

Stepping stones along my journey toward independence

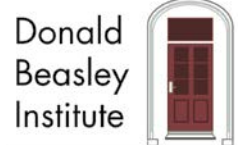
“I am here” –
The Article 19 Project



A life story co-authored by:
Angela Griffin & Paul Milner



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Disability research
and education

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TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

Angela Griffin

I want you to start with a building. And colours.

"I don't want you to start with anyone else's words," Angela instructed *"I want you to start with a building. And colours"* Colours are important to Angela. The brighter the better she tells us. Angela is visually impaired. She has a narrow tunnel of vision in which she can detect shapes and movement up to 20 meters distant and a brighter palette helps her to define the edges of things. But it's more than that. Perhaps because of their importance, colours can sometimes enhance the feelings Angela has about people and places and how they have intersected throughout her life. *"You could start with the hospital white of Templeton. The green and fawns of Iona Hostel and Fernbrook and finish here in the bright yellow of my unit."* The walls of Angela's unit are daffodil yellow. The bright walls were the first thing Angela noticed about the unit on her first visit four months ago.



Angela in her unit

Angela's unit is the first of a row of units that look east towards the wide streets of Oamaru and on towards the sea. In her mind her little unit has become totemic of the end of one journey to find a place of her own and the beginning of another, to discover herself within the sanctuary of a place she can finally call her own. "We could include the purple of the bearded iris that hangs over there," May, one of Angela's support staff painted the iris and presented it to Angela as a housewarming gift, even though she wasn't supposed to give her clients presents." The painting sits above Angela's sofa facing the door, ready to greet everyone that comes. *"Or what about the tile on the wall over there?"* The tile is one of a cluster that Angela

collected when her support service decided to close the community group home she used to live in. On the tile is an unattributed American quote about friendship. It reads; True Friends are like diamonds, Precious but rare. False friends are like autumn leaves, Found everywhere. "That's it." Angela said. "Lets start it there!"

Hospital White

"My life has been very different from most people because I came out of an institution."

One of the first things Angela will tell you about herself is that she grew up in institutions – first at Templeton and then Burwood Hospitals. Turning on the tape recorder the very first time, Angela thought she had to capture her story seamlessly in one take and, after making sure I was comfortable, she introduced herself in a careful monologue.

"My name is Angela Griffin. I come from a family of four children. I am the only one with a severe disability. I also have very poor eyesight. I have not lived in Oamaru all my life, I have lived in two institutions. But they weren't in Oamaru – they were in Christchurch. I came back to Oamaru 22 years ago because I wanted to be close to my family".

During the week that followed, the conversation would often return to the impact spending those formative years in Templeton and Burwood had had, and most especially the way being dislocated from the ordinary relationships of place and kinship had informed her sense of self. Angela also said living at Templeton was responsible for her determination to reforge an identity beyond the impress of the hospital white of New Zealand institutions. Embedded in Angela's introduction are the two cultural contexts she feels are required to 'read' her story. A determination to move beyond the shadow of institutional responses to impairment and the gravitational pull of family and a place to call home.

Angela Griffin is the third of Pat and Eileen's four daughters and was born, like her sisters before and after, in Oamaru. Oamaru is the largest town in North Otago. Sheltered behind the protection of its stone breakwater, Oamaru grew as a service centre to farms that stretch north towards the Waitaki River and south to the Kakanui mountains.

Angela's mum was born into and "*old Oamaru family*," and her father grew up in "*Listowel*," the old family home where Angela and her sisters would often stay over with their aunts, Mary and Helen. When they married, Pat was manager of the Oamaru Automobile Association and Eileen was a nurse at Oamaru Hospital. They moved into a home on South Hill that Angela described in her autobiography¹ as "*an anchor that steadied (her) in times of loneliness and frustration*." Pat and Eileen never moved and Angela goes home every Sunday to have lunch with her dad who still lives there.

At the age of five, respite care turned into a permanent placement at Templeton Hospital and Angela moved from Oamaru to live in Briar Villa with forty other patients for whom Templeton was expected to become a home for life.

¹ Griffen A. (1995). *My Life on Wheels. The Autobiography of Angela Griffin*. Invercargil. Craig Printing Co. Ltd.

She was so small, Angela wrote, that *"most of her early family life is beyond my memory."* Many of her childhood stories involve the family's efforts to seek and support intervention to help her to talk, learn more about her visual impairment and separate legs that *"crossed like a pair of scissors."* Angela also recalls the struggle she had to hold her head straight, the way her mum gave her physiotherapy and struggled to confound an early diagnosis that Angela would never speak coherently. *"My mum was told when I was one that I would never talk and mum used to say from that day I have never kept quiet."*



Pat and Eileen Griffin at home

Templeton Farm School was the first specialist institution for people with intellectual disability. It opened in 1929 in an isolated rural setting, then 15 kilometres west of Christchurch, a year after an amendment to the Mental Defectives Act made provision for the creation of "separate institutions for the care, control and training of mentally deficient children²." Before Angela was admitted, Templeton Hospital had grown to over 400 permanent residents and the creation of a new, psychopaedic curriculum in the 1960s led to the development of an on-site School of Nursing. There was a school in one and then three damp, prefabricated classrooms and a chapel and swimming pool were all built, consistent with Templeton's original aim of becoming a self-contained village able to meet the needs of residents' separated from the wider community.

When Angela moved to Templeton, the institution represented the State's only response to meeting the needs of intellectually disabled people and their families. Families struggled, not only with the lack of assistance but against an understanding of their children as lacking developmental potential. At that time, the breakdown of families caring for a person with high and complex support needs was seen as an inevitable consequence of impairment and Angela came to share this understanding too. *"Slowly,"* she said, *"I came to realise it was tied up with my disability. Mum was too tired and had no other choice so I had to get used to it whether I liked it or not. I had to grasp the idea that I had two homes, Templeton and my family home and that I could expect to spend my life moving between them."*

² Thomson, J. (1995). *Indigence to Independence: The Development of Social Policy in New Zealand For People With Intellectual Disabilities*. Unpublished Master of Social Work. Massey University. Wellington.



Angela at Templeton

"Times without number" Angela said "my parents made the three-hour drive from Oamaru" and were always there for special events like birthdays or the annual concert "everyone practiced from new year to grand finale in August to get right." Angela also went home during the holidays, but never for long enough. "I would look forward to coming down," she recalled, "but as soon as we got there we would have to turn around and go back.' Between visits Angela described periods of profound home-sickness, with her sense of dislocation heightened in times of family crisis. Times like not being able to get to Oamaru when her father had his heart attack and when aunt Mary died.

Angela's two aunts, 'The Misses Griffin,' shared 'Listowel.' Mary was the taller of the two aunts and so it was usually Mary and not Helen that Angela remembers taking "her top half" as they grappled and giggled their way up the stairs when she stayed over. It was Mary too that played the

piano in the formal lounge to an audience of nieces. In much the same way as 'hospital white,' evoked Templeton, Listowel is coloured differently in Angela's autobiography. The 'wood panelled front door with the insert of yellow glass that flooded the hall with golden light,' and "red velvet drapes" in the dining room where she and her sisters would lie and watch Mary play appear to evoke the affection Angela felt for the "The Misses Griffin."

Mary died when Angela was 14. *"It was one of the greatest upheavals of my life. How desperately I wanted to be with my family. But these trips were impossible to arrange at a moments notice during the school term and I knew there would not be any room in our house with all the relatives coming and going. All I could do was sit and cry. My parents phoned that evening and I said I couldn't understand it all. Dad assured me a letter would be easier rather than trying to share it over the phone. When this arrived, it helped a lot to make it all real."*

Angela lived at Templeton for fourteen years. In addition to the hospital white of starched uniforms and villa corridors, Angela's recollections include the rows of beds that flanked each dormitory wall and the separation of male and female patients, consistent with the Eugenic imperative to limit the fertility of the "feeble minded" which informed the New Zealand social policy at the time². She wrote too of the unbending routine of hospital life that patients and staff both kept time to. Breakfast at 7.00am after staff had finished their changeover and hurried communal showers in bathroom cubicles that had no doors. At night, supper was at 6.30 with long stretches in the dayroom interrupted twice by the daily procession to the dining room for lunch and dinner or arrival of the tea trolley.

In Briar, a few older patients provided surrogate care to very young children. Up until she left Templeton, Marjorie was to become what Angela described as her 'mother away from home,' with the woman who 'no one ever knew exactly what was wrong with' attentively caring for Angela. In the weekends, Angela remembers Marjorie wheeling her across to Nikau Villa so that they were together. At Templeton, patients didn't own their clothes. Except for the few clothes that were put away for visiting days, the lottery of what staff had grabbed from the

Community Room determined what residents wore and in that environment, Angela remembers the *'thick, fawn arran patterned jersey Marjorie made'* for her as *'one of (her) treasures.'*

At the age of twenty, Angela exchanged one Christchurch hospital for another. Group therapy sessions Angela had been attending *"sowed the seed that I might outgrow Templeton,"* Her decision to leave Templeton was also galvanised by the immanent end to Angela's education and Angela moved to Burwood Hospital a short time after.

Angela wrote that the first night she sat, waiting to be told to undress. After summoning the courage to ask, a nurse told her she could decide for herself when she went to bed. *"I simply didn't know what to make of such an answer,"* Angela wrote. *"At Templeton the nursing staff had to hurry, keeping to a strict routine and there was never time to encourage patients to think out things for themselves."* Other things were different too. Angela described being *"fascinated"* by her locker. *"Something of my own. I had storage for my own clothes beside me - and CHOICE in wearing. It took a long time for this sudden mind switch to work through fully - even to this day"*. Some things were the same. The uniforms and the corridor of beds remained alongside the persistent feeling that *"I needed to please everyone or something truly bad would happen"*.

At Burwood and at Templeton, staff occupied places of paramount importance in the lives of residents. The pages of Angela's autobiography are full of staff that found ways to alert her to latent competence and a few that found ways to crush it. Other than Angela's family and a few moments of reciprocated disclosure shared with residents like Marjorie at Templeton and Marilyn at Burwood, almost all of the interaction that informed Angela of who she was occurred within the proscribed and unequal social roles of staff and patient. When Angela wrote of her family home on South Hill *"anchoring,"* her in times of loneliness, she also said it helped her to withstand *"the frustration of not being understood."* Angela's longing for home, therefore, might also be read as a longing for relationships in which she felt authentically present.

Robert Martin, New Zealand delegate to the UN during the drafting of the Convention of the Rights of Disabled Persons, from which Article 19 is drawn, said of his experiences in a different institution, *"We were seen as incapable of making responsible decisions, so others took over the right.... I have often thought about how I became disempowered. I believe it was the people who claimed they cared about me that most took my power away. When others take over your life, they strip your power from you. You lose confidence. You get used to others deciding everything for you,"* (p. 126)³.

Angela identified one of the key differences between the relationship she had with her friend June and other relationships was that June never arrived with things for her to do. June had always insisted she was "Angela's hands, not her head," Being her own head, Angela said, was a skill she was still learning.

Interviewer: Was it challenging to be your own head?

Angela: It was hard work when we started five years ago. Even two years ago you would have seen a totally different person.

Interviewer: Who would I have seen?

Angela: An institution person! An institution person, who let other people be the boss.

Interviewer: The head and the hands?

Angela: The head and the hands.

³ Jones, R. (2006). A real life – a real community: The empowerment and full participation of people with an intellectual disability in their community. *Journal of Intellectual & Developmental Disability*, 31(2): 125-127

Angela says the same thing. The defining attributes of Templeton and Burwood were, to Angela, that they were *"places where everything (was) done for you.* For her too, the culture of having everything done was sustained by competence denied. During our time together Angela repeatedly recounted that her primary frustration at Templeton and Burwood was *"when people did not or would not understand what I had to say."* Like Robert, Angela concluded that, *"so much decision making had gone on for me for so many years that I became trapped inside of a passive mind."*

"People," Angela summed up "have no idea how important it is to be treated normally."

Angela does not have an intellectual impairment, but faced the double disadvantage of living in a place whose social conventions were informed by a psychopaedic tradition⁴ and an impairment that she described as *'trapping words inside of me.'*

Angela waited until she was seven before being allowed to go to the on-site school at Templeton and until the age of eleven she went *"for half an hour each morning in the charge of a nurse. I was given one activity only,"* she wrote, *"a board with numbers which could be turned over to form patterns with colours."* Angela writes with conviction of her gratitude to the new headmaster at Templeton School *"who first noticed me and insisted that I deserved full-time schooling."* It was the start, she said of an understanding that there wasn't anything wrong with her intelligence. *"Being fetched to go to school that first day made me feel like a sunflower opening to the touch of the sun.'*

At fifteen, Angela was enrolled at Hammersley Park School, Section for the Physically Disabled. At that time, Angela said she knew *"colours and numbers and had read "The Hungry Lambs,"* the very first of the colour coded Ready to Read series that represented a primary school milestone for generations of New Zealander's. *"It was at Hammersley Park,"* Angela says *"that I really started to grow up."* Hammersley Park School was a half hour drive from Templeton and Angela would make the trip each school day. *"When I got back,* Angela says *"staff would ask me what I learnt today and I would think, I am treated like a person, I am treated like I know something,"* Often she said she took written notes back from Hammersley Park to prove to disbelieving staff that she had done the things she claimed to have learnt at school.

While her confidence has improved greatly, gaps in experience still remain and she continues to require input from others to assist in her decision making and understanding

*Discharge Report
Hammersley Park School
February, 1985*



Hammersley Park School

⁴ The word psychopaedic is a uniquely New Zealand term, coined by Dr Blake Palmer in the 1960s and is a composite of the descriptors 'mind' and 'child.'

Angela stayed at Hammersley Park School until the term after her twentieth birthday, when she was compulsorily required to leave. While she was there, Angela was introduced to Talking Books. In addition to helping to fill the long, quiet hours at Burwood, it was their ability to expose Angela to new worlds and new words with which to understand them that Angela said she valued most. Angela also attended her first party, organized by an Occupational Therapist who thought it would help Angela to improve her socializing. She found her clear and well-moderated voice, began to write a book about her life and unwittingly penned her first lines of poetry. She had also discovered a life long love of learning. When she finally found her way back to Oamaru nearly five years later, Angela would later enrol as an adult student at St Kevins High School. In a quiet moment at home with the tape running Angela said she was *"building a list in her head of all the things she could do."* The list was her way of reminding herself, she said, of the number of different ways she had transcended disabling expectations.

Green and Fawn

One of the other aspects of Burwood, Angela said she had to adjust to was meeting patients like Marilyn and Anne and Dennis, who not only walked and talked properly but resisted impairment by trying to carry forward the agency of a former life. After two years at Burwood, Angela wrote *"the question, could I leave Burwood? Permanently? kept pushing into my head – but I didn't dare ask."*

After a sequence of trials at the Laura Fergusson Home and Hospital Flat, Angela eventually left Christchurch for Oamaru in 1989. She was 25 years old and had spent almost all of her life straddling an understanding of herself as the loved daughter of Pat and Eileen and hospital patient.

For Angela, the desire to move closer to a place she had always thought of as home wasn't only about privileging one understanding over another. She spoke both of the pull of those relationships and of reciprocally trying to ease the cost of travel for parents and siblings who had always come to see her or paid for her return. Her parents, Angela thought, worried about *"breaking ties with staff that had known and treated her for five years, with very thorough records kept,"* and an equivalent adjustment to the return of an adult daughter they had expected would live in hospital permanently. There was the resistances of staff and the "readiness model" to overcome too. *"You haven't got enough skills to even start to have such an idea,"* or *"You realise you have lots of steps before this and there is a long waiting list,"* Angela wrote, were stock responses.

Angela eventually moved to CCS Iona Hostel in the autumn of 1989. Iona was the former nursing quarters of the Iona Home and Hospital for the aged and had been converted by CCS into a hostel for 15 people. The home still ran and Angela remembers the awkward procession of chairs that would *"troupe across to the dining room at dinner time to join the residents of the Rest Home."* She also remembers the floral sheets and her room. It was a small room, big enough to turn her chair but too small to fit an armchair for visitors. Small as it was, it was Angela's room. The very first private space that Angela had had since leaving her family home. I was *"overwhelmed,"* Angela said, *"to have complete privacy and somewhere to put my own things."*

When Angela wrote about Fernbrook House, it was her room that featured prominently in the narrative again. Number 38 Fernbrook House was *"towards the end of the road facing out towards the hills,"* on the way out of Oamaru. Angela described it as a *"kind of halfway house that accommodated five people who had progressed to semi-independent flatting stage, with house parents in their own cottage on the property."* Angela was the only resident who didn't have to share a room *"because of her chair and her physical support needs. Everything was mine to decide other than the fawn carpet and the pink and green floral wallpaper. By September, 1992"* Angela wrote, *"I was happily making my home in my own room. My home! My room!"*

While she was at Fernbrook, Angela finished her autobiography, *"My Life on Wheels"* It had taken four years to write, although the very first lines of a story had originally been written a decade before while Angela was attending Hammersley Park School. A jug of water tipped over by a nurse at Burwood *"erased fifty precious pages"* that Angela had laboriously typed from handwritten transcripts and a year and a half's work.

Angela's autobiography ends wistfully. *"Dare I dream a little more for my future? Could I be more independent?"* Her ending is a quiet declaration of a vision Angela already held for herself but was too afraid to broadcast. In 2010, a policy change by CCS Disability Action to separate residential and community support foreshadowed the closure of Fernbrook House. The house would eventually empty about Angela, but before then, a flood that drowned the first floor of Fernbrook had already alerted Angela to an alternate future.

In the wake of the flood, Fernbrook residents were forced to seek alternative accommodation. For Angela, this meant living in a motel for the week it took for everything to dry. Angela said that for the first time in her life, she felt a sense of propriety over the place where she lived. *'The most important thing,'* she said, *"was it felt like it was mine."* It was also the first time Angela had experienced being, in her words, *"outside CCS's walls"* and she described experiencing the absence of a censorial support presence as equivalent to *"a feeling of independence."* *"It was like going on holiday for me - to be away from CCS."* Angela said living in the motel made her feel *"indistinguishable from everyone else,"* and, although Angela continued to receive support from the same staff, she said she also noticed a difference in the way they acted towards her. Small courtesies like knocking before entering and asking for advice contributed to the perceived change. *"I had never had so much respect in all my life,"* she confided.

During that week at the motel, Angela told her friend June that she *"wished it could be like this all the time."* With the deepening of their friendship, June had become a trusted sounding board for Angela and a safe repository for her private aspirations. June's recognition of what Angela described as a *"newfound hunger for independence,"* sustained Angela, long after her return to Fernbrook. Angela describes the years before her eventual move as time of great ferment. On the one hand, she carried with her a desperate desire to recreate the conditions for independence she experienced in that exotic week in the motel and on the other, an equally powerful fear of speaking her hopes out loud. Not declaring the vision she held for herself, Angela said, protected her from the possibility that the family she loved or the service she depended on may extinguish her momentum for change. *"My whole history,"* she explained, *"was of others telling me what was or wasn't possible."* Asking staff to break with their established ways of doing things had always been difficult for Angela. Angela said that her lived experience was one of *"forever feeling like I have to ask permission for the things I want for myself."* Without June, Angela said, she would not have had the opportunity to talk about her epiphany. The possibility of living by herself was a conversation that was too difficult to have with her support staff and so nothing changed until a phone call from Jamie Davies, came out of

the blue. Angela was the last person left at Fernbrook House and Jamie had rung to say that she had an accessible flat was looking for a tenant and could she be there in half an hour to see the property.

Angela said she always knew Claire Street would be a stepping stone, but none-the-less identified the 18 months that she lived there as a key stone in her journey towards greater independence. Claire Street, she said, was a nice place. It was painted and warm and once she had her ornaments up, Angela said it felt like home. In Angela's mind, Claire Street brought to a close her life in institutions. Most importantly, Claire Street also gifted Angela the opportunity to demonstrate to her family and support service her capacity for independence. Angela said her family worried, especially about having no support at night. Previously Angela had got stuck watching a wall for half an hour when her chair broke and her family were concerned that Angela would be even more vulnerable without the ability to summon support at night. *"The only thing that made it happen,"* Angela said, *"was my alarm. With the alarm staff could be here in 10 minutes. Claire Street proved to everyone that I could make it work. All I needed was the chance to show others."*

Daffodil Yellow

"This is the first place I can call my home. I've waited for 47 years"

Ten years ago, John Annison wrote that the term 'home' had been liberally (mis)applied to settings where disabled people lived out much of their lives. He argued that despite growing moral outrage at the 'unhomeliness' of the total institution leading to the closure of places like Templeton, we have continued to apply the descriptor without a clear understanding of its meaning or the essential elements required to transform a service setting into someone like Angela's home⁵.

In the wake of the closure of Fernbrook, security of tenure was one important element for Angela and her family. *"Brigit and John,"* who bought the unit for Angela, *"wanted somewhere permanent,"* Angela said, before recounting how stressful the search had been for her sister and how John had done all the alterations himself because they didn't have six months to wait for an Occupational Therapist to make the assessment required start the process. *"No one can ever move me again."*

There were good practical reasons for moving too. Shifting to the south end of Oamaru meant the taxi's were cheaper as Angela was much closer to her Dad and the Aquatic Centre where she would go swimming once a week when the weather warmed. Money is tight, especially since moving to the unit. *"My disability allowance gets used up to pay for the alarm that makes living in my own home possible,"* Angela tells me. *"I have \$80.00 to spend on groceries. No more! And \$20.00 to spend on what I like. Most weeks I manage to put a little away."*

It was more than its practicality that led Angela to insist I called her unit, her home. The very first day she came to look over the unit Angela whispered to her support person, *"Am I allowed to*

⁵ Annison, J. E. (2000). Towards a clearer understanding of the meaning of "home." *Journal of Intellectual & Developmental Disability*, 25(4), 251-262.

like it?" "The colour," she said, "was the first thing I noticed. It was bright, not like any place I had been before." It was also hers – hers to decorate in other ways that she felt similarly wrote something of her personality into the space. At Fernbrook and Iona, it had been Angela's bedroom that had offered her respite from staff's gaze and a refuge she could fill with self-chosen reminders of alternative social understandings. "Handmade straw hats, trimmed with flowers and ribbons arranged from largest to smallest, photos of family, ornaments given as gifts and the pictures of older breeds of dog on the wall beside the door, started by my sister Elizabeth." Suddenly, however, her home had become her canvas and Angela was especially sensitised to staff transgressions of her right to exercise authorship over the space.

Angela had her home set up the way she wanted. It was important she said, "because of my poor vision and because so many different people come through here." Having her home the way she wanted also appeared to have a wider symbolic meaning – a physical expression of Angela's ability to exercise agency over other aspects of her life.

Angela said that when staff appropriate moments of decision making in the, otherwise private space of her home, "it makes (her) feel as if (she) has no control." Complaining about staff transgressions was difficult, especially when the same person was likely to turn up the next day. Angela felt she could not choose her staff. "I only have four support workers who can do personal cares," she said. "They say they don't have enough staff for me to say who comes. There's not enough to go around." In addition to her dependence on human support, Angela reflected that her long history of institutionalisation had rendered her especially vulnerable. Her story was of having to learn not to be "an institution person, who let other people be the boss" or who feared "bad things happened when staff were displeased. "

Having your own home helped. "Now people come to my house rather than me go there (to the Daybase) " Angela observed, indicating the subtle shift in power she perceived to come with home ownership. For Angela, a redrafting of the support relationship was required and it was an exercise in (un)learning that both Angela and her staff were actively engaged in. "Every time I have a issue, staff want to fix it. I'm afraid sometimes they overstep." Many of Angela's support staff had moved with her to her unit and some spoke openly about having to (un)learn historical patterns of behaving towards each other. Angela also saw taking responsibility, not only for her home, but the people who entered it too, as another step in her journey away from the passive role of hospital patient. Angela knew staff's routine. She also knew the people who were dependant on their support and the limited time each had with the other. Having things organised for the next staff person and making sure they got away on time and was but one strand of reciprocated care that passed between Angela and her staff.

"I know what happens every day"

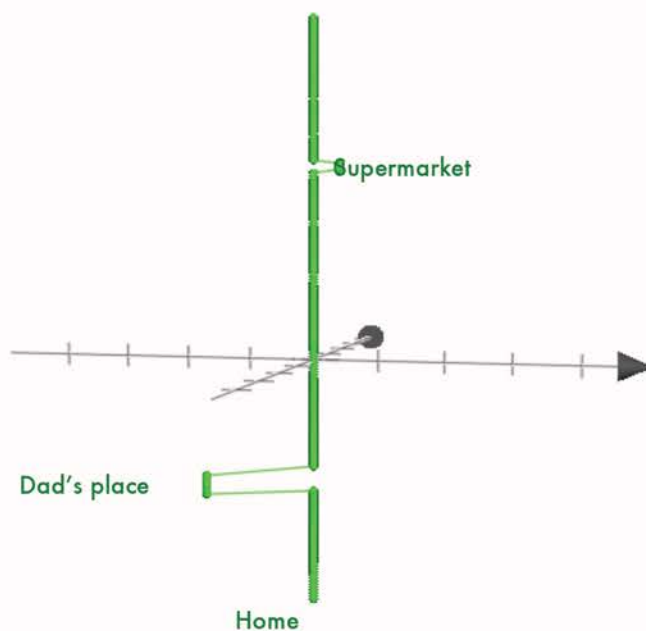
Angela receives 28 hours personal care support a week. Four hours per day. She spends two hours with her staff in the morning and one hour each at lunch and tea times with the last hour required "to be put to bed." Staff come at the same time every day, and in those hours Angela needs her staff to meet all of her intimate and personal care needs, help her to eat, to prepare meals and assist with the washing and other forms of domestic assistance. She also receives 3.5 hours Support Independent Living support, half of which is taken up by the need for staff to help Angela to navigate her way to and then shop at the Supermarket a block and a half away from her home. The rest is given over to a "cooking programme," that sometimes morphs into staff assisting Angela to become familiar with the computer she describes as her "life-line."

In some ways Angela's vocabulary has changed little since Templeton. She tells me she is "Under CCS" and understands the day-to-day rhythm of staff entrances and exits as her programme.



The weekly shop

Angela's programme is bookended by the arrival of staff at the same time every morning and finishes at the same time every night, except for the weekends when one staff member asks Angela what time she would like to go to bed. She, in turn, is equally considerate when family crises mean it is difficult to be at Angela's on time. "The latest I've ever been up is 10.30. I hate inconveniencing other people," she adds. "Even at my age I have difficulty asking for things."



Angela's time in place: 13-18 August, 2011

The same, largely inviolate daily rhythm is also expressed in the pattern to Angela's weeks. "I know what happens every day. All my programmes are in my head." Because of her poor eyesight it is impossible for Angela to go out without assistance. In the week between 13th and 18th of August, 2011, Angela spent all but four hours at home. On Sunday she went to her Dad's for lunch - like she does most Sundays and on Thursday, there was the weekly shop. The rest of the time Angela stayed at home.

Angela only has four hours SIL support each week to help her to access the community and begin to build the types of relationships that are likely to communicate a sense of belonging. Years of institutional living severed Angela from most forms of natural community, meaning that the way formal support is delivered will be an important determinant of Angela's ability to forge meaningful community connection. For Angela, the way support staff are required to "show up,"

appears to contribute to the physical separation Angela experiences from the world beyond her doorstep⁶.

Both Angela and her staff feel the press of time. *"How are we going for time?"* is a question that often passes between Angela and her staff as they both take responsibility for ensuring support needs are met before staff need to move on to the next client. *They only have a certain amount of time,*" Angela keeps telling me, *"Everything has to be done on a timetable. They are in the programme too."*

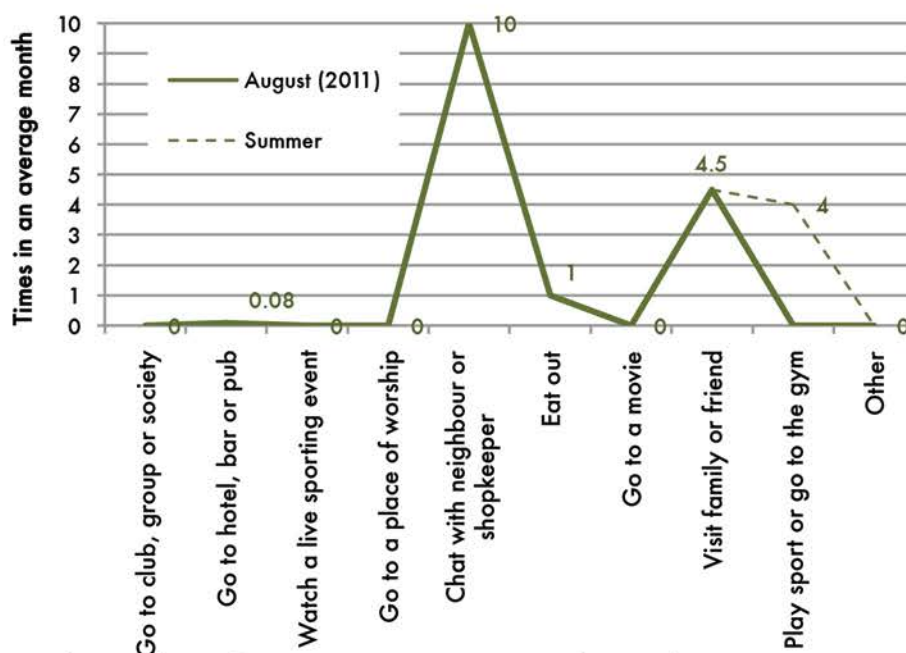
Not only does 'the programme' limit Angela's ability to respond to community events or act with any spontaneity, the limited time available also limits the community contexts that are available to Angela. *"It's impossible to go to a movie or a concert. I can't do anything out of there without somebody with me and CCS say they haven't got enough funded hours. If I wanted to go for a coffee,"* Angela said *"I would have to go without shopping."*

The other, less obvious way 'the programme' defines Angela's community, is in the way that purchased outcomes have limited how Angela and her staff understand the support role. The swimming and shopping and cooking lessons all counted as legitimate types of support activity but Angela was fearful about asking for support that could be construed as *"using her hours the wrong way."* *"It's all tied up with CCS if it can be done. If it's not something that fits their way of thinking it can - otherwise it can't. I don't feel as if it's a normal thing to do (to ask). I have to find another way."*

In an average month, Angela never went to a club or society. Never went to the movies, never watched a live sporting event nor went to a place of worship.

Once a month she would go to town for a couple of hours with Jenny O'Neil, a volunteer and would have lunch with Jenny Firman, perhaps once every three months. They might visit the shops or go for a coffee, but Angela was

careful not to demand too much of the relationship. Angela didn't go out for a meal or to a hotel much either. *"In Heritage week, when the girls are up, we might go out as a family,"* Angela said. A friendship had also started to develop with a neighbour. Maraline lived in one of the back units. They shared a driveway and Maraline had to pass Angela's on the way to the



The number of times in an average week Angela engages in a range of activities

⁶ O'Brien, J. (2012) An Ethics of Possibility. www.inclusion.com/ethicsofpossibility.pdf

letterbox. She had started to pop in, just to say hello about three times a week when the staff weren't around. *'She will become someone quite close (Angela) image(d).'*"

Angela used to belong to a writers group, but quit feeling that little accommodation was made for her visual impairment. *"Some of the things they do would do go over my head and it's too difficult for me to take my computer down and let them know I am not dumb."*

Angela also wanted to work, or at least find some way to add value to her community, but, she said, *"I don't know how to go about doing it,"* and her aspiration to find meaningful employment rarely featured in the discourse of support or support activity.

Interviewer: How well do you know Oamaru?

Angela: I know it very well.

Interviewer: How well does Oamaru know you?

Angela: Most places absolutely nobody knows me.

Interviewer: Well are there any places you feel you belong?

Angela: I wish there was. There is CCS, but things have changed. We have been told you can't just go there now. You need to make an appointment.

It was expensive to do things too. The last thing Angela had done that stepped beyond the ordinary pattern of day-to-day support was to attend a Hammersley Park School reunion, five years ago. *"Anything like that takes a great deal of organising",* Angela said. *"I had to pay for a hoist and a van and a staff person to come with me. It's very costly."*

Interviewer: How many opportunities do you get to meet new people? Do you meet many new people

Angela: No you are about the third in the past two years.

Interviewer: I am the third in the past two Years!

Because of the pattern to Angela's day-to-day life, she had almost no access to community contexts that offered her an opportunity to generate new relationships. Except for the times she was with her family, Angela was only fleetingly present in her community and in a limited range of public community spaces like the pool or the supermarket where money was the medium

of social exchange and Angela could make no contribution to the culture of the setting or the wellbeing of people she shared those spaces with.

Angela, therefore was entirely dependant upon her community coming to her.

When Angela reflected on the fact that she spent all but a handful of hours at home, she said she did not experience any sense of isolation or of being dislocated from her community. In the first place, Angela cherished the freedoms that came with privacy, enjoying, not only her new found ability to live beyond the gaze but also not to have to share her relationships. *The little independence I have, I like.*" Angela said. *"I would never have another body in here. I have had bodies everywhere. Everywhere I went there was always someone sharing my house."*

And secondly, she laughed *"I'm too busy."* Angela had, what her friend June described as "a writers heart." By serendipity, she lives a few hundred metres from the *Waimaru*⁷ house where

⁷ Oamaru is fictionalized as "Waimaru," in Frame's novels.

Janet Frame spent her childhood and like Frame, Angela too might be said to *"persevere by making designs from her dreams and going out into the world with 'no luggage but memory and a pocket full of words,'"* (p11).

Angela had begun to fill her pockets with words from an early age. Her mum would print unfamiliar words in the upper case of typewriter keys and Angela would tap them out on a machine Mrs Cooper would have ready for her father to take home when the family went to collect him from the Oamaru Automobile Association. To this day Angela intentionally uses her writing to expand her vocabulary with the support of reader writers she has employed with the aid of a small grant from the Pamela Webb Charitable Trust. In times past, Angela says her writing has acted as a concrete reminder of the progress the girl who wasn't meant to speak and who started school at 14 has made. It was also a way of demonstrating competence to others when she lacked the ready flow of spoken words. Of late, however, Angela's writing has become an important way for her to explore the way she feels and to express the things that she has not felt able to say.

Angela said she had always found it hard to express her feelings. She attributed her reluctance to having staff as confidants for most of her life. Part of it was that her feelings became service property. *"I'm afraid that everything goes back to CCS. Nothing is kept private,"* she said. Angela's silences limited the possibility that breaches of intimacy could transform her home into a more public setting. Part of it was that when Angela had drawn emotional support or felt especially close to staff she felt she may expose them both to value judgements about the appropriateness of their relationship. And it was partly because, beyond the group therapy or role-plays of Beech Villa, Angela said she had often had her feelings dismissed or minimised. *"When I felt the need to show any sort of emotion"* Angela said, *"it was pushed down. I was told not to cry, don't be angry. It is difficult for staff to listen properly"* Angela described herself as *"locked into (her)self,"* and her writing as offering a safe way for her to write herself into existence. Angela wrote everyday. She had already finished one book, started another and had folders full of poetry. *"I know my writing is not the only thing to look forward to, but that's what I live for at the moment,"* she said.



Angela's writing had also cemented a relationship with her reader/writer, June. June has worked for Angela for four years, but their relationship transcended being a job. Years of respectful conversation which had strayed into the "inner circle," of each other's lives meant that both June and Angela felt at liberty

⁸ King, M. (2000) *Wrestling with the Angel: a life of Janet Frame*. Auckland. Penguin Books.

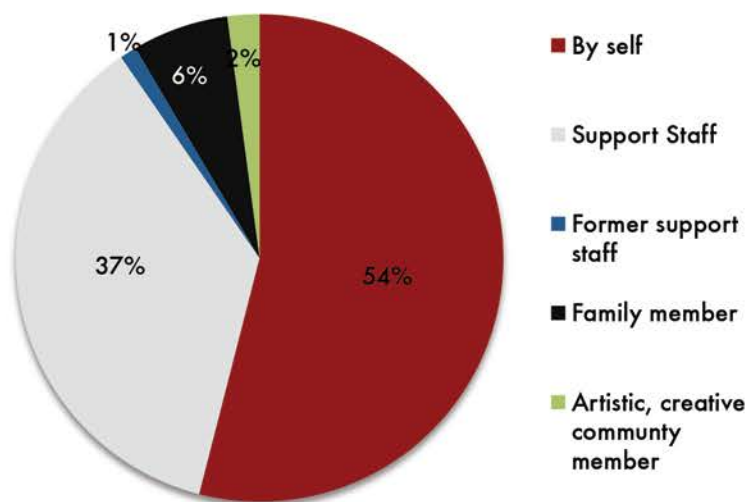
⁹ Marquis, R. & Jackson, R. (2000). Quality of life and quality of service relationships: Experiences of people with disabilities. *Disability & Society* 15(3), 411-425.

to access the vocabulary of affect so often denied people who receive and provide support. It is a relationship that Angela has had to learn to trust. *“June and Heinz have shared so much of their lives. Every time she says she is my friend I say to her, are you having me on? I have never had a friend like June,”* Angela tells us. *“Never!”*

Until June, Angela’s friendships have remained context bound. *“I have tried to make friends before and every time, no matter where I have been they say we will remain friends but no body every has.”* Theirs is a relationship characterized by quiet curiosity, both expressing delight when throwing light on each others authentic self through the medium of Angela’s writing.

When Angela isn’t writing, her computer keeps her connected to the world in other ways. Angela’s computer extended her field of vision. Freed of the constraints of space and time, Angela said she used her computer to *“take (her)self to different places.”* In the time we were together Angela took genuine delight in discovering

images of the school her sister taught at and the Bay she discovered we shared. *“If I didn’t have a computer,” she told me “I wouldn’t have a life. It’s my lifeline - literally. It’s more than my life is worth. That and June’s programme.”*



The community came to Angela in other ways too. In the week between 13th and 18th of August, 2011, Angela only spent half of her time by herself. There was the steady stream of staff that came four and sometimes five times a day bringing stories of the families Angela was vicariously embedded in. *“I like it,”* she told me, *“it helps me get to know people more, not as a support person but as a person.”* Angela also said she *“grew from it.”* Her years at Templeton had left her without a template for an ordinary life and from the stories staff brought, Angela said she could *“build a picture of a normal life, when I am sure they aren’t kidding.”* Angela didn’t care overly about the number of staff who supported her either. *“Every one bought something good,”* she said and the more different the women who supported her were, the wider the canvas of stories from which she had to learn. Angela brought stories too. In addition to the ones she had lived, Angela had a small transistor radio she kept next to her bed so she could listen to talkback at night to have something to sound her staff out about in the morning.

Staff understood too, that their families had become included within Angela's field of care. *"Seldom a shift passes without Angela asking about my family,"* staff told me, *"And we know you care by the way you remember,"* they told Angela.



Angela's bedroom (with transistor radio)

There was dad too. It had been the gravitational pull of family and the opportunity to exchange the social role of patient for the more valued roles of daughter, sister and aunt that had drawn Angela

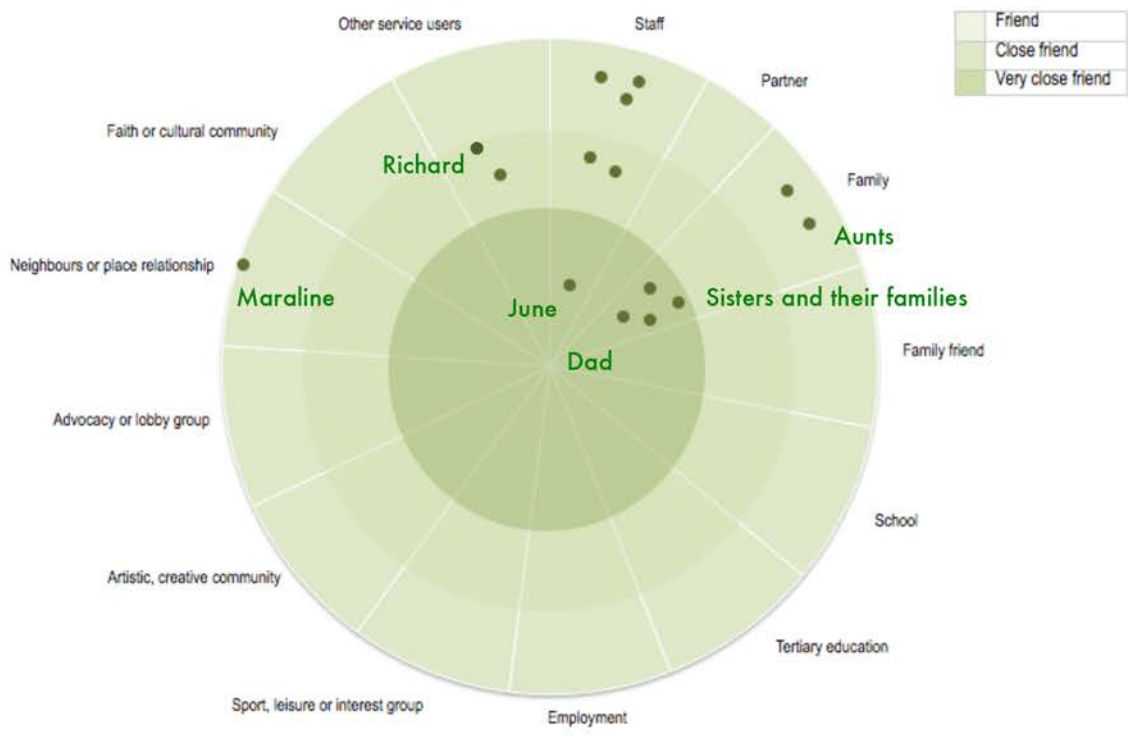
back to Oamaru. In addition to the lunches they shared Angela's dad Pat visited almost every day. He would come with news of the family and neighbourhood gossip or bring practical things - like a new beater. Angela had invited her friend Richard around for her birthday to share cake and conversation. The old beater was giving up its ghost and there was cream to be whipped for the cake. It was a present intended as much for Angela's staff, because Pat also cared for the women whose lives intersected with his own through their shared love of Angela.

Pat and her sisters also represented Angela's best chance of *"finding other ways,"* to step

beyond her programme. They connected her, not just to family and events that celebrated it, but were also the conduit to many activities beyond the ordinary round of day-to-day life, like the occasional trip to the movies or a concert. Angela adored her family. Their photos lined her wall and computer desktop and their birthdays were committed to memory. Pat, however, was 87. *"I know he is not going to last forever,"* Angela reflected and *"my sisters have their own families and their own lives to lead."*



Angela and Richard



Angela's friendship field

Angela's writing and her ability to keep herself busy, coupled with a change in the meaning of the place she now called home meant that she did not experience long hours away from her community as similar to the segregation of Templeton or Burwood. Angela's small friendship field and her absence from contexts that might lead to new relationships, however, did leave her vulnerable to a similar sort of isolation. Other than her family, every relationship Angela characterized as having the attributes of friendship shared a common connection to CCS, including an understanding of Angela informed by her service use. The clear separation between payed provider and passive recipient of support had dissolved into friendship for many staff, but except for the neighbour who had started to pop over when she knew Angela was alone and the common love of writing she shared with June, Angela had no relationships of place that had grown from common interest or of being in places that she saw as autobiographic. Moreover, the inability Angela and her support staff had to step beyond the pre-set routine of her programme meant that it was going to be difficult for Angela to begin to say she no longer felt a stranger to Oamaru.

True friends are like diamonds, Precious and rare.

When we had finished collecting the information we needed to tell her story, Angela and I went for a coffee and a walk to the Oamaru Gardens. Angela confided later that she didn't think it was possible. She *"wasn't sure CCS would let (me) take her out,"* and to date, they had only had enough time to get to the supermarket and back. *"People won't believe it when I tell them! If people can see we've made it to the Gardens without a taxi, there is no reason I can't make it to other places,"* she said. While we were at the Gardens, Angela told me how her dad used to push her manual chair around the same paths when she was little and how her sisters would clamber over the back of the chair. She looked for the hill where, she remembered, the chair would run off, but it didn't look so frightening now.

On the way back Angela cleared the mail. There was a letter from the Cerebral Palsy Association, inviting Angela to a lunch in Dunedin. *"It's nice to get the invitation,"* Angela said, *"but they don't understand what it means for me. There's the cost of the staff and the hoist and the van. They have no idea it's just not possible for me."*

Maraline meet us in the drive. She wanted to let Angela know that there would be a lot of cars coming and going because one of their neighbours had died. Angela introduced me and explained about the project. She told Maraline it wasn't the first time she had written her story and offered Maraline her autobiography, *My Life on Wheels*.

"I'm going to write a poem about today," she told me.



A VISION OF HOPE

WHEN I THINK OF OUR TOWNS PRETTY GARDENS
THE THOUGHT OF ITS PEACE AND SERENITY FILL MY MIND.
THESE GARDENS BRING ME DELIGHT FROM ALL THEIR DEEP COLOURS
BENEATH THE EVERLASTING TREES

THE SOFT AND BEAUTIFUL FRAGRANCE OF THE ROSES
REMIND ME OF MY MOTHER AND HER WARM SMILE
AND THE TIME WE WERE IN OUR GARDEN AT HOME

WHEN I GO HOME TO MY DAD
I STILL ENJOY GOING OUT
IN OUR FAMILY GARDEN
WHERE I DELIGHT IN ITS COLOUR AND PEACEFULNESS

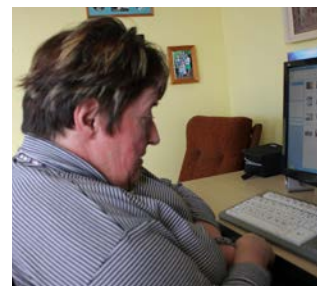
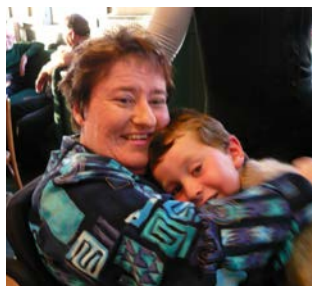
AS I SAT IN THE GARDENS I FELT A SERENITY
THAT TOOK ME OUTSIDE OF THE FOUR WALLS OF HOME
AND GAVE ME A SENSE OF PLACE
OF ESCAPE

IN THE DISTANCE I SEE A TINY SPRING FLOWER STARTING TO APPEAR

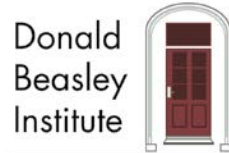
THIS PRETTY VISON
I ENJOYED AS I LOOKED AROUND
WAS LIKE A DREAM TO ME
AS I DROVE AROUND THE PATHS

THESE COLOURFUL FLOWERS ENCOURAGED ME
TO ARRANGE TO DO THIS MORE OFTEN

ANGELA GRIFFIN
TUESDAY 23 OF AUGUST 2011



CCS
disability action
Including all people



Donald
Beasley
Institute
Disability research
and education

TE HUNGA HAUA MAURI MO NGA TANGATA KATOA