

## **Alcohol Use Disorders in People With Intellectual Disability**

Dr Fionnuala Williams, MBChB(Hons) MRCPsych, ST5 in Psychiatry, Lynebank Hospital, Halbeath Road, Dunfermline, Fife, KY11 4UW

Dr Christos Kouimtsidis, MBBS, FRCPsych, MSc, PhD, Consultant Psychiatrist in Addictions Surrey and Borders Partnership NHS Foundation Trust and Honorary Clinical Senior Lecturer Imperial College London.

Professor Baldacchino, MD, MPhil, PhD, FRCPsych, FISAM, Professor of Medicine, Psychiatry and Addictions and Clinical Lead and Consultant in Addiction Psychiatry, Cameron Hospital, Leven, Fife, KY8 5RR

### Abstract

Whilst the prevalence of alcohol misuse in People with Intellectual Disability (PWID) appears to be low, it is a significant issue as this group can be more vulnerable to the adverse effects of alcohol. It is likely that many PWID who misuse alcohol are not being identified even if they are in touch with intellectual disability (ID) services. Screening tools such as AUDIT (Alcohol Use Disorders Identification Test) have been adapted and have been found to be acceptable for use in this population. Such tools should be used more frequently to ensure identification of this population. There is some discussion in the literature that alcohol limits should be lower for this population but as yet there has not been a suggestion of what these limits should be nor any research to determine if indeed such lower limits are justified.

Existing evidence suggests that PWID find it difficult to access NHS addiction services. There is limited research into the accessibility of non-NHS addiction services in the UK which provide much of the support for people who misuse alcohol. There is also little high quality evidence available regarding treatment for alcohol misuse in this population. Given the importance of communication and rapport building in this population, it is the authors' views that ID services should take a primary role in supporting PWID who have alcohol use disorders although extra training is likely necessary in many teams, and assistance should be sought from addiction services as appropriate and always in the case of dependency. Addiction services also need improved awareness of the needs of PWID and how to seek support in managing this patient group. Medications used for treating alcohol use disorders in the general population can also be applicable in this population although disulfiram needs to be risk assessed on an individual basis to ensure safe use. Use of capacity legislation in this population to manage substance misuse requires careful consideration to ensure those who lack capacity and use alcohol in a harmful way receive the input they need but also to allow autonomy to those who have capacity; without mistaking poor decision making due to addiction with lack of capacity due to ID.

### Biography

Dr Fionnuala Williams is an ST5 in Psychiatry of Intellectual Disability in Southeast Scotland. She has spent her special interest sessions in the Fife Addiction Services. Her research interests include exploring difficulties in accessing care for People with Intellectual Disability (PWID). She has previously had a study published regarding the views of PWID on Sexual Health Services.

Dr Christos Kouimtsidis, research interests include psychological interventions and hybrid models in addiction, the effect of alcohol detoxifications on the brain and alcohol clinical interventions for special populations. His clinical team had the best alcohol treatment outcomes in 2015 in England. His current NHS trust has received the 2015 HSJ Award for Clinical Research Impact. He has received the “Leadership 2017” and the “Best Employee 2009” awards of his trusts.

Professor Baldacchino works as a clinical academic in the field of addiction medicine. His research and training portfolio includes national and international projects looking at neuroscience, clinical related practice issues and policy priorities on co-morbid mental health and substance misuse problems. He is also clinical lead for an NHS addiction services in Scotland managing 1500 dependent individuals and providing support to their psychological and physical needs.

### Learning objectives

- Be aware that alcohol use disorders can be especially problematic for People With Intellectual Disability (PWID), that such disorders can often go undetected and that adapted screening techniques may be needed to identify such problems.
- Understand the difficulties that this population has in accessing addiction services and that successful management of PWID who misuse alcohol is usually dependent on appropriate joint working between ID and addiction services.
- Be aware that PWID are not a homogeneous group, that they vary widely in their abilities necessitating interventions tailored to the individual and that the use of compulsory measures to manage PWID who lack capacity regarding to their alcohol use should be done with caution.

### Introduction

With the move towards community care in the latter part of the 20<sup>th</sup> century, People with Intellectual Disability (PWID) now have more freedom over how they conduct their lives (Degenhardt 2000). This also includes greater access to alcohol and illicit drugs (Huxley 2005). Alcohol is the most misused intoxicating substance in this population group (Bhandari 2015; Chaplin 2011; McGillivray 2001; Taggart 2006; To 2014; VanDerNagel 2011). This article aims to look at alcohol use disorders (both harmful and dependent use) in PWID. This review is limited to Intellectual Disability (ID) and does not encompass other neurodevelopmental disorders commonly co-morbid with ID such as ASD. Studies have indicated that PWID develop alcohol use disorders for reasons similar to the general population with primary reasons being given as psychological trauma (e.g. multiple bereavement, rape, physical, emotional and financial abuse) and social distance from the community (e.g. isolation and lack of friendship and companionship) (Taggart 2006). These use disorders can be subsequently associated with increased problems to their physical, psychological and social well-being (Huxley 2005).

### Prevalence

The true extent of the problem is unclear as there is only limited data regarding the prevalence and severity of alcohol use disorders in PWID (Huxley 2005). The findings of the studies which have been conducted have been conflicting: some early studies indicated that PWID may be overrepresented in addiction services (Westermeyer 1996) whilst others have found no significant difference in rates of

alcohol use disorders compared with non-ID populations (Bhandari 2015, Mc Gillivray 2016; VanDerNagel 2011). However, a number of studies (Asscher 2012; Robertson 2000), including a large comprehensive population based UK study (Cooper 2007) suggest that the prevalence is low compared to the general population. This study found a prevalence of alcohol/substance use disorder of 1% on clinical diagnosis. In the mild ID group, 1.8% had an alcohol/substance use disorder. In the moderate to profound ID group 0.5% had an alcohol/substance use disorder. The study itself does not make a comparison with a non-ID group drawn from the same population nor does it separate alcohol from substance use disorder in its results, making it difficult to determine how the prevalence in PWID compared to those without.

Although the prevalence may be low, there are concerns that the figures may be an underestimate. One study screened a random sample of 40 patients from a psychiatric intellectual disability community service using the CAGE alcohol screening tool and Alcohol Use Disorders Identification Test (AUDIT) to assess alcohol use (Pezzoni 2015). This indicated 20% as being positive on CAGE (score >2) and 22.5% on AUDIT (score >8). None of the patients had such a diagnosis recorded in their notes (Pezzoni 2015).

### Significance of the problem

Even if the prevalence is low, the consequences of alcohol use disorders by PWID are significant. Continued misuse is likely to negatively affect successful community living (Barrett 2006; Huxley 2005). PWID are potentially more vulnerable to some of the physical consequences of alcohol use disorders. A number of physical health conditions (see Box 1) which can be also linked to or exacerbated by alcohol use disorders, already have higher rates in PWID, and can therefore be exacerbated further if PWID have an alcohol use disorder. To complicate matters further, in PWID these conditions are often not recognised or treated (Cooper 2004). Psychological and social consequences of alcohol use disorders for PWID are listed in Box 2 and a case vignette is described in Box 3. A study of PWID who did and did not present to the Emergency Department in crisis found that those who had alcohol or drug problems were more likely to attend the emergency department in response to crisis than those experiencing any other life event (Lunsky 2011). A number of studies support a link between alcohol use disorders and offending in PWID (Lindsay 2013; McGillivray 2001) and indeed one study into PWID in custody found that 62% of criminal behaviour was related to excessive alcohol consumption (Scott 2006).

Evidence over whether PWID have sufficient knowledge, skills and personal resources regarding alcohol use disorders and the risks entailed is conflicting. One small study indicated that PWID were very knowledgeable about why alcohol was bad for their health and were able to then make a choice to moderate unhealthy behaviour (Caton 2012). However, most other studies in this field either indicate a lack of knowledge in this area or a difficulty in acting on this knowledge to make healthier choices about alcohol use (Burgard 2000; Kuijken 2016; McCusker 1993; McGillicuddy 1999; McGillivray 2001), therefore PWID are potentially at greater risk of use disorders than the general population. Indeed, some studies indicate that when PWID use substances, they do so in a more hazardous manner (McGillicuddy 1999; To 2014). In one study of 397 homeless people, participants with suspected ID (based on a screening test) had up to two times greater odds of being classified as substance dependent than participants without ID (Van Straaten 2014). There has also been suggestion that PWID are vulnerable to the effects of alcohol at a lower level than the general

population (Westermeyer 1996), and that screening tools should be adapted and cut-off points modified (Pezzoni 2015). However, there has been no research into or even arbitrary suggestion as to what these lower levels should be.

In summary, the information available would suggest that alcohol use disorders are a problem in this population. This is compounded by the potential lack of adequate skills to make healthy choices regarding dysfunctional behaviours such as substance misuse and their adverse consequences.

#### Not a homogeneous group

Studies regarding alcohol use disorders in PWID have been affected by a number of limitations. A frequent limitation has been not considering the differences between levels of ID. PWID should not be considered a homogeneous group. As demonstrated by Cooper 2007, substance use disorders are more common in those with milder levels of ID and this is likely to be the case as they can access the community with less support. Descriptions of the functional ability expected in different levels of ID are given in Box 4. Patterns of substance use in PWID have also been found to vary due to other factors as listed in Box 5. The situation is complicated further as there is variation in the way that people with mild ID are managed in different areas as in some places they fall under the remit of general adult psychiatry.

Studies have also often looked at substance use disorders as a homogeneous concept rather than separating out different types of substance being used and different types of use disorder. In both ID and alcohol use disorders, there is a spectrum of how the individual can be affected by each disorder, and thus when a patient presents with both conditions simultaneously, it is even more important to tailor intervention to the individual's need and abilities. Some studies have attempted to make assessments accessible to those with ID, and the instruments used have not always been validated for use with PWID (Barrett 2006). As detailed below, both assessment and treatment of alcohol use disorders needs to be made accessible to PWID.

#### Problems with accessibility

ID and alcohol use disorders are conditions that individually are associated with poor engagement in care and can go undetected. It is the authors' experience that PWID struggle to access support from addiction services and complete treatment programmes, and this is supported by the literature (McGillivray 2016; Slayter 2010). Interviews with PWID indicated that their main source of support was from community ID services but that these services whilst helpful, could do little to persuade them to change their hazardous drinking patterns (Taggart 2007). Most who had used mainstream addictions services had not found their input helpful, particularly disliked group work, and felt that they had not been adequately supported with the negative life experiences underlying their substance misuse (Taggart 2007).

There has been concern expressed regarding the ability of both addiction services and ID services to meet the needs of PWID who have substance use disorders (Barrett 2006). Staff from ID services feel they lack training and expertise regarding the assessment, treatment and management of substance use disorders in PWID and in motivational interviewing (McLaughlin 2007; VanDerNagel 2011). The literature indicates that Addiction Services have limited experience and training in managing PWID (McLaughlin 2007) and Addictions staff have recognised that their services are not effectively set up

to meet the needs of PWID (McLaughlin 2007). Staff in addiction services may assume that cognitive difficulties are related to the alcohol use disorder rather than an underlying ID, or the fact that PWID may have significant difficulties in their ability to take in and retain information and adhering to treatment regimens may not be recognised (Huxley 2005). Addiction trained staff have also been found to use the same assessment schedules and therapeutic interventions with PWID as they use in the general population (McLaughlin 2007) with only minor modifications in language and duration of the intervention. PWID may therefore not be provided with the appropriate treatment strategy which may be very different to that provided to most that access addiction services (Huxley 2005). It has been recognised that Addiction services in the UK are overstretched in providing services to the mainstream population, and that they therefore may struggle even more to meet the complex needs of PWID (McLaughlin 2007, Scott 2006).

There is also a difference in approach between ID services and Addiction services. There is some suggestion that ID services may take a more paternalistic role than Addiction services, and that they need to provide people with enough information to make an informed choice about use and allow patients the opportunity for positive risk taking (Huxley 2005). There is little evidence to suggest which from ID or addiction services are best placed to support this population (Huxley 2005). Increased liaison and joint working between the two services has been suggested (McLaughlin 2007) but there is evidence to indicate that this does not often work well in practice (To 2014, VanDerNagel 2012). It tends to be *ad hoc* with professionals from ID services contacting their peers in Addiction services for advice (McLaughlin 2007). Suggestions for improvement in the literature include the development of a link person/joint person between both services who could help devise a joint working strategy to ensure that the patient would get the right services. It was also suggested that ID staff could take on an educational role towards support services and carers to promote recognition and early intervention for people with problems (McLaughlin 2007).

Many people with alcohol use disorders are managed primarily by third sector organisations. Studies from the UK exploring how Addiction Service staff manage PWID have only included NHS services so it is unclear therefore if third sector organisations can meet the needs of this group. PWID with alcohol use disorders may also present to their GP. It has been identified previously that GPs have been shown to lack skills and knowledge to identify, and offer effective care to people with substance issues (McGillion 2000), and also that GPs lack experience in working with PWID (The Scottish Government 2013). It would appear likely that primary care would struggle further in managing PWID who also have alcohol use disorders.

In terms of equality of care, PWID should be supported to access services for the general population rather than being treated separately. However, given the importance of communication skills to be able to establish a successful therapeutic relationship, at present ID services are best placed to provide support to this group in the first instance. It has been suggested that ID services upskill to take on the primary responsibility for PWID with alcohol use disorders to minimise disruption by patients being passed between services, and allows a broader view of the patient's situation to be taken (Huxley 2005). Given the reportedly low prevalence of alcohol use disorders in PWID, it may be difficult for staff in ID services to maintain these skills, although the converse would also be true for Addictions Services training up to support PWID. The authors would suggest that both sectors receive training in each other's discipline, but that ID services should take the primary supportive role. If there is dependent use (see Box 6), involvement of the addictions services is essential. It may

also be appropriate for ID services to liaise early with appropriate NHS and third sector addiction services for support even if there is no dependency in complex cases, or if the patient expresses a preference for this. The authors would suggest that Community ID staff attend Addiction appointments with the patient and go over what has taken place in the appointments at a later date if necessary to maximise understanding and engagement.

### Interventions

There have been a number of papers written suggesting how interventions aimed at the PWID group should be conducted and also studies evaluating some techniques put into practice which will we summarise here. It is assumed by some that interventions aimed at the general population will also be suitable for PWID however due to the cognitive deficits PWID have, this is unlikely to be the case (Kouimtsidis 2015), and anecdotal data suggests that treatment for these individuals require modifications to meet their needs (Burgard 2000). Highly cognitively based therapies may not be suited to this patient group (Degenhardt 2000).

A number of adaptations to treatment programmes have been suggested by the literature (Barrett 2006; Degenhardt 2000; Forbat 1999; Kouimtsidis 2017; Mendel 2002; McGillicuddy 1999; McMurrin 1993; Taggart 2007). Sessions might be more frequent, longer, and well-structured to allow them to be tailored to PWID's difficulties specifically with comprehension as well as the assimilation of, and accommodation to new ideas. Providing individual sessions on top of group sessions, connecting new ideas with things already familiar to the patient, and only progressing once skills in earlier stages are acquired can also help in this regard. Use of easy read materials and video vignettes may make treatment more accessible to PWID. Use of role playing, practising by applying skills to examples of real life situations (e.g. trip to the pub and refusing alcohol), modelling by the therapist of desirable behaviours, use of rehearsal and repetition of new ideas, and demonstration and discussion of inappropriate behaviours can help consolidate learning by putting ideas into practice in a more tangible, and therefore memorable form. Learning can be enhanced by positive reinforcement such as rewards and praise, and promoting support from carers/family. PWID often do not live completely independently of other people and this can be used to therapeutic advantage in their management (Kouimtsidis 2017).

It is also important to tackle other issues that may be contributing to the alcohol use disorder such as teaching assertiveness skills (to reduce the effect of influence/exploitation by others), teaching coping skills and providing support to manage the effects of negative life experiences (to provide an alternative to coping by drinking), and social support to help with isolation (to reduce the use of alcohol as way to seek social contact or to cope with feelings of loneliness). In a previous qualitative study PWID overall stated they would prefer one to one sessions rather than group sessions for discussing substance misuse and life circumstances (Taggart 2007), and this would also be probably more helpful to promote communication.

It is foremost important that PWID who have alcohol use disorders are identified by services to ensure they can receive intervention. The first author has conducted an evaluation of nurse-led health screening in her service, and has found that the current screening methods are potentially missing people who consume alcohol above recommended limits who could benefit from input. An

accessible form of AUDIT has been developed for use with PWID which is shown to be acceptable to this population (Kouimtsidis 2017).

There is limited evidence base for interventions specifically targeted at PWID who have alcohol use disorders. Most studies have been uncontrolled, small, many have taken place in secure settings rather than community settings, and have used measures which are either not appropriate for PWID or have been modified but not validated (Kouimtsidis 2015). Very few have looked at how interventions have affected actual alcohol consumption but most have shown positive outcomes in terms of improvement in knowledge and skills (Forbat 1999; McCusker 1993; McGillicuddy 1999; McMurrin 1993). Of note, one small study (Mendel 2002) has demonstrated that motivational interviewing techniques can be used with PWID. Brief and extended brief interventions are recommended by the National Institute for Health and Clinical Excellence (NICE 2011) for the general population. A feasibility study into an Extended Brief Intervention (EBI) targeted at PWID has been conducted. Whilst this study had difficulties recruiting participants from the community ID and social care services, and did not demonstrate advantage over usual care, it showed that the intervention is acceptable by both clients and carers. To that effect, a large scale RCT recruiting from primary care is needed to establish clinical and cost-effectiveness (Kouimtsidis 2017).

In terms of medications for alcohol use disorders, ID on its own should not affect decisions to use benzodiazepines in detoxification, nor naltrexone and acamprosate in controlling drinking. However, it is suggested by the authors that other comorbidities may be present and should be taken into account (e.g. liver function in use of benzodiazepines). It should be noted that detoxification/treatment of withdrawal can be potentially more problematic in this patient group due to: communication difficulties, lack of assessment tools accessible to this population, physical and psychiatric comorbidities, difficulties in obtaining a reliable alcohol history and possible issues with incapacity to consent to treatment (Miller 2015). Given that PWID are more likely to have carers to prompt adherence to medication, this may allow for successful use of disulfiram. However, given the significant risk in consuming alcohol on disulfiram, even that found in medications and food, the decision to prescribe this should only be made with input from addictions services, a careful consideration of the risk vs. benefits, a capacity assessment and close joint working between ID and addiction services (Miller 2015).

#### Use of compulsory measures for treatment

The management of PWID who have alcohol use disorders can lead to ethical dilemmas in balancing people's right to make decisions about their life, including negative ones, against the duty of care in protecting a group of vulnerable people from potential harm. Another issue that comes into play is when people are deemed to lack capacity to choose to use substances and whether incapacity legislation could be used to provide them with compulsory treatment for alcohol use disorders. In Scotland, a guardianship with powers to control access to alcohol can be granted for an adult with incapacity. An adult with incapacity is someone aged over 16 who by reason of mental disorder or inability to communicate because of physical disability is incapable of: acting, making decisions, communicating decisions, understanding decisions or retaining memory of decisions (Legislation.gov.uk 2000). A mental disorder is defined as a mental illness, personality disorder or learning disability however caused or manifested but there is a list of exclusions which includes use of, or dependency on alcohol or drugs. People with impaired mental functioning due to past alcohol

or drug use can be considered to have a mental disorder but not those who are temporarily under the influence of alcohol or drugs. Legislation in Scotland therefore excludes substance use or dependency alone from being used as a mental disorder to justify a guardianship order or detention under the Mental Health Act, however ID can be used.

In England, incapacity is the inability to make a decision for oneself due to being unable to: understand the information relevant to the decision, retain that information, use or weigh that information as part of the process of making the decision, or communicate his decision “because of an impairment of, or a disturbance in the functioning of, the mind or brain” (Legislation.gov.uk 2005). An impairment can be the temporary effects of alcohol (Department for Constitutional Affairs 2007) although not chronic substance use disorders. The Mental Capacity Act 2005 (MCA) could be used to restrict the access of PWID to alcohol if it was deemed to be in that person’s “best interests” but the English Mental Health Act could only be used to manage alcohol use disorders if mental illness was also present. Actively restricting someone’s access to alcohol in the community would require use of Deprivation of Liberty Safeguards which would involve an application to the supervising authority if the person lived in a care home or to the Court of Protection if they were in another setting (Social Care Institute for Excellence 2017).

The Mental Capacity Act (Northern Ireland) 2016 has a similar definition of incapacity and best interests to the English Act, although incapacity is not determined by the presence of a mental disorder and thus would not require an ID diagnosis. Actively restricting someone’s access to alcohol would likely affect their day-to-day life and therefore be deemed “treatment with serious consequences” which would need to be authorised by the relevant Health and Social Care trust, and meet the criteria for prevention of serious harm. Restrictive treatment to control someone’s alcohol use would also likely require a second opinion on capacity and best interests due to it being a “treatment with serious consequences” and also in some cases as the question about whether it is in the person’s best interests to have the treatment is “finely balanced.” (Legislation.gov.uk 2017).

Determining how much the unwise decision-making in misusing substances can be attributed to an ID, and how much to addiction requires careful judgement to ensure that those who truly lack capacity are provided with a legislative framework to keep them safe, and that those who have capacity do not have their right to make unwise decisions disregarded because they have an ID. Indeed this is reflected in the concept of “best interests” under the MCA where decisions made on behalf of the person who lacks capacity are to be made with consideration of the person's past and present wishes and feelings, and the beliefs and values that would be likely to influence his decision if he had capacity. In Scotland, there is no “best interests” concept in the legislation but any decisions made on behalf of an adult with incapacity must: benefit the adult, be the least restrictive option, and take into the present and past wishes and feelings of the adult so far as they can be ascertained, and the views of the nearest relative/carer.

Research into how incapacity legislation is currently being used to manage alcohol use disorders in this population would be helpful as there are no published studies that have looked into this area, nor any specific guidance available in Great Britain. The first author is aware through her own clinical practice in Scotland of examples where PWID have been placed under welfare guardianship with powers to limit their access to alcohol or drugs. Whilst this can be beneficial to the patient, it can be extremely difficult to enforce in more able PWID, and the feasibility of such measures should be

considered carefully. Indeed in order to enforce such powers effectively usually requires 24 hour supervision and anecdotally most cases that the author has come across are patients under welfare guardianship with high support needs due to a number of risk factors of which alcohol use disorders are only a component (e.g. PWID who are violent offenders). Due to their complexity, cases which may require the use of capacity legislation should be assessed and managed jointly between addiction and ID services.

Conclusion

Despite the concern about the increased risk to PWID from alcohol use disorders with the change from institutional to community living, the evidence base in this area is limited with regards to the prevalence of the problem, and also the strategies used to intervene. It is yet another area in which PWID continue to experience health inequality. It is crucial that health and social care staff are vigilant to ensure alcohol use disorders do not go undetected in this group and that better joint working between ID and Addiction Services occurs to maximise the success of treatment.

Boxes

<ul style="list-style-type: none"> <li>• Epilepsy</li> <li>• Gastro-oesophageal reflux disease</li> <li>• Cancer</li> <li>• Dementia</li> <li>• Accidents</li> <li>• Nutritional problems</li> </ul> <p>Box 1 Conditions with high rates in PWID which are also linked to alcohol use disorders (NHS Health Scotland 2004)</p>
--

Psychological	Social
<ul style="list-style-type: none"> <li>• Exacerbation of cognitive deficits</li> <li>• Mental health problems</li> </ul>	<ul style="list-style-type: none"> <li>• Exclusion from services due to behavioural difficulties</li> <li>• Further marginalisation and exclusion</li> <li>• Greater barriers to accessing services</li> <li>• Increased risk of unemployment</li> <li>• Increased risk of poverty</li> <li>• Increased risk of offending</li> </ul>

Box 2 Consequences of alcohol misuse relevant to PWID (Huxley 2005)

Fred is a 24 year old man with mild intellectual disability and dependent use of alcohol. Fred previously has his own tenancy but concerns were raised with social work about his ability to maintain this. He would invite people to his flat to drink with him who would then end up exploiting him for money or stealing his things. Fred found it difficult to safeguard himself from these people as he saw them as his friends. Fred was and continues to be also a frequent attender at Accident & Emergency with self-harm. This only ever occurs when he is under the influence of alcohol and once Fred sobers up, he remorseful of his actions. He also occasionally gets into fights whilst under the influence which has led to him experiencing a number of injuries. Fred has epilepsy and his alcohol use is leading to an increase in his seizure frequency. His family have been very concerned about his risky behaviour. He currently lives at home with his father who is struggling to continue to support him with his ongoing drinking. The living situation is at the point of breaking down.

Fred says he wants to continue drinking but he has some insight into the effects of his drinking and that it would be helpful to stop. He is unsure of how to achieve this and has limited understanding of safe drinking limits. Attempts have been made to engage him with local mainstream alcohol services but his father states that the staff do not know how to work people with intellectual disability.

Box 3 Case vignette

Level of ID	Level of functioning
Mild	Difficulties in acquiring and understanding complex language concepts and academic skills. The majority can manage basic self-care, domestic, and practical activities. Most can live relatively independently and gain employment as adults but they may need appropriate support.
Moderate	Usually limited to basic skills. Some can manage basic self-care, domestic, and practical activities. Most need ongoing and significant amounts of support to live independently and maintain employment as adults.
Severe	Very limited language and ability to gain academic skills. Often have motor impairments. Usually require daily support in a supervised environment for self care. Some may develop basic self-care skills with intensive support and training.
Profound	Very limited communication and ability to gain academic skills limited to basic concrete skills. Usually have also motor and sensory impairments. Usually need daily support in a supervised environment for care.

Box 4 ICD -11 beta : Descriptions of functioning of people with different levels of intellectual disability (World Health Organisation 2017)

- Psychiatric comorbidity e.g. schizophrenia spectrum disorders
- Lack of daytime activities
- Male gender
- Forensic history
- Living independently

Box 5 Factors associated with substance use in PWID (Chaplin 2011; Taggart 2006; To 2014; VanDerNagel 2011)

Three of the following:

- a strong desire to drink
- difficulties in controlling drinking
- persistent drinking despite harmful effects
- alcohol prioritised over other activities and obligations
- increasing tolerance
- physical symptoms of withdrawal

Box 6 ICD 10 Definition of alcohol dependency (World Health Organisation (2010))

## MCQs and answers

1. The prevalence of alcohol use disorders in PWID in the UK:
  - a. is higher than in the general population without ID.
  - b. is thought to be particularly high in females.
  - c. is unclear but is probably lower than in the general population.
  - d. has been reliably measured in studies to date
  - e. has decreased with the move from institutional to community care
  
2. PWID who misuse alcohol:
  - a. are less vulnerable to the physical effects of alcohol use
  - b. are not a homogeneous group and thus successful intervention requires an individually tailored approach.
  - c. are less likely to experience psychological consequences of drinking.
  - d. should adhere to stricter drinking limits than people without ID as there is strong evidence to recommend what these limits are.
  - e. find addiction services easily accessible
  
3. Concerning addiction services for PWID:
  - a. ID services are very experienced and confident in supporting this group.
  - b. Addiction services are very experienced and confident in supporting this group.
  - c. Joint working between services is well established.
  - d. PWID report difficulties in accessing support with addictions both with Addictions services and ID services.
  - e. Research has indicated that third sector organisations are well equipped to support this group.
  
4. Regarding management of alcohol use disorders in PWID:
  - a. There is a lot of evidence regarding the efficacy of interventions targeted specifically at this population.

- b. There are a number of ways in which interventions can be adapted to improve accessibility for this population.
  - c. Highly cognitive based therapies are particularly suited to this patient group.
  - d. Motivational Interviewing techniques are impossible with this patient group.
  - e. Medical management is not helpful.
5. Regarding legislative frameworks for managing PWID who misuse alcohol:
- a. Alcohol use disorder alone is a sufficient diagnosis to support a finding of incapacity regarding personal welfare.
  - b. Use of compulsory measures to manage substance use disorders are readily enforceable even in more able patients.
  - c. Decisions regarding capacity to misuse substances should be made with care in this population to discern whether the addiction or ID is driving the decision-making.
  - d. PWID should be protected from all risk-taking behaviour.
  - e. Incapacity legislation in the UK does not encompass powers to control access to substances.

Answers: 1c 2b 3d 4b 5c

#### Declaration of Interest

- None

#### References

Asscher JJ, van der Put CE, Stams GJ (2012) Differences between juvenile offenders with and without intellectual disability in offense type and risk factors. *Research in Developmental Disabilities*, **33**(6):1905-13.

Barrett N, Paschos D (2006) Alcohol-related problems in adolescents and adults with intellectual disabilities. *Current Opinion in Psychiatry*, **19**(5):481-5.

Bhandari A, van Dooren K, Eastgate G, et al (2015) Comparison of social circumstances, substance use and substance-related harm in soon-to-be-released prisoners with and without intellectual disability. *Journal of Intellectual Disability Research*, **59**(6):571-9.

Burgard JF, Donohue B, Azrin NH, et al (2000) Prevalence and treatment of substance abuse in the mentally retarded population: An empirical review. *Journal of Psychoactive Drugs*, **32**(3): 293-8.

Caton S, Chadwick D, Chapman M, et al (2012) Healthy lifestyles for adults with intellectual disability: knowledge, barriers, and facilitators. *Journal of Intellectual and Developmental Disabilities*, **37**(3):248-59.

Chaplin E, Gilvarry C, Tsakanikos E (2011) Recreational substance use patterns and co-morbid psychopathology in adults with intellectual disability. *Research in Developmental Disabilities*, **32**(6):2981-6.

Cooper SA, Smiley E, Morrison J et al (2007) Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry*, **190**(1):27-35.

Cooper SA (2004) People with intellectual disabilities: their health needs differ and need to be recognised and met. *BMJ*, **329**(7463): 414-415.

Degenhardt L (2000) Interventions for people with alcohol use disorders and an intellectual disability: A review of the literature. *Journal of Intellectual and Developmental Disabilities*, **25**(2): 135-46.

Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice*. Department for Constitutional Affairs

([https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/497253/Mental-capacity-act-code-of-practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf))

Forbat L (1999) Developing an Alcohol Awareness Course for Clients with a Learning Disability. *British Journal of Learning Disabilities*, **27**(1):16-19.

Huxley A, Copello A, Day E (2005) Substance misuse and the need for integrated services. *Learning Disability Practice*, **8**(6): 14-17.

Kouimtsidis C, Bosco A, Scior K et al (2017) A feasibility randomised controlled trial of extended brief intervention for alcohol misuse in adults with mild to moderate intellectual disabilities living in the community. The EBI-LD Study. *Trials*, **18**(1): 216.

Kouimtsidis C, Fodor-Wynne L, Scior K et al (2015) Extended brief intervention to address alcohol misuse in people with mild to moderate intellectual disabilities living in the community (EBI-ID): study protocol for a randomised controlled trial. *Trials*, **16**(1): 114.

Kuijken NM, Naaldenberg J, Nijhuis-van der Sanden MW et al (2016) Healthy living according to adults with intellectual disabilities: towards tailoring health promotion initiatives. *Journal of Intellectual Disability Research*, **60**(3):228-41.

Legislation.gov.uk(2016) *The Mental Capacity Act (Northern Ireland) 2016*

<http://www.legislation.gov.uk/nia/2016/18/contents/enacted>

Legislation.gov.uk (2005) *Mental Capacity Act 2005*

(<http://www.legislation.gov.uk/ukpga/2005/9/part/1>)

Legislation.gov.uk (2000) *Adults with Incapacity (Scotland) Act 2000*.

(<http://www.legislation.gov.uk/asp/2000/4/section/1>)

Lindsay WR, Holland AJ, Carson D et al (2013) Responsivity to criminogenic need in forensic intellectual disability services. *Journal of Intellectual Disability Research*, **57**(2):172-81.

Lunsky Y, Elserafi J (2011) Life events and emergency department visits in response to crisis in individuals with intellectual disabilities. *Journal of Intellectual Disability Research*, **55**(7):714-8.

Mendel E, Hipkins J (2002) Motivating learning disabled offenders with alcohol-related problems: a pilot study. *British Journal of Learning Disabilities*, **30**(4): 153-158.

Miller H (2015) Alcohol Use Disorders In *The Frith Prescribing Guidelines for People with Intellectual Disability 3<sup>rd</sup> Edition* (eds Bhaumik S, Gangadharan SK, Branford D, Barrett M): 203-14. John Wiley & Sons.

McGillion J, Wanigaratne S, Feinmann C, Godden T, Byren A (2001) GP's attitude towards the treatment of drug misusers. *British Journal of General Practice*, **50**(454): 385-6.

McMurrin M, Lismore K (1993) Using video-tapes in alcohol interventions for people with intellectual disabilities: an exploratory study. *Journal of the British Institute of Mental Handicap (APEX)*, **21**(1): 29-31.

McCusker C, Clare ICH, Cullen C et al (1993) Alcohol-related Knowledge and Attitudes in People with a Mild Learning Disability – The Effects of a “Sensible Drinking” Group. *Journal of Community & Applied Social Psychology*, **3**(1):29-40.

McGillicuddy NB, Blane HT (1999) Substance use in individuals with mental retardation. *Addictive Behaviors*, **24**(6):869-78.

McGillivray JA, Gaskin CJ, Newton DC et al (2016) Substance use, Offending, and Participation in Alcohol and Drug Treatment Programmes: A Comparison of Prisoners with and without Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, **29**(3): 289-294.

McGillivray JA, Moore MR (2001) Substance use by offenders with mild intellectual disability. *Journal of Intellectual and Developmental Disabilities*, **26**(4):297-310.

McLaughlin DF, Taggart L, Quinn B et al (2007) The Experiences of Professionals who Care for People with Intellectual Disability who have Substance-Related Problems. *Journal of Substance Use*, **12**(2): 133-143.

National Institute for Health and Clinical Excellence (NICE) (2001) *Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence*. NICE

(<https://www.nice.org.uk/guidance/cg115>) NHS Health Scotland (2004) *Health needs assessment report. People with learning disabilities in Scotland*. NHS Health Scotland ([http://www.gla.ac.uk/media/media\\_63872\\_en.pdf](http://www.gla.ac.uk/media/media_63872_en.pdf))

Pezzoni V, Kouimtsidis C (2015) Screening for alcohol misuse within people attending a psychiatric intellectual disability community service. *Journal of Intellectual Disability Research*, **59**(4):353-9.

Robertson J, Emerson E, Gregory N et al (2000) Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities*, **21**(6):469-86.

Scott D, McGilloway S, Donnelly M (2006). The mental health needs of people with a learning disability detained in police custody. *Medicine, Science & Law*, **46**(2):111-4.

Scottish Government (2013). *Keys to Life Improving quality of life for people with learning disabilities*. The Scottish Government (<https://keystolife.info/wp-content/uploads/2014/05/the-keys-to-life-full-version.pdf>)

Slayter E (2010). Medicaid-covered alcohol and drug treatment use among people with intellectual disabilities: evidence of disparities. *Intellectual and Developmental Disabilities*, **48**(5):361-74.

Social Care Institute for Excellence (2017). *Deprivation of Liberty Safeguards (DoLS) at a glance*.

Social Care Institute for Excellence ( <https://www.scie.org.uk/mca/dols/at-a-glance>)

Taggart L, McLaughlin D, Quinn B et al (2007) Listening to people with intellectual disabilities who misuse alcohol and drugs. *Health and Social Care in the Community*. **15**(4): 360-8.

Taggart L, McLaughlin D, Quinn B et al (2006) An exploration of substance misuse in people with intellectual disabilities. *Journal of Intellectual Disability Research*, **50**(Pt 8): 588-97.

To WT, Neiryck S, Vanderplasschen W et al (2014) Substance use and misuse in persons with intellectual disabilities (ID): Results of a survey in ID and addiction services in Flanders. *Research in Developmental Disabilities*, **35**(1): 1-9.

VanDerNagel J, Kiewik M, Buitelaar J et al (2011) Staff perspectives of substance use and misuse among adults with Intellectual Disabilities Enrolled in Dutch Disability Services. *Journal of Policy and Practice in Intellectual Disabilities*, **8**(3): 143-149.

Van Straaten B, Schrijvers CT, Van der Laan J et al (2014) Intellectual disability among Dutch homeless people: prevalence and related psychosocial problems. *PLoS One*, **9**(1): e86112.

World Health Organisation (2017) *ICD-11 Beta Draft*. WHO  
(<http://apps.who.int/classifications/icd11/browse/l-m/en#/http%3a%2f%2fid.who.int%2fcd%2fentity%2f605267007>)

World Health Organisation (2010) *ICD-10 Version:2010*. WHO  
(<http://apps.who.int/classifications/icd10/browse/2010/en>)

Westermeyer J., Kemp K., Nugent S (1996) Substance disorder among persons with mild mental retardation: A comparative study. *The American Journal on Addictions*, **5**(1): 23-31.