The Experience of Alcohol Use amongst Individuals with an Intellectual Disability in Aotearoa/New Zealand

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Abstract

**Background**: There is little research literature on alcohol use among those with intellectual and developmental disability and no New Zealand based studies of such alcohol use prior to this study. Based upon overseas research, alcohol use was associated with a number of co-existing problems such as financial problems, problems with relationships, problems with the police, and problems with mental and physical health. Within New Zealand, alcohol use is normative and the recent movement to community living by people with an intellectual disability potentially places them at increased risk of the adverse effects of alcohol misuse.

**Aim**: The aim of this research project was to investigate alcohol use amongst individuals with a mild intellectual disability in Aotearoa/New Zealand. The project’s focus will be on individuals who have sufficient autonomy to make choices about their alcohol use. The project’s research question is:

“What are the experiences with and patterns of alcohol use amongst individuals with a mild intellectual disability living in the community in Aotearoa/New Zealand?”

**Methodology**: The research utilised a critical realist perspective which sees behaviour and experiences as emerging from within, and constrained by, a multi-layered social structure. Semi-structured interviews were undertaken to investigate the experience of alcohol use among 10 individuals with an intellectual disability in Aotearoa/New Zealand. The interview transcripts were coded and themes identified utilising Braun and Clarke’s six stage approach to thematic analysis.

**Results**: Three themes were identified:

- Choices and influences of alcohol use,
- Context and location of alcohol use and
- Drinking behaviour.

In making choices about alcohol use participants were embedded in a multi-layered social structure which, combined with their disability, constrains their autonomy. Despite these constraints, it is suggested that they were able to exercise valuational agency with respect to their choices regarding alcohol. Consumption levels among participants were generally low, with limited experience of binge drinking or long term adverse effects from drinking. Four protective factors mitigated the risk of pathological alcohol consumption. These were the protective powers of family, social, spiritual, and
support networks, learning from negative personal experience, internalisation of rules, and risk aversion.

**Conclusion:** Alcohol use by people with an intellectual disability was found to take place in a highly complex and dynamic social structure. The risk of hazardous use by participants in this study was mitigated by a range of social and individual protective factors.
Acknowledgements

It has been said that each journey begins with a single step and along the way you will meet fellow travellers who will share the road and lighten the load. At this time, I wish to acknowledge those who have shared the road with me making my steps lighter.

Firstly, my sincere appreciation goes to my supervisors, Dr Simon Adamson and Dr Jenny Conder whose encouragement, guidance, and criticism helped me move beyond my preliminary rough ideas to the present form. Secondly, to my colleagues at ID Services, TKW, who listened to my random thoughts and musings and put up with my obsessions and absentmindedness. To Cindy Johns and Marg Matheson of People First and Jo Mason of Community Connections, many thanks for your assistance in recruiting participants. To Melissa at Capital Transcription, thank you for the time and care taken to transcribe the interviews. To Elsie Hill, thank you for proof reading the draft of the thesis, your insightful comments and suggestions improved the finished work beyond measure. To my friends in my life group at the Rock Church, Wellington, many thanks for your love, prayers and support. I love you all beyond words. Finally, I acknowledge those who shared their stories with me, without you this project would never have seen the light of day. I hope that I do justice to your stories. To all of you I say

*He iti ra, he iti mapihi, pounoumu.*

*I may be small, but I am an ornament of greenstone.*

*But let justice roll on like a river, righteousness like a never-failing stream*

*Amos 5:24*
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1. Introduction

1.1 Background and personal interest in the problem

The motivation for undertaking the current study stemmed from the author’s clinical work with people who have an intellectual disability. It was noted that a number of the clients had a history of alcohol and other substance use. In many cases, they consumed alcohol to hazardous levels, leading to adverse outcomes including financial difficulties and appearing before the courts. Prior to the start of this thesis, these experiences led to an investigation of the literature to see what it revealed about the patterns and experiences of alcohol use by people with an intellectual disability. The aim of this search was to better inform and improve the author’s clinical practice. Lawrence Taggart of Belfast University who, with a number of his colleagues, had researched alcohol and substance use by people with intellectual disability, was also contacted (L. Taggart, personal communication, 2013).

The initial investigation revealed that, while there is a large body of literature on the patterns of alcohol use across a wide range of settings, groups, and cultures, very few studies focused on the experiences and patterns of alcohol use by these individuals (Cosden, 2001; Taggart, McLaughlan, Quinn, & McFarlane, 2007; Taggart, McLaughlan, Quinn, & Milligan, 2006; Weinberg, 2001). Amongst the studies that explored alcohol use by this group, a common theme was the prevalence of a number of coexisting problems (Cocco & Harper, 2002; McGillicuddy, 2006; Taggart, et al., 2007).

A second related question that arose from working within Aotearoa/New Zealand was whether there was any New Zealand based research relevant to the New Zealand context. Despite an extensive search of the literature, only one brief case note was found about a client with evidence of developmental delay presenting at a New Zealand emergency department after huffing a solvent, (Yip, Ahmed, & Naudé, 2005). This suggested that there was a significant gap in the literature that needed to be filled as health practitioners in a range of settings may come across individuals who have an intellectual disability and consume alcohol. An important part of this journey prior to starting the current study was writing a submission for the alcohol law reform bill in which the author attempted to bring to the attention of the select committee the vulnerabilities of this group and the potential adverse effects of hazardous alcohol consumption (Gee, 2010).
The author’s interest in understanding the experiences of alcohol use by this population also led to the consideration of the context in which alcohol use takes place. It was realised that the experience of alcohol use does not take place within a vacuum, but is positioned within a wider social context. This context includes the regional, national and international social structures and patterns of alcohol use as well as the particular history of people with an intellectual disability within Aotearoa/New Zealand. This includes the context of deinstitutionalisation and the transition to community living. The culmination of these investigations and questions led the researcher to consider the need to formally investigate and research the experiences of people in New Zealand who have an intellectual disability. This thesis is the outcome of this process.

1.2 Thesis structure

In this section the structure of the thesis and how the study was undertaken will be outlined. Firstly, the international context of alcohol use will be described. Then, the New Zealand context of alcohol use will be briefly outlined. Thirdly, the context of deinstitutionalisation and community living will be described. Deinstitutionalisation and community living form an important policy and experiential context for the experiences of alcohol use by people with an intellectual disability.

Having established the study’s context, the theoretical framework chosen for this study will be outlined. The methodology utilised for the study will be described and the results of the literature review presented. Finally, the study results will be presented and discussed. The main sections of the thesis will be as follows:

1. Background
2. Context of study
3. Literature review
4. Research framework
5. Methods
6. Results
7. Discussion and conclusion

1.3 Definitions

The group of interest for this study is people with an intellectual disability who consume alcohol. For the purpose of this thesis intellectual disability will defined as people who have an impairment in
intellectual ability and adaptive functioning across the conceptual, practical and social domains (American Psychiatric Association, n.d.). To simplify referencing this group, they will be referred to as people with an intellectual disability, individuals with an intellectual disability, this group, this population or participants. Within the literature on psychoactive substance use, a number of terms are used including drugs, substances, and illicit substances to refer to psychoactive substances. For the purposes of this thesis, the generic term substance or substances will be used to refer to all psychoactive substances other than alcohol. Alcohol consumption will be referred to as drinking alcoholic drinks, drinking alcohol, consuming alcohol, consumption of alcohol, or simply alcohol. Alcohol and substance misuse will be used to refer to alcohol and substance use at hazardous levels, including alcohol and substance dependency. Consideration was given to utilising the first person form of self-referencing, but it was decided to remain with the third person form utilising the terms researcher or author to refer to the author of this thesis.
2. Context of study

This chapter provides context relevant to the study. A brief discussing the international context of alcohol use is followed by the history and contested policy environment of alcohol use in New Zealand. Then the movement to community living will be placed in its international context, and the particular policy developments and the New Zealand experience, post deinstitutionalisation for people with an intellectual disability noted.

2.1 International context of alcohol use

Alcohol is one of the most commonly consumed psychoactive substances both in New Zealand and overseas (Degenhardt, et. al., 2008; World Health Organisation [WHO], 2014). Degenhardt et al. compared data from seventeen countries and, whilst their study’s sample of counties was limited, their results point to very real and significant differences in the pattern of alcohol use between countries and regions. This difference suggests the influence of social structure and cultural factors in the patterning of alcohol consumption. New Zealand’s cumulative lifetime incidence of alcohol use for all age cohorts, as reported by Degenhardt et al., was third on their list of seventeen countries (94.8%), behind Germany (95.3%) and Ukraine (97.0%) as presented in Chart 1. New Zealand was also reported to have a high prevalence of early consumption of alcohol compared to other countries, ranking second out of the 17 countries for alcohol use at age 15 years, at 74.1%, behind Germany (82.1%) and ahead of France (68.2%). For the 21 years cohort New Zealand had slipped to fourth at 94.1%, behind the Ukraine (98.5%), Germany (97.8%), and France (94.5%). While the Ukraine had the highest prevalence of alcohol use at age 21, Japan was reported to have the greatest inter age increase from age 15 to 21 years, viz. 30.4% for the 15 years cohort to 91.9% for the 21 years cohort (an increase of 61.5%). Next is Ukraine (increase of 59.2%) and then Mexico (increase of 48.5%). The four Middle Eastern and African countries in the study ranked the lowest in terms of their alcohol use.

The (WHO) has recently released their analysis of alcohol consumption across member countries (WHO, 2014). The WHO have estimated that worldwide consumption as of 2010 was 6.2l of pure alcohol per capita for individuals aged 15+ years (WHO, 2014, p. 29) of which 24.8% was estimated to be unrecorded consumption (WHO, 2014, p. 30). The WHO also noted that there was considerable variation of consumption across regional areas with high income regions reporting the highest rate of consumption and hazardous drinking as can be seen from Table 1 (WHO, 2014, p. 5).
According to the WHO, females were more likely to be abstainers than males. In terms of the negative consequences of alcohol use, the WHO estimated that, as of 2012, the lifetime disability adjusted years due to alcohol use to be 139 million years or 5.1% of the aggregate disease burden due to all causes (WHO, 2014, p. xiv).

Chart 1 Lifetime cumulative incidence of alcohol use (Degenhardt et al, 2008 p. 1057)

The WHO data collected during 2008-2010 identified the country with the highest rate of alcohol consumption as Belarus with 17.5l per capita per year of pure alcohol for both sexes combined, followed by Moldova (16.8l) and Lithuania (15.4). New Zealand was ranked 31st out of the 191 countries for which data was available at 10.9l per capita per annum, equal to Gabon. Australia was ranked 18th at 12.2 per capita per annum. The WHO data reveals significant gender differences in alcohol consumption with none of the countries reporting average female consumption above that of males. Belarus exhibited the largest gender difference in absolute terms at 18.4l per capita per annum, males consuming 27.5l compared to 9.1l for females, followed by Moldova (difference of 17.0l) and Ukraine (11.3l). New Zealand had a difference of 9.4l between males (15.7l per capita per annum) and females (6.3l per capita per annum).
Table 1: WHO regional comparisons (WHO, 2014, p. 35)

<table>
<thead>
<tr>
<th>WHO region</th>
<th>Alcohol per Capita</th>
<th>Heavy Drinking</th>
<th>Alcohol per Capita</th>
<th>Heavy Drinking</th>
<th>Alcohol per Capita</th>
<th>Heavy Drinking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>6</td>
<td>5.7%</td>
<td>19.5</td>
<td>16.4%</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Americas</td>
<td>8.4</td>
<td>13.7%</td>
<td>13.6</td>
<td>22.0%</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Eastern Mediterranean</td>
<td>0.7</td>
<td>0.1%</td>
<td>11.3</td>
<td>1.6%</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Europe</td>
<td>10.9</td>
<td>16.5%</td>
<td>16.8</td>
<td>22.9%</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>South East Asia</td>
<td>3.4</td>
<td>1.6%</td>
<td>23.1</td>
<td>12.4%</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Western Pacific</td>
<td>6.8</td>
<td>7.7%</td>
<td>15</td>
<td>16.4%</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>World</td>
<td>6.2</td>
<td>7.5%</td>
<td>17.2</td>
<td>16.0%</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

2.2 Alcohol use within New Zealand

Both the research of Degenhardt et al. (2008) and the data underlying the report by the WHO (2014) support the contention that New Zealand has a high alcohol use culture. Alcohol use has been a common factor in social interaction since the early days of colonisation, though there have been significant changes in how it has been consumed over time (Hutchins, 1999). In common with other colonial societies, New Zealand’s drinking culture conforms to a “Dry” drinking culture (Cagney & Cosar, 2006). The key attribute of “Dry” cultures is that alcohol is consumed less frequently but in higher volumes per sitting. In a report on New Zealand’s drinking culture, BRC Marketing and Social Research (2004) noted that drunkenness is tolerated and, for many drinkers, there is little evidence of self-control or concern about the consequences of excessive alcohol consumption. Smith (2014), in a study of attitudes to alcohol consumption at New Zealand high school formal dances, noted that adults showed a permissive attitude towards alcohol use both by fellow adults and teenagers. Smith also found that adults were just as likely to consume alcohol to excess as high school pupils and concluded that adults needed to change their own attitudes and beliefs.
Sports, particularly rugby, play an important role in New Zealand’s culture and alcohol is central to this culture for participants and spectators. Gee and Sam (2013), in a report commissioned for the Health Promotion Agency, investigated the culture of alcohol promotion at four high profile sports events. They found that, while the specific nature of promotion differed depending upon the context of the event, a pervasive promotion of alcohol and alcohol use at each event was normal. Gee, Jackson, and Sam (2014) explored the role that alcohol played in the Wellington international rugby sevens tournament and found evidence of a “carnivalesque culture” (p. 6) where pageantry and excessive alcohol consumption were normative. Within the carnivalesque culture of sports and entertainment, drinking, alcohol promotion, and excessive consumption have become normalised. Furthermore, a cluttered landscape of branding and symbols associating alcohol with sports has developed as observed by Gee (2013) in her analysis of the culture of alcohol sponsorship during the 2011 Rugby World Cup. Fan zones were set up, such as the one on the Auckland waterfront, which was given the epithet “party central”. Such was the clutter of alcohol imagery during the Rugby World Cup, that it became impossible to avoid messages promoting alcohol consumption during this period (Gee, 2013).

Another common cultural symbol associated with alcohol consumption within New Zealand culture is the strong silent rural man. It is an image that harks back to the colonial history of New Zealand. Gee and Jackson (2012) analysed the utilisation of this cultural image in the promotion of the Speight’s beer brand in Lion Nathan’s Southern Man campaign. The campaign features a couple of laconic unemotional men from the rural South Island of New Zealand in an appeal to stereotypical images of New Zealand masculinity. Its appeal to nostalgic images of rural men who were genuine and self-reliant proved to be highly successful for Lion Nathan, as the Speight’s brand significantly increased its level of brand awareness within New Zealand.

The culture of alcohol use is historically normative in New Zealand. However, the recent debate around alcohol policy and regulation points to an increasingly contested and confusing environment, particularly with respect to the promotion, sale and consumption of alcohol (Cody & Jackson, 2014). The conflicting submissions to a number of recent reviews provide evidence of the contested nature of this environment. In the 2007 review of the regulation of alcohol advertising, youth submitters took the view that advertising does influence youth behaviour in line with other influences (Ministry of Health, 2007). Adult submitters to the same review were split along the same lines as for the
Alcohol Reform Bill. In a follow-up review of alcohol advertising and promotion in 2014, media and liquor groups argued that there was no evidence that linked alcohol advertising, promotion and sponsorship to alcohol related harm whereas health professionals, community groups and researchers argued that there were clear linkages between alcohol advertising, promotion and sponsorship, and alcohol usage and harm (Allen & Clarke Policy and Regulatory Specialists, 2014). The final report and recommendations of the 2014 review were in favour of increased restrictions particularly aimed at reducing youth exposure to alcohol advertising and promotions (Ministerial Forum on Alcohol Advertising and Sponsorship, 2014), though it is yet to be seen whether any of the review’s recommendations will be implemented.

Submissions to both the Alcohol Reform Bill 2011 and two recent reviews of liquor advertising reveal two highly divergent views with respect to the role of alcohol in New Zealand society, supporting either greater or lesser degrees of regulation. The Alcohol Reform Bill, which is now enacted as the Sale of Liquor and Supply Act, 2012, resulted in a vast number of submissions from individuals, community groups, Non Governmental Organisations (NGOs), churches, health professionals and researchers on the one hand and liquor manufactures and suppliers, retailers, hospitality industry representatives, and advertising and media groups on the other hand. Whereas the former tended to support a more regulated and controlled environment the later supported a continuation of the status quo. While the final version of the bill introduced some new controls and made reference to irresponsible promotion of alcohol, Alcohol Action New Zealand felt that the Alcohol Reform Bill tinkered with the problem of alcohol misuse and ignored the evidence in favour of greater levels of controls (Alcohol Action New Zealand, n.d.). The Green Party, writing a minority view in response to the report of the Justice and Electoral Select Committee, similarly expressed reservations over the failure of the bill to address major concerns over promotion, advertising and sponsorship of alcohol (Justice and Electoral Select Committee, 2011). In a submission to the same bill, the RTD (Ready to Drink) Producers’ Group, an industry and lobby group comprising manufacturers and suppliers of ready to drink alcoholic beverages, advocated a voluntary and collaborative approach rather than government regulation, citing the Australian government’s position at the time in support of their own (RTD Producers’ Group, 2011). They further argued that since giveaways are a common promotional tool across a wide range of retail outlets, it would be a “gross anomaly” to ban such promotions (p. 7). DB (Dominion Breweries) Breweries, one of New Zealand’s largest breweries, in their submission, argued that current standards and codes of practice were sufficient and they, like other manufacturers, wholesalers and importers, take a responsible approach to advertising and
promotion and that therefore more rigorous regulation was not required (DB Breweries, 2011). DB Breweries further argued that advertising and promotion focused on brand awareness and did not increase consumption, and therefore the proposed section on irresponsible promotion was too wide in scope.

The evidence on the influence of advertising and promotion on alcohol consumption is highly complex and contradictory and has been the subject of ongoing debate within the academic literature. Smart (1988), in a review of the observational, experimental, and econometric literature concluded that there was little evidence linking changes in consumption to advertising and bans. Saffer (1991), on the other hand, claimed to have found empirical support for the view that advertising restrictions reduce alcohol consumption. Young (1993), however, rejected Saffer’s conclusions, citing a number of methodological flaws in Saffer’s (1991) analysis. In reply, Saffer (1993) argued that Young had mis-specified his attempt at re-estimating Saffer’s (1991) model and therefore had come to erroneous conclusions. Saffer and his colleague, in a subsequent analysis, noted that there was limited evidence in the econometric literature relating total consumption to advertising and promotion, but argued that they had found evidence linking advertising bans to reductions in alcohol consumption in their analysis (Saffer & Dhaval, 2002). In a recent Cochrane systematic review Siegfried et al. (2014) highlighted a number of methodological flaws in the literature and concluded that there was insufficient evidence either for or against the hypothesis that restricting advertising reduces consumption. While the evidence on the role of advertising for the general population is mixed, research into the influence of advertising and media on adolescents supports the view that advertising and media portrayals influence decisions by this age group regarding alcohol use (Anschutz, Van de Berg, De Graaf, & Koordeman, 2014, Atkins, cited in Singer, 1985; Denniston, Swahn, Herts, & Romero, 2011; Ellickson, Collins, Hambarsoomians, & McCaffrey, 2005). Adolescents consulted for the 2007 review on New Zealand advertising regulation acknowledged that promotion may have some influence on the behaviour of some young people, but did not believe that they were personally influenced by advertising (Ministry of Health, 2007).

As noted above a number of social and cultural factors in New Zealand’s history have supported the development of New Zealand’s drinking culture (Hutchins, 1999). The current attitudes towards the consumption of alcohol are, therefore, to a significant degree performed, though subject to ongoing renegotiation and change. In a recent study commissioned by the Health Promotion Agency,
Research New Zealand (2013) found a number of attitudinal changes to alcohol use between 2009 and 2011. The main changes included a reduction in the number believing New Zealand does not have a drinking problem, increasing numbers seeing the link between alcohol and anti-social behaviour, increased awareness that alcohol use is either the most serious or one of the most serious national problems, and an increasing intolerance of drunkenness at a friend’s place or at social/family events. The attitudinal changes reported by Research New Zealand (2013) highlight the fluid nature of attitudes towards alcohol use and suggest a movement away from the dominant drinking culture might be underway, though any change is tentative at the moment.

Sub groups and sub cultures within New Zealand are likely to exhibit different attitudes, experiences, and patterns of use (Cagney & Cosar, 2006). Māori, for example, prior to contact with Pakeha had no history of alcohol use and even following initial contact referred to alcohol as “waipero” or “stinking water” (Hutt, 2003, p. 7). The initial impact of alcohol on Māori was limited and variable due to a range of protective factors (Mancall, Robertson, & Huiwai, 2000). However, changes in social structure and attitudes to alcohol use as a result of urbanisation, economic restructuring, and the increased alienation from the protective influence of the local Marae, have resulted in an increase in the negative effects of alcohol use (Awatere, Casswell, Cullen & Kupenga, 1984).

The Ministry of Health (2009), in their survey of alcohol use, found a wide diversity in the prevalence of alcohol use between major ethnic groups with European/Other having the highest lifetime prevalence at 90.3% compared to Asian who had the lowest at 54.8%. For study participants who consumed alcohol in the previous year (past year drinkers), the prevalence rates for daily drinkers followed a similar pattern with a prevalence rate of 7.6% for European/Other compared to 2.4% for Asian. The prevalence of drinking larger amounts in the last year, defined as more than six standard drinks for males and four standard drinks for females per drinking occasion, is significantly higher for Pacific Islanders (76.5%) and Māori (76.6%) compared to European/Other (62.0%) and Asian (28.6%). Utilising the AUDIT alcohol screening tool, a tool commonly used to estimate the level of hazardous drinking (Reinert & Allen, 2007), the prevalence of hazardous drinking (Audit score eight or higher) for past-year drinkers, was estimated to be higher for Māori (40.9%) and Pacific Islanders (39.7%) than that for European/Other (22.7%) and Asian (9.7%).
Religious prohibitions within some spiritual groups can influence and reduce the level of alcohol use via social influences and negative beliefs about alcohol (Johnson, Sheets & Kristeller, 2008). Islam, for example, prohibits the consumption of alcohol. Some Christian communities, denominations, and sects also place a number of restrictions or prohibitions on alcohol use. For example, the Church of Jesus Christ of the Latter-day Saints prohibits the consumption of alcohol. Conservative Baptists, Methodists, and Presbyterians have a history of being against alcohol use and were prominent in the temperance movements. Among other religious and spiritual movements, Rastapharianism has a tradition of alcohol avoidance. Hare Krishnas also believe in the avoidance of all intoxicants, including alcohol.

In conclusion alcohol use within New Zealand is widespread and socially accepted. Drinking to excess is tolerated and has been shaped and supported by a “Dry” drinking culture in common with other settler societies. Within the wider culture, there is a wide divergence of experience of alcohol use influenced by such factors as ethnicity and social or spiritual groups to which a person belongs. The histories and beliefs of sub groups and sub cultures also influence their behaviours and attitudes towards alcohol.

2.3 The context of deinstitutionalisation and the move to community living
The recent history of deinstitutionalisation has produced a significant body of work on the transition to community living (Kim, Larson & Lakin, 2001; Milner, 2008; O’Brien, Thesing, & Tuck, 2001; Stancilffe, Emerson, & Lakin, 2001). While community living is now the norm, it is a relatively recent phenomenon emerging from a more general movement towards deinstitutionalisation and normalisation since the 1970s. Within this movement, institutional care is seen as characterised by depersonalisation, rigidity of routines, block treatment, and social distancing (Mansell & Beadle-Brown, 2010, p. 105). Alternatively, community living for people with an intellectual disability is characterised by being able to access the same accommodation and living arrangements as the general population (Mansell & Beadle-Brown, 2010, p. 105-106) and involves:

1. Using accommodation located among the general population.
2. Using a range of accommodation options normally available to the general population.
3. Enabling people to choose, as much as possible, their own accommodation options.
4. Providing whatever help is required for successful community participation.
In New Zealand, prior to the era of deinstitutionalisation, people with an intellectual disability were increasingly accommodated in large institutions (Milner, 2008). Four large purpose built hospitals were developed for this purpose at Templeton near Christchurch, Braemar in Nelson, Mangere in Auckland and Kimberly near Otaki (Milner, 2008). The largest of these was the Kimberly Centre (hereafter referred to as Kimberly) which had more than 700 residents at its peak in the 1950s and still had more than 300 residents at the time of its closure (Milner, 2008). As part of the move to community living, all the large institutions were closed and former residents placed in community based accommodation.

New Zealand’s experience of deinstitutionalisation was part of an international movement advocating normalisation and greater choice for people with an intellectual disability. It has been the subject of a number of studies investigating the results of the transition to community living. Stancliffe, Emerson, and Lakin (2001), in their editorial introduction to a special edition in of the Journal of Intellectual and Developmental Disability on deinstitutionalisation, noted a number of country specific differences in the patterns of how the movement to community living has been implemented. Kim, Larson and Lakin (2001) reviewed 33 studies of the impact of deinstitutionalisation in the United States of America (USA) between 1980 and 1999. Kim et al. (2001) found an improvement in adaptive functioning across many of the studies, although differences in outcomes were noted among individual studies. Martínez-Leal, et al. (2011) studied the European experience of deinstitutionalisation, dividing the respective experiences into early and late stage deinstitutionalisation, without defining the characteristics of each stage. The authors found that people with an intellectual disability had a large number of coexisting health needs and there was a high level of variability in getting these needs met regardless of the stage of deinstitutionalisation. O’Brien, Thesing, and Tuck (2001), in a study of the experiences of 61 people with an intellectual disability who had transitioned to community living, reported that all their informants saw the move as positive leading to improvements across a number of domains of living. One of the most comprehensive New Zealand based studies on the move to community living was carried out by the Donald Beasely Institute on the closure of Kimberly (Milner, 2008). The study identified a number of positive benefits and improvements, including increased choice and improvements in adaptive living, across their sample. For many former residents of Kimberly, the movement to community living meant that they were closer to their families which improved the
chances of a successful transition. However, the results at an individual level were variable and while there were a number of successes there was a sub group who failed to thrive in the community.

The current environment for people with an intellectual disability is within the community. The particular context of accommodation may differ with a number of options available ranging from living with family members to cluster homes and group homes. As a result of this move, there is now a generation of people with an intellectual disability who have no history or experience of institutional care. They will only have experienced community living and will either be living with their own family or have moved into some form of community based accommodation. For this group, there is no before and after the institution. Therefore, their way of relating to the world, making choices, and negotiating the risks that come with making choices will be different from those who have gone through the process of deinstitutionalisation and transition to community living. This will include their decisions over their use or non-use of alcohol.

Community living poses a number of challenges different from those faced by individuals who grew up in an institution. There is now an emerging body of research that focuses on these challenges. This research has addressed issues such as autonomy (Harris, 2003; Smyth & Bell, 2006), the social networks of people with an intellectual disability (Amando, Stancliffe, McCarron & McCillion, 2013; Hillman et al., 2013; Shogren, 2013), the ecology of inclusion (Simplican, Leader, Kosciulek, & Leahy, 2015), social inclusion and the risks of social isolation (Bigby, 2008; Bray & Gates, 2003; Forrester-Jones et al., 2005; Heyman, Swain, Gillman, Handyside, & Newman, 1997; Lippold & Burns, 2009; McConkey & Collins, 2010).

How an individual experiences community living will be influenced by the funding and policy environment in which he or she is situated. Funding of support services to individuals with an intellectual disability, within the New Zealand context, is predominately out of the disability stream of the government’s health budget. The 2014 to 2018 disability support services’ strategic plan identified services to people with an intellectual disability as the largest single group receiving support services, accounting for 45% of people who received disability support (Ministry of Health, 2015). New Zealand’s current policy environment for supporting people with an intellectual disability is influenced by the 2001 disability strategy, which articulates a vision for a non-disabling society that both values the lives of people with disability and enables their full participation (Ministry of
Health, 2001). Implementing that strategy, though, has proved to be highly complex, as revealed by a review of the Ministry of Health documents pertaining to service provision for people with an intellectual disability (Evalve Research, 2013; Evalve Research, 2015; Ministry of Health, 2012; Ministry of Health, 2013a; Ministry of Health, 2015). In 2013, the Ministry of Health (2013a) reviewed the previous model and approach to providing disability services and found that there was a culture of “ticking the box” and a lack of tools to support frontline staff resulting in a reactive approach to service provision (p. 4). The review further noted that the transition from regional to national contract relationship managers (CRMs) in 2008 resulted in a loss of contact with service providers, and where multiple services are provided, the requirement to liaise with multiple contract relationship managers. Split Ridge Associates (2011) also noted that there was an inconsistent and highly variable approach to behavioural support services. In some cases, Split Ridge found clients may be referred through a Needs Assessment Service Coordination Organisation (NASC), or may self-refer.

The various governmental reviews have given rise to a number of developments within the policy environment, which will affect how people with disability access disability services and how these services will be funded. Underpinning these developments is the development of a new funding model, co-designed by the government and people with disabilities, based on a person-centric approach (Ministry of Health, 2013b; Office of Disability Issues, 2014). The aim of the new funding approach is to provide people with disabilities and their families greater choice and autonomy about what support services they are provided with. New programmes that are being demonstrated and rolled out under the umbrella of the new funding approach include individualised funding, enhanced individualised funding and Choice in Community Living (Evalve Research, 2013; Evalve Research, 2015; Ministry of Health, 2012). The objective of these developments is to provide support services that meet the needs of people with disabilities, providing them more choice and independence in how they live their lives. It is still early days in terms of the roll out of the new model, with the new tools and services still in demonstration mode. Therefore, it is still uncertain how it will affect the lives and choices of this group or those of their families, and social and support networks. The development of new models points to the increasingly dynamic, changing, and uncertain context in which people with intellectual disabilities live their lives.
The general theme then from this brief survey of the literature is that movement to community living was part of a wider international movement aimed at bringing increased levels of autonomy and choice to people with disabilities. The funding and policy environment is moving towards a more person centred model. The evidence shows that this trend can be a positive experience leading to an increased ability to exercise choice. However, with the increased autonomy and choice there are also challenges and risks that need to be managed and negotiated. One of those risks is increased access to alcohol and the risks associated with its use and misuse.
3. Literature search

Having briefly outlined the ecological context of this study in Section 2, this section will address and review the current literature on alcohol use and intellectual disability. This was undertaken as follows. Firstly, the types of studies to be reviewed and selection criteria will be outlined (Section 3.1). The search strategy and search terms will then be presented and the process of selection outlined (Section 3.2). Finally, the outcome of the literature review will be presented with the literature divided into seven thematic groups (Section 3.3 to 3.9).

3.1 Types of studies

The literature search focused on quantitative and qualitative studies of alcohol use amongst individuals with an intellectual disability as well as expert opinion and literature review articles. In order to capture all relevant studies, some of which investigate alcohol as one of a range of different substances, other substance use was incorporated into the search. Participants in the studies selected for the review could be of persons of either gender who were aged 13 years and above living in as an inpatient, including in prison and other secure forensic units, or community settings. There was no exclusion based on relationship status. Studies that included individuals with coexisting Axis I or Axis II disorders, as defined by Diagnostic Statistical Manual IV-TR (American Psychiatric Association, 2000), or a coexisting learning disability were also included. The review excluded studies focusing on individuals with a cognitive deficit due to traumatic brain injury, organic brain disorder, dementia, delirium, medical condition or consumption of a psychoactive substance after age 18.

3.2 Search strategy for identification of studies

The search strategy involved a systematic search of literature databases for articles which conformed to inclusion criteria outlined in the previous section and included articles identified in a previous literature search undertaken as part of the author’s post graduate study. The search was restricted to studies from 1980 to the present date. The date range was selected to provide a wide enough time frame to capture potentially relevant studies and articles, while excluding studies that were considered to be too old to be applicable to this study. The following databases were used in the search:
Within the literature, a number of alternative terms are used to describe both intellectual disability and substance use (McGillicuddy, 2006). In order to capture all the relevant literature the following search criteria were used in the search:

1) Intellectual disability and substance use or
2) Intellectual disability and alcohol or
3) Learning disability and substance use or
4) Learning disability and alcohol or
5) Mental retardation and substance use or
6) Mental retardation and alcohol

In addition to the key word criteria, each database had a number of additional inclusion and exclusion criteria that could be selected. For the purpose of this review, masters and doctoral level dissertations and theses as well as articles in peer reviewed journals written in English were selected. Where a qualifier existed that removed duplicates from the search, this was also selected. A physical search of reference lists of selected articles was also undertaken.

Where potential articles of interest were identified from the database search, their abstracts were reviewed for relevance. Relevance was judged according to the inclusion and exclusion criteria outlined above. If an article or dissertation appeared to be relevant to the research question, it was
either downloaded in electronic form or a paper copy was requested. They were then further reviewed for relevance. Selected articles and dissertations were then analysed in more detail for relevant themes and results. This included identification of the methodology used, data source, country the study took place in, type of journal, analytical tools used to analyse data, sample characteristics and profile, types of outputs and whether alcohol use was a primary or secondary phenomenon of interest.

Based on this process 55 articles and one master’s level dissertation were selected for inclusion in the review. Of these 27 were review and expert opinion articles, five were qualitative studies, 23 were quantitative studies and one was a mixed method study. The average number of articles and studies produced per year was 1.6 articles and studies. Most of the qualitative, quantitative and mixed method studies were based in the United Kingdom (UK, 13 studies), followed by the USA (10 studies) and the Netherlands (four studies). Belgium and Ireland accounted for one study each. The average sample size of the selected quantitative, qualitative and mixed method studies was 256.4 participants. Qualitative studies had a significantly smaller number of participants averaging 7.8 compared to 321.5 for quantitative studies. The mixed method study had just two participants.

Chart 2: Selection of literature for inclusion in review
3.3 Type of substances used

In the studies reviewed alcohol was the most common substance used. However, in many cases other licit and illicit substances were used in conjunction with alcohol. McLaughlan, Taggart, Quinn and Milligan (2007), for example, investigated the experiences of professionals who worked with individuals with an intellectual disability who had substance related problems in Northern Ireland. They found that alcohol was the main substance used while a smaller number of people also used other substances. They further found that the majority of participants were in the intellectual disability services compared to alcohol and drug services. In a related study Taggart, McLaughlan, Quinn, and Milligan (2006) utilised informants to investigate the types of substances used and their impact on 67 clients with an intellectual disability in Northern Ireland and found that alcohol was used by 100% of their sample. Other substances were used by 19.4% of their sample and included prescription medication, cannabis, ecstasy and other stimulants. Taggart, McLaughlan, Quinn, and McFarlane (2007) talked to 10 people with an intellectual disability in Northern Ireland who misused substances and again found alcohol to be the main substance used. In a study based in Flanders, Belgium To, Neirynck, Vanderplasschen, Vanhuele and Vandevede (2014) attempted to replicate and expand upon the study by Taggart et al. (2006). To et al. (2014) found that alcohol was used by 77.9% of respondents, followed by cannabis (39.4%), cocaine (12.5%), amphetamine (10.6%), and heroine (9.6%). McCrystal, Percy, and Higgins (2007) investigated substances use by UK adolescents with an intellectual disability. Alcohol was found to be the most common substances used for year nine to year twelve students with 29% having used alcohol and 25% having used tobacco. In a USA based study McGillicuddy and Blane (1999) found that alcohol was the most frequent substance used with 39% consuming alcohol at least once in the past month. Tobacco was the next most common substance (23% of participants), followed by illicit substances (4% of participants).

One study, Chaplin, Gilvarry and Tsankanikos (2011), investigated and reported on recreational substance use, including alcohol, by clients with a co-existing intellectual disability and mental disorder. Alcohol was the most common substance used, followed by cannabis. Chaplin et al. (2011) found that 11.3% of the sample reported recreational use and 6.1% disclosed heavy alcohol use. Of those who consumed any substance, or were multi-substance users, 80% consumed alcohol.

Three studies investigated the types of substances used, including alcohol, by people with an intellectual disability within the criminal justice system. McGillivray and Moore (2001) in a small
quantitative study researched substance use by male and female offenders with an intellectual disability. Amongst males in their study, 29.6% used alcohol only while a further 18.5% used alcohol and other substances. Amongst females 66.6% used alcohol while 33.3% used alcohol and other substances. Dwyer and Frierson (2006) investigated substance use and intellectual disability amongst murder defendants in South Carolina. The vast majority in the study (94.5%) consumed alcohol. Any substance use disorder was found in 61.9% of the sample. The most common substance abuse diagnosis was alcohol abuse (16.7%) and alcohol dependence (16.7%). Poly-substance abuse was found among 9.5% of the sample. Lindsay, Steele, Smith, Quinn, and Allan (2006) undertook a twelve year follow-up study of recidivism among a cohort of intellectually disabled offenders in the UK and compared the prevalence of co-existing problems such as alcohol use, drug/solvent use, problems with daily living, aggression and sexual relations. In the male sexual offending group, 9.9% reported problems with alcohol use, while for male non-sexual offenders the percentage was 22.3%. Among females, the percentage was 33.2%.

3.4 Usage patterns
The pattern of usage and duration of problems amongst people with an intellectual disability can be highly variable (Van Der Nagel, Keiwik, Buitelaar, & DeJong, 2011, Watson, Franklin, Ingram, & Eilenberg, 1998). However, Slayter and Steenrod, (2009), in a review article, noted that there was limited knowledge of the life course of alcohol and other substance use. A number of other review articles noted that usage rates tended to be lower amongst people with an intellectual disability compared to non-disabled individuals (Burgard, Donohue, Azrin, & Teichner, 2000; Degenhardt, 2000; Delany & Poling, 1990; Huxley, Taggart, Baker, Castillo, & Barns, 2007; Moore & Polsgrove, 1991; Shawna, Chapman, & Wu, 2012). Factors suggested for differences in usage rates include environmental factors (Moore & Polsgrove, 1991) and reduced access to alcohol due to the more restricted settings in which this group lived (Burgard et al., 2000). Detailed investigation in the literature of the influence these factors have on alcohol use is, however, lacking.

Three studies based in different countries, and over significant differences in time, investigated frequency of usage. Taggart et al. (2006) in a Northern Ireland study of individuals, who misused substances, found that 31.3% of their participants consumed alcohol daily, 16.4% used alcohol on weekends, 13.4% consumed once every 3-4 days and 19.1% consumed weekly. In an older USA based study DiNitto and Krishef (1984) noted a lower pattern of daily consumption with 7% of their
participants reporting daily usage, while 33% used weekly, and 47% monthly. DiNitto and Krishef (1984) recorded that beer was the most frequently consumed alcoholic beverage followed by wine. Home was the most frequent location for drinking alcohol (52% of sample) followed by pubs/bar (30%), and with friends (20%). To et al. (2014), in a more recent study in Flanders, also found that alcohol was primarily consumed at home or with friends. In reviewing these studies it is noted that there are significant differences in the countries in which the studies were undertaken and the time of the study, which may have contributed to the differences in the results.

Kristchef and DiNitto (1981) in another older USA based study compared the drinking patterns of people with an intellectual disability in two groups, members of the Association of Mentally Retarded Citizens (ARC) and individuals in an alcohol treatment programme (ATP). In the ARC, most of the individuals were in the 26-35 age-group. The age distribution was more evenly spread among those in the ATP group. The length of alcohol abuse reported by Kristchef and DiNitto (1981) was highly variable. In the ARC, the length of the alcohol abuse tended to be in the 0-5 years range while for the ATP the duration tended to be in the 6-10 year range.

Three studies investigated alcohol use by adolescents. McCrystal et al. (2007), in their Northern Island study, found that home was the main location for consuming alcohol by adolescents in year nine to twelve. By year 12 alternative venues began to emerge. Emerson and Turnbull (2005) investigated alcohol and tobacco use by adolescents in the UK. Emerson and Turnbull estimated the odds ratio for participants with an intellectual disability of having consumed alcohol at any time compared to non-disabled controls at 0.71, while the odds ratio for consuming alcohol at least once per month was estimated at 0.46. Huang (1981), in an older USA based study, studied the drinking behaviour of students with an intellectual disability in the Alabama school system. Huang found that alcohol usage was lower for individuals with an intellectual disability across all social economic groups and the age of having a first drink tended to be later, viz. 15-18 years for the intellectually disabled group, compared to 11-12 years for the non-disabled control. Friends were the most likely source of the first alcoholic drink (63%). The place of their first drink was most likely to be a friend’s place (48%) followed by their own home (41%).

Three studies investigated the health characteristics and behaviours of people with an intellectual disability including alcohol use. All three studies found low levels of alcohol consumption. Rimmer,
Braddock, and Marks (1995) undertook a study of individuals living in residential facilities who had an intellectual disability in a large Midwestern state. They found that no participant living in an institution drank alcohol. Males in group homes drank 0.57 (+/- 1.38) drinks (time period not reported) compared to 0.36 drinks for females (+/- 1.08). Males in their natural family setting drank significantly fewer drinks at 0.16 (+/- 0.83) while females in their natural family setting did not drink alcohol. McGuire, Daly, and Smyth (2007) investigated and compared the health characteristics of Irish people with an intellectual disability. McGuire et al. found that the majority of their participants never consumed alcohol (61.8%). The remainder were mostly occasional drinkers (24.2%), followed by weekly (8.4%) and daily (1.9%). In a UK based study, Robertson et al. (2000) compared the lifestyle characteristics of people with an intellectual disability across village-based, residential campuses, and community based dispersed housing. Robertson et al. found that males had a higher level of consumption compared to females. Of those who consumed alcohol, the majority were in the low consumption category (one to 10 units per week for men and one to seven units per week for women) with only 1% of males in dispersed housing consuming at moderate levels and none at the high levels of consumption (more than 21 units per week for men and 14 units per week for women).

Westermeyer, Kemp, and Nugent (1996), in another older USA based study, analysed presentations at two USA based treatment centres to find the pattern of substance use by clients with an intellectual disability compared to non-disabled controls. Westermeyer et al. (1996) found that both the intellectually disabled and the non-disabled groups had similar histories of substance use. 100% of clients with a substance use disorder and intellectual disability consumed alcohol. Clients with an intellectual disability tended to be older at the time of their first use, 17.5 years compared to 15.1 for the non-disabled group.

### 3.5 Risk factors

A number of studies investigated risk factors associated with alcohol use. Review articles noted a number of common risk factors including family history, environment, social economic factors, co-existing mental disorders, social isolation, unemployment, isolation, poor social skills, and transition to community living (Barrett & Pashos, 2006; Brown & Coldwell, 2006; Cocco & Harper, 2002; Cosden, 2001; Degendhart 2000; Huxley, Copello & Day, 2005; Mayer, 2001; Slayter & Steenrod, 2009). Slayter and Steenrod (2009) concluded that the risk factors for alcohol misuse amongst
people with an intellectual disability are similar to the non-disabled population. Weinberg (2001) concluded that risk factors for use differ from abuse/dependence as abuse/dependence depended more on physiological and psychological factors. Weinberg also noted that abuse/dependence had multiple pathways and that risk factors may moderate and mediate use or be non-causal markers. Traditional approaches, according to Weinberg, may also miss qualitative differences within groups and between groups.

The relationship between alcohol and substance use, personal choices, and personal relationships were investigated by a number of authors. Westermeyer, Phaobtong, and Neider (1988) compared individuals with an intellectual disability and coexisting substance abuse with non-substance abusing controls and found a significantly higher history of antisocial behaviour. Both McGuire et al. (2007) and To et al. (2014) identified increased levels of choice and autonomy as potential risk factors. Social isolation was also identified by Baker (2006), Krischef and DiNitto (1981), Taggart et al. (2007), and To et al. (2014). Drinking alcohol was seen as a means for developing and maintaining social relationships, but in many cases lead to exploitation by drinking peers. For others, drinking tended to take place either alone or with an intimate partner.

Drinking to self-medicate psychological pain and stress was another common theme in the literature. Shawna, Chapman, and Wu (2012) identified a common history of physical and emotional trauma and co-existing mental disorders. Rivinus (1988) noted that substance misuse can develop in response to a crisis. Taggart, Huxley, and Baker (2008) suggested stress from activities of daily living could contribute to alcohol and substance misuse. Westermeyer et al. (1988) reported that 33 out of 40 in their sample drank to relieve stress and 31 out of 40 drank to relax. Baker (2006) found painful past experiences such as bereavement, physical abuse, and sexual abuse were common factors for the use of alcohol, while Taggart et al. (2007) reported the death of a significant other, partner abuse, sexual abuse and deteriorating mental health as factors in their drinking.

Four studies investigated the role of psychological functioning for people with an intellectual disability and alcohol use. McGillicuddy and Blane (1999) compared refusal skills of substances in role playing situations and discrimination of good and bad role models between non-users, users, and abusers who had an intellectual disability. They found that misusers had significantly poorer refusal skills and discrimination between good and bad role models compared to users. Van
Duijvenbode and colleagues, (Van Duijvenbode, Didden, Bloemsaat, & Engels, 2012; Van Duijvenbode, Didden, Voogd, Korzilius, & Engels, 2012; Van Duijvenbode, Didden, Korzilius, Trentelman, & Engel, 2013) undertook a series of three studies to investigate the role of cognitive bias in choices about drinking alcohol. In the first study, Van Duijvenbode, Didden, Bloemsaat, and Engels (2012) investigated alcohol and non-alcohol stimuli in terms of attractiveness, complexity, familiarity and valence. Alcohol stimuli were found to be significantly less attractive for individuals with an intellectual disability. In the second study, Van Duijvenbode, Didden, Voogd, Korzilius, and Engels (2012) used eye tracking, approach avoidance, picture rating, and visual dot probe tasks to investigate cognitive bias. They concluded that IQ was not related to the strength of cognitive bias. In their final study, Van Duijvenbode, et al. (2013) investigated executive control, working memory, inhibitory control and delay discounting. While they found some significant differences between working memory and alcohol use, no significant differences were found for delay discounting and inhibitory control. Furthermore, impairment in executive control for individuals with mild to borderline intellectual disability was variable, and no additive differences were found with respect to executive control and coexisting alcohol use for this group.

3.6 Life impacts

A number of studies and review articles described the relationship between alcohol misuse and the adverse life impacts resulting from misuse. Slayter and Steenrod (2009) concluded that alcohol and substance misuse exacerbated problems with daily living and that there may be interactions between prescribed psychotropic medications and the use of alcohol and substance use. Alcohol use could be associated with co-existing mental health problems (Slayter & Steenrod, 2009) and other co-existing problems including higher risk of imprisonment (Poldrugo, 2009). Some of the common problems cited in the review articles included health problems, exacerbation of cognitive impairment, poor outcomes in community living, problems with the law, problems with work, conflict with significant others, behavioural and mental health problems, marginalisation, and poor economic outcomes (Barrett & Pashos, 2006; Burgard et al., 2000; Cosden, 2001; Degenhardt, 2000; Huxley, et al., 2005; Huxley et al., 2007; Mayer, 2001; Lougheed & Farrel, 2013; Moore & Polsgrove, 1991; Rivinis, 1988; Slayter, 2008; Watson et al., 1998).

Krischef and DiNitto (1981) identified that alcohol misuse was related to employment problems and problems with the police. Taggart, et al. (2006) reported verbal aggression (47%) and changes in
mood (47%) as the two most common problems in their study of misusers, followed by being exploited (31%), physical aggression (30%), attending Emergency Department (24%), offending behaviour (23%), and suicidal ideation (19%). Taggart et al. (2006) also noted that problems with relationships including verbal conflict, were common and that alcohol consumption had a negative impact on their participant’s physical, emotional and psychological health. To et al. (2014) similarly identified that alcohol misuse was associated with mood changes, verbal aggression, physical aggression, conflict with significant others, and problems with the police. Mood changes and suicidal ideations were reported at a higher rate than the non-using controls. DiNitto and Kreschef (1984) calculated that 13% of their sample had relationship problems, while 7% got into trouble with the police. Baker (2006) also noted that getting into trouble with the law, getting into fights with family and significant others, and health problems were common adverse effects of alcohol misuse.

3.7 Interventions

A number of interventions have been investigated in the literature for individuals who have developed an alcohol use disorder. However, authors have noted that a number of outstanding methodological issues still exist in evaluating interventions and have argued for more research into the effectiveness of different interventions (Barret & Pashos, 2006; Burgard et al., 2000; Cocco & Harper, 2002; Cosden, 2001; Huxley et al., 2007; McGillicuddy, 2006; Slayter, 2008). Simpson (1998) argued that it is difficult to generalise about the patterns and characteristics of alcohol usage from one cultural context to another. Simpson also noted that studies tended to suffer from a number of methodological problems including small sample size, lack of controls, and poor research design.

Slayter and Steenrod (2009) identified the need to conduct population specific screening of alcohol and substance use. Slayter (2008) also argued that current screening and assessment tools need to be revised to meet the needs of this group. According to Annand and Ruff (1998) multiple approaches are required to treat alcohol misuse in this client group. McLaughlan et al. (2007) reported that the main interventions identified in their study were the same as that used for non-disabled substance abusers. Due to their disability, clients with an intellectual disability took longer to complete tasks and were seen as unwilling participants. Krischef and DiNitto (1981) reported that most of the treatment programmes in their study utilised modifications to standard interventions including simplification, longer duration of interventions and increased focus on education and behaviour. DiNitto and Krischef (1984) in a later study identified that those who attended treatment
for alcohol problems had attended mostly Alcoholics Anonymous (AA) groups, detox, counselling, and church sponsored interventions. Baker (2006) reported three types of interventions: talking about the problem, keeping a drinking diary, and counselling.

Four studies investigated and evaluated specific interventions. Forbart (1999), following an action research design, analysed the effectiveness of an alcohol education programme for clients in a forensic setting. The aim of the intervention was to improve positive attitudes to drinking and develop informed choice. The intervention comprised eight sessions of two hours duration. All participants showed improvements in alcohol knowledge by the end of the programme and four out the five participants continued to show improved knowledge at follow-up. Mendel and Hipkins (2002) measured the effectiveness of a motivational interviewing intervention among a group of forensic clients. Group members showed movement along the DiClemente and Prochaska stages of change model with four out of six members reporting improvements in self-efficacy. Mason (2008) evaluated the effectiveness of the reparatory grid. While there was some evidence of a cognitive shift post intervention, the ideographic nature of the reparatory grid made it cumbersome to administer. Finally, McGillicuddy and Blane (1999) compared assertiveness and modelling interventions. The assertiveness approach led to improvements in knowledge, assertiveness, and refusal skills while the modelling approach led to improvements in knowledge. However, neither approach led to any change in substance use.

Kerr, Lawrence, Darbyshire, Middleton, and Fitzsimmons (2013) undertook a review of the literature to apply a framework to address the feasibility, appropriateness, meaningfulness and effectiveness (FAME) of interventions. Kerr et al. (2013) noted that there were a number of methodological issues which made evaluating effectiveness problematic. The studies they reviewed showed small improvements, but they were not statistically significant. They also noted that there was limited evidence of the feasibility of interventions.

A number of review articles noted that multiple barriers to effective intervention exist. These include poor access to services (Burgard et al., 2000; Huxley, et al, 2005; Huxley et al., 2007; Mayer, 2001; Simpson, 1998; Slayter, 2008; Slayter & Steenrod, 2009), paradigm differences between intellectual disability and substance abuse treatment services (Slayter, 2008), preconceptions that this group could have a problem with alcohol or substance use (Slayter & Steenrod, 2009), and cognitive
limitations that may mean cognitive behavioural therapy (CBT) and Alcoholics Anonymous (AA) based group approaches may not be appropriate (Burgard, et al., 2000; Degenhardt, 2000; Delany & Poling, 1990; Kerr, et al., 2013; Mayer, 2001; Rivinus, 1988; Taggart, et al., 2008; Watson et al., 1998). A variant of AA, Emotions Anonymous, which focuses on improving social skills and emotional problems, was identified as potentially beneficial for this group (Small, 1980). Other approaches such as skills training, modelling, role playing, and progression based on the level of skills acquisition may be of benefit (Degenhardt, 2000). Degenhardt (2000) concluded that detox was an important first step in treatment and pharmacotherapies such as disulfarin used in combination with behavioural interventions may increase levels of abstinence.

3.8 Skills and knowledge
A common problem identified within the literature was the lack of specific skills, knowledge and training for supporting people with an intellectual disability who use and misuse alcohol and other substances (Annand & Ruff, 1998; Barret & Paschos, 2006; Burgard et al., 2000; Clark & Wilson, 1999; McLaughlan et al., 2007; Slayter, 2008; Taggart, et al., 2008). Brown and Coldwell (2006) noted that care staff have limited appreciation of the benefits of alcohol education and had limited access to information. Problems with liaison and referral to other services were also revealed by a number of studies. Taggart et al. (2007) described a lack of referral to specific services. McLaughlan et al. (2007) identified the lack of clear protocols for inter-agency co-operation as an issue that needs to be addressed. Delany and Poling (1990) identified only one protocol in existence developed by the main Department of Health and Mental Retardation. Huxley, et al. (2007) identified the lack of identification of people with an intellectual disability, lack of awareness amongst practitioners, and lack of inter service collaboration. Annand and Ruff (1998) recommended better liaison between different support services and involvement of a broad range of people in the support of individuals with an intellectual disability who misuse alcohol and other substances. Wenc (1980) recommended a single contact person to work with people with developmental disability. The lack of communication and liaison points to a lack of responsiveness within the system.

3.9 Pathologising alcohol use and the ethics of treatment
Slayter (2008) argued that approaching alcohol and substance use amongst individuals with an intellectual disability involved the balancing of risk vs autonomy. This, in turn, requires an understanding of the ability to make informed choices and of how a person learns and engages with any intervention. Slayter (2007), working from within a dignity of risk framework, emphasised the
value of maximising the level of self-determination for the individual with an intellectual disability and the dignity of “taking risks, managing risks, and facing the consequences of their actions” (p. 654). Wenc (1980) argued that treatment should take place in the least restrictive environment and should aim to maximise personal autonomy. Slayter and Steenrod (2009) noted a significant difference between the models of care utilised by intellectual disability and substance abuse services, the former emphasising a normalisation model whilst the later emphasised a pathological model. Barret and Paschos (2006) noted that the studies they reviewed focused on the pathological aspects of usage. Simpson (1998) identified that the dominant approach to intervention is risk management, which overemphasises the pathological and ignores the social function of alcohol. For Simpson, emphasis on the pathological is due to unsubstantiated stereotypes and assumptions leading to four deficiencies:

1) Assumption of a negative correlation between IQ and antisocial behaviour.
2) Failure to take into account the marginalisation of people with an intellectual disability from mainstream social life.
3) Bias towards skills and behaviours that maximise independence/social adaptation over individual preferences and cultural norms.
4) Overriding the rights of this group – they are seen as problematic in relation to the professionally defined concept of normalisation.

Simpson (2012) also noted that one of the consequences of emphasising the pathological is the assumption, without adequate evidence, that individuals with an intellectual disability consume alcohol to be accepted. As Simpson notes, alcohol consumption may be culturally constructed and the focus on the pathological aspects of alcohol consumption may itself be culturally constructed.

3.10 Summary of literature review

The main findings of the literature review are summarised in this section. The first point is that alcohol was the main substance used amongst participants in the respective studies. A minority of participants exhibited poly substance use, consuming alcohol along with other psychoactive substances. The literature surveyed above found a wide range and variety of usage patterns. Cultural
differences between different countries in which the studies were based, as well as social change, may have contributed to the variance in results. A consistent finding was that males tended to consume more alcohol than females and that their alcohol consumption tended to be lower compared to their non-disabled peers. They also started using alcohol at a later age. There are a number of common risk factors associated with the pathological consumption of alcohol. Some of the most important factors are poor social skills, social isolation, the movement to community living, and history of antisocial behaviour. Poor refusal skills are also a contributing factor. The use of alcohol to self-medicate against adverse life experiences and trauma was found in some studies. One series of studies investigated the role of cognitive bias and found no evidence for relating cognitive bias to IQ, though some evidence supported a relationship between working memory and alcohol use. The literature reported a strong relationship between pathological consumption of alcohol and negative outcomes across a wide range of social functioning and health domains. Adverse effects of alcohol misuse included problems with relationships, aggression and getting into fights, exacerbating physical and mental health problems, and problems with the law. Effectiveness of interventions has been poorly researched and understood. Group interventions with non-disabled peers tend to be ineffective due to the differences in communication skills. The current toolbox of interventions needs to be modified if they are to be effective for people with an intellectual disability who abuse alcohol, and further work is required to reduce barriers to accessing treatment services. There is a lack of appropriate skills and knowledge to assist health care professionals supporting this group. Furthermore liaison between services is poor, creating barriers to assessment and treatment. Finally, published research appears to be biased towards pathological consumption. This tendency reinforces prevailing stereotypes while ignoring the social function of alcohol and may further isolate and stigmatise people with an intellectual disability.
3.11 Summary tables of reviewed articles

**Table 2: Quantitative research**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Research design</th>
<th>Data source</th>
<th>Sample Characteristics</th>
<th>Total sample size</th>
<th>Substance use investigated</th>
<th>Country</th>
<th>Description of assessment tools</th>
</tr>
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<tbody>
<tr>
<td>Chaplin et al.</td>
<td>2011</td>
<td>Retrospective</td>
<td>Clinical Records</td>
<td>Referrals to specialist adult mental health facility with a coexisting ID (N=115)</td>
<td>115</td>
<td>Alcohol, cannabis, cocaine, other</td>
<td>UK</td>
<td>Bivariate analysis logistic modelling of substance use patterns</td>
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<tr>
<td>DiNitto &amp; Krishef</td>
<td>1984</td>
<td>Cross sectional</td>
<td>Informant Questionnaire</td>
<td>214 interviews from 24 programs providing services to mild ID clients</td>
<td>214</td>
<td>Alcohol</td>
<td>USA</td>
<td>Descriptive statistics</td>
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<tr>
<td>Dwyer &amp; Frierson</td>
<td>2006</td>
<td>Retrospective</td>
<td>Clinical Records</td>
<td>Clinical pre-trial psychiatric assessments in South Carolina for</td>
<td>270</td>
<td>Alcohol, cannabis, cocaine, &amp; poly</td>
<td>USA</td>
<td>Descriptive statistics and prevalence rates for substance use and other</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Research design</td>
<td>Data source</td>
<td>Sample Characteristics</td>
<td>Total sample size</td>
<td>Substance use investigated</td>
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<tr>
<td>Emerson &amp; Turnbull</td>
<td>2005</td>
<td>Stratified cross sectional</td>
<td>Client Interview</td>
<td>Adolescents aged 11-15 years with an ID (N = 95) and without an ID (N = 4069).</td>
<td>4164</td>
<td>Alcohol and tobacco</td>
<td>UK</td>
<td>Self-reported descriptive statistics, prevalence rates, Odds ratios</td>
</tr>
<tr>
<td>Forbat</td>
<td>1999</td>
<td>Action research</td>
<td>Client interview</td>
<td>Participants in an alcohol education group at a forensic ID unit (N=5)</td>
<td>5</td>
<td>Alcohol</td>
<td>UK</td>
<td>Descriptive statistics</td>
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<tr>
<td>Huang</td>
<td>1981</td>
<td>Cross sectional</td>
<td>Client Questionnaire</td>
<td>Junior and Senior high school students in the Alabama school system with an intellectual disability (N = 190) in special education and without an Intellectual</td>
<td>377</td>
<td>Alcohol</td>
<td>USA</td>
<td>Descriptive statistics</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Research design</td>
<td>Data source</td>
<td>Sample Characteristics</td>
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<tr>
<td>Krishef &amp; DiNitto</td>
<td>1981</td>
<td>Cross sectional</td>
<td>Informant Questionnaire</td>
<td>Questionnaire sent to randomly selected Associations for Retarded Persons (Response 54/100) and randomly selected Alcohol Treatment Centres (Response 50/100)</td>
<td>104</td>
<td>Alcohol</td>
<td>USA</td>
<td>Descriptive statistics</td>
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<tr>
<td>Lindsay et al.</td>
<td>2006</td>
<td>Cross sectional</td>
<td>Client Interview</td>
<td>Male sex offenders (N = 121), Male other offenders (N = 105) &amp; female offenders (N = 21)</td>
<td>247</td>
<td>Alcohol and non-specified other drugs and inhalants</td>
<td>UK</td>
<td>Prevalence of index problems at assessment</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Research design</td>
<td>Data source</td>
<td>Sample Characteristics</td>
<td>Total sample size</td>
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<tr>
<td>McCrystal et al.</td>
<td>2007</td>
<td>Longitudinal</td>
<td>Client Questionnaire</td>
<td>Survey of students attending 43 mainstream schools in Northern Ireland identifying students with an ID in year 9 (N = 15), year 10 (N = 18), year 11 (N = 16) and year 12 (N=15)</td>
<td>64</td>
<td>Tobacco, Alcohol, Cannabis, Ecstasy, Cocaine, Heroin, Inhalants</td>
<td>UK</td>
<td>Descriptive statistics</td>
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<tr>
<td>McGillicuddy &amp; Blane</td>
<td>1999</td>
<td>Quasi experimental</td>
<td>Client Interview</td>
<td>Two sub samples consisting of a) individuals with ID who are either non users (N = 75) or use (N= 25) or misuse substances (N= 22) and B) substance abusers enrolled in an either an assertiveness (N= 21), modelling (N = 206)</td>
<td>206</td>
<td>Tobacco, alcohol, &amp; cannabis</td>
<td>USA</td>
<td>Eysenck-Withers Personality Inventory, Nowicki-Strickland Locus of Control Scale, Rathus Assertiveness Scale, Test of Social Inference, Alcohol Attitudes, Substance Knowledge, Refusal Skills, Model Discrimination, Alcohol, Nicotine, and</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Research Design</td>
<td>Data source</td>
<td>Sample Characteristics</td>
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<td>Substance use investigated</td>
<td>Country</td>
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<td>McGillivray &amp; Moore</td>
<td>2001</td>
<td>Cross-sectional</td>
<td>Client Interview</td>
<td>Adults involved in a Victoria State-wide program for offenders with an ID (N=30) and compared to a non-ID control (N = 30)</td>
<td>60</td>
<td>Alcohol, cannabis, inhalants and other substances</td>
<td>USA</td>
<td>Descriptive statistics, prevalence rates of substance use and type of offense, odds ratios of drug knowledge</td>
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<tr>
<td>McGuire et al.</td>
<td>2007</td>
<td>Cross-sectional</td>
<td>Informant Questionnaire</td>
<td>Carers of individuals with an ID in residential (N = 125) and non-residential (N = 125) setting. Randomly selected from</td>
<td>250</td>
<td>Alcohol and tobacco</td>
<td>Ireland</td>
<td>Descriptive statistics</td>
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<td>Mendel &amp; Hipkins</td>
<td>2002</td>
<td>Post intervention review</td>
<td>Questionnaire</td>
<td>Seven individuals with an intellectual disability in a medium secure forensic service</td>
<td>7</td>
<td>Alcohol</td>
<td>UK</td>
<td>Descriptive statistics of pre and post implementation</td>
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<tr>
<td>Rimmer et al.</td>
<td>1995</td>
<td>Cross sectional</td>
<td>Informant interview</td>
<td>Residents aged 17 - 70 with an ID living in an institution (N = 184), Group home (N = 39), Family members (N=106)</td>
<td>329</td>
<td>Alcohol and cigarettes</td>
<td>USA</td>
<td>Cigarettes per day and alcoholic drinks per day</td>
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<tr>
<td>Robertson et al.</td>
<td>2000</td>
<td>Cross sectional</td>
<td>Informant/Clinent Interview</td>
<td>Adults randomly selected from three village communities (N = 30), residential campuses (N = 30) and people supported by</td>
<td>90</td>
<td>Alcohol and tobacco</td>
<td>UK</td>
<td>Descriptive statistics</td>
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<tr>
<td>Authors</td>
<td>Year</td>
<td>Research design</td>
<td>Data source</td>
<td>Sample Characteristics</td>
<td>Total sample size</td>
<td>Substance use investigated</td>
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<tr>
<td>Taggart et al.</td>
<td>2006</td>
<td>Cross sectional</td>
<td>Informant questionnaire</td>
<td>67 Adults in northern Ireland who misused substances (N = 30)</td>
<td>67</td>
<td>Alcohol, cannabis, ecstasy, inhalants, cocaine, &amp; prescription medications</td>
<td>UK</td>
<td>Prevalence of type of substance, health problems and behavioural problems</td>
</tr>
<tr>
<td>To et al.</td>
<td>2014</td>
<td>Cross sectional</td>
<td>Informant Questionnaire</td>
<td>Informants who work with clients with an ID in Flanders (N=108)</td>
<td>108</td>
<td>Tobacco, alcohol, cannabis, stimulants, opiates &amp; hallucinogens</td>
<td>Belgium</td>
<td>Descriptive statistics</td>
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<tr>
<td>Van Der Nagel et al.</td>
<td>2011</td>
<td>Cross sectional</td>
<td>Informant/Clinical Records</td>
<td>Informants employed by one of 153 Dutch</td>
<td>153</td>
<td>Alcohol, cannabis,</td>
<td>Netherlands</td>
<td>Descriptive statistics</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Research design</td>
<td>Data source</td>
<td>Sample Characteristics</td>
<td>Total sample size</td>
<td>Substance use investigated</td>
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<tr>
<td>Van Duijvenbode, Didden, Voogd, et al.</td>
<td>2012</td>
<td>Experimental</td>
<td>Client Interview</td>
<td>Male (n = 47) and female (N = 10) clients in forensic clients in a Forensic Psychiatric Centre (FPF)</td>
<td>57</td>
<td>Alcohol</td>
<td>Netherlands</td>
<td>SumIQ, Audit, Visual dot probe, approach avoidance task, anchored visual analogue scale of craving</td>
</tr>
<tr>
<td>Van Duijvenbode, Didden, Bloemsaat et al.</td>
<td>2012</td>
<td>Experimental</td>
<td>Client Interview</td>
<td>Light drinkers with average IQ (N = 10), Heavy drinkers with average IQ (N = 10), Light drinkers with mild/borderline IQ (N = 10), Heavy drinkers with mild/borderline IQ (N = 10),</td>
<td>40</td>
<td>Alcohol</td>
<td>Netherlands</td>
<td>Likert scale measuring familiarity, liking, valence, and attractiveness</td>
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<tr>
<td>Van Duijvenbode, et al.</td>
<td>2013</td>
<td>Experimental</td>
<td>Client Interview</td>
<td>Light drinkers with average IQ (N = 10), Heavy drinkers with</td>
<td>40</td>
<td>Alcohol</td>
<td>Netherlands</td>
<td>Cori block tapping task, Self-ordered blocking task, Go/no go task, Sign stop</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Research design</td>
<td>Data source</td>
<td>Sample Characteristics</td>
<td>Total sample size</td>
<td>Substance use investigated</td>
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<tr>
<td>Westermeyer et al.</td>
<td>1996</td>
<td>Retrospective</td>
<td>Client</td>
<td>Clients sequentially presenting at two USA based university substance abuse treatment centres with ID (N = 40) and no ID (N = 308).</td>
<td>348</td>
<td>Alcohol, tobacco, cannabis, Cannabis, Stimulants, Hallucinogens, sedatives &amp; inhalants</td>
<td>USA</td>
<td>task &amp; delay discounting task</td>
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<tr>
<td>Westermeyer et al.</td>
<td>1988</td>
<td>Cross sectional</td>
<td>Informant/Clinet Interview</td>
<td>Clients with a diagnosis of SA and ID (N=40) and a control group of ID only (N=40)</td>
<td>80</td>
<td>Tobacco, alcohol, cannabis, stimulants</td>
<td>USA</td>
<td>Descriptive statistics</td>
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</table>
Table 3: Qualitative and mixed methods research

<table>
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<tr>
<th>Authors</th>
<th>Year</th>
<th>Research design</th>
<th>Data source</th>
<th>Sample Characteristics</th>
<th>Total sample size</th>
<th>Substance use investigated</th>
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<th>Description of assessment tools</th>
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<tbody>
<tr>
<td>Annand &amp; Ruff</td>
<td>1998</td>
<td>Case Study</td>
<td>Case study</td>
<td>Case study of barriers to effective treatment for a person with an intellectual disability person (N= 1)</td>
<td>2</td>
<td>Alcohol</td>
<td>USA</td>
<td>Case study</td>
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<tr>
<td>Baker</td>
<td>2006</td>
<td>Grounded theory</td>
<td>Client Interview</td>
<td>Individuals with an ID who possessed sufficient verbal skills to engage in a semi-structured interview situation (N= 10)</td>
<td>10</td>
<td>Alcohol</td>
<td>UK</td>
<td>Thematic analysis</td>
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<tr>
<td>Clarke &amp; Wilson</td>
<td>1999</td>
<td>Case Study</td>
<td>Case Study</td>
<td>Four individuals with an ID and alcohol abuse</td>
<td>4</td>
<td>Alcohol</td>
<td>UK</td>
<td>Examination of case vignettes</td>
</tr>
<tr>
<td>Mason</td>
<td>2008</td>
<td>Mixed</td>
<td>Case Study</td>
<td>Two individuals in a forensic ID service with substance abuse history who engaged in a number of therapeutic interventions</td>
<td>2</td>
<td>Alcohol</td>
<td>UK</td>
<td>Repertory grid</td>
</tr>
<tr>
<td>Authors</td>
<td>Year</td>
<td>Research Design</td>
<td>Data Source</td>
<td>Sample Characteristics</td>
<td>Total Sample Size</td>
<td>Substance Use Investigated</td>
<td>Country</td>
<td>Description of Assessment Tools</td>
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<tr>
<td>McLaughlan et al.</td>
<td>2007</td>
<td>Thematic analysis</td>
<td>Interview</td>
<td>Front line staff caring for individuals with an ID who also use substances (N = 13)</td>
<td>13</td>
<td>Alcohol</td>
<td>UK</td>
<td>Thematic analysis</td>
</tr>
<tr>
<td>Taggart et al.</td>
<td>2007</td>
<td>Thematic content</td>
<td>Interview</td>
<td>Individuals in Northern Ireland who had an ID and abused substances (N = 10)</td>
<td>10</td>
<td>Not specified</td>
<td>UK</td>
<td>Thematic content analysis using Nvivo</td>
</tr>
<tr>
<td>Author</td>
<td>Year</td>
<td>Methodology</td>
<td>Data source</td>
<td>Country</td>
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<tr>
<td>Barrett &amp; Paschos</td>
<td>2006</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Review of the recent literature on alcohol use amongst people with an intellectual disability</td>
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<tr>
<td>Brown &amp; Coldwell</td>
<td>2006</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>UK</td>
<td>Outlined an alcohol awareness programme for individuals with an intellectual disability in a forensic unit</td>
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<tr>
<td>Burgard et al.</td>
<td>2000</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Comprehensive empirical review of the literature focusing on prevalence, and interventions for misuse</td>
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<tr>
<td>Cocco &amp; Harper</td>
<td>2002</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Discussed the problems faced by people with an intellectual disability who live in the community who also misuse alcohol and other substances.</td>
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<tr>
<td>Cosden</td>
<td>2001</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Review of literature on alcohol and substance use by both adolescents and adults with an intellectual disability</td>
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<td>Degenhardt</td>
<td>2000</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Outlined the possible interventions for people with an intellectual disability who misuse alcohol</td>
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<tr>
<td>Delany &amp; Poling</td>
<td>1990</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Review article of the effects of alcohol and substance misuse amongst people with an intellectual disability</td>
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<tr>
<td>Huxley et al.</td>
<td>2005</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>UK</td>
<td>Discussed the need for integrated service provision to meet the needs of people with a coexisting intellectual disability and alcohol and substance</td>
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<tr>
<td>Author(s)</td>
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<tr>
<td>Huxley et al.</td>
<td>2007</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Discussed alcohol and substance use amongst people with an intellectual disability and its impact on both substance misuse and disability service providers.</td>
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<tr>
<td>Lougheed &amp; Farrell</td>
<td>2013</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Canada</td>
<td>Reviewed the problems and challenges faced by homeless people who have coexisting intellectual disability, mental disorders and alcohol and substance use.</td>
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<tr>
<td>Mayer</td>
<td>2001</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Provided an overview of the problem of alcohol and substance misuse amongst individuals with a co-existing mental disorder and intellectual disability.</td>
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<tr>
<td>McGillicuddy</td>
<td>2006</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Reviewed research on alcohol, tobacco and illicit substance use by individuals with an intellectual disability,</td>
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<tr>
<td>Moore &amp; Polsgrove</td>
<td>1991</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Reviewed the literature highlighting the research requirements and challenges of investigating alcohol and substance use by people with an intellectual disability.</td>
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<td>Poldrugo</td>
<td>1998</td>
<td>Expert Opinion</td>
<td>Literature</td>
<td>Not specified</td>
<td>Addressed the problem of substance use by people with an intellectual disability in the prison population recommending tailored programmes to meet their needs.</td>
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<td>Author(s)</td>
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<td>Rivinus</td>
<td>1988</td>
<td>Expert</td>
<td>Literature</td>
<td>Not specified</td>
<td>Early review article of incidence and effects of alcohol misuse amongst people with an intellectual disability</td>
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<td>Shawna et al.</td>
<td>2012</td>
<td>Expert</td>
<td>Literature</td>
<td>Not specified</td>
<td>An update of a review article of recent research on the relationship between alcohol and substance use and intellectual disability</td>
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<tr>
<td>Simpson</td>
<td>1998</td>
<td>Expert</td>
<td>Literature</td>
<td>Not specified</td>
<td>Cultural analyses of alcohol use amongst people with an intellectual disability, placing access to alcohol within a wider cultural discourse</td>
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<tr>
<td>Simpson</td>
<td>2012</td>
<td>Expert</td>
<td>Literature</td>
<td>Not specified</td>
<td>Addressed the bias within the current literature to pathologising alcohol use and the cultural exclusion of people with an intellectual disability.</td>
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<td>Slayter</td>
<td>2007</td>
<td>Expert</td>
<td>Literature</td>
<td>Not specified</td>
<td>Applies a dignity of risk framework to address the ethical problem of balancing risk and autonomy for people with an intellectual disability who use alcohol and other substances.</td>
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<td>2008</td>
<td>Expert</td>
<td>Literature</td>
<td>Not specified</td>
<td>Analysed access barriers to treatment services for people with an intellectual disability who misuse alcohol and substances.</td>
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<td>Slayter &amp; Steenrod</td>
<td>2009</td>
<td>Expert</td>
<td>Literature</td>
<td>USA</td>
<td>Reviews addiction treatment services for people with an intellectual disability. Identifies potential discontinuities in service provision.</td>
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<td>Taggart et al.</td>
<td>2008</td>
<td>Expert</td>
<td>Literature</td>
<td>Not specified</td>
<td>Review of literature on alcohol and substance misuse amongst people with an intellectual disability and reviews four projects to address the needs of this group.</td>
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<tr>
<td>Name</td>
<td>Year</td>
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<tr>
<td>Watson et al.</td>
<td>1998</td>
<td>Expert Opinion</td>
<td>Literature Not specified</td>
<td>Addresses the incidence and effects of alcohol and substance misuse amongst people with a disability, including intellectual disability.</td>
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<tr>
<td>Weinberg</td>
<td>2001</td>
<td>Expert Opinion</td>
<td>Literature Not specified</td>
<td>Reviewed the literature on risk factors for alcohol and substance misuse and the relationship with intellectual disability.</td>
<td></td>
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</table>
4. Research framework

4.1 Theoretical frame: Critical realism
In this section, critical realism and its relevance to this research project will be outlined. This will be done by firstly outlining critical realism’s ontological basis of reality. Then, the relationship between social structure and the individual and the changing nature of social reality will be discussed. Examples of how critical realism has been applied to the field of nursing will be then be outlined. The project will then be placed within the framework of critical realism. A networked ecological model, which will later be used to place the experiences of individuals who drink alcohol within their wider social context, will be described. Having established the theoretical framework for this research project, a number of practical matters on how the project was carried out, will be discussed. This includes the aims of the research project and the research question, how the sample was selected and recruited, the choice of the research approach and the approach to data analysis and how ethical issues were addressed.

4.2 The nature of reality
The framework of critical realism was developed by Roy Bhaskar and has been elaborated by many other writers since. Bhaskar’s central concern was to find a way through what he considered to be the impasse of empiricism, which he felt was trapped by the false Humian notion of causal law (Bhaskar, 2007). He further wanted to correct what he considered to be the epistemic fallacy, commonly found within empiricism, in which epistemology is confused with ontology, that is, our knowledge of reality is taken to be reality itself. A central tenant of empiricism is that all knowledge about an object or phenomenon can only come via our sense perceptions of that object (Markie, 2013). Thus any idea, hypothesis or theory that cannot be empirically tested and in some way corroborated or falsified, cannot be considered to be knowledge. This position was most fully outlined in the logical empiricism of the 1920s and 30s, a movement which included members of the Vienna Circle, Berlin Society for Empirical Philosophy and other philosophers and scientists influenced by either of these two groups (Creath, 2014). While logical empiricism, as a philosophical movement, has been superseded by other developments, it still has a strong residual influence on
the natural sciences and the philosophy of science and posits what Bhaskar would consider to be a restricted view of reality.

Bhaskar’s critique of empiricism and Hume’s concept of causal law centred on the nature of the system in which these laws are believed to operate. According to Bhaskar (2007), for such laws to operate consistently, the system needs to be closed. Only then would the conditions be present for the emergence of regularities. These regularities could then be interpreted within the framework of causal law. Bhaskar believed, however, that such closed systems were artificial constructs, bounded by the researcher in order to entice the emergence of the regularities. As soon as the confines of a laboratory experiment or randomised controlled trial are departed from, the system becomes open and less regular, no longer exhibiting the causality found in the controlled experiment.

In his Realist Theory of Science, Bhaskar (2007) introduced an alternative theory of the scientific endeavour. At the heart of his theory lies a multi-layered transcendental ontology, comprising intransitive and transitive dimensions. The intransitive dimension refers to the unchanging objects of scientific enquiry. The transitive dimension refers to knowledge about an object or phenomena of interest and as such is fallible and subject to constant revision, arising from the social and cultural milieu of scientific enquiry.

In addition to the transitive/intransitive divide, Bhaskar (2007) posited three domains (Figure 4.1). Firstly, there is the domain of the real. This domain exists independently of our perception of it. Within this domain lie the intransitive generative mechanisms which give rise to real events. These generative mechanisms exhibit what Bhaskar (2007) calls transfactuality, in which the mechanisms continue to operate irrespective of the level of openness of the system in which they are positioned and the realisation or non-realisation of events, or perception of those events. The second domain is that of the actual in which events are actualised and become available for perception and interpretation. The third domain is that of the empirical. This is the domain of perception, interpretation, and hypotheses about the phenomenon that has been actualised and perceived or investigated. Bhaskar also argued for the stratification of reality. That is, the outcome of the scientific endeavour reveals ever more details about a reality that is multi-layered or stratified.
As mentioned, Bhaskar argued for an open systems view of reality. This approach allows for a multiplicity of generative mechanisms at the level of the real, each of which influences other generative mechanisms (Bhaskar, 1998a; Bhaskar, 2007; Bhaskar & Lawson, 1998). As a result, actualisations of events may not be regularly realised in the domain of the actual. Events then exhibit a pattern of realisation that that exists somewhere between total randomness and full regularity. Lawson (1998) defined such partially regular events as demi-regularities or demi-laws. The definition that Lawson (1998, p. 148) gives for such demi-regularities is:

“a partial event regularity which prima facie indicates an occasional, but less than universal, actualization of a mechanism or tendency over a definite region of space time”

Such partial event regularities may not be observed in the presence of countervailing mechanisms if such forces dominate. Alternatively the presence of a number of strong reinforcing powers will reinforce the observed tendency. Each of these countervailing and reinforcing tendencies may be present to greater or lesser degrees at any given point in space and time. As a result of the interplay between the tendencies, the emergence of a pattern may be highly irregular and somewhat unpredictable.
4.3 The relationship between social structure and the individual

Activities performed by people operate within the context of social structure. However, there is no consensus as to what social structure means. Porpora (1998) outlines four different views, while acknowledging that these views are not a complete or comprehensive list of all the competing definitions of social structure. A significant problem in identifying and positioning social structure is that “social structure does not exist in the way that a magnetic field exists” (Manicus, 1998, p. 18). Instead such structures are peopled and are the product of the people who inhabit them. Due to the interrelationship of the people within a given social structure and the structure itself, social structure is characterised by a number of fundamental differences compared to natural structures. Bhaskar (1998b) identified three differences. Firstly, social structure lacks an independent existence. Secondly, social structure is dependent upon the respective agent’s concept of the structure. Thirdly, social structure is relatively impermanent. As a result a given structure is constantly in a state of flux and will exhibit emergent properties. Furthermore, since social structures are peopled, these structures will, of necessity, be open (Archer, 1998). The intrinsic openness of social structures is consistent with the existence of demi-regularities. Peacock (2000) argued that such demi-regularities are the point of entry for social science in their study of social structures. When people enter into a social structure, the structure is pre-formed, that is the structure has an a priori existence to the people who inhabit it (Bhaskar, 1998b). Upon entering into the social structure, an individual is both constrained and directed by that structure. They do not possess full freedom to act as they would wish, but are subject to constrained autonomy. But, while social structure can constrain some activities, it serves to facilitate others. As Lewis (2000) argued, social structure is causally efficacious as, in the absence of such a structure, an activity would not occur. While social structure may be causally efficacious, it lacks the ability to make things happen. An active agent is required. Thus, Lewis concludes that social structure is a material, not a sufficient cause of activity.

The analogy of a boat in a river may serve to illustrate this point. The banks of the river and the flow of the current constrain where the boat can go and the effort needed to move the boat. This does not mean that the boat is totally constrained by the river. There is a degree of choice within these constraints about where the boat can go. It can go upstream or downstream, or from bank to bank and any variation of these directions depending upon the choices of the person guiding the boat. Also the water flowing in the river facilitates its movement by providing flotation for the boat.
4.4 The changing nature of social structure

While social structure might not change significantly in the short term, social structure is malleable and changes significantly over the longer term. Individuals are the authors of that change, thus there is a degree of interrelationship between the individual and the social structure in which they live. This is not to say that society is created ex nihilo, or that there are no limits to the resources available for its construction and reconstruction. Rather, society is created with what is currently available (Manicus, 1998). But even with the existence of limited and constrained resources and the sunk cost of pre-existing structures, Manicus (1998) observes that the actions of agents within society change social structure over time.

The changing attitudes to alcohol, changes to the legal framework around alcohol consumption, and the institutions, organisations and settings involved in its production and consumption is one example of how malleable social structures can be over time and the effect of changes on behaviour and activities (Cagney & Cesar, 2006; Hutchins, 1999; Research New Zealand, 2013). Another example is the movement towards deinstitutionalisation for the intellectually disabled (Mansell & Beadle-Brown, 2010; Milner, 2008; Stancliffe, Emerson, & Lakin, 2001). Both of these tendencies operate in relative isolation of one another, yet both have an influence on each other as deinstitutionalisation led to individuals with an intellectual disability living in the community while the changes to alcohol law led to greater access by such individuals to alcohol. The policy changes and social structures and influences that led to both of these developments are the result of a system that is peopled and therefore open (Archer, 1998). Similarly, it is expected, based on overseas research, that the experiences of individuals will be different. They will be somewhat patterned and therefore fit the criteria of what Lewis (1998) describes as a demi-regularity. For this reason, a critical realist framework is considered to be appropriate for analysing the experiences of alcohol use amongst individuals with an intellectual disability.

4.5 Critical realism in nursing research

Nursing practice and research operates within a broader biological and social context in which health status and outcomes are influenced by a range of systemic factors. The insights of both natural and social sciences therefore help practitioners and researchers to better understand the context of
health status and health care. The framework of critical realism is believed to be consistent with the aims of nursing researchers and has begun to be utilised in an increasing number of studies (Angus & Clark, 2012). Examples of applied critical realist studies found in the literature include Sword, Clarke, Hegadoren, Brooks and Kingston (2012) who utilised critical realism as a framework for analysing the experience of post-partum depression to identify generative mechanism for its development. Littlejohn (2003) analysed the potential for psychiatric nursing to exist as an independent speciality in its own right. Littlejohn found, based upon a transcendental analysis, that psychiatric nursing can operate as a separate identity. Parlour and McCormick (2012) blended critical realism and emancipatory practice to analyse five practice development cycles within an older persons setting. Clark, Lissel and Davis (2008) identified critical realism as helpful in understanding deep causation within a complex open world. Two examples Clark et al. (2008) offered of where critical realism would be helpful included deeper understanding of the context of health outcomes, and the effectiveness of different interventions. For Clark et al. (2008) the methodological eclecticism of critical realism is its strength as understanding an open complex world requires a multiplicity of approaches.

4.6 A networked ecological model of social structure

The theoretical position adopted for this study is that of critical realism. Within this framework individuals are placed in the middle of an evolving social structure that exhibits emergent properties due to the interconnection and interworking of underlying generative mechanisms (Bhaskar, 1979; Elder-Vass, 2007). The structure of the system is multi-layered, comprising supra and sub-individual elements, that collectively form the system in which the individual is a central agent interacting with other elements and individuals within the system (Millar & Millar, 1990). This system is assumed to exhibit quasi-autopoietic properties, that is the system is, in the short term, self-replicating and self-reinforcing, but will over the longer term exhibit emergent properties resulting in structural change. The people who participated in this study and who shared their experiences of alcohol use inhabit this multi-layered dynamic structure. The ecological model being presented in this section posits and the remainder of this chapter posits experiences are simultaneously being influenced and constrained by the social structure they inhabit and their relationship with its respective elements.

Schrogen (2013) argued that an ecological perspective can provide a number of insights into the context in which people with an intellectual disability live their lives, and the influence of the
environment on the life trajectories of this group. Such a perspective is consistent with the theoretical position of this project which sees the social structure in which alcohol use takes place as multi-layered. For the purpose of this project, the networked ecological systems model of Neal and Neal (2013), a modified version of the nested ecological theory of Bronfenbrenner (1994), was utilised to identify the settings in which study participants experienced alcohol use, and to provide a framework for understanding the interaction between study participants and their environment regarding their use of alcohol. Neal and Neal utilise the same terminology as Bronfenbrenner, but interpret the system components from a network perspective. At the lowest level of Neal and Neal’s model are the microsystems which comprise the network of interconnections within a particular setting where the person is at the centre. Individuals within this network act as network nodes assessing and responding to communication flows within the system. People with an intellectual disability may simultaneously exist in, and move through multiple microsystems within their environment. Similarly, other individuals with whom these people come into contact may also be part of multiple microsystems.

A path between two microsystems which the focal person inhabits, which connects two individuals who inhabit a respective microsystem, but which does not go through the focal person, constitutes the mesosystem layer of the environment. A subsystem, which does not include the individual but in which there is a connection to that individual and whose operation directly or indirectly affects the individual, constitutes an exosystem with respect to that individual. The macrosystem will include the structures and forces that influence the formation and dissolution of interconnections. It will include the culture and social norms as well as the relevant legal, regulatory, and policy environment that influence the choices and behaviours of people with an intellectual disability.

Neal and Neal (2013, p. 22) presented a hypothetical example to illustrate how a networked ecological system could be structured. J. Neal, one of the authors of the network ecological model paper, was approached and gave approval to the author to modify their hypothetical example (J. Neal, personal communication, December 2, 2015) in order to explain how a networked ecological model could be applied to the type of situation of the participants in this study (Diagram 2). The revised example comprises three subsystems which have been labelled I, II, and III. The focal individual in this example is Andrew who is co-located in subsystem I, his family’s micro system and subsystem II, a social activity group. Since the focal individual is co-located in sub system I and II,
these are both identified as Microsystems with respect to Andrew. Microsystems I comprises four interconnected individuals: Andrew, his brothers Des and Colin, and his mother, Barbara. Microsystems II is a social activities group comprising four interconnected individuals Andrew, Elizabeth, and Fred, and a support person/facilitator, George. George is co-located in subsystem III, which is an organisation set up to facilitate and run the social activities. George is also connected to Ian, another support person involved in running a second group (not shown) and Helen, who supervises both George and Ian. Since Andrew is not part of subsystem III, it is labelled an exosystem in respect to Andrew. Barbara and George occupy two different Microsystems, I and II respectively, but are connected via the path, Barbara-George. Since Barbara and George inhabit two separate Microsystems, the path Barbara-George is, in Neal and Neal’s terminology, a mesosystemic interaction. Andrew is connected to most of the other people in the network by only one degree or link. For two people, Helen and Ian, there is no direct connection to Andrew. In both cases, there are two degrees of separation in which George is the intervening node. In the case of Ian, the path is Andrew-George-Ian, while in Helen’s case it is Andrew-George-Helen. Outside of this social network is the macrosystem of culture, beliefs, and influences.

Diagram 2 Networked ecological model (based on Neal & Neal, 2013, p. 22)
4.7 The complex nature of social networks

It can be easily seen that hypothetical social systems based on even a simple structure such as that described in the example above, can quickly become increasingly complex as more individuals are added to the network. Research into real world social systems has shown this is the case in actual social networks leading to increasingly complex interactions and behaviours by actors within the system (Strogatz, 2001). Strogatz (2001) noted that social networks may exhibit structural and dynamical complexity as well as diversity with respect to the types of connections and nodes found within the system. Connections with other individuals within and between microsystems and mesosystems evolve over time as agents enter and leave the system, and as the nature of the relationship between existing agents change (Aggarwal & Subbian, 2014). Some of the interactions and connections with other individuals will be weak and transient in nature while others will be stronger and maintained over a longer term. The strength and durability of these connections will depend upon the respective levels of time, emotion, intimacy, and reciprocity of the connections (Granovetter, 1973). The nature, strength, and characteristics of these connections will mediate the actions and identity of individuals within the network. A network that is tightly knit will be associated with a simple and relatively static identity while a network that has looser ties will mediate a more complex, dynamic identity (Wenger, 1991). The nature of these connections, as part of a social network, is likely to be that of a ‘small-world’ network (Collins & Chow, 1998; Sun, Mayo, & Ouyang, 2002; Watts & Strogatz, 1998). Such networks tend to be tightly clustered around highly interconnected communities with small path lengths between individuals (Sallaberry, Zaidi, & Melancon, 2013). Furthermore, according to Sallaberry et al. (2013), such networks are likely to exhibit scale free properties in which a few individuals have a very large number of connections while the majority of other individuals are only sparsely connected.

The central agent, within the ecological system being investigated, is the person with an intellectual disability who chooses to drink alcohol. Within their respective environment, each individual interacts with other individuals, sharing knowledge, information and resources and making choices about how to live their lives. As they interact with others, they will develop paths of behaviour that reinforces certain modes of interacting (Walter, Battiston, & Seweitzer, 2008). It is acknowledged that, in common with all individuals who inhabit a social structure, they are subject to constrained autonomy, that is, there are certain restrictions to the level of autonomy a particular agent
possesses due to both external and internal limits (Lau & Wenzel, 2015; Marr, DeVerteuil, & Snow, 2009). For people with an intellectual disability these demarcations may be the result of certain functional constrictions due to their impairment. From a critical realist perspective, impairment is a product of the actual domain, being an outcome of the underlying generative structures. Over and above the concept of impairment is the socially constructed concept of disability, which encompasses the restrictions imposed by the society in which these people live (Bray, 2003). The construction of disability is a product of the empirical domain, arising from the ideas, assumptions, stereotypes and interpretations of people with whom they come into contact as well as broader cultural influences. As a result, restrictions are imposed upon people with an intellectual disability regarding their ability to participate and be included in the full range of social activities. In such cases, the traditional liberal sense of autonomy, defined as self-regulation comprising self-reflection and making decisions based on personal desires and preferences (Herr, 2010), may not apply. Individuals with an intellectual disability who rely on, or are subject to, other people to guide and support them in their decision making activities, lack the full power over themselves that such a definition of autonomy assumes. However, they still have the ability to form preferences and, within certain constraints, follow through on their preferences. In this sense, it is argued that they still possess valuational agency, which Herr (2010) defined as the second order power to evaluate one’s first order desires in terms of strength and worth. Such agency, Herr argues, is compatible with the recognition of external influences and acceptance of an influence as authoritative.

4.8 Positioning the research project within Bhaskar’s three domains

In this section, a final note on locating the level of investigation of this project will be presented. As discussed above, critical realism posits the existence of real structures. These structures exist in the intransitive dimension outside of our perception and experience of them. Our perception of these structures occurs through the realisation of events in the actual domain that are perceived, measured and interpreted within the empirical domain. The empirical domain is fallible and transitory, but it is the point of entry for all observations and interpretations of the deeper structures of reality. It is at this level that this research project must of necessity take place. As such, it is acknowledged that interpretation of the data will be fallible (Clark, Lissel & Davis. 2008). Given that the project is investigating the experience of people with an intellectual disability there will be a hermeneutical dimension in interpreting the results. The problem of interpretation of the data is discussed in more detail in the Methods section below, in particular Section 5.6.
5. Methods

Having discussed and presented the theoretical position adopted for this study and the hypothesised ecological structure proposed to investigate the experiences of alcohol use by this group, this section will review the methods employed for this purpose. This will be achieved by stating the research aims and question, and the proposed research approach. The selection of participants will be described. In addition, this section will outline how issues pertaining to research ethics and culturally safe research practice were dealt with.

5.1 Research aims and question
The aim of this research project was to investigate the experience of alcohol use amongst individuals with a mild intellectual disability in Aotearoa/New Zealand. The project’s focus will be on individuals who have sufficient autonomy to make choices about their alcohol use. The proposed research question is:

“What are the experiences with and patterns of alcohol use amongst individuals with a mild intellectual disability living in the community in Aotearoa/New Zealand?”

5.2 Qualitative versus quantitative research approach
The preferred research methodology of this project was quantitative research. This was due to the author’s experience and skills in the use of quantitative analysis. However, in considering the appropriateness of this approach and whether qualitative approach should be chosen, a number of factors need to be taken into account. Of principle importance are the research aims and question which were developed in response to discussions with the researcher’s academic supervisors. The final research question wanted to investigate the experience of alcohol use by individuals with an intellectual disability. Investigation of experiences of a phenomena have traditionally utilised qualitative research methods which suggested a qualitative research approach. The second issue is the practical issue of being able to recruit participants. If the population of interest is small or difficult to recruit then it would be difficult to recruit enough participants to achieve statistically
significant results. Thirdly, there is the issue of the sensitivity of the subject matter. Alcohol use may be a potentially sensitive subject and qualitative research approaches are the recommended approach for investigating sensitive subjects with people with an intellectual disability (Taggart, et al., 2007; Truesdale-Kennedy, Taggart, & McIlfatrick, 2011). Fourthly, is the research approach widely used in the literature with this group? A number of qualitative studies were found that utilised qualitative semi-structured interviews and thematic analysis, thus supporting a qualitative approach (Ellen, 2012; Daya, Dillon, Taylor, & Yildren, 2011; Truesdale-Kennedy, et al., 2011). The fifth issue whether the research is consistent with the theoretical framework of the study? Critical realism allows for an eclectic approach to research and is therefore ambivalent in the choice of quantitative versus qualitative approaches (Clark, Lissel, & Davis, 2008). A qualitative approach was therefore consistent with the research paradigm adopted for this study. The final consideration is whether it will it gives voice to the experiences of a marginalised community. An ethical issue identified by Carlson (2013) was exclusion of individuals with an intellectual disability from the research canon failed to provide them with a voice and perpetuate their marginalisation. Qualitative research, however, is able to give voice to this community thereby rectifying this ethical issue.

After considering all these issues and after discussing the relative merits of qualitative versus quantitative approaches with the researcher’s academic supervisors, a qualitative research approach utilising thematic analysis was selected. The research will be situated as a thematic analysis within the broad theoretical position of critical realism, adopting an egocentric ecological model to analyse the individual experience of alcohol use by participants.

5.3 Sampling approach

Choices with respect to how participants were selected and the inclusion and exclusion criteria were dictated by the aim of the research project and the decision to utilise a qualitative research design involving thematic analysis. The population of interest was that of adults (18 years and over) with a mild intellectual disability who have consumed alcohol at least once in the past month. The sampling approach was one of purposeful sampling. Purposeful sampling is a technique utilised within qualitative research to select individuals who are knowledgeable about a phenomena, available to participate in a research project and are able to express their opinions and experiences (Palinkas et al., 2015, p. 534).
5.2.1 Inclusion and exclusion criteria

The following inclusion and exclusion criteria were developed for the study.

5.2.1.1 Inclusion criteria

1) Individuals who had a mild intellectual disability living in Aotearoa New Zealand of all genders, 18 years and over who have consumed alcohol at least once in the past month.

2) English whose language skills were at a sufficient level to allow them to comprehend the nature of the study and the study questions, communicate their answers, and provide informed consent.

3) Individuals whose living situation included living with family members, living on their own or with others, living in a flating situation, in their own home, or living in supported accommodation.

4) Individuals who had sufficient autonomy to make choices regarding the consumption of alcohol.

5.2.1.2 Exclusion criteria

The following exclusion criteria were developed for the study:

1) Individuals who had a history of a serious mental illness whose illness would render the interview process too challenging to provide meaningful responses.

2) Individuals who were currently patients in a medical or surgical ward, long term care facility, inpatients in an acute psychiatric unit, inpatients in an inpatient forensic intellectual disability or psychiatric unit, individuals residing in a custodial institution run by the department of corrections, and individuals residing in a community based forensic service.

3) Individuals who had a cognitive deficit diagnosed after age 18 due to traumatic brain injury, organic brain disorder, dementia, delirium, consumption of a psychoactive substance, or a medical condition not otherwise stated.
Individuals who were unable to understand the nature of the study or study questions, or who are unable to communicate their answer to the questions due to a lack of English language skills, a physical impairment, or a medical condition not otherwise stated.

Individuals who were unable to give informed consent.

5.2.2 Sample size, recruitment, and demographics

A target of 12 participants, to be selected via purposeful sampling, was set during the planning stage of the research project. A sample size of 12 was deemed to be sufficiently large - given the homogeneity of the population being investigated - to generate enough data for analysis (Guest, Bunce & Johnson, 2005) while taking into account the potential difficulties in recruiting participants. Community intellectual disability service providers, excluding forensic providers and consumer advocacy groups providing services to individuals with an intellectual disability, were approached. National, regional and local organisations were contacted either via email or telephone with background information on the project. A total of 22 service providers and advocacy groups were approached, of which eight responded. Of the eight organisations who responded, three indicated that they might have potential participants for the study. Recruitment of participants, however, proved to be challenging, and 10 out of a target of 12 participants were eventually recruited. In one of the organisations, the potential participants indicated that they did not want to participate. Nineteen potential participants were identified during the recruitment stage based (Table 5). Of these, three fell outside the inclusion criteria. One lived in the upper South Island and, due to the practicalities of travelling to the area they lived for just one interview, they were not included in the study. Four refused to participate in the study and one was ill during the time period set aside for interviewing and was not able to be interviewed. Of the remaining 10 participants interviewed for the study, four came from the Southern North Island region and six from the central South Island region. In two of the interviews, a support person was in the room during the interview. In five of the interviews a support person was available within the same building, but was not in the room in which the interviews took place.

According to the research plan, the first two interviews were to be used to test and review the interview questions and format. In reviewing the interviews, it was found that the overall structure and questions did not require major revision, although delivery of the interview was subject to
ongoing adjustment and a more conversational style was developed as the project progressed. Since no major modification to the questions and format were identified, data from the first two interviews were included in the final analysis of results.

**Table 5: Participants**

<table>
<thead>
<tr>
<th>Potential</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outside Criteria</td>
<td>3</td>
</tr>
<tr>
<td>Impractical</td>
<td>1</td>
</tr>
<tr>
<td>Refused</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total Not Suitable</strong></td>
<td><strong>8</strong></td>
</tr>
<tr>
<td>Not available for Interview</td>
<td>1</td>
</tr>
<tr>
<td>Interviewed</td>
<td>10</td>
</tr>
</tbody>
</table>

The mean age for participants was 31.6 years (sd 9.6 years) ranging from 20 to 50 years. Chart 3 provides the age distribution of participants. Five were under 30 years of age, two were between 30 and 40 years and two were over 40 years of age. One participant did not provide their age. Six of the participants were male and four were female, while eight out of 10 participants identified themselves as Pakeha and two were mixed Pakeha/Pacific Island ethnicity.

**Chart 3 Age distribution**

![Chart 3 Age distribution](image_url)
5.4 Semi-structured interviews

The data collection approach adopted for this study was semi-structured interviews utilising an interview schedule developed for this purpose (Appendix 1). The schedule was informed by the literature on intellectual disability and alcohol and substance use outlined in the literature review chapter, Section 3. The goal of semi-structured interviews is to enter into a conversation with another person with the aim of gaining access to the knowledge and experience of that person (Kelly, 2014). Semi-structured interviews simultaneously allow for a degree of standardisation and flexibility. Such interviews are social constructs, that is, they take place within a social context and are constructions of that context (Maxwell & Chmiel, 2014). Additionally, they possess a number of key differences from everyday conversations amongst friends, work colleagues, family members, and acquaintances (Packer, 2011). These differences are, firstly, an interview is a scheduled event. Secondly, it is an event between strangers. Thirdly, there is a difference in power between interviewer and interviewee. Fourthly, it produces spoken text. Fifthly, interviewers adopt a special stance and awareness. Penultimately, the conversation is past focused, and finally, it involves descriptions (Packer, 2011).

The heart of semi-structured interviews is language expressed through a directed conversation. It is a form of communication in which a message is conveyed, received, interpreted and responded to. Current models of communication theory hypothesise that conversations do not follow a simple code model of communication in which a message is encoded by the sender, transmitted, and decoded by the recipient (Allot, 2007). The encoding process, within the code model, involves converting a thought or concept into a linguistic representation, either as sounds or written language. This is transmitted via a common medium to a recipient who receives and translates the message. Within the code model, the relationship between the code and the message is arbitrary and, with the correct decoding algorithm, the recipient can decode the message perfectly. However, within normal conversations, neither of these two conditions holds. Instead, conversations, within contemporary models of communication, are thought to possess the attributes of a cooperative venture in which both parties seek to infer and interpret what that other has said (Scott-Phillips, 2010). It follows, then, that in any two-way conversation there will be a degree of disambiguation, or clarification of the respective meanings attached to the conversation as each of the parties seeks to interpret and understand what the other party has said (Kelly, 2014). The need to disambiguate and the tendency to seek clarification from the other party, however, creates problems for standardised interview formats utilised in conventional structured interviews as the research protocol generally
does not allow for such disambiguation. As a result standardised questions often lead to ambiguous responses (Kelly, 2014). For people with an intellectual disability the need to pay attention to and clarify interpretations and meanings is particularly acute due to potential communication problems. A highly structured approach is likely to encounter difficulties and differences in shared meanings and interpretations. Semi-structured interviews, on the other hand, have the flexibility to allow for a degree of disambiguation through such processes as repetition, rephrasing and simplification within the context of a consistent structure, paying special heed to subtle signs and signals (Kelly, 2014). As noted in section 2.2 above, within intellectual disability research semi structured interviews are widely used, pointing to their usefulness in producing meaningful data from individuals with a learning disability (Ellen, 2012; Daya et al., 2011; Truesdale-Kennedy, et al., 2011).

5.5 Transcription of interviews
The transcript according to Kowal and O’Connel (2014) is the vital first step in the analysis of the interview, but it is also deeply problematic. In the process of transcribing and preparing an interview for analysis, a number of challenges needed to be overcome and choices made about what to include in the transcript (Kelly, 2014). It was recognised that the transcript is a written record of a historic discourse fixed in time. It was also acknowledged that the transcript will be different from the discourse it records in a number of significant respects. Natural conversations contain a number of missteps, stumbles, spoken and unspoken pauses, abbreviations and informal expressions. Interlocutors in a conversation will often use heuristics and short cuts to derive meaning and respond to what the other party says. Transcription on the other hand requires attention to the details of the conversation. However, even the most comprehensive transcription is unable to capture the richness of spoken conversation in all its detail. The transcript, then, is an interpretation of the conversation which, in turn, needs to be interpreted.

It was recognised that all transcripts will inevitably contain transcription errors of the conversation and will never be a perfect replication of the original discourse (McLellan, MacQueen, & Neidig, 2003). A key part in planning for the transcription was deciding how these errors could be minimised and taken into account, and this guided the selection and development of the transcript protocol. The fact that the transcript will contain some degree of incorrect transcription meant that the resulting transcript was handled carefully and critically.
Developing the transcription protocol was a vital step in planning the management and analysis of the interviews. The transcription protocol provided the record of all the notational signs and conventions that would be utilised in the transcription of the interview (Kowal & O’Connel, 2014). A search was made to find a protocol that could be applied to this project with relevant amendments and revisions. An older protocol, suggested by McLellan, MacQueen, and Neidig (2003, p. 74-81) was found to provide a robust template from the project’s transcription protocol could be developed (Appendix 2). The key amendments to the original protocol were: changing the format of the transcribed dialogue to a format that could be more easily imported into a qualitative data analysis software package, amending transcript labels to be relevant for the current project, and taking into account the movement from analogue audiotape technology to digital technology with the concomitant development of alternative digital storage mediums, for example cloud computing technologies for storing backups. A professional transcriber was employed to transcribe the interviews and a copy of the protocol was provided to the transcriber. Utilisation of a professional transcriber provided a higher quality transcript of the interviews with a much shorter turnaround than that which would have been the case if the researcher himself had undertaken the transcription. This allowed the researcher to focus on coding and analysis of interviews.

5.6 Interpretation of the transcript
Interpreting transcripts is fundamental to qualitative research where semi-structured interviews are the means of gathering primary data. It was recognised that in interpreting the transcripts the researcher would bring his own perspective into the analysis (Rennie, 2000). It was also recognised that the interview transcripts represent a particular kind of text with its own qualities that needed to be considered during the process of analysis. The transcript would not be the same as the original interview, for in the process of transcribing the interview, the conversation becomes fixed. In deciding what and how to transcribe, the process of ascribing meaning to the interview transcript had already commenced, because transcribing the interview and interpreting the resulting transcript is to enter the domain of hermeneutics (Kowal and O’Connel, 2014; Rennie, 2000). The task of hermeneutics is to clarify the “miracle of understanding” in which meanings are shared (Gadamer, 2013, p. 303). This sharing of meaning interweaves the interpreter and interpretee in an open-ended process of interpretation (Ezzy, 2002). Engaging in the process of interpretation requires entering into the hermeneutic circle. In entering and moving through the hermeneutic circle theories and interpretations are developed with respect to the text that is subject to an ongoing and multi-
layered process of review and revision (Ezzy, 2002; Packer, 2011). Interpretation is not transposing the interpreter into the author’s mind; rather it is transposing the interpreter into the perspective of the author (Gadamer, 2013).

Transcribing the interview is a form of writing. The process of writing creates “an archive available for individual and collective memory” in which the reader is separated from the context and surroundings of the original discourse through a process of distanciation (Ricouer, 1991, p. 45). This distanciation exhibits a number of attributes that profoundly affect the way in which the text will be interpreted (Geanellos, 2000). Firstly, the spoken word is fixed in writing. Secondly, as a result of this fixation, the author’s intention is eclipsed. Thirdly, the written text is emancipated from the context of creation.

Thus freed from its original discourse, how then is a transcript of an interview to be interpreted? While the distanciation from the original discourse is not likely to be fully realised due to the memory of the discourse held by the interviewer, the act of writing will begin the separation from its original context. Thus, there will be a degree of emancipation of the transcript which needs to be taken into account when interpreting the text. One approach to interpretation is to utilise Ricouer’s (1991) idea of a hermeneutic arc in which a text is interpreted across two poles. The first pole is that of explanation. Explanation, according to Ricouer (1991), is the process of structural analysis of the text in which the constitutive parts are analysed and explained in terms of their relationship to each other. The second pole is the process of understanding. In this phase the text is appropriated by the reader, transforming their self-understanding. Understanding the transcript then becomes a journey of self-understanding and transformation as the interpreter enters into a dialogue with the text. The act of understanding, or more correctly self-understanding, requires re-entering the hermeneutic circle. The output of this process will be a written record of identified themes, fixed in time. These themes will not be an objective summary of the text, but the expression of a subjective and transformed self-understanding.

5.7 Thematic analysis

The end result of the interpretive process will be the identification of significant themes through a process of thematic analysis. While thematic analysis is widely utilised within qualitative research, it
is often poorly demarcated (Braun & Clarke, 2006). As a result it can open itself up to the “anything goes” critique of qualitative research. In attempting to put thematic analysis on a more consistent and rigorous footing, Braun and Clarke argue that the defining characteristic of thematic analysis is the identification of patterns within qualitative data which represent a patterned response or meaning. Ezzy (2002) argued that thematic analysis is an inductive approach to research, which attempts to identify themes lying within the text. As such the approach utilises open coding as a first stage to generate initial ideas about the data. Such coding identifies meanings, feelings and actions present within the text and may be seen as metaphors of the data (Ezzy, 2002). Furthermore, the codes operate hierarchically in that themes summarise and capture a number of underlying codes and sub-codes (Rennie, 2000). Themes may capture more or less detail depending upon the aims and objectives of the research (Braun & Clarke, 2006). Identification of themes requires a flexible approach in which identified themes are not merely the output of quantitative prevalence, but incorporate other, more subjective understandings (Braun & Clarke, 2006).

Apart from deciding upon the level of detail captured by themes, another important aspect is how the codes are identified (Braun & Clarke, 2006). This can be either via a “bottom up” inductive approach or a “top down” theoretical approach. For Braun and Clarke, the inductive approach is driven by the data, not the researcher’s theoretical position. Alternatively, theoretical theme generation is theory driven, that is, themes are identified on the basis of the theoretical interests and predispositions of the researcher and a pre-reading of the literature.

Thematic analysis can be utilised within both realist and constructivist epistemological positions. The epistemological position adopted will determine how meaning is interpreted within text. Within a realist position, meaning, experience, and language are directly related and themes are identified and analysed at the manifest or semantic level of conversation (Braun & Clarke, 2006). On the other hand, a constructivist approach sees language as socially constructed and seeks to identify within the data the social-political context of the conversation. The level of analysis within the constructionist position is therefore at the deeper latent level.

Thematic analysis of interviews tends to follow a general three phase process of data reduction and location, data reorganisation and categorisation and data interpretation and writing up (Rouston, 2014). Within these three broad stages, there exists a range of different options as to how the tasks
will be completed depending upon the nature of the research, the type of data generated and the theoretical orientation and approach of the researcher. It was realised that analysis of the transcript required choosing between alternative approaches to theme identification, each of which was developed from within its own theoretical position (Attride-Sterling, 2001; Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006; Marks & Yardley, 2004)

5.8 Braun and Clarke’s six stage approach

The preferred method for the identification and analysis of themes, and the one chosen for this project, is Braun and Clarke’s (2006) six stage approach. The reason for choosing Braun and Clarke’s approach is that it provides a consistent and rigorous methodology for thematic analysis that can be applied within the theoretical framework adopted for this study, viz. critical realism. It was not the intention of this study to undertake a grounded theory, phenomenological discourse or conversation analysis of the data. Instead, the thematic analysis was undertaken at the manifest level of meaning and was framed within the theoretical construct of a networked ecological model. The following will summarise each stage within Braun and Clarke’s six stage approach.

5.8.1 Familiarising yourself with the data

The hermeneutic circle was entered and the dual process of explanation and understanding began during the first stage. Familiarisation with the data was a vital first step in this process (Braun & Clarke, 2006). This was achieved by listening to the interviews and arranging for the interviews to be transcribed. A professional transcriber was employed to provide a written transcript based on the transcription protocol. Recordings of the interviews were listened to repetitively and compared to the transcripts. One interview was selected for transcription by the researcher to allow greater familiarisation with the data and comparison with the output of the professional transcriber. This comparison confirmed the high quality, efficiency, and speed of the professional transcriber’s work and some of the challenges that would be faced in coding the data due to the limited responses of the participant to some of the questions, and difficulty in hearing some of the replies. It was during this phase that some initial thoughts arose as to potential codes which were noted for use during the coding stage.
5.8.2 Generating initial codes

The stage of familiarisation with the data was followed by generating the initial codes. These codes were developed to capture an essential feature of the text and constituted the building blocks for theme generation. Following Braun and Clarke, (2006) as many codes as possible were generated, though this proved challenging for some interviews due to the limited responses. A combination of coding within Nvivo, and writing notes and codes on printed outputs of interview transcripts, were utilised. As a check on data quality, the researcher’s primary academic supervisor provided feedback on initial codes that were generated and coded one interview. This was then compared to that produced by the researcher and differences clarified. During the process of code generation, code descriptions were written and modified until a final list of codes and descriptions were defined (Appendix 3). Once codes were finalised, transcripts were coded with the final version of the codes within the Nvivo package for subsequent analysis and theme generation.

5.8.3 Searching for themes

In this stage, the initial codes were collected into themes. Braun and Clarke (2006) suggest using visual tools to assist the identification of themes. One visual tool that was utilised for this project was the cluster analysis tool contained in Nvivo. Cluster analysis has been identified as a tool that can assist the interpretation of qualitative data and identification of themes (Guest & McLellan, 2003). The Nvivo tool allows for the exploration of word similarity between codes and the production dendograms, which are visual representations of the word similarity of each code, and how they can be grouped together into common groups for further investigation and review. The assumption here is that codes that belong to a common theme will also share common words as building blocks to the meaning sets. Nvivo allows three approaches to clustering word similarity: Pearson’s correlation, Jaccard’s algorithm and Sørensen’s algorithm. For the purpose of this project Jaccard’s algorithm was selected.

5.8.4 Reviewing themes

This stage involved two levels of reviewing provisional themes. At the first level, the extracts within a given theme were reviewed for cohesiveness. The second level involved looking at the cohesiveness of the entire dataset and whether the themes were an accurate representation of the interview
transcripts. During this phase codes were grouped and regrouped until they formed a consistent theme (Appendix 4).

5.8.5 Defining and naming themes
Once a satisfactory thematic map had been generated, the generated themes were reviewed and, if required, refined. This stage required identifying the “essence” of each theme and what the theme captured (Braun & Clarke, p. 92). A detailed story of each theme and how it related to other themes and to the broader story of the study was written during this stage.

5.8.6 Producing the report
Writing the report is the final stage of Braun and Clarke’s six stage process. Results and implications are communicated to a wider audience in written form. For the purpose of this research it incorporated writing the thesis and outlining the thematic story revealed during the project.

5.9 Ethical issues
Following normal research practice, the proposal was submitted to and approved by the University of Otago Human Ethics Committee (Health), reference number H14/110 (Appendix 5). When thinking about the ethical issues, particular attention was paid to the fact that the participants comprise a highly vulnerable group. A large number within this group had been subject to stigmatisation and marginalisation (Bray, 2003), and have also suffered abuse and trauma (Taggart, et al., 2007). Many ethical issues, therefore, needed to be considered to provide a safe research environment. One issue that does not appear to have been articulated in the literature, is the tension between inclusion/exclusion (Carlson, 2013). The dangers of inclusion have been widely discussed and form a justification for the exclusion from research of people with an intellectual disability (Carlson, 2013). The two main dangers, according to Carlson (2013), arise from the historical abuses suffered by such people and their cognitive limitations. Yet, as Carson argues, applying overly strict inclusion criteria will result in their exclusion from research resulting in another form of discrimination, incorrect assumptions about their ability to give informed consent and exclusion from the benefits of research. Creating a safe space and reflecting on the positioning of
the researcher relative to the participants were important considerations (Munford, Saunders, Mirfin-Veitch, & Conder, 2008). The need for giving respect to the participants was also acknowledged (McDonald, 2012). The issue of informed consent was also considered to be of vital importance to the ethical approach of this study (Iacono & Murray, 2003).

The issue of cultural safety with respect to this group was considered. Individuals who have a disability, such as people with an intellectual disability, share common themes and experiences across the domains of the historical/linguistic, social/political, and personal/aesthetic (Peters, 2000; Dupre, 2012). People with an intellectual disability have a history of marginalisation and stigmatisation (Bray, 2003) and share a collective history and identity (Tower, 2003). One that is particularly strong, is their collective history of institutional care and deinstitutionalisation. How to safely undertake research with this population required reflection on their self-identity. This led to the awareness that this population’s self-identity is greater than the label of “intellectually disabled”, a label which Bray (2003) argues is a metaphor or social construction. Furthermore, it was recognised that, as a result of both their shared and individual experience of relating to a world comprising the “non-disabled”, they may experience that world as a confusing place and feel marginalised by it.

Taking into account the discussion above, the following ethical principles were followed in the research:

5.9.1 Informed consent
Manning’s (2009) model of informed consent/assent was applied to achieve informed consent and assent. An information sheet (Appendix 6) and participant interest form (Appendix 7), were written in plain English, outlining the objectives of the research, what to expect from an interview, rights as a participant (including withdrawal from study) and how confidentiality would be protected was given to each participant. Visual illustrations were developed to aid the comprehension of the participants. During the initial part of the interview, key concepts and study questions were repeated and explained as often as required for each participant, and a plain English consent form was provided to the participant and any support person who accompanied them (Appendix 8).
5.9.2 Beneficence and non-maleficence

The proposed research allowed inclusion of a marginalised and under-researched group, who may otherwise suffer exclusion, to give voice to their experiences (Carlson, 2013). The study adopted McCarthy’s (1998) approach of openly acknowledging the potential one-sidedness of the interaction. Participants were provided the opportunity to ask any questions they felt comfortable asking. Participants were offered the opportunity to receive the results of the study in a user friendly format. Protocols were developed to address potential issues of alcohol misuse, psychological trauma and disclosure of physical and sexual abuse (Appendix 9 and 10). Any potential ethical issues that occurred during the study were discussed with the researcher’s academic supervisors. One potential ethical issue came to the knowledge of the researcher. It was an incident involving one of the participants. Although the incident was related to the consumption of alcohol, it occurred outside of the interview and it was decided, after consultation with the researcher’s academic supervisors, that no further follow-up was required.

5.9.3 Confidentiality, access to data and privacy

Data for each participant was identified with code numbers and pseudonyms rather than their actual name and stored in password protected files that could only be opened by the researcher. Data was stored in a safe and secure location. Participants had the right to withdraw their information at any time prior to analysis (Griffen & Baladin, 2004) in which case all records would be permanently deleted. Within this thesis pseudonyms are used and potentially identifying features are excluded from the report. Participants had the right to withhold information or leave unanswered any question in the interview (Griffen & Baladin, 2004).

5.10 Involvement of Māori

This project acknowledged Māori as parties to the Treaty of Waitangi, a founding document of New Zealand, signed between the Crown and Māori in 1840. As part of the commitment to the principles to the treaty, the relevance of the research to Māori was considered throughout the study. These principles were those of protection, promotion and participation of Māori Cultural identity (Durie, 1999). While the study is not directly focused on Māori, it was recognised that the results may be of
interest to Māori and that some of the participants might identify themselves as Māori. Therefore
acknowledgement and inclusion of the principles of the treaty and undertaking the research in a
culturally safe manner were taken into account during the planning of the project. Input from the
Ngai Tahu Māori Consultancy report was incorporated in the research planning (Appendix 11). A
kaimanaaki or Māori cultural advisor, who works at the researcher’s place of employment, was
approached to provide cultural oversight. The researcher also incorporated knowledge gained from
his training in Te Tiriti and Māori cultural safety as part of his nursing study and professional
development. In this the researcher recognised that the treaty is a founding document between
Māori and the crown (New Zealand government). In this, it was recognised that the researcher had
an obligation to follow the principles of protection, partnership, and promotion when working with
Māori as outlined within the treaty. The researcher utilised this knowledge to reflect upon and be
aware of the issues of tapu (that which is sacred or forbidden) and noa (that which is free from tapu)
(Capital and Coast DHB, nd).

5.11 Summary
In this section the methods utilised in the study were outlined including the challenges faced in
identifying and recruiting potential participants as well as transcribing and interpreting the
interviews. The choice of qualitative research method utilising semi structured interviews outlined
and the justification for this approach presented. This section also noted the potential ethical and
cultural problems faced with researching vulnerable populations such as people with an intellectual
disability as well as the need for maintaining culturally safe research practice within the context of
the Treaty of Waitangi. The section outlined the strategies adopted for dealing with each of these
issues. The next chapter will then proceed to describe the results of the study and how the themes
and subthemes were developed.
6. Results

Having outlined the theoretical framework of critical realism (Section 4) adopted for this study and the methods utilised to undertake this research (Section 5), this section will outline the results of the analysis. Critical realism provided the epistemological lens through which the transcripts were viewed, while Braun and Clarke’s (2006) six stage approach to thematic analysis provided the process by which codes and themes were generated. The chapter will firstly outline the process of code generation and development of themes (Section 6.1). Then the themes and subthemes will be presented with the supporting data (Section 6.2).

6.1 Development of codes and themes

Code development followed a progressive timetable resulting from the dates when the respective interviews were undertaken. The first three interviews were undertaken during February and March 2015. While ongoing attempts were made to locate and interview more participants, the initial interviews were transcribed and coded. From the coding of these initial interviews, some tentative themes were developed, subject to ongoing review as more interviews were undertaken. The initial interviewees were highly homogenous in terms of their experiences and attitudes to the consumption of alcohol, and generated a limited number of initial codes. When the initial codes were reviewed, some were found to be poorly supported by the data, while other codes were closely related and amalgamated. The result was that only 12 codes had been generated after the initial three interviews. The second and final group of interviews were undertaken during the period June to August 2015, and generated a greater number of codes due to the participants’ more diverse and richer experience of alcohol use. Analysis of the interview transcripts produced 23 codes from the first six interviews. By the eighth interview, 29 codes had been identified and described. Interviews 9 and 10 generated no additional codes (Chart 4).

Chart 4: Code generation
The process of finding themes followed the six stage process of Braun and Clarke (2006), especially stage three to five. Nvivo’s clustering tool was used in the initial part of this process. The resulting dendogram was examined and an initial group of three clusters of codes was identified for further review and refinement. Closer inspection of the codes within each cluster, and referencing back to the code descriptions and extracts associated with each, suggested that the initial clusters did not fully cover the range of themes being investigated. There were deeper meanings and associations within and between respective codes beyond mere word similarity. Furthermore, analysis of the stability of the clusters revealed that membership of the clusters were highly unstable, a common problem in cluster analysis (Van der Kloot, Spaans, & Heiser, 2005). Thus, the next step in this process was moving codes in and out of the initial clusters to try and find a more satisfactory grouping of codes into common themes. Some of the codes naturally fitted into a single group whereas others could easily have been assigned to more than one group. Such codes then could be seen as lying close to the thematic boundary between two competing themes. These codes were moved in and out of the respective thematic groups and their descriptions refined until a more homogenous group was obtained.

6.2 Themes of alcohol use
Three themes were identified from the thematic analysis, Choices and Influences, Context and Location of drinking behaviour and Drinking Behaviour (Diagram 3 and Table 6). Some thought was given to splitting the third theme, Drinking Behaviour, into two themes, separating the longer term consequences of drinking alcohol from the episodes of drinking alcohol. It was decided that splitting
the theme would dilute its meaning too much and that they would be better handled as sub-themes. Having identified the main themes, they were then reviewed for coherence and consistency.

Codes within a theme were reviewed to see if they could also be grouped together to form a sub theme. Within the theme of Choices and Influences, three sub themes were identified: Previous and Current Influences, Taste and Personal Preference and Values and Judgements. For the theme, Context and Location of drinking behaviour, two sub themes were initially identified: Social Gatherings and Activities and Representation in Drama. However, upon review and after feedback from the researcher’s academic supervisors, it was concluded that the Representation in Drama sub theme did not have sufficient support from the data, so it was dropped from the analysis. Since this left only one sub-theme, Social Gatherings and Activities, this was also dropped and the theme Drinking Behaviour was treated as a theme with no sub themes. As for the theme, Drinking Behaviour, two sub themes were identified: How Alcohol is Consumed and the Effect of Alcohol.

**Table 6: Themes**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description of Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choices and influences</td>
<td>Choices made about consumption of alcohol and factors influencing those choices including modelling by family, peers, and social support network, internal values, judgements about other people's drinking behaviour, alcohol knowledge, media, and cultural influences</td>
</tr>
<tr>
<td>Context and location of drinking behaviour</td>
<td>The locations where alcohol is consumed and the context in which it is consumed, for example, birthdays and Christmas</td>
</tr>
<tr>
<td>Drinking behaviour</td>
<td>How alcohol is consumed, the amount consumed, what is consumed, and the consequences of drinking alcohol</td>
</tr>
</tbody>
</table>
The next section will present the themes and sub themes in more detail. For confidentiality purposes, pseudonyms instead of the actual names of participants were used. Quotes from the transcripts were edited to aid reading and flow. This included removal of spoken pauses, and fillers such as um, yeah, you know, mmm. Where references to a subject not included in the text were made, an explanation of the subject was given in square brackets []. The notation of three dots ..., was used to refer to text considered not relevant to the quote, and therefore excluded. One of the participants had a speech impediment and was accompanied by a carer who would sometimes translate the participant’s responses. In such cases these quotes were indicated by << ... >> brackets.

**Diagram 3: Themes and sub-themes**

![Diagram showing themes and sub-themes]

6.2.1 Choices and influences

Choices and influences incorporate those factors, both external and internal to the person, that inform and influence their preferences and choices about the consumption of alcohol. From this, three sub themes were identified: Previous and Current Influences, Personal Taste and Preferences, and Values and Judgements.
6.2.1.1 Previous and current influences

One of the most important influences on patterns of drinking and attitudes towards drinking alcohol, was the family. This would include the parents and other direct family members of the participant who, in the first instance, set the example for the drinking of alcohol. The most common alcoholic drinks consumed by family members were beer and wine. The consumption of spirits such as bourbon or gin by family members was also reported by some of the participants. This model of alcohol consumption seemed to provide an important protective factor for many of the participants, with copying moderate patterns of consumption among family members a common result as the following words from Jane shows:

“They don’t drink much. I mean my brother used to drink, but he doesn’t drink that much. So – and my sister doesn’t really drink at all.”

Jane also reflected elsewhere on the advice given by her father when she was old enough to start drinking. She incorporated this advice into her decisions about drinking alcohol.

“He [Jane’s Father] said, oh you can drink as long as you don’t go overboard. So I said, “okay”.”

Furthermore, Jane, when asked to elaborate upon the drinking patterns of her father, noted that since he works night shift he did not drink alcohol every day.

"He works a night shift, so – no, during the day, sorry. So he works maybe – cos he starts at about five o’clock. So – but he doesn’t drink every day. So maybe like on the Friday or the weekends, he will have just a couple at home with my mum."

In this we see a key person as role model for the avoidance of alcohol because other responsibilities take precedence over the consumption of an intoxicating substance like alcohol.
George also talked about how work responsibilities influenced the drinking patterns and choices of his family. Members of George’s family own and operate a pub, so he was familiar with alcohol being sold and consumed as a normal pattern of behaviour. He noted that, while most of his family drinks beer or wine most weekends, the responsibility of owning and running a pub meant that they had to be careful about their consumption of alcohol.

“And, cos they own a pub they have to be quite, you know, vigilant of the drinking and driving, and which they have to be. But they’re very conscious.”

Three participants had negative experiences with a close family member who drank to excess. One participant described one of their close family members as an alcoholic. The second participant had a close family member die from alcohol poisoning. The third has a family member who becomes aggressive after drinking alcohol. In all cases the negative experience did not stop them from drinking alcohol, though it influenced their level of consumption, as George notes.

“I didn’t drink for a long time because, I don’t normally tell a lot of people, and because my {family member} died of alcohol poisoning.”

As well as direct family members, extended family such as uncles and aunts, members of the participant’s wider social network, spiritual community and neighbours provided models of how alcohol was consumed. Sean, for example, lives in a supported residential living environment with neighbours who range from the 20s to 50s in age. He observed that while some of his neighbours drank alcohol, it was only every now and then.

“I mean like they might have a light drink sort of every now and then.”

Kim is a Christian and grew up with Christian aunts and uncles. She observed that her aunts and uncles did not drink because of their spiritual beliefs. She did not know any Christians who drank alcohol, only non-Christians such as her mother and step-father.
"Interviewer: Any of your uncles, aunts, [drink alcohol]?

Kim: No, they don’t drink, because they’re Christian ...

Interviewer: Do you know any Christians that drink?

Kim: No, no Christians, no.

Interviewer: All, all – so all the Christians you know, none of them drink?

Kim: No.

Interviewer: Only non-Christians, people...

Kim: Yep. Like my mum and my step-dad. They don’t believe in God."

Family members and Television (TV) were two sources of information about alcohol mentioned by participants. Kim learnt about alcohol from drinking with her parents from age 14.

“Well, they were just drinking with me. Like they were, they gave me – at the age of 14, even though I was under age, but I was with my parents, they gave me my first alcoholic drink, when I was 14. And since then I’ve been drinking, basically. Not every day, but once in a while."

Mary stated that she learnt about alcohol from family members and parents and the importance of drinking moderately from her parents.

“Not to drink too much. To drink at home. Not really go out to parties. Yeah, cos when I was younger, probably, yeah, just drink under their rules...yeah, the way they want me to drink – not go and drink myself and find somewhere I don’t know how to get home.”

In addition to family one of the participants, Tim, learnt about alcohol from a course at school during a health course.
“Tim: I learnt it through school as well.

Interviewer: Oh, school. And what was taught..?

Tim: Health.

Tim: And what do you remember about what you learnt?

Tim: Ah, when that drinking far too much is bad for your body and liver and it damages your liver.”

One of the participants, George, stated that his knowledge of alcohol before he started drinking was limited.

"Interviewer: You said that the first time you drank alcohol was at your brother’s 21st?

George: Yes.

Interviewer: And did you learn about alcohol before then or know anything about alcohol before?

George: Well, I’d known a wee bit, I guess...around my mum... But I ... didn’t know about those RTDs or anything."

Another, Jane, mentioned the news and TV ads as a source of information about alcohol. She recalled in considerable detail one TV ad which portrayed the effects of drinking and driving.

“Because there’s like one ad that it’s really interesting, because it goes like this. He’s drinking [in] a car and you have to slow down if you see a speed camera. Because sometimes if they’re driving too fast they go and ... a speed camera will get you.”
Most of the participants did not cite any external or internal stressor or trauma as a reason for drinking alcohol. Only Kim talked about feeling stressed as a factor in drinking alcohol. Reflecting on this, Kim noted that she uses alcohol to help her feel calm.

“Yeah. I don’t drink very regularly. The only time that I drink is when I’m stressed. Cos I tend like one drink of alcohol tends to mellow me out, and ... it doesn’t get me stressed. Because otherwise I stress.”

Even though Kim stated that she does not drink that often she was worried about the effect that alcohol had on her and talked about wanting to find help to stop drinking.

"Yeah. So I just, I just don’t agree with it. Like if I could get help myself to stop drinking, I would. But I haven’t been able to find anything to stop me from drinking."

For one participant, Michael, health issues influence and moderate the amount of alcohol he consumes. He has diabetes and is concerned about gaining too much weight.

"I have to watch my weight and plus of diabetes."

Another moderating influence noted by the same participant is his responsibilities when attending meetings and conferences as a representative of a disability advocacy group. Michael also stated that while attending conferences he restricted himself to, at most, two of glasses of wine at the conference dinner, as he wanted to be able to concentrate the next day.

“Occasionally I have a couple of glasses of wine. Not too many because I have to concentrate the next day for the meeting.”
Section conclusion: Family members and members of their social and, for one participant, their spiritual group provides an important influence on drinking behaviour for this group. For many, family and other people in their social network showed low levels of consumption. Other moderating influences mentioned by individuals in this study were work place and organisational responsibilities and health concerns. Knowledge of alcohol came from family members and the media. One mentioned a school health course.

6.2.1.2 Taste and personal preference
Participants in the study were able to state their preferences for the types of alcoholic drinks they liked to consume. The most common preferences were beer and wine. John liked beer because of the froth. Other participant’s preferred beer that was not too heavy or strong. Jane, for example, when asked about why she liked light beer, explained her preferences as follows:

“Interviewer: Do you still drink beer?
Jane: Yeah, yeah I do, but if I go out to a weekend, I normally have the, that light beer ... cos that’s quite good for me.
Interviewer: What do you like about that light beer?
Jane: it’s just basically just, you know, all the different beer ... cos light beer’s ... it’s light because it’s not as heavy as the other beers.”

Michael also voiced a similar preference for lighter beers, stating that that heavier style beer was too strong for his taste.

“Interviewer: What didn’t you like about the heavier beer?
Michael: Cos it’s too strong.
Interviewer: What was too strong about it?
Michael: Oh, of the, of the beer taste, like that”.

Many of the participants were able to identify the preferred brands of beer they drank. Sarah for example liked Amstel light beer. George preferred Tui and DB beer as they were not too strong. George also stated a preference for Speights beer. Sean tended to drink Mac’s Gold, Steinlager or DB Export. John liked the Heineken and Mac’s Gold brands as well as a shandy (a mix of beer and lemonade).

As with beer, the preference for wine was for wines that were not too heavy. Both red and white wines were consumed by many of the participants. However, no wine brand or style beyond the generic red, white, and sparkling wine were identified by the participants. Jane stated that her preferred type of wine was sparkling wine due to the bubbles in the wine. She also liked still white wine, comparing it to grape juice. Not all the participants enjoyed wine as the following extract with George shows:

“Interviewer: What don’t you like about wine?

George: I don’t like the taste of it.

Interviewer: Yeah, anything about the taste that you don’t like?

George: It’s just the taste of it lingers in my throat.”

Spirits mixed with mixers like soft drink or Red Bull, an energy drink used as a mixer in New Zealand, were common among the younger participants. Mary, for example, liked raspberry, lemonade or red bull with vodka. Kim liked to drink barrel 51’s, a RTD (Ready to Drink) comprising bourbon and cola, but not diesel, stating the former “goes down smoother”. Tim also stated a preference for RTDs. John, one of the more mature participants in the study, stated he did not like spirits like vodka or whisky, but he liked to drink gin and tonic. Sometimes participants would choose not to consume alcoholic drinks, preferring to drink non-alcoholic soft drinks such as Coke, Sprite, or Thriftee. For example, Mary said that when she catches up with friends she tends not to drink alcohol.
“Well when I catch up with my friends, I don’t really drink any alcohol. I just mainly, at the moment, have a glass of lemonade...or some water. Or I might go to my friend’s house, but I might just have some fizzy or just fizzy and water, mainly.”

Section conclusion: Participants were able to articulate their preferences when it came to the type of alcohol drink they preferred and why. Alcohol drinks were not the only type of drink they liked to consume, with many also stating a preference for non-alcoholic drinks at different times. Drinks that were considered to be too heavy, were avoided.

6.2.1.3 Values and judgements
Personal values and judgments over the consumption of alcohol and its effects upon people were an important influence on the choices made by participants with respect to the consumption of alcohol. Many of the participants had a strong sense of rules which they had learned and internalised from their families and support network. These internalised rules provided a strong protective mechanism for many of the participants, but could also be a source of internal tension when they failed to live up to rules. Kim, for example, is a Christian whose internal rules over the use of alcohol are strongly influenced by her Christian beliefs.

“Kim: ... and with me being a Christian, it’s very important, because I have heaps of people praying for me ... And they know my situation and how I’ve been and everything, and so they know that I don’t, just because I’m chaste and God doesn’t want that. God wants you to have a good time – not drink and you know.

Interviewer: And what’s important about keeping those rules, following those rules? Why is it a good thing to do?

Kim: Oh because you’re a Christian and if you break them rules, He’s basically gonna – how can I put it, ... well it’s, it’s good to keep the rules because God has set them rules ... for a specific reason.”
Thus for Kim keeping rules is important as God has put them in place for a reason. However, tension arises when Kim drinks alcohol which she sees, as a baptised Christian, as going against God. One way in which she tries to reconcile falling short of the rules she tries to live by is by following a religious practice of prayer, saying sorry for her actions, and reading the Bible.

“\textit{Well, I feel that I’m going against God’s word....like cos I’m a Christian I would – and i’ve been baptised. So it’s like I’m going against His word...and what it says in the Bible. So I just like I have a drink once so often...but it’s just once so often I have a drink and sometimes I say sorry to God...because I’ve been drinking, cos it’s against His word. In the Bible it says, um, He doesn’t believe in drinking and people having – ah, drinking full-stop. ... And every time, I drink, I tend to get my Bible out and read that verse to me...and think, you know, I shouldn’t be doing this. You know, I should stop doing it, and ever thing else.}”

The internal rules that participants use to guide and direct their decisions about alcohol use are often manifested in their thoughts, feelings and judgments about the behaviour of other people they see who drink alcohol to excess. Many of the participants used terms like “silly” to describe the behaviour that they have witnessed on the TV or in real life. For example, Sarah described a scene from the TV reality show, Police 10/7, in which some teenagers where shown drinking alcohol to excess:

\textit{“Sarah: And when they drink a lot, they go a bit silly.}

\textit{Interviewer: A bit silly?}

\textit{Sarah: Yeah.}

\textit{Interviewer: So how do they go silly, from what you’ve seen?}

\textit{Sarah: Oh like do silly things or something that they shouldn’t be doing or something.}

\textit{Interviewer: And what do you feel about people being silly like that?}

\textit{Sarah: I feel as if it’s not a, not a, not a good thing to do.”}
George discussed some TV shows he had seen in which people would get silly and fall over and hurt themselves. He has also seen people in real life that have had too much alcohol to drink and observed that “it’s not nice at all”. Mary talked about seeing some of her friends getting silly and said that she would walk away from them. She also expressed a view that people who had too much to drink were embarrassing and weird.

“Interviewer: How does that make you feel, seeing people act stupid?

Mary: Weird. Like, oh my God. Embarrassing, cos you don’t want to be in public like that.

Interviewer: So what’s weird about that?

Mary: Just people acting the goat, having too many – just jumping too much.”

John spoke about seeing people on TV and in real life people who had consumed too much alcohol and lost their balance as a result. He used the words “Stupid” and “not good” to describe his thoughts about what he had seen. Kim described herself as feeling “sick” when she saw people intoxicated in public. She gave an example of when she was doing shopping with her partner at a local supermarket and they came across a group who were drinking on the side of the road.

“And it’s like, my partner’s [said] to me, “babe, look at them, look at them. They’re horrible.” You know, “look at them.” They look like drunk as. And I was like, just ignore them, you know.”

Not everyone, though, was so disapproving of drinking in public. Sean, who enjoys going to sports events, observed that some people get rowdy at these events. He reflected the view that such behaviour was part of sports culture, and that it “goes with the game”.

One of the participants, Jane, expressed concern that excessive drinking leads to accidents with people getting hurt and killed. She stated that such people were “idiots” and “stupid people” who should “stick to the rules”. Two of the participants, Mary and Kim were concerned about people spending too much money on alcohol and not having enough money for food and clothes. Kim saw
spending money on alcohol as money down the drain and was worried about the children in such households being neglected. For Kim, the parent’s responsibility is to look after their children, and if they do not look after them then they do not deserve to have children.

“Like you’re spending at least $40 on alcohol, like a box of Barrel 51s. You’re spending at least $30 to $40, if they’re not on special, that is. But you know. Forty, $30 to $40 is going down the drain. Like every cent that you put down the drain is money that could be used on for example, some parents drink every day. So they could be used on clothes for the kids, you know, food in the cupboard – everything that the kids need, you know. Instead of alcohol, alcohol, alcohol, alcohol. … I’ve seen plenty of families like that, like they drink every day and there’s no food in the cupboards, the clothes (bangs table) that the kids have are like dirty, you know.”

Section conclusion: Participants in the study have a range of personal values and rules that they apply to both their own consumption of alcohol and the consumption of others. These internal rules can be a significant protective factor, but can also lead to internal tension if their behaviour deviates from the standards and values they have set for themselves.

6.2.2 Context and location of drinking behaviour

Context and location of drinking behaviour refers to the physical location in which the consumption of alcohol occurs, the social context surrounding the consumption of alcoholic drinks, and where alcohol is sourced. The consumption of alcohol, for participants in the study, often occurred in the context of social gatherings, which included birthdays, Christmas celebrations, or other social events. For many of the participants their first experience of consuming alcohol was at a birthday party such as their 21st or that of a family member. Jane, Mary, John and Michael all recalled that their 21st birthday was the first time that they consumed alcohol. Michaele said that his first experience of alcohol involved drinking from two to four glasses of wine at his 21st birthday as follow as the following quote reveals.

“I had, when I was at my 21st and have two or three or four glasses of, of wine”
Three of the participants cited a much earlier age of initiation to alcohol. Sean and Tim cited the mid teen years as the age when they first started drinking alcohol. Kim recalled that she was given an alcoholic drink by her parents at age 14.

Consumption of alcohol was associated with important life events, rituals, and celebrations. These included weddings, birthdays, christenings and Christmas time. Sarah cited such special occasions as the time when she would have an alcoholic drink. For Tim, these special occasions included birthdays and Christmas. Drinking alcohol was also associated with special occasions for Jane.

“Interviewer: So what kind of special occasions are they?

Jane: Yeah like birthdays. It was like somebody getting married. Like if it’s a special marriage or if somebody’s getting christened.”

Michael described how at Christmas times and Easter he would have a glass of bubbly wine with his family. The focus for these occasions was not on the alcohol, but on celebrating the event with his brothers and sisters. George emphasised that alcohol was drunk at Christmas times and that at other times he would have non-alcoholic drinks.

“Interviewer: Can you give an example of the type of celebration?

George: Normally around Christmas time I would have a few, but if it’s just an everyday thing, I wouldn’t, like the weekend. Like most people, I wouldn’t. I would just have Coke or something.”

As well as Christmas and birthdays, one of the participants, Mary, who plays netball with a local netball team, talked about attending the annual prize giving with her team mates where alcohol was available to be purchased. She observed that some, but not all, her team mates purchased alcohol and recounted that she had chosen not to have any alcohol at the prize giving.
“Mary: Oh, we – actually, yes, we do, because we go, when we go to our prize giving, … I’ve never had alcohol there.

Interviewer: How much alcohol would be at the prize giving?

Mary: I don’t know. You can just order it yourself… it depends where we are, how much you have, your money and it depends how much you want to drink and how much you don’t want to drink. It’s completely up to you, it’s your decision.

Interviewer: And any of your team-mates…how many of them would drink?

Mary: Yeah, not – a couple. Like probably about four, five…but, yeah, some of them don’t really wanna drink.”

Sean is involved in a theatre company, and has toured with the company around the country and overseas. At the end of each tour, and at the end of the year members of the company would have a break up or end of year celebration in which alcohol may be involved, but he emphasised that nothing too intoxicating was consumed.

“usually we might either sort of break up between Christmas, New Year’s, and that. So, we have kind of celebration, just on on-site… we won’t have anything too intoxicating.”

Participants are involved in a wide range of social activities where alcohol may be available for purchase and consumption. Music and sports events were common activities mentioned by the participants. Tim enjoyed going to sports and concerts. Sarah, prior to her interview, had been down to Blenheim with her family to attend the Taste Marlborough wine and food festival. During the festival she tasted a number of different wines and enjoyed the opportunity to listen to a band while having a wine. Peter liked to go to the Cosmopolitan Club with his mother and have a dance. Jane is a member of the local Workingmen’s Club and sometimes likes to go to listen to a band or participate in karaoke. Michael mentioned that during a trip to New Plymouth he went to a concert where he had a couple of beers.
“up in New Plymouth I went to a concert and I have a couple of glasses of beer and also a rugby game, one time, up there. It was good.”

Other activities mentioned were social outings and functions organised by groups such as People First and Life Start. While alcohol was consumed during these activities, participants sometimes choose to have non-alcoholic drinks. Examples of the types of functions and outings included day trips to Hanmer and a girl’s night arranged by Life Start at a local pub. John’s family owned a launch and when he went out with his family on the launch he would sometimes have a beer.

A common thread throughout the interviews was that the consumption of alcohol was not the primary focus of the activity; rather, it was socialising and catching up with family and friends. Sarah talked about mixing and mingling with family and friends and listening to a band at activities like the Wine and Food Festival.

*Interviewer: What do you enjoy about going down to Wine and Food [Festival]?*

Sarah: It was good.

*Interviewer: Good, yeah. Is there anything in particular that you find really ...?*

Sarah: Mm, just mix and mingle ...

*Interviewer: anything else?*

Sarah: because there’s a – they had a band.

John also would sometimes go out to a local pub or to a local working men’s club when catching up with family or friends.

"*Interviewer: What about with, when you go out with friends?*

*John: I do drink with friends.*
Interviewer: Where do you drink when you go out with your friends, when you’re having a drink?

John: Cashmere [Working Men’s Club].

Tim would also go out, catch up with family and friends, or as part of an activities group.

Tim: At a pub or some – or most of the times when I go out and have, have dinner.

Interviewer: You have dinner. Dinner – who with?

Tim: At the moment, last time was when I had dinner [with an] activities group ... on Saturday was the last time.

Sean mentioned a social group that he is involved with sometimes goes out and does fun activities which included going to a movie, or to a local restaurant.

“... me and some of my friends that I go to course with, some of us are part of another organisation., and so we kind of like have – so we kind of like do sort of fun activities ...like we go to, a bike ride to Hanmer or we kind of...did a movie night...”

Also, some of Sean's work mates would sometimes go to a local bar for after work drinks or if someone had a party or celebration.

Sean: some people might have, like after-work drinks or something, ... I used to work at a workshop in Riccarton...sometimes - you know like if someone had a party or whether it was just ... a general social...sort of thing some of them would go down to the Irish bar.

For Mary, the important thing was to “hang out” with people such as the activities group to which she belongs.
Interviewer: What about people you hang out with? You mentioned that social group. How often do you go out with them?

Mary: Oh the Life Start...we went to Hanmer yesterday – on Sunday sorry. We have like bowling, the 4th Tuesday, and, I’m just trying to think of the next social. I’m not quite sure, like a month, I think.

Michael also talked about going out and catching up with friends.

“Interviewer: ... is there anything that you are going to be doing when you catch up with friends.

Michael: Just, have a nice evening out.

Interviewer: okay.

Michael: Catch up with those friends and have a nice evening”

In terms of where and how alcohol was sourced, the main sources of alcoholic drinks mentioned by participants included pubs, working men’s clubs, the Cosmopolitan Club, and supermarkets. Family members were also a common source of alcohol, particularly for initiation to drinking alcohol. In one case, home brewed beer was supplied by a friend of the boyfriend of one of the participants.

“Kim: It was, home brew

Interviewer: Home brew?

Kim: ...yeah, yeah, home brew beer.

Interviewer: Who brews the home brew?

Kim: It was my boyfriend’s mate that did it”
Section conclusion: Consumption of alcohol was associated with important celebrations such as birthdays and Christmas. Socialising with family and friends and participating in fun activities also provided a context for alcohol consumption. Common locations for drinking alcohol were pubs and clubs, restaurants, and home. Outside of these locations, supermarkets and, in one case, a home brew beer supplied by an acquaintance was identified as a source of alcohol.

6.2.3 Drinking behaviour

The final theme explored how alcohol is consumed, the amount consumed, and the effects that the consumption of alcohol had on participants and those around them. Drinking behaviour is defined as how alcohol is consumed, the amount consumed, what is consumed, and the consequences of drinking alcohol. This theme is divided into two sub-themes: how alcohol is consumed, and the effects of alcohol.

6.2.3.1 How alcohol is consumed

Most of the participants drank only modest amounts of alcohol, and some drank only on special occasions. Sarah, for example, stated that “I don’t want to drink too much. Maybe one or two or something”. Sarah reported that she never had any experience of anyone drinking alcohol to excess and that most of her social network only drank alcohol on special occasions. Peter, when he was not catching up with family or friends liked one bottle of beer on a Friday as part of his weekly routine. Jane commonly drank only one alcoholic drink with her family and friends on special occasions. She emphasised that she was not a regular drinker and she did not drink alcohol every night, just on special occasions.

“Interviewer: What do you like about drinking?

Jane: Oh just … drinking is when you’re with friends or something, if it’s like a special occasion, so – yeah.

Interviewer: So special occasions?

Jane: Yeah.
Interviewer: So it’s not every night?

Jane: No, not every night. I don’t drink every night. I’m – no.”

Michael limited himself to just one alcoholic drink per session.

Interviewer: … from – you said one, you said one gin and tonic?

Michael: Yeah, one gin and tonic and/or...

Interviewer: Or anything else?

Michael: …or a wine, like that.

Interviewer: Or a wine. But just the one?

Michael: Yeah, just the one.

Similarly Tim limited himself to a maximum of one or two drinks per session.

Interviewer: How many would you drink in a night now?

Tim: When I do have a drink, I, I normally keep it at, at two at the tops.

George set himself a rule for how many alcoholic drinks he would have before restraining from alcohol consumption.

Interviewer: How did you decide what your limit was?

George: I don’t really know. I just said one or two and then I’ll just drink water for the next hour, and then I’ll go back on.
Kim, who sometimes has drunken to excess, also said that one bottle of beer would often be enough for the night. Sean also stated that he did not consider that he drank to excess. John usually drank at most just one or two alcoholic drinks per session. Michael would have only one or two wines with his meal when attending conferences or when in Wellington for meetings. John also would have a meal with his drink much of the time.

Interviewer: Is there anything else you like about having a beer?

John: With food.

Interviewer: With food. You like having it with food?

John: Yeah!

John: << most of the times when we go out, we’re ... at places where they’re having meal>>.

Some of the participants have experienced mild levels of intoxication or witnessed it amongst their social group. Mary described it as “they go happy” and “enjoying themselves”. Mary also described the effect of mild intoxication on her boyfriend as “good and calm” and “just really relaxed”. She also stated that “he doesn’t get angry or do anything nasty”. Kim, when discussing how alcohol affects her, stated that alcohol “makes me mellow out”.

While some of the participants had no experience of excessive levels of consumption, others have had personal experience of binge drinking. John, for example, described a time in which he had drunk too much resulting in a headache. Mary described the point in which she goes beyond her limit and start’s “to feel a bit tipsy” as the point at which she realizes that she should have cut down.

“Interviewer: ... How, how do you feel when you’re tipsy?

Mary: I think I, I say to myself, ooops, I’ve drunken too much... I should have just cut down, yeah.”
While many in the family and social network of the participants drank low amounts of alcohol, there were some exceptions. Jane had a brother who, for a period of time, drank excessively. This caused her a lot of concern.

“Interviewer: And how did you feel about your brother drinking a lot?

Jane: I was, I was like not, I was like, when I’ve heard that he was drinking, I was like, I was like oh, I said, I don’t want, I don’t want you – I said, “I don’t want you to lose everything if you got drunk and had a car crash and died in a car crash. I would - do not want to lose my brother.”

Three other participants had family members who drank to hazardous levels with one experiencing the death of a family member as a result of their drinking behaviour. One of the participants, Kim, described seeing a family member drink to excess, losing their temper, and driving while under the influence of alcohol. The experience created a lot of internal tension and uncertainty about how best to handle the situation.

“Kim: You know, so. And I don’t like seeing them at that stage. I don’t like seeing any of my family like that ... I just don’t like it.

Interviewer: What don’t you like about it?

Kim: Oh just the state that they get in, and my stepdad always decides to lose control and then he gets angry and loses his temper very fast. That’s what I don’t like about them drinking alcohol, because my stepdad goes over the – over the limit, and then he drives. So it’s like. What am I supposed to do? I can’t really tell them to not, because it’s up to him what he does.”

Kim’s response to a session of drinking to excess was to avoid drinking alcohol for a period of time after she had had a session of drinking too much.

“Yeah. And then it would be, it would be like ages until I drank again”
Kim also talked about wanting to find help to stop drinking alcohol as drinking alcohol was against her religious beliefs. George also avoided alcohol for a considerable period of time after his initial negative experience.

Section conclusion: Most of the participants drank low amounts of alcohol per sitting. Some had experienced drinking to excess and reported reducing or avoiding alcohol intake afterwards. Participants also reported seeing family members drinking to excess.

6.2.3.2 The effects of alcohol

A common effect of drinking to excess reported by participants, who have had this experience, was having a hangover. Having a headache was the most common symptom of having a hangover. Mary described the feeling of being hungover as feeling “yucky” and tended to stay in bed the next day.

“Yeah, it hurts, and you feel yucky and miserable and you feel yuck.”

John described his one and only experience of being hungover as having a headache. George talked about feeling “sick for days” and not remembering much about his brother’s party. Kim said she felt “horrible” and that it affected her whole body so that she couldn’t move and did not want to go to work the next day.

Interviewer: So when, when you have a hangover, how do you feel?

Kim: Horrible.

Interviewer: Horrible?

Kim: Yeah. Yeah, I don’t want to go to work the next day.

Interviewer: And you say horrible. In what way does it – if you say horrible.
Kim: Well it affects me horribly, basically. When I do Diesel it just affects my whole body. I can’t move.

Interviewer: Apart from not being able to move, in what way does it affect your body?

Kim: just headache and pain.”

The cost of drinking was discussed by participants. George noted that it is getting cheaper to buy at a supermarket than at a local bar.

“Interviewer: What are your thoughts about it getting cheaper and cheaper?

George: Well I just seen it’s more cheaper to buy it, um, at the supermarket and what it is to buy it at a bar...cos I was at the supermarket the other day and a box of 24 was only something like $20 and at the super-, at a - to buy a 24 of Speights, that, at a pub, that can be anywhere up to $30.”

Kim was worried about the cost of drinking and viewed spending money on alcohol as a waste of money leading to children missing out on essentials. She was also worried about the longer term effects of having alcohol readily accessible to children.

“I wouldn’t let my children do that, because you know, it’s gonna affect them later on in life, you know. Once they get older, they’re gonna be alcoholics.”

Keeping safe after consuming alcohol was another issue of concern for some of the participants. George didn’t feel safe catching a bus when drinking and normally chose not to drink out in public as he often needed to use public transport.

“I don’t drink out in public, because I normally have to bus, and I don’t like drinking when I’m bussing. I won’t do that.”
One of his main concerns was ending up in the wrong area if he caught a bus after drinking alcohol.

“Yeah, because I’m always, you know, scared I’ll end up in like Woodend or something.”

Mary also voiced a similar concern about not being able to get home safely. As a result, if she had been drinking at a friend’s place, she would stay the night rather than risk trying to make it home.

“I just tell mum if I’ve had too much to drink, I’m at my friend’s ... If I’ve had too much to drink I can just say to mum, can I please just crash the night here... I’m safe, I’ve had a bit too much. I’ll be home tomorrow. And she said, yeah, that’s cool. Because she doesn’t want me to go roaming the streets.”

Another concern about drinking alcohol expressed by some of the participants was the risk of witnessing and getting involved in fights and arguments, as the following from Mary illustrates:

Mary: People have arguments and fights and...

Interviewer: Have you seen arguments yourself?

Mary: Yeah.

Interviewer: What happened during that argument?

Mary: Just probably like relationships. Someone will say you can’t drink and then someone goes to drink and then they have too much and in the end, they, they just act stupid and hypo.

Another risk mentioned by Sean was having one’s drink spiked.
“I’ve never had it spiked, but I’m just saying, you know, it’s like sometimes you, you can’t always tell, so you sort of think, oh you know, it looks okay and you know. But I mean it’s never happened to me, but you know.”

Section conclusion: Among those who had experiences of drinking to excess, the most common result reported by participants was a hangover. At lower levels of consumption, effects such as feeling relaxed, calm or happy were reported. Keeping safe was an important concern, with a number of adverse effects mentioned such as aggression, having one's drink spiked and not being able to get home safely.
6.3 Microsystems of alcohol use

The experiences and themes described above did not arise in isolation, but occurred in a number of interconnected microsystems or settings. Reviewing the transcripts and themes revealed seven microsystems that provide the context for alcohol use. These are briefly described and outlined below (Diagram 4). A brief description of each of the microsystems is provided in section 6.3.1. Four of the microsystems emerged from the theme of Choices and Influences, while three emerged out of the theme of Context and Location. The theme, Drinking Behaviour, acted as a connecting theme for all the microsystems. Outside of these settings there exist a number of macrosystemic influences that direct, contain and facilitate the experience of alcohol use. The main ones identified for this study are the culture, history, and regulatory environment of alcohol use and the culture, history and regulatory environment of disability. The person with an intellectual disability, who drinks alcohol, is placed at the centre of the model. Not shown are the interconnections with various people within and between each microsystem. These individuals may also belong to more than one microsystem. For example, a member of the person’s social network may also be found in the pub and restaurant microsystem when they both go out on a social activity, which involves a pub or restaurant. Similarly, a family member who catches up with a person at a restaurant of pub will be co-located in the Whanau/Family and Restaurant and Pubs microsystems.

6.3.1 Descriptions of microsystems

Formal support network: The support network is the formal network of individuals, such as volunteers, or employees of a NGO, social activities group, or advocacy group, who support people with an intellectual disability during their daily activities or social outings. The level of involvement depends upon the support needs of the individual. Examples of such individuals include the staff, who provide supported living services in group homes or flats, and the support people who accompany people with an intellectual disability on group social activities such as trips to Hanmer Springs, Ten pin bowling, or group meals at restaurants.
**Whanau/family:** Direct and indirect family members were the primary informal support network. A variety of family structures existed including traditional nuclear families and blended families. Two participants were in stable long term relationships with a partner. Extended family members including aunts, uncles and cousins also formed part of the whanau/family network.

**Social network:** The social network is the system of friends and peers with which the individual may interact and socialise. Examples of the types of social activities mentioned by participants included having drinks after work, going to restaurants with friends and peers and going out for a girls' night at a local bar.

**Spiritual network:** One participant mentioned her church as an informal support network. This microsystem has been included due to its importance to this individual even though she is the only one who belongs to this type of microsystem. This network comprised an uncle and aunt and wider members of the church community, none of whom consumed alcohol. The spiritual network was a source of influence and support for the participant, but also tension when she did not strictly follow the non-drinking beliefs of the community.

**Restaurants and pubs:** Restaurants and pubs are the most common location mentioned for the consumption of alcohol. Individuals may go out with family members and friends to locations such as working men's clubs, local pubs, or restaurants. When frequenting such establishments, participants come into contact with other patrons, bar and restaurant staff and management of the establishment. Many of the establishments provide entertainment such as bands or karaoke in which individuals enjoy participating. Such establishments provide a place for social interaction with peers and other people.

**Cultural, sporting and leisure activities:** Sporting, cultural and leisure events play an important part in giving a sense of belonging to the wider social environment. The variety of such activities are wide and participants mentioned going to concerts and attending sports events such as provincial and international rugby and cricket matches. Given the wide variety of activities reported by participants, the specific nature of networks associated with each activity is highly varied.
**Home**: Home is defined as the location where people live. It may be the home of a participant or a friend or family member. Participants lived in a variety of home settings. This included flatting by themselves, flatting with a peer, living in a group home supported by an NGO, and living with parents and family members. The home environment could be connected with either the formal support network or the whanau/family network.

![Diagram 4 Microsystems of alcohol use](image-url)
6.4. Summary

In this chapter, the process for generating codes from the data was described (Section 6.1) and the resulting themes and sub themes presented (Section 6.2). Three themes were identified from the data, Choices and Influences, Context and Location of Drinking Behaviour and Drinking Behaviour. The three main themes were then synthesised into an egocentric ecological model of alcohol use by study participants. The relationships between each of the main themes were described (Section 6.3) and the microsystems inhabited by study participants, that comprise this system, were summarised. In the next section the relationship between the results of this study and the wider literature will be discussed, and the study’s implications explored.
7. Discussion

In this section the implications of the results will be discussed and explored in more detail. The experience of alcohol use encompasses a number of interconnected settings and involves social, relational and psychological aspects. Milner and Bray (2004), in their exploration of the level community participation among people with disabilities, use the words “complex” and “complexity” 21 times to describe their experience. Such a view, it was argued, is also true of the experience of alcohol use by the people interviewed for this study. They inhabit a multi-layered world and interact with a wide variety of people in a variety of settings. They are subject to a range of influences and have to make multiple choices about how to navigate a complex and changing world. Their experience of alcohol use is but a small part of this larger world. However, as it is being deeply embedded in a complex web of relationships, it cannot be understood apart from the context in which these choices are made.

This study utilised the networked ecological framework of Neal and Neal (2013) to fathom these interrelationships and complexities. This framework provided a visual reference tool for understanding each of the settings and locations of alcohol use and how they are related. It also provided a framework for locating and linking the three main themes identified within this study, drinking behaviour seen as a linking theme. The main limitation found in utilising this approach was that it was not possible to identify and describe in any detail the individuals who formed nodes in a specific microsystem and the strength, direction, and of type of communication that takes place from the qualitative data. It was possible to make some qualitative observations about the strength and protective power of individuals in a person’s social, support, and family networks, but some degree of caution needs to read into how these relationships are interpreted. There might also be other microsystems, not identified by the data, which have an important role to play in the experiences recounted by participants. Additionally, there may be relationships within a given microsystem not identified by the interviewees or missed by the researcher as a result of answers not adequately explored during the interviews, or missed during the analysis of the transcripts.

There was always the risk of reading more into the data than that intended by participants, or missing data due to certain sections of the interviews being inaudible, or difficult to interpret. The transcription protocol developed from the protocol of McLellan, MacQueen, and Neidig, (2003)
aided the transcription process and mitigated some of the problems encountered in dealing with difficult sections of the audio file and in producing consistent written records of the interviews. As mentioned in the methods section, interpretation of the interviews requires one to enter the hermeneutic circle of understanding, and this process begins right from the start of interviewing and transcription of the audio file (Kowal & O’Connel, 2014; Rennie, 2000). Understanding, as Ricouer (1991) observed, involves appropriation of the text and results in a change in one’s self understanding. The themes and networked map of the relationships involved in the experience of alcohol use are all outputs of this appropriation of the transcripts and changed self-understanding.

Even though the sample was a relatively homogenous group and there were a range of experiences which could be grouped together into common themes there were also significant individual differences in experiences. Within the critical realist perspective adopted for this study, the existence of commonalities and individual variation was unsurprising. They can be explained utilising the concept of demi-regularities (Lawson, 1998), the somewhat patterned emergence of behaviour due to the openness of the social structure which participants inhabited, and the interaction of the underlying generative mechanisms that give rise to the structures and behaviours reported on within this study.

7.1 Patterns of consumption

While some of the study participants engaged in occasional incidents of binge drinking, the most common experience was one of moderate, non-pathological consumption of alcohol. This is a result that is consistent with the literature cited in this study, viz. that consumption levels tended to be lower for people with an intellectual disability compared to the general population (for example, Burgard et al., 2000; Cocco & Harper, 2002; Degenhardt, 2000; Delany & Poling, 1990; Moore & Polsgrove, 1991). However, much of the published literature on alcohol use by this group has focused on those who consumed alcohol to excess rather than the patterns of low alcohol use reported in this study (DiNitto & Kristchef, 1984; Kritschef & DiNitto, 1981; McLaughlan et al., 2007; Shawna et al., 2011; Taggart et al, 2007; To et al., 2014). These studies also tended to emphasise and report on the adverse life impacts of alcohol use, such as co-existing mental and physical health problems, problems with relationships problems with the law and work problems - none of which featured in the comments of the participants in this study - and not the social role of moderate alcohol use. Three studies examining the level of alcohol consumption by people with an intellectual
disability which reported low to moderate use in line with this study were found (McGuire et al., 2007; Rimmer, Braddock, & Marks, 1995; Robertson et al., 2000). All three studies included alcohol use as part of a wider investigation into health status and behaviours of people with an intellectual disability, not as the primary phenomenon of interest. Drinking to cope with stress or life problems was not a major reason for drinking. Only one participant in this study cited this as one of the reasons they drank. This result contradicts the findings of previous research which identified stress and trauma as significant influences on drinking behaviour (Baker, 2006; Rivinus, 1988; Shawna et al., 2012; Taggart et al., 2007; Westermeyer et al., 1988). The results of this study provide some support for the view that there is a bias in the literature towards studying and reporting on pathological usage (Barret & Paschos, 2006; Simpson, 1998; Slayter, 2008). Consistent with the view of Simpson (1998, 2012) participants in this study drank alcohol while socialising with family and friends, not as a coping mechanism or to be accepted by non-disabled peers.

Participants’ trajectory of initiation and subsequent drinking behaviour appears to follow a significantly different path compared to that of their non-disabled peers. A common pattern for initiation to drinking alcohol in New Zealand is sipping alcohol from nine years of age or younger, progressing to drinking alcohol by age 15 with the quantity of alcohol being drunk increasing dramatically between age 13 to 15 (Casswell, Stewart, Conelly & Silva, 1991). From age 18 to 26 non-disabled peers follow a path of increasing quantity per session up to the early 20s followed by a decline in quantity per session, while the frequency of sessions per year increases linearly throughout this period (Casswell, Pledger, & Prataps, 2002). Consistent with the overseas literature on the age of initiation for people with an intellectual disability to drinking alcohol (Emerson & Turnbull, 2005; Huang, 1981), the age of initiation amongst participants tended to be much later. A common pattern for participants was initiation in their early twenties in the context of a family celebration. Even where the initiation was younger, the primary context was with parents or older members of the family rather than with peers. In line with overseas literature on the location of drinking by people with an intellectual disability (DiNitto & Kristchef, 1984; McCrystal et al. 2007; To et al, 2014), consumption of alcohol occurred in a wide range of physical locations including home, friends’ places, and pubs. These locations were similar to that for non-disabled peers (Connelly, Casswell, Stewart & Silva, 1992).

The results also suggest that there is a generational difference in the drinking patterns and preferences of the younger participants compared to older participants. Those in their 20s were
more likely to prefer RTDs compared to older participants who preferred wine and beer. Such a
genерational change is consistent with that noted by Valentine, Holloway and Jayne (2010) in their
investigation of generational patterns of consumption. There are, however, some important
differences. Valentine et al. (2010) noted that the young generation of drinkers prefer spirits and
RTDs while the mid generation preferred wine and beer. A significant difference between the
younger participants in this study and the non-disabled peers researched by Valentine et al. is that
the non-disabled younger generation tended to drink to get intoxicated whereas for both younger
and older participants in this study, drinking was a social activity which fitted more closely to the
patterns of Valentine’s mid generation of alcohol drinkers.

7.2 Environmental influences

Outside of the direct network variables, there are environmental factors that also potentially
influenced the drinking behaviour of participants. Two that were identified as forming an important
background and context for this study are the twin cultures of alcohol use and the movement to
community living for people with an intellectual disability. Given their position in forming the
context for this study, a couple of brief comments will be made on these factors.

7.2.1 Movement to community living

None of the participants discussed any experience of living in formal institutions. The younger
participants would have all lived their whole lives in an environment of post institutional care where
services were delivered in community settings. Even for the oldest of the participants who would
have lived in the shadow of deinstitutionalisation, community living is the dominant experience.
Within their residential setting, participants receive a range of services to support them in decisions
about how they lived their lives and the activities they engaged in. The process of recruitment of
participants revealed a wide range of organisations engaged in supporting people with an
intellectual disability, ranging from small localised service providers to large national bodies. The
structure of these providers ranged from kaupapa Māori, religious based organisations, private
companies and charitable trusts. Apart from the organisational diversity of service providers, there is
also a high level of variation in the range of services provided, from day services, respite care, to full
residential support.
For all the participants in this study, support people played an important role in determining how much independence they had and the choices they made across a broad range of circumstances. This is consistent with the wider literature on the role played by carers, support staff and service management with respect to how people with an intellectual disability exercise autonomy and make choices about how they want to live their lives (Harris, 2003; Simplican et al., 2015; Smyth & Bell, 2006). Their choice about where and how they consumed alcohol was just one of a range of such choices they made and was facilitated by the level and type of support they received. The type of support is, in turn, affected by the policy and funding environment in which these services are delivered. As noted in the context section of this thesis, there are significant shifts in the policy and funding environment with the development of a more person centric funding model for support services (Ministry of Health, 2015). It is uncertain, at this stage, how this will affect individuals such as those who participated in this study, particularly with respect to choices about alcohol use.

7.2.2 New Zealand’s drinking culture and regulation

As noted in the study background, New Zealand has developed a “dry” culture in which binge drinking is common and tolerated (BRC Marketing and Social Research, 2004; Cagney & Cosar, 2006). Given the pre-eminence given to alcohol and sports, and the associations with Carnavalesque culture, as well as its attachment to other images of traditional New Zealand culture as evinced in the Southern man campaign, it was somewhat surprising that these symbols were not identified as an influence on the choices about alcohol by the majority of the participants in this study. Only one participant, acknowledging excessive alcohol consumption as a normal part of such events, alluded indirectly to these cultural images. Furthermore, the role of advertising and promotion, which seems to play an important, if debated, role in choices about alcohol in the general population, was hardly mentioned by participants. When mentioned, portrayals in the media were often seen in a negative light. One possible reason for this result might be the history and culture of intellectual disability. People with an intellectual disability have a history of marginalisation and stigmatisation (Bray, 2003; Tower, 2003). They may, therefore, not relate to the messages and images of the dominant culture and, as a result, sit outside its sphere of influence, or the influence of such cultural messages might be weaker for this group compared to members of the dominant culture. Instead, other influences more closely tied to their experiences and lives, particularly the role of close members of their family, social, spiritual and support networks, in conjunction with a different developmental pathway for people with an intellectual disability, might play a larger role in the development and maintenance of their attitudes and beliefs regarding alcohol consumption. The role of the social and
support networks, as well as individual experience, will be discussed in more detail in subsequent sections.

### 7.3 Family, social, spiritual, and support networks

In a linked world of relationships the idea of “six degrees of separation” has entered popular consciousness. It is an idea that everyone is connected to everyone else by no more than six links in a chain of relationships. What is now becoming increasingly apparent is the power of influence in such networks. Influence extends beyond a single link to multiple degrees of separation (Christakis & Fowler, 2013). Christakis and colleagues explored this relationship across a range of phenomena including obesity, smoking, sleep, marijuana use, alcohol use, divorce, and cooperation. In their investigations they found the degree of influence held from two to four degrees depending upon the phenomena they investigated, that is from a friend of a friend to a friend of a friend of a friend of a friend. For alcohol use, the degree of influence extended up to three degrees of separation (Rosenquist, Murabit, Fowler, & Christakis, 2010). Three factors, which influence the uptake and spread of a behaviour in a social network, were identified by Rosenquist et al. (2010). The first is induction, which represents the spread of behaviour through a network. The second is homophily, which is the tendency for like to attract like. The third factor is confounders, which are mutually shared environmental factors. The pertinent idea here is that when people are connected, their behaviour is also connected. Thus, people who engage in drinking alcohol to excess are likely to congregate around, and be connected to, people who drink to excess. Similarly, individuals who are more moderate drinkers or abstainers are likely to be connected to individuals who are moderate drinkers or abstainers.

The social and support networks are then a key to understanding a behaviour such as experiences and patterns of alcohol consumption and how that behaviour is influenced. Living in the community for people with intellectual disability is highly complex, with many opportunities and risks that need to be navigated (Milner & Bray, 2004). A strong social and support network is an important protective factor mitigating behavioural risk factors and aiding physical, social, and mental health (Heaney & Israel, 2008). According to Heaney and Israel, such support networks provide a number of functions including social capital, social influence, companionship, and support. Prosocial involvement with family and peers are important protective factors mitigating the risk of alcohol misuse (Monahan, Oesterle, Rhew, & Hawkins, 2014; Stickley et al., 2013). For participants in this...
study, family members, peers and support staff provided the social and functional support to enable them to function in a complex social system and modelled prosocial ways of behaving including the modelling of more moderate patterns of alcohol consumption. As a result they were positively connected to society as well as to their family, which minimised the risks of marginalisation and pathological drinking behaviour. This influence was not just one way. They were also able to model lower levels of alcohol consumption to their peers and reinforce amongst their peer group less risky drinking behaviours. Furthermore, this group may have formed linked communities with their social and peer groups, where lower levels of consumption are normative compared to that found in other groups in the wider society.

This modelling of prosocial behaviour by the participant’s family, support and social networks is consistent with a social learning perspective on the role of modelling in learning adaptive behaviours. Within social learning theory, the modelling of behaviour involves an active acquisition of new cognitive skills and behavioural patterns (Bahn, 2001). This acquisition of new skills involves the mutual interaction of both the external and internal world of the person (Grusec, 1992). Central to learning is the mechanism of reciprocal causation, which is a three way interaction between the person, the environment and the behaviour (Osmond, 2010). Individuals are seen as active learners, who refine their beliefs based on experience, within this interaction. Since observation is a more efficient way of learning compared to trial and error, modelling the behaviour of those in one’s close social group is an efficient and effective means of learning adaptive behaviour, and is achieved by a combination of symbolic, vicarious and self-regulatory processes (Bahn, 2001).

According to Bandura (2010), four conditions need to be present for successful modelling to occur. Firstly, there is the attentional process in which the learner pays close attention to what is being observed. Secondly, there is the process of retention in which observations are accurately retained via internal representations and codes. Thirdly, there is the condition of reproduction in which the person is able to reproduce the observed behaviour. The final condition is motivation in which the observer possesses the motivation to replicate the observed behaviour. Observing and learning prosocial behaviour leads to self-regulation in which the individual inculcates the results of their observations according to which behaviours are beneficial and acceptable, and applies this learning to their lives.
The protective power arising from the modelling of prosocial behaviours by members of an individual’s family, social and support network found in this study is consistent with the insights of Hillman et al. (2013) who investigated the social networks of people with an intellectual disability. According to Hillman et al., healthy support networks served to actively support the person with an intellectual disability. The key attributes of a support network found by Hillman et al. were that firstly, the person with an intellectual disability was positioned at the centre of the network. Secondly, members of the network maintained a positive and respectful relationship with the aim of maximising the autonomy of the person with an intellectual disability. Thirdly, members acted as mentors and facilitators who modelled a number of behaviours. Finally, network members provided opportunities for ongoing learning and development mediated through experiences, relationships, and roles.

Widmer et al. (2008) also provided evidence for the protective power of social relationships for people with an intellectual disability. They identified two types of relationships within the social network. The first was binding social capital found in family based networks, which tended to be dense with low individual centrality. The second was friendship based networks, which provided bridging capital, important in seeking innovative solutions to problems and issues. Membership of a social network provided links to other people and social resources (Gottlieb, 1985). Bigby (2008) investigated the role of social networks and found that informal support networks, based on personal ties with family, friends, and neighbours, were an important protective factor. Where an adequate social network existed, it was positively associated with a higher quality of life (Lunsky & Benson, 2001; Van Asselt-Goverts, Embregts & Hendriks, 2015).

While positive role models are an importance source of prosocial learning, individuals also observe and learn from the negative behaviour of others and its consequences (Bandura, 2010). Examples of learning from the negative behaviour of others cited by participants in this study included situations such as seeing people intoxicated on the street or in pubs they frequented or witnessing the negative consequences of alcohol misuse by people in their family and social networks. Bandura (2010) also notes the increasing importance of electronic media in learning and acculturation. Many of the participants were able to discuss the negative examples they saw on TV, reflect on what they had observed, and make judgements about the consequences of the observed behaviour. Participants inculcated these observations and negative judgements about the consequences of
excessive alcohol consumption into their choices about their alcohol consumption, reinforcing more moderate patterns of consumption.

While participants in this study tended to have strong and supportive social networks that acted as a strong protective factor, this is not the case for all people living in the community. Many suffer from high levels of social exclusion, with staff and health professionals comprising their principle social and support network (Bigby, 2008; Bray & Gates, 2003; Forrester-Jones et al., 2005; Lippold & Burns, 2009; McConkey & Collins, 2010). Amando, et al. (2013), who investigated social inclusion and community participation for people with intellectual disability, noted that a number of this group experience loneliness. Amando et al. (2013) also observed that age and degree of disability were important factors in increasing the level of exclusion; increased age and level of disability associating with higher levels of social exclusion.

While the construction of social inclusion can be seen as an important protective factor, it suffers from a lack of precision as to what it means and where its boundaries lie. Simplican, Leader, Kosciulek, and Leahy (2015), for example, after reviewing the literature on social inclusion, found that social inclusion can be either broadly or narrowly defined and occurred across a number of different settings. Simplican et al. (2015) argued that social inclusion needs to incorporate the interrelated domains of interpersonal relationships and community participation. Despite its lack of precision, social inclusion is regarded as an important goal existing across the domains of interpersonal relationships within a social network and community participation in leisure activities, civil activities and access to the full range of societal services (Bray & Gates, 2003; Simplican, et al. 2015). In its absence, feelings of powerlessness and fatalism may arise (Heyman, Swain, Gillman, Handyside, & Newman, 1997). Feelings of powerlessness may also arise when there is a disconnection between an individual’s preferences and choices and what happens in their daily lives (Harris, 2003). For individuals with an intellectual disability, this opportunity to make fully autonomous choices is often missing (Smyth & Bell, 2006). Powerlessness and social isolation have been identified as risk factors for alcohol misuse (Baker, 2006; Krisf & DiNitto, 1981; Taggart et al, 2007; To et al., 2014). Other risk factors for alcohol misuse, closely tied to powerlessness and social exclusion identified by researchers in the area of alcohol misuse and intellectual disability, include family history, unemployment, social economic factors and poor social skills (Barrett & Pashos, 2006;
Brown & Coldwell, 2006; Cocco & Harper, 2002; Cosden, 2001; Degendhart 2000; Huxley et al., 2005; Mayer, 2001; Slayter & Steenrod, 2009).

7.4 Developing internal rules

Many of the participants followed internalised rules of behaviour that guided their decisions about how, when and where alcohol is consumed as well as negative judgements about excessive consumption of alcohol. The internalised rules tended to be highly concrete in nature and were strongly associated with their respective stage of moral development. It was found that the orientation of “keeping the rules” closely conformed to Kohlberg’s (1973) stage three and four of moral development. These stages emphasise loyalty to the prevailing social order and authority figures. The orientation towards authority figures is also consistent with the exercise of valuational agency (Herr, 2010). Stage three involves interpersonal concordance (good girl/good boy), approval of one’s behaviour by others, conforming to stereotypical behaviour and earning approval of others. At stage four there is an increasing orientation towards law and order and to rules and maintaining social order. Moral development involves the appropriation of moral principles and rules (Brugman, Keller, & Sokol, 2013) and is related to intelligence level (Gibbs et al. 2007). For people with an intellectual disability, moral development tends to be attenuated and progresses at a slower rate compared to age matched non-disabled peers (Langdon, Claire, & Murphy, 2010). Langdon et al. also noted that mental age is an important predictor of moral development, with behaviour correlated to the level of moral reasoning among people with an intellectual disability. Parents, significant others, authority figures and members of the participants’ spiritual community act to facilitate and reinforce the development of this rule based approach to moral development across a number of domains. These include the domains of autonomy which emphasises personal agency, community which emphasise communities and social groups, and divinity which emphasises transcendent spiritual values (Jensen, 2007). Furthermore, according to Jensen, moral reasoning takes place in the twin lenses of moral development which address the developmental context, and the cultural which emphasises the influence of the external culture. The resulting internalised rules and principles, it is believed, act as a protective factor reinforcing low levels of consumption, thus minimising the risk of pathological drinking amongst study participants.
7.5 Learning from negative personal experiences

Participants, despite their cognitive limitations, exhibited an ability to reflect upon their experiences of alcohol consumption and make personal judgements about alcohol use. In so doing they were exercising their autonomy and individual agency in a supported environment. One way in which this was manifested amongst participants was changing their behaviour in response to a negative experience of alcohol use, either personally, or by a person in their social environment such as a close family member. Two of the participants made long term changes to their drinking behaviour after respective incidents of drinking to excess following their initiation to alcohol. Both experienced bad hangovers after their respective episodes of binge drinking with one reporting memory loss. Other participants who reported incidents of drinking to excess reduced their alcohol intake for a period of time.

This aversion to drinking alcohol after a negative experience is consistent with the development of a conditioned taste aversion. A conditioned taste aversion (CTA) is a conditioned response to a particular food item that arises from an unpleasant experience following consumption of the item (Kimball, 2010). A common pathway for development of CTAs study is gastrointestinal distress after eating or drinking an item, although other negative experiences also result in CTAs. CTAs are more likely with novel experiences, as was the case with the two participants who suffered a major hangover after their initiation to alcohol, and tend to be robust (Berstein & Webster, 1980). It is hypothesised that conditioned taste aversions develop as a protective response to ensure avoidance of toxins (Bernstein & Webster, 1980) and involve the cholinergic and glutamatergic systems (Welz, D’Armo, & Lipp, 2001). For self-administered psychoactive substances such as alcohol, the development of CTAs are complex, reflecting drug shyness, and form a distinct class of CTAs separate from that produced by food based toxins (Hunt & Zalman, 1987). The response to the initial experience can influence future use, but the evidence is complex and subject to a high level of individual variation (de Wit & Phillips, 2012). For those participants who had a negative experience with alcohol, their differences in responses to alcohol use, both in the short and longer term, are consistent with de Wit and Phillips’ observation.
While a negative experience to alcohol may lead to the cessation of drinking alcohol in the short term, all participants who reported a negative experience eventually returned to drinking alcohol in the longer term. This suggests that the CTA to alcohol had experienced extinction. Extinction is the situation where there is a decrease in the level of responding to a conditioned stimulus (Lattal & Lattal, 2012). It arises out of an experience in which a prediction that a conditioned stimulus will lead to an unconditioned stimulus, fails to eventuate (Delamer, 2012; Lovivond, 2003). In the case of drinking alcohol, this may be a prediction that drinking an alcoholic drink will lead to hangover including nausea, vomiting, and a headache which some of the participants in this study experienced. However, at low levels of consumption the resulting negative consequences may not eventuate, leading to a falsification of the prediction, creating the environment for extinction to occur. Extinction of any conditioned learning, such as a CTA to alcohol, does not mean that the original learning has been forgotten. Rather, extinction is a form of new learning that overrides existing learning (Bouton, 2002; Lovivard, 2003) and is a process distinct from acquisition (Meyers & Davis, 2002). Furthermore, extinction is not solely dependent upon prediction error, but may also arise via observation or verbal instruction (Lovivard, 2003). The extinction of CTAs may also be influenced by context and presence of cues (Colins & Brandon, 2002). Extinction of a specific behaviour need not be permanent, but may re-emerge under certain conditions (Berman, Harvey, Stehberg, Bahar, & Dudai, 2003; Bouton, Winterbauer, & Todd, 2012).

The conclusion from the above discussion is that the alcohol induced CTA, which participants developed after a bad experience, was a protective response which is subject to a number of complex influences and processes. Even when CTAs arose, they exhibited extinction as evidenced by a return to drinking alcohol after a period of time had elapsed. The extinction of the CTA to alcohol did not erase the original learning but overrode it, thus there is the potential for the CTA to recur under the right circumstances.

7.6 Keeping safe

The desire to keep safe while drinking alcohol arose in a number of interviews. Consuming alcohol requires an assessment of the risks and benefits associated with this activity. It is an exercise in personal agency and autonomy and requires a mature and well developed awareness of both transparent and hidden risk if the risk of harm is to be minimised. However, intellectual disability is associated with poor risk awareness, particularly of the more subtle and hidden risks placing this
group at increased risk of personal or social harm (Greenspan, Switzky, & Woods, 2011). This risk unawareness can result in either highly impulsive behaviour or over estimation of the risks associated with an activity or behaviour. The normal development of risk awareness and assessment skills follows a common pathway through adolescence into adulthood, which is hypothesised to be mediated via dual neurobiological systems comprising the affective and cognitive systems (Smith, Chen & Steinberg, 2013). During adolescence the maturing brain is remodelled, middle adolescence seeing the development of the cognitive system resulting in increased connectivity between cortical and sub cortical regions of the brain (Steinberg, 2008). Late adolescence to early adulthood sees a reduction in sensation-seeking, impulsivity and reward-seeking behaviour, compared to early to mid-adolescence (Steinberg, 2010). The social context moderates this pathway with risk perceptions changing in the presence of the influence of a peer group (Knoll, Magis-Weinberg, Speekenbrink, & Blakemore, 2015). The presence of peers can increase risk taking behaviour (Chein, O’Brien, Uckert, & Steinberg, 2011). Adolescents may engage in risk taking behaviour to gain social acceptance from the peer group (Willoughby et al. 2014), and continue to take risks in the presence of peers even when the risks of adverse outcomes are known (Smith, Chein, & Steinberg, 2014). In the mature brain, both cognitive and affective systems are involved in risk assessment and behaviour (Hoffman, Friese, & Stack, 2009). Cognitive capacity acts as a limit on risk assessment capability with higher cognitive load and lower working memory implicated in higher levels of impulsive behaviour.

For people with an intellectual disability, the normal cognitive and risk assessment developmental pathway is, however, disrupted as indicated by the lower level of cognitive functioning, poorer retrospective and prospective memory, attenuation of moral development and lower mental age (Langdon, Claire & Murphy, 2010; Meilan, Perez, Arana, & Carro, 2009). Furthermore, social integration with a peer group tends to be adversely affected by the presence of intellectual disability leading to lower status and exclusion from non-disabled peer groups (Estell, et al., 2008). Thus, the influence of a peer group on risk assessment and risk taking behaviour may not be as pronounced as for non-disabled peers or follow a different pathway. While this developmental attenuation and social exclusion may result in higher levels of impulsivity, it can also lead to higher levels of risk aversion due to an over estimation of the possible harm resulting from an activity (Greenspan, Switzky, & Woods, 2011). Such risk aversion may, therefore, lead to making choices that lower the level of perceived risk in an attempt to stay safe and avoid getting into danger. The aversion of one of the participants to drinking if they had to catch public transport is an example of making choices to minimise perceived risk. Thus, this risk aversion resulting from an over estimation of risk is
hypothesised to act as a protective factor, minimising the risk of the individual with an intellectual disability making choices about alcohol use that places them at increased probability of harm.

7.7 Limitations and methodological issues
As in all studies, there are a number of limitations that need to be considered when evaluating the results. The first limitation was the small sample size. Ten participants were interviewed for this study, which may limit the range of voices incorporated into the study. The second was the homogenous characteristics of the group who were interviewed for the study. The majority of the participants were Pakeha with two of mixed Pakeha/Pacific Island ethnicity. A major weakness was the lack of Māori and Asian participants. Given the recent experience of Māori and alcohol (Awatere, et al., 1984; Hutt, 1999; Mancall, et al., 2000), the lack of Māori participants limits the ability to make any comment on the relevance of this study to Māori. Asians are an increasingly important population. Recent projections by the New Zealand Department of Statistics (2015) have Asians growing from 12.2% of the New Zealand total population (2013 base) to 20.9 % of the projected total population in 2038 and the lack of an Asian voice places similar limitations about commenting on an increasingly important group. Participants were recruited from only two organisations and are unlikely to be representative of the range of experiences of all people with an intellectual disability. Individuals in a forensic institution or forensic community provider were excluded due to potential ethical conflicts with the researcher owing to his current place of employment. Based on overseas research, such individuals are more likely to consume alcohol and consume alcohol to hazardous levels. The nature of qualitative research is that the results are not intended to be generalised in the same way as quantitative studies. As noted in the introduction to the discussion, there is always the risk that the researcher failed to ask pertinent questions or failed to follow-up on answers in sufficient depth. Concomitant with this is the risk that the researchers own voice might dominate the analysis of the results. Interviewing people with an intellectual disability can be challenging due to communication difficulties and answers were often sparse and needed considerable interpretation, leading to the possibility of misinterpretation. Also, the level of moral development, being at the good boy/girl stage might have inhibited participants from sharing more negative experiences or to underreport the level of alcohol consumption.

The qualitative software analysis package, Nvivo, was utilised for this study. While it aided in the management of transcripts and identifying extracts, it was at times frustrating to use, lacking the
flexibility to handle the data in the way the author wanted. The cluster analysis tool was used in the initial stages to help group the codes and while initially showing promise, it proved to be too limited and unreliable to be of value. The clusters produced were unstable and lacked consistently meaningful linkages to be useful.

7.8 Areas for further research and development

The context of the study was post institutional community based living. More research is required to better understand the challenges of community living by this group, especially the barriers to belonging and inclusion. The role of the social and peer network were identified as important protective factors. More research into the role, structure, and behaviour of such networks for people with intellectual disabilities would be beneficial. Individuals with a forensic background were excluded because of a potential ethical dilemma of a conflict of roles with the researcher, but there is potential for expanding the study to include their experiences in the future, if adequate ethical safeguards can be developed. The study found no clear voice of people with intellectual disability in the development of alcohol policy. Further research into how to enable this group to better engage in the informing of policy is recommended. While none of the participants showed consistent levels of pathological use, this may not be the case for all people with an intellectual disability. At the moment, though, there is, to the writer’s knowledge, no up to date assessment tool or intervention tailored to this population. Development of such tools is recommended. The literature has made some suggestions, but research into the effectiveness of the interventions is lacking and group based interventions based on AA tend to be ineffective. A peer to peer intervention based on the Stepping Stones model (Oxnam & Gardner, 2011) might hold some promise and deserves further investigation. Further investigation into the role of the media and advertising in influencing the behaviour and choices of this group may also be a fruitful area of research. Investigating the role of risk assessment and risk aversion of people with an intellectual disability is also a fruitful avenue for further research. Additionally, the impact of cultural and societal attitudes towards people with an intellectual disability and the perspectives of family, peers and their respective social networks needs investigation.
7.9 Conclusion
This study attempted to fill the gap in the literature on alcohol use among people with an intellectual disability. Working from within a critical realist perspective, three themes were identified, Choices and Influences of alcohol use, Context and Location of alcohol use, and Drinking Behaviour. Applying the networked ecological model of Neal and Neal (2013), it was argued that the experience of alcohol consumption occurred within seven microsystems. In making choices about alcohol use, it was suggested that participants exercise valuational agency within the context of constrained autonomy. Consumption levels among participants were generally low, with limited experience of binge drinking or long term adverse effects from drinking. Four protective factors were suggested that mitigated the risk of pathological alcohol consumption. These are the protective power of family, social and support networks, learning from negative experiences, internalisation of rules, and risk aversion. A number of areas of further research were identified.
8. References


URL:http://www.academia.edu/321587/Substance_Misuse_Amongst_People_With_Learning_Disabilities


Office of Disability issues (2014). *Towards an inclusive and enabling New Zealand*. Wellington: Author


Interview schedule

1. Tell me about the first time you drank alcohol?
   - Age
   - Location
   - With whom
   - How accessed
   - What type of drink
   - How much
   - Effects

2. Where did you first learn about alcohol?
   - Family & Friends
   - Newspaper
   - TV/Radio
   - Other

3. Where do you get information about alcohol now?
   - Family & Friends
   - Newspaper
   - TV/Radio
   - Other

4. Tell me about drinking of your parents, brothers, sisters, other members of your whanau?
   - Location
   - With whom
   - How accessed
   - What type of drink
   - How much
   - Effects

5. Now tell me about your current experiences of drinking alcohol?
   - Location
   - With whom
   - How accessed
   - What type of drink
   - How much
   - Effects
6. What do you enjoy about drinking alcohol?
- Give me a buzz
- Makes me happy
- Helps me relax
- It helps me fit in
- Share with family, friends, sports events, social activities
- Tastes good

7. What if anything do you don’t enjoy about alcohol?
- Gives me a headache afterwards
- Makes me feel sick
- Sometimes it makes me want to vomit.
- I forget what I did
- I lose control
- I get into trouble

8. What problems have you ever had from drinking alcohol
- Fights with my partner/boyfriend/girlfriend
- Fights with my parents & family members
- Fights with friends
- Fights with other people
- Getting into trouble with the police
- Running out of money, not being able to pay bills, pay rent, buy groceries
- Being exploited/ used by others
- Being assaulted
- Losing things
- Having things stolen from me
- Health problems

9. Have you drank too much?
- When and where
- Attempted to cut down/stop drinking
- Approached others for help with drinking
- Been to AA other self-help groups
- Interventions been helpful/not helpful

10. Has someone close to you ever thought you drank too much?
- When and where
- Attempted to cut down/stop drinking
- Approached others for help with drinking
- Been to AA other self-help groups
- Interventions been helpful/not helpful
Data Preparation and Transcription Protocol

TEXT FORMATTING

General Instructions
The transcriber shall transcribe all individual and focus group interviews using the following formatting:
1. Arial 10-point face-font
2. One-inch top, bottom, right, and left margins
3. All text shall begin at the left-hand margin (no indents)
4. Entire document shall be left justified

Labeling for Individual Interview Transcripts

Individual interview transcript shall include the following labeling information left justified at the top of the document:

Example:

Participant ID:
Interview Name:
Site/Location:
Date of Interview:
Interviewer ID:
Transcriber:

The transcriber shall insert a single blank line between the file labeling information and the actual interview transcription.

The interviewee and interviewer ID will be left justified and placed on the left hand side of the transcript and transcribed using single spacing. Interviewer and interviewee comments will be separated by a single line.

Example:
Participant ID: IE01
Interview Name: Experience of alcohol use Interview
Site: P
Date of Interview: 15/02/2015
Interviewer ID: IV01
Transcriber: John Smith

IV01: OK, before we begin the interview itself, I’d like to confirm that you have read and signed the informed consent form, that you understand that your participation in this study is entirely voluntary, that you may refuse to answer any questions, and that you may withdraw from the study at anytime.

IE01: Yes, I had read it and understand this.

IV01: Do you have questions before we proceed?
In addition, the transcriber shall indicate when the interview session has reached completion by typing END OF INTERVIEW in uppercase letters on the last line of the transcript. A double space should precede this information.

Example:

IV01: Is there anything else that you would like to add?
IE01: Nope, I think that about covers it.
IV01: Well, thanks for taking the time to talk with me today. I really appreciate it.

END OF INTERVIEW

IDENTIFYING OF INTERVIEWEE BY TRANSCRIBER

If transcriber during the course of a transcribing the interview suspects they recognise the interviewee then they will cease transcribing the interview and another transcriber will be contracted to undertake the transcription of the interview.

DIGITAL AUDIO SOURCE FILE NAME

Digital audio files of interviews will be saved and provided to the transcriber in the following format. An “SAF_” precursor which designates file as the interview audio source file, followed by an alpha character that designates the data collection site/location followed by the individual’s two-digit identification number (e.g., SAF_PI00 = People First interviewee #100).

Example:

Site designators for individual interviews are:
P = People First interviews
C = Community Connections interviews
T = Te Ara Toiora interviews

CONTENT

Digital audio files of interviews shall be transcribed verbatim (i.e., recorded word for word, exactly as said), including any nonverbal or background sounds (e.g., laughter, sighs, coughs, claps, snaps fingers, pen clicking, and car horn).

- Nonverbal sounds shall be typed in parentheses, for example, (short sharp laugh), (group laughter), (police siren in background).
- If interviewers or interviewees mispronounce words, these words shall be transcribed as the individual said them. The transcript shall not be “cleaned up”
by removing foul language, slang, grammatical errors, or misuse of words or concepts. If an incorrect or unexpected pronunciation results in difficulties with comprehension of the text, the correct word shall be typed in square brackets. A forward slash shall be placed immediately behind the open square bracket and another in front of the closed square bracket.

Example:
I thought that was pretty pacific [/specific/], but they disagreed.

☐ The spelling of key words, blended or compound words, common phrases, and identifiers shall be standardized across all individual and focus group transcripts. Enunciated reductions (e.g., betcha, cuz, 'em, gimme, gotta, hafta, kinda, lotta, oughta, sorta, wanna, coulda, could’ve, couldn’t, couldn’ve, couldna, woulda, would’ve, wouldn’t, wouldn’ve, wouldna, shoulda, should’ve, shouldn’t, shouldn’ve, shouldna) plus standard contractions of is, am, are, had, have, would, and not shall be used.

☐ Filler words such as hm, huh, mm, mhm, uh huh, um, mkay, yeah, yuhuh, nah huh, ugh, whoa, uh oh, ah, and ahah shall be transcribed.

☐ Word or phrase repetitions shall be transcribed. If a word is cut off or truncated, a hyphen shall be inserted at the end of the last letter or audible sound (e.g., he wen- he went and did what I told him he shouldn’ve).

Inaudible Information

The transcriber shall identify portions of the audiotape that are inaudible or difficult to decipher. If a relatively small segment of the tape (a word or short sentence) is partially unintelligible, the transcriber shall type the phrase “inaudible segment.” This information shall appear in square brackets.

Example:
The process of identifying missing words in an audiotaped interview of poor quality is [inaudible segment]. If a lengthy segment of the tape is inaudible, unintelligible, or is “dead air” where no one is speaking, the transcriber shall record this information in square brackets. In addition, the transcriber shall provide a time estimate for information that could not be transcribed.

Example:
[Inaudible: 2 minutes of interview missing]

Overlapping Speech

If individuals are speaking at the same time (i.e., overlapping speech) and it is not possible to distinguish what each person is saying, the transcriber shall place the phrase “cross talk” in square brackets immediately after the last identifiable speaker’s text and pick up with the next audible speaker.
Example:

Turn taking may not always occur. People may simultaneously contribute to the conversation; hence, making it difficult to differentiate between one person’s statement [cross talk]. This results in loss of some information.

Pauses
If an individual pauses briefly between statements or trails off at the end of a statement, the transcriber shall use three ellipses. A brief pause is defined as a two-to five second break in speech.

Example:

Sometimes, a participant briefly loses . . . a train of thought or . . . pauses after making a poignant remark. Other times, they end their statements with a clause such as but then . . . .

If a substantial speech delay occurs at either beginning or the continuing a statement occurs (more than two or three seconds), the transcriber shall use “long pause” in parentheses.

Example:

Sometimes the individual may require additional time to construct a response. (Long pause) other times, he or she is waiting for additional instructions or probes.

Questionable Text
If the transcriber is unsure of the accuracy of a statement made by a speaker, this statement shall be placed inside parentheses and a question mark is placed in front of the open parenthesis and behind the close parenthesis.

Example:

IE01: I went over to the ?(club on Avalon)? to meet with John.

Sensitive Information
If an individual uses his or her own name during the discussion, the transcriber shall replace this information with the appropriate interviewee identification label/naming convention.

Example:

IE01: My asked me, “IE01, where are you going tonight.”

If an individual provides others’ names, locations, organizations, and so on, the transcriber shall enter an equal sign immediately before and after the named
information. Analysts will use this labelling information to easily identify sensitive information that may require substitution.

*Example:*

IE03: We went over to =John Doe’s= house last night and we ended up going to =O’Malley’s Bar= over on =22nd Street= and spending the entire night talking.

**STORAGE OF DIGITAL AUDIO FILES**

When an audio file is not actively being transcribed or reviewed, the USB flash drive on which the interview is saved will be stored in a locked cabinet. If the file is stored on a transcribers PC, laptop or tablet then the PC, laptop or tablet is to be password protected.

**REVIEWING FOR ACCURACY**

The transcriber/proofreader shall check (proofread) all transcriptions against the audiotape and revise the transcript file accordingly. All transcripts shall be audited for accuracy by the interviewer who conducted the interview.

**SAVING TRANSCRIPTS**

The transcriber shall save each transcript as an individual Microsoft word document with a .doc extension. Individual interview transcript files shall be assigned a “T_” followed by the participant ID (e.g., T_IE01 = Experience of alcohol use interview for participant #01).

**BACKUP TRANSCRIPT FILES**

All transcript files shall be backed up on USB flashdrives or portable hard drives or utilising secure cloud storage technology. Backups will not be stored in the same location as the original digital audio files of the interviews.

**DELETING OF INTERVIEW AND TRANSCRIPT FILES**

Copies of interview and transcript files will be archived at the University of Otago for a period of ten years. All other files including backup files, files stored on USB flashdrives and portable harddisks or utilising cloud storage technologies, and files stored on transcribers PC, laptop, or tablet will be permanently deleted.
<table>
<thead>
<tr>
<th>Code</th>
<th>Description of Code</th>
<th>Theme</th>
<th>Sub Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Modelling</td>
<td>Example set by family and peers members of drinking behaviour</td>
<td>Choices and influences</td>
<td>Previous and current Influences</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Knowledge about alcohol, its use, its effects, and where to get it</td>
<td>Choices and influences</td>
<td>Previous and current Influences</td>
</tr>
<tr>
<td>Feeling stressed</td>
<td>Feeling stressed about life situations</td>
<td>Choices and influences</td>
<td>Previous and current Influences</td>
</tr>
<tr>
<td>Trauma</td>
<td>Traumatic episode resulting from the drinking of alcohol</td>
<td>Choices and influences</td>
<td>Previous and current Influences</td>
</tr>
<tr>
<td>Too easy to drink</td>
<td>Types of alcoholic drinks that are too easy to consume to excess</td>
<td>Choices and influences</td>
<td>Previous and current Influences</td>
</tr>
<tr>
<td>Meetings, business, and conferences</td>
<td>Association of drinking activity with attending meetings, business activities, and conferences,</td>
<td>Choices and influences</td>
<td>Previous and current Influences</td>
</tr>
<tr>
<td>Keeping a clear head</td>
<td>Avoiding overindulging in alcohol because of in order to keep a clear head for meetings, conferences and other activities</td>
<td>Choices and influences</td>
<td>Previous and current Influences</td>
</tr>
<tr>
<td>Health</td>
<td>Effect of drinking on health.</td>
<td>Choices and influences</td>
<td>Previous and current Influences</td>
</tr>
<tr>
<td>Preferences</td>
<td>States preferences/ what they like don't like</td>
<td>Choices and influences</td>
<td>Taste and personal preference</td>
</tr>
<tr>
<td>Non alcoholic drinks</td>
<td>Consumptions of non-alcoholic drinks as an alternative to alcoholic drinks</td>
<td>Choices and influences</td>
<td>Taste and personal preference</td>
</tr>
<tr>
<td>Keeping the rules</td>
<td>Following the rules that come out of one’s value system, rules, spiritual path, or expectations of peer’s and support network</td>
<td>Choices and influences</td>
<td>Values and judgements</td>
</tr>
<tr>
<td>Code</td>
<td>Description of Code</td>
<td>Theme</td>
<td>Sub Themes</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-------------------------------------------------------------------------------------</td>
<td>------------------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td><strong>Falling short</strong></td>
<td>Not living up to one’s value system, rules, spiritual path, or expectations of one’s peers or support network</td>
<td>Choices and influences</td>
<td>Values and judgements</td>
</tr>
<tr>
<td><strong>Judgement</strong></td>
<td>The ability to make personal judgements on an activity based on one’s personal value system and understanding of the consequences of those actions</td>
<td>Choices and influences</td>
<td>Values and judgements</td>
</tr>
<tr>
<td><strong>Initiation</strong></td>
<td>First experience of consuming alcohol</td>
<td>Context &amp; location of drinking behaviour</td>
<td>Social gatherings and activities</td>
</tr>
<tr>
<td><strong>Celebrations</strong></td>
<td>Celebrating a life event, achievement, or ritual which has meaning to the person for example Christmas or birthdays</td>
<td>Context &amp; location of drinking behaviour</td>
<td>Social gatherings and activities</td>
</tr>
<tr>
<td><strong>Activities</strong></td>
<td>Activities associated with alcohol use such as going to concerts or sports events</td>
<td>Context &amp; location of drinking behaviour</td>
<td>Social gatherings and activities</td>
</tr>
<tr>
<td><strong>Socialising</strong></td>
<td>Going out with family/or peers to pub, club or some other activity where alcohol is available and consumed</td>
<td>Context &amp; location of drinking behaviour</td>
<td>Social gatherings and activities</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td>Where alcohol is consumed</td>
<td>Context &amp; location of drinking behaviour</td>
<td>Social gatherings and activities</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td>Source where alcoholic drinks are procured, for example pubs, restaurants, or club rooms.</td>
<td>Context &amp; location of drinking behaviour</td>
<td>Social gatherings and activities</td>
</tr>
<tr>
<td><strong>Representation in theatre and drama</strong></td>
<td>Representation and symbolism of alcohol consumption in a drama played by people with an ID</td>
<td>Context &amp; location of drinking behaviour</td>
<td>Representations in drama</td>
</tr>
<tr>
<td><strong>Excess</strong></td>
<td>Feeling intoxicated or drunk due to consumption of alcohol</td>
<td>Drinking behaviour</td>
<td>How alcohol is consumed</td>
</tr>
<tr>
<td>Code</td>
<td>Description of Code</td>
<td>Theme</td>
<td>Sub Themes</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>----------------------</td>
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</tr>
<tr>
<td>Staying safe</td>
<td>Keeping oneself safe from accidents, injury, being robbed or assaulted, not getting home safely, or any other adverse events resulting from the consumption of alcohol</td>
<td>Drinking behaviour</td>
<td>Effect of alcohol</td>
</tr>
<tr>
<td>Feeling hungover</td>
<td>Feeling hungover including headache and feeling sick</td>
<td>Drinking behaviour</td>
<td>Effect of alcohol</td>
</tr>
<tr>
<td>Becoming happy</td>
<td>Feeling of becoming intoxicated not associated with any adverse effects</td>
<td>Drinking behaviour</td>
<td>How alcohol is consumed</td>
</tr>
<tr>
<td>Cost of drinking</td>
<td>The price and cost of having an alcoholic drink</td>
<td>Drinking behaviour</td>
<td>Effect of alcohol</td>
</tr>
<tr>
<td>Moderation</td>
<td>Drinking behaviour that does not result in any obvious negative consequences, for example intoxication, poor choices, hangovers etc.</td>
<td>Drinking behaviour</td>
<td>How alcohol is consumed</td>
</tr>
<tr>
<td>Time of consumption</td>
<td>Specific time of day in which consumption of alcohol took place</td>
<td>Drinking behaviour</td>
<td>How alcohol is consumed</td>
</tr>
<tr>
<td>Finding help</td>
<td>Finding help to reduce or stop drinking</td>
<td>Drinking behaviour</td>
<td>How alcohol is consumed</td>
</tr>
<tr>
<td>Avoiding alcohol</td>
<td>Avoiding any consumption of alcohol</td>
<td>Drinking behaviour</td>
<td>How alcohol is consumed</td>
</tr>
</tbody>
</table>
## Theme formation

<table>
<thead>
<tr>
<th>Cluster 1</th>
<th>Cluster 2</th>
<th>Cluster 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Initial groups</strong></td>
<td><strong>Initial groups</strong></td>
<td><strong>Initial groups</strong></td>
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<tr>
<td>Judgement</td>
<td>Modelling</td>
<td>Peeking, being treated</td>
</tr>
<tr>
<td>Activities</td>
<td>Knowledge</td>
<td>Peeking, being treated, or arrested</td>
</tr>
<tr>
<td>Socialising</td>
<td>Preferences</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Location</td>
<td>Non-alcoholic drinks</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Drink</td>
<td>Inhibition</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Staying safe</td>
<td>Seeking, hanging over</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Meditation</td>
<td></td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td><strong>Task groups</strong></td>
<td><strong>Task groups</strong></td>
<td><strong>Task groups</strong></td>
</tr>
<tr>
<td>Judgement</td>
<td>Modelling</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Activities</td>
<td>Knowledge</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Socialising</td>
<td>Preferences</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Location</td>
<td>Non-alcoholic drinks</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Drink</td>
<td>Inhibition</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Staying safe</td>
<td>Seeking, hanging over</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Meditation</td>
<td></td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td><strong>Fluid theories</strong></td>
<td><strong>Fluid theories</strong></td>
<td><strong>Fluid theories</strong></td>
</tr>
<tr>
<td>Content &amp; location of drinking behaviour</td>
<td>How alcohol is consumed</td>
<td>Perceptions or current experiences and influences</td>
</tr>
<tr>
<td>Activations</td>
<td>Peeking, being treated, or arrested</td>
<td>Peeking, being treated, or arrested, and consumption of alcohol</td>
</tr>
<tr>
<td>Location</td>
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| Peeking, being treated, or arres
Dear Ms Conder,

I am again writing to you concerning your proposal entitled “The experience of alcohol use amongst individuals with an intellectual disability in Aotearoa/New Zealand”, Ethics Committee reference number H14/110.

Thank you for your e-mail of 29th September 2014 addressing the issues raised by the Committee.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

The standard conditions of approval for all human research projects reviewed and approved by the Committee are the following:

Conduct the research project strictly in accordance with the research proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee.

Inform the Human Research Ethics Committee immediately of anything which may warrant review of ethics approval of the research project, including: serious or unexpected adverse effects on participants; unforeseen events that might affect continued ethical acceptability of the project; and a written report about these matters must be submitted to the Academic Committees Office by no later than the next working day after recognition of an adverse occurrence/event. Please note that in cases of adverse events an incident report should also be made to the Health and Safety Office:

http://www.otago.ac.nz/healthandsafety/index.html

Advise the Committee in writing as soon as practicable if the research project is discontinued.

Make no change to the project as approved in its entirety by the Committee, including any wording in any document approved as part of the project, without prior written approval of the Committee for any change. If you are applying for an amendment to your approved research, please email your request to the Academic Committees Office:
 Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval or an extension of approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,

[Signature]

Mr Gary Witte  
**Manager, Academic Committees**  
Tel: 479 8256  
Email: gary.witte@otago.ac.nz

C.C. Dr P Seaton  
Director, Senior Lecturer  
Centre for Postgraduate Nursing Studies (Chch)
Information Sheet

The Experience of Alcohol Use Amongst Individuals With an Intellectual Disability in Aotearoa/New Zealand

This form tells you about the study and what taking part would mean for you.

I want to find out more about the experiences of people with an intellectual disability who drink alcohol.

I am going to ask you a few questions about your experiences with alcohol.

The interview should last no more than one hour

You can have a friend or someone you trust with you when we talk.

I will record what we talk about to help me understand your answers better.
I will write a report about what we have talked about.

I will remove anything that may help someone else know who you are.

You can stop me at any time.

You can ask to me remove any of the answers you have given.

You can ask me anything you want to at any time during our talk.

If you have any questions after we have finished talking you can contact me or either of my academic supervisors

Contact details:

Interviewer/Student Researcher: Mr Grahame Gee
geegr906@otago.ac.nz
(04) 934-8400

Principal Academic Supervisor: Ms Jenny Conder
jenny.conder@otago.ac.nz
Secondary Academic Supervisor: Assoc Prof Simon Adamson

simon.adamson@otago.ac.nz

(03) 364 0480
The Experience of Alcohol Use Amongst Individuals With an Intellectual Disability in Aotearoa/New Zealand: Participant Interest Form

If you want to participate in the Alcohol Use study would you please answer these questions. Ask a friend, family member or support person to help you:

1. Name: __________________________

2. Preferred contact method (please circle)

   Email                              home phone   work phone   cell phone

Address:

Street/Flat Number: __________________________

Street: __________________________

Suburb: __________________________

Town: __________________________

Post Code: __________________________

Phone number: __________________________

Cellphone number: __________________________

Email: __________________________

3. Ethnicity (please tick):

   [□] Pakeha/NZ European
   [□] Māori  Iwi: __________________________
4. How old are you? ____________

5. Have you had an alcoholic drink at least once in the past month (please tick)?

   Yes ☐               No ☐
Consent Form

The Experience of Alcohol Use Amongst Individuals With an Intellectual Disability in Aotearoa/New Zealand

If you want to take part in this study please read this form, or have someone read it to you.

This form tells you what your rights are as a participant in this research.

By signing the form you are saying that you want to take part.

If you have any questions please contact me or my supervisors:

Interviewer/Student Researcher: Mr Grahame Gee
geegr906@otago.ac.nz
(04) 934-8400

Principal Academic Supervisor: Ms Jenny Conder

jenny.conder@otago.ac.nz
(03) 479 2162

Secondary Academic Supervisor: Assoc Prof Simon Adamson

simon.adamson@otago.ac.nz
(03) 364 0480
What I am agreeing to:

1. I have read the Information Sheet.
2. I understand what the study is about.
3. I have been able to have a friend, family or whanau member, or support person with me when I have learned about the study.
4. I have had enough time to talk with other people about participating in the study.
5. All my questions about the study have been answered.
6. I know that I can ask for more information at any stage.
7. **When I am talking to the interviewer I can have a support person with me if I want.**
8. I know that the interview will be recorded.
9. I know that the interview will ask me about my drinking of alcohol.
10. I can decide what I tell the interviewer about my drinking experience.

11. I do not have to answer a question if I don’t want to.

12. I will answer those questions I feel comfortable with to the best of my ability.

13. I can stop taking part at any time and I won’t be affected in any way.

14. If I no longer want to take part in the study I can ask for all my information to be removed.

15. I understand that what I tell the interviewer will be private. When the interviewer writes about me they will change my name so that no one else will know that it is me.

16. I know that when the study is completed all information that could identify me will be removed.

17. I know that all information from our talk will be placed in a safe place and kept for at least ten years by the University of Otago.

18. I know that the results of our talk may be written in a report and be available in the University of Otago Library.

19. I know that I can ask for a report of the study when it is complete.

20. I know that I will receive a gift voucher of twenty dollars ($20.00). The gift voucher is to help with any costs of taking part in the study.
I give my consent to take part in this study.

Participant Name__________________________________________

Signed ___________________________ Date ____________________

Researcher Name__________________________________________

Signed ___________________________ Date ____________________
The Experience of Alcohol Use Amongst Individuals With an Intellectual Disability in Aotearoa/New Zealand:

Protocol for dealing with alcohol misuse amongst participants

Overseas research indicates that some individuals with an intellectual disability will use alcohol to hazardous levels. Given that the focus of this study is on the experiences of individuals with an intellectual disability who use alcohol some may disclose hazardous alcohol use and abuse. The following protocol developed and modified from protocols developed by the Donald Beasley Institute’s Women’s Mental Health Study will address the situation where hazardous use and abuse is disclosed during the discussion.

Procedure: If it becomes clear through the interview process that a participant use of alcohol is at a hazardous level the following process will be followed.

1. At the conclusion of the interview, if the participant is interested, a brief intervention will be undertaken.
2. The researcher will bring the issue to supervision with his academic supervisors, one of whom is a clinical psychologist.
3. If it is concluded that referral for treatment of excessive alcohol use is indicated the preferred referral options will be determined.
4. The referral options will be communicated to the participant and if the participant so wishes the referral options will also be communicated to key support persons including significant others, family/whanau members and/or support staff.
The Experience of Alcohol Use Amongst Individuals With an Intellectual Disability in Aotearoa/New Zealand -

Protocol for dealing with abuse or psychological trauma amongst participants

Overseas research indicates that some individuals with an intellectual disability who use alcohol also suffer from past psychological trauma or from physical and sexual abuse. Consumption of alcohol is an identified risk factor or coping mechanism for past or present abuse or psychological trauma. Given that the focus of this study is on the experiences of individuals with an intellectual disability who use alcohol some may disclose physical or sexual abuse. The following protocol developed and modified from protocols developed by the Donald Beasley Institute’s Women’s Mental Health Study will be applied to address the situation where such abuse is disclosed during the discussion. In all instances the interviewer will advise and discuss with his academic supervisors what has been disclosed.

A participant may disclose that they have been abused in the past.

Procedure: Where there has been historic abuse the participant will be asked if they have received any help for the abuse in the past. If they have not received any help they will be asked if they want any assistance. If they indicate that they want assistance they will be supported to take the matter further and appropriate referrals and follow-up made.

A participant may disclose they are currently being abused.

Procedure: It will be determined if the person wants to take the matter further. If they do then they will be supported in their decision. The exception to this process will be if the abuse was
Tuesday, 13 May 2014.

Ms Jennifer Conder,
No address details found.
DUNEDIN.

Tēnā Koe Ms Jennifer Conder,

The experience of alcohol use amongst individuals with an intellectual disability in Aotearoa/New Zealand

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 13 May 2014 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states “Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago”. As such, this response is not “approval” or “mandate” for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the latest census.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

We wish you every success in your research and The Committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 13 May 2014 to 30 October 2015.
Nāhaku noa, nā

Mark Brunton
Kaiwhakahaere Rangahau Māori
Research Manager Māori
Research Division
Te Whare Wānanga o Otago
Ph: +64 3 479 8738
Email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtākou Incorporated
Kīti Huirapa Rātanga ki Puketawāki
Te Rūnanga o Moeraki