EVIDENCE-BASED PSYCHOTHERAPY TO ACCOMMODATE IDD

SUSAN LAGRONE, MS, LBSW, LPC-S
TRANSITION SUPPORT TEAM

"This document was developed under grant CFDA 93.791 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. However, these contents do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal Government."

OBJECTIVES

1. Participants will identify the prevalence of co-occurring mental illness and intellectual and/or developmental disabilities (IDD).
2. Participants will identify cognitive and emotional capacities of people with IDD
3. Participants will list traditional psychotherapies that are evidenced to be effective when adapted for IDD.

BARRIERS

- Willingness to treat
- Attitudes about mental illness and IDD
- Lack of IDD-specific skills

DIFFERENCE IN MH AND IDD SYSTEMS

- MH - care focused on cure and recovery oriented.
- IDD - care focused on habilitation, w/o expectations in significant change in functioning.

PREVALENCE OF MI/IDD

- 1 out of 3 people with a developmental disability also has a mental illness.
- Individuals with intellectual disabilities experience the full range of mental illnesses and the incidence of mental illness is much higher in the IDD population than in the overall population.
- The prevalence of anxiety and mood disorders within the IDD population is more than double that of the general population.
- When psychiatric disorders are more broadly defined to include the range of "behavioral disturbance" commonly seen in individuals with intellectual disabilities, prevalence rates have been reported to be as high as 80%.

(Burke, 2013)

FACTORS CONTRIBUTING TO HIGHER RATES OF PSYCHIATRIC DISORDERS

- Low levels of social support
- Poorly developed social skills
- A sense of learned helplessness and correspondingly low sense of self-efficacy
- Low socioeconomic level
- Increased presence of physical disabilities, especially epilepsy
- Heightened family stress and heightened maternal stress

(Razza and Tomasulo, 2005)

FACTORS CONTRIBUTING TO HIGHER RATES OF PSYCHIATRIC DISORDERS

- Increased likelihood of central nervous system damage
- Increased presence of reading and language dysfunctions
- Decreased opportunities to learn adaptive coping styles
- Increased likelihood of chromosomal abnormalities, metabolic diseases, and infections
- Increased likelihood of experiencing early trauma and abuse

(Razza and Tomasulo, 2005)

DIAGNOSTIC OVERSHADOWING

- Despite early misunderstandings and unfounded assumptions of many mental health professionals, people with intellectual disabilities experience the same types of psychiatric illness as people who don't have intellectual disabilities.
- Symptoms of psychiatric disorders have frequently gone undetected in individuals with ID because of a tendency on the part of professionals to attribute symptoms to the intellectual disability itself – "diagnostic overshadowing."
- Clinically significant psychological symptoms have been misunderstood as mere behavioral components of cognitive deficits.
- Even such severe symptoms as suicide attempts have been misconstrued as self-abusive behavior.

(Burke, 2013)

DIFFERENCES IN SYMPTOM PRESENTATION

- Cognitive Disintegration
  - Vulnerability to decompensate under stress and subsequent overload of cognitive functioning may lead to bizarre, atypical and even psychotic-like presentations
- Psychosocial Masking
  - Limited life experiences and intellectual capacity can influence the content of psychiatric symptoms

(Sovner and Hurley, 1986)

INTERFACE BETWEEN MI/IDD

- Intellectual Distortion

- Baseline Exaggeration

(Sovner and Hurley, 1986)

- Diminished abstract thinking and communication skills limit the ability of the person to accurately and fully describe emotional and behavioral symptoms

- Pre-existing maladaptive behavior not attributed to a mental illness may increase in frequency or intensity with the onset of a psychiatric disorder

CLINICAL VIGNETTE

MR. L.

Mr. L. is a 20 year old single white male who resides with his older brother and his brother's family. Mr. L. and his brother came for follow up after a medical hospitalization. In the hospital, Mr. L. had two episodes of acute agitation requiring emergency use of benzodiazepine and an antipsychotic. The exact precipitants for these episodes were somewhat difficult to ascertain, but the patient's sister-in-law, who observed one of them, indicated that Mr. L. seemed to be "giving orders to the nursing staff as though he believed he knew what treatments other patients required."

Mr. L was transported to the hospital when his family believed he was having a reaction to pain medication following a dental procedure, which they thought caused a dramatic increase In his level of energy and a complaint of feeling very anxious, irritable and unwilling or unable to focus and follow directions.

Mr. L was typically very introverted and quiet; indeed, the family was initially pleased when he appeared to be more social and talkative and more willing to spend more time with them.. They had not noticed the initial decrease in his sleep, due to his tendency to spend time in his room alone most nights after dinner. About one week prior to hospitalization, Mr. L. had insisted that he be allowed to play a video game despite having no prior interest in or skill at the game. Later, his brother discovered him endlessly looking at the graphics of the game, which featured voluptuous women, but not actually playing the game. Mr. L, began talking in an animated manner about wishing to get a car and driver's license; he was interested in becoming an emergency medical technician/firefighter and he began to make frequent requests for his allowance.

LACK OF SYMPTOM RECOGNITION

- Baseline exaggeration - subtle changes in Mr. L.'s behavior were initially overlooked due to his usual functional limitations
- Psychosocial masking - the supportive structure of Mr. L.'s environment and their own lack of experience dampened the expression and detection of psychiatric symptoms
- Intellectual distortion - Mr. L.'s his inability to articulate his thoughts and feelings more thoroughly added to the lack of recognition of psychiatric symptoms

ASSESSING THE CAPACITIES OF THE INDIVIDUAL FOR THERAPY

- Communication
- Cognitive
- Emotional

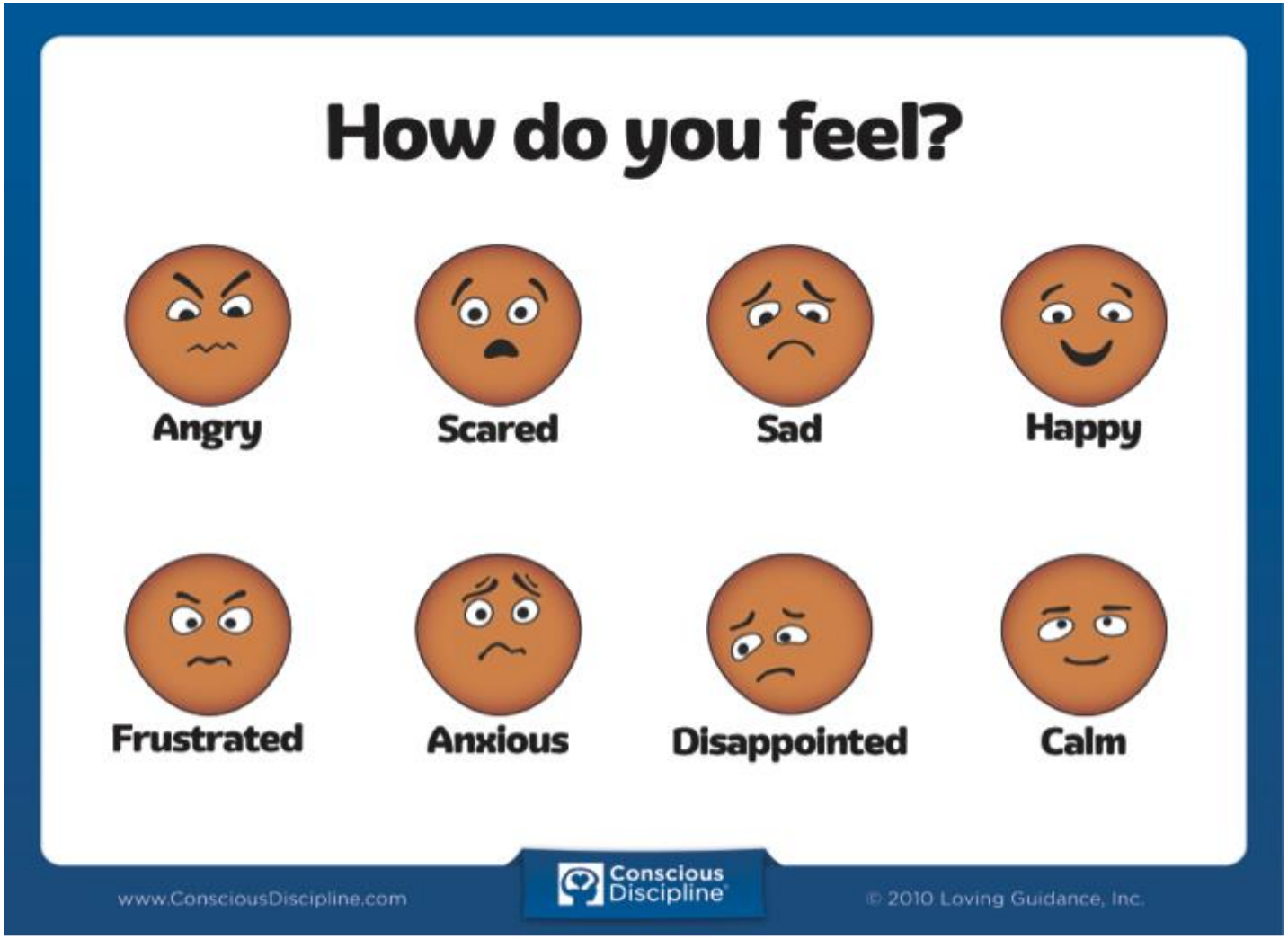
CLINICAL INTERVIEW
RETRIEVAL VS. RECOGNITION

Retrieval - pulls information from memory

Recognition - identifies something that is named and represents a simpler form of recall

PROMOTING RECOGNITION

- Use of interview questions containing multiple choice answers
- Use of line drawing/pictorial expressions
- Use of anchor events
- Clarifying, summarizing and recapping
- Meeting more frequently for shorter periods of time


How do you feel?
Angry
Scared
Sad
Happy
Frustrated
Anxious
Disappointed
Calm
www.ConsciousDiscipline.com
Conscious Discipline
© 2010 Loving Guidance, Inc.

COMMUNICATION IS THE FOUNDATION OF EVERY RELATIONSHIP

- Expressive vs. Receptive Language Skills

USEFUL GUIDELINES FOR SPEAKING/ INTERVIEWING

- Be honest when you do not understand an individual's speech or communication.
- Feel free to ask them to repeat the response or enlist the help of collateral sources in the room when appropriate. Remember to ask permission before involving collateral data sources.
- Use "who," "what," and "where," questions rather than "when," "how," and "why."
- High yield accurate information will most likely be gained from the use of pictorial multiple–choice and factual yes/no questions, closely followed by subjective yes/no questions.
- Avoid hypothetical or abstract future-oriented questions.

USEFUL GUIDELINES FOR SPEAKING/ INTERVIEWING

- Avoid jargon or slang, as well as other technical language.
- Use concrete descriptions and avoid figurative language.
- Avoid conversational punctuations such as "really" and "you know" because they may be taken literally.
- Frequently check understanding of conversation with the individual with ID.
- Ask what particular words mean to the individual and use their words when possible. This includes using their terms for body parts, events, locations, etc.

USEFUL GUIDELINES FOR SPEAKING/ INTERVIEWING

- Match questions and answers with the individual's expressive language.
- Avoid double negatives.
- Avoid abstract concepts.
- Use alternative language systems like picture and line drawings as adjunct when needed.
- Match the interviewee's mean length of utterance.
- Use plain language or language less than 6th grade level.
- Use single clause sentences.

COGNITIVE AND EMOTIONAL CAPACITIES OF INDIVIDUALS WITH ID

	IQ Range	% of ID Individuals	Piaget
Mild	50/55 to 70	85%	Concrete Operations
Moderate	35/40 to 50/55	10%	Preoperational
Severe	20/25 to 35/40	3-4%	Sensorimotor
Profound	Less than 20/25	1-2%	Sensorimotor

(Gentile and Gillig, 2012, pp. 101-104)

SEVERE/PROFOUND AND SENSORIMOTOR STAGE

- Birth until the development of language
- Individuals with severe/profound ID have limited to no development of language
- Can be observed for appearance, relatedness to others, impulse control, activity level (voluntary and involuntary motor movements), expression of affect, attention span, any unusual ritualistic, stereotypic or repetitive behaviors and external signs of anxiety

MODERATE ID AND PREOPERATIONAL STAGE

- "Preoperative stage" of cognitive development
- Language development is a hallmark of this stage
- Focus is on own perspective, not the viewpoint of others
- Tendency to focus on one aspect of an object while ignoring other facets
- Difficulty ranking the importance of various aspects of a situation or experience

MILD ID AND CONCRETE OPERATIONS

- At the level of "concrete operations"
- Ability to think logically about concrete events
- Difficulty describing symptoms and providing subjective data regarding emotion
- Pictorial representations are helpful
- Less egocentric

CONSIDERATIONS

- Do not use slang or figurative speech.
- Use cultural awareness and sensitivity.
- Keep trying – be persistent.
- Use "who," "what" and "where" questions rather than "when," "how" and "why" questions.
- Be respectful of all assistive and communicative devices and treat these devices as if they are part of the individual's personal space.

(Burke, 2013)

CONSIDERATIONS

- Attend to a patient's individual communication style or format.
- Use pictorial multiple-choice and factual yes/no questions, closely followed by subjective yes/no questions
- Paraphrase and use time anchors.
- Recap. Summarize. Clarify
- Allow more time and consider multiple meetings if needed.
- Above all, establish an alliance with the patient.

CONSIDERATIONS FOR ADAPTING PSYCHOTHERAPY

- The individual's level of intellectual functioning
- The presenting symptoms that led to the referral
- How the symptoms compare to the individual's previous level of functioning
- How mental health symptoms interact with behavior that is typical for the individual's ID or DD
- What types of stressors the individual is facing
- What skills the individual has used to manage similar stressors in the past
- The therapists' own biases about ID and their ability to engage in the treatment process

MODIFICATION OF MI TECHNIQUES FOR PATIENTS WITH ID

- Open ended-questions
- Affirmations
- Reflective listening
- Summaries
- Clinicians may only need to take a more directive approach, help the patient to identify and express feelings regarding possibility of change
- Utilize role-playing, visual prompts, pictures, therapeutic games and activities to help facilitate the patient's involvement.

MODIFICATIONS OF CBT FOR PATIENTS WITH ID

- Increase in the number of sessions
- Progress at a slower rate
- Use repetition to facilitate internalization of the necessary skills
- Elicit the participation of involved care providers to assist in with homework assignments and to help the patient recognize and identify when experiencing cognitive distortions.

CLINICAL VIGNETTE # 2

SARAH

MODIFICATIONS OF DBT FOR PATIENTS WITH ID

- Shorten group sessions (from 2.5 hr. to 1-.5 hr.)
- Increase frequency of sessions
- Simplify concepts (use concrete language, pictures or illustrations, diary cards).
- Use handouts modified to the person's level of cognitive ability
- Increase activities, such as therapeutic games, role-play, etc.
- On-going collaboration with involved caregivers
- Provide education and training to involved caregivers so they can provide reinforcement of the skills

MODIFICATIONS OF SUPPORTIVE THERAPY FOR PATIENTS WITH ID

- Simplify the interventions by reducing the complexity of the techniques and by breaking down interventions into smaller units.
- Expect longer length of treatment
- Augment techniques with activities such as therapeutic games, drawings, role-plays, etc.

MODIFICATIONS OF GROUP THERAPY FOR PATIENTS WITH ID

IBT (Interactive Behavioral Therapy)

- Orientation stage: fascinators work to shape good interpersonal behavior.
- Warm-up and sharing stage: participants set agenda items and share what issues they would like to address during the session
- Enactment stage: identified issues are explored through the use of psychodrama techniques in order to increase emotional engagement.
- Affirmation stage: each member of the group is given feedback about the strengths and gains achieved during that particular therapy session

FREQUENTLY UTILIZED PSYCHODRAMA TECHNIQUES

SOURCE ADAPTED FROM DAYTON (1994), PAGES 26, 34, 35, 71

Doubling	During role-play, group members share their view of the identified protagonist. The double acts as an inner voice and reflection of the protagonist
Role reversal	The protagonist is asked to exchange roles with another person. This enables patients to see themselves from another point of view.
Soliloquizing	The protagonist shares their most intimate thoughts about a crucial situation in their life without addressing other members of the group.
Future projection	The protagonist projects him/herself into their future life.

Kipper (2005)

PSYCHOTHERAPY TOPICS AND THE ID POPULATION

- **Grief and Loss**
- **Trauma**

PSYCHOTHERAPY TOPICS AND THE ID POPULATION - **GRIEF AND LOSS**

- Loss of a parent
- Staff turnover (abrupt end of significant relationships, w/o advance notice)
- Loss of familiar surroundings
- Loss of other relationships (friends/neighbors)

ATTACHMENT THEORY AND ITS POTENTIAL RELEVANCE FOR GRIEF AND LOSS IN PATIENTS WITH ID

Hollins & Sinason (2000) outline the following psychic organizing principles which apply to all individuals with ID, regardless of the severity of cognitive deficits:

- The existence of the disability itself including the conscious and unconscious fantasies that accompany it).
- Loss (of the normal self who would have been born).
- Sexuality (internally distorted by the impact of the disability).
- Dependency (not being able to live autonomously).
- Fear of death (being part of a group which society does not reliably accept and protect).

THEORETICAL CONCEPTUALIZATION OF LOSS ACCORDING TO LIKELY DEVELOPMENTAL LEVEL

Profound ID

- Function at sensorimotor stage of development, regardless of their chronological age. Individuals in this stage of development will view death as a loss, separation or abandonment. They will lack the ability to comprehend the concept of death, but they will notice and grieve the absence of their loved one, and their reactions will be significantly influenced by the reactions of trusted loved ones and care providers. Individuals functioning in this developmental framework will need reassurance and support as well as adherence to their typical schedule and routines.

(Burke, 2013)

THEORETICAL CONCEPTUALIZATION OF LOSS ACCORDING TO LIKELY DEVELOPMENTAL LEVEL

Severe to Moderate ID

- Function in the preoperational stage of cognitive development, regardless of their chronological age. Individuals in this stage of development will see death as temporary and reversible, and will interpret their world in a concrete and literal manner (Gentile & Hubner, 2005). They may believe that the death was caused by their thoughts, or may provide other magical explanations for the loss which can lead them to blame themselves or to believe that they are able to bring a loved one back to life. It is important to provide support and concrete explanations of the loss, and to correct misperceptions. It may be helpful to provide education regarding what the loss means, and to have discussions regarding the fact that the loved one will not return. The psychotherapist will need to spend time helping patients to identify and label their feelings around the loss (e.g. grief, sadness, numbness, anger).

THEORETICAL CONCEPTUALIZATION OF LOSS ACCORDING TO LIKELY DEVELOPMENTAL LEVEL

Moderate to Mild ID

- Function at the cognitive level of concrete operations, regardless of their chronological age. Individuals in this stage of cognitive development will understand that the death is final and irreversible, but may not believe that it is a normal part of life or that it could happen to them. The loss may be personalized, and expressions of anger toward the deceased (or toward those believed to have been unable to save the deceased) may occur. The loss may trigger fear regarding the safety of other loved ones, and they may experience anxiety or depression or may exhibit somatic complaints. It is also common to see a demonstration of aggressive behaviors, particularly in males. Providing education regarding death and dying can be helpful, and it is important to allow the individual the opportunity to participate in funeral services. It is important to facilitate the identification of emotions and the ability to express them. it may be helpful for the psychotherapist to work on activities with the individual, such as creating a memory book or making cards.

CLINICAL VIGNETTE # 3

JAMES

PSYCHOTHERAPY TOPICS AND THE ID POPULATION -**TRAUMA**

- Sexual abuse
- Physical abuse
- More vulnerable to the effects of trauma and PTSD
- Trauma informed care

PSYCHOTHERAPY WITH PATIENTS WITH ID WHO HAVE EXPERIENCED TRAUMA

- Ensure the individual will feel safe
- Ensure the individual will have a sense of control
- Avoid unnecessarily exposing to triggers
- Provide guidance and support to caregivers to help them reduce the patient's exposure to triggers.

BEST PRACTICE ADAPTATIONS

- Increase length of treatment to allow for needed repetition and implementation of additional treatment stages.
- Adjust the complexity of the interventions provided to match the patient's developmental framework.
- Reduce the level of vocabulary, sentence structure and length of utterance to match the individual's level of understanding.
- Utilize more directive methods.
- Provide the patient with visual cues to address memory issues.
- Augment interventions with activities to deepen understanding of information presented.
- Involve care providers with the consent of the patient.

ETHICAL ISSUES

- Respect for Clients
  - Person-First Language
  - Relevance
- Who is the real client?
  - Is the identified client willing to participate?
  - Is the identified client receiving any benefit from the service?
- Age-appropriate services
- Dignity of Risk

REFERENCES

- Burke, T. (2013). Dual Diagnosis: Overview of Therapeutic Approaches for Individuals with Co-Occurring Intellectual/Developmental Disabilities and Mental Illness for Direct Support Staff and Professionals working in the Developmental Disability System. White Paper sponsored by the Ohio Mental Illness/Developmental Disability Coordinating Center of Excellence. Accessed from https://mha.ohio.gov/static/learnandfindhelp/TreatmentServices/TCC/Dual-Diagnosis-MI-DD.pdf on May 17, 2023.
- Fletcher, R.J. ed. (2011). *Psychotherapy for Individuals with Intellectual Disability*. Kingston, NY: NADD Press.
- Gentile, J.P., and Gillig, P.M. (2012). *Psychiatry of Intellectual Disabilities: A practical manual*. Wiley-Blackwell.

REFERENCES

- Kipper, David A. (2005). Introduction to the special issue on the treatment of couples and families with psychodrama and action methods: the case of generic psychodrama. *Journal of Group Psychotherapy Psychodrama and Sociometry,* 58 (2), 51+. Academic OneFile, Accessed 30 Apr. 2018.
- Loving Guidance, Inc. (2010). "How Do You Feel" graphic. Accessed from https://consciousdiscipline.com.
- Mason, V.A. and Dowling, S.F. (2023). Bereavement in the Lives of People with Intellectual Disabilities. Online article published by Univerity of Herfordshire, UK. Accessed 5/18/23 from http://www.intellectualdisability.info/life-stages/articles/bereavement-in-the-lives-of-people-with-intellectual-disabilities on 5/18/2023.

REFERENCES

- Millar, C. and Greenhill, B (2022). Adapted remote cognitive behavioral therapy for comfort eating with a woman with intellectual disabilities: Case report. Journal of Eating Disorders 10:29. Accessed at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8862397/pdf/40337_2022_Article_537.pdf on 5/18/2023.
- Razza, N. J., & Tomasulo, D. J. (2005). An Introductory Tale: The Case of Martina. *Healing Trauma: The Power of Group Treatment for People with Intellectual Disabilities* (11-19). Washington, DC, US: American Psychological Association.
- Razza, Nancy J., Tomasulo, Daniel J., Sobsey, Dick (2011). Group psychotherapy for trauma-related disorders in people with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, 5(5), 40-45.

REFERENCES

- Sovner, R. & Hurley A.D. (1986). Four Factors Affecting the Diagnosis of Psychiatric Disorders in Mentally Retarded Persons. *Psychiatric Aspects of Mental Retardation Reviews*, 5(9), 45-49.
- Tomasulo, Daniel J. (2014). Positive group psychotherapy modified for adults with intellectual disabilities. *Journal of Intellectual Disabilities*, published online 6 October 2014.

QUESTIONS?

THANK YOU FOR YOUR PARTICIPATION TODAY

PLEASE COMPLETE AND RETURN YOUR EVALUATION FORMS

SUSAN LAGRONE, M.S., L.P.C.-S,

NUECES CENTER FOR MENTAL HEALTH AND INTELLECTUAL DISABILITIES

SLAGRONE@NCMHID.ORG

361-886-1437