

Community MOVES

SPRING 2020

**LIVE AND
LET LOVE**

**LOCKDOWN FAMILIES AT
BREAKING POINT**

**PETER AND THE WOLF
WORKED MAGIC**

Personally speaking



As I write this, a major review of the health and disability sector has just been released.

The report notes that more than half of those receiving disability support in New Zealand have intellectual disabilities, and the report's author, Heather Simpson, says that people with disabilities have not been well served. Her report also says that an individual's disability should not define their life chances.

At this stage we do not know what recommendations will be implemented by the Government, but we welcome suggestions that will improve people's lives. We already know that much has changed since the Covid-19 lockdown with providers trying to adapt to a future where more people move to individualised funding and direct their own support.

We are also considering some changes. For some time, the people we support, their families and our staff have talked about a more contemporary approach to vocational services that better responds to individuals' interests. We know that many young people want to have the same experiences as other people their age and want a wider range of activities. Many older people want to spend more time at home or doing their own thing and don't want their weekday lives to be dictated by the times of van runs. Many others too want things to be different – more socialising, more employment opportunities and more support to follow their own interests at the times of day when everybody else is doing those things.

At the end of May we announced that we would be widening our review of our vocational services to include our residential services. This National Service Review is about having a better connected (24/7 where needed) approach to providing services. Change can be unsettling, but we want to reassure people that this is about providing better and more individualised support.

We have opened a small number of day bases for people who live with families, in contract board or with other providers to ensure everyone is supported during the day.

We are consulting widely on these changes and have not made any decisions. The people who live in our residential services are continuing to be supported to get out and about for activities and to see friends, but they are doing that from home at the moment rather than at, or from, day bases.

We are determined to grow our business and provide the best support and career opportunities in the sector, and will keep you updated throughout this process. Please visit our website ihc.org.nz/news

Ralph Jones
IHC Group Chief Executive

Try to see it my way

Ordinary lives. This doesn't sound like much, and it's something most people take for granted. But for many with intellectual disabilities it's a dream.

That's why IHC Director of Advocacy Trish Grant is calling on all parties contesting the General Election to make the dream a reality.

"People with intellectual disabilities must navigate a complex system so they can lead ordinary lives," she says.

For instance, funding could be coming from three different government agencies, services can be provided by multiple providers, and different groups may be safeguarding one person.

"People don't know how to easily complain or get decisions that have been made about them reviewed by an independent person," Trish says.

"Services and government agencies don't talk to each other and people end up telling their stories multiple times."

Trish says the next government needs to create a centralised government agency – a commission or a department – to oversee all aspects of disability, such as funding, services, safeguarding, service improvement, protection of rights and monitoring wellbeing.

"We think people with disabilities are important enough to be reflected like



Harry Sarll, who lives in his own home in Golden Bay, north-west of Nelson, values his job. He and his support worker collect sea grass from Farewell Spit and bag up horse manure from the local Riding for the Disabled Association for local market gardens.

this in government and they need an agency to ensure that every policy is examined through a disability lens."

IHC is also calling on leaders to provide free six-monthly health checks for people with intellectual disabilities as well as increased training for healthcare workers on how to better work with and value people with intellectual disabilities.

"People with intellectual disabilities die two decades earlier than people in the general population," Trish says.

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COVER IMAGE:

More than ready to get out and about as the country went into Alert Level 2, Support Worker Finbar Drown and Marie Hunt found a friendly feline on a walk around their Hastings neighbourhood. See lockdown stories pages 8-10.

Labour and National – head to head



What Labour says:

Labour believes that a truly inclusive society is one in which disabled people have meaningful lives within their communities based on respect and dignity, have their diversity recognised, and have their human rights supported. Labour will:

- Implement the recommendations from the New Zealand Health and Disability System Review including, ensuring consistency in assessment and coordination of disability support, and extending policy promoting choice and flexibility
- Support the provision of vocational services to people with disabilities
- Encourage employers to adopt equal opportunity hiring practices, and ensure these include people with disabilities
- Ensure that all children are welcome, included, and learning to their full potential at their local schools
- Comprehensively review the entire system of special needs support so that resources are allocated based on an individual needs assessment for each child, rather than each child having to meet the criteria imposed by the system
- Review funding of physical and occupation therapy in schools
- Consider providing free annual health checks for people with intellectual disabilities.

See more: labour.org.nz/health



What National says:

National is committed to implementing the New Zealand Disability Strategy 2016–2026 and the Enabling Good Lives programme. National will:

- Continue to build on this model to provide choice and control to New Zealanders with disabilities
- Put people and families 'at the heart' of disability policy and work with them
- Work towards ensuring all government services and publications are disability friendly and accessible to all
- Improve a large and complex disability system, which has too many New Zealanders falling through the cracks and not getting the support they need
- Assess whether minimum wage exemptions or government subsidies work best for people with learning disabilities looking for work
- Have a dedicated, trained disability employment advisor in every Work and Income office. The employment rate for disabled people in New Zealand is 23 percent compared to almost 70 percent for non-disabled.

See more: national.org.nz/health

Try to see



Taking in the beauty of Lake Wairarapa after lockdown are (from

Continued from page 3

IHC wants the Government to address its concern that students with intellectual disabilities are often excluded or denied the inclusive mainstream education they are legally entitled to.

“The Government wants to allow teachers to use force, which will disproportionately affect students with difficult behaviours,” Trish says.

“We think that force should stay out of schools, and school decisions need to be reviewed by an independent body.”

The Government is spending about \$107 million more on disability support services in 2020, but disability support remains confusing and hard to access. “The review of disability support services just released identifies the need for better information about what’s on offer, easier access to streamlined support and national consistency of needs assessment and coordination services,” Trish says.

it my way



(from left), Lilli Neves, Alan Rosemergy, Natalie McCarthy, Catherine Scully and Arlene Stringer. They try to make the most of what their community has to offer.

Trish says government agencies need to radically rethink disability services funding and move towards a single personal budget for people and families to spend however they need to.

“We also think the Government should fund more advocacy services for people with disabilities so they can have someone in their corner when they want to make decisions, and also fund mandatory training for general practitioners, lawyers and judges about supported decision-making.”

The Government has funded an expansion to disability employment services but there needs to be new thinking about how to employ more people with intellectual disabilities in meaningful work.

“We think the Government should create more targeted positions in the public service for people with intellectual disabilities,” Trish says.

“People in these positions could use their lived experiences to improve government policies,

procedures and services for people with intellectual disabilities.”

As the Covid-19 lockdown has highlighted, people with intellectual disabilities often experience loneliness, isolation, and poor wellbeing. Even the comfort of having a pet is denied many disabled people.

“We also think the Government should fund a SuperGold-type card for people with disabilities so they can get out and about in the world a bit more easily,” Trish says.

Sadly, it’s children and young people with intellectual disabilities who often have a hard time getting the support they need.

During the lockdown there was widespread evidence from around the world that children with higher needs were regressing in their language and social skills because they weren’t able to access their usual specialist support.

Children here wait, on average, for 80 days to receive support they need.

In some areas children wait for up to 170 days for early intervention services. There are more than 4000 children on waiting lists and this number is increasing every year.

“More work needs to be done on scoping where demand is and determining how to provide it,” Trish says.

Children with intellectual disabilities are also at a significant risk of abuse. The World Health Organisation states that children with disabilities are 3.7 times more likely than non-disabled children to be victims of any sort of violence.

“We want the Government to target this group for added safeguarding, collect and maintain information about this group and create a taskforce to examine the deaths of children and young people with disabilities to develop strategies to protect this group,” Trish says.

It’s quite an election wishlist, but Trish says it all adds up to giving people with intellectual disabilities something extraordinary – an ordinary life.



IHC stars celebrated with Queen's Birthday honours

Two volunteers, already celebrated within IHC for their huge contributions, have been recognised with Queen's Birthday honours.

Maureen Wood, former National Council member and current Chair of the IHC West Central Auckland Association, has been made a Member of the New Zealand Order of Merit.

Neil Taylor, former Chair of IHC, has been awarded a Queen's Service Medal.

"Both Maureen and Neil have made an extraordinary contribution over nearly a century between them to improving the lives of people with intellectual disabilities," says IHC Group Chief Executive Ralph Jones. "We are delighted to see such worthy recipients honoured in this way."

As a young mother Maureen challenged the medical establishment of the time, which was separating disabled children from their parents, and for 60 years she has never stopped seizing opportunities to make people's lives better.

Maureen and her husband Ted rejected institutional care for their daughter, Jackie, born in 1958.

She joined IHC in 1961 and supported other parents to stand up to pressure to have their children admitted to psychiatric and psychopaedic institutions. "The bond was broken with families and it's very hard to get that bond back again," Maureen said in 2011 on becoming an IHC New Zealand Life Member.

During the 1980s and 1990s she lobbied for the institutions to be closed and said she would have lobbied "forever" to see them shut down. She worked to ensure there were good quality disability and health services and that the people using them had their say. She evaluated a range of residential and other disability services for auditing agencies contracted by the Ministry of Health from 2001 until early 2019.

As Chair of Waitakere Health Link, she campaigned hard for improvements at Waitakere Hospital, including getting free ambulances in 2001 and a full 24-hour emergency service running at Waitakere Hospital 10 years later.

Neil Taylor has been involved with IHC for more than 40 years and has given his time and expertise to improve the lives of people with intellectual disabilities in Taranaki and throughout New Zealand.

When Neil became involved in IHC in the late 1970s he joined a team of parents in South Taranaki who raised money 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 in 2016, 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 disabilities."

Neil was South Taranaki Branch President from 1986 to 1996. He also served as IHC Vice President, and on the boards of both IHC and Accessible Properties Ltd, chairing the audit and finance committees of both organisations. He was the IHC Board Chair from 2017 until earlier this year and remains on that board. He was made a New Zealand Life Member in 1998.

Libby plans to make acting her future

The cameras have stopped rolling, the lights have been turned off and young actor Libby Hunsdale is heading back to Whanganui Girls' College.

But for Libby the story is far from over. She identifies strongly with her character in the new feature film *Poppy*, about a young woman with Down syndrome who refuses to let other people set limits on her life and sets out to be a motor mechanic.

Libby, 18, is making her move too – she's planning a future on screen.

"The first thing I really want to do is to get an agent for new jobs," she says. "I feel so much more confident in myself career wise – where I want to go in my future."

Libby says she will finish this year and next at school. "And after that I am thinking of going to Victoria University to study film, to see the other parts of film – filming and directing. I want to do film and TV and I want to do some modelling."

Her ambition was encouraged by the film crew, who gave Libby a parting gift of a director's chair with her name emblazoned across the back. *Poppy* was the first New Zealand feature film to go back into production after lockdown. It had only one week of filming to go on the Kāpiti Coast, near Wellington, before cast and crew had to disperse.

Libby has studied drama and dance, but this was her first time in front of the camera, and it was made easier for her with acting coaching from Miranda Harcourt and Ella Hope-Higginson before filming started. Coaching on set was also provided by Stella Reid,



Libby Hunsdale with co-star Ari Boyland on the set of *Poppy* on the Kāpiti Coast. Photograph: Ness Patea.

Taylor Rogers and Jessi Williams. The IHC Foundation contributed \$25,000 towards the coaching.

"As someone with Down syndrome, I can get very tired with acting and stuff. It helped me to do my breath work and be calm," she says. "We had to do a lot of variations and a lot of takes and it was hard to get used to it. I loved it because it was a roller-coaster ride."

She also loved working with male lead actor Ari Boyland. "I found that quite a big deal to meet him in person. He has been really nice. He helped me a lot with the acting." She has mixed

feelings about the end of filming. "There is a part of me that is sad, but there is a part of me that is quite excited because I don't know what the film is going to look like."

Poppy, produced by Robin Laing and Alex Cole-Baker, is the debut feature for Raumati writer-director Linda Niccol and is based on her short story *Poppy*. The film is financed by the New Zealand Film Commission's 125 Fund set up in 2018 to celebrate 125 years of universal suffrage, and by TVNZ, NZ On Air, the IHC Foundation and private philanthropic funders. It is scheduled for release towards the end of the year.

Lockdown brought fam

Lockdown brought families living with intellectual disabilities to breaking point. While most Kiwis stayed home, fired up their wifi and began to live and work online, the isolation was extreme for families caring for young disabled children at home all day and for disabled adults living independently.

These two groups, identified by IHC as being especially vulnerable, were the focus of a series of emergency initiatives. IHC mobilised its nationwide volunteer network and worked with partners in the disability sector to connect with people online and on the phone.

IHC Director of Advocacy Trish Grant says young families had no school, no respite, no outside activities and children who wouldn't engage in online learning. "Life was pretty grim, and they had to start having four or five conversations with various agencies."

"People were panicking, 'How on earth am I ever going to be able to cope?'" Trish says. "Families were feeling quite frightened about how things might escalate. With a couple of families, I was really worried about mental health issues," she says.

"It was not just about disability support. Families live fairly highly tuned lives, so that when one thing changes then everything topples over. What we know is that systems are complex and don't work easily for young children and families."

Trish says policy and practice need to join up so that children receive the help they need. "You also need to know what you can do in the interim if your child needs something additional." She says this might mean being able to talk to a psychologist for half an hour. "Always being on the back foot is not a great place to be."



Canterbury filmmaker and mum Fiona McKenzie interviewed families about ways to get through the lockdown. She is pictured with her daughter Claudia.

She was also very concerned about the disabled people who were living independently. For weeks they often had little in the way of human contact, except for deliveries of groceries, after losing their regular support workers. "There was no question that people felt very challenged. At the start there were people who were very angry."

New Zealand became a largely cashless society, with many businesses accepting only cards. This excluded people with intellectual disabilities without credit or debit cards. "It was a real problem for people not being able to purchase things," Trish says. Many Kiwis switched to video calls to connect with families, friends and colleagues. But a lot of disabled people don't have smart phones. Only 53 percent

of the 900 people in IDEA Services' Supported Living service had mobile phones.

"It was great when we got the 0800 number up and running," she says. People First New Zealand, IHC and The Personal Advocacy and Safeguarding Adults Trust collaborated on the helpline. IHC also coordinated Awhi-at-home, a Facebook community for parents to keep connected and support each other, with input from a number of disability and government agencies. In a further initiative IHC and Carers NZ launched wecare.kiwi – a free support network for people living on their own or caring for a vulnerable person. Carers NZ triaged the requests for help and then referred family carers or the people with disabilities to IHC.

Families to breaking point

Support hours reduced

IHC Self-Advocacy Coordinator David Corner usually receives five hours' support a week from his disability service. This was reduced to one hour a week for the whole of Alert Levels 4 and 3. Realising how this was going to affect people in his position, David took action.

Every week he called 10 people and says he found that people were losing their confidence. "The staff were actually doing their shopping. That was quite sad in some cases because quite a lot of the people that I was talking to could have done their own shopping. It was sort of the only freedom – it was the only time you could get out and talk to people," he says. "I don't think bubbles were explained to them. If you lived on your own, you could add another person to your bubble."

And staying connected was difficult with pay-as-you-go phones. "Some people were a bit worried about their mobile phones and being able to top-up their mobile phones."

Fiona McKenzie manages her daughter Claudia's individualised funding and in lockdown managed all her support as well.

"For a lot of us Level 4 and Level 3 were just the way we live anyway. Suddenly, now that the whole country is in that position, the Government and the ministries have been able to free up and provide things that families have been asking for, for a long time."

Fiona, who lost her support worker for Claudia, 21, says getting respite and good support is a constant issue for families. Families might qualify for respite hours but have trouble using them.

During lockdown Fiona, a Canterbury filmmaker, was part of the Awhi-at-home crew. In a series of video interviews posted on its Facebook page Fiona talked to mothers about what they were finding hard and what worked for them. It was a lifeline for

many parents, but she says they are wondering what life will be like in the 'new normal'.

"There is a degree of cynicism and eye-rolling. How many times do we have to say that we need this and it's not available? It's not just the money; we need more options. We need enough resources to make our lives bearable."

Families are tired

Fiona says the present funding systems just add stress. "I don't talk

to other families about my budget. I am terrified that I might be getting too much or not enough. We don't want to be employers. We don't want to do timesheets and contracts," she says.

"Families are tired, and they all recognise that this is an opportunity for a personal reset. This is a good time to change the systems that are not working for families. The families are not just saying listen to us. The question now that people want to ask is how can you show me that you are listening to us?"



Darren Steward, on Auckland's North Shore, got into the lockdown handwashing routine.



Auckland pre-schooler Lachlan Gray and Victoria University music therapy student Holly McPhee make music on Zoom.

Peter and the Wolf worked magic across the miles

Three-year-old Lachlan was in Auckland having a great time making chicken music and Holly was in Southland making wolf music. Lockdown didn't stop Prokofiev's children's symphony *Peter and the Wolf* working its magic.

Holly McPhee is one of six second-year music therapy students at Victoria University of Wellington who provided free online musical interaction for families struggling to entertain young children – and the offer was music to the ears of their parents.

Daphne Rickson, Associate Professor at the university's School of Music, put the word out on the Awhi-at-home Facebook page. The sessions were designed to help parents and provide some experience for students who couldn't go to placements at early-intervention centres and schools.

In Auckland Tania Gray was caring for Lachlan and five-month-old Claire. She says that when watching Holly interact with her son, she recalled growing up with her older autistic brother. "I wish I'd had access to a programme that helped me engage with my brother

through music. We would have had more of a sibling-type relationship," she says.

"I never learned music, but I know the benefits of music and I want that for my child." Tania says she hopes parents will be encouraged to bring more music into their homes to help them and siblings connect with their child with special needs. "It's not just about the music. It's learning to listen. It's activating all parts of the brain."

Holly started her sessions with a meeting with Tania. "Tania said that *Peter and the Wolf* was a favourite of Lachie's ... and that he knew all the different themes and what instruments they were played on. I thought this would be a great familiar piece of music to create an activity around and to engage Lachie. I played each theme to him and challenged him to tell me which character it represented, and he named all of them correctly."

Daphne Rickson says while the sessions were not music therapy as such, online interaction has some advantages. "One of the things we can do is share the music resources that you can find online, as shown by Holly and Lachlan." Daphne says that the sessions could be recorded, which was another advantage, because this enabled teachers to watch the

recordings and to give detailed feedback to students by commenting directly within the timeline. "We are actually using the Awhi-at-home work as the students' mid-term assessment."

No family had to have a musical instrument to participate. Daphne says families made use of what they had at home. "If you can't have an instrument, you do body percussion, or you bang on the table." Or in Lachlan's case on the bottom of a pot.



No musical instruments are needed if a pot and a wooden spoon are handy.

Masks come off at Byron Bay



The first Autism Camp Australia camp was held in January this year at Byron Bay on the New South Wales coast. Five more camps are planned before the end of the year.

Rachel Rowe's idea is a winner. She set out to find a place where autism families could escape and be themselves. No masks needed, no one to judge.

When she couldn't find anywhere to go, she created a place. She started Autism Camp Australia (ACA) last year and families are flocking in.

Rachel picked a beautiful location for her first camp in January this year. It was held at Byron Bay on the New South Wales coast, near where she lives in the Byron Bay hinterland. Then Covid-19 arrived and three camps scheduled for autumn were postponed, soon followed by the postponement of the three winter camps. "We made the call probably a little bit earlier than others because some autistic young people have co-morbidities that make them more vulnerable to Covid-19, and we wanted our families to be safe." But camps reopen in September, with five

planned before Christmas and most are already sold out.

While families wait for a camp booking, they can keep connected with each other and in touch with ACA through Autism Camp TV, which has been providing fun ideas and support sessions during lockdown. "Everybody has had to adapt to survive."

Rachel, Chief Executive of ACA, says the idea came out of her family's need for a respite-based holiday. She wanted a place where her nine-year-old daughter could be with other autistic young people, enjoy tailor-made programmes to build her capacity in communication, social interaction and sensory and emotional regulation, among a range of skills, and be looked after by carers with lived experience of autism. It needed to also be a place where her allistic (non-autistic) sister, aged five, would feel special and supported as a sibling, and where their parents could get a break, educational support,

and some self-care and meet other parents of autistic young people.

"A big part of life for autistic people is masking, and masking has an incredibly exhausting mental load," Rachel says. The camps are a place where autistic people don't have to mask or camouflage behaviour that can be seen by allistics as socially unacceptable in order to fit in.

To check that she was on track with what other families wanted, Rachel sent out a questionnaire across Australia and had more than 800 replies – most with a resounding yes please. "The response has been huge," she says. "I formed my Board in the middle of last year and we launched in November." With the first camp opening in January it was a fast trajectory. "Well I am autistic, which means I go at about a gazillion miles an hour," Rachel says.

The camp – over five days and four nights – runs three programmes,

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Three programmes run simultaneously: one for autistic young people, one for siblings and one for parents.

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one for autistic young people aged seven to 14 years, one for siblings and one for parents/carers. Activities are a mixture of resilience building and fun for all three groups. They include proprioceptive sensory activities to reduce anxiety, social skills support, art therapy, equine-assisted learning, water sports, beach games, campfire and damper making, orienteering, bike riding and a ropes course. Workshops for parents/carers include family narratives and navigating relationships with children's schools, and self-care yoga, meditation and workout sessions.

The plan is to hold 12 camps a year, each taking up to 10 families, or 40–50 people. It will take more than a pandemic to dampen Rachel's vision. She is planning to open a second location on the Sunshine Coast in December and hopes to have a total of six locations around Australia, with 700 Australian families enjoying camps by 2023. She is also considering locations overseas, including New Zealand.

Family breaks top the list

It was the perfect time to ask families about their dream escapes.

The community of families that formed during lockdown around the Awhi-at-home Facebook page were all at home caring for disabled children with no breaks at all.

Elizabeth Goodwin, convenor of the Awhi-at-home community, says families were asked to say what they wanted in the way of respite, and the ideas came rolling in. Parents wanted breaks for themselves, but at the same time wanted their whole families to have experiences where they could create memories.

“What we did was co-design a solution with parents online during Covid. It was magical.”

Elizabeth says that, for some parents, respite was having an

hour to be able to read a book. “I interviewed a parent once who said, ‘The only social life I have is doing road patrol!’”

Elizabeth says a strong desire for regional retreats emerged from the feedback, where families could be together. “You will be with other people like you. We won't judge you. Your child will be there, and you will be you. They need to know that their children are being cared for by people they can trust.”

One parent shared a link to Autism Camp Australia as the kind of enterprise that could also work here.

Elizabeth says some parents are extremely isolated. “What we want to do is to reach parents we don't normally reach.”

A parents' collective, supported by IHC, will now explore the idea of holding regional retreats.

Lives and deaths remain under the radar

People with intellectual disabilities struggle to get a mention in official statistics while they are alive – and their deaths too have warranted little notice or curiosity.

In his report ‘Off the Record’, released in July, Chief Ombudsman Peter Boshier has identified major gaps in the Ministry of Health’s collection and use of information about the deaths of people with intellectual disabilities in full-time residential care.

He examined data collected by the Ministry about the deaths of 108 people over a two-and-a-half-year period.

“I began this investigation after being approached by people from the health and disability sector with concerns about a lack of information, follow-up and reporting, especially when there was a sudden or unexpected death,” Peter Boshier says.

IHC was one of the disability service providers urging better data collection. “We have been in dialogue with the Ombudsman’s office for several years,” says IHC Director of Advocacy Trish Grant.

The Chief Ombudsman’s investigation found that the Ministry’s systems were not adequate or robust; information collected was not complete, accurate or sufficient; and there was no evidence of it being used to make improvements in practice.

Peter Boshier says the Ministry’s record-keeping deficiencies were brought into sharp focus by the problems his investigation teams had obtaining relevant information.

“My investigation led to the Ministry service responsible for overseeing residential services identifying 30 deaths during the period under investigation that it was previously unaware of,” he says. “This was despite the information being held in other parts of the Ministry.

“People with intellectual disabilities are among the most marginalised members of society. Their overall

health is poorer compared to people without intellectual disabilities, and they have a significantly lower life expectancy.

“The Ministry of Health funds residential support services. It is also responsible for monitoring the system, quality control and leading improvements that support people to live longer and healthier lives. I fail to see how it can meet these responsibilities or measure its own performance without good data and accurate record-keeping.”

He says the Ministry has already made substantial improvements, including introducing a Standard Operating Procedure for the reporting of deaths.

“I have made 10 recommendations, which aim to ensure the new approach is fully effective and sustainable, and which look to additional opportunities for improvement. These include a recommendation that the Ministry establishes an audit process to ensure relevant information is being shared, and records are up to standard. I have also recommended that the Ministry takes steps to ensure an appropriate level of review following a death.”

Trish says mortality data is only one aspect. The recently released Health and Disability System Review also highlighted the lack of information collected about disabled people at every level. She says there has to be better data collected on the health status of intellectually disabled people. “What this report does is provide a lens on the worst end – what happens when people die,” she says. “In terms of the deaths, this an example of woeful disregard and exposes the lack of systemic monitoring and oversight.”

There was no curiosity about sudden and unexplainable deaths. If someone who hadn’t been sick died suddenly, no-one asked, “Why did they die?”

“How many deaths should have gone to the coroner and didn’t, or to the police?” Trish asks. “There is almost an acceptance that weird things are going to happen to these people.



“My investigation led to the Ministry ... identifying 30 deaths during the period under investigation that it was previously unaware of.”
Chief Ombudsman Peter Boshier

“The fact that the report can’t say how many of the deaths were preventable is a real indictment on the Ministry of Health.

“One of the most remarkable sections of ‘Off the Record’ details that Disability Service senior managers told the Ombudsman’s office that they had no mandate to obtain the outcome of a coronial inquiry into the death of a service user,” Trish says.

Tensions exist when the Ministry of Health is both a contract manager seeking to maintain trust-based relationships with providers and a regulator ensuring compliance.

“The Health and Disability System Review seeks to separate the stewardship role from the service delivery role. This is crucial. If these roles are combined it can be a conflict of interest.”



IHC Leadership Giving Manager Chansina Chin and National Fundraising Manager Greg Millar are keen to encourage donors to get more involved.

Winning the hearts and minds of donors

IHC fundraiser Chansina Chin is convinced that the more people know about the work IHC is doing, the more they will want to get involved.

Chansina is IHC's new Leadership Giving Manager in charge of bequests, grant funding and major gifts. She is keen to build stronger relationships with donors and grant funders to let them see more of what IHC is doing to transform the lives of people with intellectual disabilities.

"What I want to do is to form relationships with donors that are more than transactional," she says. That means not just them giving us money and IHC saying "thank you". "We want them to become invested in the organisation."

She says IHC has a solid base of very loyal donors and she is keen to talk to them about the scope of IHC's work with people with intellectual disabilities and their families. "We have a lot of amazing things happening," she says. And a lot more is being planned, but that is dependent on funding.

Chansina says fundraising can do

more to support the work of IHC Advocacy and the IHC Foundation. "We are talking about transformative giving that looks at changing the lives of people with intellectual disabilities."

She says donors are keen to give to specific activities. During the Covid-19 lockdown IHC received some generous donations to its Emergency Appeal to support isolated families and people with intellectual disabilities. Three individuals each gave \$10,000 and grants were received from Otago Community Trust (\$25,000), the Ministry of Social Development Covid-19 Fund (\$32,000) and Reed Charitable Trust (\$9,500).

A total of \$280,000 was raised in the appeal. The funds were used for the Awhi Community project, which put devices in our residential homes so people could stay connected with family, friends and their communities. Funds also went to Awhi-at-Home, a parent support page on Facebook, which provided advice and a supportive community for parents of children with intellectual disabilities. The appeal also funded general support for families of children with intellectual disabilities.

Now IHC is hoping to continue some

of the initiatives that came out of lockdown, such as a family respite project that started with Awhi-at-Home.

Chansina says once donors know that they can make a difference to people in a tangible way, they can be encouraged to give bigger donations. She believes many people would be open to that, and she is not afraid to be turned down. "If you don't ask you don't know. The worst they can do is to say 'no' – and they might say 'yes!'"

Chansina, who had been working in the Waikato as a fundraiser for St John New Zealand, started working for IHC in March 2019. In her new role Chansina is looking to boost income in three areas – major gifts, grants' funding and bequests. "A very small percentage of fundraising comes from major donors and grants. Bequests, direct mail and regular giving are the organisation's biggest source of income."

National Fundraising Manager Greg Millar says IHC donors have stuck by us during the Covid-19 emergency because they feel concerned for people who they see as among the most vulnerable and often the most invisible members of our communities.

What's your legacy?

You will have a lasting, positive impact on people with intellectual disabilities and their families by leaving a gift to IHC in your Will.

If you would like some more information on leaving a gift in your Will to IHC, please call 0800 746 444 or email bequests@ihc.org.nz and ask for Greg.

ihc.org.nz/bequests



NOTICE OF 2020 ANNUAL GENERAL MEETING

Notice is hereby given of IHC New Zealand Incorporated's Annual General Meeting to be held at **3:30pm Friday 11 September 2020**
The Rydges Wellington Airport, 28 Stewart Duff Drive, Rongotai, Wellington

Draft Agenda

1. Calling of Meeting
2. Obituaries
3. Welcome
4. Apologies
5. Meeting Rules and Procedures
6. Confirmation of 2019 AGM Minutes
7. Matters Arising from Minutes
8. Presentation of Annual Report, including reports from Board Chair, Chief Executive and Board Committees
9. Board Appointments Committee - Appointment of Board Members
10. Election of Patrons
11. Appointment of the Auditor
12. Annual Membership Subscription
13. Remit: Proposed Amendments to IHC's Constitution and Rules
14. New Zealand Life Membership Award
15. General Business
16. Next Meeting
17. Thanks and Closing

2019/20 Annual Report

The 2019/20 Annual Report and financial statements will be available at the Annual General Meeting. They will also be available on the IHC website ihc.org.nz prior to the Annual General Meeting.

Ralph Jones
IHC Group Chief Executive

**IHC NEW ZEALAND
INCORPORATED**
ihc.org.nz

IHC BOARD

Tony Shaw, Chair
Ralph Jones, Chief Executive
Dr Lynne Lane
Barbara Rocco ONZM
Neil Taylor QSM
Suzanne Win
Pauline Winter QSO

IHC MEMBER COUNCIL

Barbara Rocco, Chair, ONZM
Mark Campbell
Janet Derbyshire
David Howorth
Dr Diane Mara MNZM
Vicki Owen
Kay Pearce

PATRONS

Sir Roderick Deane KNZM and
Gillian, Lady Deane CNZM

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Jan Dowland MNZM
John Hanning
John Holdsworth ONZM
Shelley Payne
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Maureen Wood MNZM

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ISSN 1171-8587

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Entries close Friday 11 September

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ihc.org.nz/art-awards-2020

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