Responding to Individuals with Developmental Disabilities

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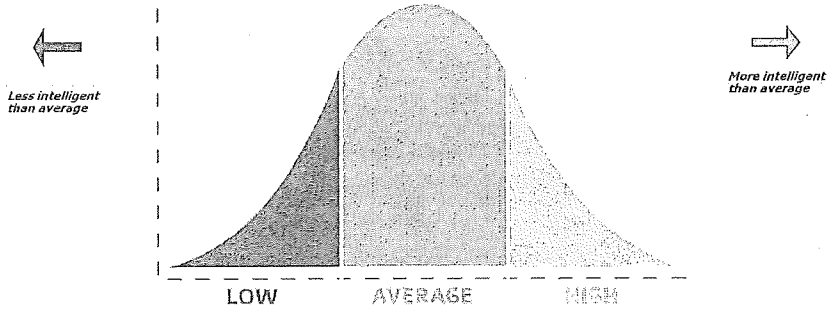
Goals of the Presentation

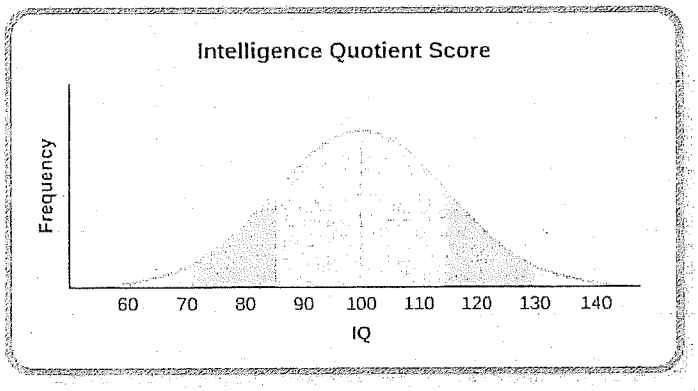
- Better identify the cognitive and adaptive deficits that are associated with developmental disabilities
- Learn about the functioning of focal regions in the brain
- Understand the basics about autism spectrum disorder
- Change the way in which behaviors are perceived
- Appreciate that all behaviors serve a function
- Increase knowledge about proactive and reactive strategies

Understanding Intellectual Disability



I/DD are noted to have over 250 causes:

- *25% are syndromal (e.g., Down, Fetal Alcohol, Rhett, Fragile X, Cornelia de Lange)*
- *75% are non-syndromal (e.g., problems during the birth process).*



Intellectual Developmental Disorder *(formerly mental retardation) has a three part definition. (1) an IQ score of 70 or below (standard error of measurement +/- 5 points) with (2) concurrent deficits in adaptive functioning, and (3) that had an onset during the developmental period from birth to 18 years old.*

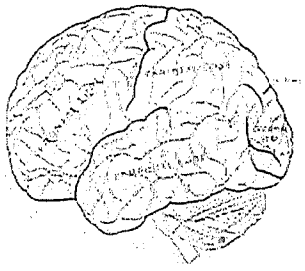
Degrees of intellectual disability

- MILD intellectual disability
  - has an IQ 50-70
- MODERATE intellectual disability
  - has an IQ 35-49
- SEVERE intellectual disability
  - has an IQ 20-34
- PROFOUND intellectual disability
  - has an IQ less than 20

Degrees of Severity

- Mild 85%
- Moderate 10%
- Severe 3%
- Profound 2%

Brain Regions



The brain has three main parts:

- Frontal lobes for higher-order thinking and executive functions: These include a sense of time and context, planning, inhibiting and initiating action, self-monitoring, and empathic understanding. The "high road."
- Limbic system that governs emotions. Key areas are the amygdala and the hippocampus. The "low road."
- Brainstem that controls vital physical functions and survival responses.

Categories of Intellectual Functioning

Verbal Comprehension:

- 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 makes individuals prone to frustration, aggression, and depression.

Perceptual Organization:

- Visual-spatial skills.
- Ability to create solutions, especially in novel situations.

Categories of Intellectual Functioning

Working Memory:

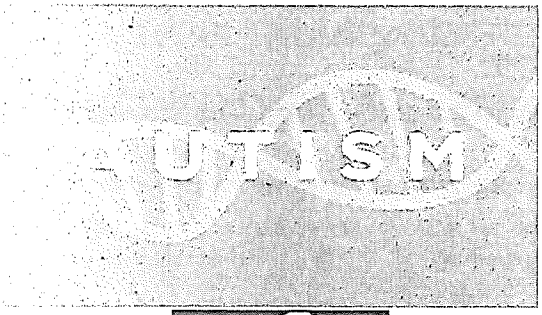
- In-the-moment reasoning tied to attention, concentration, and short-term memory.
- Important to learning, flexibility, planning, and self-monitoring.
- Sensitive to anxiety and depression.
- Related to trauma responses and anger management

Processing Speed:

- Ability to work quickly and efficiently.
- Sensitive to motivation and persistence.
- PS may negatively effect overall cognitive functioning.

Adaptive Functioning

- Based on performance of daily activities at a given age, rather than ability. That is, understanding an individual's functioning through a "developmental lens" with age-equivalents.
- Refers to how effectively people cope with common life demands across multiple environments.
- 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
  - Self-direction



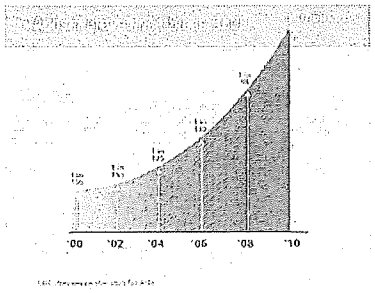
Statistics

- About 5:1 male-to-female. In 2014, it occurred in 1 in 42 boys, as compared to 1 in 189 girls.

A Steady Increase in Prevalence:

- birth year of 1992- rate 1 in 150
- birth year of 1996-rate of 1 in 125
- birth year of 2000-rate of 1 in 88
- birth year of 2002-rate of *1 in 68*

- Its found across all cultures and socioeconomic groups.



Why is the Prevalence of Autism Increasing?

- Probably genuine rates and previous underestimates
- Diagnostic changes with a broadening of categories
- Better tools and identification process (i.e., ADOS)
- More awareness (e.g., mental health providers, pediatricians, schools, media, parents)
- Improved access to services (e.g., waivers) and associated treatments (e.g., Applied Behavior Analysis, speech therapy)

Autism

- 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.

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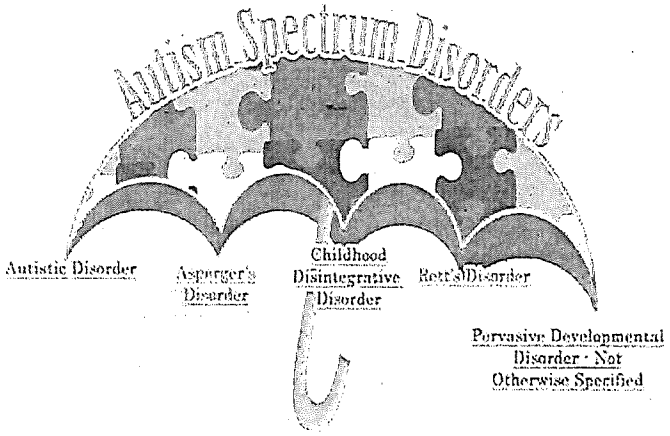
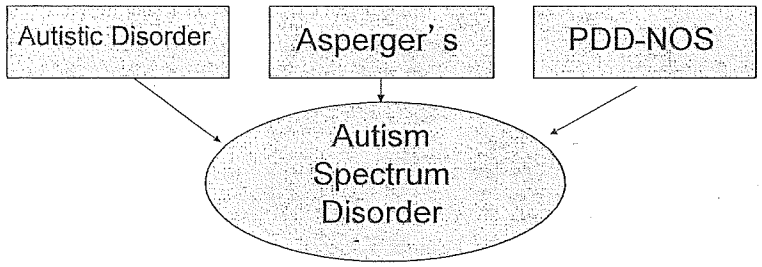
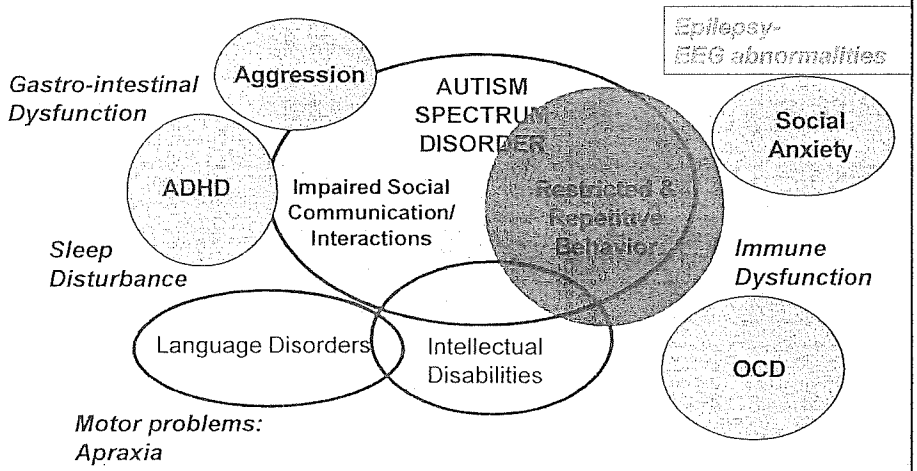


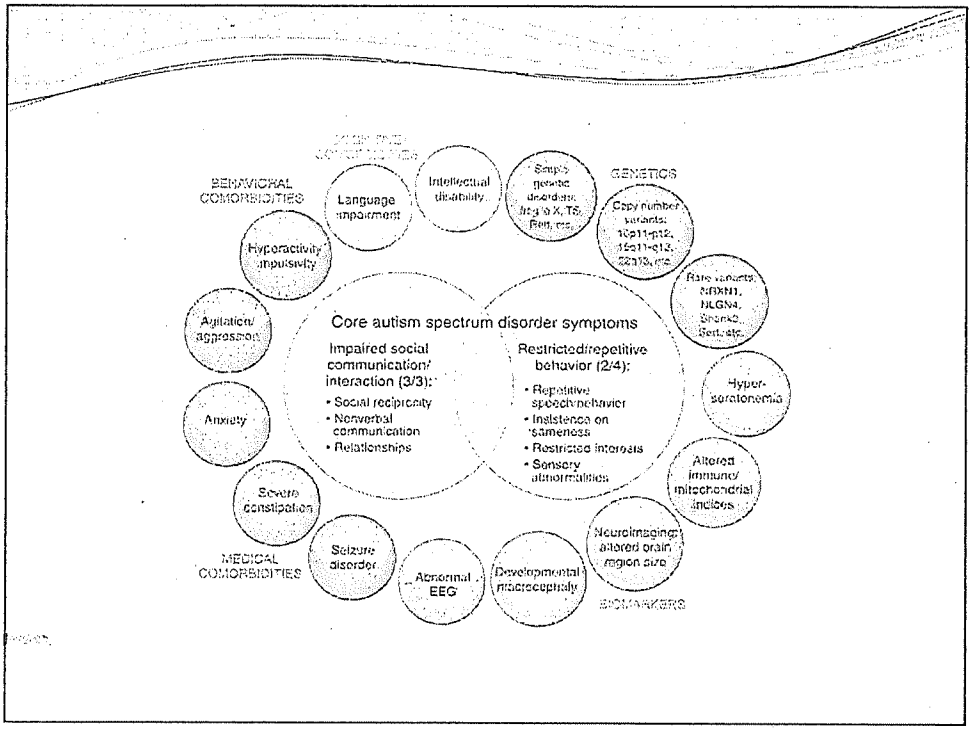
Diagnostic and Statistical Manual (DSM-5) Changes in 2013

Distinctions can be difficult across the spectrum and with other disorders



Conditions and Symptoms Associated with Autism Spectrum Disorder





Autism Themes and Variations

'Severely Affected'
Lower Functioning
Often Non-verbal
Intellectual Disability
Severe behaviors (e.g. self-injury)
Little to no social skills ('in their own world')

'Less Noticeably Affected'
Higher functioning
Average to above average IQ
Verbal
Lack social nuances
Inability to see another's perspective
Insistent on sameness

Autism Spectrum Disorder

Theory of the Mind:

- Those with an autism spectrum diagnosis often have significant difficulty understanding and appreciating that others may have thoughts, feelings, opinions, intentions, and plans that are different from their own.
- Difficulties with intuition, can result in the following:
  - Misreading body language (e.g., tone of voice, facial expression, posture).
  - Misinterpreting social cues
  - Problems with reciprocation
  - Difficulty understanding expectations
- Painful awareness of social differences and challenges with "fitting in" socially may give rise to episodes of anxiety and depression.

Autism Spectrum Disorder

- Cognitive Functioning:
  - Often rigidly cling to beliefs, convictions, or rules.
  - Autism is frequently misassociated with intellectual disability.
  - On the contrary, strong language skills can easily be misinterpreted as advanced communication/social skills, which can lead others to mislabel their actions as purposeful and manipulative.

Awareness

- Sensitives to even everyday stimuli can be uncomfortable or intolerable, especially for those with autistic features. For example, turn off sirens and flashing lights when possible or place canine partners out of sight.
- Consider physical fragility.
- Check for any special or assistive equipment. These could be signs of mobility issues.
- There is often a higher probability of neurological compromise (e.g., seizure disorder) with developmental disabilities.
- *A person might not be aware of their own deficits!*

Awareness

- Look for mental health difficulties (e.g., unusual behaviors, poor reality testing, "fight or flight" responses related to past trauma)
- Self-protective responses may not be intended as aggressive.
- Don't assume that the person is intentionally trying to be difficult, as some challenges might be out of their control. For example, inability to access vocabulary might cause problems reporting events accurately or memory deficits might lead to problems understanding multi-step directions.
- Look for signs of misunderstanding and poor comprehension, especially the use of psychosocial masking (e.g., nodding in agreement, politely saying yes) to adaptively conceal impairments.

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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.

Communication Tips

Language

- Speak clearly, calmly, and softly
- Show interest and concern
- Use direct and short phrases
- Avoid slang expressions, idioms, and metaphors (e.g., "knock it off," "cut it out," or "settle down")
- Watch for words that are "triggering" which may exacerbate agitation, such as "If/then" statements, as the person might need think contingencies are achievable.

Communication Tips

- Ask the person to repeat back information to check for understanding.
- Try other ways to communicate through alternative (non-speech) methods, such as drawings, pictures, cues, gestures, signs, or an I-Pad.
- Try to speak with the person directly even if a staff member or person without a disability is present. However, there might also be times to seek information and assistance from others at the scene, especially those who might know the individual well, such as family and friends.
- 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.

The Power of Acknowledging Perspectives:

- Active listening by being attuned (e.g., undivided attention)
- Accurate reflection to defuse negative emotions
- Validation only means *acknowledgement*, not necessarily agreement
- In the Crisis Cycle, when possible *sufficiently* validate before giving any corrective feedback, such as redirecting, limit setting, or finding solutions.
- Remember any contextual factors (e.g., holidays)

Communication Tips

Choices
Offering two to three choices when possible provides the person with a sense of control. *These choices may lead to a similar outcomes (e.g., de-escalation). Be mindful that overly negotiating may lead to confusion and disorganization for those with developmental disabilities.*

Reinforcement
Give verbal praise immediately (within 30-60 seconds) and explicitly, rather than delayed.

Compassionate Inquiry
Give them a better sense of self *(e.g., What does {positive behavior} say or tell us about you?)*

Verbal Maps
Help them connect words and actions

Shaping
Reward "successive approximations" to the desired goal

Communication Tips

Setting and Reviewing Expectations

- Allow them extra time to process and respond
- Have realistic expectations.
- Be consistent with language, especially between responders.
- Rephrase questions or restate directives as needed.
- *Learning problems may interfere with understanding what constitutes "appropriate" behavior. Therefore, directives should be very specifically convey the expectation...*

Communication Tips

The Importance of Stating Directives in Affirmative Language

- Tell the person what you want them to do, rather than what you do not.
  - *"Use an 'inside' voice," instead of "Stop talking so loudly"*
  - *"Keep your hands down," rather than "Don't hit"*
  - *"Let's relax with some slow breathing," not "Stop being so anxious"*
- *Watch for engrams (a mechanism of memory in response to external stimuli). These "hot spots" that get activated in the brain cause people to only hear the triggering part of a message!*

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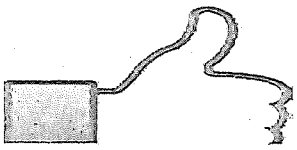
Positive Behavior Supports



A comprehensive approach that views behaviors as goal-directed and interconnected with physiology, situational context, cultural factors, as well as a person's thoughts and feelings.

Intelligence and Behavior

- *Intellectual impairment is often related to behavioral problems with delaying gratification, controlling impulses, and tolerating frustration.*
- *The best approach is building on cognitive strengths and minimizing weaknesses. For example, providing information using pictures, rather than words, to someone with visual-spatial strengths and verbal limitations.*

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Positive Behavior Support

Support for Positive Behavior

Support = Encouraging, increasing, and strengthening

Positive Behavior = desirable, adaptive, and prosocial

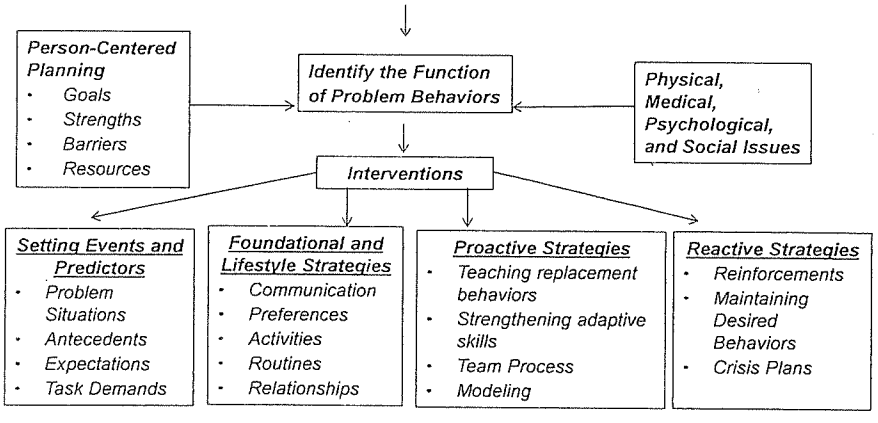
Avoids the use of aversive, humiliating, or stigmatizing interventions

Positive Behavior Support

Hallmarks and Strategies:

- Proactive setting of expectations
- Teaching acceptable behaviors
- Building on existing appropriate behaviors
- Improving quality of life
- Integrity with implementation

Positive Behavior Support Flowchart



Positive Behavior Support

Targeted Positive Behaviors:

❖ *To achieve, instill, increase, and maintain*

- Increase emotional regulation through coping strategies, self-soothing, healthy diversions, and opportunities to learn self-control.
- Become more adaptive and self-reliant by building autonomy, mastery, confidence, and self-direction.
- Increase prosocial skills and participation in community activities

Positive Behavior Support

Behaviors of Concern:

❖ *Those to decrease or eliminate.*

❖ These include verbal outbursts, physical aggression, property destruction, perseveration, poor boundaries, and refusals.

Criteria for a Behavior of Concern:

- Interferes with his or her growth, development, or progress.
- Interferes with his or her ability to make decisions and to achieve goals.
- Results in a psychotropic medication being prescribed to modify the behavior.
- Poses a risk to the health and safety of the individual and others.

Positive Behavior Support

Setting Events and Vulnerabilities

- Situations in the environment combined with individual's deficits
- Think about setting events broadly (e.g., unstable blood sugar, seizure activity, undiagnosed sleep problems, medication side effects)

Antecedents (or Triggers)

- What occurred immediately before the behavior?
- Fast versus slow precipitants?
- *External* (e.g., a conflict earlier in the day) versus Internal antecedents (e.g., feeling isolated and lonely)
- Lifestyle issues (e.g., interpersonal disappointments, problems accessing preferred activities)
- The *"universal trigger"* is often *"enforcing rules"* rather than thinking flexibly when giving direction and guidance.

Positive Behavior Support

Precursors

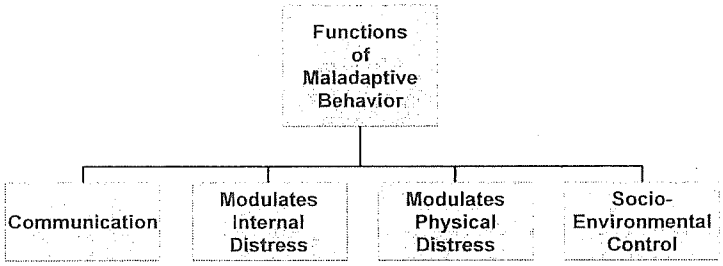
- What noticeable actions in body language came before the behavior of concern? (e.g., pacing, pressured speech, rolling their eyes, clinching their fists)

Maintaining Consequences

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

Functional Assessment of Behavior

Better Understanding Why Individuals Engage in Maladaptive Behaviors Especially Those Seen with Intellectual Disability and Psychiatric Disorders (Robert Souvner, 1991)



Be aware that functions differ for each individual. Some might be readily apparent and others might not be noticeable.

Behaviors might serve multiple functions.

Asking the right questions!

- Is the challenging behavior a *symptom of a medical disorder*?
- Is it a *side effect of medication*?
- Is it the *result of skills deficits*?

The following are some examples of how situations could have been avoided before assuming that the challenging behavior was due to mental illness or developmental disability...

Case Example One

Mr. Jones has severe cognitive deficits. He is non-verbal. He has no history of being aggressive or destructive. One evening, he began ragefully throwing the furniture in his group home. He was taken to the local emergency room and seen by a psychiatric crisis specialist. Mr. Jones was admitted to a psychiatric hospital with a diagnosis of psychosis.

Case Example Two

Ms. Smith is a woman in her thirties diagnosed with autism. She does not communicate much with words, but has strong opinions about her likes and dislikes. For many years, Ms. Smith attended a local regional center. She always refused to participate in group activities and community outings, during which she would scream, throw things, and occasionally disrobe. The center's staff was incredibly frustrated by Ms. Smith's behavior. There were numerous meetings about ways to address her unacceptable behavior, but nothing worked.

Positive Behavior Support

Caregiver Qualities

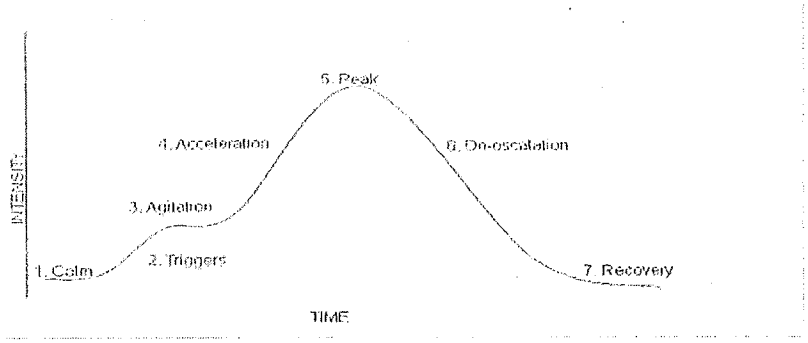
- Supportive
- Respectful
- Strengths-based
- Collaborative
- Empowering
- Give choices
- Build self-esteem

**Key factor in resilience for traumatized children:*

A person who believes in them

Positive Behavior Support

Proactive Versus Reaction Intervention Points



Benefits of Proactive versus Reactive

A	B	C
Proactive		
Interventions to prevent problem behavior	Emphasis on teaching alternative behaviors	Positive reinforcement of desired behaviors
Reactive		
Limited focus on antecedent interventions	Little focus on teaching new behavior	Punitive response to negative behavior

Positive Behavior Support
Reactive Strategies

- Caregivers' actions after a behavior of concern occurs.
- For limited use about 5 to 10% of the time.
- These should be used to help situations from escalating. For example, prompting alternative behaviors, using distractions, redirecting away from triggers, or establishing control when there is harm to self or others.
- May include crisis response, police involvement, respite care, and hospitalization.
- Reactive interventions are affected by state-dependent learning. We may lose up to 25 IQ points when upset.

Positive Behavior Support

Overarching Goal

Our aim is the presence of targeted adaptive and prosocial behaviors through instruction, not just the absence of challenging behavior.

Crisis Intervention Tips for those with Developmental Disabilities

- A process of "defusing" and "deflating" as we try to coach calmness in a situation without physical intervention when possible.
- Strive for three practical goals: **Safety, Connection, and Empowerment**
- General Techniques:
  - Show concern
  - Conceal emotions like anger and fear
  - Give hope about generating solutions
  - Ground in current reality
  - *Do not focus only on negative actions*
  - Congratulate steps toward regaining control
  - Focus on the individual's interests and goals in life

General Interaction Tips

- Announce yourself (name and role).
- Share your identification when possible.
- Have only one person act as the primary "interactor."
- Don't talk down to the person. Take an empathic stance.
- Avoid correcting behaviors. Give directives for positive behavior instead.
- Asks questions in a step-by-step manner.

General Interaction Tips

- Tell them honestly what will or is likely to happen using everyday language.
- 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.
- Look for sensory aids and allow the person to hold a soothing item if safety is not jeopardized.
- Show the person what you want them to do if possible, rather than just stating it.

General Interaction Tips

- Ask the person how you can best assist because the person with a disability can actually be their own best emergency manager.
- Taking time to explain something might actually save time in the long-run.
- Alleviate sources of distress when possible.
- Ignore self-talk that the person uses for coping unless it interferes in emergency procedures.
- A delayed or absent response to your questions or commands may not necessarily reflect a willful lack of cooperation.

Ask about Existing Crisis Plans

Proceed from least to most restrictive

Aggression:

- *Proactive Interventions:* Avoid confrontations and use a gentle approach.
- *Reactive interventions:* Give space. Provide distractions (country music, cold beverages).

Elopement:

- *Proactive interventions:* Avoid loud crowds. Be sensitive to room filling with people.
- *Reactive interventions*: Give him space to walk off anxiety.