Unpacking the Complexities of Dual Diagnosis (Mental Illness and Intellectual and Developmental Disability)

FACULTY: LUCY ESRALEW, PHD
NADD-CC

SENIOR PSYCHOLOGIST
SUPERVISOR

CALIFORNIA DEPARTMENT OF
DEVELOPMENTAL SERVICES

Disclaimer

▶ The views presented in this Webinar are solely those of the presenter and do not reflect policies, positions or viewpoints of the California Department of Developmental Services (DDS)

Learning Objectives for this session

▶ Identify at least two challenges to assessment of mental health needs among individuals with intellectual and/or developmental disorders

▶ Identify at least two treatment options for individuals with intellectual or developmental disorders and mental health needs

▶ Identify at least two forms of mental health service that may benefit individuals with dual diagnosis

▶ Provide considerations for addressing challenges to assessment, treatment and service delivery for individuals with dual diagnosis

What is Dual Diagnosis MI/DD?

▶ The term literally means that someone has been given two diagnoses

▶ The term is usually applied to individuals with mental health and substance use disorders

▶ For this presentation, we are using **Dual Diagnosis** to refer to the combination of both mental health needs and intellectual and/or developmental disorder

◉ Examples include:

› A consumer with Cerebral Palsy and Bipolar I Disorder

› An individual on the autism spectrum who carries a diagnosis of Obsessive-Compulsive Disorder

› A consumer with Down Syndrome who is depressed and/or meets criteria for a diagnosis of Alzheimer's Disease (aka dementia)

Mental Health Needs of persons with IDD

❑ You will notice that throughout this presentation, I use the term "**mental health needs**" of individuals with IDD However there are a number of ways in which this phenomenon has been referred to in the literature

❑ **Mental illness** is a term used to refer to severe and persistent psychiatric problems which may interfere with work, relationships or independent living during acute episodes

❑ *Mental health disorders* refer to any of the diagnoses that can be found in the DSM-5, DM-ID-2, ICD-10

❑ Dual Diagnosis (MI/DD, MH/IDD)

Dual Diagnosis (MI/DD)

◉ Controversy as to whether individuals with developmental disorders are prone to psychiatric illness compared with their typically developing peers.

◉ Individuals with IDD experience the same range of mental health problems that can be found in the general population.

◉ Depending upon contraindications, individuals with IDD are treated with the same types of medication as is the general population relevant to their diagnosis.

Prevalence of Dual Diagnosis (MI/DD)

▶ Estimates of dual diagnosis prevalence range from 14-70%.

▶ NADD estimates that the prevalence of individuals who have mental health needs and have an intellectual and/or developmental disorder is somewhere between 30 and 40% http://www.thenadd.org/.

▶ The National Core Indicators (NCI) identified a rate of 55% of people with IDD who have a co-occurring psychiatric disorder (National Core Indicators, 2016). This study was based on a review of patient charts from 30 states in the USA (N=13,466).

People with developmental disorders are at increased risk…

▶ Individuals with IDD are three to six times more likely to develop a mental health disorder than their typically developing peers.

▶ Psychotic disorders may occur three times more often in adults with developmental disabilities compared to the general population (Cooper et al., 2007; Turner, 1989).

▶ One large study in the U.K. reported that mood disorders (e.g., major depression, bipolar disorder, dysthymia) were three times more common in those with developmental disabilities than in the general population (Richards et al., 2001).

Characteristics of Respondents to the NCI survey who are dually diagnosed

- ▶ Less likely to live at home with family.
- ▶ Considerably more likely to need some or extensive support for both self injurious behavior and disruptive behavior.
- ▶ More likely to take medications for a co-occurring mental health condition, but also more likely to report taking medications for a behavioral challenge.
- ▶ More likely to report wanting additional assistance staying in touch with friends.
- ▶ Less likely to have a community job.
- ▶ More likely to report feeling lonely.

Characteristics of NCI Respondent Sample

Developmental Disorder	With Dual Diagnosis	Without Dual Diagnosis
Mild ID	48 %	42% N=20,778
Profound ID	7%	12%
Autism Spectrum Disorder	20%	14% N=21,750
Cerebral Palsy	12%	20% N=21,872
Down Syndrome	6%	13% N=21,835

Characterizing Behavioral Concerns

Behaviors of Concern	With Dual Diagnosis	Without Dual Diagnosis
Need for behavior support	31%	14%
Self-injurious	58%	27%
Disruptive	58%	16%
Destructive	41%	16%

Medications (NCI 2019 survey)

Medications	Without MH/DD	With MH/DD
Reported to take medication to treat mood disorders, anxiety or psychotic disorder	14%	82% N=20,307
Reported to take medications to treat behavior problems	11%	36% N=20,231

Limited Clinical Capacity

Although we know that individuals with IDD experience mental health needs at a higher rate than their typically developing peers, we are challenged to identify and treat mental health concerns:

▶ Shortage of psychiatrists

▶ Shortage of trained MH workers

▶ Shortage of DSPs

▶ Limited access to local mental health services

▶ Service delivery systems remain siloed and fragmented

▶ Measuring/evaluating success is still challenging

Methodological Limitations of existing studies

▶ There have been a few studies that have employed rigorous methodological protocols. A study conducted by Cooper, Smiley, Morrison, Williamson, and Allan (2007) used a population-based adult sample (N=1023) with a comprehensive individualized assessment model.

▶ The data indicated a point prevalence of mental illness at 40.9% (clinical diagnosis); 35.2% (DC-LD); 16.6% (ICD-10); and 15.7% (DSM-IV- 2 DM-ID-2 Textbook TR). Similarly, high prevalence rates have also been reported for children and young people with intellectual/developmental disabilities, in whom mental health problems are about four times more common than in the general population (Einfeld, Ellis, & Emerson, 2011; Emerson and Hatton, 2007).

Persons with IDD are more likely…

▶ To have co-occurring medical problems

▶ To be impulsive

▶ To demonstrate poor self-monitoring and self-regulation

▶ To have limited social problem-solving skills

▶ To have limited self-calming skills

▶ To have limited language skills with which to let others know about their emotional distress or difficult thoughts

Assessment Considerations

Issues that can complicate identification and treatment of mental health needs of persons with IDD:

▶ Limited assessment tools

▶ Limited capacity of trained professionals

▶ Difficulty with conducting Differential Diagnosis

▶ Unreliable process by which individuals with mental health needs come to the attention of a mental health professional

DSM Equivalents

- The criteria for mental health disorders listed in the DSM-5 may need to be adjusted to the presentation of individuals with intellectual and developmental disorders

- S/S of mental health disorders or mental illness may include behavioral presentation (aggression, property destruction, self-injurious behavior) not typically seen among typically developing individuals

- How familiar are practitioners with the **DM-ID 2**?
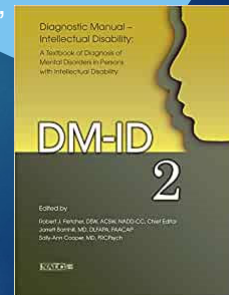
Four Non-Specific Factors (Sovner 1986)

| Factor	Definition	Clinical Impact
Intellectual Distortion	Concrete thinking and impaired communication	Limited ability to label experiences and report them
Psychosocial Masking	Impoverished social skills and limited experience	Unsophisticated presentation can be mistaken for symptoms of psychiatric illness
Cognitive Disintegration	Effects of stress-induced disruption of information processing	Bizarre presentation and psychotic like state may be misdiagnosed as Schizophrenia
Baseline Exaggeration	Increase in severity of previous cognitive and behavioral concerns due to psychiatric disorder	Makes it difficult to discern the features of current illness

MI/DD

- ▶ Unlike their typically developing peers, individuals with both IDD and mental health needs have excess disability

- ▶ Individuals with MI/DD are more likely to look "sicker" and present as more behaviorally disordered than their non-IDD peers

- ▶ Regarding MH disorders: Individuals with IDD are more likely to be undiagnosed, misdiagnosed, undertreated or mistakenly treated because of *diagnostic overshadowing*
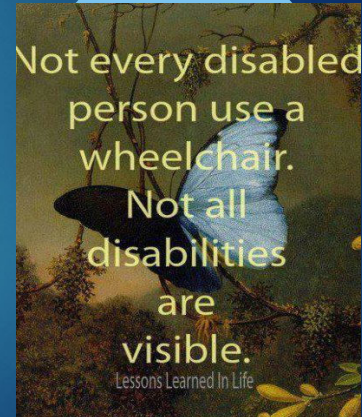
Diagnostic Overshadowing

- ▶ In 1982 Dr. Steven Reiss and his colleagues introduced the term "diagnostic overshadowing" to describe the tendency of medical and mental health practitioners to over attribute problems experienced by persons with IDD to their intellectual or developmental disorder, thereby missing other possible causes of distress or missing treatable conditions.

- ▶ It is a form of cognitive bias that can affect clinical decision-making and lead the person with IDD to be less thoroughly assessed than their typically developing peers.

DIAGNOSTIC OVERSHADOWING

SEE BEYOND THE DIAGNOSIS
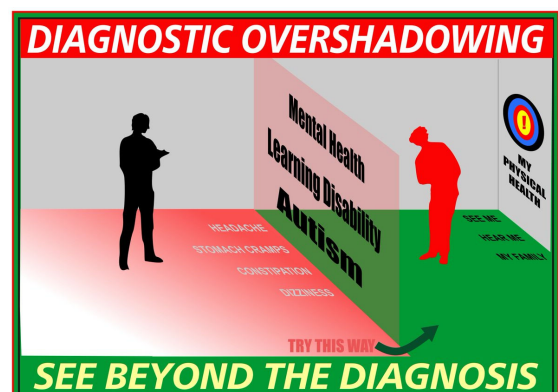
Impact of MI/DD on development

▶ A mental illness is an overlay upon already existing challenges associated with the person's developmental disorder

▶ Unaddressed mental health needs can lead to problems in learning, peer relationships, behavior, employment, community living and acquisition of age-appropriate adaptive skills

Not every disabled person use a wheelchair.
Not all disabilities are visible.
Lessons Learned In Life

Differential Diagnosis

▶ Certain genetic disorders have behavioral phenotypes which include aggression, self-injury, etc. and may be mistaken for symptoms of mental health disorders.

▶ What is the role of neurodevelopmental disorder for the person that presents with mental health needs?

▶ Behavioral and emotional regulation concerns that often accompany ASD, may be mistaken for Bipolar Disorder; stereotypies and rituals may be mistaken for OCD.

▶ An accurate assessment of mental health needs considers the role of neurodevelopmental conditions, behaviors of concern, medical issues, and environmental stressors in possible mental health disorders.

Issues that may complicate differential diagnosis

▶ Limited language skills may predispose consumers towards disruptive and aggressive behaviors as a form of communication.

▶ Organic bases for developmental disorder that represent compromised CNS and increase the likelihood of impulsive behaviors.

▶ Lower I.Q. associated with poor repertoire of coping skills.

▶ Limited opportunities to socially interact with typically developing peers may hinder the development of age appropriate social skills.

Distinguishing behavioral and psychiatric presentations

◉ What is the context for the person's behaviors of concern?

◉ Is this person presenting on a weekend or holiday when less staff is available?

◉ Did the consumer have an argument with someone in his/her residence or work program prior to presentation?

◉ Was there a recent change in the consumer's routine or support system?

◉ Is this a behavioral problem versus a psychiatric decompensation?

Medical Issues May Mimic Psychiatric Problems

- Infections such as URI or UTI
- Pain (dental, gastric, migraine)
- Thyroid imbalance
- Changes in seizure activity
- Adverse response to medications

Psychiatric versus Behavioral Problems

Mental health concerns do not usually cause behaviors of concern , but they may increase the frequency, intensity or duration of unwanted behaviors.

Environmental triggers and stressors
+
Poorly developed coping skills
+
Psychiatric illness
=
Behaviors of Concern

Obsessive Compulsive Disorder (OCD) and IDD

► Repetitive behaviors and speech

► Inability to provide reliable self-reports of internal subjective feelings

► Emphasis on behavior, observable components

► Some individuals may try to hide or reduce compulsive behavior because of a concern for societal disapproval, others may not be aware of society disapproval and so may not seek to reduce or eliminate compulsive behaviors

► Aggression may be *the* presenting symptom of OCD in ID

► To what extent would an individual on the spectrum who exhibits stereotypies or repetitive behaviors be considered as meeting criteria for OCD?

OCD and ID

► Some behaviors exhibited by consumers with OCD are different than behaviors observable among typically developing individuals diagnosed with OCD:

- ▪ Flipping objects
- ▪ Swinging objects
- ▪ Probing body parts
- ▪ Picking/pulling skin, nose, lip, etc.
- ▪ Pulling one's hair/eyebrows
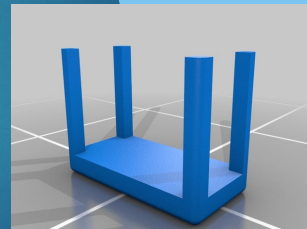
Recognizing Trauma

- Individuals with disabilities are over four times as likely to be victims of crime as the non-disabled population (Sobsey, 1996).

- Individuals with disabilities are 2-to-10 times more likely to be sexually abused than those without disabilities (Westat Ind., 1993).

THE SIX AREAS OF TRAUMA INFORMED CARE.

1. Safety.
2. Trustworthiness and Transparency.
3. Peer Support.
4. Collaboration and Mutuality.
5. Empowerment, Voice and Choice.
6. Cultural, Historical and Gender Issues.

Possible responses to trauma that are non-specific to PTSD

- Response may:
  - include physiological signs of anxiety
  - involve new separation fears
  - take the form of sleep changes
  - lead the adult to withdraw from usual activity and social contact
  - take the form of a new avoidance of certain people or situations
  - involve the display of highly sexualized or aggressive behaviors

Signs of PTSD can be missed among individuals with IDD

- ▶ Flashbacks can be mistaken for hallucinations
- ▶ Hypervigilance seen as paranoia
- ▶ Numbing may be viewed as depression
- ▶ Hyper-arousal may be seen as anxiety or mood disorder
- ▶ Avoidant behavior may be diagnosed as Schizoid or Avoidant Personality Disorder

Challenges of conducting a Suicide Risk Assessment

TRIAD:

1) Does the person have the *means* hurt herself?
2) Does the person have the *opportunity* to hurt herself?
3) Does the person have the *intent* to hurt herself?

## Considerations to address challenges in assessment

- Utilize the DM-ID-2
- Train clinicians on the use of tools developed for persons with IDD
- Provide practical field experience in assessment of persons with IDD
- Evaluate the individual across several sessions in different settings (if possible)
- Include direct assessment and collateral report
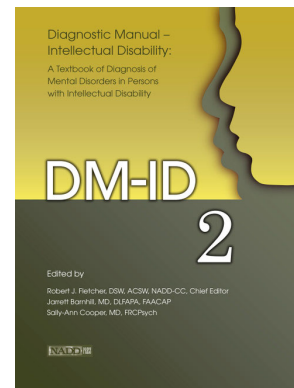
Promising Practices (non-pharmacological)

- Acceptance Commitment Therapy (ACT)
- Applied Behavior Analysis
- Bowen Family Systems Theory
- Cognitive Behavior Therapy CBT
- Dialectic Behavior Therapy (DBT
- Positive Behavior Supports
- Positive Interactive Behavioral Therapy (P-IBT)
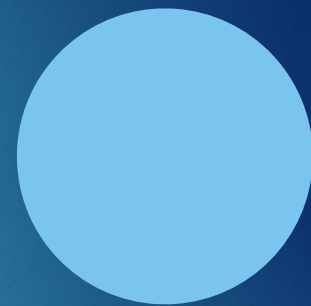
Referral to Counseling

- The consumer needs to be verbal enough and have sufficient receptive as well as expressive language skills in order to be successful in counseling.

- The consumer needs to be motivated to better understand and change maladaptive behaviors.

- The consumer needs to be willing to work with the counselor/therapist; successful counseling cannot be mandated by others.

Mindfulness Based Psychotherapy Practices

- Mindfulness skills include observing, noticing, describing, labeling, and participating are similar to those used in cognitive behavioral therapy (CBT).

- Mindfulness based psychotherapies involve behavioral practices, cognitive strategies, and practices which enhance concentration.

- The main approaches to mindfulness-based psychotherapy used with persons with IDD include:

- Acceptance and Commitment Therapy (ACT)

- Dialectical Behavior Therapy (DBT)

Acceptance Commitment Therapy (ACT)

▶ Adults with ID/ASD experience high levels of psychological difficulties.

▶ Eight studies that used ACT were included in a systematic review by Byrne and O'Mahoney (2020).

▶ ACT interventions were associated with reductions in psychological distress.

▶ Improvements were also found in adaptive skills.

▶ The limited data suggest that further adaptations are required for ACT treatments.

Applied Behavioral Analysis (ABA)

▶ A scientific approach to understanding the function of different behavior.

▶ ABA is a method of therapy based upon learning theory that is used to improve or change specific behaviors.

▶ ABA therapy is used to improve behaviors like social skills, reading, academics, and communication as well as learned skills like grooming, hygiene, fine motor dexterity, job proficiency and even simple things like a child keeping his room clean.

▶ Many BCBAs work with children on the autism spectrum; however, these principles can be applied to all ages and all neurodevelopmental disorders.

Cognitive Behavior Therapy (CBT)

▶ CBT has been shown to be effective for both the general population and individuals with intellectual or developmental disorders.

▶ CBT is based on the premise that thoughts, feelings, and behaviors are all connected. Treatment targets unproductive thought patterns and focuses on building adaptive coping skills. The primary target for intervention is changing thoughts, and potentially feelings, to enable behavioral change.

Dialectical Behavior Therapy (DBT)

▶ DBT is a form of Cognitive Behavior Therapy proposed by Marsha Linehan in 1993.

▶ The emphasis of the DBT model is on teaching the individual

1) to modulate extreme emotions and reduce unproductive behaviors that result from those emotions and

2) to trust their own emotions, thoughts, and behaviors.

3) These two goals are accomplished through multiple treatment modalities, including: individual therapy, skills training, coaching in crisis, structuring the environment, and consultation teams for providers.

Bowen Family Systems Therapy

- ▶ Based on the work of Drs. Murray Bowen and Michael Kerr.
- ▶ The individual is seen as functioning within the family, which forms an emotional unit.
- ▶ The emphasis is less on the person's disabilities or challenges and more on how members of the family interact and relate to one another.

Positive-Interactive-Behavioral Therapy (P-IBT)

- ▶ Developed by Drs. Tomasulo and Razza which they described as the "Healing Crowd"
- ▶ Group therapy utilizing psychodrama and other active techniques

Razza, N.& Tomasulo, D. (2005), Healing Trauma: The Power of Group Treatment for People with Intellectual Disabilities Washington, D.C., American Psychological Association

Positive Behavior Supports (PBS)

▶ Positive behavior support (PBS) refers to an approach which includes tools and strategies for improving quality of life and decreasing challenging, unproductive social interactions and other types of problems occurring in home, school, work, and community settings..

▶ Utilizing PBS involves enriching the person's environment, building on strengths and teaching adaptive coping skills.

▶ https://www.apbs.org/ Association for Positive Behavior Supports

Positive Psychology

Kaufman (2006) identifies four techniques for integrating Positive Psychology into therapy:

➢ Shift the individual's focus from the negative to the positive.

➢ Identify a personal strength and use it each day.

➢ Find a balance between the negative and positive.

➢ Promote feelings of hopefulness.

Who Delivers What Service?

- ▶ **Psychiatrists, APNs** prescribe and monitor psychoactive medications.
- ▶ If the consumer's medications are prescribed by a PCP (any physician can prescribe any medication) or a neurologist, it is probably wise to include consultation with a psychiatrist or APN on a regular basis.
- ▶ Licensed **Psychologists, Social Workers and Professional Counselors** provide counseling and psychotherapy.
- ▶ **BCaBAs and BCBAs** conduct Applied Behavior Analysis.
- ▶ There is no current certification for individuals who provide **Positive Behavior Supports.**
- ▶ There are NADD-certified clinicians through the National Association for Dual Diagnosis **NADD-CC.**

The Role of the Psychiatrist

- ▶ A psychiatrist is a physician who specializes in the diagnosis and treatment of mental health disorders.
- ▶ Psychiatrists prescribe and oversee the medical treatment of mental illness through the use of psychoactive medications.
- ▶ Most psychiatrists do not offer therapy along with medical treatment of mental health disorders.
- ▶ In some cases consumers see Advanced Nurse Practitioners (APN) who are supervised by Psychiatrists.

The Role of Medication

- ▶ Management of Mood
- ▶ Address delusions, hallucinations and negative symptoms of thought disorder
- ▶ Address impulsivity
- ▶ Helps with anxiety
- ▶ Is not a substitute for building relevant coping skills such as anger and stress management

The Behavior Specialist

- ◉ The Behavior Interventionist should know how to apply learning theory to develop a plan that reduces unwanted behavior and increases adaptive replacement behaviors/skills.
- ◉ The Behavior Interventionist needs to work alongside the consumer, family and staff in order to increase everyone's competencies in dealing with stressors.
- ◉ Approaches included Applied Behavior Analysis (ABA) and Positive Behavior Supports (PBS).

Family Members

- Describe the process of evaluation to family members.
- Keep the family "in the loop".
- Call upon a clinician or practitioner to confer with families.
- Help families understand their options regarding treatment for their relative with dual diagnosis.

How Can Families Help?

- Understand the nature of their relative's mental health needs including the role of medication and psychosocial interventions that are effective in treating specific mental illness.
- Encourage their relative to resume usual routine and expectations as soon as possible to the extent tolerated.
- Work alongside staff to provide supports, and opportunities to develop age appropriate social and emotional coping skills.

Providing Structure

- Clear sequence of events
- Clear expectations about behavior
- If using contingency management approach, clear link between behavior and rewards or disincentives
- Predictability
- Plan ahead for times when there will be a break in routine (vacation, summer break)
- Provide the consumer with positive practice concepts. What can this individual do to feel better?
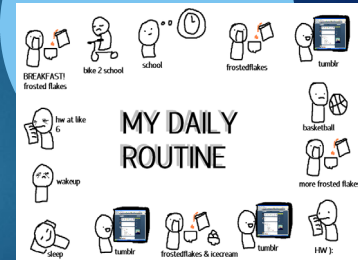
Promising Services

- Assertive Community Treatment (ACT)
- Intensive Outpatient (IOP)
- Partial Care
- Shared Responsibility groups (combining mental health and DD systems of care)

Assertive Community Treatment

▶ Assertive community treatment (ACT) is internationally a well-established and effective model for providing intensive treatment and psychosocial rehabilitation services to people with severe and persistent mental illnesses.

▶ This type of treatment service usually involves an interdisciplinary team of professionals intensively serving a set number of voluntary clients with mental health supports (e.g., mental health assessment, psychotherapy, crisis supports, medication administration) and social rehabilitation supports (e.g., case management, social and life skills training, home and job finding efforts) in the clients' home environments.

▶ Shown to effectively reduce hospitalizations in general population, less studied or applied to individuals with IDD.

Partial Care and Intensive Outpatient (IOP)

▶ If the consumer cannot work or participate in a day program because of mental health problems, they may benefit from partial care programming.

▶ Consumers may benefit from partial care or IOP if they have recently been hospitalized on a psychiatric unit and they are not ready to resume work or usual activity but would benefit from a step-down from inpatient hospitalization.

Call Crisis Assessment Response and Enhanced Services (CARES)

▶ New Jersey's crisis response team for individuals with intellectual and developmental disorder funded by the Division of Developmental Disabilities and the Division of Mental Health and Addiction Services (braided funding from DDD and DMHAS).

▶ Adults 21+ who are in psychiatric, emotional or behavioral crisis.

▶ **1-888-393-3007**

9-8-8

▶ How does 988 work?

▶ Anyone who needs suicide or mental health-related crisis support, or who has a loved one in crisis, can **connect with a trained counselor by calling, chatting, or texting 988**

988
SUICIDE
& CRISIS
LIFELINE

When to Call 9-1-1

▶ When the consumer is behaving in a dangerous way to themselves or others

▶ When usual strategies to calm down the consumer or stabilize the situation are not working…

Role of inpatient psychiatric hospitalization

▶ Reduce dangerousness

▶ Rapid tranquilization

▶ Assessment

▶ Observation

▶ May be opportunity to trial intervention that can be continued in community

▶ Hand-off to community provider or (in the case of someone who does not stabilize) hand-off to higher level, longer-term care e.g. county or state hospitalization

State hospitalization and MI/DD

▶ Promote longer term stabilization on therapeutic medication regimen

▶ Prepare for community discharge

▶ Help develop skills that will result in community integration and community tenure

▶ Help educate families and provider agencies on wellness and recovery principles and practices; direct to relevant MH resources

Promising Approaches

Multi-agency Collaboration

Identify areas of needs and strengths upon which to build collaboration and problem solving across and within program agencies

Identify multi-level system interventions to enhance overall capacity

Commit person-centered practices to provide support and treatment to individuals in a manner that meets their specific needs

Shared Responsibility

Collaborate and Coordinate within Departments & Across Silos

Create Opportunities to Utilize Technology

Develop New Models/Approaches

Explore Opportunities within Medicaid

Foster Leadership & Commitment

Promote a culture of Learning from Others
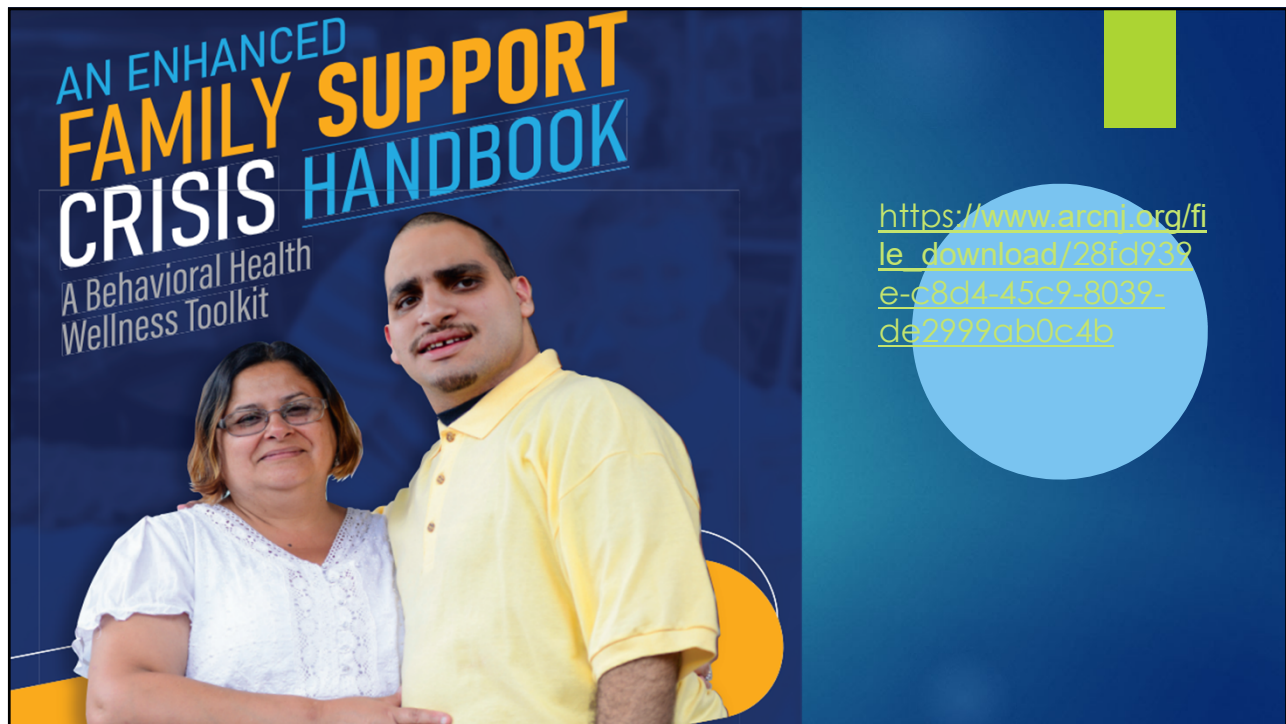
Enhance Training

Incentivize Providers

Tools

- NADD
  https://www.thenadd.org
- Wellness and Recovery Plan (WRAP)
- *An Enhanced Family Support Crisis Handbook: A Behavioral Health Wellness Toolkit*

## Wellness Recovery Action Plan (WRAP)

- https://www.wellnessrecoveryactionplan.com/product/wrap-for-people-with-developmental-distinctions/

https://www.arcnj.org/file_download/28fd939e-c8d4-45c9-8039-de2999ab0c4b

Take Home Messages

► We have come a long way (since the 1980's) in our understanding of the mental health needs of individuals with intellectual and/or developmental disorders…

► We still have a long way to go:

a) To improve the identification and assessment of mental health needs

b) To offer and evaluate the efficacy of treatment

c) To develop collaborative partnership among stakeholders that take shared responsibility for services and supports for individuals with dual diagnosis
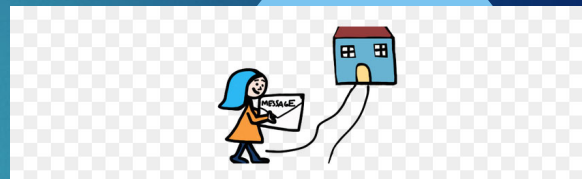
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Questions?

LUCILLE ESRALEW, PHD NADD-CC