

Community MOVES



**IHC WORKABILITY
CONFERENCE – Page 4**

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**MYSTERY DONOR
LEAVES SURPRISE GIFT – Page 10**

Personally Speaking

In two months' time IHC will host the Workability International Conference for 2016 in Auckland.



We've long been a member of Workability International, but more importantly we have always fought for a fair deal for people with intellectual disabilities in employment.

This year, we are calling on the business community to step up – the conference keynote speakers include Catalina Devandas Aguilar – United Nations Special Rapporteur on the Rights of Persons with Disabilities, Brent Wilton – Director of Global Workplace Rights at Coca-Cola and Steve Shepherd – former head of Ranstad's specialist disability recruitment team in Australia.

We have confirmed a great programme that aligns with the themes of working together at a government, business and community level to increase employment opportunities and to reduce the reliance on welfare. We have some great examples of socially responsible businesses that are making it work for their employees and their bottom lines.

We'll also be running some targeted sessions for our managers and for the Member Council at the conference.

You can read more about the conference on page 4 – and I hope to see some of you in Auckland in September.

This conference is a big project for us – but just one of many significant pieces of work under way that are over and above our core work of providing services, housing and advocacy services that make a difference in people's lives.

You can expect to see our property company Accessible Properties feature in the news as we progress our bid to acquire state houses in Tauranga. For us, the decision takes us beyond politics. We know that people are in desperate need of good quality social housing – and we are committed to using our relationships and leveraging incentives from government to grow the number of homes available to those with disabilities, older people and those on low incomes.

It's with pride that IHC is working in this space. We have been providing housing for more than half a century. IHC is already strong – but socially responsible and sage investment only makes us stronger and more resilient. A diverse business helps make sure IHC can be supporting people with intellectual disabilities for many more decades to come.

Ralph Jones
Chief Executive

PLEASE SEE THE NOTICE OF OUR AGM ON PAGE 13.



From top left to bottom right: Barbara Rocco, Sylvia Robertson, Pip O'Connell, Kay Pearce, Scott Miller, Andy Crawford, Janet Derbyshire, Danny Tauroa.

Member Council briefed on task ahead

IHC's Member Council met for the first time in June, and waiting for members were two reports – a survey commissioned by Chair Barbara Rocco about the relationships of IDEA Services' area managers with associations, and the report of a brainstorming session by association chairs about the future role of associations.

Both groups identified that an important role for associations is in reaching out to the community – especially connecting with young families. Association chairs said they couldn't do this in isolation; it had to be part of a broader organisational push to strengthen relationships.

Area managers reported that they had good relationships with associations, but were not sure about the role of associations and wanted clearer guidelines.

The IHC Board has asked the Member Council to be the key channel for IHC members and associations to raise issues with the Board. The Council will also be exploring the best way of hearing the

views of people with disabilities.

IHC received expressions of interest from more than 50 people to join the Council. The IHC Board confirmed the appointment of eight nominees – four from the South Island and four from the North Island – led by Barbara from Picton. She is an IHC Board member, former IHC president and parent of Stefano – a man with an intellectual disability.

Sylvia Robertson is IHC Otago Association Co-Chair and is also involved in Parent to Parent, Altogether Autism, and Special Olympics. She has worked as a teacher and deputy principal, and served on school boards. She is the mother of a young man with an intellectual disability, and understands the needs of families.

Pip O'Connell has worked for a number of disability organisations in New Zealand, including IHC, and is a member of the IHC North Otago Association. As the mother of a young man with an intellectual disability she has insight into the perspectives of parents who use IHC services. She has a good understanding of what IHC members want.

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COVER IMAGE:

Karen Brown returned home to her whānau marae Te Tokanganui-a-noho to perform with Te Rōpu Akoranga kapa haka group and restore a lost connection with her family. See story, page 7.



Simon Crowther with composting toilets built by Otaki-based firm Emergency Compost Toilets. The firm supports the employment of people with disabilities.

The right to work is a human right

‘Make it Work’ conference delegates to debate the issues

IHC is proud to be hosting this year’s Workability International Conference headlined by the United Nations Special Rapporteur on the Rights of Persons with Disabilities – Catalina Devandas Aguilar.

Make it Work aims to highlight the clear wellbeing and economic benefits for people with disabilities, communities and countries when all citizens are engaged in work that is paid or unpaid.

In New Zealand, as elsewhere in the world, people with disabilities continue to experience barriers to employment, perpetuating social and economic exclusion and

disadvantage. The conference calls for real employment solutions that minimise the dependency on welfare and empower individuals, communities, businesses and society alike.

People with intellectual disabilities are particularly affected.

Make it Work will showcase a number of great speakers who will profile successful examples of cutting-edge partnerships with government and the business community. We also have speakers highlighting the importance of being a socially responsible business – corporate social responsibility is becoming more mainstream as forward-looking companies embed sustainability and respect for human rights into the core of their

business operations and profiles.

The Make it Work conference gives us a forum for timely and provocative conversations and presentations about the future of disability support provision. Around the world there’s an increase in governments moving towards individualised funding models. Delegates will be able to consider what that could mean for us here in New Zealand, whether we know enough about the opportunities, threats and pitfalls of individualised funding models and what the impacts might be on both those accessing and those providing support. An international panel will consider funding, service provision and employment models and will help set an agenda for success following the conference.

COMMUNITY PARTNERSHIPS

The conference also gives us an opportunity to examine and showcase partnerships in our own communities – those that are making a real difference to people with intellectual disabilities.

We want to bring together IHC association chairs to discuss new ways of working, whether with IDEA Services or other local support and community providers. We hope to facilitate some inspiring discussions that will help contribute to and inform the IHC Member Council's work.

There is much to consider. Is there something that can be learnt from our Volunteering Programme given its engagement and reach within communities? We know some associations find it hard to identify and support families with a recent diagnosis or new baby with an intellectual disability. Is there some way of tapping into the IHC Library's Free Book scheme? Is each association getting the best out of the IHC/IDEA Services' local area manager? We invite all association chairs to attend the conference to share and learn from each other's successes. We'd love to see you there.



Trainee Rene Bunker at Hell Pizza Petone. Hell runs training schemes for people with intellectual disabilities.

Speakers include:



Catalina Devandas Aguilar – United Nations Special Rapporteur on the Rights of Persons with Disabilities.

Catalina is a lawyer and human rights advocate who has worked extensively on disability issues at national, regional and international levels. As Special Rapporteur on the Rights of Persons with Disabilities, she leads work calling for persons with disabilities to be guaranteed the full enjoyment of their human rights and freedoms without discrimination.



Brent Wilton – Director of Global Workplace Rights at Coca-Cola. Brent has previously worked as secretary-

general of the International Organisation of Employers in Geneva, and has a clear view that disability should not be a barrier to employment.



Steve Shepherd – former head of Randstad's specialist disability recruitment team in Australia.

Steve is a champion of diversity employment programmes. He will address the conference on recruitment that centres on skill and capability, rendering disability irrelevant at the interview table. Randstad is one of the world's largest recruitment and HR services providers.

Kristyn Gain, IDEA Services and Ben Cummings, Hell Pizza

ACTIVE IN HELL: Paid Training Experiences for Youth with Disabilities

Tess Casey, Inclusion and Grant Cleland, Workbridge

Working Together for Better Employment Opportunities and Outcomes

Albin Falkmer, Samhall

From Sheltered Workshops to Europe's Most Sustainable Business

John Grant, SkillWise

The 'Forgotten Learners' - The Plight of Tertiary Learners with an Intellectual Disability: An Opportunity for Provider Partnerships

Martin Reddy, RECOSI

Social Franchise (Resistance is Futile)

David Hollander, Jackson Stone

Exploring the Idea of Anonymous Recruiting

Hilary Stace, Victoria University of Wellington

From Sheltered Workshops to Human Rights: Transition Tensions

Gabrielle Hogg

Supporting Autistic Individuals Successfully in to Supported Employment

Tom Hicks, Remploy

Cross Community Collaboration: Local Solutions to Employment and Health Support in Islington, London

Selwyn Cook, Workbridge Employer Ambassador and Grant Cleland, Workbridge

Workbridge and Z Energy Partnership: Good for Business, Customers, Communities and New Zealand

Gina Rogers, IHC New Zealand

The Importance of Selling a Socially Responsible Brand and the Impact of Positive and Negative Media on Reputation and Profit

Monica Lingegard, Samhall

Identifying Talent Through a Unique Matching Method

Shamim Ferdous, Bangladesh Protibondhi Foundation

Self Employment: A Successful Model of Poverty Elevation for Persons with Disabilities in Bangladesh

Janet Doughty, People First New Zealand

Inclusion Isn't an Action It's an Attitude and Domino's Pizza Rolleston Have Slices Worth of It

Sally Powell, Bedford Group Australia

Transitioning from the Welfare Model to Meaningful Employment

To register or to find out more about Make it Work, please visit ihc.org.nz

'For sale' sign going up at Pinetree Farm



Time to say goodbye: residents Andrew Sirl (left) and Hemi Winikerei with Colin Meads at Pinetree Farm.

The 'For Sale' sign will go up later this year at the gate of Pinetree Farm in Te Kuiti. After more than 30 years, it's the end of the road for the four-hectare smallholding donated to IHC by rugby great Sir Colin Meads.

Colin, who headed up IHC in the King Country after he retired as an All Black, wanted people with intellectual disabilities to be able to learn farm skills and have the chance of employment on farms. He used the proceeds of his speaking engagements to purchase the farm in 1988.

"Back years ago, I used to raise a lot of money through speaking engagements, and I couldn't take this money because of the amateur status rules within the New Zealand Rugby Union at that time," Colin says.

Pinetree Farm – bearing Colin's nickname – was made up of nine paddocks alongside State Highway 4 on the northern outskirts of Te Kuiti. "When we first got it, we used to have pigs there. We had farm boys in the house –

and they were the farmers – but that is all gone," he says.

Apart from the five men who lived on the farm, there could be another 20 people from the day base working there in its heyday. They grubbed thistles, mended fences, cut firewood, looked after stock and collected calves for the IHC Calf Scheme. The farm used to supply the local IHC homes with meat and vegetables. But as time passed, and health and safety regulations became more stringent, it was too hard to keep the farm going.

John Mildon managed Pinetree Farm for IHC for more than 18 years. He came from a farming background at Ohaupo and had moved to Te Kuiti. He says he used to take a group of people from the day base to care for the large vegetable garden, cattle, sheep and pigs. "The highlight for them was picking up the hay and having a beer afterwards. There was a fight to get away from the workshop to make the hay."

He recalls some of the early residents of the farmhouse, people like Dean Walker who had moved out of Kimberley and Lewis Munro from Tokanui, who loved the freedom of living on the farm.

For some years Pinetree Farm has been used by local farmers to run stock in exchange for looking after the property. The house is still home to five residents but, apart from a henhouse, there is no farm work done these days.

Last year Colin suggested to the IHC King Country Association that it might be time to move on, and arrangements are being made through IHC property company Accessible Properties to sell the farm and reinvest the money in housing improvements in the King Country.

Bruce Howell, former IHC King Country Association chair, is sad to see the farm go. "Yes we will lose our flagship. It's a bit disappointing to have it gone." But he says the farm no longer fulfils the role.

It will mean a big change in lifestyle for the five men who still live in the farmhouse. Hemi Winikerei and Andrew Sirl have lived at Pinetree for 15 years, Ian Ram 12 years, Harry Wallace 10 years – and newcomer Geoffrey Triggs arrived three years ago. They will all move to other IHC homes in the Waikato/King Country area. Once this has happened, Pinetree Farm will be sold.



Homecoming: Karen Brown (third from right) and her fiancé Jason Brett are welcomed on to the Te Tokanganui-a-noho marae in Te Kuiti for an emotional homecoming. Supporting her (from left) are Rebecca Taaka-Te Kaute, Sara Anson, Te Atakura Ryan, Robyn Hanna (partly obscured), Helen Atutahi and Christina Fitzgerald.

Warm welcome for a daughter coming home

Hand in hand with supporters, Karen Brown walked on to her whānau marae in Te Kuiti, restoring a connection that was lost when she went as a child to live with foster parents.

Karen's links to Ngāti Maniapoto are through her grandmother, Louisa Winifred Ormsby, one of 22 siblings and her mother, Lani, one of 13. Karen is the youngest of 10 children. When Lani was unable to look after her, Karen was fostered by a non-Māori family in Tauranga through IDEA Services.

Karen had always wanted to return to her marae and the idea took hold when she met up with niece Rheanna Robertson, who had been researching their whakapapa. While Karen's Nan, Grandad and birth parents are all dead now, IDEA Services' Kaitakawaenga/Cultural Advisor Te Atakura Ryan helped Karen to reconnect with her marae and wider family. "She has got clear

whakapapa going back to that marae," Te Atakura says.

Karen's chance finally came, in April, when IDEA Services' Māori cultural advisors arranged a hui at Te Tokanganui-a-noho marae for Māori service users. For the pōwhiri Karen, 36, was supported by Te Atakura, who led her on to the marae. On Karen's other side was her fiancé Jason Brett and the Te Rōpu Akoranga kapa haka group from Tauranga.

As Karen approached the meeting house, she says she was "thinking about my Mum and my Nan and my Grandad. I wish they could be here today. How I feel. I feel good. I feel confident".

Te Atakura says Karen is passionate about her kapa haka and she wanted to showcase it to her family. Her kapa haka group, Te Rōpu Akoranga, performed in the meeting house for their hosts and for fellow visitors at the hui.

Kaumātua Kingi Turner spoke about the Ormsbys in his welcome.

He spoke about Karen coming from a very large whānau with strong and far-reaching connections in Maniapoto. Karen was shown pictures of ancestors on the walls of the meeting house by her hosts. "One of them said, 'Have a look at the picture', and it reminds me of my Nan," Karen says.

The Te Tokanganui-a-noho whareniui or meeting house was built in 1873 under the direction of Māori leader and prophet Te Kooti and gifted to Ngāti Maniapoto. The marae hosted around 80 service users for two days and gave them the opportunity to learn about marae protocol (kawa) and Māori tikanga (culture and customs). The hui also covered pepeha, where the visitors and tangata whenua introduced themselves, and traditional weaving or rāanga.

Te Atakura says Karen's is only one of many stories to tell about the marae visit. "Each person who attended has a connection to their whakapapa and to marae."

'Holiday' worth \$5000 for

A vision of a caravan holiday convinced the judges to give Upper Hutt artist Jo-Anne Tapiki the first prize in the IHC Art Awards 2016, worth \$5000.

Her winning work, titled *Holiday*, is a 700 x 300mm cushion embroidered with a vivid royal-blue car pulling a blue caravan through the countryside. She was named winner at the Art Awards gala night at the Michael Fowler Centre in Wellington on 16 June.

Jo-Anne started working from IHC's Arts on High studio in Lower Hutt 18 months ago and this was the first time she had entered the competition. She likes to collect brochures – particularly ones about holidays – and this was her inspiration.

Jo-Anne draws and paints, but she prefers to do embroidery on fabric using wool. She will draw an outline on the fabric with her finger, and a tutor will follow her lead with a pen, marking the outline on the fabric. She then asks the tutor to thread the needle and then it's all over to her to create the work.

The second prize of \$2000 went to Dunedin artist Becky Donovan and third prize of \$1000 was won by Karin Clayden of Wellington. For the first time the top three prizes went to an all-female line-up of artists. Becky's drawing, *Fashion Models*, was created at Artspace and Karin completed her *Māori Designs* at Alpha Art Studio in Wellington.

"The top awards went to three works that radiated that extra 'magic', whether that was a highly original sense of composition, a brilliant use of colour or an aspect of the way the artist had actually



made the piece," said Awards judge Tim Walker, Auckland-based arts and culture consultant.

This year's judges – Wellington artists Gina Matchitt and Grant Corbishley and Tim Walker – chose the winner out of 408 entries posted online. They narrowed them down to 30 finalists.

"The diversity of the work presented a real challenge. There was an amazing range of media and approaches, and so many visual delights and surprises," Tim said.

The People's Choice winner, Julian Godfery, was selected by voting on the IHC Facebook page. Julian won \$1000 for *Tapa*, a pen drawing of a tapa cloth, and was presented with his prize on Awards night.

This year for the first time artists were asked to submit full entries online for the first stage of judging. The top 100 artworks were exhibited at the Arts on

High Gallery in Lower Hutt ahead of the gala night. All the proceeds from artwork sales go directly to the artists. The highest-selling artwork at auction was Daniel Phillips' *I Always Like Being Independent! Yes! Forever Yes! Be Independent! Yes! Yes!*, which sold for \$1500.

This year six-times judge WORLD fashion director Denise L'Estrange-Corbet stepped up to the role of Art Awards Ambassador. Denise has long described the IHC Art Awards as one of the highlights of her year. "For me it's about the artists. It's about meeting talented individuals and seeing their extraordinary art.

"I think every artist with an intellectual disability should be encouraged and supported (if necessary) to enter."

The IHC Art Awards foster the artistic talents of New Zealanders with intellectual disabilities.

The Holdsworth Charitable Trust is the major sponsor of the IHC Art Awards.

IHC Art Awards winner



[Left] People's Choice winner – *Tapa*, by Julian Godfrey of Hamilton. [Above] Winning line-up – the winners in the IHC Art Awards 2016 are (from left) third place, Karin Clayden of Wellington with *Māori Designs*; first place Jo-Anne Tapiki of Upper Hutt with *Holiday*, and second place Becky Donovan of Dunedin with *Fashion Models*.



Denise L'Estrange-Corbet – IHC Art Awards Ambassador

Denise L'Estrange-Corbet, is co-founder of New Zealand fashion house WORLD. She also is an author, has done many artworks for charity, lectures extensively, and last year played the lead in an Auckland play *Sitting Pretty*, which received rave reviews.



Tim Walker – Judge

Tim Walker is an Auckland-based arts and culture consultant. After 30 years in the art gallery sector (as fine arts curator at Waikato Museum, senior art curator at National Art Gallery/ Te Papa Tongarewa and director at The Dowse) he now works with arts organisations, government departments, local government, iwi and tourism operators throughout New Zealand.



Gina Matchitt – Judge

Gina Matchitt is a Wellington-based artist whose work draws on her Māori tribal affiliations, Te Arawa and Te Whakatohea, and is a fusion of Māori and Pākehā (European) concepts. Her work is found in many major New Zealand public collections, including Te Papa Tongarewa – The National Museum of New Zealand, and Auckland Art Gallery.



Grant Corbishley – Judge

Grant Corbishley is an artist/designer and senior lecturer in creative technologies at the Wellington Institute of Technology. His PhD addresses the recent loss of community and issues facing the neighbourhood where he lives – Houghton Bay, Wellington. He has also been involved in international collaborations focusing on creating resilient human and non-human ecologies.

Mystery donor leaves surprise gift

IHC has received \$250,000 from the estate of Second World War veteran Enid Cooper. IHC is one of four charities sharing a \$1 million legacy.

The generous and unexpected gift came out of the blue and none of the charities knew much about the woman behind it.

Enid was 87 when she died and her estate was finalised by solicitors at ASCO Legal in Auckland. As well as the \$1 million shared between IHC, Barnardos, the Anglican Trust for Women and Children and the Salvation Army, she made a number of bequests to friends in New Zealand and England and to her church and the SPCA.

Enid was born in Palmerston, Otago, in 1912. She was in the United Kingdom visiting her sister Norma when war broke out. They both joined the Royal Air Force – Norma worked in intelligence for Bomber Command and Enid was a commissioned officer in the codes and cyphers department.

Enid told Auckland's *Eastern Courier* newspaper in 1989: "I was the first to break a cypher revealing when D-Day was to be ... I did move around a lot from Wales to the north of England, to a joint coastal command in Kent and finally to the Air Ministry in King Charles Street, London. That was an interesting 18 months. But as we worked in tunnels under the Thames I didn't enjoy being underground. I missed the open air." She recalled the sewer rats and the smell of Winston Churchill's cigars in the tunnels.



Wartime memories: Enid Cooper (right) with her sister Norma.

Her friend Maureen Rykers says Enid loved French shoes and history and music. Their friendship went back to 1946 and student days at the School of Home Science in Dunedin. They relocated to Wellington Hospital to train to be dietitians from 1949 to 1950 and flatted together in Oriental Bay. Enid stayed in Wellington for most of her professional career, which included work as a home science tutor at Wellington Polytechnic and as technical advisor for the Standards Association New Zealand.

Maureen and Enid reconnected when Enid and her brother Thorley moved to Auckland in the late 1970s. "She was a great shopper. She loved shoes," Maureen says. "There used to be a lovely shop up Vulcan Lane – that was the shoe shop in Auckland." Maureen recalls that on one shopping trip she asked, "Enid, how can you spend so much money?" Enid replied, "Don't worry, I will leave you enough to buy yourself a pair of French shoes in my will".

Richard and Janet Woods and their family were tenants at a flat at her St Heliers house. "Over time Enid became my great friend; someone I could trust with my own children. And near the end she allowed me to care

for her," Richard says. "Enid had many lifetime friendships, much longer than ours. She nurtured and valued those friendships. A lifetime in the service of others only reinforced her ability to give of herself. Always willing to help those who helped themselves, not surprisingly she gave her estate away to help others."

Solicitor Luzette Marrett of ASCO Legal says: "Enid was a private individual, but as a former dietitian she was used to dealing with people and their personal need. It is understood that her intention to make these bequests was not revealed to any charity before her passing, so has come as a welcome surprise to them.

"What is also interesting is that Enid had no known affiliation with the charities, but appeared to have admired them all from afar, understanding that her money would go a long way toward helping New Zealanders," Luzette says.

"We are hugely appreciative of Enid Cooper's thoughtfulness and generosity and would love to have thanked her during her lifetime," says IHC National Fundraising Manager Eleisha McNeill. "A gift of this kind makes an enormous difference to people with intellectual disabilities."



Job done – three hours later, tattooer Brooke Newnham and Edward Watkins check the final result.

There's no arguing with a leaping lion

Long before the lion leapt on to Edward Watkins' shoulder, it had been the subject of a lot of discussion.

Edward's mother Anne Gilbert was wrestling with the fact that Edward wanted a tattoo – and whether she had any say over it.

Wellington tattooer Brooke Newnham wanted to be sure that Edward knew it was permanent.

But Edward had no doubts; nor did his brother Tom, who got a tattoo at the same time.

Nor did Edward's friends and workmates at the Memphis Belle café – seven of them clubbed together recently to help pay for the tattoo as a 24th birthday present for him. "He's part of the family," says Paris Tuiomanufili. Another friend, Alex Judd, says Edward had originally wanted a love heart with the name of a girl

he is keen on, but they persuaded him to think of another design.

The tattoo led to some soul-searching for his mother Anne, Chair of the IHC Wellington Association. She wasn't enthusiastic about the tattoo but was keen on Edward being able to choose that for himself.

"I decided it wasn't any of my business, as long as he was informed, he knew what it would entail and he wasn't in any danger," Anne says. "His brother had already had a tattoo and I wished he hadn't."

Brooke, who works at the Tattoo Machine in Dixon Street, Wellington, says she got to know Edward, who was working at the Memphis Belle across the road. For the past few months he has been hanging out at the tattoo parlour, drawing and watching them work.

"He sits and he draws and if there is a free table he will sit with us." Brooke says every time he came in he talked about wanting to get tattooed.

Brooke, who is from the Sunshine Coast in Australia, has been tattooing in Wellington for the past two years. To make sure Edward knew what he was getting into, Brooke first did a trial tattoo without ink, and the three-hour session was booked.

"He said he wanted something from *The Lion King*." Brooke says they ended up with a strong American traditional design blended with Simba from the movie. American traditional is a tattooing style with typically bold lines and simple colour palette.

Brooke says she posted a photograph of Edward and his tattoo on Instagram at 9.30pm and by midday the next day she had 400 likes.

Edward is now talking about a tattoo for his left arm.

Charlie resigns after 50 years on committees

Charlie Waigh made one condition. If the IHC Counties Association was going to put on a lunch for him then he didn't want any speeches.

Charlie was stepping down from the association committee and the idea was to honour his 50 years of commitment. There was plenty to say but Charlie, who in 2011 was awarded a life membership of IHC, prefers to acknowledge all the other people who work behind the scenes improving lives for people with intellectual disabilities.

Charlie, now 92, started out with IHC in Hawkes Bay, where he helped to set up the Central Hawkes Bay sub-branch in 1966, the Pahiatua sub-branch in 1968 and the Manukau sub-branch in 1974. Most of his work has been in Auckland – Manukau, Papakura and Counties. He was chair in Manukau for six years and branch



Charlie Waigh stresses the importance of advocacy for committee members.

president of Papakura for 16 years. His wife Mary died in 1998 and daughter Catherine, who had Down syndrome, died in 2013.

"I did enjoy committee work, working with people, accomplishing targets, keeping in touch, monitoring, working with management," Charlie says.

When Charlie joined IHC its main focus was to get services established, including schools, residences and vocational centres. "Now that services sector is clearly established, our advocacy role assumes its importance. I am not sure we have fully grasped that as yet," he says. "I am happy that people within our

service are well provided for, but what of others in the community?

"While I don't miss committee work, my approach generally hasn't changed. I haven't lost touch with IHC. I have got all my friends in residential and vocational services. I keep in touch with all the people I have known for years."

The lunch was held in March at the RSA in Papakura. Among the guests welcomed by Association Chair Danny Tauroa were Charlie's daughter Theresa and three grandchildren, friends, parents, staff members, former staff members and IHC association members. Former chief executive JB Munro attended along with former New Zealand Council members Val Sheppard, Maureen Wood, Mick Irwin, Mike Maloney, Georgina Simmonds and John Palmer.

"Charlie was always wanting to do something about advocacy and for him that meant advocating for all people with intellectual disabilities, not just for those in the IHC family," Danny says.

...continued from page 3

Kay Pearce is IHC North Canterbury Association Chair and has strong connections in the North Canterbury community. She also brings a parent perspective to the Member Council. Kay has a strong desire to help bridge the gap between members and the organisation.

Scott Miller is the Chief Executive of Volunteering New Zealand, and the Chair of ComVoices – a network of national organisations in the voluntary sector. He is also Chair of the IHC Hutt Valley Association. He has set up three charities to help people with an intellectual disability enjoy a normal life.

Andy Crawford from Wellington has been a volunteer with IHC since 2009, and has experience as a mentor through the Project K initiative. Andy has extensive experience in leadership roles in the United Kingdom and New Zealand and brings a strategic approach to his work on the Member Council.

Janet Derbyshire is a member of the IHC Tauranga Association. She is the sole caregiver of her 26-year-old son, who has Down syndrome. She is passionate about connecting young parents to IHC, and wants to help ensure that IHC remains a collective voice for change.

Danny Tauroa is the IHC Counties Association Chair and whānau representative on IHC Māori advisory groups Te Anga Paua o Aotearoa (national) and Te Hoenga Waka (northern). As the whāngai (foster) father of a young man with an intellectual disability, Danny understands the perspectives of families and hopes to strengthen the ties between those with intellectual disabilities, their families and IHC.

Email the Member Council on membercouncil@ihc.org.nz, call 0800 442 442 or write to Member Council at IHC New Zealand, PO Box 4155, Wellington 6140.

Demand for aged care beats predictions

The number of older people with intellectual disabilities supported by IHC is already well ahead of predicted figures, says a new report into health and ageing by the organisation.

Wendy Rhodes, General Manager of Health and Aged Care, says IDEA Services is seeing a steady increase in the older group of people with intellectual disabilities – the number already exceeds international predictions of the percentage of people over 50 by 2020.

She says that by 2033 nearly one in five people in our services is expected to be over the age of 65 years.

As in the general population, life expectancy is increasing for people with intellectual disabilities. Studies show that the life expectancy of people with moderate and severe disabilities, however, is about 58 years.

But older age is also associated with increasing poor health.

“Substantial public health initiatives have been launched to improve the health and wellbeing of older people,” Wendy says. “However, special populations for whom ageing has specific relevance, such as those with an intellectual disability, have received little attention.

“Longevity in people with intellectual disabilities carries a burden of age-related disorders, like dementia, mental health disorders, hearing disorders, diabetes, arthritis and congestive heart disease, as in the general population. The risk of dementia for people with intellectual disabilities – and more so for people with Down syndrome – is significantly higher than that of the general population and with much earlier onset,” the report says.

“People with intellectual disabilities suffer from significantly more health problems than the general population and are more likely to have significant health risks and major health problems, yet do not receive the same level of health education, health

promotion opportunities and health screening as others.”

Wendy says people with intellectual disabilities are often critically dependent on family and others to access the health care and disability support system.

Since completing her report, Wendy has been visiting service users and family members in Northland, Waikato, Taranaki, Wellington/Hutt and Christchurch to share her findings and get their feedback on what they see as important in health care and living support.

In addition, Wendy will also be assessing our detection and care of people with dementia and looking at three critical factors for optimising health and wellbeing – exercise, mental stimulation and social connections – to see how we measure up.

At the end of this second phase of work, Wendy will be making recommendations on actions that can be taken to strengthen our response to health and ageing needs as demand grows.

IHC ANNUAL GENERAL MEETING 2016

3pm Monday
26 September 2016

Auditorium, Auckland
War Memorial Museum

The Auckland Domain,
Parnell, Auckland

AGENDA

1. Welcome
2. Meeting procedures
3. Adoption of the Minutes of the 2015 Annual General Meeting
4. Presentation of Annual Report, including reports from Board Chair, Chief Executive and Board Committees
5. Appointment of Board Members
6. Election of Patrons
7. Appointment of Auditor
8. Annual Membership Subscription
9. Board Remit
10. General Business

2016 ANNUAL REPORT

The 2016 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
Chief Executive



Robin Gray was diagnosed with cancer in 2009 and he made a list of the things he wanted to do before he died. One of them was a tandem jump with Masterton skydiving instructor Hudson Hargrave-Booth. He is still making choices and managing his condition, with the help of IDEA Services staff in Masterton.

Let's be honest – about death

Researchers exploring death and dying with people with intellectual disabilities say they want their families and support staff to be open and honest with them about what is happening. They also want plans to be focused on their lives – not just their deaths.

The research was launched in 2013 to find out what makes advance care planning – or planning for the end of life – successful for people with intellectual disabilities. Researchers say few people with disabilities have the opportunity to make their own plans and are at risk of not having their wishes met as they are dying. The research report, *Making the Final Decisions – Factors Contributing to a Positive Experience of Advance Care Planning*, has now been completed.

The project was initially delayed when researchers struggled to recruit enough people with intellectual disabilities to take part. Researcher Nic McKenzie says they went ahead with only four

participants. There were 11 other people who had been identified as possible participants, but they didn't know that they were dying.

“That was probably the thing for me that was most striking, or more unexpected. There were 11 people who were referred to us that weren't able to take part because they weren't aware, or sufficiently aware of the circumstances.”

There were two reasons for these people not being told they were dying – concern that they might not understand what was happening to them, and concern that they might not cope with knowing they were dying. Sometimes the family influenced this decision and sometimes the decision was made by the disability service provider.

“What we saw with these four people – they had their ups and downs and bumps along the way but they all coped with that knowledge,” Nic says. One participant told her, “Just be honest, ask questions and don't worry. Don't try to dodge things.”

The four participants ranged in age from 28 to 68 years – three European and one Māori – supported by two disability providers. Although it was a small number, Nic says they all had clear, strong views and this gave the researchers confidence about the information they were getting.

- They wanted advance care plans to be about their lives, not just their deaths
- They wanted to make their own decisions
- Planning had to be done at their pace
- They wanted families and staff to be open and honest with them about what was happening.

Advance care planning can be done when people are well, and by people who are unwell or dying. It usually includes talking and making choices about where the person wants to die, things they want to do, how they want to be cared for, legal and financial decisions, and what the person wants to happen after they die.

Two of the four participants have since died. “For the two people who did die, it did mean that they were able to die in the place that they wanted to die and were surrounded by the people that they loved. For the two who are still living, they know that they can keep having conversations about their health and what is happening in the future.

“We would really like to see that advance care planning takes place much more frequently for people with intellectual disabilities – that it happens for all people who are dying,” Nic says.

The project was funded by the Frozen Funds Charitable Trust. You can read the full report, an easy-read version and a summary version at donaldbearley.org.nz/resources/frozen-funds-publications.

Having the last word



When Billy Collins was dying of cancer he asked for two things: to die at home and to choose the people who would care for him.

IDEA Services staff in Gore cared for him around the clock for three months. Billy, 76, died in June 2013. Despite his fears that no one would come to his funeral, several hundred people did.

One of the toughest things our staff are called on to do is care for someone who hasn't got long to live. However,



Fiona King

arranging a funeral for someone living in a residential home brings a unique set of challenges. Wellington funeral director Fiona King is an advocate of planning ahead. "As a natural extension of their health, medical assessment, advance care, and final will and testament, each client should have a realistic funeral plan – in consultation with family where appropriate."

She says funerals need to be coordinated with the person's family, while also acknowledging the staff and house mates.

Fiona says it can be a matter of reminding the family to invite the carers and house mates to the funeral. "What I would do is ask the celebrant or minister, how can their support network contribute? – Perhaps through readings or musical recitals. If that

doesn't fly it's then about organising something within the home."

She says it is also important to create special rituals within a home when someone dies. "You declutter the room, take out all the medical equipment, create a calm space for house mates and staff to say goodbye."

Then when it comes time for the person's body to be taken away, Fiona hopes their departure can be marked in some way. "I like people to be acknowledged. I would prefer if people stood up. I would prefer them to sing a song, or clap – to have a physical cognisance of what is going on."

Colleen Ashby, IDEA Services Community Services Manager in Gore, who with Health Advisor Maria Colligan-Haggart coordinated Billy Collins' care, says the team was helped by Billy being very clear about his wishes. "He was able to articulate what he wanted and didn't want and that made a big difference. When he knew he was dying, we got the funeral director in to talk about things," she says.

"He was just worried that nobody would go to his funeral," Colleen says. Billy came from a farming community and needn't have worried – "a few hundred" people turned out to the funeral. "We were way outnumbered by his friends and family."

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