

INTELLECTUAL DISABILITY + MENTAL ILLNESS

# CONTENTS

## **Table of Contents**

#### Section 1: Dual Diagnosis

What is Dual Diagnosis?	4
What is Intellectual Disability?	4
What is Mental Illness?	5
What is the DSM?	7

## Section 2: Mental Health Disorders and those with ID/DD

Depression	10
Bipolar Disorder	14
Anxiety Disorders	30
Trauma	38
Schizophrenia	59
Personality Disorders	63
Impulse Control Disorders	66
Reactive Attachment Disorder	73

### Section 3: Important Considerations

Mental Health Medications	91
Ruling Out Medicatl Causes	91
Beyond the Behavior	122

# Diges Gon Dual Diagnosis

## Roadmap to Success & Understanding

## Credits:

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Dear Lifesharing provider,

Bringing someone new into your life and into your family is not only a monumental decision, it is a thankworthy act that adds depth to the human and family experience. Some facts that may be of interest to you are that people with intellectual and developmental disabilities (ID/DD) living with families are less lonely, less likely to feel afraid, more likely to feel happy, and more likely to like where they are living\*.

As you open your home and family to an individual with a developmental disability who also has a mental illness (dual diagnosis or DDx), you will appreciate the selection of articles included in this resource digest. Your support of the person with a dual diagnosis is of particular significance. Jo Anne Nugent, Ed D, author of A Handbook on Dual Diagnosis says it best:

In the past, there has been an unfortunate tendency to assume that the most important element of treatment is the expertise of the medical professional, such as the psychiatrist. In fact, in many situations, support people felt paralyzed until they could access this clinical expertise. Certainly, the clinical professional plays a key role in diagnosis and treatment of a person with a dual diagnosis.

However, people who support the individual on a day to day basis have just as crucial a role to play. Some of the key functions they fulfill are:

Listening sensitively to all types of communication, verbal and non verbal Teaching skills that enhance the person's quality of life Observing changes in physical health, mood, behaviors, etc. Providing habilitative environments Ensuring that proper care is accessed with respect to medical needs Monitoring treatments such as medications and behavioural programmes

Helping people to develop and maintain social supports

Participating in planning

Contributing accurate and thorough information to the treatment team

We hope that you will find the information in this resource to be a valuable support to you as you provide support to others.

If you would like to provide comments and feedback towards improving future editions of this publication, please email Mary Nau at mnau@ hcqu.org

All feedback will be considered for future editions of this publication.

\*National Core Indicators 2006-2007, 12,193 people interviewed across 19 states and one regional area.



## SECTION 1: DUAL DIAGNOSIS



## What is "Dual Diagnosis"?

The term dual diagnosis is often used to refer to people who have a substance abuse disorder and a mental illness. However, it is the same term we use in the field of intellectual and developmental disabilities (ID/DD) when we refer to someone who has an Intellectual or Developmental Disability (ID/DD) and also has a Mental Illness (MI). You may hear other terms such as comorbidity, co-occurring illnesses, concurrent disorders, comorbid disorders, co-occurring disorder, dual disorder. All of these terms are interchangeable with the term "dual diagnosis."

## What is an Intellectual or Developmental Disability (ID/DD)?



Intellectual disability used to be, and often still is, referred to as Mental Retardation. It is a term used to describe someone who is limited or slower in their ability to learn new information and develop new skills such as communication, self-care and social skills. People with ID/DD learn

and develop more slowly than typical children. The may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. As many as three out of every 100 people have an intellectual or developmental disability (ID/ DD).

The most common causes ID/DD are:

- Genetic conditions -- Abnormalities of chromosomes and genes. Examples of genetic conditions are Down syndrome (trisomy 21), fragile X syndrome, and phenylketonuria (PKU).
- Problems during pregnancy -- When the baby does not develop normally inside the mother. For example, a woman who drinks alcohol or gets an infection like rubella during pregnancy may have a baby with mental retardation.
- Perinatal problems -- Problems during labor and birth, such as not getting enough oxygen.
- Health problems -- Diseases like whooping cough, the measles, or meningitis. Mental retardation can also be caused

by extreme malnutrition or being exposed to poisons like lead or mercury.

The diagnosis of mental retardation is made by looking at two main things. These are (1) the ability of a person's brain to learn, think, solve problems, and make sense of the world (intellectual functioning or IQ); and (2) whether the person has the skills needed to live independently (called adaptive behavior, or adaptive functioning).

Intellectual functioning, or IQ, is usually measured by an IQ test. The average IQ score is, by definition, 100. People scoring below 70 to 75 on the IQ test are considered to have ID/DD. To measure adaptive behavior, professionals look at what a child can do in comparison to other children of his or her age. Certain skills are important to adaptive behavior. These are daily living skills (such as getting dressed, going to the bathroom, and feeding one's self), communication skills (such as understanding what is said and being able to answer) and social skills (interacting with peers, family members, adults, and others). Most individuals with ID/DD will be mildly affected. They may be a little slower than the average person in learning new information and skills. About 87% of people with mental retardation will only be a little slower than average in learning new information and skills. In adulthood, those with a mild intellectual or developmental disability can live independently or live with a few supportive services to help them succeed at living on their own.

The remaining 13% of those with an intellectual or developmental disability score below 50 on IQ tests. These individuals will struggle at school, at home, and in the community. A person with more severe disability will need supports that are more intensive during his or her entire life. Every individual with an intellectual disability, regardless of severity, is able to learn, develop, and grow.

## Source: http://www.medterms.com/script/main/art. asp?articlekey=20174

## What is a Mental Illness?

Mental illness is any disease or condition affecting the brain that influences the way a person thinks, feels, behaves and/or relates to others and to his or her surroundings. Although the symptoms of mental illness can range from mild to severe and are different depending on the type of mental illness, a person with an untreated mental illness often is unable to cope with life's daily routines and demands.

#### What Causes Mental Illness?

Although the exact cause of most mental illnesses is not known, it is becoming clear through research that many of these conditions are caused by a combination of genetic, biological, psychological and environmental factors. One thing is for sure—mental illness is not the result of personal weakness or a character defect, and recovery from a mental illness is not simply a matter of will and self-discipline.

Heredity (genetics): Many mental illnesses run in families, suggesting that the illnesses may be passed on from parents to children through genes. Genes contain instructions for the function of each cell in the body and are responsible for how we look, act, think, etc. But, just because your mother or father may have a mental illness doesn't mean you will have one. Hereditary just means that you are more likely to get the condition than if you didn't have an affected family member. Experts believe that many mental conditions are linked to problems in multiple genes—not just one, as with many diseases—which is why a person inherits a susceptibility to a mental disorder, but doesn't always develop the condition. The disorder itself occurs from the interaction of these genes and other factors—such as psychological trauma and environmental stressors—which can influence, or trigger, the illness in a person who has inherited a susceptibility to it.

**Biology:** Some mental illnesses have been linked to an abnormal balance of special chemicals in the brain called neurotransmitters. Neurotransmitters help nerve cells in the brain communicate with each other. If these chemicals are out of balance or are not working properly, messages may not

## SECTION 1: DUAL DIAGNOSIS

make it through the brain correctly, leading to symptoms of mental illness. In addition, defects in or injury to certain areas of the brain also have been linked to some mental conditions.

**Psychological trauma:** Some mental illnesses may be triggered by psychological trauma suffered as a child, such as severe emotional, physical or sexual abuse; a significant early loss, such as the loss of a parent; and neglect.

**Environmental stressors:** Certain stressors such as a death or divorce, a dysfunctional family life, changing jobs or schools and substance abuse—can trigger a disorder in a person who may be at risk for developing a mental illness.

#### **Can Mental Illness Be Prevented?**

Unfortunately, most mental illnesses are caused by a combination of factors and cannot be prevented.

#### **How Common Is Mental Illness?**

Mental illnesses are very common. In fact, they are more common than cancer, diabetes or heart disease. According to the U.S. Surgeon General, an estimated 23% of American adults (those ages 18 and older)—about 44 million people—and about

20% of American children suffer from a mental disorder during a given year. Further, about 5 million Americans adults, and more than 5 million children and adolescents suffer from a serious mental condition (one that significantly interferes with functioning).



Major depression, bipolar disorder and schizophrenia are among the U.S.'s top 10 leading causes of disability.

Mental illness does not discriminate. It can affect people of any age, income or education level, or cultural background. Although mental illness affects both males and females, certain conditions—such as eating disorders—tend to occur more often in females, and other disorders—such as attention-deficit/hyperactivity disorder (ADHD)—more commonly occur in children.

### **How Is Mental Illness Treated?**

A mental illness, like many chronic illnesses, requires ongoing treatment. Fortunately, much progress has been made in the last two decades in treating mental illnesses. As a result, many mental conditions can be effectively treated with one or a combination of the following therapies:

- Medication
- Psychotherapy
- Group therapy
- Day treatment or partial hospital treatment
- Specific therapies, such as cognitive-behavior therapy and behavior modification
- Other treatments available include:
- Alternative therapies, such as water therapy, massage and biofeedback
- Creative therapies, such as art therapy, music therapy or play therapy
- Hypnotherapy
- Electroconvulsive therapy (ECT)
- Vagal nerve stimulation (VNS)

## What Is the Outlook for People with Mental Illness?

When diagnosed early and treated properly, many people fully recover from their mental disorder or are able to successfully control their symptoms. Although some people become disabled because of a chronic or severe mental illness, many others are able to live full and productive lives. In fact, as many as 8 in 10 people suffering from a mental illness can effectively return to their normal activities if they receive appropriate treatment.

Source: MI\Mental Illnesses Basics on MedicineNet\_ com.mht

## What is the DSM?

Overview of the Diagnostic & Statistical Manual of Mental Disorders

The DSM-IV-TR is the standard handbook for diagnosing mental disorder. It is used by mental health professionals in the United States.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) refers to manuals published by the American Psychiatric Association (APA). The current DSM is a diagnostic tool aimed at health professionals, and is used in several countries. Early versions of the DSM incorporated statistics, hence "statistical" in its title.

#### What Is the DSM-IV-TR?

There have been four manuals (DSM I, II, III and IV) and a text revision of the fourth manual, the DSM-IV-TR, which included some changes to the descriptive text. The DSMs, including the most recent versions, have been subject to much debate amongst health professionals and researchers.

The DSM-IV-TR lists mental disorders and the associated diagnostic criteria for both children and adults. It includes diagnostic codes, which may be required by health insurers or used for research purposes. Each disorder also comes with a description of the following:

- Diagnostic features
- Subtypes and/or Specifiers
- Recording Procedures
- Associated Features and Disorders
- Specific Culture, Age and Gender Features
- Prevalence
- Course
- Familial pattern
- Differential Diagnosis

#### The DSM-IV-TR Multiaxial System

The multiaxial system (sometimes referred to as multidimensional) is used to promote an all-

inclusive evaluation of client function. The axes are as follows:

- Axis I: Clinical Disorders. The first axis describes symptoms of clinical disorders, such as mood disorders and eating disorders.
- Axis II: Personality and Mental Retardation. The second axis describes symptoms of disorders that cannot be accounted for on axis one, such as personality disorders.
- Axis III: Medical Conditions. This axis includes medical conditions that may affect disorders of the previous axes, such as brain injury.
- Axis IV: Psychosocial and Environmental Problems. This axis refers to social or environmental stressors that may impact on the client's function, such as bereavement.
- Axis V: Global Assessment of Functioning. This axis is used to evaluate the client's function overall.

#### Who Uses the DSM-IV-TR?

Although the APA is an organisation representing US psychiatrists, the DSM-IV-TR is intended for use by health professionals and researchers from various backgrounds and settings. While it may well be used by a psychiatrist working in primary care, it may also be used by a biology student. However, not all professionals using the DSM-IV-TR will be qualified to make diagnoses.

## Will There Be a DSM-V?

In July 2007, the APA issued a press release that the expected date of the DSM-V's release is May 2012.

Source: http://personalitymooddisorders.suite101.com/ article.cfm/understanding\_the\_dsmivtr



## Family Guide to Understanding Depression in Adult Persons with Mental Retardation adn Developmental Disability (MR/DD)

## **1. Symptoms of Depression**

Depression is a common problem experienced by persons with mental retardation. Persons with mental retardation have greater risk for developing depression than the general public; especially individuals with epilepsy or a family history of depression. The symptoms of depression depend upon the severity of intellectual disability. The person with mild retardation can often describe the typical symptoms of depression. Persons with moderate or severe retardation may develop behavioral problems as a symptom of depression including weight loss, diminished activity, anger, hostility, resistiveness or loss of function. Many patients with depression also develop sleep problems and signs of anxiety. The person with mild retardation may begin to express thoughts of harming themselves. Some depressed patients may begin to hear voices, see things or worry about false ideas.

## 2. Causes of Depression

Depression is a biological brain disorder. Persons with neurological damage have a greater risk for developing depression. Many medications and health problems can produce symptoms that resemble depression. Life stress can produce symptoms that resemble depression. A family history of depression may increase the risk for developing depression.

## 3. Evaluation of Depression

Your primary care doctor or the consulting psychiatrist should evaluate the patient to exclude medications, medical problems or life stressors that can mimic depression. Your psychologist or behavioral specialist can measure behaviors that suggest depression. There is no blood test or brain scan that detects depression. Diagnosis is based on your doctor's clinical judgment.

## 4. Treatment of Depression

The treatment of depression includes psychological interventions for persons with mild retardation and medication treatment for all persons with severe symptoms of depression The behavioral specialist can help with behavioral symptoms. Antidepressant medications require six weeks to 2 months to improve mood. Patients who become nervous with depression are better treated with behavioral management rather than the use of nerve pills. The antidepressant medication should improve the anxiety in four



to six weeks. Anti-anxiety medications, like Xanax or Valium, can worsen confusion and deepen the symptoms of depression.

Sleep problems produced by depression will improve when the depression is properly treated. The doctor will not know which specific medication will relieve the depression. Some patients require two or three trials of medication to find the correct drug.

Depression produces many complications in the person with mental retardation. The family and the doctor should never give up on treating depression because the vast majority of people get better with persistent treatment. Most patients require treatment for at least six months to one year.

#### 5. Duration of Treatment

The length of medication therapy varies from six months to years or decades. The duration of treatment is a decision made by your doctor, the patient, and your family. Depression may return after months or years and the patient should be monitored at regular intervals to prevent a new episode.

Family Guide to Treatment of Depression in Adult Persons with Mental Retardation and Developmental Disabilities (MR/DD)

© Richard E. Powers, MD (2005) - Bureau of Geriatric Psychiatry, 2005 DDMED 65

## Depression and a Person with an Intellectual or Developmental Disability

#### What is depression?

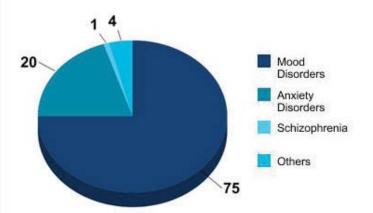
Depression is a serious medical condition which may be treated with medication and therapy.

People with Developmental Disabilities suffer from the full range of psychiatric disorders as those without developmental disabilities. These disorders often present as negative behaviors. Because our system focuses on eliminating negative behaviors, we may mistakenly misinterpret negative behavior as a character problem instead of a psychiatric illness. Depression is not well studied in people with ID/ DD compared with the "typical population."

## Mental Health Aspects of Intellectual and Developmental Disabilities:

Persons with a dual diagnosis can be found at all ages and levels of intellectual and adaptive functioning. Estimates of the frequency of dual diagnosis vary widely, however, many professionals have adopted the estimate that 30-35% of all persons with intellectual or developmental disabilities have a psychiatric disorder. The full range of psychopathology that exists in the general population also can co-exist in persons who have intellectual or developmental disabilities. The co-existence of intellectual or developmental disabilities and a psychiatric disorder can have serious effects on the person's daily functioning by interfering with educational and vocational activities, by jeopardizing residential placements, and by disrupting family and peer relationships. In short, the presence of behavioral and emotional problems can greatly reduce the quality of life of persons with intellectual or developmental disabilities. It is thus imperative that accurate diagnosis and appropriate treatment be obtained in a timely manner.

## Research & ID/DD



According to the DSM IV, Major Depression has a collection of symptoms. Unfortunately, many health professionals rely on the individual's ability to self-report before making a diagnosis. Since some with disabilities are non-verbal or do not have sufficient vocabulary to describe their feelings, depression may often be overlooked or mismanaged. The following articles explain in more detail the symptoms of depression in a person with ID/DD and ways to help support the person experiencing this particular dual diagnosis.

## Depression In Persons With Developmental Disabilities

## Major Depressive Episode Sovner & Hurley (Behavioral Presentations in a Person With A Developmental Disability)

## 1. Depressed Mood/Irritability

Description by others of a change from being happy and smiling or laughing, of having a sense of humor to an absence of these characteristics. Tearfulness, spontaneous episodes of crying and or whining, the person rarely smiles. Increase in somatic complaints. The person might be complaining constantly or regularly asks to return to a previous residential setting.

The person can be easily provoked to scream and swear. Onset of or increased shouting, yelling, blaming or spitting on others. The person is becoming uncooperative and can have "tantrums" when any request is made. Onset or increase in severity of noncompliance.

- 2. Markedly Diminished or Decreased Interest or Pleasure in All, or Almost All Activities Loss of interest in friends and refusal to participate in previously favored social/work activities. The person is more withdrawn, spends excessive time alone. The person does not respond to the typical reinforces or previously enjoyed activities.
- 3. Decrease/Increase in Appetite Significant Weight Loss/Weight Gain

The person might refuse to go to the dinner table or refuse to eat anything once there. Others may describe this as non-compliance and should be asked about it specifically. The person might reject favorite foods and lose some weight.

The person may be requesting and eating extra food or start stealing or hoarding food. The person begins to engage in pica (or there is an increase in frequency). Others might notice weight gain.

## 4. Insomnia or Hypersomnia

Behavioral disturbances in the evening might overshadow underlying sleep disturbances. The person might have difficulties falling asleep and maintaining sleep, or wake up early in the morning. Behavior difficulties (or an increase in frequency or severity) may occur at those times. The person starts sleeping 12 or more hours in a day, takes excessive naps. Sleep is the preferred activity.

5. Psychomotor Agitation or Retardation Pacing, running, spinning may be a manifestation of agitation. The person appears to be "wired", may be unable to sit still and is generally described by others as more restless. The onset of or increase in selfinjurious behavior, stereotypy, running away or aggression may also be a manifestation of agitation.

The person is emotionally needy, seems clingy and might continually repeat words or phrases in anxious and fearful tones of voice.

Retardation may be manifested by a decrease in speech inflection, volume and content or in having trouble completing activities of daily living. The person may also manifest extremely slow body movements and thinking. The person can remain virtually motionless for long periods of time.

#### 6. Fatigue or Loss of Energy

Others may notice a decrease in productivity or regression in skills. The person spends excessive time lying or sitting down. The person rarely initiates activities and appears unmotivated. Apathy.

#### 7. Feelings of Worthlessness or Excessive or Inappropriate Guilt

The person makes (or communicates in some way) negative self-statements such as "I am bad," "It's my fault," "Nobody likes me," "I can't do this job" or "I should be punished." Onset of or increase in ruminations, worries or preoccupations with previous placements and relationships.

## 8. Diminished Ability to Think or Concentrate, or Indecisiveness

Reduced work productivity or regression in skills. The individual may begin a task but not follow through. The person's workshop or day program performance has deteriorated. Decreased attention to the task may also occur. Diminished self-care skills and increased dependence on others.

## 9. Recurrent Thoughts of Death, Suicidal Ideation or Attempts

The person talks regularly about the death of relatives or friends, and/or expresses an interest in funerals. The person talks often about heaven and hell, or makes suicidal threats or attempts. Deliberate potentially lethal acts. Onset of or increase in self-injurious behavior. Offering oneself up to peers who are known to aggress.

#### **Associated Features**

- Clinging or holding onto others.
- Fearfulness.
- Decreased interest in sexuality.
- Repeated complaints of aches, pains, physical ailments.
- Onset of or increase in aggression and/or selfinjurious behaviors (SIB).
- Incontinence of urine and/or feces.
- Catatonic stupor and/or rigidity.
- A family history of mood disorder, alcoholism, and mental illness.

## Supporting a Person with ID/DD and Depression

To help support a person with ID/DD, we may want to teach vocabulary that will allow the person to speak for him/herself and not need to rely on others to communicate on his/her behalf. To teach vocabulary, start simply and go slowly. Use may use pictures that represent feelings and then say or ask what emotion the person in the picture might be feeling.

You can do this for all types of emotions to help build a "feelings" vocabulary. The use of a "Feelings Chart" may be especially helpful in teaching emotions. For someone who is nonverbal, you may ask the individual to point to pictures in response to questions about how they are feeling. There are many "Feelings Charts" that you can find online to print out and use. A few are offered at the end of this article.

Sleep is important to discuss when supporting a person with ID/DD and co-occurring depression. The amount of time a person sleeps is an important piece of information that a psychiatrist or therapist will want to know when assessing and treating depression. Collecting data on sleep is

especially important. Insomnia (sleeping too few hours) or hypersomnia (sleeping too many hours) might be missed entirely by caregivers of those who have been socialized not to complain or inform others about problems they may be feeling or experiencing, such as insomnia or hypersomnia. We may want to teach vocabulary that helps the person express if they are not sleeping well, or feel they want to sleep for very long periods. You may also want to keep a sleep chart to take to the treatment professional. This will help identify if there is a worsening or improvement in the illness over time. A sample sleep chart is provided at the end of this article.



Consider each of the symptoms of Depression illustrated here. How might the person you support who has depression express each of these symptoms?

Sovner and Hurley have gathered good examples over the years of how we might observe symptoms of depression in those with ID/DD. Tearfulness and spontaneous episodes of crying and/or whining may be observed. The person may also rarely smile.



The individual might complain constantly or regularly ask to return to a previous residential setting. S/he may be easily provoked to scream and swear, shout, yell, or blame others for problems. S/he may spit on others, become uncooperative and can have tantrums when any requests are made. There may be an onset of these behaviors or an increase in their severity as depression takes hold.



Other symptoms of depression include feelings of worthlessness or excessive or inappropriate guilt. This can be expressed by the person who communicates in some way negative statements such as:

- I am bad
- It's my fault
- Nobody likes me
- I can't do this job
- I should be punished

Onset or an increase in ruminations about worrisome matters or preoccupations with previous placements and relationships can also be symptomatic of depression in those with ID/DD.

All Behavior is a means of communication. For some of those we support, they may use language differently and show us their distress in the way that they behave or respond to the external environment or internal feelings. It is often difficult to understand feelings all the time and sometimes even more difficult to express them. Sometimes challenging behavior is the only way a person can tell us that something is wrong, that something is troubling or hurting or very disturbing for them.

One of the things we can examine is the person's communication skills and tools. If behavior that is challenging or destructive is the only means to communicate that something is wrong, they may need our help to add something to their repertoire of skills or tools so they can better communicate in a way that is less frightening for everyone. We may need to help the person find a communication method which is easier and more effective than the behavior we find challenging.

Elements in the person's environment may be contributing to his/her internal distress and/ or problematic behavior and negative feelings. Consider the person's environment-- is there a problem; is there a staff or housemate the person doesn't get along with? Are there settings where there is too much noise or light or other intense stimuli? Examine the environment and try making adaptations to determine if an environmental factor is contributing to a person's distress. Some have gotten creative and installed a "sensory room" or "sensory corner" where there are very soothing, therapeutic elements that people find calming and comforting.

**Clinical assessment** is appropriate if we have added effective communication tools & skills and adapted the environment but there is no significant positive impact. Before determining, however, that there is a psychiatric concern, it is important to rule out a medical problem. A variety of medical conditions can cause depression. These



include dietary deficiencies in vitamin B6, vitamin B12, and folic acid; degenerative neurological disorders, such as Alzheimer's

disease and Huntington's disease; stokes in the frontal part of the brain; and certain viral infections, such as hepatitis and mononucleosis. Certain medications, such as steriods, may also cause depression. A medical evaluation by the Primary Care Physician will rule out any physical causes.

Up to 70 percent of people with depression respond to antidepressant drugs. These medications appear to work by altering the levels of serotonin, norepinephrine, and other neurotransmitters in the brain. They generally take at least two to three weeks to become effective.

Electroconvulsive therapy (ECT) can often relieve severe depression in people who fail to respond to antidepressant medication and psychotherapy. In this type of therapy, a low-voltage electric current is passed through the brain for one to two seconds to produce a controlled seizure. Patients usually receive six to ten ECT treatments over several weeks. ECT remains controversial because it can cause disorientation and memory loss. Research has found it highly effective in alleviating severe depression.

In all cases, the importance of relationships in healing cannot be underestimated. Those who are experiencing any illness need people who will "hang in there' with them. Offer support as the

person struggles; walk along side them as they travel through the journey of recovery. Reassure the person that you know they are struggling and that you have worked through things together before and you will do so again. To "hang in there" is difficult to do when there is prolonged illness. Take time for yourself to rejuvenate with those people, in those places, and with those things that add joy and meaning to your life.

(Sample feelings chart on opposing page)

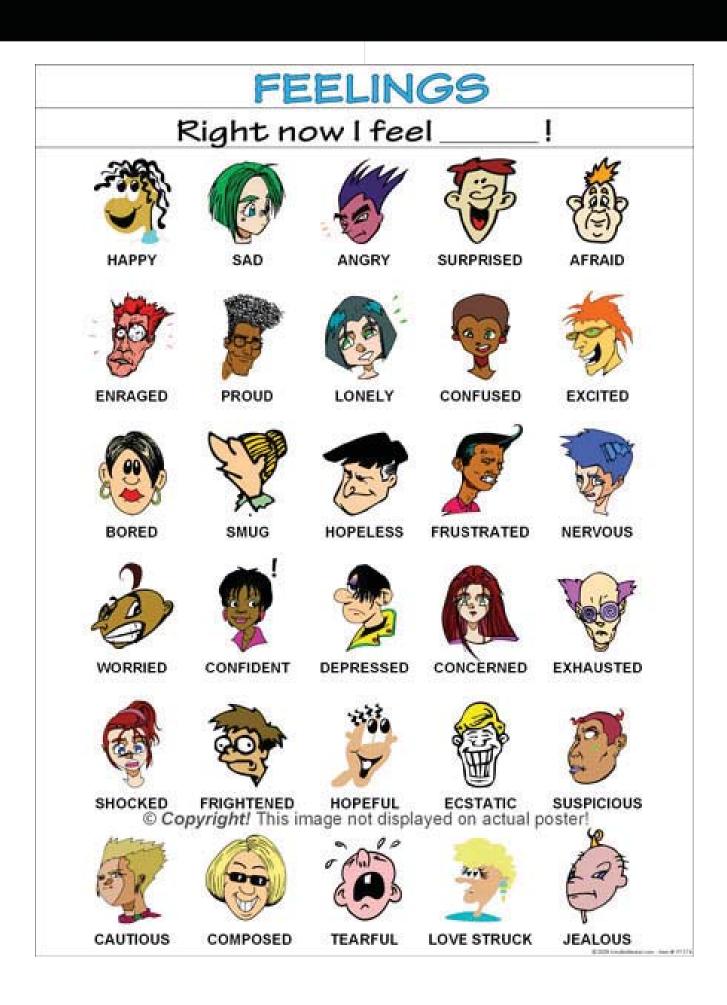
## A Family Guide To Understanding Bipolar Disorder in Persons with Mental Retardation and Developmental Disabilities (MR/ DD)

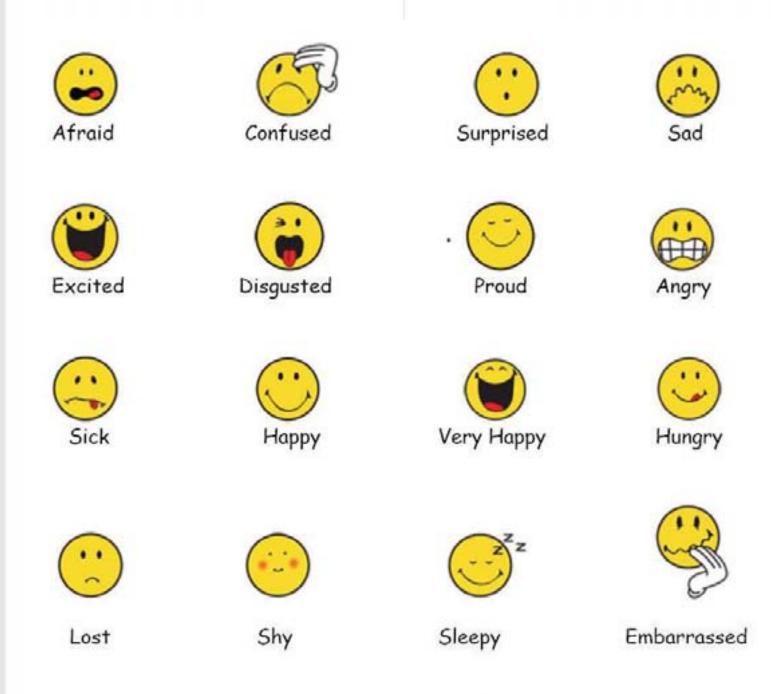
Emotions are a form of intellectual function that are controlled by the brain. Emotional regulation requires sophisticated intellectual function just like language or complex motor skills. Persons with mental retardation may have problems with regulation of mood that are called "mood disorders." Individuals can have three different kinds of mood problems: (1) too low, called depression, (2) too high, called mania, and (3) cycles between high and low, called bipolar disorder or manic depressive illness.

Mania means that a person's mood is too high and that their brain is moving too fast. The term "mania" is different from the word "maniac" and persons with mania have too much energy, excessive happiness, diminished sleep, excessive sexual drive, and excessive speaking. Persons with moderate or severe mental retardation may demonstrate restlessness, moving too much, talking too much, not sleeping enough, or unusual sexual behaviors. Some patients become grumpy, angry, hostile or assaultive. Mania can have many different symptoms depending on the kind of mental retardation. Most persons with mania may have episodes of depression at other times. A minority of patients with depression can sometimes exhibit manic symptoms. The symptoms of mania can be produced by medications, such as antipdepressants, steroids, and others.

The treatment for mania or manic-depressive illness is the prescription of mood stabilizer medications. Medications that control mood include lithium, valproic acid, and others. Mania will often last for weeks or months, and patients often require treatment for the symptoms.

"Manic-depression distorts moods and thoughts, incites dreadful behaviors, destroys the basis of rational thought, and too often erodes the desire













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# Sample Sleep Chart

# INSTRUCTIONS

1. The patient should be instructed to open the eyes, raise a hand, or move the head on the approach of a nurse.

2. Observations should be made by approaching the bed and making a very slight sound, such as rustling the apron. The patient should not be touched or addressed.

3. If the patient appears to fail to co-operate when awake, observations should be discontinued.

and half a diagonal line should be placed in the space of the next observation, the second sign corresponding to the state of the patient at the second half-hourly observation. 4. When the patient is asleep a dot should be placed in the appropriate space: when awake, a diagonal line thus 🖾 If the patient is both awake and asleep after a half-hourly observation, a dot

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# INSTRUCTIONS

1. The patient should be instructed to open the eyes, raise a hand, or move the head on the approach of a nurse.

2. Observations should be made by approaching the bed and making a very slight sound, such as rustling the apron. The patient should not be touched or addressed.

3. If the patient appears to fail to co-operate when awake, observations should be discontinued.

4. When the patient is asleep a dot should be placed in the appropriate space: when awake, a diagonal line thus 🛛 If the patient is both awake and asleep after a half-hourly observation, a dot and half a diagonal line should be placed in the space of the next observation, the second sign corresponding to the state of the patient at the second half-hourly observation.

## SECTION 2: MENTAL HEALTH DISORDERS & THOSE WITH ID/DD

and will to live. It is an illness that is biological in its origins, yet one that feels psychological in the experience of it; an illness that is unique in conferring advantage and pleasure, yet one that brings in its wake almost unendurable suffering and, not infrequently, suicide."

**Quote from Kay Redfield Jamison, Ph.D., (Who has Bipolar Disorder) An Unquiet Mind, 1995, p. 6.** (In the past, bipolar disorder was frequently referred to as Manic-Depression.)

Mood disorders are divided into two groups according to Brian Quinn, author on bipolar disorder. Those two groups are:

- 1. Unipolar disorders. Depression only
- 2. Bipolar: Depression and mania

Bipolar disorder is a mood disorder identified in the DSM IV. Bipolar is a progressive illness which means that current information about this disorder suggests that the longer the abnormal chemistry related to the illness has been present, the more difficult it will be to treat. Some refer to this as the "kindling" effect.

Bipolar disorder is an involuntary disorder. A person cannot through the power of his or her will regulate it.

It is also a biochemical disorder due to there being a deficiency of chemicals to the receptors of the brain, and affects the body both physiologically and psychologically.

When someone is struggling with mania, it is generally accepted that the person has a bipolar disorder. People experiencing bipolar disorder describe their experience as feeling helpless to control an unpredictable mood. Someone affected by this disorder can have not only high and low emotional feelings, but also a mix of both depression and manic symptoms at the same time. The person may, for instance, feel restless and unable to sit still and yet complain of exhaustion and lack of energy. The mood of a person wit mixed symptoms is often irritable or explosive.

## Symptoms of Mania

- Euphoric Mood
- Grandiosity
- Irritable modd
- Hyper sexuality
- Sleep decrease
- Pressured Speech
- Racing Thoughts
- Distractibility
- Psychomotor agitation
- Obsessions

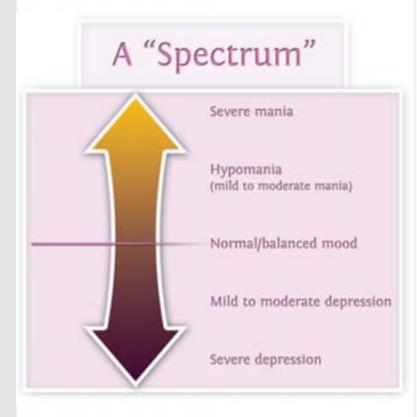
## **Symptoms of Depression**

- Depressed mood
- Irritability
- Decreased interest in pleasurable activites
- Decrease/increase in appetite
- Insomnia/hypersomnia
- Fatigue
- Feelings of worthlessness/guilt
- Diminished ability to concentrate
- Recurrent thoughts of death

According to the National Institute on Mental Health, it may be helpful to think of the various mood states in bipolar disorder as a spectrum or continuous range. At one end is severe depression, above which is moderate depression and then mild low mood, which many people call "the blues" when it is short-lived, but is termed "dysthymia" when it is

chronic. Then there is normal or balanced mood,

above which comes hypomania (mild to moderate mania), and then severe mania.



In some people, however, symptoms of mania and depression may occur together in what is called a mixed bipolar state. Symptoms of a mixed state often include agitation, trouble sleeping, significant change in appetite, psychosis, and suicidal thinking. A person may have a very sad, hopeless mood while at the same time feeling extremely energized. Often children who are diagnosed with bipolar disorder will present in a "mixed" state.

## Bipolar Disorder & Suicide

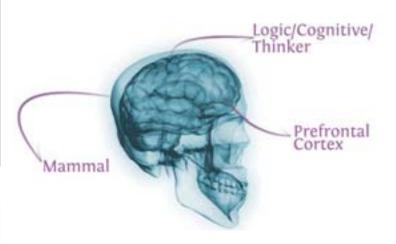
- Suicide is the leading cause of death for people with Bipolar Disorder
- 10-20% suicide rate
- 1/3 of people diagnosed admit to suicide attempts

Some people with Bipolar disorder may experience psychosis, particularly while manic. Psychosis is not necessarily because of the Bipolar disorder, but is associated more with the lack of sleep people may experience. Anyone who goes without sleep for an extended period of time may begin to hallucinate.

## Bipolar Disorder & Psychosis

- In some people psychosis may occur
  - hallucinations
  - delusions
- Usually reflective of the extreme mood state oat the time
  - Generally tied to lack of sleep

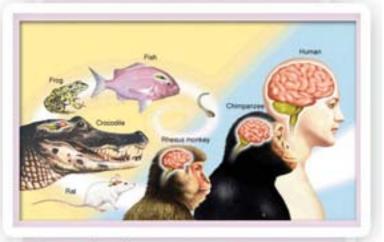
Sometimes, severe episodes of mania or depression include symptoms of psychosis (or psychotic symptoms). Common psychotic symptoms are hallucinations (hearing, seeing, or otherwise sensing the presence of things not actually there) and delusions (false, strongly held beliefs not influenced by logical reasoning or explained by a person's usual cultural concepts). Psychotic symptoms in bipolar disorder tend to reflect the extreme mood state at the time. For example, delusions of grandiosity, such as believing one is the President or has special powers or wealth, may occur during mania; delusions of guilt or worthlessness, such as believing that one is ruined and penniless or has committed some terrible crime, may appear during depression. People with bipolar disorder who have these symptoms are sometimes incorrectly diagnosed as having schizophrenia -From NIMH



#### When the Prefrontal "Bulb" Goes Out

This diagram is a very simplified breakdown of various functions of the brain. Dr. Jay Carter, PsyD, DABPS, likens the prefrontal lobe to a light bulb, and explains that during mania, this bulb "goes out". Again, this is VERY simplified, the parts of the brain where arrows are indicating are extremely general and not necessarily medical in nature. However, when we think about the brain being divided into various sections in this way it can be useful in understanding bipolar disorder and how we can be helpful.

## "Mammalian" Brain



Survival > Pleasure/pain > Stress response

The "mammalian" brain functions are related to physical survival and body maintenance digestion, reproduction, circulation, breathing, stress responses, territorial instincts, social dominance.... Functions related to the instinctive behavior patterns of self-preservation include 'primitive' behaviors. The functioning is activated when the person perceives threat and the need for survival and safety predominate. This part of the brain is active, even in deep sleep. This part of the brain strives for pleasure and to avoid pain. It is primarily programmed for SURVIVAL.

## Cognitive Brain

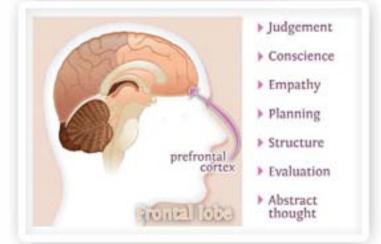
- "Rule" based
- Routine
- Consistency
- · contractions
- "Ritual"

Concrete

· Raterian

The "cognitive" brain is responsible for automatic behaviors associated with territoriality, ritualism, social dominance, status maintenance, deception, tendency to follow precedent, awe for authority, social pecking order behavior, compulsiveness, deception, prejudice and resistance to change... rigid, obsessive, compulsive, and paranoid. Very much rule-based and operates with a desire for consistency and concrete information can be ritualistic. This is the part of the brain that is extremely active during mania, a person may be consumed in the cognitive, thinking quickly and constantly at a fast rate. (Like having a Pentium 6 processor in the Brain when the rest of us have a Pentium 1).

## Prefrontal Cortex



This area of the brain is thought to be involved in planning complex cognitive behaviors and in the expression of personality and appropriate social behavior. The prefrontal cortex is essentially where judgment and our "conscience" lies, this gives us the ability to see the "big picture" and be able to play out consequences of our actions in a "minds eye" which will often help deter our doing things we know will cause problems for us or others. This is also the part of the brain where many speculate our "empathy" is. Responsible for planning, structuring, and evaluating voluntary goal directed behavior, i.e., activities requiring the constant comparison of planned acts with the effects achieved.

To help illustrate how each of the "brains" work let's tell a story about chocolate. A woman named Cheryl LOOOVES Chocolate, particularly snickers almond bars. One of those

and a Doctor Pepper and she's happy for the rest of the day. The problem is that if she eats an almond snickers every time she wants to, she will put on lots of weight and eventually won't feel very good. So let's say Cheryl is at the grocery store, her prefrontal cortex tells her to pick up a lot of healthy things in the produce section



because it can "see" into the future and is aware that the consequences of eating junk will be poor health and an unflattering figure. Her Cognitive brain is very regimented and takes her through the rest of the store in the same way she typically goes, because that's what it's used to and going any other way won't make sense. Her mammalian brain knows that the almond snickers are in the middle isle and it tells her to knock over the lady with the walker, jump over the toddlers in her way and dash to the center isle to get to those almond snickers, rip 'em open and devour them! Thankfully, her prefrontal cortex which can reason quite well and helps her stay away from the snickers is able to override that mammalian brain (most of the time). If she goes to the store and is stressed out, her mammalian brain which deals in seeking pleasure, avoiding pain and survival, may lead her directly to that candy isle as a way of coping. Then, later she may feel guilty when her pre-frontal cortex kicks in and can imagine the extra five pounds that she might gain from doing SO.

For someone with bipolar disorder, the prefrontal cortex essentially stops working during a manic episode. The "bulb" will begin to fade during the period just before mania (hypomania) and studies have actually shown that functioning is not restored completely in the prefrontal cortex until up to eight weeks following a manic episode. For people who cycle rapidly (children tend to and people who have had many untreated episodes of mania) they may almost always function with a very "dull" or busted "bulb".

DURING...

The "bulb" goes out ...

The last part of the brain to develop is your pre-frontal cortex,/frontal lobe area. It usually develops by about age 12. This part of the brain is believed to hold the ability to see "the big picture" of things. It provides you with the imagination to discern and even be aware what consequences will occur for the action you are taking. Someone with bipolar disorder and has become manic suddenly can have this function just "drop out". Once it drops out, they may not feel "right". But there is no lobe there working, so there is no way they can say "Excuse me. My ability to see the bigger picture of things just went out on me because of my mania, so I have temporarily lost my executive function" There is no way they could say that because they would need to see the bigger picture in order to be able to notice it!

Without the prefrontal cortex, people with Bipolar disorder tend to rely on the cognitive brain, which means that things will be somewhat regimented (and can sometimes even look obsessive) and logical. There is a lack of judgment without this part of the brain intervening.

## Without prefrontal cortex

- Lack of judgement
- Little or no context
  - + Here and now oriented
  - Impatience
  - ▶ Temper

Note that people with Bipolar disorder do not commit crimes and are not violent, although studies show that about 5% of people in prison are diagnosed with bipolar disorder and there are probably at least another 5% undiagnosed.

So, when a person is manic...and their thoughts are racing...they are preoccupied COGNITIVELY... and consumed cognitively to the point where they have no time to feel or be able to imagine how others feel (remember empathy is thought to be an executive function). Cognitively, they may be sharp with details, but they are not in touch with their feelings, others' feelings or the consequences of their actions in the present moment. Everything is perceived with logic, which can sometimes be cruel and cold and is very limited. In other words reality, or consequences, may not be real to that person. They are not stupid, and cognitively they may be aware that something is "wrong", but they may not be able to imagine or feel it or be conscionable about it;

for them it is just some far-off impersonal matter. Therefore, the person may be able to function and think and may even have brilliant ideas, but their judgment is way off and they have no awareness (just an impersonal intellectual understanding) for the consequences or how their actions will affect others or themselves. Mania closes the doors to the prefrontal cortex executive functions.

- Person may be preoccupied cognitively
- May be sharp with details
- Not in touch with feeling or consequences
- Perception based on logic (cold, cruel, limited)

For family/friends/supporters of someone with Bipolar Disorder, the things that happen because of this "dropping out" of the prefrontal cortex can be one of the most heartbreaking parts. Without the ability to empathize and with calculating logic operating all the time, a person with Bipolar may say and do hurtful things to those around them. The challenge is for people not to take it personally, which can be very difficult when someone is using your secrets, things you've shared in confidence or your relationship with them to hurt you. Later the person may even be argumentative and believe they didn't say those things, or they may feel very guilty and angry with themselves for being so hurtful.

## "We hurt the ones we love the most."

- Can be most difficult part for loved ones & supporters
- It's part of the mania
- It's NOT personal

During these periods the person is simply cognitively driven, moving at high speed in their own brain, which can cause them to feel frustrated when others can't keep up, or frustrated with their inability to focus on one thing and get things finished. They may also become highly distressed when things they have "planned" independently of anyone else's input can't be done. In children with Bipolar disorder this can be a big source of

## SECTION 2: MENTAL HEALTH DISORDERS

**THOSE WITH ID/DD** "tantrums" and rage that can last for hours. In an adult it can look explosive.

One of the most difficult things for people to deal with is what Dr. Jay Carter refers to as "Ego, arrogance, entitlement." It could be interpreted as narcissism and selfishness, but it is PART of the mania. People take this personally, but it isn't personal. When a loved one is manic, repeat to yourself "This is NOT about ME" even when they throw the truth in your face, remember it's not about you. Even when they say nasty things you shared as a secret...it's not about you. When you take things personally during mania you may begin to forget that it is not completely part of that person's control and it damages your relationship and becomes a potentially explosive situation.

## A note about "lying"

- The chemical imbalance can...
- Cause memory loss or "spotty" memories
- Affect state of mind

This a phenomenon that also tests those around the person with Bipolar, it can be difficult to discern this a part of the "prefrontal lobe drop out". For example, there was a ten-year-old boy who was diagnosed with bipolar who called his mother a blankety blank when he came downstairs for breakfast one morning (mornings can often be the most difficult part of the day for someone with BPD especially children). His mother immediately reprimanded him and requested that he return to his room to "think about it" and adopt a new attitude. The boy came downstairs 10 minutes later and hugged his mother. She responded "well, this much better than calling me a blankety blank!" The child looked up confused and said "I didn't call you that!" Mom said "of course you did! Your father even heard you!"The father agreed, and boy looked even more confused and insisted he simply had NOT said it. An argument ensued with mother and father trying to convince the child he had. What is the explanation?

Consider for a moment what happens when someone takes amphetamines, they affect the

same dopamine centers as mania. People who have taken many amphetamines may tell you that their memories are spotty or blank sometimes when they use. This is similar to the experience some people have when they drink too much. When chemicals in the brain are poisoning the cognitive system, we don't remember things. This boy was in a DIFFERENT state of mind.

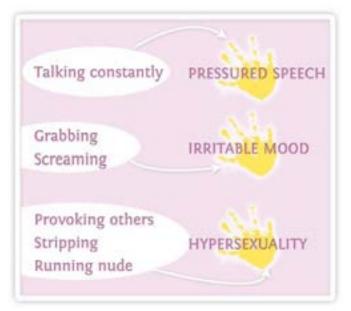
## Bipolar Disorder in a Person with an Intellectual or Developmental Disability



The person with a developmental disability may not be able to articulate their internal mood states, but their behavior may well suggest a manic

or depressed mood state. If you see these signs in a person you support, you may be looking at symptoms of mania:

- Talking constantly
- Grabbing
- Screaming
- Provoking others
- Stripping
- Running nude



Talking constantly can be a behavioral manifestation of a pressured speech, which is a sign of mania. Grabbing and/or screaming can be a behavioral manifestation of the symptom of irritable mood in mania. Provoking others, stripping, running nude, can all be behavioral manifestations of another sign of mania: hypersexuality.

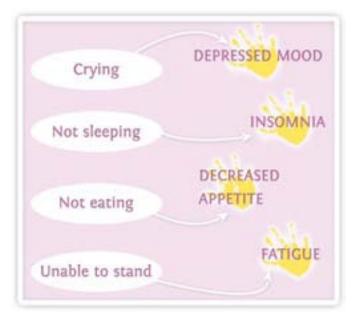
An individual with a developmental disability who is depressed will display some or all of these behaviors: Crying, not sleeping, not eating, not walking, unresponsive to questions, unresponsive to questions, dependence on others, incontinence.

## Challenging Behaviors (Depression)

Crying > Not Sleeping > Not eating > Unable to stand

(As in all behavioral health concerns, it is important to rule out a medical illness before concluding there is a mental health problem.)

Signs and symptoms of depression can be manifested behaviorally through crying, not sleeping, not eating, not being able to stand. aa



#### Support

An array of medication is used to treat bipolar disorder (manic depression). It is not uncommon for an individual to take several different types of drugs and to make frequent



changes to achieve an acceptable balance between stability and side effects.



Because of the complexity of bipolar disorder, there are wide varieties of medications used in treatment. Each group of medications treats a particular set of symptoms. Side effects are common: some may cause a patient to discontinue the medication, others may go away with time or be tolerable or treatable, and some side effects are dangerous.

Bipolar disorder medications fall into several categories:

- Mood Stabilizers
- Antidepressants
- Antipsychotics
- Antianxiety drugs
- Sedatives

Mood Stabilizers for Symptoms of Mania and Hypomania Mood stabilizers are the main treatment available for mania and hypomania. The first mood stabilizer to be used was lithium, and it is the only drug that was developed specifically for use in bipolar disorder. Today it is still mostly prescribed for bipolar patients, although it may be added to antidepressants for patients who suffer

from clinical depression (no mania symptoms).

Most the other drugs classified as mood stabilizers are medications that were first used to treat seizure disorders, such as epilepsy. They are known as "anticonvulsants," since they are designed to inhibit or reduce the frequency of seizures. Interestingly, they also help stabilize mood swings.

Finally, some heart-related medications called calcium channel blockers are being studied for use in treating bipolar disorder as mood stabilizers. Some of these drugs also have a positive effect on depression, but their primary purpose is to reduce the frequency and severity of mania and hypomania.

#### Antidepressants

Antidepressant medications are also used to treat bipolar disorder. An important thing to remember about antidepressants is that if they are not taken along with a drug that combats mania/ hypomania, antidepressants can actually cause these conditions to appear. Many people who seem to be suffering only from clinical depression are diagnosed with bipolar disorder after taking an antidepressant and experiencing mania or hypomania as a result.

There are several antidepressant classes. The names of these classes reflect either their chemical structure or, more commonly, their effect on brain chemistry. The best known at present are the SSRIs and SNRIs which are, respectively, selective serotonin reuptake inhibitors and serotonin norepinephrine reuptake inhibitors. Serotonin and norepinephrine are neurotransmitters - chemicals in the body that help the nerves pass along messages, and these medications help make more of these chemicals available.

Other classes of antidepressants include the MAOIs - monoamine oxydase inhibitors - and tricyclics, which are named for their chemical structure. There are also a few that do not fit into any of these classes and are thus called "atypical" antidepressants.

## Antipsychotics

Antipsychotic medications can eliminate or lessen the severity of symptoms like hallucinations and delusions; some also can decrease the symptoms of mania and/or help depression. There are two classes of these drugs: typical (the first-generation meds) and atypical (the second-generation meds).

#### **Anti-Anxiety and Sedative Drugs**

Anxiety and difficulty sleeping often go hand in hand with bipolar disorder. Anxiety can be a part of any type of episode - manic, mixed or depressive. The meds that treat anxiety are formally called antianxiolytics.

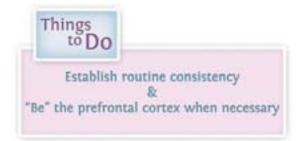
Most of the medications used to treat anxiety or promote sleep are classed as benzodiazepines, which include familiar brand names like Xanax and Valium, along with several others. Some drugs in other categories, such as antidepressants, may also have a sedating effect.

When we support someone with a Developmental Disability and Bipolar Disorder, we need to be active in collecting and looking for changes.

Source: http://bipolar.about.com/od/medications/a/ meds\_overview.htm



**Sleep** is an extremely important factor in relationship to Bipolar Disorder. Just missing out on sleep can cause a manic episode, so keeping a steady sleep routine is important, then monitoring for ANY changes to report to the doctor. Also be vigilant around travel or changes in routine as this could upset sleeping patterns as can time zone changes. Also changes around daylight savings time have been known to throw off sleeping patterns for people with Bipolar and start a manic episode. So be helpful in whatever you can to ensure the person sleeps and document as closely as you can for the physician. This is probably one of the most important factors that you can impact in some way.



Two of the most concrete things which can be very helpful are to help with a consistent routine and ensure that the person knows what to expect and when to expect it, this can help them feel much more secure, and with routine comes stability which can be very important.

Sometimes you may have to act as the person's frontal lobe when theirs "drops out", this may mean giving small step by step instructions, having visual schedules, or "talking" people into their frontal lobes.

Humor- tends to be universal, it can completely change a situation when managed correctly.

Always be sure to use KIND HUMOR, don't make fun of the person, avoid sarcasm, but don't be afraid to laugh with the person. It will help everyone feel a little less stressed.



There is a difference between acknowledging and nurturing someone's needs, as opposed to enabling them to do unacceptable things. Sometimes when people hear the word "nurture" they believe we are saying that you drop everything, let the person do what they want etc... Nurturing simply means "riding the horse in the direction it's going", It doesn't make sense to try to keep proving a point to someone who is struggling and has lost their prefrontal bulb, it will just end in tears and frustration for both of you, but you can join with the person and hopefully help to guide them gently to a point that is more comfortable for everyone.

It simply does not make sense to argue. If someone who is manic insists the sky is purple when everyone else knows it is blue, just honor that from their perspective-- at that moment for them the sky is purple. To begin some logical explanation of why they are wrong may be to make a big a mistake. Now something that could have been over in a matter of five minutes has been blown up into a two hour argument that you simply can't win and the more you try, the more exhausted you will be become and more argumentative that person may become. PICK YOUR BATTLES!

## From the Depression and Bipolar Support Alliance

## What you can say that helps:

- You are not alone in this. I'm here for you.
- I understand you have a real illness and that's what causes these thoughts and feelings. You may not believe it now, but the way you're feeling will change.
- I may not be able to understand exactly how you feel, but I care about you and want to help.
- When you want to give up, tell yourself you will hold on for just one more day, hour, minute -- Whatever you can manage.
- You are important to me. Youre life is important to me.
- Tell me what I can do now to help you.
- I am here for you. We will get through this together.

## Avoid saying...

- It's all in your head
- We all go through times like this.
- You'll be fine. Stop worrying.
- Look on the bright side.
- You have so much to live for, why do you want to die?
- ► I can't do anything about your situation.
- Just snap out of it.
- Stop acting crazy.
- What's wrong with you?
- Shouldn't you be better by now?

Dr. Carter proposes these three simple steps as a

"universal" intervention.

**Affinity-** Willingness to be in the same space, connecting physically with a person whether a pat on the back, touching an arm or just sitting close by, letting the person know you care for them.

**Acknowledgement-** Acknowledge the persons' feelings and validate what they are experiencing.

**Admiration**-Find something to admire about the person (genuinely, not a false flattery). These three things are some of the most sought after (behind love) in the human experience.

## **Winston Churchill**

Had he been a stable and equable man, he could never have inspired the nation. In 1940, when all the odds were against Britain, a leader of sober judgment might well have concluded that we were finished," wrote Anthony Storr about Churchill's bipolar disorder in Churchill's Black Dog, Kafka's Mice, and Other Phenomena of the Human Mind.

"I don't like standing near the edge of a platform when an express train is passing through. I like to stand right back and if possible get a pillar between me and the train. I don't like to stand by the side of a ship and look down into the water. A second's action would end everything. A few drops of desperation."

- Winston Churchill (1874-1965)

Churchill made frequent references to his depression, which he called his "black dog". Today we can only make a retrospective diagnosis linking Winston Churchill and manic depression if we have evidence of mood swings - not



depression alone. According to Sir Winston's close friend Lord Beaverbrook, the great man was always either "at the top of the wheel of confidence or at the bottom of an intense depression." This does sound like a description of Winston Churchill and manic depression.

Other evidence of mania that

connects Winston Churchill and manic depression

#### includes:

**Belligerence:** he was combative in his personal relationships and openly exultant about war, describing his enjoyment of WWI "this glorious, delicious war" and stating "war is the normal occupation of man". In person, many found him sarcastic and overbearing, and he was notorious for monologues that could last for up to 4 hours or longer.

**Spendthrift:** he had persistent money troubles due to his extravagance, gambling, and lifetime refusal to plan or monitor his finances.

**Abnormal energy:** his preferred working day began when he awoke at 8am and ended sometime between 2-4:30am - this has been thoroughly and bitterly documented as he expected his staff to fit in with this.

Lack of inhibition: he worked from his four poster bed in the mornings, attended by colleagues and secretaries. One General described being summoned to a meeting a 4am where Churchill appeared dressed in his bathrobe. He often distressed his staff by meeting with them while dressed in nothing but the pale pink silk underwear that he had personally tailored. He would even walk around his house completely undressed or insist on conducting meetings from his bathtub.

**Prolific writing:** at his death Churchill left 15 tons of personal papers. Most of his income was derived from his writing, and he wrote countless articles, and 43 book-length works in 72 volumes.

**Grandiosity:** he was notorious for his disdain for other people and their opinions, his unwavering belief in himself as a great man, his early sense of self-importance and grand destiny, and his many histrionic actions and speeches.

Despite all of these symptoms, in fact some people believe it was because of Bipolar, Churchill is known as one of the worlds great leaders. His memory is cherished in Great Britain and his courage and leadership during the darkest days of WWII have left a legacy of the heroic leader Sir Churchill was.-In fact in England a mental health charity erected a statue of Churchill in a straightjacket this sparked controversy as many were outraged by the attempt to link Winston Churchill and Bipolar disorder. The organizations defended the statue and said their intent was to portray a positive image of bipolar disorder, a

spokesperson said the following "The message we want to portray is that it is possible to recover from mental illness and overcome it and be successful - because Churchill is an example of someone who was able to do that."

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## **Anxiety Disorders**

## Family Guide to Understanding of Anxiety Disorders in Persons with Mental Retardation and Developmental Disabilities (MR/DD)

**Symptoms of Anxiety** Anxiety symptoms and anxiety disorders are

common in all types of mental retardation and all levels of disability. Many persons with mental retardation may exhibit symptoms of anxiety. The mildly retarded person can describe the inner sensation of jitteriness and being on edge, while the moderate or severely retarded person may exhibit behavioral problems such as irritability, restlessness, agitation, and other related symptoms. Anxiety disorders can occur in all types of mental retardation. Patients need a thorough evaluation and careful treatment with behavioral management and medications as needed.

## **Types of Anxiety**

There are many types of anxiety disorders and some "nervous" people do not have a disorder. **Table 1** includes that most common types and symptoms.

## **Causes of Anxiety**

The appearance of anxiety symptoms in persons with mental retardation may differ from symptoms in persons with normal intellect and the doctor should conduct an evaluation to understand the cause of the change. Medications, medical problems, environmental changes, depression and psychosis (hearing voices, false beliefs) can produce anxiety. Primary anxiety disorders, such as post-traumatic stress disorder and generalized anxiety disorder, do occur in persons with mental retardation.

#### **Treatment of Anxiety**

The first treatment of choice for anxiety is behavioral management.

Medications can be used with severe anxiety and new antidepressants are highly effective in some cases. Nerve pills, called benzodiazepines, such as Valium, Librium, Klonopin, Ativan, and Xanax should be used as a therapy of last resort in the person with mental retardation. These drugs produce confusion, health problems and other side effects that can worsen the condition of persons with mental retardation. Benzodiazepines are addictive. Persons who take these medications for more than one or two months should not abruptly stop these drugs. Benzodiazepines must be tapered over weeks to months to avoid withdrawal.

## **Dealing with Insurance Companies**

Health insurance and pharmacy benefit managers may restrict the number of medications available to treat anxiety. Patients should not have abrupt

Common Types	TABLE 1 of Anxiety Disorder 1s with MR/DD
Diagnosis	Symptoms
Generalized Anxiety Disorder (GAD)	Nervous most of the time
Panic Disorder	Sudden onset of severe nervousness and sometimes rapid breathing, shaking
Agoraphobia	Refusal to leave their residence
Post Traumatic Stress Disorder (PTSD)	Reaction to old, mental or physical trauma through nervousness, nightmares and excessive self-sefense

discontinuation of anxiety medications but rather a crosstitration to another equivalent medication that is available through the prescription benefit program or a gradual dose reduction over time. Cross-titration means that the doctor slowly decreases one medicine while slowly building up the other medicine with assessment to determine how well the patient is responding to the new drug. This process may take several weeks to several months for completion. Abrupt stoppage of medication or abrupt change to a different medication may cause significant behavioral relapse.

Family Guide to Treatment of Anxiety Disorders in Persons with MR/DD © Richard E. Powers, MD (2005) – Bureau of Geriatric Psychiatry DDMED 64

## Family Guide to the Use of Anti-Anxiety Medications for Persons with Mental Retardation and Developmental Disabilities (MR/ DD)

#### 1. Overview

Anxiety medications are commonly used by the American public. Almost all anti-anxiety medications work in the same way and produce the same types of side effects. Drugs like Ativan, Xanax and Klonopin belong in a class of medications called benzodiazepines. These medications can affect the brain like alcohol. In fact, doctors prescribe these drugs to treat alcohol withdrawal. The primary use of these medications is the treatment of anxiety.

## 2. Reasons to use Anti-anxiety Medications

Anti-anxiety medications are best used in patients with a clear diagnosis of anxiety disorder. Many problems will produce anxiety in the person with intellectual disability. Environmental stressors, conflict with family or roommates, pain, health problems, and some psychiatric disorders including depression can produce symptoms that resemble anxiety. The mild to moderately retarded person can describe the symptoms of anxiety; however, the severely retarded person usually lacks the capacity to explain these complex, internal events. Anti-anxiety medications are usually prescribed for specific diagnosis including



generalized anxiety disorder, phobias, posttraumatic stress disorder, and others. Anti-anxiety medications are best used after behavioral interventions fail to reduce the serious symptoms. The target symptoms of anxiety should be severe and cause the patient distress or diminished daily function.

## 3. Prescribing Anti-anxiety Medications

Persons with mental retardation are at higher risks for side effects from anti-anxiety medications. Doctors should avoid drugs that accumulate in the blood stream because they persist in the body for longer periods of time. Drugs like Valium, Klonopin, and Dalmane can linger in the blood stream for days and continuous doses will build up in the patient's body and brain. Drugs such as Ativan are preferable agents in the treatment of anxiety because the body can rapidly remove the medication. Xanax is commonly prescribed for anxiety; however, this medication is highly addictive and requires careful monitoring. Xanax is not available as an injectable medication and abruptly stopping the drug due to swallowing problems can produce a serious Xanax withdrawal. Many antidepressant medications will reduce the symptoms of anxiety. Buspar is a different type of anti-anxiety medication with fewer side-effects than the benzodiazepines.

Buspar requires several weeks to build up in the blood stream and exert its calming effect. Buspar is a good choice for chronic anxiety and benzodiazepines should be prescribed when other medications are not effective. Many patients with depression or psychosis become nervous and anxious. The recommended strategy is to treat depression or psychosis rather than prescribe medication for the anxiety. The symptoms often improve when the depression or psychosis is treated. Antipsychotic medications are rarely used to treat anxiety. Antipsychotic medications have many side effects and these powerful tranquilizers are a last choice for the treatment of anxiety in the mentally retarded person.

## 4. Side Effects

Anti-anxiety medications can produce many side effects. Sedation, confusion, difficulty with walking, problems with chewing and swallowing, irritability, impulsivity, and other side effects make the prescription of benzodiazepine medications complex for persons with mental retardation. Benzodiazepines and anti-anxiety medications have the same effect on the brain as alcohol. Like alcohol, some patients become sedated and mellow, while other individuals become disinhibited, irritable, and combative, i.e., the "rowdy drunk". Benzodiazepines increase the



risk for falls in older patients and probably produce the same risk in brain damaged younger individuals with intellectual disability. These medications can impair coordination, judgment, and reflex time. Mildly retarded persons who operate dangerous equipment or drive vehicles should not operate this equipment while taking benzodiazepines. The sedative effect of these drugs is cumulative with other medications such as anti-epileptics. The addition of benzodiazepine medications to other neurological drugs can substantially worsen the level of sedation. The dose of anti-anxiety medications depends on the patient's size and health problems as well as other medications received by the individual. Starting doses for the person with mental retardation should be one-half (1/2) to onefourth (1/4) of the dose typically started for young, healthy patients. Patients should be treated with the smallest possible dose of medication to avoid complications. Upward dose adjustment should occur on a weekly basis to allow blood levels to reach steady state. Families should be advised about side effects and possible interaction with other drugs prior to starting the medication.

## 5. Drug Withdrawal

Patients who are treated with benzodiazepine anti-anxiety medications for more than 3 or 4 months may become physically dependent on these drugs. Medication should not be discontinued abruptly. The dose taper should occur in small increments over a period of weeks or months to minimize the risk of withdrawal symptoms. The withdrawal from anti-anxiety medications resemble that for alcohol, including nervousness, sweating, confusion, seizures, and new behavioral problems.

### 6. Other Medications Prescribed for Anxiety Symptoms

Other medications are sometimes prescribed to



reduce nervous behavior in a person with mental retardation. Drugs like Benadryl, Atarax, equagesic, and others are sometimes prescribed for these individuals. These drugs are not recommended for use in patients to treat anxiety. These drugs have few beneficial affects and many side effects. These medications should be prescribed with great care. Family Guide To The Use Of Anti-Anxiety Medications For Persons With Mental Retardation © Richard E. Powers, MD (2005) – Bureau of Geriatric Psychiatry DDMED 60

## **Anxiety Disorders**

When we face a threatening situation, it is our sense of anxiety about the threat that prepares us for the dangers they represent. Our anxiety can be thought of as a call to action warning us that something is wrong and that we need to take action to stay safe. This type of anxiety is life preserving and guite appropriate. Sometimes however people become anxious inappropriately. They perceive or imagine a threat which isn't actually there. This type of anxiety is called inappropriate anxiety because it prompts us to act inappropriately, running away or hiding or losing control of ourselves in some way. When someone consistently experiences anxiety that is inappropriate, s/he is experiencing an anxiety disorder.

It is estimated by the National Institute on Mental Health that anxiety disorders affect about 40 million Americans 18 or older in any given year. Anxiety disorders are a group of related conditions that may appear quite different in their presentation from person to person. One person may have extreme attacks of anxiety without a known cause while another person may go into panic mode at the thought of having to talk to people they don't know.



There are many different forms or types of anxiety, but they all share one major symptom: persistent or severe fear or worry in situations where most people would not feel threatened.



Other symptoms may include sweating, dizziness, shortness of breath, tremors and twitches, fatigue

and insomnia. Many times people may arrive at the emergency room with these symptoms because they are attributing them to a medical condition such as a heart attack. However, a medical examination is the only completely accurate way to distinguish between the two.

When there is no outlet for anxiety it can feed on itself and continue to grow.

According to the Anxiety Disorders Association of America, **Generalized Anxiety Disorder** affects **Emotional Symptoms of Anxiety** 

- Feelings of apprehension or dread
- Trouble concentrating
- Irritability
- Feeling like your mind has gone blank

6.8 million adults, or 3.1% of the US population in any given year. Women are twice as likely as men

to be affected by this disorder. The disorder typically comes on gradually and can occur at any time during the life span. It is at it's highest occurrence between childhood and middle age. The exact cause of GAD is yet to be determined. However, some evidence suggests that there may be a link to biological factors,

## Physical Symptoms of Anxiety

- Pounding heart
- Stomach upset, frequent urination or diarrhea
- Muscle Tension
- Headaches

family background, life experiences, particularly stressful life events.

#### Obsessive-Compulsive Disorder is a disorder



in which a person has unwanted and intrusive thoughts that stick in the persons head and they just can't seem to get them to stop. These are obsessions. The obsessions then compel the person to repeat specific ritualistic routines that serve to reduce the anxiety of the obsessions. Some people are aware that the obsessions/ compulsions are irrational but they are unable to stop themselves. Some people may spend hours washing their hands, checking items such as alarms, doors or counting. These are all attempts to deal with an overwhelming sense of anxiety.

## Types of Anxiety Disorders

- General Anxiety Disorder (GAD)
- Obessive-Compusitive Disorder (OCD)
- Panic Disorder
- Posttraumatic Stress Disorder (PTSD)
- Social Anxiety Disorder
- Specific Phobias

#### Is hoarding a form of OCD?

As of now there is not a definitive answer. Current research links it to OCD but it is also being studied as to whether it may be a distinct disorder. So does every person in our system who hoards have OCD? Not necessarily, hoarding is often seen in persons with psychotic disorders, dementia, eating disorders, autism, developmental disabilities, as well as people with no psychiatric disorders, according to NAMI (National Alliance of Mental Illness). It is, however, most frequently associated with OCD. Between 25-40% of people with ODC have compulsive hoarding symptoms. Most people who hoard do not see the problem.

**Panic disorder** is an anxiety disorder and is characterized by unexpected and repeated episodes of intense fear accompanied by physical symptoms that may include chest pain, heart palpitations, and shortness of breath, dizziness, or abdominal discomfort. Symptoms can also include feelings of imminent danger with a need to escape, trembling, a smothering feeling, a feeling of choking, nausea, a sense of things being unreal, a fear of losing control or "going crazy", a fear of dying, tingling/pins and needles feeling, chills or heat flush. These symptoms can also be quite similar to those of cardiac, thyroid or respiratory diseases. It is important to have these

#### Post Traumatic Stress Disorder can be a

severely debilitating disorder. Recently, we have been hearing a lot about it in context of soldiers returning from war. Many soldiers have been exposed to life threatening situations or have seen others killed. It can occur in people who have witnessed or experienced a natural disaster, serious accident, terrorist incident, sudden death of a loved one, war, violent personal assault, or other life-threatening event.

Statistically, according to the Anxiety Disorders Association of America, 7.7 million Americans age 18 and older have PTSD. A person, with PTSD, may re-experience the trauma through intrusive and distressing thoughts of the event, flashbacks or nightmares. They may also become emotionally numb and avoid people, places or things that remind them of the trauma. The person may also experience increased autonomic arousal. This may mean that they would experience difficulty in sleeping and concentrating, as well as feeling jumpy or being easily angered or irritated.

While a huge percentage of those we support have been shown statistically to have suffered from traumatic events we do not often see a person being given a diagnosis of PTSD. According to Sue Gabriel, author The Psychiatric Tower of Babble, "Often problem behaviors go uninvestigated and without the diagnosis of PTSD a treatment plan will only continue to bury the scars under layers of compliance programming." Many times the people we support communicate non-traditionally and may not be able to verbally communicate that they have been traumatized.

**Social Anxiety Disorder** is just as it sounds. People with this disorder have difficulty in social situations. It can have a profound effect on interactions that most people take for granted. In extreme forms of this disorder, people may become so paralyzed by fear of embarrassing or humiliating themselves in a social situation that they choose to isolate to the point of having few to no relationships. This can leave the person feeling powerless and alone. phobia, experiences such an intense fear of being scrutinized in a social situation they may make themselves physically sick. This disorder may also be quite selective. For example, a person may be able to stand in a room full of people and give a presentation. Yet, the thoughts of having a conversation with a stranger, one on one, going on a date or attending a party may be completely overwhelming. Most people with this disorder recognize that this fear is excessive and irrational but they feel powerless against it.

Symptoms of Social Anxiety include blushing, profuse sweating, trembling, and nausea, In addition, a person may experience rapid heartbeat, shortness of breath, dizziness, and headaches. Persons with intellectual/ developmental disabilities are not immune to this disorder. How often might a person be put in a terrifying social situation and then display aggressive or non-appropriate behavior because we don't understand that fear?

## **Summary of Anxiety Disorders**

#### **Generalized Anxiety Disorder**

- Unrealistic worry about everyday things
- Exaggerated worry and tension
- Expecting the worst, even without cause

#### **Obsessive Compulsive Disorder**

- Unwanted and intrusive thoughts
- Repeatedly performing ritualistic behaviors/ routines

#### Why Do People Hoard?

- Excessive concerns/fears of:
- Discarding of something of value
- Losing some thing important
- Making a mistake

The person with a social anxiety disorder, or social

- Being wasteful
- Losing something that reminds them of someone
- Not doing things completely, well

#### **Panic Disorders**

- Spontaneous panic attacks
- Preoccupied with fear of another attack

#### Post-Traumatic Stress Disorder (PTSD)

- Potentially debilitating condition
- Person experiences/witnesses trauma
- Frequently relive events through flashbacks/ nightmares

#### Trauma and Developmental Disabilities

- 90% of people with ID/DD will be victimized by sexual violence
- ► 49% experience 10 or more incidents
- 15,000-19,000 people with developmental disabilities are raped each year

#### **Social Anxiety Disorder**

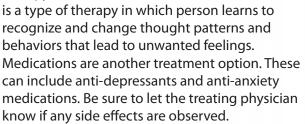
- 15 million American adults
- 36% report experiencing symptoms for 10 years prior to treatment
- Selective

Do you have a fear of spiders, large crowds, airplanes or high bridges? Most people have a fear of something. However, in general we are able to function in day to day life with our fears. A person who has a phobia of bridges, for example may feel that if they attempt to cross a bridge, the bridge will collapse and their car will go crashing into the water below. A person with specific phobia, however, typically is aware that their fear is irrational but they feel powerless to control it.

A person will do whatever they feel they need to do to avoid a phobic object, situation or place.

This can have great effects in their daily life. Most phobias arise unexpectedly during adolescence or early adulthood.

One **treatment for anxiety disorders** is cognitive behavioral therapy or CBT. CBT,



Additionally, eliminating or decreasing stimulants in a person's diet and eating a healthier diet can help decrease anxiety. Learning relaxation techniques such as deep breathing, stretching and muscle relaxation may be helpful.

## Treatment

- Cognitive-Behavioral Therapy
- Medication
- Dietary changes
- Relaxation techniques

When you or I feel anxious, we may go for a walk, talk to a friend or maybe play some music really loud. These would be our coping mechanisms. The people in our system are taught very few, if any, coping skills. While you or I may employ the coping skills that we know work for us, the person we support may engage in aggressive behavior or self injurious behavior because they have not learned any other skills for coping with their anxieties.

Ways to support someone who struggles with anxiety include the following:

Sleep- We all need to get adequate sleep. The



average adult needs to have 7-9 hours a night.

**Healthy eating-** We all probably are guilty of not eating as well as we should. The American diet typically consists of processed foods loaded with salt, sugar and fat. Moving toward healthier foods such as homemade meals, fresh fruits and vegetables and decreasing our consumption of empty calories through food and drink can make a big difference in how we deal with our daily world.

What coping skills do you use when YOU feel anxious?

What coping skills does the person you support have when they are anxious?

**Exercise**- Getting 30 minutes of exercise most days of the week can help reduce anxiety.

**Humor-** There is a Yiddish Proverb that says "What soap is to the body, laughter is to the soul." laughter has a cleansing property.

**Boundaries-** Teaching and utilizing appropriate boundaries can greatly reduce anxiety levels. This includes teaching people to say "No" and respecting their choice.

**Here and Now-** Helping ourselves and others to stay focused on the present, and trying to let go of the things over which we have no control.

**Listen and Talk-** Sometimes people just need us to listen. But we can also teach people to share/ communicate their thoughts and feelings.

**Enjoyment-** Help people to find something that they enjoy – an outlet.

**Promote self-esteem-** the better we feel about ourselves the easier it may be to deal with life's day to day anxieties.

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# NCTSN

The National Child Traumatic Stress Network



## Facts on Traumatic Stress and Children with Developmental Disabilities

National Child Traumatic Stress Network Adapted Trauma Treatment Standards Work Group

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Facts on Traumatic Stress and Children with Developmental Disabilities

From the

National Child Traumatic Stress Network Adapted Trauma Treatment Standards Work Group Subgroup on Developmental Disability

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National Child Traumatic Stress Network

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#### Contents

Federal Definition of Developmental Disability	3
Incidence of Disability in the General Population	4
Statistical Information Regarding the Incidence of Trauma for this Population	4
Special Characteristics of the Population that May Influence the Incidence of Trauma	5
Possible Reasons for a Higher Incidence of Mental Illness for Clients with Developmental Disabilities Than the General Population	7
Suggestions for Modifying Evaluation and Therapy to Meet the Needs of this Population	7
Special Diagnostic Considerations with Clients Who Have Developmental Disabilities	8
Suggestions for Therapy	9
References	10
Adapted Trauma Treatment Standards Work Group Contacts	12



#### Facts on Trauma and Children with Developmental Disabilities

#### Federal Definition of Developmental Disability

#### General

The term developmental disability means a severe, chronic disability of an individual that

- 1. is attributable to a mental or physical impairment or combination of mental and physical impairments;
- 2. is manifested before the individual attains age 22;
- 3. is likely to continue indefinitely;
- 4. results in substantial functional limitations in three or more of the following areas of major life activity:
  - a. self-care,
  - b. receptive and expressive language,
  - c. learning,
  - d. mobility,
  - e. self-direction,
  - f. capacity for independent living,
  - g. economic self-sufficiency; and
- 5. 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 lifelong or extended duration and are individually planned and coordinated.

#### Infants and Young Children

An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (a) through (g) of subparagraph (4) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

Reference: Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402.

#### Incidence of Disability in the General Population

- The national prevalence rate for developmental disabilities in the U.S. is 1.8 percent, based on an estimate conducted by Golay & Associates and used by the Federal Administration on Developmental Disabilities to extrapolate state level prevalence rates.
- About 3 percent of the population has an IQ of less than 70. The standard Wechsler IQ tests are based on a normal curve, so that 13 percent of the population has an IQ between 70 and 85, 68 percent between 85 and 115, 13 percent between 115 and 130, and 3 percent above 130.
- The exact prevelance of autism is not known, but estimates range from 1-in-250 to 1-in-1,000 in the United States (National Institutes of Mental Health, 2003).

#### Statistical Information Regarding the Incidence of Trauma for this Population

The following statistics should be interpreted with caution. Most reports regarding the incidence of trauma for people with developmental disabilities indicate it is likely the statistics reported underrepresent the prevalence of trauma. A variety of factors interfere with the ability to report, such as difficulty communicating that abuse has occurred, difficulty in being believed, and problems related to communication in general.

- Individuals with developmental disabilities are at increased risk for abuse as compared to the general population (Gil, 1970; Mahoney & Camilo, 1998; Ryan, 1994).
- Goldson, 2002 reports maltreatment among children with disabilities:

#### Incidents per 1,000

	Children without Disabilities	Children with Disabilities
Physical Abuse	4.5	9.4
Sexual Abuse	2.0	3.5
Emotional Abuse	2.9	3.5

- Individuals with disabilities are over four times as likely to be victims of crime as the nondisabled population (Sobsey, 1996).
- Sixty-four percent of the children who were maltreated had a disability. The most common disabilities were behavior disorders, speech/language, learning disability, and mental retardation. The most common type of maltreatment was neglect. Children with mental retardation were the most severely abused. Children with communication disorders were more likely to be physically and sexually abused (Sullivan & Knutson, 1998).
- Five million crimes are committed against individuals with disabilities each year in the United States (Petersillia, 1998).

- Individuals with disabilities are 2-to-10 times more likely to be sexually abused than those without disabilities (Westat Ind., 1993).
- Maltreatment of children with disabilities is 1.5-to-10 times higher than of children without disabilities (Baladerian, 1991; Sobsey & Doe 1991; Sobsey & Vamhagen, 1989; Sullivan & Knutson, 2000; Westat, 1991).
- One of 30 cases of sexual abuse or assault of persons with developmental disabilities is reported as opposed to one of five in the nondisabled population (James, 1988).
- Even when the abuse is reported, the charges are rarely investigated when the victim is disabled (Senn, 1988).
- Victims typically have difficulty accessing appropriate services (Sobsey & Doe, 1991).
- Risk of abuse increases by 78 percent due to exposure to the "disabilities service system" alone (Sobsey & Doe, 1991).
- Immediate family members perpetrate the majority of neglect, physical abuse, and emotional abuse. Extrafamilial perpetrators account for the majority of sexual abuse (Sullivan & Knutson, 2000).
- Sexual abuse incidents are almost four times as common in institutional settings as in the community (Blatt & Brown, 1986).
- Ninety-nine percent of those who commit abuse are well known to, and trusted by, both the child and the child's care providers (Baladerian, 1991).

#### Special Characteristics of the Population that May Influence the Incidence of Trauma

Abuse and neglect have profound influences on brain development. The more prolonged the abuse or neglect, the more likely it is that permanent brain damage will occur. Not only are people with developmental disabilities more likely to be exposed to trauma, but exposure to trauma makes developmental delays more likely.

- "The developing brain is exquisitely sensitive to stress." Persistent states of fear in children impair their capacity to benefit from cognitive, social, and emotional experiences (Perry, 2001).
- Exposure to trauma can modify the child's ability to access different levels of brain functioning, resulting in changes in their perception of time, cognitive style, affective tone, ability to develop solutions to problems, and ability to respond to and understand rules, regulations, and laws (Perry, 2001).
- Severe neglect can result in reduced brain size, density of neurons, and head circumference (Perry and Pollard, 1997).

#### People with developmental disabilities are

- trained to be compliant to authority figures;
- dependent on caregivers for a longer period of time for more types of assistance than a nondisabled child, and they are dependent on a larger number of caretakers;
- often unable to meet parental expectations;
- isolated from resources to whom a report of abuse could be made;
- sometimes impaired in their ability to communicate;
- sometimes impaired in their mobility;
- more likely than other children to be placed in residential care facilities;
- sometimes more credulous and less prone to critical thinking than others, which may result in it being easier for others to manipulate them;
- often not provided with general sex education, and caregivers may feel that people with developmental disabilities are asexual, although
  - for people with mild to moderate mental retardation sexual development and sexual interest occur at approximately the same age as the normal population (Tharinger, 1990), and
  - precocious puberty is 20 times more likely to occur in persons with developmental disabilities than in the normal population (Siddigi, 1999); and
- viewed negatively by society, which may label them as "bad" because they are different or may view them as less than human.

#### People with developmental disabilities may also experience

- cognitive and processing delays that interfere with understanding of what is happening in abusive situations, and
- feelings of isolation and withdrawal due to their differences, which may make them more vulnerable to manipulation because of their increased responsiveness to attention and affection.

#### In addition, the effect of trauma is increased for people with developmental disabilities due to

• a predisposition toward emotional problems and impaired resiliency before the abuse occurs (Burrows & Kochurka, 1995);

- reduced protective factors that could lessen the effects of sexual abuse (Mansell et al., 1998);
- a long-standing belief that people with developmental disabilities cannot benefit from traditional verbally oriented therapies (Mansell, et al., 1998); and
- a lack of trained professionals who are comfortable in working with people who have developmental disabilities to help them in processing traumatic incidents.

#### Possible Reasons for a Higher Incidence of Mental Illness for Clients with Developmental Disabilities Than the General Population (Avrin, Charlton, Tallant, 1998)

- It is more difficult to cope with normal life stressors given the limited resources the client has available.
- There is increased vulnerability to abuse in the home, since these children are often very difficult to raise and place a high level of strain on the family.
- These children are more vulnerable to abuse in the community because of their poor judgment and lack of self-protective skills.
- An additional stressor for the higher functioning clients is awareness of their intellectual deficits. They have many grief and loss issues associated with their functioning problems.
- People with developmental disabilities experience greater difficulty in getting help for mental illness due to communication and processing problems.

## Suggestions for Modifying Evaluation and Therapy to Meet the Needs of this Population

- Because of the high likelihood that the ability to communicate will be severely impaired, it is extremely important that a wide range of caregivers be involved in both the assessment and treatment process. These should include parents/guardians and school and daycare personnel.
- Since reporting of trauma by this population is unlikely, it is important that caregivers receive training on the type of behavioral changes that may be associated with trauma exposure so they may assist in reporting and obtaining services.
- All children with developmental disabilities tend to behave like much younger children, so when working with very young children with developmental disabilities, it is extremely important to slow down speech, use simple language, present one concept at a time, supplement therapy with drawing and play materials, and make related adaptations.

#### Special Diagnostic Considerations with Clients Who Have Developmental Disabilities (Avrin, Charlton, Tallant, 1998)

- 1. Their thought process are usually very concrete. Responses to common mental status questions may sound very bizarre because of the client's concrete interpretations.
- 2. Their concrete thought processes make the use of projective assessment techniques such as the Rorschach and TAT ineffective in identifying pathology.
- 3. If the client has sufficiently high verbal skills, sometimes the MMPI-2 or A can be helpful, if interpreted conservatively. Use of audio tapes is recommended, even if the reading level seems sufficient, as the multisensory input often improves comprehension of the questions.
- 4. People with developmental disabilities often share the following thought processes:
  - a. difficulty with fluidity and flexibility of thinking,
  - b. a dislike of ambiguity (black and white thinkers),
  - c. a tendency to concentrate on one aspect of a situation while neglecting other aspects,
  - d. difficulty prioritizing and breaking down tasks into manageable projects,
  - e. a tendency to have highly focused areas of expertise and interests, e.g., beets, weather, sports, statistics, phone numbers, dates, and so on,
  - f. a tendency for poor generalization skills—a person belongs in one and only one environment—and utilization of a skill in one situation but not others.
- 5. People with developmental disabilities often share the following communication problems and social issues:
  - a. idiosyncratic speech,
  - b. inability to perceive social cues,
  - c. difficulty utilizing or understanding nonverbal communication well,
  - d. frequent miscommunications and misunderstandings,
  - e. a tendency toward one-sided conversations,
  - f. a tendency to ask many questions, especially when uncomfortable with a conversation,
  - g. a tendency to return to familiar, rote questions, or subjects of personal interest when anxious,
  - h. intrusive behavior,
  - i. an ability to pretend to be normal,
  - j. a poor understanding of the impact of behavior on others, and
  - k. difficulty making and keeping friends.
- 6. People with developmental disabilities may also have the following miscellaneous issues:
  - a. special talents, including memory for facts, artistic talents, and unique insights (Albert Einstein, Temple Grandin);
  - b. difficulty with change, especially unexpected changes, including
    - i. anticipatory anxiety and
    - ii. continued use of a familiar plan even if it doesn't work;

- c. significant anxiety in many situations, which may present as agitation, acting out, worry, perseveration, or obsessive-compulsive behaviors, often with the following characteristics:
  - i. responses when anxious tend to be highly predictable,
  - ii. even though the pattern is predictable, it may be hard to see when the anxiety is high, and
  - iii. the acting out may be chaotic;
- d. difficulty with Impulse control, particularly when frustration, anxiety, or tension builds until behavioral acting out occurs.

Be aware that all types of psychiatric treatment are useful if properly selected and executed (Szymanski et al., 1994). Behavioral and cognitive behavioral strategies are particularly effective and easy to adapt for this population.

#### Suggestions for Therapy

(Avrin, Charlton, Tallant, 1998)

- 1. Slow down your speech.
- 2. Use visuals whenever possible to reinforce your verbal messages:
  - a. draw pictures, and
  - b. write down suggestions for change in brief, outline form.
- 3. Present information one item at a time.
- 4. Ask for feedback after each item to ensure clear comprehension.
- 5. Be specific in making suggestions for change.
- 6. Practice different ways of handling tough situations the client is likely to encounter.
- 7. Format your therapy session so that several repeats of key information occur. For example
  - a. review information covered in the previous meeting,
  - b. discuss how week has gone,
  - c. work on specific ways of handling various troublesome events that occurred,
  - d. review the key things you want the client to work on during the week, and
  - e. write the homework assignment out and review it with the client to be sure it is clear.
- 8. Work on building coping skills rather than insight.
- 9. Remember that with these clients change will occur more slowly than with others. Be content to measure change with a micrometer rather than a yardstick.
- 10. Remmber that effective treatment for people with developmental disabilities must also include a variety of support and education services for families and caregivers.

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## Post Traumatic Stress Disorder and those with ID/DD

Stress is "the nonspecific response of the body to any demand" (Hans Selye) The most extreme form of stress is stress that

results from a trau matic incident- traumatic stress.

## **Traumatic Stress**

- Stress
- Traumatic Stress
- Posttraumatic Stress
- Posttraumatic Stress Disorder

**Posttraumatic stress (PTS)** is traumatic stress that persists following a traumatic incident. When posttraumatic stress accumulates to the degree that it produces symptoms outlined in DSM-IV the term posttraumatic disorder can be applied. PTSD is considered the most debilitating. (From the Body Remembers)

## These are symptoms of posttraumatic stress (trauma)

- Mood instability
- Depression
- Nightmares
- Insomnia/sleep disturbance
- Vigilance
- Feeling powerless

- Lack of self confidence
- Poor concentration
- Difficulty making decision
- Contemplating suicide
- Inexplicable outbursts of temper
- Inability to trust people
- Uncontrolled fear
- Chronic muscle tension
- Headache, stomachache, dizziness
- Impulse to engage in self-destructive behavior
- Inability to experience pleasure/pain
- Unexplainable grief reactions
- Feeling unsafe in body in general
- Anxiety and panic attacks

This list is not all inclusive, and many of the symptoms are also those described as part of mood disorders.

## PTSD in ID/DD

- Exposure to traumatic event
  - Witnessed or confronted with actual or threatened death or serious injury or physical integrity
  - Disorganized or agitated behavior

PTSD in ID/DD is determined:

**A.** when the person has been exposed to a traumatic event in which both the following are present:

The person witnessed or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to physical integrity. **Note:** In assessing for traumatic exposure in people with ID/DD, take note that events such as de velopmental milestones, residential milestones, residential placement, and even ad ult, consensual sexual experiences have led to posttraumatic reactions in some individuals with ID/DD. It appears that the range of potentially traumatizing events is greater for individuals with a lower developmental age, though no hard data is available that would merit clear-cut distinctions for criteria between mild to moderate ID and severe/profound.

Disorganized or agitate d behavior appears to be quite common for individuals with a lower developmental age.

**B.** The traumatic event is persistently reexperienced in one or more of the following ways:

- (DSM-IV) Recurrent or intrusive recollections of the event, including images, thoughts, or perceptions. DMID- Behavioral acting out of traumatic experiences, self injurious behavior has also sometimes been an indicator of traumatic exposure
- (DSM-IV) Recurrent distressing dreams of the event. DMID- Frightening dreams without recognizable content appear to be more common in individuals with ID/DD.
- Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
- (DSM-IV)Acting out feeling if the traumatic event were reoccurring includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashbacks (including those that occur on awakening or intoxicated). DMID- Trauma specific enactments have been observed in adults with ID. These episodes require judicious assessment in that they can appear to be symptoms of psychosis in adults.

**C. Persistent avoidance** of stimulus associated with the trauma and numbing of general responsiveness, as indicated by three or more of the following:

- Efforts to avoid thoughts, feelings or conversations associated with the trauma
- DSM-IV-Efforts to avoid activities, places or people that arouse recollections of the trauma-DMID Note: Avoidance behavior may be reported by caregivers as "noncompliance," especially for people who cannot adequately verbalize their posttraumatic desire to avoid activities, places or people that arouse recollections of the trauma.
- Inability to recall aspects of the trauma. DMID-Diminished participation may be reported by caregivers as non-compliance
- Markedly diminished interest or participation in significant activities
- Feelings of detachment or estrangement from others. DMID- Caregivers may report that the individual isolates him or her self.
- Sense of foreshortened future-DMID- There may be a risk of false positives in this criteria.

## PTSD

- Persistent symptoms of increased arousal as indicated by 2 or more of the following:
  - Difficulty falling asleep
  - Irritability or angry outbursts
  - Difficulty concentrating
  - Hypervigilance
  - Exaggerated startle response

## PTSD in ID/DD

- Duration of symptoms lasts for more than one month
- Disturbance causes clinically significant distress to important areas of functioning

Co-morbid diagnoses include major affective disorders, dysthymia, alcohol or substance abuse disorders, anxiety disorders, or personality disorders. This can complicate treatment

- Generally, the more severe the life event, the more likely it is for PTSD to occur
- Many co-morbid diagnoses are associated

#### Trauma

Most recipients of services in the mental health system are trauma survivors. Survivors may carry any psychiatric diagnosis and frequently carry many.

## Trauma

"When we are puzzled with someone we are trying to support, we should consider the possible impact trauma has on one's body and the person's abilitity to live the way they want"

From trauma training developed by Doug Pickens

The first step towards being helpful may be to recognize that the trauma symptoms are adaptations. The symptoms can represent the person's attempt to cope the best way they can with overwhelming feelings.

## How to be helpful

- Acknowledge trauma symptoms as:
  - Adaptations
  - Coping mechanism
  - Involuntary

Remember that there are biological and involuntary factors at play; the person isn't knowingly doing things to upset others, these are tools the person uses to survive.

## **Guiding Principle**

- Restore power and control to the survivor
- Establishing safety is the only place to begin

Power and control was taken away from the person when the trauma occurred; we must help them reestablish it for themselves. Ask the person's permission, move at the pace that works for them, we should not take control of this process away from them. The person is the final arbiter of what works and what to do next.

Until the person feels safe they will not be able to move forward.

Central to recovery from trauma are appropriate supports. It is important that the person has access to therapeutic support and counseling. Some people may also need to be treated by a psychiatrist for other symptoms or co morbid diagnoses.

## Clinical Help

- Help the person find therapeutic support
- Recovery occurs in stages
  - Safety
  - Remembrance and mourning
  - Re-connecting with ordinary Life

"Recovery unfolds in three stages. The central task of the first stage is the establishment of safety. The central task of the second stage is remembrance and mourning. The central task of the third stage is reconnection with ordinary life. Like any abstract concept, these stages of recovery are convenient fiction, not to be taken too literally. They are an attempt to impose simplicity and order upon a process that is inherently turbulent and complex."

"At each stage of recovery, comprehensive treatment must address the characteristic BIOLOGICAL, PSYCHOLOGICAL, and SOCIAL components of the disorder. There is no single "magic bullet" for the traumatic syndromes." (Herman)

## Safety

"First do no harm: creating a safe place"

Barbara Rubin Wainrib: "First do no harm creating a safe place"

Creating a safe place provides for the following:

- Teach people how to create their own safe space
- Create a safe place for the person, that sense of safety is the single most important factor

**Bodily integrity-** Attention to basic health needs, regulation of body functions such as sleep, eating, and exercise, management of post traumatic symptoms and control of self destructive behavior (The person's control, not ours)

**Environmental issues-** Establish a safe living environment, financial security, mobility, and a plan for self-protection that encompasses the full range of daily life. Establishing a safe environment requires the mobilization of caring people and development of a plan for future protection.

**Social support-** No one can establish a safe environment alone, the task of developing an adequate safety plan always includes a component of social support. This is where the role of support staff can be most helpful, acting as Beth Barol once said "social therapists".

## Creating a Safe Place

- Bodily integrity
- Environmental issues
- Social Support

This may be a time during which the person wishes to talk about their experience, it is important to remember that however difficult or unbelievable some things may be to hear we can not dispute what happened, simply allow the person to say what they need to. People should not be asked to do this before they are ready. It is likely that once the person moves into the stage in counseling, they will also want to share with those around them.

## Remembrance & Mourning

- Tell the story of the trauma
  - Transforms the memory so that it can be integrated into the person's life story

Mourning is not about getting even or vengeance.

Mourning may have a restorative power.

- Trauma brings loss
- Telling the trauma story may plunge the survivor into profound grief
- Mourning is a necessary stage toward recovery

Now that the person has come to terms with the trauma in their past, they must create a future. The person has mourned the old self that was destroyed by the trauma, and must create a new self. The old beliefs that gave meaning to the person's life have been challenged and now they must build new beliefs. In accomplishing this the person reclaims their world.

## Reconnecting

- Person has mourned old self
- Create new self
- The survivor reclaims their world

"Resolution of the trauma is never final; recovery is never complete. The impact of a traumatic event continues to reverberate throughout the survivor's lifecycle. Issues that were sufficiently resolved at one stage of recovery may be awakened as the survivor reaches new milestones in her development." Post traumatic symptoms can likely reoccur during periods of stress.

## **Resolving Trauma**

- Resolution is never final
- Impact of traumatic event continues to reverberate through survivors lifecycle
- Issues can reemerge with new milestones

What this means for those around the person is that it's not as easy as saying "get over it" It also important to remember that the recovery process is not necessarily about stepping up so to speak. Even when it appears that someone has moved into the next stage of recovery, they can often slide back to a previous stage. This could be frustrating for people around the person (and the person) who may see it as a failure- it is not-this is how this process works. There is an ebb and flow which is a natural part of it.

## Clinical

- Behavior therapy
- ▶ Family therapy
- Cognitive therapy
- ▶ Group therapy
- Art & play therapy Medication

Clinical interventions include:

**Behavior therapy-** works to address intrusive thoughts and behavior patterns caused by trauma. May also learn relaxation techniques, identification of feeling, and connection between feelings and behaviors. **Cognitive therapy**- Assists the person in identifying personal values, goals, and the influence of trauma on the person's thoughts/ behaviors. Cognitive therapy may also help to reinterpret traumatic events and feelings in more positive ways.

**Art and play therapy-** Can be a comfortable tool/mechanism/tool for expression. Story telling problem solving, re-experiencing trauma, communicating feelings, and releasing feelings are all part of the therapeutic process.

**Family therapy**- Offers parents, siblings, etc.. A supportive environment to share feelings/ reactions. Caregivers are provided with guidance and education on ways to support their child and take care of their own needs following a traumatic event.

**Group therapy**- Can be helpful in encouraging people to share their experiences and reactions to similar events. Group members help one another to normalize feelings, fears and behaviors that are problematic for children following traumatic events.

**Medication-** can be helpful in curbing symptoms of PTSD. Symptom relief that meds. provide can assist the person in participating more effectively in supportive therapy options. Can also help with sever anxiety, depression and sleep disturbances.

#### **Concrete Ways to Help**

Establish a sense of safety and security- People may need to feel protected, safe and secure. Be sure that all basic emotional needs are met including love, care, and physical closeness. Spend extra time with the person and let them know that you care and want to provide safety and security. Providing safety may also mean watching how the person responds to things in the environment and removing things that are upsetting as possible.

**Listen to words and behaviors-** It is most important to actively listen in a non-judgmental way. It can be helpful to ask the person what other people would think/feel about the event. People may have an easier time talking about what they saw, heard and physically felt during the event. It is sometimes more difficult to attach feeling words

### Concrete ways to help

- Establish safety and security
- Listen to words and behavior
- Help the person retell
- Validate feelings
- Allow the opportunity to regress
- Clear up misconceptions
- Educate yourself about trauma & crisis
- Affirm that the person is capable of coping and healing
- Assist with professional consultation and mental health treatment
- Understand that people may
- Be tired
- Startle easily
- More Irritable
- Forgetful
- Regress
- Withdraw
- Do things/have concerns you haven't seen before
- Have stomach aches, headaches, etc.
- Fixate on one issue
- Need more nurturing
- Need fewer demands
- Need extra breaks
- Offer journals, art activities, music
- Give honest answers to questions
- Create opportunities for survivors to talk together
- Allow for repeated questions
- Maintain your sense of humor and bright outlook

to these experiences. Be empathic and offer the words.

**Help to retell the story**- Biographical timeline-People need to retell their version of the traumatic event or in some cases reenact the experience. This is a big step in the healing experience. Once the person has put words to their perception of events, they may repeat the story over and over again. Listen supportively to the retelling. This offers the opportunity to make sense of the trauma and perhaps to gain mastery or a sense of control over the trauma.

Validate feelings- Help people understand that all their feelings are acceptable. Individual's will most likely express a multitude of difficult and contradicting feelings that may include guilt, shame, rage, anger, sadness, pain, isolation, loneliness, and fear. Individuals' need to understand that all of their feelings are "normal"

Allow the opportunity to regress as necessary-Regression is one way that many people may emotionally "regroup". Try hard to be patient and not to ridicule this can be a temporary coping strategy.

**Clear up misconceptions-** Help the person understand the important details of the traumatic event. Include detailed information about safety plans, prevention, and security. Help the person get involved in advocacy, helping others if this is their choice.

Affirm that the person is capable of coping and healing after the trauma- Reinforce that people can heal from traumatic events. Outline the people who are available to the person for love, support, and security.

Assist with professional consultation and mental health treatment- Help to find professionals who have experience working with trauma. Much support may be needed. Communicate with professionals if the person wishes you to do so to learn about how you can help, and to share how things are going.

**Tired-** Provide extra quiet time, soothing things, stress the importance of rest- but don't pressure

**Startle easily-** They are on the look out for danger- keep distractions to a minimum, stick to regular routines and other things which help the person feel safe. Try not to introduce too many strangers.

**Irritable-** Remember this person is feeling powerless, among other things, try to back off and validate- don't pressure- the person has to know that they have choice and control

**Forgetful-** Instruct in short parts of time with lots of psychomotor activity, visual cues etc.. And be patient

Regress- Be gentle and patient

**Withdraw-** encourage people to participate in activities but do not push.

**People may do things you haven't seen before**remain patient and empathic, remember that this is a form of communication or an adaptation to horrible circumstances

**Have physical complaints-** Offer medical help as necessary, try to help the person feel better, avoid adopting the response that it's "all in their head" or "for attention."

**Fixate on one issue-** Allow the person to talk it through- they may be trying to gain power over it, use problem solving

**Need more nurturing-** The person may want to be physically closer to you. We need to do all that we can to let the person know they are safe with us and we are there for them. Abandonment can be a major fear.

**Minimize demands-** When a person is struggling it is not the time to add additional worries. The person may be very much unable to take on what you have asked at that moment. Offer you help, offer to do things with the person or allow them to complete the task at another time. This isn't

about a power struggle.

**Extra breaks-** relaxation can be helpful, the ability to regain some balance. Exercise can also be helpful to release stress, offer to take walks with the person or just sit together, or offer the person time alone if they so choose.

Offer the person the ability to express themselves whether they do so through music art or journaling.

A person struggling with trauma may have a lot of questions/things they don't understand, be honest and reassuring.

Create opportunities for peer support etc.. It can be helpful for a person to know "I'm not the only one."

If a person keeps asking the same question repeatedly it's because they are trying to make sense out of their confusion- be patient, it can be frustrating but think about how frustrated the person may feel.

Maintain sense of humor- Don't make fun of the person and their pain, but take opportunities for moments of joy, these can be the building block to a helpful relationship and a place where healing can begin.

Hearing some of the stories can be very painful and cause distress for the people who are supporting a survivor.

Allow opportunities for communication, rest and fun for yourself.

If the situation becomes too upsetting find someone to talk to. It's also OK if you find that you cannot work with someone dealing with trauma. Most of us have had trauma in our lives, and sometimes this can bring up feelings and emotions related to our own history. It's OK to say you can't do it.

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Andrus Children's Center http://www.andruschildren.org/Sanctuary\_Model. htm

## Family Guide to Understanding Schizophrenia in the Person with Mental Retardation & Developmental Disabilities (MR/DD)

Schizophrenia is a common psychiatric problem in the general population and this disorder is more common in persons with mental retardation. Schizophrenia is produced by problems with brain wiring in normal individuals. Since many forms of mental retardation are produced by brain wiring problems, this disorder is more common in persons with mental retardation. Schizophrenia is also more common in people with seizure disorders.

The symptoms of schizophrenia depend upon the severity of intellectual disability. Persons with mild mental retardation can describe hearing voices, seeing things, or having false beliefs. Persons with severe mental retardation are often unable to describe the symptoms of schizophrenia. Persons with normal intellect also develop social and professional decline, which is called a "negative" symptom. These "negative "symptoms are more difficult to detect in persons with intellectual disability.

The hallucinations and delusions produced by schizophrenia can be distressing to the person experiencing these symptoms. Medications are helpful for some patients. The physician can prescribe a class of medications called antipsychotic drugs. These powerful, mindaltering medications will suppress voices and false beliefs. These drugs have many side effects that require careful monitoring by the physician. Antipsychotic medications require six weeks or two months of continuous therapy to improve psychotic symptoms. The dose of medication depends upon the patient. Small, elderly or frail patients require smaller doses. Some patients can explain symptoms while others will exhibit behavioral symptoms. The family should monitor

the benefit of these drugs by observing the patient for improvement of symptoms. Both the family and the doctor should be aware of common side effects produced by antipsychotic medications. The family can monitor for potential side effects and report back to the doctor. The goal of treatment for schizophrenia is improvement of symptoms. Medications may not completely eliminate hallucinations or delusions. The medication success is measured in terms of quality of life, reduction of behavioral symptoms, and improvement of function.

#### Source

Richard E. Powers, MD (2005), Bureau of Geriatric Psychiatry

## Schizophrenia

#### What is Schizophrenia?

Schizophrenia is a chronic severe brain disorder. People with schizophrenia often hear voices, believe media are broadcasting their thoughts to the world or may believe someone is trying to harm them. In men it usually develops in teen years and early 20s; in women it usually develops in 20s and 30s.



#### Diagnosis

Currently there is no physical or laboratory test that can absolutely diagnose schizophrenia. A psychiatrist usually comes to the diagnosis based on clinical symptoms. Misdiagnosis is a common problem since schizophrenia shares a significant number of symptoms with other disorders. According to the National Depression & Bipolar Support Alliance there is an average of 10 years from onset to correct diagnosis and treatment.

There are disorders that may appear like Schizophrenia, which may account for the length of time it takes to receive an accurate diagnosis. These disorders may have features that look like schizophrenia:

- Schizoid personality
- Schizophreniform disorder
- Schizotypal personality
- Bipolar Disorder
- Asperger's syndrome

#### Symptoms of Schizophrenia

Individuals with schizophrenia experience a profound disruption in thinking and emotion affecting the most fundamental attributes of language, thought, perception, affect, and sense of self.

Symptoms of schizophrenia include both "positive" and "negative" symptoms." **Positive symptoms** are those that appear to reflect an excess or distortion of normal functions. Positive symptoms are those that have a positive reaction from some treatment. Positive Symptoms include:

Delusions are fixed beliefs that usually involve a misinterpretation of experience. "Client believes someone is reading his thoughts" Several types: grandiose, nihilistic, persecutory, somatic

Hallucinations are perceptual experiences that occur in absence of actual sensory stimuli; involves the 5 senses.

**Negative Symptoms** are those that appear to reflect a diminishing or absence of normal functions. It may be difficult to evaluate because they are not as grossly abnormal as positive symptoms. Currently there is no treatment that has a consistent impact on negative symptoms. Negative Symptoms include the following:

Examples of avolition include no longer interested in going out with friends, no longer interested in activities for which the person had enthusiasm, no longer interested in anything, or sitting in the house for hours or days doing nothing.

**Disorganized Symptoms** make up another category of symptoms. This is a somewhat new category and may not be considered valid. These symptoms include thought disorder, confusion, disorientation and memory problems.

**Cognitive Symptoms** of Schizophrenia include difficulties in concentration and memory.

#### **Summary of Symptoms**

#### **Positive Symptoms**

#### Delusions

Those where the patient thinks he is being followed or watched are common; also the belief that people on TV, radio are directing special messages to him/her

#### Hallucinations

Distortions or exaggerations of perception in any of the senses. Often they hear voices within their own thoughts followed by visual hallucinations.

- Disorganized thinking/speech AKA loose associations; speech is tangential, loosely associated or incoherent enough to impair communication.
- Grossly disorganized behavior Difficulty in goal directed behavior (ADLs), unpredictable agitation or silliness, social disinhibition, or bizarre behavior. There is a purposelessness to behavior.
- Catatonic behavior Marked decrease in reaction to immediate

environment, sometimes just unaware of surroundings, rigid or bizarre postures, aimless motor activity.

- Inappropriate response to stimuli
- Unusual motor behavior (pacing, rocking)
- Depersonalization
- Derealization
- Somatic preoccupations

#### **Negative Symptoms**

- Alogia (poverty of speech) Lessening of speech fluency and productivity, thought to reflect slowing or blocked thoughts; often manifested as short, empty replies to question.
- Avolition

The reduction, difficulty or inability to initiate and persist in goal-directed behavior. Often mistaken for apparent disinterest.

#### **Cognitive Symptoms**

Difficulties in concentration and memory: Disorganized thinking, slow thinking difficulty understanding, poor concentration, poor memory, diffulty expressing thoughts, and difficulty integrating thoughts, feelings, and behaviors

#### **Types of Schizophrenia**

There are **five types of schizophrenia**. Before a diagnosis, the psychiatrist must make a thorough evaluation including a physical/medical exam, a mental status exam, appropriate labs, and a full history. History includes changes in thinking, behavior, movement, mood, etc. as seen by the family.

The types of schizophrenia are:

#### Hebephrenic Schizophrenia

AKA disorganized schizophrenia;

characterized by emotionless, incongruous, or silly behavior, intellectual deterioration, frequently beginning insidiously during adolescence.

- May be verbally incoherent and may have moods and emotions that are not appropriate to the situation.
- ► Hallucinations not usually present.

#### **Catatonic Schizophrenia**

- Person is extremely withdrawn, negative and isolated.
- May have marked psychomotor disturbances.

#### **Residual Schizophrenia**

- Lacks motivation an dinterest in day-to-day living
- Person is not usually having delusions, hallucinations, or disorganized speech.

#### **Schizoaffective Disorder**

There will be symptoms of schizophrenia as well as mood disorder (depression, bipolar, mixed mania).

#### **Undifferentiated Schizophrenia**

- Conditions meeting the general diagnostic criteria for schizophrenia, but not conforming to any of the previous types.
- Exhibits more than on of the previous types without a clear dominance of one.

#### Medications

In general, it may take up to 6 months for medications to show consistent effects. The newest medication is Invega. Meds include atypical antipsychotics: Abilify, Geodon, Clozapine, Risperidone, Seroquel, Zyprexa. These medications may have such intolerable side



#### **Resources:**

<u>Schizophrenia Symptoms</u>, by NARSAD, The Mental Health Research Association.

<u>Schizophrenia Treatment</u>, by John Grohol, PsychCentral, 08/07/08 Psychiatric Study Guide by Central Regional Hospital

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## Physician Fact Sheet on Personality Disorder in Persons with Mental Retardation and Developmental Disabilities (MR/ DD)

- A personality disorder implies that an individual exhibits psychological or behavioral symptoms that disrupt their personal or professional life.
- 2. Personality disorders occur in 11 to 23% of the general population.
- 3. Individuals with moderate or severe mental retardation usually lack sufficient intellectual capacity to support a diagnosis of personality

disorder.

- The diagnosis of personality disorder can often produce negative responses by medical professionals, law enforcement, and social agencies.
- 5. There are many personality disorders that fit into three broad categories, termed "clusters" and occur in 2 to 22% of persons with MR/DD.
- 6. Cluster-A includes persons with thought problems such as "schizoid."
- 7. Cluster-B includes persons with impulse control and emotional regulation problems including borderline, antisocial, and histrionic.
- 8. Cluster-C includes persons with problems with initiative, such as passive-dependence.
- 9. The diagnosis of personality disorder should only be made in persons with mild mental retardation or normal intellect.
- 10. Antisocial and histrionic personality disorders are often described in persons with mental retardation.
- 11. Persons with borderline personality may demonstrate self-injurious behavior.
- 12. Medications are not effective for personality disorder but rather psychological and behavioral therapies are the major treatment modality.



#### Source

Richard E. Powers, MD (2005), bureau of Geriatric Psychiatry

## **Personality Disorders**

#### What is a personality disorder?

Personality refers to a distinctive set of traits, behavior styles, and patterns that make up our character or individuality. How we perceive the world, our attitudes, thoughts, and feelings are all part of our personality. People with healthy personalities are able to cope with normal stresses and have no trouble

forming relationships with family, friends, and co-workers.

Those who struggle with a personality disorder have great difficulty dealing with other people. They tend to be inflexible, rigid, and unable to respond to the changes and demands of life. Although they feel that their behavior patterns are "normal" or "right," people with personality disorders tend to have a narrow view of the world and find it difficult to participate in social activities. Personality disorders can cause major disruption to a person's life and are usually associated with significant distress to the self or others. Personality disorders begin in childhood and persist throughout adulthood.

The prevalence of personality disorders is not firmly established and varies for the different disorders. Borderline personality disorder is experienced by about one in 100 people.

While personality can be difficult to change, with early and appropriate treatment and support, people with personality disorders can live full and productive lives.

## What are the main types of personality disorder?

There is a wide range of personality disorders. All of them involve a pervasive pattern of behavior, which means that the characteristic behaviors and thoughts are evident in almost all aspects of

a person's life. There are ten identified personality disorders falling into three different categories, or clusters.

- **Cluster A:** Odd or eccentric behavior
- Cluster B: Dramatic, emotional or erratic behavior
- Cluster C: Anxious fearful behavior

#### **Cluster A Personality Disorders:**

#### Schizoid personality disorder

Schizoid personalities are introverted, withdrawn, solitary, emotionally cold, and distant. They are often absorbed with their own thoughts and feelings and are fearful of closeness and intimacy with others. For example, a person suffering from schizoid personality is more of a daydreamer than a practical action taker.

#### Paranoid personality disorder

The essential feature for this type of personality disorder is interpreting the actions of others as deliberately threatening or demeaning. People with paranoid personality disorder are untrusting, unforgiving; and prone to angry or aggressive outbursts without justification because they perceive others as unfaithful, disloyal, condescending or deceitful. This type of person



may also be jealous, guarded, secretive, and scheming, and may appear to be emotionally "cold" or excessively serious.

#### Schizotypal personality disorder

A pattern of peculiarities best describes those with schizotypal personality disorder. People may have odd or eccentric manners of speaking or dressing. Strange, outlandish or paranoid beliefs and thoughts are common. People with schizotypal personality disorder have difficulties forming relationships and experience extreme anxiety in social situations. They may react inappropriately or not react at all during a conversation or they may talk to themselves. They also display signs of "magical thinking" by saying they can see into the future or read other people's minds.

#### **Cluster B Personality Disorders**

#### Antisocial personality disorder

People with antisocial personality disorder characteristically act out their conflicts and ignore normal rules of social behavior. These individuals are impulsive, irresponsible, and callous. Typically, the antisocial personality has a history of legal difficulties, belligerent and irresponsible behavior, aggressive and even violent relationships. They show no respect for other people and feel no remorse about the effects of their behavior on others. These people ware at high risk for substance abuse, especially alcoholism, since it helps them to relieve tension, irritability and boredom.

#### Borderline personality disorder

People with borderline personality disorder are unstable in several areas, including interpersonal relationships, behavior, mood, and self-image. Abrupt and extreme mood changes, stormy interpersonal relationships, and unstable and fluctuating self-image, unpredictable and selfdestructive actions characterize the person with borderline personality disorder. These individuals generally have great difficulty with their own sense of identity. They often experience the world in extremes, viewing others as either "all good" or "all bad." A person with borderline personality may form an intense personal attachment with someone only to quickly dissolve it over a perceived slight. Fears of abandonment may lead to an excessive dependency on others. Selfmutilation or recurrent suicidal gestures may be used to get attention or manipulate others. Impulsive actions, chronic feelings or boredom or emptiness, and bouts of intense inappropriate anger are other traits of this disorder, which is more common among females.

Understanding borderline personality disorder is particularly important because it can be misdiagnosed as another mental illness, particularly a mood disorder.

#### Narcissistic personality disorder

People with narcissistic personality have an exaggerated sense of self-importance, are absorbed by fantasies of unlimited success, and seek constant attention. The narcissistic personality is oversensitive to failure and often complains of multiple somatic symptoms. Prone to extreme mood swings between self- admiration and insecurity, these people tend to exploit interpersonal relationships.

#### **Cluster C Personality Disorders**

#### Histrionic personality disorder

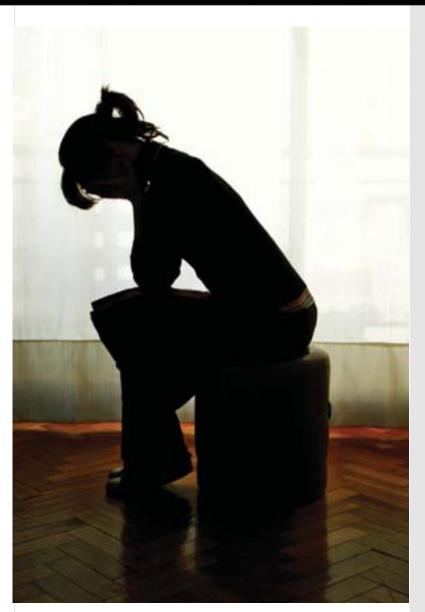
is a pervasive pattern of excessive emotion and attention seeking.

#### Avoidant personality disorder

Avoidant personalities are often hypersensitive to rejection and are unwilling to become involved with others unless they are sure of being liked. Excessive social discomfort, timidity, fear of criticism, avoidance of social or work activities that involve interpersonal contact are characteristic of the avoidant personality. They are fearful of saying something considered foolish by others; worry they will blush or cry in front of others; and are very hurt by any disapproval by others. People with avoidant personality disorder may have no close relationships outside of their family circle, although they would like to, and are upset at their inability to relate well to others.

#### Dependent personality disorder

People with dependent personality disorder may exhibit a pattern of dependent and submissive behavior, relying on others to make decisions for them. They require excessive reassurance



and advice, and are easily hurt by criticism or disapproval. They feel uncomfortable and helpless if they are alone, and can be devastated when a close relationship ends. They have a strong fear of rejection. Typically lacking in self-confidence, the dependent personality rarely initiates projects or does things independently. This disorder usually begins by early adulthood and is diagnosed more frequently in females than males.

#### **Obsessive-compulsive personality**

Compulsive personalities are conscientious and have high levels of aspiration, but they also strive for perfection. Never satisfied with their achievements, people with compulsive personality disorder take on more and more responsibilities. They are reliable, dependable, orderly, and methodical, but their inflexibility

often makes them incapable of adapting to changed circumstances. People with compulsive personality are highly cautious, weigh all aspects of a problem, and pay attention to every detail, making it difficult for them to make decisions and complete tasks. When their feelings are not under strict control, events are unpredictable, or they must rely on others, compulsive personalities often feel a sense of isolation and helplessness.

#### What causes personality disorders?

Personality disorders develop in childhood and the thoughts and behaviors become increasingly ingrained in adulthood. Some personality disorders are

more common in men (ie antisocial personality disorder) and others

are more common in women (ie borderline personality disorder). Many people with a personality disorder do not seek help until after years of distress, if at all. This contributes to our lack of knowledge about their causes and development.

Different causes appear to be associated with the different types of personality disorders. However, like most mental illnesses, the causes appear to be a complex combination of genetic factors, biochemical factors, and individual, family and environmental factors.

#### What treatment is available?

The range of treatments for personality disorders is growing. The type of treatment depends on the type of personality disorder. For borderline personality disorder, psychological therapies are the main treatment approach. Dialectical behavior therapy (DBT) is a form of cognitive behavioral therapy that targets mood instability and impulsivity. It teaches people how to manage their emotions, and re-learn ways to react to people and situations.

An important aim of treatment for people with borderline personality disorder is managing selfharm and suicidal behavior. DBT has been shown to be effective in bringing suicidal behaviors under control. While our understanding of the effective treatment of personality disorders is still growing, the earlier treatment is sought the more effective it is likely to be. The family and friends of people with a personality disorder can often feel confused and distressed. Support and education, as well as better community understanding, are an important part of treatment. Treatment may include individual, group, or family psychotherapy. Medications, prescribed by a patient's physician, may also be helpful in relieving some of the symptoms of personality disorders, including problems with anxiety and perceptions. Psychotherapy for patients with personality disorders focuses on helping them see the unconscious conflicts that are contributing to or causing their symptoms. It also helps people become more flexible and is aimed at reducing the behavior patterns that interfere with everyday living.

In psychotherapy, people with personality disorders can better recognize the effects of their behavior on others. Behavior and cognitive therapies focus on resolving symptoms or traits that are characteristic of the disorder, such as the inability to make important life decisions or the inability to initiate relationships.

Information for this fact sheet was provided primarily by Netcare Corporation 199 S. Central Avenue Columbus, OH 43223 Administrative line: (614) 274-9500 www.netcareaccess.org

## **Impulse Control Disorders**

"The Diagnostic manual-Intellectual Disability (DM-ID): is a diagnostic manual designed to facilitate an accurate mental health diagnosis in persons who have intellectual Disabilities and provide a thorough discussion of the issues involved in reaching an accurate diagnosis. The DM-ID provides state-of –the-art information concerning mental disorders in persons with intellectual disabilities."

There are several diagnoses which fall under the category of Impulse Control Disorders (ICD).

ension/arousa

Commits

act

pleasure

Regret.

self reproach

guilt

These disorders "represent the failure to resist an impulse, drive, or temptation to perform an act that is harmful to the person or to others." For most of the disorders, "the individual feels an increasing sense of tension or arousal before committing the act and then experiences pleasure, gratification, or relief at the time of committing the act. Following the act there may or may not be regret, self reproach or guilt."

Intermittent Explosive Disorder is a type of Impulse Control Disorder. It is the most

commonly diagnosed Impulse Control Disorder in those with Intellectual/Developmental Disabilities. According to DM-ID, "there is considerable debate about Intermittent Explosive Disorder. Much of this discussion centers on its validity as a distinct syndrome versus a nonspecific form of affectiveimpulsive aggression." It is "difficult to reliably differentiate IED from aggression associated with other neuropsychiatric disorders.""IED includes behaviors that occur independently of other primary mental disorders. As a result, IED in many circumstances is made by exclusion." Meaning that if other disorders do not fit, then this diagnosis may be made. Now if a psychiatrist diagnoses someone you support with IED, it is not up to us to debate the diagnosis, it is helpful for us to know however that it is a difficult conclusion to reach and many other diagnoses or contexts can also account for behavior that may look like IED.



- Debate over validity
- Difficult to "reliably differentiate EID from aggression associated with other disorders"
- Usually made by exclusion

According to the DM-ID, those with intellectual or developmental disabilities (ID/DD) are more likely to exhibit aggression that is not directly related to a diagnosable psychiatric disorder. It appears that the greater the severityof ID/DD, the less likely we will see nonspecific aggressive behavior. The more mild the ID/DD, the more likely we will see nonspecific aggressive behavior. However, there is a direct association between aggressive behavior and seizure disorders, developmental brain abnormalities, and environmental disorganization. According to the DM-ID, "The most difficult issue concerning Impulse-Control Disorders comes from an uncertainty whether such aggressive behavior represents a true disorder'

## DM-ID Criteria

- Frequent episodes that last for at least 2 months
- Degree out of proportion to precipitating stressor
- Not better accounted for by another disorder

Criteria to make a diagnosis of Intermittent Explosive Disorder include:

**A-** Frequent episodes that last for at least 2 months of failure to resist aggressive impulses that result in serious assaultive acts or destruction of property.

**B-** The degree of aggressiveness expressed during the episodes is grossly out of proportion to any precipitating psychological stressors and to the level of ID.

**C**- The aggressive episodes are not better accounted for by any other mental disorder except if the other disorder is mild compared to the aggression, or is temporarily unrelated to the aggression.

## IED and ID

- Most commonly diagnosed ICD in ID/DD
- Complicating factors
  - Phobias
  - Anxiety
  - Seizure disorders
  - Level of impact of ID
  - Social stressors
  - Trauma

When we are distressed about aggression from someone we support, we likely report it as the major issue and may not necessarily consider and report all possible symptoms. The aggression could actually be a result of any number of problems from phobias to anxiety, and seizure disorders. The DM-ID also indicates that diagnosis of Intermittent Explosive Disorder in someone who is low functioning or non-verbal, is difficult. A better case for diagnosis can be made by those who are less impacted by their Intellectual Disability. We also cannot eliminate social stressors as complicating factors such as loneliness, isolation, lack of control over own life and so on. The following is an account of one clinician's experience:

I once used to work with a man who had very scary episodes of rage and aggression, the team was bewildered and scared because sometimes these episodes seemed to happen almost out of the blue. We started to track what was happening and any changes. We immediately noticed that in the past year as his seizures had increased, so had these "episodes". We reported this to the neurologist and began closely tracking the incidents and seizures. What we discovered was that up to 3 days before and 3 days after a seizure, he would have one of these incidents. In the past, other teams had supported him and treated it as a behavioral problem, and later a psychiatric issue. He had been placed on medications that sedated him and caused significant side effects. Once we gathered all the data and took it back to his neurologist, we discovered that with better treatment of his seizures, the "episodes" almost disappeared and he didn't need the medications which created the side effects!

There are other Impulse Control Disorders besides Intermittent Explosive Disorder. These disorders are rarely made in people with intellectual or developmental disabilities, These other Impulse Control Disorders are listed below with a brief description of each.

**Kleptomania:** This is disorder in which the individual repeatedly gives in to the impulse to steal for no great gain, when he or she has sufficient money to pay for the item and no need for what is stolen.

**Pyromania:** Pyromania is the uncontrollable impulse to repeatedly set fires with no obvious motive (such as: concealment of a crime, financial gain, and such).

**Pathological Gambling:** Pathological gambling refers to the uncontrollable impulse to gamble, irrespective of the interference the behaviour has on the individual's life. It often results in disrupted relationships, financial problems, and/or criminal behavior and yet the individual is unable to refrain. In contrast, "social gambling" is not

characterized by this loss of control.

**Trichotillomania:** Trichotillomania is the uncontrollable plucking of one's hair. Although usually limited to hair on the head, removal of eyebrows, eyelashes and other body hair is not uncommon. The practice results in significant, and sometimes complete, hairloss.

#### Impulse Control Disorder Not Otherwise

**Specified (NOS):** This is a residual category for those impulse control disorders that do not fulfill either the criteria for the specific disorders outlined earlier or those other mental disorders with impulsive characteristics that have been covered in other sections of the DSM IV-TR (eg. substance abuse, paraphilias). Some of the more common impulse control disorders contained in this category include Impulsive Sexual Behaviors, Repetitive Self-Mutilation, and Compulsive Shopping.

#### **Working with Doctors and Teams**

Diagnosis of any psychiatric disorder requires a qualified professional. Physicians and psychologists have been trained specifically for this. We can be a great help to professionals in learning how to report information and participate in care.

Treatment, whatever the diagnosis, should always keep the person at the center of everything we plan and do related to their care. With that in mind, we take a holistic approach, addressing the person's needs from a variety of perspectives.





When a person has a diagnosed psychiatric illness, psychiatric care and possibly medications may be necessary to help the person gain more control over their lives and actions. It is also recommended that a person have counseling, which can offer an opportunity to process emotions, develop coping skills and better understand their illness.

Often, cognitive behavior therapy (CBT) is used to treat some Impulse Control Disorders, CD's, but methods depend on what works best for the individual.

Relationships are an integral part of care as well. Studies have shown that the quality of a person's relationships can have a direct impact on the course of illness with a more positive outcome, along with a positive impact on the person's attitude. Finally, a quality individualized support plan followed consistently and adapted as needed is essential.

There are a number of medications that a Psychiatrist might prescribe to treat an Impulse Control Disorder. Ultimately, treatment will be determined by the physician as s/he works closely with the individual. Family and staff can be helpful by observing for changes and reporting side effects. It is important to know what side effects may be expected as well as any life threatening risks. Ask the treating physician what side effects to look for and when to report them.



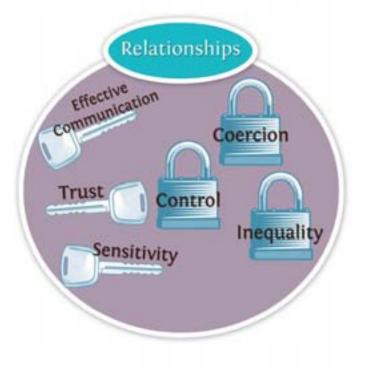
Counseling, or talk therapy, with a qualified professional may be helpful and is usually recommended in conjunction with psychiatric management to help with problem solving and developing coping skills.

Some also find group helpful. In group therapy, people are able to come together with peers who experience the same diagnosis and discuss it together as a group. Some find it helpful to know that they are not alone. Group therapy is typically used most often with pathological gambling.

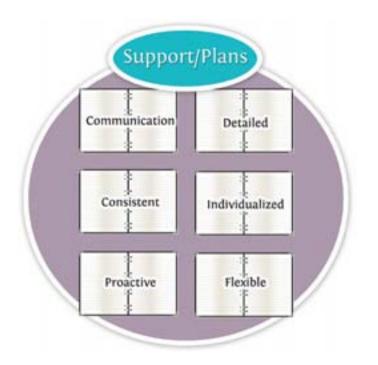


Cognitive Behavior Therapy (CBT) is a specific type of therapy sometimes used for Impulse Control Disorders. There are other types counseling as well, and typically, a therapist will use the method in which they have been trained or are most comfortable. CBT may be used for Impulse Control Disorders since it offers a way for a person to analyze situations in detail, their feelings and reactions and develop alternative strategies for when they are in similar situations or experiencing similar feelings. Sometimes people find specific programs such as 12-step programs to be helpful. Anger Management programs are sometimes recommended for people with Intermittent Explosive Disorder.

There have been books, studies and new approaches to healing that focus on the importance of relationships in treating mental health disorders. Relationships are not just those with family and friends, but also in a clinical setting or residential group home setting. We know that effective communication is important.



Listening without judgment and building trust are critical to any helping relationship. When we try to control or coerce in our efforts to help, it implies lack of trust in the person's own skill, and the human response from that person is instinctively to rebel against anyone attempting to control his/ her behavior. A trusting relationship encourages the individual to engage with us as partners in recovery.



There are keys to being supportive. A team environment, which is where we most often work, means that there should be open communication among team members and with the person who has requested services. Plans should be made with the person's input as much as possible and then followed consistently, but if they need to be changed then change them! Someone shouldn't be on the same plan for ten years! Plans should include proactive strategies and not just information on how to respond when the person is in crisis. Plans should contain information that people really need to know when working with that person, like their history, triggers, needs etc...





Since Intermittent Explosive Disorder is the Impulse Control Disorder most diagnosed in the population we support, we will look at some ways to support someone with this diagnosis..

- Understand intermittent explosive disorder. It is a behavioral condition that often causes the person to experience extreme anger and uncontrollable rage. This anger is often misdirected and can cause them to lash out at others in a variety of situations. (Some researchers believe that it is caused by low serotonin levels).
- Don't blame yourself or the person. Realize that the anger caused by Intermittent Explosive Disorder is not something you did or caused. Instead, it is an impulsive control disorder that affects many people around the world. Their outbursts are caused by real and perceived threats, so you absolutely can't blame yourself for the condition.
- Be safe and protect yourself. In some instances, the person this condition might assault or physically harm someone else or their property. So, if you believe that you are not safe, you need to protect yourself and the person to the best of your ability. Know emergency procedures and who to call.
- Be empathetic. This is a serious condition and the affected person is not just "lashing out." Encourage them to seek immediate medical attention with a physician that is specially trained to treat intermittent explosive disorder.
- Get emotional support. Join support groups for other people who are also dealing with intermittent explosive disorder.
- Plan ahead and be as proactive as you can. If you know the person is more likely to have difficulty when they are stressed or in certain places or circumstances, work with the person to avoid them, or have strategies for successfully navigating in those environments or situations.
- As difficult as it can be, it is not appropriate or helpful to lash back at the person in

frustration or anger. When you know you need to, take a break or ask for help.

By paying attention to environmental situations and personal reactions that might set-off the undesired cycle, we may be able to diffuse some of the tension or arousal that often leads to the explosive or impulsive

## Try not to ...

- Try to take control and regulate behavior
- Struggle for power
- "Mirror" the angry and impulsive behavior

#### action.

- Try not to-take control by regulating the problematic behavior. This often ends up happening with authoritarian commands, threats and even punishment, which often leads to struggles for power. We often believe it is our duty to "correct" behavior through imposing some sort of consequences for the behavior. But if the person has an ICD, they will likely react to the tension and arousal they experience and move through the impulse cycle all over again. We also need to try not to "mirror" the angry and impulsive behavior, getting caught up in the emotions of the moment. Such interactions create resistance and resentment and poison relationships.
- When someone is struggling, let him or her know that you can see the distress s/he is experiencing. Give supportive silence if the person isn't ready to interact with you. Wait until they are ready to let you engage them, then invite a conversation about ideas s/ he and you might share about how to solve problem/s (without judgment or telling the person what they SHOULD do next time).

## Try to...

- Use a soothing tone of voice
- Acknowledge the person's distress
- Offer supportive silence (being there when the person is ready)
- Offer an invitation to problem-solving
- Model
- Hang in there!
- Sometimes people may need to be taught ways to exert rational control over their emotions and impulses (and remember it may be out of their control to an extent). People may need to learn verbal (or other communication skills) for labeling feelings and generating a different response. We can teach this through modeling and hanging in there with the person.

#### Summary

- ICD's make it difficult for a person to resist an impulse and typically include a type of impulse chain or cycle.
- IED is the commonly diagnosed ICD in those who choose our services
- Diagnosis is complicated and made after exclusion of other possibilities
- We can be helpful to the psychiatrist and team
- We can help the person through our relationship and other strategies

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### Attachment Disorders

According to Evergreen Psychotherapy Center-Attachment is the deep and enduring connection between a child and caregiver in the first several

years of life. It profoundly influences every component of the human condition- mind, body, emotions, relationships and values.

Attachment is not something parents do to their children but is something that is created together in an ongoing, reciprocal relationship. Attachment to a protective and loving caregiver providing guidance and support IS A BASIC HUMAN NEED, rooted in the natural design of humans. There is an instinctive desire to attach, babies instinctively reach for the safety and security of relationship with caregivers, and generally parents instinctively protect and nurture their offspring. As human's we are "hard wired" to attach to others as we need other people to survive.

Attachment is a physiological (characteristic of or appropriate to an organism's healthy or normal functioning), emotional, cognitive and social phenomenon. Instinctual attachment behavior in an infant is activated by cues or signals from the caregiver so the attachment process can be defined as a "mutual regulatory system." The baby and caregiver influencing one another over time. Attachment becomes the basis of brain development for an infant and child.



John Bowlby devoted extensive research to the concept of attachment, describing it as a "lasting psychological connectedness between human beings" (Bowlby, 1969, p. 194). Bowlby shared the psychoanalytic view that early experiences in childhood have an important influence on development and behavior later in life. Our early attachment styles are established in childhood through the infant/caregiver relationship. In addition to this, Bowlby believed that attachment had an evolutionary component; it aids in survival. "The propensity to make strong emotional bonds to particular individuals [is] a basic component of human nature" (Bowlby, 1988, 3).

#### **Characteristics of Attachment**

Bowlby believed that there are four distinguishing characteristics of attachment:

**Proximity Maintenance** - The desire to be near the people we are attached to.

**Safe Haven** - Returning to the attachment figure for comfort and safety in the face of a fear or threat.

**Secure Base -** The attachment figure acts as a base of security from which the child can explore the surrounding environment.

Separation Distress - Anxiety that occurs in the absence of the attachment figure http://psychology.about.com/od/ loveandattraction/ss/attachmentstyle.htm

Safety and protection for children via closeness to a caregiver provides for several important functions:

- Learn basic trust and reciprocity, which serves as a template for all future emotional relationships
- Explore the environment with feelings of safety and security which leads to healthy cognitive and social development
- Develop the ability to self regulate, which results in effective management of impulses and emotions





- Create foundation for the formation of identity, which includes a sense of competency, self worth, and a balance between dependence and autonomy.
- It helps to establish a pro-social moral framework which involves empathy, compassion and conscience
- Generates the core belief system which comprises cognitive appraisals of self, caregivers, others and life in general
- Provides a defense against stress and trauma, which incorporates resourcefulness and resilience.

The long term impacts of healthy early attachment reflect that people fare better in all aspects of functioning as development unfolds. Many studies have been conducted (Longitudinally), and have demonstrated that securely attached infants and toddlers do better over time in these areas:

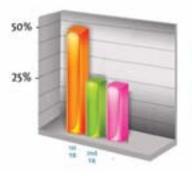
- Self esteem
- Independence and autonomy
- Resilience in the face of adversity
- Ability to manage impulses and feelings
- Long-term friendships
- Relationships with parents, caregivers and other authority figures

- Pro-social coping skills
- Trust intimacy and affection
- Positive and hopeful belief systems about self, family and society
- Empathy, compassion and conscience
- Behavioral performance and academic success in school
- Promote secure attachment in their own children when they become adults.

### **Brain Development**

Robert Fulghan wrote a book entitled "All I really need to know I learned in Kindergarten"- Looking at this chart, you can see how that truly most of what we learn does happen in the first few years of life!

#### **Critical Early Development**



- > 50% of what we need to know for life is learned year 1
- 25% learned in year 2
- From age 3 on, only 25% of life's survival skills are added

Typically, when a baby or small child is in a state of stress he cries and the parent attends the child's needs, whether by feeding, rocking or simply holding the child. EACH AND EVERY ONE OF THESE INTERACTIONS plays a critical part in assisting the development of the child's neuro-physiological control system-the system that allows the child to return back to a calm state. IT IS TRULY THROUGH THIS PARENT-CHILD RELATIONSHIP THAT WE AS HUMANS LEARN HOW TO SELF-REGULATE IN ORDER TO STAY BALANCED AND easily shift from a state of stress back to a state of calm. This regulatory mechanism is not "online" at birth, and brain research has shown

that it takes up to 30 months before this part of the brain is fully developed. Within this period, a well-attuned parent has connected with this child to calm his stress response system thousands, if not millions of times.

The human brain is an incredibly amazing and complex organ. It allows for thinking, feeling, acting, speaking, creativity and love just to name a few. It is involved in all the aspects of humanity whether good or bad, but the basic purpose of the brain is to sense, process, perceive, store and act on information from both internal and external environments to promote our survival. The brain has an efficient and logical organizational structure. It is organized in a "bottom-up" way (as described by dr. Bruce Perry) "The bottom regions i.e. brainstem and midbrain control the most important functions such as respiration, heart rate and blood pressure regulation while the top areas i.e., limbic and cortex control more complex functions such as thinking and regulating emotions." Development of the brain during infancy and childhood follows the bottom up structure. Most regulatory areas develop first (bottom) followed in sequence by adjacent but higher more complex regions.

"The process of sequential development of the brain and the sequential development of function is guided by experience. The brain develops and modifies itself in response to experience. Neurons and neuronal connections (synapses) change in an activity-dependant way. This "use dependant" development is key to understanding the impact of neglect and trauma on children." These areas of the brain organize during development and change in the mature brain in a "use dependant" way. The more a certain system is activated, the more it will "build-in" this neural state- this causes the creation of an "internal representation" of the experience corresponding to the neural activation, this is the basis for learning and memory. The result of sequential neurodevelopment is that the organizing, sensitive brain of an infant or young child is more malleable to experience than a mature brain. While experience may altar and change the functioning of an adult, experience LITERALLY provides the organizing framework for an infant and child. As different regions of the child/infant brain are organizing, they require

specific kinds of experience targeting a region's specific function (e.g., visual input while the visual system is organizing) in order to develop normally. These are critical sensitive periods. With optimal experiences, the brain develops healthy and diverse capabilities.



At the 17th week of pregnancy, fetus already has 1 billion brain cells, more than the adult brain. The cells are proliferating at a rate of 50,000/ second. These cells are not yet in the right place & only after they are formed will they travel (cell migration). At birth, the distinct areas of the brain are all in place. However, much growth will still occur. The brain is the only organ still incomplete at birth. Pathways begin to form (between neurons and synapses), and make up the wiring of the brain. The number and organization of these connections influence everything. New synapses are formed while others are pruned away. Between birth and eight months, the synapses or pathways are formed more quickly. There may be 1,000 trillion synapses in the brain at 8 months. After the first year, pruning occurs more quickly and by 10 years of age a child has nearly 500 trillion synapses, which is the same as the average adult.

Early experiences whether positive or negative have a dramatic effect on this formation of synapses. The brain essentially operates on a

# "use it or lose it" principle; only the pathways that are frequently used are retained.



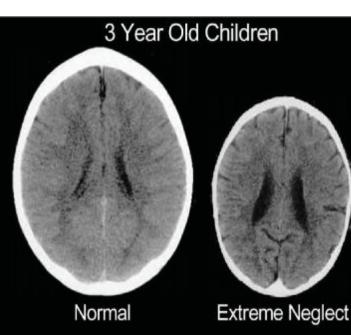
(Schore-1997) Notes that attunement between mother child is a type of "right brain to right brain communication", meaning that

the mother's right brain, seems to serve as a template for the infant's developing neural circuitry. The mother's attachment to infant, and the mirroring or interpretation of an infants feelings acts as mechanism of security for the infant. They know they are cared for, their needs are being met and they are soothed by their mother's understanding and nurturing. Interestingly, new research has been conducted and published in pediatrics, in which 28 first-time mothers viewed images of their own child and other infants while hooked up to a functional magnetic resonance imaging scanner. (MRI) It provided information on the activation of different regions of the brain as the women viewed the images of babies portraying various emotions. Researchers found that when the mothers saw happy images of their own babies, activation increased in the areas of the brain associated with reward and dopamine compared with seeing images of other babies. Researchers said "it may be that seeing your own baby's smiling face is like a "natural high".

### Early Development

### Touch > Talking > Sight > Smell

It is from early infancy to early childhood that vital connections are made permanent. Touch, talking and things an infant sees and smells all build connections if done with continuity in a loving, consistent and predictable manner. These connections die if not maintained. If there are no experiences, the connections are pruned back and the brain remains small. Children raised in environmentally deprived facilities experience fewer sounds, colors, pictures, interactions and sights. Their brains are smaller than those of children who grow up in sensually rich environments with meaningful relationships. When doctors have studied the brains of children from deprived environments, there is a strong resemblance to brains of patients with Alzheimer's. Studies done on over 1,000 abused and neglected children found that children who were rarely touched or spoken to and who had little opportunity to explore and experiment with toys, had brains that were 20-30% smaller than most children their age. In over half of these cases, parts of the brains appeared to have literally wasted away.



These images illustrate the negative impact of neglect on the developing brain. In the CT scan on the left is an image from a healthy three year old with an average head size (50th percentile). The image on the right is from a three year old child suffering from severe sensory-deprivation neglect. This child's brain is significantly smaller than average (3rd percentile) and has enlarged ventricles and cortical atrophy.

WHEN THERE IS A DISRUPTION in the timing, intensity, quality or quantity of normal developmental experiences, there can be devastating impacts on neurodevelopment and function. For millions of children, the nature of their experience adversely influences the development of their brains.

One of the most fundamental tasks an infant undertakes is determining whether and how he can get his needs met in the world in which he lives. He is constantly assessing whether his cries for food and comfort are ignored or lovingly answered. Whether he is powerless or can influence what adults do. If the adults in his life respond predictably to his cries and provide for his needs, the infant will feel secure. He can then focus his attention on exploring, allowing his brain to take in all the wonders of the world around him. If however, his needs are met only sporadically and his pleas for comfort are usually ignored or met with harsh words and rough handling, the infant will focus his energies on ensuring that his needs are met. He will have more and more difficulty interacting with people and objects in his environment and his brain will shut out the stimulation it needs to develop healthy cognitive and social skills.

### Development of Conscience

۲	Pleasur	e/pain		
۲	Shame			
•	Mature	guilt		

There is a typical way in which conscience generally develops when a child is well cared for, and there are no biological or other issues interfering. Some children do not move through the stages within the specific timeframes, others may regress during adolescence. As we will discuss later, children with Attachment disorders often get stuck in pleasure/pain.

**Pleasure/pain-**The child does what brings him pleasure and avoids what brings pain. The child has no inner moral code, and no awareness of other's feelings or needs. This stage is typical of children under age 3.

Shame- The child feels bad when criticized or punished. The child feels shame. By apologizing, asking forgiveness, distracting behaviors, or a wide range of other coping skills, the child will focus on eradicating the feeling of shame, but not on changing the behavior that led to the feeling. Sometimes the child will stick to one strategy for making the shame go away, whether it is effective or not. At this point in development, the child is not likely to be focused on the effects of his behavior on others. This stage is typical of children between 3-years of age. Before the age of five, children do not understand the concept of possession. Typical kids may not understand stealing until the age of nine. Children in this stage want parents' approval, but once they are out of your sight that is not enough to sustain them. "If I think you're watching, I'll behave"

**Mature guilt-** The child wants to live in a way that brings pleasure to himself and others. When the child hurts others, he see the effects of his behavior on the other party, feel guilt, attempt to make amends, and change his behavior. The child tries to find another way to meet his needs without hurting others. Under good conditions, this stage is typical of children age 7-11

### **Ten Things Every Child Needs**

1. Interaction- there have been a few myths told about babies. The first, that a newborn is not capable of interacting right away. The second that it takes a while for a baby to see or hear. Both have been discredited by scientists today. Infants are learning almost from the time of conception. Much work has been done to study how and what an infant learns while still in utero. The real key to interaction is in matching the adult's behavior to the needs of the child. Interactions with people and objects are as necessary to the baby as protein, fat and vitamins. All are vital nutrients for the growing and developing brain. Different experiences will cause the brain to develop in different ways due to its plasticity.

- 2. Touch-Touch is critical to development! Of all the sensory experiences, touch is how the infant first knows he is loved. It is the source of comfort. Holding is reassuring in the face of strangeness. Touch literally sends signals to the brain telling it to grow (make connectionsbuild pathways). There is much research about infant massage. In preemies, massage causes faster growth, calmer babies and better development. Babies who are massaged daily develop movement earlier, sleep more soundly and have less colic. Without this touch nurturing at an early age, infants can NEVER develop. Infants need this experience to grow. For both the brain and the body, touch is a critical nutrient as critical as vitamins. Touch lets the child know that "yes, I am wanted and it is worth survival".
- 3. Stable relationship-Studies have shown that the presence of a loving caregiver during a time of stress (shots at the doctors office) reduced the production of cortisol(stress hormone that if levels get too high the heart rate, digestive system and ability to think are affected). In studies, the child may still cry, but the smaller amount of cortisol found in saliva indicated that the body was not reacting as strongly. Frequent and prolonged exposure to elevated cortisol may affect the development of brain areas involved in memory, negative emotions and attention regulation. The early secure relationship acts as a prevention for difficulties in handling stress later in childhood. Children with a history of secure attachment come to expect their worlds to be predictable.
- 4. Safe healthy environment-diet, absence of toxins in the environment (such as lead), appropriate rest etc...
- 5. Self esteem- The root of all emotional feeling is the brain stem. It takes nearly one and half years for a child to learn how to control feelings- how well this is learned does depend on parents. According to Dr. Brazelton, he can recognize by eight months which kids expect themselves to succeed and which don't. "Children mirror what is around them- like sponges, they absorb. If a child is in a violent environment, he needs calm, nurturing and

predictable care giving. A mother only has to be good-enough, not perfect."

- 6. Quality care- "For every government dollar spent on preschool, society saves seven dollars. Today, the professional organization of prison wardens correlates the need for investing money in the first three years of life as a prevention with a later necessity to build prisons!" Studies are showing that experiences from the prenatal period through the 3rd year have direct results in the production of criminals and antisocietal people (Karr-Morse and Wiley, 1997)-Childcare aimed at learning about self, others and how to control and use one's environment is invaluable. In today's age, so many children are in childcare from early days on, it is important that the people working there be willing to spend time interacting with children.
- 7. Communication-A child's ability to communicate begins at birth. By 6 months, a child can duplicate sounds. The plasticity of the brain is what makes it possible to learn language in the first place. All the circuits are in place, they just need to be connected. The more the infant hears words, the more connections will be made. Children need to interact with people to learn language. It is critical to engage children in conversation-this is how they develop language, by hearing words repeatedly.
- 8. Play- Everything learned through play is linked to mental development. It is the experience, NOT the toy, that aids in brain growth. It has been shown that children who do best on tests are those whose parents play with them.
- **9. Music-** Some benefits of music are that it brings learning elements together, physical coordination, timing, engages memory, imagination and language, builds self-confidence, stirs a response between parents and child that helps build the connection between them. Children seem to have a natural affinity for music, and more and more studies are revealing the academic and emotional benefits of music in children's lives.

**10. Reading-** Reading has tremendous impact on children's lives, it melds the parents relationships with the child to the active reading experience. Sharing a book leads to learning to read. The more you do it, the more connections are made!

### **Attachment Disorders**

Reactive attachment disorder (RAD) is a rare but serious mental health condition in which infants and young children don't establish healthy bonds to caregivers or parents. Children with reactive attachment disorder typically were neglected or abused in infancy, passed through many foster homes, or lived in orphanages where their emotional needs were not met.

Because either basic needs for comfort, affect, nurturing and stimulation weren't met, these infants and children didn't learn how to create loving and caring attachments with other people. They cannot give or receive affection. Reactive attachment disorder is often enmeshed in controversy. Both its diagnosis and treatment are difficult, and parents and caregivers are commonly distressed as they try to cope with the disorder and a seemingly uncaring child. Some nonconventional treatment methods have been associated with the deaths of several children, escalating the controversy. Despite the challenges, a commitment to proved psychiatric treatment may help people with RAD enjoy a better quality of life and develop more stable relationships. RAD is broken into two types-inhibited and disinhibited. While some have signs and symptoms of just one type, many have symptoms of both.

-From the Mayo Clinic

These criteria are taken directly from the diagnostic manual for intellectual disabilities.

**A.** Markedly disturbed and developmentally inappropriate social relatedness in most contexts, beginning before age 5 years as evidenced by either (1) or (2)

- Persistent failure to initiate or respond in a developmentally appropriate fashion to most social interactions as manifested by failure to establish eye contact, impairment in help seeking behaviors, impaired or indiscriminate proximity seeking when distressed or in pain, impaired relatedness to parents, peers or direct support professionals, impaired reaction to the absence of preferred caregivers, or impaired or aggressive behaviors upon return of caregivers.
- Diffuse attachments as manifested by indiscriminate sociability with marked inability to exhibit appropriate selective attachments. (e.g., excessive familiarity with relative strangers or lack of selectivity in choice of attachment figures)

### **DM-ID** Classification

A. Markedly disturbed and developmentally inappropriate social relatedness in most contexts (before age 5), as evidenced by either 1 or 2.

**B.** The disturbance in criteria "A" is not accounted for by a developmental delay and does not meet criteral for Pervasive Developmental Disorder (PDD)

B. The disturbance in criteria A is not accounted for solely by developmental delay (when compared to other individuals of similar levels of measured intelligence and adaptive skills) and does not meet criteria for PDD **C.** Pathogenic care as evidenced by at least one of the following: NOTE: History of abuse or neglect during infancy, childhood and later caregivers. Persistent disregard of the basic emotional needs for comfort, stimulation, and affection, persistent disregard of the child's basic physical needs. Repeated changes of primary caregiver that prevent formation of stable attachments ) e.g., frequent changes in foster home, institutional placement etc...

- C. Pathogenic care is evidenced by at least one of the following:
  - Persistent disregard of basic emotional needs
  - Persistent disregard of basic physical needs
  - Repeated changes of primary caregiver that prevent formation of stable attachment

**D.** The slide at left describes criterion "D" for Reactive Attachment Disorder

In **inhibited reactive attachment disorder**, children shun relationships and attachments to virtually everyone. This may happen when a baby never has the chance to develop an attachment to any caregiver. Signs and symptoms (from mayo clinic) may include:

- Resisting affection from parents or caregivers
- Avoiding eye contact
- Appearing to seek contact but then turning away
- Difficulty being comforted
- Preferring to play alone
- Avoiding physical contact
- Failing to initiate contact with others

- Appearing to be on guard or wary
- Engaging in self-soothing behavior

In disinhibited reactive attachment disorder,

children form inappropriate and shallow attachments to virtually everyone, including strangers. This may happen when a baby has multiple caregivers or frequent changes in caregivers.

Signs and symptoms of the disinhibited type may include:

- Readily going to strangers, rather than showing stranger anxiety
- Seeking comfort from strangers
- Exaggerating needs for help doing tasks
- Inappropriately childish behavior
- Appearing anxious

D.Pathogenic care is evidenced by at least one of the following:

- Inhibited Type If criterion A1 predominates the clinical picture
- Disinhibited Type If criterion A2 predominates in the clinical presentation

Beverly James, in her <u>Handbook for Treatment</u> of <u>Attachment-Trauma Problems in Children</u>. Further explores specific categories of attachment problems. Following is a description from her book.

**Disturbed attachment-** Attachment disturbances develop when there is an on-going lack of attunement, or mismatch between parent and child. This disharmony can have several causes, including impairment of child or parent functioning that interferes with sending of or response to attachment signals; difficulties adapting to temperament differences; inadequate parenting skills; or inconsistent, disruptive parenting.

**Attachment trauma-** Loss of the primary attachment figure represents a loss of every thing to a child- loss of love, safety, protection, even life itself, and prolonged unavailability of the primary attachment is the same as total loss for a young child.

Children experience their primary attachment figure as necessary for survival- he or she is the person whose presence provides protection and whose actions reduce the child's terror to a manageable size and enable the youngster to cope with changing situations.

The child abused by an attachment figure suffers in multiple and complex ways. Children become afraid to protect themselves from an abusive parent as they are afraid that this will cause the parent to go away. Children in these situations will often blame themselves for the abuse.

#### Trauma-Related attachment problems- Any

traumatic even or multiple traumatic events can lead to patterns of child or parent behavior that seriously interferes with the attachment relationship. The parent might not be able to recognize or respond adequately to the child's needs; the child might not be able to adequately express needs or respond to the adult.

RAD was initially introduced to the mental health community over 20 years ago. Since then, a significant portion of the information available regarding the disorder has painted a dismal and often dangerous picture of these children. Through literature, television and other sources children with RAD have been compared to serial killers, rapists, and hard-core criminals. Therapies in the past have been highly intensive and often physically aggressive, and in some cases, unconventional parenting techniques were instructed to parents in order to "control" the children. Some examples include teaching parents to force eye contact, have children do excessive chores to feel a part of the family system, send the children to respite care out of the home for making poor choices, give up the

need to communicate love to these children, put locks on the outside of children's doors to keep them "safe". Techniques that talk in general about gaining control of a child and viewing the child as manipulative are child-blaming, parentcontrolling and devoid of scientific research.

### A New Understanding

- Initially introduced over 20 years ago
- Painted a dismal and dangerous picture
- History of fear based treatment
- Child-blaming approaches

As we look at some of the symptoms, it may be easy to see why there has been so much fear around this diagnosis, but it is important to remember that these symptoms do not characterize these children on a constant basis, and as scary or abnormal as the symptoms sound they are actually quite reasonable reactions to the experiences many of these children have endured.

Many of the symptoms are also seen in other mental illnesses, and it is important to note that often children with RAD are diagnosed with a variety of diagnoses and experience many trials with psychotropic's before they are diagnosed with RAD.

The following are **Symptoms** of Reactive Attachment Disorders:

- Intense control battles
- Resists affection on caregiver's terms
- Lack of eye contact
- Indiscriminately affectionate with strangers
- Poor peer relationships
- Steals

- May lie about the obvious
- Shows no remorse
- Destructive to property, self, and others
- Lack of impulse control
- Parents appear hostile and angry
- Hypervigilant/hyperactive
- learning lags/delays
- Speech and language problems
- Incessant chatter/and or questions
- Inappropriately demanding and/or clingy
- Food issues- hordes, gorges, refuses to eat, eats strange things, hides food
- Fascination with fire, blood, gore, weapons
- Very concerned about tiny hurts, brushes off big ones
- Was neglected and/or physically abused in the first 3 years of life

#### **Potential Causes Include the following:**

- Neglect
- Abuse
- Separation from the primary caregiver
- Frequent moves and/orplacements
- Traumatic experiences
- Maternal depression
- Maternal addiction -- drugs or alcohol
- Undiagnosed, painful illness such as colic, ear infections, etc.
- Lack of attunement between mother and child
- Young or inexperienced mother with poor parenting skills

- Death of a parent
- Premature birth
- Inconsistent caretakers
- Chronic pain
- Long-term hospitalizations with separation from th emother
- Developmental disability

Given the list of potential causes and how we are beginning to understand how RAD is caused, think about the people we have supported, and how many may have had similar life events. Think of other circumstances you believe may potentially cause RAD, Consider how often these things happen to the people we support. This certainly doesn't mean that everyone we support has RAD, but it may explain many of the behaviors and difficulty that we often view as challenging whether a person has an attachment disorder or not.

#### **Understanding RAD**

"When a child does not receive loving, nurturing care, the child's ability to develop a sufficient regulatory system is severely compromised."

As we had discussed regarding how the brain and survival mechanisms develop. In cases of severe neglect and abuse, the Childs life is literally at risk. For these children, their internal survival mechanisms become activated, dedicating all the





body's resources to remain alert in "survival mode." The world is then perceived as threatening from a neurological, physical, emotional, cognitive, and social perspective. A person with these experiences will then operate from a paradigm of fear to ensure their own safety and security. Hence, we may see an overly stressed-out child/ adult who guite often can not think clearly, and who swings back and forth in their emotional states due to underdeveloped regulatory systems. While perceived by many as dangerous, a person with RAD is essentially a scared and stressed child living out of a primal survival mode in order to maintain his/her existence. While we may feel that actions are purposeful, the person has only limited control over how they can respond to us.

People/children with RAD may see the world differently than we do. For them, life is a constant threat. Such threats can be interpreted through all manner of sensory stimulation. A sight, sound, smell, taste or elevation in body temperature can trigger an overwhelming state of fear. Because they were unable to develop the necessary ability to calm this fear early in life, they may become violently reactive. It is of little consequence to someone with RAD that their new home or environment may provide love, security and nurturance when they become frightened. The frightening event may oftentimes not be observed by those around the person because the brain of someone with RAD is hypersensitive and hyper reactive. It can and generally does occur within a millisecond and may build up throughout the course of a day, week, month, presenting as

violent and long-lasting outbursts or a period of complete disconnection and dissociation. Even someone who was adopted, or cared for in a new home at very young age may have already experienced enough trauma to impact development and stress response. Biological children who suffer a separation from their primary caregiver due to illness, etc. can equally be impacted if the event is traumatic or overly stressful.

The person with RAD having experienced past significant trauma is tremendously impaired in his/her ability to calm down. In other words, "he/ she is unable to calm the inner workings of his/her brain and body system responsible for effective stress hormone discharge and soothing. This state is trauma induced and is the brain and body's natural fear reaction gone awry. In this manner, the fetus, infant, child or adult is product to an overly stressful environment or event attributing to extreme fear sensitivity."-Post institute for Family Centered Therapy.

#### Support

"Children who exhibit signs of Reactive Attachment Disorder need a comprehensive psychiatric assessment and individualized treatment plan. These signs or symptoms may also be found in other psychiatric disorders. A child should never be given this label or diagnosis without a comprehensive evaluation.

Treatment of this complex disorder involves both the child and the family. Therapists focus on understanding and strengthening the relationship between a child and his or her primary care givers. Without treatment, this condition can affect permanently a child's social and emotional development. However, unconventional and forced treatments such as "rebirthing" strategies are potentially dangerous and should be avoided".-From American Academy of Child and Adolescent Psychiatry- http://www.aacap.org/ cs/root/facts\_for\_families/reactive\_attachment\_ disorder

Attachment therapy, psychotherapy-This

treatment focuses on teaching the caregiver how to eliminate neglect and poor parenting. In addition, the caregiver learns:

- 1. about the disorder
- 2. about activities that promote normal child development
- 3. how to play with the child
- 4. how to manage the child's aggressive and problematic behaviors
- 5. how to communicate effectively with the child

Holding Therapy or Rage Reduction Therapy are not currently accepted clinical practice. These treatments are not approved by DCFS for treatment of RAD.



Developing treatment goals is a critical step in the treatment process. Clear, objective treatment goals enable the client, family, and service provider to address the client's mental health needs.

There are two broad kinds of treatment goals: Administrative and clinical. Administrative goals involve the completion or non-completion of services. Examples of administrative goals include the number of psychotherapy sessions that a client attends. Clinical treatment goals address two domains related to a client's overall functioning: symptom or behavior change, and changes in daily functioning ability

a) Symptom change -- A change in the symptoms or behaviors associated with RAD, such as increased eye contact or improved ability to seek out appropriate caretakers when distressed.

**b)** Functional change -- A change in the areas of functioning that are typically affected by RAD, such as improved ability to get along with other young children or siblings, or fewer episodes of approaching strangers in the community.

The principles of treatment for a person with RAD may often be similar to the steps used to address trauma, keeping trauma in mind can be very helpful for clinicians and supporters. Goals of treatment include: resolution of early losses, development of trust, modulation of affect, development of internal control, development of reciprocal relationships, learning appropriate responses to external structure and societal rules, correcting distorted thinking patterns, developing self respect

Both parties have to feel safe in their own bodies and with one another-attachment is akin to falling in love, but unless both parties feel completely safe, it will not be successful. When adults are anxious, mad, tuned out or overwhelmed, they will not be able to make an attuned connection. If a child or person with RAD is overwhelmed or inconsolable, he may not be available for an attuned emotional connection. Sensory activities such as rocking, singing, moving, touching and eating can be soothing, but remember again that people vary in their sensory preferences. Shared emotional experiences should truly be shared- The key to shared emotional experience is to feel the same experience to some degree in your own body. Empathy can be a valuable tool. The shared emotional experiences can help both parties to regulate their feeling states. It is usually more important to share a negative state with someone than to problem solve. Sharing enables people to problem solve for themselves.

Positive emotional experiences are as important as negative- the shared positive emotional experiences of joy are as important to attachment as the shared negative experiences of fear, sadness, anger and shame. Some are very good at detecting another's distress and responding to it. Other's share joyous moments but leave or space out in times of trouble and unhappiness. A strong attachment includes the full range of shared emotional experience.

Initiating repair and being available after conflict can be a critical part of maintaining attachment. Whatever happens, the person needs to know that we are still there and willing to work on the relationship.

Increasingly there is hope around this issue where in the past there has been little. Past treatments have been controversial and dangerous, and while some clinicians still believe that coercive approaches are effective the NIMH and AACAP as well as recognized treatment centers for RAD, now believe that treatment can occur successfully without coercion and the basis should always be a therapeutic connection, education and treatment of the person/child and family/caregivers.

How is inadequate attachment repaired? Recent studies show that it's never too late to create positive change in a child's life, or in an adults. The learning that accompanies new experiences can alter neural connections in the brain. Relationships with relatives, teachers and childcare providers can supply an important source of connection and strength for the child's developing mind. Some things to consider are:

#### **Attachment is Interactive**

It is a fact that our brains are structured to connect to one another. The attachment process

alters the brains of both parent and child. But what makes attachment so unique is that the stronger, older, more experienced parent attunes and follows the lead of the younger, less experienced, more vulnerable child. In the case of working with adults with disabilities, we should allow them to take the lead, show us what helps them feel most comfortable and dictate what we can do to be helpful (in an appropriate and safe way of course).

#### **Attachment is a Nonverbal Process**

Attachment takes place many months and even years before speech and thought develop. Communication is accomplished through wordless means that rely on several things to convey interest, understanding and caring:

**Visual-** eye contact, facial expression, posture, gesture, body movement

**Auditory**-Tone of voice, speech rhythm and rate, timing, intensity and voice modulation

There is no one size fits all for every person in determining what constitutes "just right" communication for a particular person; it will be up to us to follow the nonverbal or verbal cues of the person. What soothes, or helps me feel better may not help that person, thus we may need to explore the best techniques for soothing and comfort for that person in order to be able form connections.

Dr. Bruce Perry, M.d., PhD, is an internationally recognized authority on brain development and children in crisis. He leads the child trauma academy and is medical director for Provincial Program's in Children's Mental Health for Alberta, Canada. He has served as a consultant on many high profile incidents with traumatized children such as Columbine, Oklahoma City Bombing and the Branch Davidian siege. As part of his work, he has developed tips for families of children with RAD, many of which can be adapted for use with adults. The following list of thoughts on what we can do to help comes directly from his writing.

#### **Appropriate Physical Caring and Loving**

Children need to be held, rocked and cuddled. While we work with adults, we may need to find a way to appropriately supplement this need for them. Be physical, caring and loving in an appropriate way. Be aware that for many, touch in the past may have been associated with pain, torture or sexual abuse. Make sure you carefully monitor how individual's respond-be attuned to their responses to your nurturing and act accordingly, in many ways you are providing replacement experiences that should have taken place during infancy, but you are doing this when their brains are harder to modify and change. Therefore, they may need more bonding experiences to help them develop attachments.



The more we learn about attachment problems, bonding, normal development and abnormal development, the more we will be able to develop useful behavioral and social interventions. Information about these problems can prevent us from misunderstanding the person's/child's behaviors. When someone hoards food for example, it should not be viewed as stealing but as a common and predictable result of being deprived of food earlier in life. A punitive approach to this problem and many others will not help the person mature. Instead, punishment may actually increase the sense of insecurity, distress and need to hoard (or engage in other protective behaviors). So many people's behaviors are confusing and disturbing to us. Get help from professionals if you find you are struggling to create or implement a practical and useful approach to these problems.

#### Meeting the Person "Where They Are"

Abused and neglected people will often be emotionally and socially delayed. Whenever they are frustrated or fearful, they will regress. This means that at any given moment, an adult with an intellectual disability and history of neglect may emotionally regress to a two-year old level. Despite your wishes that a person would "act their age" and our insistence to do so, they are not capable of that. These are times when we may need to interact with them at their emotional level. If they are tearful, frustrated or overwhelmed, use soothing verbal/non-verbal interactions. Sing quietly, offer a hug etc... This is not the time to use complex verbal arguments about the consequences of inappropriate behavior.

#### Consistency

Maltreated people with attachment problems are very sensitive to changes in schedule, transitions, surprises, chaotic social situations and in general any new situation. Busy and unique social situations will overwhelm them, even if they are pleasant! Birthday parties, holidays, trips, start of school year, summer all can be disorganizing. Because of this, any efforts that can be made to be consistent, predictable and repetitive will be very important in making one feel safe and secure. When they feel safe, they can benefit from the nurturing and enriching emotional and social experiences you provide. If they are anxious and fearful, they cannot benefit from your nurturing in the same ways.

#### Modeling

Many abused and neglected children/people do not know how to interact with other people. One of the best ways to teach them is to model this in your own behaviors, and then narrate what you are doing and why. Become a play-by-play announcer for example "I am going to the sink to wash my hands before dinner because..." or "I take the soap and put it on my hands like this..." This gives a person the opportunity to see, hear and imitate.

In addition to modeling, you can "coach" interactions in a similar play-by-play approach, but do so discreetly. For example "well, when you hit someone, they probably feel pretty upset, so if you want to have fun together then you should try..."



#### Listening

One of the most helpful things we can do is just stop, sit, listen and have fun. When we are quiet and interactive we may often find that the person will begin to show us and tell what is really inside them. As simple as this sounds it can be one of the most difficult things to do-this means we have to stop worrying about time, our next task, chore or duty and really relax into the moment with the person you are working with. Practice this and you may be amazed at the results. The person will begin to sense that you are there for them and they may understand that they are cared for.

It is during these moments that we can best reach and teach others. This is a great time to begin teaching about different feelings. Regardless of the activity, the following principles may be helpful to include:

- All feelings are OKAY to feel-sad, glad, mad, frustrated etc...
- Teach healthy ways to act when sad, mad, glad etc...
- Begin to explore how others may feel and how they show their feelings \_"How do you think your housemate feels when you shove him?" "How do you think your housemate felt when you were playing ball together?"

When you ensure that the person is clearly happy, sad, mad etc.. Ask them how they are feeling. HELP THEM BEGIN TO PUT WORDS AND LABELS TO THEIR FEELINGS.

#### **Realistic Expectations**

Have realistic expectations! Anyone who has been abused and neglected has so much to overcome. For some people with RAD, they will not overcome all their problems. For example, a Romanian orphan adopted at age 5 after spending her early years without any nurturing, the expectations may be less. She was robbed of some, but not all of her potential. We do not know how to predict potential in a vacuum, but we can measure the emotional, behavioral, social and physical strengths of the person. A comprehensive evaluation by skilled clinicians can be very helpful to define skills, as well as areas where progress may be slower. We simply have to be patient and understanding, and try to remember that the negative things are not personal, and may not be within the person's control.

#### **Be Patient**

Be patient with the person's progress and yourself. Progress may be slow. The slow progress can be frustrating and many of us may feel inadequate because all of the love, time and effort spent may not seem to have any effect. BUT IT DOES! Don't be hard on yourself. Many loving, skilled and competent parents, teachers, staff have been swamped by the needs of a child/adult with RAD.

#### **Caring for Ourselves**

For many, caring for or working with someone with a traumatic/neglected history can be exhausting and demoralizing. We cannot provide consistent, predictable, enriching and nurturing care if we are depleted. it is important to get rest and support. Respite care can be helpful if necessary (but should never be used in a punitive way). Talk openly with other caregivers, your support system, ask for a break if you need it, use your agency's resources or the community for support if you need it. We cannot be helpful to anyone else if we are not cared for ourselves!



#### **Use Resources**

Take advantage of whatever resources you can. Many communities have support groups, this may be helpful for family and loved ones, as well as supporters. Again, ask for help or a break if you need it, don't be afraid to share your feelings. Get education on RAD, trauma and any other areas that you think may be helpful. When we understand something it becomes less scary and we become better equipped to work in a helpful way.

From Beverly James' book, she offers seven tips. She says that we have to understand the real needs of the person. She points out that despite what someone says or how they behave, if they have an abusive or neglectful past, then his or her needs are pretty straightforward. She states they need the following:

Safety

Will I be safe in a nonviolent environment where my basic needs will be met?

Security

I need a structured situation where a parent is in charge and I can just be me.

Acceptance

I need people who can accept me as a person even if they don't like or accept my behavior

Belonging

I need to belong to someone; I need to be connected to others and learn to give and

#### Trust

I need to learn to trust and be trusted; I need to be treated fairly, with honesty, respect and consistency

#### Relationship

I need to be in relationships with others in a way that no one is victimized and both sides are enhanced

#### Self-awareness

I need to learn how to make changes in my personality and behavior by selfunderstanding

#### Personal worth

The final indicator of my being a success as a person is, Do I believe in myself and my own worth?

#### Summary

- Attachment is a deep and enduring connection which begins at birth
- Attachment is a "mutual regulatory system" and is critical to early development
- RAD is a rare but serious mental health condition
- RAD has long been a diagnosis which promoted fear and misunderstanding
- There is hope and support available for people with RAD and their family/friends/supporters

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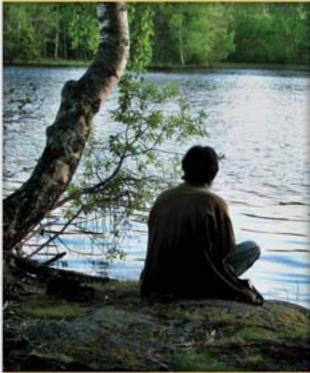
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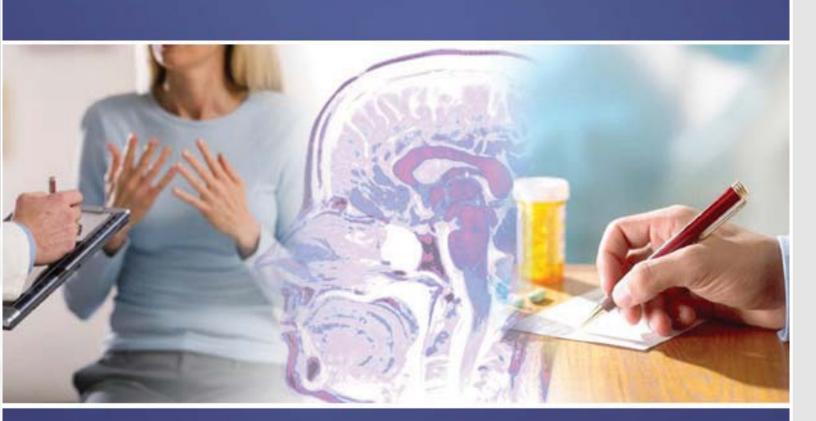


# SECTION 3: IMPORTANT CONSIDERATIONS



The "Mental Health Medications" Guide provided here is brought to you courtesy of the National Institute of Mental Health, U.C. Department of Health and Human Services, and the National Institute of Health





# Mental Health Medications

National Institute of Mental Health U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES • National Institutes of Health

#### Contents

Mental Health Medications
What are psychiatric medications?
How are medications used to treat mental disorders?1
What medications are used to treat schizophrenia?
What are the side effects?
How are antipsychotics taken and how do people respond to them?
How do antipsychotics interact with other medications?
What medications are used to treat depression?
What are the side effects?
How should antidepressants be taken?
Are herbal medicines used to treat depression?
FDA warning on antidepressants.
What medications are used to treat bipolar disorder?
Mood stabilizers
Atypical antipsychotics
Antidepressants
What are the side effects?
How should medications for bipolar disorder be taken?
What medications are used to treat anxiety disorders?
Antidepressants
Benzodiazepines (anti-anxiety medications)
Beta-blockers
What are the side effects?
How should medications for anxiety disorders be taken?
What medications are used to treat ADHD?
What are the side effects?
How are ADHD medications taken?
Are ADHD medications safe?
FDA warning on possible rare side effects
Which groups have special needs when taking psychiatric medications?14
Children and adolescents
Older adults
Women who are pregnant or may become pregnant
What should I ask my doctor if I am prescribed a psychiatric medication?16
Alphabetical List of Medications
Citations
For More Information on Medications



#### **Mental Health Medications**

edications are used to treat the symptoms of mental disorders such as schizophrenia, depression, bipolar disorder (sometimes called manic-depressive illness), anxiety disorders, and attention deficithyperactivity disorder (ADHD). Sometimes medications are used with other treatments such as psychotherapy. This guide describes:

- Types of medications used to treat mental disorders
- Side effects of medications
- Directions for taking medications
- Warnings about medications from the U.S. Food and Drug Administration (FDA).

This booklet does not provide information about diagnosing mental disorders. Choosing the right medication, medication dose, and treatment plan should be based on a person's individual needs and medical situation, and under a doctor's care.

Information about medications is frequently updated. Check the FDA Web site (<u>http://www.fda.gov</u>) for the latest information on warnings, patient medication guides, or newly approved medications. Throughout this document you will see two names for medications—the generic name and in parenthesis, the trade name. An example is fluoxetine (Prozac). See the end of this document for a complete alphabetical listing of medications.

### What are psychiatric medications?

Psychiatric medications treat mental disorders. Sometimes called psychotropic or psychotherapeutic medications, they have changed the lives of people with mental disorders for the better. Many people with mental disorders live fulfilling lives with the help of these medications. Without them, people with mental disorders might suffer serious and disabling symptoms.

### How are medications used to treat mental disorders?

Medications treat the symptoms of mental disorders. They cannot cure the disorder, but they make people feel better so they can function.

Medications work differently for different people. Some people get great results from medications and only need them for a short time. For example, a person with depression may feel much better after taking a medication for a few months, and may never need it again. People with disorders like schizophrenia or bipolar disorder, or people who have long-term or severe depression or anxiety may need to take medication for a much longer time.

Some people get side effects from medications and other people don't. Doses can be small or large, depending on the medication and the person. Factors that can affect how medications work in people include:

- Type of mental disorder, such as depression, anxiety, bipolar disorder, and schizophrenia
- Age, sex, and body size
- Physical illnesses
- Habits like smoking and drinking
- Liver and kidney function
- Genetics
- Other medications and herbal/vitamin supplements
- Diet
- Whether medications are taken as prescribed.

#### What medications are used to treat schizophrenia?



ntipsychotic medications are used to treat schizophrenia and schizophrenia-related disorders. Some of these medications have been available since the mid-1950's. They are also called conventional "typical" antipsychotics. Some of the more commonly used medications include:

- Chlorpromazine (Thorazine)
- Haloperidol (Haldol)
- Perphenazine (generic only)
- Fluphenazine (generic only).

In the 1990's, new antipsychotic medications were developed. These new medications are called second generation, or "atypical" antipsychotics.

One of these medications was clozapine (Clozaril). It is a very effective medication that treats psychotic symptoms, hallucinations, and breaks with reality, such as when a person believes he or she is the president. But clozapine can sometimes cause a serious problem called agranulocytosis, which is a loss of the white blood cells that help a person fight infection. Therefore, people who take clozapine must get their white blood cell counts checked every week or two. This problem and the cost of blood tests make treatment with clozapine difficult for many people. Still, clozapine is potentially helpful for people who do not respond to other antipsychotic medications.

Other atypical antipsychotics were developed. All of them are effective, and none cause agranulocytosis. These include:

- Risperidone (Risperdal)
- Olanzapine (Zyprexa)
- Quetiapine (Seroquel)

- Ziprasidone (Geodon)
- Aripiprazole (Abilify)
- Paliperidone (Invega).

The antipsychotics listed here are some of the medications used to treat symptoms of schizophrenia. Additional antipsychotics and other medications used for schizophrenia are listed in the chart at the end.

Note: The FDA issued a Public Health Advisory for atypical antipsychotic medications. The FDA determined that death rates are higher for elderly people with dementia when taking this medication. A review of data has found a risk with conventional antipsychotics as well. Antipsychotic medications are not FDA-approved for the treatment of behavioral disorders in patients with dementia.

#### What are the side effects?

Some people have side effects when they start taking these medications. Most side effects go away after a few days and often can be managed successfully. People who are taking antipsychotics should not drive until they adjust to their new medication. Side effects of many antipsychotics include:

- Drowsiness
- Dizziness when changing positions
- Blurred vision
- Rapid heartbeat
- Sensitivity to the sun
- Skin rashes
- Menstrual problems for women.

Atypical antipsychotic medications can cause major weight gain and changes in a person's metabolism. This may increase a person's risk of getting diabetes and high cholesterol.<sup>1</sup> A person's weight, glucose levels, and lipid levels should be monitored regularly by a doctor while taking an atypical antipsychotic medication.

Typical antipsychotic medications can cause side effects related to physical movement, such as:

- Rigidity
- Persistent muscle spasms
- Tremors
- Restlessness.

Long-term use of typical antipsychotic medications may lead to a condition called tardive dyskinesia (TD). TD causes muscle movements a person can't control. The movements commonly happen around the mouth. TD can range from mild to severe, and in some people the problem cannot be cured. Sometimes people with TD recover partially or fully after they stop taking the medication.

Every year, an estimated 5 percent of people taking typical antipsychotics get TD. The condition happens to fewer people who take the new, atypical antipsychotics, but some people may still get TD. People who think that they might have TD should check with their doctor before stopping their medication.

### How are antipsychotics taken and how do people respond to them?

Antipsychotics are usually pills that people swallow, or liquid they can drink. Some antipsychotics are shots that are given once or twice a month.

Symptoms of schizophrenia, such as feeling agitated and having hallucinations, usually go away within days. Symptoms like delusions usually go away within a few weeks. After about six weeks, many people will see a lot of improvement.

However, people respond in different ways to antipsychotic medications, and no one can tell beforehand how a person will respond. Sometimes a person needs to try several medications before finding the right one. Doctors and patients can work together to find the best medication or medication combination, and dose.

Some people may have a relapse—their symptoms come back or get worse. Usually, relapses happen when people stop taking their medication, or when they only take it sometimes. Some people stop taking the medication because they feel better or they may feel they don't need it anymore. **But no one should stop taking an antipsychotic medication without talking to his or her doctor.** When a doctor says it is okay to stop taking a medication, it should be gradually tapered off, never stopped suddenly.

### How do antipsychotics interact with other medications?

Antipsychotics can produce unpleasant or dangerous side effects when taken with certain medications. For this reason, all doctors treating a patient need to be aware of all the medications that person is taking. Doctors need to know about prescription and over-the-counter medicine, vitamins, minerals, and herbal supplements. People also need to discuss any alcohol or other drug use with their doctor.

To find out more about how antipsychotics work, the National Institute of Mental Health (NIMH) funded a study called CATIE (Clinical Antipsychotic Trials of Intervention Effectiveness). This study compared the effectiveness and side effects of five antipsychotics used to treat people with schizophrenia. In general, the study found that the older medication perphenazine worked as well as the newer, atypical medications. But because people respond differently to different medications, it is important that treatments be designed carefully for each person. You can find more information on <u>CATIE here</u>.

#### What medications are used to treat depression?



epression is commonly treated with antidepressant medications. Antidepressants work to balance some of the natural chemicals in our brains. These chemicals are called neurotransmitters, and they affect our mood and emotional responses. Antidepressants work on neurotransmitters such as serotonin, norepinephrine, and dopamine.

The most popular types of antidepressants are called selective serotonin reuptake inhibitors (SSRIs). These include:

- Fluoxetine (Prozac)
- Citalopram (Celexa)
- Sertraline (Zoloft)
- Paroxetine (Paxil)
- Escitalopram (Lexapro).

Other types of antidepressants are serotonin and norepinephrine reuptake inhibitors (SNRIs). SNRIs are similar to SSRIs and include venlafaxine (Effexor) and duloxetine (Cymbalta). Another antidepressant that is commonly used is bupropion (Wellbutrin). Bupropion, which works on the neurotransmitter dopamine, is unique in that it does not fit into any specific drug type.

SSRIs and SNRIs are popular because they do not cause as many side effects as older classes of antidepressants. Older antidepressant medications include tricyclics, tetracyclics, and monoamine oxidase inhibitors (MAOIs). For some people, tricyclics, tetracyclics, or MAOIs may be the best medications.

#### What are the side effects?

Antidepressants may cause mild side effects that usually do not last long. **Any unusual reactions** or side effects should be reported to a doctor immediately.

The most common side effects associated with SSRIs and SNRIs include:

- Headache, which usually goes away within a few days.
- Nausea (feeling sick to your stomach), which usually goes away within a few days.
- Sleeplessness or drowsiness, which may happen during the first few weeks but then goes away. Sometimes the medication dose needs to be reduced or the time of day it is taken needs to be adjusted to help lessen these side effects.
- Agitation (feeling jittery).
- Sexual problems, which can affect both men and women and may include reduced sex drive, and problems having and enjoying sex.

Tricyclic antidepressants can cause side effects, including:

- Dry mouth.
- Constipation.
- Bladder problems. It may be hard to empty the bladder, or the urine stream may not be as strong as usual. Older men with enlarged prostate conditions may be more affected.
- Sexual problems, which can affect both men and women and may include reduced sex drive, and problems having and enjoying sex.

- Blurred vision, which usually goes away quickly.
- Drowsiness. Usually, antidepressants that make you drowsy are taken at bedtime.

People taking MAOIs need to be careful about the foods they eat and the medicines they take. Foods and medicines that contain high levels of a chemical called tyramine are dangerous for people taking MAOIs. Tyramine is found in some cheeses, wines, and pickles. The chemical is also in some medications, including decongestants and over-thecounter cold medicine.

Mixing MAOIs and tyramine can cause a sharp increase in blood pressure, which can lead to stroke. People taking MAOIs should ask their doctors for a complete list of foods, medicines, and other substances to avoid. An MAOI skin patch has recently been developed and may help reduce some of these risks. A doctor can help a person figure out if a patch or a pill will work for him or her.

### How should antidepressants be taken?

People taking antidepressants need to follow their doctors' directions. The medication should be taken in the right dose for the right amount of time. It can take three or four weeks until the medicine takes effect. Some people take the medications for a short time, and some people take them for much longer periods. People with long-term or severe depression may need to take medication for a long time.

Once a person is taking antidepressants, it is important not to stop taking them without the help of a doctor. Sometimes people taking antidepressants feel better and stop taking the medication too soon, and the depression may return. When it is time to stop the medication, the doctor will help the person slowly and safely decrease the dose. It's important to give the body time to adjust to the change. People don't get addicted, or "hooked," on the medications, but stopping them abruptly can cause withdrawal symptoms.

If a medication does not work, it is helpful to be open to trying another one. A study funded by NIMH found that if a person with difficultto-treat depression did not get better with a first medication, chances of getting better increased when the person tried a new one or added a second medication to his or her treatment. The study was called <u>STAR\*D (Sequenced Treatment Alternatives</u> to Relieve Depression).<sup>2,3</sup>

### Are herbal medicines used to treat depression?

The herbal medicine St. John's wort has been used for centuries in many folk and herbal remedies. Today in Europe, it is used widely to treat mild-tomoderate depression. In the United States, it is one of the top-selling botanical products.

The National Institutes of Health conducted a clinical trial to determine the effectiveness of treating adults who have major depression with St. Johns wort. The study included 340 people diagnosed with major depression. One-third of the people took the herbal medicine, one-third took an SSRI, and one-third took a placebo, or "sugar pill." The people did not know what they were taking. The study found that St. John's wort was no more effective than the placebo in treating major depression.<sup>4</sup> A study currently in progress is looking at the effectiveness of St. John's wort for treating mild or minor depression.

Other research has shown that St. John's wort can dangerously interact with other medications, including those used to control HIV. On February

### SECTION 3: IMPORTANT CONSIDERATIONS

10, 2000, the FDA issued a Public Health Advisory letter stating that the herb appears to interfere with certain medications used to treat heart disease, depression, seizures, certain cancers, and organ transplant rejection. Also, St. Johns wort may interfere with oral contraceptives.

Because St. John's wort may not mix well with other medications, people should always talk with their doctors before taking it or any herbal supplement.

#### **FDA** warning on antidepressants

Antidepressants are safe and popular, but some studies have suggested that they may have unintentional effects, especially in young people. In 2004, the FDA looked at published and unpublished data on trials of antidepressants that involved nearly 4,400 children and adolescents. They found that 4 percent of those taking antidepressants thought about or tried suicide (although no suicides occurred), compared to 2 percent of those receiving placebos (sugar pill).

In 2005, the FDA decided to adopt a "black box" warning label—the most serious type of warning on all antidepressant medications. The warning says there is an increased risk of suicidal thinking or attempts in children and adolescents taking antidepressants. In 2007, the FDA proposed that makers of all antidepressant medications extend the warning to include young adults up through age 24. The warning also says that patients of all ages taking antidepressants should be watched closely, especially during the first few weeks of treatment. Possible side effects to look for are depression that gets worse, suicidal thinking or behavior, or any unusual changes in behavior such as trouble sleeping, agitation, or withdrawal from normal social situations. Families and caregivers should report any changes to the doctor. The latest information from the FDA can be found at http://www.fda.gov.

Results of a comprehensive review of pediatric trials conducted between 1988 and 2006 suggested that the benefits of antidepressant medications likely outweigh their risks to children and adolescents with major depression and anxiety disorders.<sup>5</sup> The study was funded in part by NIMH.

Finally, the FDA has warned that combining the newer SSRI or SNRI antidepressants with one of the commonly-used "triptan" medications used to treat migraine headaches could cause a lifethreatening illness called "serotonin syndrome." A person with serotonin syndrome may be agitated, have hallucinations (see or hear things that are not real), have a high temperature, or have unusual blood pressure changes. Serotonin syndrome is usually associated with the older antidepressants called MAOIs, but it can happen with the newer antidepressants as well, if they are mixed with the wrong medications.

#### What medications are used to treat bipolar disorder?



B ipolar disorder, also called manicdepressive illness, is commonly treated with mood stabilizers. Sometimes, antipsychotics and antidepressants are used along with a mood stabilizer.

#### **Mood stabilizers**

People with bipolar disorder usually try mood stabilizers first. In general, people continue treatment with mood stabilizers for years. Lithium is a very effective mood stabilizer. It was the first mood stabilizer approved by the FDA in the 1970's for treating both manic and depressive episodes.

Anticonvulsant medications also are used as mood stabilizers. They were originally developed to treat seizures, but they were found to help control moods as well. One anticonvulsant commonly used as a mood stabilizer is valproic acid, also called divalproex sodium (Depakote). For some people, it may work better than lithium.<sup>6</sup> Other anticonvulsants used as mood stabilizers are carbamazepine (Tegretol), lamotrigine (Lamictal) and oxcarbazepine (Trileptal).

#### **Atypical antipsychotics**

Atypical antipsychotic medications are sometimes used to treat symptoms of bipolar disorder. Often, antipsychotics are used along with other medications. Antipsychotics used to treat people with bipolar disorder include:

- Olanzapine (Zyprexa), which helps people with severe or psychotic depression, which often is accompanied by a break with reality, hallucinations, or delusions<sup>7</sup>
- Aripiprazole (Abilify), which can be taken as a pill or as a shot
- Risperidone (Risperdal)
- Ziprasidone (Geodon)
- Clozapine (Clorazil), which is often used for people who do not respond to lithium or anticonvulsants.<sup>8</sup>

#### Antidepressants

Antidepressants are sometimes used to treat symptoms of depression in bipolar disorder. Fluoxetine (Prozac), paroxetine (Paxil), or sertraline (Zoloft) are a few that are used. However, people with bipolar disorder should not take an antidepressant on its own. Doing so can cause the person to rapidly switch from depression to mania, which can be dangerous.<sup>9</sup> To prevent this problem, doctors give patients a mood stabilizer or an antipsychotic along with an antidepressant.

Research on whether antidepressants help people with bipolar depression is mixed. An NIMHfunded study found that antidepressants were no more effective than a placebo to help treat depression in people with bipolar disorder. The people were taking mood stabilizers along with

### SECTION 3: IMPORTANT CONSIDERATIONS

the antidepressants. You can find out more about this study, called <u>STEP-BD (Systematic Treatment</u> <u>Enhancement Program for Bipolar Disorder),</u> <u>here</u>.<sup>10</sup>

#### What are the side effects?

Treatments for bipolar disorder have improved over the last 10 years. But everyone responds differently to medications. If you have any side effects, tell your doctor right away. He or she may change the dose or prescribe a different medication.

Different medications for treating bipolar disorder may cause different side effects. Some medications used for treating bipolar disorder have been linked to unique and serious symptoms, which are described below.

Lithium can cause several side effects, and some of them may become serious. They include:

- Loss of coordination
- Excessive thirst
- Frequent urination
- Blackouts
- Seizures
- · Slurred speech
- Fast, slow, irregular, or pounding heartbeat
- Hallucinations (seeing things or hearing voices that do not exist)
- · Changes in vision
- · Itching, rash
- Swelling of the eyes, face, lips, tongue, throat, hands, feet, ankles, or lower legs.

If a person with bipolar disorder is being treated with lithium, he or she should visit the doctor regularly to check the levels of lithium in the blood, and make sure the kidneys and the thyroid are working normally. Some possible side effects linked with valproic acid/divalproex sodium include:

- · Changes in weight
- Nausea
- Stomach pain
- Vomiting
- Anorexia
- Loss of appetite.

Valproic acid may cause damage to the liver or pancreas, so people taking it should see their doctors regularly.

Valproic acid may affect young girls and women in unique ways. Sometimes, valproic acid may increase testosterone (a male hormone) levels in teenage girls and lead to a condition called polycystic ovarian syndrome (PCOS).<sup>11,12</sup> PCOS is a disease that can affect fertility and make the menstrual cycle become irregular, but symptoms tend to go away after valproic acid is stopped.<sup>13</sup> It also may cause birth defects in women who are pregnant.

Lamotrigine can cause a rare but serious skin rash that needs to be treated in a hospital. In some cases, this rash can cause permanent disability or be lifethreatening.

In addition, valproic acid, lamotrigine, carbamazepine, oxcarbazepine and other anticonvulsant medications (listed in the chart at the end of this document) have an FDA warning. The warning states that their use may increase the risk of suicidal thoughts and behaviors. People taking anticonvulsant medications for bipolar or other illnesses should be closely monitored for new or worsening symptoms of depression, suicidal thoughts or behavior, or any unusual changes in mood or behavior. People taking these medications should not make any changes without talking to their health care professional. Other medications for bipolar disorder may also be linked with rare but serious side effects. Always talk with the doctor or pharmacist about any potential side effects before taking the medication.

For information on side effects of antipsychotics, see the section on medications for treating schizophrenia.

For information on side effects and FDA warnings of antidepressants, see the section on medications for treating depression.

### How should medications for bipolar disorder be taken?

Medications should be taken as directed by a doctor. Sometimes a person's treatment plan needs to be changed. When changes in medicine are needed, the doctor will guide the change. A person should never stop taking a medication without asking a doctor for help. There is no cure for bipolar disorder, but treatment works for many people. Treatment works best when it is continuous, rather than on and off. However, mood changes can happen even when there are no breaks in treatment. Patients should be open with their doctors about treatment. Talking about how treatment is working can help it be more effective.

It may be helpful for people or their family members to keep a daily chart of mood symptoms, treatments, sleep patterns, and life events. This chart can help patients and doctors track the illness. Doctors can use the chart to treat the illness most effectively.

Because medications for bipolar disorder can have serious side effects, it is important for anyone taking them to see the doctor regularly to check for possibly dangerous changes in the body.

#### What medications are used to treat anxiety disorders?



ntidepressants, anti-anxiety medications, and beta-blockers are the most common medications used for anxiety disorders.

Anxiety disorders include:

- Obsessive compulsive disorder (OCD)
- Post-traumatic stress disorder (PTSD)
- Generalized anxiety disorder (GAD)
- Panic disorder
- · Social phobia.

#### Antidepressants

Antidepressants were developed to treat depression, but they also help people with anxiety disorders. SSRIs such as fluoxetine (Prozac), sertraline (Zoloft), escitalopram (Lexapro), paroxetine (Paxil), and citalopram (Celexa) are commonly prescribed for panic disorder, OCD, PTSD, and social phobia. The SNRI venlafaxine (Effexor) is commonly used to treat GAD. The antidepressant bupropion (Wellbutrin) is also sometimes used. When treating anxiety disorders, antidepressants generally are started at low doses and increased over time.

Some tricyclic antidepressants work well for anxiety. For example, imipramine (Tofranil) is prescribed for panic disorder and GAD. Clomipramine (Anafranil) is used to treat OCD. Tricyclics are also started at low doses and increased over time. MAOIs are also used for anxiety disorders. Doctors sometimes prescribe phenelzine (Nardil), tranylcypromine (Parnate), and isocarboxazid (Marplan). People who take MAOIs must avoid certain food and medicines that can interact with their medicine and cause dangerous increases in blood pressure. For more information, see the section on medications used to treat depression.

## Benzodiazepines (anti-anxiety medications)

The anti-anxiety medications called benzodiazepines can start working more quickly than antidepressants. The ones used to treat anxiety disorders include:

- Clonazepam (Klonopin), which is used for social phobia and GAD
- Lorazepam (Ativan), which is used for panic disorder
- Alprazolam (Xanax), which is used for panic disorder and GAD.

Buspirone (Buspar) is an anti-anxiety medication used to treat GAD. Unlike benzodiazepines, however, it takes at least two weeks for buspirone to begin working.

Clonazepam, listed above, is an anticonvulsant medication. See FDA warning on anticonvulsants under the bipolar disorder section.

#### **Beta-blockers**

Beta-blockers control some of the physical symptoms of anxiety, such as trembling and sweating. Propranolol (Inderal) is a beta-blocker usually used to treat heart conditions and high blood pressure. The medicine also helps people who have physical problems related to anxiety. For example, when a person with social phobia must face a stressful situation, such as giving a speech, or attending an important meeting, a doctor may prescribe a beta-blocker. Taking the medicine for a short period of time can help the person keep physical symptoms under control.

#### What are the side effects?

See the section on antidepressants for a discussion on side effects.

The most common side effects for benzodiazepines are drowsiness and dizziness. Other possible side effects include:

- Upset stomach
- Blurred vision
- Headache
- Confusion
- Grogginess
- Nightmares.

Possible side effects from buspirone (BuSpar) include:

- Dizziness
- Headaches
- Nausea
- Nervousness
- Lightheadedness
- Excitement
- Trouble sleeping.

Common side effects from beta-blockers include:

- Fatigue
- Cold hands
- Dizziness
- Weakness.

In addition, beta-blockers generally are not recommended for people with asthma or diabetes because they may worsen symptoms.

### How should medications for anxiety disorders be taken?

People can build a tolerance to benzodiazepines if they are taken over a long period of time and may need higher and higher doses to get the same effect. Some people may become dependent on them. To avoid these problems, doctors usually prescribe the medication for short periods, a practice that is especially helpful for people who have substance abuse problems or who become dependent on medication easily. If people suddenly stop taking benzodiazepines, they may get withdrawal symptoms, or their anxiety may return. Therefore, they should be tapered off slowly.

Buspirone and beta-blockers are similar. They are usually taken on a short-term basis for anxiety. Both should be tapered off slowly. Talk to the doctor before stopping any anti-anxiety medication.

#### What medications are used to treat ADHD?



ttention deficit/hyperactivity disorder (ADHD) occurs in both children and adults. ADHD is commonly treated with stimulants, such as:

- Methylphenidate (Ritalin, Metadate, Concerta, Daytrana)
- Amphetamine (Adderall)
- Dextroamphetamine (Dexedrine, Dextrostat).

In 2002, the FDA approved the nonstimulant medication atomoxetine (Strattera) for use as a treatment for ADHD. In February 2007, the FDA approved the use of the stimulant lisdexamfetamine dimesylate (Vyvanse) for the treatment of ADHD in children ages 6 to 12 years.

#### What are the side effects?

Most side effects are minor and disappear when dosage levels are lowered. The most common side effects include:

- Decreased appetite. Children seem to be less hungry during the middle of the day, but they are often hungry by dinnertime as the medication wears off.
- Sleep problems. If a child cannot fall asleep, the doctor may prescribe a lower dose. The doctor might also suggest that parents give the medication to their child earlier in the day, or stop the afternoon or evening dose. To help ease sleeping problems, a doctor may add a prescription for a low dose of an antidepressant or a medication called clonidine.

- Stomachaches and headaches.
- Less common side effects. A few children develop sudden, repetitive movements or sounds called tics. These tics may or may not be noticeable. Changing the medication dosage may make tics go away. Some children also may appear to have a personality change, such as appearing "flat" or without emotion. Talk with your child's doctor if you see any of these side effects.

#### How are ADHD medications taken?

Stimulant medications can be short-acting or longacting, and can be taken in different forms such as a pill, patch, or powder. Long-acting, sustained and extended release forms allow children to take the medication just once a day before school. Parents and doctors should decide together which medication is best for the child and whether the child needs medication only for school hours or for evenings and weekends too.

ADHD medications help many children and adults who are hyperactive and impulsive. They help people focus, work, and learn. Stimulant medication also may improve physical coordination. However, different people respond differently to medications, so children taking ADHD medications should be watched closely.

#### Are ADHD medications safe?

Stimulant medications are safe when given under a doctor's supervision. Some children taking them may feel slightly different or "funny." Some parents worry that stimulant medications may lead to drug abuse or dependence, but there is little evidence of this. Research shows that teens with ADHD who took stimulant medications were less likely to abuse drugs than those who did not take stimulant medications.<sup>14</sup>

### FDA warning on possible rare side effects

In 2007, the FDA required that all makers of ADHD medications develop Patient Medication Guides. The guides must alert patients to possible heart and psychiatric problems related to ADHD medicine. The FDA required the Patient Medication Guides because a review of data found that ADHD patients with heart conditions had a slightly higher risk of strokes, heart attacks, and sudden death when taking the medications. The review also found a slightly higher risk (about 1 in 1,000) for medication-related psychiatric problems, such as hearing voices, having hallucinations, becoming suspicious for no reason, or becoming manic. This happened to patients who had no history of psychiatric problems.

The FDA recommends that any treatment plan for ADHD include an initial health and family history examination. This exam should look for existing heart and psychiatric problems.

The non-stimulant ADHD medication called atomoxetine (Strattera) carries another warning. Studies show that children and teenagers with ADHD who take atomoxetine are more likely to have suicidal thoughts than children and teenagers with ADHD who do not take atomoxetine. If your child is taking atomoxetine, watch his or her behavior carefully. A child may develop serious symptoms suddenly, so it is important to pay attention to your child's behavior every day. Ask other people who spend a lot of time with your child, such as brothers, sisters, and teachers, to tell you if they notice changes in your child's behavior. Call a doctor right away if your child shows any of the following symptoms:

- · Acting more subdued or withdrawn than usual
- · Feeling helpless, hopeless, or worthless
- New or worsening depression
- Thinking or talking about hurting himself or herself
- Extreme worry
- Agitation
- Panic attacks
- Trouble sleeping
- Irritability
- Aggressive or violent behavior
- · Acting without thinking
- Extreme increase in activity or talking
- Frenzied, abnormal excitement
- Any sudden or unusual changes in behavior.

While taking atomoxetine, your child should see a doctor often, especially at the beginning of treatment. Be sure that your child keeps all appointments with his or her doctor.

# Which groups have special needs when taking psychiatric medications?



Provide the system of people, but some groups have special needs, including:

- · Children and adolescents
- Older adults
- Women who are pregnant or may become pregnant.

#### **Children and adolescents**

Most medications used to treat young people with mental illness are safe and effective. However, many medications have not been studied or approved for use with children. Researchers are not sure how these medications affect a child's growing body. Still, a doctor can give a young person an FDA-approved medication on an "offlabel" basis. This means that the doctor prescribes the medication to help the patient even though the medicine is not approved for the specific mental disorder or age.

For these reasons, it is important to watch young people who take these medications. Young people may have different reactions and side effects than adults. Also, some medications, including antidepressants and ADHD medications, carry FDA warnings about potentially dangerous side effects for young people. See the sections on antidepressants and ADHD medications for more information about these warnings.

More research is needed on how these medications affect children and adolescents. NIMH has funded studies on this topic. For example, NIMH funded the Preschoolers with ADHD Treatment Study (PATS), which involved 300 preschoolers (3 to 5 years old) diagnosed with ADHD. The study found that low doses of the stimulant methylphenidate are safe and effective for preschoolers. However, children of this age are more sensitive to the side effects of the medication, including slower growth rates. Children taking methylphenidate should be watched closely.<sup>15,16,17</sup>

In addition to medications, other treatments for young people with mental disorders should be considered. Psychotherapy, family therapy, educational courses, and behavior management techniques can help everyone involved cope with the disorder. <u>Click here for more information on</u> <u>child and adolescent mental health research</u>.

#### **Older adults**

Because older people often have more medical problems than other groups, they tend to take more medications than younger people, including prescribed, over-the-counter, and herbal medications. As a result, older people have a higher risk for experiencing bad drug interactions, missing doses, or overdosing.

Older people also tend to be more sensitive to medications. Even healthy older people react to medications differently than younger people because their bodies process it more slowly. Therefore, lower or less frequent doses may be needed.

Sometimes memory problems affect older people who take medications for mental disorders. An older adult may forget his or her regular dose and take too much or not enough. A good way to keep track of medicine is to use a seven-day pill box, which can be bought at any pharmacy. At the beginning of each week, older adults and their caregivers fill the box so that it is easy to remember what medicine to take. Many pharmacies also have pillboxes with sections for medications that must be taken more than once a day.

### Women who are pregnant or may become pregnant

The research on the use of psychiatric medications during pregnancy is limited. The risks are different depending on what medication is taken, and at what point during the pregnancy the medication is taken.

Research has shown that antidepressants, especially SSRIs, are safe during pregnancy. Birth defects or other problems are possible, but they are very rare.<sup>18,19</sup>

However, antidepressant medications do cross the placental barrier and may reach the fetus. Some research suggests the use of SSRIs during pregnancy is associated with miscarriage or birth defects, but other studies do not support this.<sup>20</sup> Studies have also found that fetuses exposed to SSRIs during the third trimester may be born with "withdrawal" symptoms such as breathing problems, jitteriness, irritability, trouble feeding, or hypoglycemia (low blood sugar).

Most studies have found that these symptoms in babies are generally mild and short-lived, and no deaths have been reported. On the flip side, women who stop taking their antidepressant medication during pregnancy may get depression again and may put both themselves and their infant at risk.<sup>20,21</sup>

In 2004, the FDA issued a warning against the use of certain antidepressants in the late third trimester. The warning said that doctors may want to gradually taper pregnant women off antidepressants in the third trimester so that the baby is not affected.<sup>22</sup> After a woman delivers, she should consult with her doctor to decide whether to return to a full dose during the period when she is most vulnerable to postpartum depression.

Some medications should not be taken during pregnancy. Benzodiazepines may cause birth defects or other infant problems, especially if taken during the first trimester. Mood stabilizers are known to cause birth defects. Benzodiazepines and lithium have been shown to cause "floppy baby syndrome," which is when a baby is drowsy and limp, and cannot breathe or feed well.

Research suggests that taking antipsychotic medications during pregnancy can lead to birth defects, especially if they are taken during the first trimester. But results vary widely depending on the type of antipsychotic. The conventional antipsychotic haloperidol has been studied more than others, and has been found not to cause birth defects.<sup>23,24</sup>

After the baby is born, women and their doctors should watch for postpartum depression, especially if they stopped taking their medication during pregnancy. In addition, women who nurse while taking psychiatric medications should know that a small amount of the medication passes into the breast milk. However, the medication may or may not affect the baby. It depends on the medication and when it is taken. Women taking psychiatric medications and who intend to breastfeed should discuss the potential risks and benefits with their doctors.

Decisions on medication should be based on each woman's needs and circumstances. Medications should be selected based on available scientific research, and they should be taken at the lowest possible dose. Pregnant women should be watched closely throughout their pregnancy and after delivery.

# What should I ask my doctor if I am prescribed a psychiatric medication?



ou and your family can help your doctor find the right medications for you. The doctor needs to know your medical history; family history; information about allergies; other medications, supplements or herbal remedies you take; and other details about your overall health. You or a family member should ask the following questions when a medication is prescribed:

- What is the name of the medication?
- What is the medication supposed to do?
- How and when should I take it?
- How much should I take?
- What should I do if I miss a dose?
- When and how should I stop taking it?

- Will it interact with other medications I take?
- Do I need to avoid any types of food or drink while taking the medication? What should I avoid?
- Should it be taken with or without food?
- Is it safe to drink alcohol while taking this medication?
- What are the side effects? What should I do if I experience them?
- Is the Patient Package Insert for the medication available?

After taking the medication for a short time, tell your doctor how you feel, if you are having side effects, and any concerns you have about the medicine.



#### **Alphabetical List of Medications**

This section identifies antipsychotic medications, antidepressant medications, mood stabilizers, anticonvulsant medications, anti-anxiety medications, and ADHD medications. Some medications are marketed under trade names, not all of which can be listed in this publication. The first chart lists the medications by trade name; the second chart lists the medications by generic name. If your medication does not appear in this section, refer to the <u>FDA Web site</u>. Also, ask your doctor or pharmacist for more information about any medication.

#### **Medications Organized by Trade Name**

#### **Trade Name**

#### Generic Name FDA Approved Age

#### Combination Antipsychotic and Antidepressant Medication

Combination Antipsychotic and	Antidepressant Medicati	ion
Symbyax (Prozac & Zyprexa)	fluoxetine & olanzapine	18 and older
Antipsychotic Medications		
Abilify	aripiprazole	13 to 17 for schizophrenia and bipolar; 18 and older for schizophrenia, bipolar mania, and depression
Clozaril	clozapine	18 and older
Fanapt	iloperidone	18 and older
fluphenazine (generic only)	fluphenazine	18 and older
Geodon	ziprasidone	18 and older
Haldol	haloperidol	3 and older
Invega	paliperidone	18 and older
Loxitane	loxapine	18 and older
Moban	molindone	18 and older
Navane	thiothixene	18 and older
Orap (for Tourette's syndrome)	pimozide	12 and older
perphenazine (generic only)	perphenazine	18 and older
Risperdal	risperidone	13 and older for schizophrenia; 10 and older for bipolar mania and mixed episodes; 5 to 16 for irritability associated with autism
Seroquel	quetiapine	18 and older for schizophrenia and bipolar disorder
Ctala-ina	4	10 and alden

#### Trade Name

#### **Generic Name**

#### **FDA Approved Age**

Antidepressant Medications (also used for anxiety disorders)

-	-	
Anafranil (tricyclic)	clomipramine	10 and older (for OCD only)
Asendin	amoxapine	18 and older
Aventyl (tricyclic)	nortriptyline	18 and older
Celexa (SSRI)	citalopram	18 and older
Cymbalta (SNRI)	duloxetine	18 and older
Desyrel	trazodone	18 and older
Effexor (SNRI)	venlafaxine	18 and older
Elavil (tricyclic)	amitriptyline	18 and older
Emsam	selegiline	18 and older
Lexapro (SSRI)	escitalopram	18 and older; 12-17 (for major depressive disorder)
Ludiomil (tricyclic)	maprotiline	18 and older
Luvox (SSRI)	fluvoxamine	8 and older (for OCD only)
Marplan (MAOI)	isocarboxazid	18 and older
Nardil (MAOI)	phenelzine	18 and older
Norpramin (tricyclic)	desipramine	18 and older
Pamelor (tricyclic)	nortriptyline	18 and older
Parnate (MAOI)	tranylcypromine	18 and older
Paxil (SSRI)	paroxetine	18 and older
Pexeva (SSRI)	paroxetine-mesylate	18 and older
Prozac (SSRI)	fluoxetine	8 and older
Remeron	mirtazapine	18 and older
Sarafem (SSRI)	fluoxetine	18 and older for premenstrual dysphoric disorder (PMDD)
Sinequan (tricyclic)	doxepin	12 and older
Surmontil (tricyclic)	trimipramine	18 and older
Tofranil (tricyclic)	imipramine	6 and older (for bedwetting)
Tofranil-PM (tricyclic)	imipramine pamoate	18 and older
Vivactil (tricyclic)	protriptyline	18 and older
Wellbutrin	bupropion	18 and older
Zoloft (SSRI)	sertraline	6 and older (for OCD only)

#### **Trade Name**

#### **Generic Name**

#### **FDA Approved Age**

#### Mood Stabilizing and Anticonvulsant Medications

Depakote	divalproex sodium (valproic acid)	2 and older (for seizures)
Eskalith	lithium carbonate	12 and older
Lamictal	lamotrigine	18 and older
lithium citrate (generic only)	lithium citrate	12 and older
Lithobid	lithium carbonate	12 and older
Neurontin	gabapentin	18 and older
Tegretol	carbamazepine	any age (for seizures)
Topamax	topiramate	18 and older
Trileptal	oxcarbazepine	4 and older

#### **Anti-anxiety Medications**

(All of these anti-anxiety medications are benzodiazepines, except BuSpar)

Ativan	lorazepam	18 and older
BuSpar	buspirone	18 and older
Klonopin	clonazepam	18 and older
Librium	chlordiazepoxide	18 and older
oxazepam (generic only)	oxazepam	18 and older
Tranxene	clorazepate	18 and older
Valium	diazepam	18 and older
Xanax	alprazolam	18 and older

#### **Trade Name**

#### **Generic Name**

#### **FDA Approved Age**

#### **ADHD Medications**

(All of these ADHD medications are stimulants, except Strattera.)

Adderall	amphetamine	3 and older
Adderall XR	amphetamine (extended release)	6 and older
Concerta	methylphenidate (long acting)	6 and older
Daytrana	methylphenidate patch	6 and older
Desoxyn	methamphetamine	6 and older
Dexedrine	dextroamphetamine	3 and older
Dextrostat	dextroamphetamine	3 and older
Focalin	dexmethylphenidate	6 and older
Focalin XR	dexmethylphenidate (extended release)	6 and older
Metadate ER	methylphenidate (extended release)	6 and older
Metadate CD	methylphenidate (extended release)	6 and older
Methylin	methylphenidate (oral solution and chewable tablets)	6 and older
Ritalin	methylphenidate	6 and older
Ritalin SR	methylphenidate (extended release)	6 and older
Ritalin LA	methylphenidate (long-acting)	6 and older
Strattera	atomoxetine	6 and older
Vyvanse	lisdexamfetamine dimesylate	6 and older

Medications	Organized	by	Generic	Name	
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Generic Name	Trade Name	FDA Approved Age
Combination Antipsychotic and	Antidepressant Medication	
fluoxetine & olanzapine	Symbyax (Prozac & Zyprexa)	18 and older
Antipsychotic Medications		
aripiprazole	Abilify	13 to 17 for schizophrenia and bipolar; 18 and older for schizophrenia, bipolar mania, and depression
chlorpromazine	Thorazine	18 and older
clozapine	Clozaril	18 and older
fluphenazine (generic only)	fluphenazine	18 and older
haloperidol	Haldol	3 and older
iloperidone	Fanapt	18 and older
loxapine	Loxitane	18 and older
molindone	Moban	18 and older
olanzapine	Zyprexa	18 and older
paliperidone	Invega	18 and older
perphenazine (generic only)	perphenazine	18 and older
pimozide (for Tourette's syndrome)	Orap	12 and older
quetiapine	Seroquel	18 and older for schizophrenia and bipolar disorder
risperidone	Risperdal	13 and older for schizophrenia; 10 and older for bipolar mania and mixed episodes; 5 to 16 for irritability associated with autism
thioridazine (generic only)	thioridazine	2 and older
thiothixene	Navane	18 and older
trifluoperazine	Stelazine	18 and older

#### **Generic Name**

#### **Trade Name**

#### **FDA Approved Age**

#### Antidepressant Medications (also used for anxiety disorders)

amitriptyline (tricyclic)	Elavil	18 and older
amoxapine	Asendin	18 and older
bupropion	Wellbutrin	18 and older
citalopram (SSRI)	Celexa	18 and older
clomipramine (tricyclic)	Anafranil	10 and older (for OCD only)
desipramine (tricyclic)	Norpramin	18 and older
doxepin (tricyclic)	Sinequan	12 and older
duloxetine (SNRI)	Cymbalta	18 and older
escitalopram (SSRI)	Lexapro	18 and older; 12-17 (for major depressive disorder)
fluoxetine (SSRI)	Prozac	8 and older
fluoxetine (SSRI)	Sarafem	18 and older for premenstrual dysphoric disorder (PMDD)
fluvoxamine (SSRI)	Luvox	8 and older (for OCD only)
imipramine (tricyclic)	Tofranil	6 and older (for bedwetting)
imipramine pamoate (tricyclic)	Tofranil-PM	18 and older
isocarboxazid (MAOI)	Marplan	18 and older
maprotiline (tricyclic)	Ludiomil	18 and older
mirtazapine	Remeron	18 and older
nortriptyline (tricyclic)	Aventyl, Pamelor	18 and older
paroxetine (SSRI)	Paxil	18 and older
paroxetine mesylate (SSRI)	Pexeva	18 and older
phenelzine (MAOI)	Nardil	18 and older
protriptyline (tricyclic)	Vivactil	18 and older
selegiline	Emsam	18 and older
sertraline (SSRI)	Zoloft	6 and older (for OCD only)
tranylcypromine (MAOI)	Parnate	18 and older
	Desyrel	18 and older
trazodone	2003101	
trazodone trimipramine (tricyclic)	Surmontil	18 and older
	•	18 and older 18 and older

#### **Generic Name**

**Trade Name** 

#### **FDA Approved Age**

#### Mood Stabilizing and Anticonvulsant Medications

carbamazepine	Tegretol	any age (for seizures)
divalproex sodium (valproic acid)	Depakote	2 and older (for seizures)
gabapentin	Neurontin	18 and older
lamotrigine	Lamictal	18 and older
lithium carbonate	Eskalith, Lithobid	12 and older
lithium citrate (generic only)	lithium citrate	12 and older
oxcarbazepine	Trileptal	4 and older
topiramate	Topamax	18 and older

#### **Anti-anxiety Medications**

(All of these anti-anxiety medications are benzodiazepines, except buspirone.)

alprazolam	Xanax	18 and older
buspirone	BuSpar	18 and older
chlordiazepoxide	Librium	18 and older
clonazepam	Klonopin	18 and older
clorazepate	Tranxene	18 and older
diazepam	Valium	18 and older
lorazepam	Ativan	18 and older
oxazepam (generic only)	oxazepam	18 and older

# **SECTION 3:**

#### **Generic Name**

#### **Trade Name**

#### **FDA Approved Age**

#### **ADHD Medications**

(All of these ADHD medications are stimulants, except atomoxetine)

amphetamine	Adderall	3 and older
amphetamine (extended release)	Adderall XR	6 and older
atomoxetine	Strattera	6 and older
dexmethylphenidate	Focalin	6 and older
dexmethylphenidate (extended	Focalin XR	6 and older
release)		
dextroamphetamine	Dexedrine, Dextrostat	3 and older
lisdexamfetamine dimesylate	Vyvanse	6 and older
methamphetamine	Desoxyn	6 and older
methylphenidate	Ritalin	6 and older
methylphenidate (extended	Metadate CD, Metadate ER,	6 and older
release)	Ritalin SR	
methylphenidate (long-acting)	Ritalin LA, Concerta	6 and older
methylphenidate patch	Daytrana	6 and older
methylphenidate (oral solution and chewable tablets)	Methylin	6 and older

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# For More Information on Medications:

Visit the National Library of Medicine's MedlinePlus http://www.nlm.nih.gov/medlineplus

En Español http://medlineplus.gov/spanish

For information on Clinical Trials http://www.nimh.nih.gov/health/trials/index.shtml

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# SECTION 3:

# QUICK REFERENCE TO PSYCHOTROPIC MEDICATION®

#### **DEVELOPED BY JOHN PRESTON, PSY.D., ABPP**

To the best of our knowledge recommended doses and side effects listed below are accurate. However, this is meant as a general reference only, and should not serve as a guideline for prescribing of medications. Please check the manufacturer's product information sheet or the P.D.R. for any changes in dosage schedule or contraindications. (Brand names are registered trademarks.)

- ANTIDEPI NAMES		Usual Daily Dosage				Selective Action Neurotransmit	
Generic	Brand	Range	Sedation	<b>ACH</b> <sup>1</sup>	NE	5-HT	DA
imipramine	Tofranil	150-300 mg	mid	mid	+ +	+++	0
desipramine	Norpramin	150-300 mg	low	low	+++++	0	0
amitriptyline	Elavil	150-300 mg	high	high	++	++++	0
nortriptyline	Aventyl, Pamelor	75-125 mg	mid	mid	+++	++	0
protriptyline	Vivactil	15-40 mg	mid	mid	++++	+	0
trimipramine	Surmontil <sup>3</sup>	100-300 mg	high	mid	++	++	0
doxepin	Sinequan, Adapin <sup>3</sup>	150-300 mg	high	mid	++	+++	0
clomipramine	Anafranil	150-250 mg	high	high	0	+++++	0
maprotiline	Ludiomil	150-225 mg	high	mid	+++++	0	0
amoxapine	Asendin	150-400 mg	mid	low	+++	++	0
trazodone	Desyrel	150-400 mg	mid	none	0	++++	0
fluoxetine	Prozac⁴, Sarafem	20-80 mg	low	none	0	+++++	0
bupropion-X.L.	Wellbutrin-X.L. <sup>4</sup>	150-400 mg	low	none	++	0	++
sertraline	Zoloft	50-200 mg	low	none	0	+++++	0
paroxetine	Paxil	20-50 mg	low	low	+	+++++	0
venlafaxine-X.R.	Effexor-X.R. <sup>4</sup>	75-350 mg	low	none	++	+++	+
fluvoxamine	Luvox	50-300 mg	low	low	0	+++++	0
mirtazapine	Remeron	15-45 mg	mid	mid	+++	+++	0
citalopram	Celexa	10-60 mg	low	none	0	+++++	0
escitalopram	Lexapro	5-20 mg	low	none	0	+++++	0
duloxetine	Cymbalta	20-80 mg	low	none	++++	++++	0
atomoxetine	Strattera	60-120 mg	low	low	+++++	0	0
MAO INHIBITORS		0					
phenelzine	Nardil	30-90 mg	low	none	+++	+++	++-
, tranylcypromine	Parnate	20-60 mg	low	none	+++	+++	++-
selegiline	Emsam (patch)	6-12 mg	low	none	+++	+++	++-

<sup>1</sup>ACH: Anticholinergic Side Effects

<sup>2</sup>NE: Norepinephrine, 5-HT: Serotonin, DA: Dopamine (0 = no effect, + = minimal effect, +++ = moderate effect, ++++ = high effect) <sup>3</sup>Uncertain, but likely effects

<sup>4</sup>Available in standard formulation and time release (XR, XL or CR). Prozac available in 90mg time released/weekly formulation

— BIPOLA	<b>R</b> DISOR	RDER ME	DICAT	IONS ——			
NAMES Generic	Brand	<b>Daily</b> Dosage Range	Serum <sup>1</sup> Level	NAME Generic Brand	<b>S</b> Dosage	<b>Daily</b> Range	Serum <sup>1</sup> Level
lithium carbonate olanzapine/	Eskalith, Lithond	ite 600-2400	0.6-1.5	divalproex gabapentin	Depakote Neurontin	750-1500 300-2400	50-100 (2)
fluoxetine carbamazepine oxcarbazepine	Symbyax 6 Tegretol,Equetro Trileptal	/25-12/50mg⁴ 5 600-1600 1200-2400	2 4-10+ (2)	lamotrigine topiramate tiagabine	Lamictal Topamax Gabitril	50-500 50-300 4-12	(2) (2) (3) (3)

<sup>1</sup>Lithium levels are expressed in mEq/l, carbamazepine and valproic acid levels express in mcg/ml. <sup>2</sup>Serum monitoring may not necessary <sup>3</sup>Not yet established <sup>4</sup>Available in: 6/25, 6/50, 12/25, and 12/50mg formulations

#### **ANTI-OBSESSIONAL**

NAMES			
Generic	Brand	Dose Range <sup>1</sup>	
clomipramine	Anafranil	150-250 mg	
fluoxetine	<b>Prozac</b> <sup>1</sup>	20-80 mg	
sertraline	Zoloft <sup>1</sup>	50-200 mg	
paroxetine	Paxil <sup>1</sup>	20-60 mg	
fluvoxamine	Luvox <sup>1</sup>	50-300 mg	
citalopram	Celexa <sup>1</sup>	10-60 mg	
escitalopram	Lexapro <sup>1</sup>	5-20 mg	
<sup>1</sup> often higher doses are required to control obsessive-compulsive symptoms than the doses generally used to treat depression.			

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			, , , , , , ,	

— PSYCHO-STIMULANTS ——				
Generic	Brand	Daily Dosage <sup>1</sup>		
methylphenidate	Ritalin	5-50 mg		
methylphenidate methylphenidate	Concerta <sup>2</sup>	18-54 mg		
methylphenidate	Metadate	5-40 mg		
methylphenidate	Methylin	10-60 mg		
methylphenidate	Daytrana (p	atch) 15-30 mg		
dexmethylphenidate	Focalin	5-40 mg		
dextroamphetamine	Dexedrine	5-40 mg		
pemoline	Cylert	37.5-112.5 mg		
d- and l-amphetamine	Adderall	5-40 mg		
modafinil	Provigil, Sparl	on 100-400 mg		
<sup>1</sup> Note: Adult Doses. <sup>2</sup> Sustained release				

#### ANTIPSYCHOTICS

NAMES						ACH	
Generic	Brand	Dosage Range <sup>1</sup>	Sedation	Ortho <sup>2</sup>	EPS <sup>3</sup>	<b>Effects</b> <sup>4</sup>	<b>Equivalence</b> <sup>5</sup>
LOW POTENCY							
chlorpromazine	Thorazine	50-800 mg	high	high	+ +	++++	100 mg
thioridazine	Mellaril	150-800 mg	high	high	+	+++++	100 mg
clozapine	Clozaril	300-900 mg	high	high	0	+++++	50 mg
mesoridazine	Serentil	50-500 mg	high	mid	+	+++++	50 mg
quetiapine	Seroquel	150-400 mg	mid	mid	+/0	+	50 mg
HIGH POTENCY		Ŭ					Ŭ
molindone	Moban	20-225 mg	low	mid	+++	+++	10 mg
perphenazine	Trilafon	8-60 mg	mid	mid	++++	++	10 mg
loxapine	Loxitane	50-250 mg	low	mid	+++	++	10 mg
trifluoperazine	Stelazine	2-40 mg	low	mid	++++	++	5 mg
fluphenazine	Prolixin <sup>5</sup>	3-45 mg	low	mid	+++++	++	2 mg
thiothixene	Navane	10-60 mg	low	mid	++++	++	5 mg
haloperidol	Haldol⁵	2-40 mg	low	low	+++++	+	2 mg
pimozide	Orap	1-10 mg	low	low	+++++	+	1-2 mg
risperidone	Risperdal	4-16 mg	low	mid	+	+	1-2 mg
paliperidone	Invega	3-12 mg	low	mid	+	+	1-2mg
olanzapine	Zyprexa	5-20 mg	mid	low	+/0	+	1-2 mg
ziprasidone	Geodon	60-160 mg	low	mid	+/0	++	10 mg
aripiprazole	Abilify	15-30mg	low	low	+/0	+	2 mg
Illough daily and dagage							

<sup>1</sup>Usual daily oral dosage <sup>2</sup>Orthostatic Hypotension Dizziness and falls <sup>3</sup>Acute: Parkinson's, dystonias, akathisia. Does not reflect risk for tardive dyskinesia. All neuroleptics may cause tardive dyskinesia, except clozapine.

<sup>4</sup>Anticholinergic Side Effects.

<sup>5</sup>Dose required to achieve efficacy of 100 mg chlorpromazine. <sup>6</sup>Available in time-release IM format.

NAMES		Single Dose	
Generic	Brand	Dosage Range	<b>Equivalence</b> <sup>1</sup>
BENZODIAZEPINES	;		
diazepam	Valium	2-10 mg	5 mg
chlordiazepoxide	Librium	10-50 mg	25 mg
prazepam	Centrax	5-30 mg	10 mg
clorazepate	Tranxene	3.75-15 mg	10 mg
clonazepam	Klonopin	0.5-2.0 mg	0.25 mg
lorazepam	Ativan	0.5-2.0 mg	l mg
alprazolam	Xanax, XR	0.25-2.0 mg	0.5 mg
oxazepam	Serax	10-30 mg	15 mg
OTHER ANTIANXIE			
buspirone	BuSpar	5-20 mg	
gabapentin	Neurontin	200-600 mg	
hydroxyzine	Atarax, Vistari		
propranolol	Inderal	10-80 mg	
atenolol	Tenormin	25-100 mg	
guanfacine	Tenex	0.5-3 mg	
clonidine	Catapres	0.1-0.3 mg	

<sup>1</sup>Doses required to achieve efficacy of 5 mg of diazepam

-OVER THE CO				
Name	Daily Dose			
St. John's Wort <sup>1, 2</sup>	600-1800 mg			
SAM-e <sup>3</sup>	400-1600 mg			
Omega-3 <sup>4</sup>	1-9 g			
<sup>1</sup> Treats depression and anxiety				
<sup>2</sup> May cause signifigant drug-drug interactions				
<sup>3</sup> Treats depression				
<sup>4</sup> Treats depression and bipolar disorde	er			

HYPNOTICS

NAMES	Single Dose	
Generic	Brand	Dosage Range
flurazepam	Dalmane	15-30 mg
temazepam	Restoril	15-30 mg
triazolam	Halcion	0.25-0.5 mg
estazolam	ProSom	1.0-2.0 mg
quazepam	Doral	7.5-15 mg
zolpidem	Ambien	5-10 mg ັ
zaleplon	Sonata	5-10 mg
eszopiclone	Lunesta	1-3 mg
ramelteon	Rozerem	4-16 mg
diphenhydramine	Benadryl	25-100 mg

#### **COMMON SIDE EFFECTS ANTICHOLINERGIC EFFECTS**

(block acetylcholine)

- dry mouth • blurred vision
- constipation • memory impairment
  - confusional states
- urinary retention

#### **EXTRAPYRAMIDAL EFFECTS**

- (dopamine blockade in basal ganglia) Parkinson-like effects: rigidity, shuffling gait, tremor, flat affect,
- lethargy
- Dystonias: spasms in neck and other muscle groups Akathisia: intense, uncomfortable sense of inner restlessness
- Tardive dyskinesia: often a persistent movement disorder (lip smacking, writhing movements, jerky movements)

Note: The above are common side effects. All medications can produce specific or unique side effects. For a more complete description, please see references listed below

#### **REFERENCES and RECOMMENDED BOOKS**

Handbook of Clinical Psychopharmacology For Therapists (2005) Preston, O'Neal and Talaga Quick Reference • Free Downloads Website: www.PsyD-fx.com

Clinical Psychopharmacology Made Ridiculously Simple 5th Edition (2007) Preston and Johnson

# SECTION 3:

#### **Ruling out Medical Causes**

#### **Ruling out Medical Concerns**

There are a large number of other medical conditions which have significant psychiatric overlay in the general population. Taylor refers to this as "Psychological Masquerading". (Taylor, 2000) The list of such conditions is extremely long, including headaches, hypothyroidism, menstrual problems, dental problems, and gastro-intestinal disturbances such as ulcers, kidney dysfunctions, etc.

According to Dr. Ruth Ryan, the relationship between medical concerns and mental illness takes different directions, depending on the medical diagnosis. Medical illness can:

- Cause the actual symptoms which meet full criteria for a psychiatric disorder
- Cause a feeling state or symptoms which influence behavior
- Confer treatment resistance

People with developmental disabilities are more likely to have such medical problems.

Data collected in both Los Angeles and Colorado indicated that more than 70% of the people referred for dual diagnosis evaluation are found to have one or more medical problems which contribute to their mental health problems. Also, many of the genetic syndromes discussed above include specific medical conditions. For example, people with Down Syndrome are more likely to have hearing impairments, vision problems, congenital heart defects, seizures, respiratory problems, and thyroid dysfunction.

We must also remember medication side effects, which can also present as behavioral symptoms. Since people with developmental disabilities are more likely to utilize medications, they are at greater risks for side effects and potential behaviors.

In summary, medical health impacts on mental

health and people with developmental disabilities have more medical problems.



Looking Beyond the Behavior: Exploring the importance of ruling out medical issues when a new or change in behavior has been noted.

Sometimes we must look at things differently. We may think we immediately know the reason why something is the way it is without even considering alternatives. This can also come into play with the people we support. If a person is hitting, biting, spitting, pulling our hair, engaging in SIB, or being "non-compliant" we may immediately label it as a "behavior." We may make such comments as "they are just doing that for attention", "he's just lazy", "she just likes to cause trouble" or "he's always been like that." However, there may be an underlying condition causing or exacerbating the behavior we are seeing.

Emphasizing the real possibility of a medical condition presenting as a behavioral health problem, is a study conducted by Neurologist Ruth Ryan,

From the abstract of her study:

A total of 1135 people with mental retardation referred for mental health assessment were medically evaluated according to a two-step protocol which included a screening evaluation of all persons and expanded testing, depending on clinical status. The workup was considered complete when the person with either improving clinically or had a specific terminal diagnosis and was as comfortable as possible. Medical co-morbidity was about double that of people referred for mental health assessment who do not have mental retardation. Common conditions presented in unusual ways, and less frequent conditions presented more often... Comprehensive medical assessment discloses increased medical co-morbidity in persons with mental retardation referred for psychiatric evaluation. Comprehensive treatment based on the assessment findings appears to be associated with better clinical outcomes...

About 75% of behavior problems in those with an intellectual/ developmental disability have a connection to some type of physical illness.

Rule out a medical problem first.

This is an extremely significant finding that 75% of behavior problems in those with ID/DD have a connection to some type of physical illness. It is so important that anytime we see behavioral issues we have the person thoroughly examined, by a physician, to rule out any underlying medical condition that may be the cause or a contributing factor to the behavior. Sometimes this may include having to get a second opinion.

#### **Possible Dental Pain**

Dental issues are notorious for one thing...pain. Sudden pain can occur when food gets lodged in a cavity and irritates the nerve or if you lose a filling or crown. Pain that becomes severe over time may be from food getting lodged between the tooth and gum. The longer the food is trapped there the greater the chance for irritation or infection. A big culprit can be a popcorn hull-because hulls don't break down. Pain that occurs with biting or chewing that may be associated with bad breath or a bad taste in the mouth could

## **Dental Problems**

- Sudden pain
- Pain becoming severe over time
- Pain when biting/chewing

be an abscess. How do you know if someone you support has a dental problem? How do they show you if they do not communicate in a traditional way. Are there changes in eating habits? Irritability? Self injury to the facial area?

Although, ear infections are not as typical in the adult population as they are in children and infants, they can and still do occur. This may be challenging to detect in a person who has difficulty verbally telling you that their ear hurts. What are some ways you think this might be demonstrated? We may see a person who is hitting himself in the ear/head, unusually irritable or appears to be "non-compliant" when asked to do something.

## Ear Problems

- Pain
- Fever
- Fluid from ear
- Unresponsive to quiet sounds
- Dizziness

If a person is having **changes in their vision or difficulty seeing**, what signs do you think you may see? Changes in ADL's, activities of daily living, may include changes or refusal to participate in preferred activities, losing possessions, which may in turn produce anxiety, and mismatching clothing. Mobility issues may show themselves through falling, refusing to get out of bed/perform activities, and or leaning against objects. What are some things that could

be misinterpreted about this person if we did not know the underlying cause for their actions? We may also see difficulty at meal times. The person may refuse to eat, become significantly irritated at meal times, and/or knock things over.

# Vision Problems

- Changes in:
  - > ADL's
  - Mobility
  - Eating/Drinking
  - Reading/Writing

**Sleep** is a vital component to each of our lives. Not getting enough sleep can affect almost every facet of our being. Imagine what a person would be like if loss of sleep occurred for longer than one night but there was no ability to communicate that verbally. Maybe no accommodations would be made and expectations would remain the same. Or, perhaps, demands are increased because people assumed non-compliance or laziness. How do you think you might respond? Also, we need to consider that daylight savings time changes can also influence a person sleep cycles and possibly their mood.

# Sleep Issues

- How much do you need?
  - Adolescents

8.5-9.5 hours

Adults

7-9 hours

Currently, according to WebMD, there are more than 150 diagnostic categories of **headaches.** Migraines appear to occur when overly active nerve cells send out impulses to the blood vessels causing them to constrict. They then dilate and release chemicals that cause inflammation which makes the pulsations painful. Acute onset headaches are usually due to illness, infections, colds or fever.

Trauma can involve any blow to the head. Tension headaches are caused by emotional stress from family and friends, work or school, alcohol use, skipping meals, changes in sleep patterns, tension and depression.

Headaches can be aggravating in and of themselves. Is the person engaging in selfinjurious behavior involving their head? (This doesn't mean if it is not involving the head that it 's not a headache.) In addition, it may be helpful to track behavioral issues. With women, we may want to observe if behavioral challenges occur around ovulation/menstruation.

# Headaches

- More than 150 headache categories
  - Migraines
  - Acute onset
  - Trauma
  - Tension

Numerous issues revolve around the gastrointestinal tract. Most people do not consume enough fluids which can predispose a person to constipation. In addition, many of the people within our system are on a multitude of medications. Most medications can have some effect on the GI system, particularly psychiatric medications. Keeping accurate data on bowel movements can be extremely helpful. If you are tracking bowel movements, it may give you a clue if you suddently start seeing behavioral challenges that correlate to a change in bowel patterns. Additionally, when a new medication is added or a dose is increased we want to be extra vigilant for changes in bowel patterns. GERD can cause burning in the chest, pain, difficulty swallowing, cough and excessive belching. Do you notice someone wanting to eat frequently? Is it possible that they have reflux symptoms and the food intake lessens the discomfort? Irritable Bowel Syndrome can cause abdominal pain, gas, bloating and varying between diarrhea and constipation. Hemorrhoids often occur in conjunction with constipation. In addition, if a person is engaging in rectal digging or smearing there could be some problem with constipation.

## Gastrointestinal Issues

#### Constipation

- GERD (Gastroesophageal reflux disease)
- IBS (Irritable bowel syndrome)
- Hemorrhoids

Seizures are frequently seen in people with intellectual/developmental disabilities. According to NYU Comprehensive Epilepsy Center persons with intellectual/developmental disabilities appear to have: higher rates of seizure recurrence after a first seizure, lower rates of "outgrowing" epilepsy, higher rates of sudden unexpected death after adolescence and possibly in childhood. In addition, some research has shown it may take multiple medications to control seizure activity. Seizures can have major impact on behavior. Seizures damage/ kill brain cells. Depending on the region of the brain that is affected we may see varying symptoms. If it affects emotional centers, we may see agitation, aggression, paranoia, delusional thinking, depressed mood or confusion. We may also see memory loss, incontinence, inability to reason, disheveled appearance, fatigue, loss of motivation. Do you support a person with a seizure disorder? Does the person have periods when they stare off into space appearing to ignore you? Do they become angry out of nowhere? Has

their personality changed dramatically without a known cause?

## Seizures

- 1 in 100 will experience a seizure
- Abnormal electrical stimuli
  - Confusion/agitation
  - Staring
  - Uncontrollable movements
  - Loss of consciousness

If someone did not communicate by traditional means how do you think that person might communicate to us these symptoms? Perhaps, they are grabbing their genitals or pressing their genitals into objects. How might this be misinterpreted? We may conclude that the person is engaging in sexually inappropriate behavior or that they are in a hypersexual state. Perhaps the person becomes very aggressive or volatile. With kidney infections, we may see upper back and side pain, high fever, shaking, chills, nausea and vomiting. In bladder infections, there may be pelvic pressure, lower abdominal pain, frequent, painful urination, and a low-grade fever. In a urethra infection, the person may have burning on urination. In addition, the person may become delirious. Delirium usually begins suddenly and progresses guickly. Hallmarks can include inability to pay attention, confusion, changes in awareness, sleep, personality and mood. Delirium can have a multitude of causes including urinary tract infections, dehydration, retention of urine or feces, sensory deprivation, sleep deprivation or stress.

# Urinary Tract Infections Pain > Pressure > Burning > Delirium

Other conditions that may make a person more susceptible to delirium include:

- Stroke
- Dementia

- Parkinson's disease
- Other disorders that cause nerve degeneration
- Use of three or more drugs
- Dehydration
- Undernutrition
- Immobility

Many of the people within our system are on multiple medications. It is vital that all physicians and pharmacists treating this person know ALL medications the person is taking! The more medications a person takes the higher the risk of an interaction

According to an article by Wellsphere: The most complex patients are at highest risk for DDIs (drug to drug interactions). One should consider the potential for DDIs at all steps of the drug-delivery process. In a retrospective review of patients admitted to the emergency department, patients taking 3 or more medications or patients who were 50 years or older taking 2 or more medications had a considerable risk for DDIs.[17] Furthermore, an increasing number of medications administered further increased the risk for adverse effects. Patients taking 2 medications had a 13% risk while patients taking 5 medications had a 38% risk for DDIs. Patients taking 7 or more medications had an 82% risk of developing adverse drug interactions.

#### Medication Toxicity/Polypharmacy

- Cardiac medications
- Seizure medications
- Psychiatric medications

How many people within our system have you supported that take more than seven medications in a day?

# Arthritis

- Joint swelling
- Fatigue
- Morning stiffness
- Weight loss

Other symptoms of Arthritis besides those mentioned on the slide at left may include joints that are tender to the touch, red or puffy hands, firm bumps of tissue under the skin on arms or fever. How might we see these symptoms communicated in someone with an intellectual/ developmental disability? Could this be the person we see refusing to go to work most mornings? Or, the person who once she is at work refuses to do her job, is irritable or even combative until lunch time? Could we as supporters jump to the conclusion that this person is just being non-compliant or lazy? Arthritis can be very debilitating for some people. It can cause social isolation in some people, particularly, if that person is having a flare. Possibly this person is having pain that prohibits them from engaging in activities or with other people.

Imagine having any of the symptoms listed on this slide and not understanding what is going on with your body. Any of these symptoms could produce anxiety, frustration or anger. Many of the different types of heart diseases come with warning signs. These warning signs many times are accompanied by pain. Heart disease includes coronary artery disease (symptoms: angina/ SOB /palpitations/fast heartbeat/weakness/dizziness/nausea/swelling). Heart disease leads to heart attacks (discomfort/ pressure/heaviness/pain in chest /arm/below breastbone/discomfort radiating to back/jaw/ throat/arm/fullness/indigestion/choking feeling/ sweating/nausea/vomiting/dizziness/extreme weakness/anxiety/SOB). Heart Disease includes arrhythmias (palpitations/pounding in the chest/dizziness/lightheaded/fainting/SOB/chest discomfort/fatigue). Heart Disease may mean a heart valve disease (SOB/weakness/dizziness/ discomfort in chest/palpitations), heart failure (SOB/cough/quick weight gain/swelling/fatigue/ rapid or irregular heart beat/nausea/chest pain)

and congenital heart defects (SOB/limited ability to engage in physical activity/symptoms of heart failure). All of these symptoms can manifest in a number of behavioral ways for the person who is nonverbal or has an intellectual/developmental disability. Not the least of which is anxiety.

## Heart Disease

- Shortness of breath
- Palpitations
- Weakness/dizziness
- Discomfort/pressure/heaviness in chest

Think about how you feel when you have any type of respiratory infection. If someone were to observe your behaviors when you are acutely ill what might they say? Could they say you are being non-compliant when you don't complete your work? Could they say you are being aggressive when you snap at your co-worker? If a person is hitting himself in the face, instead of being labeled as having self injurious behavior, could it be that they have a sinus infection and the pain and pressure are overwhelming?

# **Respiratory Problems**

Upper respiratory	Lower respiratory
Congestion	▶ Cough
Facial pain/pressure	Fever
Sore throat	Difficulty breathing
► Irritability	▶ Chest pain
▶ Cough	

An interesting and informative video on sensory processing disorders can be found online at: http://www.youtube.com/watch?v=MvlwB-j5QG8 viewed 10/27/09. View time 7:06.

Examples are given for each sense affected and how experiences with senses by someone with a sensory processing problem can be experienced in an overwhelmingly different way from the neuro-typical person. The behavior described gives us insight into what we might see from someone who has a sensory integration disorder.

Pain is such a significant consideration. It is vital that we don't just dismiss the possibility. Every medical possibility



may be connected in some way with pain and could be linked to a behavioral outcome if it is not addressed.

Sometimes a team approach is needed in order to discover what might be going on with a person we are finding challenging to support. It is so important that we do not exclude the person we support on this journey.

All behavior is a means of communication. For example, if you see me squint what might that communicate to you? It could communicate that possibly my glasses are not strong enough; it could communicate the sun is in my eyes or it may communicate that I have something in my eye. All of these can demonstrate the same behavior but may have several possible meanings. Sometimes



we must look at the "puzzle" from multiple angles with multiple sets of eyes to see the complete picture. We need to look at the

person's environment. Have there been changes in the physical environment? Are there changes in caregivers or roommates? Could there be sensory sensitivity? For example, does the person become agitated with excess noise?

Many times the person we support will keep presenting the answers we are looking for, we just have to slow down and listen. It is important that we attempt to keep in the back of our minds that 75% of all behavioral problems likely have a link to a medical problem.



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# Dual Diagnosis

Roadmap to Success & Understanding