

*WE'RE ALL ON THE FRONTLINES!*  
PARENTING CHILDREN WITH  
COMPLEX NEEDS DURING  
COVID-19

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Arietta Slade, Ph.D.

Professor of Clinical Child Psychology

Co-Founder and Director of Training

*Minding the Baby*®

Yale Child Study Center

# Background for this evening

- Huge thank you to the FAR Fund, especially Executive Director Shirlee Taylor, and to Beth Rosenberg, Founder of Tech Kids Unlimited, Jackie Coenzo, Founder of SNACK NYC, and Caitlin Cassaro, Executive Director of Extreme Kids and Crew. And thank you to my MTB team.
- Who am I:
  - Clinical psychologist
  - Working with parents and children for over 40 years, often highly stressed parents struggling with adversity
  - Special interest in the parent-child relationship
- How I prepared for this evening

“We are all on the frontlines!!”

Serena Flaherty  
Nurse, graduate  
student, mother  
of two school age girls  
April 10, 2020

Everything we counted on, that we worked so hard to achieve and get into working order as parents has been upended by COVID-19. Like the health care workers, we are overwhelmed, we have to start from the ground up, without enough knowledge, without certainty, and having lost much of our personal protective equipment. And there aren't enough ventilators!

“It’s a hot fucking mess.”

Caitlin Cassaro  
Executive Director,  
Extreme Kids and Crew  
April 20, 2020

# The reality today for children with complex needs...

- A range of developmental and physical challenges
- Loss of personal space
- Loss of beloved & *critical* teachers, OTs, PTs, and caregivers (including extended family, etc.)
- Loss of the routines, hands-on programs that keep them organized, learning, and functioning
- Regression, anxiety, fear, meltdowns, violence, loss of skills, and intense need for, anger at, or rejection of their parents (or all of the above)

# The reality today for parents

- Working remotely or still working outside
- Uncertain about the future
- Fear for their family's health
- Stressed by COVID precautions
- Extreme financial concerns
- Other non-COVID traumas
- Increased mental health concerns
- *Overwhelmed by their children's needs*

# The reality today for parents

- Unreasonable expectations from the educational system (retraumatizing)
- Unclear and conflicting guidance
- Major technical challenges
- Asked to take on multiple complex tasks that they do not know how to do
- Little support for the *real* challenges of the situation
- Endless bureaucratic tangles

“The D.O.E\* . is just ridiculous.”

Beth Rosenberg  
Founder, Tech Kids Unlimited  
April 10, 2020

\*New York State Department of Education

# “Teachers’ Herculean Task: Moving 1.1 Million Children to Online School”

*New York Times*

March 29, 2020

## “Teachers’ Herculean Task: Moving 1.1 Million Children to Online School”

“Looming over the whole enterprise is a cloud of fear and urgency. It is critical that remote learning succeeds. The alternative is that over a million children, in crucial developmental stages in their education, will be permanently set back, with no opportunity to salvage lost time.”

David Chen, *New York Times*

March 29, 2020

*Who is this guy??*

# An unnecessary (and absurd) burden on parents, teachers, and children

- The idea that nothing must change is *delusional*
- Zoom is not school
- Parents are not the same as teachers
- Classroom learning is not the only way children learn: There are multiple other opportunities!
- Regressions are normal, can have positive outcomes, and are expectable
- Rarely are setbacks *permanent*
- There are ALWAYS opportunities to salvage lost time

If school administrators cannot modify their expectations in *light of reality*, they cannot be helpful to parents *or* teachers

## Mayor di Blasio, April 29, 2020...

Our students, educators, and families are going through a lot right now. I know our *students are capable of excellence, and we will continue to hold them to that high standard* while adjusting our grading to reflect the unprecedented challenges created by this crisis. We will give every student the support they need to bounce back and continue on their path to success.

# The reality today

- Such enormous pressure on parents
- Emotions are intense:
  - Helplessness
  - Anxiety about the present and future
  - Anger & frustration
  - Sadness/grief
  - Loneliness
  - Longing
  - Deep exhaustion
  - Boredom

“So, on top of everything else, we’re failing.”

Jackie Ceonzo  
Founder  
SNACKNYC  
April 7, 2020

It's a collective trauma, and  
needs to be recognized as  
such.

How do we keep a trauma  
from being *traumatizing*?  
To us? To our kids?

# Acceptance

- We do not know what will happen.
- Things will not go back to what they were.
- We do not know what will be in the place of what we knew and counted on.
- There is only so much we can do

Georgie, age 9, after 7 weeks of lockdown...

...finally felt the reality of her situation, and was so sad to be missing her school and her friends...“The hardest thing is the uncertainty, and I know nobody can tell me when I’ll see my friends again, if I’ll go to camp this summer, or even if I’ll go to school in the fall.”

## Finding a new way...

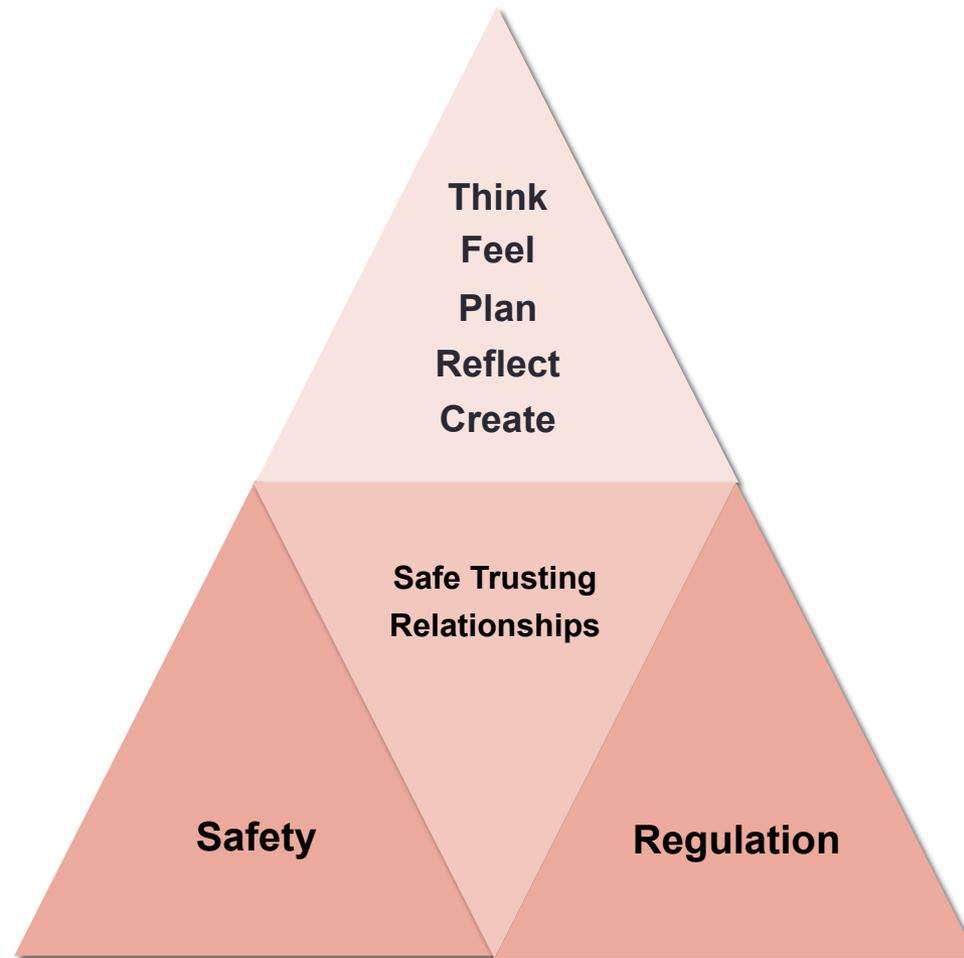
- This is so painful and scary
- We all feel helpless and tired
- But we have to start here to go forward
- *It's the only place we can be*
- We can't make the present conform to the past
- What works for me, my child, and my family now?

“As parents [of atypical kids], we are very good at rearranging expectations...we adjust our expectations all the time.”

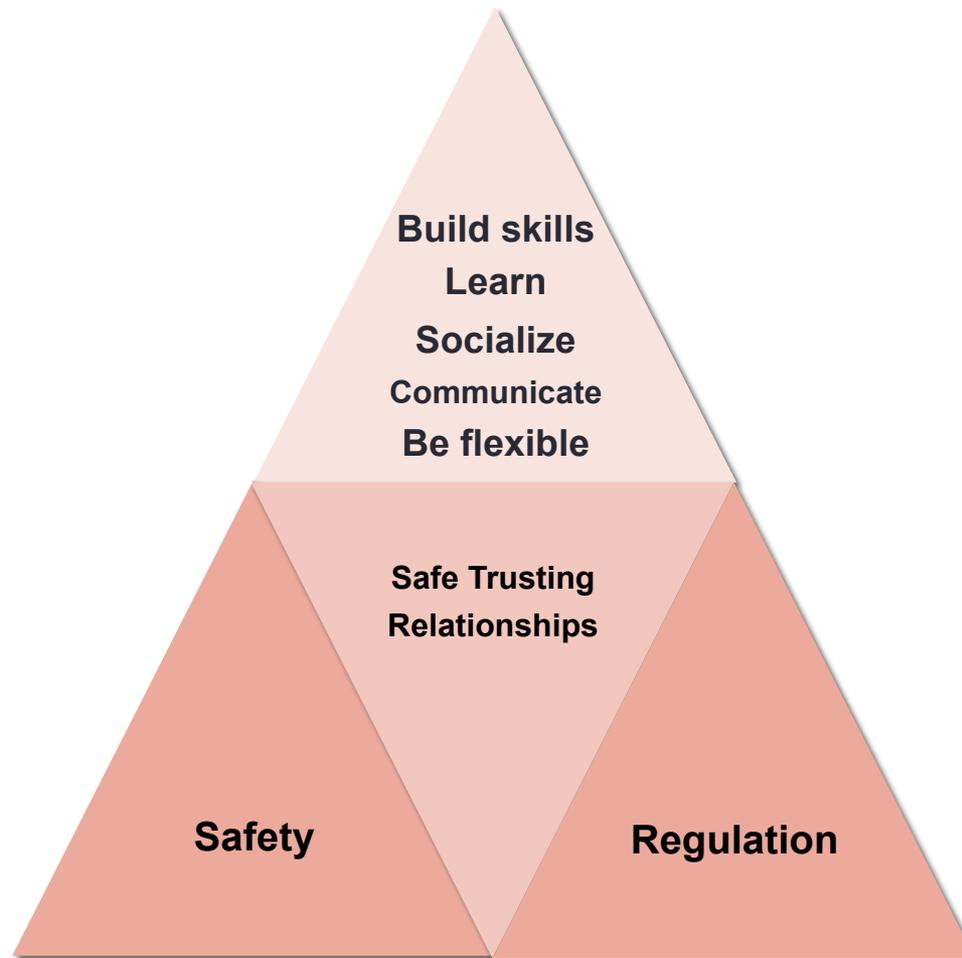
Jackie Ceonzo  
Founder  
SNACKNYC  
April 7, 2020

Where do we start?

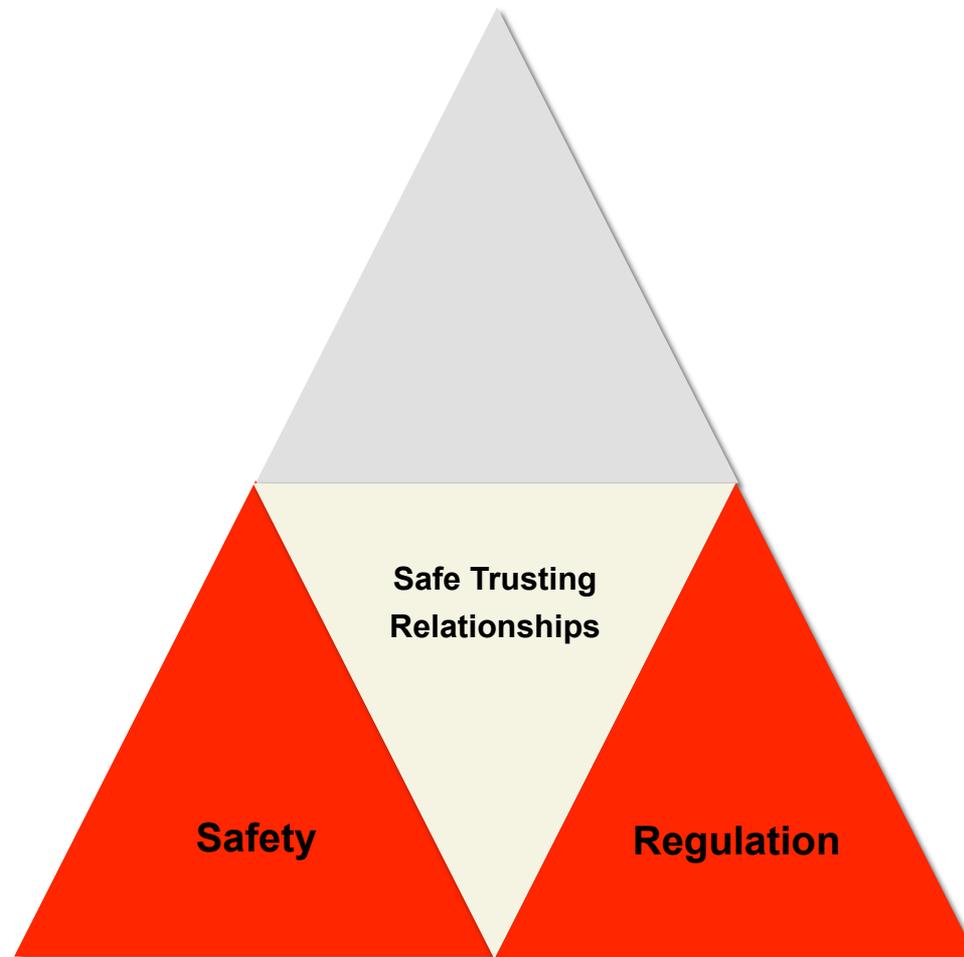
# The Foundations of Reflective Parenting



# The Foundations of Development



# The Primary Impacts of COVID-19





**Safety  
Threat**

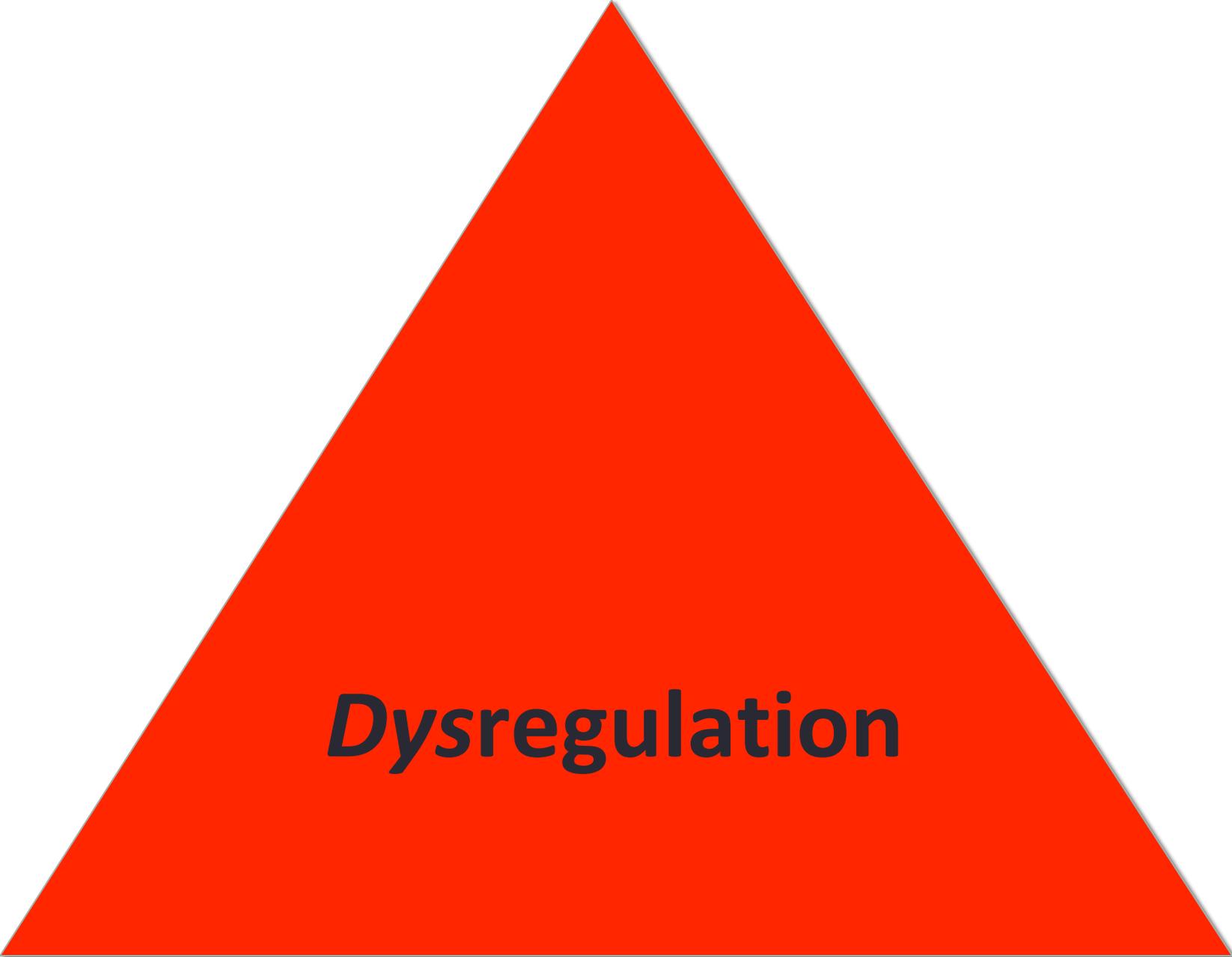
# Threats to the parent

- The unknown, enormous uncertainty
- Child's dysfunction
- Child's regression
- Loss of supports and critical relationships
- One's own and others' health
- Educational expectations
- ***Own expectations***
- Economic, employment, and housing challenges
- Family challenges
- Lack of space

# Threats to the child

- Everyone in the family is looking and acting weird
- Parents are not the same (anxious, angry, depressed) – they have “lost” you, too
- Loss of supports, including key relationships
- So many difficult transitions
- Life feels absolutely chaotic and terrifying
- Parental demands & expectations (triggering)
- Loss of routines, structure
- Educational demands

What happens when we are threatened?



***Dysregulation***

# In the parent

- Cascades of stress hormones
- Fight, flight, freezing responses
- Disruptions in bodily functioning (breathing, heart rate, body temperature)
- Disruptions in sleeping, eating, GI symptoms
- Disrupted emotions
- Disrupted relationships
- Disrupted thinking, planning, problem solving
- Signs of regression, panic

## In the child

- In addition to stress responses, and disrupted bodily, affective, and cognitive functioning....
- Disrupted, disorganized behavior – withdrawal, complete meltdowns, violence, rigidity/chaos
- Withdrawal from/conflict with significant others
- Loss of basic functions
- Loss of skills
- Regression

These are all responses to *threat*

Parent AND child are in survival mode and are highly stressed and dysregulated

# Put your own mask on first

- Are you physically safe?
- Do you have provisions and basic resources?
- Do you have emergency supplies and a plan if someone requires medical care, hospitalization?
- Establish your team, coordinate your efforts
- Do what you can to diminish threats to your safety.
- Do what you can to regulate yourself. Sleep.
- What can you let go of...NOW.



Arietta Slade, Ph.D.  
Trust Child Suck, Honor

An unnecessary (and absurd) burden on parents, teachers, and children

- This is delusional thinking
- It ignores a basic fact of child development, which is that development is flexible and adaptable
- Children learn in a variety of ways and contexts
- Regressions are normal, have positive outcomes, and in instances like this, are expectable!
- There is no such thing as a permanent setback, time
- There are ALWAYS opportunities to salvage lost
- It ignores the reality of trauma

Red boxes with text: "Red Box" and "Red Box" (partially obscured)



Thank You

Handwritten notes on a piece of paper.

Sticky notes with handwritten text.

Handwritten notes on a piece of paper.

Handwritten notes on a piece of paper.

SERRA CLUB WILDERNESS CALENDAR 2020



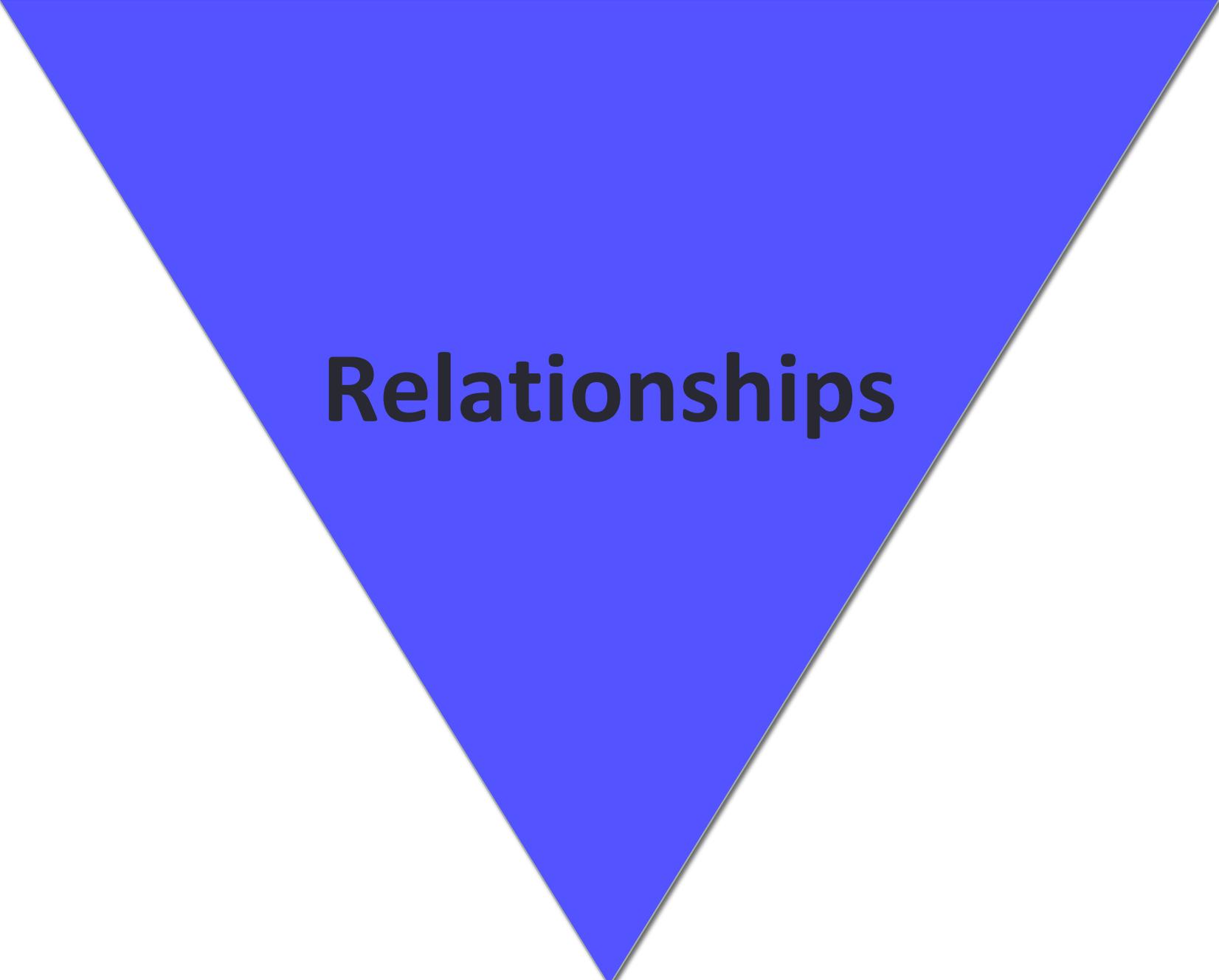
suck

BACK PILLO  
Robert Langford



# Then your child's...

- Pay close attention to what is threatening or triggering your child
- Limit threats and triggers that you can (i.e., this is not the time to decrease screen time, to establish new routines)
- Let them do comforting and familiar things that will help them feel less threatened and more regulated (even if these are old behaviors that you don't like)
- This is what they need in a time of trauma to build regulate themselves...



**Relationships**

# It's all about relationships

- The parent-child relationship provides the foundation for all learning and development
- This is especially true for neurotypical children
- When the world is falling apart, there is no one they need more than you
- And there is no one who knows them better than you
- But when (you and) they are frightened and dysregulated, they can't find you.
- How can you let your child know that you are there for them and that you understand what they are going through?

# It's all about relationships

- How can you maintain your connection to each other (which nurtures you, too)?
- What do they need right now?
- What can they tolerate and enjoy?
- Use *what you know about your child* to calm them down, to reduce threat, and help them begin to connect with you
- You have done this before...
- And you will all get through this....

## It's all about other relationships, too

- How can you maintain your and your child's connection with their teachers and other therapists?
- Which of these relationships can be sustained, and in what way?
- Which of these relationships support you?
- What skills can be practiced?
- What are reasonable expectations?
- Are there other ways – *within reason* -- to provide what's been lost?

# What about you? (after all, you are the glue):

- *Don't let yourself be alone – this is so isolating!*
- For you to be there for anyone else, you need relationships, too!!!!
- Who can you turn to, to talk, to cry, to laugh, to get meaningful support? Your family? Friends? Other parents? Parent groups? Chats?
- What kind of help do you need from others?
- Do you need mental health support?
- Do you need financial and shelter resources?

# Parenting on the frontlines...

- LISTEN.
- If you are trying to listen to your child, you are a GREAT parent!
- Find solutions that make sense *for your child and for you!*
- It is OK! (Actually, it is essential.)
- *You are preserving the vital relationships that will sustain you and your family through and after this*

# Parenting on the frontlines...

- Seek systems, supports, and people who *understand and respect* your real daily struggles, and that value relationships.
- Disregard advice/expectations that do not fit your situation.
- You can only do what you can.
- If something makes you or your child feel threatened, or dysregulated, let it go! Maybe you can come back to it.
- You know yourself and your child and your situation. Respect that.



**Thinking**  
**Planning**  
**Reflection**  
**Perspective**  
**Creativity**  
**Skill building**  
**Learning**  
**Socializing**  
**Flexibility**

## Then, begin to imagine what is possible

- Once you feel less threatened, more regulated, and your connections are re-established, you can begin to think about what is possible *today*, what makes sense *today*.
- Once your child feels less threatened, more regulated, they can begin to experience your presence, and engage in the moment.
- Learning, rebuilding skills depends upon safety, regulation, and relationships.

Slowly, the things you miss will return.  
But they will return in a different way.  
You will build new supports.  
You will find new solutions.  
But first you must find each other.

## Your goal over the next months:

- **Not** to preserve what *was*, (because you can't!) but to insure safety, regulation and connection, and avoid (re)traumatizing yourself and your child.
- IT'S A PROCESS, not a journey.
- Ongoing regressions and progressions are *the way it is*.
- Repair and move forward

## The serenity prayer...

Grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.

Ronald Niebuhr, 1932-33

# A survival mantra...

- Let go.
- Lean in to connection, and to what's possible.
- Breathe.
- Move.
- And, when you can, laugh.

# THANK YOU VERY MUCH!!!

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And thanks for the inspiration...AHMAD, A. (2020) WHY YOU SHOULD IGNORE ALL THAT CORONAVIRUS-INSPIRED PRODUCTIVITY PRESSURE. *CHRONICLE OF HIGHER EDUCATION*, MARCH 27, 2020.