

# Full of beans

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



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TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

# Richard Beale

## Game Lad out of Robyn

Richard Beale was born and grew up in Hilderthorpe, a small rural community, a few kilometres on from the Pukeuri Freezing Works, north of Oamaru. When Richard was born, it was mostly sheep farming that kept the works busy, but these days almost everyone has converted to cattle, peppering a landscape of straight lines and hard edges with new cow sheds.



Richard is the only son of Ramon and Maureen Beale. Ramon grew up in Balclutha. His family bred and trained horses and Ramon has carried the family tradition into its third generation. Maureen grew up in Hilderthorpe on the family farm Richard still calls "home." They met, according to Maureen, *"as teenagers and have been cobbles ever since."*

Richard and his parents moved into their present home about thirty years ago when the "Old House," behind the macrocarpa hedge at the end of the Hilderthorpe Road started to *"tumble down."* At the head of the driveway, a painted plate alerts those unfamiliar to the area that Richard belongs to this place. At the other end of the driveway is a wide turning circle that countless vans have looped over the years, carrying Richard to and from Hilderthorpe.

The path that takes you up to the house is just a short wheelchair push to the left. It winds its way up through one of Maureen's summer gardens and on past the lounge window where Ramon can sometimes be caught reading the paper in a favourite chair. The balcony is framed by grapes and ivy and points north-west, where, in a gap in the hedge, you catch sight of the paddocks beyond and a now empty line of weather beaten chicken sheds. Richard's grandmother raised poultry and Maureen, who *"loved the chooks,"* continued the business until her arthritis meant she had to give it up. Richard's grandmother painted too and the chooks often featured as subjects. An oil painting of one of their Brown Shaver hens hangs above Richard's Hilderthorpe bed. Maureen remembers Richard helping with the chickens, in much the same way as he would *"motor with (her) away down to the stables."*



Pet Day

At the end of Hilderthorpe Road, the water race and road both take a 90-degree turn. The stables are a little further on. A week of rain and the horse float's constant coming and going has turned the entrance into a bit of bog. The Hino truck is parked up there beside one of a number of van carcasses that have been put out to pasture on the farm. A few horses graze in the paddock in front of the stables that Ramon lends to farmers to shelter their calves and beyond that is the two mile track that Richard would sometimes fly around with dad hanging on to him at the front of the sulky.

Richard used to motor by himself down to the stables to watch the horses or to meet some of the cattle farmers, but these days the road has become too busy and Maureen likes to go with him.

Horses have played a central role in both Ramon and Richard's lives, each with their own individual personality and many, like Hanover Far and Posh Nosh, Jed and Fast Around Town, or Lively Rose and Naughty Lynn did well on well on the track too. All of the horses they raised and trained share a common lineage. Hanging in the hallway as you enter is a framed photo of Game Lad in full stride. *"He ran,"* Ramon told me, *"in the World Cup at Yonkers and won two of his heats. We all listened to the final on the radio - it was a big thing in those days. He led all the way and finished fifth and I thought to myself, well that wasn't a bad run I suppose, and then it came back; nose, nose, nose, nose, so he wasn't far away".* Game Lad nearly never ran. Ramon had got him from a friend down in Lawrence. *"He wasn't getting on*

*good with him and he had a an accident on the track and was blind in one eye. He said he was going to take him to the dog tucker man so I told him I would like to have a go with him. When I brought him home Maureen said to me, what did you bring that thing home for? He's lame. He took a bit to get going. I used to long rein him in the old plough paddock. After he won the Kaikoura Cup I went back and bought the mare. She had fourteen foals for ten winners. All of our family came from her. Her name was Robyn."*

"Horses," Maureen tells me, *"have in the past made up for Richard's lack of siblings. They are our family because we have raised them from babies. Richard regards them as siblings. They know him,"* she tells me, *"and they are very gentle. Other horses are very nervous of Richard's wheelchair because they are not used to it. Our horses aren't used to little kids running around."*

Of all of Robyn's progeny, Richard's favourite is So Green. It is apparent to others too that theirs is a special bond. As a way of making it clear to me, Richard's support worker recalled going out with Richard to visit So Green. She had been away in Christchurch for a year and Richard's dad had asked him if he would like to go out to see her soon after she returned. *"We parked in front of the paddock,"* she said, *"and So Green came straight over to Richard and mouthed his face so gently. They were saying hello."*

Maureen describes her family as *"a racing family,"* and for years they would follow their horses all over the South Island. Maureen still takes Richard to the Oamaru racecourse, for trials and they all go to the occasional racing meeting, although now they tend only to travel as far south as the Waikouiti and as far north as the Waimate tracks. Maureen and Ramon have always assumed it was their role to keep Richard embedded in the colourful world of horse racing and, she said, *"at seventy it got terribly tiring for mum and too dangerous for Richard to be with dad."*



Looking north-west, past the chicken sheds



A racing family

Whether he travels or not, Richard still follows the fortunes of his own 'family' as well as the progress of other horses he has come to know through family friends from the Oamaru racing community. Friends like Colin and Ross and Daureen who Maureen described as Richard's "surrogate grandparents." Inside the front cover of the Richard's communication diary is a racing calendar and instructions on how to tune the radio to the horse racing channel and when he goes home in the weekend, he often has a shandy and crushed chips while he and his dad watch the races or the rugby.

Richard's affinity for horses appears, however, to go beyond the familial or the colour of the track. According to Maureen, following their horses provided Richard lessons about winning and losing that have informed his world view, and whilst they are fleet of foot in a way that Richard is not, communicating with horses requires a particular attentiveness to the subtlest of body cues and other modalities of non-verbal communication – an attentiveness that Richard and his family have come to depend upon.

Richard is forty. He was born in Oamaru but transferred to Queen Mary in Dunedin soon after, because "even though he went full term he was terribly underweight." The doctors had originally told Maureen and Ramon that Richard would "probably be brain damaged because of his very low blood sugar," but Richard appeared to thrive. "Dad and I thought we were in the clear," Maureen recalled, "because he was so bright, and he had super, super hearing," but then he didn't start to meet physical milestones. Richard today has limited control over his limbs and has poor vision, but, Maureen asserts, it has been the way Richard's cerebral palsy has limited his vocabulary to all but handful of easily discernable sounds that has had the biggest impact on his life. "He couldn't have his ordinary speech," she told me, "and that is the biggest disability of all! If he had had his ordinary speech Richard would have gone to university and done all the usual things."

Maureen described Richard's childhood as often traumatic. "His body didn't work at all. He had no way to stop himself from falling" It was also difficult for Maureen and Ramon, who were busy "informing themselves about motor skill development" and coping with Richard's cares as well attending to the farm work. The sense of isolation they felt was further compounded when the Hilderthorpe School could not take Richard, distancing them from their local community and Richard from neighbourhood peers. "Richard had six to eight cousins from all about as friends"



Watching training at the Oamaru track

Maureen said *"but we never felt totally included, because of our situation."* *"We were stretched to the limit."* It was however, Richard's resolute determination to make his intelligence transparent that Maureen described as leading to a personal epiphany.

As we sat drinking thermos tea from the back of the van while Ramon and a trainer trialled three of their trotters, Maureen remembered that *"I had had a very bad day one day. I thought this little fellow, always bottom of the pile and then I thought, no! It's what sits on his shoulders – his intellect,"* gesturing to Richard, *"And we went from there."*

## **"All disabled people should have a mum like Richard's"**

Maureen says of herself that, despite Richard having moved out of the family home ten years ago, she and Richard, both exercise a controlling hand over Richard's support. For their part, the disability support services that Richard uses also acknowledge Maureen as Richard's greatest advocate. *"All people with a disability should have a mum like Richard's, they tell me. "She is a real driving force and if things aren't going well for Richard, she always gets to the bottom of it."*

For forty years Maureen has watched, read, reflected and fought to improve Richard's quality of life. *"Disabled lives are extraordinary lives,"* she tells me, *"in the sense that an extraordinary effort needs to go in,"* and over time Maureen has become an expert educator, physiotherapist, nutritionist and communicator. Given the difficulty Richard can have communicating complex needs and aspirations, Maureen has always viewed the roles of advocate and exemplar as extremely important and her energy for them has wavered little since Richard left home. *"Wednesday is my day off,"* she tells me.



Oamaru North School (1980): Richard right front

Being prevented from enrolling Richard at the local school a block from the farm Maureen said was one of the events that had galvanised a lifetime of advocacy. Richard was instead required to attend special units at Middle and later North Schools in Oamaru. Up until the age of seven or eight Maureen had home schooled Richard by adapting the Correspondence School curriculum. At the moment of entering school however, both Richard and his mum were forced to confront a very different social construction of Richard and his capacity to learn. *"We couldn't get him into mainstream classes. All the disabled children were in just one room, all gathered together,"*

Maureen said and so his classmates and his learning were tailored to people with intellectual disabilities. *"We thought we had a genius, and all (the educational psychologist) could see was a child that couldn't sit, struggled to swallow and dribbled. It could be awful for Richard. At times I would pick him up from school and he would cry all the way home. I'd just let him go. It's lonely with only your mum to communicate with but at school Richard would get frustrated because he couldn't make himself understood or experienced other forms of exclusion. It would take him all night to be able to say what had gone wrong – but he would persist,"* Maureen remembered.

In 1987 St Kevin's High School decided to take disabled students. Both Richard and his mum described St Kevin's as a "godsend." "It allowed Richard to mix with other people and the school bent over backwards to include Richard. It was the first time he had experienced no discrimination." Richard "belonged" to White House," he competed in the school cross-country in his manual chair, went to the school formal "in all his glory," and added his one note to the school choir. "I could hardly sit on my hands at his first performance," Maureen added, "to see him accepted. I was so excited!"

Richard stayed at St Kevin's until he was compulsorily required to leave at twenty-one. Despite his strong motivation, Richard has not had any opportunity to continue his education. Almost all of Richard's subsequent learning has been self-generated. From an early age Richard enjoyed talking books. Maureen described them as invaluable.



St Kevin's College (1992)



St Kevin's College formal

*"At home he would talk all day if he had the energy. That's where the books came in handy." The book could also be a welcome refuge for Richard, as disappearing outside or into his room with a book still represents one of the few chances Richard has to escape the human service world. But it has been the capacity of books to "fill the gaps in his life," that staff say Richard values most. "Richard is a walking encyclopaedia. If you look in the library at the talking books or magazines, they will have RB in the back of all of them. He gets all of his learning from books"*

*Interviewer: People describe you Richard as keen to learn?*

*Richard: Yes.*

*Interviewer: Do you get many opportunities to learn?*

*Richard: (No.*

*Interviewer: I guess your books?*

*Richard: Yes.*

*Interviewer: And so nothing since school? Not polytech or distance learning or...*

*Richard: No.*

*Interviewer: Would you have liked to?*

*Richard: Yes.*

*Interviewer: And what about work. Would you have liked to work?*

*Richard: No.*

Twelve years ago Richard moved out of his home at Hilderthorpe and into a community group home. Richard's grandparents had become unwell and Maureen devoted a considerable amount of time to their care, especially after Richard's grandfather moved into the family home. In the end, *"mum got asthma, did she,"* Maureen recounted to Richard, *"which is itself stress related,"* she added quickly, appearing to indicate that it was more than her inability to lift Richard that had led to her and Ramon to seek a more permanent living arrangement. Richard had been spending 2-3 nights a week at another group home, but in 1999, when the same provider was able to offer Richard a room that he didn't have to share, the decision was made to shift.



Returning books

Given his physical support needs, Richard's new home was the only appropriate residential placement the family saw as available to him. His house is the antithesis of Hilderthorpe. Behind the gate, locked to the street for (other) resident safety, is a purpose built home with a wet area bathroom and wide passageways, (not the skinny halls that mean Richard has to walk to and from his bedroom), an adjustable bed, (not the water bed Richard refuses to surrender at Hilderthorpe), and two staff, hoists and other lifting equipment (not Ramon or Maureen and the lifters belt she almost always carries with her). Because an intellectual disability service provider was the only residential service Richard and his family felt could provide the physical support he needed, Richard lives with four non-verbal, intellectually impaired flatmates.

*Interviewer: What do you like about living here? Is it your flatmates*

*Richard: Yes.*

*Interviewer: Is it the cooking?*

*Richard: (laughs) No.*

*Interviewer: Do you feel you had a choice about living here?*

*Richard: [Pause]*

*Staff: Richard may not want to answer. Do you have an answer Richard?*

*Interviewer: Have you ever thought of not living here?*

*Richard: No.*

*Interviewer: You were really quick to say that. Here is the ideal place for you?*

*Richard: Yes.*

*Interviewer: Have I got it right that you didn't know what other options were available?*

*Richard: Yes.*

To Richard, his staff and the people he lives with are assimilated within an extended field of care and he describes them as *"like family."* Richard also asserts with conviction that he is living where he wants and dispels any notion that the transition from Hilderthorpe to his present home was in any way a difficult adjustment<sup>1</sup>.

Richard is, however, both extrovert and gregarious. His staff describe him as someone who *"draws energy from people and particularly from conversation,"* and that without it *"he droops."* They worry, therefore, that the lack of interaction between Richard and the people he lives with denies him access to his elemental self and suggest that the satisfaction Richard expresses with his living situation may be reflective of other personal traits, like the patience and accommodation that are also so elementally Richard.

<sup>1</sup> Richard does not name his flatmates as friends in his friendship field.

Hilderthorpe and the community group home are different in other ways too and the distinction between the two settings is clearly articulated by Richard. Within Richards limited lexicon, "over there," is used interchangeably to mean the CCS Disability Action office when he is at his house, and his house when he is at the office. Hilderthorpe, however, has always been "home."

Maureen picks Richard up at 4.15 on a Friday afternoon. He stays at Hilderthorpe every Saturday and, Maureen tells me "we sneak Sunday if everything is going alright." Maureen now has rheumatoid arthritis and Ramon has a "dickie hip," so at times, meeting Richard's physical care and exercise needs can become tiring.

Hilderthorpe had always been a busy place. There was the steady stream of visitors that came with a working farm and friends from the local community that would pop over to be met with the tea and the scones that Maureen and Ramon were equally adept at turning out. "Maureen and Richard both like a social event," staff told me and as we leafed through family albums where family celebrations competed with horse racing meetings and Maureen's gardens, Maureen mused about there being "lots of parties." Celebratory events like Richard's twenty-first where Richards parents had converted the sleep-out and thrown an awning up in front of the summer garden. Ramon had organised a bar under the veranda an a country and western band played out the front for family, school and other friends Richard knew through CCS and people from all around the district.

Interviewer: Where is home?  
Staff: When Friday comes Richard is going home, because that's what he does. Home will always be at Hilderthorpe.  
Interviewer: Has [Staff name] got that right Richard??  
Richard: Yes  
Interviewer: Home will always be at Hilderthorpe?  
Richard: Yes



(Clockwise) Richard's 21<sup>st</sup> birthday, Christmas with Grandad, Ramon's 60<sup>th</sup> birthday



*"Over there"* Richard seldom gets visitors. Angela comes once a month for tea, and he goes to her flat in between, but other than the relationships Richard has with his staff and his flatmates, Richard's social spaces lie beyond the home. Similarly, whereas Richard knows, not only whose farms cluster about Hilderthorpe but how they came to be there and how their family histories overlap with his own. Richard's staff say, on the other hand, that Richard and his flatmates are strangers to the people who live in their street.

The house is also quiet. On the days that I visited, Richard and most of his flatmates ringed the lounge while staff cooked, tended to others or hunched over the breakfast bar reading notes and checking medication as the radio or television played quietly in the background. At Hilderthorpe, however, Richard was engaged in conversations that rolled on with Maureen's well-practiced ear making sure Richard took his place in the narrative.

*Ramon has made scones in readiness for our visit and Richard and I are eating them in the kitchen with Maureen. Ramon is in his favourite chair talking to Richard's staff person about her son whose picture was in the paper.*

*Richard: [Vocalisation]*

*Maureen: Dad. He wants to tell you something.*

*Richard: [Vocalisation]*

*Maureen: Lovely Scone.*

*Ramon: Oh quite good is it?*

*Richard: Yes.*

Home and the service contexts beyond appear to represent two complementary social worlds to Richard, with their own distinctive customs, social roles and expectations. At present Maureen bridges both worlds and her restless advocacy is, in part, driven by a desire to embed within the culture of support those elements of Richard's Hilderthorpe life she believes to be critical to maintaining his quality of life. In the past, Maureen's advocacy addressed the potential for Richard to be rendered voiceless by the challenges he faces each day to make himself understood. *"Richard can't organise everything,"* she told me. *"Some of the words he can't even say - so someone has to advocate."* Of late, however, bridging the gap between Richard's two social worlds has assumed heightened significance. Maureen is 71. She and Richard talk openly about maintaining the quality of his life beyond her advocacy. *"When we are not here,"* prefaces many of the conversations they have, and particularly regarding the need for Richard to *"speak up and tell people what you want."* *"She is coaching us all,"* staff tell me *"and it is being taken up by staff. We have learnt about potential from Maureen and of the importance of paying good attention - and that Richard is worthy of our being alert."*

Three strands stand out as the dominant motifs to Maureen's advocacy. A belief that Richard keeping himself well is axiomatic to his quality of life, a determination that Richard will continue to enjoy a full and interesting life, and that Richard's ability to author his own life depends on the ability other people have to understand him.

## Fighting Gravity

*"Richard had been using CCS longer than anyone around here,"* Maureen tells me, *"which is testament to the amount of effort we have put in to keeping him well. The biggest thing for Richard is that his supported seating holds him in the centre-line position."* Over the course of the next few days, Richard and Maureen tell me about all the friends Richard has lost, friends Maureen tells me that have slowly been pulled down by gravity as their bodies turned in on themselves.

*"Chairs are critical to supporting the quality of life of disabled people." Maureen tells me. "Chairs, care, diet, exercise and," she adds "the wellbeing that comes with being out and about."*



Setting Richard's chair

Richard's chair had been the focus of much of Maureen's advocacy. Rather than cast the chair to the curve of Richard's back, Maureen has battled therapists to ensure the seat remained straight and a wedged pommel was not removed from the front the chair so Richard could hold himself erect. *"The pressure from here to here (Richard's trunk) is enormous"* she tells me, insisting that by staying upright Richard is able keep the pressure off his internal organs. *"I got a terribly bad name for myself but I had to tell them in the strongest possible terms what would have*

*happened if they had take (Richard's pommel) away. That would have been the end of Richard if I had given in."* Maureen also stressed the importance of a robust chair, of finding the correct feet placement to keep his hips level and of having the chair inclined at the right angle to help minimise the risk of aspiration. Maureen has got used to operating *"outside the system,"* she tells me, by going directly to the orthotics department or the workshop and she still oversees every aspect of Richard's chair design at a local engineering company, where they have been improving and repairing Richard's chair since 1994. *"They have become experts in providing equipment for people with disabilities,"* Maureen adds. *"It's important to get this right because we are setting Richard up for the rest of his life,"* Maureen tells me.

Maureen has also emphasizes to staff the importance of Richard continuing to walk regularly. It helped, she believes, with the muscles that hold his frame as well as strengthening his heart, lungs and circulation. From an early age, Maureen kept Richard medication free, not just because of the effect she believed mediation had on his body, but because by synchronising their efforts, Richard can work with the muscle spasms medication can suppress, to weight bear as he walks. Maureen and Ramon walk Richard at Hilderthorpe and Maureen calls into the CCS office to walk Richard two afternoons a week. Richard also has a walking frame he keeps at his house. Staff hoist Richard into his frame after tea and he takes them the length of the hallway and back.



Walking with mum and dad



Walking with staff

*"You're healthy than all of us Richard,"* Maureen teased. Both of them, you suspect, taking quiet pleasure in the fact that they had succeeded in bedding in an attentiveness to Richard's physical wellbeing that would not see him pulled over like his friends.

## Richard never missed out on anything

One other aspect of Richard's life that he and his mum have managed to carry over into his support is an expectation that he live a full and active life. *"Even though Richard has a disability,"* Maureen told me, *"he has never missed out on anything."* At Hilderthorpe that meant work on the farm as well as holidays with the cousins and other celebrations of family. There were the horse racing meets and trails but also a more general attentiveness to opportunities for Richard to experience moments of drama and exhilaration. Moments like the thrill of the sulky, a banking in a helicopter broadcasting its next run of seed on the farm or the fishing trip to Kaikora that Richard spent strapped to the deck, laughing at every pitch and roll before the motor stopped.

Richard also continues to expect to exercise control over his day-to-day activity and a number of important support elements promote Richard's ability to be self-determining. Richard's communication diary is key. Every Monday morning Richard meets with his staff. The purpose of the meeting is *"so you can say what it is that you want to happen for the week isn't it Richard,"* because whilst Richard's programme provides everyone with a common framework, *"he will jump the programme if he gets a better offer."* Monday's meeting allows Richard to alert staff to the adjustments he wants to make to the programme, most often to accommodate events that he and Maureen have discussed over the weekend. *"Richard insists staff know what is happening. It's important for him to know staff have a clear understanding of what he wants for the week and if he doesn't know, he gets upset. We know Richard is anxious by the way he holds his arms."* Richard," his support staff tell me, *"is a man who drives with his head but talks with his elbows."*

Word Sound	Word Meaning
Yes	Yes
No	No
Over There	CCS office or Residential Home, used interchangeably depending on location.
Tomorrow	It's happening tomorrow or what are you doing tomorrow, depending on context.
No tomorrow	Any day except tomorrow.
Cappuccino	Cappuccino with cinnamon.
Egg Sandwich	Egg Sandwich
Egg Sandwich	Dad
Mum	Mum

In addition to the cues his body provides, Richard has a cluster of word sounds that staff are able to interpret. Almost all of the vocabulary staff can clearly understand help Richard to locate himself in time or space.

Richard receives 17.25 support hours, funded through CCS Disability Action's Ministry of Social Development Vocational Contract. His funding has not changed since he left school, but staff say that,

compared to other service users, Richard's is a generous package and the challenge for them is to provide an equivalent type of support to other clients that are funded through the same contract.

After leaving school, Richard initially came to CCS to participate in 'Centre-base' activities. In 2004 CCS Disability Action closed the Centre in order to provide more individualised support. Richard and his staff assert that the move from collective to individualised vocational support has been especially good for him. All disability support is transacted through a human relationship, but Richard's need for a communication partner committed to understanding him as well as a companion to help him to navigate with safety mean that Richard's ability to be causal in his own life is strongly influenced by the character of his support relationships and in particular the capacity of others to interpret and act on Richard's aspirations.

When Richard was *"lumped in with everyone else,"* his staff said, *"he would go inside of himself"* *"People used to be completely powerless in those places. It was like being at school,"* staff said, contrasting Richard's ability to hold his staff accountable to his programme on a Monday morning with the artificial moments of choice making and inability of service users to effect any significant influence over the culture of the day-base. *It might still be a programme,"* they told me, *"but it's Richard's programme."*

Richard sees himself as author of the programme too and would change very little about it. Because of the way his house is staffed, Richard can't leave, unless it's with his mum or an organised so getting the programme right is especially important to Richard.

Richard still begins and ends week-days at the CCS office there and he has lunch in the big room out the back most days, bantering with staff over coffee and a newspaper or catching up with other service users that drift in to the centre on a Thursday to have their lunch. Many of the people who come on a Thursday, Richard has known for much of his life. Richard has been going to the office for twenty years, longer than all of the staff and more than half of the people Richard names as his friends he meets through their common connection to the CCS office.

*Interviewer: Are there places you like being?*  
*Staff: The Cafe*  
*Richard: Yes. Over there*  
*Interviewer: At CCS? The people there?*  
*Richard: Yes*  
*Interviewer: It's about those relationships?*  
*Richard: Yes*  
*Staff: It's only about the relationships?*

The office also offers Richard a place from which to push out from and return to, safe in the knowledge that he and his support needs are both anticipated and unremarkable. He also has confidence that his staff will not give up trying to understand him.

In the past, however, the centre had also been a place of quite different fellowship. In 2004 Richard had been part of a support group that had gathered about a charismatic personality at the centre. *"Robin was a people person"*, staff at the Centre reflected. *"People listened to him and enjoyed him and he saw the big picture."* Robin was also a writer and a musician and a friend of Richards, but the fledgling group and its hope of providing peer support and collective action foundered because, *"it needed to be run by the group and there was no way of paying a facilitator outside of the programme."* Staff also feared that *"whilst many of the people who came were told that they had choices, they didn't really know what that meant,"* in the context of their own lives. Robin died in May, 2005 and now, Richard is largely serendipitous connected to his friends and the wider disability community. A smaller number of clients come to have their lunch at the Centre on a Thursday or drop in at odd times during the week. Richard will also sometimes meet other disabled people who are not necessarily affiliated to CCS Disability Action when he is out in the community and his mum describes him as *"beginning a rapport with like minded people in his community."*



Richard (middle right), Robin (centre) and the support group

Richard's programme is strongly weighted towards him being out and about in his community. "Richard loves going out and about and meeting as many people as he can", his staff tell me. "He needs people to stay stimulated. He's drawn to happy people. People that laugh a lot and tell stories- a bit like his mum and dad." He is a highly public figure in Oamaru, and can't motor a block without someone stopping to say hello or ask him if he's off for his cappuccino and whether it's the egg sandwich or the cream cake today. "It doesn't matter where you go," Ramon said, "even in Dunedin, someone will stop you to say hello."

Richard's staff are equally public companions and openly disclose that Richard has been the conduit to many of their community relationships too. "I have met so many people through Richard," many tell you. "Everyone in Oamaru knows Richard and do you know why? It's because he is always out there." For a few staff the edges

between Richard and their own social worlds have blurred, and especially for those whose relationship with Richard has been built up over years in social spaces like Oamaru's café's. On the odd Friday, for example, Richard meets his "bevy of beauties," at a local café. The line-up varies from week to week but can include Richard's friend Angela, CCS support staff and friends of theirs that have, over countless coffees, forged reciprocally valued relationships with Richard.



Richard's bevy of beauties

*Interviewer:* Are there things you would change about your life?  
*Richard:* No.  
*Interviewer:* You have always said that. Is that because life is so good?  
*Richard:* Yes.  
*Interviewer:* That's great but it's a sentence that I don't know I could say all the time?  
*Staff:* You don't swan around all day drinking coffee with women?  
*Interviewer:* (Laughs) I guess it's easy to joke, but are they the things that make life so good. I'll tell you why I'm asking. Because I don't know how many conversations I have had about coffee today. It would be quite a few?  
*Richard:* (Laughs).  
*Interviewer:* Or women and there have been quite a few about egg sandwiches.....  
*Richard:* (Laughs).  
*Interviewer:* Are they the things that make life good? The coffee and the women and the egg sandwiches.  
*Richard:* Yes. (Laughs).

For his part, the way Richard has experience being "out and about," have led him to read Oamaru as an inclusive community. Others are as likely to attribute the way his community has embraced him to Richard's inclusiveness. While we waited at the pool for Richard to get changed, a couple of ladies from the Fun Over 50s Aquarobics class wanted to know how I knew Richard. They had been coming for eight years and had known Richard since then. "He has one of the biggest fan clubs around here," they told me. "He has such a glorious smile. Richard always leaves you better than you came. He is good company," they said.

Richard's community does, however, have a distinctive geography. There are a cluster of places Richard regularly visits that fall within a short motor in his chair. There is the CCS Office, a local

dairy where Richard sometimes goes for a chat with the owner, one of the cafes Richard frequents and the bowling club. On a Thursday Richard and his CCS DA support worker have morning tea at his house before motoring to bowls. The local club have made their indoor green available to disability service users and provide a handful of volunteers to help shepherd the bowls. IDEA service users bowl from one end and CCS DA service users bowl from the other. Richard has the outside lane and bowls by himself. His support worker loads the bowl into the top of a plastic tube and Richard sends it on its predictable arch by releasing a lever. On the day we went, Richard got off to a slow start. He was much more interested in catching the conversations that were happening a few lanes over. "Now Mr Beale," a volunteer prompted, "Did you bring your coffee seen as it's so cold. I can't see any steam rising. People will think you're just here to meet girls." Richard smiled.

*Interviewer: Are there places you don't like going?*

*Richard: No.*

*Interviewer: Why is that? Because generally everyone is nice to you?*

*Richard: Yes.*

*Interviewer: How does that happen? Why does that happen for you?*

*Richard: (Smiles)*

*Interviewer: I only ask because some disabled people will tell you their community is not always inclusive. But that's not the way you experience it?*

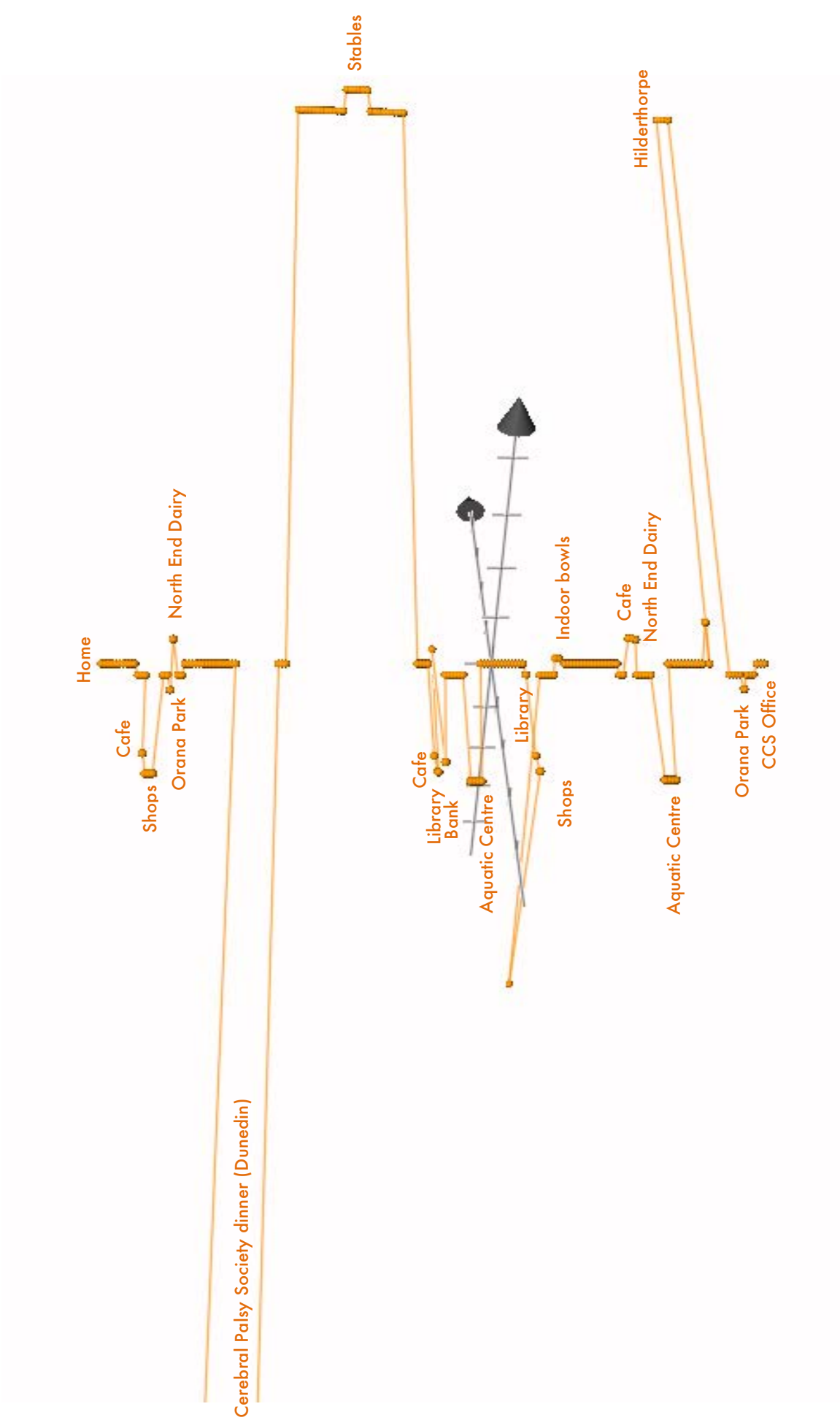
*Richard: No.*

*Staff: People are always coming up to Richard.*

*Interviewer: Well I know I don't think I know anyone so famous. They even know what you are having for lunch!*

*Richard: (Laughs)*

Figure 1: Richard's time in place: 23–28 August, 2011





The other place Richard motors to is Orana Park. Orana Park is a small community domain a block of two from the CCS Office. Richard controls his chair using buttons positioned in the headrest of his chair. For ten-fifteen minutes a few times a week Richard and his staff person go to Orana Park so he can motor without being chaperoned by a staff person. It is the only time he is able to do it.

Two mornings a week Richard goes to the Oamaru Aquatic Centre where he can stretch and uncurl his muscles. He has been coming for years, always at the same time, so he knows the women from the aquarobics class will be at the pool. The pool attendants know Richard too and usually they keep aside the plastic container with #1 on its lid for Richard's to put his valuables in. On the day we go, however, someone has absent-mindedly given it away. "It will have to be #1 4 Richard this time," they tell him, apologetically.



'Hydrotherapy' at the Oamaru Aquatic Centre

When the last strains of "love, love me do," have died, a few of the women join Richard in the spa. Richard's staff make sure he has finished his stretches before the class ends so that Richard can incline himself towards the conversation to find out whether anyone has won lotto during the week or if the aquarobics seems to be working. The women not only include Richard but join his staff in the guessing that eventually allows him to introduce me and to make clear that I will be coming to interview him that night.

Richard's staff tell me his patronage has made a difference to the accessibility of the pool for everyone in Oamaru. The Aquatic Centre installed a hoist for the spa, handles and a more appropriate changing table, largely as a response to better meeting Richard's needs, that everyone now benefits from<sup>2</sup>.

Richard travels to the pool by mobility taxi. The taxi is pre-ordered and the Oamaru drivers know Richard's programme as well as his staff. They also call at the CCS Office on Monday, Thursday and Friday afternoons, when Richard goes to town. Richard determines what happens in town. Some days it's the library to pick up or return the talking books or the magazines he has borrowed and on other days he takes his staff to the bank. Maureen and Richard have

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<sup>2</sup> Richard and his mother's lobbying have also lead to the Waitaki council to build an extension onto the public toilets so that they could accommodate wheelchairs and the installation of protective islands in the meridian of the main road, just past the CCS Office.

taught the tellers what to do when he comes *“so even if his staff are unsure what is happening, the bank staff know.”* Richard will often pop into shops enroute, mostly to say hello to people he knows, like the former support worker who now runs the gift store or the son of another support worker who works in the local appliance store and who has always enjoyed Richard’s company. On the day we were in town, Richard reminded his staff that he was going to Angela’s for a birthday tea. He wanted to buy her a card and while he was there, bought one for his mum too.



Shopping for birthday cards



Enjoying a coffee at ‘The Bean.’

*“Nothing happens, however,”* Richard’s staff tell me, *“without coffee. It is the glue,”* they tease, *“that keeps everything together.”* Richard’s love of coffee is legendary. He has a handful of cafes he likes to go to and the taxi drivers know that trips to town will end in one of them. Fridays usually end at “The Bean” where the right barista makes the “special coffee,” for Richard. Over time, their variation on the cappuccino with cinnamon has become one of the rituals of the place, as has asking Richard if he would like an egg sandwich that gets assembled out the back if he does. Richard also smiles at the idea that the café also affords him a vicarious engagement with his community as we catch ourselves straining to make out an animated conversation at an adjacent table.

Although fleeting, Richard’s inclusion within the social landscapes of Oamaru’s streets and it’s cafes, the pool and the bowling green has happened because of a repeated presence and his respectful enjoyment of the people he finds there. They are autobiographic spaces too, in the sense that, not only are they self-chosen, they inform others of how Richard sees himself.

Richard is unequivocal. He has fashioned the life he wants for himself. It is, he tells us, the coffee and the women and the egg sandwiches that make life good.

Except for the counterpoint that is his life at Hilderthorpe, the places that connect Richard to his community are, however, all public settings in which Richard is included as a consumer of a public good or service. Similarly, the relationships that he has forged in those places tend to have remained context bound. The women at the pool, for example, have never met Richard’s bevy of beauties and, in spite of the affection that Richard is so transparently met by when he is out and about, neither Richard, nor members of his community have stepped into the private social spaces of each other’s lives.

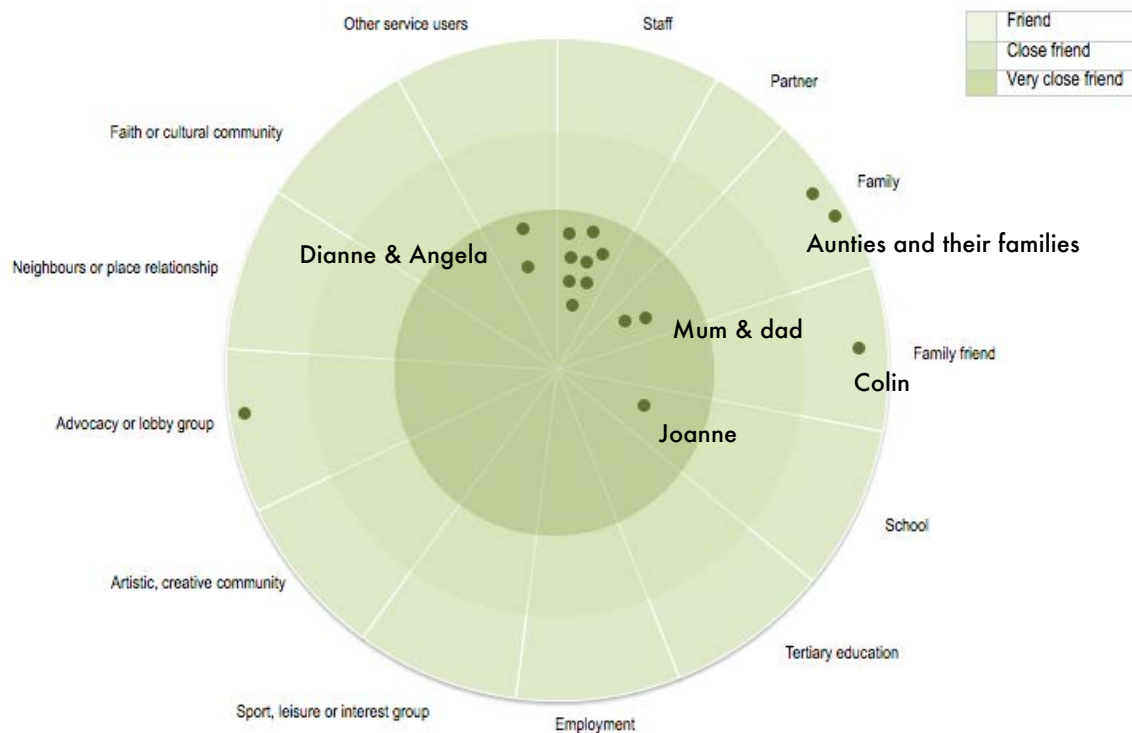
Richard said he has three friends that are neither staff nor family. Joanne and Richard have been life-long friends. Their birthdays are a day apart and they have known each other since their mothers met in the maternity ward. Richard met Dianne at CCS. For a short while they used to live in the same community group home and together made up two-thirds of a triumvirate Maureen called the *"Three Musketeers."* *"They used to go everywhere together, parties, town, everywhere. Just after Amanda died she met a young man and they fell in love and got married. But it didn't stop Richard remaining her friend and she has to do her duty on the telephone,"* she teased. Dianne now lives in another community group home just up the street.

The phone is very important to Richard. He has a hands free phone in his room and talks to Maureen and Ramon on it most nights. Richard talks to Dianne most nights too. Sometimes Richard calls and sometimes it's the other way around, but mostly its Richard that ends up phoning Joanne. Richard used to call Angela, but these days she spends a lot of her time on the internet and because she can only afford dial up, it's almost impossible to get through.

Richard seldom sees his friends. Angela has joined Richard for his Friday coffee once or twice but otherwise all three of his friends are absent from the places that Richard understands as his community. Moreover, except for the scheduled meals with Angela and the entrances and exits of support staff, no one comes to visit Richard in his Oamaru home.

It hadn't always been that way. There was, of course, the historical fellowship that had crystallized into the support group organized by Richard's friend Robin. There was the adventuring of the musketeers and perhaps even the practices and performances of the St Kevin's choir and other social events Richard shared with his school friends. There were relationships of great significance too.

Figure 2: Richard's friendship field



*“Richard and Amanda,”* Maureen said, *“loved one another.”* They were at school together but really got to know each when she came to CCS as a volunteer and fed Richard at the CCS Office. *“And they talked,”* Richard’s staff added. *“Amanda was one of the few people who truly understood Richard.”* In fact they did more than talk, *“at times they could get mad with each other. Richard is an intellectually curious man and he wants to know what you think. If you are on his wavelength he likes an argument. It forces him to question what he feels.”* Like many of Richard’s friends, Amanda died too soon. *“Richard doesn’t get many arguments now,”* they told me. *“It happens occasionally and when it does, you can see the light in his eyes.”*

Today however, it is almost exclusively with staff that Richard shares those community spaces that have included him within their social history.

Richard does not draw a firm boundary between the social roles of paid support and friend and in the absence of many other validating relationships, staff dominated Richard’s friendship field (Figure Two). Excluding his family, Richard’s staff provided him with some of his most frequent and enduring social contacts. Through a reciprocated curiosity about what was happening in the *“tomorrows”* of each other’s lives Richard and many of his staff had come to share what Marquis and Jackson describe as ‘the inner circle’ of each others lives,<sup>3</sup> the significance of which was enhanced by sharing ordinary rituals of friendship like, going for a coffee, or a swim, or finding the right card.

Understanding Richard and the daily struggle to share meaning also drew on attributes of relationship that relied upon social closeness. For Richard’s part, staff readily acknowledged the *“grace with which (he) accepts our communicative limitations,”* whereas Richard had learnt he could depend on the genuine interest, adaptation and respectful persistence of staff communication. *“It’s important to give Richard your full attention,”* a staff person told me. *“Richard visibly relaxes when he is assured that we will get to the bottom of what it is he is trying to say. He knows you have heard him and he knows we know it is important to him.”*

Interviewer: How often do you meet.....  
Is it easy to meet your friends?  
Richard: No.  
Interviewer: What about chances to meet new people. Do you get many opportunities to meet others?  
Richard: No.  
Interviewer: If you wanted to do something special is it easy to get people to do it with you?  
Richard: No.  
Interviewer: Oh! What did you have in mind by something special?  
Richard: [Pause]  
Interviewer: Doing things with friends  
Was that the sort of thing?  
Richard: Yes.  
Interviewer: Or the sorts of social events, you know the parties and visitors that we talked about happening at home?  
Richard: Yes.  
Interviewer: Most of the friends that you have named on the friendship map are staff. Do you think of them as friends?  
Richard: Yes.  
Interviewer: What about having other friends, would that be important to you?  
Richard: Yes.  
Interviewer: The sorts of friends you had at school?  
Richard: Yes.  
Interviewer: And old CCS friends?  
Richard: Yes.  
Interviewer: Do you think you will meet another Amanda?  
Richard: No.

The difficulty was, however, that Richard also said, it was difficult for him to stay in touch with other friends or to participate in his community in ways that might allow him to meet new people

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<sup>3</sup> Marquis, R. & Jackson, R. (2000). Quality of Life and Quality of Service Relationships. *Disability & Society*, 15(3), 411-425.

or forge new relationships. In a similar project conducted in 2004, adults that used CCS Disability Action Vocational Services who relied most upon staff to get them “out and about,” were also more likely to say that it was difficult for them to meet new people.<sup>4</sup>

## A, E, I, O, U

The most disabling consequence of Richard’s cerebral palsy was, according to his mum, the way it has denied him access to ordinary speech. “*Richard only has vowels,*” to build a dictionary. “*You can’t pick out words and Richard can’t get his phrases into sentences can you,*” she explained on Richard’s behalf.

Not having access to ordinary speech has meant that Richard has also often struggled to make his intellect transparent. There have been moments when Richard has lost influence over his life because of the failure of others to understand his expressions of need and hope. Maureen worries that without her ability to interpret, Richard is vulnerable to variation in the communicative skill of those he shares his life with. “*My biggest worry is that Richard will not have the communication skills and assertion to help him to retain all the programmes that have been put in place to ensure his health requirements and quality of life when I am not here,*” she told us. Richard’s programme has been strongly shaped by Maureen’s unwavering advocacy and she worries that Richard may be left exposed to an erosion of the range of ways he is present in his community in her absence. She worries too that the vigilance with which she has attended to Richard’s wheelchair and exercise requirements may not be so well replicated when she is not around and reminded us that Richard’s physical and emotional wellbeing were inextricably linked. “*When Richard is sick or in pain,*” she said, “*his speaking and ability to assert himself goes out the window.*”

Maureen’s response has been to celebrate moments of complaint and to emphasize the importance of self-determination to Richard and his staff. “*He’s a good complainer,*” she joked with Richard, without attempting to disguise her pride. She has also modelled and mentored staff efforts to replicate the narrative that she and Richard have developed over his lifetime, recognising that it has been the way that Richard’s difficulty speaking has had the potential to isolate him from others which has been one of the most difficult aspects of only having a alphabet of vowels. “*It’s been terrific learning together,*” Maureen said. “*But it’s lovely now that other people can talk to him,*” she added paying tribute to the staff that Richard has grown close to.

The importance of the communication environment and the vital role staff play in facilitating effective communication is recognised in New Zealand law,<sup>5</sup> but whereas traditional approaches to improving communication used to emphasis identifying and correcting individual deficit as the primary focus, effective communication is no longer considered an end in itself, but as a vehicle that has friendship, belonging and valued lives as its destination.<sup>6</sup> Richard’s staff describe

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<sup>4</sup> Milner, P. & Bray A. (2004). *Community Participation: People with disabilities finding their place. Report on the CCS Community Participation Project.* Wellington (NZ). CCS.

<sup>5</sup> Right 5 of the Code of Health and Disability Consumers Rights Regulation (1996) requires disability service providers to respect service users right to effective communication.

<sup>6</sup> Butterfield, N., Arthur, M. & Sigafos, J. (1995). *Partners in everyday communicative exchanges.* Sydney. McLennan & Paetty.

themselves as *"beginning to have a handle on some of his speech and what it is he is trying to convey,"* but their challenge in terms of supporting Richard to develop relationships beyond people paid to be in his life is clearly to help him find community contexts where others have an equivalent opportunity to begin to 'get a handle' on Richards communication or finding modes of communication that make the sharing of meaning easier for him.

Richard does have a DynaVox augmentative and assisted communication device. The device has a lexicon of words and common phrases and Richard has had it for a year. It can also be pre-programmed by users and Richard's pre-programmed greeting says; *"Hi. I am Richard. I have cerebral palsy. It affects my muscles, my speech but not my brain. I get frustrated when people don't understand me. My computer can help me with that."*

The device has a mount that can be fitted to Richard's chair but it has never been bolted down. Richard's computer sits instead in a bag at the back of his chair to be brought out for or half an hour most Fridays so that Richard and one of his staff can familiarize themselves with the software. During the course of the year they have managed to enter some phrases and have a general sense of how to navigate the desktop, but nobody else knows how to work the computer and when the half hour is up the computer is returned to the bag on the back of the chair.

Richard says that being able to communicate more effectively would greatly improve the quality of his life. At present he makes an alphabet of vowels and staff's understanding of a handful of phrases go a long way, but Richard is described by everyone as a curious and intellectual man. *"He has,"* his mum says, *"had a big life. He has seen a great deal of things,"* like the loss of many of his friends and the grandparents he visited so often in their house next to the Hilderthorpe School. Most of the books in the Oamaru library have 'RB' inked inside their back cover and he has found a way to *"totally accept who he is and why he - which is a remarkable thing,"* Maureen reflects.

It isn't just Richard who gets frustrated *"when people don't understand (him)."* Staff say too how hard it is for them when Richard's meaning is not transparent, perhaps explaining why many stick to the safer, less ambiguous narratives of coffee, women and egg sandwiches and not a life well unexamined<sup>7</sup>.

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<sup>7</sup> Plato records Socrates as asserting at his trial for heresy that an "unexamined life," was not worth living. Socrates asked that his service to society be rewarded with death rather than a life in prison or exile because, he argued these alternatives would rob him of the only thing that made life worth living - his ability to examine the world around him and to discuss how to make it a better place.

## Leaving Hilderthorpe

Before leaving Hilderthorpe for the last time, Richard and Maureen stopped their van half way up the drive so that Maureen could point out 'So Green.' She had been put in the paddock near the house because she was in foal. Richard was hoping for a colt.

A few moments before, Ramon had taken my hand with the strength of a man who had long-reined Game Lad nearly fifty years before and trained every generation in between. "*You must call again,*" he insisted before releasing his grip. Maureen handed me a note she had taken the trouble to type the night before. I decided to read the note over a coffee and stopped at 'The Bean.' The barista had remembered that I had come as a guest of Richard's a few days before and was friendly, but there was no special coffee nor any offer to make something out the back. Maureen's note read;

## Acknowledgement

Richard's Story is one of triumph over extreme physical disability and brain damage.

For those people who failed to perceive the fundamental requirements needed for him to have a quality of life, there are the many people who have taken up those requirements and implemented them so that he is unique in the quality of life he enjoys today.

Richard's life is a miracle and all those people who support him in so many ways are part of that miracle.





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TE HUNGA HAUA MAURI MO NGA TANGATA KATOA