

OBJECTIVE

Background

- Internalized health-related stigma stems from embarrassment about having an illness and the fear that one may encounter discrimination based on their condition
- Approximately 50% of people with epilepsy (PWE) internalize stigma
- Stigma is linked to poor epilepsy self-management, reduced quality of life (QOL), anxiety and depression, and suicide risk
- The World Health Organization declared epilepsy stigma a worldwide public health concern and the Institute of Medicine encouraged efforts on reducing stigma through behavioral health interventions

Study Aims

- Identify critical components of a behavioral health intervention to teach PWE strategies to reduce stigma and enhance QOL
- Determine shortcomings of past anti-stigma interventions and create a platform that systematically addresses these issues

METHOD

Procedures

- Targeted review of empirical and theoretical research on epilepsy stigma was leveraged to determine critical intervention components
- Two neuropsychologists, a neurologist, and a computer engineer with experience in epilepsy care, intervention development, and digital health engaged in iterative, weekly meetings for 1 year to develop an intervention appropriate for adults with epilepsy

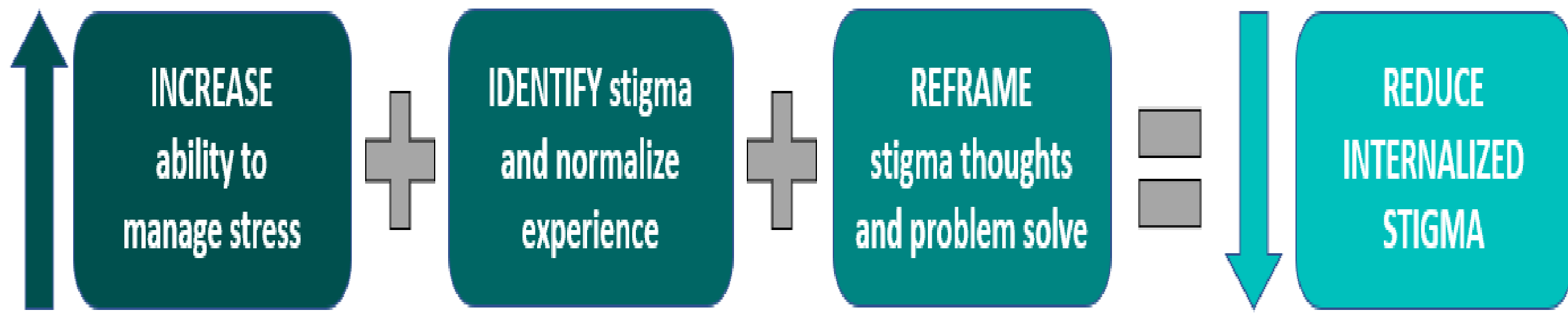
RESULTS

- Stigma manifests in education, work, healthcare and relationships
- Table 1 highlights critical components and gaps in prior interventions
- A self-administered, modular, online platform with built-in demonstration and interactive practice exercises was developed, called: ***RISE ABOVE: Reducing Internalized Stigma in Epilepsy: A Behavioral Online Video Education***

Intervention Components	Nurse Led Conversation During ER Visits	Parent-Child Education Sessions	Peer Support Groups	RISE ABOVE
Psychoeducation	✓	✓	✓	✓
Focused on Psychosocial Aspects of Epilepsy		✓	✓	✓
Co-Produced by People Living w/ Epilepsy			✓	✓
Teaches Evidence Based Coping Skills				✓
Self Administered				✓
Mobile Format				✓

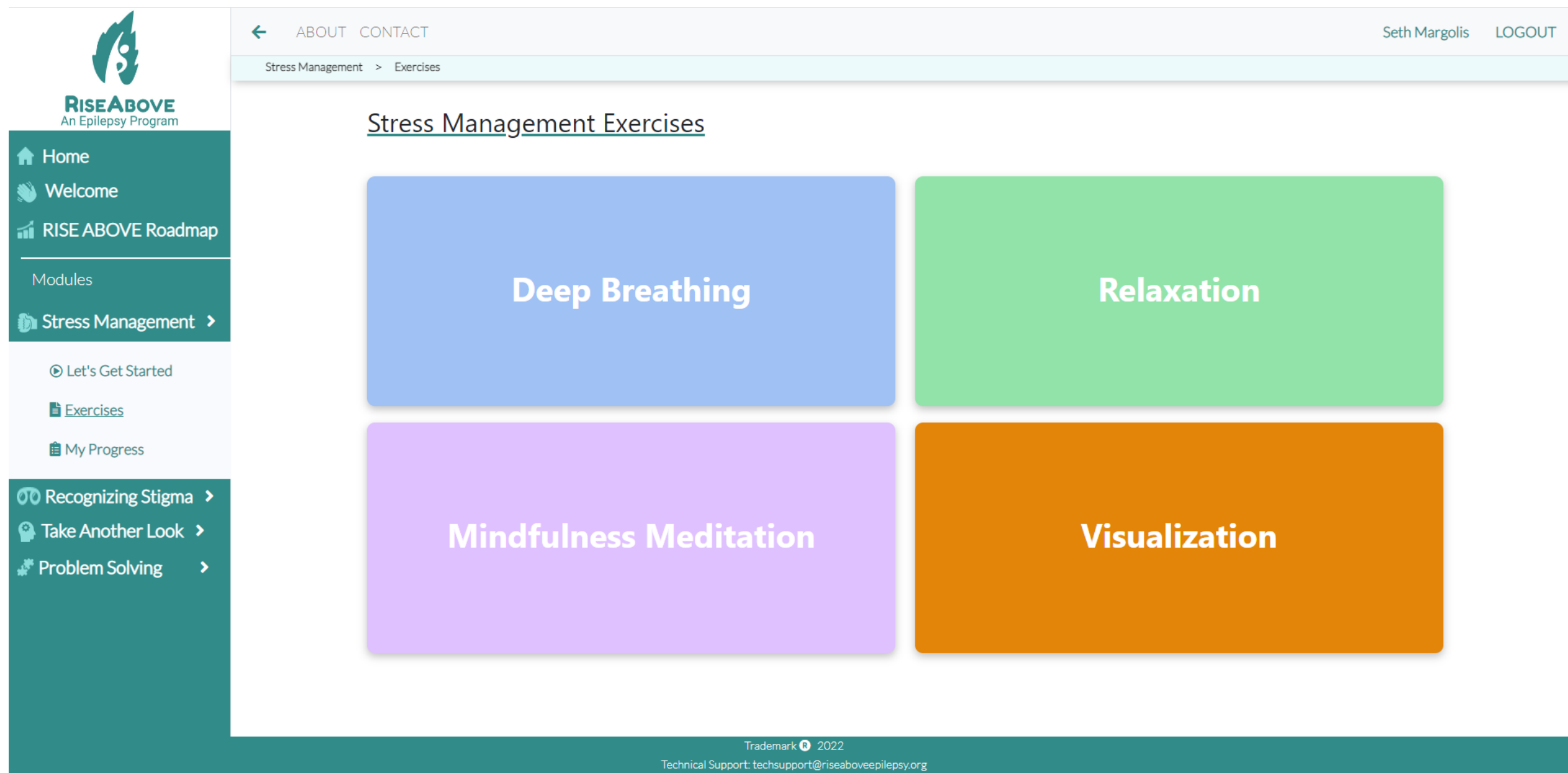
RESULTS

- RISE ABOVE aims to help PWE:



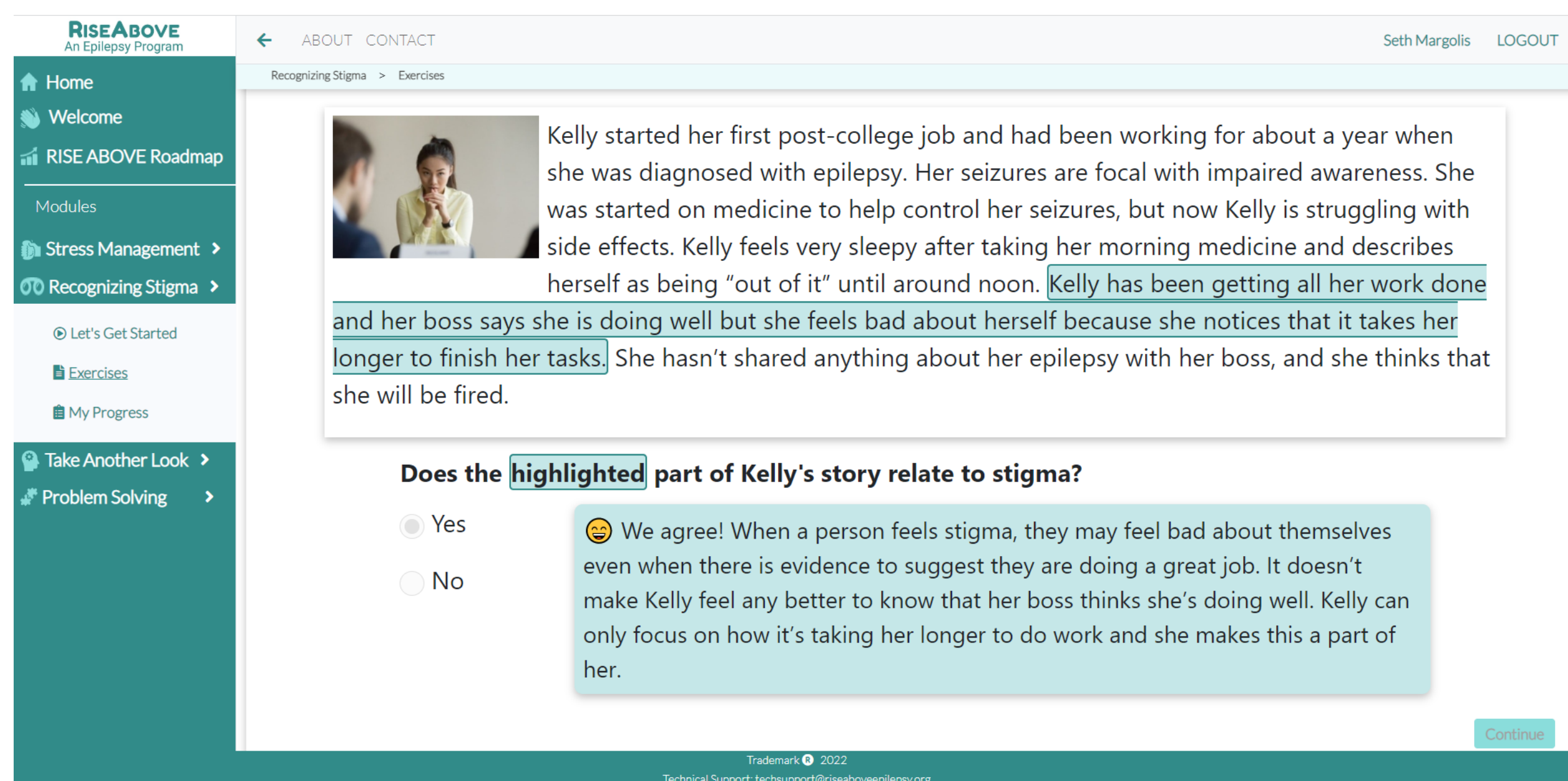
- Module 1, ***Stress Management***, teaches deep breathing, progressive muscle relaxation, visualization, and mindfulness techniques via guided demonstration and practice exercises (Fig. 1)

Figure 1: *Stress Management* Exercises



- Module 2, ***Recognizing Stigma***, uses stories adapted from the lives of PWE to teach users to identify and understand stigma-related thoughts, feelings, and reactions, and how these thoughts impact QOL (Fig. 2)

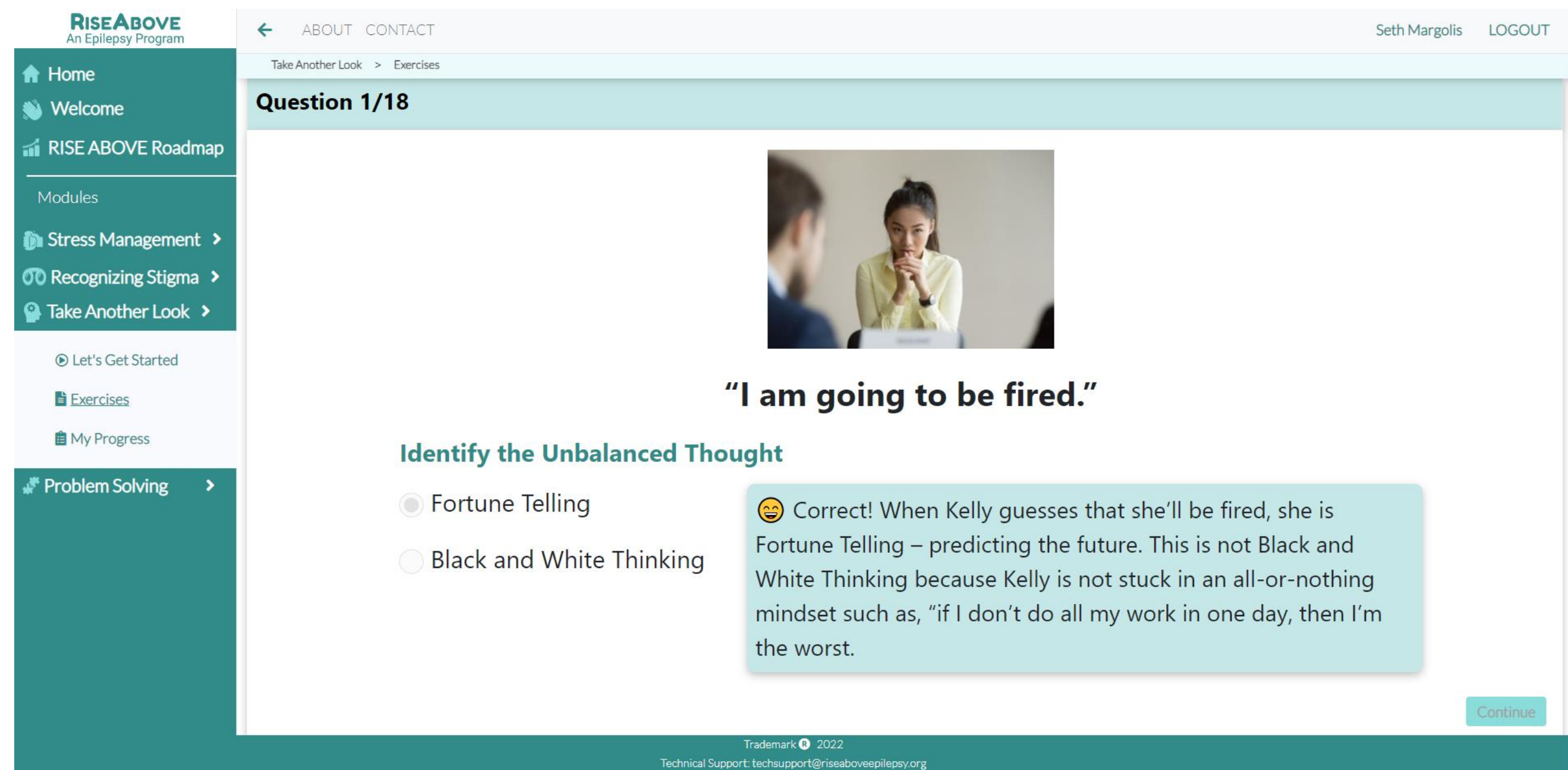
Figure 2: *Recognizing Stigma* Vignette Exercise



RESULTS

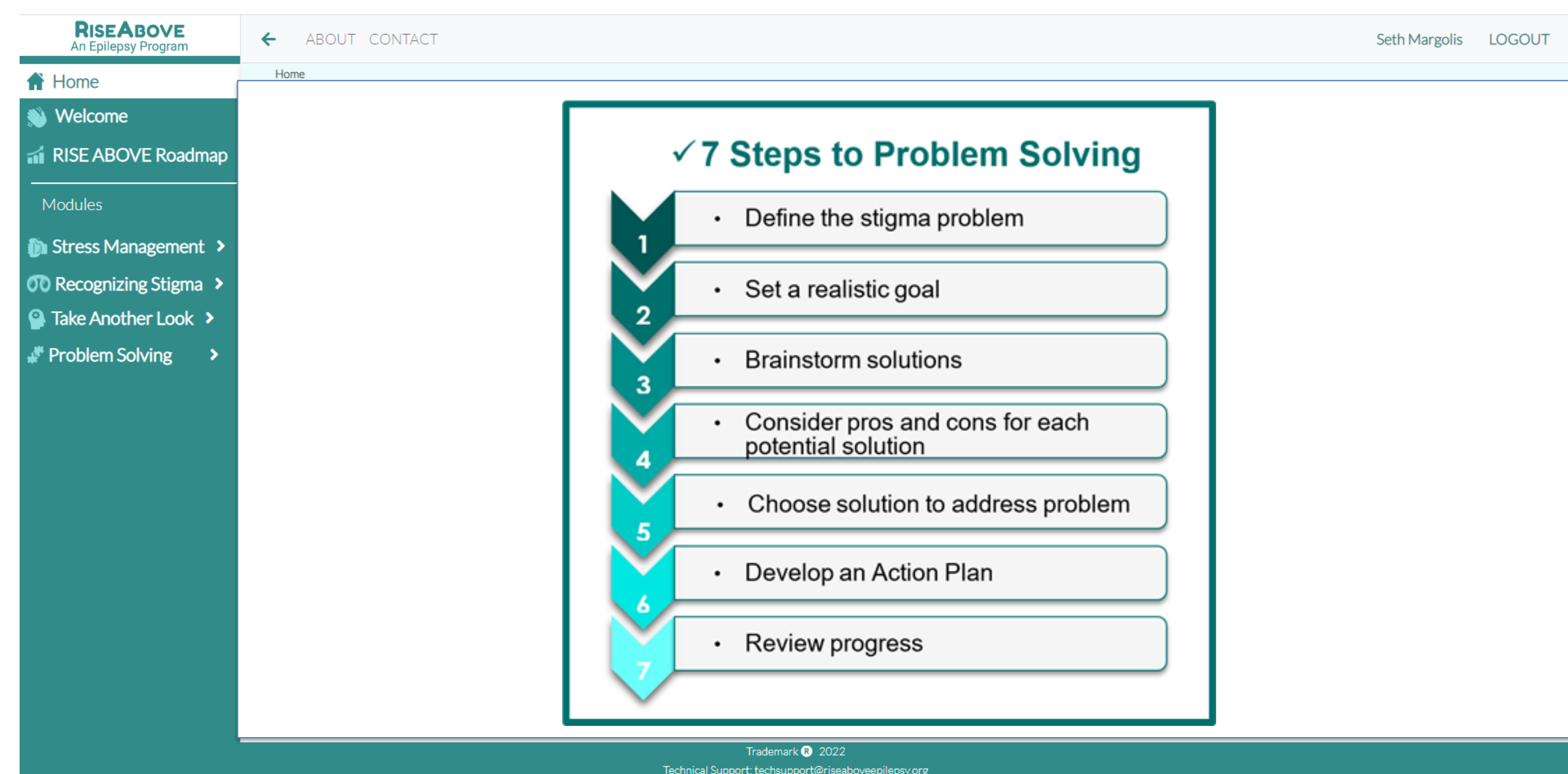
- Module 3, ***Take Another Look***, explains the concept of cognitive distortions and how they relate to stigma, then teaches 2 strategies to reframe unbalanced thoughts (Fig. 3)

Figure 3: *Take Another Look* Cognitive Reframing Exercise



- Module 4, ***Problem Solving***, guides users to apply problem solving skills to stigma situations via a step-by-step process (Fig. 4)

Figure 4: *Problem Solving* Exercise



CONCLUSION

- Drawing on research, theory, and collaborative multidisciplinary interaction, psychoeducational content employing a cognitive-behavioral framework was adapted to a self-administered, modular, online platform to mitigate the stigma felt by PWE
- Future research will elicit feedback from community stakeholders and beta test RISE ABOVE to guide its final optimization

**This project was funded by a grant from Epilepsy Foundation New England*