"I am here"
The Article 19 Project

Finding a place for the life stories of disabled people

ccs
disability action
Including all people

Donald
Beasley
Institute
Disability research
and education

TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

CCS Disability Action's vision, entitled Te Puawaitanga, puts the goal of seeing every person with a disability included in the life of their community and family firmly at its centre. This is a signal of our commitment to placing disabled people at the centre of our thinking and remaining guided by them at all levels of our organisation.

This vision of a truly inclusive society is seen in our commitment to supporting all disabled people's right to choose their place of residence, to access mainstream community based services and facilities in a way that promotes and respects their right to dignity and most importantly, realise their vision of themselves.

It's an approach that was rightly enshrined by law when New Zealand ratified The United Nations Convention on the Rights of Disabled Persons on 26 September 2008. The convention aims to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. Among 50 articles, article 19 obligates signatories to *'recognise the equal right of all persons with disabilities to live in the community with choices equal to others.'*

Despite some four years passing since we as a nation signalled our intent to put the voices of disabled people at the forefront of our legislative and policy making decisions, the lack of opportunities for meaningful social engagement and participation remains the most significant human rights issue faced by disabled people to this day.

"I am here" the Article 19 Project began as an acknowledgement that people with high and complex support needs were at greatest risk of social exclusion. Their voice has historically been further marginalised because of a perceived difficulty, accessing their unique stories and perspectives.

CCS Disability Action commissioned researchers from the Donald Beasley Institute to work alongside twelve people with high and complex support needs to tell their stories and be heard. It is hoped that their experiences will inform and shape our organisation's journey to remove disabling barriers to social inclusion and community participation.

This project has truly been labour of love for Lorraine Mamea-Hind, who has led and driven this project with an enthusiasm and passion that draws from her strong desire to see the unique mauri (spirit) of all people acknowledged and valued at an orgainisational and societal level. Her desire to put disabled people's voices at the centre of our thinking will ultimately ensure we continue to improve our support services and remain accountable to the people we support is a credit to her. On behalf of our organisation, my thanks go to Lorraine.

The partnership with the Donald Beasley Institute, and in particular the work of Paul Milner to articulate and gather these stories in an authentic way, has resulted in research that is truly world leading in its methodologies.

Our final thanks must of course go to the people, their families and whanau who so generously gave their time, insights and stories. You have all given us a great gift with your perspectives and as an organisation CCS Disability Action is committed to acknowledging your voice as we move forward to a more inclusive society.

David Matthews, Chief Executive, CCS Disability Action

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Executive summary

The origin of the Article 19 Project

The United Nations Convention on the Rights of Disabled Persons (UNCRPD) is the latest in a sequence of conventions that recognise particular categories of humanity as worthy of specific human rights protection.

New Zealand numbered amongst 81 States and the European Union in signing the UNCRPD at its Signature Opening Ceremony on 30 March 2007, and later ratified the Convention on the 26 September 2008. The aim of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, including an obligation to promote respect for their inherent dignity. The UNCRDP contains a preamble and 50 articles, the 19 of which obligates signatories to *'recognise the equal right of all persons with disabilities to live in the community with choices equal to other.'* Article 19 has a particular focus on people's ability to choose their place of residence; to access the community supports they need to prevent isolation or segregation; and to access mainstream community based services and facilities that are in turn, responsive to their needs.

Signatory States are required to ensure that all new legislation and policy is consistent with the 50 Articles embedded in the UNCRPD and Courts are able to make reference to the Convention in their decision making. Article 19 sits alongside a cluster of civil and political rights that are subject to the standard of immediate realisation.

The Article 19 Project represents a response by CCS Disability Action to an ongoing conversation with disabled people and their families that included growing disquiet that those at greatest risk of social exclusion may be experiencing difficulty realising their human right to full inclusion and participation in the community. CCS Disability Action's observation is consistent with findings reported by the New Zealand Office for Disability issues in their first report to the UN in which they described *'Loneliness, lack of participation and the ability to develop social networks within local communities,'* as problematic for disabled people and the Convention Coalition who identified social participation as <u>the</u> most significant human rights issue faced by disabled people.

Difficulty accessing the narrative of people with high and complex support needs has meant, however, that their subjective experiences are yet to inform the disability discourse or the processes of assessment in place to monitor New Zealand's implementation of the UNCRDP. To make transparent the 'un-storied lives,' of this group of New Zealanders, CCS Disability Action commissioned the Donald Beasley Institute to conduct a descriptive study to build a picture of the everyday lives of adult service users with high and complex support needs.

Article 19 Project aims and method

The overarching objective of the Article 19 Project was to use life story as the strategy through which to make transparent the day-to-day experiences of living with high and complex support needs in Aotearoa/New Zealand, with a particular focus on the ability of disabled people to access their Article 19 right to "full inclusion and participation in the community." Five key aims were identified to guide the conduct of the research.

To generate new learning from the diversity of life circumstance and resourcefulness of people with high and complex support and their allies to aid the dismantling of disabling barriers to social inclusion and community participation.

To promote organisational learning and inform service practice in ways that enhance the ability people with high and complex support needs have to feel part of their community.

To make visible the lives of a formally invisible population at a critical time in the assessment of New Zealand's compliance with international human rights legislation.

To provide 'authorised' evidence of the human rights status of people with high and complex support needs, allowing others to partner disabled people in advocating for a more inclusive Aotearoa/New Zealand

To value the life experiences and insight of people with high and complex support needs in ways that allow them to direct social action through the telling of their life stories

The ethic that guided the design of the Article 19 Project was to provide people with high and complex support needs an opportunity to tell their own story their own way. By adopting story telling as the mode of inquiry, the Article 19 Project located itself within the tradition of emancipatory narrative research. A mixed method design was adapted, using multiple data gathering elements to provide important sources of data triangulation and the chance for participants to choose from an array of different ways to generate the conversations they needed to tell their story.

Seven male and five female participants drawn from seven CCS Disability Action branches were selected as participants using a purposeful sampling. Participants' ages ranged between twenty and fifty-two years. Five of the twelve participants lived with a parent(s) in their family home, whereas two participants lived by themselves in a house they owned or flat for which they held the tenancy. Two participants lived with other adults with a physical impairment in a community group home funded through a Ministry of Health contract and one participant lived in a community group home with adults whose primary diagnosis was intellectual impairment. One participant lived with a family under a contract board arrangement and one participant flatted with other adults with physical impairments whose support was provided under a Supported Independent Living contract. Three participants were not currently using vocational support provided by CCS Disability Action to access their community.

One participant wrote her story independently. For all other participants the Donald Beasley Institute (DBI) researcher that worked with them to gather the information they needed took responsibility for writing the first draft of their life story. Space was created during the data-gathering phase for narrative form to be discussed and the motifs that would guide the story writing process were often decided prior to writing beginning. At the conclusion of the

information-gathering phase, the DBI researcher developed a short biographical sketch of each participant. Using a general inductive approach, the biographical sketches were used by the research team to develop a set of major narrative themes. In a second iterative cycle, the original set of themes was further refined by re-analysing participant narrative against the themes by drawing on all of the data gathering elements chosen by the narrator.

In this report the themes that emerged from participant narratives have been clustered in ways that address the access people with high and complex support needs have to the three specific human rights that define Article 19 of the UNCRPD.

The right to live in a place of my choosing

Six of the twelve narratives that informed the Article 19 Project told a story of adult New Zealanders whose lives had not followed the normal adult life trajectory beyond the family home. For all six participants a family member was directly involved either coordinating and/or continuing to provide direct support, most often in the family home that participants had grown in. Whilst all participants had remained at home for different reasons, the unifying theme to their narrative was of the great difficulty people perceived finding services that replicated the quality of life experienced within the ambit of familial love and aspiration.

The life trajectory of most participants, was shaped either by their resistance to or eventual acceptance of the one living arrangement they and their families perceived to be available to them. Few participants recognised living alone or sharing a small household with others with whom they had common life interests or friendship as a right translatable to their own lives. Consistent with O'Brien's observation that today's service systems appear to have developed about an unspoken assumption that people with high and complex support needs cannot have a home of their own. The community group home emerged as the only living arrangement participants or their families perceived as able to meet the physical or behavioural support needs of people with high and complex support needs. Limited placement options also meant that the only decision available to participants was to accept or reject the only service site available to them.

Half of the adults who participated in the Article 19 Project remained in their family home because of fears their life quality would be undermined in residential service settings.

A change in the physical or mental health status of mothers who had been the primary source of support had occasioned the move all but one participant had made away from the family home.

For two participants, a failure to support parents to withstand the emotional and physical demands that threatened the integrity of their family extinguished their right to the home of their choosing before they reached their teenage years.

The lack of available community residential placement options or opportunities to develop more tailored service arrangements meant that the move from home could displace participants from the social landscapes and community relationships in which participants had always experienced a sense of belonging.

All of the participants who needed behavioural support had explored and rejected the community group home as an appropriate model of support. Keeping their family at home was the way families chose to restrict the entry and exits of people they perceived to have the pre-requisite

emotional connection to ensure their family member was treated with dignity and respect in their home and community.

Although participants who lived in a community group home included their flatmates within a field of care, the inability to choose where or with whom they lived meant that they were obliged to share their home with others with whom they had little in common. Few participants included their flatmates within their social network of friends.

Participants experienced limited access to the 'personal,' and 'social' attributes of homeliness necessary to transform their residential service setting into the experience of living in ones home. People who lived in community group homes also exercised no real control over the exits and entrances of staff or the ancillary supports that regularly crossed the threshold of their home. Moreover the day-to-day routines of homemaking and the timing of support that patterned their day-to-day lives tended to reflect the customs and regulations of service culture. For all participants who lived in a community group home this meant their home was inaccessible to them during the day. Between 9.30am and 3.30pm, Monday to Friday, their houses 'closed,' denying participants the ability to direct vocational support in ways that permitted them to participate in very ordinary social moments that centred on the home, like inviting a friend over for lunch. It also meant that the sanctuary of your home or bed was often not available to people for whom feeling weak or unwell could be a constant companion. The distinction participants made between their family home and service setting as social milieu also included the failure of their residential placement to offer the gift of hospitality. Almost all social relationships were transacted beyond the community group home in public settings where it was easier to exchange the social construction of disability service user for the more valued social role of friend.

Two participants either owned or held the tenancy for their home. Both participants expressed great pride in home ownership and counted amongst the benefits the lack of compulsion to live with other disabled people. The opportunity home ownership proved for respite from surveillance including the ability to live beyond the gaze of staff or other residents was also highly valued and appeared to be experienced as a sense of independence.

The psychological comfort that came with security of tenure was also emphasised as an important attribute of home ownership.

Similarly responsibility for maintaining their home and household economy as-well-as having an ability to decorate their home in ways that were both personally functional and expressed their personality also appeared to have a wider symbolic quality, reinforcing their right to personal agency beyond the home. Both participants described home ownership as enabling them to confront disabling expectations including those they themselves had assimilated. It also, they said had allowed them the ability to renegotiate their relationship with support staff.

Home ownership also communicates important cues about the status of the occupant. Whereas participants who lived in community group homes tended to be strangers to their street, evidence was found of emergent neighbouring when participants owned their own homes, with the ability to approach potential neighbours from a position of social equity advanced as contributing to the development of these relationships of place.

Living by oneself however, tended to communicate to funders a diminished need for support, freighting the decision to live alone with the real risk of social dislocation. Participants who lived

by themselves and completed their Time in Place Diary were only beyond their own homes for an average of four hours per week.

Limited vocational staff hours denied participants who lived by themselves access to the kind of conversations likely to lead to the expression of alternative participatory aspirations. Participants waited, they said, for the penny to drop on the larger visions they had for themselves.

The right to be supported in ways that advance inclusion and prevent isolation or segregation within the community

Most people who participated in the Article 19 Project were absent from the types of social contexts that non-disabled New Zealanders derive their sense of participatory citizenship from. Moreover, not having a presence with the worlds of employment, continuing education or inclusive sporting, recreational, creative, cultural, political or geographic community simultaneously denied participants access to the valued social roles of workmate, colleague, friend and neighbour.

Only one participant had any form of paid employment, albeit part-time and casual.

Participants almost invariably remained at school until compulsorily required to leave. After school, participants and their families reported that their social worlds shrank beyond the community of school – a trend amplified by the life trajectory and interests of age peers diverging radically during the transition to adulthood. Despite their strong motivation, participants had no opportunity to recover lost learning through continuing education.

Only one participant belonged to any club or association that also included non-disabled members.

Participants varied greatly in the degree to which they were visible members of their community. Least visible were those that owned their own home. Participants who lived alone spent, on average, 90% of the week that they recorded activity in their Time in Place Diary at home with any community presence typically restricted to public spaces or segregated activity. Conversely, participants who lived in community group homes spent, on average, 52.6% of their week at home, but largely as a consequence of their residential provider 'closing,' their home between 9.30am - 3.30pm.

For a number of participants the CCS Office was an important 'safe space' and an essential conduit to the wider community. At the office, participants could be assured their personal care or health related support needs would be met with dignity and were neither remarkable nor unanticipated. They also had access to respectful communication partners who were less likely to abandon efforts to understand them, relationships that transcended superficial knowing and a place to rest and recover between forays into the community.

The closure of day base activity and canon of individualised support was identified by many participants as denying them access to the fellowship of their generation of disabled people.

Only one participant continued to use a day-base. Despite remaining in the shadows of decision-making and social knowing, the day-base provided structure and purpose to her week and was a context highly conducive to relationship building.

Most participants considered they had few friends. Participants, on average, named less than one friendship from within an artistic or creative community (0.5), advocacy or lobby group (0.2) or as being a neighbour or other place relationship (0.8). Without the skewing effect of two participants who had found their way to the national and international boccia community and a church youth group, the mean number of friends drawn from sport, leisure or interest groups (0.6) and faith or cultural groups (0.0) approximated those for all other participatory contexts. Only one participant had a partner. For the majority of participants their family (27.5%), family friends (8.2%) and support staff were the source of their most frequent, enduring and intimate social relationships.

Participants that lived at home, on average, named 2.7 times as many school friends and 1.4 times as many service users as part of their social network.

The participants whose support involved CCS Disability Action staff collaborating with families to effect community participation tended to have broader social networks and participate in a wider array of community contexts.

Whilst the sample was small, an analysis of the activities that participants in different living arrangements engaged in revealed that only those who continued to live in the family home had visited a friend at their home, attended a celebratory event, gone to the movies or a concert with a friend or attended a community event during the week that they completed their Time in Place Diary. They were also the only participants to have volunteered their labour to a public or private organisation. In addition to their autobiographic knowing and advocacy, families were also more likely to understand enhancing relationship as the destination of community participation and were, therefore, more likely to be attentive to the way people experienced community spaces, including the potential for generating and enhancing social relationships. Participants that lived at home, on average, named 2.7 times as many school friends and 1.4 times as many service users as part of their social network.

The way families read staff and understood the support role also appeared to contribute to participants' greater level of integration within relational community. Families emulated their sons and daughters in constructing staff as part of an extended family of support. Understanding support staff this way provided participants with access to private social spaces, overlapping participatory contexts and additional points of entry into community contexts where membership and not mere presence was the expected social custom. Without the strictures of a formal vocational programme, participants' 'family of support' were able to collaborate in ways that provided greater control over day-to-day activity. As a consequence, opportunities for serendipitous community connection could be captured and followed up allowing participants to be authentically present in their community in ways that 'fit' their passions rather than fit the programme.

Whereas families tended to emphasise relational indicators of inclusion, support that had its origins in service culture tended to emphasise spatial indicators of inclusion and most especially the right of disabled people to be in the ordinary spaces and places of their community. Within service culture, the role of staff was more likely to be understood, as connectors to places whereas family-led service delivery tend to understand staff's role as connectors to people.

Most participants described experiencing their community through a programme. So inviolate was the programme that many described knowing their weeks in advance of living them. Support within a participant's programme was orientated towards the completion of time-framed,

prescribed 'vocational' tasks, which constrained the types of community settings available to participants by limiting their ability to respond to opportunities for community participation with any degree of spontaneity.

Vocational support also tended to be out of cadence with the ordinary social rhythms of the community often transforming otherwise inclusive community settings into segregated social spaces.

The types of places or activity that 'counted,' as legitimate destinations for community participation tended to reflect the historical horizons and social practices of support culture. Support staff and participants appeared to have acculturated to community participation meaning service users ghosting in and out of a limited range of public spaces. Included in that range were the swimming pool, boccia hall or bowling alley, mall, supermarket, gym, library, café, public toilets, McDonalds, the Warehouse and Two Dollar Shop. Almost all of the ways participants experienced community through their programme occurred in public spaces 'on the outer fringes of the daily round of community life.' Beyond the context of family, most participants had limited access to the private social worlds of interpersonal intimacy and inclusion limiting their community presence to spaces that offered little prospect of generating new relationships. Some participants had become included within social rituals that acknowledged their place within the social landscape of settings, but most relationships they encountered through their programme remained at the level of acquaintance.

Almost all of the community activity was moderated by support staff who could unwittingly engage participants in a social bubble of interaction other community members found difficult to penetrate whilst inhibiting the possibility of disabled friends contributing to each other's life quality.

A few participants were present in their community in ways that had led to the deepening of social relationships but these relationships were typically forged when staff were 'offstage' and both partners to the relationship were able to preserve the integrity of their preferred form of social knowing.

The right to access community services and facilities for the general population on an equal basis and for services and facilities to be responsive to the needs of persons with disabilities needs.

Whilst the Article 19 Project did not specifically set out to identify barriers to meaningful participation a number of themes related to participants' access to resources they felt would have improved the accessibility of their community were present in their narrative.

In the absence of paid employment, many participants reported their lack of material resources simultaneously shrank their life space and limited the types of activities they were able to participate in. Being poor also places participants in the position of having to depend on the assistance of people within their informal social network for support whilst limiting their potential to equalise relationships through acts of reciprocity.

Capitalised benefits further undermined the ability participants had to resolve their own social and spatial mobility constraints, whilst limited use appeared to be made of alternative ways for participants to stay connected to people or places that were important to them.

Participants identified siloed service delivery and individualised programmes as making the identification of common interest and the sharing of collective resources problematic for disabled people.

Participants also told us that the physical inaccessibility of New Zealand houses prevented their inclusion within the normal rituals of social invitation. State requirements specified under Article 9 of UNCRDP, limits the discourse of accessibility to public community spaces, identifying as a State's obligation, the need to eliminate physical barriers in urban design, public buildings, public information and public transport, whereas participants in the Article 19 Project told us that their inability to visit friends and family was the issue of accessibility that most affected their life quality.

Communication that lacked the conventions and rhythms of everyday language had the potential to locate participants beyond the common vocabulary of their community. It also exposed them to social othering in community settings where they depended on the attributes of social closeness to make themselves present. Building effective communication strategies with participants who lived beyond their family home often appeared to be swamped by competing service priorities and the limited time staff had available to achieve other participatory objectives. All of the participants who relied on non-conventional expressive communication appeared to have limited access to augmentative and assisted communication (AAC) technology or staff trained in AAC.

Concluding remarks

In spite of three decades of social policy directed at reducing the number of people experiencing exclusion from 'mainstream,' society, the narrative of people who participated in the Article 19 Project informs us about a continuing failure to connect people with high and complex support needs to places or to people able to extinguish their invisibility. By denying them the quintessential human freedom 'to be present with,' participants' inability to experience community in ways that enabled them to respond **_'I am here,'_** speaks to forms of exclusion that contravene their Article 19 right to live independently and be included in the community.

The Article 19 Project adds to a small but growing body of research that has characterised the social position of people with high and complex support needs as strangers to their community, waiting to be called into existence by a society attentive to their life stories.

1 Addressing the invisibility of disabled people

1.1 Sawubona (I see you)

"Sawubona" is the opening phrase of an old South African greeting. The phrase, Orlando Bishop (2011) explains, is a primal word, carried forward from a time "when people were still able to really see each other[1]."

The greeting stems from an African folk saying, which translated means "a person is a person because of people," recognising that it is community that calls us into existence by extinguishing our invisibility. Loosely translated, *"Sawubona,"* means "I see you," to which the expected responses are: *"Ngikhona,"* (I am here) or *"Yebu sawubona"* (I see you too).

Bishop goes on to explain that embedded in the greeting is an invitation to participate in each other's lives and an obligation to interrogate what mutual potential exists as a consequence of being together in the same place at the same time. Sawubona, he adds, requires each person to acknowledge another's reality by reflecting upon the changes that need to be made in order to liberate people from their invisibility. Bishop argues that:

> *".... we have taken freedoms away from human beings, not because one culture oppresses another, but because we have lost the imagination of what sight meant (and) of what inner capacities really mean. It is important to re-establish the question, how do I have to be as a human being in order for others to be free...?. Freedom must be a mutual gift from one human being to another, recognising that if I limit one person's freedom I limit my own. Freedom is not freedom from something or to achieve something. It is the freedom to be present with."*

The United Nations Convention on the Rights of Disabled Persons (UNCRPD) is the latest in a sequence of conventions that recognise particular categories of humanity as worthy of specific human rights protection. The 19th Article of the Convention obligates States to recognise the right of all people to live in the community with choices equal to others[2]. In writing about the way Article 19 seeks to place the "**freedom to be present with"** within a legal framework, Gerard Quinn and Michael Ashley Stein (2009) wrote that one of the central motivations for the passage of the UNCRPD was the "**invisibility of disabled persons"** within the discourses of international law[3]. Megret (2008) also identified the absence of disabled people from human rights contemplation as one possible explanation for the emergence of pluralistic human rights law, but concluded that specific instruments like the UNCRDP were required when the experiences of identifiable groups are so uniquely different that a change to the vocabulary that gives expression to universal human rights is demanded[4].

One of the ways that the lived experiences of disabled people have differed from other citizens has been the historical exclusion of institutionalisation that severed generations of New Zealand men and women from the communities into which they were born. Despite the total institution

disappearing from the New Zealand support landscape when the gates of the Kimberley Centre finally swung shut in the spring of 2006, disabled people and their research allies have continued to characterize the social position of disabled people as "strangers" to their community[5], seen but not known in the deeper understanding of sight inherent in the gesture of Sawubona.

And finally, people with high and complex support needs are strangers to their community in another sense too. Despite anecdotal evidence that people with more profound impairments tend to be most weakly linked to their community through relationship, their life stories have fallen beyond the reach of conventional research methodologies. According to Atkinson & Walmsley (1999), theirs are the "ultimate lost voices," waiting to be called into existence in ways that inform the assessment of society's respect for all human rights[6].

In the Article 19 Project, researchers from the Donald Beasley Institute worked alongside twelve people with high and complex support needs to story their lives in a way that they might be able to respond, **"I am here."**

1.2 Organisation of the Article 19 Report

The overarching aim of the Article 19 Project was to use life story as the strategy through which to make transparent the day-to-day experiences of living with high and complex support needs in Aotearoa/New Zealand, with a particular focus on the ability of disabled people to access their Article 19 right to "full inclusion and participation in the community."

This report, titled ***"I am here:" an assessment of people with high and complex support needs' right to live in the community***, is the first of two pieces of research commissioned by the CCS Disability Action, National Management Team.

The twelve stories co-authored by project participants represents a separate body of work that will be released as a community resource later this year.

This report describes the major themes that emerged when all twelve stories were combined into a single narrative. It begins with a discussion of the importance of telling the largely un-storied lives of people with the most profound impairments as a way of assessing the progress New Zealand is making towards meeting its moral and legal human rights obligations.

The following chapters confront the three ways disabled people are not seen as discussed above. Chapter Two introduces the UNCRPD and discusses the progress New Zealand has made towards implementing Article 19 of the Convention. Chapter Three describes research that has sought to explore the social connectedness of disabled people in the New Zealand context and Chapter Four considers the extent to which people with high and complex support needs are present in the research literature and whether the experiences of other disabled people can be generalised to people with more profound impairments. After a description of the Article 19 Project aims and the method adopted to achieve them in Chapter Five, major themes to emerge from participants' life stories are presented in Chapters 6-8. The Chapters have been organised in ways that promote reflection related to the three specific human rights that define State obligations under Article 19 of the UNCRPD.

1.3 Terms used in the report

In this report, "disabled people" has been adopted as a referent for all people living with an acquired or congenital impairment, consistent with the political construction preferred by people with physical impairments in Aotearoa/New Zealand.

"People with disabilities" has also been used when referring to the UNCRPD, consistent with the person first language adopted as a convention in this document.

"People with high and complex support needs" is used to describe people living with more profound impairments and in particular, people that met the eligibility criteria for participation in the Article 19 Project. Potential participants were considered to have high and complex support needs if they required personal assistance for a set of prescribed support needs drawn from within the life domains of bodily support (nutrition, personal hygiene, dressing, positioning, mobility and transfer, medication and exercise), communication support, sensing or understanding others, making oneself understood) or behavioural support (behaviour that challenges others or makes it difficult to form community relationships, tends to lead to exclusion from community settings or activity, infringes on the rights of others or is potentially harmful, life threatening or dangerous to others).

2 Article 19 of the UNCRPD

2.1 The development of the UNCRPD

On the 13 December 2006, the General Assembly of the United Nations (UN) adopted the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The Convention was the first human rights treaty of the 21st century and, echoing Ambassador McKay's[1] characterisation of the Convention as embodying a paradigm shift away from State benevolence. The UNCRPD has been widely heralded as representing a *"great landmark in the struggle to reframe the needs and concerns of persons with disability in terms of human rights,"*[7] (p.2).

The negotiation process that led the eventual adoption of the Convention took four years, with many attributing its speedy passage to the transformative effect of having disabled people and their representative organisations central to the negotiation process. Disabled New Zealanders took a prominent role in the Working Group set up to develop the Convention text and were part of New Zealand's official delegation to the UN during sessions of the Ad Hoc Committee.

Moriarity & Dew (2011) argue that in addition to providing a useful model of participatory democracy, the relevance of the Convention was ultimately enhanced by the presence of disabled people because their personal narrative led delegations to a deeper understanding of the everyday human rights abuses disabled people face. Disabled delegates also described the negotiation process as a dialogue from which they derived benefits, including the opportunity to demonstrate latent competence and the sense that *"you felt your voice was actually informing the discussions and thinking*[8]*,"*(p.687).

New Zealand numbered amongst 81 States and the European Union in signing the UNCRPD at its Signature Opening Ceremony on 30 March 2007 and would later ratify the Convention on the 26 September 2008. At the opening ceremony, the Secretary-General of the UN drew attention to the UNCRPD adoption date falling in the Christian calendar on the day of St Lucy, patron saint of blindness and light and the metaphor of drawing those ***"in the darkness out of sight"*** into the light of a new era of human rights became a guiding theme for the signing[7].

2.2 State obligations as defined by the UNCRPD

The stated aim of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, including an obligation to promote respect for their inherent dignity[2].

The UNCRDP contains a preamble and 50 articles, which represents the most comprehensive exposition of human rights adopted by the UN. The Convention extends the rights discourse beyond the traditional paradigm based on able-bodied norms to address how human rights can be interpreted and applied in a manner that penetrate(s) the specific violations to which people with disabilities are subject[7].

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[1] Ambassador McKay chaired the Ad Hoc Committee responsible for drafting the Convention text and was one of a number of New Zealanders that had a prominent role in the development of the UNCRPD

Prior to the design of the Convention the UN General Assembly gave the negotiating committee a mandate to limit consideration to the application of existing human rights to the specific circumstances of people with disabilities. Consistent with the mandate, the UNCRPD is advanced as not creating a separate set of rights for disabled people, however, as noted by Kayess & French (2008), the Convention does modify and extend the traditional understanding of rights in ways that include new collective rights. These include: recognition of the right to live and participate in the community (Article 19); awareness raising (Article 8); social protection and poverty reduction (Article 28); and the right to an accessible environment for all persons (Article 9).

Signatory States are also required to ensure that all new legislation and policy is consistent with the 50 Articles embedded in the UNCRPD and Courts are able to make reference to the Convention in their decision making as a consequence of locating disabled people's human rights within the framework of international human rights law. Countries that sign the UNCRPD are also required to establish independent mechanisms to advance the aim of promoting, protecting and monitoring the implementation of the Convention (Article 33) including ensuring that persons with disabilities and their representative organisations participate fully in the monitoring process. In New Zealand, two parallel monitoring processes satisfy this requirement.

Consistent with Article 35 of the Convention, the Office for Disability Issues, as the identified focal point for disability issues, is required to submit to the Convention Committee a comprehensive report on measures taken to give effect to New Zealand's obligations codified by the Convention. This report is expected to identify areas where persons with disabilities are experiencing difficulty accessing their rights. New Zealand submitted its first report to the UN in March 2011[9].

The New Zealand Government also funds the Convention Coalition to monitor the implementation of the Convention. The Convention Coalition is a group of six Disabled People's Organisations. Included within the coalition are; the Association of Blind Citizens, Deaf Aotearoa NZ, the Disabled Persons Assembly, Nga Hau E Wha, Ngati Kāpo and People First New Zealand. In 2010 the Convention Coalition published its first report, Disability Rights in Aotearoa New Zealand[10].

2.3 Article 19

Participatory citizenship, including making explicit the State's responsibility to ensure disabled people have access to the same civil, political, social, economic and educative community spaces available to other members of the community is the unifying theme to the UNCRPD.

The right to "full inclusion and participation in the community,[2]" finds most direct expression in Article 19 of the Convention. Article 19 obligates signatories to *"recognise the equal right of all persons with disabilities to live in the community with choices equal to others,"* with a particular focus on people's ability to choose their place of residence as-well-as access the community supports they need to prevent isolation or segregation and mainstream community based services and facilities that are in turn, responsive to their needs.

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Article 19 - Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Available at http://www.un.org/disabilities/default.asp?id=259

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Figure 1 Article 19, UNCRPD

That disabled people should emphasise this right is not surprising. Up until the imposition of a moratorium on institutional admissions in 1974, the New Zealand Government had held firm to the public policy of institutional care for disabled people. As a consequence of the way Eugenic theory influenced social policy during the first half of last century, the total institution represented the State's only response to meeting the needs of people with disabilities and their families for more than a century. Generations of New Zealand citizens would live out most of their lives within gated grounds of institutions built on the fringes of New Zealand communities as a consequence[11].

In the deliberations that preceded adoption of the Convention, Article 19 was seen as a way to address the affront to human rights inherent in institutional models of accommodation.[2] As a consequence, Article 19 sits alongside a cluster of civil and political rights that are subject to the standard of immediate realisation, unlike the range of economic, social and cultural rights embedded in the Convention that States are obliged to progressively implement.

Without the symbolism of the total institution, however, how Article 19 is read and who owns the meanings that give expression to the right to *"full inclusion and participation,"* becomes critical.

The other reason disabled people emphasise the importance of Article 19 is that subsumed within the expectation of being included in the community are other rights that depend on equivalent access to a wide range of spaces implicit to participatory citizenship – rights captured in Articles 24 – 30 of the UNCRDP. These include the right to a place within inclusive education and life-long learning settings (Article 24), the habilitation and rehabilitation services required to maintain independence in the community (Article 26), opportunities to access open, inclusive and accessible work environments (Article 27) and participation in those places where the political and public life of the community are played out (Article 29) or the cultural, recreational, leisure and sporting activities are enjoyed by other citizens (Article 30).

Milner & Kelly (2009) point out, however, that in the process of depopulating New Zealand institutions "the community" became an epithet for places that looked least like the segregated settings that had been the historical experience of people with disabilities and this paradigmatic understanding of "community" predisposed policy-makers to emphasise spatial rather than social indicators of inclusion[5]. Moreover, derived service outcome measures have also acted to entrench "location" as the most important measure of inclusion. As part of their service contracts, for example, New Zealand vocational service providers are only required to forward to the Ministry of Social Development the total hours service users are actively participating in the wider community, with the wider community defined as any activity which occurs outside of the provider premises, regardless of the way that being in those "community" spaces were experienced by service users.

Disabled people, however, have been quick to remind us that we are socially connected to our communities and that whilst "places" and "activities" are important markers of access to community spaces, they become important as arenas in which moments of inclusion are transacted through the deepening of relationship and the accumulation of shared history. *"It is people, it is people, it people,"* that the adults with intellectual disabilities told the New Zealand National Advisory Committee on Health and Disability (NAC) (2003) were the most important thing of all[13] – a theme that disabled people would reiterate during the parallel monitoring and assessment processes obligated by the UNCRPD.

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[2] A research report published by Mansell, J., Knapp, M., Beadle-Brown J., & Beecham J. (2007), reported that across the 25 countries they included in their study sample approximately 1.2 million disabled people continued to live in institutional settings across Europe12.   Mansell, J., et al., *Deinstitutionalization and community living - outcomes and costs: report of a European Study. Volume 2: Main Report.* 2007: Canterbury.

2.4 Independent assessment of New Zealand's progress towards respecting the right of persons with disability to live independently in the community

As noted above, the Office for Disability Issues, submitted New Zealand's first report to the UN Convention Committee in March 2011[9].

The report opens by outlining the path New Zealand has taken towards ratification of the Convention, including the radical departure to New Zealand social policy initiated by the moratorium on institutional admissions in the 1970s before drawing attention to the legal requirement for the Minister for Disability Issues to report progress made towards the vision of a fully inclusive society to the New Zealand Parliament, as articulated by the New Zealand Disability Strategy [14].

The assessment does conclude, however, that disabled people still experience social discrimination and practical barriers to participation as a consequence of disabling attitudes and variation in the accessibility of community spaces.

With respect to the Article 19 right that disabled persons be included in the community, the report notes that:

> *"Loneliness, lack of participation and the ability to develop social networks within local communities can be problematic [9](p32)."*

The issue of social dislocation had, however, already been foreshadowed by people with intellectual impairments during their consultation with the NAC (2003) who, in the report, "To have an Ordinary Life," would describe being "disturbed" by "life-defining" services and the systemic neglect of the development potential of this group of people and their families / whānau. The NAC were similarly "worried" by the limited opportunities people had to form sustaining personal relationships and the lack of purposeful futures they observed[13](p8).

In their parallel assessment of progress made towards implementing the UNCRDP, the Convention Coalition (2010) was more direct. In summarising information provided by 98 interviews with disabled New Zealanders, the Convention Coalition identified social participation as the most significant human rights issue faced by disabled participants. Whilst noting that this included quantifiable absences, like difficulty accessing work, transport and appropriate forms of communication, they extended the rights discourse by drawing attention to the difficulty disabled people described accessing the *"true and often taken for granted drivers of social participation"* like friendship, other social networks and a place in the social and cultural worlds of community as a major contributor to other forms of marginalisation [10].

In 2009, the New Zealand Human Rights Commission had also conducted a similar online survey to determine what the most pressing human rights issues for persons with disabilities were. They found access to education, employment and equal life opportunities to be the top three issues identified by respondents[15] consistent with the expressions of marginalisation communicated to the Convention Coalition and New Zealand's first report to the UN Convention Committee. The UN would hear for example that with respect to Article 24, only half of New Zealand schools comprehensively demonstrated inclusive practices and that in spite of persons with disability having equivalent access to the same legal safeguards against discriminatory workplace practices,

disabled people were less likely to seek work, less likely to be employed and more likely to be in low paid employment, contrary to State obligations as outlined in Article 27. The Human Rights Commission also indicated that the New Zealand Disability Strategy appeared to have benefitted some disabled persons more than others and that strategies were needed to improve the quality of information to assist the most disadvantaged New Zealanders to realise their human rights.

The following Chapter outlines the efforts of disabled people and their allies in research have made to make transparent the participatory presence of people with disabilities in the research literature.

3 In or Of the community? Research that has explored the right of disabled people to be included in the community

3.1 The first wave of community participation research

The closure of the Kimberley Centre in 2006 was celebrated by the New Zealand Government as signalling an end to the era of institutionalisation and realisation of a policy objective for community living for all New Zealand citizens. It was also celebrated by disabled people as the removal of a potent symbol of their marginalisation[3].

The impetus for institutional closure has been attributed to the confluence of a number of forces for change, including a response to a growing awareness of the dehumanising conditions experienced in institutional settings, the principle of normalisation, an ancillary increase in community based services, legislative reform and the rise of the disability rights and self-advocacy movements[11]. As Australian writers Bigby, Fyffe, & Mansell (2006) noted, however, it was the inability of institutional settings to remedy the social dislocation of disabled people from their community that ultimately sounded their death knell[16] – the reverberations of which continue to ring out in Article 19 of the UNCRDP.

As a consequence, the extent to which disabled people were present in the ordinary places and rhythms of the wider community became an important focus for the first wave of community participation research as researchers sought to document the process of institutional closure and describe the outcomes for people following the diaspora. A cluster of influential meta-analyses conducted alongside the process of first-world deinstitutionalisation [17-19], including research conducted in the New Zealand context [11], consistently demonstrated a general, though not inevitable improvement in the wellbeing of former residents in the wake of resettlement. This included a tendency towards increased levels of participation in everyday activity and decision making, together with greater access to community spaces and events.

As O'Brien (2003) would later point out[20], however, being "in the community," is not the same thing as "feeling of the community," and whereas the first wave of community participation research tended to emphasise spatial indicators of inclusion, two strands of research emerged that began to suggest that in spite of the imperative to re-embed people within the community, many disabled people continued to be as socially dislocated from community relationships as they were before major institutions disappeared from the support landscape[21].

3.2 Places, people and a sense of belonging

Hall (2004) recently identified reducing the number of people experiencing exclusion from "mainstream" society contexts as the unifying theme to social policy in the United Kingdom[22]. Like the United Kingdom, New Zealand social policy has also been strongly informed by disability theorising which has emphasised the presence of disabled people in mainstream community

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[3] The New Zealand Government imposed a moratorium on institutional admissions in 1974 and announced a policy decision of community living for people in long-stay institutions in 1984.

spaces, including the principles of "normalisation," "social role valorisation," and the social model of disability. As noted previously, Milner & Kelly (2009) argue that as part of a collective attempt to escape the long shadow cast by a century of institutionalisation, the theorising that has informed our understanding of community participation has tended to focus on spatial indicators of inclusion, and in particular, whether people were present in places that looked least like the segregated settings that shaped the life experiences of generations of disabled men and women[5].

Whilst the meaning of "community" has not gone uncontested, most definitions tend to emphasise the interrelatedness of three core elements; place, people and a personal sense of belonging to both. Research that interrogated whether disabled people were included within community social networks began to contest the positive conclusions drawn from the first wave of community participation research, as would a handful of studies that used more qualitative methods to explore where disabled people experienced their sense of membership or belonging.

3.3 The social connectedness of disabled people

Furedi (2004) recently argued that it was the *"the colonisation of people's informal lives,"* that was required if disabled people were to step beyond being *"in the community,"* to also become members *"of" their local community"*[23]. Furedi's assertion echoed an observation Newton, Horner, Ard, LeBaron and Sappington (1994) had made earlier. They argued that, because social relationships could be considered the essential element to inclusion, the ability of human support service to foster and support human relationships was not only an important marker of the inclusiveness of the society in which service culture is embedded, it ought to be the primary yardstick against which disability services measured their effectiveness[24].

Newton et al (1994) were responding to a growing body of empirical research that had started to describe the social poverty of disabled people's lives.

In an early investigation, Kennedy, Horner & Newton (1989) directly observed the social contact 23 adults with intellectual disabilities had with other members of their local community. Despite living in what the authors described as relatively "enriched," services, the study found patterns of social activity characterised by very few ongoing interactions between participants and other community members[25]. On average, there were only 2.3 community members who interacted at least once in 12 of the 30 months during which the observations were conducted and only 1.2 community members who interacted in at least 20 of the 30 months. In addition to a pattern of limited social contact, people tended to have a fleeting presence within the social world of participants. Of most significance to the authors was their finding that community relationships seldom continued for more than 12 months, with family tending to provide the single continuous narrative to participants' lives.

Todd, Evans & Bayer (1990) also explored the opportunity disabled people had for wider social interaction within the community and found minimal levels of interaction, even when high levels of "participatory activity," were observed[26]. In their study, Todd Evans & Bayer examined the community activities and social networks of 318 people with intellectual disability living in Welsh communities. They reported that although participants were typically involved in a wide range of community activities, only a small number of people were engaged in types of activity that offered them the potential for ongoing social contact. They also reported that over half of the study group had no identifiable friends apart from family, paid staff or co-residents. Todd, Evans & Bayer concluded by invoking Georg Simmel's social typology of the physically present, but culturally

distant, "stranger," to describe the social position of disabled people. The characterization of disabled people as being present within "small action spaces," and on the "outer fringes of the daily round,[27]" of community life would provide a recurring theme within subsequent research.

In one of the larger investigations of the social relationships of people with high and complex support needs, Robertson et al (2001) also described a pattern of restricted social networks. In a study that included 500 disabled adults living in varied types of residential settings, Robertson et al collected information about the composition, and character of participants' currently active social network[28]. Major findings from the study included that, when staff members were excluded, the median size of participants' social networks was two people, with one quarter of participants naming one or fewer people in their social network. A paid staff member was named by 83 percent of participants as an important member of their social network and whereas staff and family members were understood as the main sources of informational, practical and emotional support, disabled people were rarely constructed as providing support to others.

In the absence of other types of community relationship, a similar pre-eminence in the social significance of paid support staff was recently reported by Chris Bigby (2008). Bigby followed 24 adults with intellectual and physical impairments out of a Melbourne institution and collected information about the size and composition of their informal social networks. In her paper titled, "Known well by no-one," Bigby described finding that five years after moving to community based services, half of the study participants had no friends other than staff and, on average, participants only had 1.92 people in an informal network that also included family members[29]. None of the study participants had had a partner in the five years since moving from the institution and despite 75 percent of service plans identifying maintaining or establishing social relationships as a goal, family contact and the number of named, unpaid close friends decreased in the five years that participants had lived beyond the institution wall. Twenty years after the first wave of deinstitutionalisation research the men and women that participated in Bigby's study remained strangers to their community, seen but typically known well by no one.

Against the backdrop of an array of studies documenting the fleeting character of community relationships, Newton, Olson & Horner took an alternative approach by seeking to identify and study stable relationships between community members and adults with intellectual disability living in community services. Of the four factors they found that contributed to the stability of relationships, qualitative aspects of relationship were to the fore[30]. The perception of reciprocity in the relationship was found to be an important determinant of relationship longevity coupled with a willingness of both partners to overcome practical barriers to regular contact. The most important predictor of relationship durability was, however, community members having previously been staff members – the first clear evidence of a shared capacity for disabled people and their staff to colonise the inner circle of each other's lives in spite of professionally constructed social roles.

3.4 The social connectedness of disabled people in the New Zealand context

Since the policy decision was made to pursue community living for all citizens, only two studies have directly examined the way disabled people are socially connected to their communities in the New Zealand context.

The first study anticipated much of the international research directed towards assessing the social connectedness of disabled people to their community. In 1997, the Health Research Council of New Zealand funded a follow-up investigation into the lives of 61 people with an intellectual disability who left Kingseat Hospital for North Island communities eight years earlier. In a study that predated Bigby's (2008) investigation of the informal social networks of adults resettled from an Australian institution by almost a decade, O'Brien, Thesing, & Capie (1998)[31] found the majority of former residents had made few, if any, community contacts. The authors also described participants as having very small friendship fields and observed that, in spite of high levels of service activity directed towards taking participants into the community, little evidence was found of focussed assistance to support the development of a growing network of friends and acquaintances upon which relationships could be built. Similarly, whilst staff and family described the acquisition of new social and self-help skills as one of the advantages of community living, these did not extend to the development of new social roles such as those of friend, neighbour, worker or club member.

Eight years after moving from Kingseat Hospital, O'Brien et al described patterns of community engagement that continued to be moderated by support staff and were almost always transacted in public rather than private community settings. Most participants, they concluded "ventured," into their communities with the authors proposing a three-fold typology that captured the way residents tended to gain a presence and participate in their community post-resettlement.

The first group they described as community venturers. These participants typically left for community spaces as part of a group of people with intellectual disabilities, supervised and supported by staff and returned having had few exchanges with the public and limited access to social connection that could lead to the development of personal relationships. The second way people frequently visited ordinary community spaces was qualitatively similar to venturing, but staff encouragement and a continuous presence had resulted in people beginning to forge social knowing, particularly by being encouraged to purchase goods and services or choose places to visit regularly. O'Brien et al described these residents as community participators and assigned 76 percent of their study participants as falling into these two categories (65% ventured and 11% participated in their community). Least typical were a group that O'Brien et al described as community networkers. Networkers frequently visited ordinary places with both disabled and non-disabled people. Their interactions with the public tended to be routine and purposeful and many belonged to clubs and associations where their sharing time in place meant that they had become incorporated within the social landscape of community spaces. Networkers were also the only group able to forge social connection beyond the gaze of professional staff. O'Brien et al also noted that the attribute this group shared was the ability to control the presence of staff. Most of the social connections that participants who fell into the networker typology had been forged when participants did not have to contend with the social construction of disability service user as staff had tended to be offstage.

The second major study was a participatory action research project commissioned by CCS Disability Action. The project's aim was to explore the understanding disabled people had of "community participation," by placing their voices at the centre of the research process. **The Community Participation Project** continues to represent the most comprehensive investigation of the access disabled people have to New Zealand communities and adds to a small but growing body of research that has explored the way disabled people subjectively experience their community[32].

3.5 Disabled people's subjective experiences of community participation

Cummins & Lau (2004) argue that the sense of community connectedness through relationship represents the very "heartland" of life quality[33]. Recent critiques of the social policy understanding of community participation as an issue of access to "mainstream" community spaces have also focussed on dimensions of social relationship. Researchers like Walker (1999), Hall (2004) and Milner & Kelly (2009),[5, 22, 34] for example, have attempted to reframe the issue of inclusion to include consideration of the access disabled people have to the richer qualitative experiences of "***being in place***" that contribute to feelings of belonging, connection and fellowship or antithetical feelings of ***"being out of place,"*** as a consequence of forms of social othering, anomie, isolation and a more general failure to acknowledge people's bodily and social realities.

In a literature review prepared for the National Advisory Committee on Health and Disability prepared to inform the "Ordinary Lives Project," Bray & Gates (2003) note that the majority of measures used in research conducted to assess the ability disabled people have to live independently and be included in the community have, to date, largely excluded people's subjective experiences of community participation[35]. Hall (2004) cites Coles (2001), who argues this exclusion is more pronounced for people with high and complex support needs because the dominant construction of people whose impairment includes intellectual disability have resulted in research designs that privilege the voice of others whilst keeping their narrative *"in the shadows"* of research and policy making[22].

Pamela Walker, however, employed participant observation and repeated interviews to provide an in-depth analysis of the experiences of seven adults with a range of impairments in one of the first attempts to represent the subjective community experiences of disabled people.

Walker (1998) described participants as spending significant amounts of time in separate spaces, often within larger community settings that also included non-disabled community members[34]. She reported that these enclaves of impairment existed across most dimensions of community life, including educational, residential, work and recreational spaces. Walker also found participants had limited social networks and, consistent with the empirically orientated studies outlined previously, spent very little time in the private social worlds of people beyond their immediate family. Like O'Brien (1998), Walker reported participants tended to experience their community in public spaces, like city streets and shops or the mall and the café, attributing their lack of access to less public community contexts to the small social networks she observed.

From the narratives of participants, Walker identified six broad themes that she suggested may be thought of as experiential continua participants used to describe community spaces. The themes included negative and positive experiences related to feeling vulnerable, anonymous, coerced or accepted, and the degree to which community settings were familiar or accommodated bodily difference.

Participants, for example, felt safest, in familiar places of their own choosing but conversely experienced a sense of greatest vulnerability in settings that were unfamiliar or in which they had experienced moments of rejection or a lack of support. Feeling known was contrasted with antithetical feelings of anonymity or of feeling isolated. Walker found that participants tended to feel more isolated in large, public spaces, even when they went regularly and that participants described places where they anticipated being excluded. In contrast, participants tended to feel a

sense of being known in smaller settings that participants chose to attend on a regular basis. The participants that spoke to Walker also distinguished between community contexts where they experienced feeling liked, contrasting them with other community settings where they reported feeling unwelcome and out of place. Familiarity also contributed to the way participants subjectively experienced their community. Knowing what to do, including being able to navigate and adapt to the social conventions and rituals of place, were found to influence participants' patterns of community use with some describing avoiding unfamiliar places for fear of exposing their "outsider" status. Participants were also aware of places where they knew their support needs would be met and other spaces that either did not make any accommodation for bodily difference or where they did not know whether support would be available.

By giving voice to the experiences of disabled people, Walker's research provided a conduit for them to contest the policy assumption that increasing the presence of marginalised populations in mainstream community spaces necessarily represented a remedy to the social exclusion of disabled people. In their narrative, participants highlighted a potentially oppressive denial of the experiential reality of community participation that, for many, also included the "normality" of disorientation, discrimination, abuse, intolerance and more subtle forms of personal exclusion[36]. Moreover, Walker's research further suggests that, when able, people were active participants in the process of community formation, gravitating towards places where they experienced positive community feelings along the six continua she identified and avoiding those places in which social interaction was experienced as exclusive. Patterns of community use similarly informed by a geography of feeling in and out of place were reported by 21 disabled people from Scotland in a study conducted by Edward Hall.

To learn more about the social geographies of disabled people in Scotland, Hall (2004, 2005) conducted group interviews in five locations. Participants were collectively invited to describe their presence in and engagement with a range of social spaces, including their homes, friends and family, work and vocational places, and their experiences, concerns and delights that related to where they lived, worked and socialised[22, 37].

Through the narrative building process, participants affirmed to each other that marginalisation was not only about not having an opportunity to participate in the same community spaces as other citizens, but was also experienced in forms of personal and bodily exclusion that occurred on a day-to-day basis regardless of the acculturative status of settings. The people who spoke to Hall described experiencing exclusion through non-verbal feelings, looks and stares and behaviours Atkinson et al (cited in Hall; 2004) argued, act to maintain the dominant (non-disabled) order of social spaces by containing the threat of bodily difference.

Experiences of exclusion and rejection were not confined to public settings, but continued within the outwardly inclusive spaces of paid work and independent living. In open employment, for example, participants described working fewer hours for less pay and of being excluded from the ordinary processes of career development and promotion. The disabled people that spoke to Hall also described occupying positions of social and spatial marginalisation, stacking produce in the freezer or wheeling trolleys in the car park, away from the social action at the heart of workplace culture. Echoing Todd, Evans & Bayer's invocation of the social typology of the "stranger," Hall argued that as a consequence of the social othering participants experienced because of an understanding of disabled people as, "out of place," in many community contexts, theirs was a *"social life characterised by physical presence and simultaneous social absence,"*[5] (p."

302). For some, he concluded, this led to shrinking social worlds and *"limited and very particular social and geographical networks of safe spaces,"* (p.302).

Like the participants whose construction of their community included an assessment of spaces along the acceptance continuum identified by Walker (1998), participants in Hall's study contrasted community contexts that were not socially inclusive with places where accommodation for impairment and the experience of feeling welcome were assured.

Hall observed that this differentiation tended to inform a mental *"map of social acceptance and rejection,"* that underscored an often-shared social geography of presence and absence. Like Walker's findings, Hall observed participants excluded themselves from certain public spaces, preferring instead others that allowed them to keep in contact with people in whose company they experienced a sense of community and safety and where disability was accepted, valued and normalised.

The participants that spoke to Hall often described experiencing community in settings that challenged the existing understanding of mainstream public spaces as the only legitimate location for community participation. Milner & Kelly (2009) argue that, by framing community participation and inclusion as occurring only within the communities that disabled people tend not to be present has the potential to blind us to the value of the multiple communities to which disabled people have always belonged[5]. Furthermore, as Hall points out, limiting the appropriate contexts for inclusion to the spaces of the social and economic majority also excludes the alternative imaginings of community held by disabled people as distant as Scotland and New Zealand, from the discourses of inclusion.

3.6 Disabled people's subjective experiences of community participation in the New Zealand context: *The Community Participation Project*

In 2003, CCS Disability Action (CCS DA) commissioned the Donald Beasley Institute to conduct a participatory action research (PAR) project that engaged adults who accessed support through their existing vocational contracts. The aim of the project was to develop shared understandings of community participation and to describe the implications that a more sophisticated understanding may have for those who use, provide and fund disability services in New Zealand.

Twenty-eight disabled adults, drawn from an array of different vocational support contexts in five CCS DA administrative regions collaborated with a research team that also included disabled researchers. Participants contributed their experiences in any or all of three ways, volunteering their narrative within focus groups, semi-structured individual interviews or self-authored stories. Participants also helped to refine analysis during two action research cycles.

The "***Community Participation Project's***" principle authors, Milner & Bray (2004) reported that participants described living dichotomised lives that oscillated between two contrasting community spaces[32]. Home and the vocational centre were at the epicentre of participants' lives. Most of their lives unfolded in these two settings and almost all activity radiated out from them. Many participants expressed feeling vulnerable to the social isolation and the vocational centre was often a welcome respite from long hours spent bored or alone at home. Common to the narratives of most participants was a sense of being socially dislocated from their community.

Most participants considered they had few friends and said their sense of marginalisation from the world of interpersonal intimacy greatly compromised life quality, as exemplified by one participant's evocation of trying to get people interested in her.

> "Well, I like to get out and meet people, get to know people, and people can get to know me. I have said to the Polytech students, if there is anything you want, give me a ring. I have even given them my number, but there is nothing out there. I wish I could get out more, meet more people, get other people interested in me,"(p.25).

Relationships within friendship circles also tended to be bound to one particular setting and staying in contact almost always involved an act of migration away from the places where participants felt known and validated to spaces where they tended to occupy positions of inferior cultural knowledge, expertise or social capital. *"No-one,"* they said, *"came to their houses."*

Beyond service settings the community tended to be experienced as fleeting and irregular visits to unfamiliar public amenities, trips to the shops and walks which broke up the routine of service provision. Staff usually accompanied service users into the community with the types of participatory activity engaged in restricted to a narrow range of "authorised," activities that tended to reflect the social practices of historical service provision rather than participants' autobiographic aspirations. Bocce, swimming, 10-pin bowling, the gym and crafts featured in all participants' activity patterns.

Participants were, however, acutely aware of the values, policies and assumptions that underscored service interpretations of "community" versus "segregated" settings and readily reflected an understanding that public spaces were the "correct" location for community participation and that involvement with other people with disabilities implied a less valid form of community connection. In their vernacular the community was *"anywhere not at home or the centre"* or *"out there!"* in spaces that offered liberation from service settings. The "publicness" of more assimilative spaces appeared to be important. For many the community only existed in spaces occupied by both disabled and non-disabled people, with their presence providing some participants with an affirming sense of public acknowledgement whilst for others it represented an expression of their political right to occupation. For people with small social networks, the community also held the promise of new relationship.

Feeling *"out there"* was contrasted with an antithetical feeling of being *"shut away,"* and being in the community was initially perceived to be diametrically different to being *"stuck"* or *"hemmed into"* the cardinal spaces of home and the vocational centre. But by locating community in anomic public spaces, beyond both the ambit of their ordinary lives and beyond their spheres of interpersonal intimacy, the CCS DA service users that contributed to the **Community Participation Project's** initial reading of "community" was at odds with the broader, societal understanding of the construct. Milner (2005) speculated that the explanation for this finding may reside in the dichotomised life-spaces participants described.

Milner (2005) used one person's fictionalised life ("Pamela") as a device with which to summarise major themes that emerged from the Community Project[38]. Plotted against the perceived proximity of social spaces (x-axis) Pamela's engagement with her community mirrored the pattern of spending long hours hemmed into residential and service settings from which she was fleetingly

liberated by visits to local cafés, the shops, bocce "walks" from the day-base and the weekly van ride that participants described. Indicative of some participants, "Pamela" was also said to do volunteer work at a kindergarten for a few hours a week, which was considered by Pamela to be "work," and by her service to be "work experience."
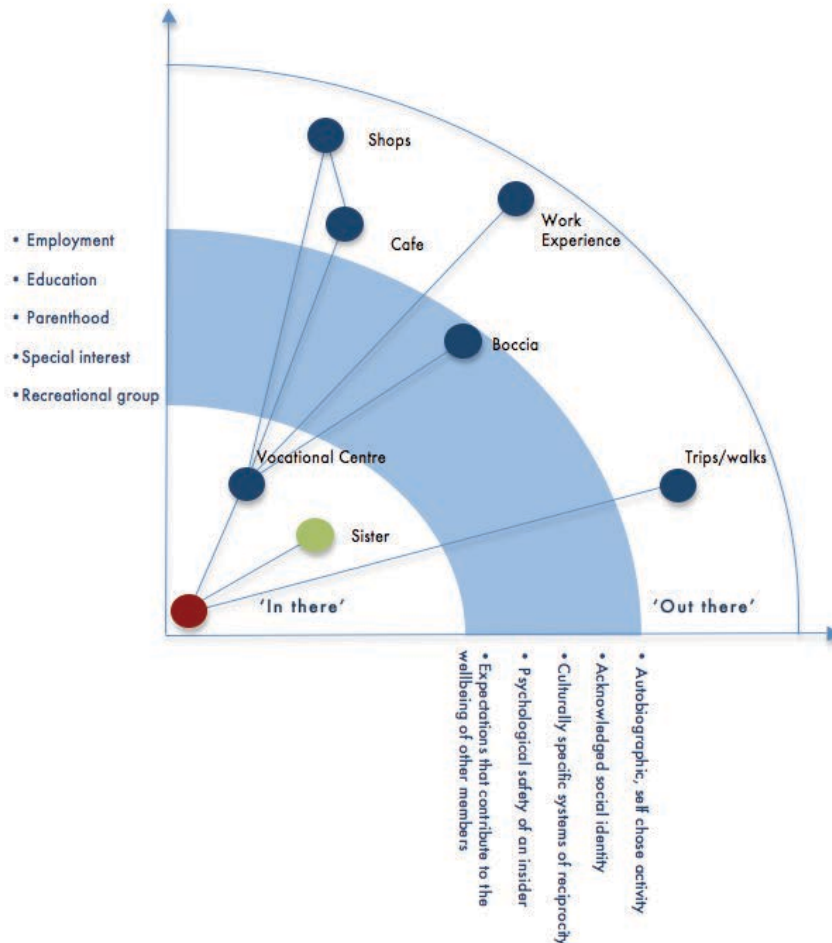
Figure 2 "Pamela's" Fictional Life Spaces

Missing from every day lives of participants that Pamela's fictionalised life summarised were the intermediary social contexts between being "stuck in there," or "out there." The people who collaborated in the Community Participation Project were all absent from the worlds of paid employment, tertiary or adult education, parenthood and neighbouring at the time of the study. Many were also absent from special interest or recreational groups that are understood by non-disabled New Zealanders as the type of community contexts that underscore a sense of participatory citizenship. The absence of participants from these social spaces was theorised as restricting the opportunities disabled service users had to access the socio-emotional attributes of belonging or membership to the two contrasting community spaces they said they experienced.

When participants spoke about where they themselves experienced a sense of belonging the acculturative status of settings became less important. What mattered most to people was not

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where but how they participated. Five key attributes of place emerged as important qualitative antecedents to a sense of participatory membership and belonging.

The most highly valued forms of participation were **self-chosen** activities that people undertook with a degree of autonomy and felt were autobiographic. Conversely, the absence of control over the timing or form of participation was experienced as demeaning and disabling. Being able to decide where, when and with whom participants were in public settings with, was a key determinant of the level of comfort they felt in the company of staff or other people with disabilities. People gravitated towards relationships and places where they felt known and affirmed. Most important was that participants felt embedded within the social history of a location. Participants' families, places of worship and a limited number of recreational settings were named as contexts where some participants had established positive **social identities** through their continuous presence. Participants consistently identified **reciprocity** as an important marker of membership as-well-as a way to challenge implied dependence. They also emphasised that finding ways to reciprocate within relationships was both the glue that bound friendships and key to humanising important relationships. Conversely limited expectations were universally perceived to be amongst the most disabling barriers to community participation. Finding opportunities to "prove" oneself was a common theme and accessing the community spaces and relationships people felt marginalised from was advanced as the way disabled people could confront debilitating expectations. In stark contrast, people with disabilities tended to influence each other's participatory expectations through processes of mentoring and encouragement. Participants therefore described feeling a sense of belonging when their community **expected them to contribute** to the wellbeing of other members. And finally, participants said they experienced a sense of belonging in social spaces that were themselves known and predictable and within which they were able to experience the **psychological safety** of feeling an "insider," aware of the social customs and mores that contributed to the culture of a setting.

Whilst participants were unequivocal, both about the dangers of becoming ghettoised within professionally authored and disempowering disability settings, when they applied their own metric of belonging to their own life spaces, it tended to be the segregated settings that stood out as beacons of relationship and knowing[5]. Similar to the communities of respite and refuge, Hall (2004, 2005) reported disabled people in Scotland had included as part of their community map, an appreciation of the way participants' disabled peers transformed the spaces they shared into more socially inclusive settings, kept threading its way through participants' narrative[32].

Being in places where bodily difference and support needs were unremarkable and anticipated contributed to a sense of personal safety. Participants also said they valued the commitment of others to finding ways for them to express themselves, including their exposure to the mentorship, empathy and self-effacing humour they saw as attributes of the culture of physical impairment. People told the research team, that these were the places where they felt most able to disclose their private selves and for some, it was one of the few contexts where they felt able to add value to the lives of other people, even if as simple as acknowledging the importance of friendship with a cup of coffee.

Milner & Bray concluded by suggesting that prioritising location as a marker community participation appeared to have led to disability support practices that made it difficult for participants to replicate similar levels of intimacy and inclusion beyond the walls of the day-base or community group home.

Participants, for example, characterised their *"doing community participation,"* as being taken by staff to community spaces as fleeting and irregular visitors. Being in the community in this way precluded the sustained presence they said helped others to see beyond their impairment and for them to become assimilated within the social landscape of a setting. Community participation supported from service settings also tended to be steered towards public spaces rather than the private social contexts where people were more likely to experience the sense of psychological safety or become embedded within the culturally specific systems of reciprocity they said were elemental to the experience of community membership or belonging (Table 1).

Table 1 Personal and service understandings of the attributes of meaningful community participation (Adapted from Milner & Kelly; 2009, p.58)

Attributes identified as contributing to a sense of membership and belonging	Attributes of "community participation" service support
A sustained presence likely to lead to a valued social identity	Fleeting and irregular community presence
Access to the private social worlds of intimacy and inclusion	A participatory presence in public spaces
Humanised relationships	Participation moderated by staff within the defined social roles of staff and service user
Self authored autobiographic activity	The timing and range of activity shaped by service practices
Being inside communities at ordinary times and places	Support delivered outside the pattern of ordinary community social rhythms
Relationship bound by culturally specific systems of reciprocity	People purchased goods and services as part of their community experience
Actively engaged in community formation and expected to contribute to the wellbeing of other community members	Adopted the more passive role of service user
Collective action	Individualised service delivery

The people that spoke to Walker (1998), Hall (2003) and Milner & Bray (2004) were, however, able to articulate their experiences in ways that did not overly tax conventional qualitative research methodologies. Their distress at being excluded from mainstream community settings also tended to be rooted in a failure of community contexts to accommodate impairments that ought not to exclude their participation. What remains unclear is how representative their narrative was of the lived experience of disabled people with high and complex support needs.

Prior to the 1980s, dominant constructions of mental capacity meant that it was unusual for the voices of those whose disability included learning or intellectual impairment to be heard in disability discourses. It was equally rare for researchers to seek out their views or attempt to understand their experiences. In the 1990s, a small number of studies, including research conducted by Tim and Wendy Booth (1996) established the views of people who were, *"chronically short of words,"* (p.60) as a narrative equally valid as the perspectives of relations, practitioners and researchers who spoke on their behalf.[39] Few studies have, however, sought to elicit the life experiences or theorising of people with high and complex support needs, an omission Boxall & Ralph (2010) view as the tail end of a wider pattern of exclusion in the lives of disabled people[40]. The following chapter outlines the thin volume of research that is available from which to make inferences about the ability people with high and complex support needs have to access their UNCRPD right to a place in the community.

4 The distinctive social lives of people with high and complex support needs

4.1 A second class of disability?

In 2010 the New Zealand Human Rights Commissioner identified disabled people as among the most marginalised in New Zealand society. In their report, The rights of disabled people - Ngā tika o te hunga hauā, the Human Rights Commissioner also noted that whilst the New Zealand Disability Strategy had improved the human rights status of some disabled people, other lives had remained largely untouched by the policy aspiration for a more inclusive society[15]. Her observation is aligned with Swift & Mattingly (2009) who, following their wider review of community-based day activities for people with learning disabilities in the UK, concluded that people with high and complex support needs represent a "second class of disability," last to benefit from service reform and most weakly connected to their community[41].

The Human Rights Commissioner and Swift & Mattingly's observations were largely impressionistic, however, their sense of the greater social dislocation of people with profound impairment tends to be borne out by a small cluster of empirical studies that include people with high and complex support needs in their exploration of disabled people's social networks. A second stream of research that sought to account for variation in quality of life outcomes revealed in the first wave of deinstitutionalisation research also highlighted type of impairment as a powerful determinant of the access people had to their right to a place in their community. Both streams of inquiry are described below.

4.2 Social network analysis that included people with high and complex support needs

One of the first studies to expose the association between participant attributes and the linkages people had to their community was the study by Todd, Evans & Bayer (1990) described previously. At the conclusion of their examination of community activity and the social networks of 318 people with intellectual disabilities living in Welsh communities, Todd Evans & Bayer described finding that participant attributes appeared to make a difference to the range and frequency of activities participants were observed experiencing[4]. Younger participants (less than 24 years) were significantly more likely to be involved in community activities than their older peers (over 45 years) as were the cohort they described as "more able,"[26].

Todd, Evans & Bayer's findings were replicated a decade later by Robertson et al's (2001) exploration of the size and composition of 500 disabled people living in different types of residential settings across the UK. Robertson and his colleagues reported that age and adaptive behaviour were amongst four personal characteristics that explained variation in the size and composition of participants' social networks[28]. Younger participants, on average, had larger social networks that were also more likely to include a relative, non-staff member and non-disabled person and "higher functioning" participants' social networks were also more likely to include a relative, non-staff member and non-disabled person. The other personal characteristics

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[4] Described in more detail in section 3.3

associated with variation in the size and composition of participants' social networks were autistic traits and behaviours described as challenging.

In their investigation of the linkages between assessments of participants' adaptive behaviour, levels of autonomy and community integration Heller, Millar & Factor (1999) also found evidence of an association between participants' level of impairment and the frequency with which they participated in a range of community contexts. Heller Millar & Factor used the Community Integration Scale, which measures the frequency of participation in 12 different types of activity to assess what impact the adaptive behaviour and opportunity to make life choices had on the ability 58 adults with intellectual and physical impairments had to access a range of community resources. They found that adults with higher levels of adaptive behaviour experienced the greatest level of community integration as measured by the Community Integration Scale and that when other variables were controlled for, variation in the opportunities people had to make life choices was explained by differences in participants' adaptive behaviour and level of community integration in ways that appeared to be self-reinforcing[42]. Whereas being able to exercise agency over one's life appeared to enhance participants' ability to access community resources, participants understood as lacking adaptive competencies were least able to experience their community in ways that may also have led to the acquisition of adaptive competencies or expand their opportunity to exercise greater control over their lives.

In a similar study, White & Dodder (2000) also explored whether adaptive behaviour influenced the degree to which disabled people were socially integrated within their community. Like Heller, Millar & Factor, they found that the lower the assessment of an individual's adaptive skills, the less often they were reported to go out during the week, the less likely they were to make choices affecting their everyday lives and the less likely they were to report liking the activities they participated in[43]. They were also less likely to engage in productive activity or have contact with a family member.

Further evidence of the pervasive influence disabled people's level of impairment has over all domains advanced as contributing to life quality came from a study by Perry & Felce (2005) that sought to account for variation in the quality of life and quality of service outcomes associated with the move to community-based services.

4.3 Quality of Life research that included people with high and complex support needs

With intellectual origins rooted in the social indicators movement of the 1960s, Quality of Life (QOL) research first proliferated within the disability discourse from the 1980s onwards, before an emerging consensus about the construct was formalised by the articulation of 12 core principles related to the conceptualisation, measurement and application of QOL research at the International Association for the Scientific Study of Intellectual Disability (IASSID) World Congress in 1996[44].

Common to all QOL models is an assumption that it is possible to identify a set of universal (etic) core domains that contribute unique variance to an overall measure of life quality, but which in aggregate represent the entire QOL construct. As theorised by Cummins (2005), subsequent deconstructions of universal QOL core domains become increasingly idiosyncratic, reflective of the unique material, social and cultural experiences that lead to a highly subjective reading (emic) of what gives life purpose, meaning and joy[45].

The year after the 1996 IASSID World Conference, Campo, Sharpton, Thompson & Sexton (1997) employed the Quality of Life Index to investigate interrelationships between personal lifestyle and community-home programme characteristics and the overall life quality of 60 adults described as having severe or profound disabilities living in American community group homes. They reported that overall QOL, as measured by the Quality of Life Index, was positively related to having a large number of socially supportive friends, a high degree of individualisation in the home environment and high levels of participation in home and community activities.

In addition to foregrounding relationship and community participation as important determinants of overall life quality, Campo et al speculated that these two cornerstone indicators of life quality may themselves be correlated. Campo et al cited Kennedy, Horner & Newton's (1989) previous finding that the number of family members in the social support network of people with high and complex support needs was positively related to the number of home and community integrated activities participants were observed to participate in and the number of friends participants had in their social networks was positively related to participation in a wide array of community activities[46].

Campo et al also found staff training in instrumental or task orientated aspects of the support role to be inversely related to participant QOL, arguing instead that staff training that stressed the importance of continuity of relationship with family and friends offered a more reliable way to maintain the life quality of people with high and complex support needs.

In the Community Participation Project, Milner & Bray (2004) would also report that following qualitative analysis of the narrative of CCS Disability Action vocational service users, participants' families appeared to be the most effective conduit to new community relationships[32]. The principle authors also concluded that, as a consequence of the greater exposure to new people and places that flowed through shared relationship, the best way for participants to become connected was to be connected. The people that collaborated with the project also told the research team that, at times, being with other disabled people made a range of community contexts more accessible. Some said being with other disabled people made it easier to confront forms of social othering they anticipated experiencing and others stressed the importance of being "in place," with others for whom their support needs and life experiences were anticipated and unremarkable. Participants that named more disabled friends in their social network tended to participate in a wider range of community activities.

Although Campo et al (1997) recruited to learn more about the life experiences of people with severe or profound impairments, their sampling frame precluded comparison with other disabled (or non-disabled) peers. In a more recent study, however, Perry & Felce (2005) included participants from across the disability spectrum, providing them with an opportunity to explore what the impact the level of impairment may have on measures advanced as important indicators of life quality.

As noted previously, all of the major meta-analyses that followed the movement of people out of first world institutions and into community-based settings reported considerable variation in the quality of life and quality of service outcomes experienced by residents who made the move. Concerned that variability in the experiences of disabled people threatened to undermine the consensus in favour of community living, Perry & Felce set out to model the association between quality of life outcomes and measures of service design, setting, process and resources to identify potential sources of variation in resident life quality.

Consistent with the underlying logic of service reform, previous research had always emphasised an assumed relationship between elements of service design and quality of life outcomes. Because research, like that outlined above, had begun to demonstrate a positive association between adaptive behaviour and objective quality of life outcomes, Perry & Felce included adaptive behaviour as a way of controlling for participants' level of impairment in their multivariate regression modelling.

In a study where proxy informants reported on the life quality of 154 adults living in 47 staffed residences in south Wales, Perry & Felce found adaptive behaviour to be the most significant influence on all objectively measured quality of life outcomes, accounting for over half of all variance in participants' ability to make life choices, engage in constructive activity and have community or social affiliations[47]. The authors concluded that; "people with lower adaptive behaviours lead lives with lower opportunities for levels of choice, less constructive occupation, and more limited (and less frequent) social and community activities (p.132)."

The level of staff attention received by participants was the second most powerful predictor of quality of life outcomes. Staff attentiveness anticipated variation in participants' ability to make life choices as-well-as their observed engagement in activity, social engagement and the range and frequency of social and community activity.

Perry & Felce's findings suggest that disabled people's level of impairment and the support practices that accompany differing social constructions of impairment represent more important determinants of autonomous community participation than the elements of service design emphasised in existing quality assurance programmes or previous disability research and a probable cause of the variation in life quality detected in the first wave of deinstitutionalisation research. Their study, therefore, added to a growing list of empirical research to suggest that people with more profound impairments were also most vulnerable to living distinctively poorer social lives.

A possible explanation for the poorer QOL outcomes related to autonomy and community participation is that the social practices of staff in human service settings may emphasise different elements of the support role for people with high and complex support needs. Maes et al (2007), for example, argue that current models of best practice for staff practitioners continue to emphasise therapeutic, custodial or medical care roles over competencies in other domains of life quality for people with high and complex support needs[48].

Against the backdrop of Mencap's (2001) findings that 60 percent of parents who continue to support children and adults with profound intellectual and medical disabilities also report spending more than ten hours per day on essential physical care and that 57 percent report spending more than eight hours per day providing therapeutic or educational activities,[5] the prioritising of physical and instructional support needs may, in part, represent an acknowledgement of the bodily difference of people with high and complex support needs[49]. Never-the-less, following their review of empirical research related to the effectiveness of quality-enhancing interventions for people with profound intellectual and multiple disabilities, Maes et al (2007) found no published intervention research between 1995-2006 that sought improvements in the quality of life domains of community participation or human rights[48]. This suggests that the

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[5] In the Mencap Survey (2001), families also reported that a negative prognosis for their child and her/his life quality was a common experience and only 6 percent of respondents thought that there were effective planning processes for the transition from child to adult services.

right of people with high and complex support needs to participate in their community with choices equal to others did not feature prominently in the lexicon of support related rights for those most vulnerable to social exclusion[6].

4.4 The "lost voices" of disability

In spite of widespread acceptance of the need for definitions of "community," to encompass the qualitative experiences of feeling in place and of experiencing a sense of belonging to the physical and social landscape that give places personal meaning, only a handful of studies have sought to make transparent disabled people's subjective experiences of community participation.[7.]

Learning more about the subjective experiences of people who "may not have many words in them," has proved even more problematic as the challenges posed by seeking to represent the lived experiences of men and women who experience difficulty with receptive or expressive forms of communication typically locate their narrative beyond the technologies of conventional modes of either quantitative or qualitative inquiry. As a consequence, disability research often concludes with the caveat that the authors were unable to access the subjective experiences of people with profound impairments.

Moreover, in spite of calls by disabled people to be recognisably present within the discourses of social change[51], caution exercised by research ethics committees regarding the appropriateness of consent and the need to protect participants' right to confidentiality have conspired to further exclude the experiences of people with high and complex support needs from disability related research[40, 51].

The voices of people with high and complex support needs are, according to Atkinson and Walmsley (1999), the ultimate " lost voices,"[52].

Rather than regarding them as people with their own story to tell, Booth & Booth note that the great weight of research has tended to regard disabled people as sources of data for researcher narratives[39]. As a population, therefore, people with high and complex support needs have had no opportunity to self author their place within our historical record, nor have they had the chance to tell us how they read the ordinary places in which their stories dwell or had an opportunity to contest the "unauthorised" representations of themselves, usually by stakeholders in the care act.

4.5 Are the "lost voices" important?

In an observation that has come to be known as Baron's paradox, Jane Baron (cited in Booth & Booth, 1996) observed that those people who most need to have their story heard are often least able to tell them. In addition to any issues of narrative legibility, what she had in mind was the conscious and unconscious marginalisation of the experiences of people who remain strangers to their communities.

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[6] The QOL domains that featured most prominently in published research that sought to enhance the life quality people with high and complex support needs through service intervention were; emotional wellbeing (n=6), interpersonal relations, most specifically related to improving the quality of staff-resident interaction (n=6) and personal development related to improving activity levels and moving with greater independence (n=4)

[7] See section 3.5 50.   Bogdan, R. and S. Taylor, *Relationships with Severley Disabled People: The Social Construction of Humanness.* Social Problems, 1989. **36**(2): p. 135-148.

More than twenty years ago, Bogdan and Taylor (1989) argued that the absence of disabled peoples' stories was the product of a society that had chosen not to listen. In the past two decades, however, post-modern scepticism about the validity of "over-determined" views of reality and a sympathetic desire to include the "voice of the other," in sociological theorising has rekindled an interest in the human story[53].

As the last in a sequence of international human rights law to recognise particular groups of humanity as worthy of specific protection the UNCRPD has also drawn attention to what Megret (2008) described as the "irreducibility of the experiences of disabled people,"[54]. She argues that, contrary to the notions of equity and universality that underscore human rights law, pluralistic human rights legislation, including the development of specific instruments like the UNCRDP, have been required because the experience of living with impairment is so intrinsic to disabled people that the articles embedded in the Convention are needed to change the language of human rights in ways that create new rights. Improving societies collective understanding of the experiences that gave rise to the development of new human rights law is therefore critical to disabled people realising the rights they fought for.

Recovering the lost voices of people with high and complex support needs carries additional importance, for until we hear from them, we can't have a complete conversation about the progress New Zealand is making towards meeting its UNCRDP obligations. This is especially true for the right to full inclusion and participation in the community expressed in Article 19 of the Convention because the experiences and theorising of those most exposed to an abuse of the right are yet to inform the dialogue of assessment.

Furthermore, positioning the right to be included in the community within the framework of international law exposes the language of Article 19 to a politically contestable discourse. As Jolly (2009) notes, who owns the meanings that give expression to the right will be a critical determinant of the life quality of disabled people[55]. Without hearing from people with high and complex support needs it is impossible for us to know whether, for example, "living independently," has a different meaning to people who depend on the constant presence of human support, or if moments of inclusion or exclusion are experienced in radically different ways or social contexts for men and women who experience authentic pleasure in conversations as simple as the reciprocated toss of a ball or empathetic touch.

And finally, attempting to support people to tell their own stories takes the emancipatory act to the level of person. The vision at the heart of the New Zealand Disability Strategy is for all people to say they live in a society that values our lives[56]. Because, as Hodge (2008) notes, people feel valued when their stories are listened to and their subjective experiences are respected and progressively understood[57] paying proper attention to the life stories of people with high and complex support needs represents one way that the vision can find expression in real lives.

The ethic that guided the design of the Article 19 Project was to provide 12 people with high and complex support needs an opportunity to tell their own story, their own way. The method used to further this aim is described in the following chapter.

5 Method

5.1 Origins of the Article 19 Project

The Article 19 Project represents a response by CCS Disability Action[8] to an ongoing conversation with disabled people and their families that has included a growing disquiet that those at greatest risk of social exclusion may be experiencing difficulty realising their human right to full inclusion and participation in the community. Except for a small number of studies investigating carers' experiences, no research has documented the day-to-day reality of living with high and complex support needs in a New Zealand context. Difficulty accessing the narrative of people with high and complex support needs has meant that their subjective experiences are yet to inform the disability discourse or the processes of assessment in place to monitor New Zealand's implementation of the UNCRDP or the effectiveness of disability related social policy

To make transparent the "un-storied lives," of this group of New Zealanders, CCS Disability Action commissioned the Donald Beasley Institute[9] to conduct a descriptive study to build a picture of the everyday lives of adult service users with high and complex support needs. The project was to have a particular focus on participants' UNCRPD, Article 19 right to live independently and be included in the community.

5.2 CCS Disability Action

CCS Disability Action is the largest provider of disability related support to people living with a physical impairment in New Zealand. Originally founded by Rotary to provide support to children with polio in 1935, CCS Disability Action is now an incorporated society governed by a board and managed by a national management team. CCS Disability Action delivers support to over 6500 (4000 on website) disabled people through a range of Ministry of Health and Ministry of Education and Ministry of Social Development contracts within 16 administrative branches across New Zealand.

CCS Disability Action has adopted the UNCRPD and New Zealand Disability Strategy as foundation documents.[10] The overarching goal of support provided through CCS Disability Action is to work alongside disabled people and their community to promote ordinary lives and for people to feel part of their community, reflective of the human rights framework demanded by these documents.

Funding for Article 19 Project was made available by the CCS Disability Action National Management Team. Lorraine Mamea-Hind – Regional Manager (Central Region) and Paul Martin - Regional Manager (Southern Region) sponsored the project and acted in an advisory capacity throughout the conduct of the research.

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[8] *www.ccsdisabilityaction.org.nz*
[9] The Donald Beasley Institute is a national, independent, not for profit research organisation dedicated to advancing the health and wellbeing of people with disability in New Zealand through applied research and education *(www.donaldbeasley.org.nz)*.
[10] Te Tiriti o Waitangi is also a CCS Disability Action Core Document.

5.3 Project Aims

The ethic that guided the design of the Article 19 Project was to provide people with high and complex support needs an opportunity to tell their own story their own way. Consistent with other transformative methodologies, the project invited disabled people to co-produce social knowledge by placing their experiences and voices at the centre of the research process. The research team were also committed to participants having control over the telling of their life story, answering the call of disabled people to be visibly present in the disability research and for disabled people to reclaim their own stories. As the first research to purposefully set out to make transparent the understanding people with high and complex support needs have of their everyday lives, the Article 19 Project sought to achieve five key aims.

- To generate new learning from the diversity of life circumstance and resourcefulness of people with high and complex support and their allies to aid the dismantling of disabling barriers to social inclusion and community participation.

- To promote organisational learning and inform service practice in ways that enhance the ability people with high and complex support needs have to feel part of their community.

- To make visible the lives of a formally invisible population at a critical time in the assessment of New Zealand's compliance with international human rights legislation.

- To provide "authorised" evidence of the human rights status of people with high and complex support needs, allowing others to partner disabled people in advocating for a more inclusive Aotearoa/New Zealand.

- To value the life experiences and insight of people with high and complex support needs in ways that allow them to direct social action through the telling of their life stories.

5.4 Narrative inquiry

In the Article 19 Project, storytelling was adopted as the strategy through which to consider the access participants had to their human right to participate in the community. In so doing, the project locates itself within a tradition of narrative research that stretches back to the Chicago School of the 1920s and 30s and was reinvigorated by feminist writers interested in listening to the previously silenced voices of women in the 1970s and 80s. Feminist researchers recognised the potential of personal narrative to challenge existing social science knowledge about society, culture and history. Furthermore, by focussing on the subjective meanings that women assigned to events and life circumstance their work also acknowledged women as social actors in their own right[58].

Whilst there are numerous strands to narrative research, all share in common an interest in biographical elements as narrated by the person who lives them[58]. Similarly, the belief that early feminist writers held that the representation of people's personal narrative had the potential to disrupt oppressive or disabling social practices has remained as a similarly unifying theme within the body of narrative research. Giving voice to marginalized people and naming silenced lives have been primary goals of narrative research[59].

Researchers have identified a number of different ways this emancipatory ethic can find expression in the act of story telling.

Firstly the act of narration can be personally emancipatory in so much as it offers the storyteller a chance for them to represent their lives and experiences in ways that resist oppressive narratives. Story telling can also provide the narrator with a window of opportunity through which to imagine the possibility for better stories for themselves, in the absence of disabling meta-narratives[58]. For those living at the margins of society, their need to stake a claim on the attention of others has an additional political dimension. Storytellers often emphasise the importance of their stories "being heard," as part of a wider politics of hope[60, 61]. The second way narrative research can be considered emancipatory, therefore, is that when given a voice, previously silenced lives can also alert society to alternative stories they had not had the opportunity to hear, for as Frank (cited in Chase, 2005) observed, taking the "others" perspective is the necessary first step to emancipatory social change.

And finally, by collecting stories, which connect one person's narrative to a broader story of marginalisation, narrative research has the potential to generate social action. Because social change has tended to be driven by communities that have come to recognise and reclaim stories that weave together their shared history, identity and politics, collected stories are integral to social movements[62, 63].

5.5 Project design

Van Maanen (1988) described narrative research as stories jointly told[64]. The act of narration is an active and creative process in which both the participant and researcher develop their own voice(s) during the struggle to fashion the story[58]. The struggle to interpret and represent participants in ways they might want their story told, however, becomes more complex when the researcher needs to loan participants their own words so that they can tell their stories[39].

Because the research team would begin their collaboration without knowing which modes of information gathering would best allow each participant to make their lived experiences transparent, a mixed method design that included an array of different quantitative and qualitative data gathering techniques was developed.

In addition to offering a pragmatic solution to the problem of depending on modalities that would otherwise have excluded a sub-set of participants, adopting a mixed method approach was considered to have a number of other important advantages.

For all narrative research, consideration of which voice(s) the researcher uses to guide interpretation and which voice(s) should be invoked to represent the participants' subjective experiences are important methodological issues. Having multiple streams of information provided important sources of data triangulation that acted to dampen researcher assumptions and limited the danger that the experiences of participants for whom communication was problematic were misinterpreted.

During the information gathering and story writing phases of the project, it was also anticipated that the researcher would be confronted with conflicting narrative details. Having an array of different information streams maximised the potential for simple readings of participant narrative to be confounded by the complex experiential realities of living with high and complex support needs. Having access to multiple information streams also offered the researcher and participant with a range of different ways of generating conversations that had the potential to lead to a deeper understanding of the social phenomena they were considering.

And finally, offering participants a range of different ways of collecting the material that would inform their story placed them in control of the data gathering process. Participants were therefore able to exercise greater control over their narrative by selecting the data streams that they perceived to be aligned with the story they wanted told. Inviting participants to design their own method. It also helped to minimise the risk that the framework for collecting the information to tell the story reflected the researcher's concerns and not participants' reading of their own life.

5.6 Data gathering elements

Eight different ways of collecting information were discussed with participants. The data gathering elements from which they chose to construct their story are described below.

5.6.1   Personal archives

Data collection began with an informal autobiographic interview. The technique borrows from the hermeneutic tradition by permitting participants to place themselves within the context of their own lives. Prior to the first meeting, participants were invited to bring ten archives or images that they believed might help the research to get to know them better. In addition to providing the scaffolding to the autobiographically orientated interview, it was anticipated that the technique would help to build a trusting rapport between the participant and researcher. Beginning the narration process by establishing that participants could direct the information gathering process also helped to demonstrate a commitment to participants exercising control over their narrative. In addition to alerting the researcher to elements of participants' life history they wished to emphasise, the technique had the added advantage of beginning to assemble resources participants might latter want to incorporate with their narrative.

5.6.2   Semi-structured interviews

As originally conceived, participants were also able to participate in three semi-structured interviews. The interviews were designed to offer a communication space for participants to discuss different aspects of their lives that had the potential to inform an assessment of the access they had to their UNCRPD Article 19 right.

In the first, Autobiographic Interview the researchers aim was to create an opportunity for individuals to describe and interpret their own personal history. The interview was organised chronologically to incorporate participants' sense of self and their community and family relationships at different times in their lives. The interview concluded by inviting participants to describe their current lifestyle aspirations.

Exploring what contributes to, or undermines life quality was the focus of the second Quality of Life Interview. The interview structure drew from the Quality of Life (QOL) paradigm by using the eight core domains advanced as representing a comprehensive first level deconstruction of overall QOL as its organising framework. The interview concentrated on participants' subjective reading of aspects of their lives included within the core QOL domains of Interpersonal relationship, Personal wellbeing, Self-determination and Social inclusion because of the emphasis disabled people place on indicators from these domains informative of life quality and their relevance to their UNCRPD Article 19 right.

The final, Challenges to Living an Ordinary Life Interview, was designed to explore whether participants believed their impairment made it difficult to live an ordinary life and what they perceived the barriers to meaningful community participation to be. An additional aim of the

interview was to identify which supports had proved especially useful, some of the creative or informal ways participants have found to generate a community presence, and what improvements to support practice or policy they perceived would help people with high and complex support needs to participate in the community with choices equal to others.

In practice, many participants chose to abandon the more structured format of the semi-structured interview. During the time participants spent with researchers, themes contained within the interview schedule became incorporated within a "running conversation," that spiralled outwards as participants reflected on their own telling of their life story and researchers learnt more about the particularities of each persons lived experience and their subjective interpretation of life events. Where permission was given, these conversations were recorded either in researcher field notes or on a digital recorder.

5.6.3   Key informant interviews

Participants were given the opportunity to nominate two key informants who they felt knew them well and were able to contribute important biographical information. Key informants could include family members, sources of historical or contemporary informal or formal support, a Needs Assessment Coordinator, or case manager. Having the capacity to include key informants provided people whose receptive or expressive communication skills might otherwise have left them without a spoken narrative. It was anticipated that key informants would add important historical and interpretive detail, enriching the reflective process of co-authorship and allowing a more well rounded description of participants' lives to emerge. Key informants were informed that participants had the ability to exercise editorial control over their stories.

5.6.4   Photovoice

Photovoice is an interactive visual methodology that was originally developed in the arena of public health promotion by researchers seeking to engage people who had been excluded from traditional talk or text based qualitative methods [40, 65]. In recent years, researchers have included the technique within a range of Participatory Action Research methods because of the way Photovoice allows participants to "own," the images and interpretation that informs social action orientated projects. Every participant was given a disposable camera and a set of plain language instructions about Photovoice. Participants were invited to create a portfolio of participatory contexts by taking photographs either of the people and places that were important to them or where or with whom they spent most of their time. Participants that used Photovoice to inform their life story posted their camera to the Donald Beasley Institute. A copy of their images were posted back to participants together with a booklet or electronic document that included questions about why they chose to take each photograph and what being in that place meant to participants. Additional questions that invited participant reflection related to themes that had emerged during conversations were often also included in the booklet. During the planning phase of data collections, participants that thought that it would be difficult for them to get the images they wanted had the ability to direct the researcher to take the photographs that they thought they needed to tell their story. All participants had editorial control over the photos that appeared in their narrative and co-authors were required to obtain written permission from people who appeared in images selected by participants on an approved consent form.

5.6.5   ComQOL-ID (Objective Scale)

In addition to capturing each participants' subjective reading of their life quality in the Quality of Life Interview, objective data from the Material wellbeing, Productivity, Intimacy and Community indicator domains drawn from Cummins (1997) ComQOL-ID was included as a data gathering element[66]. Although Cummins has recently reconfigured the ComQOL-ID, he notes that the objective scale continues to provide a good general overview of objective life quality[67]. These domains were selected for their relevance to the UNCRPD Article 19 right. Because the ComQOL has continued to be the most widely used QOL instrument its inclusion also provided the research team with an opportunity to compare participants' objective QOL to findings reported elsewhere in the literature.

5.6.6   Friendship field

In John O'Brien's influential Framework for Community Integration, he defined community participation as "the experience of being part of a growing network of personal relationships that included close friends" (p.178) and listed it amongst five accomplishments that should underpin the development of effective community living for people with disabilities[68]. To promote this objective, he included a visual template that could be used by people with disabilities or their allies to describe the attributes of people's friendship network along the dimensions of perceived intimacy and relationship context. An adaptation of O'Brien's (1997) template was offered to Article 19 Project participants as a way for them to map their friendship field. Thirteen friendship "origins" were included (Staff, Partner, Family, Family friend, School, Tertiary education, Employment, Sport leisure or interest group, Artistic or creative community, Advocacy or lobby group, Neighbour or place relationship, Faith or cultural community, Other service users) with participants invited to locate the relationship within three concentric circles of intimacy (Friend or acquaintance, Close friend, Very close friend). In addition to providing a visual representation of the pattern to participants' network of personal relationships, it was anticipated that the exercise would create a conversational space for participants to talk about their experiences of friendship and relationship formation.

5.6.7   Time in Place Diary

As a way of describing the geography of their community presence, participants were given an opportunity to create a diary that recorded where they were every half hour between 8.00am – 9.00pm for one week of their life. The Time in Place Diary recorded both where participants were and what activities they were engaged in and could be completed manually or electronically. Data from participant diaries were converted into a three dimensional map that located participants in space (distance from home in kilometres along the cardinal axes of longitude (z-axis) and latitude (x-axis)) and time (y-axis), similar to the space-time path pioneered by Swedish geographer Torsten Hagerstrand[69].

5.6.8   Participant observation

During the information-gathering phase of the project, the researcher and participant spent between 3-6 days together in a timetable directed by participants. During this time the researcher typically walked the same streets, crowded into the same vans, visited the same cafés and boccia halls and met the same people that patterned the day to day lives of each participant. Although not included as a formal element of the research design, the opportunity to closely observe and engage participants in a running conversation about their experience of being in place in

community settings contributed important biographical insight and contextual colour to the narratives that emerged.

5.7 Recruitment

Recruitment of participants occurred across all six CCS Disability Action Regions. CCS Disability Action initiated the recruitment process by informing service branches and service users of the project and its objectives through existing communication channels including, branch newsletters, the CCS Disability Action website briefings to staff and stakeholders, e-newsletters and mail outs. Potential participants were identified at the branch level through respective membership databases and sent a plain language Information Pack containing a written invitation, Information Sheet, Participant Interest Form, and self-addressed prepaid envelope. CCS Disability Action service users or their Welfare Guardian indicated their interest in participating by posting a completed Participant Interest Form back to the Donald Beasley Institute. Everyone that expressed an interest in participating was contacted by the research team at the Donald Beasley Institute to acknowledge their interest and following participant selection to inform them whether they have been chosen as one of the 12 participants.

5.8 Inclusion criteria

To be considered for the project participants need to be:

- Over 18 years;

- A current or historical CCS Disability Action service user;

- Be able to consent or have a Welfare Guardian able to consent on participants' behalf;

- Have high and complex disability support needs.

For the purposes of the project, high and complex support needs were understood as requiring personal assistance with two or more of the following types of support:

- Bodily support (nutrition, personal hygiene, dressing, positioning, mobility and transfer, medication and exercise);

- Communication support (sensing or understanding others, making oneself understood);

- Behavioural support (behaviour that challenges others or makes it difficult to form community relationships, tends to lead to exclusion from community settings or activity, infringes on the rights of others or is potentially harmful, life threatening or dangerous to others).

5.9 Participant selection and consent process

A purposeful sampling strategy was used to ensure a diversity of stories informed the research. The significance of story telling has a long tradition in Maori and Pacifica cultures. It was hoped that the qualitative orientation of the project would be conducive to creating a research context sensitive to tikanga Maori and culturally appropriate narration. A commitment to supporting participants to tell their own story (wheako whaiaro) in their own way (korero) left "space" for the alternative understandings of disability and the most effective path to community participation

within the heterogeneity of people that also identify as disabled. The age, sex, support need, living circumstance and location of potential participants were all included as variables within the maximum variation sampling strategy employed.

Written or recorded verbal consent was obtained from all participants. A plain language consent form outlining participants' rights and explaining what their participation involved was sent to potential participants alongside confirmation of their selection. The consent form was sent first to provide an opportunity for potential participants to seek advice in advance of the researcher visit. A member of the research team later went through the consent form with each participant prior to the beginning of the data collection phase of the project. Participants were able to have an advocate present during the consent process. The consent process occurred in a private place of the participant's choosing. All members of the research team were experienced at obtaining informed consent with disabled people.

To ensure everyone had an opportunity to participate, a separate process was developed for potential participants who had a Court appointed Welfare Guardian or relative/friend/whānau who was assured of their interest but were unable to consent and had no Welfare Guardian.

5.10   Article 19 Project Participants

Seven male and five female participants drawn from seven CCS Disability Action branches contributed their life stories to the project. Their ages ranged between twenty and fifty-two years.

Five of the twelve participants lived with a parent(s) in their family home, whereas two participants lived by themselves in a house they owned or flat for which they held the tenancy. Two participants lived with other adults with a physical impairment in a community group home funded through a Ministry of Health contract and one participant lived in a community group home with adults whose primary diagnosis was intellectual impairment. One participant lived with a family under a contract board arrangement and one participant flatted with other adults with physical impairments whose support was provided under a Supported Independent Living contract. Three participants were not currently using vocational support provided by CCS Disability Action to access their community.

Only one participant had any form of paid employment, working on average for 3 hours a week and one participant volunteered at her local branch of the Society for the Prevention of Cruelty to Animals (SPCA). No other participants had meaningful employment.

5.11   Data gathering elements chosen by participants

Most participants' impairment contributed to receptive, or more frequently, expressive communication challenges. In spite of the inevitability of communication difficulty, all but one participant (or their proxy) elected to include a loosely constructed verbal interview amongst the data gathering elements that would inform their life story. Five participants chose to have a support person or family member with them to act as a social interpreter but for most, their ability to assess and/or challenge the researcher's understanding of their experiences was a critical part of the co-authorship process. Similarly, not only did participants' body language and silences often stand in the place of words, communicating the bodily reality of their impairment and alerting the researcher to its impact both on their lifestyle and character appeared to be potent motivators for people without many words choosing verbal interviews.

Table 2 The living circumstances and method elements chosen by Article 19 Project participants

Participant	Flat alone	Flat with others	Community group home (PI)	Community Group home (ID)	Family home	Other	Individualised Funding	Service Contract	Paid Employment	Volunteer hours	Community Participation	Day Centre	Interviews	Key Informant Interview(s)	Personal archives	Photo-narrative	ComQol-ID	Friendship Field	Time in Place Diary	Southland	Otago	Wairaki	Wellington	New Plymouth	Rotorua	Tauranga
	Living situation						**Funding**		**Participatory context**				**Method elements**							**Region**						
Angela	✓							✓			✓		✓	✓	✓	✓	✓	✓	✓			✓				
Richard				✓				✓			✓	✓	✓	✓		✓	✓	✓	✓			✓				
Henk	✓							✓			✓		✓	✓		✓	✓	✓	✓		✓					
Emma						✓		✓		✓	✓	✓		✓			✓	✓								✓
Mela		✓					✓				✓	✓	✓	✓	✓	✓	✓	✓	✓					✓		
Ben			✓					✓			✓		✓		✓		✓			✓						
Rebecca			✓					✓				✓	✓	✓			✓	✓		✓						
Chris					✓			✓	✓			✓	✓	✓		✓	✓	✓		✓						
Jared					✓			✓			✓			✓		✓	✓	✓		✓						
Krystle					✓		✓	✓			✓			✓			✓	✓							✓	
Graham					✓						✓		✓	✓		✓		✓	✓						✓	
Duncan					✓			✓					✓	✓	✓	✓	✓	✓	✓				✓			
Total	2	1	2	1	5	1	2	10	1	1	9	5	9	11	4	8	11	11	6	4	1	2	1	1	2	1

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Conversely, a smaller number of participants contributed their own photographs for the Photovoice (4), with most preferring to direct the researcher's gaze or make use of personal photo albums. Six participants completed a Time in Place Diary but only three committed to developing a Personal archive, with busy lives and irregular or time constrained support not allowing many to overcome the difficulty they experienced operating a camera or recording text. Some participants said their decision not to seek the support was influenced by the potential for personal information to share and their preference was to stay quiet about particular aspects of their life. Similarly a number of participants did not perceive they had an opportunity to request support that deviated too far from their existing vocational programme. (Table 2)

5.12   Developing the narrative

One participant wrote her story independently. For all other participants the Donald Beasley Institute (DBI) researcher that worked with them to gather the information they needed took responsibility for writing the first draft of their life story. Space was created during the data-gathering phase for narrative form to be discussed and the motifs that would guide the story writing process were often decided prior to writing beginning.

At the completion of the first draft, each participant's life story will be sent back for self-editing in hardcopy and electronic form. Participants will be reminded that the story is their property and that they have the ability to change the text in any way they feel appropriate. During repeated cycles of member checking and narrative editing, the DBI researcher and participant will remain in contact both to aid reflection about the way content may be read by others and to ensure participants are satisfied with their narrative. Participants are at liberty to exclude sections or include new details prompted by their editing. They are also free to change the narrative form or any interpretation included in the text. Returning participant stories will also allow narrators to check the accuracy of biographical details.

An additional requirement for participant "sign-off," was included as a research protocol. To include biographic information that contained the potential for participants to be identified in the Article 19 Project Report or form of dissemination, the research team needed to obtain written or verbal consent from participants that they had had the chance to make all the changes they wanted and that they were happy for their story to be included in the project report.

5.13   Identifying narrative themes

At the conclusion of the information-gathering phase, the DBI researcher developed a short biographical sketch of each participant. Using a general inductive approach, the biographical sketches were used by the research team to develop a set of major narrative themes. In a second iterative cycle, the original set of themes was further refined by re-analysing participant narrative against the themes by drawing on all of the data gathering elements chosen by the narrator.

In this report the themes that emerged from participant narratives have been clustered in ways that address the access people with high and complex support needs have to the three specific human rights that define Article 19 of the UNCRPD.

5.14   Ethical Approval

Ethical approval for the Article 19 Project was sought and granted by the Multi-region Ethics Committee on the 16 March 2011.

6 The right to live in a place of my choosing

6.1 The meaning of home

"Home," has been described as the most basic and potent of all life spaces with the experience of feeling at home contributing greatly to a person's humanity and their positive perception by others.[70]

Twelve years ago, John Annison wrote that the term "home," had been liberally (mis)applied to settings where disabled people were are often required to live[70]. For Angela and for countless other children who would grow up living in New Zealand hospital villas, the total institution was described as their home.

At the age of five, respite care turned into a permanent placement at Templeton Hospital for Angela and she moved from her family home in Oamaru to Briar Villa to live with 40 other patients for whom Templeton was expected to be a home for life. Angela would spend the next twenty years as a patient in New Zealand institutions, first at Templeton before exchanging one hospital for another when she moved to Burwood Hospital at the age of twenty. Five years later, the gravitational pull of family and her desire to escape the legacy of institutions that Angela said had *"trapped (her) inside a passive mind,"* led Angela back to her parents, the wide streets of Oamaru and a landscape she said had always *"anchored her in times of loneliness and frustration."*

Despite moral outrage at the "unhomeliness" of the total institution contributing to the closure of places like Templeton, Annison argued that there had been a lack of commitment to arriving at a clear understanding of the meaning of home and the essential elements required to transform the next generation of service settings into places that people like Angela could call their home.

In the absence of a clear definition, people with high and complex support needs are more exposed to the risk that, they may "never arrive in their own homes," for, as O'Brien (1994) notes, today's service systems appear to have developed around an unspoken assumption that people who require a high level of personal assistance can not have a home of their own.[71]

O'Brien's paper is one of only a handful of published articles to consider the meaning of home as an adult destination for disabled people. In it, O'Brien argued that disabled people could not be understood as having a home of their own without experiencing;

- **A sense of place** including; the personalisation of one's time and the routines of home-living; legally assured tenure; the socially valued roles of neighbour; owner or tenant; control over the threshold of invitation; and the feeling that home defined who belonged whilst offering respite and refuge from the world outside. A home, O'Brien also argued, provided its owner the capacity to offer the gift of hospitality.

- **A sense of control** over the home and the necessary supports for living there including; the selection of a place to live and the people you live with. A sense of control was also experienced, he suggested, when people's houses reflected their own personal aesthetic in preference service codes or designs that assumed congregate care.

- **A sense of security** provided by the status and legal protection that comes with home ownership or tenancy. Investing in one's own home, O'Brien argued provided disabled people with the same opportunity to increase their material wellbeing, experience pride of ownership and the security that comes with not having to rely upon the patronage of a service provider's who may be required to balance a range of often competing demands on its material and human resources.

In an attempt to reach a clearer understanding of the meaning of "home," Annison (2000) drew on literature from outside the disability discourse, including research conducted by Judith Sixsmith. Sixsmith developed a model that clustered attributes of place associated with the subjective experience of "home," into three experiential modes. The "personal home," which related to the home as the emotional and physical reference point in a person's life and included feeling of happiness, belonging, responsibility, self-expression, critical experiences, permanence, privacy, personal meaning knowledge and the preference to return. The "social home," which related to the concept of home as a shared place where relationships were transacted and included experiences that spoke to the type and quality of relationship, friends and entertainment and an understanding of home as an emotional hearth. And the "physical home," which incorporated experiences which related to the architectural style, spatial arrangement and convenience of the dwelling.

Annison concluded by cautioning that, whilst it was not possible to identify any single attribute most likely to effect the transformation of a dwelling into a home, the absence of any one had the potential to render a home a "non-home."

6.2 The right of people with high and complex support needs to choose a home

In the absence of a clear articulation of what the right to "choose a place of residence and where and with whom one lives," means to people with high and complex support needs, Bigby and Fyffe (2009) echoed Annison by expressing a concern that the aspirations embedded in Article 19 may not be understood beyond meanings thought applicable to people with milder impairments able to represent themselves[72].

Conscious that the specialised support needs of people with high and complex support needs tended not to be accommodated within the innovative community based support options being developed in Australia under the rubric of Supported Living, Bigby and Fyffe filled the silence by publishing a position statement developed by members of the Annual Roundtable on Intellectual Disability Policy in Victoria (2006).

The statement asserted:

> "A person with severe or profound (intellectual) disability should be able to expect standards and outcomes for housing and support that are equal to that of people with less severe disabilities and wider community members," (p.97).

Having access to the same array of housing options, Bigby & Fyffe argued, meant that people with high and complex support needs also needed to be seen as having the right to live alone or share a small household with others with whom they had common life interests or friendship. To

facilitate the vision, Bigby & Fyffe identified that arrangements for structuring housing, support and the allocation of funding needed to achieve a better partnership between formal and informal supporters of disabled people and resource allocation commensurate with the support required to fulfil the right. It should not mean, they argued, that people with high and complex support needs were required to live in the most restrictive or congregate residential support arrangements, were forced to move when their support needs changed or that residential aged care became the default solution. It also did not mean that people with high and complex support needs were obliged to live with others with whom they had nothing in common.

6.3 The living circumstances of Article 19 Project participants

Home, for half (n=6) of the twelve adults who contributed their narrative to the Article 19 Project, meant either living with parents in the family home they had always lived in (n=5), or a home created by a family that had absorbed them, almost as an additional family member (n=1). Of those who had moved from their family home, three participants lived in a community group home with three to five other non-related adults in a house owned or leased by a disability service provider contracted to provide residential support. One participant owned his own home, one was sole tenant in a flat she rented from her sister and one participant flatted with a friend from school in a flat owned by a small trust established to provide short term accommodation for young people with physical impairments in a core and cluster support arrangement.

6.4 The gravitational hold of the family home

Six of the twelve narratives that informed the Article 19 Project told a story of adult New Zealanders whose lives had not followed the normal adult life trajectory beyond the family home. For all six participants a family member was directly involved either coordinating and/or continuing to provide direct support, most often in the family home that participants had grown up in.

Whilst all participants had remained at home for different reasons, the unifying theme to their narrative was of the great difficulty people perceived in finding services that replicated the quality of life experienced within the ambit of familial love and aspiration.

For younger participants, living with adults with whom they shared no common interest in group homes where the rhythms and routines of daily life were shaped by the culture of service provision lagged behind the aspirations they had assimilated in mainstream educational settings and were supported by Objective 8 of the New Zealand Disability Strategy[73]. For them, the gravitational hold of the family home often related to the difficulty participants and their families experienced finding alternatives to the standard model of residential support. The community group home tended to be understood by participants and their families as the only permanently staffed support model available to them but, they asserted, represented one that didn't "fit" their hopes for their future.

For a number of participants, the reticence of families to promote a transition from home had been seeded by differences they perceived between service and familial expectations for their son or daughter. Many families that added their narrative described having to temper their aspirations for fear of being cast as *"wanting too much."* Their tenacity to exploit opportunities to improve the life quality of their family member was frequently contrasted with the disappointments they had experienced with formal services along the way. Jane, the mother of

two boys, for example worked tirelessly to match the skill set of her disabled sons to participatory opportunities she perceived in the community. Scotty had a love of tractors and farm equipment and a memory he saved not just for farm machinery specifications, but other important details like the ear tag numbers and destination of bulls they had raised on the family stud. He has, his father said, the mind to run a stud and the family vision for Scott included a house with a few acres he could help farm close enough for him to continue to take his place alongside the array of contractors he and Jane have forged a connection to, in the yearly cycle of sowing, silage making, under-sowing, calving, rearing and cultivation. "Jane," Scott's father said, "will never give up," looking for opportunities to improve the competencies or life experiences for her sons – a disposition that stood in stark contrast to the supported employment service who saw Scott as unemployable and therefore ineligible for assistance or the Polytech Course that made no accommodation for Graham's restless enthusiasm and the active learning style of a man with Cohen syndrome.

The families of participants most at risk of being understood as lacking potential worried greatly about the impact of losing control over the aspirations that underscored support would have on the life quality of their family member. They also worried that when their family member did not have the ability to tell their story, the types of activities that gave them joy or the accomplishments that contributed to their sense of self that were replete in family albums would be invisible to providers or would need to be continually retold with the entrances and exits of new staff.

For many participants, and particularly for people like Scott and Graham who lived in smaller centres, moving from the family home also meant moving beyond communities that participants had belonged to their whole life. For Scott and his brother Graham, this would mean a geographic separation from the friends they went to school with, the people they met every Sunday at Church, family friends and neighbours, the people at the local store for whom Graham sorted the rural mail as well as the farmers whose place in their lives was reinforced with a handshake and a cup of tea at the calf sale that happened every week in the shed Dad had built just a short walk from the end of the drive. Participants feared their family member might struggle to replicate the level of social inclusion they experienced at home in community-based services.

No two lives were the same, however key differences were observed in the origin of relationships that populated the social lives of participants. As is discussed in more detail in Section 7.3, people that lived at home were more likely to include in their social network a gallery of family friends whose lives repeatedly intersected with their own at significant moments in their personal history. This was especially true for a few participants whose social network was entirely constituted by members of their families' social network. Similarly people who had continued to be supported in the family home were more likely to have maintained relationships with school friends and to have seen people they shared a sporting, leisure or interest activity within other social contexts. This is reflective, perhaps, of the greater autobiographical insight held by families and their determination to arrest the erosion of participants' social network beyond the community of school.

Scott was twenty-six and still lived on the family farm forty kilometres and about half and hour drive south from Rotorua. Scott had the largest social network of all participants. His Friendship Field was peppered with family friends, neighbours and people who shared his passion for farm machinery because of his engaging personality and his mother Jane's determination to embed Scott within relationships that gave him access to the annual cycle of farm work he knew so intimately.

Figure 3 Scott's Friendship Field (Greeting farmers at the calf sale)

By way of contrast, years of living in an institution had severed Angela both from natural community as well as the informal network of family friends she would have grown up alongside had she remained in Oamaru. Since moving back to Oamaru as a young woman, Angela had struggled to generate a community of friends about herself.
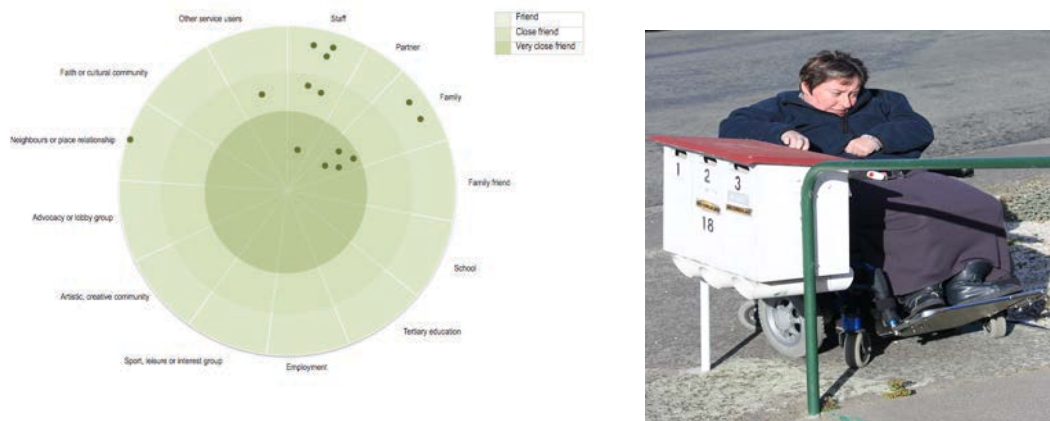
Figure 4 Angela's Friendship Field (Checking for mail)

Angela was, however the only participant who didn't live at home to name a neighbour as part of their social network. Angela lived by herself in the front flat of a row of small flats that look east towards the Oamaru breakwater. She rented the flat from her sister and had not long moved in. A year or so before, CCS Disability Action had made a decision to abandon residential support and had closed the community group home Angela lived in previously. Angela was the last of the six people that lived there to find somewhere else to live. Angela and her neighbour Maraline shared a driveway and Maraline had got into the habit of popping in to see Angela on her way to or from the mailbox. It was the first neighbourhood friendship Angela said she had had, and Angela

suspected that arriving at the relationship from a position of relative social equity had contributed to its formation. To Maraline, Angela was also a home-owner who, like her, shared a responsibility for the people and the environment that fell inside of their common zone of surveillance. Interestingly, it was Maraline's custom to pop in when Angela's support staff were "off-stage," perhaps to protect the more valued social roles of neighbour and community member from any alternative form of social knowing. "Maraline," Angela reflected, *"was someone (she) thought would become quite important."*

Angela had originally moved from Christchurch to be close to her family and the family home she said had "anchored her," when the loneliness and the frustration of living in the institution visited her. For most participants, the family home also continued to represent the emotional and physical reference point to their lives, consistent with Sixsmith's modality of the "personal home." For Scott and Graham, their place in the community, including the relationships that had contributed most to their sense of self were written into the landscape. When they sold the farm, Scott and Graham's grandparents built within sight of the family home and their brother and his new family lived over the brow of the nearest hill.

For people whose behaviour was understood to be challenging, the stakes of moving beyond familial aspiration and autobiographical knowing were higher.

All three participants who were identified as needing behavioural support continued to live in their family home. The families of two participants had explored and rejected the community group home as an appropriate model of support for their family member, and while not yet ready to hand their son over to a service, the options were limited for the third, for whom an aged care provider appeared to be the only service prepared to accommodate their son.

All three families emphasised how important having an emotional connection was for support staff to recognise the person behind their son or daughter's impairment and for them to continue to be treated with dignity and respect in the sacred spaces of their home and the community. Keeping their family member at home was the way these families chose to restrict the entry and exits of people committed or otherwise to the life quality of their family member. It also afforded them the opportunity to pass on their knowledge of the large but often small and highly nuanced ways they communicated their needs and emotions and model ways of responding that were rooted in familial love.

It was the attributes of place that acknowledged the home as an emotional hearth that tended to be emphasised by these families with the protocols and routines of service provision perceived to undermine the affect that was required for staff to continually respond in ways that allowed family members to "be themselves."

Participants with complex health needs and their allies frequently described maintaining physical wellbeing as the cornerstone of their life quality. For some, becoming unwell was not only debilitating, but could be life threatening, and those able to speak for themselves described their need to be with people who could recognise and respond appropriately when their health status was at risk was a profound influence over the decision making that shaped their everyday lives. Some participants tended to gravitate to places where their physical support needs were known and anticipated. For others, a lifetime spent sitting in a chair meant a lifetime resisting the pull of gravity on bodies that without exercise and a good diet could turn in on themselves. "Disabled lives are extraordinary," one mother told us, "in the sense that an extraordinary effort needs to go

in." After years of watching, reading, reflecting and advocating, families were typically the repository of best health related support practice and insight.

Keeping their family member well, however, meant families had to contemplate their living beyond familial care. In much the same way as families whose son or daughter needed an empathetic response to their behavioural support needs, neither participants nor their families perceived there to be any alternative to seeking a place in a community group home because of the high level of attendant care that was required to stay well. Small social networks and the desire to stay close to ones family further limited the living options available to participants. As a consequence, for people with the most significant physical or behavioural support needs the step taken or resisted beyond home was, most often, a step into the only available bed in a group home owned or leased by a residential service provider.

6.5 The community group home or non-home?

Richard, his staff will tell you, is a deeply philosophical man. His parents had always expected him to live a big life and he had done so despite having only a handful of easily recognisable phrases and an alphabet of vowels. In spite of being forced into segregated classes for most of his school years, Richard had cultivated a fierce intellectual curiosity. All of the talking books in his local library worth reading had his initials inked in the back. In spite of a common acknowledgement that Richard drew energy from people and their conversation, he lived in a community group home with four non-verbal adults with intellectual disabilities. It was the only place Richard and his parents felt confident could adequately meet his physical support needs. Richard loved the staff that worked there, who for their part, returned his affection. He also included his "flatmates," within his field of care, but he did not choose them in much the same way as he had no choice about the house or how it is run or who came and went during the day.

Richard had lived in the community group home for ten years. His decision to move was occasioned by conversation that followed his mother becoming unwell and unable to physically meet all of Richard's support needs. Maureen was in her 70s at the time and in addition to running a small business had also taken Richard's grandfather into the family home to support him through the last years of his life. Although Richard is quick to dispel any notion that his move from the family home was difficult, within his limited vocabulary he makes a clear distinction between the two settings. In his lexicon Richard used "Over there," interchangeably to mean the CCS Disability Action office or his community group home, depending on where he wasn't. "Home," on the other hand, has always meant his family home where he and his family have continued the family tradition of breeding racehorses on a farm that has been in his mother's family for three generations.

"At home," and "Over there," are antithetical settings in many ways, one emphasising Sixsmith's personal and social experiences of homeliness and the other its physical attributes.

"At home," there is a sign-written plate on an open gate at the top of the drive that announces Richard as belonging to the social landscape. "Over there," a sign on the gate instructs visitors to "Keep the gate shut for the safety of the residents." "At home," Richard knows his neighbours and how their lives intersect with his own. "Over there," Richard and his flatmates are strangers to their street. "At home," Richard is embedded in conversations that roll on all day, especially with his mum to whom Richard's oration is like a first language. "Over there," Richard's house is typically quiet. Staff hunch over rosters or medication stackers and residents drift quietly to their

seats after tea. "At home," there is a steady stream of visitors accompanied by the smell of fresh scones that Richard's parents are equally adept at turning out and the family albums are crowded with parties and family gatherings. "Over there," only staff came. "At home," there are skinny corridors that force Richard to walk to and from his room. "Over there," has wide halls and a wet area bathroom. "At home," Richard has a waterbed that he refuses to surrender. "Over there," he has a hydraulic single bed. "At home," he has his mum's embrace to help him walk. "Over there," Richard has a hoist and a walker. "At home," Richard eats crushed chips and drinks shandies with his dad while they watch the rugby or racing. "Over there," Richard goes to his room to phone family or a couple of friends.

Figure 5 The Beale's farm; Dad's 50th; Walking with mum and dad

"At home," Richard is his generation of horse breeder, watching expectantly for his favourite horse to foal. "Over there," Richard is a much loved and respected "service user."

Richard's narrative contains themes that were common to all three participants who lived in community group residential homes.

For two participants, the road that led to their current address had begun with their mother becoming unwell. Theirs was a story that had been told before by a different generation of women that had struggled to keep their children from New Zealand institutions. In separate analyses of the narrative of parents whose adult sons and daughters were being resettled from Templeton Hospital (outside Christchurch) and the Kimberley Centre (outside Levin) Mirfin-Veitch, Bray & Ross (2003) and Milner & Mirfin-Veitch (2006) both reported that parents' original decision to seek an out of home placement for their children almost always occurred at the end of a long and wearying battle to preserve family integrity[74, 75]. The catalyst to this major disruption in the life trajectory of all family members tended to be an event which altered the balance of family life in ways that compromised their ability to continue to meet the support needs of their sons or daughters. A change in the physical or mental health status of mothers was, for many families, the event that finally overwhelmed their resilience.

For families, the emotional and physical demands of caring for a person with high and complex support needs can be exhausting. In a recent survey of this generation of families who supported a son or daughter with profound and multiple disabilities, Mencap (cited by Mansell, 2010) reported that 70 percent of respondents said they had reached or nearly reached breaking point, most often because of the lack of short break (respite) services[76]. In New Zealand, two pilot studies that surveyed carers of disabled children and adults with high and complex needs living in Waitakere City (2005) and in Otago (2006) also identified the great difficulty parents experienced

accessing skilled respite care and the absence of crisis plans and counselling as issues that continued to undermine their ability to care well for their sons and daughters[77, 78].

Ben left home when he was 25 years old, because his mother, to whom he was especially close, had died. Ben's mum had been his primary carer for all of his life. Following the death of his mother, Ben's family felt it would be a good time for them to explore options for leaving the family home. Ben eventually moved to a small trust providing residential support for young people with physical impairments. Ben reckoned he had the best of both worlds; he had a close knit family who he saw often, the fellowship of other disabled people his age who also lived in the cluster of small flats that surrounded his own and good support to live his life, both from his family and from the Trust.

Emma, on the other hand, had always been mercurial. Today it finds expression in her impish humour, the attentiveness she pays to the smallest of details and in the theatrical way Emma attends to others. But Emma's mercurial nature hadn't always been so benign.

Her family are convinced both Emma and her younger sister were brain injured as a consequence of their immunisation. Happy children, meeting their milestones began screaming day and night for the next two years. To her family Emma is a stepping-stone back to a time of great turmoil and trauma. *"The girl's behaviour was so bad,"* her mum recalled, *"that it was impossible to go out with them both. I only had two hands."* Responsibility for Emma and her sister's care often needed to be shared out amongst other family members, including Emma's siblings. To her sisters Emma still embodies the stress and hard work, and the screaming and bad behaviour that filled their childhood memories. *"I loved our family,"* Emma's sister told us before courageously adding *"but the good times were always when the girls weren't there."* Times like the respite of shared care that rolled over first once a month and then once a week or the holidays they waited for all year that provided a counterpoint to the isolation of living with sisters no one would invite over, or serendipitous moments, like finding mum cooking in the kitchen when the girls weren't home from school yet. No one remembered receiving any support to learn strategies that may have helped them to manage the girls' behaviour or hold their family together. *"Without any sense that everything was going to be ok we would work towards the weekend."* Emma's mum said. *"Friday was the best day ever because when the bus came we would have each other until the girls came back on Sunday night and it was straight back into it. That's the way we lived."*

Emma's family continued living that way for two years after Emma's sister's brain injury. Emma was twelve when her shared care turned into a full time placement with a foster family. Still unable to contain her grief Emma's mum tells us it was the biggest decision of her entire life. *"It is the hardest thing to hand over your child even when it is the best and only thing to do,"* she said, *"because you had to survive. The whole family needed to survive."*

For Richard and Rebecca, the decision-making that led them to the door of a community group home wasn't a planned transition to an adult life beyond the family either, but was instead occasioned by an erosion of the resilience of aging parents forced to contemplate an alternative care arrangement.

Rebecca moved out of home when she was 42. Unlike other participants, Rebecca described experiencing a degree of pressure to move that reached a crescendo when her mum became

unwell. The only real options available to Rebecca were out-of-area placements 150 kilometres north or 70 kilometres south of the small South Island town she had lived in her whole life. She chose the community group home closest to her parents and the landscape of another life. On the face of it Rebecca had participated in the decision, but hers was a pragmatic decision, externally constrained by the limited range of service options available to her and a feeling she had no other choice. What Rebecca wanted was to live in a flat of her own, but the frequency and severity of her seizures was understood by Rebecca to make any alternative future unattainable. Rebecca instead expressed a quiet resignation that the Government would never fund a living arrangement that would keep her safe in a home of her own. Rebecca said she liked some of the people she lived with and some of the staff and took solace in the fact that she tended to get out more than she ever seemed to at home. She took pride in feeling more independent too, but it didn't stop her thinking about what it might be like to live in her own flat, in her local community, with staff of her choosing.

Chris's transition, on the other hand was driven by a desire to experience the same rite of passage as other young people, but like Rebecca, his need for 24-hour support had also led him to conclude that the community group home was his only available option. As a consequence, the service options presented to Chris would determine where and how and with whom he lived. Chris and his family used the language of "flatmate," to describe the people Chris lived with – a terminology consistent with the narrative of coming of age and agency, but as a consequence of only having one site available to him, in reality the decision about who Chris lived with had already been made. Both Richard and Chris openly expressed affection for the people with whom he shared his home, but, unlike Chris, Richard didn't include his flatmates amongst his friends. Chris, on the other hand described the relationship he had with his flatmates as "close as."

The inability to choose your flatmates means that, disabled people are sometimes obliged to live with others they do not like. Research has consistently demonstrated that disabled people are more likely to experience incidents of abuse and violence, typically within private spheres of their life like their home. In their investigation of incident reporting in community residential settings Bray et al (2002) concluded that a picture of unprovoked bullying and a pervasive culture of low-level violence emerged in settings residents neither chose nor had opportunity to flee.[79]

Having an ability to choose who you live with also appears to moderate the level of loneliness experienced by disabled people. In a recent study, Stancliffe et al (2007) explored the prevalence of loneliness amongst adults with intellectual or developmental disability living in non-family community settings in Australia[80]. The study was prompted by an earlier investigation by Sheppard-Jones, Prout & Kleinhart (2005) who reported that adults with impairment were more likely than the general adult population to be lonely[81] and a concern that the more limited and less frequent contact people living more independently (with SIL support) had with staff and other members of the community may contribute to higher levels of loneliness amongst those at greatest risk of social isolation. Stancliffe et al found that loneliness was an issue for half of the 1002 adults they sampled with one-third of the sample population reporting being lonely sometimes and one-sixth reporting that they were often lonely. Counter-intuitively, living alone was not associated with the experience of loneliness, with the highest levels reported by people who lived in larger community residential settings. Not surprisingly, more contact with family and friends and liking for the dwelling were significantly associated with lower levels of loneliness whereas feeling afraid at home was strongly associated with elevated levels of loneliness. Not having the ability to choose flatmates with whom you share a common lifestyle or interests not only introduces the risk of incompatibility, it also can reduce the opportunities flatmates have to communicate with willing

and engaged communication partners[82]. Stancliffe et al speculated that experiencing anxiety at home in the absence of positive companionship was likely to have contributed to the inverse relationship between residential size and the experience of loneliness.

The distinction Richard made between "home," and "over there," as social milieu, was another common theme. Richard, Chris and Rebecca's homes didn't make it easy for them to extend the gift of hospitality and as a consequence, almost all of their social relationships were transacted beyond the home. It wasn't just that people seldom came, participants also actively chose to conduct the rituals of intimacy and friendship in public spaces. They left their houses to go out for coffee, or have a meal or go for a drink but they often went back to the family home to share in the celebrations that cemented family or friendship ties.

By way of contrast, Ben, who lived in a small flat with his friend Todd, in a core and cluster living arrangement loved being at home because it was where his friends were. A board-walk linked flats within the residential setting that the people who received support through the Trust used to drop in and visit other residents or share a meal. Ben said that his community were the people he lived alongside and that the disability community was where he felt in place.

Unlike Ben, participants who lived in community group homes also exercised no real control over the exits and entrances of staff or the ancillary supports that regularly crossed the threshold of their home. Moreover the day-to-day routines of homemaking and the timing of support that patterned their day-to-day lives tended to reflect the customs and regulations of service culture. For Richard, Chris and Rebecca, this almost always meant their home was inaccessible to them during the day. Between 9.30am and 3.30pm, Monday to Friday, their houses "closed," with neither having the ability to direct vocational support in ways that permitted them to participate in very ordinary social moments that centred on the home, like inviting a friend over for lunch or applying for a job surrounded by your own things. It also meant that the sanctuary of your home or bed was often not available to people for whom feeling weak or unwell could be a constant companion.

When Richard was asked if he liked living where he did, he answered unequivocally "Yes." He had great affection for the staff that had worked so patiently to understand him and who had become an important part of his life. He knew in ways that didn't need to be spoken that he was safe, loved and respected. When asked if he felt he had any choice about where he lived Richard stalled. Silences are an important part of Richard's vocabulary but dangerously difficult to interpret. When asked if he had ever thought of not living there, Richard unequivocally said "No" but went on to affirm that he didn't know of any options beyond the house he still lived in. With a look that communicated more to Richard than words, his staff person filled the silence. *"Just made the best of it,"* he nodded.

Unlike the position statement articulated by Bigby & Fyffe (2009) most people living with high and complex support needs or their allies who participated in the project did not perceive they had the right to live alone or share a small household with others with whom they had common life interests. Henk and Angela, however, told a different story.

6.6 "I'm very lucky. Most disabled people never have the chance"

Henk lived in a three-bedroom villa a few blocks from the ribbon of shops and other civic amenities that line the main street of South Dunedin. His house stands proudly to the street, the

straight edges of a low block fence doing little to obscure its spearmint weatherboard and neat trim. He bought his home eighteen years ago, with the help of a CCS Disability Action social worker who stepped beyond a narrow understanding of her role to help Henk set up the trust that allowed him to make his dream of home ownership a reality.

Henk is New Zealand's most experienced international boccia player. He first represented New Zealand at the Paralympic Games in Atlanta 1996 and during the course of his career Henk has achieved the most top-10 world placing in New Zealand boccia history[83]. Henk was also one of the first disabled people to graduate with a certificate in human studies and yet in spite of his extraordinary story, it was the very ordinary adult act of owning his own home that Henk lists as the accomplishment he is most proud of. "I am lucky," he tells us. "Most disabled people never have the chance."

Homes act as an interlocutor between a person and their community by communicating important cues about the status of its occupant[70]. Beyond the shared cultural significance of owning ones own home, Henk's pride is in part derived from the way his house stands as a personal totem of the need to expanding the horizons of expectation for New Zealanders with high and complex support needs.

Owning his own flat has also been important to Henk because, he tells us, it has meant he hasn't had to live with other disabled people. When Henk first moved into his house, he rented his spare rooms to non-disabled university students. There were practical reasons for choosing to live with others as they helped Henk to pay his mortgage, but they also brought the noise and colour of young lives into Henk's South Dunedin home. It isn't difficult to imagine how Henk may have changed their lives too - exposing them to the humour, intellect and humanity of a flatmate that generously forgave the mis-steps and mis-communications of those partnering him in his day-to-day struggle to make himself clear. Henk joked that he participated in a quiet revolution to change his community simply by showing up. His bodily difference, he said, left him no choice.

The students, however, had left years ago and while Henk's bedroom is awash with his personality, including mementos that speak of his personal and sporting achievements, his lounge is now lifeless. Dust covers drape his lounge furniture and the room is spotless, swept clean of the messiness of daily living. *"It's a bit hard for me to mess it up,"* Henk joked. The only people that came to Henk's house now are all purposefully present and paid to be there. The woman who brings his "meds," calls out beyond the frame of his door on her way to the kitchen and his domestic staff come and go at their appointed times. Henk says he would still like to flat with other people but he only receives a few hours Supported Independent Living (SIL) support, (which he uses to help him pay the bills) and two hours vocational support (which he uses to help him go swimming or get to boccia) so that without going to the Centre any more he no longer has access to the conversations that originally made homeownership possible. *"I'm waiting for the penny to drop,"* on his aspiration for flatmates, Henk said wryly.

Angela's small unit at the south end of Oamaru was the first place she said she could call home. Angela's flat is daffodil yellow and it was, she said, the very first thing she noticed. *"It was bright. Not like any other place I had been before."* Angela has a significant visual impairment. She can detect shapes and movement in a narrow corridor of vision up to 20 metres distant. Bright colours help Angela to detect the boundaries between things, but colours have also assumed a symbolic quality, often standing in the place of the feelings she has about people and places too.

On first seeing the flat Angela was almost too afraid to express her excitement. *"I whispered (to my staff),"* she said, *"am I allowed to like it?"*

Both Angela and Henk described their home as providing them with a sense of "independence" neither was prepared to surrender. After living her entire life in service settings, Angela highly valued the opportunity to live beyond the gaze of staff and other residents and it was the respite her home provided from surveillance that she felt contributed to her sense of independence. *"The little independence I have I like,"* Angela said. *"I would never have another body in here. Everywhere I went, there was always someone else sharing the house."*

In addition to the security of tenure that came with owning their own home, home ownership had allowed them to exercise control over significant life decisions, including whom they shared the sacred space of their home with. Both had taken the opportunity to write themselves autobiographically into the space with their responsibility for maintaining their home and household economy appearing to have a wider symbolic quality, reinforcing their right to personal agency beyond its walls. For Angela, holding her tenancy had not only permitted her to renegotiate her relationship with the staff who now came to her home, she said, living in her daffodil yellow unit had allowed her to challenge the disabling strictures of a "passive mind," that she had inherited as a consequence of years spent living in New Zealand institutions. Both Angela and Henk perceived that these important attributes of homeliness first identified by O'Brien could be undermined by the compulsion to live with other disabled people.

Along the continuum of disability support contexts, however, living by oneself tends to be interpreted as the zenith of a different kind of independence, communicating to funders a diminished need for human support. The reality for Angela and Henk was that their decision to live by themselves was freighted with the real risk of social dislocation. Whereas Henk received one hour SIL and Vocational support each week, Angela was entitled to four hours, two of which she used to go shopping at the local supermarket with the remainder drained by her cooking programme. *"If I went for a coffee,"* Angela said, *"I would need to go without the supermarket that week."*

In the seven days between 13-18 August, Angela only spent four hours beyond her home. On Sunday she went to her Dad's for lunch just as she did every week and on Thursday a staff member escorted her to the supermarket, as prescribed by her programme. The week between 7-13 September was quiet for Henk too. Ordinarily he would have gone to boccia on a Friday, but he was feeling unwell and so only made it out of his home for an assessment at the hospital, a short "motor" to the boccia clubrooms and two regular appointments to have coffee with a friend and fellow CCS service user at the café in the mall.
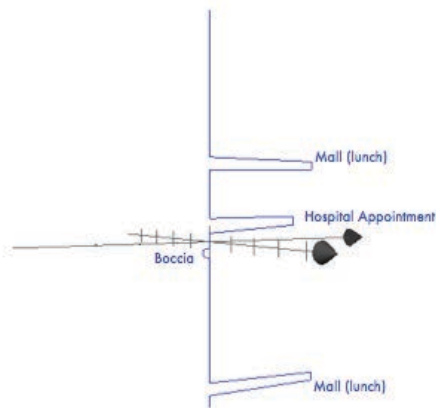
Figure 6 Henk and Angela's Time in Place map

In spite of spending only four hours beyond her home, Angela did not experience her physical separation from her community as isolation. Her community, she said, came to her in the form of staff who brought stories of the families Angela vicariously and sometimes furtively participated in four times a day. The way Angela understood her flat as gifting her a sense of authorship over the space and greater control over the relationships she had with those who crossed its threshold appeared to contribute to her feeling less lonely than she had been in the string of service settings that had been her lived experience until then.

For Henk, however, limited support hours and the closure of his day-base meant that feeling dislocated from important relationships had attenuated the pride he had in owning a home of his own.

6.7 Using the life trajectory of disabled people to evaluate their right to live in a place of their choosing

The first clause identified as giving expression to the right of disabled people to live independently and be included in the community is the State obligation to ensure:

> *"Persons with disabilities have the opportunity to choose the place of residence and where and with whom they live with on an equal basis with others and are not obliged to live in a particular living arrangement.*[2]*"*

For two of the 12 participants who volunteered their life stories, a failure to support parents to withstand the emotional and physical demands that threatened the integrity of their family extinguished their right to the home of their choosing before they reached their teenage years.

The life trajectory of most participants, however, was shaped either by their resistance to or eventual acceptance of the one living arrangement they and their families perceived to be available them. Few participants recognised living alone or sharing a small household with others with whom they had common life interests or friendship as a right translatable to their own lives. Consistent with O'Brien's observation that today's service systems appear to have developed about an unspoken assumption that people with high and complex support needs can not have a home of their own[71], the community group home emerged as the only living arrangement on the service horizon able to meet participants' physical or behavioural support needs. Half of the adults

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who participated in the Article 19 Project remained in their family home because of fears their life quality would be undermined in this service setting, beyond the ambit of familial aspiration and the communities to which they had always belonged.

Excluding the two women who were displaced from their family before adulthood, the mean age of participants who left home was 30.5 years. Moves from home, therefore tended not only to be later than the cultural norm, but away from living circumstances typical of other New Zealand citizens.

It was the responsiveness of the service sector that was the major determinant of participants' life trajectory. Henk found his way to a social worker who not only alerted him to the possibility of owning his own home, but found creative ways to make it possible. For most participants, however, the only decision they had to make was to accept or reject the one service site offered to them. For Rebecca who dreamed of a house of her own, this meant moving 60 kilometres south to live with people she had never met in a town that was not particularly familiar to her. For Richard it meant living with non-verbal adults with intellectual disability even though staff felt he wilted without the nourishment of conversation and for Jared's parents, a rest home loomed as the only alternative to the enclave of love and respect he had in his family home.

Contrary to Article 19 of the UNCRPD , the way funding and support arrangements are presently structured in New Zealand requires people with high and complex support needs to live in congregate residential support settings with others with whom they have little in common. Most exercise no choice over where they live and many have limited access to the "personal," and "social" attributes of homeliness necessary to transform a service setting into the experience of living in one's home. For some individuals seeking respite or permanent living arrangements, residential aged care facilities have also become the default support setting whilst others appear simultaneously caught by the quiescence of limited housing options and exposed to the possibility of being moved if their support needs change significantly.

In 2011, New Zealand's first report to the UN noted that,

> *"People in community services sometimes have limited choice in where and with whom they live and their daily activities,"* [9](138.2; p.32)

The report identified people using community mental health services as a population at risk of violation of their Article 19 right, without also including people with high and complex support needs. The report promoted the new independent living model, trialled in 2011, as the Government's remedial response to the problems of social isolation and the difficulty disabled people may experience living in a place of their choosing[9].

7 The right to be supported in ways that advance inclusion and prevent isolation or segregation within the community

7.1 What do we mean by inclusion?

Reducing the number of people experiencing marginalisation from mainstream society has been identified as a unifying principle to social policy development in New Zealand[5] as well as in other western economies[22, 84]. New Zealand disability policy is informed by an understanding that participating in the spatial, economic, political and social life of the community is a prerequisite to citizenship. Furthermore, progress towards the vision of a fully inclusive society originally espoused by the New Zealand Disability Strategy is similarly benchmarked against the participatory presence of disabled people within mainstream community settings[14]. Ensuring that disabled people have equal access to inclusive education and life-long learning (Objective 3) employment and economic development (Objective 4), quality community living (Objective 8) and the opportunity to participate in the recreational and cultural life of the community are, for example, all included in the Disability Strategy as discrete policy objectives.

As Clement notes, however, the disability discourse tends to be 'thick' with the affective language of objectives like 'full inclusion,' and 'active participation,' which can act to obscure the lived experiences of disabled people because of the way these policy aspirations evade precise definition or shared meaning[85].

7.2 Spatial indicators of inclusion

In the absence of any clear articulation of what is meant by "inclusion" or "community participation," disabled people have tended to be located somewhere along the exclusion-inclusion continuum, according to their level of visibility within mainstream cultural spaces[5], with the presence of disabled people in settings that exclude non-disabled people tending to be understood as the antithesis of inclusion.

Against this quantifiable yardstick of inclusion, the absence of disabled people from many ordinary cultural spaces has been interpreted as evidence that New Zealand still has some way to go to uphold rights codified in the UNCRDP or achieve the vision at the heart of the New Zealand Disability Strategy. In an online survey conducted by the Human Rights Commission in 2009, disabled people identified access to employment, education and equal life opportunities as their three most pressing human rights issues[15], with their assertions of marginalisation from these important domains of adult life supported by empirical evidence. In the arena of employment, for example, data from the Disability Survey that followed the 2006 New Zealand census revealed that less than half (45%) of the 1 in 6 New Zealanders of working age who reported having a disability were in the labour force compared to 77% of non disabled New Zealanders and that the unemployment rate for disabled citizens was increasing three times faster than for their non disabled peers[86]. People with more significant impairment were much more likely to be absent from New Zealand work places with less than a quarter (24%) of people who described receiving daily disability related support being in either full or part time employment. Researchers have estimated that between 70-90% of unemployed disabled people want to contribute to their community through paid work[87, 88]. Despite the aspiration to work often being strongest amongst

people who have historically been steered away from employment as a realistic expectation most people with high and complex support needs are forced to calibrate to lives lived without ever experiencing paid employment[32].

In the Community Participation Project, Milner & Bray (2004) reported that absence from the world of work was one of the issues CCS vocational service users also identified as compromising life quality, alongside equivalent levels of exclusion from continuing education and special interest or recreational groups likely to seed a sense of participatory membership or belonging[32].

7.2.1   The world of work

A decade on from the adoption of the New Zealand Disability Strategy, the life-stories of people who contributed to the Article 19 Project suggests that New Zealand workplaces remain largely inaccessible to people with high and complex support needs.

Of the 12 participants who took part in the Article 19 Project, Chris was the only person who was in paid employment, albeit part-time and casual. Chris's job involved him collecting mail from three local businesses and delivering it to the post office for mailing. For Chris, having a job was central to his sense of self because while working, he saw himself as an autonomous, contributing member of the community. It also allowed him to be outdoors, an aspect of the job he particularly valued. While casual employment on a very part-time basis may not have been what Chris ultimately aspired to, it did mean that time off due to ill health or bad weather was not contested. Chris's continued involvement in employment was very much dependent on his family who were instrumental in identifying opportunities for other businesses to take up his services.

Ben had had a part time paid job, doing data entry but was amongst the first to leave when the business he worked for down-sized. Ben had a love of maths and was computer literate. Despite Ben's eagerness to find another job that made use of his computer skills, no effort was being made to find him work or build further competence. Ben had instead offered to help at his local volunteer centre.

No other participants worked. Emma volunteered for a few hours a week at her local SPCA. After watching Emma's obvious affection for her two dogs, Deb, who had assimilated Emma within her family via a contract board arrangement, organised and supported Emma to help out at the SPCA kennels. For her part, Emma also kept up a constant vigil, looking for moments where she could add value to the lives of those around her. It was Emma, for example, who would shepherd tops back to their owners on outings organised by the Stewart Rehabilitation Service centre where she participated in activities alongside people recovering from brain injury and Emma who would slip into the kitchen to do the dishes or help out whenever the opportunity presented itself.

Like Chris and Emma, Graham's family and his school teachers had been instrumental in finding him voluntary work. Graham helped to sort mail at the community post office in Reporoa on a Monday. It was only for a few hours but it kept him in contact with his community and the feeling that he contributed in a small way to its wellbeing. Attempting to marry the repertoire of skills and passions her sons held with opportunities to feel a sense of productivity often surfaced when Jane spoke about their future. Jane had identified Graham's dexterity and his capacity for meticulous organization as potential assets to employers and her desire to build these skills had informed their decision to buy him his X-box and computer. It had also led them to recognise mail sorting as an ideal work experience. Conversely, Jane had identified Graham's idiosyncratic communication as a potential barrier to employment and had worked assiduously to improve his vocabulary and

social etiquette –aptitudes seldom recognised beyond familial support. In much the same way, Jane and her husband Kevin had also encouraged Scotty to buy a ride on mower. Their idea was to set up a contracting business mowing lawns by tapping his love for farm machinery and the reservoir of reciprocated affection that had built up between Scott and the farmers and contractors who recognised a kindred enthusiasm for their vocation. It didn't hurt either, that Kevin and Jane's efforts to find meaningful employment was infused with the contribution they had made to their community. In times past Kevin had helped to build the Reporoa squash courts as well as the local badminton and community halls. Hereford bulls, reared on his farm, had twice won champion bull at the New Zealand Beef Expo and he organised the weekly calf sale that drew buyers and sellers from all around the district to Reporoa. Jane, on the other hand, was not only at the heart of her church community, she had also helped other families who had children with impairments as well as local people she met through 'divine appointment,' to find employment and purpose in their lives through Graham and Scott. When Graham and Scott stepped into their community, they entered relationships within the cloak of a community's knowledge of their family history and established community connections.

In the Community Participation Project, Milner & Bray (2004) reported that families often broadened disabled people's community by providing points of entry to other networks. Like Jane and Kevin, they often also contributed material resources and a less bridled sense of aspiration and expectation[32].

Jane and Kevin had always had big dreams for their sons, but the failure of their expectations for employment to reach into the broader community was a narrative common to most participants. For example, Reporoa's understanding of Scott was informed by stories of stock agents taking bids from him at the calf sale and of Scott talking farmers out of purchasing anything other than a John Deere tractor by a considered comparison of their relative merits. Scott was acknowledged as having the *"mind of a farmer,"* but was met by supported employment services that understood him as unemployable.

The only other forms of work that participants mentioned were as Disability Awareness Educators. CCS Disability Action employed people with lived experience of disability to deliver targeted disability training to local government, health professionals, secondary and tertiary students and a wide range of other public and private community organisations. Henk was employed as a disability awareness presenter for seven years, seeing it as a natural extension to the quiet activism he couldn't avoid. It was also, in his mind, a possible career trajectory. Several years ago Henk completed a Certificate in Human Services. Although it was important to prove to others that it was possible to complete the course, Henk said that improving his prospects for employment was the primary motivation for embarking on the programme. Despite being more qualified than some of the staff who came and went, the qualification had failed to lead to employment. It wasn't that people didn't recognise Henk's capacity, but more that the type of support he received left little scope to declare employment as an unfulfilled aspiration. Over and above the personal care and domestic assistance he received, Henk was assessed as needing only two hours SIL support, which he tended to use to pay his bills and organise other aspects of life. Neither he nor his support staff constructed their relationship in ways that accommodated major life ambitions like work and in the flurry of meeting his day to day support needs Henk 'waited for the penny to drop,' on his aspiration for employment too.

Limited expectations had shaped the trajectory of participants' lives in other important domains, including their access to inclusive and continuing education.

7.2.2   The world of continuing education

The struggle to make competence clear was one of the central motifs to Angela's narrative. At the age of five she moved from Oamaru to Templeton Hospital on the outskirts of Christchurch. Angela said that the defining attribute of institutional living was that they represented places where everything was done for you and the presumption of others to make decisions on your behalf was predicated upon an assumption that you couldn't think for yourself. The effect, according to Angela, was to trap her words and her agency within the recesses of a passive mind.

Angela had to wait 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 - a board with numbers which could be turned over to form patterns with colours."* Angela spoke with conviction about how grateful she was 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. 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 was a primary school milestone for generations of New Zealander's. Hammersley Park School was a half hour drive from Templeton and Angela would make the trip each school day. *"When I got back,* Angela said *"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."* Angela stayed at Hammersley Park School until the term after her twentieth birthday, when she was compulsorily required to leave.

Richard, like most participants, stayed at school until he was compulsorily required to leave too. In 1987 St Kevin's High School decided to take disabled students. Richard was sixteen at the time and it was his first experience of mainstream education. Richard's education began at home. Generations of his family had attended the small rural community school, just over the fence from the cottage his grandparents lived in, but Richard was prevented from attending. Maureen, his mum, said the decision compounded the sense of isolation the family often experienced and she home schooled Richard by adapting the Correspondence School curriculum until he was seven or eight years old. Richard would eventually attend special units at Middle and later North Schools in Oamaru. 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 and then at school Richard would get frustrated because he couldn't make himself understood or experienced other forms of exclusion."*

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!"*

Despite their strong motivation, neither Richard nor Angela have had any opportunity to recover their lost learning through continuing education. Angela writes most days. It was, she said, a way to expand the vocabulary of words she needed to tell her story. It was also a way of reminding herself how far she had come from the disabling expectation that words would stay trapped inside of her. Angela kept a transistor radio within arms reach of her bed. She listened to it at night so that she had something to discuss with the staff that she said brought the world to her. Years of institutional living had left Angela without a template for an ordinary life and the stories that staff brought allowed her to fill in the picture. *"I'm forever asking them if they are kidding,"* she told us. Almost all of Richard's subsequent learning has also been self-generated. From an early age Richard enjoyed talking books. Maureen described them as invaluable. *"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."*

Duncan was the only participant who still went to school. He was twenty and his parents, Sue and Steve, were apprehensive about what the future held for Duncan beyond the community of his school. Sue and Steve had sought support to help them manage the transition that loomed, but the only option that appeared to be pursued was the search for an appropriate Vocational Centre rather than exploring the possibility of Duncan being a job seeker. The closest Vocational Centre that had a vacancy was miles from Duncan's home and whilst Sue and Steve were grateful that Duncan had somewhere to go post-school they worried about how he would cope with the change to his routine, the long drive to and from the Centre and how well he would adjust to being "out of place," with staff and clients he had never met. Duncan didn't go on the tour of Vocational Centres and it was unclear how much he understood about the transition that lay ahead.

7.2.3   *Worlds of special interest or recreation*

In addition to the lack of access participants experienced to the worlds of work and continuing education, no participant described currently belonging to a community group of any hue.

Mela went to an evening painting course at the Rotorua Arts Centre a few years ago and Angela used to attend a writers group, without ever feeling that she really belonged. The lack of accommodation other group members made for Angela's visual impairment, she said, left her feeling like an outsider and she eventually quit. *"Some of the things they did went over my head,"* Angela said, adding that without being able to take her computer to the group, it was difficult for her to share her writing in a way that would make her creativity transparent to other group members. *"I couldn't let them know I wasn't dumb,"* Angela lamented.

Richard and Angela did, however, belong to the Cerebral Palsy Society. Every three months the Society's magazine arrived to keep them abreast of news and events relevant to people with whom they shared common experiences, but it was the social events that provided Richard and sometimes Angela with an opportunity to catch up with others they had known for most of their lives but were otherwise estranged. The Christmas lunch provided one such opportunity to affirm common community. Last year the lunch was in Dunedin, an hour and a half's drive from Oamaru. For Richard, this presented little problem. His residential service had a wheelchair vehicle and staff available to support his attendance. For Angela, however, the drive made attending impossible. Most weeks Angela's lack of access to human or material resources shrunk the circumference of her community to a few blocks and the drive to Dad's place in the weekend. *'Its 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. I don't think they have any idea it's just not possible for me."*

No participant currently belonged to a formal sporting, leisure or recreation club that also included non-disabled people either. Deb described the group of women that she and Emma walked with as a walking group and most participants bowled or played boccia, usually as part of their vocational programme and always with other disabled people. Most participants said they went to catch up with people they knew and wouldn't otherwise have the chance to meet. Henk, however, went to practice. As noted previously, Henk had represented New Zealand at boccia for over fifteen years. He has competed at three Paralympics, narrowly missing a medal in the pairs when he and his partner Greig Jackson came forth at the Athens Paralympic Games 2004. Boccia has taken him around the world having represented New Zealand at international competitions in five continents and countries as distant as the USA, Australia, Portugal, Greece, Malaysia, Brazil, Canada, China and Hong Kong. Of all the participants, Henk and Angela's day-to-day lives were most spatially constrained, with the tension of competition and the exotic places boccia took him standing in sharp contrast to an ordinary week. Henk was proud of his sporting achievements but added that it was the relationships that he had forged through competition that contributed most to his life quality. Henk had made a lot of friends through boccia and loved catching up with them at national and international competitions. He was still friends, he said, with people that he had started playing boccia with and numbered amongst them many non-disabled friends, including the ramp assistants who sat with their back to the action, attentive only to a shared vocabulary of non-verbal cues Henk used to guide the orientation of the ramp and height the leather balls were placed. In an otherwise sparsely populated friendship field, boccia offered Henk an oasis of relationship.
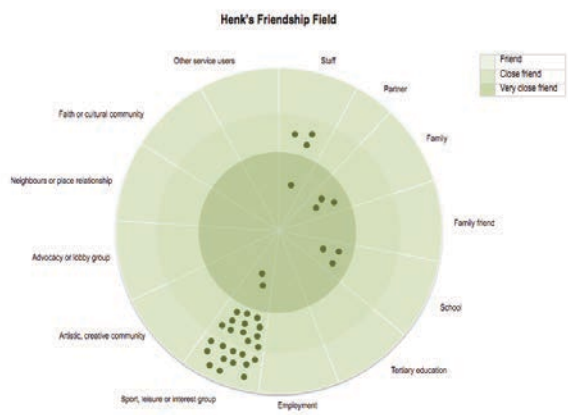
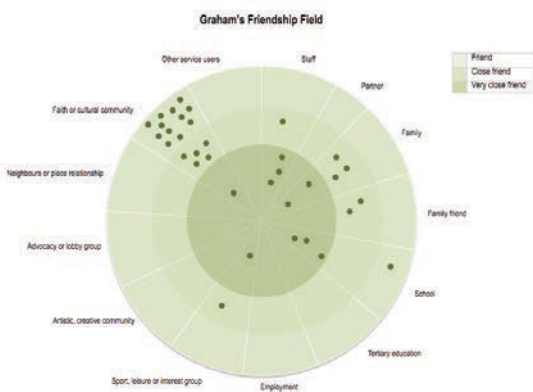Figure 7 Henk's Friendship Field (Henk and Greig Jackson v Ireland)

Figure 8 Graham's Friendship Field (Graham's 21st birthday)

Graham's Youth Group provided him with a similar wellspring of friendship. Graham's mother Jane said that he couldn't wait to leave school, but within two months Graham was desperate to go back. Graham had stayed until he was compulsorily required to leave at twenty-one too and in those two months it had become transparent to them both that beyond the community of school it was going to be difficult for Graham to maintain relationships with the people he had grown up alongside. It wasn't that living in Reporoa was isolating, it was that the life trajectory and interests of his age peers had diverged so radically in the transition to adulthood. Once a week Graham went to a Christian Youth Group in Rotorua. He usually stopped in at his friend Vika's home first and they would go together. Vika and Graham's friendship had developed from another of Jane's "divine meetings." Vika had originally approached Jane at the gym she and Graham attended. The gym owner recognised that Mary, Vika's mum and Jane shared similar aspirations for their disabled son and daughter were so similar. *"You two were meant to meet,"* he had told them and since then Graham and Vika meet regularly. Graham and Jane have also taken Vika to Auckland on one of the holidays Graham meticulously plans and anticipates months in advance. Attending Youth Group has kept Graham and Vika connected to their generation and Graham and his family find ways to add value to the relationships that evolve there, including invitations to the farm and family celebrations, like Graham's 21st birthday. Graham's love of flags had themed the evening with many of the friends arriving in national costume, adding additional colour to a party that culminated in the heraldry of a flag march around the lawn on an icy April night.

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Finding the way to communities of interest was, however, atypical of the lived experience of most participants. No other person belonged to a faith or cultural group, nor did anyone participate in community art or creative groups, advocacy or lobby groups, special interest groups or associations of place.

7.3 Where were participants present?

Participants varied greatly in the degree to which they were visible members of their community. Least visible were those that owned their own home.

Figure 9 describes the average proportion of time participants who completed their Time in Place Diary were recorded engaged in activity beyond their homes between the hours of 8.00am - 9.00pm.

Henk and Angela spent, on average, 90% of their week at home, with approximately half of the remaining time given over to the utilitarian activities of shopping, bill paying or hospital appointment. With the exception of the time that Angela spent having lunch with her dad on a Sunday and the quick visit Henk paid to the boccia hall, Angela and Henk were only visible to their community in anomic public spaces like the supermarket, hospital, bank or mall.

Angela felt she knew Oamaru *"very well."* Generations on both sides of her family had called it home and despite the interruption of institutional living, Angela had never really left. When asked how well Oamaru knew her, however, Angela said that, "*most places absolutely nobody (knew her)."* She said she wished there was somewhere she felt she belonged. "There is CCS," she added, before going on to explain that things had changed. *"We have been told you can't just go there now. You need to make an appointment."*

Own Home	CGH	Family Home
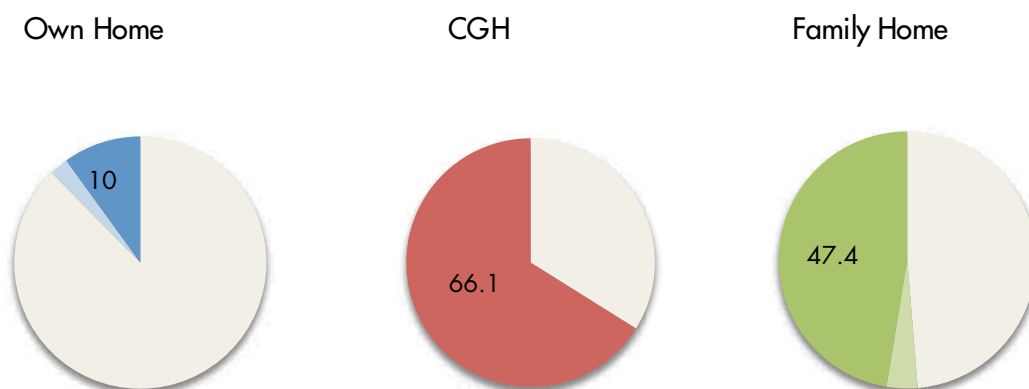
Figure 9 Average proportion of time participants were engaged in activity beyond home

Unlike Henk and Angela, Richard was a highly visible member of his community. He couldn't motor a block in town without someone stopping him, usually to ask if he was off for a cappuccino or whether it would be the egg sandwich or the cream cake today and sometimes to tease him about women. *"Everyone in Oamaru knows Richard,"* his staff told us, *"and do you know why? It's because he is always out there."*

Richard received 17.5 hours support, which funded a vocational programme strongly weighted towards keeping him "out there" in his community. Richard, like the other participants who lived in community group homes spent most of his time away from the residential setting. During the week between 10.00am – 3.00pm, people who lived in Community Group homes didn't have a choice - their houses closed, but it also reflected a preference by Richard to be exposed to people and the conversations that staff said he drew energy from.

For his part, the way Richard experienced being out and about led him to read Oamaru as an inclusive community. Others were more likely to attribute the way Oamaru publically embraced Richard to his inclusiveness. *"He has one of the biggest fan clubs around here,"* two of the ladies who had just finished their Fun Over 50s Aquarobics class told us. *"He has such a glorious smile. Richard always leaves you better than you came. He is good company,"* they added. Two mornings a week Richard went to the Oamaru Aquatic Centre to stretch and uncurl his muscles. He had been going for years, always at the same time, so he knew the women from the Aquarobics class would be at the pool and that they would drift over to the spa at the end of their session and Richard would listen attentively to discover if anyone had won lotto that week or whether the classes were working yet. The pool attendants knew Richard too. Usually they kept aside the plastic container with #1 on its lid for Richard to put his valuables in. On the day we went, however, an attendant had absent-mindedly given the box to someone else. *"It will have to be #1 4 Richard this time"* they told him, apologetically.

Richard's repeated presence had led him to be included in other rituals of place that acknowledged him as part of the Oamaru social landscape. Richard's love of coffee was legendary. *"It was the glue,"* his staff teased *"that held everything together."*

Richard had a handful of cafés he liked to go to and the taxi drivers who know Richard's programme also know his trip to town on a Friday ended at "The Bean" with his "bevy of beauties," where the right barista makes the "special coffee," for Richard. Over time, their variation on the cappuccino with cinnamon has become part of the social lore of the café, as had asking Richard if he would like an egg sandwich, which was assembled out the back when he did.
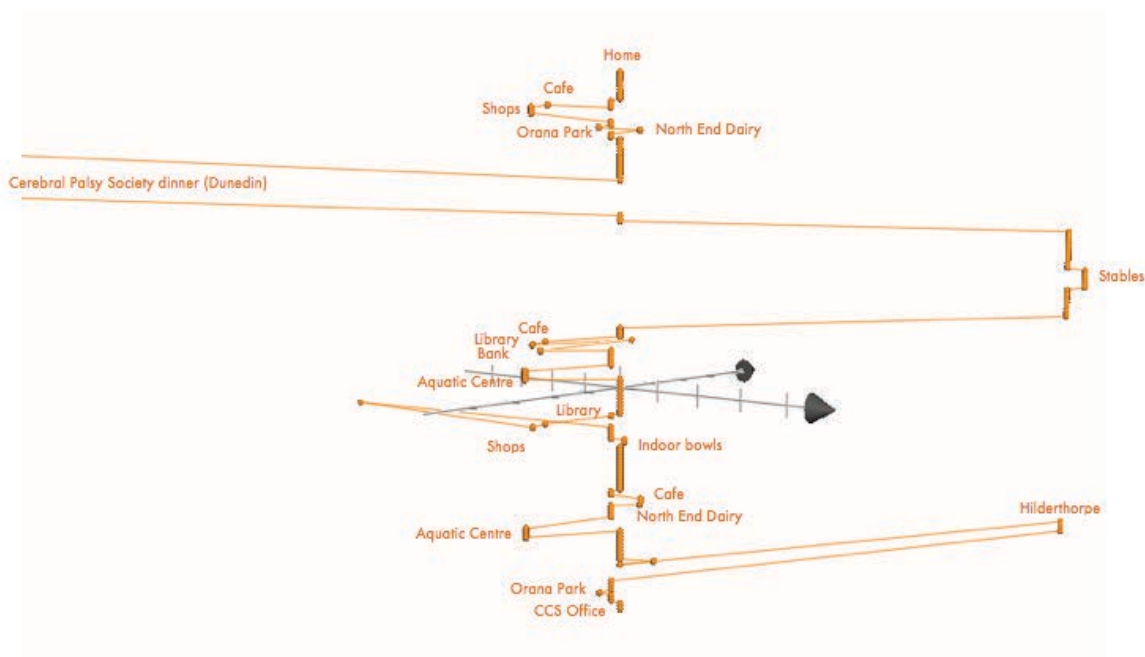
Figure 10 Richard's Time in Place map

Thursday morning meant bowls. A local bowling club had made their indoor green available to disability service users and provided a handful of volunteers to help shepherd the bowls. IDEA service users bowl from one end and CCS Disability Action service users bowl from the other. Richard has the outside lane and bowls by himself. On the morning we went, Richard got off to a slow start. He was much more interested in catching the conversations that drifted across from a few lanes over. Richard wasn't really there for the bowls. *"Now Mr Beale,"* a volunteer prompted, *"Did you bring your coffee seeing as it's so cold. I can't see any steam rising. People will think you're just here to meet girls."*

On Monday, Thursday and Friday afternoons, Richard went to town. Whilst Richard determined what happened when they got there, visits to town tended to have a predictable pattern. 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, his mum, and Richard had 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 en route, 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 had always enjoyed Richard's company. In the times in between, Richard came and went from the CCS Disability Action Office.

7.4 A safe (but segregated?) place to push out from and return to

Richard had three cardinal spaces in his life. His community group home, his family home at Hilderthorpe, and the CCS Disability Action office. All were important nodes of felt value to Richard. Despite the CCS Office ceasing to be the site of day-based activities, Richard's weekdays still began and ended at the office. It was the safe space that he pushed out from to do elements of his programme and return to, to have lunch out the back bantering with staff over coffee and a newspaper. He also caught up with other service users that still came irregularly to the centre and a smaller number that regularly came on Thursdays to have their lunch. Richard had been going

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to the office for twenty years, longer than all of the staff and many of the service-users Richard had known for most of his life. The CCS Office had also been the site where some of Richard's most significant social relationships had been forged and flourished. There was the fellowship of a support group who had gathered about one of the more charismatic service users at the Centre. There was also Dianne, who together with Richard formed two thirds of a triumvirate Maureen called the Three Musketeers. *"They used to go everywhere together, parties, town, everywhere."*

There was also Amanda. *"Richard and Amanda,"* Maureen said, *"loved one another."* They were at school together but really got to know each other 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, Richard's staff said, that *"at times they could get mad with each other. Richard is a 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 had since died. *"Richard doesn't get many arguments now,"* they told us.

The CCS office was one of the few places Richard could be confident that people would not give up trying to understand him and as a consequence, he was at greater liberty to bring different attributes of himself to relationships that transcended the superficial knowing of him as a man who enjoyed a cappuccino with cinnamon and an egg sandwich.

More than half of the relationships Richard named as his friends had either begun or continued to be affirmed at the CCS Office.
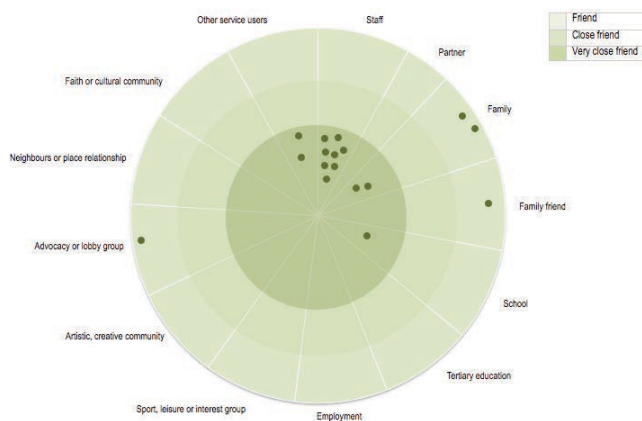
Figure 11 Richard's Friendship Field

The CCS Disability Action office was a conduit to the community for others too. Like Richard, Chris's residential group home was also closed during the day.

Chris was a man who valued his independence, and who didn't like to be tied to an unchanging routine. *"People always ask me what I am going to do tomorrow but I always say I don't know because I don't."* While Chris would not aspire to spend the day at home (as he has far

too many people to see and places to be), central to the choice and control Chris exercised over his own life was ready access to the support and service offered to him through the CCS Disability Action Office. The Office, located conveniently for Chris just outside Invercargill's CBD was critical to daily life. Chris's medical and personal care needs were complex and ongoing and he required support to manage these in order to maintain good health. For Chris, an *"outdoors man"* who liked to be occupied and to have purpose, the CCS office was also a place to rest and recover his energy between forays out into the community.

For both Chris and Richard, the office was one of the only places they could go during the day to have their personal care needs met with dignity and where their support needs were neither remarkable nor unanticipated. As Chris said *"(CCS) is a big part of my life. The people and having a place to come to is important. It is a bit like a home away from home. Whatever I need is not a problem."*

Both Walker (1998) and Hall (2004) noted that disabled people described patterns of community use that were sensitised to the richer qualitative experiences of feeling in or out of place[22, 34]. People, they said gravitated towards settings where accommodation for impairment and the experience of feeling welcome were assured. Within Richard and Chris's map of social acceptance and rejection, the CCS Office occupied a prominent place within their particular network of "safe spaces." The office was a familiar space populated by people with whom they had shared significant moments of their personal history. Many of the relationships formed there were characterised by levels of intimacy that were difficult to replicate and in much the same way that CCS Disability Action vocational service users had described to Milner & Bray (2004) eight years earlier, the office, for those able to choose, had continued to provide both a refuge from feeling different and a beacon of social knowing[32].

It hadn't always been that way. In speaking about Richard's participation at the centre when it was a day-base, his support staff observed that when he was *"lumped in with everyone else, he would go inside of himself."* Having one-to-one support *"individualised staff attention,"* and provided Richard and his staff a better opportunity to engage in the dynamic, two way process of building shared meaning. *"People were completely powerless in those places. It was like being at school,"* staff added, contrasting Richard's ability to hold his staff accountable to his programme every Monday morning with the artificial moments of choice making and inability of service users to effect any significant influence over the culture or activity of the day-base. *It might be a programme,"* they told us *"but it's Richard's programme."*

Mela was the only person who continued to attend a day-base. Mela blended individualised support provided by staff her family employed with the use of a day-base she attended three and a half days each week. She currently lived in a flat adjacent to the family home and over and above the support Mela needed to live independently, she had approximately ten hours support available to her to go shopping or participate in community activities. For Mela and her family, therefore, going to the day-base added structure and purpose to what may otherwise have been relatively "destinationless" and lonely days. Like Richard's previous experience of the day-base, however, Mela tended to get lost in a crowd of louder voices. Day-to-day activities at the day-base were programmatically organized, which meant Mela and the other men and women who went there, exercised limited control over the social practices that defined the day-base culture. It was a programme that tried to emphasise community and fellowship, but in Mela's case, misread her

participatory aspirations and undervalued important elements of her personal history that may have helped her express them. Some staff at the day-base, for example, knew that Mela liked to dance and to write poetry, but the programme staff and client's were bound to also defined their relationship in ways that made it difficult for Mela to alert others to their importance or for it to be acknowledged in her day-to-day activity. Worse still, staff at the day-base were largely deaf to Mela's anxieties, and her felt need to be away from the art class or communal share time had led Mela to be read as oppositional and problematic. Mela chose the quiet room to eat her lunch and tended to sit at the edges of tables and on the fringe of conversations. She spoke less often now than she used to and often in sentences that barely broke a whisper.

Figure 12 Mela at her day-base

Nevertheless, Mela's day-base did offer her a context highly conducive to relationship building. Many of the people who went to the day-base had been in Mela's circle of friends since childhood. They had gone to the same school together, tried flatting at a similar time and knew each other's family and their histories intimately. Mela added and subtracted to this circle of friends regularly, and whereas Richard never expected to meet another Amanda, Mela had had two long-term boyfriend relationships over the years with men she met, one at a Polytech course and her current boyfriend at a previous day centre. Mela's social life also extended beyond the day-base. She went to concerts with people she knew from the day-base, waited expectantly for their texts and invited them for meals and sometimes to stay over for the night.

For almost all other participants, it was extremely difficult to begin new friendships or deepen relationship through shared activity.

7.5 Relational indicators of inclusion

In Chapter Two we noted that people are socially connected to their community and that whilst "places" and "activities" are important markers of access to community spaces, they become important as arenas in which moments of inclusion are transacted through the deepening of relationship and the accumulation of shared history. Attending to relational markers of inclusion is the alternative route that researchers and disability rights activists have taken to explore the participatory presence of disabled people.

Within the research literature, a general consensus exists that disabled people typically have smaller social networks and experience more limited social contact than their non-disabled peers[25, 26, 30, 31, 34]. Similarly, the tendency for most social relationships to be transacted in public and not private spaces has lead a number of researchers to invoke the social typology of "the stranger," to describe the social position of disabled people[22, 26]. Someone who, despite being

physically present in community spaces, tends to be culturally distant from the social action at the heart of common community.

The empirical evidence appears to be aligned to the everyday experiences of people living with impairments in a New Zealand context. In 2001, the Convention Coalition identified social participation as the most significant human rights issue faced by disabled people in New Zealand, drawing particular attention to the "often taken for granted drivers of social participation," like friendship and a place within the social and cultural worlds that New Zealand communities draw upon in seeking to articulate a shared identity.

Marginalisation from the worlds of friendship and common community that the Convention Coalition singled out as the pre-eminent human rights issue for disabled people in New Zealand, had been foreshadowed by the CCS vocational service users who collaborated in the Community Participation Project (2004). Most participants considered they had few friends with their perceived exclusion from social relationships that communicated a sense of membership or belonging understood as compromising their life quality[32]. At the time, CCS Disability Action was contemplating the closure of Centre day-bases as part of a shift towards more individualised service delivery and participants also took the opportunity to express feeling vulnerable to social isolation beyond the two service settings that were their primary social spaces. At that time the day-base represented a place of respite from long hours spent bored and alone at home for many participants. Beyond the day-base *"there (was) nothing out there,"* and, they said, *"it was difficult to get other people interested in (them)."*

Seven years on, the people who participated in the Article 19 Project continued to describe small friendship networks with few friends named beyond relationships that came either as a birthright or were accessed through family and staff who they had come to know through a support relationship.

Figure 13 records the mean number of friendships named by participants that completed a Friendship Field.

Absence from the worlds of employment and continuing education meant that no participant named as a friend anyone drawn from these ordinary participatory contexts, so often the source of friendship for non-disabled New Zealanders.

On average, participants named 4.8 people they had met and come to know through their membership of a sporting, leisure or interest group and 2.8 people who had become friends through participation within a faith or cultural based community groups. This picture is, however slightly misleading because they are strongly skewed by friendships formed by Henk's following his lengthy participation in the boccia community (26 friends named) and Graham finding his way to the fellowship of his Rotorua Youth Group (17 friends named). The general pattern, however, was for people not to report having relationships drawn from these forms of community participation and without the skewing effect of including Henk and Graham's data, the mean number of friends drawn from sport, leisure or interest groups (0.6) and faith or cultural groups (0.0) approximated those for all other participatory contexts. Participants, on average, named less than one friendship from within an artistic or creative community (0.5), advocacy or lobby group (0.2) or as being a neighbour or other place relationship (0.8). Only one participant had a partner.
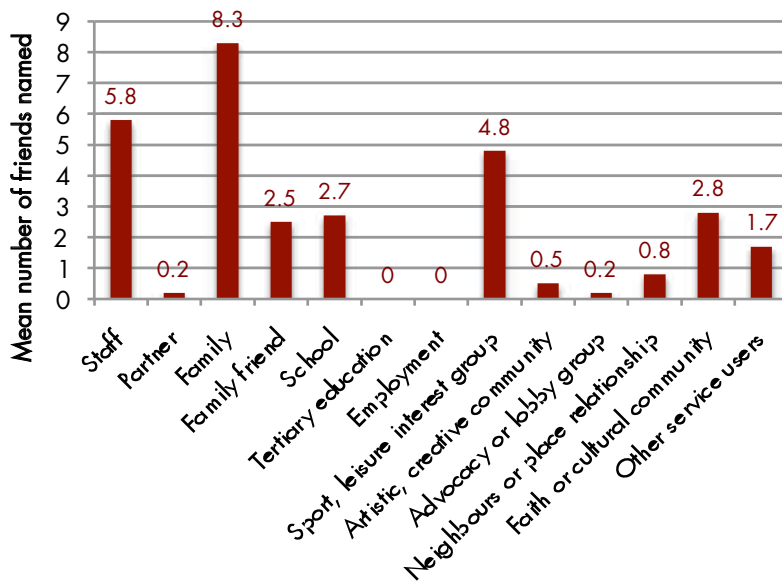
Figure 13 Mean number of friends named in participants' Friendship Fields

Research that has included people with intellectual impairment suggests that many of the relationships disabled people have with members of the community who are neither staff nor family members tend to be fleeting. Kennedy, Horner & Newton (1989), for example, found that community relationships seldom continued for more than 12 months with family usually providing the single continuous narrative to the lives of people with high and complex support needs.

For the people who participated in the Article 19 Project, their families and staff also tended to provide them with their most frequent and enduring social relationships. These two social contexts emerged as the most important sources of friendship and interpersonal intimacy. Over one-third of the people participants named in their social network were either family members (27.5%) or friends of the family (8.2%) and staff represented an additional 19.2% of the people participants included in their friendship field.

Participants' families were important to them for a range of reasons, not least because for most, remaining in touch or living with their family continued to give them access to preferred forms of social knowing. Angela had moved home to exchange the social role of patient for daughter, sister and aunt. All of her nieces and nephews birthdays were committed to memory and numbered amongst her most treasured social relationships. For Richard, his family home at Hilderthorpe connected him to the horses that had been like siblings to him as he grew up as well as other symbols in the landscape that affirmed him as belonging in that place. Signs like his name painted on the letterbox a short motor from the training track where his dad had hung on to him as they urged their trotters to go faster.

Figure 14 Duncan and his brother

Duncan was visible in his community in a "solitary" way. His family were an integral part of his life. When he was away from them, primarily at school, he appeared to feel secure in the knowledge that he would be back with them by mid afternoon. Whilst his immediate and extended family provided Duncan with access to the community through their social interests, Duncan did not participate in the activities that defined the community of his parents and grandparents.

The commitment of families to build a shared vocabulary meant that parents and siblings were often participants' most effective communication partner too. Not having access to ordinary speech meant that Richard often struggled to make himself clear. It has also meant that at times he lost influence over his life because of the failure of others to understand his expressions of need and hope and friendship. Recognising that Richard's difficulty speaking has the potential to isolate him, Maureen had attempted to model and mentor staff and their efforts to join a narrative Richard and his mum had spent a lifetime building. After 20 years, Richard's staff described themselves as *"beginning to have a handle on some of his speech and what he is trying to convey."* They have also learnt to frame their conversations in ways that make the most of Richard's restricted vocabulary, a skill that they attribute to Maureen for whom Richard's verbal and non-verbal communication had become a second language.

Parents and siblings were also free to communicate in more personally meaningful ways. As part of their introduction to a study which explored the day-to-day social interaction of one woman with high and complex support needs ("Sandra"), Johnson et al (2010) cited Findlay, Antaki, Walton & Stribling who suggested that inclusion was characterised by patterns of communication that included respectful, mutual exchanges between individuals which are rewarding to both parties[84]. They noted that types of social exchanges that were most satisfying to "Sandra," were those that enhanced social closeness and that the place that she was most likely to have access to those interactions, was at home with communication partners who reciprocally enjoyed her company and were able to return the love they received.

In the Article 19 Project Krystle stood out as someone who came to life when she was liberated from the professionally prescribed conventions of age appropriate behaviour and interaction. As an important and valued member of a large, busy family, Krystle's community frequently came to her. In her own environment Krystle was able to show a side to her personality that was likely to be rendered invisible in the meetings and communications that typically occurred during her scripted visits to the wider community. At home Krystle's interactions were not constrained by the

conventions of the "right way" to be with a woman in her 20's but instead reflected the diversity of her relationships and interests. Krystle's sister, for example, quickly elicited her bright smile and expressive eye contact by getting down on the floor with Krystle and playing a turn-taking game with a much-loved musical toy. Krystle's obvious joy at this simple interaction showed that it was an interaction personally meaningful and valuable to her.

In much the same way that Maureen worried about Richard's vulnerability to variation in the communication skills of those he would depend on for support and self-expression beyond her ability to continue to interpret, other families were similarly fearful about their family members ability to continue to access valued social identities and preferred ways of expressing social closeness beyond the ambit of their care. A number of families who continued to support their son or daughter at home expressed that any alternative future was too scary for them to contemplate.

The families of participants were important conduits to other communities too. On average, participants named 2.5 family friends as part of their friendship field.

Some came from familial communities of interest. Maureen was quick to describe Richard as part of a "racing family." Amongst the handful of people that Richard kept in contact with by phone was Colin, a family friend that had also trained and raced horses and his "surrogate grandparents," who were also part of the colour of the horse racing community. Others came from lifelong friendships, many of which had galvanised in times of stress as a consequence of support given to parents at moments when they were struggling to balance the need to learn how best to meet the needs of their disabled son and daughters without compromising the life quality of other family members. Having a disabled child, many parents said, could be isolating for the whole family, however, most were able to identify at least one other family that had offered important emotional support and normalised the experience of growing up. Emma's sister remembered that there was only one family that could be relied on not to care if Emma *"lost it."* Whereas visiting other people was stressful, she said, that family had understood. *"They were the one family that invited us places and the only ones who would come to the movies."* Nearly two decades after Emma's family sought an out-of-home placement for Emma, the children of the supportive family were able to communicate to Emma, and her wider family just how important they had reciprocally been to them by flying back from Australia to be at the 30th birthday organised by Emma's *"other mum."* Other participants named friends they had known their whole lives because of the relationships their parents had forged with other families advocating to improve the life quality of their disabled son or daughter. Dianne and Richard were born a day apart. As children they had little choice but to know each other, but their subsequent friendship included a shared history of being together in the same places at similar times in their life trajectory. They went to the same schools, entered disability services at the same time knew the same people, had had to confront the same prejudices and now lived in community group homes in the same street.

Families were also responsible for generating almost all of the neighbouring or relationships of place that participants described. Deb described the older couple who lived next door as also being very fond of Emma and Emma would often pop over too see them. Similarly, Mela had grown up in the house her mum still lives in. Her immediate neighbour had watched Mela grow up and, although Mela was described by her mum as "known only peripherally," by her street, Mela's return to the flat at the back of the property had led to the rekindling of that relationship of

place. "They don't visit," Mela's mum said, "but are pleased to see Mela if I encourage her staff to get her to pop in or make some muffins."

As noted previously, Angela's fledgling relationship with her neighbour was the only relationship of place that had taken root beyond family.

Perhaps not surprisingly, participants who still lived in their family home appeared to have the greatest access to family members and the friends that came with them. All of the participants who lived at home needed support to complete their Friendship Field and it is likely that the higher mean number of friends named for these relationship categories was influenced both by families greater level of awareness and sensitivity to the significance of the familial relationships. It is important to note, however, that living alone or in a service setting had the potential to sever people from historical relationships of great significance by distancing them from that continuous narrative as-well-as families' greater sensitivity to people who were important members of an extended family of love and support. Participants who lived away from the family home named the fewest family members as part of their friendship and only Richard, who still went home for the weekends and saw his mum most days named a family friend.

The other continuous and often unacknowledged narrative to participants' lives came from the generation of disabled peers whose own lives had always intersected with theirs. Beyond the skewing of Henk and Graham, who had found their way to communities of interest, school friends were the third most important source of participant relationship. Participants who still lived in the family home were also more likely to have remained in contact with school friends (Figure 15).

Mela had one close friend she had known all of her life. She was a constant companion to Mela in all of the photograph albums that line a shelf set aside for them in Mela's bookcase. Leafing through the pages, they sit framed as young girls on a picnic rug having lunch at a family outing. Later on they appear as classmates in each other's school photos, and in fancy dress at themed flat parties. Conscious of the significance of their friendship, Mela's mum would engage Mela in conversations that invited her to consider new ways to deepen their relationship through shared activity. Mela and her friend still go to concerts and the movies together. Mela often has her friend over to watch DVDs and sleep-over. Families had greater capacity it seemed, than either services or people living alone to support participants to sustain friendships with disabled friends. Participants who still lived in their family home, on average, named 2.7 times as many school friends and 1.4 times as many other service users as part of their Friendship Field.

Mela and her friend also saw each other during the week at the day-base. In this respect Mela's life was different to all other participants. Following the implementation of Pathways to Inclusion, many services, including CCS Disability Action, had chosen, not only to close day-bases, but to provide individualised rather than combined support arguing that neither were socially normative community experiences. By excluding the alternative imaginings of community held by disabled people, this policy decision had the effect of severing many from a community to which they had always belonged. For participants who subsequently had limited support hours or alternatively, were supported in ways that prioritised other outcomes, it had proved extremely difficult to stay in touch with people they had been friends with for their entire lives.
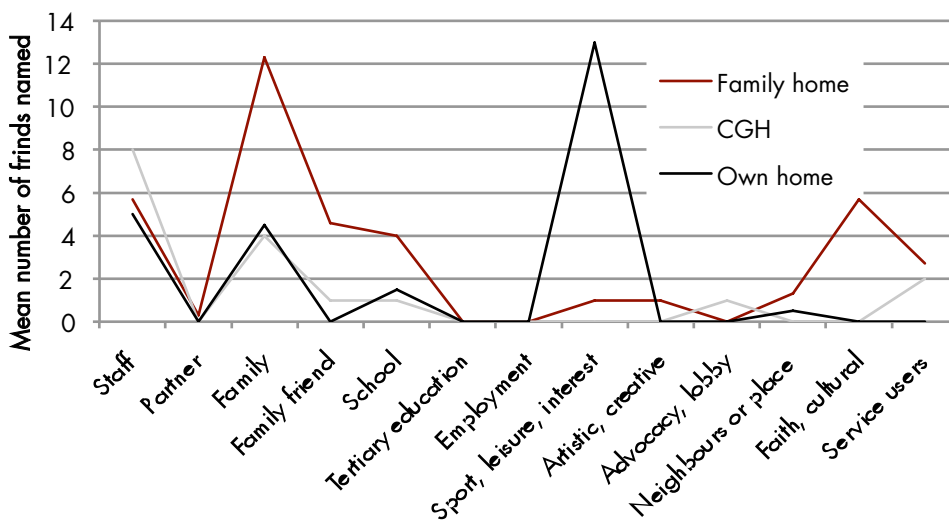
Figure 15 Mean number of friends named in participants' Friendship Fields by living arrangement

7.6 Missing the fellowship of other disabled people

In the 1990s, Steven Carnaby argued, that to achieve meaningful social inclusion a radical readjustment needed to be made in attitudes to the importance of peer relationships[62, 89]. Carnaby emphasised the political dimension to common community by suggesting transforming inclusion from an individual to the collective goal of disabled people would be the key driver. He, like others, had observed that lasting social change had always been self-authored by marginalised populations from the safe space of common community.

Disabled people themselves also describe reclaiming a sense of self within the culturally distinctive mores of the disability community, including being more able to challenge the disabling rules and identities inherent in service culture[90]. Similarly, Milner & Kelly (2009) reported that when the CCS Vocational Service Users who participated in the Community Participation Project adopted a collective strategy to community participation, some community spaces became more socially accessible[5]. Participants who named more disabled people within their social network participated in a wider array of community activities and, provided people chose when, where and with whom they participated, many also reported feeling more able to confront the social ordering of unfamiliar places in the company of their disabled peers.

Whilst the consensus was amongst participants and their allies, that individualising support had increased the editorial hand they had over their programme, for some it had also meant the loss of their access to the fellowship of other disabled people.

Henk considered he belonged to a generation of disabled people. His was a generation that had shared the same segregated primary school classrooms, broken down the barriers to mainstreaming at secondary school and graduated to the vocational day-base, together. Together, they had also resisted the worst aspects human support and similarly all discovered the social model of disability too late, together. Over the decades Henk's friends had quietly mentored each other. They shared the same subversive humour and their parents were also still part of CCS Disability Action's collective memory.

Henk said he would still go back to the day-base if he had the chance, echoing Angela's frustration at having to make an appointment now. Going to the day-base meant that Henk wasn't at home all day, but it was the chance to see his old friends that he missed.

Figure 16 Henk's friends and Richard's peer support group

Along with Malcolm and Lester, staff at the centre used to call Henk one of the "three gentlemen." Fiercely intelligent, these men shared poetry and insight as they collectively struggled to deconstruct an understanding of themselves as "clients," within a sub-culture of knowing that was often impenetrable to staff. *"We had no idea about what they were laughing about most of the time,"* Henk's staff told us. *"I don't see them now,"* Henk said. *"We don't live near each other."*

7.7   But we are only supposed to like them

Support staff are often disabled people's most frequent and enduring social contacts. A number of studies have reported that staff often occupy a place of paramount importance within the social networks of disabled people[24, 25, 91-93], providing those with limited access to other validating social relationships with some of their most important sources of self identity and social connection.

Following their discussions with disabled service users, two recent Australian studies report that people who depend on human services emphasise the relational context to support as the most important determinant of perceived service quality[93, 94]. Disabled service users said that quality support was effected by staff who were prepared to transcend the formal task orientated focus of the role with the "right attitude," experienced when interaction fostered feelings of attachment, inclusion, equality and a sense of being liked and respected. Self-disclosure and "normal talk," were said to characterize dialogue with staff that services users consistently used the language of social proximity to describe. Good staff, they said were "friends," "mates" or "like family."

In an unpublished presentation Milner (2010) reported that adults with intellectual disabilities also emphasised the relational qualities of the staff working in New Zealand residential services by echoing similar relational motifs. People who used New Zealand residential services highlighted trustworthiness - particularly with keeping confidences, the feeling that staff listened, that they were fun to be with and that they communicated a sense of liking as important qualities in the support staff who came to their home[95].

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"Sharing the inner circle," was the descriptor Marquis & Jackson (2000) used to describe service users most valued support relationships. Relationships categorized as falling within the "inner circle," had life sharing capacity, with patterns of interaction extending beyond work-time, expanding the life experiences of both partners to the relationship within an ethos of reciprocated friendship.

Within hierarchically organised services, the act of caring has itself been read as embedding an unequal power relationship between staff and clients by affirming the worth and capacity of the helper whilst suppressing the worth and capacity of the care recipient. Policies and procedures designed to control staff client relationships have had the effect, however of entrenching a different kind of inequity, whereby clients have access to a vocabulary of social closeness denied staff. In a recent study exploring turnover in New Zealand disability services, Milner (2009) reported that staff described the gravitational pull of their relationship with the people they supported as holding them in the role[96]. They worked for Mary and Jane they told the research team, and not the agency, with many expressing genuine anxiety that the depth of love and respect they felt for the men and women they supported needed to stay below the officially sanctioned radar of affect. *"But we are only supposed to like them,"* staff told the research team. Newton, Olson & Horner's (1995) finding that the most important predictor of relationship durability in their investigation of factors that explained stable relationships between disabled persons and community members was community members having previously been staff, provides additional empirical evidence of the gravitational pull of relationships that "share the inner circle[30]."

Research suggests that staff – client relationships that are experienced as friendships have other advantages to service users too, including moderating feelings of loneliness and disempowerment (Murphy 2002). In an examination of the outcomes that followed the closure of the Kimberley Centre, Milner et al (2008) also found the most marked improvements in the life quality of former residents to have occurred when people found their way to support relationships which replicated the familial attributes of affect and advocacy[11].

Support staff were an important source of friendship for all participants. Richard, the only participant who lived in a community group home to complete a Friendship Field, included eight staff members as important people in his social network, twice the number of family members he named. Participants who lived in their own home or their family home, on average, included five staff members as friends within their social network, far higher than any other non-familial relationship source.

A closer examination of friendship attribution also revealed that a significant number of staff members tended to be perceived by participants as occupying positions of greatest social closeness (Figure 17). Eighty-three percent of staff named by participants as part of their Friendship Field were assessed as being either very close (48.6%) or close (34.3%,).
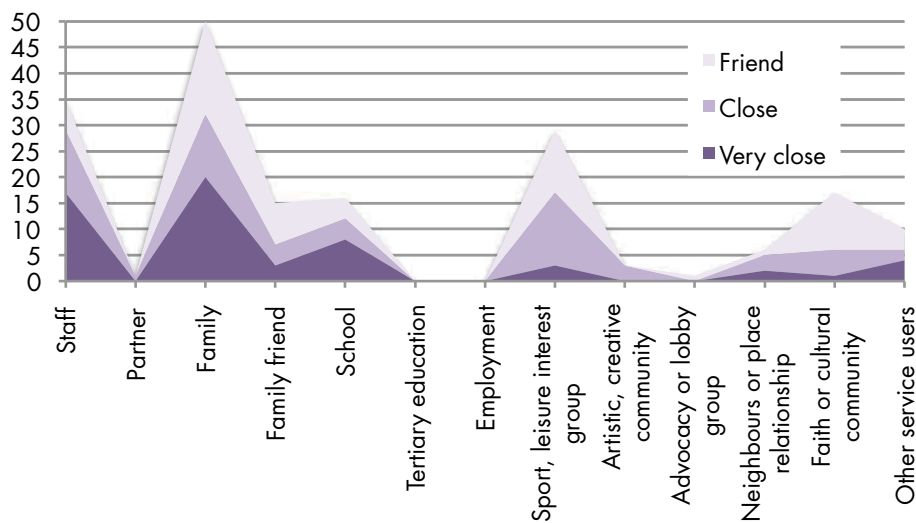
Figure 17 Participant friendship attribution

Angela named fourteen people in her Friendship Field. As well as family, there was Richard. Angela had met Richard at the CCS Office years before when they both attended the day programme. Now he is part of her programme and she sees him on the last Thursday of every month when they take turns hosting each other for a meal. Angela likes to get out, but it's sometimes not so easy to be at Richard's place. She knew she had to confront the perception of some staff that she is there to talk to them and at times she felt like a client and not Richard's friend. Because Angela lived her life almost entirely within the walls of her flat she said she used her computer to *"take her to different places."* *"If I didn't have a computer,"* she told us *"I wouldn't have a life. It's my lifeline - literally. It's more than my life is worth. That and June's programme."*

All the rest of the people that Angela named as friends had at one time been paid support staff. Most of the staff she called friends are current staff, three of whom were part of the daily ebb and flow of support that visit Angela four times a day. *"The community comes to me,"* Angela said in the form of her staff, who brought stories from the outside about the families Angela had become a vicarious member of. *"Seldom a shift passes without Angela asking about my family,"* a staff member told us, *"And we know you care by the way you remember,"* they told Angela. Embedded in the relationship were other subtle forms of reciprocity. Staff were always pressed for time and Angela knew the people who were also dependant on their punctuality so had things organised for the next staff person. Staff found ways to acknowledge Angela too. A painting of a bearded iris hung above Angela's sofa waiting to greet people that entered. May, one of Angela's support staff, had painted the flower and gave it to Angela as a housewarming gift, *"even though she wasn't supposed to give her clients presents."*
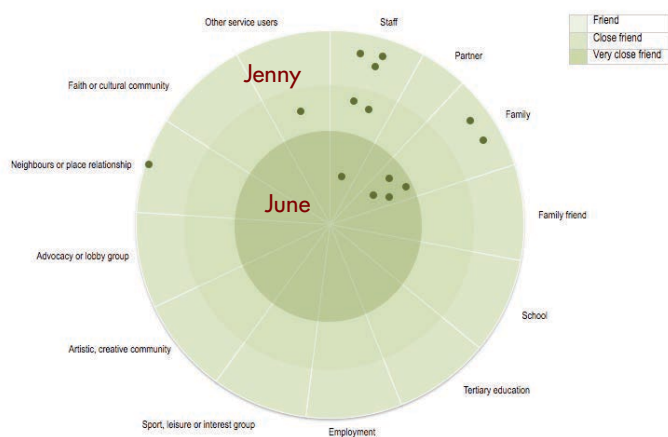
Figure 18 Angela's Friendship Field (Angela writing with her friend June)

Jenny was an ex-staff member. Angela and Jenny had remained friends after she left and once a month they would go to town for a couple of hours to visit the shops or go for a coffee. Angela described Jenny as *"volunteering her time,"* and was careful not to tax the friendship, not least because it was the only real opportunity she had to get into town to window shop.

The most precious of all of Angela's friendships was the relationship she had with her reader-writer, June. June was the last in a line of reader-writers that Angela had been able to employ with the help of a small trust. Over the years, Angela had learnt to trust June's respectful treatment of her attempts to write about the experiences that had shaped her. Angela's poetry and book writing had given her access to a new vocabulary and through their shared disclosures, June and Angela had pulled each other into the inner circle of their lives. Consistent with the research that documents the transience of community relationships for disabled people, Angela's friendship with June, however, was also freighted with anxiety. *"I have tried to make friends before,"* Angela said, *"and every time they say we will remain friends, but nobody ever has. 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. Never!"*

Angela's experience was not atypical. Henk also described his staff as his friends. Rosie had been his carer for 19 years. She had known him before he'd owned his own home and before he'd rolled his first boccia ball. Rosie still came twice a day and three times in the weekend. On Fridays Henk and Rosie met "unofficially" and in the past few months Rosie had moved to a house just a few blocks from Henk.

Unencumbered by the discourse of professional boundaries, families tended to gate keep in a different way, by choosing staff who they felt would also love their son or daughter.

For Krystle's parents it was important to preserve the family home, as much as possible, as their private space. Having a multiplicity of support workers or caregivers, not well known to them or by Krystle was not acceptable, so for this reason much of Krystle's support was provided by people they had "hand-picked." Jared's parents also shared this desire to ensure that the people who supported Jared knew both him, and them, well. Both families strove to achieve close and continuous relationships between their adult children and those who supported them. Both

families resisted being forced into a situation where their children's support was delivered in the absence of a meaningful human relationship.

In so doing families were assured that the respect and affection they held for their family member would be communicated to others when their son or daughter were supported by staff in community settings beyond the family home. Some families also spoke of the importance of being able to collaborate with staff whose love and respect for their family member meant that they could be confident their relationship was similarly infused with an ethic of advancing the ongoing viability of their son or daughter as developing people.

7.8 Choosing appropriate indicators of inclusion

Almost all participants had few friends beyond the community about their families and the staff who stepped in and out of participant lives as part of their support role. Contact with people participants named as friends beyond these two relationship contexts tended either to be infrequent and largely beyond the control of participants, or fixed as a scripted element within the vocational programme or when lives overlapped in the segregated spaces of the day-base and CCS Disability Action office.

The participants whose support involved CCS Disability Action staff collaborating with families to effect community participation tended to have broader social networks and participate in a wider array of community contexts. Whilst the sample was small, an analysis of the activities that participants in different living arrangements engaged in revealed that only those who continued to live in the family home had visited a friend at their home, attended a celebratory event, gone to the movies or concert with a friend or attended a community event during the week that they completed their Time in Place Diary. They were also the only participants to have volunteered their labour to a public or private organisation[11] (Figure 19).

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[11] Chris chose not to complete a Time in Place Diary.
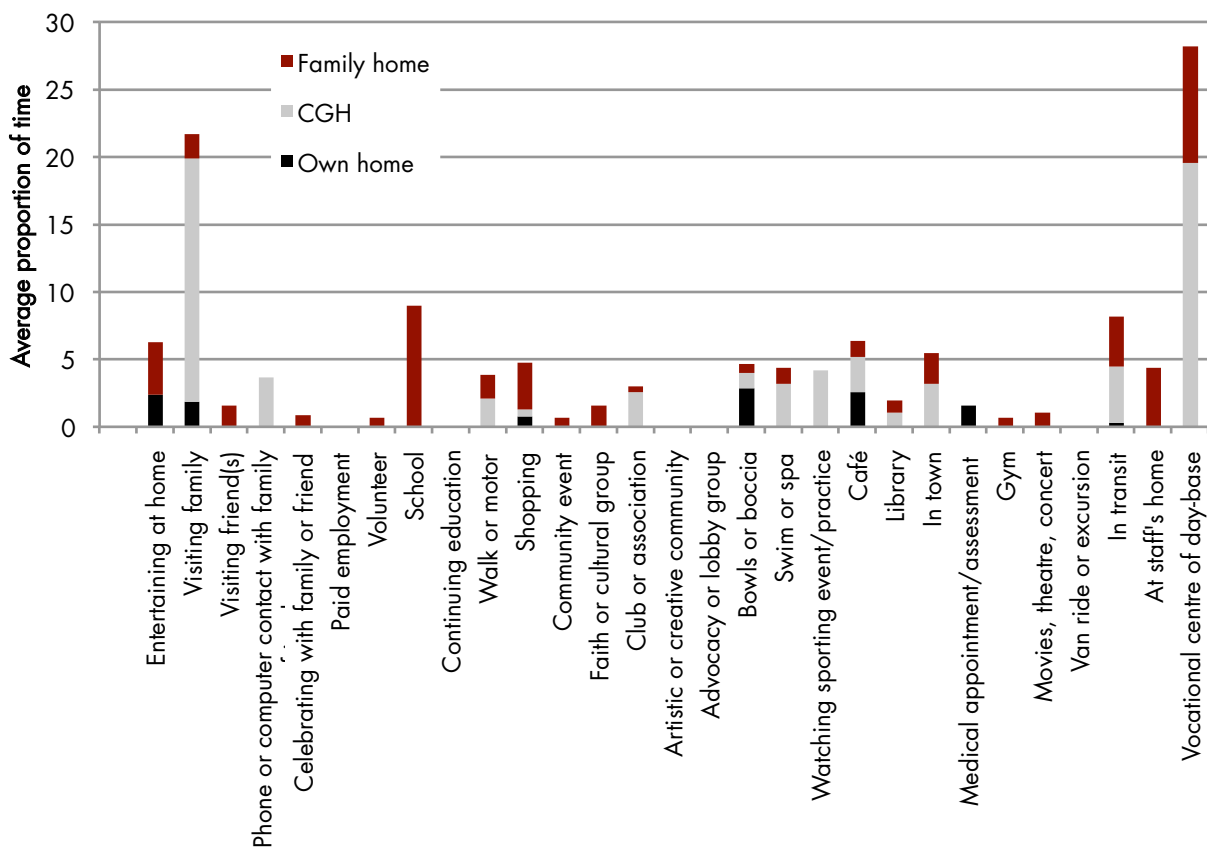
Figure 19 The average proportion of time participants recorded they were engaged in community activity beyond their home by living arrangement

In contrast to people who lived in different living arrangements, no one other than support staff visited the houses of people who lived in Community Group homes. Similarly, the only people to visit the private social spaces of staff's homes during the week were participants who had continued to live with their families. In this respect, families appeared to understand staff and their combined role slightly differently, but in a way that appeared to contribute to a more global divergence in the "outcomes" of community participation that were privileged by familial and service support.

Support that had its origins in service culture tended to emphasise spatial indicators of inclusion and most especially the right of disabled people to be in the ordinary spaces and places of their community whereas families tended to emphasise relational indicators of inclusion, emphasising the importance of locating their family member within social relationships in which they experienced a sense of joy, purpose and belonging.

Different interpretations of community participation appeared to underscore variation in support practice. When spatial indicators of inclusion were prioritised, staff's role tended to be understood as connecting people to places. When relational indicators were prioritised the aim of support became to connect people to people, contributing to the different patterns of spatial and social inclusion described above.

7.9 Getting with the programme

All twelve participants varied in the extent to which they drew on service based support to access their community. Paradoxically, Henk and Angela, who were among those who most needed human support, received the least. Henk didn't see his siblings much and his parents had died a while back and Angela's visual impairment meant that it was unsafe for her to leave her home unchaperoned. Small friendship fields and limited incomes further reduced their mobility, however, as noted previously, choosing to live in their own homes meant to funders that they were the most "independent," of clients. Henk received two hours vocational support and two hours SIL support and Angela received 3.5 hours SIL support.

The vocational (and personal and domestic) support that Henk and Angela received arrived at the same time every week. The pattern of staff entrances and exits was so inviolate that Angela found little reason to change a vocabulary she acquired at Templeton, still describing herself as *"under CCS,"* and, like most participants who lived away from the family home, as experiencing her community through *"her programme."* Participants knew their weeks prior to living them. *"I know what happens everyday,"* Angela told us. *"All my programmes are in my head."* Mobility taxis for many were pre-ordered and the drivers were as familiar with participants' week as their staff, arriving at cafés as if summoned by the draining of cups.

In addition to its largely unchanging structure, participants' programmes had a number of other common characteristics that suppressed the development of relational community.

Support hours were not only fixed, they were orientated towards the completion of a prescribed task. For Angela it was grocery shopping and the cooking programme For Henk it was bill paying and swimming on a Thursday. Jared and Krystle received their support hours through a community participation contract but in many ways their hours away from their respective family homes were similarly prescribed. Living in a rural town meant that options for new activities and experiences were limited so community participation tended to follow the same patterns and well worn routes each week. Particular cafés and shops were heavily relied upon as sites where Jared and Krystle were demonstrably "in" the community. It is unlikely however whether such activity really assisted them to become "of" their local community. Participants and their support staff both felt the press of time, collaborating together to achieve the predetermined "participatory experience" in the hour(s) they had available. *"How are **we** going for time?"* was a refrain that regularly passed between participants and their support staff. *"Everything has to be done on a timetable,"* Angela told us. *"They (staff) are in the programme too."*

Not only did "the programme" limit Angela's ability to respond to community events or act with any degree of spontaneity, the limited time available also constrained the community contexts that were available to her. *"It's impossible to go to a movie or a concert. I can't do anything out there without somebody with me and CCS say they haven't got enough funded hours.*

For people like Angela whose social network did not include others who could readily assist her, going to a movie or a weekend concert was also problematic because service support tended to be out of cadence with the ordinary social rhythms of her community. Whereas the myriad of different social, sporting, recreational, cultural, creative, political or educational experiences that seed a sense of participatory membership or belonging for non-disabled New Zealanders typically happen outside of work hours, Angela and other participants had limited access to support at

night or during the weekend. Temporal displacement from the ordinary rhythms of the community had the effect of transforming inclusive community settings into segregated social spaces too. For example, although Richard motored to indoor bowls at the local bowling club a few blocks from home, he only ever went on a Wednesday morning to bowl with other disabled people whose programmes overlapped with his. Despite enjoying the company of the bowling club volunteers who transparently also enjoyed his, Richard didn't bowl with or against them in ordinary competition, he wasn't included in ordinary club activities and he didn't come to the club at any other time. Bowling was, for Richard, day-base activity transplanted to a community setting. Similarly, although Richard enjoyed the company of the women who drifted across to the spa pool after their Over-50s Aquarobics class, going to the pool in the morning meant that Richard was unlikely to meet the age peers who he had motored past at the school cross-country or harmonized with his one note in the school choir. Chris, Jared and Rebecca also bowled with other disabled people during a regular set session at their local bowling alley.

The other, less obvious way "the programme" defined community, was in the way that it limited the understanding participants and their staff had of the support role. The types of places or activity that "counted," as legitimate destinations for community participation tended to reflect the historical horizons and social practices of support culture and not the communities of interest that participants were likely to feel authentically present. Both support staff and participants had acculturated to community participation meaning service users ghosting in and out of a limited range of public spaces. Included in that range were the swimming pool, boccia hall or bowling alley, mall, supermarket, gym, library, café, public toilets, McDonalds, the Warehouse and Two Dollar Shop. Participants tended to be diffident about asking for types of activity that deviated too far from the shared script of their vocational programme. Angela for example, was apprehensive about seeking support that could be construed as *"using her hours the wrong way." "It's all tied up with CCS if it can be done,"* she told us *"If it's 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."*

Richard also expected to exercise editorial control over his day-to-day activity and a number of support elements promoted Richard's ability to be self-determining. His communication diary was central to Richard maintaining authorship of his weekly programme. Every Monday morning Richard met with his staff. The purpose of the meeting was so that Richard could say what it is he wanted to happen because whilst his programme provided everyone with a common framework, his staff told us *"he will jump the programme if he gets a better offer."* Monday's meeting allowed Richard to alert staff to the adjustments he wanted to make to the programme, most often to accommodate events that he and Maureen have discussed over the weekend.

Richard loved his life and was equally unequivocal that it was the cappuccino, egg sandwiches and women that made it so good.

Public social space

Private social space

Private social space that offered the "gift of hospitality"
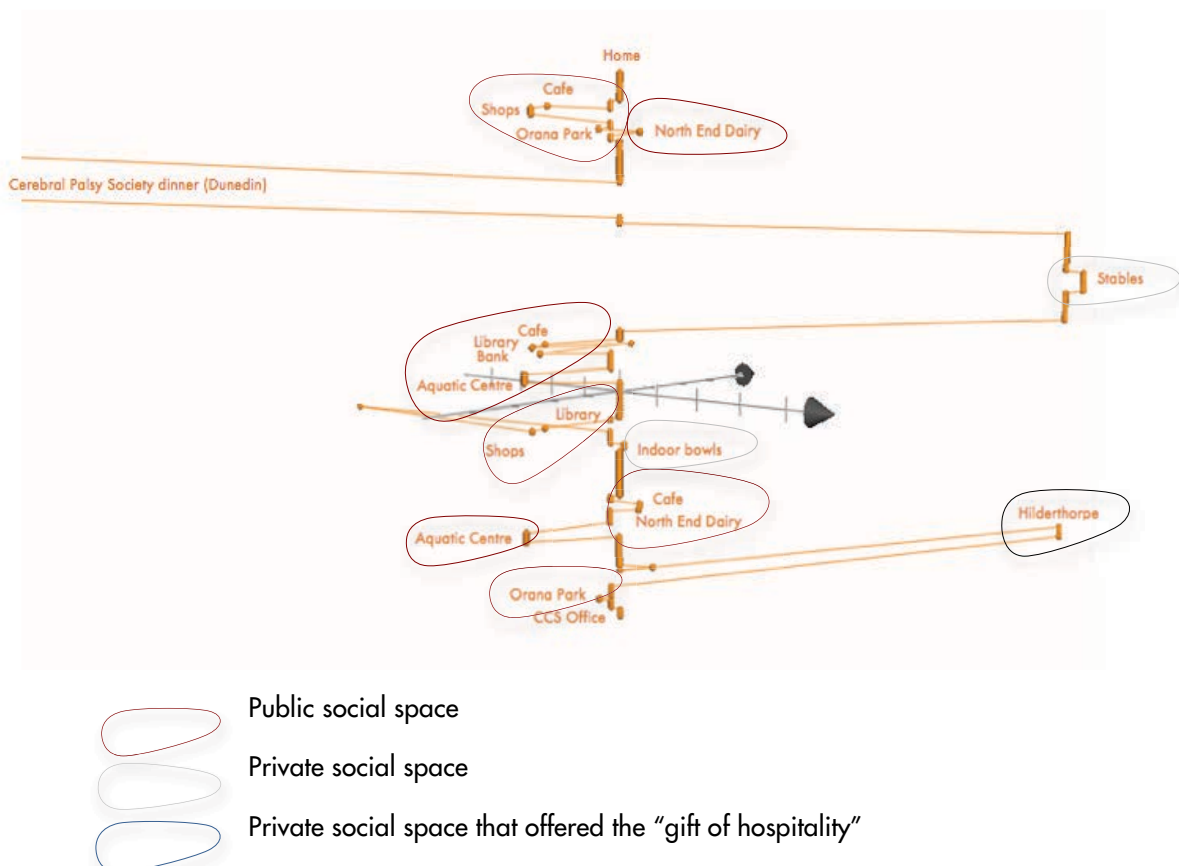
Figure 20 Richard's Time in Place map

As noted previously, Richard was not only a highly public figure in his community, he also tended to be acknowledged in the places he went regularly, like the pool and café, by rituals that communicated both liking and affirmed him as belonging within the social landscape of that setting.

Figure 21 Richard at "The Bean," Aquatic Centre and Two Dollar Shop

In the three fold typology O'Brien, Thesing & Capie (1998) developed to describe the way former residents of Kingseat Hospital were present in their community eight years after resettlement, "Participators" were described as experiencing their community with other disabled people being supervised and supported by staff but with social connections beginning to develop as a consequence of repeated visits and the purchase of community goods and services[31]. Although Richard no longer went to town as part of a group of other disabled people, his support staff did continue to moderate Richard's community participation and in all other respects the way Richard

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was supported to be present and participate in the Oamaru community most closely approximated O'Brien, Thesing & Capie's (1998) "Participator," category.

Consistent with the findings of Walker (1999), O'Brien, Thesing & Capie (1999) and Milner & Bray (2004), all of the ways Richard experienced community through his programme occurred in public spaces "on the outer fringes of the daily round of community life." Beyond the context of his family, Richard had limited access to the private social worlds of interpersonal intimacy and inclusion. In public spaces like the library, café, pool and dairy, money was the primary medium of social exchange and not the culturally specific and often complex systems of reciprocity that disabled people told Milner and Bray (2004) contributed to their sense of participatory membership and belonging. Within these settings, Richard's participatory role was restricted to that of consumer, without any additional expectation that he contribute to the wellbeing of others he shared the space with.

Aside from the support staff with whom he deepened his relationship by regularly sharing ordinary rituals of friendship like going for a swim or sharing a coffee or choosing the right card for a special occasion, Richard's relationships with the other people he met in those contexts had remained at the level of acquaintance. People had a superficial knowing of Richard. They could anticipate, for example, his choice of coffee or sandwich filling, but were much less likely to have the autobiographic insight expected within the more valued social roles of friend, neighbour, work or club mate.

Following a study Werner, Horner & Newton (1997) undertook to identify and reduce the barriers to social participation experienced by three adults with high and complex support needs, the principle authors identified the potential for support staff to supplant socially supportive roles normally filled by other community members as an "unintended," impediment to social inclusion[97]. Werner, Horner & Newton argued, that the presence of paid staff could have a variety of unintended consequences including removing the need for simple instances of support that had the potential to seed relationship and of limiting the opportunities disabled people had to contribute socially. Similarly, by signposting the need for trained support, the presence of paid staff, they explained, also had the potential to foreground a person's impediment as the most prominent social marker or engage disabled people in a "social bubble" of interaction that other community members found difficult to penetrate.

Henk met Karen every Friday for lunch before they went on to boccia at the University Clubs and Society building. They had known each other all their lives. Both of their families had contributed to CCS Disability Action as part of a wider advocacy for their children and over the years Henk and Karen had followed each other to the same kindergarten and school classrooms and shared the same circle of friends. Henk and Karen took turns to pick the café, but they tended to cycle through the three or four where they said the staff *"were good to them there."* Meeting for lunch was a recent development. Karen used to have lunch by herself. *"I'm not paid to be with (Henk),"* Karen's support staff explained. *"It's out of the goodness of my heart. He was sitting at home doing nothing and I thought, I can feed him. They have known each other for years,"* she added.

Figure 22 Henk and Karen; Chris and his tattoo artist

Both Karen and Henk enjoyed catching up and were grateful to Karen's support staff for recognising and supporting the possibility, but the short time they had available and need to accommodate personal care needs before going on to boccia meant that Karen and Henk were never alone in their friendship. Between the two of them, Karen and Henk are able to support each other. Having been friends for years, Karen's practiced ear is attuned to Henk's sentences like few others. Her hands are steady and speech clear and their intimate knowing of each other's life-story also make them effective social interpreters, but it was Karen's support staff that ordered and paid for the bacon and egg pie, held the door open on exit and filled the silences that ended when Henk and Karen were together alone.

A few participants were present in their community in ways that had led to the deepening of social relationships through shared interest or occupation. Angela was at the beginning of a relationship with her neighbour Maraline and Chris had become assimilated within a community that shared a love of body art.

Chris was in his 20's when he got his first tattoo and much of his subsequent body art has been themed around his nickname "Frog." Chris's family gave him this nickname when he was a little boy and he wore it proudly as a significant part of his persona. For Chris, body art provided him with an overt method of asserting his independence, autonomy and sense of self. "*[It is] the one thing I am able to do without my parents or friends. I love my body art. It is who I am as a man.*" Chris also clearly loved the process of getting a tattoo – the anticipation, the planning, the pain (*"a good pain"*) and the patience to wait for the real finished product to emerge over time. When he got a tattoo Chris was simply someone who loved his body art – a member of a different community of people. While Chris's impairment was acknowledged by his tattoo artist, it is secondary to his identity as a man who is seeking to add to his collection of body art. Chris commented on the closeness and quality of the relationship he shared with his tattoo artist. "*I know him really well and know what he does. He knows [my] body. That is important. He knows who I am and he knows how I move.*"

In much the same way as O'Brien, Thesing & Capie (1998) reported the group of former Kingseat Hospital residents they categorized as community "Networkers," had forged lasting social connection beyond the gaze of their service[31], Angela and Chris's staff were similarly kept "offstage," by both partners to the relationship. Timing her run to the mailbox to avoid staff allowed Angela and Maraline to preserve "neighbour" as their preferred form of social knowing whilst failing to acknowledge the few people Chris allowed to share his experience of the tattoo

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parlour as anything other than friend allowed Chris and his tattoo artist to also maintain the integrity of their form of social knowing free of the culture of disability support.

Whereas the community contexts that people gravitated to without staff support tended to offer them the prospect of meeting new people, the locations they tended to end up in as part of their vocational programme were invariably difficult contexts to generate new relationship. Moreover, by understanding locations like the café, pool, library and shopping mall as the destination of community participation rather than as a social arena in which people might "experience being part of a growing network of personal relationships[12]," any relationships of place that did emerge tended to remain fixed at the level of acquaintance and context bound. The ladies Richard met at Aquarobics, for example, would never get to know the "bevy of beauties," he met for a coffee on a Friday and in spite of their shared affection, Richard would only see the volunteers from the bowling club on a Wednesday morning from his outside lane.

Beyond the relationships that had developed with staff, no participant included in their Friendship Field, anyone they had met through their vocational programme.

For participants like Angela, who was only ever fleetingly present in her community, few opportunities existed to seed relationships. When her research partner asked whether Angela had the chance to meet new people, she told them that *"(they) were about the third (person) in the past two years,"* before correcting herself. *"Or maybe the second."*

In the paper they wrote following the CSS Community Participation Project, Milner and Kelly (2009) argued that for disabled people the arrow of inclusion only ever seemed to point outwards, involving their migration away from places they felt known and validated to spaces in which they frequently occupied positions of inferior cultural knowledge or social capital. There was no expectation, they observed, for non-disabled people to make a return journey to spaces where disabled people felt authentically present[5].

As Walker (1999) and Hall (2004) noted, one of the dangers inherent in emphasising the presence of disabled people in mainstream public spaces as the paramount indicator of inclusion, is that the systems of service delivery that emerge may be inattentive to the way disabled people experience those spaces[22, 34]. For a few participants, "community participation," took them away from places where they experienced a sense of belonging to public spaces that included the normality of disorientation, discrimination, intolerance and more subtle forms of personal exclusion.

For nine hours a week, for example, Jared left the comfort of his family home and became a service user in a community participation programme. Staff sometimes struggled to understand how to support him. Jared was unable to communicate what community participation might mean to him, or even what activities he enjoyed, so those who supported him were forced to make decisions on his behalf. In his role as service user Jared was known, but only a small number of people even come close to understanding the subtle and not so subtle ways that Jared attempted to communicate his feelings and wishes. It was when Jared ventured out into his local community that the real impact of disability was most keenly observed. Community participation dictated that Jared was required to spend his time away from the service setting. As a young man who used a

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[12] John O'Brien (1987) defined community participation as ' the experience of being part of a growing network of personal relationships that included close friends,' and included it as one of five accomplishments articulated in his influential Framework for Community Integration.

wheelchair and who couldn't see or talk, Jared appeared at best to be an object of curiosity. People of all ages reacted to Jared in a myriad of ways, and most of these ways failed to recognise his humanity or his right to a place in the community that offered him respect. If people made their way into Jared's world it was usually to acknowledge the work of his support staff rather than to engage with Jared himself. This was in stark contrast to Jared's experience at home where he fulfilled multiple roles – son, brother, nephew, cousin and family friend.

As described in Chapter Six, except for those who continued to live with their family, participants' homes rarely offered them the gift of hospitality. Whereas Richard enjoyed the stream of visitors that called expecting scones at Hilderthorpe, no one except for Angela visited him in his community group home. Dust covers draped furniture in Henk's lounge, waiting to be lifted and Rebecca and Chris only hosted family at their respective group homes.

Deepening friendship through hospitality wasn't widely understood as a participatory outcome. People went out to the community without ever inviting the community home. Moreover, the time limited and task-orientated nature of most participants' programmes denied them the opportunity for any alternative imagining of community participation to emerge. Nothing of value, John O'Brien argued, tends to happen in "productive time." He felt the sorts of relationships conducive to effective support were instead constructed in the "wasted time," disabled people and their allies spent "hanging out" talking about the seemingly unimportant stuff that allow people and their aspirations to declare themselves. Both support staff and participants were caught in a programme that required them to collaborate to achieve a purchased vocational outcome. In the meantime, Henk waited for the penny to drop on his aspirations for employment and flatmates as forms of inclusion, Krystle waited for conversations that allowed her to experience the social connection she experienced in the safe space of her home to be replicated elsewhere, Ben waited to develop relationships beyond the supportive circle of his disabled mates at the flats and Richard kept an eye out for opportunities to jump his programme.

7.10   Jumping the programme

When Angela spoke of her preference not to ask for support for activities not included in her programme, but to find *"other ways,"* to participate in her community, it was to her family that she tended to look. Similarly it was Maureen and the communities that she connected Richard to that typically generated the *"better offers"* that led him to *"jump his programme."* The support arrangements that appeared to be most successful at embedding participants in communities of choice and personal meaning were those where CCS Disability Action partnered families or others committed to their wellbeing, in the support act. In addition to their autobiographic knowing and advocacy, families were also more likely to understand enhancing relationship as the destination of community participation and were, therefore, more likely to be attentive to the way people experienced community spaces.

Graham and Scott lived with their parents on a family farm a few kilometres on from the Reporoa turnoff. Graham was twenty-two and his brother Scott, twenty-seven. Graham and Scott had Cohen Syndrome but shared little else in common. Graham was urbane, loved Auckland and knew every small town that separated Reporoa from Queen Street. He also loved clothes, had aspirations of modelling as a career and had been fascinated by buses from a young age. Scott, on the other hand, had "the mind of a farmer." October was his favourite time of year because it meant hay and silage making but his families farming connections and Scott's aptitude for drawing people close meant that farmers and contractors from all around the district would phone

to see if Scott was interested in helping them complete the cycle of farm maintenance, calving and calf rearing, sowing and cultivation that anticipated October. Threaded in between were the agricultural field days and the Beef Expo where Scott caught up with people he knew, if he wasn't distracted by the throb of farm machinery or latest John Deere Tractor. *"Living in the city for Scott,"* his mum Jane said, *"would be like expecting a trout to live on dry land."* Scott was keeping his eye out for a good farmer's wife and a way for him to stay close to people and activities he loved.

Graham and Scott's mum managed their support through an individualised funding arrangement into which Scott carried 20 hours that had originally come through a SIL contract[13] and Graham added an Individualised Funding package through Manawanui In Charge. CCS Disability Action employed their support staff. Because getting out and into the community was so central to their quality of life, Graham and Scott also used part of their benefit to purchase additional staff hours and pay petrol to get staff out from town to the farm.

In spite of living under the same roof and sharing some of the same support staff, Scott and Graham's week and the people who populated their friendship network were completely different, reflective of Jane's efforts to tailor their support to their passions. The way the family read staff and understood their role also contributed greatly to Graham and Scott's integration into their respective communities.

In writing about her sons, Jane undermined Cohen Syndrome as a way of knowing them by describing Graham and Scott as *"two inspirational young men, who have shown many people the true meaning of love and reached out to people in trust and friendship."* Jane and her husband emulated their sons' social construction of their staff by including them within an extended family of care. *"Cherry, Kathy and Jason,"* they said, *"were part of the family now,"* and Graham and Scott reciprocally shared theirs.

Stepping into the inner circle of staff's lives offered Graham and Scott safe points of entry into multiple communities and community experiences. Scott and Graham's massage therapist often brought her grandchildren out to the farm, and they had their own relationship with "the boys." Cherry's grandson was four and shared Scott's love of farm machinery. He and Scott were constant companions and mined each other's social networks for news of harvesting or hay baling whereas her grand-daughter often helped Scott to and from the calf sale that his massage took him away from. Moreover, it not only meant that they were able to add value to the lives by hosting them within their home and lifestyle, they in return, were also afforded access to the private social spaces and personal resourcefulness of their staff. Cherry's grandchildren came to Graham's 21st and joined the procession of flags around the lawn and were in turn invited to Cherry's 50th, sowing seeds of doubt in the minds of her friends about the wisdom of their choice of tractor!

Whereas Richard had islands of social contact that seldom overlapped and were transacted in public community spaces (Figure 20), Graham and Scott shared multiple social contexts with the people who filled their lives. They met at the calf sale and at church and they invited each other over for lunch. The fluid boundaries between people and place extended to staff too. In the week

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[13] Jane, Scott's mum, worried that a recent change to funding contracts which meant that SIL could not be accessed unless Scott was moving from home in 6 months threatened the viability of his support arrangement

that Graham completed the Time in Place Diary, for example, he had stayed the night with his support person Kathy and her family, visited Kathy's niece and shot hoops with her at home (Figure 23).

Without the strictures of a formal vocational programme, Graham and Scott's "family of support" collaborated in ways that permitted them to have an authorial hand over their day-to-day activity. As a consequence, Graham and Scott could be authentically present in their community in so far as their pattern of engagement typically "fit" their passions rather than fit the programme. Opportunities for serendipitous community connection or personal development were also able to be captured and followed up. Scott, for example, had learnt to drive ride-on mowers from a man who Jane described as, *"having a heart for people."* Scott met him at the beach, when out for a walk. Scott initiated a conversation with Peter McNeil and Jane followed through on Peter's invitation for them to come to his farm for a visit. And then there were the tractor reps and truck drivers that called in to see if Scott wanted a ride or the invitations from contractors or farmers Scott met at the calf sale to come and help out.

No week was the same. After Scott had wandered back up the hill so he could have his massage that first day, Graham bumped into Andrea. Andrea was his relief support person and was turning sausages on a barbeque, catering for the calf sale. Jane eventually joined them, setting off a train of conversation that began with Andrea telling Graham and Jane she could be free at 12.00 to have Scott if they wanted. Jane said that would be great because she had a meeting that afternoon, before the conversation wound it's way to the three of them discussing the possibility that Scott might go to Taranaki to see her family. Graham told Andrea he was planning a holiday of his own.

Calf sale
Pick Scott up
Youth Group   In town
Auntie Jo's   Kathy's niece
Vika's before Youth Group
Vika's for pudding   Vika's party
With Kathy's family
Watching planes
At Jason's

Milk for calves
Sort mail
Drop Scott @ farm
Church

Entertaining Cherry & Wiremu
Calf sale

Home

Public social space

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Private social space

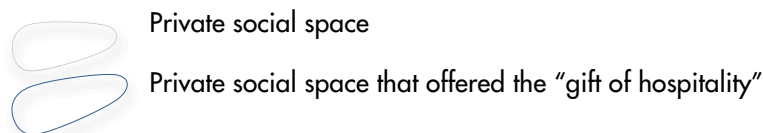Private social space that offered the "gift of hospitality"

Figure 23 Graham's Time in Place map

Once a year Graham liked to go to Auckland and his head had flooded with possibility. In other years Graham and Jane had gone to the Auckland television studios, hoping to catch 'New Zealand's Next Top Model,' and the 'Wheel of Fortune.' They caught buses to ice-skating rinks and visited only the most prestigious of car yards. He enjoyed the bustle of Auckland. *"It's a big city,"* he told us. *"Very busy!"* It was, however, the buses that were the main attraction and Britomart its holy grail. Graham had remembered a few of the route numbers, but none were more important than the *"Number 50 bus,"* that would take them from Auckland to the ice skating rink.

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

That first skate had a place in family lore, however, not because of Jane and Graham's tenacity, but because of Jane's commitment to seeing activity as a further opportunity to generate relationship. Before going to Auckland, Graham said that he had had a dream and in the months that preceded the trip repeatedly told Jane that in his dream he had skated with a girl. *"Graham has so much faith,"* Jane said, *"and when you see someone praying their heart out for something they want, you just have to help them do it."* Jane worried. Not only did she not know Auckland very well, she had never been ice-skating before, so the trip to Auckland that year was freighted with her anxiety about how Graham might react when his hopes were not fulfilled. Arriving was difficult enough, Jane decided, that, *"if we made it to the rink, we were meant to do it."* In the flurry of eventually finding the rink and getting organised to skate, Jane temporarily forgot Graham's dream until he reminded her. *"There she is!"* he declared, pointing across the ice to a beautiful young woman turning pirouettes alone in the centre of the rink. Jane's heart sank at the improbability of him skating with her, only to soar when, just as Graham foretold, she skated across the ice and offered him her hand. The young women's name was Allie and she was practicing to qualifying for the Winter Olympics. Her coach had overheard Jane telling someone watching at the side of the rink about Graham's dream and he had passed it on to Allie. As she left, Allie said to Graham that if he was ever in Auckland again he should phone her and they could go for another skate. Instead of dismissing Allie's invitation as a conversational courtesy, Jane kept the number and he and Allie have been for a few skates together at the end of a ride on the number 50 bus.

Figure 24 Looking for the closest Backpackers to Britomart; The brotherhood of stock agents and farmers; Allie, Graham and Allie's coach

Fluid and flexible support gave Graham and Scott the space they needed to build personal community. They gravitated towards people who readily recognised their common interest. Scott, for example, belonged to a brotherhood of stock agents and farmers. He had an insider's knowing of the people and customs of place, having sat and drunk countless cups of tea with them after the sale. He wore their uniform, including the John Deere cap the tractor reps had given him and the agents jersey that had come from Wrightsons. Sometimes, as noted previously, the agents took bids from Scott to bump up prices at a sale and the chief agent puts Scott's name on the reverse side of the calf tags as a symbol to Scott and to others of how much his affection for them is reciprocated.

7.11   I think of it as my job

Jane, and the staff she described as *"caring very deeply,"* for her sons worked hard to keep their lives interesting. The relationships that Cherry, Kathy, Andrea and Jason had with Graham and Scott could be characterised as having the kind of "life sharing capacity," that Marquis & Jackson (2000) found disabled people valued[93]. Having stepped into the inner circle of their lives, Graham and Scott's staff appeared to be stakeholders in their wellbeing and brought ideas and opportunities from their own lives that they felt might enhance the quality of Graham and Scott's. Ideas like the DVD that Cherry brought to Scott that she had recorded of tractors and the DVDs that Scott's staff had helped him to record on his own camera of the choreographed dance between harvester and bin truck at silage making time on a neighbouring farm to share with Cherry's grandson Wiremu.

The truth was, however, that it wasn't always easy, particularly for Jane. As part of the give and take of relationship, Graham, Scott and Jane often made accommodations for the messiness of staff's lives too. *"Scott,"* Jane said *"couldn't handle having nothing to do,"* and the lack of a formal programme meant that she had to be constantly creative in her search for new ways to soak up Scott's restless energy. Both of Jane's boys shadowed her, taking it in turns to make sure the things they wanted for themselves hadn't slipped too far from Jane's attention.

Jane had only ever had part-time employment and whilst she said she enjoyed working at the Vet Club and later a flower shop, Jane said even part–time employment was too hard to fit in. She considered making sure Graham and Scott lived big lives to be her work, sublimating the hopes she had held for herself as a young woman. *"I think of it as my job,"* she said, making sure that we understood how seriously she took the role. Jane also couldn't work because she was Graham and Scott's "back-up," when staff couldn't make it and like most parents, also filled in the gaps that needs assessments and paid support hours never met. It was Jane, for example, who helped Graham to organise his holiday to Auckland as well as build up the repertoire of phrases that he

might need when he got there. "Graham had," she told us, "been mute until the age of seventeen, so every word (was) very precious." Similarly, it was Jane who made the "job," at the post office happen and who found the Youth Group in Rotorua, in much the same way as it was Maureen who made sure Richard's chair was right and that he didn't miss their horses running at the Oamaru races, or Mela's mum who promoted her to find new ways to deepen existing relationships, or Deb who had organised the 30th birthday that filled a family forced to seek out of home placement 18 years earlier with such pride in their daughters.

Most parents who continued to support their children at home described coordinating and providing the day-to-day support their son or daughter needed to be present in the community as demanding. Jane's days were mostly shaped by her aspirations for Graham and Scott and their expectation to live full and active lives.

Jared's mum Fiona hadn't been able to work in any significant way outside of the home either. Caring for Jared was a full-time job and his parents had provided loving care 24 hours a day for twenty-five years. Often Jared's day started early, with Jared's dad getting him up and dressed before he left for work. Since leaving school three years ago, Jared had spent most of his time with his mum. Over time the house had been reorganised in ways that better met Jared's needs. His bedroom, a former sitting room opened to the kitchen and living room. That way, Jared was always part of what was going on, and got to engage with family and friends as they passed through. Despite having to find ways to make Jared's time meaningful at home, Fiona also felt she needed to work hard to ensure Jared's time away from home had real purpose. Her strategy was to complete a diary, which she sent with Jared when he was "doing" his community participation. The diary was a method for her to convey to staff all the details, large and small that had characterised Jared's week. This, she hoped, would provide some context to Jared's life – who had visited, the family events that had occurred, the meals he had enjoyed and how she thought he was feeling. This, she hoped, would give staff something to talk to Jared about. Further to this, she often gave staff messages to do, such as picking up a parcel or posting some mail as a way of infusing Jared's time in the community with real meaning. Sometimes, she said, she would have liked to have done these things with Jared herself but had given these opportunities away to help staff deliver Jared's community participation programme.

For many participants family and service culture represented two complementary social worlds with their own distinctive customs, social roles and expectations. Families, habituated to a lifetime of advocacy tended to bridge both worlds, often because of a desire to embed within the culture of support those elements of participants' lives they believed were critical to their sons and daughters maintaining a good quality of life. This was especially true for the families of participants who faced a daily challenge to make themselves understood and for aging parents.

Richard's mum Maureen was 71. She and Richard talked openly about how Richard might continue to live a big life beyond her capacity to advocate and interpret. "When we are not here," prefaces many of the conversations they have, especially regarding the need for Richard to *"speak up and tell people what you want." "She is coaching us all,"* Richard's staff told us. *"We have learnt about (Richard's) potential from Maureen and of the importance of good attention – and that Richard is worthy of our being alert."*

There are three dominant motifs to Maureen's advocacy. Her belief that Richard keeping himself well is critical to his quality of life; his ability to author his own life is dependant on the capacity of others to understand him; and a determination that Richard continues to live a full and interesting

life. What remains unspoken is that Richard currently draws much of what makes his life full and interesting from the place he continues to call home and the people who create opportunities for him to jump his programme. At Hilderthorpe, Richard has access to; intimate knowing including the continuous narrative to his life, his extended family and other relationships of place, the horses that have been his siblings and activity that affirms his identity as the last of a generation of horse breeders and trainers, the material resources of a family who love him and their unwavering advocacy. Without Maureen, Richard will have to rely on disability support services to connect him to social landscapes that retell him who he is and where he belongs.

7.12 Drawing on spatial and relational indicators of inclusion to evaluate the right of disabled people to be supported in ways that advance inclusion and prevent isolation or segregation within the community

For over a decade, reducing the number of people experiencing exclusion from mainstream society has been a primary driver of social policy. Within the research literature, however, general agreement exists that disabled people have remained one of the most socially marginalised populations.

The second clause identified as giving expression to the right of disabled people to live independently and be included in the community is the State obligation to ensure:

> *"Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community."*[2]

Difficulty accessing the narrative of people with high and complex support needs has meant that their life experiences have tended not to inform the discourses of inclusion. Evidence from the life-stories of the twelve people who collaborated in the Article 19 Project, however, aligns with the direction of research findings reported overseas and in the New Zealand context. In this respect, people with high and complex support needs may also be considered as lending their voices to those of other disabled New Zealanders who identified social exclusion as their preeminent human rights issue.

Most people who participated in the Article 19 Project were absent from contexts that non-disabled New Zealanders derive a sense of participatory citizenship from. Moreover, not having a presence with the worlds of employment, continuing education or inclusive sporting, recreational, creative, cultural, political or geographic community simultaneously denied participants access to the valued social roles of workmate, colleague, friend and neighbour.

Most participants had small social networks beyond the intimacy of their family, family friends and support staff. Two participants had found their way to communities of interest that could be characterised as having the five qualitative attributes of participation CCS Vocational Service Users had previously identified as seeding a sense of membership, but it was more usual for people not to belong to any group that expected them to contribute to the wellbeing of the community or included them as cultural insiders.

Only one person belonged to a club or association that also included non-disabled members with segregated social spaces tending to remain as islands of social knowing and one of the few community spaces that offered the potential for participants to generate new relationship.

Support that had its origins in service culture tended to emphasise spatial indicators of inclusion with the historical social practices of service delivery typically defining the way participants experienced their community. Support accessed through participants' vocational "programme," tended to be task focussed and time limited. Through their programme participants were fleetingly present in a narrow range of public spaces. Money was almost always the currency of social exchange and staff almost always accompanied participants into community settings. Within the vocational programme staff tended to be understood as connectors to place and whereas their relationships with participants were strengthened by sharing the ordinary rituals of friendship, the presence of staff may also have unintentionally impeded social inclusion by supplanting socially supportive roles normally filled by other community members or undermining the opportunity participants had to contribute to the wellbeing of others with whom they shared the space. Service based support also tended to be delivered at times that were out of cadence with the ordinary social rhythms of their community, displacing participants from the life trajectory of their peers or transplanting day-base activities by excluding non-disabled people.

Although being recognised and acknowledged as part of the social landscape of a community setting was important, most relationships participants had with other community members remained context bound and fixed at the level of acquaintance. No participant named as part of their network of friends someone they had met by participating in a Centre based vocational programme.

Families or family like support arrangements appeared to be more successful at maintaining the integrity of participants' social networks. Families also provided one of the few points of entry participants had to other communities. Living in service settings, on the other hand, had the potential to sever people from historical relationships of importance or the communities to which they had always belonged. Older participants in particular, described the quality of their lives being negatively affected by an inability to access the fellowship of their generation of disabled friends.

As a consequence of public discrimination and other forms of social and bodily othering a small number of participants experienced spatially inclusive community settings as abusive and socially isolating. For them the journey to community involved a migration away from socially meaningful and affirming relationships towards spaces of rejection and exclusion. Conversely, few people came to the homes of participants who were no longer supported by their family with the failure to recognise a shared responsibility of the community to make the return journey meaning that few participants experienced the gift of hospitality.

In 2011, New Zealand's first report to the UN noted that"

> *"Loneliness, lack of participation and the ability to develop social networks within local communities can be problematic."*[9] (138.1; p32).

The report promoted the new independent living model, trialled in 2011, as the Government's remedial response to the social isolation and exclusion experienced by disabled people.

8 The right to access community services responsive to the needs of persons with disabilities

8.1 Changing the community by being there

Prior to the social model of disability, the dominant images of disability were informed by an understanding of impairment as the cause of human limitation. In contrast to the medical model, the social model sought to reinterpret "disability," as social oppression by locating the experience of being disabled within the socio-political structures that segregated or excluded people with impairment from fully participating in society[98].

In New Zealand, as in most other western economies, the social model of disability has provided the ideological framework for recent disability policy, with the New Zealand Disability Strategy and it's derived objectives directed towards addressing domains of systemic disadvantage that deny or diminish the participatory citizenship of disabled people[14, 99].

In the past decade, a number of writers have argued for a new disability paradigm that reframes impairment as the "normal condition of humanity," rather than the core component of disability. Proponents of the "universalist" paradigm argue that no body has the complete repertoire of abilities and that societies will disable members to the extent to which a society fails to anticipate and address the full range of human capacities[100, 101].

Kayess & French (2008), argue that it is possible to detect the influence of the "universalist," position within the framework of the UNCRPD and especially the Convention's emphasis on environmental accessibility, including its mandate of universal design[7].

As part of his narrative, Henk observed that one of the consequences of having a body that was so different to others was that it was impossible for him to avoid his day-to-day life having an additional political dimension. As a man with high and complex support needs, being present in community spaces often called to attention the way New Zealand communities are differentially inclusive to citizens who occupy different positions within the spectrum of human diversity.

Disabled people are quick to remind us, however, that being present is the necessary precondition for inclusive social change and between the lines of many stories were examples of the way community participation had transformed the accessibility of community spaces in ways that undermined disabling social relationships for people beyond body types understood as disabled too. Richard and Emma, for example, had changed their community about them by engaging others in a conversation that began with how to more effectively include them.

Richard had been going to The Oamaru Aquatic Centre twice a week for over ten years. In that time, his staff told us, Richard's patronage had made a difference to the accessibility of the pool for everyone in Oamaru as the Aquatic Centre had installed a hoist for the spa as-well-as the main pool, handles around the perimeter of the pool and a more appropriate table as part of their response to better meeting Richard's needs. Richard and his mother's lobbying had also led the Waitaki Council to build an extension onto the public toilets to accommodate wheelchairs and the installation of protective islands in the meridian of the main road.

Similarly, Emma went to a local gym. Although the exercises helped Emma with her coordination and confidence, she went because the cascade of activities were fun and she enjoyed the rituals of friendship that passed between her and her instructor. Having never previously considered the health needs or benefits of exercise to disabled people, Emma's participation was an epiphany to the gym and they had subsequently designed programmes for people with a range of impairments, many of whom neither self-identified as disabled nor gymnasts. In sessions that overlapped, Emma sometimes stayed on, using her insider's knowledge of the gym and exercise routines to model and encourage younger children from around her community that came to participate in new programmes for differently configured bodies.

Figure 25 Emma at the gym; Richard at the community pool

8.2 Having the resources to make the community accessible

Whilst the Article 19 Project did not specifically set out to identify barriers to meaningful participation, a number of themes related to participants' access to resources they felt would have improved the accessibility of their community were present in their narrative.

In the absence of paid employment, many participants reported their lack of material resources simultaneously shrank their life space and limited the types of activities they were able to participate in.

Amongst the benefits Angela named as underscoring her move to the south end of Oamaru was that it meant that taxis were cheaper. "*My disability allowance gets used up to pay for the alarm that makes living in my own home possible,*" Angela told us. "*I have $80.00 to spend on groceries. No more! And $20.00 to spend on what I like. Most weeks,*" Angela said "*I manage to put a little away.*" By moving to the south end of Oamaru, Angela was much closer to her Dad and the Aquatic Centre where she would go swimming once a week when the weather was warmer, however, Angela still only had $20.00 to take her beyond the ordinary round of her weekly activity. Moreover, the orientation of participants' programmes towards community participation being transacted in public spaces like the café and pool further drew on participants' limited material resources.

Being poor not only compromised participants' ability to participate in ordinary social activity, it also placed them in the position of having to depend on the assistance of people from inside their social network for assistance. Most often that meant drawing on the support of families and as a consequence, the extent to which participants were present in their community was strongly influenced by the material resources family members were able to bring to support community

participation. Where participation was contingent on the support of other community members, participants worried about their ability to acknowledge support through acts of reciprocity, making it more difficult for them to be the active partner in the processes of friendship formation and maintenance.

As noted previously, Angela's community tended to be restricted to a few blocks from her home. Her inability to afford transport, equipment and the human resources needed to extend the boundaries of her community not only limited Angela's spatial mobility, it also impinged upon her ability to overcome the friction of distance any other way. In spite of describing her computer as a lifeline, Angela couldn't afford broadband, denying her the possibility of staying in touch with family and friends via alternative interactive media. Mela, Chris and Rebecca used their mobile phones to keep in contact with friends and family, but in general, limited use was made of alternative ways to staying connected to people or the wider community.

For participants living in community group homes, capitalised benefits further undermined their ability to resolve personal mobility constraints. Richard, for example, had always owned his own van and a few spent van carcases were still tucked away in quiet corners on the farm. Richard still used the van his family had helped him buy to get to all of the community events he regularly jumped his programme for, or go to appointments or to town with his mum. Without the van it would also have been impossible for him to get to the family home Hilderthorpe, or the racetrack or stables that contributed so much to his life quality. Since moving to a residential service, however, Maureen said Richard can no longer contribute to the van's maintenance nor fill its tank with petrol.

Similarly, although individualised support allowed participants greater authorship over where and with whom they were present in community settings, it could also, at times, unintentionally restrict the range of people and places that were accessible to them. Siloed service delivery and individualised programmes made the identification of common interest and the sharing of collective resources problematic for disabled people. For example, Richard and Angela both received invitations to the Cerebral Palsy Society dinner in Dunedin, however, despite living less than 5 kilometres apart and enjoying each other's company Richard went to the dinner by himself because his residential provider had a wheelchair vehicle, whereas Angela stayed at home. Failure to support disabled people to define and assist each other to resolve problems of access meant an opportunity was missed for Richard to contribute to the life quality of his friend by inviting her to share the resources available to him.

Disabled people could do little, however, to ameliorate one of the more commonly reported barriers to meaningful participation. As noted in Chapter 8, participants tended to experience their community in public community settings rather than the more private social spaces of friendship and belonging. Whilst small friendship fields and a determination by some to keep separate the social constructions of friend and disability service user clearly contributed to this atypical pattern of community use, participants also told us that the physical inaccessibility of New Zealand houses prevented their inclusion within the normal rituals of social invitation. Article 9 of the UNCRPD extends existing human rights legislation by foregrounding equal access to the physical environment as axiomatic to upholding the broader right for people with disabilities to live independently and participate fully in all aspects of life. However, State requirements specified under Article 9, also limits the discourse of accessibility to public community spaces, identifying as a State's obligation, the need to eliminate physical barriers in urban design, public buildings public information and public transport, whereas participants in

the Article 19 Project told us that their inability to visit friends and family was the issue of accessibility that most affected their life quality.

Having the ability to draw on human support was a primary determinant of the accessibility of participants' community. All participants required human support to have a community presence, but no transparent relationship appeared to exist between their lived experience or support need and the allocation of support hours. In addition to Angela's physical support needs, her blindness meant that she needed a companion to leave her home. Years of institutional living had severed Angela from natural community up to the age of 25 and her move to the flat at the south end of Oamaru meant that she was unfamiliar with the environment and a stranger to her community. She also lived alone and tended only to experience her community in contexts that offered few prospects of seeding new relationships. Angela had few friends beyond her staff and her siblings and extended family no longer lived in Oamaru. Angela also had limited income and yet could only access four hours support each week to participate in the life of her community.

8.3 Making the most of an alphabet of vowels

Effective communication is elemental to human functioning. Having the ability to share meaning provides the scaffolding, not only for continued personal growth and learning but the means by which to gain influence over our lives through the expression of need and hope. More importantly, however, the shared discovery and disclosure of effective communication is the language that binds community members one to another.

In recent years, definitions of effective communication have changed. Whereas assessing and remediating individual deficit had been the focus of traditional approaches to communication intervention, current best practice emphasises improving aspects of relationship as the primary goal – in particular enabling participatory social membership. Butterfield, Arthur and Sigafoos (1995), for example, describe communication, not as an end in itself, but as the vehicle that had membership as its destination. Fundamental to this re-conceptualisation of communication is an acknowledgement of the critical role relationship plays in the dynamic two-way processes of developing language competence and finding ways to share meaning[102].

Communication that lacks the conventions and rhythms of everyday language has the potential to locate disabled people beyond the common vocabulary of their community. It can also expose them to behaviour that Hall (2004) suggested reflects a deeply embedded sense of difference[22] in circumstances when they depend on attributes of social closeness like genuine interest, sensitivity, adaption, reciprocity and respectful turn-taking to become present[102]. Participants and their families both identified that at different points in their lives the relational context to communication had made it difficult for participants to arrive at the destination of socially inclusive relationships.

A number of families reported that they were met by a negative assessment of their son or daughter's potential for language acquisition in the early years of participants' lives with most families describing working hard without training or professional assistance to establish a shared vocabulary. Graham, for example, was mute until the age of 12. Jane and Graham's collaboration to improve his diction as well as the range of Graham's written and oral vocabulary continues to this day. Emma's family, on the other hand, sought to promote her cognitive development by exploring and ultimately introducing the home-based, Neuro-Developmental Therapy Programme, whilst founding the Friends of Brain Injured Children Charitable Trust to

provide peer support to other families using the programme, and Angela recounted the countless hours her parents spent trying to unlock her tongue or improve her literacy. Angela's mum would print new and unfamiliar words in the upper case of typewriter keys for Angela to over-write on a manual typewriter Mrs Cooper would have ready for her dad to take home from work at nights and in the weekend. Angela still prefers people to write in capitals, a legacy of her years tapping away at Mrs Cooper's keys. *"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,"* Angela recalled when she reflected on the all the ways her parents had worked to confound an early diagnosis that she would never speak coherently.

The most disabling consequence of Richard's cerebral palsy was, according to his mum, the way it had 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?"* Maureen explained on Richard's behalf.

For Richard and Angela, the lack of a steady flow of understandable words had led to their placement in special units and a social construction that made difficulty communicating effectively a self-fulfilling prophecy.

As a consequence of her determination to make a lexicon of Richard's vocalisations and body shapes, Maureen became an island of expression for Richard. Beyond Maureen, Richard struggled to make himself present and she worried that without her ability to interpret, Richard was exposed to the deafness of unskilled communication partners. *"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 had been to celebrate moments of complaint and to emphasise 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. As described previously, she had also modelled and mentored staff efforts to replicate the narrative that she and Richard had developed over his lifetime, recognising that it has been the way that Richard's difficulty speaking had often isolated him from others that had been one of the most significant impacts of impairment on Richard's life quality.

Henk too, spoke of the social exclusion that often followed the lack of a ready flow of words, illustrating his point by painting a picture of the nights he had sat alone in a pub full of people. Such were the social conventions of many community spaces like the pub, that Henk was unlikely to have access to the patient and committed ear he required to confront a simplistic reading of himself as a disabled man in a chair with the stories of someone who had played sport for his country on five continents and quietly challenged disabling expectations all his life.

Whereas families worked hard to ensure their family member was able to bridge the communicative divide within an ever-expanding repertoire of shared meaning, building effective communication strategies with participants who lived beyond their family home appeared to be swamped by competing service priorities and the limited time staff had available to achieve other participatory objectives.

The importance of the communication environment, including the vital role staff play in facilitating communication and the development of communicative skill is recognised in New Zealand law. In addition to Article 21 of the UNCRPD, Right 5 of the Code of Health and Disability Services Consumers' Rights Regulation 1996 requires disability providers to respect service users right to effective communication.

Research conducted here in New Zealand[11] and overseas[103, 104] has tended to describe, however, patterns of communication between disabled people and their community-based support staff characterised by fleeting, instructive or inquisitive communication events initiated by staff rather than disabled service users.

In talking together about the impact struggling to make himself understood had on Henk's life, his support person bravely volunteered that she had a tendency to fill Henk's silences with sentences of her own, limiting his ability to make himself or his needs and aspirations unambiguously clear.

An understanding of community participation as only occurring in public community spaces where some participants felt least able to express themselves in the vocabulary they had available together with service policies that restricted communicative exchange to "age appropriate," modalities could further deny participants access to conversations that had membership as its destination. After intensive observation of 4 non-verbal adults, Trevor McDonald (1997) found the New Zealand service users he followed used a wide range of strategies to communicate but that most of the opportunities they created for interaction passed unnoticed[105]. Other researchers have reported widespread failure by staff to recognise behaviour as communication.

Krystle, who had "lost her last word a few years ago," and Jared who had never had any words, were extremely disadvantaged by this lack of accessible communication. While each communicated in their own unique way, often it did not have the effect of delivering an unequivocal choice. As a result, Jared and Krystle's community participation was freighted with a sense of uncertainty about whether they were each engaging in activities of their choosing.

When staff had difficulty interpreting participants' communication they appeared to be much less likely to stray far from the path of predictable conversation. For people like Henk and Richard, who had thought deeply about the world around them and their place in it, this could mean living off a diet of conversation that was unlikely to satisfy their intellectual curiosity or lead to a deeper knowing of them or their world view. It isn't just Richard who gets frustrated *"when people don't understand (him),"* his staff told us, it was often uncomfortable for them when they couldn't decipher Richard's meaning, perhaps explaining why many stuck to the safer, less ambiguous narratives of coffee, women and egg sandwiches.

After ten years, Richard's staff did describe themselves as *"beginning to have a handle on some of his speech and what it is he is trying to convey."* The challenge they faced in terms of supporting Richard to develop relationships beyond people paid to be in his life, however, was to support Richard's wider community to have an equivalent opportunity to begin to *"get a*

handle" on his communication or find communicative modalities that made the sharing of meaning easier for him.

Richard did have a DynaVox augmentative and assisted communication device. Richard had had it for a year. The device had a dictionary of words and common phrases and it could also be pre-programmed by Richard and his support staff to articulate sentences Richard was unable to express. Richard's pre-programmed greeting, for example said; *"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 DynaVox sat instead in a bag at the back of his chair to be bought out for half an hour most Fridays so that Richard and one of his staff can familiarize themselves with the software. Richard has had the DynaVox for a year and in that time Richard and his support staff had entered a few phrases and had a general sense of how to navigate the desktop, but nobody else knew how to work the computer and when the half hour was up the DynaVox was returned to the bag on the back of the chair.

All of the participants who relied on non-conventional expressive communication appeared to have limited access to augmentative and assisted communication (AAC) technology or staff trained in AAC, consistent with a recent study that reported one-third of adults living in supported community based homes in New Zealand may be candidates for AAC and that those adults were supported by large numbers of adult carers who mostly have limited (38.7%) or no (37.1%) formal training or qualifications in AAC[106].

Research has consistently shown that there is little point assisting the acquisition of communication skills unless potential communication partners are also trained in ways that make them responsive and affirming of communicative attempts[102]. Despite the fact that a number of studies have demonstrated the effectiveness of training staff to promote language competence[107, 108], no government funding currently exists to train New Zealand staff to incorporate practices that enhance effective communication into their day-to-day support[13]. In 2003, after a two-year consultation, the National Advisory Committee on Health and Disability reported being "disturbed" by the systemic neglect of the developmental potential of disabled adult service users and "worried" by the lack of communication support available in New Zealand[13].

8.4 Evaluating the right of disabled people to access community services and facilities for the general population on an equal basis and for services and facilities to be responsive to their needs

The third clause identified as giving expression to the right of disabled people to live independently and be included in the community is the State obligation to ensure:

> *"Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."* [2]

Although the adoption of a narrative research method that promoted participant authorship of their life story made it difficult to make a direct assessment of the progress that had been made to

the realisation of this right, a number of systemic social disablers did emerge as recurrent themes within participant narrative.

Most participants identified poverty, the physical inaccessibility of New Zealand private housing stock, limited support hours and siloed service delivery including the failure of services to acknowledge the potential of disabled people to define and collectively resolve their problems of community accessibility through collective action as participatory barriers.

Participants also identified their lack of access to augmentative and assistive communication (AAC) technology and effective communication partners as limiting their ability to develop relationships or make transparent their needs or participatory aspirations.

Less obvious to participants was how their community presence was having a transformative effect of public community contexts by bending the social norms of place in ways that made space for people across the spectrum of human capacity.

No definitive conclusions related to the accessibility or responsiveness of generic community services and facilities were able to be drawn from analysis of participant narrative. New Zealand's first report to the UN also fails to identify areas of improvement that may enhance progress towards the implementation of the UNCRPD in this domain of community inclusion, highlighting this as an arena for future research and human rights based assessment.

9 Reflecting on the changes that need to be made to liberate people from their invisibility

9.1 Ngikhona (I am here)?

When New Zealand first signed the UN Convention on the Rights of Persons with Disability in March 2007, the Convention was promoted as *"drawing those in darkness out of sight, into the light of a new era of human rights."*

The overarching aim of the Article 19 Project was to use life story as a device for throwing light on to the day-to-day experiences of living with high and complex support needs in Aotearoa/New Zealand, with a particular focus on participants' ability to access their right to full inclusion and participation in the community.

Orlando Bishop explains that embedded in the gesture of Sawubona was a requirement for each partner to acknowledge the other's reality by reflecting on the changes that need to be made in order to gift "**the freedom to be present with**." Within the South African greeting, one of the expected responses to Sawubona (I see you) is Ngikhona (I am here).

Liberating people from their invisibility in ways that allow them to respond, *"I am here,"* has human rights implications that reach well beyond individual lives too. As noted in Section 4.5, until we hear from those people who are most likely to be exposed to an abuse of their Article 19 right to full inclusion and community participation, we haven't had a complete conversation about the progress New Zealand is making towards meeting its UNCRPD obligations. Similarly, locating the "freedom to be present with" within the framework of international law also exposes the language that gives expression to the Convention's articles to a politically contestable discourse. Who owns the meanings of ambiguous social objectives like "full inclusion" and "active participation" become important and until we hear from people with high and complex support needs we can't be confident that social policy or support practice takes those at greatest risk of marginalisation closer to or further from the experience of social inclusion.

To achieve its objective, the Article 19 Project sought to interrogate the life stories of 12 people with high and complex support needs to aid reflection about whether the changes New Zealand was making in pursuit of a more inclusive society had allowed their narrators to say "I am here" within New Zealand communities.

9.2 I want people to know who I am

Towards the end of their collaboration with the researcher who would write the first draft of their life story, most participants (or a family member) were asked why they had originally volunteered to take part in the project. Henk's response was *"I want people to know who I am."*

In the narrative that followed Henk suggested that he tended to be met in the community by a lack of inquisitiveness about his personhood and that he was equally vulnerable to simplistic readings of himself by those he shared his life with. To many in his immediate community, he was Henk the boccia player and to the community beyond, he was a man in a chair. Hidden to most was the

complex counter-narrative of Henk the man. *"I've been waiting for some sucker to come and write my story,"* he added quietly.

Consistent with the experiences of CCS Disability Action service users that spoke to Milner and Bray eight years earlier, community participation for Henk continued to involve an act of migration away from home to spaces of acknowledgement that, because of the way he was present offered him few prospects of generating ongoing community relationships. Support practices that were attentive to spatial rather than relational markers of inclusion meant that almost all of the ways that Henk was present in his community occurred within a narrow range of public spaces where he participated in activities that tended to reflect the historical horizons of vocational service delivery. Staff almost always moderated Henk's community presence, inadvertently contributing to a social bubble that was hard for either Henk or other community members to penetrate and, with the exception of Karen, it was with his staff and not the people who Henk had historically experienced a sense of fellowship that he shared the ordinary rituals of friendship like going for coffee or a swim at the pool and sharing the intimate social space of his own home. In fact the people who Henk described as members of his generation of the common community of disabled people had almost entirely disappeared from his life.

Like most participants Henk was also present in his community at times that were out of cadence with the rest of his age peers, transforming inclusive community settings into segregated social spaces. Further more, because Henk primarily experienced his community through a vocational programme that was strongly weighted towards completing a prescribed participatory task, he was only ever fleetingly present in community contexts where his social role was restricted to that of a consumer of public goods or services and little more than a spatial presence was the expected social norm.
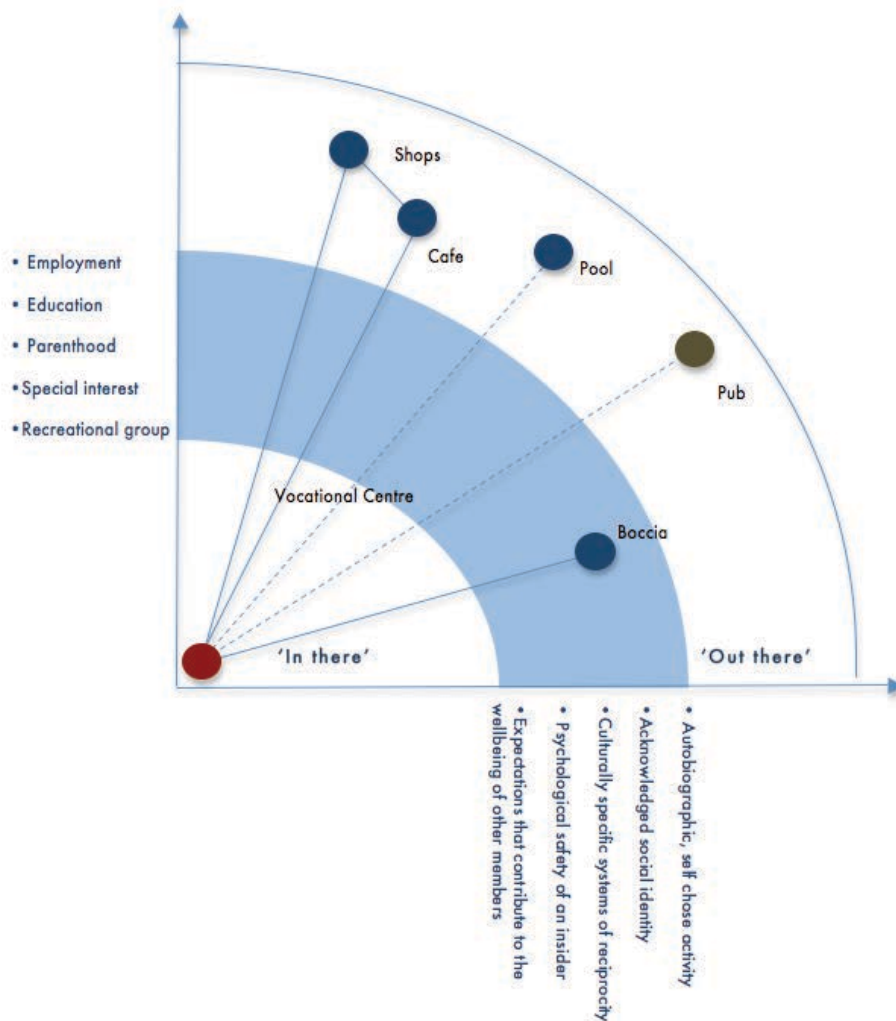
Figure 26 Henk's life spaces

The boundaries of most participants' community seldom extended beyond acknowledgement to contexts where the qualitative attributes of membership or belonging were the expected social experience of inclusion.

Restricting participants' community to public spaces on the edges of the daily round of community, like the pool and the gym or the library and the café or the Two Dollar Shop and the Warehouse not only increased the likelihood of their exposure to social othering and other forms of exclusion that can be a day-to-day reality for disabled people, it provided participants with no opportunity to develop sustainable social relationships that communicated to them a sense of belonging nor any real possibility of transforming their community by challenging the looks and stares and behaviours that Atkinson (cited in Hall; 2004) suggested act to maintain the dominant (non-disabled) order of more intimate social spaces through the emergence of deeper forms of social knowing.

Figure 1 content:

- Employment
- Education
- Parenthood
- Special interest
- Recreational group

Shops
Cafe
Pool
Supermarket
Richard's CGH
Dad's place
'In there'
'Out there'

- Expectations that contribute to the wellbeing of other members
- Psychological safety of an insider
- Culturally specific systems of reciprocity
- Acknowledged social identity
- Autobiographic, self chose activity

Figure 27 Angela's life spaces

Figure 2 content:

- Employment
- Education
- Parenthood
- Special interest
- Recreational group

Shops
Library
Orana Park
Cafe
Pool
Bowls
Angela's home
CCS DA Office
Stables
Cerebral Palsy Association
Hilderthorpe
Oamaru Race track
'In there'
'Out there'

- Expectations that contribute to the wellbeing of other members
- Psychological safety of an insider
- Culturally specific systems of reciprocity
- Acknowledged social identity
- Autobiographic, self chose activity

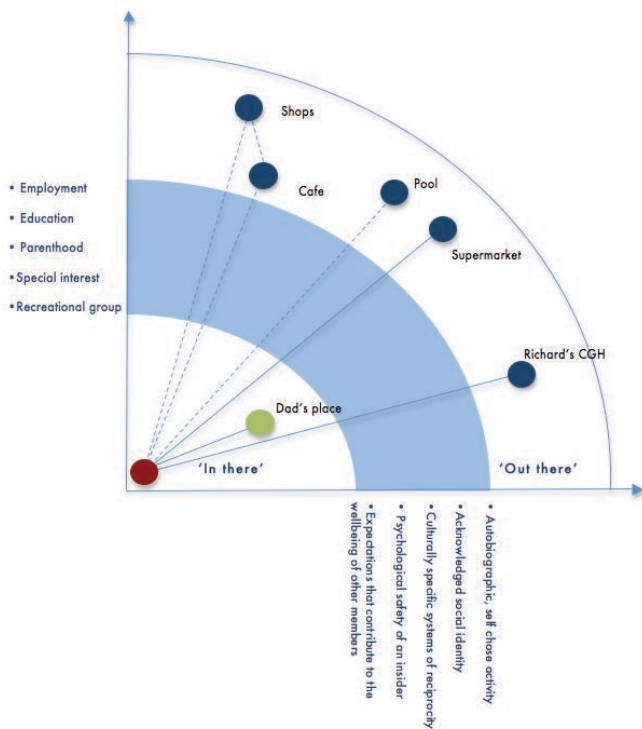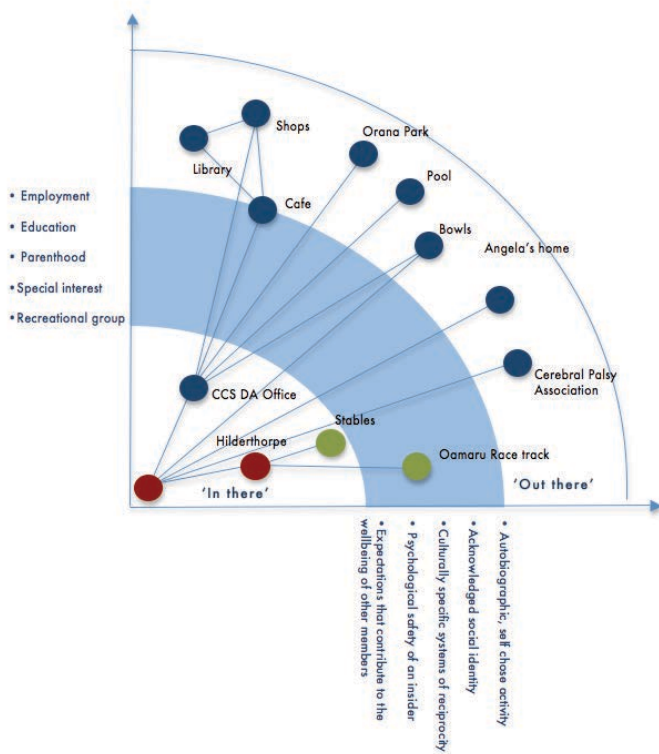**Figure 28 Richard's life spaces**

Except for the relationships that participants were embedded in through their families or, like Chris and Angela, had been forged beyond the gaze of staff or the social construction of disability service user, most participants could continue to be characterised as strangers to their community, seen but not known in the deeper understanding of sight inherent in the gesture of Sawubona. In much the same way as their forebears were described in the first wave of community participation research, most participants continued to have small social networks and very few participatory contexts that offered them the qualitative antecedents CCS vocational service users had identified eight years previously, as contributing to a sense of community membership.

It wasn't just that participants tended to be absent from the worlds of employment, continuing education or recreation and special interest that non-disabled people typically draw their sense of community membership from, even participants like Richard, who staff described as *"always out there,"* and a much loved presence in his community, had failed to draw any of the myriad of relationships he was exposed to through his programme into shared activity or reciprocated forms of social closeness. Other than participants whose families provided oversight of their vocational support, none of the ways that participants were present in their community through their programme had led to the "colonisation of people's informal lives," that Furedi (2004) had argued was required if disabled people were to step beyond being **_"in,"_** the community to being "**_of"_** their community.

Richard did, however, have a few islands of social knowing. There was the staff who had stepped towards the inner circle of his life as a consequence of the accumulation of their shared history and the day-to-day struggle to understand Richard's communication that demanded a particular type of attentiveness that he remained connected to through the CCS Disability Action office and there was the love and aspiration of his family that he remained connected to through his family home at Hilderthorpe. Some participants, like Henk and Rebecca had more limited access to similar social contexts and so were dependant upon the way staff "showed up," to the support relationship to generate a reservoir of social knowing. Both staff and participants described their relationships as having to be transacted without having access either to the "wasted and unproductive time," necessary for self-disclosure or the language of affect. Moreover, the language of formal support often denied the complex and sometimes difficult experiential realities of navigating relationships or of feeling in or out of place. As a consequence, much of the personal history that Henk needed to trouble disabling expectation was hidden from his support staff and he waited for the "penny to drop," regarding forms of community participation that were instrumental to how he understood himself and the place in his community that he imagined for himself.

Henk told us he *"want(ed) people to know who (he was)."* In spite of three decades of social policy directed at reducing the number of people experiencing exclusion from "mainstream," society, Henk's narrative instructs us of a continuing failure to connect people with high and complex support needs to places or to people able to extinguish their invisibility. By denying Henk the quintessential human freedom "to be present with," his inability to experience community in ways that enable him to respond "I am here," speaks to forms of exclusion that contravene an Article 19 right to live independently and be included in the community.

9.3 Did we see people accurately in the Article 19 Project?

In choosing life story as the method by which to explore how well people with high and complex needs were able to access their UNCRPD right to live independently and be included in the community, the Article 19 project located itself within the emancipatory tradition of narrative research. Common to all research that falls within this academic tradition is an interest in biographic elements as narrated by the person who lives them and a belief in the power of human narrative to alert societies and individuals to alternate futures by providing an opportunity to hear the silenced or delegitimised voices of people at the social margins.

Van Maneen (1998) described narrative research as stories jointly told, engaging both the participant and researcher in an active and creative process of telling a story that represents the narrator in ways they want their story told but within which both discover and develop their authentic voice.

For disempowered populations, however, the issue of authorship is critical and therefore, as noted by Chase (2005), whose voice is privileged in the process of representation is the principle methodological question to be addressed by studies that adopt life story as a research methodology. In the Article 19 Project, the issue of seeing and representing accurately people who were chronically short of the words they needed to tell their own stories or whose silences could be attributed to a legacy where subordination trapped words within "passive minds," elevated the importance of Chase's methodological question.

One of the unique features of this study's design was in the way that researchers and participants were both able to draw from a range of different conversational modalities. It was hoped that by employing a mixed method design, multiple streams of information would limit the potential for researcher misinterpretation and provide sufficient sources of data triangulation to confound simple readings of participants' lives. It was also hoped that having multiple streams of data inform participants' narrative as well as cycles of self-editing would dampen the concerns and assumption the researcher imported that had the potential to divert attention away from participants reading of their own life.

Having a range of data gathering techniques also helped to build a more nuanced picture of the day-to-day reality of living with high and complex support needs in Aotearoa/New Zealand than would have been possible had the research team relied on one information gathering technique, however, it could not completely control for alternative readings of participants' lives that propelled their story or project generalisations in a particular direction.

For example, participants who were least able to contest their narrative were more likely to live in the family home. The telling of their stories, therefore, was strongly influenced by a much wider family narrative that included access to a broader sweep of participants' lived experiences, including familial and other historical relationships, the efforts families made to promote evolving competence and embed their family member in meaningful activity and a heightened sensibility to issues like the physical wellbeing of their disabled family member or perceived historical failings of service led support that may have been hidden to other proxy informants or not prioritised in other narratives.

Six of the twelve participants that informed the project were still supported from their family home or family like support context. It is unclear to the authors how representative this is of the living circumstances of people with high and complex support needs and equally unclear how

representative the cluster of families that did volunteer were of other families that continue to support their sons or daughters at home in New Zealand. Three of the six families managed their own funding in an individualised funding arrangement and all families were actively involved in the selection and training of participants' support staff. All six families were highly motivated and innovative in their application of support. It is not unreasonable to suggest that these attributes anticipate the likelihood of families volunteering for narrative related research introducing the possibility that the findings presented in this report overestimate the participatory presence of people with high and complex support needs in spatial and relational community contexts.

Similarly, although the stories of participants supported in other living arrangements may represent an authentic rendering of their subjective experience, the small number of participants living in a community group home (n=3) or their own home (n=2) who informed the project, limits the generalisability of the more quantitatively orientated data gathering strategies.

Other aspects of the project make it difficult to draw firm conclusions about the pervasiveness of social exclusion experienced by people with high and complex needs beyond the narrative of the twelve participants. For the purposes of this project, high and complex support needs were defined as requiring personal assistance with two or more types of bodily, communicative or behavioural support. No clear consensus exists within the literature about the meaning of the terms associated with high and complex support need. As a response to the lack of clarity Rankin and Regan (2004) have proposed the term be used as a framework for understanding multiple, interlocking needs that span health and social issues. People with complex needs may, they argue, have to negotiate a number of different issues including learning disability, mental health problems, physical impairment or substance abuse[109]. They may also, Rankin & Regan argue, be living in deprived circumstances and lack access to suitable housing or meaningful daily activity. Other researchers have adopted a narrower definition, Mansell, for example (2010) including amongst his referents profound learning disability, multiple impairments, difficulty communicating and in need of high levels of human support with most aspects of daily life including assistance to moderate additional sensory or physical impairment, complex health needs, mental health difficulties or behaviours that challenge others[76]. Compared to other studies, the Article 19 Project may be said to have adopted a wider eligibility criteria. Given that general agreement exists within the body of empirical research that people with the most profound impairments are most likely to experience social dislocation from their community, it is likely that this study underestimates the level of spatial and social exclusion experienced by people with high and complex needs in Aotearoa/New Zealand.

And finally, narrative research captures people's reading of their own lives at one moment in time. Project constraints meant that researchers were only able to spend between three – five days with participants gathering the information they needed for the first draft of a participants' life story. A number of participants described taking part in the project because it represented such a radical and intriguing departure from the ordinary round of their daily lives and participants generally reported both enjoying the experience and feeling affirmed by the research collaboration. For many, the Article 19 Project gave participants an opportunity to say sentences or reveal aspects of their lives that they had either kept hidden or not had the opportunity to make transparent, contributing to a particular type of narrative form that included an aspiration to author a story in which their experiences were rendered in an equally affirming way. It isn't clear to the study's authors how well this rendering of participants' own lives translated into their day-to-day experiences beyond the research collaboration.

Participants' life trajectory also tended to be characterised by long periods of quiescence in which it was difficult to follow the life trajectory of non-disabled age peers, interrupted by swift and radical changes in life circumstance that were exogenously imposed. Changes were precipitated by events like, a break down in the resilience or health of familial caregivers, sudden changes in their own support needs or policy changes that altered the social practices of their disability service provider.

What became clear during the conduct of the research was how vulnerable participants were to events that could break their tenuous relationship with the people and places that defined their level of engagement with the community. For example, Angela's conduit to the places and relationships that she experienced as inclusive were principally through her 81 year old dad, her reader-writer June whose presence depended on continued funding from a small charitable trust and her computer that took Angela to places she couldn't otherwise get to. Like many participants, the loss of any one of these conduits threatened to further isolate Angela from meaningful community participation. The limited opportunities participants had to generate sustainable relationships beyond the social worlds of family and paid support staff afforded no protection from changes in life trajectory that had the potential to further undermine lives led at the margins of New Zealand communities.

In a project that sought to foreground the narrative of disabled people, it is appropriate to leave the last word to Angela.

> 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.

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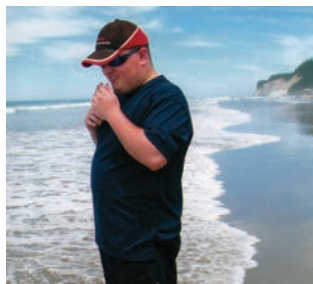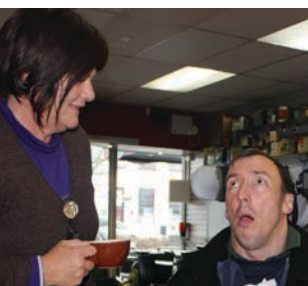
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