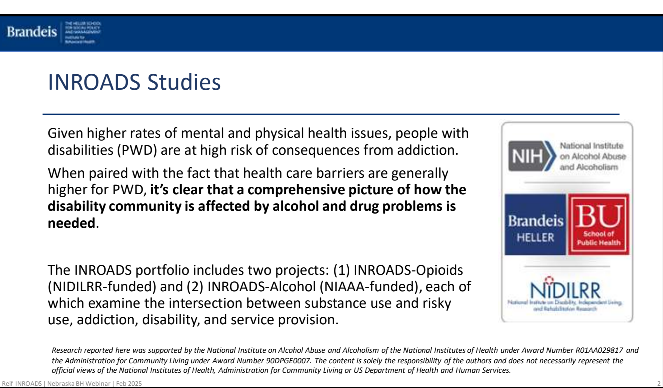
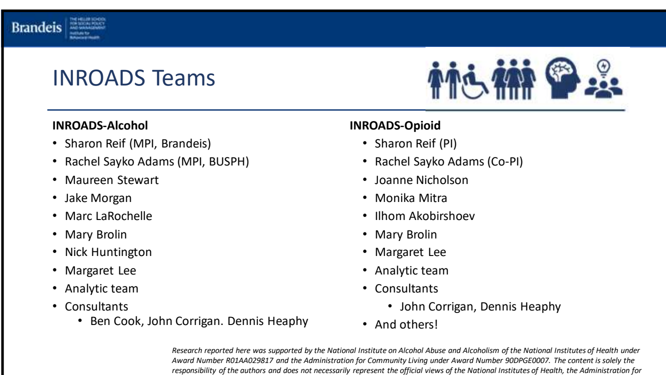
1



2



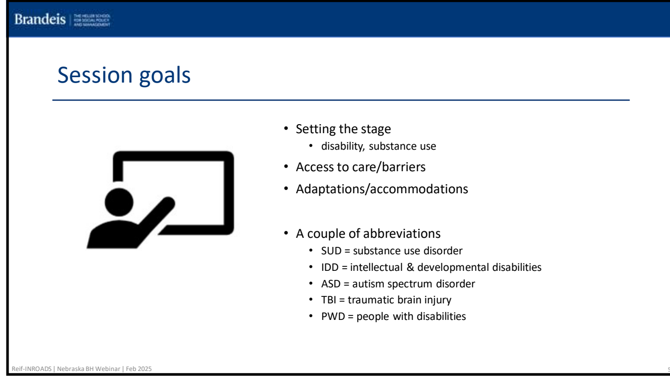
3

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

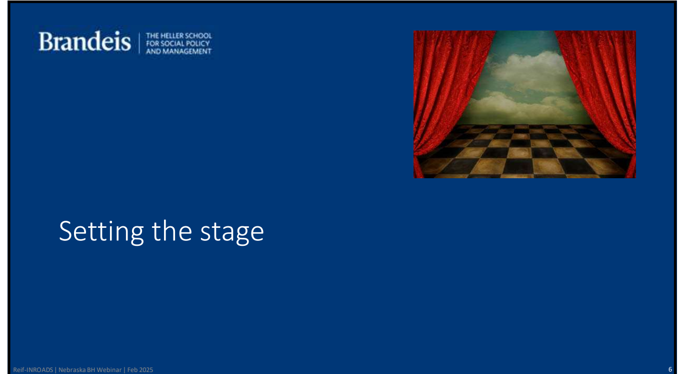
Substance use, risky use, and addiction among people with intellectual and developmental disabilities

Sharon Reif, PhD

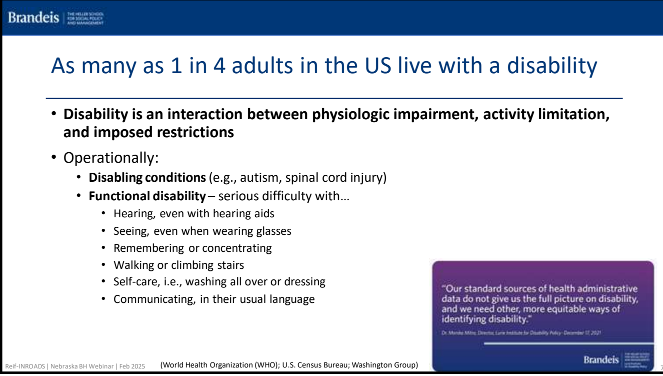
4



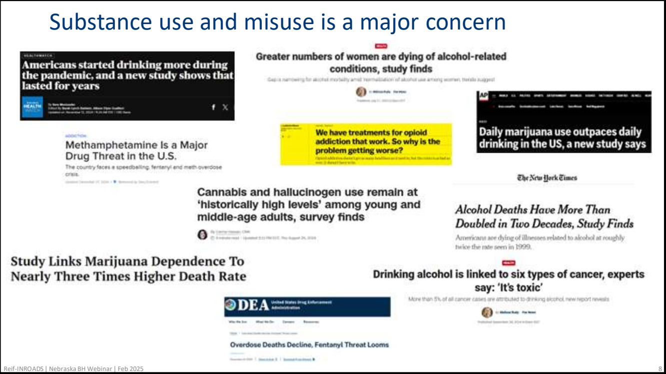
5



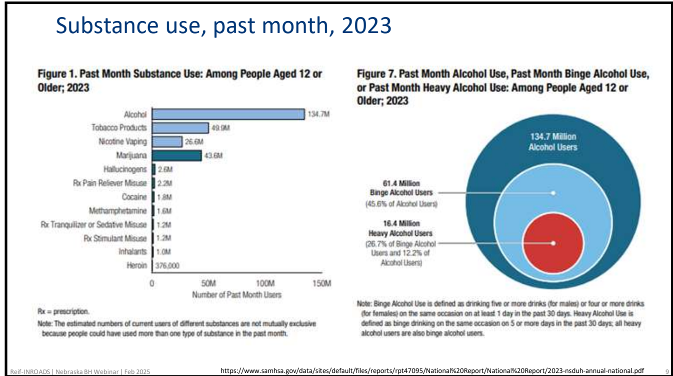
6



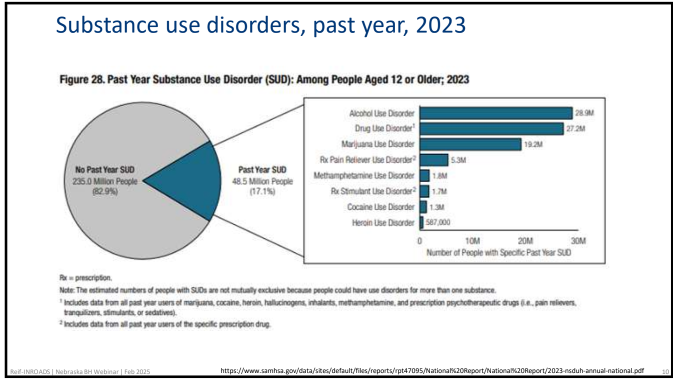
7



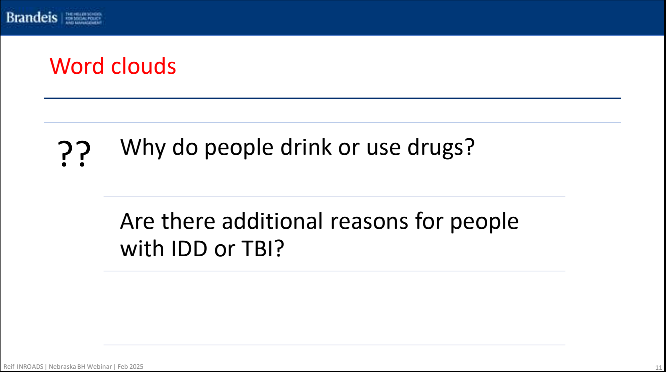
8



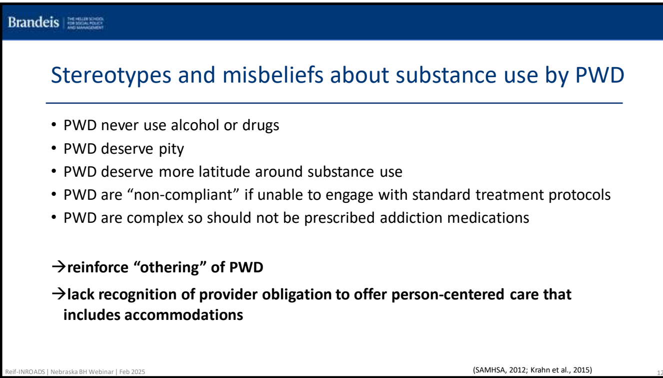
9



10



11



12

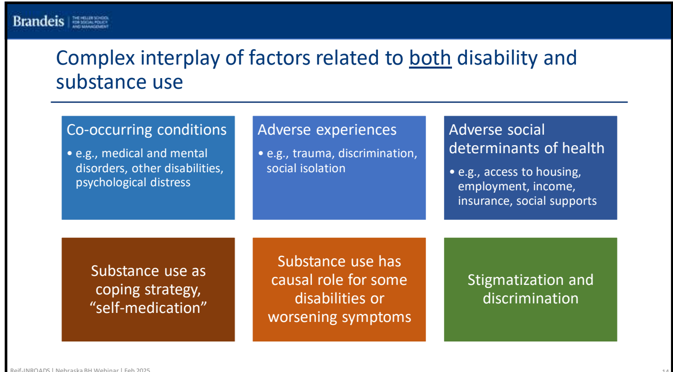
Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Starting perspective

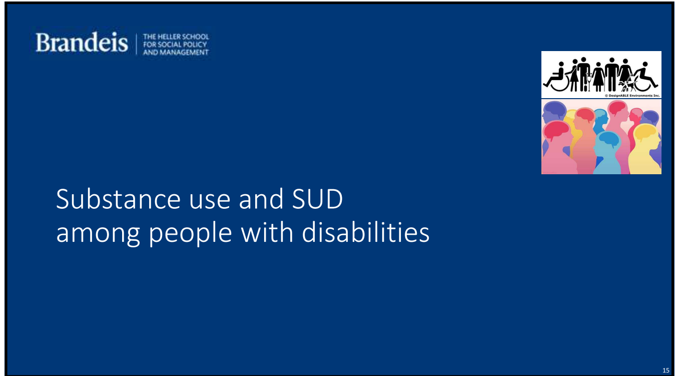
- PWD use alcohol and drugs, as do non-disabled people
  - Adverse consequences, including SUD, are potential outcomes
  - Addiction can happen to anyone, though some have greater risk
- Disability and associated challenges are stigmatized
- Ableism/discrimination frequently preclude societal inclusion 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

Reif-INROADS | Nebraska BH Webinar | Feb 2025

13



14



15

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Disability: Substance use/SUD evidence is still emerging

- **Substance misuse and SUD risk are increased in people with disability**, with higher rates of:
  - high-intensity drinking
  - binge drinking
  - combined alcohol + drug use
  - prescription drug misuse and disorder
  - opioid misuse
  - illicit drug use
  - SUD risk
- **About half of the SUD treatment population has a cognitive impairment**

**Still a small literature, with methodological challenges

Kennedy et al. 2016; Glazier & King 2013; Smedema & Ebener 2010; Burgard et al. 2000; Lauer et al. 2019, Reif et al. 2021; Reif et al. 2022, Collings et al. 2022, Adams et al. 2024)

16

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Role for pain and psychological distress?

- **Increased rates of substance use may be partly related to increased pain**
  - Self-reported chronic pain accounted for up to 38% of the association between disability and any drug use
  - Increased prescription opioid misuse by PWD no longer evident when control for access to prescription opioid medications, an indicator of pain
- **Psychological distress associated with increased substance use and misuse**, even when controlling for disability status, pain, and other variables
  - Self-medication hypothesis suggests people use substances to address psychological distress

(Reif et al. 2021, 2022)

17

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Intellectual Disability (ID)

- **Many people with ID do not drink or use drugs**
- **Reasons** for drinking include
  - being like other people, peer-pressure, reduce boredom, relieve stress, mark or deal with life events
- Of those who use alcohol/drugs, **substance misuse occurs at higher rates and with lower amounts**
  - Concepts of "low risk" or "units of alcohol" in general guidelines may be difficult to understand and apply
  - Higher rates may be related to other risk factors (e.g., co-occurring mental health disorders)
- **Additional risk factors for substance use problems**
  - increased cognitive function & community integration, perhaps related to increased access
  - severe behavioral problems, trauma history
- **Problematic use may not always be obvious or recognized as such**

(Simpson, 2012; Chapman & Wu, 2012; van Duijvenbode & VanDerNagel, 2019; Williams et al., 2018; Roux et al. 2022; Slayter 2010; Bhatt & Gentile 2016; Lin et al. 2016; Kerr et al. 2016; Guan et al. 2022)

18

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Autism Spectrum Disorder (ASD)

- **Opportunities to use alcohol/drugs may be limited**
  - fewer social contacts, literal interpretations of rules, reduced risk-taking and thrill-seeking
- **May use alcohol/drugs to:**
  - reduce social anxiety, seem more "normal", relieve boredom and isolation, cope with problems/irritability/sensory processing
- **Substance use problems may occur more quickly** than the general population
  - Substance use as pleasurable/comforting for people who are less sensitive to typical rewards
  - May become engrained, hyper-focused or repetitive behavior
- **SUD at 2-3 times the rate** of the general population, even adjusting for psychiatric comorbidities
  - Binge drinking higher even among people with autistic traits (regardless of diagnosed ASD)
- People with **ASD + SUD**
  - more psychiatric comorbidities
  - higher rates of social disability, lower quality of life, require more care

(Rengit et al. 2016; Lalanne et al. 2015; Arnevik & Helverschou 2016; Huang et al. 2021; Anderson et al. 2021; Butwicka et al. 2017; Huang, 2021; Isenberg et al. 2021; Roux et al. 2022; Stickley et al. 2023; Rothman 2022; Yule 2023)

Reif-INROADS | Nebraska BH Webinar | Feb 2025 19

19

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

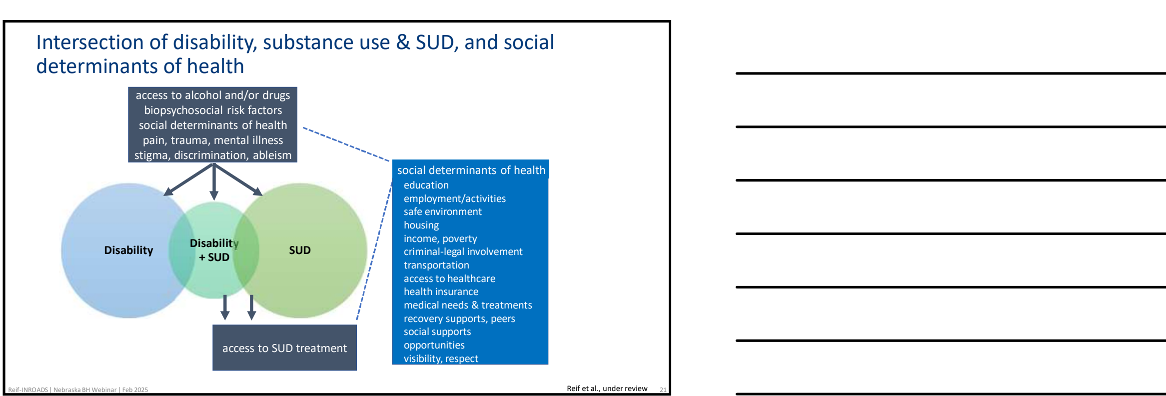
Attention Deficit Hyperactivity Disorder (ADHD)

- **Strong relationship between ADHD and SUD**
  - SUD is most frequently occurring psychiatric comorbidity with ADHD
  - SUD consequences may be higher among people with ADHD than those without
  - Treatment seeking adults with SUD are approximately 3 times have ADHD than general population
  - Risk of SUD is highest among those with ASD + ADHD, which commonly co-occur
- People with SUD + ADHD or SUD + ASD **may start using substances to cope with stress related to their ADHD or ASD**
- People with **SUD + ADHD have more severe cognitive deficits** than ADHD only
- **Prolonged substance use related to difficulties and disorganization in daily living** that are common people with ADHD

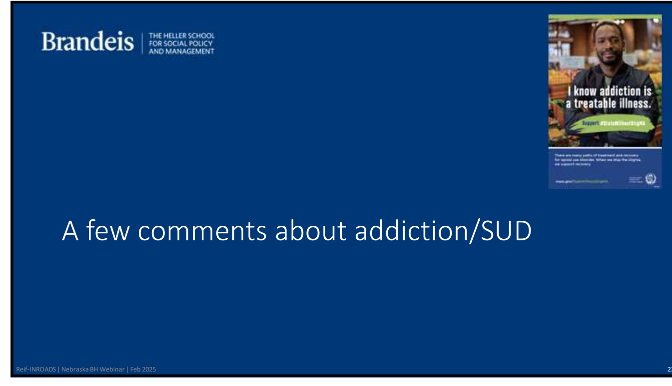
(Weir et al., 2022; Sizoo et al. 2009; Butwicka et al., 2017; Kronenberg et al., 2014, 2015; Yule 2023; Browning 2024; Choi 2022)

Reif-INROADS | Nebraska BH Webinar | Feb 2025 20

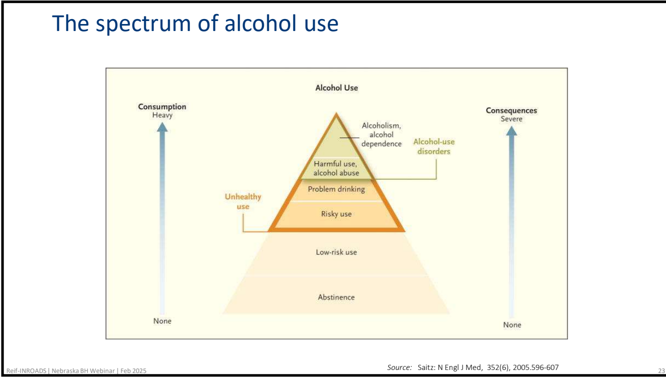
20



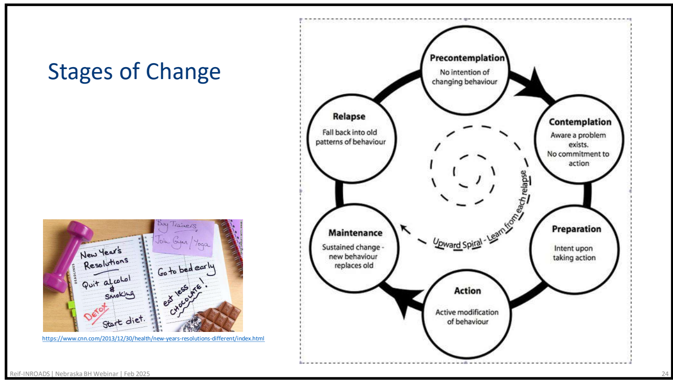
21



22



23



24

25

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

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

Reif-INROADS | Nebraska BH Webinar | Feb 2025 https://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html; http://agerrtc.washington.edu/info/factsheets/healthaccess 26

26

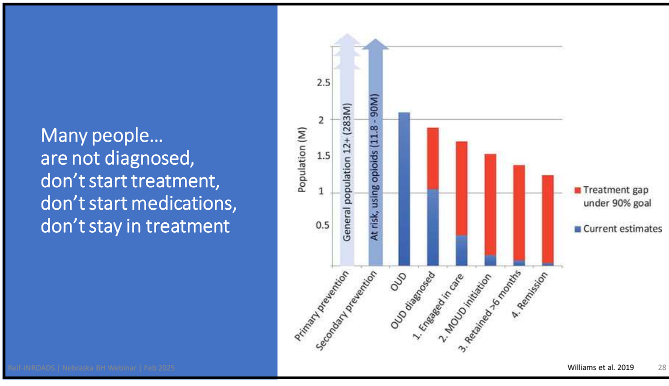
Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

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

Reif-INROADS | Nebraska BH Webinar | Feb 2025 https://www.samhsa.gov/data/sites/default/files/reports/rpt29393/2019NSDUHFFRPDFWHTML/2019NSDUHFFR1PDFW090120.pdf 27

27



28

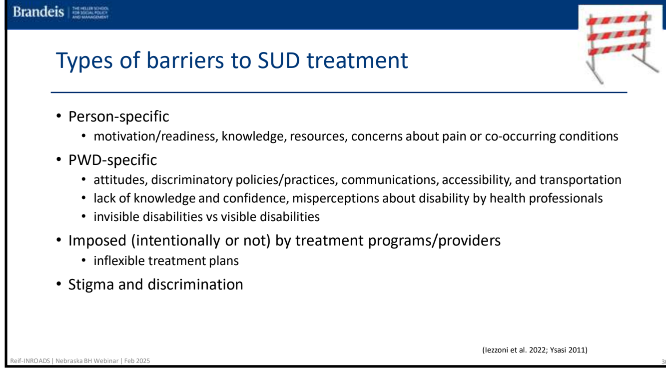
Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Access to SUD treatment for PWD

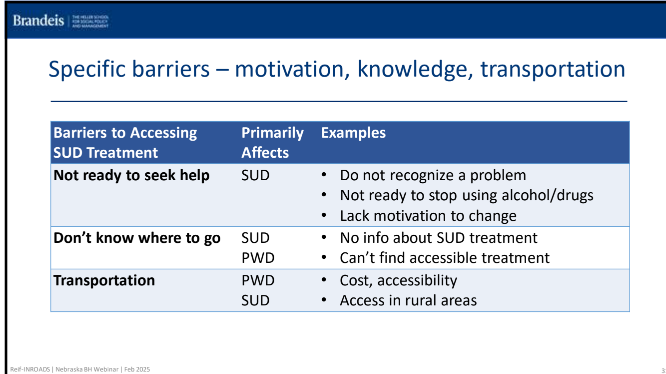
- Access to health care generally is inequitable for PWD, with variation by type of disability
- **PWD less likely to seek or receive SUD treatment**
  - despite frequently higher rates of SUD
- Examples
  - Adults with functional disabilities and prescription opioid use disorder were 40% less likely 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

Reif-INROADS | Nebraska BH Webinar | Feb 2025 (Lauer et al., 2019; Thomas et al., 2023; SAMHSA; Iezzoni et al. 2011) 29

29



30


Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Specific barriers – motivation, knowledge, transportation

Barriers to Accessing SUD Treatment	Primarily Affects	Examples
Not ready to seek help	SUD	• Do not recognize a problem • Not ready to stop using alcohol/drugs • Lack motivation to change
Don't know where to go	SUD PWD	• No info about SUD treatment • Can't find accessible treatment
Transportation	PWD SUD	• Cost, accessibility • Access in rural areas

Reif-INROADS | Nebraska BH Webinar | Feb 2025

31

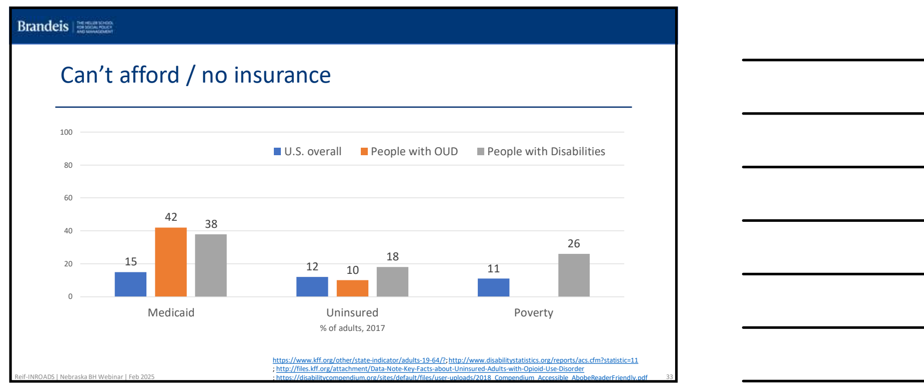
Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Specific barriers – financial, insurance

Barriers to Accessing SUD Treatment	Primarily Affects	Examples
Financial resources	PWD	• Income restrictions, higher poverty rates affect out of pocket payments, other costs
Health insurance	SUD, PWD	• Providers who do not accept public insurance (e.g., Medicaid)

Reif-INROADS | Nebraska BH Webinar | Feb 2025

32



33

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

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

http://agerrtc.washington.edu/info/factsheets/healthaccess

34

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Specific barriers – beliefs and stigma

Barriers to Accessing SUD Treatment	Primarily Affects	Examples
SUD treatment beliefs	SUD	• People always relapse • Abstinence means no addiction medications
Disability stigma & beliefs	PWD	• 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

35

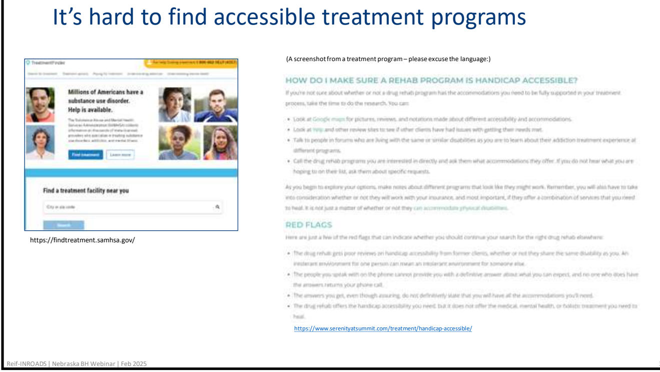
Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

Additional barriers for people with SUD and disability

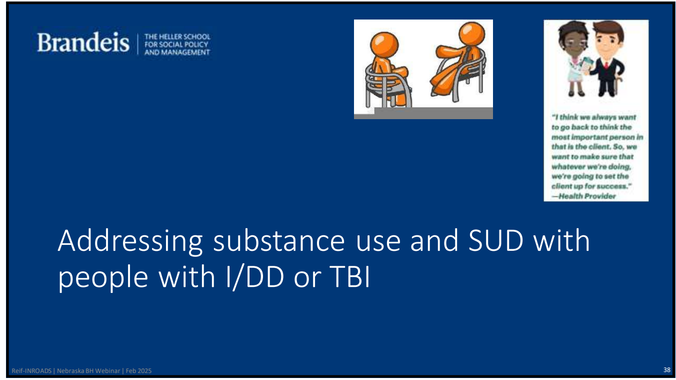
- Lack of accommodations
- Providers who don't take Medicaid or insurance
- Concerns about pain
- Provider beliefs that medication treatment not appropriate for complex patients

- History of limited accessibility by SUD treatment providers (West 2007)

36



37



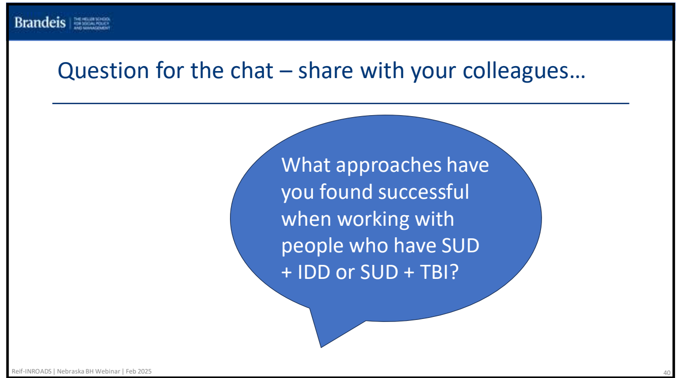
38

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

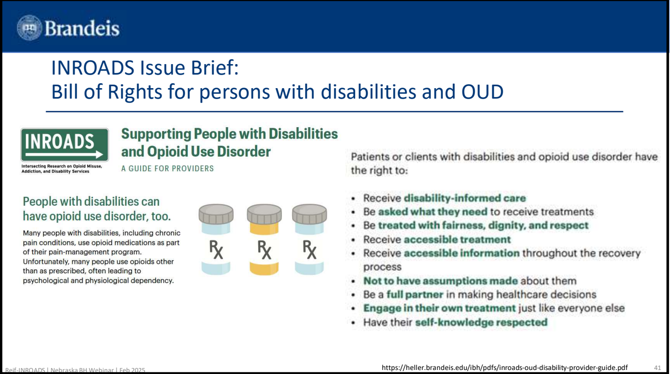
Successful approaches are possible

- Physical **accessibility & communications accommodations** may be enough for people with physical and sensory disabilities
- **Adaptations likely required** for people with intellectual, developmental, and cognitive disabilities
- **Essential to work with PWD** (and support system, as appropriate) to understand how they learn, strengths and limitations, and specific needed accommodations
- Best practice is **universal approach to accommodations**
  - Don't assume only people with visible disabilities have needs
  - Don't expect PWD to take the burden of ensuring accommodations

39



40



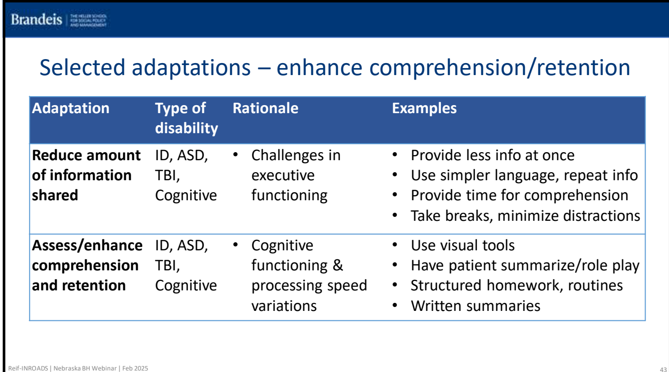
41

Brandeis

Selected adaptations – simplified information

Adaptation	Type of disability	Rationale	Examples
Simplified materials	ID, cognitive	• Limited knowledge or ability to abstract info • More likely to respond yes when do not understand	• Use simple sentences, pictures, graphics, colloquial terms (e.g., weed, not cannabis) • Avoid negative phrases or confrontational items
Simplified communications	ASD	• Concrete/inflexible thinking	• Be direct and unambiguous • Minimize non-verbal communication, metaphors

42



Brandeis | The Heller School for Social Policy and Management

Selected adaptations – enhance comprehension/retention

Adaptation	Type of disability	Rationale	Examples
Reduce amount of information shared	ID, ASD, TBI, Cognitive	• Challenges in executive functioning	• 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	• Cognitive functioning & processing speed variations	• Use visual tools • Have patient summarize/role play • Structured homework, routines • Written summaries

Reif-INROADS | Nebraska BH Webinar | Feb 2025

43

Brandeis | The Heller School for Social Policy and Management

Selected adaptations – increase insight and skills

Adaptation	Type of disability	Rationale	Examples
Motivational interviewing	ID, ASD	• Lack knowledge or reasoning to change behavior	• Educate re substance use & specific harms/negative outcomes • Increase insight & engage around reasons for treatment
Problem-solving skills	ID, ASD, TBI	• Reduced insight, motivation to change	• Build skills to refuse substance use, address cravings, anticipate impulses, practice alternatives • Identify constructive & rewarding activities to replace substance use

Reif-INROADS | Nebraska BH Webinar | Feb 2025

44

Brandeis | The Heller School for Social Policy and Management

Selected adaptations – flexible treatment approaches

Adaptation	Type of disability	Rationale	Examples
Individual therapy (vs. group-based sessions)	ID, ASD, TBI, Cognitive	• Group sessions need greater attention span, social/communication skills	• Tailor treatment to individual needs & functioning • Individual therapy • Incorporate cognitive-behavioral (CBT) approaches
Supervised medication use	ID	• Addiction medications may not be taken correctly or regularly	• Supervised administration by family, treatment providers, or others

Reif-INROADS | Nebraska BH Webinar | Feb 2025

45

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

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)

Isenberg et al. 2019

46

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

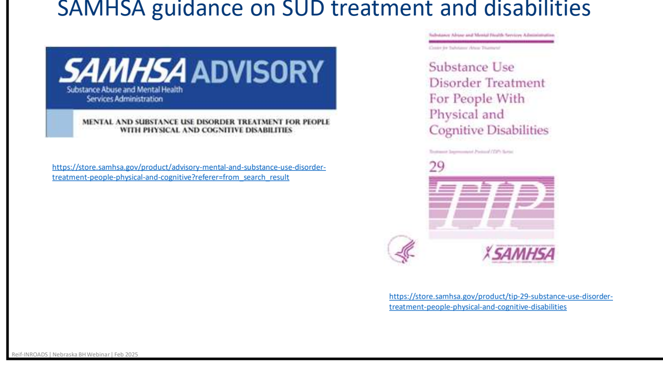
Social supports and development of healthy relationships

- 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

(Arnevik & Helverschou, 2016; Isenberg et al., 2019)

47

SAMHSA guidance on SUD treatment and disabilities



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

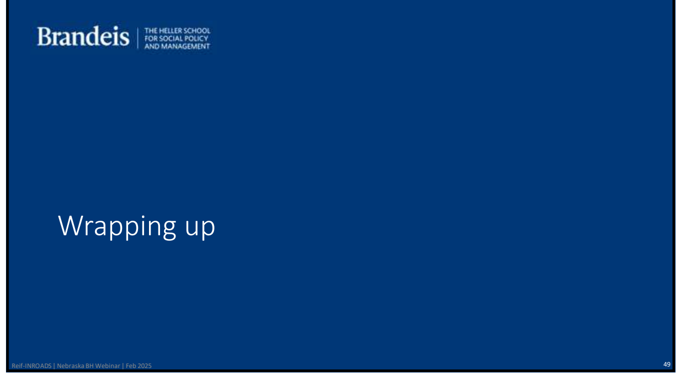
Substance Use Disorder Treatment For People With Physical and Cognitive Disabilities

29 TIP

SAMHSA

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

48



49

50

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT

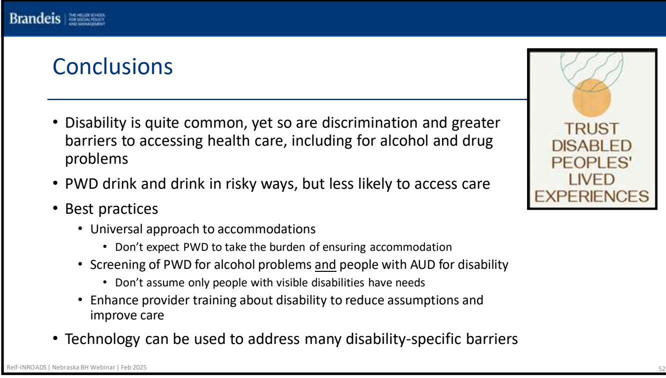
Recovery

- A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential
  - **health** and **well-being**
  - a **stable and safe place to live**
  - **activities** that give purpose and meaning
  - **relationships and social networks** that provide support, friendship, love, hope

https://mat-decisions-in-recovery.samhsa.gov/
https://www.samhsa.gov/find-help/recovery

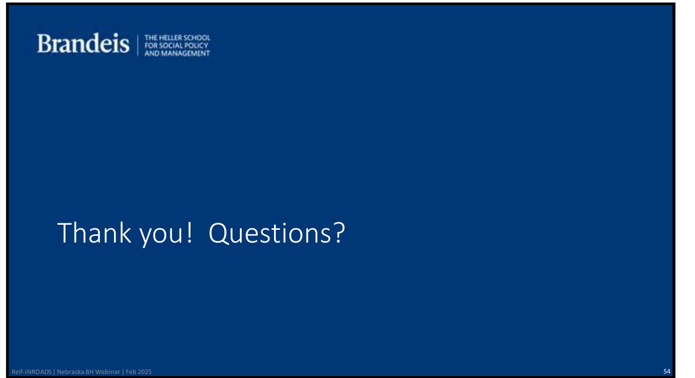
Reif-INROADS | Nebraska BH Webinar | Feb 2025 51

51



52

53



54