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Social Participation And Navigation (SPAN): An app-based coaching intervention for with teenagers with ABI

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Multi-site & interdisciplinary study Collaborators & Funding

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- **Cincinnati Children's Hospital Medical Center:** Shari Wade, 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

- **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 and content of SPAN

- Report on 10 week implementation pilot with 13 teens with TBI and brain tumors (BT)

- Discuss recommendations for SPAN and future directions

- Answer questions and generate discussion

Participation: Why important?

- "Involvement in life situations" *(WHO, 2001; 2007)*

- 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 *(Bedell & Dumas, 2004; Eccles, et al, 2003; King,et al., 2003; Larson, 1999; Mahoney, et al., 2003; Simeonsson, et al., 2001).*

  - Life situations that promote skill development, sense of accomplishment & enjoyment *(Eccles, et al., 2003; Fletcher, et al., 2003; Mahoney, et al., 2003; Rutter, 1987).*

Social Participation & Participation

- Often used interchangeably

- **Social participation**: "taking part, involvement, engagement, doing or being with others" *(Bedell, 2012)*

- **Participation:** involvement in activities that can be done with or without others

Participation of 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

- Lack of evidence on programs to promote social participation of youth with TBI/ABI (Agnihotri, et al., 2010)

- Evidence that peer mentors/coaches:
  - Help youth identify and work on goals & solve problems
  - Provide youth with emotional support along the way
    (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 and problem solving
  - Top-down strengths-based approach targeting 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 and 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 <u>via</u> Skype**

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*)

- **<u>Week 1</u>:** Meeting teen, establishing rapport, describing program & logistics

- **<u>Week 2</u>:** Reviewing Tips & Topics: Goal Setting/Planning, Social Participation; Defining social participation goal

- **<u>Week 3</u>:** Supporting implementation of plan; Reviewing progress & refining plans

- **<u>Weeks 4 - 8</u>:** Supporting refining existing goals, plans and strategies; &/or Developing new goals, plans & strategies to achieve those goals

- **<u>Weeks 8 - 10</u>:** Preparing for termination of coaching & transition to self-management/co-management with circle of support

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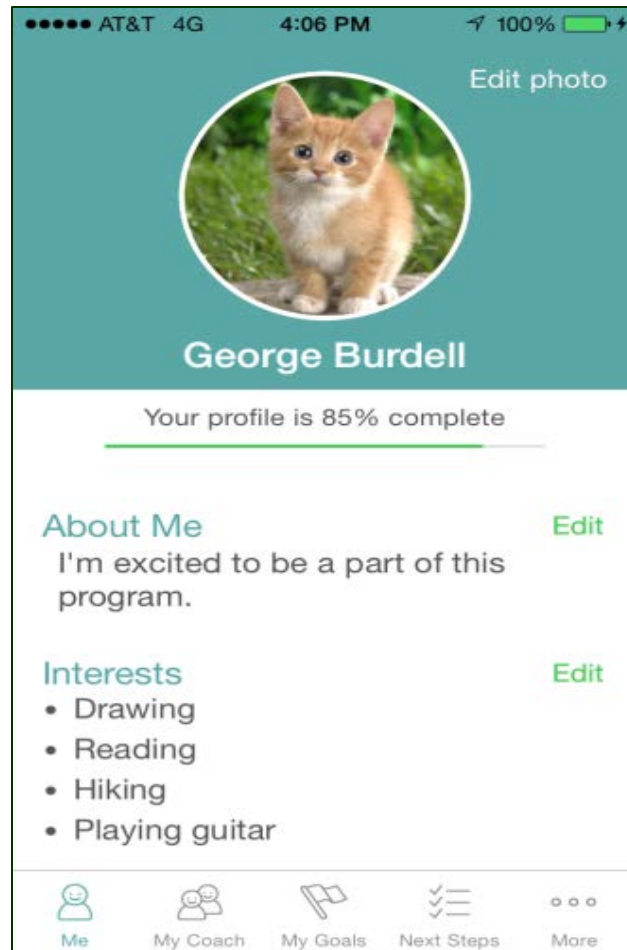
- About me
- Interests
- Strengths
- Challenges
- Social participation goals (Initial ideas)
- Help preference

Creating Goals

Creating a step (*starting the plan*)

Creating (and Monitoring) Planned Steps
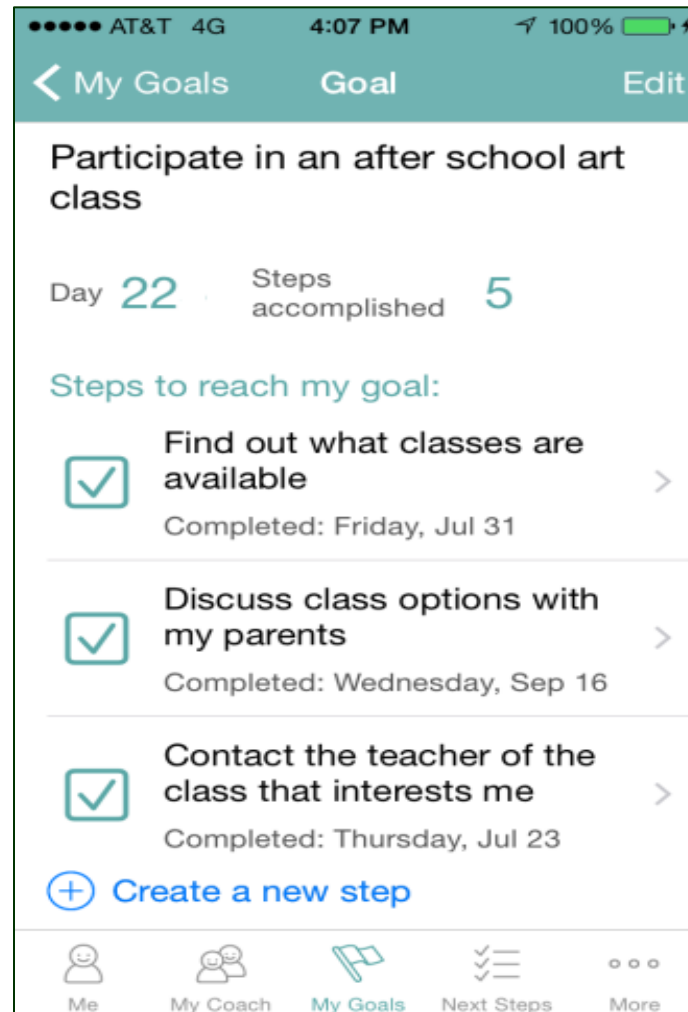
Creating additional goals
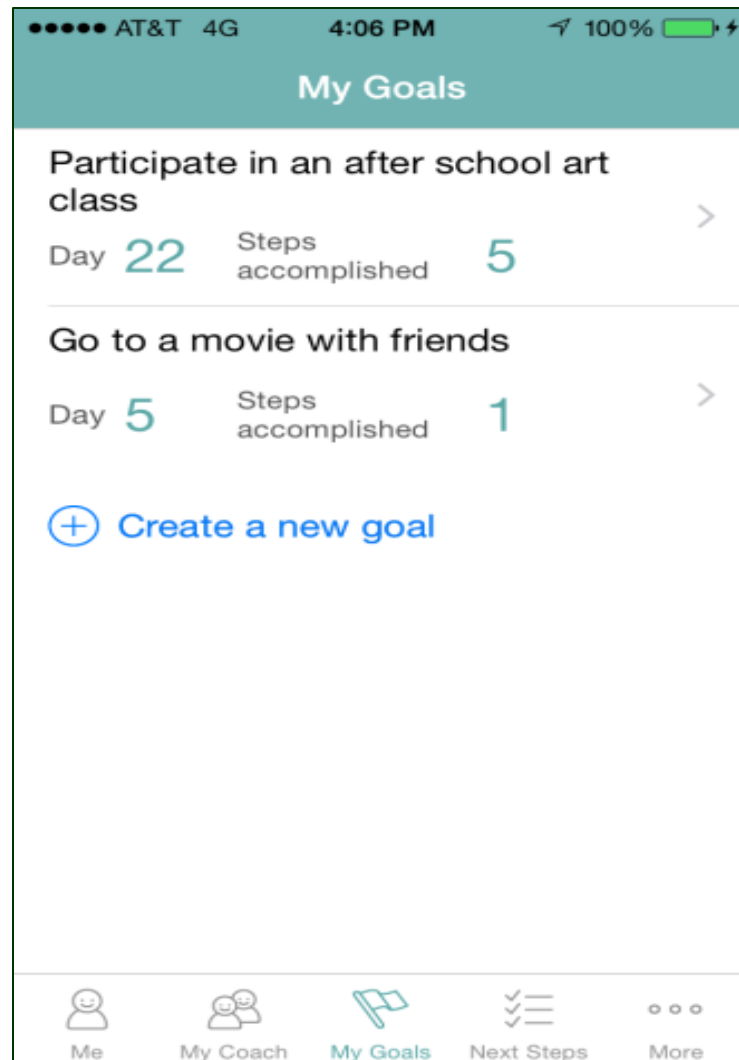
Weekly steps linked to goals
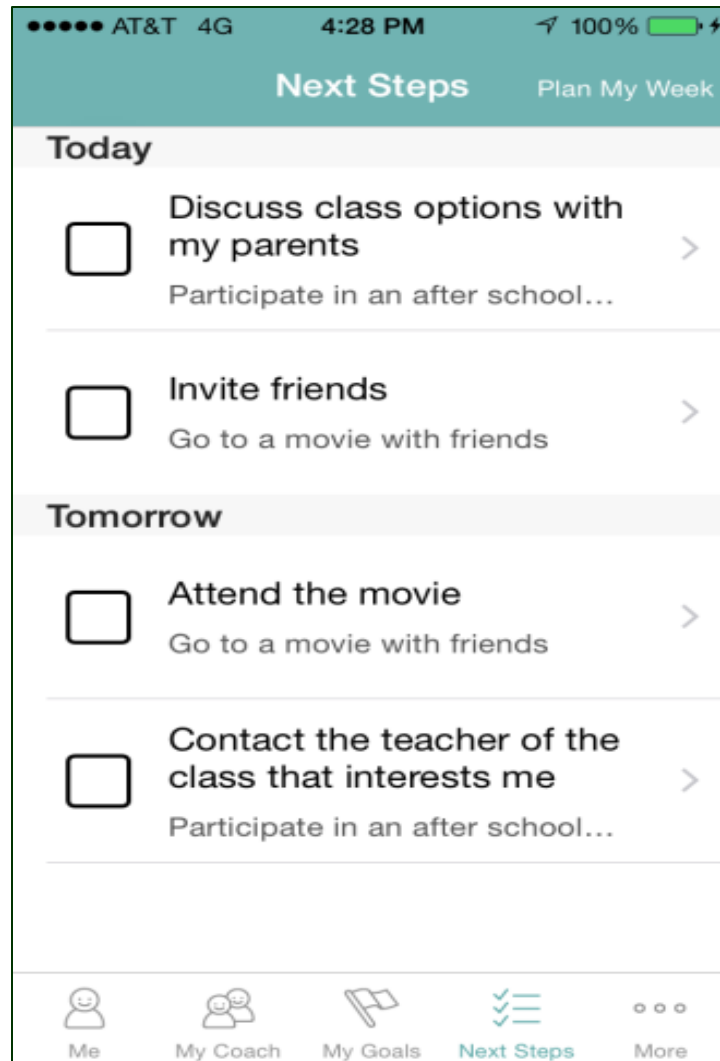
Links to tips & topics and settings
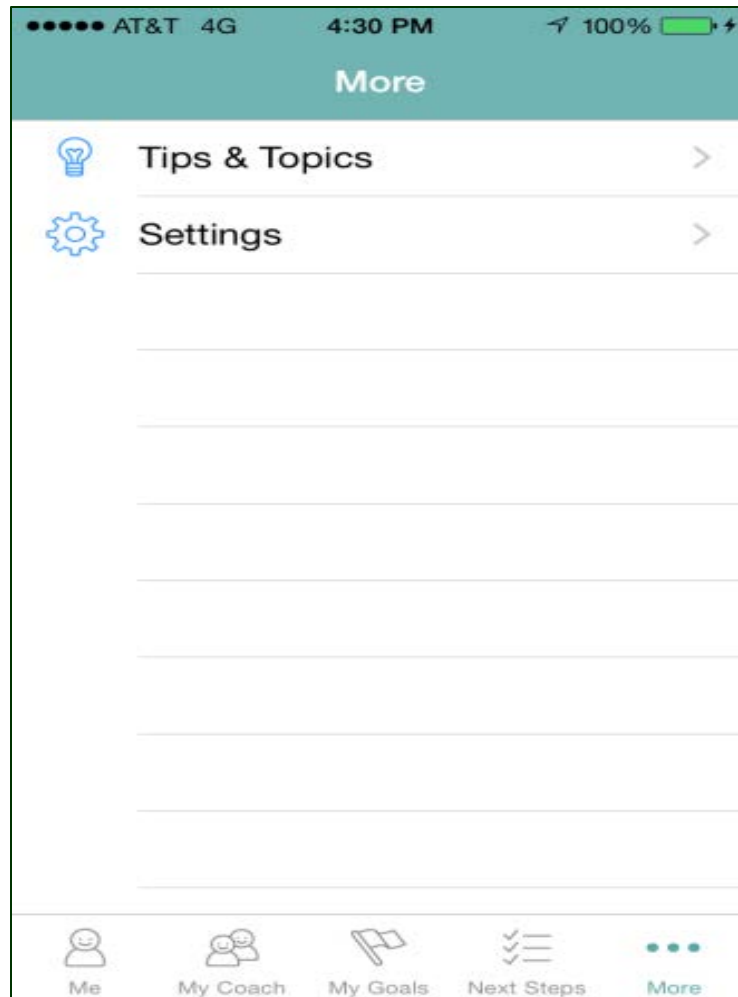
Data collection / analyses

1. Coach session & supervision notes

- *Content analyses to describe type and number of goals, implementation process, challenges*

2. Satisfaction & usability surveys completed by teens, parents & college student coaches.

- *Descriptive statistics & content analyses*

NOTE: *Will report on pre-post test changes at tomorrow's research symposium.*

Coach Session Notes

Current SPAN GOAL:

1. **What was worked on this week towards the goal?** *If goal was not worked on, what occurred?*

2. **What steps and strategies were worked on?** *What worked and did not? Any changes in Plan?*

3. **How often was the app used?** *What worked & did not?*

4. **What tips and key topics were used?** (*Please check*)

   -TIPS: ___Social Participation; ___Goal Setting-Planning; ___ Self-Monitoring (SMART); ___Self-Control (STARRS); ___Joining Conversations

   -Key Topics: ___SPAN Introduction; ___Social Participation; ___Goal setting-planning; ___Staying in Control; ___Staying Positive

5. **What were supports?**

6. **What were barriers/challenges?**

7. **Describe concerns/recommendations/comments to discuss with supervisor:**

Participant 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) *Range (14-19.5)*
Age at injury (years)	6.27 (5.50)	5.46 (4.60)	6 (5.02)
Loaner phone	3 (33%)	3 (75.0%)	6 (46%)
Race, N (%) Black:	2 (22%)	0 (0%)	2 (15%)
White:	7 (78%)	4 (100%)	11 (85%)
Sex, N (%) Male:	4 (44%)	1 (25%)	5 (38%)
Female:	5 (56%)	3 (75%)	8 (62%)
Sessions completed	7.13 (3.52)	10 (0)	8.08 (3.15) *Range (3-10)*
Goals achieved	2.88 (2.10)	3.00 (2.31)	2.92 (2.07) *Range (0-7)*

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	Number of goals discussed
1. Spend more time with friends	16	7
2. Improve social communication	11	4
3. Try new activity with friends / boyfriend	4	0
4. Try 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
Total number of goals achieved/discussed	*39*	*18*

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
Setting participation goals was easy	4.38	4	3.75	3
Liked setting goals	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
Brief Tips were useful	3.63	3.67	3.33	2
Key Topics were useful	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 meet with coach	3.86	4	3.38	3.33
Easy to get in touch with coach	4.43	5	3.63	2.33

Challenges

Challenges	# of dyads reported	# of times reported
Mental health *(anxiety, depression, and / or low self-confidence affecting participation)*	13	60
Environmental *(other people, physical barriers, financial, transportation***)**	12	41
Technological *(problems with SPAN app, phone battery, Skype)*	12	37
Scheduling *(SPAN sessions, teen's time management)*	10	26
Goal-setting *(identifying goals or planning steps for SPAN)*	4	8
Physical health *(sick, tired, headaches)*	4	7
Total	--	179

Coaching: Challenges

• Lack of hands on practice in training (supervision involved ongoing training)

• Coaches/teens started at different time periods (coaches who started earlier had more supervision prior to coaching)

• Supervision scheduling challenges (finding times, attendance, allocating time, technology connection problems)

• Coordinating with college semester, intersession & summer schedule

• Different skill levels (provided additional supervision)

• A few coaches needed extra help to structure sessions to keep teen focused on goal / plan

• Some coaches felt bad when teens missed sessions or did not return requests to reconnect, & during coaching termination

Coaching: Benefits

- Able to connect with someone close in age, brainstorm goals, obtain feedback & reinforcement on implementation of plans

- Ongoing supervision supported coaches in tailoring coaching experience in response to teens' needs

- Session notes were helpful to coach, supervisors & project (*tracked process, fidelity, challenges*)

- Coaching sessions involved social participation (practice, scaffolding, enjoyment)

- Coaches interested in working with individuals with ABI & other disabling conditions

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 loaners*)

- Problems installing app via Apple's Test Flight system
  - some did not have access to the app for initial coaching sessions & had to develop/track goals & plans offline

- Unable to develop screen-sharing due to technical issues with required third-party software,
  - coaches could not see what participants might have needed help with "in time"

Summary

- SPAN seemed to assist participants in goal achievement despite challenges with the app

- Satisfaction moderate to high overall, but some lower ratings from parents of teens with BT (*tips/topics*) and teens with TBI (*app*)

- Coaching viewed very positively by all participants despite a few challenges noted
  - Consistent with key features of coaching (*support/problem solving*)
  - Addressed key features of social participation (*sense of accomplishment / competence; possibly skill-building*)

Future directions

- **Feedback from brain tumor survivors /parents**
  - Use similar iterative design procedures
  - 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
- More stakeholder feedback

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