

Annotated Resource List
Intersection of IDD and Substance Use

Bhandari, A., Dooren, K., Eastgate, G., Lennox, N., & Kinner, S. A. (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), 571–579.

The aim of this study was to describe the social circumstances, patterns of substance abuse and related harmful behaviors in prisoners with ID who were scheduled for release from the Australian criminal justice system. The study compared prisoners with ID and who were scheduled to be released with a population of prisoners without ID in order to understand how the needs of this group compare with a mainstream prison population.

Population: Prisoners with (n=115) and without ID (n=1164) scheduled to be released within six weeks of the study.

Methods: Data for the study came from a randomized controlled trial conducted in seven prisons in Australia to assess the effectiveness of service brokerage on health outcomes within the first six months of release from prison. Cross-sectional data was collected at baseline and before randomization. Baseline interviews were conducted, and covered demographic information, social characteristics, substance use, and health and mental health behaviors. Prisoners were screened for ID using the Hayes Ability Screening Index.

Results: No significant differences exist between prisoners with and without ID. Data suggests that transitioning from prison to the community presents considerable risk of drug related harm and related consequences for both groups. Risks for the group of prisoners with ID still exist. One in

three prisoners in the study reported an HCV infection. More than one quarter of participants in the study with ID reported a history of injecting drugs. These findings suggest that programs may not be adequately addressing the needs of people with ID, and that more specialized and coordinated services are necessary to assist this group.

Braatveit, K. J., Torsheim, T., & Hove, O. (2018a). Screening for intellectual disabilities: A validation of the Hayes Ability Screening Index for in-patients with substance use disorder. *Nordic Journal of Psychiatry*, 72(5), 387–392.

<https://doi.org/10.1080/08039488.2018.1468923>

The aim of this study was to validate the Hayes Ability Screening Index for use with individuals receiving in-patient care for substance use disorder. The purpose of the index is to screen individuals for possible ID. Current research suggests that individuals with ID and substance use disorders may be underdiagnosed, thus leading to either an overlooked need for treatment or ineffective interventions.

Population: 84 individuals aged 19-64 receiving in-patient services

Methods: Participants completed the Wechsler Adult Intelligence Scale (WAIS-IV), the Vineland Adaptive Behavior Scale (Vineland II), and a self-report questionnaire to assess learning difficulties in childhood.

Results: When compared with the WAIS-IV and the Vineland II, the Hayes Ability Screening Index was well correlated. When used with individuals receiving in-patient care for substance use disorder, the authors reported good overall construct validity in detecting ID.

Braatveit, K. J., Torsheim, T., & Hove, O. (2018b). The prevalence and characteristics of intellectual and borderline intellectual disabilities in a sample of inpatients with substance use disorders: Preliminary clinical results. *Journal of Mental Health Research in Intellectual Disabilities*, 11(3), 203–220.

This study's objective was to explore ID prevalence rates in those seeking in-patient treatment for substance abuse disorder (SUD). The current body of research on ID and SUD focuses on individuals who were diagnosed with ID in childhood, but a number of individuals receiving mental health services may also have an undiagnosed ID and may require different treatment options. The researchers also explored characteristics related to education and childhood learning difficulties, public support system contact, and comorbidities including mental health concerns in both the ID and non-ID groups.

Population: 91 participants with substance use disorder receiving inpatient care at treatment facilities, aged 19-64.

Methods: A variety of questionnaires were utilized including the Wechsler Adult Intelligence Scale (WAIS-IV) to assess IQ, the Vineland Adaptive Behavior Scale (Vineland II) to assess adaptive functioning, a self-report questionnaire to assess learning difficulties in childhood, and the Mini-International Neuropsychiatric Interview (MINI) for assessment of comorbidities and substance use.

Results: Approximately 30 percent of participants met the criteria for borderline intellectual functioning or ID, though only one had been diagnosed during their treatment for substance abuse disorder. In terms of characteristics, those with ID were more likely to report learning difficulties in childhood and more contact with public support systems. Compared with the non-

ID group, participants with ID also experienced higher rates of substance use relapse during treatment. The authors suggest the need to better identify ID in those with substance abuse disorder so that appropriate and individualized treatment and support options can be provided.

Burns, J., Aspinall, C., & Matthews, C. (2011). An evaluation of an alcohol awareness group for learning disabled offenders in a secure setting. *Journal of Learning Disabilities and Offending Behavior*, 2(4), 159-166.

The aim of this study was to evaluate a forensic setting-based alcohol awareness program for individuals with learning disabilities. The alcohol awareness group was created in part due to nearly half of those who committed crimes being intoxicated during the offense. In terms of individuals with learning disabilities, nearly 45 percent of Finnish offenders with learning disabilities were under the influence of alcohol when committing offenses. The alcohol awareness group was part of an overarching initiative to ensure appropriate and integrated care delivery for patients.

Population: 34 participants of an alcohol awareness group with either learning disabilities or learning disabilities and mental health concerns in a secured facility.

Methods: Participants were assessed using the Readiness to change questionnaire (RCQ), the Alcohol-related problems and awareness inventory (ARPAI), the Self-efficacy scale (SES), and an Alcohol Awareness assessment. These assessments were completed both prior to and following participation in the 12 weeks long alcohol awareness group, which incorporated aspects of cognitive behavioral treatment.

Results: Participants' scores on all assessments improved following participation of the alcohol awareness group. The largest improvement in scores was seen in those with a lower IQ (50-59

range), suggesting participation in the intervention can benefit all. Participants with a dual diagnosis of learning disabilities and mental health concerns expressed lower levels of confidence in modifying their drinking habits than those with only learning disabilities.

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), 2981–2986.

The aim of this study was to explore patterns of recreational substance use by individuals with ID and mental health issues. Participant data was collected via referrals to a London-based mental health service specifically tailored for individuals with ID. This data included clinical and socio-demographic information, along with patterns of substance abuse.

Population: 115 referrals to London-based specialist mental health services for adults with ID; 75 were male and the average age was 40.3 years old.

Methods: Data collected via clinical, socio-demographic info, and substance use patterns.

Results: The most commonly used substance was alcohol, then cannabis and cocaine. Males with mild ID were more likely to use substances, as well as individuals with a forensic history.

Individuals with autism were the least likely to use substances. Individuals with ID and schizophrenia were 3 times more likely to use illicit substances.

Frielink, N., Schuengel, C., Kroon, A., & Embregts, P. J. C. M. (2015). Pretreatment for substance-abusing people with intellectual disabilities: intervening on autonomous

motivation for treatment entry. *Journal of Intellectual Disability Research*, 59(12), 1168-1182. doi:10.1111/jir.12221

This study tested a motivational pre-treatment intervention, “Beat the Kick”, an intervention designed to facilitate autonomous motivation to engage in an addiction treatment program, and to change behaviors related to substance use. The intervention is based on motivational interviewing (MI) techniques adapted for use with individuals with intellectual disabilities and the theoretical frameworks of self-determination. Individual intervention sessions were held in participants homes on a weekly basis over 10 weeks. Each session had the same structure: revisiting previous homework, new materials were introduced and discussed (ex. Internet assignments, studying cartoons, viewing and discussing film fragments), summary of session and a new homework assignment. After completion of the pretreatment intervention, individuals who showed autonomous motivation were then able to participate in an intervention specifically to change substance abuse itself.

Population: Six adults with mild intellectual disability or borderline intellectual functioning and a substance abuse issue (alcohol, hashish, cannabis) living in the community (Netherlands).

Method: Multiple-case experimental design with individual time series to measure day-to-day motivation to change substance abuse behaviors. Completion of a self-report inventory at baseline, during intervention, and at 1 month follow up.

Results: The results of five of the six participants showed that motivation changed from external or introjected motivation to autonomous motivation. Study participants also reported significant increases in overall need satisfaction and autonomy satisfaction, and a significant decrease in overall need frustration.

Novotna, G., Johner, R., McCarron, M., Novik, N., Jeffery, B., Taylor, M., & Jones, M. (2017). Assessment and treatment for persons with coexisting ability and substance use issues: A review and analysis of the literature. *Journal of Social Work in Disability & Rehabilitation*, 16(2), 141-160. <https://doi.org/10.1080/1536710X.2017.1299662>

This literature review provides background on assessment and treatment for individuals with differing ability and substance abuse issues. The review of existing literature reveals the need for screening and assessment instruments designed to assess substance use in individuals with differing abilities. The review also highlighted the need for treatment methods tailored to meet diverse literacy and cognitive abilities. Treatment programs located in facilities that are readily accessible, and training for providers specific to this population were also highlighted as areas of need.

Method: Narrative, integrative literature review.

Results: N/A

Sakdalan, J. A., Daniel, M. K., & Judd, D. (2017). ASAP-ID: Substance abuse programme for a forensic ID population. *Journal of Intellectual Disabilities and Offending Behaviour*, 8(4), 157-165. doi:<http://dx.doi.org.proxy.library.umkc.edu/10.1108/JIDOB-07-2017-0014>

This report focused on a pilot substance abuse program for individuals with intellectual disabilities (ID) and substance abuse issues in a forensic setting. Dialectical behavior therapy and the Good Lives Model were incorporated to develop a comprehensive program to address the

substance abuse and other co-morbid factors, and risk factors in this population. The aim of the pilot program was to provide treatment for forensic clients with ID. The core concepts of the program focused on motivational interviewing, a cultural framework (Te Wahare Tapa Wha health model), alcohol and drug education, coping skills, building healthy relationships, steps to relapse, and relapse prevention. The program used simple programming, such as visual aids, repetition, and role play to deliver the intervention.

Population: Six participants in the 27 week Alcohol and Substance Abuse Programme-Intellectual Disability.

Methods: Pre and post measures assessed readiness for change and confidence in ability to remain sober.

Results: Marked improvement in participants' confidence in ability to stay clean and sober in risky situations. Increase overall readiness for change.

Schijven, E. P., Didden, R., Otten, R., & Poelen, E. A. P. (2019). Substance use among individuals with mild intellectual disability or borderline intellectual functioning in residential care: Examining the relationship between drinking motives and substance use. *Journal of Applied Research in Intellectual Disabilities: JARID*, 32(4), 871–878.

<https://doi.org/10.1111/jar.12578>

The objective of this study was to examine the relationship between motives for drinking and substance use and mild ID or borderline intellectual functioning. Drinking motives were based on the “motivational model of alcohol use” by Cox & Klinger (1988), which include: social motives which focus on using alcohol to enjoy social events; conformity motives in which

alcohol is used to feel part of the group; coping motives in which using alcohol helps the individual cope with issues; and enhancement motives in which the individual uses substances to improve mood.

Population: 163 individuals with mild or borderline ID receiving supports in residential settings in the Netherlands, aged 11-30; 119 participants were male.

Methods: The Substance Use and Misuse in Intellectual Disability-Questionnaire (SumID-Q) and Drinking Motive Questionnaire Revised Short Form (DMQ-R-SF) were utilized.

Results: Social motives positively related to alcohol consumption while coping and enhancement motives positively related to alcohol use severity. The frequency of cannabis and hard drug use also positively related to social motives. Cannabis use negatively related to conformity for those with ID. The authors suggest the need for tailoring interventions to include the individual's motivations for substance misuse to effectively reduce substance misuse in the ID population.

Schijven, E. P., Hulsmans, D. H. G., VanDerNagel, J. E. L., Lammers, J., Otten, R., & Poelen, E.

A. P. (2020). The effectiveness of an indicated prevention programme for substance use in individuals with mild intellectual disabilities and borderline intellectual functioning:

Results of a quasi-experimental study. *Addiction (Abingdon, England)*.

<https://doi.org/10.1111/add.15156>

This study investigated the Take it Personal! Program that aims to reduce substance use. The program targets four personality traits (sensation seeking, impulsive behavior, anxiety sensitivity, and negative thinking) and includes materials tailored specifically to the individuals'

personality type. Motivational interviewing and cognitive behavioral therapy approaches are incorporated into the program, along with psychomotor therapy which focuses more on movement and less on verbal interactions. Individuals receiving the intervention attended five individual and five group sessions over a 6-week period.

Population: 66 individuals with mild or borderline ID with a history of substance use

Methods: A quasi-experimental design with two arms (those receiving the intervention and those in the control group) was utilized for this study. The Substance Use Risk Profile Scale (SURPS) was used for baseline assessment. Substance use frequency was determined using questions from the Substance Use and Misuse in Intellectual Disability Questionnaire (SumID-Q) while the Alcohol Use Disorders Identification Test (AUDIT) and Drug Use Disorders Identification Test (DUDIT) were used to assess the severity of substance use and binge drinking. Participant outcomes were assessed three months post intervention.

Results: Individuals receiving the intervention reported a greater decrease in substance use frequency than the control group. In addition, adolescent binge drinking also decreased more for those receiving the intervention. Decreases in cannabis and illicit drug use were not noted. The authors note that the program may help in decreasing an individual's substance use before their usage becomes a disorder.

Schijven, EP, VanDerNagel, JEL, Otten, R, Lammers, J, Poelen, E. (2020). Take it personal!

Development and modelling study of an indicated prevention programme for substance use in adolescents and young adults with mild intellectual disabilities and borderline

intellectual functioning. *Journal of Applied Research in Intellectual Disabilities*, 1–9.

<https://doi.org/10.1111/jar.12808>

This paper describes the theory and development behind the Take it Personal! prevention program, aimed at reducing substance use in individuals with intellectual disabilities and to decrease intention to use substances later on. The intervention targets adolescents and young adults, ages 14 to 30 years old with an ID, who are using substances in the experimentation stage or with a mild substance use disorder and who have personality traits known to contribute to substance use disorder: sensation seeking, impulsivity, highly anxious sensitivity, and negative thinking or depression. For each personality profile, a different intervention was developed based on three components, 1) psycho-education, 2) behavioral coping skills, and 3) cognitive coping skills. Intervention Mapping (IM), an evidence-based health promotion tool, guided the development of this prevention program. The intervention utilized motivational interviewing strategies (MI) and cognitive behavioral therapy to facilitate motivation for change and to change behavior patterns based on the personality profile.

Population: Youth to Young Adults, age 14-30

Method: A small modeling study was conducted with six adolescents to examine the feasibility and effectiveness of the intervention.

Results: The researchers found the intervention to be feasible and user friendly. Participants in the intervention were positive about the program, and were motivated to complete it.

Sharma, M., & Lakhan, R. (2017). Substance abuse among people with intellectual disabilities:

Areas of future research. *Journal of Alcohol & Drug Education*, 61(2), 3–6.

This editorial focuses on the unique needs of the ID population in terms of substance abuse and treatment. Individuals with ID may be more susceptible to substance abuse due to limitations in social and practical skills, along with higher rates of psychiatric comorbidities. Despite the increased risk for substance abuse in this population, there remains a gap in the literature in terms of substance abuse prevalence. Current screening tools are also inconsistent in identifying substance abuse due to the lower cognitive function and comorbidities associated with the ID population.

Population: Individuals with ID with substance abuse

Methods: N/A; editorial

Results: There remains a need for better health promotion and prevention models specifically for individuals with ID, along with clearer substance abuse treatment guidelines for this population.

The authors also suggest the need for screening tools to detect substance abuse in individuals with ID.

Slayter, E. (2016) Disparities in substance abuse treatment utilization among women with intellectual disability. *Journal of Social Work in Disability & Rehabilitation*, 15(2), 96-115, DOI: [10.1080/1536710X.2016.1162120](https://doi.org/10.1080/1536710X.2016.1162120)

The aim of this study was to extend the understanding of barriers that women with intellectual disability face in utilizing treatment programs and to identify national trends. Medicaid claims data from 49 states was analyzed for substance abuse treatment utilization.

Population: Adults aged 18 to 64 who received care in 1999

Method: Study was a retrospective, cross-sectional design. Logistic regression models of utilization were conducted.

Results: Women in the sample were less likely than men in the sample or women without intellectual disability to utilize treatment, suggesting both gender-related and disability-related barriers.

Thompson, S., Nichols, K. A., & Ebron, R. G. (2012). A snapshot of North Carolina's public mental health, developmental disabilities, and substance abuse service system. *Mental Health, 73*(3).

This article discusses the shift of North Carolina's public mental health, developmental disabilities and substance abuse service system to Medicaid managed care framework. The article provides a brief snapshot of the current system in order to provide a point of reference for reforms related to the 1915(b)/(c) waiver. The snapshot includes who currently needs services and is receiving services, the length of time it takes to receive services, and coordination of care.

Methods: N/A

Population: An estimated 536,000 non-elderly Medicaid eligible residents of the state of North Carolina.

Results: N/A

To, W. T., Neiryneck, S., Vanderplasschen, W., Vanheule, S., & Vandeveldel, S. (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. <https://doi.org/10.1016/j.ridd.2013.10.015>

This study explored the characteristics of two types of individuals with ID – individuals who use substances and those who misuse substances. Based on previous research, individuals with ID may be at greater risk for potential substance misuse if they use any alcohol or illicit drugs but less is known about the impact substance use/misuse has on overall well-being and mental health. The authors of this study surveyed caregivers of individuals with ID and a history of substance use or misuse to compare the characteristics of these groups.

Population: 104 substance users and misusers with ID in the Flanders area

Methods: Online questionnaire emailed to ID and addiction services in Flanders and completed by anonymous caregivers

Results: Alcohol, cannabis, and cocaine were the most commonly used substances reported by both substance users and misusers. The majority of substance users and misusers lived independently and were younger men with mild ID. Individuals who were identified as substance misusers were more likely than substance users to be unemployed. Substance misuse was also reported to negatively affect mood and social relationships, along with increasing rates of suicidal ideation. Substance use and misuse were also found to be risk factor for offending behavior. The authors suggest better collaboration between ID specific services and mainstream addiction services to better identify and treat substance misuse in this population.

VanDerNagel, J. (2013). Substance use among persons with Mild Intellectual Disability:

Approaches to screening and interviewing. *The NADD Bulletin*, 16(5), 87-92.

This article highlights the difficulty in identifying substance abuse in individuals with mild or borderline ID. Prevalence of substance abuse in this population is understudied and there

remains a lack of screening instruments validated for use with individuals who have ID. The authors highlighted these difficulties through three case studies including a 19-year-old male with borderline ID using alcohol, cannabis, and cocaine; a 35-year-old woman with borderline ID using cocaine; and a 38-year-old woman with Down syndrome using alcohol and cannabis. Substance misuse or abuse by individuals with ID are often overlooked by family and staff members, as individuals with ID are believed to not partake in substance use. Symptoms of substance misuse are also mistaken as stemming from the person's disability rather than substance use. The SumID-Q, a Dutch language tool used to identify substance use in individuals with ID, was also highlighted.

Population: three adults with mild or borderline ID and substance abuse, via case study

Methods: The difficulties in recognizing and screening individuals with mild or borderline ID for substance abuse were highlighted through the use of three case studies.

Results: The authors provide a detailed list of suggestions related to identifying symptoms of substance misuse in the ID population, including mental health concerns, physical symptoms, and social problems. Screening steps from the SumID-Q tool are outlined, including the importance of open and empathetic discussion about substance use. Using open-ended questions and providing pictures for clarification when discussing substance use with individuals who have ID are suggested, while a number of other interviewing recommendations are provided.

VanDerNagel, J., Kiewik, M., Buitelaar, J., & DeJong, C. (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.

<https://doi.org/10.1111/j.1741-1130.2011.00304.x>

The purpose of this study was to investigate disability service staff perspectives of substance use and misuse by individuals with ID. Staff members completed questionnaires about their clients, specific to current, lifetime, and problematic substance use. Staff were also asked to describe their agencies' policies related to substance use issues.

Population: 153 staff employed by agencies providing supports to individuals with mild or borderline ID

Methods: Questionnaires completed by key staff members at agencies providing supports to individuals with ID.

Results: Alcohol was listed as the most commonly used substance, followed by cannabis.

Younger clients were more likely to use both alcohol and cannabis, while older clients used only alcohol. Individuals identified as having problematic substance use were identified as having little involvement in daytime activities as well as having psychiatric comorbidities. In terms of substance abuse interventions, staff identified psychosocial and restrictive measures as the most beneficial; interventions deemed least effective included partnerships with addiction centers and rewarding client abstinence. VanDerNagel and associates suggest the need for additional cross-system collaboration to better support individuals with ID experiencing substance misuse.

van Duijvenbode, N., VanDerNagel, J. E. L., Didden, R., Engels, R. C. M. E., Buitelaar, J. K., Kiewik, M., & de Jong, C. A. J. (2015). Substance use disorders in individuals with mild to borderline intellectual disability: Current status and future directions. *Research in Developmental Disabilities*, 38, 319–328. <https://doi.org/10.1016/j.ridd.2014.12.029>

This paper focuses on the current gaps in knowledge related to substance use disorders in individuals with mild or borderline ID. The authors outline the limitations of existing research in this area, including the difficulty in screening and assessing this population for substance use disorder given the lack of suitable instruments for this population. Proxy reports are often used to assess an individual with ID's level of substance use, but substance usage is commonly underestimated by staff members. There is also limited knowledge related to the effectiveness of substance use disorder interventions for this population. There is some evidence that motivational interviewing and substance use education are effective, but more research is necessary.

Population: Individuals with ID and substance use disorder (SUD)

Methods: A selective and critical review of the literature was completed by the authors.

Results: The authors suggest a number of directions for future research. These include additional research on the prevalence of substance misuse disorder in the ID population, with particular attention paid to subgroups at higher risk, such as those with co-occurring psychiatric disorders.

Screenings for SUD tailored to individuals with ID are also necessary, along with increased staff training about recognizing and screening for SUD in clients with ID. Collaboration between ID service organizations and mainstream addiction services is also necessary to better serve individuals with ID and SUD.