Enhancing Care for People with Developmental Disabilities and Substance Use Disorders

Scott Walters, PhD

September 26, 2023

Mountain Plains ATTC (HHS Region 8)

ATTC Addiction Technology Transfer Center Network

Funded by Substance Abuse and Mental Health Services Administration

SAMHSA

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Thank you for joining us today!

Please Note:

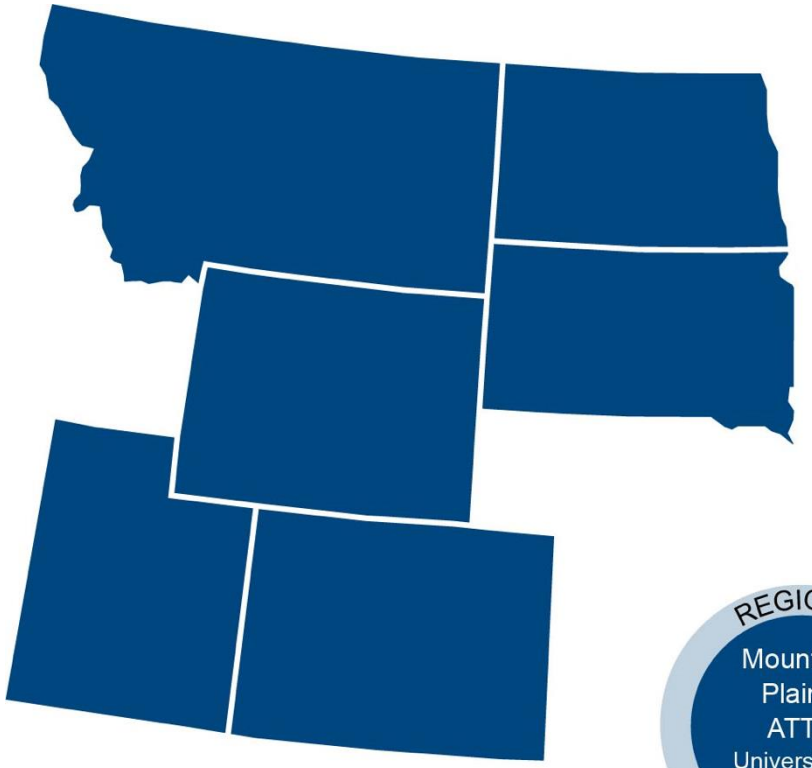
- All attendees are muted
- Today's session will be recorded

Housekeeping Items

- **All attendees are asked to remain muted** during this session.
- **Slides for today's session will be sent out after today's session.**
- This webinar is **being recorded** and will be available for future viewing on our website.
- Remember to **ask questions during the session using the chat box.**
- **Certificates of attendance are available** for today's session. Instructions will be sent in a follow-up email from Kim M. Miller kim.m.miller@und.edu

The Mountain Plains Addiction Technology Transfer Center

The Mountain Plains Addiction Technology Transfer Center (Mountain Plains ATTC) supports and enhances substance use disorder treatment and recovery services for individuals and family members throughout Region 8 (Colorado, Montana, North Dakota, South Dakota, Utah and Wyoming).



We belong to the Technology Transfer Center (TTC) Network, a national network of training and technical assistance centers serving the needs of mental health, substance use and prevention providers. The work of the TTC Network is under a cooperative agreement by the Substance Abuse and Mental Health Service Administration (SAMHSA).

Twitter: @MT_Plains_ATTC
Website: https://attcnetwork.org/centers/mountain-plains-attc/home

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At the time of this presentation, Miriam E. Delphin-Rittmon, Ph.D, served as SAMHSA Assistant Secretary. The opinions expressed herein are the views of our presenters and do not reflect the official position of the Department of Health and Human Services (DHHS), or SAMHSA. No official support or endorsement of DHHS, SAMHSA, for the opinions described in this presentation is intended or should be inferred.

The work of the Mountain Plains ATTC is supported by grant TI080200_01 from the Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

The use of affirming language inspires hope and advances recovery.

LANGUAGE MATTERS.

Words have power.

PEOPLE FIRST.

The ATTC Network uses affirming language to promote the promises of recovery by advancing evidence-based and culturally informed practices.

ATTC

Addiction Technology Transfer Center Network

Funded by Substance Abuse and Mental Health Services Administration

Evaluation Information

The AHTTC is funded through SAMHSA to provide this training. As part of receiving this funding we are required to submit data related to the quality of this event.

At the end of today's training please take a moment to complete a **brief** survey about today's training.

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What's the Relationship between DD and SUD?

Things I Wondered…

- How accurate was his self-report?
- What was intoxication vs. DD symptoms?
- Did the wait time, noise and distractions influence his behavior?
- How appropriate or valid were the screening measures I was using?
- How should I adjust my treatment recommendation based on his likely DD?
- Was group treatment a good idea? Motivational interviewing? CBT?

What is DD?

Differences that are usually present at birth and that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development

- Autism Spectrum Disorders
- Down Syndrome
- Fetal Alcohol Spectrum Disorders
- Fragile X Syndrome
- Williams Syndrome
- Prader-Willi Syndrome

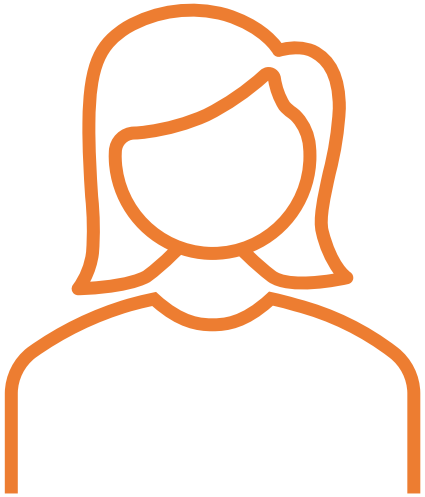
https://www.nichd.nih.gov/health/topics/DDs/conditioninfo/default?fbclid=IwAR3MHEm46X6-ZxospQsByjcyShOEzxiuOOpjVVr9C2sqwvuE_GDo_7DPrIU

DD vs. Mental Health

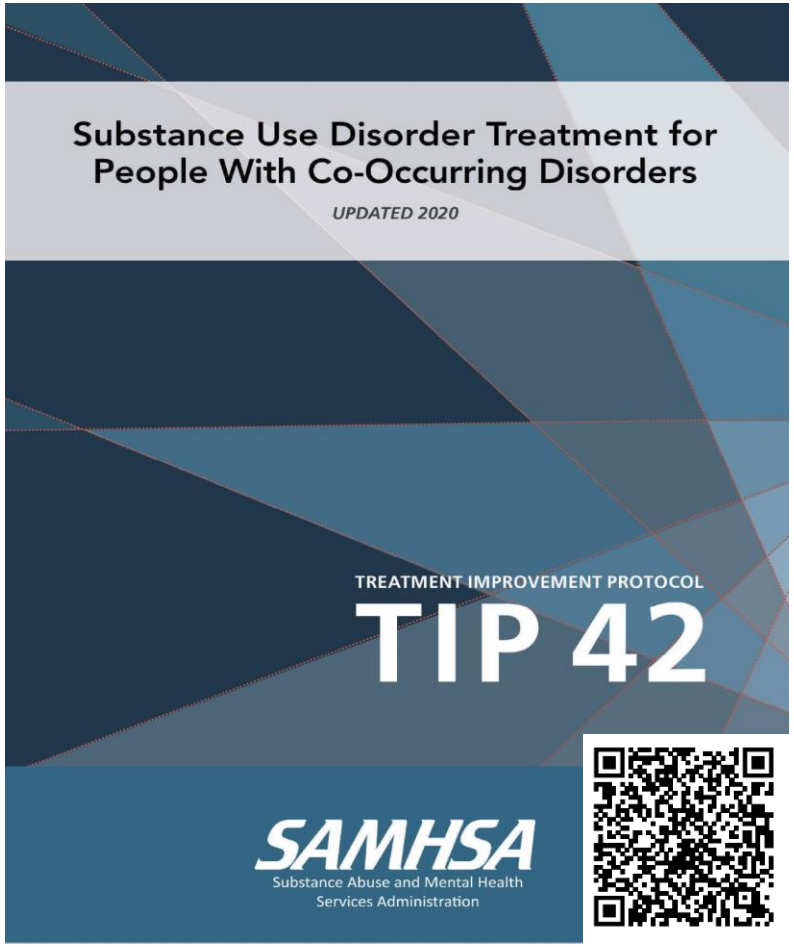
- Onset and origin
- Type of symptoms
- Stability of symptoms
- Response to treatment
- Diagnosis and assessment
- Social and emotional implications

Challenges Sometimes faced by People with DD

- Ability to Communicate
- Impulse Control
- Social & Relationships
- Difficulty Understanding
- Co-Occurring Mental Health
- Sensory Sensitivities

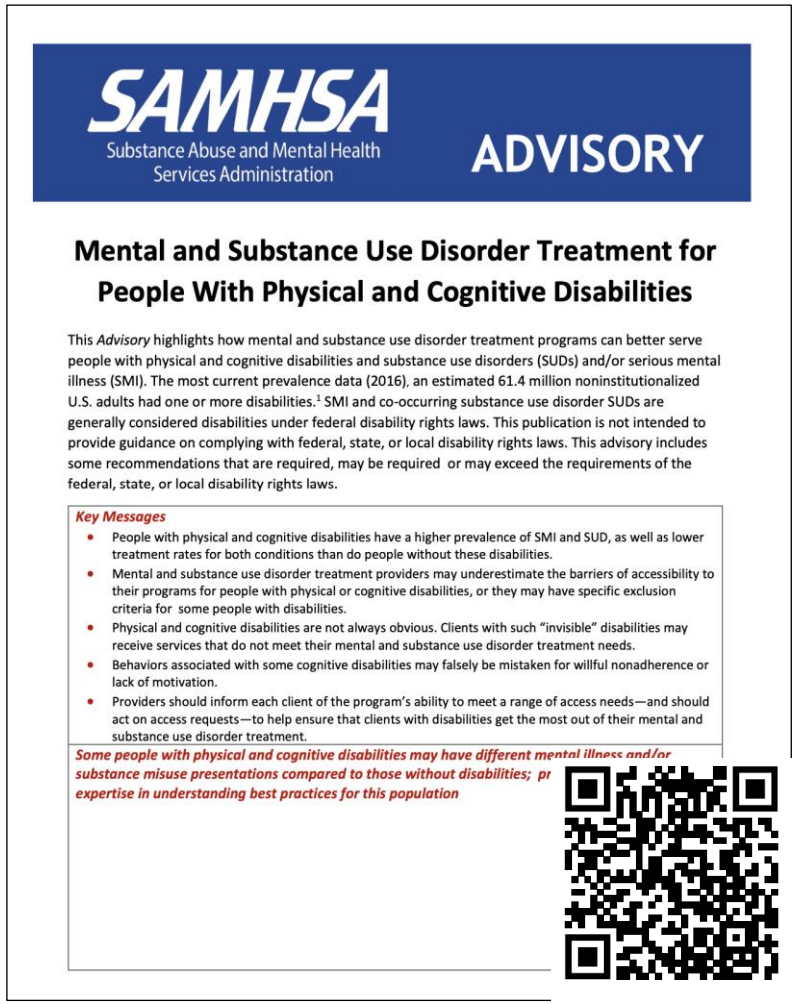


One Great Resource



- Gives guidance on diagnosing, treating, and delivering services for people with co-occurring disorders in addiction and mental health.
- Covers screening, assessment, diagnosis, treatment settings, and workforce and administration needs.
- Focuses primarily on co-occurring SUDs and MH disorders; does not address co-occurring physical conditions or behavioral addictions.
- Addresses “special populations” (homeless, CJ-involved, women, racial/ethnic minorities); limited information on people with DD.

Another Great Resource



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ADVISORY

Mental and Substance Use Disorder Treatment for People With Physical and Cognitive Disabilities

This *Advisory* highlights how mental and substance use disorder treatment programs can better serve people with physical and cognitive disabilities and substance use disorders (SUDs) and/or serious mental illness (SMI). The most current prevalence data (2016), an estimated 61.4 million noninstitutionalized U.S. adults had one or more disabilities.[1] SMI and co-occurring substance use disorder SUDs are generally considered disabilities under federal disability rights laws. This publication is not intended to provide guidance on complying with federal, state, or local disability rights laws. This advisory includes some recommendations that are required, may be required or may exceed the requirements of the federal, state, or local disability rights laws.

Key Messages

- People with physical and cognitive disabilities have a higher prevalence of SMI and SUD, as well as lower treatment rates for both conditions than do people without these disabilities.
- Mental and substance use disorder treatment providers may underestimate the barriers of accessibility to their programs for people with physical or cognitive disabilities, or they may have specific exclusion criteria for some people with disabilities.
- Physical and cognitive disabilities are not always obvious. Clients with such "invisible" disabilities may receive services that do not meet their mental and substance use disorder treatment needs.
- Behaviors associated with some cognitive disabilities may falsely be mistaken for willful nonadherence or lack of motivation.
- Providers should inform each client of the program's ability to meet a range of access needs—and should act on access requests—to help ensure that clients with disabilities get the most out of their mental and substance use disorder treatment.

Some people with physical and cognitive disabilities may have different mental illness and/or substance misuse presentations compared to those without disabilities; pr expertise in understanding best practices for this population

- Many treatment programs underestimate barriers or exclude people with disabilities.
- Highlights ways that mental and SUD treatment programs can better serve people with physical and cognitive disabilities.
- Discusses common barriers for people with disabilities.
- Offers resources to improve accessibility and intake for people with both cognitive and physical disabilities.
- Suggests ways to adapt individual and group formats.

Exploring the Connection between DD and SUD

LITERATURE REVIEW

PROVIDER INTERVIEWS

Literature Review Methodology

Inclusion	Exclusion
Peer-reviewed articles, books, book chapters	Conference papers, editorials, letters, or other non-peer-reviewed sources
Articles on the prevalence of SUD and DD	Study population younger than 18 years of age
SUD prevention and treatment recommendations for adults with SUD	Causes of DD, such as fetal alcohol syndrome
Barriers to receiving and adhering to treatment for adults with DD	Non- English

- CINAHL, PubMed, Web of Science, Academic Search Complete, PsycINFO
- Variety of search terms capturing *substance use disorder* + *intellectual or developmental disorders* + *treatment or assessment or prevalence*
- 292 original results
- 36 full text review
- 24 met inclusion

Source: Fulda et al., 2023

Questions for the Literature Review

How many people with DD are affected by SUD?

Who is most at risk of SUD?

In what systems are people with DD & SUD encountered? What are the barriers to treatment?

How is SUD screening, diagnosis and treatment tailored to people with DD?

Source: Fulda et al., 2023

How many people with IDD are affected by SUD?

- Estimates of co-occurrence vary widely based on location and substance. In some places like psychiatric facilities, it's 25-36%, while in the community, it's typically 0.5% to 2.6%
- People with DD are probably less likely to use substances compared to those without DD, but more likely to use problematically if they do use
- Risk factors include being male, middle age, lower income, having MH issues and living independently

Who is most at risk of SUD?

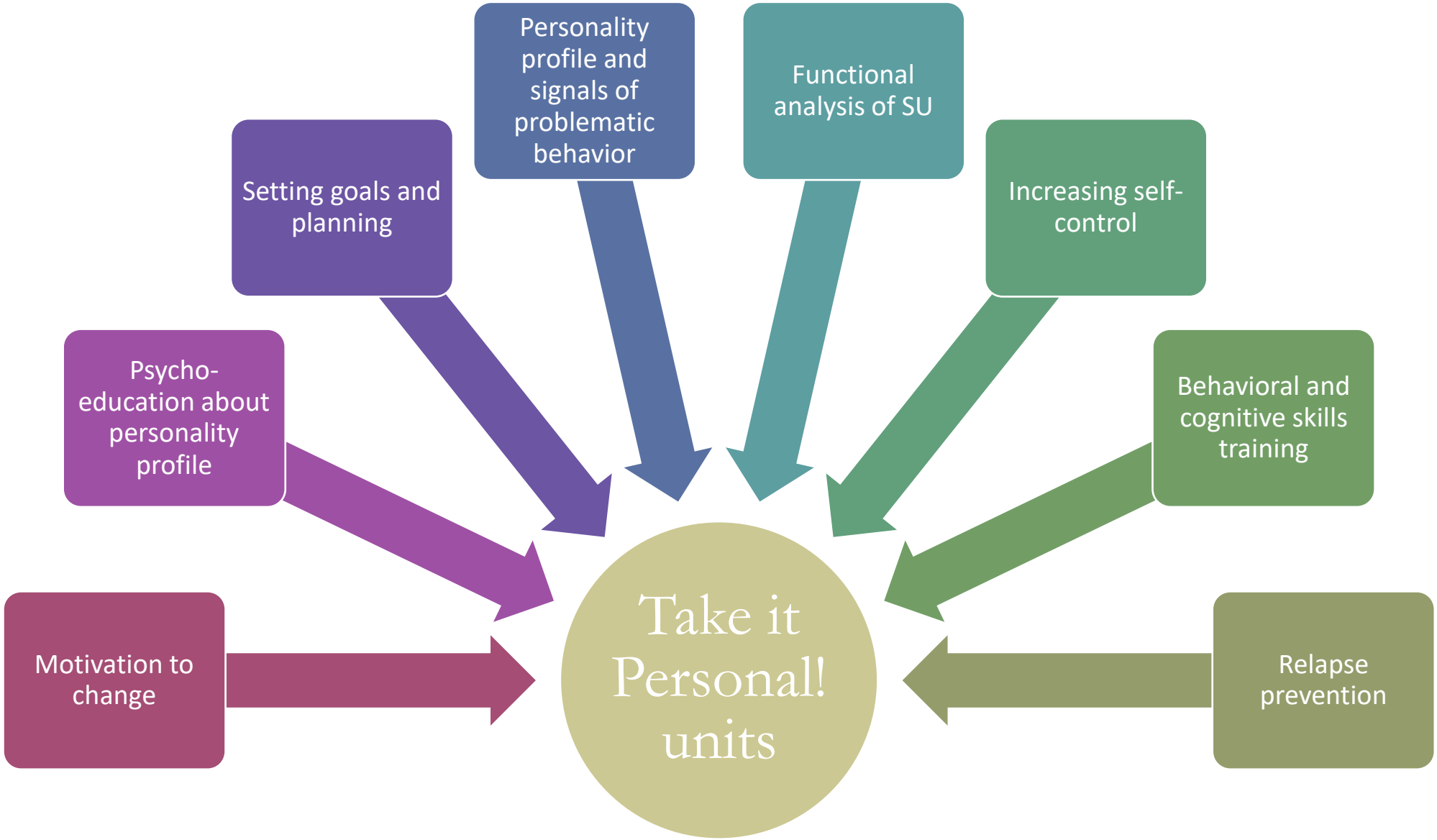
- Common risk factors with/without DD: family history, prenatal exposure to substances, co-occurring MH issues, social pressure
- Risk factors unique to people with DD: having a higher IQ (borderline DD), being male, being socially independent, and unstable family
- Social skills, self-esteem and cultural inclusion may play a role
- People who struggle with social information processing and self-regulation are at a higher risk
- Comorbid psychiatric disorders increase risk

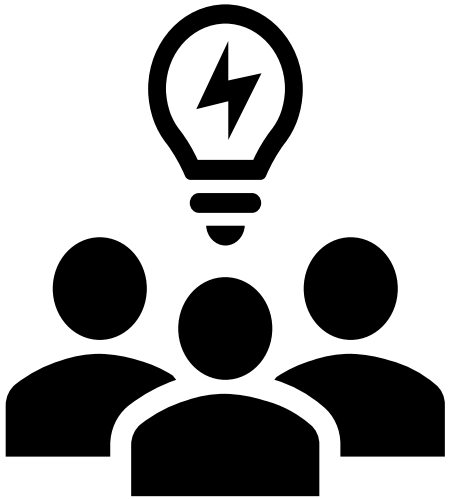
In what systems are people with IDD & SUD encountered? What are the barriers to treatment?

- Most often encountered in outpatient (non-specialized) MH settings
- Barriers to treatment include stigma, motivation, financial constraints, and a lack of specialized treatment options/guidelines and provider training
- Motivation to seek help varies, with some individuals needing external pressure to access treatment
- Caretaker involvement can either help or hinder treatment initiation and retention
- Financial barriers can be significant

How is SUD screening, diagnosis and treatment tailored to people with IDD?

- Research is lacking; not clear patterns
- Typically requires a more personalized approach
- Close coordination (and cross training) between providers is needed
- “Take it Personal” is an example of one program that tailors treatment to personality and motivation
- Future research should focus on developing training or certificates to cross-train SUD & DD providers


Personality profile and signals of problematic behavior
Functional analysis of SU
Setting goals and planning
Increasing self-control
Psycho-education about personality profile
Behavioral and cognitive skills training
Motivation to change
Take it Personal! units
Relapse prevention



Interviews & Focus Groups	#
Individual	14
Focus Group (# Participants)	1 (3)
Administrator	4
Bilingual Psychotherapist	1
Clinical Social Worker	1
Director of Clinical Operations	1
Nurse Manager	1
Peer Specialist	4
Service Specialist	1
Therapist	1
Treatment Provider	3
Total Participants	**17**

Themes from the Interviews

How DD was identified

How intake is different for people with DD

How treatment is different for people with DD

Common barriers to treatment

Involving caregivers in the process

Training experiences and needs

How DD was identified

- Most did not use formal screening tools to identify DD; often relied on past experience or documented disability
- DD screening might be referred to psychiatrist or physician
- Sometimes DD could be confused with intoxication at intake
- If screening needed, would need referral to psychiatrist or physician
- Organizations might use call center for screening which could reduce access due to technology requirements

How intake is different for people with DD

- People with DD can take more time and require assistance during the intake
- Client motivation for treatment was seen as essential
- People with DD can need more help with documentation or might need a caregiver to assist
- If known in advance, can provide environmental accommodations to minimize stress (e.g., quieter space, fewer people, private entry way)

How treatment is different for people with DD

- Severity of DD can affect treatment
- Most counselors adjusted treatment to “meet them where they’re at” without formal guidelines
- Accomodations can include shortened time, reduced stimuli, simplifying language, using compromise or negotiation, more accommodating treatment plans, individual (vs. group) format
- May need to involve caregivers and/or support groups
- Clients with DD may prefer groups designed specifically for them

Common barriers to treatment

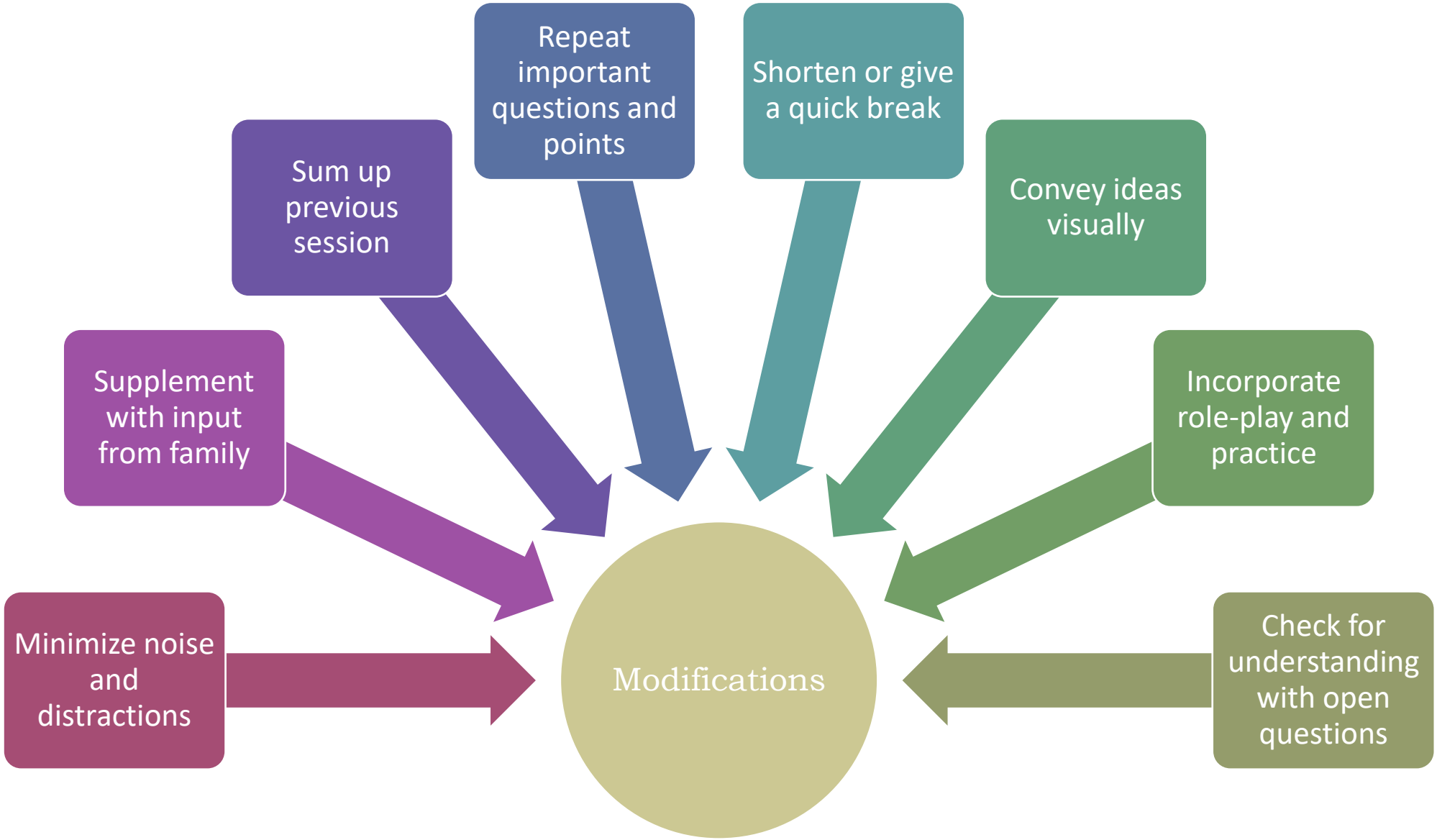
- Many of the same barriers as people without DD
- Logistical barriers include transportation, technology, insurance, health literacy, discomfort with unfamiliar places, lack of relationship with caregiver
- Some people may have low motivation and/or lack insight on how SUD is affecting them or others
- Unstable living or living with people who use substances
- People with DD may have more difficulty changing living situations

Involving caregivers in the process

- Can be essential, especially for arranging schedule, transportation, and other assistance
- Caregiver may need to verify information regarding substance use
- Caregiver is sometimes not available and/or a person with DD might deny caregiver involvement which can make treatment more difficult

Training experiences and needs

- Most reported no specialized training for SUD and DD
- Most wanted additional training, either webinar or on-demand
- Some have sought own training due to personal experiences with DD
- Most reported high confidence in their work and ability to adjust skills for people with DD, but also sometimes not being familiar with the particular needs of this group
- Wanted a better screening tool and guidelines for working with this group

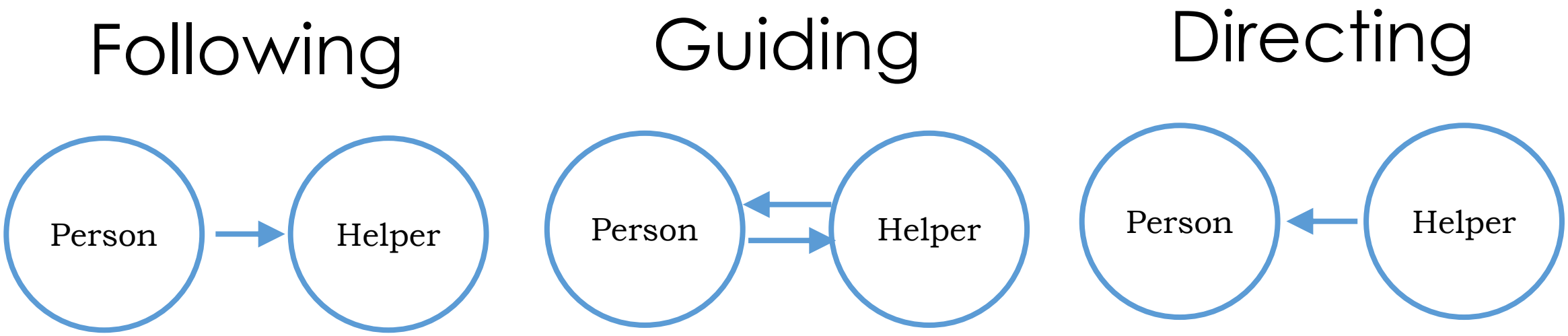


https://store.samhsa.gov/sites/default/files/pep19-02-00-002.pdf

Adapting One Treatment Approach

Motivational interviewing is a collaborative conversation style for strengthening a person's own motivation and commitment to change.

MI Uses a Balanced/Guided Style



What Does a “Guided” Style Look Like?

Less Guided	More Guided
Only one person speaks	Both people are speaking; people take turns
Information goes one way	Information goes two ways
The provider speaks mainly to get his/her point across	The provider is interested in the person’s perspective
Client is in a passive role	Client is in an active role

Core Conversation Skills

Frielink & Embregts (2013) explored how to modify MI skills for people with mild DD

OPEN-ENDED QUESTIONS

Form	Structure
• Concrete and clear • Use short sentences; avoid stacking • Start questions with a query word (avoid "why" stem) • Use questions to help client focus	• Ask one question at a time; avoid asking same question twice • Allow extra response time, especially with assistive technology • May need to help client answer question • Check for understanding if unsure; provide alternatives/examples to choose from

Source: Frielink & Embregts (2013)

AFFIRM

Form	Structure
• Be specific, with clear intonation • Use clear and concrete language	• Affirmations both verbal and nonverbal • Make eye contact; take enough time • Make it specific • Affirm when something is done well, but do not exaggerate • Some clients may find it hard to receive affirmations or see them as patronizing

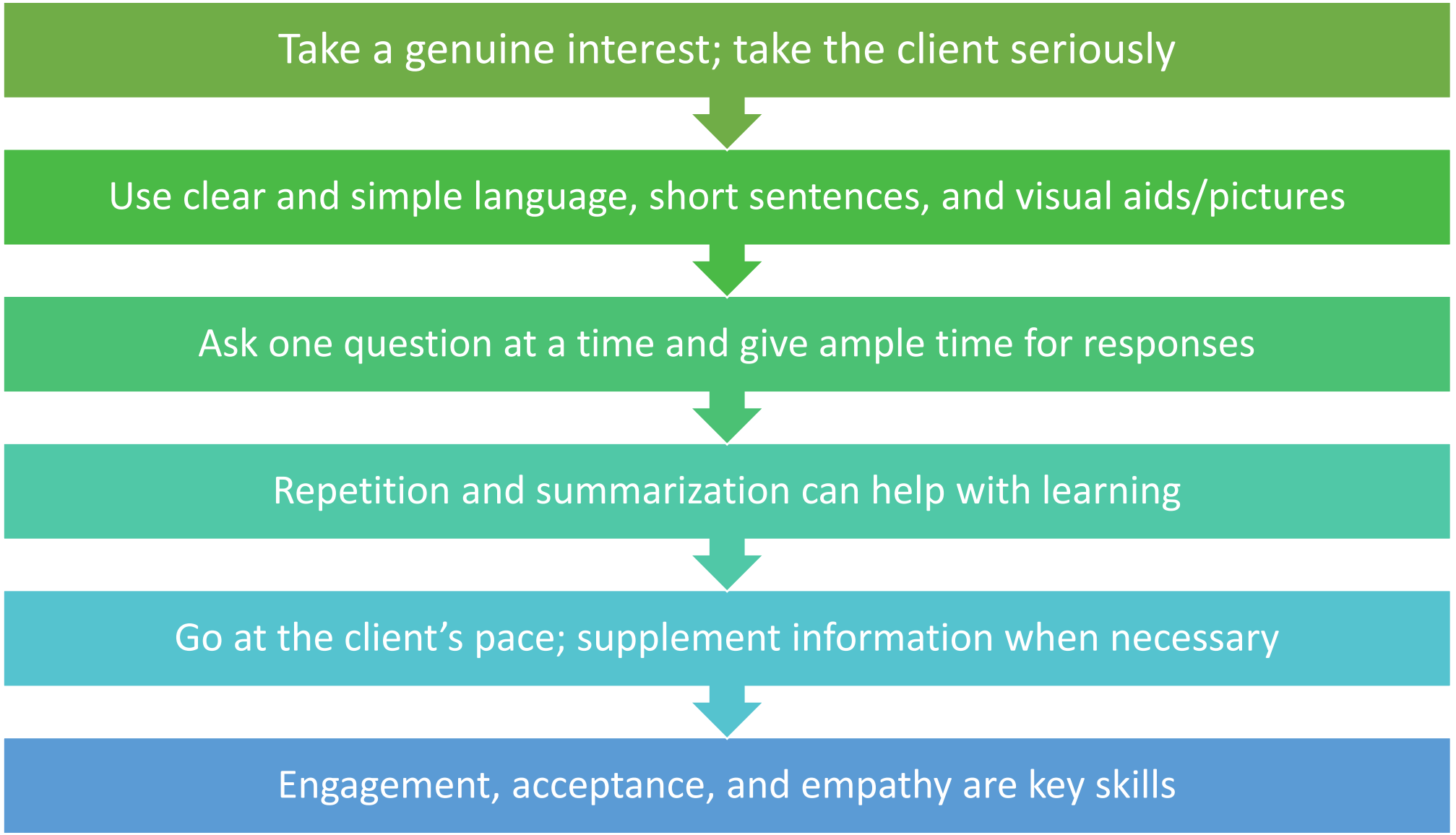
Source: Frielink & Embregts (2013)

REFLECT & SUMMARIZE

Form	Structure
• Use simple, short sentences • Avoid abstract or metaphorical language	• Clients may need help organizing language to say what they want to say (may forget or get lost in an idea) • Repetition can help • Use frequent short summaries in between topics • It can be difficult for clients to admit lack of understanding; make sure to verify

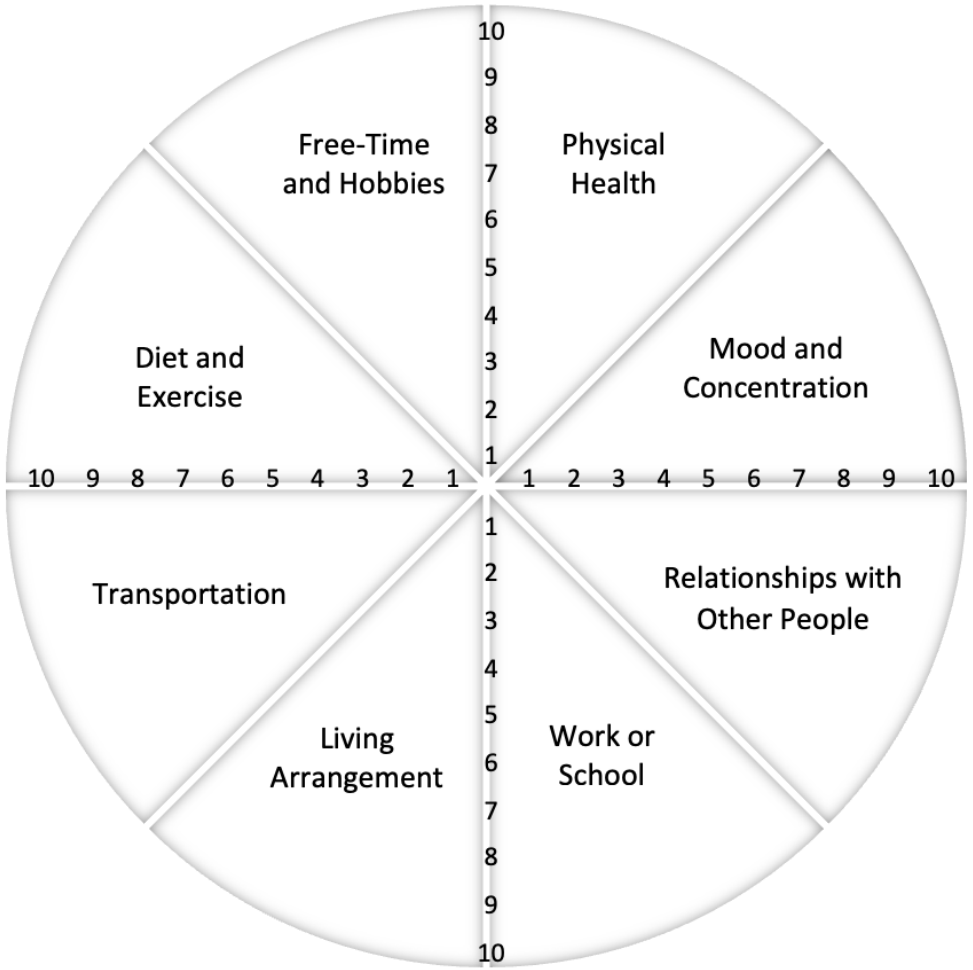
Source: Frielink & Embregts (2013)

Key Takeaways



Source: Frielink & Embregts (2013)

Your Wellness Wheel

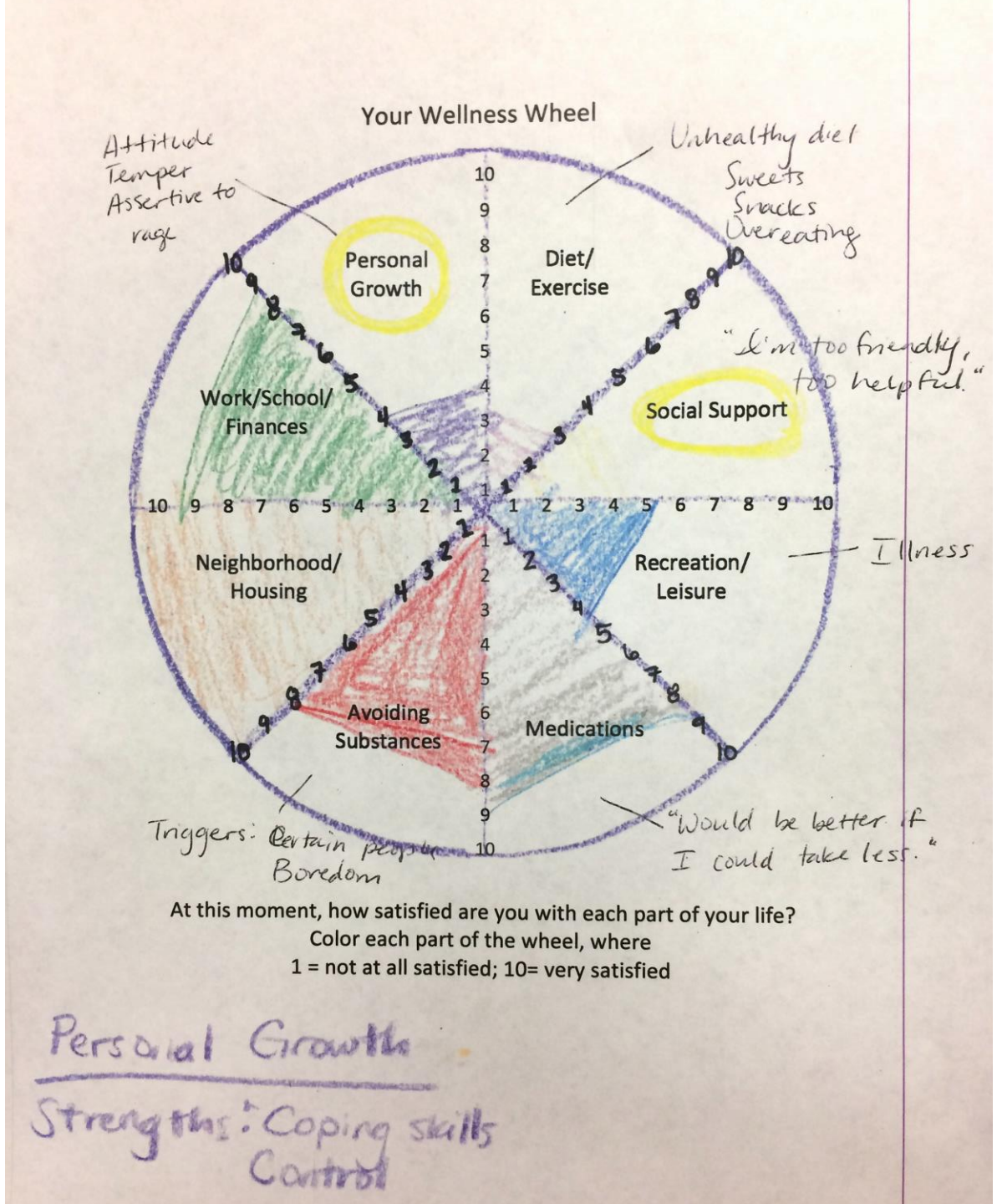


At this moment, how satisfied are you with each part of your life?
Color each part of the wheel, where
1 = not at all satisfied; 10= very satisfied

Name: _____ **My** _____ **Scale**

Rating	Looks/Sounds Like	Feels Like	I can try to
5			
4			
3			
2			
1			

The Incredible 5-Point Scale © Kari Dunn Buron & Mitzi Curtis



Name: Jordan Smelley **My** Anxiety level while at work **Scale**

Rating	Looks/Sounds Like	Feels Like	I can try to
5	I am either bawling or I am yelling	Extremely Overwhelmed	Call one of my supports so they can help me get to a 4 or lower Speak with my supervisor privately
4	Going from having my camera on to turning it off if in a virtural meeting at a random time for more than 30 seconds unable to focus or process information Struggle with verbal communication May raise voice level	Overwhelmed	I need to do deep breathing or obtain assistance from coworker or supervisor
3	Showing visual signs of frustration Start having trouble with focusing and processing information stumble for words to express myself may raise voice level	Slightly Overwhelmed	obtain assistance from coworker or supervisor Take a 5 to 10 minute break listen to music deep breathing get up and walk around the office
2	Still have a smile on my face but I am a little less chill. I am still able to focus and process information fairly easily	I feel a little fidgety	get up and walk around the office Take a 5-10 minute break listen to music
1	I am smiling and I am chill. I am able to focus and process infomration easily	I am calm	I am good

A Simple Values, Strengths & Barriers Cardsort

STRENGTHS

Picture Card Sort

Honest Strength

True ☑ False ☐

Creative Strength

Hopeful Strength

Focused Strength

Active Strength

Spiritual Strength

Organized Strength

Strong Strength

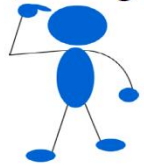
Determined Strength

Happy Strength

Forgiving Strength

Skillful Strength

Clever/Intelligent Strength



Responsible/Reliable Strength

Accepting Strength

Stuff in this presentation

Wellness Wheel

Five Point Scale

Picture Cardsort