

Spectrum Care 1994-2014
the first 20 years



Acknowledgements

There are many to thank for their willing assistance in the making of this history – our leaders and governance, staff and stakeholders and, most importantly, the people we've had the privilege to support over these past two decades.

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Spectrum Care – The first 20 years 1994-2014

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The mountain and the bridge depict local landmarks. The mountain represents the difficult climb the handicapped person has to reach their peak. The bridge supports represent those particular groups who give their services, and the main feature, that of the psychopaedic nurses medal represents all nursing staff who play the central role in the care of the intellectually handicapped person as they travel over troubled waters through their span of life.



Introduction



Our history is a story of people and relationships, of gain and loss. It is a story of fracture and healing and, in time, growth and opportunity.

First and foremost, it is a story of individuals with needs, desires and aspirations. It is about the people who've journeyed together, over many years, along the path from institutionalisation to lives of choice in the community, like any other.

Our story is about people coming together as service funders, designers, suppliers and users to achieve a shared Vision of 'People with disabilities living great lives'.

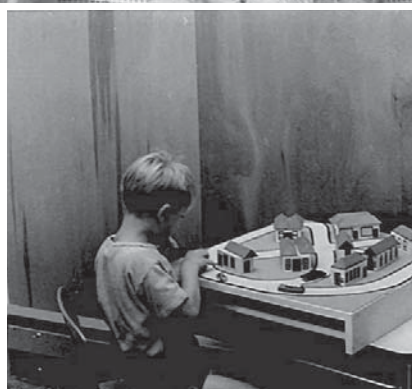
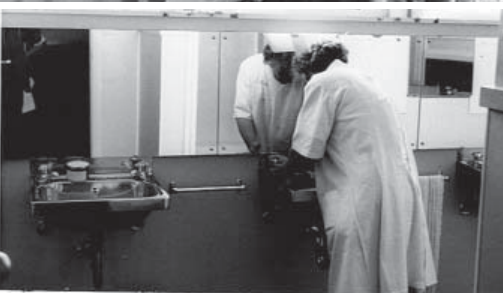
In preparing our history, we've reflected on the many changes that people with disabilities have experienced over the past 150 years. No judgement is cast on historic beliefs and attitudes. But hindsight is a valuable tool and an incisive view of the past allows us to more clearly recognise the positive changes occurring in people's lives today.

A great many people have willingly shared their time, memories and views in compiling this story of our past 20 years. For some, their perspective is a 'helicopter view', gained

4 | as they participated in forming the strategies and direction for our organisation and, in some cases, our sector. For others, their views reflect a much more active involvement in supporting and caring for people with disabilities, as they transitioned out of institutional settings. Many remain involved in the continued development of Spectrum Care, and their passion for our Vision and Values is palpable. All the stories and reflections carry similar threads from past to future – change, choice and respect.

Attitudes and approaches to ‘care’ and service delivery have changed profoundly over the past 150 years, influenced both for the better and worse by scientific knowledge and social attitudes. Writing a history, such as this, is an opportunity to examine the past objectively and glean lessons that enable us to be better at what we do and more ambitious in what we strive to achieve.

Our story is about those to whom we offer support and service, about the impact of our funding and policy landscape on the range and quality of services that people receive, and about our resilience in an ever-changing environment. Most importantly, however, it is a story of aspiration for people to live their lives of choice in the community... lives like any other.





Understanding the past



Spectrum Care is celebrating 20 years as a disability support provider and independent charitable trust. However, our present and future only truly come into focus through the lens of our past, both as an organisation and a broader society.

Our story starts over 100 years ago, with a variety of legislative Acts which led the way for people – labelled ‘mental defectives’ – to be locked away in segregated environments, often without intervention. This segregation was from society in general and also from each other, by gender.

From the mid-1870s, oversight of these institutions was conducted by external agencies, though this responsibility moved many times – from central government to the Colonial Secretary to an appointed Inspector of Asylums and on – over the years.

In 1908, a Mental Hospital Department was set up and the population upon which it focused was classified and delineated by the Mental Defectives Act 1911, which defined six classes of ‘mentally defective person’ for whom a degree of oversight, care or control was deemed necessary.

The Act differentiated between:

1. Persons of unsound mind
2. Persons mentally infirm
3. Idiots
4. Imbeciles
5. The feeble minded
6. Epileptics

Tokanui Hospital in the Waikato was opened in 1912 and designated as “...a building provided for mental defectives,” though, at that stage, no separate provision was made for people with intellectual disabilities.

In 1928, the Mental Defectives Amendment Bill allowed for the establishment of separate training institutions for intellectually disabled patients. The following year, New Zealand’s first institution for children with intellectual disabilities (then known as ‘mentally deficient’) was set up. This Bill was part of the international movement to separate the ‘mentally ill’ from the ‘mentally deficient’ and, in line with thinking of the day, aimed to reduce their ability to breed and pass on ‘weak genetic material’. This was achieved by segregating children with ‘special needs’ into institutions and services outside the mainstream education and health services.

The General Manager of the Auckland Area Health Board in the late 1980s, David King, recalls that the official advice to parents, the “norm for the time”, had devastating outcomes in terms of failing to see people with intellectual disorders as normal human beings.

Here in New Zealand, as in the rest of the world, a significant number of people with intellectual disabilities

were institutionalised into wards and training centres within psychiatric hospitals – designated for ‘intellectual handicap’ – over the following 40 years. The focus of these hospitals evolved over time based on developments in psychology and cognition, and with the development of psychotropic medications and therapeutic interventions. Once admitted, patients were not allowed to leave.

In 1966, Mangere Hospital opened as a ‘psychopaedic’ facility and, at the time, was one of two specialist institutions for people with intellectual disabilities – people who were, in that era, deemed ‘unfit to breed’. The use of the term psychopaedic is particular to New Zealand and was used to describe the facility and patients, and as a professional title for the nurses and training officers who worked there.

At the time of deinstitutionalisation (occurring over the decade from the late 1980s to the late 1990s), a number of people with intellectual disabilities had been in these hospitals since birth and had known no other home. The received wisdom of that period was that children with profound disabilities would be best-placed in a hospital environment, where they could be fully cared for and their families ‘spared’ the burden.

The language of the time was quite different from today. People with intellectual disabilities were referred to as ‘patients’ and treated as such. Privacy was not a major concern as staff were dealing with large numbers of patients. The shower regime at Mangere Hospital, for example, involved patients lining up in a communal bathroom, awaiting their turn to enter individual, open shower stalls.

The regime included medical supervision and nursing care, full personal cares, showering and dressing by a nurse. Staff recall that clothes were communal and belonged to the ward in which the person resided. It was usual practice for the person to be physically dressed by staff, with little or no independence encouraged. Meals were served at set times and no food or drink could be acquired outside those times without the permission of staff. Descriptions of the time include locked fridges and rigid adherence to timetables. "They couldn't even get a cup of tea if they wanted one," recalls one staff member.

Wards would be inspected by the senior nurse, with patients presented for inspection at their bedside. One former hospital nurse recalls that "...it was run like the military." This image was reinforced by the fact that hospital staff were obliged to wear uniforms with 'epaulets' on the shoulders denoting rank.

Up to 40 people lived on the wards, which were set out in a dormitory style. The villas were slightly different, with a mix of dormitory and small-room accommodation, but still catered for up to 50 people. All linen and furniture were mass-purchased by the institution, with little or no variety from building to building. The design of the wards and buildings was focused on safety, restraint and a 'one size fits all' approach, rather than stimulation and inclusion. Children's wards, for example, had high windows with thick, opaque plastic panes to prevent breakage by people with behavioural problems – both of which effectively precluded any glimpse of the outside world. "It was like being in one big waiting room of life, sitting all day with nothing to do or see," noted a former psychopaedic nurse.

Outings were a rare event for people living in institutions – generally only as part of large groups, rather than as individuals. Some patients had family visitors or went home for short visits, but these were exceptions. Most patients with a diagnosis of psychopaedic or intellectual disability had no familial contact whatsoever, as their families had been encouraged to sign all parental rights over to the hospital at birth or in early infancy.

Significant behavioural problems and limited communication ability were commonplace.



First steps



By the 1980s, an international movement to close institutions was gaining momentum. Here in New Zealand, the concept of ‘community care’ was gaining acceptance and a more social model of care began to emerge. There was a growing recognition that hospitals offered care to some, but not all, people with intellectual disabilities and that they were an implicitly expensive option with high overheads. In addition, most of New Zealand’s institutional buildings were aging and in need of significant investment to upgrade facilities.

Running parallel with this were wider changes, involving decentralisation of the health and disability sector based on new management structures recommended in the Sir Frank Holmes Report. This resulted in the repurposing or closure of small rural hospitals and maternity homes, significant changes in maternity service provision and, ironically, a more centralised approach to governance. The closure of psychopaedic and psychiatric hospitals was part of a wider process at this time, which forms the basis of who we, Spectrum Care, are today.

Former senior nurses of Mangere Hospital recall the idea of ‘moving out of the hospital’ first being mooted in 1986. They were told of the deinstitutionalisation process occurring in the United Kingdom and Canada, and of the plans to downsize psychiatric hospitals in New Zealand. The New Zealand government sponsored various guest speakers, including Pat McNally from the United States, who spoke to staff and parents at Mangere Hospital. Pat’s presentation ignited a spark for parent and former Spectrum Care Trust Board member John Pettit, who recalls visiting Pat in Wisconsin to learn more about models of community care.

David King, who was to play an important role in the deinstitutionalisation process which followed, was invited back to New Zealand in 1986 and 1989, following a successful initial visit with members of the King’s Fund in 1984. Core and cluster housing models were discussed, which involved patients moving to a purpose-built, village-type environment – still segregated from society, but with a more social model of care. Others, such as the Exeter model, focused on people living as members of their own local communities.

As with any significant change, the response from staff, families and even people with disabilities was mixed. Most staff were against the idea, as they could not believe that the patients could achieve sufficient independence to manage self-care and independent decision-making. Others saw a serious threat to their livelihoods, as working outside the hospital would likely change their highly unionised terms and conditions.

For some staff, however, the potential opportunities far outweighed the threats. They saw moving away from the hospital environment (and the regimented care of the past) as good for them and the people they supported. These staff members felt leaving the hospital could offer choice and a more relaxed lifestyle for people with disabilities, along with the opportunity to live in much smaller group situations, with people they knew, were similar to, or with whom they got along (though the mixing and matching of people was to become a difficult aspect of the move).

The emerging philosophy of the time centred on quality of life, reducing overheads (in order to invest in the whole of the intellectual disability community), locating services closer to where people lived, and creating opportunities to focus services on Māori and Pacific people. There was also an acknowledgement that, by the late 1980s, more people with intellectual disabilities lived in the community than in institutions.

The appointment of David King as General Manager of the Auckland Area Health Board in 1989 proved to be a significant step for the future Spectrum Care. David had been involved in the closure of psychiatric hospitals in the United Kingdom during the 1970s and '80s, and was committed to the provision of a quality life in the community for people with intellectual disabilities or mental illness. David has been described as a visionary and became an architect of post-deinstitutionalised care in the Auckland region.

Some Māori staff recall that, for them, moving out of the hospital environment offered the possibility of a

16 | more culturally appropriate service, and carried with it the opportunity to live the dream of self-determination, which was gaining momentum across the country. Although Mangere Hospital did not have a separate Māori service, a whānau support group emerged with the view that patients had a right to their culture, whatever that culture might be. It became clear that hospital closure might constitute the tipping point for the establishment of Māori-specific services in the future, a view shared by some senior administrators of that era. It was also a reflection of the Mental Health Whare Paia development and the protest movement led by Titewhai Harawira.

Through the late 1980s, staff at Mangere Hospital were supported by their managers to gradually reduce the more regimented medical and nursing model of care, and try to encourage independence in the patients. Former staff recall that psychopaedic nurses found it difficult to give up their nursing and ‘hands-on’ care role, and to allow people to attempt simple tasks such as dressing independently. Managers at Mangere Hospital and Tokanui in the Waikato recall that one of the biggest challenges was changing the attitude and practice of staff.

Parents and whānau were as divided as staff about the changes they saw ahead. One parent recalls feeling that the patients were worse off than prisoners “...without any chance of reprieve or parole.” The conditions were described as ‘dreadful’. “They lived in concrete enclosures... in some places the glass had been replaced with thick, opaque plastic, so there was not even a chance to look outside.” For other families,

however, the concept of intellectually disabled patients living in the community was totally unacceptable. Some of these views were based on horror stories from overseas about badly managed deinstitutionalisation processes and the failure of community care. A large group of parents simply wanted 'care' to be delivered by psychopaedic nurses. Yet another barrier was concern regarding mixing people with physical and intellectually disabilities in the same home. These disputes are remembered as "...bitter and divisive," and took a number of years to resolve.



Different destinations



John Stacey arrived from the United Kingdom in 1987 on secondment to New Zealand's Ministry of Health. His mandate was to assist in developing policy around the process of deinstitutionalisation, ie transitioning people with mental illness and/or intellectual disabilities from hospital environments into the community. He recognised the difficulties of moving from policy to action, particularly in the ever-changing political environment of the time.

The first step towards deinstitutionalisation at Mangere Hospital was taken in 1988, with the launch of Auckland Community Living Trust (ACLT). Set up to manage intellectual disability support throughout the Auckland region, ACLT was a joint entity combining the resources of the New Zealand Society for the Intellectually Handicapped (IHC), Auckland Hospital Board and the Department of Social Welfare. The plan involved Auckland Hospital Board purchasing houses and patients (soon to be known as 'clients') being supported through Disability Support Services benefits, provided by the Ministry of Health.

The debate about models of residential care continued to rage at Mangere Hospital and it was suggested some staff were 'feeding' the negativity of parents and families, who were against the deinstitutionalisation process. However, David King's appointment as General Manager of the Auckland Area Health Board meant that the Parent and Welfare Association's dispute did not get in the way of progress. David brought previous experience of closing institutions in the southwest of England and an ability to cut through red tape. He was also known as a strategic thinker.

A powerful ally existed in the then Minister of Health, Helen Clark, who visited Exeter to see for herself what was possible for people living within their communities and accessing a broad range of community based services.

In 1989, the members of the Auckland Hospital Board were dismissed by the Minister of Health and Harold Titter was appointed Commissioner. ACLT had stalled around this time, partly due to the burgeoning cost to the Auckland Area Health Board. That same year, David appointed John Stacey (already known to him from Exeter) as General Manager of the Auckland Area Health Board's Services for People with Intellectual Disability (SPID), which included hospital, pediatric and community support services at Mangere, St John's (a former orphanage which became a facility for children with intellectual disabilities) and North Shore Hospital (specifically Ward 11). As one parent states, from this point, "...it was full steam ahead!"

"The philosophy driving the change was aimed at supporting people to lead a better life in the community,"

John Stacey recalls. “Hospital services on offer were outdated and did not support the majority of people with an intellectual disability, who were already living in the community.” Both David and John’s approach focused on human rights and contemporary service delivery, which was significantly different from the practice of the time.

The period from 1989 to 1993 was an extremely controversial and sensitive time. At this stage, the Auckland Health Board – under its Commissioner Harold Titter – decided to sell the Mangere and St John’s facilities, in order to release equity to fund the deinstitutionalisation process and the move to community residential care and service delivery. Harold Titter is described as being “...a good mate to Spectrum Care,” and was very helpful in making funding available to purchase houses. John Stacey recalls that the Auckland Housing Options Trust (AHOT) was established in 1993 to purchase houses and facilitate this move to the community. This independent Trust was set up in order to borrow commercially from banks, which the Health Board – as a government entity – could not.

Another ‘quiet influencer’ at this stage was Greg Kaye, the finance manager of Auckland Area Health Board, who got on with finding the ways and means to smooth the journey from institutional to community based services. It was well recognised that Mangere Hospital was ageing and estimates to upgrade the facility ranged between \$8m-10m dollars. The operational costs of running a facility for a small part of the intellectual disability community were high and investing money in this way was not seen as best serving the needs of the people requiring services.

Unfortunately, tensions continued to run high. The families of approximately 60 individuals living in Mangere Hospital were described as “...fighting tooth and nail” to keep them in larger groups, using the ‘core and cluster’, village-like model with hands-on caregivers. As a result, John Pettit – who had been Chair of the Parents and Welfare Association – was asked to step down by parents who were irate about plans for their family members to leave the hospital.

Several families, supported by a small group of staff, flatly refused to leave the hospital. Their ideal was to convert Mangere Hospital to a village-like facility, specifically for people with intellectual disabilities – a difficult proposition given the site had been sold. This group of families could not be reconciled with the concept of SPID and, as a result, eventually decided to join the RESCARE Group. What followed in the early 1990s was a period of bitter disputes and damaged relationships, which happened despite senior managers’ efforts to reassure those families. “Parents were loyal to staff not to the organisation,” recalls one employee of the time. Sadly, some relationships within families and between colleagues were also damaged during this period of upheaval.

In conjunction with this, Tui Tenare (the senior nurse at Mangere Hospital) was developing an independent Māori-led service, which brought Māori and Pasifica staff (and whānau) on board with the community move under SPID. The development of culturally appropriate services and homes specifically for Māori clients was a new direction. Alongside this, acknowledgement of the Pacific people within Mangere Hospital also led to a separate service being established. Sadly,

as was found in the closure process at Tokanui and Kimberley some years later, there were no natural family links for many Māori and Pacific patients. As a result, a significant amount of work had to be undertaken to identify, contact and begin rebuilding relationships and ‘healing wounds’ with these estranged families. This involved Māori and Pacific Island staff travelling around the North Island to locate and engage with whānau and communities.

A thread running through our collective memory is the strong leadership role taken by Tui Tenare and the Māori staff at this time, whose early appreciation of the opportunities presented by deinstitutionalisation gave impetus to the process. Tui is described as quiet, gentle and unassuming, with a clear vision for what she wanted to achieve on behalf of the people living at Mangere Hospital. Tui is widely acknowledged as a driving force in the move to community living, and her support and respect for John Stacey was invaluable.

Another key supporter of the deinstitutionalisation process was Siainiu Masoe, who was instrumental in supporting Pacifica people out of Mangere Hospital and into the community. Siainiu was our first Pacifica Service Manager and also the first Pacifica social worker to work collaboratively with government agencies to support the transfer of Pacifica people between providers in returning to their families. Despite pressure to take a Pacifica service outside Spectrum, Siainiu advocated to stay within our organisation and went on to lead New Zealand’s first Pacifica homes – Maota O le alofa and Malae ola and, later, Kamata lelei and Te Akapuaga. While doing all this, Siainiu was also supporting her own autistic son.

By the early 1990s, with the institutions now closed, a new model of service provision and staff practice was required. Again, this ran parallel to the introduction of the Crown Health Enterprise and Regional Health Authority, which separated provision and purchasing of services. The whole system was in a state of change. Auckland Home Options Trust (AHOT) was set up to purchase homes in the community, with SPID delivering support services. The goal of AHOT was to buy houses that were as far from institutional living as possible, "...homes that anyone could live in," was the memory of Tracey Adams. John Stacey recalls that "...by 1992, there were 30 homes supporting 150 people in the community, with a further 30 planned."

These enterprises were supported by the three Auckland health boards, each of which nominated a Board member for AHOT. Robyn Stent was nominated from Auckland, Tracey Adams from Waitemata and Lester Levy from Counties. It was from these entities – AHOT and SPID – that Spectrum Care emerged. A significant negotiation took place with the Public Service Association, which resulted in community staff being covered by a Collective Employment Agreement and removed a major hurdle in the development of community services.

On 15 June 1994, Spectrum Care Trust Board received its certificate of incorporation as a charitable trust and held its inaugural meeting, with Robyn Stent (Chair) and Tracey Adams (Deputy) joined by Sir John Ingram and John Pettit. These trustees were then joined by Rev Hone Kaa, Dr Anne Simpson and Brian Cutting. At this stage, all trustee appointments were nominated by Auckland and Waitemata Crown Health Enterprises (CHEs), as Counties had chosen to

exit the relationship at the time Spectrum Care was formed. CHE oversight continued until 1997, when a mutually agreed separation occurred.

John Stacey was appointed as Chief Executive of Spectrum Care at this time and held the role until 1995. John had managed and developed some extremely successful community service models following deinstitutionalisation in England and was seen by David King as a strong leader, with an exceptional ability to stick to the issues and not allow personal attacks to impede progress. John's role in our history was to manage a period of enormous change and upheaval, before handing the reins over to a new pair of hands.



The excitement builds



When recollecting this time in our history (from 1993 to 1995), we hear the word ‘exciting’ used time and again by former staff, managers, families and trustees. “Setting Spectrum free was always a highlight of the break-up of the ADHB,” recalls Board chair Robyn Stent. Lorraine Bailey, a former nurse and manager at Mangere Hospital, who went on to become Māori Service Manager at Spectrum and then General Manager of kaupapa Māori support provider Te Roopu Taurima o Manukau says, “We loved it! There was so much excitement and creating enthusiasm for families.”

The philosophy that drove the Board was twofold. The first part was to “...get out of Mangere Hospital” and the second was to “...provide an infrastructure for a safe living and service provision environment in the community for all people with intellectual disability.” The former was impeded in part by the group of parents and staff who did not wish to change the model of care or leave the perceived security of the hospital environment. As a result, a Board decision was taken to unbundle the funds allocated to this group of 60 people and simply “...cut loose”.

Psychiatric hospitals were closing at the same time and the wider community was naturally sensitive about 'who was moving in next door'. Petitions were signed and there were many examples of NIMBY-ism (ie 'Not In My Backyard'), which John and his staff worked very hard to overcome. The team invested a lot of time and energy to reduce the negativity and build community support to join 'neighbourhoods', and staff recollect it being an excellent opportunity to observe strong leadership behaviours and role-modelling by senior staff. It was a time of great change for New Zealand society as we moved away from a "...lock-up-and-leave mentality," as one staff member described it.

Following the formation of Spectrum Care, purchasing of houses gathered pace and 'clients' moved into the community in groups of four or five. A number of staff from this period remain with Spectrum Care and have now been a part of our organisation for two decades. They recall the immediate differences which began to infuse every aspect of people's lives. The words staff use about this time are highly emotional: "exciting", "amazing", "totally different", "growth", "choices", "freedom", "learning", "getting out", "apprehension" and "challenging". No-one described this time as boring or monotonous! People who'd lived the majority of their lives in a segregated world were now able to make choices. The differences between institutional life and that lived in the community were enormous – for the people, for the staff, and for the families and whānau.

The staff and management felt they were making enormous strides in creating a good and 'normal' life for

people, and hold very clear memories from this period. They remember how quickly life changed once a house was found and a group knew they were moving into the community. “We were people on a mission,” says one former staff member. Another fondly relates this period to being like the “...Wild West frontier,” in that it was ground-breaking and there was a sense of “...winging it” to some degree. There were few rules and regulations in place at a national or local level, which was both beneficial and problematic.

Safe infrastructure and communication presented interesting challenges for the Board and management. In 1994, there were few mobile phones and no computers available to staff and, consequently, the Chief Executive and Board had to think carefully about a communications structure which incorporated the houses and various parts of service provision to allow managers to be fully engaged and accountable. Part of this risk-management process was to allocate a number of houses to each trustee and make them responsible for reporting back to the Board. This prevailed for the first 10 years, but became increasingly untenable as the number of houses rose each year to 80 in total, and spread far and wide across the Auckland region.

The challenges were great as the organisation tried to build its infrastructure and core business practices, while also finding and setting up houses, and transitioning people safely into new homes and lives in the community. From the start, John Stacey and the Board realised that quality was important and, in 1994, a quality accreditation was undertaken with an external body called Quality Health. “This was ambitious, given

the environment in which we were operating,” recalls John. “The reason for this decision was to demonstrate that we were establishing quality services and to answer detractors, who said it was all about saving money and offering an inferior service.”

Our headquarters from 1994 was described as “...a relaxed rural setting,” in a former ward building at Gadsby Road (on the Mangere Hospital site). There was also a specially constructed six-bedroom residential unit adjacent. All around the new organisation, houses were springing up as subdivisions were quickly developing on the former hospital land. In the first few years, the headquarter staff comprised the Chief Executive, finance, admin and human resources. At this time, Spectrum had pockets of operations around Auckland which included a number houses, a Behaviour Support team based in Grey Lynn, and the North West coordination office. Approximately 30 houses had been purchased in a variety of suburban and rural settings over the previous 18 months. People recount anecdotes of John Stacey and John Pettit setting out together and travelling around Auckland with the sole intent of buying houses. These were pioneering days!

Due to the behavioural issues exhibited by people in the hospital environment, decisions were taken to move some clients to houses in relatively isolated settings. As a result, houses were purchased in Helensville, Coatesville, Kumeu and Pukekohe – areas that were very rural at the time. In addition to the residential services, four ‘Work Option’ day service sites were set up across Auckland.

Life for people moving out of Mangere Hospital was full of new and interesting experiences. For the first time in their lives,

they were able to have their own personal bedding and bedroom furniture. It's hard to imagine what this would have been like – one day a person is living in a ward with 30 or more others, and the next day they're in their own room in a normal house, in an average Auckland suburb. The majority of furniture for the living rooms was chosen by the House Leaders, with one recalling the pleasure of buying the furniture from a store and having it delivered, "...all brand new and fresh!" In some cases, a person's bedroom furniture was chosen and purchased for them by Spectrum, but all of the furniture was new and it was theirs – either bought with their own money from the savings they'd accumulated while in Mangere Hospital, or paid for by Spectrum. Wherever possible, people were taken to the shops to choose bedding, clothes and ornaments or pictures for the wall. A House Leader describes a middle-aged client on the first night in her new home, "She sat on her bed, just stroking the duvet cover and smiling!" Another describes a lady who would carefully arrange her ornaments and then tidy them all away into boxes because she struggled to grasp that this was her room and that someone wouldn't come in and take them away.

Clothes were no longer shared or communal. One support worker has a strong memory of "...throwing away the Roman sandals and grey clothes. It was such a difference for people to have their own clothes in their own wardrobe," that they'd been to a shop to choose and participate in purchasing.

Another major difference in people's lives related to the ratio of staff to people living in the house. Neither was accustomed to the increased one-on-one time and some adjustment was required from both parties. "Freedom and

32 | people getting more attention were the biggest changes,” says one staff member. “They were more ‘present’ and less ‘background!’”

Access to food and beverages in the institution had been tightly controlled but, in the houses, there was an opportunity for more flexibility – although some staff found it hard not to maintain the rigid meal times and routines. Allowing people to have a cuppa and a snack when they wanted and, at the same time, regulate special dietary or behavioural requirements was another item on the list of adjustments. Staff with no former relationship to Mangere Hospital noted that some former psychopaedic staff found it harder to break the institutional mode than the people living in the houses. “Some staff carried the ‘command and control’ behaviour from the hospital,” said one of our long-serving staff members. “Not all stayed – they couldn’t transition.”

Sometimes the groups of people in the residential houses did not work well together and what had seemed a likely group in the planning and preparation stage (due to age, type of disability or ward they came from) simply didn’t work. Sometimes families were the main driver of who was placed together in which house, and this required some careful negotiation. Despite everyone’s best efforts, however, some circumstances were not always manageable, as parents and families held strong views which were not always aligned with those of staff or, indeed, the person themselves. It was a steep learning curve for everyone. Despite the difficulties, however, faith in the integrity of this change remained steadfast.

A moving observation was made by a member of the Behaviour Support team who described feeling privileged to have observed the lives of people in both worlds and their amazing achievements, “We couldn’t even imagine that this would have been possible!” Moving into the community required a major culture shift that would take many years, but “...every journey starts with a single step,” and Spectrum had put its best foot forward!



Where the rubber hits the road



John Stacey, having fulfilled his role in the deinstitutionalisation and change-management process, felt it was time to move on and left a very strong legacy. In 1995, Bob Simpson was appointed Chief Executive. Bob had previously project-managed the privatisation of the Auckland Area Health Board laundry and, subsequently, set up a company of his own. His appointment was in line with many health and disability sector appointments of the time, in an effort to bring a more commercial perspective into the sector. The Board felt that the organisation's needs were changing and welcomed his commercial experience.

At the time of Bob's appointment, Spectrum supported 300 people in 60 residential homes, with approximately 700 staff. Eighty-five percent of our revenues came via contracts managed by the Northern Regional Health Authority. Bob's first impression was that the staff and Leadership Team had a strong clinical background, but lacked management skills. He clarifies this by pointing out that it was the start of the 'general management era' across the health and disability sector, and he felt he needed to bring a more commercial approach to our organisation.

While this was, indeed, a period of growth for Spectrum Care, Bob's contribution to this growth veered away from the purely commercial. Bob recalls a defining moment being his attendance at a seminar by visiting American consultant Michael Kendrick, who pointed out "...what a huge responsibility [he'd] taken on." Until that moment, Bob hadn't really understood the nature of this 'responsibility' but, on reflection, he realised he "...could bring to Spectrum a view of what a normal life was."

During this time, our housing stock increased to almost 100 homes through a combination of new clients and the changing needs of existing clients, as they settled into the community. Over the following three years, we continued to explore different revenue streams and contract opportunities, including the development a mental health service for Waitemata Health. Though small, relative to the intellectual disability service, it catered for a wide range of people, including a specific house for 'forensic' mental health patients. Managers complained that, despite being five percent of the service, it consumed 20 percent of their time – an issue which continued over the next few years.

House staff recall life being "...free and easy," compared to that of the institution. But, as our service provision became larger and increasingly complex, the need for robust policies and procedures became more pressing. We had, however, retained a focus on quality over the years, and a positive outcome from this led, in August 1996, to Spectrum Care becoming the only community based trust to obtain 'Certification' from Quality Health New Zealand.

The challenges of community inclusion continued to consume a significant amount of time and energy for the Chief Executive and staff, as they tried to foster community acceptance of people with disabilities. There were incidents of name-calling, neighbours trying to exclude people with disabilities from living in their neighbourhood and ongoing complaints, some petty, some more serious. People with challenging behaviours were already living in isolated rural settings – a practice which continued in an attempt to “... appease the neighbours,” rather than service the needs of those with a disability, staff recall.

Day service and community support offerings for families continued to grow alongside the residential service, as did the Behavioural Support Service during this time. The four ‘day services’ were, at this stage, “...running on a shoe string” and providing a variety of activities, from gardening and outdoor work at Little Orchard in Kumeu to more handicraft-type activities at The Barn in Pukekohe. These facilities were also used by people who were not part of our residential services. Bob recalls his respect for staff across these various services, “I’d never met such a really caring group of people and they were so committed to what they were doing.”

As part of the gradual maturation of the organisation and what had become a continual focus on quality, a more structured approach to staff training was designed. In the early years, the orientation programme was a half-day. However, over the next few years, this increased to three days, held centrally at head office. Lorraine Bailey, Māori Service Manager at this time, was very proud of the fact that,

“...Spectrum Care had more appropriately trained Māori staff than any other organisation.”

In late 1996, the Waikato’s Midland Regional Health Authority sharpened its focus on the closure of Tokanui Hospital and set an ambitious 18-month deadline to exit the facility. As a result, Spectrum was contracted to open six houses in Hamilton to support those departing Tokanui, some of whom had profoundly challenging behaviours. Judy Fynn, Service Coordinator in the Hamilton region, recalls people leaving the hospital with one suitcase containing a few clothes and a month’s worth of medication – not much to show for a lifetime in an institution. There were no day services available for people as they left the hospital, which meant that staff were both developing the homes and providing 24-hour support. Staff worked very hard helping people adjust to life in a home environment and recall a very chaotic time. Like the Mangere Hospital closure, staff recall people “...guarding their food,” and adjusting meal times so that life could be more flexible. One former patient asked a staff member for their service key (an example pictured p34), as she wanted to put it on her wall as a reminder that she was no longer locked up.

The growth in house and staff numbers across the organisation continued, as did the funding challenges. Hamilton houses were funded using a Transparent Pricing Model (or TPM), which came out of the Midland Regional Health Authority (RHA) and followed a different funding algorithm than the model used in Auckland.

The external environment of this time was in a state of change as a result of the 1996 election. In 1997, the RHA

structure was disbanded from four regions to a single Health Funding Authority, leading to significant structural changes related to the funding of disability services. The MoH set up a number of Needs Assessment and Service Coordination (NASC) agencies across the country to provide these functions on their behalf. These organisations were mandated to assist people in identifying and prioritising their disability support needs, within the context of their funding, their natural resources and their existing supports.

In parallel with the formation and capacity building of these new funding and service structures, Spectrum was also growing and changing, and trying to keep up with the new funding relationships. As people settled into their new lives in the community – from Helensville in the north to Tuakau in the south – it became clear that friendships from Mangere Hospital were likely to be lost. A variety of networking events were proposed, with the aim of ensuring people remained connected with friends – the first of which was the Spectrum Care Sports Day.

“No-one did any sport,” recalls Bob Simpson, “No-one entered into anything outside!” So he pursued the idea of a sports day, where people could have the opportunity to participate. “It was a real hoot because the whole thing was just a big reunion,” says Bob. On reflection, it was a far greater success as a networking opportunity than a sports day! Another such event, instituted during Bob’s tenure, was the Spectrum Care Gala Ball (the brainchild of Phyllis Trelease, a former Service Manager and psychopaedic nurse) – a glittering evening that provides a high note of the annual

social calendar for the people we support and a tradition that continues today.

Bob felt that one of his most significant contributions was the opportunity for staff to ‘network’ and swap ideas for things to do together or individually, such as taking people skating or to a swimming pool. This was really focused on supporting staff to create networks across the organisation, and enable greater community engagement by getting people together across houses and regions.

Around this time, a combined independent training organisation known as Community Support Services Industry Training Organisation (CSSITO) – of which Bob Simpson was the Chair – was set up to provide training for the aged care, mental health and disability sectors. This organisation was to be the foundation of Careerforce, New Zealand’s health and community support services Industry Training Organisation.

Also around this time, a Memorandum of Understanding was signed between the newly formed Te Roopu Taurima O Manukau (TRT) and Spectrum Care outlining the transition of Māori services to a separate service under the former’s banner. In November 1999, TRT formally separated its services from Spectrum Care to become an independent kaupapa Māori organisation, funded directly by the Ministry of Health (MoH). At its formation, TRT supported 60 ‘mokopuna’ (people) in 13 ‘whare’ (houses), staffed mainly by Māori ‘kaimahi’ (workers). Of those 60, the majority were Māori, with a small number of Pasifica people and one NZ European.

Once again, Spectrum was unbundling funding and assets, such as specific houses for Māori clients, contents and

chattels, the staff who were attached to those homes and the relevant vehicles. This appears to have been a difficult time for both organisations in terms of contracts, with the funders and various external parties being brought in to assess values and contract dollars. At the time of this separation, "...the relationship between the two organisations was not good at a professional level," says Lorraine Bailey.

With financial separation and cost management a key focus during this time, it became imperative to address some of the high cost drivers, such as the remuneration packages negotiated at the time of exit from Mangere Hospital. A major break with the past was represented by the removal of penalty rates for working weekends and nights. This was a hospital construct that led to staff working these shifts being paid significantly more than those who worked during the day. Not everyone was pleased with the change but, eventually, staff were persuaded by the benefits of receiving a "...normal remuneration package," as Bob describes.

It was also a difficult time for the sector and providers began to feel that they were being played off "...one against the other" by the MoH. Providers reported that the contract managers would say "'Provider A' does so and so and you're not, and we'd like you to do that within your current contract fee," which was seen as being focused on driving cost down, rather than being person-centred approach or improving service quality. Support providers began to realise they were all being treated differently and the 'level playing field' simply didn't exist, either within the region or nationally. Bob took matters into his own hands by ringing around the other

providers and inviting them to a meeting, which was attended by about 20 representatives and, from which, the National Residential Intellectual Disability providers' organisation (NRID) was formed. The inaugural Chairs were Richard Thomson (Hawkesbury Trust) and Bob Simpson. The main purpose of NRID was to promote transparency within the sector by ensuring providers were being treated equally and interpreting the contract specifications in the same way.

Following this lead, the Board continued to look at its strategy and whether its focus should be on further growth or redefining its core business. The latter was chosen.

A significant step for the organisation occurred when our head office moved away from the Gadsby Road site to what became known as 'the Hub' in Onehunga – a step which severed all ties with Mangere Hospital. Nine years had elapsed between purchasing our first community house and finally exiting the Hospital site in 2003. While this move signalled the closing of one part of our journey, it also set the stage for the next phase of our development, bringing together services and managers scattered across the Auckland region.

In 2001, we undertook the development of Child, Youth and Respite Services, appointing Jacki Richardson manager. This was a brand new service which required a careful approach to ensure quality of service delivery and, at the same time, cater to the rapid growth in referrals. During an 18-month period, the residential stream of this service expanded from four to 16 houses, which involved the purchase or rental, where appropriate, through Housing New Zealand; the creation of 'home' environments; the training of staff; and the support of

clients (and their families). The majority of these new clients were young men, predominantly on the autism spectrum, who were leaving the family home for the first time. This constituted a very different group to those already being supported by Spectrum Care in residential homes.

In order to keep pace with our rapidly expanding and changing organisation, a new, comprehensive quality framework was sought. Our first exposure to a holistic and internationally validated quality management system, in the form of the Baldrige Criteria for Performance Excellence, happened at this stage. The drive came from the Chief Executive, Bob Simpson, who realised staff required not only the right tools, but also the ability to judge for themselves (against appropriate, internationally validated measures) whether they were contributing positively to the organisation and, most importantly, to the people we support. At this time, we focused on the first two categories of the Baldrige methodology, which the Board deemed to be appropriate and constitute the best approach for a Not-for-Profit organisation. “It was a proactive quality field,” recalls Bob. “It wasn’t just about measuring things...”

In 2001, the US-based Council for Quality and Leadership (CQL) was invited to present to the Board and staff. The Council was (and remains) a recognised leader in supporting organisations to improve quality of life for people in person-centred services. This was to become a significant cornerstone for our organisation and signified the start of a journey towards person-centredness, Values-based service delivery and an abiding focus on Personal Outcome Measures for the people we support.

One of the key tenets of the CQL approach is ‘responsiveness to people’ and CQL’s Personal Outcome Measures are focused on the quality of life of an individual, rather than a quantitative and compliance approach, and based on specially designed interviews which are appropriate for the people we support. These interview outcomes are also evaluated in a person-specific way, based on the unique needs and abilities of that individual.

Our adoption of the CQL system was a significant step towards supporting people to achieve their potential. We invested in the training and development of staff in this area, and opened up our training to the wider sector as part of our desire to create better outcomes for all people with disabilities and connect with other organisations. Another key step in the development of this approach was the conception of an Outcomes-focused support role, which would come to have a significant impact in later years.





Extreme measures



Significant structural change continued to occur in the health and disability sector over the next few years. Around the turn of the millennium, Spectrum Care dealt with six separate Needs Assessment and Service Coordination agencies (NASCs) across Auckland and the Waikato, which not only absorbed a significant amount of time in building and maintaining relationships, but also created concern on many levels. Following the 2000 general election, Crown Health Enterprises (CHEs) and the centralised Health Funding Authority were reconfigured into a District Health Board (DHB) model, with both service provision and funding transferring to the 21 newly formed DHBs. The incoming government believed that decision-making should be based closer to the populations being served.

At this stage, the sanction to agree appointments to Spectrum's Board was transferred from the CHE to Auckland DHB. For disability, including intellectual, funding and strategic decision-making stayed within the MoH and assessments continued to be made at a local level by the NASCs. However, in both funding and provision of service, fresh challenges and a new period of activity lay ahead.

Our organisation had been operational for six years and a number of changes had been noted in the lives of the people we support (or ‘clients’, in the vernacular of the time), and their ability to participate in daily living. Staff noted the pleasure people derived from having their own belongings and having their personal interests reflected in the way they decorated their rooms. More day services were available and, with the introduction of the Outcomes philosophy (based on CQL Personal Outcomes Measures), choice and self-direction were becoming realities for the people we support.

Staying financially viable was still a challenge – particularly in Hamilton, as a result of its unique Transparent Pricing Model. In addition, concern was expressed by the Board about the lack of referrals from the local NASCs due, it was believed, to the influence of ex-Tokanui staff who appeared to control this process.

The Board continued to refine our core purpose and query the different service streams which, at this time, included referrals from mental health and Corrections Services. Management was divided over the Mental Health Service – it was clinically and financially successful, but absorbed significant time and effort, which arguably diluted our core capacity to support those with intellectual disabilities.

In April 2001, the *New Zealand Disability Strategy* was launched. “The aim of the *New Zealand Disability Strategy* – *Making a World of Difference*, is to remove the barriers which prevent disabled people from participating fully in society,” said then Prime Minister, Helen Clark. Government

departments were tasked with preparing annual work plans regarding their intention to implement the strategy and Spectrum's Board, delighted people with disabilities were gaining some visibility in society, was keen to use the strategy to guide its thinking.

Another important government-level document, *To Have an Ordinary Life*, was launched two years later and examined the barriers faced by adults with an intellectual disability. The report from the National Health Committee provided "...evidence for change and outlined practical steps to implement the *New Zealand Disability Strategy*." Jacki Richardson recalls that this report "...gave impetus to what we wanted to achieve." It also aligned with our thinking at that time and became a key reference document.

As part of the multi-faceted strategies emerging from these documents, a government decision was taken to move to a single Needs Assessment and Service Coordination provider for the Auckland region. With an MoH contract in place, Taikura Trust opened its doors in July 2002 and the services of Auckland's five separate NASCs were brought together. Once again, Spectrum was building a new contract management relationship.

Throughout this period, due to a lack of appropriate foster homes and providers serving young intellectually disabled children with complex diagnoses, our Child, Youth and Respite (CYR) Services continued to grow. By 2002, Spectrum had a range of residential and structured-access respite houses in Auckland and Hamilton, offering much-needed support to families.

In June 2003, after eight years at the helm, Bob Simpson stepped down from his role as Chief Executive. This coincided with the end of Tracey Adams' term as Chairperson and the appointment of Don Clark to the role. Since its inception, the Board had been fortunate to have attracted professional directors to become trustees and to retain a focus on strong governance. These trustee appointments continued to be 'endorsed' by the Waitemata and Auckland DHBs, a practice which started 10 years previously in the days of Auckland Housing Options Trust. Changing the Trust deed to reflect the development and maturity of the organisation was added to the Board work plan.

After a robust recruitment process, registered nurse and manager of our CYR Services Jacki Richardson was appointed to the role of Chief Executive. Jacki had a passion for quality in service delivery and, as a qualified evaluator and national judge with the Business Excellence Foundation, set about reintroducing the Baldrige Criteria for Performance Excellence to Spectrum Care – little realising the significant role Business Excellence would have in our future.

Over the following year, we took the time to look very carefully at our Vision and direction, and to refocus on our core business. Our new Vision 'People with an intellectual disability living a great life' was born, and the process of refashioning our Values and branding created an opportunity for everyone across our organisation to be a part of what and who we were, and where we wanted to go.

The image of the sunflower, which remains central to our brand identity, came from Jacki herself. She spoke of the

heliotrope (ie the family of flowers to which the sunflower belongs) seeking out and growing towards the sun, and articulated that this was how she believed we should be as an organisation, creating a positive and forward-looking culture. Coupled with the direction from the *New Zealand Disability Strategy*, Spectrum had started on the next phase of its journey. A 'Vision board' was placed in the entrance of the Hub to ensure that the our Vision and Values were highly visible.

For some staff, this was a difficult stage in our journey. A new and tighter management structure was introduced, with the aim of increasing our focus on quality in service delivery (and providing the Chief Executive with fewer direct reports). We were striving towards significantly strengthened policies and procedures, an emphasis on risk management and an abiding focus on the people we support. This was timely, as we had – to this point – focused primarily on transitioning people from institutions to the community, and on growth.

We now had more than 80 houses and in excess of 900 staff working across residential, respite and day services from Helensville to the Waikato. It was a complex organisation with some very high-needs clients – some with challenging behaviours, others medically frail, and some very young and active. Although management turnover was relatively high at this time, it was recognised that major change often impacts retention, and efforts were made by the Board and Senior Management Team (comprising both the Leadership Team and senior managers) to manage this.

Frontline staffing was also an issue at this time, due in part to the strong economy and availability of job

opportunities, and rosters were regularly bolstered with casuals and expensive agency or 'bureau' staff, impacting the balance sheet. The cost of bureau staff remained a concern at Board level for several years, and a variety of approaches were discussed before focusing on medium- to long-term strategies to reduce cost and risk, and increase quality.

Unfortunately, it was not uncommon for people to apply for jobs in the disability and aged care sectors "...because there was nothing else", as opposed to seeking out such opportunities. Although we'd made progress in transitioning from an institutional to community model, it was apparent that the 'culture shift' for both clients and staff still had some way to go, and quality staffing was a perennial focus.

The importance of our workforce was wholly recognised and significant effort went into identifying training opportunities and qualifications which would support better outcomes for people with disabilities. Community Support Workers and House Leaders of the time recall the many opportunities that started to emerge, including access to both in-house and external courses and qualifications.

This was a time of tight control, as the organisation utilised new methods of quality management, and implemented a wider range of policies and procedures. To this end, Spectrum continued to have "...an unrelenting focus on quality and staff training," recalls one senior staff member.

Staff have long acknowledged that we invest heavily in training and, from the immediate post-institutional days, we realised that a well-trained and skilled workforce would better enable us to achieve high-quality outcomes for the people we

support. However, as one long-term staff member reported, “Availability of training has always been excellent, but staff haven’t always taken advantage of it or been able to be freed up from the house.” This was frustrating for trainers and those wishing to attend, and was the subject of many discussions at a senior level. Well-trained staff were part of our long-term strategy of supporting people to achieve their Personal Outcomes, and also for addressing issues of staff recruitment and retention. To this end, we started offering a wide range of opportunities, including funding towards relevant tertiary level qualifications, as well as in-house and sector training.

During 2004, the Board and Senior Management Team decided to exit from the mental health contract with Waitemata DHB, on the basis that it was no longer a good fit with our suite of services or core competencies. This decision posed quite a problem for Waitemata DHB and the MoH, as there was no precedent for organisations exiting successful services. A due process was followed both internally and externally and, by December 2004, the exit was complete.

Working on the relationships with the MoH and NASCs took a significant amount of time for the senior team. During Jacki Richardson’s four-year tenure, she recalls that “...there were to be 28 contract/account relationship managers from the MoH!”

We were still very focused on our internal world, while also trying to cope with the increasing demands of Certification and Accreditation, and our desire to incorporate the Baldrige Criteria. While the MoH credentials are the sector’s compliance benchmarks, they absorb large amounts

54 | of staff and management time, while not necessarily driving or improving quality outcomes for the people we support. As one senior staff member said, “The focus from the MoH was on outputs, not outcomes.” The measures were relevant to hospital care, but not life in a home, which created an ongoing tension with our desire to achieve Personal Outcomes.

Another key relationship that was refocused as a priority by the Chief Executive was that with Te Roopu Taurima O Manukau (TRT). This began with a powhiri to welcome TRT back into Spectrum and start the healing process. Following this, an after-work, social petanque series at the Neilson Street head office (the Hub) brought together staff from Spectrum Care, TRT and Taikura Trust to build and strengthen relationships.

In tandem with this external relationship-building, we began investigating different approaches to cultural support and the importance of relevant governance representation. Following the departure of TRT, our specialist Māori cultural team – known as the Awhi Group – had been significantly reduced in number and operated in small pockets of cultural activity. The farewell of former Chief Executive Bob Simpson presented an opportunity to come together and rebuild their mana and leadership within the organisation. At this stage, a Service Manager with knowledge and expertise in tikanaga Māori was appointed and, by default, became the Māori figurehead – reflecting our broadly ‘operational’ relationship with Māori culture at this stage in our development.

Another initiative which commenced around this time was the introduction of a Consumer Reference Group,

chaired by disabled advocate and spokesman Barry de Geest. It took time for the people we support, commonly referred to as 'service users' at this time, to understand the purpose of the group, as it was aimed at empowering and involving them in decision-making, rather than relying on staff and families taking the lead. While modest in its initial mandate and scope, this group would go on to inspire the formation of a Board-level advisory group comprising people with disabilities, advocating for and by themselves, known as the Participant Advisory Group.



Looking outward



In 2005, the closure of the Kimberley Centre in Manawatu brought a new group of formerly institutionalised people to Spectrum Care. Chief Executive Jacki Richardson attended meetings at Kimberley and offered our considerable experience in transitioning people from institutional settings to the community. Once again, we had people arriving with institutionalised behaviour and no experience of community living and, once again, the community was suspicious. Our Adult Services Manager, Phyllis Trelease, had been a significant player in the Mangere and Tokanui transitions, and was well placed to support a smooth transition to their new home in Helensville.

Staff recall some incidents which reflect what this transition meant for the former Kimberley residents, “When a lady from Kimberley first came to her new home in Massey, she was fascinated by the washing machine and used to observe the laundry process (even at night) for ages... Another person refused to get out of the car and wanted to be taken for ride after ride in a vehicle.” These were just two everyday experiences these people had not had until their mid-life.

Our organisation continued to grow, as did the sophistication of our business skills. 'Merlin Thinking', a tool for conceptualising our future, was introduced in 2005 and started a process where the Senior Management Team could collaborate in drawing a vision of our future. This was to be a significant step in the journey towards our Value of 'excellence' and a thread that would continue through the next decade.

Despite such quantum leaps, we continued to face a number of complex challenges. *To Have an Ordinary Life* (as outlined in the government's 2003 publication) was an admirable vision but, for organisations like our own, this vision was implicitly tempered by risk management for the people we support, the expectations of society (and, sometimes, families) to 'protect' individuals, and the administrative and compliance issues demanded by the MoH. This 'protective' expectation was also not far removed from institutionalisation and naturally at odds with our more person-centred approach. Our role was to find the middle ground and never lose focus on our Vision of 'People with an intellectual disability living a great life'. To that end, we continued to develop quality systems and processes, and strengthen the skill base of our workforce. Reflecting the clarity of that focus, in October 2006 Jacki was awarded a meritorious service award by Standards New Zealand for her unwavering passion for service quality.

Jacki also began focusing on the cultural gaps left by the withdrawal of the TRT staff. Many Māori staff remained with Spectrum and Jacki recognised the need to maintain strength in our cultural focus and respect for the Treaty

of Waitangi. Reinforcing the appointment of a Service Manager with Tikanga Māori experience, a paid, part-time Kaumatua position was created in 2004, which formalised previous volunteer arrangements. A powhiri process was also established, led by our Spectrum Care Awhi Group, but there was still a long way to go.

In 2007, there were changes at the top of the organisation as our well-respected Board Chair, Don Clark, resigned and was replaced by Richard Hanna. Jacki also felt it was time for a new challenge and suggested an interim replacement might ensure the Board could take a measured approach to finding a new Chief Executive. Jacki suggested Denis Snelgar would be an ideal candidate to assist in readying the organisation for a new leader, as Denis had held the role of Chief Executive during deinstitutionalisation and retained a lifelong interest in the health and disability sector. He recalls arriving into a very well-managed organisation with a strong focus on quality processes.

Unlike many Not for Profits, Spectrum was in reasonably strong financial shape, which he felt was due to prudent financial oversight from the Board, coupled with strong internal financial management. In general, Denis was inspired by the commitment of staff and, in order to smooth the transition between Chief Executives, undertook some 'scenario setting' for sustainability and also conducted a survey to elicit staff opinion on the organisation and future direction. At this stage, it was important to introduce some small changes based on staff feedback, so that life did not go 'on hold' before the incoming Chief Executive was appointed.

Denis quickly recognised our commitment to constantly improving our quality framework. He also saw that, despite our desire to move forward into a more innovative model of support that encouraged independence and improved the lives of people with disabilities, we were constantly constrained by risk aversion at the MoH. Along with other providers, we realised that one of our greatest challenges was the lack of a sustainable MoH strategy which took into account both the *New Zealand Disability Strategy* and the recommendations made within *To Have an Ordinary Life* to allow people with disabilities to live their lives of choice.

In November 2007, Chris Harris was appointed Chief Executive and brought a mix of skills from his career in the NGO and mental health sectors, which the Board felt suited this particular juncture in our organisational lifecycle. This skillset was complemented by a focus on people, developed through his leadership experience at Outward Bound, Framework Trust and Waikato DHB.

Building on the solid foundations of the past, the Board and new Chief Executive identified a range of key growth and development areas – one of the first being to develop the depth of talent in Spectrum’s middle and senior management tiers. Staff saw greater transparency emerge and felt confident in the new structure. Audrey Walker, a House Leader in Spectrum’s Central region, recalls hearing that “...House Leaders are the most important people in our organisation,” and being delighted that the value of her role in the lives of the people she supported was being acknowledged. This recognition also reflected the functional synergy amongst direct reports and

the wider team, which was sought as a priority by the Board in the pursuit of organisational sustainability and future-proofing.

In 2008, a variety of internal and external forces aligned to ‘unleash’ the organisation. Across the sector, organisations focused on social models of support (rather than medical care) began openly questioning the applicability of MoH performance measures. While the MoH’s minimum standard of Certification was a ‘must do’, required by contract, we had – to this point – chosen to measure ourselves against the optional, higher-level Accreditation standards.

Having achieved this higher level for four consecutive years, we felt less and less benefit for the people we support was being derived from the process. The clinical focus of such performance measures is implicitly at odds with our Vision of ‘People with an intellectual disability living a great life’ and operational aim of supporting people to live lives of choice in their own communities.

This view crystallised at the 2008 NRID conference, where we formally and publicly handed back our Accreditation and announced our intention to follow the much harder, but more beneficial, path of Business Excellence. The response from our peer organisations was mixed, with some focusing on the risk of this new pathway, some simply seeing the choice as ‘mad’ and others expressing a desire to join us on the journey, were it not for the lack of governance support. We had weighed the risks, the opinions and the potential benefits, and decided to set the goal of achieving a Bronze Award by 2013.

In May 2008, a special celebration occurred to mark the 10-year anniversary of the people who moved out of Tokanui and into supported residential services within Spectrum Care. Attendees were encouraged by the obvious wellbeing of the people we support, and their ability to participate in the ceremonial and social aspects of the event.

Outside our core residential contracts, other services continued to challenge our thinking. Some developed as the sector strove to meet the original purpose of deinstitutionalisation, ie to support all people with an intellectual disability within their communities of choice, while others were less successful. Respite services in Auckland were growing significantly, while Waikato's adult-focused respite contract was struggling to generate adequate referrals from the Needs Assessment and Service Coordination (NASC) agency. Taking those learnings on board, we agreed to undertake a period of due diligence with a view to securing an adult respite service contract in the Bay of Plenty. This service had a similar profile to its Waikato counterpart and went on to become an important support option for the region.

Another non-residential service commenced in 2009, meeting the needs of young people with profound difficulties who are categorised as being within the highest need for special education. Transition Services, funded through the Ministry of Social Development, provides support for 25 young people each year in their movement from school environments into the community via work and education opportunities.

Continual improvement and an ongoing focus on Active Support led to a review of our Aspirations Services, also

commencing in 2009. This service had started life as a day service following the closure of Mangere Hospital and had, over the years, included people from the community. It was operating within an old paradigm, based on the 'sheltered workshop' concept and, at the time of the review, was focused on group rather than individual solutions. The review outcomes were to align with other important work streams in the year ahead.

Another new line of service came in the form of a School Holiday Programme for South, North and West Auckland. This bulk-funded contract caters to children from five to 16 years and is free, bringing high demand from families seeking some much needed and appreciated support.

During 2008, the Board recognised the need to have a clearly defined approach to our housing portfolio, including funding and investment. This was to be the start of an in-depth and significant piece of work, and was to play a major role in shaping our future. The year ended with an amended trust deed being signed off, which cut all historic ties with the institutional past of Mangere Hospital. After 14 years, Spectrum Care was finally out of the shadow of the institution and looking forward to a new horizon.

As 2009 dawned, we began a year of significant activity both internally and externally. In a drive towards further quality improvements and away from the compliance monitoring, the New Zealand Business Excellence Foundation award process was mooted by the Leadership Team. This was championed by our General Manager of Organisational Excellence Brett Marsh – a key figure in our ongoing drive towards person-centred excellence. Governance-level commitment to apply for a Business Excellence award was requested and the Board

was asked to “...trust the culture of the organisation,” in being able to undertake this rigorous process and take the learning on board. Ten years previously, Bob Simpson had introduced the Baldrige criteria and Jacki Richardson had continued to advocate for the Baldrige/Business Excellence quality framework, so the Board felt that it was acknowledging and building on the past. The application process was an incredible opportunity to holistically review all our business practices and to clearly define what drove us as an organisation.

The concept of the New Zealand Disability Support Network (NZDSN) was also introduced to the Board in 2009, along with an outline of the advantages to both Spectrum Care and the sector. Planned for launch in April 2010, NZDSN was to be an incorporated society, represented by a Board, with a vision for ‘An inclusive New Zealand’. The organisation would share some similarities with NRID (albeit with a wider mandate) in that it wished to provide a strong voice to government on matters of common interest. The Board supported our Chief Executive, Chris Harris, taking the role of transitional NZDSN Board Chair, as well as the ongoing involvement of Spectrum’s Communications Manager, Justin Walsh, who continues to hold the same role with both organisations.

As 2009 drew to a close, a governance-level decision was taken to appoint a Board member who could represent and link with our cultural Pasifika leader, staff and people and be a strong presence in the Pacific community. This undertaking led to Aseta Redican joining our Board of Trustees and signified an important moment in Spectrum’s history, as Pacific people were a significant group within the demographic profile of the people we support.





Our journey towards business excellence



Organisations are like tapestries, made up of many threads – some bright and bold, others subtle, but all contributing to the beauty and strength of the whole. As our organisation evolved, we became more aware of the threads that drew together to form our collective ‘fabric’. Language was changing and developing, defining the clarity of the pattern and individuals once known as ‘patients’, then ‘clients’, then ‘service users’ were now becoming known as ‘people we support’ or simply ‘people’. By 2010, some 15 years post deinstitutionalisation, the people we support had moved from the periphery of the ‘pattern’ towards the centre. This coincided with a refinement of our Vision to the more inclusive ‘People with disabilities living great lives’.

Unfortunately, the year also began with a tragedy, as a young boy in our respite care absconded and drowned in a nearby pond. We were all profoundly affected by the loss and the repercussions continue to be felt. The need to learn from this tragedy and drive our standards of safety and quality even higher was evident and sharpened our focus once again.

Reflecting our need to place people at the centre of our organisational world, supported by highly trained staff, our top strategic priorities for 2010 put 'Outcomes' first and 'Workforce' second, with 'Quality Improvement and Excellence' third and contingent on first two. Staff recognised that the organisation had grown through several developmental stages and was now at a turning point, where the people we support were moving to the centre of all that we designed and delivered.

Our 'Outcomes philosophy' was instrumental in moving our focus from a 24/7 residential construct towards a 'customer of one'. In other words, our organisation was working hard towards continuous quality improvement, while never losing sight of the fact that each individual set their own goals and would be their own 'control' comparison. For some individuals, the goals, steps and ultimate outcomes would be small and slow but, for others, there were bigger goals and fast-track paths. Our Service Manager for CYR, Darryl Bengé, reflects this focus: "Outcomes was a key driver for residential services and got everyone on the same page with a holistic, shared vision."

In both day and residential services, we needed to be mindful that some of the people we support did not want change, either to their home or the way they spent their day. As a result, our journey together had to be respectful and realistic. For young people, prioritising the skills for independence with their needs and desires is a constant balancing act, and the process requires many people in the young person's life to be involved in the discussions.

We also set about pursuing our Value of 'excellence' through learning and research in partnership with external stakeholders,

and investing time and effort at all levels of the organisation to support Careerforce (the former CSSITO) and its role in the sector. Members of our Leadership Team were playing a significant part at a governance level, and in developing training programmes and materials. This was particularly significant as Careerforce was astounded by the achievement of our staff and their ability to progress through the levels of training. We were looking forward to celebrating the success of 140 graduates from our workforce the following year!

In March 2010, an NGO/MoH working group was set up, with our Chief Executive Chris Harris elected to represent the disability sector. The sector had high hopes for this group and a report – *An NGO perspective on the reorganisation of the planning and funding environment* – was duly submitted to the MoH. Despite these hopes, however, no change ensued from this work. Undaunted, the sector continued to work hard and we drew another thread into our developing ‘pattern’ as we supported the official launch of NZDSN in April.

A focus on acknowledging and celebrating our past in the spirit of ‘Ka mura, ka muri – we walk backwards into the future, our eyes fixed on the past’ led to the inauguration of a Wall of Fame for people who had played a significant role in our past. The first people to be acknowledged were Tui Tenare, John Pettit and John Stacey for their vision and determination in the early days of deinstitutionalisation and pursuing ‘real’ lives for people with disabilities. Reflecting this thread of acknowledgement and celebration, the book *Extraordinary Journeys* was also launched in 2010 and documented the life stories of 12 extraordinary people as they

retraced their journeys from institutional care to supported community living. The book was the culmination of a year-long project and crystallised not only the importance of our Vision and mission, but also what we wanted to leave behind in terms of organisational culture and practice.

Spectrum, by this time, was seen as a strong collaborator and partner in the sector and, as such, was approached by a smaller organisation, Hamilton Residential Trust (HRT), with a view to merger. The external environment, funding, expensive compliance measures, ability to attract referrals and retain good staff made it difficult for some smaller providers to stay afloat. In addition, the rhetoric of the time was focused on 'economies of scale'. The two Boards commenced a due diligence exercise and were on the verge of taking the next step when the MoH undertook to manage performance issues with HRT through the imposition of a statutory manager. Productive discussions between Spectrum, HRT and the MoH eventually led to a very strong mentoring relationship being established, with the Service Manager of our South region (and leader of our Awhi Cultural Group) Maui Paraki mentoring HRT and reporting on progress to the MoH. The outcome of this exercise was judged to be extremely successful by all parties, and became the subject of presentations and discussions at sector level. It was hoped that this model would be adopted, in place of statutory management, as it offered significant opportunities for the organisations to learn, and allowed senior managers to extend themselves and gain new experience.

Another external recognition of our strong management capabilities came with an invitation for the Service Manager of

our Central region (and leader of our Pasifika Cultural Group) Amerika Wilson to join the Faiva Ora National leadership group, "...to ensure our Pacific people with disabilities had a voice." This was a significant acknowledgement of Amerika, but also of the people he would represent – the people we support, our workforce and the sector in general.

Opportunities were also being taken to further strengthen the interconnectedness of our Māori cultural group and rebuild relationships with Te Roopu Taurima O Manukau, particularly as many of our staff mourned the passing of Tui Tenari and attended her tangi. Our Senior Management Team had long seen cultural engagement as a priority and the Awhi, Pasifika and embryonic Asian groups sought to recognise the importance of culture in a person's life, regardless of what that culture might be. This cultural commitment also led to an increasing confidence, capability and comfort with cultural practice and protocol.

2010 continued to demand progress across many fronts. Our Leadership Team's commitment to pursuing excellence in the area of 'Workforce' led to a coordinator being appointed to oversee the effective utilisation of our 'casual' staff. This built on work started two years previously to reduce the use of external 'bureau' staff and to increase quality by having a workforce more skilled and experienced in our Values and practices. Pursuing excellence in service delivery through better workforce utilisation had an important spinoff in that we significantly reduced overheads (by several million dollars) and, consequently, were able to redirect this into frontline service development.

By this stage, we'd been able to measure the value of investing in a three-week staff induction period, initiated

in the mid-2000s, which combined both theoretical and practical experience. It was pleasing for the organisation to see a significant reduction in staff turnover in the first 12 months of employment, as well as the positive attitude and commitment to the organisational culture, which translated into person-centred practice.

Reinforcing our now established leadership approach, Spectrum continued to pursue new service delivery options to better achieve our Vision. The Board was presented with concepts such as Lives of Choice, supported independent living and further developments following the review of our Aspirations Services, which enabled people not already receiving residential services to better engage with their communities.

Staff satisfaction and engagement surveys demonstrate that staff were feeling positive about Spectrum Care at this stage, a situation which the Board was keen to monitor regularly as the organisation moved swiftly forward. Staff were encouraged by their engagement in the Vision and Values and a strong sense of ownership.

Fittingly, after so much effort and change, 2010 ended with a spectacular piece of news – we had achieved the Silver Business Excellence Award, a result far beyond our expectations and reflecting the whole-of-organisation support for this process. It was interesting to compare what appeared a deeply ambivalent response to our application and achievement from our public sector stakeholders, with the very positive response from the private sector. That notwithstanding, we were already pushing ahead and focusing on the next level of excellence – we were going for Business Excellence Gold!





Going for gold



‘E xcellence’ for a service organisation like ours requires cultural maturity, and perhaps the strongest signal of our cultural and organisational maturation came with the tragic events of the 2011 Christchurch earthquake. Some of our staff believe that this was our finest hour.

With the extensive damage to houses and infrastructure, many elderly and disabled people were shipped north with urgency to places of safety. We took a ‘brokerage’ role and committed to meet 26 people as they stepped off an RNZAF plane at 3am, with only the clothes they were wearing. We were able to pull together an assessment process and appropriate accommodation, with facilities to accommodate a large group of bewildered, displaced people with disabilities. This was made possible by our strong relationships with Tainui Iwi and access to the local Pukekohe Nga Hau e Wha Marae. The elders were extremely supportive in allowing our Awhi Group to take the lead on the Marae for this unprecedented event. Maui Paraki, Service Manager of our South region, reflected that it was a “...whole-of-organisation approach, supported spontaneously by the local community, who turned up in the early morning

with extra blankets, food and other useful items.” This event exemplified the many threads that we’d woven together over the years in planning, cultural sensitivity, person-centred practice and working with stakeholders to achieve positive outcomes for all people with disabilities.

The threads in our tapestry relating to our Vision and Values, and our approach to the specific Value of ‘excellence’, continued to be drawn through everything we did. Our Chief Executive, Chris Harris, believed it was important that the Board had confidence not only in his role, but also in the Leadership and Senior Management teams. “The Board needed to understand the depth of talent in the organisation, as it’s important for the perceived leadership integrity and transparency within Spectrum Care,” he said. Such recognition was very important given the amount and depth of change taking place within the organisation and, from a leadership and governance perspective, to ensure our senior teams were both acknowledged and respected for their significant contributions.

The capacity of these teams to achieve to a high and consistent standard had certainly been demonstrated through the many initiatives that were presented to the Board, then commenced and completed each year. Ahead of the organisation lay plans to improve wellbeing and health outcomes, and develop more robust practices to ensure the people we support who were young and anxious to be out in the community could be supported to do so, while the more profoundly disabled or aged members of our Spectrum family were also supported in their life ambitions.

There were many threads, but also a profound willingness to achieve – as illustrated in the actions of our staff and also in the results of the staff satisfaction survey. The Business Excellence application process continued quietly in the background, underlining how far we had to go in some areas and how much progress we were making in others, particularly in enabling positive Outcomes for the people we support.

Sometimes those we support suffer health and wellbeing issues, and the nature of their disabilities can lead to premature aging, chronic health conditions and inaccurate diagnoses of acute conditions. We were aware of these issues, but had not been able to get significant traction in addressing them until 2010, when a joint pilot project commenced with Counties Manukau District Health Board to offer community support for aging people with intellectual disability. That was an important first step in a series of initiatives focusing on improving health outcomes for the people we support. In early 2011, as a result of increasing concern about poor health outcomes for this population, the Comprehensive Health Assessment Programme (CHAP) tool was introduced as a pilot project in Hamilton. The tool was developed by Professor Nick Lennox, an Australian GP with New Zealand experience, and signalled the start of a series of health-outcome-related initiatives emerging from our desire to be true to our stated Vision and Values, and our commitment to personal Outcomes.

When reflecting on our commitment to health outcomes, a Service Coordinator commented that, “Our greatest achievement is that we’re always looking forward and asked

78 | to think about improvements for the people we serve.” Our previous, long-serving Finance Manager, Kim Casey, likewise commented, “The commitment of the Board and Leadership Team to the wellbeing, safety and welfare of the people we support has been unwavering over the years.” This commitment, along with an increasing confidence in our own contributions, has resulted in more opportunities to change GP and secondary care attitudes, an increasing in-house skill base and sector knowledge, better demographic data collection and primary care health structures, and a growing focus on consumer engagement.

Further reflecting the aforementioned desire to be true to our stated Vision and Values, and continuing our tradition of ‘never standing still’, the Senior Management Team suggested that we could work within our existing residential contract to offer new opportunities for supported independent living in the community. We called this new initiative ‘Lives of Choice’. As positive results began emerging from the pilot project, the MoH was invited to consider our new approach as a potential contract variation. It’s not surprising therefore, that the ‘Choice in Community Living’ contract came into being and residential options for people with disabilities began expanding across the sector.

Outcomes training continued to be front-of-mind and, in October 2012, the Board undertook formal Outcomes training to better understand the strategies which underpin what remains a whole-of-organisation commitment. The Outcomes concept encompasses the whole of a person’s life under the headings ‘My Life’, ‘My World’ and ‘My Dreams’

and, in tandem with the new Lives of Choice project, drove significant discussions at Board level relating to our housing stock and configuration. The question to be addressed was, “Are our properties fit for purpose?” The stocktake that followed led to a focus on the quality of our property portfolio, its appropriateness for the lifestyles and relationships that people wanted and what an organisation like ours could (or should) afford. Operating predominantly in the Auckland region, we compete to purchase or rent in a housing market that’s rising much faster than our income. New Board members appointed at this stage were surprised to discover that service providers in the Auckland region did not receive an additional premium, despite the marked difference in housing prices in Auckland and the cost of transport across New Zealand’s largest city.

The middle tiers of the organisation reported an increased sense of transparency and a belief that there were ‘no hidden agendas’, which is a vital component of success. Staff recalled the then-incoming Chief Executive Chris Harris acknowledging the primary importance of people at his welcome powhiri in 2007 and, with hindsight, they recognised this as a significant step in our evolution – and one that was continually reinforced with small and large celebrations taking place on a regular basis. The annual Staff OSCARs (or ‘SOSCARs’) event, the annual Spectrum Care Gala Ball (for the people we support), acknowledgements in our internal newsletter *Talking Point* and graduation ceremonies for those completing significant studies were all opportunities to acknowledge, celebrate and collaborate to achieve our goals.

As 2013 ended, we had the very great honour of once again celebrating Business Excellence success, this time with an unprecedented Gold Award, which acknowledged Spectrum Care as operating at a truly world-class standard. Chris Harris' reflections at the time of the award captured the nature of our Business Excellence journey and characterised our successes.

"From the moment we first encountered the world of Business Excellence, it became apparent we could never again be satisfied with 'good enough'," says Chris. "We've long believed that we hold ourselves to a higher standard, to loftier ideals and a more holistic world view, due first and foremost to our person-centred Vision and Values, and our capacity to support people with disabilities to live great lives. We've also sought to move beyond the minimum standards that define the quality monitoring context of the health and disability sector, and the Baldrige Criteria for Performance Excellence has allowed us to take this important step – refocusing on an aspirational journey which embraces excellence and best practice.

"However, validating ourselves against a world-class set of business criteria has exposed every aspect of our organisation and operations to incisive, critical review. Despite being at times daunted by this commitment to excellence, the rewards have been incalculable. Not only have we become better able to fulfil our Vision of 'People with disabilities living great lives', but we've significantly grown our workforce capacities, process capabilities, strategic vision, quality and sustainability.

“Above all, our Business Excellence journey is an expression of our organisational commitment to making a difference for the people we support. We seek to support people with disabilities to live great lives. Not only do we want to be the best that we can be, but we want families to know that we deserve their trust as an effective and innovative provider, that funders can have confidence in our systems and processes, and that staff can have justifiable pride in being part of a successful organisation that supports positive outcomes for people with disabilities.

“There are milestones, achievements and, in some instances, awards, but it’s the Business Excellence journey itself that sets it apart – in our experience, it’s a way of life. For while the process of collating a Business Excellence award application is an extraordinarily challenging task in and of itself, the daily reality of being on this journey provides extraordinary rewards. Each step on the Business Excellence journey, no matter how hard, brings us closer to realising our organisational potential and builds a better, brighter future for the people we support.”

Here Chris expressed our ongoing challenge – to surpass any achievement or award by staying true to our Vision and Values, and focused holistically on the people we support. In the language of the ‘customer of one’, the achievement of life Outcomes for the people we support is our truest measure of success.

Here in the present day, there is so much going on and so many threads being woven into our tapestry that we’re not short of new challenges. Our continued focus on Outcomes

(underpinned by our most recent support initiative, Basic Assurances), enables more choice and control for the people we support over their everyday lives. Engagement on both sides of the Outcomes process, however, requires good communication skills and tools so, in order to achieve this, we've recently appointed a Communication Practice Leader to develop such tools, with a particular focus on the profoundly disabled.

This role will go on to form a significant thread in our overall pattern of support provision, within the broader context of our practice and quality frameworks. As General Manager of Service Delivery Warren Herring reflects, "Successful Personal Outcomes depend on skilled staff, the language they use, their reflective practice and living our Values." Continuing our focus on practice and quality frameworks, we're currently setting up six 'Service Excellence' pilot sites across the Auckland and Waikato regions. Like Lives of Choice, this is not a contractual obligation but part of our drive to maintain, strengthen and exceed the achievements we've enabled for the people we support.

In the years that have passed since undertaking to support and mentor Hamilton Residential Trust, the relationship has become more significant and longer term, based on an alignment of core values. "Collaborating and working in partnership became an easy thing to do," said HRT Chief Executive Simone Molenaar. This has resulted in a shared office space and, more importantly, a shared Memorandum of Understanding, which secured the identity and autonomy of each organisation, and created space to explore and collaborate. The Chief Executives and Service Managers from

both organisations recognise the value of opportunities such as shared training and casual staff, and leveraging off strengths such as cultural and advocacy services. More recently, HRT has seconded one of our key Hamilton staff – instrumental in the peer mentoring process in 2010 – into a management role. This move was wholly reflective of our desire to add value to the broader sector and in the spirit of seeking to create better life outcomes for all people with disabilities.

“Spectrum is fantastic to work with and our commitment to each other and the growth of the sector is steadfast,” enthuses Simone Molenaar. “We believe in people living a life that really matters and know that, together, we can build on each other’s strength, passion and enthusiasm, so we really make a positive difference in the lives of people we serve.”

It’s no bed of roses, however, and some of our current challenges – such as recruitment and retention of a skilled workforce, training, safety and risk management – have existed since we formed in 1994. We approach these issues differently in 2014, within the context of a maturing organisation, increasing staff and Senior Management capacity to manage challenges, and a changing external environment.

An example of these changing environments is the competitive contract process entered into by the MoH for Behaviour Support Services (BSS). Across the country, successful services such as that provided by Spectrum Care had their contracts withdrawn. Organisations with many people requiring support for high-and-complex needs had to rethink their internal BSS strategies and structures. The challenge will be to turn this clear and present threat into

an opportunity for the future. Another ongoing challenge is the continued pressure for safety and risk management. In general, staff, families, the people we support and the Board want to ensure that safety is paramount, but not at the cost of 'a life like any other', nor at the risk of reconstituting 'institutional' care within the community. We must, therefore, be ever mindful of the maxim 'Nothing about us without us' and never lose the voice of the people we support, for their challenges are their own. Across much of the western world, people with disabilities now have a stronger voice and their opinion is actively sought. People with disabilities have opportunities and options, and our most important challenge is in meeting these expectations.

So what have we achieved in 2014, after 20 years of operation? We've focused on the scope and quality of our services, rather than growth. For those with profound support needs, we can offer a home option and a raft of integrated services, with a range of staffing options to meet individual support needs. We offer home and respite support from as little as three hours per week to nearly 70, and offer community networking and training opportunities through our Aspirations Services. We support families through our Respite Services and School Holiday Programme, and enable the people we support to achieve life Outcomes and lives in the community like any other. We're changing the language we, as a community, use about people with disabilities, as well as our collective expectations and approaches. We've remained steadfast in our commitment to our Values, and focus intently on support practices that ensure the achievement of Basic

Assurances, Personal Outcomes and service excellence. But, most significantly, we've worked with a singular focus towards the achievement of our Vision of 'People with disabilities living great lives'.

As we celebrate our 20-year anniversary and reflect on the lessons of our and our country's past, we can see that certain threads remain constant. The needs of people with disabilities and their families have always been present but, at some stages in the past century, they've been relegated to the background. As we look to the future, it's imperative we ensure those particular threads are clear and bright. As an organisation, we want to actively listen, to work alongside as 'supporters' and not 'providers', and work tirelessly to enable a future not yet imagined. We have so much further yet to go and, as General Manager of Service Delivery Warren Herring aptly puts it, "Someone will look back in another 20 years and wonder what took us so long!"



Facing the future



As we look to the future, it seems that there are more questions than answers and, sometimes, life appears circular. In the early days of New Zealand (ie the mid-19th Century), people with an intellectual disability lived at home within their communities. By the turn of the millennium, this was once again becoming the first choice for families. Residential services are only a small part of the suite of support options available to people with disabilities and their families, and many people now live either with their families or in a property not owned or managed by a support provider. However, there is still a long way to go if people are to achieve a life in the community like any other.

What hasn't changed since the inception of the Auckland Community Living Trust in 1988 is the importance of strong governance, and Spectrum has benefited from robust, independent governance since its foundation. From the first Auckland Housing Options Trust Board, chaired by Robyn Stent, to the current Spectrum Care Trust Board, chaired by Richard Hanna, the passion, energy, insight and empathy

88 | for the people we support have been significant factors in our ongoing quest for excellence in service delivery and our willingness to learn and evolve.

Looking ahead to the next 20 years, resilient leadership will continue to be a pivotal factor. Our capacity to respond effectively to a changing environment will be vital to our sustainability and ability to effectively fulfil our Vision. Focusing on the voice of people with disabilities (and their families) and tailoring services to meet those needs will be paramount in delivering a suite of person-centred, Outcomes-focused services.

The *New Zealand Disability Strategy* laid a strong foundation with the expectations it placed on our society. It presented "...a long-term plan for changing New Zealand from a disabling to an inclusive society." *To Have an Ordinary Life* provided specific advice and insights into how New Zealand could meet the needs of people with disabilities across their lifespan. This is an influential document which has been continually overlooked in government policy and priorities. It has been 'arrested' in its ability to make a difference at a national level, in the same way that institutional living 'arrested' individual development. We, however, are committed to using it as a guiding document.

Our current Chief Executive, Chris Harris, refers to the unintended structural and policy barriers placed in the way of people with disabilities. Can we realise the core principles of these key strategy documents, while also moving funding and service delivery to an as yet unimagined levels of flexibility?

An opportunity before us all, as support providers, families and funders is to once again raise the profile of *To Have an Ordinary Life* on behalf of the people we support. We must remind ourselves of the fundamental reality that we are all individuals and, therefore, support services and constructs must reflect this individualisation, among people and across lifetimes.

Given the current sector focus on risk and health and safety issues, we may be at a crossroads. Can we hold fast to a person-centred, Outcomes-focused support model, which strives towards lives in the community like any other, when such a vision inherently exposes people with disabilities, the organisations supporting them and funders to more risk? Will we be forced to moderate this vision in order to balance risk vs return, encourage private sector competitiveness and a focus on cost reduction?

Recent international dialogue has been focused on the language of cost reduction, efficiency, rationalising and learning from manufacturing, and the private sector has begun a concerted push into the disability support sector. There are significant benefits for the people we support in improved systems and processes, as our commitment to (and outcomes from) Business Excellence attests. But people are not products and the cost of living an ordinary life should be compromised neither by fear of the unknown nor shareholder returns.

History should be our guide. In the early days of Spectrum, people with disabilities were in the background, while staff, families and government battled to retain or change models of care. Our future, however, must focus on supporting people to

have their own voice, to express themselves, their worlds and their dreams. It's also imperative that we embrace the role of the family, whānau and friends in the planning and delivery of supports, and we need to be very clear that the people we support are absolutely and unequivocally at the centre of all decision making. Staff, family, friends and funders are in orbit around the people they support, for they are the stars in our metaphoric galaxy.



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Images

All references clockwise from top left

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2. Mangere Hospital Training Centre
3. Mangere Hospital Training Centre
4. Mangere Hospital graduating class – 1969
5. Principal Nurse Les Ellwood receiving the keys to a Commer van, donated by the Prince Arthur Hotel
6. Mangere Hospital's Nursing Education and Training Centre faculty
7. Mangere Hospital and Training School logo and meaning (centre)
8. Mangere Hospital Training Centre

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2. The Commer van, donated to Mangere Hospital by the Prince Arthur Hotel

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1. Off-duty Nurse Aids, Mangere Hospital
2. Time capsule cairn celebrating 25 years at Mangere Hospital
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1. Rescare village – another residential provider to emerge following the closure of Mangere Hospital
2. Lorraine Bailey
3. Residential living was very different to that of the institution
4. Siainiu Masoe (far right) at the opening of Maota O le alofa house
5. The opening of Serenity House, a community outreach base to support people emerging from institutional life
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7. Spectrum Care's 'taonga' gift to Te Roopu Taurima O Manukau

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1. A ward key for Tokanui Hospital, compared to a contemporary key
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1. Spectrum Care Day Services
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1. 'Outcomes' is a philosophy which guides person-centred support
2. Lives of choice in the community like any other are now a reality for the people we support
3. The Spectrum Care Gala Ball is always attended by Leadership Team and Board members
4. Tui Tenare
5. Spectrum Care has a long history sponsoring the Franklin Canteen Bike Bash

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1. The annual Spectrum Care Pacific Group Christmas Party is a key feature of our annual calendar
2. Residents enjoy their own home together
3. People we support and staff working through their first aid training
4. The biennial Spectrum Care Talent Quest features more than 10 individual and group performances over a very full day
5. The Spectrum Care Pacific Group Christmas Party

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1. People we support and staff working through their first aid training
2. Orakau House is our specialist facility for infants and children requiring 24-hour support
3. The annual Staff Oscars or SOSCARS is a key event to celebrate person-centred Values-based support
4. The Spectrum Care Sports Day
5. People we support and staff graduating with their first aid certificates

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- 1-4 Lives of choice in the community like any other are now a reality for people we support, several of whom now have their own homes

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1. Business Excellence Silver Award ceremony – 2010
2. Careerforce Core Competencies graduate Viliamu Nainai with Te Pou Chief Executive Robyn Shearer
3. The Careerforce Core Competencies graduation ceremony – 2012
4. Our response to the needs of people with disabilities during the 2011 Christchurch earthquake was described as ‘...our finest hour’

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- 1-3 Spectrum Care Gala Ball
4. Spectrum Care Sports Day
5. Business Excellence Gold Award ceremony – 2013
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1. The Lawns Crew – a Spectrum Care Business Enterprise run for and by the people we support
2. The people we support work full- and part-time in professional and socially valued roles in the community. Paul is a qualified fork-hoist operator
3. Casey also recently graduated with his fork-hoist licence
4. Spectrum Care Sports Day
5. Catherine recently won gold and bronze for freestyle swimming and silver for backstroke at the Special Olympics

Spectrum Care is celebrating 20 years as a disability support provider and independent charitable trust. Emerging from the closure of Mangere Hospital, a psychopaedic institution, our organisation embarked on an extraordinary journey of its own, marking its progress through the eras of deinstitutionalisation and supported group homes, on to independent community living and person-centred, self-directed services.

Our history is, first and foremost, a story of individuals with needs, desires and aspirations. It is a story of people and relationships.

Over the past two decades, we've strived to stay true to our Vision of 'People with disabilities living great lives', and focused holistically the achievement of life outcomes for the people we support. This is our truest measure of success.

Each step on this journey has brought us closer to realising not only our organisational potential, but – more importantly – has built a better, brighter future for the people we support.

'People with disabilities living great lives'

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