# Strong Voices

Autumn 2023 It's time for disabled students **Experts in the room IHC Live rocks** 



## Kōrero

We have made changes in our services over the past couple of years, particularly in the way we support people to have more choice, control and flexibility in how they spend their time.

We know from talking to and working with people we support that things are better for many of them - but there will always be more to do.

We also commissioned an independent survey to hear the views of whānau. We randomly selected 542 people we support and, where possible, contacted their whānau. Of these whānau, 359 completed the survey - that's a whānau member for 16% of the people supported by IDEA Services residential services. This is what the survey told us:

- · Trust and confidence in the support workers who provided direct support to their family member: 88% of respondents were positive (satisfied or very satisfied), 4% were negative (unsatisfied/very unsatisfied)
- · Involvement in their family member's decision-making and day-to-day life: 78% positive, 9% negative
- · Overall experience and relationship with IDEA Services in providing support to their family member: 89% positive, 5% negative
- · The way IDEA Services supported their family member during COVID-19: more than 99% were positive/happy
- · Communication with Service Manager: 68% positive, 14% negative. Many said they did not know their Service Manager due to staff changes. We'll be looking at how we can ensure more consistency with those relationships.
- · Overall experience and relationship with IDEA Services in relation to providing support to their family member: 88% positive, 5% negative.

Whānau were asked about the way we handle complaints. A third of respondents had laid a complaint and two-thirds said it had been resolved to their satisfaction. That left 14% of all respondents saying their complaints had not been resolved to their satisfaction. Some of those complaints were historical (up to 20 years ago) but others said that they hadn't been well listened to or that agreed changes didn't go far enough. We are looking into this.

Whānau were also asked what we did well, what we could do better and what they valued most about what we do. People wanted better communication, more staff (including more consistent staffing) and more activities for the people we support. They often told us the most important things were keeping people A) healthy (37%), B) happy (28%), C) occupied (25%), D) safe (14%) and E) properly cared for (14%). The most common responses to a question on what they valued most about IDEA Services were trust in the organisation (37%), genuine care for people supported (32%), the Support Workers (28%) and the long-term relationships (22%).

We received these survey results at the end of last year and, naturally, are pleased with some of the results and considering ways to address the areas where we need to do better. We look forward to updating you,

Ralph Jones **IHC Group Chief Executive** 

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## Join the conversation:

We want to keep you posted. Be the first to read the news and views across the IHC Group and disability sector. We'd love to hear from you.







## Cover image:

Joy Lennox has volunteered on Christchurch city conservation projects for more than 20 years. She leaves home at 6am to volunteer at the Bottle Lake Forest Park in Burwood. Photograph by David Bayley of Bayley Photography. David is also an IDEA Services Support Worker.

#### Back page image:

The dancer in the centre, Lachlan Oakes, performs Break my silence with the Jolt dance company. His mother, Helen Oakes, is the photographer.

## Change is coming for IHC Associations and Member Council

IHC







IHC Chair Tony Shaw says this year the organisation will focus on providing a clearer role for IHC Associations and the Member Council and improving communication with all members.

In December, Tony told members that an independent review of the IHC Member Council and IHC Associations had suggested some changes in approach.

The review was discussed at a forum before last year's Annual General Meeting in early October and recommendations from the forum were then considered by the IHC Board. The Board has agreed to adopt the following feedback:

- Retain Associations and the Member Council with reduced functions, making them fit for the future.
- $\cdot$  Better resource the Member Council.
- Create more meaningful contact between the Council and the Board and the Council and Associations.
- Amplify the voice and participation of self-advocates.
- Improve IHC's communication with all members.

An Association and Member Council Working Group has been formed to consider the next steps. Membership was finalised after nomination closed at the end of January – three of the 11 members have been appointed by the IHC Board and eight further members joined after the nominations process. There are four from the

South Island, four from Wellington, one from Auckland and two from the Bay of Plenty. They are: David Corner, IHC Self-Advocacy Coordinator; Geoffrey Downing, Self-Advocate and Association committee member; Kim Pollock, Self-Advocate; Lynne Renouf, Association committee member; Anne Gilbert, Member Council; Fiona Diack, Association committee member; Cassy Williams, Member Council; Tony Shaw, IHC Board Chair; Suzanne Win, IDEA Services Board Chair; Barbara Rocco, Member Council Interim Chair; Janine Stewart, General Manager IHC Programmes.

The working group is being facilitated by IHC Director of Advocacy Tania Thomas. The group will meet once the Board has agreed on the detailed scope of work.

The working group will provide regular progress reports to the Board, Associations and Member Council.

The final working group report and recommendations will go to the Board by the end of April 2023.

Tony says IHC has around 1500 members and some of those most connected with the organisation are involved with Associations or the Member Council. He says the Board has acknowledged that changes need to be made and this year the organisation as a whole will discuss the need for a refreshed strategy.

"Recommendations include retaining both Associations and the Member Council but being clearer and more defined about their role and scope. The report also recommended we review and improve communications with members at all levels."

Retiring Member Council Chair Barbara Rocco will stay on until a new Chair is appointed. She says last year's review was a chance to think about how membership, Associations, the Member Council and the IHC Board all operate together. "Our Associations are often a key part of communities, but many Associations work differently from each other as they respond to local need."

She says the review included a comprehensive survey and many interviews. "We know that, like me, our members are passionate about our organisation and have a real interest in the services it provides, changes within the organisation and our charitable and community programmes."

Barbara, IHC President from 1994 to 2002, was appointed Member Council Chair by the IHC Board in 2015 and took up the role saying she wanted to give a voice to IHC members who felt disconnected from the organisation. Barbara is also standing down from the IHC Board.

Above: IHC Director of Advocacy Tania Thomas, IHC Board Chair Tony Shaw and retiring Member Council Chair Barbara Rocco.



## Will 2023 finally be the year for disabled students?

For years IHC has been telling the Government that disabled students are not getting the education they are entitled to.

Now, just when IHC's 14-year-old education complaint is getting close to a hearing in the Human Rights Review Tribunal, there has been a change of

In November, Associate Education Minister Jan Tinetti said the system for disabled learners was one of the most broken areas in education and announced that the Government would develop a new funding and support system.

"We have been talking about this for 14 years and suddenly they are agreeing

with us," says IHC Education Advocate Trish Grant, who has led the long campaign to fully include students in their local schools and end the discrimination.

Trish believes the pressure of the litigation has been very important in getting the parties to think differently.

"When we get a Minister saying the system is broken, there is greater acknowledgement at the official and Ministry of Education level that disabled children have missed out."

Complaints about the education of disabled students reached a tipping point late last year with three reports echoing the concerns IHC has been

In September, the Education Review Office (ERO) released two reports saying the families of many disabled learners are being discouraged from enrolling their children in early childhood services and schools.

ERO found that as many as one in four parents are being asked to keep their disabled child home.



The reports, Thriving at school? Education for disabled learners in schools, and A great start? Education for disabled children in early childhood education, found many early childhood and school teachers lacked the confidence to teach disabled learners, particularly those with complex needs.

"Their findings directly mirror the issues that we highlight in our statement of claim," Trish says.

Then in November the report of a six-month Ministry of Education Highest Needs Review was released. The review, which received over 1000 submissions, was told there was an urgent need for change because the current rigid funding system creates discrimination and lifelong disadvantage for students, families and schools.

The Government has outlined a 10-year plan to turn the system around.

Trish says the issue for IHC has always been about inclusion. "Inclusive communities begin with schooling when you go to the local school with your brothers and sisters and the kids from down the road," she says.

"IHC has been very clear with the

Ministry and Crown Law about what is required to achieve that vision.

"The system doesn't recognise disabled students as learners, it doesn't provide them with what they need to learn in their local schools, and it doesn't provide schools with what they need for successful inclusion of all students."

She says there is not enough data – the Ministry of Education doesn't know how many disabled students there are, where they are and what they need to access education. There is not enough money, not enough resourcing and not enough training for teachers.

"We have also got problems with the way we monitor the participation and achievement of students," Trish says.

"The fact that they are not counting what happens to disabled students means they are not valuing those students as learners."

Trish says we need to reset the Ongoing Resourcing Scheme (ORS) funding, improve teacher capacity and support, improve and acknowledge the rights of disabled students, and ensure access to specialist supports.

Meanwhile Trish says the IHC education complaint is moving forward with a timetable for a five-day hearing.

Before that IHC will be gathering evidence and witnesses.

"For the first part of this year we will be out talking to families. We will be talking to schools. We will be talking to witnesses. We are confident we are going to get that support. There are people lining up to give evidence and we are delighted with that.

"We have never been as close as we are now."

## Tell us your story

One in four families is being told to keep their disabled child at home. One in five is being discouraged from enrolling their disabled child in their local school.

This is not just what IHC says. This is official – from two latest reports from the Education Review Office looking at the experiences of disabled students at school and pre-school. ERO has recommended the relevant agencies report improvements by July this year.

What has been your experience? IHC is now gathering evidence to lodge ahead of a five-day hearing in the Human Rights Review Tribunal. Because of the importance of the case, Michael Timmins, the Director of the Office of Human Rights Proceedings, is providing legal representation for IHC.

"We want people to tell their stories because we know that many people's stories involve difficulties getting in the door – with enrolment," says IHC Advocate Trish Grant.

She says there are problems with teachers not knowing how to teach, and children being disciplined for behaviour relating to their disabilities.

"We want to hear evidence of all these things."

Trish says families and others who have direct experience of difficulties involving disabled students can log their experiences on the IHC website campaigns.ihc.org.nz or email us at advocacy@ihc.org.nz





Every five years Stats NZ runs the census - counting how many people and dwellings there are in New Zealand. The next census day will be Tuesday, 7 March 2023.

The 2023 Census will include a new question about limitations on daily activities. It will ask people whether a disability, long-term condition, or mental health condition limits their ability to carry out daily living activities.

Stats NZ will use the answers to this question to select people to take part in the 2023 New Zealand Disability Survey. It will also ask for people's phone numbers so it can contact them if they are selected to do the survey.

This year everyone can choose whether they do the 2023 Census online, or whether they do it on paper.

In February, Stats NZ is sending an access code to every household in New Zealand for people to use to fill out the online forms. These forms can be completed using a mobile phone, desktop, laptop or tablet. Many New Zealand homes will also receive paper forms.

IDEA Services is working with Stats NZ to make sure there will be support available for people living in residential homes and in our Supported Living Services to fill out the forms.

Information from the census helps the Government to plan how billions of dollars of government funding is spent. Because information is collected about everyone in New Zealand, it can be used to make plans such as hospitals, kōhanga reo, schools, roads and public transport and where they should be located.

Government Statistician and Chief Executive of Stats NZ Mark Sowden says the 2023 Census is being designed to enable people to participate in the way that works for them.

"The 2023 Census will be the most inclusive census yet. People will have more choice about how they participate, either online or on paper. We will have significantly more paper forms available than for the previous census and will make these forms available earlier.

"We are also doing more to support people whose first language is not English and will deliver the census in a wider range of accessible formats to better meet the needs of disabled people."

For help, or to request a paper copy of the census forms, call 0800 CENSUS (0800 236 787).

For more information about the census, go to census.govt.nz

## Key facts

- · Households are being sent a letter with an access code or paper forms in February.
- · Watch out for your letter in your mailbox
- $\cdot$  A census form must be completed for every member of the household.

Above: IDEA Services will support people in residential services and Supported Living to fill out the census.

## New, fresh look for IHC website

If you have visited the IHC website recently, you will have noticed some changes.

While you were enjoying a summer holiday, we were quietly launching a new website designed to make it easier for families, whānau and everyone else to find what they are looking for.

On top of our regular content there's a new section with information specifically for families.

"We have restructured it to be more user friendly and user focused," says IHC Senior Advisor for Content Management Heather Bruerton.

Heather says the website will help you find your way to all the new, cool stuff, such as our new Stand Tall gaming app and IHC Media live sessions.

There is information about what IHC can offer and how you can get involved in what IHC does.

At present, we are collecting evidence about the experiences of disabled students and their families to support our education complaint, which has a hearing coming up in the Human Rights Review Tribunal. Read about the issues that have led to the complaint and add your voice at campaigns.ihc.org.nz

The website is also where you can go to find out about anything else new that we are doing. Heather says news highlights will be featured on the home page.

The goal has been to use plain English and to make the website as accessible as possible for everyone who wants to visit.

And you can find it all at the same address - ihc.org.nz.

Come and visit.



# Powerlifter gets her chance to compete in Berlin

SECTOR

Medal-winning powerlifter Lynett Williams will now get her chance to compete in the 2023 Special Olympics World Summer Games in Berlin this year.

Lynett, from Invercargill, who won two silver medals and two bronze at the Special Olympics Summer Games in Hamilton in December, originally missed selection in October for the Berlin games. But she was a late addition to the 40-strong squad after a second selection process.

"It came as such a shock to her because she thought she wasn't going," says IDEA Services Support worker Melanie Vermeulen. Lynett, 30, has been supported by IDEA Services since 2011 and she started powerlifting eight years ago.

Her weekly training sessions with Special Olympics Southland will now ramp up with the New Zealand squad's powerlifting team coach Sonia Manaena. Sonia, herself a former champion powerlifter, will travel to Berlin as coach for the three powerlifters, including Ryan Stewart (Otago) and Caroline Tangitau (Tauranga).

"I have coached Lynett for eight-and-ahalf years. I know what she is capable of." Sonia says Lynett was chosen for the powerlifting team in November. She and Special Olympics Southland Chair Donna Milne decided to keep back the news for a couple of days so they could announce it at the Southland athletes' Christmas dinner on 25 November.

"Her reaction was quite extraordinary. She is a very shy young lady. "She just stood there, quite shocked," Sonia says. "She had tears coming down her face.



It was just great. She was very proud of having that opportunity."

"I couldn't say much," Lynett says.

But Lynett had to put all thoughts of the Berlin games aside to focus on the National Summer Games in Hamilton in December. Lynett competed in a 'three lift' – squat, bench press and deadlift. Her strongest event is the deadlift, and she recorded a personal best when she lifted 102.5kg, but Sonia says she has lifted more than that in training.

The Berlin games will be held from 17-25 June and more than 7000 athletes from 190 countries will compete in 26 sports. It is the world's largest inclusive sporting event. The New Zealand squad will compete in nine sports. The New Zealanders will first travel to the south of Germany, where they will be hosted by the city of Garching on the outskirts of Munich from 12 June. They will move into the Berlin athletes' village ahead of the

opening ceremony on 17 June.

It will cost \$17,000 for Lynett to travel to Berlin. Much of that will be met by Special Olympics New Zealand, but Lynett has to find \$3000. Melanie says there will be local fundraising to help her make the journey.

## "I hope to come home with a medal around my neck"

She is now looking forward to a visit to Queenstown to stay with friends before she gets down to the hard work and extra coaching sessions each week starting with cardio and general fitness and flexibility, then more powerlifting sessions.

"I hope to come home with a medal around my neck," Lynett says.

Above: Lynett Williams competes in the Southern Strength powerlifting competition in Invercargill in July.

Left: Lynett Williams (front row right) and Invercargill's Special Olympians show off the medals they won at the National Summer Games in Hamilton. Pictured (back, from left) are Dylan Stuart and Cameron Blackley and (front, from left) Sherryl Saunders, Jacqui Glew and Sarah Chambers. Photograph: Southland Express.



## IHC boosts support for families in the north

IHC is expanding its Family-Whānau Liaison team in Northland and Auckland to make sure more families caring for people with intellectual disabilities can get the help they are missing out on.

IHC has employed Family Liaisons since 2018 to link families to information and services, local support groups and other families. The team has concentrated on building trust with families and relationships with local support organisations.

But as the number of referrals to the team have grown, the demands have stretched the four staff who cover Northland, Auckland, Horowhenua and Christchurch. And in each area the challenges are unique. In Whāngārei services are limited and overloaded and families struggle to trust and navigate the disability support system. The average age of those being referred is 13. In Auckland, the wide range of ethnicities requires tailored approaches for an older demographic, with an average age of 29.

Frequently the team has to navigate other issues too affecting family wellbeing - poverty, unemployment, rental costs, no transport, the rising cost of living and unforeseen traumatic events in community (COVID, storms, and violence).

A priority for the team is to connect with families who have children who have been newly diagnosed with intellectual disability. But there are many children who are undiagnosed. Often the first

step for the liaison team is to support a family to get a diagnosis, which unlocks the funding that provides disability support services.

Family Liaisons hold regular 'Wellness workshops' to give family carers a breather.

Two new Family Liaison roles have been created this year to ease some of the pressure in the north - a second team member for Northland, based in Kaikohe, and another one for Auckland, based in the south-east.

Meanwhile. IHC has asked some specialists to measure the impact of our Family-Whānau Liaison work in changing lives. ImpactLab has been talking to IHC Family Liaison Jim Callaghan in Whāngārei about the work he does

National Fundraising Manager Greg Millar says the cost of the assessment has been covered by IHC donors Glenn and Sonja Hawkins and it is an opportunity to examine the growth and impact of the work.

"It will be looking at the effectiveness of this one position in Whāngārei. It looks at what the potential consequences would be if that Family-Whānau Liaison wasn't there

Greg says, for example, it can look at the impact on parents when a child has to be kept home from school.

"What would happen if that family didn't get a diagnosis for their child and if the child didn't get the support from the Ministry of Education?" he says.

"These families are often very resilient, but there are critical moments when they need support. It's about that person - Jim - being there at the right time. It's not about walking hand in hand with that family for the rest of their lives. It's about helping that family find their own solutions."

Greg says ImpactLab will look at the social value of the investment in the liaison's work. "For every dollar invested, this is the potential return."

The Family Liaisons are funded by the IHC Foundation and by Foundation

Below: A group of Whāngārei mothers and carers recently met Whāngārei MP Dr Emily Henderson to discuss the pressure on disability services in the north. (From left) Cassy George, Hope Bucknell, Tareen Ellis, Kristy Kewene, Jim Callaghan, Emily Henderson (MP for Whāngārei), Trudy Paul and Kerri





IDEA Services

Napier's much-photographed Pania of the Reef was attracting attention from a group of people with cameras. But this time they weren't tourists.

The scrutiny of the bronze statue of Pania on Marine Parade was from participants in a six-week photography workshop run by Hastings photographer Shayne Jeffares.

Shayne runs Foto iwi, a not-for-profit organisation that encourages creativity through digital media, photography and video. For six weeks in the run-up to Christmas a group of people we support in IDEA Services from Hastings and Napier were learning about angles, light and composition.

They focused on popular Hawke's Bay attractions like Marine Parade in Napier and Cornwall Park, Rush Munro's and the historic St Matthew's Anglican Church in Hastings.

"Each week we have been talking about angles and light," Shayne says. "With Pania, we were talking about composition." The stained-glass windows and timber architectural features of St Matthew's were an opportunity to talk about 'leading lines' – drawing the eye to a destination. The shop fronts and businesses of both cities were a chance to notice signage and reflections.

IDEA Services Area Manager James Leigh says the photography workshop, funded by Hastings District Council and Napier City Council through Creative Communities grants, paid for eight participants and was part of an IDEA Services community action engagement plan. At the final workshop, held just before Christmas, the photographers displayed their best work to families, friends and IDEA Services staff. Shayne chose a stand-out image from their portfolios to present to each of the participants.

Shayne says the photography competition, Capture the Moment, launched by IHC last year has given the photographers a goal to work towards and he is keen to offer a more advanced course next year.

One of the workshop participants, Eddie Stalker from Napier, was a finalist in Capture the Moment with his photograph *Lonely Plane*.

Capture the Moment grew out of the success of the IHC Art Awards, as an opportunity for disabled New Zealanders to create in a photographic medium.

Above: (from left) Foto iwi Facilitator Shayne Jeffares, Pat Donnelly, Johnny Andrews, Eddie Stalker, Desiree Osgood( behind) Zoe Thrussell, Doug Brough and Alisa Lythgoe examine Pania's statue on Marine Parade.

Right, top: Eddie Stalker and Desiree Osgood were drawn to photograph the striking flowers of the Bird of Paradise plant on Marine Parade.

Right: Eddie Stalker recently entered his photograph *Lonely Plane* (right) in the IHC Capture the Moment photography competition.









## The hard work is much more satisfying since a group of Christchurch IDEA Services volunteers joined the Student Volunteer Army.

People we support in Christchurch have been volunteering in the community in all kinds of ways and for a long time. But recently they have been energised by signing up with the Student Volunteer Army (SVA) Service Award. Their volunteer hours are now logged each week on the SVA app and count towards badges that recognise their contribution.

Using the app, volunteers can log any type of volunteering online and are sent their first SVA Service Badge after they have recorded five hours of volunteering. There are five award levels – member, bronze, silver, gold and the Top Volunteer Award.

Christchurch woman Joy Lennox has volunteered on city conservation projects for more than 20 years. On Mondays and Wednesdays, she leaves home in Papanui at 6am to volunteer at the Bottle Lake Forest Park in Burwood. She catches two buses, with a stop for breakfast in between at Muffin Break, and then walks for the last 20 minutes from the Burwood Hospital bus stop. "No, it's not long. It's good for my legs," she says.

Her husband Brian Lennox often comes with her – he always has a bagel for breakfast; Joy has a sausage roll. But Brian also has a paid job at PAK'nSAVE, so he can't log as many volunteer hours as Joy.

For 16 years, Support Worker Tess Abbott has managed the small team of between seven and eight volunteers at Bottle Lake, working alongside park rangers from Christchurch City Council. Four volunteers, including Joy and Brian, receive supported living services from IDEA Services and two men come with a support worker from an IDEA Services residence. Others join from other service providers.

They gather in a small hut next to the park rangers' headquarters and Tess is briefed by the rangers on what work needs doing.

IHC and IDEA Services have been working with park rangers at Bottle Lake for more than 30 years on projects including planting native species, mulching, weeding and chopping down lupins. "There is a lot of loading up the trailer and taking it away," Tess says.

"It's good physical work. The guys really enjoy it. Nobody is forced to come here



and do it. They do it because they want to.

"If I put down two hours' work and log it, then it's two hours real, physical work and I don't include the travel," she says. "At the end, you stand back and be proud of what you have done."

Another team of around eight conservation volunteers works nearby with IDEA Services Support Worker Cherie Prangnell and the park rangers at Travis Wetland Nature Heritage Park. Cherie has been working for IDEA Services since 2004.

Volunteers grow vegetables on both sites and can take home the produce. At Travis, they have planted a whole field of flax, pa harakeke, specifically for weavers. "Being a Māori woman, I am really proud of looking after the land and looking after the people," Cherie says.

The collaboration with SVA started in February 2022 and by the end of December 3768 volunteer hours had been logged by 51 volunteers. Service Manager Phillippa Johnson-Alatalo got the scheme up and running for IDEA Services in Christchurch.

Phillippa says while the app is easy to use, you need a device and an email address to log your hours, which is a barrier to some people we support.

She worked with SVA to adapt the app so that hours could be logged by an administrator. Dianne Pelvin volunteers by going into the IDEA Services office in Christchurch each month to log the hours for other volunteers. Dianne is part of a small committee of people we support who meet once a month to come up with ideas for volunteering projects. Committee members also phone the various facilities to remind them to send in their hours for logging.

IDEA Services Area Manager Michelle Hickey says being part of the SVA Service Award programme has been "manaenhancing" for the volunteers. She says SVA has been very supportive, holding weekly meetings for several months with IDEA Services at the start.

Michelle says individual volunteers, some with complex needs, are getting involved. Some have adopted a park to look after, remove graffiti, or deliver meals to those who are isolating. Volunteers can also choose to get involved in other great things that are happening in the community – cleaning war graves ahead of Anzac Day commemorations and helping to plant 1000 native plants to mark Travis Wetland Trust's 30th anniversary.

Others are clocking up the hours without ever leaving home. Two women, house mates Lisa Turner and Sarah Rodden, were the first to be awarded gold badges after logging 500 hours of knitting blankets for the SPCA. And they haven't stopped yet.

"What I love about this is that anyone with any kind of disability can be part of this," Michelle says. And volunteers are sticking with it. "People are just as excited and just as engaged as they were at Day One," she says.

"People feel proud. Having the Student Volunteer Army participating with us makes them feel proud as well."

The Services Senior Management Team is now planning to extend SVA Service Award participation to IDEA Services volunteers in other parts of the country.

Left: Joy and Brian Lennox chop down lupins at Bottle Lake.

Above: working at the Bottle Lake Forest Park (from left), Joy Lennox, Brian Lennox, Tess Abbott, Cameron Hepburn and Kieran Krammer.

Photographs by David Bayley of Bayley Photography. David is also an IDEA Services Support Worker.



## All school staff to be trained to avoid physical restraint

The Ministry of Education has launched new rules and guidelines to help schools understand more about student distress and minimise the use of physical restraint. The guidelines also aim to eliminate the use of unjustified restraint.

The rules and guidelines took effect from 7 February 2023 and signal the start of mandatory training for all school staff.

All teachers and authorised staff members will have to complete online training to identify stress triggers, understand unmet needs and prevent, minimise and respond to student distress. The aim is not to use physical restraint except as a last resort.

Training for school staff must be completed by February 2024. New staff will need to complete the training as part of their induction.

Since changes were made to the Education and Training Act 2020, schools can use physical restraint on students only when there are no other options to keep everyone safe.

A new online reporting form has also been launched this year to make it simpler to report incidents effectively. It will also be mandatory to record if the child being restrained has a learning support need or a disability.

"We already know it's disproportionately Māori and now we will know that it will be disproportionately disability," says IHC Advocate Shara Turner.

The guidelines were created in response to the changes and to calls from schools for more clarity about when it is acceptable to use physical restraint and what is acceptable physical contact.

"The new guidelines will hopefully get more schools to think about moving to zero restraint," says Shara, who was a member of the Physical Restraint Advisory Group of parents and education sector and disability sector representatives working with the Ministry of Education.

"We don't think kids should be restrained because of disability-related behaviours," she says. "I don't think any teacher enjoys restraining kids. But with the family, it affects them for a long time. Restraint is harmful and we need to realise that."

Shara says a lot of the behaviour is

actually about communication. "If restraint is happening, then something is going on."

Shara says the research available on restraint has found that the person doing the restraint and the person being restrained are impacted.

"Families talk about trauma a lot when it comes to restraint - the trauma of being restrained but also the fact that disabled students are often retriggered by earlier incidents of restraint or responses from people that lack understanding."

She says it will be really good for the data on the use of physical restraint to be collected for all schools.

The changes would allow future reporting through schools' student management systems and make the process simpler for schools.

Above: restraint guidelines were initially asked for by teachers. Photograph by Taylor Flowe on Unsplash.



## An accident 20 years ago on a gravel road put an end to Duane Harrington's forestry work.

Duane was coming home from working on a forestry block just outside Palmerston, north of Dunedin, when the vehicle he was in went out of control. Surgeons had to insert a metal rod into his badly broken leg.

After his leg mended Duane tried to get back to pruning trees, but he was no longer up to it. "I had gone back to the pruning. They wanted at least 100 a day. That was all ladder work," he says. "I pretty much decided to flag it because he wanted the numbers and I just couldn't handle it. That was pretty much it, until now."

Duane had been out of work for 11 years when he signed on with IHC company Choices NZ in 2020. He is supported to live independently by IDEA Services.

"His last job was in 2010 when he worked as a labourer," says Choices NZ Facilitator Ashleigh Pawsey. "While the rod was in his leg he couldn't exercise or stand on his leg too long as it was painful. He had this removed in 2017, so his leg is a lot better and less painful. This has been a

traumatic part of his life and has made it hard for him to get back into the workforce."

But Duane, at 41, was determined to get back to work again. Ashleigh saw there were openings in hospitality, and they made a plan. She arranged for Duane to get work experience as a kitchen hand at Highview Rest Home in Dunedin and then, to get used to the pace in a busy restaurant, he did more work experience at Amigos Mexican restaurant in Dunedin.

Ashleigh says Duane became familiar with the large commercial pass-through dishwashers and was ready for a paid restaurant job. She saw that the Grand Casino in Dunedin was advertising for a kitchen hand and got in touch to advocate for Duane to be given an interview. It led to him being offered the job. He started there at the end of September last year, and it has been a good fit for Duane and the casino staff.

"In my eyes he is an absolute superstar," says Grand Casino Food and Beverage Manager Marco Muetze. "He just puts his head down and gets the job done.

I would like more people like him." Marco

says it was a "massive relief" to find Duane as there was a shortage of kitchen staff.

Grand Casino Human Resources Adviser Laura Dixon says Duane has been employed in a part-time permanent position. "He has been amazing since he started. The whole kitchen team is very impressed."

Duane works from 11am to 3pm, Monday to Friday, in the staff cafeteria doing dishwashing and cleaning up. And there is potential to try other roles in the future. Marco says the casino always makes sure its staff get a good meal and that's something Duane appreciates.

"Duane often texts me with what he is eating that day," Ashleigh says. "Macaroni is his favourite meal.

"One of the things that Duane was looking forward to around getting a job was making some new friends." And he has.

Above: Duane Harrington (right), with Grand Casino Food and Beverage Manager Marco Muetze.



# Manaakiao shares his name with new term for Williams syndrome

When Manaakiao was diagnosed with Williams syndrome at the age of four, his parents Jamie-Leigh and Puke Timoti asked what the Māori term for Williams syndrome was.

#### Sector

The answer was that there was none. But, in collaboration with Māori linguist Keri Opai (author of *Te Reo Hapai, The Language of Enrichment*) a new term, Manaakiao, has been created for Williams syndrome.

With their new diagnosis for Manaakiao, Jamie-Leigh and Puke approached Keri Opai to discuss identity and strengths-based language for him. Keri then met with New Zealand Williams Syndrome Association members in the Waikato to learn more and to spend time with the members and their whānau.

After this time of building relationships or whakawhanaungatanga, Keri asked Jamie-Leigh and Puke for permission to use their son's name, Manaakiao.

"Those with Williams syndrome are known to be kind with high emotional recognition. When seeing someone needing emotional support, they are there to awhi and lift the spirit of the other – embracing all without prejudice," says Jamie-Leigh.

She says Manaakiao, meaning 'world

embracer' or 'embracer of the world', is an amalgamation of two words 'manaaki' and 'ao' and focuses on the most prominent positive traits of people with Williams syndrome – their kind spirit and endearing nature, their ability to empathise and forgive, and their care and selflessness. "It is a deliberate move away from a deficit model and has been co-created with Williams syndrome whānau.

"As a whānau Māori with a recent diagnosis of Williams syndrome, we wanted to turn that around and curtail the negatives and emphasise the gifts they bring to this world," Jamie-Leigh and Puke Timoti said in their story published on the New Zealand Williams Syndrome Association's website.

"Williams syndrome was discovered and defined by Dr John Cyprian Phipps Williams in New Zealand in 1961. The description is heart-breaking and can be overwhelming. In one form or another we as parents went through shock and then a phase of grief, consciously and unconsciously," they said.

"With time, late-night Google searches and through reaching out to other parents, we began to accept and adjust to navigating this new path. One that included nurses, hospital appointments, funding applications, respite, teacher aides, IEP meetings, NASCs, and the many other acronyms.

"Our boy is full of joy, always seeking to 'catch a smile' and is a defender of justice (unless it's against his favour). He has an ability to read emotions, is curious, adventurous and has many special interests. He keeps us grounded, hyperaware of his presence and can melt a hard day away with a hug and a smile, a big smile."

Left: Manaakiao, "a boy full of joy", has helped to define a new Māori term for Williams syndrome.

Below: The Timoti family – Back row (from left) Puke, TeAotarewa, Maioha and Jamie-Leigh. Front row (from left) Manaakiao and Te Haruru. Photographs by Alan Gibson and used with permission from Your Way | Kia Roha.





The families who make up the New Zealand Williams Syndrome Association met for their summer camp in Whanganui in January – and there was a lot to catch up on.

It was the first time the families had been able to get together in four years. They usually meet every second year, but the pandemic intervened.

It was just 'the experts in the room' this time. Usually, the association invites a local or overseas expert working or doing research with Williams syndrome, and this year that wasn't possible.

"We are working with the experts in the room," says New Zealand Williams Syndrome Association National Coordinator Christina Stilwell. "I always feel we have a lot of wisdom already."

Christina says it has been hard trying to arrange a camp with COVID-19 in the mix. "This is our third attempt. It is four years since we last met. Because the 'Williamses' are so social it is actually quite a massive thing not to be able to meet.

"Because it has been such a long time, we really needed a time to catch up with each other. Our focus this time is just reconnecting and hearing each other's stories," she says.

Christina says most families with Williams syndrome share similar experiences. "They know the genetics; they know the health issues and they can talk about what it was like for them. It's not an expert who can tell us this."

Six newly diagnosed families joined in the fun. Around 120 adults and children - 27 with Williams syndrome - got together at Whanganui Collegiate School for a range of family activities, including the usual highlight - the talent quest 'Williams Got Talent'.

Bob Hastie entertained the audience on the Collegiate's drum kit after the talent quest organiser, music teacher Stu Green and others, assured the school of Bob's skill on the drums – and the fact that he had already brought his own drumsticks. The drums were in good hands.

The camp was supported by the IHC Foundation.

Top: Campers have a blast aboard the Tot Town Railway at Kowhai Park, Whanganui. Reagan Todd and Bob Hastie are in the foreground.

Right: Bob Hastie was a winner with his skill on the drums.

Far right: Jessica McClintock enjoys an outing on the Whanganui River aboard the historic Paddle Steamer Waimarie.









## IHC Media provides pathways to leadership and creativity

Out of challenges can come great opportunities and that is certainly the case with IHC Media.

IHC Media is an online platform launched in 2022 with content created for and by people with intellectual disabilities.

IHC Media was born out of the COVID-19 lockdowns. "The first lockdown in 2020 caught us all by surprise," says IHC General Manager of Communications Gina Rogers. "We had to think quickly of a way for us to connect with the people we support and for them to connect with each other."

It began as a 'Give it a Go', which live-streamed Zoom sessions into IDEA Services houses during lockdown. It was then decided to make it a permanent thing and take it into the wider community.

"We want a way for the people we support to tell their own stories and create pathways for leadership and creativity," says Gina.

IHC Media was launched in 2022 with IHC Live offering livestreamed Zoom

sessions of music therapy, drumming and dance. There will eventually be three channels. The second, IHC Korero, launches this February with interactive webinars on self-advocacy run by David Corner, IHC's National Self Advocacy Coordinator. A third channel, offering a gateway to further education, is in the planning stages.

IHC Live's 2023 calendar includes Music with Ahjay, Drumming with Chewy, Dance with Jolt, Draw with Lindsey and Move with Bex. Ahjay Stelino is a song writer and music therapist. Chewy Wilson has been playing drums (Djembe) for about 20 years and has a passion for all music, especially world music. Christchurch-based Jolt is an innovative and inclusive dance company. Lindsey Myers is an artist and graphic designer working in the IHC Communications team. Auckland-based move therapist Rebekah Williamson (Bex) works with PHAB, an organisation promoting self-reliance and enhancing social opportunities for disabled and non-disabled people.

"Anyone can join these 45-minute sessions," says Gina. "You just need to go to ihcmedia.org.nz to register. And work out how to chrome cast from your device to a smart TV.'

Support is still required from carers and support workers during the sessions. "Often during the sessions you will need to mute and unmute your microphone and it's important to have someone standing by to help with this," Gina says.

Brothers Quintin and Joshua, who live in rural Canterbury, attend the IHC Live sessions and are looking forward to the 2023 programme.

Their family says, "Our young men look forward to the sessions, especially Jolt dance and joining with their Jolt friends on Zoom. They also like joining with friend Chewy in the drumming and Ahjay who does music.

"All the presenters' programmes provide a balance of familiar and new content. They work hard to make the sessions personal and to have communication with each attendee."

Above: Quintin (left) and Joshua are enthusiastic regulars at IHC Live sessions.



Warren Erickson is a beef and sheep farmer from Gore who hasn't done a lot of bike riding since he left school. That's about to change.

On 16 February Warren left the farm in his son Nathan's hands to travel to Cape Reinga. There, he got on his bike to spend however long it takes to cycle to Bluff to raise money for IHC.

His wife JA (Judith Ann) is his support crew. She's travelling in the couple's ute, tracking her husband by phone and posting progress reports and photographs on their Facebook page.

Now semi-retired from the farm, Warren had the dream of doing a long cycle ride, but he wanted it to count for something. He chose to raise funds for IHC, an organisation he and JA have been supporting for 35 years. Those years have been spent working on their local Gore committee and taking their turns with others to lead the group. Warren is Chair of the IHC Gore Association.

"I want to average a minimum of 100 kilometres a day, but that is dependent on weather. My other concern is traffic. I don't know the roads in the North Island," he says.

"The aim is to try and ride every day, even if one day is only 50 kilometres," he says. Warren has set a target for the first three days from Cape Reinga – 175 kilometres for day one, 180 kilometres for day two and 140 kilometres for day three.

"The ride is approximately 2300 to 2400 kilometres using a road bike – all pedal power," he says. And he's been training hard.

Warren and JA have been part of IHC since 1988 when their daughter Hannah was born with Down syndrome. Hannah, the eldest, is supported to live independently in Invercargill by IDEA Services and she has just started a new job sorting plastics with Recycle South.

Hannah has three younger brothers – Nathan, Ayden and Ash. Warren says raising their children was like having several sets of twins, as each of the boys would catch up with Hannah and be at the same stage of development for a while, before going past. "Hannah didn't walk until she was three," Warren says.

Ayden, living in Oamaru, is handling the social media posts on the ride's Facebook page and he plans to cycle a section of the ride with Warren once his dad gets near Oamaru. The family have set up a Givealittle page for donations – givealittle.co.nz/fundraiser/cycling-top-to-bottom-for-ihc

"This is all done by us as a family. We are taking all the costs on board," Warren says.

## Late news

Warren was in the North Island when Cyclone Gabrielle struck and he decided to give the bulk – 75 percent – of what he raises to IHC Associations in Hawke's Bay and Gisborne. The rest will be distributed to Associations throughout New Zealand.

He had to step up the pace when he realised that if he didn't make his scheduled ferry crossing to the South Island on 23 February, he wouldn't get another one easily because of the disruption to services. He pedalled 500 kilometres in two days from Otorohanga to Wellington to catch his ferry.

Above: Warren Erickson cycles into Beaumont, near Raes Junction, Otago, on one of his training rides.

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