



Substance Use Disorder in Persons with Intellectual Disabilities and Related Conditions

A proposed treatment curriculum

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Introduction

Persons with Intellectual and Developmental Disabilities and Related Conditions (IDD/RC) may also have Substance Use Disorder (SUD). The extent to which persons with IDD/RC may have SUD and the best practices for treating those people are not well understood. Most research for SUD does not include persons with IDD/RC overtly and does not incorporate them in treatment strategies, and there exist substantial barriers to treatment for persons with IDD/RC in the current system.

This document will explore what is known about the extent of the problem and how it is manifested in the community and will examine the current treatment landscape for substance use disorder in IDD/RC and how the current environment poses barriers to treatment for persons with IDD/RC and SUD. We will then examine the evidence around best practices for treatment for SUD in general and for substance specific treatment differences and include what data exists for the treatment for persons with IDD/RC and SUD across disease subtypes (e.g. Opioid Use Disorder or Amphetamine-type Substance Use Disorder).

We will first define what we mean by intellectual and developmental disability and then what we mean by substance use disorder. Next we examine the epidemiology of SUD in IDD/RC to the extent that it is known. We will follow with an exploration of the assessment of IDD/RC in SUD, including various proposed assessment techniques. We will then examine treatment models and potential treatment locations as well as whom should staff each level of treatment. We will examine what an ideal treatment environment might look like, including physical access, intake process, treatment plans, assessment tools to facilitate these assessments, and discharge processes best practices. Proposals for post discharge treatment environments and tracks will follow.

The document will conclude with examples of assessment and treatment for patients with different forms of IDD/RC and SUD, including assessment leading to an individual treatment plan.

Appendices include different assessment instruments and descriptions of levels of care.

Persons with Intellectual and Developmental Disabilities and Related Conditions (IDD/RC)

IDD/RC encompass a broad spectrum of intellectual functioning and developmental variance including difficulties in learning, reasoning, problem solving, or other skills and/or deficits in adaptive behavior including life and social skills.¹

Broadly, IDD/RCs are a set of heterogeneous conditions with a variety of legal, medical and educational definitions. They involve deficits in cognitive skills including the ability to learn, reason and solve problems as well as differences in adoptive behavior, and these traits develop before the age of 22.²⁻⁴ The deficits can be the result of inborn errors of metabolism, maternal infections during pregnancy, maternal intoxicant ingestion, maternal trauma, genetic or chromosomal conditions (Down Syndrome, Fragile X, etc) or other stressors on maternal health (starvation, extreme stress). Complications immediately after birth or in the early years of development (kernicterus, head trauma, infection, malnutrition) can also lead to difficulties. There is extensive research on the variety of conditions leading to delays.^{5,6}

For the purposes of this document we will be focusing on persons with ongoing disruption in intellectual and social functioning and learning. We will present data on intellectual deficits that appear after adulthood (traumatic brain injury, e.g.) as they significantly affect both learning and disrupt social functioning. We will not include the problem of dementia or severe declines in function in later life although these persons can develop or have substance use disorders.

According to the CDC, roughly 1 in 6 American children from 3 to 17 have one or more developmental disabilities, and between five to seven million Americans have a developmental disability. These conditions include (but are not limited to) Attention Deficit and Hyperactivity disorder (ADHD), Autism Spectrum Disorder (ASD), Cerebral Palsy, Fragile X syndrome, Tourette Syndrome, Learning disabilities (dyslexia, dyscalculia, dysgraphia), and many others. These conditions affect people to varying degrees – we will focus on those with more profound disabilities that require support.⁸

Epidemiology of Substance Use Disorder in IDD/RC

Definitions of Substance Use Disorder vary across time and across healing/helping professions. Three predominant definitions (from the American Society of Addiction Medicine (ASAM)), the diagnostic and statistical manual V (DSM-V), and the National Survey on Drug Use and Health (NSDUH)) are used in most contexts. ASAM's current definition of Addiction is a "(t)reatable, chronic medical disease involving complex interactions among brain circuits, genetics, the environment, and an individual's life experiences. People with addiction use substances or engage in behaviors that become compulsive and often continue despite harmful consequences."⁹ The Diagnostic and Statistical Manual V (DSM V)¹⁰ reframed the disease as Substance Use Disorder with mild, moderate, and severe designations. The DSM-V lists four categories (impaired control, social impairment, risky use, and pharmacological dependence (tolerance and withdrawal) further divided as:

1. Substance is taken in larger amounts or over longer periods than was intended.
2. There is a persistent desire or unsuccessful effort to cut down or control substance use.
3. A great deal of time is spent in activities necessary to obtain substance, use substance, or recover from its effects.
4. Craving, or a strong desire or urge to use substances.
5. Recurrent use of the substance is resulting in a failure to fulfill major role obligations at work, home, or school.
6. Continued use of substance despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of the substance.
7. Important social, occupational, or recreational activities are given up or reduced because of substance use.
8. Recurrent substance use in situations in which it is physically hazardous.
9. Substance use is continued despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance.
10. Tolerance, as defined by either of the following: A need for markedly increased amounts of the substance to achieve intoxication or desired effect A markedly diminished effect with continued use of the same amount of the substance.
11. Withdrawal, as manifested by either of the following:
(Withdrawal does not apply for every substance.) The characteristic withdrawal syndrome for that substance. The substance is taken to relieve or avoid withdrawal symptoms.¹¹

Further, the manual breaks the disorders down by substance or substance type: alcohol, caffeine, cannabis, hallucinogen, inhalant, opioids, sedative, hypnotic or anxiolytic use, stimulant-type, tobacco or other/unknown.¹² For the purposes of this guide, we will use the DSM-V criteria as studies more frequently use DSM-V codes. The ASAM definition informs our approach that the disease has an underlying genetic and

neurobiological basis outside of the substances used. We will occasionally reference the NSDUH definition in the context of referencing their studies.

The prevalence of SUD in persons with IDD/RC is estimated to range from 2.3% to 6.4%^{1,13,14}. According to data from the National Survey of Drug Use and Health, persons with IDD are more likely than those without to have SUD, but are less likely to have access to treatment. Specifically, per the IBM Watson Health study, persons with IDD were more likely to have opioid use disorder than those without in a Medicaid database (6.6% vs 4.2%) but were much less likely to have a prescription for medications intended to treat addiction (11% vs 32%).¹⁵ Persons with IDD/RC are less likely to receive therapy for SUD than persons without disabilities (PWD).¹⁶

In a survey of clinicians, community organizations, consumers of SUD treatment or IDD/RC treatment, research teams, national organizations and federal partners, more than half the respondents noted difficulties accessing treatment in persons with IDD/RC.¹⁵ In the survey, respondents cited physical barriers, lack of confidence in treating persons with IDD/RC, insurance policies not reimbursing for treatment, difficulty generalizing treatments to from PWD to persons with IDD/RC, and lack of medications being prescribed.

Therapists, physicians and others providing SUD services professed a lack of confidence in being able to provide adequate services to those with IDD/RC and those providing IDD/RC services professed a lack of training in SUD treatment. As a result, many treatment facilities that provide services to either population barred either persons with SUD or persons with IDD/RC from treatment. Precise data regarding the extent of this practice is not available at the time of this writing as they are not tracked.

In Utah, Medicaid does cover substance use disorder treatment at all levels of treatment, but does not subsidize sober living accommodations after treatment. Medicare does not cover residential treatment, so persons who have granted full disability and have Medicare as a payment method are not eligible for residential treatment.

Summary Points:

- Persons with IDD/RC are more likely than PWD to have SUD, but receive treatment at a lower frequency than PWD.
- Barriers to treatment include physical barriers (lack of ADL accommodations), policy barriers (policies barring persons with IDD/RC from treatment), and perceived inability to provide services due to training gaps.

¹ One study noted a rate of over 30%, but this was a limited self report study of persons in residential care during COVID-19, and does not account for the elevated rates of SUD in hospitalized patients.

Part of the purpose of this manual is to help close those gaps in training.

SUD in persons with IDD/RC – known patterns of presentation

Surveys of persons with substance use disorder found that 6.2% had SUD vs 1-3% in surveys of the general population. It appears that SUD begins in early to late adolescence in most cases, which is similar to that of the general population. The most frequent preferred substances include alcohol, tobacco (nicotine) and both of these outnumber other illicit substance use.¹⁷ Approximately 7-8 million persons with IDD/RC suffer from SUD in the US¹⁸, and 191,000 were living in Utah at the time of the 2020 Census.¹⁹ Relative to the general population, persons with IDD/RC are less likely to receive treatment or screening for SUD.^{20 21}

Persons with IDD/RC and SUD have varying characteristics across studies. Consistent findings include persons with lower SES, members of minority groups, are more often male than female. Alcohol and tobacco are the most common intoxicants used, followed by cocaine and inhalants³³. In one program the breakdown of persons with cognitive dysfunction was 59% with alcohol use disorder, 18% with cannabis use disorder, 15% had stimulant-type use disorder (including amphetamines and cocaine), and 4% had opioid use disorder.²³ Other small scale epidemiological studies only offered percentages for alcohol and tobacco use.

One study of admitted patients (into treatment for IDD/RC) showed no difference in adaptive skills, but did have a more palliative coping style and a greater prevalence of emotional and/or behavioral problems.²⁴

Tobacco Use Disorder is the most common substance use disorder in the IDD/RC population. In an older study it was noted that 20% of those with IDD/RC living independently in the community smoked (vs 3.1% living with family or friends and 5.2% living in a care facility).²⁵ Persons with mild intellectual disabilities appear to be more likely than those with more profound difficulties, which may be associated with their living situation.²⁶ Persons with more than one disability are more likely to smoke, with those with three or more disabilities who were living independently having a prevalence of up to 60%.²⁷ Persons without disabilities smoke at an estimated 11.6% rate²⁸, so persons with IDD/RC use tobacco at a much higher rate than the general population.

As with substance use disorder in general, programs for tobacco cessation are targeted at the general population, and far fewer persons with IDD/RC are presented with smoking cessation options than PWD (18% vs 55%). Medical interventions for tobacco use disorder appear to be equally effective in persons with IDD/RC (nicotine products, bupropion and varenicline), but formal independent studies are not available at the time of this writing.²⁷ The CDC has a brochure and other programs available for persons with disabilities, and references Michigan's quit line (which has resources for IDD/RC) and printed and online materials.²⁹

The Ohio State University (OSU) developed a program for smoking cessation for persons with disabilities called the LIFT (Living Independent From Tobacco) program. Quit rates are not available at this writing, but

the program is available online and the handouts and training videos created will be included in the appendix.³⁰ New Hampshire developed a general training program for healthcare professionals to assess persons with disabilities. It is not specialized for persons with IDD/RC but does include screening tools that would identify persons with IDD/RC more readily.³¹

Alcohol Use Disorder is next in order of prevalence; up to 50% of persons with alcohol use disorder have a cognitive disorder, but much of this is driven by alcohol itself and is not due to IDD/RC³². Predictive factors for risk in the IDD/RC population include: psychiatric comorbidity (bipolar or schizophrenic disorders), a lack of structured daytime activities, male gender, independent living, and a criminal record.³³ While there are several articles that propose varying treatment modalities, none track outcomes beyond client/therapist satisfaction with the results.^{34,35}

Opioid Use Disorder – In one study from Medicaid recipients, persons with disabilities (Autism spectrum disorder, IDD/RC and TBI) were much less likely than those without to receive medical treatment.³⁶ Further complicating this state of affairs is an elevated incidence of chronic pain in persons with IDD/RC. In an Ontario matched cohort study initial opioid prescriptions were significantly more likely to lead to hospitalization, death, or a diagnosis of an opioid use disorder.³⁷ It is not clear how well standard treatments work in this population. There are many case reports but at the time of this writing there were no prospective and outcome driven studies regarding the treatment for this population in opioid use disorder.

Stimulant Use Disorder. ADHD (one type of developmental disorder) is highly correlated with stimulant use disorder.^{38,39} Cocaine dependence is the third most common substance of choice in persons with mild/borderline intellectual disability in at least one large study,¹³ and as many of one in four persons with ADHD prescribed stimulants overuse or abuse their prescriptions.⁴⁰ Further, amphetamine withdrawal is prolonged and inattention is a central feature of that syndrome, making diagnosing ADHD in those recently recovering from stimulant overuse problematic.⁴¹

There were no studies outlining a percentage of persons with StUD and IDD/RC. There are also no distinct treatment guidelines for this population.

Barriers to Treatment

The National Institute on Disability, Independent Living, and Rehabilitation Research's (NIDILRR) issued a Request for information in 2018. Within those responses, the Cross Colorado Disability Coalition (CCDC) reported several logistical barriers to treatment. Medicaid (the most common source of insurance) would not cover residential treatment and there was a dearth of covered detoxification facilities. Further, mental health and addiction facilities frequently turned away persons with IDD (reasons not cited). Persons with a serious physical disability requiring physical assistance were not accepted at most psychiatric or behavioral health facilities.¹⁵

Additionally the dearth of research on the treatment of SUD in IDD/RC poses some difficulties for developing and executing treatment plans. This lack of research was recognized as early as the mid 1990s. Early calls for change mostly called for SUD treatment to be centered in separate facilities rather than integrated into the existing process.²⁵ In an updated TIP, SAMHSA proposes adapting mainstream facilities so as to expand access to those with IDD/RC. Adaptations include having all facilities perform a client pathway analysis – identifying physical barriers (e.g., parking, ramps, bathrooms), policies, and treatment materials (large print, language grade level) as well as staff bias. Having staff take the disabilities implicit attitudes test and then review materials on how to provide better care to those with disabilities. Further, providing cognitive testing for all entrants to treatment in addition to other psychological assessment²⁶ tools to ensure that the program is aware of client needs. As all programs are required to provide an individualized treatment plan for clients already, incorporating an assessment of physical and cognitive needs of individual clients would not impose a burden on most programs.²⁶

Housing insecurity is prevalent for all persons with IDD/RC in Utah due to a lack of accessible and affordable housing.⁶² Utah does offer waivers for Medicaid for persons that meet financial and medical qualifications that can subsidize housing costs at a skilled facility or in the person's home.⁶³ Cited indications for housing assistance do not include ongoing treatment for substance use (through sober living or otherwise). Through the Independent Living Research Utilization (ILRU), persons with IDD/RC can find assistance in locating housing resources and applying for state and independent funding.⁶⁴ While there are a variety of resources for persons with IDD/RC, none of these cover ongoing housing while in treatment.

The burden of locating resources for treatment falls on the individual with substance use disorder. Persons with training in addiction treatment have little training in caring for persons with IDD/RC, even the 85% who have mild impairment and have expressed discomfort with their capacity to provide adequate care. Many facilities offer no physical or programmatic adaptations for IDD/RC, and when there are inpatient or residential facilities that offer adaptations, there are not adequate facilities for long term care⁴. In Utah, Medicaid current (2025) does cover residential or inpatient treatment for substance use disorder treatment, but does not provide coverage for sober living or appropriate residencies after finishing residential treatment. Sober living facilities are regulated, but those regulations do not provide for care for those with IDD/RC.^{27,28} Proposals to adapt existing IDD/RC facilities to care for SUD treatment are generally unrealistic

outside those who need ASAM level 1 (outpatient only) care. Proposals to separate treatment for those with IDD/RC from the standard population are in violation of the ADA and have not received much attention.

In one smaller study that regarded gender as well as IDD/RC status indicated that women are less likely to receive treatment for SUD than men.⁶⁷ Persons in non-urban areas and non-white persons had a higher rate of using substance use disorder treatment than those in urban areas and who were described as white in Medicaid data.

Summary

- The burden of finding treatment currently falls on the individual in the US.
- In Utah, Medicaid and Medicaid expansion plans cover residential treatment (level three care), although Medicare does not. No coverage is provided for sober living or prolonged supervised care after residential treatment.
- Expert opinion supports integrated treatment for persons with IDD/RC with PWD.
- Housing resources don't explicitly support IDD/RC persons during ongoing substance use treatment.

Appropriate Location of Treatment and Staff Training

What support teams/staff should be involved in the care of the patient with IDD/RC and SUD largely depends on the level and intensity of care involved. If the patient is admitted to an inpatient medical or psychiatric facility, generally outside staff should be involved in placement decisions; given the nature of hospitalized care, normal support staff that are not credentialed at the hospital won't be able to participate. Residential treatment is highly specialized and should similarly be located in the developed treatment center. However, physical and communication adaptations that may be necessary should involve the patient's normal support team, as that team will know best what the patient prefers. Conference calls or occasional on site visits *may* help to ease the transition to the site, but we were not able to locate specific studies on the best practice.

For transition to outpatient, the client is usually situated in their normal residence unless they would benefit from a sober living. Sober living homes are regulated at the state level, and are generally ADA compliant, but they are not supported by insurance payments. Costs for a room in a sober living home range between \$600 and \$1000 a month for a shared room plus urine drug screening, and does not include meals or ongoing therapy. Studies of transitioning persons with IDD/RC to community homes (like US sober living) demonstrated improvement when there was clinical supervision²⁹ but there was no comparator group without supervision. Similar studies in the US are not available.

Persons with IDD/RC who require support in the home and who are suitable for level 2 or lower care would likely do well in those settings with ongoing screening through their SUD treatment program. There is a large research gap regarding the best location of care, appropriate staffing, and length of treatment in the post inpatient or residential treatment period. The NIH and American Addiction Centers both call for staff trained in both IDD/RC care and SUD treatment.

In those with IDD/RC, Utah offers extensive support in the community to maintain the highest degree of independence, including behavioral supports, companion services, environmental adaptations, rehabilitation support, supported living and coordination of support services.³⁰ Currently, there is little knowledge of these resources in the SUD treatment community and it is not required that SUD treatment centers are aware of or have training in IDD/RC behavioral techniques. Current statutes and regulations would support coordination of services to best allow persons with IDD/RC to continue in the community (including working with recovery housing), but such use is uncommon. It is likely that providing supports into the client's recovery program would work well.

There was not a study of Utah SUD programs regarding IDD/RC and SUD treatment. A study of California programs demonstrated that staff had little training in IDD/RC care, and program directors did not feel like they had adequate resources to care for them. They did not receive additional money if they cared for persons with IDD/RC. Providers cited time constraints and a lack of interest in IDD/RC care. In cases where resources were approved/provided to augment care, facilities complained that adding these services took too much time. Programs that reported success with treating IDD/RC made minor modifications to their programs (including giving out group questions in advance, etc.) Similarly, directors of residential programs

for IDD/RC expressed a lack of training in SUD and stated they lacked support to perform ongoing treatment after a residential treatment program. They noted a lack of coordination between SUD programs and IDD/RC programs.³¹ Most research calls for effective methods to improve coordination of care, but beyond emphasizing the need to do so there are not practical solutions.³²

What is also clear is that healing professionals need further training to inform them regarding the assessment of the specific needs of individuals with IDD/RC. Addressing implicit ableism, mistaken beliefs and the stigma towards disabled persons. Adapting treatment programs to allow for a flexible application of a treatment program for individuals should enhance overall care and reduce barriers to treatment.⁷²

Summary

- Scientific data on best staffing practices for persons with IDD/RC during SUD treatment are nearly absent
- Current statutes and policy in Utah allows for training and coordination of care support between any living environment and the client's IDD/RC supports, including providing physical, behavioral and communication support in the client's environment.
- Development of best practices for integrating supports that are known to work in the community into SUD treatment structures is indicated.
- Coordination between SUD and IDD/RC programs tends to be nonexistent to the poor, with institutional apathy partially responsible for this gap. Cross training may improve such communication.

Assessment of Substance Use Disorder

We will review the existing tools for assessment of substance use disorder and how they may apply to persons with IDD/RC, then review existing barriers to accessing care for persons with IDD/RC.

Appendix 1 covers the four levels of care available. When assessing a new patient/client properly to initiate care, finding the appropriate level of care is crucial. Triaging patients to an inappropriate level of care worsens outcomes¹⁶ – either placing the patient inappropriately low or high.

A survey of existing programs in California that regularly treat persons with IDD/RC have a variety of approaches. Some had specific curriculum for persons with IDD/RC and one gave those patients questions for groups up to two days before. Overall, most programs expressed frustration regarding inadequate funding and follow up programs for persons with IDD/RC as well as a well thought out program.⁴³

Diagnostic tools for establishing a diagnosis of substance use disorder

When a clinician suspects their client of having problematic use or substance use disorder, there are several potential diagnostic tools available¹⁷. Any provider or therapist can use several of the simpler instruments, most of which are available through the National Institute on Drug Abuse (NIDA) website, which will also provide a score and a scoring sheet to interpret it. It is not established which instrument is best, but most are short, free, and many cover alcohol, tobacco and other intoxicants. However, none of these instruments are validated in the IDD/RC population.¹⁸

One instrument for the IDD/RC population is the Substance Use and Misuse in Intellectual Disability Questionnaire (**SumID-Q**)¹⁹. While other tests may yield useful information regarding the severity of use and consequences, most tests assume knowledge of substances and use terminology, don't account for the tendency of those with IDD/RC to be agreeable to questions asked or to say no in to violating social taboos.²⁰ This instrument provides straightforward language, has visual aids (photos) available and has a simple scoring approach.

Another tool includes the Hayes Ability Screening Index (HASI). This instrument was designed to identify persons with SUD who have IDD/RC, and was found to have a sensitivity and specificity of 78% and 72%.²¹ This tool can be used for all persons in SUD treatment and would not be applied in a discriminating fashion. The Montreal Cognitive Assessment was administered in a single program. In that program, 31% were found to have cognitive deficits, with patients suffering from Alcohol Use Disorder had lower cognitive function.²²

Proposed additions to admissions /assessment to treatment for persons with SUD are to estimate the degree of cognitive impairment and preferred communication styles. The Learning Disability Screening Questionnaire is a seven item questionnaire and places a low burden on the assessor and the individual client, and allows for appropriate assignment of resources with a reported 91% positive predictive value.²³. It

has not been validated in a SUD treatment context but it should fit well within the intake flow and can be easily administered to all patient intakes.

The Communication Device Checklist (ChDCh) evaluates the need for specific alternative methods of communication with clients while not adding significant time to the intake process.²⁴ Utilizing the above outlined process provides a potential intake screening into an appropriate treatment plan.

A study of traumatic brain injury (TBI) patients with mental health problems including substance use disorder concluded that current approaches offered an inadequate integration of care, and that cognitive accommodations should be integrated across care settings and embedded in all stages of mental health treatment.⁵¹

There are several known in depth assessment tools for new patients with SUD; the most widely used is the ASAM assessment, which underwent revision in 2024. It is used by nearly all institutions that provide substance use treatment as an initial overall evaluation and risk stratification tool. The revised edition dropped the 4th dimension of assessment (readiness to change) and added a new 6th dimension (Person Centered Considerations). There are several online training resources for both addiction professionals and for behavioral health workers who do no work in specialty treatment environments. The model suggests continually reassessing clients as they progress through treatment in order to ensure that the client's plan remains dynamic. We will provide a written and video example of how to appropriately review this assessment.

In general the patient/client should be referred to admitted to the highest level of care within any one dimension. If psychiatric or medical admission is called for, it is generally recommended to admit for medical inpatient care.

Initial assessment should involve all six dimensions: Dimension 1 involves their current level of intoxication and associated risks, withdrawal risk, and medication needs for initial and ongoing treatment. Based on this dimension alone patients may be assigned to hospital care (Level 4 care) or social detoxification.

Dimension 2 evaluates known biomedical conditions. The patient's physical condition and associated risks help determine if the patient needs medical monitoring during treatment. Patients with moderate to severe health problems should be regularly medically monitored. Controlling severe health conditions is vital to enabling patients to engage in treatment. Bringing patients up to date on their medical treatment is also an important part of long term recovery.

Dimension 3 involves psychological or psychiatric conditions. Appropriate therapeutic and medical treatment for other conditions are addressed. Dimension 4 has been updated to assess Substance Use Related risks – specifically risks of overdose, or medical, social, or legal risks of current use patterns.

Dimension 5 has been updated to recovery environment interactions, and assesses client safety, functional

impairment, and existing support from persons in their home environment. Dimension 6 is called “person centered considerations.” The assessor investigates willingness to participate in the recommended level of care including any perceived or actual barriers to treatment.

The ASAM basic assessment tools are available freely online, although there will be a paid online algorithm for those who want or need assistance in scoring level of care/triage.

Normally, based on the findings of the ASAM assessment and/or other instruments used during the intake/assessment process the medical and clinical support teams develop an individualized plan of care. Adding the ChDCh, the LDS-Q and SUMID-Q should augment the ASAM process and allow for the appropriate triage and care plan for those with IDD/RC and PWD.

Summary Points:

When a person with IDD/RC is suspected of having substance use disorder the clinician or provider should use one of the many simple screening tests. For persons with mild or moderate IDD/RC we suggest using the SumID-Q.

Using the ASAM criteria as augmented by the LDS-Q and the ChDCh should provide assessment tools that allow treatment facilities to triage patients to the correct level of care and develop treatment plans.

Another approach to assessment of persons with mild IDD/RC is the “Take It Personal! +” assessment. The study involved a 7-11 day baseline assessment, an eleven week treatment phase, and a one month follow up phase. The assessment uses a combination of motivational interviewing (MI) and cognitive behavioral therapy (CBT) [a summary of the program is presented in the appendix]. The study was preliminary and largely was designed to assess the potential for use. The primary outcome was perceived treatment effectiveness, and it was noted to be useful and effective by all subjects.^{52,53}

Withdrawal risk assessments

One key portion of the assessment of the patient when initiating treatment is gauging the risk for severe withdrawal. Some agents have inherently higher risk for death or medical complications than others, although there is no risk free withdrawal process. The assessment should be done by medically trained and licensed personnel with specific knowledge about intoxicant risk. Alcohol, benzodiazepines, barbiturates usually have an elevated risk and require close observation/scrutiny to ensure that the process is safe.⁵⁴

Assessment tools have been developed for individual substances in order to assess severity of illness. For Alcohol Withdrawal there are several, the most commonly used are the the Clinical Institute Withdrawal Assessment Alcohol Scale Revised (CIWA-Ar), the Minnesota Detoxification Scale (MINDS), and the Richmond Agitation-Sedation Scale (RASS).⁵⁵ All of these are readily available online as calculators, but the assessment

should be done by trained medical personnel and should result in referral to the appropriate level of care needed as alcohol withdrawal can result in significant medical complications including death.⁵⁶

For Opioids, the Clinical Opioid Withdrawal Scale (COWS) and Clinical Institute Narcotic Assessment (CINA)⁴⁴, are the most commonly used. While opioid withdrawal rarely results in serious debility or death, the severe discomfort suffered during this period poses a large barrier to recovery for most opioid sufferers and should be treated. Using objective assessment tools to rate ongoing suffering and guide medical treatment during this period has been demonstrated to reduce suffering.⁵⁷

For benzodiazepines and other sedative hypnotics there is the the Clinical Institute Withdrawal Assessment- Benzodiazepines (CIWA-B).⁵⁸ Sedative hypnotic withdrawal has substantial medical risk and should be carried out and result in immediate referral to appropriate levels of care. Seizures and death can easily follow if care is not rendered.⁵⁹

Amphetamines, tobacco, hallucinogens and other drugs don't have readily available scale scores. Appropriate assessment requires expert review and should be integrated into any treatment plan.

Summary Points

- When starting substance use treatment, one part of the comprehensive evaluation must include withdrawal risk.
- Objective tools are available to aid in that assessment and reassessment, although there is not a consensus on which ones are best.
- Using these tools to appropriately place individuals for medical safety is essential.

Suggested Treatment Methods

Research on which therapeutic or treatment techniques are effective in persons with IDD/RC and substance use disorder in general, and in many of the specific subtypes there is no data available.

A small study from the Netherlands evaluated a program (Take It Personal!+) designed for persons with borderline intellectual functioning and substance use disorder.⁷³ The program used motivational interviewing and cognitive behavioral therapy that was modified to use simplified language with repetition. The program assessed the application of the program in twelve clients. The study demonstrated a decrease in severity of substance use for those patients for whom data was available.

Non substance specific treatments that have been shown to be effective include: modified mindfulness programs, Contingency Management, Cognitive Behavioral Therapy, and Medication. All of these have limited data to support use in this population. While goals of treatment vary by program, most focus on either harm reduction and maximizing/optimizing function or focus on abstinence, although there is limited data on which model (harm reduction vs abstinence) is more effective in the IDD/RC population.³⁴ Harm reduction has been shown to be beneficial when compared against required abstinence in severely disadvantaged populations (eg Homeless and severely mentally ill), so it is probable that HR is advantageous in persons with IDD/RC as well.⁷⁵

SAMHSA recommends that all programs do the following:

- Asking simple questions and repeating them if necessary.
- Teaching refusal skills.
- Avoid generalizing, i.e. explain that the same refusal skills that are used at a party can also be used at a bar. Have the individual repeat back a concept to make sure they understand.
- Utilize role-playing.
- saving the individual focus on specific goals, i.e. not cashing their SSI check at a liquor store.
- Address trauma in psychotherapy if it is an issue.
- Medication Assisted Treatment.
- Modify Alcoholics Anonymous (AA) groups.⁷⁶

Cognitive Behavioral Therapy: A series of studies in the Netherlands examined the suitability of CBT for IDD/RC. Treatment outcomes were measured with SUMID-Q. Therapists found that a modified CBT program (with simplified language and the used the preferred communication styles of the client) was feasible with little additional training. Clients demonstrated reduced severity of disease over time.⁷⁷ Modifications included.

Mindfulness: One institution implemented a program for mindfulness in persons with TBI. Staff and residents reported a perception of improved care after implementation.³⁵ Long term outcomes were not collected, and the exact program was not laid out in detail in the methods section. It is also not clear how

well this program generalizes to persons with IDD/RC (as the cognitive deficits in this program were not clearly delineated).

Medication treatment (methadone, buprenorphine or naltrexone) for Opioid Use Disorder for persons with IDD/RC appears to be as successful as in those without disabilities, but far fewer received treatment. It was not clear why the intervention was used less often in disabled persons as most studies were done with chart review or Medicaid coding data.³⁶

Dialectical Behavioral Therapy has been used in persons with challenging behaviors and has demonstrated applicability in IDD/RC. It is not clear if it is applicable in SUD specifically, but it may be useful.⁸⁰

SAMHSA suggests that a modification of the **Illness Management and Recovery (IMR)** model created by the Vineland National Center in Minnesota may be of potential use. The IMR was developed for persons with severe mental illness, and does contain some elements that are directed at reducing substance use. SAMHSA's advisory report suggests the following elements to be included in demonstration programs: Ask simple questions and repeat them if necessary. 1) teach refusal skills.; 2) avoid generalizing; 3) have the individual repeat back a concept to make sure they understand; 4) utilize role-playing.; 5) having the individual focus on specific goals; 6) address trauma in psychotherapy if it is an issue.; 7) Medication Assisted Treatment; 8) Modify Alcoholics Anonymous (AA) groups.^{18,61}

Alcohol Use disorder treatment including CBT, mindfulness, and twelve step facilitation all have limited data in IDD/RC. Medication treatment was utilized within programs, but it was not clear if there were differences in what was used or in outcomes. Data from programs in Ontario and California indicate that programs with adapted versions of their existing programs showed some success with a reduction in alcohol and tobacco use and increased periods of sobriety/reduced negative behaviors. Adaptations included having simplified reading material, visual and video aids (eg alternative learning formats), and providing group material 1-2 days prior to group.³¹

Teaching refusal skills (e.g., focusing on learning to say no and to decline participation in harmful activities) in the residential setting has been shown to increase harm reduction. This program was studied in developmental disability services housing, but should be teachable in level 2 or 3 care. Success in the program was predicted by group attendance rather than individual characteristics such as higher test scores.⁸¹

Stimulant Use Disorder treatment for persons without disabilities in the US continues to struggle to find successful therapeutic and medication treatment methods. The latest SAMHSA TIP on stimulant use disorder does not include IDD/RC in considered subpopulations.³⁷ There were no studies in the literature specifically examining treatment of this substance with IDD/RC despite it (probably) being the third most common set of substances used by that population. The modality that is most successful in persons without disabilities is contingency management. CM centers on giving rewards to persons who have exhibited positive changes in behavior (e.g., reduced use, avoid negative interactions, etc); rewards can be vouchers or

money, or even the opportunity to win prizes.³⁸ Given its simplified structure it may translate well into the IDD/RC population.

Summary

- There are no established best practices for substance use disorder in persons with IDD/RC.
- Most treatment recommendations are based on expert recommendations and small scale studies without hard outcomes.
- Cognitive behavioral therapy, contingency management, dialectical behavioral therapy and mindfulness therapeutic approaches are all likely to work provided that the communication preferences of the individual's clients are honored and adequate time is taken to communicate.
- Individualized and appropriate medical therapy should be offered to all persons with SUD.

Maintenance Treatment (Prolonged Treatment)

After establishing a degree of recovery, ongoing treatment for this chronic relapsing disease is indicated. After an initial period of more intense treatment, clients normally develop a long term recovery plan. Plans should address relevant circumstances and be in the clients' own words.

One small study investigated the utility of developing refusal skills while in either residential or day use facilities for persons with IDD/RC and was applied by regular staff. While attendees showed an increase in refusal skills it is not clear how well this translates into reduced use in the longer term.⁸¹

Summary

- After initial treatment many persons with SUD benefit from ongoing maintenance treatment.
- Encouraging refusal skills does appear to assist ongoing recovery efforts and fits within the harm reduction model (see below).

Harm Reduction

Most substance use treatment is focused on a goal of obtaining abstinence. The last decade has demonstrated that reducing use or making use less harmful. The harm reduction movement has various forms and philosophies, but the overarching themes can be expressed in a few points:

- 1) Intoxicant use exists and will continue to exist – minimizing harm from the substances rather than ignoring damaging aspects;
- 2) Successful policies should be measured by improved quality of life rather than obtaining abstinence;
- 3) Incorporates input from persons who use intoxicants into intervention measures;
- 4) Does not minimize the real harm and suffering that may occur due to intoxicant use.⁸⁴

Harm reduction strategies range from needle exchange programs (or allowing for the purchase of syringes/needles without a prescription), providing HIV PrEP treatment, providing naloxone (opioid reversal agent), providing housing (“housing first” models)^{85–88}. Patients provided with harm reduction are less likely to avoid healthcare services, more often successfully reduce use over time, and have lower rates of overdose. There is no primary research on persons with IDD/RC and harm reduction, but many states and institutions have policy statements regarding its use.

One key component of harm reduction is to not punish individuals who can not achieve abstinence by removing access to resources (medication, housing). Alternate housing accommodations may be necessary if a client is not able to sustain abstinence (e.g., a sober living facility would not be suitable), but homelessness as a punishment for an inability to sustain recovery continuously.

Restrictive housing against the will of the client has not been demonstrated to provide any lasting benefit to the individual or the community.

Summary

- Harm reduction has been shown to increase willingness to participate in the recovery process and early data supports that it reduces use and consequences to sufferers.
- There are no specific data for the application of harm reduction models to the IDD/RC population, although many states have adopted this approach from a policy perspective, so we should anticipate data in the near future.

Case Presentations

Case Presentation 1

Jane, a 34 year old female with mild IDD living at home with her family is brought to her primary care provider with the suspicion that she has been drinking excessively. Jane has denied drinking any alcohol when asked by her parents, but has been observed to be intoxicated on a number of occasions and smells of alcohol at her clinic appointment. Her provider administers the CAGE-AID questionnaire but Jane answers all questions in the negative. Her provider still suspects that Jane is drinking to excess, and refers back to her therapist.

Jane has a therapist that does specialize in intellectual disability. Her therapist administers the SUMID-Q, and is able to ascertain that Jane does, in fact, have a serious alcohol problem. Jane's parents note that she is drinking between 470 and 750ml of hard alcohol daily over the course of the day. Given the amount of alcohol she is consuming, her therapist and her parents agree on a medically driven detoxification program that leads directly into a residential program.

At the residential program, staff struggle with keeping Jane's IV in place and she often refuses medications. As she becomes very agitated medical staff agree to use intramuscular injections to ease her detoxification. Jane feels very isolated and refuses to participate in programming while in the medical detoxification program. Case management approaches her parents about discharging Jane to her home rather than a residential program given the fear that she will refuse to cooperate with ongoing treatment.

Her residential program, in talking to her parents, agrees to consult with her normal therapist. Her therapist agrees to help with the intake process and is initially present to greet her when she arrives. The program, on the therapist's advice, agrees to add more visual and auditory learning modules to their program, to allow Jane to use a tablet to record her assignments, and to have one weekly session with her outpatient therapist a week to help ease the transition. The program involves a mix of CBT and 12 step facilitation, and mixes in movies, audio material and more. On arrival, Jane is started on depot naltrexone (e.g., Vivitrol) and topiramate to reduce her risk of relapse.

Jane finishes the program in ninety days, but her parents are very concerned that she will return to heavy use if she returns home. She is too high functioning to qualify for placement in a residential program. The treatment program identifies a sober living for women that has a level 2.7 program on site. The program offers a skills refusal class and has taken persons with IDD/RC in the past, and has trained staff on IDD/RC therapeutic and behavior management techniques.

Jane completes the program and returns to home, and continues to follow up with her level 2.7 program at level 1 care, while continuing with her previous individual therapist. She continues on her medications and follows up with an addiction medicine physician once a month. She struggles with attending AA meetings, but does find going to USARA helpful and makes a few sober friends there.

Case Presentation 2

Sam is a 24 year old with Downs who has suffered multiple orthopedic injuries and was started on opioids for pain control. Sam complained of escalating pain and had escalating opioid doses and regularly runs out early. His neighbor sells him her “extra” opioid tablets and he rapidly escalates into high dose use. Sam lives in an independent living with professional support. He was employed with assistance prior to his becoming ill and had some access to independent funds. Sam inadvertently overdoses and is taken to a community hospital and is admitted to the ICU for two days, he is discharged to inpatient psychiatry as it was not clear if he was suicidal initially.

Sam’s regular therapist and primary care provider were contacted to assume care after his discharge. He was not discharged on buprenorphine as he could not express understanding about how to take the medication. He was not provided alternative means of learning how to take the medication.

Given his overdose and use patterns, his therapist decides that testing for opioid use disorder is not necessary. His primary care does not feel comfortable prescribing buprenorphine to him as Sam is not able to sign an in clinic treatment agreement. He does refer Sam to an outpatient addiction treatment program; his independent living moves him into the supervised residential setting.

He undergoes an assessment at the SUD treatment facility. His residential facility contacts them and lets them know about a few assessment tools. The intake therapist uses an ASAM assessment tool after establishing that he needs simpler questions that don’t fall into his tendency to decline to answer questions. The facility contacts DHHS and arranges for him to have a companion during treatment hours. The facility agrees to take on his medication treatment; the addiction medicine physician obtains his medical records including his psychiatric records. The team meets and develops a treatment program for him that includes avoiding written assignments, uses direct language, and has objectively verifiable goals.

Assessment and Treatment – Process Summarized

- Individuals who are thought to have SUD should be assessed using a validated assessment tool (see appendix).
- As part of the assessment, intellectual capacity and behavioral limitations should be assessed and findings should be incorporated.
- Individuals should be assigned to the appropriate level of treatment.
- The facility and the client should develop an individualized plan including recovery goals.
- If residential or inpatient treatment is required, choose an appropriate location for ongoing recovery treatment afterwards. Modify the treatment plan and goals as the client progresses.
- For patients that are not able to achieve cessation but are able to reduce use, this should not be a reason to force the client out of treatment altogether or deny resources altogether. While alternative accommodations may be needed for persons who are not able to remain physically sober (e.g., a sober living may not be the most appropriate location), the goal of treatment should be to maximize the health of the client.
- Substance Use Disorder treatment can be very successful when appropriate resources are available.

Assessment Tools

National Institute on Drug Abuse (NIDA):

<https://nida.nih.gov/nidamed-medical-health-professionals/screening-tools-resources/chart-screening-tools>

(Includes TAPS (<https://nida.nih.gov/taps2> and other screening tools)

University of Wisconsin has DSM-V checklist available as a word document:

<https://arc.psych.wisc.edu/self-report/dsm-5-checklist-dsm5/>

NIDA Audit (alcohol use disorder identification test) screening:

<https://nida.nih.gov/sites/default/files/files/AUDIT.pdf>

American Society of Addiction Medicine – Intake assessment tool:

<https://www.asam.org/asam-criteria/implementation-tools/criteria-intake-assessment-form>

UCLA has a guide available on how to use the guide:

<https://uclaisap.org/ASAMCriteriaAssessmentInterviewGuide/>

The Current Opioid Misuse Measure is available on the University of Wisconsin Website:

<https://familymedicine.uw.edu/improvingopioidcare/wp-content/uploads/sites/9/2018/02/Current-Opioid-Misuse-Measure.pdf>

The SUMID-Q is currently not available for free.

<https://www.kennispleingehandicaptensector.nl/tips-tools/tools/methode-sumid-q>

The Hayes Ability Screening Index is not available for free – here is a link for purchase:

<https://www.hasi.com.au/pricing/>

The Montreal Cognitive Assessment tool is available for free: <https://www.mocacognition.com/the-moca-test/> . There are both paper options and online/app tools.

The Learning Disability Screening Questionnaire is available here for adults and adolescents:

<https://learningdisabilitymatters.co.uk/tools/>

The Take it Personal!+ program is summarized below. A detailed guide is not available.

ASAM Levels of Care⁹

ASAM has developed a series of categories of treatments that have largely been incorporated in insurance coverage and are used to assess treatment by the state. While description of the system of care is outside the scope of this document, we will provide a brief summary. ASAM revised their criteria in 2024, this summary reflects this update.

Level 1 care is “regular outpatient”. Level 1.0 is long term remission monitoring, 1.5 is Outpatient therapy (usually one individual and one group weekly), 1.7 is Medically managed outpatient (1.5 plus medication management).

Level 2 care is IOP/HIOP. Level 2.1 is Intensive Outpatient (usually 9-15 hours a week of therapy (mix of group and individual). Level 2.5 is High Intensity Outpatient (previously Partial Hospitalization programs 16-20 hours/week of therapy), and Level 2.7 is Medically Managed Intensive Outpatient care.

Level 3 care is residential care. Level 3.1 is Clinically Managed Low Intensity Residential, 3.5 is Clinically Managed High Intensity Residential, and level 3.7 is Medically Managed High Intensity Residential.

Level 4 care is Medically Managed Inpatient. Persons with medical (including withdrawal risk) or psychiatric care that requires continuous monitoring in a hospital environment should initiate treatment in a hospital environment.

There is no evidence to suggest that persons with IDD/RC should or should not be assessed in the same way as persons without disability (PWD). We were not able to locate any formal research into the appropriate risk stratification of persons with IDD/RC for addiction treatment.

Summary Points

- There are four overall levels of care in addiction treatment as noted above.
- There is currently no guidance to suggest risk stratification for persons with IDD/RC.
- As the treatment resources are distributed according to ASAM levels of care, persons with IDD/RC should be assigned to an ASAM level of care in order to integrate into available treatment resources.

External Training Guides

The LIFT program through Ohio State University (OSU): <https://nisonger.osu.edu/education-training/ohio-disability-health-program/tobaccoprofessionals/>

The DHHS/SAMHSA Illness Recovery and Management Program can be found here:
https://library.samhsa.gov/sites/default/files/buildingyourprogram-imr_0.pdf

Take It Personal!+Program Summary

A summary of the 11 week program from the published study. The length of the program can be modified by the therapist.

	Description	Examples
Week 1-2	Motivating to change SU	● Focus on MI ● Exercises (i.e., “Identify problems,” “Cons of SU and pros of changing SU”)
	Psycho-education concerning the personality profile	● Tailoring a game to the personality profile, and discussing it afterwards
	Making a change plan and setting goals	● Mapping future wishes ● Making a change plan ● Setting specific goals (weekly goals are set from week 2 onwards)
Week 3-9	Experiencing personality profile and associated signals of problematic behavior	● Doing a personality-specific game to recognize signals
	Functional analysis of SU	● Making a functional analysis during the sessions (i.e., with use of exercises)
	Increasing self-control skills	● Different self-control skills are discussed and learned through exercises (e.g., seeking distraction and thinking differently)
	Behavioral and cognitive coping skills training	● Practicing skills through exercises (e.g., saying “no” in difficult situations)
Week 10-11	Relapse prevention	● Making a relapse prevention plan

SU=Substance Use; MI=Motivational Interviewing

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