Responding to Individuals with Developmental Disabilities

Southbury Volunteer Fire Department
October 29, 2023

DDS State of Connecticut
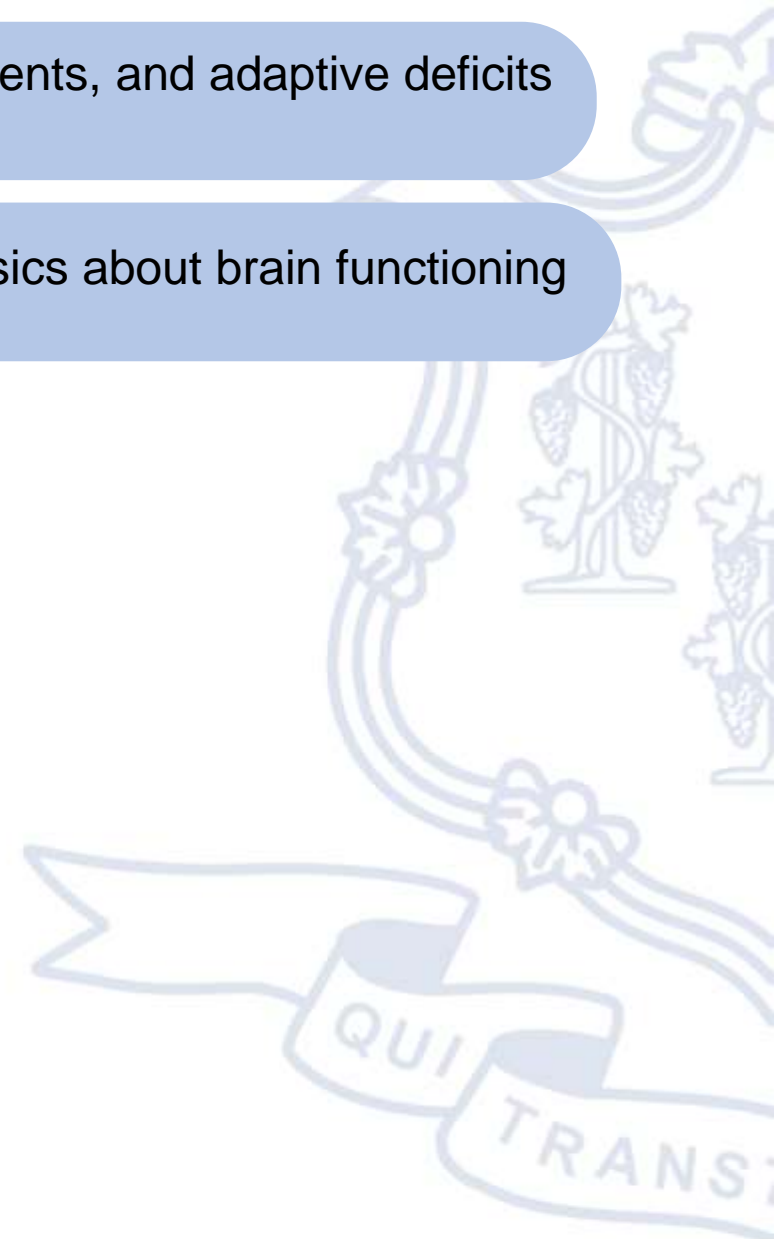Department of Developmental Services

Better understand neurodiversity, cognitive impairments, and adaptive deficits associated with developmental disabilities

Presentation Goals

Better understand neurodiversity, cognitive impairments, and adaptive deficits associated with developmental disabilities

Learn some basics about brain functioning

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Change the way behaviors are perceived

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Better understand neurodiversity, cognitive impairments, and adaptive deficits associated with developmental disabilities

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Understand the rudiments of autism spectrum disorder

Gain knowledge about positive behavior supports, particularly proactive interventions and reactive strategies

Change the way behaviors are perceived

Appreciate various communication tips and de-escalation techniques

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Neurotypicality

Refers to brain processing and behaviors that are considered standard.

Neurotypical people meet developmental milestones the same rate as those of a comparable age.

They go through life without having to wonder if their brains function in the same as others and usually never discuss the subject.

Neurodiversity

Umbrella term coined by Judy Singer, an Australian sociologist, in 1998. It recognizes how brains process information differently.

It means that an individual has cognitive strengths and weaknesses from those who develop typically.

It embraces differences and treats them neutrally, rather than something bad, wrong, or problematic.

It manifests on a continuum from mild signs that most people would not notice to much more pronounced and obvious presentations.

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The Broader Context

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Intellectual disability is the most common developmental disability

Genetic Syndrome

- Down syndrome

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- Down syndrome

Acquired forms

- Meningitis
- Encephalitis

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Neurocognitive Disorder
(i.e., loss of ability):

- Traumatic Brain Injury

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- Rett syndrome

Intellectual Developmental Disorder and Neurodiversity

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Prenatal
- Maternal disease,
- Environmental influences

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- Labor- and delivery-related

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- Epilepsy
- Social deprivation
- Toxicity

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I/DD has over 250 causes: 25% are syndromal and 75% are non-syndromal

Prenatal
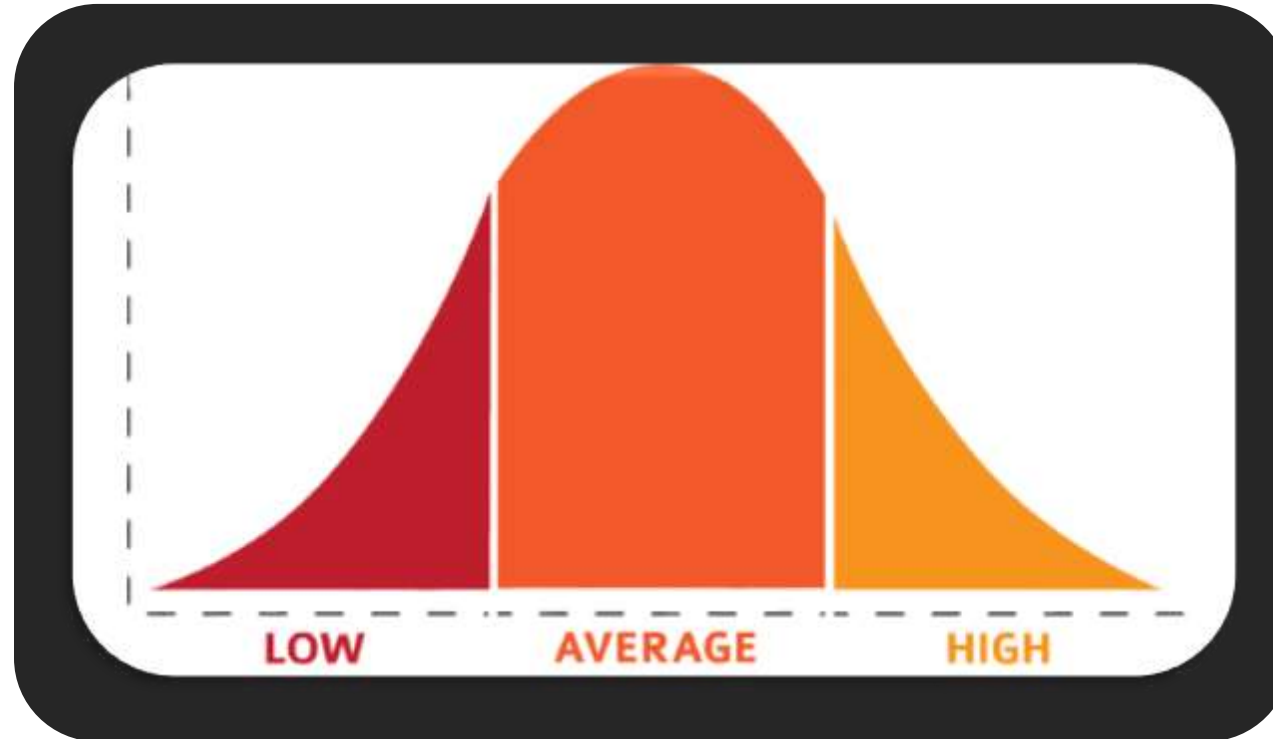- Maternal disease,
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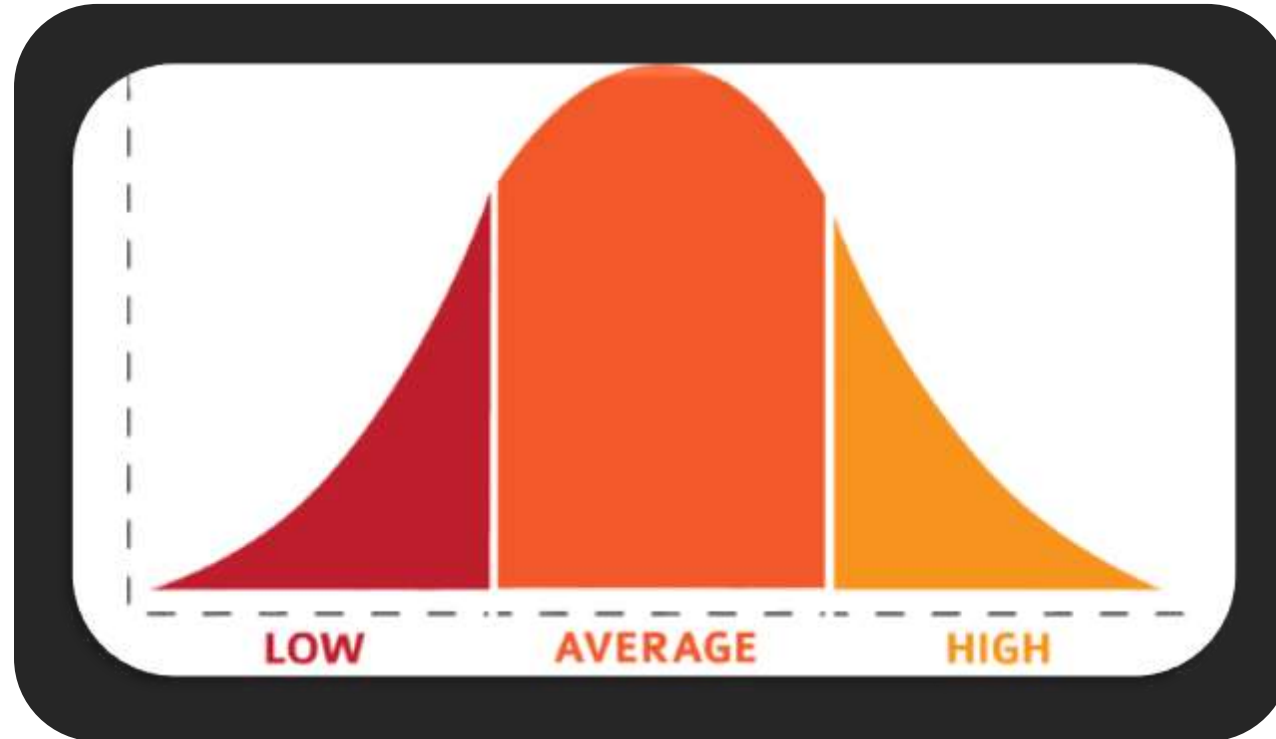- Labor- and delivery-related

Postnatal
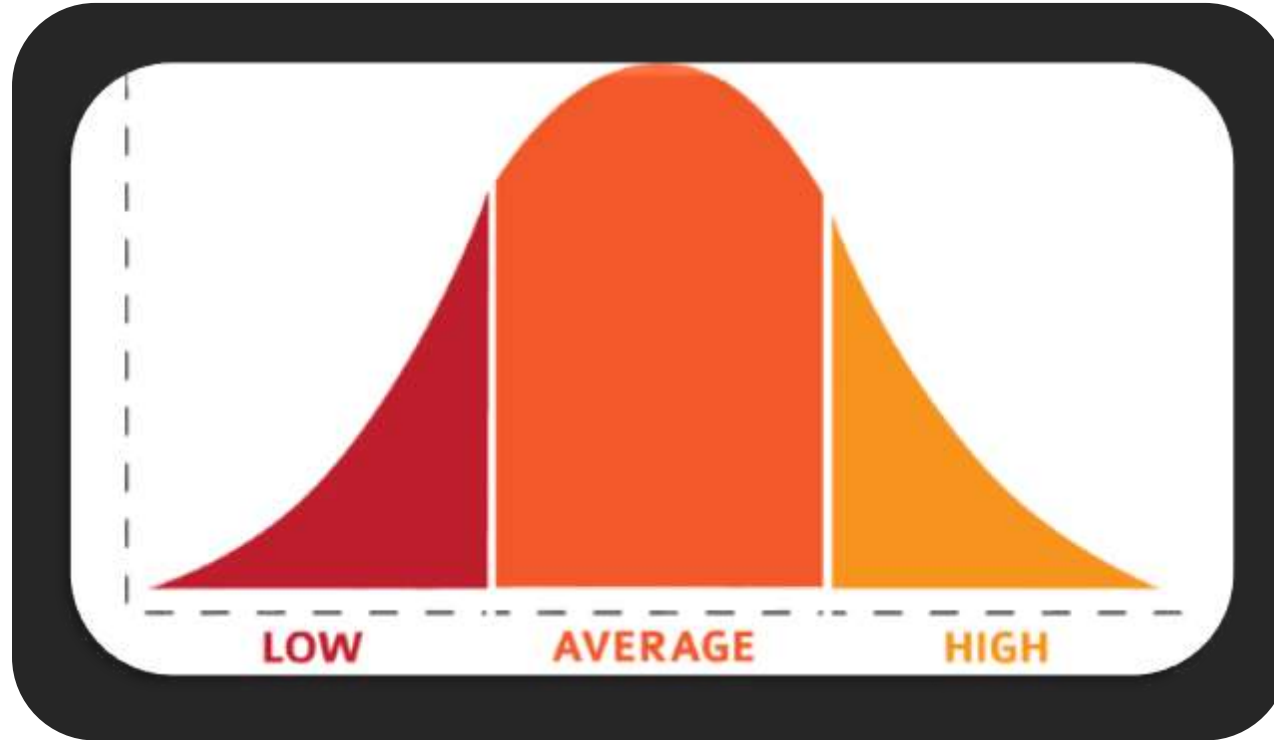- Epilepsy
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Understanding Intelligence

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Less intelligent than average

LOW   AVERAGE   HIGH

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Understanding Intelligence

Less intelligent than average ←

More intelligent than average →

LOW   AVERAGE   HIGH

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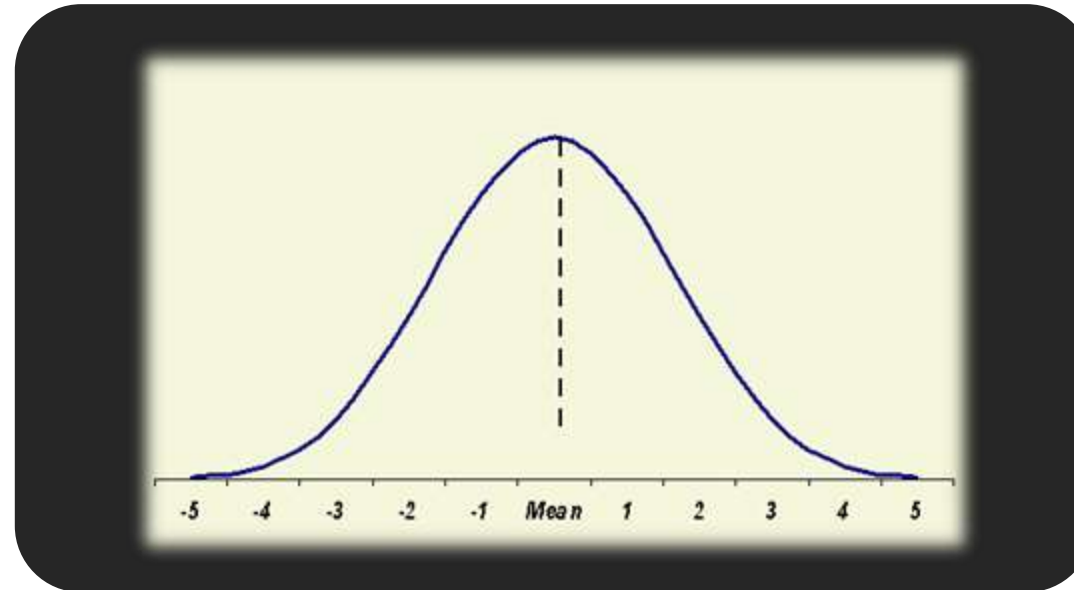# Understanding Intelligence

Less intelligent than average

More intelligent than average

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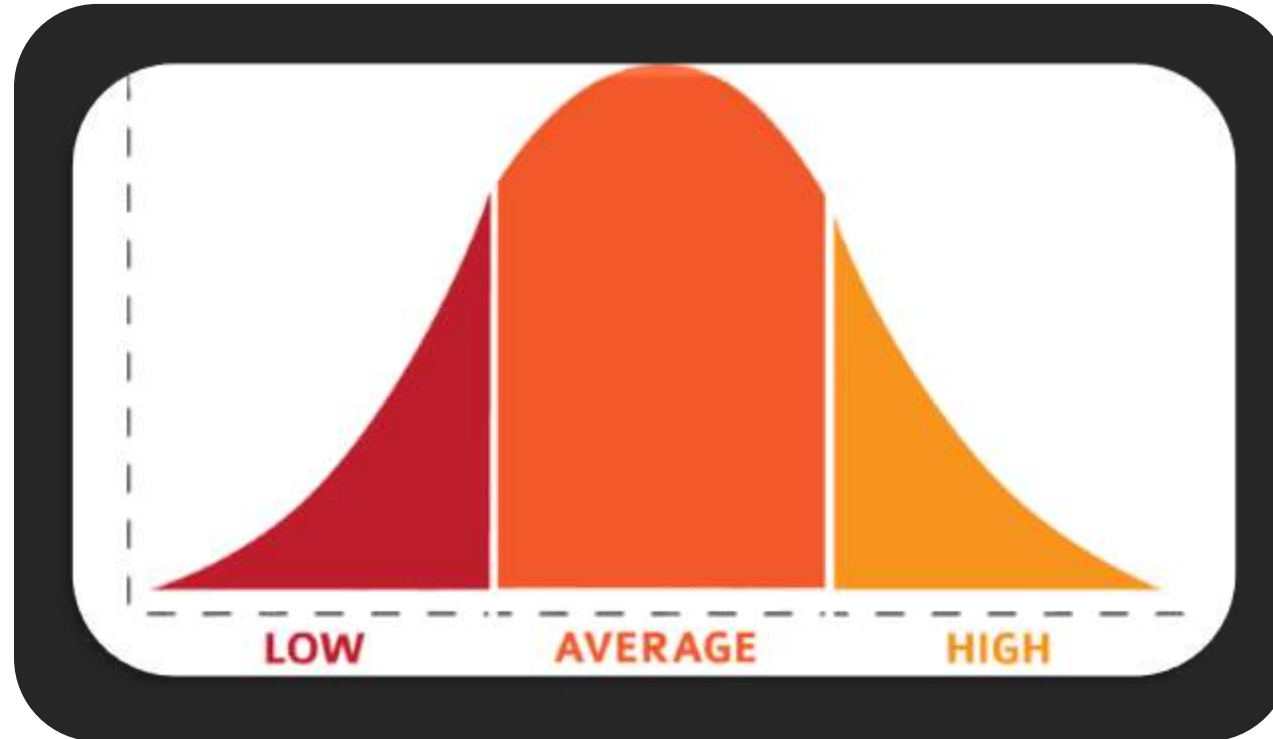
Average Full-Scale IQ is 100. 50% of adults fall between 90-100
I/DD percentile rank is two!

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Understanding Intellectual Disability

Three-part Intellectual Developmental Disorder diagnosis (formerly mental retardation). Differs from DDS eligibility!
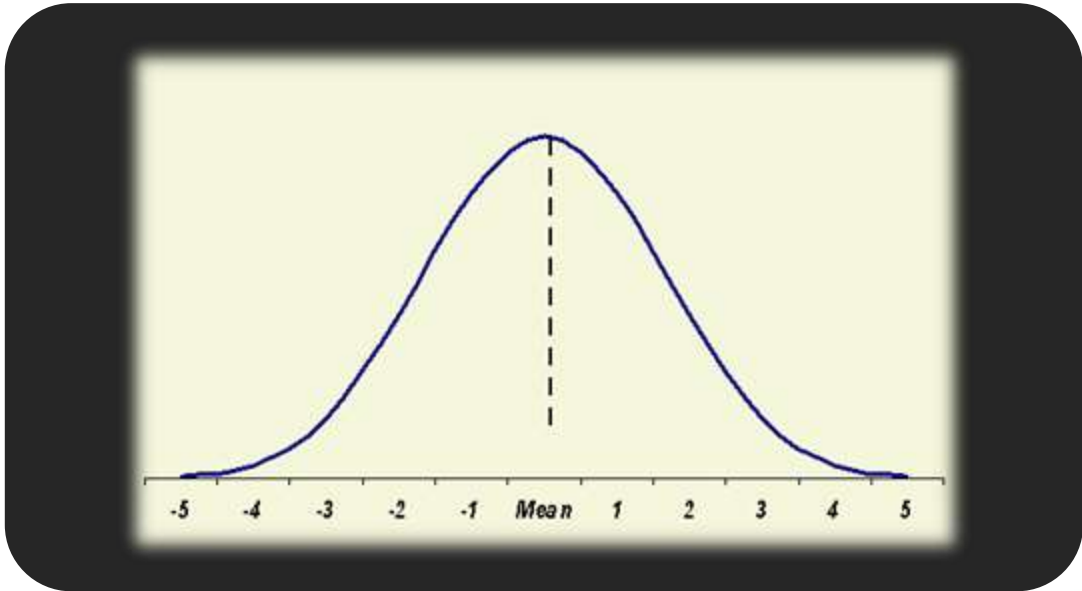
Intellectual impairment is an FSIQ = 70 +/- 5 points
Adaptive deficits
Evidence of onset between birth to 18 years old

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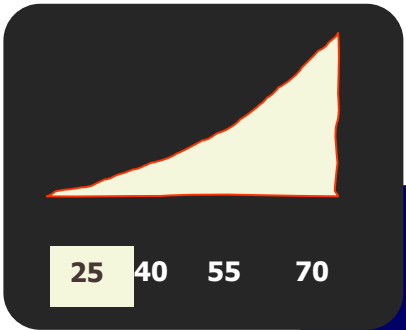Adaptive deficits
Evidence of onset between birth to 18 years old

Degrees of Intellectual Disability

- MILD
- MODERATE
- SEVERE
- PROFOUND

Degrees of Intellectual Disability

MILD

Has an IQ 50-70

MODERATE

SEVERE

PROFOUND

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Degrees of Intellectual Disability

MILD — Has an IQ 50-70

MODERATE — Has an IQ 35-49

SEVERE

PROFOUND

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Degrees of Intellectual Disability

Has an IQ 50-70 — MILD

Has an IQ 35-49 — MODERATE

Has an IQ 20-34 — SEVERE

PROFOUND

Degrees of Intellectual Disability

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Has an IQ Less than 20 — PROFOUND

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Degrees of Intellectual Disability

Has an IQ 50-70   MILD

Has an IQ 35-49   MODERATE

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Has an IQ Less than 20   PROFOUND

Degrees of Severity
- Mild 85%
- Moderate 10%
- Severe 3%
- Profound 2%

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Intellectual disability classifications and the support that person will require:

Has an IQ 50-70 — **MILD**

Has an IQ 35-49 — **MODERATE**

Has an IQ 20-34 — **SEVERE**

Has an IQ Less than 20 — **PROFOUND**

MILD

MODERATE

SEVERE

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Has an IQ 50-70	MILD
Has an IQ 35-49	MODERATE
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MILD

85% Intermittent Support
Individuals require little intervention to function. They may need support during times of distress.

MODERATE

SEVERE

PROFOUND

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Individuals can learn skills but may require additional support to navigate through everyday situations.

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SEVERE — **3% Extensive Support** Individuals may have some communication and self-help skills, but mainly rely on daily support to function around the clock.

PROFOUND

Intellectual disability classifications and the support that person will require:

Classification	IQ Range
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Has an IQ 35-49	MODERATE
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Has an IQ Less than 20	PROFOUND

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Individuals can learn skills but may require additional support to navigate through everyday situations.

SEVERE
3% Extensive Support
Individuals may have some communication and self-help skills, but mainly rely on daily support to function around the clock.

PROFOUND
2% Pervasive Support
Individuals require extensive and lifelong support in nearly every aspect of their routine

Intellectual Functioning Indexes

Verbal Comprehension Index:

- General knowledge and reasoning skills. Related to formal and informal education.
- Language is central our ability to label, organize and manage our internal experiences and the external environment.
- Difficulty putting feelings and needs into words hinders adaptation.

Perceptual Organization Index:

- Visual-spatial skills.
- Ability to create novel solutions

Working Memory Index

- In-the-moment reasoning
- Important to learning, flexibility, planning, and self-awareness.
- Related to coping (e.g., seeing options to manage anger)

Processing Speed Index:

- Ability to work quickly and efficiently.
- Sensitive to motivation and persistence.
- May negatively affect overall cognitive functioning.

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Adaptive Functioning

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Adaptive Functioning

Intellectual impairment is often problems with delaying gratification, controlling impulses, and tolerating frustration.

The best approach is focusing on cognitive strengths and minimizing weaknesses. For example, providing information using pictures, rather than words, to someone with visual-spatial strengths and verbal limitations.

Adaptive Functioning

- Adaptation is based on performance in daily activities. How effectively people cope with common life demands across multiple settings.
- Understanding functioning through a "developmental lens" with age-equivalents.
- Domains of Practical, Conceptual, and Social skills.
- Specific areas may include the following:
  - Self-care (e.g., hygiene and grooming)
  - Expressive and Receptive Communication
  - Social and Community Activities
  - Independent living skills (e.g., housekeeping)
  - Health and safety
  - Vocational abilities

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What does it mean to be diagnosed with intellectual disability?

What does it mean to be diagnosed with intellectual disability?

Interpret and interact with the world differently

Intellectual Developmental Disorder and Neurodiversity

The possibility of a co-occurring mental or physical condition in the context of intellectual disability is three-to-four times higher than the general population.

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Conditions that are dispositional
to intellectual disability:

Intellectual Developmental Disorder and Neurodiversity

Autism Spectrum Features

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Communication disorders

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Conditions that are dispositional
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Autism Spectrum Features

Motor and sensory integration issues

Communication disorders

Intellectual Developmental Disorder and Neurodiversity

Conditions that are dispositional to intellectual disability:

- Autism Spectrum Features
- Communication disorders
- Motor and sensory integration issues
- Mood dysregulation

Intellectual Developmental Disorder and Neurodiversity

Autism Spectrum Features

Conditions that are dispositional to intellectual disability:

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Communication disorders

Mood dysregulation

Sleep disturbances

Intellectual Developmental Disorder and Neurodiversity

Autism Spectrum Features

Conditions that are dispositional to intellectual disability:

Motor and sensory integration issues

Sleep disturbances

Communication disorders

Mood dysregulation

Attention deficit / hyperactivity traits

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Intellectual Developmental Disorder and Neurodiversity

Conditions that are dispositional to intellectual disability:

Autism Spectrum Features

Motor and sensory integration issues
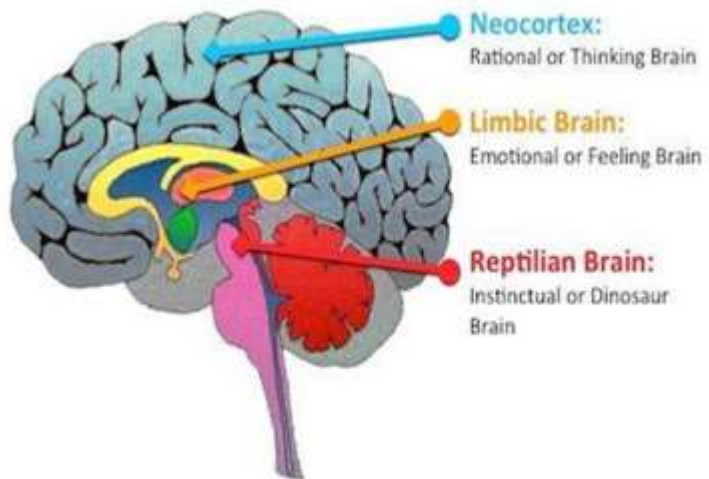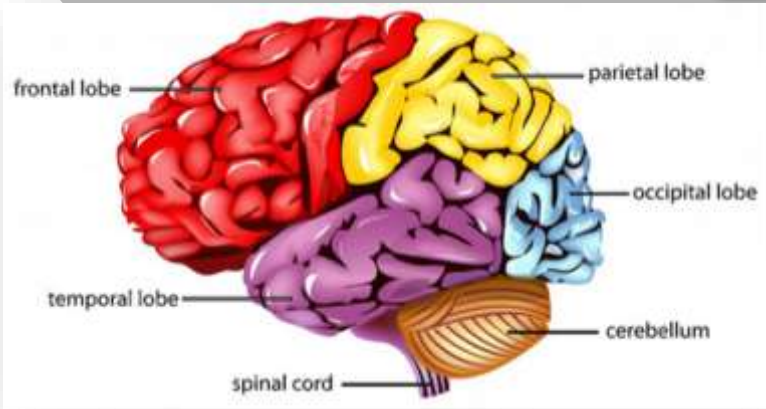
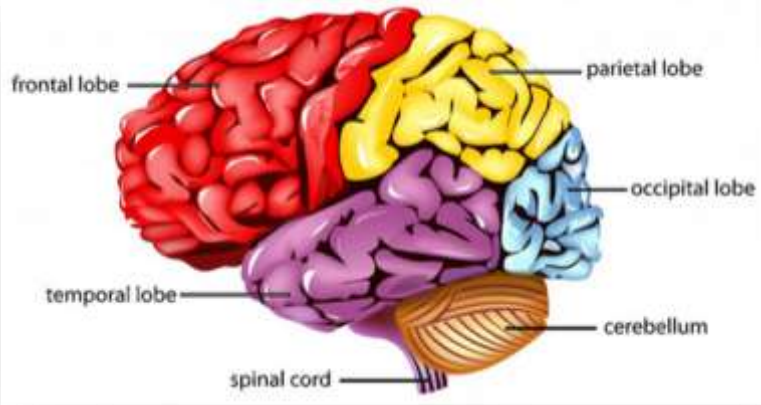Communication disorders

Mood dysregulation

Sleep disturbances

Impulse control problems

Attention deficit / hyperactivity traits

Regions of the Brain

frontal lobe
parietal lobe
occipital lobe
temporal lobe
cerebellum
spinal cord

Neocortex: Rational or Thinking Brain

Limbic Brain: Emotional or Feeling Brain

Reptilian Brain: Instinctual or Dinosaur Brain

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Regions of the Brain

The brain has **three** main parts:

- **Brainstem** that controls vital physical functions and survival responses.

- **Limbic system** that governs emotions (i.e., amygdala for fight, flight, and freeze reactions and the hippocampus for memory).

- **Cortex and Front Lobes** for executive functions: These include a sense of time, planning, thinking flexibly, decision-making, inhibiting and initiating action, self-monitoring, and empathic understanding.
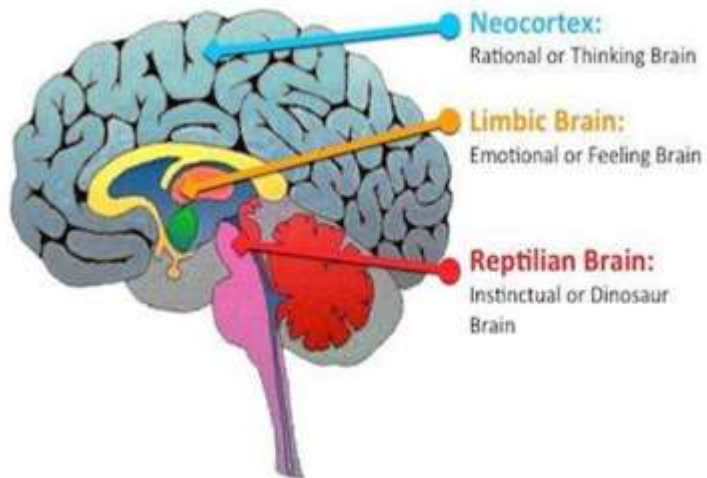
Autism Spectrum Statistics

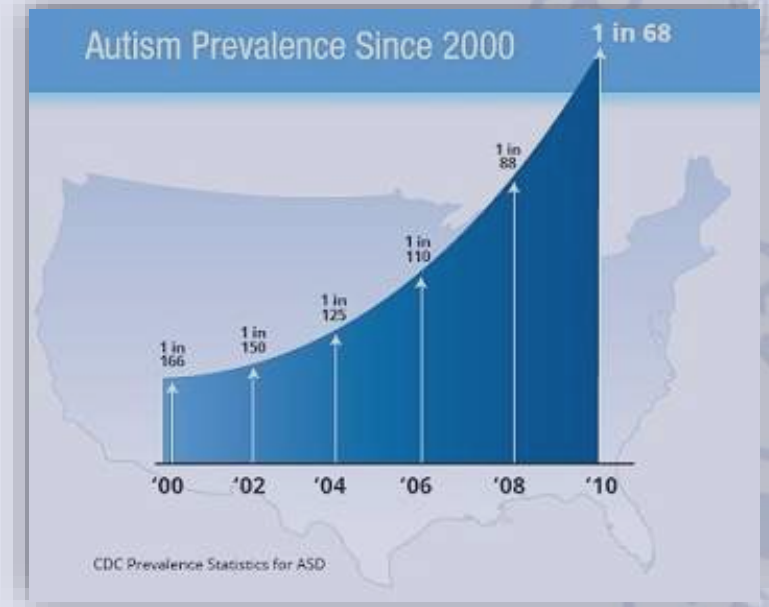2023 incidence is 1 in 36 births. About 4:1 male-to-female

A Steady Increase in Prevalence by Birth Year:
1992- 1 in 150
2000- 1 in 88
2014 it was 1 in 42 boys; 1 in 189 girls

Found across all cultures and
socioeconomic groups.

Autism Prevalence Since 2000

CDC Prevalence Statistics for ASD

Why is Autism increasing?

- Previous underestimates

- Broadening diagnostic categories

- Better tools for identification

- Greater awareness among mental health providers, pediatricians, schools, media, and parents

AUTISM

The Heterogenous Autism Spectrum

❖ It's called a spectrum condition because of its extreme complexity.

❖ Functional capabilities and needs vary widely from person-to-person. For example, some can access language, transition in the daily routine, and perform self-care, others may require assistance.

❖ Some may use rocking, flapping, spinning, etc. for self-regulation.

❖ They may easily become overwhelmed in a crisis and engage in challenging behaviors that might be misinterpreted as disrespectful. These might include invading personal space, giggling, speaking loudly, talking about unrelated topics.

❖ Some may not feel or express physical pain (sensory integration dysfunction)

❖ Some may process information better when avoiding eye contact and may look like they don't want to pay attention.

Autism Spectrum Disorders

Autistic Disorder

Asperger's Disorder

Childhood Disintegrative Disorder

Rett's Disorder

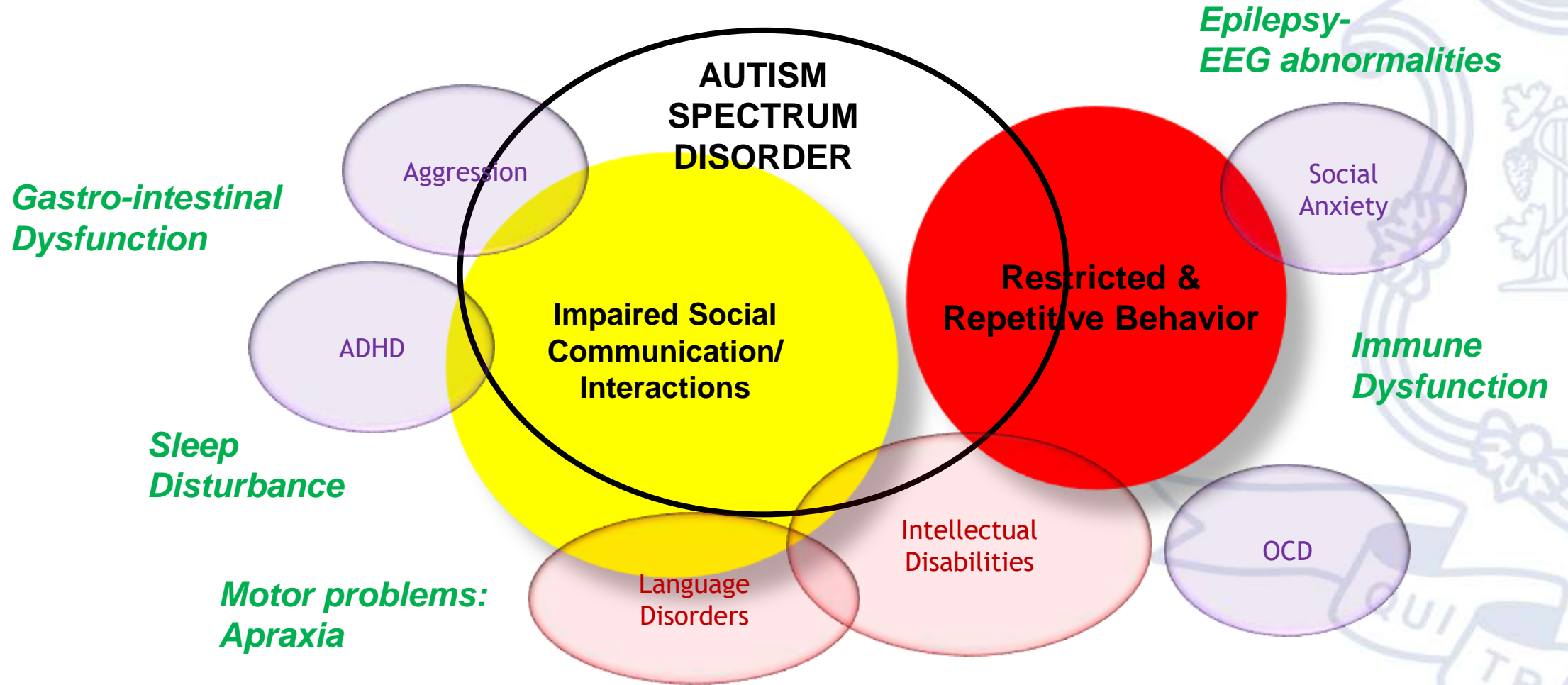Pervasive Developmental Disorder - Not Otherwise Specified

Autism Spectrum Disorder -2013

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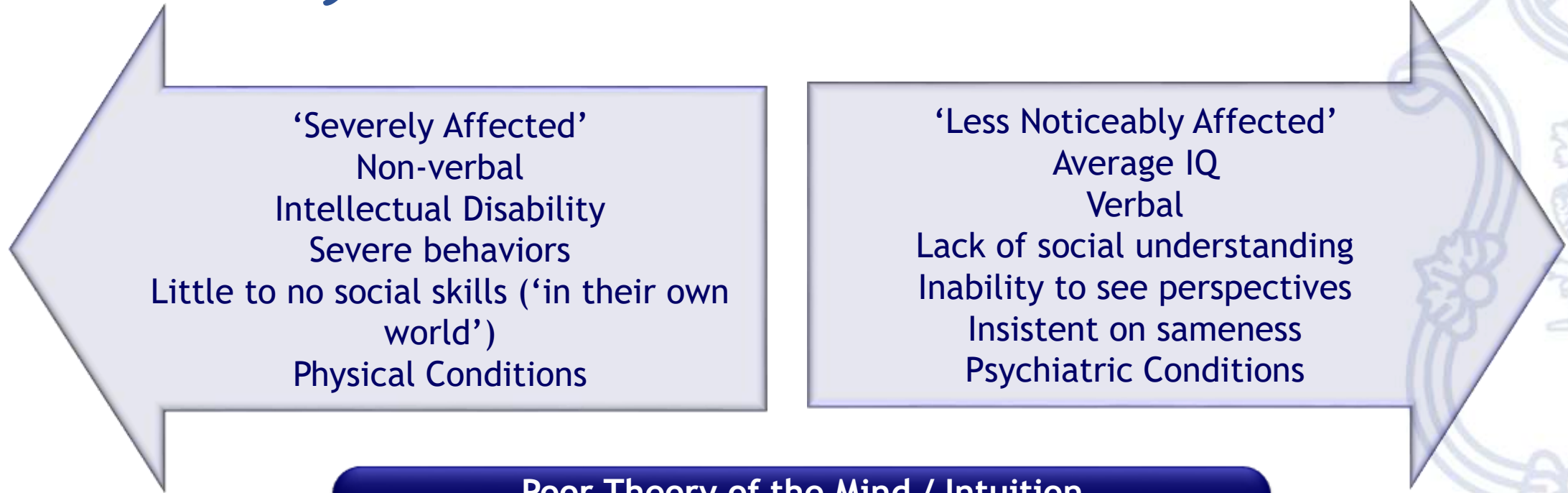# Core Autism Domains with Associated Conditions

Understanding the Autism Spectrum
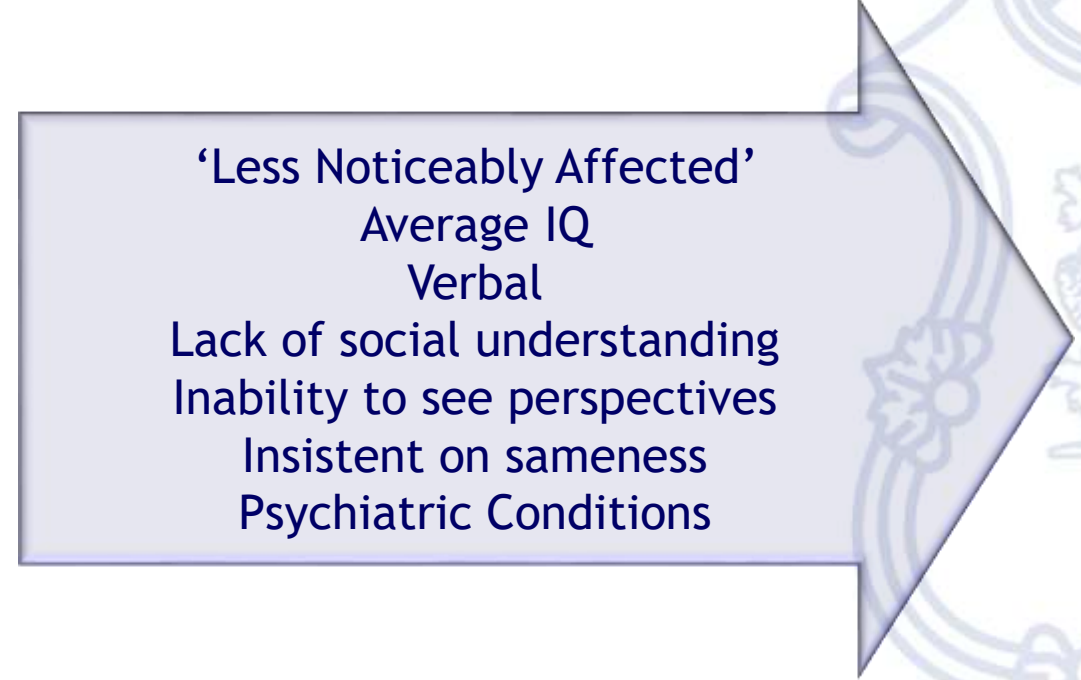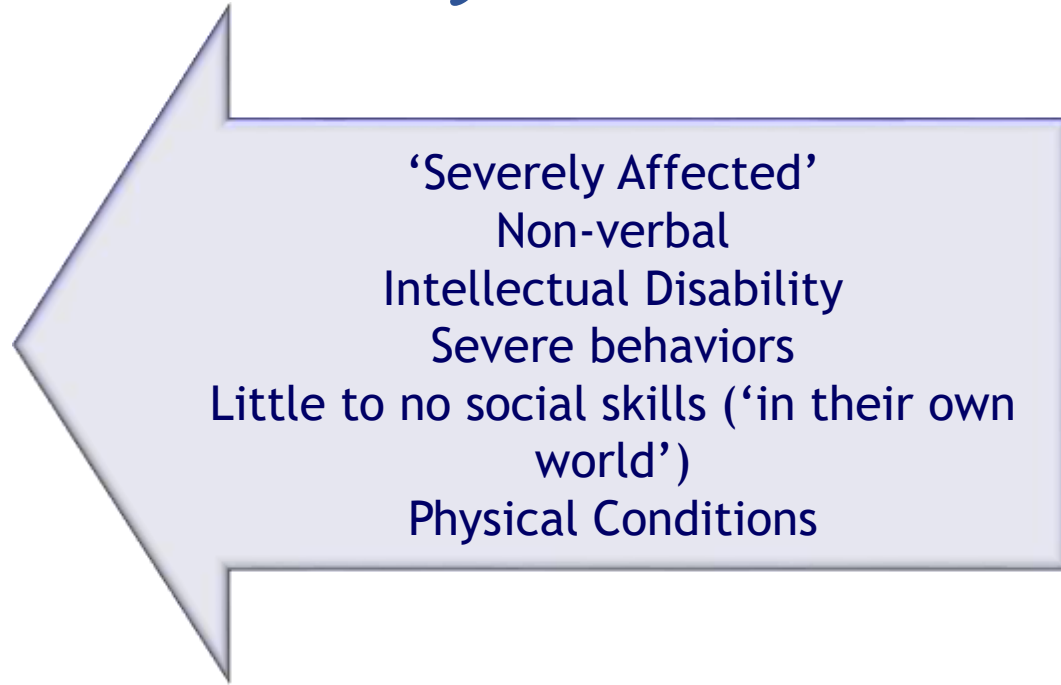
'Severely Affected'
Non-verbal
Intellectual Disability
Severe behaviors
Little to no social skills ('in their own world')
Physical Conditions

'Less Noticeably Affected'
Average IQ
Verbal
Lack of social understanding
Inability to see perspectives
Insistent on sameness
Psychiatric Conditions

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Poor Theory of the Mind / Intuition
- Misinterpreting body language and subtle social cues
- Problems with reciprocation and understanding expectations

Positive Behavior Supports

A comprehensive approach that views behaviors as goal-directed and interconnected with an individual's psychology, physiology, emotions, situation, and culture.

Contemporary Definition of PBS is an Integration:

1. Person-Centered practice and

<u>With</u> normalization/inclusion

2. Best practices for behavior change

Positive Behavior Supports

Contemporary Definition of PBS is an Integration:

1. Person-Centered practice and
   With normalization/inclusion
2. Best practices for behavior change

Positive Behavior Support

- It's individual and family-centered, rather than expert driven.
- Support (encouraging and strengthening) for positive behavior (desirable and prosocial), not stigmatizing and humiliating interventions.

Positive Behavior Supports

Setting Events and Vulnerabilities
- Situations in the environment combined with an individual's deficits

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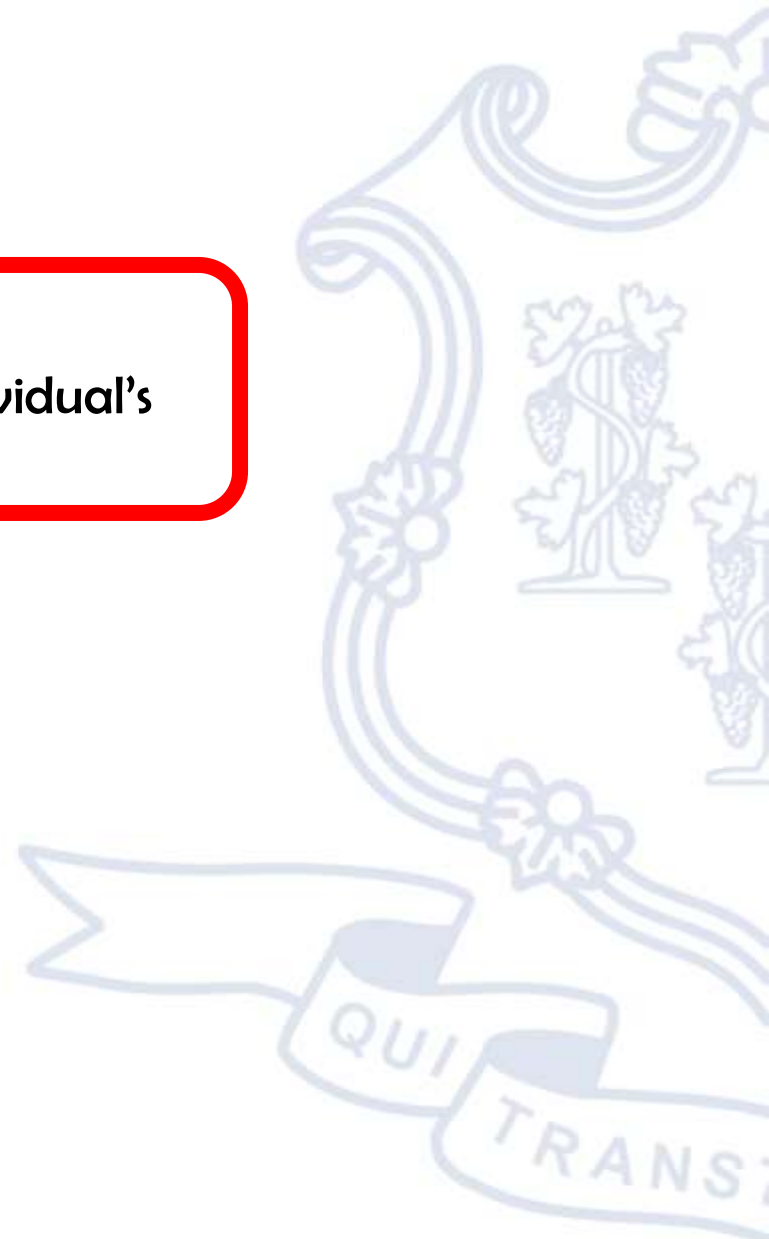
Setting Events and Vulnerabilities
- Situations in the environment combined with an individual's deficits

Antecedents (or Triggers)
- What occurred immediately before the behavior?
- Fast versus slow; Internal vs. external

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Precursors
- What noticeable actions in body language came before the behavior of concern? (e.g., pacing, pressured speech, clinching fists)

Precursors
- What noticeable actions in body language came before the behavior of concern? (e.g., pacing, pressured speech, clinching fists)

Maintaining Consequences
- What occurred immediately after the behavior of concern?
- How did the caregivers respond? Is there inadvertent reinforcement?

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Targeted Positive Behaviors
To achieve, instill, increase, and maintain
Categories: Increase emotional regulation, independence, and socialization

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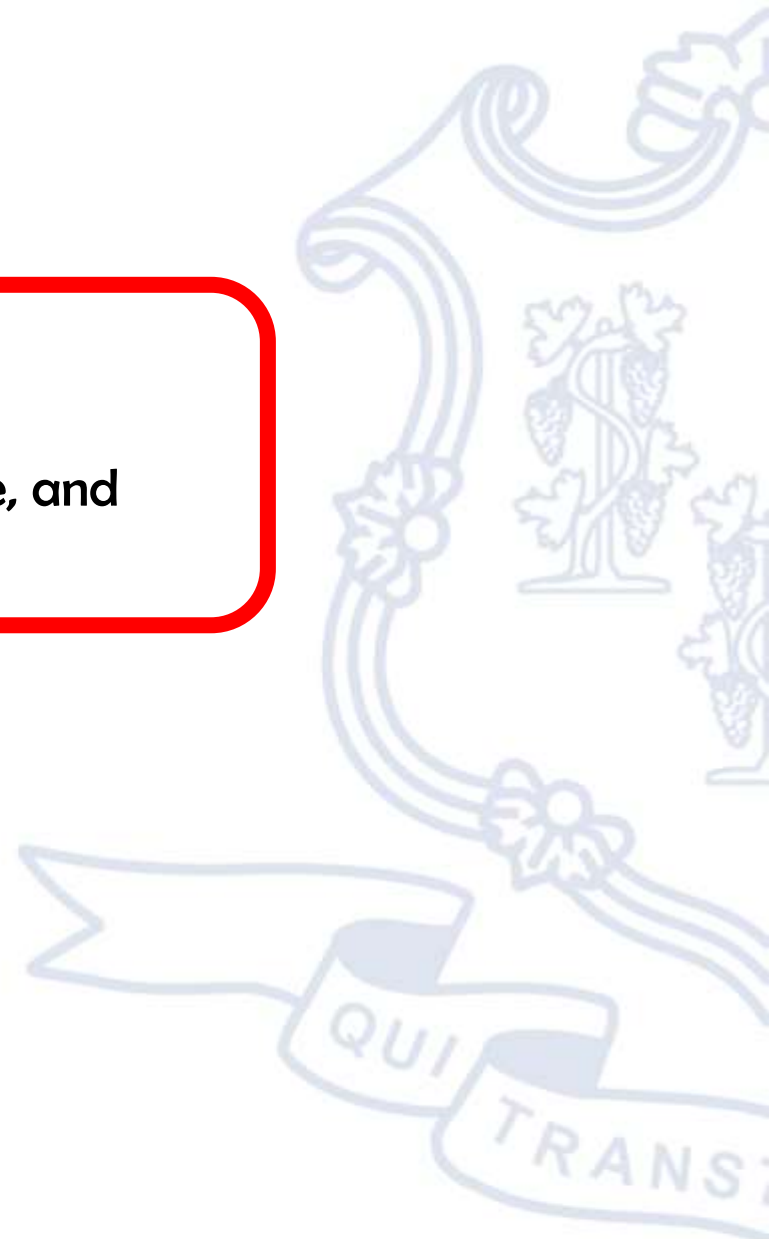
Targeted Positive Behaviors
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Behaviors of Concern
- To decrease or eliminate.
- These include verbal outbursts, physical aggression, property destruction, poor boundaries, and refusals.

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Every behavior serves a function or purpose! These include Communication, Regulation of Emotions or Pain, and Social/environmental Control

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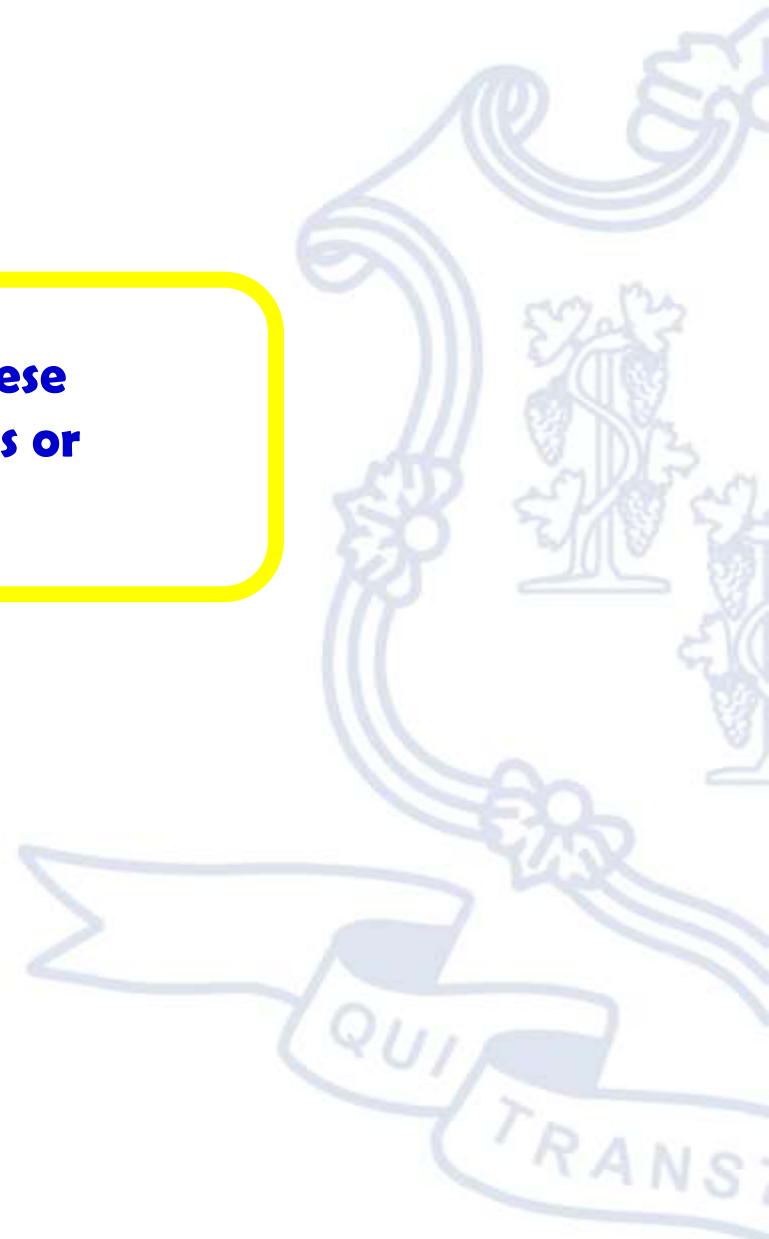
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Overarching goal of PBS is building positive behaviors to meet wants and needs, so that the negative behaviors become unnecessary!

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Where to intervene in the Crisis Cycle

Positive Behavior Support

Benefits of Proactive over Reactive

Proactive

Reactive

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Benefits of Proactive over Reactive

Proactive

Interventions to prevent problem behavior

Reactive

Positive Behavior Support 👍

Benefits of Proactive over Reactive

Proactive

Limited focus on antecedent interventions

Reactive

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Positive Behavior Support 👍

Benefits of Proactive over Reactive

Proactive

Emphasis on teaching alternative behaviors

Reactive

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Benefits of Proactive over Reactive

Proactive

Reactive

Little focus on teaching new behavior

Benefits of Proactive over Reactive

Proactive

Reactive

Positive reinforcement of desired behaviors

Benefits of Proactive over Reactive

Proactive

Reactive

Punitive response to negative behavior
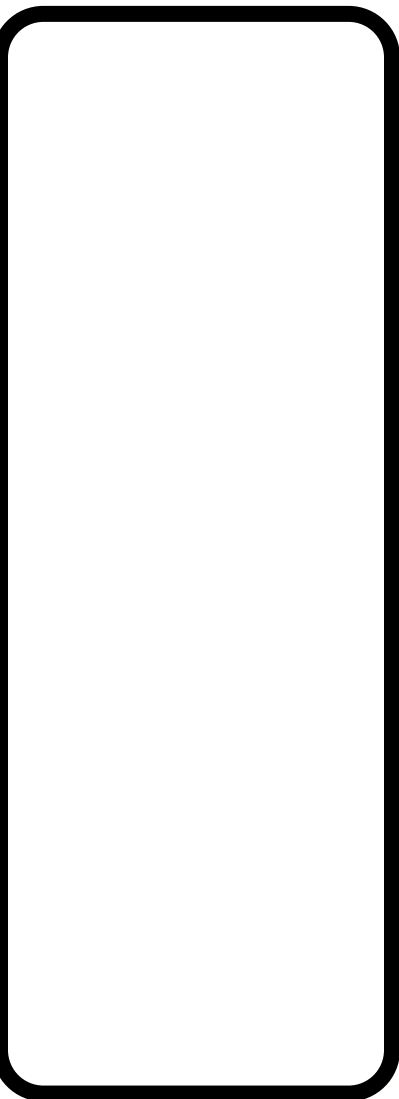
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Directions given and reviewed at regularly.

Be very specific and easily convey the expected behavior.

Tell the person what you want them to do, rather than what you don't.
Use Affirmative Language

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Tell the person what you want them to do, rather than what you don't.
Use Affirmative Language

"Use an 'inside' voice," instead of "Stop talking so loudly"

"Keep your hands down," rather than "Don't hit"

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Learning and memory problems interfere with understanding and remembering what constitutes "appropriate" behavior.

Watch for engrams (a mechanism of memory in response to external stimuli). These "hot spots" that get activated in the brain causing people to only hear the triggering part of a message!

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- Caregivers' actions after a behavior of concern occurs.
- Ideally, for limited use about 5 to 10% of the time.
- Used to help situations from escalating. For example, using distractions, redirecting from triggers, or establishing control when there is harm to self or others.
- Reactive interventions often ineffective, as we may drop up to 25 IQ points when upset.

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👍 Problems with Adverse Consequences

Different than natural and logical consequences.
It may include the following:
Ignoring (spontaneous and planned
Taking away rights and privileges
Forcing apologies
Threatening restraint or seclusion

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When minor coercion that was once effective ceases to work, those inclined to use it tend to increase their level of coercion, rather than decrease it.

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Choices

When possible, offer a few choices to provide the person with a sense of control. *These choices should all lead to a similar outcome (e.g., de-escalation).*

Applying Behavioral Strategies in the Field

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Premack Principle
First, after, or when/then.
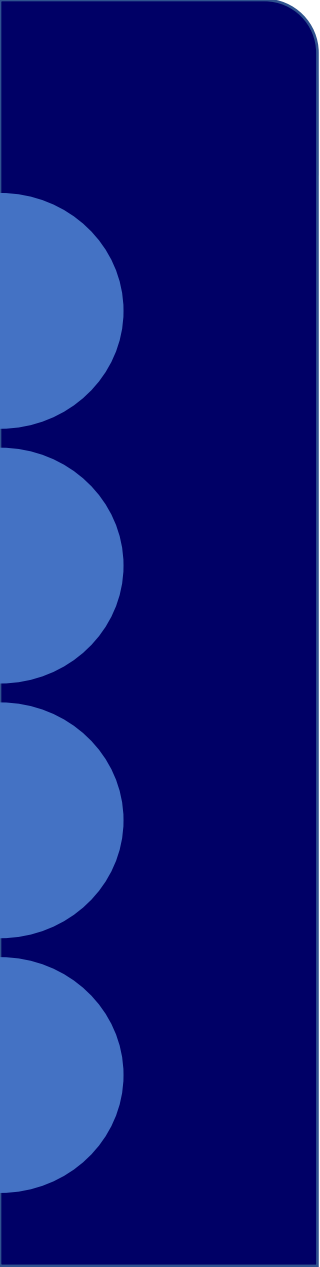
Communication Tips in the Field

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- Speak clearly, calmly, and softly
- Show interest and concern
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- It's okay to rephrase questions or restate directives
- Watch for words that are "triggering" which may exacerbate agitation, such as "If/then" statements, as the person might not think contingencies are achievable

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Communication Tips in the Field

- Ask the person to repeat back information to check for understanding.
- Try alternative ways to communicate (non-speech) methods, such as drawings, pictures, cues, gestures, signs, or an I-Pad.

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- Always speak respectfully in the person's presence. Use "person-first" language (e.g., An individual with disability).
- Share what you learn about the person with others who will be assisting.

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Communication Tips in the Field

The Power of Acknowledging Perspectives

- Active listening by being attuned
- Accurate reflection
- **Sufficient validation** only means acknowledgement. Not necessarily acceptance and agreement
- Validate before redirection or feedback
- Remember any contextual factors (e.g. holidays)

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Communication Challenges

- Some people with disabilities can understand even if they can not express themselves (expressive language disorder).
- On the contrary, some who speak may not understand or may say things out of context (receptive language disorder).
- It's okay to ask the person to repeat themselves or to demonstrate (contextual grounding) something for you.

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A person might not be aware of their own deficits!

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- Avoid correcting behaviors. Give directives for positive behavior instead.

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A delayed or absent response to your questions or commands may not necessarily reflect a willful lack of cooperation.

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Interaction Tips / De-escalation Strategies

- Try to coach calmness without physical intervention when possible

- Strive for three practical goals: **Safety, Connection, and Empowerment**

- Ask the person or the responsible party how you can best assist. "What has helped in the past in situations like this?" "Do they have a crisis plan?"

- Look for sensory aids and soothing items if they don't jeopardize safety.

- Tell them honestly what is likely to happen using everyday language.

- Show the person what you want them to do, if possible, rather than just stating it.

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- Avoid sudden and unpredictable movements.

- Avoid stopping their repetitive behaviors unless there is a risk of injury, as it they might be a means of self-regulating.

- Ignore self-talk that the person uses for coping unless it interferes in emergency procedures. This may sometimes include profanity or verbal threatening behaviors.

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Thank you for your attendance
and participation!