

Behavior and Self Regulation Strategies



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Director, Down Syndrome Behavioral Health Collaborative
Children's Hospital Colorado

Where I Work



What I Do

Toilet training

Behavior Management

School Consultation

Desensitization to Using Medical Equipment

Feeding intervention

Diagnosis of autism in Down syndrome

Research in Down syndrome

Teaching Emotion Regulation

Independence

Self-Advocacy

Objectives

- ✓ Explore factors that impact behavioral presentation
- ✓ Learn about proactive strategies to effectively support the individual
- ✓ Identify the functions of a behavior and how to address them

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Factors Impacting Behavioral Presentation

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Setting Events

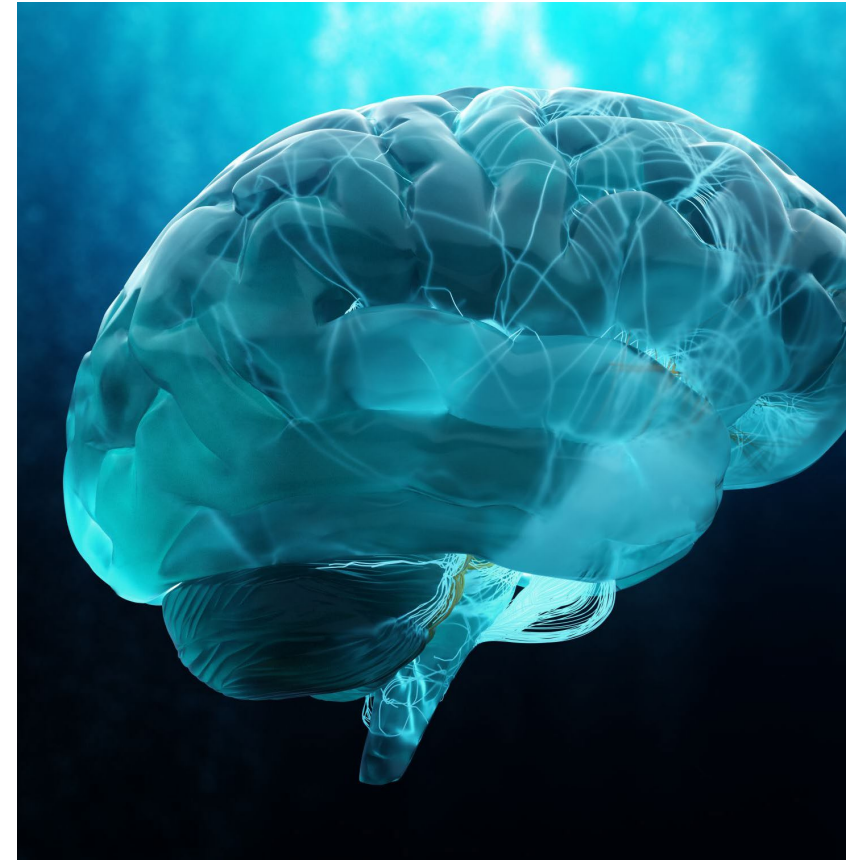
- A setting event is an environmental, physical, or social factor that happens before a behavior and makes that behavior more or less likely to occur.
- These events can include things like fatigue, hunger, communication challenges, .
- Unlike an immediate trigger, a setting event doesn't directly cause the behavior but makes it more probable.
- Neurodevelopment can be considered a setting event.

Brains of Individuals with Down syndrome

- At or just before birth, the brain of an individual with Down syndrome is almost indistinguishable from the brain of individuals without any genetic anomalies
- Neuropathological differences begin to show after 3–5 months of age and demonstrate definite differences by 6 months.
- Once mature, the brains of people with Down syndrome are about 20% smaller than average and have fewer neurons, as well as abnormal connections between cells.

Areas of the Brain that are Affected

- Areas of the brain that seem to have differences in volume or circuitry include:
 - **Hippocampus** which is responsible for memory and learning
 - **Prefrontal Cortex** responsible for higher level cognitive tasks such as planning, decision making, problem solving, personality expression, modulation of social behaviors, inhibition, etc.
 - **Cerebellum** responsible for coordination of movement and learning, as well as attention and language.



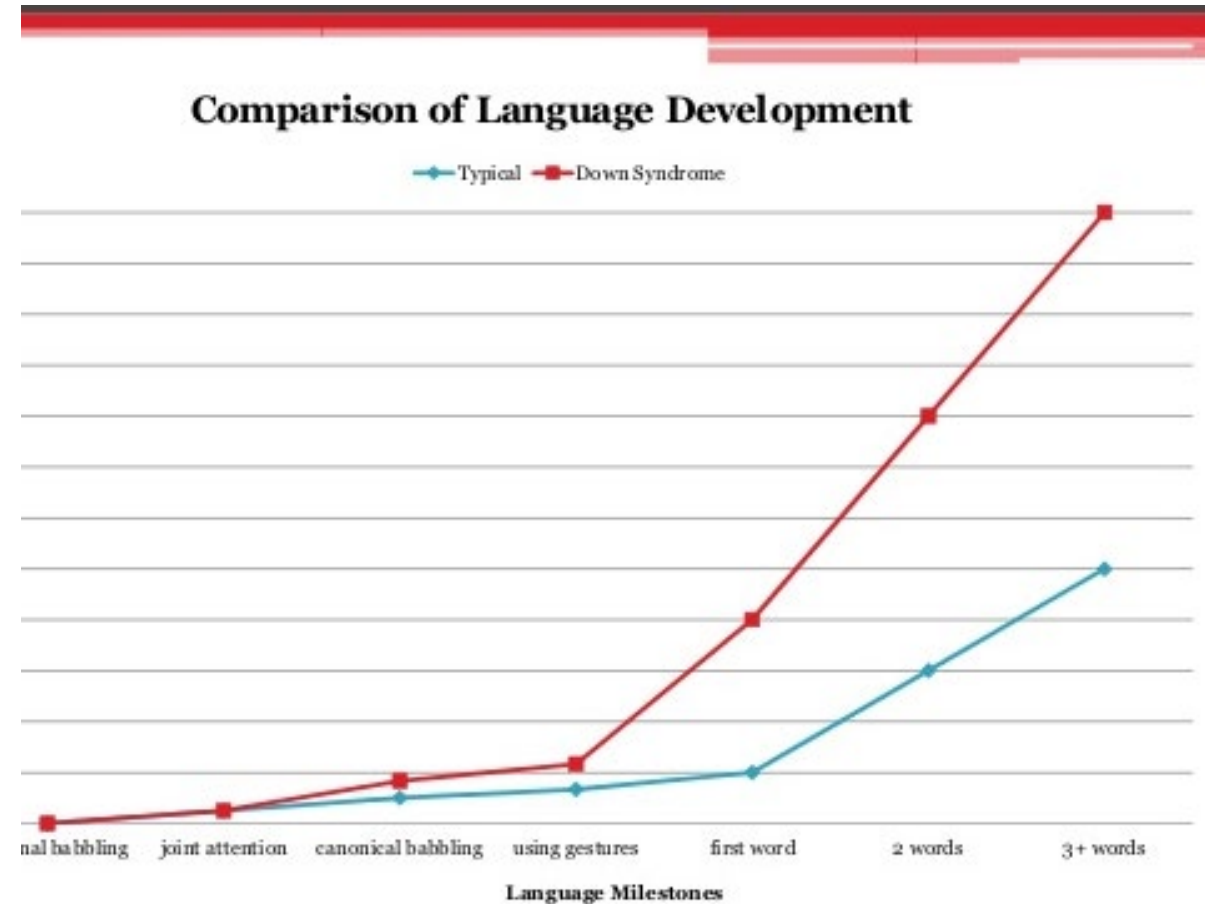
Probabilistic Behavioral Phenotype

More likely to show one or more of these characteristics or behaviors, but this does not mean every individual with Down syndrome will display these characteristics or behaviors.



Neurological Differences + Typical Changes

Individuals with Down syndrome still go through the typical stages of development on top of having these neurological differences. In the research world, this is a “developmental approach”.



Additional Setting Events

Setting Events Checklist

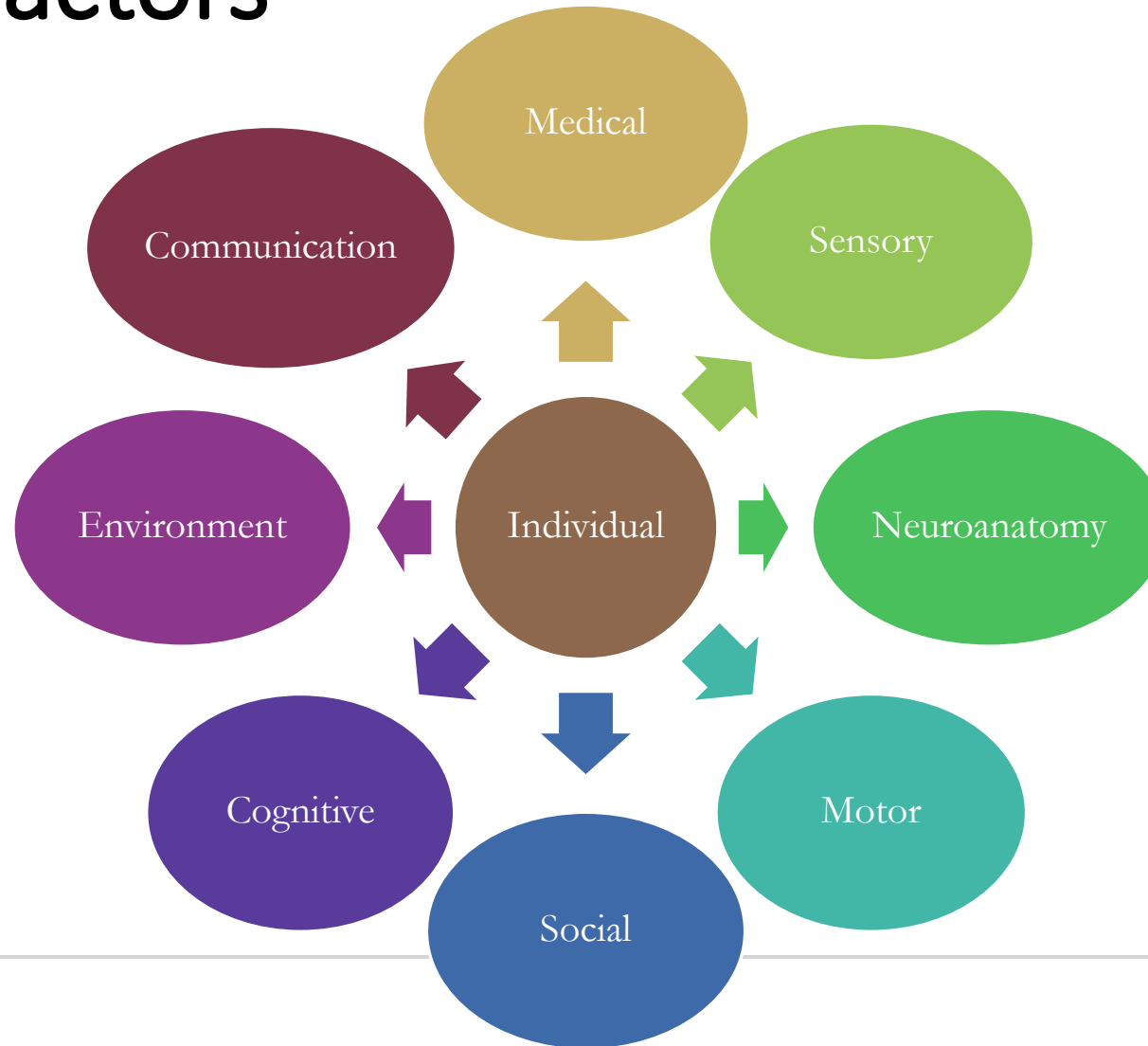
Student: _____ Respondent: _____

Behavior Interest: _____ Date: _____

Instructions: The list below includes events that could possibly increase the likelihood of problem behavior occurring. If an event contributes to the student's behavior, check the appropriate column to indicate when the event occurs in relation to when it contributes to the problem behavior. For longstanding influences, note only those that contribute to the current incident or behavior.

SETTING EVENT (by type)	Same Day	Day Before	Within Week	Long Standing
Physical				
Meal time change or meal missed				
Sleep pattern (including duration) atypical				
Medications changed or missed				
Appeared or complained of illness				
Appeared or complained of pain or discomfort				
Allergy Symptoms				
Seizure				
Chronic health condition				
Other (specify):				

Behaviors are Impacted by Multiple Factors



So What?

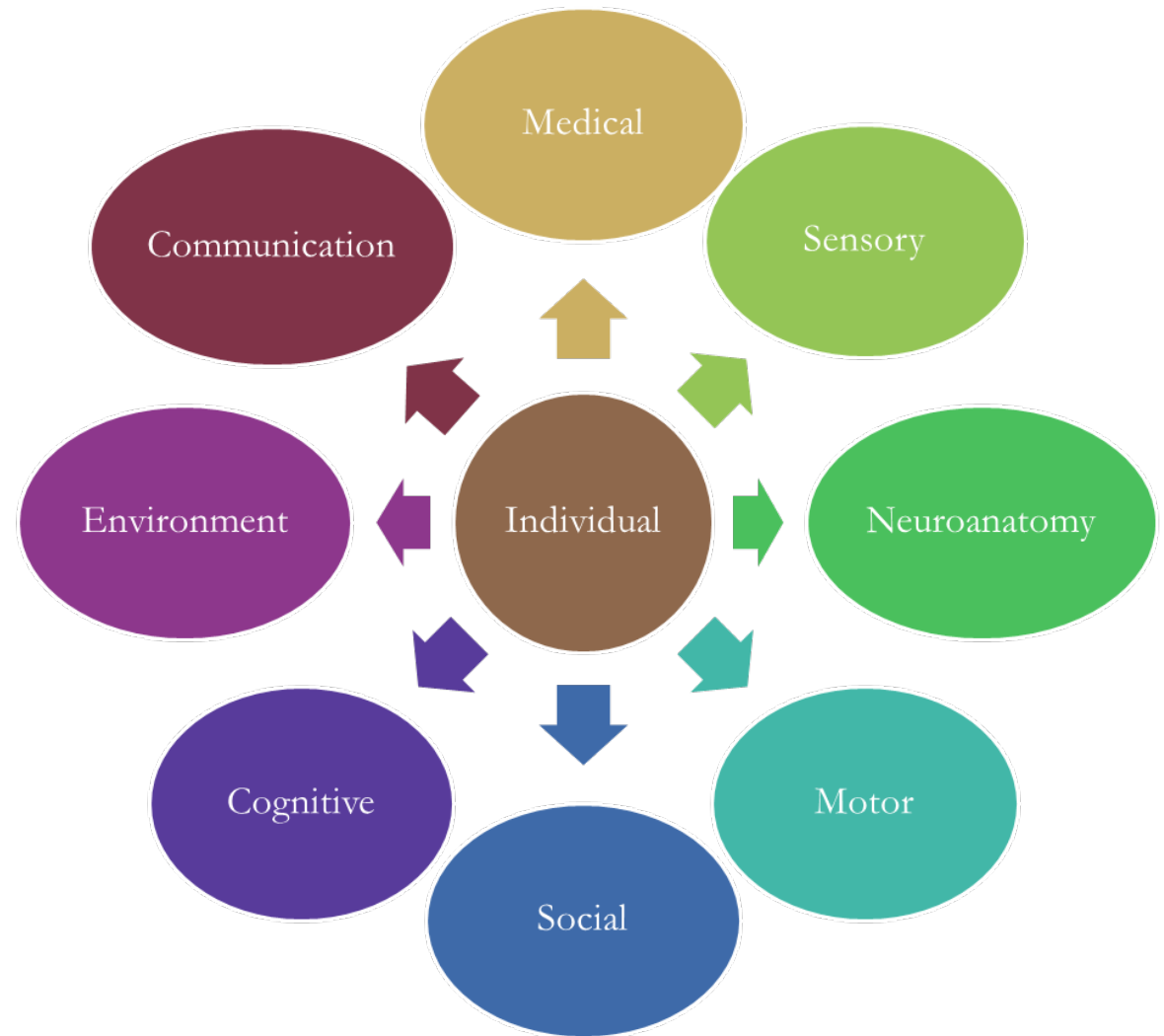


Behaviors occur with the context of a situation but also occur within the context of neurodevelopment and chronic issues. Understanding that better prepares us to find a more meaningful solution.

**Challenging Behaviors/Changes in Behaviors =
Communication**

Addressing Behaviors

- We can address behaviors in many different ways, but the first step is to gather information to determine the source of the change



Possible Follow Up

- Medical workup
- Neurological workup-bring videos
- Psychological evaluation-bring videos
- Interviewing teachers, therapists, community helpers/staff
- Observation: When, where, what context...

Interventions

- Use of medical equipment, change in medication, resolution of acute pain
- Reinstating neurodevelopmentally-sensitive, proactive strategies and environmental modifications to address change in cognition
- By working on development of specific pivotal skills that will impact multiple areas
- In the moment (A-B-C)

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Proactive Strategies

Compensatory Strategies to Address Neurodevelopment and Setting Events

Visual schedules and “first-then” directives

Break down tasks into smaller components

Use a multimodal approach to teaching including modeling (Learn by “doing”)

Turn the abstract into something concrete

Limit visual/auditory overstimulation

Prespecified reinforcer

Offer an adult directed choice

Use strengths and interests to engage

Give time to process

Errorless learning

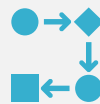
Visual Roadmap



Components of a Schedule



“What do I do?”



“How much work needs to be done?”



“When am I finished?”



“What happens next?”

First



$2 + 4 = 6$

magnetic numbers

Then



ball bounce



wash



toilet



get dressed



breakfast



brush teeth



bath



pajamas



milk

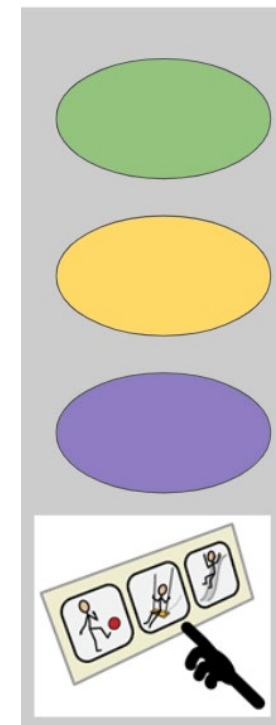


story



bedtime

My Schedule & Check-In				
	just right voice	in my space	yes	no
	just right voice	in my space	yes	no
	just right voice	in my space	yes	no
	just right voice	in my space	yes	no
	just right voice	in my space	yes	no
	just right voice	in my space	yes	no
	just right voice	in my space	yes	no
	just right voice	in my space	yes	no
	just right voice	in my space	yes	no



Types of Schedules

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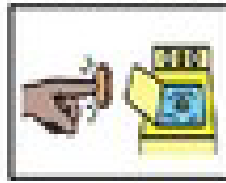
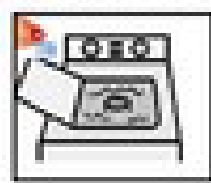
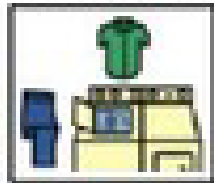
Errorless learning

Visual Roadmap

Examples



Put clothes in washer. Add 1 cup detergent. Put detergent in washer. Turn machine on.



Take clothes out of washing machine.



Put in dryer.



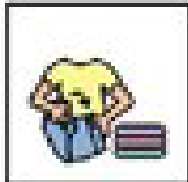
Turn dryer on.



Take clothes out of dryer.



Fold clothes.



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Visual Roadmap

Least Restrictive / Most Independent

Most Restrictive / Least Independent

		➔					
		Visual	Verbal	Gestural	Modeling	Partial Physical	Full Physical
		Visual clue or guide	Telling	Pointing or motioning towards	Demonstrating	Guiding by elbow	Hand-over or hand-under hand
Goal	What prompt level is needed for this student to complete his / her IEP goal?						

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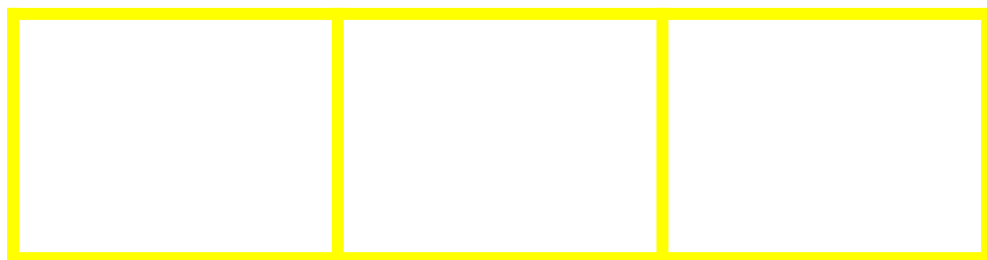
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Visual Roadmap

Time



Visual Countdown Timer 4+
Fun visual countdown timer
Fehners Software LLP
★★★★★ 4.6, 9K Ratings
Free · Offers In-App Purchases



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Over and under stimulation

- Planned sensory breaks
- Planned sensory diet for input
- Minimize visual and auditory stimulation
- <https://www.youtube.com/watch?v=plPNhooUUuc>



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I am working for



I am working for.....



I am working for...



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Reinforcement/Reward Inventories

Sometimes this can involve another object or sometimes it might be something that they do repetitively with their body and do not seem to have a clear purpose. We call these sensory seeking behaviors.

Auditory (Sound)

Behaviors you may observe: humming, verbalizations, tapping on objects, listening to music, putting ear to objects.						
Behaviors observed that may be auditory seeking:				Who has access? <i>(list any additional environments your child may go)</i>		
Liked	Disliked	Things to try:	Home	School		
		Toys that make noise				
		Drums				
		Triangles				
		Tambourine				
		Bells				
		Keyboard				
		Whistles				
		Radio				
		Push / Pull toys that make noise (See and Say)				
		Music boxes / Jack in the Box				
		Hair Dryers				
		Books on Tape				
		Music				

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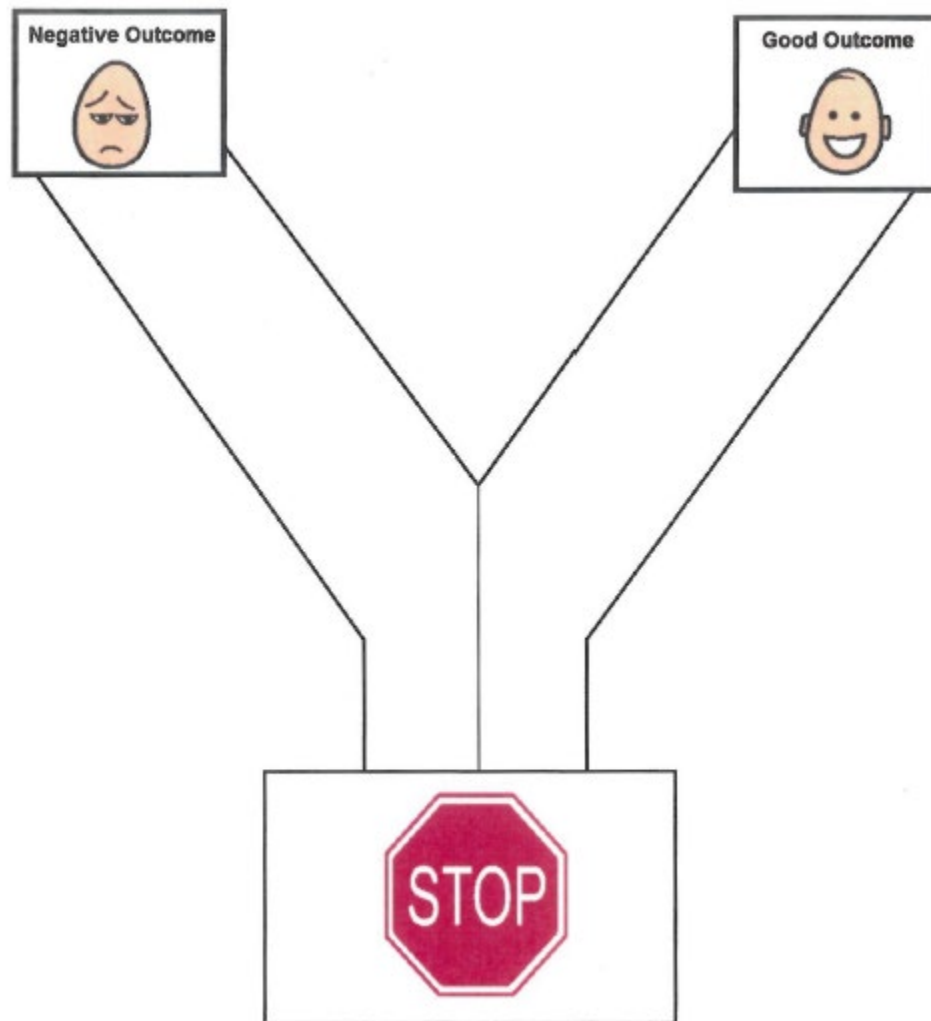
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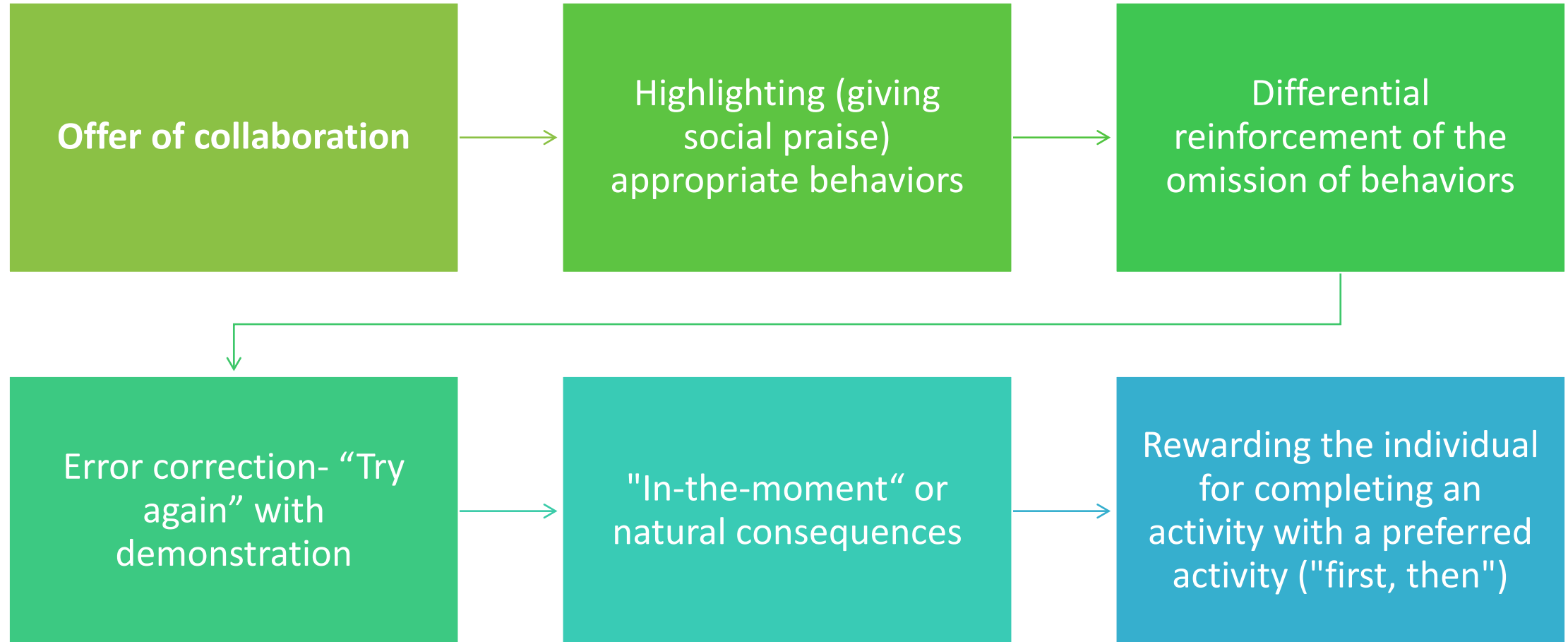
Visual Roadmap





Consequence Strategies

Ensures the behavior will or will not happen again





Pivotal Skill Development

Example

Immediate Proactive Strategies (Identification of Strengths and Challenges)	Long-Term Proactive Strategies (Skill Acquisition)	In-the-Moment Strategies to Address Antecedents (A-B-C)
-Clear expectations	- Emotional regulation training	- Deep breathing
- Visual schedules	- Social skills development	- Use calm voice
- Errorless Learning	- Self-monitoring techniques	- Offer choices
- Visuals in the Environment	- Independence building skills	- Provide space
- Routine & consistency	- Desensitization to Sensory Sensitivities	- Redirect attention

What are you loved one's "pivotal areas"?

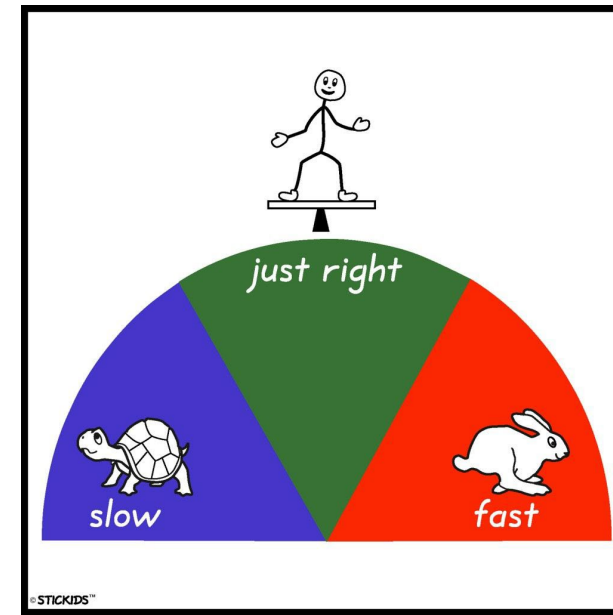
Game Changers



How to Show I'm Calm

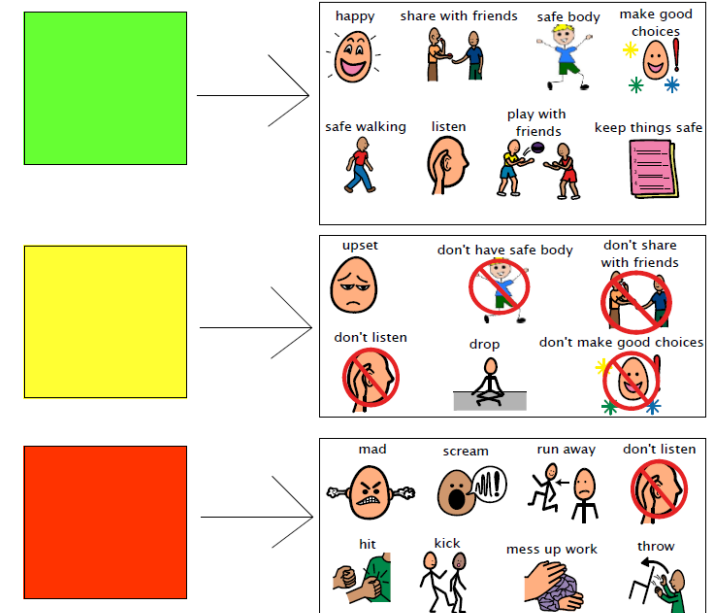


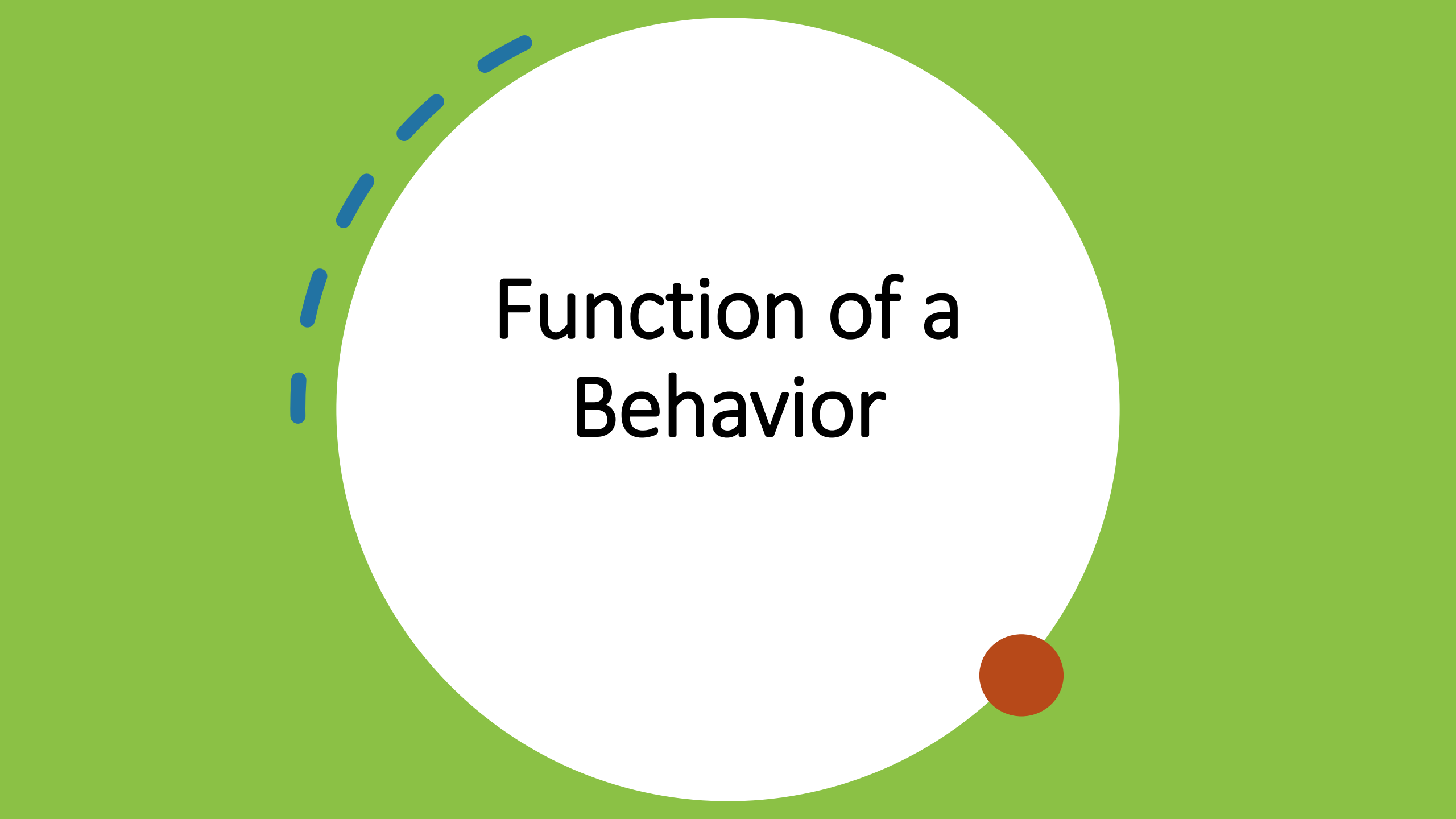
	Sit 
	Show safe hands 
	Deep belly breaths 
	Use your words 



The ZONES of Regulation®

			
BLUE ZONE	GREEN ZONE	YELLOW ZONE	RED ZONE
Sad Sick Tired Bored Moving Slowly	Happy Calm Feeling Okay Focused Ready to Learn	Frustrated Worried Silly/Wiggly Excited Loss of Some Control	Mad/Angry Mean Terrified Yelling/Hitting Out of Control





Function of a Behavior

Common Functions of Behavior



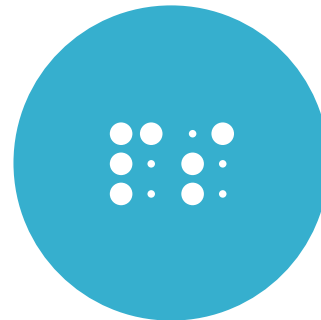
Social Attention: A person may engage in a certain behavior to gain some form of social attention or a reaction from other people. For example, a child might engage in a behavior to get other people to look at them, laugh at them, play with them, hug them or scold them.



Tangibles or Activities: Some behaviours occur so the person can obtain a tangible item or gain access to a desired activity. For example, someone might scream and shout until their parents buy them a new toy (tangible item) or bring them to the zoo (activity).



Escape or Avoidance: Not all behaviours occur so the person can “obtain” something; many behaviours occur because the person wants to get away from something or avoid something altogether (Miltenberger, 2008).

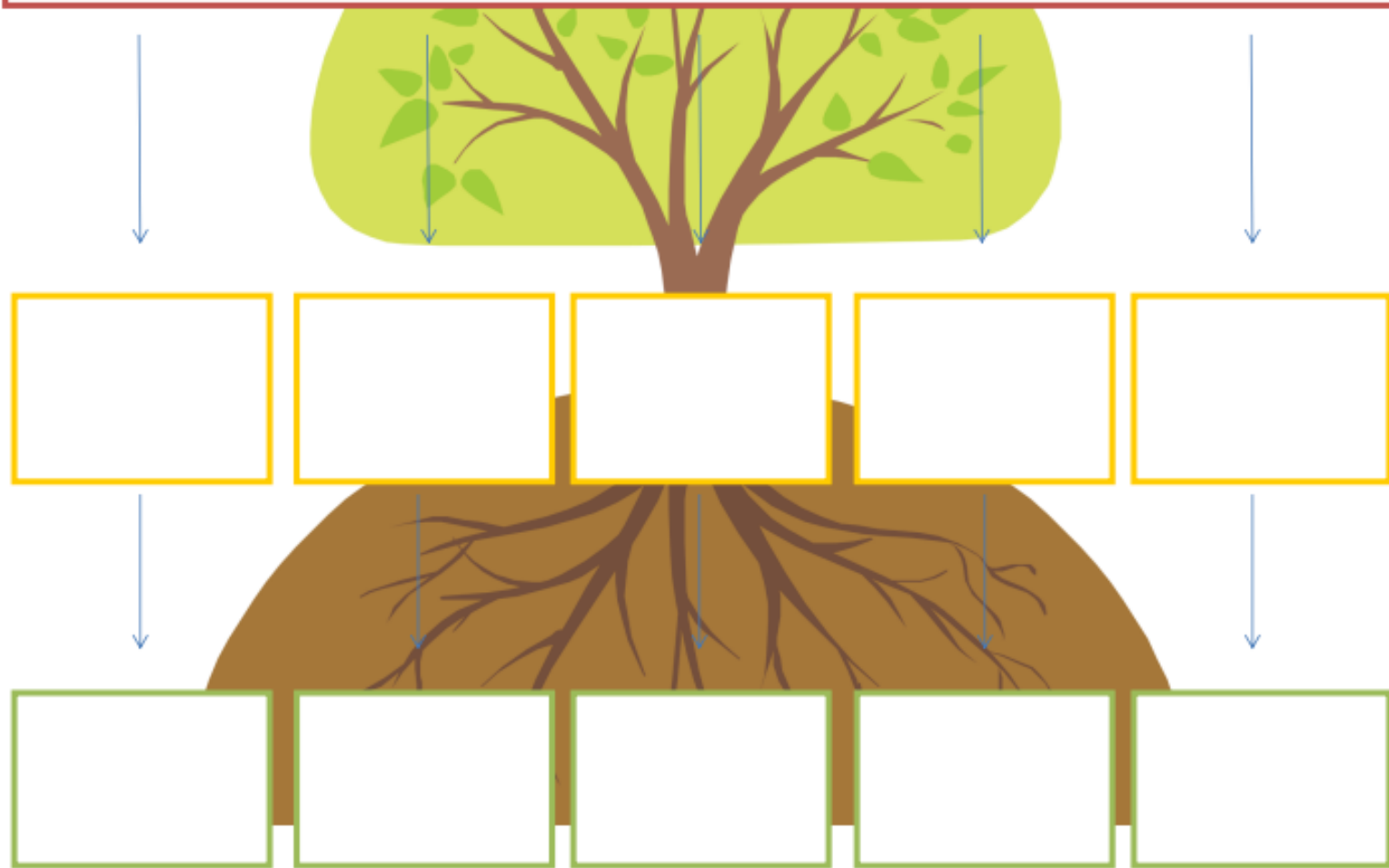


Sensory Stimulation: The function of some behaviours do not rely on anything external to the person and instead are internally pleasing in some way.

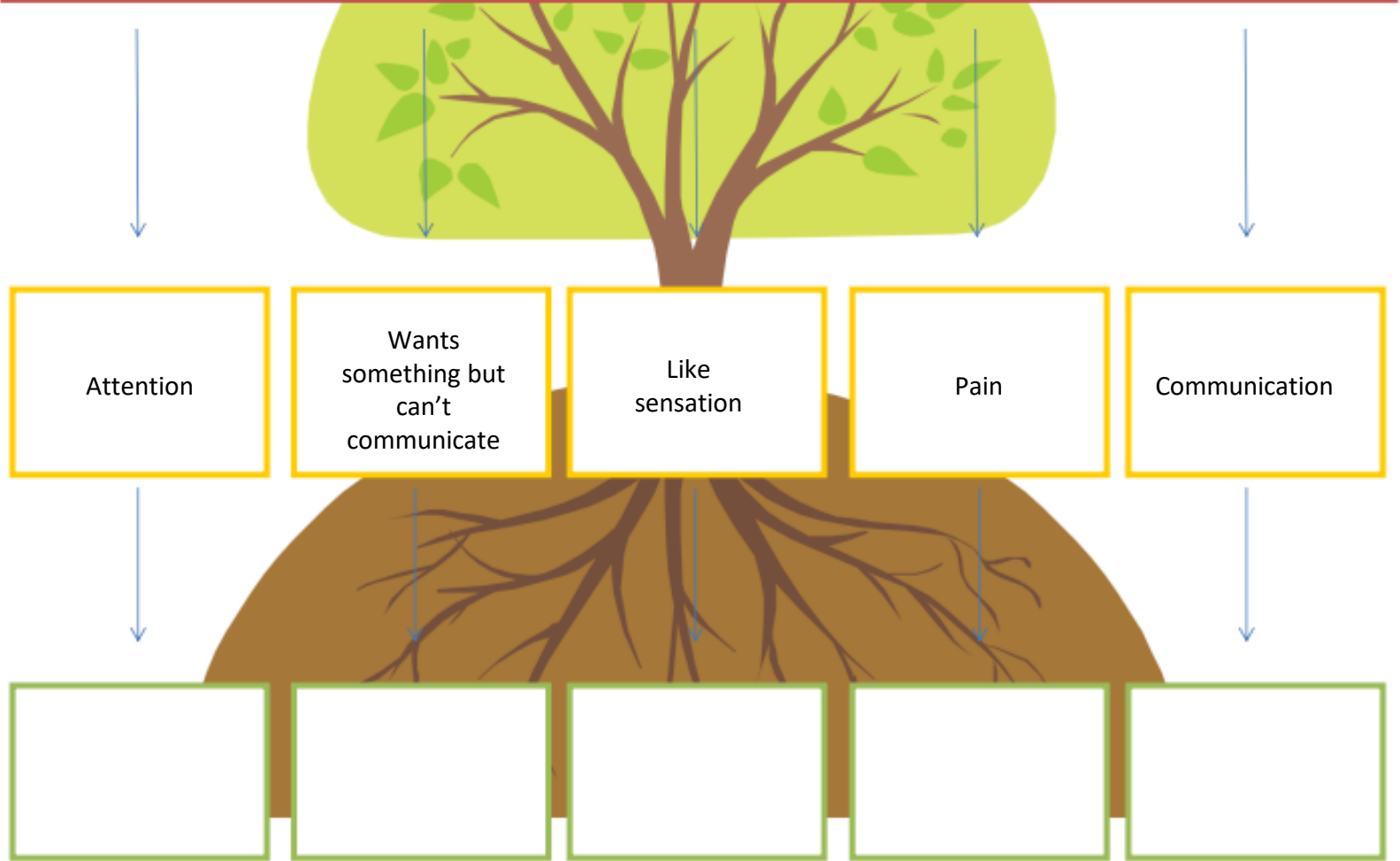
Data Tracking

Time/ Date/ Activity Initials of person documenting	Antecedent/ Trigger/ What happened right before?	Behavior/ Details of behavior	Consequence/ What happened after?	Function of the behavior?

Observed Behavior



Observed Behavior
Hitting self in the head



The important point is that difficult behaviors do not occur by accident, or because someone has a disability. Difficult behaviors are expressions of real and legitimate needs. All behavior, even if it is self-destructive, is “meaning-full”.

David Pitonyak, PhD
Blacksburg, VA
Down Syndrome News

Help support Down syndrome research!

You can participate in one of the largest and most comprehensive studies of Down syndrome in the world!

The Crnic Institute Human Trisome Project (HTP)!

- The HTP aims to significantly increase the speed of Down syndrome research and the understanding of conditions such as leukemia and Alzheimer's disease.

Who can participate?

- People with Down syndrome and their siblings 6 months - 89 years old



Use QR code or learn
more at www.trisome.org



LINDA CRNIC INSTITUTE
for DOWN SYNDROME
GLOBAL DOWN SYNDROME FOUNDATION

Research opportunity for people with Down Syndrome Regression Disorder (DSRD)

Scientists and physicians have teamed up to identify effective treatments for DSRD.

Why participate?

- Examine the safety and effectiveness of different treatments for DSRD: lorazepam, IVIG or tofacitinib

Who can participate?

- People with Down syndrome between 8-30 years old who have symptoms or a diagnosis of DSRD. Additional participation criteria apply.

Email DSresearch@cuanschutz.edu to learn more.



LINDA CRNIC INSTITUTE
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Parent Survey

Develop a New Measure of Problematic Behavior for Down Syndrome

We are inviting parents of a child with Down syndrome (ages 2-17 years) to take part in an online research study led by researchers at Cincinnati Children's Hospital. The goal of our research study is to create a new tool to better measure problematic behaviors in children with Down syndrome. To do this, we need your help!

Who qualifies? Caregivers of a child with Down syndrome ages 2 to 17 years who live in the USA.

- **What is involved?** Eligible caregivers complete a confidential online survey regarding how often behaviors occur and how severe certain behavioral concerns are. Caregivers also provide information about basic demographic information and their child's medical conditions. The survey will take about 20-50 minutes to complete, and you can return to the survey if needed. Optional additional surveys may be offered, to complete validation behavioral surveys, or complete the initial survey two weeks.
- **Interested?** Please click on the following link when you are ready to start the survey: <https://redcap.link/BIDS2>
- **Thank you!** Caregivers will be compensated for their time (\$25). Caregivers completing the second survey will receive an additional compensation (\$20).
- **Questions?** Please contact the Project Team at dsresearch@cchmc.org

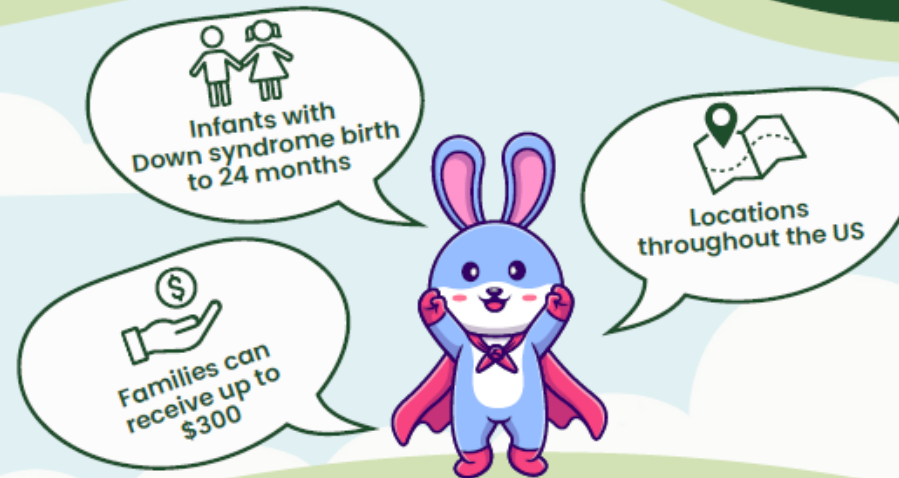
Si prefiere hacer la encuesta en español, haga clic aquí:
https://redcap.link/BIDS2_es



NEW RESEARCH PARTICIPATION OPPORTUNITY!

ENROLLING NOW THROUGH 2028

IRB Approved at the
Study Level
Apr 25, 2024



Project CAPE-abilities

Communication And Play Early
abilities in Down Syndrome

The DD Lab at CSU has a new research study that focuses on how young children with Down syndrome play and communicate!

Play and communication are important for a child's development. This study will show how these skills grow in children with Down syndrome and how they connect to other health conditions and autism.

We are excited to learn more about your child's CAPE-abilities!

CONTACT OUR TEAM!



DEVELOPMENTAL DISABILITIES
RESEARCH LABORATORY
COLORADO STATE UNIVERSITY

970-491-1969 | ddlabcsu@gmail.com
Study Lead: Deborah Fidler, Ph.D. at CSU



NEW STUDY OPPORTUNITY! — EARLY HEALTH & MOTOR ABILITIES IN DOWN SYNDROME

The DD Lab is conducting a new study on the early foundations of health and motor abilities in children with Down syndrome.

- Participants will engage in playful assessment activities and wear a physical activity watch at home.
- Caregivers will be invited to complete questionnaires and can opt to wear a physical Activity watch.
- Our study activities are designed to be fun and children usually find our studies a positive experience. Your participation will help us learn how to best promote healthy outcomes!



Children ages 18-47 months



Families can receive up to \$100 per year



Locations in Fort Collins and Denver

DEVELOPMENTAL
DISABILITIES LAB
COLORADO STATE UNIVERSITY

CONTACT:

✉ DDLABCSU@GMAIL.COM
☎ 970-680-3415
📱 @FACEBOOK.COM/CSUDDLALAB