

# Social Participation and Navigation (SPAN) Program for Adolescents With Acquired Brain Injury: Pilot Findings

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**Purpose/Objective:** Our goal was to examine the feasibility and preliminary efficacy of an app-based coaching intervention (Social Participation and Navigation; SPAN) to help survivors of acquired brain injury attain social participation goals. **Research Method/Design:** This is a nonrandomized pilot trial of SPAN, including 15 adolescents (9 with traumatic brain injury, 6 with brain tumor) between the ages of 14–22. The SPAN intervention consisted of a mobile app to support the development and implementation of social participation goals, weekly video-conference coaching sessions to identify goals and step-by-step action plans, and online didactic materials. Assessments were completed pre- and postintervention. Satisfaction with the intervention, confidence in the adolescents' ability to participate in and plan social activities and manage their emotions and behaviors, and frequency and satisfaction with social participation were assessed via self- and parent-report questionnaires developed for this project. Behavior problems, social competence, and social problems were measured by using the Child Behavior Checklist and the Youth Self-Report. **Results:** High levels of participant and parent satisfaction were reported. Increases in parent-reported frequency of social participation and teen-reported confidence in their ability to participate and develop social participation goals and plans were observed. A decline in parent-reported total problems, internalizing problems, externalizing problems, and social problems was noted. **Conclusion/Implications:** Results support the feasibility of the program, because participants were able to successfully meet with their coaches and use the app to develop and accomplish social participation goals. Further research will be needed to refine the app and program, particularly when reaching out to populations beyond traumatic brain injury.

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**Impact and Implications**

This study describes the refined Social Participation and Navigation (SPAN) program; discusses the feasibility, utility, and satisfaction with the program; and presents preliminary outcome data. The study confirms the acceptability of the app based coaching intervention to set and achieve social participation goals. Further development of content and materials is needed to make the intervention more applicable/tailored for additional acquired brain injury populations.

*Keywords:* brain injury, brain tumor, adolescence, social participation, peer coaching intervention

**Introduction**

Acquired brain injuries (ABIs) resulting from trauma or illness are a leading cause of morbidity in adolescents and young adults and contribute to persistent alterations in cognition, behavior, and social participation (Prigatano & Gupta, 2006; Rosema, Crowe, & Anderson, 2012; Turkstra, Politis, & Forsyth, 2015). Although learning and behavioral challenges following ABI in adolescence have been well documented, the social consequences are less well understood. Findings suggest that adolescents with traumatic brain injury (TBI) often experience limitations in their social participation in school and the community and concomitant social isolation, lack of meaningful friendships, and exclusion from social opportunities (Bedell, Cohn, & Dumas, 2005; Bedell & Dumas, 2004; Gauvin-Lepage & Lefebvre, 2010; Law, Anaby, DeMatteo, & Hanna, 2011; Mealings & Douglas, 2010; Prigatano & Gray, 2007; Sharp, Bye, Llewellyn, & Cusick, 2006; van Tol, Gorter, Dematteo, & Meester-Delver, 2011), with similar challenges noted among survivors of pediatric brain tumors (BTs; Carpentieri & Mulhern, 1993; Foley, Barakat, Herman-Lui, Radcliffe, & Molloy, 2000; Fuemmeler, Elkin, & Mullins, 2002; Vannatta, Gartstein, Short, & Noll, 1998).

In the International Classification of Functioning, Disability and Health (ICF), the World Health Organization defines "Participation" as involvement in a life situation (World Health Organization, 2007). Social participation can be characterized as involvement, engagement, and doing or being with others (Bedell, 2012). Social participation contributes to feelings of accomplishment, enjoyment, and skill development (Eccles, Barber, Stone, & Hunt, 2003). More important, it may also protect socially and educationally at-risk children and youth against later mental health, academic, vocational, and social problems (Eccles et al., 2003; Larson & Verma, 1999; Mahoney, Cairns, & Farmer, 2003; Rutter, 1987). ABI places children at risk for persistent deficiencies in social participation because of limited opportunities in school and community, problems with foundational skills (e.g., social communication and problem solving), and physical and social barriers in the environment (Anaby, Law, Hanna, & DeMatteo, 2012; Bedell, 2009, 2012; Bedell & Dumas, 2004; DeMatteo et al., 2008; Law et al., 2011; van Tol et al., 2011). Children and youth with ABI participate in fewer activities than children and youth without disabilities (Law et al., 2011) and experience greater participation limitations (Bedell & Coster, 2008). Participation limitations for children with ABI are often greatest in social activities and structured events in the community and at school (Bedell & Dumas, 2004). In a study of 60 children who had received inpatient rehabilitation after ABI, the type and severity of social, behavioral,

and cognitive impairments; level of children's functional deficits; and social and attitudinal barriers to participation explained 82% of the variance in participation as measured by the Child and Adolescent Scale of Participation (CASP; Bedell, 2009; Bedell & Dumas, 2004). These findings suggest that youth with ABI participate less than their healthy peers as a function of both individual and environmental characteristics.

Although social participation deficits are common and potentially debilitating for youth with ABI, they have received limited attention from interventionists. Other negative outcomes, such as executive function deficits and externalizing or dysregulated behaviors, may pose greater challenges for parents and teachers, and consequently have been the focus of the majority of intervention studies (Janusz, Kirkwood, Yeates, & Taylor, 2002; Wade et al., 2010, 2011). Programs targeting social skills and relationships have shown some limited effectiveness for youth with ABI (Cooley, Glang, & Voss, 1997; Glang, Todis, Cooley, Wells, & Voss, 1997; Gresham, Sugai, & Horner, 2001) but have failed to directly address social participation. In addition to the dearth of evidence-based interventions, barriers to intervention delivery abound. Most notably, outpatient services may be unavailable altogether, or families may be required to travel significant distances to receive appropriate care. The delivery of the intervention through a telehealth medium addresses this barrier by increasing accessibility. Recent studies suggest that telehealth approaches provide an effective means of delivery interventions to adolescents with TBI and their families while reducing barriers such as time, distance, and available transportation (Wade, Carey, & Wolfe, 2006; Wade et al., 2015).

Intervention effectiveness may be boosted by using peers or peer coaches to promote change (Braga, Rossi, Moretto, da Silva, & Cole, 2012; Selman & Schultz, 1990; Selman, Watts, & Schultz, 1997). Peer coaching is a model in which peers serve as mentors for development and promotion of skills and knowledge and is an ecologically valid approach to achieving generalization of skills learned in therapy. Peers often exert greater influence on adolescent behavior than do parents or other adults, particularly in social interactions (Berndt, 1979; Chein, Albert, O'Brien, Uckert, & Steinberg, 2011). As such, feedback from peer coaches may be more powerful than feedback from a therapist who is likely to differ from the participant in a number of relevant ways (e.g., age, interests, social experiences). The value of peer coaches extends to the ABI literature where greater generalizable benefits have been found for interventions that involve peers (Fraas & Bellerose, 2010; Hibbard et al., 2002; Kolakowsky-Hayner, Wright, Shem, Medel, & Duong, 2012; Struchen et al., 2011; Turkstra & Burgess, 2007).

We report findings regarding the feasibility, utility, and preliminary efficacy of a new program, Social Participation and Navigation (SPAN). SPAN integrates an iPhone-based app and “peer” coaching to facilitate social participation in adolescents with ABI. SPAN was developed through iterative process incorporating stakeholder feedback and further refined following an abbreviated 4-week usability trial (Bedell, Wade, Turkstra, Haarbauer-Krupa, & King, 2017; Narad et al., 2017). The refined SPAN program was tested in an open pilot with 15 adolescents and young adults with ABI from trauma or BTs. We examined participants’ perceptions of ease of use and helpfulness, attainment of social participation goals, and improvements in social participation, behavior, social competence based on participant- and parent-report measures.

## Method

Potential participants were recruited using Trauma Registry, the inpatient rehabilitation unit, and outpatient oncology and brain injury clinics from a single tertiary care children’s hospital in the United States. Recruitment was initially limited to individuals with a history of TBI but subsequently expanded to include survivors of BTs because of recruitment challenges. This population was selected as they are a significant portion of the ABI population, and demonstrate deficits in social competence and functioning (Fuemmeler et al., 2002) similar to those with a history of TBI. Eligibility criteria included age of enrollment between 14 and 22 years and a history of moderate to severe TBI or history of any type of BT. BT survivors had to be 2 years out from treatment completion (or 2 years out from diagnosis if treatment was not indicated). TBI severity was defined based on the lowest Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974). Consistent with previous investigations, severe TBI was defined as a Glasgow Coma Scale (GSS) of 8 or less; moderate TBI as a GCS score from 9 to 12 or a GCS score >12 with abnormal neuroimaging (Fletcher, Ewing-Cobbs, Miner, Levin, & Eisenberg, 1990; Wade et al., 2017; Yeates et al., 2002). All participants had to be sufficiently recovered to actively participate in the intervention (i.e., communicate with coach, access/utilize app and program materials), and this was assessed via parent report. Finally, for adolescents to be eligible for the study, parents had to express some level of dissatisfaction with their adolescent’s social participation. To determine the presence of participation concerns, parents were questioned regarding their dissatisfaction with the (a) quality and (b) quantity of their adolescent’s social participation. Dissatisfaction was rated on a scale of 0 (*not at all*) to 3 (*a great deal*). Parents were also asked to rate their desire for their adolescent or young adult to have improved quality and quantity of social participation, using a scale of 0 (*not at all*) to 3 (*a great deal*). To be considered for the study, the sum of the ratings on the two dissatisfaction items were required to total 2 (*a medium amount*) or higher, and 1 (*a little*) or higher for desire to change. Adolescents were excluded if English was not the primary language spoken in the home or if the adolescent had a psychiatric hospitalization prior to the injury or tumor diagnosis. Adolescents were included even if they did not have the requisite technology (i.e., iPhone) to participate.

A total of 359 individuals (332 TBI; 27 BT) were identified as meeting basic eligibility criteria and of those 132 (119 TBI; 13 BT) were successfully contacted. Seventy-five adolescents (72 TBI; 3 BT) were excluded for not meeting inclusion criteria, such

as failing the initial screening questions, the adolescent was no longer living in the home, or English was not the primary language spoken in the home; and 42 adolescents (38 TBI; 4 BT) declined to participate. A total of 15 adolescents (9 TBI; 6 BT) were enrolled in the study.

## The SPAN Program

The SPAN program consisted of three components: an iPhone app, a website with “Brief Tips” and “Key Topics” (described in last paragraph of this section), and videoconferencing meetings with a trained undergraduate college-student coach. The primary function of the SPAN app was to support the development and implementation of social participation goals (Narad et al., 2017). This process was supported by the coaches, during 10 coaching sessions. Coaches worked with adolescents individually via Skype to identify achievable goals and used the app to create a step-by-step action plan for achieving each goal. The app allowed the participant to create deadlines for each step and provided reminders and reinforcement (i.e., praise for successful completion; Narad et al., 2017). Student coaches provided further support and reinforcement and helped the participants identify barriers and additional supports and resources, and to refine their action plans as appropriate.

When participants initially logged onto the app, they were asked a series of questions to create a profile of their current level of participation, supports and challenges, and strategies for achieving goals. Following an initial orientation by the research coordinator and virtual introduction to the coach, each adolescent met weekly with his or her coach via Skype for 30–60 min, with the goal of completing 10 sessions with their coach. During the initial meeting, the adolescent and coach reviewed the adolescent’s profile as a basis for discussing the adolescent’s interests and his or her goals for the program. During the second videoconference session, the participant and coach used the app goal-planning feature to establish a specific participation goal and define specific steps and a timeline for goal achievement. Subsequent video conference sessions focused on progress in achieving the goal. If the goal was met, the coach reinforced the adolescent’s success and together they defined a new goal. If the goal was not met, the coach problem-solved with the adolescent to identify and address barriers and to modify steps and timelines as needed. Both the coach and the app provided reminders and encouragement via texts and e-mail regarding steps to be completed and praise for completion of steps.

Participants also had access to a website with didactic information presented as Key Topics. This content provided a written introduction and overview of SPAN, as well as information regarding: (a) social participation, (b) goal setting and planning to achieve social participation goals, (c) staying positive, and (d) staying in control/self-regulation. These topics, as well as self-monitoring and joining a conversation, were further reinforced through 1-page Brief Tips that could be reviewed in the app in vivo. These materials were adapted from established intervention programs for youth with TBI (Wade et al., 2010, 2011).

## SPAN Coaches

Coaches were recruited via fliers distributed to undergraduate classes and relevant student organizations at two large universities.

All coaches completed a face-to-face screening interview and provided two references that were verified by project staff. A total of 10 (8 female, 2 male) coaches with an average age of 20.2 years (range = 18–22) participated in the program. The group of coaches was quite diverse (4 White, 1 Latina, 3 Asian, 1 African, 1 multiracial), with a wide range of majors including: psychology, child development, biology, cognitive and brain sciences, community health, electrical engineering, biochemistry, and communication sciences and disorders. Finally, one coach reported a history of TBI.

A coaches' manual was developed by an interdisciplinary team of occupational therapists, psychologists, and speech-language pathologists drawing on manuals from programs providing coaching and problem-solving training to adolescents with TBI (Haarbauer-Krupa, Meulenbroek, Gibbs, & Turkstra, 2010; HeadStrong for Life, 2017; Wade et al., 2014). Coaches received initial orientation and training during a live 90-min videoconference led by a speech-language pathologist, a clinical psychologist and occupational therapist. During this training, coaches were trained in common sequelae experienced by adolescents and young adults with TBI, potential social participation limitations of this population, and the main tenants of the SPAN intervention. The coaches were also given a short demonstration of the app and didactic information. Skills (i.e., communication, goal setting, problem solving) required for successful implementation of the intervention, and appropriate goal selection were also reviewed. In addition, coaches received ongoing training and supervision during weekly group conference calls with a clinical psychologist and occupational therapist. As part of the additional training, coaches completed readings that provided greater detail regarding the empirical foundation for the Brief Tips and Key topics. They were also required to use the app features to create a goal and to implement the steps of their plan, thereby giving them firsthand experience with the process. During supervision calls, coaches received additional training in the skills (goal setting and problem solving) needed to support successful intervention implementation. In addition, coaches reviewed their partner's goals and were given feedback regarding the appropriateness of the goal and potential approaches to refining the goal to improve its specificity and attainability. Some coaches also met weekly with their on-site supervisors if they needed additional scaffolding. Coaches

kept detailed session notes to ensure fidelity to the principles of the intervention that were reviewed during supervision. Dr. XXX (PhD in clinical psychology) and Dr. XXX (PhD in occupational therapy) ensured fidelity to the program via discussion with coaches and review of materials during weekly supervision. It was rare that all 10 coaches were available at a single time for supervision, often requiring Drs. XXX and XXX to conduct 2–3 supervision group calls a week resulting in a time commitment of 3–4 hr per week for supervision of all coaches. Coaches were not paid for the engagement in the program but were provided with a small gift at completion of the project.

## Procedure

See Figure 1 for a visual depiction of project procedures. After parents and participants provided informed consent/assent, a baseline assessment was completed that elicited information about family background and demographic characteristics, current level of social participation and parents' and adolescents' ratings of behavioral concerns. Participants were trained on how to use the app by the research coordinator, and each participant was introduced to his or her coach via Skype. Follow-up assessments were completed after the completion of the 10-week SPAN program, which was an average of 19 weeks after baseline assessment (range = 12–33). These assessments included the same measures completed at the baseline assessment as well as a questionnaire for parents and participants regarding the perceived utility and value of the program. It is worth noting that the above description reflects the ideal flow of activities as designed for the program and trial. Technical issues impacting aspects of program activities are discussed in below.

## Measures

**Feasibility.** Feasibility of the program was assessed through examination of the number of sessions completed and the number of social participation goals achieved during the intervention.

**Participant goals.** Coaches received training in working with adolescents to identify appropriate social participation goals (i.e., well defined, measurable, clear outcomes). Coaches reviewed par-

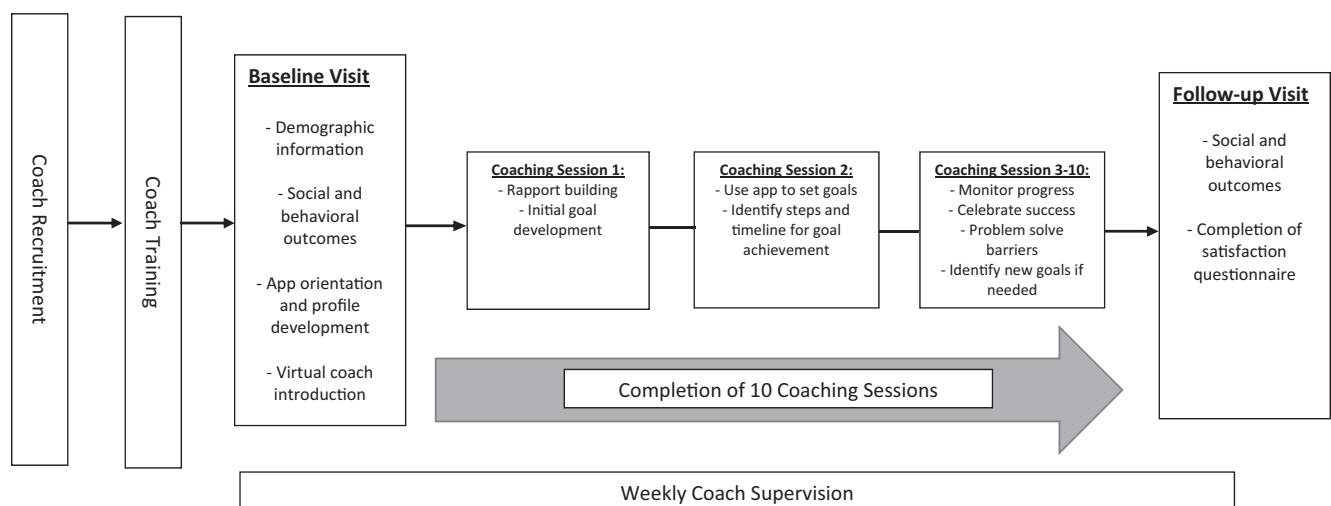


Figure 1. Timeline of project procedures.

ticipant information collected during the baseline assessment and worked with the adolescent during video conferencing sessions to identify appropriate goals. Coaches also reviewed goals in weekly supervision to determine appropriateness of the goal, and all goals were deemed appropriate in that they focused on the broad definition of social participation provided to participants: “spending time and/or doing activities with others.” Content analyses of coach session notes identified the goals achieved and discussed by each participant, and a table of all goals achieved and discussed was created and reviewed by one research assistant and one investigator. All goals were then further categorized into specific types of social participation goals. Identified goal categories were refined and confirmed by the investigative team. The research assistant then classified each goal and recorded the number and types of goals discussed and achieved by each participant, and this classification was subsequently double checked by one of the principal investigators and confirmed by the rest of the investigative team.

**Ease of use/satisfaction.** Satisfaction questionnaire: We developed a brief questionnaire to assess ease of use and helpfulness of various aspects of the program (mobile app, coach, web-based communication, Topics and Tips). Participants and their parents rated helpfulness, ease of use, and satisfaction with specific components of the program, and the program as a whole on a 5-point Likert scale (1 = *strongly disagree*, 2 = *disagree*, 3 = *neutral (neither agree or disagree)*, 4 = *agree*, 5 = *strongly agree*). Mean ratings for each item across participants and frequency of agree/strongly agree ratings for each item were used as outcome variables. Scores on each item range from 1–5.

#### **Preliminary efficacy.**

**Social participation.** A 30-item social participation scale was developed for this project to assess the frequency and satisfaction with social participation across a number of domains (1) online, phone, and social media: 2 items, (2) home and family: 8 items, (3) school participation: 7 items, and (4) neighborhood/community: 13 items). Both parents and adolescents reported on frequency of the 30 activities using a 5-point Likert scale (5 = *quite often*, 4 = *often*, 3 = *sometimes*, 2 = *rarely*, 1 = *not at all*) and satisfaction with involvement in the 30 activities using a 5-point Likert scale (5 = *extremely satisfied*, 4 = *very satisfied*, 3 = *satisfied*, 2 = *somewhat satisfied*, 1 = *not at all satisfied*). Participation frequency (sum of frequency ratings on all 30 items; range = 30–150) and participation satisfaction (sum of satisfaction ratings on all 30 items; range = 30–150) scores from parent and adolescent questionnaires were used as dependent variables.

**Self-efficacy.** A 20-item self-efficacy scale was used to assess confidence in the adolescent’s ability to (a) participate in social activities and develop social participation goals and plans (10 items) and (b) keep track of and manage emotions and behaviors (10 items). Both parents and adolescents rated their level of confidence using a 5-point Likert scale (5 = *extremely confident*, 4 = *very confident*, 3 = *confident*, 2 = *somewhat confident*, 1 = *not at all confident*). Parents and adolescents completed this measure pre- and postintervention. Confidence in participation (sum of 10 items assessing confidence in social participation; range = 10–50) and confidence in emotion regulation (sum of 10 items assessing confidence in ability to monitor and control emotions and behaviors; range = 10–50) were used as dependent variables.

**Social competence and problems.** Participants completed the Youth Self Report (YSR) and their parents completed the Child Behavior Checklist (CBCL; Achenbach, 1991) to provide information about perceived social competence, social problems, and behavioral concerns more broadly pre- and postintervention. One participant was older than 18-years of age and completed the Adult Self Report (ASR), and her parent completed the Adult Behavior Checklist (ABCL). The CBCL and YSR is made up of 112 items (ABCL/ASR is made up of 123 items) and reporters are asked to rate how true each statement is on a 3-point Likert scale (0 = *not true*, 1 = *somewhat or sometimes true*, 2 = *very true or often true*). Responses are scored using age and sex-based norms resulting in *T* scores for each subscale. *T* scores have a mean of 50 and *SD* of 10. *T* scores between 65 and 70 fall within the borderline clinical range, and *T* scores >70 fall into the clinical range. *T* scores on the internalizing problems (composite of anxious/depressed scale, withdrawn/depressed, and somatic complaints scales), externalizing problems (composite of rule breaking behavior and aggressive behavior scales), total behavior problems (YSR/CBCL only: based on all items except for allergies and asthma), and social problems scale (YSR/CBCL only) were used as dependent variables. The social competence scale (YSR/CBCL only) was measured via report of the number of organizations, clubs, or teams the adolescent is involved in; how often and how well he or she participates in the organization (below average, average, above average), number of friends (none, 1, 2 or 3, 4 or more), frequency of contact with friends (less than once a week; 1 or 2 times a week, 3 or more times a week), how well he or she gets along with siblings, other kids, parents (worse, average, better), and how well he or she plays and works alone (worse, average, better). Responses are scored based on age and sex norms resulting in a social competence *T* score. *T* scores between 30 and 35 fall into the borderline clinical range, and scores <30 fall into the clinical range. Social competence *T* score was also used as a dependent variable.

#### **Analyses**

Descriptive statistics were used to characterize the sample. The number of sessions completed and number of goals achieved were examined to assess feasibility of the program. Satisfaction and ease of use information was characterized for adolescents and parents separately. In addition, the frequency of positive ratings (>neutral) were examined. Differences in satisfaction and ease of use ratings for TBI and BT participants were compared using independent samples *t* test for continuous ratings and  $\chi^2$  analyses for frequency measures. Because of the small sample size, Wilcoxon signed-ranks test were used to examine change in parent and participant scores (social participation scale, self-efficacy scale, CBCL, and YSR). Because the intervention was originally designed for use with a TBI population, effect sizes were calculated for the TBI and BT groups separately to examine whether there were differential effects between these groups.

#### **Results**

A total of 15 participants, nine with TBI and six with a history of BT, were enrolled. Six participants used loaner phones to complete the program. Follow-up data were collected on eight youth and young adults with TBI and four BT survivors (80%

follow-up rate; Table 1). Two participants dropped out after completing the baseline assessment and one completed the intervention but not the follow-up assessment. Participants who did not drop out completed an average of eight sessions with the coach (range = 3–10) and achieved an average of three participation goals (range = 1–7). These goals were varied and focused on increasing participation with friends in school, with extracurricular activities, with coworkers, and with family members. Nine types of goals were identified: spend more time with friends, improve social communication, try a new activity with friends/significant other, try a new activity with family, make new friends, take a lead role in a new activity, help a friend/family member, participate in a large social event, and join a new online social network. The number of goals achieved and discussed (set but not achieved by the completion of the SPAN program) within each category are presented in Table 2.

### Ease of Use

Table 3 provides parent- and participant-reported ease of use data. All participants reported using the mobile app, and participants with BTs rated the app as significantly easier (100% easy or very easy) to use than did participants with TBI (37.5% easy or very easy,  $p = .04$ ). All but one adolescent reported accessing the Brief Tips, and two adolescents reported not accessing the Key Topics. Although not statistically significant, none of the parents in the BT group rated the Brief Tips as easy to use and understand compared with two thirds of parents in the TBI group. Similarly, 33% of BT survivors and 75% of youth with TBI rated the Tips as somewhat or very easy to use and understand. Similar ratings of ease of use and comprehension were noted for the Key Topics. The college-student coaches were rated as easy or very easy to work with by all but one parent and all adolescents. However, this intervention component received lower ratings when participants and parents rated how easy it was to meet with the coach, with 50% of BT survivors and 71% of participants with TBI rating it as easy or very easy (Table 3).

### Satisfaction

Table 4 provides parent- and participant-reported satisfaction data. All but two participants (1 with TBI and 1 with a BT) reported that they enjoyed the program, but fewer than half rated the program as useful or very useful. Parents rated the program

Table 2

*Type and Number of Goals Discussed and Achieved During the Social Participation and Navigation (SPAN) Program*

Type of goal	Number goals achieved	Number of goals discussed
1. Spend more time with friends	16	7
2. Improve social communication	11	4
3. Try new activity with friends/significant other	4	0
4. Try a new activity with family	3	2
5. Make new friends	2	1
6. Take lead role in a new activity	1	1
7. Help a friend/family member	1	1
8. Participate in a large social event	1	1
9. Join a new online social network	0	1

*Note.* Goals achieved includes the number of goals in each category that were set, worked on, and achieved throughout the SPAN program. The goals discussed includes the number of goals in each category that were set and discussed but not achieved prior to completion of the program.

more highly overall, with 82% rating the program as useful or very useful. Three of four BT survivors and four of eight participants with TBI rated the app as somewhat or very helpful. There were differences in perceptions of the helpfulness of the Tips and Topics between participants with TBI and BTs, with no participant with a BT and 62.5% of participants with TBI rating the Key Topics as helpful. However, parents and youth in both groups viewed the coaching positively, with all but one parent and all youth/young adults rating the coaching component as helpful or very helpful.

### Preliminary Efficacy

Means, *SDs*, and effect sizes for parent- and participant-reported measures of behavioral outcomes, social participation outcomes, and self-efficacy outcomes by ABI types are presented in Table 5. Wilcoxon signed-ranks test revealed a greater parent-reported frequency of social participation postintervention than preintervention, with a greater effect size noted in the BT sample (Cohen's  $d = 4.00$ ) than the TBI sample (Cohen's  $d = .93$ ). Finally, adolescent report of confidence in their ability to participate and develop social participation goals and plans was significantly greater at posttest than pretest. Again, effects were large in both groups with a larger effect noted in the BT sample (Cohen's  $d = 2.33$ ) than the TBI sample (Cohen's  $d = 1.17$ ). In addition, significantly lower levels of parent-reported total problems, internalizing problems, externalizing problems, and social problems on the CBCL at the postintervention assessment compared with the preintervention assessment (Table 5). Examination of effect sizes within each of the ABI groups revealed a stronger effect for the intervention within the TBI sample (Cohen's  $d = .87$ – $1.32$ ) than the BT sample (Cohen's  $d = .16$ – $.61$ ). No significant difference in levels of social competence on the CBCL was noted from preintervention to postintervention scores. Analyses of the YSR failed to reveal significant prepost changes on any of the assessed subscales. However, examination of effect sizes within ABI groups revealed a worsening of behaviors in the BT sample (Cohen's  $d = .27$ – $.93$ ) and an improvement in behaviors among the TBI sample (Cohen's  $d = .07$ – $.63$ ).

Table 1

*Participant Characteristics for Those Completing Pre- and Postintervention Assessments*

Variable	TBI	BT	Total sample
Age (years)	16.59 (1.18)	18.25 (1.88)	17.15 (1.58)
Age at injury (years)	6.27 (5.50)	5.46 (4.60)	6 (5.02)
Loaner phone	3 (37.5%)	3 (75.0%)	6 (50%)
Race, <i>N</i> (%) non-White	2 (25%)	0 (0%)	2 (16.7%)
Sex, <i>N</i> (%) male	4 (50%)	1 (25%)	5 (41.7%)
Sessions completed	7.13 (3.52)	10 (0)	8.08 (3.15)
Goals achieved	2.88 (2.10)	3.00 (2.31)	2.92 (2.07)
Goals discussed	4.50 (2.67)	5.00 (.82)	4.67 (2.19)

*Note.* TBI = traumatic brain injury sample; BT = brain tumor sample.

Table 3

Results of Independent Samples *t*-Tests (TBI vs. BT) and Descriptives (*M* [*SD*]) of Parent- and Adolescent-Reported Ease of Use Ratings

Variable	Ease of use					
	TBI ( <i>n</i> = 8)	BT ( <i>n</i> = 4)	<i>p</i>	TBI agree/ strongly agree	BT agree/ strongly agree	<i>p</i>
Adolescent report						
Setting goals to participate was easy	4.38 (1.06)	4.00 (1.41)	.61	7 (87.5)	3 (75.0)	.58
App was easy to use	3.25 (1.39)	4.50 (.58)	.12	<b>3 (37.5)</b>	<b>4 (100.0)</b>	<b>.04</b>
App was easy to understand and navigate	3.75 (1.04)	4.25 (1.50)	.51	5 (62.5)	3 (75.0)	.67
Brief Tips were easy to use and understand	3.88 (1.55)	3.33 (.58)	.58	6 (75.0)	1 (33.3)	.20
Key Topics were easy to use and understand	3.88 (1.46)	3.00 (.00)	.59	5 (62.5)	0 (.0)	.24
Coaches were easy to work with	4.88 (.35)	4.50 (.58)	.19	8 (100.0)	4 (100.0)	1.00
Easy to meet with coach	3.86 (1.35)	4.00 (1.15)	.86	5 (71.4)	2 (50.0)	.48
Easy to get in touch with coach	4.43 (1.13)	5.00 (.00)	.35	6 (85.7)	4 (100.0)	.43
Easy to work on goals with coach	4.29 (.76)	4.25 (.96)	.95	6 (85.7)	3 (75.0)	.66
Parent report						
Setting goals to participate was easy	3.75 (1.16)	3.00 (1.73)	.42	6 (75.0)	2 (66.7)	.78
App was easy to use	3.50 (1.31)	4.00 (1.00)	.57	4 (50.0)	2 (66.7)	.62
App was easy to understand and navigate	3.43 (1.39)	4.00 (1.00)	.54	3 (42.9)	2 (66.7)	.49
Brief Tips were easy to use and understand	3.67 (1.51)	2.00 (1.41)	.22	4 (66.7)	0 (.0)	.10
Key Topics were easy to use and understand	3.83 (1.60)	2.00 (1.41)	.20	4 (66.7)	0 (.0)	.10
Coaches were easy to work with	4.71 (.49)	4.00 (1.00)	.15	7 (100.0)	2 (66.7)	.11
Easy to meet with coach	3.38 (1.19)	3.33 (.58)	.96	3 (37.5)	1 (33.3)	.90
Easy to get in touch with coach	3.63 (1.06)	2.33 (.58)	.08	4 (50.0)	0 (.0)	.12
Easy to work on goals with coach	3.75 (1.04)	3.67 (1.53)	.92	5 (62.5)	2 (66.7)	.90

Note. TBI = traumatic brain injury sample; BT = brain tumor sample; Likert scale for responses: 1 = *strongly disagree*, 2 = *disagree*, 3 = *neutral* (neither disagree or agree), 4 = *agree*, 5 = *strongly agree*. Bolded items indicate statistically significant difference. The frequency (percentage) of parents and adolescents who reported greater than neutral ease of use ratings, and results of  $\chi^2$  analyses (TBI vs. BT) are also reported.

## Discussion

Results from our open pilot of the SPAN program provide preliminary support for its feasibility, as participants were able to meet with their coach, develop and achieve social participation goals, and experienced improvement in select domains of social and behavioral outcomes. While some aspects of the program were not rated very highly in terms of satisfaction or ease of use, adolescents and parents rated the overall program positively, with the coaching portion of the program receiving the highest ratings. Adolescents completed an average of 8 meetings with their coaches and use the app to develop and accomplish social participation goals. Interestingly, all patients with a history of BTs attended all 10 coaching sessions, while adolescents with a history of TBI completed fewer, and a more variable number of sessions. While this unanticipated finding may be associated with the adolescents' impressions of the program (see below), it is possible that the type of insult played a role. For example, patients with a history of BTs are used to attending multiple follow-up appointments with a number of specialists and continued long-term surveillance to monitor for disease progression or reoccurrence, and adherence to this follow-up care is quite important and potentially life saving. Conversely, adolescents with a distant history of TBI are less likely to have continued monitoring by specialist years after injury, especially if they are experiencing minimal physical or cognitive sequela. The differential view on the importance of adherence to appointments between the two groups may have played a role in their level of adherence to the treatment protocol.

High levels of participant and parent satisfaction, particularly with the program as a whole and the coaching component, also

support its further use and development. However, as discussed in greater detail below, many participants did not find the app easy to use and overall they did not rate the program as useful. Adolescents with TBI and BTs viewed the program differently with BT survivors rating the app as easier to use. Youth in both groups reported higher levels of confidence in their social participation at follow-up with very large effect sizes. In addition, parents, but not adolescents, noted a higher frequency of social participation at follow-up. Reductions in parent-reported behavior problems were also observed with greater effects in the TBI group. These findings suggest the need for further refinements to improve usability and optimize the program content for individuals with both TBI and other forms of ABI. As described in greater detail below, this pilot can inform further development of programs to promote social participation for youth and transition-age young adults with ABI.

Despite an iterative development process incorporating stakeholder feedback throughout, participant and parent ratings of ease of use were lower than anticipated. Several factors likely contributed to this. First, the app was designed for iPhones and iPhones were provided to participants who did not already have one. While this approach guaranteed that all potentially eligible individuals could participate, it also required approximately half of the participants to use an unfamiliar phone operating system. Moreover, these participants had to use two cell phones (their own and the loaner phone) during the course of the study. As a result, many of those who loaned a phone for the intervention completed a number of activities (problem solving, step-planning, etc.) offline without the use of the phone. While this did not appear to impact outcomes of the intervention (outcomes were similar for those using a loaner

Table 4  
*Results of Independent Samples t-Tests (TBI vs. BT) and Descriptives (M [SD]) of Parent- and Adolescent-Reported Satisfaction*

Variable	Satisfaction					
	TBI (n = 8)	BT (n = 4)	p	TBI agree/ strongly agree	BT agree/ strongly agree	p
Adolescent report						
Liked setting goals	4.00 (1.31)	3.50 (1.91)	.60	6 (75.0%)	2 (50.0%)	.39
Glad to do program	4.13 (.64)	4.25 (.96)	.79	7 (87.5%)	3 (75.0%)	.58
Recommend program to others	4.25 (.71)	4.50 (1.00)	.62	7 (87.5%)	3 (75.0%)	.58
Program was what was expected	3.13 (1.46)	3.25 (1.50)	.89	3 (37.5%)	2 (50.0%)	.68
Program was useful	3.14 (1.46)	3.75 (1.50)	.53	3 (42.9%)	2 (50.0%)	.82
Enjoyed program	4.25 (.71)	4.25 (.96)	1.00	7 (87.5%)	3 (75.0%)	.58
Liked using the app to set goals	3.00 (1.51)	3.75 (1.89)	.47	4 (50.0%)	3 (75.0%)	.41
App was what was expected	3.00 (.93)	4.00 (.82)	.10	<b>1 (12.5%)</b>	<b>3 (75.0%)</b>	<b>.03</b>
App was useful	3.13 (1.36)	3.75 (1.89)	.52	4 (50.0%)	3 (75.0%)	.41
Enjoyed the app	3.13 (1.36)	4.00 (1.15)	.30	4 (50.0%)	2 (50.0%)	1.00
Liked to use Brief Tips	3.50 (1.77)	3.33 (.58)	.88	4 (50.0%)	1 (33.3%)	.62
Brief Tips were useful	3.63 (1.69)	3.67 (1.15)	.97	5 (62.5%)	1 (33.3%)	.39
Liked to use Key Topics	3.75 (1.49)	3.00 (.00)	.65	4 (50.0%)	0 (0%)	.34
Key Topics were useful	3.88 (1.46)	3.00 (.00)	.59	5 (62.5%)	0 (0%)	.24
Liked working with coach	5.00 (.00)	4.50 (.58)	.03	8 (100%)	4 (100%)	1.00
Coaching was useful	4.88 (.35)	4.50 (.58)	.19	8 (100%)	4 (100%)	1.00
Parent report						
Liked setting goals	3.88 (.99)	4.00 (1.00)	.86	6 (75.0%)	2 (66.7%)	.78
Glad to do program	4.63 (.74)	4.67 (.58)	.93	7 (87.5%)	3 (100%)	.52
Recommend program to others	4.50 (.76)	4.67 (.58)	.74	7 (87.5%)	3 (100%)	.52
Program was what was expected	3.88 (1.38)	4.33 (.58)	.59	6 (75.0%)	3 (100%)	.34
Program was useful	4.25 (1.16)	4.33 (.58)	.91	6 (75.0%)	3 (100%)	.34
Enjoyed program	4.13 (.83)	4.33 (.58)	.70	6 (75.0%)	3 (100%)	.34
Liked using the app to set goals	3.50 (1.31)	3.67 (1.15)	.85	4 (50.0%)	1 (33.3%)	.62
App was what was expected	3.38 (1.30)	3.67 (1.15)	.74	3 (37.5%)	1 (33.3%)	.90
App was useful	3.25 (1.39)	3.67 (1.15)	.66	3 (37.5%)	1 (33.3%)	.90
Enjoyed the app	3.25 (1.39)	3.67 (1.15)	.66	3 (37.5%)	1 (33.3%)	.90
Liked to use Brief Tips	3.33 (1.63)	2.00 (1.41)	.35	3 (50.0%)	0 (0%)	.21
Brief Tips were useful	3.33 (1.63)	2.00 (1.41)	.35	3 (50.0%)	0 (0%)	.21
Liked to use Key Topics	3.67 (1.50)	2.00 (1.41)	.22	4 (66.7%)	0 (0%)	.10
Key Topics were useful	3.33 (1.63)	2.00 (1.41)	.35	3 (50.0%)	0 (0%)	.21
Liked working with coach	4.71 (.49)	4.33 (.58)	.31	7 (100%)	3 (100%)	1.00
Coaching was useful	4.43 (.79)	4.33 (.58)	.86	6 (85.7%)	3 (100%)	.49

Note. TBI = traumatic brain injury sample; BT = brain tumor sample; Likert scale for responses: 1 = *strongly disagree*, 2 = *disagree*, 3 = *neutral (neither disagree or agree)*, 4 = *agree*, 5 = *strongly agree*. Bolded items indicate statistically significant difference. The frequency (percentage) of parents and adolescents who reported greater than neutral satisfaction ratings, and results of  $\chi^2$  analyses (TBI vs. BT) are also reported.

phone compared with those using their own phone), it does speak to feasibility. Second, we encountered a number of technical challenges with the app that adversely affected user perceptions. Some participants experienced problems installing the app via Apple's TestFlight system and did not have access to the app during their initial coaching sessions. Although we had planned to add a feature that allowed coaches and participants to collaboratively work on goals together via in-app video chat and screen-sharing, this did not prove possible because of technical issues with the required third-party software. As a consequence, a number of participants developed and tracked their goals offline rather than using the app. Finally, the decision to broaden enrollment criteria to include individuals with BTs was made midway through the trial because of challenges with enrollment of participants with TBI. Thus, the development process and training materials focused on youth with TBI and program content was not tailored for individuals with BTs or the broader population of youth with ABI.

Although satisfaction was high overall, BT survivors rated the program less favorably across a number of dimensions and had

significantly lower ratings of satisfaction working with the coach. As noted earlier, future versions of SPAN would benefit from additional input from BT survivors, following the iterative procedures we used for participants with TBI. The Key Topics and Brief Tips, in particular, were not developed to address concerns of BT survivors and this was reflected in the ratings from both the BT survivors and their parents. For example, one of the Topics on Staying in Control addressed the emotional lability and dysregulation that are common following TBI, issues that are less common concerns for brain injury survivors. However, we had no Tips or Topics addressing coping with anxiety and depression, which are more common concerns for BT survivors (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013; Shah et al., 2015; Zebrack et al., 2004).

The coaching aspect of the program was viewed most positively by participants. In particular, participants valued the opportunity to connect with someone close in age, brainstorm possible participation goals, and obtain feedback and reinforcement about implementation of their social participation plans. Ongoing supervision



Table 5

*Adolescent and Parent Reported Behavioral Outcomes, Social Participation Outcomes, and Self-Efficacy Outcomes*

Variable	Outcomes							
	Full sample		TBI			BT		
	<i>p</i>	<i>d</i>	Pre ( <i>n</i> = 9)	Post ( <i>n</i> = 8)	<i>d</i>	Pre ( <i>n</i> = 6)	Post ( <i>n</i> = 4)	<i>d</i>
Adolescent report								
Participation frequency	.84	.02	84.63 (17.65)	88.25 (26.45)	.22	95.25 (32.43)	86.75 (16.21)	.28
Participation satisfaction	.29	.29	112.00 (23.72)	102 (19.08)	.36	101.25 (30.93)	98 (15.71)	.11
Confidence: Participation	<b>&lt;.01</b>	<b>1.45</b>	31.75 (10.25)	36.13 (9.06)	1.17	34.5 (8.35)	40 (6.53)	2.33
Confidence: Emotion	.53	.08	34.75 (9.97)	37.25 (6.86)	.30	36 (12.83)	33 (11.83)	.30
Total problems	.48	.48	53.88 (6.42)	50.38 (7.50)	.54	45.33 (14.64)	51.33 (16.86)	.49
Internalizing problems	.41	.41	56.88 (8.59)	53.00 (7.19)	.63	48.67 (15.53)	52.33 (10.97)	.27
Externalizing problems	.57	.57	52.38 (5.10)	48.63 (4.90)	.60	45.33 (9.81)	50.33 (16.01)	.58
Social problems	.50	.50	54.75 (4.83)	54.50 (4.90)	.07	52.67 (3.79)	59.67 (8.50)	.93
Social competency	.73	.73	44.00 (8.91)	48.75 (9.87)	.52	44.00 (10.82)	40.33 (7.02)	.78
Parent report								
Participation frequency	<b>.01</b>	<b>1.11</b>	77.63(12.67)	88.86 (10.33)	.93	95 (25.63)	103.33 (24.58)	4.00
Participation satisfaction	.32	.38	75.88 (19.41)	87.14 (20.16)	.41	95.67 (22.50)	98.33 (22.50)	.31
Confidence: Participation	.31	.36	24.33 (4.41)	33 (8.06)	.98	34.50 (7.33)	31.33 (5.13)	1.52
Confidence: Emotion	.14	.6	24.75 (8.21)	30.88 (10.68)	.93	34.75 (6.6)	35.67 (8.08)	.55
Total problems	<b>&lt;.01</b>	<b>.96</b>	57.00 (7.82)	46.88 (8.22)	1.32	56.00 (2.65)	55.00 (5.20)	.25
Internalizing problems	<b>.05</b>	<b>.73</b>	58.63 (7.82)	48.00 (10.03)	.92	56.00 (2.65)	55.00 (8.66)	.16
Externalizing problems	<b>.02</b>	<b>.79</b>	54.00 (10.14)	45.88 (6.10)	.96	53.67 (2.52)	52.67 (3.06)	1.00
Social problems	<b>.02</b>	<b>.82</b>	57.00 (5.81)	52.63 (3.78)	.87	65.00 (7.55)	62.67 (7.57)	.61
Social competency	.57	.27	40.14 (10.17)	44.43 (13.75)	-.35	45.33 (2.52)	45.67 (4.16)	.05

*Note.* TBI = traumatic brain injury sample; BT = brain tumor sample. *d* = Cohen's *d* effect size. Bolded items indicate outcomes variables with statistically significant changes from pre to post intervention.

supported coaches in tailoring the coaching experience in response to the adolescent's needs. For example, one participant had social anxiety and preferred to conduct coaching sessions via text rather than Skype.

Using number of participation goals achieved as our primary metric of program effectiveness, 12 of the 13 participants made at least some improvements in social participation, with an average of 3 goals attained. These findings suggest that the SPAN program can effectively support goal implementation. Increases in social participation were also noted by parents, with large effect sizes in both groups. Although the adolescents themselves did not report higher levels of participation at follow-up, they did rate themselves as more confident overall in their social participation suggesting that the program may have had meaningful effects beyond the specific goals that were addressed.

Parent-reports also reflected reductions in behavior problems, an unanticipated finding, but no statistically significant changes in social competence were found. No statistically significant changes on the YSR were found; however, post hoc analyses showed a worsening of self-reported social problems for BT survivors despite the fact that they completed more sessions. The discrepancy between parent perceptions of increasing frequency of social participation in the BT group and self-report of increasing social problems points to a need to better understand how these individuals responded to the program. Given the brevity and limited scope of the program, it is perhaps unsurprising that we found only limited changes on measures of parent- and self-reported participation, but it also is possible that more sensitive measures such as the Canadian Occupational Performance Measure or Goal Attainment Scale might have detected additional program-related

changes in social participation goal setting and follow-through (Kiresuk & Sherman, 1968; Law et al., 1998).

Our study had a number of limitations. It was a small pilot, with no comparison or control condition, and the study may not have been powered to detect statistical significance. Further, increased attention to social participation variables, by being a part of this project, may have played a role in change in outcomes. Inclusion of participants with BT introduced additional heterogeneity and treatment effects may have been dampened by a failure to optimize intervention materials and coach training to address the differing needs of this population. In addition, goals were not directly linked to pretreatment behavior, but rather were determined to be appropriate if they met our definition of a social participation goal. While the coaches had access to their participant's social participation functioning details collected from the adolescent and his or her parent at the baseline visit, and used this information to help with goal development, it is possible that adolescents were setting appropriate social participation goals that did not address their individual social participation concerns. We also had a relatively short follow-up period. Longer follow-up could be helpful in elucidating whether participants continued to set and achieve social participation goals.

## Conclusions

Taken together, findings from this pilot indicate the potential promise of the SPAN program and underscore the need for further development/refinement and investigation. It is unknown which aspects of the program (mobile app, goal setting, vs. coaching) are associated with satisfaction and behavioral change; therefore, it

would be important for future trials to examine how each separate aspect of the program, and their combination, are received by participants and their families and function to improve social participation and behavioral outcomes relative to usual care. Once identification of the most important/well received aspects are determined and further developed, the next step will be examining the effectiveness of SPAN relative to usual care or other programs for brain injury survivors such as the Teen Online Problem Solving program (Wade et al., 2006, 2010, 2011, 2015). Through identifying which aspects of the program work best for which patients and disseminating those findings as well as the program to clinical care settings, clinicians will have access to an intervention to address social participation which is an area of great need for intervention. In addition, further development and tailoring is particularly necessary to improve SPAN's utility and relevance for BT survivors. This would involve focus groups and key informant interviews to determine barriers to social participation that may be unique to this population, and piloting of the newly developed materials.

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