Mental wellness refers to a state of being in which a person is able to deal with the demands of everyday life. This also means a person thinks, feels, and behaves in ways that are appropriate for his/her age, relationships, and responsibilities. Mental health disorders cause distress and can interfere with a person’s ability to cope with daily life. Both wellness and mental health disorders are experienced among people who have intellectual/developmental disabilities (IDD) and among the general population.

Anxiety disorders affect behavior, thoughts, emotions and physical health. Research is still identifying the specific physical causes. A combination of physical factors and a person’s circumstances or life experiences causes most cases.

The Diagnostic and Statistical Manual of Mental Disorders, fifth revision (DSM 5), is the guide for diagnosing mental disorders. It is published by the American Psychiatric Association. According to the DSM 5, anxiety disorders include all disorders that “share features of excessive fear and anxiety and related behavioral disturbances.”

“Fear is the emotional response to a real or perceived threat. Anxiety is anticipation of future threat.”

For a diagnosis of anxiety disorder, a person must be experiencing the specific symptoms of the disorder (diagnostic criteria). The symptoms must be severe, meaning that they interfere with the person’s ability to function in a job, social and personal relationships, and carry on with daily routines and life tasks.

The DSM 5 details 11 subcategories of anxiety disorders as follows:
- Separation Anxiety Disorder
- Selective Mutism
- Specific Phobia
- Social Anxiety Disorder (Social Phobia)
- Panic Disorder
- Agoraphobia
- Generalized Anxiety Disorder
- Substance/Medication – Induced Anxiety Disorder
- Anxiety Disorder due to Another Medical Condition
- Other Specified Anxiety Disorder
- Unspecified Anxiety Disorder
Among the general population, between 10 percent and 18 percent of people have anxiety disorders.iii People who have intellectual/developmental disabilities (IDD) may experience the different types of anxiety disorders in the same way as the general population. However, it’s difficult to determine how frequently they occur. It is likely that anxiety disorders are underdiagnosed for people with IDD for several reasons. The symptoms of anxiety could be inappropriately considered part of the intellectual disability instead of a symptom of a mental health disorder. iv

People who have an IDD can experience the range of mental health problems that are experienced by the general population, including anxiety disorders.

**Causes and development**

Anxiety disorders likely develop as a result of a combination of factors:

- Genetic factors — having a family history of anxiety disorders
- Environmental factors — situations, circumstances or experiences in life that cause stress (e.g., relationships, loss, financial worries)
- Psychological factors — psychological traits that reduce the ability to manage stress (e.g., negative thoughts or a person’s belief about their inability to manage a situation)
- Developmental factors — a person’s stage of development impacts how they process and respond to situations that may cause stress and anxiety

There are several genetic causes of intellectual disabilities that lead to a greater likelihood of developing anxiety. That means the genetic difference leads to increased possibility of an anxiety disorder developing. Among these genetic syndromes are Williams Syndrome, Klinefelter’s syndrome and Prader-Willi syndrome. As a result of the genetic differences causing the syndromes, anxiety is an expected feature. Autism spectrum disorder also is associated with high levels of anxiety. People with syndrome-related anxiety will benefit from supports and strategies to address their anxiety, regardless of its causes.

The limbic system is responsible for managing emotions and memories.v,vi The limbic system is part of the body’s neurological system. It is involved in regulating how we manage stress and fear. Research is progressing relating to how a problem in the limbic system can contribute to developing an anxiety disorder. The exact relationship between the limbic system and anxiety disorders is still being researched. Once this relationship is identified, more effective treatments can be developed.

**Signs and symptoms**

Anxiety disorders include a large number of conditions characterized by:

- Sense of dread and uneasiness
- Physiological symptoms — sweating, increased heart rate, increased rate of breathing
- Restlessness, fatigue, irritability, sleep disturbances, difficulty concentrating, muscle tension, personality changes
- Lack of cause or situation does not match the extent of the reaction.vii
Signs and symptoms are different depending on type of anxiety disorder, but each one shares a number of signs and symptoms. Common symptoms are generally:

- Feelings of panic, fear and uneasiness
- Uncontrollable, obsessive thoughts
- Repeated thoughts or flashbacks of traumatic experiences
- Nightmares
- Ritualistic behaviors, such as repeated hand washing
- Problems sleeping
- Cold or sweaty hands and/or feet
- Shortness of breath
- Palpitations (feelings of having rapid, fluttering or pounding heart)
- An inability to be still and calm
- Dry mouth
- Numbness or tingling in the hands or feet
- Nausea
- Muscle tension
- Dizziness

Most people experience anxiety at different times such as when taking a test or going for a job interview. What is different for people who have anxiety disorders is the amount of impairment the disorder causes in their everyday lives. The worry and fear people with anxiety disorders experience can seriously interfere in their lives on a daily basis. viii

**Diagnosis**

A thorough biopsychosocial assessment, including health, mental health and intellectual disability, is recommended for any mental health disorder. Diagnosis of anxiety disorders is more complicated for people with an IDD for a number of reasons.

- The need to identify and express feelings and thoughts to talk about what they are experiencing
- Reliance on informant description of behavior — an observer needs to be able to report what difference in behavior they see
- Diagnostic criteria (symptoms needed to make the diagnosis) need specific modifications to consider the how the disorder may be expressed differently for a person who has an IDD.

Diagnostic criteria are often based on the person being able to report their own symptoms and experiences. The ability to self-report can be difficult for people who have trouble identifying and describing to others how they are feeling and what they are thinking at times.

The Diagnostic Manual – Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID 2) offers suggestions for modifications to the diagnostic criteria contained in the DSM - 5 for people who have intellectual disabilities. The DM-ID 2 recommends a strong reliance on reports from care providers. It also recommends considering the impact of the IDD on anxiety disorders.
When care providers are able to contribute to the diagnostic process, there is a better likelihood of an accurate diagnosis. Care providers can provide examples of observed behavior that may be considered in the process of diagnosing the anxiety disorder. For example, the care provider may report the person has an excessive focus on a topic that causes them to worry. This could be interpreted as a symptom; worry and difficulty controlling the worry.

Difficulty concentrating or mind going blank are very difficult observations to make when a person has a severe or profound IDD. However, anxiety can be observed as a variety of behaviors including:

- Self-injury (skin picking, pinching, etc.)
- Pacing
- Inability to settle (restlessness)
- Muscle rigidity (tension)
- Changes in sleep patterns
- Hyper-arousal
- Exaggerated startle responses

A person with IDD may experience anxiety as a loss of skills that they previously had. This is even more obvious for tasks that need a number of different steps to complete, like doing laundry, meal preparation, personal hygiene, etc.

Family practice doctors and other properly credentialed mental health professionals, which in Minnesota include:

- Clinical nurse specialist (CNS)
- Licensed independent clinical social worker (LICSW)
- Licensed marriage and family therapist (LMFT)
- Licensed professional clinical counselor (LPCC)
- Licensed psychologist (LP)
- Mental health rehabilitative professional
- Psychiatric nurse practitioner (NP)
- Psychiatry or an osteopathic physician
- Tribal certified professionals

are the only professionals who can complete a formal assessment and diagnosis for mental health conditions.

Generalized anxiety disorder, when diagnosed early, is easier to treat successfully.

**Supports and strategies**

Supports and strategies for anxiety disorders should consider any life changes and transitions (like changes graduating high school, moving or even changing activities) that may be happening in the person’s life. Preventative care, supports and effective interventions can help reduce anxiety in these circumstances.

The first line of treatment for anxiety is likely to be medication treatment. Medication can assist the person to become more stable so they can benefit from other treatment and recovery approaches. Once the person is stabilized, then other supports can be considered. Treatments may include:
• Psychotherapy with a focus on understanding and managing anxiety disorder
• Environmental and social changes that can reduce or eliminate issues that are contributing to anxiety
• Social skills training
• Regular exercise
• Wellness-based approaches
• Learning stress management strategies
• Anti-anxiety medication

Strategies that teach and model how to calm and relax can help people manage their own anxiety. Relaxation exercises also help by distracting the person’s attention from the source of the stress. Distraction can help focus the person on an appropriate behavior. There are many types of relaxation exercises. The following are two simple strategies that care providers can model and teach.

**Deep breathing**
1. Sit or lie down.
2. Breath in slowly through the nose and try to ensure the stomach rises.
3. Slowly exhale while counting or saying “relax.”
4. Repeat 10 times.

**Progressive Muscle Relaxation (PMR)**
1. Sit in a relaxed position.
2. Focus on yourself and on achieving relaxation in specific body muscles.
3. Tune out all other thoughts.
4. Squeeze fists together tightly. Slowly count to five and release.
5. Shrug your shoulders up to your ears for five seconds. Relax.
6. Arch your back for five seconds. Relax.
7. Squeeze legs tightly and slowly count to five and release.
8. Repeat for other body parts that are tense.
9. Avoid body parts that are sore or uncomfortable.

Cognitive Behavior Therapy (CBT) can be effective in helping people function. It works through helping people identify beliefs, feelings and behaviors. In CBT, overall functioning is improved by helping people develop skills. CBT teaches people to be aware of their thought patterns and helps them change the ones that contribute to anxiety. There is a great deal of research on the benefit of CBT with people who have an IDD.

**Including anxiety disorders in a functional behavior assessment and positive behavior supports**

Anxiety disorders should be considered in a Functional Behavior Assessment (FBA). Anxiety disorders could be considered as a “setting event,” which increases the likelihood of a behavior happening. Anxiety can directly impact the function or purpose of a behavior. An anxiety disorder should be included in a hypothesis statement if the anxiety disorder helps explain why the behavior occurs.
Anxiety disorders often are associated with higher intensity escape-motivated behaviors. A person with an
anxiety disorder may find certain events anxiety-provoking and may engage in a behavior to escape from that
event and the anxiety it causes. To an average person, this might not make much sense; but when we consider
the anxiety that the person experiences from the event, the behavior makes sense.

Positive Behavior Support (PBS) involves changing situations and events that people with problem behaviors
experience to reduce their occurrence. It supports people to increase social, personal and professional quality in
their lives. Research-based strategies and tools are used to increase the quality of life.

Within a PBS model for anxiety disorder, management of problem behavior relies on identifying reasons for
problem behavior. It also identifies the behavior itself as a symptom. It considers the different areas of life in
terms of understanding problem behaviors; taking into consideration physical, intellectual and developmental
characteristics.

PBS strategies focus on planning and support based on a person’s strengths. Support is also provided based on
focusing on the person’s strengths. Positive Behavior Supports also promote wellness approaches.

For more information about anxiety disorders

Government of South Australia – Intellectual disability and anxiety disorders (PDF). Provides information about
IDD and anxiety disorders; recognition, diagnosis and treatment.

The Intellectual Disability Mental Health First Aid Manual (PDF). Resource for people supporting adults who have
intellectual disability who are experiencing an emerging mental health problem or mental health crisis. While it
provides information on resources specific to Australia, the information and guides are universally accepted.
Pages 46 – 52 address anxiety and intellectual disability.

PAS-ADD (Psychiatric Assessment Schedules for Adults with Developmental Disabilities). PAS-ADD is the general
name for a set of mental health assessments originally developed for people with intellectual disability. On this
UK website you will find information on the PAS-ADD suite of mental health assessments published by Pavilion
Publishing (Brighton) Ltd (www.pavpub.com). The suite includes the PAS-ADD Checklist, Mini Pas-ADD, ChA-PAS
and the PAS-ADD Clinical Interview.

NADD Bulletin Volume XI Number 1 Article 3 - The intersection of best practice in dual diagnosis and positive
psychology. “This paper provides a description of positive psychology and notes the contributions that positive
psychology offers to support for people with the dual diagnoses of an Intellectual or Developmental Disability
and a Mental Illness.”

Effective Strategies Checklist Children and Youth with Developmental Disorders and Challenging Behavior (PDF).
This paper provides resources and strategies that have improved outcomes and lowered costs, while diminishing
risk for institutional placements, referrals to juvenile justice and child welfare.

i,ii, American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA:
American Psychiatric Publishing.


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