Tobacco and alcohol use in people who have a learning disability: giving voice to their health promotion needs

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Finally, we are grateful to Dr Alison Munro for her helpful comments regarding the analysis of the alcohol-related data.
Executive Summary

Aim
The aim of the study was to explore the tobacco and alcohol-related health promotion needs of people with mild/moderate learning disabilities.

Methodology & Methods
The design of the study was grounded in the principles of the Medical Research Council’s Framework for the development and evaluation of complex healthcare interventions. Specifically, a developmental approach was adopted, where evidence was gathered and data collected and synthesised to inform the development of subsequent interventions. Systematic review methods were used to facilitate the gathering of evidence regarding the effectiveness of previous tobacco and alcohol-related interventions designed for people with learning disabilities (PwLD). Following this, a qualitative research approach was adopted, with purposive sampling techniques being used to recruit participants from two NHS Board areas in Scotland. The participants included people with mild/moderate learning disabilities (n=16), health and social care professionals who have regular contact with people who have learning disabilities (n=15) and family carers (n=2). The data, which were gathered using focus group and telephone interview techniques, were analysed thematically. The collection and analysis of the data was underpinned by social cognitive theory.

Key Findings
The systematic review of the literature was undertaken to ensure that any relevant studies were identified that had developed and tested tobacco or alcohol-related interventions for people with learning disabilities. Our aim was to ensure that we uncovered any information pertinent to the development of our own intervention/s. The review demonstrated that worldwide, the body of evidence that has focused on developing and testing tobacco and alcohol-related interventions for people with learning disabilities is small (n=5). While the studies identified had significant methodological limitations, and therefore told us little about what types of intervention are effective, some important issues linked to the feasibility and appropriateness of health promotion interventions for this client group were highlighted. For example, some useful information was provided on the content and mode of delivery of the interventions, such as the use of role play, visual aids, vignettes and strategies to enhance levels of self-efficacy.

In the qualitative element of the study, seven of the participants with learning disabilities were current smokers, with an additional three being former smokers. Fifteen of the sixteen participants had consumed alcohol at some point in their lives, with 12 being current drinkers. Many had drunk excessively at some point in their lives and a few continued to do so at the time the data were collected.
The findings highlight the important influence of family and friends in the initiation of smoking and drinking. When considering factors that encouraged continuation, the smoking/drinking habits of friends and family were again influential, as were factors such as anxiety, mental health problems, lack of meaningful activity and a perceived need to ‘belong’ or to ‘fit in.’ The health and social care professionals expressed concern that the move from institutionalised care to more independent living in the past decade had resulted in an increase in alcohol consumption in this client group. The low cost of alcohol was also thought to be a factor that encouraged high levels of consumption.

An exploration of the participants’ (PwLD) knowledge of the adverse health effects of smoking and excessive alcohol consumption demonstrated that this was quite basic. The health and social care professionals and family members felt that health promotion messages are often quite complex and can therefore be difficult for people with learning disabilities to assimilate. Also, while the association between an acute condition and smoking or alcohol may be understood, the professionals thought that it was unlikely that many people with learning disabilities would understand that long-term smoking/alcohol-related conditions might develop in the future. There was also little understanding that health problems might improve following cessation of smoking or a reduced in alcohol consumption.

When discussing the consumption of alcohol it was apparent that the participants generally had a good degree of awareness of the potential negative consequences of being drunk. They had either experienced being drunk themselves or had observed drunken behaviour in others. The health and social care professionals were concerned that people with learning disabilities sometimes stopped taking medications (e.g. anti-epileptics) so that they could consume alcohol. Family carers were particularly worried about the increased vulnerability associated with drinking, particularly in terms of aggression and sexual activity.

Discussion of the tobacco and alcohol-related health promotion needs of people with learning disabilities highlighted that there was an awareness that partnership working was necessary (i.e. learning disability services and addiction/smoking services working together). However, while there were some good examples of joint working, they appeared to be the exception. The need for a person-centred approach, with the tailoring of interventions to meet the individual needs of clients with learning disabilities was also raised.

When considering appropriate health promotion approaches for people with learning disabilities, the participants described a need for interventions that deliver health promotion messages using ‘simple’ language, supported by images, which aim to convey abstract concepts in concrete terms. Interventions need to be tailored to meet the specific communication and learning needs of individuals. The effectiveness of health promotion messages also needs to be assessed for
understanding and impact. In terms of alcohol, there appears to be a need for educational interventions that enable people with learning disabilities to understand what constitutes ‘sensible’ drinking. Such interventions should include an easy-to-use tool that individuals can apply to actual drinking situations.

The increasing level of autonomy in people with learning disabilities was evident, as were the choices that they make about the use of tobacco and alcohol. This should be considered when designing health promotion interventions. There is a need to ensure that mechanisms are in place to empower people with learning disabilities to make informed decisions regarding lifestyle issues.

In terms of the practical support required to assist people with learning disabilities in making lifestyle choices, the important role of support workers was emphasised. Health and social care professionals and family carers discussed the need for training/education in the best ways to encourage and support people who wish to stop smoking and/or cut down their consumption of alcohol. The potential for peer support and buddy systems was also highlighted. Finally, the health and social care professionals suggested that training of people with learning disabilities in assertiveness skills might prove a useful strategy to help them resist peer pressure.

**Implications for Practice, Research & Education**

Implications for practice include the need for joint service provision and the delivery of interventions that are accessible to people with learning disabilities. A person-centred, individualised approach is required, which takes account of the learning and communication needs of individuals. Support workers and other health and social care professionals who work with this client group should receive tobacco and alcohol-related training/education that will allow them to effectively encourage and support health promotion efforts. People with learning disabilities should be helped to acquire skills that will enhance meaningful participation, including assertiveness training. Innovative approaches to the development and implementation of support mechanisms, such as peer mentoring and buddying are recommended. Finally, there is a need to ensure that the efficacy of any interventions delivered is formally evaluated.

**Future Plans**

The findings from this study, including the systematic review of the literature, will be used to develop evidence-based tobacco and alcohol-related interventions, the efficacy of which will be tested in future work.
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1. Introduction

1.1 Aim

The aim of the study was to explore the tobacco and alcohol-related health promotion needs of people with mild/moderate learning disabilities.

1.2 Background

The number of people with learning disabilities in Scotland is unknown. However, estimates suggest that 20 people in every 1,000 have a mild or moderate learning disability and 3-4 people in every 1,000 have a severe or profound learning disability (NHS Health Scotland, 2004). Approximately 18,000 adults with learning disabilities are currently known to Local Authorities in Scotland (NHS Health Scotland, 2004).

Scottish health policy has stressed that the health and well-being of people with learning disabilities should be prioritised (NHS Health Scotland, 2004). While the life expectancy of people with learning disabilities is increasing it is still lower than the general population and they are known to have more complex health needs than their non-disabled counterparts (NHS Health Scotland 2004).

In recent years there has been increasing concern regarding the mortality, morbidity and behavioural determinants of health among people with learning disabilities (NHS Health Scotland, 2004; Emerson & Hatton, 2008). While a high level of health needs has been identified, much still has to be accomplished in the delivery of services to address these needs and thus reduce health inequalities (NHS Health Scotland, 2004).

The importance of health promotion interventions for people with learning disabilities is increasingly recognised (NHS Health Scotland, 2004). However, while there is some evidence of health promotion activity related to diet, physical activity, tobacco, alcohol and sexual health (e.g. Robertson et al., 2000; Flynn & Hollins, 2003; Marshall et al., 2003), there remains a dearth of work in this area. Of particular note is the very limited focus, to date, on smoking and alcohol consumption.

With the closure of long stay institutions, more people with learning disabilities are being supported to live in the community. As they lead more ordinary and less restricted lives they may experience social pressures to conform and also the financial freedom that might lead to an increased use of tobacco and alcohol (Taggart et al., 2008). Additional factors that can make people with learning disabilities more vulnerable include the fact that they may have low levels of self esteem, limited self control and they can have poor social and communication skills (Taggart et al., 2008).
The prevalence of smoking among people with learning disabilities, as a whole, has been shown to be lower than in the general population (McGillicuddy, 2006). However, rates of lung cancer among adults with mild learning disabilities are similar to the general population which suggests that the prevalence of smoking is likely to be similar (Patja et al., 2001). The prevalence of smoking in Scotland is currently 27%; with levels being as high as 35-40% in areas of high socio-economic deprivation (Scottish Government, 2008).

While little research has focused, to date, on the use of tobacco in people with learning disabilities, what has been shown is that their knowledge of the health effects of smoking can be poor (Taylor et al., 2004).

Recent information from the Scottish Government suggests that up to 50% of men and 30% of women in the general population are exceeding the recommended weekly guidelines of 21 units for men and 14 units for women (Scottish Government, 2009). When considering the prevalence of alcohol consumption/excessive alcohol consumption in people with learning disabilities, there are a number of methodological problems that make it difficult to provide accurate estimates (Taggart et al., 2008). One of the problems is that there is a lack of consensus regarding the definition of what constitutes ‘use’ or ‘abuse’. Additionally, it is difficult to identify the learning disabled population, as the number of people known to services is only a small proportion of the total population (Taggart et al., 2008). The methodology employed to collect data (e.g. staff reports, self-reports, whether assurances of anonymity are given) and the level of learning disability in the individuals being assessed are also known to be factors that will influence estimates of prevalence (Taggart et al., 2008).

Taking into account the above methodological difficulties, a small number of studies have reported prevalence rates of alcohol use and misuse in people with learning disabilities. Generally speaking the prevalence has been reported as lower than in the general population (e.g. Emerson & Turnbull, 2005; Johnson et al., 2005; Taggart et al., 2006); however, the difference in adolescent cohorts appears to be small, particularly when comparing people with mild learning disabilities (McGillicuddy, 2006).

Excessive alcohol consumption in people with mild-moderate learning disabilities presents a number of concerns, including risks to personal safety, interpersonal relationships and physical and mental health (Taggart et al., 2008). In addition there is some evidence to suggest a link between alcohol use and offending in this population (McGillivray & Moore, 2001).

An initial scoping exercise, undertaken by members of the Research Team suggested that, to date, little has been done to formally identify and address the tobacco and alcohol-related health promotion needs of this client group. We
therefore sought funds from the QNIS to allow us to undertake the current study, which sought to gather data to inform the development of tobacco and alcohol-related health promotion interventions. The intention is that the interventions will be developed and tested in future work.

2. Project management

2.1 Research team

Dr Maggie Lawrence, Research Fellow/Principal Investigator, School of Health, Glasgow Caledonian University (GCU)

Dr Susan Kerr, Reader, School of Health, GCU

Dr Christopher Darbyshire, Senior Lecturer in Learning Disabilities, School of Health, GCU

Mr Alan Middleton, Lecturer in Community Health (Learning Disabilities), School of Health, GCU

Professor Hazel Watson, Professor of Nursing, School of Health, GCU

Ms Lorna Fitzsimmons, Training Fellow/Research Assistant and Clinical Nurse Specialist, NHS Greater Glasgow and Clyde

2.2 Recruitment of the Training Fellow/Research Assistant

We successfully recruited and negotiated the secondment of an experienced practitioner, Ms Lorna Fitzsimmons, to the post of Training Fellow/Research Assistant. Lorna is a Clinical Nurse Specialist/Joint Team Co-ordinator in the Learning Disability - Child & Adolescent Mental Health Service, NHS Greater Glasgow & Clyde. Lorna took up post in January 2009.

Originally, Lorna’s post was funded two days per week for six months. Additional funding, awarded by the QNIS, allowed us to extend the post by three months (i.e. July – September 2009). This extension enabled Lorna to complete the analysis of the telephone interview data, which she had collected, and to participate in dissemination activities.

2.3 Research advisory group

Mrs Lisa Curtice, Director, Scottish Consortium for Learning Disability, Glasgow

Ms Linda Allan, Consultant Nurse, Learning Disabilities, Primary Care Liaison Team, NHS Greater Glasgow & Clyde

Dr Douglas Paterson, Consultant Psychiatrist in Learning Disabilities, Arrol Park Resource Centre, NHS Ayrshire and Arran

Mr Joseph Kelly, lay representative
3. The study

3.1 Methodology

The design of the study is grounded in the principles of the Medical Research Council’s (MRC) framework for the development and evaluation of complex healthcare interventions (MRC, 2008), and aligns with the development phase, where evidence is gathered and data are collected and synthesised to inform the development of subsequent interventions.

In this study, several methods were used to gather relevant data/evidence:

a) Systematic review methods were used to facilitate the gathering of evidence regarding the effectiveness of any previous tobacco and alcohol-related health promotion interventions designed for people with learning disabilities.

b) Focus group interviews were used to gather data from people with mild/moderate learning disabilities.

c) Telephone interviews were used to gather data from family carers and health and social care professionals.

The qualitative methods were used as a means of ascertaining the views and perspectives of people with learning disabilities themselves and also the professionals and family carers with whom they have regular contact. Our aim was to provide a platform to capture their views and to ensure that these views informed the development of future tobacco and alcohol-related health promotion interventions.

The collection and analysis of the qualitative data was underpinned by Social Cognitive Theory (SCT) (Bandura, 1986), which enabled exploration of the personal and environmental factors that influence smoking and alcohol consumption. Derived from social learning theory, SCT proposes that behaviour is influenced by environmental factors (including other people’s behaviour and social norms), personal factors (including motivation and identity) and attributes of the behaviour itself. Each may affect or be affected by either of the other two (reciprocal determinism). Central tenets of SCT include, self-efficacy, observational learning and the value placed on the perceived outcomes or consequences of a change in behaviour (expectancies). SCT was used to assist our understanding of how people with learning disabilities (PwLD) acquire and maintain behavioural patterns. SCT may also provide an appropriate theoretical base upon which to found the development of subsequent interventions.
3.2 Ethics

3.2.1 Ethical approval

As recruitment of PwLD and family carers was conducted through voluntary sector organisations, NHS approval was not required. We therefore sought and were granted ethics approval for these elements of the study from the Glasgow Caledonian University Ethics Committee.

However, as we also aimed to recruit health and social care professionals, ethics and Research and Development (R&D) approval, was required from the NHS and Local Authority areas in which we wished to conduct the study. The process of gaining ethics approval was rather protracted, due in part to the introduction of new systems, and the need to acquire permission/signatures from a range of senior healthcare and social work professionals based in a number of organisations/locations. The application for NHS ethical approval was submitted in October 2008 and granted later that month. R&D approval was granted in December 2008 with site-specific R&D approval being granted by NHS Ayrshire and Arran in January 2009, and by NHS Greater Glasgow and Clyde in February 2009. Approval to recruit social workers was granted in April 2009. The lengthy nature of the approval processes affected the timescales for the project, which, in agreement with QNIS, were revised accordingly.

The study was conducted in line with the requirements of the Data Protection Act 1998 (UK Parliament, 2005) and the Research Governance Framework for Health and Social Care (Scottish Government Health Department, 2006).

3.2.2 Ethical issues

PwLD are recognised as a vulnerable group. Therefore, we made efforts to ensure that professionals who have experience in the area of learning disability were involved in all aspects of recruitment, data collection, data analysis, reporting and dissemination. We also made efforts to involve people with mild-moderate learning disabilities in an advisory capacity, to ensure that the ‘voice’ of this group of people was being represented.

4. Structure of the report

In the following sections of the report, the evidence gathering and synthesis activities described above, i.e. the systematic review, the focus group and telephone interview studies, are reported separately in sections 5-7. The results and findings from these separate pieces of work are then brought together in the Discussion and Conclusion (section 8), with section 9 discussing implications for practice, education and research. Section 10 presents our plans for dissemination with section 11 discussing our future
plans. Section 12 provides reflections on the research training element of the study, with the final section (section 13) presenting our financial report.

5. Systematic review of the literature

5.1 Introduction

As discussed, the scoping exercise undertaken before the study commenced suggested that there is currently a very limited evidence-base to inform the development and implementation of tobacco and alcohol-related health promotion interventions for people with learning disabilities. However, to ensure that any relevant studies were identified and that information pertinent to the health promotion needs of this client group was uncovered, we undertook a systematic review of the literature. The systematic review formed one of the three evidence gathering phases of the study.

5.2 Aim

The aim was to identify and summarise published studies that had assessed the Feasibility, Appropriateness, Meaningfulness and Effectiveness of tobacco and/or alcohol-related health promotion interventions for people with mild/moderate learning disabilities. The term Feasibility relates to evidence about the extent to which an activity or intervention is practical. Appropriateness relates to evidence about the extent to which an activity or intervention is ethical or culturally appropriate (in this instance we were also interested in the appropriateness of interventions for people with learning disabilities). Meaningfulness relates to evidence about the personal opinions, experiences, values, thoughts or beliefs of clients, families and professionals in relation to interventions, with Effectiveness relating to evidence about the effects of a specific intervention. The approach taken, known as the F_A_M_E approach to systematic reviewing, was developed by the Joanna Briggs Institute for Evidence-Based Healthcare (Pearson, 2004).

In addition to identifying and summarising relevant papers, we aimed to comment on any methodological limitations in studies undertaken previously and to highlight gaps in the current evidence-base.

5.3 Methods

5.3.1 Search strategy

The search terms applied were: ‘learning disabilities’, ‘intellectual disabilities’, ‘mental retardation’, ‘health promotion’, ‘tobacco’, ‘smoking’, and ‘alcohol’. No language limitation was specified and the currency included the past 10 years. Where MESH terms were available, they were exploded and combined.

For the search: [1] subject headings ‘learning disabilities’, ‘intellectual disabilities’, and ‘mental retardation’ were combined with the Boolean operator ‘OR’. [2] Subject headings ‘health promotion’, ‘alcohol’ and ‘smoking’ were combined with the Boolean operator ‘OR’. The results of searches [1] and [2] were combined with the Boolean operator ‘AND’ (appendix 1). Details of the full search results can be found in appendix 2.

5.3.2 Inclusion/exclusion criteria

Following completion of the literature search, the Abstracts of the papers identified were reviewed, with broad inclusion/exclusion criteria initially being applied. Papers were included at this stage if they had a focus on learning disability and tobacco and/or alcohol. Our next step was to apply narrow inclusion/exclusion criteria, with the aim being to exclude papers that did not report results from studies that had delivered alcohol and/or tobacco-related health promotion interventions. This process was guided by an adaptation of the PICO framework (table 1). Where insufficient detail was provided in the abstract, the full papers were screened.

The inclusion/exclusion criteria were applied by two members of the research team independently (CD and SK). The researchers then met to discuss any discrepancies and reach consensus.

5.3.3 Data extraction

Data were extracted from the papers included, following the application of the narrow inclusion/exclusion criteria, using a data extraction tool (appendix 3). This tool was developed specifically for the project to ensure consistency within and among the reviewers (CD, SK, ML). The data extraction process for each paper was undertaken independently by two reviewers who then met to discuss any discrepancies and reach consensus. The data extracted from each study included details of authors, date of publication, country of origin, aims, sample selection and size, the intervention, data collection and analysis and the findings/results (see tables 2–4).
Table 1. PICO Framework (adapted)

<table>
<thead>
<tr>
<th></th>
<th>Include</th>
<th>Exclude</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study design</td>
<td>All designs not listed in the exclusion criteria.</td>
<td>Discussion papers; personal accounts; literature reviews; systematic reviews</td>
</tr>
<tr>
<td>Population</td>
<td>People with a mild-moderate learning disability</td>
<td>People with a moderate-severe learning disability</td>
</tr>
<tr>
<td>Intervention</td>
<td>Information/advice; education; brief interventions, intensive interventions; group support; other psychological interventions; pharmacological interventions (e.g. nicotine replacement therapy)</td>
<td>Interventions that did not include at least one lifestyle component</td>
</tr>
<tr>
<td>Outcomes</td>
<td><strong>Tobacco</strong>: CO levels, cotinine levels, self-reported consumption, health-related quality of life, knowledge, attitudes</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Alcohol</strong>: biological markers (e.g. gamma-glutamyl transferase (GGT)), self-reported consumption, health-related quality of life, knowledge, attitudes</td>
<td></td>
</tr>
</tbody>
</table>

5.3.4 Quality Ratings (QR)

We used a seven-point rating scale, adapted from the one discussed in the National Institute for Health and Clinical Excellence (NICE) publication *Moving beyond effectiveness in evidence synthesis* (Popay, 2006), to assess the quality of the studies reviewed. Studies were assessed in relation to: a) theoretical underpinnings; b) clarity of aims and objectives; c) sampling; d) the description of the intervention; e) data collection and analysis, f) reliability and validity; and g) the presentation of the results/findings (see appendix 4).

5.4 Results

5.4.1 Searches and inclusion/exclusion of papers

As indicated in figure 1, the searches initially identified a total of 57 papers (Stage 1). Following application of the broad inclusion/exclusion criteria at Stage 2, 26 papers were excluded leaving a total of 31 papers. At Stage 3, application of the narrow inclusion/exclusion criteria, using the PICO Framework, resulted in the exclusion of a further 27 papers, leaving four papers in the review. A scan of the reference lists of all papers at this stage identified one additional paper that fitted the inclusion criteria. A total of five papers were therefore identified.
5.4.2 Summary of the papers reviewed

5.4.2.1 Country of Origin

As indicated, two of the final five papers identified focused on alcohol-related interventions, two on tobacco-related interventions and one study reported on an intervention designed to address both the use of tobacco and alcohol.

As indicated in tables 2–4, one of the tobacco-related studies was undertaken in the UK (Kelman et al., 1997) and the other in Australia (Tracy & Hosken, 1997). Both
alcohol-related studies were undertaken in the UK (Steel & Ritchie, 2004; Mendel & Hipkins, 2002). The study that focused on both tobacco and alcohol was conducted in the USA (Demers et al., 2000).

5.4.2.2 Aims

Both of the tobacco-related studies aimed to design and test health education courses. One sought to increase knowledge levels linked to the physical, social and financial consequences of smoking (Kelman et al., 1997) and the other sought to encourage smokers to make a cessation attempt.

The alcohol-related interventions aimed to increase knowledge and motivation to change behaviour (Steel & Ritchie, 2004) and to increase clients' readiness to change (Mendel & Hipkins, 2002).

The final study (Demers et al., 2000) aimed to evaluate a school-based health education programme designed to address/prevent the use of tobacco and alcohol in 14-17 year olds.

As the description of the aims of the five studies lacked clarity, it was difficult to determine whether the aims had been achieved. None of the studies reported testing hypotheses.

5.4.2.3 Design

Two of the studies used a case-study approach, while the other three were described as being pilot studies/preliminary evaluations. The preliminary evaluation undertaken by Demers and colleagues (2000), which aimed to evaluate a tobacco and alcohol-related health education programme, adopted a quasi-experimental design.

5.4.2.4 Sample selection and size

Details of the approaches used to select participants were generally very limited. In all five studies it appeared that convenience sampling had been used.

In four of the five studies, the sample size was very small (n=1-11). The study undertaken by Demers and colleagues (2000) had the largest sample i.e. 13 teachers (6 intervention; 7 control) and 138 students (65 intervention; 73 control). None of the studies discussed the small sample size as a limitation and power calculations were not mentioned. Only one study reported using a control group (Demers et al., 2000).
5.4.2.5 Interventions

Both of the tobacco-related interventions appeared to take an educational approach (Kelman et al., 1997; Tracy & Hosken, 1997). The interventions took the form of weekly sessions delivered over a period of 7 weeks. Kelman and colleagues (1997) sought to develop a course that could be delivered in group sessions or on a one-to-one basis, whilst Tracy and Hosken (1997) using a group approach. A number of standard educational approaches were adopted including role-play, quizzes, videos, board games, visual prompts. The course developed by Tracy and Hosken (1997) was adapted from a smoking-cessation course previously developed for people who do not have learning disabilities.

The alcohol-related interventions used motivational interviewing techniques (Steel & Ritchie, 2000; Mendel & Hipkins, 2002). The course developed by Steel and Ritchie (2000) ran over a period of 12 weeks, although it is likely that only 6 of these weeks focused on alcohol (this is not clear from what is reported). Limited detail is provided on the mode of delivery; however, it is clear that modified handouts were used, sessions were summarised, and participants were given ‘homework’ on a weekly basis. The course developed by Mendel & Hipkins (2002), which ran over a period of two weeks, made use of visual aids, case vignettes and references to celebrities. It was delivered by trainee clinical psychologists and support workers.

Finally, the schools-based PALS programme developed by Demers and colleagues (2000) ran throughout one academic year. The programme appeared to include five specific lessons, in addition to which teachers were encouraged to take advantage of ‘teachable’ moments. The PALS programme appeared to focus on the attitudes and skills required to prevent/address the use of alcohol and tobacco.

5.4.2.6 Methods (data collection and analysis)

The tobacco-related studies both used questionnaires to collect data. Neither discussed the reliability or validity of the instruments, which appeared to have been developed specifically for the studies. Kelman and colleagues (1997) collected their data at baseline, 1 week and 3 months post-intervention, whilst Tracy and Hosken (1997) collected data at baseline and immediately after the delivery of the 7 week course. Basic descriptive statistics were employed.
Table 2. Interventions related to smoking

<table>
<thead>
<tr>
<th>Authors, Aim, QR</th>
<th>Sample</th>
<th>Intervention</th>
<th>Methods</th>
<th>Results/Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kelman et al (1997) Scotland, UK</td>
<td>Recruitment: adult training centres + group homes; convenience sampling</td>
<td>Content: provision of information on the harmful physical, social and financial consequences of smoking and the benefits of being a non-smoker.</td>
<td>Data collection: questionnaire used to assess knowledge of smoking; data collected at baseline, 1 week (Time 2) and 3 months (Time 3) after the health education programme</td>
<td>Feasibility/appropriateness/meaningfulness: - all participants reported as taking an active role in the group sessions - some interesting misconceptions highlighted i.e. you can get AIDS from smoking, smoking makes your hair fall out - no knowledge of passive smoking previously - varied awareness of the health effects of smoking prior to the intervention (some had little awareness) - limited ability to translate general messages to self (e.g. risk to own health).</td>
</tr>
<tr>
<td></td>
<td>Sample size: n=5</td>
<td>Mode of delivery: role play, video recording, visual prompts, quizzes, use of everyday items e.g. clothes that smell of smoke; designed to be delivered to groups and individuals</td>
<td>The potential scoring range was 0–40</td>
<td>Effectiveness: Baseline scores ranged from 15-33; Time 3 scores ranged from 28-37. Knowledge levels in all 5 participants increased from baseline to Time 2. While dipping slightly at Time 3, an increase in knowledge levels was maintained.</td>
</tr>
<tr>
<td></td>
<td>Control group: none</td>
<td>Length: 7 weekly sessions</td>
<td>Data analysis: basic descriptive statistics</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Level of LD: borderline, mild and moderate</td>
<td>Delivered by whom: care staff in adult training centre</td>
<td></td>
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<tr>
<td></td>
<td>Demographics: 2 smokers + 3 non-smokers; 26-40 years of age; 3 females, 2 males; 4 living alone; 1 living in a group home</td>
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<td></td>
</tr>
<tr>
<td>Tracy &amp; Hosken (1997) Australia</td>
<td>Recruitment: tertiary education facility, convenience sampling</td>
<td>Content: a modified version of the Fresh Start course (an established generic smoking cessation programme) was used, taking account of the cognitive difficulties of the client group; no other details of content</td>
<td>Data collection: questionnaire used to assess smoking habits and interest in stopping; data collected at baseline and at the end of the course</td>
<td>Smoking habits: - 3/11 had stopped smoking by the end of the course (no details of how this was determined i.e. was it objectively assessed) - 3/11 had significantly cut down their smoking (no detail on what their level of smoking was initially)</td>
</tr>
<tr>
<td></td>
<td>Sample size: n=11</td>
<td>Mode of delivery: - large and small group discussions - short information giving segments - videos - role playing - concrete demonstrations - education board game - incentives (pens, badges, certificates)</td>
<td>The potential range of scores was not provided.</td>
<td>Interest in quitting: - 5 people expressed a desire to quit at the start of the course, with 9 expressing a desire at the end, presumably this included the 3 who had actually stopped, although this is not clear</td>
</tr>
<tr>
<td></td>
<td>Control group: none</td>
<td>Length: 7 weekly sessions</td>
<td>Data analysis: basic descriptive statistics</td>
<td>Experience in quitting: - during the course all were challenged to give up for a day; 9/11 managed to do this; all 9 reported that they had learned about their habit and addiction by doing this</td>
</tr>
<tr>
<td></td>
<td>Level of LD: mild</td>
<td>Delivered by whom: Unclear</td>
<td></td>
<td>Knowledge of health effects of smoking: - all participants reported as having an increased knowledge of the effects of smoking at the end of the course (no scores provided). - at the beginning of the course, health concerns were vague, at the end there were specific concerns e.g. bronchitis, lung cancer, heart disease</td>
</tr>
<tr>
<td></td>
<td>Demographics: all participants were smokers; all were &lt; 25 years; 8 males, 3 females; no details of living arrangements</td>
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</tr>
<tr>
<td>Authors, Aim, QR</td>
<td>Sample</td>
<td>Intervention</td>
<td>Methods</td>
<td>Results/Findings</td>
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<td>-----------------</td>
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</tr>
<tr>
<td><strong>Steel &amp; Ritchie (2004)</strong> Scotland, UK</td>
<td><strong>Recruitment:</strong> secure accommodation; convenience sampling</td>
<td><strong>Content:</strong> provision of information on: the effects of alcohol; alcohol and the law; sensible drinking; what influences alcohol use; physical + psychological dependence; substance use and mental health; health issues</td>
<td>Data collection: knowledge questionnaire; 20 alcohol-related questions, with true false responses; data collected at baseline and post-intervention; potential range of scores 0-20</td>
<td>Data analysis: descriptive statistics</td>
</tr>
<tr>
<td>Aim: To explore the potential of a psycho-educational approach to increase knowledge and motivation to change behaviour (alcohol and drug use)</td>
<td><strong>Sample size:</strong> n=1</td>
<td><strong>Mode of delivery:</strong> - motivational interviewing techniques - at each session reviewed previous session (including homework); focus on new topic; summarising + setting of new homework tasks - modified handouts were provided</td>
<td><strong>Data collection:</strong> CAGE (used at baseline only): range 12–288 units/week; mean = 101 (prior to admission to secure unit – relied on retrospective memory) <strong>Alcohol Related Problems (used at baseline only):</strong> 6 of the 7 participants identified problems with their drinking prior to admission including: accidents hospital admissions, arguments with family, getting into trouble with the police, aggressive behaviour</td>
<td><strong>Readiness to Change Questionnaire:</strong> <strong>T1 (baseline):</strong> pre-contemplators n=2; contemplators n= 5; action n=0 <strong>T2 (end of course):</strong> pre-contemplators n=1; contemplators n=1; action n=5 While motivation to change had generally increased and 5 participants were reported to be in the ‘action’ phase, post intervention, they were currently living in secure accommodation. This prevented them from testing out skills learned and carrying out plans to change their behaviour. The authors raise concerns about the validity and reliability of the measures used with this client group.</td>
</tr>
<tr>
<td><strong>QR: 3</strong></td>
<td><strong>Control/comparison group:</strong> none</td>
<td><strong>Length:</strong> 12 sessions of 40 minutes (this included sessions on drug use) <strong>Delivered by whom:</strong> unclear</td>
<td><strong>Feasibility/appropriateness:</strong> - participant remained willing to engage with the intervention for the duration of the programme - easily distracted by his surroundings and this inability to remain focused on discussions appears to have inhibited his ability to retain some information - homework, did well with this and appeared to use modified handouts as instructed</td>
<td><strong>Effectiveness:</strong> - alcohol-related knowledge level rose from 8 at baseline to 14 at the end of the 12 week course</td>
</tr>
<tr>
<td><strong>Mendel &amp; Hipkins (2002)</strong> UK</td>
<td><strong>Recruitment:</strong> referrals from participants’ key workers, consent was subsequently obtained</td>
<td><strong>Content:</strong> the Alcohol Awareness Course aimed to: provide information on alcohol; encourage the development of learning skills; help the participants make informed choices re. alcohol consumption</td>
<td>Data collection: CAGE: 4 item measure, assesses quantity + frequency of alcohol consumption; no details of scoring Readiness to Change Quest.: 12 item measure; no details of scoring <strong>Alcohol Related Problems Quest:</strong> checklist to assess relationship between drinking + problems caused ; no details of scoring</td>
<td>Data analysis: no details provided</td>
</tr>
<tr>
<td>Aim: To apply motivational interviewing techniques to assist clients in moving through the Stages of Change process, linked to their alcohol consumption</td>
<td><strong>Sample size:</strong> n=7</td>
<td><strong>Mode of delivery:</strong> motivational interviewing techniques used, FRAMES model (feedback, responsibility, advice, menu of alternatives, empathy, self-efficacy); interactive sessions, group exercises; visual aids; case vignettes, references to celebrities, individual information files, summaries of session content</td>
<td><strong>Data collection:</strong> CAGE (used at baseline only): range 12–288 units/week; mean = 101 (prior to admission to secure unit – relied on retrospective memory) <strong>Alcohol Related Problems (used at baseline only):</strong> 6 of the 7 participants identified problems with their drinking prior to admission including: accidents hospital admissions, arguments with family, getting into trouble with the police, aggressive behaviour</td>
<td><strong>Readiness to Change Questionnaire:</strong> <strong>T1 (baseline):</strong> pre-contemplators n=2; contemplators n= 5; action n=0 <strong>T2 (end of course):</strong> pre-contemplators n=1; contemplators n=1; action n=5 While motivation to change had generally increased and 5 participants were reported to be in the ‘action’ phase, post intervention, they were currently living in secure accommodation. This prevented them from testing out skills learned and carrying out plans to change their behaviour. The authors raise concerns about the validity and reliability of the measures used with this client group.</td>
</tr>
<tr>
<td><strong>QR: 4</strong></td>
<td><strong>Control group:</strong> none</td>
<td><strong>Length:</strong> 3 x 1 hour sessions over a 2 week period <strong>Delivered by whom:</strong> 2 trainee clinical psychologists + 2 support workers</td>
<td><strong>Effectiveness:</strong> - alcohol-related knowledge level rose from 8 at baseline to 14 at the end of the 12 week course</td>
<td></td>
</tr>
<tr>
<td><strong>Level of LD:</strong> mild</td>
<td><strong>Demographics:</strong> all males; 18-54 years of age; resident in a medium secure unit for people with LD; all had alcohol-related problems, a factor related to their offending behaviour</td>
<td><strong>Data collection:</strong> CAGE: 4 item measure, assesses quantity + frequency of alcohol consumption; no details of scoring Readiness to Change Quest.: 12 item measure; no details of scoring <strong>Alcohol Related Problems Quest:</strong> checklist to assess relationship between drinking + problems caused ; no details of scoring</td>
<td><strong>Feasibility/appropriateness:</strong> - participant remained willing to engage with the intervention for the duration of the programme - easily distracted by his surroundings and this inability to remain focused on discussions appears to have inhibited his ability to retain some information - homework, did well with this and appeared to use modified handouts as instructed</td>
<td><strong>Effectiveness:</strong> - alcohol-related knowledge level rose from 8 at baseline to 14 at the end of the 12 week course</td>
</tr>
</tbody>
</table>

**Table 3. Interventions relating to alcohol**
Table 4. Intervention relating to smoking and alcohol

<table>
<thead>
<tr>
<th>Authors, Aim, QR</th>
<th>Sample</th>
<th>Intervention</th>
<th>Methods</th>
<th>Results/Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demers et al (2000) USA</td>
<td>Recruitment: students and teachers from 6 special education schools were recruited; the method of sampling is not discussed</td>
<td>Content: <strong>Teachers:</strong> Taught to adapt existing health promotion messages for children with special educational needs <strong>Students:</strong> PALS Program focuses on dangers of alcohol and tobacco, as well as skill building in areas such as recognising and resisting peer pressure; avoiding particular ‘risky’ situations, dealing with stress; learning to ask questions about alcohol and tobacco</td>
<td>Data collection: <strong>Teachers:</strong> questionnaire used to collect data on how useful the training was, whether the teachers thought that they would use the information in their classrooms; how often they thought they provided prevention messages; data collected at baseline, post-training and at the end of the academic year <strong>Students:</strong> questionnaire used to determine: if ever used alcohol and tobacco (A&amp;T); use of A&amp;T in last 30 days; peer pressure related to A&amp;T; self-image; portrayal of friends use of A&amp;T (7 criteria)</td>
<td>Teachers: Prior to the training the majority of the teachers reported that they never or rarely provided alcohol and tobacco prevention activities in their classrooms. Immediately after the training the teachers reported that they now understood that they had been providing prevention messages much more frequently than previously thought. Their estimates changed, on average, from less than once a year to about once a week. When completing the end of year survey the teachers unanimously expressed support for the PALS programme and most were able to cite examples of how they thought it had made a difference to their students. No information is provided on the teachers from the ‘control’ schools.</td>
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<tr>
<td></td>
<td>Sample size: 13 teachers; 138 students</td>
<td>Mode of delivery: <strong>Teachers:</strong> trained by PALS staff, also provided with a copy of a resource guide <strong>Students:</strong> lessons delivered during class time; teachers also encouraged to take advantage of ‘teachable’ moments; no other details provided</td>
<td>Data analysis: <strong>Teachers:</strong> Descriptive statistics <strong>Students:</strong> Inferential statistics: chi-square + Mann-Whitney U Test</td>
<td><strong>Students:</strong> The results demonstrate that levels of smoking and alcohol consumption in the PALS school were similar, or slightly greater than in children who were being educated in schools for children who did not have special educational needs. Grade 9: smoking 30.9% alcohol consumption 33.8% Grade 10: smoking 47.9% alcohol consumption 49.3% Grade 11/12: smoking 50% alcohol consumption 53.3% On all 7 criteria the performance of the students in the intervention group, at the end of the school year, was higher or more positive than students in the control group. However, the results were not statistically significant. The authors consider the reasons for the failure to reach statistical significance, but make no comment on the small sample size.</td>
</tr>
<tr>
<td></td>
<td>Intervention/control groups: <strong>Schools:</strong> 3 intervention; 3 control <strong>Teachers:</strong> 6 intervention; 7 control <strong>Students:</strong> 65 intervention; 73 control</td>
<td>Level of LD: no details provided</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Demographics: <strong>Teachers:</strong> no details provided</td>
<td><strong>Students:</strong> 80 males, 20 females; 9th-12th grade (14-17 year olds, majority 14-15 years); 104 Caucasian, 28 African American, 3 Hispanic, 3 Native American</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>The demographics of the students in the intervention and control groups were said to be similar (no details provided)</td>
<td>Delivered by whom: <strong>Teachers:</strong> PALS staff <strong>Students:</strong> teachers + PALS staff helped to facilitate</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5.4.2.6 Methods (data collection and analysis) (contd.)

The two alcohol-related studies also used questionnaires to collect data. Steel and Ritchie (2004) developed their own questionnaire, based on the content of the educational programme, while Mendel and Hipkins (2002) used instruments validated with a population who do not have learning disabilities (e.g. CAGE, the Readiness to Change Questionnaire). Both studies gathered data at baseline and at the end of the course. Basic descriptive statistics appear to have been employed; however, the level of detail is limited.

The PALS study, undertaken by Demers and colleagues (2000), gathered data from teachers and from students. The instruments appeared to have been developed by the PALS staff; the reliability and validity of the instruments is not discussed. Data were collected from the teachers at baseline, immediately after the training and at the end of the academic year. Data were collected from the students at baseline, just before the winter break and at the end of the academic year. Descriptive statistics were used to analyse the data from the teachers, whilst descriptive and inferential statistics were used to analyse the data from the students.

5.4.2.7 Results

The tobacco-related knowledge levels of the participants in the study undertaken by Kelman and colleagues (1997) were higher post-intervention than they had been at baseline. While this may suggest that the intervention holds ‘promise’, the small sample size (n=5) and lack of control group mean that little can be deduced from the results.

Tracy and Hosken (1997) report that three of their 11 participants had quit smoking by the end of the course and three had cut down the number of cigarettes that they smoked. While this self-report data is of interest, no objective evidence is provided (e.g. CO levels) to back-up the self-report data. Also, knowledge levels are reported as increasing, but no scores are provided.

When considering the effect of the alcohol-related interventions, Steel and Ritchie (2004) report that the knowledge score of their one participant rose from 8 at baseline to 14 post-intervention (potential score 0-20). Again, the sample size and lack of control group negate any generalisation of the results.

Mendel and Hipkins (2002) report an increase in readiness to change alcohol-related behaviour following delivery of their intervention. However, as the participants had no access to alcohol (they were currently in secure accommodation and no details of their release dates were provided), the relevance of moving participants into the ‘action’ phase is difficult to judge. Again, the sample size was small and there was no control group.
Finally, the study that focused on the use of tobacco and alcohol (Demers et al., 2000) found that on all 7 criteria, the performance of the students in the intervention group was higher or more positive than that of students in the control group. The seven criteria included use of alcohol and tobacco, peer pressure and self-image. While the scores were higher in the intervention group than the control group, the difference was not statistically significant. The authors speculate on the reasons for this, but do not appear to consider the size of the sample. No power calculations were discussed.

5.4.2.8 Quality Ratings (QR)

The methodological quality of the papers reviewed was generally poor, with two of the papers scoring 2 out of 7 (Kelman et al., 1997; Tracy and Hosken, 1997), two scoring 3 out of 7 (Steel & Ritchie, 2004; Demers et al., 2000) and one scoring 4 out of 7 (Mendel & Hipkins, 2002).

5.4.3 Discussion

This review has demonstrated that worldwide, the body of evidence that has focused on the development and testing of tobacco and alcohol-related interventions for people with learning disabilities is small (n=5). While the studies identified have significant methodological limitations, important issues linked to the feasibility and appropriateness of health promotion interventions for this client group have been highlighted. The reported studies focus, on the content of the interventions and their mode of delivery, thus demonstrating an awareness of the need to tailor interventions to meet the specific needs of PwLD. Importantly, some of the studies also commented on the participants’ level of engagement with the intervention.

To summarise the methodological limitations, the studies were generally conducted with very small convenience samples. Only one of the studies used a control group. None of the studies were hypothesis-driven, which would be expected when assessing effectiveness. Details of the data collection and analysis processes were weak in most studies. An additional issue is that only two of the five studies appeared to be underpinned by theory i.e. the two alcohol-related studies used motivational enhancement techniques, with one also incorporating the concept of Readiness to Change, which links to the Transtheoretical Model of Behaviour Change (Prochaska & DiClemente, 1992). This is surprising as the expectation would be that studies designed to increase knowledge (as most were) would be underpinned by an appropriate learning theory (e.g. behaviourism) and that interventions designed to alter behaviour would be underpinned by appropriate behaviour change theory (e.g. social cognitive theory).

Another relevant point is that a number of the studies reported making alterations to existing interventions. More information regarding specific adaptations would have been informative.
5.4.4. Conclusion

In sum, this systematic review of the literature has demonstrated that little is currently known about what approaches are effective in addressing the tobacco and alcohol-related health promotion needs of people with learning disabilities. The review has provided some limited evidence on the feasibility and appropriateness of particular health promotion approaches.

The gap in the current evidence-base is clear. There is, therefore, an urgent need to develop tobacco and alcohol-related health promotion interventions for this client group and to ensure that the effectiveness of these interventions is tested in appropriately designed trials.

6. Focus group study

6.1 Objectives

Several objectives were identified for the focus group study; namely to explore with people with mild-moderate learning disabilities,

- their views on the use of tobacco and the consumption of alcohol,
- factors that they perceived as influencing their own use of tobacco and alcohol,
- their knowledge and understanding of the health risks associated with smoking and excessive alcohol consumption,
- their views on their own tobacco and alcohol-related health promotion needs, and
- their views on appropriate tobacco and alcohol-related health promotion approaches.

As discussed above (section 3.1), a qualitative approach, underpinned by social cognitive theory, was selected as this enabled an exploration of the participants’ views and perspectives and demonstrates congruity with the research aim and objectives (Meyrick, 2006).

6.2 Methods

6.2.1 Sample

The sample was recruited purposively (Kuzel, 1999) from two NHS Board areas in the West of Scotland. This provided geographical spread and ensured that participants were recruited from both urban and rural locations. We recruited through voluntary organisations. A number of organisations were contacted by
telephone and email and, where possible, face-to-face meetings were arranged in the first instance, with the managers of the various organisations and then with potential participants. We recruited successfully from four organisations. The sample comprised PwLD who had views they wished to share with regard to tobacco use and alcohol consumption.

Recruitment was conducted on a face-to-face basis and was supported by the use of information resources developed specifically for the project, including participant information (appendix 5) and consent forms (appendix 6), and a recruitment DVD. Guided by the expertise of members of our advisory group, the participant information and consent forms were designed to be accessible by people with a range of communication difficulties/impaireds. This was achieved by simplifying the language and by using graphics to illustrate meaning. The DVD featured AM talking through the information provided on the participant information sheet and consent form. This medium enabled potential participants to get to ‘know’ AM, to familiarise themselves with the information, and to share the information with family members and others who might help them to decide whether to participate.

Approximately 50 recruitment packs were distributed. Twenty signed consent forms were initially returned to AM; however four people subsequently elected not to participate in the study, either by failing to attend the focus group discussion at the agreed date, and/or by stating on the telephone that they had changed their mind.

In total, sixteen PwLD participated in six focus groups (January-May 2009). Support workers who, amongst other things, provided communication support, accompanied eight of the participants. All participants supplied written consent prior to the commencement of the focus groups.

6.2.2 Data collection

Focus groups were selected as the means for collecting data from PwLD, as this method of data collection has previously proved successful with this population (Fraser & Fraser, 2001). The focus group discussions were led by AM, who has experience both as a specialist community learning disability nurse and as a focus group moderator. Members of the project team who have focus group experience and experience of working with people who have a learning disability (SK & ML) supported AM as co-moderators. As the research team was keen to ensure that PwLD had an opportunity for meaningful engagement, rather than tokenistic involvement, we made efforts to create an environment that enabled the ascertainment of the views of PwLD (Fraser & Fraser, 2001). For example, to engender a sense of security, the focus groups were conducted in venues familiar to the participants, and ground rules such as respecting one another’s
right to contribute without interruption, were agreed prior to the commencement of the focus group discussion.

A semi-structured interview schedule (appendix 7) was developed to support group discussion. Visual aids (appendix 8), including empty cigarette packets with pictures of diseased organs and empty beer/wine bottles, were assembled to stimulate discussion on specific issues.

To allow for comfort breaks, to help draw a distinction between the two topic areas i.e. ‘smoking’ and ‘alcohol’ and to assist with issues related to the attention span of the participants, the focus groups were paused midway. Food and soft drinks were also provided during this break in proceedings.

Demographic data were collected from participants prior to commencement of the focus group (appendix 9). Participants who needed assistance with this were helped by their support workers or by the researchers, as appropriate.

All focus groups were recorded digitally using an Olympus recorder and software. The digital recordings were transcribed verbatim and the anonymised text was checked for accuracy before being entered into the qualitative analysis software package, QSR NVivo v.8.

6.2.3 Data analysis

The analysis of the data was undertaken by AM. The transcripts were read to identify units of meaning (first level nodes) which were then grouped together to form themes (second level nodes) from which were described broad domains (third level nodes). SK supported AM throughout the process and the findings were peer reviewed by SK and ML. The broad topic areas in the interview schedule (appendix 7) were used to guide the initial stages of the data analysis process.

6.2.4 Verbatim quotes and presentation of findings

Verbatim quotes have been used to illustrate the main findings. Individual participants are identified by using the codes PwLD (person with a mild-moderate learning disability), by participant number (i.e. 1-16) and gender (M (male); F (female)). Each quote also includes the relevant focus group number (i.e. FG 1-6).

To aid understanding and to ensure anonymity, text describing group interactions, replacing missing words or replacing names of individuals and specific locations has been inserted in square brackets within the quotes.

As some of the participants had communication impairments, AM made efforts, during the course of the focus groups, to ensure that participants’ intended meaning was understood. This is reflected, as appropriate, in the verbatim quotes with the
addition of words to aid the reader’s understanding of the participants’ intended meaning. These insertions are presented in square brackets.

The findings are presented in the following section, using four headings that link to the study objectives,

- Views on tobacco use/alcohol consumption and what influences its use
- Knowledge of the health risks associated with smoking/excessive alcohol consumption
- Health promotion needs
- Appropriate health promotion approaches

6.3 Findings

6.3.1 Demographic data

As indicated in Table 5, twelve of the participants were male and four were female. The disproportionate number of male participants may, at least partially, be influenced by the fact that some learning disabilities are genetically determined and are specifically associated with male gender (NHS Scotland, 2004) i.e. more males than females have learning disabilities. The median age was 38 years, with the range being 18-64 years. All participants were single and all were white, European (table 5). Three participants worked part-time, one in a voluntary capacity.

The DEPCAT scores were derived from participants’ postcodes, using the Carstairs scoring system (McLoone 2001). DEPCAT scores are calculated using indicators of disadvantage and are a method of quantifying levels of relative deprivation or affluence in localities throughout Scotland. The scoring system ranges from DEPCAT 1 (the most affluent postcode sectors) to DEPCAT 7 (the most deprived). As indicated, the majority (62.5%) of the participants were living in areas of high socio-economic deprivation (i.e. DEPCAT scores of 6 and 7).

As indicated, seven of the participants were current smokers, with 3 being former smokers. The number of cigarettes smoked on a daily basis ranged from 10-40, with an additional participant stating that she smoked occasionally, generally when she was socialising. Twelve of the participants stated that they currently consumed alcohol.
Table 5. People with Learning Disabilities: demographic data

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>12</td>
<td>75</td>
</tr>
<tr>
<td>female</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 25 yrs</td>
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</tr>
<tr>
<td>25-34 yrs</td>
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6.3.2 Views on tobacco and what influences its use

6.3.2.1 Initiation and continuation of smoking

The factors that had encouraged the participants to start smoking were explored. The pattern of experimenting with tobacco and/or starting to smoke discussed appeared to reflect that of the general population (ISD, 2009). The current/former smokers had generally started to smoke in their teens.

The most common reason for starting to smoke was peer pressure, a factor previously reported in research undertaken with other populations (ISD, 2009).

*PwLD3 M:* I’ve been smoking at sixteen because ma pal [said], ‘If you smoke, I’ll let you be in my team, in my gang.’ so I thought, ‘Oh fine, I’ll smoke.’ (FG01)

The influence of family members who smoke and being exposed to a smoke-filled environment also appeared to play a part in the initiation of smoking,
PwLD8 M: They were all smokers, ma grandparents, and that so I was surrounded by smoke. (FG03)

For a small number of the participants, smoking was seen as a way of coping with day to day life stresses,

PwLD2 F: I wis sixteen and I wis out the house and I wis livin in a hostel and just so much pressure because I got diagnosed with depression at sixteen and then fae there I just smoked. (FG01)

A number of non-smokers participated in the focus groups and they described their thoughts about smoke and smoking. For one participant, the smell had been enough to put him off,

PwLD6 M: All I really have tae dae to get ma fill of that is to go past ma mum and dad’s bedroom and that was it … totally put off! Just absolutely bogging [horrible]. (FG03)

Another individual, who under the influence of peers had tried smoking, quickly realised it was not for him,

PwLD11 M: Ma pal used tae smoke and … he said, ‘Man, have a wee smoke.’ So I took a smoke and naw, I don’t like it cause ma heed went roon and roon and I went, ‘It’s no’ for me, I don’t like it.’ (FG05)

When considering the reasons that the participants continued to smoke, boredom and stress relief were discussed,

PwLD7 M: It jist gives you something to do. (FG03)

PwLD8 M: Stress relief with life and if you’re depressed … [smoking] helps it. The [number of] people I lost in ma family, it’s just coping wae [that], it’s helping. (FG03)

Interestingly, one participant who initially said that he smokes to help cope with stress, demonstrated some insight as he acknowledged that smoking may not actually help to reduce stress,

AM: How does [smoking] help your stress?

PwLD12 M: I don’t know, I just think it makes you worse. (FG05)

When asked to discuss the reasons that they continued to smoke there was no overt mention of addiction or habit, which is an important issues in terms of knowledge and understanding.
6.3.3 Knowledge of the health risks associated with smoking

Following the discussion of factors that influenced the initiation and continuation of smoking, we sought to explore the participants' knowledge of the associated health risks.

The participants discussed the issue of smoking-related ill health in detail. However, at times, it was evident that understanding of physiology and terminology was limited and it was apparent that there was often a limited in-depth understanding of the specifics. That said, most participants demonstrated a basic level of understanding, as the following examples demonstrate.

One smoker described some of the extreme consequences of her smoking-related cough,

\[ PwLD2 \text{ F: If you've got a really bad cough, your lungs end up all sore, because my cough's been so sore [I'd] end up fracturing a rib again ... through my coughing. (FG01)} \]

A younger participant, who had recently stopped smoking, picked up the empty cigarette packet with the picture of someone with throat cancer, which was one of the visual aids that we provided, and observed,

\[ PwLD 3 \text{ M: Right, see when you smoke, it will tell you on the packet right, see that there [shows picture on cigarette packet] ... that's what you can get. (FG01)} \]

When asked what ‘that’ was, his response was that he did not know, which suggests that he had grasped the health promotion message that it was not good to smoke, but that he did not fully understand the specific health implications. Similarly, although other participants raised the issue of the link between cancer and smoking, their understanding appeared superficial,

\[ PwLD4 \text{ M [person with communication difficulties]: I, you cancer ... smoking cigarettes ... you could die, couldn't you? (FG02)} \]

\[ PwLD8 \text{ M: It can spread throughout all parts of your body and sometimes you can't cure it. It could spread through your back and then all around your body, which kind of sucks, even when you find you've got it. (FG03)} \]

\[ PwLD2 \text{ F: ... but then you smoke all the tobacco so [it goes] inside your body ... it can cause cancer. (FG01)} \]

The relationship between smoking and heart and lung function was also raised in the focus groups although, again, this appeared to demonstrate a basic level of understanding. However even this basic level of understanding is important, as it
demonstrates that important health promotion messages are being taken onboard by PwLD,

\[ PwLD8 \text{ M: Your lungs and your heart yeah, what's the thing about your lungs? What's that important stuff? Breathing! You need to breathe [or] your lungs go black, and that's you. (FG03)} \]

\[ PwLD14 \text{ M: It's bad for your lungs. It can go in to your chest ... and give you a heart attack. (FG06)} \]

Perhaps the most basic of health promotion messages in relation to smoking and ill health is illustrated by the quote below. The message is simple but the point is certainly not lost,

\[ PwLD13 \text{ M: All I know [is] you would die from it eventually. (FG05)} \]

In addition to the above, we sought to explore the participants’ understanding of the health risks associated with environmental tobacco smoke (i.e. passive smoking). Non-smokers voiced concerns about the effects of passive smoking on their health,

\[ PwLD6 \text{ M: Well I used tae hang aboot wae guys and they were smoking and we would just be in the same atmosphere. Big worry for me ... (FG 03)} \]

\[ PwLD13 \text{ M: That's a known fact ... passive smoking is worse for the person that's breathing it in [than] the person that's dain the smoking. (FG 05)} \]

As can be seen in the above quote, while there was an awareness of the danger, of environmental tobacco smoke, knowledge was not always accurate.

Recent health promotion television advertising campaigns regarding the effects of passive smoking appear to have been successful with regard to getting the message across to PwLD, as the following example indicates,

\[ PwLD3 \text{ F: Aye that's a good [advert] and then [you] see all the smoke going in like to the baby and everything, do you know what I mean, and all the smoke and everything, and then it's going everywhere, do you know what I mean? (FG 03)} \]

However, whilst this quote demonstrates that the dramatic nature of the advert does appear to be conveying the message that smoking is harmful, it does not show whether the participant had understood the underlying, more complex, health promotion message.
Most participants supported the recent smoke free legislation (i.e. the ban on smoking in public places), with both smokers and non-smokers supporting the change in the law, and the comments made suggested an awareness of the dangers of passive smoking. For example,

\[ PwLD11 \text{ M: [the ban is] a good thing, it means [cigarette smoke is] no’ going to pollute the air. (FG 05)} \]

\[ PwLD16 \text{ F: Aye they’ve banned it now ‘cause too many people smoke … in the pubs, and it [smoke] comes to other folk. (FG 06)} \]

Some of the participants who were non-smokers exerted control in their homes indicating that they did not allow visitors to smoke,

\[ PwLD5 \text{ F: If I have people up at my house I have one rule, smoke outside! (FG 03)} \]

Participants who were living in individual flats within a supported group-setting also reported exerting control over their home environment, imposing a smoking ban on other residents, support staff and visitors,

\[ PwLD16 \text{ F: … they’re [residents, support staff and visitors] no’ allowed tae smoke in people’s houses … If they want tae smoke, they can go out the back. (FG 06)} \]

Finally, some of the smokers within the groups demonstrated their consideration for others when smoking,

\[ PwLD7 \text{ M: When I smoke, I don’t sit near them. When I’m smoking, I go somewhere else and smoke. (FG 03)} \]

\[ PwLD8 \text{ M: I don’t smoke in the house no, if I go smoking I’ll go out somewhere and go for a smoke, down to the beach or something, out of people’s way. (FG 03)} \]

6.3.4 Health promotion needs

6.3.4.1 Previous attempts to stop

When exploring their tobacco-related health promotion needs we asked the participants to discuss any previous attempts to stop smoking. A small number of participants had either stopped smoking or were in the early stages of contemplation and planning to stop. One participant who had attended the local pharmacy and, with the help of his Support Worker, was following a smoking cessation programme, had set a date upon which to start his quit attempt,
PwLD1 M: I’m gonnae stop, on Tuesday … when I finish that packet [of cigarettes], my last packet, I’m buying nae mair. (FG01)

For other participants, the habit of smoking was proving more difficult to break due to other factors impacting on their lives, and of course the fact that nicotine is highly addictive (Royal College of Physicians, 2000). A number of the participants who were smokers reported that they had made attempts to stop smoking over the years. One who had previously tried to quit and failed, asserted that she still wanted to stop smoking and would try again,

PwLD2 F: I tried eh two year ago, before ma dad’s illness got worse … I got the patches … that time wisnae a great time … I waited, and everything wis fine but … something came up, happened, and I had tae deal wae that and I thought that wisnae [the] right time … I’m gonnae try the, no’ the chewing gum, but the tablet. (FG01)

A male participant described a similar process of failed quit attempts,

PwLD8 M: I find it a bit hard to try and quit smoking. I’ve managed to quit before … just [by] no’ goin oot as much and stayin in the house. I can do without them. I’ve managed to stop for a few months and then went back on it. Last time I stopped was before Christmas … I went without them for three weeks. It was tough but I managed. (FG03)

It is important to acknowledge in this context that it generally takes a number of attempts to stop smoking before being successful (NHS Choices, 2009).

6.3.4.2 Influence of family and friends

In terms of addressing their health promotion needs, often, ‘other people’ exert a considerable influence on the lives of PwLD (Smyth & Bell, 2006), and decisions around smoking, or whether to stop smoking and how, are subject to similar powerful influences.

PwLD5 F: Yeah, my mum and dad, they’ve stopped twice, eh, I think they’re totally off it right now … it was my mum’s health and my dad’s chest [problems] [that made them quit]. (FG03)

PwLD6 M: Well, my mum had stopped for a while, I think she managed to stop [for], I don’t know, two or three years, [then] my dad passed away and that kicked her off again. (FG03)

Personal accounts of successful quit attempts may be used to exert a positive influence over decision-making. These participants were discussing the use of nicotine patches and gum,
PwLD11 M: Her support worker, she got them [patches] ... ever since I've not seen her smoking, I think that helped. (FG05)

PwLD15 M: Well my dad’s trying to stop smoking. Well, he’s trying chewing gum, the kind to help him stop smoking. (FG06)

Similarly, if an individual has experience, directly or indirectly, of a failed quit attempt, this may influence thoughts regarding the usefulness of the method,

PWLD 16 F: Ma pal stopped smoking but she stopped it for a couple of weeks and wanted tae go back on it again. She couldnae stop smoking but she had they wee patches, she had they wee patches, and they didnae work, [she] took a wee fag. (FG06)

6.3.4.3 Other factors that might encourage a quit attempt

For any individual, a trigger or reason to make a quit attempt is required, and amongst the general population, such factors may include perceived health benefits and the opportunity to save money (Kerr et al., 2006). PwLD require similar triggers/reasons, however, for this client/patient group these should be concrete/tangible rather than abstract. If PwLD can be helped to understand, at a basic level, the benefits to health, this basic understanding provides a foundation from which important health promotion messages may be developed,

PwLD3 M: [Smoking is] bad for you so … when you’re [agitating] for a cigarette … just say, ‘No, it’s bad for me. I shouldn’t be smoking anyway.’ (FG01)

For some participants, the cost of smoking was proving to be a sufficient incentive to make them consider quitting,

PwLD12 M: [cigarettes] cost a fortune … nearly three pound for a packet of ten and nearly seven or six pound [for twenty]. If I was [to] pay a tenner for a packet of twenty fags, I would not pay it. (FG05)

However, in recent years, following the move to community-living, many PwLD have had their Social Security benefits maximised and they have a reasonable amount of disposable income (Gillespie et al., 2007). Therefore, for some participants, expense exerted only a limited influence on their smoking habit,

PwLD8 M: I only have ten a day so that’s less than smoking forty a day, ten’s more better than buying twenty, twenty’s quite a lot of money to go. (FG03)
6.3.4.4 Knowledge and experience if formal/informal services and resources

Participants demonstrated a level of awareness with regard to the formal methods of smoking cessation support. Most of the available methods were discussed (e.g. nicotine replacement therapy, one-to-one support, group support) and a range of first hand experiences were reported. Some of the attempts made by participants and the methods used (nicotine patches, chewing gum and ‘tablets’) were highlighted in previous sections. In one focus group, a participant recommended using a nicotine inhalator and offered advice on its use,

_PwLD3 M_: I know what you could use [addresses support worker], see that white stuff [nicotine powder capsule] you put a wee, you put in a wee eh thingy [holder, shaped like a cigarette] … you lock it in … you can try one of them. (FG03)

For some participants, smoking cessation advice had originated from health professionals, and with essential support from Support Workers, attempts to stop smoking were progressing. For one individual, GP advice, the backing of a Support Worker and a coincidental quit attempt being made by a family member appeared to be a successful combination to support his own quit attempt,

_PwLD3 M (Support Worker)_: [the doctor] suggested that it would be good for him, one of his doctors suggested it would be better to cut down. Yeah, he suggested it would be a good idea for him … he wanted to as well, his mum was giving up at the same time … (FG01)

As described above, specific methods and formal approaches may exert a positive influence on an individual’s smoking habits, however as the account below demonstrates, the success of such strategies may be enhanced if encouragement and guidance from a key individual are forthcoming. In addition to exerting a positive influence on an individual’s health behaviour, this approach may also positively influence the support person e.g. a member of the Support Staff.

_PwLD10 F_: (Support Worker) [the pharmacist] gave you a leaflet … away with you as well, didn’t they? We just kind of went [to the pharmacist] … and then as [PwLD10] progressed [the pharmacist] cut … down [the dose of nicotine replacement therapy], yeah and, went in every week to pick [the patches] up. [PwLD10] was telling everybody else [residents and support workers] about it, didn’t you? I took a look at the feedback sheets as well, and some of the other workers that were here as well. [Remember] you told [name]? and she [said], ‘Good on you! if you can try, it so can I.’ (FG04)
6.3.4.5 Choosing to continue smoking

Many PwLD, like the general population, take a decision, informed or otherwise, to continue smoking,

PwLD4 M (Support Worker): The GP has raised the issue because they know he smokes, so they have said to him just about probably every time he goes in, ‘Are you still smoking, [name]?’ and they have said … ‘It’s bad for you,’ …

Researcher: Do they suggest any help?
PwLD4 M (Support Worker): Well, not really … [name is] quite a determined person, so to try to stop him smoking, they realise he’s not interested and I think, you know, that if you [are going] to stop smoking, he needs to be interested. He knows, you know … he knows the risks (FG02)

This anecdote suggests that for PwLD the desire to stop smoking needs to be ‘owned.’ Others may influence the decision but ultimately, individuals will decide for themselves.

In terms of health promotion needs, what has been highlighted is that, similar to the generally population, some PwLD have tried to stop smoking and have been successful, some have tried to stop smoking and have failed and a few people are just not interested in trying to stop stopping. What we have sought to explore in this and the previous section is what the potential triggers might be that would encourage cessation attempts in this client/patient group. A key role for professionals and other who have contact with PwLD is to ensure that they are provided with accessible information and advice about smoking/smoking cessation on a regular basis so that they can make as informed a decision as possible about continuing to smoke or attempting to stop. If making a cessation attempt, high levels of support are likely to be required. The participants’ views of approaches that might be appropriate to encourage/support cessation attempts are discussed in the next section.

6.3.5 Appropriate Health Promotion approaches

6.3.5.1 Smoking cessation support and advice

Participants were asked what, if any, specific advice could be targeted at PwLD. This was explored in some detail and suggestions and recommendations for practice were identified. The input of the Support Staff, whose recommendations and suggestions complemented the views of PwLD, was of particular value.

When discussing the possibility of PwLD accessing mainstream services and smoking cessation groups in particular, some individuals highlighted the difficulties experienced by some PWLD with regard to understanding complex health messages. Several participants wondered whether staff working in mainstream services could tailor services to meet the learning needs of individual PwLD.
However one participant was of the opinion that PwLD should have the opportunity to attend mainstream support groups,

\[ \text{PwLD12 M: I think it [would] be good for everybody, no’ just [people with] learning disabilities but other people, we were all born in the same world. (FG05)} \]

The opportunity for PwLD to attend groups along with an advocate could enable their participation in mainstream smoking cessation groups, as demonstrated in the following exchange between a participant and his support worker,

\[ \text{PwLD1 M (Support Worker D): The chemist can give you [an information] pack and you can phone up the number for smoking cessation groups.} \]
\[ \text{PwLD1 M: Do you want to phone it up for me, [name]? Do you want to phone it up for me?} \]
\[ \text{PwLD1 M (Support Worker F): … would you like to go to a group, would you?} \]
\[ \text{PwLD1 M: If you took [me].} \]

One participant proposed radically, that PwLD could be taken to see at first hand, the adverse health effects of smoking,

\[ \text{PwLD6 M: See my dad, he died of emphysema, which you probably know can be smoking related. I would say that somebody with a learning disability [should] see [that] pretty blooming deadly disease in action, it would change their mind, like that [clicks fingers]. (FG03)} \]

Although this particular suggestion is rather extreme, it does provoke thought regarding the various media by which health promotion messages may be conveyed. Less radically, a few participants suggested that giving individuals the opportunity to sit and discuss an issue on a one-to-one basis would be beneficial, and in particular for those who do not have good literacy skills. For example,

\[ \text{PwLD14 M: [Some people] need help … if they cannae read or write. What about people going into a shop [where] people sit in a seat and talk [to you] aboot it. (FG06)} \]

The issue of using pictures to supplement the written word was discussed and participants were asked about the pictures of smoking-related diseases on cigarette packets. Some people, as described above, thought that these images were sufficient to deter people from smoking. However, while the message and the impact of the photograph were thought to be powerful strategies, by some, other were cynical about the effect,

\[ \text{PwLD5 F: See if somebody’s addicted, right, I think I’d say fifty per cent wouldn’t even look at that picture, it depends what side they’re opening it on. I don’t think they’re going to really take much notice. (FG03)} \]
PwLD13 M: It is a good thing, but most people just ignore these things. (FG05)

6.3.6 Summary

In sum, the reasons that PwLD start and continue to smoke appear to be similar to the general population. The majority of the study participants appeared to have a basic understanding of the health risks associated with smoking, including the risks of environmental tobacco smoke. When considering the health promotion needs of PwLD, professionals need to be aware of the factors that encourage them to continue smoking and, importantly, the triggers that can encourage cessation attempts. It was clear from what they reported that with appropriate help and support smoking cessation attempts could be successful. While the input of health professionals (e.g. pharmacists) appeared to be important, the need for regular support from support workers and/or family members was evident.

6.3.7 Views on alcohol and what influences its use

All but one of the sixteen participants reported that they had consumed alcohol and 12 were current drinkers. Nine of the participants stated that they had drunk excessively at some point in their lives, although most believed that they were now drinking within the sensible drinking limits.

6.3.7.1 Initiation of drinking

When the participants were asked to discuss the reasons that they had started to drink alcohol, peer pressure was discussed.

PwLD6 M: Mostly when I was younger it was mostly cider because you can get drunk, a high CO2 content goes to your head a bit quicker and [you] get plastered [drunk] … I was dain it every single night me and my mate … through my teens. (FG03)

PwLD13 M: Somebody … actually forced [alcohol] on me literally … a couple of them [said to me], ‘You’re a coward!’ … I was only seventeen, just turned seventeen, just turned the age to get drink, they gave me vodkas, a line of vodkas on the mantelpiece, a line of them, the wee halfs, all straight vodkas, and they said, ‘I bet you couldn’t drink all these!’ So I did, oh! … that’s where it started … (FG05)
As might be expected, participants’ reports of their drinking habits and the amount of alcohol consumed varied considerably. For example, one individual summed up his feelings about why he only drank a limited amount of alcohol,

PwLD4 M: I don’t, don’t, don’t, don’t feel right wae two pints … fu Rabbie Burns, weren’t ye? (FG02)

As this participant had communication difficulties, his support worker expanded on what had been said, and described the level of choice and control the PwLD had in his life, and the decisions he made in relation to his drinking,

PwLD 4 M [Support Worker]: Em, the only thing I can say is [PwLD4] enjoys a drink, he’s not a heavy drinker but [he] will have a pint of shandy, and it’s his choice when to have it or not, if you’re out for a night at a party, or at the summer ball, or wherever, [he’ll] maybe have two or three pints, but that’s his choice, but he knows when to stop … because he knows what he wants, or doesn’t want. His pal will bring … a bottle of lemonade and they will share a can of beer, but it’s always in his house, and it’s his choice if he wants it … (FG02)

Other participants described similar, moderate drinking habits,

PwLD6 M: You’re lucky if I have it once a month. (FG03)

PwLD16 F: I just have a drink at the weekend … I drink … martini … I put lemonade in it, and I take eh, Budweiser. (FG06)

PwLD13 M: Aye only a couple noo … about three times a week … sometimes only two. (FG05)

PwLD15 M: Yeah I drink, I drink only like a few weeks, I don’t drink every night … Budweiser … only three …Yeah, it’s enough and cause I’m not, I don’t drink much, that’s how many I take. (FG06)

However, some participants were drinking excessively, including ‘binge drinking’ as the following examples indicate,

PwLD8 M: Quite a lot, I’d go through a few bottles of vodka and then go on Jack Daniels and then probably cider and then beer … and then After Shock. (FG03)

PwLD7 M: On Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday … every day, aye … Em, twelve bottles of beer … em, a couple of glasses of wine, blue WKDs, a bottle of blue WKD em, em, red cola that’s like vodka … I usually start drinkin about … six o’clock at night and that would be me to em, one o’clock, two o’clock. (FG03)
6.3.7.3 Reasons that PwLD continue to drink

When asked why they continue to drink, reasons akin to those observed in the general population were discussed (e.g. Scottish Government Social Research (SGSR), 2008). For example, alcohol was viewed as a social lubricant,

PwLD6 M: You wouldn’t chat up a woman [if you didn’t have a drink first]! I did that at ma mates party … I had no idea what I was saying half the time, we, literally, we couldn’t remember our names [laughter]! (FG03)

PwLD11 M: Say like the fibaw team wins, you want to go out and celebrate, dancing, eh, parties, if you want tae drink, I know it’s no’ a nice thing to say but, some people drink at a funeral after somebody in their family gets buried or cremated they go for the [wake], and [you] have a drink at a wedding. (FG05)

However, for some, who were drinking excessively alcohol consumption was associated with mental health problems, as one participant described in the following exchange,

PwLD7 M: I think because I’ve got em, em mental health problems, I like to block it but some of the time its difficult, and I wake up in the morning and I’ve done something wrong, because the polis has been at my house and said I’ve phoned them half a dozen of times [and they say], ‘Why are you [calling] us oot here?’ it’s just because, em, if you drink too much like I do, you lose yourself completely, you get scared and you don’t know what tae dae. You want somebody to talk to but, em, I’m sad because I have to phone polis and just say to the polis, ‘Look …’ and if they know me … they’re sympathetic and if they don’t know me, they’re no’ …. PwLD6 M: That’s got a bad side as well though because you phone them up and then they say, ‘It’s just, [name], dain his thing,’ and you might actually need them. PwLD7 M: I know exactly aye but. (FG03)

Others linked excessive drinking to difficult events in their lives, including bereavement,

PwLD5 F: Basically … what I was going through was a very difficult time, because I lost my granddad, and then my mum and dad they were moving [abroad], and then at the same time I was getting victimisation … and basically before that it was my marriage breakdown, right, and that was messy … (FG03)

PwLD8 M: I know I used to drink heavy a lot, but you know, when I lose someone I care about, that I love close, and it just feels like I’m building up
anger and ready to explode, I find that, if I go for a drink, it’s safety, it’s kind of like to stop the pain and anger and hate, because they wouldn’t listen to you. (FG03)

A number of the participants described having altered excessive drinking habits. They had reduced their levels of consumption, or cut out alcohol altogether,

PwLD1 M (Support Worker): He used to go to the pub quite a lot, but he’s swapped the pub for café … [he drinks] cappuccinos now. (FG01)

PwLD2 F: Naw I gave it up … I’ll never say that I’ll never drink, right, but I just take wan day at a time saying I’m no’ takin a drink. Two year[s] I had to give it up … I wis a heavy drinker oh, fae twenty-four right up to twenty-nine, I never drank in ma thirties, I didnae drink in ma thirties and I’m thirty wan and I’m thirty-two now (FG01)

PwLD7 M: It’s been going on for about em eh a good year and a half, I used to drink a lot and get myself into a lot of problems. (FG03)

While others had had to moderate their drinking because of health conditions such as diabetes, or because of the side effects of certain types of medication. For example,

PwLD6 M: Now, I’ve got my diabetes, I’ve had that for the past 9 years, I’ve had to obviously cut [alcohol drinking] back a lot. I particularly remember one session when ma mate was up at his house, this was all in one evening, and me and him drank two twenty-four packs of Tennents [lager] between us … you could say I was pretty steamin [drunk] when I went hame! You know, to say I wis pretty pissed would have been an understatement! … I’m surprised I got home alive [laughter]. We used to do that every night, and we were drinking cider. (FG03)

PwLD16 F: We [PwLD] are no’ allowed, we can only take so much drink with our problems, the doctor [said] we can only have four or five, that’s the limit … I’m on tablets and they’ve got, I’m no’ being cheeky here, but I’ve bad balance and in case I fall and that, and you go to the doctor, you can’t … say people go in and drink, we only can take one, that’s aw we can take, cause if we take more than that, our balance goes away. (FG 06)

6.3.8 Knowledge of the health risks associated with alcohol

The participants discussed the potential negative sides to drinking alcohol, and their perceptions mirrored those of the general population (e.g. Peggy et al, 2006). For example, participants discussed amnesia, negative effect on mood, weight gain, nausea and hangovers,
Everybody called me a Lambrini girl … I used tae wake … [and] I used tae say tae maself, ‘Am I in ma own bed, or am I in somewhere else?’ … half the time I wis somewhere else. (FG01)

If you’re fed up and it just makes you tired, you just want to go to your bed and lie down, and that makes you crabit sometimes, I think it makes you crabit. (FG06)

and if you drink a lot, you can put the weight on. (FG06)

It makes you feel sick and you have a stinking hangover in the morning. (FG03)

Participants’ awareness of the negative sides to drinking extended to some of the more serious issues associated with drinking alcohol to excess, such as symptoms of withdrawal, dis-inhibition, antisocial behaviour and domestic violence. Some participants described both their own experiences and their observations of the consequences of excessive drinking in others,

Aye, it wis really hard because I had the DTs [delirium tremens] … I wis in hospital because I wis hallucinatin, I wis freekin oot and aw that … I can only remember bits aboot it. (FG01)

And then you get all these ones that drink too much, aw these young wans that are walkin aboot wae blades an’ that … especially doon ma area … hingin aboot the streets or hingin aboot the close drinkin and all that … leavin their mess for me tae clean up … I’ve got bottles throwin in ma garden, so the neighbour says tae me last year, I didnae know you were back on the drink!’ I says, ‘I’m no’ on the drink … they’re no’ ma bottles … it’s the boy upstairs pals’ bottles.’ (FG01)

Indecent exposure, goin about the street butt naked and doing something stupid … in front of a police station. (FG03)

One participant described having experienced physical abuse at the hands of a relative who drank excessively, an experience, which appeared to have influenced his own drinking,

My first dad, both my fathers, had an alcohol problem … mum thought he was very, very abusive, he would come home every night drunk and, you know, thought nothing of giving mum a punching and [he] abused me a couple of times, you know, putting cigarettes out [on me] and my mum decided at that point [that] he was out the door. With me seeing all that, for a while my mum thought I was going in that same direction, but I’ve seen all they’ve done, and I decided, I made myself a promise that I was not going down that line (FG03)
The participants’ knowledge regarding the health problems known to be associated with drinking alcohol was less comprehensive than their knowledge of the health problems associated with smoking. However, participants were aware of an association between alcohol and liver disease, sometimes because of first-hand experience,

\[PwLD8\text{ M: It can cause liver damage. (FG03)}\]

\[PwLD2\text{ F: Ma liver wis unhappy for a while, so it wis, but the only way it wid repair itself is if I stop drinking, and my blood levels recently [have] been normal … it’s repaired itself, but it took a long time. (FG01)}\]

However, as previously stated, sometimes when an issue is expressed very simply, the impact of the message may be clear and powerful,

\[PWLD10\text{ F: I know one guy that drinks too much … he died … too much alcohol … it killed him … aye. (FG04)}\]

6.3.9 Health promotion needs

6.3.9.1 Knowledge and experience of alcohol services

The participants discussed health promotion needs, including the methods and supports available to help individuals to reduce or stop drinking alcohol. They identified generic healthcare personnel such as doctors, nurses and pharmacists, as well as specialist services, including rehabilitation units. As before, participants drew on personal experiences and anecdotes. One participant, who previously had been dependent on alcohol, had first-hand experience of a range of support services. When asked about her experiences of rehabilitation, which she had not found to be a positive experience, she described,

\[PwLD2\text{ F: I've been in rehab., I only lasted five weeks because it wis in the middle of nowhere … they dae groups, they dae groups or … you've got tae dae your chores, you go oot for walks, and you've got tae be supervised, you've got tae be in it more than four weeks, and [on] Friday you can go [into town] for a couple of hours. (FG01)}\]

However, her experience of locally based counseling services was more positive,

\[PwLD2\text{ F: Well, I went eh to [town] eh, to see the alcohol counseling … I wis [referred] there through the court … it wis jist a one-to-one. We had a group … [but] they cancelled it, so it wis jist a one-to-one but I liked ma counselor … and I still went back [on a] voluntary basis and a completed [the counseling] … but he jist sits there and listens tae you, but he wis a really nice guy. (FG01)}\]
This was similar to the experience of another female participant who described her experience of accessing a mainstream counseling service, however she had also accessed specialist Learning Disability services (LDS),

PwLD5 F: I got counseling through Women’s Aid ... and I got a lot of help through [an NHS LDS] as well, for what I was going through as well. (FG03)

Many participants were aware of Alcoholics Anonymous (AA), a national self-help organisation. Participants who had approached AA for support, described their varying perceptions of the experience; clearly for some, the service had not met their needs,

PWLD2 F: I’ve been tae AA, I went tae AA two year ago but its aw right goin tae it, but see tae be honest wae you, I don’t need tae go, because I could still go if I want, but I don’t need tae go. (FG01)

PWLD7 M: I’ve been there [AA], and I’ve done it, it doesn’t help, em, all they say is, like if you’re drinking twelve bottles, it’s just, ‘Why don’t you cut it down to, em, likes of, em em, take away a bottle, or take two bottles away, and [have] ten bottles?’ (FG03)

PWLD13 M: I stopped drinking by myself ... for six months, and then I went back on to it, went back on to the same routine, and then I phoned up somebody, they gave me a number and I phoned them up, and the AA came out. (FG05)

6.3.9.2 Understanding units of alcohol

The concept of ‘units of alcohol’ is complex and one. A recent Scottish survey found that only 50% of people were able to identify the number of units in a pint of beer, and only 15% were able to correctly identify the number of units of alcohol in a bottle of wine (SGSR, 2008). The complexity is compounded as alcohol is sold in varying volumes, of varying strength. For many PwLD, this degree of complexity makes the concept difficult to understand and almost impossible to apply to their actual drinking behaviour. Participants were generally aware that the recommended ‘sensible’ drinking levels for women are lower than those for men, and, when asked about the number of units of alcohol that is considered ‘sensible’, the responses varied widely,

PwLD6 M: Fourteen units for a woman, and I think it’s twenty something for a man ...

PwLD8 M: Is it thirteen units, or is it twenty? ...

PwLD2 F: It’s a glass, one glass or something for a woman ... and one of them for a guy [indicates the empty pint glass]. (FG 03)
PWLD15 M: on the label of the back of a bottle it tells you how many … how many drinks a woman and man can have … it’s three or four units [and for] a man it’s five or six. (FG 06)

An additional factor that complicates understanding of alcohol units is that they are now often discussed as ‘daily’ rather than ‘weekly’ limits (Scottish Government 2009). Daily limits are 2-3 for women, 3-4 for men, with a recommendation of two alcohol free days per week.

Any knowledge that the participants had of weekly/daily limits did not generally extend to having a good understanding of what actually constituted a single unit of alcohol. One female participant knew, for example, that the recommended daily amount for women is no more than three units a day; however, when asked to define ‘three units’, she replied,

PWLD2 F: Three glasses of wine, am I right? … Aye, small glasses, right? (FG 01)

While this participant’s knowledge levels were generally good, it should be noted that a small glass of wine (125mls) is more likely to contain 1.5 units of alcohol rather than 1 unit (12.5% abv). What the participant considered to be three units was therefore more likely to be at least 4.5 units. That said, her knowledge levels were probably similar to many in the general population (SGSR, 2008).

It was evident that other participants had great difficulty in understanding the concept of units, and one participant described the feelings of frustration generated by this complex concept,

PWLD13 M: Why can you no’ call it pints or glasses? I hate that word ‘unit’! That’s what drives people round the bend! (FG 05)

When asked if this is because people do not understand what a unit is he continued,

PWLD13 M: Exactly! That’s why [people] are getting fed up with it, you know what I mean, a lot of people say, ‘What’s a unit? Oh, I don’t know!’ (FG 05)

When considering the health promotion needs of this client/patient group, issues to take account of include the level of alcohol being consumed (quantity and frequency) by PWLD, their knowledge of the potential health and social effects of excessive drinking and their understanding of what constitutes excessive alcohol consumption.

6.3.10 Appropriate health promotion approaches

6.3.10.1 Advice and information

As with smoking cessation advice, the selection of appropriate communication media was a topic for discussion. The consensus was a preference for written information
supported by pictures and other visual information, and verbal reinforcement. Some participants described a need for verbal information and advice, and opportunities for the confidential discussion of alcohol-related issues,

*PwLD14 M:* You can go see somebody … get help … talk to somebody about it. Take them somewhere so people cannae listen … somewhere private. (FG06)

Some participants had been given advice concerning alcohol consumption in relation to medication side effects. For example, one participant, who has communication support needs, had never tried alcohol, and when asked, his support worker revealed that this was because alcohol was contraindicated,

*Researcher:* What happens with the tablets, what’s the problem with the tablets if you drink on the tablets, does it make you really unwell?
*PwLD3 M (Support Worker):* Yes it just reacts to the tablets.
*Moderator:* What sorts of affects do you get?
*PwLD3 M (Support Worker):* We’re not keen to try it (laughter) (FG01)

Both the individual concerned and the support worker appeared to accept this situation and were happy to maintain the status quo in relation to alcohol consumption. As described previously, this attitude of acceptance was observed amongst other participants who had been advised to keep alcohol consumption to a minimum because of medication side effects.

Participants felt that there was a limited amount of health promotion information available regarding alcohol consumption. The campaigns that had caught their attention were aimed at drivers, particularly during the ‘festive season’. One participant suggested that these advertising campaigns should be extended,

*PwLD 2 F:* you jist see adverts, know, mostly at Christmas and the New Year, you see a lot of the adverts about the drinkin, drink drivin right, how do they no’ jist dae it aw year roon, and instead of jist Christmas and New Year? because if people, like drivers, right, [on a] Friday, Saturday night are maybe wantin tae go oot and go tae wherever, right, and [have] a couple of glasses of wine, but some … end up drivin home, or else they would jist leave their car, but it’s no jist at Christmas and New Year. (FG01)

Another participant demonstrated an awareness of the wider problems faced by society, which had been brought to his attention by mass media coverage of the contemporary drinking culture in Scotland,

*PwLD11 M:* You see it in the paper, it’s in the Record [red-top newspaper] the amount of Scotland on the binge wae alcohol we’ll be a nation of alcoholics here. (FG05)
The two examples given above indicate that people with a learning disability are aware of the media campaigns and advertising and as a medium, there is an opportunity to consider how they can be used in specific health promotion work. The use of a familiar aspect can be a useful link to focusing the attention of the individual and assisting them in grasping the concept.

6.3.11 Summary

In sum, 15 of the 16 participants had consumed alcohol at some point in their lives. A high percentage of this number had drunk excessively and a few continued to do so at the time the data were collected. It should be noted in this context that the participants who were drinking excessively were known to local alcohol services. The reasons for drinking and drinking excessively appeared to mirror those of the general population. Knowledge of the potential negative effects of being drunk was generally good and the participants appeared to be aware of the fact that excessive alcohol consumption can be harmful to your liver. Otherwise knowledge of the potential health effects of excessive alcohol consumption was rather cursory. Knowledge and understanding of ‘units of alcohol’ was generally poor. The need to tailor alcohol-related health promotion messages and services to individual needs was evident, as levels of knowledge and understanding varied considerably. Interestingly, the participants felt that, when compared to cigarette smoking, health promotion messages linked to alcohol consumption are not so evident in the media.

7. Telephone interviews: health/social care professionals and family carers

7.1 Objectives

Several objectives were identified for the telephone interview study; namely to explore with health and social care professionals and family carers,

- their views and experience of the use of tobacco and alcohol in PwLD,
- their views on factors that influence the use of tobacco and alcohol in PwLD,
- their views on the knowledge and understanding that PwLD have in relation to the health risks associated with smoking and excessive alcohol consumption,
- their views on the tobacco and alcohol-related health promotion needs of PwLD, and
- their views on appropriate tobacco and alcohol-related health promotion approaches for PwLD.

As described above (section 3.1), a qualitative approach was selected as this enabled an exploration of participants’ views and perspectives and demonstrated congruity with the research aim and objectives (Meyrick, 2006).
7.2 Methods

7.2.1 Sample

The sample was recruited purposively (Kuzel, 1999) from two NHS Board areas in the West of Scotland. This provided geographical spread and ensured that participants were recruited from both urban and rural locations. The sample comprised health and social care professionals (HSCPs) whose work brings them into regular contact with PwLD, and family carers of PwLD, who had views they wished to share with regard to tobacco use and alcohol consumption.

7.2.2 Recruitment of HSCPs

The HSCPs were recruited from multi-disciplinary Community Learning Disability Teams (NHS Learning Disability Partnerships) and through General Practices (practice nurses). Recruitment packs developed for the project included a letter of invitation (appendices 10 & 11), a participant information sheet (appendix 12) and a consent form (appendix 13). Recruitment packs for the Community Learning Disability Teams were initially distributed to the research collaborators in both health board areas and to heads of service in the relevant social work departments. These key individuals then disseminated the recruitment packs to professionals in the areas selected by the Research Team. Recruitment through these sources was facilitated by means of face-to-face meetings with the research collaborators/heads of service. The Practice Nurses were recruited with the assistance of the Scottish Primary Care Research Network, who distributed the study recruitment packs to practices nurses in the areas identified by the Research Team. We aimed to recruit 15 HSCPs.

7.2.3 Recruitment of family carers

Family carers were recruited through voluntary sector organisations. A recruitment pack, which comprised a letter of invitation (appendix 14), participant information sheet (appendix 15) and consent form (appendix 16), was developed for the project. The recruitment packs were distributed to the managers/organisers of voluntary organisations who passed them on to potential participants. Where possible, recruitment was facilitated by face-to-face meetings with the managers. We aimed to recruit 10 family carers.

7.2.4 Data collection

Telephone interviews were used to gather data from the HSCPs and family carers, as this is a cost-effective method of data collection (Watson et al., 2004). Telephone interviews also minimise the time-imposition, thereby increasing the potential response rate (Sturges & Hanrahan, 2004). The interviews were conducted by LF, an experienced Clinical Nurse Specialist in the field of Learning Disability. Members of the project team who have expertise in qualitative
interviewing and some experience of working with people who have a learning disability (SK & ML), supported LF.

Semi-structured interview schedules (appendices 17 & 18) were developed to support the interview process. The HSCP interview schedule was piloted with two professionals prior to its use in the main study. The piloting of the interview schedule also helped LD to hone her interviewing skills.

Demographic data were collected from participants prior to commencement of the interview (appendices 19 & 20). All interviews were recorded digitally. The digital recordings were transcribed verbatim and the anonymised text was entered into the qualitative software package, QSR NVIVO v.8. All participants supplied written consent prior to the commencement of the telephone interview.

7.2.5 Data analysis
The analysis of the data was undertaken by LF. The transcripts were read to identify units of meaning (first level nodes) which were then grouped together to form themes (second level nodes) from which were described broad domains (third level nodes). SK and CD supported ML during the data analysis process and the findings were peer reviewed by SK and ML. The broad topic areas in the interview schedules (appendices 17 & 18) were used to guide the initial stages of the data analysis process.

7.2.6 Verbatim quotes and presentation of findings
Verbatim quotes have been used to illustrate the main findings. The professionals and carers are identified by their role (e.g. nurse) The abbreviation FC is used to denote family carers.

LF made efforts, during the course of the interview, to ensure that participants’ intended meaning was understood. This is reflected, as appropriate, in the verbatim quotes with the addition of words which aid understanding of the participants’ intended meaning. These insertions are presented in square brackets.

Linked to the study objectives, the findings are presented in the following section, using four headings,

- Factors that influence tobacco use/alcohol consumption
- Knowledge of the health risks associated with tobacco use/alcohol consumption
- Health promotion needs
- Appropriate health promotion approaches
7.3 Findings

7.3.1 Demographic data: HSCPs

Contrary to expectations, recruitment was slow in the larger health board despite repeated attempts by senior managers to promote the project. In total, 156 recruitment packs were distributed, and reminders issued by telephone and by email. Unexpectedly, we received more completed consent forms from NHS Ayrshire & Arran (n=17) than from NHS Greater Glasgow & Clyde (n=5). However, eventually more completed consent forms were returned (n=22) than were required (n=15).

Fifteen telephone interviews were conducted between April and June. Five of the participants were employed by NHS Greater Glasgow and Clyde; 10 by NHS Ayrshire and Arran. As indicated in Table 6, 13 of the participants were female. The median age was 44 years, with the range being 27-58 years. The average number of years’ experience of working with PwLD was 13 years (range 4-34 years). When asked whether they had received any training/education relating to tobacco and/or alcohol, the majority had not (80% tobacco, 67% alcohol).

Table 6. Health & Social Care Professionals: demographic details

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7.3.2 Demographic details: family carers

Between June 2008 and June 2009, members of the research team attempted to make contact, by telephone and/or by email, with key individuals in nine voluntary sector organisations. Despite repeated attempts, no response was obtained from five of these organisations. However, successful contact was established with two voluntary sector carers’ organisations in each of the two participating health board areas. Between April 2009 and July 2009, 30 recruitment packs were distributed to these four organisations. Disappointingly, no signed consent forms were returned, therefore reminders were sent, by email or by telephone, following which two signed consent forms were returned, one from each of the two recruitment areas. Two telephone interviews were conducted between June and August 2009. The two female participants were full-time carers and were aged 41 and 60 years. One was the foster carer for a young male, who smoked and drank alcohol; the other was the mother of a young woman with a mild-moderate learning disability, who had never smoked and drank small amounts, socially. The participants had been carers for 8 years and 19 years respectively. The young adults they cared for were aged 22 and 19.

7.3.3 Factors that influence tobacco use in PwLD

The professionals and family carers were asked to discuss factors that, in their view, influenced the use of tobacco in PwLD. The areas discussed are presented below.

7.3.3.1 Environment

HSCPs, who in the past had worked with clients who had lived in long stay institutions, reflected on the prevalence of smoking at that time. They described high levels of smoking and the role of cigarettes as currency,

*Psychiatrist 16: in institutions … the currency used to be cigarettes … [people] swapped cigarettes for various articles.*

However, PwLD are now living in the community and this exposes them to new influences on lifestyle behaviours, including control of their own finances and determining spending priorities,

*Psychiatrist 16: Now [PwLD] are [living] in the community and they have to buy [cigarettes] in packets of 20 … so it’s more expensive on a daily basis, so I’ve seen that … people are smoking less than they used to … 20 years ago*

Mental health problems are common in PwLD (Emerson, 2003; Raghavan & Patel, 2005) and many are referred to general psychiatric services where the prevalence of
smoking is known to be high (Coultard, 2002). The potential negative influence exerted by this environment was also highlighted,

Nurse 4: I had one client who had actually stopped, who went back into [psychiatric] hospital and started smoking again … if they have a very mild learning disability, they use the general psychiatric services if they’re mentally unwell, and I do feel [that] in that area, there’s a lot of heavy smoking going on.

7.3.3.2 The influence of ‘others’

The professionals discussed the smoking behaviour and attitudes of others, in particular family members and peer groups, commenting on the considerable influence that this had on the smoking behaviour of PwLD. The perception was that PwLD want to feel as if they are like other people, and that they often adopt behaviours that help them to ‘fit in’,

Psychologist 5: A lot of [PwLD] … would see people … without learning disabilities, smoking … that would be [an influential] factor, but I think probably by far the biggest factor is familial; if people in the family smoke then that person’s more likely to do so.

Practice Nurse 13: If they were going to a club, or going to bingo, or going to something like this, then they would feel the same as everybody else, because they smoke.

The family carers agreed with the HSCPs’ perception of the influence exerted by others, describing PwLD as wanting ‘to be the same’ as their peers. As one of the participants described,

FC 14: [His] friends were smoking in school, his older sister smoked … It was a] mainstream [school] but with a special needs unit in it, I think there was a wee group of them, smokers.

However, the influence exerted by family members and peers can, of course, also discourage people from smoking,

FC 17: Her father and I don’t smoke and none of her brothers or sisters smoke, and really, I don’t think really anybody in our family smokes … we always say, ‘Oh, it’s bad for you’, you know, but also in school, the school was very good at prompting [smoking cessation], in college they got onto this healthy living, and that’s one of the things that’s a no-no, and she just accepts that.
7.3.3.3 Health promotion campaigns

Health promotion messages are designed to influence lifestyle behaviours. These messages can be conveyed through television advertising campaigns and the professionals who participated in the study reported that television-based health promotion messages seemed to be having some effect on PwLD,

*Social Worker 3:* [PwLD] say that the television kinda puts them off [smoking] … [because of] the damage that it does, health-wise.

*Practice Nurse 12:* Well some of them realise the disease-related issue[s] … if there’s been a big campaign or something on the television … they’ll come in and ask about it a wee bit more, or ask when they’re in.

Health promotion messages can also delivered through the education system. PwLD may attend either segregated schools, special education needs schools, or integrated schools. In integrated schools, health promotion messages may not be delivered in ways that are accessible to PwLD and also PwLD are in contact with, and therefore subject to the influence of, non-disabled peers who smoke. In contrast, in special education needs schools, there may be less emphasis on the educational aspects of health promotion; however, a greater level control may be exerted over lifestyle behaviours,

*Psychologist 7:* I think for some younger people who have not been excluded or segregated through the school system [and who] have a peer group that includes people [who don’t] have learning disabilities, I think there is some kudos attached to smoking … You can stand there and … look … cool without having to contribute. I think … a bit of that … goes on … [However], within the special school system, I think there’s probably less of that around, probably because it’s a more controlled environment.

7.3.3.4 Positive perceptions of tobacco use

Other influences on smoking-related behaviour include individual and societal perceptions of the positive aspects of tobacco use. The HSCPs’ views on the perceived benefits associated with smoking, from the perspective of PwLD, included the enjoyment associated with smoking, and the fact that it was used as a coping strategy. The HSCPs also reported that PwLD enjoyed the comfort derived from the rituals associated with smoking, and one participant described the belief that tobacco curbs the appetite and so helps with weight management,

*Psychologist 7:* [PwLD] tell me how much they enjoy smoking, so there’s the physical pleasure of smoking and it’s often described … [by] those that don’t want to stop and [by] those that don’t want to be controlled in their intake, it’s usually because they’re saying they enjoy it.
Psychologist 2: She’ll say it calms her down, it makes her feel better, it gives her time to stop and have a think if she gets away to have a cigarette … in terms of her anger, it’s very much … ‘I’m not coping, I’m away to have a fag’.

Practice Nurse 12: I do really think it’s habitual … [PwLD] think I has a calming influence, because it’s something to do with their hands … it’s a reassurance thing, but I also … they’ve mentioned that if they stop smoking they think they will put weight on, they think it stops them eating.

7.3.4 Knowledge of health risks associated with smoking

When asked to discuss what PwLD might consider to be the negative sides to smoking, the HSCPs raised the issue of smoking-related ill-health, including some basic knowledge of cancer, respiratory disorders, cardiac disease, and cosmetic effects, such as damage to teeth,

Nurse 9: I think, certainly from the three guys that I’m referring to, they’re aware of, for example, the damage that it does to their lungs, they’re aware of the damage that it does to their teeth ‘cause they can see it and have issues with that, they’re aware of the fact that … they find it harder to get up and down the stairs [to their flats].

However, as in the general population (e.g. Kerr et al 2006), awareness of the negative consequences of smoking does not always lead to quit attempts, possibly because the perceived benefits associated with smoking exert greater influence than the perceived negative effects.

Psychologist 7: I actually had a long conversation with [a patient who smokes] a couple of weeks ago about the dangers to health … she was very clear what those dangers were … but was of the opinion that, she was 65, [she] loved her cigarettes [and] she had to die at some point … I mean, she was very clear that she had no intention of reducing or stopping smoking.

While a basic knowledge of the health effects of smoking was discussed, levels of understanding were raised as an important issue. Health promotion messages can be complex and therefore difficult for PwLD to assimilate. The HSCPs’ experience was that PwLD often find it difficult to make the link between smoking and its effects on physical health and also to understand that a health condition might improve, if they stop smoking,

Physiotherapist 6: She just relates [asthma] to being part of her, she doesn’t … seem to understand that if she didn’t smoke it wouldn’t be quite as bad … I would know it was linked to smoking, but she doesn’t kinda understand
Some HSCPs, who worked with PwLD with respiratory problems, thought that those individuals were able to understand the association between their own acute health condition and smoking. However, with regards to smoking-related conditions that might develop in the future, such as cancer, the HSCPs felt that PwLD were not necessarily able to understand the association,

Social Worker 1: There is an awareness that smoking can damage their health. Some of them do have chest problems, you know, and particularly some already have asthma and stuff like that. They know that smoking will not help chest conditions. They are aware of that.

Psychiatrist 16: I think if it's something particularly obvious to see, like a cough, they can relate it [to smoking] and if it's a bit more subtle, like the effects on their heart or circulation, they might not see the link. Yeah, I don’t think they would think, ‘If I’m smoking today, I might get lung cancer in 20 years time.’ It’s very, very rare to come across somebody who could make that link and apply it to themselves.

7.3.5 Health promotion needs

7.3.5.1 Accessibility

The professionals felt that smoking cessation services and interventions designed for the general population, are not fully accessible for PwLD and this was therefore highlighted as an important health promotion need. Practical issues such as transportation were raised as were social issues such as confidence and an ability to participate as an equal,

Practice Nurse 12: I think obviously there’s the social thing if it’s a group … we have a [smoking cessation] group … and I think [PwLD] are very conscious of the social element in the group and maybe not been able to speak as well as some other people … or say what they think, I think that’s maybe, or getting transport to groups or places is another issue.

Similarly, the HSCPs felt that smoking cessation literature should be easily accessible for this client group. Their perception was that current written material, and even some pictorial representations of smoking-related diseases were not necessarily appropriate to meet the needs of PwLD,

Psychiatrist 16: I think sometimes the language that [is used in] the health promotion literature … might be too complex for them.

Nurse 8: I’m not sure that the literature hits the mark, you know, [such as] the pictures on cigarette packets, I’m not sure they see any significance in that
Interestingly, there was a general perception that health professionals often fail to target PwLD with health promotion messages,

*Nurse 4:* I find that a lot of [PwLD] don’t get touched by the general services … I don’t know if they get as much [support as non-disabled people] when they go to see GPs about it … I don’t think they get as much pushed at them to [encourage them to] stop.

7.3.5.2 Support in addressing factors that encourage continuation

The professionals discussed the fact that in order to make a successful quit attempt, issues such as addiction (including coping with cravings), habit, boredom and lack of motivation would need to be addressed,

*Social Worker 3:* [My clients] are saying that they can’t physically stop it, they find it very, very difficult.

*Physiotherapist 6:* A lot of [her dependence upon smoking is] habit because she’s in her house herself all … day and what else does she do but sit and watch TV and smoke?

*Nurse 8:* I think people who live on their own struggle, because they use [smoking] to … combat boredom and … they find it much harder to stop because they’re there’s not really any motivation to stop smoking when you sittin’ yourself in your house, and people often say that, ‘Well, I’ve nothin’ else to do, so I sit and smoke’

The HSCPs also identified the difficulties experienced by PwLD who used cigarettes as a self-calming strategy when no alternative coping strategies had been found to be effective,

*Psychologist 2:* [Cigarettes] help her feel a bit calmer … certainly when she’s very agitated, you know. We’ve worked on a number of things, but that’s still her first port of call is to go and have a cigarette

Another area that was highlighted was the lack of ability to implement strategies that had been discussed during smoking cessations interventions,

*Social Worker 1:* I think … some of them have … spoken to GPs and nurses, but haven’t been able to … carry through the … programme. I don’t know whether the programmes are not geared at their level of understanding, or [if they] can’t maintain it, I couldn’t be clear about that.

*Social Worker 3:* Two of them I’ve actually taken along and tried to get support groups for them … but it’s worked for a very short time … and I’m talking two or three weeks, it never really lasts, and I have tried on umpteen occasions.
The above said, it is obviously common for people who do not have a learning disability to lapse/relapse and it often takes as many as six attempts to stop smoking before it is successful (NHS Choices, 2009).

7.3.5.3 The knowledge and skills of the HSCPs

Ideally, in order to meet the smoking-related health promotion needs of PwLD, HSCPs should have knowledge, skills and expertise in both smoking/smoking cessation and learning disability. However, few of the professionals had undertaken formal education/training linked to health promotion or smoking cessation. In many cases it was evident that the HSCPs’ awareness of the health promotion issues relating to smoking were derived from the media and personal experience rather than from specific, evidence-based sources,

Social Worker 10: The only thing I’ve maybe seen is anything you’d see in your own doctor’s … [I have some knowledge] from my own personal experience … but on a professional level, no

Psychologist 2: [Health promotion] is not something you ever [laughter] do in your training, and I’m not a smoker.

Although some HSCPs identified a need for more knowledge, for others it was not a priority, as they said they had minimal contact with people who smoke.

7.3.5.4 NHS Stop Smoking Services

The ability of smoking cessation services to address the support needs of PwLD will vary in accordance with their knowledge, skills, and experience of the needs of this client/patient group. A small number of the professionals provided examples of positive experiences, where smoking cessation advisors had recognised the need for additional knowledge and skills and had sought appropriate training. Subsequently, they had been able to deliver interventions in a manner that was accessible to PwLD,

Social Worker 3: They [local GP] usually run their own smoking group and they have facilitated ones who need that wee bit extra help, people with mental health problems or learning disabilities or whatever … the nurses there are trained up and … I thought it was very good, I thought they pitched it very well, because a lot of our [clients], the barrier is communication. It was at a level that they understood, you know, really basic terms, but not patronising. I was quite impressed with it.

In contrast, the participants described some instances of what they felt was poor practice, such as services that offered only short appointment times. This sort of inflexibility is not conducive to supporting the needs of individuals with cognitive and communication difficulties. Other instances of practice that effectively excluded
PwLD included distributing information in inaccessible formats, and providing cessation interventions designed for use with the general public, which are not accessible by PwLD,

_Psychologist 5: Our experience is that GP’s probably still have a lot of work to do in terms of [pauses] doing things to improve their work with people with disabilities. The standard GP appointment time doesn’t really lend itself well to working with a person with a learning disability._

_Practice Nurse 12: I think … a lot of the teaching and study days … are maybe just related to the public in general, I don’t particularly remember it being directed immediately [at] learning disabilities, maybe something down that road would be a bit more helpful_

Some of the HSCPs thought that specific learning disability services or joint services would be more successful in terms of reinforcing smoking cessation interventions,

_Nurse 8: There’s a group of Public Health Nurses that work closely with the Learning Disability Nurses to bring about that sort of change for people … when we work together, we can give them the support from the learning disability angle and the Public Health Nurses come from the Public Health approach._

The practice nurses who participated in the study demonstrated an awareness of the need to consider the specific communication and learning needs of PwLD,

_Practice Nurse 12: How to convey the message … what kind of terms we should be using for them, what way can we support them, would they need slightly more support?_

7.3.6 Appropriate health promotion approaches

7.3.6.1 ‘Encouraging’ smoking cessation attempts

Most of the HSCPs said that they believed that they had a role in encouraging PwLD to stop smoking. They reported that they did this by highlighting negative aspects such as the health and wealth implications of smoking and by emphasising the benefits of quitting. They acknowledged the need to revisit the issue, as appropriate,

_Social Worker 1: Reminding them of the damage that smoking can do, the kind of financial gains that they might have if they weren’t smoking, what they could maybe do with that … if they weren’t smoking._

_Psychologist 2: We all have a role in terms of being a health worker, if you like, in terms of pointing out to someone that the effects of their smoking probably aren’t good – they’re not helping._
The professionals reported using educational and supportive techniques, which included providing leaflets, sharing their own experiences of quitting, and supporting access to smoking cessation services,

*Nurse 8: I gave her some leaflets, but her literacy skills are poor … so it was more word of mouth … and I've told her how [since I've quit smoking] I've felt better, my house is cleaner, and things like that … we have events here as well, where we have the [smoking cessation service] group and we've encouraged our clients to go along to their stand and look at the videos and pick up the literature.*

Most HSCPs said that they would mention smoking in the course of their encounters with PwLD. However, some learning disability nurses and practice nurses had a more focused approach because of the annual health assessment process,

*Practice Nurse 12: Yeah, we ask, at every single visit, we ask for smoking status and obviously we try and convey the message that would they possibly even think about it and that, you know, again, reiterate all the benefits and say that there is support available, but we certainly ask at every consultation, we definitely would, we actually make a mark on the computer that we've offered Smoking Cessation advice.*

However, some HSCPs did not see health promotion as part of their role and would discuss the issue of smoking cessation only if it were raised by the PwLD.

*Social worker 3: [I mention smoking] only if they bring it up first.*

7.3.6.2 ‘Supporting’ smoking cessation attempts

Most HSCPs identified the GP as the first point of referral, if they had identified that a PwLD was motivated to stop smoking. They also mentioned community learning disability nurses as the key professionals that they would refer PwLD onto, or whose help they would enlist either to provide a smoking cessation intervention or to support the individual to access smoking cessation services,

*Social Worker 10: I’d definitely be making a referral across and perhaps [be] supporting them to attend their GP … we’ve got very clear roles here [health and social care] but it does overlap … we’ve got our community learning disability team … and they are very heavily involved with a lot of people that we work with … and if we were looking for that kind of support, initially … it would depend on what the person’s needs were … in terms of communication and things like that. If they were felt [to be] well able to go and speak to [their] doctor [by] themselves, and if they had good relationship with their own GP, then that would probably be the first port of call, but if … they needed a little bit more support with communication, and*
… [to] keep [them] going with [the quit attempt], then I think … [referral to] our community learning disability nurses would be crucial.

Psychologist 5: Within my team, the nurses would tend to pick up on smoking cessation work … I would say I’ve got a very small role … it’s really not an issue we tend to pick up on, it would really be the nurses within the team.

The HSCPs reported that they aimed to support PwLD to maintain their involvement in cessation programmes, and that they would do this by using positive feedback. For example, they would acknowledge the efforts made by the individual and reinforce positive messages,

Social Worker 1: Encouraging them to continue with the programme and … giving them recognition that they were doing well

Nurse 4: I did a lot of verbal prompting and a lot of positive reinforcement … which keeps the flow going every time I see him. If I see him every week, I’m reinforcing it every week.

This reflected one of the family carers’ experiences, where they had attempted to support a quit attempt. However, they felt that professional support may have a greater chance of achieving positive outcomes,

FC14: He used the patches but ended taking them off and having a smoke with his pals at college… We have a great local health visitor … who runs a group and he’d be able to go there … but he’s not interested just now … financially it’s just one of the reasons … and I’ve always said to him … ‘this is what you’re smoking every year,’ and he’s [expresses great surprise] and I [say] … ‘how many Play Station games could you get for that?’ … and he says, ‘… that’s it! I’m stopping on Monday’, [laughs] he doesn’t really take it in, to be honest … I think it’d be quite good … if social work were to step in and say, ‘right! we’re gonnae try this … [and] see how many of you can do it … you can have your name up on the wall, [if you] … have managed to quit,’ … He’d be tickled pink … if he’s had goals before to do stuff … he’s done them, a hundred per cent.

7.3.6.3 Conveying the health promotion message

As discussed, the HSCPs and family carers recognised that PwLD can have difficulty in understanding the association between smoking tobacco and adverse health effects. In general, participants expressed a need for concrete messages about the effects that smoking has on the body and on health. It was suggested that visual images should be used to deliver and reinforce such health promotion messages,
Practice Nurse 11: You could limit the amount of words and have quite pictorial things ... it's not something you could just hand them and say, ‘Here! Take that home and have a look at it,’ but I do think if you went over it and they then looked at it ... they would remember some of the stuff that went with [the pictures]

FC 14: I think a lot more visual things would be [better], maybe horrible and not very nice pictures ... it needs to be something visual

One participant proposed that the health links to heart disease should be emphasised rather than cancer as this might have a bigger impact as, whether one smokes or not, cancer is perceived as a risk,

Psychologist 7: I think [for] some younger people ... the quite graphic health messages are quite useful, I certainly think that using the graphic pictures of tumours etc. on the packets has helped but ... I think probably one of the biggest messages that needs ... to be got across is ... the link to heart disease as opposed to the link with cancer, because I think for most people they think ... that you're going to get [cancer] at some point, irrespective of what they do.

In the main, participants were of the opinion that smoking cessation interventions for PwLD should utilise the same techniques and same content as those designed for use with the general population, but that these should be adapted to suit the needs of the individual. Effective smoking cessation interventions might include one-to-one discussion, group discussion and role play, and should be supported by materials, available in a range of formats to enable HSCPs to select appropriate resources according to individual need,

Psychologist 7: All the usual stuff! I think you have to have smaller numbers, you have to make it as visual as you can, you have to make sure that they're engaged, and that they're doing things in the group ... I think that the talking approach doesn't work [but] the role playing ... practicing things ... talking things through, I think all that helps.

Nurse 8: I think whatever resource you’re using, whatever is available, they would still need support to work through it ... but something visual, not relying too heavily on the written word.

The professionals thought that first-hand experience of ill-health related to smoking, either in the individual or in a family member, was likely to have a significant impact on PwLDS’ decision-making around continuing to smoke or quitting smoking. Dramatic television advertising campaigns were also thought to have a similar impact,
Practice Nurse 12: I think … if they know somebody, a family member or a friend, who’s maybe been … affected by a smoking-related disease, then they can relate to it better, or if they’ve … seen one of the campaigns that shows them something like that, then I think it makes more sense to them.

7.3.6.4 Attitudes of HSCPs

PwLD are a potentially vulnerable group of people with special needs and, HSCPs’ attitudes towards PwLD and how best to meet their needs, may influence the ways in which they deliver services and interventions. HSCPs’ attitudes to PwLD may range from inclusive and person-centred (i.e. supporting individuals and empowering them to make their own lifestyle choices) to paternalistic (i.e. responding to impaired functioning levels by exerting controlling influences on such choices). Such attitudes raise ethical dilemmas and are likely to influence the professionals’ approach to the delivery of health promotion interventions for PwLD. The comments below highlight different approaches,

Psychologist 7: I think with people living in private tenancies now with provider organisations, I think they have more choice, so I think that’s an issue.

Practice Nurse 11: We wouldn’t let a child do certain things because, as a parent or guardian, you would say, ‘I’m the person that’s got your interests at heart and I know this isn’t good for you’. And, while I respect completely … that they are adults and they are trying to lead an independent life, I do sometimes think we are kind of being a bit stupid about it, in that we’re giving them choices … and making [things] possible … that they haven’t maybe got the insight to understand the consequences of … [I think we should be] overriding people’s rights in certain situations, I think smoking is like that … I don’t want to sound as though … I’m trying to rule their lives, but I do think that you’ve got to have a bit of common sense about it.

7.3.6.5 Tailoring interventions

Many of the HSCPs identified the need for smoking cessation approaches to be tailored to take into account individual’s learning needs, and the level of support required,

Social Worker 10: I think it really does depend on individuals’ needs and abilities, I mean what suits one person, might not suit another … I think having a varied wealth of information and maybe in video form, maybe a book even, pictures … for some people it maybe something on tape, discs … a lot of the time a barrier to a lot of these things is literacy skills.

This perception was also supported by the family carers,
FC 14: I think it depends on the [individual’s] needs to be honest with you, as I say, the health visitor really would be just fine for our laddie’s situation but I think maybe someone with more profound difficulties … I think they would need maybe more support.

7.3.6.6 Support

Given the strong influence of others on the health behaviours of PwLD, one of the main factors identified by the HSCPs regarding health promotion interventions for smoking was the availability of one-to-one support. A number of sources of support were described, including social care support staff. Support staff are well placed to support PwLD to make quit attempts as they have an understanding of individuals’ abilities and communicate needs. However, to enable support staff to take on this role, they would need appropriate education and training, including how to access smoking cessation services,

Psychologist 5: The people who actually have most contact with this client group [support workers] are probably the most useful in terms of enlisting … to the cause. [They need to know] where to point people … where they get information that is accessible for that person, how to support the client, should the client wish to use … nicotine replacement or something like that … They would probably be the most powerful people to use, because if the person decided to stop smoking, it would be the day-to-day carer that would … have the most contact with the person.

The importance of the support worker role in providing support for quit attempts was also described by a family carer,

FC 14: I think there should be someone in the residential home that some kind of training’s given to … [so, if] someone does go down that line … [they can say], ‘I’m trained in that, I can step in and give them the help that they need’

Several of the HSCPs also described buddy systems as a potentially effective support mechanism,

Psychologist 2: I think having someone who has maybe been through it, who is patient, understands it, you know, is able to take it at the pace that this person wants to go at, and just there to answer any questions … I think something like that would be good because quite often people want someone who’s been through something similar.

Family carers also identified ‘buddying’ as being particularly appropriate for individuals with mild learning disabilities, who are perhaps most likely to be influenced by the desire ‘to be like’ and ‘to fit in with’ others. An ideal buddy was considered to be someone of a similar age, who had successfully stopped smoking i.e. someone who can relate to the individual’s experiences,
FC 17: [People with] mild learning [disabilities], I think that a lot of them are very streetwise … I think somebody kinda young and ‘with it’ and they could relate to, rather than [the] likes of somebody like me at 60 and saying, ‘well, I’ve never really had this problem and I don’t really understand it’. You know somebody young, outgoing, that they would relate to, and maybe telling them the benefits, or, ‘Look at the money that I save! and I can go this holiday, or I can buy clothes with that money … and I’m a bit healthier!’ … Maybe someone who’s done it themselves, somebody youngish that they would kinda look up to.

The HSCPs also suggested delivering smoking cessation messages to peer groups via health promotion road shows at clubs, day centres, further education colleges and schools attended by PwLD,

Social Worker 3: A lot of our [clients] use community halls and local facilities like that, I think if there were … road shows or that kinda thing … if they’ve even got a wee inkling that they want to stop smoking, or even if they’ve not thought about it, they’ll say, ‘Oh well … I could maybe think about it,’ … I think services going into the types of places they use would put less pressure on them … day centres, community centres, things like that. We’ve got an awful lot of people who don’t use day services … who have no opportunity to maybe get this information, [we could reach them] by using places … that people do go to, like drop-in centres, community centres, libraries, these kind of places.

Psychiatrist 16: I think … there could be a health promotion group, and probably are, in some day centres to encourage them to stop smoking, in day centres, colleges, wherever there [are] cohorts of people with mild learning disabilities.

Interesting, one of the nurses reported that this type of approach was being implemented in the area where she worked,

Nurse 9: There’s a group … aimed at men … [that focuses on] improving health and wellbeing … a number of people with very mild learning disabilities have gone along, and the idea is that if they reduce smoking … through coming along to this group, that they will then be supported, for example, to go along to the gym and exercise … things like that, so they’re providing alternatives.

Peer support was also discussed by the family carers, as a potentially effective means of supporting smoking cessation attempts,

FC 17: if you could get [PwLD] all together, that they would all maybe try to stop smoking together, I think that you’d have more strength in the numbers, doing it together, rather than one out of all that group [saying], ‘I’m
stopping smoking’ … maybe they wouldn’t be brave enough to do it, or to be seen to be different, I think getting a peer group together would be better … a lot of [PwLD] go to day centres … and college, and I think where they go is probably the best place to target … a group.

7.3.7 Summary

In sum, the HSCPs and family carers discussed factors that influence the use of tobacco in people PwLD. The important influence of peers and family members was clear. The fact that smoking was considered to have many positive aspects was also felt to be influential (e.g. helping to reduce stress). When asked about knowledge of the health risks of smoking PwLD were considered to have a basic knowledge; however, it was considered that understanding of what might be the long-term consequences of a tobacco habit was limited. In terms of health promotion needs, issues of accessibility were raised. The participants stated that if health promotion services and resources are not tailored to meet the needs of PwLD it is unlikely that they will be able to make successful in quit attempts. The need for training/education and for smoking cessation and learning disability professionals to work together was emphasised. When considering appropriate health promotion approaches, the important role of support workers was discussed. The use of buddy systems and peer support was also raised.

7.3.8 Factors that influence the use of alcohol in PwLD

The health and social care professionals (HSCPs) who participated in the study did not always know whether their clients/patients consumed alcohol. They reported that they were often unaware of people who were drinking within the ‘sensible’ drinking limits, but tended to have it brought to their attention if problems had been identified that were associated with harmful levels of alcohol consumption, including binge drinking. In terms of gender and age, no differences were noted. Alcohol dependency was thought to be unusual in PwLD.

Social Worker 3: I think it depends on the circumstances and on the person. You know, obviously I knew about his alcohol ‘cause he gets into trouble and things and I would bring it up, but there’s some of my clients I don’t even know if they take a drink. If it’s not an issue, I tend not to inquire too much. If there’s nothing relating to health or behaviour … I don’t tend to ask them.

7.3.8.1 Independent living

The professionals expressed concern that, for PwLD, the move from institutionalised care to independentsupported living in the community may have resulted in an increased use of alcohol,
Psychologist 7: I’d say younger people are drinking more. I would say that, historically, people with a learning disability did not have drink problems because they didn’t have access; people were more controlling of them, they didn’t manage their own money, and I think that, nowadays, there’s more availability, there’s more access, there’s obviously not as much money, but they … buy an awful lot of cheap booze.

Psychiatrist 16: Some [PwLD] drink [alcohol] to excess and run into real trouble, but on the whole, most of them don’t. Again, it’s a growing problem as more people are in the community than in institutions because [it was] very difficult for them to get access to alcohol in the old, long-stay hospitals.

7.3.8.2 Lack of meaningful activity

The HSCPS experience was that many PwLD are not employed and that some lack structure in their daily lives. This can result in feelings of boredom and loneliness which may encourage alcohol consumption,

Nurse 8: I think … people that live on their own, they’re drinking when they’re lonely

Practice Nurse 11: [Many PwLD] are not working, so they’re free during the day and I think a lot of people with learning disabilities will go out [drinking] on their own more regularly during the day than they will at night.

7.3.8.3 Low cost of alcohol

Many PwLD who live independently have a low income (although, as discussed previously benefits have been ‘maximised’ in recent years). The HSCPs highlighted the fact that a low income is not necessarily a factor which militates against the excessive consumption of alcohol, as strong alcohol can be cheap and easily accessible in large quantities,

Psychologist 2: The few, maybe three or four, that I’m thinking of, didn’t have a job, weren’t really going to college, they were sort of 19, 20 and the routine very quickly became sort of, Friday, Saturday night … out with the guys … whatever kind of cheap booze they could find … if you’ve got limited money resources and … you can go to the local shop and buy fairly strong alcohol, at a relatively cheap cost, then that’s certainly what they would do … and it was with the intention of getting very, very drunk.

7.3.8.4 Medication

Alcohol is contraindicated when taking certain prescription medications, such as anti-epileptic drugs. Whilst the HSCPs reported that most PwLD follow medical advice
not to mix medication and alcohol, some of their patients/clients, who regularly took such medication, were not deterred from drinking alcohol,

*Practice Nurse 12:* I think that sometimes it’s down to if they are on a lot of medication, they’re very wary of taking alcohol at all … and if they have other conditions, such as epilepsy and diabetes, then the alcohol intake tends to be very low.

*Nurse 8:* I think, although we tell people, ‘You’re better not drinking when you’re taking medication,’ I don’t think that’s making any difference to their lives … whether they’re … aware that it impacts on their seizures or not, I don’t know, because it disnae stop them.

Alternatively, the HSCPs reported that some of their patients/clients elected not to take their prescribed medication, so that they could drink alcohol. The professionals were concerned that some of these individuals may not fully understand the consequences of their actions,

*Social Worker 1:* The main difficulty, for some of my clients, is alcohol and … other medications they’re on … some of them can work out, ‘well, if I don’t take the medication, I can drink,’ which brings on other problems.

7.3.8.5 The influence of other people

Similar to comments made in relation to smoking, other people were seen by the HSCPs and family members to exert considerable influence over the drinking behaviours of PwLD. These people included family members, disabled and non-disabled peers and support workers,

*Psychologist 5:* There’s probably a very high degree of control and fear of [PwLD] drinking alcohol … whether that’s parents or paid carers.

*FC 14:* He [son with a learning disability] has a couple of bottles in the house maybe on a Saturday night … my partner, he’ll have a couple of bottles of beer, he doesn’t really drink that much, but [he and my son] love a couple of beers in the house … If [my son is] going to a night out with his friends … I know he’s going to have quite a lot to drink, ‘cause all his friends will be drinking.

Support workers were sometimes seen as exerting control as it was seen as being part of their role and responsibilities as paid, and accountable carers,

*Psychologist 5:* I think there’s also fears within, say, paid care groups, that they’ll not be able to control that person … if the person was to get drunk … they’ve got their own care responsibilities, and they would, I think, prefer if
the person didn’t drink … in case something went wrong and that then reflected badly on how they were looking after the person.

When considering the influence of non-disabled peers the HSCPs felt that PwLD were often striving for social acceptance. Drinking was thought to be associated with social kudos, helping PwLD to feel like others and that they are part of a group,

\[\text{Nurse 4: It's the company he keeps, his friends … there's a lot of drink and trouble with his friends and his peer group, and he's quite easily influenced that way … it's definitely social.}\]

The HSCPs reported that increasingly, as they mimic the behaviour of their non-disabled peers, young adults with mild learning disabilities are seen to be engaging in binge drinking,

\[\text{Psychologist 2: Certainly more … binge drinking in that age group … certainly more recently more young guys, you know, I've got someone who's quite young, mild learning disability … there's an issue about drinking alcohol at the weekends, so yeah, there's probably more of an increase over the years}\]

However, PwLD who frequent clubs and groups for the learning disabled were considered to be much less likely to consume alcohol and therefore levels of hazardous and harmful drinking in this group were considered to be rare,

\[\text{Physiotherapist 6: The majority of clients would socialise within their own clubs rather than going to 'normal' bars, so there wouldn't be alcohol available.}\]

7.3.8.6 Positive perceptions of alcohol

The HSCPs reported that for PwLD, the perceived positive aspects of drinking alcohol included enjoying the social contact, the physical sensations and taste, and the sense of it being a treat,

\[\text{Psychologist 5: within the younger groups that I work with, going out to the pub and having a drink is certainly seen as a social activity, something that they can group together and do together. I think a lot of other people would see it as a luxury, a 'treat.'}\]

There was a perception that drinking alcohol enhances social opportunities and interactions, as it boosts confidence and lowers inhibitions,

\[\text{Nurse 4: [PwLD] like feeling more confident, they like the ability to go out and chat to people and have friends, but when they're sober they can't do that, they find it more difficult to have friends and they're more isolated, but with drink they feel more confident}\]
In addition to social factors the professionals felt that some PwLD use alcohol as a means of helping them to cope with stress, anxiety, and other problems,

Social Worker 1: It kind of makes them feel good at the time, they enjoy the company they’re in when they’re drinking … they do enjoy the kind of social aspect. But the other ones, that are possibly drinking on their own, [feel] that it relieves some of the stresses that they’re under.

Social Worker 10: [PwLD] definitely use it as a stress, you know, managing stress, ‘Can’t cope with x, so I lose myself in a bottle’,

Family Carers also identified alcohol as a means for PwLD to enhance feelings of social inclusion, and as a means by which individuals can assert their adulthood,

FC 14: Maybe once a week he’ll pop down to the pub to watch football and play pool and he’ll have two or three pints then, but that’s about him … when they [siblings] became of drinking age, he progressed into going to parties with them, and down to the local pub with them … he was adamant he was trying a couple of pints when he was 18.

FC 17: She’ll tell you, ‘I’m allowed one glass of wine,’ if it’s maybe the weekend, or if it’s a special occasion, or a family meal … quite often on a Sunday we’ll have wine and [daughter]’s allowed a glass of wine … she turned 18, she was saying, ‘oh! We need to get the champagne out!’

7.3.9 Knowledge of the health risks associated with drinking

The HSCPs and family carers felt that PwLD are generally aware of the short-term negative effects of excessive alcohol consumption on their physical health and wellbeing. For example,

Social Worker 1: The negative side effects can be hangovers.

Social Worker 10: Things like being sick and you don’t feel very well if you have too much.

FC 17: She is aware that if you take too much, it’s not good for you … that you’d maybe not feel very well and you would maybe be sick.

Other short-term consequences of drinking alcohol included accidents (e.g. accidental fire setting), low moods following binge drinking, and losing parts of the day and associated activities,

Practice Nurse 12: Some of them kind of express their feeling of self loathing after a binge, if they’ve been binge drinking, they can go into a … depression afterwards
Nurse 8: [He] was drinking later at night, so therefore he was going to bed later and he was sleeping later in the morning, so he couldn’t take any part in activities that we … were organising, if they happened in the mornings.

The impact on individuals’ decision-making abilities and emotional responses such as anger and aggression were also discussed. This was linked to antisocial behaviours and contact with police,

Nurse 4: They know that getting stopped by the police isn’t a good idea, but they’ll say, ‘I know I shouldn’t do this, and I know the drink makes me more aggressive,’ but the next night they’re out at the pub again. It’s ‘cos they’re sitting in the house with nothing to do, so they go to the pub.

The family carers reported that they were concerned about the increased vulnerability of PwLD who have been consuming alcohol, as this compounds existing vulnerability associated with having a learning disability. Their concerns related specifically to aggression and sexual behaviour,

FC 14: [He’s] very vulnerable, that’s why I always make sure to have somebody with him and we know where he is [and] the locals that drink in the bar know him … and the guy behind the bar will say, ‘Right son! that’s your second one, no more!’ so they’re quite good that way … if he’s had too much to drink he’s got to a tendency to stare at people … and he’s not aware he’s doing it, and I just feel if he was in an environment with other people that have been drinking … you’re going to get some thug that’s going to say, ‘What the hell are you staring at?’ … so I feel he’s vulnerable that way

FC 17: [PwLD] have got hormones like everybody else and I think a lot of them could end up in some trouble … obviously anybody has too much to drink their defences are down anyway, you know, they’re more relaxed … that that is another worrying issue for any parent of a special needs child, you know … if she was more outgoing and was able to be more independent then the issues would be, she’d be more vulnerable … and if she was to drink she would be 100% more vulnerable than she already is.

Although the HSCPs described an awareness of short-term negative effects of alcohol consumption amongst PwLD, they were less certain that PwLD understand the association between excessive and prolonged alcohol consumption with chronic health problems, such as liver disease,

Psychiatrist 16: I think most people are aware that … drinking too much isn’t very good for you … Because the liver isn’t something you can see, I don’t think they can immediately relate [drinking alcohol] to liver damage, not unless they’ve drunk so much that they’re well into real problems with their liver.
7.3.10 Health promotion needs

The professionals reported that they had worked with only a few PwLD who wanted to reduce their alcohol consumption or stop drinking, even if advised that they should so. For those who did, it appeared that the impetus to change often arose from others’ concerns (e.g. family, carers, and health staff) rather than the individual,

*Psychologist 5:* I haven’t come across any [clients] that have said that they wanted to cut down or reduce their alcohol consumption. There certainly has been a handful where we’re quite clearly saying to them, ‘This is part of the problem for you, and you need to look at it’.

*Psychiatrist 16:* I wouldn’t say the motivation has come from them … I think the people around them have been quite keen for them to reduce their drinking.

7.3.10.1 The role of the HSCPs

When considering the health promotion needs of this client/patient group, a key issue that was highlighted was that not all HSCPs routinely assessed alcohol use. Those who did conduct routine assessments were normally the learning disability nurses, practice nurses involved in health checks, or psychologists assessing parameters of certain behaviours. Different professionals were considered to have different roles.

*Social Worker 1:* My first route would be through the LD team, but if there isn’t anyone in that group that’s trained to do [alcohol] counselling, they would make the decision to refer on to mainstream, and on occasions where I’ve had that, it hasn’t been very successful.

*Nurse 8:* If we couldn’t manage it ourselves … we might get the addictions team involved … we’ve done that in the past very successfully … we were giving advice on how best to communicate with people with learning disabilities … what sort of activities would be beneficial for them and what sort of resources to best use, and they knew from the alcohol side what they wanted to use.

Some of the HSCPs described tools that they used to assess alcohol consumption, including diaries of consumption, information from carers and simple questions of quantity/frequency and types of alcohol consumed. The Practice Nurses reported that they used assessment tools such as FAST (Fast Alcohol Screening Test) (Hodgson et al., 2002). All of the professionals reported difficulties in accurately assessing alcohol consumption as accounts from individuals who did not understand volumes or ‘units of alcohol’ were unreliable and also some PwLD denied drinking,
Nurse 4: I try to assess … I’ll say, ‘How many drinks did you have yesterday? And he’ll say, ‘2 pints,’ but when you actually speak to him and say, ‘What did you do in the morning?’ ‘I went to the pub,’ then ‘What did you do at the pub? … You had four pints, then what did you do?’ ‘I went home, had my lunch, then went back to the pub’, ‘What did you have then?’ ‘I had this and this.’ It turns out he’s had eight pints and two whiskies, but he’s saying to me, ‘two pints!’ … and other clients well, you just see what’s lying about the house.

Overall, the HSCPs reported that they would be concerned if PwLD were getting drunk on a daily basis, or drinking above the recommended weekly limits, i.e. 21 units for men and 14 units for women. They would also be concerned if the individual was binge drinking, using alcohol as coping mechanism, if they said they were worried about their own drinking, or if there were incidents involving the police,

Social Worker 10: If you see somebody who is using [alcohol] as a coping mechanism for stress, or who is drunk all the time or most of the time that you see them, then that would be concerning for me.

Nurse 8: I think we would be concerned if somebody was drinking every day or every night or, they were going out and getting into trouble at the weekend through alcohol you know, maybe drinking all their units at the weekend

However, due to the increased vulnerability of PwLD, some HSCPs stated that they would be concerned by lower levels of consumption than described above,

Practice Nurse 11: I think it would concern me at a much lower level than someone whose not got [a learning disability] and maybe that’s wrong but I would be concerned … its more to do with them putting themselves in danger, because if they’ve already got a bit of a learning disability and you put alcohol on top of that then from every aspect from crossing the road, to being sexually active, to being taken advantage of … alcohol has the effects it has on everyone else, but in their case, I think the consequences could be [greater].

7.3.10.2 The knowledge and skills of the HSCPs

Most HSCPs had some knowledge and skills in relation to alcohol but this was not specialist knowledge; some reported that their skills were out of date, due to limited use. Interestingly, the HSCPs equated their knowledge regarding the safe use of alcohol to that of the general public i.e. what was learned from television health promotion campaigns and/or health promotion leaflets,

Psychologist 2: probably what you see on the TV … in terms of [my knowledge of] units and measures and stuff like that.
The HSCPs generally felt that this level of knowledge was sufficient to enable them to raise the issue of alcohol consumption if they were concerned, to intervene appropriately, and to assess when and how to link to specialist services. Specialist learning disability professionals were able to approach other services for advice or help or work jointly with specialist alcohol services,

Social Worker 1: I think I have a good skill in [health promotion regarding alcohol use] in the years I've been working in Social Work, I have an understanding of that … I know when to intervene, and when I need to approach other people for assistance.

Psychologist 7: If the person is clearly struggling with alcohol … then I would usually contact our addiction service … where I was concerned about their alcohol intake and felt they needed a specialist approach to that … and I would be happy to work with the alcohol team, or the addiction team, to try and address this with the person.

7.3.10.3 The knowledge and skills of alcohol specialists

When considering the health promotion needs of PwLD, some of the HSCPs thought that specialist alcohol services often struggled to support PwLD particularly with regard to communication issues and delivering health promotion interventions at a level appropriate to their learning needs. For example, group sessions in mainstream services were thought to be challenging and intimidating for PwLD,

Psychologist 2: We have some [GP] practices who are very good and some who aren't quite so … LD friendly … they're not so aware of our clients' needs as other ones … I would be thinking about the dynamics of that for [our clients], you know, is that a situation they're going to struggle with, are they going to get the most out of it, are they going to feel intimidated, or is it going to be too much for them to deal with?

However some HSCPs did describe positive experiences of alcohol services taking up the offer of working jointly with HSCPs from specialist learning disability services,

Psychologist 7: We have certainly offered to work with those agencies in ensuring that they're tackling things at the right level, so that the person that they're talking with is understanding what they're saying … I think they know about the change in drinking habits in people but they don't know how to target people with learning disabilities.

7.3.10.4 Accessibility of information

The HSCPs felt that health promotion information is often inappropriate for PwLD. They identified barriers, which include literacy, numeracy, and comprehension. 'Units
of alcohol' is a difficult concept and in particular is difficult to understand, and apply to, drinking situations,

Psychologist 7: I would certainly not describe [alcohol consumption] in terms of units for them … I would talk about how many cans they’re having or how many glasses of wine they’re having … quite often we draw it

Nurse 15: You’d pitch it saying, ‘Well, this is how many of that you’re allowed over the week,’ … I think the units, it can be quite difficult … obviously it might be on the can of lager … or whatever they’re having, but sometimes the person doesn’t know to look and see that is two units, a unit and a half, or whatever … [units] can be hard to gauge.

The HSCPs thought that education to promote health should start in schools, including Special Education Needs (SEN) schools, as PwLD who had not had appropriate education and who had not previously observed safe drinking behaviours, were identified by HSCPs as likely to experience problems when they did start to drink. Similarly, PwLD whose alcohol consumption had been controlled by others but who had not received health promotion education, e.g. people living in supported accommodation, lacked appropriate benchmarks against which to measure their behaviour,

Practice Nurse 11: [Health promotion education] certainly needs to start [in school] rather than wait until they’re leading independent lives with fifty quid in their pocket.

Nurse 8: I’m … not sure that young people [with learning disabilities] get the same opportunities to experience alcohol. You know, people who are living in staffed accommodation or staffed houses, supported tenancies, they’re really discouraged from drinking, so they’re not really being educated in sensible drinking … because somebody else is taking responsibility … so that’s not really educating people, that’s just controlling.

The family carers felt that PwLD experienced barriers to understanding about safe consumption of alcohol and they expressed doubts concerning the ability of PwLD to assimilate health promotion messages. They also questioned whether interventions were appropriate to meet the needs of PwLD,

FC 14: A leaflet would be right over the top of his head, I mean he’s a clever laddie in his own way, but giving him a leaflet to read on you … shouldn’t drink because this and that, it would go over his head.

FC 17: I think it depends if they’re living independently, you know, a lot of them do it with a lot of back up [so] it depends on their carers, to a certain extent as well … their influence on them … depends on the quality of care that they’re getting, it depends on the organisation, the standards within the organisation.
7.3.10.5 Positive perceptions of alcohol use

As described above, HSCPs were aware that for some PwLD alcohol consumption is related to inclusion i.e. socialising and being part of a group, ‘belonging’; for other PwLD alcohol represents their principal coping strategy. The HSCPs felt that these positive perceptions of alcohol use represent a barrier to health promotion, as it is difficult to positively influence behaviour change, if the perceived benefits of the behaviour outweigh the perceived disadvantages,

Psychologist 2: The pull of being included if you like, or part of the group, part of the gang, certainly for the … younger adults is a huge barrier … falling back on it as a coping strategy, if it has become a coping strategy, you know, that’s another barrier

Nurse 4: There are too many positive effects with alcohol – feel more confident, feel better, feel happier when drinking – just the whole confidence thing’s there, that outweighs the negatives even though some clients can list 20 negatives and only 2 positives, the positives are far more stronger than all the negatives put together … They feel more confident, it’s all about the confidence, the clients that are very quiet normally, you find them in the pub drinking and they’re more confident in how they talk and speak, and how they communicate. They definitely seem to like that better. That outweighs the negatives.

7.3.10.6 Cognitive impairment

The professionals discussed the fact that PwLD often have difficulties with memory, concentration, consequential thinking and planning, and therefore have difficulty in learning, and more particularly, in applying abstract knowledge to actual social contexts,

Psychologist 5: A lot of [PwLD] have impairments of memory and concentration and so on, so that idea, that they’re aware of how much they’re drinking, might actually be more difficult for them.

A key issue in terms of health promotion needs is that PwLD often require support to assist them with daily living. Similarly, in order to effect change in a lifestyle behaviour, such as drinking, individuals with PwLD are likely to require long-term support. It was considered to be very hard for PwLD to maintain behaviour change in the long-term if they lived alone and/or if they attended time-limited groups,

Nurse 8: For the duration of the group, they were able to come and say, ‘I’ve not been drinkin’ as much this week,’ but as soon as the group finishes they just go back to their lifestyle that they had prior to that … I think it’s just a deep seated behaviour it’s very, very difficult to eradicate.
7.3.11 Appropriate health promotion approaches

The majority of the HSCPs advocated a person-centred approach to health promotion interventions, in which the learning needs are assessed and addressed on an individual basis. HSCPs and family carers agreed that health promotion materials and resources should be available which use a range of accessible methods, which make use of pictures and other graphic media to support messages which are expressed simply and in concrete terms,

Social Worker 13: Pictures are quite good, but I think somebody explaining to them, just sitting down and explaining basic things … they can ask their own questions, because they've all got different ideas of it, and need to ask questions themselves.

FC 14: Visual things tend to have more impact on [PwLD].

Social Worker 10: Clear messages that are not wordy and … using simple language … pictures and videos, you know, how many pints is safe? How many glasses of wine? … What will happen if you drink a whole bottle of vodka? You won’t be very well … just very clear and simple kind of concise, very concrete, that’s the key thing.

Other key issues were thought to include recommendations regarding the amount of alcohol that should not be surpassed on a single occasion, the need for alcohol-free days, the physical effects of varying degrees of alcohol consumption, and the link between alcohol consumption and accidents and antisocial incidents. PwLD should also be encouraged to reflect on first-hand experience,

Practice Nurse 11: I think the conception of, ‘Well, why don’t we try cutting [alcohol] out two nights a week … a couple of nights of the week you’ll have none,’ and that’s a easy thing to ask … even it meant saying, ‘On a Tuesday and a Thursday,’ you know … being a bit more specific.

Psychologist 5: We need to be much more specific about, you know, ‘Don’t have more than three drinks a night,’ for example, something that’s concrete and very, very easy for people … I think the idea of looking over your week and counting the units you’re drinking is probably quite difficult.

The HSCPs suggested that enabling individuals to take personal control in the face of peer pressure, for example, by providing assertiveness skills training, could be an effective tactic. They also suggested that practical interventions in the places where people drink, might be useful in supporting PwLD to understand concepts relevant to sensible drinking, such as the volumes and strengths of different types of alcoholic drinks,
Nurse 4: [PwLD] actually need someone in a bar to show them what you can and cannot do ... but I don't know if that's a feasible thing to do ... certainly it involves going over and over, and over the same stuff again.

However, if PwLD are to be encouraged to forgo drinking alcohol as means of combating stress and boredom, for example, they will require assistance in finding alternative behaviours and interests,

Nurse 15: Support to allow [PwLD] to stop drinking ... it could just be somebody there that says, 'Right, instead of going to a pub on a Saturday night, let's do something different,' even the introduction of something totally different to take away the need to go to the pub, you know what I mean, and if it’s been your norm for 20 years, if it’s been your norm for even a year, sometimes it’s just somebody prompting you to do something different, to introduce you to different things.

The HSCPs suggested that existing health promotion packages should be adapted for use with PwLD. However, the need for continuous or repeated interventions was emphasised,

Practice Nurse 11: You have to accept that [PwLD] are different from the general population ... you can’t just do it and then it’s done ... it’s got to be a fairly ongoing thing ... I don’t mean you drone on about it every time you see them, but I just think it’s got to be part of the whole structure.

The family carers recommended that individuals who deliver health promotion should be aware of the vulnerability issues associated with learning disability and should assess learning needs on an individual basis,

FC 17: I think the people who deal with [people with] special needs, whether it’s family, family friends, or carers, or professionals, they have to be aware that [PwLD] are all individuals ... but as a whole, they’re all more vulnerable, and they need a lot more backup, they need a lot more taught to them, but these issues are real issues and you need to be safe, whether it’s don’t take too much alcohol because it will make you more vulnerable because your defenses will be more down ... but it’s getting it across it’s difficult ... knowing the level that they’re going to understand as that can be difficult as well.

The family carers also highlighted personal or individual support as a factor crucial to the effectiveness of health promotion interventions, in terms of conveying and reinforcing health messages, and in providing continuous support. To support them in this role, social care staff and residential staff could receive awareness training and skills enhancement regarding the safe use of alcohol,

FC 14: If its residential [accommodation] ... maybe there should be an alcohol counselor there ... somebody that’s got ... a wee insight into it ... it
would be good to have a course on alcohol counseling, or alcohol guidance … for the [worker] … that’s allocated to one person or two people, [I] think that would be a great idea.

In general, the perception was that health promotion interventions should be reinforced by all those who are in contact with the individual, whether in a professional role or as a carer. In terms of accessing health promotion interventions, no professional group was identified as the lead, and professional groups other than health and social care professionals were identified as having key roles, for example, staff in SEN schools and colleges,

Nurse 9: I think [health promotion interventions] have got to involve everybody, the education services as well as colleges etc.

Nurse 15: I think basically whoever’s involved with the person, there could be two or three different disciplines all involved with this person, and it’s better that you deliver it in a coordinated style.

7.3.12 Summary

In sum, the professionals expressed concern that the move to more independent living had resulted in an increase in alcohol consumption in PwLD. Excessive alcohol consumption was considered to be associated with stress, boredom, the low cost of alcohol and the influence of others, including peers. Of some concern is the fact that some PwLD were known to stop taking medications so that they could consume alcohol. PwLDs’ knowledge of the health risks associated with alcohol consumption was mainly confined to an awareness of the short-term consequences e.g. being drunk or having a hangover, rather than the long-term consequences. Family carers were particularly worried about the increased vulnerability associated with excessive alcohol consumption. When considering the health promotion needs of PwLD, the difficulty that the specialist alcohol services can have in supporting PwLD was raised, with the importance of joint working being emphasised. The need to deliver simple and very concrete messages was discussed. Helping PwLD to resist peer pressure, by developing assertiveness skills, was also thought be a useful strategy.

8. Discussion

8.1 Introduction

We undertook the study reported here with the aim of gathering data to inform the development of health promotion interventions, specific to the needs of people with learning disabilities. Our first step was to undertake a systematic review of the literature. This was followed by the gathering of qualitative data from people with
learning disabilities, family carers and health and social care professionals. The qualitative elements of the study were underpinned by social cognitive theory (SCT) (Bandura, 2006). SCT was used to explore the factors that influence the use of tobacco and alcohol in people with learning disabilities. A theoretically-driven understanding of the factors that influence lifestyle behaviours, such as tobacco and alcohol use, is essential when seeking to develop health promotion interventions which aim to support lifestyle behaviour change.

The findings are summarised below and are then considered through the lens of social cognitive theory in the section that follows (section 8.4).

8.2 Previous research

The systematic review of the literature was undertaken to ensure that any relevant studies were identified that had developed and tested tobacco or alcohol-related interventions for PwLD. Our aim was to ensure that we identified any information pertinent to the development of our own intervention/s. The review demonstrated that worldwide, the body of evidence that has focused on developing and testing tobacco and alcohol-related interventions for people with learning disabilities is small (n=5). While the studies identified all have significant methodological limitations, and therefore tell us little about what types of intervention are effective, some important issues linked to the feasibility and appropriateness of health promotion interventions for this client group were highlighted. For example, some useful information was provided on the content and mode of delivery of the interventions, such as the use of role play, visual aids, vignettes and strategies to enhance levels of self-efficacy.

8.3 Findings from the qualitative interviews

8.3.1 Factors that influence smoking/drinking alcohol

The PwLD who participated in the study included smokers, former smokers and non-smokers. The reasons for starting to smoke and continuing echoed those of the general population (ISD, 2009; Kerr et al., 2006). For example, responding to pressure from their non-disabled peers, many participants had tried smoking when they were teenagers; most had continued to smoke, although one had never smoked again. Participants described smoking currently as a means of relieving stress or boredom; a small number smoked only ‘socially’. Some of participants reported that they had stopped smoking (n=3) and a small number were planning or attempting to stop smoking at the time they were interviewed. Others felt that it would be too difficult to stop smoking and/or were resolute smokers.

Fifteen of the sixteen PwLD who participated in the study reported that they had consumed alcohol at some point in their lives, many had drunk excessively and a few continued to do so at the time the data were collected. As with smoking, many
participants reported having first tried alcohol as teenagers, sometimes feeling that they had been coerced by excessive levels of peer pressure. As adults, participants described a range of drinking habits that echo those of the general population (Scottish Government, 2009). For example, some participants described themselves as ‘social’ drinkers, others were ‘binge’ drinkers and some had problems with excessive alcohol consumption. The reasons given for drinking also echoed those of the general population (SGSR, 2008). For example, participants described drinking alcohol to ease social interaction and to cope with stress. Some participants described having chosen to moderate their drinking, usually because of specific health issues, such as diabetes and ataxia. However, others reported frequently drinking excessive amounts of alcohol and for some this was associated with mental health problems.

The HSCPs expressed concern that the move to independent or supported living had resulted in an increase in alcohol consumption amongst PwLD, as increasing numbers of PwLD have their own homes and, importantly, have control over how they live their lives and how they spend their money (Gillespie et al., 2007). The fact that large quantities of strong alcohol can be purchased very cheaply was considered to be unhelpful and in Scotland this issue is one that is thought to encourage the drinking culture (Scottish Government, 2009). Excessive alcohol consumption amongst PwLD was thought to be associated with stress, boredom and a lack of meaningful occupation, and was also thought to be influenced by a perceived need to belong or to ‘fit in’ with others. In addition, PwLD were observed to be influenced by the drinking behaviours of their non-disabled peers.

8.3.2 Knowledge of adverse effects of tobacco use/drinking alcohol

In terms of knowledge of the adverse health effects of tobacco use, PwLD were aware of the relationship between smoking and heart and lung disease and cancer. Often however, it appeared that their understanding of the implications of these physical disorders was limited, as previously described by Taylor and colleagues (2004). The exceptions were those individuals who described having observed the effects of such diseases in family members, and the subsequent effect of such experiences on their decision to refrain from/quit smoking. HSCPs had also noted that, amongst PwLD, understanding of the long-term health implications of smoking appeared superficial. However, they had also observed that firsthand experience of the effects of smoking on an individual’s health, or on the health of others, often exerted a positive influence on lifestyle decision-making.

In terms of the adverse effects of drinking alcohol, PwLD appeared to have a good degree of awareness regarding the negative aspects of being drunk. Participants were able to describe negative effects of excessive drinking such as lowered inhibitions, nausea and hangovers (BMA Board of Science, 2008). They also had some knowledge of the adverse health effects of excessive and/or prolonged alcohol
consumption. For example, some of the participants were aware of the fact that excessive alcohol consumption can damage the liver. Often, as with smoking, this awareness derived from personal experience or from observation of the effects in others, such as family members. However, it was unclear whether participants had any real understanding of the health implications of alcohol abuse, or the implications of liver disease.

Similarly, the HSCPs reported that PwLDs' knowledge of the health risks associated with alcohol consumption was confined to an awareness of short-term consequences, such as being drunk or having a hangover, rather than having an understanding of possible long-term consequences of drinking at hazardous/harmful levels. Worryingly, some HSCPs reported that some PwLD, having been made aware of the unpleasant effects associated with mixing alcohol with their prescription medications elected not to take their medication so that they could drink alcohol.

The focus group discussions with PwLD revealed that there was some understanding of contemporary 'sensible' drinking advice (Scottish Government 2009). However, knowledge of the weekly and daily recommended limits for males and for females in terms of 'units' varied greatly, and when pressed, participants were unclear as to what constitutes a 'unit of alcohol'. This degree of variability and uncertainty reflects the knowledge levels reported in the general population (SGSR, 2008).

Family carers confirmed the HSCPs' views that PwLD may have a superficial understanding of the adverse effects of tobacco use and of excessive alcohol consumption. In particular, family carers were concerned about the increased vulnerability of PwLD who drink, particularly in terms of sexual vulnerability and aggression.

8.3.3 Barriers to accessing health promotion education and services

As described above, PwLD had difficulty understanding complex health promotion messages linked to the use of tobacco and alcohol. They discussed the possibility of obtaining support from mainstream services, including smoking cessation groups, GPs and pharmacists. They identified a need for the staff working in these services to make adjustments that would ensure that the service met the needs of individuals with learning disabilities, such as engaging PwLD in one-to-one discussions (NHS Scotland, 2004). However, such an individualised approach is likely to represent a significant challenge for both mainstream services and specialist LD services, as the development and delivery of such a person-centred approach may make greater demands on resources (NHS Scotland, 2004). The HSCPs reflected on such difficulties faced by specialist alcohol services wishing to offer support and interventions, appropriate to the needs of PwLD. Joint working between specialist
health promotion and specialist learning disability services was discussed as an important and potentially effective means of service delivery.

8.3.4 Appropriate health promotion approaches

As discussed, the findings from the focus group and telephone interviews demonstrated that, amongst PwLD, levels of knowledge and understanding varied considerably regarding the adverse effects of tobacco use and alcohol consumption (Taylor et al., 2004). There was agreement amongst the participants (PwLD, HSCPs and family carers) regarding the need for individualised or person-centred approaches to the delivery of health promotion interventions and services.

There was also agreement that simply stated messages are an effective means of relaying health promotion information regarding the adverse effects of tobacco use and alcohol consumption to PwLD. Therefore, when developing health promotion materials, consideration should be given to determining the essential elements of information that are to be conveyed, and which will enable the individual to make an informed choice. Participants (PwLD, HSCPs and family carers) described a need for interventions that deliver health promotion messages using ‘simple’ language supported by images, which aim to convey abstract concepts in concrete terms and which are reinforced verbally. They also described opportunities for one-to-one discussion as useful, and identified a need for interventions tailored to meet the specific communication and learning needs of individuals. PwLD identified dramatic images and dramatic TV advertising campaigns as effective means of conveying health promotion messages. However, although such images may have a powerful effect on individuals, they do not necessarily instill understanding. The HSCPs and family carers also described the use of images, and in particular ‘dramatic’ images, as important health promotion tools. Therefore, the effectiveness of the various communication media used to convey health promotion messages should be assessed in terms of impact and understanding.

In terms of alcohol consumption specifically, the interventions or tools currently available, for example FAST, are not designed to support individuals’ decision-making whilst in drinking situations (Hodgson et al., 2002). Consequently, there appears to be a need for an educational intervention that enables PwLD to understand what constitutes ‘sensible’ drinking in social contexts (NHS Scotland, 2004). Such an intervention should include an easy-to-use tool that individuals can apply to actual drinking situations and habits.

8.3.5 Supporting PwLD to make lifestyle choices

The increasing level of autonomy evident within the lives of PwLD affects important issues such as making healthy lifestyle choices and prioritising how money is spent (Taggart et al., 2008), and should be considered when designing health promotion
interventions. There is a need to ensure that mechanisms are in place to empower PwLD to make informed decisions in relation to smoking tobacco and drinking alcohol.

In terms of the practical support required to help PwLD make lifestyle choices, participants highlighted the role of support workers as being particularly influential. HSCPs and family carers pointed to the need for appropriate training and resources for support workers. Similarly, peer support, which is known to be effective in terms of making successful smoking cessation attempts in certain disadvantaged groups (e.g. Solomon et al., 2000), and which has been used successfully with PwLD in educational settings, (e.g. Carter et al., 2005), might prove a useful support mechanism, particularly if appropriate training, support and health promotion materials were made available to 'health promotion peers'. The HSCPs also suggested that helping PwLD to resist peer pressure by developing assertiveness skills, might prove a useful strategy and again, this has been used successfully by others (e.g. Connor, 1994).

8.4 The link to social cognitive theory

As discussed, social cognitive theory, proposes that behaviour and behaviour change are affected by environmental influences, personal factors and attributes of the behaviour itself (Bandura, 1986). Each may affect or be affected by either of the other two (reciprocal determinism).

The findings very clearly demonstrate the influence of the participants' social and physical environment on their use of tobacco and alcohol. Social influences include friends, family and health and social care professionals. Factors in the physical environment thought to have influenced lifestyle behaviours include the closure of institutions and the resultant rise in independent/supported living over the last decade (Scottish Executive, 2000) and the recent smoke-free legislation (Scottish Government, 2006). The low cost of alcohol is another important environmental factor thought to influence consumption of alcohol.

When considering personal factors that influence lifestyle behaviours levels of self-efficacy are thought to be particularly influential. An individual with learning disabilities must believe in his or her own capability to perform a particular behaviour (i.e. to be able to stop smoking successfully) and must perceive an incentive to do so (i.e. positive expectations from performing the behaviour must outweigh the negative expectations). Additionally, the individual must value the outcomes or consequences that he or she believes will occur as a result of performing a specific behaviour. Outcomes may be classified as having immediate benefits (i.e. increased disposable income) or long-term benefits (e.g. improvements in health). As these expected outcomes are filtered through a person’s expectations or perceptions of being able to perform the behaviour in the first place (e.g. cut down alcohol consumption), self-
efficacy is believed to be the single most important characteristic that determines a change in a person’s behaviour (Bandura, 2006).

Self-efficacy can be increased in several ways, for example, by providing clear instructions, providing the opportunity for skills development or training and modeling the desired behaviour (i.e. by using role models). To be effective, role models must evoke trust, admiration and respect from the observer (PwLD), models must not, however, appear to represent a level of behaviour that the observer is unable to visualise attaining (Bandura, 1986).

People with learning disabilities may have problems with consequential thinking and planning, memory and concentration and may have difficulty applying abstract knowledge to actual social contexts. This links to behavioural capacity, which is a concept in SCT that refers to the knowledge and skills required to perform a particular task e.g. to stop smoking or cut down alcohol consumption. Health and social care professionals working with PwLD have a key role to play in helping to address health promotion needs by promoting mastery and learning, through skills training.

Consideration of self-control, another key concept in SCT, is also important when working with this client group. Many PwLD are impulsive and may have difficulties with self-control. PwLD are likely to need support in personal regulation of goal-directed behaviours (e.g. cutting down alcohol consumption). Professionals can assist with the provision of opportunities for self-monitoring (e.g. use of diaries, if appropriate), goal setting (e.g. not drinking on 3 days of the week), problem solving (working out when the difficult times are) and self-reward (e.g. buying a treat with the money saved when stopped smoking).

Finally, tobacco contains nicotine which is known to be highly addictive, and as such, is an attribute of smoking that encourages people to keep smoking and stops them making cessation attempts. Alcohol may also be addictive, if consumed in sufficient quantities. Both smoking and drinking can be habit forming and this is another factor that encourages continuation i.e. these lifestyle behaviours may form a core part of an individual’s daily life. On this note, PwLD can be particularly resistant to changing their daily activities and habits (Bhaumik, et al., 1997). An additional issue is that smoking increases dopamine levels in the brain causing a stimulant effect and feelings of pleasure (Royal College of Physicians, 2000). This is something that encourages continuation and reduces willingness to stop. The relaxing properties of alcohol also encourage its use.

In sum, viewing the findings through the lens of SCT has helped us to gain an understanding of the mechanisms that impact on the health promotion needs of people with learning disabilities. Such insights, in addition to the findings from our review of the literature, will assist in the development of tobacco and alcohol-related health promotion interventions that will be tested in future work.
8.5 Limitations/Reflections on project process

8.5.1 Systematic review

We used a systematic method to review the literature pertaining to the effectiveness of health promotion interventions. However, the scope of the review was limited as the search strategy focused on tobacco and alcohol, rather than on a range of lifestyle issues, and on health promotion per se rather than on a range of educational interventions. Searching more widely is likely to have yielded a larger number of papers for analysis in the final stage of the review. This would have provided greater depth and scope of evidence with which to inform a health promotion intervention. Consequently, the scope of the review will be extended in subsequent work.

8.5.2 Qualitative study: recruitment and sampling

We recruited PwLD to the project through voluntary sector organisations. This proved a lengthy process that made heavy demands upon the researchers’ time as, for example, eliciting a response from some organisations ultimately proved impossible. Choosing to recruit PwLD from voluntary sector organisations limited the heterogeneity of the sample. In future studies, ethical approval will be sought from the NHS to allow access to PwLD who are in contact with statutory services. However, it is known that many PwLD do not access support services (voluntary or statutory); such people remain a ‘difficult to reach’ group.

Recruitment of carers also proved extremely difficult, in spite of the strenuous efforts made by the members of the research team to engage with representatives of a variety of organisations. Disappointingly, only two carers were recruited to the study thus limiting the potential transferability of the FC findings. Further consultation with carer organisations is required to enable us to identify how best to secure the involvement of informal carers in our research. It may be that alternative means of data collection, such as focus groups based on pre-existing carers groups, may prove effective, as demonstrated in our work with relatives/carers of people who have had stroke (Lawrence et al., 2009).

We elected to recruit to the study health and social care professionals who represented the several disciplines involved in the delivery of community learning disability services. However, our discussions with participants highlighted the important and potentially influential nature of the role filled by formal, or paid, support workers. In future work, we would also seek to recruit support workers and other paid carers.

8.5.3 Time management

The study was designed to be conducted over the course of nine months, with a research assistant (RA), seconded from practice, working on the project for six
months. However, certain elements of the project (e.g. the ethics and R&D approval processes and the various recruitment processes) required a greater time commitment than anticipated. Fortunately, we obtained support from the QNIS and the NHS, which enabled us to extend Lorna’s (the RA) contract by three months. This enabled Lorna to continue her engagement with the project through to the final stage of analysis and reporting. This extension ensured that Lorna gained maximum benefit from her research experience (section 12). It also ensured that the project derived maximum benefit from Lorna’s clinical expertise and experience. In future work will aim to replicate this mutually beneficial experience in order to ensure the clinical relevance and utility of project outcomes.

8.6 Conclusion

The tobacco and alcohol-related health promotion needs of PwLD is an under-researched area. We undertook the study reported here with the aim of gathering and synthesising data that would inform the development of tobacco and alcohol-related health promotion interventions. This involved conducting a review of the literature in order to ascertain the nature and scope of the existing evidence base. We also undertook a qualitative exploration of the factors that influence the lifestyle behaviours of PwLD, from the perspective of people with learning disabilities, health and social care professionals and family carers. Using the evidence generated by this work, we are able to embark on the next stage of our research, in which an intervention, or interventions, will be developed and tested.

9. Implications for practice, research and education

9.1 Practice

Joint service provision is recommended as an approach that may further enhance the effectiveness of health promotion interventions.

Health promotion interventions should provide a range of materials and resources, delivered in a range of formats which exploit the potential of contemporary communication media.

A person-centred, individualised approach to the assessment of the learning and communication needs of PwLD with regards the delivery of health promotion interventions is recommended.

Support workers should be encouraged to undertake health promotion skills training.

PwLD should be supported to acquire skills that will enhance meaningful participation, including assertiveness training.
An innovative approach to the development and implementation of support mechanisms, such as peer mentoring and buddyng, is recommended.

9.2 Research

There is a need for further research in which health promotion interventions for PwLD are developed and tested for feasibility, acceptability, meaningfulness and effectiveness.

9.3 Education

Undergraduate and post-graduate programmes of education should incorporate a health promotion element which will equip HSCPs to provide appropriate and effective tobacco and alcohol health promotion interventions for PwLD.

10. Dissemination

Following submission of the final report, extensive efforts will be made to disseminate the project findings to community learning disability nurses, other nurses and health and social care professionals who work in primary care, and other key stakeholders in Scotland and the UK. The findings will be disseminated in peer reviewed and professional journals, and at appropriate conferences.

10.1 Dissemination activities already undertaken

A poster, ‘Tobacco and alcohol use in people who have a learning disability: giving voice to their health promotion needs’, was presented at the QNIS Annual Conference, in March 2009.

A presentation, ‘The challenges and triumphs of carrying out a community-based project’, was made to the QNIS Research Fellows and Projects Forum, March 2009. The presentation was based on the experiences of the research teams involved in this project and the Lisbeth Hockey Community Nursing Research Training Fellowship, 2008.

A paper, 'Smoking cessation: what are the issues for people with learning disabilities in accessing health promotion interventions?’ has been presented to the Scottish Smoking Cessation Conference, 2009.

10.2 Planned dissemination activities

A paper summarising the findings from this study will be presented to the RCN Annual International Nursing Research Conference, May 2010, as part of a symposium, being delivered by the Glasgow Caledonian University 'Improving
Health and Wellbeing’ research group. The focus of the symposium is on the development and implementation of complex interventions designed to improve health.

Two papers are being prepared for publication in peer-reviewed journals, 1) the systematic review of the literature and 2) the qualitative findings. An additional paper, an overview of the project, will be prepared for submission to a practice-related journal.

If funding permits, we anticipate hosting a seminar to disseminate findings to community nurses and other healthcare and social care professionals. The project team will engage in discussions with the QNIS Projects Co-ordinator, regarding a dissemination event which will focus on QNIS-funded learning disability research.

11. Future developments/next steps

The findings from the current project, in combination with the review of the literature, will be used to inform the development of health promotion interventions on smoking and alcohol consumption, specifically tailored for people who have a learning disability and informal carers. The interventions will be developed for use by community learning disability nurses, and members of the primary care team who work with people who have a mild to moderate learning disability.

Following the development of the health promotion interventions mentioned above, it is anticipated that their efficacy will be tested in future work for example, in a randomised controlled trial. Our ultimate aim is to develop interventions that will help to improve the health of people with learning disabilities.

12. Report from the Research Training Fellow – research skills development

In this section, the report prepared by Lorna Fitzsimmons, project research assistant and training fellow, is presented.

12.1 Project responsibilities

- To develop a working knowledge of topic being studied including the theoretical underpinnings. Involved learning around study themes (tobacco and alcohol, health promotion) and underpinning theory (social cognitive theory). The training log is presented in appendix 21.

- Recruitment and interviews of professionals and family carers; telephone interviews with both groups using an interview schedule that aims to elicit the experiences and views of those recruited. Involved learning around and
development of interview schedules; learning around research method, interviewing techniques, telephone interviewing. Development and use of demographic data collection tool.

- Collection, organisation and analysis of data from telephone interviews. Involved training in and use of data management systems (NVivo v7, SPSS v16); learning around data analysis procedures (qualitative and quantitative).

12.1.2 Additional activities

Contributing to: Research Team meetings; Steering Group Meeting; writing of the interim report; dissemination activities (i.e. poster design, seminar/conference presentations).

12.2 Recruitment and Telephone Interviews

Recruitment of professionals in the field did not pose too many barriers in terms of access and knowledge of those professionals because of my field of practice. Although others on the team were also Learning Disability (LD) professionals in academic practice I felt my working knowledge and experience of who the professionals were, how they worked and linked with each other, added to this. The points of contact were peers in some cases and perhaps trusted my position in the study. I had a sense that they encouraged the invitees to participate with me in mind, as well as the importance of the study. Where professionals were non LD professionals my practice role enabled me to guide them in thinking of the specific group of people with learning disability the study focused on.

When interviewing, my main challenge was in balancing my knowledge and my assumptions of participants’ meanings and experiences, with a researcher’s objective perspective. This resonated with my practice which involves interviewing skills, and I gained a perspective of that shared dilemma in practice. From interviews of both groups I gained a deeper sense of the realities of current local practice in this field, including joint work and liaison and the issues impacting on practice. This awareness I carry back to practice to influence future liaison with such services and practitioners.

Recruitment of personal carers was more difficult; given there is no single point of contact for the specific group we sought to connect with. I became more aware of carers organisations and their roles and functions, as well as some of the more pertinent issues for carers currently (in addition to the study topics). This insight was certainly useful for the study in identifying issues around carer recruitment. I also felt a personal benefit in a broader connection with this group and their issues, and reflected this isn’t always the case in practice.
Issues around engagement in the study included the study topic of alcohol consumption not always an easy topic to discuss. A main feature of my practice is such discussions of very personal and difficult health-connected behaviours. Thinking about this from a carer’s perspective for the study purpose gave me space for deeper reflections on my interpersonal communication styles in discussing sensitive topics, and highlighted the perspective of others. I can carry this further developed insight with me.

As a LD nurse I brought an awareness of another group of formal social carers involved in the lives of the population in the study. Although not included in the sample I was able to offer reflections of how this might have impacted on recruitment, and future dissemination or study. Such situations enabled a sense of me bringing something to the study as well as gaining something in learning, experience and skills development.

12.3 Data analysis and write up

The process of analysing the data collected came towards the end of the secondment and due to the delays at the beginning, felt pressured at times. On reflection, this is a stage requiring one to be immersed in the data and so requires being with the data on a regular basis over extended periods of time. The end of the secondment and intermittent connection with the data (only working 2 days per week, and being engaged in other activities such as the preparation of a paper for presentation at a national conference) made this a challenging experience. However it proved a valuable experience in focusing and working to deadlines. It also highlighted the connection between the previous stages in the research and the insight and knowledge of the data I carried, having been through this process. This reinforced my experience of development, as well as my role within the research team, leading to a commitment to participate as fully as possible until the completion of write up. Being with the data and identifying themes provoked thoughts of future questions, related areas of practice, and implications for changing practice. This brought alive for me the nature of research enquiry as related to the world of practice and allowed me the experience of contributing to this world.

12.4 Total time commitment

The need to extend the secondment (and an additional contribution made in my personal time) reflects a common experience in research where timetables can be affected at different stages of the process. Difficulties in recruitment at the start can and did slow the whole journey, altering the anticipated timescales. The opportunity to continue the secondment enabled continued involvement through all stages of the study giving a more rounded experience. That it was sought by the research team, and supported by QNIS, gave an experience of having some worthwhile contribution
to the process and really being part of the team. The understanding and support provided by NHS Management and the QNIS in extending the secondment was much appreciated.

12.5 Personal development

The opportunity to be seconded to undertake the research training fellowship enabled:

- Participation in research which results in the opportunity to affect change in practice. Such experience may not have been available in practice roles or may not have been sought due to lack of familiarity with, or skills in research.
- Working with a larger academic research team having their knowledge, guidance and expertise at hand to improve research enquiry skills and be guided through the process of research.
- Professional participation in the process of organizing the secondment and so improving links with academia and NHS, and highlighting need for/importance of nursing research.
- Insight into what a nurse in practice can bring to a research team, in terms of contact with the population and their lived experiences. As well as offering a visible link for potential professional participants/nurses in practice, who may be reading and implementing research; making connections between the research and practice worlds.
- Increased insight into the process of research and being a reflective thinker. Observing and participating in the research process. Improving critical appraisal and analytic skills. Involvement in preparing literature for publication and disseminating information.

Having time away from practice in what initially looks like a different experience actually highlighted the similarities and the areas of connection with practice. This served not only to equip me with additional knowledge, skills and experience in research methods but also to provide lived experience of the connection between research and practice in the topics studied and the tools and methods used. That areas of practice (past and current) came to mind throughout the experience reinforced this connection and space for reflection for me. Previous study of research theory brought a shift in the accessibility of research for me; in the breaking down of the language barrier, understanding of the processes and methods, and the development of critical appraisal skills. The secondment opportunity built on this and further broke down the barrier of actually doing research, putting the theory into practice, and ultimately making research an achievable ability. Since returning to practice I have been in contact with the research team within my own service and will be talking about my experience of research to nurses in practice in a personal development group. However I also have more confidence in discussing potential
research topics and seeing the potential of becoming involved in research in practice in the future.

I will also continue my links with the GCU Research Team and will contribute to the dissemination of the project findings (publications and conference presentations).

Lorna Fitzsimmons (RN, LD)
(Clinical Nurse Specialist in LD-Child and Adolescent Mental Health Service)
Research Assistant
School of Health
Glasgow Caledonian University

13. Financial report

The total amount of funding awarded by the QNIS was £36,403.29. Details of the amount of funding requested for each of the itemised costs are provided in column two (table 7). The actual amount spent is detailed in column three. Column four provides information on under-spent and over-spent items. Two items that had not initially been costed had to be paid for from the project budget. These items included a transcription pedal and payment for the practice nurses to participate in the study. A transcription pedal had not been costed as the Team had access to one that had been purchased for another study. However, the pedal broke early in the transcription process and a new pedal had to be purchased. Recruitment of the Practice Nurses, with the assistance of the Scottish Primary Care Research Network, necessitated payment of the Practices that employed them for the time that they took to participate in the study. As indicated, the total budget under-spend was £499.69.

Table 7. Financial report

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References


Lawrence, M., Kerr, S., Watson, H. and Paton, G. The views of patients and their families regarding secondary prevention lifestyle information following stroke: findings from a focus group study. *In submission*


APPENDICES
Appendix 1: Systematic Review Search Strategy

1. (learning adj3 disabil$).mp. [mp=ti, ot, ab, hw, kw, tc, id, tx, ct, sh, de, cc, nm]
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5. (mental adj3 retard$).mp.
6. mental retardation.mp.
7. 6 or 4 or 1 or 3 or 2 or 5
8. exp ethanol/
9. (alcohol$ or ethanol$ or wine or beer or spirit$ or ((problem or hazardous or harmful) adj3 drink$)).mp.
10. 8 or 9
11. tobacco.mp.
12. exp smoking/
13. exp smoking cessation/
14. smok$.mp.
15. 11 or 13 or 12 or 14
16. 7 and 10
17. 7 and 15
18. 16 or 17
19. limit 18 to human
20. limit 19 to yr="1998 - 2009"
21. limit 20 to humans
22. remove duplicates from 21
23. (health adj3 promot$).mp.
24. exp health promotion/
25. 24 or 23
26. 25 and 18
27. remove duplicates from 26
Appendix 2: Systematic review: - search results

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## Appendix 3: Data Extraction Tool

Tobacco and alcohol use in people who have a learning disability: giving voice to their health promotion needs.

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<td>Location (e.g. primary care; educational establishment)</td>
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<td>Description of the participants (e.g. age, gender, socio-economic status, ethnicity, level/type of LD)</td>
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<td>Details of any randomisation, including methods</td>
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<td>Intervention</td>
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<td>Outcome measures/data collection</td>
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<td>Secondary outcome measures (quantitative studies), include when, where + by whom</td>
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<td>Reliability &amp; validity of instruments</td>
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<td>Data collected (qualitative), how, where, when, by whom, what, length</td>
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<td><strong>Data analysis</strong></td>
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<td>whether appropriate)</td>
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<td>Qualitative analysis:</td>
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### Appendix 4: Quality assessment tool

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<th>Criteria</th>
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<tr>
<td>Explicit theoretical framework</td>
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<td>Aims and objectives clearly stated</td>
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<td>Clear description of intervention</td>
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<td>Clear description of the sample and how it was recruited</td>
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<td>Clear description of methods used to collect and analyse data</td>
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<td>Attempts made to establish the reliability or validity of data collection and analysis</td>
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<tr>
<td>Inclusion of sufficient original data to mediate between evidence and interpretation</td>
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Adapted from the NICE publication *Moving beyond effectiveness in evidence synthesis: methodological issues in the synthesis of diverse sources of evidence* (Popay, 2006).
Talking to people with a learning disability about smoking and drinking alcohol

My name is Alan Middleton.

I am a nurse and I work at Glasgow Caledonian University. I work with other nurses and we are doing a research study.

Research is a way of finding out facts and opinions.

We would like to talk to people who smoke or drink alcohol. We would also like to talk to people who have recently stopped smoking.

We want to find out what you think about smoking and drinking alcohol.

While it will not benefit you at this time, we hope it will help people to live healthier lives.
We would like you to join a group to discuss smoking and drinking alcohol.

There will be about 5 people in the group.

You can bring a friend, relative or support worker with you.

You can leave at any time if you change your mind.

The discussion will last for about 1 hour.

You will only have to come to the group one time.
We will record the discussion so that we can remember what you say.

Your personal details will be kept **private**.

We will not tell other people about the things you say unless you tell us something that means you need help to keep you safe. Then we will tell someone who can help you like your support worker or your doctor.

Some of the things you say will be used to write reports about the study. We will not use your name so no-one will know what you said.

We will pay for your travel to the group.
We will pay for lunch.

You do not have to take part in the study if you do not want to.

Would you like to take part?

Yes or No

If Yes, I will ask you to sign a consent form.

You can ask me questions and you can contact me:

Alan Middleton
Glasgow Caledonian University
Cowcaddens Road
Glasgow G4 0BA
Telephone: 0141 331 3811   E mail: alan.middleton@gcal.ac.uk
Appendix 6: Consent forms - PwLD

Talking to people with a learning disability about smoking and drinking

Please tick the boxes if you agree:

- I have been told what the study is about.

- I know that the group discussion will be tape-recorded. Some of the things I say may be used to write reports about the study.

- I know that my personal details will be kept private.

- I know that the only reason for not keeping my details private would be if I needed help to keep me safe.
• I have had a chance to ask questions. ☐

• I can decide to take part in the discussion group. ☐

• I agree to take part in the study. ☐

Please print your name: ________________________________
Signature: __________________________________________
Address: ____________________________________________
Telephone number: _________________________________
Date: _______________________________________________
Researcher’s signature: _______________________________

You can contact me: Alan Middleton
Glasgow Caledonian University
Cowcaddens Road, Glasgow G4 0BA
Telephone: 0141 331 3811  E mail: alan.middleton@gcal.ac.uk
Appendix 7: Interview schedule - focus groups

Putting the group at ease

Relaxed, informal, conversational, as far as possible
Start with easy questions to increase confidence of respondent

Explain

What the purpose of the focus group is
What questions will be asked
Who and what the information is for
Why the information is important
How long the focus group will take
Remind participants the discussion is taped
The limits on the focus group confidentiality
Check understanding of these
Set ground rules: e.g. turn taking (especially for the recorder) and listening
Introductions (for the recorder)

Smoking

First we are going to talk about smoking.

Who in the group smokes or has smoked or tried smoking in the past? If stopped when?

Why do you/people smoke?

What are the good things and the bad things about smoking? Is there anything you do not like about smoking?

Can the smoke do anything to other people?

Tell me about trying to stop smoking? Have you or someone you know ever tried to stop? Tell me more about that?

Where can you/someone get help if they want to stop smoking?

What things might help you or someone else with a LD to stop smoking?

(5 Minute Break before next section)
Alcohol

Now we are going to talk about drinking alcohol.

Who in the group drinks alcohol? Has stopped drinking alcohol? Has tried drinking alcohol in the past? If stopped when?

Why do you/people drink alcohol?

What are the good things and the bad things about drinking alcohol?

How much alcohol is it okay to drink in a day? How many glasses of...?.....would it be ok for you to drink?

What happens if you drink too much alcohol?

Why do some people drink too much alcohol?

Where can someone get help about drinking alcohol?

What things might help you or someone else with a LD learn about drinking alcohol safely?

Thank you for taking part in the discussion what you have said will be really useful. Remember we will not use your name at any point. We can send you a summary of our report if you would like one once we have finished the research.
Appendix 8: Visual aids for use in focus groups

Smoking

Cue card with title ‘Talking about smoking’
Pictures of people smoking
Photograph of a full ashtray
Photograph of someone making a ‘roll up’ cigarette
An empty ten packet of cigarettes with a photograph of throat cancer on the back

Alcohol

Cue card with title ‘Talking about alcohol’
Pictures of people drinking alcohol
Photograph of a pint of beer
Photograph of a glass of whisky
Photograph of glasses of red and white wine
Photograph of someone drinking from a bottle of Buckfast tonic wine
Photograph of several alcoholic drinks lined up on a bar
An empty bottle of champagne/cava
An empty whisky bottle
An empty wine bottle
An empty lager can
A wine glass
A pint glass
A small ‘spirits’ glass
Appendix 9: Demographic Questionnaire (PwLD) - Some questions about you

1. **Sex**
   - Male □
   - Female □

2. **Age**
   - ___ years

3. **Marital status**
   - Single □
   - Married/living with partner □
   - Divorced/separated □
   - Widowed □

4. **Living arrangements**
   - Lives alone □
   - Lives with one other person □
   - Lives with others □
   - Provide details of who you live with (e.g. partner, friend, supported accommodation) ______________________________

5. **Postcode**
   - ___ ___ ___ ___

6. **Ethnic group**
   - White □
   - Asian □
   - Black □
   - Chinese □
   - Other □ (details) __________

7. **Employment status**
   - Employed □
   - Unemployed □
   - Attends college □

8. **Smoking**
   - Current smoker □
     - please state how many cigarette per day ____
   - Former smoker □
   - Never smoked □

9. **Alcohol**
   - Currently drinks alcohol □
   - Used to drink alcohol □
   - Has never drunk alcohol □
Appendix 10: Letter of Invitation – Community Learning Disability Teams

[date to be added]

Dear Colleague,

**Study title: Tobacco and alcohol use in people with a learning disability: giving voice to their health promotion needs.**

I am writing to invite you to take part in a study that will explore the tobacco and alcohol-related health promotion needs of people who have a mild to moderate learning disability. The information gathered will be used as a basis for future work that will develop and test specially tailored health promotion interventions in these key areas. We hope that this will help to improve the health of people with a learning disability.

I have enclosed an Information Sheet that provides details of the study and what your participation would involve. If after reading the information you would like to take part in the study, please complete and return the Consent Form in the envelope provided within 7 days.

If, on the other hand, you would like more information about the study, before making up your mind, please contact me on the following telephone number 0141 331 8370 or e.mail Lorna.Fitzsimmons@gcal.ac.uk. I will be very happy to answer any questions that you might have.

Yours sincerely,

Lorna Fitzsimmons RN(LD)
Research Assistant
Dear Practice Nurse,

**Study title: Tobacco and alcohol use in people with a learning disability: giving voice to their health promotion needs**

I am writing to invite you to take part in a study that will explore the tobacco and alcohol-related health promotion needs of people who have a mild to moderate learning disability. The information gathered will be used as a basis for future work that will develop and test specially tailored health promotion interventions in these key areas. We hope that this will help to improve the health of people with a learning disability.

I have enclosed an Information Sheet that provides details of the study and what your participation would involve (i.e. a 30 minute telephone interview). If after reading the information you would like to take part in the study, please complete and return the Consent Form in the envelope provided within 7 days.

If, on the other hand, you would like more information about the study, before making up your mind, please contact me on the following telephone number 0141 331 8370 or e.mail Lorna.Fitzsimmons@gcal.ac.uk. I will be very happy to answer any questions that you might have.

Finally, please note that if you agree to take part in the study, the Practice that employs you will be reimbursed for the time that you spend taking part in the interview (£23/hour, pro-rata).

Yours sincerely,

Lorna Fitzsimmons RN(LD)
Research Assistant
Appendix 12: Participant information sheet – HSCP

Study title

Tobacco and alcohol use in people who have a learning disability: giving voice to their health promotion needs.

You are being invited to take part in a research study.

I am writing to invite you to take part in a study which is being undertaken in NHS Greater Glasgow & Clyde and NHS Ayrshire & Arran. This information sheet explains what the study is about and tells you what you will be asked to do if you agree to take part.

Please take time to read the information carefully and discuss it with others, if you wish, before making up your mind.

What is the purpose of the study?

The purpose of the study is to explore the health promotion needs of people with a mild to moderate learning disability, in relation to tobacco and alcohol. The information gathered will be used to inform future work that will develop and test specially tailored health promotion interventions. We hope that this will contribute to improving the health of people with a learning disability.

Who is conducting the study?

The study is being undertaken by a team that includes myself (Lorna Fitzsimmons), Maggie Lawrence, Susan Kerr, Chris Darbyshire, Alan Middleton and Hazel Watson. We are all experienced nurses who are now employed as researchers and lecturers at Glasgow Caledonian University (GCU).

The study is based in the School of Nursing, Midwifery and Community Health at GCU and we are working with colleagues in the NHS, the voluntary sector, service users and formal/informal carers. The study will be conducted over a period of nine months and is due to be completed by June 2009. The Queen’s Nursing Institute Scotland (QNIS) has funded the study.

Why have you been contacted?

I have contacted you because you are working in the community or in primary care and may have contact with people who have a mild to moderate learning disability and who smoke or drink alcohol. You have been contacted along with other professionals who work in NHS Greater Glasgow & Clyde and NHS Ayrshire & Arran.

If you agree to take part in the study, what will this involve?

If you agree to take part in the study I will contact you within two weeks to discuss your participation and to answer any questions that you might have. Your participation in the study will involve an interview which will be conducted over the telephone and which will last approximately 30 minutes. The telephone interview will be arranged at a time that is convenient for you.
During the interview, I will ask you for your views on the use of tobacco and alcohol in people with a mild to moderate learning disability and your understanding of health promotion issues related to tobacco and alcohol. With your permission, I would like to audio-record the interview to ensure that I have an accurate account of what we discuss.

**Will my taking part in the study be kept confidential?**

Your personal details and the content of the interview will be confidential. Your name will be replaced with an identification number and you will not be identified in anything connected to the research. As part of the reporting process of a research study some parts of a participant’s conversation during the interview may be used to illustrate the findings. However, please be re-assured that you will not be identified in any way.

**What will happen to the results of the study?**

The results of the study will be used as a basis for future work that will develop and test specially tailored health promotion interventions, in relation to tobacco and alcohol, for people with mild to moderate learning disabilities.

The results will be published in a report that will be submitted to the funding body, the Queen’s Nursing Institute Scotland. In addition, the intention is to publish in an appropriate learning disability journal (e.g. British Journal of Learning Disabilities) and to disseminate the findings at conferences. While we plan to disseminate the findings widely, please be re-assured that people who have taken part in the study will not be identified in any way.

If you would like a summary of the findings, I will be happy to send this to you when the study is complete.

**Who has reviewed the study?**

All research in the NHS is reviewed by an independent group of people in a Research Ethics Committee. This study has been reviewed and given a favourable opinion by the NHS Greater & Clyde and NHS Ayrshire & Arran Ethics Committees.

**What should you do if you want more information or if you would like to take part?**

If you would like further information about the study before making up your mind, please contact me on Tel. 0141 331 8370 or e mail Lorna.Fitzsimmons@gcal.ac.uk. I will be happy to answer any questions that you may have.

If you have read the information and would like to take part in the study, please complete the enclosed Consent Form and return it to me in the envelope provided within the next 7 days.

**What will happen if you don’t take part?**

Participation in the study is on a voluntary basis. You are also free to change your mind and withdraw from the study at any point, without providing a reason.

*Thank you for taking the time to read this information*
Appendix 13: Consent form - HSCP

Study Number:
Participant identification number:

Study title: Tobacco and alcohol use in people with a learning disability: giving voice to their health promotion needs.

Name and address of Researcher: (name to be added), School of Nursing, Midwifery and Community Health, Glasgow Caledonian University, Cowcaddens Road, Glasgow G4 0BA Tel: 0141 3318370.

Please tick the boxes and sign below

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without providing a reason.

3. I agree to the interview being audio-recorded.

4. I agree to take part in the above study.

_________________________ ____________ ___________________
Name of participant   Date    Signature

_________________________ ____________ ___________________
Name of researcher   Date    Signature

If you wish to participate in the study please provide the following information:

Name (please print): _____________________________
Workplace address: _______________________________________
Contact telephone number at place of work: _______________________
E mail address: _______________________________________

Please return the signed consent form in the envelope provided
Appendix 14: Letter of invitation - family carers

[sent out on headed notepaper]

[date to be added]

Dear Carer,

**Study title: Tobacco and alcohol use in people with a learning disability**

My name is Lorna Fitzsimmons and I am Clinical Nurse Specialist in Learning Disability Nursing who also works at Glasgow Caledonian University, in the School of Nursing, Midwifery and Community Health.

I am writing to invite you to take part in a research study. In this part of the study I am hoping to speak to carers to find out their views on the use of alcohol and tobacco by people who have a mild or moderate learning disability. I am also interested in hearing carers’ views on what information, help and support is needed about alcohol and tobacco for people who have a learning disability and their carers.

I have enclosed a sheet which provides more information about the study and what your participation would involve. If after reading the information you would like to take part in the study, please complete and the Consent Form and return it to me in the envelope provided within the next 7 days.

If, on the other hand, you would like more information before making up your mind, please contact me on the following telephone number 0141 331 8370 (Monday or Tuesday) or e.mail Lorna.Fitzsimmons@gcal.ac.uk. I will be very happy to answer any questions that you might have.

Best wishes,

Lorna Fitzsimmons
Appendix 15: Participant information sheet - family carers

**Study title**

Tobacco and alcohol use in people who have a learning disability: giving voice to their health promotion needs.

**You are being invited to take part in a research study**

I am writing to invite you to take part in a research study. Before you decide if you want to take part, it is important for you to understand why the research is being carried out and what it involves.

Please take time to read this information sheet. It explains what the study is about and tells you what you will be asked to do if you agree to take part. Discuss it with friends and relatives if you wish. Please ask if there is anything that is not clear or if you would like more information. My contact details can be found on the next page.

**What is the purpose of the study?**

The purpose of this section of the study is to find out the views of carers on the use of tobacco and alcohol by people who have a mild to moderate learning disability. We are also interested in hearing carers’ views on what information, help and support is needed about tobacco and alcohol for people who have a learning disability and their carers.

**Who is carrying out the study?**

The study is being undertaken by a research team that includes myself, Lorna Fitzsimmons, Maggie Lawrence, Susan Kerr, Chris Darbyshire and Alan Middleton. We are all experienced nurses who are employed as researchers at Glasgow Caledonian University.

The Queen’s Nursing Institute Scotland (QNIS) is funding the study.

**Why have I been contacted?**

You have been contacted because you are a carer of a person with a mild or moderate learning disability. A number of other carers in Glasgow and Ayrshire have also been contacted about the study.

**If I decide to take part study what will it involve?**

If you decide to take part in the study it will involve an informal interview over the telephone which will last about 30 minutes. I will contact you in approximately two weeks to arrange a suitable time for the interview.

During the interview we will discuss the use of tobacco and alcohol by people who have a mild or moderate learning disability. I am particularly interested in your views on what information, help and support is needed about tobacco and alcohol for people who have a learning disability.

With your permission the interview will be tape-recorded. This is to make sure that I have an accurate record of what we discuss. The interview will be typed up by a secretary who will not know who has taken part in the study.
## Will my taking part in the study be kept confidential?

Your personal details and what you say during the interview will be confidential. I will replace your name with an identification number and your name will not be used in anything connected to the research.

## What will happen to the results of the study?

We hope that the information from this study will be used to help people with a learning disability to lead healthier lives.

The study findings will be published in a report and in journals for nurses and people who work in healthcare settings. They will also be discussed at conferences. Please be reassured that if you agree to participate in the study you will not be identified in any way when the findings are being presented.

If you would like a summary of the findings, I will be happy to send this to you when the study is complete.

## Who has reviewed the study?

The study has been reviewed by the Ethics Committee of Glasgow Caledonian University and also by the NHS Ethics Committees in Glasgow and Ayrshire.

## What should I do if I want more information or I want to take part?

If you would like more information about the study before deciding whether to take part, please contact me on Tel. 0141 331 8370 (Monday or Tuesday) or e mail Lorna.Fitzsimmons@gcal.ac.uk. I will be happy to answer any questions that you may have.

If you have read the information and you would like to take part in the study, please complete the enclosed Consent Form and return it to me in the envelope provided within the next 7 days.

## Do I have to take part?

No, taking part in the study is voluntary. It is up to you to decide. You are also free to change your mind and leave the study at any time. You do not need to give a reason.

*Thank you for taking the time to read this information*
Appendix 16: Consent Form - Family Carers

Study title: Tobacco and alcohol use in people with a learning disability

Name and address of researcher: Lorna Fitzsimmons, School of Nursing, Midwifery and Community Health, Glasgow Caledonian University, Cowcaddens Road, Glasgow G4 0BA. 
Tel: 0141 331 8370 or e mail: Lorna.Fitzsimmons@gcal.ac.uk

Please tick the boxes and sign below

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. □

2. I understand that my participation is voluntary and that I am free to leave the study at any time, without giving a reason. □

3. I agree to the interview being tape-recorded and I understand that some parts of my interview may be used in reports of the study findings (my name will be replaced with an ID number). □

4. I agree to take part in the study. □

_________________________ Date ____________________
Name of participant Signature

_________________________ Date ____________________
Name of researcher Signature

If you wish to participate in the study please provide the following information:

Name (please print): ________________________________

Address: __________________________________________

Postcode: ___________

Contact telephone number: _________________________

Please return the signed consent form in the envelope provided
Appendix 17: Interview Schedule - Health & Social Care Professionals

Level of contact with people with a learning disability who drink alcohol

Community learning disability teams:
- Do many of your clients who have a mild/moderate learning disability drink alcohol? (ask for details, including proportion and actual numbers)
- Are there any gender differences between those who do and those who don’t drink alcohol? (if yes, ask for details)
- Are there any age differences between those who do and those who don’t drink alcohol? (if yes, ask for details)
- Have you noticed any changes in the level of alcohol consumption in the patients/clients you have contact with over the years? (if yes, ask for details).

Practice Nurses:
- Do many of your patients who have a mild/moderate learning disability drink alcohol? (ask for details, including proportion and actual numbers)
- Are there any gender differences between those who do and those who don’t drink alcohol? (if yes, ask for details)
- Are there any age differences between those who do and those who don’t drink alcohol? (if yes, ask for details)
- Have you noticed any changes in the level of alcohol consumption in the patients/clients you have contact with over the years? (if yes, ask for details)

Views on factors that influence alcohol use in this group
- What do you think are the factors that influence whether people with a mild to moderate LD drink alcohol or not?
  - Ask for details/examples from own experience (e.g. influence of staff/peers/access to alcohol/financial/level of LD/control/understanding/lack of other leisure/social status/access to education/medical advice linked to medication etc.)

Views on the use of alcohol by people with learning disability
- Why do you think that people with a mild/moderate LD drink alcohol?
  - Ask for detail/examples from own contact/discussions with clients/patients, including any positive sides (e.g. addiction, habit, social norms, pleasure)

- Do you think that there are any negative sides to drinking for people with mild to moderate LD?
  - Ask for details/examples (e.g. health, finance, medication, accident, crime-perpetrating/victim of)?

Views on health promotion needs of this group
- Do you ever assess how much alcohol your clients/patients are consuming?
  - If yes, how do you assess their alcohol consumption (explore the use of formal assessment tools such as FAST and AUDIT, also quantity/frequency measures.
    - What level of alcohol consumption might concern you? (explore awareness of hazardous and harmful levels of drinking)
If someone was consuming alcohol at a level that concerned you, what action would you take? (explore whether delivers a brief intervention, whether refers, whether involves family members)

If No, why not (explore the reasons behind a failure to explore this issue, including views on own role).

• Do you think that you have an appropriate level of knowledge and skills to be able to assess alcohol use and take appropriate action (e.g. deliver a brief intervention, refer to appropriate agencies), if it were required?

• What do you know about current alcohol services in your area (ask for details)?

• Are you aware of any guidance on safe alcohol consumption?

• Do you think that (you PN) other professionals (e.g. GP, Drug and Alcohol Services) have the knowledge, skills and experience to support a person with a LD in changing their alcohol consumption?
  - Ask for details that will back up what has been said.

• Do you think there are barriers to cutting down on / drinking within safe limits for people with mild to moderate LD?
  - ask for details of what these barriers might be, based on own knowledge/experience (e.g. access to info and support)

• Do you think people with mild to moderate LD are getting the same information and support on safe alcohol consumption, as the rest of the population?
  - if yes, from where?
  - if no, what prevents/ influences this?

• Over the years, have many of your clients wanted to cut down their alcohol use?
  - details of clients (proportion, gender, age, why)

• Did / do your clients link drinking alcohol to their health in any way?
  - Ask for details (EG- mental health/ weight/ concentration/ effect of medication/ exacerbation of other illness like epilepsy etc)

• To date, have you encouraged any / many of your clients to change their drinking?
  - how successful was this?
  - what approach did you take? (amounts of alcohol/behaviours, ? specific LD resources)

**Views on appropriate health promotion approaches for this group**

• What specific approaches might be useful for people with a learning disability to learn about safe drinking limits?

• What specific approaches might be useful to support people with a learning disability to keep drinking within safe limits/ or to cut down if drink excessively?
  - ask for details linked to content, mode of delivery (taking account of the level of functioning of this patient/client group) (including specific LD resources).
Appendix 18: Interview schedule - family carers

The person/people with a learning disability

Reminder of Age/gender.......... 

Level of LD/how they understand or communicate/level of support?

_________________________________________________________________________________

The use of tobacco

• Does ______ currently smoke?

IF YES

  o How much does ____ smoke a day?
  o (Typical day?)
  o What age was ____ when __ started smoking?
  o Why ___ started smoking? (explore reasons)

IF NEVER

  o What factors/influences do you think prevented ______ smoking? (MOVE TO ALCOHOL SECTION)

IF SMOKED IN PAST

  o What age did __ start smoking?
  o Why did ___ start smoking?
  o How much did ____ smoke a day?
  o Why did _____ stop?
  o Did ______ stay stopped?
  o How many attempts to stop?
  o What support did ______ get to stop/try to stop? (NRT products + services - including individual health professionals)
  o How useful/helpful was this? (MOVE TO ALCOHOL SECTION)

Factors that appear to influence smoking behaviour (if still smoking)

• Does anyone else in _____ life smoke? (family/friends/cares)

• Is _____ more likely to smoke alone or with others who are smoking? (e.g. service users group, group of friends)

• What does ____ like about smoking/any positive effects?
  o How important are these effects?
• What does _____not like about smoking/are there any negative effects?
  o How concerned is _______ about these things/effects?
• Does _____ link smoking to health in any way?
• Do you feel you understand the health risks enough to discuss them?
• Are there any times or situations when ___ smokes more than normally would? 
  (e.g. increase in income, mental health, stress)
• Are there any times or situations when ___ smokes less than normally would? 
  (e.g. good times, bad, financial constraints, mood states)?
• What about the smoking ban- has that had any effect on _______ smoking?
• Do you think there are any other factors that influence people with learning 
  disabilities re. smoking?

Smoking Cessation
• Does_______ ever want to stop smoking?
• Has_____ ever stopped/tried to stop smoking (details of number of times 
  stopped and for how long)?
  o Did _____ stay stopped?
  o How many attempts to stop?
  o Why did ____ start smoking again?
  o What support did_______ get to stop/ try to stop? (NRT products + 
    services - including individual health professionals)
  o How useful/helpful was this?
• Do you think it’s important that ________ stops smoking, whether now or in the 
  future?
• What do you think would help ____ to stop smoking?
• Have the health professionals you are in contact with (GPs, nurses, 
  psychiatrists etc.) ever talked about smoking? (advice, information, referral to 
  services)
• Do you know what help is available and how to get that help?

Specific HP approaches
• Do people with learning disabilities need the same or different help to stop 
  smoking? (provide details)
• What would help people with learning disabilities stop smoking? (e.g. support 
  groups, 1:1 counseling, relaxation sessions, NRT, stress management, 
  confidence/assertiveness training etc.)
Alcohol consumption

• Does _____ drink alcohol? (Amount / frequency)

IF YES
  o Has this changed over the years?
  o What age when started?
  o Why ___ started?

IF NO
  o Why not?  (MOVE TO SECTION ON HEALTH PROMOTION)

IF USED TO DRINK
  o What age when started?
  o Why started?
  o How much in past? (Amount/ frequency)
  o Why stopped? (Influences)
  o How stopped? (Supports/people/professionals)

  (MOVE TO SECTION ON HEALTH PROMOTION)

Factors that appear to influence alcohol consumption (if currently drinks)

• When does _____ usually drink?
  o Are there particular times in the day/days in the week/ occasions that _____ drinks less or more?

• Does anyone else in _____ life drink?
  o Do their opinions re. alcohol matter/influence ___?

• What does _____ like about drinking alcohol/ any positive effects?
  o How important are these effects?

• What does _____ not like about drinking alcohol /are there any negative effects?
  o How concerned is ________ about these things/effects?

• Do you think there are any other factors that influence people with learning disabilities re. drinking alcohol?
HP needs

- Does _____ link drinking alcohol to health in any way?
- Do you think there are any other risks for _____ when drinking?
- Do you feel you understand the risks enough to discuss them?
- Has _____/you ever been concerned about how much alcohol ___ is drinking?
- What would make you worry about ______ drinking alcohol? (level/ amount/ type of/ where)
- Have the professionals you are in contact with (GPs, nurses, psychiatrists, SW etc.) ever talked about drinking alcohol (advice, information, referral to services)?
  - What?
  - How presented?
  - How useful?
  - How accessible to a person with LD?)
- What do you know about current alcohol services in your area? (details)
- Are you aware of the guidance on safe alcohol consumption? (what/how)
- Do you think that professionals (e.g. GP, Drug and Alcohol Services) have the knowledge, skills and experience to support a person with a LD in changing their alcohol consumption? (details to back up?)
- Do you think there are barriers to cutting down/drinking within safe limits for people with mild to moderate LD? (details of e.g. access to information and support)

Specific HP approaches

- Do people with learning disabilities need the same or different help to know about the risks of drinking? (provide details)
- What would help people with learning disabilities learn more about drinking/drink in a safe way? (e.g. support groups, 1:1 counseling, relaxation sessions, NRT, stress management, confidence/assertiveness training etc.)
  - What's the best way to provide this help? (individual, group orientated, combination)
  - How long should support last for?
  - Who is best to give this help? (specialist staff, mental health staff)
Appendix 19: Demographic Questionnaire – HSCP

1. Professional group

Psychiatrist ☐ LD Nurse ☐ Nursing Assistant ☐ Occupational Therapist ☐
Physiotherapist ☐ Social Worker ☐ Psychologist ☐ Practice Nurse ☐
Speech & Language Therapist ☐ Other ☐ __________________________

2a) Number of years experience in current/similar role ______ years

2b) Number of years experience working with people with mild to moderate LD ______ years

3. Do you work full-time ☐ part-time? ☐

If part-time, how many hours per week ______

4. Health Board area

NHS Greater Glasgow & Clyde ☐ NHS Ayrshire and Arran ☐

5. Gender Male ☐ female ☐

6. Age ______ years

7. Have you had any specific training in relation to Health Promotion for smoking and/or alcohol consumption?

a) Smoking Yes ☐ No ☐

Please provide details, including when undertook the training, who provided the training

b) Alcohol Yes ☐ No ☐

Please provide details, including when undertook the training who provided the training,
## Appendix 20: Demographic Questionnaire - family carers

1. **Are you a full-time carer** ☐ **part-time?** ☐
   
   If part-time, how many hours per week ____

2. **Age** ___ years

3. **Gender**
   - Male ☐
   - Female ☐

4. **Health Board area**
   - NHS Greater Glasgow & Clyde ☐
   - NHS Ayrshire and Arran ☐

5. **Number of years caring for person/s with learning disabilities?** ___ years

6. **Relationship to person with learning disability you care for?**
   - Mother ☐
   - Father ☐
   - Sibling ☐
   - Friend ☐
   - Other ☐ __________

7. **Age of person you care for?** ___________ years

8. **Gender of person you care for?**
   - Male ☐
   - Female ☐
## Appendix 21: QNIS Training Fellowship - Training log

<table>
<thead>
<tr>
<th>Topic/title</th>
<th>Training provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitative research approaches</td>
<td>Self directed reading and notes</td>
</tr>
<tr>
<td>Research proposal and outline</td>
<td>Guided by SK, CD</td>
</tr>
<tr>
<td>Research interview skills</td>
<td>Self directed reading and notes (paper re learning and thoughts to date to SK, ML.)</td>
</tr>
<tr>
<td></td>
<td>Guided by SK, CD</td>
</tr>
<tr>
<td>Telephone interviewing skills</td>
<td>Self directed reading and notes (paper re learning and thoughts to date to SK, ML.)</td>
</tr>
<tr>
<td></td>
<td>Guided by SK, CD</td>
</tr>
<tr>
<td>Qualitative Data analysis</td>
<td>Self directed reading and notes</td>
</tr>
<tr>
<td></td>
<td>Discussion of process for data organising and data analysis (paper re learning and thoughts to date to SK, ML.) Team discussions re process and data reviewing by peers</td>
</tr>
<tr>
<td></td>
<td>Guided by SK, CD</td>
</tr>
<tr>
<td>NVivo qualitative data analysis package – introductory workshop</td>
<td>Jamie Frankis, Research methods lecturer</td>
</tr>
<tr>
<td></td>
<td>NMCH GCU</td>
</tr>
<tr>
<td>Development of interview guide</td>
<td>Self directed reading and notes</td>
</tr>
<tr>
<td></td>
<td>Guided by SK, CD</td>
</tr>
<tr>
<td>Refworks bibliography software- introductory</td>
<td>Marion Kelt/ Elizabeth Crawford, GCU Librarians</td>
</tr>
<tr>
<td>Development of interview schedules, demographic questionnaires, interview</td>
<td>SK discussion, study of previous examples, self directed reading</td>
</tr>
<tr>
<td>invites, information packs</td>
<td></td>
</tr>
<tr>
<td>Research methodologies - overviews</td>
<td>GCU Seminar</td>
</tr>
<tr>
<td>SPSS Statistical package</td>
<td>SK discussion and training re data entry, then practice with user guide</td>
</tr>
<tr>
<td>SPSS Statistical package</td>
<td>SK discussion and training re data analysis, then practice with user guide</td>
</tr>
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