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Curriculum Authors and Training Presenters

Peggy S. Terhune, Ph.D., MBA, OTR/L
President and CEO
Monarch

B. Todd Posey, M.Ed., LCMHCS, LCAS, CCS
Vice President of Operations, Outpatient Clinical Services
Monarch

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About Monarch

Our Mission

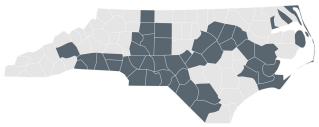
Monarch is committed to supporting, educating, and empowering people with developmental and intellectual disabilities, mental illness, and substance use disorders to choose and achieve what is important to them.

Who We Are

Established in 1958, Monarch is a leading provider of behavioral health services in North Carolina, serving more than 31,000 people annually. Monarch has received The Gold Seal of Approval® from The Joint Commission, indicating the alignment with the highest quality standards in health care delivery.

Where We Are

Monarch provides innovative, life-changing services at more than 186 locations in 43 North Carolina counties. We serve people from 95 of North Carolina's 100 counties.



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About this Curriculum

- Grant-funded project from NC DHHS.
- Designed to meet a need for a population for whom little direct support for addiction exists.
- Created with the involvement of I/DD and SUD experts.
- Developed with the input of people with lived experience and their families
- Includes materials created with the target population of individuals with I/DD with an IQ of 50 to 70 in mind, but can also be used with others to explain and address concepts of addiction.
- Created to help clinicians and caregivers provide better support for people with I/DD living with a substance use disorder.

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Training Learning Objectives

- Clinicians and caregivers will recognize characteristics of I/DD.
- Clinicians and caregivers will identify adaptations to assist people with I/DD in learning key concepts in addiction and recovery.
- Clinicians and caregivers will employ strategies to make individual and group therapy more effective for people with I/DD.
- Clinicians and caregivers will develop confidence in utilizing the evidence-informed curriculum.

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Part One:
Understanding Intellectual and Developmental Disabilities

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Question:
What comes to mind when you hear the phrase “intellectual and developmental disability?”

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Causes of Developmental Disability

- Trauma before, during, or after birth
- Genetics
- Chromosomal changes (inherited or acquired)
- Down Syndrome (presence of trisomy 21 chromosome), Prader Willi (Chromosome 15), Fragile X
- Health disparities
- Substance use disorder in mom OR dad
- Males (78%), females (22%)

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Federal Definition of Developmental Disabilities

According to the Developmental Disabilities Act, section 102(8), "the term 'developmental disability' means a severe, chronic disability of an individual 5 years of age or older that:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. Is manifested before the individual attains age 22;
3. Is likely to continue indefinitely;
4. Results in substantial functional limitations in three or more of the following areas of major life activity;
   1. Self-care;
   2. Receptive and expressive language;
   3. Learning;
   4. Mobility;
   5. Self-direction;
   6. Capacity for independent living; and
   7. Economic self-sufficiency.
5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.”

Source: The Developmental Disabilities Assistance and Bill of Rights Act of 2000; Sec. 102. Definitions [42 USC 15002] http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/p2_II_subtitleA.aspx

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Examples of Developmental Disability

- Autism
- Behavior disorders
- Brain injury
- Cerebral palsy
- Down syndrome
- Fetal alcohol syndrome
- Intellectual disability
- Spina bifida
- Pervasive developmental disabilities
- Specific learning disabilities

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The Difference

- Developmental Disability is the overarching term.
- Intellectual disability is a subset of Developmental Disability.

Therefore…

- I can have a developmental disability and not have an intellectual disability.
- If I have an intellectual disability, I have a developmental disability.

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What is an Intellectual Disability?

Accordingly, “intellectual disability” is defined as… “…significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance.” [34 CFR §300.8(c)(6)]

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What is an intellectual disability?

Three areas of adaptive functioning are considered:

1. **Conceptual** – language, reading, writing, math, reasoning, knowledge, memory.
2. **Social** – empathy, social judgment, communication skills, the ability to follow rules and the ability to make and keep friendships.
3. **Practical** – independence in areas such as personal care, job responsibilities, managing money, recreation, and organizing school and work tasks.

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What is an intellectual disability?

- Adaptive functioning is assessed through standardized measures with the individual and interviews with others, such as family members, teachers and caregivers.
- Intellectual disability is identified as mild (most people with intellectual disability are in this category), moderate or severe. The symptoms of intellectual disability begin during childhood. Delays in language or motor skills may be seen by age two. However, mild levels of intellectual disability may not be identified until school age when a child has difficulty with academics.

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Intellectual Disabilities

- In 2010, Rosa's Law replaced the term "mental retardation" with intellectual disability as a matter of U.S. federal law. In keeping with this change, DSM-5 has also replaced the diagnosis mental retardation with intellectual disability.
- DSM-5 defines intellectual disabilities as neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living.
- CDC states 1 in 6 children born today will have a developmental disability.

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Who are people with I/DD?

- People with I/DD could be your neighbors.
- Some people with I/DD can read and write.
- Some people with I/DD go to college
- People with I/DD can work.
- Some People with I/DD can live on their own.

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People with I/DD are no different than anyone else. They have the same hopes, dreams and interests that we all have.

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Working with People with I/DD

- Assume competence.
- Provide dignity.
- Ask the person to tell you what you have said in their own words.
- Expect to repeat a concept. If you have to repeat, use different words.
- If you cannot understand someone, tell them.
- Pay a lot of attention to non-verbal cues.
- Use short words and phrases until you are sure the person understand more complex terms.
- Behave with the person the same way you would behave any other patient.

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What You Need to Know

1. Don't make people acutely aware of their disability.
2. Don't be afraid of the person. They don't plan to hurt you.
3. **Give time to someone to respond. You may need to allow silence.**
4. Assume competence.
5. Use the skills the therapist already has when dealing with a person who may be in crisis.
6. Focus on similarities, not on differences.
7. **Therapists should give the benefit of the doubt that the person has skills – the person may assume you also have skills.**
8. **If you cannot understand what someone is saying, ask the person, how best to communicate. The person can tell you how to understand them.**
9. If the therapist tries to listen, it will become easier to understand the person.
10. Have mutual respect.
11. **In terms of disability, the person is the expert.**
12. **Ask the questions to the client, not the person with them, even if the person with them needs to do most of the talking.**
13. Some people with difficulty speaking have "interpreters" who can re-state what they are saying. Make sure the interpreter is saying what the client is saying, not their own language.

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What You Need to Know (cont.)

14. There are many ways people can communicate and doesn't just have to be verbal.
15. **Don't expect the person to come to where you are intellectually but go to where they are.**
16. Be patient with the communication process.
17. Sometimes using your hands, either with sign language or to express yourself is helpful.
18. Be prepared to switch modes of communication.
19. **If a person gets upset about something, even if they can typically communicate verbally, they may stop talking, and may need a different mode of communication.**
20. The person also needs to get accustomed to you.
21. Tell the person what you think they said to confirm that you understand a person. Even use of certain words may have different meanings.
22. People are not offended if you say, "What did you say?"
23. **Better to confirm understanding than feign understanding. Don't pretend you understand.**
24. Could also be, "what I'm hearing you say is this….", instead of continuing to ask the person to repeat themselves.
25. Pictures may help.

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Part Two:
Substance Use Disorder Treatment for I/DD

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Substance Use and People with I/DD
(Carroll-Chapman and Wu)

- Illicit drug use rates are lower among people with I/DD.
- Alcohol use rates are similar to the general population.
- Tobacco/nicotine use rates are the same as the general population.
- Risk of developing a SUD is higher than the general population.

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Substance Use and People with I/DD
(Carroll-Chapman and Wu)

- Begin using substances at an earlier age.
- Higher rates of trauma than the general population.
- Less likely to receive SUD treatment.
- Less likely to stay in SUD treatment.

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Key Concepts According to SAMHSA

- 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 (this is not specific to those with I/DD issues, only generally applies to those with disabilities).
- Mental and substance use disorder treatment providers may underestimate the barriers of accessibility to their programs for people with physical or cognitive abilities.
- Physical and cognitive disabilities are not always obvious.
- Behaviors associated with some cognitive disabilities may be mistaken for willful nonadherence or lack of motivation.

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SAMHSA Tips on SUD Counseling for People with Cognitive Disabilities (Group Therapy)

- Minimize noise and distraction.
- When permissible and appropriate (especially during treatment planning), supplement the client's report with input from family members or caregivers (with consent) on the client's strengths and preferred learning style.
- Go over group rules, including confidentiality, at each session.
- Summarize the previous session (this is a good idea regardless of the population served).

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SAMHSA Tips on SUD Counseling for People with Cognitive Disabilities (Group Therapy)

- Repeat important questions and points.
- Give the group a short break during the session if needed.
- Incorporate skills practice (refusal skills, deep breathing, etc.).
- Ask open ended questions to verify understanding.

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SAMHSA Tips on SUD Counseling for People with Cognitive Disabilities (Individual Therapy)

- Emphasize concrete actions steps and healthy routines instead of abstract concepts.
- Consider having more frequent, but shorter sessions.
- Minimize distractions.
- Use repetition of key concepts.
- Take short breaks when needed.
- Convey ideas visually.

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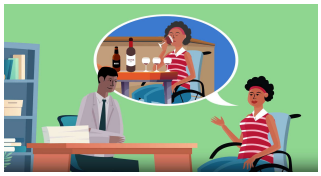
Motivational Interviewing and I/DD
OARS



- Open-ended questions
- Affirmations
- Reflective listening
- Summaries

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Motivational Interviewing and I/DD
Adaptations

Bhatt and Gentile in the AIMS Public Health article suggest:

- Take a more directive approach.
  - Not advocating undermining their autonomy. Supporting autonomy is one of the core principles of MI.
- Help them identify and express feelings about change.
- Address barriers related to communication issues.
  - Use roleplays
  - Visual prompts
  - Pictures
  - Therapeutic games and activities

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Alcohol

- Observable indications of use—Slurred speech, unsteady gait, loud voice, impaired motor control or clumsiness, flushed face, odor of alcohol on breath/body
- Effects of use—Feelings of intoxication, sensory alteration, anxiety reduction (for a time), increased heart rate
- Duration of effects—dose dependent, varies

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Alcohol

Note: Possible difference with I/DD and alcohol use

- For people with certain conditions, their coordination and motor control may actually ***improve***!
- The muscle spasticity associated with some development disabilities may become less pronounced with alcohol use and coordination/motor control is enhanced.
- Be alert for changes in baseline functioning.

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Part Three:
Curriculum and Facilitator Guide Overview

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Key Considerations

- When people with I/DD issues have a SUD, it is most likely to be an Alcohol Use Disorder. As a result, this curriculum addresses alcohol. However, this material is easily adaptable to address SUDs other than alcohol.
- Unless you have experience working with those with issues related to I/DD, you will likely be surprised by this population's ability to understand. While it is important to be concrete in communicating with those with I/DD concerns (i.e. avoiding metaphors, figures of speech, and abstract concepts), you will find that they are able to understand and relate to some fairly complex recovery concepts.
- In an intentional effort to increase understanding, some of the recovery concepts may be expressed differently than you have previously encountered them.

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Key Considerations

- When all is said and done, people with I/DD and SUD issues are just people. Treat them as such. Don't talk down to them. The more that you're able to connect with them as individuals while recognizing and validating their value, worth, and dignity, the more successful this group will be.
- As with any population, the introduction of new concepts should allow for repetition and discussion to ensure understanding. The videos, discussion, and handouts have been designed to complement one another in reinforcing the learning of each topic.

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Key Considerations

- Less is more. The group sessions are designed to be relatively brief (30-45 minutes max.) and typically present a single concept. This is intentional. Do not try to cover too much material at one time.
- While this guide provides structure for the group sessions, it is not intended to be a script. Become familiar enough with the content so that your facilitation is natural and conversational. Review the video content for each session in advance. Also, feel free to draw from your experience in providing examples of the concepts presented.

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Curriculum Components

- **Video** – each video introduces and summarizes the topic for the session.
- **Psychoeducation** – educational material that expands on the video content.
- **Discussion** – items for the group members to consider and discuss.
- **Activity** – this will help solidify the content in the member's mind.
- **Summary and review** – a brief review of the session content. This is facilitated by the distribution and review. Participants will keep the handouts to enable them to review the material on demand to aid retention.

While it is not specified in the facilitator guide, in therapy it is customary to review the content from the previous session at the beginning of a new session. This is especially important in working with those with I/DD. Keep it short and simple.

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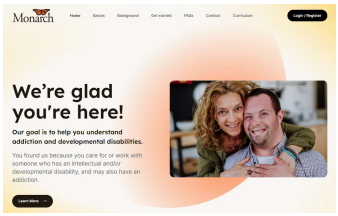
Review of Online Curriculum Materials



https://understanding.monarchnc.org/

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Questions?

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Resources and References

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Peer Recovery Support Groups

- Some Alcoholics Anonymous (AA) areas and districts now have accessibility committees (also called special needs committees) that work to meet access needs. They may provide Braille materials, wheelchair ramps, sign language interpretation, or easy to read literature. Call or check the websites of your local AA area and districts for more information.
- You can use AA's online locator at www.aa.org to help you find these websites and meeting locations.

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I/DD Resources

- Arc – www.thearc.org
- AAIDD – www.aaidd.org
- Individuals with Disabilties Education Act (federal education law) - https://sites.ed.gov/idea/
- NC Council on Developmental Disabilities (every state has something similar)
- Protection and Advocacy Agencies (again, every state has one. In North Carolina, it is Disability Rights).
- National Association for the Dually Diagnosed (NADD) – www.thenadd.org
- Ancor – www.ancor.org

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