Part 1
The mental health aspects of ID/DD

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The Importance of Listening

"Time after time, I have found that when people are taken seriously, when they are respected, when their behavior is interpreted, understood and responded to accurately, when they are engaged in mutual dialogue rather than subjected to unilateral schemes of "behavior management", somehow as if miraculously, they become more ordinary. I know a number of people who have had severe reputations who have shed them when those supporting them listened more carefully".

Herb Lovett, Ph.D.

85% of referrals to emergency services precipitated by aggression why?

Effective Services:

The 3 A's

- Access
- Appropriateness
- Accountability

Access

- Timeliness
- Array of services
- Availability
- Geographic proximity
- Resources alone should not define service use…

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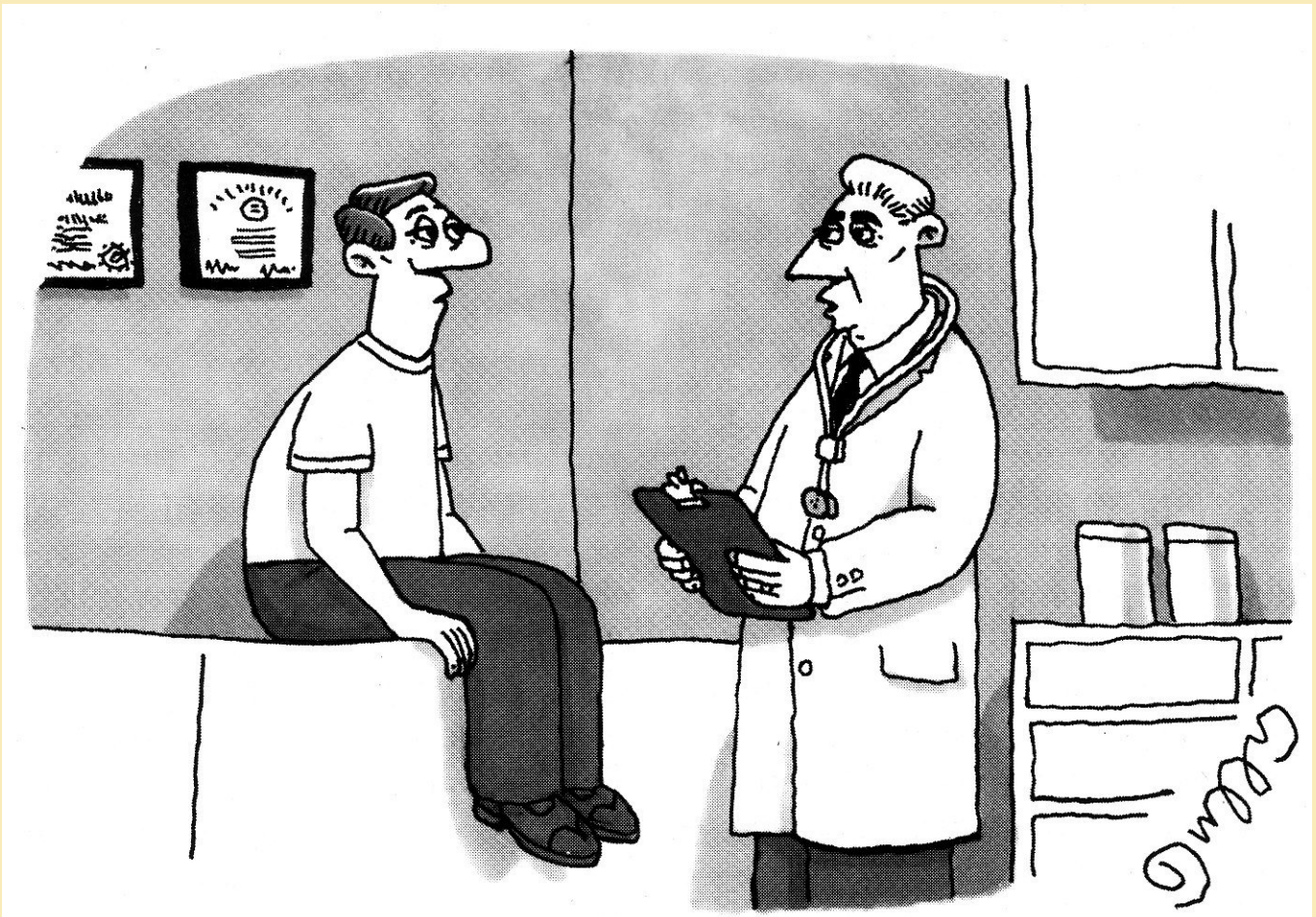
Appropriateness

- Roles are clear
- Providers have expertise
- Defining the problem
- Service matches needs…



"I'm afraid it's your body, Mr. Haskins."

Diagnostic overshadowing

- Will most likely simplify the complex, or complicate the simple
- Attributed to what you "know" about the person i.e., they have "Mental Retardation"; they are on medication, etc.
- More likely to occur if you use a single mode of assessment i.e., *behavioral or mental health*

"It could be one of those things that crawl into your ear and lay eggs, and the eggs hatch and burrow into your—nope. It looks fine."

Four aspects of mental retardation that influence that diagnosis and treatment of mental illness (Sovner, 1986)

Psychosocial masking

Limited social experiences influence the content of psychiatric symptoms (less colorful, therefore less evident)

Cognitive disintegration

Decreased ability to tolerate stress, leading to anxiety induced confusion (can be misconstrued as psychosis).

Baseline exaggeration

Quantitative rather than qualitative changes in maladaptive behavior may be indicative of mental illness

Intellectual distortion

Symptoms are masked by deficits in abstract thinking and expressive language (patients unable to describe experience)

Accountability

- There is consensus with regard to roles and responsibilities on the part of providers
- Services are cost effective
- Recipient is satisfied with services
- Services meet objectively established goals
- Services change with the changing needs of the service user
- Listening and mutual respect in the system is required…

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Analysis of factors that may lead to difficulties

- Communication issues
- Rule out non-psychiatric causes (change in life circumstances, pain and discomfort, illness, med side effects, etc.)
- Find out usual level of function
- Assess symptoms or behaviors, when are they most likely to occur? How often? (data collection)
- Assess the presence of mental health related symptoms (this can be difficult and requires data collection too)
- Learned behavior?
- All of the above?

Nature of an Integrated Biopsychosocial Assessment (Gardner)

Areas of Assessment for the Integrated Biopsychosocial Model

BIO (medical)- medical, psychiatric, medication reactions, syndromes, neurological state

PSYCHO (logical)- current psychological features and skill deficits

SOCIAL- environmental, interpersonal, programmatic, physical

Gathering a Psychological History

Important events might include:

·History of emotional/physical or sexual abuse
·Significant medical procedures (especially involving hospitalization or invasive procedures)
·Family disruption (violence/divorce/remarriage/birth of siblings)
·Educational milestones
·Environmental changes (moves, significant changes in living arrangements or socio economic status)
·Grief or loss [due to death, abandonment, or change (i.e., change of a caregiver)]
·Change of jobs

Issues in Assessment of Persons who are Nonverbal or Profoundly Challenged

•a number of formidable challenges are encountered when assessing individuals who do not communicate verbally. These challenges are due to a number of factors, including:

•the lack of firsthand information from the individual him or herself and the need to rely on information from other sources (e.g., interviewing others, direct observation of person's behaviour).

Issues in Assessment of Persons who are Nonverbal or Profoundly Challenged

- the co-existence of medical or sensory conditions which can further complicate the picture.

the finding that psychiatric illness may manifest differently in these individuals and that diagnostic criteria for specific disorders may need to be translated into "developmental disability equivalents" (e.g., Pary, Levitas & Hurley, 1999).

Mental Health: Vulnerability

Vulnerabilities - Check List

Circumstances causing or contributing to mental health and behavioural disturbances in persons with developmental disabilities:

Biological

Brain Damage; Dementia; Epilepsy; Sensory (e.g., vision, hearing) impairments; Sensory (e.g., visual , auditory) processing problems; Physical illnesses and physical disabilities; Cerebral Palsy; Genetic / familial conditions; Drugs / alcohol abuse; Medication / other medical treatments

Mental health: Vulnerability

Psychological

Distorted personality development; Separations / losses; Deprivation / abuse / trauma; Other life events; Positive / negative learning experiences; Self-insight / self- esteem; Communication difficulties; Language disorders; Psychological impact of the above biological factors on the individual

Social

Attitudes - negative social feedback; Labeling; Rejection; Infantilization; Victimization; Unrealistic expectations; Few / limited repertoire of coping strategies;
Inadequate supports / relationships; Inappropriate environments / services; Under-/ overstimulation; Valued / stigmatized roles; Financial / legal disadvantage

Mental health: Vulnerability

Family

Diagnostic and bereavement issues; Life cycle transitions / crises; "Letting go"; Psychiatric and emotional disorders in immediate family members;
Stress / adaptation to disabilities; Relationships / resources (financial, emotional, supports)

Problems to address

- "Technical difficulties": how to we apply current diagnostic strategies?

- Medication responses: what do we know about treatment effectiveness?

- Crisis prevention and intervention. How do we get the help we need?

DM–ID
Diagnostic Manual – Intellectual Disabilities

Developed By

The National Association for the

Dually Diagnosed (NADD)

In association with

The American Psychiatric Association (APA)

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Description of DM-ID

- An adaptation to the *DSM-IV-TR* designed to facilitate a more accurate psychiatric diagnosis
- Based on Expert Consensus Model
- Same diagnostic nosology system as *DSM-IV-TR* (Childhood and Adult Mental Disorders)

Description of DM-ID
(continued)

- Empirically-based approach to identify specific psychiatric disorders in persons with ID
- Provides state-of-the-art information of mental disorders in persons with ID
- Provides adaptations of criteria

DM–ID: Two Manuals

1. ***Diagnostic Manual – Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability***

2. ***Diagnostic Manual – Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability***

DM-ID
Diagnostic Chapter Structure

Adaptation of the DSM-IV-TR Criteria

- Addition of symptom equivalents
- Omission of systems
- Changes in required symptom count
- Changes in exclusion criteria
- Modification of age requirements
- Addition of ID special examples
- Addition of explanatory notes

DM-ID

Diagnostic Chapter Structure

Major Depressive Episode

DSM-IV-TR Criteria	Adapted Criteria for Mild to Profound ID
A. Five or more of the following symptoms have been present during the same 2 week period and represent a change from previous functioning. At least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure. **Note:** Do not include symptoms due to a general medical condition, or mood-incongruent delusions or hallucinations.	A. **Four** or more symptoms have been present during the same 2 week period and represent a change from previous functioning. At least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure or (3) **irritable mood.**

FOR FURTHER INFORMATION, CONTACT:

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Positive Developments in CT.

- UMASS inpatient and outpatient services
- Comprehensive service evaluations and consultation
- Cross systems crisis planning
- MOU between DMHAS and DMR
- The Woodbridge Project
- New diagnostic manual

Part 2
Cross systems crisis planning

What is a crisis?

What is the cross systems crisis plan?

- Demographic information
- Pbsp
- Contract between providers
- Roadmap to prevent the system form going into crisis

The Six Elements of the Cross-Systems Crisis Prevention and Intervention Plan

1. The Face sheet
2. General guidelines
3. Hierarchy of behaviors
4. Disposition recommendations
5. Back-up protocol
6. Signature page

The face sheet

- Demographic information
- DSMIV diagnosis (need to reach consensus)
- medical issues/allergies
- medications

Assessments in Developing the crisis plan

Approaches include:

- **applied behavioral analysis-** to better understand the conditions under which complex behaviors are more likely to occur

- **behavior communication theory-** acknowledging that challenging behaviors are often attempts to communicate needs, advocates for teaching more acceptable methods of self-expression

- **systems theory**- systems are sets of components, which when coupled together, interact and influence each other to form a whole. Behavior occurs within a social context. Assist the system to not go into crisis when the person has difficulties.

- Talk, talk, talk , talk, talk…. What worries you? Debriefing, etc.

General guidelines

- Psychosocial summary: strengths and abilities, vulnerabilities, anniversaries of significance, etc.
- communication style and abilities
- things that work, things to avoid
- Factors that contributed to problems in the past

Positive psychology: analysis of behavioral problems in the context of a strategy to promote wellness

The assumption is that when conditions to promote wellness are undermined, problem behaviors may occur.

Health/mental health – identification and understanding behavior in the context in which it occurs. Includes an evaluation of biomedical and mental health issues as instigators or perpetuants to challenging behavior.

Communication - looking at an individual's behavior as a form of communication that has function and meaning.

The need for meaningful life experiences: Stimulation - heightening exposure to fun and stimulating activities not contingent on behaviors.-humor

The need for rewarding experiences: Reinforcement - advocating intense non-programmatic and non-contingent reinforcement that occurs on a frequent basis.

The environmental social context of wellness: Redirection - changing aspects of the individual's environment and interaction pattern; capitalizing on stimulus change opportunities.

Coping - teaching methods and skills to handle stressors and friction.

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Effective crisis prevention and intervention plans

Consistency - one cannot implement an effective plan on a part-time, haphazard basis. Protocols of support should be established to promote a positive, methodical response to the problematic behaviour.

Portability - the plan must have the ability to move with persons in the various settings in which they interact - staff and family in all locations must be trained in the interact ional approaches.

Intensity - the frequency and quality of interactions with individuals during the course of the day needs to promote a wellness approach rather than a management model for crisis prevention and intervention.

Change - rearrange the environment or caregivers to become sensitized to stimuli or triggers that cue behaviours, with a focus on prevention of these behaviors manifesting themselves, in other words crisis prevention techniques require educated flexibility on the part of staff and the system of support- requires cross systems collaboration

Part III: Hierarchy of behaviors in a bio- psycho-social context

A Comprehensive Assessment of crisis event- debriefing (Behavior problems occurs in a context)

- Common sense setting events: affective state (mood); behavior state (relationships); physiological state (fatigue, pain)
- Look for any correlations between stressful life events, changes, and onset of or increase in problem behavior
- Informants may underestimate the social context of problem behavior

Setting events: Biological, affective, cognitive

- Side effects of medications
- Mental health symptoms
- Illness or pain
- Fatigue (physical or social)
- Hunger/thirst
- Hot or uncomfortable
- Sexual frustration
- Temperament
- Frightened, worried, anxious
- Sad or depressed
- Cognitive processing deficits

Delineation of triggering & contributing variables and interventions

- Contributing- setting events ("the cumulative straw")
  - increases the likelihood of a challenging behavior occurring when a triggering event is present
- Triggering- demand (the "last straw") antecedents that may elicit or trigger occurrence of a challenging behavior, from infrequently - always
    - i.e. unwanted demand
    - or activity that individual finds to be enjoyable that reduces the likelihood of challenging behavior

Causes of stress

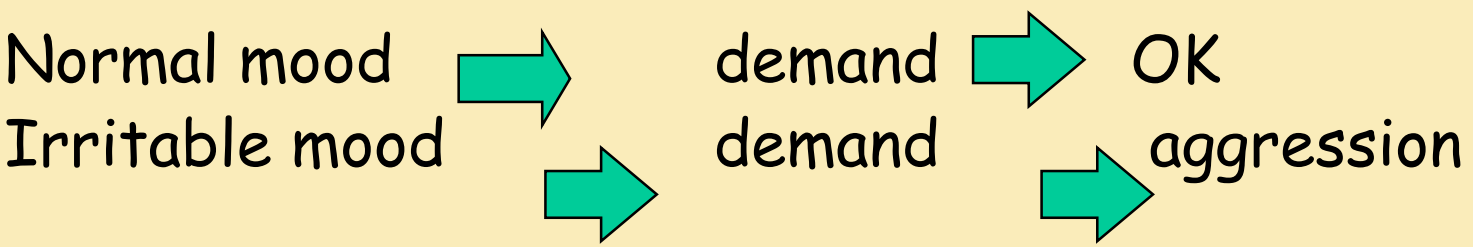
- Sedation
- Emotional exhaustion
- Over stimulation
- Social pressure
- Poor communication/rapport
- Unwanted demand
- Coping with physical discomfort
- Boredom

Stress &Behavioral problems

- Stressful events may have direct or indirect effects
- Directs effects - lowering the threshold for or precipitating behavior problem,
- Indirect - triggering mental illness that lowers the threshold for aggression

Establishing Operations

- Mood state alters response to environmental contingencies



- Intervention at 2 levels :
  - Interventions that decrease irritability
  - Other interventions related to the demand situation

Establishing Operations

- Rapport alters response to environmental contingencies

Good rapport → demand → OK

Poor rapport → demand → aggression

- Intervention at 2 levels :
  - Consider rapport when paired with demand
  - Demand situation to increase rapport

"Learned mal(adaptive) behavior"

- What purposes does the behavior serve?
- What makes the behavior worse?
- What makes the behavior better?

Individualized crisis intervention strategies

- Intervention should be derived directly from assessments
  - i.e. What are the variables contributing to a lowering of the threshold for problem behavior? Are they addressed in the plan?
- Generate "hypotheses" as part of the planning process,
- Use multiple modalities as indicated
- Measure before, during, after: team debriefing is essential
- Does the caregiver have the support and understanding needed?

Interventions occur on a progression

- Map out a prevention and intervention strategy

- Consider both the individual and the support system

- Consider multiple variables at once

Interventions to try in the current setting

Interventions with Anxiety, General Issues

- Decrease stimulation/ social demands
  - provide focused activity
  - Rapport with support person
- Increase structure
  - increase predictability of routines
- Create a safe environment
- Minimize choices temporarily
- Address sleep and medical issues

Interventions to assist with Anxiety

- **Desensitization- rehearsal**
- **Relaxation**
- **Art, Music, Exercise**
- **Diet**
- **Sleep**
- **routine**

Developmental Issues in the preventing Anxiety: social awareness

- People without cognitive concepts of future who have significant anxiety, can't cope with knowing too much in advance

Interventions that require outside support (planned)

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When to call for "planned" outside assistance

- Changes in the environment: additional support
- Mental health provider: Understanding mental illness, symptom monitoring. Medications treat a cluster of symptoms, rather than behavior problems.
- Temporary "respite": Stress reduction with a change of environment.

Interventions that require immediate assistance

- The benefits of mobile crisis support
- Preventing the system from going into crisis
- Delineation of roles and responsibilities
- Don't wait too long!
- Check out your assumptions. Debriefing is essential.

Back-up protocols: roles and responsibilities

Safety first!

The Signature page

Review of sample crisis plan, case example

Junior

- 26 year old male with mild mental retardation
- Lived with family until 5 years ago when moved out as a result of assaulting grandmother
- Worked successfully until 4 years ago
- Was hospitalized numerous times for extreme aggression

Junior

- Diagnosed with a mood disorder
- Had 2 bouts of NMS, in a coma lost all abilities was in rehab program following episode
- Placed in staffed apartment program where he appeared to be very unsettled

Junior

- Request for a treatment and crisis plan
- Mother is a very strong advocate
- Admitted to DD neuropsych unit, placed on mood stabilizers
- First plan focus was on learning about Junior, 2 more admissions…

Junior

- Plan revised 5 or 6 times
- Review plan…
- The role of the crisis plan: the need for on-going education and training, a road map

Crisis related incidents

- The day of the Haldol/ the bracelet
- The arrest
- Communication and collaboration about early warning signs
- The day with the heat stroke
- How he is doing now…