# Unlocking and Treating Depression: Adults with Intellectual Disabilities

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# Overarching Goal

- Discuss depression, assessment, interventions and use of psychiatric medications in both general populations and intellectually/developmentally delayed (I/DD) populations.

# Objectives

- List the *prevalence of depression* in general and I/DD populations.
- Identify the *range of depressive symptoms* in general and I/DD populations.
- Describe the *impact of COVID-19 and pandemic* upon general and I/DD populations.
- Outline *basic assessment* for depression in I/DD population.
- Recognize *evidence based psychotherapeutic treatments* for depression in I/DD population.
- State *evidence based psychiatric medications* for depression in general and I/DD populations.

# Depression in General Population

- Facts
- Depressive Illness on a Spectrum
- Risk Factors
- Diagnosis
- Extent of problem in adults, adolescents and children

# Definition of Depression

- Normal human emotion we sometimes call "depression" is a common response to a loss, failure or disappointment.

- Major depression is different.
  - Serious emotional and biological disease that affects one's thoughts, feelings, behavior, mood and physical health.

  - Life-long condition in which periods of wellness alternate with recurrences of illness

  - May require long-term treatment to keep symptoms from returning, just like any other chronic medical illness.

# Depression in Adults in General Population

- Prevalence Major Depression aged 12 and over
  - In any 2 week period 7.6% (Pratt & Brody, 2014).
  - Lifetime prevalence of 4.9-17.1% (Pignone, 2002).
  - Persons *living below the poverty level* were nearly 2½ times more likely to have depression than those at or above the poverty level. (Pratt & Brody, 2014).
- Women are 70 % more likely than men to experience depression during their lifetime
- 15 - 20% of adults older than 65 experience depression (Ciechanowski, 2004)

# Depression Facts

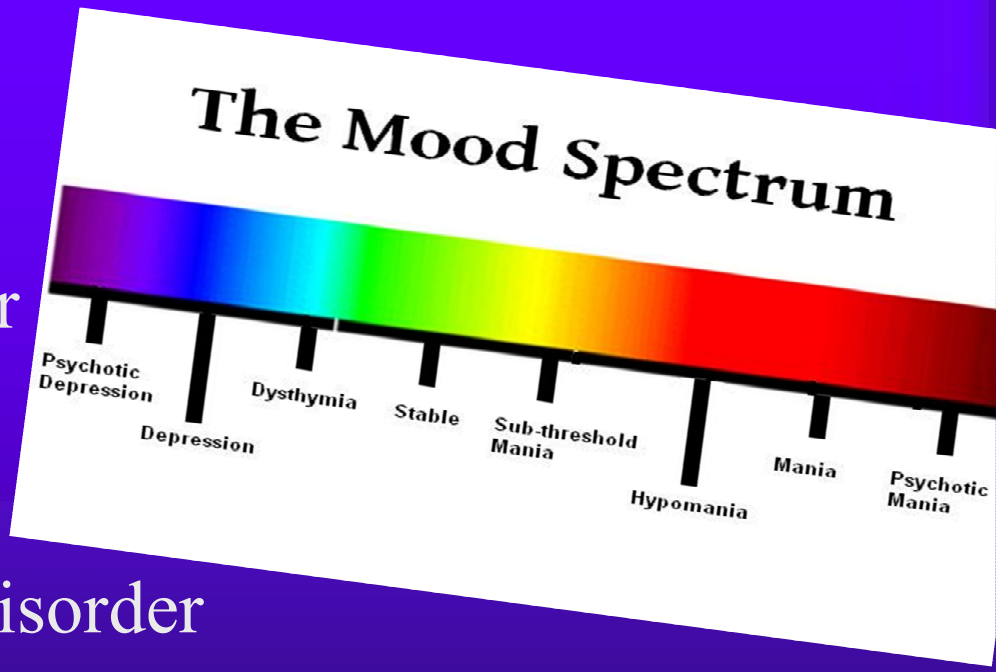
- Estimated 25 million Americans affected by MDD in a given year.
- Depression is the leading cause of disability and the second leading contributor to global disease.
- 10 to 20% of mothers after childbirth have depression.
- Patient's culture, gender, and/or predominance of somatic symptoms can *impede the detection of depression.*
- Up to 70% with depression are seen by their PCP and up to 50% are misdiagnosed.

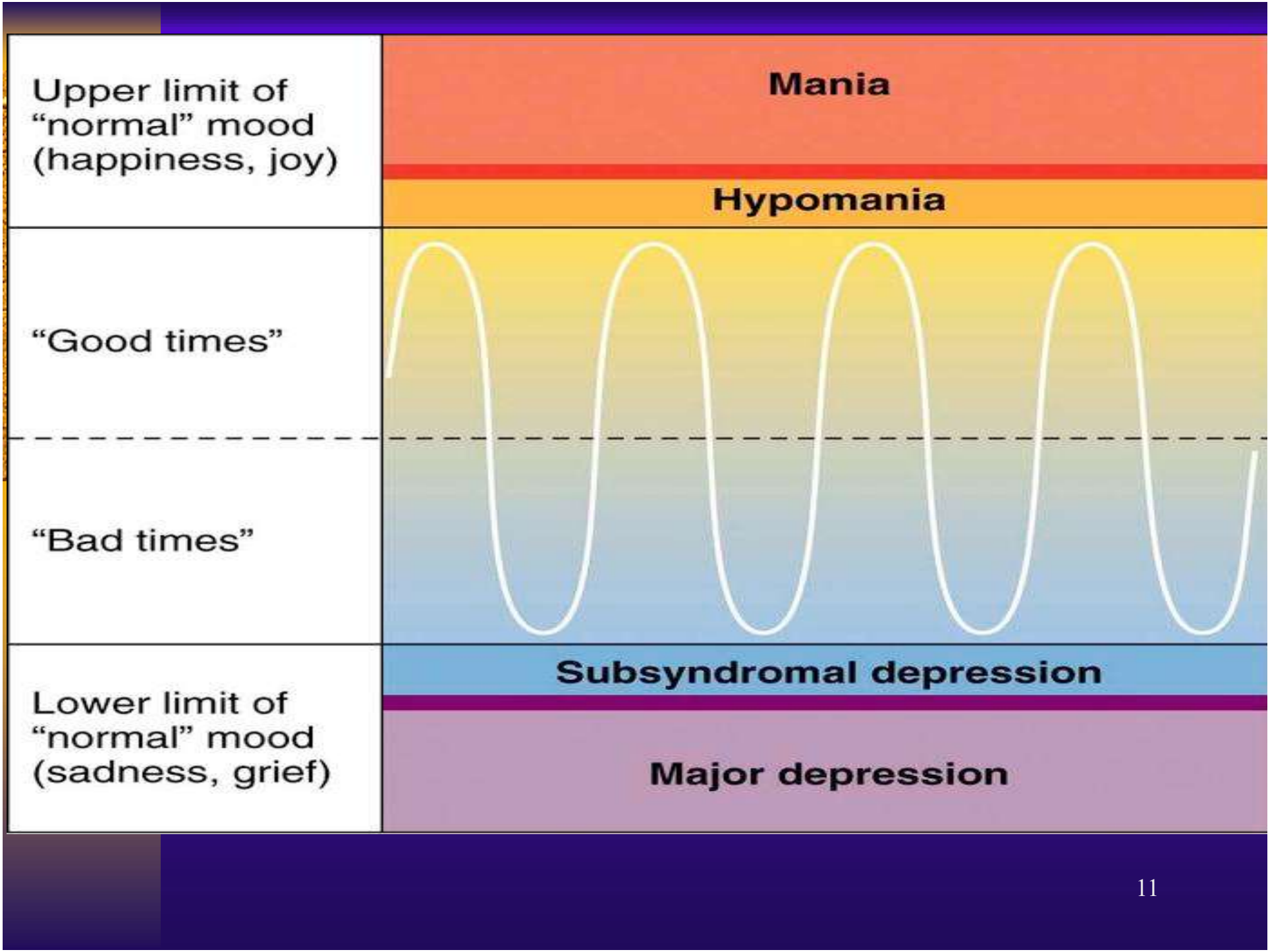
# Depression in Adults in General Population

- Average age of onset is 32 years of age
- 50% treated in primary care
- Not uncommon to have both an anxiety disorder and depression

# Depressive Illness on a Spectrum

- Transient Sadness
- Grieving
- Adjustment Disorder
- Dysthymia
- Major Depressive Disorder
- Bipolar Illness




Upper limit of "normal" mood (happiness, joy)
Mania
Hypomania
"Good times"
"Bad times"
Subsyndromal depression
Lower limit of "normal" mood (sadness, grief)
Major depression

# Varied Symptoms of Depression

## Cognitive

- Difficulty concentrating/thinking
- Slowed thinking
- Obsessive/ruminative
- Loss of confidence
- Self blame
- Difficulty making decisions

## Behavioral

- Loss of functional or self-care skills
- Aggression
- Irritability
- Thoughts of death
- Suicidal thoughts/actions or other self harm

## Emotional

- Crying
- Withdrawal
- Anxiety
- Guilt
- Hopeless
- Worthless
- Low self esteem
- depressive delusions

## Somatic

- Fatigue
- Headache/ Stomachache
- Aches and pains
- Heart palpitations
- Sweaty palms
- Increase/decrease in appetite
- Early morning waking
- Inability to sleep/sleep too much/waking during night

# Clinical Depression

- Spectrum Disorder
  - Subsyndromal (dysthymia) to syndromal symptoms (MDD)

- Syndromal disorder (MDD)
  - At least 2 weeks of persistent change in mood manifested by either depressed or irritable mood and/or
  - Loss of interest and pleasure plus a
  - Wishing to be dead,
  - Suicidal ideation or attempts
  - Increased/decreased appetite, weight, or sleep
  - Decreased activity, concentration, energy, or self-worth

- Change from previous functioning that produces impairment in relationships or in performance of activities.

# DSM V Diagnostic Criteria for Major Depression

Depressed mood or markedly decreased pleasure in most activities that occurs for 2 weeks or more defines a major depressive disorder. Patients will experience at least five of the following symptoms nearly every day. These symptoms cause clinically significant distress or impairment in social, occupational, or other functioning. To be considered a major depressive disorder, psychotropic drugs or a general medical condition aren't the cause of these symptoms and they don't occur within 2 months of the loss of a loved one:

- Depressed mood (irritability in children and adolescents) most of the day, nearly every day
- Markedly diminished interest or pleasure in almost all activities most of the day, nearly every day, as indicated either by subjective account or observation by others
- Significant weight loss or gain
- Insomnia or hypersomnia
- Psychomotor agitation or retardation
- Fatigue or loss of energy
- Feeling of worthlessness or guilt
- Impaired concentration or indecisiveness
- Recurrent thoughts of death or suicide.

# How Do I Know if I Have Depression?

- Markedly diminished interest or pleasure in almost all activities nearly every day
- Recurring thoughts of death or suicide (not just fearing death)
- A sense of restlessness or being slowed down
- Significant weight loss or weight gain
- Loss of interest in activities once enjoyed

# How Do I Know if I Have Depression?

- 5 Symptoms Simultaneously
- Daily or nearly every day
- For 2 wks or more
- Different severity, frequency or duration of symptoms

1. A depressed mood during most of the day, particularly in the morning
2. Fatigue or loss of energy almost every day
3. Feelings of worthlessness or guilt almost every day
4. Impaired concentration, indecisiveness
5. Insomnia (an inability to sleep) or
6. Hypersomnia (excessive sleeping) almost every day

# Risk Factors for Depression

- ✓ Prior episode or episodes of depression
- ✓ Prior suicide attempts

- ✓ Being in the postpartum period
- ✓ Medical co morbidity

- ✓ Lack of social support
- ✓ Stressful life events

- ✓ History of sexual abuse
- ✓ Current substance abuse
- ✓ Woman (2x as likely to be depressed as men)

# Depression in Children

Prevalence

- 0.3% of preschoolers
- 2% elementary school-age children

Ethnic Prevalence

One study of 9863 students ages 10-16 years found

- 29% of American Indian youth exhibited symptoms of depression
- 22% of Hispanic,
- 18% of Caucasian,
- 17% of Asian-American,
- 15% of African-American youth.

# Depression in Adolescents

- Major Depressive Disorder
  - Prevalence 4% - 8% in adolescents
  - 1:1males to females ratio before puberty
  - 1:2 male to female ratio after puberty
- By age 18 incidence is ~ 20%
- Dysthymic Disorder-prev of 1.6% to 8.0% in adolescents
- Since 1940 each successive generation is at greater risk of developing depressive disorders & depressive disorders have their onset at a younger age

# Depression in Adolescents

- Treatment of depression in childhood can help to prevent mental health problems or drug and alcohol misuse in later life.
- Adults seen for depression can trace its origins to childhood/ adolescence

# Depression in General Population
## Pre and During COVID19 Pandemic
(Ettman, et al., 2020)

- Mental health is sensitive to traumatic events >disasters, epidemics, or civil unrest (9/11, Ebola virus/SARS outbreak, 2019 Hong Kong civil protests).

- Nationally representative sample of US adults aged 18 years or older
  - In the US depression *more than 3-fold higher during COVID-19* compared with before the COVID-19 pandemic.
  - Depression Pre COVID 8.5% vs 27.8% during COVID
  - Individuals with lower social resources, lower economic resources, and greater exposure to stressors (eg, job loss) reported a *greater burden of depression symptoms.*

# COVID-19 and Depression

- Distressing, uncertain time.
- The end may still seem a long way off.
- Job loss
- Financial loss
- Grieving loss of loved ones or patients/clients
- Frustrated, cut off by social distancing
- Isolation and loneliness fuels depression> we are social creatures.
- Being cut off from the love, support, and close contact of family and friends can trigger depression or make existing symptoms worse
- Troubled relationship> spending months quarantined in a troubled, unhappy, or abusive relationship can be even more damaging to your mood than being alone.
- Anxiety can lead to depression and panic and anxiety.
- Stress levels up
- To cope we drink too much, abuse drugs, or overeat junk food in an attempt to self-medicate mood and deal with stress.

# COVID-19 Nature of *Global* Losses and Communal Grief

- ✓ Trust and certainty in the future
- ✓ Life as we knew it to be before the pandemic.
- ✓ Freedom, physically & at times psychologically
- ✓ Routines lost.
- ✓ Planning for the future.
- ✓ Direction & movement in life.
- ✓ Safety in our family, community, state, country, world.
- ✓ Financial means.
- ✓ Special events, milestones.
- ✓ Rituals of grief, mourning and joy.

# COVID-19 *Personal* Loss and Grief

- *Drastic change* to one's schedule
- Inability to be comforted when one is ill.
- *Financial loss* or reduction in income.
- Inability to be with a loved one when they die.
- *Social support*.
- Support services.
- *Employment*.
- Inability to fully reassure your children or feel that you can keep them safe.
- *Cannot connect in-person* with friends, family or religious organizations.
- May also *feel a sense of guilt* for grieving over losses that seem less important than loss of life.

# Compounding issues of COVID-19

- Older and oldest age vulnerable.
- Three fourths of all COVID-related deaths are in hospitals (CDC, 2020).
- "Bad deaths"-physical discomfort, breathing difficulties, psychological distress, unable to follow preferences of the patient. (Krikorian, Maldonado, & Pastrana, 2020).
- Multiplicity of loss associated with pandemic or disaster.
- Fear and anxiety for self and others.
- Disruption of cultural norms, rituals, and usual social practices related to death and mourning.
- COVID-19 affects ability for an individual to connect with the deceased both before and after the death.
- Social isolation

# Change Your Focus to Combat Depression

- Maintain a routine.
- Exercise.
- Eat healthfully.
- Distract yourself.
- Find simple sources of joy.
- Limit consumption of news.
- Practice mindfulness and relaxation techniques.
- Express gratitude.
- Meet friends in socially distancing way.
- Zoom/FB meetings.
- Share about yourself.
- Move beyond small talk.
- Nothing needs to be "fixed".
- Sleep well.
- Reminders to keep self on track.*

- *handout

# COVID-19 pandemic could be an opportunity to *improve mental health services.*

(Moreno, Wykes, Galdersi, Nordentoft, Crossley, et al., 2020).

- "The interconnectedness of the world made society vulnerable to this infection, but it also provides the infrastructure to address previous system failings by disseminating good practices that can result in sustained, efficient, and equitable delivery of mental health-care delivery.

# Michelle Obama, First Lady


bing

# Depression in Adults with I/DD

# Definition:
# Intellectual Disability

- Intellectual disability is the term used to define a developmental disorder characterized by deficits in both:
  - Intellectual ability (low IQ) less than 70
  - Adaptive functioning
    - Activities of daily living
    - Social
    - Work
    - Relationship

# Prevalence and Progress: Intellectual Disability

- Prevalence of I/DD 1.5 to 2% of population in Western countries
- DSM 5 replaced "mental retardation" with intellectual disability
- Change led by renaming of organizations
  - 2003 President's Committee for People With Intellectual Disabilities
  - 2006 American Association on Intellectual and Developmental Disabilities

# Depression in Adults with I/DD

1980s

- General belief people with I/DD did not have a cognitive capacity to experience mental health problems

- Behavioral disturbances were *attributable to their learning disability*.

Last 30 years

- Significant interest/effort to understand and expand knowledge mental health problems in I/DD

- Care shifted from *state hospitals* to *community setting* w/o experienced providers

- 

- Increased need for *medical and psychiatric care* in community

- Created barriers to accurate assessment and intervention

(Aggarwal 2013; Smiley, 2005)

# Depression in Adults with I/DD

Today

- Accepted that people with I/DD experience mental illness as non I/DD experience mental illness
- More vulnerable

- Seen as *common disorder* in adults with I/DD and higher than in general population, and difficult to recognize. (Gentile, Cowan, & Dixon, 2019; Hamers, Festen, & Hermans, 2018).

- Studies measuring rates and factors I/DD produce different and sometimes contradictory results

**Individuals with Intellectual Disability**

# Depression in Adults with I/DD

- Difficult to obtain accurate data..
- What interferes with obtaining accurate data?
  - Communication of internal state/symptoms difficult
  - Absence of recognition by caregivers/providers
  - Data obtained from different settings, study designs, definitions
  - Definitions of different severities of depression and I/DD

# I/DD Predisposition for Depression
(Gentile, et al, 2019).

- Individuals with ID:
  - more likely to experience real and perceived losses throughout their lifetime>pets, loved ones peers, roommates or caregivers.
  - Stress and grief from these losses may predispose them to more episodes of depression than general population.
  - May find that they have diminished control in their lives with activities and life events dictated by caregivers, payees, guardians, and staff members>contributes to depression
  - Personality structure can play a role in depression, exacerbated by feelings of rejection and internalization of negative interactions.
  - Medical conditions in those with ID may be co-occurring, exacerbate, or mimic depression.
  - Pain should always be considered with acute changes in behaviors or mood.

# Most Common Genetic Causes of I/DD

- Trisomy 21 (Down syndrome)
  - detectable in chromosomal studies since 1959
  - most important chromosomal cause if I/DD

- Fragile X
  - most common of inherited syndromes caused by a single-gene defect phenotype in males (Mefford, Batshaw & Hoffman 2012)

# Mental Illness
# I/DD vs Non I/DD

- Prevalence of psychiatric disorders in I/DD higher
- Typically mental illnesses are more severe in I/DD
- Rates of depression in I/DD at least approach – if not exceed
- Often easier to diagnose mental illnesses in mild I/DD vs severe I/DD
- More difficult to diagnose
- Degree of variability of cases greater



(Aggarwal 2013)

# Depression in I/DD
## Contributing Factors

- Biological and Etiological (i.e., Down syndrome)
- Cognitive (i.e., automatic negative thoughts)
- Educational:
  - Learned Helplessness
  - Outerdirectedness
  - Inattention
- Life Events:
  - Negative social conditions (ridicule, rejection, etc.)
  - Negative events without support
  - Common life transitions(i.e., puberty, high school graduation)

## Self-Awareness

- "They can tell when others look down upon them, they are hurt emotionally when people ridicule them, and they realize that their opportunities are restricted because others think they are incapable" (Reiss & Benson, 1984, p. 90)

# Epidemiology-

study of disorder and knowing distribution of a disorder
can increase understanding of the causes and how best to manage it

**FIGURE 1: COMMONLY USED MEASURES OF DISEASE FREQUENCY**

| Measure | Definition |
|---|---|
| Point prevalence rate | Refers to the proportion of people in a defined population who are affected by the disorder at a given point in time. |
| Period prevalence rate | Proportion of people who are affected by a disorder at any time within a stated period. |
| Incidence rate | Measure of new episodes of illness: the proportion of formerly well subjects who developed an illness in a defined period of time (usually 1 year) |
| Relative Risk (RR) | The ratio of the incidence of an outcome in those that are exposed to a certain risk factor compared to the incidence in an unexposed group |
| Odds Ratio (OR) | The ratio of the odds of disease in exposed individuals relative to the unexposed |
| Number needed to treat (NNT) | Meaningful way of expressing the benefit of any intervention: relates to how many individuals need to be treated for one individual to benefit |

**Individuals with Intellectual Disability**

# Prevalence of Depression in Adults with I/DD

- 1.5 to 2 x higher than non I/DD
- Depression most common diagnosis for all levels of I/DD- up to 42% in some studies (Hurley, Folstein, Lam, 2003)
- Point prevalence of depression is around 3–4% (Smiley, 2005).



# Depression in Children & Adolescents w I/DD

- 1.5 to 13.7% - similar rates as nondisabled peers (Whitaker & Read, 2006)

- 16.7% of adolescents with mild intellectual developmental disability in one study had significant depressive symptoms (McCall, 2006)

# What is the Reality?

- 62% of people with ID and mental health needs do not receive services (Fletcher, 1988)
- 75% of psychiatrists feel they do not have sufficient training, 39% would prefer not to treat (Lennox & Chaplin, 1996)
- Internal Barriers: communication, finances, lack of self-referral
- External Barriers: fragmentation between agencies, lack of professionals with training and desire

# COVID-19: Challenges of and Interventions of Living through the Pandemic for I/DD

# Vulnerabilities of I/DD Population

(Alexander, Ravi, Barclay, Sawhney, Chester, Malcolm, et al. 2020).

- Individuals with I/DD are vulnerable related to disparity in healthcare provision and physical and mental health multimorbidity.
- Most people will develop *mild symptoms* with COVID19 and some will develop serious complications
- Substantial disease comorbidity (O'Leary, Cooper, & Hughes-McCormack, 2018).
- Increased rate of mental illness (Cooper et al, 2015)
- Increased rate of physical health problems and organic related disorders (hypothyroidism, congenital heart problems, hearing and vision issues, cerebral palsy, epilepsy with illness such as pneumonia, dysphagia, gastroesophageal reflux, feeding issues.
- Lifestyle issues-sedentary, obese, dif to maintain hygiene independently.
- Mortality rates substantially with death being 20 years earlier for this population.

# I/DD and COVID

- Study of 500 I/DD patients with COVID 19 compared to non-I/DD patients
- 3% of non-I/DD individuals vs 4.5% of I/DD with COVID-19 between the ages of 18-74 died.

- IDD patients under the age of 18 are also more likely to die from COVID-19 than their young non-IDD peers, the study found.

- People with IDD living in residential settings experienced… the 'perfect storm' for COVID-19.

- Rely on hands-on assistance from other people with daily self-care tasks, making social distancing particularly challenging and further increasing risk of disease transmission.

- Not only are people with IDD who do not live independently at risk, but their *caregivers are as well* AND they ace competing obligations.
- Stay home if they are feeling sick? or help the individuals who rely on them for daily functioning.

(Turk et al. 2020)

TABLE 1 Group at risk because they are clinically vulnerable due to severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) infection who need particularly stringent social distancing measures

- Aged 70 or older (regardless of medical conditions)
- Under 70 with an underlying health condition listed below (that is, anyone instructed to get a flu injection as an adult each year on medical grounds):
- Chronic (long-term) mild-to-moderate respiratory diseases, such as asthma, chronic obstructive pulmonary disease (COPD), emphysema or bronchitis.
- Chronic heart disease, such as heart failure.
- Chronic kidney disease.
- Chronic liver disease, such as hepatitis.
- Chronic neurological conditions, such as Parkinson's disease, motor neurone disease, multiple sclerosis, or cerebral palsy.
- Diabetes.
- A weakened immune system as the result of conditions such as HIV and AIDS, or medicines such as steroid tablets.
- Being seriously overweight (a body mass index (BMI) of 40 or above).
- Pregnant women.
- People with intellectual or other developmental disabilities and one or more of the following conditions:
- Diagnosis of severe and enduring mental health problem or multiple mental health diagnoses within the acute phase or taking medication that requires close monitoring (e.g., clozapine).
- Increased likelihood of escalation or re-emergence of challenging behavior that will severely reduce quality of life.
- Coexisting physical vulnerabilities including epilepsy, dysphagia, bowel problems including constipation, gastroesophageal reflux disease (GORD), sensory deficits, or other serious physical conditions not named in the lists

# COVID-19
# Mental Health and Challenging Behavior

- Social distancing
- Isolation and changes in schedule.
- Change in structure and loss of predictability.
- Issues with communication (PPE, masks, intelligibility), understanding changes, mental health problems.
- Changes to key staff due to illness/family illness, coverage: carers, visiting family members.

- Behavior support plans may need to be revised.
- Assure psychiatric medications are being administered and that supply is uninterrupted.
- Allow socially distanced visitation when able.
- Keep tone calm, simple, focused and reassuring.

# Physical Symptoms of Depression

High percentage of all patients with depression seeking treatment in a primary care setting report only physical symptoms

Makes depression very difficult to diagnose.

Very important to recognize if you care or work with I/DD

# Its All About Neurotransmitters…

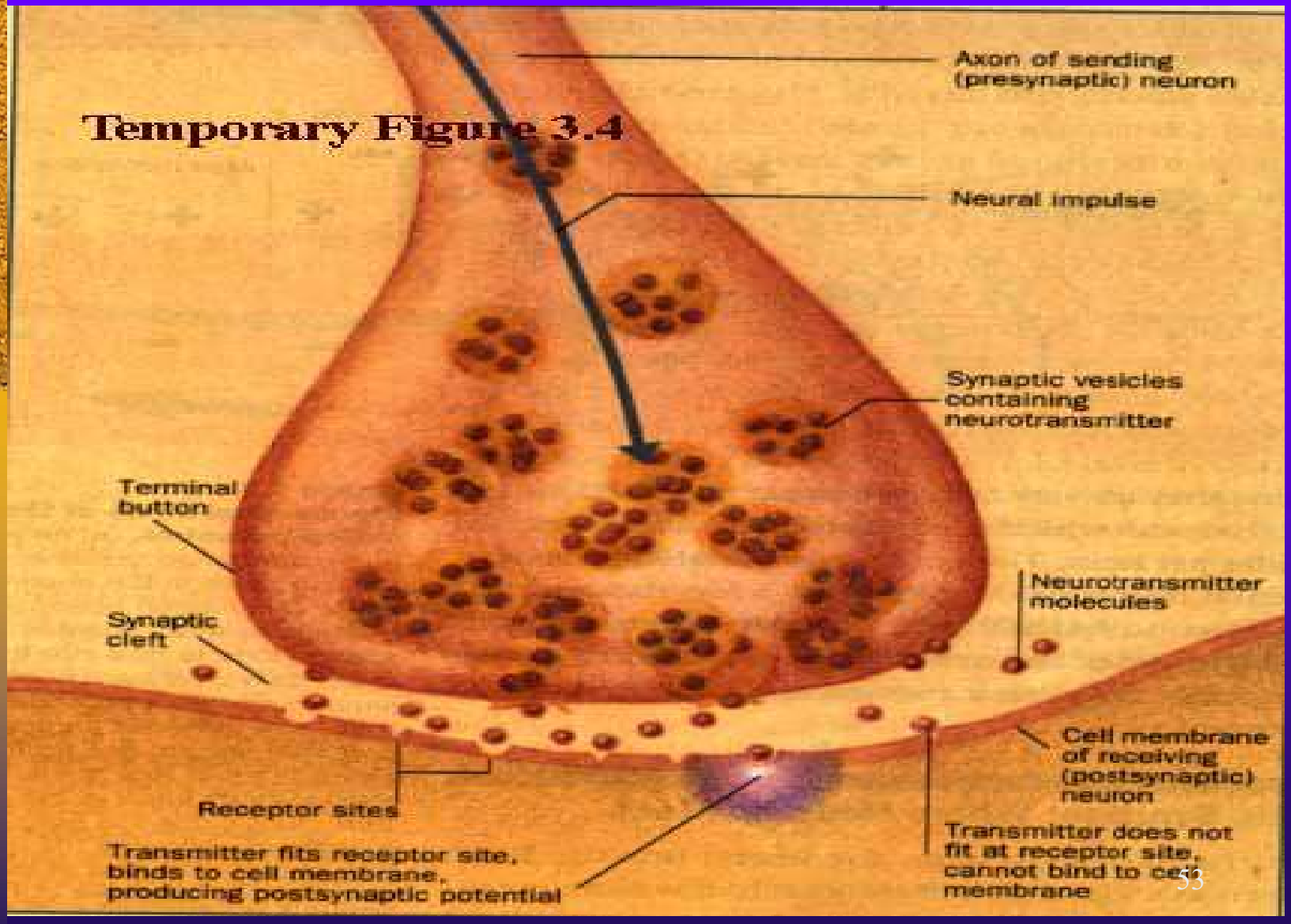
The chemical communication between neurons of neurotransmitters across the synapse and these are implicated in one's mood…..

**SUMMARY TABLE**

**MAJOR NEUROTRANSMITTERS AND THEIR EFFECTS**

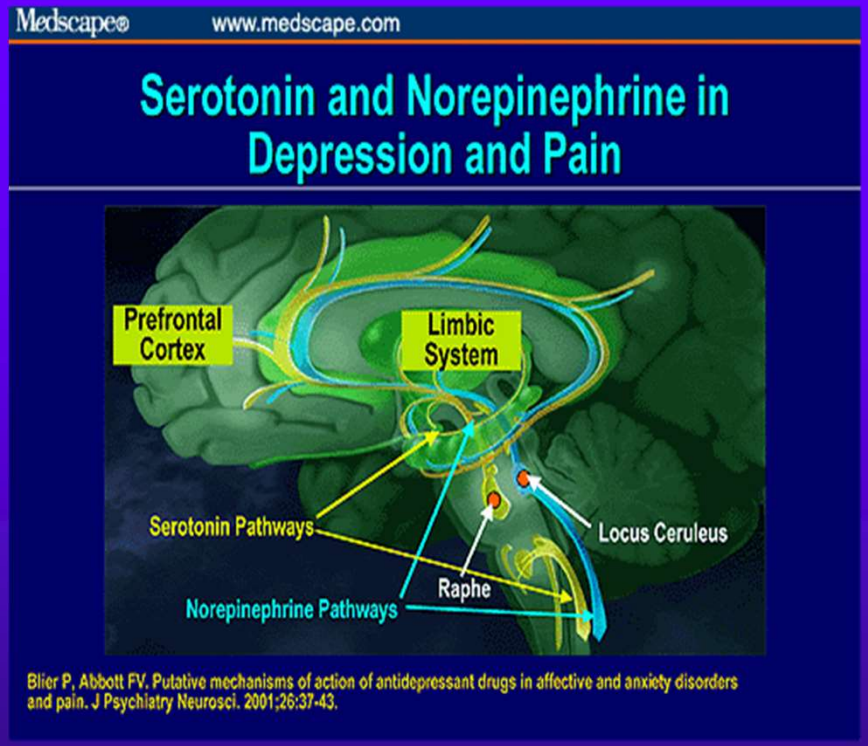
| | | |
|---|---|---|
| **Acetylcholine (ACh)** | Generally excitatory | Affects arousal, attention, memory, motivation, movement. Too much: spasms, tremors. Too little: paralysis, torpor. |
| **Dopamine** | Inhibitory | Inhibits wide range of behavior and emotions, including pleasure. Implicated in schizophrenia and Parkinson's disease. |
| **Serotonin** | Inhibitory | Inhibits virtually all activities. Important for sleep onset, mood, eating behavior. |
| **Norepinephrine** | Generally excitatory | Affects arousal, wakefulness, learning, memory, mood. |
| **Endorphins** | Inhibitory | Inhibit transmission of pain messages. |

# And Synapses!



# Neurotransmitters

- Serotonin and epinephrine neurotransmitters influence both pain and mood.
- Dysregulation of these transmitters is linked to both depression and pain.
- Antidepressants that inhibit the reuptake of both serotonin and norepinephrine may be used as first-line treatments in depressed patients who present with physical symptoms



# Physical Symptoms of Depression

- Chronic joint pain
- Limb pain
- Back pain
- Gastrointestinal problems
- Tiredness
- Sleep disturbance
- Psychomotor activity changes
- Appetite changes

# Depressive Symptoms
# Mild to Moderate I/DD

- Same full range of depressive symptoms as nondisabled peers
- Common symptoms:
  - Sad appearance
  - Depressed mood
  - Irritability
  - Fatigue
  - Hopelessness
  - Guilt
  - Loss of interest in activities
  - Tantrums
  - Self-injury (Aggarwal, 2013)

# Depressive Symptoms
# Moderate to Severe I/DD

- Changes in sleep patterns
- Depressed affect
- Withdrawal

- Expression of behavior may be different
  - Statements about self being "retarded"
  - Feelings of worthlessness
  - Not as interested in positive reinforcements
  - Perseveration about deaths, funerals of loved ones
  - Thoughts of death persistent

( Reudrich, Noyers-Hurley, & Sovner, 2001)

# Depressive Symptoms in Severe/Profound I/DD

Particularly if nonverbal

- Aggression
- Tantrums
- Screaming
- Self injurious behavior
- Crying
- Stereotypies
- Psychomotor agitation

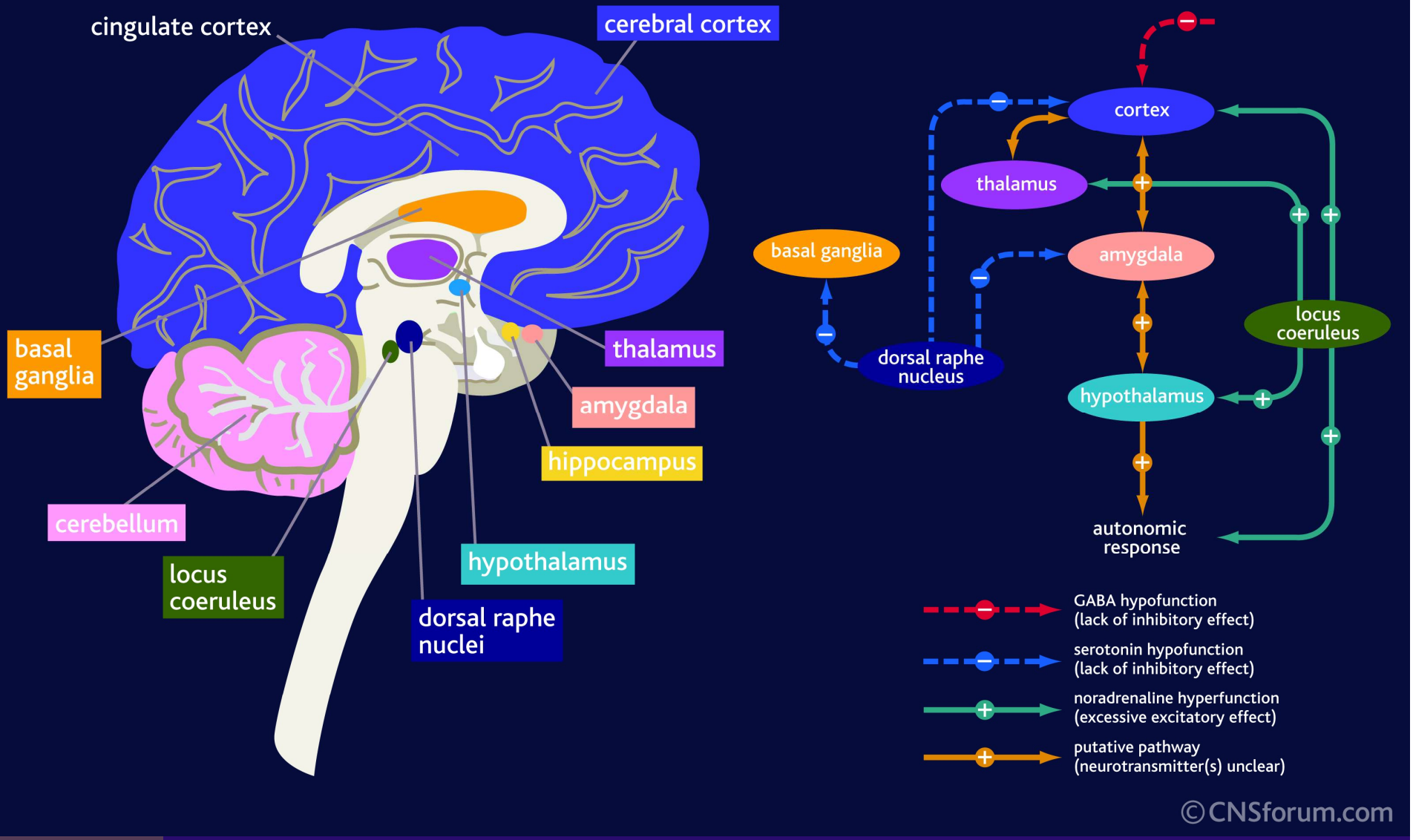
# Causes of Depression?

- Genetic
- Biological
- Environmental

# Depression
## Moderate Genetic Heritability

- 40-50% inheritability for major depression and may be higher for severe depression (ref)
- Parent has history of depression child has 2 to 3 x greater risk
- Parent has recurrent depression- child or sibling has 4 to 5 x risk

# Brain Structures
## Implicated in Mood Regulation

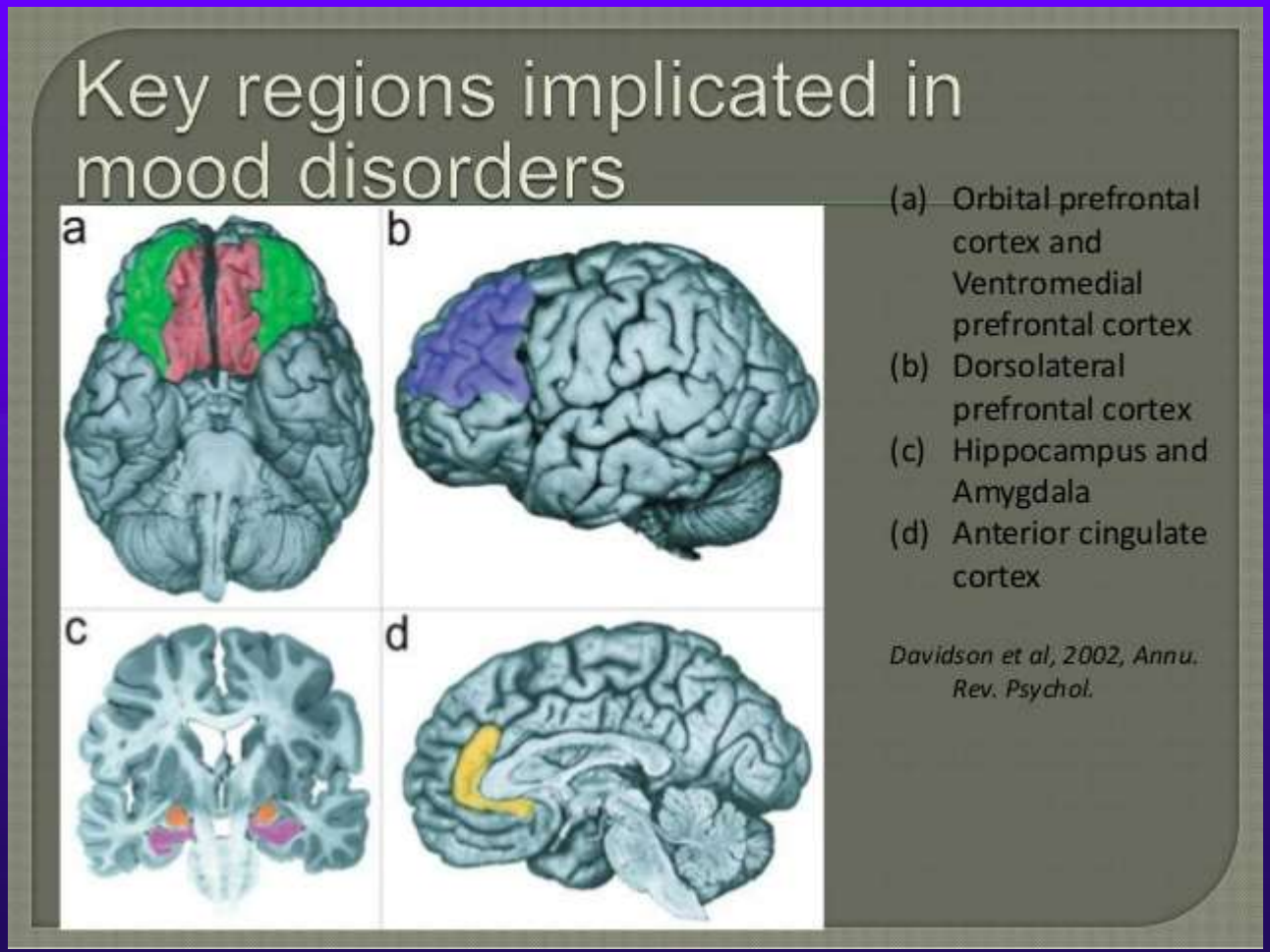





Normal regulation - may depend on the integrity of pathways linking the paralimbic frontal cortex and the basal ganglia.

# Two Systems Act in Concert

1. orbitofrontal–amygdala network that supports emotions and moods
2. hippocampal–cingulate system that supports memory encoding and explicit processing (among other functions)



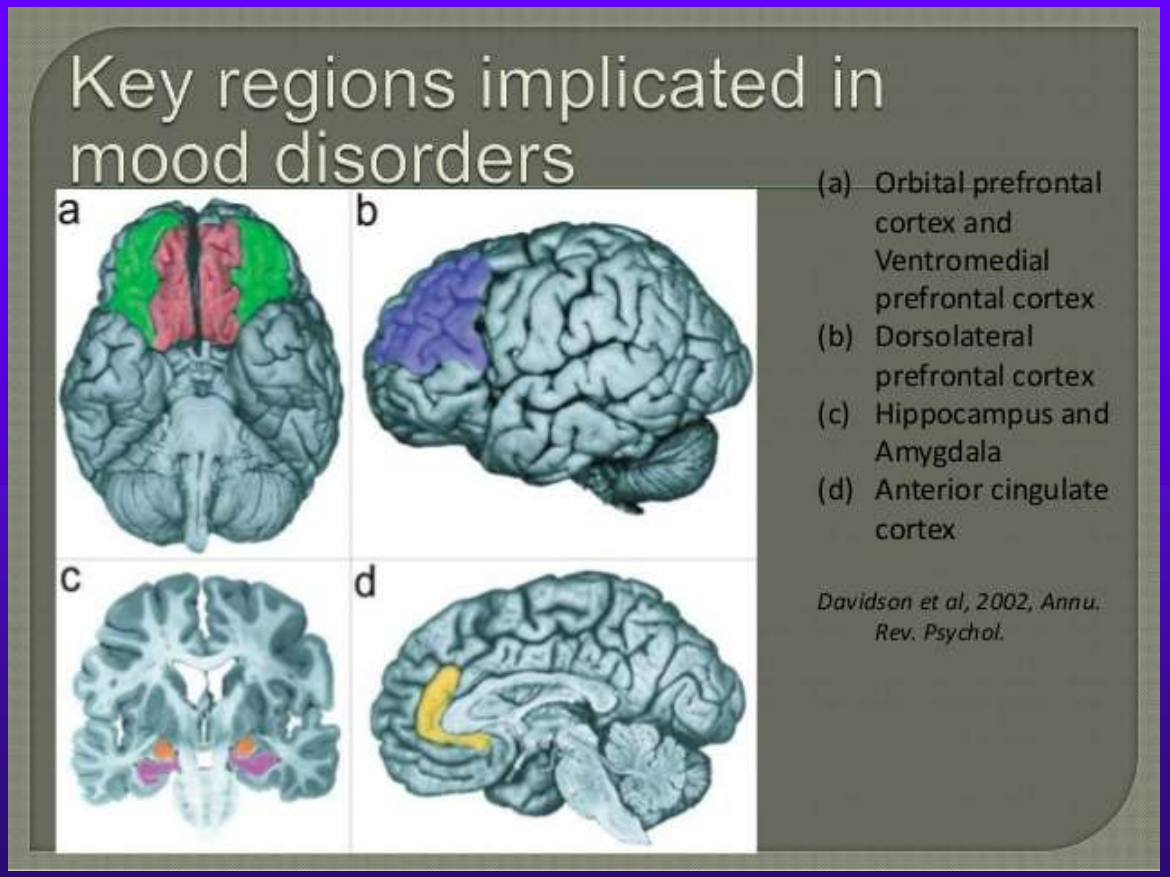
## Hippocampus

-not solely responsible for all of symptoms seen in depression

-highly plastic

-stress-sensitive

-could play a central role in depressive illness

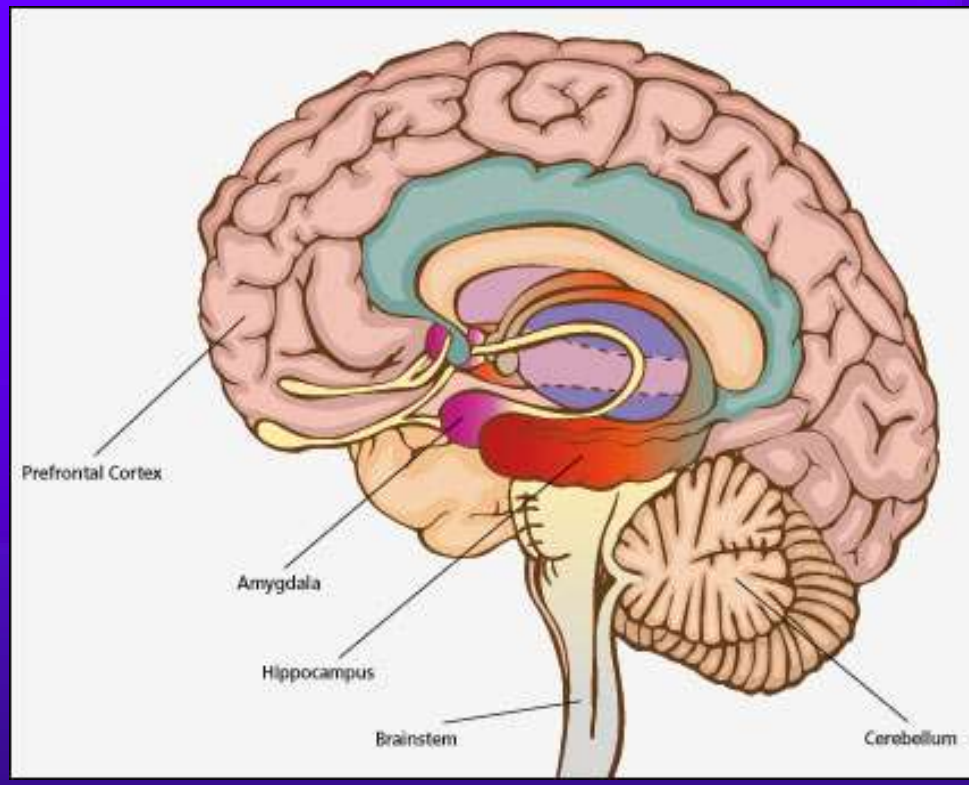


# Biology
# No Single Brain Structure or Pathway

Hippocampus -

Memory storage

- Smaller in people with hx of depression most frequently reported neuroimaging finding
- Have fewer serotonin receptors
- WHY?
- Theory of excess production of cortisol which can shrink hippocampus or
- Born with smaller hippocampus



# Life Events

(Hastings, Hatton, Taylor & Maddison 2004)

- Study of community 1100 community dwelling adults with I/DD.
- Report from caregivers/parents who knew them well
- Assessed using the PAS-ADD Checklist (Psychiatric Assessment Schedule for Adults with a Developmental Disability)
- Life events that occurred 12 months prior to data collections

# Life Events

*5 most frequently* experienced

1. 15.5% -Moving residence
1. 9.0% -Serious illness of close relative or friend
2. 8.8%- Serious problem with close friend, neighbor or relative
1. 8.5%- Serious illness or injury to self
1. 8.3% -Death of close family friend or other relative

- 46.3%- Experienced one or more significant life events in the previous 12 months
- One or more life events in the previous 12 months added significantly to the classification of psychiatric disorder
- One or more life event in this study contributed 2.23 x to the development of an affective disorder.



(Hastings, Hatton, Taylor & Maddison, 2004)

# Difficulty with Accurate Assessment

# Why Is Depression Hard to See in Clients with I/DD?

- Atypical presentations
- Diagnostic limitations secondary to communication barriers
- Lack of formal diagnostic tools used proficiently and consistently
- Valid diagnostic information hard to obtain
- Difficulty describing internalizing symptoms
- Deficits in communication, social skills and intellectual functioning.
- Challenging behaviors may mask depression
- Limited number of empirical studies
- Lack of standardized assessments specific to diagnosing clients with IDs and psychiatric co morbidities

Proposing modified diagnostic criteria

# Practitioner Issues

- Practitioners often feel inadequate to assess, diagnose and treat ID population, particularly if psychiatric issues in ID population.[8]
- 90.2% of psychiatrists felt inadequate to diagnose problems in I/DD population due to lack of training (Werner, 2006)
- Practitioner anxiety can often interfere with ability to provide good care.

Individuals with Intellectual Disability

# Assessment for Depression

- Biological Psychological Social= BIO-PSYCHO-SOCIAL

Presenting complaint

Recent life events

Changes/moves

Medical History

Medication History

Psychiatric History

Trauma History

Family History

Physical

Possible Labs

# Assessment

- Multi disciplinary
- Thorough assessment for possible physical cause of behavior/agitation that might mask depression
- Applied behavioral analysis
- Multiple resources- home, work, family, particular those who know individual for long period of time
- Any recent trauma or anniversary or LOSS?

# General Guidelines for Evaluation of Depression in I/DD (Gentile, et al., 2019).

- Establish clear picture of patient's baseline.
- Rule out medical conditions>first step to eval of mental health.
- Use developmentally appropriate language when questioning patient.
- With limited verbal communication skills or cognitive abilities, yes/no or close ended questions best.
- Visual scales or inquiries about mood change
- (e.g., feelings of sadness) should be performed in conjunction with observation by the provider.
- Information from caregivers and family objective as possible with specific behaviors identified & attention given to acute changes.
- Psychosocial factors>PROFOUND effects.
- Develop a timeline and the course of symptoms from caregivers
- if patients are unable to be specific.
- Ask about the time frame surrounding symptoms;
  - changes to routine, living conditions, social involvement, occupational changes, family members, stressors, or trauma.

# Assessment

- Collateral info more importation than from non I/DD being evaluated.

# Major Depressive Disorder in I/DD

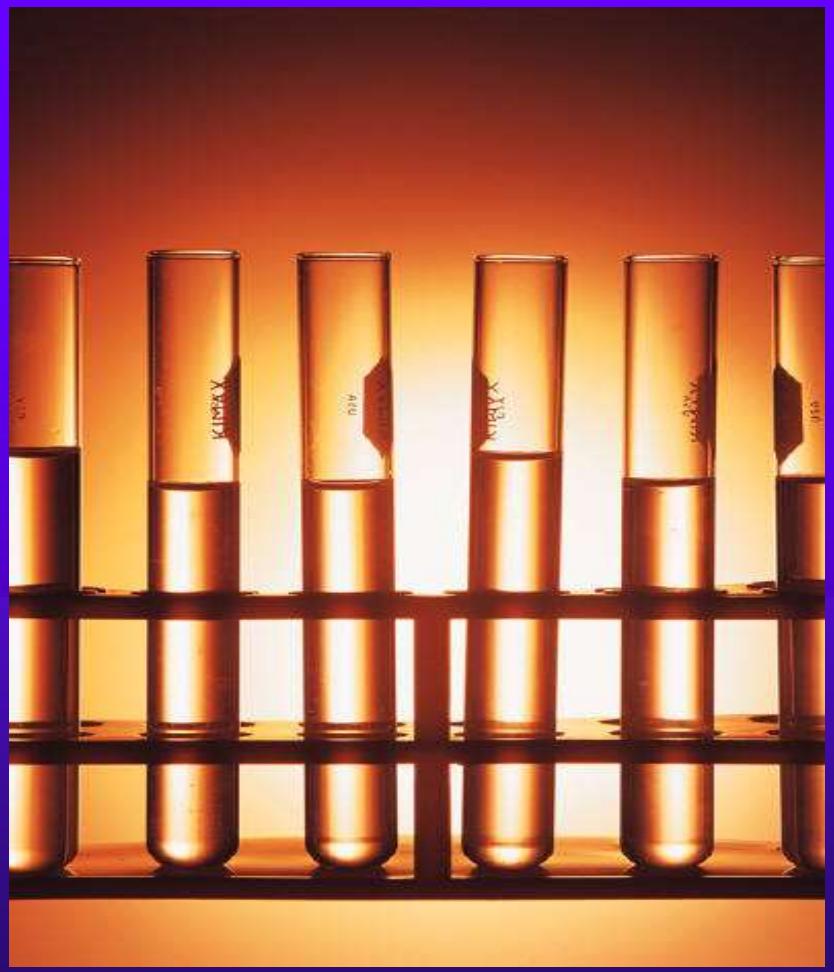
- Patients with ID may reach the threshold of clinically significant depression with fewer symptoms than required for the general population.
- Symptoms must be present for longer than 2 weeks.
- Depressed mood may be observed as no longer smiling or laughing, crying, flattened affect, or sadness.
- Irritability is commonly seen in lieu of, or in addition to, depressed mood and anhedonia> angrier affect with agitation.
- Establish an understanding of patient sleeping patterns, habits, behaviors, and environment (e.g., bedtime, waking
- time, nocturnal waking, daytime naps, quality of sleep, nightmares/dreams, snoring, sounds in room, temperature
- fluctuations, type of bedding, roommates, etc.):
- — Rule out obstructive sleep apnea or other sleep disorders

- Guilt/worthlessness may be observed as an increase in self-deprecating remarks, blame, or fears of punishment:
- Change in typical functional level, amotivation, fatigue by patient.
- Decreased concentration by changes in ability to work or play, intermittent difficulties with memory, or difficulty completing common tasks.
- Appetite changes by refusal to eat favorite foods, weight loss/gain, and obsessing about or stealing food.
- Psychomotor changes to typical behaviors, less sitting, agitated behaviors, or increase in verbalizations.
- Thoughts of death or suicide observed by increased talk of death or losses, talk of hurting themselves or others, increased focus on violence, or suicide attempts.
- Always evaluate for safety, especially regarding self-harm or harm to others. Establish intent, desire, plan, opportunity, and lethality.
- Involve caregivers and family in monitoring of changes in safety status and establishing safety plans.
- While atypical depressive symptoms may be more common with individuals with ID, pursue a thorough evaluation to rule out other causes and identify etiology (e.g., agitated irritability, visual hallucinations, olfactory hallucinations, mania, or hypomania).
- Individuals with ID may not fully meet criteria for depression; and up to the clinician's judgement to determine.



# Lab Tests

- TSH
- FT4
- ECG (TCA)
- Urine Drug Screen
- Chem 7
- CBC w/diff
- LFT
- Pregnancy test
- Fasting lipids/glucose



# Depressive Disorder Differential

- ✓ Somatic complaints may contain hidden signs of depression

- Sx-loss of energy or fatigue unexplained pain

- ✓ GI sx
- ✓ headache
- ✓ insomnia
- ✓ dizziness
- ✓ palpitations heartburn
- ✓ numbness
- ✓ loss of appetite
- ✓ PMS

- ✓ Insomnia, specifically early morning awakening, is a reliable and early indicator of depression

- Dx made after medical etiology ruled out.

- ✓ Hypothyroidism
- ✓ Neurosyphilis
- ✓ Substance abuse
- ✓ Major organ system disease
- ✓ Multiple sclerosis

- ✓ Medications
  antihypertensives
  anticonvulsants
  beta-blockers
  steroids
  chemotherapy
  levodopa
  benzodiazepines

Individuals with Intellectual Disability

# Assessment for Depression

- Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS–ADD; Moss et al, 1993b:, Smiley 2005).
- Reasonable reliability and validity
- The PAS–ADD Checklist -for carers and staff to help decide if individual requires further assessment
- Useful screening tool to identify possible cases of mental illness

# Psychopathology Instrument for Adults with Mental Retardation (PIMRA).

- First scale for assessing psychopathology for persons with ID appeared in 1983 (Kazdin, Matson, & Senatore, 1983).
- Still widely used
- Many scales based on or cross validated with
- Corresponding caregiver form

# Frequently Used Screens

- Child Behavior Checklist (CBCL) Developmental Behavior Checklist (DBC)
- Diagnostic Assessment for the Severely Handicapped II (DASH-II)
- Nisonger Child Behavior Rating Form (NCBRF)
- PAS-ADD, Mini PAS-ADD, PAS-ADD 10
- Reiss Screen

# Depression Scales I/DD

- Self-report-
  - the Glasgow Depression scale
- Informant report-
  - Assessment of Dual Diagnosis
  - Reiss Screen for Maladaptive Behaviour
  - The Children's Depression Inventory
- Psychometrics
  - Valid and reliable
  - Still issues with sensitivity and specificity in the ID population
  - More study needed

( Herman & Evenhuis, 2010)

# Case example

- Jon is a 41 year old male patient who has profound intellectual disability who has recently been biting his forearm so hard he has broken the skin. He also has refused to eat and has lost 5 pounds in the last month. Previously a good sleeper, with a regular schedule, he awakens at 330 am every morning and can't seem to get back to sleep. His his usual caregiver, Annie had been with him for many years. She recently became ill with COVID, and he has had a capable, new, caregiver, but his symptoms have not abated. Although Annie had not been severely ill, they want her to test negative for COVID 2 times prior to returning to work.

- A team meeting was called. Annie was due to return to work in 2 weeks but in the meantime, the team set up a socially distanced meeting where Annie could talk to Jon through the window of his room. They also consulted with Jon's medical provider to see if there was some adjustment that could be made to his medication to improve his mood and reduce his anxiety.

# Depression Assoc w/Medical Illness and/or Substance Abuse or Alcoholism

- ✓ **Cardiac disease**
- ✓ **Cancer**

- ✓ **Neurologic disease**
  Parkinson's disease
  Chronic headache
  Traumatic brain injury
  Stroke
  Dementias
  Multiple sclerosis

- ✓ **Metabolic disease**
  Electrolyte disturbances
  Renal failure

- ✓ **Gastrointestinal disease**
  Irritable bowel syndrome
  Inflammatory bowel disease
  Cirrhosis
  Hepatic encephalopathy

- ✓ **Endocrine disorders**
  Hypothyroidism
  Hyperthyroidism
  Cushing's disease
  Diabetes mellitus
  Parathyroid dysfunction

- ✓ **Pulmonary disease**
  Sleep apnea
  Reactive airway disease

- ✓ **Rheumatologic**
  Systemic lupus erythematosus
  Chronic fatigue syndrome
  Fibromyalgia
  Rheumatoid arthritis

# Suicide

# Suicidality in I/DD

- Suicidal ideation and attempts 17 to 23% (Lunsky, 2004)
- Sample of 42 adolescents with mild ID showed 38% thought about killing themselves while nearly 5% wanted to (McCall, 2006).

# A Review of Suicidality in I/DD

(Merrick, Merrick & Lunsky, 2006)

- Only two studies had systematically examined differences between suicidal and non-suicidal individuals with ID with regard to risk factors.
- Limited research on intervention in the I/DD population
- Professionals should consider risk factors for suicide w/I/DD
- Intervene when suicidal risk/behavior is found.

Risk Factors for I/DD

- Hx of psychiatric hospitalization
- Comorbid physical disabilities
- Loneliness
- Sadness
- Depression or anxiety

# Assisting Potential Suicidal Patients

- ✓ Be attentive
- ✓ Remain calm and do not appear threatened
- ✓ Stress a partnership approach
- ✓ Discuss suicide in a calm, reasoned manner
- ✓ Listen to the patient
- ✓ Emphasize that suicide causes a great deal of pain to family members

# Suicide Assessment: Warning Signs

- ✓ Pacing
- ✓ Agitated behavior
- ✓ Frequent mood changes
- ✓ Chronic episodes of sleeplessness
- ✓ Actions or threats of assault, physical harm or violence
- ✓ Delusions or hallucinations
- ✓ Past suicide attempt
- ✓ Recent loss
- ✓ Threats or talk of death (e.g., "I don't care anymore," or "You won't have to worry about me much longer.")
- ✓ Putting affairs in order, such as giving possessions away or writing a new will
- ✓ Unusually risky behavior (e.g., unsafe driving, abuse of alcohol or other drugs)

# Suicide Risks

Older than age 65

Male sex

White race or Native-American ethnicity

Single, divorced, separated, or widowed (especially without children)

Unemployment

History of admission to a psychiatric ward

Family or personal history of one or more suicide attempts

Drug or alcohol abuse

Severely stressful life event in recent past

Panic attacks or severe anxiety

Severe physical illness, especially of recent onset

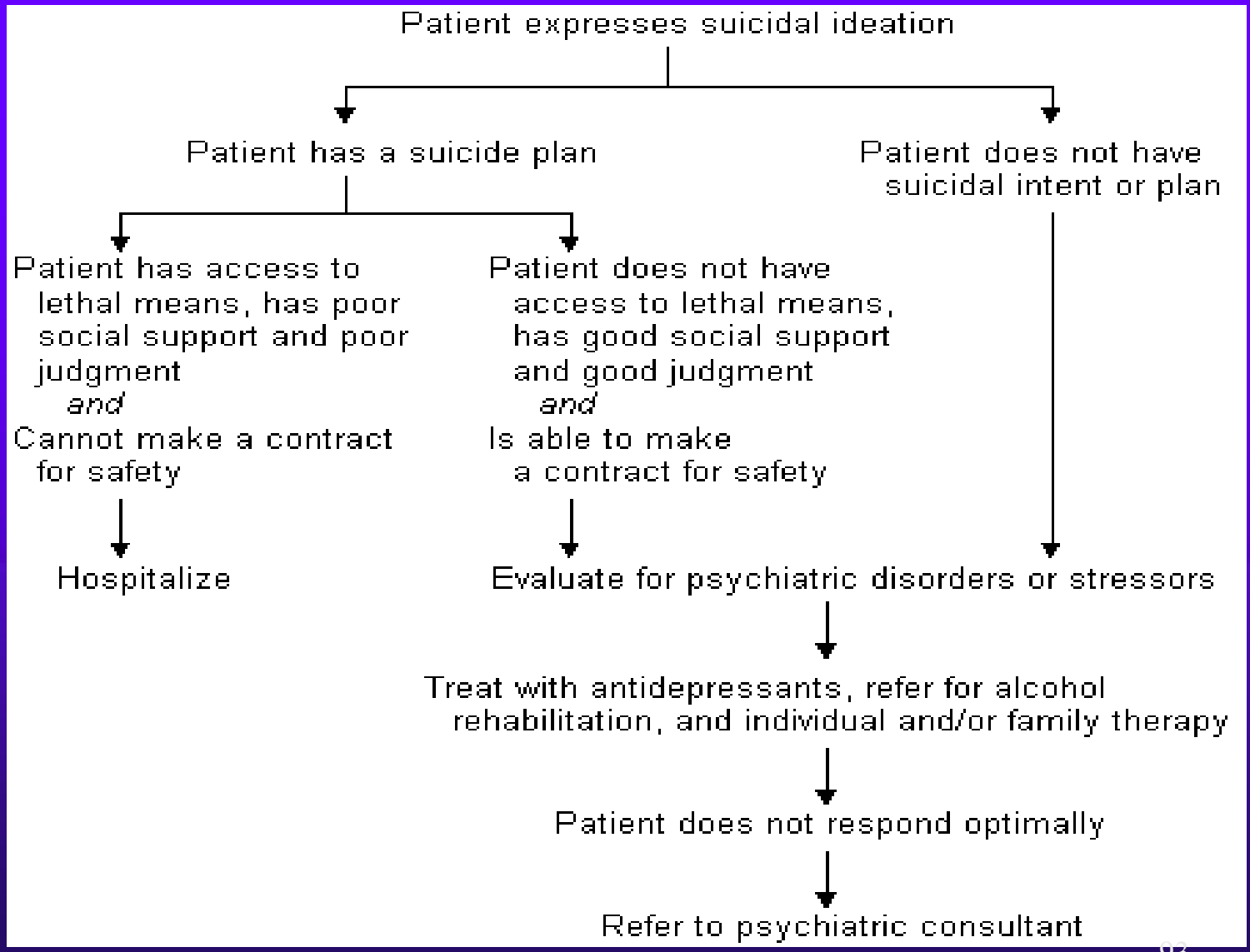
Severe hopelessness

Anhedonia

Specific plan for suicide

Access to firearms or other lethal means

# Suicide Algorithm



# Suicide
# Summary Recommendations

- Watch for warning signs and do not disregard them given the diagnosis of intellectual disability.
- Incorporate family input and involvement at any level of intervention.
- Consider the individual: self-awareness, self-perception, involvement and various types of activities, etc.
- Consider the system: training, awareness, understanding of parents, educators, and other health facilitators.

# Non-pharmacological Treatments for Depression in Intellectual Disability.

(Hamers, Festen, & Hermans, 2018)

- Systematic review and meta-analysis of 4267 papers from multiple database; main exclusion reason was the *absence of study results;* included 15 studies, not all RCTs.

- Five different types interventions
  1. Cognitive Behavioral Therapy (CBT), mild to moderate ID
  2. Behavioral therapy, mild, moderate, severe ID
  3. Exercise Intervention
  4. Social Problem-Solving Skills program, mild ID
  5. Bright Light Therapy (BLT), profound ID

# Depression in I/DD
# CBT Example

- 2 hours 1x/week for 5 weeks
- Group format: adults with mild-moderate intellectual disability.
- Emphasis
  - meaning of depression
  - support networks
  - link between thoughts and emotions
  - development of positive self-statements
  - role play for problem solving
  - development of realistic goals
- Improved symptoms, automatic thoughts; benefits persisted 3 months after group ended

(McCabe, McGillivray, & Newton, 2006)

# CBT Approaches for Depression with Intellectual Disability

- Self-Instruction
  - Encourage use of positive self-statements with prompts, reinforcement
  - Internalized statements change cognitions and behavior
- Problem Solving
  - Direct instruction, practice, role play
- Modeling
  - Observe models, practice behavior

# CBT Approaches for Depression in I/DD

- Behavioral Techniques
  - Identification and manipulation of setting events
  - Positive Reinforcement
  - Teaching of alternative desired behaviors
- Cognitive Techniques
  - Positive self-statements
  - Self-monitoring of thoughts, mood

# Skills Training Approaches

- Social Skills: modeling, role play with practice and feedback
- Relaxation: deep breathing, guided imagery
- Assertiveness: instruction, modeling, practice
  - Differentiate from passivity, aggression
- Anger Management: coping statements, problem solving, relaxation

# Coping-Based Therapies with I/DD

- Bereavement in I/DD
  - Prolonged, atypical grief, often unrecognized
  - Often encouraged to hide emotions, not attend events
  - Randomized to two different therapeutic interventions
    1. Traditional Counseling by volunteer bereavement counsellors
    2. Integrated intervention by carers offering specific bereavement support
       - Content: Education about death, participation loss rituals and sharing, encouragement of family contact, coping strategies, sharing objects, journaling, writing letters, visiting sites, sense of control over own life
  - Reduction of depressive symptoms across all levels of I/DD.

(Dowling, Hubert, White, & Hollins, 2006; Stoddart, Burke, & Temple, 2002)

# Treatments and Interventions

- Psychotherapy
  - Can be successful with modifications
  - Play media, art, drama

  - Focus on present, goals, impact of I/DD
  - Individual, group, and family

  - Has been used successfully with clients with intellectual disability but limited studies

# Psychotherapy Modifications (McCall, 2006)

- Concrete, structured format
- Simplified concrete language

- Therapist with more direct role
- Slower pace, shorter sessions

- Frequent checks for understanding, repetition
- Repeated, clear permission to express emotions

- Recognize, address impact of disability, repeated negative life experiences, external systems (Levitas & Gilson, 1989; Lynch, 2004)

# Psychotherapy Precautions (McCall, 2006)

- Play media must be age-appropriate
  - Act out TV show vs. playing with dolls
  - Role play
- Increased dependency on therapist
- Therapist should not display inappropriate "rescue" mentality
- Goals do not ignore the individual
  - Tailor to reality and experiences, including disability
  - Encourage independence in setting, meeting

# Group Psychotherapy (McCall, 2006))

- Goals: improve self-image, acceptance of disability, understanding of disability, coping skills.
- Effective for multiple purposes across levels of intellectual disability.
- 6-8 individuals w/ similar cognitive and verbal abilities, motivation, needs (Monfils, 1989).
- Develop relationship, encourage self-disclosure.
- Discussion, problem solving, role play, reinforcement, feedback, social outings.

# An Example of Group Psychotherapy

- Adolescents with developmental disability (Thurneck, Warner, & Cobb, 2007).
- Improve coping strategies for failure.
- Group listening games, discussion of negative experiences.
- Visits by students w/out disabilities to share experiences – commonality.
- Increased sense of belonging.

# Group Psychotherapy: Advantages

- Share common experiences of disability.
- Healthy emotional release with support, encouragement of others.
- Strong sense of group cohesion.
- Secure environment to explore feelings, problems
- Increased self-esteem, self-image, life strategies.

Individuals with Intellectual Disability

# Pharmacological/Medication Treatment for Depression

Not first line.

Ideal is to have therapy AND medication.

I/DD increased sensitivity to side effects/and or disinhibition.

Accurate Diagnosis a MUST.

# Prescribing of Medications

- Symptom driven
- Diagnosis driven
- Co-morbidity

- Best Evidence
- Age of patient
- Side effect profile

- Ease of administration/dosing
- Compliance Issues

- Safety issues, i.e., suicidality (TCA).

- Belief system of parents and I/DD.

- Cultural issues.

# Additional Factors to Consider When Selecting an Antidepressant

- ✓ Past history of response to an antidepressant
- ✓ Hx of antidepressant response in a first-degree relative, name of med
- ✓ Medical status
- ✓ Drug-food interactions
- ✓ Drug-disease interactions
- ✓ Safety of agent following overdose (especially with tricyclic antidepressants)
- ✓ Cost
- ✓ Familiarity and comfort of the physician's assistant with the pharmacology of the antidepressant agent
- ✓ Drug-drug interactions

# Pharmacology

Selective Serotonin Reuptake Inhibitors/ SSRIs-

- inhibit the reuptake of serotonin in the synapse
- so it is more available to the neuron
- thereby increasing a sense of well being

SSRIs

✓ Citalopram (Celexa)

20-60 mg

✓ Fluoxetine & weekly (Prozac) 10-80 mg

✓ Paroxetine (Paxil)

10-60 mg

✓ Sertraline (Zoloft)

50-200 mg

✓ Fluvoxamine & ER (Lexapro) 25-100

# SSRI Potential Side Effects

Common Side Effects

- ✓ Headache
- ✓ GI upset, nausea, diarrhea
- ✓ Mild sedation w/some
- ✓ Sexual dysfunction, decrease libido
- ✓ Sweating

**Serious Side Effects**

- ✓ Withdrawal Syndrome
- ✓ Serotonin Syndrome
- ✓ Mania
- ✓ Sz (rare)
- ✓ Hyponatremia
- ✓ Bleeding
- ✓ EPS

# Pharmacology

- ✓ Bupropion (Wellbutrin) SR
  norepinephrine/dopamine reuptake inhibitor

Start:100 mg bid or LOWER, incr after 3d 75-150mg q d Max 450mg qd

SR-150 bid, Max400 mg

Contraindicated w/hx of seizures, bulimia, anorexia nervosa

SE-headaches, jitteriness, insomnia, tics, sz at doses over 450mg/day

- ✓ Trazodone (Desyrel)

Start: 150 mg/d, incr by 50mg q 3 d Max 400mg/d, take w/food

SE- sedation, dizziness, bitter taste, tremor

Serious-hypotension, *priapism,* syncope

- ✓ Venlafaxine (Effexor)
  norepinephrine/serotonin/dopamine reuptake inhibitor

Start: 37.5 mg bid, incr dose q 4d; max 375 mg/d; take w/food; taper dose over 2 wk period

- ✓ Venlafaxine, extended-release (Effexor XR)

Start: 37.5 mg qd, incr by 75 mg q 4-7 d; max ww5mg/day taper by 75mg/wk

SE-headache, hypertension, insomnia

# Follow-up Visits

- ✓ Med chosen and initiated, allow 4-6 wks for full effectiveness
- ✓ Severely depressed -weekly follow-up visits
- ✓ Less severe- every 10 to 14 days during the first six to eight weeks of treatment.
- ✓ Telephone visits can be effective
- ✓ After symptoms begin to remit-more severely depressed patients can be seen every four to 12 weeks.
- ✓ The patient should be informed that the med provider is available between visits to address his or her concerns

# Maintenance

- ✓ After remission of a first episode of depression, four to nine months of continuation therapy at the same dosage is recommended
- ✓ After remission of a second episode, maintenance therapy for at least one year, and possibly two, is appropriate
- ✓ After a third episode, long-term maintenance treatment, possibly indefinitely, may be indicated
- ✓ Patients with risk factors for recurrence (e.g., frequent relapses with severe episodes associated with suicidality and psychosis, poor recovery between episodes) may require lifelong therapy

# Maintenance (continued)

- 6 weeks is the optimal therapeutic trial
- Adequate dosage but has not responded or has experienced only *minimal* relief at 6 weeks *reassess diagnosis of depression* and *adequacy of treatment*
- Underlying substance abuse and/or the presence of a general medical condition or a chronic social stressor, such as domestic violence, can contribute to treatment failure
- If none of these are found on reassessment, at weeks 4 to 6 the dosage should be *increased*
- If response is *still inadequate* after 8 weeks of treatment, the *dosage* may need to be *adjusted* or *another medication* selected.

# Summary

- Depression more of a problem for I/DD population
- Often missed due to inherent problems assessment and inability to disclose internal states
- Good assessment gives proper diagnosis
- Evidence based tools best
- Many therapies can be quite helpful in I/DD
- Meds are SECOND line and in combination with therapy
- Collaborate and consult

# Sheila C. Hutton Website
http://www.intellectualdisability.info

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# Online Resources

- How to Get Therapy When You Can't Leave the House https://www.npr.org/2020/04/03/826726628/how-to-get-therapy-when-you-cant-leave-the-house
- National Alliance for the Mentally Ill
  800-950-6264
  www.nami.org
- National Depressive and Manic Depressive Association
  800-826-3632
  www.ndmda.org
- National Foundation for Depressive Illness
  800-239-1265
  www.depression.org
- National Institute of Mental Health
  301-443-4513
  www.nimh.nih.gov
- Sheila C. Hutton Website
  http://www.intellectualdisability.info