did last year.”

Farmers are now asked to arrange transport of their IHC calves to the sales along with their own calves. Greg says from talking to farmers at Fielddays this year, many seem to appreciate the flexibility of being able to take their calves to sale in their own time. It was also good to be able to reassure farmers that the scheme was still going strong.

Taranaki farmer Barry Kowalewski has donated to the scheme for a number of years – this year, like last, he’s arranging to transport the stock himself.

“I just send a line of calves to the sale and then donate the proceeds of one to IHC,” says Barry.



Morrinsville farmers Kelly and Hamish Martin sign up to pledge a calf with Fundraising Coordinator Lynda Young-Kennedy.

He says it’s been a tough time for farming fundraisers but is happy to help in any way he can.

“What you sow is what you reap, so I’ve always, I suppose, felt that desire to help out any area of society that’s underprivileged.”

Greg says in some ways it becomes much easier for farmers because they’re able to transfer their stock at times that suit them, rather than with arranged pick-ups.

“If you aren’t able to send your calf or calves to sale with your own lot, IHC can pay to get it there. You just need to organise this with your local transporter and let us know,” says Greg.

The annual Fielddays sausage sizzle put on by Volkswagen for the Calf and Rural Scheme this year raised \$3400, double that of last year.

IHC would like to thank PGG Wrightson Livestock, which for more than 30 years has provided generous and unwavering support.

For people who wish to donate in lieu of a calf, the IHC Virtual Calf Scheme option is still available via our website ihc.org.nz/calf or phone 0800 442 500.

How to get your calf to sale:

- 1. CONFIRM** your pledge with IHC and we will send you a pink IHC ear tag
- 2. SELECT & TAG** your IHC calf with both your NAIT tag and the pink IHC tag
- 3. INFORM** your sales agent of the IHC calf or calves coming with your lot
- 4. WRITE** ‘IHC calf’ on the ASD form going in with your IHC calf
- 5. CONTACT** your local transporter to arrange collection

Did you know we are on Twitter and Instagram? Follow @ihccalfandrural for up-to-date information about the Calf and Rural Scheme and some great images from supporters in rural communities around New Zealand.



Anthony never believed it would happen



Anthony Waite with the Curative production company crew – Senior Designer Logan Bradley (left) and Project Manager Sarah Wilson.

Anthony Waite has a home of his own – something he didn't think was possible for a man like him, with an intellectual disability. But having his own place has transformed his life.

Anthony works very hard at maintaining his independent life. He cleans ambulances five days a week at St John in Auckland, and when he's not there he is working at Totara Hospice in Manurewa.

For the past three or four years he has been living with a flatmate in a Papakura townhouse. He keeps the section smart and tenants of the other townhouses pay him to mow their lawns too.

And still he has time to be a video star. Anthony recently featured in 'We Believe', a video produced as part of a campaign

by the Auckland Community Housing Providers' Network to reinforce the fact that everyone has the right to a home of their own. "I never believed I'd have somewhere stable to live," he says in the film, which shows him caring for his two budgies.

The video highlights the part that network members have played, and can continue to play, in housing those who can't afford to house themselves.

Anthony, who is supported by IDEA Services to live independently, rents his townhouse, one of a block of four, from IHC subsidiary Accessible Properties New Zealand Limited (APNZL). He says he likes living there. "I like to talk to the other neighbours." Anthony also liked taking part in the filming. "I was thinking I was cool when I saw myself there.

Yes, it turned out good," he says. "I could do more acting."

APNZL is one of 21 community housing organisations operating across Auckland that have formed the Auckland Community Housing Providers' Network.

APNZL Chief Executive Greg Orchard also added his on-screen support: "Over the past 30 years, we have provided warm, dry, safe homes to over 25,000 New Zealanders. We believe everyone has a right to a home to call their own".

In June APNZL won the Leading Asset Management category for 'Tauranga Portfolio Asset Management in a Changing Political Environment' in the New Zealand leg of the Australasian Housing Institute (AHI) Awards. The AHI Awards presentation was held during the Shift Aotearoa Conference in Wellington.

Liaison team uncovers gaps in support for families

The lonely and stressful road for some families raising children with intellectual disabilities has been starkly revealed by IHC's new Family-Whānau Liaison team.

Four liaison staff, who have been working in Northland, Manawatū-Horowhenua, Canterbury and North Otago for the past year, report that they are seeing families urgently needing help but not getting it for all kinds of reasons.

The team has been surprised to discover children and young people with undiagnosed intellectual disabilities who are missing out on services. The team is being asked to help children as young as three, right through to young adults left high and dry after leaving school. And, above all, they say families are asking for more respite support so they can have breaks from the demands of being carers.

The IHC Family-Whānau Liaison team was established a year ago as a pilot project, and funded by the IHC Foundation to support families to find services in their communities that can help them.

The Family-Whānau Liaison team reports that the gaps in support and services are exacerbated by other issues, including inadequate housing, transport and, in Northland in particular, distance from centres where support is available.

Jim Callaghan is IHC Family-Whānau Liaison in Whāngārei. He says once students with

intellectual disabilities leave school – even with the best plans in the world – there is virtually nothing for them to transition to. “It is also becoming harder to access educational funding and support.”

At the other end of the country, Yvonne Ball in Oamaru and Sheridan Myall in Christchurch are seeing the same thing. Yvonne says there is nothing being offered to those who have left school that encourages them to contribute to their communities plan their lives or learn new skills. She says they are missing out on the things that would increase their sense of wellbeing and make them feel valued as part of their communities. Sheridan says many people with



Jim Callaghan – Whāngārei.



Yvonne Ball – Oamaru.



Sheridan Myall – Christchurch.

intellectual disabilities are not able to find jobs.

In Manawatū-Horowhenua, Suzanne Downes says the highlight of her role is being able to make something happen for someone by knowing the right person in the community to contact. “Often it is being able to solve the simplest requests that bring the biggest rewards, for example connecting a child with ASD with a local footie team; placing a ‘Gardening Work Wanted’ ad on the local New World noticeboard for a solo mum that has now provided her with a couple of days’ work per week at a retirement village and boosted her confidence.”

Team manager Sue Kobar says the lack of respite support is evident across the country, as are issues with inclusive education. “Some schools are just not inclusive, even though they are required to be,” she says. “Lack of affordable housing is very much a concern.” Sue says fatigue with red tape is wearing families down and they welcome people who will stick with them. “They feel very, very let down by agencies. I think they have been promised things before, and nothing has eventuated. People say thank you for coming back, thank you for following through.”



Suzanne Downes – Manawatū-Horowhenua.

IHC volunteers show the love

A satisfaction survey asking IHC volunteers about their experiences has revealed that the volunteers love what they do, and are hugely appreciated.

An overwhelming number – 99 percent of the volunteers who gave feedback – rated their experience as positive and said they would recommend the IHC Volunteer Programme to their friends.

“This is a fantastic result and shows that volunteers clearly place value on their experience as an IHC volunteer,” says IHC National Manager of Volunteering Sue Kobar.

Another stand-out from the survey was that volunteers feel valued by both IHC and their friends, with 99 percent saying they felt appreciated.

Sue says it's important to check in regularly to make sure volunteers are well supported so we can identify areas for improvement. “The feedback we receive helps us to ensure we are providing the best possible experience for volunteers and their friends – this is very important to me.”

Between June 2018 and June 2019, 806 volunteers gave more than 24,500 hours to the IHC Volunteer Programme, creating many strong friendships. “We are extremely grateful to IHC volunteers for the positive impact they make in someone's life and for their support of IHC,” says Sue.

The award-winning IHC Volunteer Programme started in 2006, offering people with intellectual disabilities friends who were not paid to spend time with them. The programme gives people with intellectual disabilities important



Pictured from left are Chris McClimont and William Revelo, who met each other last year as part of the IHC Volunteer Programme. What started as a skill-based assignment, with William helping Chris to access music and videos on his iPad, has turned into a strong friendship.

community connections and above all one-to-one friendships, which are an integral part of health and wellbeing.

Last year the IHC Volunteer Programme won an Outstanding Achievement award in the Minister of Health Volunteer Awards. Regional programmes and individual volunteers have also been recognised. In the most recent awards in June, Waikato volunteers won second place for Team Excellence in the Waikato Volunteer Excellence Awards.

In 2015 we introduced the Skill-based Learning Programme, aimed at helping people with intellectual disabilities to learn

something new. People with intellectual disabilities told us they would like to learn how to do such things as budgeting, cooking, finding a job and using an iPad.

Sue says the programme has also adapted to changes in how volunteers want to donate their time. “Instead of committing a year or more to the programme, volunteers can opt to do skill-based learning over 10–12 weeks.”

If you would like to find out more about IHC's Volunteer Programme or would like to sign up, please call 0800 442 442 or email volunteering@ihc.org.nz. We welcome applicants aged 17 and over.

Banks agree to make banking easier

From January 2020, banks will follow new guidelines to make banking easier for older and disabled customers and protect them from potential abuse.

The revised guidelines, written in clear language, will be mandatory for banks.

Minister for Disability Issues Carmel Sepuloni launched the New Zealand Bankers' Association's (NZBA's) revised guidelines in April, saying they were in line with the Government's focus on increasing accessibility for all New Zealanders.

She says financial abuse is as much a concern for the disability community as it is for older people.

"Ensuring that all banks have guidelines to mitigate potential abuse of the elderly and the disabled is essential to protecting them from harm."

NZBA Chief Executive Roger Beaumont says the guidelines were first launched back in 2009. "Back then they were voluntary for our banks. All of our retail members have now committed to follow the revised guidelines by 1 January 2020."

Banks say they will train staff to understand and help meet the needs

of older and disabled customers and to consider older and disabled customers' needs when publishing information, designing physical spaces, and developing ATM and electronic services.

NZBA consulted its Older and Disabled People Focus Group in developing the revised guidelines. IHC was represented in the Focus Group.

IHC Director of Advocacy Trish Grant welcomes the new mandatory guidelines, which she says will go some way towards protecting the interests of people with intellectual disabilities. There is still work to be done with banks to make sure that people with disabilities can make their own decisions about their affairs, with support.

"Article 12 of the United Nations Convention on the Rights of Persons with Disabilities says that everyone, no matter what their disability, has full legal rights. But in New Zealand we are still trying to work out the best way to support people with intellectual disabilities to make their own decisions – including financial decisions."

The revised guidelines are available at nzba.org.nz (search banking guidelines).

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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

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ISSN 1171-8587

Notice of 2019 IHC Annual General Meeting

The 2019 Annual General Meeting of the Society will be held at:

5pm, Friday 13 September 2019, Rydges Hotel, Featherston Street, Wellington

Agenda

- 1. Welcome**
- 2. Meeting Procedures**
- 3. Adoption of the Minutes of the 2018 Annual General Meeting**
- 4. Presentation of the Annual Report, including Reports from the Board Chair, IHC Group Chief Executive and Board Committees**
- 5. Appointment of Board Members**
- 6. Election of Patrons**
- 7. Appointment of Auditor**
- 8. Annual Membership Subscription**
- 9. General Business**

2019 Annual Report

The 2019 Annual Report and financial statements will be available at the Annual General Meeting. They will also be available at ihc.org.nz before the Annual General Meeting.

Ralph Jones

IHC Group Chief Executive

