



Life Unlimited and AccessAbility: Leaving a legacy



COVER IMAGES

Top left: Jack Lovett-Hurst

Top right: Man using drill

Bottom left: Barry Hutchinson

Bottom right: Jaime McEwan

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Our history

Two organisations, each with a long history of serving New Zealand’s disabled community, began a new chapter in June 2021. A shared dedication to supporting disabled people to live the lives they aspire to, saw the amalgamation of Life Unlimited and AccessAbility, forming an organisation that delivered on its commitment to enabling people with disabilities to live the life they choose.

This legacy book, dedicated to the journeys of each organisation, aims to record the history of these charitable trusts to ensure their work, service, commitment, and endless advocacy is recognised and remembered as the new organisation takes shape.

A story of shared vision

Life Unlimited Charitable Trust Established 1979, Hamilton

The Waikato Disabled Living Centre Waikato Trust aimed to be an umbrella body for disabled organisations, and its first premises was a leaky building loaned by the Hamilton City Council. “We started with nothing,” recalls Hamilton accountant John Dobson, who was chairman of the Trust for many of its 43 years.

The Trust “looked for the gaps” in the disabled service market, rather than doing what other bodies were already doing. And it aimed to do so in a business-like way. “Good businesses can do more for the disabled people they serve,” says John. The other main force of the Trust, Bruce Tocker, himself disabled and in a wheelchair, had the same attitude.

The organisation’s first CEO – Life Unlimited had only two paid staffers and a dozen volunteers – was the “extremely capable” Louise Pentecost, says John. There was so little money within the organisation, Bruce recalls, he and John told Louise they’d pay her wages for a couple of weeks while she ‘scouted around to see if she could get sponsorship to cover them.’ If she didn’t, they would continue to pay her. Bruce says: “Within a month she had come back with the money and had sussed out a lot of other things as well!”



*“Life, standing for
Living Independence
For Everyone.”*

One early gap to be filled was the lack of taxis in Hamilton with the ability to take people in wheelchairs. The Trust bought two vans with hoists and put them to work. Later, a commercial taxi service saw the gap in the market and took over the wheelchair taxi service.

The Trust always wanted to grow while keeping its books in the black. John says it became an efficient fundraiser, both by ‘begging’ money from philanthropic trusts and through its annual Rose Day. It opened a shop where disabled people could sell their wares and learn skills – a “sheltered workshop” in the non-PC language of the day, recalls John. By 1987 it had opened a new building filled with organisations working for the disabled.

In 1990 the Trust made the decision to stop relying on handouts and to switch its focus to winning government contracts. The first was to provide home services and assessment of support needed for disabled people in the community. In 1996 the Trust decided to let go the home-based support part of the contract and focus on needs assessment and services coordination – NASC, in the jargon. The Trust would help the disabled person decide what they needed and put them in touch with the service providers. NASC contracts became a large part of the business.

A new CEO gave the Trust a new name and a new impetus. Adri Isbister was “a whirlwind,” says John. The Trust, now rebranded as Life Unlimited – “Life” standing for “Living Independence for Everyone” – expanded its NASC work into Tairāwhiti and the Hutt Valley; it opened new disability resource centres in Gisborne and Tauranga; and it won a string of business awards including one for CEO Adri Isbister.

Adri shared John’s commitment to growth, sound business practices, and enjoyment. Charities must be good businesses “because otherwise you don’t survive and you don’t keep doing the good work you’re doing,” she says. But you can have fun while you’re doing it. Adri used to take her German Shepherd along to the social skills programme the Trust ran for people who had left Tokanui Hospital. “She used to love it”, says Adri, “and so did I.”

This was the age of deinstitutionalisation, the final shutdown of the state institutions where inmates had sometimes spent decades after being incarcerated as children. The Trust won a contract to assess the needs of people from the Kimberley Hospital – “the last institution standing” – as they shifted into the community.

TOP LEFT
Group photo

BELOW LEFT
Mobility Store

“We would bring people on and they would be apprenticed to us for two years and then they’d come out the other end as fully qualified hearing therapists.”

– Adri Isbister

“Every time an institution closed, all the really hard cases went to Kimberley,” Adri says. She recalls one man with an intellectual disability who also had a swallowing reflex which meant that he had great trouble eating. Mealtimes at Kimberley had lasted half an hour “and he had never properly eaten food.” Now he got the help he needed “and it doesn’t matter if it takes four hours to eat a meal, does it?”

She also went to public meetings to allay the fears of local people worried about what the intellectually handicapped people might do once released from hospital. Adri also took the Trust into two important new areas of work. It won a Ministry of Health contract to provide hearing therapy services and, as part of the deal, it moved into education, creating a qualification for hearing therapists. “We would bring people on and they would be apprenticed to us for two years and then they’d come out the other end as fully qualified hearing therapists.”, says Adri.



TOP LEFT
Disability Living Centre Vehicle

BELOW LEFT
Man in wheelchair accessing Disability Living Centre Vehicle

TOP RIGHT
Disabled Living Centre Hamilton

BELOW RIGHT
Dial A Ride vehicle



“We were still hungry for growth, but there weren’t the same opportunities.”

– Mark Brown

The Trust became a major provider of services for people with autism and their families, starting with a disability information and advisory services contract, which they partnered with Parent to Parent to deliver.

The Trust also became deeply involved in assessing young people who could no longer live with their parents to see whether they qualified for an independent youth benefit. This started as a regional contract and grew into a major national one worth millions of dollars.

In 2010 Mark Brown took over as CEO and a period of consolidation began. “We were still hungry for growth,” says Mark, “but there weren’t the same opportunities.” The Trust also wanted to make sure that what it was doing was making a difference and was still needed.

One area of success was the new Enabling Good Lives project, where disabled people were given personal budgets to manage. A trial programme began in the Waikato in 2016, and the concept was to become increasingly important for the disabled community in the future. The Trust, however, faced a steep learning curve in managing the idea in practice.

“Different people want different amounts of help,” says Mark, and the Trust had to learn how to manage this. “We really built up quite a bit of expertise and became a good example of how

that can be done. We weren’t expecting to actually do that, but that came about because we were willing and open to try new things, I guess.”

A much less encouraging event, however, was the loss in 2017 of the national independent youth benefit contract, now known as the Family Breakdown Assessment service. However, Mark says he was ambivalent about the contract because it was doing what was simply a function of government rather than a service for the disabled. “When we lost it, it was a bit of a juggle because we lost quite a bit of revenue,” he says. “We had to do quite a bit of belt-tightening and run a leaner organisation.”

Another challenging area was providing information and equipment. In its early days, the Trust had started selling equipment, such as aids, appliances, and wheelchairs. In 1999 it had set up a show home next to its office in Hamilton with each room displaying how an accessible home for disability would look.

“That was a great idea, but unfortunately proved in the end not to be a viable proposition,” says Mark. During his time the Trust put a lot of effort into reconfiguring its retail stores “so that they were providing information for disabled people, but they were also operating as profitable stores.”

TOP LEFT
Hamilton Office Construction 1

MID LEFT
Hamilton Life Unlimited Office / Disability Resource Centre Waikato

BELOW LEFT
Mobility Van – Product panel

TOP RIGHT
Hamilton Office Construction 2

BELOW RIGHT
Lady in wheelchair and Mobility Van



“We really built up quite a bit of expertise and became a good example of how that can be done. We weren’t expecting to actually do that, but that came about because we were willing and open to try new things, I guess.” – Mark Brown



“Change in the sector indicated that to be a little bit bigger and stronger, we would have a bigger voice and so could provide better outcomes.”

– John Dobson

In 2017 the Trust bought a successful disability equipment retail business in Lower Hutt and opened a new store in Hastings. The strategy was successful in many ways but, under the new CEO Megan Thomas, the decision was made to close two stores in Rotorua and Gisborne. Today, the stores are operating profitably for the Trust.

The Trust had a policy of giving money to other charities working in the same field and pursuing similar goals, such as Parafed Waikato, which supports competitive disabled sports.

The board was keen to grow and to merge with other charities, says John Dobson. “Change in the sector indicated that to be a little bit bigger

and stronger, we would have a bigger voice and so could provide better outcomes.” Mark Brown reiterates the sentiment. “The government has been signalling for some time that it would prefer to deal with fewer and larger organisations in the sector”.

Over its life, the Trust had partnered with many organisations, some more successful than others. John says that it learned how to handle the “softer issues” of putting together two complex organisations. The Trust “jumped straight out of the pot into the fire and got together with AccessAbility, which we’d been having a courtship with for about nine months.”





By now, the Trust had grown into a substantial organisation, employing 80 people, holding government contracts for autism, hearing and disability services and information and providing NASC and Local Area Coordination (LAC) disability support in Hutt Valley and Tairāwhiti as well as community programmes in the Waikato.

The merger, says John, builds on the similar values and business practices of the two organisations, and will allow it to make its services for the disabled even stronger. It will allow a better focus on the Enabling Good Lives policy of giving disabled people the budget and the power to make their own decisions about their lives. In short, “Nothing about us without us.”

LEFT
Members of the NYC Achilles Track Club

TOP RIGHT
Members of the Running Club

TOP LEFT
NYC Marathon Training



AccessAbility Charitable Trust Established December 1997, Taranaki

Lorna Sullivan and Jan Scown wanted to put disabled people at the centre of the system that was supposed to help them. Lorna worked for CCS (Crippled Children Society, later renamed CCS Disability Action) in the Bay of Plenty; Jan was CEO of Community Living Trust in the Waikato, which provided community-based services for people discharged from Tokanui Hospital. They knew how the system worked and how they wanted to change it.

In the mid-1990s formal assessment of the disabled person's needs by NASC (Needs Assessment and Service Coordination) organisations was relatively new. In 1996, Lorna and Jan got together to plan a NASC that would support disabled people to pursue the lives they wanted. The new organisation would be "alternative-thinking and disability-focused."

AccessAbility was set up in December 1997 as a charitable trust, with funding from CCS and Community Living Trust, brought together by founding board members Kaye Taylor and Peter McRae. Jan Scown was the CEO.

In the same year the new organisation won a contract to provide NASC services in Taranaki and Whanganui. The initial contract was a whole-of-life contract, with two teams working alongside young people and those over 65 with age-related needs.

ABOVE
AccessAbility started 1997

TOP LEFT
First office in Hawera

BELOW RIGHT
Team 1999



“The aim of Imagine Better was to educate the disability sector, with a goal of moving towards individually designed support for disabled people to “live self-fulfilled lives as valued members of society.”

The vision developed over the years with the aim of improving outcomes for people and families supporting people with a disability or disabilities.

In 2000, Pip Nicholls became CEO and AccessAbility won a contract to provide NASC services in South Auckland. The following year it began NASC in Auckland and Northland and took up the Regional Disability Care Agency (RIDCA) for the same areas. A RIDCA was a contract which looked after intellectually disabled people requiring compulsory care.

Auckland AccessAbility followed with a contract specifically to support disabled people aged 16–65. In the same year AccessAbility won a NASC and a RIDCA contract for Otago and Southland and took over the contract for people with disabilities from CCS (under 65).

Rachel Stephenson, a board member since 2008 and chairperson from 2013 till 2021, says AccessAbility had always been run in a business-like way and it wanted to grow, “but only if it was growth in the right direction.”

“We weren’t interested in growth for growth’s sake. We’ve always been really really clear that our values are more important than anything and upholding the rights of disabled people was more important than anything.”

AccessAbility took a major new step into advocacy for, and education of, the disabled and their families in 2003, by setting up Standards Plus (later renamed Imagine Better) as a wholly owned company with Lorna Sullivan as CEO.

The aim of Imagine Better was to educate the disability sector, with a goal of moving towards individually-designed support for disabled people to “live self-fulfilled lives as valued members of society.”

Imagine Better raised its money from philanthropic trusts and its parent body, AccessAbility, of which Judy Bilderbeck was CEO at the time, thereby avoiding the government ban on advocacy by government-funded organisations.

Imagine Better’s education function was very important, explains Rachel Stephenson, former AccessAbility Chair “and still is to this day, providing workshops and helping families.”

Julia Genet, a board member of both AccessAbility and Imagine Better from 2012 till 2021, can attest to the reality of Imagine Better’s “individually designed supports for disabled people.” Lorna helped her set up a company to provide for the 24-hour care needed by her severely autistic son Richard. The approach worked “amazingly well.”



In 2007, AccessAbility celebrated its 10th birthday and moved into a new field, winning contracts with the Accident Compensation Corporation (ACC), providing supported living and supported employment for people with disabilities caused through accident.

He Ara Tumanako was also established. While this was an innovation, it did not prove to be cost-effective, says Rachel. It required spending on staff and infrastructure but there was no guarantee there would be any referrals from ACC. That line of work was not renewed.

There were strategic lessons to be learnt here, says Rachel. Should an organisation like AccessAbility have diversified at any cost and risk spreading itself too thin? “Or should we concentrate on what we do and do that exceptionally well? And that’s what we chose to do.”

In 2010, AccessAbility, now a charitable trust rather than a limited liability company after buying out its shareholders, launched its first national conference for the disabled. This and later conferences between 2012 and 2015, had a big influence on the disabled community. For the first time disabled people spoke for themselves in a major forum.

Disabled people and family members gave joint papers with academics and other professionals.

“We weren’t interested in growth for growth’s sake. We’ve always been really really clear that our values are more important than anything and upholding the rights of disabled people was more important than anything.” – Rachel Stephenson

AccessAbility failed to win renewed NASC and RIDCA contracts in Auckland in 2012. It therefore shut its Auckland office and the organisation launched a review of its strategic direction.

Also in 2012 Imagine Better merged with Voice Advocacy Trust, an organisation providing independent advocacy services. Further national conferences in partnership with other organisations were run in 2012, 2013 and 2014.

In 2013, major restructuring of the organisation took place. CEO Judy Bilderbeck stepped down after nine years in the role and 16 years with AccessAbility. Lorna Sullivan stepped down after nine years as CEO of Imagine Better.

Tony Blackett, who had worked for a variety of organisations including Greenpeace and Deaf Aotearoa, became Chief Executive of both AccessAbility and Imagine Better.

“We decided that the business was unsustainable and having two CEOs was also unsustainable,” says Rachel.

From then on, the organisation concentrated on its core business of running NASCs and LACs and continued its advocacy and education work.

In 2014, AccessAbility won the contract to run Local Area Coordination in Central Otago and Southland; Imagine Better won the contract to run Local Area Coordination in the Bay of Plenty.

Between 2016 and 2018, AccessAbility replaced national conferences with regional forums discussing issues facing the disabled.

Disability Advocate, Julia Genet points to the complexities of putting the disabled person at the centre of the system. “It is not simply a case of enabling the person to have a good life,” she says. “We don’t want a good life; we just want an ordinary life. You have the good and if you don’t have the bad, you don’t learn. But if you don’t have the good, you can’t keep going.”

Everyone learns and grows from their mistakes, including people with disabilities. “If disabled people don’t have that opportunity for growth, they’re not living in a real world. I think they don’t grow,” she says.

Angela Te Whaiti, a long-time manager of AccessAbility and national manager of the merged organisation operating under the name Life Unlimited, says disabled people must have the power to make wrong decisions as well as good ones. She likens this to a young person who leaves home to go flatting and ends up coming home again. “It shouldn’t be seen as a failure, but rather just learning along the way,” she says. “That will help shape the next choice and helps the person to develop.”

In 2018, Tony Blackett left as CEO and was replaced by Tony Paine. Tony had a vast amount of experience in government bodies and NGOs, but the board particularly liked “his lived experience with a disabled daughter” and his involvement in philanthropic bodies.



AccessAbility set up a third company – Journey Together – to run the Local Area Coordination contract in Bay of Plenty, leaving Imagine Better to focus on disability research, training, and advocacy.

AccessAbility is proud that disabled people had an important part in leading the organisation. Long-serving board member Gary Williams notes that the board has always had a majority of disabled members, including himself, although “I think that was driven by practice rather than policy.”

In 2019, informal talks began between AccessAbility and Life Unlimited. The drive to merge with Life Unlimited, says Rachel came from the similar values and practices of the two trusts, but also because of the synergies and strength gained by the single body. “It makes us one of the biggest [NASCs] in the country – in the top three,” she says.

The merged organisation would also mean that Imagine Better’s education and advocacy work could be expanded in a way that the single organisation could not do.

In 2020, AccessAbility and Life Unlimited combined their NASC and LAC teams under a shared national manager.

On July 1, 2021, AccessAbility and Life Unlimited merged. And that, Rachel Stephenson said, meant a new and stronger voice for the disabled.



Stories from the people involved

Both organisations have championed support for disabled people across Aotearoa to live the lives they aspire to. Within Life Unlimited and AccessAbility there are plenty of stories to be told. We hear from some of those individuals who were unwavering in their vision to see New Zealand's disabled community supported, advocated for, and represented to live the life they choose.

Bruce Tocker *Life Unlimited*

Bruce Tocker was only 14 years old when a mysterious virus made him a paraplegic. "I had no history of ill health, and I had no reason as to why I got the paralysis," he says. His family had just moved to Hamilton from Taranaki, and he had not yet made many friends.

The teenager's success at competitive swimming and his determination to keep succeeding helped him cope. "To be a top sportsman you've got to be committed and focused. I think that all the attributes that I had for swimming helped me in terms of dealing with the disability."

Bruce also played many wheelchair sports and, in 1996, became the New Zealand chef de mission at the Atlanta Paralympics Games.

After school he got a job in an accounts office and rose over the years to become a finance manager. His ability to manage the books made him a natural partner for accountant John Dobson, his fellow-founder of the charity that became Life Unlimited.

The Waikato Disabled Living Centre ran a tight ship. Working very hard to form partnerships with other charities, with the aim of having a one-stop shop in Hamilton where disabled people could get information, proved less successful than they hoped.

"The disability system is fragmented and requires organisations to compete against each other for government funds. As a result, many keep themselves to themselves," says Bruce.

He enjoyed his many years on the board of the Trust, setting trends and adding value to the people who used the organisation to find their way through a complex system.

Larger organisations were more likely to thrive and to survive any sudden changes in government policy, he believes. The financial management and good business practices had left Life Unlimited with substantial reserves.

"I believe the merger between Life Unlimited and AccessAbility will provide many benefits amid the uncertainties of the competitive system," concludes Bruce.

LEFT
Barry Hutchinson

John Dobson *Life Unlimited*

John Dobson has spent more than 40 years serving disabled people while keeping the books in the black. “If charities are to do good, they need to be good businesses,” says the veteran former chairman of Life Unlimited.

John had just become partner in a Hamilton accounting firm when he was told to go and do good works. “Young partner,” said the senior partner Malcolm Brooker, “you need to get out in the community and do something. Your father did everything he could for the community, so you can do the same.”

In mixing business and philanthropy John was continuing the work of his father, a businessman and leading figure in the local Jaycees, the Anglican Church and many different charities. “I was brought up in a philanthropic environment,” says John, “and I’ve always wanted to help and do good.”

“Brooker was big in the Crippled Children’s Society and didn’t feel it was right for them and other charities to be competing for funding and resources that were already very scarce,” John recalls.

“They wanted to create a new organisation in the disability sector. It was world-changing in those days, an aspirational dream.” The gap between the dream and the reality was striking. The proposed umbrella group was the Disabled Living Centre Waikato Trust.

The Trust’s aim was to look for the gaps in the help given to the disabled community. One of the biggest gaps was transport for people in wheelchairs. “We got involved in setting up a taxi service with vans – the first vans in New Zealand to have hoists on them.” The subject became topical and taxis soon got on board and took over the service from them.

Other gaps were much harder to fill. People with disabilities had trouble getting work. The Trust rented a store where the disabled community could sell their wares and learn skills known as – “sheltered workhouses.”

In those days the Trust was sustained through fundraising in the community. The main fundraiser was Rose Day: “We got roses from wherever we could and sold them for donations. I knew that model wasn’t sustainable – we needed to get out and find sources of income,” explains John.

The new Trust won government contracts and found a new way of doing things. If it made a surplus from the contract, the profit would be put towards further charitable work. Business and good works now went hand in hand. John says: “Improving the life and wellbeing of people who have, or are affected by, disability; that’s where my passion is.”

Adri Isbister became Chief Executive Officer and greatly expanded the work of the organisation. She too was wedded to the idea that the charity should be a good business. Under the new name Life Unlimited, the charity won a string of Westpac Business Awards.

“One of my fundamental rules is if you’re not having fun, there’s something not going right. There’s something not right in the organisation’s culture. The morale of an organisation like Life Unlimited is particularly important.”

John believes the merger of the two charities will produce a greater voice and better services for the disabled community and will continue to be run by great people.

Angela Te Whaiti *AccessAbility*

AccessAbility was founded in 1997 with the aim of being an alternative-thinking and disability-focused body that supported disabled people to pursue the lives they wanted.

Angela, a mother to a son who had additional needs, joined the AccessAbility team in Dunedin in 2004. Initially employed as an Assessment Facilitator, Angela has seen a lot of change and development within the teams, communities, and the wider disability sector. “I am very proud of what we achieved at AccessAbility. We have come a long way from when we used to have to book in time to share the one PC we had in the office. We’ve gone through a full organisational and digital revolution since then!” explains Angela.

In the early days, AccessAbility had teams based in Auckland, Taranaki, Whanganui, and the Bay of Plenty. Over the years they moved from working in their local communities to developing an approach that maintained regional flavor and incorporated a national approach and team.

The organisation grew at pace, down in part to the people and culture. “We have seen some good people come and go over the years. What has remained consistent is our will to enhance our teams and culture, and to work alongside individuals and whānau to pursue a good life.”

“We have always focused on forming a relationship, adjusting our approach to respond to the individual’s needs and ultimately connecting them to other community services and supporting them to live a good life,” Angela says. “Our aim is not just to tailor the discussion to the individual, but to tailor the funding too.”

AccessAbility and Life Unlimited have a history of working together and shared a vision for the future. Both organisations were successful in implementing Local Area Coordination in three communities – a community-based approach to working with disabled people to make plans and work towards the life you can imagine.

In 2020, with an awareness of the changing environment and actively listening to the needs of our communities, further conversations took place that resulted in a merger with Life Unlimited.

Latterly, Angela was the National Manager for Needs Assessment and Service Coordination and Local Area Coordination at Life Unlimited.

Life Unlimited also wants to forge closer partnerships with other disability organisations so that they can continue to “walk together” with the disabled person.

“I’m constantly motivated and impressed by how far we’ve come – the outcomes, developments and collaborations – all the while valuing the contribution of those with lived experience and maintaining our commitment to cultural responsiveness.”

Angela believes the merger of the two charities will produce an even greater organisation. “We had two like-minded organisations with the right values and the will to want to do something truly different for our communities, transform the existing system and carve out a new space in the sector.”

Mark Brown *Life Unlimited*

In 2010 Mark took over as Chief Executive of Life Unlimited from Adri Isbister, who had overseen a period of massive growth. Mark's time was a period of consolidation while also trying to make a real difference for the disabled community.

Mark came to the charity with much experience in the private sector and government. He was Regional Manager of Presbyterian Support Services, and then worked for the Regional Health Authority during the major health reforms of the 1990s before going on to work as General Manager of Healthcare New Zealand.

Mark is proud that Life Unlimited built an existing autism contract into an organisation which is now a highly respected brand. Altogether Autism has a distinctive, strictly evidence-based approach to providing reliable information and support to autistic people and families. Mark was pleased to see Altogether Autism secure contracts and funding to allow professional development and training to be offered to staff employed in the disability and education sectors.

Mark and the team spent a considerable amount of time reconfiguring the way the organisation approached its information services and NASC services, always seeking to be progressive in their thinking and responding to government initiatives in system transformation and Enabling Good Lives.

“We were able to be successful in supporting a good number of people with managing their personal budgets through Enabling Good Lives. We had not actually planned to develop in this area, but we went with the idea that we would do whatever it would take to support each person and family. Each person wanted different levels of support and had varying aspirations for their lives. We experienced a steep learning curve, but quickly built up expertise and a good reputation because we were willing and open to try new things.”

Mark is proud that he upheld the workplace culture of Life Unlimited. “It was important to me when staff were in sometimes stressful roles supporting people, that they were able to experience a workplace where staff for the most part enjoyed coming to work and felt good and safe about the environment, and where there was an opportunity for personal growth.”

Ross Brereton *AccessAbility*

Former Human Rights Commissioner Ross Brereton says AccessAbility played an important role in promoting the rights of disabled people.

The rights of disabled people have taken a long time to win recognition in our domestic laws. It was only in 1993 that the Human Rights Act outlawed discrimination on the grounds of disability.

New Zealand took a leading role in the push for the United Nations Convention on the Rights of Persons with Disability. It signed the convention in 2007 and ratified it in 2008. By that time, Ross remembers, “a lot was starting to happen” in the way disabled people were supported.

Now the disabled person was at the centre of what needed to happen, rather than trying to retrofit a service. AccessAbility put the disabled person first rather than trying to squeeze the individual into the funding framework.

“The whole concept of individualised funding started to happen and again AccessAbility played a role in promoting it. That gave the disabled person far more control over their lives. A lot more disabled people themselves started to take on more and more roles within the sector, and that’s continued,” Ross explains.

“AccessAbility was highly respected for the work they were doing in this area.”

Ross joined the board in 2001 and stayed for 10 years. “The organisation also developed more strategic thinking about how we could continue to progress, given the funding and the terms of reference of the contracts that they had. They had a much more goal-setting visionary aspect to the view of the individual who was being assessed, really thinking about what sort of future they might want to have and how needs assessment could really help them,” Ross explains.

During the 1970s and 1980s the actual voice and representation of people with disabilities was very small. Services for disabled people were essentially run by able-bodied people. AccessAbility came at a time when disabled people themselves were starting to take their place on boards and in senior staff positions.

The board of AccessAbility put the “disability-led” concept into practice at the board level, where most members were people with disabilities.

“The disability movement also helped to change the language. Not that so long ago the language used by media was dreadfully disrespectful. It was the disability community itself that met with the news media and talked to them about the importance of positive language relating to disabled people,” Ross says.

AccessAbility’s own name was an example of that positive linguistic change.

Barbara Tane *Life Unlimited*

Māori are disproportionately affected by disability – but Māori tradition also provides special ways of dealing with it.

“Māori values provide the best support for Māori with disabilities,” says Barbara Tane. “When the disabled and their families are on the marae they’re not judged. They’re treated the same as everybody else.”

“There’s that manaaki (support), there’s that wairua (soul), there’s that whakawhanaungatanga (process of establishing relationships) when they’re on the marae or at any social gathering where there are other whānau members. They’re included in everything that’s happening. That’s really important.”

Barbara, a Māori needs assessor with Life Unlimited, typically visits the family at home.

“We start off with whakawhanaungatanga, greeting the family, learning more about them and making that connection. I ensure they feel comfortable having me in their home and we start building up that rapport and trust before we even get down to discussing and establishing the service that they might need.”

Barbara uses a Māori assessment tool called Te Aromatawai based on the structure of Whare Tapa Whā, or the four-sided house. This centres the care on the disabled person’s tinana (body), wairua (soul), hinengaro (mind) and their whānau. “We work with all that because it involves all the family. It’s not just about the individual.”

Much of Barbara’s work is with whānau with autistic children. “A lot of our Māori parents are very protective of their autistic child. To them they’re special, they’re a taonga (treasure).”

“Some parents choose to homeschool their children because there is not enough support at school or because of the level of autism of the child’s behaviour. At home there’s usually more whānau support.”

Barbara joined Life Unlimited 22 years ago after spending 26 years in the occupational therapy department of Tokanui Psychiatric Hospital. She was involved in setting up a programme – Nga Mara Atea, or Seeds that Grow – for the disabled community at Kirikiroa Marae in Hamilton East, backed by Life Unlimited until its funding was taken over by the Ministry of Health.

Barbara affiliates to Ngāti Maniapoto and Ngāti Ngutu through her mother (her father was Pākehā) and grew up understanding Māori. Her mother was a fluent speaker and Barbara’s passion is Te Reo.

“Life Unlimited”, says Barbara, “practises manaakitanga with its staff as it does with its clients. It employs disabled people and supports them; it celebrates the anniversaries and the triumphs of its staff and supports them in times of trouble.”

“I love what I do. I love supporting the people. I’m part of an awesome organisation and that’s what gets me up in the morning.”

Rachel Stephenson *AccessAbility*

Rachel Stephenson joined the board of AccessAbility in 2008, wanting to reduce inequality among people with disabilities. But, she says, there is still much to be done.

“If you fall off a ladder and break your back you will be looked after by ACC, but if you’re born with a congenital disability affecting your back you will be much worse off. There are deep disparities among people with disabilities,” she says.

“The disability sector is comparatively underfunded, even compared with mental health, traditionally an underfunded part of the health system,” explains Rachel. Disability funding doesn’t keep up with inflation and yet the number of people with disabilities continues to grow.”

“People live much longer than they used to and improvements and advances to healthcare means they face the disabilities of ageing. In the end we all end up with a disability. More and more people are going to need some sort of aid to lead a good life.”

Rachel started her career as a nurse, specialising in Mental Health and Addictions working in Northland and the Waikato. Health and disability were often intertwined and by 2008 she had become interested in pursuing opportunities in governance and joined the board of the charitable trust, AccessAbility.

“Nothing about us without us – I really connected with that phrase and the board of AccessAbility really walked the talk, with half of board members having a disability or a family member with disability. This was achieved without any formal quota. The organisation was genuinely disability-led.”

AccessAbility was primarily a NASC, a needs assessment service coordination service. It managed its government contracts well and generated surpluses which could be reinvested.

At the same time, it had seen the need for more advocacy for people with disabilities, and in 2003 set up Imagine Better, an independent advocacy and training service. Ministry of Health contracts forbid those receiving the money from advocating for more. “As an independent body Imagine Better is able to play the role of advocate and has been accepted as such by the Ministry,” Rachel explains.

The merger of AccessAbility and Life Unlimited means the two charitable trusts will have greater scalability and size, while retaining the independent advocacy and training service of Imagine Better.

The merger helps counter the fragmentation of the sector that reduces its power and has made it difficult to come together as a united movement. “Many disability organisations are struggling to survive. It takes egoless leadership and a stronger voice.”

Rachel is now chair of Community Living Trust, which provides services for people with disabilities in the Midland Region.

John McIntosh *Life Unlimited*

John McIntosh never let his disability stop him – but when a group of children pushed him into the Hutt swimming pool, he didn't resurface. The metal brace on his upper body was so heavy he sank to the bottom of the pool.

"I could see everybody looking down through the water and no matter what I did I couldn't get up there because there was this heavy weight holding me down. In the end someone realised I'd be down there a bit too long and they'd better pull me out," John said.

"One of the children jumped in and pulled me to the surface. I've had a real fear of water ever since. I never learnt to swim."

John, characteristically, turned his near drowning into a joke. He was the only disabled child in the school, and they had no idea how to help a young boy with scoliosis, so he taught them.

After finishing school John became a laboratory technician at a Hamilton milk treatment station, took a food degree at Massey University and ended up running the lab. This took him to working for 15 years at a cattle breeding company as he worked his way up to being national sales manager for Ambreed.

John later became National Business Manager at Workbridge, the government agency helping disabled people into employment, and in 2003 was headhunted by then Life Unlimited Chief Executive, Adri Isbister. As business manager he did many things, including managing the charity's assets, and later running its stores in Rotorua, Tauranga, Gisborne, and Hamilton.

He also managed a nationwide contract delivering the independent youth benefit for the government. This involved interviewing young people who could no longer live at home to see if they qualified for the benefit. "I love people and I love managing people; bringing people together as a team and getting the best out of them is a passion of mine," he said.

Life Unlimited's mission is to help people with disabilities choose the life they want and get the best out of it. "We listen and work hard to understand what's best for the individual," John says.

Most recently, John has been working with Life Unlimited in a community liaison role, encouraging employers to take on people with disabilities. John pointed to the upside of changing the workplace to suit people with disabilities.

"Sooner or later nearly all of us become disabled and businesses that recognise diversity, both among their workers and their customers, will ultimately perform better," explains John.

John believed passionately in the concept of Enabling Good Lives and believed the merger of Life Unlimited and AccessAbility would mean a greater commitment to it.

Gary Williams *AccessAbility*

Gary Williams is Ngāti Porou and his “impairment label” is cerebral palsy. But that label says little about who he is or what he’s achieved in his life.

“If you’re a disabled Māori, you have to present yourself as a disabled person first,” he says.

“Whereas I don’t. I like to present myself as Māori first, because that has more mana. I know where I come from. I know who my ancestors were, and I don’t want to forget it,” Gary explains.

Gary has had a distinguished career as a champion of disabled people, spending more than 10 years as Chief Executive of the Disabled Persons’ Assembly and 11 years as a board member of AccessAbility. He now serves on the board of Life Unlimited.

He’s also a digital expert. He grew up in Tokomaru Bay and moved to Wellington at 18 years old where he went on to work as a software developer at GNS Science for 20 years. Now he and his wife run a small company in Christchurch. “I’m quite well known in the disability sector, and I’ve been less well known in the Māori sector,” he jokes, “but I’m working on that.”

He says one of AccessAbility’s main achievements during his time were nationwide conferences in 2010 and 2012-15, where disabled people and their families came together with academics, overseas experts and charities to discuss ideas and issues.

The other big success was its work in local area coordination, where disabled people are put in touch with the services that can help them.

“Disabled people deserve and need the ability to decide what’s important and helpful to them.”

Gary continues, “I’m really confident that the merger will be a good thing. It’s a huge opportunity for the new organisation to take a leap of faith, to stretch, grow and stand out from the crowd.”

Adri Isbister *Life Unlimited*

Adri Isbister was six when she and her family arrived in New Zealand. Born in Indonesia to Dutch parents, Adri spoke no English. She remembers how at school she would have to count to 10 in Dutch before her peers would let her pass. Growing up with a loved uncle with Asperger's, her lived experience is reflected in her choices as an adult. As a young mother Adri was aware of the value in continuing her education: "I've always had a sense of urgency," she explains.

Adri's first career was in mental health and addiction. She joined Workbridge as a Regional Manager and in 1996 joined the Disabled Living Centre (Waikato) Trust, branded as the Disability Resource Centre in Hamilton (later renamed Life Unlimited). It had 12 staff, many of whom had disabilities. Some staff were volunteers.

"In consultation with the community, the Trust and the team, a new name and brand identity for the centre was developed," recalls Adri. "We decided on Living Independence for Everyone. It just happened to spell Life."

Many services were developed in the early years; one was a social skills programme for people who had left Tokanui Hospital.

After becoming aware of an opportunity for disabled people to join an athletics club called Achilles Track Club, Adri and her team decided to become involved. In the first year a huge fundraising effort raised \$72,000 to send seven people with disabilities and their volunteer support to take part in the New York Marathon. There was criticism, but the discipline of regular training and being part of a motivated team proved a springboard for some of the athletes towards employment opportunities. "I just said, hey, \$72,000 for seven people to experience such an enduring change in their life is pretty amazing."

Adri and the Life Unlimited Board saw the opportunities to provide services for the community they service and ventured into national growth. The Trust successfully tendered for a contract to provide national hearing therapy services and in addition set up a new qualification to train hearing therapists.

At that stage, Life Unlimited also successfully tendered for the deinstitutionalisation work at the Kimberley Institute in Levin.

The Trust also tendered for contracts delivering Needs Assessment Service Coordination, which saw Adri herself do some time as a needs assessor to give her a greater understanding of the work.

Life Unlimited went on in partnership with Parent to Parent to successfully tender for a national contract to provide a service called Altogether Autism. Along the way Adri also did a Master's degree in business administration and picked up a series of business awards.

In 2006 Life Unlimited became the first "Not for Profit" to win various gongs at the Westpac Chamber of Commerce Business Excellence Awards, and was named most excellent business overall. Adri was very aware that a "Not for Profit" is a business and, in order to meet the needs of all people served, had a duty to be a "Not for Loss" concludes Adri.

Adri left Life Unlimited in 2010. She has continued to work in the health and disability sector and is now Deputy Director-General, Disability, for the Ministry of Health.

Julia Genet *AccessAbility*

Julia Genet has spent decades “fighting for an ordinary life” for her autistic son Richard. Imagine Better gave her crucial help and she ended up on its board.

Richard Genet loves to use his tractor to dig potholes and plough the dirt with a back blade he calls “the Lute”. The Genet family has to have enough room in their lives for a 1972 Holder tractor. His sister often asks, “Why couldn’t his passion be goldfish?”

The Genets have retained their sense of humour after 45 years of caring and supporting Richard; it hasn’t always been easy. Julia recalls how at one point “Richard was having terrible trouble showering and getting dressed. He was so destructive and upset in the bathroom.” It became clear that having a shower for Richard was so sensory it was causing him to be absolutely overstimulated. The family learnt that Richard needed a bath instead of a shower.

Julia designed a cottage for Richard on the land the family owned in Maketu: it included a bath and strengthened walls that he couldn’t punch holes in. “He always bangs on the wall, which a lot of children with ASD do, but now he’s a big man!” explains Julia.

In 2003 Richard was living in a Tauranga residential home “that was really awful, there’s no other word for it,” explains Julia. A meeting with Lorna Sullivan of Imagine Better helped them set up a new life for Richard. On Lorna’s advice they set up a company, New Breeze Limited, as their property was on a windy hill at Maketu where the family was to live. It was a pioneering move in the new age of individualised funding, says Julia, and it really did put Richard at the centre of everything.

“The new approach, where support workers worked in 24-hour shifts with Richard in his own cottage, worked amazingly well for Richard,” says Julia. Lorna edited a book titled *Believing in Better*, a guide for families of people with disabilities which included a chapter by Julia on her experiences with Richard, under the name “James”.

She liked the disability-led philosophy behind Imagine Better and AccessAbility and was interviewed to join both. So, in 2012 she became a trustee of AccessAbility and a board member of Imagine Better. She was already an experienced “committee woman”, having worked at a national level for Autism New Zealand and for the Disabled People’s Assembly, as well as several other non-profit organisations.

“It was a really exciting time in disability,” she says. “The board’s strength was its people. They had lived experiences, mostly from having a disability themselves, everybody was there because of their values.”

“We enjoyed good open debate. You could agree to not agree, which was very healthy. I don’t think many committees I’ve been on have had that robust discussion option.”

Later there was discussion about the future of the organisation. “We were becoming too small to get bigger contracts. That’s where the discussion came on about looking at amalgamating with a like-minded organisation.” And although Julia decided to step down from the board for personal reasons the discussions regarding the scope of the organisation’s future, eventually led to the merger between AccessAbility and Life Unlimited, and the expected emergence of a new organisation to support people with disability now, and into the future.



A move forward

Karen Coutts, Chair of the Life Unlimited Charitable Trust, says there must be a fundamentally different approach and structure. Life Unlimited will create better services by being disability-led and by offering service users real choice.

Both charitable trusts, which retained the name Life Unlimited upon merging, always claimed that they put disabled people at the centre of decision-making, Karen says, “but the evaluations showed that not all the service users felt that happened, because there was a limited choice. The process still meant you had to choose from what services were on offer.”

The new approach should be to support the person in “whatever way you wish to lead your life. It’s not limited by us and how we have a set range of services.” While the focus would be on the Needs Assessment Service Coordination (NASC) and Local Area Coordination (LAC) work, in time this approach “will start to create an overall shift in expectations regardless of services.”

The organisation would be genuinely disability-led, from the board – where most members are disabled – and through the other levels as well. It would be accountable for its performance through the new national Disability Leadership Group. The board was now considering how to make it accountable at the local level as well.

“What we want to do is ensure how we operate is led by how the service user says they want that service to be delivered. Because commercially, that’s the best thing you can do, as well as in terms of ethics, that’s the best thing we can do. They match perfectly.”

Tony Paine, former Deputy Chief Executive of the new Life Unlimited, says the two organisations were doing very similar work as NASCs and there were significant economies of scale from a merger. “For example, Life Unlimited had been outsourcing its corporate services and that wasn’t working for them. So, it meant that we were able to contemplate a merger and a process where no one lost their job.”

The merger also produced a stronger organisation better able to negotiate the huge changes coming in the NASC area and in the whole disability sector. The previous NASC structure was very bureaucratic and slow but involved a lot of government money (about \$2 billion a year spent on approximately 45,000 people). There were gaps in the service across the country and a lot of very traditional approaches which didn’t meet the needs of disabled people.

The challenge was to have “a system where people have more choice and control” while recognising that the government vote was limited – “the government is never going to give a blank cheque.” That helped explain why the government was so slow to make the changes. The new organisation is contributing to the design of the new system.

Life Unlimited would help staff develop a new more flexible way of working while having to comply with contractual obligations and a limited budget. This more intensive form of work meant that more people would probably be needed rather than fewer; there would certainly be no job losses in the new organisation.

Megan Thomas, Chief Executive of the merged Life Unlimited, says the merger was needed because each of the two organisations in their NASC work was “too big to be small, too small to be big.” Both had similar values and by coming together in a period of great change the organisation could secure its position and make the rights of disabled people central to its work.

“What we want is the Enabling Good Lives principles to be central to everything we are doing in our work going forward,” she says. “It’s really about a shift of power: how do we move power from the organisation to the disabled person, their family and whānau? That’s what’s central to what we’re talking about.”

Disabled leadership would be present throughout the new organisation. There would have to be a behavioural change among staff to transfer their power to disabled people. While both organisations felt they were already doing that, “the reality is we work within a structure and rules and processes that can be quite defined,” says Megan.

The new organisation has a pretty good idea about how the long-awaited new system will work and that Life Unlimited could work well within it. It would be focused on the Enabling Good Lives principles which Life Unlimited has been making central to all its work. The future landscape for NASCs remains unclear; the organisation has done all it can to be in a good position to deliver quality services in a new environment.

Advocacy would be central to the work of the new organisation, including advocacy for individuals, for communities, and in different areas such as hearing and autism. Advocacy was “not just about being a rattly can and making a noise – it’s about solutions and encouraging action.” It would not be advocacy against the organisation’s government funder but advocating about broader systemic issues.

The organisation could “just keep on going and sure, we did it pretty nicely, generally. But is that good enough?” asks Megan. “And if the disabled community is saying it’s not good enough, then let’s stand up and do something different.”

TOP

Codie Shannon and Jeanette Tioke,
Local Area Coordinator for Journey Together

LEFT

Cheryl Wallace

RIGHT

Noopii Rouvi







Your Way | Kia Roha vision is “disabled people thriving, living the lives they choose in their communities”.

In 2022, after 18 months of operating under the name Life Unlimited, both organisations rebranded to become known as Your Way | Kia Roha, a name that honoured the past of two strong organisations that came together to creating meaningful impact in the lives of disabled people.

The establishment of this bi-cultural name recognised the history of an organisation grounded in Te Ao Pākehā (the Pākehā world) and the aspiration of the new organisation to establish and maintain connections between Te Ao Māori (the Māori world) and Te Ao Pākehā in the context of tangata Whaikaha (disabled people) and Te Tiriti o Waitangi.

Your Way refers to the fact that each person is unique, hence on a unique journey. Each person we work with can express their choice and control over decisions impacting their life. It speaks to self-determination.

Kia Roha means to spread your wings and fly. It speaks to people being aspirational, actively seeking and reaching their goals.

The logo was pulled from stylised woven rope. Within the design we can see a twisting and a crossing of paths with no clear beginning or end. The logo indicates that people are in charge of their own path, whatever that may be, bringing many different strands together to meet their goals.

The name and logo combined tell the story of our role in the community. Each person we work with determines their way to achieve their aspirations. Many strands of guidance, resources and connections are available for people to weave together in a way that meets their aspirations and forms a community response.

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