Total Health for Chronic Moderate-to-Severe Brain Injury:

Maximizing Function and Quality of Life through Community-Based Physical, Cognitive and Social Programming

Presenters:

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Total Health is a series of health and wellness programs created by Supportive Living, along with many collaborating individuals and organizations, to improve life for survivors of brain injury. These collaborating partners are all members of the SLI Brain Injury Research Council and have created, tested, researched and studied the effectiveness of these physical, cognitive and social fitness programs.

The objective of this work is to share evidence based positive outcomes of health and wellness programs that can be replicated in an effort to help serve more survivors of brain injury.
Total Health program partners include:

- Advocates, Inc.
- Access Sport America
- The Center for Balance, Wellness and Mobility
- Krempels Center
- The Real School of Music
Total Health program research has been sanctioned by (IRB approved):

• Brandeis University
• Northeastern University
• MCPHS University
• Some of the studies referenced throughout this presentation have been done by us and some by others.
• We have provided “recommended readings” and “references” to support the concept of a “Total Health” approach to programming for chronic moderate to severe brain injury.
• We hope they will be useful to you as you consider using or developing Total Health programming for people with chronic brain injury and advocate for participation, collaboration and funding.
Total Health  Internship relationships include:

- Boston University
- Brandeis University
- Gordon College
- Merrimack College
- Northeastern University
- University of Massachusetts Lowell
Supportive Living
SLI was formed in 1991 with a mission to *raise the quality of life for survivors of brain injury.* To achieve this mission SLI:

- Develops appropriate, affordable, supportive housing
- Provides life-long physical, cognitive and social fitness through “Total Health” programming
- Fosters research aimed at improving the lives of those affected by brain injury
Affordable Housing
SLI has developed 4 residential communities providing affordable housing and support services for survivors of brain injury.

- Warren House – 1997, 16 residents
- McLaughlin House – 2002, 8 residents
- Douglas House – 2008, 15 residents
- Old Farm Rockport – 2014, 7 residents
Brain Injury Wellness Center and Programs

• Established 2012
• Physical Fitness study and programming – 2013
• Cognitive fitness study – 2013
• Social fitness studies – 2011 and 2014
• Center for Balance, Mobility and Wellness – satellite physical fitness program – established 2014
• Horticulture Center and program – 2015
• Summer Camp – 2016 - combining physical, cognitive, social fitness & other therapeutic offerings
Total Health from Supportive Living
Health and Wellness Programs for Survivors of Brain Injury

- **Total Health** is a comprehensive, holistic approach to meet the unique needs of people living with chronic brain injury.
- **Total Health** approaches the brain and body as integrated and inseparable, and offers complementing physical, cognitive and social fitness programs to help improve life for survivors of brain injury.
Total Health

Proven Programs

- Physical Fitness
- Horticulture Therapy
- Music Appreciation
- Creative Arts
- Cooking and Nutrition
- Social Activities
- Support Groups
- Game clubs
- and more
Physical Fitness Programming

Fitness Function Fun
Physical Fitness Programming

Exercise is Medicine

• Recovery from Brain Injury is a life-long process.¹,²
• Research has proven, over and over, that a consistent physical exercise program after the injury will promote recovery in all aspects of life.³
Exercise is Medicine

A Successful Exercise Program Requires

- Participants have Realistic Goals
- Staff have Positive Attitudes
- Interns Bring Enthusiasm
- The Group Provides Encouragement
- Everyone Must Have Fun

Fitness Function Fun
Exercise is Medicine

An Effective Exercise Program Needs

- 25 Minutes Cardio
- 25 Minutes Strength and/or Stretch
- 3 Sessions a Week
- 40 Weeks a Year

Fitness Function Fun
Exercise is Medicine

Benefits of a Successful Program

- Health
- Function
- Cognition
- Emotion
- Social
- Quality of Life

Fitness Function Fun

All of these benefits can be measured
Exercise is Medicine

Health Benefits

- Cardiovascular Condition $^{8,9}$
- Exercise Capacity $^{10}$
- Physical Function $^{11}$
- Weight & Blood Pressure Management $^{12,13}$
- Bone Density $^{14}$
- Strength & Flexibility $^{15}$

Fitness Function Fun
Exercise is Medicine

Functional Improvements 4,5,6

- Dressing
- Balance
- Walking
- Personal Hygiene
- Eating (from your own garden)

Fitness Function Fun
Exercise is Medicine

Cognitive Improvements

- Attention / Focus
- Time Management
- Processing Speed
- Problem Solving
- Task Initiation

Fitness Function Fun
Exercise is Medicine

Emotional Benefits: 4, 5

- Improves Mood
- Enhances Self-Esteem
- Builds Confidence
- Reduces Anxiety and Depression
- Have Fun

Fitness Function Fun
Exercise is Medicine

Social Benefits 4,5
In a gym / group setting

• Active in the Community
• Reduced Isolation & Loneliness
• Create New Friends
• Develop New Social Group

Fitness Function Fun
Exercise Programs Need to Be Assisted, Accessible, Affordable

• **Assistance** - a majority of survivors of moderate to severe brain injury will need some level of assistance for life. It may be physical, cognitive, memory, cueing, behavioral and other.

• **Accessible** - specialized, or adaptive equipment is often needed for participants, from raised garden beds, to fitness equipment. Facilities, homes, restaurants, banks – these all need to be accessible as well.

• **Affordable** - most survivors living with chronic brain injury were injured when younger and have no financial means, or injured later in life and all assets have been depleted due to the high cost of care. Very few have the financial ability to pay for the care and programming they need and deserve.

Fitness Function Fun
Exercise is Medicine – Reality:

• Exercise is medicine, and we should provide it as often as possible.

• Unfortunately, providing exercise programs for many survivors of brain injury is very difficult.

• However, creative collaboration with interested entities, local universities, and others, can make this medicine available to many more people.

• Let’s get creative.

Fitness Function Fun
Cognitive Fitness Programming
What Is Cognition?

“Cognition is a group of thinking abilities (for ex: attention, memory, and problem solving) that work together and enable an individual to be meaningfully productive.”

(T. O’Neil-Pirozzi, 2017)
What Is Cognitive Fitness?

“Cognitive fitness is the health of an individual’s thinking abilities and that person’s related ability to complete functional activities and maintain a healthy quality of life.”

(T. O’Neil-Pirozzi, 2016)
What Is Cognitive Fitness Programming?

...any activity a person engages in to ‘exercise their brain’/ ‘keep their brain in shape’

(T. O’Neil-Pirozzi, 2016)
Examples of Cognitive Fitness Programming\textsuperscript{1,2}

- Computer thinking games
- Crossword puzzles
- Hobbies/Leisure activities
- Physical exercise
- Socialization
- Sudoku
Is There Evidence that Cognitive Fitness Programming Works?

The jury is still out...²,³,⁴,⁵

• Neuroplasticity post-brain injury
• Generalizability of program-based improvement
• How to measure?
How to Measure if Cognitive Fitness Programming Works? \(^{2,3,4,5}\)

- Neurocognitive test scores
- Quality of life/Satisfaction with life
- Life function/Life participation
- ???
Challenges to Cognitive Fitness

Outcomes 2,6,7

• Cost
• Discipline
• Motivation
• Time
Cognition Is Part Of All Activities

I’ve just started a new study exploring benefits of different activities on cognitive fitness - stay tuned!
Social Fitness Programming
Social Fitness Programming: A Focus on Arts and Interactions

Creative Arts programming is known to:

• Enhance engagement\(^1\)
• Enrich communication\(^2,3\)
• Facilitate conversation, reflection and focus\(^4,5\)
• Enhance mood and emotion (and reduce pain, stress)\(^6,7,8\)
• Increase understanding of oneself and others\(^8\)
• Alter behaviors and thinking patterns\(^8\)
• Have positive effects on health\(^9\)
Types of Creative Arts Programming

• **Visual Arts** help people express experiences difficult to put into words\(^9\)

• **Music therapy** calms neural activity in the brain, reduces anxiety and restores immune system function\(^{10,11,12,13}\)

• **Expressive writing** can improve physical health, reduce healthcare visits and improve immune system function\(^{14,15}\)
Group Activities

Create art that tells a group story and encourages social interaction – and interaction with the knowledge produced!

Almost everyone can make a small picture that becomes part of a group picture...
Individual Activities

Create art that reflects and communicates something of importance to the individual. Even people with serious impairments can create with support. Let participants lead the process and make decisions about topic, colors, content, form as you collaborate together. They want to do more — so let them!
Evaluating Outcomes

- Standardized measures\textsuperscript{18}
- Focus group discussions
- Written evaluations
- Individual interviews
- Physical health
- Brain injury function\textsuperscript{19}
Challenges to Outcomes

Challenge for facilitators...
Finding a balance between control and support. Give people choices!

- Need for one-to-one supports
- Inability to focus on task
- Uneven participation (scheduling conflicts)
- Comorbidities (anxiety, pain)
- Inconsistent implementation
A Story....

You don’t have to go home, you can stay here!

You can get in this bathroom at a local medical facility, but you can’t get out. Once you are inside, you are at the mercy of someone else to come let you out. I use paper towels or something as a door jam, but where you have a brain injury it’s easy to forget. Bathrooms should all have handicapped buttons. Bathrooms are something everyone needs.

Think “community” before you design and build!

This participant increased his Satisfaction with Life Scale (SWLS) scores by 33% (4 points) between pre-test and post-test.
In sum...

• Creative Arts programming requires investments – in therapists, supplies, interns
• Blending group and individual activities means being person-centered
• To understand return on investment, evaluation is needed
• Outcomes can be improvements in emotional health, social health, physical health, cognitive health
• Consistent opportunities throughout the year may build potential for improved outcomes over time

*Creative Arts = Expressive Arts*  
*Whatever name you choose, the goal is similar: help people to create along with others – and enjoy the process and interactions.*
Total Health - Summary:

• Research has proven that the chances of leading a healthy life, with or without a brain injury, will improve if you: Exercise regularly - Maintain a healthy diet - Spend time with friends - Engage in new activities - Laugh, have fun.

• Unfortunately for many survivors of brain injury these basic activities for a healthy life are limited. Many of the obstacles to these activities have been identified. The challenge is overcoming them.

• Our goal for Total Health is to find creative collaborative ways to provide these opportunities. Our overall objective is to find ways to replicate Total Health programs for as many survivors as possible.
A Plea!

- We hope that this presentation inspires **YOU** to adapt this Total Health model to your clients and to help people with more severe injuries have better access to meaningful recreational activities.

- **The result?** People with chronic brain injury who have better access to quality programming will maintain and improve their overall health function and their quality of life.
Q & A

Some suggested questions/food for thought:

• What do you already have in place that is meeting the needs of community-based individuals with more severe injuries?

• What, if any, Total Fitness programming could you adapt to your clients?

• What types of supports could help your efforts?

There is much experience and knowledge in this room. Let’s be resources for each other!
Recommended Readings

**Exercise (Physical Fitness)**


**Cognitive (Cognitive Fitness)**


**Expressive Arts (Social Fitness)**

References – Physical Fitness

5. Carmichael J, Chinn R, Lorenz L. "I feel better being active": Motivations to exercise among group home residents with chronic brain injury. under development.
References – Cognitive Fitness

References – Social Fitness


5. Oliffe JL, Bottorff JL. Further than the eye can see? Photo elicitation and research with men. *Qualitative health research*. 2007;17(6):850-858.


18. [https://www.commondataelements.ninds.nih.gov/TBI.aspx#tab=Data_Standards](https://www.commondataelements.ninds.nih.gov/TBI.aspx#tab=Data_Standards)