Summary of St. Jude’s Brain Injury 101 (Fall 2020 to Spring 2021)

In 2020, telemedicine quickly became the norm, and “boundary-free” services were recognized as an emerging need by federal and state programs. Insights were derived from six months of virtual support groups that were attended by survivors of brain injury from across the United States and Canada. These support groups were designed to facilitate communication, provide social feedback, present psychoeducation, and allow for frequent in-vivo assessments of community-based needs; these were all incorporated into a pre-existing in-person program (Appendix B). The current program is comprised of three complementary components: a hybrid group that combines elements of brain injury education (e.g., symptom identification, management, therapies) and peer emotional support; one-on-one cognitive coaching with an individual coach to generalize course material to assist with daily stress management; and a neurocognitive assessment component to track progress over three months. All components were developed from previous versions of the program (currently in the seventh iteration; first iteration was in Spring 2018) and has been adapted to be provided over virtual platforms.

Therapeutic principles (e.g., cohesion, altruism, universality) were combined with Group Interactive Structured Treatment (GIST) and technology to create activities within the behavioral medicine framework. The individual component of the program was designed to assist survivors with the implementation of the compensatory strategies taught in the weekly interactive lectures. The “four core” strategies of the course were using a Home for your Stuff (e.g., decorative bowl on the nightstand for wallet or phone), Automatic Places (e.g., key ring by the door), the use of calendars (either electronic or paper-based), and developing a system of tracking experiences (e.g., thoughts, feelings, behaviors) in a journal. The final component of the course measured multiple domains using a mobile cognitive testing application (BrainCheck), self-reported surveys, and facilitated questions delivered in structured group interviews.

Elements of third-wave cognitive behavioral modalities were incorporated (should you be interested/looking for a therapist, these are the kinds of therapists to look for). Dialectical Behavior Therapy (DBT) was used to encourage mindful self-awareness of emotional experiences. Acceptance and Commitment Therapy (ACT) was also used to improve psychological flexibility to reframe, evaluate, and self-monitor performance with kindness and self-compassion. Through systematic measurement and tracking, participation in the program aspired to increase self-awareness into cognitive, emotional, and behavioral cycles that could be used to facilitate successful community engagement.

“You can’t fix something, if you don’t know its broke...”

Neurocognitive results revealed that on the average participants improved in working memory, immediate recognition, and delayed recognition. These significant improvements corroborate the findings of the in-person iterations (improved immediate and delayed memory). There were also significant reductions in endorsements of depression and anxiety over the
duration of the program. Improvements were also observed in daily life functioning as measured by the utilization of strategies, homework completion, and reports of task organization.

Although depression and anxiety reduced significantly over time, other self-reported measurements suggest that stress (not necessarily depression or anxiety, per se) was associated with cognitive difficulties. Additional self-endorsements for Attention-Deficit Hyperactivity Disorder (ADHD) were also integrated into the program, which did not reveal positive scores for any participant that would warrant further clinical investigation; suggesting that, on the average, there may be other problems related to processes “higher up” than attention in the Flow of Cognitive Processes model (Appendix H). Recent researchers have proposed that changes in daily executive functioning were not directly related to scores on neuropsychological tests; possibly because self-ratings measure a different aspect of functioning (Siponkoski et al., 2021).

Therefore, when thinking of “improvements” consider more than just one neuropsychological score; take them all into consideration and incorporate with other measurements.

The group format allowed survivors to practice their social skills and receive immediate feedback every week. Survivors connected with one another in a manner that emphasized their shared lived experience; ones that are typically invalided by individuals without brain injury (a type of “cognitive privilege”). Privilege is commonly used to describe difficulties experienced disproportionately by ethnic minorities. In this case, privilege is referring to individuals who do not have to navigate persistent cognitive difficulties, which worsened stress management. In general, the brain manages depression, anxiety, and stress. So, the strategies and lessons learned in the program are designed to reduce strain and support the brain when the “thing that manages problems is the thing, itself, with the problem.”

Participating survivors endorsed a sense of interpersonal connection with one another; this is significant when considering that the program was completely virtual. A shared sense of community, belongingness, and group cohesion is not limited to just in-person programming. Overall, findings suggest that increased ability to manage symptoms (e.g., stress, short-term memory) appeared to enhance survivors’ capacities to acclimate to their environments, and shift perspectives from “returning to pre-injury self” to “maximizing post-injury adaptation.”

https://doi.org/10.1080/09602011.2021.1890138
Executive Summary of Program (Brain Injury 101: 2017-2021)

St. Jude’s Brain Injury 101: Cognitive Rehabilitation is a training program that is offered every Spring and Fall for 12-weeks. The overall program focused on the provision of psychoeducation, psychotherapy, and cognitive rehabilitation in the group modality both in-person and over virtual platforms. Psychoeducation highlighted the physical, cognitive, and socioemotional sequelae of TBI, while peer support group programming validated the lived experiences of survivors. Elements of psychoeducation and psychotherapy were combined to design a training workshop that has been offered for the past four years. The program incorporates elements of behavioral medicine to integrate psychosocial, behavioral, and biomedical science as applied to prevention, diagnosis, treatment, and rehabilitation.

Insights over the years have highlighted the need for emotional, behavioral, and cognitive supports in a scaffolded manner delivered in accessible formats to enhance function; not only to strengthen weaknesses, but to accommodate. Using Luria’s three-zone neurocognitive model (attention, memory, executive functions), results revealed that neuropsychiatric symptoms were frequently endorsed and associated with neurocognitive difficulties. Using neuropsychological assessments, group cognitive rehabilitation that combined compensatory and restorative exercises significantly improved immediate and delayed memory performances, and revealed that self-reported stress, not depression or anxiety, predicted changes in self-reported cognitive symptoms over 12 weeks.

For the past year, the present cognitive training program transitioned to virtual platforms to provide interactive lectures, small group interactions, neuropsychological assessments, and individual cognitive coaching services. Forty-nine participants engaged in this program in the past year. Each week, participants also engaged in individual therapy for an additional one-hour to help generalize material from the two-hour interactive workshops to their daily lives. The primary structure of Brain Injury 101 shifted from Luria’s model to the Flow of Cognitive Processes model, such that two weeks were dedicated to each step: alertness, attention, information processing, memory, and executive functions. The last two weeks focused on skill integration depending on context to enhance social competence. The executive functions and social competence segments leveraged the functions of virtual platforms.

Brain Injury 101: Cognitive Rehabilitation combines contemporary cognitive theories from the Ohio Valley Center for Brain Injury Prevention, CogSMART (www.cogsmart.com), Brainwave-R, and Amen Clinics: Concussion Rescue programs. Concepts were also integrated from Division 22 (Rehabilitation Psychology) and Division 40 (Clinical Neuropsychology) of the American Psychological Association (APA). Survivors learned cognitive strategies, incorporated course material, socialized in structured activities, and processed challenging experiences using elements of third-wave cognitive-behavioral modalities. The educational slides, handouts, worksheets, and videos from the class are available on our website for download separated by each week (www.tbioc.org/hicares).
RECOMMENDATIONS FROM THE CLASS

COURSE MATERIALS

1. To revisit any of the Powerpoint slides, handouts, or videos from our program, see:
   a. www.tbioc.org/hicas - organized by week (1 to 12)

2. Educational Presentation Videos & Slides: (visit www.tbioc.org/braineducation)
   a. Cognitive Care Solutions
   b. Neurologic Music Therapy
   c. COVID 19 & Brain Injury
   d. HI CARES 2021 TBI Symposium
   e. Amen Clinic's Katie Dimedio Hyperbaric Oxygen chamber Treatment
   f. Dr. Almouradi Neuro Optometry & Brain Injury
   g. Bloch Wellness: Alternative Brain Injury Therapeutic Modalities
   h. Casa Colina Rehabilitation Hospital
   i. Transcranial Magnetic Stimulation Health & Wellness
   j. Goodwill Assistive Technology Center

COGNITIVE RESOURCES/REFERRALS:

1. Cognitive Care Solutions (accepts MediCare) for individual cognitive enhancement therapy (www.cognitivercaresolutions.com)
   a. Every Tuesday: FREE Brain Exercises Group 10 am to 11am
   b. email allyson@cognitivercaresolutions.com 714 356 7383

   a. CogSMART is an online platform designed to teach compensatory strategies
   b. This is a training package developed at UC San Diego VA

3. Chapman university Adult Learning Lab:
   a. free diagnostic and intervention services
   b. contact 7145327865 or Lisa Lachance at llachanc@chapman.edu

4. Mt. SAC ABI program (walnut, ca) schedule an “ABI program new student intake”
   a. Valentina Gaete (909.274.5563)

5. Coastline college ABI program (Newport beach) 714.241.6214 x17217

6. B.R.A.I.N. (Cypress) 7148281760 - ask for their cognitive rehabilitation.

7. UCLA Brain Boot Camp (los Angeles): Due to COVID-19, this program has been modified and is only offered virtually.
a. To learn more about the modified version of the program, contact Patricia Ramos at pmramos@mednet.ucla.edu
b. https://www.semel.ucla.edu/longevity/brain-boot-camp

8. **Need detailed neuropsychological testing** to help clarify your areas of improvement or to assist with a formal diagnosis of cognitive difficulties?
   a. Contact Omid Institute $50/hour for testing and report writing is included FREE (949 502 4721)

**HELP GETTING BACK TO WORK, SCHOOL, or HOME?**

1. **Department of Rehabilitation (DOR)**
   a. Find an office near you here: https://www.dor.ca.gov/Home/FindAnOffice
   b. HOWEVER, they will not find you a job (per se), they will help support you in the process though.
   c. For example, get you a job coach or send a letter to your employer so that you don't have to tell them about your disability status yourself
      i. get paid for clothes, gas, tuition, work materials, etc.

2. **In-home support:**
   a. There is a social service referred to as "In-Home Support Services" that is administered California Department of Social Services
      i. The Orange County number is: (714) 825-3000
   b. There are 3 eligibility requirements:
      i. disabled, blind, or 65+
      ii. unable to live at home safely without help
      iii. meet financial need requirements (if receiving SSI, then you automatically qualify). If you do not and your income is higher, you may still qualify for services - just call to find out!

3. **Full “neuropsychological assessment” to further clarify potential deficits as well as cognitive strengths to capitalize on for work purposes.**
   a. Neuropsychological assessments can be expensive ($3000-4000), so consult insurance company or contact a lower-cost alternative
      i. OMID: 949 502 4721 – ask for neuropsychology department $300-400
         1. https://omidinstitute.org/neuropsychology-servers

4. **Home & Community-based Rehabilitation contacts: In home rehab services**
   a. Rehab Without Walls: NeuroSolutions
      i. 909 396 0250 x 306
   b. Learning Services: Home & Community Neurorehabilitation Program
      i. Contact Maxine Colvin (mcolvin@learningservices.com)
      ii. (888) 419-9955 x 2 www.learningservices.com
5. **Reduce environmental distractions/stimulation such as light or sound:**
   a. Simple accommodations like wearing sunglasses (even indoors)
   b. Wearing earplugs or noise cancelling headphones
      i. Earplugs for sleep to maximize comfort (32dB sound blocking plugs)

**EMOTIONAL SUPPORT REFERRALS:**

1. **St. Jude’s Brain Injury Network Support Group programs:**
   a. Tuesdays at 6:30 pm PST: [https://zoom.us/j/9956799150](https://zoom.us/j/9956799150)
   b. Friday at 11:00 am PST: [https://zoom.us/j/9956799150](https://zoom.us/j/9956799150)

2. **Caregivers of TBI... looking for support? Kimberly @ askkimgully@gmail.com**
   b. 5/5 - Caregivers of survivors ONLY
   c. 5/12 - Survivors ONLY
   d. 5/19 - BOTH Caregivers & Survivors
   e. 5/26 - Women of Faith

3. **EMDR (Eye Movement Desensitization and Reprocessing)**
   a. Psychotherapy that enables people to heal from the symptoms and emotional distress that are the result of trauma.
   b. Interested in accessing EMDR? Medi-Cal/Medi-Caid/CalOptima?
   c. For referrals, contact [patricia@emdrempowered.com](mailto:patricia@emdrempowered.com)

4. **Other Virtual Support Groups (get support from us or from one of our friends!):**
   b. Contact Stephanie Heil: [stephanie.heil@rehabwithoutwalls.com](mailto:stephanie.heil@rehabwithoutwalls.com) 909.396.0250

5. **NEW PROGRAM:** Group Interactive Structured Treatment for Emotion Regulation
   a. This FREE program is based on the input and Mount Sinai NY’s program.
   b. If INTERESTED in participating, start will be in Summer of 2021
      i. Contact [dignacio@omidinstitute.org](mailto:dignacio@omidinstitute.org)

   a. Free 10-week program: check out the homework videos from
      i. HOMEWORK #1 ([https://youtu.be/0S6colwJUGI](https://youtu.be/0S6colwJUGI))
      ii. HOMEWORK #2 ([https://youtu.be/IJBK7OhOK2g](https://youtu.be/IJBK7OhOK2g))
      iii. HOMEWORK #3 ([https://youtu.be/0whshEYR1Dg](https://youtu.be/0whshEYR1Dg))
      iv. HOMEWORK #4 ([https://www.youtube.com/watch?v=CHxMEv-xYDA](https://www.youtube.com/watch?v=CHxMEv-xYDA))
      v. HOMEWORK #5 ([https://youtu.be/ur_lpFj8Ek](https://youtu.be/ur_lpFj8Ek))
NEED DIAGNOSTIC GUIDANCE?

1. If you do not yet have a formal diagnosis yet, get one to help you access services to get you back on track!! Consult with primary care physician for ICD 10 Medical codes:
   a. head trauma diagnosis (S06.XXXX)
   b. mild neurocognitive disorder (G31.84)

2. Psychologists use DSM 5 Mental Health codes (different diagnostic system):
   a. Cerebrovascular Accident (stroke – blood clot or brain bleed):
      i. Probable Major Vascular Neurocognitive Disorder 290.40 (F01.50)
   b. Traumatic Brain Injury (TBI) or concussion
      i. Major Neurocognitive Disorder due to TBI (F02.80)
         1. Mild Neurocognitive Disorder due to TBI 331.83 (G31.84)
Psychogenic Sources of Cognitive Deficits: STRESS

HOW STRESS AFFECTS THE BODY

**BRAIN**
Difficulty concentrating, anxiety, depression, irritability, mood, mind fog

**CARDIOVASCULAR**
higher cholesterol, high blood pressure, increased risk of heart attack and stroke

**JOINTS AND MUSCLES**
increased inflammation, tension, aches and pains, muscle tightness

**IMMUNE SYSTEM**
decreased immune function, lowered immune defenses, increased risk of becoming ill, increase in recovery time

**SKIN**
hair loss, dull/brittle hair, brittle nails, dry skin, acne, delayed tissue repair

**GUT**
nutrient absorption, diarrhea, constipation, indigestion, bloating, pain and discomfort

**REPRODUCTIVE SYSTEM**
decreased hormone production, decrease in libido, increase in PMS symptoms
Neurogenic Causes of cognitive problems
- Head trauma, brain injury, concussion, stroke
- If interested, contact is included in the attached flyer

### Mild TBI/Concussion Quick Reference Guide

<table>
<thead>
<tr>
<th>Symptoms of Mild TBI/Concussion</th>
<th>Behavioral Signs that may indicate Mild TBI/Concussion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive Symptoms:</strong></td>
<td><strong>May:</strong></td>
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<tr>
<td>• Attention/concentration difficulties</td>
<td>• Avoid reading</td>
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<tr>
<td>• Difficulty with multi-tasking</td>
<td>• Be unable to find car in parking lot</td>
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<tr>
<td>• Memory problems</td>
<td>• Get lost while driving</td>
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<tr>
<td>• Orientation problems</td>
<td>• Miss appointments</td>
</tr>
<tr>
<td>• Cognitive fatigue</td>
<td>• Stop watching TV or movies</td>
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<td></td>
<td>• Stop playing video games</td>
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<tr>
<td><strong>Physical Symptoms:</strong></td>
<td><strong>May Demonstrate:</strong></td>
</tr>
<tr>
<td>• Headaches</td>
<td>• Irritability</td>
</tr>
<tr>
<td>• Dizziness</td>
<td>• Sleepiness during the day</td>
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<tr>
<td>• Insomnia</td>
<td>• Low tolerance for noise</td>
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<tr>
<td>• Fatigue</td>
<td>• Avoidance of driving</td>
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<tr>
<td>• Unsteady gait</td>
<td>• Avoidance of activities that require walking</td>
</tr>
<tr>
<td>• Nausea</td>
<td>• Poor appetite</td>
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<tr>
<td>• Blurred vision</td>
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<tr>
<td>• Seizures</td>
<td></td>
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<tr>
<td><strong>Behavioral Symptoms:</strong></td>
<td><strong>May Demonstrate:</strong></td>
</tr>
<tr>
<td>• Irritability</td>
<td>• Low tolerance for overstimulating activity in environment</td>
</tr>
<tr>
<td>• Depression</td>
<td>• Spending a lot of time alone</td>
</tr>
<tr>
<td>• Anxiety</td>
<td>• Worry about upcoming events</td>
</tr>
<tr>
<td>• Sleep disturbance</td>
<td>• Avoidance of large gatherings</td>
</tr>
<tr>
<td>• Emotional outbursts</td>
<td>• Crying more easily</td>
</tr>
<tr>
<td>• Loss of Initiative</td>
<td>• Arguing frequently with others</td>
</tr>
<tr>
<td>• Problems at work or in school</td>
<td>• Lack of respect for others</td>
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To learn more about the Rehab Without Walls Mild TBI/Concussion Program, please call 888.556.5096
Flow of Cognitive Processes

1. Alertness
2. Attention
3. Processing
4. Memory
5. Executive Function

Cognitive Model of Brain Injury 101
Handouts ([www.tbioc.org/hicares](http://www.tbioc.org/hicares))

<table>
<thead>
<tr>
<th>Define the problem:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brainstorm solutions below</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Evaluate solutions</th>
<th>Easy?</th>
<th>Cost OK?</th>
<th>Likely to work?</th>
<th>Other notes</th>
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Select a solution (or >1 solution) to try

Try out solution(s)

Evaluate again. Is your problem solved? If not, try a new solution or solutions.

*Don’t forget to schedule in your breaks!*

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**A: LIST** (write down ALL the things you need to complete soon in any order & in any way – just get them down!)

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**B: PRIORITIZE** (triage and place items in “list” into HIGH, MEDIUM, or LOW priority of completion)

<table>
<thead>
<tr>
<th>HIGH</th>
<th>(items to complete TODAY)</th>
<th>MEDIUM</th>
<th>(items ok to move to tomorrow/another day)</th>
<th>LOW</th>
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**C: SCHEDULE** (take items from HIGH “priority” and schedule down below, only 1 item per line)

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*Don’t forget to schedule in your breaks!*
Define the goal or project:

<table>
<thead>
<tr>
<th>Target Date</th>
<th>Step</th>
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*Don’t forget to schedule in your breaks!
THANK YOU FOR SHARING YOUR STRATEGY TEMPLATE WITH US, CHRIS!

Project Template
Start date:

PROBLEM(S) TO SOLVE/GOAL(S):
  ●

TIMELINE:
  ●

PRE/PROJECT ORIGINAL DETAILS/SPECIFICATIONS:
  ●

STEPS:
  1.

    TRIAL & ERROR
      ○

TOOLS:
  ●

MATERIALS
  ●

NETWORK/HELPERS:
  ●

GENERAL KNOWLAGE
  ● Links:
    ○
    ●

QUESTIONS
  ●

JOURNAL/GENERAL NOTES
  ●