

# Getting the Life I Want

## Key Informant Interviews



Promoting the employment and participatory aspirations of disabled people:  
Learning from the individual narratives of disabled New Zealanders.

A report prepared for  
CCS Disability Action  
February 2017  
P. Milner, L. Schmidt,  
B. Mirfin-Veitch & S. Brown  
Donald Beasley Institute  
[www.donaldbeasley.org](http://www.donaldbeasley.org)



TE HUNGA HAUĀ MAURI MŌ NGĀ TĀNGATA KATOA





**Address**

Level 1, 55 Hanover Street  
PO Box 6189  
Dunedin, 9059  
New Zealand

**Phone**

+64 3 479 2162



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# INTRODUCTION

## The “*Getting the life I want*” Project origin and aims

Following their investigation of the human rights status of disabled people, the New Zealand Human Rights Commission (2010) concluded that disabled people were amongst New Zealand’s most marginalized citizens. The unequal access disabled people experience to the worlds of employment and community participation were identified by the Human Rights Commission as arenas of significant disadvantage.

In the past decade, CCS Disability Action has demonstrated a strong commitment to addressing the marginality experienced by many disabled people by commissioning evidence-based research that draws on the narrative of disabled people to inform and reshape disability support practice.

The “*Getting the life I want*” Project represents the third in a sequence of research collaborations between CCS Disability Action and the Donald Beasley Institute intended to assist disabled people to transform New Zealand into a more inclusive society. Like the other two research collaborations that preceded it, the “*Getting the life I want*” Project applies a human rights framework to effect change in the key life domains of employment and participatory citizenship.

The catalyst to this scoping study was an invitation by Peter Wilson (National Manager of Partnerships and Projects: CCS Disability Action) to contribute to the development of research method that could inform on ongoing review of CCS Disability Action vocational service delivery.

The aim of the research was to provide a mix of empirical and best practice evidence that could inform the wider review goal;

*“To consider the transformation of Vocational Service within all regions so that the way [CCS Disability Action] deliver support provides the options for people to get what they want.”*  
(Vocational Service Scoping Document, 2016)

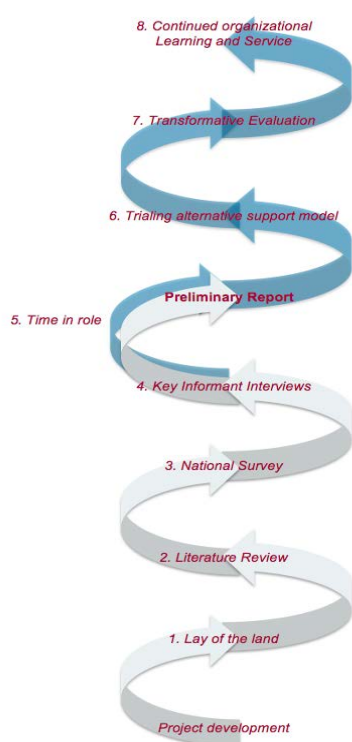
## Project design

To conduct the research, the Donald Beasley Institute (DBI) employed transformative methods. Transformative methods seek to learn more about the value people place on something and to draw conclusions about the effectiveness with which existing knowledge is used to inform and guide practical action.

The intention of transformative research is to engage research participants as an action-orientated learning community. By respecting and learning from each other, research participants are expected to collaborate in ways that reimagine or remake disabling social practices (Mertens, 2009).

In the Project Development phase of the research, members of the National Management Team and researchers from the Donald Beasley Institute worked together to establish an overall framework for the project and to refine its methodological elements.

As originally conceived, the project intended to incorporate an Advisory Group of disabled leaders. Whilst time and budgetary constraints meant that it was not possible to set up the Advisory Group, the project did make space for the voices of disabled people in two important ways.



The process of providing all people who accessed vocational support (through CCS Disability Action's vocational contract) with the chance to inform the project was acknowledged as providing CCS Disability Action with an opportunity to access the diverse and often "unheard" voices of vocational support. To utilise this opportunity, a National Online Survey and Key Informant Interviews were included in the methodology to better understand the experiences and aspirations of people who were sometimes at the margins of service delivery.

And secondly, during the Project Development phase of the study, the Project's role was also reconsidered and reframed as providing data that could inform subsequent cycles of service planning, innovation and transformative evaluation.

In this respect, the *"Getting the Life I want"* Project was (re)conceptualized as providing an empirical starting point from which disabled people, their families, CCS Disability Action staff and the wider disability community might respond by becoming increasingly engaged as stakeholders in the longer-term processes of ongoing organisational learning and service change.

A mixed method approach was employed as a way of blending information acquired through three core methodological elements. Adopting a fluid research design also meant that emerging findings could sequentially inform other methodological elements. The three methodological elements used to generate data in the order in which they were consecutively executed were:

- An integrated literature review of the research and practice literature with a particular focus on some of the more innovative ways disabled people have been supported to achieve aspirations subsumed within common understandings of vocational support.
- A National Online Survey offered to all people using CCS Disability Action vocational support intended to provide a "snapshot" of respondent's lived experiences, which provides an opportunity to: detect differences in the value identifiable populations placed on different vocational outcomes; capture any alternative visions disabled people had of effective vocational support; and provide feedback that could inform the review of vocational support currently being conducted by CCS Disability Action.
- Key Informant Interviews intended to reach a "thicker description" of disabled people's personal aspirations and the ways in which vocational support can either help or frustrate people's ability to transact their vision.

## Defining what we mean by "vocational"

Within the disability and social policy discourses, no universal understanding of what is meant by "vocational activity" exists. Practitioners from different disciplines have not only adopted slightly different common understandings of what is meant by "vocational," those meanings have also themselves been subject to change over time. This is particularly the case with respect to the emphasis placed on employment as the intended outcome of vocational support or intervention.

Within this project we have adopted a wider definition that locates employment and other ways of providing a living wage as one of a range of possible outcomes that fall within a

broader interpretation of "vocational support" – that being a type of support that assists people to engage in:

*meaningful, routine, sustained activity that enhances personal growth, is personally rewarding and productively connects people within a community.*

---

(Adapted from Nicholas et al, 2014)

This report presents preliminary research findings for the Key Informant Interviews. The Survey was designed to learn more about the value people who access vocational support from CCS Disability Action place on different ways of engaging in vocational activity, including the kinds of assistance they think may assist them to get the lives they want.

This report presents research findings following analysis of data collected during the Key Informants Interviews. The interviews complimented the National Online Survey by providing a more a detailed description of people's lives and aspirations, including their understanding of the purpose of vocational support and support experiences. Talking to informants also provided a narrative that the research team could draw on to assist them to interpret preliminary findings reported for the National Online Survey.

In the next section we describe in more detail the method used to conduct and analyse the Key Informant Interviews before presenting the findings themselves.

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# METHOD

## Recruitment and interview informants

Included at the conclusion of the National Online Survey was an invitation to all respondents to express an interest in contributing further to the *“Getting the life I want”* project by participating in follow-up telephone interview.

Potential informants we told that the research team was interested in hearing more about their experiences of vocational support and in particular the ways that CCS Disability Action could support them to get the lives they wanted (see Appendix 1). Key Informants registered their interest anonymously by including their name and contact details within the appropriate survey fields.

Fifty-two males and 46 females contributed to the project via the National Online Survey, yielding a potential pool of 97 informants.

The Survey closed on the 30 December, 2016, by which time 19 people had expressed an interest in participating via a follow-up telephone interview. Fifteen potential informants expressed their interest online and an addition four respondents were assisted to express their interest by CCS Disability Action support staff who contacted the research team directly.

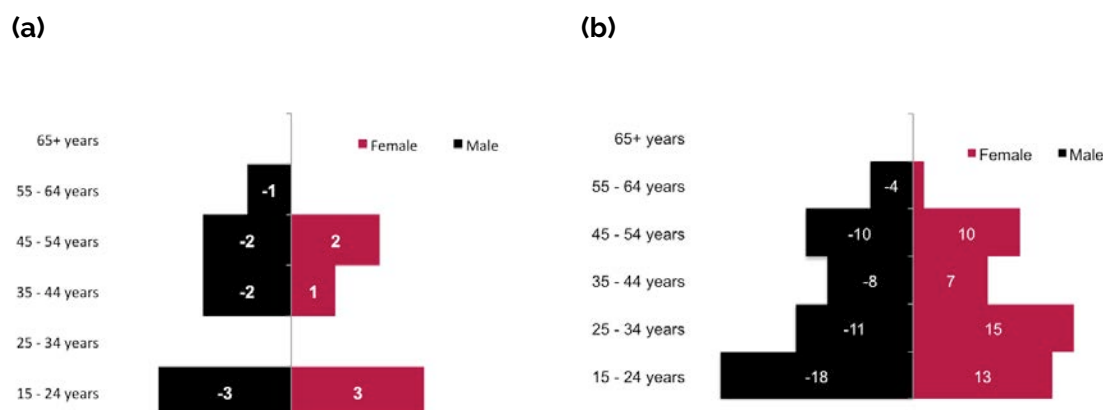
A researcher from the Donald Beasley Institute attempted to contact all potential informants by phone, to remind informants of the primary aims of the project and to answer any questions they may have had about the interview or reporting processes. Although formal ethical approval was not required for the Scoping Study, the research team followed best practice by seeking written or verbal consent from all informants. The research team, also took the opportunity to ask potential informants the best way for them to receive the Project Consent Form. The Consent Form reminded informants of project aims and detailed their rights as project participants (see Appendix 2). During the initial contact phone call, informants were also able to nominate a preferred interview time.

The research team was not able to contact six people who expressed an interest in contributing a follow-up interview. All other potential informants chose to participate and their interview narratives inform the findings presented in this report.

Eight males and six females currently accessing vocational support from CCS Disability Action contributed interviews. Informants were aged between 19-62 years, and with the

exception that no one aged between 25-34 years spoke to the research team, the age and sex distribution of informants approximated the profile of survey respondents.

**Figure 1 The age and sex profile of project informants (a) and survey respondents (b)**



Half of the respondents who contributed a follow-up interview described themselves as unemployed and looking for work (50%). Forty-five percent of National Online Survey respondents described themselves the same way.

**Table 1 The age, region and employment status of Key Informants**

|                   |                                  | Male    | Female  |
|-------------------|----------------------------------|---------|---------|
| Number            |                                  | 8       | 6       |
| Age range (years) |                                  | 22 - 62 | 19 - 48 |
| Mean age (years)  |                                  | 39.6    | 33.7    |
| Region            |                                  | -       | -       |
|                   | Northland                        | -       | -       |
|                   | Auckland                         | -       | -       |
|                   | Waikato                          | -       | -       |
|                   | Bay of Plenty                    | -       | 2       |
|                   | Wairarapa                        | -       | -       |
|                   | Tairāwhiti                       | 3       | 2       |
|                   | Manawatu                         | 1       | -       |
|                   | N. Taranaki                      | -       | 1       |
|                   | S. & C. Taranaki                 | 1       | -       |
|                   | Whanganui                        | -       | -       |
|                   | Wellington                       | 1       | -       |
|                   | Nelson/Marlborough               | -       | -       |
|                   | Canterbury/W. Coast              | -       | -       |
|                   | S. Canterbury                    | -       | -       |
|                   | Waitaki                          | -       | -       |
|                   | Otago                            | 2       | -       |
|                   | Southland                        | -       | 1       |
| Employment status |                                  |         |         |
|                   | Unemployed; looking for work     | 6       | 1       |
|                   | Unemployed; not looking for work | 1       | 1       |
|                   | Part-time employment             | 2       | 1       |
|                   | Business Enterprise              | 1       | -       |
|                   | Daybase                          | 2       | -       |

## The Key Informant interview

All interviews were semi-structured, providing enough 'space' for informants to direct the research team towards their personal understanding of the purpose of vocational support and the way it intersected with their own lives (see Appendix 3).

Interviews typically took between 45 – 60 minutes and were organized in such a way to explore in greater detail; the pattern of people's day-to-day lives and life circumstances, how they experienced vocational support, what they thought the purpose of vocational support was and what they valued or would change about their support. The interviews also sought informant's views about the importance of employment and of being connected to one's community as vocational outcomes and ways to give effect to these common participatory aspirations. The research team also asked informants about the assessments they gave of the personal importance of ten alternative support models they were exposed to in the National Online Survey.

## Data analysis

All informant interviews were digitally recorded and transcribed. A general inductive approach was used to code and analyse key informant data.

The general inductive approach was developed in New Zealand specifically for use in health and disability evaluation and *"provides an easily used and systematic set of procedures for analysing qualitative data"* (Thomas, 2006, p.237). The general inductive approach involves a thematic analysis process whereby themes or categories most relevant to the research objectives are identified, making it a particularly useful methodology for research intended to generate evidence about the effectiveness of disability support practice.

Individual members of the research team independently read through key informant transcripts to identify major themes and an initial coding framework. After preliminary coding the research team met again to refine the coding structure, identify emergent sub-themes and to explore strands of variation within participant narratives.

The analysis that follows is reflected in the organization of this report including findings related to:

- Engaging with a larger discourse about the kinds of marginalities that appeared to contribute to informant's "longing" to be(come) more connected to their community.
- Whether the purpose of vocational support aligned with informant's vision of a more inclusive community.
- The search for places of belonging in and beyond employment.
- Informants valuing of support that helps them to navigate towards the lives they want.

Where respondents have been quoted directly, their narrative has been *italicized and coloured*.

# THE YEARNING TO BELONG

When people spoke to us about *"getting the lives they wanted,"* they inevitably talked about the lives they felt they hadn't had an opportunity to live and within their collective narrative, it was possible to identify a cluster of major life domains in which unequal access was commonly read as undermining life quality. These conversations tended not to explicitly express a sense of disablement (consistent with the Social Model of Disability) or even of feeling a different kind of (disabled) citizenship (consistent with human rights based discourses) but more a sense of feeling marginalized from the life trajectory people believed might contribute to an enhanced sense of personal wellbeing.

Often, but not always, the point of comparison was what was perceived to be the "ordinary lives" of other (non-disabled) New Zealanders' - *"to be able to find a job and have friends like any other person,"* was the point of vocational support, we were told. But equally often, people simply identified the kinds of interrelated marginalities that contributed to an impoverished sense of being in, and belonging to the places and people that populated their community.

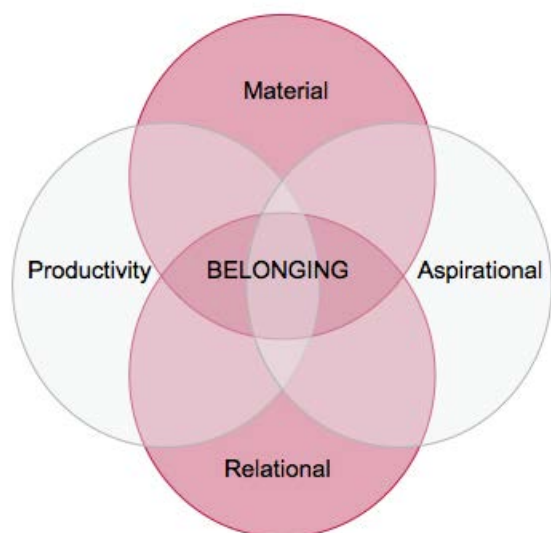
Observers have noted that in the past decade a (re)languageing of those disability rights that relate to disabled people's participatory citizenship has occurred, whereby the old social policy aims of "community participation" and "inclusion" are increasingly reimagined as the conduit to the much more humanizing experience of "belonging." Hall (2013), for example, illustrates the point by foregrounding the preamble to the UN Convention on the Rights of Persons' with Disability (UNCRPD) in which the *"full enjoyment by persons with disabilities of their human rights and fundamental freedoms,"* is framed as occurring when *"full participation ..... result(s) in (an) enhanced sense of belonging"*

Identifying and responding to the marginalities that disabled people identify as undermining their *"sense of belonging"* represents a new and potentially useful lens through which to explore and reconfigure disability related support. This way of thinking about service change fits with recent theorizing about the transformative potential of "belonging" too, including Probyn's (cited in Hall, 2013) deconstruction of belonging being more than simply (be)ing in place but also (longing)ing or an *"active wanting to be in sets of relationships that are something more and something better than this place now."*

Whilst located within a broader conversation about vocational support, four major themes were detected within the yearnings participants expressed for something more and something better for themselves. People spoke often about way both material and relational poverty severed them from the lives they wanted for themselves. But within these

conversations people also spoke of the way feeling dislocated from relationships within which they could experience a sense of being productive members of their community also limited their ability to challenge the more material (quantifiable) marginalisations perceived as acting as a barrier to transcending *“this place now.”*

**Figure 2 Responding to poverty as a new lens for transforming vocational support**



In the following section, we explore people's sense of marginalization before considering how those impressions were shaped by existing disability support practice before suggesting what this might mean for changing support in ways that respond to the four experiential poverties informants described.

# EXPOSING PERCEIVED MARGINALITY

## Material Poverty

Material poverty was one of the more obvious ways that people said they felt marginalized from their community. More than seven out of every ten people who responded to the National Online Survey described themselves as unemployed (72%) despite 80% of respondents expressing an aspiration to work one or more hours a week. Respondents who were employed typically worked within what Robyn Hunt (1994) described as the “expendable fringe” of the New Zealand labour market, in part-time, low skilled and poorly paid occupations. Eight out of every ten respondents worked less than 10 hours a week and the average number of hours that people worked was only 3.8 hours (Milner et al, 2016).

Most informants spoke directly of the way material poverty restricted the compass of their lives, by defining what they felt was and was not possible to do. By limiting the contexts in which people could be present, material poverty was also perceived to define the limits of informant's community presence, including marking people out as marginalized because of their absences from very ordinary community places and spaces, including employment.

*Interviewer: You seem to be saying to me that if you had the chance you would like to come off the benefit.*

*Respondent: Yeah I would because I have seen it. My mum was on a benefit and she stays in the house. I don't want to be anything like her. I want a full-time job.*

People repeatedly told us that the benefit left them unable to live the full life that they longed for and employment was viewed as a potential path to their preferred lifestyle.

*Respondent: I want to have a job a full-time job I want to you know? I want to do stuff. I have to save up to do stuff. If I want to go to the movies. I haven't gone to the movies for over half the year now. Half a year since I have been to the movies because I can't afford it. So yeah I would love this lifestyle where I could buy a house and you know? But I can't. It's getting harder and harder.*

Informants tended, therefore, to view paid employment as their conduit to enhanced autonomy, with most imagining it offered the freedom to live fuller lives. For some, the hope of employment, therefore, also sustained a hope that they may eventually be able to do the things that spoke to who they were and who they might (one day) become.

*Respondent: You said about goals and I have got lots of little goals. Like I like to learn languages, musical instruments and music – that sort of thing. Yeah it's down to the money you know..... I used to get really down but now I go with the flow and I think it will happen one day.*

The other advantage of employment identified by informants was that it offered a way to challenge the social constructions they felt others held of them. Most informants spoke of wanting to come off the benefit as a way of escaping the interactions they were obliged to have with Work and Income (WINZ). Informants who spoke of their dealings with WINZ said they found the bureaucracies of unemployment confusing and at times dehumanizing.

*Respondent: I want to be independent and earn and have an income. Plus I don't want to be reliant on WINZ for income.*

*Interviewer: Why, this might sound like a silly, question but why don't you want to be relying on WINZ for an income?*

*Respondent: Um two reasons one you don't get much. I appreciate what I get but its not enough to sort of get what I want you know? The second reason it is pretty belittling because I have got disability and it is not very private at WINZ and um the last place where I came from, they used to have a private room, but I used to have so much hassle getting it with WINZ. It was just a pain in the arse. I think until the last year they just made it so difficult.*

Without employment, however, poverty wore at informant's resilience and shaped the forms of participation that were available to them.

*Interviewer: What made you decide on work as a goal? What made it so important?*

*Respondent: Because I am so poor. I really just need. You know living on a benefit all you do is pay your electricity, phone and um, you know, all the essential stuff and you are left with nothing. Just groceries – but it's basics. And it's just not much to life sort of thing, you know.*

And sometimes, it was informant's inability to afford even basic necessities like clothing that defined how they were present in their community.

*Respondent: .... this is an embarrassing question for me. Well its not a question its just a statement, I am really short of clothes. I have got good clothes but I am on a farm I need casual clothes. I go out of them pretty fast the dog jumps up and scratches my pants and put holes in them and all that sort of thing stuff like that and they suggested that I go to, like a what do you call it, a second hand shop.*

Not surprisingly, addressing material poverty featured prominently amongst a range of key drivers of informant's aspiration to realize paid employment. More than half of male respondents (54%) and 43% of female respondents who named one or more vocational goal(s) in the National Online Survey identified finding employment as their preeminent support goal. Milner et al (2016) suggested, however, that this finding underestimated respondent' aspiration to find paid work. Consistent with Statistics New Zealand's (2014) estimate that 74% of unemployed disabled New Zealanders aged between 15-64 years would like to work if a job was available, 80% of "Getting the life I want" Survey respondents wanted to work one or more hours a week and 57% wanted 15 or more hours paid employment.

## Employment as a social policy outcome

Reducing material poverty by promoting disabled people's participation in the labour force has been a central justification to welfare restructuring and social policy reform occurring in the UK and throughout Europe from the 1990s onwards (Barnes, 2000; Hyde, 2000). Rather than addressing poverty directly or the underlying causes of disabled people's exclusion from the labour market (including State' macro-economic priorities, the 'nature' of available employment or those attitudes and social practices that underscore employers reluctance to hire and include disabled people), the "New Deal for Disabled People" and its associated welfare reforms focus instead on a range of "supply side" initiatives intended to oblige and incentivize work within an unmodified labour market. In this respect, the Ministry of Health's Draft Proposals for Change to Employment, Participation and Inclusion Services (Ministry of Health, 2015) follows a similar trajectory by also:

- Triaging disabled people into one of three mutually exclusive "outcome streams," based on a functional assessment of the likelihood a person might achieve "sustainable employment" (defined as more than 15 or more hours paid employment a week) in an agreed time.
- Incentivising the outcome of "sustainable employment" through differential funding in a way likely to select out people perceived as offering a poor fit with the existing labour market.
- Moving back to a "work-readiness" vocational model that similarly relocates the problem of disabled people's absence within the atypical minds and bodies of disabled people that can be moderated or modified in ways that fit with the demands of the labour market.

In the UK, vocationally related social welfare reform has also sought to leverage increased employment by using "functional assessment screening" to exclude entitlements to those deemed "capable of working," whilst conversely encouraging people to take up unpaid or low-paid work by providing financial incentives to disabled people working at least 16 hours a week combined with the threat of benefit withdrawal for those who refuse work placement, trials or training.

For an increasing number of disability writers and activists, these changes reflect an expansion of a wider neo-liberal ideology that has had the effect of shifting the moral responsibility for welfare away from the State and towards the individual. Writers like Hyde,

(2000), Hall (2013) and Barnes (2000) argue the neo-liberal agenda of reducing welfare dependence and the scope of State responsibility reframes citizenship in a disquietening way for disabled people. Within this ideology, qualifying for the entitlements or the rights of citizenship is framed as contingent upon reciprocal obligations, and most especially, the obligation to work.

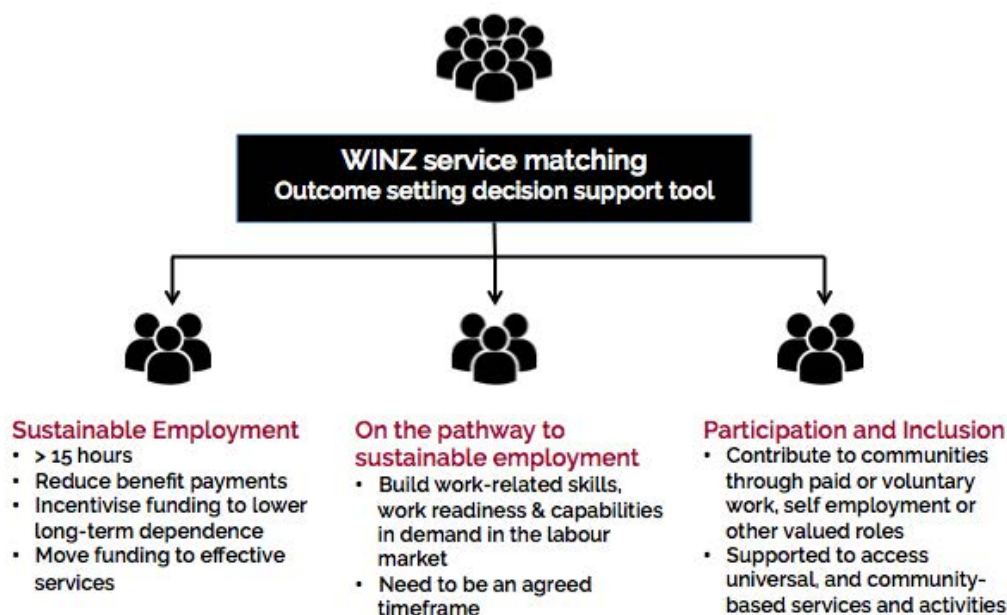
In addition to having a negligible effect on the rate of employment (Hermeston, 1999), recent assessments of the effectiveness of neo-liberal vocational reforms in the UK highlight a number of “worrying” impacts for disabled people. Rather than ameliorating poverty, the reforms that began in the 1990s have, according to Hyde (2000), resulted in more intense forms of material deprivation for particular groups of disabled people. Disabled people have also increasingly been steered towards underemployment and low paid occupations with greater job insecurity. Welfare reforms, Hyde (2000) argues, have also intensified the stigmatization of impairment by exposing disabled people to higher levels of bureaucratic and systemic social controls, including functional assessment and eligibility testing.

What the reforms fail to acknowledge is the social and power relationships within which particular ideologies and social practices are sustained, including assumptions about the place of disabled people in the labour force held by employers or by institutions contracted to deliver on social policy outcomes.

## Draft proposals for change to employment, participation and inclusion services

One potentially troubling aspect of the Draft Proposals for Change to Employment, Participation and Inclusion Services (Ministry of Social Development, 2015), is that the agency responsible for directing people towards the kinds of support that might assist them to address material poverty through paid employment is the organisation within which most informants said they were met by a confusing, stressful and, at times, dehumanizing bureaucracy. Under the proposed changes, WINZ will be responsible for the development and administration of an “Outcome Setting Decision Support Tool,” intended to draft and match disabled people to a service within one of the three mutually exclusive outcome streams “according to their current preparedness to work” (Ministry of Social Development, 2015: p7).

**Figure 3 The proposed outcome pathways for people accessing Employment, Participation and Inclusion Services**



The impact of material poverty also spilled over into other important life domains, including informant's ability to stay connected to and to contribute to their community. A number of informants described living isolated lives, contributed to in part, by their inability to afford to go out.

*Respondent: I want somewhere to earn money because if I was going to get transport out then I need income to cover that.*

Not having much money didn't just define people's community by restricting their mobility, we also listened as informants told us that material poverty severed them from relational intimacy in ways that went beyond being physically present too.

*Interviewer: I was trying to get a sense of your day-to-day week. Do you get out much?*

*Respondent: I get out, um maybe three times a week*

*Interviewer: And what do you tend to do when you go out?*

*Respondent: Oh, mostly shopping and stuff.*

*Interviewer: How do you stay connected to people?*

*Respondent: I don't (laughs)*

*Interviewer: You don't?*

*Respondent: I don't, at the moment. But we're working on it through [Disability Support Organisation], we're working on it. Um I've had to put an application in to them, to try and get a Dell computer. I've got a scanner to read all my mail. But I'm missing out because I'm not being able to do the email. I'm not able to flick an email off to somebody*

*Interviewer: Right, jeppers. That sounds quite isolating*

*Respondent: Yeah it is.*

We also suspect that material deprivation suppressed community participation by colouring informant's perception of their potential value to the community groups they might otherwise have wanted to belong to.

*Respondent: I would say getting a job is more important first up and then being able to be supported in the community from there it kind of goes without saying really.*

*Interviewer: And so why is getting a job more important first up?*

*Respondent: Because once you have got a job you can contribute to your community. And so it opens up a whole lot of opportunities.*

In the National Online Survey, we found that respondent's rating of the importance of belonging to a community group was significantly higher if they were also employed (Milner et al, 2016). One possible explanation is that that the variation we observed might be accounted for by the known association between employment and subjective wellbeing, including measures of self-esteem (Griffin, 1996; Jolly, 2000) and mental health (Griffin, 2000, Petrovsky & Gleeson, 1997; Waddell & Burton, 2006).

Included in the set of relational markers that disabled people told Milner & Bray (2004) represented more valid indicators of inclusion were; that people were embedded within culturally specific forms of reciprocity, including acts of kindness and consideration that bind community members together, and being met by the expectation that members contribute to the wellbeing of others in the community (see Table 2). Milner & Bray's finding is consistent with Hall's (2005) observation that the geography of disabled people's community is often shaped by the "pull" of places that recognize and make use of the social capital of disabled people and the push of places where they experience a sense of being an "outsider." Disabled people speak often of the importance of "adding value to their community, (Milner & Bray, 2004) perhaps as a way of contesting the disabling social construction of them being dependent or a tax-payer burden. It is possible, therefore, that people who, like the informant above, felt that they lacked the material (or social) capital to make a contribution were more likely to eschew very ordinary forms of participatory citizenship and the prospect of more proximal relationship.

## Relational Poverty

More than a decade ago, Cummins & Lau (2004) wrote that it was *"the sense of community connectedness through relationship that represents the heartland of life quality"* (p190).

The other major poverty identified by informants was how a perceived marginality from relationships separated them from the lives they wanted.

In the National Online Survey, respondents rated the personal significance of "remaining in contact with friends and family" most important, and "belonging to a community group" the third most important of the life domains we sampled for (Milner et al, 2016). Almost half of the people who responded to the survey said they wanted to spend more time with friends and their yearning to experience a sense of belonging through relationship was detected in their narrative too.

Feeling isolated from the community was a common motif. For a number of informants, long and lonely days were said to have severed them from the intimacies and ordinariness of friendship. Many described feeling hemmed in to the cardinal spaces of their own homes and of welcoming moments of liberation from the otherwise socially isolating cadence of their day-to-day lives. People told us of *"having to sit around and be bored,"* or of being *"stuck at home in my flat all the time,"* or of welcoming the chance to *"get to be out of my bedroom."*

*Interviewer: How often are you out of the house?*

*Respondent: Not very often now. Not very often. That was only I go out on a Monday but it's because I have had problems with my legs.*

Consistent with previous research commissioned by CCS Disability Action (Milner & Bray, 2003; Milner & Mirfin-Veitch, 2012), we found that people's homes tended not to offer them what O'Brien (1994) coined the *"gift of hospitality,"* Other than paid staff, most informants said they had didn't have many visitors, compounding their sense of feeling disconnected from their community.

*Respondent: Like I find it really hard at home apart from doing the course, to think what life's all about. I am a Christian, which really, really helps. It has helped me though the most difficult times. But you know when you are home all the time. I don't really get a lot of visitors because of where I am and I don't know a lot of people because I am new to the area um and I don't drink so I don't really go out to mix with people. It can be really depressing at home.*

As was reported in the Community Participation (Milner & Bray, 2003) and Article 19 Projects (Milner & Mirfin-Veitch, 2012), disabled people often report having small friendship fields dominated by family members or staff who, as a consequence of being repeatedly present in ways that also respond to each other's changing circumstances, could occupy an important place in people's relational-lives. A number of informants expressed the same sentiment.

*Interviewer: You said you loved your support staff?*

*Respondent: The lady that comes into my house and helps me. You get that bond with them. Yeah they become a friend to you.*

*Interviewer: You were saying you liked the way that particular staff person talked to you. You said like a human being.*

*Respondent: Yeah. Listened to and communicated to and being nice you know.*

People seldom spoke of impairment or people's reaction to bodily difference as underscoring their sense of social dislocation. They were more likely to describe feeling disabled as a consequence of perceiving themselves to be separated from the ordinary life trajectory of their peers.

*Respondent: And my goal is like meeting new people is a big goal for me because I have anxiety I don't like to just go down the street and meet someone. And CCS has helped lots with that so far.*

*Interviewer: Cool. This may sound like a bit of a strange question but why would it be important for you to feel ok about going down the street to meet someone?*

*Respondent: Because I see other people doing it and that is why I want to do it as well.*

Having a sense of being relationally different appeared to be most acutely experienced by younger informants, most of whom had experienced a "mainstream," education that included their assimilation of ordinary life aspirations but the flight of friendship that frequently occurs for disabled people beyond the common community of their school (Milner & Mirfin-Veitch, 2012; McDonald et al, 2012).

*Interviewer: So what do you think the purpose of vocational support is?*

*Respondent: Well, I thought it was to like get me in touch with the community and get me outside more often doing things that most people my age do.*

Not having friends to pull people into the "*doing the things that most people my age do*," obliged some to look to CCS Disability Action support to help them to become more connected. Populating people's social lives with paid support staff, however, shaped the way informants stepped into and were present within their community, in a number of important ways.

Firstly, it influenced what was seen as the range of possible or appropriate contexts in which to seek to generate a community presence. Perhaps more importantly, however, was it also defined the range of contexts that were not imagined. In this respect, social isolation, and especially from one's age peers, made finding contexts that might seed relationship all the more difficult.

*Respondent: Oh well, there are things that I'm missing out on, like going to different things and stuff like that because the information isn't always available. Like going to free concerts and stuff like that.*

The consequence for some young people was a kind of demographic dislocation.

*Respondent: I feel pretty good at the moment. But I want to get more connected with people my age. So I go to church on Sunday night, but it is people older than me and then I help at a holiday programme, but it is with kids younger than me. So I want to meet people my own age.*

What this informant recognized was that it was the contexts within which she was present that determined the pool of potential relationship.

At first reading, the number of National Online Survey respondents who reported belonging to one or more community groups, clubs or organizations was encouragingly high. Seven out of every ten people reported belonging to at least one community group (70%), slightly higher than the rate of membership estimated for the New Zealand general population (64%) (Statistics New Zealand, 2015).

The pattern of group membership, however, differed for both populations. Respondents were more likely to belong to a church, religious or spiritual group or volunteer than other New Zealanders and less likely to belong to the contexts were most New Zealanders typically experience a sense of participatory citizenship. Included in the groups or organisations respondents were more likely to be absent were; sports or recreation groups, hobby groups, professional associations or trade unions (Milner et al, 2016). Respondents were also significantly more likely to belong to "Other" kinds of organisations, principally those in which they were able to access the fellowship and collective advocacy and support of other disabled people. Such groups included disability support organisations like the Blind Foundation, Deaf Society, MS Society, creative or other groups that fall within the umbrella of the Disability Arts Movement, advocacy groups like Disabled Person's Assembly (DPA) or People First, and sporting organisations like Special Olympics or Paralympics.

What the statistics could not tell us though, was the way that people experienced their membership. One possible indication that survey respondents might have had a more marginal status within these organisations was the way respondents described the amount

of contact they had with different community groups. Within the New Zealand general population, Statistics New Zealand (2015) reported that, on average, 10% of community group members wanted more contact with a community group, club or organization. The people who completed the National Online Survey were up to eight times more likely to report wanting more contact, including 82% who said they would like more contact with a hobby club or interest group, 67% who wanted more contact with a political organization (including an advocacy group) and 60% who wanted more contact with a neighbourhood or community group.

In their interviews, a number of people also spoke of feeling on the margins of group culture, *"sitting on the side because I use a wheelchair"* or *"out of place"* in outwardly inclusive social settings. To them feeling "out of place" was communicated by subtle and at times unconscious forms of social othering that, according to Hall (2005) can act to maintain the dominant (non-disabled) order of community social spaces.

*Respondent: I've often been um told, oh no you can come to our group but you'll have to bring a carer*

*Interviewer: Right, so that's a lack of confidence on the part of those groups, around your disability*

*Respondent: Yeah*

*Interviewer: What would you need your carer for?*

*Respondent: Ah, not much (laughs). Then you end up stuck in the corner talking to them, and you don't end up talking to the people you're supposed to be talking to.*

In this narrative, the informant identified the presence of support staff as interfering with a process of relationship development already compromised by this particular groups lack of confidence in their ability to include disabled people as members. Her observation aligns with previous New Zealand research that has identified staff as a potential barrier to community connectivity by; removing the possibility of simple acts of assistance seeding relationship during moments of encounter, or by enveloping people within the social construction of "dependent service user." Being present with staff also carries the risk identified by the informant, of declaring to others that being in a relationship with a disabled person is a skilled occupation (Milner & Kelly, 2009).

The presence of staff affected the way people felt about being in community spaces in other ways too, and a number of younger informants singled out the age of support staff as another factor that may have contributed to the difficulty they were experiencing populating their relational lives with people their own age.

*Interviewer: You would be changing the name (from CCS Disability Action), are there other things that you would change?*

*Respondent: I would like get more younger people working there as well. The older ones they are nice but sometimes it feels like you are going out with the babysitter*

In a recent study, Higgins et al (2009) estimated that approximately two thirds of the New Zealand disability support workforce was aged 45 years or older (64%). There was also a strong gender skewing to the workforce. Higgins et al (2009) found that three quarters of the disability workforce were women (76%), arguing that the demography of the disability workforce may have implications for the way support is transacted. One of the possible ways this may play out is by defining the types of communities that staff act as a gateway to, or alternatively feel comfortable supporting people to become included within.

Results from the National Online Survey indicated that male respondents (44%) were more than three times more likely to report not belonging to any community group, club or organization than female respondents (15%) with the research team suggesting that the pattern of membership and community participation we observed may have been influenced by historical patterns of vocational support (Milner et al, 2016). It may also have reflected patterns of support influenced by the gendered composition of the workforce. As reported previously, eight out of every ten survey respondents (82%) said they wanted to have more contact with a hobby or interest group(s) and whilst the respondent below attributes not being able to continue with a rewarding activity to his having to sell his tools, it is possible that non-one imagined alternative ways to keep him connected to people that shared and could help him continue to be creative.

*Respondent: So I'm not doing any carpentry or cabinetry no and I should be because I like doing it.*

*Interviewer: So what gets in the way of doing it?*

*Respondent: Well I haven't got the tools..... I was short of money and had to pay different things to get up here and it's the storage thing.*

When people felt supported by someone who shared the same interests, many said the experience of support was different, including keeping them engaged with communities of interest, even if vicariously.

*Respondent: I like that they matched me with a support worker who kind of has the same interests that I do. We can talk about anything.*

Within the social practices of disability support, a person's Individual Plan, including the more formal articulation of a person's specific "vocational goals" represents the contractual element to "getting the life (people) want"



Responding to the perceived marginalities of material and relational poverty featured prominently in the goal setting of people who responded to the National Online Survey. In the following sections, we report on what informants said about the purpose of vocational support and the goal setting process before discussing in more detail the near global aspiration *"to be able to find a job and have friends like any other person."*

# THE PURPOSE OF VOCATIONAL SUPPORT

## Vocational goals

Within existing Vocational Contracts, the role articulated for Disability Providers by the Ministry of Social Development (MSD) is to facilitate and/or support people to participate in their communities in ways that are meaningful to them and enhance their quality of life and mana. To do this, the Provider is required to develop an Individual Plan as the vehicle for realising a person's goals.

When asked what they thought the purpose of vocational support was, only one informant interpreted the role of support so expansively.

*Interviewer: What would you say the purpose of vocational support is?*

*Respondent: It is to assist disabled people with what they want to do with their lives and how they want to achieve it*

Within the policy document *Pathways to Inclusion* the stated aim of vocational support funded through the Ministry of Social Development is “to achieve greater participation of people with disabilities in employment and in our communities,” (Minister for Disability Issues, 2001; p.4). Most people imagined a purpose that approximated the two policy aims of “*Pathways to Inclusion*,” but which coincidentally also sought to redress the marginalities they described in the previous section.

The search for paid employment was preeminent amongst the support goals people who responded to the National Online Survey identified. More than half of male survey respondents (54%) and slightly fewer female respondents named finding paid work as their desired support outcome (Milner et al, 2016). The majority of informants told us that “*the ultimate objective (for them was) to find satisfying employment*.”

*Respondent: The reason, I guess I am seeking support is that I have been out of work, have had no income from WINZ or work for well over two years now. I guess I was being over-sensitive in a way, but I started to see patterns with my work where they kind of, um in general often were sort of six-month stints. My longest was 18, but they were getting shorter and shorter. So I figured that I want to be employed basically. And I'm not and I want to be. So that was kind of why I approached (CCS Disability Action) in the first place.*

Another motivation respondents expressed for finding employment was the interruption it was perceived to provide to what many described as “*wasted*” days and geographically restricted life-spaces.

*Interviewer: (Underemployment) is better than you know having to sit around and be bored at stuff at home stuck at my flat all the time and being bored because I don't have a computer to play on and things and not being....*

As noted previously, some informants welcomed the opportunity vocational support provided for them to *"get outside"* the day-to-day cadence of their everyday lives, even if the destination was the relative anonymity of staying *"in touch with the community,"* rather than specific forms of participatory membership.

*Interviewer: What do you think the purpose of vocational support is?*

*Respondent: Um well I thought it was to like get me in touch with the community and get me outside more often.*

*Interviewer: And is it different from other kinds of supports that you receive?*

*Respondent: Yes it is different because my other supports don't really do we don't do what I want to do. Like we do things that I have to do, but with CCS I can do things that I want to do.*

Eleven percent of male and 8% of female survey respondents named participating in public community spaces or activities as a vocational goal, more than named finding or developing friendship(s) (8% male, 5% female respondents) or of joining a community group (0% male, 4% female respondents).

What people, like the informant above said they did like, was that vocational support provided them an opportunity for self-direction, often denied by other types of disability support. As is discussed in more detail below, respondent's true aspirations were often unexpressed in formal goal setting and what people subsequently spoke of was that their community presence offered points of entry beyond the anonymity of public encounter.

For one informant, the planning process and goal setting that occurred at the beginning of the support relationship had provided him the space to rethink and redefine the ways he wanted to connect with his community following impairment. Part of that recalibration involved replacing work with alternative ways of continuing to make a contribution to his community.

*Respondent: (I'm) trying to set an example too to my kids. That I am seen in a positive light not just dad who does the washing at home and cooks the meals but he is also part of the community and he is doing things in the community getting involved yeah. So I think that if anything that is what has transpired since I have had the CCS involvement here in town.... I am on the board of trustees at for the school (and) I have enrolled in my studies for next year so that's a positive.*

Perhaps not insignificantly, this respondent had lived a full life prior to becoming unwell. He was also pulled into his community by the connectivity and busy lives of his wife and children.

*Interviewer: How connected to the community do you feel? You talked about being on your school board of trustees is that right?*

*Respondent: Yes so I have recently been elected on the school board of trustees. So my wife is actively involved in the community not too far from where we live so she is on the marae committee. She is also on the school board of trustees. She is a teacher so she does relieving at the local school just down the road from us and she also has a contract with Te Wananga o Aotearoa here in town which is quite a big quite a big tertiary provider here and she has extensive networks through her family and business people in town*

*Interviewer: And you are just about to get embraced by the academic community.*

*Respondent: Yeah well my kids go to taekwondo I am part of that. I take them swimming a couple of times a week and they what else do they do we do something else in town. I sit there and I talk to the people I know the instructors I make sure that I introduce myself and have a chat and engage with people*

Those who didn't have similar experiences to draw on, typically struggled to say how they wanted to become productively engaged in their community. Despite knowing that the relational destination they sought were relationships that extinguished loneliness or addressed their sense of living "wasted" lives, most people found it difficult to identify potential places of belonging or how they might make themselves transparent in ways that communicated membership.

*Interviewer: In what sort of ways do you think they might help you to get involved?*

*Respondent: Well they could give me some ideas. And maybe tell the people in the group about me and me about them.*

In this respect, the goal setting process that defined support activity appeared to be shaped by two, sometimes self-reinforcing influences; firstly, the compass of people's imagination (or self-confidence) - most often shaped by the range of lived experiences and secondly, the social construction or perceived social capital others engaged in the planning process brought to people's goal setting. Poverty of imagination, therefore, might be considered as one of the other ways disabled people can be marginalized.

## Poverties of imagination

For a few people, like the respondent who used the planning process to call out an alternative version of himself to himself, goal setting had the potential to alter the trajectory people's lives by mapping what the "*next-steps*" might be (see the final chapter). Most informants engaged in a different kind of conversation, however, circumscribed by a more restricted vision of what might be possible or indeed how to get there.

*Respondent: Like I can see that it is useful for some things maybe getting people online, on track. I mean one of the problem as well is that you kind of have to choose your goals and um and work out what you want and stuff and for me I would potentially need someone to help me with that.*

As is discussed in more detail later in this report, people who had acculturated to some of the marginalities of disability looked to the planning process as a way of maintaining the status quo or of continuing to navigate problems they were likely to encounter in their day to day lives. This meant that it was difficult to direct their support in ways that were likely to lead to alternative futures too.

*Respondent: So I would rather get a full time job with someone. And I don't think I mean I guess they could help me but I don't know how they could help me.*

John O'Brien once wrote the perhaps the most significant disabler that people with an impairment face is the way others "show up" to relationship with them. A lack of clarity about what was possible, either in terms of an alternative personal future, or the range of different ways support might be transacted, exposed people to the lack of imagination or the social constructions of support staff. Some informants reported that a narrow vision of disability support could interfere with progress, even when "*big ideas*" could be articulated.

*Respondent: Yeah I can take the big ideas to them, but then they don't go very far (laughs)*

*Interviewer: Why?*

*Respondent: I don't know. I don't know why they don't go very far.*

*Interviewer: Is it because, the only way that you have to kind of transact them is in a phone call, maybe twice a month? Do you think that has an impact?*

*Respondent: No, I just think people haven't thought. You can come up with all these ideas but how do you get them further?*

*Interviewer: I don't know, how do you get them further?*

*Respondent: (laughs) you know.....*

Informants also appeared to suggest that establishing guidelines for planning at the start of the relationship was an important determinant of its subsequent success, including their ongoing investment in the process. Allowing people an opportunity to continue to develop

and (re)place themselves within a broader directional framework rather than a viewing planning as a single event whose purpose was to generate specific and quantifiable outcomes was said to be of central importance.

*Respondent: So the objective of that is to obviously figure out, figure myself out a bit and I would have liked to figure out the best. One thing that I before I even started at it I would have liked to work out what I should be doing in my life and so that would be whether it was like I call it a tea packing job or you know a bread and butter job to support something else or what is the something else or can I keep doing the architecture stuff or should I change that a bit or diversify or specialise or whatever. So I would have liked to work that out. And like I had a document written out with information that I had got together and no one really progressed that at all. So I would have liked to have, but I don't know I might be being unrealistic but I would like to know what I should be doing.*

Without establishing that planning architecture, the goal setting process could become increasingly abstracted from people's lives or alternately viewed as merely one of the social practices of service delivery.

The National Online Survey began by asking respondents about their current vocational goals. Four out of every ten respondents (41%) and approaching half of the men who answered the survey (47%) did not know what their current goals were and almost all respondents who named a goal volunteered a single outcome only (Milner et al, 2016). We also found goal setting hid an unexpressed aspiration by many to work and to find belonging within community. For example, three quarters of survey respondents said they worked fewer hours than they wanted (74%) and an equivalent proportion of respondents who named a vocational goal but did not identify employment as an outcome said they wanted to work (75%) elsewhere in the survey, suggesting that the goal setting process was often insensitive to a pervasive yet undisclosed aspiration to find paid employment. Similarly, although 82% of respondents reported wanting to have greater contact with a hobby or interest group and 67% wanted greater contact with a neighbourhood or community group, less than 2% of respondents named these forms of participation as a vocational goal.

For many the lack of engagement with goal setting or failure to see the process as a way of significantly altering the trajectory of people's lives could be explained by the way support was transacted. It appeared to the research team that some of the social practices of support had evolved as a way of responding to the perceived limitations of the National Vocational Contract, and most especially the way support hours needed to be rationed. For most informant's support was described as a periodic "checking in" or was available to people when they needed help with disability related events or negative life consequences, making it difficult to both declare and to receive assistance to achieve larger life goals.

- Interviewer:* And so how often would you see or have contact with [Support staff]?
- Respondent:* Whenever I need it. I just contact her and she will contact me. Its only when I need it, I contact her.
- Interviewer:* Right so you are the one who makes the contact yeah?
- Respondent:* Yes because I am pretty good with stuff like that
- Interviewer:* Yeah I can tell. So how often would you need to call?
- Respondent:* About once a month maybe?
- Interviewer:* Once a month. So for what sorts of things?
- Respondent:* WINZ and stuff like that.
- Interviewer:* Well if they were to ask you today, what sort of goals would you say? What do you hope for yourself?
- Respondent:* I don't know. Just get a job and I have got a job get more hours and get off the benefit and you know? Get off WINZ. That is what I would love to do

In the context of ordinary disabled lives, planning wasn't represented as a moment in time, but rather an ongoing process of reflection and responding, typically to changes in life circumstances. For many informants, it appeared that once the opportunity to declare major life aspirations had past, it was difficult to continue to see the goal setting process as helping them to "get the lives they wanted." Failure to approximate the ordinary planning process and a perceived lack of ownership of goal setting process had led many to frame individual goal setting as a service rather than a personal outcome.

- Respondent:* So yeah at the start it was good and then I would say I don't know it was probably late last year or something that things started changing and it just felt like she was ticking boxes so you know there were forms and you were signing redoing your goals she was suggesting that they were all not all but fairly well ticked off kind of and I didn't think they had been. I don't think their goal kind of system quite works. I get what they are doing I like I mean it is good to be clear about what your intention is but I don't know it feels a bit forced and a bit you know like they got me to re-sign stuff and I don't know .....

For one respondent, it was something as simple as who wrote the goals that had undermined the sense of self-authorship.

- Respondent:* Well my goal is to be fulfilled and to be a contributing member of society. I would have told them that. They never let me write stuff. They they always write stuff themselves.

Maintaining motivation in the face of slow or attenuated progress towards major life goals also appeared to undermine informant's enthusiasm for the planning process. Informant narrative suggested that some had become dislocated from the annual cycle of reviewing people's Individual Plan and it is possible that the low National Online Survey response rate (14.6%) might be partly explained by a cohort who felt similarly dislocated from vocational support.

- Interviewer: Do you have any goals that you have told CCS Disability Action about?*  
*Respondent: They haven't been done. There are supposed to be goals every year. They haven't done goals for me for almost 2 years.*  
*Interviewer: Right. Why do you think that is?*  
*Respondent: I don't know. I thought that I was supposed to do it every year that was the arrangement but I have never done it. And they are meant to do reviews and all that stuff but they never come around so.*

Informant's lack of knowledge about alternative ways their vocational support might be organized meant that the pattern of support was largely defined by the historical practices of CCS Disability Action. In addition to knowing little about the array of different approaches to delivering Supported Employment and/or promoting other participatory outcomes, informants were not in a position to exercise authorial control over service delivery. This lack of ability to direct support ranged from contributing to discussions about best support practice through to exercising control over the timing and duration of available support. Informants did not know, for example, whether it was possible to aggregate and then fade support (hours) as part of an intentional strategy to achieve major life goals.

The other way that CCS Disability Support staff influenced people's understanding of what represented valid life or support outcomes was staff's perception of the social capital of the people they supported. Disability writers argue that societal values and the social policy framework within which disability support is embedded inevitably shape support practices and the narrative of many informants was punctuated by their belief that they had been steered away from more authentic life goals in favour of outcomes support staff thought were more achievable.

- Interviewer: If you were to say, I would actually like to work, I would like to come off the benefit, what are the things that you would want me to do for you?*  
*Respondent: I don't know. I don't really know to be honest with you. It's hard*  
*Interviewer: So if I was to ask you what your dream job was, what would you say?*  
*Respondent: Teaching. Teaching full stop. I would like to be an early childhood teacher. I would love to go to uni but I am not smart enough and I would love to be an early childhood teacher. I would love to work in a day care. And specialising in special needs.*  
*Interviewer: Has anybody every explored that with you?*  
*Respondent: No.*  
*Interviewer: And why do you think that is?*  
*Respondent: I don't know I think it is more like oh well you have got a part-time job so keep it going you're all good. We will move on to the next person. It feels like that is the, you know? That ok you don't need our help that's ok. See you. Do you know what I mean?*

The danger inherent in adopting a Social Investment Strategy to welfare provision is that policy instruments like the Outcomes Based Framework excludes the aspirations of people who are perceived as having little to contribute within mainstream (non-disabled) social spaces like the labour market. Without working either to improve the inclusiveness of New

Zealand workplaces and/or to destabilize current understandings of the social capital of impairment, disabled people will continue to remain disproportionately beyond employment and will continue to have to dilute their life ambitions to fit existing support practice.

The failure to recognize and promote the economic and social advantages of including all people within the spaces and places of the economic majority represents the forth kind of marginality disabled people expressed experiencing that is perhaps best illustrated within the context of employment.

# FINDING PLACES OF BELONGING WITHIN EMPLOYMENT

## Employment and life quality

In a research collaboration commissioned by CCS Disability Action, Milner & Bray (2004) described the desire to find paid work to be an almost universal aspiration amongst the disabled people they spoke to. Their observation was consistent with more recent findings reported for disabled people by Statistics New Zealand (2014) and a range of similar international studies.

More than a decade later, the disabled people who responded to the National Online Survey did the same. Eighty percent of respondents who completed the survey expressed an aspiration to find some form of paid employment (80%) whilst getting a job was overwhelming the most pervasive of all vocational goals named (and unnamed) by respondents (Milner et al, 2016). The informants we spoke to also repeatedly told us that, *"the ultimate objective would be to be in satisfying employment,"* or to *"make a contribution by finding a job"*

Like all citizens, disabled people tend to regard paid employment as the most socially valued way of earning a living (Lovgren & Hamreby, 2010; Humber, 2013). As a consequence, employment represents an important marker of citizenship to disabled people (Kiernan, 2000; Milner & Bray, 2004; Stephens et al, 2005), and a potent symbol of having followed the ordinary adult life trajectory emphasized in New Zealand social policy as indicative of an inclusive society (Minister for Disability Issues, 2001). Unlike their non-disabled peers, however, disabled people also tell us that paid employment provides them with one of the few opportunities they have to contest the disabling cultural scripts that have historically cast them as dependent members of their community. Being unemployed, Glesson (1998) notes, does nothing to challenge the enduring social construction of disabled people as 'less productive.'

In the Community Participation Project, the disabled men and women who spoke to Milner & Bray (2004) said that their unemployment was in part explainable by a their becoming trapped within wider cycles of marginalization including having more limited access to education and training tailored to their needs, skill development, appropriate work experiences and forms of vocational steerage that reflected the more limited expectations and/or a failure by non-disabled people to recognize and promote the social capital of impairment.

Being unemployed also contributes to other forms of economic and social marginalization. For all citizens, the nature and extent of participation in the workforce is the primary determinant of personal living standards. Whether or not someone derives an income from employment influences people's ability to access other community resources and as a consequence, the extent to which people can exercise agency over our own lives. Material and social deprivation also increases the likelihood that disabled people will become dislocated from the economic and social life of their community (Human Rights Commission, 2010) and new research is describing an association between unemployment and negative quality of life outcomes across all major life domains, including personal health and wellbeing (Griffin et al, 1996; McDonald, cited in Alward, 2008; Statistics New Zealand, 2008; Waddell & Burton, 2006)

The people we spoke to in the *"Getting the life I want"* project identified a similar range of reasons for emphasizing employment as their preeminent vocational goal.

## The personal importance of employment

For 76% of working age New Zealanders, going to work is an ordinary aspect of everyday adult life (Statistics New Zealand, 2014). For most New Zealanders, therefore, work patterns their day-to-day lives, given that most of the institutions and cultural mores of citizenship are constructed about the assumption that paid employment will be a normal adult life experience.

Many informants were acutely conscious of the way their unemployment transgressed the normal cultural script and in so doing marked them out as atypical citizens. *"Doesn't everyone want to do that?"* we were asked?

*Interviewer: Why? What appeals about working?*

*Respondent: I just want to be like everyone else. You know contributing to society and just sort of making my own way in life you know*

In the previous section, we described how poverty was an inevitable consequence of informant's un(der)employment and how, in addition to making life more difficult, their lack of material resources limited the compass of their lives. Being poor greatly restricted the range of ways that people could be present and in doing so limited the contribution they wanted to make within everyday community spaces and places.

- Interviewer: Were there other things that motivated you to look for work?*  
*Respondent: Yes I wanted to live like properly*  
*Interviewer: What do you mean by properly?*  
*Interviewer: A more full life doing things. Rather than just. Because if I didn't work I wouldn't have anything to do most of the time.*

It was also seen as enhancing people's ability to exercise agency over their lives in ways that made "getting the lives they wanted" more achievable.

- Interviewer: What is it about having a job that makes you think that it is, that lead you to rate it as really important?*  
*Respondent: Um not to be on the benefit all your life all the time*  
*Interviewer: Yeah why would that be important?*  
*Respondent: Because they you have your own money to do what you want with it.*

Conversely, "*being on the benefit all the time*" was almost universally seen as the antithesis of the autonomy informants sought. In addition to the problems of navigating the bureaucracies of WINZ, described previously, being on the benefit was perceived as contributing to an understanding of disabled people as dependent members of society. For many, therefore, employment was read as providing an opportunity to contest this disabling social construction by overtly adding value to the lives of others. Employment was also seen as offering a point of entry into a culture in which employees were expected to contribute their labour and creativity further destabilizing the non-disabled narrative of impairment. For one informant, work also represented a more personal expression of her belief that its value lay in the way she might benefit others, even if for only a few hours a week.

- Interviewer: Can I take you back to your work? What is good about your teacher aiding? Like do you like your job?*  
*Respondent: Yes I love the children. I love the children and that is the main point I stay because I love the children. They mean the world to me*  
*Interviewer: Right and I guess you have got an important role, you know, because you like them, you are also helping them in a way too isn't it. You are adding something to their lives?*  
*Respondent: Yeah that's what I like about my job*

Other informants believed work might provide structure and purpose to their lives in ways likely to enhance wellbeing. For some, it was as simple as "*having a routine and knowing what you (were) doing.*" And for others, the proscriptions of employment as well as the chance to learn and apply new skills was seen as offering a sense of personal momentum when compared to the stasis of unemployment and job training.

- Respondent: I have heard of life skills and to me it seems like just going there regularly and not really doing anything. Having a job you get to like complete tasks for other people.*

And almost all informants spoke of employment as a way of demonstrating latent but largely unrecognized potential. *"Finding a job was important,"* they said, *"because it helps you do what you are gifted at doing."*

In a recent New Zealand research project, disabled people told Conder et al (2009) that feeling a sense of accomplishment and being around others who assumed and depended on your competence supported emotional wellbeing. Conversely, international studies have repeatedly demonstrated a negative association between unemployment and self-esteem (Griffin et al, 1996; Jolly, 2000) and psychological wellbeing (Jaranek & Kirby, 1990; Petrovsky & Gleeson, 1997). The consequences of being excluded from the workforce appear so deleterious, that Dr Ewan McDonald, described 'worklessness' as the most significant risk to public health, citing research that estimated the damage to health associated with unemployment to be the equivalent of smoking 200 cigarettes a day (McDonald, cited in Alward, 2008).

*Interviewer: You seem to be saying to me that if you had the chance to come off the benefit you would actually like to come off the benefit?*

*Respondent: Yeah I would because I have seen it my mum was on the benefit and she stays in the house. I don't want to be anything like her I want to have a job a full-time job I want to you know? I want to do stuff. I have to save up to do stuff. If I want to go to the movies I haven't gone to the movies for over half the year now. Half a year since I have been to the movies because I can't afford it. So yeah I would love this lifestyle where I could buy a house and you know? But I can't. It's getting harder and harder.*

In the Community Participation Project, people receiving vocational support from CCS Disability Action in 2003 described knowing the outside but not the inside of their community (Milner & Bray, 2004). In 2016 many of the informants we spoke to continued to feel community life happened beyond their own and employment was perceived as a possible gateway to more exotic forms of participation. In talking about his job, this informant described the way fellow employees had filled out the otherwise hidden geographies of his community to be one of the more important attributes of his part-time employment.

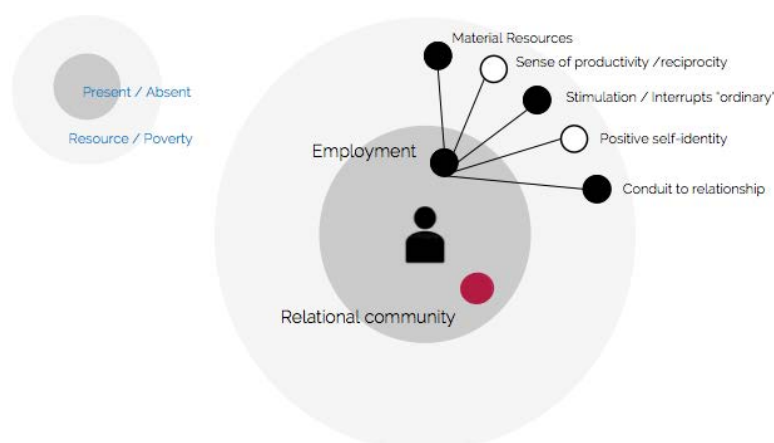
*Respondent: Just being aware of what is going on, whether it is political events, sports events, cultural events as well. I think that is important.*

*Interviewer: So what do you get out of that?*

*Interviewer: I get, I guess I get a sense of belonging*

Disabled people tend also to view employment as a possible conduit to rewarding relationship. As noted previously, in two studies commissioned by CCS Disability Action, disabled people were found to have extremely small friendship fields with most relationships beyond the intimacy of their family stuck at the level of acquaintance, largely as a consequence of having more limited access to social contexts like employment (Milner & Bray, 2004; Milner & Mirfin-Veitch, 2013). Disabled and non-disabled people who are in employment share in common that work affords them the chance to forge new relationships that sometimes spill out beyond workspaces and into the community (Forrester-Jones, 2004). Research has also identified employment as promoting the development of important social skills, including the conventions and etiquettes that connect people to people (Fillary & Pernice, 2005).

**Figure 4 The attributes of employment informants identified as personally important**



Whilst few informants worked and even fewer mentioned the flourishing of relationship within employment settings there were exceptions. One informant had been supported to find work inside of a tattoo parlour. She loved the work, but equally importantly, had become assimilated within the community of people who loved body art. At the very epicentre of her employment was the relationship she had with her boss, whose reciprocated respect was broadcast to that community in Facebook posts that alerted others to the contribution she made or moments when managing her impairment made it impossible for her to come to work or that she might appreciate an empathetic post.

*Respondent: Um my boss is amazing. She works like she would do anything and I love tattoos so I love watching them get done on people everyday.*

## Employment as an extraordinary experience

In contrast to the more seamless transition to employment for non-disabled New Zealanders, few people who received vocational support from CCS Disability Action and who contributed to the “*Getting the life I want*” project currently accessed the worlds of paid employment. Seventy-two percent of people who responded to the National Online Survey reported not being in any form of paid employment and only 8% of respondents worked for more than the 15-hour threshold, defined by the Ministry of Social Development as “sustainable employment.” Only two respondents worked for 30 hours or more (Milner et al, 2016).

Most informants had only experienced part-time and/or temporary employment and a significant number had been unemployed for more than two years. Whilst some had already acculturated to lives in which employment had ceased to be an ongoing expectation, the reality was always couched in regret.

*Respondent: I do craft work. Yeah I make baskets*  
*Interviewer: Do you sell them?*  
*Respondent: No I don't sell them, but I make them out of cane*  
*Interviewer: Gosh. You're talented. You are bilingual (reads/interprets braille), are a musician, you work on committees .....*  
*Respondent: I know (unclear...sounds like wasted 46:04)*  
*Interviewer: What did you say? I'm wasted?*  
*Respondent: Yeah (laughs)*  
*Interviewer: Right, if we weren't to waste you, what would you be doing?*  
*Respondent: Um, probably all of the above,*

Listening to a narrative that continued to emphasize how difficult it was to find work for disabled people appeared to shape informant's sense of themselves and their employability in a range of ways. Some respondents spoke of historically wanting to work, as if the aspiration belonged to a previous life or alternate self. The leaching of aspiration evident in the transcript extract below was indicative of many who had lost confidence in themselves as employees or who feared the length of their absence from work made them increasingly unemployable.

*Interviewer: As a non-disabled person, like a life not working is never, is something I've never had to think about. I've always assumed that I would work. When you were younger did you assume that you would work?*  
*Respondent: I hoped I would. I'd get trained up to something that I could do. Oh anyway get the training so that I could make my own business or something. Yeah I always hoped that I would.*  
*Interviewer: But you seem a very able, um person to me... and jobs like where you, you didn't have to move and tire yourself that way, um I would have thought would have easily, been able to do.*

*Respondent: Yeah. I could have done that.*  
*Interviewer: You keep using the past tense. You said "could"*  
*Respondent: Well, a lot of it is taken over by computers, which is a bit of a shame.*

One of the other consequences of finding it difficult to get work was the number of informants who had drifted towards underemployment in the expendable fringe of the labour market. Accountants contemplated shop work, informants who were trained in NICAD software and database entry volunteered in community gardens hoping it might turn into paid employment and architects cleaned toilets.

*Respondent: ..... well as I said I was employed for 18 months or employed for 6 months or whatever and then I sort of did stuff like working for [Business] and working for, kind of not really with my well not with my strengths but just trying to find a job. And now I am actually cleaning toilets. Which pisses me off because that's what CCS think that they have succeeded because I am cleaning toilets for 11 hours a week.*  
*Interviewer: So you are an architect did you say?*  
*Respondent: I am trained in architecture yeah.*  
*Interviewer: Yeah when you were doing the work for 18 months what was that job?*  
*Respondent: That was architecture. That was in an office*

What concerned this informant was that vocational support that focused on employment as a service outcome, underwrote an employment trajectory that both denied and de-emphasized her skills and capacities. Rather than taking her towards her chosen profession, vocational support had taken her further from it. Equally troubling was that she felt what was perceived to be a "successful placement," made it less likely that her support staff would work hard to arrest an employment trajectory she found demeaning. This informant's comments aligned with other people who had either trained or worked in professional occupations who expressed concern that vocational coordinators either lacked the skills or vocabulary to effectively represent their social capital to employers and therefore tended to restrict their search behavior to a narrow range of less skilled occupations described later in this report.

The other troubling aspect of the drift towards un(der)employment was that, over time, informants appeared to reposition the cause of their marginalization. In codifying the right to work in Article 27 of the UN Convention on the Rights of Persons with Disability (the Convention) the convention places on obligation on the State to ensure that disabled people can work "*on an equal basis with others; (including) the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities,*" (UN, 2016).

Rather than attributing their failure to access employment on an equal basis with others to work environments that failed to meet standards of openness, inclusivity or accessibility, informants were much more likely to internalize their marginality, locating the problem instead within minds and bodies that didn't easily fit the labour market.

*Respondent: I don't think so. Because the only problem with me not staying at work longer is I am permanently in a wheelchair so hard for me to get to the toilet and stuff and healthcare can come to the workplace and toilet me there but there is not enough room for a hoist or a toilet chair or anything like that so but I think that is something that is always going to be there and no way that you could help with that or anything.*

Acceptance of the master narrative that unemployment was explained by bodily difference meant that informants were also less likely to attribute the difficulty they were experiencing finding employment to the social practices of vocational support. Almost all informants appreciated the assistance they received from CCS Disability Action staff, even though aspects of the way support was delivered may have made it more difficult for people to find the jobs they wanted.

Most informants described experiencing their support as an episodic and infrequent event, often, many said merely to check on *"how things were going."*

The pattern to support appeared to be that informants typically received more frequent contact close to the time of their referral, usually to define a person's interests and previous work experiences both to inform a possible search strategy and as a prelude to updating people's curriculum vitae or writing cover letters in a first flurry of activity. A number of informants described this support as dissipating over time, to the point where the purpose of support became less clear and/or informant's status as a vocational support recipient became less well defined. In the National Online Survey, for example, half of the respondents reported either not being supported or having no contact with a CCS Disability Action Vocational Coordinator in the previous four weeks (49%) and approximately two out of every three respondents (64%) said they had had no contact beyond one conversation (Milner et al, 2016). The waning of contact outlined in the informant narrative below is typical of the support trajectory a number of informants described.

*Interviewer: So you have been getting that support from CCS Disability Action. How often do you see them?*

*Respondent: Um initially it was weekly and then I think they might have told me that it was being reduced to fortnightly but then it was reduced to I think monthly, but they never actually told me that.*

Rather than aggregating support in a concentrated (and collaborative) effort to find a preferred placement, the limited, and for many, eroding nature of support appeared to communicate dispiriting cues about a person's value within the labour market, both to informants and to the support staff who were contractually obliged to effect employment as a support outcome. Cues informants suggested required monitoring and occasionally, mitigating.

*Interviewer: What are the things that you really like about the ways that you are being supported? What is good about their support?*

*Respondent: They do work a bit harder than I would*

*Interviewer: Right they are not giving up. That's a great insight. Why would you give up? Just because it is dispiriting putting in applications and not getting anything?*

*Respondent: Yeah I have had a bit of that issue.*

Support activity, and most especially the job search process, was also often described as occurring in the absence of informants. This attribute of vocational support was perceived as disempowering by some, further reinforcing their marginal status as passive recipients of support instead of modeling a partnership that might contribute to an alternative social construction of disabled people as resourceful, connected and creative causal agents in their own right.

*Respondent: They (CCS Disability Action) were really friendly and proactive. I mean she didn't actually find me a job but she was trying. She didn't tell me about it, that is something she could have done better, I would have liked to know who she was asking. Not necessarily done it myself ....*

For others, however, this attribute of vocational support remained unquestioned, because the delineated roles of "client," and "support worker," or "vocational coordinator," were prescribed by deeply entrenched historical support practices.

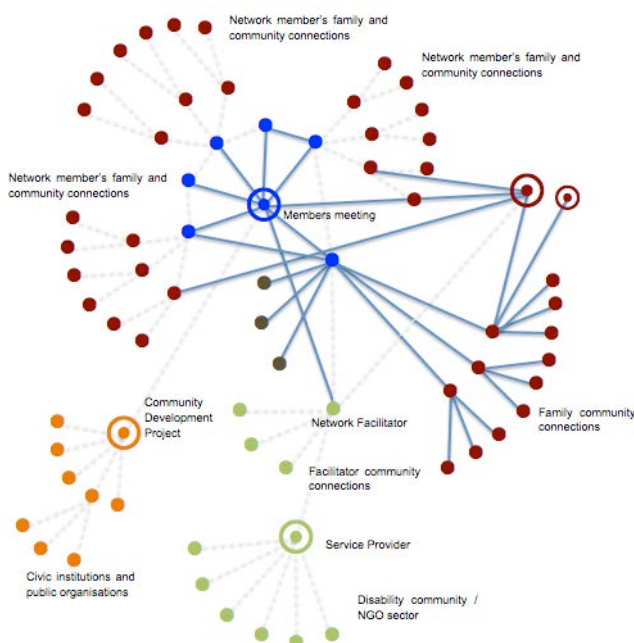
## Practicing beyond community assemblages

Similarly unquestioned, was an assumption that vocational support would only be transacted within the support receiver-provider dyad. Consistent with the shift towards models of support that frame disabled people as autonomous/individual consumers of disability support, informants described support staff as working in isolation from other community agencies or resources. They also described their support as occurring in ways that failed to tap the caring relationships, community ties and associations they brought to the support relationship.

In writing about the way dis/abled narrative can both affirm and yet simultaneously “*trouble, reshape and re-fashion ideas about (normative) citizenship*,” Goodley & Runswick-Cole (2014) drew attention to the way disabled people's experiences provide an opportunity to reappraise non-disabled understanding of constructs like “autonomy” and “independence.” Goodley & Runswick-Cole (2014) wrote that when they examined the “normal lives” of dis/abled people, they found “dis/ordinarily” forms of community support tended to underscore personal autonomy. Re-framed this way, autonomous citizenship, they argued, might be seen to find universal expression through community *assemblages* within which new relationships, alliances and communities of common interest were an ever-present possibility.

Milner & Mirfin-Veitch (2015) reached similar conclusions following their evaluation of the New Zealand Network Project. The Network Project was a support initiative trialed in Palmerston North by Community Connections. The project was modeled on the KeyRing Network pioneered by Karl Poll in the UK during the 1990s. Networks involve up to nine disabled people meeting and working together to provide each other with practical and emotional (peer) support.

**Figure 5 The (latent) connectivity of community networks [source: Milner & Mirfin-Veitch; 2014]**



In the New Zealand Network Project, members also combined two hours of their support funding to purchase a "network facilitator" to assist members to define and meet their own support needs. One of the unanticipated consequences of the Network Project was that collective membership greatly increased the access members, their families and a range of community organisations had to the material and human resources of an ever-expanding relational community.

Unlike the Network model, informant narrative suggested that the search for employment was usually conducted by CCS Disability Action staff who tended to work independent of communities of possible support, rather than seeking to build and engage existing community collectives and assemblages.

One of the consequences of restricting the number of people engaged in the processes of finding and supporting employment can be that it separates disabled people from the creativity, connectivity, material resources and motivation of their own relational networks as-well-as the array of "mainstream" or community agencies that might otherwise have contributed to a more collective (or "braided") response to informant's aspiration to work.

In line with the *Enabling Good Lives* principle "Mainstream First", current Vocational contracts express an expectation that providers will work towards disabled peoples increased use of generic community services. Disability Providers are also expected to play a role in building "*inclusive and welcoming mainstream services*" (Ministry of Social Development, 2016). Within the employment space, however, disabled people are typically steered towards specialist placement services or agencies that hold Supported Employment contracts. Redirecting support in ways that partner and build capacity within "mainstream" recruitment services and/or the range of business support organisations present within a community has a number of potential advantages for disabled people. At a pragmatic level, working with other agencies exposes disabled people to wider pool of job vacancies and a more expansive network of potential employers. Perhaps more importantly, however, it provides disabled people with an opportunity to exercise greater control over the narrative of employment, including promoting the benefits of hiring disabled people rather than framing employment as an act of social responsibility. As is discussed in more detail in the Literature Review, working with employers, business support organisations and/or mainstream recruitment services also provides disabled people with access to the vocabularies of business, including more authentic advocacy for the economic advantages of workforce diversity also including disabled people.

For the small number of informants who had previously worked in a professional occupation, the issue of representation was critical. They told us that buried within the interactions they had with employers were cues and vocabularies that signposted skills easily missed by those unfamiliar with their vocation. Both informants who had worked in a professional occupation previously assumed personal responsibility for future employment, both as a way of communicating competence and, for one person, to remove any ambiguity that employment represented *"a charitable act."*

*Respondent: Really the knowledge of my support person. They really aren't that knowledgeable and experienced in my area. My goal would probably be just to get some current experience, so to look for a contract position and then just take it from there.*

*Interviewer: And so is that why you see finding employment as your responsibility? You know, you described them as "inexperienced."*

*Respondent: Well not to be rude but they don't have a lot of experience. I have already done a lot of contract work. I have been thrown in the deep end in a lot of different environments. I also have a double major in law and political science ... It's really a matter of credibility in many ways. That when you get in front of an employer you can say well I have done this and this and they are able to say I see you have done that and that and that and they can tell through the conversation we have ourselves that I know what I am doing, I have good knowledge and I can step into this job and get up to speed quite quickly.*

Perhaps as a consequence, the kinds of employment informants reported receiving assistance to achieve tended to be within a narrow range of less skilled occupations. A number of informants we spoke to expressed reservations about declaring larger visions they held for themselves or of bigger visions being acted upon.

*Respondent: I think now I looked separately and she looked separately. And she sent me maybe 3 or 4 links to work over the time and I did lots of applying for jobs. I mean I would have been encouraged but by just talking each time. There was always kind of tea packing jobs I guess and then was also other jobs like more serious jobs that I might be doing like quantity surveying or something but no one ever helped me with that.*

## Staircase or cul-de-sac?

The other form of steerage informants spoke of was towards voluntary employment. A number of people spoke of being encouraged to contemplate volunteer work as a more viable employment option and as a way of acquiring the kind of skills and "work" history that might, in time, assist their search for paid employment. So pervasive was volunteering as a first response to unemployment, that some informants described the *"purpose of vocational support (as being) to help you go and do voluntary work or something like that."* Others had the sense that it was a more formally articulated element of vocational support practice.

*Respondent: Well they have a policy about trying to get people volunteer jobs first. For me that is not what I wanted. I wanted somewhere to earn money because well if I was going to get transport out and have to pay part of that transport then I needed income to cover that.*

Three out of every five people who responded to the National Online Survey said they currently engaged in some form of voluntary work (61%), two times the rate of volunteering Statistics New Zealand (2016) reported for the New Zealand general population (Milner et al, 2016).

Most informants described valuing voluntary work for the same reasons that non-disabled people do. For example, Statistics New Zealanders (2016) reported that New Zealanders who undertook voluntary work experienced significantly higher levels of life satisfaction, a finding that accords with international research that has found volunteering to be associated with improved mental and physical health, life satisfaction and levels of social engagement (Balandin et al, 2006). Balandin et al (2006), also found a desire to help others or to make a difference typically motivated volunteering and the same motivation found expression in the narrative we heard from informants.

*Respondent: I have done volunteer work at the SPCA shop. Which is like a second-hand shop. So other people who didn't have disabilities were doing volunteer work there as well which is good because it is was all volunteer. But if it is a paid job, why should people go in there and volunteer when they could get paid for it? I found it good because I was helping other people and not just myself. And I felt like I could do something that mattered.*

For this informant, the fact that her work at the SPCA shop was voluntary made this form of contributing within her community both more accessible and also changed the nature of being in place in ways that made it was experienced as more inclusive. In speaking about their voluntary work, almost all informants mentioned volunteering represent one of the few contexts in which they were able to meet, engage and enjoy being with others from a position of relative social equity. *"It is good,"* one informant said of her voluntary work *"because disabled and non-disabled volunteers all give a hand. Everyone can do what they can do to help."* Informants suggested co-volunteers were more likely to recognize and celebrate a shared motivation to make a contribution their community whilst the less hierarchical nature of the work equalized relationships of place. *"I am,"* we were told, *"no different from anyone else there because everyone is there for the same reason."*

Unlike the general population, volunteering interrupted days that many informants described as otherwise purposeless. *"Before (volunteering),"* one informant told us, *"I didn't really have much to do. I was just sitting at home twiddling my thumbs."* Moreover, the sense that

voluntary work provided informants with an opportunity to transparently and unequivocally add value to their community appeared to have additional resonance to most people we spoke to. Their common desire to *"help other people and not just myself,"* emerges as a motif within all of the research commissioned by CCS Disability Action that has captured the narrative of people accessing vocational support (Milner & Bray, 2004; Milner & Mirfin-Veitch, 2014). Milner & Bray (2004) speculated that for some people, the imperative to add value to other's lives had additional significance because of the way it helped to undermine the social construction of disabled people as less productive or more dependent members of society. In this respect, volunteering represented one possible way of destabilizing that social construction, as well as providing people with a degree of access to the enhanced sense of subjective wellbeing, self-esteem (Griffin et al, 1996; Jolly, 2000) and psychological wellbeing (Jaranek & Kirby, 1990; Petrovsky & Gleeson, 1997) known to be associated with employment but denied by informants "workless" or otherwise subjectively experienced *"wasted lives."*

- Interviewer: I'm getting a sense that volunteering and contributing to the community is kind of important to you*
- Respondent: Yeah it is.*
- Interviewer: Right. Are there other things that you do?*
- Respondent: Um I'm on the ABC, and the blind association committee.*
- Interviewer: And what's so important about your volunteering?*
- Respondent: Well um, I think it's a life wasted if you don't do something with it.*

Unfortunately, however, informants tended to occupy more marginal positions within volunteer culture. More than half of the people who completed the National Online Survey and who volunteered, did so for less than 5 hours a week (53%) and 85% of respondents who volunteered gifted their labour for less than 15 hours a week (Milner et al, 2016).

The other commonly reported problem was that volunteering appeared to many informants to be a "placement" in its own right. Rather than stair-casing" people towards employment, volunteering appeared to represent something of a vocational cul-de-sac for most informants. Of all of the variables we tested, the only predictor to explain variation in the likelihood respondents would be in paid employment was whether they volunteered. The odds that someone who volunteered would have paid work were eleven times lower than survey respondents who did not volunteer (Milner et al, 2016). One possible explanation is that seeing voluntary work as an outcome decreased the obligation staff felt to continue to find paid employment for people for whom unpaid work was considered a more viable option.

- Interviewer: Has anybody helped you look for work?*
- Respondent: Just the voluntary the volunteer centre. That's all I have had help me*

*Interviewer: Right so they have helped you get the voluntary job?*

*Respondent: Yeah*

The net effect for many was that volunteering took them away from rather than towards their 'true' but often unspoken vocational aspirations. For some, therefore, this meant having to reconcile a life trajectory they felt "undersold" their personal repertoire of skills whilst also communicating a wider undervaluing of the social capital of disabled people as employees.

*Interviewer: And so how much of your week is taken up by the community gardening?*

*Respondent: Four days out of five.*

*Interviewer: Well that sounds quite a commitment. Are there things that you enjoy about it?*

*Respondent: Well, I enjoy working with the people in the garden.*

*Interviewer: Hmm. Very good. But gardening wouldn't be your career of choice would it? You were telling me before about your photography and your CAD design.*

*Respondent: Yeah. But they are getting me nowhere at the moment.*

*Interviewer: Where would you like them to get you to?*

*Respondent: Some job where I can actually incorporate them.*

## Advancing the social capital of embodied difference

Historically, we have tended to frame the unequal access that disabled people have to employment as an issue of social (in)justice. As a consequence, the act of employment for disabled people has also tended to be packaged as an act of social responsibility, unwittingly contributing to an understanding of disabled minds and bodies as lacking capacity relative to their non-disabled peers or of failing in some way to fit the demands the labour market. For other formally marginalized populations, empirical evidence demonstrating the business advantages of greater workforce diversity have steadily undermined their exclusion from the worlds of work. Few would now contest, for example, that including women or employees of diverse ethnic, age or gender identity has made an important contribution to transforming workplace culture(s). Greater workforce diversity also enhances business profitability and can improve the efficacy or reach of goods and services. Whilst similar research has documented the business advantages of including disabled people in the workforce, (described in more detail in the Literature Review) no traction has been made in increasing the presence of disabled people within New Zealand workspaces (Statistics New Zealand 2016). Similarly, whilst a few early innovators, like Microsoft and Starbucks now actively recruit and support the evolution of a more inclusive workplace, the argument that hiring disabled people constitutes an act of informed business self-interest is yet to find expression within the narrative(s) of vocational support.

Rather than seeing the role of vocational support as assisting businesses to access the known benefits of employing disabled people (demand side support), informants tended to imagine support as either promoting their personal interests or improving their employability within a labour market that was extremely difficult for disabled people to gain a foothold within (supply side support). This construction of support can be seen as reinforcing an understanding of bodily difference as being a barrier to employment rather than an advantage to potential employers.

Threaded through the interviews was a quieter conversation about the unique and yet latent attributes informants offered their community because they had led experientially different lives. People whose visual impairment, for example, meant they were bilingual and had at other moments in their life assisted others to know the world or make themselves known through touch but who now sat at home. Architects with an embodied understanding of issues of accessibility and how to construct spatially inclusive environments but who cleaned toilets or volunteered in a community garden. Informants with nimble and creative fingers or who were musical and whose talents or interests could have been used to generate an income that had never contemplated self-employment. Or an informant whose physical impairment meant that she looked directly into the eyes of those children for whom she suspected she brought a different kind of energy and empathy and a story of inclusion bourn of a common need to be continually creative.

*Interviewer: What you do think you add to the classroom? Why do they like you there?*

*Respondent: I don't know. I think it is more the positive. I am positive and I try to be positive in everything I do.*

*Interviewer: Do you think it is good for a disabled person to be in the classroom, someone like yourself?*

*Respondent: Yes. I think my disability makes it is easier for me to relate to the children. I don't know.*

Typically, however, the master narrative for informants was one that had led them to conclude that it was their bodies and/or minds that separated them from employment. Moreover, the sense of needing to better fit a labour market that similarly failed to recognize the advantages of bodily diversity appeared to erode confidence and promote a negative sense of self as a prospective employee for most informants "*I can quite easily talk about my many flaws, but not really what I am good at easily,*" we were told by one informant, introducing himself to the project.

As noted previously, some informants did worry about the way they were being represented to potential employers and there was a general feeling that support to market disabled people's skills or to generate employment often lacked energy or creativity. In the National

Online Survey one respondent fed back that *"it would be nice to have a person who believes in what I am good at, helps, me get out there and 'sell' my skills and to be creative and innovative."* Their observation found similar expression in many of the interviews we conducted too, including by informants who described wanting *"the kind of people who can think outside the box or a bit bigger"* or *to know more about AS (Autistic Spectrum) including what we are good at* or *"to train (staff) to be creative."*

Although not included within the interview framework, we heard little evidence that the support informants described approximated the more innovative vocational practices outlined in more detail in the Literature Review, including:

- "Demand side" initiatives like job carving, sharing or shadowing,
- Braided or person-centred support that made use of community or a person's informal networks,
- Peer support,
- Community development approaches,
- Use of mainstream recruitment agencies, recruitment fairs or other marketing strategies,
- Adoption of information sharing technologies like portals to connect employers with disabled job seekers and disabled people with best-practice,
- Or micro-enterprises and other forms of self-employment.

## The impact of setting a "sustainable" employment threshold

The other impediment to achieving "sustainable" employment that emerged from informant narrative was an almost universal fear of the consequences and uncertainties of benefit abatement we were told followed working more than 15 hours a week. Whilst all informants wanted paid employment, more than half of the people we spoke to preferred to work less than the Ministry of Social Developments incentivized employment threshold. For some, the preference was economically rational, they argued, given that working for more than 15 hours was perceived as the same as volunteering their labour. *"If I earn say 16 or 17 hours a week,"* we were told, *"well basically every dollar I earn they take off me."* For others, however, part-time employment responded to the embodied realities of impairment, including tiredness and discomfort or other health related considerations.

*Respondent: I think at the moment that with my physical health and mental health that working these times is just enough at the moment. Because I get*

*fatigue really easily so if I worked anymore ..... I don't want to exhaust myself and not physically feel up to walking.*

Fearfulness, not just of becoming unwell, but of what might follow episodic periods of ill-health, also underscored the preference some informants had for both part-time employment and the greater accommodations volunteering was perceived to offer.

*Interviewer: So why haven't you said (you wanted fulltime employment) to anyone?*  
*Respondent: Because I am scared to do it. I am nervous that I might lose a job and I won't have any job and yeah. It's just a nervous confidence thing. And I worry about getting sick again*  
*Interviewer: So is the way that you are thinking is that it is better to hold on to your part-time job than risk it by trying something different?*  
*Respondent: Yes*

Concerns about maintaining good health and the way that benefit abatement might play out in people's lives are likely have contributed to findings reported for the National Online Survey too Forty-two percent of survey respondents preferred to work for less than the 15 hour threshold defined by the Ministry of Social Development as representing "sustainable" employment and more than half of the respondents who did want to work preferred to do so for between 10-25 hours (56%) rather than fulltime employment (Milner et al, 2016).

The other reason respondents mentioned for not seeking full-time employment was to preserve alternative forms of participation and/or ways of expressing themselves creatively. Even informants who worked or volunteered for less than ten hours spoke of the need for some "*work – life balance*" or that they "*had more important things to do than work.*"

Informant's sense that there were "*more important things to do than work*" appeared to represent an amalgam of different life experiences. On the one hand, some informants were responding to the kind of work that people thought was valid and in particular, forms of underemployment described previously in this report and elsewhere in published research. Consistent with the narrative of the disabled employees that Hall (2004) spoke to in Scotland, a number of informants also described themselves as being on the fringes of workplace culture, with their marginality experienced through subtle forms of bodily and social exclusion, including being absent from ordinary workplace practices, processes and expectations. Like the work stories of the people who spoke to Hall (2004, 2005), informants also described the normality of various forms of discrimination and exclusion and how alternative ways of being and becoming productively engaged within their community were sought out as ways of ameliorating some of the more harmful employment experiences.

*Respondent: I think that community is more important (than work) actually to an extent. I mean you can be lonely and sort of feeling like you have no one to talk to and that is not being fulfilled in a work place situation.*

A number of informants also spoke of the negative impact that failing to accommodate for bodily difference had in employment settings, not just in terms of accessing employment but of feeling of being “in place,” and of being valued by or “belonging” within a wider community of employees.

*Interviewer: Yeah. Well the other thing is (that community groups that “other” disabled people) may unwittingly shut out somebody who is really community minded, and could really help them think broadly about how to include all people.*

*Respondent: Yeah I think that’s sad*

*Interviewer: Do you think you could use the same argument for employment? That businesses would be better off with disabled people?*

*Respondent: Um, if you want an all round. If we did it right, it would work. Um, if people got the right equipment through their life and actually learnt what the piece of equipment does, instead of actually having to find a job then find the equipment. Doing it the other way around is too hard. I tried to do a course and had to give up because of equipment. It’s the same with work.*

## A road-map to help businesses to access the benefits of greater workforce diversity

In 2012, the New Zealand Convention Coalition wrote in their report to the UN, that the work experiences of many disabled people in employment could be qualitatively different from the non-disabled employees they worked alongside. They coined the phrase “*occupational segregation*,” (Convention Coalition, 2012; p.52) to describe the experiences of people who “failed to fit” the customs and conventions of workplaces designed for non-disabled bodies.

In 2004, disabled people who accessed vocational support also contested more simplistic readings of inclusion by asserting that “*it wasn’t so much where people were that counted, but how people were in place that mattered*,” in their research collaboration with the Donald Beasley Institute (Milner & Bray, 2004).

In recent years, businesses have begun to catch up with their theorizing, as issues of “inclusion” have become a dominant theme within the management and organizational psychology literature (Shore et al, 2011; Nishii & Mayer, 2009; Leung et al, 2008; Bilimoria, Joy & Liang, 2008; Roberson, 2006). The reason for the interest is because it has become increasingly clear that the advantages of greater workforce diversity, including increased

profitability, are only accessible to employers who develop *inclusive* workplace practices (Chrabot-Mason & Thomas, 2002). Whereas disability writers have tended to emphasize the transformative effect of employment on disabled employees, the business community has approached the issue of inclusion from the opposite direction, emphasizing instead the transformative effect (for business organisations) of including culturally distinctive employees within the social and organizational fabric of their workplace (Milner & Paris; 2013).

Fortunately for business, the disabled people who spoke to Milner & Bray (2004) provided a road-map, detailing the qualitative attributes of relationship that disabled people identified as more appropriate markers of inclusion than vocational "placement" or "mere presence," (see Table 2 p.58 )

No evidence was detected in the conversations we had with informants, however, that consideration of the way that people were relationally present in employment was considered by vocational support staff as a way of monitoring whether informants were experiencing forms of "*occupational segregation*," or alternatively, to support employers to access the known benefits of including disabled employees within their workforce.

## (Further) marginalising disabled people with the most to gain from paid employment

It is important to conclude, however, by reiterating that discovering the road-map is a matter of some urgency to disabled people. Consistent with the research literature, finding paid employment was a near universal aspiration amongst the people we spoke to. Eighty percent of people who responded to the National Online Survey reported the same aspiration (80%) with sources of variation most likely accounted for by the degree to which people had acculturated to "workless" lives and/or the belief that employment remained an unlikely option for them.

It is similarly important to note that in addition to 72% of National Online Survey respondents not being in paid employment (despite wanting to work), only 8% were employed for more than the 15-hour threshold defined by the Ministry of Social Development as representing sustainable employment. This finding might be read as evidence of the pervasive underperformance of vocational service provision and an argument for moving towards an "Outcomes Based (Vocational) Framework that incentivizes lifting the number of disabled people employed for more than 15 hours as a driver of the proposed vocational reform.

The seemingly intractable un(der)employment of disabled people might equally be read as evidence of forms of discrimination and exclusion that have always been present within the spaces and places of the economic and social (non-disabled) majority that disabled people and their allies are working hard to dismantle.

In feedback provided by service providers to the Ministry of Social Development, most providers identified the way the proposed changes draft disabled people towards three mutually exclusive outcome streams represented a clear transgression of the right to employment for those most likely to be discriminated against (CCS Disability Action, 2015; Wellington After-Care Association Inc, 2015; Blind Citizens NZ; IHC, 2015; Inclusive NZ, 2015). Using the "Outcome Setting Decision Support Tool" to draft people less likely to *"get part-time or full-time sustainable employment in an agreed time"* (Ministry of Social Development, 2015; p8.) and incentivizing 15 hours paid employment by funding in a way that makes supporting people to access fewer hours employment more costly to providers, is likely to further marginalize people with less typical bodies and minds from this central domain of participatory citizenship.

Paradoxically, however, many of the people who experienced the greatest lift in life quality were those who had succeeded in finding their way to very part-time employment. For these informants, the seemingly small increase in their discretionary income that came with part-time work had a significant and liberating impact on; their ability to make discretionary life choices, eat a little better, attend to bills they previously had no idea how to pay, go to town or to travel to places they couldn't ordinarily afford to get to or to address many of the other marginalities associated with material poverty. People's work and workplaces were typically a source of great pride, interrupting previous feelings of living *"wasted lives,"* or of not contributing to their community in ways that others ordinarily did. For those hemmed into the cardinal spaces of home or who said they had lived lives largely disconnected from people and the intimacies of relationship, even very part-time employment opened new social worlds and offered a new way to enter relationships within the more valued social roles of colleague, co-worker or staff.

Applying the Outcomes Framework in a way that triages people with the most to gain from employment beyond the assistance of vocational support contravenes the right of all disabled people *"to the same opportunities to gain freely chosen and accepted employment,"* codified in Article 27 of the UN Convention on the Rights of Persons with Disability. It is similarly at odds with the Social Policy from which the proposed changes are purportedly derived, given *Pathways to Inclusion's* unequivocal acknowledgement that disabled people *"want to determine their own futures,"* (p.9) and *"want greater access to employment assistance*

*regardless of the level of support they would require or the number of hours they could work” (p.9) (Ministry of Social Development, 2001). And finally, the proposed changes also represent a transgression of the relanguaging of disability rights and emerging business best-practice that have, albeit from opposite directions, both come to recognize that finding a place for greater “diversity” and “belonging” represents the most effective way of transforming the institutions of a civil society.*

*Interviewer: Can I take you back to your work? What is good about your teacher aiding? Like do you like your job?*

*Respondent: Yes I love the children. I love the children and that is the main point I stay because I love the children. They mean the world to me*

*Interviewer: Right and I guess you have got an important role you know because you like them, you are also helping them in a way too isn't it. You are adding value to their lives yeah?*

*Respondent: Yeah that's what I like about my job*

## FINDING PLACES OF RELATIONAL BELONGING

Relationship and life quality

As mentioned previously in the section reporting on relational poverty (p17), when writing about the centrality of human relationships to life quality, Cummins and Lau (2004) argued that, *"community connectedness through relationship represents the very heartland of life quality."* The preeminence of interpersonal relationship as a predictor of subjective wellbeing has been repeatedly demonstrated in research drawn from within the Quality of Life paradigm, including for disabled people in the New Zealand context (Conder et al, 2009). *"What is the most important thing?"* the National Advisory Committee on Health and Disability (2003) asked in the whakatauki that opened *"To have an 'ordinary life.' 'He tangata. He tangata. He tangata."* (It is people. It is people. It is people), they answered (NAC, 2003).

Included as an element within a project that sought to assist New Zealanders with a learning disability to develop and administer a quality of life instrument that responded to the areas of life they identified as contributing to life quality, Conder et al (2009) asked people, "what made life great?" The question generated 544 individual statements, 41% of which disabled co-researchers assigned to two core domains. Consistent with Cummins & Lau's (2004) assertion, people responded in ways that suggested "Friendships and relationships" and "Participating in my community" were situated at the very heartland of their life quality too.

Conder et al (2009) noted that the result was not surprising, given that disabled people have been telling us of the importance of feeling a sense of connection and of contributing to their community through reciprocally valued relationship for more than a decade and those who responded to the National Online Survey or who contributed interviews reminded us again through their participation in the *"Getting the life I want"* project.

Within the National Online Survey, respondents were asked to rate the personal importance of participation in six key life domains. Staying in contact with friends and family (average rating= 81%) and belonging to a community group (average rating= 62%) rated the highest and third highest domains respectively (Milner et al 2016). We also asked people how much time informants felt they spent with family, friends and neighbours and almost half of the survey respondents said they wanted more contact with friends (48%).

During the interviews, we were struck by many people's sense of feeling isolated from their community and how, in particular, sometimes lonely days severed a number of informants from the interpersonal intimacies and ordinariness of friendship. Finding a friend featured prominently in survey respondent's goal setting and in their narrative, with informants often looking to a more active involvement with their community as a way of addressing their sense of social dislocation.

*Interviewer: How important is it to be involved in community groups?*

*Respondent: Quite important.*

*Interviewer: And what is it about being involved in the community that makes it important to you?*

*Respondent: I think that sense of not being alone. Sort of having some like-minded people to associate with.*

For a small number of informants, the internet represented their primary means of contact. Of concern, however, was that three of the four informants who appeared to rely the most on electronic media said that not being able to afford to buy or repair the technology they needed, disconnected them from world(s) beyond their home. As noted earlier, for one informant whose visual impairment meant that she couldn't leave her flat unsupported, this lack of technology was particularly isolating.

## Patterns of participation

The impression that informants had few friends or other relationships of place is consistent with findings reported in two previous research projects commissioned by CCS Disability Action. In the Community Participation (Milner & Bray, 2004) and in the "*I am Here*" Article 19 (Milner & Mirfin-Veitch, 2013) projects, disabled people typically described having very small friendship fields, dominated by family and/or their support staff. The lack of relationships drawn from other life domains tended to reflect participant absence from the kinds of social contexts within which non-disabled people ordinarily forge friendships and experience a sense of participatory citizenship. These included participant's marginalization from the worlds of work, parenting, ongoing education, neighbouring and membership of recreational or interest groups, clubs or associations.

Seven out of every ten people who responded to the National Online Survey said they belonged to one or more different types of community groups (70%) (Milner et al, 2016). This rate of group membership was slightly higher than that reported for the New Zealand general population (64%) (Statistics New Zealand, 2016). Moreover, respondents who did belong to one of more community group, club or organization were less likely to say they didn't spend enough time with their friends, suggesting that group membership had, for some, become a location for reinforcing emergent friendship (Milner et al, 2016).

Two attributes of respondent's community group participation did differ from the general population.

In the section on relational poverty we also described how the patterns of disabled and non-disabled group membership were dissimilar. Compared to other New Zealanders, respondents were much more likely to belong to a church or spiritual group or to a voluntary

association and conversely less likely to belong to a sports club, interest group or to a professional association or trade union. Respondents were also much more likely to say they belonged to an "other" community group that almost invariably meant forms of association that allowed respondents to access the fellowship, collective agency, shared histories and support of other disabled people.

The other, implied, difference appeared to be in the way that respondents experienced their membership. We learnt too that whereas within the general population only 10% of respondents expressed wanting more contact, respondents were between 4 – 8 times more likely to report not having enough contact with a range of different community groups or organisations. More significantly, the community groups that respondent's felt most estranged from were those that they were both less likely to participate in and that non-disabled New Zealanders ordinarily develop friendships and experience a sense of community contribution. Eight out of every ten respondents said they didn't have enough contact with a hobby club or interest group (82%), and six out of every ten respondents said they wanted more contact with neighbourhood or community groups (60%) (Milner et al, 2016)

## Disability as a community in its own right

One explanation for disabled people's marginality from and/or within community group culture offered by informants was that community groups were not always welcoming places for disabled people to be. A number of respondents spoke of feeling "out of place" within outwardly inclusive settings like interest groups or other community groups or organization as a consequence of subtle and sometimes unconscious forms of othering that they were met by.

*Interviewer: Do you belong to other groups or organisations?*

*Respondent: Um, nope.*

*Interviewer: Is that a choice, or you know like, do you*

*Respondent: No it's not a choice. I've often been um told, oh no you can come to our group but you'll have to bring a carer*

*Interviewer: God what would you need your carer for?*

*Respondent: Ah, not much (laughs). Then you end up stuck in the corner talking to them, and you don't end up talking to the people you're supposed to be talking to.*

For some informants, disabled people's exclusion from ordinary spaces of relationship and participation like community groups, represented a new frontier of activism and education. Their vision, was that transforming participatory contexts into more inclusive spaces allowed community groups to access the divergent skills and experiences of all citizens.

*Interviewer: Do you think there is a role for vocational services to educate community groups? About impairments or to help make community groups more inclusive? Or do you see that as your role?*

*Respondent: Um I think there's a role for somebody to do it. I think there's a role from the top of CCS to actually help communities realise that actually, you know, your community group is better off with members that are disabled and not disabled.*

Informants also appeared to suggest that they were less likely to have to contend with the social otherings they sometimes experienced, when the culture of community contexts had been shaped by the presence disabled people, perhaps explaining the high levels of membership of community groups that advocated for and/or celebrated disabled lives.

Analysis of the feedback provided by people who responded to the National Online Survey revealed a clear preference by many to address a sense of isolation by doing things with other people, rather than being continually chaperoned into "mainstream" social spaces as a visitor or outsider. Informants expressed similar sentiments in their interviews too.

*Respondent: So for me socially just mixing with people is hard. So I don't know (if I was CSS Disability Action) CEO I would probably get a lot more going on like a lot more contact and get the clients more involved. More client contact with each other and more things going on that we could sort of chew over, to do together or to look out for employment*

For this informant, doing things (together) with other disabled people appeared to represent a way that he might access the possibilities of peer support as an adjunct to the benefits (and limitations) of individualized service delivery. His observation is consistent with recent research that is describing the outcomes that follow disabled people defining and responding to their own aspirations as a collective. In the *Community Participation* and *"I am Here; Article 19"* Projects commissioned by CCS Disability Action, we learnt that many disabled people lamented the way that recent shifts in support policy and practice have severed them from the fellowship, shared histories and culturally distinctive support and activism of their disabled friends. We learnt too that it is often easier to contest the disabling social scripts or otherings disabled people sometimes encounter in "mainstream" (able-bodied) community spaces from within the protective korowai (cloak) of peer support. Moreover, having contexts in which bodily difference disappeared as a form of social knowing and/or that support needs were anticipated and unremarkable could also contribute to the respite and insider status experienced within places of "belonging."

## A road-map to help all communities access the benefits of human diversity

Consistent with the vision of the informant above who wanted "*a lot more client contact and a (to) get the clients more involved,*" disability writers are beginning to describe some community contexts co-authored by disabled people as liminal ("in-between") spaces (Hall, 2013) or "moorings" (Milner & Luskie, 2016) within which disabled people can access the qualitative attributes of relationship they articulate as underscoring a sense of membership or belonging (see Table 2) and from which they can push out from and return to as part of the ongoing process of community and experience building.

**Table 2 Five relational indicators of belonging identified by disabled people [Source: Milner & Bray, 2004]**

## Inverting the arrow of inclusion

Some informants took the theorizing a step further, by seeing spaces authored by disabled people, as spaces of invitation. Within their world-view, disabled spaces might also be a community resource that had the potential to transform non-disabled as well as disabled

| Relational markers of inclusion (or belonging) |                                                                                                                                |
|------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------|
| Autobiographic                                 | Speaks to how self a person understands and identifies (them)self                                                              |
| Social Identity                                | Being present contributes to a communities understanding of itself and a person is represented in its social history as member |
| Reciprocity                                    | A person is connected to others through sympathetic acts of culturally specific reciprocity                                    |
| Psychological safety                           | A person participates in the conventions of place and experience an "insiders" sense of respite & safety                       |
| Expectation                                    | A person is expected to contribute to the wellbeing of other members including being "productive" in collectively defined ways |

lives.

*Respondent: I would change it so that it wasn't it wasn't just for people with that no. I would change it so that when like when there are like 6 or 7 people meeting up I would change it so it is not just disabilities meeting up. Like I would make it like open somewhere so that other people can join as well. So it is not just for disabilities.*

Included within the National Online Survey were ten alternative support ways of providing vocational support the research team was aware of, both through research they had conducted previously and the literature review conducted in first phase of this project. Five of the models outlined in the survey responded to the social marginalization of disabled people. In the survey, we invited respondents to rate the personal usefulness of each of the

different ways of providing support and the interviews provided an opportunity for the research team to ask people what they liked or didn't like about the models they preferred.

The two most highly rated models that responded to the social marginalization disabled people describe were titled *"Inviting the community in"* (average rating= 52) and *"A community development approach to social (ex)inclusion."* (average rating= 51). (See Appendix 4 & 5). Common to both models were that they involved disabled and non-disabled people collaborating to accomplish things together and a clear intention to change non-disabled people's understanding of the social capital of impairment.

For example, "Inviting people in" involved supporting disabled people to create participatory contexts that inverted the normal arrow of inclusion by inviting non-disabled people into spaces where disabled people felt known, validated and had greater cultural knowledge or social capital. Examples given in the survey included: inclusive dance, theatre, cabaret, writing, and other creative modalities that fall within the compass of the Disability Arts Movement, accessible bike building, maintenance and hiring collectives, computer literacy or Alternative and Augmentative Communication, Easy Read or New Zealand sign language classes run by disabled people.

Proponents of inclusive spaces authored by disabled people advance a range of advantages including; exposing non-disabled citizens to the experiences, energy and creativity of disabled people, as well as new ways of thinking and seeing the world. *"Inviting (non-disabled) people in(to)"* disabled spaces changes power relationships in a way that can undermine the social script that disabled people are "less productive" community members.

Informants who rated the personal importance of *"Inviting the community in,"* and *"A community development approach to social (ex)inclusion"* highly, emphasized similar attributes as underscoring their liking for these alternative support models. Preeminent in the minds of informants was that they offered forms of participation that exposed others to skills and capacities that challenged the social construction of "disabled" meaning "less able." *"What people need to realize, we were told, is that people with disabilities can do things"* and that disabled and non-disabled working together reinforced the idea that *"(disabled people) benefit society instead of society looking at them like they are a burden – which they are not."*

At the centre of informants thinking appeared to be the idea that, if properly constructed, disability support might offer a working model of inclusive community, including demonstrating the relational attributes that would allow all members to make a contribution. The *"whole CCS thing is quite open and welcoming of all types of (dis)ability,"* one informant noted, leaving sufficient space for new ways of imagining "competence," to emerge. For

example, most informants appeared to value the collective or collegial attributes of these alternative support models, because doing things together allowed them to access the "distributive competencies" or "collective capacity" of disabled (and non-disabled) people alike. *"I like the idea of collective work,"* one informant said, *"because I don't think I can work.... I don't think people can do it (by themselves)."*

*Respondent: I am (a volunteer) with the Blind Foundation and I am actually involved I should tell you, in a fortnightly Christian fellowship for the disabled. And lots of the people there volunteer. Like there are a few nondisabled volunteers and the disabled people give a hand and it is a good time because everyone can do what they can do to help.*

After listening to the disabled people who collaborated with them in the Community Participation Project, Milner & Kelly (2009) concluded that one consequences of the dismantling of vocational day-bases and the parallel shift towards individualized support was to dislocate people from the relationships and common community of other disabled people. They argued that, although depopulating day-bases represented an appropriate response to the discriminatory social segregation and power relationships embedded in that form of institutionalized support, this change in service values tended to elevate the importance of spatial (where people were) rather than relational (how people were in place) indicators of inclusion. Within the new set of service values, disabled people doing things together also tended to be seen as socially atypical and consistent with the prioritising of space related markers of inclusion, evidence of the continuation of support practices that corralled disabled people into the "special" and "segregated" social spaces that had been their historical experience.

Similar concerns were expressed by informants we spoke to in the *"Getting the life I want"* project as, although most people we spoke to tended to feel that community groups led by disabled people represented an equivalently valid path towards a more inclusive society, others worried that models that inverted the arrow of inclusion may emphasize difference rather than common community.

*Respondent: I think all the services that you have told me so far are good. I think in terms of this one (Inviting the community in) I wouldn't invite you know able-bodied people into the disabled people community they should just all be one. I think at the moment you have got disabled people and then you have got what is called abled bodied people and I think if you could bring the two together and say we are one community*

The people who spoke to Milner & Kelly (2009) more than a decade before were unequivocal in asserting that they did not want to become ghettoized within "disability spaces," too, but they also appeared to take an alternative view that what mattered was

whether or not people had access to the attributes of belonging they described as important (Table 2) regardless of whether the people they shared communities of place with had an impairment or not. Within their world-view, sufficient space was created for all people to be together and for new and “unauthorized” imaginings of community to emerge.

## People experiencing attributes of belonging

In the “*Getting the life I want*” project, two informants did describe themselves as embedded within relationships that allowed them to experience a sense of fellowship and an expectation that they contribute to the wellbeing of other community members. For one informant, this included the intimacies and reciprocity of neighbouring, although it wasn't clear to the interviewer whether she was describing the fellowship and peer support of disabled and/or non-disabled friends.

*Respondent: I am in my own flat but I have got friends that live right next door to me so I am always at their house and then I can go home to my own house and have my own time or I can go next door and see my friends which is just awesome.*

*Interviewer: Do you know you would be one of the few people that I have spoken to that actually has relationships with their neighbours?*

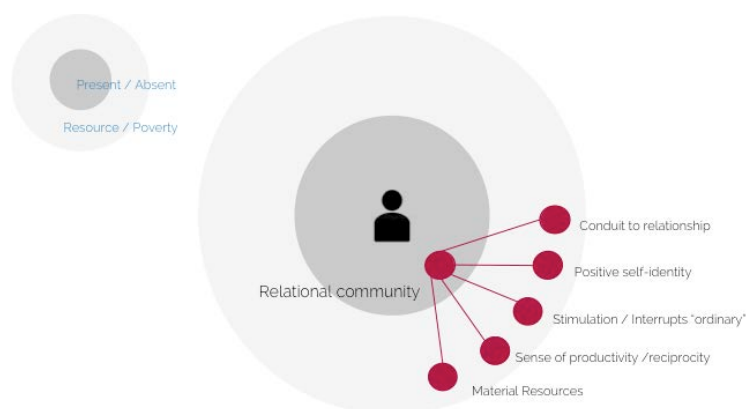
*Respondent: Yeah well one of the girls become my best friend and I met her through there and she became my best friend and then my other best friend moved into the neighbourhood after I moved in and that was quite awesome as well yeah so we have got a lot of community. Everyone looks after everyone else.*

Another informant also described a life in which he had a high level of involvement, both within his local and other communities of interest. Significantly perhaps, impairment had interrupted this informant's life trajectory and the support he described seeking was to rethink and reconfigure his life in ways that allowed him to get back to the levels of community engagement he had enjoyed prior to his illness.

*Respondent: I thought yeah if you are going to fill this out and go through this then you have to actually make it substantial you know? This is the real deal. I was talking to [Support person] I said well it is not about getting the mail or take a walk out of the house or going down to the local church for a cup of tea or something like that it has actually got to make this, set this in concrete so I can do it. Make this a foundation so I can actually build on this and yeah so and she was like oh sure. And what has transpired out of that is a few things one of them is that I am on the board of trustees for the school I have like I said enrolled in my studies (PhD doctorate) for next year so that's a positive.*

For this informant, the template for social inclusion had been established in his non-disabled life, including the “*real deal*” of participatory citizenship transcending mere presence at destinations like his mailbox or local church.

**Figure 6 The attributes of community participation informants identified as personally important**



Consistent with the relational attributes identified by disabled people as indicative of being somewhere you belonged, this informant's narrative emphasized the importance of doing things that he felt authentically spoke to who he was. The scope vocational support provided by CCS Disability Action gave to choose what they did in self-defining ways was mentioned by other informants as distinguishing it from the other kinds of support they received too.

*Interviewer:* And so what would you say the purpose of vocational support is?

*Respondent:* Um well I thought it was to like get me in touch with the community and get me outside more often doing things that most people my age might do.

*Interviewer:* And is it different from other kinds of supports that you receive?

*Respondent:* Um yes it is different because my other supports don't really do we don't do what I want to do. Like we do things that I have to do, but with CCS I can do things that I want to do.

Just as importantly, the informant above suggested that his sense of belonging was enhanced by adding value to the lives of others and by bringing him into closer relationship with others through a shared expectation that members respond to each other's lives. Other informants felt the same way.

*Interviewer:* Why is being involved in your community important?

*Respondent:* Because we are created as interpersonal beings. We are not supposed to be just living for ourselves. And it brings a more-well rounded perspective to life if we are giving and helping other people.

## Being in but not of a community

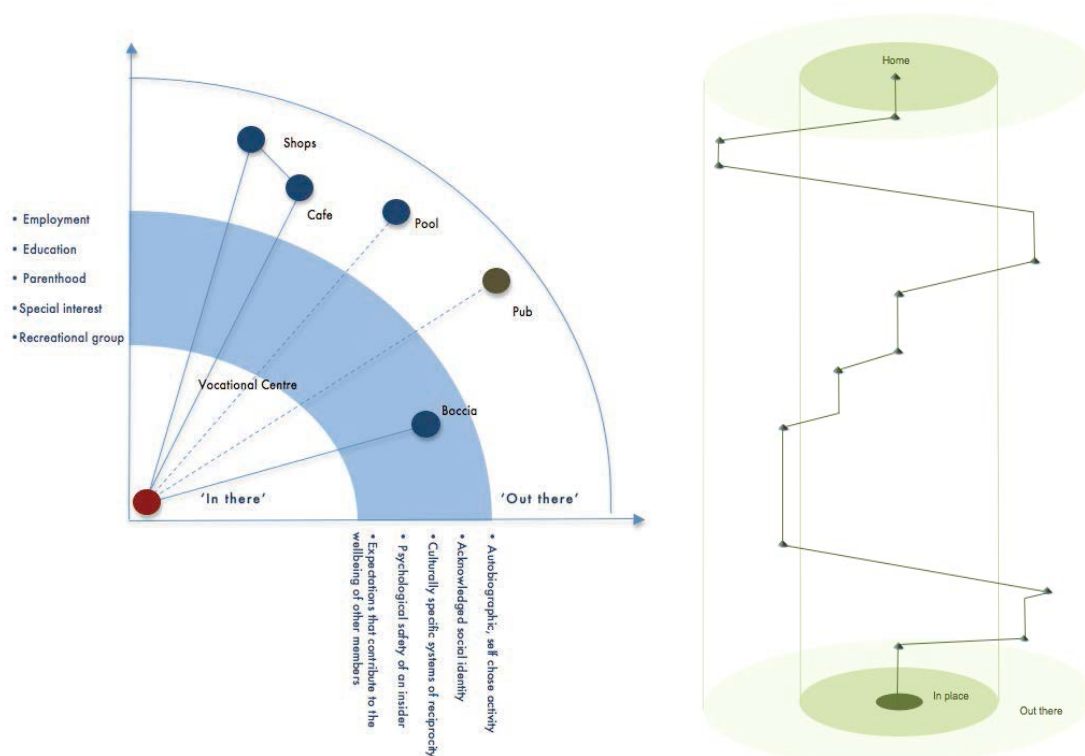
One of the more consistent themes to emerge from the *"I am here": Article 19 Project* commissioned by CCS Disability Action was that what disabled people and their families were looking for in their support was not to connect people to places but to connect people to people. (Milner & Mirfin-Veitch, 2014).

To Milner & Mirfin-Veitch (2014), an unintended consequence of prioritizing individualized support and/or spatial indicators of inclusion, was a, sometimes oppressive, inattentiveness to how people were experiencing forms of "community participation." In the stories of the people whose stories they helped to co-author, were examples of men and women taking bus or van-rides to no-where or who were, on occasions, forced to weather stares and social otherings they were met by in their weekly circumnavigations of public spaces like the library or post-office and the café or two-dollar shop.

Although findings from The *Article 19 Project* were used in an extensive awareness raising campaign, an opportunity exists for disabled New Zealand lead global service development by drawing on the research to develop tools and support practices that promote greater relational inclusion. Finding a way for marginalized populations to map the way they are relationally present (or absent) within their community by using the five markers of inclusion identified as communicating a sense of belonging will advance disabled people's ability to access their Article 19 Right to *"full inclusion and participation in the community"* (UN, 2016), in a number of ways, including:

- Allowing disabled people and disability providers to identify support practices that promote community membership and belonging, including enhancing the experience of belonging within peoples pre-existing communities of interest or place.
- Helping communities to identify relationally (ex)clusive community contexts and identify populations most at risk of marginalization,
- Providing a way to demonstrate the impact (in)accessible physical environments, transport or support has on disabled people's experiences of their physical and relational community.
- Providing a way of capturing disabled people's alternative imaginings of community participation
- Assisting disabled people to monitor and report on their rights protected in the UN Convention on the Rights of Persons with Disabilities.

### Figure 7 Mapping places of belonging



Perhaps the most important and immediate way developing and using a relational mapping tool could improve the life quality of people who access vocational support is, however, in the way that it provides an opportunity for people to remake support practices that fail to address disabled people's social marginalization by disabled people training and mentoring disability support staff.

Although a few informants were able to tell us about relationships they had that communicated to them a sense of being an active participant within their community, it was more typical for people to struggle to articulate a sense of belonging beyond their voluntary work placement and/or paid membership of disability organisations like the Blind Foundation or MS Society.

In the conversations we had with informants, people were able, however, to identify elements of their support they felt made it difficult for them to move from the outside to the inside of their community.

## Support practices that frustrate the aspiration to belong

In the report that followed the *"I am Here:" Article 19 Project*, Milner & Mirfin-Vietch (2014) described their disabled co-authors as *"living lives on the outer edges of the daily round of community life"* in public spaces like the supermarket or library, swimming pool or gym,

boccia hall, coffee shop or the mall. Most coauthors had few friends beyond their family or support staff and the kinds of activities that filled their days were conducted in places in which it was extremely difficult to seed new relationship or to experience a sense of belonging.

Milner and Mirfin-Veitch (2014) also noted that, despite the two projects that CCS Disability Action commissioned being separated by a decade that saw; the closure of vocational day-bases, widespread adoption of individualised and person-centred planning and New Zealand's ratification of UN Convention on the Rights of Persons with Disability, the "life-spaces" of those who contributed stories in 2012 looked disquieteningly similar to those described by participants in 2003.

Milner & Mirfin-Veitch (2012) argued one possible explanation for this finding was that, although the human rights discourse had changed the narrative of both public policy and disability service provision, little change had occurred in the social practices of day-to-day support intended to realise those rights.

In spite of an equivalently universal aspiration to become more connected to their community, all but one informant in the "*Getting the life I want*" project struggled to define the kinds of participatory experiences they hoped would forge those relational connections. It was not, it seemed, part of an ongoing dialogue that many people had with their support staff.

*Interviewer: In what ways do you think CCS Disability Action could help to get you more connected with your community?*

*Respondent: Wow I am not really sure to be honest.*

*Interviewer: Yeah so it sounds like at the moment they sort of take you out for coffee and swimming and that kind of thing.*

*Respondent: Yeah.*

*Interviewer: So were there any other ways that you could think of that would be useful?*

*Respondent: I can't think of any. Well they could give me some ideas*

A number of informants found it difficult to imagine alternative futures for themselves and in the absence of a larger vision were less likely to challenge support practices that reflected historical patterns of service delivery, including an entrenched understanding of the meaning of community participation for disabled people.

In the "*Getting the life I want*" project, for example, a number of informants described experiencing their community in the same programmatic way that people who used vocational support more than a decade before had also described.

*Respondent: What they are is they are going to do is get me out of the house, do art and craft, go to the library on Monday and they want me to go swimming on a Monday with one of the support people and then Tuesday I have shopping. Wednesday and Thursday I am meant to go for a walk down by the new walk way where they can stand and have photos down on this special seat and that's meant to be for only 1 hour for Wednesday and Thursday. Friday ..... I don't know what is going to happen on Saturday and Sunday.*

Echoing the findings of Milner & Bray (2004) and Milner & Mirfin-Veitch (2012), this informant's participatory experiences were restricted to public community spaces within which she was only ever a fleeting presence. Moreover, ghosting into and out of settings like the café or library or swimming pool meant that she was unlikely to seed relationships that might continue beyond these social spaces or engage in the kind of reciprocities likely to nurture latent friendship or invitation.

All informants understood "community participation" to be a public act requiring their migration away from private and more intimate social places towards spaces of encounter and anonymity, perhaps having assimilated service values that have historically emphasised (outside) place(s) as a more important vocational outcome,

*Respondent: No I don't have much fun my CCS coordinator wants me to go out with one of my pen friends to have a or have coffee with CCS people and meet new people ..... to get out of the house to meet new people but not meeting at a club or anything like that*

Receiving timetabled, or more programmatic support also meant that opportunities to act on ideas or to exploit moments of possible engagement that arose serendipitously were more likely to be lost. Some informants spoke of feeling they didn't have sufficient time with their support staff and of how scripted support outcomes mitigated against the kind of "wasted" or "purposeless" time they felt was necessary to say the things that were important for discovery and imagination to flourish.

*Respondent: Well they are sort of doing the best that they can for me by supporting me.... It might be harder for them to spent time with me*

*Interviewer: You just said it again. "Spend more time with me." You know like you don't have the time to say the things that are important?*

*Respondent: Yes. That's right. Some of them don't stay long enough to listen to me.*

Almost always without realising it, some informants described day-to-day lives that failed to reflect their (less articulated) interests or participation in activities where others were most likely to recognize a kindred passion.

*Respondent: I am good at talking. I like some dancing. Line dancing. I don't know what else. I used to do knitting like baby hug me tight like a jacket sort of thing. What else I do TV guides and used to play ultimate mahjong on my*

*computer but my computer is down at the moment because it froze up on me so I can't use the computer at the moment.*  
*Interviewer: Do you still do line dancing?*  
*Respondent: No I used to be taken to line dancing but it is too far from me*  
*Interviewer: You keep saying "I used to," I used to do line dancing I used to do knitting I used to...*

When we asked people what their vocational goals were in the National Online Survey, getting a job emerged as the preeminent vocational outcome. As we described previously, more than half of male (54%) and 43% of female respondents who named a goal, identified finding paid employment as their desired support outcome. In the interviews we conducted, we also got the impression that informants tended to see employment as a more valid "vocational" outcome than supporting other forms of participation or alternative ways to contribute within ones community. In informant's minds, (un)employment also appeared to represent a more demonstrable expression of the discrimination disabled people often experience than other less quantifiable forms of marginalization like their absence from intimate and personally rewarding relationship or of having a "sense of belonging" within the institutions and forms of association that collectively define the culture of a society.

It is not possible to say definitively, however, how much of any emphasis on employment as a goal, represents an uncontaminated expression of the hopes and dreams of informants and to what extent it might be attributable to a wider (neoliberal) imperative to reduce benefit dependence as the preeminent concern of "vocational" support.

It is reasonable to suggest, therefore, that support practices shaped by a belief that employment represented a more important measure of service efficacy may have diluted an alternative understanding of the purpose of vocational support being to assist people to identify and become valued members of other forms of participatory citizenship. This assertion aligns with the finding that respondents who only received vocational support were more than twice as likely not to belong to a community group, club or association (46%) than respondents who said they received other types of disability support (19%) (Milner et al 2016).

The other important finding reported by Milner et al (2016) was that whether respondents were employed or not made a significant difference to their rating of the personal importance of belonging to a community club, group or association. The odds that a respondent who was employed for more than 15 hours would rate the importance of belonging higher than two thirds of the scale maximum were 13 times higher than respondents who were unemployed and the odds that respondents who were employed less than 15 hours would do the same were 3 times higher than respondents who were unemployed.

As is described in more detail in the National Online Survey Report, this finding was interpreted as evidence of the protective effect of employment, including that respondents who were employed felt more able and more confident to contribute within other community contexts as a consequence of having greater access to the material and social capital that follows employment. As Milner et al (2016) note, results from the National Online Survey suggest that, not only is it possible to identify a population of disabled people, doubly disadvantaged by their marginalization from the worlds of work and other forms of community participation, but that the association between employment and other participatory outcomes would seem to argue for a “whole of life approach” to vocational support as opposed to than viewing them as separate (triagible) service outcomes.

In the interviews, informants tended to interlace their hope(s) of finding a job and of becoming more relationally connected to their community and in the section that follows, we describe in more detail how, within the context of disabled lives, these two outcomes were often contingent.

## Employment and community participation as covariant vocational outcomes

Within the Ministry of Social Development's Draft Proposals for Change to Employment, Participation and Inclusion Services (Ministry of Social Development, 2015) “Sustainable Employment” and “Participation and inclusion” are considered as separate outcomes that sit at either pole of three mutually exclusive “outcome streams.”

Although the social policy document *“Pathways to Inclusion”* identifies employment as representing a near universal aspiration for disabled people (Minister of Disability Issues; 2001), those able to access specialist employment support within the new vocational framework will be people assessed as *“likely to get part-time or full-time sustainable employment in an agreed time”* (Ministry of Social Development, 2015; p8). People assessed as falling outside of a threshold, yet to be written into the *Outcomes Setting Decision Making Tool*, will alternatively be directed towards services for which; *“finding alternative ways to make a contribution, experience valued roles or access universal, community-based services and amenities”* is the outcome purchased on behalf of disabled people.

The proposed framework for realizing disabled people's support ambitions is, however, at odds with the more complex narrative we heard from informants who were much more likely to see the life domains of employment and community participation as interconnected.

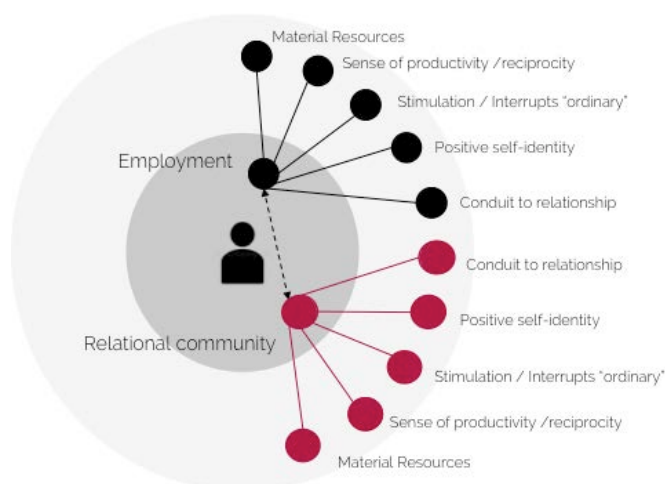
Rather than positioning them as discrete outcomes, people typically viewed improvements in one life domain as promoting the likelihood of improvement in another.

When asked about the relative importance of support intended to assist people to find employment or to become more involved in their community most informants weighted them evenly. *"They were about the same,"* we were repeated told, or *"were on an equal footing."*

The impression we gained was that informants tended to see both employment and becoming more actively involved in the life of their community as responding to similar marginalities and, not surprisingly therefore, named a coincident set of reasons for seeking an enhanced sense of belonging within the two participatory contexts. Informants saw employment and greater community participation as possible conduits to:

- Valued relationships
- A positive self-identity
- Stimulation or an interruption to the isolation and/or boredom of "wasted" days.
- A sense of productivity or reciprocity.
- Greater material and human resources.

**Figure 8 The interlaced outcomes respondents sought from employment and community participation**



More importantly, informants gave examples of how they viewed seeking employment and greater community connection as complementary rather than competing support objectives. For example, within the context of their everyday lives, getting a job was perceived as a

possible point of entry into personally rewarding relationships and of gaining greater access to the material and experiential resources people needed to become better connected and/or to contribute to communities of interest beyond the workplace.

*Respondent: (Community participation and employment) are both on equal footing. I would say getting a job is more important first up and then being able to be supported in the community from there it kind of goes without saying really.*

*Interviewer: And so why is getting a job more important first up?*

*Respondent: Because once you have got a job you can contribute to your community. You have the finances to do so. And also it opens up a whole lot of opportunities.*

In previous research conducted by researchers at the Donald Beasley Institute, we have observed how the relationships disabled people form, even through part-time work, can extend beyond the factory floor or work setting, including workmates providing colleagues a safe point of entry into the communities to which they already belong (Milner & Parish, 2013). We have also seen how employment as-well-as greater community connectivity can help people who feel on the outside of their community to fill in gaps that exist in their mental maps of the people and place that are part of a wider community landscape (Milner & Mirfin-Veitch, 2015). Informants recognized the potential of employment to do the same, even when they had no job.

*Interviewer: And so obviously money is a motivator for getting work, but are there other reasons that you think having a job would be important?*

*Respondent: I think it gives you a purpose in life. Like I find it really hard at home, you know when you are home all the time. I don't really get a lot of visitors because of where I am and I don't know a lot of people because I am new to the area um and I don't drink so I don't really go out to mix with people. It can be really depressing. So yeah I think a job is good because it gets you out and see what is going on.*

We heard evidence that more expansive relational networks improved the prospects of finding employment too.

In 2015, Milner & Mirfin-Veitch (2015) described the connectivity of disabled people's interpersonal networks as a largely "untapped" community resource. Although evidence suggests that person-centred support practices, including "circles of support" tend to be more effective at achieving vocational outcomes than individualized support (Hillman et al, 2013; Milner & Mirfin-Veitch, 2015), person-centred support continues to be family rather than a service facilitated support model. In New Zealand, disability support services have also been slow to adopt collective rather than individualized models of support too, missing an

opportunity to explore ways of drawing communities of support together and/or of tapping the resources, creativity and energy of much wider networks via models like peer or "circles of support," micro-boards and/or community assemblages.

In the conversations we had with informants, we found evidence of the latent potential expanding and drawing in the support of others may hold for disabled people seeking employment.

*Interviewer: How did that come about that job? Like how did you find out about it?*

*Respondent: Through someone that I knew as a child. A lady at the church we went to got to know me and she Facebook messaged me and told me to contact her daughter about a job.*

We also found evidence that adopting a "whole of life" rather than a siloed approach to support broadened the support conversation in ways that allowed people to continually (re)define and reshape their vision for themselves and to respond to the way employment and participatory opportunities often (and unexpectedly) intersected.

*Respondent: My kids got to taekwondo I am part of that. I take them swimming a couple of times a week and they what else do they do we do something else in town. I sit there and I talk to the people I know the instructors I make sure that I introduce myself and have a chat and engage with people so*

*Interviewer: Do you see that as part of the vocational conversation as well? Do you know what I mean? Would you include that as part of the conversations that you had with your vocational support?*

*Respondent: Yeah I would involve that because that is all part of the networking. Seeing what is out there what work is available what is happening within the community. Yeah. To give you an example just through networks and talking to people I have managed to get my hobby my passion my DJing side of things up and running and you know there are a couple of business a couple of clothes shops in town that sell surf gear and that and I have approached them and them and there you go. That was one of my goals*

What informant's unequivocally said the welcomed about vocational support was the opportunity it provided to engage in conversations about their future and the resources that might help them to "get the life they wanted." We got the impression that these conversations punctuated service delivery and assisting people to "navigate" the trajectory of their lives emerged as perhaps one of the most valued and yet largely unrecognized attribute of the support CCS Disability Action provided.

## NAVIGATING LIFE'S TRAJECTORY

Providing disabled people with more choice and control over their support and funding is the cornerstone principle of the "New Model" of disability support (Ministry of Health, 2016). Proponents of self-directed service delivery argue that disabled people are best placed to recognize and respond to their own support needs and the development of the 'New Model' and its four key elements is occurring against the backdrop of a more global shift away from service led support towards ways of assisting people that enhance and acknowledge individual citizenship (Duffy, 2006).

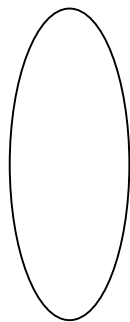
As is explained in more detail in the National Online Survey Report, to further the project aim of exploring how to deliver vocational support *"in ways that ensure people get the life that they want"* (CCS Disability Action, 2016), survey respondents were invited to indicate how important a range of ten different support outcomes were by deciding how much of an "imaginary" funding budget they would allocate to each option.

What we discovered was, that when given the opportunity to self-direct their (notional) funding, respondents expressed their valuing of support that helped them to *"plan for their*

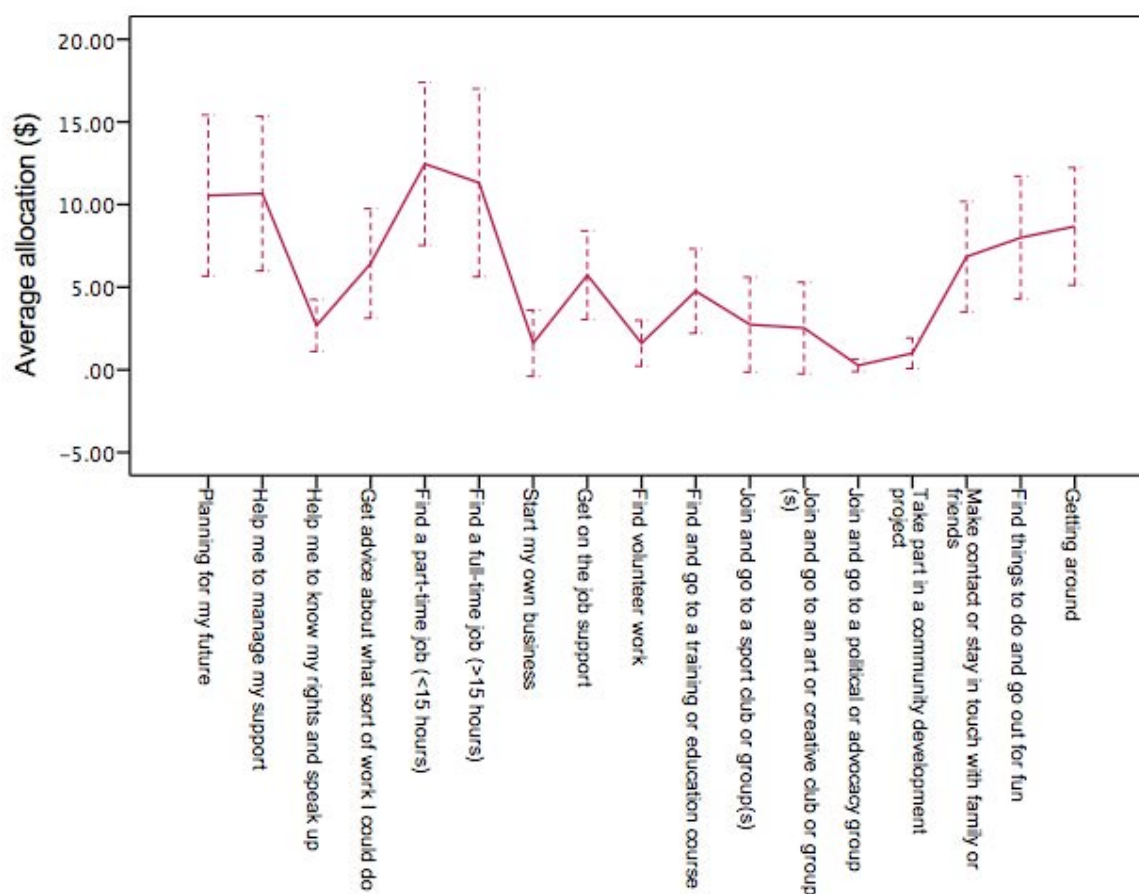
*future*" (average allocation= \$10.56) and *"manage their support"* (average allocation= \$10.66) by allocating more of their budget to these support elements than almost all of the other outcomes prioritized in conventional funding contracts.

At the heart of the "New Model" and other initiatives intended to provide disabled people with more choice and control over their support are support elements that depend on someone fulfilling the role of "navigator" or "life coach." Informants told us, however, that planning for the future and organising support were not single events, but rather an ongoing process of reflecting and responding to changes in life circumstance and aspiration. What people said they valued about CCS Disability Action support was their ability to access elements of "navigation" as part of their everyday support.

**Figure 9 The average (notional) funding respondents allocated to different support elements**



When we asked informants what they felt CCS Disability Action did well, everyone spoke of



the way their support was transacted, and in particular how the relationships that they had with CCS Disability Action staff accommodated, on the one hand, support that allowed them to step outside of their day to day lives and on the other, support that responded to the complexities and everyday realities of living disabled lives.

Some informants, for example, described their support as “circuit-breaking” what could become “*the cycle of disability*,” including, “*allow(ing them) to identify the next steps (in their life journey).*”) Having an opportunity to step beyond the day to day realities of disability appeared to be especially important to informants who had an acquired impairment, one of who told us that this attribute of service “navigation” permitted him to reclaim a sense of sovereignty or chiefly authority over his life trajectory.

*Interviewer:* In the last interview I did (the person I spoke to) was saying that most critical thing is that “I need someone to help me to define what the next step is” and I am kind of hearing that in your narrative too

*Respondent: Absolutely. Sometimes you can't see the tree for the hills. Sometimes the disability can actually be too overwhelming and you get caught into the cycle of disability itself and I have been there personally and so it was about that for me. It was about how do I regain my rangatiritanga and get myself back on track and do this for myself but also for my family to ensure that I am here in the future and that I leave a legacy behind in terms of my education and that.*

Consistent with the definition of vocational" support as meaning support that assists people to engage in "meaningful, routine, sustained activity, that enhances personal growth, is personally rewarding and connects people within a community,' (Nicholas et al, (2014), the majority of informants interpreted the purpose of their support broadly. Common to all understandings of support though, was informant's shared belief that it needed to governed by the visions disabled people held for themselves. *It (was),*" we were told, *"to assist disabled people with what they want to do in their lives and how they want to achieve it.*

Having someone intimate and familiar, but at the same time disconnected from one's ordinary informal network of relationships did, however, appear to change the conversations people had in ways that augmented the process. Having the space to articulate a new (wider) vision for oneself to a support person had the effect of holding some informants accountable to an alternative and more positive future. It was a way, they said, of calling themselves out to themselves.

*Respondent: Well I think it is someone independent talking to me about it. Because I am always harping on about this sort of stuff to my partner and she sort of rolls the eyes whatever you say go enrol darl. But it never happens. So ok that's the attitude. But when I was talking to the CCS person and we are setting the goals down I thought no I actually have to do something about this now. I am obligated to I am saying to people I am putting it out to the universe that this is what I am about this is what I am going to do. Yeah so then ok if I am talking to [Support Staff] in town here in then she is probably thinking yeah whatever, this guy is off in cuckoo-land, he is saying all these things but he is not doing nothing, so I am actually starting to walk the talk now*

In all of the interviews we conducted, informants mentioned valuing the opportunity support staff had given them to reimagine their personal futures and/or expand their thinking about the range of ways they could connect with or contribute to communities of place or interest.

Most informants also spoke of valuing staff's knowledge of the complex and fragmented world of disability and all informants recalled instances where they had relied on support staff to help them navigate the confusing and sometimes dehumanizing bureaucracies of health and disability support.

*Respondent: Well I can only speak from my point of view as to what they do for me. Um they do a lot of support work like at WINZ because I think I had an accident a motor accident. I can't think things out quite as good as I used to, since the accident and I have got a support person when I need one to go to WINZ. Which, the person I got is excellent. She knows so much. It's been such a help. And also different support things. So if I have to go to town sort of thing and things like that and CCS the person I have got has given so much support. In getting things and helping me get the course. The list is incomprehensible. I got the word out! Essential things like transport costs and um and they have helped me at the doctor .....*

Equivalently important was that support was informed by knowledge of a person's impairment and in particular the way that impairment impacted informant's lives. Support guided by an empathetic imperative was highly valued, with informants instructing us that what they most appreciated was *"that (their support person) understands what I go through,"* or that, *"there was no need to explain (oneself)"*

*Respondent: No I don't have to explain myself and yeah so if my eye is weeping or I can't close my hand properly because arthritis has kicked in or I am dragging my leg a bit you know people think oh I am on some sort of drug or I have had stroke it is actually because it is a bad day for me and you know that is just how it is so someone like [Support person] understands that and if I need to sit down if I can't stand up and I just need to have a seat and have a bit of a rest and get myself back up to scratch then they understand all that sort of stuff. I mean from the outside I look like a big buxom sort of chap and you know burley sort of guy and that but at times there are real bad days that I have and I am not even able to function so having someone who can understand all that.*

Moreover, the steady accumulation of support staff's knowledge of impairment, more intimate personal knowing, understanding of disability rights and the range of possible responses when people's rights and/or wellbeing were compromised were said to be key attributes of vocational support. *"Understanding what I am going through,"* contributed to the advocacy that informants said they sometimes needed.

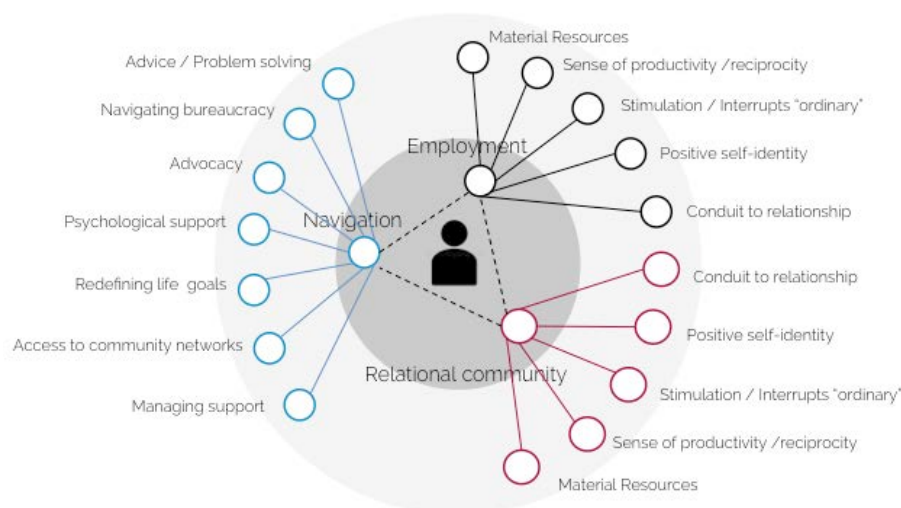
*Respondent: Well I had to relearn how to deal with that sort of system. Because obviously I was used to dealing with Study link and all those sorts of things over the years and I knew how student administration worked within tertiary providers but dealing with Work and Income that was just a whole new ball game and eye opener. So no disrespect intended to that particular Ministry or the people who work there but man that system was just absolutely crazy. So it was the CCS people that helped me to basically get an appointment and at that time I wasn't in a position to sit there and talk to people so they became my advocate.*

All informants conveyed a sense that, in addition to the more formal architecture of their support arrangements, CCS Disability Action advice and assistance sat in the background of people's lives - available to them when they felt they needed it. We were told repeatedly

that what distinguished CCS Disability Action support from other types of support was that, *"if you need help they are there"* or that *"they help me out when I am having trouble,"* or that people felt *"lucky because I can call them whenever I get stuck."* Simply knowing that someone was available to offer non-judgmental advice and/or assistance appeared to provide people with a significant source of psychological support.

*Respondent: I mean knowing that there is someone out there in the community that is going to bat for you, you know what I mean? I mightn't actually engage with them on a daily bases or even a weekly basis but I suppose passively knowing that there is somebody out in the community that can actually advocate on your behalf. I mean that's huge. You need that you need that reassurance that there is someone there. You know so we are talking about rangatiritanga or self-determination - part of that self-determination is knowing that you have that backup of your support networks. Whether that be at your marae level or your whanau level or out in the community. You know that's what CCS does.*

**Figure 10 Linking elements of support through 'navigation'**



The other attribute of vocational support that informants said contributed to a sense of psychological support was that, in addition to their ability to call for assistance, vocational coordinators or support staff would also periodically *"call (them) just to see how (they were) getting on."* This proactive element to support was experienced by some as affirming, communicating as it did a *"genuine interest in (themselves) and (their) life."*

And finally, informants mentioned how they also valued the way the tendrils of CCS Disability Action's connections fingered out across their community. We heard a number of different accounts of how CCS Disability Action staff's knowledge of other community agencies and resources had assisted people to take greater control of their lives. For one informant, it was their close working relationship with the Brain Injury Association that made a difference.

*Respondent: She has put me onto a lady that's another support thing she has done. Is to do with brain injury that has opened my life something terrific. I think I have been about 3 or 4 months with this other lady and um my world has just opened.*

And for another it was their knowledge of where to go to improve their mobility.

*Respondent: The lady who helped me was really cheerful and positive and she had really good ideas. And she applied for some funding which I didn't know about. And she helped me apply for funding for transport.*

Within the Ministry of Social Development's Draft Proposals for Change to Employment, Participation and Inclusion Services, all of these, less quantifiable, but none-the-less potentially life-changing (navigational) support transactions remain unrecognized and unfunded.

Similarly, within the four elements that collectively advance the "New Model," the role of "navigation" has purposefully been located beyond what is presently considered traditional disability support services.

When we spoke to informants, however, their narrative suggested that key elements of the navigator role were already embedded within the social practices of their vocational support.

Moreover, when we spoke to informants about the personal usefulness of "direct funding" most people recoiled against the idea of having to take on the responsibilities of deciding how to allocate their funding and of employing or managing staff. *"It was,"* we were told, *"a lot of responsibility"* or that *"I'm not really into that,"* or that *"I would need to be educated to use it,"* or that *"personally what I need with me is to be around people who are experienced, are empathetic and have a good understanding of my neurological condition."*

When we talked more about informant's apprehensiveness to engage with direct funding and/or the management of their support, what people really appeared to be concerned about was the potential for greater autonomy to distance them from the conversations and relation attributes of navigation they currently accessed and valued as part of the way CCS Disability Action transacted its support.

It is important to emphasize that none of the people we interviewed had experienced "navigation" as operationalized (and evaluated) within the Enabling Good Lives or Local Area Coordination models of support established under the "New Model" or indeed "Life Coaching" accessed by disabled people and their families accessing Individualised Funding. Theirs are, in fact, the first voices of people receiving support from a disability service

provider to be heard in the wake of service and support initiatives intended to give disabled people *"more choice and control over their support and funding."*

What they appear to suggest is that the social practices of service delivery can compromise unfettered self-determination, but that when the risk of a loss of autonomy is open for discussion, disabled people can also access the benefits of navigation within a service context.

Similarly, their narrative also hinted at possible advantages of embedding navigation as the driver of support within as well as beyond disability support services.

All informants described valuing the way that day-to-day support created the space for them to engage in the ordinary planning processes of reflecting and responding to changes in their life circumstances. Moreover, people appeared to suggest that it was advantageous to them to draw on support that stretched from providing practical advice, advocacy and physical support within their everyday lives but was also informed by an ability to step beyond the everyday realities of disabled lives to contemplate alternative futures. What mattered to people, was that those who entered their life through the support act; *"listened to me"*, *"got where I am coming from,"* acted in ways they authored and were available in ways that might be more difficult to access through alternative navigational models.

Similarly, the other advantage of embedding "navigational" support within the relationships that disabled people experience their most immediate support, is that it provides an additional opportunity to negotiate when and for what purpose disabled people draw on their day-to-day support.

Recent changes to the Enabling Good Lives and Choice in Community Living support models permit disabled people to hold their funding allocation within disability support services. People funded under an Individualised Funding contract also have the ability to subcontract disability support services, including to provide elements of navigation and support management. The intention of these changes appears to be to shorten the distance between disabled people and their funding entitlements by sidestepping the increasing complexities and costs of the emergent infrastructure of the disability support. Given that the people we spoke to described valuing the assistance they received through vocational support because it helped them to navigate their life trajectory, their narrative ought also to be included in the conversations that are currently spiraling off the "New Model" in search of ways that disabled people might better define and achieve, "getting the lives they want."

## The last word

From its beginning, the *"Getting the life I want"* project was intended to be transformational. The aim of the research was, *"to consider the transformation of Vocational Services within all regions so that the way CCS Disability Action deliver support provides the options for people to get what they want"* (CCS Disability Action, 2016), and to do that, CCS Disability Action sought to access the diverse and often "unheard" voices of people for whom vocational support is part of the fabric of their day-to-day lives.

Consistent with the transformative imperative, the research is intended to provide an empirical starting point from which disabled people, their families, CCS Disability Action staff and the wider disability community can become increasingly engaged as stakeholders in the longer-term processes of organizational learning and service change.

One of the key findings of the research was that the people we spoke to invited other New Zealanders to assist them to identify and respond to the myriad of different and interrelated ways that disabled people can find themselves at the margins of participatory citizenship, and most especially, to their exposure to material, relational, aspirational, and productive poverties.

When taken together, the stories of the people we spoke to provide CCS Disability Action with a range of different ways to alter the social practices of support that answer their almost universal yearnings to contribute to their community through paid employment and to belong within sets of relationships that are something more and something better than this place now.

Their narrative also forewarns of the potential dangers of social policy that commodifies people's personal hopes and dreams. By imposing a narrow understanding of the purpose of vocational support, Social Investment approaches to service provision run the risk of failing to capture the way *"whole of life"* and *"navigational"* support elements were seen by informants as providing opportunities to improve life quality across the spectrum of life domains. Moreover, advancing support that has predefined (and mutually exclusive) service "outcomes" has the potential to undermine a transition taking place in New Zealand towards more self-directed service delivery.



Asking disabled people how they can get the lives that want couldn't, therefore, be more timely. The next step(s) will be to continue to engage disabled people in the transformational conversations that have begun and for a project that sought to privilege the voices of people who access vocational support it is appropriate to leave the last word to them.

*Respondent: "If we keep creating the same world, we are going to get the same world."*

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## APPENDICES 1-5

## Appendix 1: Participant Interest Form (Telephone interview)

|                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                          |                                          |              |                                          |               |                                          |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------|------------------------------------------|--------------|------------------------------------------|---------------|------------------------------------------|
| <div style="display: flex; justify-content: space-between; align-items: center;"> <div style="display: flex; align-items: center;">  <div style="margin-left: 5px;"> <b>ccs disability action</b><br/> <small>including all people</small> </div> </div> <div style="display: flex; align-items: center;">  <div style="margin-left: 5px;"> <b>DONALD BEASLEY</b><br/> <small>INSTITUTE</small> </div> </div> <div style="text-align: right;"> <b>Getting the life I want: Paper version</b> </div> </div>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                          |                                          |              |                                          |               |                                          |
| <b>Follow up telephone interview</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |                                          |                                          |              |                                          |               |                                          |
| <p>As part of this study, we are interested in hearing more about your experiences of vocational support and in particular, ways that CCS Disability Action can support you to get the life you want.</p> <p>If you would like to take part in a 30 to 40 minute telephone interview with a researcher from the Donald Beasley Institute could you please let us know by filling in the panel below.</p> <p>The interview will be anonymous.</p> <p>Researchers from the Donald Beasley Institute will be the only people to listen to your interview. When the Donald Beasley Institute write their report they cannot identify you or your family in anyway.</p> <p>If you give us your contact details a researcher from the Donald Beasley Institute will get in touch with you to tell you if you have been selected as a participant (or not) and to arrange a time to talk.</p> <p><b>45. I am interested in participating in a follow up telephone interview</b></p> <p> <input type="radio"/> Yes<br/> <input type="radio"/> No         </p> <p><b>46. If yes, please provide your contact details</b></p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 20%;">Name</td> <td><input style="width: 80%;" type="text"/></td> </tr> <tr> <td>Phone number</td> <td><input style="width: 80%;" type="text"/></td> </tr> <tr> <td>Email address</td> <td><input style="width: 80%;" type="text"/></td> </tr> </table> <p style="text-align: center; margin-top: 20px;">Thank you for helping us by being part of this study.</p> | Name                                     | <input style="width: 80%;" type="text"/> | Phone number | <input style="width: 80%;" type="text"/> | Email address | <input style="width: 80%;" type="text"/> |
| Name                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | <input style="width: 80%;" type="text"/> |                                          |              |                                          |               |                                          |
| Phone number                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | <input style="width: 80%;" type="text"/> |                                          |              |                                          |               |                                          |
| Email address                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | <input style="width: 80%;" type="text"/> |                                          |              |                                          |               |                                          |

## Appendix 2: Interview Consent Form



### Getting the life I want: Interview Consent Form

CCS Disability Action are interested in finding out if they are offering disabled people vocational services and supports that work and in line with people's goals and aspirations. To do this, CCS Disability Action contracted the Donald Beasley Institute to conduct a scoping study. The purpose of the study is to generate information that CCS Disability Action can use to inform the development of their vocational support service.

The study will be informed by an online survey and a series of semi-structured interviews with CCS Disability Action staff and people who use CCS Disability Action vocational support services.

The interviews are designed to learn more about what types of vocational outcomes disabled people value and how we might develop vocational support services to better meet the goals and aspirations of disabled people.

The interviews will take approximately 45-60 minutes and will be conducted by a researcher from the Donald Beasley Institute. All interviews will occur at a time of your choosing. We would like to record the interview to help us to remember what you said and whether common themes emerge from the stories people tell us.

Your information will only be seen by the research team at the Donald Beasley Institute. All interviews are confidential and the research team is legally obliged to report their findings in a way that doesn't identify you, your family or any other study participants.

Although formal ethical approval is not required for a scoping study, the research team wanted to provide you with information about the project and inform you of your rights as a potential participant, including seeking consent in the normal way.

If you would like to take part in this important project, could you please indicate that you know the following by signing this consent form.

1. I will be interviewed by a researcher from the Donald Beasley Institute.
2. The interview will be tape recorded to help the research team to look for common themes.
3. Once the research team has finished the study the recording will be erased.
4. The information I provide will inform a project to help CCS Disability Action to develop their vocational support service.
5. I have the right to choose whether I take part or not and that not taking part will not affect my relationship with CCS Disability Action or the support I currently receive.
6. The information I provide will only be seen by the research team from the Donald Beasley Institute.
7. The research team can't report their findings in a way that it is possible to identify my family or me.
8. I understand that I can contact a Health and Disability Consumer Advocate if I want to know more about my rights as a research participant. The phone number is 0800 555 050.
9. I know I can contact Paul Milner or Brigit Mirfin-Veitch at the Donald Beasley Institute if I have any questions. The phone number is 0800 878 839.



I give my consent to be interviewed for the *Getting the life I want Scoping Study*.

Name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

## Appendix 3: Semi-structured interview schedule

### Semi-structured interview: Person receiving vocational support

1. Tell me a little about yourself.
  - a. Where do you live?
  - b. What does a normal week look like?
2. How long have you been receiving vocational support from CCS Disability Action?
3. What do you think the purpose of vocational support is?
  - a. Is it different from other kinds of support you receive?
4. What are your current vocational goals?
  - a. Are they written down?
  - b. What made you decide on those goals?
  - c. Have your goals changed or remained the same as other years?
  - d. Are there any things you want for yourself that aren't written down?
5. How do you receive your vocational support?
  - a. How often do you talk with someone? (Who do you talk to?)
  - b. What do you normally do together?
6. What are the things you like/value about the way you are supported by CCS Disability Action? What are they doing well?
7. What are some of the things you think they may not be doing so well or think they could do better?
8. Finding a job is often thought of as an important outcome for vocational support?
  - a. [In the Survey you said you were working ?? hours but would ideally like to work ??] Can you tell me more about why that would be ideal for you?
  - b. [You rated the importance of having a job as ..] What is it about having a job that led you to rate its importance this way?
  - c. Can you think of other ways that CCS Disability Action might help you get the job you want?
9. How connected do you feel to your community?
  - a. [You rated the importance of belonging to a club group or organisation as ..] What is it about belonging to groups that that led you to rate its importance this way?
  - b. How might you be best supported to join and belong to the community groups you would like?
10. Do you feel that being supported to be part of your community is more important, less important or similarly important to being supported to find a job?
11. Do you like the idea of getting your vocational funding directly (as a payment)?
  - a. If you did, in what ways might you want to change the way you were supported?
12. In the Survey Workbook we described a bunch of different ways that support services like CCS Disability Action are supporting disabled people.
  - a. Were there any that you thought were especially useful?
  - b. You rated [Model] highly. What did you like about that?
  - c. Do feel able to change the way CCS Disability Action supports you?
  - d. What about changing the way it delivers support to disabled people generally?
13. Are there other things that you would like to be doing that CCS Disability Action could help you to achieve?
14. What kind of things make it hard for you to achieve the things you want for yourself?
  - a. How could CCS Disability Action help you to overcome those barriers?
  - b. Do you think it is CCS Disability Action's role (or do you think other community organisations would be better placed to help you?)
15. CCS Disability Action want to learn what people want from their vocational support. Is there anything else that you think might help CCS Disability Action better support disabled people?

## Appendix 4: The “Inviting the community in” support model

### Inviting community in

When people think about what “inclusion” means for disabled people they almost always think it means disabled people going into “mainstream” community spaces without ever thinking that non-disabled people might need to make a return journey to places in which disabled people know the most or are most comfortable.

Turning the direction of “inclusion” around by inviting non-disabled people into places where disabled people feel known and have greater knowledge (social capital) has a number of advantages for everyone, including:

- Helping non-disabled people see new ways of thinking and seeing the world, as well as learning about disabled people’s experiences, creativity and emotions.
- Allow disabled people the chance to make community spaces that celebrate their own culture and benefit from the friendship and wisdom of people who have had similar life experiences.
- Change the way disabled people are sometimes represented as “less-productive” members of the community.

Examples of projects in which disabled people have invited non-disabled people into common community include, but are not limited to:



Inclusive dance, theatre, cabaret, writing, painting and visual media groups encompassed with a disability arts movement intent on “sowing the sliver of difference into the safe spaces of the majority,” (Kuppers, 2003)



Accessible bike building and maintenance collectives, some of which also lend bikes to visitors or members of their community



Computer literacy and Alternative and Augmentative Communication classes run by disabled people for the benefit of all members of the community

## Appendix 5: The “Community Development approaches to social (ex)inclusion” model

### Community Development approaches to social (ex)inclusion

Many disabled people say that it is difficult for them to make and keep friends or become more involved in their community. In Bendigo (Australia) a disability provider used a community development approach to bring a community together to help to change this.

#### **Trees, Webs and Hives ([vimeo.com/111176843](https://vimeo.com/111176843))**

“Trees, Webs & Hives” was a project centred on the Bendigo Library that was designed to build relationships between people living in Bendigo.



The main task of the project was for disabled and non-disabled community members to work together to create an art installation for the Bendigo library. The brief for the art was that it be about the way all things are connected. As a way of thinking about the art as-well-as people in the Bendigo community who were not so well connected, disabled people organized a series of talks that ran alongside the project with speakers all talking about the different ways people and the environment are connected. The workshops were another way to get people talking about their connectedness and to begin to build relationships between the disabled and non-disabled artists and other community members.

By hosting the project, the Bendigo Library became a model of the range of different ways to connect and share people’s knowledge and experiences.



**ccs**  
**disability action**  
Including all people

TE HUNGA HAUĀ MAURI MŌ NGĀ TĀNGATA KATOA



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