

**AN EXPLORATION OF SUBSTANCE  
MISUSE IN PEOPLE WITH LEARNING  
DISABILITIES LIVING WITHIN NORTHERN  
IRELAND**

**Research Commissioned by the Review of  
Mental Health and Learning Disability,  
Northern Ireland.**

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## Executive Summary

This study had three core objectives, firstly, to describe the characteristics of people with learning disabilities who misuse alcohol and / or other substances, and examine the effects of such abuse across four Community Trusts in Northern Ireland (Study 1). Secondly, to investigate the equity of whether alcohol and drug education programmes are delivered across both mainstream and learning disability schools (Study 2). And thirdly, to examine service provision for this population who misuse substances across both learning disability and mainstream addiction services (Study 3).

There were 41 participants who took part in Study 1. Based upon this sample, the prevalence rate of substance misuse in this population across the four Community Trusts in Northern Ireland equated to 0.02% of the total adult learning disability population. There were 21 males and 20 females, with the majority having a borderline to mild learning disability and a third of the sample aged between 18 – 30 years. A third were identified to have a co-existing mental health problem and a third were found to live on their own. The most commonly reported substance to be misused by all of the participants was alcohol, with a small number of participants also found to be abusing a combination of 'cannabis', 'ecstasy', 'prescribed medications' and 'amphetamines'. Both the learning disability and mainstream addiction professionals highlighted that 'social' (i.e. that is to 'fit in' with their peers), and the physiological / psychological benefits that such substances can have, were the two core reasons for use of such abuse.

Study 1 shows the distressing pattern of the broad range of substance-related problematic behaviours that have profoundly impacted upon the persons' biological, psychological and social functioning. The community informants frequently reported erratic 'mood changes', 'verbal aggression', 'being exploited by others', 'physical aggression', 'suicidal ideations', 'offending behaviour', 'rows with carers', 'physically injuring self' and frequently 'attending the A & E hospital departments' as the main consequences of such abuse.

Study 2 found that three quarters of the mainstream schools compared with less than half of learning disability schools, were providing Alcohol Education Programmes in the forthcoming year. However, the majority of the mainstream schools in comparison to less than three-quarters of the learning disability schools were providing Drug Education Programmes during the forthcoming academic year. These results reflect, that mainstream and learning disability schools differed in terms of provision of Alcohol Education Programmes. In terms of service provision for adults, Study 3 showed unanimous agreement between both mainstream addiction and learning disability services that there was no strategy to prevent or minimise substance related harm for adults with a learning disability.

With regards to treatments / interventions, the mainstream addiction professionals in Study 3 indicated that they had the appropriate skills and

knowledge to help a person without a learning disability and a substance issue, unfortunately the professionals were in agreement that they struggled in communicating with people in this population. On the other hand, the learning disability professionals identified their competencies and confidences in effectively communicating with this population, but stressed that they lacked the knowledge and skills needed in assessing, treating and managing people who misuse substances.

Overall, Study 3 presents a picture of where service provision in Northern Ireland for people with learning disabilities who misuse a range of substances, mainly alcohol, was provided on an ad-hoc basis with both learning disability and mainstream addiction services being fragmented with no written policies / guidelines promoting joint working. Study 3 further highlighted that both mainstream addiction and learning disability professionals both indicated that their current services could provide better care and interventions for a population whose needs are complex and often ignored.

### **Definition of learning disability**

The term 'learning disability/disabilities' is synonymous with the terminology 'mental handicap' and 'learning difficulties' that has been used in the UK, and 'mental retardation' that has been employed in North America. The World Health Organisation (WHO) (1992) has adopted the term 'intellectual disability'; this term has also been employed in the Irish Republic and in the developing countries. However, as the term, 'learning disability' is favoured in the UK and the Dept. of Health & Social Services (Northern Ireland) (1995), this term will be employed throughout this study.

Historically, a number of definitions have been socially constructed and placed into legislative definitions; for example, 'idiots', 'imbeciles', 'mental defectives' and 'sub-normal' have been used in the Mental Deficiency Acts of 1913 and 1927 in the UK. However, even these definitions have been subjected to criticism given their excessive reliance upon intelligence alone to make a diagnosis, with IQ's of less than 70 indicating that an individual has a learning disability. 'Mental impairment' and 'mental handicap' replaced these derogatory terms in the Mental Health Act's of 1959, 1961 and 1983 in the UK, and the corresponding legislation of the Mental Health Order (1986) in Northern Ireland, which emphasised the importance of measuring both the person's adaptive/social functioning in conjunction with their IQ.

The concept of these adaptive/social functioning competencies relates to every day life and how the person copes with the demands of his/her own environment. This assessment identifies the degree of assistance required by the person in providing the appropriate care and support to live in his / her own social environment. Consequently, classification systems universally agree that there should be three core criteria employed in making a diagnosis of a 'learning disability' today (International Classification System (ICD-10) - World Health Organisation, 1992, Diagnostic Statistical Manual of Mental Health (DSM-4) - American Association on Mental Retardation

(AAMR), 1994). These are:

- Significant impairment of intellectual functioning,
- Significant impairment of adaptive/social functioning (of at least two or more adaptive skills (i.e. communication, self-care, home living, social skills, community use, health and safety, leisure, work)),
- Age of onset before eighteen years of age.

However, there are a number of inherent difficulties in attempting to provide satisfactory terminology for individuals who have a 'learning disability'. This not only includes legal and lay terminologies but cultural definitions. Although terminology has changed throughout the last century (e.g. 'patient', 'resident', 'individual'), this shift has not totally been dependent upon a transformation in society's acceptance towards this population. Greenspan (1999) highlighted that more recent terminologies (i.e. 'service user', 'tenant') have evolved as a direct consequence of the prevailing service models and the ideologies that underpin the models of 'Normalisation' (Wolfensberger, 1972) and an 'Ordinary Life' (King's Fund, 1980).

## **Background**

### **Introduction**

*Due to the growth of 'substance abuse' (i.e. alcohol, illicit drugs and over use of prescribed medications) in both the general and psychiatric populations, there is also a growing trend for people with learning disabilities to misuse such substances (Degenhardt et al., 2000, Sturmey et al., 2003). However, there has been a dearth of literature that has comprehensively examined the 'use' and 'misuse' of these substances in people with learning disabilities across both sides of the Atlantic. In clearly describing the characteristics of those individuals with learning disabilities who misuse substances, the effects of such abuse, the health promotion / educational material and the state of current services provided for this population, this information should help to identify the types of services / supports required to meet the heterogeneous needs of this population in the future. This is a population who have often been both ignored and neglected by both learning disability and mainstream addiction services (ARAC, 2002, Sturmey et al., 2003).*

### **Substance abuse in the general population**

Investigations of 'substance abuse' in the general population in both Europe and the USA have highlighted the growth of this misuse with significant costs to the person, their carers and the community they live in. There is strong empirical evidence to show that alcohol misuse is highly associated with physical diseases (i.e. liver damage, immune suppression disorders, stroke, cancers), can cause premature birth, increases the levels of risk-taking behaviour including suicide, higher risk of alcohol-related accidents, and more likely to be violent and offend, including domestic violence (National Institute on Alcohol Abuse and Alcoholism, 1997). Furthermore, those who misuse alcohol are more likely to have a co-existing mental health problem (Hall et al., 1999). As a direct consequence of such costs, many countries have subsequently developed public health strategies in attempt to address and possibly diminish the growing rates of alcohol and illicit drug misuse: particularly aimed at young people. More recent campaigns have also targeted 'binge drinking' in the adult population.

In July 2004, the United Kingdom (UK) government launched an 'Alcohol misuse enforcement campaign' focussing upon educating young people against the pitfalls of misusing alcohol. Similarly, the UK government has published a White Paper entitled "Tackling drugs to build a better Britain" (Dept. of Health, 1998); this document focused upon preventing illicit drug abuse in young people. However, both documents do not include information for people with learning disabilities who also misuse alcohol and / or drugs, and also for their carers, concerning the types of treatments available and services on offer to support this population.

### **Substance abuse in the psychiatric population**

Similarly, there is strong empirical evidence to highlight the extent of such 'substance abuse' in people with a psychiatric disorder (Duke et al., 2001, Weaver et al., 2003, Menezes & Ratto, 2004). This dual diagnosis of a psychiatric disorder and a 'substance abuse' problem have been highly correlated with higher levels of aggression and substance-related offending behaviour (Scott et al., 1998), increased levels of psychiatric hospital admissions (Sullivan et al., 1995) and poorer compliance with treatment regimes and clinical outcomes (Owen et al., 1996).

Reiger et al. (1990) reported that 22.3% of people with a psychiatric disorder in the UK were found to be misusing alcohol (i.e. diagnosed with a 'alcohol abuse disorder'); this is compared to 13.5% of the general population. Likewise, 14.7% of people with a psychiatric disorder were reported to be misusing illicit drugs compared to 6.1% of the non-disabled population in the UK. These figures equate to percentages reported in a number of European and American epidemiological studies further highlighting greater substance misuse in the psychiatric community (Reiger et al., 1990, Dept. of Health, 1998, NHSDA, 2001).

### **Substance use / abuse in the learning disability population**

Despite the scant literature on this topic, 'substance use' in people with learning disabilities is generally reported to be lower compared with the use of such substances in both the general and psychiatric populations across both sides of the Atlantic.

Similarly, 'substance abuse / misuse' in people with learning disabilities has also been reported to be lower compared with the figures for the non-disabled population (Huang, 1981, Edgerton, 1986, Jacobson et al., 1988, Christian & Poling, 1997, Annand & Rus, 1998, Burgard et al., 2000, Haverkamp & Scandlin, 2002, Sturmey et al., 2003). However, Degenhardt (2000) in a review of the alcohol literature accentuates that although prevalence rates are lower compared to the general population, 'the rate of problems among drinkers was greater for those with a learning disability' (p. 138). This statement suggests that people with learning disabilities have a lower threshold for alcohol-related problems requiring less alcohol (Westermeyer et al., 1996).

Nevertheless, there remains variation in the reported prevalence rates in people with learning disabilities who abuse / misuse alcohol and / or drugs (Clarke & Wilson, 1999, Sturmey et al, 2003). Such discrepancies centre upon methodological problems often associated with the lack of clear operational definitions of 'abuse / misuse' (i.e. dependence, intoxication and withdrawal), the methodology employed (i.e. self-reports, informant reports, surveys, case studies), the level of learning disability (i.e. borderline / mild versus moderate cognitive impairment), location (i.e. community versus hospital samples), time-frame (i.e. current use, past 30 days, within twelve-months life-time prevalence) and whether persons are known to learning disability services or not.

In a recent review of the literature pertaining to substance-related disorders in this population, Sturmey et al. (2003) stated that "it is difficult to define any consensus among the studies as to the prevalence of alcohol misuse among people with learning disabilities, however, prevalence rates may vary somewhere between 0.5% - 2% of this population" (p. 44). Figures for illicit drug misuse in people with learning disabilities also indicate far lower prevalence rates (Westermeyer et al., 1988, Gress & Boss, 1996, Christian & Poling, 1997, Pack et al., 1998). Nonetheless, ARAC (2002) have reported that few learning disability, and also mainstream addiction, service providers have clear written policies and procedures for co-working with this population. Consequently, both service providers have reported a number of difficulties in recognizing and meeting the complex needs of this population.

### **Possible increase of substance misuse in people with learning disabilities**

As many more people with learning disabilities today are being successfully supported to live in a variety of accommodations in their local communities (i.e. with families, supported living schemes, on their own), they therefore have greater opportunities to engage in using alcohol and other substances with both their disabled and non-disabled peers (Lindsay et al., 1991, Christian & Poling, 1997). In the same way, as more people with learning disabilities today are being afforded the opportunity to take-part in a range of activities (i.e. various paid and voluntary employment schemes, attending colleges of further education and taking part in a broader range of recreational pursuits), this may further provide the person with greater prospects to use and abuse such substances. This is accompanied with greater access to readily available cash, transport and support networks (Lottman, 1993, Robertson et al., 2000, Stavrakaki, 2002, Sturmey et al., 2003). Consequently, as a feature of engaging in similar lifestyles as their non-disabled counterparts, this population may be equally exposed to similar stressors of living in a modernised culture thereby leading them to use such substances as a coping mechanism / stress reliever (Longo, 1997, Manthorpe, 1997, Mc Gillicuddy & Blane, 1999, Barnhill, 2000, Sturmey et al., 2003).

Moreover, the person with a learning disability may also see alcohol and / or illicit drugs as a method of 'fitting in', 'socialising' and making new friends with one's non-disabled peer group (Christian & Poling, 1997, Manthorpe, 1997,

Degenhardt, 2000). This process of 'fitting in' may compensate for the isolation, lack of social skills / supports / friendships / relationships and frustrations frequently described by people with learning disabilities for many years (More & Polsgrove, 1991, Gress & Boss, 1996, Clarke & Wilson, 1999, Sturmey et al., 2003). Alongside this, this is a population who have been found to have low self-esteem, and poor social, communication and refusal skills further suggestive of a population who may be highly susceptible to developing substance related problems (Russell, 1997, Stavrakaki, 2002).

### **Health promotion / education**

There is strong empirical evidence to indicate that people with learning disabilities have poorer physical, and mental, health compared to their non-disabled counterparts (Rimmer et al., 1993, Turner, 1997, Bouras, 1999, 2003, Roberson et al., 2000, IASSID, 2002). From these and similar findings, the Dept. of Health (1995) published 'The Health of the Nation: A strategy for people with learning disabilities'. This document advocated that people with learning disabilities need to make better choices concerning their overall health. Within this document there was also information about the use of alcohol and need for health promotion education / material in this area (i.e. educational material promoting safe drinking and highlighting the effects of such abuse). Note, no mention was given regarding illicit drug and prescribed medication abuse. Nevertheless, the development of health promotion literature concerning alcohol, and drug, use / abuse has been given little attention (Christian & Poling, 1997).

O'Farrell et al. (1993) found that skills training have resulted in reduced drinking patterns. Mattick & Jarvis (1993) have shown reductions in alcohol use in both short and long-term after such social skills training. Paxon (1995) has argued that social and refusal skills training, role-play and modelling can be used effectively to develop appropriate alcohol management skills particularly for people with learning disabilities. McGillicuddy & Blane (1999) developed a preventative programme that combined both assertiveness training and modelling. Assertiveness training was used to teach the necessary skills to refuse alcohol when it was offered, whereas modelling was used to teach about appropriate and inappropriate drinking behaviours. Despite these results, Clarke & Wilson (1999) highlighted the dearth of such preventative material and what has been developed has not been appropriately evaluated to examine the most effective form of delivery for this population. Stavrakaki (2002) concluded that 'prevention (primary and secondary) is the best way of avoiding such (substance-related issues) problems' (p. 474) in people with learning disabilities from occurring.

Of the few published drug preventative programmes for this population, Moore & Ford (1991) developed an educational package designed to teach staff about the risk factors of drug abuse in persons with learning disabilities. Included in this package was a screening tool. Although the results appear promising there has been no independent evaluation of this programme.

More recently, the document 'Guidance for Schools' (DENI, 2004) highlighted the significant role that schools have in educating children and young people concerning the wide range of issues about 'Alcohol, Drugs and also Smoking'. This guidance from DENI (2004), and the Northern Ireland Council for the Curriculum, Examinations and Assessment (NICCEA, 2004), have been issued to all schools across Northern Ireland with the main purpose to underpin well-managed and well-resourced Health Education Programmes.

### **Service provision**

There is strong empirical evidence to highlight that the needs of people with learning disabilities who misuse a range of substances have rarely been addressed (Christian & Poling, 1997, Lance & Longo, 1997). Some mainstream addiction services totally exclude people with learning disabilities highlighting a lack of knowledge of this specific population (Lottman, 1993, Degenhardt, 2000, ARAC, 2002, Sturmey et al., 2003). On the other hand, some learning disability service providers struggle to manage those individuals with a learning disability who are misusing alcohol and / or illicit drugs claiming a lack of knowledge regarding addictions. Consequently, many people with learning disabilities who have a substance related problem today continue to 'fall through the cracks' in both learning disability and mainstream addiction services. Both service providers highlight the lack of resources to support this population, and that of their carers, in both services (Lance & Longo, 1997).

Tyas & Rush (1993) found that despite the small but significant number of individuals with learning disabilities and substance-related problems in Canada, relatively few agencies reported services tailored for this population. The authors found that most agencies thought that these individuals should be treated in specialised programmes instead of mainstream addiction services. A major issue uncovered by Tyas & Rush (1993), was whether mainstream addiction services or learning disability services could effectively assess, treat and manage this population. Mainstream addiction services yet having the expertise and potential to provide a range of therapeutic interventions, however may struggle to manage this population given their associated difficulties (i.e. cognitive restrictions, communication deficits, mental health problems). Alongside this, mainstream addiction professionals also lack the expertise in confidently and competently working with this population, consequently diminishing the success of such interventions being offered and delivered. On the other hand, specialised programmes delivered by learning disability professionals may not provide the desired effect as many learning disability personnel lack the training and expertise in addiction knowledge and competencies.

Westermeyer (1990) suggested that other more contemporary models of service provision exist focussing upon the development of specialised services across both mainstream addiction and learning disability services. This would also involve incorporating early identification and intervention programmes for this population in those settings where alcohol and / or drug related problems often surface. However, despite such innovative models,

The Merton Drug Action Team (ARAC, 2002) and the Borough of Wandsworth Society (2003), undertaken in the South of England, both recently reported that learning disability service providers had no identified strategies regarding inter-agency working and joint care planning for this population. Referral to mainstream addiction teams by community learning disability teams, if offered, remained ad hoc with learning disability service providers mainly being given advice only.

Campbell et al. (1994) identified five barriers to treatment for chemical dependency among people with learning disabilities, these include:

- Existing mainstream treatment models may need to be substantially adapted in view of their emphasis on insight, which the authors suspect is not always possible for people with learning disabilities,
- People with learning disabilities may lack the necessary skills to cope with and benefit from group-based therapies used for their non-disabled peer,
- The emphasis on effecting positive life changes may not reflect the real choices available to most people with a learning disability,
- Alcohol counsellors (including 'dual diagnosis workers') do not receive training in working with people with learning disabilities as part of their general training and may base their assessments and interventions on stereotypes or inaccuracies
- And there is a low level of integration between services for people with a learning disability and mainstream addiction service making it difficult for professionals to work closely together.

## **Aims of the study**

There were three core objectives of this study:

- 1) To describe the characteristics of people with learning disabilities who misuse alcohol and / or other substances, and examine the effects of such abuse, across four Community Trusts in Northern Ireland.
- 2) To investigate the equity of whether alcohol and drug education programmes are delivered across both mainstream and learning disability schools.
- 3) To examine service provision for this population who misuse substances in both learning disability and mainstream addiction services.

## **Study 1: Characteristics of people with learning disabilities who misuse substances**

### **Methodology**

#### **Design**

As the core objective of this study is to describe the characteristics of people with learning disabilities who misuse alcohol and / or other substances, and the effects of such abuse, across four Community Trusts in Northern Ireland. It was therefore deemed that a quantitative approach would be more advantageous in meeting these aims across a wide geographic area and diverse learning disability population.

### **Operational definition of substance abuse / misuse**

There are a number of substances that can be either used or abused / misused, which can have a broad range of effects on the person (i.e. physiological, psychological, social), and also can affect the persons' families and communities. These include alcohol, illicit drugs (i.e. opioids, cannabis, ecstasy, cocaine, amphetamines, hallucinogens) also inhalants and over use of prescribed medications (i.e. painkillers, anti-depressants, anxiolytics including benzodiaepines such as diazepam and barbiturates).

Note, although other 'drugs' such as nicotine and caffeine can also be classified under the umbrella term of 'substances', this study excludes these two substances from this investigation. Nevertheless, Hymowitz et al. (1997) reported that people with learning disabilities who smoke were also more likely to drink and use other substances (see Sturmey et al. (2003) for a more detailed review of the literature on both nicotine and caffeine use in people with learning disabilities).

According to the DSM-4 Classification System (APA, 1994), 'substance abuse' has been defined as 'a maladaptive pattern of significant impairment or distress as manifested by one, or more, of the following characteristics':

- 1) A failure to fulfil major role obligations (i.e. work, school or home),
- 2) Persistent or recurrent social and interpersonal problems exacerbated by the effects of the substance(s) (e.g. arguments with family members, physical fights),
- 3) Recurrent substance-related legal problems (e.g. arrests for substance-related disorderly conduct)
- 4) And undertaking hazardous tasks (i.e. driving) while under the influence of such substances.

These aforementioned characteristics as identified by the DSM-4 must be observed within a 12-month period.

Given that this operational criterion for 'substance abuse' has been developed for the non-disabled population, this study has adapted this definition and criterion thereby defining 'substance abuse / misuse' as: 'the consumption of alcohol, illicit drugs and over use of prescribed medications which has been proven to be harmful to the persons' physical, psychological and social functioning'. Furthermore, in observing the DSM-4 criteria of a set period, this study also applies the same time-period that such misuse of substances must be consumed within the last twelve-months. Participants who have been identified as misusing such substances over the specified twelve-month period will be excluded from the study.

### **Participants**

A total of 41 participants took part in the project: there were 21 males (51.2%) and 20 females (48.8%). The criterion for inclusion in this study were based upon the individual having a learning disability, in contact with either a community nurse and / or social worker for people with learning disabilities (hereafter known as the 'community informant') and identified by the community informant as misusing substances using the criterion set out above. One participant was excluded from the study as s/he were identified to be misusing alcohol over the twelve-month time criteria.

### **The Community Trusts within Northern Ireland**

Northern Ireland is divided into four Health and Social Service Boards (HSSB). Two of these HSSB's between them commission services from six separate Community Trusts. This study selected four of these Community Trusts based upon the close working links staff at the University of Ulster have developed over the years. Alongside this, identifying these four Community Trusts provided a sample that comprises of both urban and rural populations. Table 1 summaries the size of the adult non-learning disabled population and the estimated learning-disabled population in receipt of services for each of the four Community Trusts.

**Table 1: Estimated learning and non-learning disabled populations across the four Community Trusts in Northern Ireland**

|         | Estimated Adult Learning Disabled Population using services | Estimated Adult Non-Learning Disabled Population |
|---------|---|--|
| Trust 1 | 1115  | 252,000  |
| Trust 3 | 850   | 110,000  |
| Trust 4 | 680   | 152,000  |
| Trust 5 | 709   | 115,000  |
| Total   | 2354  | 632,000  |

(Adapted from the Department of Health, Social Services and Public Safety Office figures published for the year 2000/2001)

### **Materials**

As no standardised questionnaires were commercially available, the research team developed a questionnaire that sought to collect information about people with learning disabilities who were identified by their community informant to be 'misusing alcohol and / or other substances' (i.e. prescription and non-prescription drugs like cannabis, solvents, etc). Furthermore, given that no information existed across Northern Ireland about this population, it was identified that using a postal questionnaire would be the most appropriate method to collect this information thereby targeting a larger population.

The questionnaire was divided into four distinct parts; the first section sought information regarding the community informant who completes the questionnaire (i.e. name, contact details, Community Trust). The second section asked questions about the person with the learning disability (i.e. age, gender, where

they live, level of learning disability, where they attended school, who they live with and any health problems). Thirdly, the questionnaire sought information on the type of substances the person is currently misusing (i.e. length of use, who the person uses these substances with, how does the substance effects the persons' health including relationships with family, peers and professional staff, and daily routine).

### **Procedure**

Initial informal meetings took place with two community learning teams to discuss some of the issues pertaining to people with learning disabilities who misuse a range of substances. On the basis of these two informal discussions and a review of the literature, although this was limited, the research team developed a questionnaire. This questionnaire was then piloted with five community learning disability team members; all the respondents reported that there were no difficulties in completing the questionnaire and further commented upon its comprehensiveness.

After the names of all the community learning disability team leaders were obtained, and subsequently contacted, they were then informed about the nature of the project. Each community team leader was then asked to distribute the questionnaire out to their team members at their team meetings where upon each community informant was then asked to complete the questionnaire for the number of individuals on their caseloads who met the criterion for the study. Each community informant was reminded to ensure that no identifiable information was written on the questionnaire. Furthermore, to diminish the possibility of duplicating two questionnaires being completed by a person's social worker and community nurse, each of the community informants were asked to communicate with each other prior to the completion of the questionnaire to avoid this happening.

A covering letter was developed for the community team leaders and another covering letter was developed for the community informants. The letter emphasised the confidentiality of the information and the purpose of the study. Accompanying each questionnaire was a prepaid stamped addressed envelope for the community informant to return the completed questionnaire.

### **Ethical considerations**

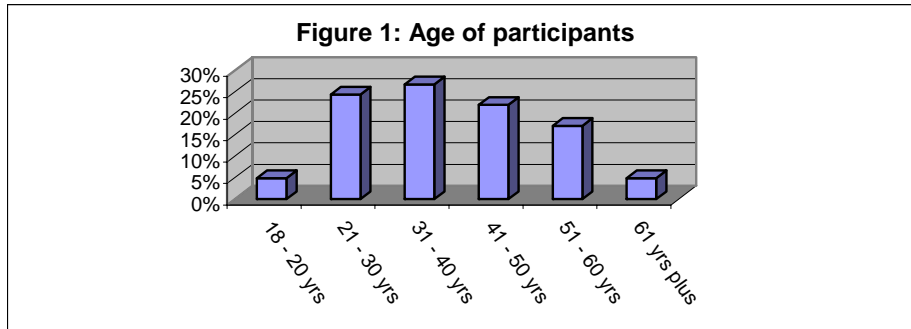
The Health and Personal Social Services Research Ethics Committee granted ethical approval for this project in terms of collating and transferring confidential information on named individuals from different community personnel to the research team. This information was gathered via a questionnaire and coded within SPSS and Word files. Each questionnaire contained no identifiable information about the participant.

### **Results**

#### **Demographics**

In total there were 41 participants who took part in this study. Based upon this sample, the prevalence rates of substance misuse in this population across the four Community Trusts equated to 0.02% of the total adult learning disability population (see Table 1 above (Department of Health, Social Services and Public Safety Office, 2000/2001)).

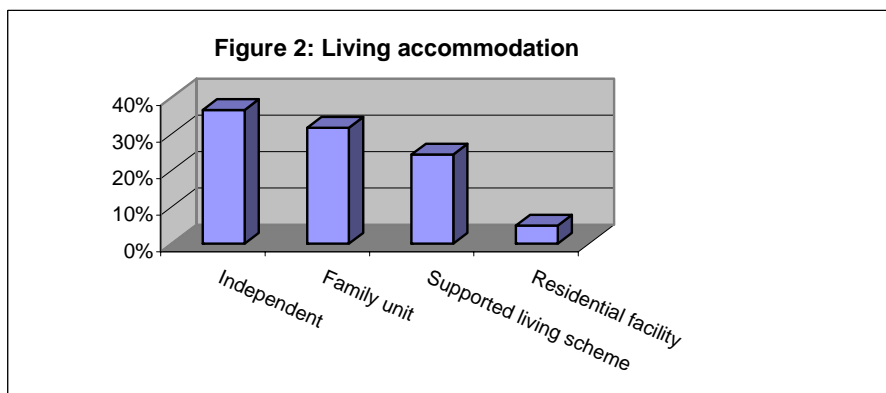
Figure 1 shows the age of the participants, it can be observed that 26.8% were aged between 31 – 40 years and 24.4% were aged between 21 – 30 years. A small percentage (4.9%) of the sample were aged between 18 – 20 years. For 6 participants (14.6%) the community informants identified them as having a borderline learning disability and for 24 participants (58.6%) their level of learning disability was identified as a mild learning disability. For 11 participants (26.8%) they were reported to have a moderate learning disability. No participants were identified to have a severe learning disability.



In regards to the question which school did participants attend, informants reported upon only 24 participants, as this information was unknown for the remainder of the participants. Of these 24 responses, 11 participants (45.8%) attended a school for children with a mild learning disability, 7 participants (29.2%) attended a mainstream school and 6 participants (25%) attended a school for children with severe learning disabilities.

### Living arrangements of participants

Figure 2 shows that the majority of participants were residing in accommodation with support / supervision with 13 participants (31.7%) living within a family unit, 10 participants (24.4%) residing within a supported living scheme and 2 participants (4.9%) living within a residential facility. This study found that for a third (36.6%) of the participants that they lived independently in their own flat or house.



### Health problems

In addition to a diagnosed learning disability the community informants were asked to state the participants additional disabilities. The main additional disability that the community informants identified was that of a mental health problem. Figure 3 shows that 11 participants (26.8%) had a diagnosed mental health problem (mhp) and a further 4 participants (9.8%) had a suspected mental health problems. One participant had a diagnosis of Alcohol Dependence Syndrome. The most common of these diagnosed mental health problems were that of a

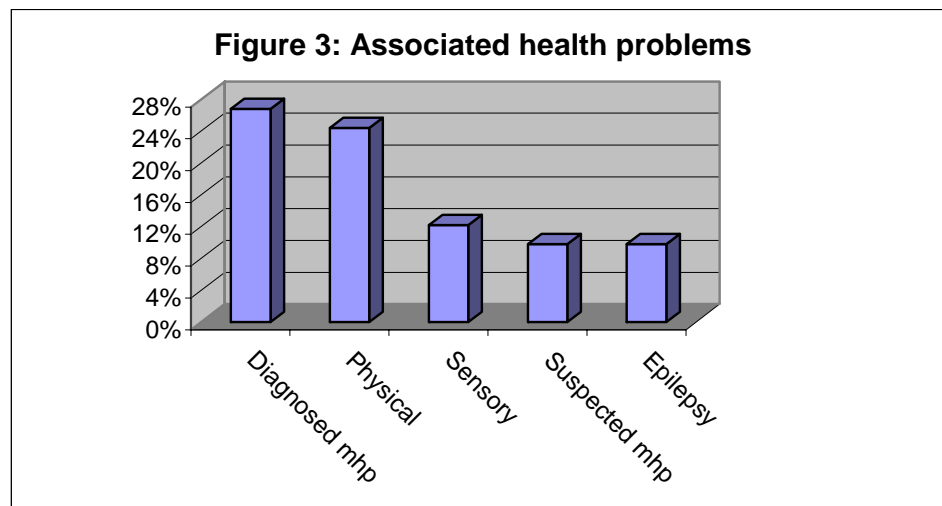
psychotic disorder (i.e. schizophrenia), followed by an affective disorder (i.e. depression). Comments from the community informants concerning the participants' mental health status included:

"N has depressive episodes regularly, insomnia, and loss of appetite, apathy and occasional suicidal ideation".

*"Panic attacks and some paranoia".*

"Periods of bizarre behaviour, extreme aggression, inappropriate emotional responses at times, extreme anxiety".

Figure 3 shows that the second additional disability was that of a physical health problem identified for 10 participants (24.4%) (i.e. asthma, gout, arthritis, high blood pressure and an unsteady gait). This was followed by a sensory disability for 5 participants (12.2%) and 4 participants (9.8%) were reported to suffer from epilepsy.



### **Information on substance misuse**

The most commonly reported substance to be misused by all of the participants (100%) as identified by the community of informants was that of 'alcohol'. Other substances that the participants were reported to be using, along with the alcohol, included 'cannabis' (N= 4), 'ecstasy' (N=3), 'prescribed medications' (N= 2) and 'amphetamines' (N= 1). One participant was also described to be addicted to 'gambling machines'. Comments for the community informants indicated the frequency and intensity of such use:

*"N uses alcohol, the frequency of this depends on the person's mood and can be daily but usually 2-3 times per week".*

*"N uses a wide range of substances including alcohol, prescribed medications and also non-prescribed medications particularly ecstasy, cannabis and amphetamines".*

*"N misuses alcohol, mostly cider and vodka. She will go on drinking binges for 3 to 4 days then sober for one or 2 days. When drinking she will consume on*

average 2 litres of cider and a ten glass bottle of vodka. She drinks until she collapses usually and sustains multi-superficial injuries”.

“It is hard to establish the level of alcohol abuse at times but N said she drinks beer and vodka and she says that it has been at times a bottle of vodka per day”.

“N uses alcohol, mostly beer, possibly 4 cans per day or more. Not known to be addicted to painkillers but takes paracetamol and ibuprofen”.

“N uses alcohol, at least 6 tins of beer per day plus one bottle of wine”.

### Length of substance misuse

The frequency of substance misuse within a 7-day period ranged from 12 participants (29.3%) reported to misusing substances at weekends (i.e. over 2 to 3 nights). The community informants indicated that 9 participants (21.9%) misused substances on a daily basis. This was followed by 8 participants (19.5%) who were reported to be misusing substances approx. every 3 – 4 days and another 8 participants (19.5%) were reported to be misusing substances on a weekly pattern. For 4 participants (9.7%), the community informants did not provide clear information on the participants’ pattern of substance misuse. As cited above, the main substance used was that of alcohol.

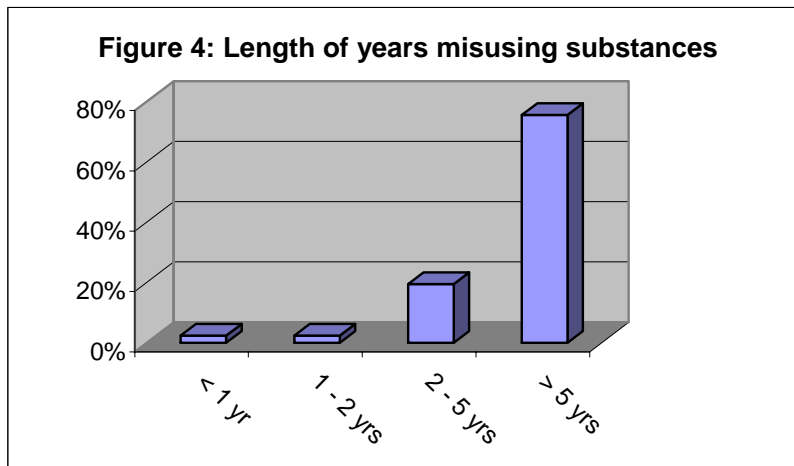
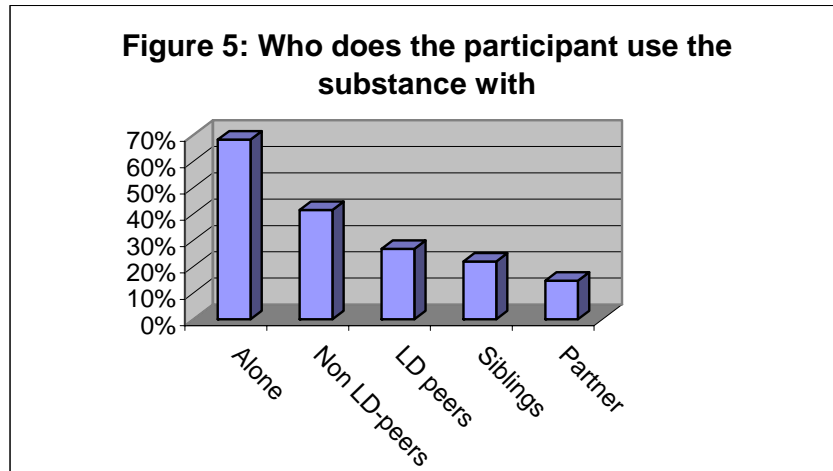


Figure 4 shows the length of the participants’ substance misuse. It can be observed from Figure 4 that for 75.6% of the participants have been misusing a range of substances for over 5 years, this was followed by 19.5% of the participants misusing such substances between 2 – 5 years. One participant (2.4%) was reported to be misusing substances less than one year and one participant (2.4%) was cited to be misusing between 1 – 2 years. These figures highlight that the majority of participants have been misusing a range of substances for a minimum of two years thereby accentuating the durability of such behaviours.

### Who does this participant use the substances with

Figure 5 shows that 28 of the participants (68.3%) used the substances alone. The community informants reported that for 17 participants (41.5%) they used

these substances with non-disabled peers. Just over a quarter of the participants were reported to use these substances with learning-disabled peers, 9 participants (22%) used these substances with siblings and 6 participants (14.6%) used such substances in the company of their partner.



In terms of where such substances were consumed, the community informants reported that the participants' 'own home' was used by 30 participants (73.2%). For 19 participants (46.3%) the community informants reported that these participants used 'bars / clubs', 'other friends homes' were used by 12 participants (29.3%) and for 11 participants (26.8%) 'public places' were utilised.

### **Effects of substance misuse on the participants' health**

Table 2 shows a wide range of behaviours that the community informants reported occurred when the participants were under the influence of the substances identified above. It can be observed from Table 2 that 'mood changes' were identified for over three quarters (75.6%) of the participants; this was closely followed by 'verbal aggression' (i.e. including being 'demanding' 'argumentative' and 'confrontational') (65.9%). These mood changes ranged from 'feelings of worthlessness', 'despair', appearing 'depressed', having 'low motivation', 'poor social judgement' and 'less co-operative'. Other comments provided by the community informants regarding the effects of the substance misuse on the participants' health included:

*"N substance misuse results in an increase in psychotic symptoms auditory and visual hallucinations and paranoia, poor concentration".*

*"N uses alcohol to numb the pain of bereavement, she has refused to engage in therapy thereby not processing the bereavement".*

*"N will allege rape / assault by unknown men, she can also become physically ill, neglect personal care, become paranoid and depressed after binges of drinking".*

*"N has presented at A & E Departments in a very distressed state, often she does not return home following a night-out drinking causing concern for her parents: some*

*nights she has ended up in other people's houses, we all wonder was she sexually exploited?"*

Table 2 further highlights that for half of the participants they have been previously 'exploited by others' (53.7%), this included financially and also sexually. 'Physical aggression' to either formal or informal carers, and / or others (i.e. members of the 'public', other 'health care staff', other 'family members' and other 'people with learning disabilities' which has resulted in the police being involved) was identified as problematic for nearly half of the participants (48.5%).

**Table 2: The effects of substance misuse in people with learning disabilities**

| <b>Behaviour</b>                    | <b>No. of Cases<br/>(N= 41)</b> | <b>Percentage<br/>%</b> |
|-------------------------------------|---------------------------------|-------------------------|
| Changes in mood                     | 32                              | 75.6                    |
| Verbal aggression                   | 27                              | 65.9                    |
| Exploited by others                 | 22                              | 53.7                    |
| Physical aggression                 | 20                              | 48.5                    |
| Suicidal ideations / thoughts       | 13                              | 31.7                    |
| Offending behaviour                 | 13                              | 31.7                    |
| Rows with care staff                | 13                              | 31.7                    |
| Physically injures self             | 12                              | 31.7                    |
| Attends A&E department              | 11                              | 26.8                    |
| Rows with partner / family member   | 6                               | 14.6                    |
| Overdosing on prescribed medication | 6                               | 14.6                    |
| Exploiting others                   | 5                               | 12.2                    |
| Other                               | 3                               | 7.3                     |
| Increases in epileptic activity     | 2                               | 4.9                     |

For approx. a third of the participants (31.7%) 'offending behaviour' (i.e. 'history of anti-social behaviours', 'shop lifting'), 'suicidal ideations / thoughts', 'physically injuring self' and 'rows with care staff' were identified as four other problematic behaviours causing the community informants serious concerns. For one participant he was involved in 'paramilitary activities' often associated with 'heavy drinking'.

For 26.8% of the participants the community informants reported that as a result of the persons' specific substance related problems they had to attend the local Accident & Emergency Unit (A&E) for treatment. One community

informant stated that the participant 'turns up at A & E every 4 – 6 weeks complaining of chest pain, seizures and others injuries caused by excessive drinking'. Other physical effects of the substance misuse reported by the community informants include 'gastro-intestinal problems', poor personal hygiene and appearance', stops eating', 'stays in bed for days', 'prone to accidents and falls' and 'avoids others'. One informant stated that:

*"Physically N has prematurely aged facially, she has black circles under her eyes, her skin and hair are dry and dull, her teeth are brown due to neglect and nicotine consumption (heavy). She has a persistent cough, low energy, irregular bleeding / menstruation and a speech impediment which becomes increasingly marked when drinking. Mental health is, low motivation, despair, poor social judgement, low mood, worthlessness and irritability leading to aggression".*

For less than a fifth of the participants (14.6%) 'rows with partner / family member' was also identified as specific issues. More alarming, for six participants (14.6%) the community informants reported that as a result of using alcohol these people have 'overdosed on prescribed medication' (i.e. 'diazepam', 'pain killers') and can avoid taking prescribed medication to manage the person's epilepsy. Comments from the community informants stress the significance of the substance abuse upon the participants' physical health:

*"N has been admitted to hospital due to an attempted overdose of painkillers due to excessive drinking which has been brought on by erratic mood swings".*

*"N has regular has thoughts of self-harm after drinking, he can also become non-compliant with his medication at times".*

*"When binge drinking, N neglects all aspects of his health becoming non-compliant with prescribed medication, becomes doubly incontinent, has low self-esteem and has thoughts of suicide".*

Other behaviours included 'exploiting others' (12.2%), increases in 'epileptic activity' (5.3%). Furthermore, three participants (7.3%) were reported to have made 'allegations of sexual harassment against unknown males' while under the influence of substances.

### **Effects of substance misuse on the participants' relationships**

With regards to the participants' relationships with both informal and formal carers, and also peers, the community informants reported that numerous difficulties arising from the persons' substance misuse patterns of behaviour. The community informants reported that the majority of the participants (92.6%) had some form of difficulties / problems (i.e. 'verbally aggressive' and 'threatening', often 'getting into rows') in maintaining positive relationships with their partners, parents and siblings. Such problems can be observed in the statements given by the community informants:

*“Relationship with mother is strained due to mother’s intolerance of alcohol (recovering alcohol herself). Relationship with father remains unstable and fraught with tension however, this is where (family home) this client chooses to reside despite a history of abuse and the fact that the father is a long-term chronic alcohol misuser. N’s partner is a long-term alcoholic and also drug misuser, and also non-learning disabled. Former partners have been physically abusive and had to be removed by legal orders”.*

*“N can disappear for weekends when drinking, N would not contact her mother and this has led to a breakdown in her relationship with her mother”.*

*“N has not developed a bond with her child, her relationship with mother has broken down and there are strained relationships with community staff”.*

With regards to peers, the community informants have reported that there appears to be marked difficulties for the participants in maintaining friends / peers. Where the participant has friends, these may not be positive relationships characterised by unequal relationships based upon financial and sexual exploitation. Below are some of the community informants’ statements:

*“N is exploited by those he drinks with, they abuse his hospitality by spending long periods of time in his home taking advantage of him financially”.*

*“N has lost all her friends, he is not welcome in the pubs and clubs and has been the victim of taunting, stoning and beatings around certain areas of the city while drinking”.*

*“N’s friends are transient alcohol and drug misuser’s who financially exploit this woman regularly”.*

*“N has alienated himself from friends and family members”.*

Similarly, the community informants (i.e. the community nurses and social workers) have reported difficulties in maintaining positive working relationships with these participants. Such difficulties have led community staff in problems in engaging the participant in substance misuse awareness and management programmes. This is reflected in the informants’ statements:

*“N withdraws from those who he knows care about him (professionals and family) when he is drinking. He is difficult to contact, not answering his phone”.*

*“N relationships with professionals follow cycles of wanting frequent contact to aggression and abuse when things are not going to plan”.*

*“N regularly misses appointments with professional staff (community social workers and psychiatrist at the community clinics)”.*

*“N is argumentative with her carers (community staff), verbally and physically aggressive, and has also made false accusations towards them”.*

## **Effects of substance misuse on the participants’ social life**

With regards to the participants' social life such as attendance at day centres, higher education facilities and / or (supported) employment, the community informants reported the many difficulties that this population has encountered. This study only found that 6 participants (14.6%) were engaged in some form of supported employment mainly on a part-time basis with limited difficulties. Similarly, 4 participants (9.7%) were found to be attending a Community Trust's day-care facility with limited problems / complaints. No participants were reported to be attending an educational facility.

More alarmingly, for the remaining 31 participants (75.6%) the community informants reported that they were not availing of any form of daily structured activities. For these participants they were reported to have encountered many problems in gaining, and more importantly maintaining, a day centre and / or employment placement as a direct consequence of their substance misuse behavioural patterns. The reasons for such high figures of lack of service utilisation range from 'continual drinking patterns', 'refusal to get out of bed', 'reluctance to attend', 'poor co-operation', 'low motivation' and the work placement being 'suspended'. Below are some of the comments the community informants reported:

*"N attends a day care facility and due to a recent self-harm attempt this placement has been suspended".*

*"N has no daily structure or routine, she has disengaged from all employment brokers and declines to attend any day occupation of any kind including women's groups or education. Former supported employment placements broke down due to absenteeism and ongoing drinking habits".*

*"N lies in bed and refuses to go to work, N states that she is too tired to do anything, neglecting herself and her daily chores".*

*"N has lost several work placements, he has had 10 accommodation moves in the last 2 years having had to leave hostels and accommodation rented as a result of his behaviour when drinking".*

*"N cannot concentrate on work, he forgets or fails to understand instructions when working, will not attend leisure activities, refuses to consider day care".*

A reoccurring theme from the community informants was the 'isolation', and for some 'boredom', that many of the participants were experiencing as a result of a lack of engagement in external activities such as day centres, higher education facilities, employment and recreational facilities. Many of the participants were reported to be spending large parts of their day on their own drinking. Some comments from the community informants included:

*"The client is socially isolated, occasionally goes to a friend's house that lives two doors away to drink. N Refuses to attend any day centres spending the day alone in room watching television or listening to music".*

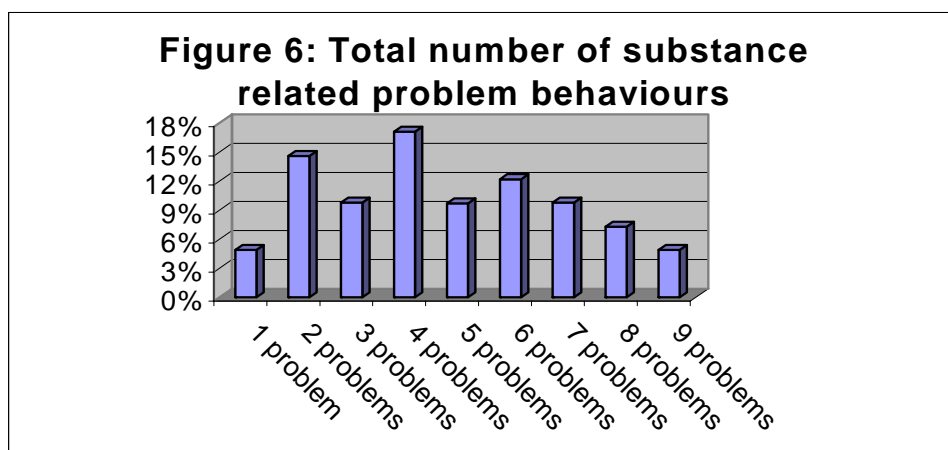
*“N tends to go out to buy beer then lie upstairs in bed drinking this. Does not wash, does not attend day care. Spends time at home watching and viewing from window and sits in the kitchen. N tends not to cook for self much”.*

*“N is unemployed and will stay in bed all day or drink all night and sleep all day”.*

*“N tends not to attend his day centre spends his day hanging around the streets, spends long periods away from his home causing his parents great anxiety”.*

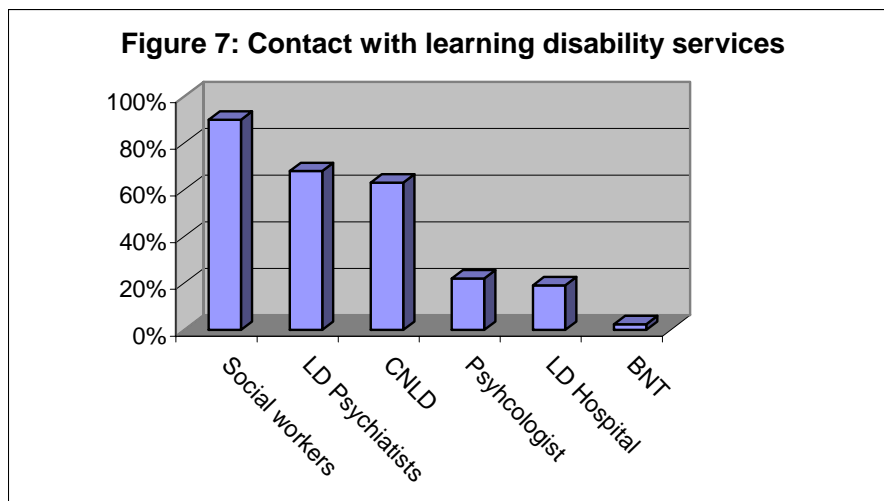
### **Total number of substance related problem behaviours**

Figure 6 shows the total number of substance related problem behaviours; these include problems concerning the participants’ physical and psychological health, personal relationships with family, peers and health personnel. The median number of problem behaviours was 4, with a minimum number of 1 and a maximum number of 9 problematic behaviours as reported by the community informants. This figure presents a distressing and worrying account of a population with multiple complex needs.



### **Contact with professionals**

Figure 7 shows which learning disability professionals the participants were in contact with. It can be observed from this Figure that the community social workers (90.2%) were in contact with the majority of the participants. This was followed by the learning disability consultant psychiatrist (68.3%), Community Learning Disability Nurses (CNLD) (63.4%), learning disability psychologists (22%), learning disability hospital (19.5%) and for one participant they were in contact with the Behaviour Nurse Therapist (2.4%).



This study found that for 12 (29.3%) of the 41 participants with a substance misuse problem, they have been in contact with one or some of these mainstream addiction services. These included: the Dunlewy Substance Advice Centre; Ward 15, Downshire Hospital; St. Conellos; The Bridge; the AA; Shaftsbury Square Hospital and a number of the Community Trust’s mainstream addictions teams. Two participants (5.3%) were in contact with a ‘dual diagnosis’ worker (a health professional who specialises in mental health problems and substance misuse). Similarly, 1 participant (2.4%) was in contact with a mainstream mental health psychiatrist and 1 participant (2.4%) was in contact with a Community Psychiatric Nurse (CPN). Comments made on how effective these services were from the community learning disability informants included:

*“Initially good, although due to participants inability to comprehend and understand this service was of limited value”.*

*“N have been receptive and responsive to all enquiries but not fully utilised by ourselves”.*

*“This service has refused to work with this lady because she has expressed a desire to keep drinking”.*

*“Have only the community addiction team for advice as N refused to engage”.*

*“This has given N a weekly opportunity to discuss issues relating to alcohol abuse with a counsellor, N enjoys this, but it has not altered drinking behaviour”.*

**Study 2:  
An examination of Alcohol and Drug Education programmes  
across mainstream and learning disability schools**

**Methodology**

**School respondents**

A questionnaire seeking information on Alcohol and Drug Education programmes across a range of mainstream (i.e. Primary, Secondary and Grammar) and learning disability schools (i.e. mild learning disability, severe learning disability, emotional & behavioural schools) were distributed to a total of 227 throughout the Belfast, North-Eastern and South-Eastern Education and Library Boards in Northern Ireland. In total, 227 questionnaires were forwarded to all the primary, secondary and grammar schools, including learning disability schools, in this geographical region. Of these 227 questionnaires, 71 (32%) were returned. This comprised of 17 Primary Schools and 44 Secondary / Grammar schools. Note, the total number of learning disability schools forwarded a questionnaire was 34, although only 10 questionnaires were returned giving a response rate of 29.4 %.

### **Materials**

The questionnaire was developed by the research team to obtain information on the extent to which the individual schools' delivered an Alcohol and Drug Education Programme. There were ten questions that sought information pertaining to the following areas related to the planning, provision and delivery of Alcohol and Drug Education programmes across both mainstream and learning disability schools:

1. School alcohol and drug policy
2. Nominated person responsible for alcohol/drug education
3. Planned alcohol education for current school year
4. Planned drug education for current school year
5. Development and delivery of programme
6. Content and level of alcohol/drug programme
7. External agencies involved in programme delivery
8. Assessment of student learning
9. Evaluation of programme effectiveness

### **Ethical considerations**

Ethical approval for the study was granted by the Research Council of Northern Ireland and also by individual Health and Social Services Trusts.

### **Procedure**

Having obtained ethical approval, the Alcohol and Drug Education Questionnaire was sent to all 227 Primary, Grammar and Secondary Schools within the Belfast, North-Eastern and South-Eastern Education and Library Boards at the beginning of the new school year. Similarly, all the learning disability schools within the aforementioned area were also identified. A covering letter was sent with the Alcohol and Drug Education Questionnaire and posted to the Principal of each of the Schools. Accompanying each questionnaire was a prepaid stamped addressed envelope for the School to return the completed questionnaire.

### **Results**

This study comments on the extent to which schools are implementing Alcohol and Drug Education programmes using the ten areas identified in the Material sections of this study.

### **School alcohol and drug policy**

The majority of the school respondents indicated that a statement / policy about Alcohol and Drug Education existed as part of the schools Health Education Programme. In total, 57 (95%) of the mainstream schools (i.e. primary, secondary and grammar) and 8 (80%) of the learning disability schools reported having a statement policy pertaining to the school having an Alcohol and Drug Education policy.

### **Nominated person responsible for alcohol/drug education**

In terms of whether a nominated person was responsible in each school for overseeing the implementation of this Alcohol and Drug Education, 58 (96.7%) of the mainstream schools and 7 (70%) of the Special Needs schools had identified personnel. These results show that the majority of mainstream schools had a specifically nominated person, called a 'personal health and social education coordinator', who took responsibility for this education / programme. By far the most common rank of professional within all school groups taking responsibility for this education programme was at a senior level, which concurs with the Guidelines for schools:

*... 'In view of the responsibilities involved, it is recommended that the designated teacher should be a member of the schools senior management team' (DENI, 2004).*

Within the learning disability schools, this responsibility was found to be delegated to a number of different staff ranging from the 'Principle', the 'Head of Pastoral Care', 'Head of the Department' to a 'Senior Teacher'.

### **Planned Alcohol and Drug Education Programme for current school year**

All schools were asked if an Alcohol Education Programme was planned for their students in the current new school year 2004 / 2005. In total, 45 (75%) of the mainstream schools indicated that there were plans to run such a programme compared with 4 (40%) learning disability schools. These figures show that over half of the learning disability schools surveyed had no planned Alcohol Education Programme for the forthcoming year compared with two-thirds of the mainstream schools.

Similarly, 55 (91.7%) of the mainstream schools reported that a Drug Education Programme was planned for the current school year 2004 / 2005. This again compares less favourably for the learning disability schools that reported that 7 (70%) of these schools had planned to deliver a Drug Education Programme. These results demonstrate a higher number of planned Drug Education Programmes over the Alcohol Education Programmes across all the mainstream school. However, these results also highlight that the learning disability schools were providing less planned

Alcohol and Drug Education Programmes compared to their non-disabled mainstream schools.

### **Content and level of Alcohol and Drug programme**

Table 3 shows the main topics / skills covered in the planned Alcohol and Drug Education programmes identified above by the school respondents together with the year levels at which they appeared to be more likely to occur. It should be pointed out that the schools interpretation of the questions relating to the nature of a topic or skill varied considerably. The amount of time spent on alcohol and drug education was found to vary widely, it was estimated that the average time spent by both mainstream and learning disability schools on both Alcohol and Drug Education at each year, was estimated at approximately 6 hours per year.

**Table 3: Content and level of Alcohol and Drug Programme**

| <b>Topic / Skill</b>                                  | <b>Predominant Year Levels</b> |
|---|--------------------------------|
| Drugs, drug use/ abuse, consequences, and solvents    | Years 6 - 14                   |
| Alcohol /Alcohol limits/Binge Drinking/Alcohol Abuse  | Years 5 - 13                   |
| Alcohols effect on the body / Biology                 | Years 5- 11                    |
| The law, availability and role of media               | Years 11- 13                   |
| Dealing with peer pressure                            | Years 9 - 12                   |
| Decision making / personal development / Safe choices | Years 7 - 14                   |
| Attitudes, Values and life skills education           | Years 8 - 11                   |
| Smoking   | Years 4 -12                    |

### **Development and delivery of programme**

All schools were asked about the nature of the development of their teaching programme and resources they employed to deliver such programmes. Just over two-thirds (70%) of the mainstream schools and 60% of the learning disability schools indicated that they used programmes that had been internally developed and resourced by the teachers within each of these schools. In addition to developing internal Alcohol and Drug Education programmes, 86.7% of the mainstream schools and 50% of the learning disability schools indicated using external resources / agencies (i.e. statutory organisations such as guest speakers).

### **External agencies involved in programme delivery**

All Schools were asked to indicate if they used external agencies to carry out alcohol and drug problems and if so, by whom. In over half of the mainstream schools (55%) reported using external agencies with specialist knowledge of Alcohol and Drug issues compared to 30% of the learning disability schools involved. The PSNI were reported as being the most frequently used external organisation across all schools who responded to this study. DENI (2004) recommended that external agencies are not '*an acceptable substitute for an*

*effective drugs education programme, but rather a potential resource which can be deployed within such a programme'.*

### **Assessment of student learning**

Less than half the schools involved in the study reported assessing student knowledge on Alcohol and Drugs related issues following completion of the students' education programmes. Just less than half of the mainstream schools (41.7%) and 3 (30%) learning disability schools indicated conducting assessments of the students learning following the Alcohol and Drug Education programmes.

### **Evaluation of programme effectiveness**

Both the mainstream and learning disability schools were asked to indicate if the teachers within these schools evaluated the Alcohol and Drug Education programmes provided to the students. The majority of mainstream schools (88.3%) and 7 (70%) of the learning disability schools reported undertaking such evaluations of these Alcohol and Drug Education programmes. Conducting an evaluation of the effectiveness of these Alcohol and Drug Education programmes should ensure that the messages of appropriate management are appropriate to the age, maturity and level of ability of all students.

## **Study 3:**

### **Service provision for people with learning disabilities who misuse substances**

#### **Methodology**

##### **Recruitment of participants**

Four Health and Social Services Trusts were targeted across Northern Ireland for this study. Managers from mainstream addiction teams and learning disabilities teams were contacted and asked to speak to their staff to gain consent to take part in the study. The nature of the study and the ethical approval were explained. The managers then provided the researchers with names of professionals whom the researchers could contact. Each professional was then invited to take part in a one-to-one interview.

##### **The Data Collection Process**

Careful preparation is vital for the research interview to run smoothly and successfully (Krueger, 1994; Lincoln & Guba, 1985; Sullivan, 1998). A full introductory statement regarding the study and its ethical implications were read out prior to commencing the interviews. All respondents gave their consent to take part in the study. The researcher explained that with their permission, would audiotape the interview, a common approach to recording interview data (Krueger, 1994; Lincoln, and Guba, 1985). When all the questions were answered and participants' queries addressed, the researcher thanked the participants and ended the interview.

##### **Research instrument**

The research instrument was developed by the researchers to generate discussion during the one-one interviews; the following questions were used:

- How many people with a learning disability and an alcohol and or drug problem, have you worked with?
- What substances have they used?
- Why do you think that they used these substances?
- What problems/issues have you come across in working with this population?
- How do you assess these people?
- How do you treat these people?
- What specific skills or training have you received to help these people?
- What specific skills or training do you require to help these people?
- Do you think your team works effectively, for this group of people?
- Do you liaise with other professionals, when caring for this group of people, if so who are they?
- What prevention strategies are in place within your service to minimise or prevent this type of problem?

- Does your service have written policies/guidelines/frameworks to work with learning disabilities/alcohol and drug teams?
- Have you any other information regarding developing services for this population?

### **Ethical Issues**

Ethical approval was obtained from the Health and Personal Social Services Research Ethics Committee for Northern Ireland, to carry out this piece of work. During the interviews the professionals were being asked to speak freely about a challenging group of clients that have been marginalized, confidentiality and informed consent were of great importance (Sullivan, 1998). Assurance of confidentiality was given; the recordings of the interviews were kept secure and participants were informed that all recordings would be destroyed at the completion of the study.

### **Data Analysis**

After completion of the one-to-one interviews with the mainstream addiction professionals and the learning disabilities professionals the interviews were listened to on a number of occasions, the interviews were transcribed and the transcriptions were read and re-read to gain meaning and understanding from the data. The interview schedule was employed as a template for the content analysis, which is a well-recognised and accepted approach in qualitative investigation. Dr McLaughlin and Dr Taggart carried out this task independently and then met to compare and contrast their findings, to aid the trustworthiness of the research.

### **Results**

*In total thirteen professionals took part in this study: five professionals (38.5%) worked within the mainstream addictions and eight personnel (61.5%) worked in the learning disabilities arena. Each section will first address the issues concerning to the mainstream addiction personnel, followed by the results relating to the learning disability professionals. A number of themes emerged from the data these will be highlighted by relevant citations from respondents.*

How many people with a learning disability and an alcohol and / or drug problem, have you worked with?

#### Mainstream Addiction Professionals:

The number of people with a learning disability being referred to mainstream addiction services was not a pressing issue for these professionals, one informant stated;

*“Well in my experience to date I have only met one...” (Participant 9, Alcohol and Drug Professionals (ADP))*

Another had experienced more people with learning disabilities, stating;  
*“Over the past couple of years there would maybe, maybe about five.” (Participant 3, ADP)*

### Learning Disabilities Professionals:

In contrast the learning disability informants had experienced higher numbers of people who had a learning disability and an alcohol and/or drug problem. One informant stated the following when asked how many people he/she had worked with, stating;

*“ Well into double figures...” (Participant 4, Learning Disability Professional (LDP))*

Another informant stated it was not just the actual number of people but also the percentage of people with alcohol and drug problems, saying:

*“...five maybe out of a complement of probably forty four in the in patients at the moment. So it is a significant number.” (Participant 10, LDP)*

This same professional went onto say that he felt this was a hidden issue and therefore the real size of the problem maybe hidden, stating:

*“...so the extent of the problem might not be known...” (Participant 10, LDP)*

What substances have they used?

Mainstream Addiction Professionals: The main substance of choice for a person with a learning disability coming into contact with alcohol and drug services was alcohol, one professional stated:

*“The three that I am thinking of it was solely alcohol.”(Participant 2, ADP)*

Not all referrals had alcohol as the sole problem, one professional had experienced people presenting with alcohol and illicit drug use, stating:

*“...mostly it has been alcohol and as I say cannabis would be a big thing.” (Participant 3, ADP)*

Another ADP had also experienced similar issues with alcohol and cannabis being used:

*“Alcohol and one of them had alcohol and cannabis...” (Participant 12 ADP)*

Learning Disabilities Professionals: The learning disability personnel also reported that alcohol was the most widely used substance with the clients they worked with, one stated:

*“It would be alcohol with all the ones that I am thinking about.” (Participant 11, LDP)*

Other learning disability personnel had experienced their clients reporting to consume a range of substances one stating:

*"...and one fella would use drugs in the sense of cannabis, ecstasy, whatever he has at the time." (Participant 13, LDP)*

Another stated;

*"I have some out patients who have substance abuse within their history certainly I have one with very heavy cannabis use problem, some using ecstasy as well although that is less common." (Participant 10, LDP)*

Why do you think that they used these substances?

Mainstream Addiction Professionals: All the ADP had clear views as to why these people with a learning disability would have used their substance, they all pointed to social issues, one professional stated:

*"...to fit in this guy is functioning at a fairly high level, he lives on his own and I think socially he obviously sees other people out and about going to the pub and doing things so he wants to do that too... to be able to mix with other people. Loneliness living on his own, while he had his family close by there was still a degree of loneliness, so going out to the pub he would have met people and he would have been quite sociable that way." (Participant 9, ADP)*

Another stated;

*"I feel that a lot of it is to do with social using, you know to just kind of fit in with people who are deemed normal as such... I feel, in my opinion a lot of it would be for social inclusion, to be accepted." (Participant 3, ADP)*

This theme is reinforced again; an ADP said;

*"I think it is probably, they are trying to be normal and accepted you know into society and part of society..." (Participant 8, ADP)*

Learning Disabilities Professionals: The learning disability personnel felt that the person with a learning disability may have used a substance, for a mixture of social reasons and genetic or biological issues, the classic nature/nurture debate. One LDP stated;

*"Well one of them it was in her family environment, her mother was an alcoholic. And I imagine she perhaps learned that behaviour and she would have also lived in a housing executive estate were there would have been a culture of drinking and partying late at night..." (Participant 1, LDP)*

Another professional could clearly see the social and the biological nature of this woman's difficulties stating:

*"...she drinks because she is lonely, she drinks to be social and she drinks in parks which is the difficulty and gets into that company where she is accepted so I suppose, she is addicted I mean there is the chemical reason she is addicted but I think the social reason is acceptance. If she drinks a lot she can mix in with crowds of people who will accept her." (Participant 5, LDP)*

Finally one LDP felt it was related to social isolation saying:

*“Loneliness. The majority of people you are talking about individuals have mild learning disability how are living alone and are terribly lonely, which is the same reason but all the other problems and issues and things that they have, but yes that would be the main reason. That would be a trigger for binge drinking and things like that.” (Participant 11, LDP)*

What problems/issues have you come across in working with this population?

Mainstream Addiction Professionals: A very real issue for the mainstream addiction personnel was the level of vulnerability they could identify in the people referred to their service with a learning disability. This vulnerability relates to impact the persons substance use has on their biological, psychological and socially well being. One ADP said the following:

*“Again a lot of physical problems, maybe presenting to causality, overdosing self harming just self neglect again one or two of them very vulnerable and I feel that a lot of them have maybe exploited, financially and query sexually.” (Participant 3, ADP)*

This concern was expressed by another ADP who said:

*“... when somebody comes through to our service...with a learning disability it does normally cause quite a degree of concern or worry, often about their vulnerability or how they can be exploited. That would be a major concern for us ...” (Participant 9, ADP)*

Another ADP found similar concerns, stating:

*“The guy was referred to me through sort of the key workers in (names unit), they were noticing that he was missing days at work, smelled of alcohol when he came in, he was lying tired or whatever.” (Participant 12, ADP)*

Learning Disabilities Professionals: The theme of vulnerability appears to resonate strongly with learning disability personnel also. One worker related incidents, which were frightening about the vulnerability of clients, saying:

*“Well in the first instance, the first fella he lost his job, got involved with the police appeared in court and as I say he was involved in anti-social behaviour so there was paramilitary involvement as well. The second fella again lost his place in the day centre, admission to hospital on two occasions, aggression, he became very aggressive regularly and went practically looking for beatings, it got so severe that his mum put his photograph, name and address in the (names hospital) causality because he was there so many times, so that they contacted her straight away.” (Participant 13, LDP)*

*Another learning disability worker also had experienced clients who had experienced profound problems and had caused this professional obvious concern:*

*"I would have to call them hangers on for lack of a better description, but people who would have recognised his weakness and his defences were down because of his drinking and he was prescribed valium as part of his medication regime and his friends would have known that if they got close to him during time when he was drinking they could get his prescription... Another one would have had his drinking mates, they would have moved into the house and spent days on end drinking and smoking because it was a nice warm comfortable environment for them have and an example of how they exploited him...people just zoom in on a person with learning disabilities, they see their abilities they see the opportunity to exploit them and very often it is other drinkers that do it, it is not always... Basic safety issues, another guy I am thinking of would often be seen at all times of the day, wandering the streets drunk and he would stagger of the footpath and into the path of the traffic regularly..." (Participant 11, LDP)*

How do you assess these people?

Mainstream Addiction Professionals: The issue of assessment of a person with a learning disability had a united response from the mainstream addiction personnel interviewed. They all appeared to use the standard assessment schedule the only real change appeared to be the language used in the delivery of this assessment tool. This was well summed up by the following:

*"Well to be honest I would assess everyone the same way. Now I would maybe use our standardised forms and what ever but certainly language I would have been careful to make sure that my language was clear and understandable and try to avoid any complex terms but again I would do that for all clients because there is nothing worse than trying to blind someone with science. I want to make sure that my language is humane and clear and concise."(Participant 9, ADP)*

Another ADP simply stated:

*"They don't have any actual separate assessment for someone with learning disabilities..." (Participant 8, ADP)*

Learning Disabilities Professionals: The learning disability personnel reported great communication skills and developing therapeutic relationships with their clients. What was absent from their assessment was any formal assessment tool for issues around alcohol and drug. One LDP when asked about methods of assessment stated;

*"It is ad hock...You actually can't assess it because you are not there all day...I say the reason you get to assess properly is when you develop a relationship with them...I assess the impact on her behaviour..." (Participant 5, LDP)*

Another LDP reported a very similar approach, stating:

*“Assess them well, assess their needs, well I got them as referrals and we had a discussion and we talked about things, built up a relationship over a period of time and them found out, they started to tell me things. Working with the family through home visits who would inform me if alls well...” (Participant 13, LDP)*

Another reported that there was no formal assessment tool for this area of concern, stating:

*“I wouldn’t pretend to use any particular models, or specific treatment plans that you could apply to if he was a person that you could deal with sort of thing or, or. How would you assess what they drink, just on going, contact with them and getting to know them.” (Participant 11, LDP)*

How do you treat people with learning disabilities who also misuse substances?

Mainstream Addiction Professionals: When it came to the issue of active treatment again there was great consistency in the responses of the mainstream addiction personnel interviewed. It was clear the treatment approach was unchanged, but the method of delivery was slightly altered.

One reported the following;

*“Really the majority of the interaction I had with the client was a very basic information giving and I would have set him very basic homework tasks which seemed to be the only way to engage him. When it got to any kind of cognitive work it was very, very difficult.” (Participant 12, ADP)*

This was reinforced by another who stated;

*“In the same way that we treat all our clients. I don’t know any other way to treat, so I treat them all the same whether they have a learning disability or not and I come back to the point about time. With a person that does not have a disability it can be much quicker, with someone who has a disability you have to be that more patient and that bit more resourceful.” (Participant 2, ADP)*

Unfortunately on occasions this change in method of delivery could have some un-welcomed ‘side effects’, as one ADP explained:

*“Basically what I would try to do initially what I would try to ... not go straight in there and kind of ask them about their drinking, just have a chat with them to try and relax them and then maybe just ask them when you out would you drink or would you drink in the house. Try the softly, softly approach and again maybe I am undermining their abilities as well but I try to talk to them the same way I would maybe talk to a child.” (Participant 3, ADP)*

### Learning Disabilities Professionals:

In relation to treating these issues the learning disability personnel had no real structured approach, often people have been referred to specialist teams or learning disability personnel gave out advice built on lay health beliefs, one LDP said;

*“Depending, some of mine have gone to the addiction team, and have been involved in the addiction team, although that has not been successful.” (Participant 6, LDP)*

When asked why this should be, stated:

*“It seems to be that with the addiction team either you have to be willing to come of the alcohol...”(Participant 6, LDP)*

When asked what was done then, stated:

*“Generally if it is the addiction it would be education from ourselves and advice from ourselves and that would generally be it.” (Participant 6, LDP)*

Others took a very behavioural approach, one LDP stated:

*“...try to rationalise with them, try to talk to them about it, try to limit their access to drink.” (Participant 4, LDP)*

One LDP reported to be giving recognised interventions in the form of motivational interviewing, yet appeared frustrated that the person was still drinking saying;

*“Counselling, I can tell you the model I use the only one there is, motivational counselling, you know the alcohol model, non confrontational and all this. It seems to be effective in the sense that it keeps her on board, but she is still drinking so I am having to look at, I am desperately trying any model at the moment nothing works...”(Participant 5, LDP)*

Later this same LDP stated that he/she had received no formal training in substance issues, which is at least puzzling as to what is actually going on, the LDP stated:

*“...no official training...” (Participant 5, LDP)*

Another LDP took a very pragmatic harm minimisation approach, reaching this approach without any apparent formal education but out of a need to help a person in a very difficult situation, stating:

*“Yeah I made him up a wallet because when he had a lot of drink in him he couldn't get his way home, his communication skills weren't great. So I made him up a wallet to say who he was, where he lived that he had a learning disability and that his mum would pay the fare when he got him home, if he hadn't the money on him or a number to call you know so he could give it to the taxi driver and he has used it and the taxi driver has brought him home...”*

*The dad spoke to the doormen and the doormen know that they give the dad a ring and he comes and gets him before he has too much alcohol but it is mostly for social drinking and let him stay there and not be wondering round going to different places, places where it is not safe for him and to keep him in a safe area because, we are trying to work on his alcohol but we can't stop him drinking but while we are getting there we want to make sure he is safe. So that is the main reason you know and he is agreeing to this and it is working you know.” (Participant 13, LDP)*

What specific skills or training have you received to help these people?

Mainstream Addiction Professionals: Again there was a high level of agreement in relation to this issue with the mainstream addiction personnel. Their education and skills development happened a very long time ago or did not happen at all. One ADP stated;

*“Thirteen weeks training, now when I say training it was placement up in (names hospital) and that was in 1983.” (Participant 3, ADP)*

Another ADP when asked about training or skills in this area simply stated:

*“None.” (Participant 2, ADP)*

Yet another ADP echoed the same message, stating:

*“No specific training.” (Participant 8, ADP)*

Learning Disabilities Professionals: When asked about the training they had received the learning disability personnel were very clear in that they had received no formal training in the arena of substances issues or what they had got was minimal. Four learning disability personnel, which is half of the total learning disability personnel, responded with the exact same answer when asked about the training they had received, they all said:

*“None.” (Participants 1, 5, 6 & 7, LDPs)*

One LDP reported a small number of one-day training issues around alcohol and drugs stating:

*“ I have attended a couple of one-day courses just on alcoholism and drug abuse and things like that, through the health promotion people.” (Participant 4, LDP)*

What specific skills or training do you require to help these people?

Mainstream Addiction Professionals: This line of inquiry produced a very strong response from the mainstream addiction personnel, in that the development of communication skills to assist the ADP to be able to engage with the person with a learning disability more effectively. One ADP reported to need the following;

*“Well I think if perhaps you had some specific training in relation to how to interact with people...” (Participant 12, ADP)*

Another ADP stated:

*“... I suppose some skills in learning how to approach these people and I suppose understanding their disability in order to help me with the information I have to impart to these people.” (Participant 2, ADP)*

Learning Disabilities Professionals: This produced a strong response from learning disability personnel in relation to developing knowledge and skills about substance issues but also to ‘link up’ with alcohol and drug services in an attempt to share their knowledge of learning disability with alcohol and drug services, one LDP said:

*“Well I think you need to be aware of the signs and symptoms, just to be able to pick it up in the first place. Then you know I would like to have some input from the addictions team in what methods of work they use and how they could be adapted for people with learning disabilities, its’ a whole field of unknown. You know they have all this knowledge and skills we don’t have but we have the knowledge and skills where the disability is concerned...” (Participant 1, LDP)*

Another felt that with the involvement of the alcohol and drug services in the development teaching packs could be helpful for learning disabilities services, stating:

*“I would say probably that we would need to be involved to some degree in the addiction team and from there maybe developing a teaching package that is going to be suitable to our clientele in learning disability.” (Participant 6, LDP)*

Another felt straight education and skills development would be sufficient, saying:

*“I suppose just an awareness and research that has been done and how best to manage it, or even educational skills that you would use with the person.” (Participant 7, LDP)*

Do you think your team works effectively, for this group of people?

Mainstream Addiction Professionals: This issue had a fairly strong response, in that most of the mainstream addiction personnel felt that their services did not work that well or effectively for people with a learning disability. One participant reported the following:

*“Well possibly not because we perhaps, the type of service we provide isn’t particularly well geared up for people with learning disability...” (Participant 12, ADP)*

Another ADP reported very similar experiences, saying:

*"I don't know, I think that again a lot of it is down to communication and peoples knowledge and skills in that area that there are more people there with learning disabilities and yes we do try to do as much as we can but I feel that a lot more could be done and maybe through working more closely with different services as such." (Participant 3, ADP)*

Another worker reported a very positive individual response, to the interventions this ADP provided, stating:

*"Well, I certainly feel that I am working effectively with this young man..." (Participant 9, ADP)*

Learning Disabilities Professionals: The majority of learning disability personnel felt that their clinical input in this area was limited and could be improved, one stated:

*"I think that it is limited. I think they work effectively in some areas they can help with general support, with communication, with liaison... I think we do struggle to provide therapeutic input in terms of motivational interviewing; we don't easily have access to medications or the ability to monitor in some cases, which is most important. So I don't have specialist input. I am aware of guidelines in regards to opiates nothing in relation to cannabis or ecstasy, in particularly in terms of the out patient population and we struggle to provide a therapeutic input there." (Participant 10, LDP)*

Another LDP was very pessimistic about the whole issue of people with learning disabilities and substances issues, stating:

*"I don't think there is an effective answer to it with learning disability, again because of their understanding their, with most alcoholics, they have to accept that they have a problem to start with and if they won't accept that they have a problem, maybe they don't have a problem, maybe we are the people who have a problem with them drinking rather than, they don't perceive it as a problem." (Participant 4, LDP)*

Another LDP was very up beat and positive about the effectiveness, of the team he/she works in due to the fact it is a team effort, stating:

*"I think really yeah. I think because we go at it from a multi-disciplinary approach." (Participant 7, LDP)*

Do you liase with other professionals, when caring for this group of people, if so who are they?

Mainstream Addiction Professionals: All of the mainstream addiction personnel reported to liaise with other professionals as appropriate, when a person is attending their service, one stated;

*“When a referral is made, we will refer with the clients G.P and the referring agent who ever that is, be it a psychologist or a social worker or what ever.”*  
(Participant 2, ADP)

Another simply said:

*“Well am, if required absolutely...”* (Participant 12, ADP)

Learning Disabilities Professionals: This line of questioning produced a strong response with all the respondents’ liaising with others about these issues. In some instances it was well structured on other occasions it was more ad hoc, one a comprehensive use of available resources LDP stated;

*“Yes the addictions team would be one, we have our own psychology department and behaviour support team, so we would use them as well.”*  
(Participant 1, LDP)

Another reinforced this structured approach by stating:

*“Yes there would be the community addictions team and the G.P’s and the consultant.”* (Participant 6, LDP)

Another LDP reported a more ad hoc arrangement when it came to the issue of liaison, stating:

*“Not with any proper addictions teams or whatever, I think years ago I did contact people on a couple of occasions, not on a regular basis so, who we work with, or line of disability, professional colleagues, consultant psychiatrists, GP’s and social workers, would all be multi-disciplinary within learning disability team but would acknowledge the fact that we don’t, I think that we should, I think that we should but it doesn’t happen.”* (Participant 11, LDP)

What prevention strategies are in place within your service to minimise or prevent this type of problem?

Mainstream Addiction Professionals: Once again this line of questioning produced a united response from the mainstream addiction personnel; no professionals interviewed carried out any preventative activity, or were aware of any preventive strategies to avert or minimise substance problems for people with a learning disability. In fact many felt that the remit for this would sit with the Health Promotion Agency. One ADP stated;

*“To be honest no, we have no specific strategy aimed at preventing substance problems with people who have learning disabilities, I would have thought that*

would be down to health promotion, to develop some type of strategy or framework.” (Participant 9, ADP)

Another stated;

*“Am to prevent, it is difficult to say because most of our work is done with people who don’t have learning disabilities and most of our work comes form the client. I think that if you were to go out there and do preventative work I think we are more or less inclined to leave that to health promotion because like that is more their field than ours.”(Participant 8, ADP)*

Learning Disabilities Professionals: This issue produced a strong and consistent response from the learning disability personnel, in that there was no strategy in place to prevent or minimise substance problems for people with learning disabilities. One LDP stated;

*“There is not really...” (Participant 4, LDP)*

Another stated;

*“None that I know of.” (Participant 7, LDP)*

One LDP was wanting a strategy but a comprehensive not just based about substances issues, possible a strategy about the health and well-being of people with learning disabilities, stating;

*“...I think there is a danger that pieces little bits that aren’t joined up and people will go off training for something that doesn’t get going, so if there was a co-ordinated strategy which would include addictions as part of a whole lot of other things...” (Participant 10, LDP)*

Does your service have written policies/guidelines/frameworks to work with learning disabilities/alcohol and drug teams?

Mainstream Addiction Professionals: This area again produced a clear response from the mainstream addiction personnel interviewed, none of these people were aware of any policy or guideline for working with a learning disability team. Interestingly two mainstream addiction personnel stated the exact same response when asked about policies, stating;

*“Not that I am aware off.” (Participant 2&3, ADP)*

Another ADP was very aware of different general guidelines, but nothing specific about working with learning disabilities services. This person said;

*“No, but we would have written guidelines in our service profile which is about you know co-working with other services, such as working with mental health clients. They would just be really guidelines in and around the note keeping, referral processes, calling case conferences you know so there would be general guidelines.” (Participant 12, ADP)*

Learning Disabilities Professionals: Here again there is a united response to this issue from mainstream addiction personnel and learning disability personnel, all the learning disability personnel recognised that there were no specific policies for these two services to work together, some did recognise a series of generic policies, one LDP said;

*"If there is, I should know and I don't know." (Participant 11, LDP)*

Another LDP simply said:

*"Not that I am aware of." (Participant 13, LDP)*

Have you any other information regarding developing services for this population?

**Mainstream Addiction Professionals:** Finally the mainstream addiction personnel were asked about what they believed would need to be done for this group of people. The way forward appeared to be through education and a 'cross fertilization' of alcohol and drug teams and learning disabilities teams. The teams would educate each other in relation to their individual strengths and work together when issues arose. One ADP stated;

*"Well I think that it could be a trial I don't necessarily mean that we can only teach them, they can also teach us. So there is a need for sort of cross training between the services, between all services, so that they know something about alcohol and we know something about learning disabilities and how which is the best course to take with somebody with learning disabilities." (Participant 8, ADP)*

Another stated;

*"The main thing that I think would be useful would be some type of guidance maybe written policy and protocols, what we should and should not do and obviously training where we can come together and learn from each other..." (Participant 9, ADP)*

One ADP felt that the emphases should be on the learning teams to come up to speed with alcohol and drug issues, with support and supervision coming from the alcohol and drug services, stating:

*" I would suggest that perhaps the most effective and efficient way to do that would be to have someone within the learning disability team skilled up to some degree in relation to addictions, models of addictions, treatments, general information, assessment and screening tools and indeed you could perhaps have that person getting some supervision through the addictions service." (Participant 12, ADP)*

**Learning Disabilities Professionals:** The learning disability personnel interviewed had numerous suggestions on how to develop services for this client group. One LDP stated;

*"I think initially awareness raising is very important, a lot of people don't believe that people with a learning disability have a drink problem or could have a drink problem. I don't know where they get that thinking from. I think the second thing involving people with a learning disability with early education, I am not sure how much goes on in schools in teenage years about alcohol the same way as people with non disabled." (Participant 5, LDP)*

Another LDP put forward a sharing of skills and a link professional, saying:

*"...learning disability nurses have well I am not just specifically meaning them, but they have the skills for communicating and working with people. Other people have the skills of dealing mainly with drugs and alcohol you know a combination, having both skills would be, somebody having both skills or a link person between somebody from drug and alcohol and learning disability working could draw up some sort of a joint sort of thing you know." (Participant 13, LDP)*

## **Discussion**

The objectives of this study were threefold, firstly to describe the characteristics of people with learning disabilities who misuse alcohol and / or other substances, and to examine the effects of such abuse across four Community Trusts in Northern Ireland. Secondly, to investigate the equity of whether alcohol and drug education programmes are delivered across both mainstream and learning disability schools. And thirdly, to examine service provision for this population who misuse substances across both learning disability and mainstream addiction services.

Prevalence rates of substance misuse in people with learning disabilities  
Study 1 reported a prevalence rate of 0.02% of its adult learning disability population misusing a range of substances across the four Community Trusts based upon recent population estimates (Department of Health, Social Services and Public Safety Office, 2000/2001). This prevalence rate figure is lower, as expected, than both the general and psychiatric populations reports earlier (Reiger et al., 1990, Dept. of Health, 1998, Hall et al., 1999, NHSDA, 2001). Moreover, this prevalence rate figure of 0.02% is also lower compared with previous learning disability and substance misuse studies and that cited by Sturmey et al. (2003) of "between 0.5% - 2%" (p. 44).

However, in conducting this study a number of questionnaires were not forwarded within the specified time-period due to the community informants being off ill, not completing the form, etc; although approximately another ten participants were known to learning disability services and misusing alcohol and / or drugs. Furthermore, this study only included those participants who were known to learning disability services and aged 18 years and over. Thereby, those individuals in contact with mainstream addiction services and / or still residing within a school setting (including schools for young people with mild learning disabilities and in 'special units' in mainstream schools), and also people known to neither service, have not been included in these

prevalence rates. Consequently, it could be argued that this figure of 41 participants (0.02%) is a lower estimate and must be interpreted with some caution, as the true prevalence rate may be higher if a more comprehensive sample was obtained. Future studies should utilise a broader sample of people with learning disabilities who use both learning disability and / or mainstream addiction services and / or educational facilities.

In addition, this study examined those participants with current alcohol and / or drug misuse using operational criterion for 'substance abuse' as identified within the DSM-4 classification system (see above). This stringent criterion may exclude a number of participants, whose substance related-behaviour problems may not meet the specified criterion, further restricting those participants who could have been classified within the prevalence rate figures although are still misusing such substances. One of the difficulties in undertaking a prevalence rate study like this is a lack of appropriate comparisons due to the range of methodological variations of earlier studies as highlighted above.

### **Characteristics of substance misuse in people with learning disabilities**

Study 1 found that 41 people with learning disabilities were identified to be misusing substances, of which two-thirds of the individuals were found to have a borderline to mild learning disability. These results replicate findings that have been reported in previous substance misuse studies (Jacobson, 1988, Rimmer et al., 1995, Sturmey et al., 2003). Of the 41 participants, 29.3% were found to fall between the ages of 18 – 30 years and another 26.8% fell between the ages of 31 – 40 years: these results reflect similar findings (Gress & Boss, 1996, Wilens et al., 1996, Robertson et al., 2000). However, this study found no gender differences among the sample. This latter finding contrasts with earlier alcohol and drug studies undertaken with this population, that reported that the participants should be predominantly male (Gress & Boss, 1996, Wilens et al., 1996, Robertson et al., 2000).

Over a third of the participants (36.6%) in Study 1 were reported to be living independently in their own home and another 24.4% of the participants were residing in a supported living scheme with minimal support. This is in comparison to just over a third of the participants were living with their families or in a residential facility with some form of continued supervision. These findings are similar to those studies that reported that persons living in various community semi / independent accommodations with low levels of supervision were more likely to have access to a range of substances, improved communication skills to negotiate the substance transactions including having more readily available cash (Lindsay et al., 1991, Moore & Polsgrove, 1993, Rimmer et al., 1995, Christian & Poling, 1997, Barnhill, 2000, Robertson et al., 2000).

Alongside a diagnosis of a learning disability, Study 1 indicated that 26.8% of participants were reported to have a diagnosed mental health problem. Psychotic and affective Disorders were identified as the main psychiatric diagnoses, with one participant reported to have a diagnosis of Alcohol

Dependence Syndrome. Furthermore, another 9.8% of the participants were suspected to have a mental health problem. These findings support previous studies that examined this 'triple diagnosis' of a learning disability, a substance misuse problem and a mental health problem as described by Barnhill (2000) (Drake et al., 1993, Verheul et al., 2000, Mayer, 2001, Stavrakaki, 2002).

More importantly, over a third of the participants having a co-existing mental health problem as well as an 'alcohol problem', exceeds those figures reported for the general population and the psychiatric population of 13.5% and 22.3% respectively (Reiger et al., 1990). Although, it is important to note that there is growing evidence to indicate that people with learning disabilities are more likely to have a higher incidence of a mental health problem compared to the general population (Bouras, 1999, Deb et al., 2001, IASSID, 2001). But whether the participants' mental health problem leads to the person developing a substance abuse problem, or vice versa, whether having a substance abuse problem leads to or exacerbates a mental health problem is unclear and requires further scrutiny. Nonetheless, these results strongly emphasise the importance for early screening for mental health problems in this learning disability population and also the necessity to screen for alcohol problems in people with learning disabilities who have a mental health problem to identify such risks from occurring in the future.

### **The types of substances misused by people with learning disabilities**

Study 1 found that 'alcohol' was the main substance abused by the all 41 of the participants, with the majority misusing alcohol as the only substance for regular periods / 'binges' throughout the week. A small number of participants were also reported to be misusing illicit drugs (i.e. 'cannabis', 'ecstasy' and 'amphetamines') along with the alcohol. Two participants were reported to be misusing prescribed medications (i.e. painkillers) and one participant was reported to be addicted to 'gambling'. Study 3 further collaborated these findings. More alarmingly, Study 1 found that for over 75% of the participants, alcohol and other substance misuse have been continuing for over a five-year period demonstrating the durability, and resilience to interventions, of such misuse.

Such substances were reported to be used in a number of ways: using substances 'alone', with 'non-disabled peers', with 'learning-disabled peers', with 'siblings' and with their 'partners'. This misuse of such substances was consumed across a variety of settings with the preferred place to use such substances being in the participants' 'own home', followed by 'public bars / clubs', 'other friends houses' and in 'public places' such as parks / streets.

### **Reasons for substance misuse**

Study 3 reported that both the learning disability and mainstream addiction informants highlighted a number of reasons for the participants' use of such substances, these can be dichotomised into two broad areas: firstly 'social' (i.e. that is to 'fit in' with their peers and to avoid 'loneliness'), and secondly

due to the physiological / psychological benefits that such substances can have (i.e. the high, euphoria, etc.). These findings equate to earlier studies that examined the reasons for such substance use / misuse in this population (More & Polsgrove, 1991, Gress & Boss, 1996, Christian & Poling, 1997, Manthorpe, 1997, Clarke & Wilson, 1999, Degenhardt, 2000, Sturmey et al., 2003). Although Study 3 reported varying discrepancies in both groups of informants' responses to this question, this difference may be accounted for by the lack of opportunity of the mainstream staff to engage meaningfully and successfully with people with learning disabilities in a range of interventions. This is compared to learning disability personnel who have received in-depth training, accompanied with a wealth of experience, in working with a population with a range of cognitive impairments, communication deficits, intra and inter-personal difficulties and other co-existing 'conditions' (i.e. mental health problems, challenging behaviours, epilepsy).

### **The effects of substance misuse in people with learning disabilities**

The findings above have clearly demonstrated the distressing pattern of the broad range of substance related problematic behaviours that have profoundly impacted upon the persons' biological, psychological and social functioning. Study 1 has also shown the numerous negative effects of such misuse upon the persons' personal relationships with family, peers and professional care staff, and upon the persons' social life. Additionally, both learning disability and mainstream addiction informants in Study 3 reported a similar range of problems / issues in working with people with learning disabilities as found in Study 1, further highlighting the negative effects of such substance abuse in this population. It is worth noting, that none of the community informants reported the positive effects of using such substances upon the participants' health, personal relationships and social life.

From Table 2, it can be observed that the community informants frequently reported erratic 'mood changes' by the participants when they had consumed alcohol and / or the other substances. Such effects of the substance also lead to a range of other difficult to manage and challenging behaviours such as 'verbal aggression', 'being exploited by others', 'physical aggression', 'suicidal ideations', 'offending behaviour', 'rows with carers', 'physically injuring self' and frequently 'attending the A & E hospital departments'. This study found that the median number of substance related problematic behaviours was four, with the range from 1 to 9, highlighting the often complexities found in assessing, treating and managing this population. These findings parallel the few other studies that have examined the effects of substance misuse in this population and the significance of such misuse for the individual, the carers and service providers (Westermeyer et al., 1988, Pickens et al., 1993, Lezak, 1995, Ling et al., 1996, Clarke & Wilson, 1999, ARAC, 2002, Wandsworth Project, 2003).

Findings in Study 1 also parallel early research that reported that there was a strong link between people with learning disabilities who misuse substances and offending behaviour (Hayes & McIlwain, 1988, Hayes, 1989, Jones &

Coombes, 1990, Kilimecki et al., 1994, Mc Gillivray & Moore, 2001). Community informants reported a number of participants getting into substance-related offending behaviour and for one participant paramilitary activity as identified in Study 3.

Study 1 also found that over 90% of the participants were reported to have recently had some form of difficulties / problems in maintaining positive relationships with their informal carers including partners, peers and professional care staff (i.e. social workers and community nurses). Such interpersonal difficulties have again been reported to be a consequence of the participants' substance related behaviours (i.e. 'verbal and physical aggression', and frequently 'getting into rows'). With regards to the participants' relationships with his / her peers, this study found that for over half of the participants that they have been 'exploited' by their peers both 'financially' and more disturbingly 'sexually'. These findings reflect earlier results reported by a number of studies (More & Polsgrove, 1991, Gress & Boss, 1996, Clarke & Wilson, 1999, Sturmey et al., 2003).

Although a quarter of the participants continuing to maintain their structured routines (i.e. day-care centre, employment), the majority of the participants were unable to sustain these daily schedules as a consequence of the participants' substance related behaviours as identified above (see Table 2). As a result of this discontinuation from the participants' daily structured activities, the community informants have reported that many of these participants were currently left feeling 'isolated' and 'bored' with excessive amounts of free time. Such factors have also been reported by a number of researchers who postulate, that excessive amounts of free time can predispose, precipitate and / or maintain this population to misuse alcohol and / or drugs (Jahoda et al., 1988, Cocco & Harper, 2002, Stavrakaki, 2002, Emerson, 2003, Sturmey et al., 2003).

Despite the broad list of negative effects described in Table 2, Study 1 did not find any reports of sexually transmitted diseases (including HIV), that Walkup et al. (1999) found in his sample of people with learning disabilities who when under the influence of alcohol who were sexually exploited: yet this was a reoccurring event for a number of female participants in Study 1. This discrepancy may have been a methodological error, as this issue was not addressed within the questionnaire. Future studies may seek to identify if some participants who are currently misusing substances have been screened for sexually transmitted diseases and to examine whether such abuse has been reported to the appropriate authorities.

Although Study 1 failed to identify whether people with learning disabilities who misuse use a range of substances were more likely to lead to an admission into a specialist hospital as a result of the substance related disruptive / unmanageable behaviours, Study 3 reported on a few participants where this has occurred. This supports two previous studies that have suggested this tentative link (Doody et al., 2000, Taggart, 2003). One possible explanation for this disparity may be that as this study focussed upon

participants currently residing within a community setting and not a hospital, then such participants residing within in-patient facilities have not subsequently been included: this was beyond the scope of this study. Nevertheless, future studies could investigate those participants who have been hospitalised as a result of their substance-related behaviours; as this could be a more problematic population with greater complex needs resulting in both long-term admissions and possibly a 'revolving door' pattern who may also have a co-existing mental health problem as previously stated.

### **Equity of health promotion / educational material across schools**

Study 2 found that the bulk of mainstream schools (95%) and learning disability schools (80%) had a statement / policy pertaining to Alcohol and Drug Education as part of the identified Health Education Programme as stipulated by both DENI (2004) and NICCCEA (2004). Study 2 found that three quarters of the mainstream schools (75%), compared with only 40% of learning disability schools, were providing Alcohol Education Programmes in the forthcoming year. However, the majority of the mainstream schools (91.7%) in comparison with 70% of the learning disability schools were providing Drug Education Programmes during the forthcoming academic year. These results reflect, although greater importance given to Drug Education over Alcohol Education, that mainstream and learning disability schools differed in terms of provision of Alcohol Education Programmes.

Moreover, the majority of the mainstream and learning disability schools both failed to assess student learning following the delivery of these Alcohol and Drug Education Programmes. In its 'Guidance for Schools', DENI (2004) recommended that teachers in the learning disability schools take into account the young people's individual ability to interpret advice given which would suggest that mechanisms to do just that should be in place.

Study 3 further showed unanimous agreement among the mainstream addiction and the learning disability informants in that there was no strategy to prevent or minimise substance related harm to people with a learning disability. The only difference is that the mainstream addiction personnel pointed to the Health Promotion Agency as to the organisation that should develop such strategies, whereas the learning disability informants did not mention the Health Promotion Agency. One explanation for this disparity concerns the fact that there have been a number of substance related campaigns aimed at the general population generated by the Health Promotion Agency looking at issues around alcohol, illicit drugs and solvents: all of which would be to the fore in the minds of mainstream addiction staff. However, there have been no campaigns in relation to people with learning disabilities who misuse substances, never mind any other health related topic (i.e. mental health), on any issue by the Health Promotion Agency.

### **Assessment, treatment and management of substance misuse in people with learning disabilities**

Study 3 reported that the mainstream addiction informants applied the same standardised assessment schedules as employed for individuals without a learning disability, with the only difference of using jargon friendly language. Moreover, the learning disability personnel reported a dearth of specific assessment tools to screen for substance use / abuse and related problematic behaviours in this population. This latter group of informants however did stress the importance of developing a therapeutic rapport with the participant. Sturmev et al. (2003) indicated that there should be at least one question in the screening / assesment stage examining whether the person uses / misuses alcohol and / or other substances. Other questions should also focus upon whether the person has access to substances and do they have the means of obtaining such substances. If a problem was possibly detected, then a more in-depth screening instrument could be employed such as Moore's (1998) eighteen item screening interview that probed for the presence of various kinds of substance related disorders in people with learning disabilities.

With regards to treatments / interventions, the mainstream addiction informants in Study 3 indicated that they had the appropriate skills and knowledge to help a person without a learning disability with a substance issue, unfortunately the informants were in agreement that they struggled in communicating with people in this population. On the other hand, the learning disability personnel identified their competencies and confidences in effectively communicating with this population but stressed that they lacked the knowledge and skills needed in assessing, treating and managing people who misuse substances. Often the learning disability informants relied upon their own lay health beliefs regarding treatment. These latter two themes have been reported in earlier studies that have examined the assessment, treatment and management complexities often found by staff in working with people with learning disabilities (Lottman, 1993, Degenhardt, 2000, ARAC, 2002, Sturmev et al., 2003). Although this was an emotive theme for the learning disability informants, a number of informants indicated that this lack of appropriate and effective treatment / interventions required urgent attention from senior management to ensure staff became competent to work efficiently with such people. One informant indicated developing a harm minimisation approach for a young man: again such practices appear to be based upon the innovation and previous experience of single personnel rather than a systematic approach developed by senior management involving inter-agency working.

The informants in Study 3 have also highlighted a serious problem in attempting to engage with people with learning disabilities who misuse substances, in that sometimes these people can be 'unwilling' or 'unco-operative' further complicating the delivery, maintenance and success of such interventions: findings reported previously (Rivinius, 1988, ARAC, 2002, Borough of Wandsworth Society, 2003, Sturmev et al., 2003). Additionally, a theme that did not arise in the interviews with the informants although there has been some discussion within the scant literature is that of the goal of the treatment. Degenhardt (2000) indicated that for people with learning disabilities who misuse alcohol, 'abstinence' may be a more appropriate

treatment goal in comparison to 'controlled drinking' thereby overcoming the many difficulties this population may experience in engaging in a treatment regime. 'Controlled drinking' involves understanding the rules concerning 'units of alcohol', 'when' and 'where' to drink and what 'not' to drink whereas 'abstinence' only requires the individual to totally restrain from consuming alcohol.

### **Service provision, written policies and inter-agency working strategies**

Overall, Study 3 presents a picture of where service provision for people with learning disabilities who misuse a range of substances, mainly alcohol, was provided on an ad-hoc basis with both learning disability and mainstream addiction services being fragmented with no written policies / guidelines concerning joint working. Study 3 further highlights that both mainstream addiction and learning disability informants were very similar in that they believed that their services could provide better care and interventions for a population whose needs are complex. These findings reflect the results of earlier studies that examined service provision for this population (Campbell et al., 1994, ARAC, 2002, Borough of Wandsworth Society, 2003). Although a small number of informants reported innovative care packages and positive interventions; this was found to be to reflect one off successes rather than a consistent pattern of effective interventions.

Study 3 highlighted the lack of policy guidance in relation to working with people with learning disabilities who misuse a range of substances particularly concerning the assessment, treatment and management of this population, and also the lack of inter-agency joint working. Despite some informants across both the mainstream addiction and learning disability services indicating some level of liaison between both service providers, these again were found to be exceptions. Two recent studies in South England have reported similar findings regarding the lack of formal arrangements about inter-agency planning / joint working to address the needs of this population between both mainstream addiction and learning disability services (Campbell et al., 1994, ARAC, 2002, Borough of Wandsworth Society, 2003).

Nonetheless, there appears to be broad agreement among both sets of informants in Study 3 about the way forward focussing upon developing joint inter-agency working for the benefit of all involved: individuals, carers, staff and service providers. Moreover, the learning disability informants in Study 3 have also suggested, the establishment of developing links / partnerships between both learning disability and mainstream addiction services by identifying one or two personnel from either or both services to work with this specific population. Such innovative practices have been developed but these are few and little has been written about these.

### **Staff training in substance management for people with learning disabilities**

Study 3 identified that the similarities between the learning disability and mainstream addiction personnel to be uncanny in that they each group of

professionals have received no specific education / training on substance use / misuse management for people with learning disabilities. Both groups of professionals also strongly highlighted the need for some form of education / training in this specialist area of expertise. The mainstream addiction personnel requested specific training in communicating / working with people with learning disabilities and how to modify their models of assessment, treatment and management to this population. The learning disability personnel also advocated that they needed education / training in specific substance use / misuse concerning the range of assessment, treatment and management techniques and models similar to those employed by mainstream addiction personnel. These findings parallel those studies that examined the training needs of both mainstream addiction and learning disability staff who work with people with learning disabilities who misuse a range of substances (Campbell et al., 1994, ARAC, 2002, Borough of Wandsworth Society, 2003, Sturmev et al., 2003).

## Recommendations

In order to provide a more effective service for this population a number of recommendations are given in this paper for future service provision in Northern Ireland. These recommendations are based upon the findings of the current 3 studies and supplemented with the most recent empirical evidence that has examined contemporary models of service provision (IASSID, 2001, Jacobson et al., 2002a, b, Stavrakaki, 2002, Bouras, 2003, Sturmey et al., 2003). It is envisaged that the recommendations will provide the impetus for the development of a new service provision model in order to meet the holistic needs of this population. However, it is also recognised that such recommendations will require further evaluation.

- The four Health & Social Service Boards within Northern Ireland should develop new co-ordinated strategic plans and policies, which will allow for the development of the joint collaboration of learning disability and mainstream addiction services to work effectively together targeting children, adolescents and adults.
- The four Health & Social Service Boards should ring fence and provide the fiscal resources to develop and implement a range of specialist clinical services based upon a bio-psycho-social approach to assessment, treatment and management of this population.
- Managers should play an important lead role in both developing these specialist clinical services, displaying a strong commitment towards providing a holistic approach to care.
- Training for both sets of professionals need to be addressed as a matter of urgency using a two-tier approach:
  - **Tier 1:** Service providers should ensure that all front-line staff within both learning disability and mainstream addiction services have at least a one-day course in this area. Due emphasis should be placed upon raising awareness of the issues regarding substance misuse in people with learning disabilities and information about preventative strategies.
  - **Tier 2:** The development of a theoretical module based upon a bio-psycho-social approach. This module could be developed and provided by a consortium of health specialists co-ordinated by one of the universities within Northern Ireland, in order to provide staff with a model regarding substance misuse in people with learning disabilities.

- The development of a link professional between both mainstream addiction and learning disability services would be a practical and cost effective way of establishing clear channels of communications between both services and further offering expertise and advice on a range of evidence-based practices and management strategies for this population.
- The use of early screening questions and tools to detect possible substance-related behaviours, and also mental health problems, therefore allowing staff to make a more prompt referral for a comprehensive assessment.
- The delivery of an eclectic range of evidence-based interventions that addresses the bio-psycho-social person involving a range of 'talk therapies' (i.e. psychotherapy, counselling, cognitive-behavioural therapy, psycho-educational programmes, motivational interviewing).
- In delivering such interventions it is vital that all these are thoroughly evaluated to examine the effectiveness of the treatment(s) upon the persons' behaviours and quality of life, and that of their carers.
- The continuing support of current community learning disability services in providing a range of services that enables the person to live successfully within their local community using a greater variety of respite opportunities, promoting greater use of social support networks (i.e. Befriender schemes, circles of support, advocacy schemes) and recreational opportunities.
- A stronger emphasis should be placed upon the provision of more meaningful activities such as supported employment schemes, Colleges of Further Education and day-care facilities, and the maintenance of the person within these facilities.
- Greater emphasis placed upon educating the person focussing upon both intra and inter-personal training, social relationship skills building, promoting adaptive coping strategies and educating individuals regarding 'safe practice' if using alcohol and / or drugs.
- A Health Promotion Strategy should be developed that looks at the health and well-being of both young people and adults with learning disabilities promoting the appropriate emotional literacy skills concerning 'safe practice' around alcohol and / or drugs.
- Alcohol and Drug Education programmes should be delivered in all schools using guidelines from (DENI, 2004) and the Health Promotion Agency with an ability to take into account a range of developmental and experiential factors of people with learning disabilities.

- Schools should be assisted to access community agencies and specialist addiction intervention services, including counselling, in order to more appropriately meet the needs of individual students with learning disabilities who are misusing alcohol and / or drugs.
- More research needs to be conducted into this area. This study has focussed upon professionals' views of service provision. There is a clear need to conduct research with people who have a learning disability and a substance issue to get a clearer understanding of their experiences of treatment and what lessons can service providers can learn from the service user. It would be vital to conduct research with relatives and the support groups in the area of learning disability to produce a comprehensive overview of the situation.
- A regional multi-professional interest group should be developed in relation to the planning, delivery, evaluation and promotion of current evidence-based practices for this population within Northern Ireland. This would allow for further research to be commissioned, jointly undertaken and broadly disseminated throughout Northern Ireland.

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