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

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Multi-site & interdisciplinary study

Affiliations & Funding

- **Tufts University**: Gary Bedell, Co-PI, Michele Jacquin, Sally Ann Marie Cocjin
- **Cincinnati Children’s Hospital Medical Center**: Shari Wade, PI, Megan Narad, Jessica King
- **University of Wisconsin-Madison**: Lyn Turkstra, Co-I
- **Georgia Institute of Technology**: Jeremy Johnson
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Objectives

• To discuss what “participation” is and why it is important

• To give overview on participation of children & youth with ABI and factors associated with their participation

• To describe SPAN

• To briefly report on 4-week usability trial with initial prototype (with 4 teenagers with TBI):

  • To discuss recommendations for SPAN for use in our current 10-week implementation trial

• To answer questions and generate discussion
Participation: What it is & why important

• “Involvement in life situations”  
  *International Classification of Functioning, Disability & Health (ICF)*  
  (WHO, 2001, 2007)

• Multi-dimensional & universal  
  *(Coster & Khetani, 2008; Larson & Verma, 1999; Law, 2002; McConachie, et al., 2006;).*

• Intersection of person-task-environment  
  *(King, et al., 2003; Law, 2002; Mallinson & Hammel, 2010)*

• Key aim of rehabilitation, education & community programs  
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**
Means to Ends

• Enables children to interact, work and live with others and function in society
  (Law, 2002; Larson & Verma, 1999; Mahoney, et al., 2003)

• Associated with enhanced quality of life, social competence and educational success
  (Bedell & Dumas, 2004; Eccles, Barber, 2003; King, et al., 2003; Larson, 1999; Law, 2002; Mahoney, et al., 2003; Simeonsson, et al., 2001).

• Emphasis on participation in activities that promote skill development, and provide a sense of accomplishment and enjoyment
  (Eccles, et al., 2003; Fletcher, et al., 2003; Mahoney, et al., 2003; Mahoney, et al., 2003; Rutter, 1987).
Participation of children with ABI

- Children & youth with ABI often restricted in their participation in school, home, and community life

- Associated factors:
  - Severity of injury, age, age of / time since injury, physical /social environment factors, type & level of impairment, functional skills

- Children / youth with ABI and parents use strategies to promote participation despite obstacles
Rationale for SPAN

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

• Evidence that peer mentors/coaches can
  • Help youth identify and work on goals and solve problems
  • provide youth with emotional support along the way
    (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 populations
  (Dunn, et al., 2012; Glang, et al., 1997; Graham, et al., 2009; 2010; Palisano, et al., 2013)

• Key features:
  • Goal setting and problem solving
  • Top-down approach targeting real-life goals and settings (Brewer, et al., 2014; Novak, 2014; Ylvisaker, et al., 2005)

• Teens frequently use smart phones and apps in their everyday lives (Lenhardt, 2015)
Developmental Process

- Informed by work of our interdisciplinary SPAN research team and colleagues that have influenced us*

- Focus groups with stakeholders (teens and college students with and without TBI; parents of teens with TBI)

- Development of content, procedures, and i-phone app prototype

- 4-week usability test of app with coaching support (*this study*)

- Advisory board feedback throughout

- Further refinements prior to larger 10-week trial (*in progress*)

SPAN: Content & procedures

1. iPhone app to support goal setting and implementation of planned steps and strategies to accomplish social participation goals

2. Teen and coach profiles

3. Online Key Topics and Brief Tips with information and strategies to support social participation
   - Problem solving, self monitoring, self control, staying positive, joining conversation/groups

4. Weekly coaching sessions via Skype
   - College students complete coach session notes

5. Coach training and weekly supervision (online; in-person as needed)
App Design
Setting Social Participation Goals

What are activities or social participation goals that you would like to focus on?

- Joining a class
- Interacting with peers
- Add a goal
Identifying Strengths

What are things about yourself that will help you reach your participation goals?

- Good communicator
- Sense of humor
- Adaptive

Add a strength
Identifying Challenges

What are things that might make it harder to reach your participation goals?

- Shy
- Anxious about new situations

Add a challenge
Accomplishing Participation Goals

My Goals

- **Start a band**
  - Day 180 Steps accomplished 2

- **Join art class**
  - Day 165 Steps accomplished 1

- **Go to concert**
  - Day 0 Steps accomplished 1

Create a new goal
Planned steps to reach goals

**Start a band**

**Day 180**  Steps accomplished  **2**

Steps to reach my goal:

- **Plan a time to meet**
  Completed: Friday, May 8

- **Name the band**
  Completed: Friday, Jul 31

- **Meet the first time**
  Due: Saturday, Sep 12

**Create a new step**
Strategies for reaching goals

Meet the first time
Due: Saturday, Sep 12

Helpful strategies:
Organize dates with planner
SPAN Usability Study

SAMPLE:

- 4 teens (3 females, 1 male)
  - Teens were, on average, 15.73 years old and injured an average of 8½ years earlier
- 4 coaches
  - 2 female graduate students in Occupational Therapy
  - 2 male graduate students in Speech Pathology/Neuroscience

PROCESS:

- Teens and coaches met weekly for four weeks via Skype
- Coaches met weekly for supervision (Clinical Psychologist & Occupational Therapist)
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. Please describe concerns/recommendations/comments to discuss with supervisor:
Measures

1. Type and number of goals achieved and action plans were recorded.

2. Satisfaction and usability surveys designed for study were completed by teenagers, parents and college student coaches.

3. Coach session notes (process and outcomes data)

4. Pre- and post-test measures completed by teenagers and parents:
   b. The Quality of Communication Life Scale (Frattali, et al., 2004) modified for adolescents (Burgess & Turkstra, 2010)
# Teenagers’ Goals & Plans

<table>
<thead>
<tr>
<th>Goals</th>
<th>Steps for Goal Achievement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Become more social and meet new friends</td>
<td>1. Talk to new people&lt;br&gt;2. Do more one-on-one work with classmates to build more intimate acquaintances</td>
</tr>
<tr>
<td>Spend more time with extended family</td>
<td>1. Call grandmother to schedule a visit</td>
</tr>
<tr>
<td>Plan an outing with friends</td>
<td>1. Start a conversation with friends to gather interest and ideas</td>
</tr>
<tr>
<td>Keep up with existing friendships</td>
<td>1. Text friends more often&lt;br&gt;2. Make plans to hang out outside of school&lt;br&gt;3. Talk to people in person more often</td>
</tr>
<tr>
<td>Hang out with friends outside of school</td>
<td>1. Use occasions (holidays, birthdays, etc.) to make plans&lt;br&gt;2. Engage in activities that keep you occupied</td>
</tr>
<tr>
<td>Practice cello more regularly in a social way</td>
<td>1. Talk to acquaintances&lt;br&gt;2. Talk to and practice with cello instructor&lt;br&gt;3. Discuss music interests, theory, or practice techniques with other musicians</td>
</tr>
<tr>
<td>Invite a friend to go to the amusement park</td>
<td>1. Decide which friend to invite&lt;br&gt;2. Invite friend to the park&lt;br&gt;3. Follow through with plan and go to amusement park with friend</td>
</tr>
</tbody>
</table>
Teens’ Experience with the Process (video)

https://www.youtube.com/watch?v=NeZq1AdHA0c
Additional feedback

• **Benefits:**
  - SPAN prototype was feasible to implement
  - Most satisfied with key features
  - Liked coaching for building rapport and trouble-shooting around issues (coach & teen)
  - Step by step goal-setting process leads to real outcomes.
  - Valuable experience for both parties

• **Concerns/discussions:**
  - Challenges with scheduling Skype visits
  - Key topics were too long, used jargon & not so enjoyable to read
  - Confusion about difference between ‘steps’ and ‘strategies’
  - Some initial navigation challenges – limited in-app directions
  - Not possible to share app while chatting
  - No push notifications (reminders about steps and timelines)
  - Difficult to know how to manage parental involvement (coaches)
  - What is “social participation” (team)
Satisfaction with SPAN

(1 = not; 2 = somewhat; 3 = helpful; 4 = very; 5 = extremely)
## Change from pre-test to post-test

<table>
<thead>
<tr>
<th></th>
<th>Pre-test Mean (SD)</th>
<th>Post-test Mean (SD)</th>
<th>Effect size (Cohen’s d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Competence (Teen - YSR)</td>
<td>48.25 (9.91)</td>
<td>52.50 (4.12)</td>
<td>0.56</td>
</tr>
<tr>
<td>Social Problems (Teen - YSR)</td>
<td>55.25 (4.65)</td>
<td>52.00 (2.00)</td>
<td>0.91</td>
</tr>
<tr>
<td>Total Problems (Teen - YSR)</td>
<td>48.25 (5.56)</td>
<td>42.75 (3.77)</td>
<td>1.16</td>
</tr>
<tr>
<td>Quality of Communication Life (Teen)</td>
<td>4.07 (0.57)</td>
<td>4.41 (0.53)</td>
<td>0.62</td>
</tr>
<tr>
<td>Social Competence (Parent - CBCL)</td>
<td>56.00 (8.87)</td>
<td>57.00 (14.70)</td>
<td>0.08</td>
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<tr>
<td>Social Problems (Parent - CBCL)</td>
<td>56.25 (9.32)</td>
<td>58.00 (13.47)</td>
<td>0.15</td>
</tr>
<tr>
<td>Total Problems (Parent - CBCL)</td>
<td>47.00 (10.80)</td>
<td>46.50 (14.93)</td>
<td>0.04</td>
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</tbody>
</table>
Change from pre-test to post-test: Summary

• Increase in self-reported social competence scores on the Youth Self Report (YSR)\textsuperscript{19} = medium effect size.

• Decrease in self-reported social problems and total behavior problems on YSR\textsuperscript{19} = large effect sizes.

• Increase in Quality of Communication Life\textsuperscript{21} scores = medium effect size.

• No to very small change in parent-reported scores (Child Behavior Checklist – CBCL)\textsuperscript{19}
Recommendations

• Make app easier to use by building a tutorial and simplifying in-app instructions and integration.

• Provide programmed reminders about action steps planned on specific days.

• Allow screen sharing on the iPhone between teen and coach.

• Shorten key topics, make more interesting, add narration and hyperlinks, remove jargon.

• Create clearer expectations regarding parents’ roles
Selected References

Selected References

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Thank You!

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