

Disclosures

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Social Participation And Navigation (SPAN): Implementation pilot of an app-based coaching intervention with teenagers with ABI

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Multi-site & interdisciplinary study

Collaborators & Funding

- **Tufts University:** Gary Bedell, Co-PI, Michele Jacquin
 - **Cincinnati Children's Hospital Medical Center:** Shari Wade, Co-PI, Megan Narad, Jessica King
 - **University of Wisconsin-Madison/McMaster University:** Lyn Turkstra, Co-I
 - **Georgia Institute of Technology:** Jeremy Johnson
 - **Children's Healthcare of Atlanta:** Juliet Haarbauer-Krupa
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- **Funding: National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant #H133G130272)**
 - NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS), USA.

Objectives

- Describe development & content of SPAN
- Report on 10 week implementation pilot with 13 teens with TBI & brain tumors (BT)
- Discuss implications & future directions

Importance of Participation

- “Involvement in life situations” (*WHO, 2001; 2007*)
 - **Social participation:** “taking part, involvement, engagement, doing or being with others” (*Bedell, 2012*)
- Key aim of rehabilitation, education & community programs (*Bedell & Dumas, 2004; Fougeyrollas, et al, 2014; King, et al, 2003*)
- Enables children/youth to interact, work & live with others & function in society (*King, et., et., 2003; Larson & Verma, 1999; Mahoney, et al, 2003*)
- Associated with enhanced quality of life, social competence & educational success (*Eccles, et al, 2003; King, et al., 2003; Larson, 1999; Mahoney, et al., 2003; Simeonsson, et al., 2001*)
- Life situations that promote **skill development & a sense of accomplishment & enjoyment** (*Eccles, et al., 2003; Fletcher, et al., 2003; Mahoney, et al., 2003; Rutter, 1987*)

Participation of adolescents with ABI

- Children & youth with ABI often restricted in participation in school, home, & community life
- Associated factors:
 - Severity of injury, age, age of / time since injury, physical /social environment factors, type & level of impairment, functional skills

(Anaby, et al., 2012; Bedell & Dumas, 2004; De Kloet, et al., 2015; Fougeyrollas, et al., 2014; Galvin, et al., 2010; Rivara, et al., 2012; Shuhua Foo, et al., 2012; Van Tol, et al., 2011)

- Children & youth with ABI & parents use strategies to promote participation despite obstacles

(Bedell, et al., 2005; 2012; Gauvin-Lepage & Lefebvre, 2010; DeMatteo, et al., 2008; Mealings, et al., 2012; Sharp, et al., 2006)

Rationale for SPAN

- ↓ Evidence on programs to promote social participation of youth with TBI/ABI (Agnihotri, et al., 2010)
- ↑ Evidence that peer mentors/coaches help with goal setting/planning/problem solving; provide emotional support (Braga, et al, 2012; Haarbauer-Krupa, et al., 2010; Keller et al., 2005; Rhodes, et al., 2006; Struchen, et al., 2011; Williams, et al., 2012; Zand, et al., 2009)
- Promising participation approaches with other groups, but focus on parents (Dunn, et al., 2012; Graham, et al., 2009; 2010; Palisano, et al., 2013)
- Key intervention features: Goal setting / Problem solving; Top-down; Strengths-based; Target real-life goals/settings (Brewer, et al., 2014; Glang, et al., 1997; Novak, 2014; Wade, et al., 2010; Ylvisaker, et al., 2005)
- Teens often use smart phones/apps in everyday life (Lenhardt, 2015)
- Promising mobile health interventions for teens (Fedele, et al., 2017)

Iterative Person-centered Design

- **Phase 1:**

- Informed by work of our interdisciplinary SPAN research team, literature & colleagues who have influenced us
- Focus groups/interviews with stakeholders (teens & college students with & without TBI; parents of teens with TBI) (Bedell, et al., 2016)

- **Phase 2:**

- Development of content, procedures, & i-phone app prototype (*advisory board feedback*)
- 4-week usability test of 1st SPAN iteration (accepted with revision, 2017)

- **Phase 3: *Current findings***

- SPAN refinements – 2nd iteration (*advisory board feedback*)
- Implementation & testing of 10-week pilot trial

SPAN: Content & procedures

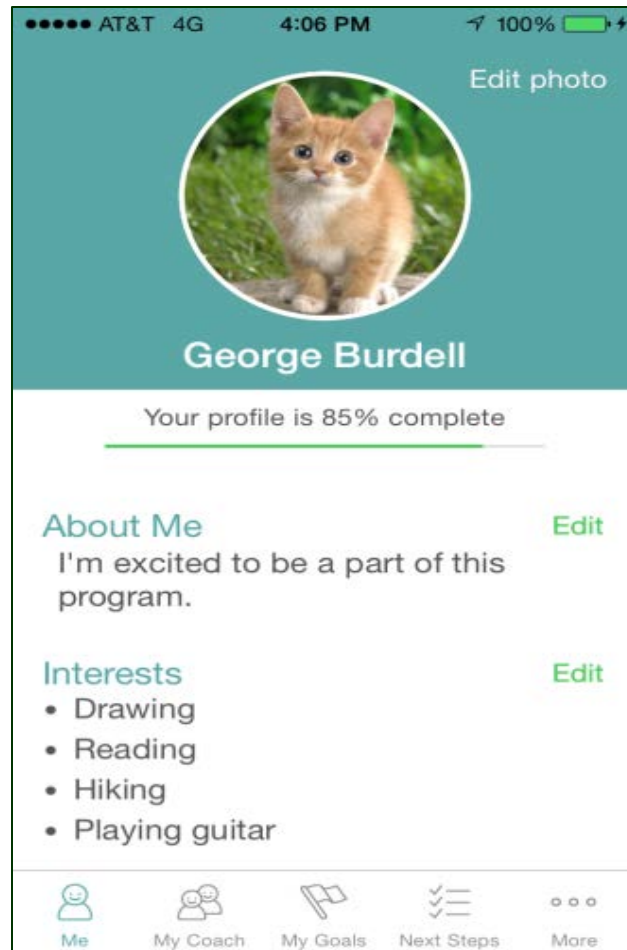
- 1. iPhone app to support goal setting, planning & implementation**
 - Teen / coach profiles (linked in app)
 - Push notifications for reminding / reinforcing
- 2. Online Key Topics and Brief Tips**
 - Goal setting/planning; social participation, self monitoring, self control, staying positive, joining conversation/groups
- 3. Weekly coaching sessions via Skype with college students**
- 4. Coach training**
 - 1.5 hour virtual didactic & group discussion session
 - Review training manual and readings
 - Practice using app/creating goals/plans & reviewing tips and topics
- 5. Coach weekly supervision** (group phone call; in-person as needed)
 - Led by Clinical Psychologist & Occupational Therapist
 - Discuss logistics, challenges & successes; Problem solving; Support

Coaching Sessions format

(10 sessions within 15 weeks)

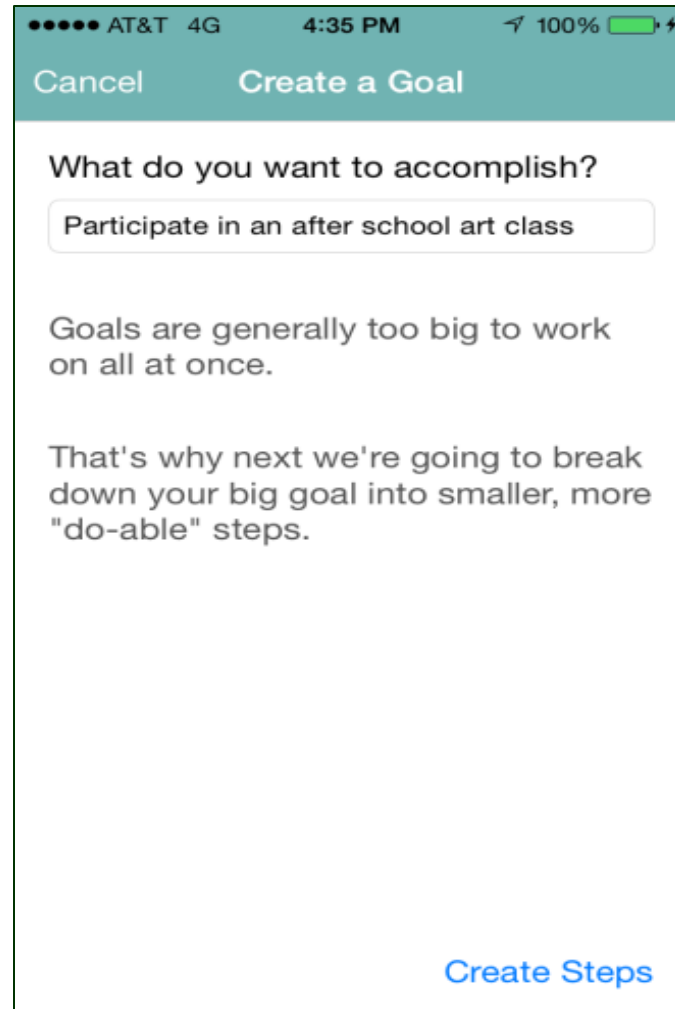
- **Week 1:** Meeting teen, establishing rapport, describing program & logistics
- **Week 2:** Reviewing Tips & Topics: Goal Setting/Planning, Social Participation; Defining social participation goal
- **Week 3:** Supporting implementation of plan; Reviewing progress & refining plans
- **Weeks 4 - 8:** Supporting refining existing goals, plans and strategies; &/or Developing new goals, plans and strategies to achieve those goals
- **Weeks 8 - 10:** Preparing for termination of coaching and transition to self-management/co-management with circle of support

Teen profile



- About me
- Interests
- Strengths
- Challenges
- Social participation goals (Initial ideas)
- Help preference

Creating Goals



The screenshot shows a mobile application interface for creating goals. At the top, the status bar displays 'AT&T 4G', '4:35 PM', and '100%' battery. Below the status bar is a teal header with 'Cancel' on the left and 'Create a Goal' in the center. The main content area has a white background and contains the following text:

What do you want to accomplish?

Participate in an after school art class

Goals are generally too big to work on all at once.

That's why next we're going to break down your big goal into smaller, more "do-able" steps.

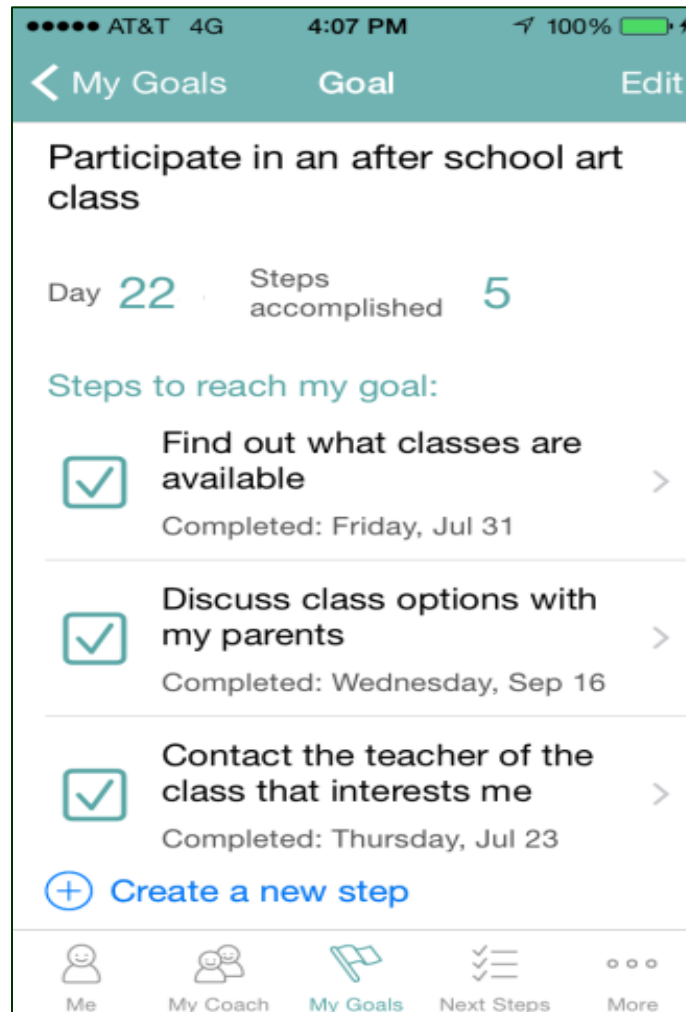
At the bottom right, there is a blue button labeled 'Create Steps'.

Creating a step (*starting the plan*)

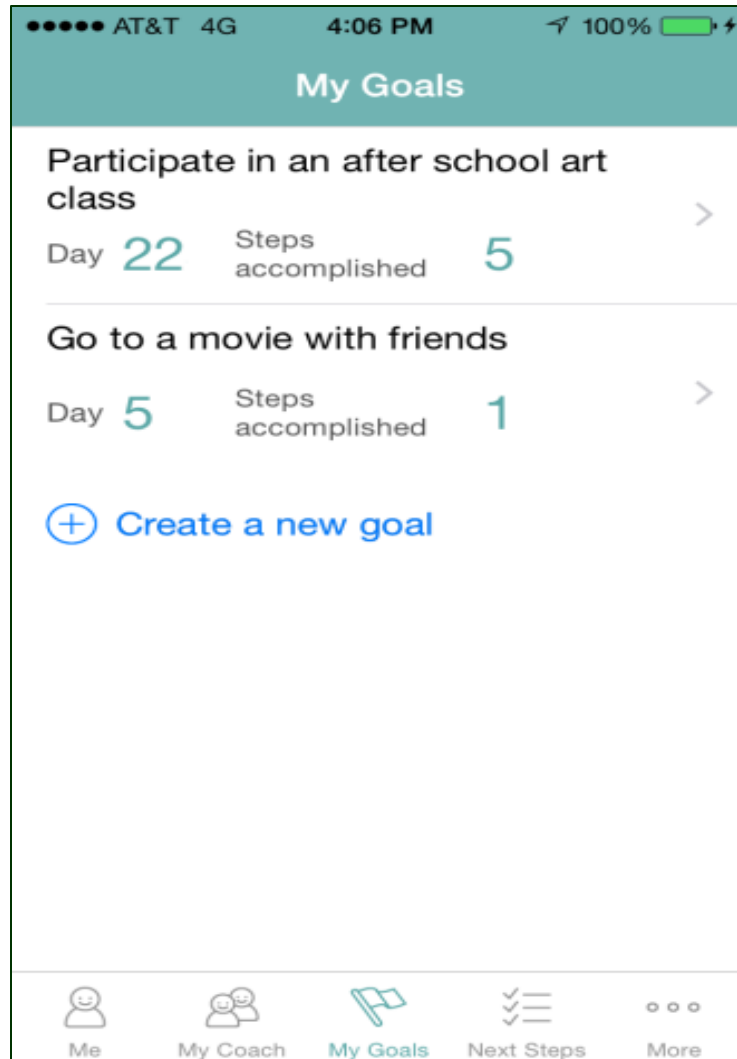
The screenshot shows a mobile application interface for creating a step. At the top, the status bar displays 'AT&T 4G', '4:37 PM', and '100%' battery. Below the status bar is a teal header with three buttons: 'Cancel', 'Edit Step', and 'Done'. The main content area is white and contains the following elements:

- A question: "What is a specific action you can take to help you reach your goal?"
- A text input field containing the text "Find out what classes are available".
- A paragraph of instructional text: "A good step is an action that is small and doesn't seem too difficult to acheive."
- A "Due Date" section with a radio button selected for "No due date".
- A "Notes" section with the text: "Check the website. Ask Mrs. Wallace if I need help."
- A blue link at the bottom: "Create another step".

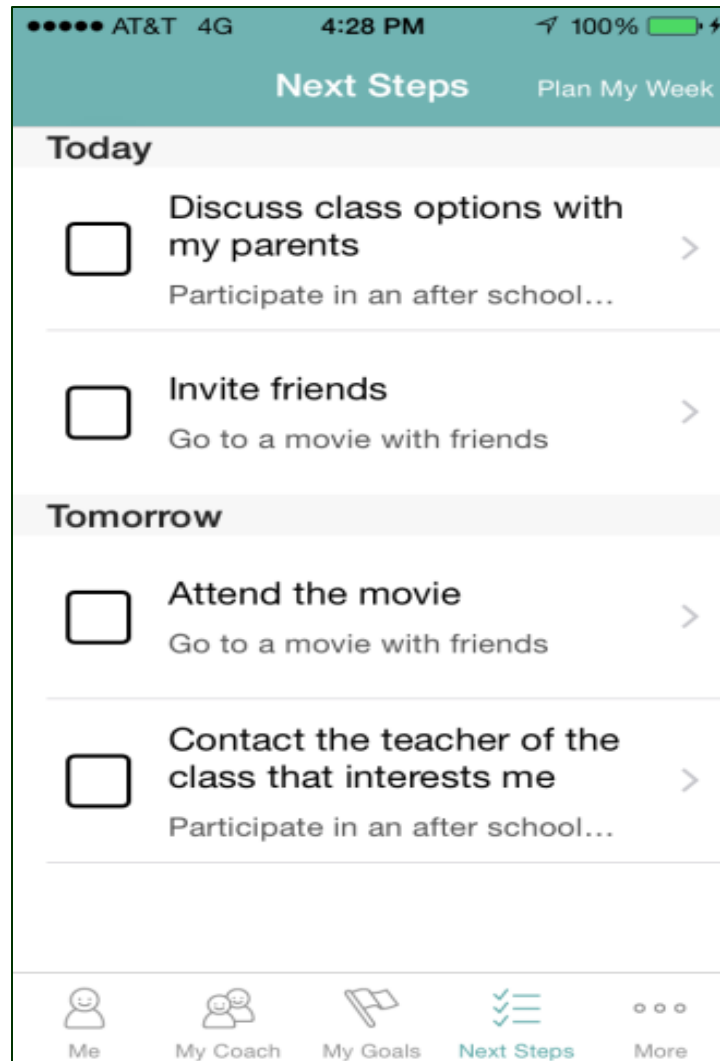
Creating (and Monitoring) Planned Steps



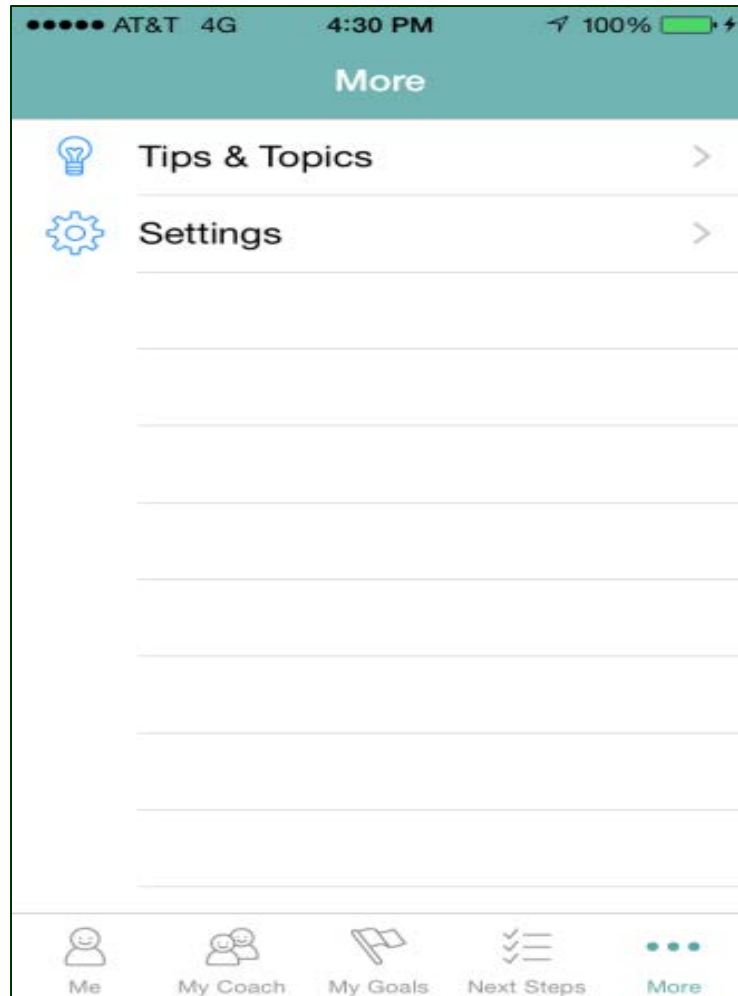
Creating additional goals



Weekly steps linked to goals



Links to tips & topics & settings



Data collection / analyses

1. Type & number of goals achieved (*Content analyses of coach session notes*)
2. Pre- & post-test measures completed by teens & parents (*Descriptive statistics & effect sizes computed*)
 - Total Behavioral / Social Problems & Social Competence Scales of Child Behavior Checklist (**CBCL**; parent-report) & Youth Self Report (**YSR**) (Achenbach, 1991)
3. Satisfaction & usability surveys completed by teens, parents & college student coaches (*Descriptive statistics*)

Teenager Characteristics

	TBI (n=9, 69%)	BT (n=4; 31%)	Total (n=13)
Age (years)	16.59 (1.18)	18.25 (1.88)	17.15 (1.58) <i>Range (14-19.5)</i>
Loaner phone	3 (33%)	3 (75.0%)	6 (46%)
Race, N (%)	Black:	2 (22%)	0 (0%)
	White:	7 (78%)	4 (100%)
Sex, N (%)	Male:	4 (44%)	1 (25%)
	Female:	5 (56%)	3 (75%)
Sessions completed	7.13 (3.52)	10 (0)	8.08 (3.15) <i>Range (3-10)</i>
Goals achieved	2.88 (2.10)	3.00 (2.31)	2.92 (2.07) <i>Range (0-7)</i>

Undergraduate student coaches (n=10)

- **Colleges:** Tufts (n=6); University of Wisconsin-Madison (n=4)
 - 3 coaches paired with two teenagers
- **Ages:** 18-22
- **Sex:** 8 females; 2 males
- **Race:** White (n=6); Black (n=1); Asian (n=5), Asian/White (n=1)
- **Ethnicity:** Hispanic (n=2)
- **Undergraduate class:** Senior (n=1); Junior (n=7); Sophomore (n=2) Freshman (n=3)
- **Majors:** Psychology (n=2), Child development /Psychology (n=2); Biology/Chemistry (n=2), Engineering/Computer science, Cognitive sciences (n=2), Communication science (n=2)

Type and number of goals

(Goals achieved by teens: Mean=3; Range = 0-7)

Type of goal	Number of goals achieved
1. Spend more time with friends	16
2. Improve social communication	11
3. Try new activity with friends / boyfriend	4
4. Try new activity with family	3
5. Make new friends	2
6. Take lead role in a new activity	1
7. Help a friend / family member	1
8. Participate in a large social event	1
<i>Total number of goals achieved</i>	<i>39</i>

Pre-to Post changes

(Youth Self Report (YSR) measure)

	TBI			Brain Tumor (BT)		
	Pre	Post	Cohen's d	Pre	Post	Cohen's d
Total Problems	53.88 (6.42)	50.38 (7.50)	0.54 ↓	45.33 (14.64)	51.33 (16.86)	0.49 ↑
Social Problems	54.75 (4.83)	54.50 (4.90)	0.07 ↓	52.67 (3.79)	59.67 (8.50)	0.93 ↑
Social Competence	44.00 (8.91)	48.75 (9.87)	0.52 ↑	44.00 (10.82)	40.33 (7.02)	0.78 ↓

Pre- to Post changes (CBCL, parent-report measure)

	TBI			Brain Tumor (BT)		
	Pre	Post	Cohen's d	Pre	Post	Cohen's d
Total Problems	57.00 (7.82)	46.88 (8.22)	1.32 ↓	56.00 (2.65)	55.00 (5.20)	0.25 ↓
Social Problems	57.00 (5.81)	52.63 (3.78)	0.87 ↓	65.00 (7.55)	62.67 (7.57)	0.61 ↓
Social Competence	40.14 (10.17)	44.43 (13.75)	0.35 ↑	45.33 (2.52)	45.67 (4.16)	0.05 ↑

Summary: Effect sizes (pre-test to post-test changes)

● Traumatic Brain Injury (TBI)

- ↑ Social competence (YSR = medium; CBCL = small)
- ↓ Total & Social problems (YSR = medium & negligible; CBCL = large)

● Brain Tumor (BT)

- ↓ Social competence (YSR = large)
- ↑ Social competence (CBCL = negligible)
- ↑ Total & Social problems (YSR = medium & large)
- ↓ Total & Social problems (CBCL = small & medium)

Program Satisfaction/Usability

(Strongly disagree = 1 to Strongly Agree = 5)

Selected Items	Teens (TBI)	Teens (BT)	Parents (TBI)	Parents (BT)
Recommend program to others	4.25	4.5	4.5	4.67
Program was useful	3.14	3.75	4.25	4.33
Enjoyed program	4.25	4.25	4.13	4.33
<i>Setting participation goals was easy</i>	4.38	4	3.75	3
<i>Liked setting goals</i>	4	3.5	3.88	4
Liked using the app to set goals	3	3.75	3.5	3.67
App was easy to use	3.25	4.5	3.5	4
App was useful	3.13	3.75	3.25	3.67
<i>Brief Tips were useful</i>	3.63	3.67	3.33	2
<i>Key Topics were useful</i>	3.88	3	3.33	2
Liked working with coach	5	4.5	4.71	4.33
Coaching was useful	4.88	4.5	4.43	4.33
Easy to get in touch with coach	4.43	5	3.63	2.33

Limitations

- Broadened enrollment for teens with BT midway due to enrollment challenges with teens with TBI
- App used in pilot designed for iPhone (~50 % had loaner phones)
- Problems installing app via Apple's Test Flight system,
 - Some did not have access to app for initial coaching sessions & developed/tracked goals & plans offline
- Coaches started at different time periods (had more supervision) & had different skill levels
- Unable to develop screen-sharing due to technical issues with third-party software
 - Coaches could not see how teens were using app "in time"

Summary

- SPAN seemed to assist with goal achievement
- Pre to post score differences reflected positive changes for participants with TBI and mixture of positive (*parent measures*) and negative (*teen measures*) changes for those with BT
- Teen scores indicated less problems when compared with parent scores (*especially BT scores*)
- Teens with BT may have become more aware of their problems
- Satisfaction moderate to high overall except for ratings from parents of teens of BT on tips/topics & getting in contact with coaches
- Coaching viewed very positively by all participants
 - Consistent with key features of coaching (*support/problem solving*)
 - Addressed key features of social participation (*provided a sense of accomplishment /enjoyment*)

Future directions

- **Feedback from brain tumor survivors /parents**
 - Develop Topics /Tips to address their concerns
- **Improve usability of SPAN**
 - Make app easier to use /navigate; make usable on multi-platforms/ devices
 - Consider need for screen sharing
 - Shorten / simplify key topics/tips
 - Clearer expectations for parents (*tailor to preferences*)
 - Examine usability post-SPAN
- **Explore use with other populations / settings**
- **Additional stakeholder feedback & testing**

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Thank You!

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