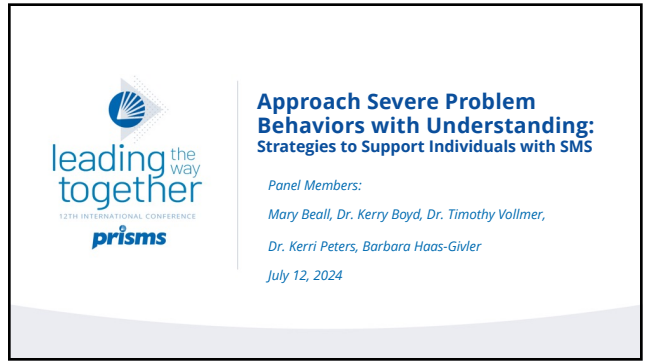
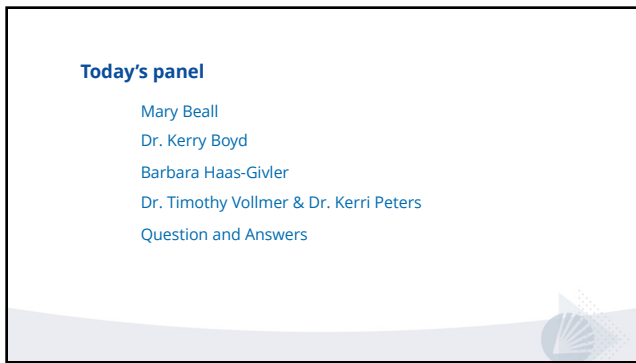




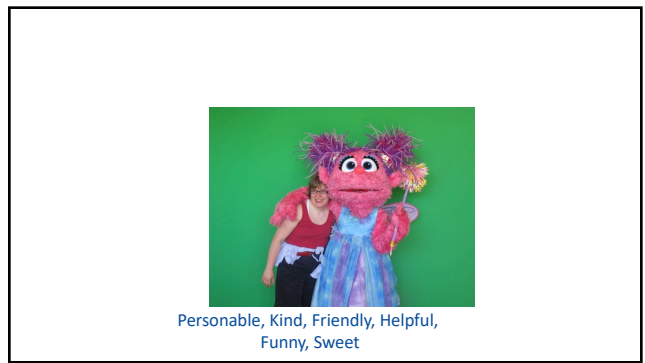
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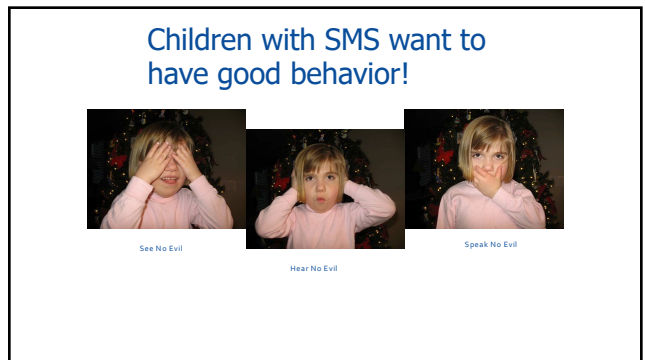
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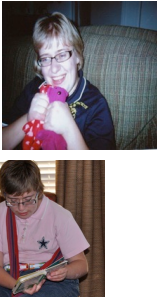
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6

Emotional Immaturity...


- A low tolerance for frustration
- A need to do things for themselves
- Negativity
- Mood Swings
- Short attention span
- Tantrums
- Separation anxiety
- Resistance to changes in routine
- Repeated (unrelenting!) questioning



7

You have to try to Keep a Lid on It!
Help them stay in control

- SMS causes many behaviors that are difficult to control.
- All of us feel "out of control" at times, but people with SMS have to cope with so many tough situations.
- Wouldn't you be tempted to boil over?



8

Prevention: "Only You Can Prevent SMS Fires" ... Your Child Can't!

How to Control the Flames:

Stop, Breathe, and Get Control. (of yourself first)

Do something to slow down or eliminate the "fight or flight" adrenaline.

(Distract, whisper, laugh, or sometimes, do nothing...just wait.)



9

Coping with Big Meltdowns

<p>Don't</p> <ul style="list-style-type: none"> • Interact • Threaten • React - to their words or deeds trying to "get to you" • Assume - that the child is doing this on purpose • Expect - child to be able to reason or talk it out • Worry - about proving who is "Boss" • Punish - for behaviors that happen during the meltdown 	<p>Do</p> <ul style="list-style-type: none"> • Prevent! (the best intervention) • Distract • Control - your own voice and body language • Give them some space • Move them (if you can, safely, and without increasing their rage) • Praise - any attempt at controlling themselves • Wait calmly
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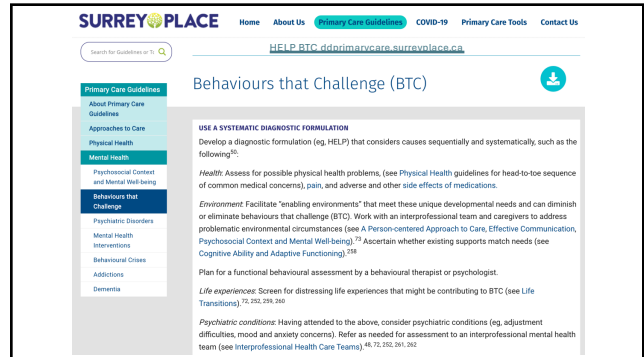
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Kerry Boyd

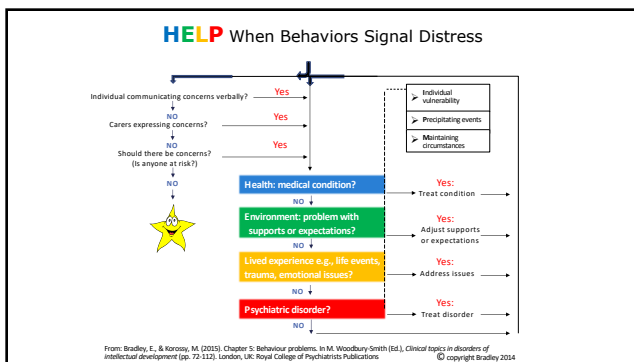
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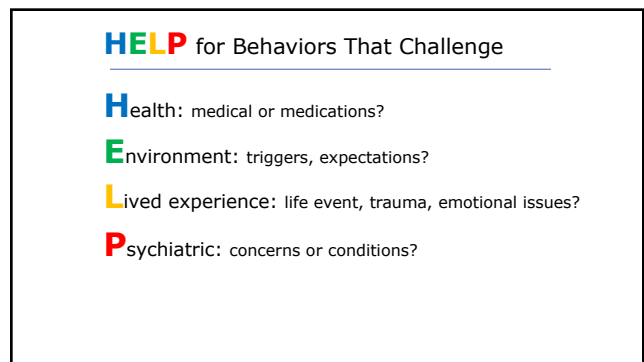
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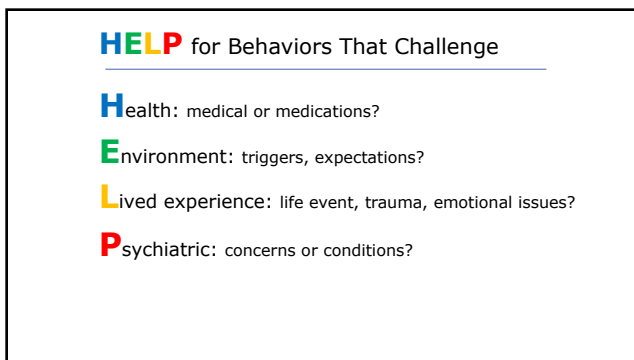
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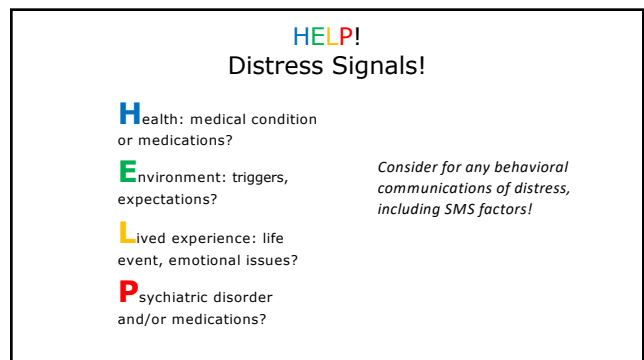
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HELP!
Distress Signals!

H health: medical condition or medications?	H health: insomnia, pain constipation, med SE
E nvironment: stressors, expectations?	E
L ived experience: life event, emotional issues?	L
P sychediatric disorder and/or medications?	P

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HELP!
Distress Signals!

H health: medical condition or medications?	H health: insomnia, constipation, meds SEs
E nvironment: stressors, expectations?	E nvironment: change; over/under-stimulating
L ived experience: life event, emotional issues?	L
P sychediatric disorder and/or medications?	P

20

HELP!
Distress Signals!

H health: medical condition or medications?	H health: insomnia, SEs
E nvironment: stressors, expectations?	E nvironment: sensory, support mismatch
L ived experience: life event, emotional issues?	L ife event: stressful transition, losses, traumas
P sychediatric disorder and/or medications?	P

21

HELP!
Distress Signals!

H health: medical condition or medications?	H health: insomnia, SEs
E nvironment: stressors, expectations?	E nvironment: sensory, support mismatch
L ived experience: life event, emotional issues?	L ife event: stressful transition, losses, traumas
P sychediatric disorder and/or medications?	P sychediatric: NDD, anxiety, mood...

22

Barbara Haas-Givler

24

C

- Strengths: funny, considerate, fun to hang out with, smart, rule governed (but only from a 3rd party or the official source), does well with concrete examples
- Areas of Need: working with and around peers, completing work he did not want to do (or appropriately say he did not want to do them), work with staff that were less preferred, transition between activities

25

School Placement

- 2013-2021: attended an approved private school with Educationally Integrated Behavior Support (EIBS). School team utilizes ABA and has many trained BCBA's and RBT's on staff.
- C received 2:1 staffing; worked away from classmates
- Self-Injury: hitting himself (chest and head), skin and nail picking
- Aggression: hitting others, kicking others, throwing furniture, breaking furniture beyond repair
 - This led to very restrictive interventions
 - Successfully escaping non-preferred conditions, and accessing negative social attention

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Treatment Interventions: 2019

- Environmental Enrichment
- Work in separate, more preferred location
- Use of humor to redirect
- Use of social stories/writing things down
- **DRA: grasp leisure item when in a non-preferred condition; posting on door**
maximize reinforcement for desirable behaviors while minimizing reinforcement for challenging behaviors
- Functional Communication Training (FCT)

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Treatment Interventions: 2019

- Self-monitoring to relinquish items (use of a timer)
- **Differential and contingent reinforcement**
- Punishment: loss of electronics for full day for aggression
- Punishment: 1 hour time-out of access to item not relinquished within set criteria
- Seclusion
- "Use of treatment room" (door closed but not locked)
 - Emergency procedures: bear hug control, secure escort, 2-person 2 arm control and escort, or use of mats surrounding C to safely implement voluntary escort, supine, 4 person carry, seated floor, extended arm

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Turning Point: "My Way Please" FCT

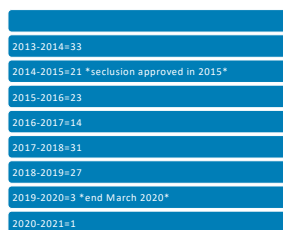
- Visual on desk with words "my way please"
 - visual had video controller on it
- Open response class: touch, say, hand card
- When FCR was used, C had a more preferred staff and task switch, and less preferred staff and task went away
- Independently requesting this within 3 hours
- When C had to learn he could not "get his way" ...
 taught him to independently get preferred fidgets to play with

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Number of Debriefs Per School Year

Debrief

Required within 5 school days for any PE(personal emergency intervention) utilized. Multiple crises can be discussed in 1 debrief, therefore information does not reflect the number of crises, only debrief meetings.

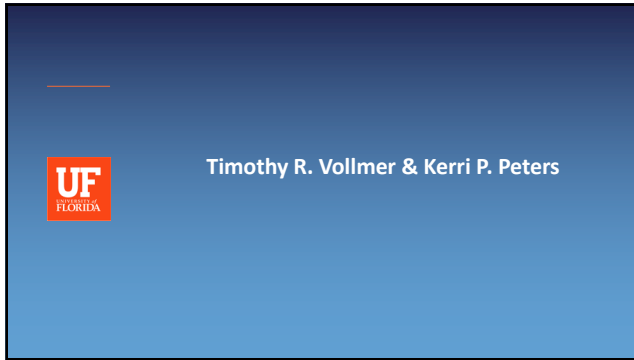


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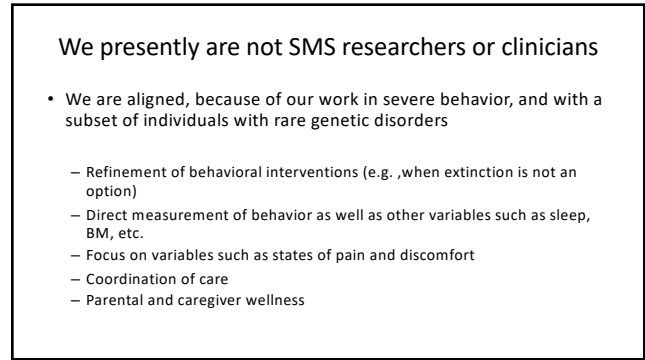
How is C Now?

- Lives at home
- Family discontinued intensive in-home services
- Goes out in the community for leisure trips, and volunteers volunteer
- Loves IT work

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32



33

We presently are not SMS researchers or clinicians

- We are aligned, because of our work in severe behavior, and with a subset of individuals with rare genetic disorders
 - Refinement of behavioral interventions (e.g., when extinction is not an option)
 - Direct measurement of behavior as well as other variables such as sleep, BM, etc.
 - Focus on variables such as states of pain and discomfort
 - Coordination of care
 - Parental and caregiver wellness



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