

Final Grant Report

Promoting Positive Family Adaptation following Pediatric Brain Injury:
Development and Pilot Trial of “Road to Recovery for Caregivers after TBI” (R2R-TBI)

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Table of Contents

Introduction.....	3
Executive Summary	5
Background and Rationale for the R2R-TBI Program	5
Aims.....	7
Information/Qualifications of the Principal and Co-Investigators.....	8
The Setting	9
The R2R-TBI Program	9
Stages of Development.....	9
Delivery	10
Content.....	11
The R2R-TBI Program Modules	11
Pilot Testing	14
Participants	14
Procedure	15
Measures.....	16
Data Analysis.....	19
Results.....	19
Analysis of Researchers' Findings.....	23
Conclusions and Recommendations	24
Notes	25
References.....	26
Appendix.....	31

Introduction

Pediatric traumatic brain injury (TBI) is a leading cause of acquired disability in childhood and can result in a range of short- and long-term challenges for children/adolescents and their families. These include emergent internalizing and externalizing behavior problems, particularly among children/adolescents who have sustained moderate to severe TBI (e.g., Bloom et al., 2001; Li & Liu, 2013; Schwartz et al., 2003). An important, though often overlooked factor in child/adolescent outcomes following pediatric TBI is the influence of parent/caregiver psychological functioning. Poor caregiver psychological functioning has been found to exacerbate child behavior problems following injury (e.g., Raj et al., 2014), and this is particularly notable given that parents of children with TBI report more family problems and greater levels of stress than parents of non-injured children (Hawley et al., 2003).

Recognizing that (1) caregivers of children who have sustained TBI are at risk of worsening psychological well-being and that (2) parent functioning in turn impacts child recovery; intervening and supporting parents in the acute phase following may set families on a positive path to recovery. The aim of this pilot study was to develop and conduct usability testing of a self-guided responsive web design (RWD) program, i.e., the Road to Recovery for Caregivers after TBI (R2R-TBI), designed to improve caregiver functioning and increase positive parenting behaviors in the acute phase following pediatric TBI. Stages of development of the R2R-TBI intervention included review of the literature, consultation with a parent advisory council (consisting of three parents of children with brain injuries who have become parent leaders/advocates), consultation with providers, preliminary usability testing/feedback sessions with five parents of children with brain injuries, and pilot testing with 22 caregivers (average age: 32.5 years, range: 18 to 51 years) with a child (average age: 4.62 years, range: 4

days – 14 years) sustaining a TBI within the previous 3-months. Caregivers who participated were predominantly mothers (93%; 7% fathers) and varied with regard to demographic background including level of education (32% with up to high school diploma/GED, 32% with up to 2-years of college, and 36% with a Bachelor's degree and higher), household income (annual income range: less than \$20,000 to over \$100,000), and race/ethnicity (59% Caucasian American, 32% African American, and 9% Other).

Caregivers reported high levels of satisfaction with the program. All reported that the program was helpful to them and most (80%) reported that they learned tips to be a better parent and almost all (93%) reported making positive changes as a result of the program. Qualitative feedback included that the program “was very informative,” “helped me better understand what my child might be going through,” and “helped me with controlling my emotions.” Parents also reported that “some of the guides to dealing with stress and self-care were very good” and “this experience was very informative and has opened my eyes to the reality of my situation.” Overall, participants considered the website usable with some providing higher usability ratings than others. Suggestions/feedback included tailoring content to smaller age groups (from the parent of a 6-month old) and including opportunities to speak with a provider. Data analyses is ongoing and we will explore caregiver factors that may impact satisfaction and usability. Feedback from this trial will be used to further develop the program.

To our knowledge this is the first self-guided web-based intervention targeting parent/caregiver functioning in the acute phase following pediatric TBI. Given challenges parents of children with TBI may experience accessing traditional in-office interventions targeting their well-being and/ or parenting, the R2R-TBI program may be a cost-effective resource to support the hundreds of families impacted by pediatric TBI in Ohio each year.

Executive Summary

Background and Rationale for the R2R-TBI Program

Over 600,000 children between the ages of 0 and 14 years are seen in emergency rooms across the country each year due to traumatic brain injury (Taylor, Bell, Breiding, & Xu, 2017). Children who sustain moderate to severe TBI are at risk for persistent impairment in daily functioning, including deficits in self-care, communication skills, social development, and externalizing behavior problems (e.g., Janusz et al., 2002; Langlois et al., 2006; Thurman et al., 1999, Max et al., 1998). Emergent externalizing behavior problems such as aggression, conduct problems, and oppositional defiant behaviors (Li & Liu, 2013) are particularly common among children/ adolescents who have sustained moderate to severe TBI (e.g., Bloom et al., 2001; Schwartz et al., 2003). These behaviors can result in negative life trajectories, which contribute to the over-representation of adolescents with TBI in juvenile justice settings (Perron, 2008). An important, though often overlooked factor in child/adolescent outcomes following pediatric TBI is the influence of parent/caregiver psychological functioning. Poor caregiver psychological functioning has been found to exacerbate child behavior problems following injury (e.g., Raj et al., 2014), and this is particularly notable given that parents of children with TBI report more family problems, poorer psychological functioning such as higher rates of depression and anxiety, and greater levels of stress than parents of non-injured children (Hawley et al., 2003; Wade et al., 1998).

Parent functioning is important to target in the acute phase following pediatric TBI as poor parent functioning and parent-child communication has been found exacerbate negative child outcomes following injury. For example, in a sample of children with moderate and severe TBI, higher levels of parent psychological distress at 6 months predicted more child behavior

problems 6 months later (Taylor et al., 2001). In a recent study, Raj et al. (2014) found that poorer parent psychological health was associated with more adolescent externalizing behavior problems in the initial months following TBI. In contrast, more positive parent-adolescent communication was associated with fewer behavior problems (Raj et al., 2014). In younger child samples, Wade et al. (2008) found that parents of children with TBI showed less warm responses to their child compared with parents of children with orthopedic injuries, and this lower level of warmth was associated with higher rates of externalizing behavior problems among young children. Similarly, harsh critical parenting also contributed to higher levels of attention-deficit hyperactivity symptoms among children with severe TBI (Wade et al., 2011a).

Despite growing evidence of the powerful impact of parent functioning and behaviors on child outcomes following pediatric TBI, to our knowledge, there are no interventions specifically targeting parent needs and well-being in the acute phase following injury. Indeed, there is a dearth of interventions for families impacted by pediatric TBI (Brown et al., 2013). A number of existing interventions, such as McLaughlin, Glang, and colleagues' (2013) web-based training in family advocacy, focus on chronic needs, and not on functioning in the immediate weeks after injury. There are a number of factors that hamper intervention efforts with parents affected by pediatric TBI. For example, parents who are already burdened with their child's medical needs may have neither the time and resources, nor inclination to seek supports for themselves. Traditional barriers to help seeking, such as perceived stigma (Corrigan, 2004) may also prevent parents from accessing psychological interventions targeting caregiver functioning and/ or parenting (e.g., individual or group therapy). Moreover, other barriers to accessing services such as living in rural areas or lack of transportation and financial resources are also relevant to families affected by TBI, particularly those from lower income backgrounds. As such, traditional

in-office psychological interventions that target psychological health and parenting behaviors may not be desirable or easily accessible to parents of children with TBI who would benefit from these services.

Recognizing that (1) caregivers of children who have sustained TBI are at risk of worsening psychological well-being and that (2) parent functioning in turn impacts child recovery; intervening and supporting parents in the acute phase following injury is crucial. In addition, it is essential that these interventions are accessible and convenient to families who are already struggling with injury-related burden and distress. As our society becomes more familiar with and reliant on the internet and smartphones, delivery of behavioral health interventions via these platforms is increasing (Luxton et al., 2011). Moreover, interventions delivered via smartphone may reduce barriers to help-seeking and promote evidence-based interventions that are both accessible and efficient (Luxton et al., 2011). Web-based interventions delivered via smartphone and computer (such as the R2R-TBI program) may be particularly suited to the needs of parents in the acute phase after pediatric TBI, as parents can access the program at their own convenience, for example while their child receives outpatient therapies, and do not have to concern themselves with arranging child-care, or travelling with a child who may have mobility challenges and/or challenging behaviors.

Aims

The aim of this pilot study was to develop and conduct usability testing of a self-guided responsive web design (RWD) program, i.e., the Road to Recovery for Caregivers after TBI (R2R-TBI) designed to improve caregiver functioning and increase positive parenting behaviors in the acute phase following pediatric TBI. Given the impact of parent functioning on child outcomes, it was proposed that intervening early at the caregiver level would set families on a

positive path of recovery and result in more positive long-term child outcomes. This pilot study also examined preliminary efficacy and satisfaction data.

Information/Qualifications of the Principal and Co-Investigators

Shari Wade, PhD – Primary Investigator. Dr. Wade is an experienced pediatric psychologist who has been investigating predictors of family adaptation to pediatric TBI for more than 25 years and has developed and tested web-based interventions to reduce behavioral morbidity and family consequences for over 15 years. She is a leader in multi-center clinical trials for pediatric TBI, having directed eight completed and one ongoing trial. She is the Principal Investigator and Director of the Rehabilitation Research and Training Center (RRTC) for Pediatric Brain Injury Interventions, the only federally-funded center for pediatric TBI.

Stacey Raj, PhD – Principal Investigator. Dr. Raj is a licensed Clinical Psychologist and an Assistant Professor in Psychology at Xavier University, Cincinnati, OH. She completed her post-doctoral fellowship at Cincinnati Children's Hospital Medical Center, focusing on research and clinical interventions with children and families impacted by pediatric TBI. She has worked on a number of grant-funded studies examining outcomes and interventions for children and families affected by pediatric TBI. She has published several papers on outcomes of interventions for pediatric TBI including first author papers published in the Journal of Pediatric Psychology and the Journal of Head Trauma and Rehabilitation.

Matthew Schmidt, PhD – Co-Investigator. Dr. Schmidt is an Associate Professor of Educational Technology at the University of Florida (starting Fall 2019; formerly Assistant Professor in Instructional Design and Technology at the University of Cincinnati). Dr. Schmidt is a certified usability evaluator, has received numerous awards for his research, and has authored and co-authored numerous refereed publications on the use of technology to enhance learning

and instruction. He has worked on numerous grant funded studies with collaborators at Cincinnati Children's Hospital Medical Center including efforts to develop web-based interventions for children/families impacted by epilepsy, concussion, and TBI.

Setting

Participants were recruited at Cincinnati Children's Hospital Medical Center (CCHMC). The provision of all clinical care at CCHMC is driven by the premises of continuous quality improvement based on the best available evidence and an ongoing integration of data collection and research throughout the continuum of care. As the only Level One pediatric trauma center in the area, CCHMC receives 97% of the county's pediatric admissions, thus providing an exceptional opportunity for clinical studies that matter to the county and state. In addition, CCHMC is one of just three Level One pediatric trauma centers across Ohio. The Division of Physical Medicine and Rehabilitation where this study was based has an excellent track record of pioneering interventions for children and families affected by TBI. In addition, the investigators on this study have been involved in numerous studies documenting short and long-term sequelae of pediatric TBI.

The R2R-TBI Program

Stages of Development

Development of the R2R-TBI program began with a literature review of challenges experiences by caregivers and families post-injury, as well as current interventions of caregivers of children with traumatic brain injury. Next, we consulted with care providers (pediatric rehabilitation nurses and physicians). This was followed by consultation with a parent advisory council consisting of three parents of children with brain injuries who have become parent leaders/advocates. Each parent advisory council session was held separately with the parent

engaging with the research team. During these sessions, parents reviewed and provided feedback on website design and content. Feedback from these sessions were used to further develop the website. Next, usability testing was conducted with 5 caregivers of children with a brain injury. Each parent reviewed one (or two) modules that had been developed with a usability testing expert. These sessions were guided by use of eye-tracking software and each session was recorded, transcribed, and reviewed by the team. Participants reported that the website was easy to use and navigate. Feedback from each parent was incorporated and the program was further refined prior to pilot testing.

Delivery

Research shows that the impact of parent functioning/ behaviors on child outcomes are apparent in the initial months following injury (e.g., Raj et al., 2014). It is possible that intervening during this acute phase may serve a protective function to children and families, and set families on a positive path to recovery. The R2R-TBI program was thus designed to target caregiver functioning and well-being in the first three months following pediatric TBI.

Recognizing that families of children with TBI and other disabilities may have difficulty accessing services due to child care, transportation, and cost issues, the R2R-TBI program was designed to be a self-guided intervention that caregivers could access any time at their convenience. Moreover, the program was designed to be delivered via multi-platform web devices (e.g., smartphone, laptop, tablet) that would be accessible to all families who are able to access the internet (e.g., through home internet service, public library, etc.). Changes in technology use in the past 5 years, makes a multi-format intervention particularly important. Recent data released by the Pew Research Center (2015) indicate that about 79% of US adults ages 30 – 49 years own a smartphone, and this figure is 85% for adults ages 18 to 29 years. Of

these smartphone users, up to 15% have few other options for accessing the internet (i.e., no home internet access). Clearly, accessing web-based content via smartphone is familiar to most parents, and it is worth noting that 68 – 85% of smartphone users aged 19 to 49 years report accessing health information through their smartphones, suggesting a high level of comfort with these technologies (PEW Research, 2015). Given the frequent changes in technology, delivering R2R-TBI via multi-format devices would likely support efficacy, satisfaction, and accessibility for parents managing myriad challenges in the acute phase following pediatric TBI.

Content

The R2R-TBI program is based on research evidence of parents' needs following pediatric TBI, as well as feedback from parents and families who have participated in other TBI studies at CCHMC. Parents have consistently asked for more information on what to expect in the weeks and months following their child's TBI, and the R2R-TBI program couples this information with positive parenting strategies to alleviate and manage some of these concerns. Moreover, recognizing that parent psychological functioning may be adversely impacted following pediatric TBI, this intervention targets caregiver self-care. Essentially, the R2R-TBI program addresses parent functioning and parenting behaviors, with the view that intervening in the acute phase following injury may establish a positive path of recovery for children and their families.

The R2R-TBI Program Modules

The interactive nature of the R2R-TBI program encourages active parent participation and allows parents to select information that is pertinent to them. By enabling parents to self-guide through the web platform, parents are able to tailor the program to their specific needs. In addition, the R2R-TBI program encourages active participation in the modules, and parents are

afforded opportunities to practice skills introduced in R2R-TBI program. For example, there are progressive muscle relaxation video clips for parents to use at that moment, or go back at a later time.

Below is a brief overview of the content of the R2R-TBI program. Please see the Appendix for sample screen images of the intervention.

Module 1: What to expect?

Among the most common concerns raised by parents of children who have experienced TBI is the question of how their child's injury will impact their short and long-term outcomes (Prigatano & Gray, 2007). Although outcomes of children with TBI vary, parents benefit from ongoing information (Savage et al., 2005) and providing accurate information on what to expect may help reduce parental distress (Prigatano & Gray, 2007). In the first module, parents will learn about TBI and are given an overview of common sequelae of injury (e.g., confusion, memory loss, emotional lability, etc.) and how these consequences may manifest themselves at various ages. As parents proceed through this module, they are able to select and learn more about symptoms that their child may be experiencing.

Module 2. Problem solving your child's recovery.

Now that parents have a sense of what to expect in the short and long-term recovery process, this module teaches parents skills to manage various challenges that may arise. For example, parents learn strategies and skills to manage common (and some uncommon) sequelae of pediatric TBI. Parents also learn a problem solving framework to navigate challenges,

Module 3: Positive parenting.

In this module, parents learn positive parenting skills such as how to set their child up for success, creating a home environment that promotes positive behavior, as well as boundary

setting techniques. Parents can select information that is specific to the general ages of their child (i.e., 0 to 4 years, 5 to 11 years, and 12 to 18 years).

Module 4: Taking care of yourself.

In this module parents learn the importance of good self-care and learn about the reasons why we feel stress and how stress can impact our bodies and our lives. Parents then learn strategies to manage stress such as progressive muscle relaxation, relaxed breathing, and imagery. Parents are able to practice these skills with the support of the R2R-TBI program.

Module 5: Working with your child's school.

In this module, parents learn how they can support their child's reentry into school and how they can work together with their child's school to ensure that their child's needs are met. Parents will learn about different levels of services and supports (e.g., IEP, 504-Plan, etc.) available to children who are experiencing academic, mood, and/or behavioral challenges resulting from TBI. Parents are important advocates for their child's academic needs, and we believe that providing parents with this information may support their confidence in advocating for their child's needs at school and elsewhere.

Module 6: Guilt, grief, and caregiving

Parents of children with TBI often experience feelings of guilt for not being able to protect their child, and many experience grief over the changes they see in their child (Aitken et al., 2004). In this module, parents learn that they are not alone in their feelings of guilt and grief and hear about experiences of other caregivers. Parents also learn strategies to manage feelings of guilt and grief, and are presented with information on respite care services available to families caring for a child with a serious injury.

Module 7: Marital communication.

Parents will learn about common relationship stressors following pediatric TBI (e.g., differing parental expectations, poor communication, financial concerns, etc.). Parents will also learn tips for improving communication with their spouse/partner and will be able to practice effective talking/ listening skills.

Module 8: Sleep issues.

Many children with TBI may experience sleep difficulties and this module teaches parents about possible reasons for their child's sleep difficulties. Strategies that parents can use to support their child's healthy sleep are offered. This module also offers parents techniques and strategies to improve their own sleep.

Module 9: Parents and siblings.

Parents learn about typical sibling reactions to TBI and strategies they can use to support the well-being of their un-injured child/ren. In addition, parents will learn about distinctions between normal sibling reactions and warning signs of more serious problems.

Module 10: After high school.

This module is for parents of children with challenges following brain injury who are transitioning out of high school. It provides parents with information on their child's legal rights pertaining to education and job training after high school. Parents are also provided with information and links to organizations that may be able to support their child's transition, including the State Vocational Rehabilitation Agency.

Pilot Testing

Participants

Participants were identified and recruited from the CCHMC Trauma Registry, inpatient units, and the CCHMC Pediatric Rehabilitation clinic. Inclusion criteria included being a

caregiver of a child (ages 0 – 18 years) hospitalized for moderate to severe TBI (GCS score of \leq 12 or a GCS of 13-15 accompanied by abnormalities on imaging) within the past 3-months.

Injury severity has been found to be a robust predictor of child outcomes, with more severe injuries associated with greater short and long-term challenges. Additional inclusion criteria included the caregiver having access to the internet (e.g., smartphone, access at a public library, home computer, etc.), residing with the injured child for the duration of the study, and use of English as the primary language in the home. Exclusion criteria included non-blunt head trauma (e.g., gunshot wound). The pilot testing was approved by the CCHMC IRB (study number: 2016-4732).

At the time of this report, 29 caregivers have been recruited. Twenty-two have completed baseline measures, 15 have completed follow-up measures, and 4 are actively enrolled. Please see Table 1 for a summary of child and caregiver demographics at baseline.

Table 1. Demographic data for child and caregiver at baseline (N=22).

Demographics	Average (Range) or Percentages
Child and Injury Characteristics	
Child age	4.62 years (4 days – 14 years)
Length of stay at hospital	6.47 days (2 days – 35 days)
Glasgow Coma Scale score	12.05 (6 – 15)
Caregiver Characteristics	
Age	32.5 years (18 years – 51 years)
Caregiver Completing Forms	
Mother	93%
Father	7%
Race/Ethnicity (%)	
Caucasian American	59%
African American	32%
Other	9%
Highest Level of Education	
<HS Diploma/GED	5%
HS Diploma/GED	27%
2 or less years of college	32%

Bachelor's degree	23%
Graduate degree	14%
Marital Status	
Married	36%
Never married	23%
Living with someone	27%
Divorced	14%
Annual Household Income	
<\$20,000	18%
\$20,000 - \$39,000	18%
\$40,000 - \$59,000	26%
\$60,000 - \$79,000	5%
\$80,000 - \$100,000	5%
>\$100,000	14%
Not reported	14%

Procedure

Caregivers who were eligible to participate received a flyer and/or phone call with information about the study when their child was discharged from the hospital and at follow-up visits with their child's provider. Eligible caregivers who consented to participate were emailed a link to complete baseline questionnaires. Once baseline forms were complete, caregivers received a link with access to the R2R-TBI program. A month later, caregivers received a link to complete the follow-up forms. Caregivers were compensated for their time.

Measures

Participants completed the following self-report measures. All forms were completed at baseline and at the one-month follow-up unless otherwise noted:

Satisfaction (only administered at follow-up). Caregivers completed an intervention satisfaction survey that has been used in prior studies. This satisfaction survey captured both satisfaction with the content as well as with the web-delivery of the intervention.

Parents/caregivers were also encouraged to provide feedback and suggestions (via surveys and

interviews) on how to strengthen the intervention.

Usability (only administered at follow-up). The System Usability Scale (SUS; Brooke, 1996) was used to assess the usability of the program. The SUS is an industry-standard scale consisting of 10 items with five Likert-scale response categories (Strongly agree to Strongly Disagree). The SUS was developed for evaluation of a wide variety of products and services including websites and computer applications. It has been shown to be easy to administer, provides reliable results even with small sample sizes, and produces valid results. Scores range from 0-100 with higher scores indicating greater usability.

Parenting stress. The short form version of the Parenting Stress Index- 3rd Edition (PSI; Abidin, 1995) was used to assess parenting stress. Parents rated their level of agreement on 36 statements reflecting stress in the parenting domain. The Total Stress Scale of the PSI captures overall level of parenting stress. Scores are reported as percentiles with scores between the 15th and 80th percentile considered to be in the normal range, and higher scores viewed as indicative of greater levels of stress.

Parent distress and depression. Parent mental health functioning was assessed using two self-report measures. The Brief Symptom Inventory (BSI, Derogatis, 1992) was used as a measure of overall parent psychological distress, and the Center for Epidemiological Studies Depression Scale (CES-D, Radloff, 1977), was used to measure parent depression. Scores on the BSI are reported as T values, with scores of 63 and higher defining clinically significant levels of distress. Scores on the CES-D range from 0 to 60, with higher scores reflecting higher levels of depression.

Perceived parenting efficacy. The Caregiver Self-Efficacy Scale (CSES; Boothroyd & Evans, 1997) was used to assess parenting efficacy. The CSES is a 25 item self-report scale that

captures parenting confidence and efficacy. Parents rated how comfortable they were in aspects of parenting, including their ability to control their child's behavior, praise their child, and say no to their child. Scores on the measure range from 25 to 100, with higher scores indicating greater perceived parenting efficacy.

Burden of injury. The Family Burden of Injury Interview (FBII) was used to assess injury-related stress in the domains of child functioning and behavior, spousal relationship, and relationship with other members of the family in the acute phase following injury. The FBII is a reliable and valid assessment measure for families affected by TBI (Burgess et al., 1999).

Family functioning. Family functioning was measured using the 12-item Global Functioning Scale of the McMaster Family Assessment Device (FAD-GF, Epstein, Baldwin, & Bishop, 1983), a self-report measure of family functioning with established reliability and validity (Miller, Epstein, Bishop, & Keitner, 1985). The FAD-GF is recognized by the Pediatric Common Data Elements (CDE) workgroup as a core measure of family functioning following TBI (McCauley et al., 2012). Primary caregivers rated their level of agreement (i.e., strongly agree, agree, disagree, strongly disagree) to statements reflecting their family's functioning. Scores on the FAD-GF range from 1 to 4 with higher scores indicating poorer family functioning.

Child emotional-behavioral functioning. Caregivers of children ages 1.5 to 18 years completed the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001). The CBCL is a parent report measure of child/adolescent emotional and behavioral functioning, and has separate forms for children ages 1.5 to 5 years, and those ages 6 to 18 years. The CBCL is recommended by the Common Data Elements workgroup as a sensitive and relatively brief measure of behavior problems following pediatric TBI (McCauley et al., 2012). Scores are reported as T values with

higher scores indicating greater behavior problem severity; a T score of 63 is at the 90th percentile. In clinical settings, a T score of 65 to 69 is considered in the borderline clinical range, and T scores of 70 and higher (>97th percentile) are clinically elevated (Achenbach & Rescorla, 2001).

Data Analysis

Frequencies and univariate statistics were used to examine the distributional properties of all variables and summarize results. In this pilot study, descriptive analyses primarily focused on parent reports of usability and satisfaction with the R2R-TBI program. Paired t-tests were conducted to examine pre- and post-scores on child and caregiver measures. Due to the small sample size and lack of control condition, these pre-post analyses are exploratory.

Results

Satisfaction

Participant's responses to the satisfaction survey are summarized in Table 2. All participants reported that the program was helpful and all but one reported making positive changes. Most (87%) reported feeling better prepared to handle crises and would recommend the program to others. While many were satisfied, a number of participants (27%) reported that the content was not relevant to them and 33% continued to experience stress. As more data is collected, further analyses will be run to explore participant factors that may impact their experience and satisfaction with the web-program.

Table 2. Summary of participants responses on the satisfaction survey (n=15).

	Item	Percent Agree/Strongly Agree	Percent Disagree/Strongly Disagree
1	The R2R program was helpful to me.	100%	0%
2	The information helped me understand my child more.	73%	27%
3	I have learned tips to be a better parent.	80%	20%
4	I know how to handle a crisis when it comes up.	87%	13%
5	I get along with family members better.	80%	20%
6	I feel less stressed.	67%	33%
7	The program was too long.	33%	67%
8	The program was too short.	13%	87%
9	The information did not apply to me or my family.	27%	73%
10	I would do the program over.	67%	33%
11	I would recommend the program to others.	87%	13%
12	My questions about brain injury have been answered.	73%	27%
13	I have made positive changes.	93%	7%

Free response (qualitative feedback) from caregivers. Caregivers were encouraged to provide feedback on their experiences with the R2R-TBI program and their suggestions. Below is a summary of feedback provided. Please note that responses in italics are verbatim.

General experiences with the R2R-TBI program and what was helpful:

- *I liked the general format. It was easy to navigate through sections and the content was easy to digest.*

- *I really feel like it has helped me with controlling my emotions and helping my child control their emotions. I feel that I can communicate with them much better. I am learning to accept what happened and stop blaming myself.*
- *This experience was very informative and has opened my eyes to the reality of my situation. Although my child is discharged from the hospital, their recovery stage will be a bit longer than we expected*
- *I very much enjoyed the R2R program. It helped me to better understand what my child might be going through, as it is hard to communicate with my child sometimes due to their age. I did get some answers to questions I have had about the injury, and I appreciated the helpful tips for dealing with my child after their injury.*
- *Lots of information about dealing/coping with brain injury.*
- *It gave me helpful tips even when I didn't ask for it.*
- *It was helpful to hear feedback from other parents and know that other people go through the same stress. Some of the guides to dealing with stress and self-care were very good.*
- *It was helpful to learn how to deal with my child's behavior and how to help me cope with the situation.*
- *The questions alerted me to pay more attention and notice things that I didn't even know were a problem that I had difficulty understanding before I was asked.*
- *I appreciated the strategies it gave me for dealing with my child after an injury. I also found it helpful to have tips for communicating with my child's school and dealing with marital issues, and personal issues, such as taking care of myself and dealing with sleep problems.*

- *It was helpful to learn the explanation of why brain injured children act aggressive, AND how to deal with it.*

Caregiver suggestions and feedback:

- *Including more real-life examples. Perhaps tailoring the content to smaller age groups. As the parent of a six-month old it was hard to relate to some of the content.*
- *Although some of the situations did not apply to my family, due to age mostly, I did not find that there was anything that was unhelpful.*
- *More education on dealing with the [child's] attitude and helping the other household members adjust to the change. How to get my other children to understand the do's and don'ts process while my child is recovering and how we all can help each other...*
- *Showing ways to teach family and friends that are not in the home on how to deal with a brain injured child, so parents could be more willing to have 'me time' [time away for the caregiver to de-stress]*

A few caregivers suggested including opportunities for caregivers to connect with a provider through the program. For example, it would be helpful, “To speak with a behavioral specialist for both of us [caregiver and child] in person,” and, “It may be more helpful for the ability to write in specific questions for the doctors that could be submitted and answered.”

Other less common feedback included one parent experiencing trouble accessing videos on the website, and another parent wishing that they and their spouse could access the web-program together however noting that this was not possible due to “different shifts and family priorities.”

Usability

Overall, participants considered the website usable. The mean score on the SUS was 69.6 ($n=14$) which is considered average (Sauro, 2011). Scores ranged from 50 to 90 indicating that

some participants found the web-program more usable than others. Further analyses will be run to explore whether participant demographics (e.g., familiarity with technology) and usage factors (e.g., accessing web-program via laptop or smartphone) impacted usability.

Caregiver, family, and child functioning

Please refer to Table 3 for a summary of scores at baseline and the 1-month follow-up.

No significant differences were found between baseline and follow-up.

Table 3. Baseline and Follow-up Scores for Child and Caregiver Measures

Domain	Measure	Baseline (n=23)		Follow-up (n=16)	
		Mean	SD	Mean	SD
Parenting stress	Parenting Stress Index- 3rd Edition (PSI; percentile score)	57.59	33.63	59.63	35.54
Caregiver distress	Brief Symptom Inventory (BSI; T-score)	52.30	11.63	54.88	12.39
Caregiver depression	Center for Epidemiological Studies Depression Scale (CES-D; total score)	15.13	12.30	15.33	12.90
Family functioning	Global Functioning Scale of McMaster Family Assessment Device (FAD-GF)	1.80	0.35	1.77	0.36

Note that data for the Child Behavior Checklist, Caregiver Self-Efficacy Scale, and Family Burden of Injury are being analyzed.

Analysis of Researchers' Findings

Participants in this study were diverse with regard to demographic factors including race/ethnicity (41% non-Caucasian American), age (range: 18 to 51 years), level of education, and household income (see Table 1 for summary of demographic information). In addition, range of child injury severity, length of hospital stay (range: 2 to 35 days), and age (range: 4 days to 14 years old) also varied considerably. Preliminary analyses of the pilot study with this diverse sample of caregivers suggests that caregivers were satisfied with the R2R-TBI program and found the program usable. All reported that the program was helpful to them and most reported

that they learned tips to be a better parent (80%) and had made positive changes (93%) as a result of the program. While most participants provided good usability ratings and high satisfaction, a few caregivers were less satisfied or did not find the program as usable. As we conclude the study and continue to analyze data, we will explore possible mediating and moderating influences of demographic data on caregiver response and satisfaction with the R2R-TBI program.

Conclusions and Recommendations

TBI is a leading cause of death and disability in childhood and impacts children and families from all backgrounds. The acute phase post-injury can be a challenging time as caregivers experience growing burdens resulting from their child's injury. To our knowledge, this is the first self-guided web-based intervention targeting parent/caregiver functioning in the acute phase following pediatric TBI. Given challenges parents of children with TBI may experience accessing traditional in-office interventions targeting their well-being and/or parenting, the R2R-TBI program may be a cost-effective resource to set families on a positive path to recovery.

Further pilot testing is planned and caregiver feedback will be used to improve the program before a larger trial to examine short and long-term efficacy. In addition, feedback from this pilot study will be used to inform efforts to support families in the acute phase post-injury.

Notes

The Co-I (Dr. Schmidt) showcased the R2R-TBI program at the Conference for the Association for Education Communication Technology, and the program won second place for the Division of Distance Learning Crystal Award.

Data is being prepared for dissemination in peer reviewed journals in psychology and instructional design/adult learning.

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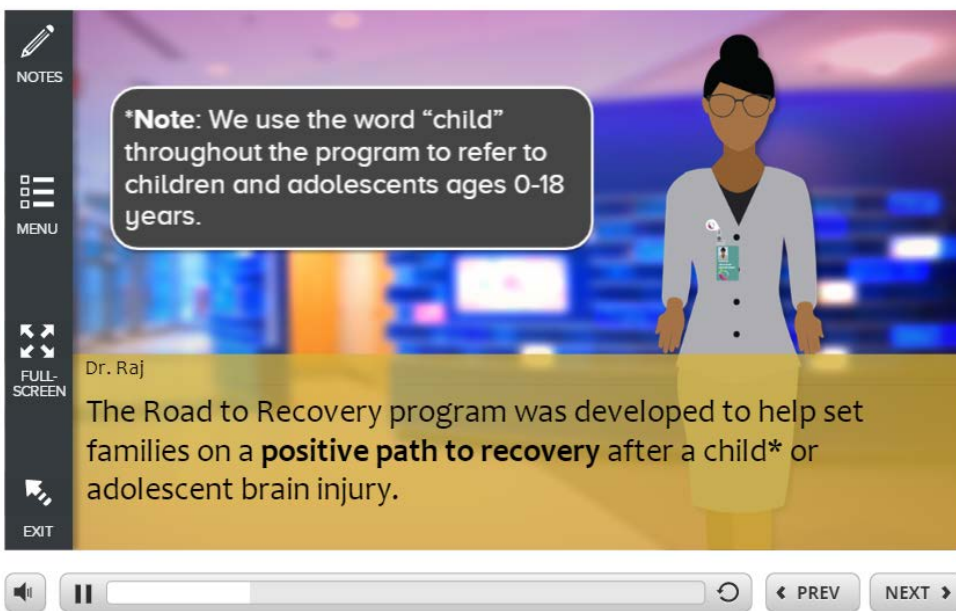
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Appendix

Sample screenshots of the R2R-TBI Program





NOTES

MENU

FULL-SCREEN

EXIT

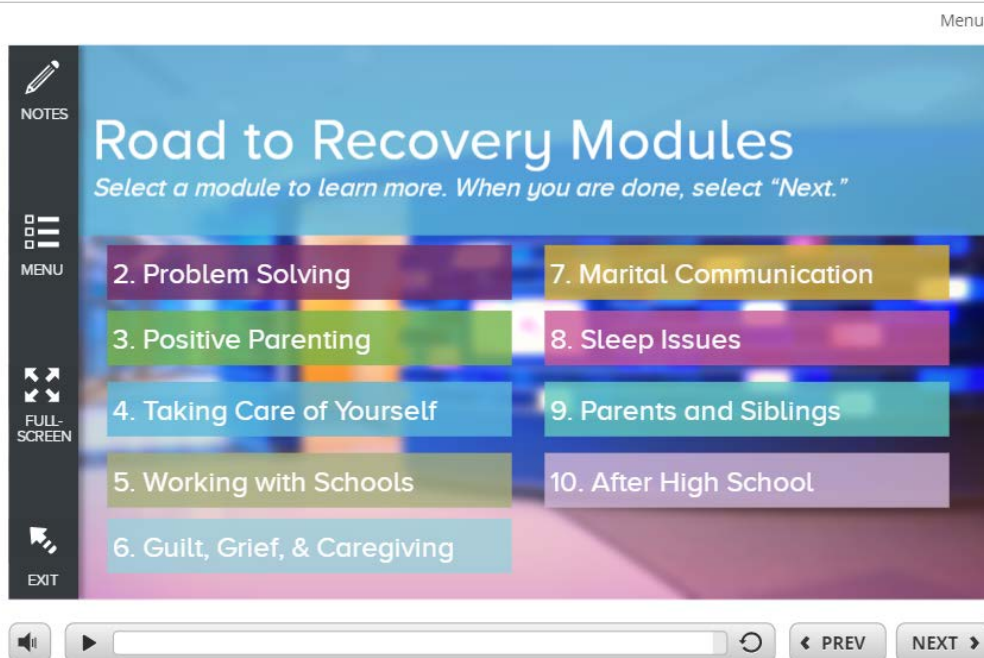
***Note:** We use the word “child” throughout the program to refer to children and adolescents ages 0-18 years.

Dr. Raj

The Road to Recovery program was developed to help set families on a **positive path to recovery** after a child* or adolescent brain injury.

◀ PREV NEXT ▶

Menu



NOTES

MENU

FULL-SCREEN

EXIT

Road to Recovery Modules

Select a module to learn more. When you are done, select “Next.”

2. Problem Solving	7. Marital Communication
3. Positive Parenting	8. Sleep Issues
4. Taking Care of Yourself	9. Parents and Siblings
5. Working with Schools	10. After High School
6. Guilt, Grief, & Caregiving	

◀ PREV NEXT ▶

Menu | Resources

NOTES

CLIP BOARD

EXIT

ROAD TO RECOVERY

Positive Parenting for 5-11 year-olds

Click here
to continue

Audio controls: Play/Pause, Progress bar, Repeat, Previous, Next

Menu | Resources

NOTES

CLIP BOARD

EXIT

Dr. Wade

Hi there. Dr. Wade here. Welcome to our learning module focusing on **Positive Parenting**.

Audio controls: Play/Pause, Progress bar, Repeat, Previous, Next

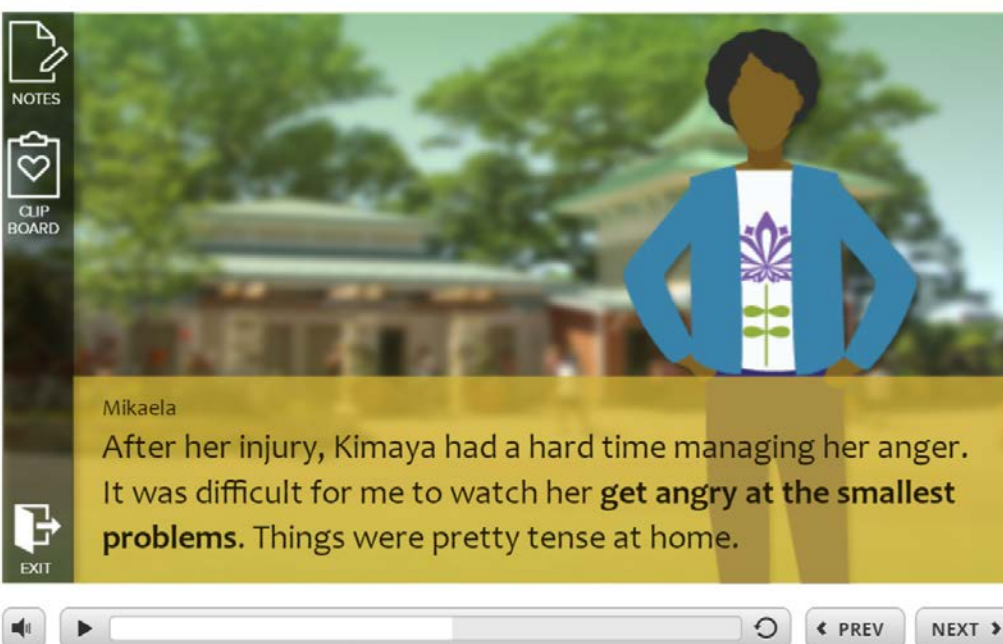


Contents
Positive Parenting Children 0-4 Years Old

- 1. Introduction (Start Here)
- 2. Strategies to develop your relationship
- 3. Setting your child up for success
- 4. Structure and Discipline
- 5. Wrap-up (Finish Here)

NOTES
CLIP BOARD
EXIT

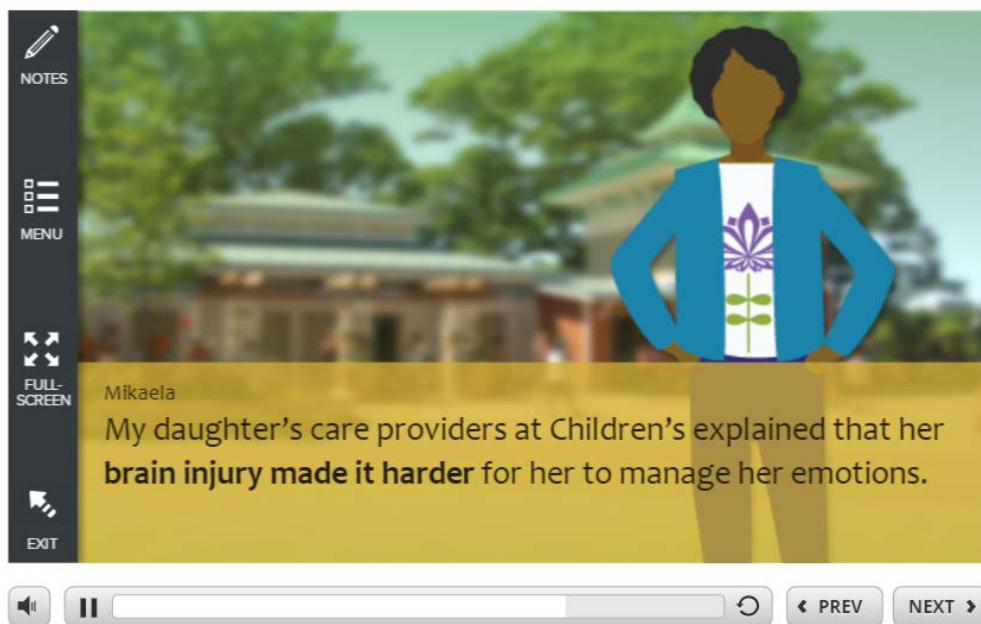
Audio controls: Play/Pause, Progress bar, Repeat.



Mikaela
 After her injury, Kimaya had a hard time managing her anger. It was difficult for me to watch her **get angry at the smallest problems**. Things were pretty tense at home.

NOTES
CLIP BOARD
EXIT

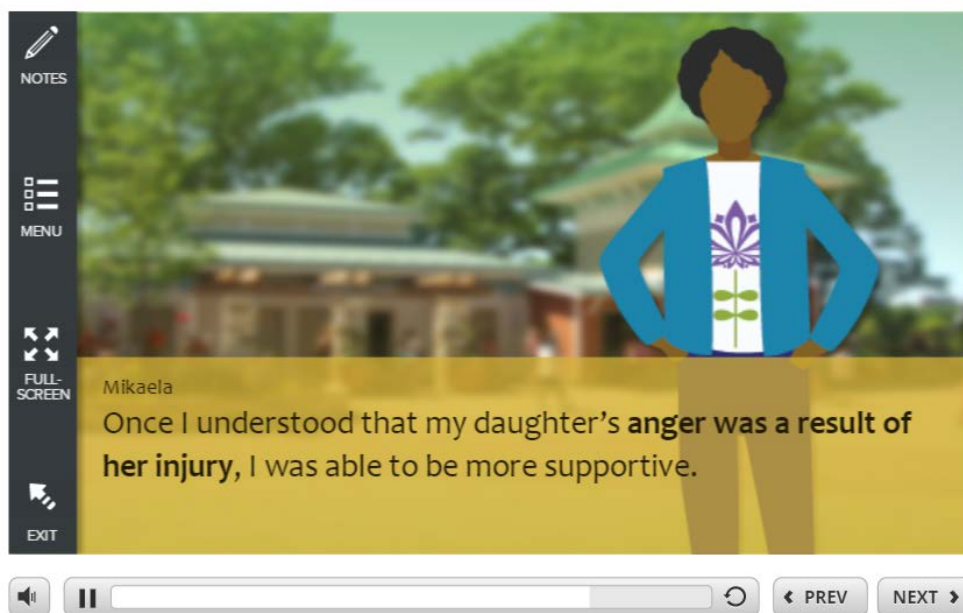
Audio controls: Play/Pause, Progress bar, Repeat, Previous, Next.



The video player interface includes a dark sidebar on the left with icons for NOTES, MENU, FULL-SCREEN, and EXIT. The video content shows a woman with dark skin and short dark hair, wearing a blue jacket over a white shirt with a purple floral design. She is standing in front of a blurred background of trees and a building. A yellow text box at the bottom of the video frame contains the following text:

Mikaela
My daughter's care providers at Children's explained that her **brain injury made it harder** for her to manage her emotions.

Below the video frame is a playback control bar with a volume icon, a play/pause button, a progress slider, a refresh button, and buttons for PREVIOUS and NEXT.

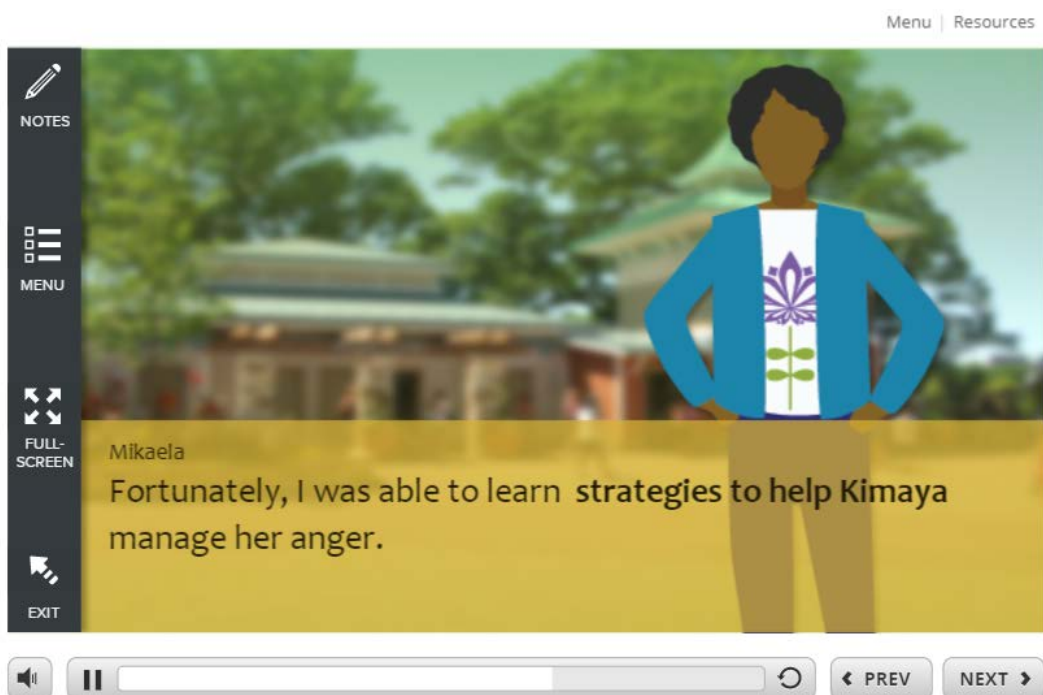


The video player interface is identical to the one above, showing the same woman and background. The yellow text box at the bottom of the video frame contains the following text:

Mikaela
Once I understood that my daughter's **anger was a result of her injury**, I was able to be more supportive.

Below the video frame is a playback control bar with a volume icon, a play/pause button, a progress slider, a refresh button, and buttons for PREVIOUS and NEXT.

Menu | Resources



NOTES

MENU

FULL-SCREEN

EXIT

Mikaela

Fortunately, I was able to learn strategies to help Kimaya manage her anger.

PREV NEXT

Menu | Resources



NOTES

CLIP BOARD

EXIT

Consequences need to be...

Select correct responses below

Consistent and Predictable

Delayed

Immediate

Nice and easy

Fair and Reasonable

Different each time

Click here when done

PREV NEXT



Menu | Resources

NOTES

CLIP BOARD

EXIT

Immediate

  **That's right!**

Consequences should always come **immediately after the behavior**. This way there is no confusion for the child about what behavior caused the consequence.

easy date each time when done

PREV NEXT

Menu | Resources

NOTES

MENU

FULL-SCREEN

EXIT

ROAD TO RECOVERY

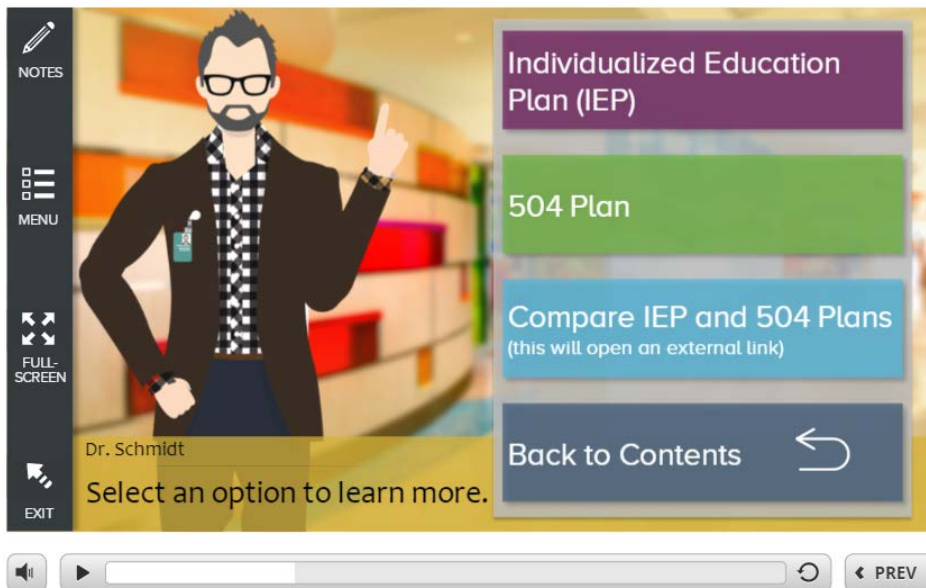


Working with Your Child's School

Click here to continue

PREV NEXT

menu | resources



Dr. Schmidt

Select an option to learn more.

- Individualized Education Plan (IEP)
- 504 Plan
- Compare IEP and 504 Plans
(this will open an external link)
- Back to Contents

NOTES

MENU

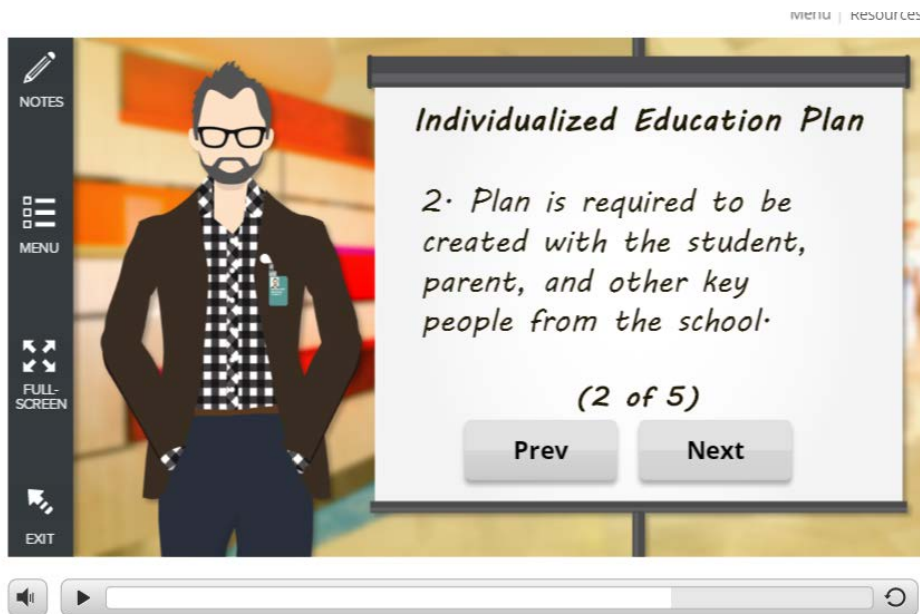
FULL-SCREEN

EXIT

PREV

This screenshot shows an interactive menu screen. On the left, a vertical sidebar contains icons for 'NOTES', 'MENU', 'FULL-SCREEN', and 'EXIT'. The main area features a cartoon character, Dr. Schmidt, pointing towards a menu of four options: 'Individualized Education Plan (IEP)', '504 Plan', 'Compare IEP and 504 Plans (this will open an external link)', and 'Back to Contents'. A 'PREV' button is located at the bottom right of the screen.

menu | resources



Individualized Education Plan

2. Plan is required to be created with the student, parent, and other key people from the school.

(2 of 5)

Prev Next

NOTES

MENU

FULL-SCREEN

EXIT

This screenshot shows a presentation slide titled 'Individualized Education Plan'. The slide content includes a list item: '2. Plan is required to be created with the student, parent, and other key people from the school.' Below the list item, it indicates '(2 of 5)' and provides 'Prev' and 'Next' navigation buttons. The same vertical sidebar with 'NOTES', 'MENU', 'FULL-SCREEN', and 'EXIT' icons is visible on the left. A 'PREV' button is also present at the bottom right of the screen.

Menu

NOTES

ROAD TO RECOVERY

MENU

FULL-SCREEN

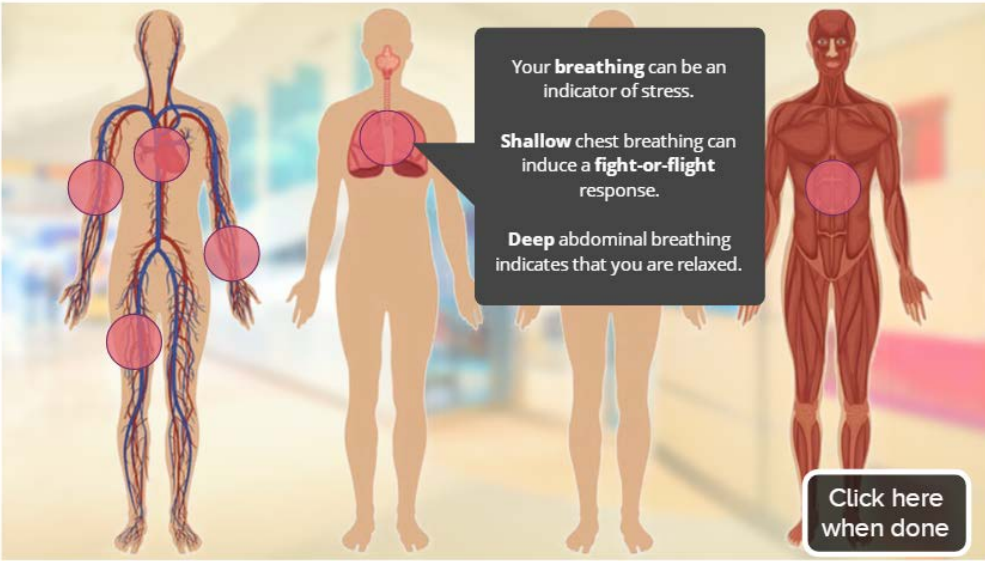
EXIT

Taking Care of Yourself

Click here to continue

◀ PREV NEXT ▶

Menu



Your **breathing** can be an indicator of stress.

Shallow chest breathing can induce a **fight-or-flight** response.

Deep abdominal breathing indicates that you are relaxed.

Click here when done

◀ PREV