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 Olympic HAS Health Promotion screen

August 2013

A report prepared by:
Paul Milner, Brigit Mirfin-Veitch & Jenny Conder
Donald Beasley Institute.
www.donaldbeasley.org.nz

Donald Beasley Institute

Disability research and education

A report prepared by:
Paul Milner, Brigit Mirfin-Veitch & Jenny Conder.
Donald Beasley Institute

Specialist Statistical Advice:
Dr. Andrew Gray & Dr Ella Iosua
Department of Preventative and Social Medicine
University of Otago

August, 2013.

Donald Beasley Institute

Disability research and education

The *"On the Margins of Good Health"* project was made possible by;

The ongoing support of Special Olympics New Zealand and their commitment to conducting and disseminating research findings generated the Special Olympics Healthy Athletes® Programme.

A Lottery Health Research Grant

The research team would also like to thank Special Olympics New Zealand for the use of images from the Special Olympics Healthy Athletes® Programme

Table of Contents

List of Tables

List of Figures

Executive summary

Current systems of health care rely on health literacy in so far as they are dependent upon the ability of an individual to recognise and respond appropriately to their own or others health care needs. Research evidence suggests that, not only are people with a learning disability at greater risk of experiencing negative health outcomes, they are doubly disadvantaged by a lack of acknowledgement of their specific health needs by community based health providers and by population based health promotion strategies. People who by definition have difficulty learning therefore tend also to be least well informed about their own health and the behaviours that may support or undermine wellbeing.

In the absence of other epidemiological studies, the regular cycle of Special Olympic Healthy Athlete (HAS) screen testing has, until recently, provided the only data from which to estimate the prevalence of a range of health conditions experienced by people with a learning disability in New Zealand. In August 2011, Special Olympics New Zealand (SONZ) added the HAS Health Promotion screen to the suite of four other standardized health assessment screens offered to Special Olympic athletes at designated Special Olympic events since 2005.

The Special Olympic Health Promotion screen is a standardized health assessment and educative tool. The broad aims of the screen are to educate to improve the health literacy and health behaviours of Special Olympic athletes and to increase the investment of health promotion leaders in addressing the health needs of people with a learning disability. To accomplish this, self-reported health information relating to the tobacco use, eating and drinking habits, knowledge of sun safety and amount of physical activity engaged in by screen participants is collected alongside standardized protocols for the measurement and recording of participant's height (m), weight (kg), waist circumference (cm), blood pressure (mmHg) and calcaneus bone mineral density (T-score).

The overarching aim of the "On the Margins of Good Health" project was to analyse data collected by Special Olympics New Zealand following administration of the Health Promotion screen, to learn more about variation in the health knowledge and health status of people with a learning disability. The study sought to promote a better understanding of the linkages between health literacy and behaviour and the poorer health outcomes experienced by people with a learning disability by advancing five key objectives:

1. Estimate the prevalence of poor health outcomes related to the body mass, blood pressure, bone density and incidence of diabetes experienced by adults with a learning disability living in two Special Olympic regions.
2. Describe the self-reported health behaviours and health literacy of people with a learning disability in the domains of tobacco use, nutrition and hydration, sun safety and physical activity.

3. Explore what medication adults with a learning disability regularly used.
4. Describe the contribution different aspects of the lived circumstance of people with a learning disability make to their health behaviour, health literacy and health status.
5. Assess whether Healthy Athlete® screen data represents a valid estimate of the prevalence of health conditions amongst the general population of adults with a learning disability.

One hundred and thirteen male and 92 female participants aged between 9 – 65 years who lived in a range of different living situations contributed health information at two screen events held at Dunedin (n=125) or Palmerston North (n=81).

Six out of every ten participants at both screen locations self-reported being a SONZ athlete with the age-sex profile of athletes more closely approximating the age-sex profile of recent estimates of the population of New Zealand adults with a learning disability.

Volunteer students from the School of Nursing administered the Health Promotion screen and provided targeted health information at the Dunedin site and nurses employed by the Mid-Central DHB and community practices, Special Olympic staff and family members fulfilled the same role in Palmerston North. Administrator training and clinical oversight was provided by Special Olympics New Zealand at both locations.

The "On the Margins of Good Health" project adds to an emerging picture describing people with a learning disability as being at greater risk of experiencing a range of health conditions than other New Zealanders.

- Adults who completed the Health Promotion screen were more likely to have a BMI in the obese range than other New Zealanders.
- 27% of male and 40% of female participants had a Body Mass Index (BMI) in the obese range and 62% of male and 73% of female participants had a BMI in the overweight or obese range.
- Participants living in the most independent support contexts were significantly more likely to have a BMI in the obese range.
- 20% of participants had a systolic blood pressure indicative of hypertension and/or took medication prescribed for high blood pressure/cholesterol/heart condition.
- The proportion of participants who took medication prescribed for high blood pressure/cholesterol/heart condition was higher than other New Zealanders across all age categories even though the prevalence of undetected hypertension was estimated to be around 50%.
- The proportion of participants whose calcaneus bone density indicated osteoporosis was slightly higher than self-reported by New Zealanders and 40% of male participants had a T-score within the range used to classify osteopenia.

The "On the Margins of Good Health" project also provided a seminal opportunity to explore the health literacy and self-reported health behaviour of people with a learning disability in four health behaviour domains that have featured prominently in generic public health campaigns.

- Although the prevalence of self-reported smoking was much lower for participants who completed the Health Promotion screen (6.8%) than self-reported by other New Zealanders (18.4%), participants who lived in a flat they rented with others (18.2%) were as likely to self-report being a current smoker as the New Zealand general population.
- Approximately half of the people who completed the Health Promotion screen reported that someone smoked in front of them (44.2%). Support staff were the second most frequently named source of exposure to smoking for people who did self-report smoking and the most commonly reported source of exposure to smoking for participants who did not smoke and being exposed to smoking significantly increased the likelihood participants would also report smoking.
- Participants who lived in a flat they rented by themselves were significant less likely to self-report eating fruit daily (60.0%) than participants who lived in a (staffed) community group home (95.5%). They were also most likely to have a BMI in the obese range (66.7%), leading to speculation that higher levels of poverty, lack of oversight of participants day-to-day diet and support that failed to prioritise nutritional literacy and good eating influenced eating habits in ways that explained the association between living in more independently and obesity.
- Approximately eight out of every ten participants said they knew using sunscreen (81.5%) and wearing a hat (77.9%) were ways to reduce their exposure to UVR. Fewer participants volunteered looking for shade (51.3%) or wearing sunglasses (60.5%) as sun-smart actions, highlighting these as possible ways to improve the sun-safety of people with a learning disability through targeted health promotion.
- Eight out of every ten participants self-reported exercising for more than 30 minutes per day on three or more days a week (80.0%).
- Conversely, whereas 15% of adult New Zealanders self-report doing less than 30 minutes of physical activity in a week only 3% of Health Promotion screen participants self-reported exercising for more than 30 minutes on no days and 17% self-reported exercising for more than 30 minutes for between 1-2 days per week. It was not possible to determine, however, what contribution "pro-social" response bias made to the findings.

Collecting information about participants' medication use provided an opportunity to explore whether New Zealanders with a learning disability remain exposed to the health risks associated with over medication, the use of out-dated medication or the use of psychoactive medication in the absence of a diagnosed mental health condition.

- Consistent with a recent Ministry of Health finding that people with a learning disability were likely to be dispensed almost twice as many different types of prescription drugs as other New Zealanders, seven out of every ten participants for whom information was available reported regularly taking prescription medication (69.6%).
- More than half of participants screened were described as not knowing what medication they took (52.3%). This gap in participants' health literacy limited their ability to access Health and Disability Service Consumer's Code Rights to be fully informed, make informed choices and give informed consent. It also reduced their ability to maintain good health by engaging in conversations about the health risks or possible side effects associated with their current medication use.
- One out of every three participants for whom medication data was available were recorded as taking one or more psychoactive medication types (35.6%), and 26.9% of participants who took psychoactive medication had been prescribed two or more psychoactive medications.
- A failure to report an underlying mental health condition for participants who regularly took antidepressant and antipsychotic medication was observed, indicative of either a continuation of historical prescribing practices including the use of psychoactive medication to manage behaviour, the stigmatising of mental illness, diagnostic overshadowing or a lack of awareness by people with a learning disability or their support staff of participants mental health status.
- Despite well replicated findings demonstrating an association between increasing age and the prevalence of a range of mental health conditions, almost one in three participants aged less than 20 years regularly took psychoactive medication (30.4%) and the prevalence of antidepressant (15.2%) and antipsychotic (15.2%) use was higher for participants aged less than twenty years than for all other age cohorts.

A primary aim of the project was to explore the strength of association between potential demographic and environmental predictors of a range of direct measures of health status as well as the self-reported health literacy and health behaviour of participants.

- Contrary to published research, male participants (19%) were significantly more likely to be recorded as regularly taking antidepressant medication than female participants (3%), although it was unclear whether the prevalence of depression was lower in female participants, males were more likely to be prescribed antidepressant as part of response to other behavioural presentations or female participants were less likely to have an underlying mood disorder recognised and treated.
- 40% of male compared to 17% of female participants were recorded as having a Bone Mineral Density (BMD) within the range used to categorize osteopenia, although no association was found between participant sex and the likelihood they would have a BMD less than the normal range.

- Unlike the general population, male participants (9.7%) were approximately three times more likely to self-report smoking than female participants (3.4%).
- Older participants were significantly more likely to be recorded as regularly taking medication and have high blood systolic blood pressure and/or take medication prescribed for high blood pressure/cholesterol/heart condition.
- 37.5% of participants aged 50 – 59 years and 50.0% of participants aged 60 – 69 years had high blood systolic blood pressure and/or took medication prescribed for high blood pressure/cholesterol/heart condition.
- Two out of every three participants who had a systolic blood pressure above 139mmHg and four out of every five participants who had a diastolic blood pressure above 89mmHg did not take medication for high blood pressure/cholesterol/heart, emphasising the need for regular testing.
- The living situation of participants was the strongest statistically significant predictor of the likelihood participants would regularly take medication and the second strongest statistically significant predictor of the likelihood that participants had been prescribed psychoactive medication.
- Nine out of every ten participants who lived in a (staffed) community group regularly took medication (89.7%) compared to less than half of the participants who lived with a family member (43.9%).
- The odds that a participant who lived in a community group home regularly took psychoactive medication (57.1%) were five times the odds a participants who lived with a family member (18.9%) would do the same, despite an observed trend towards higher rates of prescribing for younger participants.
- Participants who lived in New Zealand community group homes were being prescribed psychoactive medication at the extreme end of prescribing rates described in international research.
- 66.7% of participants who lived in a flat by themselves had a BMI in the obese range, much higher than estimates of the prevalence of obesity for people with a learning disability reported in international studies and higher too than the 26% of participants who lived in a (staffed) community group home or the 21% of participants who lived at home with their parents.
- Differences in material deprivation and participant's access to support that prioritised nutritional literacy and healthy eating habits was advanced as possible explanations for the association between living situation and the prevalence of obesity.

The final objective of the project was to explore how representative SONZ athletes were of the general population of people with a learning disability by comparing the health status and health literacy and self-reported health behaviours of athlete and non-athlete participants.

- An expectation that SONZ athletes would experience more positive health outcomes than non-athlete participants tended to be reflected in the study findings. Special

Olympic athletes were less likely than non-athlete participants to; take medication regularly, have a BMI in the overweight or obese range or the obese range, have a diastolic blood pressure above 89mmHg or take medication for high blood pressure/cholesterol/heart condition, or to self-report Type 2 diabetes. They were also more likely to self-report exercising for more than 30 minutes for more than five days a week.

- Special Olympic athletes (26.8%) were significantly less likely to be taking psychoactive medication regularly than non-athlete participants (53.1%).

Whilst the "On the Margins of Good Health," project advances our ability to identify people with a learning disability who are at greatest risk of experiencing poorer health outcomes, reaching a more sophisticated understanding of the beliefs and customs that underscore health related action or inaction by people with a learning disability, their sources of support and the health professionals they meet along the way will be critical to the design of health promotions strategies that aim to bring people with a learning disability back from the margins of good health.

1 Introduction

1.1 People on the margins of good health

Many children and adults with a learning disability live with undetected yet eminently treatable health conditions. International research has consistently described people with a learning disability as experiencing poorer health outcomes than the general population[1],[2] with obesity and diabetes, mental health problems, dental disease, hearing and visual impairment, thyroid and gastro-oesophageal diseases and skin disorders all identified as key health issues for people with a learning disability[3],[4],[5],[6]. Since the closure of New Zealand institutions, responsibility for the provision of primary health care for children and adults with intellectual disability has shifted to an array of community based services. Disability writers have argued that, in the wake of institutions, systems of community-based primary and secondary health service delivery have changed little from those designed for the general population[7] with the health status of children and adults with a learning disability further compromised by health practitioners and educators who have been denied exposure to the communication styles and specific health care needs of disabled men and women that would otherwise have taken their place in New Zealand communities.

Following their two and a half year investigation of government-funded adult disability services, the National Health Committee (NHC) characterized health care provision for adults with a learning disability in New Zealand in 2003 as "disturbing."[8] In their report, To Have an 'Ordinary' Life - Kia Whai Oranga 'Noa,' the NHC asserted that a lack of health promotion material to improve the health literacy and health behaviours of people with a learning disability contributed to many experiencing prolonged suffering from health conditions that were treatable, relievable and curable. The NHC also identified a failure of support staff and primary health providers to recognise and respond appropriately to the ongoing and complex heath needs experienced by people with a learning disability and an associated acceptance of poor health and medication use as concomitant with learning disability as underscoring significant health inequality.

The NHC were similarly troubled by what they described as "disturbing prescribing practices"(p9), including evidence of over-medication, the use of out-dated medication and widespread use of psychoactive medication in the absence of a diagnosed mental health condition.

In the final report, the NHC made a number of recommendations to address the systemic neglect of the health of adults with a learning disability. Their recommendations focused on improving the health literacy of people with a learning disability and those on whom they

depended for timely and appropriate health care. The NHC recommended developing: comprehensive health assessment tools for people with a learning disability, education programmes for support staff and primary health providers, and accessible health promotion material.

Background papers prepared by the Donald Beasley Institute also identified the paucity of New-Zealand specific indicators of the health status of people with a learning disability as an issue affecting their quality of life[9]. Six years later, the US Centre for Disease Control and Prevention would describe people with a learning disability as "largely undetected in population health surveillance[10]. Not only has the absence of epidemiological inquiry denied people with a learning disability the opportunity to quantify levels of health inequality, it has also made it difficult to develop health promotion strategies to address the underlying causes of poor health exposed by the NHC report.

A decade on from To Have An 'Ordinary' Life, the health status of people with a learning disability remains only sketchily known. Only two studies have purposefully set out to describe a broad range of health outcomes for people with a learning disability in New Zealand in the ten years that have elapsed since the NHC report.

In 2011, the New Zealand Ministry of Health sought to compare the health status and service use of people with and without a learning disability, using a range of Ministry of Health databases to first define[i] and then compare the pattern of health care service use by both cohorts.[11] Within the research, 31 847 people were identified as having a learning disability (0.7% of the study population) and when compared the general population, the Ministry of Health concluded that people with a learning disability were more disadvantaged in terms of their health and life expectancy than other New Zealanders across all of the health status indicators they developed.

Key findings reported by the Ministry of Health included;

- Males with a learning disability had an average life expectancy 18 years below the average life expectancy of New Zealand males and females with a learning disability had an average life expectancy 23 years below the average life expectancy of female New Zealanders.
- Compared to people without a learning disability, people with a learning disability were about 1.5 times more likely to receive care or treatment for chronic respiratory disease, almost twice as likely to receive care or treatment for coronary heart disease and diabetes, over four times more likely to receive morbid obesity treatment in a

[i] The databases used to generate the sample population of people with a learning disability were: National Minimum Dataset (NMDS), Mental Health Information National Collection (MHINC), Client Claims Processing System (CCPS), and SOCRATES (NASC information system).

public hospital, over 30 times more likely to receive care or treatment for epilepsy and over three times more likely to receive care or treatment for a mental disorder.
- People with a learning disability were likely to be dispensed almost twice as many different types of prescription drugs from community pharmacies.
- People with a learning disability were four times more likely to have public hospital admissions that could have been avoided than people without a learning disability.

Aspects of the Ministry of Health's research design meant, however, that the study had a number of acknowledged limitations. With the exception of the life expectancy data, the health indicators reported by the Ministry of Health related to service use and not to direct measures of people's health status. Despite knowing that people with a learning disability tend to have a decreased ability, willingness and/or recognition of the need to seek help for health conditions, estimates of the prevalence of health status indicators could not include estimates of unmet or undiagnosed health need. An additional consequence of using Ministry of Health databases to identify people with a learning disability was that people who did not use a disability support or health services during the study period were not included in the study population. The health status of people with a mild learning disability and/or living more independently in their community were, therefore, less likely to have been included in the study findings.

Recent research commissioned by Special Olympics New Zealand has included direct measures of the health status of New Zealand Special Olympic athletes.

1.2 The Special Olympics Healthy Athletes® Screening Programme

As part of their response to the poorer health outcomes experienced by people with a learning disability, Special Olympics International developed the Healthy Athletes® programme (HAP). The HAP includes seven standardized health assessment screens (HAS) that have been offered to Special Olympic athletes at designated Special Olympic events since 1997.

Special Olympics New Zealand has been working to improve the health status of Special Olympic athletes for over eight years using the HAP and has, at various times during that period, provided athletes and recently non-athletes an opportunity to participate in five individual health screens.

In February 2011, Special Olympics New Zealand commissioned the Donald Beasley Institute to conduct an analysis of Healthy Athletes® Screening (HAS) data collected from athletes who chose to complete one or more of the Opening Eyes, Healthy Hearing, Special Smiles or Fit Feet screens made available at the 2005 and 2009 National Summer Games. Pre-coded data from 2,996 individual screens administered at the 2005 Summer Games and 3,118 individual Healthy Athletes® screens administered at the 2009 Summer Games were combined and

analysed to provide a snapshot of the visual, auditory, oral and podiatry health status of New Zealand Special Olympic athletes. The research represented the first comprehensive analysis of HAS data in the New Zealand context but was also intended to provide baseline empirical evidence of the health status and health needs of men and women drawn from within the wider population of people with a learning disability in New Zealand[12].

Key findings from the research included;

- Recommendations for corrective lenses were made for one out of every three athletes who competed at the 2005 Summer Games and half of the athletes who competed at the 2009 Summer Games.
- Seven out of every ten athletes aged 60 years or older self-reported not having an eye examination in the previous three years of whom 80% required new corrective lenses.
- An external eye health problem was detected in approximately half of the athletes who competed at the 2009 Summer Games and internal eye health problem detected in one out of every five athletes screened at the same event.
- Cataracts were discovered in 13% of athletes and blepharitis detected in 15% of athletes screened at the 2009 Summer Games.
- Three out of every four athletes screened at the 2009 Summer Games failed the otoacoustic emissions screen and 45% were found to have a full or partial blockage in one or both ears.
- Untreated tooth decay was found in one out of every four athletes screened at the 2009 Summer Games.
- One or more biomechanical abnormalities were detected in eight out of every ten athletes screened at the 2009 Summer Games.
- Approximately one in every five athletes screened at the 2005 and 2009 Summer Games presented with a fungal nail infection.

In August 2011, Special Olympics New Zealand added the Special Olympics Health Promotion screen to the repertoire of HAS screens available to New Zealand Special Olympic athletes.

1.3 The Special Olympic Health Promotion Screen

The Special Olympic Health Promotion screen is a standardized health assessment and educative tool developed by Special Olympics International as part of the Healthy Athletes® programme. The broad aims of the screen are to educate to improve the health literacy and health behaviours of Special Olympic athletes and to increase the investment of health promotion leaders in addressing the health needs of people with intellectual disability[13]. To accomplish this, self-reported health information relating to the tobacco use, eating and drinking habits, knowledge of sun safety and amount of physical activity engaged in by

participants is collected within educational displays and interactive activities designed by local health professionals to promote good health behaviour alongside standardized protocols for the measurement and recording of participant's height (m), weight (kg), waist circumference (cm), blood pressure (mmHg) and calcaneus bone mineral density (T-score).[ii]

1.4 Aims of the project

Current systems of health care rely on health literacy in so far as they are dependent upon the ability of an individual to recognise and respond appropriately to their own or others health care needs. Research evidence suggests that, not only are people with a learning disability at greater risk of experiencing negative health outcomes, they are doubly disadvantaged by a lack of acknowledgement of their specific health needs by community based health providers and by population based health promotion strategies. People who by definition have difficulty learning therefore tend also to be least well informed about their own health and the behaviours that may support or undermine wellbeing.

The overarching aim of the "On the Margins of Good Health" project was to describe and learn more about variation in the health knowledge of people with a learning disability as a preliminary step towards a developing a better understanding of the linkages between health literacy and behaviour and the poorer health outcomes experienced by people with a learning disability.

In 2001, a New Zealand study that sought to improve the health knowledge of women with a learning disability using a participatory action research design described women as experiencing both unmet health need and difficulty accessing appropriate health information[14]. No systematic survey of the health knowledge or health behaviours New Zealanders with a learning disability has subsequently been conducted. Beginning the process of building a picture of the health literacy of New Zealand children and adults with a learning disability was a primary aim of the project. A hope that analysis of the Special Olympic Health Promotion screen data may also provide a benchmark against which to determine the efficacy of future health promotion strategies also informed the project design (Objectives 1,2).

Evidence of both regional and generational differences, coupled with the high incidence of health conditions sensitive to the hygiene practices of athletes previously reported by the Donald Beasley Institute suggested it may be possible to identify common environmental determinants of poor health amongst the a Special Olympic athlete population[12]. In addition to adding a number of important direct measures of the health status of people with a learning disability, analysis of the Special Olympic Health Promotion screen data also included an exploration of the strength of association between demographic and environmental predictors

[ii] Appendix 1

of participant body mass, blood pressure and bone density and the health literacy of people with a learning disability (Objectives 1 & 4).

In the absence of other epidemiological studies, the regular cycle of Healthy Athlete screen testing has, until recently, provided the only data from which to estimate the prevalence of a range of health conditions experienced by people with a learning disability in New Zealand. Given that physical activity is known to influence a range of health conditions and that athletes competing at a national event may represent an atypical cohort in terms of other aspects of their lived experience, understanding how representative Special Olympic athletes are of the health status of their peers is an important pre-requisite to establishing whether HAS data is a reliable estimate of the prevalence of health conditions within the general population of people with a learning disability. By purposefully recruiting non-athletes with a learning disability, an additional aim of the project was to reflect on the external validity of HAS data as an estimate of the prevalence of health conditions (Objective 5).

In spite of the NHC describing medication prescribing practices as "disturbing," a lack of subsequent empirical inquiry has meant that little is known about current medication prescribing practices or whether people with a learning disability continue to be exposed to the health risks associated with overmedication, the widespread use of out-dated or psychoactive medication prescribed in the absence of a diagnosed psychiatric condition. Exploring medication use with a particular focus on the psychoactive medication screen participants described taking regularly was a further aim of the project (Objective 3).

Table 1 Objectives of the "On the Margins of Good Health" project

Key Objectives of the "On the Margins of Good Health" project	
Objective One	Estimate the prevalence of poor health outcomes related to the body mass, blood pressure, bone density and incidence of diabetes experienced by adults with a learning disability living in two Special Olympic regions.
Objective Two	Describe the self-reported health behaviours and health literacy of people with a learning disability in the domains of tobacco use, nutrition and hydration, sun safety and physical activity
Objective Three	Explore what medication adults with a learning disability regularly used.
Objective Four	Describe the contribution different aspects of the lived circumstance of people with a learning disability make to their health behaviour, health literacy and health status.
Objective Five	Assess whether Healthy Athlete® screen data represents a valid estimate of the prevalence of health conditions amongst the general population of adults with a learning disability.

2 Methods

2.1 Recruitment

Special Olympics New Zealand recruited study participants by launching the Health Promotion screen at two New Zealand sites: Dunedin during the weekend of 29-31 August 2011 and Palmerston North on 4 August 2012.

Special Olympic athletes and other people with a learning disability within these two Special Olympic regional catchments were sent an information sheet about the Health Promotion Screen, and an invitation to participate by the Lower South Island and Taranaki/Wanganui/Manawatu/Horowhenua Regional Sports Coordinators using their existing communication networks.

Informed consent was provided, either by individual participants, family or friends or Court appointed Welfare Guardians.

2.2 Health Promotion screen administration

At the Dunedin site, volunteer students from the School of Nursing administered the HAS Health Promotion screen and provided targeted health information. Special Olympics New Zealand Lead Clinical Director, Geraldine Whatnall and Special Olympics New Zealand Community Network Manager, Mike Freeman orientated volunteers and also provided clinical oversight during the event.

At the Palmerston North site, nurses employed by the Mid-Central DHB and community practices, Special Olympic staff and family members administered the HAS Health Promotion screen and provided targeted health information. Special Olympics New Zealand Lead Clinical Director, Geraldine Whatnall and Special Olympics New Zealand Community Network Manager, Mike Freeman also orientated volunteers and provided clinical oversight at the Palmerston North screen event.

A one-day training session was provided to all volunteer screen administrators.

2.3 Health Promotion screen participants

2.3.1 Demographic profile

One hundred and thirteen males and 92 females aged between 9 – 63 years contributed health information at in either the Dunedin or Palmerston North Special Olympic Health Promotion screens. One hundred and twenty-five people with a learning disability attended the Dunedin screen and 81 attended the Palmerston North screen. The mean age of participants who attended the Dunedin screen was slightly younger (m=32.0, sd=14.62) than participants who attended the Palmerston North screen (m=37.4, sd=13.45).

Table 2 The sex, age and number of Special Olympic athletes and non-athletes who attended the Dunedin and Palmerston North Health Promotion screens

	Sex		Age		SO Athlete	
	Male	Female	Mean	SD	n	(%)
Dunedin	65	59	32.0	14.62	75	60.5
Palmerston North	48	33	37.4	13.45	50	61.7
Overall	113	92	34.1	14.39	125	61.0

Four out of every ten participants self-reported living in a (staffed) community group home (CGH) with other people (n=84, 41.0%), 28% self-reported living at home with their parents (n=58, 28.3%) and 16% self-reported living in a flat they rented with others (n=33, 16.1%).

Table 3 The self-reported living situation of Health Promotion screen participants by screen location

	Dunedin		Palmerston North		Overall	
	n	%	n	%	n	%
At home with my parents	42	33.9	16	19.8	58	28.3
I board with a non-family member	3	2.4	0	0	3	1.5
In a (staffed) CGH with other people	34	27.4	50	61.7	84	41.0
In a flat I rent with others	26	21.0	7	8.6	33	16.1
In a flat I rent by myself	9	7.3	4	4.9	13	6.3
In a house I own	4	3.2	3	3.7	7	3.4
In a hospital	0	0	0	0	0	0
In a retirement or old person's home	0	0	0	0	0	0
In cluster housing	0	0	0	0	0	0
Other	6	4.8	1	1.2	7	3.4

Participants who attended the Palmerston North screen were significantly more likely to self-report living in a staffed community group home (n=50 61.7%) and significantly less likely to self-report living at home with their parents (n=16, 19.8%) than participants who attended the Dunedin Health Promotion screen (n=34, 27.4% and n=42, 33.9% respectively).

More than nine out of every ten participants who attended the Special Olympic Health Promotion screen at Dunedin (n=117, 94.4%) and at Palmerston North (n=74, 91.4%) self-reported their ethnicity to be New Zealand European. Overall, eight participants self-reported their ethnicity to be Māori (n= 8, 3.9%), one participant described themselves as Chinese (1.2%), one participant described themselves as Indian (1.2%) and three participants described themselves as of "Other," ethnicity. Population based health studies have consistently identified Māori as a health disadvantaged population and to explore whether Māori with a learning disability also experience poorer health outcomes than their peers, participants were grouped into Māori and New Zealand European/Other (n= 197, 96.1%) ethnicities for the purposes of analysis.

In the Special Olympics Health Promotion Screen participants were asked whether they knew what type of disability they had. Screen administrators were instructed to tick all impairments a participant or their support person volunteered. Six categories of impairment were available as choice points on the day (Autistic Spectrum Disorder [including Asperger's syndrome], Down syndrome, Other syndrome or condition [i.e. William's syndrome, Fragile X, Rett syndrome], Epilepsy, Head injury or environmental impairment, Unknown aetiology). Approximately two out of every three administers wrote participant responses on the screen form, with many descriptors falling outside of the original taxonomy. At the analysis stage, administrator descriptors were post-coded with a wider range of impairment types used for subsequent analysis[iii].

Within the new taxonomy, Down syndrome (n=40, 19.5%), Autistic Spectrum Disorders (n=23, 11.2%) and Epilepsy (n=20, 9.8%) were the most commonly self-reported disability types. The prevalence of most self-reported disability types varied little between the two Health Promotion screen sites[iv].

[iii] Congenital or acquired learning disability was assumed for all participants (see Appendix 2)

[iv] It is important to note that self-reported prevalence of disability types is likely to be affected by the inclusion or exclusion of different disability types in the original screen taxonomy and, therefore are not a reliable estimate of true prevalence.

Table 4 The self-reported disability type of Health Promotion screen participants by screen location

Disability type	Dunedin		Palmerston North		Overall	
	n	%	n	%	n	%
ASD (including Asperger's syndrome)	14	11.3	9	11.1	23	11.2
Down syndrome	22	17.7	18	22.2	40	19.5
Genetic disorder (Other syndrome)	5	4.0	3	3.7	8	3.9
Medical condition	1	0.8	4	4.9	5	2.4
Sensory impairment	1	0.8	2	2.5	3	1.5
Cerebral palsy	5	4.0	7	8.6	12	5.9
Mental health condition	1	0.8	6	7.4	7	3.4
Epilepsy	10	8.1	10	12.3	20	9.8
Head injury	2	1.6	0	0	2	1.0
Environmental injury	1	0.8	2	2.5	3	1.5
Other	2	1.6	2	2.5	4	2.0

2.3.2 The demographic profile of Special Olympic athletes and non-athletes

Six out of every ten people who participated in the Special Olympic Health Promotion screen at the Dunedin (n=75, 60.5%) and Palmerston North events (n=50, 61.7%) self-reported being a Special Olympic athlete.

Two out of every three participants who self-reported being a Special Olympic athlete (n=82, 65.6%) were male. Conversely a positive skew towards female participants was observed for non-athlete participants and six out of every ten non-athlete participants were female (n=49, 61.3%) with a statistically significant association found between participant sex and the likelihood they would self-reported being a Special Olympic athlete.

Special Olympic athletes were, on average, younger than non-athletes and a statistically significant difference also emerged between the mean age of athlete (m=31.3 years, 95% CI= 28.7 – 33.8) and non-athlete participants (m=39.0 years, 95% CI= 35.7 – 42.3).

Forty-five percent of Special Olympic athlete participants were aged less than 25 years (n=52, 45.2%) whereas only 12% of non-athlete participants were aged less than 25 years (n=8, 12.1%). Conversely, whereas 22.6% of Special Olympic athlete participants were aged 45 years and older (n=26), 39.4% of non-athlete participants were aged 45 years or older.

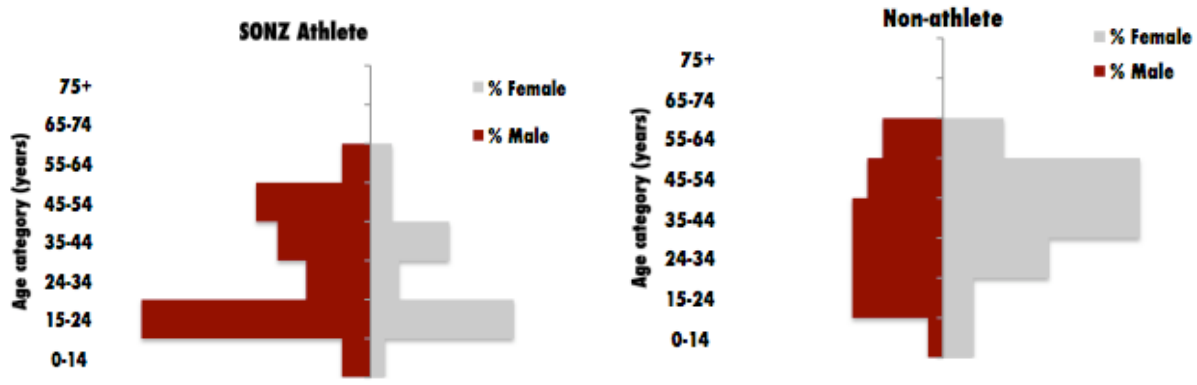

Figure 1 The age sex profile of Special Olympic athlete and non-athlete participants

2.3.3 How representative was the sample population of adults with learning disability?

To explore how representative the Special Olympic athlete and non-athlete adult sample populations were of the general population of people with a learning disability in New Zealand, comparisons were made with population estimates drawn from the Statistics New Zealand's Disability Counts Survey (2006)[15] and the Ministry of Health's recent capture-recapture prevalence estimates (1 July 2007- 30 June 2008)[11].

Despite estimates of the true prevalence of learning disability in the New Zealand population varying between the 2006 Disability Counts Survey (50 600, prevalence =1.3%) and Ministry of Health capture-recapture estimate (46 664, prevalence =1.1%), their estimates of the proportion of male and female New Zealanders living with a learning disability are very similar. Both estimates report people with a learning disability are more likely to be male. Statistics New Zealand estimated that for every male New Zealander with a leaning disability there are 0.067 female New Zealanders with a learning disability (Sex ratio 1:0.672) and the Ministry of Health estimated that for every male New Zealander there are 0.68 female New Zealanders living with a learning disability (Sex ratio 1:0.681).

Of the two study populations, adults who self-reported being a Special Olympic athlete represented a closer approximation of reported estimates of the age-sex profile of New Zealanders with a learning disability. For every male Special Olympic athlete participant there were 0.55 female Special Olympic athlete participants (Sex ratio 1:0.55). Atypical gender skewing towards female participants in the non-athlete study population meant that for every male non-athlete participant there were 1.46 female non-athlete participants (Sex ratio 1:1.46).

Table 5 The number of male and female Special Olympic athletes and non-athlete participants

	Male (n)	Female (n)	Sex ratio
SONZ Athletes	78	43	1:0.550
Non-athlete	28	41	1:1.146
Statistics NZ Disability Counts 2006	30 200	20 300	1:0.672
MoH C-R prevalence estimate (2007-2008)	27 757	18 904	1:0.681

A closer examination of the age profile of the Special Olympic athlete and non-athlete adult study populations also revealed the age distribution of people who self-reported being a Special Olympic athlete represented a closer approximation of existing estimates of the prevalence of learning disability by age category.

Figure 2 describes the proportion of adult participants who self-reported being a Special Olympic athlete (maroon) or non-athlete (black) against the Ministry of Health's capture-recapture estimates of the prevalence of learning disability by adult age category (blue).

No Health Promotion screen participant was aged over 65 years, meaning that both SONZ athlete and non-athlete sample populations underestimated the 20.7% of adults with a learning disability the Ministry of Health recently estimated to be more than 65 years old.

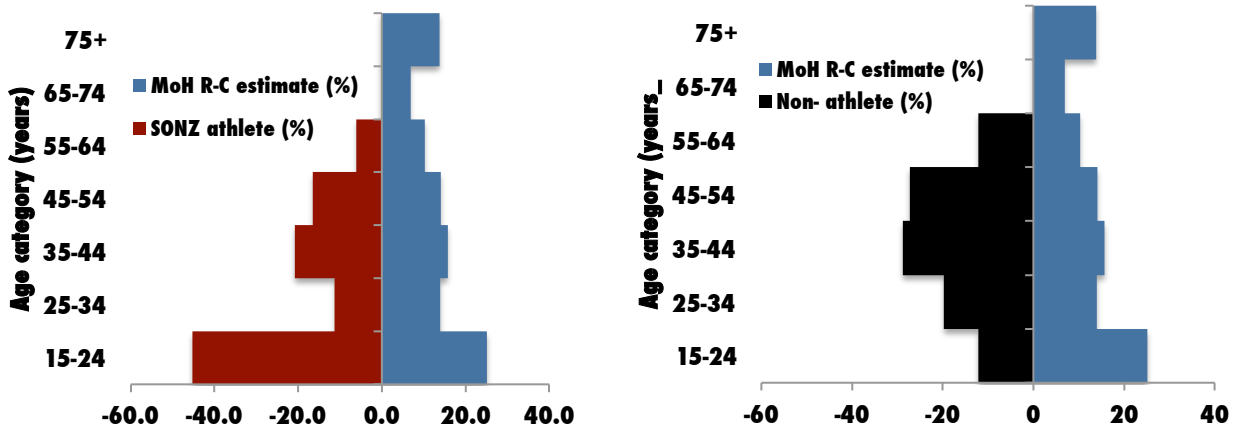

Figure 2 The proportion of Special Olympic athlete and non-athlete participants by age category

Forty-five percent of Health Promotion screen participants who reported being a SONZ athlete were aged less than 25 years (n=52) compared to the New Zealand Ministry of Health's estimate that 25.0% of the adult population of people with a learning disability were aged between 15 – 24 years in the year ending June 2007. Younger adults with a leaning disability were, therefore, over-represented in the adult SONZ athlete sample population, but the

proportion of participants aged between 25 – 64 years (n=63; 54.8%), otherwise tended to approximate estimates for the national population of people with a learning disability.

Non-athlete Health Promotion participants aged between 15 – 24 years (n=8; 12.1%) tended, on the other hand, to be under-represented and participants aged between 35 - 54 years (n=37; 56.1%) over-represented in the sample population when compared to the Ministry of Health's estimate of the proportion of adults aged over 15 years living in New Zealand aged between 35 - 54 years (29.8%) in the year ending June 2007.

Not surprisingly therefore, participants who did or did not self-report being a Special Olympic athlete also tended to report residing in different living situations.

One out of every three participants who self-reported being a Special Olympic athlete said they lived at home with their parents (n=45, 36.0%) significantly fewer than non-athlete participants (n=13, 16.3%). Non-athlete participants, on the other hand, were significantly more likely to report living in a staffed community group home (n=42, 52.5%) than participants who self reported being a Special Olympic athlete (n=42, 33.6%).

Table 6 The living situation of Special Olympic athlete and non-athlete participants

	Non-athlete		SONZ athlete	
	n	%	n	%
At home with my parents	13	16.3	45	36.0
I board with a non-family member	2	2.5	1	0.8
In a (staffed) CGH with other people	42	52.5	42	33.6
In a flat I rent with others	16	20.0	17	3.6
In a flat I rent by myself	3	3.8	10	8.0
In a house I own	3	3.8	4	3.2
In a hospital	0	0	0	0
In a retirement or old person's home	0	0	0	0
In cluster housing	0	0	0	0
Other	0	0	6	4.8

2.3.4 How representative was the sample population of other New Zealanders?

Older people tend, on average, to experience more negative heath outcomes than younger people across most health status indicators. Because the life expectancy New Zealanders with a learning disability is much lower than their age peers in the general population (males 18.7 years; females 22.9 years) the age profile of people with a learning disability is younger than the New Zealand population.

Figure 3 compares the proportion of male and female adult Health Promotion screen participants with Statistics New Zealand's (2013) estimate of the adult age profile of the New Zealand general population in the year ending 2012[16].

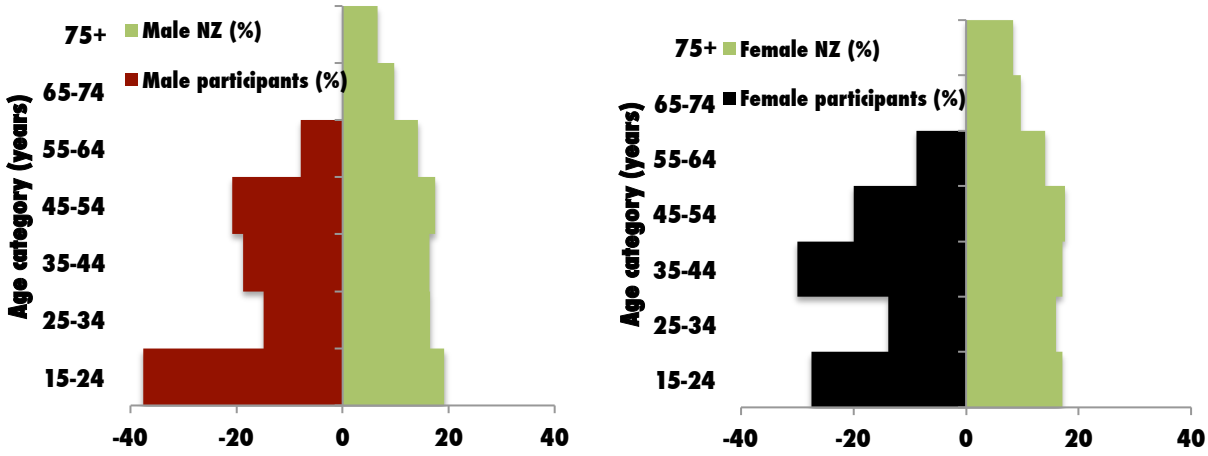

Figure 3 The proportion of adult Health Promotion participants and New Zealand male and females by age category

Male (n=38; 37.6%) and female (n=22; 27.5%) participants aged between 15 - 25 years were over-represented in the study population compared to their adult age peers in the New Zealand general population (19.2% & 17.1% respectively) and no participants aged older than 65 years completed the Health Promotion screen compared to 16.3% of male and 18.1% of the female adult New Zealanders estimated to be older than 65 years in 2012.

2.4 Data coding and analysis

Self and/or support person-reported health information relating to the eating and drinking habits, knowledge of sun safety, tobacco use and frequency of physical exercise was collected alongside the height (m), weight (kg), waist circumference (cm), blood pressure (mmHg) and calcaneus bone mineral density (T-score) of Special Olympic Health Promotion screen participants. Data was recorded on the standardized HAS Form with ethnicity, disability type, living situation and medication taken included as additional information fields. To ensure compatibility with previous analysis, coding conformed to protocols developed by the Donald Beasley Institute to analyse health screen data collected at the 2005 and 2009 New Zealand Summer Games. Data was managed using IBM®SPSS® Statistics 19 statistical software.

Descriptive statistics were the primary method used to describe the prevalence and identifiable differences in key health status outcomes or the self-reported health literacy or health behaviour of Health Promotion screen participants.

Binary logistical regression modelling was also used to explore the strength of association between potential demographic and environmental predictors of a range of direct measures of health status, including; body mass, blood pressure, calcaneus bone mineral density and self-reported diabetes as-well-as the self-reported health literacy and health behaviour of participants. Analysis focussed on participant sex, age, ethnicity, living situation, screen

location and whether participants were Special Olympic athletes or not as potential predictors of variation in selected measures of health status, health literacy or health behaviour.

The purposeful selection process proposed by Hosmer and Lemeshow was implemented to guide the selection of covariates for inclusion in all multivariate regression models (Adjusted Models)[17]. A set of preliminary models, involving univariate analysis of each potential predicator (Unadjusted Models) was conducted with all variables that satisfied the univariate test and had a p-value < 0.25 considered as candidates for inclusion the final model. Ten cases per parameter was adopted as a "rule of thumb" and for some analyses, determined the number of variables included in the Adjusted model.

2.5 Ethical Approval

An application for ethical approval was prepared and sent to the National Ethics Advisory Committee prior to commencing the study. Following the Committee's review of the application they advised the project's Principle Investigator that the study's use of secondary data, ordinarily collected by Special Olympics New Zealand, meant that ethical approval for the research was not required. As a further precaution, consent for "*information gathered as part of the screening process (to be) used in group form (anonymously) to assess and communicate the health needs of athletes and to develop programs to address those needs,*" was also sought from each participant before they began the Health Promotion screen.

2.6 Terms used in this report

In this report, "people with a learning disability" has been adopted as a referent for people who participated in the Special Olympic Health Promotion screen as-well-as people living with an acquired or congenital intellectual impairment referred to in the disability literature or published research findings. "People with a learning disability," is the term preferred by national self-advocacy organisation, People First New Zealand.

3 Currently taking medication

Despite national and international studies consistently describing a range of poorer health outcomes for people with a learning disability, recent research conducted in New Zealand found people with a learning disability were more likely to be enrolled in a primary health organisation (PHO) in the year ending June 2008 and were nearly 1.5 times more likely to consult a general practitioner than other New Zealanders that year[11]. The same study also reported that people with a learning disability were likely to be dispensed almost twice as many different types of prescription drugs than other New Zealanders. In the year ending June 2008, the Ministry of Health reported people with a learning disability were each dispensed an average of 5.8 different types of pharmaceutical from community pharmacies. No other study has sought to describe the pattern of medication use by people with a learning disability living in New Zealand, despite the high prevalence of medication use having been identified as significant health challenge for people with a learning disability within a growing body of international research[18] and disquiet expressed by the National Advisory Committee on Health and Disability (NHC) regarding prescribing practices for adults with a learning disability living in New Zealand[8]. Following their two-year consultation, the NHC cited evidence of a tendency towards unnecessarily high levels of medication, including co and poly-pharmacy and a support culture that appeared to accept poor health and high levels of medication use as concomitant with learning disability.

This year, Doan et al (2013), reported that seventy-nine percent of adults with a learning disability who participated in a trial of the Comprehensive Health Assessment Programme (CHAP) health-screening tool in Brisbane, Australia, self-reported currently taking medication[19]. The number of medications participants self-reported ranged between 1-12, with a median of three medications per person named. Whilst Doan et al's estimate of overall medication use by people with a learning disability living in Australian community settings was, therefore, lower than that reported by the New Zealand Ministry of Health, it is important to note that in Doan et als' study, medication information was provided by people who lived in private residences and/or did not receive 24-hour support. This population would have been least visible within the sampling strategy adopted by the New Zealand Ministry of Health and perhaps least likely to have been exposed to the historical prescribing practices and the culture of support that had previously concerned the New Zealand NHC.

Participants were asked; whether they took any medication (excluding PRN), whether they knew what medication they took; and the medication including dose and times a day the medication was taken. Administrators were asked to record all information a participant or their support person could provide.

One hundred and ninety-four people who completed the Special Olympic Health Promotion screen provided self or proxy reported information about the medications they routinely took.

Seven out of every ten participants self-reported currently taking medication (69.6%; 95% CI = 63.1 – 76.1) with a median of 1 (range = 0 – 9) medication per person self-reported.

Direct binary logistical regression was performed to assess what impact a range of potential predictors had on the likelihood that participants were recorded as taking medication. Participant's sex, age, living situation, athlete status and the screen location were entered as independent variables within the adjusted model and participants' living situation and age were found to make unique, statistically significant contributions to explaining variation in the likelihood participants would self-report taking medication when other potential predictors were held constant.

Table 7 Association between participant demographic characteristics and self-reported medication use

		Unadjusted		Adjusted		
		n (%)	(p-value)	(p-value)	OR	95% CI
Sex	Male	73 (67.6)				
	Female	62 (72.1)	0.499			
Age			<0.001	0.013	1.044	1.009 – 1.081
Ethnicity	NZ European & Other	129 (69.0)				
	Maori	6 (85.7)	0.363			
Athlete Status	SONZ athlete	79 (64.8)				
	Non-athlete	56 (77.8)	0.059	0.822	1.103	0.471 – 2.581
Living situation	Family / Family like	25 (43.9)	<0.001	0.001		
	Community Group Home	70 (89.7)	<0.001	<0.001	7.611	2.585 – 22.409
	Supported Living Context	37 (71.2)	0.005	0.377	1.434	0.594 – 3.960
Location	Dunedin	76 (65.5)				
	Palmerston North	59 (75.6)	0.134	0.774	0.774	0.398 – 1.986

Where people lived was the strongest predictor of the likelihood that a participant would take medication. Almost 90 percent of participants who lived in (staffed) community group home self-reported currently taking one or more medications (89.7%; 95% CI = 82.9 – 96.6). Conversely, less than half of participants who described living at home with their parents or in a family like setting (43.9%; 95% CI = 30.6 - 57.1) reported taking medication and the odds that participants who lived in a (staffed) community group home with other people would be reported as regularly taking medication were approximately eight times (OR=7.6; 95% CI= 2.6 – 22.5) than participants who lived at home with their parents when other potential predictors included in the adjusted model were controlled for.

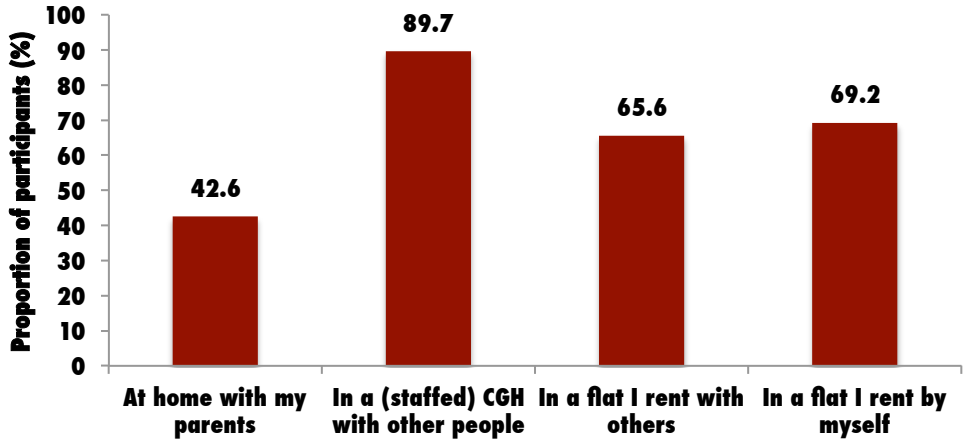

Figure 4 The proportion of participants who took medication by living situation

The older participants were, the more likely they were to be recorded as taking medication and the age of participants was found to make a unique, statistically significant contribution to explaining variation in the likelihood participants would be recorded as taking medication in the adjusted model. Less than half of participants aged between 10-19 years reported taking medication (42.4%: 95% CI = 24.6 - 60.2) whereas every participant aged over 60 years reported taking medication (100.0%). The odds of taking medication increased by 4% each year older a participant was at the time of screening (OR = 1.04; 95% CI= 1.01 - 1.08).

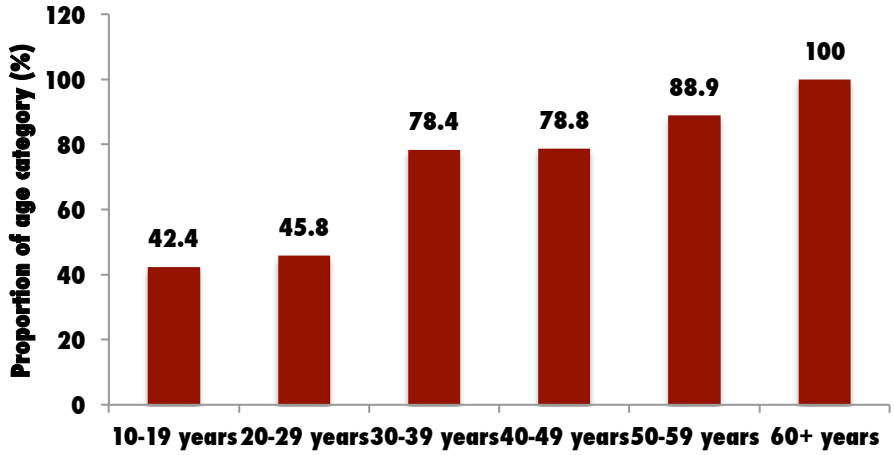

Figure 5 The proportion of participants who took medication by age category

Special Olympic athletes were less likely to report taking medication (64.8%; 95% CI =56.2 - 73.3) than non-athletes (77.8%; 95% CI = 67.9 - 87.6) but when the age, living situation and screen location of participants were held constant, whether participants were Special Olympic athletes or not did not make a statistically significant unique contribution to explaining variation in the likelihood they would reported taking medication.

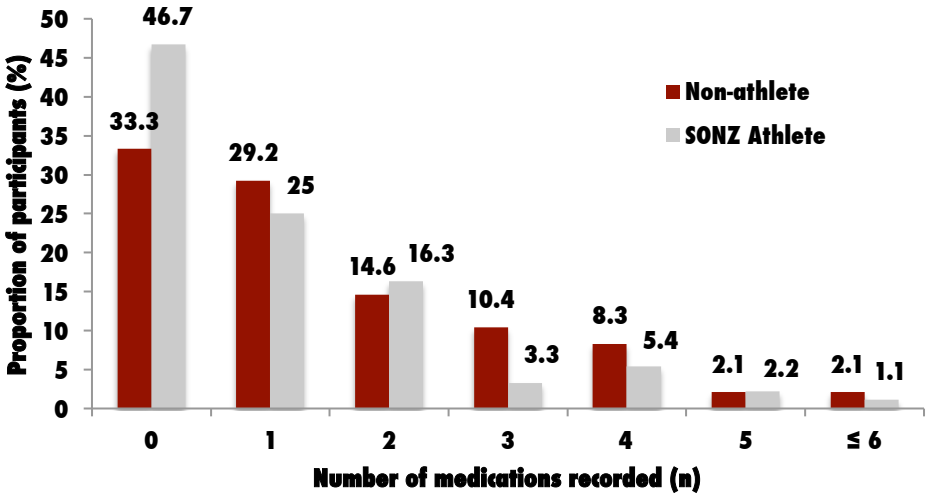

Figure 6 The number medications taken by of Special Olympic athletes and non-athletes

3.1 Did participants know what medication they took?

As consumers of health and disability services, people with a learning disability share rights to; effective communication, including the right to communication in a form that is understandable and enables open and honest dialogue, be fully informed, and to give informed consent, including the right to be presumed competent, to make choices equivalent to their level of competence and to refuse services or withdraw consent[20]. This cluster of legislated rights is affirmed, both in the standards against which health and disability service providers are audited against, including an obligation for providers to demonstrate how they actively involve consumers in their recovery, care, treatment and support[21], as-well-as in best practice guidelines for the administration of medication which codify the right of patients to refuse medication, except where undergoing assessment or when subject to compulsory treatment orders under the Mental Health Compulsory Treatment and Assessment Act 1992[22].

Maintaining the ability to access one's health related rights, is arguably most tenuous for people for whom difficulty assimilating or communicating information is a defining attribute. In spite of anecdotal evidence that many people with a learning disability are not provided with medication information in a form that allows them to be active participants in decisions that affect their health and wellbeing, the authors could find no evidence of research seeking to describe the medication health literacy of people most vulnerable to abuse of their health and disability code rights.

In a recent study, Halder et al (2012) did, however, seek to explore the prevalence of covert (disguised) medication administration by carers of adults with a learning disability in Manchester, England across a range of different support settings[23]. Sixteen percent of carers self-reported administering medications covertly, although Halder et al suspected this finding may have grossly underestimated the prevalence of the practice. None of Halder et al's participants were caring for people detained under the UK Mental Health Act. Moreover, despite the UK Mental Health Act (2005) containing similar statutory principles for medication

administration as the New Zealand Code of Health and Disability Consumers' Heath Rights, no record of mental capacity was recorded for 78 percent of care recipients and only 22 percent of responsible clinicians and 11 percent of pharmacists were made aware of the practice of administering client medication covertly.

Of the one hundred and twenty-seven participants for whom medication information was provided, approximately half were recorded as knowing what medication they took (52.3; 95% CI = 43.6 – 61.0). Because it was not possible to determine whether family or support staff had assisted participants to complete the screen and if they had reported knowing what medication participants took rather than the person they supported, or whether participants were able to name all of the medications they took, it is probable that this finding over-estimates the prevalence of participant knowledge of the medication they took.

Direct binary logistical regression was performed to assess whether it was possible to detect any association between a range of participant demographic characteristics and the likelihood that they were reported as knowing what medication they took.

Table 8 The association between participant' demographic characteristics and the likelihood they were recorded as knowing what medication they took

		Unadjusted		Adjusted		
		n (%)	(p-value)	(p-value)	OR	95% CI
Sex	Male	40 (57.1)				
	Female	28 (46.7)	0.234	0.217	0.641	0.316 – 1.299
Age			0.504			
Ethnicity	NZ European & Other	64 (51.6)				
	Maori	4 (66.1)	0.477			
Athlete status	SONZ athlete	41 (52.6)				
	Non-athlete	27 (51.9)	0.943			
Living situation	Family / Family like	13 (48.1)	0.639			
	Community Group Home	33 (50.0)	0.871			
	Supported Living Context	20 (58.8)	0.407			
Location	Dunedin	45 (60.0)				
	Palmerston North	23 (41.8)	0.042	0.039	0.472	0.232 – 0.963

Participant's sex and the screen location were entered as independent variables within the adjusted model and the location at which participants were screened was the only variable to make a unique, statistically significant contributions to explaining variation in the likelihood participants were recorded as knowing what medication they were taking.

Sixty percent of participants from Dunedin (60.0%; 95% CI = 48.7 – 71.4) were recorded as knowing what medication they took whereas only 42% of participants screened at Palmerston North (41.8%; 95% CI= 28.4 – 55.3) were similarly reported as knowing what medication they took. The odds that a participant from Palmerston North would be reported as knowing what medication they took were approximately half that for participants who attended the Dunedin screen (OR = 0.47; 95% CI= 0.23 – 0.96).

3.2 What type of medication did participants routinely use?

Eleven categories of medication type were created to explore the type of medication participants routinely used. Five classes of psychoactive medication were included in the taxonomy (antipsychotic, benzodiazapine [anti-anxiety], antidepressant, methylphenidate [CNS stimulant] and anticonvulsants) alongside categories to determine the prevalence of medication prescribed for pain relief (Analgesic), hypertension, high cholesterol or heart medication, diabetes, asthma or respiratory illness, medication to aid digestion and other types of medication.

The proportion of participants recorded as taking each medication type is described in Table 9.

Findings related to the prevalence of medication prescribed to treat: i) hypertension, high levels of cholesterol or a heart condition; ii) diabetes; and iii) asthma or a respiratory illness are presented in Chapters 5, 7 & 8 respectively. In the following section, the prevalence of psychoactive medication routinely used by participants who completed the Special Olympic Health Promotion screen is explored.

Table 9 The number and proportion of participants recorded as taking medication by medication type

	Antipsychotic	Benzodiazapines	Antidepressant	Methylphenidate	Anticonvulsant	Asthma / Respiratory	Analgesic	Hypertension / Cholesterol / Heart	Diabetes	Digestion	Other
Number of participants taking	17	7	18	3	21	8	6	17	3	14	36
Proportion of participants	11.5	4.7	12.2	1.5	14.2	3.9	4.1	11.5	2.0	9.5	24.7
No data available (n)	*57*	*57*	*57*	*57*	*57*	*57*	*57*	*57*	*57*	*57*	*57*

3.3 Psychoactive medication

Psychoactive drugs are medications that produce behavioural, emotional or cognitive change in the individual taking them[24].

High rates of psychoactive medication use by people with a learning disability was first described in institutionalised populations by Lipman (1970) who noted that in some institutions, up to 80 percent of residents regularly took psychoactive medication[25].

Analysis of medication information contained in the files of 43 residents resettled from New Zealand's last total institution, the Kimberley Centre, revealed similarly high levels of psychoactive medication use within New Zealand institutions[26]. Eighty-eight percent of Kimberley Centre residents who participated in the study were prescribed psychoactive medication. Seventy-six percent were administered two or more psychoactive medications on a daily basis and more than half took three or more psychoactive medications on a daily basis.

Evidence has also recently emerged that the move to community-based services has not been associated with any significant reduction in the prescribing of psychoactive medication to people with a learning disability, particularly for those living or resettled to residential service settings.

After following a group of former residents of the Hallsetheimen central institution for the mentally retarded in Norway, Nøttestad & Linaker (2003), reported no change in either the frequency or dosages of psychoactive medication prescribed to former residents eight years after medication information was first collected in the institution in 1987[27]. Not only had there been a slight increase in the prevalence of psychoactive medication use from 50 – 54% between 1987 – 1995, the use of antipsychotics in particular appeared to be unrelated to an underlying mental health diagnosis either in or out of the institution. Nøttestad & Linaker found that, despite lacking any theoretical or empirical support for the practice, the strongest predictor of neuroleptic medication use was whether participants had previously exhibited challenging behaviour whereas former residents were as unlikely to have psychotic symptoms treated in community services as they were in an institution. Citing previous research findings reported by Day (1985), Nøttestad & Linaker noted that challenging behaviours were the most common reason for referral to a psychiatrist in the UK. They concluded, alongside other researchers, that a continuation of the historical practice of using antipsychotic medication to manage challenging behaviour was the most likely explanation for the rate of prescribing of neuroleptic medication to greatly exceed the prevalence of psychosis in people with a learning disability now living in the community.

In their investigation of medication use by Australian adults with a learning disability living in the Brisbane community, Doan et al (2013) reported psychotropic medications (excluding anticonvulsants) were prescribed for 35 percent of the 117 participants who self-reported medication information within the CHAP health screen. Antipsychotic medications were the most commonly prescribed psychotropic agents and were taken by 21 percent of the people who contributed medication information within the study. Twenty-six percent of participants self-

reported regularly taking anticonvulsant medication[19]. Their findings are consistent with a range of studies that have reported rates of antipsychotic medication use by between 20 – 50% for people with a learning disability who live in institutional or community based service settings, despite a general consensus that the prevalence of psychotic disorders within the general population of people with a learning disability is around 4 – 6%[28].

A small number of studies have reported that people with a learning disability who live with their natural or surrogate family may be less likely to be prescribed psychoactive medication. Clarke et al (1990) and Kiernan et al (1995), for example, both estimated the prevalence of psychoactive medication prescribed to alter behaviour by people living in familial settings in Birmingham, England and antipsychotic medication use by people living in familial settings in North-West England to have been around be 10%[29, 30].

Where people lived and being understood as having challenging behaviour also emerged as significant predictors of the receipt of psychoactive and antipsychotic medication in a study conducted by Robertson et al (2000). Robertson et al sought to identify factors that predicted a range of psychoactive medications prescribed for 500 adults with a learning disability living in three different types of service setting across the United Kingdom[28]. They found people living in a National Health Service (NHS) residential campus were significantly more likely than people who lived in either village communities or dispersed community housing to receive antipsychotic[v], antidepressant or anticonvulsant medication regularly. From an array of different factors that sampled for participant and service delivery characteristics, Robertson et al found that the receipt of antipsychotic medication was predicted by (in order of importance); having no mobility problems, exhibiting socially challenging behaviour, living in an NHS residential campus, having a high BMI, not having epilepsy, not moving to the participants current service setting from their family home, and senior staff having a nursing qualification. No association was found between the likelihood of receiving antipsychotic medication and participant's mental health as measured by the PASS-ADD Checklist. Robertson et al argued that antipsychotic medication was likely to be prescribed for people with a learning disability whose behaviour was harder to manage due to their mobility and possibly their size, rather than any consideration of an underlying mental health problem. The note, however, that the association between BMI and antipsychotic medication use may also have been explained by weight gain - a known side-effect of taking antipsychotic medication that itself has significant morbidity and mortality implications. They similarly noted that the high levels of antipsychotic medication use by participants who lived in NHS residential campuses may represent the historical legacy of previous institution-based medication regimes. Whilst not drawing attention to the relationships, it seems likely that the lower prevalence of antipsychotic use reported for participants who came from their family home and/or did not have senior staff who had a nursing qualification may be reflective of differing social constructions of learning disability, including the way behaviour that may be read as challenging was interpreted and responded to.

[v] Antipsychotics were regularly used by 56% of participants living in NHS residential campuses, 17% of participants living in village communities and 27% of participants living in community-based dispersed housing.

Of all the prescribing practices that concerned the NHC, it was the prescribing of psychoactive medication that "worried," them the most. In their report, To Have an 'Ordinary' Life, Kia Whai Oranga 'Noa' the NHC reported that of a sample of 2500 pharmaceutical records they had access to, 40% of adults who were being treated with psychotrophic medicines did so in the absence of a diagnosed psychiatric condition. In spite of widespread concern about the high use of psychoactive medication by people with a learning disability, including possible inappropriate use of psychoactive medication to sedate or manage behaviour, very little research has sought to establish the prevalence of psychoactive medication use by people with a learning disability living in New Zealand community settings.

3.4 The prevalence of psychoactive medication use

In the present study approximately one out of every three participants for whom data was available was recorded as taking one or more of the five psychoactive medication types outlined above (35.6%; 95% CI = 27.8 – 43.5).

Direct binary logistical regression was performed to assess whether it was possible to detect any association between a range of participant demographic characteristics and the likelihood they were recorded as regularly taking psychoactive medication (including anticonvulsant medication). Participant' living situation and athlete status were included as possible predictors of psychoactive medication use within the adjusted model.

Table 10 Association between participant' demographic characteristics and psychoactive medication use

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	32 (37.6)				
	Female	20 (32.8)	0.546			
Age			0.262			
Ethnicity	NZ European & Other	49 (35.8)				
	Maori	3 (60.0)	0.265			
Athlete status	SONZ athlete	26 (26.8)				
	Non-athlete	26 (53.1)	0.002	0.007	0.346	0.159 – 0.758
Living situation	Family / Family like	10 (18.9)	0.001	0.003		
	Community Group Home	24 (57.1)	<0.001	0.001	5.036	1.954 – 12.953
	Supported Living Context	16 (36.4)	0.056	0.131	2.080	0.803 – 5.387
Location	Dunedin	37 (37.4)				
	Palmerston North	15 (35.6)	0.520			

Whether participants were Special Olympic athletes or not and where they lived were both found to make statistically significant unique contributions to explaining variation in the likelihood participants would be recorded as taking psychoactive medication regularly within the adjusted model.

Whether participants were Special Olympic athletes or not was the strongest predictor of the likelihood that a participant would take psychoactive medication. Fifty-three percent of participants who were not Special Olympic athletes (53.1%; 95% CI= 38.6 – 67.5) were

recorded as taking one or more psychoactive medications whereas 27% of Special Olympic athletes (26.8%; 95% CI= 17.8 – 35.8) reportedly took one or more psychoactive medications. The odds that a Special Olympic athlete would be reported as taking psychoactive medication decreased by 65% compared to non-athletes (OR=0.35; 95% CI= 0.14 - 0.78) when all other factors included in the adjusted model were controlled for. This finding suggests that data provided by Special Olympic screens that sample athletes only may under-estimate the prevalence of psychoactive medication use by the general population of people with a learning disability.

More than half of the participants who lived in a (staffed) community group home with other people were reported as taking one of more psychoactive medications (57.1%; 95% CI= 41.5 - 72.8) whereas less than one in five participants who lived with a family member were reported to be taking psychoactive medication (18.9%; 95% CI= 8.0 - 30.0). The odds that participants who lived in a (staffed) community group home would be reported as taking psychoactive medication were approximately five times than for participants who lived with a family member (OR=5.04; 95% CI= 1.95 - 12.95) when other potential predictors included in the adjusted model were controlled for.

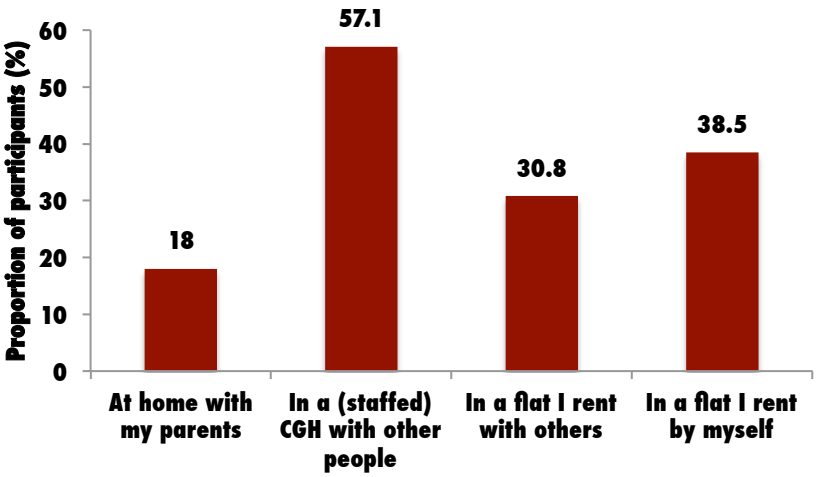

Figure 7 The proportion of participants taking psychoactive medication by living situation

The highest proportion of participants reported as taking one or more psychoactive medications were aged between 30-39 years (50.0%; 95% CI= 30.3 – 69.7) and lowest proportion reported for participants aged between 20-29 years (24.3%; 95% CI= 9.8 – 38.8).

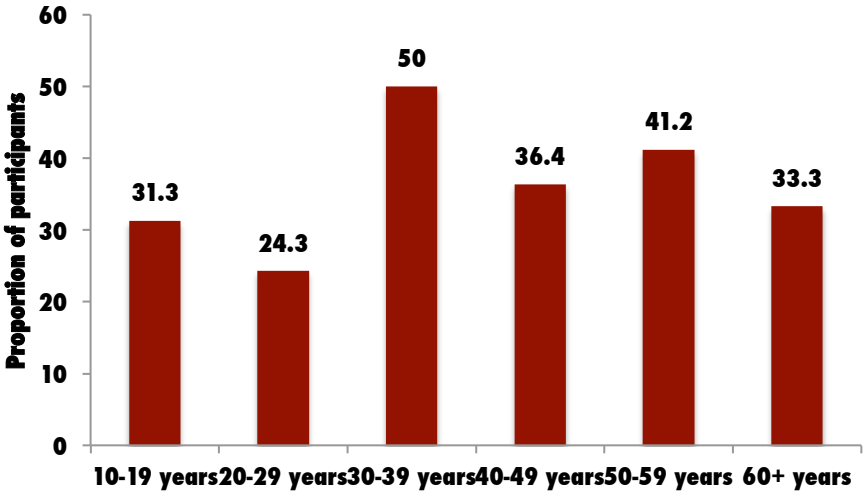

Figure 8 The proportion of participants taking psychoactive medication by age category

The sex or age of participants, however, did not make a statistically significant contribution to explaining variation in the likelihood they would be recorded as taking psychoactive medication.

3.5 Psychoactive medication prescribed for children and young adults

In the past decade, concern about an observed increase in the prescribing of psychoactive medication to children and young adults in the general population has gathered momentum, particularly related to a documented increase in the prescribing of central nervous system stimulants, a new generation of antidepressant medication (selective serotonin reuptake inhibitors) and atypical antipsychotics to children and young people[31].

Approximately one out of every three participants aged between 10-19 years who completed the Special Olympics Health Promotion screen was recorded as taking one or more psychoactive medications (31.3%; 95% CI= 14.3 - 48.2) and the only participant aged less than ten years was also recorded as taking one or more psychoactive medications.

As a first step towards exploring the pattern of prescribing for young people with a learning disability in a New Zealand context, including establishing whether trends in prescribing for the general population are reflected in the pattern of prescribing for this population, a more detailed analysis of the medication recorded as regularly used by participants aged less than 20 years was conducted.

Medication information was provided for thirty-three participants aged less than twenty years. Slightly less than one out of every three participants aged less than 20 years were recorded as taking psychoactive medication (30.4%; 95% CI= 13.8 - 46.9) with five participants recorded as regularly taking at least two different types of psychoactive medication (15.2%).

Antipsychotic and antidepressant medication were the two most commonly prescribed psychoactive medication types for participants aged less than 20 years.

Five participants aged less than 20 years were recorded as regularly taking antipsychotic medication (15.2%; 95% CI= 2.2 - 28.1). Three participants who regularly used an antipsychotic medication had also been prescribed antidepressant medication and one participant took their antipsychotic medication in conjunction with an anticonvulsant. No participant recorded as regularly taking antipsychotic medication described having a psychotic disorder. Two participants were recorded as having an autistic spectrum disorder as their type of disability, one participant was recorded as having a bipolar disorder and it was not possible to determine the type of self-reported disability for the other two participants aged less than 20 years who regularly took antipsychotic medication.

Five participants aged less than 20 years were also recorded as regularly taking antidepressant medication (15.2%; 95% CI= 2.2 - 28.1). Most participants aged less than 20 years who had been prescribed antidepressant medication regularly took the newer generation selective serotonin reuptake inhibitor antidepressants (n=4) with only one participant aged less than 20 years recorded as regularly taking a tricyclic antidepressant. No participant aged less than 20 years recorded as taking antidepressant medication was recorded as having either a mental health condition or mood disorder.

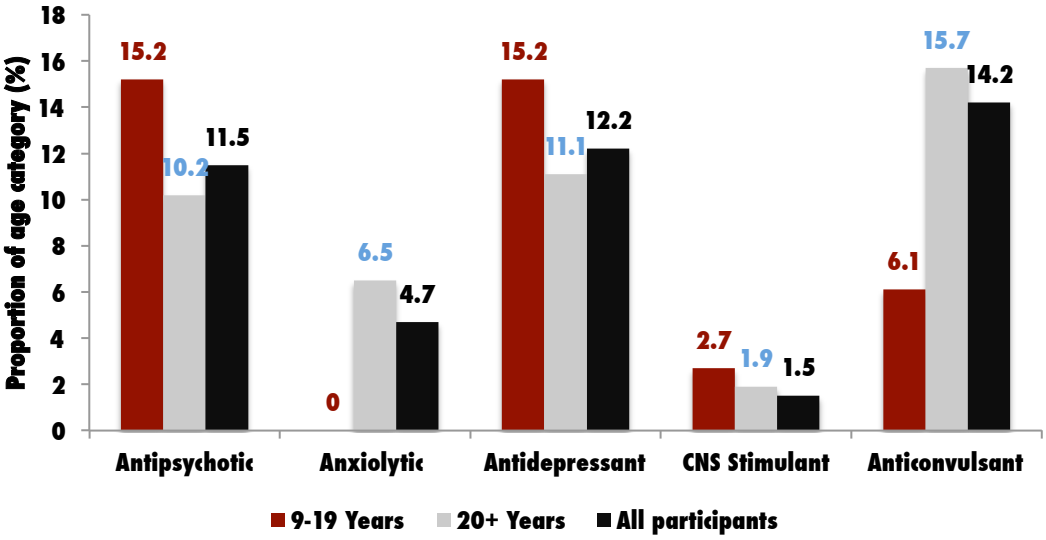

Figure 9 The proportion of participants aged less than 20 years regularly using psychoactive medication by medication type

Recent research conducted by the New Zealand Ministry of Health found the rate of treatment for psychosis and mood disorders for people with a learning disability increased with age in the year ending June 2008[11]. Whilst the differences are small, it is interesting to note that the prevalence of antipsychotic and antidepressant use was higher for participants aged less than twenty years than for Health Promotion screen participants aged 20 years or over (10.2%; 95% CI= 4.4 - 16.0, and 11.1%; 95% CI= 5.1 - 17.1, respectively).

The proportion of participants aged less than 20 years who were recorded as taking anticonvulsant medication (6.1%; 95% CI=- 0.0 - 14.7) was, however, lower than the prevalence of anticonvulsant medication use for Health Promotion screen participants aged 20 years or over (15.7; 95% CI= 8.8 -2 2.7). Neither of the two participants aged less than 20 years recorded as taking anticonvulsant medication were recorded as having epilepsy. One participant was described as having a general learning disability and the other as having a bipolar disorder.

3.6 The number of psychoactive medications regularly used

Although the term "poly-pharmacy," has evaded precise definition, it is most often used within the learning disability literature to refer to the practices of prescribing multiple (often non-redundant) medications or of combining two or more drugs from the same therapeutic class.

The practice of prescribing two or more medications from the same therapeutic class is most commonly seen in the combining of antipsychotic medication. Because of the lack of evidence regarding the efficacy of combining antipsychotics, difficulty detecting any therapeutic benefit and widespread concern about the potential for adverse side effects the practice is not supported either by the New Zealand Ministry of Health who describe the practice as "pharmacologically unjustified" (p. 7)[32] or by the Royal Australian and New Zealand College of Psychiatrists[33]. Similar concerns about the potentially harmful effects of taking multiple medications in general and psychoactive medication in particular often find expression in research exploring the use of psychoactive medication by people with a learning disability.

In Robertson et al's (2000) study of prescribing practices in the UK described previously, Robertson et al reported that 11% of participants who lived in NHS residential campuses were likely to receive both antipsychotic and antidepressant medication within their daily medication regime and 7% of participants received more than one type of antipsychotic on a regular basis. Participants who lived in NHS residential campuses were also significantly more likely to be exposed to the risks of poly-pharmacy than participants who lived in either village communities or dispersed community housing. Two percent of participants who lived in dispersed community housing reportedly received both antidepressant and antidepressant medication within their daily medication regime and 2% also received more than one type of antipsychotic on a regular basis[28].

Very similar rates of prescribing more than one antipsychotic medication were reported by Doan et al (2013) who found that 2.6 percent of participants living in community settings in Brisbane, Australia regularly used two or more antipsychotic medications[19].

Approximately three out of every four of the 52 participants recorded as taking psychoactive medication were recorded as taking one psychoactive medication only (73.1%; 95% CI= 60.6 – 85.6). Of the participants who were recorded as taking psychoactive medication, nine were recorded as taking two psychoactive medications (17.3%: 95% CI= 6.7 - 27.9) and five

participants were reportedly taking three psychoactive medications regularly (9.6%; 95% CI= 1.3 - 17.9).

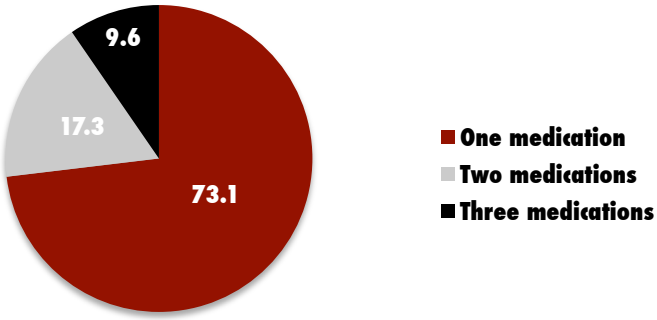

Figure 10 The proportion of participants who regularly took psychoactive medication prescribed one - three psychoactive medications

As would be expected, the number of psychoactive medications participants were recorded as taking varied according to medication type. Seventeen participants were recorded as taking antipsychotic medication of whom 65% took two or more additional psychoactive medications, whereas 24% of the 21 participants who were recorded as taking anticonvulsant medication took two or more additional psychoactive medications.

Participant took antipsychotic medication

Participant took anticonvulsant medication

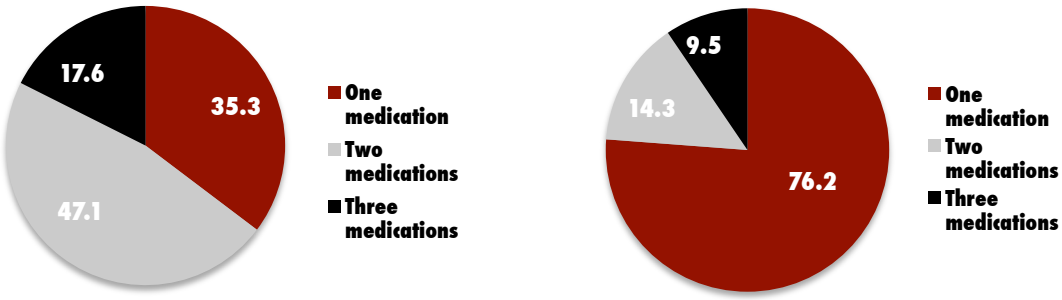

Figure 11 The proportion of participants prescribed antipsychotic and anticonvulsant medication who regularly took between one - three psychoactive medications

Table 11 The proportion of participants prescribed more than one psychoactive medication type by medication type

	Antipsychotic		Anxiolytic		Anticonvulsant		Antidepressant	
	n (%)	Prop. class (%)	n (%)	Prop. class (%)		Prop. class (%)	n (%)	Drug class (%)
Antipsychotic	0 (0)	0	2 (1.4)	11.8	3 (2.0)	17.6	7 (4.7)	41.2
Anxiolytic	2 (1.4)	28.6	0 (0)	0	0 (0)	0	3 (2.0)	42.9
Anticonvulsant	3 (2.0)	14.3	0 (0)	0	3 (2.0)	14.3	1 (0.7)	4.8
Antidepressant	7 (4.7)	38.9	3 (2.0)	16.7	1 (0.7)	5.6	0 (0)	0
	Took 2 or more medications of the same class							

Forty-one percent of participants whose daily medication regime included the use of antipsychotic medication had also been prescribed one or more antidepressant medications (41.2%; 95% CI= 15.1 – 67.3). Anticonvulsant medication was concurrently prescribed for 18 percent of participants who regularly took antipsychotic medication (17.6%: 95% CI= 0.0 – 37.9) and anxiolytic medication concurrently prescribed for 12% of participants recorded as regularly taking antipsychotic medication (11.8%; 95% CI= 0.0 – 28.8). No evidence was found of polypharmacy involving the concurrent prescribing of more than one antipsychotic drug in this study population.

Anticonvulsants were the most commonly reported medication type used by participants, but with the exception of their concurrent use with antipsychotic medication, anticonvulsants were least likely to be prescribed with other drug types. Fourteen percent of participants recorded as regularly taking anticonvulsant medication were, however, taking at least one other anticonvulsant regularly (n=3; 14.3%).

3.7 Antipsychotic Medication

Antipsychotic medication is commonly prescribed to treat psychotic disorders including, schizophrenia, paranoid states, and other psychoses.

Recent evidence suggests that people with a learning disability experience higher rates of mental disorder, including psychotic disorders than the general population. In the 12 months to 30 June 2008, the New Zealand Ministry of Health estimated that 3.7% of people with a learning disability received care or treatment for a psychotic disorder[11], consistent with international studies that report prevalence rates to lie within the range of 2-4%[28]. When adjusted for age, the Ministry of Health found people with a learning disability were 17 times more likely receive care or treatment for a psychotic disorder than people who did not have a learning disability and that males were more likely than females to receive care or treatment for a psychotic disorder. Evidence of care or treatment for psychosis peaked for people with a learning disability aged between 35-54 years.

As noted previously, evidence of a disparity between estimates of the prevalence of psychotic disorder and antipsychotic medication use by people with a learning disability have led to widespread concerns about the inappropriate use of psychoactive medication to manage social behaviour understood to be challenging.

Seventeen participants who completed the Special Olympic Health Promotion screen were recorded as regularly taking antipsychotic medication. Consistent with previously reported findings male participants (14.0%; 95% CI= 6.5 - 21.4) were more likely to have been prescribed antipsychotic medication than female participants (8.1%; 95% CI= 1.1 - 15.0), but no association was found between participant sex and the likelihood they had been prescribed antipsychotic medication.

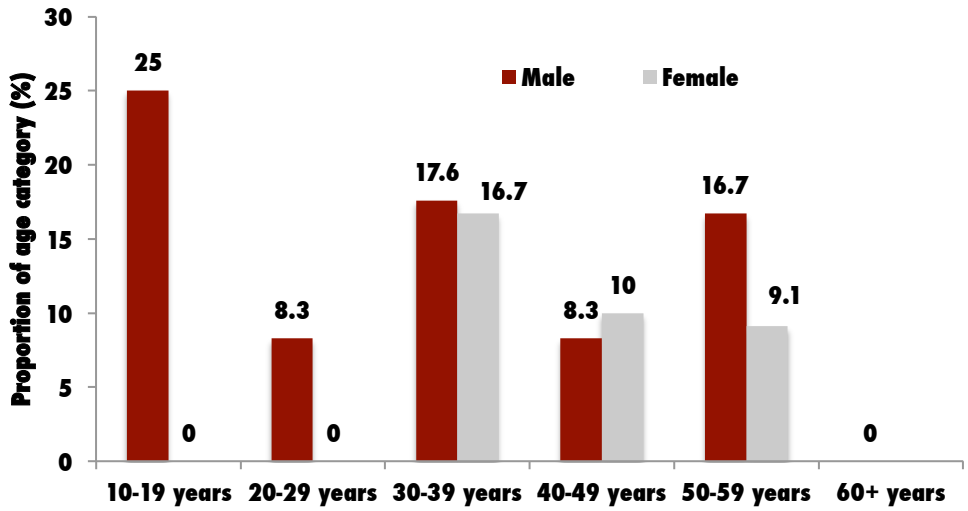

Figure 12 The proportion of male and female participants recorded as regularly taking antipsychotic medication by age category

One out of every four male participants aged less than 20 years was recorded as regularly taking antipsychotic medication (25.0%; 95% CI= 4.2 – 45.8). Previous studies have tended to report that treatment of psychotic disorders, including medication, peaks during older adulthood. Although the number of participants is small, the finding that younger men were more likely to be prescribed antipsychotic medication than any other age category may represent the emergence of a more generalised trend towards an increase in the prescribing of psychoactive medication in children and young adults.

Direct binary logistical regression was performed to assess whether it was possible to detect any association between a range of participant demographic characteristics and the likelihood they were recorded as regularly taking antipsychotic medication. Participant' ethnicity and where athletes were screened were included as possible predictors of antipsychotic medication use within the adjusted model.

When the screen location was held constant, participant ethnicity was found to make a unique, statistically significant contribution to explaining variation in the likelihood a participant would be recorded as regularly taking antipsychotic medication.

Although the number of participants who self-identified as Māori and for whom medication information was available was very small (n=5), the ethnicity of participants was found to make a statistically significant contribution to explaining variation in the use of antipsychotic medication when screen location was held constant in the adjusted model. Forty percent of Māori participants were recorded as regularly taking antipsychotic medication (40.0%; 95% CI = 0.0 – 100) compared to 11% of participants grouped as New Zealand European or Other (10.5%; 95% CI = 5.4 – 15.6).

Table 12 Association between participant' demographic characteristics and antipsychotic medication use

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	12 (14.0)				
	Female	5 (8.1)	0.273			
Age			0.806			
Ethnicity	NZ European & Other	15 (10.5)				
	Maori	2 (40.0)	0.068	0.038	8.451	1.126 – 63.455
Athlete status	SONZ athlete	7 (13.7)				
	Non-athlete	10 (10.3)	0.537			
Living situation	Family / Family like	4 (7.5)	0.237			
	Community Group Home	8 (18.2)	0.124			
	Supported Living Context	4 (9.1)	0.783			
Location	Dunedin	14 (14.1)				
	Palmerston North	3 (6.1)	0.053	0.105	0.317	0.079 – 1.271
BMI	Normal	3 (7.1)				
	Overweight or obese	13 (15.7)	0.189			

This finding is consistent with the New Zealand Ministry of Health's recent finding that Māori were the ethnic group most likely to receive care or treatment for a psychotic disorder, but the prevalence of antipsychotic medication use in this small sample greatly exceeded the sex adjusted rate of care or treatment for a psychotic disorder reported by the Ministry of Health (7.7%)[11]. In addition to the possibility that the prevalence of psychotic disorders are higher for Māori with a learning disability than other ethnicities, it is possible, given Robertson et al's (2000) explanation for the association they found between participant mobility and/or size and the receipt of antipsychotics[28], that the social behaviour of Māori with a learning disability may also be more likely to be interpreted as challenging within disability support settings.

All participants who self-identified as Māori and were recorded as taking antipsychotic medication, lived in a (staffed) community group home. Participants who lived in a community group home were twice as likely to have been prescribed antipsychotic medication (18.2%; 95% CI = 6.3 – 30.0) as participants who lived in more independent support contexts (9.1%; 95% CI = 0.25 – 17.9) or with a family member (7.5%; 95% CI = 0.2 – 14.9), however, the association between living situation and antipsychotic medication use was not found to be statistically significant.

Given Robertson et al's (2000) hypothesised relationship between the BMI and receipt of antipsychotic medication, whether participants were recorded as having body mass index (BMI) in the overweight or obese range was also included as a possible predictor of the likelihood they would regularly take antipsychotic medication. As would be anticipated by their findings, participants whose BMI was in the overweight or obese range were more likely to have been prescribed antipsychotic medication (15.7%; 95% CI = 7.7 – 23.7) than participants who were recorded as having a BMI in the normal range (7.1%: 95% CI = 1.0 –

15.3), however the association between BMI and antipsychotic medication use was also not found to be statistically significant.

3.8 Antidepressant medication.

In the general population, mood disorders, including depression, bipolar disorder and dysthemia are most often treated with antidepressant medication, a form of psychological therapy or a combination of them both. In the New Zealand Health Survey (2008), participants were asked whether they had ever been diagnosed with a mood disorder. One in ten adult New Zealanders (10.9%, 95% CI= 10.3-11.5) reported ever having been diagnosed with a mood disorder in the 2008 survey, nearly all of whom reported being diagnosed with depression (10.5%, 95% CI= 9.9 - 11.1)[34]. In the 2011/12 Health Survey, the proportion of New Zealanders that self-reported being diagnosed with depression increased to 14% of the general population[35].

International research suggests that the incidence of depression or depressive equivalents may be more common for people with a learning disability[11]. Recent findings reported by the New Zealand Ministry of Health appear align with international research. To estimate the prevalence of mood disorder in a calendar year, the Ministry of Health adopted a narrower definition and found that 9.6 percent of people with a learning disability received government-funded care or treatment for a mood disorder in the year ending June 2008. When adjusted for age, people with a learning disability were found to be more than twice as likely to receive treatment than people who did not have a learning disability[11]. The same study also found females were more likely than males to receive care or treatment for a mood disorder and that people with a learning disability aged between 55-74 years had the highest rate of treatment.

As part of a wider investigation of the impact closing New Zealand's last institution had on the quality of life of former residents, Milner et al (2008) reported that only a small number of people with a learning disability who were resettled from the Kimberley Centre had been prescribed antidepressant medication[26]. Very little research has attempted, however, to describe the prevalence of antidepressant use by people with a learning disability who have either moved or never lived in a New Zealand institution.

Approximately 12% of participants were recorded as taking antidepressant medication (12.2%; 95% CI= 6.8 – 17.5) of whom, half were recorded as taking one psychoactive medication only. A mental health condition including mood disorder was only indicated in one of the eighteen participants who took antidepressant medication, suggestive perhaps of a tendency to misattribute low affect to learning disability (diagnostic overshadowing) and/or the widespread prescribing of antidepressant medication alongside medication prescribed to treat other mental health conditions.

Direct binary logistical regression was performed to assess whether it was possible to detect any association between a range of participant demographic characteristics and the likelihood they were recorded as regularly taking antidepressant medication. Participant' sex and their living situation were included as possible predictors of antipsychotic medication use within the adjusted model and both were found to make a unique statistically significant contribution to explaining variation in antidepressant medication use.

Table 13 Association between participant' demographic characteristics and antidepressant medication use

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	16 (18.6)				
	Female	2 (11.1)	0.012	0.049	0.210	0.044 – 0.995
Age			0.533			
Ethnicity	NZ European & Other	16 (11.2)				
	Maori	2 (40.0)	0.080			
Athlete status	SONZ athlete	10 (10.3)				
	Non-athlete	8 (15.7)	0.345			
Living situation	Family / Family like	3 (5.7)	0.003	0.011		
	Community Group Home	12 (27.3)	0.007	0.013	5.622	1.442 – 21.923
	Supported Living Context	2 (4.5)	0.805	0.948	0.940	0.147 – 6.028
Location	Dunedin	13 (13.1)				
	Palmerston North	5 (10.2)	0.752			

As was the case more generally, where people lived was the strongest predictor of whether a participant would be recorded as taking antidepressant medication. Twenty-seven percent of participants who lived in a (staffed) community group home were recorded as regularly taking antidepressant medication (27.3%; 95% CI= 13.6 – 41.0) compared to 6% of participants who lived with a family member (5.7%; 95% CI= 0.0 – 12.1) and 5% of participants who lived in more independent support contexts (4.5%; 0.0 – 11.0). Participants who lived in a flat they rented with others were the least likely to report taking antidepressant medication regularly (3.8%; 95% CI= 0.0 – 11.8) The odds that participants who lived in a (staffed) community group home with other people would be reported as regularly taking antidepressant medication were approximately six times higher than the odds a participant who lived with a family member (OR=5.6; 95% CI= 1.4 – 21.9) when participant sex was controlled for in the adjusted model.

Contrary to a well replicated finding that the prevalence of mood disorder tends to be higher in females than males with a learning disability, sixteen male (18.6%; 95% CI= 10.2 – 27.0) and only two female (3.2%; 95% CI = 0.0 – 7.8) participants were recorded as being prescribed antidepressant medication.

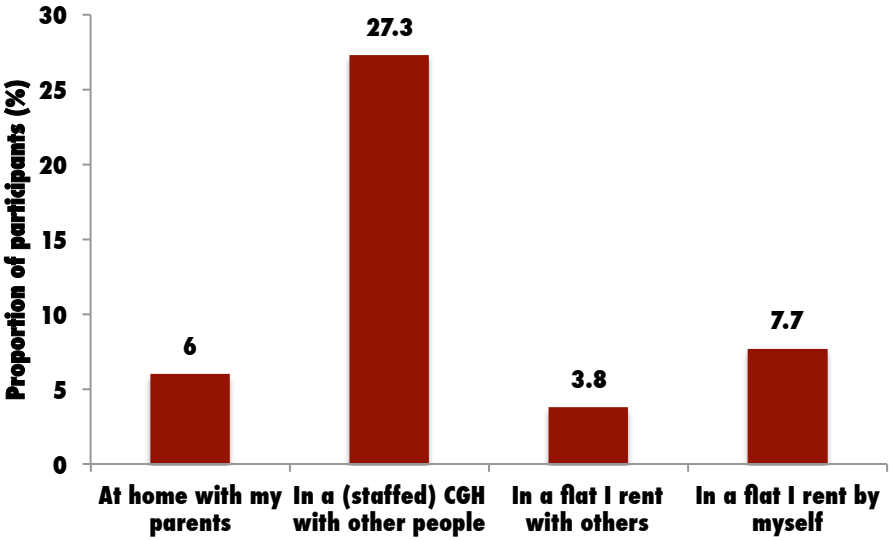

Figure 13 The proportion of participants recorded as regularly taking antidepressant medication by living situation

The sex of participants made the second most important statistically significant contribution to explaining variation in the likelihood participants were recorded as taking antidepressant medication. The odds that a female participant would regularly take antidepressant medication decreased by 80% compared to the odds for male participants (OR=0.2; 95% CI = 0.04 – 1.04) when participant' living situation was controlled for in the adjusted model.

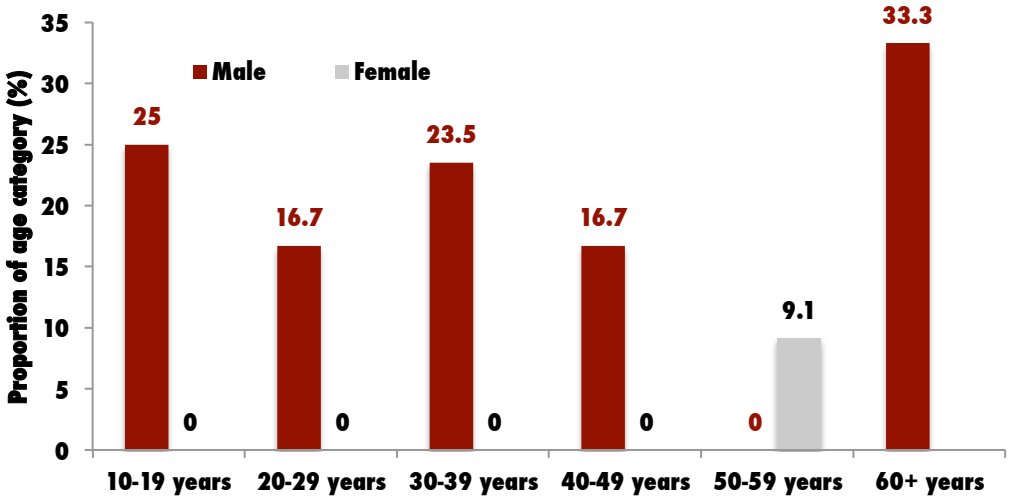

Figure 14 The proportion of male and female participants recorded as regularly taking antidepressant medication by age category

One male participant aged over sixty years was recorded as taking antidepressant medication (33.3%; 95% CI= 0.0 – 1.0). The age group with the second highest proportion of participants for whom antidepressant medication had been prescribed were participants aged less than 20 years. One out of every four male participants aged less than 20 years was recorded as a taking antidepressant medication (25.0%; 95% CI= 4.2 – 45.8). The only female participant

recorded as taking antidepressant medication, whose age was known, was aged between 50-59 years.

3.9 Anticonvulsant medication

Anticonvulsant medication is most commonly prescribed to control epileptic seizures but can also be used to alter mood.

The prevalence of epilepsy in people with a learning disability is higher than the general population, affecting approximately one in five people with a learning disability who do not have cerebral palsy and approximately half of people with a learning disability that do[9].

Similar findings were reported by the New Zealand Ministry of Health (2011)[11], who estimated in the year ending June 2008, 15.4% of people with a learning disability had had two or more inpatient or outpatient attendances that included a diagnosis of epilepsy, received two or more anticonvulsants or had one or more inpatient or outpatient attendance that included a diagnosis of epilepsy and received one or more dispensed anticonvulsant medications.

Within the general population, the prevalence of epilepsy has been estimated to be between 0.5 - 1%.[9] In New Zealand, 0.5% (95% CI= 0.3 - 0.7) people who responded to the 2006/07 New Zealand Health Survey reported having being diagnosed with long-term epilepsy[34].

Few studies have sought to describe either the prevalence of anticonvulsant use by people with a learning disability in New Zealand or to discriminate between the prevalence of prescribing to control epileptic seizures or the use of anticonvulsant medication to manage affect. In their investigation of the impact of closing the Kimberly Centre, Milner et al (2008) reported anticonvulsant medication was the most commonly prescribed psychoactive drug and that two out of every three Kimberley residents who left for community-based services took anticonvulsant medication[26]. The authors also noted that a high proportion of former Kimberley Centre residents had at one time also been diagnosed with epilepsy, accounting in part for the high rates of anticonvulsant medication use in the formally institutionalised population.

In the present study, 14% of participants who completed the Special Olympic Health Promotion screen were recorded as regularly taking anticonvulsant medication (14.2%; 95% CI = 8.5 – 19.9).

Direct binary logistical regression was performed to assess whether it was possible to detect any association between a range of participant demographic characteristics and the likelihood they were recorded as regularly taking anticonvulsant medication. Participant' age and their living situation were included as possible predictors of anticonvulsant medication use in the adjusted model, but no variable was found to make a unique statistically significant unique contribution to explaining variation in anticonvulsant medication use.

Table 14 Association between participant' demographic characteristics and anticonvulsant medication use

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	10 (11.6)				
	Female	11 (17.7)	0.296			
Age			0.053	0.286	1.032	0.981 – 1.066
Ethnicity	NZ European & Other	21 (14.7)				
	Maori	0 (0)	0.999			
Athlete status	SONZ athlete	11 (11.3)				
	Non-athlete	10 (19.6)	0.175			
Living situation	Family / Family like	4 (7.4)	0.236	0.699		
	Community Group Home	8 (18.2)	0.124	0.506	1.653	0.376 – 7.268
	Supported Living Context	8 (18.2)	0.124	0.403	1.881	0.428 – 8.268
Location	Dunedin	12 (12.1)				
	Palmerston North	9 (18.4)	0.309			

Female participants (17.7%; 95% CI= 8.0 – 27.5) were more likely than male participants (11.6%; 95% CI= 4.7 – 18.5) to have been prescribed one or more anticonvulsants and a trend for the prescribing of anticonvulsant medication to increase with age was observed for both male and female participants, although no statistically significant associations were found between the likelihood of taking anticonvulsant medication and any of the demographic characteristics included as potential predictors.

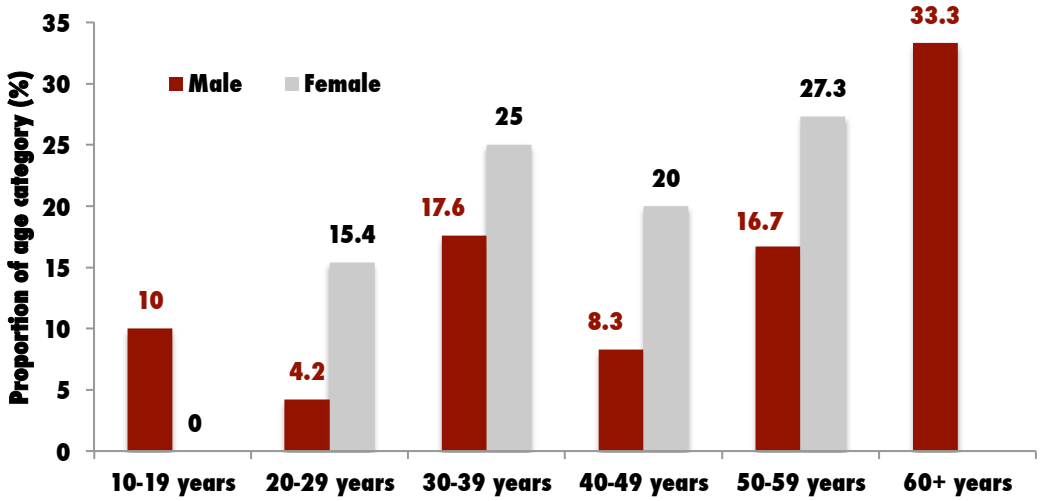

Figure 15 The proportion of male and female participants recorded as regularly taking anticonvulsant medication by age category

Epilepsy was indicated as a disability type for less than half of the participants recorded as taking anticonvulsant medication (47.6%; 95% CI= 24.3 – 70.9).

4 Body Size

A person's body size has increasingly been recognised as an important determinant of good health and wellbeing, especially as evidence of grows of an association between obesity and a range of adult health conditions, including: cardiovascular disease, various types of cancer, type 2 diabetes, kidney and liver diseases, osteoarthritis, sleep apnoea and a range of other medical conditions[34]. Reduced self-esteem, depression and exposure to discrimination have also been identified as additional possible negative effects associated with obesity[34].

Body mass index (BMI) is a measure of weight adjusted for height and is the most widely used classification system for estimating the proportion of the population with increased risk of heath conditions associated with obesity.

Participant height without footwear was measured (to the nearest 0.1cm) using a portable stadiometer and weight without footwear or bulky clothing measured (to the nearest 0.1kg) using a digit scale. Participant' BMI was calculated and recorded by administrators who used a metric BMI wheel.

Participant BMIs were grouped consistent with the WHO classification cut off points : underweight <18.5kg/m^2, normal range 18.5 - 24.95kg/m^2, overweight 25.0 - 29.95kg/m^2 and obese≥30.05kg/m^2

A body mass index was calculated for one hundred and seventy-one participants who completed the Special Olympic Health Promotion screen.

4.1 Obesity in people with a learning disability

International studies have tended to report obesity being more common in people with a learning disability than the general population, with estimates of the prevalence of obesity ranging from 29 – 50%[9],[10].

Within the research literature, a consensus appears to be emerging that the likelihood of being exposed to the health risks associated with obesity are different for men and women with a learning disability and vary also according to where people live.

In a study of people with learning disability living in community support settings across the United Kingdom, Bell & Bhate (1992) found 48% of men and 73% of women sampled were either overweight or obese[36] and that the prevalence of obesity was higher for people who lived at home (55%) when compared to people who lived either in a community group home (40%) or institutional setting (16%). The research also indicated that adults with Down syndrome were 1.5 times more likely to be obese than other people with a learning disability.

In a more recent American study Rimmer et al (2010) explored the prevalence of obesity and obesity related secondary conditions experienced by adolescents (12 - 8 years) who had an intellectual or developmental disability[37]. Parents of this group of young people responded to a web-based survey that asked questions about their child's health status, including body weight and existing health conditions. Comparisons with published research relating to young people without intellectual or developmental disability found young people who had autism, Down syndrome, or a learning disability were two to three times more likely to be obese, and to have a range of secondary health conditions related to being overweight. Rimmer et al. contended that the prevalence of obesity and obesity related secondary conditions are strongly linked to the health disparities experienced by people with an intellectual disability in adulthood and, consequently, that there is a strong need to create and evaluate the effectiveness of a range of strategies that may help to reduce obesity for this group.

In another American study Janeki et al (2002) reported that 50% of a sample of over one thousand adults with a learning disability living in residential services were found to be obese[38]. Despite this, little attention or action had occurred with regard to the delivery of health care, leading Janicki et al. to suggest that obesity may be seen as the norm for people who have a learning disability.

Two studies that have drawn data from athletes who participated in national and/or international Special Olympic HAS Health Promotion screen events have also contributed to the emerging picture of higher rates of obesity for adults with a learning disability.

4.2 The prevalence of obesity in Special Olympic athletes

Following their analysis of data volunteered by athletes competing at the 1999 and 2001 World Games, Harris et al (2003) reported that 33% of athletes aged 21 years or younger had a BMI in the overweight or obese range and 46% of athletes aged over 21 had a BMI in the overweight or obese range.[39] They also reported that athletes from North America were 3.1 times more likely to be overweight or obese (prevalence= 65%) than non-North American athletes (prevalence=33%).

Ten years later Temple et al (2013) found evidence of regional differences in the prevalence of obesity in large study that accessed the BMI records of 11 643 athletes available through the Special Olympics International Health Promotion database[10]. Temple et al (2013) found that approximately one out of every three athletes screened had a BMI in the overweight or obese range in all six Special Olympic world regions except for male athletes from Africa/MENA and male and female athletes East Asia. When compared to World Health Organisation (WHO) estimates of the prevalence of overweight or obesity amongst the general population, Special Olympic athletes were found to have similar rates of overweight or obesity except that male and female athletes from North America were significantly more likely and male athletes from Africa/MENA and Latin America were significantly less likely to have a BMI in the overweight or obese range than the general population within their world regions. The prevalence of having a BMI in the overweight or obese range was highest in athletes from the

North American, of whom 68% of male and 76% of female athletes were found to be overweight or obese.

Temple et al reported that athletes' age was a significant predictor of the likelihood of having a BMI in the overweight or obese range. For every year an athlete aged, the odds of having a BMI in the overweight or obese range across all regions increased by 1.06 times.

New Zealand is located within the Asia-Pacific Special Olympic World Region where 37% of male (37.0%; 95% CI= 30.7 - 43.1) and 40% of female athletes (39.4%; 95% CI= 30.1 - 49.1) were found to have a BMI in the overweight or obese range. Unlike most other world regions, where female athletes were significantly more likely than males to have a BMI in the overweight or obese range, the sex of athletes had no impact on the prevalence of overweight or obesity within the ethnically heterogeneous Asia-Pacific region. The age of athletes was, however, found to make a unique, statistically significant contribution to explaining variation in the likelihood they would have a BMI in the overweight or obese range. Every year older an athlete was at the time of screening, the odds of having a BMI in the overweight or obese range increased by 7% (OR=1.07; 95% CI= 1.03 - 1.12).

Despite being identified as an important arena of health inequality, very little research has sought to describe the prevalence of obesity in adults with a learning disability living in the New Zealand context. Two recent studies appear to suggest, however, that the prevalence of obesity in people with a learning disability who live in New Zealand more closely approximates their peers living in North America and the United Kingdom than people with a learning disability in the Asia-Pacific Special Olympic health region.

4.3 The prevalence of obesity for adults with a learning disability living in New Zealand.

In 2008, Stedman & Leland (2010) accessed the anonymised archival data of 98 adults with a learning disability who accessed support from a disability service provider that providing support, primarily to men and women living autonomously in their own flats in the Otago-Southland region[40]. Stedman & Leland reported finding that 17.4% of participants had a BMI in the overweight range and 51% had a BMI in the obese range, significantly higher, they noted, than contemporaneous estimates of obesity within the New Zealand general population (ID=51.02%; GP=29.99%). Within their study, Stedman & Leland found that, not only were women with a learning disability more at risk of having a BMI in the obese range than male participants (Women=65.63%; Men=43.95%) women with a learning disability were twice as likely to be obese as women in the general population (ID=65.63%; GP=30.2%), whereas men were one and a half times as likely to be obese (ID=43.94%; GP=29.72%).

Although the difference was not statistically significant, Stedman and Leland observed that the prevalence of obesity was higher for participants who received less than five hours support when compared to the smaller number of participants who received higher levels of support (< 5 hours support prevalence= 53.6%; >5 hours support prevalence= 47.6%) but acknowledged

that drawing data from one service that tended to support adults with a learning disability to live in autonomous support contexts limited the generality of their findings.

In the second study, the New Zealand Ministry of Health sought to estimate the prevalence of morbid (potentially life-threatening) obesity for people with a learning disability by counting how many people received hospital treatments for morbid obesity in the year ending 30 June 2007. The research found that, when adjusted for age, people with a learning disability were over four times more likely to receive morbid obesity treatments than people without a learning disability and that females had twice the male rate of morbid obesity treatment[11].

4.4 Mean (average) BMI

To permit a comparison to be made with findings reported in the New Zealand Health Survey (2008), participants younger than 15 years were excluded from the analysis. Adult participants aged 15 years or older had a mean BMI of 29.2 kg/m2 (95% CI = 28.2 – 30.3), 1.8 kg/m2 higher than the national average as reported by the Ministry of Health for the year ending June 2007 (m=27.4 kg/m2; 95% CI= 27.3 – 27.5)[34].

Female participants had a higher mean BMI than male participants across all age categories and peaked for males aged between 40-49 years (m=29.9kg/m^2; 95% CI=26.0-33.5) and females aged 30-39 years (m=32.5kg/m^2; 95%CI=28.0-37.0)[vii].

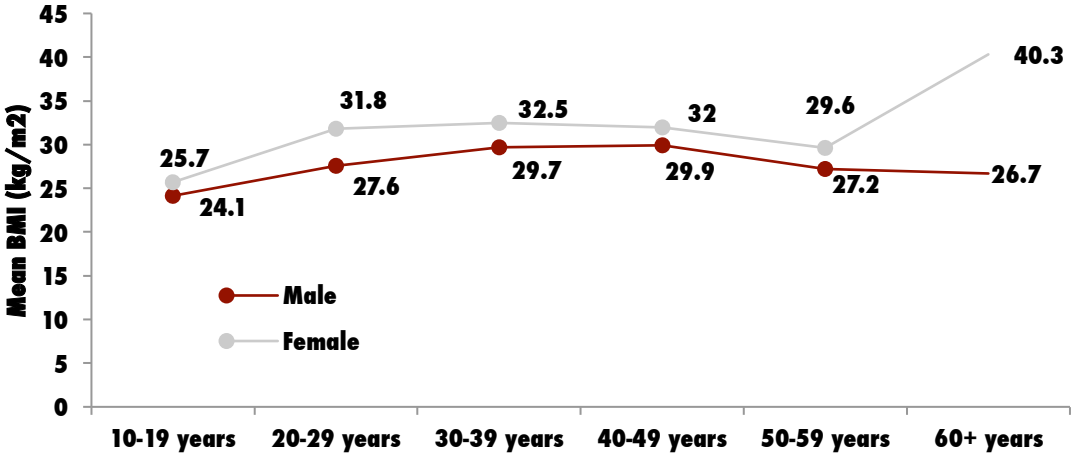

Figure 16 Mean BMI by age category

[vii] The mean BMI for women aged ≤ 60 years was 40.3 kg/m^2; (95%CI [-102.7-183.2]) but the age category only included two participants at opposite extremes of the BMI distribution

4.5 The prevalence of being overweight or obese

Sixty-seven percent of participants were found to have a BMI in the overweight or obese range (67.3%; 95% CI= 60.4 - 74.36), higher than global estimates of prevalence of being overweight or obese among people with a learning disability, but very similar to Harris (2003) and Temple et al's (2013) prevalence estimates for athletes from the North American world region[10, 39].

The tendency for females with a learning disability to be more at risk of being overweight or obese was also observed in the New Zealand context. Sixty-two percent of male participants (62.4%; 95% CI= 52.3 - 72.4) and 73% of female participants (73.1%; 95% CI= 63.0 - 83.1) had a BMI in the overweight or obese range, although the 11% difference in prevalence of overweight or obese between sexes was not found to be statistically significant.

Table 15 The body size of Health Promotion screen participants by BMI classification

	NZ Participants	SOI World Region		
		Asia-Pacific	Europe/Eurasia	North America
Male				
Underweight	1.1%	13.6%	4.7%	3.1%
Normal range	36.6%	49.5%	47.5%	28.7%
Overweight	35.5%	23.4%	31.4%	29.7%
Obese	26.9%	13.6%	16.4%	38.5%
				Female
Underweight	2.6%	18.0%	4.4%	2.7%
Normal range	24.4%	42.3%	39.0%	20.9%
Overweight	33.3%	24.3%	26.3%	24.0%
Obese	39.8%	15.3%	30.3%	52.4%
				BMI ≥ 25
Male	62.4%	37.0%	47.8%	68.2%
Female	73.1%	39.6%	56.6%	76.4%

Direct binary logistical regression was performed to assess whether it was possible to detect any association between a range of participant demographic characteristics and the likelihood of having a BMI in the overweight or obese range. Participant' sex, age, living situation and athlete status were included as possible predictors of having a BMI above 25.0 kg/m^2 in the adjusted model.

Participant's living situation made the largest contribution to explaining variation in the likelihood of having a BMI in the overweight or obese range (Wald=2.47; p=0.291), however, when all other factors were held constant, no independent variable entered into the adjusted model was found to make made a unique, statistically significant contribution to explaining variation in the prevalence of being overweight or obese.

Table 16 Association between participant' demographic characteristics and being overweight or obese

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	58 (62.4)				
	Female	57 (73.1)	0.139	0.391	1.386	0.657 – 2.952
Age			0.075	0.267	1.017	0.987 – 1.049
Ethnicity	NZ European & Other	108 (66.3)				
	Maori	7 (87.5)	0.240			
Athlete status	SONZ athlete	73 (64.0)				
	Non-athlete	42 (73.7)	0.207	0.842	0.921	0.409 – 2.073
Living	Family / Family like	30 (60.0)	0.090	0.291		
situation	Community Group Home	42 (63.6)	0.689	0.916	0.953	0.388 – 0.2341
	Supported Living Context	39 (79.6)	0.037	0.218	1.885	0.688 – 5.167
Location	Dunedin	77 (63.7)				
	Palmerston North	38 (61.3)	0.212			

4.6 The prevalence of being overweight or obese

Within the New Zealand general population, the New Zealand Ministry of Health estimated that 28% of New Zealand adults were obese (28.4%; 95% CI= 27.3 – 29.6) and a further 35% of adults were overweight in the year ending June 2012[35]. In the only New Zealand study to explore the prevalence of obesity in people with a learning disability, Stedman and Leland (2010) reported that more than half of the people who participated in their study had a BMI in the obese range, (51.0%), with a further 30.6% of participants also recording a BMI in the overweight range[40].

Although slightly higher than the estimated prevalence of obesity in the general population, the finding that 32.8% of people who participated in the Special Olympic Health Promotion screen were obese (32.8%; 95% CI= 25.6 – 39.9), with a further 34.5% of participants having a BMI in the overweight range (34.5%; 95% CI= 27.3 – 41.7) represents a closer approximation of national estimates of obesity than that previously reported for New Zealand service users.

The majority of people who participated in Stedman & Leland's (2010) study were, however, being supported to live autonomously in their own flats and one possible explanation for the difference in estimated prevalence is that, consistent with a trend they observed within their own data, people with a learning disability who live by themselves may be more at risk of becoming obese than people who live in other support contexts.

Where people lived was included alongside participant's sex and screen location as independent variables within a direct binary logistical regression performed to assess what impact a range of demographic characteristics had on the likelihood participants would have a BMI in the obese range.

Within the adjusted model participants' living situation was the only variable found to make unique, statistically significant contribution to explaining variation in the likelihood they would have a BMI in the obese range when other potential predictors were held constant.

Table 17 Association between participant demographic characteristics and obesity

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	25 (26.9)				
	Female	31 (39.7)	0.076	0.228	1.575	0.753 – 3.293
Age			0.052	0.520	1.010	0.980 – 1.042
Ethnicity	NZ European & Other	54 (33.1)				
	Maori	2 (25%)	0.634			
Athlete status	SONZ athlete	33 (28.9)				
	Non-athlete	23 (40.4)	0.136			
Living situation	Family / Family like	11 (22.0)	0.002	0.006		
	Community Group Home	17 (25.8)	0.640	0.637	1.283	0.457 – 3.604
	Supported Living Context	26 (53.1)	0.002	0.007	4.071	1.476 – 11.227
Location	Dunedin	41 (63.7)				
	Palmerston North	15 (24.2)	0.074	0.093	0.500	0.222 – 1.124

Sixty-seven percent of participants who lived in a flat they rented by themselves (66.7%; 95% CI= 35.4 – 98.0) had a BMI in the obese range compared to 21% of participants who lived with a family member (21.3%; 95% CI= 9.1 – 33.4) and 26% of participants who lived in a (staffed) community group home (25.8%; 95% CI= 14.9 – 36.6). The odds that a participant who lived either in a flat they rented by themselves or in a flat they rented with others had a BMI in the obese range were four times the odds for participants who lived with a family member (OR=4.1; 95% CI= 1.48 – 11.23) with the prevalence of obesity positively associated with living situations understood as more independent support contexts.

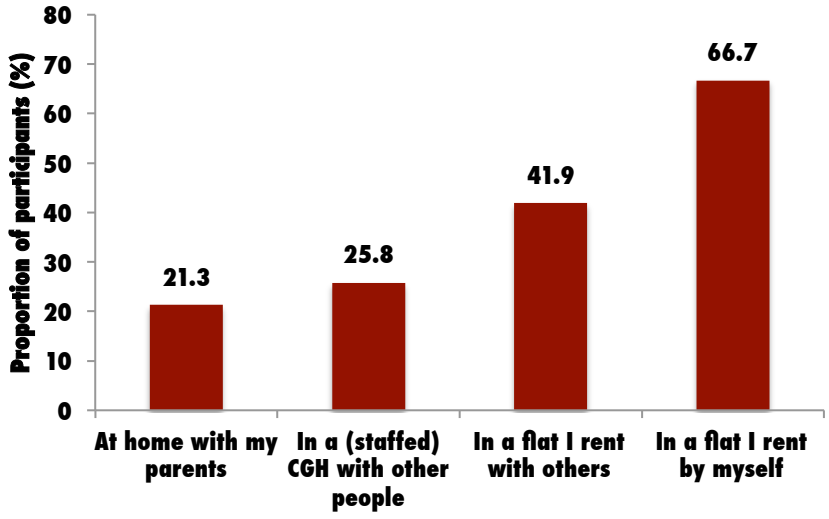

Figure 17 The prevalence of obesity by living situation

The NZ Health Survey has consistently reported that within the general population the proportion of adults with a BMI within the obese range increased sharply for people living in the most deprived neighbourhoods (NZDep2006 quintile 5)[34, 35]. Given the more limited access people with learning disabilities who live in more independent support contexts have to resources, it is likely, therefore that material deprivation also contributed to this finding. People with a learning disability who currently live more independently may also have been less likely

to have nutritional literacy or the development and oversight of healthy eating habits acknowledged as an element of purchased staff support.

Four out of every ten female participants (39.7%; 95% CI= 28.64 – 50.85) had a BMI in the obese range, compared to 26.9% of male participants (26.9%; 95% CI= 17.70 – 36.06) and although this finding is aligned with international research, the difference in the prevalence of obesity between male and female participants was not found to make a statistically significant unique contribution to explaining variation in obesity in the adjusted model.

When compared to women in the general population, however, women with a learning disability were found to be at greater risk of being exposed to the health related risks of obesity than other New Zealand women.

Despite New Zealand having the third highest obesity rate in the OECD[34], women who participated in the Special Olympics Health Promotion screen were significantly more likely to have a BMI in the overweight and obese range (73.1%: 95% CI= 63.0 – 83.1) than women in the New Zealand general adult population (59.5%)[viii] and were similarly more likely to have a BMI in the obese range (39.7%; 95% CI= 28.6 - 50.9) than women in the New Zealand general adult population (28.8%; 95% CI= 27.4 - 30.3) in the year ending June 2011[35].

Male participants, on the other hand, were slightly less likely to have a BMI in the overweight and obese range (62.4%; 95% CI= 52.3 -72.4) than men in the New Zealand general population (68.3%)[viii] and were as likely to have a BMI in the obese range (26.9%; 95% CI= 17.7 – 36.1) than were other men living in New Zealand communities (28.1%; 95% CI= 26.2 – 30.0).

Table 18 compares estimates for the proportion of adult New Zealanders within each BMI classification range in the year ending June 2007 with similarly classified adult Health Promotion screen participants. Not surprisingly, adult Health Promotion screen participants were found to be less likely to have a BMI in the normal range 31.0% (95% CI= 24.0 – 38.0) and were more likely to have a BMI in the obese range than adult New Zealanders who completed the New Zealand Health Survey (36.1%; 95% CI= 35 - 0-37.1)[34].

Table 18 The proportion of Health Promotion screen participants and adult New Zealanders within each BMI classification range

	NZ Health Survey Prevalence (95%CI)	NZ Health Survey Prevalence (95%CI)
Underweight	1.8 (0.2 – 3.7)	1.3 (1.0 - 1.6)
Normal range	31.0 (24.0 – 38.0)	36.1 (35.0-37.1)
Overweight	34.5 (27.3 – 41.7)	36.2 (35.2-37.1)
Obese (all classes)	32.7 (25.6 – 39.9)	26.5 (25.5-27.5)

[viii] *Confidence intervals for the prevalence of overweight or obese were not published in the New Zealand Health Survey 2011/12*

As noted, female participants accounted for the observed trend towards higher levels of obesity in the study sample. In the New Zealand general population, women were found to be significantly more likely than men to have a BMI both in the normal and extreme obesity ranges. Whilst the finding that women who participated in the Health Promotion screen (24.4%; 95% CI= 14.6 – 34.1) were less likely than men (36.6; 95% CI= 26.6 - 46.5) to have a BMI in the normal range aligns with international disability research, it is a odds with differences in the average body size reported for men and women in the New Zealand general population.

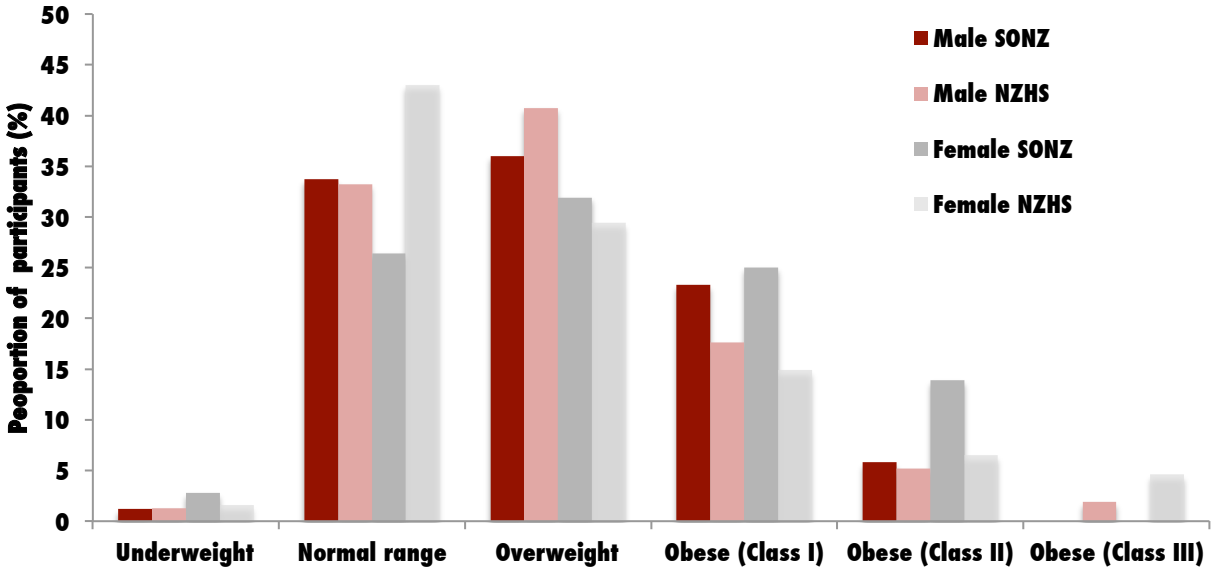

Figure 18 The proportion of Health Promotion screen participants and adult New Zealanders within each BMI classification by sex

In the year ending June 2007, women in the New Zealand general population were also significantly more likely to have a BMI in the extremely obese range (Obese classes II & III) and in this respect, women who participated in the Health Promotion screen mirrored findings reported for the general population. Women participants (15.4; 95% CI= 7.2 – 23.6) were significantly more likely than male participants (5.4%; 95% CI= 0.7 – 10.1) to have a BMI in the obese (class II) range. The odds that a woman participant would have a BMI in the obese (class II) range were three times higher than for men (OR=3.2; 95% CI= 1.08 – 9.53), although, because male participants were 1.4 times more likely to be a Special Olympic athlete, caution needs to be exercised interpreting this sex-related finding.

Special Olympic athletes were less likely to have a BMI in the overweight and obese (64.0%: 95% CI= 55.1 – 73.0) and obese ranges (28.9%; 95% CI= 20.5 – 37.4) than non-athletes (73.7%; 95% CI= 61.9 – 85.5) and (40.4%; 95% CI= 27.2 – 53.5) respectively, but athlete status was not found to make a statistically significant unique contribution to explaining variation in the likelihood participants would have a BMI above 25-kg/m^2 (overweight or obese) or above 30.05kg/m^2 (obese).

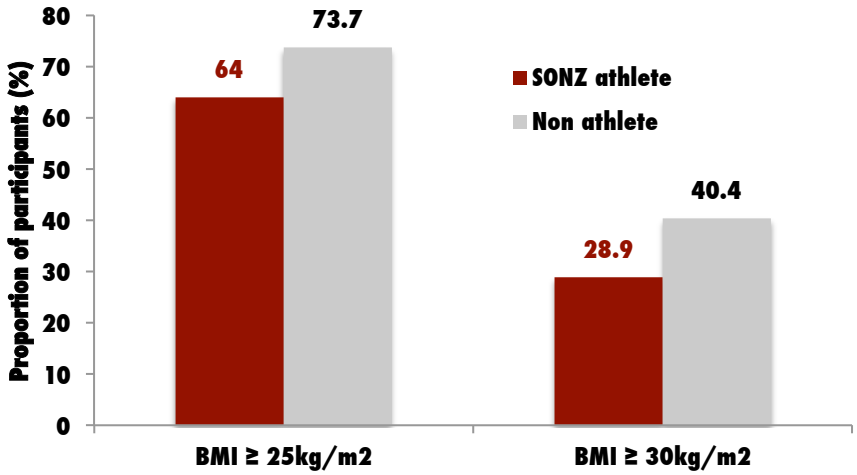

Figure 19 The proportion of Health Promotion screen participants with a recorded BMI in the overweight and obese and obese range by athlete status

4.7 Did having Down syndrome or taking psychoactive medication predict obesity?

Higher levels of obesity have also been reported in the literature for adults with Down syndrome and for people with a learning disability who regularly take psychoactive medication.

No association was found between the prevalence obesity and medication type. Sixty-two percent of participants who were recorded as taking anticonvulsant medication had a BMI within the obese range (61.5%; 95% CI= 30.9 – 92.1) compared to 31% of participants who did not take anticonvulsant medication (31.1%; 95% CI= 22.2 – 40.1), however it is likely the small number of participants taking anticonvulsant medication (n=13) made it difficult to detect any association.

Participants with Down syndrome were more likely (41.2%; 95% CI= 23.8 – 58.6) to have a BMI within the obese range than participants who did not have Down syndrome (31.5; 95% CI= 23.2 – 39.7), however no association between Down syndrome and the likelihood of having a BMI within the obese range was found either.

5 High blood pressure (Hypertension)

Blood pressure is a measure of pressure on the walls of blood vessels exerted by circulating blood. High blood pressure (hypertension) is a known risk factor for heart disease, stroke and renal failure.

The World Health Organization (WHO) recently estimated that one in three adults worldwide have high blood pressure with the prevalence of hypertension increasing with age from one in ten people aged between 20-30 years old to five in ten people aged 50-60 years old[41]. The WHO selects a priority area of public health concern as the theme for World Health Day, and in 2013, the theme is high blood pressure.

The New Zealand Ministry of Health estimated that, in the year ending June 2012, one in six adult New Zealanders took medication for high blood pressure, but noted that the 16% of people who self-reported taking blood pressure medication in the New Zealand Health Survey (15.8%; 95% CI= 15.1 – 16.5) underestimated the true prevalence of hypertension in the New Zealand general population[35]. Women were more likely to be taking medication for high blood pressure (17.1%; 95% CI= 16.1 – 18.0) than men (14.5% CI= 13.4 – 15.5) and the rate of medicated high blood pressure increased with age. Approximately half of New Zealand adults aged 65 years or older took medication for high blood pressure.

Little is known about the prevalence of high blood pressure in people who have a learning disability. Special Olympics International recently estimated that more than 20% of Special Olympic athletes had elevated blood pressure[42] but no research has sought to describe the prevalence of hypertension in people with a learning disability living in New Zealand.

Systolic and diastolic arterial blood pressure (brachial artery) was measured once in participants' left (n=170) and right (n=143) arms and the analysis that follows uses data recorded for the more frequently measured left arm.

A systolic pressure above 139mmHg and diastolic pressure above 89mmHg are the most widely used thresholds for classifying high blood pressure and these were adopted as identifying screen participants at risk of having high blood pressure and associated health conditions.

Left arm systolic and diastolic blood pressures were recorded for 170 participants who completed the Special Olympics Health Promotion screen.

5.1 Systolic blood pressure

Systolic blood pressure ranged between 90.0 - 158.0mmHg with a mean systolic blood pressure of 122.3mmHg found for screen participants (122.3 mmHg; 95% CI= 120.4 – 124.1). Twenty-one participants (12.4%; 95%CI= 7.4 – 17.4) were recorded as having a systolic blood pressure higher than 139mmHg.

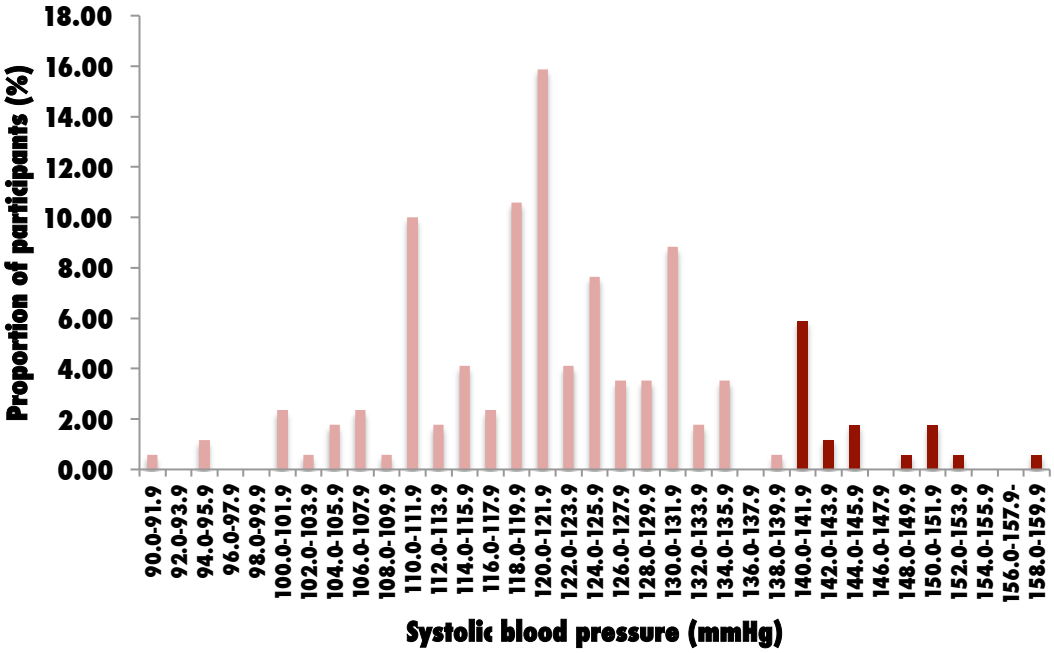

Figure 20 Left arm systolic blood pressure (mmHg)

Seventeen participants were recorded as taking blood pressure/cholesterol/heart condition medication (11.5%; 95%CI= 6.3 – 16.7), slightly lower than the proportion of New Zealand adults estimated as taking medication for high blood pressure and one in five participants either had a systolic blood pressure greater than 139mmHG and/or were recorded as taking blood pressure/cholesterol/heart condition medication (20.0%; 95% CI= 13.0 – 26.1).

Direct binary logistical regression was performed to assess what impact a range of demographic characteristics had on the likelihood participants were recorded as having a systolic blood pressure greater than 139mmHG and/or were recorded as taking blood pressure/cholesterol/heart condition medication. Participants' sex, age and living situation were entered as independent variables within the adjusted model and participants' sex and age were found to make unique, statistically significant contributions to explaining variation in the likelihood that participants had a systolic blood pressure greater than 139mmHG and/or were recorded as taking blood pressure/cholesterol/heart condition medication.

Table 19 Association between participant' demographic characteristics and medicated or high systolic blood pressure

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	25 (25.3)				
	Female	9 (12.7)	0.047	0.029	0.362	0.146 – 0.902
Age			0.001	0.002	1.056	1.021 – 1.093
Ethnicity	NZ European & Other	33 (20.2)				
	Maori	1 (14.3)	0.701			
Athlete status	SONZ athlete	24 (21.6)				
	Non-athlete	10 (16.9)	0.469			
Living situation	Family / Family like	8 (14.5)	0.124	0.358		
	Community Group Home	12 (19.0)	0.517	0.346	0.568	0.175 – 1.843
	Supported Living Context	14 (31.1)	0.051	0.835	1.133	0.349 – 3.679
Location	Dunedin	18 (17.0)				
	Palmerston North	16 (25.0)	0.208			

Consistent with findings reported for the New Zealand general population, systolic blood pressure and the rate at which participants were talking medication for a heart or circulatory condition increased with participants' age. For every year a participant aged, the odds that their systolic blood pressure would be higher than 139mmHg and/or they would be recorded as taking blood pressure/cholesterol/heart condition medication increased by 6% when other factors in the adjusted model were controlled for (OR=1.06: 95% CI= 1.02 - 1.09).

The prevalence of high systolic blood pressure peaked for participants aged between 50 - 59 years. A systolic blood pressure in excess of 139mmHg was detected in 29% of participants (29.2%; 95% CI= 9.6 – 48.8) and approaching four out of every ten participants aged between 50 - 59 years had a high systolic blood pressure or took blood pressure/cholesterol/heart condition medication (37.5%; 95% CI= 16.6 – 58.4). Although the prevalence of high systolic blood pressure was lower for participants aged over 60 years (25%; 95% CI= 0.0 – 100.0), participants aged over 60 years were more likely to be taking blood pressure/cholesterol/heart condition medication which, if managed well, may have reduced the prevalence of hypertension in this age cohort. Half of the participants aged over 60 years had a systolic blood pressure in excess of 139mmHg and/or took blood pressure/cholesterol/heart condition medication (50.0%; 95% CI= 0.0 – 100.0).

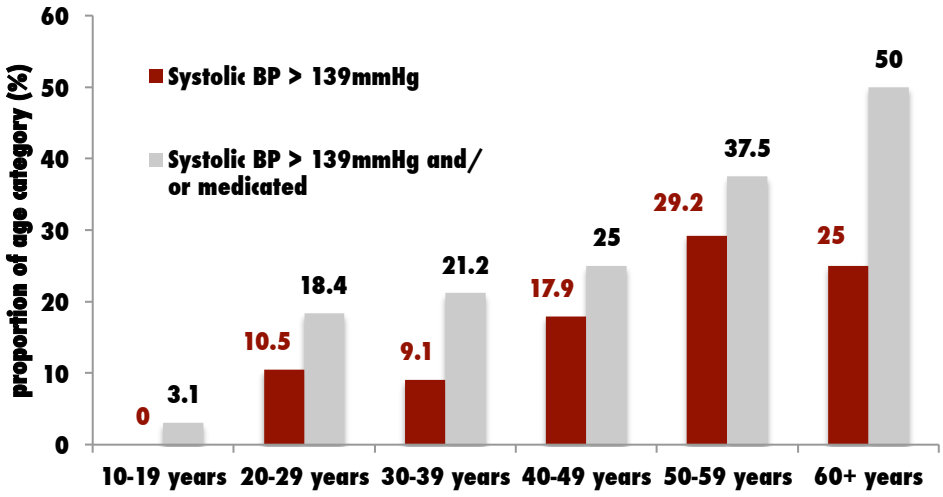

Figure 21 The prevalence of high systolic blood pressure including participants recorded as taking blood pressure/cholesterol/heart condition medication

In the absence of research that has used direct measures hypertension, little is known either about the "true" prevalence of high blood pressure in the New Zealand general population or, therefore, whether people with a learning disability are more or less exposed to the health related risks of high blood pressure than other New Zealanders. Comparing the self-reported use of medication to treat high blood pressure reported by New Zealanders who completed the New Zealand Health Survey with the prevalence of medication use by Health Promotion screen participants revealed the rate at which medication was prescribed to participants for heart or circulatory health conditions was lower than the prevalence of medication use for high blood pressure reported for the New Zealand population. It is important to note that findings reported for the New Zealand Health Survey relate only to medication prescribed for high blood pressure, excluding, we assume, medication prescribed for high cholesterol and heart conditions, included in the more general medication classification adopted for analysis of the SONZ Health Promotion screen.

When considered alongside the very small proportion of participants aged 40-60 years who appeared to have systolic blood pressure effectively managed by medication, this finding introduces the possibility people with a learning disability may be at greater risk of experiencing a range of health related conditions associated with "undetected" hypertension than other New Zealanders.

Given the known association between age and hypertension and the younger age profile of people with a learning disability, extreme caution needs to be exercised interpreting these findings. When medication use by participants was compared to their age peers in the general population, participants were more likely to be taking medication prescribed to treat either high blood pressure, high cholesterol or a heart condition than their age peers were to be talking medication prescribed for high blood pressure alone. Although the higher prevalence of medication use by Health Promotion screen participants was repeated across all comparable age categories, the rate of prescribing for participants aged between 45-54 years

(17.4%; 95% CI= 0.6 – 34.2) and 55-64 years (37.5%; 95%CI= 0.0 – 80.8) was found to approximate the self-reported use of medication to treat high blood pressure in the general population (13.5; 95% CI= 11.7 - 15.4 and 29.2; 95% CI= 26.9 – 31.6, respectively). This finding is consistent with the possibility that people with a learning disability aged between 40 - 60 years may represent a population at greater risk of undetected hypertension, however the high levels of prescribing among younger participants may also be explained by a higher incidence of detected heart conditions or other co-morbidities in younger people with a learning disability.

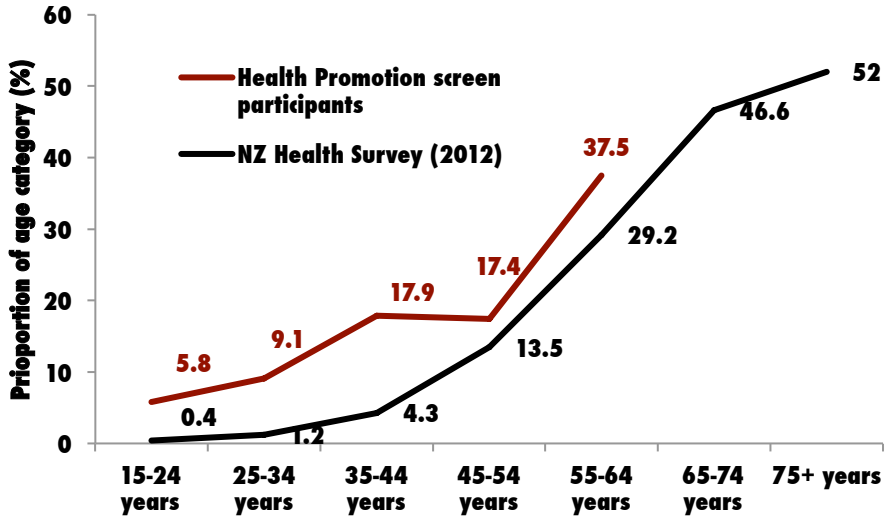

Figure 22 The prevalence of medication prescribed for high blood pressure/cholesterol/heart condition for Health Promotion screen participants and high blood pressure in the New Zealand general population by age category

The sex of participants also emerged as a significant predictor of the risk of having a high systolic blood pressure and/or taking medication for high blood pressure/cholesterol/heart condition. Mean (average) systolic blood pressure peaked for both males and females over the age of 50 years and the mean systolic blood pressure of males was higher than for females across all age categories.

Unlike the New Zealand general population where women were more likely than men to be taking medication for high blood pressure, one quarter of male participants had a systolic blood pressure greater than 139mmHg and/or took medication prescribed for high blood pressure/cholesterol/heart condition (25.3%: 95% CI= 16.5 – 34.0) compared to only 13% of female participants (12.7%; 95% CI= 4.8 – 20.6). The odds that a female participant would have a systolic blood pressure higher than 139mmHg and/or they would be recorded as taking blood pressure/cholesterol/heart condition medication were 60% lower than the odds for males when other factors in the adjusted model were controlled for (OR= 0.4; 95% CI= 0.15 – 0.90). Male participants were also more likely to self-report taking medication to treat high blood pressure/cholesterol/heart condition (14.0%; 95% CI= 6.5 – 21.4) than female participants (8.1%; 95% CI= 1.1 -15.0) although the difference between sexes was not found to be statistically significant.

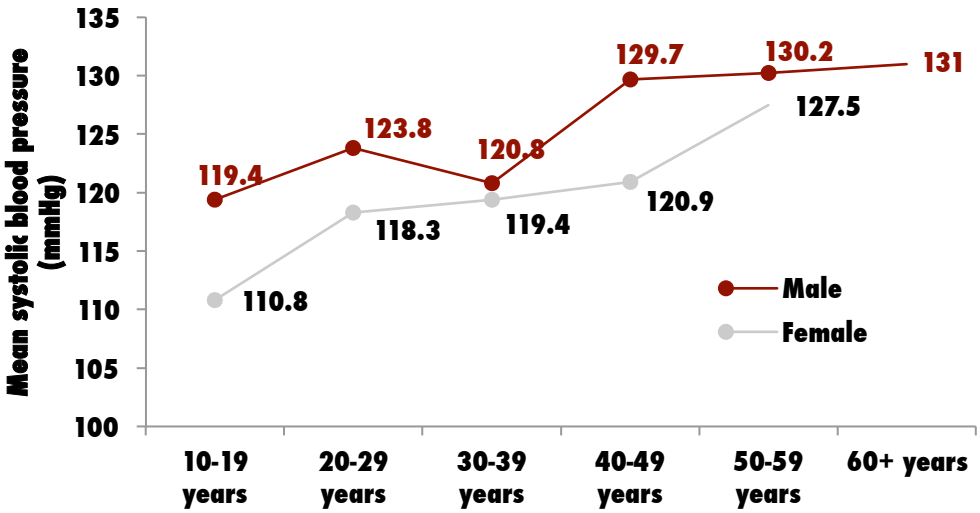

Figure 23 The mean systolic blood pressure of male and female participants by age category

5.2 Diastolic blood pressure

Diastolic blood pressure ranged between 50.0 - 95.0mmHg with a mean diastolic blood pressure of 75.2mmHg found for screen participants (75.2mmHg; 95% CI= 73.8 – 76.7). Sixteen participants (9.4%; 95% CI= 5.0 – 13.9) were recorded as having a diastolic blood pressure greater than 89mmHg.

Seventeen percent of participants either had a diastolic blood pressure greater than 89mmHg and/or they were recorded as taking blood pressure/cholesterol/heart condition medication (17.0%; 95% CI= 11.3 – 22.6).

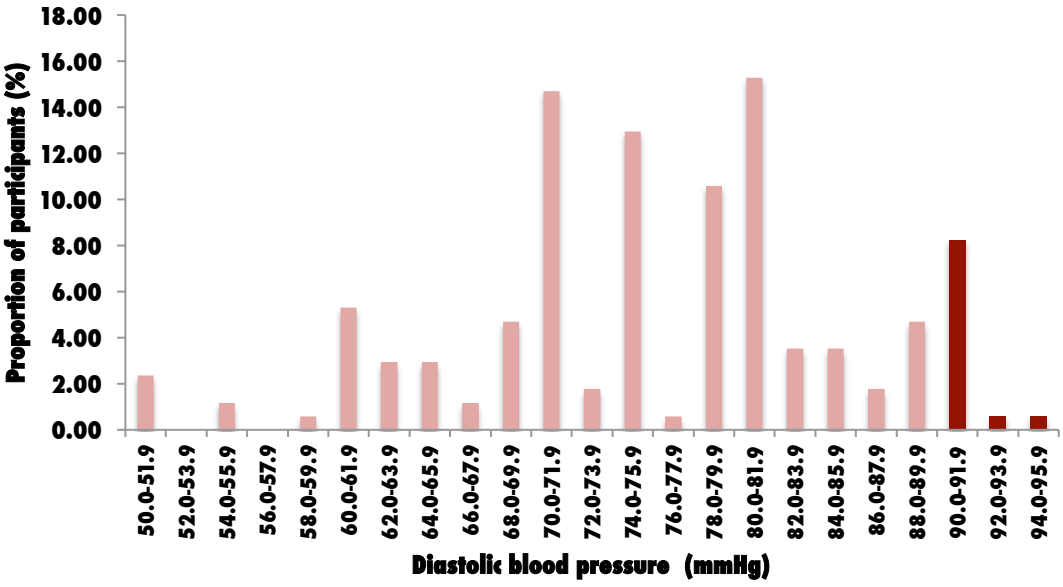

Figure 24 Left arm diastolic blood pressure (mmHg)

Similar to the findings reported above for systolic blood pressure, participant' age made a statistically significant unique contribution to explaining variation in the likelihood they would have a diastolic blood pressure above 89mmHg and/or were recorded as taking blood pressure/cholesterol/heart condition medication.

Participants' age and living situation were entered as independent variables within an adjusted binary logistical regression model performed to assess what impact a range of demographic characteristics had on the likelihood they were recorded as having diastolic blood pressure above 89mmHg and/or took blood pressure/cholesterol/heart condition medication.

For every year a participant aged the odds that their diastolic blood pressure would be greater than 89mmHg and/or they were recorded as taking blood pressure/cholesterol/heart condition medication increased 8% (OR=1.08; 95% CI= 1.03 – 1.12), very similar to that found within the adjusted model for systolic blood pressure.

Table 20 Association between participant' demographic characteristics and diastolic hypertension and/or taking blood pressure/cholesterol/heart condition medication

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	17 (17.2)				
	Female	12 (16.7)	0.931			
Age			<0.001	<0.001	1.076	1.033 – 1.120
Ethnicity	NZ European & Other	27 (16.5)				
	Maori	2 (28.6)	0.412			
Athlete status	SONZ athlete	18 (16.2)				
	Non-athlete	11 (18.3)	0.725			
Living situation	Family / Family like	5 (9.1)	0.003	0.127		
	Community Group Home	7 (10.9)	0.739	0.289	0.464	0.113 – 1.916
	Supported Living Context	15 (33.3)	0.004	0.607	1.420	0.373 – 5.411
Location	Dunedin	17 (16.0)				
	Palmerston North	12 (18.5)	0.682			

As was also the case for systolic blood pressure, the prevalence of high diastolic blood pressure peaked for participants aged between 50 - 59 years, of whom, in excess of one in three participants had a diastolic blood pressure greater than 89mmHg (37.5%; 95% CI= 16.6 – 58.4) and half had a diastolic blood pressure greater than 89mmHg and/or took medication prescribed for high blood pressure/cholesterol/heart condition (50.0%; 95% CI= 28.4 – 71.6).

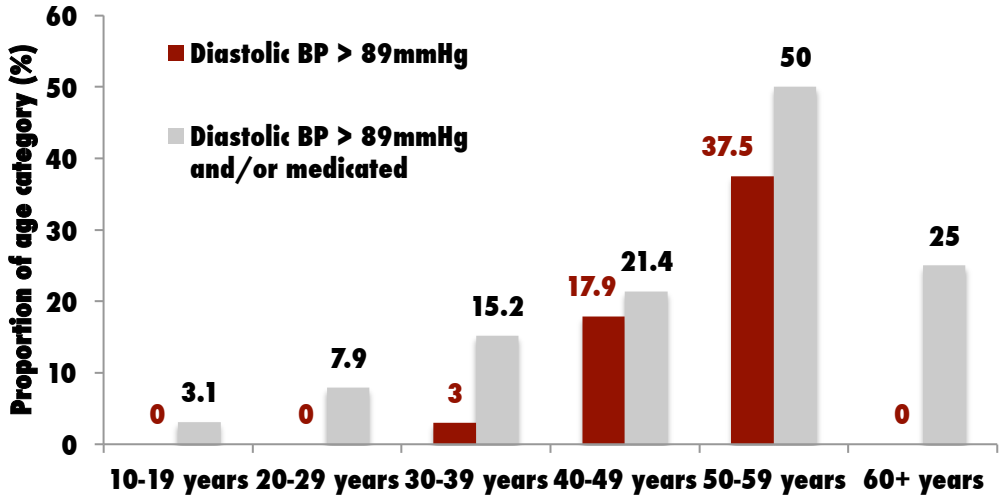

Figure 25 The prevalence of high diastolic blood pressure including participants recorded as taking blood pressure/ cholesterol/heart condition medication

Unlike for systolic blood pressure, no association was found between participant sex and diastolic hypertension or the likelihood participants would have a diastolic blood pressure greater than 89mmHg and/or took blood pressure/cholesterol/heart medication.

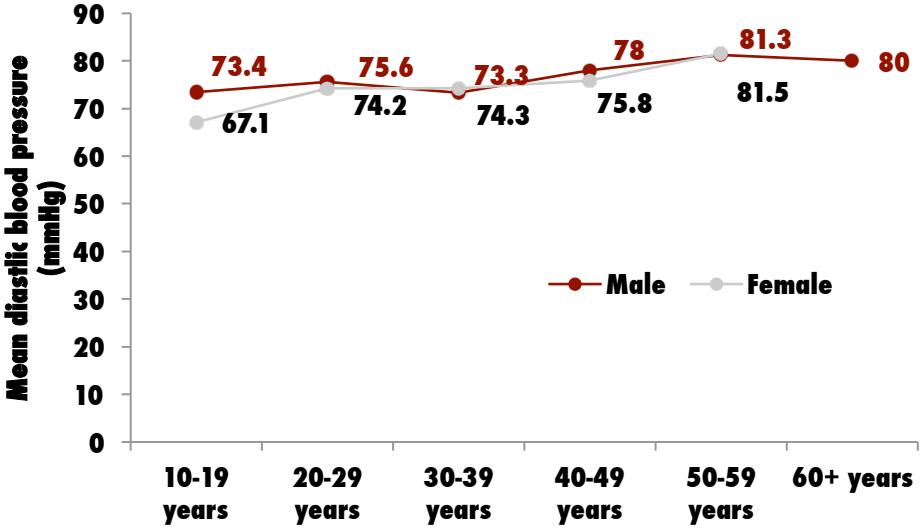

Figure 26 The mean diastolic blood pressure of male and female participants by age category

5.3 Was their any association between hypertension and body size?

Modifiable risk factors for high blood pressure include physical activity, salt and alcohol intake and obesity.

A small, statistically significant positive correlation was found between participant BMI and their systolic blood pressure ($r=0.193$, $p<0.001$) and a moderate, statistically significant positive correlation found between participant BMI and their diastolic blood pressure ($r=0.303$, $p<0.001$) using Pearson product-moment correlation coefficient.

Hierarchical multiple regression was used to assess how much additional variance in systolic and diastolic blood pressure was explained by participant BMI after controlling for the age, sex, athlete status and living situation of participants and whether they were Special Olympic athletes or not.

Slightly more than 17% of variance in systolic blood pressure was explained when the four control variables were entered at Step 1. After entering participant BMI, at Step 2, the total variance in systolic blood pressure explained by the model as a whole was 22% with participant BMI explaining an additional 4.% of variance (r square change=0.042, $p=0.007$).

In the final model, participant BMI made the third most important statistically significant unique contribution to explaining variation in systolic blood pressure (beta=0.218, $p=0.007$) behind participant age (beta= 0.315, $p<0.001$) and sex (beta= -0.257, $p=0.002$).

Participant BMI made a more important contribution to explaining variation in participant diastolic blood pressure. When the four control variables were entered in Step 1, the resultant model explained 12% of the total variance in diastolic blood pressure. Entering BMI at Step 2 explained an additional 7% of variance (r square change=0.074, $p<0.001$) and participant BMI (beta = 0.289, $p< 0.001$) emerged as a more important predictor of diastolic blood pressure than age (beta= 3.171, $p= 0.002$) in the final model. No other variables entered into the final model made a statistically significant unique contribution to explaining variation in diastolic blood pressure.

As was reported in Chapter 5, an association was found between participants' living situation and obesity. Perhaps not surprisingly, therefore, a similar relationship was also found between participants' living situation and the likelihood that they were recorded as having high systolic or diastolic blood pressures and/or were taking medication for high blood pressure/cholesterol/heart condition.

Forty percent of participants who lived in a flat by themselves had systolic hypertension and/or were taking medication prescribed for high blood pressure/cholesterol/heart condition (40.0%; 95% CI= 3.1 – 76.9) compared to 14% of participants who lived in their family home (13.5%; 95% CI= 3.9 – 23.1) and 30% of participants who lived in a flat by themselves had diastolic hypertension and/or were taking medication prescribed for high blood

pressure/cholesterol/heart condition (30.0%; 95% CI= 0.0 – 64.6) compared to 10% of participants who lived in their family home (9.6%; 95% CI= 1.3 – 17.9).

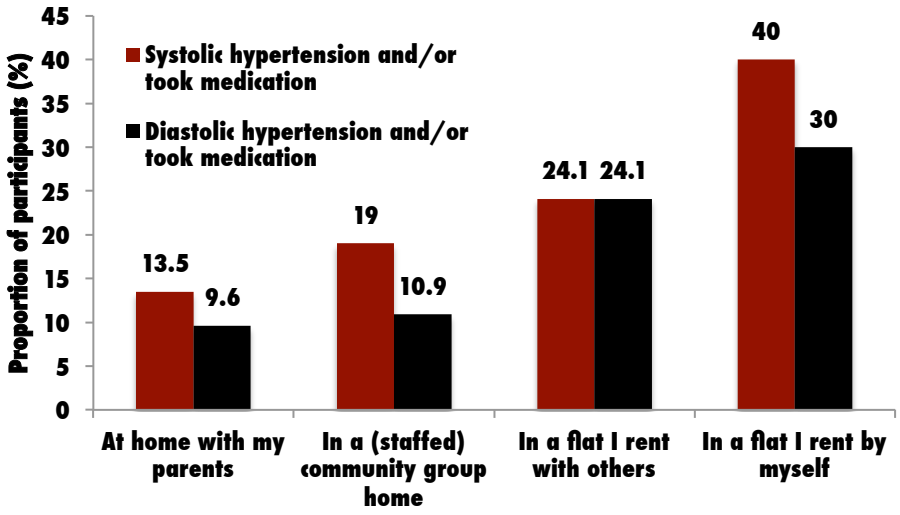

Figure 27 The prevalence of systolic and diastolic hypertension and/or medication use for high blood pressure/cholesterol/heart condition by living situation

Chapters 8 & 9 describe differences in the health behaviour of participants that may also have contributed to people living more independently to be at greater risk of hypertension. People living flats, for example, were more likely to smoke and were significantly less likely to eat fruit and other vegetables daily. Participants who lived in flats were also, however, more likely to be older. The mean age of participants who lived at home with their parents was 22.1 years (95% CI= 19.5 – 24.6) almost half the age participants who lived in a flat they rented with others (40.8y ears; 95% CI= 36.1 – 45.5) and 35.3 years for people who lived in a flat by themselves (95% CI= 26.6 – 44.0) and when age was controlled for in the adjusted model, participants' living situation failed to make a statistically significant unique contribution to explaining variation in either diagnosed or undiagnosed systolic or diastolic hypertension.

5.4 Did taking psychoactive medication influence systolic or diastolic blood pressure?

Forty-one participants were recorded as taking one or more psychoactive medications. The mean systolic (m=122.0mmHg; 95% CI= 118.2 – 125.7) and diastolic (m=75.4 95% CI= 72.6 – 78.3) blood pressure of participants who took psychoactive medication was marginally higher than for those who did not (m=121.0mmHg; 95% CI= 118.4 – 123.5 and m=74.9, 95% CI= 72.7 – 77.1, respectively) and no significant difference was found between either the systolic or diastolic blood pressure of people who did and did not take psychoactive medication.

A series of independent sample t-tests were conducted to compare the mean systolic and diastolic blood pressure of participants who did and did not take different types of

psychoactive medication. The only medication type for which a statistically significant difference in blood pressure was detected was for participants who did or did not take antidepressant medication. The diastolic blood pressure of participants who took antidepressant medication (m=80.3mmHg, 95% CI= 77.8 – 82.7) was significantly higher than participants who did not take antidepressant medication (m=74.3mmHg; 95% CI= 72.4 – 76.2) but the magnitude of the difference in means (mean diff=5.92mmHg, 95%CI= 0.9 -10.9) was very small (eta=0.04).

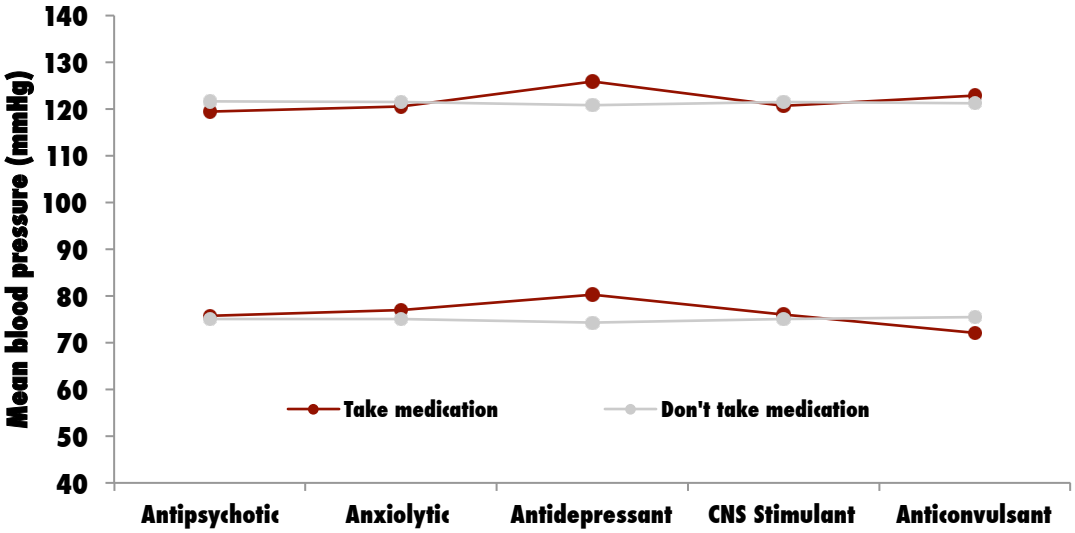

Figure 28 The mean systolic and diastolic blood pressure of participants recorded as taking or not taking a range of psychoactive medication

5.5 Estimating the prevalence of undiagnosed high blood pressure

Because high blood pressure is usually asymptomatic, many people who have high blood pressure remain unaware of the condition.

As noted above, 17 participants were recorded as taking medication prescribed either for high blood pressure, high levels of cholesterol or a heart condition, of whom four (23.5%) were recorded as continuing to have a high systolic and/or high diastolic blood pressure.

The proportion of participants with high systolic or diastolic blood pressure who were not recorded as taking medication for the condition provides an indicator of the prevalence of undiagnosed hypertension.

Four out of every five participants who had a systolic blood pressure above 139mmHg did not take medication prescribed for high blood pressure, high levels of cholesterol or a heart condition (n=17, 81.0%). If one assumed that every participant who took medication for high blood pressure, high levels of cholesterol or a heart condition had at one time been diagnosed with a systolic blood pressure above 139mmHg, the prevalence of undiagnosed high systolic blood pressure was approximately 50 percent.

Three out of every four participants who had a diastolic blood pressure above 89mmHg did not take medication prescribed for high blood pressure, high levels of cholesterol or a heart condition (n=12, 75.0%). If one assumed that every participant who took medication for high blood pressure, high levels of cholesterol or a heart condition had at one time been diagnosed with a diastolic blood pressure above 89mmHg, the prevalence of undiagnosed high diastolic blood pressure was 41.4% percent.

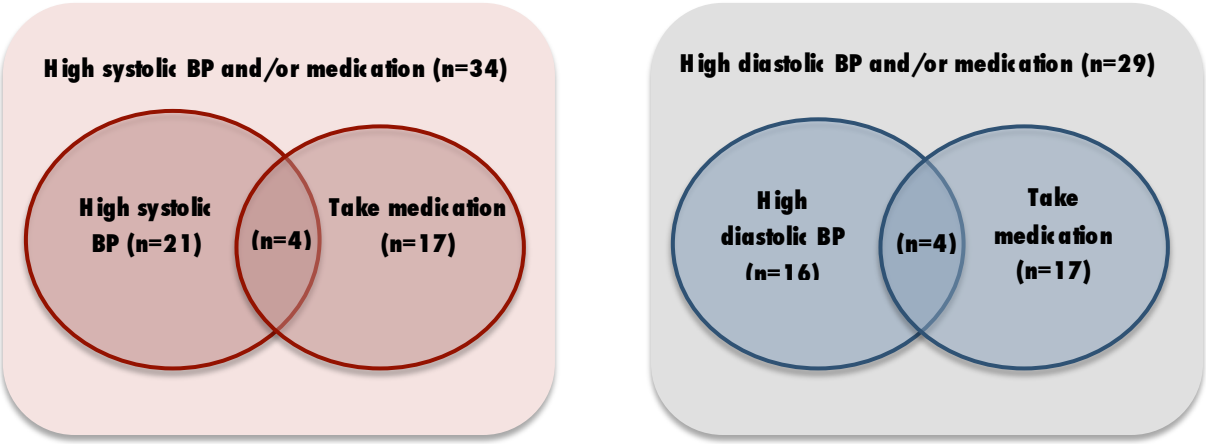

Figure 29 The number of participants with systolic and diastolic hypertension and who self-reported taking medication for high blood pressure/cholesterol/heart condition

6 Osteoporosis

Osteoporosis is the thinning of the bones and occurs when bone mineral density is reduced as a consequence of insufficient new bone being formed, too much bone is reabsorbed, or both. Osteoporosis causes bones to become brittle and more likely to fracture and is more common in women, particularly following menopause when a drop in oestrogen results in accelerated bone loss. Other modifiable risk factors include; heavy alcohol consumption, vitamin D deficiency, tobacco smoking, malnutrition, low body weight, low levels of weight bearing physical activity and the long-term use of some medications, including oral steroids, L-Thyroxine over-replacement and lithium use.

In the 2006/07 New Zealand Health Survey one in 34 adults surveyed reported having being told by a doctor that they had osteoporosis (2.9%; 95% CI= 2.6 - 3.2)[34]. Consistent with epidemiological evidence, the New Zealand Health Survey also found the age standardised prevalence of osteoporosis to be much higher for women than men with the risk of osteoporosis increasing significantly as age increased for women.

Although an increased prevalence of osteoporosis among people with learning disability and higher rates of fracture in adults with a learning disability living in residential support settings have consistently been documented in international research[43], few studies have identified the risk factors for low bone density in people with a learning disability. In the small number of studies that have been conducted, non-ambulation, anticonvulsant use - especially in postmenopausal women and Down syndrome have been identified as potential risk factors for osteoporosis and osteopenia[44],[45]. No research has sought to describe the prevalence of osteoporosis in people with a learning disability living in a New Zealand context.

Osteoporosis is conventionally diagnosed when bone mineral density is less than or equal to 2.5 standard deviations below that of a young healthy adult of the same sex and ethnicity (T-score ≤ -2.5). The World Health Organisation has established diagnostic guidelines for classifying bone mass density degeneration and these have been adopted for analysis.

Ultrasound measurement of the calcaneus (heel bone) bone mineral density of participants screened at the Dunedin site were conducted and participant T-scores recorded and grouped according to the WHO diagnostic classification categories.

Bone mineral density T-scores were recorded for seventy-three participants who completed the Special Olympic Health Promotion screen.

6.1 Bone Mineral Density

Bone mineral density (BMD) T-scores for the 38 male and 35 female participants who provided data ranged between T= -3.9 - -4.1. Unlike findings reported for the New Zealand general population, female participants were more likely (77.1%; 95% CI= 62.5 – 91.8) than male participants (57.9%; 95% CI= 41.5 – 74.3) to have a bone mineral density within the normal range with the mean BMD for males also found to be slightly lower (m= -0.52, sd=1.25) than for female participants (m= 0.19, sd=1.48). No association was found, however, between participant sex and the likelihood they would have a bone mineral density within the normal range.

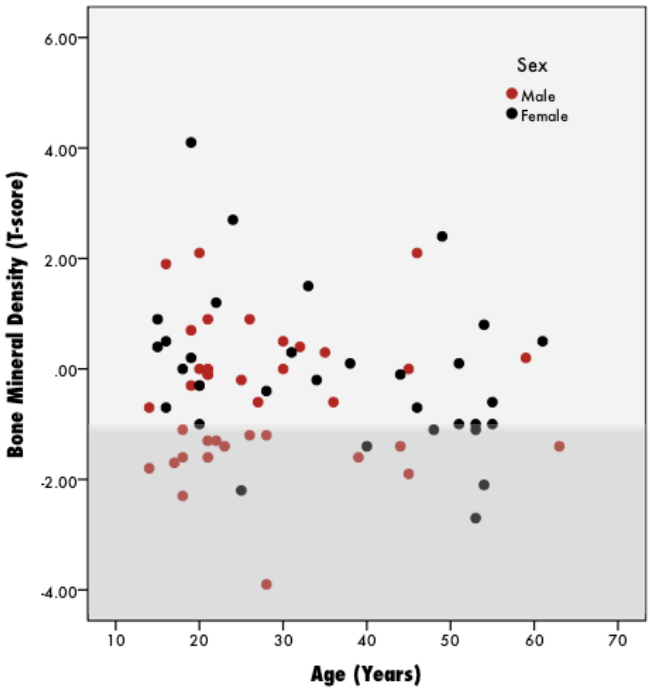

Figure 30 The bone mineral density (T-socores) of male and female participants by age

6.2 Osteopenia

Osteopenia is a condition where bone mineral density is lower than normal but not low enough to be classified as osteoporosis. It is considered by some physicians to be a precursor to osteoporosis. Forty percent of male (39.5%; 95% CI= 23.2 – 55.8) and 17% of female participants (17.1%; 95%CI= 4.0 – 30.3) had a bone mineral density within range used to categorise osteopenia.

Table 21 The bone mineral density of male and female participants by WHO diagnostic category

	Overall		Male		Female	
	n	Prevalence (95%CI)	n	Prevalence (95%CI)	n	Prevalence (95%CI)
Normal range	49	67.1 (56.1 – 78.2)	22	57.9 (41.5 – 74.3)	27	77.1 (62.5 – 91.8)
Osteopenia	21	28.8 (18.1 – 39.4)	15	39.5 (23.2 – 55.8)	6	17.1 (4.0 – 30.3)
Osteoporosis	3	4.1 (-0.6 – 8.8)	1	2.6 (-2.7 – 8.0)	2	5.7 (–2.4 – 13.8)

The prevalence of osteopenia did not vary greatly across age categories for male or female participants, peaking for males aged between 35-44 years (50%; 95%CI= 0.0 – 1.0) and 55-64 years (50%; 95% CI= 0.0 – 1.0), of whom osteopenia was detected in one in every two males, and for females aged between 35 - 44 years (33.3%; 95% CI= 0.0 – 1.0) and 45 - 54 years (30.0%; 95% CI= 0.0 – 64.6), of whom osteopenia was detected in one out of every three females.

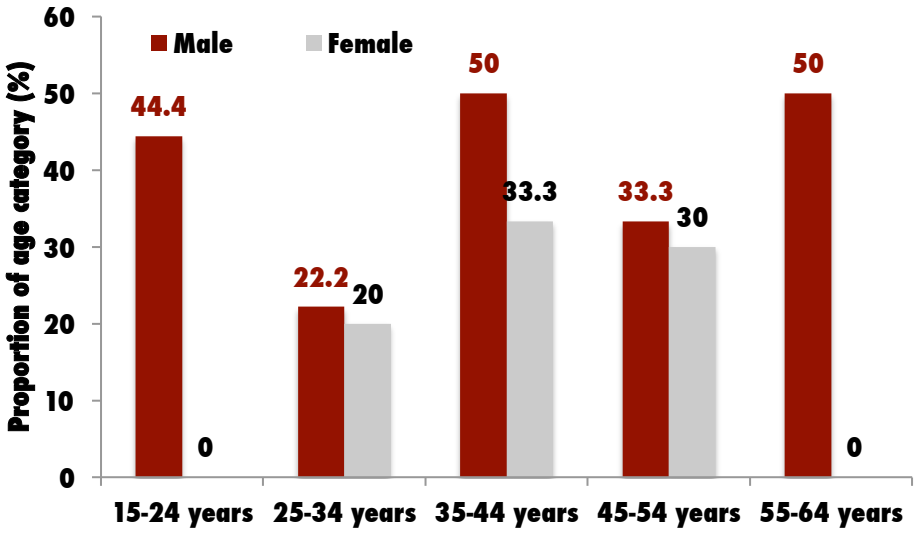

Figure 31 The prevalence of osteopenia for male and female participants by age category

6.3 Osteoporosis

Three participants had a BMD T-score less than or equal to 2.5 standard deviations below that of a young health adult of the same sex and ethnicity – one male participant aged 28 years and two female participants, one of whom was aged 53 years and another whose age could not be determined.

Four percent of Health Promotion screen participants were found to have a BMD within the range used to classify osteoporosis (4.1%; 95% CI= 0.0 – 8.8). The prevalence of osteoporosis indicated by bone mineral density alone was therefore slightly higher for SONZ participants than was self-reported by the general population, however, given the small sample size, and difference both in population age-sex profiles and the inclusion criteria used for both surveys, little can be read into comparison.

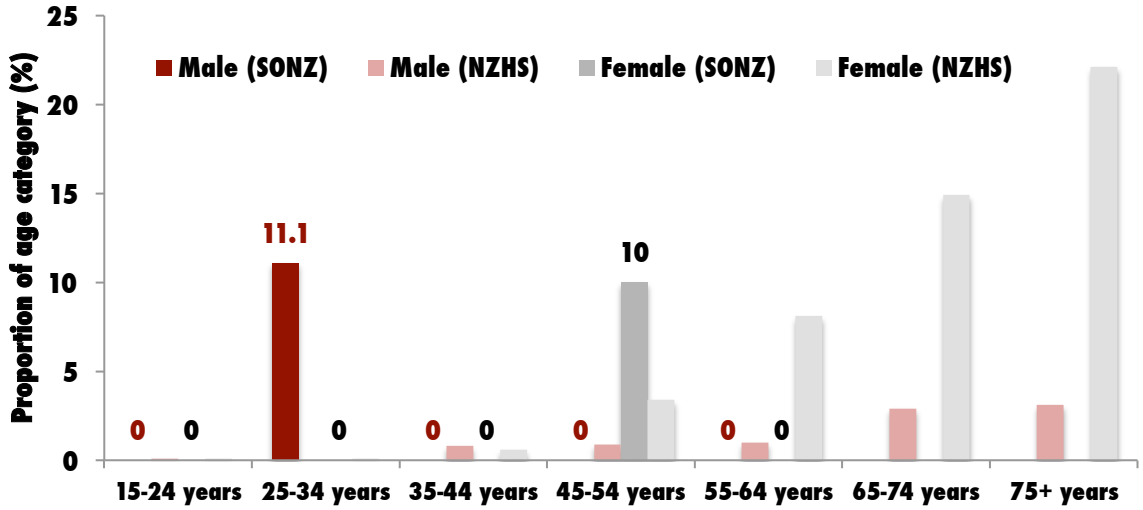

Figure 32 The prevalence of osteoporosis for male and female participants by age category

No obvious association was found between bone mineral density and the age of the small number of participants tested in the SONZ Health Promotion screen.

6.4 Bone mineral density less than the normal range

One out of every three Health Promotion Screen participants had a bone mineral density less than the normal range (32.9%; 95% CI= 21.8 – 43.9). As a consequence of the high proportion of male participants who had a bone mineral density within range used to categorise osteopenia, male participants were more likely to be recorded as having a bone mineral density lower than the normal range (42.1%; 95% CI= 25.7 – 58.6) than female participants (22.9%; 95% CI = 8.2 – 37.5). Although the 19.2 difference in the prevalence of bone thinning between male and female participants failed to achieve statistical significance (95% CI= 0.0 – 41.3; p=0.082), the finding that males with a learning disability were more likely to present with bone thinning is inconsistent with findings reported for the general population and therefore warrants further investigation.

Fifteen Special Olympic athletes had a bone mineral density less than the normal range and despite the proportion of athletes who had a BMD T-score <-0.1 being slightly greater (35.7%; 95% CI= 20.6 – 50.8) than for non-athletes (29.0%; 95% CI= 12.1 – 46.0), the difference was not statistically significant.

Direct binary logistical regression was performed to assess what impact a range of demographic characteristics had on the likelihood their bone density T-score would less than the normal range (T-score < -0.1). Participant sex was the only independent variable that exceeded the threshold for entry into an adjusted model, but as noted previously, failed to achieve statistical significance.

Table 22 Association between participant' demographic characteristics and a bone mineral density less than the normal range

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	16 (42.1)				
	Female	8 (22.9)	0.084		0.407	0.147 – 1.128
Age			0.662			
Ethnicity	NZ European & Other	24 (32.9)				
	Maori	-	-			
Athlete status	SONZ athlete	15 (35.7)				
	Non-athlete	9 (29.0)	0.549			
Living	Family / Family like	8 (27.6)	0.633			
situation	Community Group Home	7 (41.2)	0.345			
	Supported Living Context	8 (34.8)	0.577			
Location	Dunedin	24 (32.9)				
	Palmerston North	-	-			

A series of independent sample t-tests were also conducted to explore the strength of association between previously identified risk factors and the likelihood participants would have a BMD less than the normal range, including whether participants were recorded as taking anticonvulsant medication, self identified as having Down syndrome and whether they smoked or not. It was not possible to explore the strength of relationship between the regularity of participant's physical activity and their bone mineral density.

Of the six participants who were recorded as taking anticonvulsant medication, no participant had a bone mineral density T-score less than the normal range.

Five of twelve participants who self-reported having Down syndrome had a bone mineral density score below the normal range (29.4%; 95% CI= 5.3 – 53.6) and 34% of participants who self-reported not having Down syndrome (33.9%; 95%CI= 21.1 – 46.7) with no association was found between Down syndrome and the likelihood a participant's bone mineral density would not be within the normal range.

Three out of every five participants who reported using tobacco products (60%; 95% CI= 0.0 – 1.0) did have a bone mineral density less than the normal range compared to 31% of participants who did not smoke (30.8%; 95% CI= 19.2 – 42.3, however, the small number of participants who smoked prevented a meaningful comparison.

7 Diabetes

Diabetes is a metabolic condition characterised by raised blood glucose due to insulin deficiency or insulin resistance. In addition to being an important cause of mortality in New Zealand, diabetes can lead to cardiovascular disease, blindness, and poor circulation.

Recent estimates of the prevalence of diabetes within the general population of New Zealand adults vary as a consequence of differences in sampling strategy and timing. Common agreement exists, however, that the prevalence of diabetes in the New Zealand population has been slowly increasing over time, especially for adult women[35].

The New Zealand Health Survey 2011/12 found approximately one in eighteen[35] New Zealanders had doctor-diagnosed diabetes (excluding diabetes during pregnancy) which was a statistically significant increase in the rate of diagnosed diabetes than was self-reported by New Zealand adults in the 2006/07 Health Survey. In 2011/12, men (6.0%; 95% CI= 5.3 – 6.6) were 1.2 times as likely to self-report being diagnosed with diabetes than women (5.0%; 95% CI = 4.4 – 5.6) when standardised for age and the risk of being diagnosed with diabetes increased with age. New Zealanders aged 55 years or older were more likely to have previously been diagnosed with diabetes with one in ten adults aged over 65 years self-reporting the diagnosis.

Research has also consistently reported undiagnosed or poorly controlled diabetes to be relatively common in the New Zealand and other national populations. The New Zealand Adult Nutrition Survey 2008/09 estimated that one in four cases of diabetes as indicated by a blood test were undiagnosed and that only half of adults who had been diagnosed had good diabetes control[46]. Little is known about the prevalence of diabetes in people with a learning disability or how well they manage their blood sugar levels following diagnosis.

A number of international studies have reported that the prevalence of diabetes for people with a learning disability appears to be similar to the general population in the UK and USA[9], but recent research conducted by the New Zealand Ministry of Health found that, when adjusted for age, people with a learning disability were almost twice as likely to receive diabetes care or treatment as people without a learning disability in New Zealand in the year ending June 2008 [11].

The Ministry of Health's estimate of the prevalence of diabetes was generated by counting how many people received public health treatment for diabetes (excluding diabetes during pregnancy), took two or more diabetes related prescription medicines, used services at a diabetic clinic or were referred for four or more blood glucose tests. The Ministry of Health found 7.3% of all people with a learning disability received one or more of the types of diabetes care or treatment they sampled for and that, when adjusted for age, females (8.0%) were more likely than males (6.5%) to receive diabetes care or treatment. Given that the prevalence of diabetes is generally found to be higher in males, this finding suggests that rate

of undiagnosed and/or untreated diabetes may be higher for New Zealand men with a learning disability.

Consistent with epidemiological research, the Ministry of Health also found the prevalence of diabetes increased with age with people with a learning disability aged between 65-74 years being most likely to receive diabetes care or treatment (24.6%) followed by those aged over 75 years (21.2%).

Obesity is a major risk factor for diabetes and, in comparison with the general population, people with Down syndrome have an increased probability of being obese. A small number of studies appear to indicate people with Down syndrome are more at risk of having diabetes at a younger age[9].

Participants were asked if they had diabetes and if so, to indicate whether they had Type 1 or Type 2 diabetes.

Diabetes medication was also coded for in the section that asked participants to name any medication they were currently taking (excluding PRN).

One hundred and seventy-one participants indicated whether they had diabetes or not and provided self or proxy reported information about whether they routinely took diabetic medication.

7.1 Self-reported diabetes

The prevalence of self-reported diabetes among adult SONZ Health Promotion screen participants was lower than both the Ministry of Health' estimate of the proportion of people with a learning disability who received diabetes care or treatment in the year ending July 2008 and the overall prevalence reported for the New Zealand general population by the Ministry of Health. Four male (4.3%; 95% CI= 0.1 – 8.4) and two female (2.6%; 95% CI= 0.0 – 6.2) participants reported having Type 2 diabetes.

Table 23 Estimates for the prevalence of diabetes for the New Zealand adult population, people with a learning disability and Special Olympic Health Promotion screen participants

	Overall Prevalence (95%CI)	Male Prevalence (95%CI)	Female Prevalence (95%CI)
NZ Adult Health Survey (2011/12)	5.5 (5.0 – 5.9)	6.0 (5.3 – 6.6)	5.0 (4.4 – 5.6)
MoH Health Indicators for NZID (2007/08)	7.3	6.5*	8.0*
SONZ Health Promotion Screen (2012)	3.5 (0.7 – 6.3)	4.3 (0.1 – 8.4)	2.6 (0.0 – 6.2)

* Adjusted for age

It is possible, however that self-report may be an especially poor way to estimate the prevalence of diabetes for people with a learning disability given the potential for participants

to either not recall the diagnosis or misperceive the question or for the rate of undiagnosed diabetes to be different for this population of New Zealanders.

Both within the general population and in people with a learning disability, the prevalence of diabetes is known to increase with age. In the New Zealand Health Survey 20011/12 the prevalence of diabetes was highest in men aged 65-74 years, who were significantly more likely than women in the same age group to report having doctor diagnosed diabetes. In the New Zealand Health Survey 2011/12, 84% of adults who self-reported being diagnosed with diabetes were aged 45 years or older.

Five of the six participants who reported having diabetes in the Health Promotion screen were aged 44 years or older, including three participants aged between 55 - 64 years. A 21 year-old man also self-reported having been diagnosed diabetes.

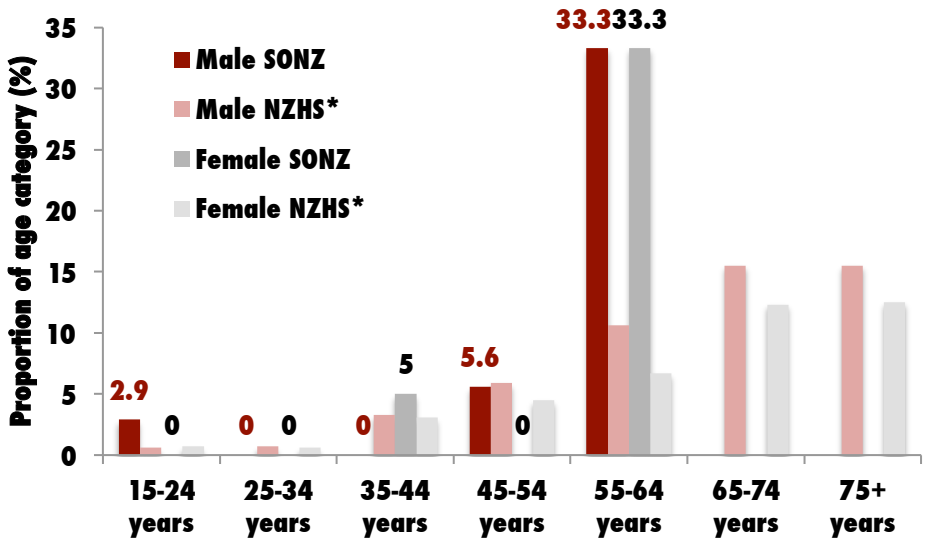

Figure 33 The prevalence of self-reported diabetes for male and female participants by age category

Direct binary logistical regression was performed to assess what impact a range of demographic characteristics had on the likelihood participants would self-report having been diagnosed with diabetes. Participant age was the only variable to exceed the threshold for inclusion in an adjusted model and a statistically significant association was found between age and the prevalence of self-reported diabetes. For every year participants aged, the likelihood they would self-report having been diagnosed with diabetes increased by 1.1 times (p= 0.018; 95% CI= 1.02 – 1.18).

Table 24 Association between participant' demographic characteristics and self-reported diabetes

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	4 (4.3)				
	Female	2 (2.6)	0.562			
Age			0.018		1.094	1.015 – 1.179
Ethnicity	NZ European & Other	6 (3.7)				
	Maori	0 (0)				
Athlete status	SONZ athlete	3 (2.7)				
	Non-athlete	3 (5.2)	0.405			
Living	Family / Family like	0 (0)	0.394			
situation	Community Group Home	2 (3.0)	0.997			
	Supported Living Context	4 (9.5)	0.172			
Location	Dunedin	3 (2.8)				
	Palmerston North	3 (4.8)	0.482			

7.2 Currently taking diabetes medication

Two male (2.3%; 95% CI= 0.0 – 5.6) and one female (1.6%; 95% CI= 0.0 – 4.8) participant self-reported taking medication prescribed to manage diabetes. Of the three participants who self-reported diabetes but for whom no medication information was recorded, two did not know what medication they took and one did not know and the person administering the screen had relied on a proxy informant.

Estimates of the prevalence of undiagnosed diabetes in the New Zealand population vary from one-quarter[46] up to one half[47] of the total population of New Zealanders who have Type 1 or Type 2 Diabetes. Although the small sample size precluded any definitive conclusions, the small proportion of participants who self-reported being diagnosed with diabetes coupled with evidence of elevated levels of obesity seems to suggest people with a learning disability may represent a population who also have high levels of undiagnosed diabetes.

7.3 Was there an association between obesity and diabetes?

Half of the participants who self-reported having Type 2 diabetes (n=3) also had a BMI in Obese range (50.0%; 95% CI= 0.0 – 1.0), but the small number of participants prevented valid statistical testing.

The type of data collected also made it difficult to make any inferences about the nutritional literacy or eating behaviour of participants and the likelihood they would self-report having diabetes. Similarly, only three of the six participants who self-reported having diabetes participated in the Palmerston North screen and were therefore asked how many days per week they exercised for at least 30 minutes. Diabetes is also a known risk factor for high blood pressure. Systolic and diastolic blood pressure data was available for five of the six participants who self-reported having diabetes of whom 40% had a systolic blood pressure higher than 139mmHg and/or were taking blood pressure/cholesterol/heart condition medication (95%CI = 0.0 – 1.0), however, the small number of participants also prevented valid statistical testing of this potential association.

8 Smoking cessation

Tobacco smoking is the primary cause of lung cancer and chronic obstructive pulmonary disease and is a risk factor for cardiovascular disease, a number of respiratory diseases and a range of other cancers.

In 2011, the New Zealand Government identified smoking as the single leading preventable cause of early death in New Zealand and adopted Recommendation 1 of the Māori Affairs Committee Inquiry into the tobacco industry in Aotearoa, to make New Zealand smoke-free by 2025[48]. In 1990, the government had previously sought to provide legal protect from second hand smoke by passing of the Smoke-free Environments Act 1990 and a number of public health campaigns have subsequently promoted smoking cessation, none of which have been specifically identified disabled New Zealanders as a target population.

Smoking rates have been gradually falling in New Zealand since the 1970. In 2012, the Ministry of Health estimated that less than one in five adult New Zealanders currently smoked (18.4%, 95% CI= 17.4 – 19.5)[35]. No difference was detectable between the age-adjusted prevalence of current smoking between New Zealand men (19.4%; 95% CI= 17.9 – 20.8) and women (17.5%; 95% CI= 16.3 – 18.7), however the same study found that although the daily smoking rate had decreased between the 2006/07 and 2011/12, a statistically significant decrease in the daily smoking rate had occurred for men, but not for women.

Among people who currently smoked, most smoked at least once a day and almost two-thirds of current smokers self-reporting smoking between 6 – 20 cigarettes a day (63%). Younger adults were more likely to be current smokers, particularly for women. Smoking peaked for women between the ages of 18-24 years (30.8%; 95% CI= 25.9 – 35.9). Men aged between 25-34 years were, on the other hand, more likely to be current smokers (30.7%; 95% CI= 26.7 – 34.9) with smoking declining with age for both genders thereafter.

A small number of international studies conducted in the 1990s found that whilst, as a group, people with a learning disability may be less likely to smoke, people with a mild impairment tended to have smoking habits similar to the general population[9], although typically without being aware of the association between smoking and respiratory disease.

Participants were asked if they used tobacco products with supplementary questions that sampled for the type of tobacco product used (with; cigarettes, cigars, pipe and chew tobacco as choice points) and how many participants smoked (per day, per week, per month or per year as choice points).

Participants were also asked if anyone smoked in front of them (with; dad, mum, grandparents, brothers and sisters, partner, care staff, relatives, coach, friends, and others as choice points).

One hundred and ninety participants responded to questions related to the use of tobacco products and 165 participants responded to questions related to exposure to the smoking behaviour of other people.

8.1 Use of tobacco products

Approximately one in fifteen participants self-reported using tobacco products (6.8%; 95% CI = 3.2 – 10.5), far fewer than the approximately one in five adults reported as being current smokers in the New Zealand Health Survey 2011/12. Eleven participants said they smoked cigarettes and one reported chewing tobacco.

Most current smokers for whom data was available smoked at least once a day (90%; 95% CI= 67.4 – 100.0) however, unlike the New Zealand general population, seven out of every ten participants reported smoking fewer than 6 cigarettes per day (70.0%; 95% CI= 35.4 – 100.0) compared to two out of every three current smokers who reported smoking between 6-20 cigarettes per day in the New Zealand Adult Health Survey 2011/12.

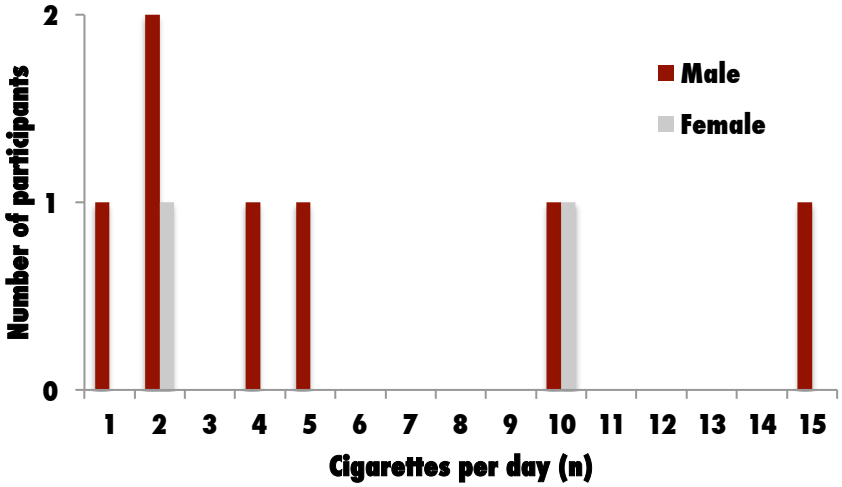

Figure 34 The number of cigarettes current smokers self-reported smoking per day

Similarly, whereas no difference was found between the likelihood men or women would smoke in the general population, male participants (9.7%; 95% CI= 3.9 – 15.5) were almost three times more likely to report using tobacco products than female participants (3.4%; 0.0 – 7.3)

Despite it being illegal to purchase tobacco, the New Zealand Health Survey 2011/12 found 8% of New Zealanders aged between 15-17 years self-reported being current smokers. No Special Olympic Health Promotion screen participant aged between 15-17 years reported using tobacco products.

Direct binary logistical regression was performed to assess what impact a range of demographic characteristics had on the likelihood participants would self-report using tobacco products. Participant' age and screen location were the only variables to exceed the threshold

for inclusion in an adjusted model, however the small number of smokers did not permit more than one potential predictor to be entered into the final model. Without controlling for other factors, no association was found between participant sex or the screen location and the likelihood they would self-report using tobacco products.

Table 25 Association between participant' demographic characteristics and self-reported tobacco product use

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	10 (9.7)				
	Female	3 (3.4)	0.103		0.332	0.088 – 1.248
Age			0.894			
Ethnicity	NZ European & Other	11 (6.0)				
	Maori	2 (25.0)	0.60			
Athlete status	SONZ athlete	9 (7.6)				
	Non-athlete	4 (5.6)	0.612			
Living situation	Family / Family like	0 (0)	0.443			
	Community Group Home	5 (6.8)	0.997			
	Supported Living Context	7 (13.7)	0.202			
Location	Dunedin	11 (9.2)				
	Palmerston North	2 (2.8)	0.109			

A closer examination of the prevalence of smoking behaviour of participants who lived in different living situations did, however, reveal significant differences in the likelihood participants would self-report smoking. Participants who lived at home with their parents (0.0%) or in a staffed community group home with other people (6.8%; 95% CI= 0.9 – 12.6) were least likely to self-report smoking, whereas, similar to the one in five New Zealanders who self-reported being a current smoker, 18 percent of participants who lived in a flat they rented with other people (18.2%; 95% CI= 4.3 – 32.1) said they used tobacco products. Participants who lived in a flat they rented with others were significantly more likely to self-report smoking than participants who lived at home with their parents (p= 0.006; 95% CI= 3.6 – 32.7).

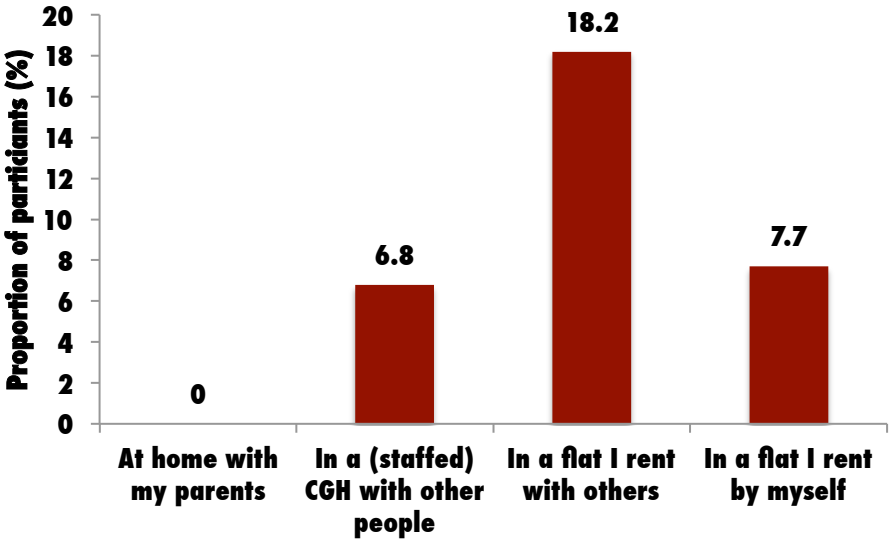

Figure 35 The prevalence of self-reported smoking by living situation

Nine Special Olympic athletes reported using tobacco products. The proportion of athletes who smoked (7.6%) was similar to the proportion of non-athletes who also reported using tobacco products (n=4, 5.6%) and no association was found between athlete status and the likelihood participants would report smoking.

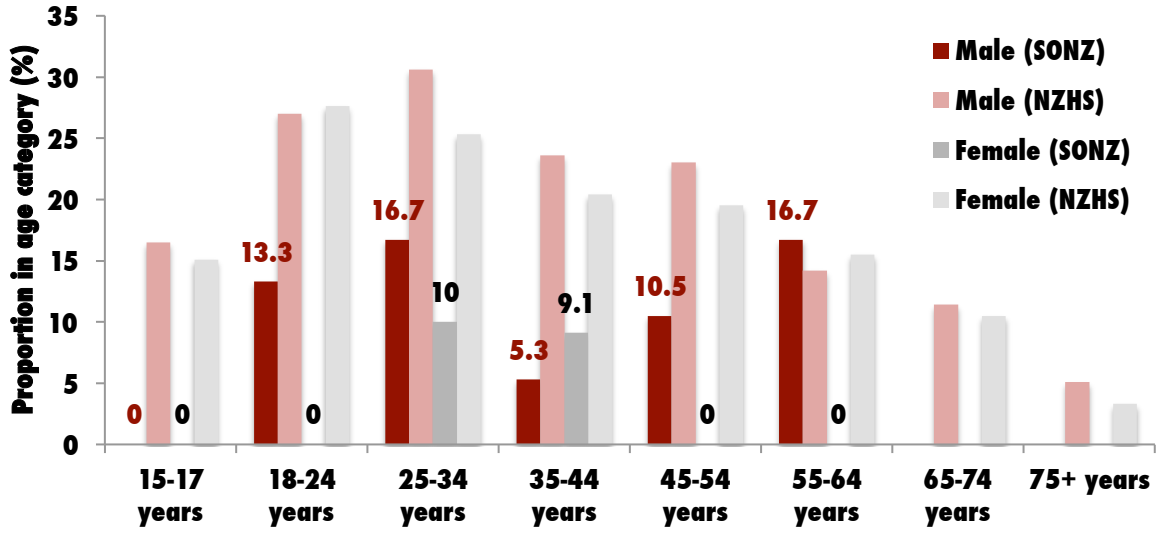

Figure 36 The prevalence of self-reported tobacco use by age category

8.2 Exposure to smoking

Almost half of the participants who completed the Special Olympic Health Promotion screen reported that someone smoked in front of them (44.2%; 95% CI= 36.6 – 51.9).

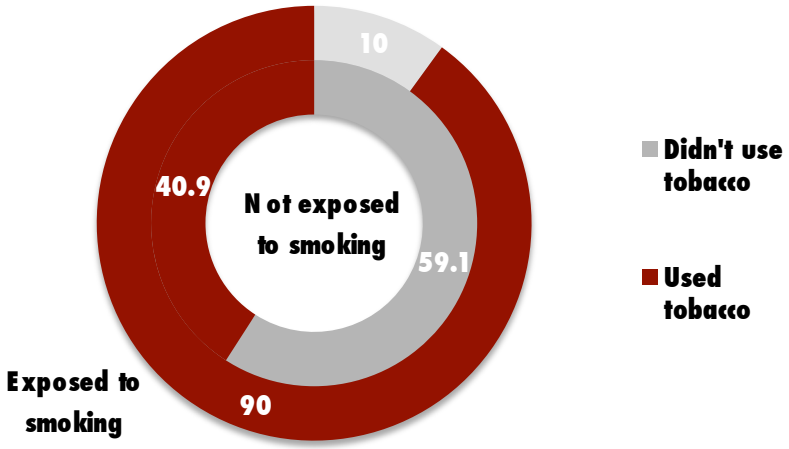

Figure 37 The proportion of smokers and non-smokers exposed to others smoking behaviour

Participants who used tobacco products were much more likely to report that someone smoked in front of them. Ninety percent of participants who said they smoked also reported others smoked in front of them (90.0%; 95% CI= 67.4 – 100.0) whereas 41% percent of participants who did not use tobacco products reported being exposed to others smoking (40.9%; 95% CI= 3.1 – 48.8) and a significant association was between tobacco use and the likelihood others smoked in front of participants.

Whilst not directly comparable, the New Zealand Health Survey 2006/07 found one in 13 adult non-smokers (7.5%, 95% CI= 6.9 - 8.2) were exposed to second hand smoke in their home[34]. The context in which Special Olympic Health Promotion screen participants were exposed to people smoking in front of them was not limited to their home, however, the disparity between self-reported exposure to others smoking between Health Promotion screen participants and the general population suggests that people with a learning disability may be more at risk to exposure to smoking behaviour and second hand smoke.

One possible explanation is that people with a learning disability are exposed to the smoking behaviour of support staff. Participants who did not use tobacco products were most likely to name care staff as exposing them to smoking behaviour (18.6%; 95% CI= 12.2 – 25.0) and 40% of participants who did use tobacco products named staff as a source of their exposure to smoking behaviour (40.0%; 95% CI= 3.1 – 76.9).

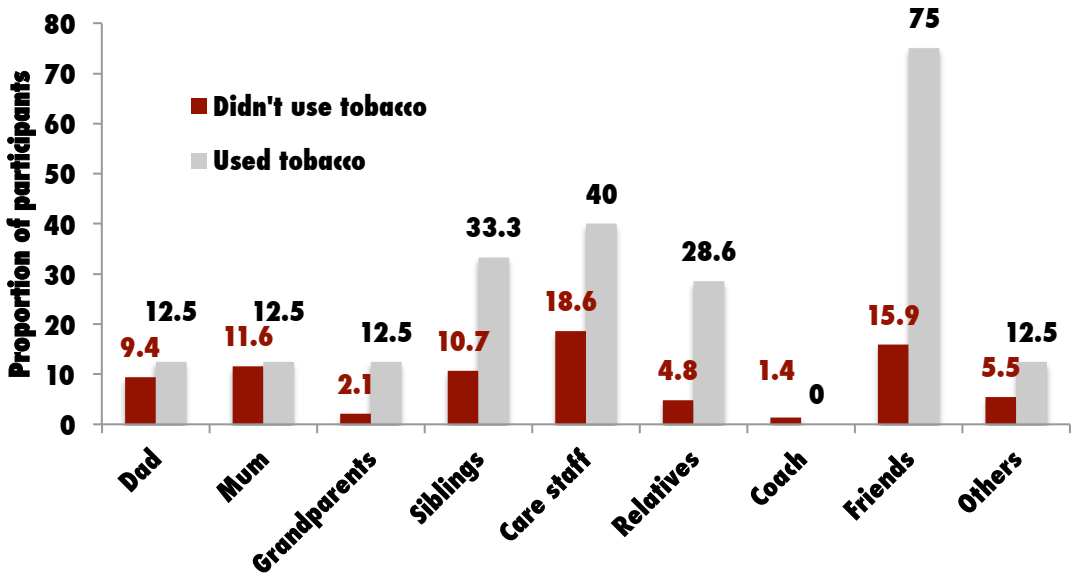

Figure 38 The origin of participants' exposure to smoking

Age peers and/or young people also featured prominently as sources of exposure to smoking behaviour. One out of every three participants who smoked said a brother or sister smoked in front of them (33.3%; 95% CI= 0.0 – 71.8) and three out of every four participants who smoked also had a friend that smoked in front of them (75.0%; 95% CI= 36.3 – 100.0). Friends were also the second most frequently named source of exposure to smoking behaviour participants who did not smoke named (15.9%; 95% CI= 9.8 – 21.9).

Participants who lived at home with their parents were less likely to report being exposed to the smoking behaviour of others (35.6%; 95% CI= 21.0 – 50.1) than living situations where it could reasonably be assumed care staff were more likely to be present. Conversely, almost half of the participants who lived in a staffed community group home described being exposed to the smoking behaviour of other people (47.0%; 95% CI= 34.6 – 59.3) although no association was found between whether participants lived at home with their parents or in a (staffed) community group home and the likelihood they would self-report others smoked in front of them.

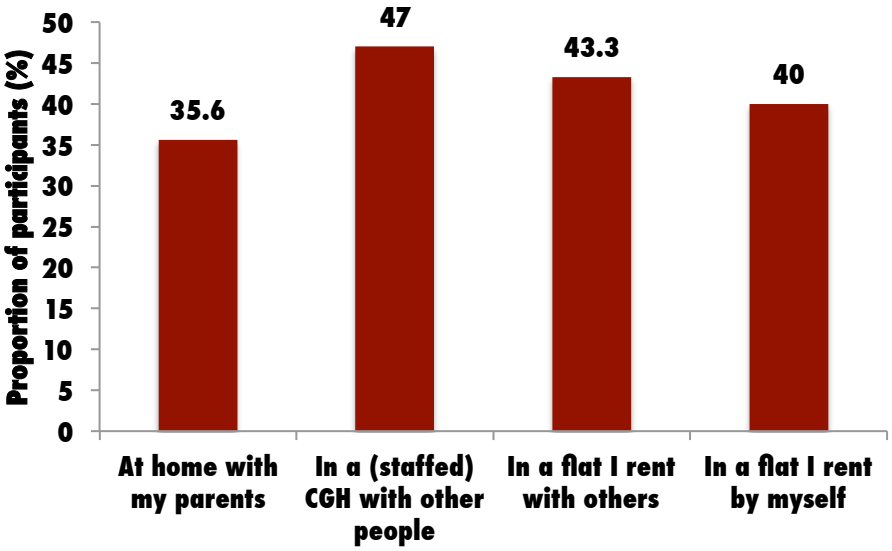

Figure 39 Exposure to smoking by living situation

Direct binary logistical regression was performed to assess what impact a range of demographic characteristics had on the likelihood participants would self-report being exposed to the smoking behaviour of others. The location at which participants were screened was the only potential predictor to reach the threshold for inclusion in the adjusted model.

Table 26 Association between participant' demographic characteristics and exposure to the smoking behaviour of others

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	41 (45.1)				
	Female	32 (43.2)	0.816			
Age			0.799			
Ethnicity	NZ European & Other	71 (44.7)				
	Maori	2 (33.3)	0.620			
Athlete status	SONZ athlete	42 (41.2)				
	Non-athlete	31 (49.2)	0.314			
Living situation	Family / Family like	18 (37.5)	0.600			
	Community Group Home	31 (47.0)	0.314			
	Supported Living Context	19 (42.2)	0.642			
Location	Dunedin	56 (56.6)				
	Palmerston North	17 (25.8)	<0.001		0.266	0.135 – 0.526

Over half of the participants screened in Dunedin said others smoked in front of them (56.6%; 95% CI= 46.6 – 66.5) whereas one in four participants screened in Palmerston North said others smoked in front of them (25.8%; 14.9 – 36.6). The 31% difference in the proportion of participants who self-reported someone smoked in front of them between the two locations was statistically significant (p<0.001; 95% CI= 15.9 – 45.7) suggesting either that the prevalence of smoking within the general population was much higher in the Dunedin than in the Palmerston North region, or that screen administrators and participants interpreted the question differently at each location.

9 Nutrition

In addition to their nutritional value, eating sufficient vegetables and fruit has been shown to protect against heart disease, stroke, hypertension and a range of different cancer types.

In New Zealand, the Ministry of Health recommends adults eat at least three servings of vegetables and at least two servings of fruit per day.

In the latest New Zealand Health Survey, the Ministry of Health (2012) reported that seven out of ten adults self-reported eating at least three servings of vegetables each day but that women were more likely to eat the recommended amount of vegetable servings (72.2%; 95% CI= 70.0 – 74.2) than men (64.4%; 95% CI= 61.8 – 67.1)[35].

New Zealand adults were less likely to eat the recommended amount of servings of fruit. Six out of every ten adults surveyed reported eating two or more servings of fruit each day with women also more likely to eat the recommended amount of servings (64.2%; 95% CI= 62.7 – 65.7) than New Zealand men (52.6%; 95% CI= 50.9 – 54.2).

Older women were more likely to eat the recommended amount of servings of both vegetables and fruit and older men were more likely to eat the recommended amount of servings of vegetables, but no major trend by age was found for men meeting the daily recommended fruit guidelines and less than 60% of men in all age groups ate at least two servings of fruit each day.

A clear relationship was also found between neighbourhood deprivation and the likelihood that New Zealand Health survey respondents would report eating the recommended amount of servings of vegetables and fruit. People living in the most deprived neighbourhoods were less likely to eat three or more servings of vegetables (59%) or two or more servings of fruit (50%) than the proportion of people who ate the recommended amount of servings of vegetables (73%) or fruit (65%) in the least deprived neighbourhoods.

Although a number of New Zealand service providers have developed their own programmes to encourage healthy eating by people who use their service for support, no national health promotion programme has identified disabled people as a target population and little is known either about the nutritional health knowledge, health behaviours or the contribution diet makes to the poorer health outcomes experienced by people with a learning disability.

Participants were asked how often they ate food (i. Daily; ii More than once a week; iii. Never) from five different food group categories (i. Dairy products; ii. Fruit & vegetables, [Dark green & leafy vegetables, Other vegetables and Fruit]; iii. Meat, eggs, poultry, fish, beans & peas; iv. Bread, cereals & grains; v. Fats, oils & sweets).

Between 173 (fats, oils and sweets) – 185 (dark green and leafy vegetables) participants responded validly to questions related to what kind of food they eat each day.

9.1 Food group consumption

In excess of nine out of every ten participants reported eating bread, cereal & grains (94.6%; 95% CI= 91.3 – 97.9), other vegetables (92.0%; 95% CI= 87.9 – 96.0) and meat, eggs, poultry fish, beans or peas (91.1%; 95% CI= 86.9 – 95.3) every day. Conversely, only 17% of participants reported eating fats oils & sweets every day (16.8%; 95% CI= 11.1 – 22.4). It is unlikely that the findings reflect a real difference in the consumption of this food group as the small proportion of participants who reported eating Fats oils and sweets may also reflect a poorer understanding of the sources of food included in this food group and a known bias towards pro-social responding among people with a learning disability.

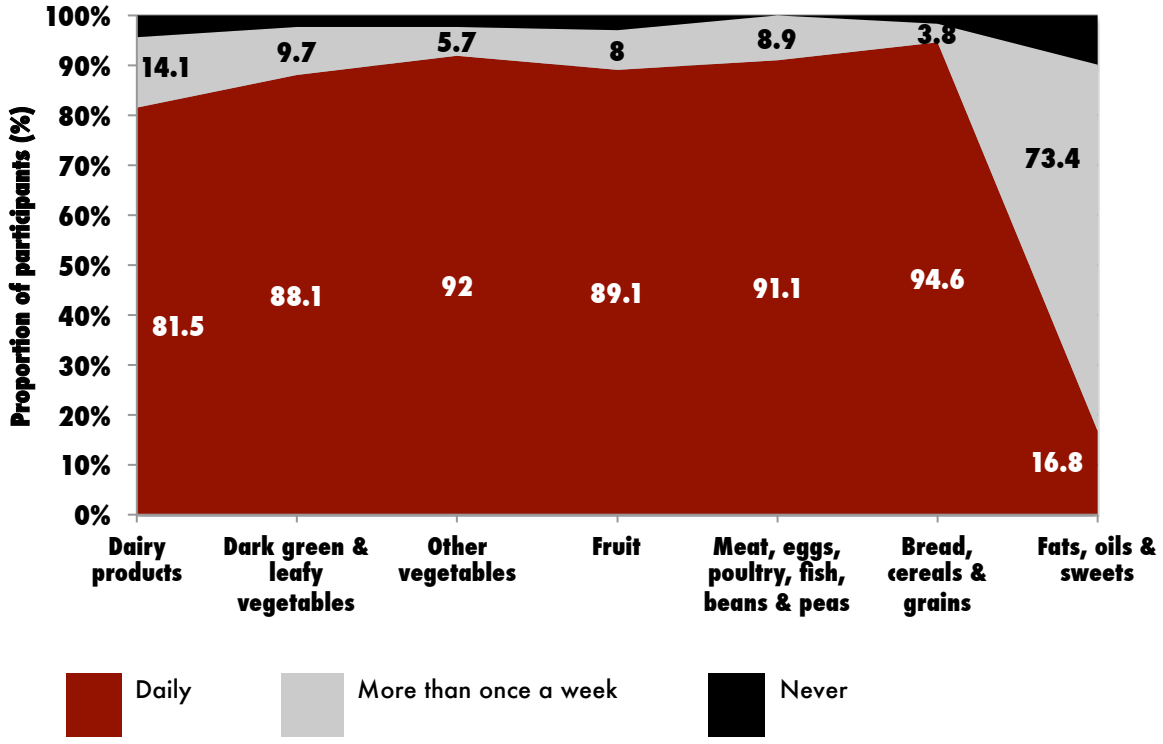

Figure 40 The kind of food participants reported eating each day by food group

A high proportion of participants also reported eating Fruit (89.1%; 95% CI= 84.4 – 93.8) and dark green & leafy vegetables (88.1%; 95% CI= 83.4 -92.8) on a daily basis, although no data was collected on the number of daily servings of vegetables or fruit, preventing a direct comparison to be made with findings for the general population reported in the New Zealand Health Survey.

Little difference was observed between the pattern of consumption of all food groups between male and female participants who completed this element of the SONZ Health Promotion screen. Males were slightly more likely to report eating dairy products (85.6%; 95% CI= 78.5 – 92.7) and meat, eggs, poultry, fish, beans & peas (92.8%; 95% CI= 87.5 – 98.0) every day than female participants (77.0%; 95% CI= 68.0 – 86.0) and (89.2%; 95% CI= 82.3 – 96.0) respectively. Consistent with findings reported for the general population, female participants were, on the other hand, slightly more likely to report eating dark green and leafy vegetables every day (90.8%; 95% CI= 84.6 – 97.0) than male participants (85.7%; 95% CI= 78.7 – 92.8).

Table 27 The kind of food male and female participants reported eating each day by food group

	Male		Female				
	n	Prop (%)	n	Prop (%)	$\chi 2$	p	phi
Dairy products	83	85.6	67	77.0	1.70	0.193	-0.110
Dark green, leafy vegetables	84	85.7	79	90.8	0.71	0.401	0.078
Other vegetables	86	92.5	74	91.4	0.00	1.000	-0.020
Fruit	84	90.3	71	87.7	0.10	0.750	-0.043
Meat, eggs, poultry, fish, legumes	90	92.8	74	89.2	0.35	0.555	-0.064
Breads, cereals & grains	94	95.9	81	93.1	0.27	0.603	-0.062
Fats, oils & sweets	14	15.2	15	18.5	0.14	0.707	0.044

In the New Zealand Health Survey the proportion of New Zealanders who ate the recommended number servings of fruit and vegetables increased with age and a similar trend was observed for participants who completed the SONZ Health Promotion screen. Younger participants aged between 10-19 years were least likely to report eating Dark green & leafy vegetables (81.8%; 95% CI= 67.9 – 95.7), Other vegetables (87.1%; 95%CI= 74.6 – 99.36) or Fruit (81.3%; 95%CI= 67.0 – 95.6) daily whereas participants aged over 50 years were consistently most likely to report eating Dark green and leafy (96.2%; 95%CI= 88.2 -100.0) or Other vegetables (96.2%; 95%CI= 88.2 -100.0) and fruit (100.0%) on a daily basis.

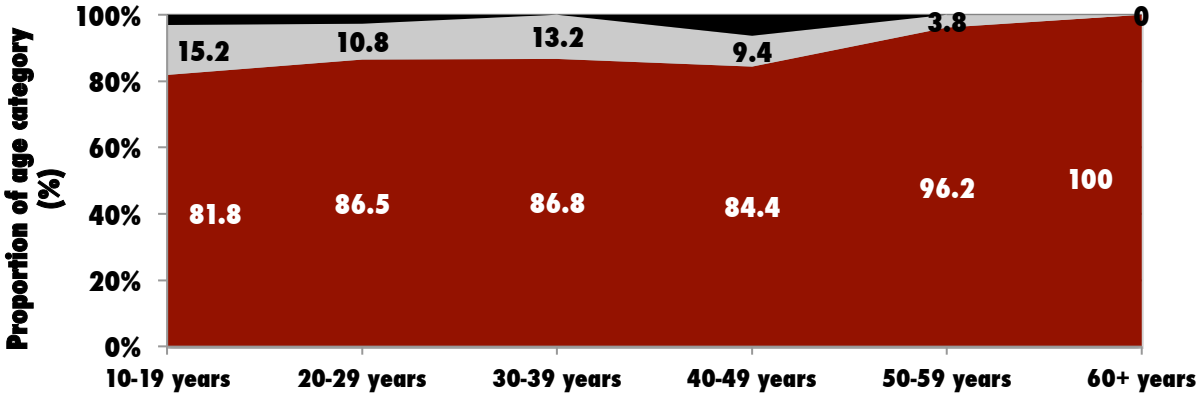

Figure 41 The proportion of participants who reported eating dark green and leafy vegetables each day by age category

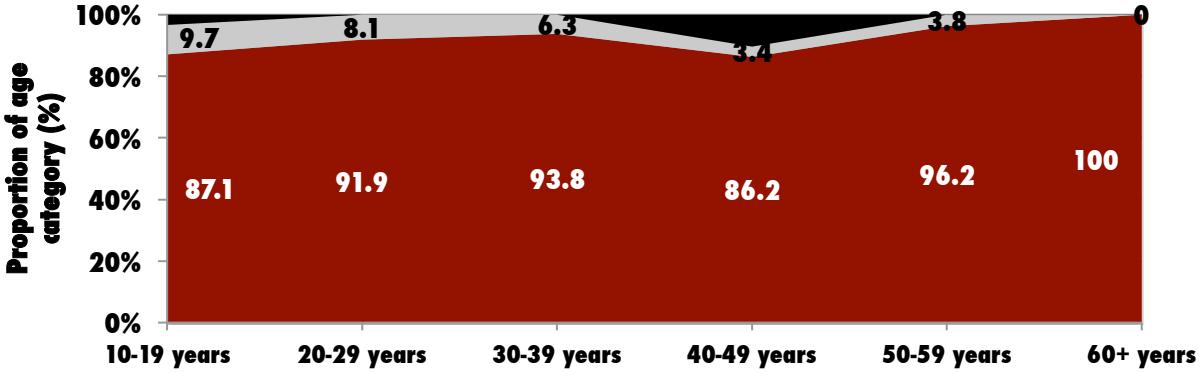

Figure 42 The proportion of participants who reported eating other vegetables each day by age category

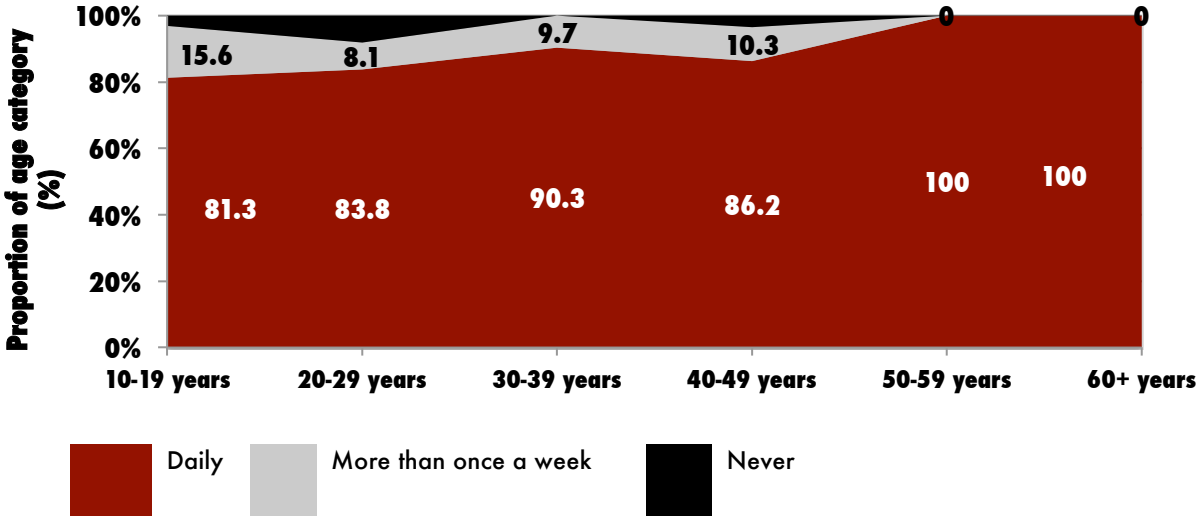

Figure 43 The proportion of participants who reported eating fruit (including juice) each day by age category

Where participants lived appeared to be associated with small but consistent differences in the daily consumption of vegetables and fruit. Participants who lived in a flat they rented by themselves were least likely to report eating Dark green vegetables (80.0%; 95% CI= 49.8 –

100.0), Other types of vegetables (80%; (80.0%; 95% CI= 49.8 – 100.0) and Fruit (60.0; 95% CI= 23.1 – 96.9) than other living situations.

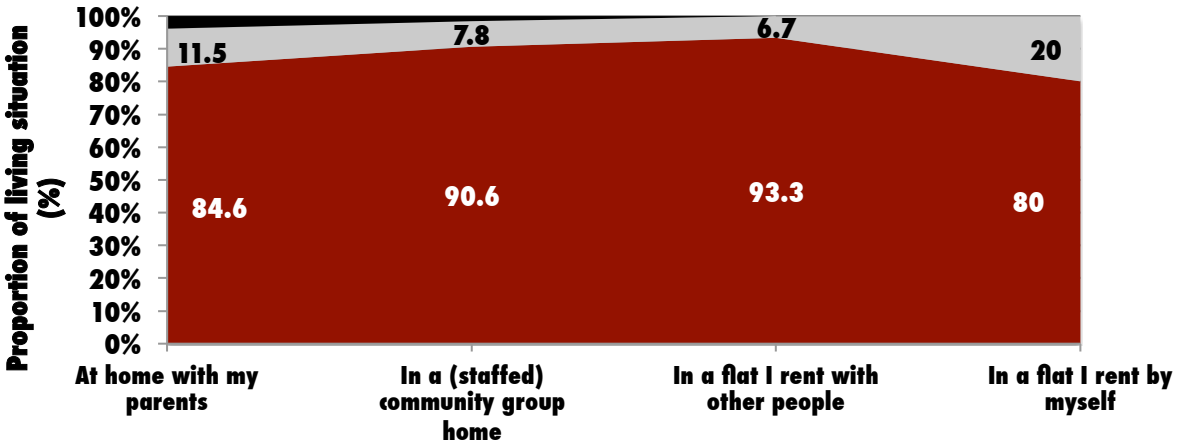

Figure 44 The proportion of participants who reported eating fresh green leafy vegetables each day by living situation

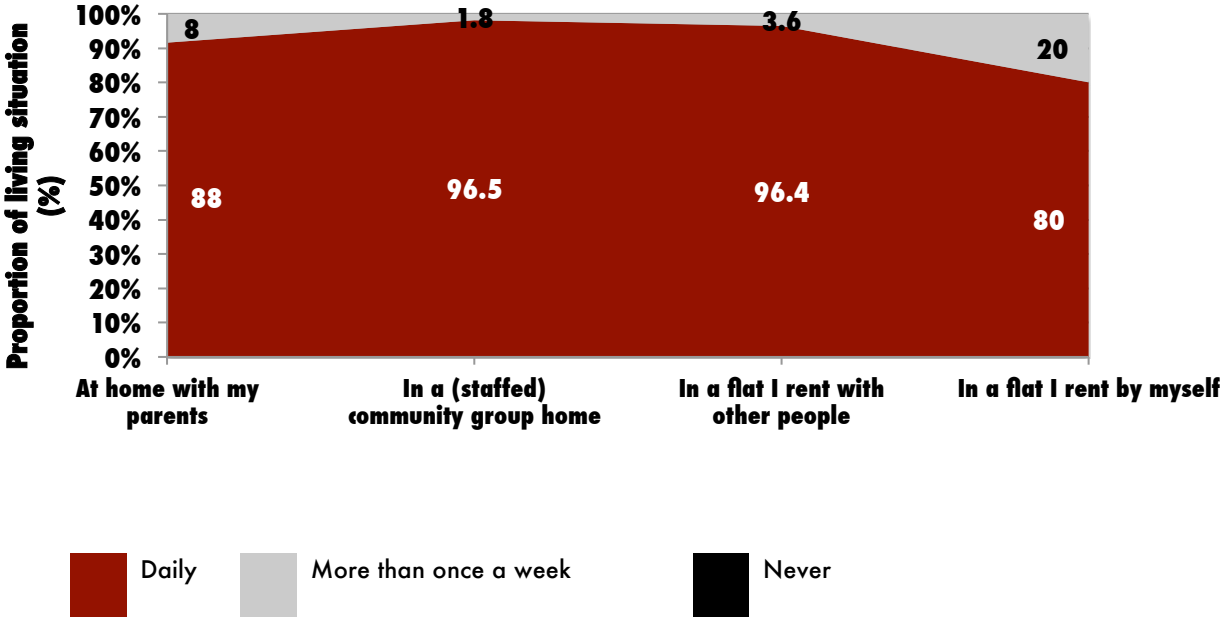

Figure 45 The proportion of participants who reported eating other vegetables every day by living situation

Participants who lived in a flat by themselves were the only identifiable group to self-report eating fruit daily less often than the proportion of New Zealand's who ate the recommended amount of fruit servings as described in the New Zealand Health survey 2011/12.

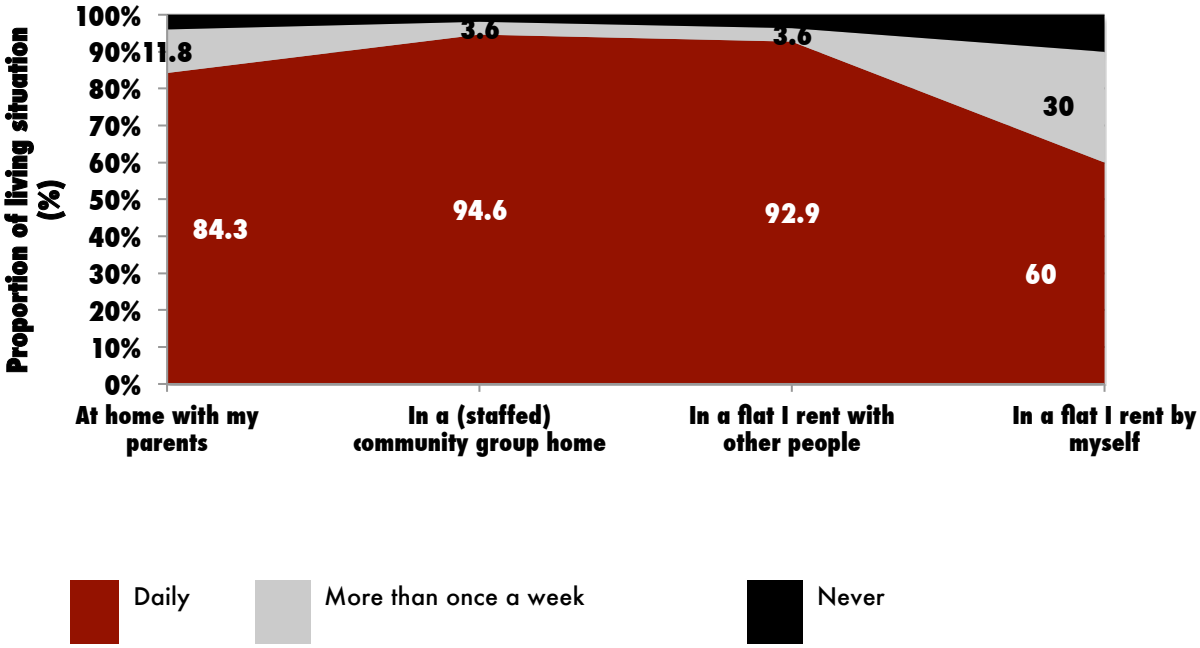

Figure 46 The proportion of participants who reported eating fruit each day by living situation

A series of direct binary logistical regressions were performed to assess what impact a range of demographic characteristics had on the likelihood participants would self-report eating Dark green and leafy vegetables, Other vegetables and fruit on a daily basis.

The location at which participants were screened was the only potential predictor to achieve the selection criteria for inclusion in an adjusted model of the likelihood participants would self-report eating Dark green and leafy vegetables daily. The odds that a participant from Palmerston North would self-report eating Dark green and leafy vegetables (94.5%; 95% CI= 88.6 – 99.9) were almost three times the odds (OR= 3.0; 95% CI= 1.0 – 9.2) of participants screened in Dunedin (84.5%; 95% CI= 77.8 – 91.2), although the difference between screen locations fell just short of statistical significance.

Table 28 Association between participant' demographic characteristics and self-reported daily consumption of Dark green & leafy vegetables

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	84 (85.7)				
	Female	79 (90.8)	0.289			
Age			0.214			
Ethnicity	NZ European & Other	156 (88.1)				
	Maori	7 (87.5)	0.957			
Athlete status	SONZ athlete	106 (89.8)				
	Non-athlete	57 (85.1)	0.339			
Living situation	Family / Family like	48 (85.7)	0.523			
	Community Group Home	68 (91.9)	0.266			
	Supported Living Context	42 (87.5)	0.790			
Location	Dunedin	98 (84.5)				
	Palmerston North	65 (94.2)	0.057		2.985	0.966 – 9.22

Participant living situation was the only potential predictor that achieved the selection criteria for inclusion in an adjusted model of the likelihood participants would self-report eating Other vegetables daily. No association was found, however, between participant' living situation and the likelihood they would describe eating Other vegetables daily.

Table 29 Association between participant' demographic characteristics and self-reported daily consumption of Other vegetables

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	86 (92.5)				
	Female	74 (91.4)	0.788			
Age			0.400			
Ethnicity	NZ European & Other	153 (91.6)				
	Maori	7 (100.0)	0.999			
Athlete status	SONZ athlete	103 (92.8)				
	Non-athlete	57 (90.5)	0.590			
Living situation	Family / Family like	48 (88.9)	0.244			
	Community Group Home	65 (97.0)	0.095		4.062	0.786 – 21.010
	Supported Living Context	42 (91.3)	0.689		1.312	0.347 – 4.969
Location	Dunedin	106 (90.6)				
	Palmerston North	54 (94.7)	0.353			

Participant living situation was also entered as a potential predictor of the likelihood participants would self-report eating fruit on a daily basis together with participants' age in the adjusted binary logistical regression model. Consistent with findings reported for the New Zealand general population, participants' age made a statistically significant unique contribution to explaining variance in the likelihood they would report eating fruit daily. For every year a participant aged, the odds that they would report eating fruit daily increased by 10% (OR= 1.1; 95% CI= 1.0 – 1.1) when living situation was controlled for in the adjusted model.

Where participants lived was not found to make a statistically significant unique contribution to explaining variation in the likelihood they would report eating fruit in the adjusted model, however, the 35.5% difference in the proportion of participants who reported eating fruit daily who lived in a (staffed) community group (95.5% 95% CI= 90.3 – 100.0) and who lived in a flat by themselves (60.0%; 95% CI= 23.1 – 96.9) was statistically significant when equal variances were not assumed (p= 0.05; 95% CI= 0.1 – 72.6). One possible explanation for this finding is that it may be indicative of differences in the material wellbeing of participants living in the two different living situations as would be anticipated by the New Zealand Adult Health Survey finding of an association between material deprivation and the likelihood people would eat the recommended number of servings of fruit.

Table 30 Association between participant demographic characteristics and self-reported daily consumption of fruit

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	84 (90.3)				
	Female	71 (87.7)	0.574			
Age			0.051	0.027	1.062	1.007 – 1.120
Ethnicity	NZ European & Other	148 (88.6)				
	Maori	7 (100.0)	0.999			
Athlete status	SONZ athlete	97 (87.4)				
	Non-athlete	58 (92.1)	0.346			
Living situation	Family / Family like	47 (85.5)	0.175	0.250		
	Community Group Home	63 (95.5)	0.070	0.678	1.375	0.306 – 6.173
	Supported Living Context	40 (87.0)	0.828	0.218	0.417	0.104 – 1.678
Location	Dunedin	103 (88.0)				
	Palmerston North	52 (91.2)	0.528			

10 Sun safety

New Zealand and Australia have the highest rates of skin cancer in the world. In 2009 the Ministry of Health reported 2212 melanoma registrations and 326 melanoma related deaths that year[49]. Melanoma cancers are the only officially registered skin cancers in New Zealand, making estimation of the prevalence of skin cancer in the general population difficult. It is estimated, however, that approximately 67 000 New Zealanders are diagnosed and treated for skin cancer each year, making skin cancer the most common cancer in New Zealand[50].

Exposure to excessive Ultra Violet Radiation (UVR) is the main modifiable risk factor for the development of skin cancers. "Sun Smart" is the national brand for the promotion of sun safety, within which seeking shade between 11am – 4pm, wearing protective clothing and a sun protective hat and using sunscreen and sunglasses are promoted as sun smart actions to reduce exposure to UVR.

The Health Sponsorship Council and Cancer Society of New Zealand developed the Sun Exposure Survey (SES) in 2009 following a review of the Triennial Sun Protection Survey that had been conducted every three years since 1994. The objective of the survey was to provide information about the sun behaviour and risk factors for over-exposure to UVR in the New Zealand community as a way of informing skin cancer programmes. Little is known about the sun behaviour or effectiveness of sun safety public health messages for people with a learning disability and the SES did not sample for disability.

In 2010, 81 percent of people who responded to the SES spent more than 15 minutes outside on Saturday or Sunday during the previous week, of whom approximately half said they had used sunscreen to cover up (51%) and/or worn a hat (48%). Slightly more respondents who had spent 15 minutes or more outdoors during the weekend reported staying out of the sun or in the shade at some time (59%) and three out of every five respondents (61%) reported wearing sunglasses[51].

Following questions that prompted for hair (i. Blond/red, ii Brown, iii. Black) and eye colour (i. Blue/green, ii. Hazel, iii. Brown) participants were asked which of four sun smart actions they knew as ways to protect their skin from the sun (i. Use of sunscreen, ii. Wear a hat, iii. Look for shade, iv. Wear sunglasses).

Participants were also asked when exposed to the sun in summer did they: i. Burn, ii. Burn and sometimes blister, iii. Burn then tan, or iv. Tan?

A final question asked if participants used sunscreen in the winter months.

Two hundred participants responded to the questions that prompted for their knowledge of the four sun smart actions sampled for of whom 19 did not provide sufficient information for a determination of their skin type to be made.

10.1 Knowledge of sun smart actions

Four out of every five participants reported knowing the use of sunscreen (81.5%; 95% CI= 76.1 – 86.9) and/or wearing a hat when outdoors (77.9%; 95% CI= 72.1 – 83.7) were ways to reduce their exposure to UVR. In contrast to the health behaviour of the general population, participants were less likely to volunteer looking for shade (51.3%; 95% CI= 44.3 – 58.3) or wearing sunglasses (60.5%; 95% CI= 53.7 – 67.3) as strategies for minimising their exposure to UVR, highlighting these sun smart actions as potential arenas for improving the health literacy of people with a learning disability.

It is important to note that preeminent goals of the Sun Safety station within the SONZ Health Promotion screen were to "increase awareness of the health risk of overexposure to the sun's UVR and the importance of sun safety" and to "teach participants healthy sun protection habits"(p20)[13]. It is unclear whether any protocols were developed and consistently applied regarding the extent to which participants were promoted for their knowledge of sun smart actions or the degree to which survey administers controlled for the known response biases of primacy and recency, acquiescence and socially appropriate responding by people with a learning disability.

It is also important to note that, unlike the SES, which sampled for health behaviour, the Special Olympics Health Promotion survey explored participants' sun safe literacy. No conclusions can be drawn about whether participant's health knowledge informed their health behaviour and specifically whether people with a learning disability are at greater or lesser risk from exposure to UVR than the general population.

10.2 Skin type

Skin type is the primary risk factor for developing melanoma. As a consequence of producing less melanin, fair-skinned people are at greater risk of burning and developing skin cancer than darker skinned people and therefore need more protection against exposure to UVR.

Special Olympic Health Promotion screen participants indicated what colour their hair and eyes were as part and these two phenotypes were used to group participants into two risk categories based upon the dispositional characteristics adopted in the Fitzpatrick Skin Type Scale. Thirty-eight participants had blonde or red coloured hair and blue, green or hazel coloured eyes and were subsequently grouped into the most at risk category (Skin type 1-2).

Little difference was observed between the health literacy of participants grouped into the two skin type categories and a series of Independent sample t-tests found no association between skin type category and the likelihood a participant would report knowing any of the four sun smart actions as ways to reduce their exposure to UVR.

Table 31 Participant' knowledge of sun smart actions to reduce their exposure to ultra-violet radiation by skin type

	Skin type 1-2		Skin type 3-6		p	95% CI
	n (%)	95% CI	n (%)	95% CI		
Use sunscreen	34 (89.5)	79.3 – 99.7	124 (86.7)	81.1 – 92.3	0.65	-14.8 – 9.3
Wear sunhat	32 (84.2)	72.1 – 96.4	120 (84.5)	78.5 – 90.5	0.97	-12.8 – 13.4
Look for shade	21 (55.3)	38.7 – 71.8	80 (56.3)	48.1 – 64.6	0.92	-16.9 – 19.1
Wear sunglasses	23 (60.5)	44.2 – 76.8	97 (67.8)	60.1 – 75.6	0.09	-9.8 – 24.4

10.3 Skin sensitivity to sun

A person's perception of their skin's sensitivity to sun can influence their behaviour in ways that affect their exposure to UVR.

In the SES, respondents were asked what would happen if their untanned skin was exposed to sunshine at the start of summer, using no sun protection for 30 minutes. In 2010, nearly three out of every five respondents said they would burn first and tan later (57%). One out of every five respondents said they would just burn (20%) or just tan (21%)[51].

At first reading, the participants who responded to the SONZ Health Promotion screen appeared more cautious in their estimate of their skins sensitivity to sun. In contrast to findings reported for the general population, seven out of every ten participants reported that when exposed to sun in summer their skin either burned (50.3%; 95% CI= 42.5 – 58.2) or burned and sometimes blistered (21.4%; 95% CI= 14.9 – 27.8). Whereas 57% of SES respondents said they first burned and then tanned later, only 15.7% of SONZ Health Promotion screen participants reported burning then tanning (95% CI= 10.0 – 21.4) and 12.6% reported tanning (95% CI= 7.4 – 17.8).

There was a noticeable trend within the data, however, for participant responding to be positively correlated to question order. The prevalence of primacy and acquiescent response biases are known to be higher for people with a learning disability and it is not possible therefore to exclude biases in responding as contributing to these findings.

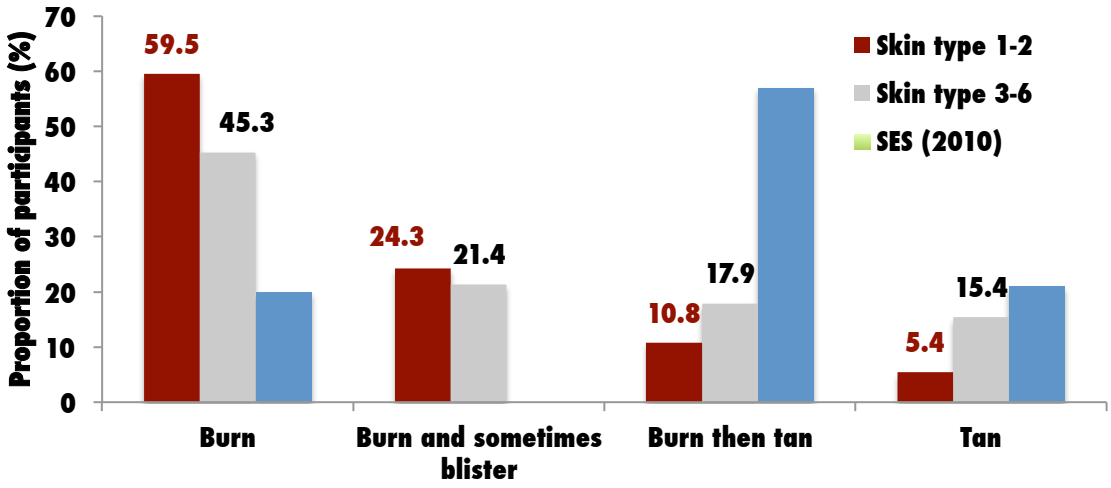

Figure 47 Self-reported skin sensitivity by skin type compared to the sun sensitivity self-reported by New Zealand SES (2010) respondents

Participants who self-reported burning and sometimes blistering were more likely to report adopting all of the four sun smart actions sampled for than participants who described tanning, with the largest difference evident in the proportion who described seeking shade, however, no association between self-reported skin sensitivity and the likelihood a participant would report knowing any of the four sun smart actions as ways to reduce their exposure to UVR was subsequently found.

Table 32 Participant knowledge of sun smart actions to reduce their exposure to ultra-violet radiation by self-reported skin sensitivity

	Burn Prop (%)	Burn / tan Prop (%)	Tan Prop (%)	Burn / blister Prop (%)	$\chi 2$	p	Crammer's V
Use sunscreen	90.0	88.0	85.0	91.2	0.60	0.897	0.061
Wear sunhat	82.3	80.0	80.0	91.2	1.94	0.584	0.111
Look for shade	55.0	68.0	40.0	70.6	6.20	0.102	0.197
Wear sunglasses	66.3	64.7	64.0	70.0	0.22	0.975	0.037

Participants whose skin type placed them at greater risk of developing a melanoma (Skin type 1-2) were also more likely to report burning (59.5% v 45.3%) and burning and sometimes blistering (24.3% v 21.4%) and were less likely to report burning then tanning (10.8% v 17.9%) or tanning (5.4% v 15.4%) than participants with skin type 3-4, but no association between skin type category and participants' self reported skin sensitivity to sun was found either.

10.4 Were there differences in participants sun safe literacy?

The prevalence of skin cancer in the New Zealand population is higher for males. In 2009, male registration rates for melanoma were 27.3% higher than for females and the death rate from melanoma was twice that for women[50].

Men who completed the Special Olympics Health Promotion screen were marginally less likely to report using sunscreen (79.8%; 95% CI= 72.2 – 87.5) or wear a hat (77.1%; 95% CI= 69.1 – 85.1) than female participants (83.5%; 95% CI= 75.8 – 91.3) and (78.9%; 95% CI= 70.3 – 87.5) respectively but no association was found between participant sex and the likelihood they would report using sunscreen, wear a hat or know any other sun smart action.

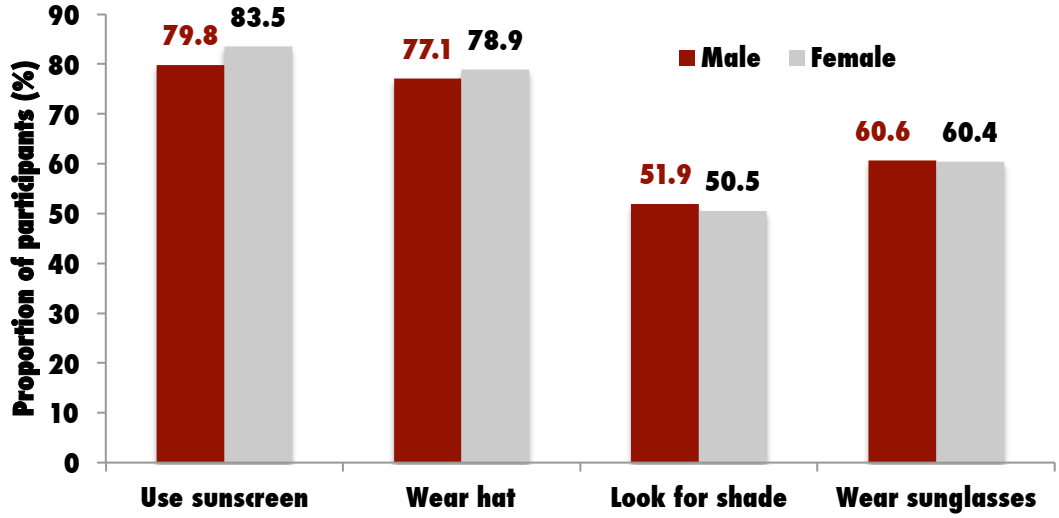

Figure 48 Participant' knowledge of sun smart actions to reduce their exposure to ultra-violet radiation by sex

A series of direct binary logistical regressions were performed to assess what impact a range of demographic characteristics had on the likelihood participants would report knowing any of the four sun smart actions as ways to reduce their exposure to UVR.

Participants who lived where there was likely to be more familial (At home with my parents) or staff supervision (In a [staffed] CGH with other people) were slightly more likely to report knowing the use of sunscreen, wearing a hat and looking for shade were ways to reduce their exposure to UVR than participants living more independently, but no association was found between living situation and the likelihood participants would report knowing any of the four sun safe actions were ways to reduce their exposure to UVR.

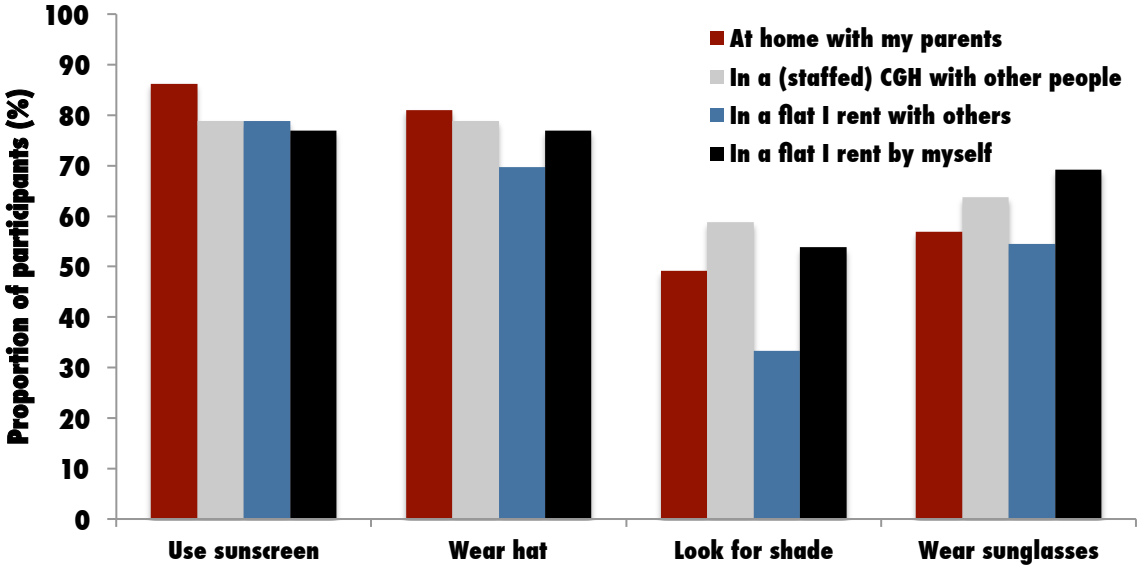

Figure 49 Participants knowledge of sun smart actions to reduce their exposure to ultra-violet radiation by living situation

Similarly, Special Olympic athletes were more likely than non-athletes to report knowing all of the sun smart actions to reduce their exposure to UVR sampled and although whether participants self-reported being a Special Olympic athlete or not crossed the threshold four inclusion in three of the four adjusted models, no association between athlete status and sun safe literacy was found for any sun smart action.

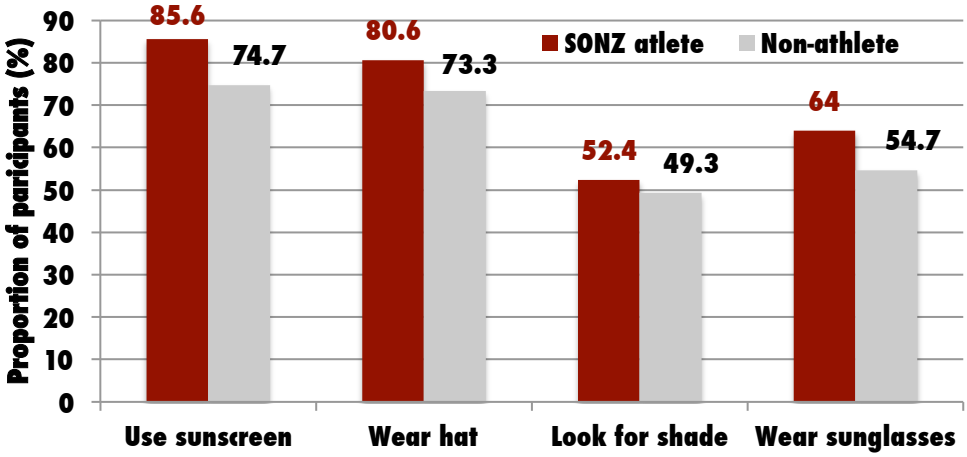

Figure 50 Participant knowledge of sun smart actions to reduce their exposure to ultra-violet radiation by athlete status

Where participants were screened was the only variable to explain variation in participants' sun safe literacy. The odds that a participant screened in Palmerston North (64.0%; 95% CI= 52.9 – 75.1) would report knowing looking for shade was a way to reduce exposure to UV radiation were two times higher (OR= 2.1; 95% CI= 1.1 – 4.0) than the odds participants

screened in Dunedin (43.6%; 95% CI= 34.7 – 52.4) would do the same when other variables were controlled for in the adjusted model.

Participants screened in Palmerston North (77.6%; 95% CI= 68.1 – 87.2) were also more likely to report the sun smart action of wearing sunglasses than participants screened in Dunedin (50.0%; 95% CI= 41.1 – 48.1). The odds that a participant screened in Palmerston North would report knowing wearing sunglasses was a way to reduce exposure to UV radiation were more than three times the odds for participants screened in Dunedin (OR= 3.3; 95% CI= 1.7 – 6.4) when participant' ethnicity and athlete status were controlled for in the adjusted model.

In a year, Palmerston North (1733 hours) typically receives more sunshine hours than Dunedin (1585 hours)[52]. Whilst variation in participants' exposure to UV radiation may have contributed to differences in participant sun smart literacy between the two regions, it is probable that variation in the administration of this element of the Health Promotion screen may explain these findings.

Table 33 Association between participant' demographic characteristics and the likelihood they would self-report knowing looking for shade lowered exposure to UV radiation

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	56 (51.9)				
	Female	46 (50.5)	0.855			
Age			0.193	0.209	1.017	0.991 – 1.044
Ethnicity	NZ European & Other	96 (50.3)				
	Maori	6 (75.0)	0.189	0.259	2.683	0.483 – 14.887
Athlete status	SONZ athlete	65 (52.4)				
	Non-athlete	37 (49.3)	0.673			
Living situation	Family / Family like	31 (51.7)	0.122	0.220		
	Community Group Home	47 (58.8)	0.404	0.665	0.826	0.349 – 1.957
	Supported Living Context	21 (40.4)	0.234	0.110	0.478	0.193 – 1.182
Location	Dunedin	54 (43.5)				
	Palmerston North	48 (64.0)	0.006	0.033	2.056	1.058 – 3.993

Table 34 Association between participant' characteristics and the likelihood they would self-report knowing wearing sunglasses lowered exposure to UV radiation

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	66 (60.9)				
	Female	55 (60.4)	0.987			
Age			0.294			
Ethnicity	NZ European & Other	114 (59.4)				
	Maori	7 (87.5)	0.147	0.220	3.865	0.445 – 33.598
Athlete status	SONZ athlete	80 (64.0)				
	Non-athlete	41 (54.7)	0.192	0.253	1.427	0.776 – 2.624
Living situation	Family / Family like	35 (57.4)	0.734			
	Community Group Home	51 (63.7)	0.442			
	Supported Living Context	31 (59.6)	0.810			
Location	Dunedin	62 (50.0)				
	Palmerston North	59 (77.6)	<0.001	<0.001	3.324	1.736 – 6.363

10.5 Vitamin D

Vitamin D is responsible for the intestinal absorption of calcium and phosphate and is important for bone health and immune system functioning. Vitamin D can be obtained from a range of foods and can be synthesized by the body from cholesterol with sufficient sun exposure.

In New Zealand, the Ministry of Health recommends sun exposure through a daily walk or another form of outdoor physical activity in the early morning between the months of September – April and during the day between the months of May – August[53].

To explore whether people in New Zealand acted in ways intended to improve their vitamin D level, all SES respondents who had spent at least 15 minutes outdoors during the weekend were asked if they had done anything specific to improve their vitamin D level. Only one in ten respondents (9%) said they had acted to improve their vitamin D level, of whom 53% had changed their behaviour in the sun by; spending time outdoors in the sun (47%), sunbathing (3%) or not wearing sunscreen (3%)[51].

In the Special Olympic Health Promotion screen, participants were asked if they used sunscreen in the winter months. Seven out of every ten participants reported not wearing sunscreen in the winter months (70.1% 95% CI= 58.9 – 81.4) although no record was kept of whether participant actions were motivated by an intention to improve their Vitamin D level.

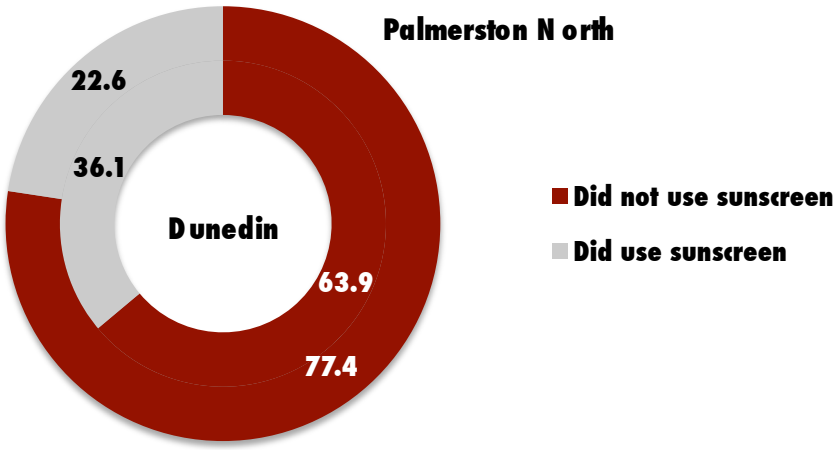

Figure 51 The proportion of participants who did and did not self-report using sunscreen in winter by screen location

Sixty-four percent of participants who completed the SONZ Health Promotion screen in Dunedin reported not using sunscreen (63.9%; 95% CI= 47.4 – 80.4) compared to 77% of participants screened in Palmerston North (77.4%; 95% CI= 61.8 – 93.0). Given that participants screened in Dunedin (latitude 45.89 South) were less likely to be exposed to the sun in winter, the greater use of sunscreen in winter months is counter-intuitive, however, no

association was ultimately found between screen location and the likelihood participants would self-report using sunscreen in winter.

11 Physical Exercise

The New Zealand Ministry of Health recommends that adults do at least 30 minutes of moderate intensity physical activity at least five days a week[53]. Engaging in regular physical activity is promoted by the Ministry of Health because exercise is protective against heart disease, Type 2 diabetes and a range of cancers[54]. Physical activity also helps to reduce risk factors for heart disease and Type 2 diabetes including high blood pressure and obesity and has also been found to improve bone health.

In their sample of the general population, the New Zealand Health Survey 2011/12 reported approximately half of all adults (53.9%; 95% CI= 51.5 -56.3) engaged in at least 30 minutes of physical activity per day on five or more days in the week prior to completing the survey[35]. When adjusted for age, men (57.3%; 95% CI= 54.7 – 59.9) were significantly more likely than women (50.7%; 95% CI= 47.7 – 53.7) to be regularly physically active with the prevalence of regular physical activity declining in women aged over 65 years and in men aged over 75 years. Fewer adult New Zealanders living in the most deprived areas were found to be physically active (47.0%; 95% CI= 43.4 – 50.6) than adults living in the least deprived communities (59.2%; 95% CI= 53.5 – 64.7).

Little is known about the about level of engagement in physical activity undertaken by people with a learning disability in the New Zealand context. A small number of international studies have reported low levels of cardiovascular fitness are more prevalent in people with a learning disability and that their leisure activities are much less likely to include participation in physical activity than the general population[9].

Participants who completed the SONZ Health Promotion screen in Palmerston North were offered a supplementary question that asked how many days per week they exercised for at least 30 minutes. Their responses were grouped into four activity categories (No days, 1-2 days, 3-5 days, Everyday).

Sixty-five participants screened in Palmerston North self-reported the number of days per week they exercised for more than 30 minutes.

11.1 Engagement in physical activity

Eighty percent of participants reported exercising for more than 30 minutes for three or more days per week (80.0%; 95% CI= 70.0 – 90.0) of whom half reported exercising everyday (40%; 95% CI= 27.8 – 52.2). Only two participants reported exercising for more than 30 minutes per day on no days. Unfortunately, however, the way participant responses were grouped precluded reporting on the proportion who met the Ministry of Health definition of

"regularly physically active" (five or more days) or a direct comparison with the New Zealand Health Survey estimates for the general population.

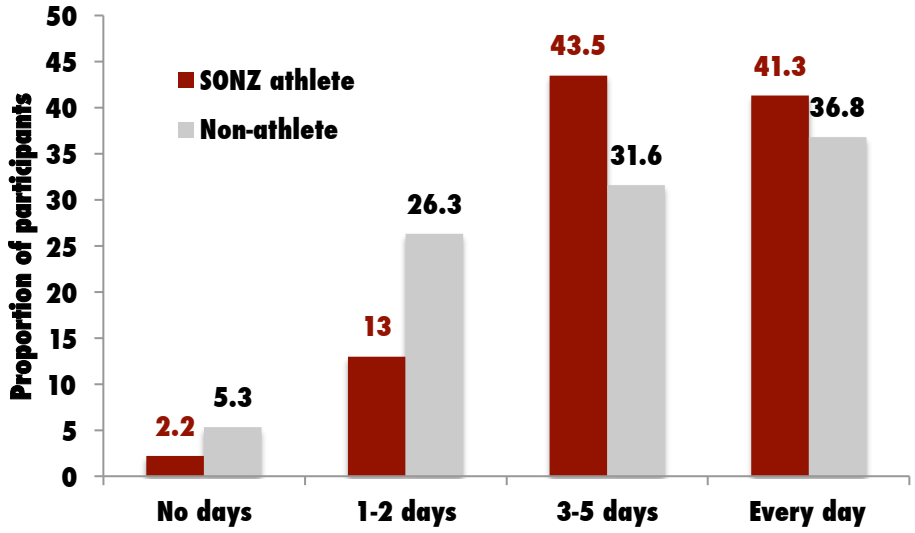

Figure 52 The number of days participants self-reported exercising for more than 30 per day

Special Olympic athletes were more likely to report exercising for 30 minutes per day for three or more days (84.8%; 95% CI= 74.0 – 95.6) than non-athletes (68.4%; 95% CI= 45.4 – 91.4) but no association was found between participants' athlete status and the likelihood they would self-report exercising for 30 minutes on three or more days a week.

The category "Everyday" was used as an approximation of the Ministry of Health's definition of "regularly physically active" and the analysis that follows uses the definition of "exercising everyday," as "regularly physically active" for Special Olympic Health Promotion screen participants.

Unlike the New Zealand general population where men were more likely to meet the Ministry of Health's recommended level of physical activity, no difference was observed between the proportion of male or female participants who self-reported exercising everyday. Forty percent of both male (39.5%; 95% CI= 23.2 – 55.8) and female participants (40.7%; 95% CI= 20.9 – 60.6) self-reported exercising for more than 30 minutes everyday.

Participants aged between 20-59 years were most likely to self-report being physically active every day, but whereas in the general population adults aged between 14-24 years were most likely to self-report engaging in physical activity for 30 minutes everyday, only 11% of Health Promotion screen participants aged less than 20 years self-reported being physically active for more than 30 minutes everyday (11.1%; 95% CI= 0.0 – 36.7), suggesting younger people with a learning disability may be more at risk of developing the health risks associated with less active lifestyles than their age-peers in the New Zealand population. No participant aged over 60 years reported exercising for more than 30 minutes a day, everyday. In the New Zealand general population, the proportion of adults who self-report meeting the Ministry of Health's physical activity recommendation remained similar across all age groups until the age of 75 years. The finding that no participant aged over 60 years exercised for 30 minutes

every day may also indicate people with a learning disability face barriers to remaining physically active earlier than their age peers in the New Zealand population, however the very small sample size and different measures of physical activity adopted between the two surveys prevents any valid conclusions being drawn.

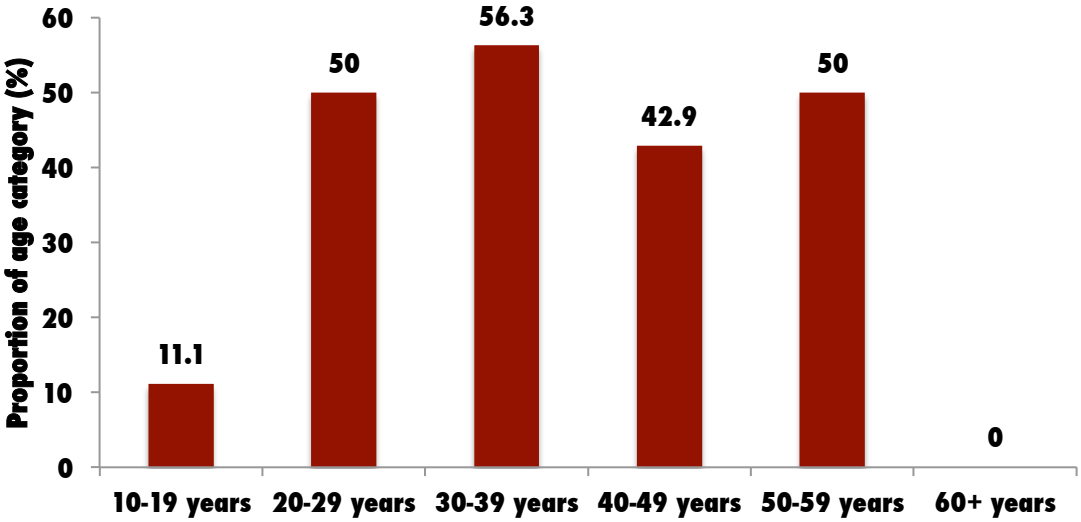

Figure 53 The proportion of participants who self-reported being regularly physically active by age category

The proportion of participants who self-reported exercising for more than 30 minutes per day, every day also increased for living situations understood as more independent living contexts. Participants who lived at home with their parents were least likely to report being regularly physically active (20.0%; 95% CI= 0.0 – 42.9) and participants who lived in a flat they rented by themselves were the most likely to report being regularly physically active (50.0%; 95% CI = 0.0 – 1.0).

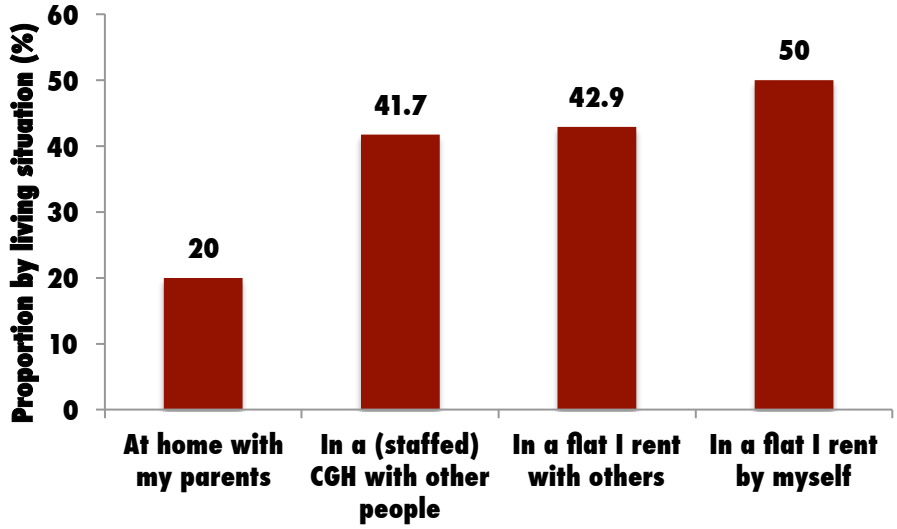

Figure 54 The proportion of participants who self-reported being regularly physically active by living situation

Direct binary logistical regression was performed to assess what impact a range of potential predictors had on the likelihood that participants would self-report exercising for more than 30 minutes a day every day. Participant's ethnicity and living situation were entered as independent variables within the adjusted model but no predictor was found to make unique, statistically significant contribution to explaining variation in the likelihood participants would be physically active every day.

Table 35 Association between participant' demographic characteristics and the likelihood they would self-report exercising for more than 30 minutes per day, every day

		Unadjusted		Adjusted		
		n (%)	(p-value)	(p-value)	OR	95% CI
Sex	Male	15 (39.5)				
	Female	11 (40.7)	0.918			
Age			0.269			
Ethnicity	NZ European & Other	23 (37.7)				
	Maori	3 (75.0)	0.177	0.231	4.206	0.401 – 44.150
Athlete status	SONZ athlete	19 (41.3)				
	Non-athlete	7 (36.8)	0.739			
Living situation	Family / Family like	3 (20.0)	0.186	0.237		
	Community Group Home	15 (41.7)	0.150	0.206	2.540	0.600 – 10.759
	Supported Living Context	7 (53.8)	0.071	0.092	4.251	0.790 – 22.889
Location	Dunedin	-				
	Palmerston North	26 (40.0)	-			

11.2 Sedentary Lifestyles

In the New Zealand Health Survey 2006/07, respondents who reported doing less than 30 minutes of physical activity in the week prior to completing the survey were described as sedentary. The survey estimated that one in seven adults (15%; 95% CI= 14.2 - 15.9) were sedentary and that when adjusted for age, women (15.7%; 95% CI= 14.5 - 16.9) were more likely than men (12.2%; 95% CI= 11.2 - 13.2) to be sedentary[34].

Unfortunately, the four activity categories (No days, 1-2 days, 3-5 days, Everyday) adopted in the SONZ Health Promotion screen bisected the definition used to sample the general population, preventing a direct comparison.

Two participants who completed the Palmerston North Health Promotion screen reported exercising for more than 30 minutes on "no days" (3.1%; 95% CI= 0.0 – 7.4) and eleven participants reported exercising for more than 30 minutes for between 1-2 days (16.9%; 95% CI= 7.6 – 26.3).

Female participants were more likely to self-report exercising for 30 minutes per day for two or fewer days a week (25.9%; 95% CI= 8.3 – 43.6) than male participants (15.8%; 95% CI= 3.6 – 27.9).

Direct binary logistical regression was performed to assess what impact participant' demographic characteristics had on the likelihood they would self-report exercising for more than 30 minutes per day for two or fewer days a week. Whether participants were a Special Olympic athlete or not was the only potential predictor to cross the threshold for inclusion in an adjusted model. Non-athletes (31.6%; 95% CI= 8.6 – 54.6) were almost twice as likely as Special Olympic athletes (15.2%; 95% CI= 4.4 – 26.0) to self-report exercising for 30 minutes a day for two or fewer days a week, however, no association was found between athlete status and the likelihood participants would self-report a sedentary lifestyle.

Table 36 Association between participant' demographic characteristics and the likelihood they would report exercising for 30 minutes a day for two or fewer days a week

		Unadjusted n (%)	(p-value)	Adjusted (p-value)	OR	95% CI
Sex	Male	6 (15.8)				
	Female	7 (25.9)	0.318			
Age			0.587			
Ethnicity	NZ European & Other	13 (21.3)				
	Maori	0 (0)	0.999			
Athlete status	SONZ athlete	7 (41.2				
	Non-athlete	6 (31.6)	0.141		0.389	0.111 – 1.369
Living	Family / Family like	3 (20.0)	0.452			
situation	Community Group Home	9 (25.0)	0.702			
	Supported Living Context	1 (7.7)	0.370			
Location	Dunedin	-				
	Palmerston North	13 (20.0)	-			

11.3 Television watching

Television watching is a sedentary activity that displaces opportunities for more active pursuits. Watching television also exposes an audience to commercial advertising and studies have shown television watching to be associated with increased consumption of energy dense foods and drinks and increased risk of obesity[34]. After following a cohort of New Zealand children born in 1972/73, the Dunedin Multidisciplinary Study found watching television for more than two hours a day in childhood and adolescence explained 17% of variance in being overweight, 15% of variance in raised blood cholesterol, 17% of variance in the prevalence of smoking and 15% of poor fitness at age 26 years[34].

Sport and Recreation New Zealand and the Ministry of education recommend that 5-18 year olds spend less than two hours a day in front of television, computers and game consoles.

The New Zealand Health Survey 2006/07 only sampled for the television watching habits of children aged between 5-14 years. The survey found two out of every three children aged 5-14 years usually watched two or more television a day (64.1%; 95% CI= 62.1 - 66.2)[34].

In the Special Olympic Health Promotion screen, participants screened in Palmerston North were asked how many hours a day they watched television or played computer/video games. Approximately two out of every three participants self-reported usually watching two or more

hours television per day (61.4%; 95% CI= 48.4 – 74.4), very similar to that reported for the cohort selected in the New Zealand Health Survey 2006/07.

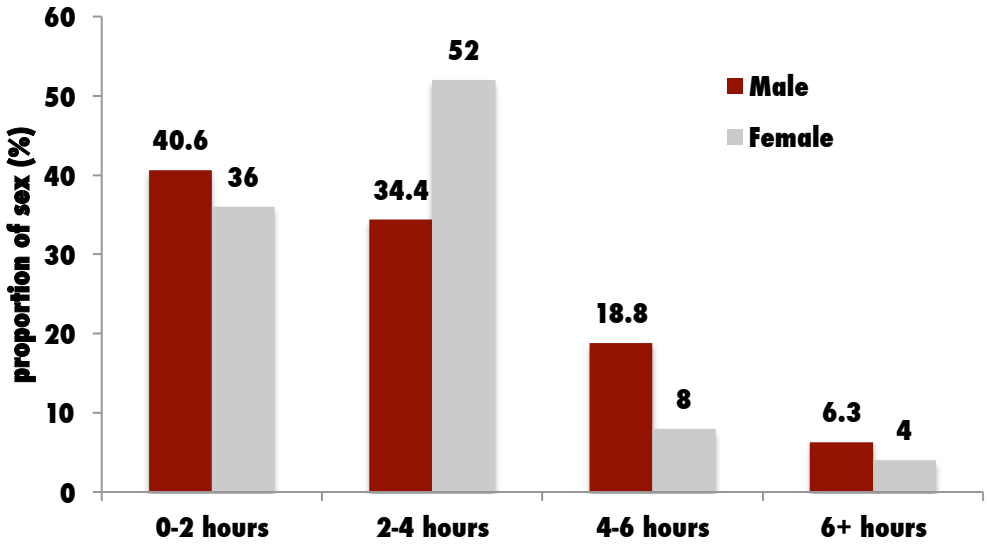

Figure 55 The number of hours participants self-reported watching television or playing computer/video games by sex per day

Watching television for between 0-2 hours a day was the most commonly reported time male participants said they typically watched television or played computer games (40.6%; 95% CI= 22.6 – 58.6) although males were more likely to report spending more than four hours a day watching television (25.0%; 95% CI= 9.1 – 40.9) than female participants (12.0%; 95% CI= 0.0 – 25.7). Slightly more than half of female participants reported spending between 2-4 hours watching television daily (52.0%; 95% CI= 31.0 – 73.1).

Consistent with the finding of lower rates of physical activity self-reported by participants who lived at home with a family member, participants who lived at home with their parents were also amongst those most likely to report watching two or more hours television per day (71.4%; 95% CI= 44.4 – 98.5). Participants who lived by themselves were most likely to watch two or more hours television per day (75.0%; 95% CI= 0.0 – 100.0) and participants who lived in a flat with others were least likely (42.9%; 95% CI= 0.0 – 92.3).

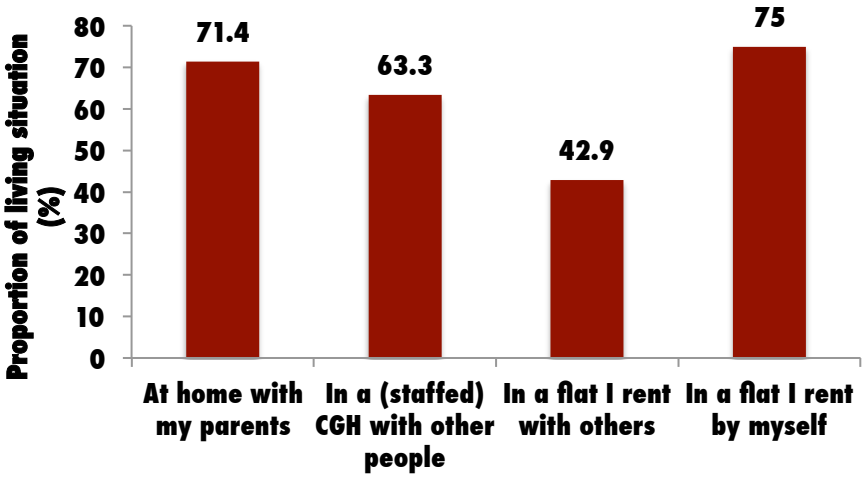

Figure 56 The proportion of participants who self-reported watching two or more hours per day watching television or playing computer/video games by living situation

12 Project Summary and Conclusions

In the previous two decades, responsibility for the provision of primary health care for children and adults with a learning disability has increasingly shifted from institutional to community health providers. International research has consistently demonstrated people with a learning disability experience poorer health outcomes than the general population and writers have been quick to attribute health inequality to a neglect of the specific health needs, communication styles and health literacy of people within the community-based systems of health delivery that disabled people now rely upon.

People with a learning disability have also been largely invisible within the health statistics that inform public health policy. In addition to denying people with a learning disability the opportunity to sensitise the health and disability community to the key health issues they face, the absence of people with a learning disability from population-based health surveillance has also made it difficult to develop health promotion strategies designed to improve their disadvantaged health status.

In 2003, the National Health Committee identified improving the health literacy of people with a learning disability and those upon whom they depend for timely and appropriate health care as prerequisite to addressing what they described as the "disturbing" status of health provision for adults with a learning disability[8].

12.1 The "On the Margins of Good Health" project objectives

Educating to improve the health literacy and health behaviour of Special Olympic athletes and increasing the investment of local health promotion leaders in recognising and responding to the health needs of people with a learning disability are the two primary aims of the Special Olympic Health Promotion screen.[13] The "On the Margins of Good Health" project builds upon these objectives by analysing health information provided by people with a learning disability who participated at one of two New Zealand Health Promotion screen events.

12.2 Objective One

In the absence of other direct measures, the Special Olympic Healthy Athlete Screening programme has provided the only data with which to estimate the prevalence of a range of health conditions experienced by people with a learning disability in New Zealand. The "On the Margins of Good Health" project contributed four additional important health status indicators to direct measures of the visual, auditory, oral and podiatry health of New Zealand Special Olympic athletes available through the Healthy Athletes Programme.

Objective 1 of the project was to estimate the prevalence of poor health outcomes related to the body mass, blood pressure, bone density and incidence of diabetes experienced by adults with a learning disability living in two Special Olympic regions.

The "On the Margins of Good Health" project adds to an emerging picture that documents people with a learning disability being at greater risk of a range of health conditions associated with higher levels of obesity than other national citizens. Twenty-seven percent of male and 40%

of female participants had a BMI in the obese range. Whilst these findings are consistent with international estimates of the prevalence of obesity[9],[10], a comparison with findings reported in a large study that accessed the records of 11 643 Special Olympic athletes suggests New Zealanders with a learning disability may be at greater risk of obesity than athletes from most Special Olympic world regions[10]. Sixty-two percent of male and 73% of female participants had a BMI in the overweight or obese range, similar to the prevalence reported for athletes from North America and higher than estimates for the general population in both countries.

The mean BMI of adult Health Promotion screen participants was 1.8kg higher than reported for the New Zealand national population. Adults who completed the Health Promotion screen were also less likely to have a mean BMI in the normal range and more likely to have a BMI in the obese range than reported for the national population in the 2006/07 and 2011/12 New Zealand Health Surveys[34, 35]. Not surprisingly, therefore, the increased prevalence of obesity among people with a learning disability reported here aligns with the recently reported finding that people with a learning disability were more than four times more likely to receive morbid obesity treatment than other New Zealanders[11].

An array of health conditions are known to be associated with obesity, most of which also appear to be more common in people with a learning disability. Improving the health literacy and health behaviour of people with a learning disability in ways likely to contribute to a reduction in the prevalence of obesity represents an important way public health promotion interventions can improve the life quality of this population.

The "On the Margins of Good Health" project also found the odds that a participant who lived in a flat they rented by themselves had a BMI in the obese range was seven times higher than for participants who lived at home with their parents. It is likely that higher levels of poverty, the lack of oversight of participants day-to-day diet and support that failed to prioritise nutritional literacy or good eating habits are among a mix of factors that might explain the association between living in more independent support contexts and obesity. Against the backdrop of a global increase in the prevalence of obesity[10] and evidence that people with a learning disability typically live more sedentary lifestyles[9], the aspiration expressed by many people with a learning disability to find alternative living situations to their family or community group homes ought to provide additional impetus for the need to develop effective health promotion strategies to address the health risks of obesity. The "On the Margins of Good Health" project provides a useful benchmark against which the success of future health promotion strategies that target this area of health inequality might be evaluated.

Little is known about the prevalence of high blood pressure in people who have a learning disability despite the WHO identifying hypertension as a priority health area. Twelve percent of participants had a systolic blood pressure indicative of hypertension and one in five participants were found either to be taking medication prescribed for blood pressure/cholesterol/heart condition medication or had a systolic blood pressure above 139mmHg. Similarly, 9% of participants had a diastolic blood pressure indicative of hypertension and 17% of participants were found either to be taking medication prescribed for blood pressure/cholesterol/heart condition medication or had a diastolic blood pressure above 89mmHg. As a group, participants were slightly less likely to be taking medication prescribed for blood

pressure/cholesterol/heart condition than adult New Zealanders who self-report taking medication for high blood pressure[11]. When compared to the New Zealand population, however, the proportion of participants who took medication was higher across all age categories suggesting an under-representation of older participants in the study population may have contributed to this finding. The proportion of participants with undiagnosed and therefore un-medicated hypertension was also high. High blood pressure is usually asymptomatic and four out of every five participants who had a systolic blood pressure above 139mmHG and three out of every four participants who had a diastolic blood pressure above 89mmHg were not recorded as regularly taking medication prescribed for blood pressure/cholesterol/heart condition. Assuming that every participant who took medication for high blood pressure, high levels of cholesterol or a heart condition had at one time been diagnosed with a systolic or diastolic blood pressure indicative of hypertension, the prevalence of undiagnosed high systolic blood pressure was approximately 50% and undiagnosed diastolic blood pressure was 41%, emphasising the need for regular health checks that include testing for high blood pressure. In a population who often depend on the health literacy of others, the proportion of participants for whom medication had not reduced their blood pressure and a known association between obesity and high blood pressure further underscored the need for regular health checks. High systolic and diastolic blood pressure was detected in approximately one in every four participants who already took medication prescribed for blood pressure/cholesterol/heart condition. A well-replicated association was also found between participant BMI and variation in systolic and diastolic blood pressure in a population for whom this research indicates is more likely to have a BMI in the obese range than other New Zealanders[9],[10].

One male and two female participants had a bone mineral density T-score in the range conventionally used to support a diagnosis of osteoporosis. Previous research suggests the prevalence of osteoporosis may be higher for people with a learning disability[43] and although the proportion of participants whose calcaneus bone density indicated osteoporosis was larger than self-reported by New Zealanders in the New Zealand Health Survey[34], differences in the use of direct and indirect measures and variation in the age-sex profiles of the two sample populations meant that little could be read into this finding. Forty percent of male participants had a T-score within the range used to classify osteopenia. No statistically significant association between participant sex and the likelihood of having a bone mineral density below the normal range was found, however, the high proportion of male participants who experienced bone mass density degeneration and the finding that osteopenia was more likely to be detected in male participants is not consistent with international findings and warrants further investigation.

In the New Zealand Health Survey, one in eighteen adult New Zealanders self-reported doctor diagnosed diabetes[35]. The proportion of Special Olympic Health Promotion screen participants who self-reported having Type 2 diabetes was slightly lower than that reported for the general population but consistent with a small number of international studies that have found the prevalence of diabetes in people with a learning disability to be similar to the general population[9]. Estimates of the prevalence of undiagnosed diabetes in the New Zealand population vary from one in four to one in two people who have Type 1 or Type 2 diabetes. Given the known association between body mass and Type 2 diabetes and evidence that people with a learning disability are at greater risk of obesity, it is possible that the level of

undiagnosed diabetes may be higher for people with a learning disability. A recent finding reported by the New Zealand Ministry of Health that people with a learning disability were almost twice as likely to receive diabetes related care or treatment than New Zealanders without a learning disability[11] may reflect either a higher prevalence of diabetes that was under-reported by this study sample and/or better rates of detection and treatment in people with a learning disability.

12.3 Objective Two

Since 2003, there has been no systematic survey of the health knowledge or behaviours of people with a learning disability and, other than "in-house" initiatives taken by individual disability service providers, people with a learning disability have not been identified as an at risk population in any publicly funded health promotion strategies.

The "On the Margins of Good Health" project provided a seminal opportunity to explore the health literacy and self-reported health behaviour of people with a learning disability in four health behaviour domains that have featured prominently in generic public health campaigns. Objective 2 of the project was to describe the self-reported health behaviours and health literacy of people with a learning disability in the domains of tobacco use, nutrition and hydration, sun safety and physical activity.

As was anticipated by the small number of international studies that have explored the smoking behaviour of people with a learning disability, this study found the prevalence of self-reported smoking to be much lower for participants who completed the Special Olympic Health Promotion screen than self-reported by the New Zealand population[9]. Approximately one in five adult New Zealanders self-report regularly smoking and, consistent with other published research, this study found the prevalence of smoking by participants who lived in more independent living situations to be similar to the New Zealand general population. In spite of comprising less than 19 percent of the sample population, more than half of the people who self-reported using tobacco products lived in a flat with other people of whom all smoked two or more cigarettes per day. It is possible that smoking behaviour in this sub-population may be more resistant to change for a range of reasons, including a diminished awareness of the health risks associated with smoking.

The "On the Margins of Good Health" project also identifed the smoking behaviour of others, and of support staff in particular, to be a potentially important determinant of smoking behaviour in people with a learning disability. Four out of every ten participants who did not smoke described being exposed to the smoking behaviour of others compared to nine out of every ten participants who did smoke. Approximately half of the people who completed the Special Olympic Health Promotion screen reported that someone smoked in front of them, suggesting that people with a learning disability may be at greater risk of exposure to smoking than other New Zealanders. One possible explanation for this finding was participants increased reliance on external support. Support staff were the second most frequently named source of exposure to smoking for people who did self-report smoking and the most frequently reported source of exposure to smoking for participants who did not smoke.

Although considerable investment has been made to learn more about the dietary habits of the New Zealand general population, little is known either about the nutritional health knowledge or eating habits of people with a learning disability. Within the Special Olympic Health Promotion screen, information was sought about the frequency with which participants ate food from five different food categories and at first reading the data suggests that participants ate healthily. Although the screen did not permit a direct comparison with findings reported for the general population, including whether participants ate the number of servings of fruit and vegetables recommended by the New Zealand Ministry of Health[34], in excess of eight out of every ten participants self-reported eating food from four of the major food groups at least once a day. In stark contrast, only 17 percent of participants self-reported eating "Fats, oils and sweets," once a day. The self-reported eating habits of participants were sought within the screen element that unambiguously sought to promote healthy eating. Pro-social and acquiescent responding are amongst a cluster of response biases known to be more common in people with a learning disability[55] and it was not possible to determine whether the high proportion of participants who reported eating at least one serving of vegetables or fruit per day represented an accurate representation of participants actual eating habits. Six out of every ten participants who lived in a flat they rented by themselves said they did not eat fruit daily and were significantly less likely than participants who lived in a (staffed) community group home to do so. Participants who lived by themselves were also most likely to have a BMI in the obese range. As reported previously, the odds participants who lived in a flat by themselves had a BMI greater that 30.05kg/m^2 was four times higher than for participants who lived with a family member. This finding led to speculation that higher levels of poverty, lack of oversight of participants day-to-day diet and support that failed to prioritise nutritional literacy and good eating habits may explain the association between living in more independently and obesity. Participants who lived in a flat by themselves, however, may have been less likely to respond in socially appropriate ways meaning it was not possible to exclude differences in the prevalence of response bias as also having contributed to this finding.

Skin cancer is the most commonly reported cancer in New Zealand with an estimated 67 000 New Zealanders diagnosed and treated for skin cancer each year[50]. Reducing New Zealanders exposure to the risk of developing skin cancer has been the focus of a prolonged public health campaign that has centred on promoting the widespread acquisition of four "sun-smart" actions. Little is known, however, either about the sun behaviour of people with a learning disability or by definition, the effectiveness of generic public health campaigns designed to reduce New Zealanders exposure to ultra-violet radiation (UVR). Approximately eight out of every ten participants who completed the Special Olympic Health Promotion screen said they knew that that using sunscreen and wearing a hat were ways to reduce their exposure to UVR. The Health Promotion screen did not prompt for actual sun behaviour. While it was not possible, therefore, to know whether participant's self-reported sun-smart literacy influenced actual sun behaviour, the proportion of participants who self-reported being aware of these two sun-smart actions was approximately 1.8 times the proportion of New Zealanders who spent more than 15 minutes outside in the weekend prior to completing the New Zealand Sun Exposure Survey (SES) self-reported using as a strategy to reduce their exposure to UVR[51]. Participants were much less likely to volunteer looking for shade or wearing sunglasses as ways to reduce their exposure to UVR, highlighting these as possible ways to improve the health behaviour of people

with a learning disability through targeted health promotion. The authors note, however, that it was not possible to determine the extent to which locating questions within an educative screen element influenced the likelihood that sun-smart actions would be volunteered by participants and that an observed trend for both the proportion of participants who named sun-smart actions and self-reported sun-sensitivity to coincide with prompt order made it difficult to exclude recency bias as also influencing participant responding.

A person's perception of their skin sensitivity can influence sun behaviour in ways that affect their exposure to UVR and participants, on average, were far more likely to self-report burning and burning and blistering than New Zealanders who completed the SES. Seven out of every ten participants self-reported that when exposed to the summer sun their skin either burned or burned and sometimes blistered compared to an estimated two in ten New Zealanders who perceive they burn if exposed to summer sun without protection for more than 30 minutes. Although participants whose skin type put them more at risk of developing a melanoma were more likely to report burning, no association was found between skin type and self-reported sun sensitivity or the likelihood participants would name any of the four sun-smart actions advocated by the current sun-smart health promotion campaign.

Estimates suggest that approximately half of adult New Zealanders achieve the New Zealand Ministry of Health's recommended 30 minutes of moderate intensity physical exercise at least five times a week[35, 53]. The small number of international studies that have explored people with a learning disabilities engagement in physical activity report they are less likely to engage in physical activity as part of their leisure activity and are more likely to have poorer cardiovascular fitness than the general population[9]. It was expected, therefore, that the self-reported engagement in physical activity of participants who completed the Special Olympic Health Promotion screen would be lower than the activity levels self-reported by adult New Zealanders. Differences in the scale used to estimate the frequency with which people who completed the Special Olympic Health Promotion and New Zealand Health Surveys exercised for more than 30 minutes a day meant that it was not possible to make a direct comparison, but, contrary to our expectation, the finding that eight out of every ten Health Promotion screen participants self-reported exercising for more than 30 minutes on more than three days a week would appear to suggest that people with a learning disability may be at least equivalently and if not more likely to engage in physical activity than other adult New Zealanders. Conversely, whereas 15% of adult New Zealanders self-reported doing less than 30 minutes of physical activity in the week prior to completing the New Zealand Health Survey[34], only 3% of Health Promotion screen participants self-reported exercising for more than 30 minutes on no days and 17% self-reported exercising for more than 30 minutes for between 1-2 days per week. It is important to re-emphasize, however, that it was not possible to control either for the pro-social response biases discussed previously or for any differences in participants understanding of the meaning of physical "exercise," arguing for the need for direct measures before drawing conclusions about people with a learning disabilities ability to experience the health benefits of regular physical exercise. Although no statistically significant association was found, participants who lived in a flat by themselves were most likely to self-report exercising, further underscoring diet as a critical determinant of the higher prevalence of obesity in this sub-population.

12.4 Objective Three

In 2003 the NHC felt that at that time, a pervasive and unchallenged acceptance existed within adult disability support services that poor health and high medication use were concomitant with intellectual disability[8]. A decade on, the New Zealand Ministry of Health's finding that people with a learning disability were likely to be dispensed almost twice as many different types of prescription drugs from community pharmacies as New Zealanders who do not have a learning disability[11] would seem to suggest a continuation of the historical prescribing practices the NHC observed. A lack of empirical inquiry has meant, however, that very little is known about current medication use by people with a learning disability, including whether they remain exposed to the health risks associated with potential over medication, the use of out-dated medication or the widespread use of psychoactive medication in the absence of a diagnosed psychiatric condition. Objective 3 of the project was to explore what medication adults with a learning disability regularly used.

Seven out of every ten participants for whom information was available reported regularly taking prescription medication. The two Health Promotion screen events from which data for the "On the Margins of Good Health" project was taken represented the first time medication information had been sought alongside administration of a Special Olympic HAS screen. At these events, the collection of medication information relied on participant and/or proxy self-report. During the screens, administrators noted that participants often could not name all of the medication they took. Similarly, it is likely that many participants failed to recognise a small number medications they regularly took as medication. Only one participant, for example, described taking contraceptive medication. As a consequence, estimates of the proportion of participants who took medication and of the prevalence of specific medication type use will underestimate "true" prevalence. Even though proxy informants supported many participants to complete the Health Promotion screen, only half of the participants screened were described as knowing what medication they took. This gap in the health literacy of participants has significance not only in terms of their ability to access Health and Disability Service Consumer's Code Rights to be fully informed[20] or to make informed choices and give informed consent[20], but also in terms of their ability to maintain good health by engaging in conversations about the health risks or possible side effects associated with medication use.

In their review of the literature, Aman, Sarphare & Burrow (1995) reported psychoactive medication prescribing rates for people with a learning disability to range between 29%-53%[56]. The concern they expressed was that this level of prescribing suggested widespread use of psychoactive medication to sedate or manage behaviour. One out of every three participants for whom medication data was available were recorded as taking one or more psychoactive medication types. The NHC also reported finding evidence of the use of co-pharmacy (the simultaneous use of two or more drugs to treat a single condition) and polypharmacy (the use of multiple medications). One quarter of participants for whom psychoactive medication had been prescribed took two or more psychoactive medications with the prescribing of more than one psychoactive medication most prevalent for participants who regularly took antipsychotic medication. Two out of every three participants who regularly took antipsychotic medication took two or more psychoactive medications.

Mood disorders[57] and psychiatric conditions[11] have both been found to be both more prevalent and more commonly treated in people with a learning disability. Approximately 12 percent of participants were recorded as taking antidepressant medication, similar to the New Zealand Ministry of Health's estimate that 9.6 percent of people with a learning disability received government-funded care or treatment for a mood disorder in the year ending June 2008. Of the 18 participants who took antidepressant medication regularly, only one was also described as having a mental condition or mood disorder. Twelve percent of participants were also recorded as regularly taking antipsychotic medication, far higher than the 3.7% of people with a learning disability the Ministry of Health estimated received care or treatment for a psychotic disorder in the year ending June 2008. A similar failure to report an underlying mental health condition was observed with no participant who regularly took antipsychotic medication recorded as also having a psychiatric disorder. This failure to report diagnosed mental health conditions may simply reflect reluctance on the part of participants or proxy informants to disclose a diagnosed mental health condition. A range of alternative explanations exist, all of which have less benign implications for the health status of people with a learning disability. One possible explanation is that the finding reflects a continuation of historical prescribing practices including the prescribing of psychoactive medication for the management of behaviour in the absence of a diagnosed mental health condition. It is possible, however, that the failure to report diagnosed conditions may represent an expression, either of a known tendency to misattribute low affect and disordered thinking to learning disability (diagnostic overshadowing) and/or an associated gap in the mental health literacy of participants who did not know why they took medication. Whether explained by a continuation of historical prescribing practices, the stigmatising of mental illness, diagnostic overshadowing or a lack of awareness by participants of their own mental health status, this failure to recognise psychoactive medication as remedial to an underlying mental health condition would seem to indicate a diminished capacity to recognise and respond appropriately to the mental health needs of a population for whom mental health conditions are known to be more common than the general population.

Although the sample population was very small, it also appeared that the relatively high prevalence of antidepressant and antipsychotic medication use by participants was in part explained by a trend towards higher levels of prescribing for younger participants. Within the wider population, concern is being expressed about an increase in the prescribing of psychoactive medication to children and young adults. Fifteen percent of participants aged under twenty years regularly took antidepressant or antipsychotic medication and, despite well replicated findings demonstrating an association between increasing age and the prevalence of mood disorders and psychiatric conditions[11], the prevalence of antidepressant and antipsychotic use was higher for participants aged less than twenty years than for all other Special Olympic Health Promotion screen participants. In this respect the "On the Margins of Good Health" project provides an initial benchmark against which to assess the extent to which the trend towards higher prescribing rates for psychoactive medication in children and young adults is expressed in a population that continues to be medicated at a higher rate than the general population.

12.5 Objective Four

In their analysis of Special Olympic HAS screen data, collected at the New Zealand Summer Games 2005 & 2009, researchers from the Donald Beasley Institute found evidence of both generational and regional variation in the visual, auditory, oral and podiatry health status of athletes that may have been explained by a range of common environmental determinants[12]. By including a range of additional information field, the "On the Margins of Good Health" project provided a first opportunity to use HAS data to explore the strength of association between potential demographic and environmental predictors of a range of direct measures of health status, including; body mass, blood pressure, calcaneus bone mineral density and self-reported diabetes as-well-as the self-reported health literacy and health behaviour of participants. Objective 4 of the "On the Margins of Good Health" project was to describe the contribution different aspects of the lived circumstance of people with a learning disability make to their health behaviour, health literacy and health status.

Analysis focussed on participant' sex, age, living situation, screen location and whether participants were Special Olympic athletes or not as potential predictors of variation in selected measures of health status, health literacy or health behaviour.

The sex of participants was found to make a statistically significant unique contribution to explaining variation in two health status indicators. International research has repeatedly reported mood disorders to be more common in females with a learning disability. Not surprisingly, therefore, the New Zealand Ministry of Health recently reported that women were more likely than men with a learning disability to have received care or treatment for a mood disorder in the year ending June 2008[11]. Contrary to these findings, only 3% of female participants were recorded as regularly taking antidepressant medication compared to 19% of male participants and a statistically significant association was found between participant sex and the likelihood they would be recorded as taking antidepressant medication. Because medication use is an indirect measure of the prevalence of mood disorder, it is not possible to determine whether in this small sample, female participants were less likely to present with a mood disorder or have an underlying mood disorder recognised and treated with medication.

In the Ministry of Health's analysis of the health status of people with a learning disability, males were significantly more likely to receive care or treatment for a psychotic disorder. A similar, although not statistically significant trend for males to be more likely to be prescribed antipsychotic medication was found in the "On the Margins of Good Health" project and it is possible that the concomitant use of antipsychotic and antidepressant medication may also have contributed to the unexpected finding that male participants were more likely to be taking medication prescribed for a mood disorder.

The sex of participants also made a statistically significant unique contribution to explaining variation in the mean systolic blood pressure of participants and the likelihood participants would have a systolic blood pressure above 139mmHg and/or take medication prescribed for high blood pressure/cholesterol/heart condition. Male participants were recorded as having a higher mean systolic blood pressure than female participants across all age categories, however, the sex of participants only explained less than 3% of the variance when other

potential predictors were held constant. One-quarter of male participants were found to have a systolic blood pressure greater than the threshold used to classify hypertension and/or took medication prescribed for high blood pressure/cholesterol/heart condition compared to only 13% of female participants and the odds a female participant would have a systolic blood pressure higher than 139mmHg and/or they would be recorded as taking blood pressure/cholesterol/heart condition medication were 60% lower than the odds for male participants. This finding is aligned with studies that have explored the prevalence of hypertension in the general population and identify males at slightly greater risk of having elevated blood pressure[34].

Conversely, no association was found between the sex of participants and health indicators previous research indicated an association might reasonably be anticipated.

International studies, including those that have used data collected through the Special Olympic HAS screening programme have consistently reported females to be significantly more likely than males to have a body mass index (BMI) in the overweight or obese range. Temple, (2003), for example, reported that when data collected from Health Promotion screens administered globally were analysed, the odds of males having a BMI in the overweight or obese range were almost half that of female participants[39],[10]. Consistent with these findings, the New Zealand Ministry of Health found that, in the year ending June 2008, females had twice the rate of morbid obesity treatment as males with a learning disability[11]. Although female participants were more likely to have a BMI in the overweight or obese range than male participants and women in the New Zealand general population, participant sex was not found to make a statistically significant unique contribution to explaining variation in the like likelihood a participant would have a BMI in the overweight or obese range or the obese range.

Women are also consistently reported to be more at risk of experiencing the negative health consequences associated with osteoporosis and osteopenia. With in the New Zealand general population, the New Zealand Health Survey found the age standardized prevalence of osteoporosis to be much higher for women than men with the risk of osteoporosis increasing significantly as women aged[11, 34]. Only three participants had a calcaneus bone mass density T-score within the range used to categorize osteoporosis, two of whom were women, however, when the analysis was extended to include BMI T-scores that also fell within the range used to categorize osteopenia, no association was found between participant sex and the likelihood they would have a BMD less than the normal range and 40% of male compared to 17% of female participants were recorded as having a BMD within the range used to categorize osteopenia. A small number of studies have described the prevalence of osteoporosis to be more common in people with a learning disability[43], but few have identified risk factors for low bone density in this population and no research has sought to describe the prevalence of osteoporosis in the New Zealand context. Whilst the current study is too small to draw any conclusions about the sex related prevalence of either osteoporosis or osteopenia, the finding that male participants were more likely to present with a BMD within a range that some physicians consider to be a precursor to osteoporosis is interesting. In the absence of other empirical evidence further investigation is required to determine whether low bone density represents an unacknowledged health risk for New Zealand men with a learning disability.

In their survey of the health status of the general population the New Zealand Ministry of Health found that, when standardized for age, males were significantly more likely to self-report being diagnosed with diabetes than females[47]. In a subsequent investigation of the health status of people with a learning disability the Ministry reported that when adjusted for age, people with a learning disability were twice as likely to receive care or treatment for diabetes but that females with a learning disability were more likely to receive diabetes related care or treatment[11]. Approximately 5% of male and 3% of female participants self-reported having been diagnosed with Type 2 diabetes but this study was too small to be definitive about whether diabetes is more prevalent in males with a learning disability in New Zealand and whether, therefore, sex related differences in care or treatment is aligned with diagnosed diabetes.

No sex related differences were observed in the health literacy and most health behaviours self-reported by participants.

Unlike the general population, male participants were approximately three times more likely than female participants to self report using tobacco products, but the small sample size and lower prevalence of smoking by participants meant that it was difficult to detect any association between sex and smoking behaviour.

Within the general population, the prevalence of skin cancer and death rate for melanoma are both higher for males and, although male participants were marginally less likely than female participants to report knowing using sunscreen or wearing a hat were ways to protect their skin from exposure to ultra-violet radiation, no association was found between participant sex and the likelihood they would report knowledge of any sun-smart action. No association was also found between participant sex and the likelihood a participant would report eating food from any food group daily or exercise for more than 30 minutes or more everyday either.

In their analysis of Special Olympic HAS data collected from athletes competing at the 2005 and 2009 New Zealand Summer Games, researchers from the Donald Beasley Institute found age to be an important predictor of athletes' visual, auditory, oral and podiatry health. For participants who completed the Special Olympic Health Promotion screen, age was also found to make statistically significant unique contributions to explaining variation in two heath status indicators.

Given the association previous research has demonstrated between age and a range of health status indicators, the finding that older participants were more likely to be recorded as regularly taking medication when other potential predictors were controlled for was not a surprise. In spite of the Ministry of Health reporting that the rate of treatment for psychosis and mood disorder for people with a learning disability increased with age[11], no association was found between participant age and the likelihood they would be recorded as taking any psychoactive medication or medication prescribed for psychosis or a mood disorder. As discussed previously, this finding could in part be attributed to what may emerge as a trend towards higher rates of prescribing psychoactive medication to younger people, or that participants' living situation, which did make a statistically significant contribution to explaining variation was controlled for in the analysis.

Hypertension is also known to increase with age with the World Health Organisation estimating that globally, as many as five out of every ten adults aged between 50-60 years may have high blood pressure[41]. Approximately four out of every ten participants aged between 50-59 years and five out of every ten participants aged 60 or more years either regularly took medication for high blood pressure/cholesterol/heart condition and/or had a systolic blood pressure higher than 139mmHg and five out of every ten participants aged between 50-59 years either regularly took medication for high blood pressure/cholesterol/heart condition and/or had a diastolic blood pressure higher than 89mmHg. Participant's age made the largest statistically significant unique contribution to explaining variation in the likelihood participants systolic blood pressure would exceed the threshold used to classify hypertension and/or they would report regularly using medication prescribed for high blood pressure/cholesterol/heart condition when their sex and living situation were controlled for and was the only potential predictor to make a statistically significant unique contribution to explaining variation in the likelihood participants diastolic blood pressure would exceed the threshold used to classify hypertension and/or they would report regularly using medication prescribed for high blood pressure/cholesterol/heart condition. The prevalence of medication prescribed for high blood pressure/cholesterol/heart condition was higher for participants than has been reported for the New Zealand general population across all age categories for which comparable data was available. Two out of every three participants who had a systolic blood pressure above 139mmHh and four out of every five participants who had a diastolic blood pressure above 89mmHg were, however, not taking medication for high blood pressure/cholesterol/heart, emphasising the need for regular testing to ameliorate the health risks of high blood pressure for people with a learning disability.

No association was found between age and the likelihood that a participant would have a BMI in the overweight or obese range or that participants' bone mineral density would be lower than normal. Research that has drawn data from the Special Olympic Health Promotion screen has consistently reported age to be a significant predictor of whether Special Olympic athletes would have a BMI in the overweight or obese range[39],[10] and, although age did make the largest contribution to explaining variation in the likelihood of having a BMI higher than the normal range, no association was found. Within the New Zealand general population, the risk of osteoporosis has been found to increase significantly with age, especially for women[34]. Contrary to expectations, no association was found between the age of participants and the likelihood their bone mineral density would be below the range used to classify osteopenia, however, only eight percent of the sample population was aged over 55 years and it is probable that the small number of participants entering the most at risk age cohort made any association difficult to detect.

No association was found between participant age and any of the health literacy and most self-reported health behaviours sampled for.

Older participants were found to be more likely to self-report eating fruit daily. For every year a participant aged the odds that they would report eating fruit every day increased by 1.1% and whilst this finding is consistent with findings reported for the New Zealand general population, no other associations were found between participant' age and their self-reported eating habits.

Whereas the prevalence of smoking in the general population has been found to peak in early adulthood and then decline with age[34], no participant aged under 17 years self-reported using tobacco products and smoking behaviour appeared to emerge at a later age, especially for female participants. Although participants' exposure to the smoking behaviour of others, did appear to influence the likelihood that they would self-report using tobacco products, it is not unreasonable to suggest that the likelihood that people with a learning disability may smoke may also be influenced by their capacity to be self-determining or escape the kind of surveillance that prevents them engaging in riskier health behaviours. As is discussed below, the association between participants' living situation and the likelihood they would self-report smoking was the only statistically significant relationship found between participant' characteristics and smoking behaviour. It is possible, therefore, that the delayed transition many people with a learning disability experience to more independent living situations and the greater likelihood of being exposed to the smoking behaviour of support staff in more independent support contexts may together have contributed to the smoking behaviour of participants peaking later than the general population.

No association was found between participant' age and the likelihood that they would self-report exercising for more than 30 minutes per day for more than 5 days a week, however few participants had entered the age categories at which the New Zealand Health survey found that physical activity declined within the general population of male and female New Zealanders.

At the conclusion of their analysis of the visual, auditory, oral and podiatry health of athletes who competed at the 2005 and 2009 Special Olympic Summer Games, researchers from the Donald Beasley Institute also suggested that it was possible that regional and generational differences in the health status of Special Olympic athletes that emerged may have had common environmental determinants[12]. The researchers identified their inability to assess what impact differences in athlete's living situation made to their health status to be an important but remediable omission in HAS screen programme. The "On the Margins of Good Health" project represented the first time participant living situation had been included as an information field within a HAS screen. Living situation is, however, a complex variable that, within the context of health promotion, codes for a range of factors with the potential to influence the health status, health literacy or health behaviour of participants. These factors include potential variation in; participants access to health promotion initiatives or information, the health literacy of people who act in a support role, vigilance or the prioritising of health outcomes in the delivery of support, the social construction of learning disability and historical health related social practices, exposure to the positive and negative health behaviour of others, poverty and access to material or other resources likely to affect health behaviour and the possibilities of escaping surveillance or engaging in riskier health behaviour as-well-as the potentially confounding effects of differences in age, type of impairment and attendant health need.

Of all of the explanatory variables of interest, where participants lived was the potential predictor most likely emerge as making a statistically significant unique contribution to explaining variation in the health status, health knowledge or self-reported health behaviour of Health Promotion screen participants.

The living situation of participants was the strongest statistically significant predictor of the likelihood that participants would regularly take medication and the second strongest statistically significant predictor of the likelihood that they had been prescribed psychoactive medication.

Nine out of every ten participants who lived in a (staffed) community group regularly took medication compared to less than half of the participants who lived with a family member. The odds that a person who lived in a community group home regularly took medication were approximately eight times higher than their peers who lived in their family home. Similarly, the odds that a participant who lived in a community group home regularly took psychoactive medication were five times higher than participants who lived with a family member, in spite of a trend towards higher rates of prescribing for younger participants. Whereas two out of every ten participants who lived with a family member were reported as taking psychoactive medication, approximately six out of every ten participants who lived in a (staffed) community group regularly took psychoactive medication. As described above, estimates of the prevalence of psychoactive medication use by people with a learning disability previously ranged between 29%-53%, leading to concerns both about poor prescribing practices and the inappropriate use of psychoactive medication to sedate or manage behaviour. Fifty-eight percent of participants who lived in a (staffed) community group home were recorded as regularly taking psychoactive medication, placing them at the extreme end of the prescribing rates described by Aman, Sarphare & Burrow (1995)[56].

Living in a community group home was found to increase the likelihood that a participant would regularly take antidepressant medication in particular. Twenty-seven percent of participants who lived in a (staffed) community group home were recorded as regularly taking antidepressant medication compared to 6% of participants who lived with a family member and 4% of participants who lived in a flat with other people. The odds that a participant who lived in a (staffed) community group home would be reported as regularly taking antidepressant medication were approximately nine times the odds of participants who lived with a family member.

One possible explanation for medication use to be more prevalent in service settings may be that the observed differences in the rate of prescribing between living situations reflected the legacy of historical prescribing practices and an orientation within service settings towards a more biomedical social construction of learning disability. Without further inquiry, however, it is not possible to conclude that people with a learning disability who live in service settings continue to be exposed to the risks of overmedication or the inappropriate use of psychoactive medication as it is also likely that participants who lived in a staffed community group home were more likely to have medical or mental health support needs able to be remediated by medication.

The other way in which participant's living situation appeared to be associated with indicators of the health status or self-reported health behaviour was an observed trend for poorer outcomes to be more likely when participants lived alone or in more independent support contexts.

Previous studies had found the prevalence of obesity to vary with the living situation of people with a learning disability. Bell & Bhate (1992), for example, reported the prevalence of obesity to be significantly higher for people who lived at home when compared to people who lived in

a group home or institutional setting[9]. In this study, almost seven out of every ten participants who lived in a flat by themselves had a BMI in the obese range, much higher than estimates of the prevalence of obesity for people with a learning disability reported in international studies and higher too than the 26% of participants who lived in a (staffed) community group home and 21% of participants who lived at home with their parents who had a BMI in the obese range. Participants living situation was the only potential predictor to make a unique statistically significant contribution to explaining variation in the likelihood participants would have a BMI in the obese range and the odds that a participant who lived in a flat by themselves or with others would have a BMI greater or equal to 30kg/m^2 were four times higher than the odds for participants who lived with a family member. In the general population the prevalence of obesity has been found to increase sharply for people who live in the most deprived neighbourhoods, leading to speculation that the greater material deprivation often experienced by people with a learning disability who live by themselves may also have influenced participants ability to eat healthily. In addition to perhaps lacking a similar motivation to cook and eat well, participants who lived by themselves were also least likely to have external oversight of their day-to-day diet. Support provided to people who live in more independent living situations is less likely to prioritise nutritional health literacy or healthy eating habits as a component of purchased staff support, meaning that not only was it possible for this group of participants' poor eating habits to go unchallenged, it may have been difficult for them to replace unhealthy eating habits with a healthier and affordable diet. Some evidence of this reality was found following analysis of participants' self-reported consumption of different food groups.

Very little difference emerged in the self-reported eating habits of participants both because the Health Promotion screen only asked whether participants ate food from each food group "Daily" rather than the Ministry of Health's recommended daily servings of fruit and vegetables and suspected pro-social responding by screen participants. Four out of every ten participants who lived in a flat by themselves did, however, report not eating fruit on a daily basis compared to 16% of participants who lived with a family member and 5% of participants who lived in a (staffed) community group home. Differences in the self-reported daily consumption of fruit between people who lived in a flat by themselves and in a community group home was statistically significant.

Given the trend away from parental and more congregate support towards more independent living situations for people with a learning disability, the finding that seven out of ten participants who lived more independently were at risk of developing a range of health conditions known to be associated with obesity emphasises the need to develop effective health promotion strategies to reduce the prevalence of obesity in this at risk, but difficult to access population.

Participants who lived in a flat they rented by themselves were also more likely to self-report using tobacco products. As noted previously, whilst the overall prevalence of smoking was far lower than that reported for the New Zealand general population, 18 percent of participants who lived in a flat they rented with other people self-reported smoking, very similar to the less than one in five New Zealand adults the New Zealand Health Survey estimated to be current smokers[35]. Conversely, no participant who lived at home with their parents and seven percent of participants who lived in a (staffed) community group home self-reported using tobacco

products and the difference in the self-reported smoking behaviour of people who lived in a flat they rented with others or with a family member was found to be statistically significant.

In addition to the greater liberty participants who lived in more independent support contexts had to engage in riskier health behaviours, support staff emerged as a significant source of exposure to the smoking behaviour of others. A positive association was also found between the tobacco use and the likelihood others smoked in front of them and whilst it was beyond the scope of this research to detect what influence the presence of support staff who smoked had on a population for whom the ability to engage in riskier health behaviour may have been a marker of adulthood, it is possible staff's smoking behaviour did influence the likelihood participants would either take up or fail to cease using tobacco products. No public health campaign has identified disabled people as a target population for a smoking cessation campaign despite evidence that people with a learning disability may be less likely to recognise the wider health implications of cigarette smoking[9] and now evidence that the prevalence of smoking for people with a learning disability who live in more independent support contexts appears to be very similar to the New Zealand population for whom generic campaigns are designed.

12.6 Objective Five

In the absence of other epidemiological research, Special Olympic athletes who participated in the regular cycle of Healthy Athlete HAS screen testing have provided the only data from which to estimate the health status of people with a learning disability living in New Zealand. Without the participation of Special Olympic athletes, people with a learning disability would have continued to be absent from wider population health surveillance until the Ministry of Health's recent attempt to estimate the prevalence of health conditions from indirect indicators of the health status of people with a learning disability visible to them through a range of Ministry of Health databases[11].

As a sample population, however, little is known about the representativeness of athletes competing at the Special Olympic Summer Games, introducing the possibility that findings drawn from the HAS programme may underestimate the prevalence of key health status indicators within the general population of people with a learning disability. Physical activity, for example, is known to be protective against heart disease, Type 2 diabetes, hypertension, obesity, osteoporosis and a range of cancers. Evidence is also starting to emerge that physical activity may also have a role to play in preventing serious mental illnesses and moderating mood[58]. Intuitively, one would expect that athletes screened at the Special Olympic Summer Games would be more likely to engage in regular physical activity than their non-athlete peers. Other differences in the lived experiences of athletes competing at a national level may also mean they may be atypical of their age peers living in New Zealand communities, including differences in their; ability to access material or human resources, type of impairment, living situation or a range of other factors known to influence the health status or health behaviour of people with a learning disability. In attempting to account for the lower prevalence of obesity found by Harris et al (2003) following their analysis of Health Promotion screen data volunteered by American Special Olympic athletes competing at international events when compared to the estimate Temple et al (2013) made of the prevalence of obesity in American

Special Olympic athletes from data drawn from the Special Olympics International Health Promotion database, Temple et al speculated that sampling at the international level underestimated the 'true' prevalence of obesity because of the atypicality of the cohort[10]. Extrapolating further, it is probable that sampling for athletes competing at a national event may also exclude populations most at risk of poorer health outcomes within local communities.

By purposefully recruiting non-athlete participants the final objective of the "On the Margins of Good Health" project was to assess whether Healthy Athlete® screen data represents a valid estimate of the prevalence of health conditions amongst the general population of adults with a learning disability.

The research team anticipated that Special Olympic athlete participants would experience more positive health status outcomes than non-athlete participants and that their greater exposure to health promotional information in the course of preparing for athletic events may also contribute to improved levels of health literacy.[ix] In general terms this expectation was reflected in the study findings. Special Olympic athletes were less likely than non-athlete participants to; take medication regularly, have a BMI in the overweight or obese range or the obese range, have a diastolic blood pressure above 89mmHg or take medication for high blood pressure/cholesterol/heart condition, to self-report Type 2 diabetes. They were also more likely to self-report exercising for more than 30 minutes for more than five days a week.

The only health status indicator for which being a Special Olympic athlete or not made a statistically significant unique contribution to explaining variance, however, was the likelihood a participant regularly took psychoactive medication. Twenty-seven percent of Special Olympic athletes regularly took psychoactive medication, compared to 53% of non-athlete participants. When all other potential predictors were held constant, whether a participant was a Special Olympic athlete or not was the strongest predictor of the likelihood a participant would have been prescribed psychoactive medication. The odds that a non-athlete would regularly take psychoactive medication were three times higher than the odds for Special Olympic athletes.

Two potentially self-reinforcing explanations may account for this finding. Firstly, it aligns with recent research that indicates a positive association between physical activity and mental health status[58]. It is not unreasonable to suggest that Special Olympic athletes' mental health may also have been improved by the benefits of camaraderie and competition that come with Special Olympic membership. A more negative interpretation of these findings is that having a mental health condition may limit people with a learning disability's ability or desire to engage in physical activity through organised sport or recreational activities like Special Olympic membership. Either way, these findings suggest that data provided by Special Olympic Health Promotion screens that exclude non-athletes are likely to underestimate the prevalence of psychoactive medication use in the general population of people with a learning disability.

[ix] It is important to note that participants at the Dunedin & Palmerston North Health Promotion screen events only indicated whether they were a Special Olympic athlete or not. Most Special Olympic participants will not have competed or have been screened at a national event, meaning that data collected at the Summer National Games as part of the ordinary cycle of HAS programme may also underestimated the prevalence of health conditions reported for Special Olympic athletes in the "On the Margins of Good Health Project.

Caution needs to be exercised in the interpretation of findings related to the representativeness of Special Olympic athletes taken from this study, however, given that the sample population of Special Olympic athletes provided a closer approximation of the age:sex profile of the wider population of people with a learning disability. Comparison with population estimates from the Statistics New Zealand Disability Counts Survey and Ministry of Health's recent capture-recapture prevalence estimates revealed that females and participants aged between 35-54 years were over-represented in the non-athlete sample population with the gender and age skewing reflected in differences in the proportion of participants who lived with a family member or in a (staffed) community group home. Forty-five percent of Special Olympic athletes lived at home with their parents compared to 16% of non-athlete participants and whereas 34% of Special Olympic athletes reported living in a (staffed) community group home, 53 percent of non-athlete participants reported living in that setting.

Table 37 Association between participant demographic characteristics and the range of health status and self-reported health literacy and behaviours included in SONZ Health Promotion screen

		Sex	Age	Ethnicity	Athlete status	Living situation	Screen location
Health status indicators	Took medication regularly		✔			✔	
	Knew what medication they took						✔
	Took psychoactive medication regularly				✔	✔	
	Took antidepressant medication regularly	✔				✔	
	Took anticonvulsant medication regularly						
	Took antipsychotic medication regularly			✔			
	Had BMI in obese/overweight range						
	Had a BMI in obese range					✔	
	Systolic blood pressure > 139mmHG and/or take medication	✔	✔				
	Diastolic blood pressure > 89mmHG and/or take medication		✔				
	Bone mineral density < normal range						
	Self-reported diabetes		✔				
Health knowledge or behaviour	Use of tobacco products					✔	
	Exposure to smoking*						✔
	Self-reported eating dark green leafy vegetables*						
	Self-reported eating other vegetables						
	Self-reported eating fruit		✔			✔	
	Knew using sunscreen reduced exposure to UVR						
	Knew wearing a hat reduced exposure to UVR						
	Knew looking for shade reduced exposure to UVR						✔
	Knew wearing sunglasses reduced exposure to UVR*						✔
	Exercise for 30 minutes or more than 5 days per week						
	Exercise for 30 minutes or more for 2 or fewer days per week						

12.7 Limitations of the project

The overarching aim of the "On the Margins of Good Health" project was to describe and learn more about variation in the health knowledge of people with a learning disability as a preliminary step towards developing a better understanding of the linkages between health literacy and behaviour and the poorer health outcomes experienced by people with a learning disability in New Zealand. Three direct (body, size, blood pressure, bone mineral density) and two indirect (type of medication, self-reported diabetes) measures of the health status of participants who completed the Special Olympics Health Promotion screen were available. In addition to exploring what contribution a range of potential predicators (sex, age, living situation, screen location, Special Olympic athlete/non-athlete) made towards explaining variation in the health status of participants, the research sought to establish whether variation in participant health literacy or self-reported health behaviour in the domains of tobacco smoking, nutrition, sun-safety and physical exercise modified participants health risk. Aspects of the research design, however, made it difficult to detect linkages between the health status and the health knowledge or self-reported health behaviour of participants.

Special Olympics New Zealand launched the HAS Health Promotion screen at events held in Dunedin and Palmerston North. Because both events occurred outside of the ordinary cycle of Special Olympic HAS screening, Special Olympics New Zealand did not have the pool of athletes who attend the National Summer Games from which to recruit from. Two hundred and five people with a learning disability volunteered health information. The small sample size meant that it was generally difficult to detect associations between potential predictors of variation in the health status of participants or their self-reported health behaviour, but was especially problematic for health conditions or health behaviours where prevalence was expected to be low. Contrary to findings previously reported following larger epidemiological studies, the small number of participants who regularly took antipsychotic (n=17) or antidepressant (n=18) medication, had a BMD in the range used to categorize osteoporosis (n=3), self-reported diabetes (n=6), said they used tobacco products (n=13) or did not eat food from the majority of food groups daily (<20%), undermined attempts to model variation in target outcomes.

The Ministry of Health recently estimated the average life expectancy of males with a learning disability to be 18 years below the average life expectancy of New Zealand males and the life expectancy of females with a learning disability to be 23 years below the average female life expectancy in New Zealand[11]. As a consequence, the population profile of people with a learning disability is much younger than the New Zealand general population. Comparison with population estimates from the Statistics New Zealand Disability Counts Survey and Ministry of Health's recent capture-recapture prevalence estimates, however, also indicated that older people with a learning disability were under-represented in the "On the Margins of Good Health" project sample population. Age has been identified as a risk factor for a range of mental health conditions, obesity, hypertension, osteoporosis and diabetes. Only 10% of participants were, however, aged 54 years or over, meaning that not only was the prevalence of conditions for which age is a known risk factor likely to have been underestimated in this

study, fewer participants in the 'at risk' age cohort also made it difficult to detect other potentially confounding associations.

Special Olympic Health Promotion screen protocols and clinical oversight and training provided at both screen events supported the accurate measurement and recording of all direct measures of the health status of participants. Difficulties were experienced, however, collecting indirect measures that relied on participant self-report. The opportunity to collect information about the range of medication participants regularly took was considered important because historical prescribing practices had been identified as a significant health issue for people with a learning disability in New Zealand. Controlling for the confounding effects of medication use was also important for analysis and the type and prevalence of medication use provided an additional lens through which to explore health conditions like mental health and the prevalence of undiagnosed conditions. Self-report was, however, an ineffective method for collecting medication data. No medication information was provided for 37% of participants and of the remainder, approaching half were recorded as not knowing what medication they took. Failures to report, to recall and to recognise types of medication as appropriate to volunteer were observed during screen data collection, meaning that it probable that the prevalence of medication use has been differentially underestimated in ways that are impossible to quantify and that the validity of findings which include medication as an independent or dependant variable are compromised.

Measures of the health literacy (knowledge of sun-smart actions) and health behaviour (diet and physical activity) also relied on participant self-report. Two of the primary aims of the Special Olympic Health promotion screen are to educate to improve the health literacy and health behaviour of Special Olympic athletes and to increase the investment of local health promotion leaders in recognising and responding to the health needs of people with a learning disability. A range of response biases, including acquiescence, pro-social recency and latency response biases, are known to be more common in people with a learning disability and it is difficult to determine whether this educational imperative influenced participant responding. Pro-social responding was suspected for participants' self-reported eating habits and engagement in physical activity. For example, despite previous research describing people with a learning disability as less likely than the general population to include participation in physical activity as part of their leisure activity, 80% of participants reported exercising for more than 30 minutes per day for three or more days compared to the 50% of adult New Zealanders who reported engaging in physical activity for more than 30 minutes per day for five or more days. No pre-screen protocol for eliminating acquiescent or serial position response biases was administered and the emphasis on increasing emerging health professionals' exposure to the communication styles and health needs of people with a learning disability introduced the possibility that screen administrators were either naïve to or may not have had strategies that would have helped to reduce response bias. It is interesting to note that where participants were screened made statistically significant unique contributions to explaining variation three self-report measures, for

which it was not possible to exclude differences in the way screen administrators sought or recorded self-reported health literacy or health behaviours[x].

Reducing response bias was important because, without knowing whether the self-described health behaviour or health literacy of people with a learning disability translate to "actual" health behaviour, the linkage between health literacy and the negative health outcomes they experience will be difficult to establish. Further research that adopts both observational and qualitative research methodologies will be required if we are to learn more about the origin of barriers to good health that can be attributed to gaps in the health literacy of people with a learning disability or to barriers in the health literacy or social practices of those who have the potential to recognise and respond to the needs of a population currently on the margins of good health. Why is it, for example, that when people with a learning disability report knowing of the benefits of eating well, those most able to be self-determining continue to experience higher levels of obesity and associated health conditions? Or why is it that, in spite of being alerted to the human rights violations of historical prescribing practices, 50% of people with a learning disability do not know what medication they take and the odds that people who live in community group homes are five times more likely to take prescribed medication than their peers?

12.8 Concluding remark

The "On the Margins of Good Health," adds to the picture of relative health disadvantage experienced by people with a learning disability that has recently emerged from research conducted by the New Zealand Ministry of Health as-well-as the Donald Beasley Institute's analysis of HAS screen data drawn from the 2005 and 2009 Special Olympic National Summer Games.

Of particular concern was the high rate of medication use especially for people who lived in (staffed) community group homes, including evidence of a continuation of psychoactive medication prescribing practices the New Zealand NHC had formerly described as "disturbing." The findings also affirm previous research that describes the prevalence of obesity in people with a learning disability as higher than the general population and identifies people living in more independent support contexts as an especially at risk population. Concern was also expressed that people with a learning disability may be at greater risk of having undiagnosed hypertension and Type 2 diabetes than the New Zealand population.

The "On the Margins of Good Health," project also advances our ability to identify people with a learning disability who are at greater risk of experiencing poorer health outcomes. Consistent with research that identified the age of Special Olympic athletes as an important predictor of their visual, oral, auditory and podiatry health, similar associations were found between participant age and the likelihood they regularly took medication or presented with

[x] Screen location made a statistically significant unique contribution to explaining variation in the likelihood participant would self-report: exposure to smoking, eat dark green leafy vegetables daily and know wearing sunglasses reduced their exposure to UVR.

hypertension. The "On the Margins of Good Health" project also represented the first time participant living situation had been included as an information field and where people lived emerged as an important predictor of the likelihood participants would be prescribed medication, have a BMI in the obese range, eat less well and report using tobacco products.

Although associations found between negative health outcomes and potential predictors like the living situation of people with an intellectual disability may alert us to where to look to address health inequality, understanding how a myriad of different forces may intersect to give expression to poorer health outcomes will, however, not be possible without qualitative inquiry. Moreover reaching a more sophisticated understanding of the beliefs and customs that underscore health related action or inaction by people with intellectual disabilities, their sources of support and the health professionals they meet along the way will be critical to the design of health promotions strategies designed to bring people with a learning disability back from the margins of good health.

References

1. Barr, O., et al., *Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland*. Journal of Advanced Nursing, 1999. **29**(6): p. 1482-1491.
2. Beange, H., N. Lennox, and T.R. Parmenter, *Health targets for people with intellectual disability*. Journal of Intellectual & Developmental Disability, 1999. **283-297**(24): p. 4.
3. Beange, H., A. McElduff, and W. Baker, *Medical disorders of adults with mental retardation: A population study*. American Journal on Mental Retardation - AJMR, 1995. **99**(6): p. 595-604.
4. Jensen, D.E.M.C., et al., *People with intellectual disability and their health problems: a review of comparative studies*. Journal of Intellectual Disability Research, 2004. **48**(2): p. 93-102.
5. Felce, D., et al., *The impact of checking the health of adults with intellectual disabilities on primary care consultation rates, health promotion and ocntact with specialists*. Journal of Applied Research in Intellectual Disabilities, 2008. **21**(6): p. 585-596.
6. Emerson, E. and J. Robertson, *The estimated prevalence of visual impairment among people with learning disabilities in England*2011 UK: Department of Health.
7. Horwitz, S.M., et al., *The health status and needs of individuals with mental retardation*, 2000, Department of Epidemiology and Public Health & Department of Psychology, Yale University: New Haven, Connecticut. p. 177.
8. National Advisory Committee on Health and Disability, *To have an 'ordinary' life. Kia whai oranga 'noa'. Community membership for adults with an intellectual disability*, 2003, National Advisory Committee on Health and Disability,: Wellington.
9. National Advisory Committee on Health and Disability, *To have an 'ordinary' life. Kia whai oranga 'noa'. Background papers to inform the National Advisory Committee on Health and Disability. Health about the lives of adutls with an intellectual disability in New Zealand*, 2004, National Advisory Committee on Health and Disability,: Wellington.
10. Temple, V.A., J.T. Foley, and M. Lloyd, *Body mass index of adults with intellectual disability participating in Special Olympics by world region*. Journal of Intellectual Disability Research, 2013. **Early View Online Version**.
11. Ministry of Health, *Health indicators for New Zealanders with intellectual disability*, 2011, Ministry of Health,: Wellington.
12. Milner, P. and B. Mirfin-Veitch, *Special Olympics New Zealand Athlete Health Overview* Unpublished.
13. Special Olympics - Healthy Athletes Health Promotion, *Healthy choices, healthy athletes. Health promotion guide for clinical directors* 2007, USA: Special Olympics - Healthy Athletes Health Promotion,.
14. Donald Beasley Institute, *Taking more control of my health. A health guide for women*.2001, Dunedin, New Zealand: Donald Beasley Institute.
15. Statistics New Zealand. *2006 Disability Survey Highlights*. 2007 [cited 2013 30 May 2013]; Available from: http://www.stats.govt.nz/browse_for_stats/health/disabilities.aspx.
16. Statistics New Zealand. *National Population Estimates*. 2013; Available from: http://www.stats.govt.nz/browse_for_stats/population/estimates_and_projections/NationalPopulationEstimates.
17. Hosmer, D. and S. Lemeshow, *Applied Logistic Resgression*2000, New York: Wiley.
18. Vahabzadeh, A., V. Delaffon, and A. Biswas, *Meeting the health care needs of people with learning disabilities*. InnovAiT, 2010. **3**: p. 328-332.

19. Doan, T., et al., *Medication use among Australian adults with intellectual disability in primary healthcare settings: A cross - sectional study*. Journal of Intellectual & Developmental Disability, 2013. **38**(2): p. 177 - 181.
20. Health & Disability Commissioner. *The Code (full). The HDC Code of Health and Disability Services Consumers' Rights Regulation 1996*. 1996 2009 [cited 2013; Available from: http://www.hdc.org.nz/the-act–code/the-code-of-rights/the-code-(full).
21. Standards New Zealand, *New Zealand Standard Health and Disability Services (Core) Standards: NZS8134.1:2008*, 2008, Standards New Zealand.
22. Ministry of Health, *Medicine Care Guid for Community Residential and Facility-based Respite Services - Disability, Mental Health and Addiction*, 2012, Ministry of Health: Wellington.
23. Halder, N., et al., *An audit on covert administration of medications to adults with learning disabilities*. International Journal of Developmental Disabilities, 2012. **58**(3): p. 129-136.
24. Reiss, S. and N.E. Aman, *Psychotropic medications and developmental disabilities: The International Consensus Handbook*.1998, USA: Nisonger Center for Mental Retardation and Developmental Disabilities, The Ohio State University.
25. Lipman, R.S., *The use of psychopharmacological agents in residential facilities for the retarded*, in *Psychiatric approaches to mental retardation*, F.J. Menolascino, Editor 1970, Basic Books: New York. p. 387-398.
26. Milner, P., et al., *An examination of the outcome of the resettlement of residents from the Kimberley Centre*2008, Dunedin: Donald Beasley Institute.
27. Nøttestad, J. and O. Linaker, *Psychotropic drug use among people with intellectual disability before and after deinstituionalisation*. Journal of Intellectual Disability Research, 2003. **47**(6): p. 464-471.
28. Robertson, J., et al., *Receipt of psychotropic medication by people with intellectual disability in residential settings*. Journal of Intellectual Disability Research, 2000. **44**(6): p. 666-676.
29. Clarke, D., et al., *Psychotropic drugs and mental retardation: disabilities and the prescription of drugs for behaviour and for epilepsy in three settings* Journal of Mental Deficiency Research, 1990. **34**: p. 385-395.
30. Kiernan, C., d. Reeves, and A. Alborz, *The use of anti-psychotic drugs with adults with learning disabilities and challenging behaviour*. Journal of Intellectual Disability Research, 1995. **39**: p. 263-274.
31. Zito, J., et al., *A three-country comparison of psychotropic medication*. Child and Adolescent Psychiatry and Mental Health, 2008. **2**(26): p. 2-26.
32. Ministry of Health, *Guidlines for Prescribing Psychotropic Drugs*, 1996, Ministry of Health: Wellington.
33. Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for the Treatment of Schizophrenia and Related Disorders, *Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of schizophrenia and related disorders*. Australian & New Zealand Journal of Psychiatry, 2005. **39**: p. 1-30.
34. Ministry of Health, *A portrait of Health. Key Results of the 2006/07 New Zealand Health Survey*, 2008, Ministry of Health,: Wellington.
35. Ministry of Health, *The Health of New Zealand Adults 2011/12: Key findings of the New Zealand Health Survey*, 2012: Wellington.
36. Bell, A.J. and M.S. Bhate, *Prevalence of overweight and obesity in Down's syndrome and other mentally handicapped adults living in the community*. Journal of Intellectual Disability Research, 1992. **36**(4): p. 359-364.

37. Rimmer, J.H., et al., *Obesity and obesity-related secondary conditions in adolescents with intellectual/developmental disabilities*. Journal of Intellectual Disability Research, 2010. **54**(9): p. 787-794.
38. Janicki, M.P., et al., *Health characteristics and health services utilization in older adults with intellectual disability living in community residences*. Journal of Intellectual Disability Research, 2002. **46**(4): p. 287-298.
39. Harris, N., et al., *Prevalence of obesity in international Special Olympic athletes as determined by body mass index*. Journal of the American Dietetic Association, 2003. **103**(2): p. 236-237.
40. Stedman, K. and L. Leland, *Obesity and intellectual disability in New Zealand*. Journal of Intellectual & Developmental Disability, 2010. **35**(2): p. 112-115.
41. World Health Organisation. *World Health Day - 7 April 2013*. 2013 [cited 2013 7 April 2013]; Available from: http://www.who.int/world-health-day/en.
42. Hejlik, K. *Hypertension - the "Silent Killer"*. 2013 March 21, 2013 [cited 2013; Available from: On the Margins 30.1.14 2.docx.
43. Wilkinson, J. and M. Cerreto, *Primary care for women with intellectual disabilities*. The Journal of the American Board of Family Medicine, 2008. **21**(3): p. 215-222.
44. Schrager, S., *Epidemiology of osteoporosis in women with cognitive impairment*. Mental Retardation, 2006. **44**(3): p. 203-211.
45. Jaffe, J.S., et al., *Risk factors for low bone mineral density in individuals residing in a facility for the people with intellectual disability*. Journal of Intellectual Disability Research, 2005. **49**(6): p. 457-462.
46. University of Otago and Ministry of Health, *A focus on nutrition: Key findings of the 2008/2009 New Zealand Adult Diet & Nutrition Survey*, 2011, Ministry of Health,: Welllington.
47. Ministry of Health, *Diabetes in New Zealand. Models and forecasts 1996-2011*, 2002, Ministry of Health,: Wellington.
48. New Zealand Parliament, *Government Response to the Report of the Māori Affairs Committee on its Inquiry into the tobacco industry in Aotearoa and the consequences of tobacco use for Māori*, House of Representatives, Editor 2011, New Zealand Government: Wellington.
49. Ministry of Health, *Cancer: New registrations and deaths 2009*, 2012, Ministry of Health,: Wellington.
50. Health Promotion Agency. *Skin cancer in New Zealand: the facts and statistics*. 2013 [cited 2013; Available from: http://sunsmart.org.nz/skin-cancer/skin-cancer-facts-and-statistics.
51. Gray, R., *Sun Exposure Survey 2010: Topline Time Series Report*, 2010, Health Sponsorship Council Research and Evaluation Unit,: Wellington.
52. NIWA. *Climate Summaries 97/2000*. 2013 [cited 2013; Available from: http://www.niwa.co.nz/education-and-training/schools/resources/climate/summary.
53. Ministry of Health. *How much activity is recommended?* 2012 09 July 2012 [cited 2013; Available from: http://www.health.govt.nz/your-health/healthy-living/food-and-physical-activity/physical-activity/how-much-activity-recommended.
54. World Health Organisation and Food and Agriculture Organization of the United Nations, *Diet, nutrition and the prevention of chronic diseases. Report of a Joint WHO/FAO Expert Consultation*, in *WHO Technical Report Series*, WHO, Editor 2003, World Health Organisation,: Geneva.
55. Perry, J. and D. Felce, *Subjective and objective quality of life assessment: Responsiveness, response bias, and resident: Proxy concordance*. Mental Retardation, 2002. **40**(6): p. 445-456.

56. Aman, M., G, G. Sarphare, and W. Burrow, H., *Psychotropic drugs in group homes: Prevalence and relation to demographic/psychiatric variables*. AJMR, 1995. **99**(5): p. 500-509.
57. Marston, G.M., D.W. Perry, and A. Roy, *Manifestations of depression in people with intellectual disability*. Journal of Intellectual Disability Research, 1997. **41**(6): p. 476-480.
58. Fox, K.R., *The influence of physical activity on mental well-being*. Public Health Nutrition, 1999. **2**(3A): p. 411-418.