

# **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
  - **Children's Healthcare of Atlanta:** Julie Haarbauer-Krupa
- 
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  - NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS), USA.

# 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**

*(Bedell & Dumas, 2004; Fougeyrollas, et al, 2014; King, et al, 2003; Law, 2002; Mallinson & Hammel, 2010)*

# 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 End

- 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, et al, 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; 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

*(Anaby, et al, 2012; Bedell, 2009; Bedell & Dumas, 2004; De Kloet, et al, 2015; Fougeyrollas, et al, 2014; Galvin, et al.,2010; Law et al, 2011; Shuhua Foo, et al., 2012; Van Tol, et al., 2011; Wells, et al., 2009)*

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

*(Bedell,et al, 2005; 2011; Dumas, et al., 2004; 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 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*)

\*Beauchamp & Anderson, 2010; Bedell, et al, 2005. Haurbaur-Krupa, et al., 2010; King, et al, 2003; Law, 2002; Turkstra, et al., 2015; Wade, et al, 2010; Ylvisaker, et al, 2005

# 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

The screenshot shows a mobile application interface for setting goals. At the top, the status bar displays 'Verizon', signal strength, Wi-Fi, the time '11:29 AM', location services, a lock icon, and a 100% battery level. Below the status bar is a teal header with three buttons: 'Cancel' on the left, 'My Goals' in the center, and 'Save' on the right. The main content area has a white background and contains the text: 'What are activities or social participation goals that you would like to focus on?'. Below this text are three items: 1) A red circle with a white minus sign followed by a rounded rectangular input field containing the text 'Joining a class'. 2) A red circle with a white minus sign followed by a rounded rectangular input field containing the text 'Interacting with peers'. 3) A green circle with a white plus sign followed by the text 'Add a goal'.

# Identifying Strengths

●●○○ Verizon 10:51 AM 100% 🔋

Cancel My Strengths Save

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

- Good communicator
- Sense of humor
- Adaptive
- + Add a strength

# Identifying Challenges

Verizon 10:51 AM 100%

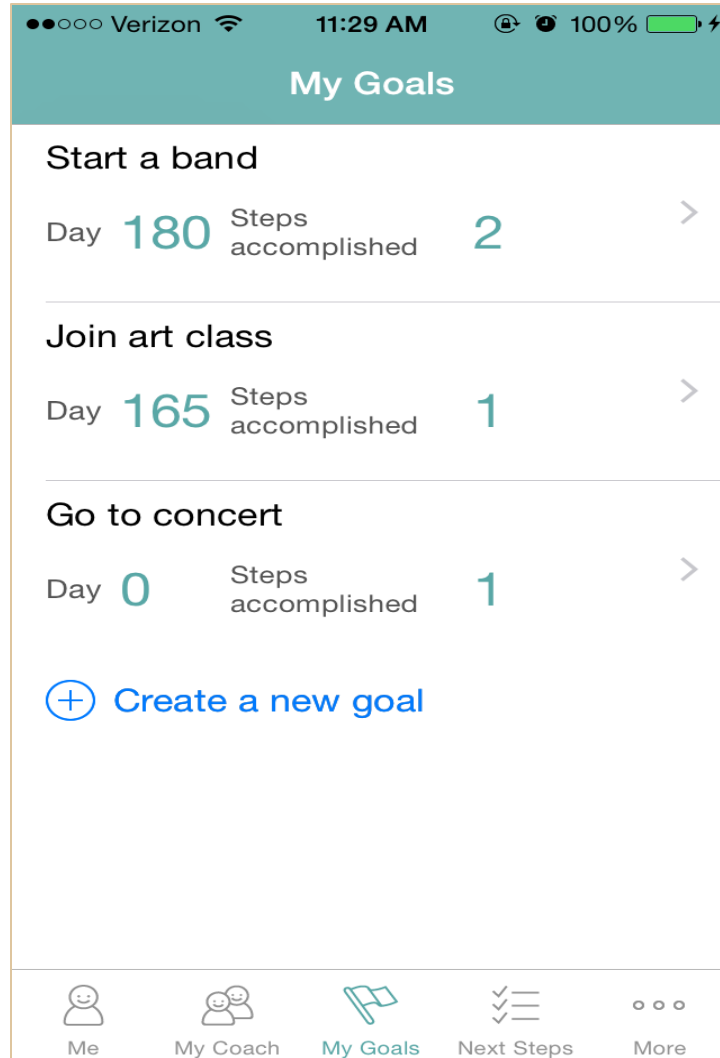
Cancel My Challenges Save

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

- Shy
- Anxious about new situations
- Add a challenge

The image shows a mobile application interface for identifying challenges. At the top, there is a status bar with 'Verizon', '10:51 AM', and '100%' battery. Below that is a teal header with 'Cancel', 'My Challenges', and 'Save' buttons. The main content area asks 'What are things that might make it harder to reach your participation goals?'. There are three items listed: 'Shy' and 'Anxious about new situations', each with a red minus sign to its left, and 'Add a challenge' with a green plus sign to its left.

# Accomplishing Participation Goals



# Planned steps to reach goals

The screenshot shows a mobile application interface for tracking goals. At the top, the status bar displays 'Verizon', signal strength, Wi-Fi, time '11:31 AM', location services, alarm, and 100% battery. Below the status bar is a teal header with a back arrow, 'My Goals', 'Goal', and 'Edit'.

The main content area is titled 'Start a band'. It shows 'Day 180' and 'Steps accomplished 2'. Below this is the section 'Steps to reach my goal:' with three items:

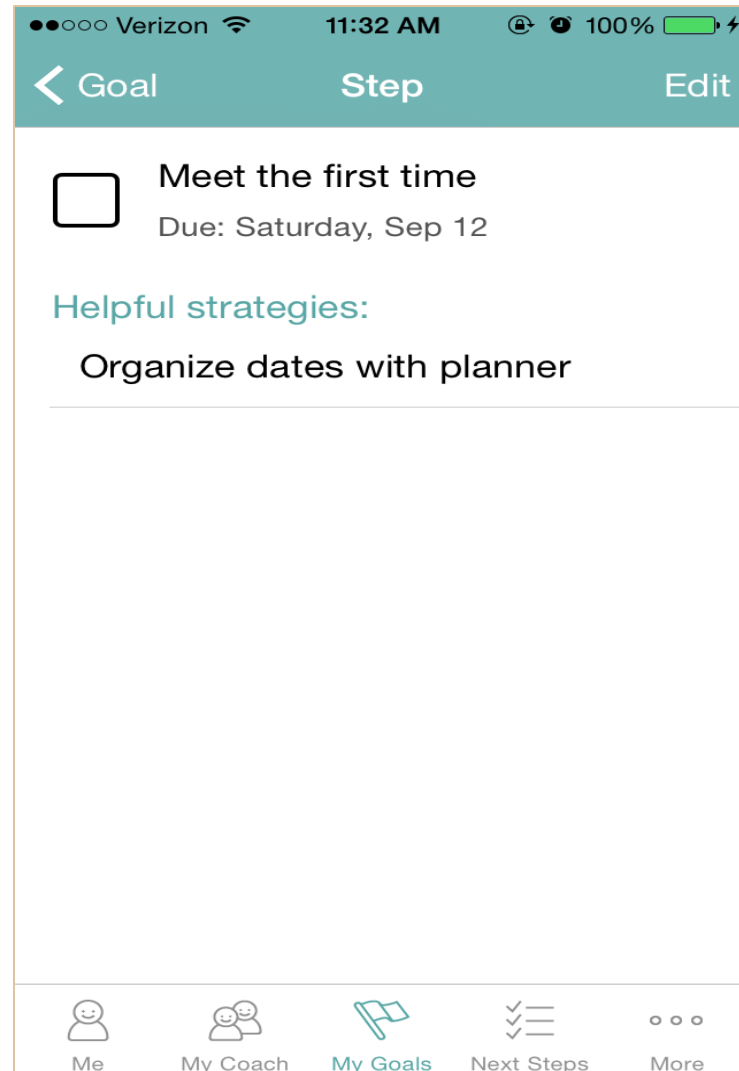
- Plan a time to meet  
Completed: Friday, May 8
- Name the band  
Completed: Friday, Jul 31
- Meet the first time  
Due: Saturday, Sep 12

At the bottom of the list is a blue button with a plus sign and the text 'Create a new step'.

The bottom navigation bar contains five icons: 'Me' (person), 'My Coach' (two people), 'My Goals' (flag), 'Next Steps' (checklist), and 'More' (three dots).



# Strategies for reaching goals



# SPAN Usability Study

## SAMPLE:

- **4 teens (3 females, 1 male)**
  - Teens were, on average, 15.73 years old and injured an average of 8 ½ 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:
  - a. The Social Competence Scales of the Child Behavior Checklist and Youth Self Report (Achenbach, 1991)
  - b. The Quality of Communication Life Scale (Frattali, et al., 2004) modified for adolescents (Burgess & Turkstra, 2010)

# Teenagers' Goals & Plans

Goals	Steps for Goal Achievement
Become more social and meet new friends	<ol style="list-style-type: none"><li>1. Talk to new people</li><li>2. Do more one-on-one work with classmates to build more intimate acquaintances</li></ol>
Spend more time with extended family	<ol style="list-style-type: none"><li>1. Call grandmother to schedule a visit</li></ol>
Plan an outing with friends	<ol style="list-style-type: none"><li>1. Start a conversation with friends to gather interest and ideas</li></ol>
Keep up with existing friendships	<ol style="list-style-type: none"><li>1. Text friends more often</li><li>2. Make plans to hang out outside of school</li><li>3. Talk to people in person more often</li></ol>
Hang out with friends outside of school	<ol style="list-style-type: none"><li>1. Use occasions (holidays, birthdays, etc.) to make plans</li><li>2. Engage in activities that keep you occupied</li></ol>
Practice cello more regularly in a social way	<ol style="list-style-type: none"><li>1. Talk to acquaintances</li><li>2. Talk to and practice with cello instructor</li><li>3. Discuss music interests, theory, or practice techniques with other musicians</li></ol>
Invite a friend to go to the amusement park	<ol style="list-style-type: none"><li>1. Decide which friend to invite</li><li>2. Invite friend to the park</li><li>3. Follow through with plan and go to amusement park with friend</li></ol>

# Teens' Experience with the Process (video)

# Additional feedback

- **Benefits:**

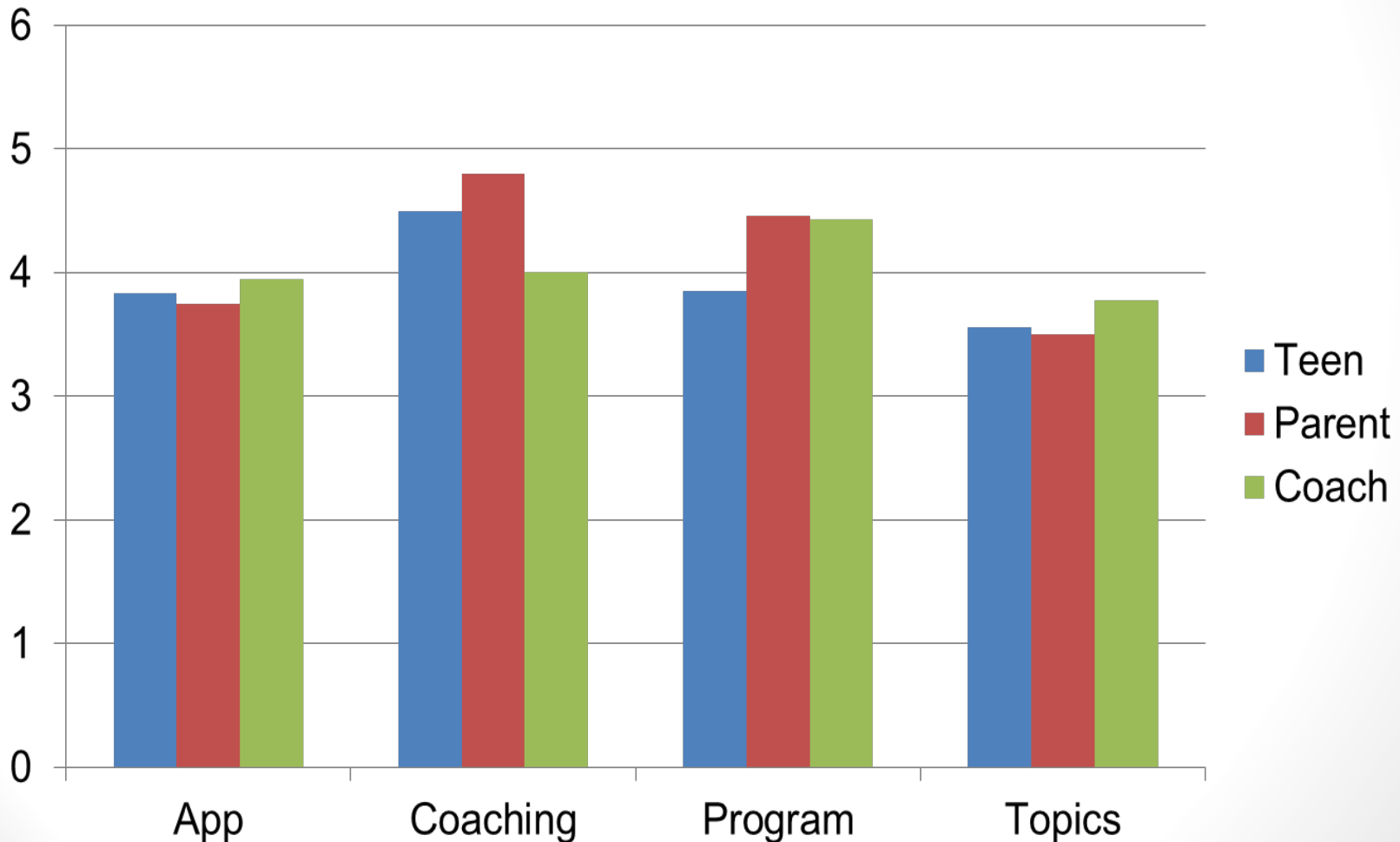
- SPAN prototype was feasible to implement
- Most satisfied with key features
- Liked coaching for building rapport and trouble-shooting around issues (coach & teen)
- Step by step goal-setting process leads to real outcomes.
- Valuable experience for both parties

- **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

	Pre-test Mean (SD)	Post-test Mean (SD)	Effect size (Cohen's d)
Social Competence (Teen - YSR)	48.25 (9.91)	52.50 (4.12)	<b>0.56</b>
Social Problems (Teen - YSR)	55.25 (4.65)	52.00 (2.00)	<b>0.91</b>
Total Problems (Teen - YSR)	48.25 (5.56)	42.75 (3.77)	<b>1.16</b>
Quality of Communication Life (Teen)	4.07 (0.57)	4.41 (0.53)	<b>0.62</b>
Social Competence (Parent - CBCL)	56 .00 (8.87)	57.00 (14.70)	0.08
Social Problems (Parent - CBCL)	56.25 (9.32)	58.00 (13.47)	0.15
Total Problems (Parent - CBCL)	47.00 (10.80)	46.50 (14.93)	0.04

# Change from pre-test to post-test: Summary

- Increase in self-reported social competence scores on the Youth Self Report (YSR)<sup>19</sup> = medium effect size.
- Decrease in self-reported social problems and total behavior problems on YSR<sup>19</sup> = large effect sizes.
- Increase in Quality of Communication Life<sup>21</sup> scores = medium effect size.
- No to very small change in parent-reported scores (Child Behavior Checklist – CBCL)<sup>19</sup>

# 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

- Achenbach, T. M. (1991). *Integrative guide for the 1991 CBCL/4-18, YSR, and TRF profiles*. Burlington, VT: University of Vermont, Department of Psychiatry.
- Agnihotri, S., Keightley, M., Colantonio, A., Cameron, D., Polatajko, H. (2010). Community integration interventions for youth with acquired brain injuries: A review. *Developmental Neurorehabilitation, 13*, 369-382.
- Anaby D, Law M, Hanna S, DeMatteo C. (2102). Predictors of change in participation rates following acquired brain injury: Results of a longitudinal study. *Developmental Medicine and Child Neurology, 54*, 339–346.
- Beauchamp, M.H. & Anderson, V. (2010). SOCIAL: An integrative framework for the development of social skills. *Psychological Bulletin, 136*, 39-64.
- Bedell, G. (2012). Measurement of Social Participation. In V. Anderson, & M. Beauchamp (Eds.), *Developmental Social Neuroscience and Childhood Brain Insult: Implication for Theory and Practice*. New York, NY: Guilford Publications.
- Bedell, G. M., Cohn, E. S., & Dumas, H. M. (2005). Exploring parents' use of strategies to promote social participation of school-age children with acquired brain injuries. *American Journal of Occupational Therapy, 59*, 273-284.
- Brewer, K., Pollock, N., & Wright, F.W. (2014) Addressing the challenges of collaborative goal setting with children and their families. *Physical & Occupational Therapy in Pediatrics, 34* , 138-152.
- Burgess, S., & Turkstra, L. S. (2010). Quality of Communication Life in adolescents with high functioning autism and asperger syndrome: A feasibility study. *Language, Speech, and Hearing Therapy in Schools, 41*, 474-487.

# Selected References

- Dunn, W., Cox, J., Foster, L., Mische-Lawson, L., & Tanquary, J. (2012). Impact of a contextual intervention on child participation and parent competence among children with autism spectrum disorders: a pretest-posttest repeated-measures design. *American Journal of Occupational Therapy*, 66, 520-528.
- DeMatteo CA, Cousins MA, Lin CA, Law MC, Colantonio A, & MacArthur C. (2008). Exploring post-injury living environments for children and youth with acquired brain injury. *Archives of Physical Medicine and Rehabilitation*, 89, 1803-1810.
- Eccles, J. S., Barber, B.L., Stone, M., & Hunt, J. (2003). Extracurricular activities and adolescent development. *Journal of Social Issues*, 59, 865-889.
- Fletcher, A. C., Nickerson, P., & Wright, K. L. (2003). Structured leisure activities in middle childhood: Links to well-being. *Journal of Community Psychology*, 31, 641-659.
- Fougeryrollas, P., Lepage, C., Boissière, L., Deaudelin, I., & Doré, L. (2014). Assessment of Social Participation in Three Measurement Times in Children with Traumatic Brain Injuries (TBI) Based on Parental Perceptions. *Open Journal of Therapy & Rehabilitation*, 2, 156-165.
- Galvin, J., Froude, EH, & McAleer, J. (2010). Children's participation in home, school and community life after acquired brain injury. *Australian Occupational Therapy Journal*, 57, 118–126.
- Gauvin-Lepage, J. & Lefebvre H. (2010). Social inclusion of persons with moderate head injuries: The points of view of adolescents with brain injuries, their parents and professionals. *Brain Injury* 24, 1087-1097.
- Glang, A., Todis, B., Cooley, E., Wells, J., & Voss, J. (1997). Building social networks for children and adolescents with ABI: A school-based intervention. *Journal of Head Trauma Rehabilitation*, 12, 32-47.
- Graham, F., Rodger, S., & Ziviani, J. (2009). Coaching parents to enable children's participation: An approach for working with parents and their children. *Australian Occupational Therapy Journal*, 56, 16-16.

# Selected References

- Graham, F., Rodger, S., & Ziviani, J. (2010). Enabling occupational performance of children through coaching parents: Three case reports. *Physical & Occupational Therapy in Pediatrics*, 30, 4-15.
- Haarbauer-Krupa, J., Meulenbroek, P., Gibbs, J., & Turkstra, L. S. (2010). The BRAIN program: A model for transition to adult lives for teens with acquired brain injury. *Journal of Head Trauma Rehabilitation*, 25, 396-397.
- Keller, T.E. (2005). A systematic model of the youth mentoring intervention. *Journal of Primary Prevention*, 26, 169–188.
- King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. (2003). Conceptual model of the factors affecting recreation and leisure participation of children with disabilities. *Physical and Occupational Therapy in Pediatrics*, 23, 63-90.
- Larson, R. W. & Verma, S. (1999). How children and adolescents spend time across the world: Work, play, and developmental opportunities. *Psychological Bulletin*, 125, 701-736.
- Law, M. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy*, 56, 640-649
- Law M, Anaby D, & DeMatteo C, Hanna S. (2011). Participation patterns of children with acquired brain injury. *Brain Injury*, 25, 587-595.
- Lenhart, A., Smith, A., Anderson, M., Duggan, M., & Perrin, A. (2015). *Teens, Technology and Friendships*, from <http://www.pewinternet.org/2015/8/06/teens-technology-and-friendships/>
- Mahoney, J. L., Cairns, B.D., & Farmer, T.W. (2003). Promoting interpersonal competence and educational success through extracurricular activity participation. *Journal of Educational Psychology*, 95, 409-418.
- Mallinson T, & Hammel J. (2010). Measurement of participation: Intersecting person, task, and environment. *Archives of Physical Medicine & Rehabilitation*, 91, S29-33.
- McConachie, H., Colver, A.F., Forsyth, R.J., Jarvis, S.N., & Parkinson, K.N. (2006). Participation of disabled children: How should it be characterised and measured? *Disability & Rehabilitation*, 28, 1157-1164

# Selected References

- Mealings, M., Douglas, J., & Olver, J. (2012). Considering the student perspective in returning to school after TBI: A literature review. *Brain Injury*, 26, 1165–1176.
- Novak, I. (2014) Evidence to Practice Commentary: New Evidence in coaching interventions. *Physical & Occupational Therapy in Pediatrics*, 34, 132-137
- Palisano, R., Chiarello, L., King, G., Novak, I., Stoner, T., & Fiss, A. (2012). Participation-based therapy for children with physical disabilities. *Disability & Rehabilitation*, 34, 1041-1052.
- Paul, D., Frattali, C. M., Holland, M. L., Thompson, C. K., Caperton, C. J., & Slater, S. C. (2004). *Quality of Communication Life Scale*. Rockville, MD: American Speech-Language-Hearing Association.
- Rhodes, J.E., Spencer, R., Keller, T.E., Liang, B., & Noam, G. (2006). A model for the influence of mentoring relationships on youth development. *Journal of Community Psychology*, 34, 691–707.
- Rivara, F., Vavilala, M.S., Durban, D., & Jaffe, K.M. (2012). Persistence of disability 24 to 36 months after pediatric traumatic brain injury: A cohort study. *Journal of Neurotrauma*, 29, 2499-2504.
- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry*, 57, 316-331.
- Sharp, N.L., Bye, R.A., Llewellyn, G.M., & Cusick, A. (2006). Fitting back in: Adolescents returning to school after severe acquired brain injury. *Disability & Rehabilitation*, 28, 767-778.
- Shuhua Foo, W., Galvin, J. & Olsen, J. (2012). Participation of children with ABI and the relationship with discharge functional status. *Developmental Neurorehabilitation*, 15, 1-12.
- Simeonsson, R. J., Carlson, D., Huntington, G.S., McMillen, J., & Brent, L. (2001). Students with disabilities: A national survey of participation in school activities. *Disability & Rehabilitation*, 23, 49-63.
- Struchen, M. A., Davis, L. C., Bogaards, J. A., Hudler-Hull, T., Clark, A. N., Mazzei, D. M., Sander, A.M., & Caroselli, J.S. (2011). Making connections after brain injury: Development and evaluation of a social peer-mentoring program for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 26, 4-19.

# Selected References

- Turkstra, L.S., Politis, A.M., & Forsythe, R. (2015). Cognitive–communication disorders in children with traumatic brain injury. *Developmental Medicine & Child Neurology*, 57, 217-222.
- van Tol, E., Gorter, J. W., DeMatteo, C., & Meester-Delver, A. (2011). Participation outcomes for children with acquired brain injury: a narrative review. *Brain Injury*, 25, 1279-1287.
- Wade, S.L., Walz, N.C., Carey, J.A., & Williams, K.M. (2010). A randomized trial of teen online problem solving for improving executive function deficits following pediatric traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 25, 409-415.
- Wells, R., Minnes, P., & Phillips, M. (2009)/ Predicting social and functional outcomes for individuals sustaining paediatric traumatic brain injury. *Developmental Neurorehabilitation*, 12, 12-23.
- Williams, R.M., Bambara, J, & Turner, A. P. (2012). A scoping study of one-to-one peer mentorship interventions and recommendations for application with veterans with post-deployment syndrome. *Journal of Head Trauma Rehabilitation*, 27, 261-273.
- World Health Organization [WHO]. (2001). *International Classification of Functioning, Disability and Health*. Geneva: WHO.
- World Health Organization [WHO]. (2007). *International Classification of Functioning, Disability and Health. Version for Children and Youth*. Geneva: WHO.
- Ylvisaker M, Adelson DP, Braga L, et al. (2005). Rehabilitation and ongoing support after Pediatric TBI: Twenty years of progress. *Journal of Head Trauma Rehabilitation*, 20, 95-109.
- Zand, D.H. , Thomsona, N., Cervantes, R., Espiritu, R., Klagholz, D., LaBlanc, L., & Taylor, A. (2009) The mentor–youth alliance: The role of mentoring relationships in promoting youth competence. *Journal of Adolescence*, 32, 1–17.



# Thank You!

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