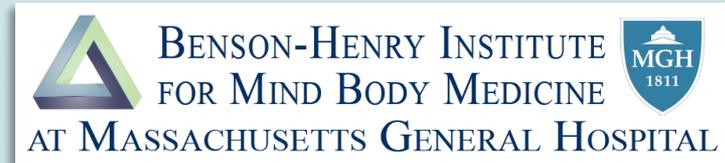


A Virtual Resiliency Treatment for Parents of Children with Learning and Attentional Disabilities (LAD) and Autism Spectrum Disorders (ASD)

Elyse R. Park, Ph.D., MPH
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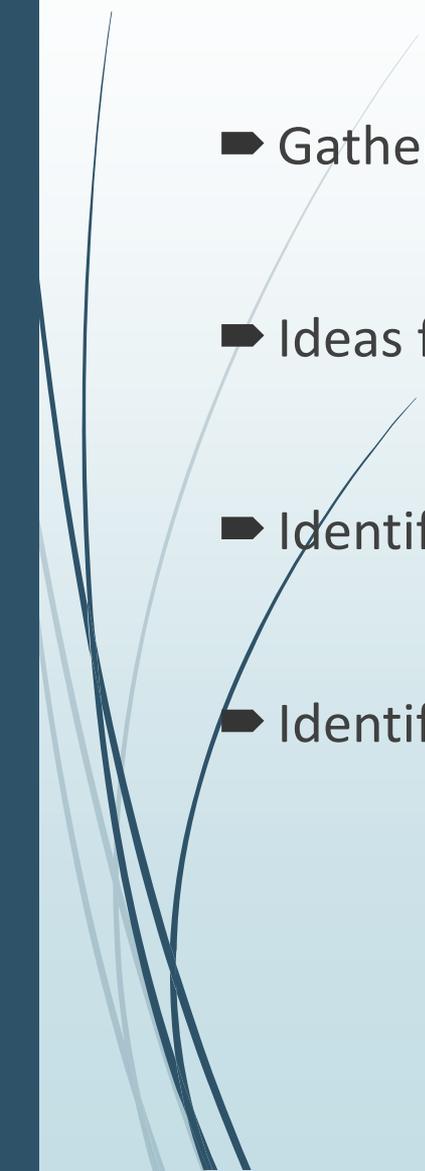
Karen A. Kuhlthau, Ph.D.
Associate Professor of Pediatrics, HMS



MARINO HEALTH FOUNDATION INC



Questions for Discussion

- ▶ Gathering input/feedback on study results
 - ▶ Ideas for implementation trial (e.g., clinician or peer delivered)
 - ▶ Identifying funders
 - ▶ Identifying organizational partners, particularly for parent referrals
- 

Benson-Henry Institute for Mind Body Medicine

- The Benson-Henry Institute (BHI) is an independent thematic center at MGH
- Clinical practice, research, and education
- Focused on mind-body medical techniques, including: meditation, yoga, tai chi, etc.

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MASSACHUSETTS GENERAL HOSPITAL
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We offer clinical care to nearly 2,000 patients per year. We offer both individualized care and group programs for symptom management and disease prevention.

Communication and Behavior of Physician Important in Managing Chronic Pain

September 2014

Paris—Treatment of chronic pain can be challenging, partly because of the associated problems of depression and anxiety. The patient-provider relationship is one of the key components of managing the psychological aspects of chronic pain, according to experts addressing attendees at the recent 2014 annual meeting of the European League Against Rheumatism.

READ MORE: ARTICLE ABOUT CHRONIC PAIN FROM PAIN MEDICINE NEWS

BHI Calendar (2)

September 2014						
S	M	T	W	T	F	S
31	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27

Stress Response

- ▶ Walter B. Cannon described the “fight or flight” response to stress, a consistent set of physiologic changes that occur when individuals are exposed to stress.
- ▶ The stress response prepares the body for a physical reaction to a real threat – to fight or to flee.

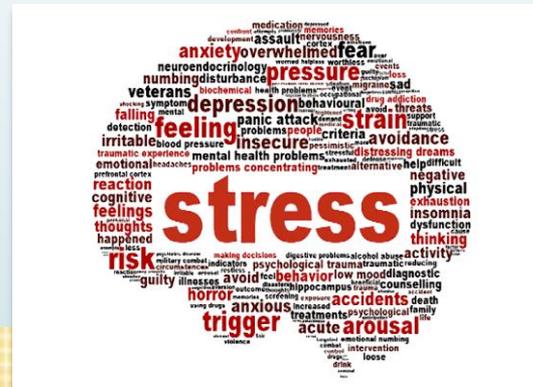


Photo by: <http://www.neuralconnections.net/2014/07/stressappraisal-and-adaptation.html>

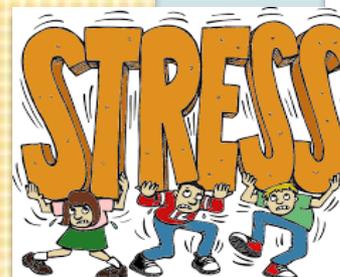
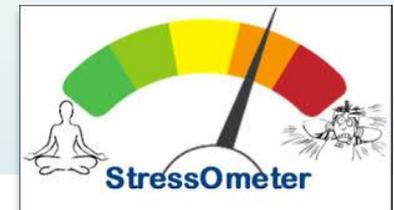
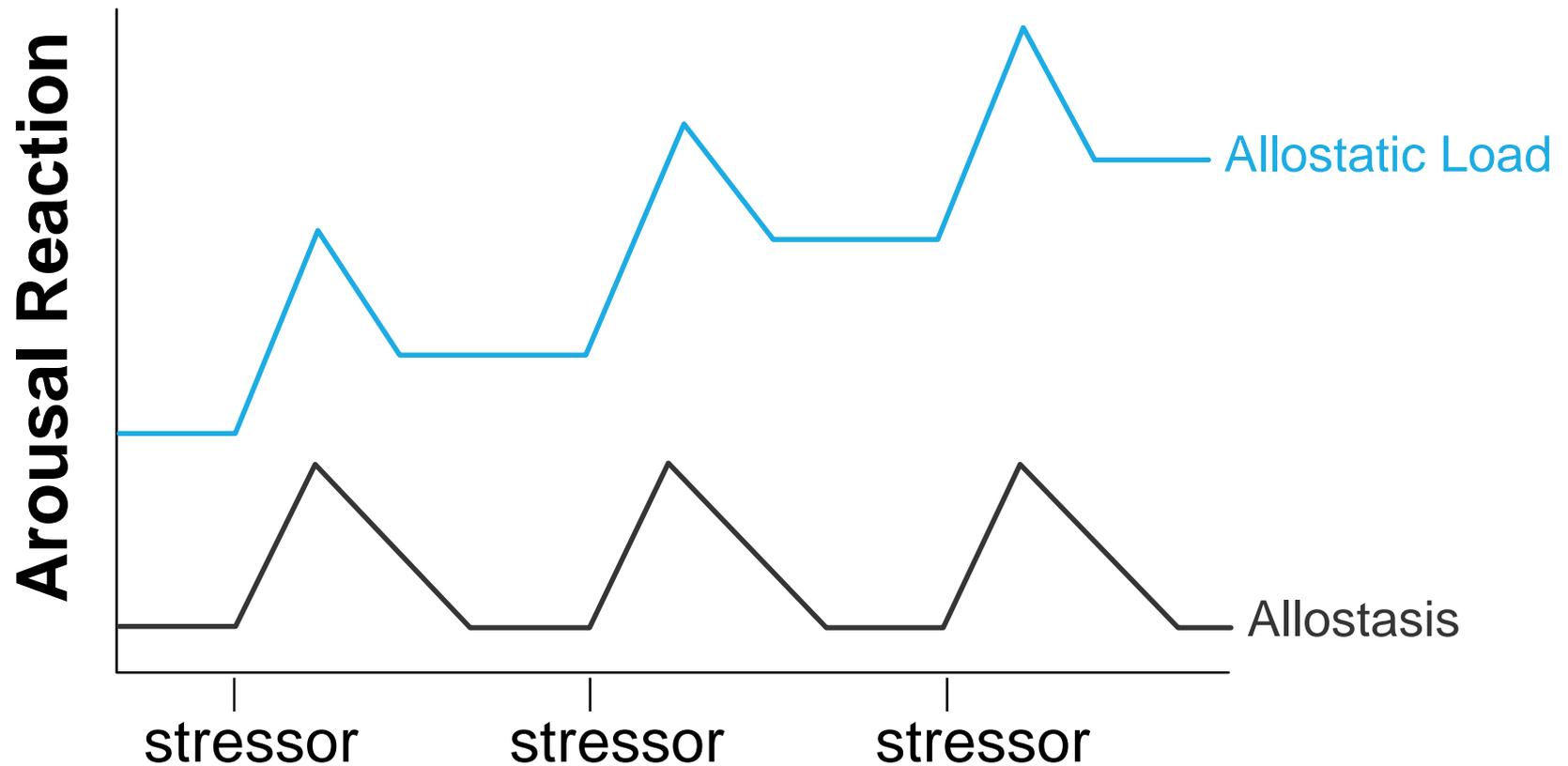


Photo by: Aoife McLoughlin <http://elt-connect.com/fun-with-word-stress/>

Photo by: www.gabankruptcylawyersnetwork.com

Normal vs. Maladaptive Responses to Stress

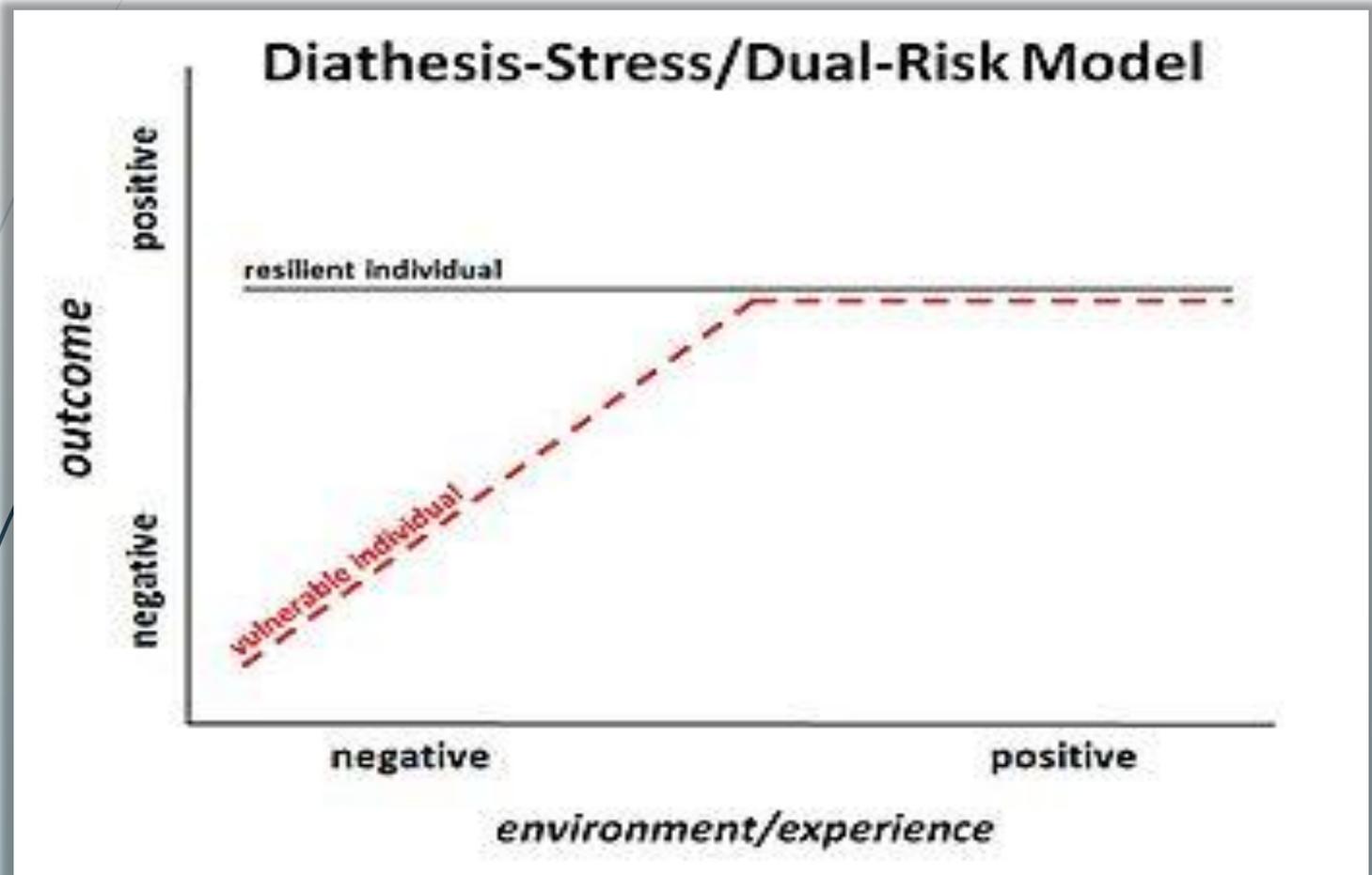


Resilience?



- The ability to adapt successfully in the face of stress and adversity.
- The capacity and dynamic process of adaptively overcoming stress and adversity while maintaining normal psychological and physical functioning (Wu et al., 2013)
- Characteristics that promote resiliency may help to buffer parents from the stress related to caring for a child with LAD or ASD

Diathesis-Stress Model





BHI Resiliency Perspective

Resiliency is characterized by the ability to:

- Adapt to stress by eliciting the RR
- Generate adaptive thoughts
- Engage in healthy lifestyle behaviors
- Experience pleasure and appreciation
- Engage in empathic and pleasant behaviors



Relaxation Response Resiliency Program (3RP) Core Elements

- Skills building in eliciting the RR
- Decreasing stress reactivity by increasing awareness of stress response components
- Practicing adaptive strategies:
 - Positive Perspectives/creativity
 - Healthy lifestyle behaviors
 - Social connectedness
 - Reexamination and coping/humor

RR Elicitation

RESILIENCY

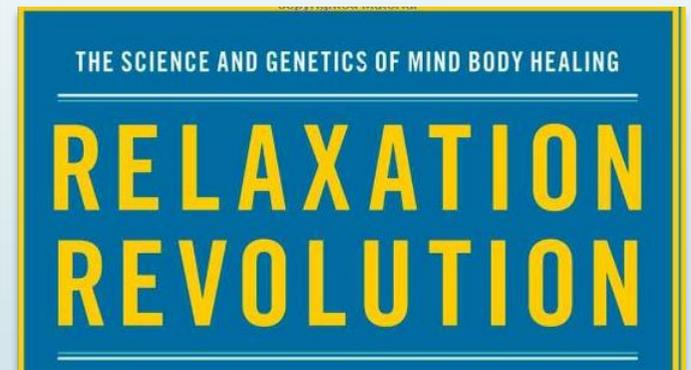
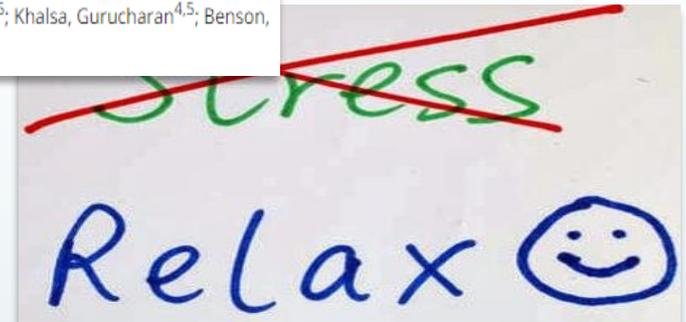
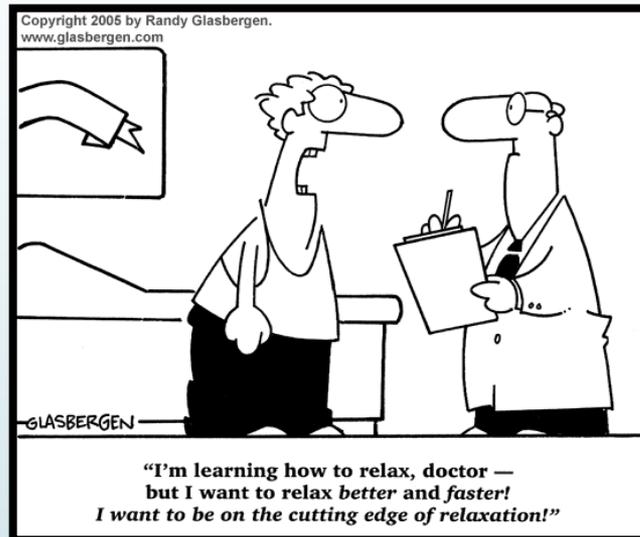
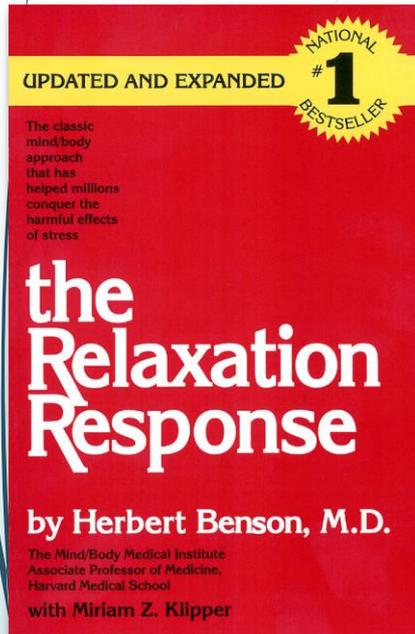
Stress Awareness

Adaptive Strategies

Relaxation Response

Functional brain mapping of the relaxation response and meditation

Lazar, Sara W.^{1,2,6}; Bush, George^{1,2}; Gollub, Randy L.^{1,2}; Fricchione, Gregory L.^{3,5}; Khalsa, Gurucharan^{4,5}; Benson, Herbert^{4,5}



THE LANCET, FEBRUARY 23, 1974

DECREASED BLOOD-PRESSURE IN PHARMACOLOGICALLY TREATED HYPERTENSIVE PATIENTS WHO REGULARLY ELICITED THE RELAXATION RESPONSE

HERBERT BENSON BERNARD A. ROSNER
BARBARA R. MARZETTA HELEN M. KLEMCHUK

*Thorndike Memorial and Channing Laboratories,
Harvard Medical Unit, Boston City Hospital,
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Medicine, Harvard Medical School,
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Original Research Reports

The Development of a Patient-Centered Program Based on the Relaxation Response: The Relaxation Response Resiliency Program (3RP)

Elyse R. Park, Ph.D., M.P.H., Lara Traeger, Ph.D., Ana-Maria Vranceanu, Ph.D.,
Matthew Scult, B.S., Jonathan A. Lerner, Ph.D., Herbert Benson, M.D.,
John Denninger, M.D., Ph.D., Gregory L. Fricchione, M.D.

A dark grey arrow points to the right from the left edge of the slide. Below it, several thin, curved lines in shades of blue and grey sweep across the left side of the slide.

Component 1: RR elicitation goals

- ▶ Achieve an ongoing RR practice
- ▶ Identify which RR elicitation strategy is best for you
- ▶ Feel skillful at eliciting the RR
- ▶ Experience the RR “opening” effect

RR Elicitation

Mindfulness Eating

Use all of your sense to notice what eating is like.

Imagine you are describing the food to someone who has never seen, smelled, touched or tasted it.



Slow down, pause between bites. Take time to savor.

Notice how eating this way is different from how you normally eat.



Component 2: Decrease stress reactivity

- ▶ Identify your stress warning signs
- ▶ Build your stress coping resources
- ▶ Proactively develop your positive cognitions, pleasant emotions and health promoting behaviors

Exercise: Energy Battery

Withdrawals (*drain battery*)



Deposits (*charge battery*)

↑

Busy day at work.
Fought with my spouse.
Ate lunch too quickly.
Spent time organizing a get-together for a friend.
Didn't get enough sleep.
Had an argument with my mother.
Did not have enough time to exercise.
Worried about my weight.
Was late for a meeting.
Rushed around all day doing errands.
Didn't feel well this morning.

↓

Got award at work
Began reading a new book.
Had a visit from childhood friend
Went to bed early this week
Exercised.
Had a picnic in the park.
Mindfully ate lunch.
Saw a movie with friends.
Enjoyed time with family.
Did an RR practice.
Took a walk during my lunch break.

Component 3: Adaptive Strategies

- ▶ Reappraisal & Coping
- ▶ Positive Perspectives
- ▶ Social Connectedness
- ▶ Lifestyle Behaviors



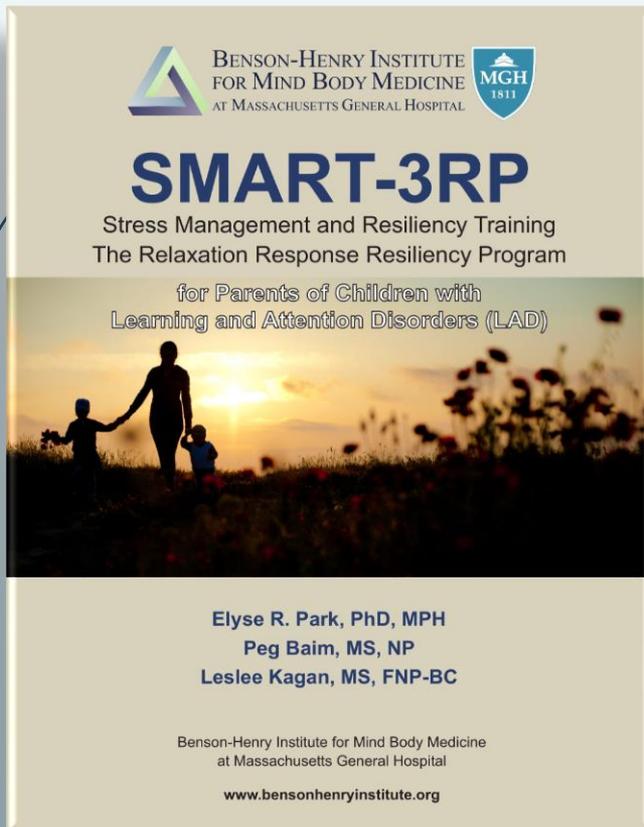
Types of Social Support

- Emotional
- Informational
- Tangible
- Self-esteem/affirmation
- Belonging



Virtual Resiliency Treatment for Parents of Children with Learning and Attentional Disabilities (LAD) or Autism Spectrum Disorders (ASD):

Two Randomized Pilot Trials



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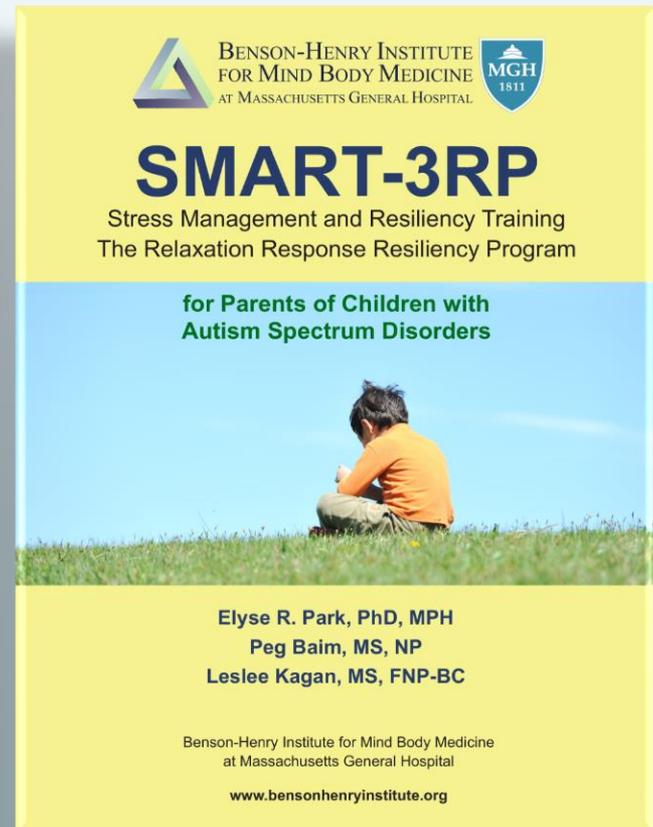
SMART-3RP

Stress Management and Resiliency Training
The Relaxation Response Resiliency Program

for Parents of Children with
Learning and Attentional Disorders (LAD)

Elyse R. Park, PhD, MPH
Peg Baim, MS, NP
Leslee Kagan, MS, FNP-BC

Benson-Henry Institute for Mind Body Medicine
at Massachusetts General Hospital
www.bensonhenryinstitute.org



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Why a Virtual Resiliency Program for Parents of Children with LADs or ASD?

- ▶ Parents of children with LAD and ASD are vulnerable to high levels of distress, and subsequent health risks
- ▶ A comprehensive treatment program focused on the needs of parents of children with LADs or ASD in relation to their stress and health has not been developed, particularly one using a video conferencing platform
- ▶ A video conferencing platform offers the opportunity to unite parents across the United States and enables participation because of scheduling flexibility



Study Background

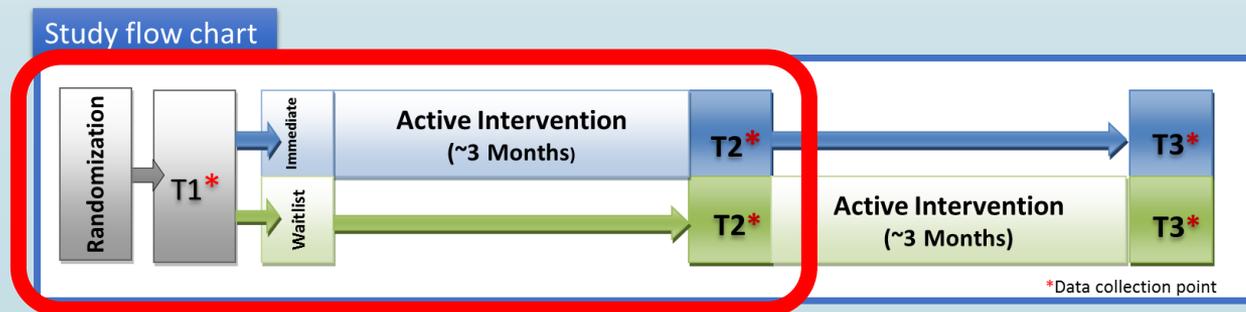
- ▶ This pilot study examines the feasibility and acceptability of the Stress Management And Resiliency Training-Relaxation Response Resiliency Program (SMART-3RP) program for parents of children with LADs or ASD
- ▶ 9-session 1.5 hour/week virtual SMART-3RP adapted using focus group interviews with parents and professionals
- ▶ Seeks to decrease distress and increase resiliency, stress coping, social support, and mindfulness in parents of children with LAD or ASD across the United States.

SMART-3RP Intervention Curriculum

Session	Session Content
1	Introducing Resiliency and the Relaxation Response <i>RR Practice:</i> Simple Breath Awareness
2	SMART-3RP and The Science of Mind-Body Medicine <i>RR Practice:</i> Single-pointed focus meditation and body awareness
3	The Relaxation Response and Recuperative sleep <i>RR Practice:</i> Body scan and the mini
4	Stress Awareness: Mindful Awareness and Social Support <i>RR Practice:</i> Mindful awareness and mindful body meditations
5	Mending Mind and Body: Thoughts and Movement <i>RR Practice:</i> Yoga, walking meditation
6	Creating an Adaptive Perspective and Healthy Eating <i>RR Practice:</i> Insight imagery and joyful place imagery
7	Promoting Positivity and Physical Activity <i>RR Practice:</i> Contemplation
8	Healing States of Mind, Empathy, and Creative Expression <i>RR Practice:</i> Loving Kindness, I am... at peace meditation
9	Humor and Staying Resilient <i>RR Practice:</i> Idealized Self meditation

Study Methods

- Design: Randomized, waitlist controlled pilot trial (09/2016-04/2017)
- Participants: Parents of children with LADs and or children with ASD
- Procedure:
 - Immediate vs. waitlist intervention (control group)
 - Self-report measures collected at: baseline (T1), at 3 months (T2), and at 6 months (T3)
 - Immediate group received virtual SMART-3RP intervention from T1 to T2 with no active intervention from T2 to T3.
 - Waitlist arm received the intervention from T2 to T3.





Outcome Measures

- ▶ Primary outcome measures:

- ▶ Distress (Visual Analog Scale; primary [VAS])

- ▶ Resiliency (Current Experiences Scale [CES])

- ▶ Secondary outcome measures:

- ▶ Stress coping (Measure of Current Status part A [MOCS-A])

- ▶ Social support (Medical Outcome social support survey [MOS])

- ▶ Mindfulness (Cognitive and Affective Mindfulness Scale – Revised [CAMS-R]).



Analyses

- ▶ For immediate treatment subjects, we assessed feasibility and acceptability by examining attendance and responses to a feedback form.
- ▶ Pre-post change from T1 to T2, controlling for sociodemographic baseline characteristics.

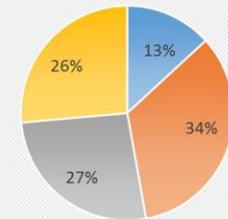
Results: Demographics

Parent Demographic Characteristics		
Demographic	n(%) or M±SD	
	LAD (n=53)	ASD (n=51)
Age (years)*	47±5.7	45±7.6
Female	48 (90.6)	49 (96.1)
Hispanic/Latino	2 (3.8)	2 (3.9)
Race		
White	48 (90.6)	43 (84.3)
Black or African American	2 (3.8)	3 (5.9)
Asian	2 (3.8)	2 (3.9)
Other	0 (0.0)	3 (5.9)
Marital Status*		
Married/Living as married	48 (90.6)	41 (80.4)
Education Level*		
College graduate	51 (96.2)	43 (86.0)
Employment Status*		
Employed/self-employed	37 (69.8)	33 (66.0)
Number of children in household		
0-1	39 (73.6)	23 (45.1)
≥2	13 (24.5)	28 (54.9)
Age of child(ren) with ASD		
2-11	28 (47.5)	26 (51.0)
≥12	31 (52.5)	25 (49.0)
Diagnosis(es) (LAD Only)		
Dyslexia/learning difficulties	23 (43.4)	
Attentional	11 (20.8)	
Both	19 (35.8)	

Enrollment by U.S. Region

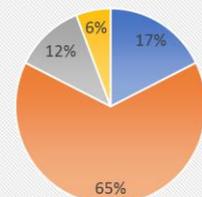
Parents of Children with LAD

- Mid-West (n=7)
- Northeast (n=18)
- South (n=14)
- West (n=14)



Parents of Children with ASD

- Mid-West (n=9)
- Northeast (n=33)
- South (n=6)
- West (n=3)



Results: Feasibility and Acceptability

- LAD Study:
 - 43.9% enrolled and were randomized to the immediate (n=31) or waitlist (n=23) condition.
 - In response to the question, “How successfully do you think this treatment will reduce your stress-related symptoms” (1=not at all to 9=very), intervention participants responded on average 7.1 (SD=1.9)
 - 70.4% of intervention participants completed 6 sessions or more.
 - 81% reported practicing relaxation response exercises at least weekly.

Results: Feasibility and Acceptability

➤ ASD Study:

- 56.7% enrolled and were randomized to the immediate (n=25) or waitlist (n=26) condition.
- 65% of intervention participants completed 6 sessions or more
- 83% reported practicing relaxation response exercises at least a few times a week
- In response to the question, “How successfully do you think this treatment will reduce your stress-related symptoms” (1=not at all to 9=very), intervention participants responded on average 6.7 (SD=1.8)

LAD Study Results: T1-T2 comparisons

Between-group differences in change scores from enrollment (time 1) to three months post-enrollment (time 2) of immediate and waitlist participants.

Variables	M (SD)		M diff	95% CI	t	p	d
	Immediate	Waitlist					
Distress (VAS)	-1.47 (2.44)	.48 (2.23)	-1.95	-3.44,-.46	-2.65	.01	.83
Resiliency (CES)	8.17 (7.29)	1.24 (8.88)	6.93	1.60,12.26	2.63	.01	.85
Stress coping (MOCS-A)	7.74 (7.59)	-.95 (4.57)	8.69	4.72,12.65	4.44	<.001	1.39
Social support (MOS)	5.28 (8.25)	-.19 (7.19)	5.47	.46,10.48	2.21	.03	.71
Mindfulness (CAMS-R)	2.83 (4.11)	-.62 (3.88)	3.45	.86,6.05	2.70	.01	.86

d= Cohen's d (effect size); sample sizes for analyses reflect available data from study completers at time 2 for the immediate (n=19) and waitlist (n=21) groups.

- Among intervention participants, improvements were reported on distress, resiliency (CES), mindfulness (CAMS-R), and stress coping (MOCS-A) (all $p < .05$).
- Significant improvements in primary outcomes: distress (VAS; $p = .05$), and resiliency (CES; $p = .01$)
- Significant improvements in secondary outcomes: mindfulness (CAMS-R; $p = .01$) and stress coping (MOCS-A; $p = .001$), but not in social support.

LAD Study Results: T2-T3 comparisons

Changes from time 2 to time 3 within the immediate treatment group (n=18)				
Variables	M (SD)		t	p
	3 months (T2)	6 months (T3)		
Distress (VAS)	3.9 (1.8)	4.4 (1.7)	-.86	.40
Resiliency (CES)	92.2 (10.3)	91.7 (11.2)	.27	.79
Stress coping (MOCS-A)	30.5 (6.0)	31.4 (6.5)	-.53	.60
Social support (MOS)	76.6 (14.8)	74.1 (15.1)	.94	.36
Mindfulness (CAMS-R)	42.1 (3.1)	42.4 (3.2)	-.62	.55

Sample sizes for analyses reflect available data from study completers at time 3 for the immediate treatment group.

- Maintenance effects were observed in the immediate treatment group from T2 to T3 in resiliency (CES), stress coping (MOCS-A), social support (MOS), and mindfulness (CAMS-R).

ASD Study Results: T1-T2 comparisons

Differences in change scores between the immediate (n=20) and delayed (n=22) treatment groups from T1 to T2

Variables	M (SD)		M diff	95% CI	t	p	d
	Immediate	Waitlist					
Distress (VAS)	-1.35 (2.50)	-.36 (2.74)	-0.99	-2.63,0.65	-1.22	.23	.38
Resiliency (CES)	6.05 (8.74)	.27 (8.72)	5.78	.33,11.23	2.14	.038	.66
Stress coping (MOCS-A)	7.60 (7.24)	-.18 (6.66)	7.78	3.45,12.12	3.63	.001	1.12
Social support (MOS)	4.15 (11.29)	-2.73 (9.70)	6.88	.33,13.42	2.12	.040	.65
Mindfulness (CAMS-R)	2.95 (3.47)	.27 (3.53)	2.68	.49,4.87	2.47	.018	.77

d= Cohen's d (effect size); sample sizes for analyses included study completers at T2

- Immediate treatment group showed greater improvement in resiliency relative to the delayed treatment group, (CES; p=.038).
- The immediate treatment group showed a small improvement in distress (VAS) relative to the delayed treatment group, although these differences did not reach statistical significance (p=.23).
- Immediate treatment participants showed improvements in stress coping (MOCS-A; p=.001), social support (MOS; p=.04) and mindfulness (CAMS-R; p=.018).

ASD Study Results: T2-T3 comparisons

Changes from time 2 to time 3 within the immediate treatment group (n=17)

Variables	M (SD)		t	p
	3 months (T2)	6 months (T3)		
Distress (VAS)	3.9 (2.5)	4.7 (3.4)	-1.18	.26
Resiliency (CES)	92.1 (18.7)	93.2 (20.9)	-.57	.58
Stress coping (MOCS-A)	28.8 (9.5)	30.1 (11.4)	-.76	.46
Social support (MOS)	73.3 (16.0)	73.8 (17.6)	-.25	.81
Mindfulness (CAMS-R)	41.1 (5.1)	42.6 (6.4)	-1.51	.15

Sample sizes for analyses reflect available data from study completers at time 3 for the immediate treatment group.

- Maintenance effects were observed in the immediate treatment group from T2 to T3 in resiliency (CES), stress coping (MOCS-A), social support (MOS), and mindfulness (CAMS-R).



Conclusions

- ▶ Pilot trial findings show promising feasibility, acceptability, and efficacy
- ▶ Virtually-delivered resiliency treatment improved parents' overall levels of distress, stress coping, and resiliency.
- ▶ Video conferencing-based interventions may help to better reach, and connect, parents of children with LADs or ASD who may otherwise be difficult to engage in programs due to the demands of caregiving
- ▶ Post-treatment improvements in psychosocial outcomes were sustained at T3 (6 months post-enrollment)



Next Steps: Your Input

- ▶ Gathering input/feedback on study results
- ▶ Ideas for implementation trial (e.g., clinician or peer delivered)
- ▶ Identifying funders
- ▶ Identifying organizational partners, particularly for parent referrals

Thank you!