THE CENTER FOR START SERVICES

*University of New Hampshire*
*Institute on Disability/UCED*

# Understanding Mental Health Diagnosis in Children with IDD: Implications for Treatment

Jill Hinton, PhD
Clinical Director

www.centerforstartservices.com

- *“Saying someone has a ‘behavior problem’ is like saying they have a fever”*

# IDD and Behavioral Problems

- Mental health and/or behavior problems may be symptoms related to the onset of a medical condition (e.g., ear infection, UTI, diabetes, seizure disorder, thyroid disorder, etc.) or factors related to the environment
- In most cases, co-occurring complex behavior problems in individuals with ID are caused or maintained by a combination of factors
- Behavioral problems may also arise as a result of past traumatic experiences
- Medications can play a major role – too many meds, not the right meds, side effects of medications

# BioPsychoSocial Approach

- Takes into account biological, psychological and social factors that may contribute to an individual experiencing a crisis
- Provides a person-centered understanding of the individual's history and life experiences
- Provides context to explain why a trigger is a trigger for that individual

# Neurodevelopmental Disorder (DSM 5)

- Intellectual Disability
- Autism Spectrum Disorder
- Attention Deficit Hyperactivity Disorder

# Intellectual Disability

- Intellectual disability is a disability characterized by significant limitations both in **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills.

**DSM 5 Criteria**

1. Deficits in **intellectual functioning**
   - Deficits affect reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience
   - Has to be confirmed by clinical assessment and individualized, standardized intelligence testing
   - Generally an IQ score of 70 or less indicates a limitation in intellectual functioning
   - Four levels of severity –
     - Mild (80%)
     - Moderate (15%)
     - Severe (4%)
     - Profound (1%)

# Intellectual Disability

**DSM 5 Criteria**

2. Deficits in **adaptive functioning**

- That results in failure to meet developmental and sociocultural standards for personal independence and social responsibility
- Without ongoing support the adaptive deficits limit functioning

- **adaptive behavior** includes three skill types:
  - Conceptual skills—language and literacy; money, time, and number concepts; and self-direction.
  - Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
  - Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

# Intellectual Disability

**DSM 5 Criteria**

3. Onset of intellectual and adaptive deficits during the developmental period

- Term Intellectual Disability = Intellectual Developmental Disorders (ICD-11)
- 2010 Federal Statute in United States (Public Law 111-256, Rosa's Law) replaces mental retardation with Intellectual Disability
  - Named for Rosa Marcellino, a young girl in Maryland with Down Syndrome

# ASD Characteristics – DSM 5

- **Social Communication/ Social Interaction**
  - Deficits in social-emotional reciprocity
    - Abnormal social approach, failure of normal back-and-forth conversation, reduced sharing of interests, emotions, or affect; failure to initiate or respond to social interactions
  - Deficits nonverbal communicative behaviors used for social integration
    - Limited eye contact and body language, deficits in understanding and use of gestures, decreased facial expressions and non-verbal communication
  - Deficits in developing, maintaining, and understanding relationships
    - Difficulty adjusting behavior to suit various social contexts, difficulty in sharing imaginative play or in making friends, absence of interest in peers

# ASD Characteristics – DSM 5

- **Repetitive/restrictive patterns of behavior, interest or activities**
  - Stereotyped or repetitive motor movements, use of objects or speech
    - Simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases
  - Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
    - extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day
  - Highly restricted, fixated interests that are abnormal in intensity or focus
    - Strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests
  - Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment
    - Apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement
- **Thinking/Learning**
  - Cognitive inflexibility
  - Focus on details/miss big picture
  - Difficulty integrating information

# Attention Deficit/Hyperactivity Disorder

**Present Prior to age 12; Present in two or more settings; Interferes with social, academic, occupational functioning**

- Hyperactivity and impulsivity
  - Fidgets
  - "on the go"
  - Runs/climbs in situations where it is inappropriate
  - Talks excessively
  - Difficulty waiting his/her turn
  - Interrupts or intrudes on others
- Inattention
  - Decreased attention to detail
  - Decreased sustained attention
  - Avoidance of difficult tasks
  - Difficulty organizing tasks and activities
  - Loses things, easily distracted, forgetful

# Attention Deficit/Hyperactivity Disorder

- Most frequently seen diagnosis in children who are referred for behavioral concerns
- Signs and symptoms mimic several other diagnosis
- Differing levels of severity depending on how the symptoms affect daily functioning
- Important to consider level of IDD and executive functioning deficits
- Consider impact of trauma and associated diagnosis:
  - Reactive Attachment Disorder
  - Disinhibited Social Engagement Disorder
  - Posttraumatic  Stress Disorder
  - Acute Stress Disorder
  - Adjustment Disorder

# Psychiatric Disorders

- Oppositional Defiant Disorder
- Conduct Disorder
- Intermittent Explosive Disorder
- Bipolar Disorder
- Disruptive Mood Dysregulation Disorder
- Obsessive-Compulsive Disorders
- Trauma and Stress-Related Disorders

# Oppositional Defiant Disorder

**Over 6 months duration; persistent pattern; exhibited with at least one person who is not a sibling**

- Angry/Irritable Mood
  - Often loses temper
  - Often touchy or easily annoyed
  - Often angry and resentful
- Argumentative/Defiant Behavior
  - Argues with authority figures
  - Defies requests or rules
  - Deliberately annoys others
  - Blames others for his/her mistakes
- Vindictiveness
  - Spiteful at least twice in 6 month period

# Conduct Disorder

## Persistent pattern; three criteria in past 12 months; causes significant impairment in functioning

- Aggression to people and animals
  - Bullies, intimidates others
  - Initiates physical fights
  - Physically cruel to animals;
  - physically cruel to animals
  - Has stolen from a person
- Destruction of property
  - Fire setting
  - Destroyed property
- Deceitfulness or Theft
  - Broken into house, building, care
  - Lies to obtain goods
  - Stolen
- Serious Violations of Rules
  - Stays out at night
  - Runs away
  - Truant from school

- Specify if limited prosocial behaviors: lack of remorse, lack of empathy, unconcerned about lack of performance, shallow affect.
- Specify severity: mild, moderate, severe

# Intermittent Explosive Disorder

**failure to control aggressive impulses; at least 6 years of age**

- Recurrent behavioral outbursts
  - Verbal aggression
  - Physical aggression
  - Three behavioral outbursts involving damage or physical injury within a 12-month period
- Behavior is out of proportion to stressor
- Not premeditated or intended to achieve a goal
- Outbursts cause distress

# Considerations for ODD, Conduct Disorder and Intermittent Explosive DO

- Developmental level (bio)
- Executive functioning (bio)
- Past trauma (psycho)
- Current environment (social)

# Bipolar

- Bipolar occurs when a person experiences episodes of depression and mania over a distinct period of time
- Individuals with IDD are 2-3 times more likely to be ***diagnosed*** with Bipolar Disorder than the general population
- Some genetic disorders may predispose individuals for Bipolar
  - Fragile X, Prader-Willi, Rubenstein-Taybi
- ***Rule outs*** – chronic sleep problems, agitated behaviors due to other factors
- **CAN NOT be diagnosed in children under 12 years**
- Manic symptoms may manifest in different ways for people with IDD
  - Irritable mood, labile affect, over-activity, and decreased sleep are core clinical features of mania in people with IDD
  - Cognitive symptoms of mania (i.e., inflated self-esteem or grandiosity) may be affected by the individual's developmental profile and delusions may be simplified
  - Pressured speech may appear as increased vocalization (rate or volume) or gesturing in individuals with limited expressive language
  - ***Sleep Data!*** Tracking sleep patterns (insomnia vs. hyper-somnia) very important

# Disruptive Mood Dysregulation Disorder

- Severe recurrent temper outbursts grossly out of proportion in intensity or duration to the situation or provocation
- Inconsistent with developmental level
- Persistently irritable and angry most of day
- No episodic mania or hypomania
- Tantrums >/= 3x per week
- >/= 12 months
- At least 2 of 3 settings
- NOT diagnosed before 6 or after 18 years
- Onset before 10 years

# DMDD

- Outbursts, expansive or elevated mood longer than few hours, more likely mania
- Diagnosed between 6 and 18
- Onset typically before 10

# Obsessive Compulsive Disorder

- **Obsessions** – involuntary and seemingly uncontrollable thoughts, images, impulses
- **Compulsions** include:
  - Behaviors or rituals one feels driven to act out again and again
  - Performed in an attempt to make obsessions go away
  - Relief is brief, obsessive thoughts usually come back stronger
  - The compulsive behaviors often cause anxiety themselves
- OCD is not uncommon with individuals with IDD
- Sometimes a person can have symptoms that look like OCD but are characteristics of other disorders such as ***Autism***

## Anxiety Disorder vs. Impulse Control Disorder

- Anxiety Disorders are often misdiagnosed as Impulse Control Disorder NOS
- Chances of misdiagnosis increase
  - The more significant the intellectual disability is
  - If the person has limited or no communication

# Trauma in IDD

- Trauma has an impact on the maturation of biological as well as psychological processes.
- Traumatic exposure disrupts the development of self-regulatory processes, leading to chronic affect dysregulation, destructive behavior toward self and others, learning disabilities, dissociative problems somatization, and distortions in concepts of self and others
- The brain responds differently after trauma – less executive functioning and more "fight or flight"

# Trauma in IDD

- Reviewing the issues related to trauma and developmental level suggests that people with ID might be more vulnerable than the general population to the disruptive effects of trauma
- Research indicates that the high level of self-injurious behavior among individuals with ID may be a function of exposure to trauma at lower developmental levels, regardless of chronological age
- Other symptoms which can appear to be the result of ID, might be the function of, or made worse, by traumatic exposure
  - Symptoms such as “acting out” rather than “think through” when distressed
  - Difficulty describing emotional states
  - Difficulty in understanding causality, including the role of one’s own behavior
  - Distorted self-concept

# PTSD

- Alarmingly, one of the most frequent diagnoses preceding an accurate diagnosis of PTSD in individuals with IDD is either *no diagnosis or schizophrenia*
- Children may be misdiagnosed as Conduct Disorder, ADHD, Disruptive Mood Dysregulation Disorder or Bipolar Disorder

# Trauma- and Stressor- Related Disorders (DSM-5)

- Reactive Attachment Disorder
- Disinhibited Social Engagement Disorder
- Posttraumatic Stress Disorder

# Reactive Attachment Disorder

- Inhibited, emotionally withdrawn behavior toward caregivers. Rarely seeks comfort or responds to comfort
- Social and emotional disturbance
    - Minimal responsiveness to others
    - Limited positive affect
    - Irritability, sadness, fearfulness in non-threatening interactions
- Child has experienced social neglect or deprivation, basic emotional needs were not met
- Physical or sexual abuse increase the risk of RAD
- For IDD, consider developmental level and social context. While RAD is higher in children with borderline/mild ID, most children with ID are securely attached even though they show atypical attachment behaviors

# Disinhibited Social Engagement Disorder

- Reduced or absent reticence in interacting with unfamiliar adults
- Overly familiar physical or verbal behavior
- Diminished 'checking back' with caregiver after venturing away
- Willingness to go off with an unfamiliar adult
- Has experience a pattern of insufficient care: neglect, deprivation, institutional settings, repeated changes in primary caregiver
- Neglect and emotional deprivation increase risk of DSED
- Indiscriminately going with strangers can be a sign of poor judgment associated with ID and not a sign of DSED. Individual must have a history of neglect or disordered attachment to make this diagnosis

# Post Traumatic Stress Disorder

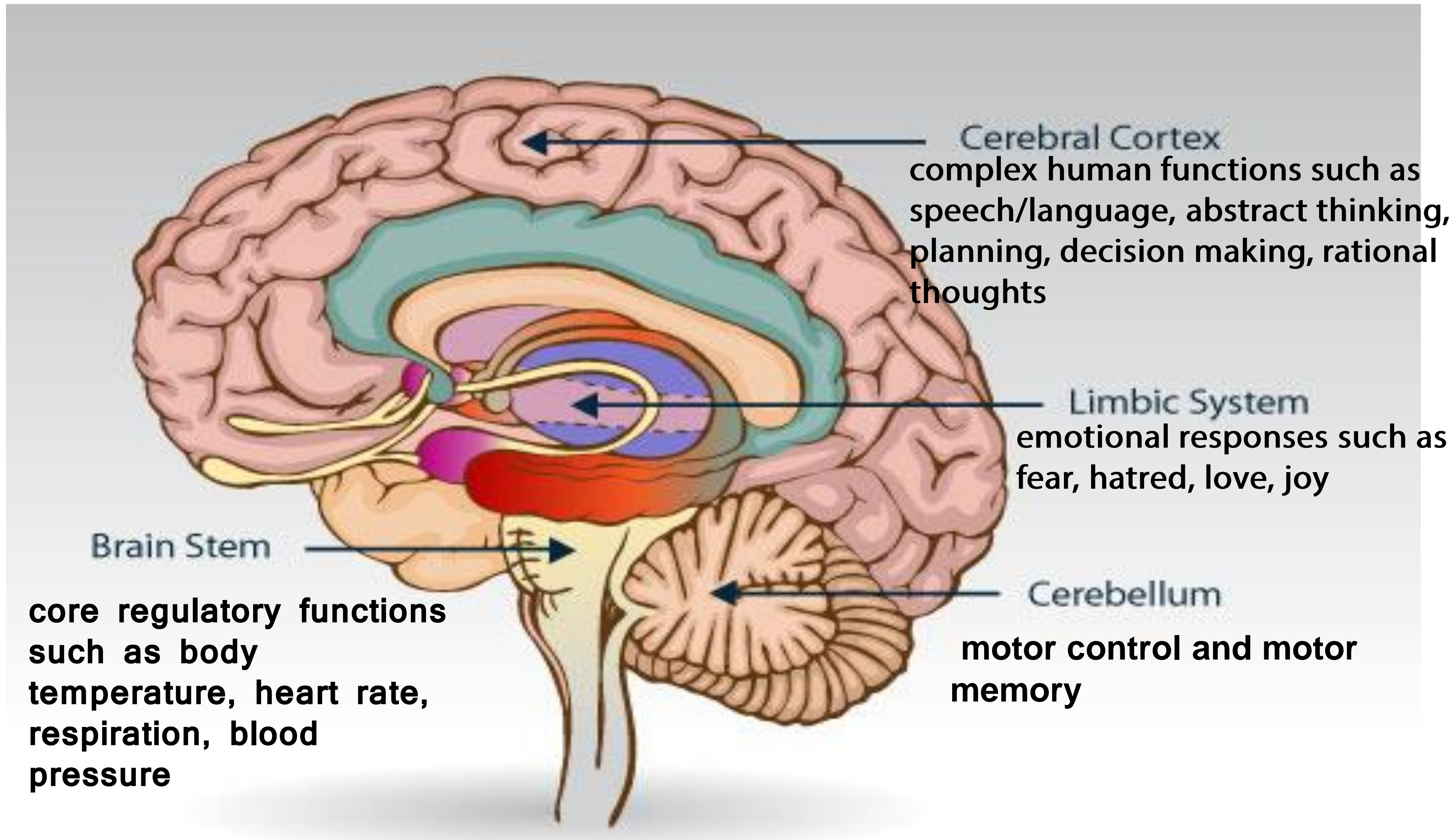
- Exposure to actual or threatened death, serious injury or sexual violation (experiencing, witnessing, learning about)
- Intrusive symptoms: memories, flashbacks, dreams, physiological symptoms. Reliving the experience
  - In IDD, re-experiencing the traumatic event may manifest in symptoms that are more overtly behavioral (concrete) and may include self-injurious behavior and trauma-specific re-enactments. Re-enactments can look quite bizarre and it is important to distinguish such symptoms from psychotic disorder symptoms

# Post Traumatic Stress Disorder

- Avoidance and emotional numbing
  - IDD, this can sometimes be seen or described as non-compliance
- Alteration in cognition and mood: negative beliefs about self or others, negative emotional state
  - In IDD, negative emotional state may present in externalizing behaviors
- Alterations in arousal: hypervigilance, irritable behavior, exaggerated startle response, aggression
  - In IDD, aggressive behavior is often described as 'coming out of nowhere'

# PTSD and IDD

- The diagnosis of PTSD in the population of IDD is complex
- Intellectual and communication deficits may interfere with the individual's capacity to give a coherent and reliable narrative disclosing trauma experience
- Thus, the burden typically falls upon others to recognize significant departures from baseline behavior which may signal traumatic response, particularly in individuals who are non-verbal or minimally verbal
- Common referral problems such as noncompliance, self-injury, aggression, outbursts of anger and irritability can be manifestations of PTSD
- An individual may be misdiagnosed when symptoms of extreme stress reaction are mistaken for "behavioral problems" or other psychiatric disorders


Cerebral Cortex
complex human functions such as speech/language, abstract thinking, planning, decision making, rational thoughts
Limbic System
emotional responses such as fear, hatred, love, joy
Brain Stem
core regulatory functions such as body temperature, heart rate, respiration, blood pressure
Cerebellum
motor control and motor memory

# Bruce Perry

- Persistent trauma leads to a "dysregulated" brain stem – which manifests with symptoms such as impaired cardiovascular regulation, extreme affective lability, and poor impulse control

- People who are aroused from fear cannot take in cognitive information. They are too busy watching for threatening gestures, and not able to listen to what is being said

# "The State Becomes a Trait"

- Rather than recognizing a fear-based brain state, or attempt to manage or prevent fear, a person may be diagnosed incorrectly with:
  - Obsessive compulsive disorder
  - Psychotic disorder
  - Bipolar disorder
  - Borderline personality disorder
  - Intermittent explosive disorder
  - Oppositional defiant disorder
  - Disruptive behavior disorder

# Commonalities

kindness adventurous
humor sensory loyalty
love executive
emotional
dysfunction
dysregulation

# What Does Not Help?

- Assuming behavior is an attempt to gain a specific outcome or manipulate
- Assuming the child has control over behavior in a crisis situation
- Oversimplified focus on contingencies
- Restriction or control (fuels feelings of powerlessness and may increase agitation)
- Expecting that re-exposure or discussing their trauma will decrease "outbursts"

# What Does Help?

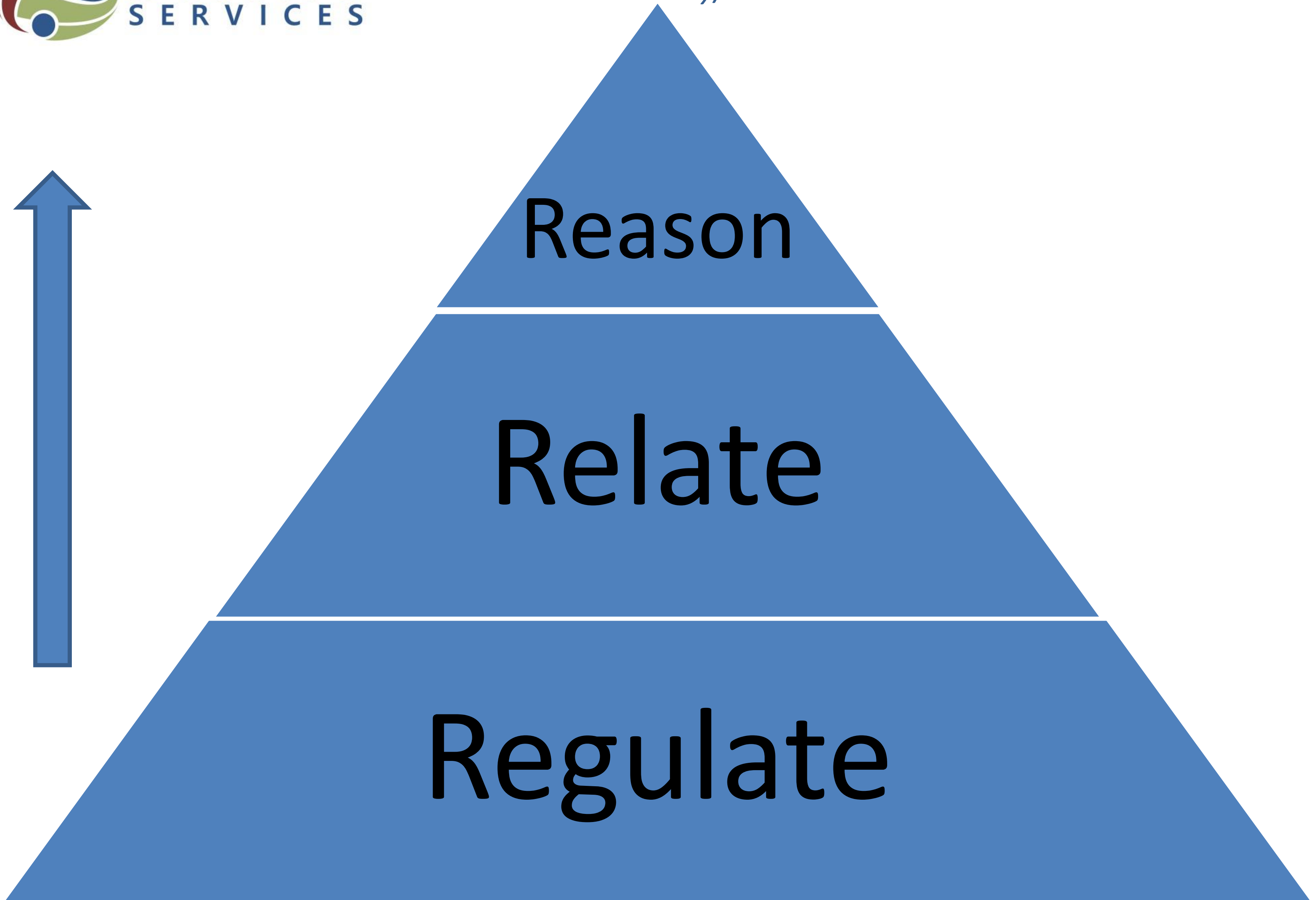
- Positive supports and positive psychology
- Focus on increasing happiness
  - Engagement and attachment
  - Developmentally appropriate expectation
  - Enhancing relationships
- Replacement skills
  - Functional communication
  - Ability to label feelings, calming skills
- Positive identity
  - Focus on strengths
  - Nurtures sense of identity vs. reducing people to their "behavior"

# Core Elements of Positive Therapeutic Experiences (6 R's)

- Relational: safe
- Relevant: developmentally appropriate
- Repetitive: patterned, predictable
- Rewarding: pleasurable and positive
- Rhythmic: resonant with neural patterns
- Respectful: of individual, family, culture

THE CENTER FOR START SERVICES

*University of New Hampshire*
*Institute on Disability/UCED*



- Present: reassuring, calm presence
- Parallel: being present without demands or requiring interaction
- Patient: waiting it out