IDD AND MENTAL HEALTH

With Dr. Jill Hinton and Jennifer Mahan

Co-Occurring Diagnosis

- Defined as occurring together or simultaneously
  - *Ex: DD/MH/health issues*
- ”Primary” diagnosis is an artificial construct…

Individuals with co-occurring mental health and behavioral problems often face more obstacles to service and acceptance by community service providers than their peers without a dual diagnosis.

Scheerenberger, 1983

IDD and Mental Health

- Individuals with IDD can exhibit the full range of psychiatric disorders experienced by people without disabilities
- Most common mental health disorders:
  - trauma, depression and anxiety
- Bipolar Disorder and Psychosis are FAR less common
  - Very severe when they occur

IDD and Mental Health

- 30-40% of all persons with IDD have a psychiatric disorder compared to 27% of the general population
- 10-20% of those present with challenges (self-injury, aggression, destructive behavior) severe enough to impair daily life
- Yet, they are under-diagnosed, not treated, or inappropriately diagnosed
- Symptoms of mental illness often present differently in individuals with intellectual disabilities
- Determining accurate psychiatric diagnosis becomes especially difficult as the level of intellectual functioning declines

Factors that make Psychiatric Diagnosis More Difficult

- Cognitive abilities limit understanding of questions and answers
- Differences in receptive and expressive language
- Difficulty in ability to articulate abstract concepts such as depressed mood
- People with IDD have a tendency to “please” others, some may not answer questions the way people expect them to
- Atypical symptoms/presentation can lead to incorrect diagnosis

  Ex: trauma → psychosis,   anxiety → non-compliance

Interpretation of Symptoms

- **Diagnostic Overshadowing** – when all behavioral, emotional or social issues are seen as being due to one diagnosis
  - *Any difficulties a person has are because they have ASD*
- **Baseline Exaggeration** – behavioral presentation changes in frequency, intensity but people miss the change
  - *Someone usually taps their face now hitting their face*
- **Intellectual Distortion** – questions or ideas are more complex/abstract than the person can understand
  - *Asking a person with ASD if they hear voices – yes because they hear the person talking to them, or self-talk*

Interpretation of Symptoms

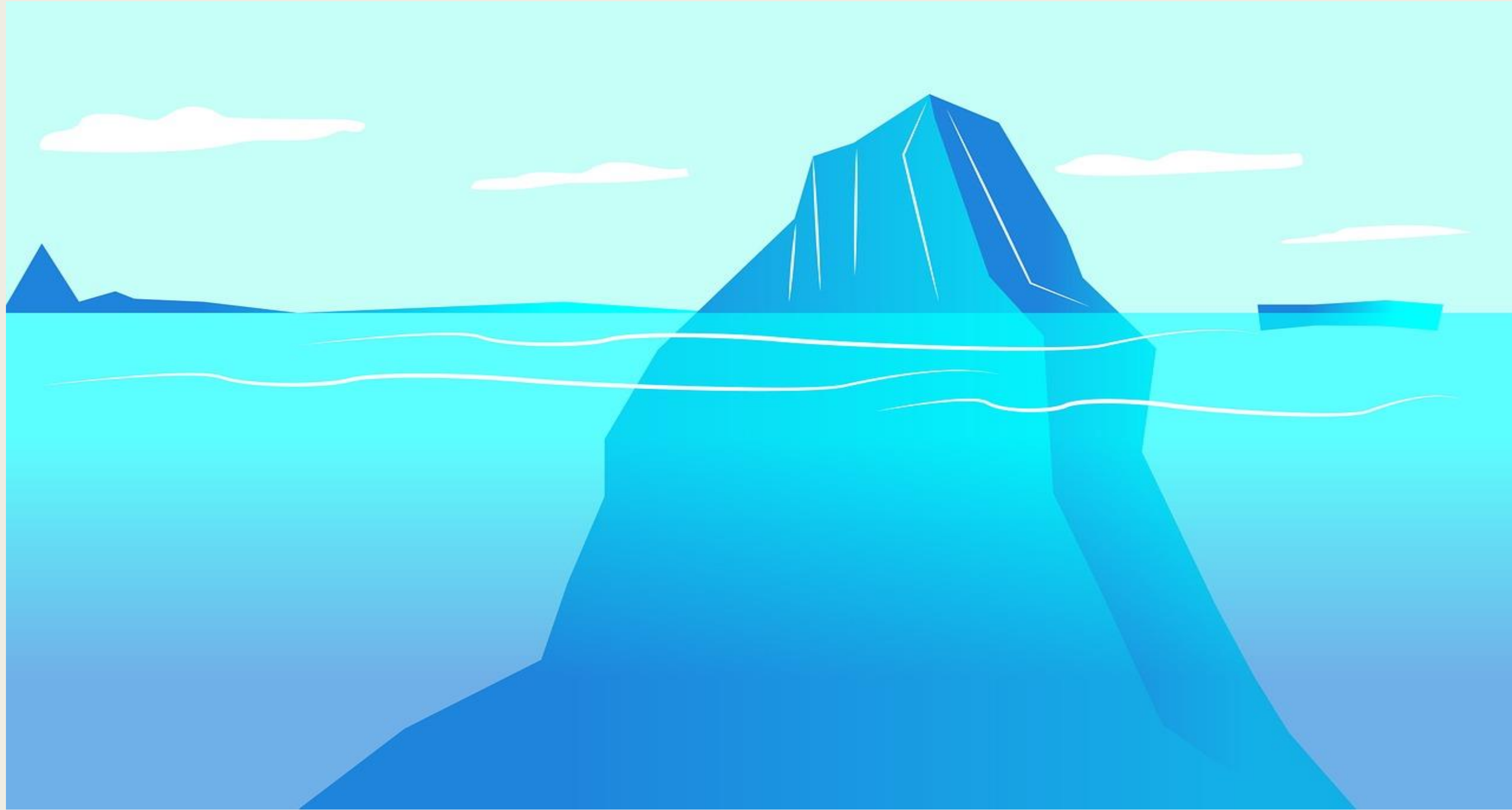
- **Psychosocial Masking** – Something that is developmentally appropriate is seen as a possible psychiatric symptom
  - *Thinking that a person with IDD having an imaginary friend means they are psychotic*
- **Cognitive Disintegration** – decreased cognitive resiliency means stress can have a significant impact
  - *Stress may lead to a decline in communication, skills, etc. but no one considered the stressors*

“Saying someone has a ‘behavior problem’ is like saying they have a fever”

-Dr. Jarrett Barnhill

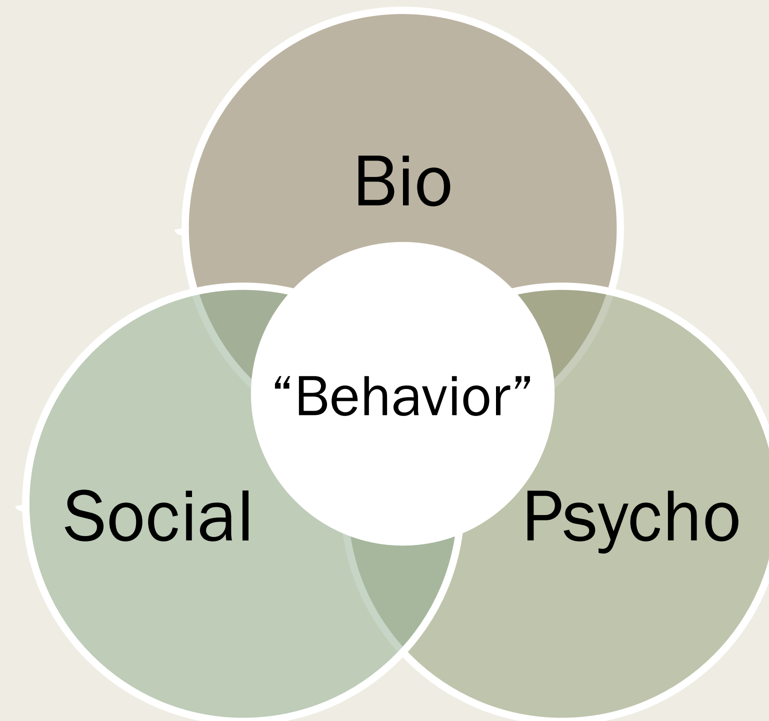
Former Medical Director NCSS

Iceberg



IDD and Behavioral Challenges

In most cases, co-occurring complex behavior problems in individuals with ID are caused or maintained by a combination of factors



Support versus Treatment

Support –

Address underlying deficits of IDD

Long-term

structure, schedules, visual supports, social skills support, positive supports, positive identity, adaptive coping skills

Treatment –

Address psychiatric symptoms

Shorter-term

CBT, DBT, EMDR to address depression, anxiety, trauma and stressor related disorders

General Adaptations

People with IDD can benefit from evidence-based treatment approaches

- Language
- Frequency
- Shorter sessions
- Duration of treatment
- Structure/Directive Approach
- Communicate with Collaterals
- Modify to developmental level
- Support
- Flexibility

Adaptations have been developed for specific practices – CBT, DBT, EMDR

Difference in Viewpoints

- I/DD has traditionally focused on “habilitation” or maintaining skills and long term supports
- MH/SUD has traditionally focused on “rehabilitation” or a recovery model with shorter term interventions, coupled with longer-term but less frequent supports
- Much more in common than different: in both brain development and functioning are different and need services and supports to have good quality of life

Systems Challenges

- Funding for IDD services and MH/SUD services are often separate
- Policies for services and clinical guidance prevents people from getting integrated IDD and behavioral health supports
- Providers often specialize in only one area: MH or IDD or SUD, not integrated.
- Systems don’t reward cross training, integrated supports
- Providers with integrated, cross trained approached are limited

Provider challenges

- Reluctance to diagnose at early age
- Missed opportunities to spot autism, FASD, mental health challenges, trauma, at risk populations
- Limited early intervention programs without diagnosis, or without health coverage
- Few are fully trained across MH/DD/SUD

Individual/Family/Community Challenges

- Stigma of diagnosis
- Uncertainty due to long waiting lists, lack of adequate health care coverage
- System too complex to navigate, not integrated

Impacts of Waiting Lists, Lack of Services

- Lack of supports makes I/DD skill loss and MH problems worse
- Early intervention lacking, worsens outcomes
- Being left out of community life worsens mental well being
- Transition age youth and adults see peers going on to college, employment, independent living, starting families

Results

- System requires a “primary” diagnosis.
- Individuals and families are forced to choose a primary set of supports: often a binary choice between mental health/behavioral interventions and long-term IDD supports
- Most children and youth in ERs, waiting for inpatient have complex needs ie overlapping MH/SUD and I/DD
- Worse outcomes for those with more than one diagnosis

Opportunities

- Making entire system “IDD and MH/SUD” informed by requiring cross training, removing barriers to integrated supports
- Focusing system on early intervention with at risk populations
- Removing funding silos, policy barriers
- Training 988 operators on IDD and autism, recent research on differences in suicidal expression in IDD
- Ending the waitlist for IDD services, implementing a TEFRA waiver in Medicaid to ensure children across diagnosis are served earlier

Opportunities: Your Solutions Here

- What would you do? Suggest?