



Zaina has her own ace team of supporters [Page 4](#)

Skill-based projects on offer for volunteers [Page 6](#)

New law needed to safeguard children's rights [Page 8](#)

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# Personally Speaking

In February every year IHC holds its Annual Appeal to seek financial help from the public to continue our work supporting people with intellectual disability.

This year our focus was on those who step up to support a family member with an intellectual disability. People with intellectual disabilities are living longer and often outliving their parents so, increasingly, brothers and sisters are providing that care.

This year's Annual Appeal features retired couple Robin and Linda Millen. They care fulltime for Robin's sister Wendy, who has Down syndrome and has recently developed dementia. You can read more about Robin, Linda and Wendy at [ihc.org.nz/appeal2015](http://ihc.org.nz/appeal2015)

In this issue, we also profile the Almesfer family who share the around-the-clock care of Zaina, who has Angelman syndrome. Their story is on pages 4 and 5.

Some families need a lot of support and some need only a little – either way IHC is here for the people with intellectual disability and for their families – but we can't do it alone.

Donations to IHC make an enormous difference to people throughout the country – 35,000 people in New Zealand have intellectual disability. The money raised through the Annual Appeal is spent on IHC services not funded by the Government, including:

- Community information sessions to simplify bureaucracy and make families aware of what they are entitled to and how to most easily access it
- Advocacy on behalf of individuals or wider groups struggling to get a fair deal
- IHC's library – the largest intellectual disability library in the country providing free information to anyone in New Zealand
- A volunteering programme that encourages long-term one-to-one friendships and provides short-term programmes where a person with an intellectual disability can learn a specific skill.

It is crucial work in line with IHC's philosophy of advocating for the rights, welfare and inclusion of all people with an intellectual disability, and supporting them to lead satisfying lives in the community.

If you are someone who gives to IHC as part of the Annual Appeal, or through any of our fundraising programmes, please accept my personal thank you.

Ralph Jones  
Chief Executive



# JB Munro Citizen Volunteer

JB Munro won the Attitude Awards highest honour in December, being inducted into its Hall of Fame for lifelong service to the disability community.

The award acknowledges his significant impact on the sector over a career far broader than his 20-year role as head of IHC.

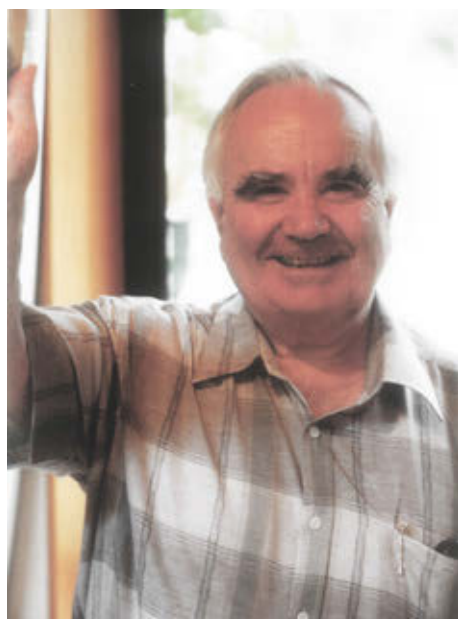
He was the first person to do disability television. Long before Attitude TV, JB fronted for the camera at the Avalon Television Studios in Lower Hutt with a show focused on IHC news. The Sunday morning shows – *Get Together* and *IHC Update* – started in the early 1990s.

Dr Hilary Stace, a researcher who is writing a JB biography supported by the IHC Foundation, says: "It was the forerunner of disability TV. There were no cue cards. It was him and a cameraman basically."

As Invercargill MP and Chair of the Social Services Select Committee, he helped bring in the Disabled Persons' Community Welfare Act in 1975, which was a milestone in improving accessibility for disabled people. "I was so frustrated at the lack of action in getting people with disabilities recognised in the system," JB says.

He contracted polio as a baby and was one of seven children fostered, then adopted, by the Munro family. His adoptive brother was Burt Munro, the motorcycle racer of *The World's Fastest Indian* fame.

His interest in disability and the welfare of people in care has been lifelong. For seven years, JB was president of the New Zealand Federation of Voluntary Welfare agencies.



*JB Munro's impact on the disability sector went far wider than his 20-year role leading IHC.*

"He was a supreme fundraiser and IHC went through some tough times in the 1980s and '90s," Hilary says. "One of the things he did was to set up the Fundraising Institute of New Zealand."

JB was Vice-Chairman of the 1981 Telethon fundraiser for the International Year of Disabled Persons, which raised more than \$6m. New Zealand's Total Mobility scheme and Teletext were both started with Telethon funding.

He was appointed IHC National Secretary in 1977, retiring as Chief Executive in 1998. "He came to the organisation when it was becoming professionalised," Hilary says. But still JB would personally intervene to assist people with intellectual disabilities and families. "He built those personal relationships," she says.

"He lived his job. He was a grassroots organiser. He had this vision for a better life for everyone. He describes himself as a 'Citizen Volunteer'. It's not just IHC, it's Rotary, it's Polio, it's Abbeyfields [retirement housing]," Hilary says.

Hilary is keen to hear from anyone with JB stories. You can contact her at [hilary.stace@vuw.ac.nz](mailto:hilary.stace@vuw.ac.nz) or 04 463 6569.

## Contents

- 2 Personally Speaking
- 3 JB Munro Citizen Volunteer
- 4 Zaina has her own ace team of supporters
- 6 Skill-based projects on offer for volunteers
- 8 New law needed to safeguard children's rights
- 9 Expert ponders impact of Kiwis' laid-back style
- 10 Members wanted for Self Advocacy Committee
- 11 Fasten your seatbelts and hang on

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*Cover image: Georgia Strangman, Matthew Slone and Henry Stilwell hear from the experts at the New Zealand Williams Syndrome Association camp in Auckland in January.*

# Zaina has her own ace team

Zaina Almesfer can rely on her brothers and sisters when help is hard to find.

She has seen a parade of home support workers come and go over the years. Four of them lasted no more than a day; some lasted a few weeks; a few have managed a year.

This is because caring for Zaina, a young woman with Angelman syndrome, is too tough for many people. The syndrome is a genetic disorder caused by a missing gene. It results in severe intellectual and developmental disability.

Zaina, 18, is unable to speak, she needs help with personal care and she struggles to feed herself. Like others with Angelman syndrome she frequently laughs and smiles and she is full of activity. The problem is she never stops, not even at night. Those with Angelman need little sleep.

Luckily Zaina has her own team of supporters. She is the youngest of seven and her sisters and brothers help their parents with the round-the-clock job of caring for her. One sister, Maryam Williams, balances her work as a pharmacist in Pukekohe with an extra day supporting her. Maryam applied to work as a home support worker with IDEA Services to make sure their father – Zaina's primary carer – can get a regular break on Sundays.

Zaina's parents Hussain and Abby Almesfer immigrated to New Zealand from Kuwait in 1995. They live in Whitford – a rural area near Botany in Auckland. Hussain is from Iraq and Abby from Kuwait. Zaina was born in New Zealand in 1996 and she was diagnosed with Angelman when she failed to crawl at the usual age. "She has blond hair and blue eyes. We have all got dark hair and brown eyes," Maryam says. Light colouring is also characteristic of Angelman syndrome.

"She does need pretty much someone with her the whole time. She can walk around the house but if she tries to run she will fall over. She will start pulling things out of the pantry. Most of the time she doesn't really sit still," Maryam says.

Their Mum Abby works fulltime caring for disabled children and doing home help so Hussain, who is now retired, is on hand for the hours that Zaina isn't at school. He also takes the night shift.

"After my Dad takes her to bed at 9.30 or 10 she will sort of fall asleep at 11. Some nights she will get up at 3am



Maryam Williams (right) balances her work as a pharmacist in Pukekohe with an extra day supporting her father.

and wander around the house, or play with one of her toys or watch TV," Maryam says. "She really has got used to my Dad. He has to sleep in the same bedroom; she won't sleep in the room by herself."

Hussain has health problems and when he is ill Zaina's other siblings also step in to help. Except for one brother in Australia, all her brothers and sisters live close by. One sister and two of her brothers still live at home.

"My Dad is 67 years old now and sometimes I just look at him and he looks really tired," Maryam says.

"Dad goes over to Waiheke Island on Sundays with his Gold Card. It's his time out – he goes every second Sunday. I will come over for a few hours and we will normally take Zaina out to a park or to a café, or something."

# n of supporters



extra day caring for Zaina.

Zaina is entitled to 14 hours of home support and Maryam works for seven of those hours, sharing the job with another home support worker. She can only be employed to do home support because she no longer lives at home.

"My parents have tried to get more hours and it went up from 12 to 14 hours." But Maryam says even with the additional hours the problem is getting people to do the home support. And she says Zaina finds it easier if the family care for her. "When she has someone she doesn't know come into the home, she feels uncomfortable."

Their parents prefer it that way too. "They keep saying to me that family is best and that seems to work out well. I said to my Dad, 'luckily you have seven children'."

"It has brought us closer because we have to all stay in contact about who will look after Zaina when my Dad is unwell!"



## IHC Annual Appeal honours the quiet achievers

Siblings are often the ones who keep the family show on the road while parents manage the care of a brother or sister with an intellectual disability.

These brothers and sisters are likely to be in the background – but step up when needed to be the friends, protectors and advocates for family members struggling to find acceptance in the community.

However, many people with disabilities are now living longer and many siblings are now taking a more prominent role in care when parents die. Robin and Linda Millen, who feature in this year's IHC Annual Appeal, are spending their retirement in Waihi looking after Robin's younger sister Wendy who, at 53, has Down syndrome and dementia.



Robin and Wendy Millen

Sometimes the task of caring is too big for parents alone, as with Zaina Almesfer's family, and siblings step in to provide support.

Our Annual Appeal acknowledges the important role that brothers and sisters have always played in the lives of people with intellectual disabilities. We are asking donors to fund the services that IHC provides to support them.

Read about Robin, Linda and Wendy and the IHC Annual Appeal at [ihc.org.nz/appeal2015](http://ihc.org.nz/appeal2015)

Please donate at [ihc.org.nz](http://ihc.org.nz) or call 0800 746 444.

# Skill-based projects on offer for volunteers

The IHC Volunteer Programme now recruits volunteers to work with disabled people on developing specific skills.

IHC National Volunteer Coordinator Sue Kobar says IHC's unique one-to-one friendship programme has expanded to include skill-based volunteering. These are shorter, focused projects based on goals the person wants to achieve.

IHC's original friendship programme involves a volunteer getting to know a person with intellectual disabilities. "We ask people to make a 12-month commitment with us," Sue says. But she says the skill-based programme is more flexible. "It makes it easier for us to recruit volunteers because they understand the time commitment is for six to eight weeks and for a specific purpose." And she finds that people are responding to that.

She believes that IHC's focus on encouraging people to live in more independent living situations will increase demand for skill-based volunteering.

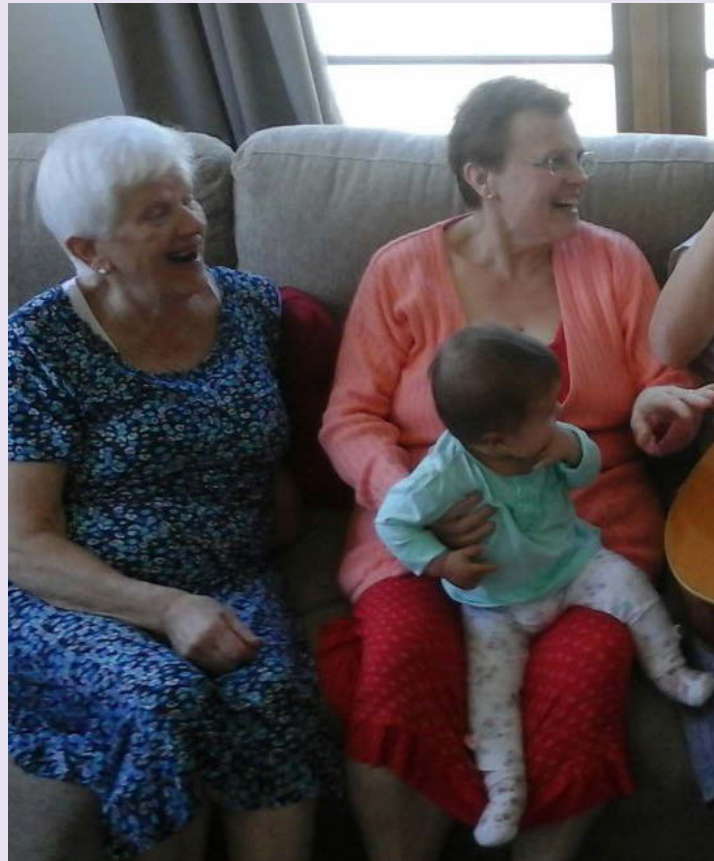
Sue manages a 420-strong volunteer workforce across New Zealand and over the past two years has been carrying out research to refine the programme.

"I wanted to get complete understanding of IHC Volunteering – how old were our volunteers? How long were they staying?"

IHC volunteers range in age from 17 to over 70, and the average age is 38. Auckland, Waikato and Otago have the greatest proportion of volunteers in the 20–29 age range, many of them students.

"I was really pleased to see that our age group is as young as it is. This is because a lot of referrals that are coming through are for younger people with intellectual disabilities. They already have a lot of older people in their lives and they want to meet younger people and get involved in their community," Sue says.

Sue says there is a shortage of volunteers in North Canterbury, Tauranga, Christchurch, Pukekohe and North Shore. People interested in volunteering with IHC can contact us on 0800 442 442 or email [volunteering@ihc.org.nz](mailto:volunteering@ihc.org.nz)



## It goes without saying

Blake Nicholson and Fabiano Frangi

Words take second place to music and laughter when Blake and Fabiano get together.

Marlborough men Blake Nicholson and Fabiano Frangi are building a friendship based on a shared love of music. Fabiano picks up a guitar even though he says he can't play, and they sing and clap. Blake loves the sound no matter what.

"I just pretend. I don't know any notes on the guitar, but he pushes me to play more," Fabiano says. Fabiano, from Como in Italy, manages the Clos Henri vineyard

near Blenheim. He has been in New Zealand since 2008. He met Constanza, from Como, and she put him in touch with Blake. Blake Volunteering friends

Blake lives in an IDEA Services house in Blenheim. He has a hearing aid but Fabiano is more of a listener. "I guess we don't talk quite well, because I don't speak Italian. Fabiano is getting used to my English. Now we can understand his

## On the buses

Candyce Eltringham and Marina Johnson

Marina Johnson can now catch the bus every day to her IDEA Services day

base and home again. Candyce is mentoring from IHC. Candyce Eltringham.

Twice a week, for example, Candyce accompanied Marina Johnson by bus to the St John



*Fabiano (centre with guitar) has some family time with Blake (right), his daughter Olivia, and his mother Daniela and grandmother Enrica, who were visiting from Italy.*

as been living in 2007 and is married Chile. He was keen community and was take through the IHC hip programme.

A Services group home difficulty speaking than happy to fill any complete each other can't stop speaking." sed to picking up cues are at the point where answers and I can

understand his mood," he says.

"I am very happy when I see Blake; he makes my day. You see your own problems for what they are. Compared to Blake's problems, mine are a walk in the park."

Blake's family live on the West Coast and it's a big journey to Blenheim to see him. "Blake is a character and has a love of music," says Nicky Williams, Blake's Mum. "I am very happy Blake has found a friend in fabulous Fabiano. He has given me peace in my heart to know there is someone sharing and enjoying my son's life."

n – thanks to some volunteer Candyce

ght weeks, Candyce a while she travelled n Street vocational

centre in Tauranga until Marina gained confidence to use the bus on her own.

Candyce walked with Marina to the bus stop, confirmed with the driver that she was on the right bus, helped her to swipe

*Continued on page 10*

## Putting on the style

Erin Jaques and Sara Hillier-Jones



*Erin Jaques (left) and Sara Hillier-Jones have it covered with the summer and winter 'Style Files.'*

Erin Jaques loves heading off for weekends with her family. But deciding what to pack in the suitcase was always hard.

So IHC volunteer Sara Hillier-Jones was called in. Sara's assignment was to help Erin pack her suitcase for her fortnightly trips to stay with each of her three sisters and brother, to make sure Erin had put in the right clothes for the right occasions.

After an initial meeting and some window shopping in Tauranga, Sara went to Erin's house with her daughter Ellen, a photographer. Ellen photographed Erin in many different items of summer clothing. They chose which items went together and what was appropriate for different occasions – even down to the shoes.

The photos were enlarged, laminated, and then put together in a folder in different categories. Erin named it her 'Style File'. The summer style file was created first, and then Sara was asked to help with a winter style file.

Erin's sister Mary Jaques is her chief clothes shopping companion and they hunt down the bargains. "She likes lots of clothes," Mary says. "I am always buying them with her."

Sara, who trained as an occupational therapist, has been volunteering for more than two years and finds the skills-based programmes over six to eight weeks suits her. "It really makes use of my work skills." Watch Erin and Sara put their Style File together. See the video at [ihc.org.nz/volunteer](http://ihc.org.nz/volunteer)

# New law needed to safeguard children's rights

IHC is hoping ground-breaking legal action this year will create new case law to safeguard the rights of disabled children in schools.

The issue comes under the spotlight with two legal cases. There was a preliminary Human Rights Review Tribunal hearing in February on the IHC discrimination complaint against the Ministry of Education and, in July, Green Bay High School's appeal against the High Court decision last year to quash the school's exclusion of a student with Asperger syndrome is scheduled to be heard in the Court of Appeal. IHC is an 'intervening' party in that appeal as is the Human Rights Commission and Attorney-General.

IHC lodged its complaint with the Human Rights Commission in 2008 about practices at local schools that discriminate on the basis of disability. Now, nearly seven years on Director of Advocacy Trish Grant says IHC's commitment is unwavering.

"Systemic change takes time – sometimes it's like water on a stone. You've got to be prepared to be in it for the long haul."

Trish says disabled children are often caught in an education system that does not enable them to participate and achieve. She says the Ministry's briefing to incoming Education Minister Hekia Parata has presented a very rosy picture about special education, saying 99.6 percent of disabled children are being educated in local schools.

"We are saying in our complaint that although you have got 99.6



*High five – Seven-year-old Charlie Ussher is making friends, learning and having fun at Berhampore School in Wellington. Charlie has autism and is mainstreamed in a Year 2–3 class. There were closer schools, but "this is about perfect for him", says Dad Mark.*

percent in regular schools, all is not happy there. For example how do we measure quality for these children? It's very difficult when the Ministry doesn't collect data on these children – that is another example of systemic neglect," she says.

"We have got endless cases that illustrate that despite Ministry involvement there is no requirement on the schools to fix the problems with full access to education by disabled children. And schools are saying that we haven't got from the Ministry what we need to fix these problems."

Trish says, however, that thanks to the debate there is now greater recognition that full participation in school life is a human right.

Trish says the Green Bay case is an opportunity to make new law around 'reasonable accommodation' under the UN Convention on the Rights of Persons with Disabilities. "The convention says that

educational bodies must reasonably accommodate children with disabilities at school and not to do so amounts to unlawful discrimination.

"Reasonable accommodation means that adjustments that can reasonably be made to give the child equal access to education must be made. These include teacher-aide hours and access to speech and language therapists.

"Reasonable accommodation is to be treated differently in order to be treated the same," she says.

"What other way can children get a fair deal in schools without those human right commitments? In terms of the child's right to education, legal action is the only port of call.

"There is very little case law around disability rights generally. This is a very new area in New Zealand and globally. Around the world, we are grappling in this space – this case is being watched."



# Expert ponders impact of Kiwis' laid-back style



Getting acquainted at the Williams Syndrome Association camp (from left) are Jessica McClintock, Dr Karen Levine, Henry Stilwell and Tatiana Vaireka.

## New Zealand might just be the perfect place for someone with Williams syndrome.

Visiting US disability expert, Dr Karen Levine, here for the New Zealand Williams Syndrome Association camp and conference in Auckland in January, says she has the impression that the more laid-back social style here might work very well for people with the condition.

Karen says this is based on a casual observation, but she would be interested to see some research on the topic.

"New Zealand's social culture may be a bit more understated in terms of emotional expression overall than many parts of the US. This may be helpful to people with Williams syndrome, who tend to experience emotions pretty intensely. Maybe the more laid-back, calm, cultural social style helps people with Williams syndrome sustain more emotional regulation more easily," she says.

"At the end of every Williams syndrome event I've been to in the US there are extensive hugs and tears by people with Williams syndrome as they say their emotional goodbyes. At the end of this camp, where wonderful times were had by everyone with Williams syndrome, they hugged their goodbyes but I

didn't see tears, more just, 'See you in two years!'"

Williams syndrome is a non-hereditary genetic condition and affects only one in 10,000 people born. Around 25 adults and children with Williams syndrome and their families attended the conference and three-day camp, which was supported by funding from the IHC Foundation.

"Because there are so few people with Williams syndrome, this camp provides a rare opportunity for these children and adults with WS and their families to come together and share time with others who walk the same road," Karen says.

Karen, a developmental psychologist from Massachusetts, spoke to participants about desensitising and dealing with phobias and anxiety that affect people with Williams syndrome through her play-based diagnostic therapy. She says people with the condition have anxiety about many issues, especially those that are sound-related such as alarms, sirens, vacuum cleaners or hand dryers. She says breaking down the elements of a thunderstorm, for example, can help people deal with

their anxiety. She shows people a video of thunderstorms with the volume turned down and minimises the anticipatory anxiety by explaining how the sound always follows the flash of lightning.

She says children with the condition have a strong and instinctual drive to engage with strangers and have no concept of stranger danger. "One thing on parents minds very much in New Zealand as well as in the US is how to deal with over-friendliness in crowded situations, with many parents worried about losing their friendly kids in places like the mall.

"I was talking to one girl who said, 'I just want to make everybody happy!'"

Karen says a young woman in the States told her she took her parents' advice on boyfriends – 'if I am dating someone, I bring him home to my parents to see if he is going to be nice to me, because I can't tell.' "It's knowing what you need help with."

Karen has a new book coming out soon, *Attacking Anxiety*, a step-by-step guide to treating anxiety and phobias in children with autism and other developmental phobias.

## On the buses

*Continued from page 7*

her Smartride card, find a seat and then to get off at the correct stop. After eight weeks Marina was ready to go it alone.

Candyce says Marina has the number of the bus written on the back of her bus card, which she wears around her neck.

Family/Whanau Coordinator Kara Tuhua says Marina is very confident and she absolutely loves catching the bus. "It's an extra skill that she can have. It opens her whole world up."

Marina and Candyce have both benefited from the bus skills project, says IHC Volunteer Coordinator Brenda Evans. Candyce, who also has a disability, started volunteering as a way to build her own skills and confidence with the goal of getting a job. She has now completed three volunteering assignments on the IHC Volunteering skill-based programme



*Marina Johnson (left) and Candyce Eltringham are now moving on to the next stage of their bus-riding skills project.*

and has one more project lined up with Marina. She will be helping Marina catch the bus to Bayfair shopping complex to increase her bus-riding range and independence in the community.

Marina, meanwhile is now passing on her bus-riding skills to Margaret Wilcox, who shares her house while on respite care. Margaret will ride to and from the day base with Marina to gain more confidence with travel.

## Members wanted for Self Advocacy Committee

Do you have great ideas about how IHC could support people with intellectual disability?

We are looking for people with intellectual disability who want to be part of the IHC Board's Self Advocacy Committee.

This is a group of up to six people who advise the board on ways to improve support for people with intellectual disability and alert the board to any issues that are impacting on their lives.

Director of Advocacy Trish Grant says IHC has always prioritised hearing the voices of disabled people. She says members of the committee must have the ability to read,

to travel independently and to have support in their local areas so they can prepare for committee meetings, report back to people in their areas and consult when needed.

Trish says IHC needs committee members who know about the organisation, are involved in IHC Associations and who can take an active interest in the way support services are run.

The committee vacancies will be advertised on the IHC website and on our Facebook page and people are free to put their names forward

or to suggest other people. A short-list of candidates will be profiled on Facebook and people can let us know who they want on the committee.

The final decision on who gets to join the Self Advocacy Committee will be made by IHC President Donald Thompson.

If you need further information, please contact Trish Grant on [trish.grant@ihc.org.nz](mailto:trish.grant@ihc.org.nz) Application/nomination forms will be available on the IHC website and Facebook pages in March.

# Fasten your seatbelts and hang on



Front row (from left) Axel Evans and Jacob Dombroski. Second row (from left) David Cree and Michael Heberton. Third row (from left) Catherine McBride and Kwame Williams-Accra. Back row Janiece Pollock.

Switch seats on this long-haul flight and you could be mistaken for a spy. Or you could end up with fish instead of chicken, due to prior passenger selection.

In *Wake Up Tomorrow* Wellington theatre-makers and a group of young people with intellectual disability, explore the bewitched, bothered and bewildered state of the long-haul passenger.

*Wake Up Tomorrow* is part of the 2015 Circa Theatre programme during the New Zealand Fringe Festival. Directed by Isobel MacKinnon, the show is a collaboration between the Everybody Cool Lives Here Trust, co-founded by two Wellington-based theatre practitioners Nic Lane and Rose Kirkup, and Active, an IDEA Services group for young people with intellectual disability.

The creators of *Wake Up Tomorrow* start out with some larger-than-life

characters dreamed up by Active members and send them flying on an 'Active Airlines' flight. Audiences are transported from mind-numbing moments to bizarre and hilarious scenarios.

A spy has gone missing and a fellow passenger is expected to carry out his secret mission. There are two elderly women passengers who are not what they seem to be. There's some kind of party going on in the first-class section ... "The idea is that when you are on a long-haul flight you get into this weird state of delirium," Rose says.

We may or may not arrive at the expected destination. The show is partially improvised and none of the six performances will be the same.

Rose says the characters have been devised by Active members and theatre practitioners have helped them to weave a show around the characters. "Our main goal is to really foster their creative voices," she says. "It's fun and exciting and the characters are really great." She says many of the young people involved have travelled on long-haul flights and this has come directly out of their experience.

"The IHC Foundation is pleased to support this exciting partnership, which will see people with intellectual disability participate as actors, designers and production assistants alongside a professional theatre troupe in a professional theatre space," says IHC Foundation Chair Sir Roderick Deane.



# COMMUNITYMOVES

March 2015

15