

SELF-ADVOCACY AFTER BRAIN INJURY: AN EVIDENCE-BASED MODEL OF EMPOWERMENT

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PARTICIPANTS WILL BE ABLE TO:

- ✓ Describe the concept of self-advocacy as it relates to individuals living with chronic effects of brain injury
- ✓ Summarize the major components of Self-Advocacy for Independent Life (SAIL) intervention
- ✓ Describe research demonstrating the efficacy of SAIL
- ✓ Describe strategies for applying SAIL in outpatient and community settings

ADVOCACY

Promoting or supporting a cause

- 1. Systems Advocacy:** Advocating to change policy, laws or rules for a specific cause (climate change, etc.)
- 2. Peer Advocacy:** Advocating for others who are facing similar challenges
- 3. Personal Self-advocacy:** Advocating for yourself/family



SELF-ADVOCACY DEFINED

Recognizing and communicating your needs and wishes, and making informed decisions to fulfill them (Stodden et al, 2003)

What does it take?

- Self assessment
 - Self efficacy beliefs
 - Communication
 - Problem solving
 - Decision making
 - Emotional regulation

CONCEPTUALIZING SELF-ADVOCACY

Component of Self Determination

- Experiencing quality of life consistent with your own preferences, strengths and needs (Turnbull & Turnbull, 2006)



Related To

- **Self Management** – Managing chronic condition; problem solving for one's well-being (Lorig & Holman, 2003)
- **Empowerment** – Assisting a person in gaining control over one's life (Browne, 1995)

SELF-EFFICACY IS A CORE ELEMENT OF SA

*Self Efficacy: An individuals belief in his/her ability to succeed at a task
(Bandura, 1977)*

Associated with life satisfaction and life quality post-TBI

The first step to SA is to believe in yourself and know you are worthwhile and capable (<https://www.mentalhelp.net>)

WE ALL HAVE A NEED FOR SA – COMMUNITY, WORK, HOME

The need increases when faced with unique challenges

Literature: Developmental disability or chronic health conditions - cancer, diabetes, mental health

Key Finding: SA interventions should address self awareness, resource knowledge, communication skills. (Merchant & Gajar, 1997, Kissel, 2006, Test et al., 2005)

BI Literature: Sparse, focused on family advocacy – p/BI, self, family system

Man: Family empowerment: self-efficacy, knowledge, support, & hope (1998)

Glang, McLaughlin, et al: Parental advocacy training – increased communication skills, resource knowledge (2007; 2013)

Brown et al: Individual and family; peer/systems advocacy (tx vs unstructured group) (2015)

Bringing like-minded people together to address advocacy is an important ingredient.

SELF-ADVOCACY AFTER BI: A CHALLENGE

1. The very skills required for self-advocacy are often affected by the injury:
 - Self-awareness, communication, problem solving, emotional regulation
2. BI presents a complex, sudden change:
 - Sudden increased need for specialized services
 - The needs are unique and “unseen,” and resources are scarce
 - For many, unmet needs continue a year or more post injury (Corrigan, et al, 2004)

SO WHY SELF-ADVOCACY AFTER BI?

- Others provide advocacy – social worker, physician, family
- Necessary in some instances
- Family members and person with the BI often work as a team

- The process of advocating for oneself has value:
 - Steering the course of your own life
 - Choice, autonomy, purpose, self-determination
 - Increased self efficacy and life satisfaction

STEERING THE COURSE OF YOUR OWN LIFE



There are different ways to direct your life. You don't have to do it alone.

Photo by Bill Brine <https://www.flickr.com/photos/8099556@N08/44542063951/>

SELF-ADVOCACY FOR INDEPENDENT LIFE: SAIL

- 1992 RMRBIS grant to BIAC for *family* advocacy training
- myself & community committee; focused on both individual and family
- Original Workbook (not alone, SA basics, resources) www.biacolorado.org
- Workshops - bringing communities together; Peer coaches – support/resources
- Positive anecdotal feedback
- Group intervention model developed in private practice
- Craig Research
- Implementation and integration of group model



SAIL GROUP INTERVENTION- KEY INGREDIENTS

Theoretically Based - Social Learning, Self-determination, Neuro-rehabilitation

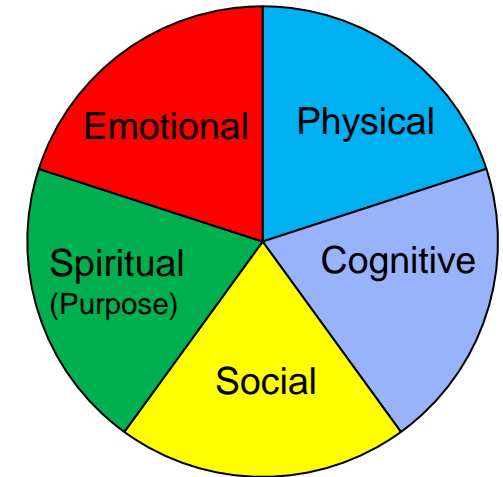
- Self awareness and goal setting
- Self-efficacy
- Group process – university, social learning, cohesion

- Skills – self-care, organization, communication
- Knowledge – about your needs and resources



SAIL CORNERSTONES

- **Take Care of Yourself**
 - In all areas of wellness; not a luxury, part of the job
- **Gather Information**
 - Knowledge empowers you
 - About the injury, your needs, resources
- **Be Organized and Prepared**
 - Organize information; organize SA team
 - Prepare before meetings and calls
 - Document what has occurred
- **Assertively Communicate and Negotiate Your Wishes/Needs**
 - Be assertive rather than passive or aggressive
 - Develop active listening skills



ASSERTIVE COMMUNICATION

- ✓ Exercise your rights without negating the rights of others
 - ✓ Attack the problem, not the person – “How can we solve this together”
 - ✓ Start with “I” – need, want, prefer
 - ✓ Express emotions directly “I feel frustrated...”
 - ✓ Gestures, expressions, tone of voice count
 - ✓ Focus on getting needs met
-
- ❖ Active Listening is key – show it, give feedback, confirm

SAIL RESEARCH

1. Validation of 2 Personal Self-Advocacy Measures, 2016
2. Randomized Pilot Feasibility Study, 2017
3. NIDLLR funded Randomized Controlled Trial, 2022

** Focused thus far on individual with the injury, rather than family advocate*

MEASURE DEVELOPMENT

Self Advocacy Scale (SAS): 8 item domain specific self-efficacy

Personal Advocacy Activity Scale (PAAS): 12 item self-rating of personal SA behaviors; modeled after Advocacy Activity Scale (AAS) (Malec et.al 2010)

Both measures reliable and valid

- Panel Review – Survey – Rasch Analysis
- Item reliability of 0.97
- Significantly correlated with each other
- Concurrent validity with established measures

THE SELF ADVOCACY SCALE

1- Not Confident

2 - Somewhat Confident

3 - Mostly Confident

4 - Very Confident

Examples:

- ✓ I can control my emotions when I am talking to people about my needs.
- ✓ I can keep track of important information that I need.
- ✓ I can work with other people to solve problems.
- ✓ I can listen to other people and consider their point of view.

PERSONAL ADVOCACY ACTIVITY SCALE

In the Past 6 Weeks: Not at All 1 – 4 Times 5 or More Times

Examples:

- ✓ How many times have you written a follow-up email to verify what was decided in a meeting or call?
- ✓ How many times have you done something to improve your physical health?
- ✓ How many times have you worked together with someone to solve a problem in your life?
- ✓ How many times have you gotten new information about brain injury or resources?

FEASIBILITY STUDY

- ✓ 12 community living individuals, 1 – 23 years post injury
- ✓ Randomized to T: SAIL Group & Workbook; C: Self Study of SAIL Workbook
- ✓ Feasible for further study
- ✓ Self-advocacy beliefs can develop even 23 years post
- ✓ Individual SA goals can be set and met
- ✓ SAS and PAAS offer measures of personal self-advocacy beliefs and behaviors

ENHANCING SELF-ADVOCACY AFTER TRAUMATIC BRAIN INJURY: A RANDOMIZED CONTROLLED TRIAL 2017- 2022

RESEARCH TEAM

PI: Lenny Hawley, LCSW; Cynthia Harrison-Felix, Ph.D.

Study Coordinator: Clare Morey, MA

Biostatistician: Mitch Sevigny, MS, Jessica Ketchum, Ph.D.

Consumer Advisor: Richard Owens

Scientific Advisor: Grahame Simpson, Ph.D.



Design: Longitudinal two-arm randomized controlled trial

Primary Hypothesis: *Participants receiving SAIL intervention will demonstrate significantly greater improvements in SA beliefs (SAS) baseline to post-T*

Participants: 67 community-dwelling individuals meeting inclusion/exclusion criteria

Outcome Measures: SAS, SWLS; General Self Efficacy Scale (GSES); PAAS; Flourishing Scale (FS); PART-O

4 points: baseline, post-treatment, 6-weeks post, 12-weeks post

METHODS

- ✓ Participants block randomized into 5 waves of 16
- ✓ Inclusion criteria:
 - TBI due to external mechanical force
 - More than 9 months post-TBI
 - Discharged from TBI rehabilitation
 - 18 or older
 - Travel independently in the community
- ✓ Exclusion criteria:
 - Non–English-speaking
 - Previously completed SAIL
 - GSES score ≥ 32 (high general self-efficacy)

INTERVENTION

- 10-week SAIL group intervention
- Four 3-hour sessions: 3 consecutive, final 3 weeks later
- Weekly home assignments involving support person
- 2 booster phone calls (weeks 8 and 10)

CONTROL CONDITION

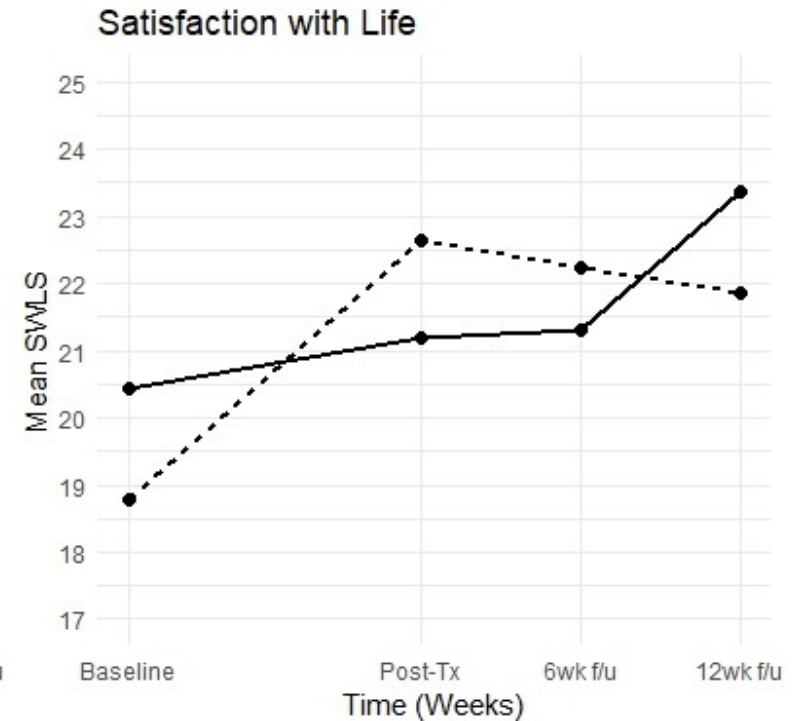
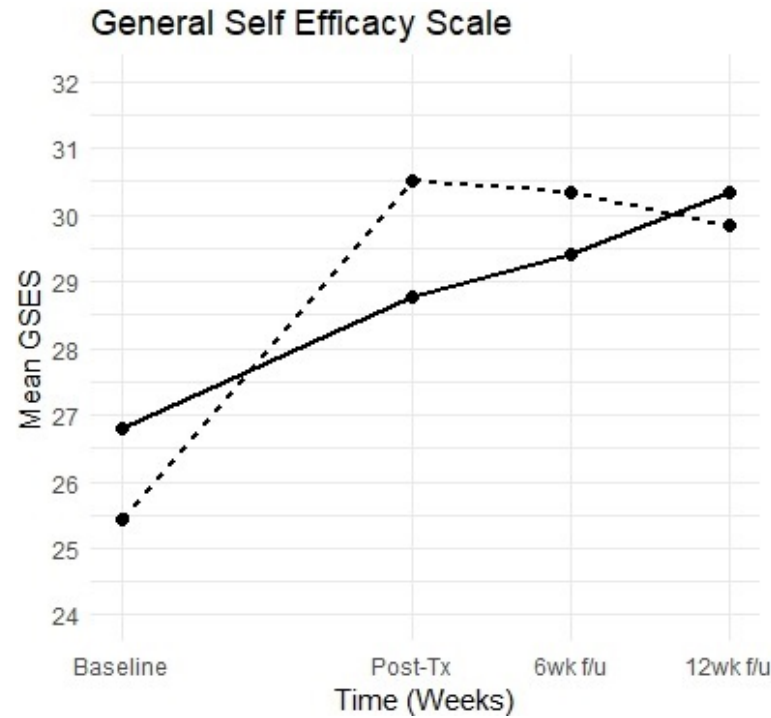
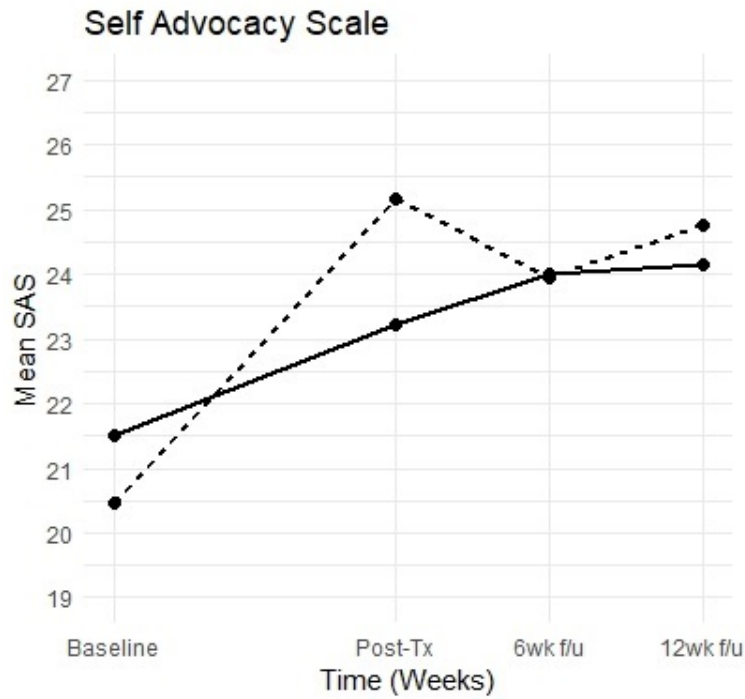
- Treatment as usual for self advocacy
- Receive workbook at end of trial

RESULTS

- Primary Hypothesis met: T group showed significantly greater improvement than C group from baseline to the end of treatment on the primary measure (SAS)
- Similar results were found on secondary measures of GSES and SWLS
- Significant differences did not maintain over time on follow-up

RESULTS CONT.

Group — Control - - - Treatment



DISCUSSION AND CONCLUSIONS

- Why did C group improve: T had the group taken away, C did not. (Satisfaction survey, importance of group). C group's interaction was with the evaluator, relationship continued through all points.
- Individuals living with the chronic effects of TBI can improve GSE, self-efficacy related to SA, and SWL years post-injury.
- SAIL is a theoretically-based program for empowering individuals living with TBI with self-efficacy and resources for self-advocacy.
- Continuation of gains may require lifelong support systems in community.

SAIL APPLICATION/DISSEMINATION

- SAIL intervention group workbook and leader workbook
- Train the Trainer –integrate into state services/support groups
- Rising in Search of Excellence – RISE
 - Somewhat modeled after Coastline, Mesa
 - Collaboration: Craig, Arapahoe Community College, Mindsource
 - SAIL core class

RISE Program at Arapahoe Community College

Arapahoe Community College, in collaboration with **Craig Hospital** and **MINDSOURCE - Brain Injury Network** at the Colorado Department of Human Services, is offering a new program designed to bridge the transition between hospital-based rehabilitation and return to the community for adults living with Acquired Brain Injury (ABI), a brain injury that has occurred after birth. **The ABI community includes those that are living with traumatic brain injuries (TBI).** The courses in the program address the cognitive and psycho-social skills needed to achieve post-injury social, educational and/or vocational goals.
(CONTACT: cory.wendling@arapahoe.edu)



[RISE Website
Click Here](#)

Targeted Skills Include:

- memory and organization
- time management
- self-advocacy
- self-awareness and goal setting
- problem solving
- social interaction and communication
- psycho-social resilience and self-efficacy
- use of compensatory technology



EMPOWERMENT: OUR ROLE

Recognize the expertise and right to self-advocate

Provide lifelong support, information, skills and resources

Transition from medical model to social disability model*

- MM: *Patient* has a problem to be fixed, we're the experts
- SDM: *Society* poses barriers, requires changes in attitudes, awareness, resources; empowering with the knowledge and skills to advocate for themselves

For many, not so much a chronic disease but a life journey to navigate

*Hawley L, Hammond FM, Cogan AM, Juengst S, Mumbower R, Pappadis MR, Waldman W, Dams-O'Connor K. **Ethical Considerations in Chronic Brain Injury** *J Head Trauma Rehabil.* 2019 Nov/Dec;34(6):433-436.



A silhouette of a person with their arms raised in a celebratory gesture, set against a bright, glowing sun. The background is a soft, warm gradient of light colors.

WISDOM FROM EXPERIENCE

“This is not a short race, it’s a marathon.”

**“The more prepared I am, the more I think,
‘Oh yeah, I got this.’”**

KEY REFERENCES

Hawley, L. “Self-Advocacy for Independent Life: A Program for Personal Self-Advocacy after Brain Injury”. *Contemporary Perspectives on Social Work in Acquired Brain Injury*, Ed. Grahame Simpson & Francis Yuen, London/New York, Routledge, Taylor & Francis. 2018.

Hawley, L., Gerber, D., Pretz, C., Morey, C., Whiteneck, G. Initial Validation of Personal Self-Advocacy Measures for Individuals with Acquired Brain Injury. *Rehabilitation Psychology* 2016 May 12.

Hawley, L, Gerber D, Morey C. Improving Personal Self-advocacy Skills for Individuals with Brain Injury: A Randomized Pilot Feasibility Study. *Brain Injury*, 2017, Vol 31, Issue 3, 290-296

Hawley, L; Morey, C; Sevigny, M; Ketchum, J; Simpson, G; Harrison-Felix, C; Tefertiller, C. Enhancing Self-Advocacy After Traumatic Brain Injury: A Randomized Controlled Trial.. *J Head Trauma Rehabil*, 2022, Vol 37, No2, pp 114-124.

Self Advocacy video: craighospital.org/resources/self-advocacy-your-guide-to-a-fulfilled-life

HANDOUTS*

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Weehaken Trail, Ouray