

Brandeis THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

BU School of Public Health

Risky Substance Use Among People with Intellectual, Developmental, & Other Cognitive Disabilities

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NEBRASKA BEHAVIORAL HEALTH PROFESSIONALS WEBINAR – FEBRUARY 13, 2025

Intersecting Research on Addiction and Disability Services (INROADS)

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INROADS Studies

Given higher rates of mental and physical health issues, people with disabilities (PWD) are at high risk of consequences from addiction.

When paired with the fact that health care barriers are generally higher for PWD, it's clear that a **comprehensive picture of how the disability community is affected by alcohol and drug problems is needed.**

The INROADS portfolio includes two projects: (1) INROADS-Opioids (NIDILRR-funded) and (2) INROADS-Alcohol (NIAAA-funded), each of which examine the intersection between substance use and risky use, addiction, disability, and service provision.




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INROADS Teams



<p>INROADS-Alcohol</p> <ul style="list-style-type: none"> • Sharon Reif (MPI, Brandeis) • Rachel Sayko Adams (MPI, BUSPH) • Maureen Stewart • Jake Morgan • Marc LaRochelle • Mary Brolin • Nick Huntington • Margaret Lee • Analytic team • Consultants <ul style="list-style-type: none"> • Ben Cook, John Corrigan, Dennis Heaphy 	<p>INROADS-Opioid</p> <ul style="list-style-type: none"> • Sharon Reif (PI) • Rachel Sayko Adams (Co-PI) • Joanne Nicholson • Monika Mitra • Ilhom Akobirshoev • Mary Brolin • Margaret Lee • Analytic team • Consultants <ul style="list-style-type: none"> • John Corrigan, Dennis Heaphy • And others!
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Substance use, risky use, and addiction among people with intellectual and developmental disabilities

Sharon Reif, PhD

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Session goals




- Setting the stage
 - disability, substance use
- Access to care/barriers
- Adaptations/accommodations
- A couple of abbreviations
 - SUD = substance use disorder
 - IDD = intellectual & developmental disabilities
 - ASD = autism spectrum disorder
 - TBI = traumatic brain injury
 - PWD = people with disabilities

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Setting the stage

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As many as 1 in 4 adults in the US live with a disability

- Disability is an interaction between physiologic impairment, activity limitation, and imposed restrictions
- Operationally:
 - Disabling conditions (e.g., autism, spinal cord injury)
 - Functional disability – serious difficulty with...
 - Hearing, even with hearing aids
 - Seeing, even when wearing glasses
 - Remembering or concentrating
 - Walking or climbing stairs
 - Self-care, i.e., washing all over or dressing
 - Communicating, in their usual language

"Our standard sources of health administrative data do not give us the full picture on disability, and we need other, more equitable ways of identifying disability."

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Substance use and misuse is a major concern

Americans started drinking more during the pandemic and a new study shows that lasted for years

Methamphetamine is a Major Drug Threat in the U.S.

Greater numbers of women are dying of alcohol-related conditions, study finds

We have treatments for opioid addiction that work. So why is the problem getting worse?

Daily marijuana use outpaces daily drinking in the US, a new study says

Cannabis and hallucinogen use remain at 'historically high levels' among young and middle-age adults, survey finds

Alcohol Deaths Have More Than Doubled in Two Decades, Study Finds

Study Links Marijuana Dependence To Nearly Three Times Higher Death Rate

Drinking alcohol is linked to six types of cancer, experts say: 'It's toxic'

Overdose Deaths Decline, Fentanyl Threat Looms

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Substance use, past month, 2023

Figure 1. Past Month Substance Use: Among People Aged 12 or Older, 2023

Substance	Number of Past Month Users
Alcohol	134.7M
Tobacco Products	49.9M
Nicotine Vaping	26.0M
Marijuana	43.0M
Hallucinogens	2.0M
Rx Pain Reliever Misuse	2.2M
Cocaine	1.8M
Methamphetamine	1.6M
Rx Tranquilizer or Sedative Misuse	1.2M
Rx Stimulant Misuse	1.2M
Inhalants	1.0M
Heroin	376,000

Figure 7. Past Month Alcohol Use, Past Month Binge Alcohol Use, or Past Month Heavy Alcohol Use: Among People Aged 12 or Older, 2023

- 134.7 Million Alcohol Users
- 61.4 Million Binge Alcohol Users (45.6% of Alcohol Users)
- 16.4 Million Heavy Alcohol Users (26.7% of Binge Alcohol Users and 12.2% of Alcohol Users)

Note: Binge Alcohol Use is defined as drinking five or more drinks (for males) or four or more drinks (for females) on the same occasion on at least 1 day in the past 30 days. Heavy Alcohol Use is defined as binge drinking on the same occasion on 5 or more days in the past 30 days; all heavy alcohol users are also binge alcohol users.

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Starting perspective

- PWD use alcohol and drugs, as do non-disabled people
 - Adverse consequences, including SUD, are potential outcomes
 - Addiction can happen to anyone, though some have greater risk
- Disability and associated challenges are stigmatized
- Ableism/discrimination frequently preclude societal inclusion and access to services
 - despite statutory protections (e.g., Americans with Disabilities Act – ADA)
- Accessibility and accommodations are essential and enhance person-centered care
- Focus here on SUD + disability, but other conditions and experiences play a role

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Complex interplay of factors related to both disability and substance use

Co-occurring conditions • e.g., medical and mental disorders, other disabilities, psychological distress	Adverse experiences • e.g., trauma, discrimination, social isolation	Adverse social determinants of health • e.g., access to housing, employment, income, insurance, social supports
Substance use as coping strategy, "self-medication"	Substance use has causal role for some disabilities or worsening symptoms	Stigmatization and discrimination

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Substance use and SUD among people with disabilities

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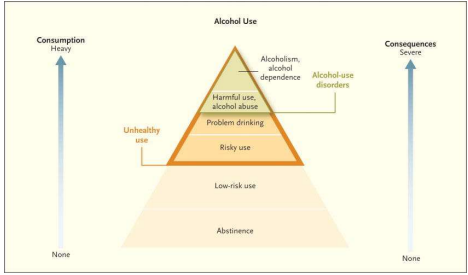


A few comments about addiction/SUD

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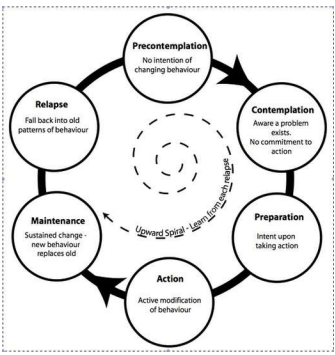
The spectrum of alcohol use



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Stages of Change



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Access to care

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People with disabilities have barriers to good health

- Physically inaccessible health care facilities and equipment
- Lack of health professional knowledge and comfort level
- Being patronized
- Focus on disability when not the key concern
- Experiences are downplayed or not taken seriously enough
 - especially for "invisible disabilities"
- Communications challenges and lack of understanding by providers

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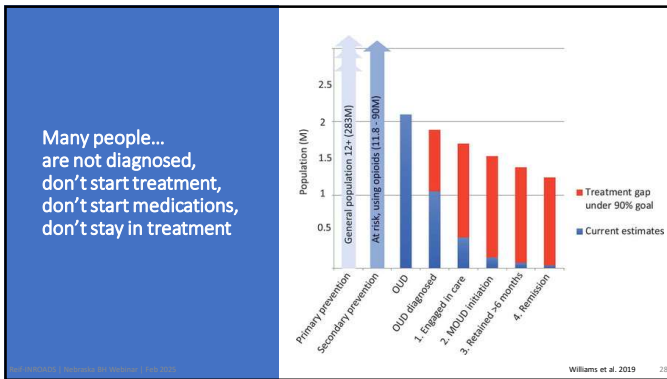
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Wide-ranging barriers to seeking SUD treatment

- Only 15% of people with SUD seek and get specialty SUD treatment
 - Most of those who did not seek treatment do not perceive a need for treatment
- Barriers are wide-ranging and are both individual and structural
 - Not ready to stop
 - Cannot afford / no insurance
 - Stigma / fear of negative repercussions
 - Don't know where to go
 - Can't access treatment they want

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Access to SUD treatment for PWD

- Access to health care generally is inequitable for PWD, with variation by type of disability
- **PWD less likely to seek or receive SUD treatment**
 - despite frequently higher rates of SUD
- **Examples**
 - Adults with functional disabilities and prescription opioid use disorder were 40% less likely to access SUD treatment than non-disabled peers
 - Adult Medicaid enrollees with OUD and disability nearly 50% less likely to receive medications to treat OUD, an evidence-based practice, than non-disabled enrollees

(Lauer et al., 2019; Thomas et al., 2022; SAMHSA; Iezzoni et al. 2011)

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Types of barriers to SUD treatment

- **Person-specific**
 - motivation/readiness, knowledge, resources, concerns about pain or co-occurring conditions
- **PWD-specific**
 - attitudes, discriminatory policies/practices, communications, accessibility, and transportation
 - lack of knowledge and confidence, misperceptions about disability by health professionals
 - invisible disabilities vs visible disabilities
- **Imposed (intentionally or not) by treatment programs/providers**
 - inflexible treatment plans
- **Stigma and discrimination**

(Iezzoni et al. 2022; Yastri 2011)

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Specific barriers – motivation, knowledge, transportation

Barriers to Accessing SUD Treatment	Primarily Affects	Examples
Not ready to seek help	SUD	<ul style="list-style-type: none"> Do not recognize a problem Not ready to stop using alcohol/drugs Lack motivation to change
Don't know where to go	SUD PWD	<ul style="list-style-type: none"> No info about SUD treatment Can't find accessible treatment
Transportation	PWD SUD	<ul style="list-style-type: none"> Cost, accessibility Access in rural areas

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Specific barriers – financial, insurance

Barriers to Accessing SUD Treatment	Primarily Affects	Examples
Financial resources	PWD	<ul style="list-style-type: none"> Income restrictions, higher poverty rates affect out of pocket payments, other costs
Health insurance	SUD, PWD	<ul style="list-style-type: none"> Providers who do not accept public insurance (e.g., Medicaid)

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Can't afford / no insurance

Category	U.S. overall	People with OUD	People with Disabilities
Medicaid	15	42	38
Uninsured	12	10	18
Poverty	11	-	26

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<https://www.kff.org/other/state-indicator/adults-19-64/>
http://www.disabilitystatistics.org/reports/acs_dms?statistics=11
<https://nces.ed.gov/ipeds/data/ipedsdatatool/states.asp>

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Financial barriers faced by people with disabilities

- Multiple ongoing needs for medications, medical procedures, or equipment can become expensive and not always fully covered by insurance
- Higher poverty rates and greater social determinants of health needs
- Public benefits or coverage may limit their financial capacity (e.g., earnings) to cover healthcare costs

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Specific barriers – beliefs and stigma

Barriers to Accessing SUD Treatment	Primarily Affects	Examples
SUD treatment beliefs	SUD	<ul style="list-style-type: none"> • People always relapse • Abstinence means no addiction medications
Disability stigma & beliefs	PWD	<ul style="list-style-type: none"> • Ableism, focus only on disability • PWD don't use substances, will be non-compliant, make others uncomfortable • PWD don't belong – different learning styles, communication, adherence to social norms

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Additional barriers for people with SUD and disability

- Lack of accommodations
- Providers who don't take Medicaid or insurance
- Concerns about pain
- Provider beliefs that medication treatment not appropriate for complex patients
- History of limited accessibility by SUD treatment providers (West 2007)

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Question for the chat – share with your colleagues...

What approaches have you found successful when working with people who have SUD + IDD or SUD + TBI?

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INROADS Issue Brief: Bill of Rights for persons with disabilities and OUD

INROADS Supporting People with Disabilities and Opioid Use Disorder
A GUIDE FOR PROVIDERS

People with disabilities can have opioid use disorder, too. Many people with disabilities, including chronic pain conditions, use opioid medications as part of their pain management program. Unfortunately, many people use opioids other than as prescribed, often leading to psychological and physiological dependency.

Patients or clients with disabilities and opioid use disorder have the right to:

- Receive **disability-informed care**
- Be **asked what they need** to receive treatments
- Be **treated with fairness, dignity, and respect**
- Receive **accessible treatment**
- Receive **accessible information** throughout the recovery process
- **Not to have assumptions** made about them
- Be a **full partner** in making healthcare decisions
- **Engage in their own treatment** just like everyone else
- Have their **self-knowledge** respected

<https://hellr.brandeis.edu/bh/pdf/inroads-oud-disability-provider-guide.pdf>

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Selected adaptations – simplified information

Adaptation	Type of disability	Rationale	Examples
Simplified materials	IDD, cognitive	<ul style="list-style-type: none"> • Limited knowledge or ability to abstract info • More likely to respond yes when do not understand 	<ul style="list-style-type: none"> • Use simple sentences, pictures, graphics, colloquial terms (e.g., weed, not cannabis) • Avoid negative phrases or confrontational items
Simplified communications	ASD	<ul style="list-style-type: none"> • Concrete/inflexible thinking 	<ul style="list-style-type: none"> • Be direct and unambiguous • Minimize non-verbal communication, metaphors

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Selected adaptations – enhance comprehension/retention

Adaptation	Type of disability	Rationale	Examples
Reduce amount of information shared	ID, ASD, TBI, Cognitive	<ul style="list-style-type: none"> Challenges in executive functioning 	<ul style="list-style-type: none"> Provide less info at once Use simpler language, repeat info Provide time for comprehension Take breaks, minimize distractions
Assess/enhance comprehension and retention	ID, ASD, TBI, Cognitive	<ul style="list-style-type: none"> Cognitive functioning & processing speed variations 	<ul style="list-style-type: none"> Use visual tools Have patient summarize/role play Structured homework, routines Written summaries

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Selected adaptations – increase insight and skills

Adaptation	Type of disability	Rationale	Examples
Motivational interviewing	ID, ASD	<ul style="list-style-type: none"> Lack knowledge or reasoning to change behavior 	<ul style="list-style-type: none"> Educate re substance use & specific harms/negative outcomes Increase insight & engage around reasons for treatment
Problem-solving skills	ID, ASD, TBI	<ul style="list-style-type: none"> Reduced insight, motivation to change 	<ul style="list-style-type: none"> Build skills to refuse substance use, address cravings, anticipate impulses, practice alternatives Identify constructive & rewarding activities to replace substance use

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Selected adaptations – flexible treatment approaches

Adaptation	Type of disability	Rationale	Examples
Individual therapy (vs. group-based sessions)	ID, ASD, TBI, Cognitive	<ul style="list-style-type: none"> Group sessions need greater attention span, social/communication skills 	<ul style="list-style-type: none"> Tailor treatment to individual needs & functioning Individual therapy Incorporate cognitive-behavioral (CBT) approaches
Supervised medication use	ID	<ul style="list-style-type: none"> Addiction medications may not be taken correctly or regularly 	<ul style="list-style-type: none"> Supervised administration by family, treatment providers, or others

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Parent/guardian involvement

- Especially for children/young adults
- Parents may consider substance use acceptable self-medication
- Educate parents on alternative coping strategies
- Explicitly state parental responsibilities
- Use similar approaches as for the PWD (e.g. direct, specific, literal)


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Social supports and development of healthy relationships


- May need to be nurtured among some PWD
- Concrete definitions and examples of healthy relationships
- Formulate strategies to improve existing relationships or connect with people who are more positive influences
- Educate family/friends to support healthy coping strategies that are not substance use



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SAMHSA guidance on SUD treatment and disabilities



SAMHSA ADVISORY
Substance Abuse and Mental Health Services Administration

MENTAL AND SUBSTANCE USE DISORDER TREATMENT FOR PEOPLE WITH PHYSICAL AND COGNITIVE DISABILITIES


https://store.samhsa.gov/product/advvisory-mental-and-substance-use-disorder-treatment-people-physical-and-cognitive?ref=from_search_result

Substance Abuse and Mental Health Services Administration
Center for Substance Abuse Treatment

Substance Use Disorder Treatment For People With Physical and Cognitive Disabilities

Technical Assistance Product (TAP) Series

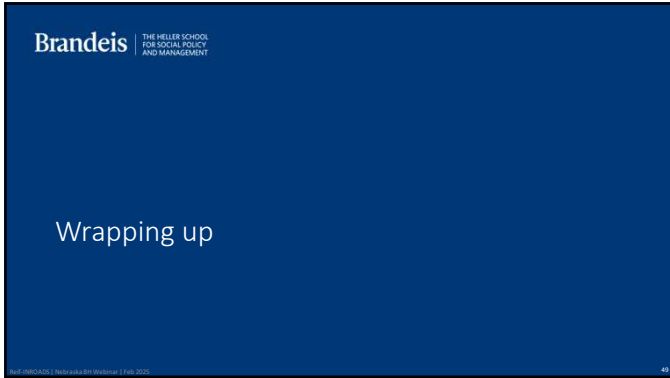
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<https://store.samhsa.gov/product/tip-29-substance-use-disorder-treatment-people-physical-and-cognitive-disabilities>

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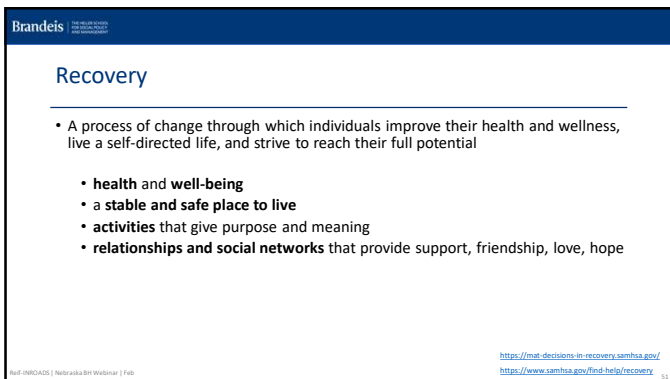
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Conclusions

- Disability is quite common, yet so are discrimination and greater barriers to accessing health care, including for alcohol and drug problems
- PWD drink and drink in risky ways, but less likely to access care
- Best practices
 - Universal approach to accommodations
 - Don't expect PWD to take the burden of ensuring accommodation
 - Screening of PWD for alcohol problems and people with AUD for disability
 - Don't assume only people with visible disabilities have needs
 - Enhance provider training about disability to reduce assumptions and improve care
- Technology can be used to address many disability-specific barriers



TRUST DISABLED PEOPLES' LIVED EXPERIENCES

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Trust PWD lived experience



SUGGESTIONS

- Offer telehealth
- Offer American Sign Language (ASL) translators
- Respect people with disabilities
- Don't assume incompetence
- Listen to access needs

People with disabilities can experience opioid use disorder, too!

It may be harder for them to get treatment due to ABLEISM, which is discrimination against disabled people.

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Thank you! Questions?

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