

**An exploration of psychosocial risk factors of hazardous  
alcohol use in people with learning disabilities**

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## **Summary**

There is a dearth of research that has explored alcohol misuse in people with learning disabilities. The aims of this study were twofold: firstly, to examine the insight of this population regarding the reasons and impact of this usage, and secondly to explore the effectiveness of services that this client group has received.

This study interviewed ten individuals with learning disabilities who were deemed to be hazardously abusing alcohol and some people who were also hazardously using illicit drugs as well. One overarching theme as to the reasons for such abuse was labelled as that of 'self-medicating against life's negative experiences'. This was divided into two sub-themes: 'psychological trauma' and 'social distance from the community'. All the individuals reported that the main source of support came from learning disability services in both educative and liaison roles. Although seven of the individuals were referred to mainstream addiction services, they perceived this as negative.

In order to address the underlying problems of this population, better access to a wider range of specialist services is required. Learning disability and mainstream addiction service providers also need to be more effective in the prevention and treatment of alcohol abuse by employing techniques such as motivational interviewing.

## **Background**

### **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 report.

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 criterion 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 learning 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).

### **Introduction to alcohol abuse**

Due to the growth of 'alcohol abuse/misuse' in both the general and psychiatric populations, there is also a growing trend for people with learning disabilities to misuse alcohol (Degenhardt et al., 2000, Sturmey et al., 2003, Taggart et al., 2006). However, there has been a dearth of literature that has comprehensively examined the 'use' and 'misuse' of alcohol in people with learning disabilities across both sides of the Atlantic. In clearly describing the characteristics of those individuals with learning disabilities who misuse alcohol, 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, Taggart et al., 2006).

### **Alcohol abuse in the general population**

Investigations of ‘alcohol 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 also 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 alcohol and 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.

### **Alcohol abuse in the psychiatric population**

Similarly, there is strong empirical evidence to highlight the extent of such ‘alcohol abuse’ in people with psychiatric disorders (Duke et al., 2001, Weaver et al., 2003, Menezes & Ratto, 2004). This dual diagnosis of a psychiatric disorder and a ‘alcohol abuse’ problem have been highly correlated with higher levels of aggression and alcohol-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 an '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 alcohol misuse in the psychiatric community (Reiger et al., 1990, Dept. of Health, 1998, NHSDA, 2001).

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

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

Similarly, 'alcohol 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, Havercamp & Scandlin, 2002, Sturmey et al., 2003, Taggart et al., 2006). 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 also 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 alcohol-related disorders in this population, Sturme 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 alcohol 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, Taggart et al., 2006). 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 alcohol. 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 alcohol as a coping mechanism / stress reliever (Longo, 1997, Manthorpe, 1997, Mc Gillicuddy & Blane, 1999, Barnhill, 2000, Sturmey et al., 2003, Taggart et al., 2006).

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, Taggart et al., 2006). 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, Taggart et al., 2006). 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 alcohol 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 (alcohol-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 alcohol 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, Sturmev 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 an alcohol 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 alcohol-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 alcohol 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 peers,
- 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 services making it difficult for professionals to work closely together.

### **Justification for this study**

Given the growing recognition and value of incorporating the individuals' voice into planning and developing future services for people with learning disabilities, it is therefore important that such marginalised groups are represented (Chappell, 2000). Furthermore, it has been strongly argued that obtaining the insights of people with learning disabilities has the potential to emancipate and empower this client group (Atkinson, 2005). In obtaining this information, this data will help both learning disability and mainstream addiction service providers to identify the specific support systems needed to meet the needs of this population: hence services will be service user led.

### **Method**

Qualitative methodology is being employed more recently to further engage with people with learning disabilities; often such methods have successfully used focus groups and semi-structured interviews (Barr et al., 2003, Mc Conkey et al., 2004, Atkinson, 2005). This study used semi-structured interviews.

The individuals that took part were identified from an earlier study that explored alcohol misuse in people with learning disabilities across Northern Ireland (see Taggart et al., 2006). Within this earlier study, community informants (i.e. the person's social worker/community nurse) across both learning disability and/or mainstream addiction teams completed a questionnaire on a total of 67 adults who were deemed to be misusing a range of substances (i.e. alcohol, illicit drugs and over use of prescribed medications).

### **Recruitment of individuals**

Each of the community informants who completed a questionnaire on an individual in the earlier study were contacted, and then asked whether the person would be willing to take-part in an interview. From the 67 individuals identified to have a co-morbidity of a learning disability and alcohol related problems, only ten individuals could be recruited. The majority of the community informants reported that their clients were not '*willing*' to

be interviewed about their alcohol habits, as they did not perceive themselves as having any 'problems/issues' with their alcohol use.

It is interesting to note that these community informants had completed a questionnaire earlier about their clients alcohol-related behaviours based upon adapted criterion employed in DSM-4 for a 'alcohol abuse disorder': '*hazardous consumption of alcohol, illicit drugs and/or over use of prescribed medications which has been proven to be harmful to the persons' physical, psychological, interpersonal and social health within a 12-month period*' (APA, 1994). Aspects of the definition relating to role obligation, legal implications and hazardous tasks were deemed to be less relevant for people with learning disabilities.

The informants reported that a small number of their clients were '*emotionally unwell*' at that time to engage in an interview. For three individuals they had been recently hospitalised as a result of the latest episode of alcohol-related behaviours (i.e. head injuries, mental health deterioration/behavioural problems).

### **Procedure**

After initial contact had been made with the community informants, written information was forwarded to them explaining the purpose and nature of the project. Similarly, written information in a simplified format was also provided so the informants could provide their clients with information explaining the nature of the project, the procedure (i.e. the audio-taping of the interviews), consent and reassuring confidentiality.

When a suitable date, time and location were agreed, two members of the research team met the individual. For eight of the individuals this meeting took place within a private room in a health centre or day centre, whereas for two individuals the interviews took place within their own home. All the individuals were asked whether they would like to have their social worker or community nurse present during the interview. Eight of the individuals requested this, and one of the individuals who lived with his family asked that both his social worker and mother sit in on the interview.

After initial greetings the lead researcher, using a simplified individual information sheet and consent form, read out an introductory statement regarding the purpose and nature of the study. In terms of the recording of the interviews, eight individuals give their permission for the interviews to be audiotaped whereas the other two individuals asked that the interviews not be taped; although they did give their approval for the research assistant to take notes. All the individuals were informed about the confidentiality of the audiotapes and notes that no detailed information would be shared and that this data would be destroyed after a report had been written. All the individuals provided written consent.

### **Interview format**

All the interviews followed a loosely developed structure, firstly asking questions regarding the type and frequency of alcohol and/or drug use. Other questions focussed upon the individuals' insights regarding the cause of their hazardous patterns of alcohol use and their worries about their use upon their body and mind, how drinking affected their relationships with those they live with and their friends. Questions were also asked about the services the individuals had received to help/support them with their alcohol-related behaviours and other underlying issues. The interview schedule also included a number of probing questions that would aid the individual to expand upon their answers thereby providing further clarity and explanation. Two pilot interviews were conducted; no difficulties were identified. Each interview lasted approximately forty to fifty minutes.

### **Ethical considerations**

The Health and Personal Social Services Research Ethics Committee in Northern Ireland granted ethical approval for this project. Informed consent was sought from each individual in two ways. Firstly, each community informant spoke with the individual about the project and provided them with a written copy of the simplified 'individual information sheet'. The community informant after getting verbal consent from the individual then arranged a date and time for the research team to meet with the

individual. Secondly, the lead researcher upon meeting with the individual reiterated the purpose of the study and the nature of the interview procedure, this also included emphasising the confidentiality of what would be said.

### **Data Analysis**

After completion of the semi-structured interviews, the interviews were transcribed and the transcriptions were read and re-read to gain meaning and understanding from the data. The data was subjected to a thematic content analysis using Burnard's framework (1991). Key points made by the individuals were identified and assigned a colour code. Similar codes were gathered together into themes and sub-themes. In order to ensure the accuracy of the meanings from the ten transcripts, two members of the research team met to compare their findings. Any disagreements regarding the emerging themes and sub-themes were discussed and agreement sought.

### **Findings**

#### **Individuals**

Ten individuals took part in the semi-structured interviews; there were 7 females and 3 males. Their ages ranged from 28 years to 52 years. Nine of the individuals were reported by the community informants to have a borderline/mild learning disability and one person had a moderate learning disability.

With regards to the individuals living arrangements, five of the users lived independently within their own flat/house, two lived with a family member, two resided within a supported living scheme and one individual lived within a residential facility. Only one individual was cohabitating; this woman's partner was reported by the community informant to have a 'dual diagnosis' (a psychiatric disorder and alcohol problems). Another female individual had a boyfriend who was also misusing alcohol. The other eight individuals were currently not in relationships. Two females reported that they had one child each; for one of these women her child was being brought up in England with relatives.

The community informants reported that four had a psychiatric diagnosis of an Affective Disorder: three individuals were suspected to have a mental health problem as well. Some of the reasons cited for this suspected diagnoses included '*a history of sexual abuse by her father*', '*history of self-harm*', '*suicidal ideation*', '*cutting wrists*', '*overdosing*', '*insomnia*', '*loss of appetite*', '*apathy*' and '*obsessional behaviour*'.

Seven of the individuals reported using alcohol only. Three women reported using a combination of alcohol, illicit drugs (e.g. 'cannabis', 'ecstasy') and prescribed medications (e.g. 'paracetamol', 'codeine and 'diazepam'). The frequency of this substance misuse was reported to occur as frequently as daily at times, to weekends and for some users they misused on a weekly pattern. All the individuals reported that they had long histories of alcohol misuse for over 5 years: the community informants supported these findings. Nevertheless, within the last twelve months two people had stopped abusing alcohol because of specific life circumstances (i.e. '*a miscarriage*' and '*physical health deterioration*') and for another six people they had reduced their patterns of hazardous alcohol usage now using alcohol in moderation. However, for another two people they continued to engage in a harmful pattern of alcohol abuse.

### **Reasons for abusing alcohol**

The overall arching theme that emerged from the transcripts was labelled as that of 'self-medicating against life's negative experiences'. This theme could be divided into two emotive sub-themes, firstly 'psychological trauma' and secondly 'social distance from their community': both these sub-themes were closely related.

#### **'Psychological trauma'**

Within this theme one man spoke of experiencing multiple deaths of close family members, including losing his brother as the result of a '*sectarian killing*' (P. 9, male). Two females reiterated accounts of the loss of their boyfriends, with one woman finding her boyfriend dead in the bed beside her. Other female individuals told disturbing accounts of how they have suffered long-term physical, emotional and financial abuse at the hands of their partners who they had lived with previously. One woman reported that

she had been '*sexually abused by her father*'. Another woman told a harrowing story of how she was raped on two separate occasions when intoxicated. These disturbing accounts of the individuals' lives can be documented in the statements below.

*"Well after my brother died, he was shot dead you know, and then my sister died, and my mother died as well. It plays on your mind and I drink to kill the pain, when you have drink in you you're in a different world but it (the pain) is still there the next day". (P. 9, male)*

*"It made me forget the past and everything that happened about the rapes". (P. 4, female)*

*"When he came home after the pub drunk, he would hit me for no reason, one day he hit me in the face that he knocked my teeth out" (service user showed me her false teeth) (P. 4, female)*

*"He (partner) made me buy the drink, then we sat and drank together, if I didn't get the drink for him he would put me against the wall many times hitting me." (P. 2, female)*

Another recurring theme that developed from the interviews with a number of the individuals was a deterioration of their mental health when drinking. For some individuals they hazardously abused alcohol when '*feeling down*', whereas for others bouts of '*depression*' occurred after binge drinking. Three of the women spoke of their attempts to self-harm when drunk. One woman also spoke poignantly of how she tried to take an '*overdose*' and then attempted to '*hang-herself*', as well as '*cutting her wrists*'. These individuals reiterated how these painful memories of loss, sadness, despair, confusion and hurt were some of their reasons for this long-term use/abuse of alcohol.

*"When I try and come off the drink I seem to get depressed....I just feel lonely and all that". (P. 5, female)*

*“Sometimes it makes me feel good other times it doesn’t help me because I get very depressed ..... sometimes I don’t know what I am doing then, I slashed my wrists (service user shows me the scars on her wrists: twice)”*. (P. 6, female)

#### **‘Social distance from their community’**

Many of the informants also spoke of the lack of companionship, of having no friends whether non-disabled or disabled and the loneliness of living by oneself. Others accounted stories of being exploited by their *‘drinking peers’*, people who they drank with on the streets, in the pubs and in their own homes as well. These *‘so-called friends’* used one person’s goodwill to use their flat, their money, their food and also her personal possessions. For another man he accounted the years of being *‘bullied at school’* because of his cognitive deficits and being *‘different’*, and more recently having to live with a *‘colostomy-bag’*. Overall, a disturbing trend that could be heard throughout many of the interviews was that of *‘isolation’* and *‘loneliness’*.

A number of individuals also reported drinking either with their partner or alone in their own home. Some individuals drank in the bars alone in an attempt to meet / talk to somebody. Others reported that they drank with people who they believed were their friends (non-disabled people) in the bars, clubs and on the streets, but on hindsight these so called *‘friends’* were actually exploiting the individuals for their own gain either for money to buy drink, food and in some cases sexually. On the other hand, some individuals reported that they were aware of this particular scenario but were contented to have some company despite the potential risks that may occur.

*“I gave them (her non-disabled drinking peers) drink, food or that but I was buying my friendship, see when you have money they want you and now that I don’t have any money they don’t want you no more, they just say to me you have to give me stuff.”* (P. 6, female)

*“Ones who I thought were my friends but weren’t really, they were using me, stealing from me, stealing money and my mobile phone.”* (P. 1, female)

*“I kept going to the pub for company; even though I sit at the bar and get drunk by myself as least it gets me out of the house”. (P. 9, male)*

*“For the criac, its good fun, the company in the bar..... everyone knows me in my local bar and the staff and all know me..... You can make new friends in the pub”. (P. 3, male)*

*“After my partner had died I became lonely and all that.....there was no one living in the flat with me..... I just feel lonely and all that: I have nothing to do but watch TV”. (P. 5, female)*

*“I was bullied at school because of the way I behaved, I didn’t fit in ... I also have a colostomy bag now and don’t want to go out”. I just drank up in my bedroom just upstairs by myself..... I was bored, no work”. (P. 8, male)*

### **The effects of the alcohol use**

Information was sought from the individuals about their own insights into their knowledge of how the hazardous alcohol misuse had affected them. Four sub-themes emerged from the transcripts. These focussed upon the physiological effects, the effects upon the persons’ mind and the financial implications (including loosing their own independence and home). Lastly, the individuals also spoke about how their relationships with their families, partners and peers had deteriorated often resulting in verbal and physical confrontations when drinking.

It can be observed from the statements below that all the individuals had some insight about the effects of drinking excessively regarding their physical health. One woman reported that she had been taken into an acute medical hospital, twice within a short period of time, as result of the affects of excessive drinking. Consequently, she has controlled her drinking patterns, as she was ‘afraid’ of further complications regarding her health.

*“I worry about it because I could go into a diabetic coma; you see I am a diabetic too.”*  
(P. 6, female)

*“When I drink my blood sugars seem to drop.....I also worry about my fits (epileptic seizures)... .. as sometime I forget to take my tablets”.* (P. 5, female: suffers from epilepsy, asthma and renal problems)

*“You could be going without food for days when you’re on a binge”.* (P. 9, male: suffers from diabetes and high blood pressure)

*“I get such hangovers and forget to take my medication ..... I fell down the stairs and cut my head open twice”.* (P. 6, female: suffers from angina, hypertension, diabetes and is described as being over-weight)

*“It affects your liver, it affects your heart and it affects every part of your body: but I don’t worry about that because I haven’t got to that stage yet”.* (P. 7, female)

More worryingly, one woman reported that:

*“Because I lost my baby, miscarried when I was drinking previously... so when I found out I was pregnant again, I stopped drinking immediately.”* (P. 2, female)

The majority of the individuals also spoke of the effects of the hazardous use of alcohol upon their mental health. Some individuals reported periods where they could not remember the previous night’s activities. Another disturbing area that emerged was the number of woman who reiterated accounts of suicidal ideation and actual self-harm.

*“When I drink I get very down”.* (P. 2, female: has a diagnosis of an Affective Disorder)

*“Sometimes I don’t know what I am doing; I have slashed my wrists before when drinking heavily”.* (P. 6, female: living in a residential facility, reports to be unhappy there)

*“Well your mind would have blanked out for days; when you are drinking heavy you aren’t able to remember things”.* (P. 3, male: has a diagnosis of an Affective Disorder)

*“Yes, a bit because I was slicing my wrists and took an overdose”.* (P. 1, female: suspected of having a mental health problem, suicidal ideation, history of sexual abuse by father)

*“When drinking heavily I want to forget about everything..... I was trying to forget the past..... I ended up crying..... I get depressed when I am like this cause you can never forget”.* (P. 4, female: community informant reports this service user is sexually vulnerable)

*“I attempted suicide twice, tried using a razor blade and a rope”.* (P. 10, female: this service user showed me the scars upon her forearms, suspected to have a mental health problem)

For a number of individuals the consequences of prolonged hazardous drinking accompanied with numerous alcohol/drug related behaviours have resulted in conflicts with those they live with. For two individuals who had lived in their own accommodation, they had subsequently lost their independence as they had to return to live with their family or be placed within a supported living scheme. The majority of the individuals also reported frequent arguments they had with family members, partners and peers. For some individuals they had become physically violent towards a family member or their partner. Conversely, their family member or partner had also been become physically violent towards them after various arguments when both parties were intoxicated. For other individuals their drink related behaviours resulted in them getting into trouble with the police.

*“I stopped hitting my mum when I wasn’t drinking. When my mum drinks Smirnoff we always argue, like about three weeks ago my mum was drinking and we got into a massive argument and she hit me, so I hit her back and I was so scared when she was hitting me that I hid under the kitchen table from her.”* (P. 1, female)

*“They (parents) put me out of the house because of my behaviour (violence)”.* (P. 8, male)

*“When I was drunk, I would shout at my friends (peers living in supported living scheme)..... you could have heard me from the corridor”.* (P. 7, female)

*“I hate it; I don’t get on with the staff”.* (P. 6, female, living in a residential facility)

*“During a bout of heavy drinking I ended up throwing things in the house, breaking things..... I (physically) hit my mum.....the police were called and I was cautioned”.* (P. 8, male)

*“I was arrested for assaulting two police officers while drunk but was released on bail into the care of my sister when it was explained that I had a learning disability”.* (P. 1, female)

Furthermore, all of the individuals reported that they were conscious of the financial implications of their spending, finding there was little food in the house.

*“I was afraid I was going to lose my flat because I was going to drink all the money”.* (P. 5, female)

*“Yes, I have ran out of money for food, that’s what my mummy always shouts at me to make sure you have enough money for your food and whatever else you need”.* (P. 7, female)

### **Supports/services**

When the individuals were asked about the support systems and services that they had received to manage their drinking patterns, three main health groups were identified.

### **Learning Disability Services**

All of the individuals reported being in contact with members of the community learning disability team (i.e. community social worker and/or nurse). Many of the individuals indicated the positive educative role that these personnel attempted to undertake regarding controlling their drinking habits and about the dangers of excessive drinking. Another function that such informants provided was a liaison role with the individuals' families, day centres/employers, their GP's, acute and learning disability hospitals and also, where appropriate, mainstream addiction services.

Two individuals indicated that they were admitted into a hospital for people with learning disabilities. One woman reported that she was admitted for a six-week period. This removal from her home and life circumstances, accompanied with advice from the hospital staff resulted in her reducing her harmful consumption levels of alcohol. However, for many of the individuals they reported that these community personnel, although extremely beneficial in terms of advice and practical help, could do little to persuade them to halt their hazardous drinking regimes.

*"X (the social worker) contacts me at least twice a week by either telephone calls or visits, she helps me stick to my goals and staying off the drink." (P. 1, female)*

*"We used a wee diagram looking at the different parts of the body and how it is affected you..... this was helpful." (P. 7, female)*

*"When I came out (of the hospital) I didn't even have the taste for drink." (P. 10, female: although she still drinks this is in moderation now)*

*“No I don’t need help; the only one who can help you stop drinking is yourself.” (P. 3, male)*

### **Mainstream Addiction Services**

Seven individuals reported they were referred to mainstream addiction services by their social worker and/or nurse. Of these individuals, the majority indicated that they attended group sessions based upon the provision of educational leaflets, video’s and group sharing. The majority of the individuals reported that the group sharing was ineffective and more worrying they felt perturbed at sharing their personal life stories in settings with other patients. Many of these sessions ended abruptly with the person refusing to go back to the mainstream addiction services.

*“..... I don’t like sitting in meetings and just tell them (mainstream addiction staff) because I would be too scared.....I don’t liked being asked personal questions in front of all them (other patients).” (P. 6, female)*

*“I went to a dry out ward but I only stayed for about two weeks and lay in bed crying to go home, I was scared because people were sitting in a circle talking about their lives that scared me .....I felt forced to talk about my family history..... I didn’t want to do that.” (P. 1, female)*

*“..... going into all that again, I don’t mind talking in confidence with one person but when there are a lot of people, I won’t talk.” (P. 7, female)*

Nevertheless, for two individuals they reported a positive experience in their interactions with these services: meeting regularly with an addiction counsellor and working together on a one-to-one basis. However, for both individuals to have been seen by the addiction counsellor, the person had to be ‘*off the drink*’:

*“I went to a counselor from the addiction services... it was grand I talked to him openly and it was good you know... You have to be dry before the addiction services will work with you and not drinking”. (P. 8, male)*

### **Primary care services**

All the individuals reported speaking to their GP's at some stage about their alcohol abuse and related problems. The individuals indicated that the GP's attempted to offer little more than advice, providing some individuals with information leaflets, and encouraging them to diminish their drinking patterns totally. For other individuals they were also prescribed anti-depressants to manage their mental health:

*"My GP put me on depression tablets..... after he (boyfriend) kicked me teeth in". (P. 2, female)*

### **Utilisation of specialist support networks/groups**

More distressing, when the individuals were asked whether they were referred or did they attend any specific support networks/groups to address their negative life experiences (i.e. bereavement and other losses, mental health problems, domestic violence, sexual abuse), all of the individuals reported that they had not been offered/received the opportunity to attend any specific supports.

Sadly, one woman summarised the futility and helplessness of this situation that many people with learning disabilities have to face:

*"Nobody wanted to help me unless I was lying half dead or something...my mummy tried to get me help with my depression and the drink... nobody did anything about it." (P. 10, female)*

### **Service developments**

When the individuals were asked about how future services should be developed to meet the needs of similar people like themselves, a number of themes were identified. Overall, the individuals reported that they would prefer discussing their alcohol related problems, and also life circumstances, on a one-to-one basis compared to the intimidating group sessions that some individuals had experienced in the past (see above). The availability of

a wider network of friendships where the person can engage in various recreational/diversional pursuits was also suggested: this would widen the persons' social support network. Some people also identified the provision of more formative structures during the day focussing upon employment and education. Other individuals also suggested greater family support and involvement in the persons' treatment package.

Alongside these constructive suggestions for how service providers should develop treatment packages, another theme that also clearly emerged from the transcripts was that concerning the person's motivation to lessen or discontinue their hazardous patterns of alcohol use (i.e. '*wanting to give up yourself*' or '*taking control of yourself and of your own life*'). This can be summarised by the following quote:

*"I wouldn't tell them (other people with learning disabilities) to stop; I would tell them it doesn't solve your problems they are still there the next day"*. (Participant 9, male, lost his home after alcohol related behaviours, now a moderate drinker)

## **Discussion**

This study has shown that the hazardous use of alcohol by people with learning disabilities accompanied with a range of underlying issues such as: mental health problems, self-harm, domestic violence, bereavements, physical and/or sexual abuse, can be engaged in discussions around such emotive issues. However, in conducting this research with this marginalised population, sensitivity and meticulous care needed to be taken in order to protect the individuals involved (Atkinson, 2005).

It is vital that the individuals are fully informed about the nature of the interviews, with appropriate participation information sheets, clear guidance given about informed consent, choice of where the interview is to take place, interviews are flexible using appropriate language, and given the opportunity to have their community informant present or not. In many cases, the presence of the social worker or community nurse seemed not to restrict the content of the interview as one might have expected. On the contrary, the community informant prompted the individual to answer more fully and clarified some of the individuals' answers. Moreover, given the poignant responses that

many of the individuals highlighted in why they used/abused alcohol and the impact this has had upon their well-being, this support from the informants also offered the individuals further reassurance to feel comfortable in disclosing parts of their life stories; albeit ones already known to these staff.

This study has shown that people with learning disabilities use alcohol, and other substances, for the same reasons as their non-disabled peers (Banerjee et al., 2002) although little research has been published on this. This includes both its positive (i.e. relaxation, enhancing social relationships with others) and negative (i.e. to bereavement, abuse, depression and loneliness) reinforcing properties. Moreover, for a number of the people interviewed they drank as a means of '*fitting in*' and '*being accepted*' by their non-disabled peers and to avoid the '*loneliness*'. This study further found that many of the people interviewed reported having limited work and recreational opportunities; consequently this has also lead them to use a range of substances as another means to the avoid '*boredom*' and to integrate with others.

It therefore can be argued that this population have a number of related reasons for their long-term hazardous alcohol use patterns. This 'multiple diagnoses' thereby extends Barnhill's (2000) label of a 'triple diagnosis' (i.e. an learning disability, a mental health problem and a alcohol related disorder): further accentuating to the complex issues that need to be managed by front-line care staff, many of whom have not had specific training in this area. Hence the community learning disability teams were partially managing this heterogeneous population through limited supports. Although a number of individuals were referred to mainstream addiction services, this was reported to be ineffective. This has further put strain upon those health personnel who have to manage this population mainly alone, with little training and resources in alcohol related issues. This is in addition to the other negative life experiences presented within this population of mental health problems, self-harm, domestic violence, bereavements, physical and sexual abuse, exploitation, lack of structure in the person's day and, isolation and loneliness.

Likewise, none of the individuals reported being referred onto other specialist services such as bereavement groups, domestic violence units, cognitive-behaviour therapy or

other psycho-therapies to address these negative life experiences: a population who have been hazardously using alcohol for five-years plus. In order that the needs for this population be fully met and not superficially addressed, service providers will need to provide a more holistic multi-modal treatment package of care that involves an integrative approach between learning disability services, mainstream addiction teams and other healthcare specialists. Moreover, services need to address these issues pro-actively rather than managing the consequences of such negative life experiences in this re-actionary or crisis management scenario that is currently operated within many geographic regions across the UK. If such strategies continue, then it can be assumed that the prevalence rates of alcohol use and misuse will increase in people with learning disabilities, particularly as many more people are being supported to live independently (Taggart et al., 2006).

All of the individuals were able to report many of the negative effects of this hazardous drinking and alcohol use upon their physical and mental health, as well as the implications upon their relationships. These risks that the individuals place themselves in require to be attentively observed and managed: yet this is mainly a population who live independent lives, with some people not known to services until the problems are deep seated (Taggart et al., 2006). This is a scenario that also has to be balanced regarding each person's right to 'independence' and 'inclusion' that is being strongly advocated in current legislation across the UK (England & Wales: 'Valuing People', 2001, Scotland: 'Same as You', 2001, Northern Ireland: 'Equal Lives', 2005). But there is little emphasis being placed upon promoting safe drinking patterns, policies of abstinence/moderation, and developing an integrated approach between learning disability and addiction services for this population.

This study was not without its difficulties. Despite having the access to a sample size of 67 individuals, this study could only enrol ten individuals. The research team contacted each of the community informants who had previously completed a demographic questionnaire in an earlier study (Taggart et al., 2006). However, the majority of the informants highlighted that over fifty of the clients were not willing to engage in the

interviews, as they did not perceive themselves as having an alcohol and/or drug related problem (Rivinius, 1988); and were therefore not motivated to engage with services or make any change to their current behaviours. This is in direct comparison to the ten people who did take-part in this study, as each person was aware of the impact of such alcohol misuse upon their well-being (i.e. '*physical and mental health*', '*exploitation*', '*miscarriage*', '*becoming pregnant*', '*physical health deterioration*' or '*losing your home*'). As a consequence of this populations greater insight into their alcohol related behaviours, and a determined '*willingness*' to change their behaviours, the majority of these people have recently diminished their hazardous regimes of alcohol use either employing a total abstinence approach or now drinking moderately.

The importance of motivation for change in the prevention and treatment of alcohol and also drug abuse is widely recognized in the mainstream addiction literature, as it is believed that treatment failure is also partly due to the lack of the person's personal motivation. Miller (1983, 1988) introduced an approach called '*motivational interviewing*', which de-emphasises labelling, encourages individual responsibility and increases the person's dissonance between their goal and present behaviour. Recently, both mainstream mental health and addiction treatment services have been effectively using motivational interviewing techniques as one of the most appropriate ways to motivate clients moving them from a pre-contemplation to a contemplation mind frame; and then onto action and maintenance. Using the '*stages of change*' model as developed by Prochaska and Di Clemente (1986), the particular stage where a person is at during the process can be assessed with precision. The therapist is tasked to measure the persons' "*readiness to change*" so that he/she can be matched to the appropriate stage of treatment.

This approach may be also beneficial when working with individuals who have a learning disability and are using alcohol in a harmful way, and with mental health problems. It is important that interventions are adapted to meet the needs of this population who may have difficulties with cognitive deficits, concentration, memory and abstract reasoning. Key to all interventions is a positive therapeutic relationship as therapist behaviour can directly affect all clients' motivation for change and the availability of a trained

counsellor/therapist who can work on a one-to-one basis. Although no studies have examined the use of or the efficacy of motivational interviewing for people with learning disabilities, a small number of innovative practitioners are employing these techniques with promising success (Mendel & Hipkins, 2002).

## **Conclusion**

This study has shown that people with learning disabilities abuse alcohol similar to their non-disabled peers, to 'self-medicate against life's negative experiences'. These life stories accompanied with harrowing accounts of bereavement, mental health problems, self-harm, domestic violence, physical and sexual abuse, loneliness and isolation further emphasises the enduring cost of this abuse upon the persons' well-being. Current service provision has failed to address the reasons for this population's hazardous alcohol regimes. Focus needs to be placed upon this population having greater access to a wider range of specialist services that can address these negative life experiences. Similarly, both learning disability and mainstream addiction staff have to utilise more recent advancements (i.e. motivational interviewing) in order to fully engage and work with this resilient population.

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