

Dual Diagnosis I: Intellectual Disabilities and Mental Health Disorders

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This product is available in alternative format upon request.

TABLE OF CONTENTS

	Page
CHAPTER 1: Definitions, History, Treatment Models	3
Chapter 1: Study Questions	7
Chapter 2: Mental Health Professionals and Programs	8
Chapter 2: Study Questions	19
Chapter 3: Understanding What We See	20
Chapter 3: Study Questions	27
Chapter 4: Common Mental Health Disorders	28
Chapter 4: Study Questions	52
Chapter 5: Services	55
Chapter 5: Study Questions	60
Chapter 6: Treatment	62
Chapter 6: Study Questions	69
Study Questions Keys	70
Glossary	80
References	83
Case Study Assignment	85

CHAPTER 1 – Definitions, History, Treatment Models

Objectives

Upon successful completion of this lesson, staff members will be able to:

- Define dual diagnosis
- Define mental disorder, mental illness, intellectual and developmental disability (I/DD)
- Identify prevalence of dual diagnosis in the intellectual and developmental disability population
- Identify challenges a person faces when mental illness is not treated
- Recognize historical changes in treatment methods of mental illness in the general population and population diagnosed with an intellectual and developmental disability (I/DD)

Definitions

In order to learn about dual diagnosis, one needs to understand terms. Your role as a direct support professional (DSP) requires working with other professionals who may use different terms. In order to understand the questions they ask or the instructions they provide, you will need to understand the terms they use.

Dual Diagnosis (DD) refers to the co-existence of the symptoms of both intellectual and developmental disabilities (I/DD) and mental health problems.

Developmental Disability refers to a severe, chronic disability of an individual that:

- (i) is attributable to a mental or physical impairment or combination of a mental and physical impairment,
- (ii) is manifested before the age of 22,
- (iii) is likely to continue indefinitely,
- (iv) results in substantial functional limitations in three or more of the following areas of major life activity:
 - (I) self-care
 - (II) receptive and expressive language
 - (III) learning
 - (IV) mobility
 - (V) self-direction
 - (VI) capacity for independent living
 - (VII) economic self-sufficiency; and
- (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of a lifelong or extended duration and are individually planned and coordinated.

Intellectual Disability is under the umbrella of developmental disabilities. It is the cognitive part of the developmental disability definition. An intellectual disability is characterized by significant limitations in both intellectual functioning and adaptive behavior. Both intellectual and adaptive functioning are measured using standardized tests with 100 considered as average. Scores less than 70 on both are required to meet the criteria, with adaptive behavior deficits below 70 in at least one of the three adaptive areas of social, practical, and conceptual skills. The disability must also have begun during the developmental period (before 18 years old). There are four levels of intellectual disability – mild, moderate, severe, and profound. The level is determined by the level of adaptive behavior. (DSM-5, 2013 and AAIDD, 2010)

Mental Health Problems are severe disturbances in behavior, mood, thought processes and/or relationships. The *Diagnostic and Statistical Manual of Mental Health Disorders* (DSM-5) lists the different types of mental disorders.

Mental Health refers to our emotional, psychological, and social well-being. It is all about how we think, feel, and behave. According to WHO (World Health Organization), mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community. WHO emphasizes that mental health is not just the absence of a mental health disorder.

Mental Health Disorder (also called mental illness or a psychiatric disorder) is a mental or behavioral **pattern** that causes either suffering or an impaired ability to function in ordinary life.

Comorbid refers to existing simultaneously (at the same time) and independent of another medical condition. You won't see this term used in this module but other professionals may use it and you need to understand what they are talking about.

Demographics

Not everyone with the diagnosis of intellectual/developmental disabilities (I/DD) will have the label of dual diagnosis (DD). Although these are separate diagnoses, the prevalence of DD among people with I/DD is greater than the prevalence of mental illness in the general population. A licensed professional evaluates both the person and the information that is provided to diagnose specific mental health disorders in a person with I/DD.



How prevalent is mental illness in the population of people with I/DD? Approximately one-third (32.9%) of the total number of individuals with I/DD served by state developmental disabilities agencies nationwide have both I/DD and a mental illness, or “mental health disorder” (National Core Indicators, 2013). When compared to people with I/DD who do not have a mental illness, people with I/DD **and** a mental illness have found to have these significant characteristics:

- the average age is 44.8 years old
- the person is likely to live in a group home
- the person is more likely to take at least one psychotropic medication*
- the person is more likely to have a diagnosis of a mild intellectual disability, and
- the person is more likely to self-report feeling lonely.

*This report by the Human Services Research Institute (2014) also discovered that there is a high rate of use of psychotropic medications for people within the I/DD population that **do not** have a dual diagnosis – as much as 30% reported use of psychotropic medications in persons with I/DD who do not have a mental health disorder diagnosis.



History and Future Needs for Treatment

Treatment for mental disorders in the general population has progressed from the 5th century when there were many superstitions around the condition. Current treatment programs view mental health disorders as illnesses. Today, the current U.S. nationwide system of mental health care is thought to be the most progressive in the world. However, many people still do not receive appropriate diagnosis or treatment.

In the 1840s, Dorothea Dix was successful in persuading the U.S. government to fund the establishment of state psychiatric hospitals. Over the years, however, the inpatient treatment model became underfunded and understaffed. This led to poor and harsh living conditions. In the 1950s and 60s, a variety of psychotropic drugs were developed that enabled many people to return to their home communities. Advocates pushed for and achieved deinstitutionalization and the creation of outpatient treatment models.

The movement toward more community-based mental health and developmental disabilities services has led to a team approach in planning services. The person's unique needs and abilities are the focus. Program Managers are responsible for coordinating community services geared to the unique needs of the person. Advocates continue to stress the need for more high-quality community programs that provide for crisis care, more structured environments, and better wrap-around services including program management.

Treatment for mental health disorders in the world of people with developmental disabilities has followed a similar path. Prior to the 1960s, common myths about people with I/DD included regarding them as “worry-free” or incapable of expressing feelings. When maladaptive behavior (typical of a mental disorder) was observed, it was incorrectly viewed as a result of the intellectual disability and thus not treatable. Stakeholders (people with an interest or concern in something) at the state and national level have forced policy makers to examine the poor performance of the system. While progress has been made, states continue to struggle to provide a system that provides continuous and comprehensive supports for this population.

The **community-based model** is the current and most preferred service approach. The goal is to fully support people in their communities. It includes supporting the families of people with DD. A best practice within this model is the provision of crisis intervention and prevention services. Families and community agencies need support on a 24-hour basis. Service models should be based on Positive Behavior Supports. It is critical that they also emphasize crisis prevention and include training and education for families and professionals.

The community-based model requires that different “branches” or parts of the social service system work together. Everyone needs to understand the person and their needs as well as their

abilities. Instead of focusing on deficits/problems and “fixing” people, service models should focus on person-centered approaches. These approaches recognize each person’s disability but **focus on their abilities and desires**. Teams work together to build a plan that includes **what is important to and for that person**. It requires effective interagency collaboration. It also requires a well-trained and supported workforce including DSPs.

If Left Untreated

A person with **intellectual disabilities**, like anyone else, cannot reach their full potential if mental health needs are not supported. If the **mental health disorder** (mental illness) is untreated, the person:

- may have difficulty maintaining relationships with family and friends
- may be unable to get a job or stay employed
- generally will not be a healthy, stable individual
- may bring undue attention to oneself, causing others to avoid him or her which will limit opportunities for inclusion
- will be affected further emotionally
- may have an impaired ability to feel successful and accepted by others
- may be unable to plan for their future, have goals and meet personal outcomes



Summary

People who experience a mental health disorder and who have a diagnosis of I/DD are considered dually diagnosed. While this diagnosis was considered an impossibility in the past, these myths have dissipated and services for people with a dual diagnosis have evolved. These changes led to the development of community-based services based on person-centered planning, interagency collaboration, and the use of community resources. If the mental health disorder is left untreated, the person will be unable to lead a fulfilling life. People with DD (dual diagnosis) need the same types of supports as people with I/DD, but have the additional complexity of the mental illness. As we will see, our colleagues in mental health often are unsure of how to support people with I/DD. These professionals may need help to understand the intellectual disability aspect of the dual diagnosis. We need to be prepared to provide that information.

Chapter 1 Study Questions

1. List 3 characteristics of the community-based model of treatment for people with a mental health disorder and I/DD.
2. List 2 myths that were prevalent prior to 1960 regarding people with I/DD and who displayed mental health disorder symptoms.
3. Define dual diagnosis.
4. Define mental health disorder.
5. List at least three outcomes a person may experience, if their mental health disorder is left untreated.

CHAPTER 2 – Mental Health Professionals and Programs

Objectives

Upon successful completion of this lesson, staff members will be able to:

- Explain the use of the DSM diagnostic criteria used in diagnosis
- Identify roles of professionals in services for people with dual diagnosis
- List aspects of good mental health
- Identify types of services
- List aspects of assessment and diagnosis

What is Mental Health?



Mental health includes our emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make choices. Mental health is important at every stage of life, from childhood and adolescence through adulthood.

Many factors affect our mental health. People respond to those factors differently. Almost everyone experiences problems or issues at some time in their lives (losing a job, fear of rejection, or disagreements with friends or family). Most people do not develop mental disorders as a result of these experiences. However, the ability to cope with challenges vary considerably from one person to the next. Sue may cope with depression by eating more and Tom might eat less. A person's mental health is at risk when the person's behavior results in a behavioral **pattern** that causes suffering or a decreased ability to function in ordinary life.

Mental health is sometimes referred to as well-being. However, the general definition of well-being encompasses both mental and physical health. Being healthy physically contributes to good mental health. In simple terms, well-being can be described as viewing life positively and feeling good. Positive mental health allows people to:

- Realize their full potential
- Cope with stresses of life
- Work productively
- Make meaningful contributions to their communities

Mental health is influenced by:

- Quality relationships
- Living conditions (housing)
- Mental activity/engagement (employment or other opportunities to contribute)
- Physical activity
- Coping skills

Agencies that serve people with I/DD are held to standards in service that address the well-being of each individual. Agencies evaluate whether basic outcomes are present in a person's life. The Council on Quality and Leadership provides the following guidelines or Personal Outcome Measures to assist agencies in addressing each individual's quality of life:

- People are connected to natural support networks
- People have intimate relationships
- People are safe
- People have the best possible health
- People exercise rights
- People are treated fairly
- People are free from abuse and neglect
- People experience continuity and security
- People decide when to share personal information
- People choose where and with whom they live
- People choose where they work
- People use their environments
- People live in integrated environments
- People interact with other members of the community
- People perform different social roles
- People choose services
- People choose personal goals
- People realize personal goals
- People participate in the life of the community
- People have friends
- People are respected



If these outcomes are present in a person's life, we would think that mental health is also present. This is not necessarily true. For instance, people without intellectual disabilities usually take steps to ensure they are safe and free from abuse and neglect. They exercise their rights, are self-directed, and are self-determined. They may have all the Personal Outcomes listed above present in their lives but still experience a mental health disorder. They may have a phobia or experience difficulties in their ability to keep a job because of depression or schizophrenia.

People with I/DD often need support from others to achieve Personal Outcomes because they lack skills (e.g., social skills) or have limited communication. Often they have more limited experiences and opportunities and need support in self-determination. These additional challenges may create additional barriers to the development of the key elements of mental health mentioned earlier: physical and mental activity, social relationships, and coping skills.

Assessment and Diagnosis

Unpleasant/upsetting issues or circumstances happen to all of us, including people with IDD. People experience a loss of a family member, severe illness, accidents, and trauma. These are real life issues that we all may face. People experiencing these events may respond with behaviors that look like symptoms of a mental illness. We might see behavior that looks like symptoms of depression, such as eating alone, staying away from others, a sad demeanor, or an erratic sleep pattern. Remember, these symptoms alone do not qualify as a diagnosis for a mental disorder.



A symptom only reflects a mental disorder when it is a part of a specific symptom constellation (group of behaviors). Specific mental health disorders refer to certain patterns of behavior. Observing patterns of behavior may lead psychiatrists or clinical psychologists to give a specific diagnosis. The pattern of the behavior is a major part of coming to a diagnosis, but the pattern is not the only factor that contributes to a diagnosis.

Psychiatric assessment usually consists of 8 steps:

1. Obtaining a history (social, psychological, past psychiatric history, family, and medical)
2. Evaluating the person's mental status (behavior, speech, emotions, cognitive, and perceptual processes)
3. Collecting auxiliary data (psychological and neurological)
4. Summarizing principle findings (summary of the major findings with a statement on immediate threat to life, such as suicide)
5. Rendering a diagnosis
6. Making a prognosis
7. Providing a bio-psychosocial formulation (psychiatrist's explanation and rationale for conclusions)
8. Determining a treatment plan

The Diagnostic Statistical Manual (DSM) is used in making a diagnosis. The American Psychiatric Association has authored this guide since 1952. The information in this module is based on the DSM-5 (2013). Since the first publication, the number of disorders listed has increased from 106 listed in the DSM-1 to 157 in the DSM-5 (<http://real-psychiatry.blogspot.com/2013/10/dsm-5-total-diagnoses-revealed.html>).

The DSM has 19 broad categories of psychopathology (mental health disorders). The specific diagnosis and the criteria for each are listed within each category. The DSM also discusses general information about each diagnosis to help the diagnostician decide between different diagnostic groups, as it can be very difficult to determine the specific diagnosis. This information includes a general description of important aspects of each diagnosis, problems that may co-occur with such a diagnosis, cultural and gender issues, and information about how many people have the diagnosis (how common it is). It also contains information concerning what usually happens to people with the diagnosis over a period of years, how likely it is to occur in relatives

(genetic) and some tips on “look-alike” diagnoses. An example of the Diagnostic Criteria for ADHD from the DSM-5 is found on the following two pages.

Attention –Deficit/Hyperactivity Disorder

A. A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, as characterized by (1) and/or (2):

1. **Inattention:** Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:

Note: the symptoms are not solely a manifestation of oppositional behavior, defiance, hostility, or failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required.

- a. Often fails to give close attention to details or makes careless mistakes in schoolwork, at work or during other activities (e.g., overlooks or misses details, work is inaccurate).
- b. Often has difficulty sustaining attention in tasks or play activities (e.g., has difficulty remaining focused during lectures, conversations, or lengthy reading).
- c. Often does not seem to listen when spoken to directly (e.g., mind seems elsewhere, even in the absence of obvious distraction).
- d. Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g., starts tasks but quickly loses focus and is easily side-tracked).
- e. Often has difficulty organizing tasks and activities (e.g., difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganized work, has poor time management; fails to meet deadlines).
- f. Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (e.g., schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers).
- g. Often loses things necessary for tasks or activities (e.g., school materials, pencils, books, wallets, tools, keys, paperwork, eyeglasses, mobile phones).
- h. Is often easily distracted by extraneous stimuli (for older adolescents and adults, may include unrelated thoughts).
- i. Is often forgetful in daily activities (e.g., doing chores, running errands; for older adolescents and adults, returning calls, paying bills, keeping appointments).

2. **Hyperactivity and impulsivity:** Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:

Note: The symptoms are not solely a manifestation of oppositional behavior, defiance, hostility, or a failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required.

- a. Often fidgets with or taps hands or feet or squirms in seat.
 - b. Often leaves seat in situations when remaining seated is expected (e.g., leaves his or her place in the classroom, in the office or other workplace, or in other situations that require remaining in place).
 - c. Often runs about or climbs in situations where it is inappropriate. (**Note:** in adolescents or adults, may be limited to feeling restless).
 - d. Often unable to play or engage in leisure activities quietly.
 - e. Is often “on the go,” acting as if “driven by a motor” (e.g., is unable to be or uncomfortable being still for extended time, as in restaurants or meetings; may be experienced by others as being restless or difficult to keep up with).
 - f. Often talks excessively.
 - g. Often blurts out an answer before a question has been completed (e.g., completes people’s sentences; cannot wait for turn in conversation).
 - h. Often has difficulty waiting his or her turn (e.g., while waiting in line).
 - i. Often interrupts or intrudes on others (e.g., butts into conversations, games, or activities; may start using other people’s things without asking or receiving permission; for adolescent and adults, may intrude into or take over what others are doing).
- B. Several inattentive or hyperactive-impulsive symptoms are present prior to 12 years of age.
- C. Several inattentive or hyperactive-impulsive symptoms are present in two or more settings (e.g., home, school, or work; with friends or relatives; in other activities).
- D. There is clear evidence that the symptoms interfere with, or reduce the quality of, social, academic, or occupational functioning.
- E. The symptoms do not occur exclusively during the course of schizophrenia or another psychotic disorder and are not better explained by another mental disorder (e.g., mood disorder, anxiety disorder, dissociative disorder, personality disorder, substance intoxication or withdrawal).

American Psychiatric Association (2013)

Remember: Do not be quick to look for a diagnosis. Full patterns must exist, not just one or two symptoms. Keep in mind also, these are considered diagnostic guidelines and a psychologist, psychiatrist, or physician may give the diagnosis even though the individual “does not quite” meet all of the criteria. These professionals can also decide that a person does meet the diagnostic criteria listed in the DSM, but does not have the disorder and make the decision not to give them such a diagnosis.

Caution must be used when deciding not to consider the behavior as a mental health disorder. Until recently, when a person with I/DD hurt him or herself with violent, hyperactive, repetitive behaviors, he or she was said to do so “because of their intellectual or developmental disability.” Many professionals believed the problem behavior was due to the person’s poor learning skills

and would not consider a mental health diagnosis. This is called **diagnostic overshadowing**, or the process of over-attributing a person's symptoms to a particular condition. Diagnostic overshadowing occurs when health care practitioners ignore mental health problems because the symptoms are judged to be "just" part of the developmental disability. We now know that sometimes there are other reasons for these behavioral patterns. A mental health disorder is just one of the possible reasons for behavior that is not typical.

Professionals who Evaluate, Assess, and Diagnose Mental Health Disorders

There are a number of professionals who support people with dual diagnosis (DD). Those professionals who have the ability to contribute to and render a diagnosis are:

Psychiatrist: A psychiatrist is a physician who has completed a specialty residency in psychiatry at an approved training site. Psychiatrists first obtain their Bachelor's degree (usually four years), then attend medical school for about four additional years to obtain the M.D. degree or a D.O. degree. After they become a physician, they must complete a residency in their specialty area. The residency in psychiatry is usually an additional five years, practicing under the supervision of a group of psychiatrists. Psychiatrists are physicians who prescribe medications and other medical tests. Because of the medical focus of their training, many psychiatrists tend to view people with mental health disorders from a "medical model" perspective. The medical model is a school of psychological thought in which mental disorders are believed to be the product of physiological factors. The medical model treats mental disorders as physical diseases. Medications are often used in treatment. This is important to remember when seeking services.



Physician: A physician can be from a variety of specialties within the medical field, including psychiatry. However, many physicians prescribe medication we might think of as "psychiatric drugs." For example, physicians other than psychiatrists prescribe **more than half** of the medications prescribed to treat depression. These physicians may be family practitioners, general practitioners, pediatricians, or neurologists.

Psychologist: A psychologist has a Doctorate degree (Ph.D. or Psy.D.) in clinical, experimental, social, counseling or developmental psychology which is first obtained by completing a Bachelor's degree. They usually spend four or five years working on their Ph.D./Psy.D. degree, often obtaining their Master's degree after the first two years. A psychologist is not a physician and does not prescribe medication. Because of their training, they tend to view people with mental health disorders in terms of the influence of the people and events around them. Intellectual testing, an important part of diagnosing intellectual disabilities, is the responsibility of the psychologist.

Qualified evaluators are defined as those licensed individuals who are qualified to evaluate and diagnose mental health disorders or who may serve as **members of a diagnostic team**. These professionals may include:

- psychiatrist
- clinical social worker
- licensed counselor
- neurologist
- mental health nurse practitioners
- school psychologist

It is important to remember that each team member brings a different perspective to the evaluation of an individual. A diagnosis from a psychiatrist may be primarily based on the medical model. A psychologist and social worker may view the person from a social and psychosocial perspective. These perspectives will each be a part of the overall evaluation and resulting diagnosis.

Professionals who Support People with Dual Diagnosis

Exempt psychologists, psychology associates, school psychologists: This sub-group of the psychology profession is generally associated with human service centers, state hospitals, and facilities such as the Life Skills and Transition Center. Licensed exempt psychologists or psychology associates are people who have obtained their Master’s degree in psychology and are called “psychologists” by special permission. Testing skills and an emphasis in behavior analysis are an important part of this position. School psychologists are limited to working within the educational setting.

Behavior Analyst: Behavior analysts focus on collecting data about people supported to better understand what they are doing and why. They develop plans to help the person learn more effective behavior. Behavior analysts focus on collecting data on behavior patterns to better understand the function or purpose of the problem behavior. When the purpose of the behavior is better understood, the behavior analyst helps the team develop teaching skills to replace problem behavior or strengthen emerging coping skills. This person may also use the title of Licensed or Registered Applied Behavior Analyst.

Direct Support Professional: This person is responsible for delivering the services prescribed by the diagnostic team, the behavioral analyst, and other team members. The support is provided at the person’s home, worksite, community, or school settings. This role is critical in helping a person accommodate and adjust.

Support Coordinator: This person is responsible to ensure training and services are effectively delivered to the person. This position requires a Bachelor’s degree and at least one year of working experience with people who have been diagnosed with I/DD. Agencies use a variety of titles for people who have this role, including: program coordinator, case manager, or a QDDP (qualified developmental disabilities professional).

Types of services

Since the premise of person-centered services is to use the community services available to any member, the descriptions that follow are services available to any person who is seeking help regarding a mental health disorder. Historically, many people with I/DD have experienced exclusion from mental health services because of diagnostic overshadowing. Remember, diagnostic overshadowing occurs when the symptoms a person presents are inappropriately attributed to their developmental disability rather than treated as a separate condition. Services are still limited in some regions.

There are a variety of mental health services available for people living in their communities. Some private companies and public agencies offer their staff Employee Assistance Programs (EAP) as a part of their benefit package. EAP provides employees with a place to seek help when they have difficulties.

There are community-based counselors available for individual, family or group therapy to work on personal issues and financial difficulties. Employment counselors assist with other specific personal problems. School districts have also added school counselors available to all grade levels. Counselors encourage positive behaviors and attitudes. Schools involve all personnel in positive behavior supports through the Response to Intervention (RTI) programs.

Regional Human Service Centers: More specialized services are available through the North Dakota Department of Human Services, which operates eight regional human service centers. The centers serve all ages through counseling, mental health services, psychology, and psychiatry. Services for a person with I/DD are accessed through their Developmental Disabilities Program Manager.

Regional Psychosocial Rehabilitation Centers: The mission of the Regional Rehabilitation Center is to:

- build quality relationships
- improve the quality of life of members through social-recreational opportunities
- ensure the continuum of care through established lineages with referral sources and community resources.

Local Hospital Mental Health Centers: Many hospital systems have mental health centers, sometimes referred to as “psychiatric centers.” These centers offer short-term psychiatric stabilization services. The focus of each center is to help the person achieve stability and return to their home as quickly as possible.

- Mental health workers try to return the person to the community quickly. A speedy return to the community and regular living conditions are important for recovery. Long stays make the transition back home more difficult.

North Dakota State Hospital: This hospital is located in Jamestown, ND and provides a variety of mental health **hospitalization** services. It serves adults with mental health disorders and provides substance abuse treatment programs. It is often used to provide evaluations about the abilities of a person who may be involved in a court case or legal matter. The hospital also treats people that need hospital stays longer than the local mental health centers provide.



People with I/DD are sometimes served at the State Hospital when the mental health disorder is the significant issue. The most important goal for each person is to return to their home. The State Hospital may recommend referral to the Life Skills and Transition Center for people with I/DD who are not prepared to go home right away.

Life Skills and Transition Center (LSTC): This center is located in Grafton, ND and provides intermediate care in residential and vocational services as well as clinical and health supports. Services at this center are provided by referral of the Regional Human Service Center **only when all other alternatives have been exhausted.** The Life Skills and Transition Center is publicly operated and accredited by the Council on Quality and Leadership (CQL).

A comprehensive array of supports and specialized services are available, including:

- | | |
|--------------------------------|---------------------|
| -Medical | -Dental |
| -Speech and Language Pathology | -Psychiatry |
| -Nursing | -Recreation |
| -Audiology | -Adaptive Equipment |
| -Pharmacy | -Psychology |
| -Vocational | -Laboratory |

Each person admitted to the Life Skills and Transition Center has a support plan team. The team consists of those people/services that can most directly help them. Admission to this program is considered the last choice and they are required to access the **CARES** (Clinical Assistance, Resource, and Evaluation Services) program. The CARES program provides an individualized support team to join with the person's current team. Not every discipline is needed on each person's team but are available when needed. The goal of the joint problem solving is to keep the person in their home community. People receiving supports at the Life Skills and Transition Center explore work opportunities, community social activities, and care for themselves as independently as they are able.



Most support needs can best be studied in the person's natural environment (home, community, and work settings). The CARES staff, DSPs, psychologists, and other professionals will visit to make observations with the local staff and team. The strength of cooperative problem solving is used to design supports to help people with mental health disorders to be successful in their current settings or help design more appropriate supports.

The STOP (Structured Treatment of Offenders Project) is for those who have displayed or committed sexually inappropriate behaviors. STOP can conduct more extensive assessment services. Most supports can be designed for delivery in the community. The STOP program does not provide residential services.

Mental Health Peer Support and Advocacy Groups: Peer support and advocacy groups for people with disabilities at the local, state, and national levels include:

- North Dakota Protection and Advocacy Project (www.ndpanda.org)
- The NADD – (National Association for the Dually Diagnosed-www.thenadd.org)
- National Alliance on Mental Illness (NAMI)
- National Federation of Families for Children’s Mental Health (www.ffcmh.org)
- North Dakota Federation of Families for Children’s Mental Health (www.ndffcmh.org)
- Mental Health America (www.nmha.org)
- Mental Health Association of North Dakota (www.mhand.org)
- 2-1-1 – Get Connected Get Answers
- North Dakota Mental Health Planning Council (NDMHPC)
- Centers for Independent Living

Summary

Mental health refers to having a positive outlook on life; however, all of us may experience problems along the way. When the behavioral patterns used to cope with problems cause suffering or a decreased ability to function in daily life, mental health is at risk. The DSM-5 is a manual used by qualified professionals to determine if the behavioral pattern fits criteria of common disorders. It is important that teams consider the symptoms a person with I/DD is displaying as not just attributed to the cognitive disability, but that it could also be symptoms of a mental health disorder. Psychologists, DSPs, and Behavior Analysts may be part of a person’s team. Mental health services should be premised on person-centered planning and use community and regional services. More specialized services are offered through the Department of Human Services in North Dakota.

Chapter 2 Study Questions

1. The Diagnostic Statistical Manual is
 - a. Used to make a diagnosis.
 - b. Used in collecting data.
 - c. Used by behavior analysts to determine the function of a behavior.
2. T F A mental health disorder refers to a certain pattern of behavior(s).
3. T F The identification of the pattern of behaviors is only one factor that contributes to a diagnosis.
4. List the steps of a psychiatric assessment.
5. Diagnostic overshadowing is the process of attributing a person's symptoms to a specific condition. Choose the example of diagnostic overshadowing below.
 - a. Kristen's arguing and isolation may be due to her recent loss of her sister.
 - b. Ray's self-injurious behavior is caused by his cognitive disability.
6. Circle those professionals that are able to render a mental health disorder diagnosis.
Physician
Behavior Analyst
Psychiatrist
Neurologist
Support coordinator
Clinical Social Worker
7. List the name of the local or regional agency or institution that provides the following service:
 - a. Psychologist or psychiatrist -
 - b. Short term psychiatric stabilization -
 - c. Hospitalization -
 - d. Advocacy -

CHAPTER 3: Understanding What We See

Objectives

Upon successful completion of this lesson, staff members will be able to:

- Define the terms behavior, maladaptive behavior, and adaptive behavior
- List the causes for maladaptive behavior
- Compare symptom vs. behavior
- List psychosocial vulnerabilities people with I/DD have that put them at risk of developing a mental health disorder
- Explain the term diagnostic equivalent

Understanding Behavior

Direct Support Professionals work with people. Effective support requires understanding human behavior. The work requires an understanding of “typical” behavior but also behavior that is not “typical” or easily understood.



Behaviors are observed actions such as walking, sleeping, arguing, and crying – actions you can see and describe. In this field, behaviors are often described in terms of **adaptive** or **maladaptive**.

Adaptive behaviors are those behaviors that help people be independent. They are the types of behaviors we strive to develop, and continue to use throughout our lives. They are the actions that get us through the day, earn us a paycheck, allow us to make and keep friends, and help us survive. They include actions such as eating, walking, working, smiling, and crying. They are useful, functional, and necessary to survive and be happy.

Maladaptive behaviors interfere with independence. They get in the way of the adaptive behaviors. In some cases, the person may get what they want in the short run, but are prevented from getting what they really need. These are inappropriate responses to problems in life. They prevent us from working, having friends, being happy, and generally doing well. These are inappropriate ways of responding to internal feelings and what goes on around the person.

Mr. A was desperate. He was about to lose yet another job, not because he was at risk for being fired, but because his lying behavior had finally boxed him into a corner. He had lied repeatedly to his colleagues, telling them that he had an incurable disease and was receiving palliative treatment (comfort measures only). Initially, his coworkers treated him with sensitivity and concern, but as the weeks wore on, they became suspicious. He had to tell more and more outrageous lies to cover his tracks and justify having a terminal illness. Finally, when the heat became too unbearable, he suddenly stopped going to work. On the face of it, it would seem Mr. A told these lies to gain the sympathy of his colleagues, but the consequences of his lying, in terms of emotional distress and potential loss of job, far outweighed any perceived gain. Mr. A had lost several other jobs

in the past because of his lying, and he was becoming frustrated. Family members reported that he often told blatant lies, and even when confronted, and proved wrong, he still swore they were true. Mr. A finally sought psychiatric help after concluding that he could not stop himself from lying.

Dike, C, 2008

Mr. A's need for sympathy and attention resulted in making up stories, which caused him to tell more lies. This was maladaptive behavior. It fulfilled his desire or want in the short term but his need for a job and friends who cared for him was not fulfilled, and his maladaptive behavior actually created more problems.

Other examples of maladaptive behavior we may see in people who have I/DD are:

- Hurting others
- Injuring self
- Drug and alcohol abuse
- Self-stimulation
- Destroying property
- Running away
- Sexual inappropriateness



Behavior has a Purpose

People with I/DD do not exhibit maladaptive behavior solely because of their disability. If the behavioral reason or motivation is not easily understood, it is the responsibility of the person-centered team to conduct a functional behavioral assessment. This assessment will help the team make a “best guess” on the purpose of the maladaptive behavior. This information will also be shared with the medical professionals who render diagnoses. It is important to consider causes of behavior that is maladaptive.

Causes of Maladaptive Behaviors

Normal Reaction to Stress

When it is time to go to work, does the person get angry, claim to be ill, or simply refuse to go? Could it be she is bored with the job? Maybe she hates her work.

When a new roommate moves in, does the person behave in a different way? Does he/she avoid meals? Do they become moody and irritable? Could it be a personality conflict with the new roommate? The person may feel that they are getting less attention and feel jealous and threatened.

Although the reasons for these behaviors may not always be obvious, the behaviors are personal reactions to stress the person is experiencing. Whether the motivation is boredom, stress, fear, loneliness, or jealousy, these actions cause a behavioral response that we need to understand.

Medical

Have you ever experienced such pain that you reacted in an uncontrollable manner? An abscessed tooth may make you want to scream. Unrelieved pain causes very strong emotions. Some sources of pain are visible. Be alert to ingrown toenails, red marks, bruises, or blisters. Other causes may not be visible, such as constipation, menstruation and PMS (premenstrual syndrome), allergies, arthritis, or just an annoying headache. Imagine not being able to understand the cause of your pain or communicate how you feel.

Many signs and symptoms of these conditions are observed first by DSPs. It is important to report observations promptly and accurately. It is also important to advocate for action when you recognize discomfort or a change in the person's typical behavior or responses.

Remember that people supported may be receiving medications that cause side effects. Know where information on medication side effects is kept in the setting where you work. Be aware of the medications and their side effects for all the people you support. Adverse conditions that may be caused by these medications should be reported according to agency procedures.

Some types of seizures may cause brain activity which results in a person becoming aggressive. These actions are beyond the person's control and should be considered a medical issue. Medication may help control the behavior resulting from the seizure.

Learned

Learned maladaptive behaviors develop when the person doesn't have an appropriate adaptive behavior. If a person has learned that every time he screams he is given a can of pop, how else would he let you know that he wanted a soda? How long would it take to change his behavior if he would get the same response by asking for pop with a sign, touching a soda machine, or displaying a picture of a can of soft drink?

Maladaptive behavior is learned because it is **reinforced**.

Every time the mother approaches the grocery store checkout, her 2-year-old begins to cry and scream for the candy in the display. The mother doesn't want her son to eat candy, but due to the embarrassment of dealing with a screaming child in front of all the other people, she usually gives in to the tantrum and buys the candy.



The "maladaptive behavior" in this example is the tantrum. Even though it is typical behavior for the toddler to scream and cry, there are better ways to ask for candy. The "reinforcement" is the mother giving in to the tantrum and buying the candy. It is highly likely that the child will use the same behavior next time at the checkout. The tantrum is a learned and reinforced behavior.

What behavior is learned if staff only interact with a person when they bang their head on the wall? It would be better to give attention when the person is smiling and vocalizing and reinforce the behavior that is adaptive (smiles and vocalizations).

Note: It may take a while to change habits or maladaptive behavior. A behavior that has been working for a person for years will take a well-planned, coordinated, and consistent effort for the person to learn a more adaptive way to get what they desire. Remember that the maladaptive behavior we see is the person's best effort to be successful.

Other

Behavioral Phenotypes: Some syndromes or diagnoses have high rates of specific behaviors or tendencies. For instance, people with autism are more likely to present obsessive or compulsive-like behaviors. Lesch-Nyhan syndrome is a rare syndrome but is known for self-injurious behavior. People who have the diagnosis of Prader-Willi syndrome usually have difficulty controlling their obsession with food, which can lead to high levels of frustration and overt physical aggression. People with Williams syndrome have well developed language skills but have attention deficits.

Psychosocial: It is important to remember that many people with I/DD have had experiences that are not typical of the general population. Those experiences can shape a person's responses to stress and can interfere with normal development of adaptive behaviors. For example, a person with I/DD may have experienced bullying. They may have watched brothers or sisters go off to college while they were not allowed to do so. They may live with other non-related adults well into middle age and often didn't choose the people that they live with. They may experience anxiety and fear when they cannot communicate their emotions. These events, combined with a lack of experience or opportunities and diminished ability to learn, impact a person's psychosocial development.

It is important to be mindful of the pre-judgments we, as supporters, might have regarding maladaptive behavior. It is vital to recognize what the person with I/DD considers a real life problem rather than basing our support on our personal definition of a real life problem. We judge ourselves by our intentions or why we do something. However, it is easy to judge another person's maladaptive behavior by its impact. The maladaptive behavior we see might be quite adaptive for that person and makes sense for them in the circumstances. As caregivers we need to focus on the function of the behavior but also be aware that the behaviors we see could be symptoms of a mental health disorder.

Challenges to DSPs/Teams

The previous information on maladaptive behavior was meant to help DSPs understand how difficult it is to diagnose a mental health disorder in a person with I/DD. Many of the symptoms of mental health disorders are what we might perceive as maladaptive or bizarre type behaviors. How does a person who is non-verbal let us know what is wrong? How does a person who uses only a few signs tell us about very complicated feelings? An emotion that cannot be expressed in words can be very difficult to understand.

DSPs and team members must become very good observers. The most important information is gathered by getting to know the person well and understanding their mode of communication. The person may communicate with gestures, facial expressions, or sounds. People who have trouble communicating feelings will send out clues. Members of the team including DSPs need to be detectives or skilled observers of what a person is trying to tell them.



Think of people you know. Many do not have to tell you how they feel, yet you are aware of their feelings by interpreting the clues or signs in their behavior. You may recognize silence in a spouse as a sign of anger or frustration. You might notice if a friend is teary-eyed, has shaky hands, or appears nervous. Some people display fear by being overly talkative. These behaviors may be indications of a bad day, the result of an unpleasant encounter, or they could be symptoms or clues of a more serious underlying mental health problem.

Identifying these hidden symptoms is essential in developing treatment plans for people with dual diagnosis. Successful intervention plans are often the result of collaboration between staff and family; the people who are in the best position to observe and gather information. It is not the job of the DSP to speculate about what these behaviors mean. Your job is to document what you see, whether or not there is an underlying physical or mental health problem.

Adaptations for Diagnosis of Mental Health Disorder

Diagnostic Manual for People with Intellectual and Developmental Disabilities (DM-ID) or Diagnostic Equivalents

Clinicians began to realize the symptoms or patterns listed in the DSM often did not apply to people with I/DD. For many people with I/DD, it is difficult to determine if the person meets the criteria necessary for diagnosis. Symptoms are now being categorized as **diagnostic equivalents in people with intellectual disabilities**. The diagnostic equivalents identify the symptoms of a diagnosis as they would be **observed and measured** in an individual with I/DD.

The NADD (National Association for the Dually Diagnosed) published the *Diagnostic Manual – Intellectual Disabilities: A Clinical Guide (DM-ID)* in 2007. The manual was created by professionals in the field of I/DD with expertise in mental health disorders, in cooperation with editors of the DSM. The result is a manual that provides a guide for finding behavioral equivalents that apply to people with I/DD.

For example, in diagnosing **Major Depression**, the DSM-5 lists the symptoms needed to confirm a diagnosis of depression in the general population. The following table identifies the symptoms found in the general population on the left, and provides Adapted Criteria in the right column. Psychologists, psychiatrists, and other physicians are using Adapted Criteria, with the intention that it will make a difference in the *reliability* and *validity* of the diagnosis. Staff are able to support a diagnosis by systematically observing and recording behaviors. It is hoped that this information will allow professionals, DSPs, and teams to be better able to judge interventions that are most effective.

Here is a sample table of the *DM-ID* that is also available on their website: <http://www.dmid.org>

DSM-IV-TR criteria	Adapted Criteria for Mild to Moderate I/DD	Adapted Criteria for Severe- Profound I/DD
<p>Note: A panic attack is not a codable disorder. Code the specific diagnosis in which Panic Attack occurs (e.g., Panic attack is a discrete period of intense fear or discomfort in which four (or more) of the following symptoms develop abruptly and reached a peak within 10 minutes</p> <ol style="list-style-type: none"> 1. Palpitations, pounding heart, or accelerated heart rate. 2. Sweating 3. Trembling or shaking 4. Sensations of shortness of breath or smothering. 5. Feeling of choking 6. Chest pain or discomfort 7. Nausea or abdominal distress 8. Feeling dizzy, unsteady, lightheaded, or faint 9. Derealization (feelings of unreality) or depersonalization (being detached from oneself) 10. Fear of losing control or going crazy. 11. Fear of dying 12. Paraesthesia (numbness or tingling sensations) 13. Chills or hot flashes. 	<p>No adaptation</p> <ol style="list-style-type: none"> 1. No adaptation 2. No adaptation 3. No adaptation 4. No adaptation 5. No adaptation 6. No adaptation 7. No adaptation 8. No adaptation 9. No adaptation (note: Derealization/ depersonalization may be difficult to elicit in persons with moderate /IDD 10. No adaptation 11. No adaptation 12. No adaptation 13. No adaptation 	<p>Note: A Panic Attack is not a codable disorder. Code the specific diagnosis in which Panic Attack occurs (e.g., Panic Disorder with Agoraphobia. A Panic Attack is a discrete period of observed intense fear of discomfort in which three (or more) of the following symptoms develop abruptly and reached a peak within 10 minutes (i.e. Panic Attacks might be observed rather than self-reported in this population. The person appears to be intensely frightened/agitated/distressed).</p> <ol style="list-style-type: none"> 1. Pounding racing heartbeats and skipped beats might be identified by taking he pulse or listening through a stethoscope. 2. May be observed rather than self reported. 3. May be observed rather than self reported. 4. Shortness of breath may be observed if the person is gasping for breath, overbreathing/hyper ventilating. Smothering sensation usually cannot be detected in this population. 5. Choking may be observed. The person may be having difficulty breathing, having a weak cry or cough, wheezing, retraction of ribs/chest, turning blue. 6. Consider that chest pain may be present if the person is clutching or rubbing the chest 7. Nausea could be observed as retching or vomiting 8. Dizziness and unsteadiness could be observed as seeing the person go “grey” and staggering or collapsing. 9. Derealization and depersonalization cannot be detected in this population. 10. Cannot be detected in this population. 11. Cannot be detected in this population. 12. Cannot be detected in this population. 13. Chills and hot flashes may be observed rather than self-reported.
		<p>Note: Extreme panic may result in irritability, aggression, and destructive behavior, and may also cause lashing out of arms, legs, and head banging.</p>

Summary

In order to provide supports to people with dual diagnosis, it is important to know the person and understand their behavior. Behavior that is adaptive is useful and functional and leads to a quality life. Maladaptive behavior interferes with getting what we really need. Maladaptive behavior can be caused by a reaction to stress, by a medical condition, or it can be learned. In most cases the behavior is the person's best effort to gain relief from their symptoms or be successful. In order to make sense of the maladaptive behaviors, team members need to be good observers. Successful intervention plans are often the result of collaboration between staff and those who know the person best. In order to address assessment of maladaptive behaviors, the NADD has published the DM-ID.

Chapter 3 Study Questions

1. Which description is considered a maladaptive behavior?
 - a. Answering the phone when it rings.
 - b. Putting the phone in the toilet when it rings.
 - c. Pressing the correct button to answer the phone.

2. Which description is considered an adaptive behavior?
 - a. Greeting co-workers as you meet them for the beginning of the work period.
 - b. Grunting when a co-worker says good morning.
 - c. Looking at the floor and not responding when a co-worker says “good morning.”

3. Define behavior.

4. People use maladaptive behaviors for a variety of reasons. List three reasons

5. Symptoms are behavioral markers of a particular diagnosis. What is a symptom of depression?

6. Behaviors are things we do. What behavior might you do if you get a flat tire in the middle of heavy traffic?

7. Define Diagnostic Equivalent.

8. People with Prader-Willi syndrome are more prone to
 - a. Frustration because of their obsession with food
 - b. Attention deficits
 - c. Maladaptive communication behaviors.

9. We judge ourselves by our _____ but it is easy to judge others’ maladaptive behavior by its _____.

CHAPTER 4: Common Mental Health Disorders

Objectives

Upon successful completion of this lesson, staff members will be able to:

- Recognize limitations related to I/DD that could be confused with mental health disorders
- Identify staff supports for people experiencing specific mental health disorders
- Recognize signs of mental health disorders in people with I/DD

This section will discuss groups of disorders. There are many more diagnoses than those listed here. This chapter will cover:

- Personality disorders
- Anxiety disorder
- Psychotic disorders
- Mood disorders
- ADHD

Autism and dementia are not included in this module because there are separate modules on these topics. See *Aging I & II*, *Alzheimer's – Providing Effective Supports to Individuals with Alzheimer's Disease and Developmental Disabilities*, and *Autism* in the North Dakota Community Staff Training Curriculum.

Personality Disorders

This group of disorders applies to an enduring (long-term) pattern of dysfunctional (maladaptive) behaviors and their symptoms. In defining **personality disorder**, we should also define personality. We often hear phrases such as “she has such a great personality” or “he has no personality”, etc. We are referring to a person’s character traits; the way he/she thinks and behaves, the distinct way a person acts and reacts to others, and the qualities that make each person unique. These traits are developed in each of us over a lifetime of experiences.

Hollywood has used personality disorders as storylines for many movies. The movie *Beware of Mr. Baker* is about narcissistic personality disorder, *We're the Millers* is about antisocial personality disorder, and *The Remains of the Day* is about schizoid personality disorder. These are just a few of many movies about personality disorders.



The DSM-5 classifies personality disorders in three clusters or general groupings.

Cluster A – characterized by odd or eccentric behaviors

Cluster B – characterized by overdramatic, emotional, or erratic behavior

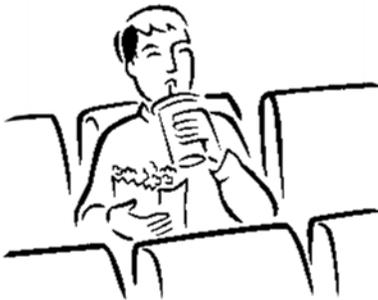
Cluster C – characterized by anxious or fearful behavior

Cluster A – Odd or eccentric behaviors

Paranoid – A pervasive (all-encompassing) and unwarranted (needless) tendency to interpret the actions of people as deliberately demeaning or threatening. This would be the individual who imagines that people are “out to get him.” This person would interpret an innocent remark as an insult or threat.

A woman believed, without cause, that her neighbors were harassing her by allowing their children to make loud noises outside her apartment door. Rather than asking the neighbors to be more considerate, she stopped speaking to them and began a campaign of unceasingly antagonistic behavior: giving them “dirty looks,” pushing past them aggressively in the hallway, slamming doors, and behaving rudely toward their visitors. After over a year had passed, when the neighbors finally confronted her about her obnoxious behavior, she accused them of purposely harassing her. “Everyone knows that these doors are paper thin,” she said, “and that I can hear everything that goes on in the hallway. You are doing it deliberately.” Nothing that the neighbors said could convince her otherwise. Despite their attempts to be more considerate about the noise outside her apartment, she continued to behave in a rude and aggressive manner toward them.

Schizoid – A pattern of indifference to social relationships and restricted range of emotional experience and expression. The central features of a schizoid personality disorder include: 1) minimal or no social relations, 2) restricted expression of emotion, 3)



a striking lack of warmth and tenderness, and 4) an apparent indifference to others. People with schizoid personality disorder are often absentminded, loners, detached from others, self-involved, and “not connected.” What may appear as aloofness might be profound shyness. Avoidant personalities want friends but people with schizoid personality disorder don’t. People with schizoid personality disorder are alone because they want to be and not because they are afraid of people.

Schizotypal – Acute discomfort in close relationships, distorted views and thoughts, eccentric (odd) in appearance and behavior. People with schizotypal personality disorder are hypersensitive (oversensitive) to criticism and anxious around people. They are more likely to display bizarre and peculiar traits, have fanatic (extreme) or eccentric (peculiar) beliefs, and may evolve into schizophrenia. This disorder does run in families, (Maxmen, Ward, & Kilgus, 2009).

Cluster B – Overdramatic, emotional, or erratic behavior

Histrionic – Pervasive extreme emotionality and attention seeking. This person displays emotions that are not consistent with the cause. In other words, the event that caused them distress is relatively minor compared to the person’s reaction. People with histrionic

personality disorder are overdramatic and always calling attention to themselves. They may:

- Constantly seek reassurance or approval
- Be excessively sensitive to criticism
- Be inappropriately seductive in appearance or behavior
- Have somatic symptoms (feel ill) and use these as a means of gaining attention
- Have a low tolerance for frustration and delayed gratification
- Have a tendency to believe that relationships are more intimate than they actually are

Narcissistic – Pervasive grandiosity in fantasy or behavior, lack of empathy and hypersensitivity (oversensitive) to how others might view them. This person believes that the world revolves around them. They tend to be extremely sensitive to real or perceived criticism. This person craves attention and wants everyone to like them. They tend to be very interpersonally selfish. They have a sense of entitlement or belief that they are privileged and are not concerned about others.

Antisocial – A pattern of disrespect for and violation of the rights of others. People with antisocial personality disorder have a radar for people’s weaknesses and manipulate, exploit, control, deceive and intimidate (threaten) others. People with antisocial personality disorder crave stimulation and are always on the move. They often get in trouble with the law.



Borderline – A pervasive instability of mood, interpersonal relationships, and self-image with marked impulsivity. The interpersonal relations of people with borderline personality disorder swing between suffocating dependency and mindless self-assertion. They hate being alone and latch onto others to avoid feeling abandoned.

Such an individual will call a recently made friend every day about a “disaster” needing immediate attention. Initially, the friend is flattered by the new friend’s “idealization” of her, yet she soon finds herself sucked into a gooey, all-consuming relationship. When she tries to cool things, the person with borderline personality disorder devalues her with a vengeance, pouring ink on her couch, demanding money, and accusing her of being “miserly”, calling her at 3:00 am to complain.

Maxmen, J., Nicholas, W., Kigus, M. (2009)

Cluster C – Anxious or fearful behavior

Avoidant – Pervasive discomfort, fear of negative opinions by others, and timidity. This is an overly sensitive individual who is constantly apologizing for fear of having hurt someone’s feelings. This person wants affection, but not as much as they fear rejection. Because they dread the slightest disapproval and will misunderstand comments by others

as insulting, they will have few, if any friends. They may become angry and upset with their inability to relate and they will try to prevent rejection by doing things they think will win the approval others.

Dependent – A pervasive dependent and submissive behavior related to the excessive need to be taken care of. The “clinging vine,” lacks any real sense of individual identity.

Ethel refers to herself as “man’s best friend.” Her man is Mitch, a husband who schedules her days, tells her what foods to eat, picks her doctors, chooses her clothes, and selects her friends. This arrangement has pleased both for years until Mitch announced he was going to China for three weeks on business. Ethel was frantic and sought treatment. Like most dependent personalities, she wanted help not for dependency, but for losing it.

(Maxmen, Nicholas, & Kigus, p. 576).

Obsessive compulsive – A preoccupation with orderliness, perfectionism, and control. The perfectionist tends to be hard on themselves and anyone around them when things do not go according to **their** plan. Their perfectionism interferes with the ability to grasp “the big picture.” They insist that others submit to their way of doing things. They are devoted to work and productivity. They have trouble making decisions. This **must not** be confused with Obsessive-Compulsive Disorder which is an anxiety disorder and very different from Obsessive-Compulsive Personality Disorder.



I/DD and Personality Disorders

It is difficult to diagnose personality disorder in people with I/DD for a number of reasons. The diagnosis requires subjective information about thoughts and emotions, which can be difficult to obtain from those with limited verbal ability. The diagnosis also relies on the person’s experiences with others in relationships. Many people with I/DD haven’t had close friends and lack the ability to understand manipulation of others. They may have limited understanding of abstract concepts such as empathy or remorse. It is suggested that a person’s motivation and the way they react emotionally to life circumstances could impact their personality. Exposure to social experiences that are unpleasant can also contribute to personality disorders. (Zigler & Bennett-Gates, 1999).

Treatment

Symptoms of some personality disorders can be improved with psychotherapy, if the person is able to develop a self-awareness of their key problem behaviors. However, therapy focused on “insight” alone is seldom effective since a key part of the disorder is the lack of awareness of the effects they have on others. People with mild ID may benefit from group psychological support with others who experience similar difficulties. Cluster B personality disorders may benefit from

medications, but psychological and behavioral interventions are preferable to medication intervention.

Some suggestions for people who are anxious, fearful, or dependent (Cluster C) include:

1. Support success. Provide as little or as much assistance for the person to be successful.
2. Believe the person is doing their best to cope. Interpret their behavior as needing rescue from their stress.
3. State how confident you are in their ability to respond well.
4. Tell the person exactly what they need to be doing to be successful –*“Terry you need to use your schedule on your bulletin board to tell me what comes next.”*
5. Display confidence, calm, and stability. Do not look frustrated, angry, or distressed.
6. Make transitions (to the next activity, or environment) predictable. Use visual schedules, social stories, etc.
7. If the person “falls apart” help him/her orient to what is next.

Anxiety Disorders

Generalized Anxiety Disorder

Generalized Anxiety Disorder is the most common anxiety disorder. Approximately 18% of the general population are given this diagnosis at some point in their life (Maxmen, Nicholas, & Kigus, p. 373).

A person with anxiety anticipates and worries about future danger or misfortune, whether it is real or very unlikely. People with anxiety disorders worry excessively when there is no real danger. This hyper-alert state is often severe enough to be frightening and can prevent them from participating in everyday activities. Anxiety is a sign of real personal suffering; it’s not an act to get sympathy. It can cause marked interference in people’s lives, reducing their work performance and interfering with friendships/relationships.



The EPICS curriculum from the Kansas University Center of Developmental Disabilities (2002) provides these guidelines for recognizing Generalized Anxiety Disorder in persons with I/DD:

- The person quickly becomes irritable or aggressive.
- Situations that typically are handled well become intolerable.
- Reinforcers for adaptive behavior or explanations that typically help the person control their behavior are ineffective.

Support for people with anxiety disorders begins with a general medical assessment. Untreated allergies, anemia, sinus infections, or other health problems make it harder for anxious people to cope. It is also necessary to thoroughly examine the function of the behavior before diagnosing anxiety. Boredom, discomfort, or skill deficits might all contribute to behaviors such as pacing, hyperactivity, or short attention span. The possible role of medication/substances also must be

ruled out before a diagnosis of anxiety is made. The use of some substances (e.g., caffeine, amphetamines) and the withdrawal of other substances (e.g., alcohol, narcotics, tobacco) can cause the signs and symptoms of anxiety.



Understanding how anxiety is fueled can assist in defusing the spiral.

Wagner (2005) explains the anxiety triad as the **thoughts, physical symptoms** and **behaviors** working together as fueling factors that feed the fire of anxiety. The anxious person might be excessively cautious regarding danger, making them overly sensitive to physical symptoms. They remain poised and ready for easy escape. Anxious thoughts and physical symptoms are converted to anxious self-talk and these drive avoidance and escape behaviors.

Over time, an accumulation of these experiences cements the anxious person's sense of danger.

*Joel thinks people avoid him because he cannot speak clearly and that no one really likes him (**thoughts**). At social events where he has to talk to people, he becomes nauseated (**physical symptoms**). He starts to fidget and look at things or the floor; then he goes to a place where he feels comfortable. He tries to find a place where there is no one else around or where there are small children where conversation is not needed (**behavior**).*

The negative reinforcement of avoidance (relief) in the example above actually fuels the anxiety (discomfort) and is reinforcing the belief that this escape behavior is the only way to overcome anxiety (Wagner, 2005 p. 72). The support professional should not reinforce the relief but teach and provide tools to react and respond to anxiety. This is addressed more specifically in Dual Diagnosis II.

After medical issues have been ruled out, the health care professional will work with the team to develop a multifaceted treatment plan that might include:

- Teaching the person relaxation techniques
- Modification of stressors in the environment
- Teaching the person coping skills
- Psychotherapy
- Medication

Anxious people feel calmer when life is predictable. Support professionals should help the person plan routines and post schedules that provide a sense of control and order.

Anna is a 48-year-old woman who has a mild developmental disability as well as a diagnosis of Generalized Anxiety Disorder. Anna is fairly independent and has a boyfriend. Anna has become increasingly anxious regarding her relationship with her boyfriend. She is afraid that he won't call, or won't answer his phone, or that he will find another girlfriend. All these fears seem unfounded as he is a very caring and always picks her up at set times and calls back if he missed her call. After a long chat with Anna, it was found that 12 years ago the boyfriend had gone to the swimming pool with another

woman. The memory of this incident was still on her mind. Telling her to stop being afraid and that she had nothing to worry about was insufficient.

Tholiefsdottir (2014)

Johanna Westby (2008) recommended the following strategies to help people develop coping skills to manage their own anxiety. The person may need:

- Tools to relax: mental imagery, abdominal breathing, progressive muscle relaxation.
- Tools to cope with worry. Westby suggests: locking up worries in a box, setting a scheduled time to worry, and “pulling the plug on worry.”
- Learn to take risks: use of self-talk instead of imagining the worst, reminding the person of times they were brave or handled a situation well.
- Exercise: physical exercise improves energy and helps people take their mind off worries.



Nathan Ory (1995) recommends the following responses to emotional distressed behavior:

- Remove social/emotional expectations that are the source of the person’s anxious behavior. Do they have to speak in public, if that causes a great deal of anxiety?
- Give clear, concrete, realistic and achievable expectations (e.g., “We are going to stay at the party for 15 minutes, then we can leave.”).
- Remove pressure. Don’t demand performance that will be beyond the person’s ability at this time of anxiety.
- Slow down. Do not put pressure on the person to move or work faster or better.
- Never criticize performance. Instead, use encouragement and positive direction (e.g., “You need to...”).
- Have a positive expectation that the person will be successful. Modify supports until they are successful.
- Use social stories to familiarize the person with a situation that is coming up. Teach coping skills.

Specific Phobias

A specific phobia is an extreme and unreasonable fear that occurs when a certain object or situation is present or expected. Common phobias fall into five general classes:

1. Blood/injection/injury
2. Animals (e.g., mice, dogs, snakes)
3. Natural environment (storms, water, or other natural objects)
4. Situational (fear of heights, elevators)
5. Other

To be classified as a phobia, the person must avoid the object, situation, or experience extreme distress when it cannot be avoided. The distress must interfere with routines, activities, functioning, or relationships. People without disabilities realize that their phobia is excessive or unreasonable, but that might not be true for people with I/DD. Some conditions contribute to the development of phobias including poor coordination, poor motor control or balance, visual or other sensory impairments, abnormal muscle tone, skeletal deformities, obesity, or poor balance.

Once a fear is identified, the person and his or her team, with the support of a mental health professional, develop an intervention plan that may include:

- Avoiding the object or situation
- Relaxation
- Providing reinforcement to overcome avoidance behaviors
- Exposure treatment – repeated exposure where the trigger loses its effect
 - Systematic desensitization - gradually exposing the person to the feared object.
The person learns to tolerate increased exposure bit by bit.
- Modeling – observing someone else engage in the activity that produces their fear
- Cognitive therapy – helping a person understand the reality surrounding their fear.
- Medications – to help the person relax. These are commonly used for a seldom encountered situation such as an airplane flight.

A systematic desensitization program may take concerted effort, but the lasting skills are worth the effort in making someone's life more fulfilling:

Alice was a 16-year-old female diagnosed with autism and intellectual disability. Alice's significant weight loss caused the team concerns but Alice did not tolerate any medical treatment. She would not get out of the vehicle when arriving at the physician's office. She allowed a passive exam only when she was sedated for dental procedures. Her desensitization program consisted of graduated exposure steps in tolerating the waiting room, complying with height and weight measurements, sitting in the exam chair, complying with blood pressure measurement, stethoscopes, lying on exam tables, tolerating eye exams, ear exams, abdominal exams, and mouth/throat exams. With 51 sessions Alice progressed from a baseline of no cooperation (not willing to exit the vehicle) with challenging behavior to participating in a full exam.



Cavalari, Dubard, Luiselli, & Birtwell (2013)

Social Phobias

Social phobias relate to a fear of humiliation or embarrassment when doing something in front of unfamiliar people. The person has the ability to perform the social skill in the presence of familiar people but is afraid or anxious in the presence of strangers.

Treatment strategies for social phobias include relaxation strategies, teaching and practicing the social skill, systematic desensitization, teaching coping skills to allow for failure or disapproval, and cognitive therapy to help develop more realistic expectations. Group therapy or support groups may help people with I/DD learn to cope by improving self-concept and pride. Medications are sometimes included in the treatment plan if the anxiety is so severe that the individual cannot enter a social situation to practice their skills.

Obsessive Compulsive Disorder (OCD)

OCD consists of repeated obsessions and compulsions that are distressing and interfere with day-to-day functioning.

Joe cannot get to work on time. He washes his hands, closes the bathroom door as he leaves, then returns to rewash his hands. This goes on until he is late for work. If he does get to work, this same pattern persists and he cannot get any work done. It is difficult to get Joe interested in any hobbies or outings; he is too busy washing his hands.

Joe is distressed by these behaviors and asks others to help him stop. He clearly says that he would rather go on these activities than washing his hands, but when the time comes, he cannot do so without others intervening. Joe suffers from an obsessive-compulsive disorder (NOTE: this is NOT the same as an Obsessive-Compulsive Personality Disorder described earlier).



Obsessions are unwanted, unfounded and upsetting thoughts, images, or urges that are unrelenting, uncontrollable and unstoppable. They can be bizarre, frightening and disturbing. Compulsions (also known as rituals) are deliberate physical or mental actions that are geared toward relieving worry and discomfort created by the obsessions. They are not pleasant but help the person relieve their anxiety. Some examples include:

- Insisting that all activities be completed at the same time each day
- Sniffing things
- Putting clothes off and on repeatedly
- Arranging objects in a certain pattern in a room

People with OCD that need to feel “just right” might feel intensely uncomfortable and unable to proceed with an activity or action until they achieve a sense of closure. The person who needs certainty might ask the same questions repeatedly. The person with fear of contamination might wash their hands an excessive number of times throughout the day. The person who is obsessed with order and symmetry might count or arrange things, and the hoarder might feel something bad will happen if they throw things away. He/she might need it later.

Therapy for OCD

Cognitive Behavior Therapy focuses on thoughts and how these can become exaggerated and unhealthy. The individual is then shown how to respond to obsessive thoughts to lessen the need for compulsions. Exposure and prevention of a person’s maladaptive response is a form of

desensitization. The person does whatever makes them anxious but refrains from using the maladaptive behavior he used in the past. Medication is sometimes used in conjunction with therapy. Medication is rarely used alone.

It doesn't help to try to show people with OCD the error of their ways. Most know it's illogical and ridiculous. Trying to show them they're wrong is judgmental and makes you look like you consider yourself above them. It's best to stay positive and open. Remember that change is stressful and that it can cause a rise in OCD like behaviors. Caregivers should not accommodate the compulsion but instead be matter of fact. If questions are repeated, only answer once. If the person insists on going a weird way to the restaurant, don't do it. When you're in the car ready to leave and they're locking the doors and unlocking the doors over and over, go on your way. Of course, these courses of actions should only be done systematically and with the consultation of a psychologist and the rest of the team. When everyone is consistent with the methods to support someone with OCD, there is a much better chance the person will not need the compulsion to relieve their anxiety.

It is important to note that if the person is unaware of the effects of their behavior on their life, the accurate diagnosis may NOT be Obsessive Compulsive Disorder but may actually be in the Obsessive-Compulsive PERSONALITY Disorder diagnostic area. People with Autism Spectrum Disorder often display behavior described as "compulsive" or express repetitive thoughts we think of as "obsessions," but the treatment of these characteristics in Autism Spectrum Disorders are very different. See the *Autism* module from the North Dakota Curriculum for further information on this.

Post-Traumatic Stress Disorder (PTSD)

Post-traumatic stress disorder is an anxiety disorder in which a person continues to re-experience a trauma from earlier in his/her life. We hear a lot about PTSD these days. It could be that people are more open about their experiences or possibly because more traumatic events are reported in the news media. People suffering from PTSD:

- Continue to experience the trauma
- Will avoid anything that reminds them of the incident
- Experience nervousness and tension, creating stress that affects their ability to lead a normal life.



In the past, it was widely believed that people with I/DD could not recognize or understand trauma or loss and consequently did not experience the symptoms of PTSD. It was even assumed that they could not remember or be affected by trauma. Because some people with I/DD have not developed a way to express their feelings, their distress may be expressed in the form of physical symptoms such as illness or maladaptive behavior.

In people with dual diagnosis, the effects of PTSD may take other forms. A person may exhibit fear, run away, or avoid certain people, places, or activities. They may become aggressive when this avoidance is not possible, have nightmares, or appear very nervous or tense. Traumas can

leave a person very vulnerable. They may lose communication skills needed to express, explain, or understand the trauma. Here are some traumas that may result in a diagnosis of PTSD:

- Sexual abuse
- Spousal abuse
- Child abuse
- Living in a gang-riddled neighborhood
- Living through natural disasters such as floods, hurricanes, or tornadoes
- Unexpected death of someone close
- Experiencing something frightening such as a dog attack, near drowning, institutionalization, or plane crash.



People with I/DD may express their fear verbally but they may also express resistance or emotion that is consistently repeated in the same environment. Below are some examples:

- A person hits you while you are assisting them to a dentist or doctor.
- The smell of chlorine at a swimming pool causes the person to run away crying.
- Anyone who wears glasses is avoided or causes a startle reaction.
- Certain events (e.g., Halloween (costumes), 4th of July (fire crackers)) may cause a person to stay in their room. They may have nightmares or become aggressive.

These examples describe trends that may be identified in a person's behavior. As a DSP you will need to be a detective and look for patterns. Reactive behaviors can be analyzed by looking for sights, sounds, smells, events, and people who are in proximity. The person's behavior may not make sense to you, but remember – you did not experience the trauma.

Identifying patterns of behavior is critical to providing the treatment necessary before the person can get on with life without stress resulting from past trauma. Your observations are a vital part of that treatment.

If a person's trauma is not addressed, the treatment or intervention will focus on the observable behaviors and not on the root cause of the behavior. If the person's fears and losses are not openly acknowledged or socially supported, the plan will fail. Examining the person's past can provide insight regarding challenging behaviors and ongoing interpersonal or relational difficulties.

Weston was abandoned by his mother when he was 12 years old. His mother experienced many domestic violence episodes and Weston was also beaten by the men who lived with them. Weston's mother was also physically violent to him. He was dropped off at a social service agency by his mother and then moved to a group home. He never heard from her for four years. Weston was highly anxious and occasionally aggressive. One day Weston received a card from his mother with \$5. When the card was read to him by a DSP, he dropped to the floor and went into a fetal position and groaned and screamed. He was fearful and distraught. The DSP, knowing Weston's history, told him that he had

power and he could do whatever he wanted. He could keep the card and throw away the money, or keep the money and throw away the card. It was all up to him. He decided to keep the money and throw away the card.

Without knowledge of Weston's background, the DSP might have concentrated on the observable behavior only and missed an opportunity to support Weston and empower him. It certainly is not a cure. However, in the future, Weston may feel more control over his impulses and aggressive behavior.

Treatment for PTSD includes taking steps to provide a safe environment and getting to know the person well. DSPs help the team identify **triggers**, or situations that cause the person fear and remembering. Spend time with the person in places that he or she enjoys, during times of the day that he or she chooses. Share success stories and successful strategies with other staff.

Supports for people with PTSD might look like the following:

- Help the person feel safe. Provide predictable schedules, order in the environment and relationships.
- Make activities or situations predictable.
- Help the person make relationships with people who are not paid to be with them. Find community recreation and leisure activities they would enjoy where they can form relationships over time.
- Keep your promises. Build trust.
- Make home a relaxing place to be. Provide privacy and space to do enjoyable activities.
- Help the person establish healthy routines.
- Help the person set goals and make plans. Make daily and/or weekly schedules.
- Help the person have fun. This should not be contingent on the person's behavior. Make fun a part of every day.
- Don't force the person to revisit the incident.
- Limit exposure to triggers.
- Avoid punishment strategies and restraints in behavior programs
- Teach coping skills. Practice and rehearse when they feel safe and comfortable.
- Help the person rehearse how to respond to triggers – count to ten or go for a walk.
- Give power and control to the person – give choices, not ultimatums.
- Encourage aerobic exercise.
- Develop a support strategy for crises. It helps to know what to do.



Other methods might include medications, but usually only if the anxiety is disabling. Desensitization and therapy may help.

Psychotic Disorders

Schizophrenia spectrum disorder and other psychotic disorders

Schizophrenia has a profound impact on people. It can impact families as well as the person who exhibits the symptoms, which include:

- Delusions, hallucinations, disorganized speech, catatonia, disorganized behavior, and flat affect.
- Chronic deterioration of functioning
- Duration that exceeds 6 months
- The absence of concurrent mood disorder, substance abuse, or general medical condition.

The prognosis is usually poor. Many people with schizophrenia will have difficulty achieving full developmental potential. Below is a personal story from a mother.

My son was diagnosed as a paranoid/disorganized schizophrenic in Sept of 1995. The first signs we saw were: he wouldn't eat, everything tasted "funny," or he thought I was putting something in the food to make it taste "funny." He wouldn't even eat McDonald's food, which he always loved. Below are the first signs that we saw over a 9 – 10 month period, before he received treatment.

1. He lost 50 lbs. during this time (6 – 7 months). I took him to our family doctor who did a series of tests, including a drug test, which all came back negative. (Started in Jan '95)

2. He then started to zone out for long periods of time (1 – 2 hours). He wouldn't blink very often or change his expression. I would ask him if anything was wrong and he'd just shake his head no. He then started to laugh during these times for no reason. (Started in May '95)

3. He would sit and stare at his hands for hours, and when I would ask him what was wrong with his hands, he would say they are different then they used to be.

4. During this entire period, his grades in school went from C's – D's to all F's. The school would call and say he would get up and walk out of class and just roam the halls.

5. Starting in June '95, he started getting very aggressive, talking to himself and laughing in his room. He would get very upset and run out of his room, down the stairs and outside. He started doing this every day. It started really going downhill from there.

6. He would never say he was hearing voices, but it was very apparent he was. God told him what numbers to play for the lottery, if I bought a ticket I would win millions. He heard other voices, I would hear him talking to them.



7. *He started talking in a language we did not understand. After research I found these to be called “word salads.” He would call me by a name that no one understood, he said I was from a different planet sent here to kill him. He told his siblings they were from his planet and they were here to protect him from me. He would come out of his room, scream at all of us in the foreign language, and tell us we all were going to die.*
8. *He would no longer watch T.V., just listened to Pink Floyd “The Wall” over and over again. In fact he broke his CD player by doing this.*
9. *He paced constantly or do just the opposite; not get out of bed for hours during the day. (He would not sleep at night.)*
10. *He started to hallucinate. The walls had bugs on them, we all looked different, my eyebrows were pointed upward and my ears had grown. He said things were moving when they were not. During this time I was totally freaking out.*

The above is a brief summary of what was happening, so many things. Much during this period I can’t remember or have blocked some of it out. I was able to admit him to the hospital by telling him we were just going to the doctor for a check-up. The psychiatrist we saw here in St. Louis only treats Schizophrenics and I had faxed him a long letter explaining Rhett’s behavior before our first visit. He had three security guards come to his office and escort Rhett to the ICU locked floor. When we arrived in the locked unit, Rhett did sign himself in “Thank God”.

Linda (nd)

Schizophrenia spectrum disorder is a disturbance that lasts at least six months and includes at least one month of active-phase symptoms. People who experience schizophrenia are not functioning with normal adaptive behavior.

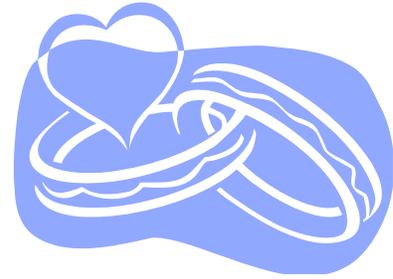
Eugen Bleuler (1857 – 1939) was a Swiss psychiatrist that invented the term schizophrenia to depict a shattered or fragmented personality. He did not mean “split personality” or multiple personality. Most people with schizophrenia spectrum disorder do not commit violent crimes.

When they are arrested, it is most often related to vagrancy or disturbing the peace. They are most often frightened or incapacitated by their symptoms rather than motivated to violence. The most life-threatening complication of schizophrenia spectrum disorder is suicide. At least 1 in 10 people with schizophrenia will die by suicide (Maxmen, *et.al.*, p.301).

The cause of schizophrenia is unknown. But the prognosis for recovery is improved if it is caught early. Those factors that contribute to a better prognosis are:

- An abrupt or acute onset
- Clear precipitating event (an event that is connected to the onset of the symptoms)
- Confusion or disorganization that later completely resolves

- Highly systematized and focused delusions that have a clear connection to the precipitating event
- Being married
- Good functioning prior to the onset
- A family history of depression or mania
- No family history of schizophrenia spectrum disorder
- A supportive family
- Low number of symptoms



People who have the diagnosis of I/DD and are not able to verbalize or use a formal communication system can be diagnosed with a psychotic disorder. Some nonverbal behaviors can indicate hallucinations or delusions (brushing unseen material off the body or nodding as if speaking). **Caution:** Every person who has delusions or hallucinations **does not** automatically carry the diagnosis of schizophrenic spectrum disorder. Hallucinations can also result from a high fever, extreme fatigue, dementia, or drug and alcohol abuse. There are several psychotic disorders that may have these symptoms.

Recall an experience you may have had, like waking up from a nightmare that was so real it took you a few minutes to calm and realize it was only a dream. Remember being convinced someone was outside your house trying to break in. You are sure you heard noises. Remember how real this was; how your heart was pounding and adrenaline pumping. Now imagine that episode in 3D and real sound. Imagine it lasting for hours or days without the ability to shut it off. This is what it can be like to have schizophrenia spectrum disorder.

The brain is sending incorrect and false messages to the person. The “computer” is not working. You can see the importance of your abilities as a staff to observe what is happening to a person who is experiencing hallucinations, delusions, and/or illusions. Being a good observer will assist in understanding this health disorder.



Understanding the true nature of schizophrenia spectrum disorder will help in focusing on the behaviors we see and coming to the correct conclusions about the person. We won't be focusing on “noncompliance” or “refusals” or “avoiding assigned tasks” but instead on understanding beyond just what we see and understanding the cause of these behaviors.

The main recognizable characteristic of schizophrenia spectrum disorder is **hallucinations**, which sometimes occur in combination with **delusions**, and **illusions**. Hallucinations are imagined sensations that seem frighteningly real and can take control of the person. Imagine what it would be like to see a strange person walk into your room, a fire in the corner of the house, or to hear a voice telling you what to do over and over. Imagine feeling strange body sensations like you are turning to stone or losing all bodily sensations. When a person with I/DD sees something, whether real or not, they may use body gestures such as pointing, staring, or covering their face in avoidance. The person may run away, strike out, or even throw something in an effort to protect themselves. Facial expressions may show fear, surprise, joy, or confusion. The person may use vocalizations such as moaning, crying, or laughing. A person you support

may not have the complex language skills to explain what they are experiencing. However, if you know the person well, you will be able to identify sad, happy, angry, or fear sounds.

A person may also experience **delusions**. A delusion is a belief. It is not a sensory misinterpretation. The individual is sure he is dying, or is convinced people are reading his mind, or believes that the TV, radio, or a song is speaking directly to him. Delusions are more reality based in that real people and events are being misread, as opposed to hallucinations, where the people and events are imaginary.

To the individual with schizophrenia spectrum disorder, **illusions** may cause harmless everyday objects to appear bizarre or even life threatening. For example, a piece of rope becomes a snake or a stuffed animal suddenly appears to come to life.

Hallucinations may occur in stages and it is helpful to know the signs to watch for. As your experience with the person you support grows, you will become better at understanding what is occurring and you will become more effective at intervening.

Stage 1 – Comforting. The person begins to be anxious and nervous, appears unsettled, and may be experiencing feelings of loneliness or guilt. The DSP may be able to relieve anxiety just by being there and providing quiet activities and closeness.

Stage 2 – Condemning. The individual becomes more anxious. The hallucination becomes more powerful and the person begins to experience voices and images. The person becomes afraid, or wants to withdraw from everyone. The person becomes more distractible. Your efforts to comfort them become less effective. Their heart rate, respiration, and blood pressure may increase.

Stage 3 – Controlling. The person is now experiencing extreme anxiety. The voices and images come and go. The voices may be saying nice or friendly things. The voices become stronger and more controlling as the “real” environment becomes less real and the hallucinations become a substitute for reality. The person may have very brief or no attention span. The person may start to sweat.

Stage 4 – Conquering. The voices are now giving orders and are not friendly. The hallucination may become more complex by including illusions and delusions. They may last for hours or days and the person may consider not wanting to live. The person may become irritable, confused, and violent.

Hallucinations may be very tiring. When the episode ends, it is better not to try to get the person right back to everyday routines but instead offer rest and quiet. The goal is to stop the hallucination from reaching stage 4. If no attempts are made, the hallucination will last longer and be more severe.

Support during Hallucinations

- Become someone to trust. Be there to help.
- Be consistent. Show acceptance. Be calm and do not show fear or anxiety.
- Be a good listener. Your body language will be readily observed.
- Be a good detective. Look and listen for the “messages” in the person’s behavior.
- Remember and record. The more detailed description of the episode the better. Record what the person did and what they said.
- **DO NOT LEAVE THE PERSON ALONE** if they are hallucinating.
- Do not argue about the person’s reality – to them it is real.



Mood Disorders

Mood disorder is the overall category for individuals whose predominant symptom is either a pathological (unreasonable) low – such as depression (dysthymia) or a pathological high – such as bipolar disorder.

Major Depressive Disorder

The acronym **DEPRESSING** can be used to help remember the criteria for depression:

- D – depression (sadness)
- E – energy (loss of)
- P – pleasure (diminished interest)
- R – retardation (psychomotor slowing or agitation)
- E – eating (changes in weight or appetite)
- S – suicide (recurrent thoughts of death)
- S – sleep (insomnia or hypersomnia)
- I – indecisive (poor concentration)
- N – negative thinking (worthlessness, hopelessness)
- G – guilt (inappropriate)



To be diagnosed with major depressive disorder, a person must display at least five of these major symptoms during the same two-week period and represent a change from previous functioning.

A subtype of major depressive disorder is **psychotic depression**. In addition to the symptoms listed above, the person diagnosed with this disorder must also display delusions, hallucinations, and/or anxiety symptoms.

Dysthymia

Although symptoms of dysthymia are similar to those of major depression, they are less severe. People with dysthymia feel “down in the dumps” most of the time, but are not as severely depressed as those with major depression. Dysthymia tends to persist more or less continuously in a milder, but nagging, form over a period of many years, sometimes over a lifetime. People diagnosed with this disorder are perceived as excessively whining and complaining. Following are some of the traits of dysthymia:

- Depressed mood
- Suicidal ideation or attempts/vegetative symptoms
- Anxiety and other neurotic symptoms
- Initial insomnia and general sleep disturbance
- Behavioral problems such as aggressiveness, temper tantrums, and irritability

Mood disorders are often undiagnosed or misdiagnosed in people with I/DD. It is difficult to diagnose depression reliably in individuals with ID, particularly in those with severe ID. Some criteria such as feelings of worthlessness or guilt or suicide cannot be assessed in individuals with limited understanding or limited adaptive skills. The symptoms exhibited may differ from those exhibited by the general population. People with limited communication skills show a variety of symptoms. In addition to the symptoms listed above, people with I/DD **may** display major depressive disorder with challenging and aggressive type behavior.

Bipolar Mood Disorder (BMD)

In the DSM-5, Bipolar Mood Disorder has been divided into Bipolar I and Bipolar II. Bipolar I is more akin to the classic manic-depressive disorder. By definition, a person with bipolar disorder displays mania with or without a period of depression. An elevated, euphoric (joyful or excited), expansive, or irritable mood is the main feature of mania. People with mania may be hyperactive, highly distractible, and grandiose. They may experience flight of ideas, pressured speech, and a diminished need for sleep.

Lydia is attending a small college. For the past five days she has gone without any sleep whatsoever and she has spent this time in a heightened state of activity, which she describes as “out of control.” For the most part, her behavior is characterized by strange and grandiose ideas. Some of Lydia’s bizarre thinking centers on the political, such as believing that she had somehow switched souls with the senior Senator from her state. From what she believed were his thoughts and memories, she developed six theories of government that would allow her to single-handedly save the world from nuclear destruction. Lydia often worries that she will forget some of her thoughts and has begun writing notes to herself everywhere: in her notebooks, on her computer, even on the walls of her dormitory. Lydia has experienced two previous episodes of wild and bizarre behavior similar to what she is experiencing now; both alternated with periods of intense



depression. When she was in the depressed state, she could not bring herself to attend classes or any campus activities. She suffered from insomnia, poor appetite, and difficulty concentrating. At the lowest points of the depressive side of her disorder, Lydia contemplated suicide.

Bipolar disorders manic episodes are recognized by the presence of:

- A rapid speech pattern, known as **pressured speech**
- Rapid flight of ideas
- An inflated sense of self-esteem
- Acting impulsively
- Going for days without sleep
- In extreme cases, hallucinations

Depression often, but not always, follows the manic episode. The depressed person often has a faulty perception of reality. Events that simply cause a downcast mood in most of us will have a much more profound impact on the depressed person. Bipolar depression can destroy the person's ability to find pleasure in the everyday activities enjoyed by others. The depressed person may lose their appetite, display difficulty in concentrating, have difficulty making decisions, and appear to be indifferent to the world around them.

Depression in people with I/DD is often associated with poor social skills and limited social support. Aggression, self-injury, and property destruction occur frequently in people with I/DD and mood disorders. Mood disorders among people with I/DD are more often atypical, chronic or rapid cycling (four or more episodes per year). This may be due to an increased incidence of central nervous system dysfunction such as a seizure disorder. (EPICS, 2001)

Prevalence of mood disorders in persons with I/DD

The Dual Diagnosis Curriculum through Kansas University Center on Developmental Disabilities (2002) estimated that as many as one in ten people with developmental disabilities experience depression and as many as one in twenty experience a manic episode. People with I/DD experience all types of mental health disorders, including mood disorders three to four times as often as the general public.

We must be careful to avoid mistakes of **over**-diagnosing depression, using broad labels and medications when a person is merely experiencing personal frustration, disappointment, or sadness. When something happens that could make any of us sad, such as a death in the family – use of antidepressants can actually **delay** the emotional processing necessary to regain our emotional balance. The cause of severe sadness or depression can be a lack of an interesting environment or engaging activities.



The frequency and diagnosis of depression among people with ID is a challenging issue. There are several reasons for this, the most important being the differences in the symptoms of

depression found in people with I/DD and the mental health professionals' lack of familiarity with the concept of depression among this population.

The symptoms of depression are believed to be different when a person has a lower intellectual functioning. The differences in depression symptoms are strongly influenced by the person's ability to express him or herself verbally. In general, the ability to verbally express grief, sadness, and hopelessness is found only among people with less severe disabilities. For people with more severely impaired intellectual functioning, the clinician must often rely on behavioral clues other than what the person says. Typically, what is more likely to be observed are "masked" symptoms of depression, such as agitation, irritability, mood swings, eating, and sleep disturbances.

The following two tables are examples of a "system", or checklist, of symptoms you might observe in the person with an intellectual disability who is experiencing a manic and depressive episode. In Table 2, the first column lists the traits of a manic episode that would be present in a person who does not have an intellectual disability.

TABLE 2. DSM-5: Diagnostic Criteria for a Manic Episode of Bipolar I Disorder with behavioral equivalents in Individuals with Intellectual Disability.		
Abnormally and persistently elevated, expansive, or irritable mood, elevated goal-driven and high-energy activity lasting at least 1 week and present most of the day. During the period of mood disturbance three or more of the following symptoms are present to a significant degree and are considered a noticeable change from usual behavior.		
DSM-5 Criteria	Observed Equivalents in Individuals With Intellectual Disability (what you see)	Objective Behaviors Which might be monitored (document)
Inflated self-esteem/grandiosity	Thought content may center on mastery of daily living skills	Measure rates of smiling and laughing, measure inappropriate remarks
Decreased need for sleep	Increased maladaptive behavior at bedtime	Monitor sleep pattern, use 30 minute intervals
More talkative/ pressured speech	Increased frequency of vocalization regardless of whether the person is verbal	Measure rates of swearing, singing, screaming
Flight of fancy, thoughts, ideas	Disorganized speech	
Distractibility	Decrease in work performance	Use work performance data
Increased goal-directed activity psychomotor agitation	Aggressive behavior and negativism may be present	Measure aggressions, requests, refusals per week, pacing
Excessive involvement in pleasurable activities	Teasing behavior, fondling others, public masturbating	Measure when the behavior occurs

The first column in Table 3 lists the traits of depression that would be observed in a person who does not have an intellectual disability. **The observed equivalents in Individuals with Intellectual Disability** lists similar, but not identical, behaviors you might observe (see) in a person who has I/DD. Finally, the **Objective Behaviors Which Might be Monitored** identifies behaviors staff might be asked to "measure." The data staff collect will help in assessment.

TABLE 3. DSM-5: Diagnostic criteria for Major Depression and Behavioral Equivalents in Individuals with Intellectual Disabilities. 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 a (1) depressed mood or (2) loss of interest or pleasure.

DSM-5 Criteria	Objective Behavior in Persons with Intellectual Disability (what you see)	Objective behaviors which might be monitored (document)
Depressed mood, irritable mood in children and adolescents	Apathetic facial expression with lack of emotion re-activity	Measure rates of smiling, responses to preferred activities, crying episodes
Generalized decrease in interest or pleasure by self-report or observed apathy	Withdrawal, lack of reinforcers	Measure time spent in room
Significant decrease or increase in appetite or weight	Agitation may present as self-injurious behavior or aggression, pacing	Measure meal refusals, change in weight
Insomnia or hypersomnia	Change in total sleep time	Use sleep chart to record sleep
Psychomotor activity or retardation	Agitation may present as SIB or aggression	Time spent in bed spontaneous verbalizing
Fatigue or loss of energy	Retardation may present as decreased energy, passivity	
Feeling of worthlessness/inappropriate guilt	Statements such as "I'm retarded"	Requires expressive language to determine if symptom is present
Decreased concentration/indecisiveness or diminished spontaneous ability to think	Change in workshop performance	Use workshop performance data
Recurrent thoughts of death/suicide ideation	Perseveration of the deaths of family members and preoccupation with funerals	Requires expressive language to determine if symptom is present

Treatment for Mood Disorders

Intervention strategies for people with I/DD and mood disorders can be very productive. Treatment may target biological factors, psychological vulnerability, and/or environmental stressors. Interventions are often multifaceted and include more than one of these strategies in addition to daily support responding to signs and symptoms.

1) Strategies can be aimed at reducing the signs and symptoms of mood disorders (biophysical).

Medications – antidepressants and mood stabilizers are commonly prescribed to treat mood disorders. It is important to know that there are many types of medications. They each act on neurotransmitters in the brain differently. If one medication does not work, another medication might be effective. Medications may be the sole intervention or be combined with other approaches. Some medications take a few days to a few weeks for the full benefits to be seen. When signs and symptoms are no longer present, the mental health professional may consider a medication reduction. Once again, the data collected and often reported by DSPs are critical in these decisions.

Diet – It is known that caloric intake, vitamin and mineral intake, food allergies, and food choices can affect mood and behavior. Poor diet can lead to fatigue, weight gain or loss. These changes can be signs and symptoms of mood disorders. While there are many

claims about specific foods to choose or avoid, casual relationships for specific foods are often not proven when the methods of the research are examined closely. There are some dietary restrictions for some medications used to treat mood disorders.



Exercise – regular exercise should be included in the development of a treatment plan. Regular exercise often assists with the treatment of depression.

2). Strategies can be aimed at building positive mental health habits and decreasing vulnerability to future episodes (psychological or environmental). The previous strategies focus on biophysical causes of mood disorders and not with any other underlying causes. Treatment plans include strategies involving psychotherapy, counseling, skill building and environmental modifications to provide emotional support and reduce stressors.

Most treatment plans include individualized skill building components to help the person build self-confidence, develop or strengthen social networks, teach social skills, and decrease conflict. Increasing activity levels is often a critical element. Most people successfully deal with sadness and depression through other activities that are distracting and uplifting.

3). As a DSP, your daily interactions are critical to the treatment of mood disorders in people with I/DD. In daily interactions you should:

- Adjust your expectations to be realistic and provide additional support when needed.
- Do not take the person’s behavior or statements personally.
- Structure the environment and supports to keep the person safe.
- Do not reinforce signs or symptoms, but don’t argue or confront the person’s delusions.

The Dual Diagnosis Curriculum through Kansas University Center for Developmental Disabilities (2002) recommends the following daily supports for a person with I/DD experiencing a **depressive and manic episode**.

Sign or Symptom	Support Strategies for Depressive Episode
Diminished interest	Offer a variety of preferred activities. Reinforce participation with positive statements, but do not require sustained involvement. If necessary have a plan for taking the person home, if they tire of an activity and need to go home. After an initial refusal, wait and ask again.
Weight loss	Prepare preferred foods and have it available throughout the day. Provide small amounts and reinforce any effort to eat. Make the eating environment pleasant.
Insomnia	Encourage a regular sleep schedule but don’t force the person to go to bed at a certain time. Help the person establish a bedtime ritual and limit naps. Reduce intake of alcohol, nicotine, caffeine, and other stimulants. Exercise but not late at night. Don’t go to bed too early.

Physical agitation	Find constructive ways to use energy. Allow the person an escape from activities that cause agitation.
Fatigue	Plan brief activities and give the option to leave when tired. Adjust expectations to match the level of energy. Gentle insistence, but don't push to take on too much too soon.
Feelings of worthlessness	Point out strengths, stay positive, provide praise (don't overdo). Make small frequent opportunities for the person to succeed. Avoid too many demands. Gently help them to be more realistic if they express guilt over things that were out of their control or not their fault.
Diminished ability to think	Speak slowly, quietly, one step at a time. Repeat concerns. Provide limited number of options when giving choices (2-3 only).
Weight gain	Provide healthy snacks/low calorie substitutes for favorite foods. Encourage exercise.
Thoughts of death	Don't ignore or reinforce this behavior and seek advice.

The following supports are recommended for the person experiencing a **manic episode**.

Sign or Symptom	Support Strategies for Manic Episodes
Elevated, expansive mood	Redirect the person to positive activities.
Irritable mood	Encourage in a supportive manner. Avoid criticism. Ignore.
Physical agitation	Find constructive ways to use energy. Allow the person an escape from activities that cause agitation.
Distractibility	Make expectations clear and realistic. Use frequent prompts, small steps. Minimize distractions in the environment.
Decreased need for sleep	Provide activities that will not disturb roommates. Reduce intake of nicotine, caffeine, and other stimulants.
Excessive involvement in pleasurable activities	Ensure the person is safe and safeguard his financial resources. May need to work with the team to limit dangerous or expensive activities such as long-distance calls, internet shopping.
More talkative	Go to settings where talking will not cause a problem.
Inflated self-esteem	Do not argue or make fun of delusions. Make sure the individual doesn't get into trouble for this behavior.
Flight of ideas	Focus on conversation. Don't expect rational discussion.

Attention-Deficit/Hyperactivity Disorder (ADHD)

ADHD features include hyperactivity, short attention span, and impulsivity that are developmentally inappropriate and endure at least six months. Typically, this condition is recognized before or during the early elementary school years. Symptoms of ADHD may disappear at puberty or continue into adulthood. About half of children diagnosed with ADHD have a good outcome. However, if childhood ADHD is severe, the chances of it persisting into adulthood are high. Approximately 50-60% of children with ADHD continue to have symptoms

into adulthood (Maxmen, et al., 2003). Adult symptoms include inattention, disorganization, and failure to finish things. In adults, ADHD affects the person's quality of life due to difficulties on the job and in relationships. ADHD contributes to an increase in co-occurrences of oppositional defiant disorder, conduct disorder, bipolar disorder, depression and anxiety and sleep disturbances. ADHD in adulthood has a high connection to anxiety and depression (Yang, Tai, Yang, & Gau, 2013).

Mr. Johnson is concerned that his inability to provide structure for his son and daughter might jeopardize his custody battle with his former wife. He is currently unemployed but did, at one time, work as a seasonal construction worker. On most days, he sleeps late and has difficulty getting his kids to their extra activities on time. He has trouble concentrating and is very distractible. He almost started a fire near his house when he was grilling. He forgot about the grill because he got distracted with his flower garden and started to gather tools to fix the front door.

Approximately 75% of adults diagnosed with ADHD have one or more co-morbid conditions (Barkley & Gordon, 2002). It is generally best practice to treat the co-morbid condition that is causing the severe disruption in the person's life along with treatment for ADHD. For instance, if the person also has depression, the physician will prescribe a combination of drugs for ADHD and depression. Other types of treatment include:

- Psychosocial treatment – teaching skills such as time management, or organizational skills, which are specific to the needs of the individual. It may include education on ADHD and how it can affect a person's life.
- Cognitive behavioral therapy – teaching self-management such as self-talk. Group or individual therapy may be used.
- Medications – generally stimulants are prescribed.
- Family counseling – with help from all members of the family, the person's success is greatly increased. Counseling usually concentrates on interactions within relationships.



The debate about ADHD being a viable diagnosis for people with I/DD has been ongoing. However, researchers conclude that it can be (Neece, Baker, Crnic, & Blacher, 2013).

Summary

This chapter has concentrated on four categories of mental health disorders. Each category has specific symptoms and criteria for diagnosis. People with I/DD will have the same symptoms but express them in behavior that is not equivalent (the same) as what is displayed in the general population. Diagnostic equivalents are provided in the DM-ID manual. Each person with dual diagnosis will need supports to cope with the mental health disorder. The person's team will develop individualized programs that address his/her specific needs.

Chapter 4 Study Questions

True or False

- _____ 1. Personality disorders are an enduring, long-term pattern of dysfunctional behaviors.
- _____ 2. Personality refers to a person's character traits.
- _____ 3. Personality is reflected in the way a person acts and reacts to others.
- _____ 4. Personality is formed over a lifetime of experiences.
- _____ 5. A person with schizotypal personality disorder may display eccentric beliefs.
- _____ 6. People with a narcissistic personality disorder are hypersensitive to criticism.
- _____ 7. Obsessive-Compulsive Personality Disorder and Obsessive-Compulsive disorder are the same disorder.
- _____ 8. Treatment for personality disorders usually relies on psychological and behavioral interventions.
- _____ 9. Generalized Anxiety Disorder is the most common anxiety disorder in the general population.
- _____ 10. People with I/DD experience mood disorders three to four times more than the general population.
- _____ 11. People with Obsessive-Compulsive Disorders are unaware of the effects of their behavior on their life.
- _____ 12. The main recognizable characteristic of schizophrenia is hallucinations, which sometimes occur in combination with delusions and illusions.
- _____ 13. It is best not to try to intervene when someone is experiencing a hallucination.
- _____ 14. While major depression tends to occur in separate episodes for a limited amount of time, dysthymia tends to persist more or less continuously in a milder, but nagging, form over a period of many years, sometimes over a lifetime.
15. People with paranoid personality disorder have a tendency to:
16. Name three features of the schizoid personality disorder:
17. List three methods of support for people who are emotionally distressed or have high anxiety.
18. Why is it difficult to diagnose a mood disorder in a person with I/DD?
19. Describe symptoms of Bipolar disorder manic episodes (Bipolar I & II).
20. List masked symptoms of depression in people with I/DD.
21. What should be the DSP's reaction to the symptom of inflated self-esteem in a person experiencing a manic episode?
22. What might contribute to a phobia (fear) for a person with I/DD?

22. Give three examples of typical behaviors of a person diagnosed with OCD (Obsessive-Compulsive Disorder)?
23. How might a person dually diagnosed with PTSD express their fear?
24. List four strategies that are considered best practice for supporting individuals who experience Post-Traumatic Stress Disorder.
25. What is one thing a DSP can do when a person displays feelings of worthlessness (depression and a manic episode)?
26. It is difficult to diagnose personality disorders in people with I/DD because (more than one answer may be correct)
- The diagnosis requires subjective information about thoughts and emotions.
 - People with I/DD have personalities shaped by their diagnosis
 - The diagnosis relies on experiences with relationships, which is usually lacking in a person with I/DD's life.
 - People with I/DD usually have limited understanding of abstract concepts such as intimidation, manipulation, remorse, or empathy.
27. A person with Generalized Anxiety Disorder displays (circle all that apply):
- Worry about future danger
 - Avoid close relationships
 - Worry when there is no real danger
 - Person anticipates future danger
 - Manipulates others
 - Lacks empathy
28. A person who is dually diagnosed and has Generalized Anxiety Disorder may display anxiety by (circle all that apply):
- Sadness
 - Irritability
 - Refusal to do daily routines
 - Eccentric or peculiar beliefs
 - Pacing
29. What are the criteria for the diagnosis of depression (use the acronym DEPRESSING).
30. To be diagnosed with a phobia, the person must avoid the _____, _____, or _____ with extreme _____ when it cannot be _____. The distress must interfere with _____, _____, _____, or _____.

31. _____ is a disturbance that lasts at least _____ and includes at least _____ of active-phase symptoms of the following: delusions, hallucinations, disorganized speech, disorganized or catatonic behavior.
32. Which of the following statements about schizophrenia is true?
- a) Persons with schizophrenia are always dangerous to others.
 - b) Schizophrenia is caused by poor parenting.
 - c) Persons with schizophrenia have a split personality.
 - d) It is possible for a person to have a psychotic disorder even though the person does not speak or use a formal communication system.
 - e) Every person who has a hallucination or delusion has schizophrenia.
33. _____ are imagined sensations that seem frighteningly real and can take control of the person.
34. Explain the difference between hallucination, delusion, and illusion.
35. List at least three ways to support someone who is experiencing a hallucination.

Chapter 5: Services

Objectives

Upon successful completion of this lesson, staff members will be able to:

- Compare medical model services to person-centered model services for people with dual diagnosis
- List various roles/perspectives of person-centered team members
- Define baseline
- Describe behavioral indicators that signal a need for referral
- List information used in background reporting

In serving people with dual diagnosis, one of the greatest challenges for clinicians and service providers is to accommodate the dual nature. The combination of I/DD and a mental health disorder presents challenges for assessment because of the reliance on self-reporting to make a typical diagnosis. Many people with I/DD cannot tell others their symptoms. The individual's limited understanding of social and relationship concepts also makes it difficult to assess mental health disorders in persons with I/DD. Treatment or support services require personnel that are trained in I/DD but also mental health disorders. This combination of training is specialized. Most higher education programs specialize in one or the other but rarely in the combination of both. This dual nature requires understanding on how the mental health disorder affects I/DD and how I/DD affects the mental health disorder.

Treatment includes a collection of highly specialized, individualized programs that focus on the long-term management of both disorders. Long-term care may include residential placement, counseling, day support programs, vocational rehabilitation and respite care for families. Crises management requires emergency intervention, specialized respite care, hospitalization, and transition services.

In the past, these types of services were provided in large hospital-type settings where clinical and psychological treatments were directly supervised by psychiatrists and psychologists. With the movement to more community-based services provided by private agencies or non-profits, multiple modes of service delivery of services are required. Community-based services require the integration of behavioral intervention, medical, and psychiatric services. This results in complex case management and coordination of community resources, prevention and outreach, patient advocacy, emergency and crisis care, hospitalization, discharge planning and coordination, and residential, family, and in-home services.

Cities are better suited to provide services than rural areas. Even though communities may not have the services from specialized agencies, person-centered teams can build individualized treatment plans or person-centered plans that fit the specific needs of the individual.

Developing an individualized, person-centered plan for a person with dual diagnosis may be complex. To serve people with dual diagnosis, the following are needed:

- Assessment
- Multiple modes of treatment
- Advocacy
- Integration
- Ongoing quality assurance
- Collaboration among professionals and service agencies

Need for referral?

Before the team decides to make a referral to a mental health professional (clinical psychologist or psychiatrist), the following considerations need to be reviewed:

- Do symptoms occur in most or all settings?
- Is there little change with medical or appropriate behavioral support?
- Have there been changes in sleep, appetite, or sexual function?
- Have hallucinations been observed?
- Have strong autonomic symptoms (flushing, sweating, high pulse rate, tremors) been observed in conjunction with hallucinations?
- Is the person in physical pain?

The answers to these questions will assist the clinician when referral occurs.

Collaboration among Professionals – Person-Centered Teams

Person-centered planning, developing plans based on the capacities of the person with I/DD, can be reviewed in the *Team Planning, Assessment and Setting Goals* and *Achieving Personal Outcomes* of the North Dakota Community Staff Training curriculum. Developing person-centered plans for individuals with dual diagnosis requires the team to be interdisciplinary and cross-system. This requires knowledge sharing between team members from the medical profession and those with more experience in the person-centered supports. The desired quality life for the person supported has to be the focus.

The table below compares the medical and person-centered models.

Medical Model	Person-Centered Model
Disability is seen as something that could hold a person back.	Disability is only a difference like gender or race.
Disability is a personal problem.	Having a disability is neither good nor bad, it is just part of who you are.
The person needs a cure or something to make them less disabled.	Problems come from a person with a disability trying to function in an inaccessible society.
Only professionals can help the person fit in and be made better.	The person, an advocate, or someone who wants to help can make the changes needed.

In a typical team there might be a psychiatrist, direct support professionals (DSP), Program Coordinator/Internal Case Manager/QDDP, family members, psychologists/behavior analyst, and of course, most importantly – the individual who has the diagnosis of I/DD and mental health disorder. The skills and experiences of all will be varied. However, all should come to the

planning table with the goal of educating each other to provide effective services. This planning should have the outcome of an improved quality of life for the individual/family.



To come together as a team requires that each member understand the perspective and background in training and experience of the other. What might a typical team member bring?

Person with Dual Diagnosis: This person may come to the team with support from family but may be feeling that most of the people on the team are strangers or only acquaintances. Others on the team talk a lot about things this person might not be familiar with and maybe say things that are negative. Depending on his/her self-advocacy skills, the person may not speak up during the formal meeting.

Direct Support Professional (DSP): This team member understands how the person with the mental health disorder lives from day-to-day. DSPs see the behaviors and evidences of the disorder across environments. However, they may not have worked or cared for this person for a long period of time so they may not know their history. They do have a good understanding of how the person's symptoms have affected their daily life.

Psychiatrist: This person is trained as a physician with several years of study and practice before being licensed. Typically psychiatry looks at mental health disorders as psychopathology (impairment and distress) with intervention that may include medications, cognitive behavioral therapies, family support, and shared decision-making. The psychiatrist considers the prognosis (course or likely outcome) of the disorder and usually bases this on experience and research on that disorder. They rely on those close to the person to give accurate information regarding behavior and history (medical, developmental, etc.).

Family: They know the person intimately and understand the intrinsic motivations of the person. They know the history of the person and how the disabilities, both cognitive and mental health, have affected the development of their family member. They know the strengths and weaknesses of the individual. They may feel intimidated by professionals and the team process. They are committed to the individual and will be one constant member of the team.

Program Coordinator/Internal Case Manager/QDDP: This person is responsible to coordinate the person-centered plan and navigate the service system to obtain the services and supports. This person has the complex job of monitoring the implementation of the plan across environments, agencies, and people to make sure quality is upheld. He/she carries the responsibility of making sure other team members are doing what they said they would do.

Psychologist/Behavior Analyst: This person is typically involved to help the team deal with challenging behavior that is interfering with the person’s continued growth. Typically this behavior is hindering the person’s ability to learn and remain in the community or with the general population. His/her training in applied behavior analysis will assist the team to implement specific methods to support the person’s behavior. This professional may also be involved with counseling to help the person “sort out” feelings that may be motivating challenging behavior.

This typical group not only has the challenge of developing a plan for long-term treatment of the mental illness but also for becoming a “team” that works together to support the person. Teams serving people with dual diagnosis have to educate themselves on how the mental health disorder affects the intellectual disability and how the intellectual disability affects the mental health disorder. This requires diligence and creativity.

Assessment

Every team needs to have accurate assessment data to determine the course of the person-centered plan. This might include behavioral baseline data collected from the residential and vocational program staff. Other data might include interviews and historical information from the family and medical records. It should also include interview results from the person supported.

From the psychiatrist’s point of view, the assessment is a “time-limited, formal process that collects information from many sources in order to reach a diagnosis, to make a prognosis, to render a bio-psychosocial formulation, and to determine treatment” (Maxmen, 2009, p. 21). From the psychologist/behavior analyst’s perspective, the assessment phase should take baseline data on the current challenging behavior and/or symptoms of the mental disorder. **Baseline data** is the initial data with which future data can be compared. For ongoing measurement of how well the treatment/person-centered plan is progressing, the Program Coordinator/Internal Case Manager/QDDP and entire team will need to know, “What was the person doing before we started the plan?” For example:

Before the plan was implemented, Chris was refusing to eat, and when he did eat, it was in his room without anyone watching him. Now – after three months of implementing the methods in the behavior plan, training of staff in how to deal with the specific mental disorder, and three months of one-to-one counseling, Chris is now eating at the dining room table with at least three or four people around him for every meal.

Baseline data will be used by the psychiatrist to make a diagnosis but will also be used to determine progress. All team members, particularly those taking baseline data, must observe and record objectively and accurately. Reports from DSPs will be used to identify the challenging behavior. The importance of reporting accurately and objectively and how to do this is discussed in *Writing Behavioral Objectives and Measuring Behavior*, *Positive Behavior Supports* and *Designing and Implementing Positive Behavior Supports* modules in the North Dakota Community Staff Training curriculum.

The family and those who know the person will be asked to give information related to events that have occurred in the past such as developmental history, family dynamics, or recent changes in appetite, sleeping pattern, weight gain or loss. The family and DSPs should also be prepared to share the strengths, desires, capacities and goals the person has for their life. Person-centered planning is centered on gifts and capacities. To ignore this in the assessment phase may result in a deficit-oriented plan, with a focus on “fixing” the person.

Background information should answer the following questions:

- Description of the presenting problem:
 - What is happening?
 - Why has this referral been made?
 - What problems have occurred because of the person’s behavior?
 - How long has this been occurring?
- What may have caused the change? Did any physical or emotional event cause a change in the person or their environment?
- Background in the diagnosis of I/DD
- What is the person’s present lifestyle (friends, where do they live, daily schedule, recreation, sleep and eating pattern)? What does life look like when they are doing well?
- Any medical problems?
- Any abuse of alcohol or drugs?
- Past mental health history?
- What has changed? The person once was ____ but now is ____.

Depending on the person’s ability to communicate, these questions should also be asked of the person supported. It is very important to avoid having professionals make all the judgments. If communication is a barrier, assist the professional in finding ways to directly interview the person. Those who know the person and currently communicate with him/her should make every effort to help the person convey their information with professionals.

Summary

Person-centered teams are challenged to keep the person’s quality of life at the center of all planning. Each team member comes with various perspectives and expertise but the person with the dual diagnosis needs members who will be open to new ideas and focus on the person’s capacities/strengths. Team members need to answer important questions before a referral is made and be prepared to gather baseline data to determine the effectiveness of the plan. The service that results from team planning should be based on how the person is affected by the mental health disorder and by the intellectual disability.

Chapter 5 Study Questions

True or false

- _____ 1. The medical model relies solely on professionals to help the person with dual diagnosis.
- _____ 2. Person-centered planning uses the capacities of a person with dual diagnosis to plan.
- _____ 3. Person-centered plans require teams to share knowledge.
- _____ 4. The medical model focuses on the capacities of the person with dual diagnosis to develop a treatment plan.

5. Define baseline data.

6. Circle those data that would be considered baseline.

- a) Sleep pattern before intervention.
- b) Response to medication
- c) Eating habits before the intervention
- d) Incidents of challenging behavior after medication was started.
- e) Incidents of challenging behavior before the medication was started.
- f) Incidents of refusals to do activities of daily living before the intervention.

7. List at least two perspectives/attitudes/concerns each team member will bring or have at the planning meeting.

- a) Psychologist/Behavior Analyst
- b) Direct Support Professional
- c) Psychiatrist
- d) Family member
- e) Person supported
- f) Program Coordinator/Internal Case Manager/QDDP

8. List the questions the team should ask before a referral to a psychiatrist or clinical psychologist is made.

9. List at least five questions that should be asked when gathering background information.

Chapter 6 – Treatment

Objectives

Upon successful completion of this lesson, staff members will be able to:

- Describe how medications, behavioral support, and cognitive therapy are used in treatment plans.
- Describe best practices in treatment of mental health disorders for people with dual diagnosis.
- Define how cognitive dysfunction/deficits affect treatment selection.
- List typical treatments for mental health disorders
- Describe the general actions medications do for people with mental health disorders.

Treatment in the General Population

Generally treatment for people **without** I/DD who have a mental health disorder involves these options:

- Psychotherapy
- Medication
- Peer Support Groups

Psychotherapy includes several intervention types, but most are considered Cognitive Behavior Therapies. They are all based on modifying thought patterns and associated behaviors. Some examples are:

- Dialectical Behavior Therapy
- Psychoanalysis
- Systemic therapy or family therapy
- Motivational Interviewing

Medications do not cure mental health disorders. However, they can often significantly improve symptoms and help promote recovery. They are recognized as first-line treatment for most people in the general public. Some of the most commonly used are antidepressants, anti-anxiety, anti-psychotic, mood stabilizing, and stimulant medications. Some people may only need to take medications for a short time. People with disorders like schizophrenia or bipolar disorder may need medication long term.

Some side effects of medications for mental health disorders are:

- Weight gain
- Sexual problems
- Sleep disturbances
- Chemical dependency
- Headaches, nausea, and dizziness

Treatment for People with Dual Diagnosis

One might assume that treatment for people without I/DD would also work for people who have dual diagnosis. However, only recently is it acceptable to believe that people with I/DD can actually have a co-occurring mental health disorder. This belief has led to limited access to treatment generally available to the public. Medications as a treatment for people with I/DD have been over- or misused.



The 1972 court case, *Wyatt v. Stickney*, about the deplorable conditions in Alabama's state institution, brought to light the excessive and unnecessary use of medications. In 1980, *Clites v. Iowa*, an individual with I/DD was awarded damages because he developed tardive dyskinesia from long-term use of anti-psychotic drugs.

From these legal cases and public scrutiny, a change in attitude occurred. Services moved from the medical model of treating disability (along with dual diagnosis) to the habilitation model. According to Gualitieri (1988), this created a gap or a separation from psychiatry for people with dual diagnosis. Instead of using the treatments the general population has available, more regulations on the use of medication were created. These regulations or standards viewed the use of medications as "chemical restraints." Agencies supporting people who needed treatment for a mental health disorder were required to be more specific in defining the challenging behavior. A data collection system to justify the use of the medication was also required. Regulations specifically required that:

- Active treatment (behavior support plan) must accompany any use of a psychotropic drug used to control behavior.
- The team must attempt drug reduction along with the advice of a physician.
- The team must monitor side effects of the drug.
- Teams must know and define the targeted behaviors specifically.

More recently the focus of support for people with dual diagnosis has shifted to quality of life issues, which includes best practices in diagnosis and treatment. These practices are based on the functional assessment process. The medical variables, environmental factors, and social factors are examined. Services are based on an outcome-based quality model.

Medications continue to be the primary method of treatment for people with dual diagnosis. However, medications should not be the only intervention. A person with diabetes will not survive with just insulin if they have an inadequate diet, or poor exercise, or poor eating habits. The right medication at the right time can have a positive effect on treatment of mental health disorders. The wrong medication can also have dramatic, even lethal effects.

A study conducted by Singh & Matson (2009) identified the rationale used to prescribe medications to individuals who had been prescribed medication for challenging behavior. The three primary approaches were:



- **Target symptom approach** – If the cause is not identified, the behavior can still be treated directly without knowing the underlying cause. For example, severe rage is responsive to certain medications used for other psychiatric conditions.
- **Primary illness approach** – If the mental health disorder that underlies the target behavior can be identified, then the disorder may be responsive to medication treatment. For example, if aggression is the behavioral indicator of the underlying psychosis or mood disorder, then aggression will decrease when the psychosis or mood disorder is treated with medication.
- **Behavioral-pharmacological hypothesis approach** – For example, aggression (e.g., self-injury) may occur as a result of a chemical imbalance in the body and using a medication to restore this imbalance will likely reduce or eliminate this type of aggression.

In prescribing medication for the psychiatric disorders, physicians used the primary illness approach with 75 of the 87 individuals (86%). They used the target symptom approach with 9 individuals (10%), and used no apparent rationale with the remaining 3 individuals (4%). The behavioral-pharmacological approach was not used at all. Limitations to this study were a small sample and assessment and diagnosis was not examined.

When psychiatrists choose medications, they do so on the basis of a drug's action on neurotransmitter systems in the brain. When several medications are likely to be equally effective, the medication choice is often based on side effects. For instance; valproate used for treatment of epilepsy has also shown (through common use) to be effective for bipolar disorder.

It is the responsibility of team members to know the medication. This information should include the purpose or desired effect of the medication and side effects. Staff should be informed on the response time as well. When medication dosages are changed, or when medications are added or discontinued, the DSP must remember (as well as the PC/ICM/QDDP) to observe and report behavioral changes. Accurate data will help the team make more accurate decisions.

Cognitive Behavioral Therapy

In previous chapters, you read about how past attitudes assumed people with I/DD were not capable of experiencing a mental health disorder. With research, this assumption has been dispelled. Still, barriers exist with regard to the use of psychotherapy or Cognitive Behavioral Therapy as a viable method of treatment for people with dual diagnosis. These barriers include, but are not limited to:

- The hesitancy to use a treatment method that relies heavily on memory, language/communication, adaptive behavior, and social knowledge, which are limited in people with I/DD.
- The common practice of paying attention more to the topography (objective description) of the symptoms/challenging behavior and not identifying the possible motivation or

emotion driving the behavior. Usually the absence of the symptoms are used as indicators that the intervention has been successful.

Cognitive Behavior Therapy (CBT) examines how a person's thoughts, feelings and behavior can get stuck in unhelpful patterns. The person and therapist work together to develop new ways of thinking and acting. Therapy usually includes tasks or practices to perform outside the therapy sessions. The goal is to directly target the "wrong thinking" patterns that are feeding the observable symptoms. CBT may be useful in the treatment of depression, anxiety disorders and psychotic disorders such as bipolar disorder and schizophrenia.

David Pitonyak, a nationally recognized behavioral consultant, states that while we describe the observed function of a challenging behavior, we should also be asking why a person feels they need to resort to the challenging behavior. For instance let's return to our example of Chris in Chapter 5.

Before the plan was implemented, Chris was refusing to eat, and when he did eat, it was in his room without anyone watching him. Now – after three months of implementing the methods in the behavior plan, training of staff in how to deal with the specific mental disorder, and three months of one-to-one counseling, Chris is now eating at the dining room table with at least three or four people around him for every meal.

In this example, the team decided to not only work on the isolation behavior but also arrange for counseling to help Chris deal with the underlying reason for isolation.

Tiffani was engaging in more elopement from her home. This behavior was observed across all settings and times. She would run out to the street and stand at the curb or continue on down the sidewalk until staff caught up with her. Usually, with encouragement, she would return to the previous setting. An ABC analysis revealed that she did this when no staff were interacting with her. The team assumed that the behavior was occurring because she was bored, but Tiffani confided that she wanted to ride the city transit. She admitted she did not know the bus schedule. The next question might be, "Why did she have the need to ride the city transit?"



Previously it was stated that a team needs to understand how the intellectual disability affects the mental health disorder and how the mental health disorder affects the disability. More specifically the question is, "How do the cognitive deficits (memory, communication, problem solving, concrete thinking, and social skill deficits) affect motivation?"

R is a 29-year-old woman with a mild intellectual disability who lives with her parents in a small town and attends a vocational program. At home, she displays intense anxieties in relation to children. She will shout at them, straighten the tops of bushes that screen the house, and keep vigil beside a window with a street view. During an interview, it was discovered she did these to protect her dog and family from perceived plots. From

historical information, R was always very helpful in school, straightening chairs at school or papers – these behaviors did have some obsessional tendencies. Recently R had lost her job and now her town was experiencing intimidation from a gang of youths. The town took collective action. R was not allowed to participate in the community's actions but her younger sister was. R began to be confrontational towards adults and children in her community. R interpreted children looking at her, using her dog's name, or playing in the street and making noise as threatening. Her family was very concerned that her behavior towards children was an illness. R viewed her behavior as a way to control the threats and it was successful because the family and her dog did not come to harm. This led to strengthening of her obsessional behaviors.

(Willner & Goodey, 2006)

Willner & Goodey (2006) identified four ways R's intellectual disability may have influenced her behavior:

1. Secondary disability – R's not being allowed to participate in protecting her town exacerbated the loss of self-efficacy, self-esteem, and control. She was perceived as not capable of participating.
2. Limited social understanding – generally people with I/DD have limited social skills and a poor grasp of social rules. This was apparent in R's failure to understand the consequences of her behavior of yelling and confrontation.
3. Temporal confusion – R's poor sense of time maintained her belief of the children as she claimed they continued to threaten her by throwing rubbish in her garden. Upon investigation this was found to have occurred once (a piece of paper) 18 months prior.
4. Extreme irrationality – The magnitude of R's irrational thinking (thinking a pre-verbal baby was making fun of her by smiling) sustained her beliefs. R did not question the conclusions of her beliefs, which is generally a difficulty for people with I/DD.

Through Rational-Emotive Therapy R was supported to consider alternative explanations for the children's behavior. She was then able to choose a more rational belief and consequently more adaptive behavior.

There are different emphases in various cognitive therapies. For instance Dialectical Behavior Therapy is used with people with borderline personality disorder. It helps people with managing emotions and their responses. Rational-Emotive Therapy is concerned with changing distortions people have. People do not merely get upset by hard times, but also by how they create their views of reality through their language, evaluative beliefs, meanings and philosophies about the world, themselves and others (Rational Emotive Therapy, 2014). Motivational Interviewing is a collaborative, person-centered form of guiding a person to prompt and strengthen motivation for change.

Cognitive Behavioral Therapies assume that all people have an intrinsic meaning to their behavior and that self-determination can be fostered through therapy.

Diagnostic Variability

In reviewing many reports on a person, one often finds a wide range of diagnoses from different settings, professionals, and even from the same professional. A mental health diagnosis is **often**

inconsistent between professionals and the diagnosis frequently varies over time. This can seem very confusing to the person and the people who support him or her. While it is confusing to try to follow these different diagnoses, there are some reasons for this “variability.”

For many physical health diseases, there are blood tests or scans (MRI or CT) that can make the accuracy or validity of the diagnosis much more on target than they were 100 years ago. Mental health has not had such improvements. There are no blood tests and very few scan-type diagnostic procedures.



Mental health diagnoses are **very** dependent upon verbal reporting of what the person is experiencing. The problems that interfere with accuracy in diagnosing are:

1. **Intellectual distortion.** The information the doctor gets may be filled with gaps and with personal interpretations by others who mean well but can only give their perspective. People with I/DD may not know how to answer more clearly or accurately.
2. **Psychosocial masking.** The lack of life experiences typical of many people with I/DD limits their ability to explain their experiences.
3. **Cognitive disintegration.** This is a common reaction to extreme stress. An example of this may be when a new staff shows up after the loss of a favorite staff. This may be more stressful than everyone realizes and the person loses simple skills as a result.
4. **Baseline exaggeration.** In many cases, the person already has a number of unusual behavioral patterns and they simply become worse. Often this is unrecognized as distress or a symptom of a developing mental health disorder. Trying to sort out what mental health disorder is occurring becomes even more complicated because of the difficulties in understanding the person’s experience.
5. **Medical conditions.** Simple medical conditions can also be experienced equally or more stressful and overwhelm the person’s coping skills. An ear infection might stress the individual and a challenging behavior might develop.

The result of all this uncertainty leads different diagnosticians, psychologists, psychiatrists, and other physicians to arrive at very different conclusions. Getting the right diagnosis is important, but it can take years of trial and error. The process may involve trying different intervention strategies, a combination of approaches, environmental changes, training, and careful data collection and monitoring across all of these.

How reliable each professional is in their knowledge about the person supported and about their area of expertise will impact the validity of the diagnosis. If several different doctors



(psychiatrists, psychologists, or other physicians) see the person, they may each get a different sense of the complex person in front of them. The team plays a critical role in sorting out the issues. We can discover many important pieces of information by tracking data very closely and comparing the person’s reactions over time to the different interventions: medications, living arrangements, support providers, reinforcement strategies, etc. If

we are lucky, a clear picture eventually emerges and it is easier to draw conclusions for interventions. It does not mean that those with other diagnoses are “poor” at their job, as it can be hard to get it right.

Support for People with Dual Diagnosis

There is no one best way to support people who have this diagnosis. Teams must use principles and values from person-centered planning to help the person lead a quality life. The quality of the interventions and plans will depend largely on how well the team gathers baseline data; how well the team considers the goals, dreams, and capacities of the person supported; and how well they educate themselves and each other; and, above all, how well they **know** person they support.

The many options for interventions include changing the environment, teaching new skills, prescribing the appropriate medication, and implementing a positive behavior support plan.

Summary

Treatment options for individuals with dual diagnosis should be the same as people who have a mental health disorder that are from the general population. It is only recently that cognitive behavioral therapies have been considered a viable treatment for people with I/DD. Treatments that include only medications do little to address the underlying beliefs and cognitive distortions held by people with I/DD. Diagnostic variability is a challenge to teams but careful collection of data can reduce the time and energy needed to come to an effective plan.

Chapter 6 Study Questions

1. For people without I/DD the usual treatments for a mental health disorder include: (circle all that apply)
 - a. Psychoanalysis
 - b. Family therapy
 - c. Weight loss
 - d. Shock therapy
 - e. Support groups
2. Describe how a psychiatrist might use medications to treat a mental health disorder.
3. Describe how a behavior support plan might be used in a treatment plan for a person with a dual diagnosis.
4. Describe how a method of Cognitive Behavioral Therapy may be used in a treatment plan for a person with dual diagnosis.
5. List one reason Cognitive Behavioral Therapy might not work in a treatment plan for a person with dual diagnosis.
6. A person you support has just changed medications for their mental health disorder. List your responsibilities related to this change.

Chapter 1 Study Questions Answers

1. List 3 characteristics of the community based model of treatment for people with a mental health disorder and I/DD.
 - *Supports families with training and education*
 - *Uses the person-centered approach*
 - *Requires interagency collaboration*
 - *Prevention services*
 - *Crises intervention*
 - *Based on positive behaviour supports*
2. List two myths that were prevalent prior to 1960 regarding people with I/DD and who displayed mental health disorder symptoms.
 - *People with I/DD are worry free*
 - *People with I/DD are incapable of expressing feelings*
 - *Mental health disorders could never co-exist with an I/DD*
3. Define Dual Diagnosis.

The co-existence of the symptoms of both intellectual and developmental disabilities and mental health problems.

4. Define Mental Health Disorder.

A behavioral pattern that causes suffering or impaired ability to function in ordinary life.

5. List at least three outcomes a person may experience, if their mental health disorder is left untreated.
 - *May have difficulty maintaining relationships with family and friends.*
 - *May be unable to get a job or stay employed*
 - *Will not be a healthy or stable individual*
 - *May bring undue attention to self, causing others to avoid him or her which limits opportunities for inclusion*
 - *May not feel successful or accepted by others.*
 - *Unable to plan for future, have goals and meet personal outcomes*

Chapter 2 Study Question Answers

1. The Diagnostic Statistical Manual is
 - a. Used to make a diagnosis.
 - b. Used in collecting data.
 - c. Used by behavior analysts to determine the function of a behavior.
2. T F A mental health disorder refers to a certain pattern of behavior(s).
3. T F The identification of the pattern of behaviors is only one factor that contributes to a diagnosis.
4. List the steps of a psychiatric assessment.
 - *Obtain a history (social, psychological, psychiatric, family, medical)*

- Evaluate person's mental status (behaviour, speech, cognitive and perceptual processes)
 - Collect auxiliary data (psychological and neurological)
 - Summarize principle findings (summary with a statement on immediate threat to life such as suicide)
 - Render diagnosis
 - Make prognosis
 - Provide a bio-psychosocial formulation (psychiatrist explanation rationale for exclusions)
 - Determine treatment plan.
5. Diagnostic overshadowing is the process of attributing a person's symptoms to a specific condition. Choose the example of diagnostic overshadowing below.
- a. Kristen's arguing and isolation may be due to her recent loss of her sister.
 - b. Ray's self-injurious behavior is caused by his cognitive disability.
6. Circle those professionals that are able to render a mental health disorder diagnosis:
- Physician
 - Behavior analyst
 - Psychiatrist
 - Neurologist
 - Support coordinator
 - Clinical Social Worker
7. List the name of the local or regional agency or institution that provides the following service:
- a. Psychologist or psychiatrist
 - b. Short term psychiatric stabilization
 - c. Hospitalization
 - d. advocacy

Regional or local services with names of agencies

Chapter 3 Study Question Answers

1. Which description is considered a maladaptive behavior?
 - a. Answering the phone when it rings.
 - b. Putting the phone in the toilet when it rings.
 - c. Pressing the correct button to answer the phone.
2. Which description is considered an adaptive behavior?
 - a. Greeting co-workers as you meet them for the beginning of the work period.
 - b. Grunting when a co-worker says good morning.
 - c. Look at the floor and not responding when a co-worker says "good morning".
3. Define behavior.

Behaviors are observed actions such as walking, sleeping, arguing, and crying. Actions you can see and describe

4. People use maladaptive behaviors for a variety of reasons. List three reasons
 - *It is the easiest and quickest way to get what they need.*
 - *They don't know any other way to get what they need or want.*
 - *They have learned to use that behavior and no one has taught them a better way.*

5. Symptoms are behavioral markers of a particular diagnosis. What is a symptom of depression?

Isolation, not eating, irritability, lack of concentration, sad facial expressions

6. Behaviors are things we do. What behavior might you do if you get a flat tire in the middle of heavy traffic?

Any description of what they would do that can be visualized, be observable

7. Define Diagnostic Equivalent.

*The diagnostic equivalents identify the symptoms of a diagnosis as they would be **observed and measured** in an individual with I/DD*

8. People with Prader-Willi Syndrome are more prone to

a. Frustration because of their obsession with food

b. Attention deficits

c. Maladaptive communication behaviors.

9. We judge ourselves by our intentions but it is easy to judge others' maladaptive behavior by its impact.

Chapter 4 Study Questions Answers

True or False

 T 1. Personality disorders are an enduring, long term pattern of dysfunctional behaviors.

 T 2. Personality refers to a person's character traits.

 T 3. Personality is reflected in the way a person acts and reacts to others.

 T 4. Personality is formed over a lifetime of experiences.

 T 5. A person with schizotypal personality disorder may display eccentric beliefs.

 T 6. People with a narcissistic personality disorder are hypersensitive to criticism.

 F 7. Obsessive-Compulsive Personality Disorder and Obsessive-Compulsive disorder are the same disorder.

 T 8. Treatment for personality disorders usually relies on psychological and behavioral interventions.

 T 9. Generalized Anxiety Disorder is the most common anxiety disorder in the general population.

 T 10. People with I/DD experience mood disorders three to four times more than the general population.

 F 11. People with Obsessive-Compulsive Disorders are unaware of the effects of their behavior on their life.

 T 12. The main recognizable characteristic of schizophrenia is hallucinations, which sometimes occur in combination with delusions and illusions.

 F 13. It is best to not try to intervene when someone is experiencing a hallucination.

- __T__ 14. While major depression tends to occur in separate episodes for a limited amount of time, dysthymia tends to persist more or less continuously in a milder, but nagging, form over a period of many years, sometimes over a lifetime.
15. People with paranoid personality disorder have a tendency to:
Interpret the actions of people as deliberately demeaning or threatening.
16. Name three features of the schizoid personality disorder:
- *Acute discomfort in close relationships, distorted views and thoughts,*
 - *Eccentric (odd) in appearance and behavior.*
 - *Hypersensitive (oversensitive) to criticism and anxious around people.*
 - *Likely to display bizarre and peculiar traits, have fanatic (extreme) or eccentric (peculiar) beliefs,*
17. List three methods of support for people who are emotionally distressed or have high anxiety.
- *Tools to relax: mental imagery, abdominal breathing, progressive muscle relaxation.*
 - *Tools to cope with worry. Westby suggests: locking up worries in a box, setting a scheduled time to worry, pulling the plug on worry.*
 - *Learn to take risks: use of self-talk instead of imagining the worst, reminding the person of times they were brave or handled a situation well.*
 - *Remove social/emotional expectations that are the source of the person's anxious behavior. Do they have to speak in public, if that causes a great deal of anxiety?*
 - *Give clear, concrete, realistic and achievable expectations (i.e., "We are going to stay at the party for 15 minutes, then we can leave.").*
 - *Remove pressure. Don't demand performance that will be beyond the person's ability at this time of anxiety.*
 - *Slow down. Do not put pressure on the person to move or work faster or better.*
 - *Never criticize performance. Instead, use encouragement and positive direction (e.g., "You need to...").*
 - *Have a positive expectation that the person will be successful. Modify supports until they are successful.*
 - *Use social stories to familiarize the person with a situation that is coming up. Teach coping skills.*
 - *Exercise: physical exercise improves energy and helps people take their mind off worries*
18. Why is it difficult to diagnose a mood disorder in a person with I/DD?
- *Some criteria such as feelings of worthlessness or guilt or suicide cannot be assessed in individuals with limited understanding or limited adaptive skills.*
 - *The symptoms exhibited may differ from those exhibited by the general population.*
 - *People with limited communication skills show a variety of symptoms.*
 - *In addition to the symptoms listed above, people with I/DD may display major depressive disorder with challenging and aggressive type behavior.*

19. Describe symptoms of Bipolar disorder manic episodes (Bipolar I & II).

An elevated, euphoric (joyful or excited), expansive, or irritable mood is the main feature of mania. People with mania may be hyperactive, highly distractible, and grandiose. They may experience flight of ideas, pressured speech, and a diminished need for sleep.

20. List masked symptoms of depression in people with I/DD.

Symptoms of depression, such as agitation, irritability, mood swings, eating, and sleep disturbances.

21. What should the DSP's reaction to the symptom of inflated self-esteem in a person experiencing a manic episode?

- *Do not argue or make fun of delusions.*
- *Make sure the individual doesn't get into trouble for this behavior*

22. What might contribute to a phobia (fear) for a person with I/DD?

Some conditions contribute to the development of phobias including poor coordination, poor motor control or balance, visual or other sensory impairments, abnormal muscle tone, skeletal deformities, obesity, or poor balance.

22. Give three examples of typical behaviors of a person diagnosed with OCD (Obsessive Compulsive Disorder)?

- *Insisting that all activities to be completed at the same time each day.*
- *Sniffing things*
- *Putting clothes off and on repeatedly*
- *Arranging objects in a certain pattern in a room.*

23. How might a person dually diagnosed with PTSD express their fear?

A person may exhibit fear, run away, avoid certain people, places, or activities. They may become aggressive when this avoidance is not possible, have nightmares, or appear very nervous or tense. Traumas can leave a person very vulnerable. They may lose communication skills needed to express, explain, or understand the trauma.

24. List four strategies that are considered best practice for supporting individuals who experience Post Traumatic Stress Disorder.

- *Spend time with the person in places that he or she enjoys, during times of the day that he or she chooses.*
- *Share success stories and successful strategies with other staff.*
- *Help the person feel safe. Provide predictable schedules, order in the environment and relationships.*
- *Make activities or situations predictable.*
- *Help the person make relationships with people who are not paid to be with them. Find community recreation and leisure activities they would enjoy where they can form relationships over time.*
- *Keep your promises. Build trust.*
- *Make home a relaxing place to be. Provide privacy and space to do enjoyable activities.*
- *Help the person establish healthy routines.*
- *Help the person set goals and make plans. Make daily, weekly schedules*

- *Help the person have fun. This should not be contingent on the person's behavior. Make fun a part of every day.*
 - *Don't force the person to revisit the incident.*
 - *Limit exposure to triggers.*
 - *Avoid punishment strategies and restraints in behavior programs*
 - *Teach coping skills. Practice and rehearse when they feel safe and comfortable.*
 - *Help the person rehearse how to respond to triggers – count to ten or go for a walk.*
 - *Give power and control to the person – give choices not ultimatums.*
 - *Encourage aerobic exercise.*
 - *Develop a support strategy for crises. It helps to know what to do.*
 - *Other methods might include medications, but usually only if the anxiety is disabling.*
 - *Desensitization and therapy may help.*
25. What is one thing a DSP can do when a person displays feelings of worthless (depression and a manic episode).
- *Point out strengths, stay positive, provide praise (don't overdo)*
 - *Make small frequent opportunities for the person to succeed.*
 - *Avoid too many demands.*
 - *Gently help them to be more realistic if they express guilt over things that were out of their control or not their fault.*
26. It is difficult to diagnose personality disorders in people with I/DD because (more than one answer may be correct)
- a) The diagnosis requires subjective information about thoughts and emotions.
 - b) People with I/DD have personalities shaped by their diagnosis
 - c) The diagnosis relies on experiences with relationships which is usually lacking in a person with I/DD's life.
 - d) People with I/DD usually have limited understanding of abstract concepts such as intimidation, manipulation, remorse, or empathy.
27. A person with generalized anxiety disorder displays (circle all that apply):
- a) Worry about future danger
 - b) Avoid close relationships
 - c) Worry when there is no real danger
 - d) Person anticipates future danger
 - e) Manipulates others
 - f) Lacks empathy
28. A person who is dually diagnosed and has generalized anxiety disorder may display anxiety by (circle all that apply):
- a) Sadness
 - b) Irritability
 - c) Refusals to do daily routines
 - d) Eccentric or peculiar beliefs
 - e) Pacing

29. What are the criteria for the diagnosis of depression- use the acronym DEPRESSING.

D – depression (sadness)

E – energy (loss of)

P – pleasure (diminished interest)

R – retardation (psychomotor slowing or agitation)

E – eating (changes in weight or appetite)

S – suicide – (recurrent thoughts of death)

S – sleep – (insomnia or hypersomnia)

I – indecisive – (poor concentration)

N – negative thinking (worthlessness, hopelessness)

G – guilt (inappropriate)

To be diagnosed with major depressive disorder, a person must display at least five of these major symptoms during the same two week period and represent a change from previous functioning.

30. To be diagnosed with a phobia the person must avoid the object, situation, or experience with extreme distress when it cannot be avoided. The distress must interfere with routines, activities, functioning, or relationships.

31. Schizophrenia is a disturbance that lasts at least six months and includes at least one month of active-phase symptoms of the following: delusions, hallucinations, disorganized speech, disorganized or catatonic behavior.

32. Which of the following statement(s) about schizophrenia is true?

a) Persons with schizophrenia are always dangerous to others.

b) Schizophrenia is caused by poor parenting.

c) Persons with schizophrenia have a split personality.

d) It is possible for a person to have a psychotic disorder even though the person does not speak or use a formal communication system.

e) Every person who has a hallucination or delusion has schizophrenia.

33. Hallucinations are imagined sensations that seem frighteningly real and can take control of the person.

34. Explain the difference between hallucination, delusion, and illusion.

- *Hallucinations are imagined sensations that seem real.*

- *Delusions are beliefs, not sensory misinterpretations.*

- *Illusions are misinterpretations of real objects.*

35. List at least three ways to support someone who is experiencing a hallucination.

- *Become someone to trust. The person may be more able to relax, express and feel comfortable because you are there.*

- *Be consistent. Show acceptance. If you are afraid, nervous, and anxious, you will not be of much help.*

- *Be aware of your body language and that it is being observed. Be a good listener.*
- *Look and listen for the messages of body gestures and/or facial expressions*
- *Remember what you observed for later recording. This data will be important in developing intervention plans.*
- *If a person is not able to describe what is happening, record this information.*
- ***Do not leave the person alone if they are hallucinating.***
- *Do not argue with the person about what he is experiencing. To the person it is a real experience.*

Chapter 5 – Study Question Answers

True or false

- T 1. The medical model relies solely on professionals to help the person with dual diagnosis.
- T 2. Person-centered planning uses the capacities of a person with dual diagnosis to plan.
- T 3. Person-centered plans require teams to share knowledge.
- F 4. The medical model focuses on the capacities of the person with dual diagnosis to develop a treatment plan.

5. Define baseline data.

Baseline data is the initial data with which future data can be compared.

6. Circle those data that would be considered baseline.

- a) Sleep pattern before intervention.
- b) Response to medication
- c) Eating habits before the intervention
- d) Incidents of challenging behavior after medication was started.
- e) Incidents of challenging behavior before the medication was started.
- f) Incidents of refusals to do activities of daily living before the intervention.

7. List at least two perspectives/attitudes/concerns each team member will bring or have at the planning meeting.

- a) Psychologist/Behavior Analyst
 - *Will need to have and discuss baseline data*
 - *Will be responsible for developing methods to teach coping skills/replacement behavior*
 - *May be called on to provide counseling*
- b) Direct Support Professional
 - *Knows the person and how they function in daily life.*
 - *Knows how the current dual diagnosis is interfering with their daily life.*
 - *Sees evidences of the disorder across environment*
- c) Psychiatrist
 - *Gathers data by interview, considers historical, medical, and developmental information*
 - *Sees the disorder as an impairment.*
 - *Determines a prognosis*
 - *May prescribe medications*
- d) Family member
 - *Knows the person the best*
 - *Concerned about long-term care of person*

- *Will be there when others of the team move on*
- *Might be intimidated by professionals*
- e) Person supported
 - *Might feel intimidated by team members (unknown or doesn't understand language used)*
 - *May be a self-advocate and talk for self*
- f) Program coordinator/internal case manager
 - *Person who will carry out parts of the plan*
 - *Will monitor quality of the plan*
 - *Must work to bring the team to consensus*
 - *Seeks services in the community*

8. List the questions the team should ask before a referral to a psychiatrist or clinical psychologist is made.

- *Do symptoms occur in most or all settings?*
- *Is there little change with medical or appropriate behavioral support?*
- *Has there been changes in sleep, appetite, or sexual function?*
- *Have hallucinations been observed?*
- *Have strong autonomic symptoms (flushing, sweating, high pulse rate, tremors) been observed in conjunction with hallucinations?*
- *Is the person in physical pain?*

9. List at least five questions that should be asked when gathering background information.

- *Description of the presenting problem:*
 - *What is happening?*
 - *Why has this referral been made?*
 - *What problems have occurred because of the person's behavior?*
 - *How long has this been occurring?*
- *What may have caused the change? Did any physical or emotional event cause a change in the person or their environment?*
- *Background in the diagnosis of IDD*
- *What is the person's present lifestyle? (Friends, where do they live, daily schedule, recreation, sleep and eating pattern). What does life look like when they are doing well?*
- *Any medical problems?*
- *Any abuse of alcohol or drugs?*
- *Past mental health history*
- *What has changed? The person once was ____ but now is ____.*

Chapter 6 – Study Question Answers

1. For people without I/DD the usual treatments for a mental health disorder include: (circle all that apply)
 - a. Psychoanalysis
 - b. Family therapy
 - c. Weight loss
 - d. Shock therapy
 - e. Support groups

2. Describe how a psychiatrist might use medications to treat a mental health disorder.
 - *Treating the behavioral indicator of a mental health disorder – reduction or elimination of symptoms (behavioral indicators)*
 - *Using a side effect of a medication to treat the behavioral indicator.*
3. Describe how a behavior support plan might be used in a treatment plan for a person with a dual diagnosis.
 - *Teach skills to replace the maladaptive behavior.*
 - *Attend group or one-to-one counseling sessions.*
4. Describe how a method of Cognitive Behavioral Therapy be used in a treatment plan for a person with dual diagnosis.

There are different emphasis in various cognitive therapies. For instance Dialectical Behavior Therapy is used with people with borderline personality disorder. It helps people with managing emotions and their responses. Rational-Emotive Therapy is concerned with changing distortions people have. People do not merely get upset by hard times, but also by how they create their views of reality through their language, evaluative beliefs, meanings and philosophies about the world, themselves and others (Rational Emotive Therapy, 2014). Motivational Interviewing is a collaborative, person-centered form of guiding a person to prompt and strengthen motivation for change.

5. List one reason Cognitive Behavioral Therapy might not work in a treatment plan for a person with dual diagnosis.

The team does not know the person well enough. The person may not have a reliable form of communication. The person may not have life experiences that will help in communicating feelings, understanding relationships. The person may not have understanding of how their behavior affects others.
6. A person you support has just changed medications for their mental health disorder. List your responsibilities related to this change.

When medication dosages are changed, medications are added, or discontinued, the DSP must remember (as well as the case manager) to observe and report behavioral changes. Accurate data will help the team make more accurate decisions. It is the responsibility of team members to know the medication. This information should include the purpose or desired effect of the medication and side effects. Staff should be informed on the response time as well.

Glossary

Acute: Severe symptoms with a short duration.

Adaptive Behavior: Behavior that aids in adjustment or improvement. Appropriate behavior.

Affective Disorder: A disorder characterized by disturbance of mood as a predominant feature. Depression, bi-polar, and mania are the major examples of affective disorders

Anxiety Disorders: Disorders indicated by the presence of excessive fears, frequent somatic complaints, and excessive nervousness that can interfere with functioning. Examples of anxiety disorders include panic attack, PTSD, and obsessive-compulsive disorder.

Antisocial: A person whose outlook and actions are socially negative and whose behavior conflicts with what society considers normal..

Avoidant: A personality disorder characterized by a pattern of interpersonal avoidance accompanied by sensitivity to criticism or disapproval. This is not merely an extremely shy individual.

Behavior Modification: A method of altering behavior that places an emphasis on defining problems in terms of behavior that can be measured in some way while using changes in the behavioral measure of the problem as the best indicator of the extent to which the problem is being helped.

Bi-polar Depression: “Two pole” depression. A depression that also includes manic episodes.

Borderline: The person who is borderline usually engages in impulsive behavior (self-mutilation or drug abuse). This individual engages in relationships that alternate from superficiality to an intense dependence. This person can be manipulative, demanding, and physically aggressive.

Chronic: Of long duration.

Delusions: A false belief brought about without any external action or stimulus. For example, seeing a real person and for no reason believing that the person is planning to harm us.

Dependent: Excessive need to be taken care of that leads to submissive and clinging behavior and fears of separation.

Developmental Disability: Refers to people who are at least five years of age with a mental and/or physical impairment that occurs before age 22 and limits them in at least three of the seven major life activities, such as language, self-care, and economic contribution.

Diagnostic and Statistical Manual of Mental Disorders (DSM): This manual identifies, classifies, and provides guidelines for diagnosing mental health disorder. It is used in all areas of mental health care and is upgraded at regular intervals. The current edition is the DSM-5 (2013).

Dual Diagnosis: Co-existence of the symptoms of both intellectual disability and mental health disorder.

Hallucinations: A false perception that is not related to reality. Hallucinations may be visual, auditory, or olfactory (smell). Hallucinations are totally imaginary such as seeing a non-existent person.

Histrionic: The person behaves in an overly dramatic, theatrical way for drawing attention.

Illusions: Inaccurate perception or misinterpretation of what the senses may be telling us. Different from a hallucination, which has no external origins. An example would be seeing a mannequin and believing it is a living person.

Maladaptive Behavior: Pertaining to behavior traits that are not in the person's best interest.

Manic: A mood that is characterized by excessive energy, impulsiveness, agitation, frenzied movement, and decreased need for sleep.

Narcissistic: An inordinate sense of self-importance, extreme self-centeredness, and a lack of interest and empathy for others.

Obsessive-Compulsive Disorder: Behavior characterized by repetitive, irrational thoughts called obsessions and actions called compulsions. The person recognizes the problematic behavior but is usually at a loss to stop or prevent it themselves. Note: as differentiated from Obsessive-Compulsive Personality Disorder.

Obsessive-Compulsive Personality Disorder: Lifetime pattern of behavior (personality) characterized by compulsive behaviors and rigid thinking (rules). The person is generally unable to recognize the problematic nature of their behavior and sees the problem as the fault or responsibility of those around them.

Paranoia: A mental disorder characterized chiefly by systematic delusions especially persecution and grandeur.

Passive Aggressive: The individual is dependent and lacks self-confidence and has no insight that their own actions cause this difficulty. Symptoms include procrastination, irritability, sulkiness, slowness at work, having an unrealistic opinion about the high quality of their work, and constantly demeaning those in authority.

Personality Disorder: If we can define personality as one's characteristic way of interacting with others, personality disorders would be defined as behavior when a person interacts in ways that are maladaptive or dysfunctional.

Pressured Speech: Loud and emphatic speech that is increased in amount, accelerated, and usually difficult or impossible to interrupt. Present in manic episodes.

Psychopathology: The study of the causes and nature of mental disease and abnormal behavior. Generally referred to as mental health disorders.

Psychosis: A mental disorder that is so severe that the result is personality disintegration and loss of contact with reality.

Psychotic Disorders: The group of disorders which indicate the presence of delusion, hallucinations, disorganized behavior and impairment in reality testing. An example of a psychotic disorder is schizophrenia.

Reinforcement: The reward for the appropriate response in a learning situation. The reinforcement can be positive such as praise or food, or negative such as brushing teeth to avoid tooth decay.

Schizophrenia: Psychosis (see definition) characterized by withdrawal from reality, delusions, and progressive deterioration.

Schizotypal: Has many similarities to schizophrenia but it is not the same. The person who is schizotypal will engage in odd or eccentric behavior. The person diagnosed as schizotypal may believe that he has special powers to predict the future, to transmit thoughts, or control events. This person often has a strong belief in magic.

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DSP Case Study Practice for Dual Diagnosis .53

This case study requires analysis/discovery of information related to a person supported with a dual diagnosis. After consulting with your trainer or supervisor, complete this case study related to the individualized supports for one individual with a dual diagnosis. Follow your agency procedures for gathering information to complete this exercise. Use as much room as you need to complete each question.

1. Diagnosed mental health disorder:

2. Describe the full pattern of behaviors that are displayed by this person that are related to the diagnosis.

3. Copy of or summation of the psychiatrist's examination/report:
(Psychiatrist's explanation and rationale for conclusions)

3. Psychiatrist's treatment plan:

4. Describe behavior support plan
 - a. Environmental adaptations/supports
 - b. Skill instruction
 - c. Behavioral data collected
 - d. Medications (desired effects, side effects)
 - d. PRN medications, desired effects, side effects