

Improving access to primary care for disabled people

The NATIONAL CENTRE *of* MENTAL HEALTH RESEARCH,
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Te Pou
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Contents

Acknowledgements.....	3
Contents	4
List of figures.....	5
List of tables	6
Executive summary.....	9
Background.....	9
Method	9
Results.....	10
Recommendations	11
Conclusion	12
Background.....	14
Introduction.....	14
Method	15
Survey.....	15
Key informant interviews.....	16
Analysis.....	16
Results	18
Survey respondents.....	18
Primary health initiatives.....	22
Barriers to primary care.....	37
Workforce training needs in primary health and disability	39
Strategies for improving the health of disabled people.....	42
Summary	44
Consultation with primary health and disability key informants.....	46
Barriers to primary care.....	46
Strategies for improving the health of disabled people.....	49
Summary	52
Discussion	54
Health initiatives	54
Barriers to primary health care initiatives.....	55
Workforce training needs in primary health and disability	55
Limitations	55
Recommendations	56
Conclusion	57
Appendix A	58
Letter of Introduction.....	58
Primary Health and Disability Survey.....	60
References.....	70

List of figures

<i>Figure 1</i> The proportion of residential and non-residential services providing disability support by disability type.	19
<i>Figure 2</i> The proportion of residential and non-residential services supporting disabled people by age group...	19
<i>Figure 3</i> The proportion of residential and non-residential services providing support by service contract.	20
<i>Figure 4</i> The proportion of residential and non-residential services providing support by service contract.	20
<i>Figure 5</i> The proportion of residential and non-residential services that employed staff in a health promotion role.	22
<i>Figure 6</i> The proportion of residential and non-residential services that employed staff in a health promotion role by the number of service contracts held by providers.	22
<i>Figure 8</i> The proportion of residential and non-residential services that reported developing one or more health initiatives or strategies.	24
<i>Figure 9</i> The proportion of residential and non-residential services with and without health promotion roles who reported having developed one or more health initiatives or strategies.	24
<i>Figure 11</i> The proportion of residential and non-residential services that had developed one or more health initiatives or strategies by health domain.	26
<i>Figure 12</i> The number and proportion of providers that did and did not employ staff in a health promotion role who reported developing one or more health promotion initiatives or strategies.	27
<i>Figure 13</i> The proportion of respondents who partnered a primary health provider in the delivery of a health initiative that described the service or primary health provider as initiating the partnership.	29
<i>Figure 15</i> The proportion of residential and non-residential services that developed a health initiative or strategy that determined the initiative to have been successful.	30
<i>Figure 16</i> The method of data a collection that providers that developed a health initiative used to evaluate their intervention.	31
<i>Figure 17</i> The proportion of respondents that had developed a health initiative or strategy that reported health outcome data was held by the service and/or provider health provider(s).	32
<i>Figure 18</i> The proportion of providers that had used a health screening tool.	32
<i>Figure 19</i> The proportion of service providers an/or service users that paid for an annual check up within disability support services that reported routinely providing health checks.	34

List of tables

Table 1 <i>Number and Proportion of Residential and Non-residential Services Providing Disability Support by Disability Type, Age, and Funding Contract</i>	18
Table 2 <i>Number and Proportion of Residential and Non-residential Services Providing Disability Support by the Number of People Using the Service</i>	21
Table 3 <i>Number and Proportion of Residential and Non-residential Services that Developed One or More Health Initiative or Strategy by Health Domain</i>	25
Table 4 <i>The Health Screening Tool Residential and Non-residential Services Reported Using</i>	33

Executive summary

Background

Research has consistently identified disabled people as experiencing poorer health than their peers in the general population, and as being disadvantaged in their access to primary health services. In New Zealand, some disability services have attempted to address these concerns by implementing health initiatives designed to progress the goal of improved health for disabled people. Despite this activity, little is known about the extent and types of initiatives that have been implemented. The current report presents results from a research project that explored primary health initiatives used to improve the health of disabled people within disability support services; the perceptions of disability service providers and primary health professionals of the barriers to primary health care for disabled people; and related training needs for the primary health and disability sectors.

The Donald Beasley Institute was commissioned to conduct the project which is comprised of three parts: a literature review, a survey of disability services, and a consultation process. All parts of the project explored the health needs and barriers to primary health care for disabled people including those with physical, intellectual and sensory impairments. The literature review is presented in a companion document titled *Primary Health and Disability: A Review of the Literature*. This report details the results of a survey of disability services administered in June 2013, and also provides qualitative analysis of data derived through the survey and consultation process.

Method

A questionnaire titled *Te Pou O Te Whaakaro Nui Primary Health and Disability Survey* was developed by the Donald Beasley Institute. The questionnaire included 29 questions and covered a range of topic areas including: service type and size; disability type and age of service users; employment of staff in health related roles; type of health initiatives being undertaken; the perceived success of health initiatives; and the involvement of primary health services in implementing health initiatives. The survey also sought open-ended responses to questions about barriers to the implementation of primary health initiatives, suggested strategies for improving health outcomes, and training needs for the primary health and disability workforces. Disability support providers were invited to take part in the electronic survey, and 40 providers responded. At the conclusion of the survey a consultation process was conducted with primary health and disability sector key informants to generate further qualitative data relating to the topics under study.

Quantitative survey data were analysed using the IBM SPSS Statistical Software Package. Descriptive statistics were the primary method of analysis used, with the proportion of provider responses and appropriate confidence intervals reported where relevant. The General Inductive Approach to thematic analysis was used to analyse the qualitative data.

Results

Primary health initiatives

The findings from the *Primary Health and Disability Survey* contribute to a better understanding of the initiatives that disability services are pursuing in order to address the health needs of disabled people. Survey respondents reflected the diversity of disability support services in New Zealand and most were found to be involved in the delivery of health initiatives designed to meet the health needs of disabled people accessing formal services. Key results were:

- almost 80 per cent of survey respondents having developed one or more health promotion initiative within their service and about two-thirds of providers considered these to have been successful¹
- health initiatives were more likely to have been developed in services that employed health promotion staff, which was more common in residential services (40 versus 30 per cent for non-residential services)²
- service providers were most likely to have developed initiatives in the areas of healthy eating and exercise³
- only half the survey respondents had partnered with primary health providers to develop or implement an initiative - when partnerships were in place, disability providers stated almost without exception, that they had initiated the partnership
- 35 per cent of survey respondents were using health checks, which were commonly administered annually and paid for either by the disabled person (40 per cent), the disability provider (33 per cent), or a combination of the person and disability provider (27 per cent).⁴

Barriers to primary care

Barriers to primary care for disabled people included:

- general practitioners' (GPs) lack of knowledge in the area of disability
- the specific health needs of disabled people not receiving adequate attention within medical training
- GPs being ill-equipped to respond to the diverse communication needs of disabled people
- the 15-minute GP consultation model being highly inadequate for disabled patients⁵
- the cost of primary health care⁶
- the absence of an agreed plan supporting the widespread implementation of health checks.

¹ In total, 29 providers had developed a health initiative and collected data. Of these, 18 considered the initiative to have been successful and 11 remained undecided about the outcomes. No respondents thought their health initiative had failed. Most evaluation data was collected internally and took the form of self-reported, observed and direct measures of health improvements. Less than one-quarter (22 per cent) of respondents had involved external health professionals in their evaluation.

² In the case of residential services, the larger the provider, the greater the likelihood that someone would be employed in a health promotion role.

³ The health areas least likely to have been the focus of health initiatives were diabetes prevention, mental health, and dental or oral health.

⁴ There were inconsistencies in the amount charged for health checks in primary health care environments.

⁵ Who often require additional time both within the examination phase of the consultation, and to receive health information in an accessible format.

⁶ Even for those eligible for subsidies due to their low socio-economic status.

Workforce training needs in primary health and disability

To develop workforce capacity within disability services it was considered necessary for support workers to receive:

- a general level of education about the health status and health needs of disabled people
- information about primary health and primary health care services available within the community
- advocacy and assertiveness training to equip support workers with the right skills to effectively advocate on behalf of disabled people with regards to their health.

Finally, it was seen as important that disability and primary health sector collaboration was advanced to ensure each sector had a well developed understanding of the responsibilities each has with regard to improving the health and well being of disabled people.

Strategies for improving the health of disabled people

Three main strategies were identified through key informant interviews for improving the health outcomes of people with disabilities.

- Annual health checks for people who have an intellectual disability were seen as an important tool, which could contribute to decreased rates of GP visits, reduce the need for secondary care, and a means by which disability support staff could observe and measure changes in the health status of people in their care.
- Rethinking the role of disability support staff to ensure they can appropriately and safely monitor the health of people they support.
- Improving communication within and across the primary care and disability sectors.

The latter, was determined to be the most cost-effective and easiest strategy to implement in order to more effectively care for people with disabilities who utilised primary health care services.

Recommendations

The specific actions recommended based on the findings of this project include:

- the Ministry of Health
 1. funding research to investigate, identify and evaluate a standardised health check tool for use with people who have an intellectual disability
 2. funding GPs to undertake health checks for people with an intellectual disability
 3. increasing funding to disability support services to improve their ability to implement primary health initiatives, and to cover the medical costs and prescription charges of disabled people
 4. continuing to fund training to support the development of disability support workers' knowledge and skills related to disabled peoples' health status and needs, health promotion and advocacy
 5. continuing to fund health education training to support disabled people and their family/whānau to make informed health care decisions

- education providers increasing the disability content within GP's medical education, including the social determinants of health for disabled people, common health conditions and health care barriers, along with communication training
- health care providers ensuring health information is accessible for disabled people (including the use of Braille, Easy Read and sign language interpreters where appropriate)
- primary health care practitioners improving their capability to support disabled people, including increasing their knowledge of the social determinants of health, common health conditions and health care barriers, and undertaking communication training
- PHOs and DHBs developing intellectual disability specific nursing roles, which can provide education to health practitioners and act as a liaison between different health care services
- PHOs better utilising practice nurses in the provision of services to disabled people
- PHOs and disability support services developing collaborative relationships to support the successful implementation of primary health initiatives
- disability support workers undertaking training on the health needs of disabled people they assist and advocacy training.

Conclusion

This research has identified that New Zealand disability service providers have responded to concerns about the health status and access to primary health care for disabled people by implementing a range of health initiatives, many of which have been considered successful. The initiatives have typically responded to a small range of key health concerns, and have not usually been accompanied by dedicated health funding.

The barriers to primary health care impacting on disabled people, and the strategies for improving health outcomes are consistent with international research findings and can help guide future action to improve health outcomes in New Zealand. This includes building the knowledge and skills of disability support workers to better understand and advocate for the health care needs of disabled people, and improving the capability of primary health care professionals in responding to the needs of disabled people. Future research is required to explore the findings generated through this study with disabled people themselves to ensure that all critical areas to facilitate advancement in this area have been identified.

Background

Introduction

Research has consistently identified disabled people as experiencing poorer health than their peers in the general population (Emerson & Baines, 2010; G. Jones, Crews, & Danielson, 2010; Park et al., 2009), and as disadvantaged with regard to their access to primary health services and care. In New Zealand, serious concerns have been expressed about the health status of disabled people (National Health Committee, 2003), however there has been an absence of integrated policy and practice to address this issue. In an attempt to achieve progress toward the goal of improved health and access to health care, some disability support services have implemented health interventions and initiatives. These have largely occurred in isolation, with individual disability services choosing to pursue health projects that appear to have potential to meet the needs of the individuals who use their particular service. As a result, beyond the services involved, little is known about the range of initiatives that have been implemented, how they have been delivered and funded, who has been involved, and whether improved health outcomes have been achieved for disabled people. The current report presents results generated through research conducted to answer these and other questions.

In February 2013 the Donald Beasley Institute was commissioned to conduct a project in the area of primary health and disability. Primary health is understood to mean the first level of contact that individuals have with the health system. Primary health is community-based, typically delivered by GPs or practice nurses, and includes a broad range of health related services including health education, counselling, disease prevention and screening.

This project was underpinned by the *Disability Support Services Workforce Action Plan* (2009) objective, which aimed to strengthen the capacity of organisations to improve service quality and safety through workforce innovations by promoting relationships between disability support services and primary health care organisations, and identifying primary health initiatives that are applicable to disability support services. The project comprised three components: a literature review, a survey of disability services, and a consultation process. All parts of the project were designed to explore the health needs and barriers to health care experienced by disabled people. The literature review component considered New Zealand and international research and policy related to primary health and disability and led to the production of a report titled *Primary Health and Disability: A Review of the Literature*. The literature review is intended to be a companion document to this report.

This report presents results generated through an analysis of data collected through a survey of disability services and consultation process. The disability survey was designed to capture information related to the range and type of health related initiatives being implemented by disability service providers and the perceived and/or measured outcomes of such activities. The consultation process provided an opportunity to engage disability and primary health service providers in more in-depth discussion about the health needs and barriers to primary care experienced by disabled New Zealanders.

Method

Survey

In order to gain an understanding of the health interventions and initiatives currently being implemented by disability support services in New Zealand, a survey methodology was implemented. Administration of a survey was appropriate in this situation as it enabled a consistent set of questions to be asked of a diverse range of services and organisations within a specified time period.

A questionnaire titled *Te Pou O Te Whaakaro Nui Primary Health and Disability Survey* was developed by the Donald Beasley Institute and covered a range of topic areas including: service type and size; disability and age of service users; employment of staff in health related roles; type of health initiatives being undertaken; perceived or measured success of health initiatives; the involvement of primary health services in the implementation of health initiatives; perceived barriers to primary care for disabled people; and training needs for the primary health and disability workforces. The final questionnaire comprised 29 questions, including a number of multi-choice and open-ended questions. Most of the questions had a single-response rate. However, several questions allowed for multiple responses or required numerical responses, such as the approximate number of patients/clients. In addition, a number of questions offered the category *other*, where respondents could specify non-standard responses. At the conclusion of the questionnaire respondents were invited to indicate whether they would be willing to take part in the consultation phase of the project (see Appendix A).

The questionnaire was piloted with a small number of disability service providers before it was administered to test for its ease of response and to ensure the estimated time required to complete the survey was accurate. No substantive changes were made to the questionnaire. However, the estimated time required for completion was extended by 10 minutes on the basis of feedback received during piloting.

Survey administration

In order to reach as many potential respondents as possible the survey was disseminated using two main strategies. First, permission was gained to send a letter of invitation electronically to the memberships of two large disability provider organisations, the New Zealand Disability Support Network (NZDSN) and Vocational and Support Services (VASS). In order to include services that may not have been a member of either organisation, an approach was also made to individual services identified through a Te Pou O Te Whaakaro Nui database. The survey was sent to the contact email addresses of each organisation, with the URL link embedded in the email letter of invitation. The letter included a request that the survey be forwarded to the person in the organisation best suited to respond to questions related to health promotion and workforce development.

The survey was administered to the disability support providers via SurveyMonkey, a web survey development cloud based (SaaS) company (SurveyMonkey Inc, 2013). This tool allows users to create their own surveys using question format templates. The basic version of SurveyMonkey is free; an enhanced version is also available at a cost. All data was kept on the SurveyMonkey database, which was only accessible to the three researchers using a password system. All of the respondents were kept anonymous from each other. The survey was administered

on 6 June 2013 and the survey remained open for completion until 28 June 2013. Responses were collected from a range of small, medium and large-scale disability support organisations nationwide.

Key informant interviews

The consultation phase of the project involved key informant interviews with primary health and disability service providers. Key informant interviewing is a qualitative research method used to gather detailed information and perspectives about an issue in a community from a limited number of well-connected and informed experts. Key informants are selected purposefully, and can provide useful insights on issues and give recommendations for solutions. Key informant interviewing is often used as a supplement to other data-gathering methods, such as surveys, as a means of elaborating on important issues identified in the data-gathering process.

After analysing data generated from the *Te Pou O Te Whakaaro Nui Primary Health and Disability Survey*, it was decided it would be useful to explore supplementary data on responses to open-ended survey questions about workplace development and training, and the perceived barriers to primary care for people with disabilities. Each key informant was asked a number of questions addressing the following themes: health status for people with disabilities; perceived barriers to, and strategies for improving, access to primary care for people with disabilities; and development of capacity building within the primary health and disability workforces. In most cases, key informants expanded on the responses they provided in the survey, which provided a useful context for the discussion.

Seven key informant interviews were held between 19 June and 4 July 2013. Of the 40 surveys completed, 20 respondents from the disability sector indicated willingness to be contacted for a brief, 15-minute telephone interview. The researchers contacted primary health professionals directly and invited them to contribute to the project through key informant interviews. All key informants were involved either in the primary care or disability sector, and at least one key informant had significant experience working in both sectors. The tape-recorded, semi-structured interviews lasted between 10 and 25 minutes. Five of the seven consultations took place over the telephone, as this was the most convenient and least time-intensive means of gathering data.

Analysis

Survey Analysis

Provider responses to the online survey were exported and analysed using the IBM SPSS Statistical Software package (IBM Corp, 2010). Descriptive statistics were the primary method of analysis used, with the proportion of provider responses and appropriate confidence intervals reported as findings.

Confidence intervals provide an estimate of values that are likely to include the “true” mean or proportion calculated from an “observed” population. In this study, a 95 per cent Confidence Interval (CI) has been selected, meaning that if we assume the distribution of provider responses will be normally distributed, we would expect 95 per cent of responses to fall within the CI range and only 5 per cent of responses to fall outside

the range by chance. Greater variation in observed values and/or a smaller population sample will yield wider CIs. CIs were calculated for all statistical tests and are reported where appropriate.

Independent sample t-tests were used to compare the responses of providers who were grouped in ways that might affect the way they perceived or responded to the health needs of people who used their services. An alpha level of 0.05 was chosen (a 5 per cent chance any observed difference in responding may have happened by chance) except where multiple comparisons were made in which case an alpha level of 0.01 was adopted as an informal way of controlling for Type I errors (rejecting the null hypothesis of no difference falsely).

Qualitative data analysis

Two sets of qualitative data were collected for the purposes of this research. First, qualitative comment was sought through the questionnaire used in the survey. Second, the final consultation phase of the project involved qualitative interviews with primary health and disability professionals. Both sets of data were analysed independently from each other using the General Inductive Approach (Thomas, 2006). The General Inductive Approach is a form of thematic analysis specifically developed for use in the area of health services evaluation research and was an appropriate analytical approach in the current context.

Results

The first section of this results chapter presents quantitative and qualitative analysis of the *Te Pou o Te Whaakaro Nui Primary Health and Disability Survey* (hereafter referred to as the survey).

Survey respondents

Forty disability providers responded to the survey and reflected a range of small, medium and large disability support organisations (see Table 1). Half the survey respondents delivered support funded through Residential Intellectual Disability Supported Accommodation Services (RIDSAS) and/or National Intellectual Disability Care Agency (NIDCA) contracts. Service providers that supported people through a residential contract (RIDSAS and/or NIDCA) were grouped together for analysis to distinguish them from other providers that provided intermittent support or did not support people to live in their own homes. The other non-residential services included those providing Supported Independent Living (SIL), household management/personal care, Individualised Funding (IF), Vocational Assistance (VA) and/or other types of disability support.

Table 1 Number and Proportion of Residential and Non-residential Services Providing Disability Support by Disability Type, Age, and Funding Contract

	Disability type				Age Group			Service Type						
	Intellectual	ASD	Physical	Sensory	Children (0-18 years)	Adults (19-64 years)	Older persons (>65 years)	Residential / RIDSAS	Supported Indep. Living (SIL)	NIDCA	Household / Personal Care	Individualised Funding	Vocational Assistance	Other
Residential 20 (50%)	19 (95)	17 (85)	17 (85)	13 (65)	10 (50)	19 (95)	16 (80)	20 (100)	9 (45)	1 (5)	10 (50)	7 (35)	10 (50)	5 (25)
Other 20 (50%)	16 (80)	15 (75)	15 (75)	16 (80)	11 (55)	19 (95)	9 (45)	0 (0)	2 (10)	0 (0)	3 (15)	3 (15)	10 (50)	15 (75)
Total 40 (100%)	35 (88)	32 (80)	32 (80)	29 (73)	21 (53)	38 (95)	25 (63)	20 (50)	11 (28)	1 (3)	13 (33)	10 (25)	20 (50)	20 (50)

Who were survey respondents providing services to?

The respondents to this survey supported adults and children with a diverse range of impairments. Thirty-two respondents (80 per cent) described supporting people with more than one type of disability. Nearly 9 out of every 10 respondents reported that people who had intellectual impairments used their service (88 per cent), whereas slightly fewer providers reported supporting people with sensory impairments (73 per cent).

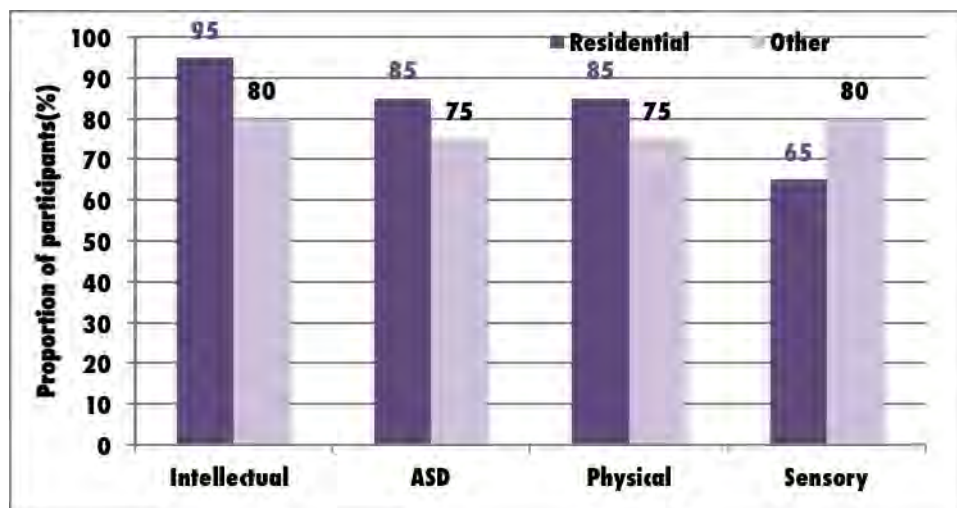


Figure 1 The proportion of residential and non-residential services providing disability support by disability type.

Note. ASD = Autism spectrum disorder.

The age groups supported by respondents

Nearly all (95 per cent) respondents reported that adults (19-64 years) received support from their service, while just over half provided support for children (53 per cent) or older persons (63 per cent). Obviously, some services were supporting children, adults and older adults. Residential services were more likely to report supporting people aged 65 years or older (80 per cent) than non-residential services (45 per cent).

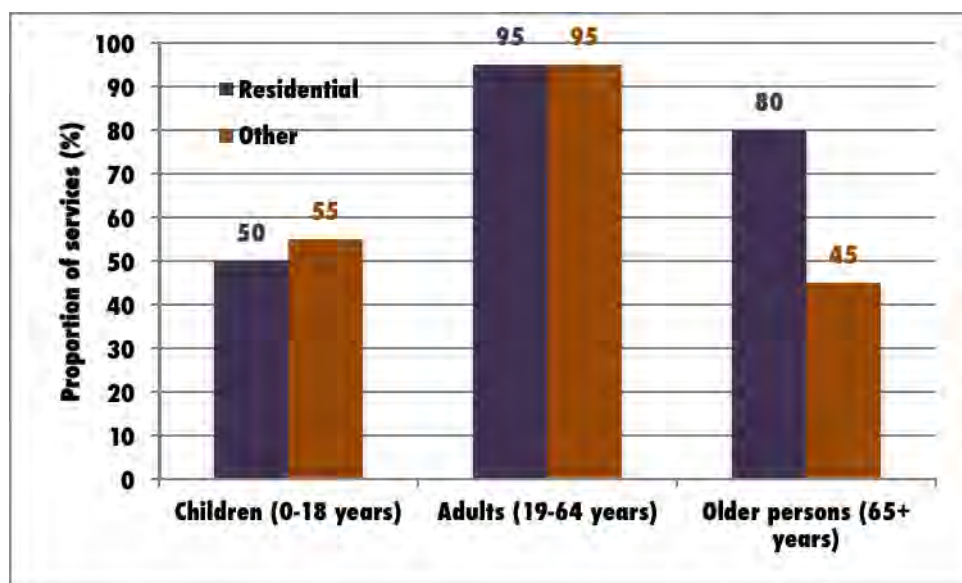


Figure 2 The proportion of residential and non-residential services supporting disabled people by age group.

The services provided by survey respondents

Survey respondents tended to provide a range of different services. Respondents reported that they provided residential [RIDSAS] (50 per cent; 95 per cent CI= 33.8 – 66.2), vocational assistance (50 per cent; 95 per cent CI= 33.8 – 66.2) and other types of disability support (50 per cent; 95 per cent CI= 33.8 – 66.2).

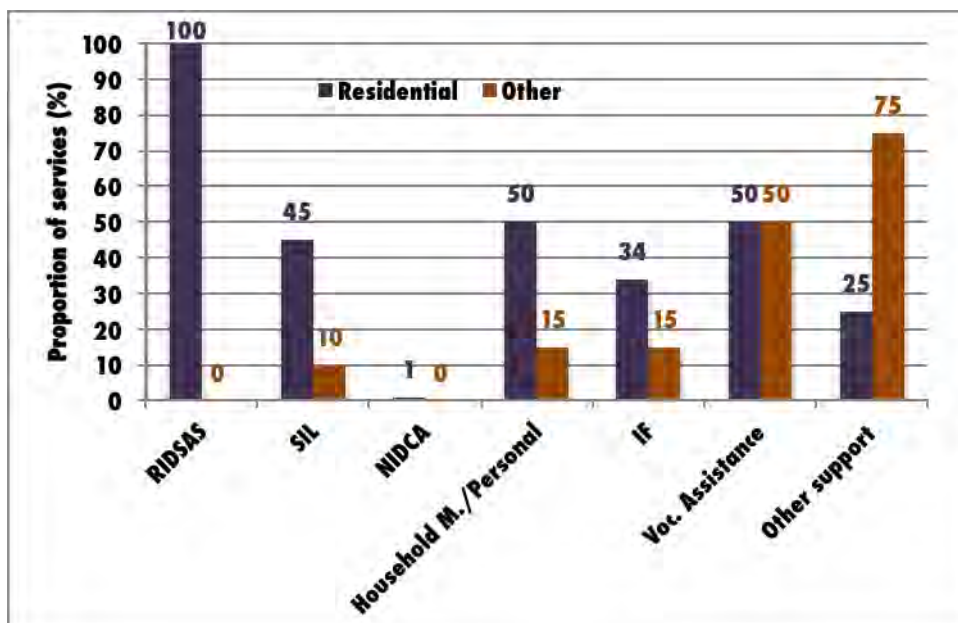


Figure 3 The proportion of residential and non-residential services providing support by service contract.

The number of services provided by respondents

Sixty per cent of respondents described providing services under more than one type of disability support contract. Non-residential providers were more likely to provide only one type of service (55 per cent) than residential providers (25 per cent; CI= 4.2 – 45.8).

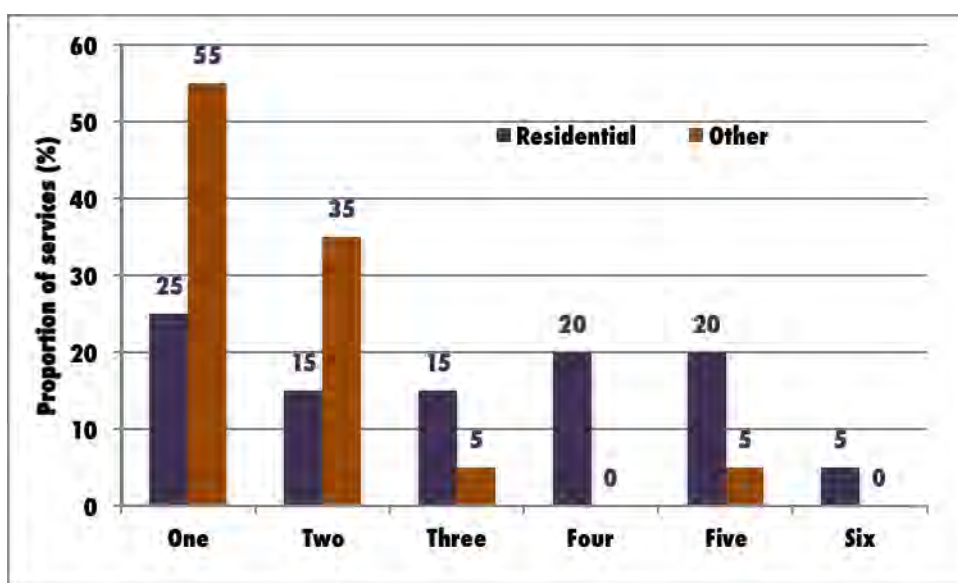


Figure 4 The proportion of residential and non-residential services providing support by service contract.

The number of disabled people (aged >65 years) supported by respondents

Nearly half of all survey respondents provided disability related support to between 50–300 people. Twenty-four per cent of respondents provided support to between 50-99 people, and 24 per cent of respondents provided support to between 100-299 people.

Respondents were grouped into services providing support to more or less than 100 people to explore whether service size affected the way disability providers perceived and/or responded to the health needs of people who used their service. Fifty per cent of residential and 53 per cent of non-residential services provided support to 100 or more people.

Table 2 Number and Proportion of Residential and Non-residential Services Providing Disability Support by the Number of People Using the Service

	Number of people supported						
	0-9	10-49	50-99	100-299	300-1999	>2000	Missing
Residential 20 (50%)	3 (15)	3 (15)	3 (15)	5 (25)	3 (15)	1 (5)	2
Other 20 (50%)	1 (5)	2 (11)	6 (32)	4 (21)	5 (26)	1 (5)	1
Total 40 (100%)	4 (11)	5 (14)	9 (23)	9 (23)	8 (22)	2 (5)	1 -

Primary health initiatives

Proportion of services that employed staff in a health promotion role

Slightly more residential services reported employing staff in health promotion roles than other services. Four out of every 10 residential services (40 per cent) and 3 out of every 10 non-residential services (30 per cent) employed staff in dedicated health promotion roles. In this small sample, no association was found between service type and the likelihood respondents would employ someone in a health promotion role.

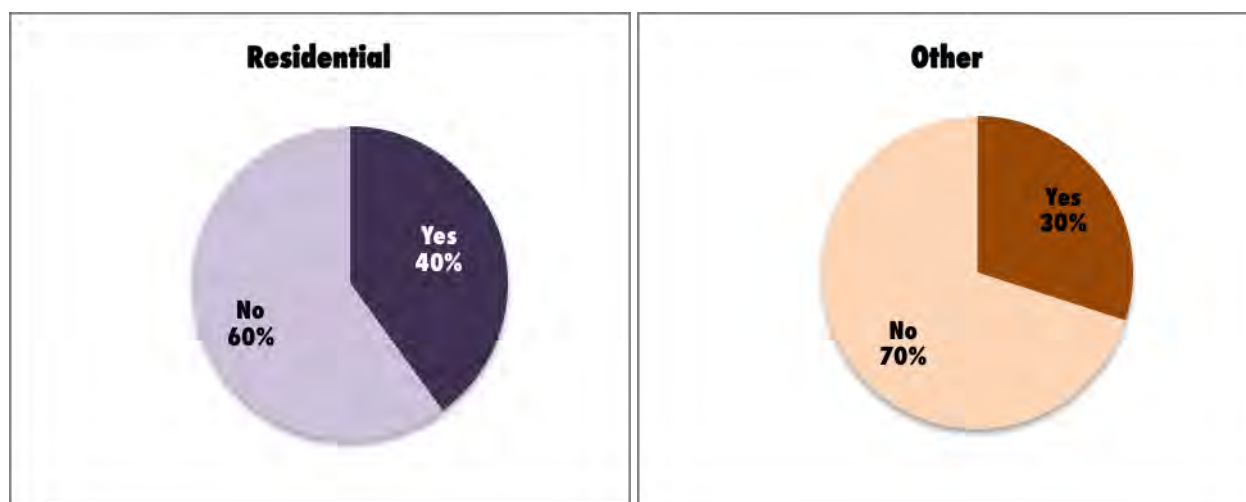


Figure 5 The proportion of residential and non-residential services that employed staff in a health promotion role.

Did the number of services provided by respondents affect the likelihood of employing staff in a health promotion role?

Two indicators were used to test whether service size affected the likelihood respondents would employ staff in health promotion roles: number of service contracts and service size.

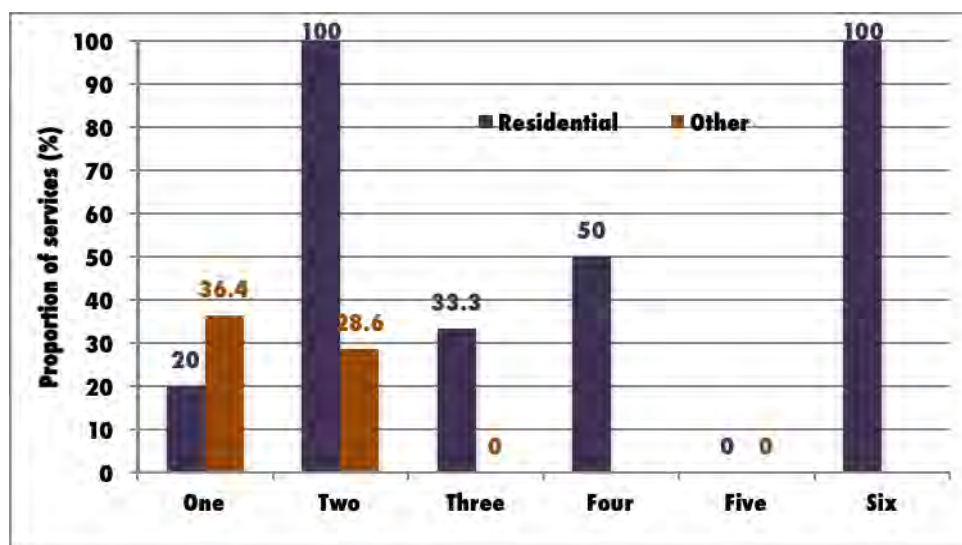


Figure 6 The proportion of residential and non-residential services that employed staff in a health promotion role by the number of service contracts held by providers.

It was difficult to detect any relationship between the number of different service contracts residential services held and the likelihood they would employ staff in a health promotion role. However, non-residential services that provided support under one (36 per cent) or two (29 per cent) different types of service contracts did appear more likely to employ staff in health promotion roles than non-residential services providing support under a larger number of service contracts.

Did the number of people supported by respondents affect the likelihood they would employ staff in a health promotion role?

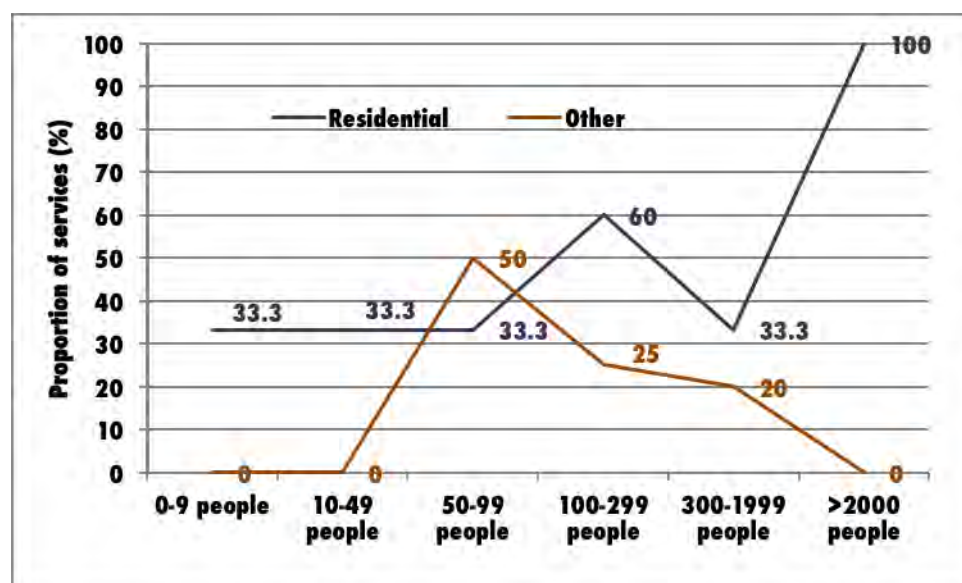


Figure 7 The proportion of residential and non-residential services employing staff in a health promotion role by the number of people using the provider for disability support.

When the data was disaggregated, the relationship between service size and the likelihood of employing someone in a health promotion role appeared to be different for agencies that were or were not predominantly residential providers. For residential providers, the likelihood of employing someone in a health promotion role tended to increase with agency size. Thirty-three per cent of residential services that provided support to less than 100 people employed staff in health promotion roles, compared to half (56 per cent) of residential services that supported more than 100 people. No smaller non-residential services (<50 people) employed staff in a health promotion role and yet the proportion of services supporting fewer than 100 people that employed staff in a health promotion role was still marginally higher (33 per cent) than non-residential services that supported more than 100 people. Twenty per cent of non-residential services that supported more than 100 people employed staff in a health promotion role.

Had respondents developed any health promotion initiative?

Eight out of every 10 survey respondents had developed one or more health promotion initiatives as an element of service delivery (78 per cent). Ninety-five per cent of residential service providers described having developed one or more health promotion initiatives, compared to 60 per cent of non-residential service providers.

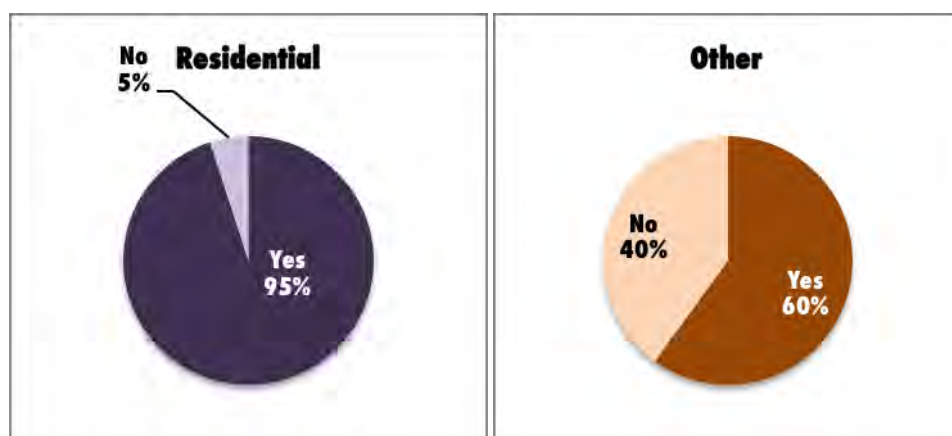


Figure 8 The proportion of residential and non-residential services that reported developing one or more health initiatives or strategies.

Whether respondents provided residential or non-residential disability support was found to affect the likelihood they would report having developed one or more health promotion initiative or strategy. The 35 per cent difference between residential and non-residential services that had developed health promotion strategies or initiatives was statistically significant (95 per cent; CI= - 10.-59.9; $p=0.007$).

Did employing someone in a health promotion role affect the likelihood of having developed a health promotion initiative?

Having staff employed in a health promotion role increased the likelihood respondents would report developing one or more health promotion initiatives within both residential and non-residential services.

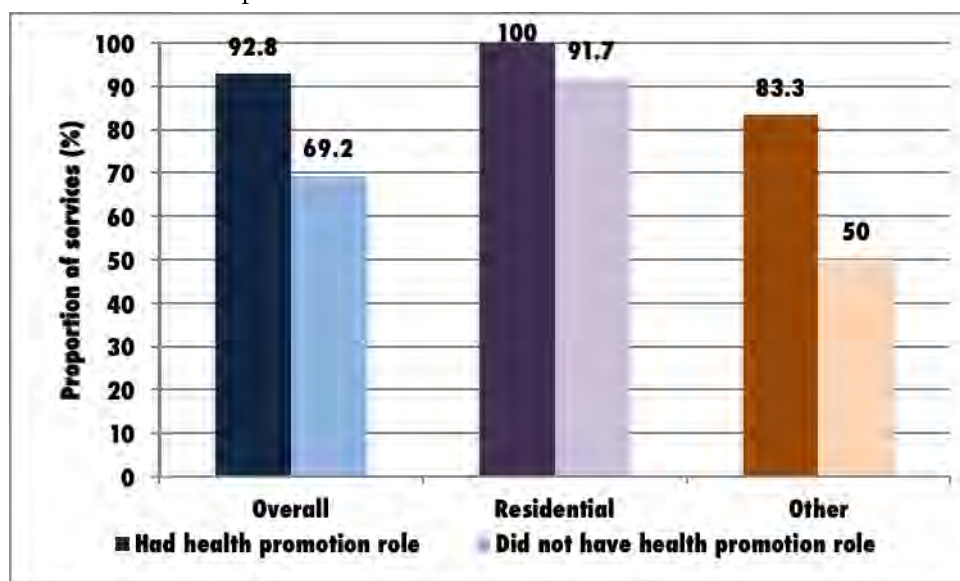


Figure 9 The proportion of residential and non-residential services with and without health promotion roles who reported having developed one or more health initiatives or strategies.

Nine out of every 10 respondents who reported their service employed staff in a health promotion role had developed one or more health promotion initiatives or strategies (93 per cent). Whereas 7 out of every 10 respondents who did not employ staff in a health promotion role reported developing one or more health promotion initiative or strategy (69 per cent).

Employing staff in a health promotion role made the most difference to the likelihood respondents had developed a health promotion strategy within non-residential services. Eighty-three per cent of non-residential respondents reported developing a health promotion initiative compared to half of the respondents who did not employ staff in a health promotion role (50 per cent). No association was found between employing staff in a health promotion role and the prevalence of health promotion initiatives by non-residential service providers in this small survey.

In what health areas had health promotion initiatives been developed?

Table 3 Number and Proportion of Residential and Non-residential Services that Developed One or More Health Initiative or Strategy by Health Domain

	Overall		Residential		Non-residential	
	Number (%)	95%CI	Number (%)	95%CI	Number (%)	95%CI
Health assessment/screen	16 (40)	24.1 – 55.9	15 (75)	54.2 – 95.8	1 (5)	-5.5 – 15.5
Health promotion/education	18 (45)	28.9 – 61.1	12 (60)	36.5 – 83.5	6 (30)	8.0 – 52.0
Smoking cessation	14 (35)	19.6 – 50.5	11 (55)	31.1 – 78.9	3 (15)	-2.2 – 32.2
Weight loss	16 (40)	24.1 – 55.9	12 (60)	36.5 – 83.5	4 (20)	0.8 – 39.2
Healthy eating	27 (68)	52.3 – 82.7	18 (90)	75.6 – 100.0	9 (45)	21.1 – 68.9
Mental health	12 (30)	15.2 – 44.8	9 (45)	21.1 – 68.9	3 (15)	-2.2 – 32.2
Dental/oral health	13 (33)	17.3 – 47.7	10 (50)	26.0 – 74.0	3 (15)	-2.2 – 32.2
Exercise/activity	26 (65)	49.6 – 80.5	14 (70)	48.0 – 92.0	12 (60)	36.5 – 83.5
Sexuality/sexual health	17 (43)	26.5 – 58.5	13 (65)	42.1 – 87.9	4 (20)	0.8 – 39.2
Diabetes prevention	9 (23)	9.0 – 36.0	6 (30)	8.0 – 52.0	3 (15)	-2.2 – 32.2
Sun safety	16 (40)	24.1 – 55.9	11 (55)	31.1 – 78.9	5 (25)	4.2 – 45.8

Service providers were most likely to have developed initiatives or strategies in the health related areas of healthy eating and exercise. Approximately 7 out of every 10 respondents had developed an initiative or strategy to promote healthy eating (68 per cent), and 65 per cent to encourage exercise or greater activity.

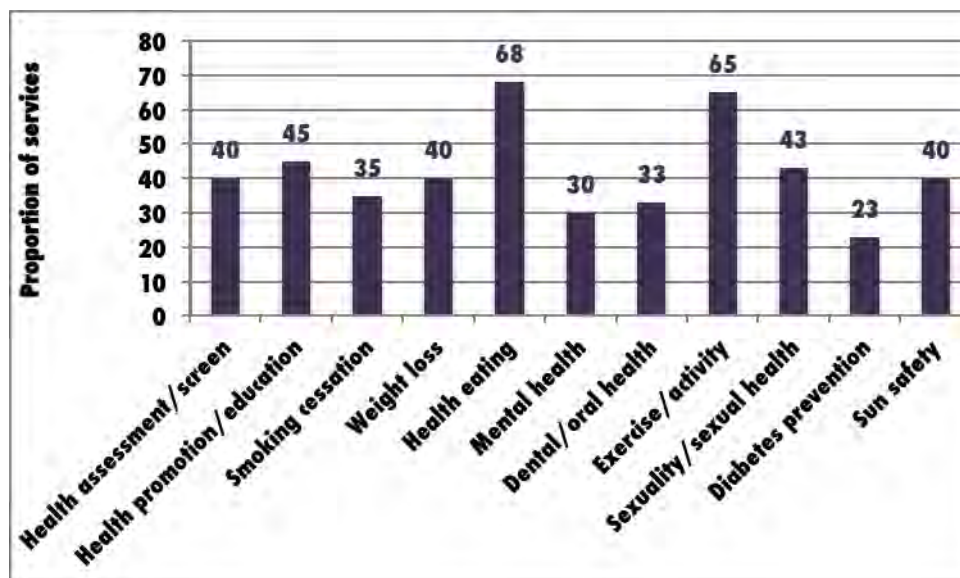


Figure 10 The proportion of providers that had developed one or more health initiatives or strategies by health domain.

The health domains that respondents were least likely to have developed initiatives in were the areas of diabetes prevention (23 per cent), mental health (30 per cent), and dental or oral health (33 per cent).

Differences in the health areas addressed through residential and non-residential health initiatives

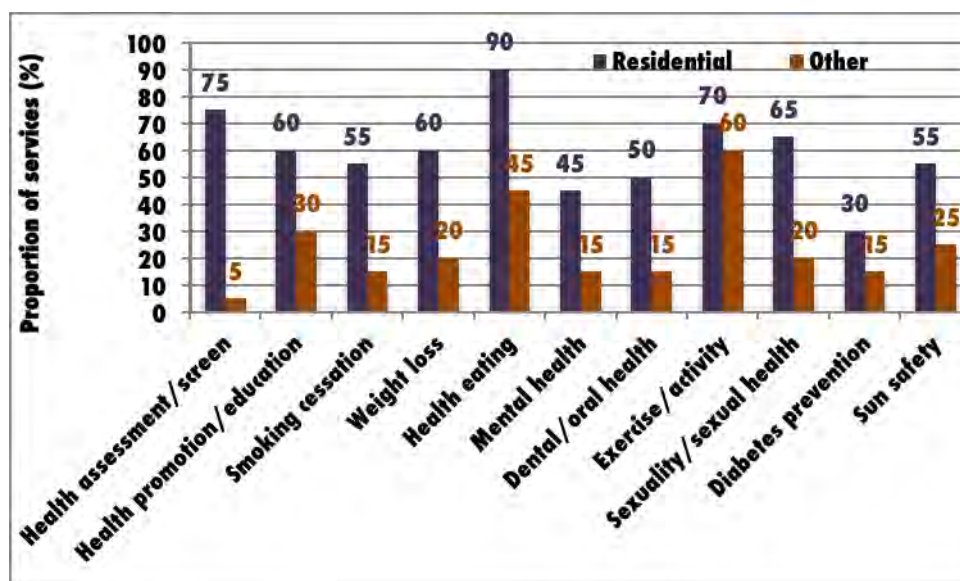


Figure 11 The proportion of residential and non-residential services that had developed one or more health initiatives or strategies by health domain.

Residential service providers were more likely to report having developed an initiative to promote increased health literacy or health behaviours across all health domains explored in this survey. Consistent with the overall trend, residential service providers were most likely to describe having developed initiatives or strategies in the areas of healthy eating (90 per cent), and exercise and activity (70 per cent). However, 75 per cent of residential service providers also reported having developed an initiative in the area of health assessment or screening (75

per cent) compared to only 5 per cent of non-residential service providers. The 70 per cent difference in the proportion of residential and non-residential providers that reported having developed a health initiative or strategy in the area of health screening or assessment was statistically significant (99 per cent CI= 47.5 – 92.5; $p < 0.001$). Other statistically significant differences in the proportion of residential and non-residential providers that had developed initiatives to promote better health literacy or health behaviours occurred in the health domains of smoking cessation (99 per cent CI= 11.6 – 68.4; $p = 0.007$), weight loss (99 per cent CI= 10.6 – 69.4; $p = 0.009$), healthy eating (99 per cent CI= 18.0 – 72.0; $p = 0.002$), and sexuality or sexual health (99 per cent CI= 16.1 – 73.9; $p = 0.003$).

In what areas did employing staff in a health promotion role make a difference to the number of health strategies or initiatives trialled?

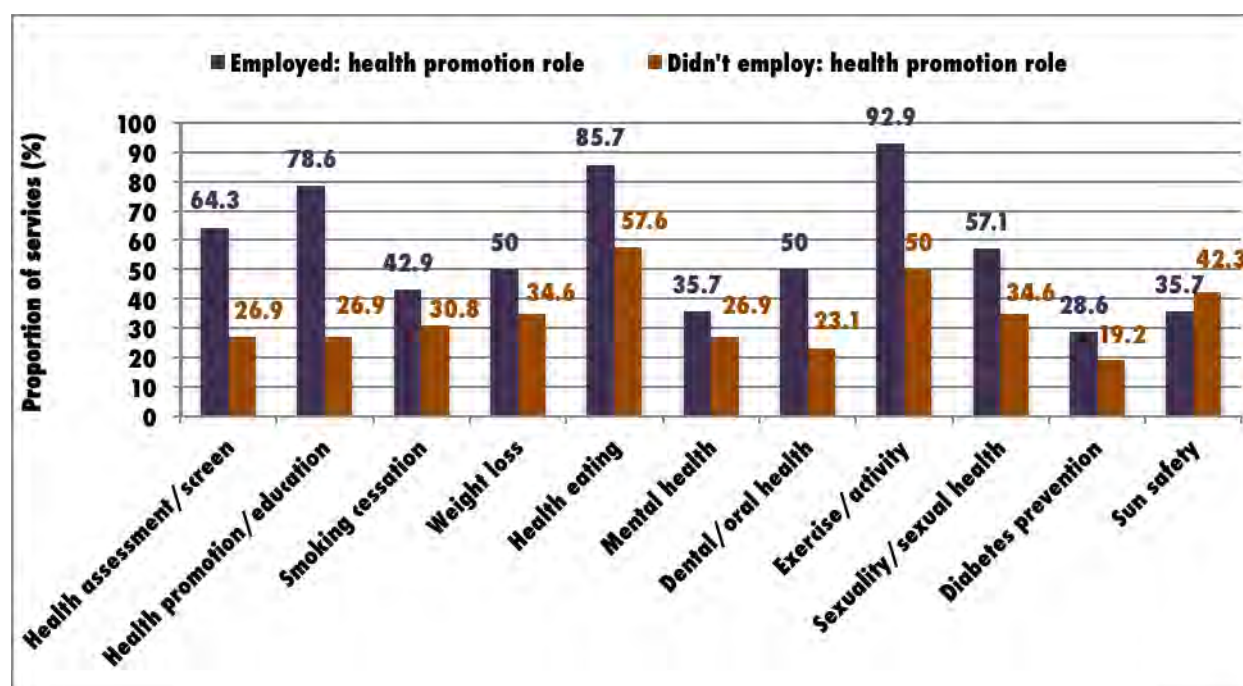


Figure 12 The number and proportion of providers that did and did not employ staff in a health promotion role who reported developing one or more health promotion initiatives or strategies.

Statistically significant differences in the likelihood providers who did or did not employ staff in a health promotion role would report developing an initiative or strategy to improve the health literacy or health behaviours of service users in two health domains were found. Almost 8 out of every 10 service providers that employed staff in a health promotion role had developed an initiative in the area of health promotion or education (79 per cent; 95 per cent CI= 54.0 – 100.0), whereas approximately one-quarter of service providers that did not employ staff in a health promotion role had developed an initiative or strategy (27 per cent; 95 per cent CI= 8.7 – 45.2). The 37 per cent difference in proportion of services that had developed a health education strategy was statistically significant (95 per cent CI= 5.9 – 68.8; $p = 0.001$).

Almost all service providers that employed staff in a health promotion role reported developing an initiative to promote exercise or activity (93 per cent). Conversely, only half of the services that did not employ staff in a

health promotion role reported developing a similar initiative (50 per cent). The 43 per cent difference between service providers that did or did not employ staff in a health promotion role also proved to be statistically significant (95%CI= 13.2 – 72.5; $p=0.006$).

Although service providers that employed staff in a health promotion role were more likely to report developing health related initiatives to improve health outcomes across all health areas, no other associations were found between a dedicated health promotion role and the development of health initiatives or strategies to improve the health literacy or health behaviour of disabled service users.

Did employing health promotion staff improve the likelihood that primary health and disability providers would partner in the delivery of initiatives?

Service providers that employed staff in health promotion roles were marginally less likely to partner with a primary health provider (PHP) in the delivery of one or more health initiatives. Forty-six per cent of service providers that employed staff in health promotion roles reported partnering with a PHP, whereas 53 per cent of service providers that did not employ staff in a health promotion role reported partnering with a PHP to deliver one or more health initiatives.

Were residential services more likely to partner with primary health providers to deliver health initiatives?

Eighteen residential providers had developed one or more initiatives to improve health literacy or health behaviours, of whom exactly half said they had partnered with a PHP to deliver their initiative (50 per cent). Similarly, exactly half of the 12 non-residential service providers that had developed one or more initiatives to improve the health literacy or health behaviours also said they partnered with a PHP in the delivery of their initiative (50 per cent). No association was found between service type and partnering with PHPs in the delivery of health initiatives.

Who initiated the partnerships?

Every service provider that had partnered with a PHP in the delivery of health initiatives indicated they had been responsible for initiating the partnership. Survey respondents were also asked to indicate whether the PHP they were partnering with had initiated the relationship. Two service providers reported that their PHP partner had also initiated a relationship (15 per cent), perhaps indicative of the PHP role in the development of one or more of a range of projects in which they partnered with primary health providers, or to communicate a collaboration with a PHP in the development and implementation of one or more health related initiatives.

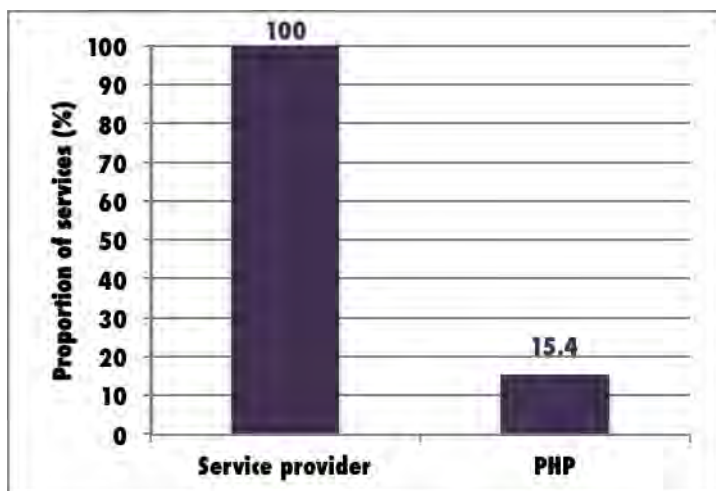


Figure 13 The proportion of respondents who partnered a primary health provider in the delivery of a health initiative that described the service or primary health provider as initiating the partnership.

Who did disability service providers partner with in the delivery of health literacy or health behaviour initiatives?

Eighty per cent of the 15 service providers that reported partnering with a PHP to deliver a health initiative reported partnering with a specific general practice (80 per cent) and/or DHB (80 per cent).

Residential providers appeared more likely to have formed a relationship with a specific general practice to deliver a health initiative or strategy. Every residential provider who reported developing an initiative to improve health said they partnered with a specific general practice to deliver the initiative compared with only half of the non-residential providers (50 per cent).

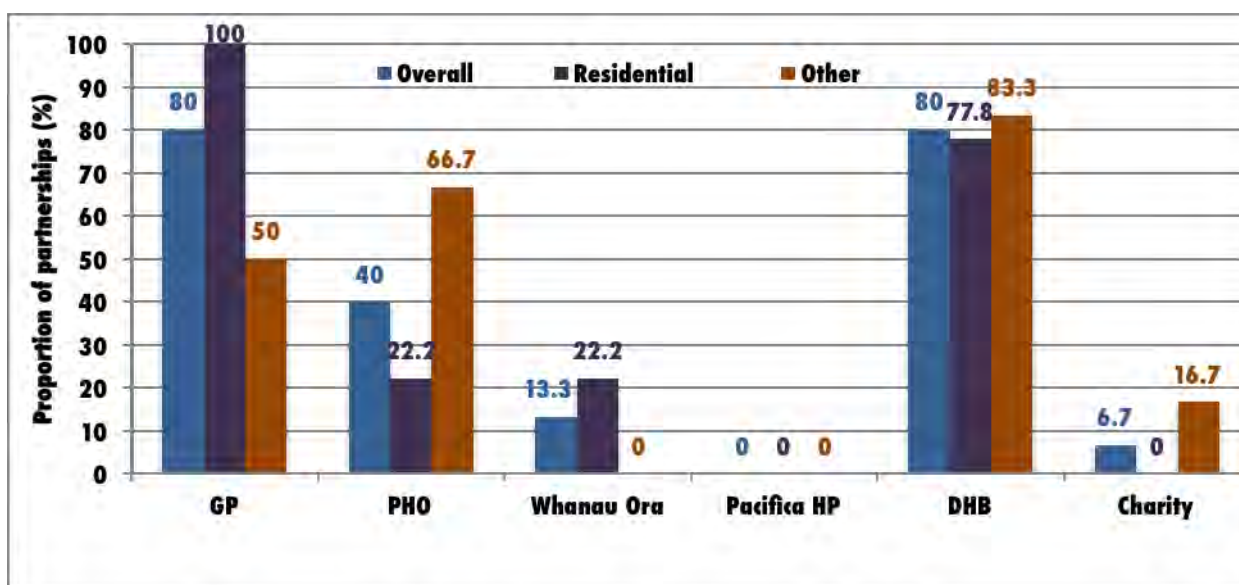


Figure 14 The proportion of residential and non-residential services that partnered a primary health provider by provider type.

Conversely, two-thirds of non-residential providers described contracting with a specific Primary Health Organisation (PHO) to deliver a health initiative they had developed (66.7%; 95%CI= 12.5 – 100.0), compared to 22 per cent of residential providers (22.2%; 95% CI= -11.7 – 56.1). However, it is important to note that the small number of residential ($n=9$) and non-residential ($n=6$) providers that reported partnering with a PHP in the delivery of a health initiative meant that small variations in the number of respondents reporting partnerships with specific PHPs effected large changes in the prevalence of partnerships with specific providers.

What proportion of providers implemented successful health initiatives?

Of the 29 providers that reported developing a health initiative and for which data was available, 62 per cent considered the initiative to have been successful and 38 per cent remained undecided about the outcome. No respondent thought their health initiative had failed.

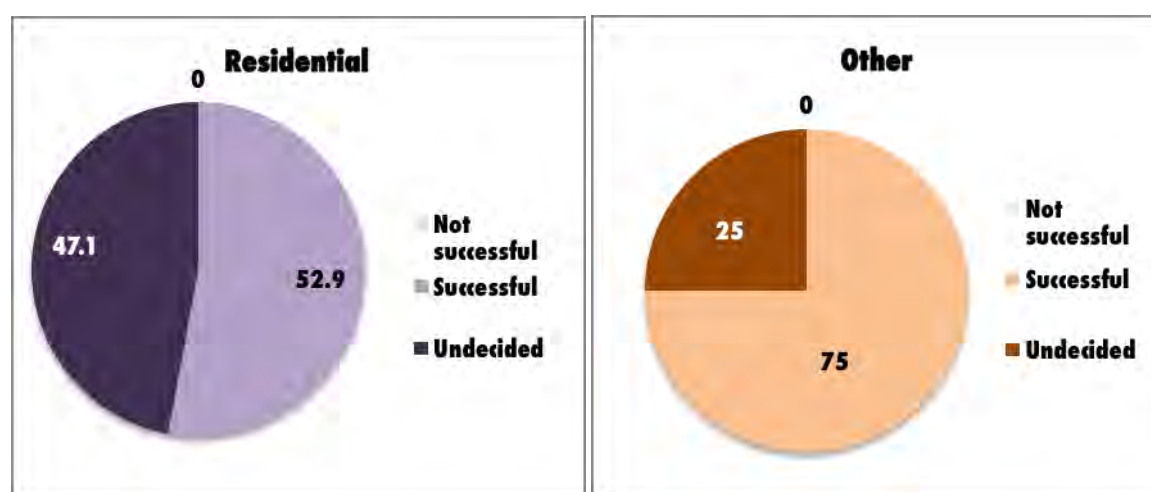


Figure 15 The proportion of residential and non-residential services that developed a health initiative or strategy that determined the initiative to have been successful.

Residential providers were more likely to be undecided about the success of the initiatives they had developed (47 per cent) than non-residential providers (25 per cent). However, no association was found between provider type and their assessment of the success of the health initiative they had developed.

Did providers collect data to evaluate the outcome of their initiative?

One-third of the 28 providers that reported developing a health initiative or strategy said they collected data to inform an evaluation of the health initiative(s) they had developed (36 per cent). Residential (38 per cent) and non-residential services (33 per cent) were almost equally likely to collect evaluation data and no association was found between provider type and the likelihood that evaluation data would be collected.

Four out of every 10 providers that employed staff in health promotion roles described collecting data to inform an evaluation (42 per cent; 95 per cent CI= 9.0 – 74.4) and 3 out of every 10 services that did not employ staff in a health promotion role also described collecting evaluation data (33 per cent). No association was found between having staff in a dedicated health promotion role and the likelihood an evaluation would be informed by data collection.

What type of data did providers collect

The most preferred methods for collecting evaluation data were those that providers could collect internally. All providers that collected evaluation data reported being informed by self-reported or observed improvements in the health of disabled service users. Eight out of the nine providers that collected evaluation data described having access to direct measures of client health status (89 per cent), and seven of the nine providers reported interviewing service users as part of their evaluation (78 per cent).

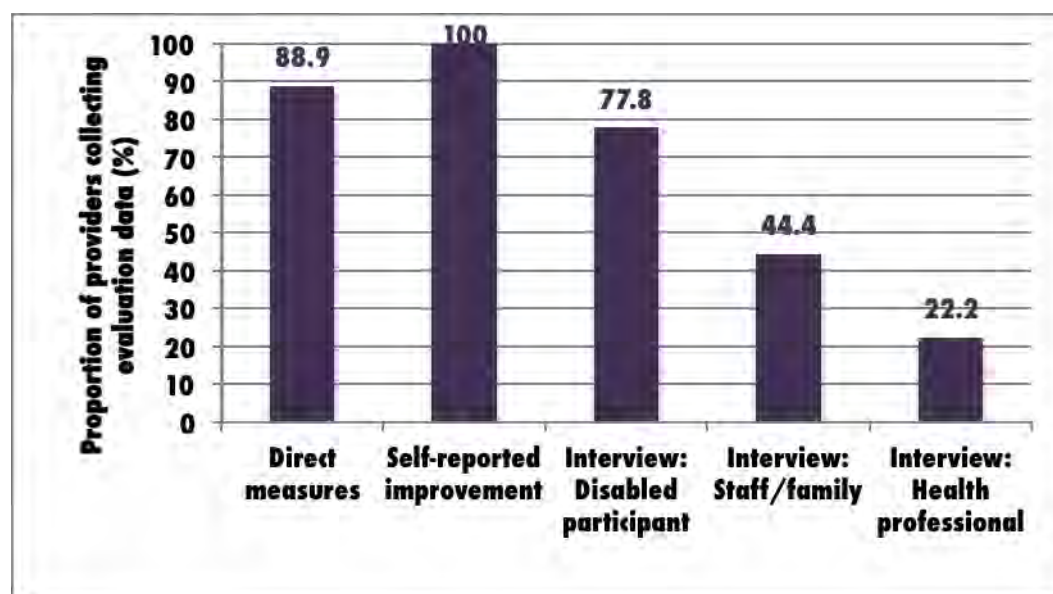


Figure 16 The method of data a collection that providers that developed a health initiative used to evaluate their intervention.

Providers were least likely to interview a health professional as part of their evaluation. Only two of the nine providers who reported collecting evaluation data were informed by an external health professional (22 per cent).

Who held health outcomes data?

It is important to note that 36 providers responded to the question about who held health outcomes data and was more than the number of respondents who reported developing a health initiative or strategy. Whilst many will have read the question as relating to their intervention(s), other respondents appear to have understood the question as relating to the wider principle of whether their service collects and holds health related information on people who use their service. Analysis of this question assumes respondents are reporting on the wider question of whether they collect and hold health related data.

When all responses were analysed, nearly half of the providers indicated their service held health outcomes data (47 per cent). Four out of every 10 respondents reported that a PHP held outcomes data (39 per cent), and 14 per cent reported that health outcomes data was held by both disability and primary health providers.

When the data was screened to exclude responses from providers that did not report developing a health initiative or strategy, little change was observed in the reported holder of health outcomes data. Although, as

might be expected, providers were slightly more likely to report holding health outcomes information themselves (48 per cent) or in conjunction with a PHP (16 per cent).

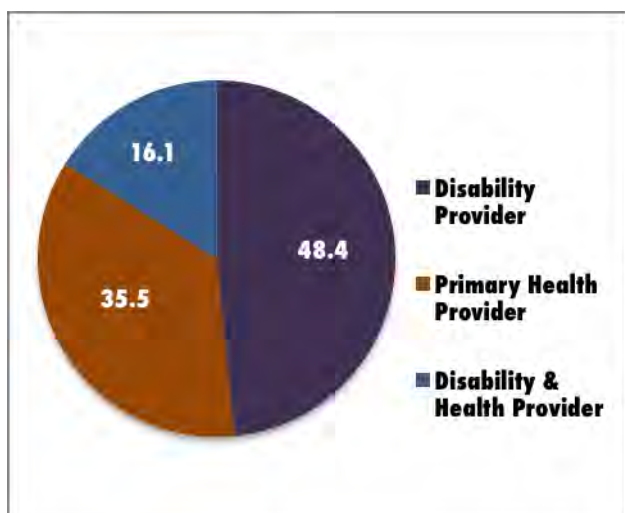


Figure 17 The proportion of respondents that had developed a health initiative or strategy that reported health outcome data was held by the service and/or provider health provider(s).

What proportion of disability services used a health screening tool?

Approximately one-third of respondents reported having used or made a health screening tool (35 per cent) available for use with people with an intellectual disability.

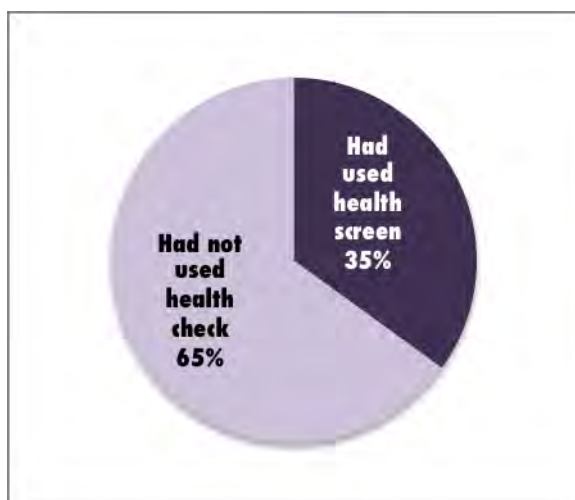


Figure 18 The proportion of providers that had used a health screening tool.

Table 4 The Health Screening Tool Residential and Non-residential Services Reported Using

	Overall		Residential		Non-residential	
	Number (%)	95%CI	Number (%)	95%CI	Number (%)	95%CI
CHAP	2 (14.3)	0.00 – 25.3	2 (15.4)	0.0 – 38.1	0 (0)	-
OK Health Check	2 (14.3)	0.00 – 25.3	2 (15.4)	0.0 – 38.1	0 (0)	-
Cardiff Health Check	8 (57.1)	27.5 – 86.8	7 (53.8)	22.5 – 85.2	1 (100)	-
Other	4 (28.6)	1.5 – 55.6	4 (30.8)	17.4 – 59.8	0 (0)	-

Note. CHAP = Comprehensive Health Assessment Programme

The Cardiff Health Check was the most commonly reported health screening tool used by the 16 providers that described using a health screen as part of their service delivery. Twenty-nine per cent of providers that used a health screen reported using an alternative health screen to the three most commonly used standardised screens. One provider described using a modified version of the CHAP, two providers had developed a check-list to be used at the time of an annual check up, and one provider used another tool alongside the Cardiff Health Check. Only one non-residential provider reported using a health screening tool and that respondent was aligned with a major residential service provider that used the Cardiff Health Check as an element of its residential service provision.

How often were health assessments performed?

All providers who reported using a health screening tool reported that checks were either done annually or that an annual check was the target. Only one service providing a health screening tool said that service users exercised any discretion about whether they used the tool or not.

Respondents were asked to provide qualitative comment about the frequency of health checks. Thirteen survey respondents answered this question. All respondents were providers of disability support to people who have an intellectual disability and all identified that health assessments were performed on an annual basis. Additional comments showed that additional health assessments would be undertaken if a change was noticed in an individual's general health and well-being. It was also noted by one respondent that a small minority of people who have an intellectual disability refuse to participate in health assessments but no further detail was provided with regard to the reasons for refusal.

Who paid for annual health checks?

Four out of every 10 providers reported that the people using their service paid for their annual health checks unsubsidised by either their disability provider or PHO (40 per cent). Conversely, one-third of providers reported absorbing the cost of annual health checks themselves (33 per cent) and 27 per cent of providers reported the costs were shared between the disability provider and person receiving the annual check up.

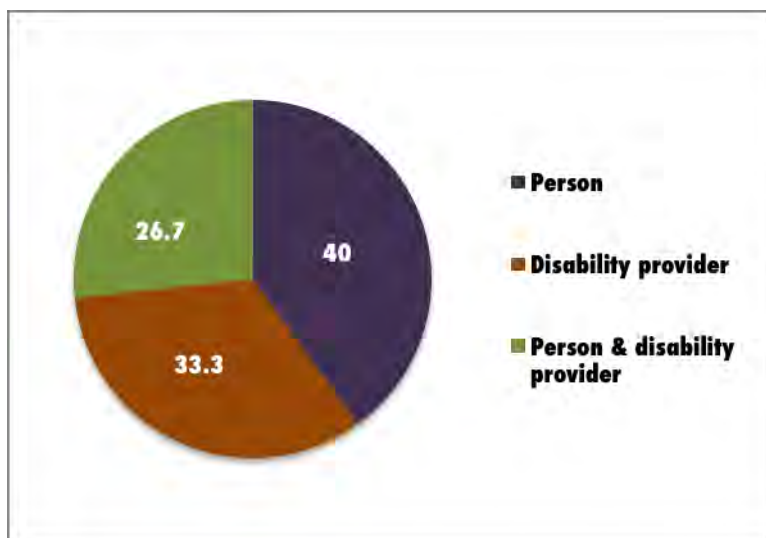


Figure 19 The proportion of service providers and/or service users that paid for an annual check up within disability support services that reported routinely providing health checks.

How much do health assessments cost?

Respondents were invited to provide qualitative comments regarding the cost of health assessments.

Information relating to the cost of health assessments for people who have an intellectual disability showed a large degree of variation. Reported costs of a health assessment ranged from no charge to \$165 per assessment. One service that was implementing a specific health assessment as part of a service driven health initiative reported a 133 per cent increase in GP costs for those involved with the initiative. Therefore contributions toward these costs were absolutely necessary for people on extremely limited incomes.

Most services were unclear about how much individuals who used their services were actually being charged for health assessments. This was reported as being due to the fact that costs differed across general practices. Whether or not assessments were conducted by a GP only, or whether a practice nurse was involved, and whether they required a double appointment all impacted on the final cost. There was some evidence that primary health services had engaged with the health needs of disabled people with one service reporting that they had been offered 150 free double appointments for people using their service, however this had been a one-off offer. Other contributors were unsure whether or not general practices were already being subsidised to conduct health assessments, highlighting a lack of shared understanding about funding and/or subsidies available to vulnerable population groups through primary health services.

Summary

Although the response to the survey by disability support services was low, the survey generated results that can contribute to a more developed understanding of the initiatives that disability services are pursuing in order to address the health needs of disabled people.

Survey respondents reflected the diversity of disability support providers in New Zealand highlighting that it is typical for providers to: hold a range of contracts; support people with a range of impairments; and in some cases meet the needs of children, adults and older adults within a single service. It is also important to note that vocational service providers responded to the survey and reported involvement in the implementation of health initiatives. Forty per cent of residential services and 30 per cent of non-residential services were found to employ staff in health promotion roles evidencing the disability sectors commitment to improving health outcomes for disabled people. In the case of residential providers, the larger the service, the greater the likelihood that someone would be employed in a health promotion role.

Most disability support services who responded to the survey were involved in the delivery of health initiatives designed to meet the health needs of disabled people accessing formal services. In total, almost 80 per cent of survey respondents reported having developed one or more health promotion initiatives within their service. Nine-five per cent of residential providers identified that they had been involved in such activity compared to 60 per cent of non-residential providers. Analysis determined that having staff employed in a health promotion role was associated with an increased likelihood of health initiatives having been developed. Furthermore, the presence of health promotion roles within non-residential services was found to strongly influence whether or not health initiatives were developed and implemented.

There was a high degree of consistency with regard to the focus areas of health initiatives. Service providers were found to be most likely to develop initiatives in the areas of healthy eating and exercise. The health areas that were least likely to be the focus of health initiatives were diabetes prevention, mental health, and dental or oral health. Seventy-five per cent of residential providers reported having developed an initiative in the area of health assessment or screening in comparison to five per cent of non-residential providers reporting the same. Unsurprisingly, health promotion activities were more frequently reported by services that employed staff in health promotion roles. Despite delivering initiatives in the area of primary health, only 50 per cent of survey respondents indicated they had partnered with PHPs to develop or implement initiatives.⁷ Furthermore, when partnerships were in place, disability providers stated almost without exception, that they had initiated the partnership. Where partnerships were in place, most involved specific general practices or DHBs. However, non-residential services were more likely to have partnered with PHOs to deliver their initiative. Nearly two-thirds of respondents described their initiative as having been successful.

With regard to the collection of health outcomes data, 36 per cent of those who had delivered initiatives had also collected health data for the purposes of evaluation. Most evaluation data were collected internally and took the form of self-reported, observed and direct measures of health improvements. Interviews with disabled

⁷ A lack of well-developed relationships was seen as impeding the development of health initiatives.

participants were also a relatively common strategy used to evaluate the impact of health initiatives. However, only 22 per cent of respondents to this question reported that an external health professional was involved in the evaluation.

A low proportion (35 per cent) of survey respondents were using health assessment tools (health checks), which were commonly administered annually. Payment for the health checks was made either by the disabled person (40 per cent), the disability provider (33 per cent), or a combination of the person and disability provider (27 per cent). The survey highlighted inconsistencies in the amount charged in the primary health care environment.

Barriers to primary care

Survey respondents were asked to comment on factors that posed barriers to the implementation of primary health initiatives, strategies for increasing access to primary health and improved health outcomes for disabled people, and training needs for the disability and primary health workforces.

Knowledge and understanding

Survey respondents typically believed GPs lacked knowledge and understanding of disability in general, and the health needs of disabled people in particular. This lack of knowledge and understanding was seen as a significant barrier to the implementation of primary health strategies. There was a strong perception that GPs were not always cognisant of, or responsive to the communication needs of disabled patients. Specific comment related to this point was made predominantly by respondents providing services for people with intellectual disability, and by respondents involved in the Deaf community. In the case of people who have an intellectual disability, concerns centred on the ability of GPs to communicate health information in an accessible manner. For Deaf patients, the need for health information to be delivered in New Zealand Sign Language (NZSL) was identified.

GP's lack of awareness of the health needs of disabled people was understood as being a consequence of limited emphasis on this topic within medical education. The absence of contact with disabled people, or understanding of the factors that impact on their lives, were seen as having the potential to compromise patient care. In particular, disabled people were identified as requiring extended consultation time in order to be able to communicate their health needs to their GP, and to process the health related information that their GP may need to communicate to them. Specific mention was made by several respondents about the need for NZSL to be used to communicate health information to those who are Deaf. It was also acknowledged that this requirement was often not met due to both the cost and a lack of availability of NZSL interpreters. It is important to note that while GPs were often criticised for a lack of understanding and awareness of the needs of disabled people in the primary health environment, registered nurses were viewed more favourably. Nurses were seen as having the skills, and in some cases the additional time, to respond to disabled users of primary health services. Several service provider respondents reported that their service enjoyed positive relationships with primary health professionals in their respective regions and perceived that they shared a commitment to improving the health of disabled people.

Time constraints

As mentioned above, the issue of inadequate consultation time was a significant theme with a large number of respondents who emphasised that the regular model of patient consultations within general practices was disadvantageous to disabled people. Ten to 15 minute consultations were seen as hugely inadequate and as constituting a barrier to quality primary health care. Furthermore, this issue was not always easily solved by booking double appointments due to the prohibitive cost associated with doing so.

Funding Issues

In general terms, the cost of primary health consultations and resulting prescription charges were seen as barriers to primary care for disabled people. Respondents were consistent in their identification of funding as the most significant barrier to the implementation of primary health initiatives. While disability services were committed to undertaking strategies that had the potential to better meet the health needs of disabled people who used their services, funding difficulties and constraints limited their ability to do so. A number of respondents were of the view that comprehensive health assessments (health checks) should be more widely available to people who have an intellectual disability. Amongst these respondents there was a perception that this had not been achieved due to conflicting views about whether funding for such initiatives should be the responsibility of the Ministry of Health's Disability Support Services Group or another area of the Ministry of Health. There was a perception that funding could be made available through re-directing funds from DHBs to PHOs, or from one PHO stream to another.

A number of respondents commented that disabled people who are formally supported by services are expected to pay all their own medical, pharmaceutical and disability needs. In many cases, service users do not understand this, and as a consequence often do not have the financial reserves to pay for medical attention when it is required. Services are then put into the position of assuming these costs. One respondent suggested that to avoid this situation, a system of forwarding specified funding to a trust account designated for medical needs could be implemented.

Collaborative relationships

The need for increased collaboration between disability and primary health services was seen as critical to reducing the barriers to effective health care. Elaborating on this issue further, one respondent asserted that a significant barrier to the implementation of health initiatives was caused by each sector failing to have a clear understanding of the other. It was noted that both sectors have a different approach to health and wellbeing with the disability sector working from a position of promoting independence in all facets of a person's daily life, and primary health working from a perspective of preventing and detecting disease, promoting health and managing long term conditions.

A lack of well-developed relationships between PHOs and disability support services was perceived as impeding the development of health initiatives. In particular, it was noted that disability providers do not always know which PHOs the people they support are registered with. This was seen as reducing opportunities for providers to strongly advocate for current health initiatives that disabled people may be entitled to.

Health checks

A number of respondents were convinced of the potential of health assessment tools (health checks) for improving the health status of people who have an intellectual disability. Some contended that a lack of consistency in the use of health checks has meant it has been difficult to gain traction with regard to encouraging GPs to use health check tools to guide their assessment of the health of this group. It was suggested that if all intellectual disability providers agreed to use a specific health check that more progress might be made toward

establishing this approach within the primary health care context. As previously mentioned, the cost of health checks was perceived as a significant barrier to the implementation of this strategy to address the health needs of people who have an intellectual disability.

Health knowledge of disability support workers

The health knowledge of disability support workers was perceived as either a facilitator or barrier to disabled people being able to access primary health. A number of respondents noted that it is important for support workers to be well informed about health and health promotion, to take a role in recognising potential health issues, and in some cases, to advocate on behalf of the people they support.

Workforce training needs in primary health and disability

One of the primary functions of this project was to determine workforce development needs relating to the primary health and disability sectors. Survey respondents were asked to record their views on perceived training and education needs within the disability workforce. Responses showed variation but generally could be clustered into several key areas, which are outlined below.

Disability workforce

General education about the health status and health needs of disabled people

Respondents to this survey were clear about the important role that support workers play in the health of disabled people. To this end, a number of services had implemented training opportunities for support workers to learn more about health related issues. Alerting support workers to the social determinants of health, such as the impact of isolation was also seen as important. It was noted however, that some support workers need a more general understanding of the health status and health needs of disabled people (perhaps within Level 2 or 3 training), and about how to observe changing health needs. Education in the area of activity and healthy lifestyles was also seen as necessary.

General education about primary health and primary health care services

A key issue identified was the need for disability support workers to become more informed about the meaning of the term primary health and its relevance and importance to the lives of disabled people. Linked to this, education for support workers about the range of primary health services available within local communities, and how to access them, was suggested.

Advocacy training

A number of respondents considered that disability support workers would benefit from education in the area of advocacy to enable them to effectively and ethically support the health needs of disabled people. While not all disabled people require others to advocate on their behalf with regard to their health needs, it was acknowledged that disability support workers and/or services sometimes need to advocate strongly for individuals who access formal support. It was suggested that training on the Code of Rights should be one aspect of advocacy-based

education, along with a component on assertiveness, that may facilitate more effective interactions with GPs and other primary health professionals.

Disability and primary health sector collaboration

It is important to highlight that a small number of respondents commented on the need for a clear understanding that disability support services and support workers are *not* health services or health professionals. Therefore, it was considered that education and training in this area should be focused on the ways in which the health of disabled people can be enhanced or improved through the *actions* of the disability sector. Respondents acknowledged that a critical aspect of this was related to the development of positive and informed relationships between disability services and the primary health sector. Respondents who had implemented health checks saw these as providing a structured way of facilitating communication between disabled people, support providers, and primary care professionals, such as practice nurses and GPs.

Primary health care providers

Respondents identified similar training needs for primary health care providers as they did for disability support workers.

Increased awareness of disability policy and legislation

It was suggested that health outcomes for disabled people may be improved by primary care professionals receiving specific disability related education based around the *Health and Disability Code of Rights*, the *New Zealand Disability Strategy*, and the *United Nations Convention on the Rights of Persons with Disabilities*. Such training would alert them to the policy and legislative context that underpins the disability sector and to better understand their own responsibilities to disabled people.

Communication training

Effective communication was seen as a critical component of primary health service provision. Respondents from the Deaf community emphasised the need for primary health services and professionals to understand how to create accessible and effective health interactions with Deaf patients. Deaf awareness training was a strategy identified as broadly required across the primary health service sector. It was also acknowledged that NZSL interpreters would greatly enhance health interactions for Deaf patients. At a more general level, communication education was seen as being required to ensure that primary health professionals recognised and responded to the disabled person, spoke in a way that was accessible, and did not prioritise the contributions of the support person during consultations.

General education in the area of the health needs of disabled people

The medical education of primary health professionals was perceived as having little emphasis on the relationship between disability and health. Therefore respondents highlighted the need for disability content to be increased. The need for primary health professionals to have an up to date knowledge of the health status and health needs of disabled people, including health conditions associated with specific syndromes was also highlighted. Administering comprehensive health assessments, which include such information, was seen as an

effective strategy for addressing the health needs of people with intellectual disability while at the same time facilitating an increase in the knowledge and skill of GPs and practice nurses. Education in the area of dual diagnosis and autism spectrum disorder was also perceived as being important and currently necessary for primary health professionals. Finally, developing expertise in how to make accurate diagnoses for people who have no verbal communication was noted as a critical area for GP training.

Strategies for improving the health of disabled people

The survey generated a large body of qualitative data on strategies for increasing access to primary health and improved health outcomes for disabled people. Many of the suggested strategies emphasised training and education thus having a distinct overlap with other questions which were specifically related to the perceived training needs within the disability and primary health workforces. Some suggestions were relatively broad, for example emphasising the need for attitudinal change and greater understanding of health issues impacting on disabled people, while other strategies were very specific.

Greater responsibility from the primary health sector

A number of respondents highlighted the need for the implementation of policy that requires PHOs to improve their knowledge of disabled people, including their health needs, and the barriers they face in accessing health services and health promotion. Further to this, it was noted by a small number of respondents that primary health services and organisations should actively disseminate information about what their service offers disabled people so that access into such services is improved. It was noted that it is not always obvious how disabled people fit within generic primary health strategies.

Investment in annual health checks for people with intellectual disabilities

There was a strong emphasis on the implementation of health checks as an important strategy for achieving improved health outcomes for people who have an intellectual disability. Key steps for achieving national implementation were identified as requiring the establishment of a Ministry of Health steering committee to:

- resolve funding issues associated with widespread implementation of government mandated health checks
- facilitate the selection of a single health assessment tool to be utilised by all disability service providers
- determine a standardised cost for health checks
- develop an evaluation strategy to determine the impact of health checks.

Intellectual disability nursing specific roles within DHBs and PHOs

There was a significant focus on the need to develop intellectual disability specific nursing roles. It was specifically suggested that intellectual disability nurse specialists could provide education to health practitioners within DHBs and PHOs and act as a liaison between primary care, disability services and disabled people. Linked to this was a call for the development of regionally based working parties that include representatives of both the disability and primary health sectors in order to establish a shared vision for improving health outcomes for disabled people.

Greater nursing involvement

The positive role that practice nurses frequently played during health consultations within general practice context was noted. In particular, practice nurses were seen as having more time, and were therefore more able to develop personal knowledge of an individual, and to communicate health information in an accessible manner. It was suggested that making the practice nurse the first point of contact as a person enters a practice may be a

positive initiative for people who have intellectual disabilities. Linked to this, comments were also made about the need to support the re-professionalising of specialist nursing in the area of intellectual disability.

Increased disability content in medical education

There was a widespread view that the disability content in current medical education is insufficient to equip health professionals to knowledgeably and responsively meet the needs of disabled people. Increased content was recommended in the areas of: the social determinants of health for disabled people (for example, isolation and poverty); the particular health conditions that are known to be more prevalent amongst people with an intellectual disability or those with specific syndromes; and known health care barriers for disabled people. Inclusion of education and training to enhance communication and service accessibility was seen as critical within medical education.

Accessible health information

As previously highlighted, a focus on accessible health information and health promotion was seen as necessary for improved health outcomes for disabled people. Accessible health information and promotion was identified as that which is responsive to a person's cultural needs, as well as their disability support needs. The need for health information to be presented in formats including Braille and Easy Read, and wider availability of NZSL interpreters was asserted.

Increased funding to enable disabled people to access health care

Significant emphasis was placed on the need to increase the availability of health related funding in order for disabled people to achieve improved health outcomes. It was reported that some disabled people did not make medical appointments due to a lack of money. In the case of people who have an intellectual disability, services reported that they frequently funded the primary health care of residential service users. Suggested strategies to address this funding issue included: government funded annual health checks; increased subsidy levels for disabled people in the high health needs category; health subsidies to be extended to include podiatry and dental care; funding for transport to health related appointments and consultations; free or cheap gym memberships included as part of the Green Prescription programme; and more funding for NZSL interpreters within the context of health consultations.

Increased education opportunities for disabled people, support workers and families

The need for improved health literacy for both disabled people and support workers was acknowledged. In order to self-manage their health and make informed health care decisions, disabled people and particularly those who have an intellectual disability, need access to health education. They also need to be informed about community-based health initiatives they may be able to access. Some aspects of this information may be most effectively delivered by support workers, or family members who may also require health education themselves in order to be able to appropriately take on this role. It was noted that education relating to activity, nutrition and healthy lifestyles is not currently included within the Certificate of Human Services.

Summary

Respondents perceived that GPs lacked knowledge in the area of disability and that the specific health needs of disabled people do not receive adequate attention within medical training. GPs were also seen as ill-equipped to respond to the diverse communication needs of disabled people. Within the primary health context, the model of 15-minute GP consultations was seen as highly inadequate for disabled patients who often require additional time both within the examination phase of the consultation, and to receive health information in an accessible format. The cost of primary health care was also highlighted as a barrier, even for those eligible for subsidies due to the low socio-economic status of many disabled people. Another impediment to primary health was seen as being related to a lack of collaboration between the disability and primary health sectors. The absence of an agreed plan toward the widespread implementation of health checks was seen as a systemic barrier to primary care, as was inadequate health knowledge on the part of disability support workers.

Systemic and practice level changes were asserted as being necessary for disabled people to achieve greater access to primary care. Specific suggestions included:

- encouraging the primary health sector to take greater responsibility in meeting the health needs of disabled people
- investing in the implementation of health checks for people who have an intellectual disability
- increasing intellectual disability nursing specific roles within DHBs and PHOs
- encouraging greater nursing involvement at the general practice level
- increasing disability content within medical education
- ensuring health information is being communicated in more accessible formats
- increasing health funding for disabled people
- increasing education opportunities for disabled people, support workers and families.

Four key areas were determined to be critical to ensuring the disability workforce is able to develop the capacity to respond to the health needs of disabled people. Support workers frequently play important roles in supporting the health and health needs of the disabled people they assist. Therefore, it is critical they receive a general level of education about the health status and health needs of disabled people. It was also asserted that support workers require information and knowledge about primary health and primary health care services available within the community. Advocacy and assertiveness training was also recommended as being necessary to equip support workers with the right skills in order to be able to effectively advocate on behalf of some disabled people with regards to their health. Finally, it was seen as important that disability and primary health sector collaboration was advanced to ensure that each sector had a well developed understanding of the responsibilities they each have with regard to advancing the health and well being of disabled people.

In contrast, the primary health workforce was considered to need training that would lead to an increased awareness of disability policy and

legislation. It was also seen as critical for primary health professionals to understand how to create accessible and effective health interactions with disabled and Deaf patients. Prioritising education about the health status and health needs of disabled population groups was also seen as central to moving toward more responsive primary health contexts.

Consultation with primary health and disability key informants

The third component of the research involved consultation with a small number of key informants drawn from the primary health and disability sectors. The function of this consultation process was to gain more detailed or new information, relating to primary health care access and strategies for improving health outcomes for disabled people. The following themes were identified within the data generated through this aspect of the project. Verbatim quotes are used to support themes.

Barriers to primary care

Cost

Cost was identified by all of the key informants as a significant barrier to primary care for disabled people regardless of impairment type. A primary health professional described several ways in which cost dictated whether or not a decision was made to access primary care:

People don't want to pay, or they can't pay, or they have a huge bill and they don't want to get the third degree from reception before they get in here.

Precious and limited financial resources were also seen as contributing to an inability, or in some cases unwillingness, to spend money on healthcare. One disability key informant noted that: *"many people would rather spend their money on a can of coke"*. Echoing the point made by a primary health professional, two disability key informants perceived that some disabled people avoided attending their general practice through fear of being reprimanded by reception staff if money was already owed.

Another factor that made access more difficult was a lack of awareness amongst some patients that medical care was actually necessary. A disability key informant commented:

Even just identifying that there's something wrong with them, limits their access because they don't know to go.

Barriers to access were perceived as being compounded by communication difficulties for some people. A primary health professional, who worked in a busy PHO, suggested that some of the people who had an intellectual disability within her practice found it too difficult to arrange a consultation by telephone:

Many of these people can't cope with ringing the clinic number, because once they get put through to the second person they don't know what's going on. For people whose lives are pretty scattered and disorganised, making a doctor's appointment can be a challenge.

One key informant also mentioned inappropriate communication on the part of some health care workers as a barrier preventing better access to primary care:

Some staff members don't know how to interact or listen to or communicate with the person, which is a poor reflection [on] nurses' training.

Another barrier identified by one of the informants related to the broader area of diagnosis, noting that *"those who do have a classification are generally doing quite well because they're under an agency ... and it's clear cut"*. Also on this issue, a primary health professional stated that:

People who don't have a clear diagnosis or who are on the border don't fit into a clear funding bracket for support. So we think the people without diagnosis are at risk and are harder to get to, and harder to find them a place to get that support, because they can't communicate those needs and it's often reactive care as opposed to proactive care. But it's hard to be proactive with that sort of population.

Time constraints

A second barrier identified by several of the key informants related to the customary 15 minute doctor's appointment, described by one person as *"an awkward business model because primary care is partly private and partly government funded."* It was strongly argued by the an experienced primary health professional that 15 minutes is an inadequate amount of time to provide appropriate and effective health care for disabled people. She stated:

Some patients with intellectual or sensory disabilities take longer to divulge information about their symptoms or illness. I must emphasise that this is a process that cannot be rushed.

It was noted by several key informants that patients with physical disabilities can also be disadvantaged by this system. One primary health professional described a number of incidents in which extra aspects of the consulting process could not be contained within the 15 minutes allocated, giving the example of one patient who spent most of the appointment time getting into the examination room using her walking frame. More generally, a tension was identified between the need for primary care to move towards a team approach to delivering health care with other support (such as nursing staff, occupational therapists and community agencies), and the restrictions experienced by 15 minute appointments. In fact, it was reported that many GPs themselves subsidise a second appointment for disabled patients in order to extend the time they can spend with them.

Funding

The issue of inadequate health funding was raised by both primary care and disability key informants. Several issues related to funding were identified as problematic. First, primary health services receive inadequate resources to meet the broad health brief they now have. One key informant stated:

General practices are given the responsibility of maintaining community health, preventing overstrain on hospital and A&E services, but they are not given the resources to do so in an effective manner.

A disability sector key informant also commented on this issue.

The funding comes through DHBs - everyone wants it. We can't afford it because we're not funded for it so it needs to come from the DHBs through the PHOs and then it can be monitored properly. Money is the biggest issue. Doctors are happy to do an hour assessment if they're paid for an hour assessment.

Another primary health informant concurred with this view commenting that becoming part of a PHO had impacted on the way in which funding was allocated in the clinic in which she worked:

Now we're part of a PHO it's harder to access that funding, because it all goes into a big pot. Before we could do what we wanted without funding, and that's how we got the van, free appointments. But now we have to start charging people under 18 so all these ways we try and provide access.

This same person commented that health funding is allocated according to diagnosis, which can disadvantage those whom she is employed to support in her care:

People who don't have a clear diagnosis or who are on the border don't fit into a clear funding bracket for support.

That is, a number of the patients this person supports in a primary health context do not receive services that those who have a diagnosed disability are able to access:

So we fill in that gap. But we can only do that because we're such a big organisation. There are a lot of other people who belong to PHOs that don't have the capacity to employ people like me.

It is important to note that the issue of non-diagnosis is significant enough that some PHOs employ staff specifically to support those patients who have undiagnosed disabilities, impairments and mental health issues. A key informant who held such a position described her role.

We work in teams with the GP. We do advocacy for some, like going to Work and Income. But don't have the capacity to do that a lot. It's amazing how things happen when you've got someone advocating for you. So we are navigators for these people, coordinators.

Strategies for improving the health of disabled people

As part of the consultation process, key informants were asked to elaborate on strategies for improving health outcomes for disabled people. Several strategies were identified.

Annual health checks

Annual health checks were identified by all of the key informants as having the potential to improve health outcomes for people with intellectual disabilities. One disability key informant contended that progress toward widespread use of health checks would be increased if the intellectual disability sector agreed to use one health assessment tool commenting:

Then the GPs would engage better with us, because a lot of the providers have different tools, and they have different expectations... so there are five or six different tools or they've created their own they don't know what to expect. So one provider might have a really good relationship with one GP for two or three people, the next GP you go to might not know what you're talking about, because they've dealt with a different one with a different provider... so providers need to use one so that the GP will then invest in working with them so that we can together get better outcomes.

The issue here is twofold: the use of different tools creates difficulties in measuring health outcomes, but also contributes to difficulties in communication between GPs and the disability support providers. A disability informant described how the disability service she worked within was responding to this issue.

It's never been highlighted with GPs either so they don't know what they're meant to be doing which is why we implemented the CHAP. We're collecting data about this over the next three months for publishing to show that in New Zealand a CHAP makes a huge difference.

This person went on to say:

I think the way we resource and manage it isn't right. There are very specialist people in the community and we should be resourcing them to do the service. It is difficult to get experts in the chronic conditions in an individual practice nurse level. It's a big ask. It's about connecting with the community to make that happen.

Further, possibilities were identified in which health checks could be more effectively utilised by the primary care and disability workforces. One of the ways that this could happen was through building better communication between the sectors.

Staff are not contacting the practice nurse with their concerns, thinking they have to go and see the GP, which [could] actually streamline and make primary health services better. Developing this relationship is very valuable. The CHAP actually reduces the number of times a person accesses primary or secondary health care. At the moment we're subsidising people to go for a longer appointment. If we

can reduce, even by five per cent, the number of times people are accessing primary care because of unmanaged conditions, the CHAP is going to pay for itself every year for the rest of their lives.

It was also suggested that comprehensive health assessment tools actually reduce the amount of *other* health related training support workers may need to access.

By using specific tools such as CHAP they don't need to know everything because the CHAP will prompt them about what they need to do. If you want to make a difference you put in tools.

Overall, despite the problems that were identified, there was overwhelming support for the use of annual health checks for monitoring the health and wellbeing of people with disabilities. This was primarily because it was seen as a preventative tool, a proactive rather than reactive means of supporting good health and wellbeing for people with disabilities.

Rethinking the role of disability support care staff

Another area in which improvements could be made was through redefining the role of disability support staff.

Support workers are in the homes daily: they should be observing changes in conditions of their clients. It is simplistic getting people to identify basic things. I don't think we do enough in that area to gather basic information. We so underutilise these support workers. If we were smart about how we do some of that they could be giving us a huge amount of support.

Similarly, another key informant commented:

Respect needs to be shown in someone's physical space but also the opportunity to be observant. People with changing health needs in a physical way could probably be identified a lot more strongly.

This person suggested that having basic observational skills, a basic knowledge of how particular medicines are stored, products that contain paracetamol, and some basic knowledge of tikanga Māori, would work to support clients in their own homes. This in turn could effectively reduce the number of doctor visits as well as the misuse of medications. Given that support workers are in the position of being in the homes of these people, they also have the opportunity to observe and report if their client is not reporting important information about their health to their primary care provider.

However, it was also noted that significant changes would need to occur in the disability workforce in order for these to be effective, because at present:

Health promotion is actually not what we're contracted to deliver. We don't provide any training around working with a client along these lines. The fact that we could also be using the opportunity to observe what they're eating, for example. But we're not actually providing that training to be able to deliver that type of support, and rightly so, unless they were skilled at it.

In summary, it was agreed that capacity exists for disability support staff to take on the responsibility of observing changes in the health status of those whom they support. It was stressed, however, that these observations should be strictly managed through the use of a health assessment tool by which differences could be measured and noted.

Improved communication between primary care and disability support sectors

Underlying all of the suggested changes to the way in which primary care is delivered to people with disabilities was the need to greatly improve channels of communication between the disability support and primary care workforces. Key informants perceived that ineffective communication was making it difficult for disabled people to access primary care:

Primary health doesn't value community and community's experience as already having done it. I think there's a need for some links between primary and community and the NGO sector because I think we have a lot to offer in terms of designing programmes that are appropriate. We actually do that with our primary rehab programmes. We're contracted by the PHO to provide that programme and I'm convinced that making those links makes the links between primary health out into the community. We're the cheaper option. We can do a lot of the things that they can't do out there and develop things that if you left at primary level are too expensive.

This informant cited the use of Clinical Bay Navigator, a portal used by the DHBs and primary health to make referrals and access information. She also made the following suggestions for improving communication between the sectors:

You can muscle into primary health initiatives: practice nurse education programme. Community organisations can be involved in that by having representatives of the person with the disability. They need to have the voice of the people that they're serving around the table. An awareness thing and being visible, and making those tangible interventions.

It was also acknowledged that increased education was needed for health care professionals and that this could be achieved by increasing the time spent on placement in primary care organisations. One person commented that this training “*needs to be more robust, about the communication and the valuing and respect of intellectual disability*”. In fact, the need for an increased awareness of the range of needs of people with disabilities was identified across both sectors. This could be seen as a particular challenge for some disability support staff.

They struggle with their own communication in dealing with professionals in their own lives let alone now advocating and supporting someone with a disability. So in their eyes the doctor is a big scary person, so there needs to be some work within the disability sector workforce about primary health needs and recognising them as advocates.

Some of those working in the disability sector had experienced the benefits of a closer and more integrative approach to working alongside primary care.

I know that we certainly have some good relationships with some of the GPs. We've had some really good results and worked through some really difficult relationships with GPs who haven't been aware of what we've been trying to achieve and hadn't been good at communicating and we worked through it.

It was suggested that another reason to spend time developing communication between the sectors would be to ensure that health promotion information is more accessible to people using the services. Three of the key informants noted that in many cases, clients don't know what primary health services they are able to access free of charge:

Clear understanding is needed between disability providers and PHOs and what PHOs can actually offer and what services are free to access. Some of the information that our staff are not up to date about where their primary health is actually at. And they will influence client choice.

Importantly, it was noted that communication between the sectors is currently limited by a profound difference between the sectors both in the terminology used, as well as the actual differences in the approaches to support and care. One person, who had worked extensively in both the primary health and disability support sectors, used the following example to illustrate this point.

In primary care you would, for example, support smoking cessation by providing information and other supports. In the disability sector you wouldn't do it at all: sometimes the worker might actually hold the cigarette for the person.

Summary

Key informants across both the primary care and disability sectors largely agreed about the main barriers experienced by people with disabilities in accessing appropriate and adequate primary care. Of particular significance was the cost incurred by the patient in paying for health consultations. This was further complicated by the time limitations inherent in the standard 15-minute consultation, whereby extra support and appropriate resources could not be incorporated. Funding changes brought about by the integration of PHOs was also identified as impacting on access to primary care for people with disabilities.

Three main strategies were identified for improving health outcomes for people with disabilities. Annual health checks for people who have an intellectual disability were seen as an important tool both as a preventative measure which could result in decreased rates of GPs visits, reduce the need for secondary care, and as a means by which disability support staff could observe and measure changes in the health status of the people in their care. Rethinking the role of disability support staff to ensure they could appropriately and safely monitor the health of the people they support was also identified as an effective means of increasing access to primary care.

Finally, improving communication within and across the primary care and disability sectors was determined to be the most cost-effective and easiest strategy to implement to more effectively support people with disabilities.

Discussion

The project was underpinned by the *Disability Support Services Workforce Action Plan* (2009) objective of strengthening the capacity of organisations to improve service quality and safety through workforce innovations by promoting relationships between disability support services and primary health care organisations, and identifying primary health initiatives that are applicable to disability support services. The current report explored primary health initiatives implemented by disability support services to improve the health needs of disabled people who use formal services; disability service providers' and primary health professionals' perceptions of the barriers to primary health care for disabled people; and related training needs for the primary health and disability sectors. The survey has contributed to a better understanding of the context within which such primary health initiatives have occurred. A more comprehensive picture of the barriers to primary care, workforce training needs, and strategies that have the potential to lead to improved health outcomes for disabled people was gained through key informant interviews.

Health initiatives

The research found New Zealand disability services have been actively addressing concerns about the health of disabled people through the implementation of health promotion initiatives. The primary health and disability survey generated a sample of 40 respondents who represented a range of disability services. Nearly 80 per cent of survey respondents indicated their disability support service had developed and implemented health initiatives. Such activity was highly apparent within the sample of residential service providers with 95 per cent of this group identifying that they had been involved in health initiatives compared to 60 per cent of non-residential providers. The presence of health promotion roles within disability support organisations appeared to increase the likelihood that health initiatives had occurred. Forty per cent of residential services and 30 per cent of non-residential services reported employing staff in health promotion roles. Overall, nearly two-thirds of respondents described their health initiatives as having been successful.

Diet and exercise

Research in the broad field of disability has consistently highlighted concerns regarding the increased risks for and prevalence of health issues related to obesity, and under-activity (Milner, Mirfin-Veitch, & Conder, 2013; Reichard, Stolze, & Fox, 2011; Stedman & Leland, 2010; Temple, 2013; White, Gonda, Peterson, & Drum, 2011). Awareness of such concerns was identified in the current research through the finding that health initiatives were most often centred on healthy eating and exercise. In contrast, health initiatives were least frequent in the areas of diabetes prevention, mental health, and oral or dental health despite the fact that research has also identified these as areas of health concern for disabled people (Barnett et al., 2011; Emerson & Baines, 2010; White et al., 2011).

Health assessments

Also reflective of international research, intellectual disability service providers reported using a range of health assessment tools with their service user group (Baxter et al., 2006; Lennox et al., 2007; Matthews & Hegarty,

1997) and that there was a great deal of variability in the cost of such checks. At present, people who have an intellectual disability who are receiving health checks are most likely to be paying for them themselves.

Barriers to primary health care initiatives

This research generated qualitative data through the *Primary Health and Disability Survey*, and subsequent key informant interviews about: the barriers to the implementation of primary health initiatives; workforce training needs; and strategies for increasing access to primary health and improved health outcomes for disabled people. Analysis showed remarkable consistency between the issues and solutions discussed by New Zealand disability and primary health providers and the published literature in this area.

Barriers to primary care and the implementation of primary health initiatives have been identified in the literature as being created by:

- inadequate GP knowledge (McColl, Jarzynowska, & Shortt, 2010; Scheier, 2009)
- inadequate consultation time (Ziviani, Lennox, Allison, Lyons, & Del Mar, 2004)
- inaccessible health information (E. Jones, Renger, & Firestone, 2005)
- lack of qualified sign language interpreters (Iezzoni, O'Day, Killeen, & Harker, 2004; Pereira & Fortes, 2010)
- the cost of health care (Becker & Stuijbergen, 2003)
- lack of collaboration between the primary health and disability sectors (Crews, Kirchner, & Lollar, 2006).

All these factors were identified as impacting on disabled people in New Zealand at the present time.

Workforce training needs in primary health and disability

A lack of health knowledge on the part of disabled people, their families and their support workers has been acknowledged in previous research (Parish, Moss, & Richman, 2008) and highlighted again in the current study. In order to develop workforce capacity within disability services it was considered necessary for support workers to receive a general level of education about the health status and health needs of disabled people. It was also asserted that information about primary health and primary health care services available within the community needs to be communicated to this workforce. Advocacy and assertiveness training was also recommended to equip support workers with the right skills to effectively advocate on behalf of disabled people with regards to their health. Finally, it was seen as important that disability and primary health sector collaboration was advanced to ensure that each sector had a well developed understanding of the responsibilities they each have with regard to improving the health and well being of disabled people.

Limitations

A number of factors need to be taken into account when interpreting the results of the current study. Information was gathered from primary health and disability service providers. The perspectives of disabled people and their family/whānau were not captured and require further investigation to ensure all critical areas

have been identified to support improved health outcomes for disabled people. In addition, survey participants were primarily invited to take part through an advertisement in the NZDSN and VASS newsletters. While it is not possible to determine the exact survey response rate, the response was lower than expected based on the number of disability support services in New Zealand. Survey participants may have been more likely to have implemented and interested in health initiatives compared with non-respondents. As a result, the extent to which health initiatives have been implemented in the disability sector may have been overestimated and there may be other primary health care barriers not captured by this project. Furthermore, only one-third of providers that had developed a health initiative had collected data to evaluate this (using a range of methods that likely varied in quality). As a result, this research has not assessed the effectiveness of different types of health initiatives. The implementation of primary health initiatives within disability services should incorporate a robust evaluation strategy. Finally, given the cross-sectional survey design it is not possible to determine cause and effect. For example, it may be that services who were focused on delivering health initiatives were more likely to have established health promotion roles to support their work, rather than these being initiated by health promotion staff.

Recommendations

Despite limitations, strategies that have the potential to increase access to primary health care and contribute to an overall improvement in health outcomes for disabled people have been identified and mirror those presented in international research. Research has highlighted that systemic changes at a policy level (Barnett et al., 2011) and operational change at the primary health practice level (Pharr & Chino, 2013) need to occur to achieve significant advances in reducing health inequalities for disabled people. With regard to the current project systemic and operational strategies were also suggested as being necessary in the New Zealand context.

The specific actions recommended based on the findings of this project include:

- the Ministry of Health
 1. funding research to investigate, identify and evaluate a standardised health check tool for use with people who have an intellectual disability
 2. funding GPs to undertake health checks for people with an intellectual disability
 3. increasing funding to disability support services to improve their ability to implement primary health initiatives, and to cover the medical costs and prescription charges of disabled people
 4. continuing to fund training to support the development of support workers' knowledge and skills related to disabled peoples' health status and needs, health promotion and advocacy
 5. continuing to fund health education training to support disabled people and their family/whānau to make more informed health care decisions
- education providers increasing the disability content within GP's medical education, including the social determinants of health for disabled people, common health conditions and health care barriers, along with communication training
- health care providers ensuring health information is accessible for disabled people (including the use of Braille, Easy Read and sign language interpreters where appropriate)

- primary health care practitioners improving their capability to support disabled people, including increasing their knowledge of the social determinants of health, common health conditions and health care barriers, and undertaking communication training
- PHOs and DHBs developing intellectual disability specific nursing roles that can provide education to health practitioners and act as a liaison between different health care services
- PHOs better utilising practice nurses in the provision of services to disabled people
- PHOs and disability support services developing collaborative relationships to support the successful implementation of primary health initiatives
- disability support workers undertaking training on the health needs of disabled people they assist and advocacy training.

Conclusion

This research has identified that New Zealand disability service providers have responded to concerns about the health status and access to primary health care for disabled people by implementing a range of health initiatives, many of which have been considered successful. The initiatives have typically responded to a small range of key health concerns, and have not usually been accompanied by dedicated health funding.

The barriers to primary health care impacting on disabled people, and the strategies for improving health outcomes are consistent with international research findings and can help guide future action to improve health outcomes in New Zealand. This includes building the knowledge and skills of disability support workers to better understand and advocate for the health care needs of disabled people, and improving the capability of primary health care professionals in responding to the needs of disabled people. Future research is required to explore the findings generated through this study with disabled people themselves to ensure that all critical areas to facilitate advancement in this area have been identified.

Appendix A

Letter of Introduction

Dear Disability Support Provider

You are invited to participate in a brief survey about improving access to primary health care for disabled people. You have been included in this survey in your capacity as a provider of support to people who have intellectual, physical or sensory impairments.

The Donald Beasley Institute has been contracted by Te Pou o Te Whaakaro Nui (Disability Workforce Development) to conduct a project that is focused on disability and primary health. Part of this project involves administering a national survey about health initiatives and programmes that your service may have implemented, for example, regular screening programmes, that have been designed to meet the specific primary health needs of disabled service users. We would also like to collect your views on other strategies that may lead to improved health outcomes for disabled people, including strategies related to workforce development

To access the survey itself please click on the URL below:

<http://www.surveymonkey.com/s/CMQZ9MJ>

Please follow the instructions provided on the first page to the questionnaire itself. Using this format helps to ensure your willingness to participate and keeps responses completely anonymous and confidential. The questionnaire includes questions with multi-choice responses as well as those that ask you to provide more detailed answers based on your views and experiences relating to disability and primary health. The questionnaire will take approximately 20 - 25 minutes to complete. Please note that according to HDEC Guidelines 2012 this survey does not require ethical approval, as your response to it denotes consent.

Please feel free to forward this request to another person in the organisation who has particular responsibility for health or health promotion. If you are a large national organisation we understand that there may be different health initiatives occurring regionally. Please feel free to complete a separate questionnaire for each region. Finally, if you do not offer any specific health initiative there is still the opportunity to contribute to aspects of the survey and we welcome your response. It would be most appreciated if you could respond to this questionnaire by Friday 14 June 2013.

Thank you for taking the time to read this invitation.

Yours sincerely

Brigit Mirfin-Veitch, PhD

Director, Donald Beasley Institute

PO Box 6189, Dunedin

Ph (03) 4792162

Primary Health and Disability Survey



Te Pou o Te Whaakaro Nui (Disability Workforce Development) Survey Primary Health and Disability

Questionnaire for Disability and Primary Health

1. What is the name of your service?

.....

2. Do people using your service have the following disabilities? Tick all that apply.

Intellectual ☐

ASD ☐

Physical ☐

Sensory ☐

3. What age group do you support? Please tick those that apply.

- Children (0-18 years) ☐
- Adults (19-64 years) ☐
- Older persons (65+ years) ☐

4. What services do you provide? Please tick those that apply.

- Residential Community ☐
- Residential (RIDSAS) ☐
- Supported Independent Living (SIL) ☐
- NIDCA ☐
- Household Management/Personal Care ☐
- Individualised Funding ☐
- Vocational Assistance ☐
- Other ☐

Please describe:

.....

5. How many disabled people (aged under 65) use your service?

.....

6. Does your service employ staff in health promotion roles?

Yes ☐

No ☐

If yes, what qualifications are held by the person/people employed in this role?

.....

.....

7. Does your service employ people to assist disabled people in meeting their health needs?

Yes ☐

No ☐

If yes, what qualifications are held by the person/people employed in this role?

.....

.....

8. Has your service developed any initiatives or strategies designed to meet the health care needs of disabled people?

Yes ☐

No ☐ please go to Question 17.

9. In what areas has your service developed health initiatives or strategies? Tick those that apply.

- | | |
|-----------------------------|--------------------------|
| Health assessment/screening | ☐ |
| Health promotion/education | ☐ |
| Smoking cessation | ☐ |
| Weight loss | ☐ |
| Healthy eating | ☐ |
| Mental health | ☐ |
| Dental/oral health | ☐ |
| Exercise/activity | ☐ |
| Sexuality/sexual health | ☐ |
| Diabetes prevention | ☐ |
| Sun safety | ☐ |
| Other | ☐ |

Please state:

10. Do you partner with a primary health provider to deliver your health initiative(s)?

No ☐ please go to Question 13.

Yes ☐

11. If yes, who do you partner with? Please tick those that apply.

- | | |
|--|--------------------------|
| Specific General Practice | ☐ |
| Contract with a specific Primary Health Organisation (PHO) | ☐ |

- Whanau Ora Health Provider ☐
- Pacifica Health Provider ☐
- District Health Board (DHB) ☐
- Charity-based Health Provider ☐
- Other ☐

Please state:

12. Who initiated the partnership?

- Your service ☐
- Primary Health provider ☐

13. Do you consider the initiative/strategy to be successful?

- No ☐
- Yes ☐
- Undecided ☐

Please explain your answer (provide as much detail as you are able)

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.....

14. In what areas did the initiative result in measurable improvements in health outcomes for disabled people? Please tick those that apply.

- | | |
|---|--------------------------|
| Blood pressure | ☐ |
| Body Mass Index (BMI) | ☐ |
| Smoking cessation | ☐ |
| Blood Cholesterol level | ☐ |
| Increase in uptake of Breast/Cervical screening | ☐ |
| Increase in uptake of Diabetes Checks | ☐ |
| Increase in immunisation rates | ☐ |
| Other | |
|
 | |
| We don't hold this information | ☐ |
| Don't know | ☐ |

15. Have you collected data to evaluate the outcome of your initiative?

Yes ☐

No ☐ Please go to Question 17.

If yes, what type of data did you collect? Tick all that apply:

Direct measures of health status (eg change in blood pressure, weight loss)

☐

Self-reported improvement in health, observed improvement in health or health behaviour)

☐

Interviews with disabled people who participated in the initiative

☐

Interviews with staff and/or family, others)

☐

Interviews with health professionals

☐

16. Who holds the health outcome data? Tick that which applies.

Your service ☐

Primary Health Provider ☐

17. Have you used health screening tools in your service to identify disease and support early intervention?

Yes ☐

No ☐

If yes, please tick all screening tools you have used.

CHAP (Comprehensive Health Assessment Programme) ☐

OK Health Check ☐

Cardiff Health Check ☐

Other ☐

Please state:

18. How often are the health checks done?

.....

19. Who pays for the annual health checks?

Person themselves ☐

Disability service provider ☐

Primary Health Organisation

☐

Other

☐

Please state:

20. How much is charged for each assessment? Please state.

.....

21. How was the initiative or programme funded? Please state.

.....

22. In your view, what are the barriers to developing and/or implementing primary health initiatives designed to meet the health needs of disabled people? Please explain.

.....

23. What strategies do you think would contribute to increased access to primary health and/or improved health outcomes for disabled people? Please detail as many strategies that you think are relevant to this goal.

.....

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24. What training would help the disability workforce to improve disabled people's access to primary health providers?

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.....

.....

25. What training do you think primary health care providers need to improve health outcomes for disabled people?

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.....

.....

26. Are you happy to be contacted by one of our researchers for a brief follow-up conversation?

Yes ☐

No ☐

If yes, please include your contact details below.

.....

.....

25. Please record any further comments below.

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.....

Thank you for taking the time to complete this survey.

Please note: under the Health and Disability Ethics Committee Guidelines 2012, this survey does not require ethical review.

References

- Barnett, S., Klein, J., Pollard, R., Samar, V., Schlehofer, D., Starr, M., . . . Pearson, T. (2011). Community participatory research with Deaf sign language users to identify health inequities. *American Journal of Public Health, 101*(12), 2235-2238.
- Baxter, H., Lowe, K., Houston, H., Jones, G., Felce, D., & Kerr, M. (2006). Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practice, February 2006*, 93-98.
- Becker, H., & Stuifbergen, A. (2003). What makes it so hard? Barriers to health promotion experienced by people with multiple sclerosis and polio'. *Family & Community Health, 27*(1), 75-85.
- Crews, J., Kirchner, C., & Lollar, D. J. (2006). The view from the crossroads of public health and vision (re)habilitation. [Article]. *Journal of Visual Impairment & Blindness, 100*, 773-779.
- Emerson, E., & Baines, S. (2010). *Health inequalities & people with learning disabilities in the UK: 2010*. Durham: Learning Disabilities Observatory.
- IBM Corp. (2010). IBM SPSS for Mac, Version 19.0. Armonk, NY: IBM Corp.
- Iezzoni, L., O'Day, B., Killeen, M., & Harker, H. (2004). Communicating about health care: Observations from persons who are deaf or hard of hearing. *Improving Patient Care - Annals of Internal Medicine, 140*(5), 356-363.
- Jones, E., Renger, R., & Firestone, R. (2005). Deaf community analysis for health education priorities. *Public Health Nursing, 22*(1), 27-35.
- Jones, G., Crews, J., & Danielson, M. (2010). Health risk profile for older adults with blindness: an application of the International Classification of Functioning, Disability, and Health Framework. *Ophthalmic Epidemiology, 17*(6), 400-410.
- Lennox, N., Bain, C., Rey-Conde, T., Purdie, D., Bush, R., & Pandeya, N. (2007). Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomised trial. *International Journal of Epidemiology, 36*, 139-146.
- Matthews, D., & Hegarty, J. (1997). The OK Health Check: A health assessment checklist for people with learning disabilities. *British Journal of Learning Disabilities, 25*(4), 138-143.
- McCull, M. A., Jarzynowska, A., & Shortt, S. E. D. (2010). Unmet health care needs of people with disabilities: population level evidence. *Disability & Society, 25*(2), 205-218.
- Milner, P., Mirfin-Veitch, B., & Conder, J. (2013). *On the margins of good health: An analysis of the health status, health knowledge and health literacy of people with a learning disability who completed the Special Olympics International HAS Health Promotion screen*. Dunedin: Donald Beasley Institute.
- Ministry of Health. (2009). *Disability support services workforce action plan*. Wellington: Ministry of Health.
- Ministry of Health. (2013). *Disability workforce action plan 2013 - 2016*. Unpublished: Ministry of Health, Retrieved from http://www.nzdsn.org.nz/uploads/news/Draft_Disability_Workforce_Action_Plan_2013_2016.pdf.
- National Health Committee. (2003). *To have an 'ordinary' life jia whai oranga 'noa': A report to the New Zealand Minister of Health and the Minister for Disability Issues on community membership for adults with an intellectual disability*. Wellington: National Advisory Committee on Health and Disability.
- Parish, S. L., Moss, K., & Richman, E. L. (2008). Perspectives on health care of adults with developmental disabilities. *Intellectual and Developmental Disabilities, 46*(6), 411-426.
- Park, J. H., Lee, J. S., Lee, J. Y., Gwack, J., Park, J. H., Kim, Y. I., & Kim, Y. (2009). Disparities between persons with and without disabilities in their participation rates in mass screening. *European Journal of Public Health, 19*(1), 85-90. doi: <http://dx.doi.org/10.1093/eurpub/ckn108>
- Pereira, P., & Fortes, P. (2010). Communication and information barriers to health assistance for deaf patients. *American Annals of the Deaf, 155*(1), 31-37.

- Pharr, J., & Chino, M. (2013). Predicting barriers to primary care for patients with disabilities: A mixed methods study of practice administrators. *Disability and Health Journal*, 6(2), 116-123. doi: <http://dx.doi.org/10.1016/j.dhjo.2012.11.003>
- Reichard, A., Stolzle, H., & Fox, M. H. (2011). Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disability and Health Journal*, 4(2), 59-67. doi: <http://dx.doi.org/10.1016/j.dhjo.2010.05.003>
- Scheier, D. B. (2009). Barriers to health care for people with hearing loss: a review of the literature. [Article]. *Journal of the New York State Nurses Association*, 40(1), 4+.
- Stedman, K., & Leland, L. (2010). Obesity and intellectual disability in New Zealand. *Journal of Intellectual & Developmental Disability*, 35(2), 112-115.
- SurveyMonkey Inc. (2013). SurveyMonkey Inc. Retrieved 5 July 2013, from SurveyMonkey Inc, <http://www.surveymonkey.com/>
- Temple, V. A., Foley, J.T. and Lloyd, M. (2013). Body mass index of adults with intellectual disability participating in Special Olympics by world region. *Journal of Intellectual Disability Research, Early View Online Version*.
- Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation*, 27(2), 237-246.
- White, G. W., Gonda, C., Peterson, J. J., & Drum, C. E. (2011). Secondary analysis of a scoping review of health promotion interventions for persons with disabilities: Do health promotion interventions for people with mobility impairments address secondary condition reduction and increased community participation? *Disability and Health Journal*, 4(2), 129-139. doi: <http://dx.doi.org/10.1016/j.dhjo.2010.05.002>
- Ziviani, J., Lennox, N., Allison, H., Lyons, M., & Del Mar, C. (2004). Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, 29(3), 211-225.

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