Getting the Life I Want

Online Survey

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

A report prepared for
CCS Disability Action
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ccs disability action
Including all people
TE HUNGA HAUĀ MAURI MŌ NGĀ TĀNGATA KATOA

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NATIONAL ONLINE SURVEY

GETTING THE LIFE I WANT

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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 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 in an attempt 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 research 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 National Online Survey. 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 they might assist them to get the lives they want.

This Report follows the structure of the Online Survey and is, therefore, organised in the following way.

In the next section, we describe in more detail the method used to conduct and analyse the National Online Survey. The report then goes on to detail our research findings in a way that follows the structure used in the survey itself. Chapters therefore describe the Survey respondent's;

- Vocational goals
- Sources of vocational support
- (Un)employment
- Employment-search support types they receive
- Volunteering
- Training and education
- Community membership and belonging
- Community group membership
- Friends, family and neighbours
- Control over their support
- Views on different ways of providing support
- Views and feedback about their vocational support

METHOD

The Survey

The "*Getting the life I want*" National Online Survey (the Survey) was a 44 item questionnaire that used a mix of forced choice and open ended questions that prompted for respondent's; attributes and lived experiences, understanding of vocational support, vocational support experiences, personal support priorities, and their assessment of a range of alternative vocational support models discovered through the Integrated Literature Review.

The survey was hosted on SurveyMonkey©**, a** cloud-based survey platform, with a paper-based survey also made available to people who could not access the website or people who found it difficult to complete the online survey independently. Potential participants could also access the survey on a device brought to them by a CCS staff member and all respondents could request assistance to complete the survey from a CCS Disability Action staff member.

Letters were posted (n= 506) or emailed (n= 159) to all people identified as currently receiving vocational support via the National Office database (n= 665). The letter alerted potential respondents to the aims of the project and included an invitation to contribute by completing the National Online Survey.

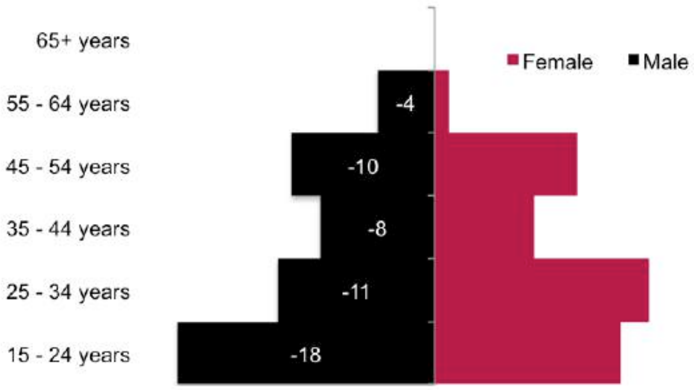
The survey opened on 1 September, 2016 and was originally intended to close on 16 September, 2016. Concern about the slow response rate led to a reminder letter re-emphasising the aims and objectives of the project and extending the survey deadline until 30 September, 2016.

Ninety-seven people contributed to the project by responding to the survey, yielding an overall response rate of 14.6%. The highest response rate was from people receiving vocational support in the Waitaki (n= 5; 50.0%) and Southland (n = 4; 44.4%) regions and lowest in the Waikato (n = 0) and Northland (n = 4; 7.8%) regions.

Participants

A total of 51 males and 46 females contributed to the project via the online survey. The age of respondents ranged between 18 – 62 years with the average age of male respondents being slightly higher (34.1 years) than for female respondents (33.7 years).

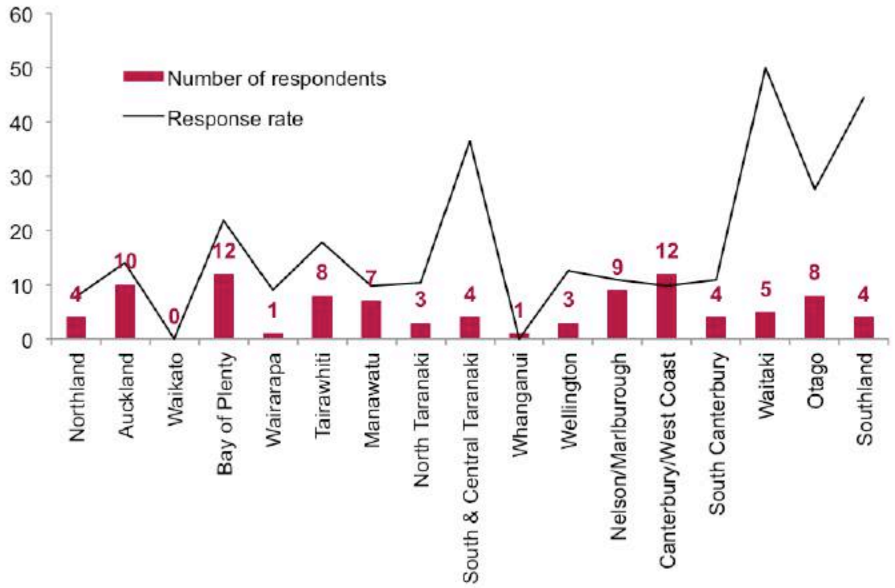
Figure 1. The age/sex profile of survey respondents



Close to nine out of every ten respondents described their ethnicity as New Zealand European (n = 83; 85.6%). Seven respondents self-identified as Māori (7.2%), two as Pacifica (2.0%) and three as Indian (3.1%).

Respondents were drawn from most CCS Disability Action regions. More populous regions tended to contribute the largest number of survey respondents (Canterbury / West Coast= 12, Bay of Plenty= 12 Auckland= 10) although the Canterbury / West Coast region (response rate= 9.8) was under-represented in terms of the number of people who accessed vocational support in that region.

Figure 2. The number and response rate by CCS Disability Action region



For approximately six out of every ten respondents, vocational support was provided in addition to other types of disability support (59%). It was more common for respondents to describe accessing support from at least one other support contract (58%), with the most commonly named sources of alternative support being; Supported Independent Living (46%), Residential support (15%) and Domestic and Personal Assistance (15%). Thirteen respondents reported receiving two or more types of disability-related support in addition to the vocational support they accessed.

Data analysis

Respondent information collected from the online and paper versions of the survey were entered as data and managed using IBM®SPSS® Statistics 19 statistical software.

In addition to descriptive statistics, binary logistical regression modeling was used to explore the strength of association between (dichotomous) vocational outcomes (for example, as to whether a respondent was employed or not) and potential predictors, including; respondent attributes (sex, age, ethnicity); support attributes (contact with Vocational Coordinator, received other types of support); and a respondent's level of community participation (employment status, volunteered, participated in ongoing education, belonged to a community group).

The purposeful selection process proposed by Hosmer and Lemeshow was used to guide the selection of potential predictors in all multivariate regression models. A set of preliminary models, involving univariate analysis of each potential predictor (Unadjusted model) was conducted with all variables that satisfied the univariate test and had a p-value < 0.25 considered as candidates for inclusion in the final model (Adjusted model). Ten cases per parameter was adopted as a "rule of thumb."

Respondent narratives, taken from the open-ended survey questions, has also been used to support the interpretation of survey findings. Where a respondent has been quoted directly, the narrative has been *"italicized and coloured."*

VOCATIONAL GOALS

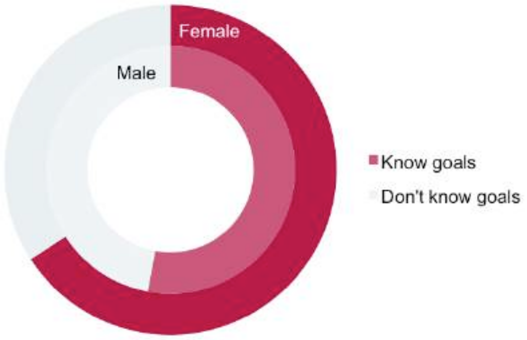
Within existing Vocational Contracts, the role articulated for Disability Providers by the Ministry of Social Development (MSD) is to facilitate and/or support people to participate in their communities in ways that are meaningful to them and enhance their quality of life and mana. To do this, the Provider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

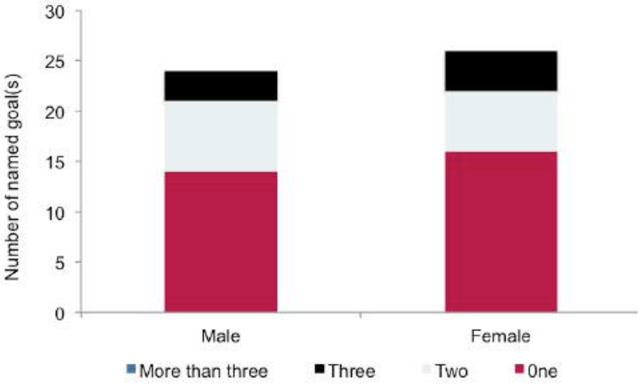
Approximately four out of every ten respondents who completed the *"Getting the life I want:"* National Online Survey said they didn't know what their vocational goal(s) were (42,1%). Male respondents (47%) were more likely to describe not knowing what their goals were than female respondents (34%).

For most respondents, goal-setting also appeared to be relatively circumscribed. Question seven of the survey asked respondents what their current goals were. Six out of every ten respondents who named a vocational goal(s) volunteered a single goal (males = 58%; females = 62%).

Figure 3.a (left) The proportion of male & female respondents who named one of more vocational goal(s)

Figure 3.b (right) The number of goals named by male & female respondents





Getting a paid job emerged as the preeminent vocational support outcome. Thirty-five percent of male and 25% of female respondents described finding 15 or more hours paid employment as their current vocational goal and an additional 19% of male and 18% of female respondents named finding part-time work (less than 15 hours paid employment) as a current goal. Altogether, more than half of the male respondents who named one or more vocational goal(s) described finding employment as a desired support outcome (54%) whilst slightly fewer female respondents did the same (43%).

This finding is consistent with international findings that describe employment as an almost universal aspiration amongst disabled people, including the New Zealand Disability Survey (2013), which estimated that 74% of disabled adults not currently employed in New Zealand would work if a job were available to them.

In their goal setting, it was clear that some respondents read their unemployment as separating them from the ordinary life trajectory of other adult New Zealanders. The vocational outcome they sought was *"to be able to find a job and have friends like any other person."* For many, paid employment held such personal significance that their employment conditions were less important that achieving a foothold within the world of work. Their goal was, they said, *"to try to find any work, full or part-time."* Other respondents, however, asserted that it was personally important to find employment that was *"full-time (and) productive and fulfilling,"* rather than the types of occupations or forms of community participation they had historically been steered towards. One respondent's goal, for example, was *"wanting paid work, but not doing mail boxes."* Whilst their aspiration aligns with the stated aim of vocational support (that is: facilitating meaningful forms of community participation) it also reflects the kind of underemployment that contributes to disabled people being over-represented within the expendable, unskilled and poorly-paid fringes of the New Zealand labour market.

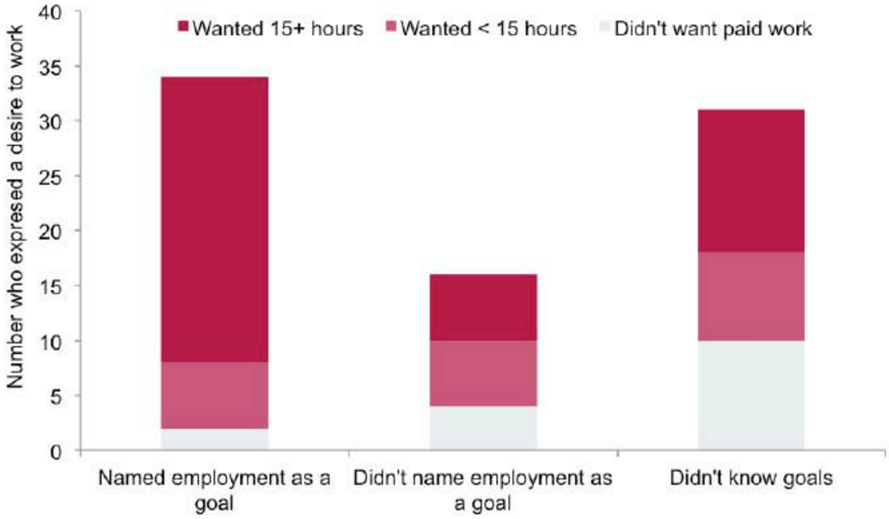
Moreover analysis of participant narrative presented later in this report suggests that the Survey's goal-related findings under-estimate people's aspiration to work. As is discussed in more detail later in this report, people often spoke of tempering their aspirations after years of unsuccessfully seeking work or of attributing their ongoing unemployment to their lack of fit with the labour market. People's diminished expectation of achieving employment found expression in respondent's goal setting in two ways.

Firstly a number of respondents, and in some cases proxy informants, expressed the view that paid employment was not a realisable goal. Some respondents wrote, for example, that employment was *"not (personally) applicable"* or that *"no vocation (was) possible. Volunteer work here and there."*

Survey question 13 asked respondents how many hours a week they would like to work in a paid job. Comparing the number of hours respondents said they would ideally like to work in a paid job with the vocational goals they identified as current allowed us to get some measure of respondent's "unexpressed" aspiration to work.

When asked what their current vocational goals were, 42% of respondents named wanting to find employment. When asked how many hours respondents would like to work, however, more than twice that proportion indicated an often "unspoken" aspiration to work. For example, 75% of respondents who did not name employment as a known goal wanted either less (38%) or more (38%) than 15 hours paid employment. Within the group of respondents who said they did not know their current vocational goal(s), 68% of respondents described wanting either less (26%) or more (42%) than 15 hours paid employment.

Figure 4. The proportion of respondents who named work as a vocational goal who expressed a desire to work more or less than 15 hours



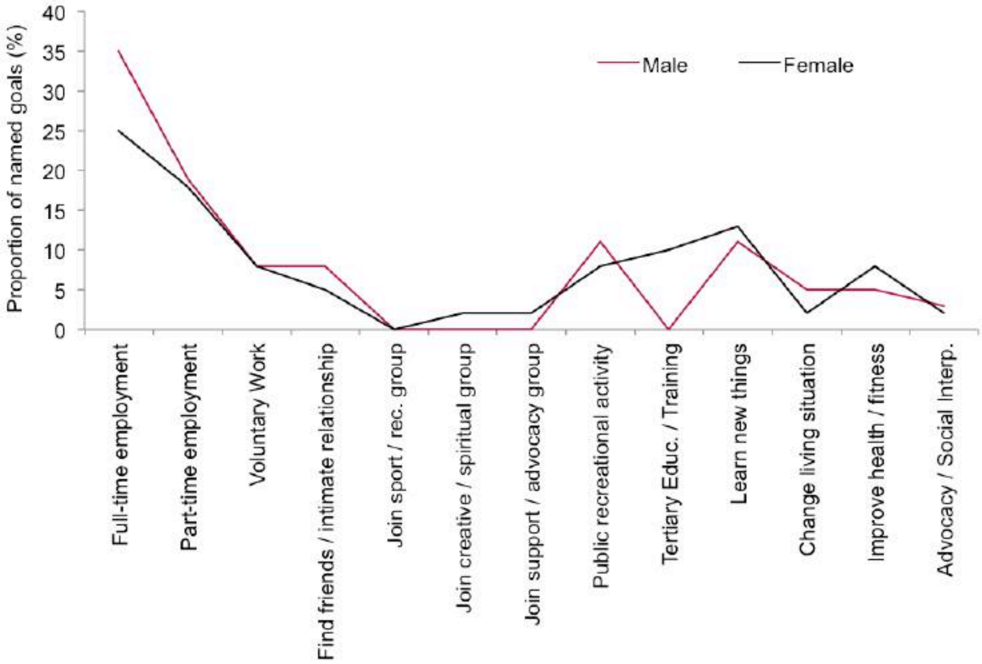
Taken in isolation, the lack of sensitivity to respondent's wider aspiration to work as expressed in their goal setting raises possible concerns about support staff's belief in the viability of employment as an achievable outcome. It may also reflect the lack of access respondents had to conversations that would allow them to express their aspiration to work or that would challenge those who perceived themselves as having little to contribute within a work setting.

The other major life domain emphasised in vocational social policy is that of: enhancing disabled people's ability to experience a sense of belonging within the cultural institutions that define a community. Whilst respondents were less likely to name vocational goals within life domains beyond employment, having friends and being present through everyday community relationships was, for a number of respondents, similarly indicative of the ordinary adult life trajectory. Their goal was *"to be able to find a job* ***and*** *have friends like any other person."*

The more limited expression of other forms of community participation might, in part, be attributable to a historical emphasis on "vocational support" as being understood as the process of assisting people to find work or engage in "work like" activity. The origins of these understandings of "vocation" can be traced back to the rehabilitative care tradition that informed the development of supported and sheltered employment. Within this tradition, employment tended to be prioritised as an outcome, with community participation more latterly advanced as improving the life quality of people for whom employment was deemed unlikely. It is possible, therefore, that respondents tended to reflect back these historical service values in their goal setting.

Within the narratives of the people accessing vocational support that we spoke to during the interviews, however, finding friends and addressing the isolation many people described experiencing, emerged as an important support priority. However, within people's vocational goal setting, this aspiration to become more relationally connected was typically expressed either a global hope (like "to meet more people" or "to have friends") or by drawing on support to achieve a greater presence within public community spaces. For example, whereas goals like "getting out-and-about in the community" and "to participate in the community" were sometimes named as vocational goals, no one described wanting to join a sport or recreation club, hobby or interest group, neighbourhood or local community group. Only one person named joining a creative or cultural group and only one person named joining a support or advocacy group. This finding is consistent with previous research commissioned by CCS Disability Action that reported finding the participatory presence of disabled New Zealanders is often experienced on the outer edges of community life, such as in public settings in which few opportunities existed to generate new relationships and relationships seldom transcend mere acquaintance (Milner & Bray, 2003; Milner & Mirfin-Veitch, 2012).

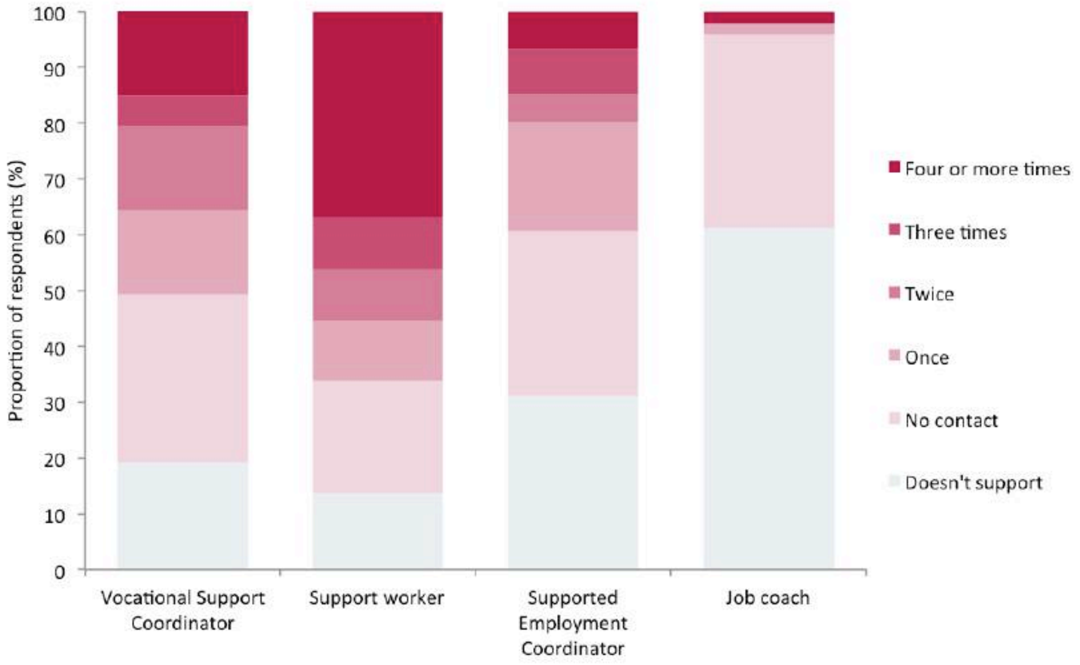
Figure 5. The types of participation respondents named as a vocational goal(s)



SOURCES OF SUPPORT

Respondents most commonly described their vocational support as being provided by a single person or role. Six out of every ten respondents named a single CCS Disability Action role as providing them with their vocational support (63%). However, 30% said they received vocational support from staff working in two or more different roles and 11% described receiving support from CCS Disability Action staff working in three or more different roles. Support Workers were the most commonly named source of vocational support (n = 46; 54%). Four out of every ten respondents named a Vocational Support Coordinator (n = 35; 41%) as providing them with vocational support and 14% described receiving support from the similar role of Community Support Coordinator (n = 12).

Figure 6. The amount of contact respondents had with vocational staff by role



Support workers were also, on average, respondent's most frequent source of contact. Fifty-five percent of respondents said they received vocational support from a CCS Disability Action Support Worker at least twice in the previous four weeks, within which 37% of respondents reported receiving support four or more times. Many respondents also said they received support through different service contracts. Six out of every ten respondents received ongoing support through other service contracts, the most common being Supported Independent Living (45.7%) and Domestic and Personal Assistance (15.2%). It is likely, therefore, that respondent's reporting either acknowledged the support they received through these contracts as also advancing their vocational goals and/or that ongoing support was delivered in an integrated way.

Respondents tended not to have contact with a Vocational Coordinator as frequently. Thirty-six percent of respondents said, in the previous four weeks, they had contact with their Vocational coordinator two or more times, but a similar proportion reported having no contact with their Vocational Coordinator (30.1%).

(UN)EMPLOYMENT

Within the social policy discourse, disabled people's access to paid employment has emerged as perhaps the most often used barometer of whether progress is being made towards the vision of a non-disabling society. Improving disabled people's participation in employment finds expression as the fourth objective of the New Zealand Disability Strategy (Minister for Disability Issues, 2001, 2016) and as the preeminent aim of Pathways to Inclusion (Minister for Disability Issues, 2001). Being able to work on an equal basis with others is also codified as a human right within the UN Convention on the Rights of Disabled Persons or "UNCRPD" (UN, 2016). In seeking to apply the principle of non-discrimination to every human life, Article 27, recognises the right of persons with disabilities to the same opportunities to gain freely chosen or accepted employment within work environments that are open, inclusive and accessible.

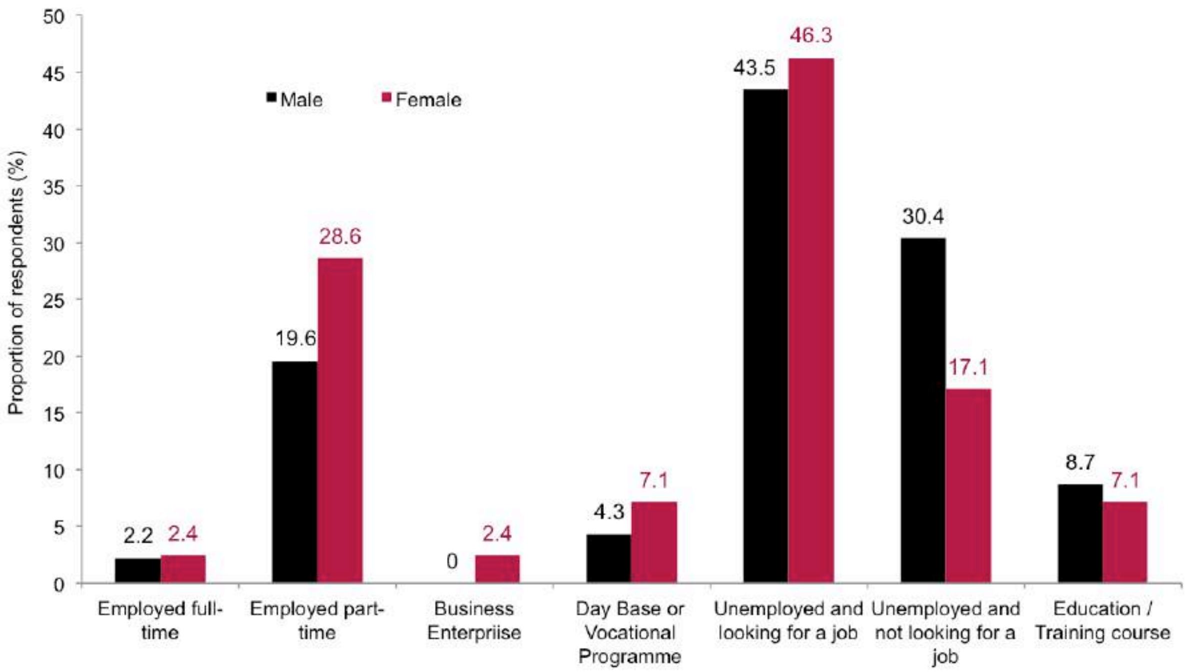
In spite of its status as a key indicator of inclusion, the proportion of disabled people living beyond employment has remained both disproportionally and persistently high. In 2013, Statistics New Zealand (2014) estimated that disabled adults were: less likely to be participating in the New Zealand labour market (50% disabled, 76% non-disabled); and almost twice as likely to be unemployed (9% disabled, 5% non-disabled) as non-disabled citizens. As a consequence, in 2013 less than half of disabled adults in New Zealand reported being employed for one or more hours a week (45%) compared to 72% of non-disabled New Zealanders.

Given the way employment connects with most other domains of life quality, access to employment has always featured prominently in disabled people's consideration of their human rights status. In their second report to the United Nations on the progress New Zealand was making to realising rights articulated in the UNCRPD, the New Zealand Convention Coalition identified Article 27 as an arena of particular importance to the disabled community. However, they pointed out in the report that, in addition to the unequal access disabled people had to employment, the worlds of work often were qualitatively different for disabled employees (Convention Coalition Monitoring Group, 2012). They noted that disabled people tended to cluster within what Robyn Hunt (1994) described as the "expendable fringes" of the New Zealand labour market, working in menial, casualised and part-time occupations for lower wages and with fewer opportunities for career advancement than non-disabled New Zealand employees.

Question 11 of the *"Getting the life I want"* Online Survey asked respondents about their present employment status. Of the 88 people who responded to the question, only two described themselves as having full-time employment.

Whilst it was more common for respondents to report having a part-time job, less than one-quarter of respondents described themselves as being in part-time employment (24%). Female respondents (29%) were more likely than males (20%) to report being in part-time employment. This finding is consistent with the national trend for women to be over-represented in casual or part-time employment but is at odds with their under-representation in the labour market, suggesting that the kind of work that disabled people often find themselves steered towards are roles traditionally occupied by women.

Figure 7. The employment status of male & female respondents



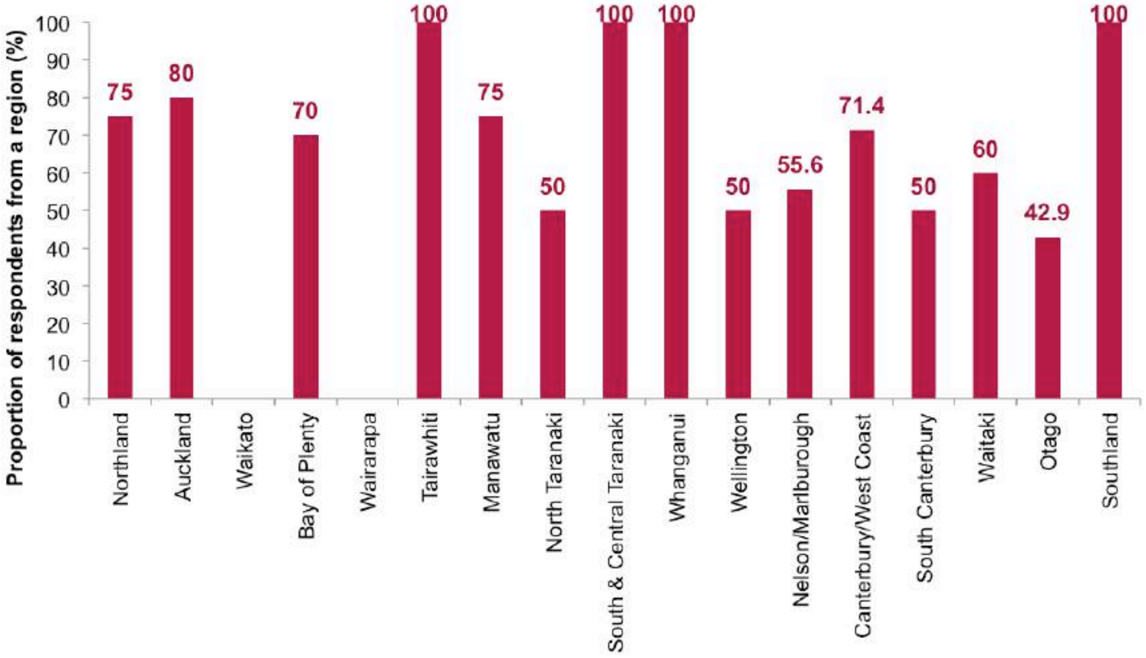
Whether or not a respondent participated in voluntary work had a significant impact on the likelihood they would describe themselves as in part-time employment. Only 12% of respondents who said they did voluntary work also described themselves as in paid, part-time employment compared to 43.3% of respondents who did not do voluntary work. The odds that a respondent who **did not** do voluntary work would have a part-time job were 5.8 (95% CI = 1.88-18.18) times higher than respondents who did.

Rather than voluntary work "stair-casing" people towards employment, the opposite seemed to be true. One possible explanation is that voluntary employment may have been seen as a vocational outcome in its own right, decreasing the obligation on support staff to continue the search for paid employment once voluntary work was found. The finding reported previously, that a significant proportion of respondents did not name finding any kind of employment as a vocational goal(s) (57%), despite a much more universal aspiration to work would lend further support to this possible explanation. As noted previously, 75% of respondents who knew their goals but did not name getting a job amongst them described wanting paid work hours later in the survey, suggesting that "voluntary work" for this cohort may already have been constructed as a more viable outcome than the employment they otherwise aspired to. Comparing the number of hours respondents actually worked to the number they said would have liked to work further reinforced the argument

The most obvious disparity we discovered was between the proportion of respondents who said they were unemployed (72%) and whose preference it was not to work (20%). All respondents were of working age and yet in excess of seven out of every ten people reported not being in paid employment.

By region, the proportion of respondents who said they were not in any form of paid employment ranged from 100% in the Tairawhiti (n=7), South and Central Taranaki (n=4), Whanganui (n=1) and Southland (n=100) regions through to 42.9% of respondents in the Otago region. Whilst providing a broad brush-stroke of regional variation in unemployment, the small number of respondents means that these findings may not be a reliable estimate of the 'true' rate of unemployment in these CCS Disability Action regions.

Figure 8. The proportion of respondents who were unemployed by region

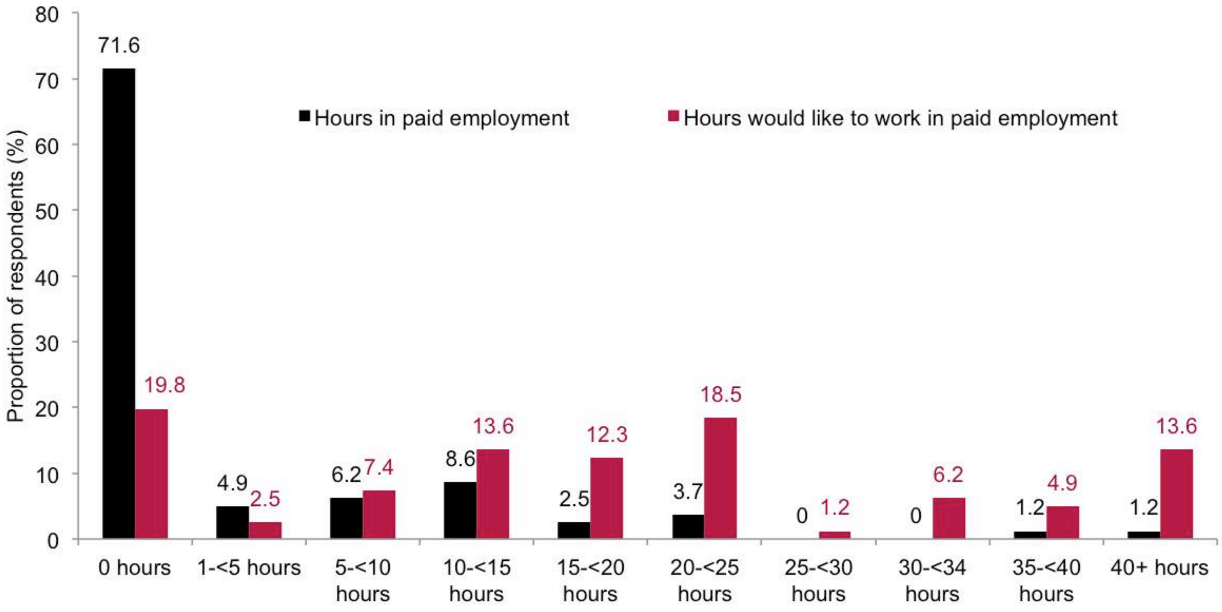


As with the findings presented previously, respondents who said they did voluntary work were significantly more likely to also be unemployed. The odds that a respondent who did voluntary work would be unemployed were 3.4 (95% CI = 1.12-10.16) times higher than for respondents who did not do voluntary work.

People's ethnicity also appeared to have an impact on the likelihood a respondent would be unemployed. Whereas, two thirds of respondents who self-identified as New Zealand European were unemployed (66%), no one who self-identified as Māori (n=7), Pacifica (n=3) or of Indian (n=4) ethnicity were in paid employment for one or more hours a week.

A closer examination of the number of hours that people said they were in paid employment revealed that in excess of nine out of every ten respondents were either not in paid employment or worked for less than 15 hours (92%).

Figure 9. The number of hours per week participants said they were in & would like paid employment



In the recent discussion document, *Employment, Participation and Inclusion Services: Draft Proposals for Change,* the Ministry of Social Development (2015), henceforth "MSD", argued for the adoption of an outcomes-based. Key elements of the proposed changes include;

- A focus on supporting people "who are seeking and likely to get part-time or full-time sustainable employment within an agreed period of time" by restricting eligibility for employment related vocational support to people assessed as meeting this criteria.
- Incentivising "sustainable" employment as an outcome, by establishing 15 hours paid employment as the benchmark for enhanced funding.
- A signal that the MSD would direct future funding towards Providers that are more effective at supporting people to achieve Sustainable Employment outcomes.

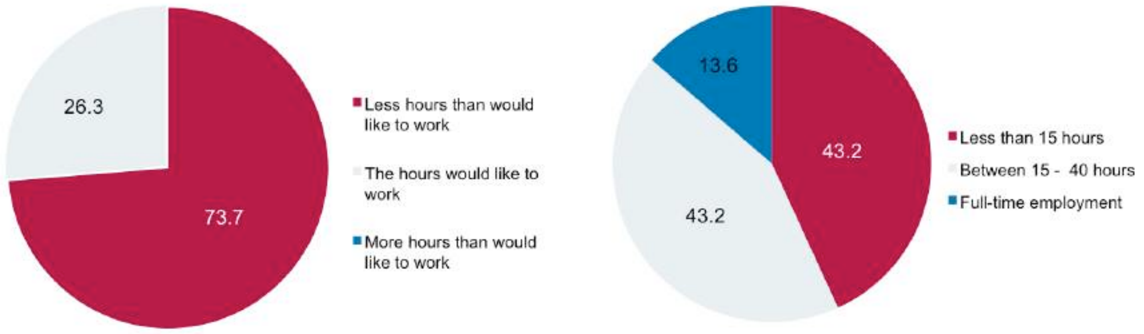
Implied, but not said, in the discussion document is that Vocational Providers are currently underperforming in their role of supporting disabled people into paid employment and, most especially, not moving people into the kind of employment that would result in their *"being able to stop receiving a benefit or receive reduced benefit payments because of the income they earn"* (Ministry of Social Development, 2015).

At first blush, our finding that only 8% of respondents reported working more than 15 hours a week appears to support the Ministry's assertion that vocational services may not be achieving the employment outcomes that disabled people are seeking.

Further evidence of "under performance" might also be read into the finding that 74% of people who completed this part of the survey reported being employed for fewer hours than they would have preferred to work.

Figure 10.a (left) The proportion of respondents who wanted to work more hours than they were currently

Figure 10.b (right) The number of hours respondents said they wanted to work



The people who completed the *"Getting the life I want"* Survey were, on average, in paid employment for 3.8 (SD= 8.4) hours a week. When we asked people how many hours they would have liked to work, respondent's preference, on average, was to have been in paid employment for 18.0 (SD= 16.4) hours. Moreover, whereas 8% of respondents reported working for more than 15 hours a week, 57% said they would have liked to be working for more hours than the MSD threshold of 15 hours paid employment and 14% said they would have liked to have been in full-time employment.

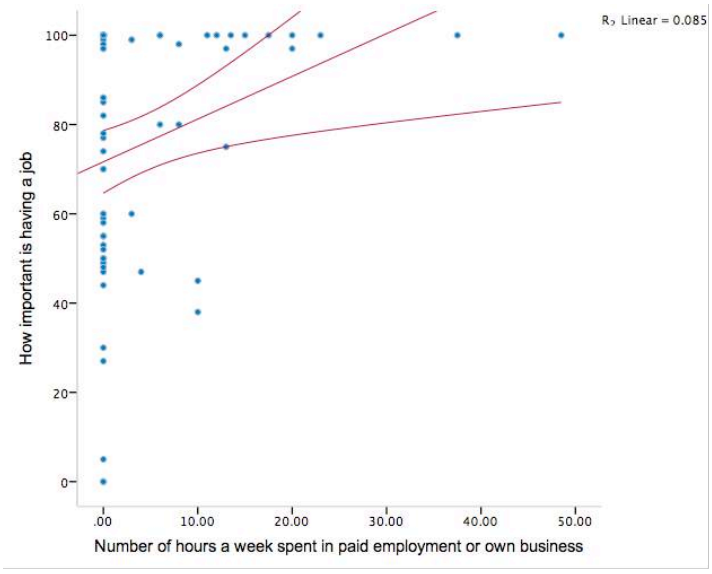
As is discussed in greater detail later in this report, the narratives of disabled people revealed a much more complex picture of the way (un)employment intersected with their lives than is communicated by these findings.

Two out of every ten respondents reported a preference not to be in paid employment (20%). Similarly, more than four out of every ten respondents said that, whilst they wanted paid work, they wanted to be employed for fewer than the MSD threshold of 15 hours (43%). All the participants we spoke to who preferred to work fewer than 15 hours, said employment played an important role in lives, including describing an array of different ways their lives would have been impoverished without being able to access to the world(s) of work.

It is also important to note that only 13.6% of respondents who answered the "*Getting the life I want*" Survey said they were looking for full-time employment and of the remainder of respondents who expressed a preference for working for more than 15 hours only 12% wanted to work for between 25 – 40 hours. It was much more common for people to say they wanted to work for between 15 – 25 hours (31%). In speaking to respondents about their employment decisions, however, we observed a high degree of ambivalence towards working between 15-25 hours. Whilst those who preferred working between 15-25 hours typically liked the prospect of more work, including feeling that it was a good fit with the demands of managing their impairment, they also reported feeling exposed to the uncertainties of benefit abatement and impact that intermittent ill-health might have on future income and entitlements.

Regardless of their employment status, respondents tended to rate the importance of employment highly. On a 100-point scale with "extremely unimportant" (0) and "extremely important" (100) as scale anchors, respondents, on average rated the importance of employment at 74.6 (SD= 29.6). Contrary to the finding reported by Milner & Bray (2004) that the people who accessed CCS Disability Action vocational support in 2003 who appeared most sensitised to their absence from the world of work were participants most marginalised from employment, the trend found in the "*Getting the life I want*" Survey was for respondent's rating of the importance of employment to increase with the number of hours they worked.

Figure 11. The relationship between the number of hours respondents worked and their rating of the importance of work



Whilst the average rating of the importance of employment given by respondents who were unemployed was high (70.0 points), respondents who were employed for less than 15 hours a week, on average, rated its importance higher (82.4 points) and respondents who worked for more than 15 hours a week rated its importance as significantly higher (99.6 points).

One possible explanation is that people who were not and/or had not ever worked, had organised their lives in ways that responded to the distinct possibility of never realising paid employment. This argument is consistent with research that is emerging from within the Quality of Life paradigm that suggests that people tend to re-weight the importance of quality of life domains like “productivity” in order to maintain a sense of subjective wellbeing (Cummins et al, 2002). If correct, not having employment represented as a viable outcome either by employers, sources of support or the proposed Vocational Outcomes Framework is likely to have affected disabled people’s perception of the personal importance of employment.

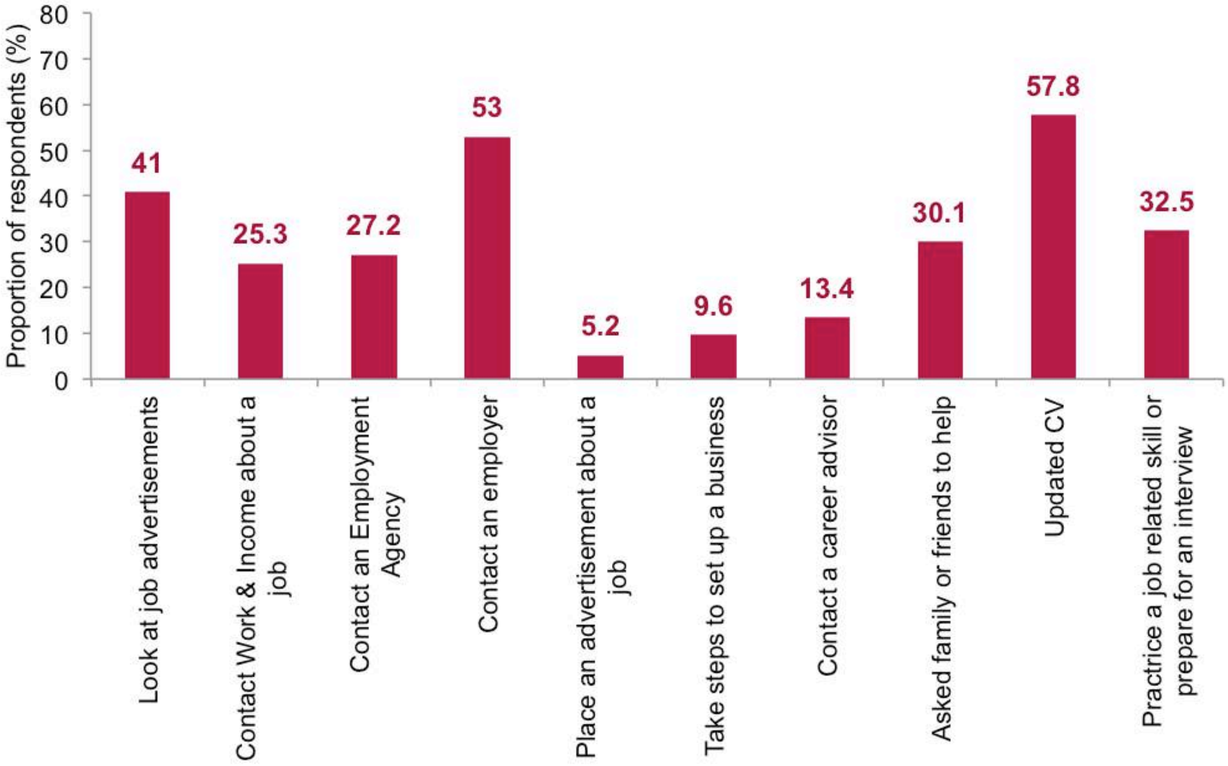
The type of employment search support people received

Respondents were asked which, of a range of different ways, someone from CCS Disability Action had assisted and supported them to search for a job.

Two of the most commonly reported ways respondents said CCS Disability Action had helped involved passive, rather than active, search strategies. Close to six out of every ten respondents said that they had received support to update their CV (58%) and four out of every ten respondents reported receiving support to look at job advertisements (41%).

More than half of the respondents did say, however, that someone from CCS Disability Action had helped them to look for a job by contacting an employer (53%).

Figure 12. The range of ways respondents said they had been supported to search for employment



Much less commonly reported were strategies that involved CCS Disability Action collaborating or coordinating the employment search alongside either mainstream or informal sources of support.

Twenty-seven percent of respondents said someone from CCS Disability Action had assisted them to contact and Employment Agency (43%), with participant narrative suggesting that this typically involved searching job postings rather than developing a relationship with a placement service or orientating an agency to a person's individual strengths or attributes. No evidence was found of vocational support seeking to change the narrative of employment in ways that alerted potential employers to the business advantages of including disabled people within a more diverse workforce. Similarly, only 13% of respondents reported being supported to contact a careers advisor and 30% of respondents said CCS Disability Action had sought to engage a person's family or friends as part of a more person-centred search and job support strategy. Research evidence and participant narrative both suggest that the network of community associations, through which disabled people's family and friends are connected to their community, are often an effective conduit to employment. On the strength of this evidence, our findings suggest that improving relational connectivity remains an untapped source of future vocational support.

Other strategies that took more time and required developing and collaborating with others were also less common. Eight respondents said that they had received support to explore setting up a business or micro-enterprise (10%).

One quarter of respondents indicated that CCS Disability had assisted them to contact Work and Income about a job (25%). In the conversations we had with participants, many people spoke of valuing the way CCS Disability Action had helped them to navigate the difficult and at times dehumanising bureaucracies of Work and Income and MSD. It is not possible to know whether people's responding included the support they had received to manage their relationship with Work and Income New Zealand.

Respondents were also invited to name other types of support they had received to help them find a job. Almost all of the 'other" ways respondents mentioned involved CCS Disability Action staff encouraging them or connecting them to voluntary work in their community.

VOLUNTEERING

Not-for-profit organisations, many of whom depend on volunteers, make an important contribution to New Zealand society. It has been estimated that one in three New Zealanders undertake voluntary work and two out of every three New Zealanders report doing “unpaid work” for community organisations (Statistics New Zealand, 2016).

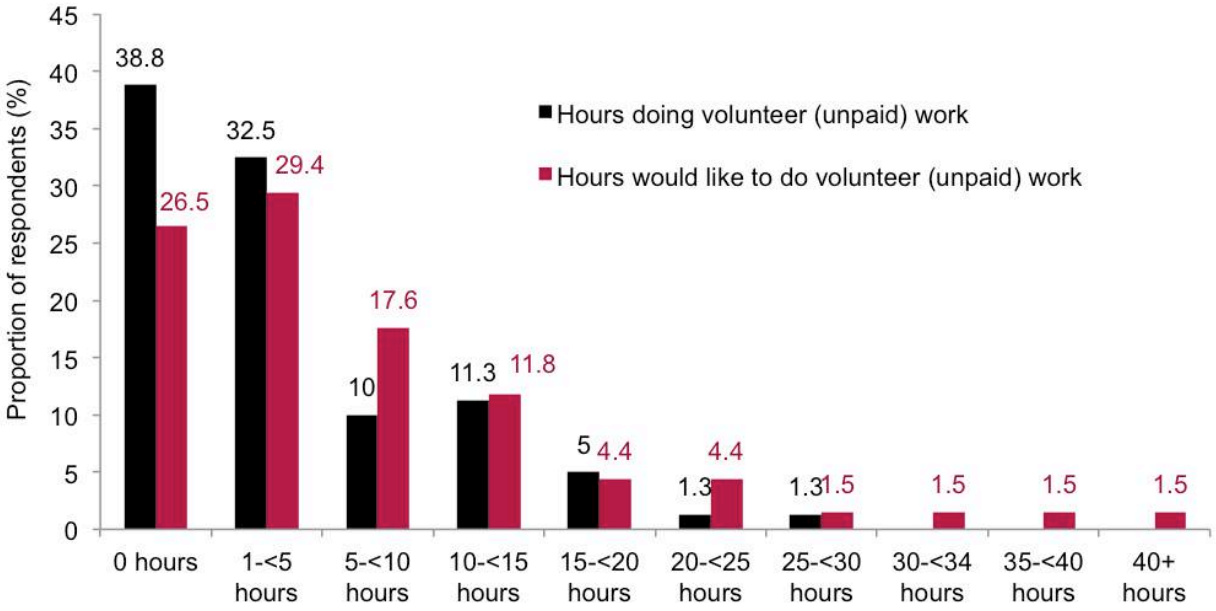
Statistics New Zealand also reports that New Zealanders who undertake voluntary work experience higher levels of life satisfaction, a finding that aligns with international studies that have found volunteering to be motivated by a desire to help others or make a difference and that volunteering is associated with improved mental and physical health, life satisfaction and levels of social engagement (Balandin et al, 2006).

Despite a steadily increasing reliance on volunteer labour, evidence suggest volunteering is declining, with community organisations expressing concern about the sustainability of community-based services. Disabled people may, therefore, represent an important community resource, whose contribution through volunteering may help build disability capacity and improve the inclusiveness of New Zealand communities.

Findings from the *“Getting the life I want”* Survey suggest that disabled people who are in receipt of vocational support may be twice as likely to undertake voluntary (unpaid) work as other New Zealanders. More than six out of every ten respondents described doing voluntary (unpaid) work for one or more hours a week (62%).

Female respondents (66%) were slightly more likely to undertake voluntary (unpaid) work than male respondents (58%) and younger respondents (67% aged 15-24 years; 76% aged 25-34 years) were more likely than older respondents (44% aged 45-54 years; 25% aged 55-64 years), suggesting that building “work experiences” may have informed the decision-making that preceded respondent’s voluntary work.

Figure 13. The number of volunteer hours respondents said they did & would like to do



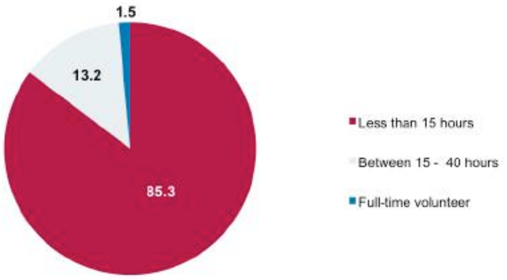
The other significant difference between survey respondents and the general population was that respondents were more than twice as likely to be in voluntary (unpaid) work than to be in paid employment. Whereas 72% of respondents reported having no access to paid employment only 38% of respondents did not do some form of voluntary (unpaid employed.)

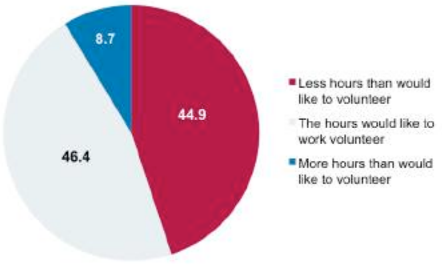
More importantly, the single most important predictor of who was or was not likely to report doing unpaid voluntary work was the employment status of respondents.

Just as with paid employment, most respondents worked in an unpaid voluntary role for less than 15 hours a week (85%) with one third of all respondents working for less than five hours a week, meaning that respondents were typically located at the margins of both paid and unpaid work culture. In fact, little difference emerged in the average number of hours respondents reported working in paid (3.8 hours; SD= 8.4) and unpaid (4.3 hours; SD= 5.6) employment, even though twice as many people said they volunteered within their community.

Figure 14.a (left) The amount of hours per week respondents volunteered

Figure 14.b (right) The proportion of respondents who wanted to do more volunteer hours



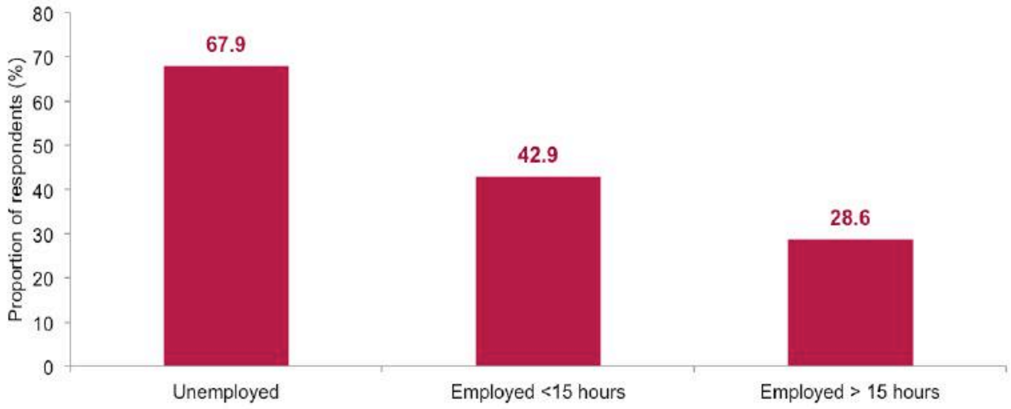


Previously in this report, we speculated that for many people "volunteering" may have been seen as an outcome in its own right and that this was particularly the case for people for whom volunteering may have been seen as more realisable outcome than paid employment. We reached this conclusion because the odds of being employed were nearly six times higher if a respondent **did not** do voluntary work. Further evidence that some people may have been steered towards voluntary (unpaid) work might also be inferred by the fact that, whereas paid employment featured prominently in respondent's goal setting, doing voluntary work did not feature as much and 74% of respondents said they worked fewer hours in paid employment than they wanted to. By way of comparison, only 45% of respondents expressed a preference for doing more voluntary hours and 9% of respondents saying they felt they worked too many hours in unpaid employment.

Perhaps the strongest evidence that people were either directed towards paid or voluntary work can be found by exploring the association between respondent's employment status and the likelihood they would be engaged in voluntary (unpaid) work.

The number of hours that respondents were employed had a significant impact on the likelihood they would report doing voluntary hours. Respondents who were unemployed were most likely to work in voluntary (unpaid) employment with 68% of people volunteering as an alternative to paid employment. Conversely, respondents who said they were employed for 15 hours or more were least likely to be in voluntary (unpaid) employment, volunteering at a rate slightly below that reported for the New Zealand general population (29%). The odds that an unemployed respondent would be working as a volunteer were 11.2 (95% CI= 1.63-76.92) times higher than a respondent who worked in paid employment for 15 hours or more.

Figure 15 The proportion of respondents who volunteered by employment status



What did not differ from the overall NZ population was respondent's assessment of the value of voluntary (unpaid) work.

In their narrative, participants described valuing a number of attributes of unpaid, voluntary work, many of which have been reported by the general population and some of which are distinctively different as a consequence of the lived experiences of disabled people. Many respondents described valuing the way their voluntary work was a welcome interruption to the isolation and boredom of their week. *"It gets me out of the house,"* one respondent noted. For a number of people, social contact emerged as the pre-eminent reason for volunteering and most especially for those who choose forms of volunteering that matched their interests. Volunteering in ways that people cared about allowed them to participate in their community in ways that were self-defining and to work alongside people who were most likely to recognise and share their interests and passions.

Others spoke of the way that volunteering, as opposed to the more hierarchically organised worlds of employment and disability support, tended to equalise relationships of place. For a small group of people, volunteering was valued as a way of destabilising assumptions about the contribution disabled people make to their community by contributing in ways that transparently held no material advantage. *"In lots of ways my volunteer work is more important than my paid job,"* someone told us, *"because I am no different to anyone else there. We are all there for the same reason."*

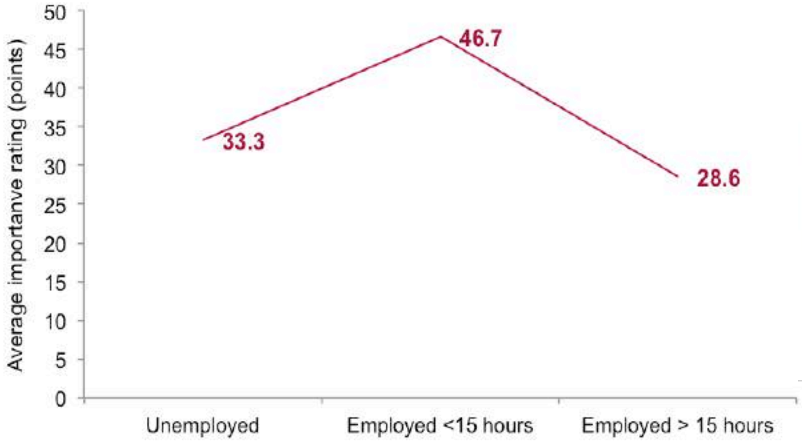
Respondents who volunteered rated the importance of volunteering significantly higher than respondents who did not. On a 100-point scale with "extremely unimportant" (0) and "extremely important" (100) as scale anchors, respondents who volunteered, on average, rated the importance of their voluntary (unpaid) work at 65 points. This rating was ten percent lower than respondent's overall assessment of the importance of paid work (75 points), but significantly higher than the average rating given by respondents who weren't engaged in voluntary work (42 points).

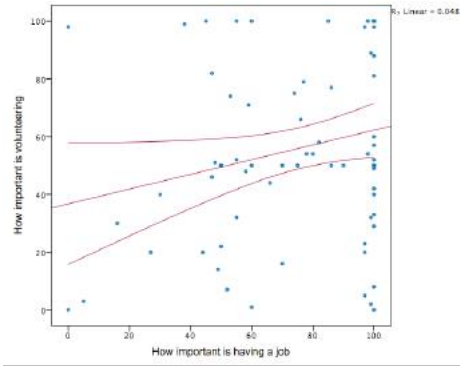
Female respondents (64 points) also rated the importance of voluntary work significantly higher than the ratings of male respondents (49 points) but, perhaps more importantly, people's employment status appeared to make no difference to the value they attributed to voluntary work.

Little difference was observed between the average rating of the importance of volunteering given by respondents who were unemployed (33 points) or those who were either employed for less than (48 points) or more than 15 hours a week (27%). Moreover, not only did respondents who were employed tend to rate the importance of volunteering higher than respondents who were unemployed, a significant positive correlation was also found between respondents rating of the importance of both paid and unpaid voluntary work. People who rated the importance of employment highly were significantly more likely to rate the importance of volunteering highly too.

Figure 16.a (left) respondent's average rating of the importance of volunteering by employment status

Figure 16.b (right) The relationship between respondent's ratings of the importance of employment & volunteering





Rather than viewing voluntary work as a more achievable alternative to paid employment, the clear implication of this finding is that unpaid voluntary work is viewed as having the potential to improve the life quality of people in a way that is insensitive to whether respondents were currently in or out of paid employment and needs, therefore, to be considered as a valid vocational outcome for all people who receive vocational support.

TRAINING AND EDUCATION

Within the vocational paradigm, vocational training has historically been emphasised as a way of supporting employment by improving the "job readiness" of disabled people. In more recent times the rationale for vocational training has been challenged, both by cornerstone principles of the Supported Employment movement and by disabled people themselves. Central to Supported Employment best practice are the beliefs that all disabled people should have direct access to open employment, regardless of their impairment, and that active support within the workplace promotes better learning and employment outcomes than abstracted pre-vocational training. These principles align with the experiences of some disabled people who have expressed frustration at feeling forever caught on a treadmill of pre-vocational training that never seems to end in employment (Milner & Bray, 2004).

Conversely, disabled and non-disabled employees typically value "on-the-job training," equating it with a sense of feeling valued as an employee and a commitment to a person's career trajectory. Anecdotal evidence is emerging that "on-site" vocational training may also support disabled people to appreciate the significance of specific job skills and competences, whilst also helping people to learn the often "unspoken" social and organizational conventions of workplace culture (Milner & Parish, 2012).

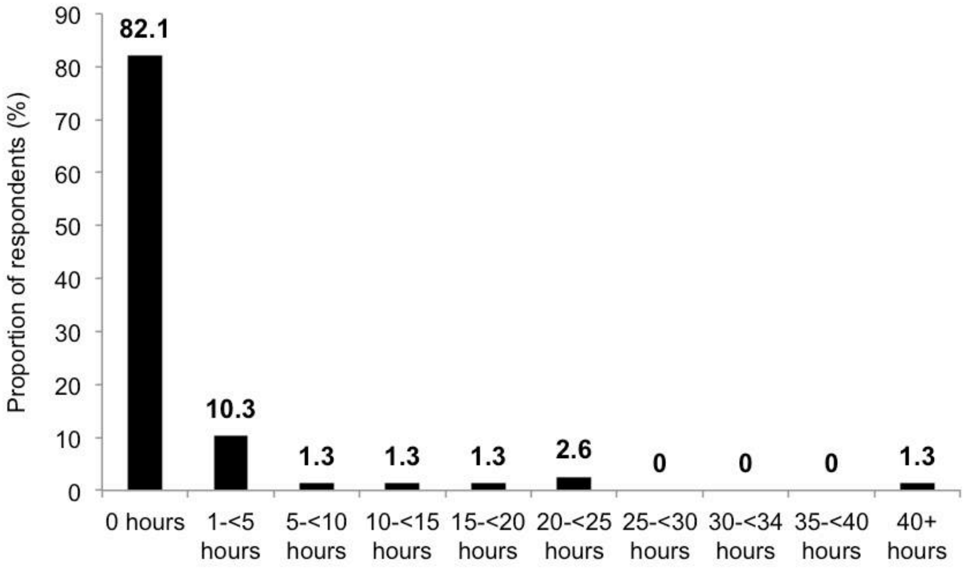
More latterly, attention has turned towards disabled people's ability to engage in lifelong learning. Article 24 of the UNCRPD codifies disabled people's right to inclusive education across the entire education system. The convention asserts that lifelong-learning is elemental to the full development of a person's potential, viewing effective individualised educational support as prerequisite to disabled people ability to develop their personality, talents and creativity. Within the UNCRPD, life-long learning is also acknowledged as advancing effective participation in a free society.

One of the ways that life-long learning is known to have an impact on people's participatory presence is within the domain of employment. In 2014, Statistics New Zealand (2014) reported that a person's educational qualifications made a considerable difference to the labour force participation of both disabled and non-disabled New Zealanders. They noted that employment tended to increase with the level of qualification. For example, for disabled people, participation in the New Zealand labour market increased from 36% for people with no formal qualification to 71% for people with a university degree.

Disabled adults typically have fewer qualifications than their non-disabled peers. In 2013, disabled adults were more than twice as likely to have no formal qualification than nondisabled adults. In 2013, 33% of disabled adults had no formal qualification compared to 15% of non-disabled adults and, conversely, just 12% of disabled adults had a university degree compared to 25% of non-disabled adults (Statistics New Zealand, 2014). In a discussion document commissioned by CCS Disability Action and Workbridge, Cleland & Smith (2010) argue, therefore, that disabled people are doubly disadvantaged within the New Zealand labour market because, in addition to differences in their ability to access the kind of inclusive educational experiences that might lift educational qualifications, disabled people with post-school qualifications tend only to be employed at the same rate as non-disabled New Zealanders with no formal qualifications.

Only seven respondents reported currently participating in an educational or training course (8%). Question 19 of the *"Getting the life I want"* Survey asked people to state how many hours a week they spent either at school or doing course related study and slightly more participants reported studying for one or more hours (n= 14; 18%). However, only five respondents reported being engaged in course related study for more than ten hours a week, meaning that 95% of respondents either did not participate or had a very part-time engagement with ongoing education or training, despite many reporting spending long hours not productively engaged.

Figure 17. The number of hours respondents reported spending at school or doing course related training



Female respondents (23%) were more likely to report spending one or more hours a week on course related study than males (14%) and respondents who self-identified as Māori (29%) were more likely than respondents who self-identified as New Zealand European (16%). However, the small number of people who were participating in training or education meant that it was not possible to determine whether the gender or ethnicity of respondents explained any variation in the likelihood people were participating in ongoing learning.

Although only 14 people said they spent one or more hours at school or doing course related study, 74 respondents rated the importance of continuing to study. On the same 100-point scale anchored by "extremely unimportant" (0) and "extremely important" (100) we used to capture respondent's assessment of the importance of paid employment and volunteering, people, on average, rated continuing to study (58 points), slightly higher than their rating of the importance of volunteering but less important than paid employment.

Two factors were found to have a significant impact on the rating respondents gave of the importance of continuing to study. They were being engaged in course related study and whether respondents belonged to a community group or not.

Perhaps not surprisingly, respondents who spent one or more hours doing course related study rated the importance of ongoing education (80 points) significantly higher than respondents who did not participate in an education or training course (52 points).

Embedded in the processes of attending and learning, however, are a range of different experiences that may have contributed to the higher value people who participated in ongoing education ascribed. A possibility that the perceived benefits of participating in ongoing learning might extend beyond personal development or self-expression was suggested by the other factor found to influence respondent' rating.

Respondents who described themselves as not belonging to any community group or organisation rated the importance of ongoing education (67 points) significantly higher than respondents who were a member of one or more community group(s) or organization(s) (52 points). One possible explanation for this finding is that people who felt more socially dislocated recognised ongoing learning as a way to include oneself within a community of other learners. In their narrative, a number of respondents described experiencing a shrinkage in their social world after leaving school and it is possible that continuing to learn alongside others was seen as one possible gateway to the kind of relationships people said they had left behind in their transition beyond the community of their school.

Against a backdrop of having more limited access to paid employment and the other social worlds (discussed in more detail in the following sections), a surprisingly small number of participants said they were currently engaged in ongoing training and education. Respondents absence from institutions of learning mirrored a more pervasive difficulty that disabled people describe in having access to their right to inclusive education. As a consequence of this dislocation, respondents may also have simultaneously been distanced from the personal, relational and participatory benefits known to accompany life-long learning.

COMMUNITY MEMBERSHIP AND BELONGING

Within New Zealand social policy, the aim of enhancing people's ability to participate in the life of their community can be traced back to the development of the social welfare system. For disabled people, employment tends to have been emphasised as the most valid form of community participation. This, in part, is a response to the impact that the absence from the worlds of work and the impact that inequality within the labour market has had on disabled people's ability to participate in all other domains of community life.

Over the past three decades, the concept of "social inclusion" has become ubiquitous in disability policy (Power, 2013) as the Social Model of Disability has increasingly informed national and transnational policy in ways that have prioritised the removal of "disabling" barriers to social and economic participation. Within social policy like the New Zealand Disability Strategy "valued lives" have increasingly become benchmarked against the participatory presence of disabled people across the spectrum of "mainstream" spaces and places, including having a presence within the social, cultural, recreational and political communities that define a society.

The right to live and be included in the community and to be supported in ways that prevent isolation and segregation finds direct expression in Article 19 of the UNCRPD.

CCS Disability Action has commissioned two descriptive research projects that have sought to explore: the meaning of "community participation" to disabled people; and the ability of people with high and complex support needs to access their Article 19 right to live and participate in their community. The two pieces of commissioned research were separated by ten years, the closure of vocational day-bases, the adoption of person-centred planning and New Zealand's ratification of the UNCRPD. What the research discovered, however, was that the life-spaces of the disabled people who collaborated with the research team in both projects were remarkably similar. In 2003 and in 2013, disabled people tended to experience a community presence through their vocational support as:

- An act of migration away from places of social knowing towards public spaces of acknowledgement.
- A fleeting presence on the margins of community life in spaces like the supermarket, gym, pool, public library, boccia hall and the two-dollar shop.

- An absence from the participatory contexts from which most New Zealanders would derive a sense of participatory citizenship, including paid employment, ongoing education, parenthood, neighbouring or community organisations including spiritual, cultural, interest or sport or recreational groups.
- A sense of having almost no access to communities where they were likely to experience a sense of membership or belonging.

Within that decade, the concept of "belonging" filtered into the international lexicon of social policy. In the preamble to the UNCRPD, we find, for example, the old social policy objective of "full participation" reframed as a conduit to the more humanising experience of *"feeling an enhanced sense of belonging."*

One reason that academics suggest may account for this re-languaging of inclusion, is that being able to access a sense of "belonging" expands our understanding of social inclusion beyond the simple binaries of "inclusion" meaning being present and "exclusion" being absent. Through their narrative, disabled people have increasingly challenged these simplistic readings of (ex)inclusion by describing new geographies of feeling in and out of place within "mainstream' and "unauthorised social spaces.

The stories told by people who collaborated in the two projects commissioned by CCS Disability Action has contributed to the process of re-languaging social inclusion by providing a set of signposts to "belonging." In the "Community Participation Project," Milner & Bray (2004) asked disabled people what needed to be in place if they were to experience a sense of membership or belonging to their community and the participants instructed them to pay attention to five qualitative attributes of relational proximity, which is described in more detail in the Literature Review.

In writing about how creating art or performance pieces within disability exclusive places can offer some disabled people a safe space within which they can create, geographer Ed Hall (2013) expanded our understanding of belonging further. In a paper he wrote in 2013, Hall argued that (Be)(Longing) is not just about *"be"*-ing in place, but also the "longing" or *"yearning for some form of attachment [….] an active wanting to be in spaces and sets of interrelationships that are something more and something better than this place now"* (Hall, 2013). Whilst acknowledging the transformational hope embedded in a universal yearning to belong, Milner & Mirfin-Veitch (2016), however, align themselves with those disabled people who have argued that becoming a more inclusive society requires New Zealanders to step across the bright line of social distance in ways that expose disabled and nondisabled people to each other's (alternative) imaginings, creativity and humanity. To do this, disabled people tell us, requires an understanding of inclusion as involving relational as well as spatial closeness.

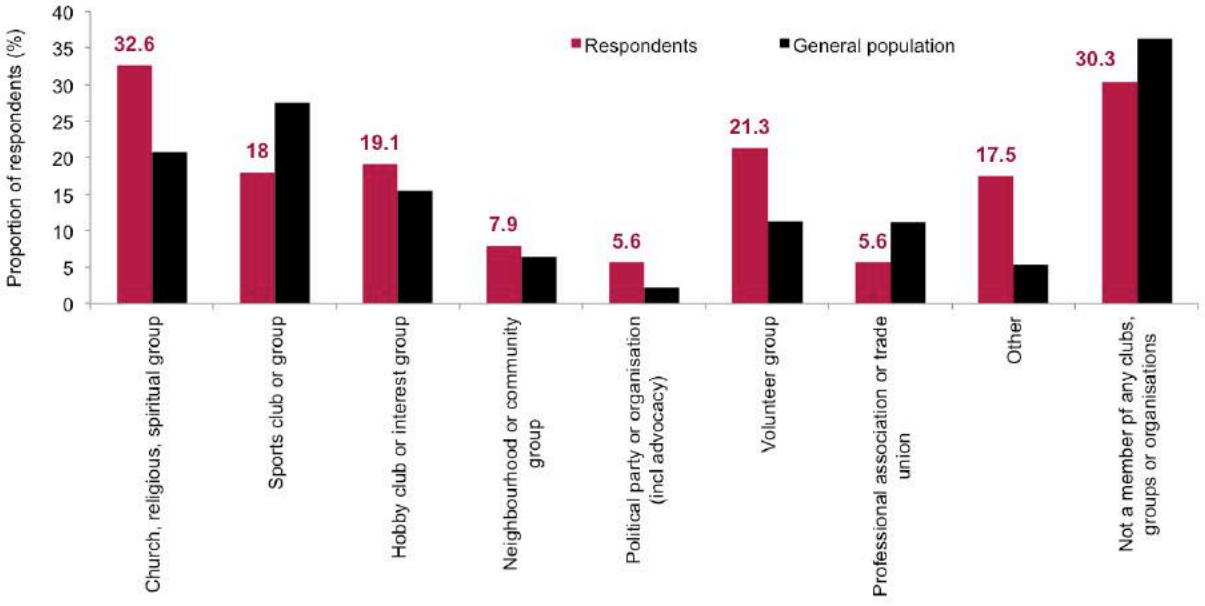
In the following sections, we describe; the range of community contexts in which the people who completed the *"Getting the life I want"* Survey said they belonged, how much contact they had with their friends, family and neighbours and how difficult it was for people to be present in their community. This exploration of people's relational connection to their community is followed by an examination of the different ways respondents would spend their vocational funding as a way of reflecting on the yearning for something more and something better that underscores "belonging."

Community group membership

Question 21 of the "Getting the life I want" Survey asked respondents what groups, clubs or organisations they belonged to. The question replicated another taken from the New Zealand General Social Survey: 2014 (Statistics New Zealand, 2016) and survey findings are present alongside those for the general population in Figure 16.

Seven out of every ten respondents said they belonged to one or more different types of groups, clubs or organisations (70%), a slightly higher rate of club membership than that reported for the New Zealand general population (64%).

Figure 18. The proportion of survey respondents who reported belonging to different community groups, clubs or organisations



The pattern of club membership, however, differed from profile of community participation reported by the New Zealand general population (Statistics New Zealand, 2016). Compared to other New Zealanders, survey respondents were more likely to belong to a church, religious or spiritual group (33% v 21%) or a Volunteer group (21% v 11%), but less likely to belong to a sports club or group (18%). For other New Zealanders, belonging to a sports club or group represented their most common form of community participation (28%).

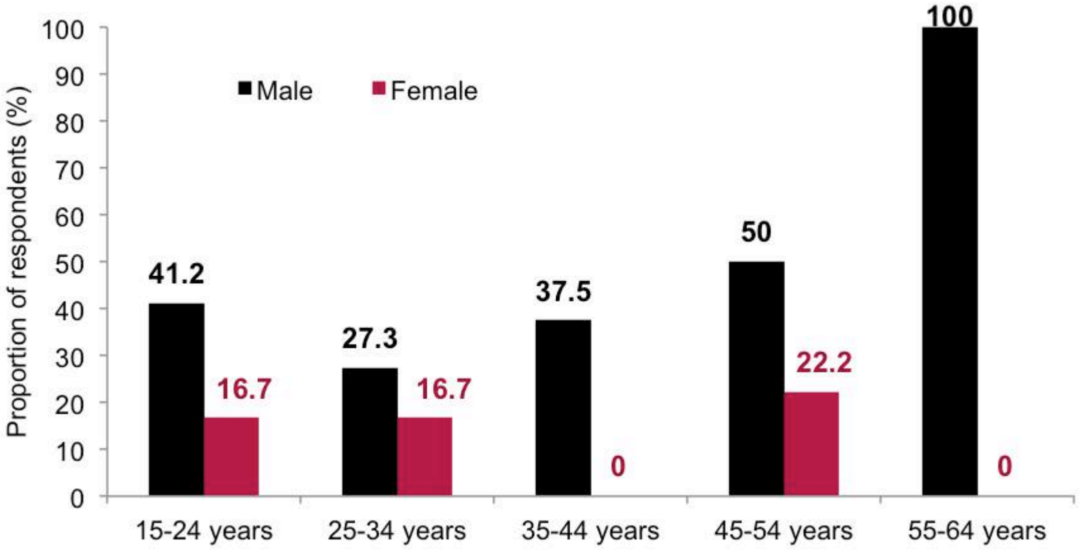
Survey respondents were also much more likely to say they belonged to another type of group or association (18% v 5.4%), with a more fine-grained analysis of their responses revealing most people named a disability related support groups (including; the Blind Foundation, Deaf Society, MS Society) or disability arts or creative groups. Interview data also suggested that other types of community group membership had a disability focus too, with the difference in political affiliation between respondents (6%) and the general population (2%) reflective of their membership of disability advocacy groups and disabled person's organisations, and sports club membership reflective of respondent's participation in Paralympic and Special Olympic sports teams.

Respondents were approximately half as likely as other New Zealanders to report belonging to a professional association or trade union (6% v 11%), consistent with disabled people's lower rate of labour force participation, higher rate of unemployment and more limited access to professional and managerial occupations (Statistics New Zealand, 2014).

Two factors were found to have a significant impact on the likelihood respondents would report **not** belonging to community group, club or organization.

Male respondents (44%) were more than three times as likely to report not belonging to any community group, club or organisation in comparison to females (15%), with male respondents aged 45 years or older (67%) and younger males aged between 15-24 years (41%) reporting the lowest levels of community participation through group membership. The odds that a male respondent would report not belonging to a community group, club or organisation were 3.2 (95% CI= 0.988 – 11.364) times higher than female respondents, suggesting that disabled men and particularly older men who access vocational support may be most at risk of social isolation as a consequence of more limited access to community organisations.

Figure 19. The proportion of male & female respondents who did not belong to a community group, club or organisation



The amount of contact respondents had with disability support staff also emerged as a significant predictor of whether they described belonging to a community group, club or organization. Respondents who said they had had contact with a CCS Disability Action Vocational Coordinator two or more times in the previous four weeks were less likely to report **not** belonging to a community group, club or organisation (12%) than respondents who said they saw a Vocational Coordinator less than twice in the same period (32%).

Perhaps more importantly, respondents who said support workers were a presence in their lives, as a consequence of receiving other types of disability support (19%), were more than twice as likely not to report not being a member of a community group, club or organisation (46%). Approaching half of the respondents who only received vocational support did not belong to a community group, club or organization. This finding is consistent with the observation reported previously that respondents tended not to include different forms of community group membership within the array of vocational goals they described.

A number of possible explanations might account for this finding. Firstly, people who only received vocational support may not have valued relational connectivity through community membership as highly as people who received other types of disability support. However, although respondents who only received vocational support were less likely to rate the importance of belonging to a community group, club or organisation higher than 66% (33%)

than respondents who did receive other types of disability support (42%), no association was found between the type of support people received and their valuing of community membership. Moreover, most of the people we spoke to during the study described experiencing a sense of dislocation from their community, including identifying the need to respond to their sense of isolation as a key support priority.

An alternative explanation is that having support staff in disabled people's lives does make a difference to people's ability to join community group, club or organisation, but that the way support is delivered through a vocational contract is not having the same impact as other types of disability support. Reasons for this might include the more limited contact people who only receive vocational support have with support staff. Another and perhaps related reason might be that supporting people to identify and to become a valued member of a community group, club or organisation is either less of a priority or more difficult achieve given the way vocational support is configured, This explanation is consistent with the observation that fewer people identified forms of community membership as a vocational support goal.

A key finding of the two research projects previously commission by CCS Disability Action was that disabled people's support staff often occupy a central place in the friendship fields of the people they support. In more self-directed support arrangements, where staff can become included within an extended family of care, support staff were found to act as conduit to a person's own community of interests as-well-as provide a safe point of entry into the communities to which they already belonged. Whilst support staff in more formal support arrangements can also act as a bridge to community groups, clubs or organisations, Milner & Mirfin-Veitch (2014) found that disabled people's pattern of community participation in New Zealand tended to shaped by the historical horizons of support practice, including supporting people to participate in: disability exclusive sports and recreational activities, volunteering, craft and hobby groups; and by maintaining a community presence in public, rather than the private, social spaces. Milner and Mirfin-Veitch's (2014) findings align with the pattern of club membership described by survey respondents.

Research in the New Zealand context has also exposed a gender and age skewing to the disability support workforce. In their survey of New Zealand disability sector, Higgins et al (2009) reported that more than three-quarters of the disability support workforce were women (76%) and that two out of every three staff who worked for a disability service were aged 45 years or older (64%). Higgins et al (2009) suggested that the demography of disability support may have implications for the relationships within which disability support is transacted. One of the possible ways this may play out in the lives of disabled people is in defining the types of communities that staff provide a gateway to and/or are more comfortable supporting inclusion within. If, as is suggested by these findings, contact with support staff increases the likelihood that respondents belonged to a community group, then it is possible that having fewer male staff may have contributed to the lower rates of membership experienced by male respondents.

In their interviews, younger participants also feedback that the demography of support work affected the way they were present in the community and the places they went. One young woman, for example, told us that CCS Disability Action *"needs to have more younger staff in the service"* and another said that it was *"sometimes like going out with a child-minder."*

Whilst documenting which community groups, clubs and organisations that disabled people report belonging to does help build a picture of the inclusiveness of a society, it tells us very little about the ways in which people were present, including whether they were able to access the relational attributes of "being" in places elemental to experiences of membership and belonging.

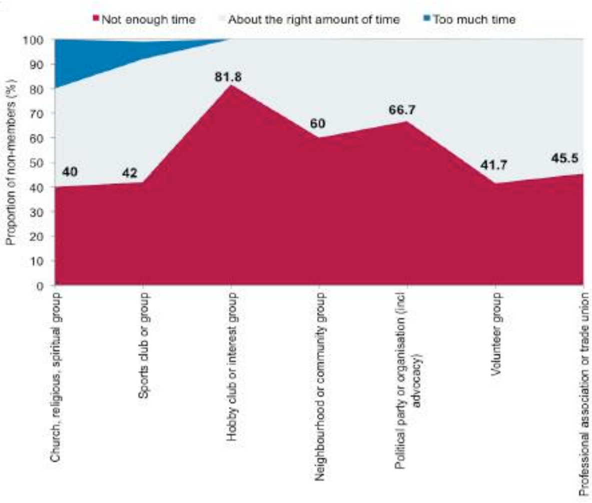
In the survey, we also asked respondent to describe the amount of time they spent with the different types of community groups, clubs or organisations. This question also replicated one drawn from the "*New Zealand General Survey: 2014*" that was used to draw inferences about whether members of a community were able to contribute to the extent that they would like. In the "*New Zealand General Survey: 2014*," 90% of New Zealanders reported having about the right amount of contact with community group members and 10% expressed a preference for more contact.

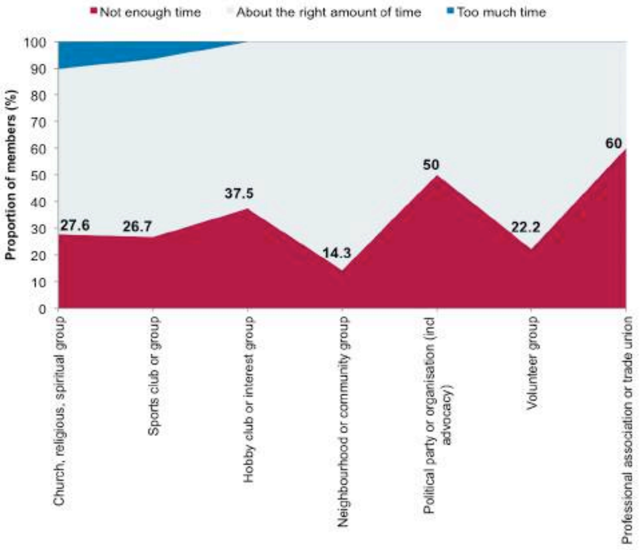
Compared to the New Zealand general population, people who responded to the *"Getting the life I want"* Survey, were much less satisfied with the amount of contact they had with members of all of the different types of community groups included in the survey. This was especially true for people who described themselves as not belonging to a particular type of community group.

Knowing the proportion of respondents who were **not currently a member** of a particular type of community group that expressed a preference for more contact provided a useful indicator of the kind of participatory experiences that people valued but had no access to. Analysis of the responses given by "non-members" revealed a strong preference to participate in the groups, clubs and organisations that all respondents were **least likely** to belong to. Eighty two percent of respondents who did not belong to a hobby club or interest group reported not spending enough time within that type of community and in excess of six out of every ten "non-members" reported not having enough contact with a political party, organisation or advocacy group (66%) or neighbourhood or community group (60%). Conversely, “non-member” respondents were less likely to report not having enough contact with the kinds of community groups, clubs or organisations that disabled people were more likely to attend. Approximately four out of every ten respondents who did not belong to a church, religious or spiritual group (40%), volunteer group (42%) or sports club or group (42%) described not having enough contact with those kinds of communities of common interest. However, although the proportion of people who expressed a preference for greater contact with more commonly attended community groups was lower than other forms of community participation, “non-member respondents” were four times more likely to want more contact than the New Zealand general population (10%).

Figure 20.a (above) The time "non-member" respondents said they would like to spend in community groups

Figure 20.b (below) The time "member" respondents said they would like to spend in community groups





Looking at the issue of community membership by exploring the responses of respondents who **did belong** to a particular type of group provided a useful indicator of the perceived accessibility of different forms of community participation. Respondents who did belong to a community group were less likely to report not spending enough time engaged with the group but were still more than twice as likely to want more contact than the New Zealand general population. The pattern of feeling as if they did not have enough contact with groups that disabled people were less likely to belong to was repeated for members of those groups. Thirty-eight percent of respondents who were members of a hobby or interest group felt they did not spent enough time within that community and 50% of members of political party, organisation or advocacy group and 60% of respondents who were members of a professional association or trade union felt they did not spent enough time within those communities to which they already belonged.

For members as well as non-members, therefore, the pattern of responding suggested people who received vocational support tended to feel a greater sense of estrangement from those community contexts within which other New Zealanders ordinarily experience a sense of participatory citizenship.

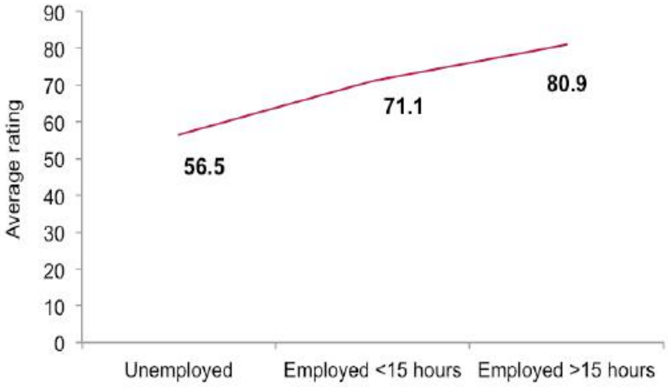
When asked to rate the importance of belonging to a group, club or organisation, respondents, on average, rated memberships lower than employment but higher than either volunteering or ongoing education. On a 100-point scale with “extremely unimportant” (0) and “extremely important” (100) as scale anchors, respondents rated the importance of belonging to a community group at 62 points.

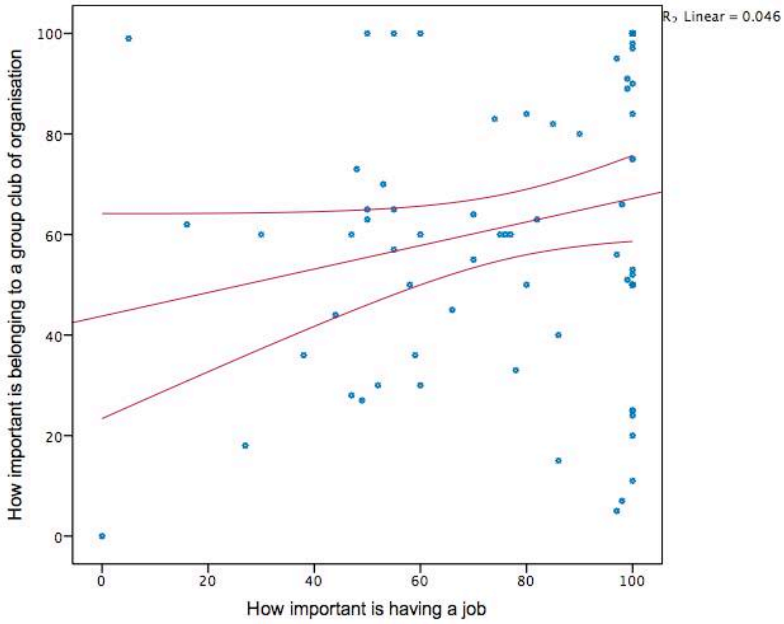
Unlike the association found between the amount of support respondents received and the likelihood they would belong to a community group, no difference was found between the ratings people gave of the importance of belonging and the amount of contact they had with a Vocational Coordinator or other types of disability support.

Whether or not a person was employed, however, was found to have a significant impact on the ratings respondents gave of the importance of belonging to a community group, club or oraganisation. Respondents who were employed for more than 15 hours a week (81 points) were, on average, more likely to rate the importance of belonging higher than respondents who were employed for less than 15 hours (72 points) and significantly higher than respondents who were unemployed (56 points). The odds that a respondent who was employed would rate the importance of belonging to a community group, club or organisation higher than 66 points was 13.3 (95% CI= 1.116-159.839) times higher than respondents who were unemployed.

Figure 21.a (above) Respondent's average rating of the importance of belonging to a community group by employment status

Figure.b (below) The relationship between respondent's ratings of the importance of employment & of belonging to a community group



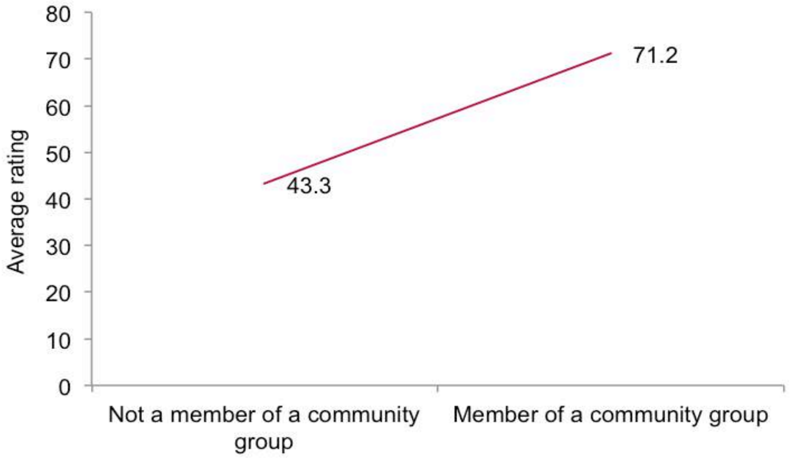


There are a range of possible and potentially interlaced explanations for this finding, one of which could be that differences in the rating of the importance of belonging evidenced the protective effect of employment. The relationship between employment and self-esteem and a range of other measures of wellbeing is now well established in the research literature and it is possible that respondents who were employed rated other forms of participatory citizenship more highly because they felt both able and confident enough to contribute. Included amongst the relational signposts that disabled people instructed others to look to as signposting inclusion were: an expectation that members contributed to the wellbeing of others in the community; and that they were embedded within the culturally specific forms of reciprocity that brought members into closer relationship. Feeling as if one has neither the material nor human capital to contribute in these ways is likely to deter people from seeking membership. It is consistent with Hall's (2013) observation that the geography of disabled people's communities is often shaped by the pull of places that recognise and make use of the social capital of impairment and the push of places where they experience a sense of being an outsider.

Within economies like New Zealand, whether one is employed or not continues to be a marker of a person's status and productivity. It is also the most important determinant of a person's income and the disabled people we spoke to as part of this project told us repeatedly that material poverty made it extremely difficult for them, not only to get out of, but also to afford to belong to community groups and associations. It is also possible, therefore, that in the same way that we speculated that respondents who were unemployed may have reweighted the importance of employment, people who experienced difficulty accessing a community group may have rated belonging to a group, club or organisation not so highly as a way of maintaining a sense of subjective wellbeing.

Two other findings support this potential explanation. Firstly, respondents who rated the importance of employment highly were significantly more likely to also rate the importance of belonging to a community group highly and, secondly, respondents who said they were a member of one or more community groups, clubs or organisations (71 points) rated the importance of belonging significantly higher than respondents who said they were not a member of a community group (43 points). The odds that a respondent who was a member of a community group would rate the importance of belonging higher than 66 points were 27 (95% CI= 2.571-333.33) times higher than a respondent who said they did not belong to a community group, club or organisation.

Figure 22 The average rating of the importance of belonging to a community group given by respondent group members and non-members



A more benign explanation is that people who did not see the value of belonging to a community group were less likely to become a member, but the narrative of respondents suggests that, given the opportunity, people would have chosen to improve their engagement with the community. If true, one of the implications of these findings are that it is possible to identify a highly marginalised population of disabled people who are both disconnected to the worlds of employment and the many other ways to connect and contribute within one's community.

The other clear implication is that it would seem to make no sense to separate the vocational outcomes of employment and community participation. Respondents who were employed were most likely to value and to seek other forms of community participation. On the other hand, people most marginalised from community group membership also had most to gain from the material and psycho-social benefits known to be associated with inclusive employment.

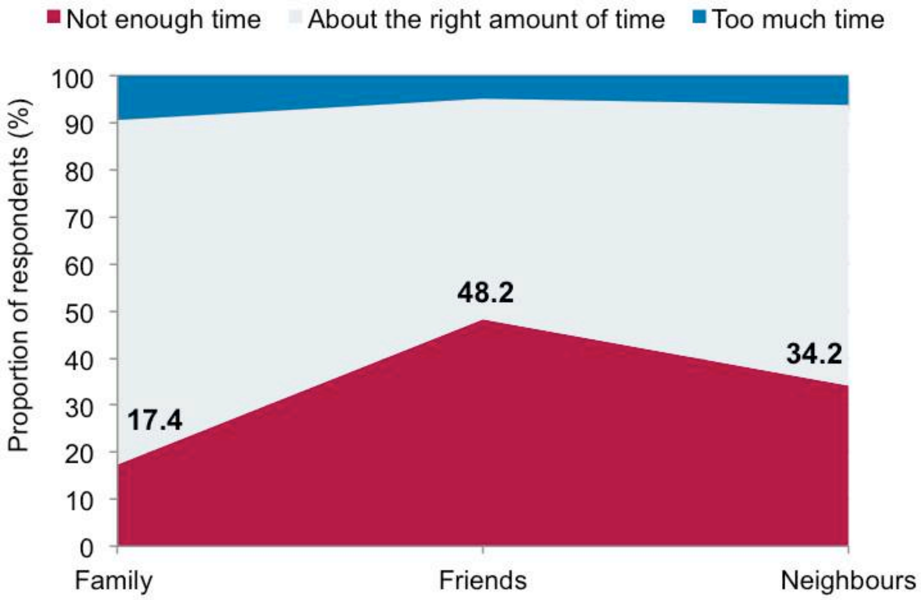
Friends, family and neighbours

Whilst the "in-between" (laminal) spaces of community group membership appear to be important sites for expressing citizenship, it tends to be our family, friends and sometimes neighbours with whom we share our most important and self-defining social moments. Question 24 of the *"Getting the life I want"* Survey asked respondents how they would describe the amount of time they have with family, friends or neighbours.

For almost a century, many disabled people were at risk of dislocation from their family as a consequence of the social policy of institutionalisation. Since closing New Zealand's major institutions, some New Zealand families have continued to express a sense of being marginalised from the lives of their children or siblings by some of the social practices of residential service provision (Milner et al, 2008). Disabled people have continually identified issues of transport and mobility, including the pervasiveness of disabling architectural design as severing them from the people and places that are important to them too (Milner & Bray, 2004).

More than seven out of every ten respondents, however, described feeling that they had about the right amount of time with their family (73%) whilst 17% felt that they did not have enough time with members of their family.

Figure 23. Respondent's assessment of the time they spent with family, friends & neighbours



Respondents were slightly more likely to report not having enough time with their neighbours. One out of every three respondents who answered the question said they felt that they did not have enough contact with the people with whom they shared their neighbourhood (34%). In a recent narrative research project commissioned by CCS Disability Action, Milner & Mirfin-Veitch (2014) contrasted participant's family home with the estrangement people often experienced from their neighbourhood after moving out. Milner & Mirfin-Veitch reported that the family home continued to be the physical and social reference point to disabled co-author's lives sometimes decades after moving. In the "*Article 19*" Project, only one of the seven co-authors who lived away from their family described interacting with a neighbour and people who lived in a community group home appeared most likely to become *"strangers to their street"* (Beale & Milner, 2014).

The group of people to whom respondents were most likely to report not having enough time with was their friends. Approaching half of the respondents who completed this section of the survey said they wanted more contact with their friends (48%). As noted previously *"having friends"* was seen as indicative of the ordinary adult life trajectory, and arresting a sense of isolation through the intimacy and closeness of friendship featured prominently in respondent's goal setting.

Respondent's aspirations *"to meet more people"* and "*to have friends"* is consistent with the now large body of research that documenting the smaller interpersonal networks of disabled people, including the narratives of New Zealander's who participated in the *"Community Participation,"* and "*Article 19*" Projects commissioned by CCS Disability Action. Within these projects, participants typically had extremely small friendship fields, populated mostly by family members and support staff. Milner & Mirfin-Veitch (2014) also found that many disabled people expressed sadness at the way individualised service delivery had severed them from the fellowship of other disabled people with whom they had shared life experiences and forged a sense of political community by resisting forms of social othering and exclusion.

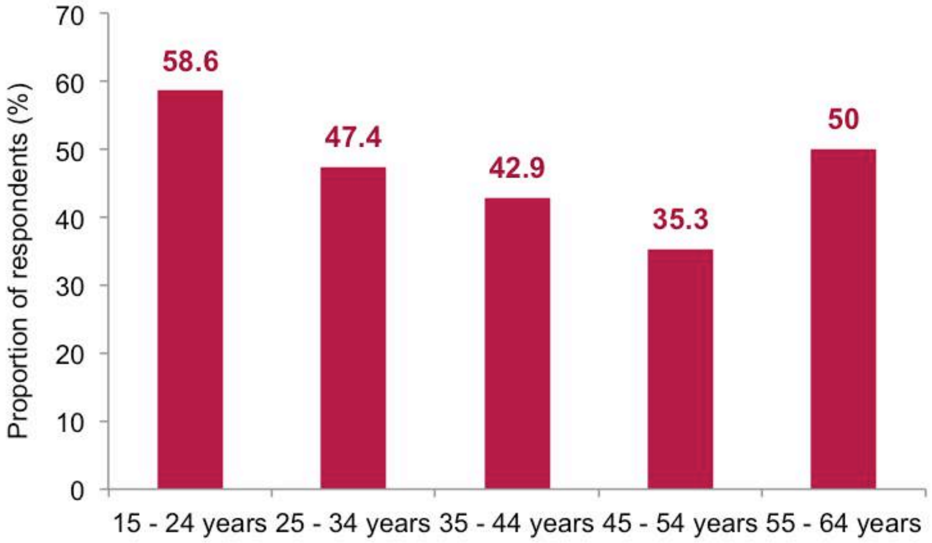
When we asked people to rate the importance of having contact with family, friends and neighbours, respondents rated it as more important than all other vocational domains. The average rating respondents gave on the same 100-point scale was 81 points.

In spite of consensual agreement that relationship lies the very heartland of life quality and its subsequent articulation in disabled people's vocational goal setting, supporting people to develop relationships of interpersonal intimacy isn't prioritised as a vocational outcome. Moreover, after talking to people who used vocational support in 2003, Milner & Kelly (2009) concluded that support practice often frustrated possible friendship as a consequence of staff steering people towards places in which it was difficult to transcend mere acquaintance and by eliminating ordinary moments of assistance and communicative ambiguity that can seed relationship.

Analysis of people's responses revealed, however, that it was difficult to identify populations most at risk of feeling as if they didn't have enough time with their friends. Respondent's sex, ethnicity, employment status and the amount of contact they had with their Vocational Coordinator or other types of disability support, all made very little difference to likelihood they would report feeling they didn't have enough contact with their friends.

Younger people aged between 15-24 years (59%) and older respondents aged between 55-64 years were most likely to report not having enough time with their friends.

Figure 24. The proportion of respondents who reported not spending enough time with their friends by age category



That younger people would report not having enough time with their friends is consistent with the commonly reported narrative that young disabled people can experience a sense of social isolation after transitioning from the community of their school as lives take different trajectories and relationships lost are not replaced by new ones. (Milner & Mirfin-Veitch, 2016; McDonald et al, 2014). Younger people may also have been less mobile than other age cohorts too.

In an increasing mobile society, older people are also often at greater risk of becoming dislocated from their friends and family as people move and the communities people are pulled into through the lives of their children and friends begin to disappear. Whilst the survey results suggest that these two age cohorts may be more at risk of to become separated from the intimacy of friendship, it is important to stress that no statistically significant association was found between respondent's age and the likelihood they would report not having enough contact with their friends.

Being a member of a community group, club or organisation also appeared to make a small difference to the likelihood that respondents would report not having enough time with their friends. In addition to the possibility that a community group may itself represent a location in which existing friendships were reinforced, it is also possible that membership of a group, club or orgainsation also afforded people access to the collective resources and reciprocities that enhance mobility. Active involvement in a community may also have buffered people against a sense of feeling isolated from others, although whilst people who said they were a member of a community group (45%) were less likely to say they did not have enough time with friends than people who said they were not a member (56%), no association was found community group membership and the likelihood they would report not having enough contact with their friends.

CONTROLLING MY SUPPORT

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 has occurred against the backdrop of a more global shift away from "professional gift models of support" towards ways of supporting people that enhance and acknowledge individual citizenship (Duffy, 2006).

At present, CCS Disability Action's vocational contract is a national contract, with regional funding allocated by CCS Disability Action National Office, limiting the opportunity people have to exercise control over their support to the existing protocols of CCS Disability Action vocational service delivery.

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 options were to them by deciding how much of an imaginary funding budget of $100 they would spend on each option. The online survey was designed in a way that ensured respondents had to, but could not exceed spending their "imaginary" funding allocation. The intention was to learn more about respondent's self-identified-support priorities by emulating self-directed service delivery.

In broad terms, we found that respondents tended to allocate their "imaginary" funding in ways that correlated with their assessment of the importance of vocational domains, supportive of the argument advanced by proponents of self-directed service delivery.

"Having a job" received the second highest importance rating (75 points) and, on average, respondents allocated the largest proportion of their imaginary budget to this vocational outcome. As reported previously, seven out of every ten respondents said they were not in any kind of paid employment (72%) and a similar proportion told us that they were currently working fewer hours than they would have preferred (74%). Respondents were divided about whether to allocate funding to achieve either employment for less than 15 hours a week (average= $11.56) or more than 15 hours a week (average= $13.85).

Forty-five percent of respondents, allocated part of their "imaginary" funding to finding employment for 15 hours or more, resulting in an average allocation of $13.85. Taken overall, respondents were prepared to spend most of their (notional) vocational funding to achieve this outcome. This finding is consistent with the prioritising of employment respondents reported, including that 43% of respondents expressed a preference for working for more than 15 hours and the average number of hours that people said they would have preferred to have been in paid employment was 18 hours.

It is interesting to note, however, that whilst respondents, on average, spent slightly less to achieve the outcome of being in employment for less the MSD's incentivised threshold of 15 hours ($11.46), more respondents chose to spend their allocation to achieve this outcome. Half of the respondents who answered this survey question directed their funding towards achieving part time employment (50%) but, perhaps not surprisingly, respondents who did were more likely to direct their funding to achieving other goals, lowering their average spend.

One of the rationales for establishing the 15-hour threshold appears to be that abatements to the Independent Living Benefit that would follow part-time employment make incentivising this outcome a worthwhile social investment. What concerned the disabled people that we spoke to was that crossing this employment threshold exposed them both to a reduced and more uncertain income should they become unwell or similarly experience workplace discrimination or dismissal. It is possible, therefore, that in addition to further marginalising the group of New Zealanders most at risk of not having their right to participate in the labour-force acknowledged, steering disabled people assessed as not likely to achieve 15-hours employment away from employment and incentivising the 15-hour threshold may further entrench disabled peoples' apprehensiveness about working more hours. Moreover, more than four out of every ten respondents said that, whilst they wanted to access the benefits of paid employment, their preference was to work for less than 15 hours a week (43%). Included in their decision-making was concern about the personal toll of working longer hours, with the imposition of a 15-hour steering gate representing a denial of the embodied realities fatigue or of having to manage the demands of their impairment.

Some of the people we spoke to also described having to weigh the material benefits of possible employment against the cost having to exchange forms of community participation they enjoyed and felt validated doing for employment within the *"expendable fringe"* of the New Zealand labour market. As reported previously, disabled people tend to be clustered in manual, part-time and low-paid occupations in which they commonly experience both under-employment and/or the social experiences that can follow not being met by an inclusive workplace culture.

When the averages were combined to also include funding allocated; to getting employment advice ($7.01), starting my own business ($3.77) and getting on the job support ($5.66), a total of $41.75 was, on average, spent by respondents overall, in seeking either to find or maintain paid employment, indicative both of the importance of respondent's ambition and perhaps also of the difficulty they perceived in overcoming the barriers to employment without support.

The second highest average funding allocation for a domain that we also asked respondents to rate the importance of, was staying in contact with family, friends and neighbours ($7.17). Although developing and/or maintaining interpersonal relationships did not appear to feature prominently in support practice, respondents gave their highest rating to the importance of staying in contact with family, friends and neighbours (81 points). Social isolation and a sense of being marginalised from interpersonal intimacy emerged as important themes within the conversations we had with respondents. Forty-eight percent of respondents reported not feeling as if they were not able to spend enough time with their friends and given (notional) control of their funding, respondents seemed prepared to allocate funding to improve this important domain of life quality.

When asked to rate the importance of belonging to a community group, club or organisation, respondents, on average, rated community participation through group membership relatively highly (62 points). Although distributed across a range of different types of group membership, including belonging to a sports club or group ($3.40), arts of creative group ($3.93), political or advocacy group ($0.59), respondents appeared less likely to allocate significant funding to achieve community group membership than in other life domains.

Although beyond the scope of the survey, it is interesting to speculate why this may have been so. One possible explanation is that, relative to other vocational outcomes, it was easier for respondents to access group membership as a form of community participation. Seven out of every ten respondents described belonging to one of more of a range of different types of community group(s) (70%) slightly higher than the group membership rate reported for the New Zealand general population (Statistics New Zealand, 2016).

Compared to the general population, however, respondents were significantly more likely to express a "yearning" to belong. For example, 56% of respondents said they didn't send enough time with a hobby or interest group, 46% with a neighbourhood or community group and 63% with a political or advocacy group, compared to less than 10% of the New Zealand general population who reported not feeling they spent enough time with a community group or its members. And yet respondents were still less prepared to allocate funding to community group membership as a vocational goal.

Figure 24. The average "imaginary" funding allocated to different vocational outcomes

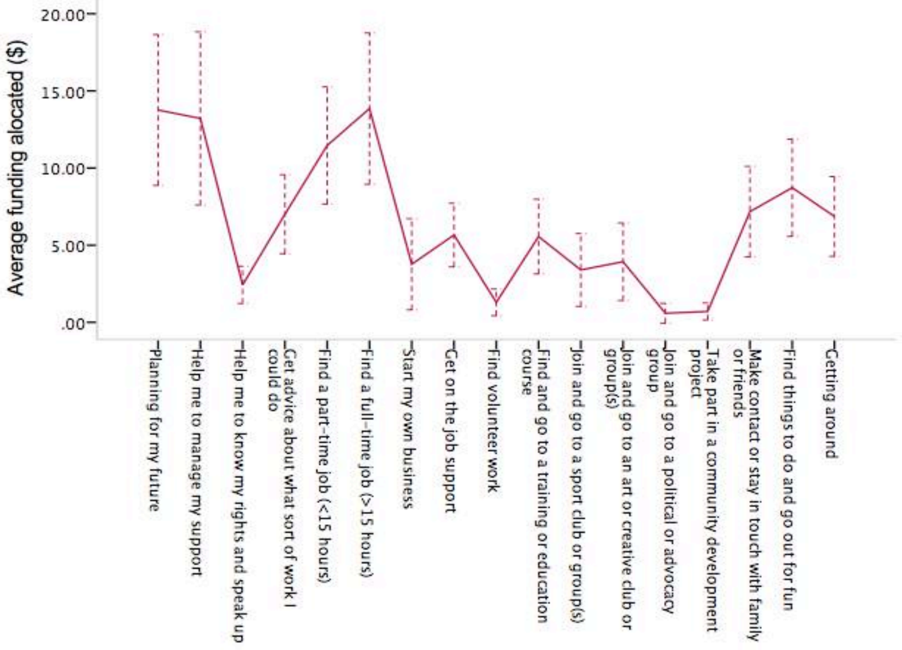
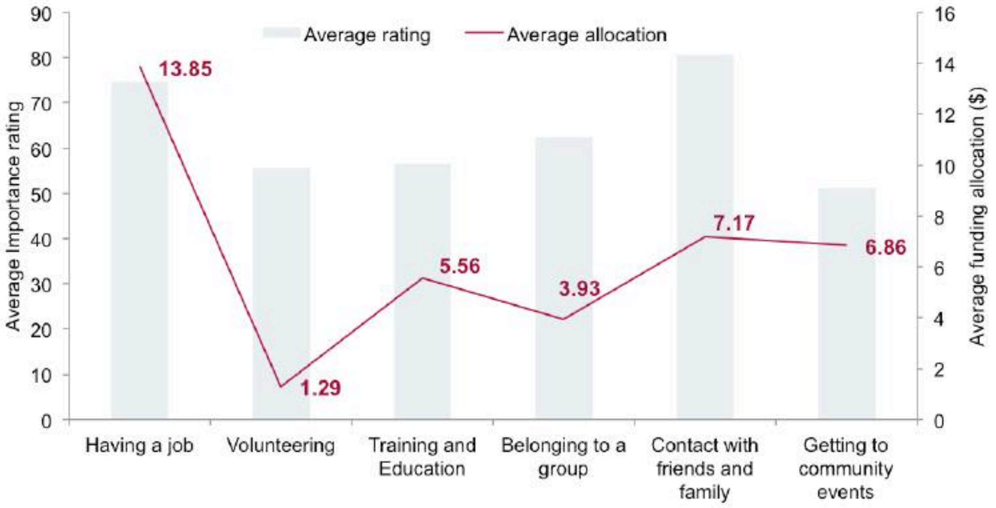


Figure 25. Respondent's rating of the importance & average "imaginary" funding allocated to major life domains



Allocating funding to enhance group membership may be a “riskier investment,” however, if disabled people tend to remain on the margins of community group culture (as might be inferred by the high proportion of both group non-members and members who expressed an aspiration for greater contact). Disabled people have told us that they can often feel “out of place” in outwardly inclusive social contexts as a consequence of subtle and often unconscious forms of social othering. In interviews, respondents told us that they *“ended up just sitting on the side because they used a wheelchair”* or that having to come with a carer meant “*you get stuck in a corner, talking to them and not talking to the people you are supposed to.”* Conversely, people have also descried how disability exclusive settings can sometimes represent safer social spaces in which impairment and difference disappears in ways that allow disabled people to shape the culture of membership (Hall, 2010, 2013; Milner & Kelly, 2009). Not only would the high proportion of respondents who chose forms of membership that celebrated or advocated for bodily difference appear to support their observation, our finding that respondents who were unemployed rated the importance of belonging to a community group significantly lower than respondents who were employed suggested that disabled people may be doubly disadvantaged by the psycho-social impacts of their marginalisation from the worlds of employment and discriminatory attitudes about the social capital of disabled people within community groups and organisations.

An alternative, (but perhaps compounding) explanation, is that material poverty simply made it more difficult for respondents to remain in contact with, or to contribute to a community group in ways that they would otherwise have wanted to. That people’s relative reluctance to direct (notional) funding towards achieving community group membership might also be reflective of their appraisal of the difficulties associated with remaining in close contact with group members is supported by their weighting of outcomes that enhanced their mobility.

Whilst not considered a vocational outcome in its own right, respondents, on average, allocated $8.69 towards “getting around.” Maintaining their mobility through vocational support was the fifth highest (notional) funding application. Moreover, self-directing (notional) funding towards the goal of “finding things to do and go(ing) out for fun” also spoke to an experiential dislocation from one’s community contributed to by a lack of mobility. Many of the people we spoke to described being hemmed into the cardinal spaces of their own homes. In speaking of the importance of part-time employment, for example, one respondent told us, *“at least it gets me out of my bedroom.”* Some said they almost never went out for fun, explaining their isolation in terms of not being able to afford to go out, having a lack of support or of having no one else go out with. Respondent’s, on average, allocated $7.99 of their (notional) funding budget to “finding things to do and go(ing) out for fun.”

Perhaps the most significant finding, however, was the weighting given by respondents to helping them to plan for their future and manage their support. In their narrative, respondents told us how highly they valued CCS Disability Action staff's knowledge of the complex and fragmented world of disability support and in particular how support staff had helped them to navigate the bureaucracies of health and disability support in times crises. *"Knowing that there was someone out in the community that can actually advocate on your behalf. I mean that's huge,"* people said. We were also told how people appreciated the breadth of CCS Disability Action's connectivity to their local community and most especially how their being connected had helped respondents reimagine their own lives. A number of respondents told us that what they appreciated most was the way their support had expanded their thinking about the range of different ways they might also connect and contribute to communities of place and of interest. Many saw the vocational planning as central to the process of re-visioning their lives, affording the chance to speak out loud hitherto hidden personal aspirations and to have them affirmed by others and to develop allies with whom to collaborate in the design of concrete steps to make goals happen. *"I just needed someone outside my immediate family to help me define what the next step might be,"* we were told.

Within the existing "Outcomes Based Framework" (described in the Key Informant Report p. 13-16), these less quantifiable but none-the-less potentially life-changing support transactions go largely unrecognised and unfunded. When given the opportunity to self-direct their (notional) funding, however, respondents expressed their valuing of these support elements by allocating, on average, more of their budget to "planning for their future" ($10.56) and managing their support ($10.66) than almost all of the outcomes prioritised in conventional vocational 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 and funding are service elements that depend on someone fulfilling the role of "navigator" or "life coach." If the goal of these and other sector initiatives is to shift service delivery away from the professional gift model and towards self-directed service delivery, it is essential that the assumptions that underpin self-directed support become widely embedded, including within the relationships within which disabled people experience their most immediate support. Planning for the future and organising support are, however, not just single events, but are an ongoing process of reflecting and responding to changes in one's life circumstance. People we spoke to said that what they valued about CCS Disability Action was their ability to access forms of "navigation" as part of their everyday support, although clear differences emerged in peoples valuing of planning and of organising support as expressed by their allocation of (notional) funding. These and other identifiable differences in funding allocation revealed by examining variation in the responses of people according to their employment status, group membership and age.

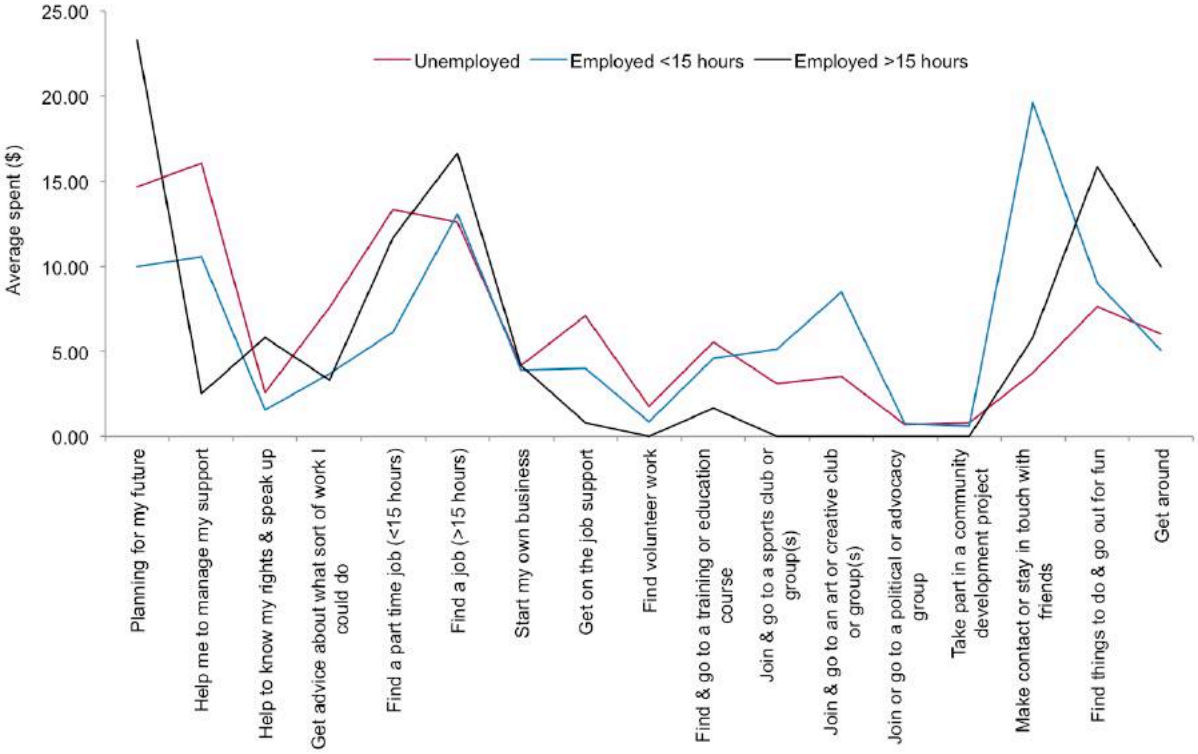
Differences in respondent's allocation of "imaginary" funding by employment status

The importance of planning a future and helping to manage support varied for respondents according to their employment status. Respondents who were employed for 15 hours a more or week, on average, allocated more of their (notional) funding ($23.33) than respondents who were either employed for less than 15 hours ($10.00) or unemployed ($14.70). For the group of respondents who were employed for more than 15 hours a week, planning for the future represented the highest average use of their (notional) discretionary funding. Whilst this finding may partially be explained by (notional) funding not being siphoned off in the search for employment, it is also likely to be reflective of the way the impact of employment spills over into other life domains. Being employed locates people within relationships and through greater disposal income and connectivity and improves the accessibility of both physical and relational community, diminishing the perceived need to direct funding towards these life domains. It also improves people's sense of personal agency. In talking to respondents, what people who were employed appeared to be telling us was that whilst they were responsible for their level of engagement with people and place within most domains of their lives, what they valued was having access to conversations that altered the horizons of their personal life trajectory. What they were prepared to purchase was support that validated and identified a path towards "*something more and something better than this place now*" (Hall, 2013).

The opposite was true for the process of managing support. Respondents who were employed for more than 15 hours, on average, allocated much less of their (notional) funding to this support element ($2.50) than to respondents who were employed for less than 15 hours ($10.56) or who were unemployed ($16.08). For respondents who were unemployed, assistance to manage their support emerged as their highest average funding allocation. It is tempting to speculate that the community presence of people whose unemployment may have undermined their sense of agency was, in part, determined by the timing and purpose of their support. The finding that respondents who said that support staff were a presence in their lives through other types of disability support and those who had more contact with their Vocational Coordinator were significantly more likely to belong to a community group, club or organisation would appear to support the proposition that for many disabled people, staff and their support were an important conduit to community participation. People with high and complex support needs appeared to be particular vulnerable to dislocation from their community, including from the world of work, and, as reported in previous research commissioned by CCS Disability Action, many experience lives in which they are only infrequently within community spaces that remain accessible only through the support of their staff. In the absence of employment, alternative forms of community participation become increasingly important as social contexts in which one might access the attributes of relationship disabled people identified as prerequisite to the experience of belonging to one's community.

Our finding that respondents who were employed for less than 15 hours ($8.50) or who were unemployed ($3.53) were, on average, more likely to allocate (notional) funding to finding and going to an arts or creative group or any of the other types of group membership included in the survey question than respondents who were employed ($0.00) appears to support this interpretation.

Figure 26. The average amount of "imaginary" funding allocated to vocational outcomes by respondent' employment status



Being able to exercise control over the timing and purpose of support activity will for many, therefore, be a key determinant of the kind of participatory citizenship they experience and it is perhaps not surprising that more marginalised respondents identified assistance to organise their support as their most important priority. There are a number of important implications of this finding if people with more complex support needs are to *"get the lives they want."*

Firstly, that employment appears to offer a level of protection against kind of dependencies that would make managing support such a priority for this cohort. For this reason, people with more complex support needs ought not to be steered away from work as a valid vocational outcome.

Secondly, support practices should acknowledge the prioritising of this support element by providing all people with the assistance they need to exercise greater control over the timing and purpose of support. Doing so would greatly expand the reach of the principles that underscore Enhanced Individualised Funding and the New Model of disability support.

Perhaps more troubling, however, was that what seemed to differentiate the allocation of (notional) funding we observed between respondents who were employed more than 15 hours a week and those who were unemployed, was that for people who were employed, agency was sought as a way of *"planning for their future,"* and for *"defining and taking the next steps."* People who were unemployed, however, also appeared to be seeking greater agency, but to *"manage their support"* in ways that maintained pre-existing connections and established ways of being in the community. If true, the cohort with the most to gain from contesting social conventions that have contributed to their marginality may be least able to do so as a consequence of not being supported to reimage alternative futures or to plan in ways that stretch the horizons of possibility for all New Zealanders.

Previously in this report, we suggested that one possible reason for 43% of respondents wanting to work for less than 15 hours was that working for longer in the kind of roles that they felt steered towards was perceived to undermine life quality by drawing time and energy from more personally rewarding forms of community participation. In a number of respondent' narratives, we heard people conducting a kind of cost-benefit analysis in which they appeared to be weighing up the benefits of employment against the potential loss of income and their alternative "unauthorised" imagining of what being productive and contributing members of their community may mean. Examples included the range of ways people volunteered, belonged to art and cultural groups that "gifted" their creativity, were involved in the disability and advocacy movement, and supported friends and community groups.

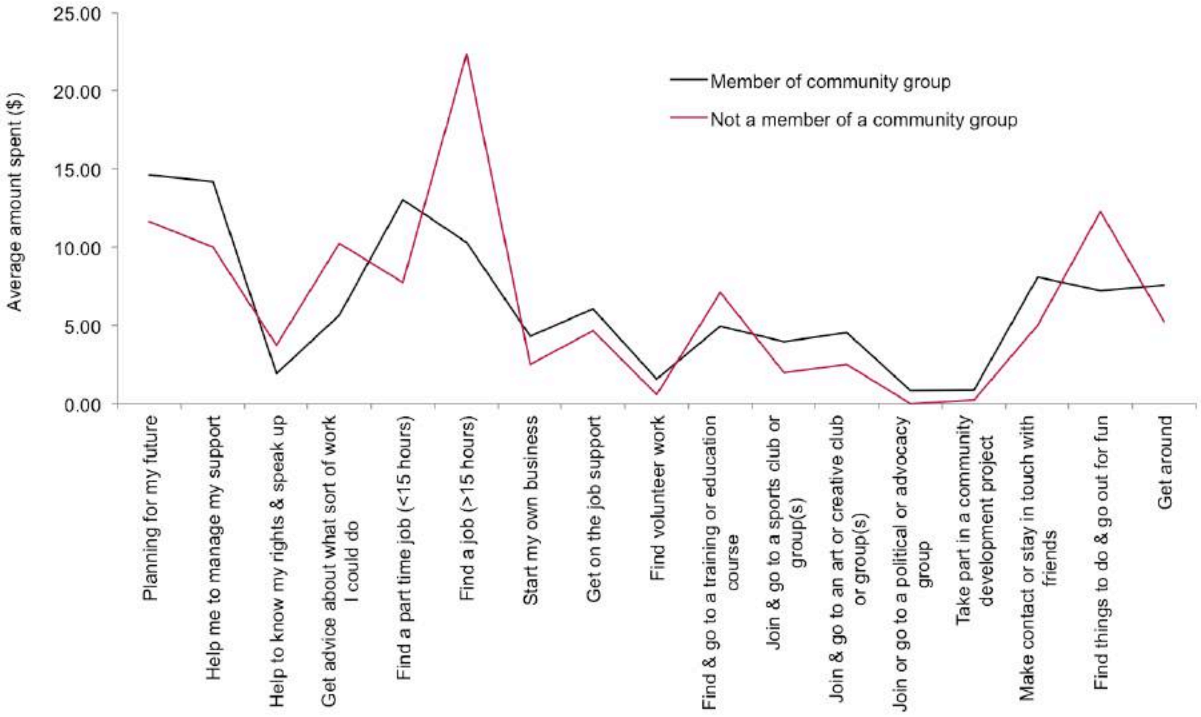
It is interesting to note, therefore, that respondents who worked for less than 15 hours were most likely to allocate funding to achieving alternative forms of community participation and connectivity. For example, participants who were employed for less than 15 hours were, on average, most likely to allocate (notional) funding to joining and going to an art or creative group ($8.50) or sports and recreational group ($5.15) than other respondents. They were also significantly more likely to allocate funding to make contact and stay in touch with family and friends ($19.64) than respondents who were unemployed ($3.72) or employed 15 hours or more ($5.83).

Finally, an association was also found between respondent's employment status and the amount of (notional) funding they allocated to on the job support. Respondents who were unemployed, on average, allocated most (notional) funding to on the job support ($7.03), and people who were employed for more than 15 hours the least ($0.83), suggesting that many respondents were seeking support to go beyond job placement and that people who worked less or were unemployed worried about and wanted the reassurance of on the job support to be good employees.

Differences in respondent's allocation of "imaginary" funding by group membership

We also compared the (notional) funding allocations of people who did and did not say they belonged to a community, club, group or association. Respondents who were not a member of a community group ($22.35), on average, allocated significantly more of their (notional) funding to finding more than 15 hours a week paid employment than respondents who said they were member of a community group ($10.31). A number of possible explanations might account for this association, including that people who were not a member of a community group looked to employment to provide them with a sense of contribution to their community, stimulation and relationships that were more difficult to access in the absence of other forms of community participation. Another, and perhaps complementary explanation is that people assessed as least likely to achieve 15 or more hours a week paid employment were supported to connect to community groups as an alternative to employment in ways that others were not or did not prioritise.

Figure 27. The average amount of "imaginary" funding allocated to different vocational outcomes by community group membership



Whilst it is interesting to note that respondent's who were not a member of a community group appeared to privilege employment over other vocational outcomes, consistent with the steering obliged by the new Vocational Outcomes Framework (Ministry of Social Development, 2015), the majority of respondents who were members of a community group (70%) allocated, on average, more of their (notional) funding to achieve the goal of less than 15 hours a week paid employment ($13.05) than to employment above the 15 hour threshold ($10.31).

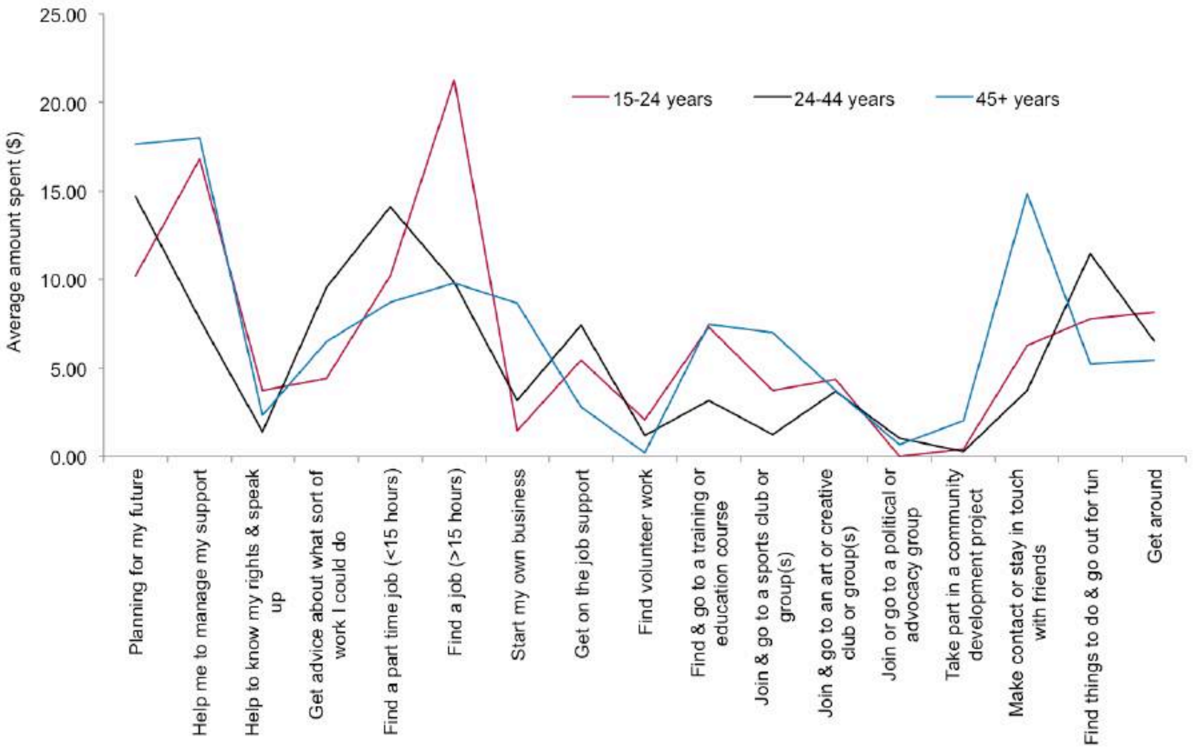
The age of respondents also appeared to influence the way they allocated their (notional) funding. Younger respondents aged 15-24 years typically allocated more funding to finding 15 or more hours paid employment a week ($21.25) than respondents aged 25-44 years ($9.83) or 45+ years ($9.80). In the general population, rates of unemployment are highest amongst younger New Zealanders, however, for the group of respondents who were still at or who had just left school, the “mainstreamed” aspiration of transitioning from school to adult employment is likely to have been both more pervasive and least challenged by diminished expectation, service steerage or a legacy of seeking (but not finding) employment.

Differences in respondent's allocation of "imaginary" funding by respondent's age

We also found an association between respondent's age and the amount of their (notional) funding allocated to the goal of making contact and staying in touch with family or friends.

Respondents aged 45+ years ($14.81), on average, allocated significantly more of their (notional) funding to staying in touch with family and friends than respondents aged 15-24 years ($6.25) and aged 25-44 years ($3.72). It is probable that this difference in the weighting of the importance of staying in touch with family and friends is reflective of a more pervasive reassessment of life's priorities as people friends and family age, have children and/or become increasing separated by physical distance and decreasing mobility. However, it is interesting to note that, in previous research commissioned by CCS Disability Action, it had been older participants who had grown up alongside other disabled people who lamented the social dislocation that followed the vocational reforms of the past 20 years (Milner & Mirfin-Veitch, 2014).

Figure 28. The average amount of "imaginary" funding allocated to different vocational outcomes by respondent's age



In the *"Article 19"* Project, Milner & Mirfin-Veitch (2014) described how people with high and complex support need's family home had continued to represent the emotional and relational hearth to their lives and it is also possible, therefore, that respondent's sensitivity to remaining in contact with their friends and family may partly represent a response to the increased likelihood of becoming dislocated from relationships that reminded people who they were and where they came from.

DIFFERENT WAYS OF SUPPORTING PEOPLE

The other way we attempted to throw light on the how to support people to *"get the lives they want(ed)"* was invite feedback about alternative ways they could be supported through a vocational contract.

Survey questions 30-39 asked respondents to rate how helpful ten different vocational support models would be to them. Two of the models drew on previous research commissioned by CCS Disability Action and represented possible "action-based," responses to human rights issues identified by the Community Participation and Article 19 Participatory Action Research Projects. The remaining eight models were drawn from the literature review conducted in Phase I of the *"Getting the life I want"* Vocational Project.

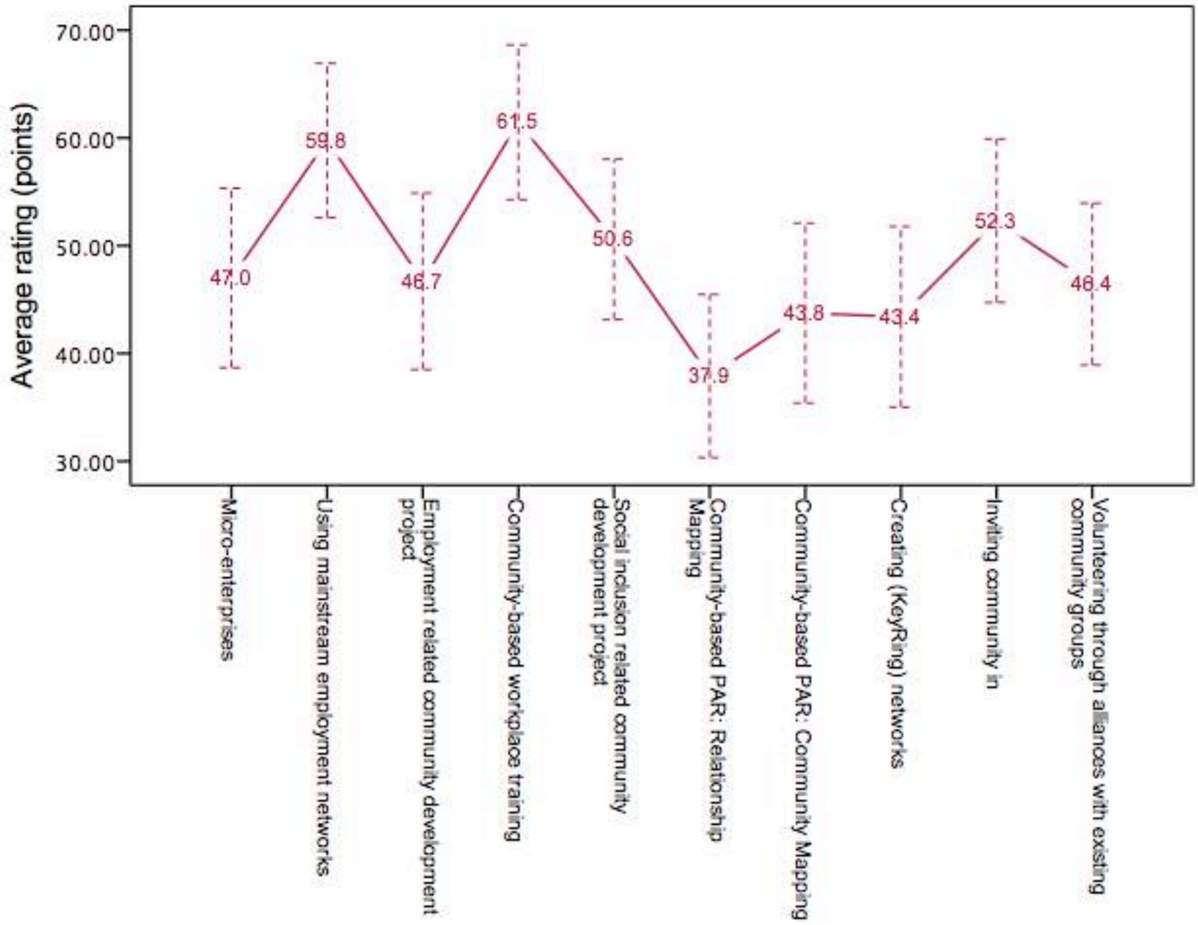
Respondents were sent a Workbook that provided a brief, plain language introduction to each model, including where to go for additional information. People who completed this part of the survey were invited read the Workbook and rate how helpful they thought each model might be as a way of supporting them on a 100-point scale that adopted "extremely unhelpful" (0) - extremely helpful (100) as scale anchor points.

Models that responded to unemployment

The two models that, on average, rated most highly where both employment focused and used individualised support as the way to address employment inequality rather than building a community response the unequal access disabled people work.

Respondents, on average, rated collective work-based training as the most useful vocational model (62 points). Rather than being taught generic employment skills beyond the workplace, work-based training involves improving the "work-readiness" of "trainees" by supporting them to complete real work on-site. The example provided involved a collaboration between vocational provider Enrich+ and local business (Manuka Health) that involved "trainees" and their employment mentor working together to label, package and ready products for distribution. The programme was evaluated by researchers from the Donald Beasley Institute, who reported that "trainees" said they liked the programme because it provided: a safe place in which to learn many of the unspoken rules of employment; the chance to try employment and rethink aspirations; and an opportunity to develop a work history. "Trainees" also told the evaluators that doing the same work as everyone else had improved their self-confidence and that working in the factory had been a gateway to relationships that had continued outside of the factory. For a number of trainees, the progamme had provided a springboard to employment, including paid employment within the factory itself. Hosting the trainees had a number of benefits for the business too, including eliminating a labour costs for an element of production. Whilst community-based (collective) workplace training might represent an answer to the demand for on-site employment support expressed by unemployed respondents, the evaluators also pointed out that running training programmes like the Manuka Health initiative confronts vocational providers with important ethical questions, including: as to whether the benefits of the programme adequately compensated "trainees" for doing real work **without** real pay; and what to do when trainees were thought to have learned all they could but wanted to continue with the programme for fear of losing the quality of life improvements associated with contributing to a community business.

Figure 29. Respondent's average rating of the importance of 10 different vocational support models



Using "mainstream" employment networks rated second highest amongst the array of different vocational support models introduced to respondents (60 points). Current Vocational contracts express the expectation that providers work towards disabled peoples increased use of generic community services. Vocational providers are also expected to play a role in building "inclusive and welcoming mainstream services" (Ministry of Social Development, 2016). A small but growing body of research is beginning to document better employment outcomes for disabled people as occurring when disability providers have partnered with "mainstream" employment services and others as part of a "community of support." Within the employment space, however, disabled New Zealanders have continued to be steered towards "specialist" employment services and supported employment providers have worked independent of other mainstream services and community organisations. Partnering with mainstream providers has a number of potential advantages for disabled people, including providing access to established employment networks and a wider pool of job vacancies. More importantly, building capacity within mainstream employment services and/or business collectives provides disabled people with a better opportunity to contest many of the (incorrect) employer attitudes that act as barriers to employment and to shift the narrative of employing disabled people away from it being an issue of social justice and towards alerting employers to the business advantages of including disabled people within an increasingly diverse workforce.

In the interviews that we conducted, some respondents expressed a degree of reservation about how well their Vocational Coordinator was able to represent their skillset and/or recognise an appropriate employment or business opportunity. This was especially true for people who had previously worked in professional occupations and who were aware of the "cultural" cues and language that communicated a person's value to potential employers. For a number of people, therefore, working alongside mainstream employment agencies may provide a better conduit to the skilled occupations disabled people are disproportionately absent from.

Models that responded to social isolation

The third and fourth ranked alternative models of support identified by respondents addressed social isolation or feelings of being dislocated from the worlds of relationship and intimacy that many respondents described experiencing. In contrast to respondent's preference for individualised approaches to finding employment, people, on average, rated support approaches that involved doing things together. The two models they preferred also shared in common seeking community change by transforming non-disabled people's understanding of the social capital of impairment.

Inviting the community in to do things together that disabled people were good at achieved the third highest average rating of personal helpfulness (52 points). Within traditional vocational service delivery, community participation has always been understood as involving an outwards migration away from places of social knowing and relational intimacy towards an array of public spaces in which disabled people typically experience difficulty seeding relationships and/or transcending "mere presence."

Supporting disabled people to create contexts for themselves that invert the normal route to participation by inviting people into spaces where they feel known, validated and have greater expertise (social capital) has a number of advantages. Examples given in the Workbook included; inclusive dance, theatre, cabaret, writing, painting and other creative endeavors that fall within the compass of the Disability Arts Movement, accessible bike building, maintenance and hiring collectives or computer literacy or Alternative and Augmentative Communication, Easy Read or New Zealand sign language classes run by disabled people. The advantages of these and other similar responses to social exclusion are that they expose non-disabled New Zealanders to the experiences, energy and creativity of disabled people including new ways of thinking and seeing the world. Collective support can also provide disabled people with opportunities to create community spaces that celebrate cultural distinctiveness and/or and to continue to access the fellowship of other disabled people. Finally, changing the power relationship helps to undermine the social construction of disabled people as "less productive" community members. In spite of these advantages, approaches that draw on the community development or social action as practice frameworks are not commonly included in the array of vocational support options offered to disabled people.

The other preferred alternative support model did draw on the community development paradigm. Community Development is defined as "*a process where community members come together to take collective action to generate solutions to common problems"* (UN, 2016). In the Workbook we outlined a Community Development Project led by disabled people and their vocational provider in Bendigo, Australia. The project, *"Trees, Webs and Hives,"* engaged the local community with the issue of social exclusion through an intentional community building event. Whilst the aim of the project was to create a large-scale, collaborative art instillation for the local library, a series of parallel workshops themed around the significance of personal, social and environmental connectivity brought disabled and non-disabled community members together in ways that expanded people's appreciation of each others capacities and social realities. Respondents rated this as an example of a Community Development approach to social (ex)inclusion the fourth most useful alternative support approach (51 points).

Caution needs to be exercised in interpreting these findings, however, as a high degree of variation existed in the assessments people gave of each of the alternative models of support. As became increasingly clear in the interviews we conducted, people's reasons for seeking vocational support, the aspirations they held for themselves and the ways in which they preferred to be supported were as divergent as life stories they told.

To provide respondents with an opportunity to tell us more about the attributes of vocational support they valued, the survey concluded with questions that invited people to identify what they thought CCS Disability Action were currently doing well and might consider as alternative ways of supporting them. This is explored in the next section.

WHAT PEOPLE SAID ABOUT THEIR SUPPORT

For people who access vocational support, the assistance CCS Disability Action provides is transacted through their support relationships. In the "*Getting the life I want*" Project Brief, (CCS Disability Action, 2016) CCS Disability Action stressed the importance of learning; what elements of support people valued and saw CCS Disability Action as doing well and whether people recognised opportunities to transform service delivery in ways that would help them to get the lives they wanted.

Questions 42- 44 of the *"Getting the life I want"* Survey were open-ended and asked respondents, when they thought about the vocational support they received, what they felt CCS Disability Action: did well; did not do well; and might be other ways of supporting them. For the purposes of this report, the analysis of the final two questions have been combined.

What is CCS Disability Action doing well?

One third of people who completed the *"Getting the life I want"* Survey responded to the invitation to say what they thought CCS Disability Action did well (33%). Rather than identifying outcomes or accomplishments, almost all respondents who answered wrote about the way their support was transacted and, in particular, those attributes of the relationship with staff they valued the most.

Preeminent amongst the things respondents felt CCS Disability Action did well was to provide support characterised by an authentic interest in a person. Respondents valued the way staff *"always listened"* but more importantly listened in ways that were *"affirming"* and expressed a *"genuine interest in who (they were)."*

Knowing that they had *"someone to listen when (they) need(ed) help"* or *"were worried about something"* also appeared to provide an important and yet unquantifiable source of everyday vocational support. Being able to access non-judgmental advice or draw on support when they felt they needed it, appeared to offer respondents a sense of psychological support that extended beyond the contact they had with CCS Disability Action staff. As a consequence, relational attributes like *"loyalty,"* and *"sticking with you"* featured prominently in respondent's comments.

A number of respondents mentioned that the more intimate knowledge staff had acquired was experienced as *"understanding what I feel like."* In the interviews that we had with respondents, we learnt that this was especially important to people whose impairments were less visible and a number of people said it was important to have an advocate to whom they didn't always need to explain things and when having an ally was required.

Advocacy emerged as both important to respondents and an attribute of their support that many felt CCS Disability Action did well. A number of respondents described valuing the way their support had helped them to navigate the bureaucracies of (un)employment, health and disability service provision, including *"difficult paperwork and dealing with difficult people"* but which didn't encroach upon their ability to make choices and exercise agency over their lives. Respondents appreciated the way staff "*gave (them) the right information,"* or *provided good advice* but allowed them "*to make my own choices."* One respondent wrote, *" We work together."*

The other attribute of the communication a number of respondents reported CCS Disability Action did well was the way they continued to *"keep in touch."* Regular contact appeared to communicate a sense of being valued that was especially important to respondents who otherwise felt isolated. "*Visiting you to check up on you,"* and *"keeping in touch to see what I'm up to"* or "*how work is going"* or *"checking on my health,"* were all mentioned as things CCS Disability Action did well. For a small number of respondents, the regular contact also helped to ensure momentum in their life was maintained as the *"checking in"* required acting on the aspirations they articulated.

Relatedly, a number of respondents also described valuing the way CCS Disability Action support had expanded the horizons of their out their own personal futures. Support as life coaching emerged as a theme in some respondent's reflections about what CCS Disability Action did well. A number of respondents identified "*helping (them) with (their) ideas"* or "*identifying the next step"* and of "*taking (them) beyond their comfort zone"* as valued support attributes rather than the linearity of progress towards prescribed outcomes.

Similarly, whilst a number of respondents did acknowledge the support that CCS Action had provided them was instrumental to their achieving life goals like "*gaining work experience,"* or *"allowing them to go forward with their job seeking"* or "*getting into training"* and "*volunteering,"* respondents were as likely to identify what CCS Disability Action did well as being experienced as embodied changes and most especially in repaired confidence. Respondents wrote that for them, the consequence of the way support was delivered had been "*giving me back my confidence"* or of "*helping a lot in pushing my confidence when it* *comes to joining activities and looking at ideas I could possibly take on."* For some people, the measures they valued above others were personal and unquantifiable, including that *"I am now definitely more happy and confident."*

Other ways people wanted to be supported

Slightly more than half of the people who responded to the survey took the opportunity to identify the ways in which they would like to be supported by CCS Disability Action that they weren't currently (54%). The dominant theme to the feedback was for CCS Disability Action to respond to their, often long-standing un(der)employment with greater energy and creativity. Previously we noted that, 72% of respondents were not in employment and 74% worked fewer hours than they wanted, even though employment emerged as the respondent's preeminent vocational goal. Many respondents identified the length of their unemployment as contributing to an erosion of self-confidence, including in the skills and capacities they offered potential employers. They told us, for example, that the support they needed was to "*help to find work in a market where (they were) feeling increasingly unemployable as time passes."* As a consequence, a number of respondents were anxious to join the workforce before having to recalibrate to the expectation of long-term unemployment.

A number of respondents wrote that some of the difficulty they were experiencing finding employment reflected a wider failure to recognise latent skill and capacity. A similar theme emerged within the narrative of the people we spoke to who described themselves as *"wasted"* members of their community, whose vision of the different ways that they could contribute within the workplace or community didn't inform the efforts that were being made as part of their support, which is perhaps best summarised by a respondent who wrote *"it would be nice to have a person who believes in what I am good at help me get out there and 'sell' my skills and to be creative and innovative."* This person's evocation includes a number of barriers to employment that respondents identified when asked in what other ways they would like to be supported.

Firstly, a sense that many had that they would be difficult to "place" in employment because they had little to offer employers. Some respondents described experiencing the absence of *"belief"* or of undervaluing of the contribution they could make as a form of steerage towards training and voluntary work. In responding to the question, what are the things that CCS Disability Action didn't do well, one respondent spoke for others who identified *"job seeking, because,"* they said, *"(CCS Disability Action) look for volunteer jobs first,"* The second barrier identified in the feedback above included the failure to market or *"sell their skills."* Whilst it is probable the respondent was simply meaning a failure to "market" the range of experiences and capacities that they might offer an employer, the observation sits within a broader discourse seeking to acknowledge and promote the social capital of disabled people within the labour market. In particular, shifting the narrative of supported employment away from employment being an issue of social justice and towards discussing the business advantages of including disabled people within an increasingly diverse workforce. Proponents of this argument point out that selling employment as an act of social good undermines the ability of disabled people to "market" the advantages of including bodily difference and new ways of thinking and acting within workplace culture.

And the final barrier identified by this respondent was a lack of creativity and innovation in responding to their right to work on an equal basis with others (Article 27, UNCPD). In the discussions that we had with respondents, people spoke of a range of conventional approaches that had been employed as part of the employment search. Whilst respondents were appreciative of the assistance given by CCS Disability Action to re-write their CV, check websites, cold call or to door knock, little evidence emerged of more *"creative or innovate"* approaches to employment creation. For example, almost all of the support provided appeared to focus on the "supply" and not the "demand" side of the employment equation. We heard little evidence of the CCS Disability Action: working to develop an understanding of employer need, collaborating with employment services or other community business associations; supporting responses that drew on a respondent's network of formal and informal relationships; or supporting the connectivity of other disabled people, job carving or job sharing, community development approaches, recruitment fairs, marketing strategies or of providing people with the assistance they needed establish their own micro-enterprises. *"Targeting employers"* and *"looking at setting up my own business"* numbered amongst the ways respondents said they would like to be supported in ways that they currently weren't, suggesting that in an increasingly self-directed support sector, an opportunity exists for CCS Disability Action to develop new and collaborative ways of supporting disabled people into employment.

A number of respondents highlighted improving the way CCS Disability Action communicated as also improving the way they experienced support. That *"services need to be a lot more online"* or *"to keep up with 21st century technology"* featured in respondent feedback. One respondent wrote, for example, *"that "CCS Disability Action need to develop a separate database of jobs and their own networks of work opportunities, in addition to the regular "Trademe," Seek, Indeed.com which I am already familiar with."* Making use of new communication modalities opens a space for new approaches to employment creation, including; job bulletin boards, a portal for employers to identify workforce needs and job opportunities or for disabled people to define and broadcast their unique skills and competences in more creative ways, circulate stories that change the narrative of disability employment or inspire or alert others to best practice and service innovation, inform people of training and funding opportunities and, perhaps more importantly, connect disabled people in ways that allow them to assist each other find employment.

Some respondents said they felt dislocated from their support. *"My support worker hasn't been in contact with me for about four months"* one respondent to us, before going on to say, *"and then rings me up a few days ago. I could do with more support as I don't know what's happening."* Whilst not typical of most people's experiences, this respondent's comment does capture something of the anxieties others reported about the timeliness of staff responses or of not feeling fully informed about events and opportunities or progress being made towards mutually agreed actions. In addition to answering these concerns, making use of new ways of staying in touch, like Facebook, FaceTime, tweeting or Whatsapp, might also be a useful way to connect disabled people and build community in ways that allow them to inform each other, identify new things to do together or even to assist each other to achieve life goals like employment.

The conversations we had with respondents suggested that support tended to be limited to the provider (staff)–receiver (disabled person) dyad rather than a person's support staff acting as the conduit to other people or community agencies. As noted previously, one group who were especially sensitised to the limitations of this model of support were respondents who had come from or were seeking to enter skilled occupations. A number of respondents told us that what would have been useful to them was to *"find some other professional to talk to"* or relatedly access mainstream employment brokers to promote their particular skill set.

One respondent wrote of feeling that *"having more choice as to what I can use my funding for, particularly around the hours (they were) allocated and used"* would be a more effective way of *"having (their) opinion heard."* The call for disabled people to have greater control of the resources required to direct support and service delivery in ways that meet their needs and aspirations is commonly expressed in social policy by disabled advocates and aligns with the core principle of the "New Model" of disability support. As is discussed in more detail in our analysis of the interviews respondents gave, most of the respondents we spoke to were reticent about having direct control of their funding and support arrangements. Many were apprehensive about their ability to spend their funding allocation well and their nervousness was reflected in the feedback respondents gave that they would like *"more support with* *financial decisions"* or to become more active agents in the processes of *"supporting (them) to help themselves."* We got the impression, however, that people's reluctance to engage with direct funding was also underscored by their fear that greater autonomy may sever them from the contact and conversations that they experienced through the relational attributes we described in the previous section. Although constant but intermittent contact did respond to the social isolation some people described experiencing and to the importance of having access to coaching or navigational conversations, where people found it difficult to act with agency in other life domains, this kind of support did little to advance major life goals or larger vocational outcomes. A few respondents told us, therefore, that what they were looking for was for support staff *"to spend more time with me."*

Improving the connectivity of people's interpersonal networks and sharing resources with other disabled people would also respond to the social isolation many described experiencing. During the interviews, we were struck by how distant some respondents were from the ordinary spaces and relationship that might contribute to a sense of their belonging to their community. Respondents with a visual impairment or high and complex support needs appeared most marginalised, with some depending on support simply *"to get me out of the house."* For this group, their place in the community was largely defined both by the timing and perceived purpose of their support. For some, being habitually assisted to "go shopping" or "go out for a coffee" represented a barrier to historical forms of community participation or the pursuit of other self-defining passions or interests. For others, it was simply described as preventing them from *"finding new, fun things to do and get to them with friends."*

Many people wrote of feeling marginalised from relationship, and the clear preference of those that did appeared to be to do things with other people rather than being chaperoned into community by individualised support. Respondent's repeatedly told us that they wanted "*more opportunities for social interaction"* and that this was often best experienced by "*mixing with other groups as a group."* As is expressed in the quote above, whilst the aim was to "*find new, fun things to do"* the destination most people sought was *"friends(hip)."*

A decade on from the closure of vocational day-bases, one respondent found it significant enough to write, "*they closed down my group that my friends belonged to."* The "(Be)(Longing)" that this person wrote of, found expression in other respondent's aspiration to (re)connect with the fellowship of other disabled people too. People wrote, for example, of wanting a "*pen-pal (with) disabilities (as a) friend to email"* or of wanting to meet people who had lived similar lives. For a few, the community of other disabled people had a political dimension, as connecting with "*many disabled people who have had the same problems would help CCS Disability Action to address it.*"

For others, however, doing things with other people was seen as a conduit to the kinds of intimacy that seldom featured as a vocational goal but which may represent the most elemental expression of our humanness. For one person, the alternative way they wanted CCS Disability Action to support them that they weren't currently was, "*to make friends, go out with people as a group, link me with other people with autism or like chicks to become friends.*"

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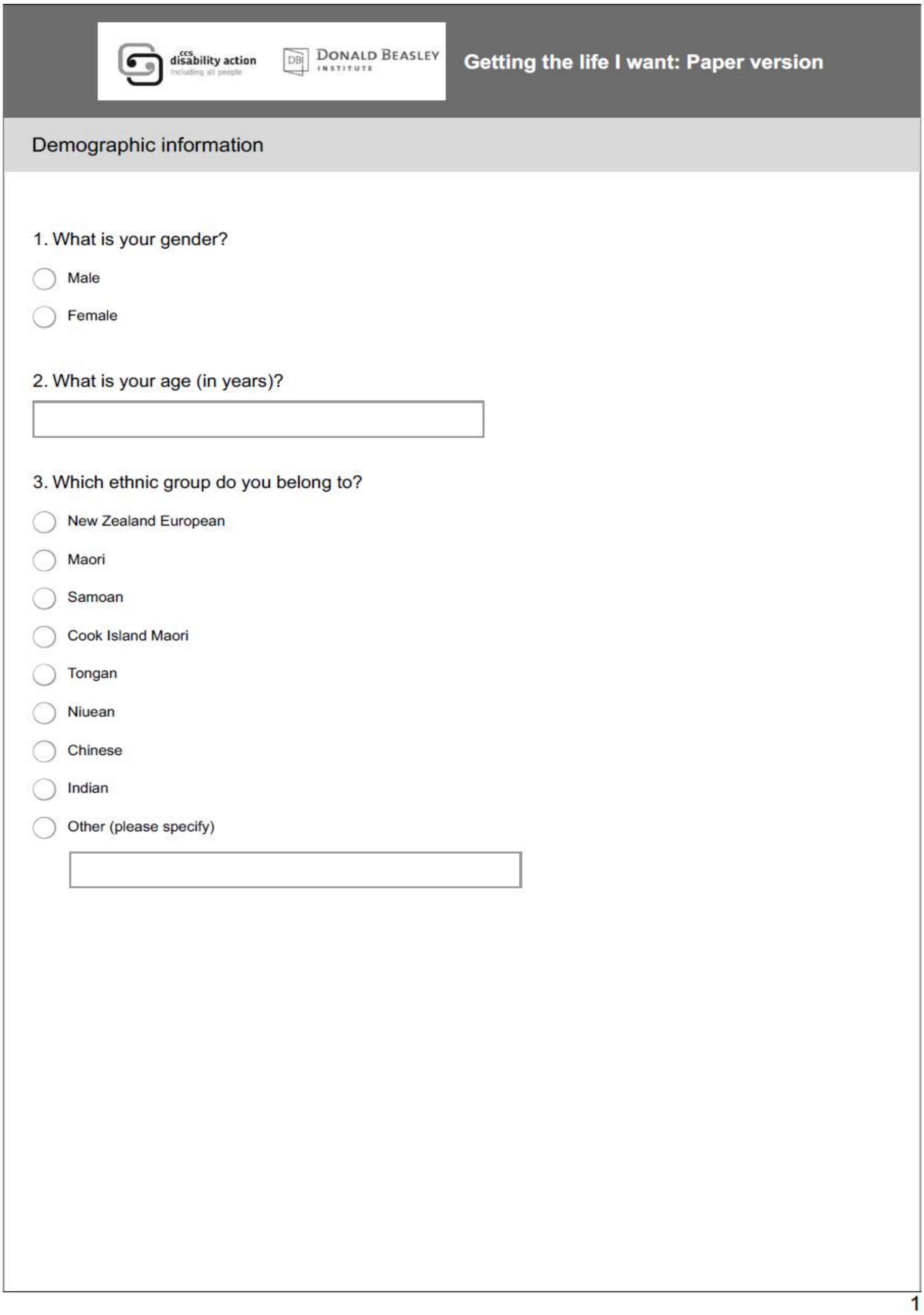
APPENDIX A

“Getting the life I want” Survey: Paper version



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Getting the life I want: Paper version

Demographic information

1. What is your gender?

○ Male
○ Female

2. What is your age (in years)?

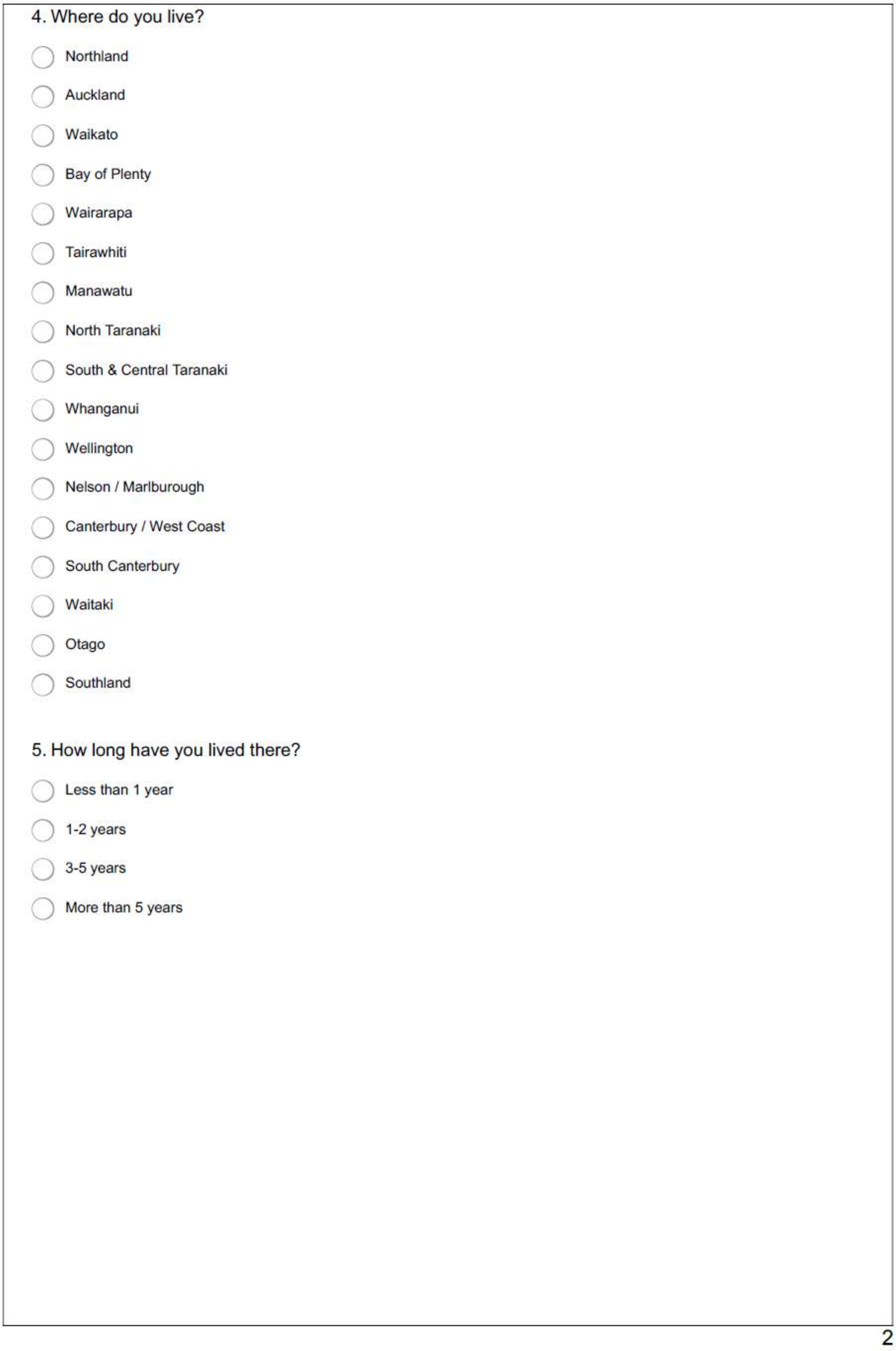
☐

3. Which ethnic group do you belong to?

○ New Zealand European
○ Maori
○ Samoan
○ Cook Island Maori
○ Tongan
○ Niuean
○ Chinese
○ Indian
○ Other (please specify)

☐

1



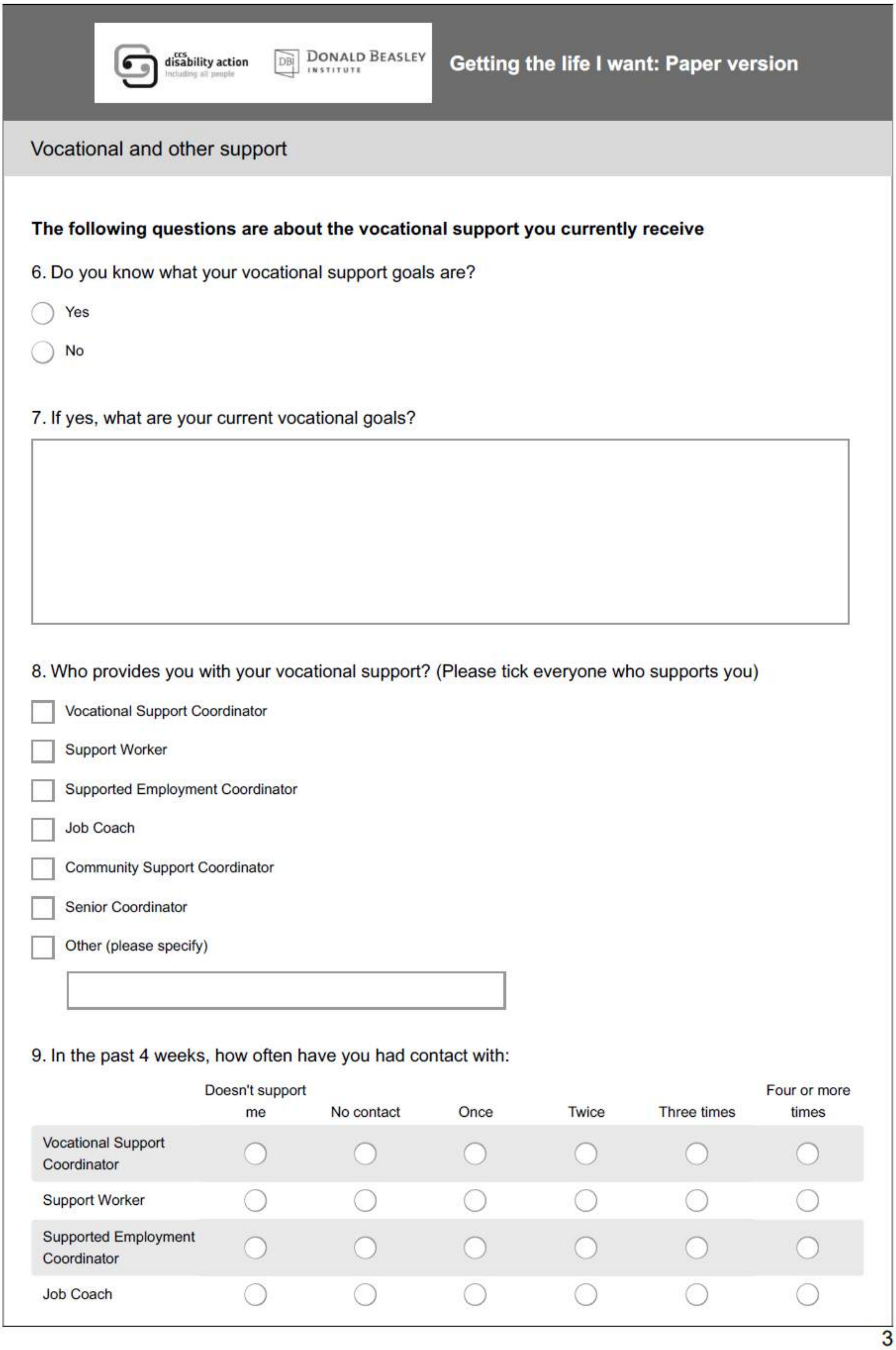
4. Where do you live?

○ Northland
○ Auckland
○ Waikato
○ Bay of Plenty
○ Wairarapa
○ Tairawhiti
○ Manawatu
○ North Taranaki
○ South & Central Taranaki
○ Whanganui
○ Wellington
○ Nelson / Marlborough
○ Canterbury / West Coast
○ South Canterbury
○ Waitaki
○ Otago
○ Southland

5. How long have you lived there?

○ Less than 1 year
○ 1-2 years
○ 3-5 years
○ More than 5 years

2



Getting the life I want: Paper version

Vocational and other support

The following questions are about the vocational support you currently receive

6. Do you know what your vocational support goals are?

○ Yes

○ No

7. If yes, what are your current vocational goals?

8. Who provides you with your vocational support? (Please tick everyone who supports you)

☐ Vocational Support Coordinator

☐ Support Worker

☐ Supported Employment Coordinator

☐ Job Coach

☐ Community Support Coordinator

☐ Senior Coordinator

☐ Other (please specify)

9. In the past 4 weeks, how often have you had contact with:

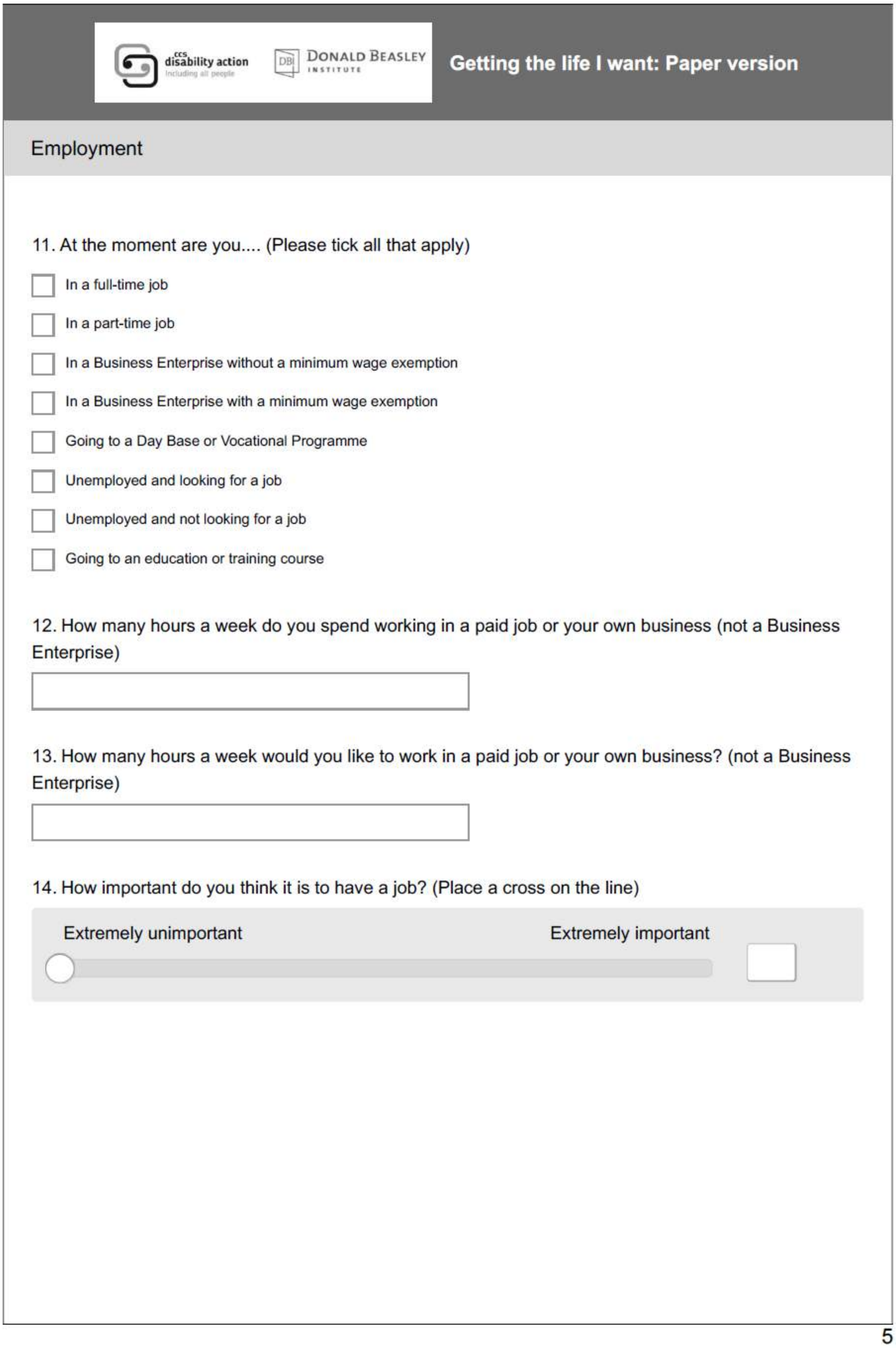
	Doesn't support me	No contact	Once	Twice	Three times	Four or more times
Vocational Support Coordinator	○	○	○	○	○	○
Support Worker	○	○	○	○	○	○
Supported Employment Coordinator	○	○	○	○	○	○
Job Coach	○	○	○	○	○	○

3

10. Do you receive any other types of disability support? (Please tick all of the other types of support you get)

☐ Residential Support
☐ Supported Independent Living
☐ Very High Needs
☐ Domestic and Personal Assistance

4



Getting the life I want: Paper version

Employment

11. At the moment are you.... (Please tick all that apply)

☐ In a full-time job

☐ In a part-time job

☐ In a Business Enterprise without a minimum wage exemption

☐ In a Business Enterprise with a minimum wage exemption

☐ Going to a Day Base or Vocational Programme

☐ Unemployed and looking for a job

☐ Unemployed and not looking for a job

☐ Going to an education or training course

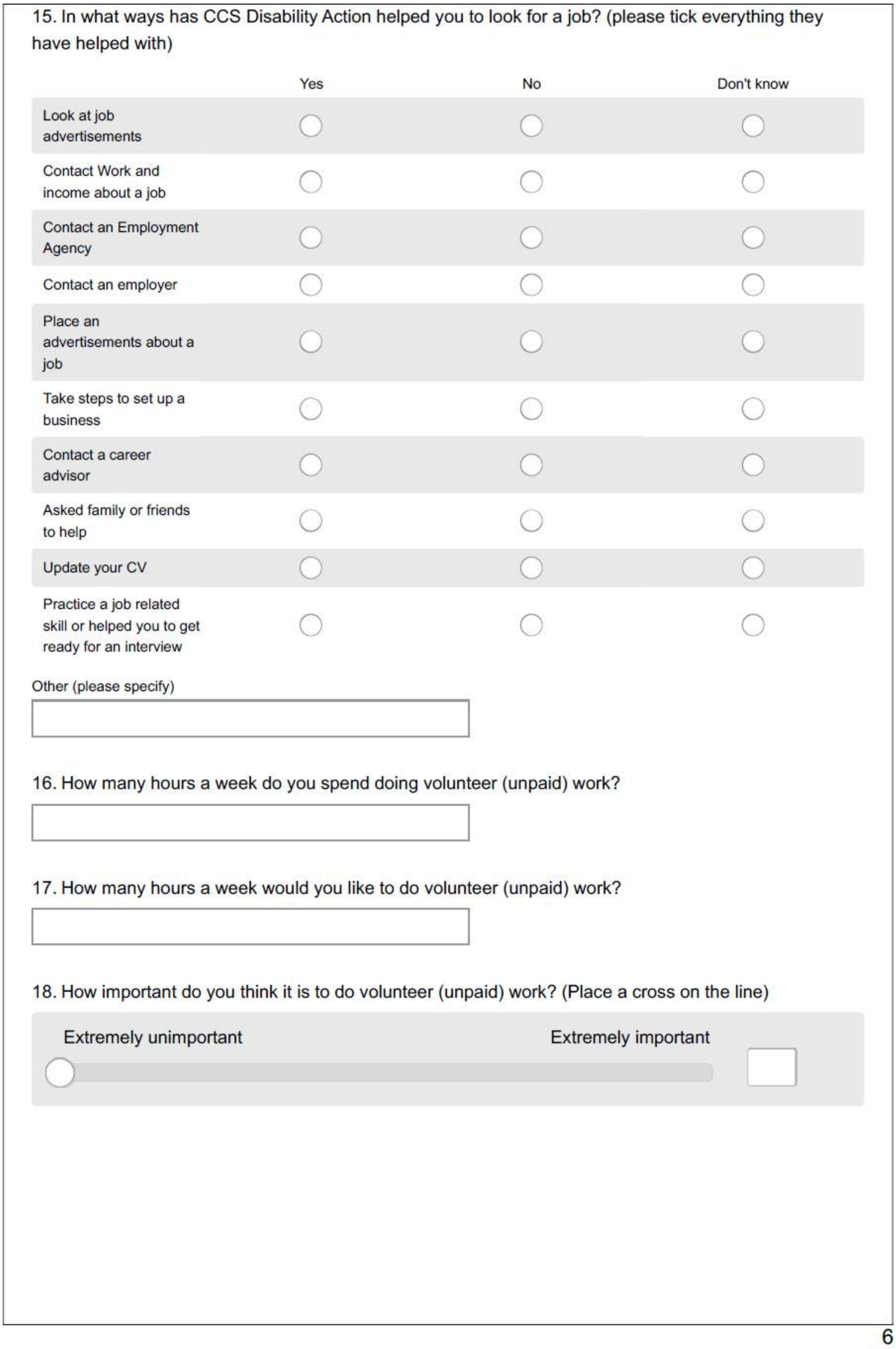
12. How many hours a week do you spend working in a paid job or your own business (not a Business Enterprise)

13. How many hours a week would you like to work in a paid job or your own business? (not a Business Enterprise)

14. How important do you think it is to have a job? (Place a cross on the line)

Extremely unimportant　　Extremely important

5



15. In what ways has CCS Disability Action helped you to look for a job? (please tick everything they have helped with)

	Yes	No	Don't know
Look at job advertisements	○	○	○
Contact Work and income about a job	○	○	○
Contact an Employment Agency	○	○	○
Contact an employer	○	○	○
Place an advertisements about a job	○	○	○
Take steps to set up a business	○	○	○
Contact a career advisor	○	○	○
Asked family or friends to help	○	○	○
Update your CV	○	○	○
Practice a job related skill or helped you to get ready for an interview	○	○	○

Other (please specify)

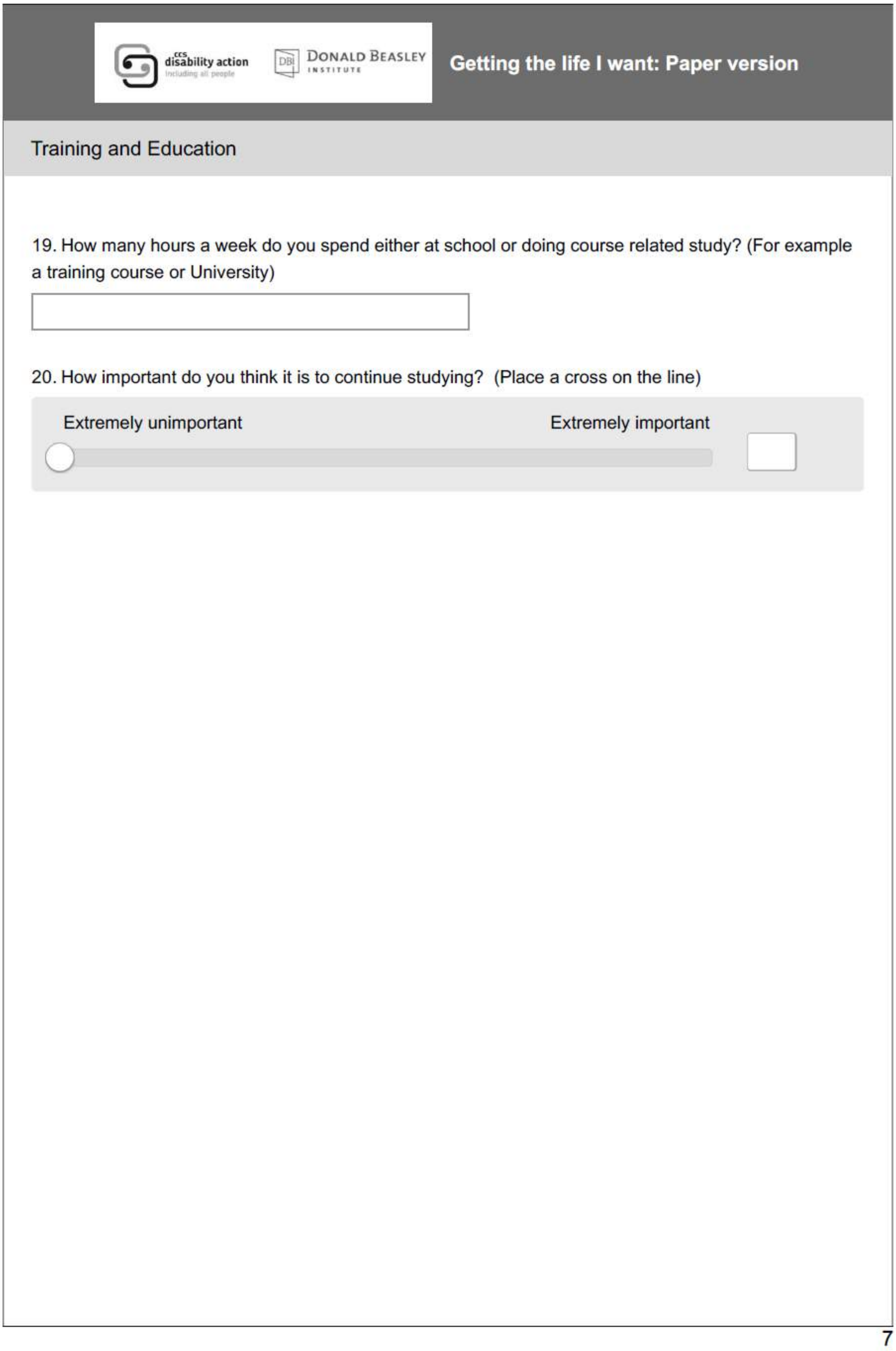
16. How many hours a week do you spend doing volunteer (unpaid) work?

17. How many hours a week would you like to do volunteer (unpaid) work?

18. How important do you think it is to do volunteer (unpaid) work? (Place a cross on the line)

Extremely unimportant ○ Extremely important

6



Getting the life I want: Paper version

Training and Education

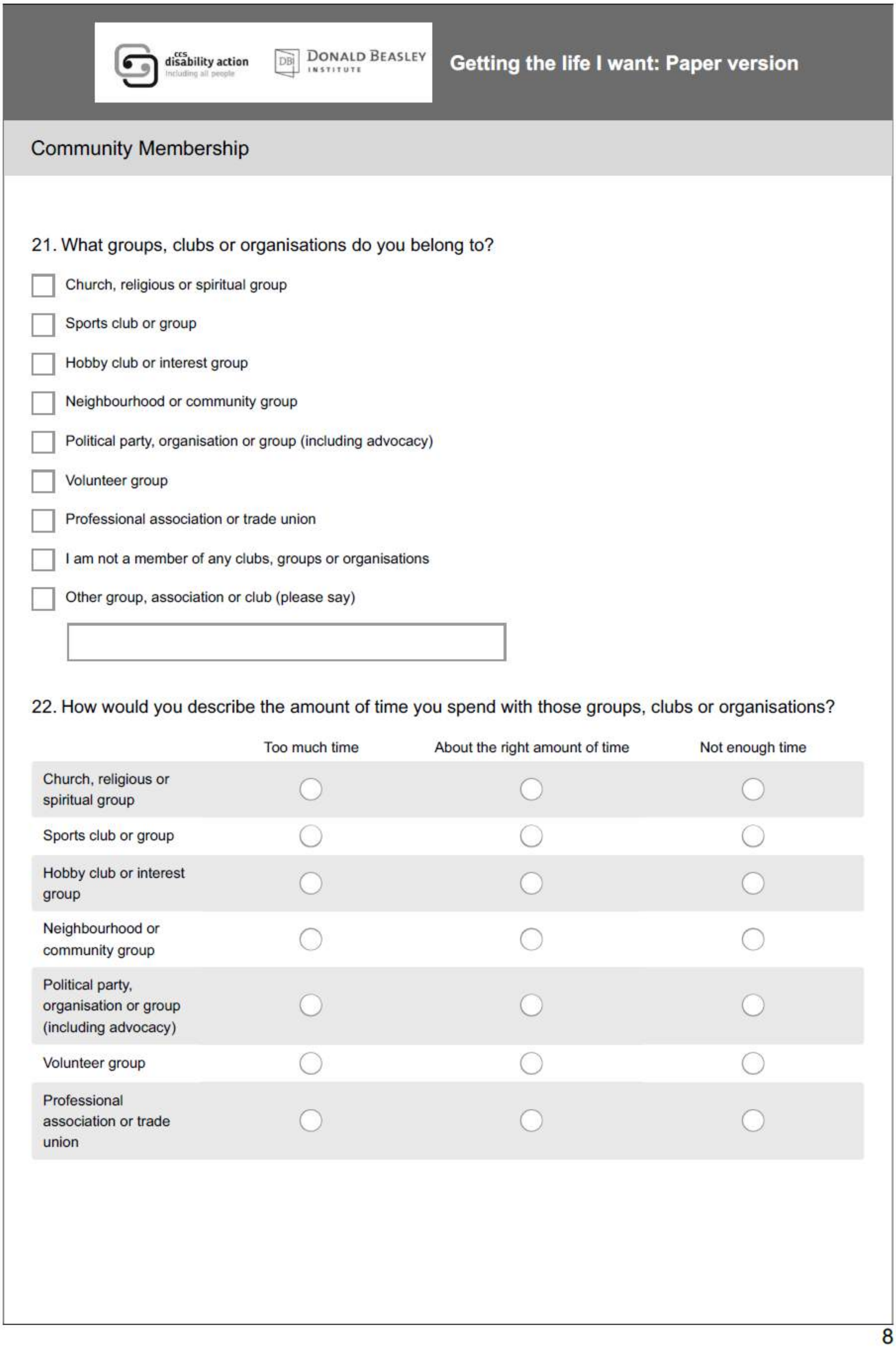
19. How many hours a week do you spend either at school or doing course related study? (For example a training course or University)

☐

20. How important do you think it is to continue studying? (Place a cross on the line)

☐

7



Getting the life I want: Paper version

Community Membership

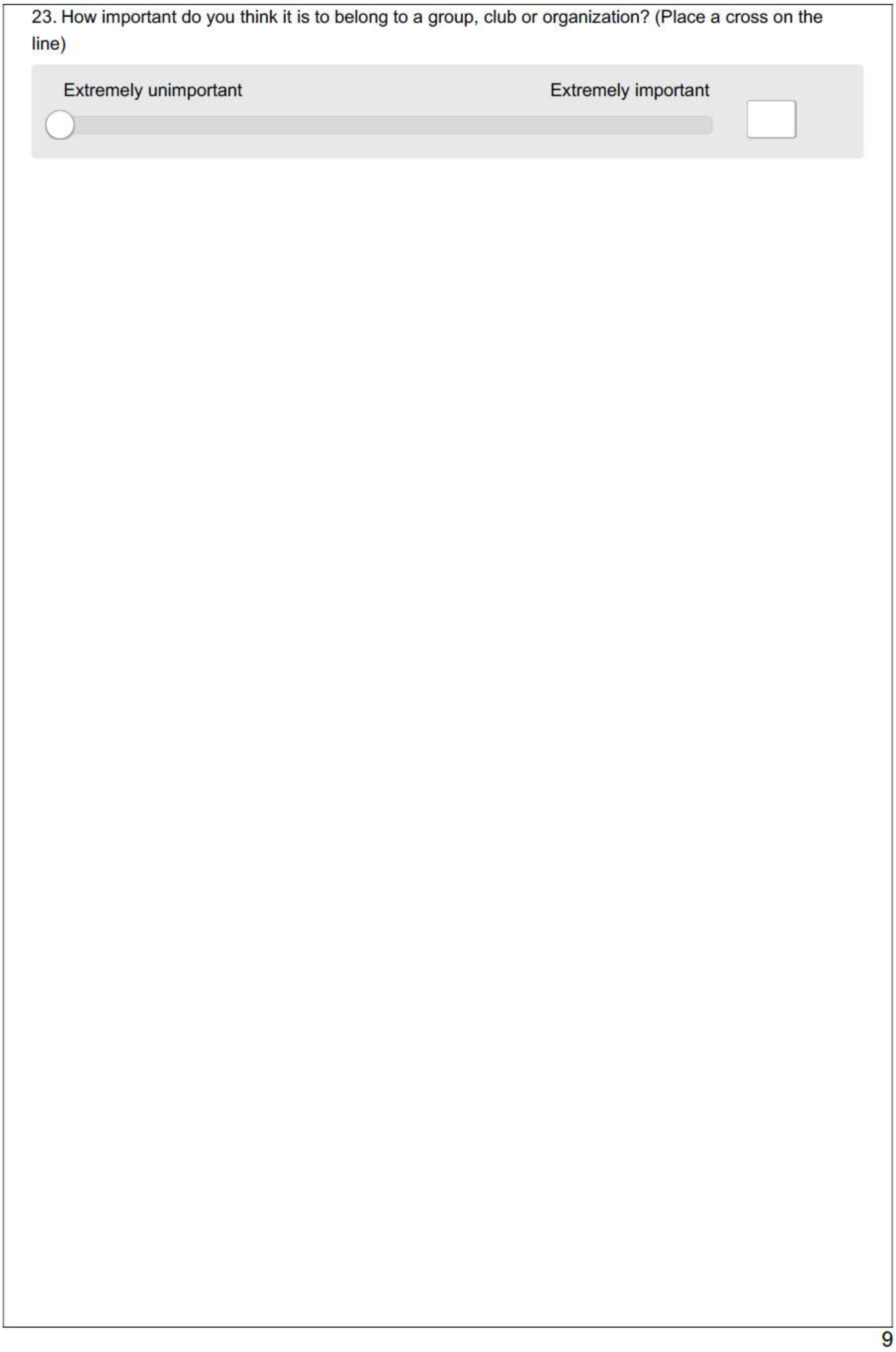
21. What groups, clubs or organisations do you belong to?

☐ Church, religious or spiritual group
☐ Sports club or group
☐ Hobby club or interest group
☐ Neighbourhood or community group
☐ Political party, organisation or group (including advocacy)
☐ Volunteer group
☐ Professional association or trade union
☐ I am not a member of any clubs, groups or organisations
☐ Other group, association or club (please say)

22. How would you describe the amount of time you spend with those groups, clubs or organisations?

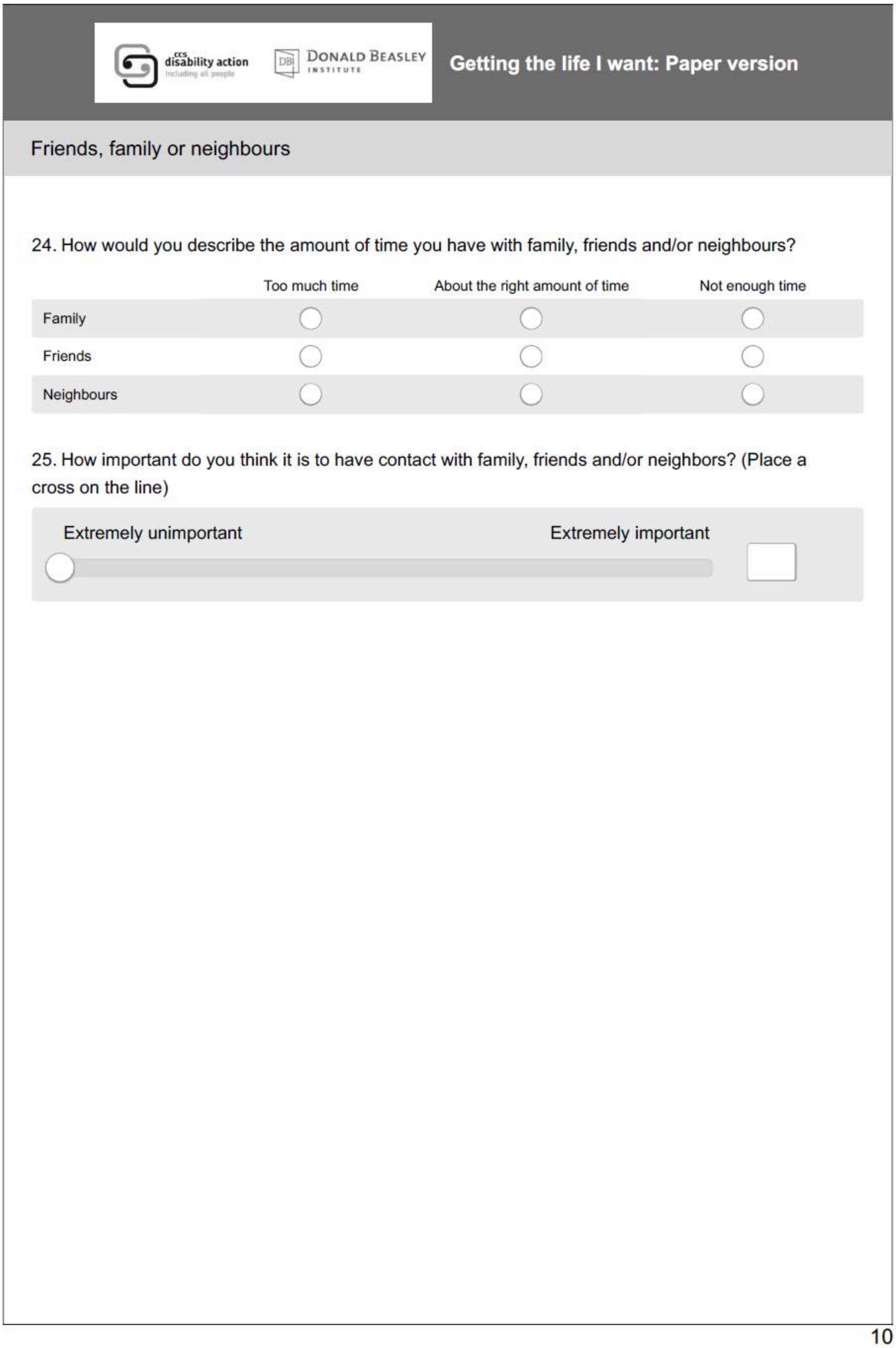
	Too much time	About the right amount of time	Not enough time
Church, religious or spiritual group	○	○	○
Sports club or group	○	○	○
Hobby club or interest group	○	○	○
Neighbourhood or community group	○	○	○
Political party, organisation or group (including advocacy)	○	○	○
Volunteer group	○	○	○
Professional association or trade union	○	○	○

8



23. How important do you think it is to belong to a group, club or organization? (Place a cross on the line)

9



Getting the life I want: Paper version

Friends, family or neighbours

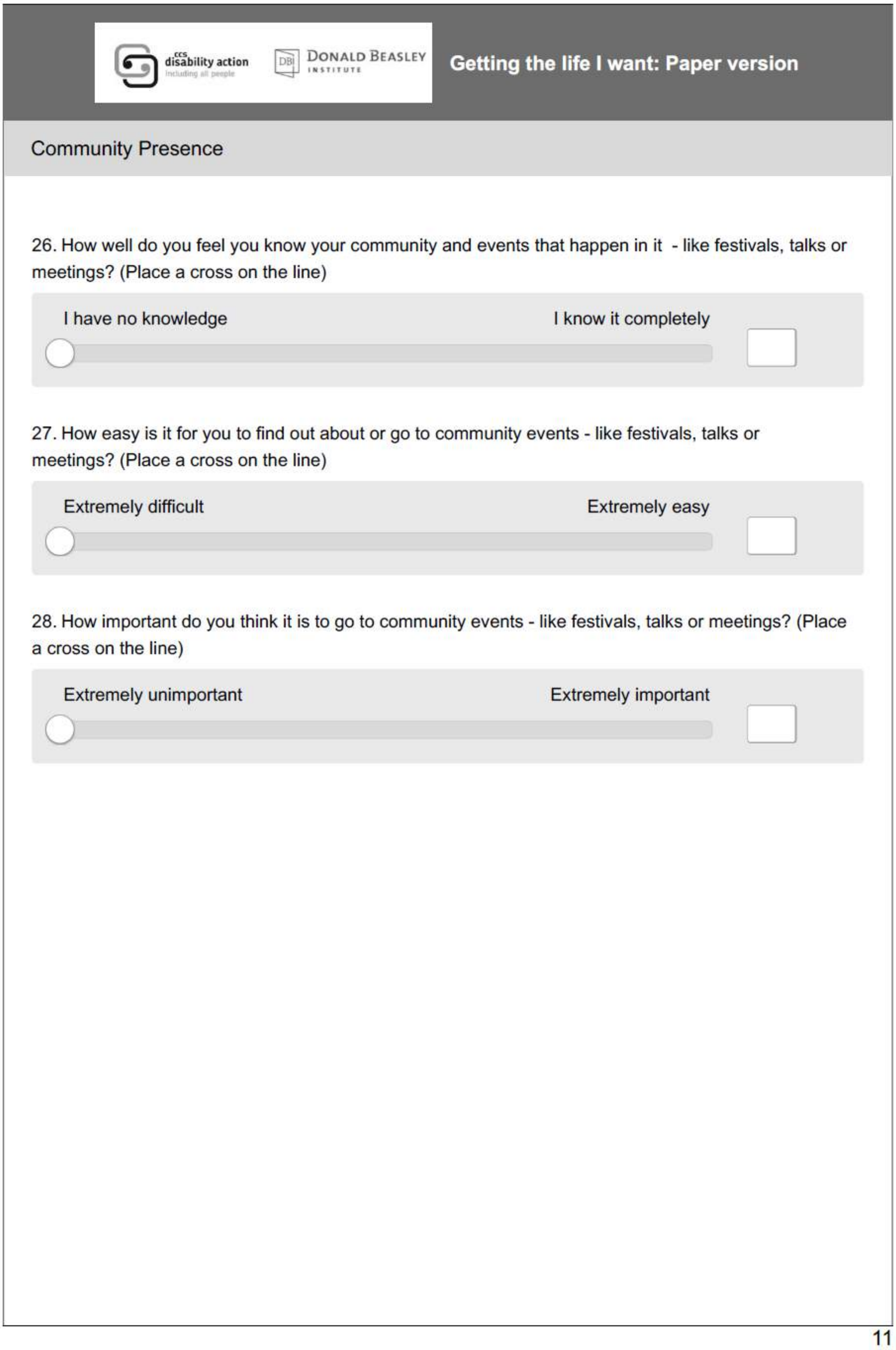
24. How would you describe the amount of time you have with family, friends and/or neighbours?

	Too much time	About the right amount of time	Not enough time
Family	○	○	○
Friends	○	○	○
Neighbours	○	○	○

25. How important do you think it is to have contact with family, friends and/or neighbors? (Place a cross on the line)

Extremely unimportant ○ Extremely important ☐

10



Getting the life I want: Paper version

Community Presence

26. How well do you feel you know your community and events that happen in it - like festivals, talks or meetings? (Place a cross on the line)

I have no knowledge ○ I know it completely ☐

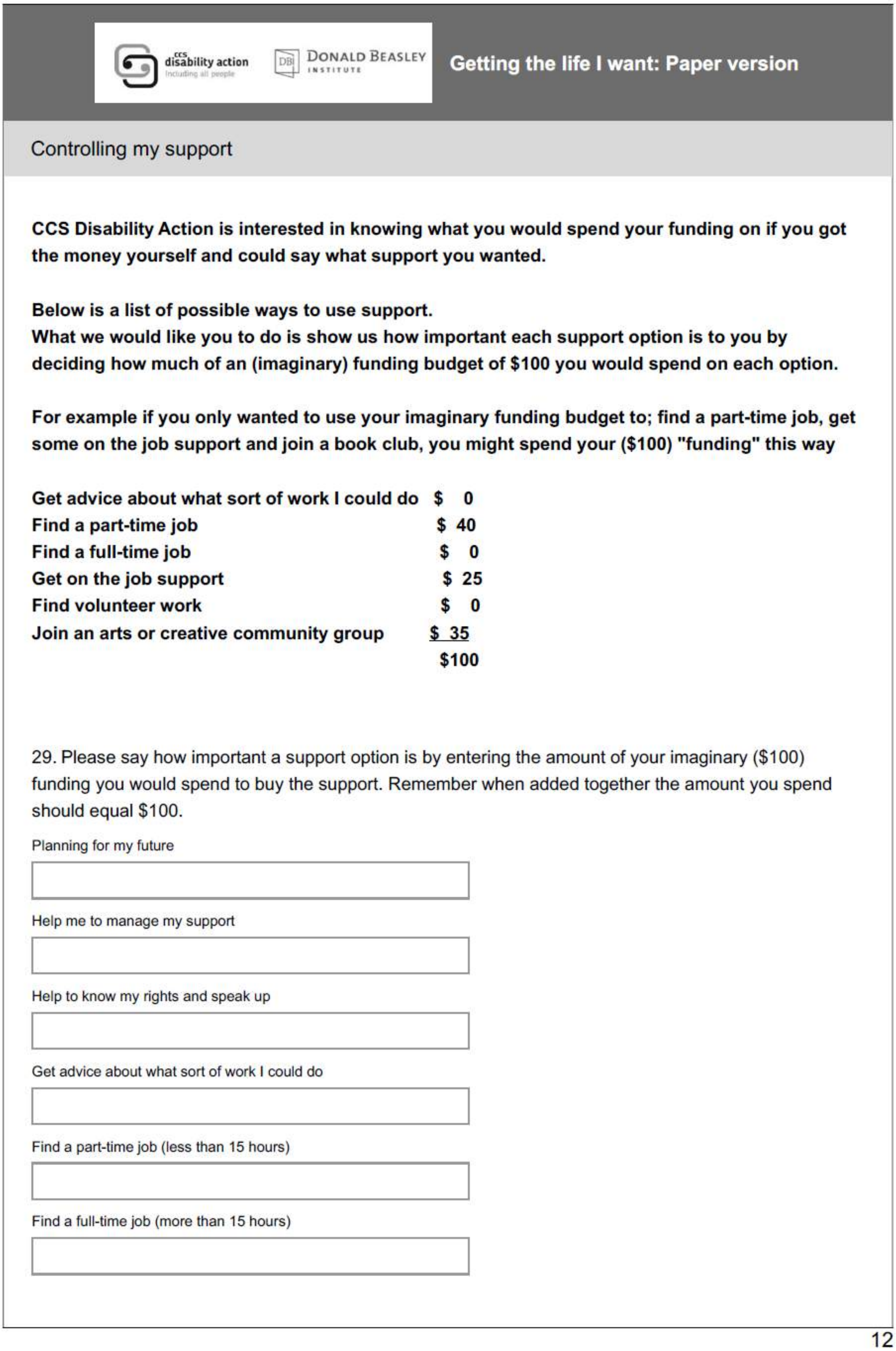
27. How easy is it for you to find out about or go to community events - like festivals, talks or meetings? (Place a cross on the line)

Extremely difficult ○ Extremely easy ☐

28. How important do you think it is to go to community events - like festivals, talks or meetings? (Place a cross on the line)

Extremely unimportant ○ Extremely important ☐

11



Getting the life I want: Paper version

Controlling my support

CCS Disability Action is interested in knowing what you would spend your funding on if you got the money yourself and could say what support you wanted.

Below is a list of possible ways to use support.
What we would like you to do is show us how important each support option is to you by deciding how much of an (imaginary) funding budget of $100 you would spend on each option.

For example if you only wanted to use your imaginary funding budget to; find a part-time job, get some on the job support and join a book club, you might spend your ($100) "funding" this way

Get advice about what sort of work I could do	**$ 0**
Find a part-time job	**$ 40**
Find a full-time job	**$ 0**
Get on the job support	**$ 25**
Find volunteer work	**$ 0**
Join an arts or creative community group	**$ 35**
	$100

29. Please say how important a support option is by entering the amount of your imaginary ($100) funding you would spend to buy the support. Remember when added together the amount you spend should equal $100.

Planning for my future

Help me to manage my support

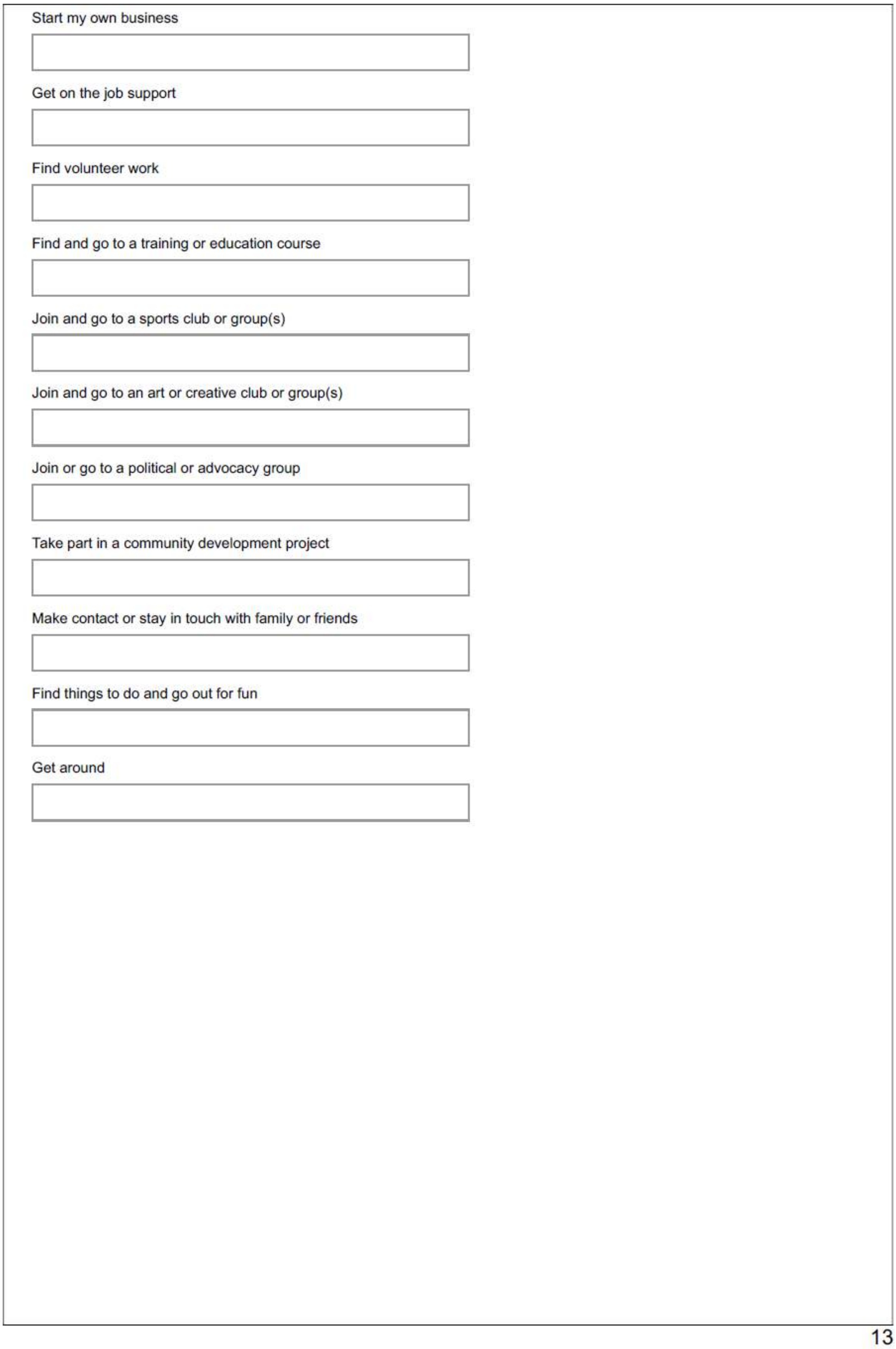
Help to know my rights and speak up

Get advice about what sort of work I could do

Find a part-time job (less than 15 hours)

Find a full-time job (more than 15 hours)

12



Start my own business

Get on the job support

Find volunteer work

Find and go to a training or education course

Join and go to a sports club or group(s)

Join and go to an art or creative club or group(s)

Join or go to a political or advocacy group

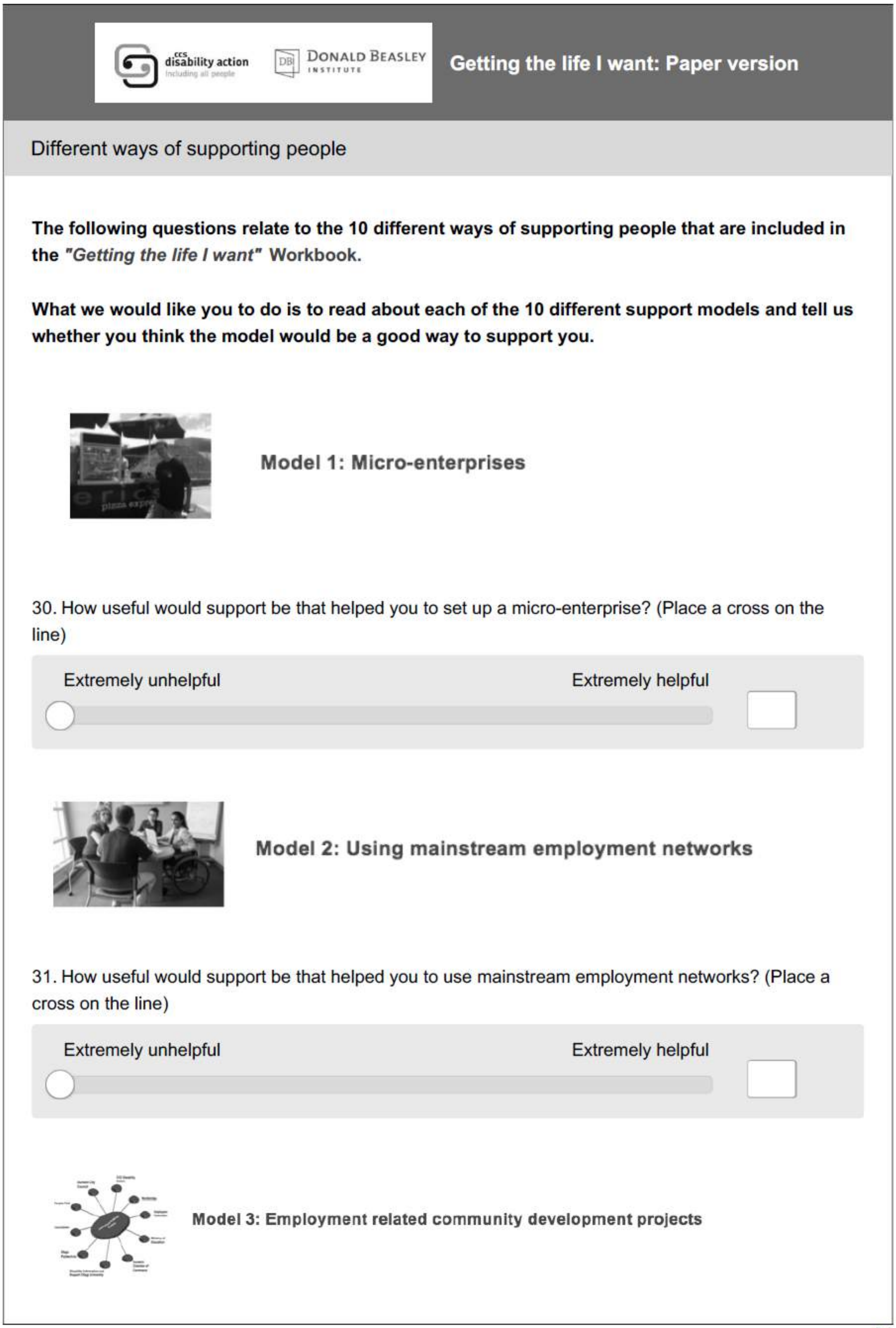
Take part in a community development project

Make contact or stay in touch with family or friends

Find things to do and go out for fun

Get around

13



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Different ways of supporting people

The following questions relate to the 10 different ways of supporting people that are included in the *"Getting the life I want"* Workbook.

What we would like you to do is to read about each of the 10 different support models and tell us whether you think the model would be a good way to support you.

Model 1: Micro-enterprises

30. How useful would support be that helped you to set up a micro-enterprise? (Place a cross on the line)

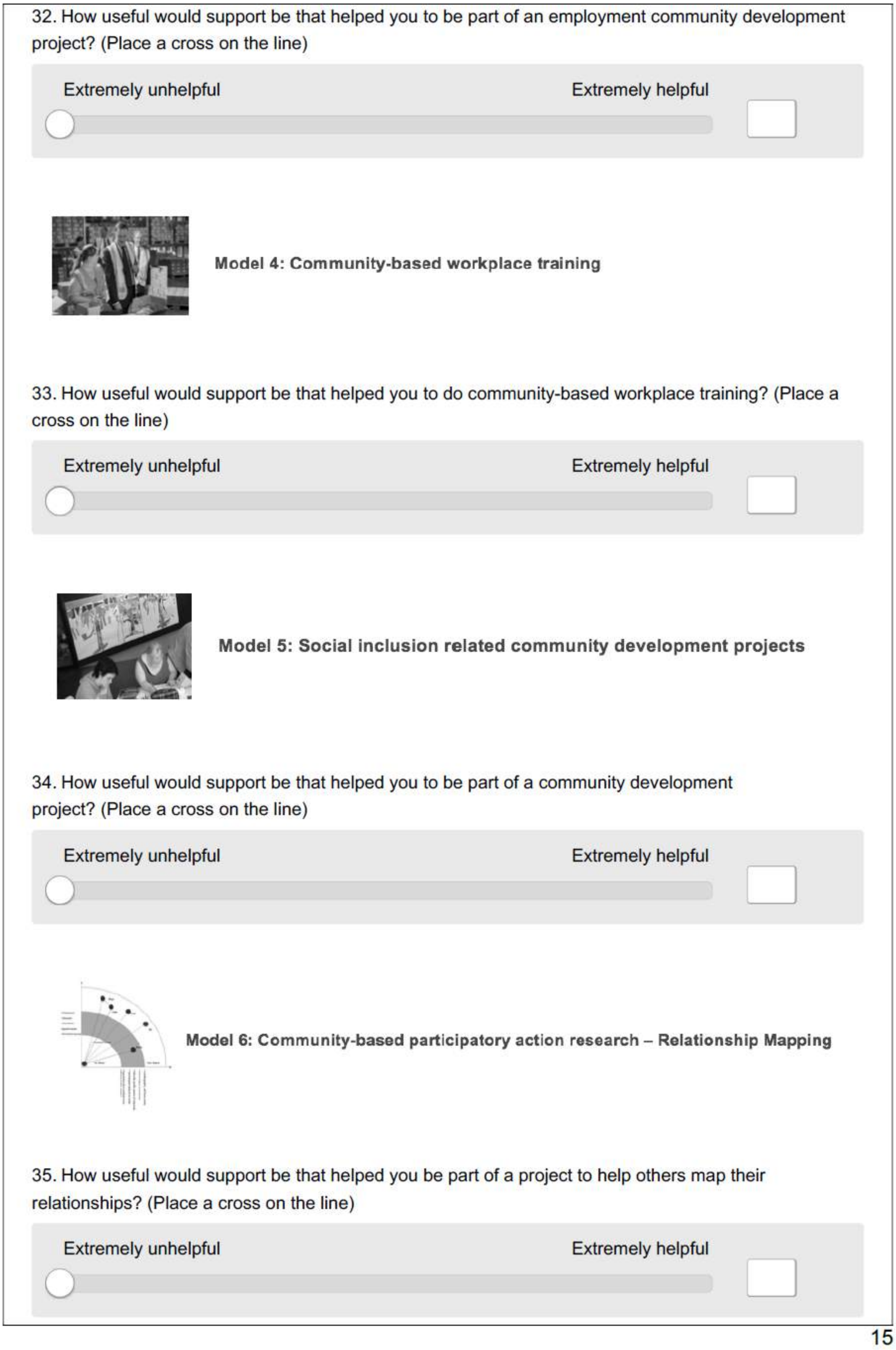
Extremely unhelpful ○ Extremely helpful ☐

Model 2: Using mainstream employment networks

31. How useful would support be that helped you to use mainstream employment networks? (Place a cross on the line)

Extremely unhelpful ○ Extremely helpful ☐

Model 3: Employment related community development projects



32. How useful would support be that helped you to be part of an employment community development project? (Place a cross on the line)

Extremely unhelpful ○ Extremely helpful ☐

Model 4: Community-based workplace training

33. How useful would support be that helped you to do community-based workplace training? (Place a cross on the line)

Extremely unhelpful ○ Extremely helpful ☐

Model 5: Social inclusion related community development projects

34. How useful would support be that helped you to be part of a community development project? (Place a cross on the line)

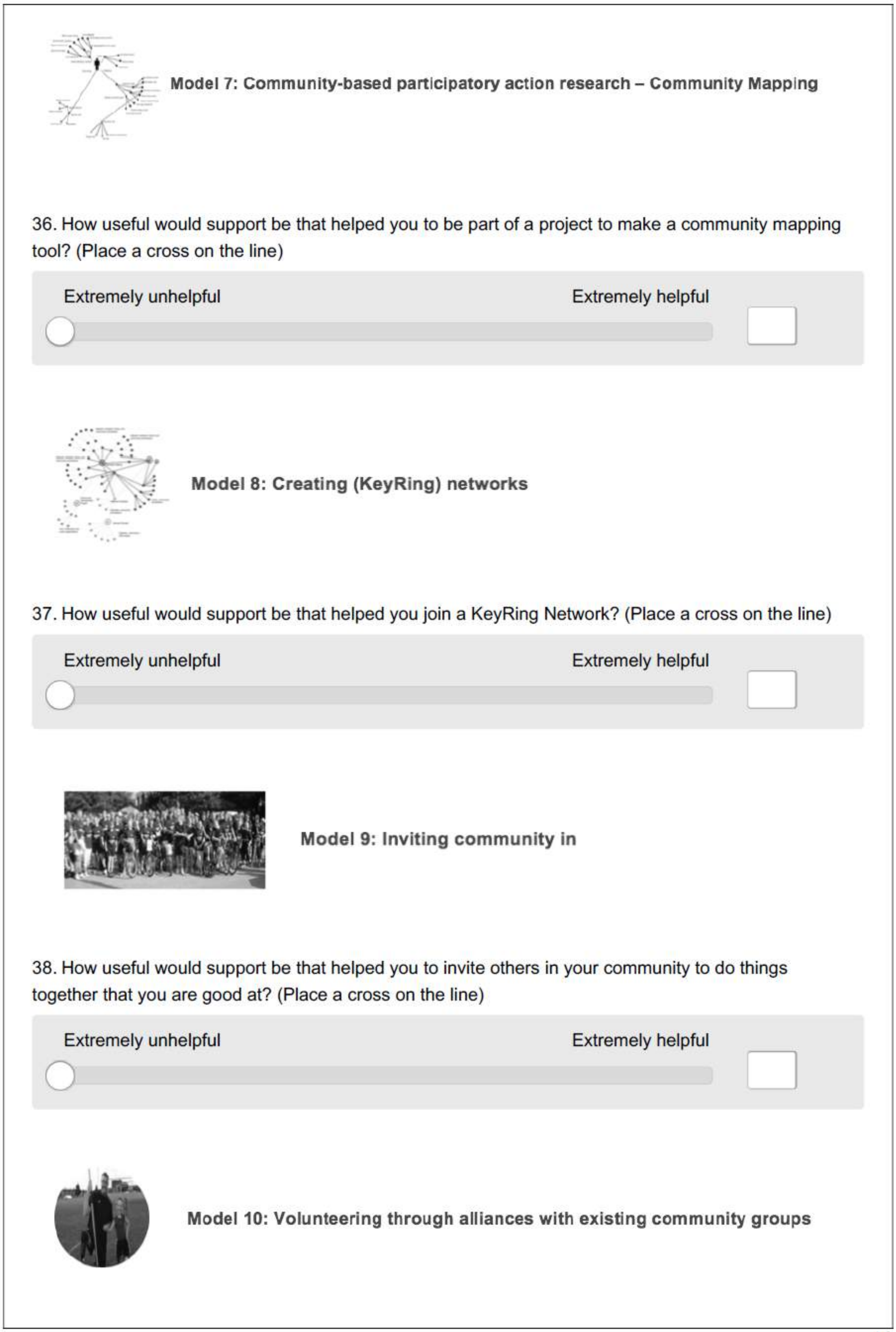
Extremely unhelpful ○ Extremely helpful ☐

Model 6: Community-based participatory action research – Relationship Mapping

35. How useful would support be that helped you be part of a project to help others map their relationships? (Place a cross on the line)

Extremely unhelpful ○ Extremely helpful ☐

15



Model 7: Community-based participatory action research – Community Mapping

36. How useful would support be that helped you to be part of a project to make a community mapping tool? (Place a cross on the line)

Extremely unhelpful ○ Extremely helpful ☐

Model 8: Creating (KeyRing) networks

37. How useful would support be that helped you join a KeyRing Network? (Place a cross on the line)

Extremely unhelpful ○ Extremely helpful ☐

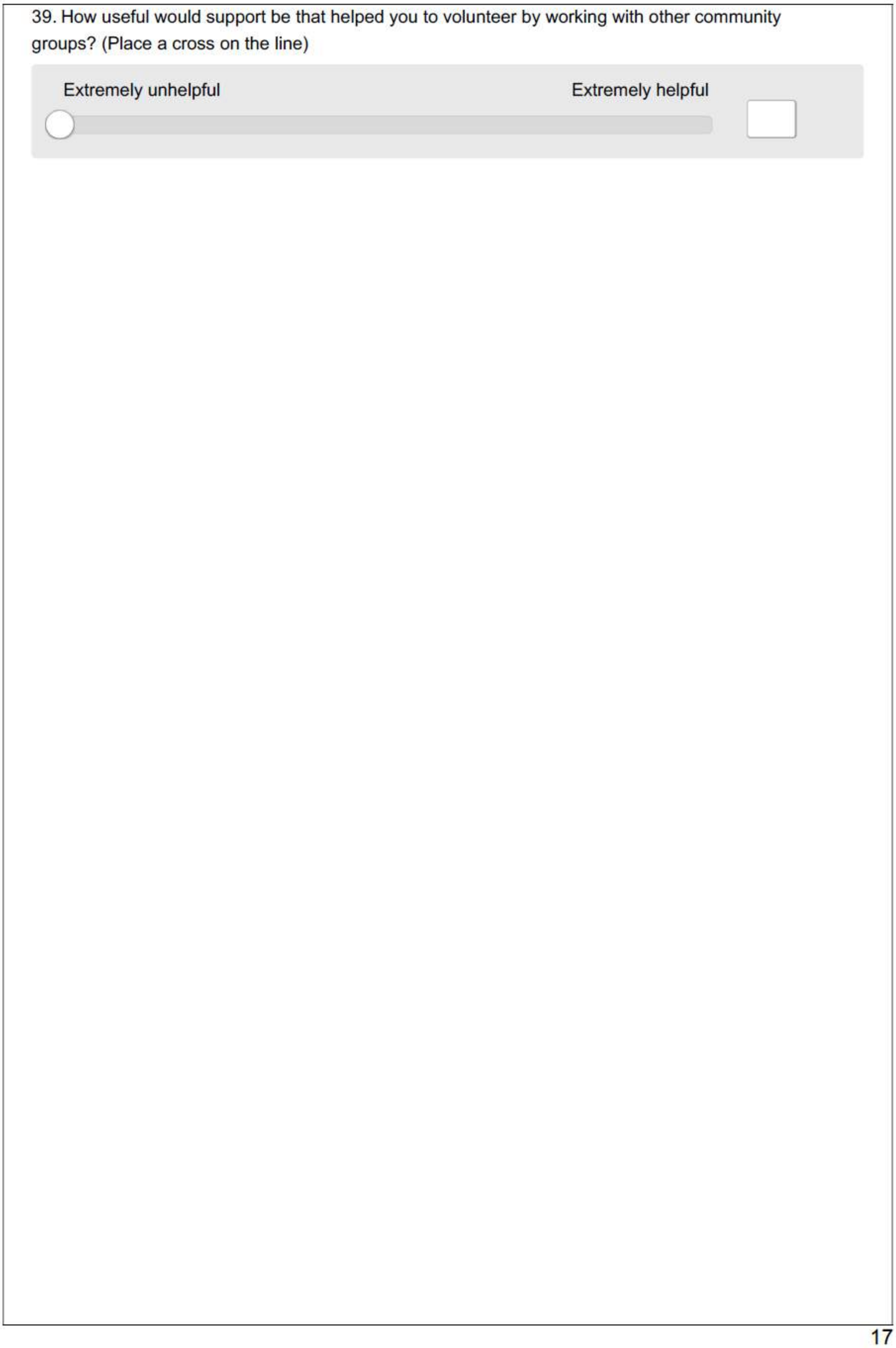
Model 9: Inviting community in

38. How useful would support be that helped you to invite others in your community to do things together that you are good at? (Place a cross on the line)

Extremely unhelpful ○ Extremely helpful ☐

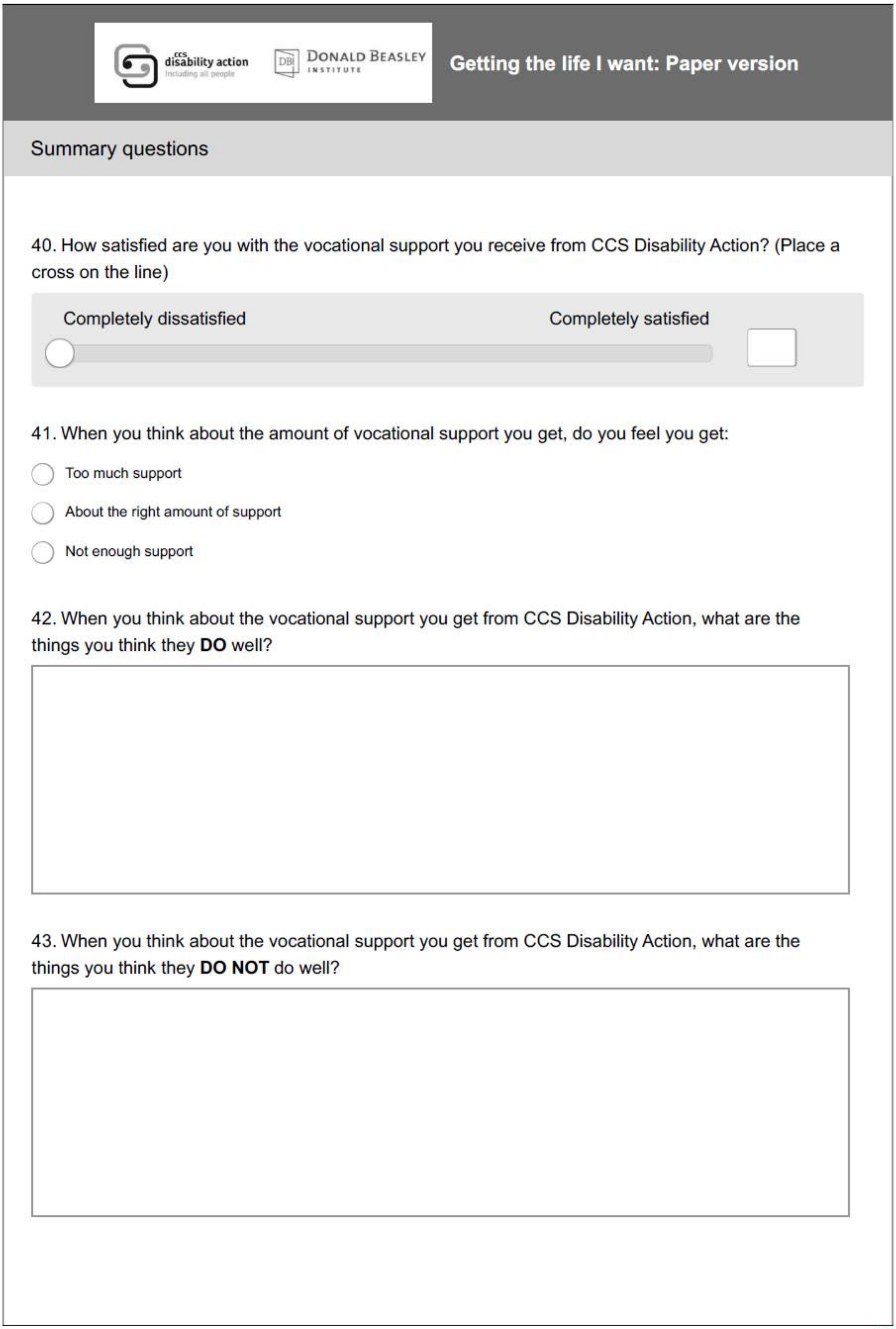
Model 10: Volunteering through alliances with existing community groups

16



39. How useful would support be that helped you to volunteer by working with other community groups? (Place a cross on the line)

17



Getting the life I want: Paper version

Summary questions

40. How satisfied are you with the vocational support you receive from CCS Disability Action? (Place a cross on the line)

Completely dissatisfied ○———————————— Completely satisfied ☐

41. When you think about the amount of vocational support you get, do you feel you get:

○ Too much support

○ About the right amount of support

○ Not enough support

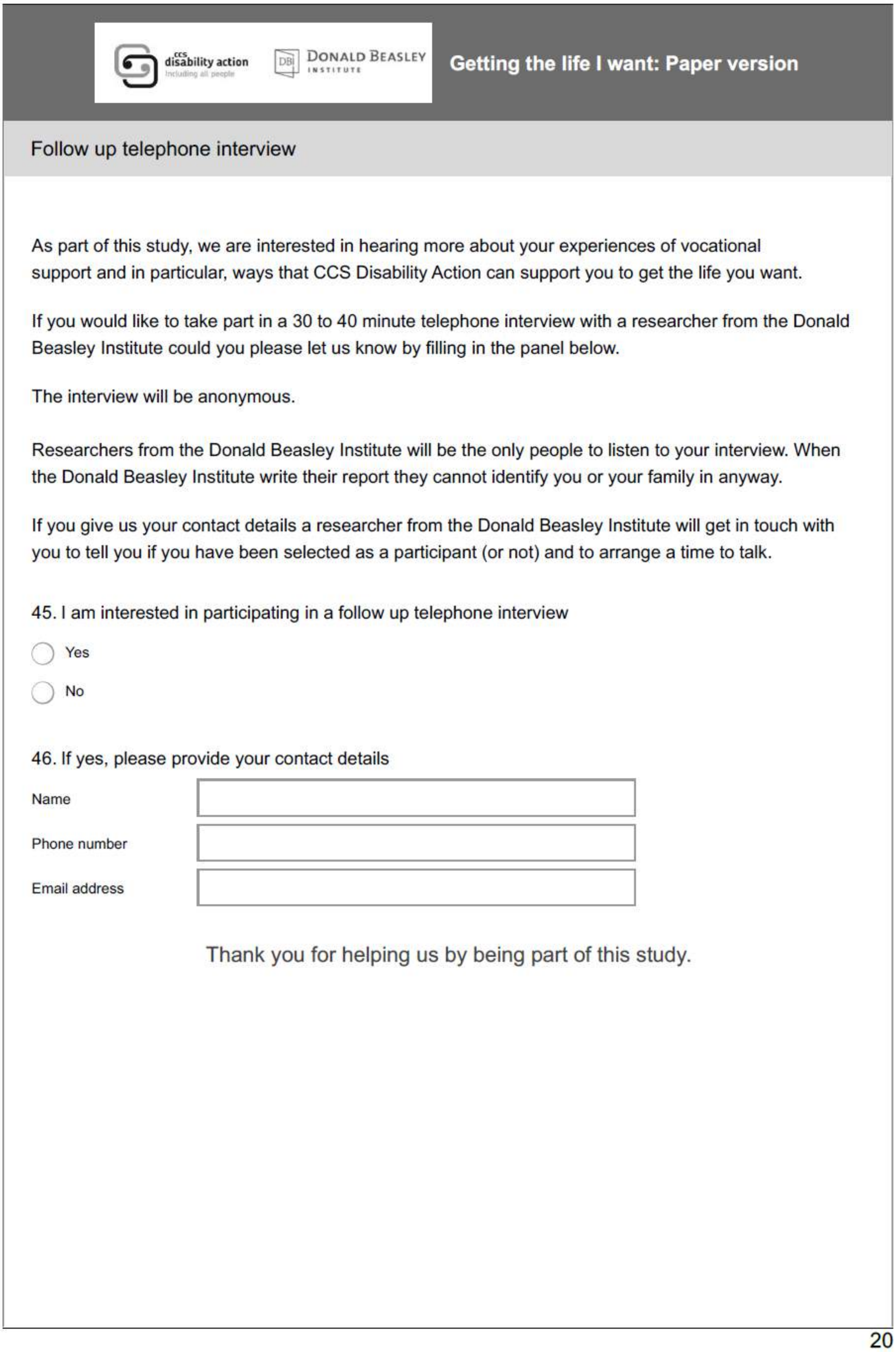
42. When you think about the vocational support you get from CCS Disability Action, what are the things you think they **DO** well?

43. When you think about the vocational support you get from CCS Disability Action, what are the things you think they **DO NOT** do well?

18

44. Can you think of other ways you would like to be supported?

19



Getting the life I want: Paper version

Follow up telephone interview

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.

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.

The interview will be anonymous.

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.

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.

45. I am interested in participating in a follow up telephone interview

○ Yes

○ No

46. If yes, please provide your contact details

Name	
Phone number	
Email address	

Thank you for helping us by being part of this study.

20

APPENDIX B

The “Getting the life I want” Handbook

The *“Getting the life I want”* Handbook

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TE HUNGA HAUA MAURI MO NGA TANGATA KATOA

DONALD BEASLEY INSTITUTE

1. Micro-enterprises

Micro enterprises are very small (often single person) businesses owned by a disabled person. With the assistance of individualised support, disabled people are successfully operating businesses that are as different as their interests and talents. Eric's Pizza Express is just one example of a micro-enterprise.

"Eric's Pizza Express" sells pizzas, sandwiches and drinks made at a local restaurant. A family friend helped Eric to write a business plan. As part of the Eric helped a hot-dog vendor learn more about what was involved. Before starting his business Eric also got help from a "job developer" who supported him to meet with officials to learn more about the rules for having a food cart. His job developer also helped Eric to talk to the local restaurant about a possible business partnership and to find the money he needed to start the business. Eric used a mix of disability funding and a donation from a community organization who agree to give money to Eric in return for being able to use his cart themselves when he didn't need it to raise money for themselves. A "circle of support" helps Eric to run his business. Eric's "circle" includes an accountant who helps him to balance his books, and an employee from the local restaurant who provides job coaching. Eric works five days a week during the summer. He is working towards running the business independently and to hire someone else. http://www.realworkstories.org/self-employment/eric-starting-and-maintaining-a-business-through-a-circle-of-sHangten2015

Other examples of micro-enterprises run by disabled people include: courier services, lawn mowing and gardening, dog grooming and walking services, muffin making kits, cafés, motor dismantling, dance companies, a (now franchised) dating agency, pet food making, greeting card manufacture, art work and photography, flower arranging, document destruction….

2. Using "mainstream" employment networks

"Mainstream First", is the idea that service providers like CCS Disability Action should support people to get the help they need from services used by everybody else (mainstream) first. To do that service providers like CCS Disability Action are also expected to help mainstream service to become more welcoming and responsive to disabled people.

When it comes to getting a job, however, disabled people usually use specialist employment services that have contracts with the Government.

Working with and helping mainstream employment services to get better at helping disabled people to get a job might be a better way of doing things for lots of reasons, like;

- It would make it easier for disabled people to tell employers about the range of ways employing a disabled person would be good for their business.
- It would give disabled people looking for work access to a much wider network of possible employers.
- It would mean that disabled people looking for work would have more possible job vacancies to choose from.
- Businesses might be more likely to listen to mainstream employment services.

3. Employment related community development projects

In a “community development project” people from a community all work together to try to solve a common problem. Most often the “problem” to be fixed is how to make a community a good place to live for everyone and the idea is that by working together communities are made stronger and fairer.

The *‘Having a job like anyone else”* Community Development Project

The “Having a job like anyone else” project was a community development project that wanted to make it easier for disabled people in Dunedin to get a job by involving the whole community.

The project began when the Otago People First Group told community leaders how much harder it was for them to find work and what it meant to have a job before asking them to help them to do something to change things.

Funding was sought so that a range of community organisations could all start talking to each other, share their ideas and resources, come up with a plan and see whether it was working or not. The project was to be led by disabled people supported by researchers who were experts in doing community-based projects.

All of the organisations liked the idea and wanted to be part of the project, but it didn’t get funded.

4. Community-based (collective) workplace training

Workplace training for disabled people usually involves being taught skills outside of a workplace. In the example below a disability support service (Enrich+) worked with a local business (Manuka Health) to run a training programme within a factory.

Manuka Health & Enrich+ Partnership

By having a work experience programme in Manuka Health's Te Awamutu factory, Enrich+ gave disabled people a chance to train for a job in a real workplace *(www.thinkdifferently.org.nz/Enrich-Manuka-Health)*. Within the factory, "trainees," and their support worker, worked as a team to label, package and get Manuka Health products ready to leave the factory. Trainees said they liked the programme because;

- The factory was a safe place to learn workplace rules that are hard to know about if you don't have a real job.
- Doing the same work as everyone made them more confident about what they could do and made them feel the same as everyone else in the factory.
- Doing real work made them rethink what they wanted for their lives.
- The friendships that trainees made with other factory workers carried on outside of the factory making other places like the rugby club more welcoming.
- They could tell employers they had done real work and left the factory with job references.

For many trainees, the programme had led to a paid job including a small number who had gone on to paid employment in the factory.

Having trainees at the factory was good for Manuka Health too. Managers at Manuka Health said that having trainees at the factory had made it a much nicer place for everyone to be.

Having disabled people take over part of the factory also saved Manuka Health money because they didn't have to pay someone else to do the work they were doing.

Enrich+ said that balancing people's right to "real pay for real work" against all of the good things that came with training people in a factory was difficult. They also said it was not easy to know what to do when they thought that people had learnt everything they could but still really wanted to work in the factory.

5. 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)

"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 instillation 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.

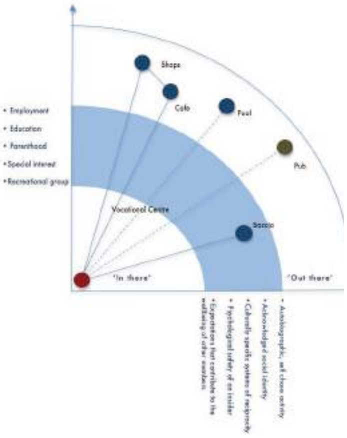
6. Community-based participatory action research – Relationship Mapping

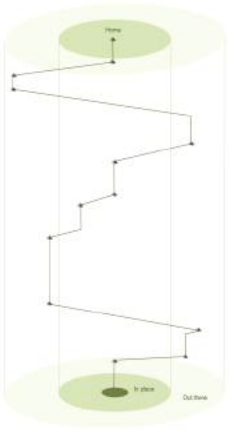
Community-based participatory research (CBPAR) involves disabled people in every stage of a research project intended to do something to improve people's lives

CCS Disability Action asked research to help them do two projects that used this way of doing research. In 2003 CCS Disability Action commissioned the ***Community Participation Project*** and in 2013, the ***"I am Here:" The Article 19 Project.*** *www.donaldbeasley.org.nz/assets/Uploads/.../article-19-research-full-report.pdf*

In both projects, disabled people told the research team that how people felt when they were in community places was often more important than where they were. They also said that it was harder for disabled people to be in the kind of places that other New Zealanders felt a sense of membership or belonging. CCS Disability Action used the research to let other New Zealanders know about what disabled people told them, but the research team thought that it would be good if disabled people could led a project that set out to help all people that id not feel they belonged to their community as much as they would like.

Mapping relational belonging.



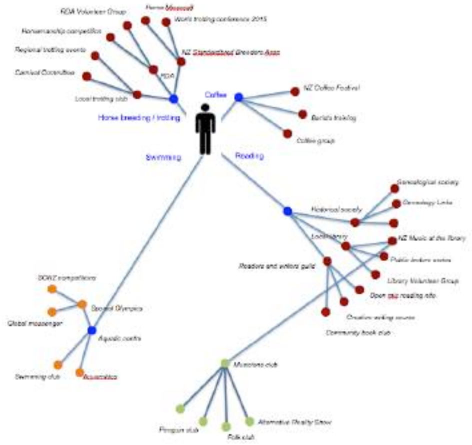


One way of doing this would be to come up with a way of mapping the places in someone's community that they do or don't feel they belong. In the 2003 project, disabled people told what to look for but no-one has tried to map how people are relationally connected to their community.

Being able to do that would allow

- Disabled (and other) people to make it clear whether the way they were being support was helping them to feel as if they belonged to their community.
- Disability Service like CCS Disability Action to know which ways of supporting people worked the best.
- Allow communities to see who was most at risk of not feeling they belonged.
- Allow communities to identify what places included or did not include disabled (or other) people.
- Mobility advocates demonstrate the importance of accessible environments.
- Disabled people to show others alternative imaginings of community and belonging they have.
- Disabled people to monitor and report on progress made towards realising rights protected in the UN Convention.

7. Community-based participatory action research – Community Mapping



In the two projects mentioned before, disabled people told the research team that they tended to go to places that CCS Disability Action staff often went rather than finding new ways to do the things they were really interested in doing. Many people also said they did not know their community very well either.

Always going to the same kinds of places meant that people were less likely to go to places where people were interested in the same things.

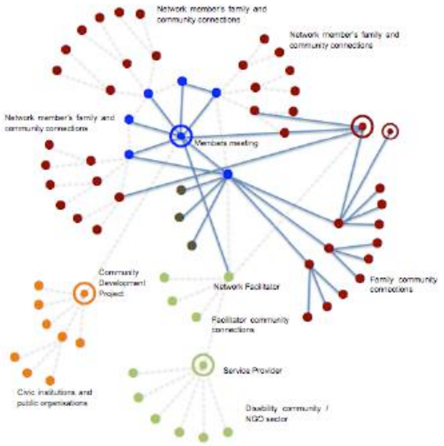
Mapping personally valued community organisations

Another project that disabled people could lead and continue to work on would be to develop an online tool that would help people to find community groups that they could think about joining. Once set up, the online mapping tool could be used by everyone in a community to find discover community groups and organisations that liked doing the same things they did.

8. Creating (KeyRing) Networks

KeyRing Networks involve up to nine disabled people meeting and working together to provide each other with practical and emotional (peer) support. In some networks, network members also use a small amount of their support funding to hire a "network facilitator" to help them to do the things they want to do.

The first Network in New Zealand started in Palmerston North in 2013. In that network, members decided what the purpose of the group would be and the way it would work.



An evaluation of the Palmerston North network was done and found that members spent a lot of time making sure the network was a safe space within which everyone listened to each other and decided what to do. Over time members began to develop friendships and started to invite each other to each other homes for regular get-togethers. They also used the network as a way to plan to do things together that they wouldn't ordinarily do.

Being in a network also meant that members were also linked to each other's families and other community connections in the first two years of the network.

9. Inviting community in

When people think about what "inclusion" means for disabled people they almost always thing 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

10. Volunteering through alliances with existing community groups

Lots of organisations that help make New Zealand a better place to live rely on volunteers. Statistics New Zealand say that as many as one in three New Zealanders do voluntary work and two out of every three New Zealanders do “unpaid work” for community organisations (Statistics New Zealand, 2016).

They have also found that people who do voluntary work usually have higher levels of life satisfaction. This finding is similar to other studies that have found that volunteering usually improves people’s mental and physical health, levels of social engagement and happiness. (Balandin et al, 2006).

Although the amount of organistions that rely on volunteers has grown, the number of people who can volunteer is getting smaller, leading many organisations to worry about their future. Recognising that disabled people may be a largely untapped resource and that having disabled people help also enables community organisations to learn more and get better at including all people, a small number of disability providers have been trying to form strategic alliances with networks of “like-minded” community organisations.

Such “community assemblages” that include and draw on the strengths of disabled people might include but not be restricted to;

APPENDIX C

Vocational Outcome Regression Models

Rated the importance of having a job > 2/3 SM

		Unadjusted model		Adjusted model		
Sex		n (%)	p-value	p-value	Odds ratio	95% CI
	Male	29 (67.5)	0.58			
	Female	34 (61.5)				
Age	15-24 years	19 (65.5)	0.31			
	25-34 years	11 (52.4)				
	35-44 years	7 (58.3)				
	45-55 years	13 (86.7)				
	55-64 years	3 (60.0)				
	65+ years	0				
Ethnicity	NZ European	45 (64.3)	0.56			
	Māori	3 (60.0)				
	Pacifica Peoples	3 (100)				
	Indian	-				
	Other	2 (50.0)				
Contact with Vocational Coordinator	Less than two times	27 (65.9)	0.22			
	Twice or more	11 (50.0)				
Other support	Did not receive other	27 (71.1)	0.28			
	Did receive other	25 (59.5)				
Employment status	Unemployed	29 (55.8)	0.04	0.401		
	Employed < 15 hours	12 (75.0)		0.177	2.379	0.677-8.368
	Employed < 15 hours	7 (100)		0.999	-	-
Volunteered	Don't volunteer	21 (72.4)	0.40			
	Volunteer	29 (63.0)				
Community connectivity	Member of a community group	35 (63.6)	0.62			
	Not a member of a community group	18 (69.2)				
Region	Northland	1 (25.0)	0.61			
	Auckland	7 (70.0)				
	Waikato	-				
	Bay of Plenty	8 (72.7)				
	Wairarapa	-				
	Tairawhiti	2 (66.7)				
	Manawatu	2 (50.0)				
	North Taranaki	1 (33.3)				
	South & Central Taranaki	2 (50.0)				
	Whanganui	1 (100)				
	Wellington	3 (100)				
	Nelson / Marlborough	7 (77.8)				
	Canterbury / West Coast	5 (62.5)				
	South Canterbury	3 (75.0)				
	Waitaki	2 (40.0)				
	Otago	7 (87.5)				
	Southland	2 (50.0)				

Unemployed

		Unadjusted model		Adjusted model		
Sex		n (%)	p-value	p-value	Odds ratio	95% CI
	Male	32 (76.2)	0.34			
	Female	26 (66.7)				
Age	15-24 years	19 (70.4)	0.31			
	25-34 years	13 (65.0)				
	35-44 years	12 (85.7)				
	45-55 years	9 (60.0)				
	55-64 years	5 (100)				
	65+ years	-				
Ethnicity	NZ European	44 (65.7)	0.08	-		
	Māori	7 (100)		-	-	-
	Pacifica Peoples	3 (100)		-	-	-
	Indian	4 (100)		-	-	-
	Other	-		-	-	-
Contact with Vocational Coordinator	Less than two times	28 (71.8)	0.94			
	Twice or more	17 (70.8)				
Other support	Did not receive other	23 (69.7)	0.84			
	Did receive other	33 (71.7)				
Volunteered	Don't volunteer	17 (56.7)	0.02	0.03	3.375	1.122-10.155
	Volunteer	36 (81.8)				
Community connectivity	Member of a community group	39 (68.4)	0.38			
	Not a member of a community group	18 (78.3)				
Region	Northland	3 (75.0)	0.58			
	Auckland	8 (80.0)				
	Waikato	-				
	Bay of Plenty	7 (70.0)				
	Wairarapa	-				
	Tairawhiti	7 (100)				
	Manawatu	3 (75.0)				
	North Taranaki	1 (50.00)				
	South & Central Taranaki	4 (100)				
	Whanganui	1 (100)				
	Wellington	1 (50.0)				
	Nelson / Marlborough	5 (55.6)				
	Canterbury / West Coast	5 (71.4)				
	South Canterbury	2 (50.0)				
	Waitaki	3 (60.0)				
	Otago	3 (42.9)				
	Southland	3 (100)				

Employed part-time

		Unadjusted model		Adjusted model		
Sex		n (%)	p-value	p-value	Odds ratio	95% CI
	Male	9 (19.6)	0.32			
	Female	12 (28.6)				
Age	15-24 years	8 (27.6)	0.36			
	25-34 years	5 (21.7)				
	35-44 years	2 (13.3)				
	45-55 years	6 (37.5)				
	55-64 years	0 (0)				
	65+ years	-				
Ethnicity	NZ European	20 (27.0)	0.26			
	Māori	0				
	Pacifica Peoples	1 (33.3)				
	Indian	-				
	Other	0				
Contact with Vocational Coordinator	Less than two times	11 (26.2)	0.84			
	Twice or more	6 (24.0)				
Other support	Did not receive other	9 (24.3)	0.99			
	Did receive other	12 (24.5)				
Volunteered	Don't volunteer	13 (43.3)	0.001	0.002	0.172	0.055-0.533
	Volunteer	6 (12.0)				
Community connectivity	Member of a community group	17 (27.4)	0.26			
	Not a member of a community group	4 (16.0)				

Volunteered

		Unadjusted model		Adjusted model		
Sex		n (%)	p-value	p-value	Odds ratio	95% CI
	Male	25 (58.1)	0.48			
	Female	25 (65.8)				
Age	15-24 years	18 (66.7)	0.16	0.261		
	25-34 years	16 (76.2		0.593	1.501	0.339-6.648
	35-44 years	8 (61.5)		0.495	0.59	0.129-2.689
	45-55 years	7 (43.8)		0.203	0.38	0.086-1.683
	55-64 years	1 (25.0)		0.099	0.121	0.01-1.484
	65+ years					
Ethnicity	NZ European	41 (60.3)	0.42			
	Māori	6 (85.7)				
	Pacifica Peoples	2 (66.7)				
	Indian	-				
	Other	1 (33.3)				
Contact with Vocational Coordinator	Less than two times	23 (60.5)	0.88			
	Twice or more	15 (62.5)				
Other support	Did not receive other	25 (71.4)	0.08	0.103	0.397	0.131-1.204
	Did receive other	23 (52.3)				
Employment status	Unemployed	36 (67.9)	0.05	0.028		
	Employed < 15 hours	6 (42.9)		0.145	0.373	0.099-1.409
	Employed < 15 hours	2 (28.6)		0.014	0.089	0.013-0.614
Region	Northland	1 (25.0)				
	Auckland	4 (57.1)				
	Waikato	-				
	Bay of Plenty	10 (83.3)				
	Wairarapa	-				
	Tairawhiti	4 (66.7)				
	Manawatu	1 (25.0)				
	North Taranaki	1 (50.0)				
	South & Central Taranaki	3 (75.0)				
	Whanganui	1 (100)				
	Wellington	3 (100)				
	Nelson / Marlburough	4 (50.0)				
	Canterbury / West Coast	5 (55.6)				
	South Canterbury	0 (0)				
	Waitaki	1 (20.0)				
	Otago	6 (75.0)				
	Southland	4 (100)				

Rated the importance of volunteering > 2/3 SM

		Unadjusted model		Adjusted model		
Sex		n (%)	p-value	p-value	Odds ratio	95% CI
	Male	13 (28.9)	0.15	0.364	1.565	0.595-4.116
	Female	16 (44.4)				
Age	15-24 years	8 (28.6)	0.28			
	25-34 years	9 (40.9)				
	35-44 years	6 (50.0)				
	45-55 years	6 (42.9)				
	55-64 years	0				
	65+ years	-				
Ethnicity	NZ European	27 (39.0)	0.23			
	Māori	2 (40.00				
	Pacifica Peoples	0				
	Indian	-				
	Other	0				
Contact with Vocational Coordinator	Less than two times	15 (36.6)	0.63			
	Twice or more	9 (42.9)				
Other support	Did not receive other	15 (40.5)	0.26			
	Did receive other	12 (28.6)				
Employment status	Unemployed	17 (33.3)	0.83			
	Employed < 15 hours	7 (46.7)				
	Employed < 15 hours	2 (28.6)				
Volunteered	Don't volunteer	7 (24.1)	0.06	0.08	2.526	0.895-7.128
	Volunteer	21 (45.7)				
Community connectivity	Member of a community group	18 (33.3)	0.51			
	Not a member of a community group	11 (40.7)				
Region	Northland	1 (25.0)	0.42			
	Auckland	1 (11.1)				
	Waikato	-				
	Bay of Plenty	3 (27.3)				
	Wairarapa	-				
	Tairawhiti	2 (50.0)				
	Manawatu	0				
	North Taranaki	1 (33.3)				
	South & Central Taranaki	2 (50.0)				
	Whanganui	1 (*100)				
	Wellington	3 (100)				
	Nelson / Marlborough	3 (33.3)				
	Canterbury / West Coast	4 (50.0)				
	South Canterbury	2 (50.0)				
	Waitaki	2 (40.0)				
	Otago	3 (42.9)				
	Southland	1 (25.0)				

Engaged in ongoing training or education

		Unadjusted model		Adjusted model		
		n (%)	p-value	p-value	Odds ratio	95% CI
Sex	Male	6 (14.0)	0.31			
	Female	8 (22.9)				
Age	15-24 years	4 (15.4)	0.92			
	25-34 years	4 (22.2)				
	35-44 years	3 (21.4)				
	45-55 years	2 (12.5)				
	55-64 years	1 (25.0)				
	65+ years	-				
Ethnicity	NZ European	11 (16.5)	0.45			
	Māori	2 (28.6)				
	Pacifica Peoples	0				
	Indian	-				
	Other	1 (50)				
Contact with Vocational Coordinator	Less than two times	7 (19.4)	0.91			
	Twice or more	4 (18.2)				
Other support	Did not receive other	7 (21.2)	0.58			
	Did receive other	7 (16.3)				
Employment status	Unemployed	11 (22.0)	0.19			
	Employed < 15 hours	1 (7.1)				
	Employed < 15 hours	0				
Volunteer	Don't volunteer	4 (13.3)	0.61			
	Volunteer	8 (17.8)				
Community connectivity	Member of a community group	10 (18.2)	0.93			
	Not a member of a community group	4 (17.4)				
Region	Northland	1 (33.3)	0.19			
	Auckland	1 (14.3)				
	Waikato					
	Bay of Plenty	2 (18.2)				
	Wairarapa					
	Tairawhiti	3 (42.9)				
	Manawatu	0 (0)				
	North Taranaki	1 (33.3)				
	South & Central Taranaki	2 (66.7)				
	Whanganui	1 (100)				
	Wellington	0				
	Nelson / Marlborough	1 (14.3)				
	Canterbury / West Coast	0				
	South Canterbury	0				
	Waitaki	0				
	Otago	2 (25.0)				
	Southland	0				

Rated the importance of ongoing education > 2/3 SM

		Unadjusted model		Adjusted model		
Sex		n (%)	p-value	p-value	Odds ratio	95% CI
	Male	15 (37.5)	0.95			
	Female	13 (38.2)				
Age	15-24 years	9 (36.0)	0.97			
	25-34 years	7 (41.2)				
	35-44 years	6 (42.9)				
	45-55 years	4 (30.8)				
	55-64 years	2 (40.0)				
	65+ years					
Ethnicity	NZ European	23 (35.9)	0.73			
	Māori	2 (40.0)				
	Pacifica Peoples	1 (50.0)				
	Indian	-				
	Other	2 (66.7)				
Contact with Vocational Coordinator	Less than two times	14 (36.80	0.50			
	Twice or more	5 (27.8)				
Other support	Did not receive other	16 (48.5)	0.11	0.346	0.589	0.196-1.769
	Did receive other	12 (30.0)				
Employment status	Unemployed	16 (34.8)	0.47			
	Employed < 15 hours	4 (30.8)				
	Employed < 15 hours	4 (57.1)				
Ongoing education	Not engaged in education	18 (34.0)	0.07	0.091	3.109	0.833-11.604
	Engaged in education	8 (61.5)				
Community connectivity	Member of a community group	14 (28.6)	0.02	0.095	2.665	0.843-8.422
	Not a member of a community group	14 (56.0)				

Don’t belong to a club, group or organisation

		Unadjusted model		Adjusted model		
Sex	Male	21 (43.8)	<0.01	0.072	0.312	0.088-1.111
	Female	6 (14.6)				
Age	15-24 years	9 (33.3)	0.11			
	25-34 years	5 (21.4)				
	35-44 years	3 (20.0)				
	45-55 years	6 (35.3)				
	55-64 years	4 (80.0)				
	65+ years	-				
Ethnicity	NZ European	24 (32.0)	0.80			
	Māori	1 (14.3)				
	Pacifica Peoples	1 (33.3)				
	Indian	-				
	Other	1 (25.0)				
Contact with Vocational Coordinator	Less than two times	14 (31.8)	0.07	0.384	0.509	0.111-2.328
	Twice or more	3 (12.0)				
Other support	Did not receive other	18 (46.2)	0.01	0.022	0.207	0.054-0.797
	Did receive other	9 (18.8)				
Employment status	Unemployed	18 (31.6)	0.61			
	Employed < 15 hours	3 (18.8)				
	Employed < 15 hours	2 (28.6)				
Volunteered	Don’t volunteer	12 (38.7)	0.12			
	Volunteer	11 (22.4)				
Ongoing education	Not engaged in education	19 (29.7)	0.934			
	Engaged in education	4 (28.6)				
Region	Northland	2 (50.0)	0.19			
	Auckland	2 (20.0)				
	Waikato					
	Bay of Plenty	2 (18.2)				
	Wairarapa					
	Tairawhiti	1 (12.5)				
	Manawatu	1 (25.0)				
	North Taranaki	2 (66.7)				
	South & Central Taranaki	2 (50.0)				
	Whanganui	0				
	Wellington	0				
	Nelson / Marlburough	3 (33.3)				
	Canterbury / West Coast	5 (55.6)				
	South Canterbury	3 (75.0)				
	Waitaki	0				
	Otago	3 (37.5)				
	Southland	0				

Rated the importance of belonging >2/3 SM

		Unadjusted model		Adjusted model		
Sex	Male	14 (33.3)				
	Female	16 (47.1)	0.22			
Age	15-24 years	9 (32.1)				
	25-34 years	8 (44.4)				
	35-44 years	4 (36.4)	0.66			
	45-55 years	8 (53.3)				
	55-64 years	1 (25.0)				
	65+ years	-				
Ethnicity	NZ European	16 (40.6)				
	Māori	0				
	Pacifica Peoples	1 (33.3)	0.14			
	Indian	-				
	Other	3 (75.0)				
Contact with Vocational Coordinator	Less than two times	16 (42.1)				
	Twice or more	9 (45.0)	0.83			
Other support	Did not receive other	12 (33.3)	0.44			
	Did receive other	16 (42.1)				
Employment status	Unemployed	13 (27.7)		0.06		
	Employed < 15 hours	8 (57.1)	0.022	0.141	2.779	0.714-10.821
	Employed < 15 hours	5 (71.4)		0.041	13.356	1.116-159.839
Volunteered	Don't volunteer	11 (40.7)	0.99			
	Volunteer	18 (40.9)				
Ongoing education	Not engaged in education	23 (39.0)				
	Engaged in education	4 (40.0)				
Community connectivity	Member of a community group	27 (51.9)	<0.01	0.006	0.036	0.003-0.389
	Not a member of a community group	3 (12.5)				
Amount of support	Not enough	7 (38.9)				
	About the right amount	22 (47.8)	0.52			
	Too much					

Not enough contact with friends

		Unadjusted model		Adjusted model
Sex				
	Male	23 (50.0)	0.713	
	Female	17 (45.9)		
Age	15-24 years	17 (58.6)	0.633	
	25-34 years	9 (47.4)		
	35-44 years	6 (42.9)		
	45-55 years	6 (35.3)		
	55-64 years	2 (50.0)		
	65+ years	-		
Ethnicity	NZ European	34 (49.3)	0.944	
	Māori	3 (42.9)		
	Pacifica Peoples	1 (33.3)		
	Indian			
	Other	2 (50.0)		
Contact with Vocational Coordinator	Less than two times	19 (45.2)	0.717	
	Twice or more	11 (50.0)		
Other support	Did not receive other	19 (51.4)	0.745	
	Did receive other	21 (47.7)		
Employment status	Unemployed	25 (48.1)	0.846	
	Employed < 15 hours	6 (40.0)		
	Employed < 15 hours	3 (42.9)		
Volunteered	Don't volunteer	12 (42.9)	0.342	
	Volunteer	26 (54.2)		
Ongoing education	Not engaged in education	32 (51.6)	0.720	
	Engaged in education	6 (46.2)		
Community connectivity	Member of a community group	26 (44.8)	0.350	
	Not a member of a community group	14 (56.0)		
Amount of support	Not enough	11 (55.0)	0.597	
	About the right amount	24 (48.0)		
	Too much	-		
Region	Northland	2 (66.7)	0.119	
	Auckland	4 (44.4)		
	Waikato	-		
	Bay of Plenty	6 (54.5)		
	Wairarapa	-		
	Tairawhiti	3 (37.5)		
	Manawatu	3 (75.0)		
	North Taranaki	3 (100)		
	South & Central Taranaki	0		
	Whanganui	0		
	Wellington	3 (100)		
	Nelson / Marlborough	4 (44.4)		
	Canterbury / West Coast	4 (50.0)		
	South Canterbury	0		
	Waitaki	1 (20.0)		
	Otago	3 (37.5)		
	Southland	3 (100)		

Rated knowing community and events <1/3 SM

		Unadjusted model		Adjusted model
Sex	Male	15 (34.9)	0.91	
	Female	13 (36.1)		
Age	15-24 years	11 (40.7)	0.73	
	25-34 years	3 (15.0)		
	35-44 years	3 (25.0)		
	45-55 years	9 (60.0)		
	55-64 years	2 (40.0)		
	65+ years			
Ethnicity	NZ European	27 (39.7)	0.21	
	Māori	0		
	Pacifica Peoples	0		
	Indian	-		
	Other	1 (25.0)		
Contact with Vocational Coordinator	Less than two times	16 (41.0)	0.34	
	Twice or more	6 (28.6)		
Other support	Did not receive other	13 (36.1)	0.97	
	Did receive other	15 (36.6		
Employment status	Unemployed	20 (40.8)	0.38	
	Employed < 15 hours	5 (33.3)		
	Employed < 15 hours	1 (14.3)		
Volunteered	Don't volunteer	13 (44.8)	0.16	
	Volunteer	13 (28.9)		
Ongoing education	Not engaged in education	20 (33.9)	0.97	
	Engaged in education	4 (33.3)		
Community connectivity	Member of a community group	18 (33.3)	0.57	
	Not a member of a community group	10 (40.0)		
Amount of support	Not enough	6 (31.6)	0.649	
	About the right amount	18 (37.5)		
	Too much			
Region	Northland	2 (50.0)	0.29	
	Auckland	1 (12.5)		
	Waikato			
	Bay of Plenty	5 (45.5)		
	Wairarapa			
	Tairawhiti	1 (33.3)		
	Manawatu	1 (25.0)		
	North Taranaki	2 (66.7)		
	South & Central Taranaki	1 (25.0)		
	Whanganui	1 (100)		
	Wellington	0		
	Nelson / Marlborough	2 (22.2)		
	Canterbury / West Coast	2 (25.0)		
	South Canterbury	3 (100)		
	Waitaki	3 (60.0)		
	Otago	2 (25.0)		
	Southland	2 (50.0)		

Rated easy to get to community events <1/3 SM

		Unadjusted model		Adjusted model
Sex				
	Male	12 (28.6)		
	Female	10 (27.8)	0.94	
Age	15-24 years	67 (23.1)		
	25-34 years	6 (30.0)		
	35-44 years	4 (33.3)	0.93	
	45-55 years	5 (33.3)		
	55-64 years	1 (20.0)		
	65+ years	-		
Ethnicity	NZ European	20 (19.9)		
	Māori	1 (20.0)		
	Pacifica Peoples	0		
	Indian	-		
	Other	1 (25.0)		
			0.79	
Contact with Vocational Coordinator	Less than two times	10 (26.3)	0.85	
	Twice or more	6 (28.6)		
Other support	Did not receive other	7 (20.0)	0.11	
	Did receive other	15 (36.6)		
Employment status	Unemployed	13 (27.1)		
	Employed < 15 hours	6 (40.0)		
	Employed < 15 hours	1 (14.3)		
			0.43	
Volunteered	Don’t volunteer	8 (27.6)	0.93	
	Volunteer	12 (26.7)		
Ongoing education	Not engaged in education	15 (25.4)	0.25	
	Engaged in education	5 (41.7)		
Community connectivity	Member of a community group	16 (29.6)	0.68	
	Not a member of a community group	6 (25.0)		
Amount of support	Not enough	6 (31.6)		
	About the right amount	11 (23.4)	0.49	
	Too much	-		
Region	Northland	1 (25.0)		
	Auckland	1 (12.5)		
	Waikato			
	Bay of Plenty	4 (36.4)		
	Wairarapa			
	Tairawhiti	1 (33.3)		
	Manawatu	2 (50.0)		
	North Taranaki	2 (66.7)	0.29	
	South & Central Taranaki	1 (25.00		
	Whanganui	1 (100)		

Wellington	0
Nelson / Marlborough	2 (22.2)
Canterbury / West Coast	1 (12.5)
South Canterbury	1 (50.0)
Waitaki	3 (60.0)
Otago	0
Southland	2 (50.0)

ccs
disability action
Including all people

TE HUNGA HAUĀ MAURI MŌ NGĀ TĀNGATA KATOA

DONALD BEASLEY
INSTITUTE