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

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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: mediation, yoga, tai chi, etc.
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.
Normal vs. Maladaptive Responses to Stress

Arousal Reaction

stressor  stressor  stressor

Allostasis

Allostatic Load

Adapted from McEwan B, Neuropsychopharmacology, 2000
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

Stress Awareness

Adaptive Strategies

RESILIENCY
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
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

<table>
<thead>
<tr>
<th>Withdrawals (drain battery)</th>
<th>Deposits (charge battery)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Busy day at work.</td>
<td>Got award at work</td>
</tr>
<tr>
<td>Ate lunch too quickly.</td>
<td>Had a visit from childhood friend</td>
</tr>
<tr>
<td>Spent time organizing a get-together for a friend.</td>
<td>Went to bed early this week</td>
</tr>
<tr>
<td>Didn't get enough sleep.</td>
<td>Exercised.</td>
</tr>
<tr>
<td>Had an argument with my mother.</td>
<td>Had a picnic in the park.</td>
</tr>
<tr>
<td>Did not have enough time to exercise.</td>
<td>Mindfully ate lunch.</td>
</tr>
<tr>
<td>Worried about my weight.</td>
<td>Saw a movie with friends.</td>
</tr>
<tr>
<td>Was late for a meeting.</td>
<td>Enjoyed time with family.</td>
</tr>
<tr>
<td>Rushed around all day doing errands.</td>
<td>Did an RR practice.</td>
</tr>
<tr>
<td>Didn't feel well this morning.</td>
<td>Took a walk during my lunch break.</td>
</tr>
</tbody>
</table>
Component 3: Adaptive Strategies

- Reappraisal & Coping
- Positive Perspectives
- Social Connectedness
- Lifestyle Behaviors
Types of Social Support

- Emotional
- Informational
- Tangible
- Self-esteem/affirmation
- Belonging
Appreciation
Virtual Resiliency Treatment for Parents of Children with Learning and Attentional Disabilities (LAD) or Autism Spectrum Disorders (ASD):

Two Randomized Pilot Trials
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.
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

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

<table>
<thead>
<tr>
<th>Parent Demographic Characteristics</th>
<th>n(%) or M±SD</th>
<th>LAD (n=53)</th>
<th>ASD (n=51)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)*</td>
<td>47±5.7</td>
<td>45±7.6</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>48 (90.6)</td>
<td>49 (96.1)</td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>2 (3.8)</td>
<td>2 (3.9)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>48 (90.6)</td>
<td>43 (84.3)</td>
<td></td>
</tr>
<tr>
<td>Black or African American</td>
<td>2 (3.8)</td>
<td>3 (5.9)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2 (3.8)</td>
<td>2 (3.9)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>0 (0.0)</td>
<td>3 (5.9)</td>
<td></td>
</tr>
<tr>
<td>Marital Status*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/Living as married</td>
<td>48 (90.6)</td>
<td>41 (80.4)</td>
<td></td>
</tr>
<tr>
<td>Education Level*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>College graduate</td>
<td>51 (96.2)</td>
<td>43 (86.0)</td>
<td></td>
</tr>
<tr>
<td>Employment Status*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed/self-employed</td>
<td>37 (69.8)</td>
<td>33 (66.0)</td>
<td></td>
</tr>
<tr>
<td>Number of children in household</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-1</td>
<td>39 (73.6)</td>
<td>23 (45.1)</td>
<td></td>
</tr>
<tr>
<td>≥2</td>
<td>13 (24.5)</td>
<td>28 (54.9)</td>
<td></td>
</tr>
<tr>
<td>Age of child(ren) with ASD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-11</td>
<td>28 (47.5)</td>
<td>26 (51.0)</td>
<td></td>
</tr>
<tr>
<td>≥12</td>
<td>31 (52.5)</td>
<td>25 (49.0)</td>
<td></td>
</tr>
<tr>
<td>Diagnosis(es) (LAD Only)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyslexia/learning difficulties</td>
<td>23 (43.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attentional</td>
<td>11 (20.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both</td>
<td>19 (35.8)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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).
Among intervention participants, improvements were reported on distress, resiliency (CES), mindfulness (CAMS-R), and stress coping (MOCS-A) (all ps<.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.
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).

<table>
<thead>
<tr>
<th>Variables</th>
<th>3 months (T2)</th>
<th>6 months (T3)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distress (VAS)</td>
<td>3.9 (1.8)</td>
<td>4.4 (1.7)</td>
<td>-.86</td>
<td>.40</td>
</tr>
<tr>
<td>Resiliency (CES)</td>
<td>92.2 (10.3)</td>
<td>91.7 (11.2)</td>
<td>.27</td>
<td>.79</td>
</tr>
<tr>
<td>Stress coping (MOCS-A)</td>
<td>30.5 (6.0)</td>
<td>31.4 (6.5)</td>
<td>-.53</td>
<td>.60</td>
</tr>
<tr>
<td>Social support (MOS)</td>
<td>76.6 (14.8)</td>
<td>74.1 (15.1)</td>
<td>.94</td>
<td>.36</td>
</tr>
<tr>
<td>Mindfulness (CAMS-R)</td>
<td>42.1 (3.1)</td>
<td>42.4 (3.2)</td>
<td>-.62</td>
<td>.55</td>
</tr>
</tbody>
</table>

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

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

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 (CAMR-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!