

I/DD SUD Roundtable White Paper

Integration of Services for People with Intellectual and Developmental Disabilities and Substance Use Disorders

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Introduction

In the United States, approximately seven to eight million individuals with intellectual and developmental disabilities (I/DD) have a substance use disorder (SUD) (Bhatt & Gentile). I/DD is distinguished by limitations in intellectual functioning (e.g., reasoning, learning, problem-solving) and in adaptive behavior, which encompasses a wide range of social and practical skills (Tasse, 2016).

I/DD are differences that are usually present at birth and affect the physical, intellectual, and/or emotional development of an individual (NIH, 2021). The American Association on Intellectual and Developmental Disabilities (AAID) defines intellectual disability (ID) as a condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22 (AAID, 2022). The term developmental disability (DD) is a broader category for disabilities that can be physical, intellectual and/or both (NIH, 2021). I/DD is the term often used to describe situations in which intellectual disability and other disabilities are present (NIH, 2021).

Most DD begin before birth and last throughout lifetime. The cause of DD is often unknown and may be a complex mix related to a genetic disorder, birth-related trauma or substance use during pregnancy. Some DD can happen after birth because of injury, infection, stroke, or other factors. DD occur among all racial, ethnic, and socioeconomic groups and include the following physical and intellectual disabilities (CDC, 2022):

- attention-deficit/hyperactivity disorder (ADHD)
- autism spectrum disorder
- cerebral palsy
- hearing loss
- intellectual disability, (including fetal alcohol spectrum disorder, down syndrome and fragile X syndrome)
- learning disability
- vision impairment
- and other developmental delays

The National Institute of Mental Health (NIMH) defines substance use disorder (SUD) as a mental disorder that affects a person's brain and behavior, leading to a person's inability to control their use of substances such as legal or illegal drugs, alcohol, or medications. SUDs can range from mild to moderate to severe and can look different depending on the type of substance use (NIMH, 2021). SUDs occur

Aim

To increase awareness of and interest in closing the gaps in behavioral health and healthcare services offered to individuals with intellectual and developmental disabilities (I/DD) and substance use disorders (SUD).

Who Should Use This Paper?

- People with I/DD
- People with SUD
- Anyone who cares for people with I/DD and/or SUD
- Behavioral Healthcare Professionals
- Recovery Support Specialists
- Family members
- Healthcare Professionals

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when recurrent use causes problems in life areas such as school, work, relationships, and health (SAMHSA, 2022). Risk factors for substance use disorders can include a family history, association with peers, childhood abuse, school problems and mental health issues (CDC, 2020).

Individuals with I/DD are at risk for developing SUDs, including alcohol, cannabis and opioid use disorders (Schijven, Engels, Kleinjan, and Poelen, 2015). Individuals with I/DD and SUD are more vulnerable to the consequences of SUD across all life domains, such as disparate health outcomes, stigma, social isolation, and reduced social functioning. Risky social behavior, which often coincides with SUD, can also place people with I/DD at heightened risk for victimization, such as assault or robbery (Slayter, 2010).

Screening, assessment, and treatment services including the prescribing of medications for people who have both I/DD and SUD often occur separately, with little integration or communication between treatment settings. Additionally, SUD screening, prevention, intervention, and treatment programs are not adapted for use with individuals with I/DD (Duijvenbode & VanDerNagel, 2019). Individuals with I/DD who are in mainstream SUD treatment programs have reported negative experiences with treatment (Baatviet, Thorsheim, & Hove, 2018). When individuals have negative experiences or are not able to understand the intervention they are more likely to drop out of the programs (Baatviet, Thorsheim, & Hove, 2018). A better understanding of the nature of SUD and the intersection with I/DD is needed to better support this population in the areas of prevention, intervention, treatment, and recovery.

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Addressing the Problem

A group of stakeholders from the *Opioid Response Network*, Mid-America Addiction Technology Transfer Center, and University of Missouri-Kansas City Institute for Human Development convened as a workgroup to address the existing gaps in research, knowledge, communication, and service provision for people at the intersection of I/DD and SUD.

The workgroup conducted literature searches and consulted with subject matter experts to learn about the evidence-based practices used for people with co-occurring I/DD and SUD and service gaps that exist. Finally, the workgroup facilitated a roundtable discussion, inviting providers of services in the Mid-America region, to describe their experiences, identify their needs, and share their recommendations.

This paper describes the findings from the searches, information from subject matter experts, and suggestions from the provider discussion groups to address service gaps and the particular needs for individuals at the intersection of SUD and I/DD.

Summary of the Problem

- **Limited availability of screening and assessment tools.**
- **Little to no evidence of research for integrated care.**
- **No models of integrated care or services.**
- **Common promising practices used separately.**
- **No evidence of trainings and competencies for care providers.**

Summarizing the Findings

Literature Search Results

The workgroup conducted a comprehensive search of the literature and resources available on the intersection of I/DD and SUD and developed an annotated resource list of the literature using validated review tools. The search identified a small body of literature on the intersection of SUD and I/DD in research, prevention, and treatment services. Little information was found pertaining to practices used exclusively for both I/DD and SUD (Webb, C., et. al, 2020). A systematic review of articles about individuals with SUD and I/DD found that prevalence rates vary and may not be accurate, systematic screening and assessment is lacking, minimal information on integrated treatment models is available, and more education and prevention programs is needed (Duijvenbode and VanDerNagel, 2019).

Subject Matter Expert Consultations

Members of the workgroup met with multiple subject matter experts, including interviews with Joseph Sakdalan, MD, MPH, PhD (J. Sakdalan, personal communication, May 4, 2021), Ram Lakhan, DPH (R. Lakhan, personal communication, May 7, 2021), and Jonathan Wai, MD (personal communication, July 14, 2022). A workgroup member summarized the National Council for Mental Wellbeing 2022 Annual Conference presentation by Frank E. Shelp, MD (Shelp, 2022). The subject matter experts confirmed the literature search results outlined above and highlighted several major points concerning the intersection of I/DD and SUD.

- Prevalence of I/DD is greater than previously appreciated and goes unrecognized in treatment settings.
- Currently, individuals with I/DD who also have SUD are placed in SUD treatment programs that are not equipped to address and meet their needs.

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- There is more than one type of I/DD and some severely affect cognitive functioning more than others. Identifying the number and type of I/DD that exists with SUD is critical in designing appropriate treatment. I/DD can include: Attention-Deficient/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Social Communication Disorder (SCD) and Specific Learning Disorder (SLD), Down Syndrome, Fragile X Syndrome, and Fetal Alcohol Spectrum Disorder. Some people may have more than one disorder in the I/DD classification.
- Individuals with I/DD have specific needs related to SUD treatment due to possible limited capacity to integrate new learning and knowledge, heightened impulsivity, reduced impulse control, and limitations with future-thinking and goal setting.
- Effective programs for providing care for people with I/DD are available, but treatment needs vary based on the specific type of I/DD disorder.
- No accepted protocols, screening tools, or practice guidelines for treating individuals with I/DD and a co-occurring SUD have been identified.
- Separate screening tools exist for individual disorders, but multiple screening tools would need to be used to separately to identify I/DD and SUD. Staff would have to be trained and qualified to administer multiple screens.
- Co-occurring ADHD and SUD have the most promising evidence for screening, treatment and diagnosis using a combination approach of medications and psychotherapy (Crunelle, et al., 2018).
- Individuals at the intersection of I/DD and SUD have unique vulnerabilities as they have traditionally been protected by family members and supported housing. In recent years, many people may have been integrated into the community where they are vulnerable to exploitation and abuse.
- Individuals with co-occurring I/DD and SUD may have complex medication needs as medications essential in the treating of both disorders may interact adversely. A team approach for treatment and careful monitoring are beneficial (Allen, 2019). (See pull out box)
- The most commonly used substances by individuals with I/DD are alcohol, tobacco, marijuana, methamphetamine and other stimulants, and inhalants.
- Inhalant use is of particular concern due to ease of access, availability, and lack of detection.

Medication Considerations for Individuals with Co-Occurring I/DD and SUD

- Medications are often an essential component of both I/DD and SUD treatment. Utilization of a collaborative team approach in treating co-occurring I/DD and SUD can be effective in assessing the interactions, risks, benefits, and potential adverse effects associated with any medication treatment.
- Medication for SUD treatment is often under-prescribed for individuals with I/DD (Allen, 2019).
- Medication compliance is achievable and can be supported by family members etc. (Allen, 2019).
- There is the potential for dangerous interactions between medications used to treat mental disorders and SUDs, and other medications that people with physical and cognitive disabilities may be prescribed. For example, anticonvulsant medications—which people with I/DD may take can interact with methadone (SAMHSA, 2019).
- When starting and titrating medications for SUD treatment, always monitor patients carefully for benefits and adverse effects (Allen, 2019).

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- Individuals with I/DD and SUD can be supported in treatment and community settings by using simpler, more visual models of existing tools, shortening group sessions, developing individualized treatment, utilizing community supports and decreasing isolation and loneliness in recovery.
- Family support and resources for caring for people with I/DD is critical for long-term health and success.

Roundtable Discussion Results

Professionals with expertise in treating people with I/DD and SUD were invited to a roundtable discussion about the need for integrated evidence-based practices for those with I/DD and SUD. The workgroup members facilitated large and small group discussions about the providers' experiences and suggestions for closing the gaps in services in the Mid-America region (Kansas, Missouri, Iowa and Nebraska).

Twenty-three professionals participated in a roundtable discussion on June 26, 2021. Discussions were convened virtually and focused on three areas: prevention, treatment, and recovery. Each professional had the opportunity to contribute to each of the three focus areas.

Participants' input and ideas were recorded and are summarized in the following points and further illustrated in the tables.

People with I/DD can and do struggle with SUD.

Prevention, treatment, and recovery needs are not adequately addressed for individuals with co-occurring I/DD and SUD.

There is a lack of awareness among families, communities, and professionals concerning the intersection of I/DD and SUD.

No substance use screening tools are validated for use with individuals with I/DD and protocols are not available to meet the needs for identifying individuals with co-occurring I/DD and SUD.

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June 26, 2021 Virtual Roundtable Discussion Concerning Service Gaps related to the Intersection of I/DD and SUD.		
I/DD/SUD Prevention Needs		
Public administrators, consumers, and guardians need awareness and involvement in addressing issues and programming gaps.	There is a lack of adequate training and education in both I/DD and SUD for all levels of professionals including medical professionals.	There is a lack of opportunity for I/DD/ SUD treatment and research professionals and families/caregivers to interact and come together.
Education about the intersection of I/DD and SUD is lacking.	Lack of funding is a barrier for research, education, community services, and collaborations.	
I/DD/SUD Treatment Needs		
I/DD are often unidentified when an individual presents for SUD treatment.	There is a lack of assessment/screening tools.	Intake tools need to be designed with prompts for identifying I/DD.
Treatment adaptations need to be made to support individuals with I/DD and SUD.	SUD professionals lack training in I/DD. I/DD professionals lack training in SUD.	For individuals with communication deficits, support is needed to assist with communicating feelings and needs and the individual's understanding of treatment.
Protocols to assure that each individual is in the appropriate level of treatment in the best setting are needed.	Protocols that identify which treatments are most appropriate for the different types of I/DD are needed.	Treatment reimbursement is an issue due to the individualized needs of the I/DD population.
I/DD/SUD Recovery Needs		
Stigma for individuals and family members needs to be addressed. Stigma can prevent individuals from accessing treatment or services at the appropriate time, level and setting. Stigma can result in individuals with I/DD being taken advantage of or targeted for abuse.	Opportunities for developing healthy long-term supports and relationships are needed.	Support is needed in recovery to stabilize family relationships including reunification with children.

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Suggestions/Recommendations:

- Develop professional development and training programs and opportunities for all levels of I/DD and SUD professionals
- Develop screening and intake tools to identify individuals with I/DD and SUD and to determine the appropriate treatment methodology and setting.
- Provide supports and develop protocols to assist individuals who have been separated from their children.
- Explore funding issues to encourage research and reimbursement for individualized treatment options.
- Include family and other support persons in prevention, treatment, and recovery.

I/DD and SUD Training Needs

Roundtable Participants identified the following needs to expand the behavioral health workforce, close service gaps, and increase prevention, treatment and recovery effectiveness.

- Awareness of the prevalence of I/DD and SUD and of the gaps in service
- Awareness and knowledge of vulnerabilities and disparities to address stigma
- Knowledge of screening and assessment tools
- Knowledge of evidence-based interventions and treatment approaches
- Knowledge and skills to deliver evidence-based approaches
- Skills to identify all types of I/DD for SUD professionals

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Equity in Delivery of Care

In addressing a lack of awareness, closing service gaps, and delivering effective treatment for individuals at the intersection of I/DD and SUD, the workgroup recognized the importance of understanding the intersection of the racial inequities and disparities within our care delivery systems.

We understand there is a significant gap in access to services because of racial segregation, mistrust in the medical system, the criminalization of Black and Indigenous people of color (BIPOC) who use illicit substances, and the overall stigma for people with I/DD and SUD. White people seek treatment earlier than Black people and many Black people receive treatment only after they've been mandated by the court system (Cook, 2013). Latinx people are half as likely to seek treatment at all. These delays in care impact overall health outcomes.

When we consider the adverse childhood experiences (ACES) as reported by parent or guardian, we see a higher impact on the mental health and health outcomes of Black and Latinx people compared with White and Asian people. Data from the 2016 National Survey of Children's Health (NSCH) shows that Black and Hispanic children and youth in almost all regions of the United States are more likely to experience ACES than their White and Asian peers. These racial disparities may be attributed to the long-term impact of discriminatory and unequal systems, policies, and practices such as unfair housing and employment, law enforcement biases and immigration policies that disproportionately affect Black and Hispanic children. (Sacks and Murphy, 2018). The table illustrates the breakdown of children in the U.S. who have two or more adverse experiences according to the NSCH report.

As we explore the intersection and needs for integrating services for people who have I/DD and SUD, it is imperative that we also highlight the larger gaps for BIPOC people.

Percentage of Children in the U.S. who have two or more adverse experiences broken down by race.

Source: Sacks and Murphy, 2018

Race/Ethnicity	Percentage
Black	33%
Latinx	21%
White	19%
Asian*	5%

*The relative confidence level for this percentage is greater than 120% and should be interpreted with caution.

Next Steps

Promising Approaches

Members of the workgroup gathered resources on the types of interventions used with people with I/DD and SUD and identified several tools as promising approaches that may be used for both.

Some models of care are used in the treatment of both individuals with I/DD and SUD. For example, Cognitive Behavioral Therapy and Motivational Interviewing are used by providers for assisting people with I/DD and SUD. Others have been used exclusively for one or the other group and could potentially be adapted for both. The table below outlines some models the workgroup considered as interventions or promising approaches that could be applied and studied for the treatment of co-occurring I/DD and SUD.

Applied Behavioral Analysis (ABA) therapy: ABA therapy is often used to treat individuals with ASD and other I/DD. Utilizing ABA therapy with adults with I/DD includes teaching the behaviors needed

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to function in the community, school, or in the home. It can also help to reduce severe behaviors that may limit ability to function in school, or in the community, and that may endanger an individual with I/DD (Warren, 2022).

Screening, Brief Intervention and Referral to Treatment (SBIRT): SBIRT is a process used in primary medical settings to screen, have brief conversations with and to refer people, when applicable, to treatment for their SUD (SAMHSA/SBIRT, 2022). SBIRT may be used in different healthcare settings, and the context for implementation and types of strategies used to support implementation may vary by setting (Thoele, 2021).

Cognitive Behavioral Therapy (CBT): CBT is a form of treatment that has been effective for a range of problems including depression, anxiety, substance use, eating disorders and other mental health problems. CBT is also effective for individuals with mild I/DD and ASD (Informedhealth.org, 2016).

Dialectical Behavioral Therapy (DBT): DBT was developed by psychologist Marsha Linehan to treat suicidal behavior in individuals with borderline personality disorder. It is a flexible, stage-based therapy that combines principles of ABA, CBT, and mindfulness. The foundational premise of DBT is on helping individuals learn both to regulate and to tolerate their emotions (American Psychological Association, 2022). DBT is seen as a promising approach for I/DD, as it has been shown to effectively reduce challenging behaviors in other emotionally dysregulated populations (Brown, et al., 2013). Several randomized clinical trials have found that DBT may be helpful for individuals with SUDs who have co-occurring disorders or who have not responded to other evidence-based SUD therapies. (Dimeff and Linehan, 2008).

Motivational interviewing (MI): MI is an evidence-based approach to behavior change. MI is a style of communication designed to strengthen personal motivation for and commitment to change a particular goal. MI began with a focus on the treatment of SUD in the 1980s and since, has proven effective in other areas of behavioral and health care. For example, MI research supports the effectiveness with adherence to treatment, achieving treatment goals, and for dental and other healthcare improvements (Miller and Rollnick, 2013).

Promising Approaches that may be adapted for the intersection of I/DD and SUD							
Approach Name	Applied Behavioral Analysis (ABA)	Screening, Brief Intervention, and Referral to Treatment (SBIRT)	Cognitive Behavioral Therapy (CBT)	Dialectical Behavioral Therapy (DBT)	Motivational Interviewing (MI)	Contingency Management (CM)	Contingency Reinforcement and Family Training (CRAFT)
I/DD	X		X	X	X	X	
SUD		X	X	X	X	X	X

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Call to Action

The I/DD and SUD workgroup's literature search, consultations with subject matter experts, and roundtable discussions confirmed that much work needs to be done to address the needs of individuals with I/DD and SUD. Those individuals at the intersection of I/DD and SUD need integrated prevention, treatment, and recovery services. Integrated services can only occur if there is expanded education and training for the community, healthcare professionals, and the behavioral healthcare workforce. Awareness, education, and expanded services will assist in closing I/DD and SUD service gaps, reducing health disparities, and providing equitable care for all people, including those at greatest risk for health disparities. The workgroup members, subject matter experts, and the roundtable participants recommend the following actions to support individuals at the intersection of I/DD and SUD.

Prevention Call to Action

- Raise awareness of the needs of people with I/DD who also have SUD and the gaps that are present in evidence-based prevention, treatment, and recovery approaches.
- Inform decision and policymakers of the standards of care necessary to improve access to prevention, treatment and recovery supports, and services for people with I/DD and SUD.
- Create universally accessible prevention materials.
- Create and design SUD prevention programs that are adapted to the needs of people with I/DD.
- Provide training for prevention providers to incorporate information about the needs of individuals with I/DD and SUD and their children and families.

Treatment Call to Action

- Increase research around evidence-based SUD treatment approaches for people with I/DD.
- Conceptualize and create a continuum of care for people with I/DD and SUD that incorporates interdisciplinary teams.
- Develop and provide training for SUD treatment and prevention providers on the need for individualized, accessible communication for people with I/DD.
- Develop and provide training for SUD treatment providers on specialized, accessible treatment tools.
- Utilize SBIRT training tools for SUD treatment providers to identify/screen and assess for people with I/DD.
- Produce an abbreviated toolkit to highlight the resources that are available.
- Design adapted treatment approaches for people with I/DD and SUD.
- Provide accessible treatment programs and services.

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Recovery Call to Action

- Provide supports to assist people with I/DD to maintain recovery from SUD.
- Design adapted approaches to reduce stigma for people who have I/DD and SUD.
- Provide tools and resources for parents/family members of people with I/DD, including patient information and strategies for support.
- Include the community in developing resources and supports for those with I/DD and SUD to decrease isolation and vulnerability.
- Utilize organizations that exist to provide I/DD and SUD support and resources. The National Association of State Directors of Developmental Disabilities Services (NASDDS, 2022) provides state specific, education, resources and support for I/DD. SAMHSA provides a coordination and directory of single state agencies for substance abuse services (SAMSHA, 2022).

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