Alcohol and illicit drug misuse in people with learning disabilities: implications for research and service development

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Abstract
This paper offers readers a review of the literature on alcohol and illicit drug misuse in people with learning disabilities, focusing on six key areas. First, clarity is provided on the definition of 'misuse'. Second, prevalence rates are examined along with the methodological difficulties involved in such studies, the authors arguing that prevalence rates are higher than current estimates. Third, the authors explore the relationship between the intra- and inter-personal risk factors. Fourth, the nature of the substance misuse is explored, with a focus on offending behaviour. Fifth, a range of treatment modalities are described with a series of recommendations for more robust evidence-based interventions. Last, the authors explore the gaps in policy that lead to a dearth in service provision as well the barriers which people with learning disabilities face on entering treatment services. The paper cites four innovative projects that address this population's needs in England, and illustrates how Northern Ireland has positioned the needs of this hidden population within the Department of Health, Social Services and Public Safety (Northern Ireland).

Key words
learning disabilities; alcohol; drug; substance; misuse

Introduction
In the last decade, there has been growing interest in alcohol and illicit drug misuse in people with learning disabilities on both sides of the Atlantic (Christian & Poling, 1997; Degenhardt, 2000; Stavrakaki, 2002; Sturmey *et al*, 2003; McGillicuddy, 2006). More recently, in the United Kingdom (UK) a number of empirical studies have offered greater insight into the needs of such individuals (Emerson & Turnball, 2005; Taggart *et al*, 2006, 2007; Baker, 2007; McLaughlin *et al*, 2007). Similarly, several innovative service initiatives have been developed in England that are currently addressing the complex health and social needs of this hidden population; these are exemplary services that could be used as benchmarks for future service development (Borough of Wandsworth Study, 2003; Huxley *et al*, 2007).

Given such growing awareness, it is surprising that people with learning disabilities who misuse alcohol and illicit drugs continue to receive minimal recognition from the UK Government's mainstream alcohol and drug policies (DoH, 1998; Prime Minister's Strategy Office, 2004; NICE, 2007). Likewise, UK governments' learning disability policies fail to highlight the range of issues associated with people with learning disabilities who misuse substances (DoH, 2001; Scottish Executive, 2001; DHPSSNI, 2005). This deficit means that policy planners, commissioners and service providers in many parts of the UK and beyond have failed to identify and meet the needs of this population, particularly since many people with learning disabilities fall between mainstream addiction and learning disability services because integrated service provision has not yet been developed (Huxley *et al*, 2005, 2007; Huxley & Copello, 2007; McLaughlin *et al*, 2007).

This literature review offers a synopsis of the topics about people with learning disabilities who misuse alcohol and illicit drugs, with regard to definition, prevalence, risk factors, nature, assessment and treatment, and service provision. The

review highlights some of the current issues identified in the literature and a clinical perspective on offering solutions for future service direction.

Literature search

The information for this review was obtained from a search of electronic databases. Because a number of the terms used to refer to the same phenomenon on both sides of the Atlantic vary, we used several combinations of the key words: 'intellectual disability', 'learning disability' and 'mental retardation', accompanied by 'substance, alcohol and drug' and 'misuse, abuse and problems'. This approach was used to narrow the search, and it helped to identify relevant sources of information. Manual searching of relevant journals and sourcing of secondary references extended the search. All publications between 1995 and 2007 which appeared relevant to the topic were identified.

Definition

According to both the DSM-IV (APA, 1994) and the ICD-10 (WHO, 1992) there are a number of substances that can be misused, including alcohol, illicit drugs (cannabis, opiates, stimulants, ecstasy, inhalants), prescribed medications (such as amphetamines, benzodiazepines, sedatives, pain killers), nicotine and caffeine. This literature review will focus on alcohol and illicit drug misuse. Other reviews have focused on nicotine and caffeine use in people with learning disabilities (Gress & Boss, 1996; Blum *et al*, 2001; Sturmey *et al*, 2003; Emerson & Turnball, 2005). ***Box 1***, below, provides a summary of diagnostic guidelines for dependence syndrome.

Box 1: ICD-10 diagnostic guidelines for dependence syndrome

- A definite diagnosis of dependence should usually be made only if three or more of the following have been present together at some time during the previous year.
  - (a) A strong desire or sense of compulsion to take the substance
  - (b) Difficulties in controlling substance-taking behaviour in terms of its onset, termination or levels of use
  - (c) A physiological withdrawal state (see F1x.3 and F1x.4) when substance use has ceased or been reduced, as evidenced by the characteristic withdrawal syndrome for the substance, or use of the same (or a closely related) substance with the intention of relieving or avoiding withdrawal symptoms
  - (d) Evidence of tolerance, such that increased doses of the psychoactive substances are required in order to achieve effects originally produced by lower doses (clear examples of this are found in alcohol- and opiate-dependent individuals who may take daily doses sufficient to incapacitate or kill non-tolerant users)
  - (e) Progressive neglect of alternative pleasures or interests because of psychoactive substance use, increased amount of time necessary to obtain or take the substance or to recover from its effects
  - (f) Persisting with substance use despite clear evidence of overtly harmful consequences, such as harm to the liver through excessive drinking, depressive mood states consequent on periods of heavy substance use, or drug-related impairment of cognitive functioning; efforts should be made to determine that the user was actually, or could be expected to be, aware of the nature and extent of the harm
- Narrowing of the personal repertoire of patterns of psychoactive substance use has also been described as a characteristic feature (such as a tendency to drink alcoholic drinks in the same way on weekdays and weekends, regardless of social constraints that determine appropriate drinking behaviour).
- It is an essential characteristic of the dependence syndrome that either psychoactive substance taking or a desire to take a particular substance should be present; the subjective awareness of compulsion to use drugs is most commonly seen during attempts to stop or control substance use. This diagnostic requirement would exclude, for instance, surgical patients given opioid drugs for relief of pain, who may show signs of an opioid withdrawal state when drugs are not given but who have no desire to continue taking drugs.
- The dependence syndrome may be present for a specific substance (eg tobacco or diazepam), for a class of substances (eg opioid drugs) or for a wider range of different substances (as for those individuals who feel a sense of compulsion regularly to use whatever drugs are available and who show distress, agitation, and/or physical signs of a withdrawal state upon abstinence).

Includes: chronic alcoholism, dipsomania, drug addiction.
Adapted from the ICD-10 Clinical Diagnosis Manual (www.who.int/substanceabuse/terminology/ICD10ClinicalDiagnosis.pdf, p5)

This review defines 'dependence syndrome' as:

> *A cluster of physiological, behavioural, and cognitive phenomena in which the use of a substance or a class of substances takes on a much higher priority for a given individual than other behaviours that once had greater value. A central descriptive characteristic of the dependence syndrome is the desire (often strong, sometimes overpowering) to take psychoactive drugs (which may or may not have been medically prescribed), alcohol or tobacco. There may be evidence that return to substance use after a period of abstinence leads to a more rapid reappearance of other features of the syndrome than occurs with nondependent individuals*
> (www.who.int/substanceabuse/terminology/ICD10Clinical Diagnosis.pdf, p.4).

Box 1 provides further information on diagnostic guidelines for obtaining a diagnosis of dependence syndrome. However, difficulties may arise in attempting to diagnose a person with learning disabilities with a dependence syndrome, as their behaviours, while not evidently be indicative of such a condition, may constitute hazardous misuse of alcohol and drugs. Caution needs to be taken in using standardised classification systems; if the person with learning disabilities does not meet the specific inclusion criteria, then they may not be identified as fitting the category. Aspects of the definition relating to role obligation, legal implications and hazardous tasks are therefore deemed to be less relevant for people with learning disabilities, so it is important to adapt the definition accordingly in any screening and future research (Taggart *et al*, 2006).

Prevalence

Debate exists regarding the prevalence rates of alcohol 'use' and 'misuse' in people with learning disabilities, and prevalence figures also differ with regard to illicit drug misuse in this population. Such discrepancies in prevalence rates arise from methodological problems often associated with the lack of clear operational definitions of 'use' and 'misuse', as well as the label of 'learning disabilities', the methodology employed (staff reports, self-reports, whether assurances of anonymity given or not), the level of learning disability, location (community/hospital), time-frame and whether people are known to learning disability services or not.

Despite these methodological difficulties, a number of studies have reported lower prevalence rates of alcohol use and misuse in adolescents with learning disabilities than in their non-disabled peers (Gress & Boss, 1996; Pack *et al*, 1998; Blum *et al*, 2001; Emerson & Turnball, 2005; Johnson *et al*, 2005). However, McGillicuddy (2006), in a review of the substance use research literature, highlights that the difference between the adolescent cohorts 'is not very large', particularly compared with adolescents with mild learning disabilities. Several studies have also reported alcohol use and misuse in adults with learning disabilities to be lower than in the non-learning disability population (Christian & Poling, 1997; Annand & Gug, 1998; McGillicuddy & Blane, 1999; Burgard *et al*, 2000; Taggart *et al*, 2006).

Equally, figures for illicit drug misuse also indicate lower prevalence rates for adolescents and adults with learning disabilities (Gress & Boss, 1996; Christian & Poling, 1997; Pack *et al*, 1998). However, Westermeyer *et al* (1998), in a study of 642 adults attending a drug treatment programme in the USA, reported that 6.2% of this sample had learning disabilities, indicating a high prevalence rate.

Overall prevalence studies report a lower rate of 'use' and 'misuse' among people with learning disabilities than among their non-disabled peers, but these figures may be an under-estimate. Whitaker (2004) suggests that about 1–2% of people in the general population will have learning disabilities, meaning an IQ of approximately 70 or below, and also low social skill deficits (APA, 1994). The actual number of people known to 'learning disability services' is lower than these prevalence estimates. There appears to be some degree of consistency in the estimates, reporting between 0.23% and 0.29% of this population in contact with learning disability services (Whitaker & Porter, 2002). Most of this unidentifiable learning disability population are probably those with borderline to mild learning disabilities living independently in the community, a sub-group of people who may be at greater risk of developing a substance-related disorder (see below). McGillicuddy (2006) argues that the potential for people with learning disabilities who use alcohol to misuse both alcohol and illicit drugs is greater than for their non-learning disabled counterparts, as a result of their 'intra' and 'interpersonal' characteristics.

Risk factors

A clearer picture is emerging of the intra- and inter-personal characteristics that put individuals with learning disabilities most at risk from misusing alcohol and drugs (***Box 2***, overleaf) (Gress & Boss, 1996; Walkup *et al*, 1996; Christian & Poling, 1997; McGillicuddy & Blane, 1999; Robertson *et al*, 2000; Mayer, 2001; McGillivray & Moore, 2001; Cocco & Harper, 2002; Stavrakaki, 2002; Sturmey *et al*, 2003; McGillicuddy, 2006; Taggart *et al*, 2006, 2007; Baker, 2007).

As more men and women with learning disabilities are supported to live in a variety of accommodations in the community and given more freedom, they may be exposed to greater social stressors. This exposure may lead to greater use of alcohol and illicit drugs as a coping mechanism/stress reliever (McGillicuddy & Blane, 1999; Barnhill, 2000; Sturmey *et al*, 2003; Baker, 2007; Taggart *et al*, 2007). As more people with learning disabilities live in facilities, including family homes, with minimal supervision than ever before, they will have greater access to readily available cash to obtain such substances. The person with learning disabilities may then see alcohol and illicit drugs as a method of 'fitting in' and 'socialising' with non-disabled peers, adopting an identity that is consistent with non-learning disabled populations. This

Box 2: Identified risk factors for substance misuse in people with learning disabilities

Intra-personal variables

- Having a borderline to mild learning disabilities
- Being young and male
- Having a specific genetic condition
- Adolescents with conduct disorders, ADHD and anti-social personality disorders
- Compromised tolerance to drugs
- Coming from an ethnic minority group
- Co-existence of a mental health problem
- Low self-esteem
- Disempowerment
- Inadequate self-control/regulatory behaviour
- Impulsivity
- Cognitive limitations (illiteracy, short attention span, memory deficits, poor problem-solving skills, tendencies to distort abstract cognitive concepts, over-compliant dispositions)
- Frustration

Inter-personal variables

- Living in the community with low levels of supervision
- Poverty
- Parental alcohol-related neuropsychiatric disorders
- Presence of negative role models with punitive child management practices
- Family dysfunction
- Negative life events (eg neglect, abuse, bereavement)
- Unemployment
- Limited educational and recreational opportunities
- Excessive amounts of free time
- Deviant peer group pressure
- Limited relationships/friends
- Lack of meaning in life
- Lack of routine
- Loneliness
- Desire for social acceptance/method for 'fitting in'

process of 'fitting in' may compensate for the lack of social skills, supports, friendships and relationships, isolation and frustrations frequently, and for many years, described for people with learning disabilities. These are individuals who have also been found to have low self-esteem, inadequate self-control, impulsivity, and poor social and communication skills, suggesting a population who may be susceptible to developing substance-related problems because they lack the adaptive skills to protect against misusing substances (Gress & Boss, 1996; Clarke & Wilson, 1999; Stavrakaki, 2002; Sturmey *et al*, 2003; Baker, 2007; Taggart *et al*, 2007).

Until very recently the voice of people with learning disabilities who abused a range of substances was not heard. Baker (2007) interviewed ten people with learning disabilities in England about their hazardous patterns of alcohol misuse. Likewise, Taggart and colleagues (2007) in Northern Ireland conducted one-to-one interviews with ten people with learning disabilities who met the ICD-10 criteria for dependence syndrome. Both studies reported that people with learning disabilities misused a combination of alcohol, illicit drugs and prescribed medications to 'self-medicate against life's negative experiences' as a result of 'psychological trauma' (such as bereavement, rape, physical and psychological abuse, deterioration of their mental health) and 'social distance from the community' (for example being bullied or exploited, lack of companionship, loneliness, isolation). Many of the participants were also aware of the negative impact that such substance misuse had on their physical and mental health and their relationships with families and formal carers, as well as the financial implications, yet continued to abuse such substances.

Gress & Boss (1996) in the USA identified several characteristics that might help explain why young people with learning disabilities turn to misuse alcohol and illicit drugs. They included the inability:

- to establish self-identity
- to develop social attachment
- to project affective social images within their own peer groups
- to experience immediate gratification of beliefs or desires.

Gress and Boss have therefore suggested strongly that these characteristics result in the individual's experiencing difficulty in resisting outside temptation, and exhibiting poor insight which then increases the foundations of such substance misuse.

Nature of the substance misuse

A number of studies have explored the nature of alcohol and illicit drug misuse in people with learning disabilities; no studies have compared this data with that for the non-disabled population abusing similar substances. These studies have been mainly 'single case scenarios' (Clarke & Wilson, 1999), the majority of studies employing survey methods that use staff reports (Walkup *et al*, 1999; Doody *et al*, 2000; Mayer, 2001; McGillivray & Moore, 2001; ARAC, 2002; Emerson & Turnball, 2005; Taggart *et al*, 2006). ***Box 3***, opposite, clearly demonstrates the distressing and multiple pattern of impact that alcohol and drug misuse has on people with learning disabilities (aggression, mental health problems such as depression, bipolar mood disorders, anxiety disorders and schizophrenia, exploitation and greater health risks). ***Box 4***, opposite, provides a case study.

Box 3: Impact of substance misuse in people with learning disabilities described by staff

- Greater risk of verbal and physical aggression
- Changes in mood
- More likely to have a co-morbid mental health problem
- Be placed in a position to be exploited by others (eg physically, psychologically, sexually) and to exploit others
- Cardiovascular, respiratory tract and gastrointestinal problems
- Strong link with offending behaviour
- Increased epileptic activity
- Higher levels of risk-taking behaviour (including suicide attempts)
- Greater likelihood of attending A&E departments and being admitted to hospital
- Greater risk of contracting various physical diseases (including sexual diseases and HIV)

Box 4: Case study of client attending a community forensic learning disability service

Sarah (not her real name) was referred to a community forensic learning disability service (a psychiatrist, psychologist, social worker and a clinical nurse specialist) and to a clinical psychologist within the addiction team, after her arrest for a public disorder offence. Sarah was well-known to the local vulnerable person's police officer, and had come into regular contact with the police for persistent and prolific offending.

At MDT assessment, we were able to ascertain that Sarah was a 23-year-old woman of white UK heritage who was resident in supported accommodation. She had been part of the community adult learning disability services. She was described as having 'borderline learning disabilities, substance misuse problems and difficulties with her identity'. A referral was made to the forensic learning disability services, as Sarah had recently been charged with threatening behaviour due to being intoxicated from excessive alcohol consumption. Before this she had been involved in the criminal justice system for abusive and threatening behaviour while intoxicated.

Sarah had a long history of problematic substance misuse. At the time of the assessment she reported drinking daily, usually around three or four cans of strong cider, using crack cocaine several times a week and daily cannabis use. She did not consider herself to have a dependency that would warrant formal pharmacological intervention from a specialist drug treatment team. Additions to her choice of substances were cannabis, alcohol and crack cocaine, and at present the evidence for prescribing replacement medication for these substances is not clear. Sarah reported that she used as part of networking, and that she did not purchase the substances but would use with her partner. There was feeling among the team that Sarah was vulnerable in the company of others, and it was not clear whether Sarah chose to use substances or did so as a result of pressure from her peer group.

During her engagement with the treatment service Sarah was offered psycho-social interventions to help her make reductions in her substance misuse and as a way to reduce the likelihood of future offending behaviour. Sarah had expressed a desire to make changes in her use of substances, but did not feel confident about being able to make these changes. Sarah was engaged in an intervention that sought to enhance her intrinsic motivation to change her substance misuse behaviour, mainly in the form of educational material about the effects of substances and the personal costs to Sarah if she continued to use. A motivational enhancement intervention helped Sarah consider these issues, and she was able to make some changes in an out-patient treatment setting. Unfortunately, Sarah disengaged and lapsed back into problematic use. She was arrested after an incident in the community, and was admitted to hospital for a period of assessment. Sarah's social network and environment made it difficult for her to make the required changes in her drug and alcohol use. The outcomes of the intervention in this case were limited, and Sarah was, inappropriately, placed in a hospital.

A number of studies have proposed a link between substance abuse and offending behaviour in people with learning disabilities (Hayes, 1996; Cockram *et al*, 1998), a link also found in the non-disabled prisoner population. Holland *et al* (2002), in a review of the literature on the prevalence of criminal offending in people with learning disabilities, reported that the main feature of such individuals:

> *is one of social disadvantage and mental ill health (particularly substance abuse), coupled with intellectual impairment* (p6).

Klimecki *et al* (1994) found that of 75 offenders with learning disabilities in Australia 45.1% of first offenders, 71.4% of second offenders, 66.6% of third offenders and 87.5% of fourth offenders had histories of alcohol misuse, and legal and illicit drug misuse on the day of the arrest.

Huxley *et al* (2007) clearly summarises the consequences of alcohol and illicit drug misuse for people with learning disabilities, which are more significant than for the non-disabled population because they will experience:

- increased risk of developing physical and psychiatric difficulties
- exacerbation of existing impairments (such as cognitive deficits, mental health problems, behavioural problems)
- more difficulties regarding additional marginalisation and exclusion from learning disability services
- more difficulty in accessing mainstream services
- greater risk of experiencing unemployment, isolation, poverty and crime.

Assessment and treatment

Given the evidence above that people with learning disabilities who misuse substances can also experience related difficulties (such as aggression, mental health problems, health-related issues, offending behaviour), assessment and treatment of such individuals are often fraught with difficulty (Degenhardt, 2000; ARAC, 2000; Sturmey *et al*, 2003; McLaughlin *et al*, 2007; Huxley & Copello, 2007).

People with learning disabilities who misuse substances can be 'unwilling' or 'unco-operative' about engaging fully in a range of assessment procedures and therapeutic interventions, which further complicates delivery, maintenance and success of such treatment packages (McLaughlin *et al*, 2007). Huxley and Copello (2007) highlighted that this 'unco-operativeness' should not be interpreted as poor motivation, since sometimes it is due to their lack of understanding of their care plan or treatment. A number of explanations for these difficulties in engagement centre on this population's learning disabilities and associated cognitive deficits (slower learning, communication difficulties, illiteracy, short attention span, memory deficits, low self-esteem, inadequate self-control/regulatory behaviour) (McGillicuddy & Blane, 1999; Degenhardt, 2000; McGillivray & Moore, 2001; Sturmey *et al*, 2003; McGillicuddy, 2006). These individuals have also been found to know less about the effects of taking excessive amounts of alcohol and drugs (McGillivray & Moore, 2001). Many researchers and clinicians argue that any successful treatment package must be adapted to reflect the learning style of people with learning disabilities.

Compared with the non-disabled population, Degenhardt (2000) has indicated that for people with learning disabilities who misuse alcohol, 'abstinence' might be a more appropriate treatment goal than 'controlled drinking'. 'Controlled drinking' involves understanding the rules about 'units of alcohol', 'when' and 'where' to drink and what 'not' to drink, a and gives the individual responsibility for managing their own consumption, whereas 'abstinence' requires the individual to abstain totally from alcohol. Nevertheless, a number of interventions have been offered to people with learning disabilities who have misused alcohol and illicit drugs, and overall the results appear promising. Interventions range from medication, support groups, education to behavioural programmes and staff education (***Box 5***, opposite) (McGillicuddy & Blane, 1999; Barnhill, 2000; Mayer, 2001; Mendel & Hipkins, 2002; Stavrakaki, 2002; Sturmey *et al*, 2003; McGillicuddy, 2006).

Although these studies have been informative, they provide little more than descriptive accounts of either mainstream or modified interventions. Many of these studies have been found to be methodologically poor (Burgard *et al*, 2000; Sturmey *et al*, 2003; McGillicuddy, 2006), and they tend to reflect case studies rather than pragmatic trails in 'real life' clinical settings. Limitations include small sample sizes, lack of reliable and valid measurement tools, studies undertaken in hospitals where the person's access to alcohol is limited, lack of control groups, lack of generalisability and no long-term follow-up. Few studies have reported on the efficiency of the treatment strategies offered.

Studies based on more robust methods are needed, conducted using both objective and subjective forms of measurement alongside appropriate follow-up. Where possible, the sample should be of an appropriate size, using a matched control group so generalisations can be made. Such studies could focus on developing proactive preventative programmes aimed at young people with learning disabilities, and promote safe practice in drinking and halting illicit drug misuse. These health education programmes could be commenced in childhood and the individuals could be followed through their early adult life to promote those factors that protect against harmful patterns of alcohol and drug misuse, as well as those that diminish the factors which place people from abusing such substances (***Box 2***). McGillicuddy (2006) stated that:

> *without the necessary research, knowledge about effective treatment components will remain unknown* (p44).

Other programmes could be developed and targeted at those who fall into the 'at risk group', employing well-designed packages of interventions that incorporate a bio-psycho-social perspective. More important, development of this holistic package of intervention would have to address the intra- and

Box 5: Summary of bio-psycho-social interventions for people with learning disabilities who misuse alcohol and illicit drugs

- Detoxification ensuring client safety (from eg seizure risk and risk of suicide), deterioration of mental health and management of withdrawal symptoms
- Use of psychopharmacology treatments (antabuse, naltrexone, methadone and serotonin specific re-uptake inhibitors (SSRIs)
- Individual education (including anger management, relaxation training, challenging negative statements)
- Modifications of AA & Twelve Step Programme
- Use of group therapy (including art therapy) to promote feelings of acceptance, belonging and peer support
- Use of social skills training (eg develop coping and refusal skills, self-monitoring skills, promote interpersonal communication, facilitate expression of emotions, respond appropriately to criticism, engage in realistic role plays)
- Behavioural and cognitive approaches (for example assertiveness skills, distinguishing between positive and negative roles models in substance abuse situations)
- Motivational interviewing
- Relapse prevention programmes focusing on self-regulation of thinking and feeling, accepting past relapses, identifying the causes of relapse and learning to prevent and interrupt relapses
- Mainstream addiction and learning disability staff education on preventative programmes, identification of intra-personal and interpersonal risk factors, promoting early recognising/screening and prompt referral
- Promotion of social support including family, friends, neighbours, social support groups, education, recreational opportunities and employment
- Environmental/milieu therapies such as diversional activities, learning new hobbies and developing new friendships

inter-personal risk factors identified in ***Box 2*** that predispose, precipitate and maintain the individual's misuse of alcohol and/or illicit drugs. Examples might include:

- addressing the person's intrinsic motivation fully to want to change their substance-misusing behaviour and to engage in self-help, possibly by using the techniques of motivational interviewing rather than enforcing motivation from external sources such as court directions
- offering both group and one-to-one sessions with more time flexibility, based on repetition and greater use of role-play scenarios
- individual and group education about the harmful effects of the substance misuse on people's bodies, minds, relationships and lifestyle, using accessible information, fit for purpose
- addressing unresolved problems (for example depression, anxiety, bereavement, sexual abuse, unemployment, relationship difficulties, isolation) and providing more robust coping and problem-solving skills for these personal problems
- greater use of cognitive behaviour, focus on brief solutions and family systematic therapies such as social behavioural network therapy (Copello *et al*, 2002); for an overview of psychological therapies for substance misuse see Huxley & Copello (2007)
- targeting specific offending behaviours
- identifying trigger factors of relapse
- emphasis on primary and secondary health promotion from an early age and within schools, and more positive social interactions in the local community.

Service provision

Questions are being raised about the service needs of people with learning disabilities who misuse substances, and service models are being examined. In the past, addiction services excluded people with learning disabilities, highlighting lack of knowledge and communication skills in this population (Campbell *et al*, 1994; Degenhardt, 2000; Huxley *et al*, 2005, 2007; Huxley & Copello, 2007; McLaughlin *et al*, 2007). On the other hand, learning disabilities service providers reported that they have struggled to manage this doubly challenged population, claiming lack of knowledge about substance misuse assessment and treatment strategies (ARAC, 2002; Borough of Wandsworth Study, 2003; McLaughlin *et al*, 2007).

Box 6: Barriers that deter people with learning disabilities from engaging with mainstream addiction services

- Existing mainstream treatment models may have to be substantially adapted in view of their emphasis on insight/self-report
- People with learning disabilities may lack the necessary cognitive and communicative skills to cope with and benefit from the group-based therapies used for their non-disabled peers
- People with learning disabilities when chemically dependent are more difficult to treat effectively with short-term interventions
- The emphasis on effecting positive life changes may not reflect the real choices available to most people with learning disabilities, as they may be dependent on both informal and formal carers
- Dual-diagnosis workers (staff trained to work with people with psychiatric problems and a substance misuse disorder) 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
- There is little integration between services for people with a learning disability and mainstream addiction services, making it difficult for professionals to work closely together.

Other barriers have been put forward to argue that people with learning disabilities who misuse alcohol and illicit drugs cannot engage successfully with mainstream addiction services (***Box 6***, above) (Campbell *et al*, 1994; Seminar Report, 1998; Clarke & Wilson, 1999; ARAC, 2002; Borough of Wandsworth Study, 2003; Sturmey *et al*, 2003). Consequently, many people with learning disabilities continue to 'fall through the cracks' between services as they lack the appropriate personnel and resources to manage this population (Huxley *et al*, 2007; McLaughlin *et al*, 2007). In a number of studies that examined joint working in the UK, learning disability service providers had no identified strategies or policies in place to forge inter-agency working and joint care planning with mainstream addiction teams for this population (ARAC, 2002; Borough of Wandsworth Study, 2003; McLaughlin *et al*, 2007). Referral to mainstream addiction teams by community learning disability teams, if offered, was *ad hoc*, most learning disability service providers being given advice only.

In the absence of any learning disabilities and alcohol/drug policies that promote collaborative community-based integrated programmes, four innovative projects or models have been developed to address the needs of this population.

In Birmingham & Solihull Mental Health NHS Trust, England, a clinical psychologist (second author) in the mainstream addiction team has attempted to reduce the barriers to addiction services by offering services to people with learning disabilities who misuse alcohol and/or illicit drugs and who might not be in contact with treatment services. No formal evaluation has been undertaken, although results are promising.

In Derbyshire Mental Health Trust, England, a senior nurse for learning disabilities (third author) works jointly with the clinical nurse specialist for the mainstream addiction service, co-working assessment and treatment of adults with learning disabilities who present with an alcohol and/or drug problem. Currently no data is available on this project, although reports are extremely promising. A database is being developed.

In the Joan Bicknell Centre, London, a social worker works within the community learning disability team takes on any referrals from members of the MDT about individuals with learning disabilities who have alcohol and/or drug problems. This is a successful service, with favourable outcomes (Borough of Wandsworth Study, 2003).

In the Central Lancashire NHS Care Trust, England, a community learning disability nurse works part-time within the mainstream addiction team. As part of best practice, the Green Light Tool Kit (Foundation for People with Learning Disabilities, 2005) highlighted this model.

Although no service developments have been initiated yet in Northern Ireland, the results of a recent study conducted into substance misuse in people with learning disabilities (Taggart, 2004)[1] have been subsequently embedded in the Department of Health, Social Services and Public Safety (Northern Ireland): Alcohol and Substance Misuse Strategy (2005). Future government mainstream alcohol and drugs policies, as well as learning disability policies, should acknowledge the growing literature on this population and make a list of requirements as identified in ***Box 7***, opposite.

Conclusion

This paper has offered a detailed review of the literature on the issues concerning people with learning disabilities who misuse alcohol and/or illicit drugs. We have examined six key issues and identified a number of methodological problems with such papers; recommendations for clinical practice and also future research are

[1] www.rmhldni.gov.uk/an_exploration_of_substance_misuse_in_people_with_learning_disabilities_living_in_northern_ireland.pdf.

Box 7: Recommendations of the Department of Health, Social Services and Public Safety (Northern Ireland): Alcohol and Substance Misuse Strategy (2005)

(1) People with learning disabilities and substance-related problems should be able to access mainstream services. However, given the co-existing problems that may also occur for this population, people with learning disabilities and substance-related problems may need to be supported by learning disability personnel to use the services offered by the mainstream addiction teams.

(2) There should be collaboration between both learning disability and mainstream addiction services, including development of a link expert based within learning disability services and also working in mainstream addiction services.

(3) Screening tools should be explored to assist staff to detect possible substance-related behaviours and mental health problems.

(4) An eclectic range of bio-psycho-social interventions should be available. They should be evidence-based and embedded within the care plan, which should be person-centred.

(5) A health promotion schools strategy should be developed to target the health and well-being of people with learning disabilities.

(6) A regional multi-professional interest group should be developed for planning, delivery, evaluation and promotion of current evidence-based practices, and to promote further research for this population in N. Ireland.

(7) Particular efforts should be made to address people with learning disability living independently, with detection, support and education of those most at risk.

Source: www.rmhldni.gov.uk/alcohol_substance_misuse_consultation_report.pdf (p56)

provided. Despite the lack of empirical evidence and of policy, we have clearly argued that specialist services for people with alcohol and drug-related problems are needed and can be developed and delivered successfully, although verification of these projects' success must be evidenced. The needs of this population should be embedded within the national learning disability and alcohol/drug agendas, so that policy planners, commissioners and service providers can plan and deliver effective services. Joint working is a prerequisite of any effective service.

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