

# Why don't you come to my place?

## “I am here” – The Article 19 Project



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TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

# Scott & Graham McDonald

## Being in place

The township of Reporoa is approximately half an hour and 40 winding kilometres south of Rotorua and north of Taupo. It sits in the hollow of the Reporoa Caldera, a 10 kilometre wide geothermal sink formed over 200 000 years ago. Prior to European settlement Reporoa was almost constantly underwater, but the swamps have long been drained and bush sickness that weakened cattle that grazed the pumice soils long resolved. Today the Reporoa basin is home to approximately 2000 people, most of whom farm or provide agricultural services or supplies, fell or mill timber or work at the Fonterra dairy factory. They live in a landscape of steam and rolling pasture framed by the orderly rows of pine that pin-stripe the Kaiangaroa plateau.

Reporoa itself is a small village. The community newsletter boasts, perhaps ironically, that the village is *"the business centre of the valley,"* famous, it adds *"for having one of the most rurally situated roundabouts in the country"*<sup>1</sup>. As if not incongruous enough, a wire statue cemented to its base has the stylized silhouettes of a cyclist, runner and swimmer seeming to equivocate about which of the four roads that fan like cardinal points they ought to be taking out of Reporoa<sup>2</sup>. Should they choose to go north, up Settlers Road, they would quickly pass the Corner Dairy and Happy Grazer Takeaway, were a ute is almost always to be found parked with its door hanging open for the time it takes to finish an Oxford pie. Across the road is the Reporoa Traders, rural vet and a little further on, the local squash club hidden behind a row of willows. Heading east down Guthrie Road would take them past the community chapel before coming to a stop outside Reporoa College, whereas the medical centre, primary school, Memorial Hall and Woolshed Tavern all crowd into the first block south, down Broadlands road. The only other alternative is to head west to re-join the thermal highway.

Scott and Graham live with their parents a few kilometres on from the Reporoa turnoff. Kevin and Jane breed Hereford's and the farm they share with their sons has been in Kevin's family for two generations. The farmhouse sits on the brow of a small knoll looking out to the hills and to the house Kevin's parents built on their retirement. From the lounge window you can also see the calf sale yard that Kevin built. In the season, the sale yard attracts buyers and sellers from all around the district. Scott and Graham's older brother Jeffrey and his family live on the farm over the brow of the nearest hill and share the same gravel road that snakes around the "Kairuru,"<sup>3</sup> property and on to the distant hills.

Scott is twenty-eight and his brother Graham twenty-three. They are the youngest of Kevin and Jane's three sons and similar only in so far as they share a common community and the same genetic disorder.

Both Scott and Graham have Cohen syndrome, a rare genetic disorder that can include global developmental delay, visual impairment, autistic traits, hearing difficulty, compromised immunity and anxiety amongst an array of physical expressions. At the time of Scott's diagnosis fewer than 100 cases were known and even today, fewer than 1000 people have been diagnosed world-wide. To Scott and Graham, however, the diagnosis is meaningless. Cohen syndrome also means nothing to a small community that has come to recognise Scott and Graham as individuals, in part defined by their respective passions.

Scott is lean and sinewy, partly because he has never been good at eating and partly because of his restless energy. Scott measures time by the yearly cycle farm activity and October is his favourite time of year, bringing as it does the migration of combine harvesters and balers that herald the start of the hay and silage-making season. Before moving on to his farm, Jeffrey had worked for, Mark Miers, a local agricultural contractor, as his manager of baling. Kevin estimated that Jeffrey had wrapped over 50 000 silage bales for Mark and, after buying a wrapper themselves, Scott, Jeffrey and Kevin continue to do

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<sup>1</sup> Reporoa Valley Traders: [www.reporoa.co.nz](http://www.reporoa.co.nz)

<sup>2</sup> The silhouettes are a landmark for contestants in the Taupo iron man who, in the first week of every March lap the Reporoa roundabout on their way back to Taupo.

<sup>3</sup> Kairuru is the name of the family farm and takes its name from the trig station that provides a 360 degree view over the entire Reporoa Valley.

relief wrapping on farms throughout the district. Scott is fascinated by farm machinery. His wardrobe is lost to the rising tide of farm machinery catalogues and promotional magazines that distributors post to Scott who, for his part, remembers the specifications with unerring accuracy. Mark Miers has over a dozen tractors, none quite as good as Scott's John Deere 6230, but good enough, his mum tells us that Scott would regularly accept invitations from Mark to come up for a ride on one of the tractors.

Mark is but one of a number of farmers and contractors that collectively keep Scott embedded in the yearly cycle of sowing, silage making, calving, rearing, cultivation and farm maintenance that has always been his life's rhythm. In addition to Scott and his family keeping a weather eye open for opportunities to participate in farm activity, a handful of local contractors who know of Scott's passion for farm machinery occasionally stop at the gate to pick him up or phone the night before to see if he would like to spend the day with them.

"Scotty," Kevin tells us *"has the mind of a farmer"* and could probably manage a stud farm. His memory for detail, for example, extends to remembering the ear tag numbers of some of the Kairuru best bulls which he can peel off in a seamless whakapapa. "*Ricardo*" he reminds Kevin was "46," and "*Aberdeen*," "0347." Before they changed the system of identifying bulls, five or more years ago, the ear tags had begun with the first initial of the bull, so "*Villan*," Scott remembered was "V9." Scott's recall, however, goes even further back. "*What about 'Nepia.'* What was his number?" Kevin called into the kitchen, before telling me that Nepia had been sold 15 years ago when Scott was only 12. Scott distractedly called back that Nepia was "N31," before reminding Kevin that Nepia had gone to Palmerston North. "*We never taught him*," Kevin told me. "*He just has the mind to run a stud.*" Scott, however, was more interested in rekindling the conversation that had been taking place around the kitchen table a few moments before. Jeffrey had dropped over before the calf sale. He and Kevin had been debating how plausible the claims made for a new petrol additive might be over mugs of tea and biscuits before turning their attention to who might be buying at the sale that morning. Scott had fallen silent to make sure he caught every word.

For the length of the sale season, the cattle sale bought Scott's community to him once a week. Scott and Graham both gravitate towards people who readily recognise their common interest, but for Scott especially, the sale yard represented an oasis of contact from which he has built his community. Over the years Scott had come to belong to the brotherhood of stock agents and farmers with whom he shared the sale yard at the bottom of his drive. He has an insiders knowing of the people and customs of place having hung out for countless hours at the sale shed. He wore their uniform, including the John Deere cap the tractor reps had given him and agent's jersey gifted to Scott by Wrightsons. On occasions, agents took bids from Scott to bump up the prices and the chief agent puts Scott's name on the reverse of the calf tags as a symbol to Scott and to others of how much his affection for them is reciprocated.



**Figure 1 Scott at the calf sale**

Graham is equally social, but unlike Scott, tends to measure time by the distance to important events, many of which he organises himself. In addition to the annual countdown to birthdays or to Christmas, Graham occasionally plans "get togethers," with his friends and always takes the lead role in organising a trip to Auckland.



Whereas Scott's interests don't stray far from the farm, Graham is urbane. He loves clothes, fast cars and the bustle of city life. One day, Graham hopes to become a model.

Once a year he and his mum liked to go to Auckland. Planning for the trip began months in advance during which time Graham's head floods with possibility. In sentences stitched together with laboured care Graham told us Auckland was a "Big city. Very busy." "August," he added would "not (be) busy." "September, not busy. October, very busy." This year Graham and Jane were planning to go in October and Graham emphasised each month that needed to pass by counting them off on the fingers of one hand, in much the same way as he could enumerate every small town that separated Reporoa from Queen Street.

With Jane's assistance, Graham would plan almost every aspect of the trip. This year he wanted to stay in a backpackers hostel in central Auckland. He had seized on the idea from a stray comment, but within the hour the idea had gained momentum. Graham decided that this year he wanted to stay at double-storied backpackers overlooking the Britomart Transport Centre and with Jane's assistance, began his search.



**Figure 2 Graham riding the Auckland buses and searching for accommodation**

Buses had fascinated Graham for most of his life. Jane thought his fascination may have begun on one of their holidays to the Mount. "A bus pulled up right outside our holiday house and dropped a load of tourists off," she recalled. "Graham wandered over and the bus driver took a shine to Graham. He had an hour to kill so the driver ended up showing Graham how the bus worked, letting him work all the levers. It was one of the kneeling buses," she said, "so Graham was opening the doors and getting the bus to kneel down."

To Jane, the trip to Auckland was more than a holiday. There was the cascade of learning that always anticipated their trip, like earning and saving money, buying clothes and searching the internet for an up-to-date bus timetable or booking accommodation, but most importantly, the trip provided Graham with a chance to alert everyone to his passions. Over the years that they had been going, Graham and Jane had been to the Auckland television studios hoping to catch New Zealand's Next Top Model and Wheel of Fortune. They had caught buses to and from Auckland's ice-skating rinks and only ever visited the most prestigious of car yards. "We are always met with great kindness," Jane observed after recalling how television presenter Matt Chisholm had taken the time to provide Graham and his friend Vika a personal tour of the TVNZ studios to find the abandoned Wheel of Fortune set and how the year before, Graham's face had become so familiar amongst the audience that Jason Gunn was in the habit of greeting him personally.



**Figure 3 Vika and Graham with guide, Matt Chislom and the Bentley or the Lamborghini?**

For Graham, however, it was the Auckland buses that were the main attraction to their pilgrimage and Britomart Auckland's holy grail. "Me. Very Busy man. Number 50 bus. Britomart," Graham prompted. "Number 50 bus."

Graham always got an all-day travel pass when he went to Auckland and although he could remember a few route numbers, it was to the "Number 50 bus" that his conversation repeatedly returned. The number 50 bus takes you out passed Botany Downs and the ice-skating rink where Graham first met Allie.

"Graham likes to go ice skating," Jane told us. "He thought of it by himself." In order to skate, however, Graham had had to strengthen his ankles and prior to their first skate he and Jane had worked hard to build Graham's leg strength.

That first skate had a place in family lore, however, not because of Jane and Graham's tenacity, but because of Jane's commitment to seeing activity as a further opportunity to generate relationship. Before going to Auckland, Graham said that he had had a dream and in the months that preceded the trip repeatedly told Jane that it was his dream to skate with a girl. "Graham has so much faith," Jane said, "and when you see someone praying their heart out for something they want, you just have to help them do it." Jane worried. Not only did she not know Auckland very well, she had never been ice-skating before, so the trip to Auckland that year was freighted with her anxiety about how Graham might react when his hopes were not fulfilled. Arriving was difficult enough, Jane decided, that, "if we made it to the rink, we were meant to do it." In the flurry of eventually finding the rink and getting organised to skate, Jane temporarily forgot Graham's dream until he reminded her. "There she is!" he declared, pointing across the ice to a beautiful young woman turning pirouettes alone in the centre of the rink. Jane's heart sank at the improbability of him skating with her only to soar when, just as Graham foretold, she skated across the ice and offered him her hand. The young woman's name was Allie and she was practicing to qualifying for the Winter Olympics. Her coach had overheard Jane telling someone watching at the side of the rink about Graham's dream and he had passed it on to Allie. As she left, Allie said to Graham that if he was ever in Auckland again he should phone her and they

could go for another skate. Instead of dismissing Allie's invitation as a conversational courtesy, Jane kept the number and he and Allie have been for a few skates together after their ride on the number 50 bus.



**Figure 4 Mark Aldred (coach), Graham and Allie Rout (New Zealand figure skating champion 2008-2010)**

## On the morning we first met

On the morning we first met, Scott was standing erect at the lounge window. It was calf sale day and in the ring of vision he has in his right eye, Scott was looking for the tell-tale flash of colour that would tell him which transport contractor had arrived to ferry calves to or from the sale. Every now and then he would spring vertically, like a Masai warrior, excited by the prospect of meeting the familiar faces he had deduced would be waiting at the yard. Graham wasn't so interested in the sale. He was in the first flush of organising his holiday to Auckland and would flit between playing the car racing game that was running on an X-box and his mum, seeking to engage her in conversation about the thoughts that were flooding his head.

The formality of introductions ended quickly as Scott and Graham took turns to draw anyone who fell within earshot of their impassioned thinking into their square dance of conversation. Jane and her sons collectively decided that the best way for me to begin to get a sense of their lives was to start at the calf sale. In spite of his visual impairment, Scott strode off at pace to reach the yards where Kevin had already begun to triage the calves into stalls according to those he thought might go for the best price. Jane, Graham and I trailed behind but caught Scott twice en route, first when he stopped to check the mailbox, hoping for a rural trader or one of the catalogues the farm machinery retailers would routinely send and again just beyond the yard gate, before the promise of familiar faces and fresh introductions pulled him away from the throb of a water pump that had arrested his progress.



**Figure 5** Scott at the mailbox, Waiting on Scott to finish his massage with Cherry, Graham greeting Andrea

The mailbox totemically connected Graham to his community too. *"Last year the mail-lady got wind of Graham's birthday and left a helium balloon weighted down with lollies for him to find,"* Jane mused as we passed the farm gate.

Where as Scott has a well-practiced handshake, Graham seemed to prefer to hug the people he loved. The first recipient that morning was Graham and Scott's relief support staff. Andrea was at the calf sale turning sausages on a barbeque for the stream of farmers lured across by the smell of hotdog that hung in the air. Jane eventually joined Graham and Andrea, initiating a train of conversation that began with Andrea saying she would be free after 12.00 if there was something that Scott wanted to do and ended with them discussing the possibility that Scott might go with her to Taranaki when she next visited her daughter. Andrea's daughter Nicola lived on a dairy farm in Stratford and Scott loved spending time with Nicola and her family. Graham told Andrea he was planning a holiday of his own, at a back-packers near Britomart.

Scott and Graham met their massage therapist at the sale yard too. Cherry had arrived at the house to find it empty and wandered down the hill realising that that's where Scott and Graham would be. Cherry had her grandchildren, Wiremu and Angel with her and Angel was the recipient of Graham's second hug. *"Massage,"* Cherry would later tell me *"had made an enormous difference to the boys,"* In addition to relaxing taut and sinewy muscles, Scott and Graham had learnt to recognise the therapeutic benefits of massage and now took control by directing Cherry to areas they felt she needed to work on. *"They are so much more flexible now,"* Cherry said. *"When we first started Graham couldn't even get on the table."* *"Scott,"* Jane added, *"used to be very stooped and hunched but*



*now stands straight and tall and is able to manage the pain he routinely gets in his hips and spine."*

When Graham was ready, he and Cherry and her grandchildren wandered back up the hill to the farmhouse, leaving Graham to socialise under the watchful gaze of his community. Jane said she was beginning to trust that Scott and Graham were safe in a few social settings like the calf sale, but that forever scanning to know where both boys were was a habit that was proving difficult to break. *"I'm learning to have faith – to stand back and let others help,"* she said. *"Like the time I left Scott with the Stock Agents - Oh that's fine! We all know Scott and Graham they said,"* Jane recalled a little incredulously despite appreciating the social knowing and collective care that had accumulated about her two sons.

As we left the sale yard, Jane returned a wave from the cab of a ute that was slowly disappearing behind a cloud of road dust. *"That's Aart,"* she explained. *"He and Scott share a love of machinery."* Aart Maandonks owned "Brutus," an International Harvester tractor that he had modified. *"Anyone that is interested in tractor pulling knows Aart,"* Jane continued, before pointedly adding that Aart had a real love for people like Scott and Graham.

When we got back, Scott had almost finished his massage. Angel sat in a lounge chair, adding a new picture to the exercise book she had brought with her and Wiremu was watching a DVD that Scott had made him of the carefully choreographed pas de deux between harvester and silage truck on one of their visits to a neighbouring farm. They would stay for lunch, although Scott was keen to get back to the yards. *"Can Angel take me down to see the trucks?"* he asked, before Angel answered for everyone. *"Ok Scotty,"* she said. *"Angel,"* Scott replied, *"I'll take you to the trucks. I'll make sure they're there Angel."*

## Being the same as everybody else made me feel like we were parenting the way that we were meant to

Chinese geographer Yi Fu Tuan believed that physical landscapes are imbued with social meaning and that the feelings we have for particular places are built up through the accumulation of experiences that layer sentiment, one horizon upon another<sup>4</sup>.

Scott and Graham had lived their entire lives at Kairuru. The landscapes that informed them of who they were and where they belonged were shared with people similarly linked to the intimate social spaces and rituals of a small rural New Zealand farming community. The linkages between people and place stretched back a number of generations for most of the Reporoa community and Scott and Graham were no different. Jane's parent's Neil and Robin Pirrit were considered pioneers, breaking in 1000 acres from scrub in the 1950s at Broadlands, just 20 minutes from the Kairuru property. They had originally lived in a tent before Neil built a one room "whare" with a tractor shed attached to house his bulldozer. As pioneers, Neil and Robin were key figures within a developing community. Jane said Neil served on a number of different committees and was the driving force behind the building of the Broadland's Community Hall and in the 1970s set up the first geothermal steam driven lucerne drying plant. Kevin's family came to Reporoa in the 1966 where they too were quickly assimilated within a community that replaced the expansive network of family and friends they had left behind in Hunterville. Kevin's father Ron, taught bowls to children and as involved in a number of different sports committees while his mother Audine was for many years President of the Women's Division of Federated Farmers.

When Scott and Graham entered their community, therefore, they entered within the cloak of a communities' knowledge of their family history, including the contributions Kevin and Jane had subsequently made to physical and social townscape of Reporoa. Hereford bulls reared at Kairuru had twice won Champion Bull at the National Beef Expo and in addition to the calf sheds that drew buyers

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<sup>4</sup> Tuan, Y. (1977). **Space and Place: The Perspective of Experience**. London. Edward Arnold (Publishers) Ltd.

and sellers from all around the district, Kevin had also laboured alongside other community members to build the Squash Club hidden behind the oak tree down Settlers Road, as well as the Mihi School Hall. Jane, on the other hand, was at the heart of the local church community. Jane and Graham were seldom absent from the congregation that worshiped beneath the A-frame of St Stephens community church. Her support of the school communities and of the people she met through 'divine appointment' who found employment and purpose through their connection to Scott and Graham were acknowledged in the way Jane's community knew her.

Like many small towns, Reporoa's schools played an important role in galvanising community including locating Scott and Graham within their generation. Scott had originally attended a Special Needs Unit attached to a Taupo Primary School, but returned to finish his education at Reporoa College, following a recommendation by Ian Hunter<sup>5</sup> to mainstream Scott. Jane described ultimately feeling affirmed by the contrasting educational expectations she observed between the mainstream and "Special" educational settings Scott experienced, but said at the time, their decision to move Scott back into his local community was a huge and frightening step. *"We didn't know what mainstreaming would be like, nor what supports would be available when Scott started,"* Jane recalled, *"He was eight, but from the first day he walked into that school he was happy. He couldn't do anything, other than walk. He couldn't get his lunchbox. I don't think he could even say his own name, but he was happy because he was around other kids. You could see his whole countenance change,"* Jane said. Jane remembered Scott's teachers included him in everything. She also impressed on us the importance of his teachers expecting Scott to read. *"First we need to get him looking at the page,"* Jane recalled Scott's first teacher saying, and although it took them all of that first year to get Scott's eye consistently to the page, Scott now reads.

Jane said that when it came time for Graham to start school, there was no decision to be made before quickly adding that at his primary school, Graham had genuine friends. *"Friends,"* Jane said *"that he spent a lot of time with and who stayed happily in his company all day."* Jane always found plenty of reasons to invite classmates to the farm for visits and on birthdays, schoolmates joined family for the celebration. *"Parties,"* Jane explained, *"were a good way to get people into Scott and Graham's life, although,"* she continued, *"for all the parties we had out here, I don't think they ever got invited to one birthday party in return."*

Scott and Graham both stayed at school until they had to leave at twenty-one. Graham, Jane remembered, couldn't wait to leave school, but the dislocation that followed meant that within three months of leaving, he was asking if he could go back. *"The teenage years were very lonely,"* Jane recalled, a reality she attributed to the very different life trajectories their age peers began to take in adolescence. In a few short years the social conventions that signposted the passage from child to emergent adulthood and the places and activities that preoccupied their friends changed with a suddenness that left Scott and Graham in their wake. *"It was so abrupt. People got caught up in their own world."* Jane said, reflecting on world's that slowly excluded her sons.

Both Scott and Graham did, however, still count classmates from College amongst their circle of friends. In a small town, the inevitable intersection of lives continued to reinforce friendships initially forged and reinforced in the school playground, but as the boys had gotten older, Jane felt that they were qualitatively different relationships now. *"At primary school Graham had a group of friends who hung out all day, every day just because they were friends. Today there are lots of people that Graham cares about who also care about him – But true friends. Friends that are willing to come and spend time voluntarily – he has very few. Graham is craving that. He doesn't want someone to come every two months for a get together. Graham wants a true friend."* Jane went on to say, however, that Graham was not daunted by the loss of his friends. *"He is a very optimistic person."*

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<sup>5</sup> Ian Hunter developed a programme of physical therapy that Jane followed when Scott (8 years) and Graham (3 years) were young. The aim of the Neuro-Developmental Therapy Program (NDTP) was to promote brain recovery by replicating the sequential acquisition of physical competencies through repeated exercise and Scott and Graham spent several hours a day being exercised by a roster of 30 community volunteers who *"kept the boys busy five days a week for 18 months."*



Jane said. *"His credo has always been 'don't be shy – have fun.' Even when he could hardly talk, he always sought people out."*



**Figure 6 Parties at the farm and Graham at Broadlands Primary School**

While Scott and Graham were at school, their being in the same place as everyone else made an important difference to Jane and Kevin too. Leafing through a family album, Jane paused at an image of Graham's teacher, stooped to present her small son with an award to the applause of the school. *"It meant so much to be the same as everybody else,"* she reflected. *"Inclusion was what made me as a parent. When the boys were included, I felt different. When you are not in an inclusive setting, you only focus on disability. Being the same as everybody else made me feel like we were parenting the way that we were meant to."* Jane's belief that Scott and Graham should participate in their community in ways that were culturally normative was one of the central motifs to the story she told, however, whereas being present was easy when her son's were at school, Scott and Graham tended not to be met by a similar expectation beyond the school gate.

Scott and Graham number amongst the first generation of children with high and complex support needs to experience mainstream schooling and whereas Jane felt that her son's had assimilated the aspirations that followed growing up alongside their peers, she wondered whether adult disability services were sufficiently resourced or had changed in ways that accommodated the mainstreamed aspirations of Scott and Graham's generation.

**"It's not a proper expression of life. Of them."**

The sanguinity with which Graham reacted to the shrinkage of his social network was an attribute he appeared to share with his brother. Scott and Graham both looked forward with a sense of optimism and although this may have been dispositional, Kevin and Jane had also instilled in their sons and the people who supported them, a belief that their dreams were the starting place from which to build a future.

Scott declared his love of farming and farm machinery so transparently that it was impossible to miss or ignore. He was the last in a long lineage of farmers and possessed, according to his father, *"the mind of a farmer."* *"Scotty would have the ability to run an agricultural contract business if he didn't have his eye-sight problem,"* Kevin told us, with Scott's intimate knowledge of the rhythms and routines of farming blinding Kevin to the significance of any developmental delay. To his farming father, Scott's poor vision was the only impediment he recognised as standing in Scott's way.

When Kevin thought about Scott's future, he imagined a house and a small plot of land of his own. He could with support, Kevin believed, grow his own vegetables and perhaps raise and ultimately sell his own stock alongside the brotherhood of stock agents and farmers to which he already belonged.

Kevin and Jane had already attempted to match Scott's passion for farm machinery with meaningful employment. As a young boy, Scott had learnt to drive ride-on mowers from Peter McNeal, a man who Jane also described as *"having a heart for people."* Scott had introduced himself to Peter while the family was walking the beach at Mount Manganui and Peter had invited them all to come and visit his farm. Peter taught Scott to drive his lawnmower at the farm and a years later, Jane supported Scott to buy his own ride on mower. Their idea was to set up a mowing lawns business by tapping Scott's love of tractors and the reservoir of reciprocated affection that had built up between Scott and the farmers and contractors who recognised a kindred enthusiasm for their vocation.



**Figure 7 Scott learning to drive Peter's ride-on mower**

The seed of the idea had, Jane said, been planted by an inspirational story she had read of a service that had enabled a client to set up his own courier business by providing a staff person to drive the van. *"Scott had been out of school for three years with no support for day activities that would suit him and I thought, why can't Scott do something like that? Why can't we get funding for Scott to do things that he would enjoy doing on farms, so I wrote the Minister for Disability Issues a six page letter outlining the frustrations we have had and how much potential I could see and I got a letter back to say Pathways to Inclusion had been enacted and to their knowledge was delivering the services it was intended to deliver."*

Jane said she had *"tried so hard,"* to make the lawn mowing enterprise work, but that it was difficult to transport the mower and, she said, the *"OSH implications of having Kathy running beside a lawnmower coupled with the logistics of the whole operation,"* eventually exhausted their enthusiasm for the project. *"Encouragement is vitally important to maintaining the energy you need to put in"* Jane explained, before adding that *"It (was) a scare commodity when you are isolated."* Jane had, however, continued to alternative ways to find personally meaningful employment for Scott and Graham. In describing his wife, Kevin told us that one of her defining qualities was that *"Jane would never give up,"* and with undiminished resolve Jane explained that her most recent idea was to make use of Scott's new found enjoyment of filmmaking. As Scott knelt keenly watching the DVD he had made for Wiremu, Jane said that she had thought about approaching the farm machinery showrooms that Scott frequented to see if they were interested in Scott making promotional DVDs of the farm equipment they were selling that they could use on the closed circuit TVs that hung on the showroom walls. Scott, she thought would be happy to build them a library of instructive DVDs.

Jane's belief in Scott and Graham's capacity, however, stood in stark contrast to the service response they had been met with.

Jane and Kevin had looked into but rejected Centre-based vocational service delivery for their sons. None of the services Jane had looked at appeared to her to offer Scott or Graham an opportunity to expand upon the set of vocational skills they already had, nor it appeared to them, could they use Scott

or Graham's passions as the medium for further personal growth. In her letter, Jane outlined to the Minister that, *"Scott not only thought about farming and farm machinery from dawn to dusk, he probably dreamed about it too."* For her, the network of people and places Scott was exposed to through the home-based programme they had developed offered him the best opportunity for life-long learning and life quality. *"Taking Scott away (from his community) would be like expecting a trout to live on dry land. I would never let him go into services just to fill a gap,"* she told the Minister. Living with Cohen syndrome also meant that Scott and Graham made frequent calls on others attention and experienced moments of profound anxiety. Jane felt that the Centre-based vocational services available to Scott and Graham were not staffed at a level that would always keep her sons safe and stimulated.

Jane had also explored Workbridge and a Supported Employment Provider as service options for Scott, both of whom assessed Scott as unemployable. *"What attracted me to Workbridge,"* Jane explained, *"was the 'Job Coach.' In addition to developing work based skills, (the promotional literature indicated) Scott would have job related support."* In her enthusiasm Jane compiled a long list of Scott's repertoire of skills, but was informed after a three-week trial that *"(Workbridge) didn't believe Scott would ever be employable and (they) were withdrawing support for him. It was never disclosed (Workbridge) were assessing Scott,"* Jane said. *"Scott and I put in a whole lot of work and they never said there was a criteria. We discovered later that clients needed to be able to be independently employed in one to two years to be eligible. I would have known that (Scott would need ongoing support) but they never asked me."*

Jane had also sought to enrol Scott and Graham in the Work and Community Skills course at their local Polytechnic, only to find it too could find no place for the learning style and restless energy of two men with Cohen syndrome. *"I thought Graham had sufficient skills,"* Jane said. *"He can use a calculator and computer, his speech is developing, he can persevere and stay on-task, he has fine motor skills and he loved the school environment. I thought Polytech would be great for Graham. A chance to mix and learn with his peers but all those dreams were dashed when they turned him away because they felt it was too much responsibility to ensure Graham's safety around campus."* Jane explained that because the Work and Community Skills course was classed as a pre-employment course, Graham was not entitled to the level of support he previously been able to access at school, because the level of support he required, indicated to funders that he would not be employable.

To Jane, therefore, it appeared as if the very institutions established to address the lack of access disabled people had to the worlds of continuing education and meaningful employment had themselves legitimised Scott and Grahams exclusion on the grounds of their impairment. Similarly, whereas many people in the Reporoa community had come to recognise Scott and Graham's latent capacity for work and personal growth, the disability services they had looked to for assistance reflected back an understanding of her sons that accentuated their lack of developmental or employment potential.

Jane said that years later she still felt angry and a deep sense of sadness at the unfairness of Scott and Graham's exclusion, but that she had come to recognise that it may have been a blessing in disguise. *"I came to realise,"* she said, that beyond the straight jacket of a curriculum that paid no heed to her son's passions or capacities *"Scott and Graham's lives were better in the real world, with real life situations to learn and grow from."* As we spoke it became increasingly clear to Jane that a positive consequence of the relative isolation she described experiencing was that that her reading of Scott and Graham had not been contested by professional services or the well-worn path through service provision. Jane said she had no idea how typical or otherwise her situation was and attributed her belief in providing as normal a life as she could for Scott and Graham to the absence of anyone narrowing their horizon of possibility. *"Services have even acknowledged to me that they wished everyone had this life for their kids,"* Jane continued. *"We try to give them normal life,"* she said, *"where they can do their own things. Not doing that wouldn't be a proper expression of life. Of them."*



## Miracle people

Supporting her sons to find a proper expression of themselves had become Jane's life work. Jane said she had only ever had part-time employment and although she had enjoyed working, it was, she confided, too hard to fit everything in. Jane considered making sure Graham and Scott lived rewarding lives to be her work, sublimating the hopes she had held for herself as a young woman. *"I think of it as my job,"* she said, making sure that we understood how seriously she took the role. In more recent times work was impossible because Jane was Scott and Graham's "back-up," when staff couldn't make it and like many parents with disabled sons or daughters, she also filled the gaps that needs assessments and paid support hours never met. It was Jane who helped Graham to organise his holidays and build the repertoire of phrases he would need when he got there. Similarly, it was Jane who supported Graham access the "job," his school had organised for him at the post office. Graham sorted mail at the community post-office on a Monday. It was only for a few hours, but it kept Graham in contact with his community and the feeling that he contributed in a small way to its wellbeing. She had also contacted the bus company down the road to see if Graham could come and clean their buses and it was Jane who found the Youth Group in Rotorua that had filled the social vacuum left after Graham left the community of his school. *"When the boys were younger, Jane said "there were plenty of times I wanted to run away from it all, but a friend once said to me, if your life's purpose keeps getting interrupted, maybe the interruptions are your life's purpose."* From that moment Jane said making Scott and Graham's lives worthwhile, became an understandable life purpose.

As Scott and Graham began their adult lives, Jane had continued her role as their primary source of support. From 1998, Jane had managed Scott and then Graham's support through an individualised funding arrangement into which Scott carried 20 hours that had originally come through a Supported Independent Living contract and Graham added sixteen hours Individualised Funding accessed through Manawanui InCharge. Getting out and into the community was central to Scott and Graham's quality of life. Because Individualised Funding fails to recognise support needs beyond the domains of personal care and domestic assistance Scott and Graham also used part of their benefit to purchase additional staff hours and pay for the petrol they needed to get from town to the farm. Similarly, Supported Independent Living funding could only be accessed if Scott or Graham either moved or were within six months of leaving their family home. *"There is nothing available,"* Jane said, *"to fill the great vacuum left by not having suitable day support services for people with high and complex support needs."*

CCS Disability Action employed Scott's support staff, but in all other respects, Jane found, managed, trained and supported her son's staff to develop and give expression to programmes that were as different as her two boys. Without the inflexibilities of a formal vocational programme, Graham and Scott's *"family of support"* collaborated in ways that permitted them to have an authorial hand over their day-to-day activity. As a consequence, Graham and Scott could be authentically present in their community in so far as their pattern of activity typically fit their passions and any opportunities for serendipitous community connection could be captured and followed up.

Every week was different. Graham's impairment meant that he could not leave home without someone with him and yet, despite only receiving sixteen funded support hours, Graham typically participated in wide array of public and private community spaces. Because of the way his formal and informal support was configured, Graham spent 42 hours embedded in community settings beyond the family home between 8.00am – 9.00pm in the week of 9–15 September, 2012 (Figure 9).

Although Jane's preference was for more opportunities to be found for Graham to add value to his community, Graham voluntarily sorted mail at the Reporoa Traders on a Monday morning and vacuumed the Hospice Store in Rotorua for an hour on a Tuesday supported by his regular staff person, Jason. Graham was also a regular user of his local library, typically to rent DVDs or games for the X-box and he and Jason would visit other civic amenities too, including going to the park to walk Jason's dog or airport to watch planes and people come and go. His week, however, differed from those lived by many disabled people in so far as over three-quarters of the places Graham visited were private social spaces and not the anomic public spaces that disability writers have described as the outer fringes of the

daily round of community life.<sup>6</sup> In contrast to the more public lives of other disabled people, Graham's life space appeared to reflect a prioritising of people over place and a preference for more intimate social spaces as contexts for learning and relationship building. Thoughtful use of support time appeared to Jane to be providing Scott and Graham with opportunities to continue their developmental trajectory or to deepen those relationships that added quality to their lives. *"It's not places or buildings that keep people safe or happy,"* Jane mused, *"it's the care and respect of people,"* and as a consequence, Jane and her family had a very different understanding of the role staff played in the lives of her family.



**Figure 8 At the library**

In writing about her sons, Jane described Scott and Graham as *"two inspirational young men, who have shown many people the true meaning of love and reached out to people in trust and friendship."* Jane included Scott and Graham's staff amongst the many people whose lives they had touched and she and Kevin emulated the more personal understanding Scott and Graham had of their staff by also including them within an extended family of care. *"Cherry, Kathy Andrea and Jason, Vanessa and Phil"* they said, *"were part of our family now."*

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<sup>6</sup> Laws, G. and Radford, J. Place, identity and disability: narratives of intellectually disabled people in Toronto, in Kearns, R. and Gesler, W. (Editors) (1998) **Putting health into place: landscape, identity and wellbeing**. Syracuse. Syracuse University Press

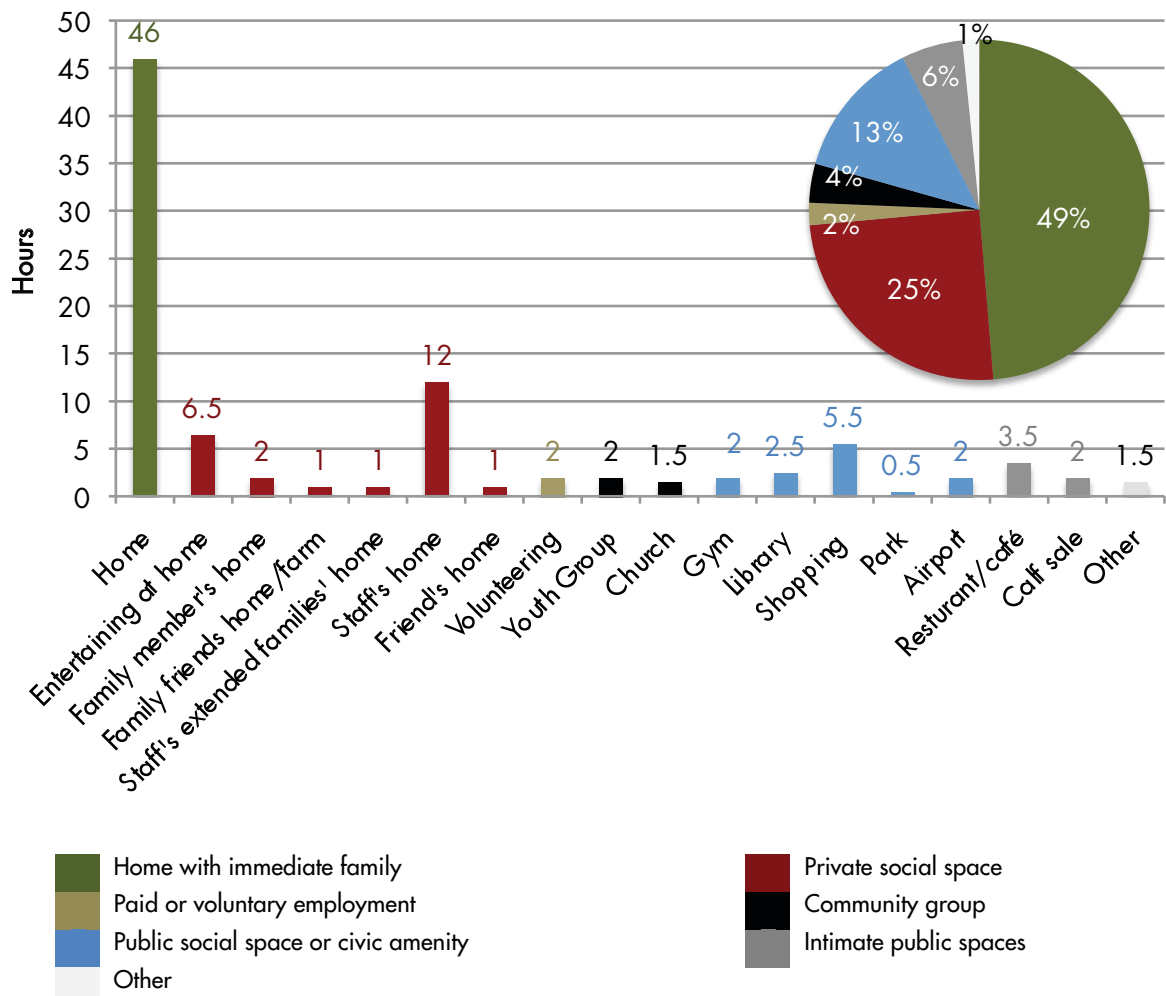
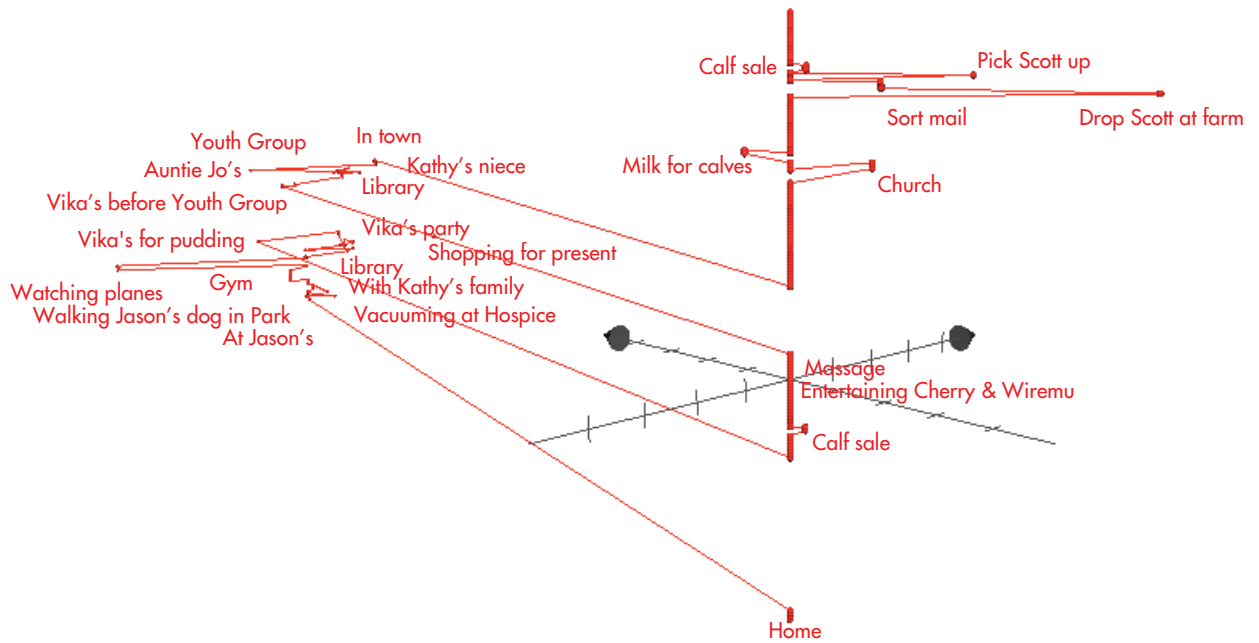


Figure 9 Graham's time in place: 9-15 September, 2012



Although Jane had advertised for staff in the past, Jane had met all of the people who currently worked for Scott and Graham when their paths crossed in what Jane described as *"divine appointments."* Staff like Kathy who Jane said had come into their lives when she was at a low ebb with Scott. In desperation Jane said she had phoned a service provider who told her about a woman who was thinking about moving to Reporoa but was unsure whether to stay. Jane said that when Kathy first decided to come to Reporoa, she had heard the call of a tui from her lounge, which Kathy had been told would be a sign to her that staying was God's purpose. Kathy's story only came to light, however when on their first meeting, Scott had asked Kathy whether *"the tui bird sang where she lived."* *"I think I am meant to work here,"* Kathy told Jane, who subsequently found Kathy a *"lovely little house on a farm where tuis hung off the rose bushes."*

Jane, said Scott and Graham's staff all *"cared very deeply,"* for her sons. *"What you are seeing,"* Jane told us, *"is a very good part of our lives compared to what it has been in the early years with no support. The thing that has made it so different is that we have people helping us. We have found the right people."* To an outsider, *"finding the right people,"* meant finding people who shared a common vision of the support relationship. *"It was important,"* Jane conceded to find *"staff who fit the family culture,"* a culture in which everyone shared a common understanding that the support role had 'life sharing capacity'<sup>7</sup> and could be best delivered within an extended family of care. For Scott and Graham's staff, this meant they had uncontested access to a vocabulary of love. *"The biggest strength of what we are doing here for me as a mother,"* Jane said, *"is watching my children go off with someone that loves, cares and involves them as if they were members of their own family."*

As a consequence of the way their role was read, Scott and Graham's staff also offered them safe points of entry into different communities and community experiences. Previous research has found that the best way for disabled people to become connected (to their community) is to be connected.<sup>8</sup> Without the sharp delineation between staff and clients lives, Scott and Graham, staff provided them with a conduit to a number of communities to which they already belonged, including staff's own families. Andrea, for example, had opened up the landscapes of Taranaki and the loving presence of her daughter's family to Scott and Kathy had included both Scott and Graham within her family too. *"I trust Kathy and her children as part of our collective family network,"* Jane said. *"It's very seamless. One day a week Graham goes into town (Rotorua) and often will stay overnight with Kathy and her family. We respect it if the boys don't want to go because they are the ones determining what they do, but then she comes in here and they are always pleased to see her."* In the week between 9–15 September, Graham spent an evening with Kathy and her family and also visited Kayla, Kathy's niece before going into town and then on to Youth Group.



<sup>7</sup> An expression used by Marquis & Jackson to describe the attributes disabled people said they most valued in their support staff in Marquis, R. and Jackson, R. (2000). Quality of Life and Quality of Service Relationships: the experiences of people with disabilities. **Disability & Society**. 15(3), 411-425.

<sup>8</sup> Milner P. & Bray A. (2004) **Community Participation: People with disabilities finding their place. Report on the CCS Community Participation Project.** Wellington. CCS.

**Figure 10 Graham and Jason and Cherry, Wiremu and Angel leaving the farm**

In addition to returning their love and respect, Scott and Graham were reciprocally safe points of entry for staff into the community of their own family with the family home offering both young men an opportunity to return staff's hospitality. The boundaries between formal and informal support often blurred as organised activity drifted into lunch or tea with the family, or Graham would shoot hoops on the driveway with Cherry's grandchildren Wiremu and Angel and Scott made use of Angel's vision to get to the calf sale on the pretext of making sure she didn't miss the trucks. Family celebrations were also not complete without the presence of the people with whom they shared much of their lives, so Cherry, Angel and Wiremu all came to Graham's 21<sup>st</sup> birthday. Graham's love of flags had themed the evening with many of his family and friends arriving in national costume, adding additional colour to a party that culminated in Cherry and her family joining the heraldry of a flag march around the back lawn on an icy April evening. Scott and Graham were, in turn, invited to Cherry's 50<sup>th</sup>, a party at which one of Cherry's friends had told her that he had been about to buy a new Massey Ferguson tractor for his farm until talking to that fellow over there, (pointing to Scott) who had convinced him that he should be buying a John Deere instead followed by a considered comparison of the two tractors relative merits.

Jane said she had always felt a deep disquiet about the language of service provision and especially descriptors like "client," and "service user." The nomenclature was not a form of social knowing that had any meaning to Scott and Graham, their staff nor the community about them. "Angel and Wiremu," Jane said "have only ever known 'Scott,' and 'Graham.'"



**Figure 11 Cutting the cake and Graham's 'South African' friends from Youth Group who came to Graham's 21st**

Having stepped into the inner circle of their lives, Graham and Scott's staff appeared to be stakeholders in their wellbeing, bringing ideas from their own lives to enhance the quality of Scott and Graham's. Ideas like the exchange of self-made DVDs that passed between Scott and Wiremu that had prompted Jane to explore the potential of film-making as a possible avenue to meaningful employment. "The feeling of gratitude to staff is overwhelming," Jane said. "They all give a bit of their lives. Seeing the difference in Scott – it's enormous. God bless them. They are miracle people." Jane recognised, however, that change was often bi-directional and that Scott and Graham had a ministry of their own. Jane didn't believe in coincidence. She said she had come to see that staff may also have been brought to Scott and Graham to learn more about themselves and to grow as people. "So we treat the people who work for us like family<sup>9</sup>. We work through problems and, like Scott and Graham, see the joy of their lives turning around too."

## Why don't you come to my place?

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<sup>9</sup> Italian and a number of Kopapa Maori service providers also use 'family' as the template for disability support. For a more comprehensive discussion see Carnaby, S. (1998) Reflections on Social Integration for People with Learning Disabilities: Does Interdependence have a Role? **Journal of Intellectual and Developmental Disability Research**, 23(3), 219-228.

Such was their level of closeness, Graham and his mum both numbered staff as belonging within the circle of Graham's most intimate social relationships. Also named as 'very close' were a handful of school friends, most of whom Graham met serendipitously now rather than purposefully. Chris was the only person that Jane said still "voluntarily called in now and then."



**Figure 12 Graham's friendship field**

There was Vika too. Vika had introduced herself to Jane at the gym. She was training for a Special Olympics event and had started chatting to Jane while she stood at a treadmill with Graham. "Vika was," Jane said, "more friendly than you would expect of other people," and Jane and Graham both warmed to her. "Within a week of meeting Vika," Jane went on to explain, "she had joined Graham on one of his Auckland holidays," and since then Vika had joined Graham and Jane on a couple of their trips to Auckland. She had also twice accompanied Graham as his partner to the Reporoa College ball. Vika was, according to Jane, "perhaps Graham's only true friend" and whilst she suspected their relationship might change with time, for the moment their lives and life interests intersected in ways that cemented their friendship. Like Graham's staff, Vika had also "become part of the family now. And Vika saw it that way too," Jane added.

Whereas many disabled people's relationships are often context bound, Graham and Vika's friendship tended to be transacted in multiple rather than single social settings, including the private social spaces of each others homes. Vika would often come to the farm and Graham frequently popped in to see Vika. In the week between 9 – 15 September, for example, Graham went to the Lonestar with Vika's family and friends to celebrate her birthday before going back to Vika's place for cake and coffee. They met at the gym and on Friday night, Auntie Jo dropped Graham off at Vika's before they both went together to Youth Group in Rotorua.

Graham belonged to two faith-based communities, his Youth Group and the Reporoa community church congregation, which he attended most weeks. Beyond Graham's family and their network of family friends, the Youth Group and church were amongst a small number of community settings that offered Graham a genuine opportunity to forge new, adult relationships. "The first time Graham went," Jane said of his Youth Group, "he couldn't speak and everyone was a little perplexed as to why he was standing so close or shaking their hand, but over time, he has become one of the



crowd.” Jane added, however that although the young people who went were really friendly towards Graham and Vika, she felt Graham did not consider himself to be close to any members of his Youth Group. They were “more acquaintances,” she said “that he hung out with at Youth Group and would have a chat with if he bumped into them on the street. The time they spend with Graham outside of Youth Group is minimal - nothing really. They don’t,” Jane went on to explain, “ever say to Graham, why don’t you come to my place.”

Scott and Graham were different in so far as Jane considered Scott to be a more independently minded person, fulfilled by his own interests. Scott, she felt, enjoyed people because they affirmed and expanded his interests, but “friendship,” Jane said “wasn’t such a big deal.” Graham on the other hand “prayed to have a close friend.” Jane was hopeful that by sharing social history, the friendliness Graham experienced at Youth Group might one day grow into genuine friendship. To help seed the process, Graham had invited his friends from his Youth Group to his 21<sup>st</sup> and they had come, contributing to the colourful League of Nations, just as many had also come to visit Graham on the farm following Jane’s invitation. Mindful of Graham’s longing for friendship, Jane said he was getting to know two of the young people who went to their church too. “Those relationships,” she mused “have potential.”



**Figure 13 Friends from the Youth Group visit Graham at the farm**

## **A work in progress**

Jane had a mothers knowing that it was the sense of being connected to the community through relationship that represented the very heartland of life quality for Graham<sup>10</sup> and that, whilst the landscapes of Reporoa had assumed importance as the arenas within which the deepening of relationship and social knowing had historically occurred, Graham’s ‘colonisation of other people’s informal lives<sup>11</sup>’ would be important if he was to continue feeling “of” and not simply “in” his community. As a consequence, Jane emphasized the importance of providing opportunities for Graham to seed or sustain existing relationships as a preeminent goal of support, seeing herself and Graham’s staff, not as connectors to place, but to people. When Jane rode buses, for example, she did so with a heightened awareness of the people and conversations that sprung up about her and her sons. She took strangers to Auckland for holidays within weeks of meeting them, kept addresses to follow the sometimes casual invitations of people they meet by divine appointment and unconsciously interrogated the potential for new relationship in almost all of the places Graham was present in his community, sometimes with great dividend.

In 2009 Graham told Jane that, unlike the year before when he had gone alone, this year he wanted to take a partner to the school ball. The ball was the highlight of the Reporoa College year but “Graham

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<sup>10</sup> Cummins and Lau (2004) cited in Milner P. & Kelly. B (2010). Community participation and inclusion: people with disabilities defining their place. *Disability & Society* 14(1), 47-62 used the expression the ‘heartland’ of life quality, to describe the sense of community connectedness through relationship.

<sup>11</sup> Furedi (2004) cited in Milner P. & Kelly. B (2010). Community participation and inclusion: people with disabilities defining their place. *Disability & Society* 14(1), 47-62

found that none of the girls that went to his school from Reporoa wanted to go with him." As time went by Jane and Graham grew increasingly resigned to his not being able to take a partner, especially as Jane and Kevin were leaving for Denmark the week before the ball. On the day that they were to leave, Jane kept Graham home. "We had a day in town," Jane recalled "and when went to get Graham's glasses from the optometrist, Graham told one of the receptionists about the ball. She instinctively replied, 'Oh Graham! Take me with you.'" Graham took her seriously and as the significance to Graham of his being able to take a partner to the ball became increasingly clear, the other receptionist told a disbelieving Jane that her daughter Holly would go with Graham and, "while I was away," Jane said, "Holly set it up with the staff who were caring for him and he achieved his dream of taking a beautiful young woman to the ball."



**Figure 14 Dancing at the school ball and relaxing with Holly**

Jane knew she had adult sons and that living at home with their parents would not always be the ordinary expression of life she sought for them. "I've had people tell me that you've done your job now. The boys are grown up. It's time to let go and put them into a place. I have listened to those people with a mother's instinct and I don't believe Graham and Scott are quite ready. We haven't finished what we can teach them yet. All the little failures in the system we have encountered along the way have turned me into a stronger person, able to trust my intuition. Jane said, "But I have often posed myself the question; will I ever be able to trust enough to let go?" "I am a work in progress," she said.

Finding support contexts willing or able to replicate the commitment Jane had to forging social connection was one of Jane's concerns. Her other worry was that beyond the ambit of parental love and expectation, they would have to surrender the larger vision Scott and Graham had for their lives. Of all the missteps and misdiagnoses that had occurred, the unwillingness of the local Polytech to enrol Scott or Graham and the failure of adult services to adopt a longer timeframe or brighter hope for their sons, had most undermined the trust Jane and Kevin required to overcome the gravitational hold of family love. Jane said that in the past five years her sons had flourished, with the cascade of growing competence, maturity and effective communication attributed to "the boy's" staff and the ethos of support that had developed about Scott and Graham. It was, she said, the very antithesis of what she had seen in vocational services and a stark counter-narrative to the absence of expectation with which they were met by adult disability support services. "If they could not find space for young people with such potential," Jane said of their exclusion from Polytech, "what hope."

Jane's determination to maintain the developmental trajectory of her sons was, however, rooted in her knowledge of the tenacity with which Scott and Graham had fought to overcome obstacles to their learning. Jane said there were many times she had felt like giving up, but her witness to the length of the journey that Scott and Graham had already taken was insight not immediately transparent to others that they met along the way.

When the boys were young, Jane said she and Kevin received almost no professional help. As a parent of profoundly disabled children, "you tread a lonely life," Jane said. "There was no manual or handbook and you can't go to friends as ask, how do I deal with this? What did you do with your kids, because there is no one to ask." There was the physical and often social isolation to deal

with too. *"It was a tricky time,"* Jane said. *"People couldn't tolerate the boys' atypical behaviour."* Scott would scream all the time and both boys carried with them the anxieties and behaviours of children frustrated by not hearing or being understood well. *"There were so many people I couldn't visit when the boys were little. Even my own family were so stressed it was easier not to visit them"* Jane said. *I couldn't relax. I would sit on the edge of the chair ready to jump in and would only ever pop in for a cup of tea, even to my mothers."*

Oases of progress were separated by long periods of inertia and seemingly fruitless effort. *"For years and years,"* Jane said, *"it was just putting one foot in front of another, literally. Every morning we woke and went through the motions of looking after disabled children. There was no joy because they weren't progressing and everything was so repetitive - all day long - everyday."* Jane said she had also had to battle the sadnesses that visit the parents of children who never seem to get to the milestones her friend's children regularly reward their parents by passing. *"Grief has a big part to play,"* Jane said. *"For me it was a seven year process that happened twice."*

Our conversation had, in part, been occasioned by a photograph of her two boys, sitting on the trampoline that used to be out the back of the old farmhouse. Graham was sitting off to the side while Scott leaned against the family dog about which the photograph had been composed. The dog had been a Christmas present to Scott. *"It was hard,"* Jane recalled, *"to find presents for Scott. All he wanted was a tractor. He never played with toys."* Jane explained that at the time Scott couldn't throw. *"He couldn't do so much,"* she said *"but we thought having a dog might give him an incentive."* When Jane phoned the SPCA to see if they had a dog, they told her that they had a beautiful two-year old Labrador, but that they had already turned down a couple of people who had wanted her. *"After explaining our circumstances, they said, ah. I think you had better come down. At that time,"*



Jane said she was feeling *"very much a failure as a mother. You can't measure progress by normal milestones and you live with the constant feeling of failure. The fact that the SPCA chose us and thought that we were the ideal family for that beautiful dog was just so wonderful. And she was just wonderful. She was like my guardian Angel."*

**Figure 15 Scott, Graham and Bessie**

Like the parents of many children with high and complex support needs, Jane and Kevin said the stresses and isolation of parenting had taken them to their breaking point.<sup>12</sup> *"We got to the place,"* Jane said, *"where we both wanted to walk out on each other, and then we realised the real problem was the kids and we couldn't walk out on the kids."* On reflection, Jane and Kevin told us that their darkest hour had also been an important turning point *"We couldn't send them back,"* Kevin chipped in. *"We realised we were both in this together."*

Jane said, when that when Graham turned seven, her grief lifted. Although she never made the connection herself, it is possible that the personal metamorphosis she described from *"a shy, reserved person who conformed to everyone's expectations,"* to a person *"who trusted her intuition and was slow to give up,"* may have underscored her new-found resolve. In the fourteen years that had elapsed, Jane had become an accomplished reader of her son's and had identified and responded to the

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<sup>12</sup> In their survey of parents who acted in a primary support role to children or adults with high and complex support needs, Mencap reported 80 percent of parents described having reached 'breaking point' as a result of not getting the help and support they needed.

Mencap. (2001). **No ordinary life: the support needs of families caring for children and adults with profound and multiple learning disabilities.** London. Royal Society for Mentally Handicapped Children and Adults.



myriad of impairments that were Scott and Graham's embodied reality. *"Just about every professional that gave me advice,"* Jane said, *"also let me down. I don't hold this against them,"* she said. *"I just came to the point where I realised that my instinct as a mother was as powerful as their knowledge as a professional."*

Scott, Jane said, was ten before anyone could understand him and Graham, effectively mute until the age of 17. The fact that Scott and Graham both now speak is testament to the countless hours Jane invested to gift them words. Jane taught herself and her sons to sign and had used pictures and symbols to support their language acquisition. Her efforts continue to this day. Scott and Jane are now using story telling to promote creative self-expression and more effective communication. It was, however, Jane's discovery that her sons didn't hear the same way other people did that she identified as one of their most important watershed moments.

Much like many other life changing moments, Jane's epiphany began with a conversation. Scott and Graham, Jane said, didn't respond to verbal instructions and, in the early days, would often take off unpredictably so she had her *"radar going all the time."* When the boys were small she took them for a swim at the hot pools at Mount Manganui, and was surprised when the woman next to her kept reassuring Jane that *"Graham was there"* and *"Scott was over there,"* whenever her anxiety surfaced. *"It kept happening,"* Jane said and in the conversation that followed Jane learnt that the woman had children with impairments too and that they had used auditory integration therapy with some success. Jane said she was sceptical and the course was expensive, but that she felt compelled to investigate. *"If I don't try it,"* she thought, *"I will never forgive myself if I find out in twenty years that it would have made a difference."* *"I decided to quiz Mike McCarthy like no-one else,"* Jane said, *"and if I trust him on the basis of his replies, then I would be prepared to take a risk."*

*"Graham had had his ears tested when he was at the hospital and they said he could hear, but what we discovered from Mike McCarthy,"* Jane said, *"was that Graham was getting conflicting messages from both ears which would shut the message off in his brain."* Jane explained that the process took ten days, during which Graham would listen to sounds, twice a day for 30 minutes and that process gradually reintegrated the auditory information he received in both ears. *"He had always hated sound,"* Jane said. *"I used to play the piano, but I stopped because Graham couldn't stand it. He always used to turn the car radio off too but about half way through the therapy, Scott, who was sitting in the front seat turned the radio on but when Graham went to climb over to turn it off, just like he always done, he suddenly stopped and listened."* A short time afterwards, Jane said she had called down the school corridor for Graham to pick up his bag only to watch him stoop, pick it up and hang it on its assigned hook. *"It was "the first time he had followed a verbal instruction,"* Jane said, recalling the event, *"and it was like a whole new world had just opened up. He could learn through hearing,"* Graham was twelve<sup>13</sup>.



**Figure 16 Graham receiving auditory reintegration therapy from Mike McCarthy**

Jane discovered Scott's visual impairment incidentally too. Like Graham's hearing, Jane had taken Scott for eye tests but said she was repeatedly told that *"until he could talk and know letters or symbols well enough to read a chart, they would just have to keep coming back."* *"When Scott was little,"* Jane explained, *"I made a board of his favourite things and hung it on his wall. He never noticed them or commented on them and I just put that down to Scott. It never occurred to me that he wasn't seeing until we were renovating the house and I took the board down and put it in the hall so that we could paper his room."* When the board was at the edge of his vision, *"Scott went*

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<sup>13</sup> Jane said that eleven years later, Graham was the family DJ and continued to be absorbed by music.

*straight to it and suddenly started pointing to everything. He was only making sounds, but I knew he was naming them. It was the first time I was sure he couldn't see properly."* Scott was six<sup>14</sup>.

## **Oh Graham – Come on in**

Between the moments of great discovery, however, was the more pedestrian progress towards building a vocabulary for Scott and Graham. When they eventually came, words had to be deconstructed and endlessly rehearsed so Scott and Graham could turn their thoughts into recognisable sounds and sounds transformed into shared meanings in a process that carries on to this day.

*"Au gust. Not busy."* Graham repeats following Jane's quiet prompting for him to break each month into its constituent syllables, *"Oc to ber. Very busy!"*

*"Graham's language development has been critical to the way people interact with him,"* Jane told us. *"Even three years ago people related to Graham quite paternalistically. Today,"* Jane said, *"it's totally different. If I could just squeeze out a bit more they might say, Oh Graham – Come on in."*

Over the course of their lives, Jane had worked hard to smooth Scott and Graham's passage towards personally rewarding relationships in other ways too. Recognising that having an awareness of the social conventions of their community were as important as other forms of shared meaning, Jane had worked hard to build and reinforce a social vocabulary too. When the boys were young Jane had had to work hard to curb the inappropriate grabbing, noises and outbursts that were the outward expressions of Scott and Graham's anxiety or frustration. She had patiently taught Scott to look people in the eye and hold their gaze, and had provided her sons with the hugs and handshakes they now used to draw a community about themselves.

Without seeming to be conscious of doing so, Jane's interaction with Scott and Graham was punctuated with her efforts to improve their listening and conversational turn taking. Her task wasn't easy. In our time together, the sound-scape of the farmhouse filled with Scott and Graham's need to generate activity and seek reassurance that their day would play out the way they anticipated. Both men shadowed Jane, eager to call to attention their passions. *"It can be very intense,"* Jane confided. *"It's just the way they are. They both take all your focus to understand."* As tiring as it was, Jane would have it no other way. *"These boys have waited their whole life to speak,"* she said. *"Their words are precious."*

As our conversation continued, Jane said that she thought one of the important differences for Scott and Graham was *"that I have made sure that I have had the time."* Even though it was only for a couple of days a week, Jane said that when she had worked part-time, Scott and Graham had suffered. *"It was,"* she said, *"too much for our family."* Jane's constant presence had provided Scott and Graham with the responsively attentive communication partner they needed to begin to speak, but *"having time,"* meant more than that. It had also, Jane felt, provided Scott and Graham with the space they needed to declare troubles as-well-as the hopes they harboured. In return I told Jane I had once heard disability writer John O'Brien say of support relationships that, *"nothing of any real consequence happens in productive time. It only ever happens,"* he said, *"in the time you waste together."*

Since Scott and Graham had left school, Jane explained that she had *"taken on the role of service provider to stretch what was possible for Scott and Graham with the funding they had available."* To this point, whenever she had posed the question *"was it time for her to trust enough to*

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<sup>14</sup> Scott's has a reduced field of vision and retinitis pigmentosa, which, in dull or bright light limits the vision he has in his one working eye. His glasses also correct for myopia. Jane said that when she questioned whether it was normal for Scott to sit so close to the television she was told that it was *"quite normal for children with disabilities. Lots of them do it."*

*let go?"* she had been able to satisfy herself that the family home was the best place for her sons. On the one hand, Scott and Graham were still young enough that their family home remained a culturally normative social setting and on the other, living at home provided them with a quality of life Jane felt would be difficult for existing disability support services to replicate. Her question, however, would not go away and as Scott and Graham grew to men, the calculus would continue to shift.

For Scott and Graham, moving from the family home could eventually mean moving beyond the physical and social landscapes that told them who they were. It could also mean moving from the parental love and aspiration that had helped embed them so deeply within the Reporoa community. The stakes were high. Without the ability to tell their story, Jane and Kevin worried that the types of activities that gave their sons joy and the accomplishments that buttressed their sense of self worth might be invisible to providers or need constant re-telling with the exits and entrances of new support staff. What Kevin and Jane were looking for was the support of professionals who also recognised the promise in the two remarkable boys they had nurtured to manhood.

For Scott, Kevin's mind kept returning to 30-40 acres of land upon which he thought Scott could be supported to rear cattle and continue to chinwag with the stock agents who lingered after a successful sale at the yards. Jane, on the other hand thought Scott would like to own his own tractor and machinery and with the right support contract in much the same way as they had begun to explore with the lawn mowing enterprise. For Graham, Jane imagined something more urbane where Graham worked and celebrated his life with friends who shared his love of "big cities" and being a "very busy man."

Echoing a previous generation of parents who sixty years before had established New Zealand's first community-based vocational and then residential services<sup>15</sup>, Jane saw promise in the collaboration of like-minded families. *"Having to depend on a national organisation just isn't normal."* She felt what was needed were clusters of *"four to five families with a similar vision of what might be possible."* Jane didn't reject partnering established services. In truth she had sought the collaboration for all of Scott and Graham's lives, but the stark alternatives she perceived following her investigation of residential support options for Scott and Graham had fallen well short of Jane's vision of a normal life for her sons. Jane felt she currently had three equally unacceptable options open to her. *"Residential care where families stop being able to make a significant contribution to their sons or daughter's lives, Supported Independent Living which assumed levels of independence Scott or Graham would never approximate and Individualised Funding which has no capacity to fund the overnight care they need nor the activities that sustain their life quality."*

Jane repeatedly returned to the contrast she saw between the support Scott and Graham had received to prepare them to take their rightful place in the community while they were at school and the support that was available to them as they sought to fulfil that promise as adult members of society. *"In much the same way as teacher aide hours eventually became personalised and linked to the child's individualised learning needs,"* Jane said, *"the same quantum leap needs to be made in residential support. A care support package that was built about a person and not a provider would open up a myriad of creative options, allowing groups of like-minded families to work together to set up long-term, satisfying, productive partnerships between themselves and services."*

*"I can't see how to achieve all this right now, so I guess it's not supposed to happen yet,"* Jane concluded, embracing her second eldest son. *"When things are meant to happen, I find they tend to happen easy."*



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<sup>15</sup> Frustrated by their fruitless search for alternatives to institutional placement for their son, Margaret and Harold Anyon embarked on a campaign to establish an occupational centre for people with intellectual disability in Wellington. The campaign led to the formation of the Intellectually Handicapped Children's Parent's Association (later IHC and then IDEA), the establishment of the first non-voluntary community day service in 1953 and articulation of the goal to replace large State institutions with "cottage" homes.



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