

OVERCOMING CHALLENGES AND FINDING SOLUTIONS WHEN WORKING WITH PEOPLE WITH MI/DD

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Goals for Today's Presentation

- ▣ Provide a lifespan perspective in consideration of intellectual and developmental disabilities and co-occurring mental health disorders (MI/ID)
- ▣ Consider brain-behavior connections including developmental disabilities, co-occurring mental health problems and neurobehavioral problems
- ▣ Implications for mental health providers, law enforcement, families and service systems

Introducing Robbie and Caryn

- During today's presentation you will learn about two individuals who will guide our consideration of dual diagnosis (MI/DD) and implications for legal involvement:
- 35 year old *Robbie* who places on the Autism Spectrum and suffers from significant co-occurring Obsessive Compulsive Disorder (OCD)
- 21 year old *Caryn* who has Fetal Alcohol Spectrum Disorder (FASD) and co-occurring anxiety and impulse control disorder

More about the two of them, later...

Using a Lifespan Perspective

- ✓ **Prospectively:** what implications does the child's challenges have for him/her in the future?
- ✓ **Retrospectively:** To what extent did early experiences and interventions (or lack thereof) equip the person as he entered adulthood or older age with MI/DD?

What is Intellectual Disability?

- ▣ Full Scale I.Q. 55-69 Mild Impairment
- ▣ FS IQ 40-55 Moderate Intellectual Impairment
- ▣ FS IQ 20-40 Severe Intellectual Impairment
- ▣ FS IQ \leq 20 Profound Intellectual Impairment

The most common form of developmental disability is ID of unknown etiology. Most individuals with ID are within the moderate to mild range and live in the community. The most common known inherited cause of ID is Fragile X

What is Dual Diagnosis MI/DD?

- The co-occurrence of an intellectual and/or developmental disability and mental health disorder
- Examples include:
 - › Someone with Cerebral Palsy and Bipolar I Disorder
 - › An individual on the spectrum with OCD
 - › A person with Down Syndrome and depression and/or dementia

Impact of MIDD on development

- ❑ A mental illness is an overlay upon already existing deficits associated with the person's developmental disability
- ❑ This leads to problems in learning, peer relationships, behavior, employment, community living and acquisition of age-appropriate adaptive skills

Mental health problems and co-prevalence with IDD

- ❑ Autism and OCD
- ❑ Autism and Bipolar disorder
- ❑ Down Syndrome and depression and/or dementia (\geq age 50)
- ❑ Fragile X and impulsivity/ rage issues
- ❑ Fetal Alcohol Spectrum Disorder and impulse control disorder

What complicates assessment ?

- ▣ **Intellectual Distortion** resulting in limited ability to communicate emotional distress
- ▣ **Psychosocial masking** refers to limited social experience which may influence psychiatric presentation
- ▣ **Cognitive Disintegration** resulting to limited coping skills and limited ability to tolerate stress
- ▣ **Baseline Exaggeration** resulting in increase in maladaptive behaviors during times of stress
- ▣ **Behavioral Overshadowing** refers to missing that behavior may reflect signs and symptoms of psychiatric illness
- ▣ **Medical Overshadowing** resulting in missing signs and symptoms of medical illness

Diagnostic Overshadowing

Is everything about I.Q. or developmental disorder?

- ▣ Knowing someone has an intellectual or developmental disability, may obscure other important considerations:
 - ✓ The 17 year old male with Asperger's who was denied admission to a CCIS on the basis of his linkage to DDD;
 - ✓ The 12 year old with FASD whose seizure disorder was overlooked due to her "behavioral presentation"

Psychiatric versus Behavioral Problems

- Psychiatric illness does not cause behavior problems, but may increase the frequency, intensity or duration of unwanted behaviors

Environmental triggers and stressors

+

Poorly developed coping skills

+

Psychiatric illness

=

Unwanted behaviors

Behavioral Phenotypes

- Select developmental disorders are associated with characteristic behavioral features:
 - ✓ Autism and catastrophic reactions, narrow band of interest, stereotypies
 - ✓ Lesch-Nyan Syndrome and Cornelia deLange Syndrome and serious self-injury
 - ✓ Praeder-Willi and indiscriminant overeating (to point that can be life-threatening)

Adaptive Skills

- ❑ The lower the I.Q., less likely the person will acquire age appropriate self-help skills
- ❑ The lower the I.Q., the less likely the person will acquire age appropriate social and emotional coping skills
- ❑ An assessment of adaptive skills is always needed to determine if the individual is developmentally disabled

Language skills

- ❑ Individuals with IDD
 - ✓ May have a poorly developed vocabulary for emotion and may not be able to label different types of emotional reaction
 - ✓ May have poor verbal conceptual ability and communicate in a very concrete basis about immediate needs
 - ✓ May need a functional communication system (PECS) or communicate by gesture

MI/DD and legal involvement

- Neurobehavioral problems + psychiatric problems may result in:
 - ✓ Increased susceptibility to criminal activity
 - ✓ Increased vulnerability to victimization
 - ✓ Poor judgement
 - ✓ Difficulty inhibiting impulsive responding
 - ✓ Difficulty understanding consequences of behavior (cause-effect)
 - ✓ Difficulty using past experience to guide behavior

Autism Spectrum Disorder (ASD)

- Group of neurodevelopmental disorders characterized by deficits in communication, socialization and restricted/repetitive behaviors:
 - ✓ Autism
 - ✓ Pervasive Developmental Disorder (PDD)
 - ✓ Asperger's Syndrome (AS)
 - ✓ Childhood Disintegrative Disorder
 - ✓ Rett's Disorder

Robbie

- ▣ As a very young child:
- ✓ Difficult to comfort
- ✓ Had gastrointestinal problems
- ✓ Typical acquisition of language skills
- ✓ Developmental milestones on schedule
- ✓ Very clingy to Mom
- ✓ Showed an interest in peers but tended to stay to self
- ✓ Gross motor problems – could not learn how to ride a bicycle, difficulty throwing and catching a ball, etc.
- ✓ Fascination with fires including starting fires began before the age of 5

Evident from an early age and continues through the present...

- ▣ Narrow range of interests and activities
- ▣ Social skills deficits and social anxiety
- ▣ Heavy reliance on family
- ▣ Talented artist who is unlikely to advance his talents without family support
- ▣ Vulnerable to manipulation by others because of poor Theory of Mind (ToM)

Think of the implications of the aforementioned for his life outcomes including relationships, activities and QoL

Understanding Brain–Behavior Connections

- ❑ Brain based deficits in reciprocal social behavior, social communication and stereotyped, repetitive activities
- ❑ High functioning individuals (hfASD) may go undiagnosed and without services into adulthood because of normal language development and average intellectual ability

Communication

- ❑ Impaired social and emotional reciprocity
- ❑ Deficits in verbal and non-verbal communication
- ❑ Deficits in developing, maintaining and understanding relationships

Restrictive and Repetitive Behaviors

- ❑ Stereotyped movements, use of objects or speech
- ❑ Insistence on sameness; inflexible adherence to routine
- ❑ Highly restricted, fixated interests
- ❑ Hyper-hypo sensitivity to sensory input

Neurocognitive Deficits of ASD

- ❑ Impaired higher level cognitive shifting
- ❑ Deficits in memory, planning, inhibition, flexibility and self-monitoring
- ❑ Weak central coherence: poor ability to integrate information from environment into a meaningful whole; tendency to focus on details at the expense of global meaning
- ❑ Decreased motivation to orient to social stimuli
- ❑ Theory of Mind (ToM) deficits

Life Challenges for Individuals on the Spectrum

- ❑ Limited adaptive skills (*capacity versus functionality*)
- ❑ Limited social supports
- ❑ Co-occurring medical problems (seizures, gastric problems)
- ❑ Co-occurring mental health disorders (Bipolar, Anxiety, OCD, specific phobias)
- ❑ Problems obtaining and maintaining employment, sustaining relationships and living independently

Robbie's Challenges

- ❑ Social Pragmatic Communication problems
- ❑ Rigidities in thinking, difficulty with novel situations and making transitions
- ❑ Uncomfortable about relating to anyone other than family members
- ❑ Significant obsessions and compulsions that further limit him
- ❑ Narrow and intense preoccupation with fire-setting with little concern about consequences

Possible risk factors for legal involvement

- ✓ History of few or no friends, long history of narrow pursuits, often bullied
- ✓ Deficits in ToM (inability to pick up on social cues)
- ✓ Behavioral addictions (intense preoccupation with violent or sexual material)
- ✓ Problems with “central coherence” - focus on interest while ignoring social consequences

Distinctive features of offenders on the Spectrum

- ▣ Individual makes no attempt to conceal offense behavior
- ▣ Offense behavior based on special interest
- ▣ Presents as naïve
- ▣ Offending behavior results from misreading social cues
- ▣ Offending behavior may be linked to depression or psychiatric illness

Takeaways for law enforcement

- ❑ Aggressive behavior is not the same as violent crime; there is no reason to believe that individuals on the Spectrum are more likely to commit violent offenses
- ❑ Important to understand problems with social cognition, a hallmark feature of ASD—individual may appear to lack empathy or remorse (this does not play well with judges or juries)
- ❑ Need to identify co-occurring psychiatric problems

Caryn

- ❑ As a very young child:
 - ✓ Hyperactive/hyperkinetic
 - ✓ Limited attention span
 - ✓ Difficult to manage
 - ✓ Not accepting of reasonable limits
 - ✓ Learning problems
 - ✓ Behavioral problems

Evident from early age and will follow her into the future...

- ❑ Learning problems
- ❑ Impulsive, short attention span
- ❑ Anxious
- ❑ Difficulty with rule governed behavior
- ❑ Poor social judgement
- ❑ History of shoplifting and kleptomania that began in adolescence

Think of the implications of the aforementioned for her life outcomes including relationships, activities and QoL

Fetal Alcohol Spectrum Disorder (FASD)

- ❑ Umbrella term that encompasses:
 - ✓ Fetal Alcohol Syndrome (FAS)
 - ✓ Fetal Alcohol Effect (FAE)
 - ✓ Alcohol Related Birth Defects (ARBD)
 - ✓ Alcohol Related Neurodevelopmental Disorder

Alcohol is a teratogen that passes through the placental barrier and affects the developing fetus and affects development throughout lifespan

Cognitive Deficits and FASD

- ❑ Leading cause of preventable intellectual disability
- ❑ Learning problems including lower performance on reading, spelling and math
- ❑ Auditory and visual attention deficits
- ❑ Verbal learning and memory problems
- ❑ Problems with comprehension of high order language: *metaphors, sarcasm idioms, pragmatic language*
- ❑ Executive Dysfunction: *organization, cognitive flexibility, verbal concept formation, response inhibition*

Life Challenges of individuals with FASD

- ❑ Higher likelihood of school failure/dropping out
- ❑ Inability to secure or hold employment
- ❑ Co-occurring mental health problems (ADHD, ODD, CD, OCD)
- ❑ Delinquency or involvement with the law because of impulsivity and poor social judgement

Adaptive Behavior Challenges for linked with FASD

- ❑ FASD linked with restlessness, impulsivity, inattention, disruptive or aggressive behavior
- ❑ More likely to have social boundary problems
- ✓ May be perceived as socially intrusive
- ✓ Lack awareness of social dangers
- ✓ Lack social judgement
- ✓ Difficulty learning and generalizing from social experiences

Risk factors for offending by individuals with FASD

- ❑ Difficulty understanding consequences of actions
- ❑ Difficulty learning from past mistakes
- ❑ Impulsivity
- ❑ Vulnerability to high risk behaviors
- ❑ Poor adaptation to social expectations for behavior
- ❑ Lack of guilt after misbehaviors

Risk factors

- ▣ Timing of diagnosis
- ✓ Later the diagnosis, the less likely individuals have received relevant services and supports
- ✓ Later diagnosis associated with adverse life outcomes
- ✓ Vulnerability to manipulation
- ✓ More inclined to acquiesce to manipulation
- ✓ Provide false confessions
- ✓ Problem with understanding legal cautions and consequences

Protective Factors

- ▣ Stability of home, particularly stability of caregivers
- ▣ Stable residence and living arrangements
- ▣ Lack of exposure to violence
- ▣ Being diagnosed before the age of 6
- ▣ Receiving disabilities services early in life

Families

- ▣ Families of offending individuals with developmental disabilities often need:
 - ✓ Social support
 - ✓ Resources
 - ✓ Structured home environment
 - ✓ MoM2MoM
 - ✓ Intensive Family Support Services (IFSS)
 - ✓ Training in relevant parenting/behavioral skills
 - ✓ Therapy to address stress linked with their relative's externalizing behaviors

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 Role of Behavioral Intervention

- The Behavior Interventionist should be someone who knows about the principles of learning and 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

The Role of Mental Health Programming

- ▣ If the consumer cannot work or participate in a day program because of mental health problems
- ▣ If a consumer has recently been hospitalized on a psychiatric unit and is not ready to resume work or usual activity but needs a step-down from inpatient hospitalization

Coping skills

- ◉ Work with the consumer on building social and emotional coping skill
- ◉ Help the consumer look at his own behavior and become a better self-monitor of mood, thinking and behavior
- ◉ Help the consumer develop more effective coping strategies to deal with everyday hassles and stressors
- ◉ Incorporate wellness and recovery principles into daily activity

Remember Robbie and Caryn?

- ▣ **Robbie** was arrested because he set a series of fires to garbage cans in his neighborhood
- ▣ Charges were dropped but he spent time, unnecessarily, on an inpatient psychiatric unit
- ▣ **Caryn** continued an untreated pattern of kleptomania which ended in her arrest and fines for shoplifting at a local department store at which she worked. She lost a job which she enjoyed and the contact with co-workers which she valued

Implications for involvement in the legal system

- ❑ Heightened impulsivity
- ❑ Difficulty with rule governed behavior
- ❑ Vulnerability to manipulation by others
- ❑ Status conferred for gang membership
- ❑ Early patterns of obtaining non-normative and illegal means of gratification

Take Home Messages...

- ❑ Accurate diagnosis of developmental disabilities and:
 - ✓ Behavioral phenotypes and neurobehavioral problems
 - ✓ Co-occurring psychiatric problems
- ❑ Early intervention:
 - ✓ Build language skills
 - ✓ Build social skills
 - ✓ Build coping skills
 - ✓ Special education focus on emotion and mental health

Some more take home messages...

- ❑ Behavior problems are not the same as criminal behavior
- ❑ Jails are not the place to address neurobehavioral or psychiatric problems
- ❑ Inpatient units are not the place to address neurobehavioral problems or criminal behavior not associated with psychiatric illness
- ❑ Early intervention needs to match the individual's needs with relevant resources and approaches

What might help Robbie and Caryn?

- ❑ Robbie would benefit from the medication management and non-pharmacological approaches to address his OCD
- ❑ His family and those who support him need to understand his behavioral addiction and take relevant steps to keep him and others safe
- ❑ Caryn would benefit from treatment of anxiety and impulse control problems and behavioral shaping techniques

Assessment, Timely treatment, Early behavioral intervention services, Integrated approach across settings

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