Planning Services for Persons with Developmental Disabilities and Mental Health Diagnoses
• Persons with Intellectual Disabilities (ID) have mental disorders three to four times more frequently than do persons in the general population.

• The rate of mental disorders for persons with ID ranges from about 30% to 40%.

• This population is one of the most underserved in our nation.
• In the past, practice focused on the primary diagnosis.
• The determination of “primary diagnosis” often implied what service system would serve the individual.
• Manolascino and others proposed the concept of dual diagnosis, meaning that the conditions co-exist, possibly with mutual impact on the person’s well-being and functioning.
• Vulnerabilities for mental disorders include:
  – Genetic factors
  – Environmental factors
  – Interaction of genetic and environmental factors
• Mental Disorders are described using the Diagnostic and Statistical Manual of Mental Disorders IV-TR

• Insurance companies (Medicaid) use the International Classification of Disease (9 or 10)
• Axis I of the DSM–IV- TR refers to the principle psychiatric disorder.
• Axis II, indicates the personality disorder that may be shaping the current response to the Axis I problem. Axis II also indicates any developmental disorders, such as an intellectual or a learning disability.
• Axis III lists any medical or neurological problems that may be relevant to the individual's current or past psychiatric problems. For example, someone with severe asthma may experience respiratory symptoms that may precipitate a panic attack.

• Axis IV codes the major psychosocial stressors the individual has faced recently; e.g., recent divorce, death of spouse, job loss, etc.
• Axis V codes the "level of function" the individual has attained at the time of assessment. This is coded on a 0-100 scale, with 100 being nearly "perfect" functioning (not quite sure who scores a 100).
• Anxiety Disorders are the most common type of mental disorders in the general population and with people with ID.
• An Anxiety Disorder diagnosis is used when the person’s anxious response is greater than what would be expected under the circumstances.
• Common Anxiety Disorders include:
  – Panic Disorder
  – Obsessive-Compulsive Disorder
  – Post-Traumatic Stress Disorder
  – Attention Deficit Hyperactivity Disorder
• A Mood Disorders diagnosis is used when people have the inability to control their emotions.
• These can impact eating behaviors, sleeping patterns, concentration, management of time and money, and memory.
• Diagnostic categories under mood disorders include:
  – Dysthymic
  – Major Depression
  – Bi-Polar I and II
• Psychosis is a thought disorder.
• Persons with psychoses may not have the ability to determine what is real and what is not, sometimes having trouble determining what is happening inside their thoughts and what is happening in reality.
• Persons can become overwhelmed by their thoughts.
• Common disorders include:
  – Schizophrenia
  – Schizophreniform
  – Schizoaffective disorder
• Axis II
  – Personality Disorders
  – Intellectual Disabilities

• Personality Disorders are sometimes described under three groups:
  • Odd/Eccentric
  • Dramatic/erratic
  • Anxious/fearful (Durand and Barlow, 2003)
• Odd/Eccentric:
  – Paranoid
  – Schizoid
  – Schizotypical
• Dramatic/erratic:
  – Antisocial
  – Borderline
  – Histrionic
  – Narcissistic
• Anxious/Fearful
  – Avoidant
  – Dependent
  – Obsessive-Compulsive
• Most insurance companies and Medicaid pay only for Axis I mental (psychiatric) disorders.
• Axis II diagnoses however, can have a significant impact on treatment and outcomes and sometimes are the focus of the treatment.
• In order to access mental health services, you must have an Axis I diagnosis.
• It has only been in the last two decades that professionals have agreed that persons with ID have mental (psychiatric) disorders.
• Psychiatric diagnoses are usually based upon self-report in psychiatric semi-structured interviews.

• Communication levels with persons with ID may be a limiting factor in making an accurate diagnoses.
• Other issues can also impede the diagnostic process:
  – Psychosocial Masking: lower levels of social skills and life experiences can lead to unsophisticated presentation of issues.
  – Cognitive Disintegration: stress-induced disruption of information process can present as bizarre behavior.
• Baseline exaggeration: an increase in pre-existing cognitive deficits or maladaptive behaviors.

• Overshadowing: practitioners assume that behaviors are due to the ID, and psychiatric conditions are not considered (Bouras, 1999).
Behaviors associated with the developmental level could be misunderstood:

- Talking to oneself
- Solitary fantasy play
- Imaginary friends (Hurley, 1996)
• Because of all these issues, psychiatrists need additional information to make a good diagnosis.

• Support coordinators and family members can help the individual prepare for the examination.
• Must find mental health practitioners that are willing to work with you.
• These practitioners must understand that behaviors are often a means of communication for persons with ID.
• Presenting problem is described as a change in the person’s functioning.
• The psychiatrist will need:
  – Psychosocial history
  – Current medical information
  – Recent psychological assessments
  – An informant who knows the individual well and has observed the individual in multiple settings (observations must be objective)
• Attribution can distort information.
• Often people describe the actions of individuals with ID from a behavioral perspective rather than as a result of an emotional response.
• Phenotype relationships: examples
  o Down’s Syndrome- Depression, Obsessive-Compulsive, Anxiety, hypothyroidism-associated mental disorder, early onset Alzheimer’s
  o Fragile X Syndrome- Avoidant Personality, Schizotypal Personality, Major Depression,
  o Prader-Willi Syndrome- Obsessive-Compulsive, Affective Disorders, Psychotic Disorders
  o Williams Syndrome- Anxiety, Depression
• Tools have been developed to help psychiatrists collect information; a few special ones have been developed for persons with ID.
• Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD).
  – Used as a semi-structured interview with individuals with ID and informants.
  – Shorter version (Moss, 1998) screening tool
• Assessment of Dual Diagnosis (ADD)
  – Developed for persons with mild or moderate ID.
  – Based upon the DSM-IV-TR.
• Diagnostic Assessment for the Severely Handicapped – II (DASH-II)
  – Intended for persons with severe or profound ID.
• Aberrant Behavioral Checklist – may be better to track treatment results
Tips for mental health practitioners when conducting the semi-structured interview:
- Use very simple vocabulary.
- Create short sentences.
- Do not ask yes or no questions.
- Ask one simple question at a time.
- Wait for the answer before proceeding.
• Tips continued:
  – Check back with the individual for confirmation that they have correctly understood the question.
  – Remember that the person with the intellectual disability thinks in concrete terms and may answer based on their experiences and not understand the implications.
  – Remember that some persons with ID want to please others (Hurley et al. 2007) and may answer accordingly.
• In most cases where challenging behavior is involved, a full biopsychosocial evaluation is recommended.

• This requires:
  – A review of the collateral information
  – Full medical examination
  – Functional behavioral analysis
• A biopsychological evaluation should be done by an interdisciplinary team, including the individual receiving services, persons that know them best, family members, a certified behavioral analyst (especially if the person has limited or no verbal skills), and mental health practitioners.

• Recent medical information is essential.
• Medical conditions can result in behavioral/emotional changes that may appear to be psychiatric disorders.
• Persons with ID may not be able to express physical complaints, symptoms, or pain that could be impacting their functioning.
• Many physical conditions may have symptoms similar to mental illness:
  – Hypothyroidism – depression
  – Hyperthyroidism – mania
  – Pain, both chronic and severe – aggression
  – Diabetes – confusion, depression

• Possible medical issues should be ruled out before a psychiatric diagnosis is attempted.
• How can a biopsychosocial evaluation be purchased? A combination of:
  • Medicaid funded Community Behavioral Health Service, and
• Community Behavioral Health Services will provide:
  – Psychiatric evaluation
  – Psychiatric review of records
  – In-depth assessment
  – Bio-psychosocial testing
  – Psychological testing
• Developmental Disabilities Waiver:
  – Behavioral analysis services, including a full behavioral assessment with in-depth functional assessment.
  – Results of functional assessment should be shared with the mental health practitioners. For many persons with ID, their behavior is their communication.
• Trauma Informed Care
  – Research is now highlighting the significance of traumatic events in a person’s life, and the association of trauma with mental disorders.
  – Chronic trauma in children can impact neurological development and can make the person more vulnerable to mental illness.
  – Acute trauma is also associated with mental illness, especially post traumatic stress disorder.
• The use of physical restraint and seclusion has been found to be re-traumatizing to people who have experienced trauma.
• Many mental health programs have eliminated the use of these techniques.
• Trauma informed care systems recognize that many of the persons that they serve have been traumatized and use methods to make the people feel safe and not threatened.
• Community Behavioral Health Services available:
  – Individual and Family Counseling: persons with mild and moderate ID have been shown to benefit from counseling services.
  – Psychiatric Rehabilitation Services: social skills training, symptom management, coping skills, etc. (probably beneficial for persons with mild ID).
• Companion Services from the DD Waiver:
  – Behavioral Analysis Services: include a full range of behavioral services.
  – Specialized Mental Health Services: these services include specialized individual, group, and family therapy provided to recipients using techniques appropriate to this population.
• Combining services from the Community Behavioral Health program and the DD waiver can create a comprehensive service package.
• Providers must be willing to work together as an interdisciplinary team.
• Use of psychotropic medications:
  – Psychotropic medications can be very helpful for anyone with a psychiatric condition, including individuals with ID.
  – However persons with ID may respond differently to the medications than persons in the general population.
• Centers for Medicare and Medicaid Services (CMS) developed recommendations for use of medications with persons with ID:
  – Keep the regime simple: start low and go slow.
  – Use the same or lower minimum and maximum dosages as in the general population.
  – Periodically consider gradual dose reduction and go at same rate or slower than for persons in the general population.
  – Avoid frequent drug and dosage changes.
• Evaluating side effects:
  – Use a structured method to monitor for side effects. Medical staff should do so at least monthly.
  – Staff and family members should be informed of signs of side effects, and monitor continually.
  – If using an atypical (newer psychotropic medication), monitor for changes in weight, glucose, and lipid levels.
• Evaluate for treatment effects and outcomes:
  – Use an interdisciplinary team approach.
  – Compare behavior to baseline.
  – Track certain target behaviors using established measurement practices.
  – Whenever possible, involve the individual in describing changes in emotional status.
  – Provide psychiatrist/mental health practitioner with data about behavioral status on a regular basis.
• Providing interdisciplinary and integrated care across two systems can be complicated.
• The support coordinator or the family must be familiar with the Medicaid Mental Health Plans and understand how to access Medicaid funded mental health services.
• Medicaid provides mental health and substance abuse services through the Community Behavioral Health Services Program.
• Community services are provided through managed care plans.
• In the Medicaid Reform areas, Provider Service Networks (PSNs) and Health Maintenance Organizations (HMOs) provide these services (persons with DD may opt out of these plans).
• In other parts of the state, HMOs and Prepaid Mental Health Programs provide them.
• Prepaid Mental Health Plans provide mental health services for persons covered through Medipass.
• The Plans are operated by the Florida Health Partnership (affiliated with Value Options) and Magellan Health Care.
• HMOs provide mental health services for their enrollees.
• Each plan has its own requirements for determining medical necessity and approving services.
• The Florida Health Partnerships and Magellan both provide information on their websites.
• The HMOs may have to be contacted directly to obtain this information.
• Knowing this information is helpful when planning services.
• In many cases, there may not be mental health providers willing to work with persons with ID.
• Medicaid managed care plans are required to be able to serve persons enrolled in their plans.
• Persons with ID who meet medical necessity definitions and can benefit from community mental health services are entitled to these services.
• Preplanning in the local area with Medicaid mental health providers, the Medicaid local office, and the Agency for Persons with Disabilities (APD) may be necessary to develop capacity and create interagency agreements.

• Mental health programs should be approached about being part of the APD provider network.
• Establishing person-centered interdisciplinary teams to serve individuals with dual diagnoses is important to providing quality services.
• The teams should be involved in the assessment process, and treatment planning and monitoring.
• Reimbursement for communication among members and team meetings is very limited.
• Practitioners must be committed to the process and find ways to effectively communicate.
• In summary, persons with ID do have mental disorders.
• They need a combination of psychiatric care, developmental services, behavioral assistance, and likely a medication regime to deal with this condition.
• Individuals with intellectual disabilities should have the opportunity to access and benefit from mental health treatment geared to their needs.