

**PSYCHOSOCIAL EFFECT OF A YEAR ROUND MENTORING & ONLINE SUPPORT  
PROGRAM FOR ADOLESCENTS WITH PHYSICAL DISABILITIES ATTENDING A  
RESIDENTIAL MEDICAL CAMP**

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**Abstract**

Medical specialty camps are known to provide short-term psychosocial improvements for pediatric clients yet extinguishing effects are common after returning to home communities. Despite the growing criticism, the literature is void of attempts to improve the medical camp model nationally. With over 400 medical camps offered annually serving approximately 30,000 pediatric participants, this setting provides a potentially advantageous vehicle to counter common pediatric psychosocial health issues if improvements are made. The current study addresses this problem area by testing a year-round mentoring and online support program created as a follow-on booster to a residential medical specialty camp for adolescents with physical disabilities. Youth are assigned an adult mentor with a similar physical disability for one-year post camp and are also enrolled in a monthly online support curriculum. Research aims examine the effect of this program for adolescents that have been enrolled in the intervention compared to a comparison group yet to participate. Research approaches include a repeated measures ANOVA examining self-esteem and mattering, an egocentric social network analysis analyzed with a chi-square test, and a qualitative phenomenological approach to elicit emerging themes related to participation from both mentor and mentee perspectives. Findings suggest this is a promising psychosocial intervention with the need for future program refinement and further research.

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## Curriculum Vitae

# Chapter One

## Introduction & Background

### Specific Aims of Study

Medical specialty camps are known to provide short-term psychosocial improvements for pediatric clients yet extinguishing effects are common after returning to home communities. Despite the growing criticism, the literature is void of attempts to improve the medical camp model nationally. With over 400 medical camps offered annually serving more than 30,000 pediatric participants, this setting provides a potentially advantageous vehicle to counter common pediatric psychosocial issues if improvements are made. The current study addresses this problem area by testing a mentoring and online support program that has been created intentionally as a follow-on psychosocial booster to a residential medical specialty camp for adolescents with physical disabilities. Youth are assigned an adult mentor with a physical disability for one-year post camp and are also enrolled in a monthly online support curriculum. Youth and their corresponding mentors share in a common diagnosis of cerebral palsy, spina bifida, spinal muscular atrophy, or other neuromuscular conditions that affect the physical and psychosocial health domains. Research aims are intended to examine the effect of this program for adolescents that have been enrolled for at least one year compared to a comparison group yet to participate. Research approaches include a repeated measures ANOVA examining self-esteem and mattering, an egocentric social network analysis analyzed with a chi-square, and a qualitative phenomenological approach to elicit emerging themes related to participation.

**Specific Aim 1:** Identify any differences in the reported alters of adolescents that have taken part in the Beyond the Woods Mentoring Program compared to participants at the same camp that have yet to establish a mentor relationship.

**Specific Aim 2:** Test for any differences in the perceived self-esteem and mattering of youth with physical disabilities enrolled in a year-long mentoring and online support treatment program after attending medical camp compared to a control group of similar youth only attending the residential medical camp.

**Specific Aim 3:** Through qualitative phenomenological interviews, establish emerging themes related to the lived experiences of both the mentor and the mentee in order to identify specific program successes, failures, and trends.

## **Research Strategy**

### **Significance**

Isolation, lack of social acceptance, discontent with social and leisure participation, and higher rates of suicidal ideation have been noted in people that have physical disabilities (Chavira, Accurso, Garland, & Hough, 2010; Haring & Breen, 1992; Knapp, Devine, Dawson, & Piatt, 2015; Raghavendra, Newman, Grace, & Wood, 2013). A meta-analysis of 954 studies with 104,867 children and adolescents provides evidence that youth with chronic physical illnesses appear to have greater functional impairments in social, academic, and physical domains while those with spina bifida and cerebral palsy appear to be at greatest risk (Pinquart & Teubert, 2011). Youth with physical disabilities may be at particular risk in the social domain as they are less involved in social activities (Meijer et al., 2000). The need for interventions that counter the psychosocial effects of pediatric physical disabilities is well documented (Groce, 2004; Haring & Breen, 1992; Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000).

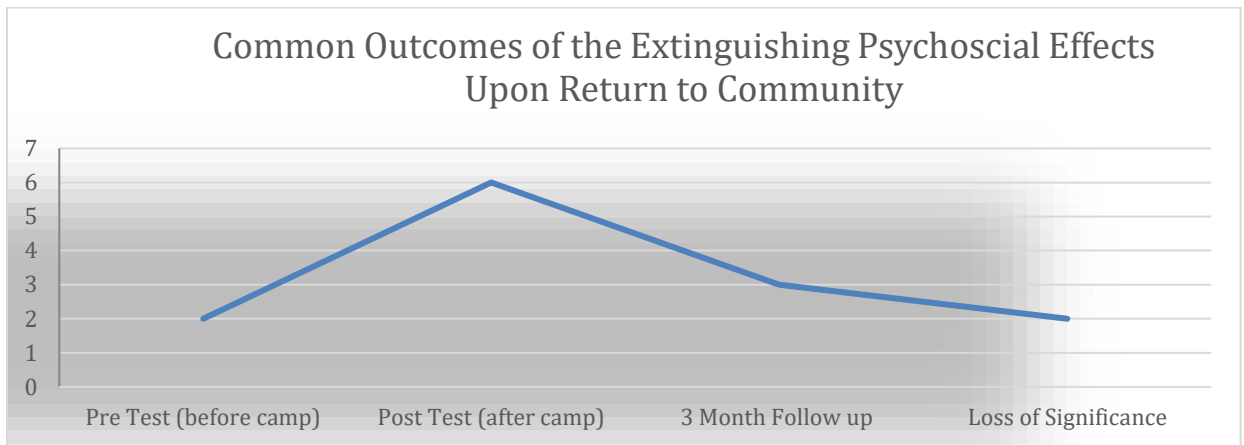
Plante, Lobato & Engel (2001) reviewed pediatric group interventions and found camps to be one of five major categories of treatment typically provided. There are over 400 medical camps operating nationally serving thousands of youth with health conditions annually. These camps are designed to provide programming without restrictions, to build skill sets and independence, and to allow campers to be around others with similar medical conditions

(Cushner-Weinstein, Berl, Salpekar, Johnson, Pearl, Conry, & Weinstein, 2007; Devine & Dawson, 2014). Camps designed for youth with health conditions may be a place that provides short term relief of the aforementioned psychosocial support needs in youth with health conditions. A recent meta-analysis of 31 camps found that children's psychosocial self-perceptions improved while at camp and remained small but significant post camp. However, a decaying trend was clearly present in follow-up evaluation data upon return to community life (Odar, Canter, & Roberts, 2013). Epstein, Stinson, & Stevens (2005) reviewed 18 studies on camp as a method of improving quality of life and found supportive evidence in a sample of 1,270 participants. A national study on 19 camps found that friendship development skills, competence, connection, and social acceptance were positive outcomes from participation (Devine & Dawson, 2014). The authors also note extinguishing effects were present in most cases, especially for those with the highest stigma, i.e., females with disabilities and those with visually obvious health conditions. These extinguishing effects are routinely seen in the medical camp literature and have been a major criticism of the camp model as a pediatric intervention (Plante, Lobato, & Engel, 2001). Despite ongoing criticism, explanations for extinguishing effects from a theoretical perspective are not present nor has there been an attempt to create a medical camp framework to improve practice.

Social inoculation has been identified as concept that references creating a socially conducive environment rich with positive social connections that support health (Evans & Getz, 2003; Pilisuk, 1982). It is feasible that the small but significant outcomes routinely identified in camp studies can be explained by a social inoculation effect. Medical camps may provide unique friendship and support opportunities with similar others yet provide little access to this same supportive group once camp ends. An inability to meaningfully connect with similar others



for support may be lacking once campers return to their integrated home communities. Social network research suggests that similarities between actors results in increased connections, or what is referred to as homophily (McPherson, Smith-Lovin, Cook, 2001; Rice, et al., 2012). Since youth with health conditions may not be similar to their peers in integrated home community settings, homophily may be even more difficult for this population while outside of camp. Having an opportunity to experience homophily and subsequent social comparisons with similar others after the camp experience could potentially provide more lasting psychosocial support while living in integrated settings.



*Figure 1. Common trend line for psychosocial residential medical camp outcomes to lose significance upon return to integrated home communities. Follow on programs to access homophily and social comparison rich environments should be explored further.*

A social network analysis has yet to be applied as a research approach in the medical camp setting. Social network analysis has the potential to map the socially supportive people within a person’s life including the strength of social ties, level of friendship reciprocity, and density of the support network (Scott, 2012). A few non-camp related programs have had preliminary success in applying a social lens to design. For example, Heaney & Israel (2008) identified successful support programs as having used interventions to enhance networks through

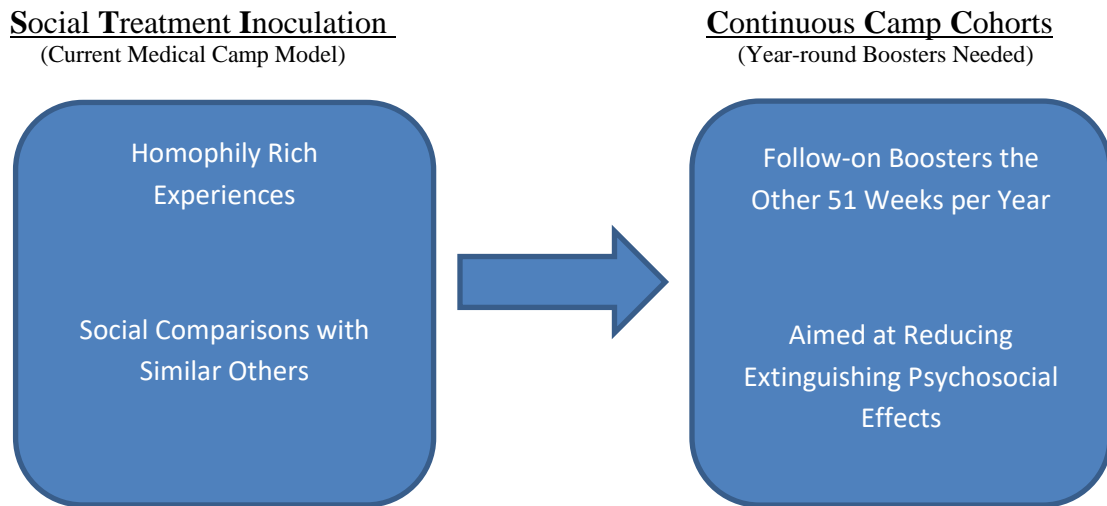
individuals indigenous to the group as well as programs that improve social connections, i.e. including individuals with the same group identifying characteristics may be useful to support interventions. Sociograms have commonly been utilized to identify social relationships related to school based educational and psychiatric settings in order to highlight feeling of isolation and to identify groups these youth feel included or excluded from (Drahota & Dewey, 2008). Social network techniques could be highly effective in determining differences in social networks at camp and integrated community settings in terms of network density, reciprocity of friendship, and centrality of networks. Looking at pediatric medical camp participation through the lens of social networks may be helpful in understanding the potential reason for a lack of carry over effects upon return to home communities. Identifying these active ingredients may then lead to an improved medical camp framework that addresses the commonly seen and often criticized extinguishing effects.

### **Innovation**

Applying social network intervention designs to medical camps may be useful in improving lasting treatment outcomes. New year-long approaches could be useful in combating the consequences of stigma and loneliness associated with a respective diagnosis for example. Moreover, social network cohorts of similar others (e.g., medical camp cohorts) with the same health condition may prove useful in providing reciprocity of friendship and needed support both at camp and while living in integrated home settings. Strategies to capitalize on the possible social inoculation at camp to mitigate extinguishing effects upon return to home communities are lacking in practice and in the literature. To date, the vast majority of medical camp programming and research consists of 1-2 week residential experiences only. This is despite documentation of the growing frustrations from participants with the lack of similar resources outside of the camp

experience (Knapp, Devine, Dawson, Piatt, 2015). Booster programs may help mitigate the loss of treatment outcomes upon return to these home communities the other 51 weeks per year. The current study aims to further the research by testing a follow on booster program through the lens of social network analysis.

### **“S.T.I.C.C.C. With It” Medical Camp Framework**



*Figure 2. Proposed medical camp framework to guide research testing aimed at reducing the extinguishing effects of camp upon return to home communities (Dawson, 2017)*

### **Approach**

Mentoring interventions for youth development are common in the literature. Mentoring interventions and peer support have shown positive results in a variety of populations especially when sound theory is included in program design (DuBois, Holloway, Valentine, & Cooper, 2002). Several noteworthy programs exist such as Big Brother Big Sisters, Best Buddies, and Alcoholics Anonymous just to name a few. Britner, Balcazar, Blechman, Blinn-Pike, and Larose (2006) reviewed programs targeting youth with disabilities, pregnant or parenting adolescents, juvenile offenders, abused and neglected youth, and those that are academically at risk. The authors pointed out possible theoretical underpinnings, risk associated with the programs, and

benefits of these types of interventions overall. They also noted that careful planning, training, recruitment strategies and monitoring to protect the vulnerable youth are essential. With this type of planning, youth can certainly benefit from mentoring. They also point out that many mentoring programs are offered in conjunction with other existing programs and serve as an adjunct.

The Beyond the Woods Mentoring Program was created in 2014 to provide adolescents attending a medical camp for physical disabilities a year round support system. Adult mentors are recruited that are successful adults in that they have attended college, work, or have succeeded in other life events. Mentors have similar physical disabilities and interest as the adolescents attending camp. Each camper is assigned one adult mentor and are introduced while at camp during a half-day event. Mentors are then trained prior to the start of the program. Mentors work on encouraging campers while also discussing life issues such as driving a vehicle with adaptations, dating, stigma, applying for college, and the general emotions associated with pediatric disability. The following research study is focused on exploring the efficacy of this program.

**Aim 1: Identify any differences in the reported alters of adolescents that have taken part in the Beyond the Woods Mentoring Program compared to participants at the same camp that have yet to establish a mentor relationship.**

### **Introduction (Aim 1)**

Egocentric network analysis procedures provide a clear method of mapping the important matters discussant group members (alters) of an ego (camper). This method is of particular interest in working with people with disabilities including adolescents given the social domain issues faced by these clients. The approach in this study will provide data that identifies

supportive individuals, the type of support provided, quality of that support, and role relation of the alter. This will be important to understanding where support comes from and where it is lacking among adolescents with physical disabilities. Mentors, amongst other supportive alters, may potentially be identified as an alter to the ego (camper) in this portion of the study.

### **Justification & Feasibility (Aim 1):**

Several studies have been conducted at this facility including investigation of camps for youth with hearing impairments (Devine, Piatt, & Dawson, 2015), youth with physical disabilities reporting frustration with lack of similar resources in home settings compared to camp (Knapp, Devine, Dawson, & Piatt, 2015), and the increase in self-esteem and social acceptance during camp with subsequent loss of significance upon return to home communities for youth with cranial facial differences (Devine & Dawson, 2010). A pilot test was conducted in 2014 to determine the egocentric networks of 70 youth with physical disabilities (Dawson, McCormick, & Li, 2018).

## **Pilot Study Data**

### **Setting of Pilot Study**

A preliminary study was conducted at this camp, a 2,436-acre outdoor center that is universally designed to enhance physical access to trails, cabins, and disability specific programming (Dawson, McCormick, & Li, 2018). A total of 76 campers (aged 8-18 years) attending a two-week residential camp with a diagnosis of muscular dystrophy, spinal muscular atrophy, cerebral palsy, or spina bifida participated in the study. The purpose of the pilot study was to identify reported alters within the important matters discussant groups of these youth.

## **Pilot Study Method**

Egocentric networks were identified via an “important matters” discussant group name generator created specifically for this population based on previous empirical data supporting the creation of sound egocentric social network tools (Hlebec, & Kogovšek, 2013; Kogovšek, & Hlebec, 2009; Marin, & Hampton, 2007; Pustejovsky & Spillane, 2009). Network members were identified by asking participants “with whom do you discuss important matters,” an approach that is less time consuming and more straightforward which meets the needs of these pediatric campers with disabilities. Marin and Hampton (2007) noted the “important matters” approach as having the potential to capture a large portion of social networks. Participants identified up to four (4) important matters discussants in their networks. A role-relation approach (Marin, & Hampton, 2007) utilized to elicit demographic information and roles each alter played (e.g., relative, friend, professional, camper, etc.) as well as the setting in which alters are found (e.g., school, camp, home). Campers were also asked to rank alters in hierarchical order from 1<sup>st</sup> as the most important through the 4<sup>th</sup> person they go to for important matters. The 5<sup>th</sup> question asked the camper if any of the identified alters come to them for important matters, i.e., does a reciprocal relationships exist.

## **Analysis of Pilot Study Data**

Networks were first examined to identify reciprocity. A true reciprocal relationship was defined as identical person match within exchange and role questions, while a relaxed reciprocal relationship was based on identifying a matched role not a specific person. Wilcoxon rank-sum test was used to examine any potential difference between children’s and adolescents’ network composition relative to non-relative peers or camp-related alters identified. A Kruskal-Wallis test was conducted to see if there was a significant difference in the years attending camp of different

true and relaxed reciprocal relationships. Finally, a Chi-Square Goodness of Fit test was performed to examine if proportions were equally represented at 0.25 for the four reported alter roles, i.e., relative, camp, friend, professional. Statistical analyses were performed using SAS 9.3 (SAS Institute, Cary, NC).  $P < 0.05$  was considered statistically significant. Alter frequencies were shown for the important matters and reciprocal exchange relationships through descriptive statistics.

### Results of Pilot Study

Findings indicated that adolescents reported significantly more non-relative peers and friends as compared to children (one-sided  $p = 0.02$ ). No significant difference was found between child and adolescents in terms of probability of egos going to camp-related alters for important matters ( $p = 0.51$ ). Hence, there is not enough evidence to support there is a difference between the percentage of children and adolescents going to camp-related people for important matters. The Kruskal Wallis test results ( $p = 0.78$  and  $p = 0.64$ ) show there is not sufficient evidence to support a difference in the distribution of years of attending camp for reported (both true and relaxed) reciprocal relationship roles.

Using a Chi-Square Goodness of Fit Test elicited several findings that were significant. Preferences were not equally distributed for *important matters one* (*Chi – sq statistic*  $X^2(3, N = 76) = 83.99$  ,  $p < 0.001$ ), *important matter two* ( $X^2(3, N = 73) = 31.49$ ,  $p < 0.001$ ), *important matter three* ( $X^2(3, N = 71) = 18.86$ ,  $p < 0.001$ ), and *important matter four* ( $X^2(3, N = 63) p = 0.02 < 0.05$ ). In examining *who goes to the camper for important matters*, preference was not equally distributed ( $X^2(3, N = 46) = 16.4348$ ,  $p = 0.001$ ). *True reciprocal relationships* were equally preferred (distributed) for the four possible roles ( $X^2(2, N = 18) = 2.33$ ,  $p = 0.31$  ) as well as for the *relaxed reciprocal relationship*

question ( $X^2(2, N = 36) = 0.5, p = 0.78$ ).

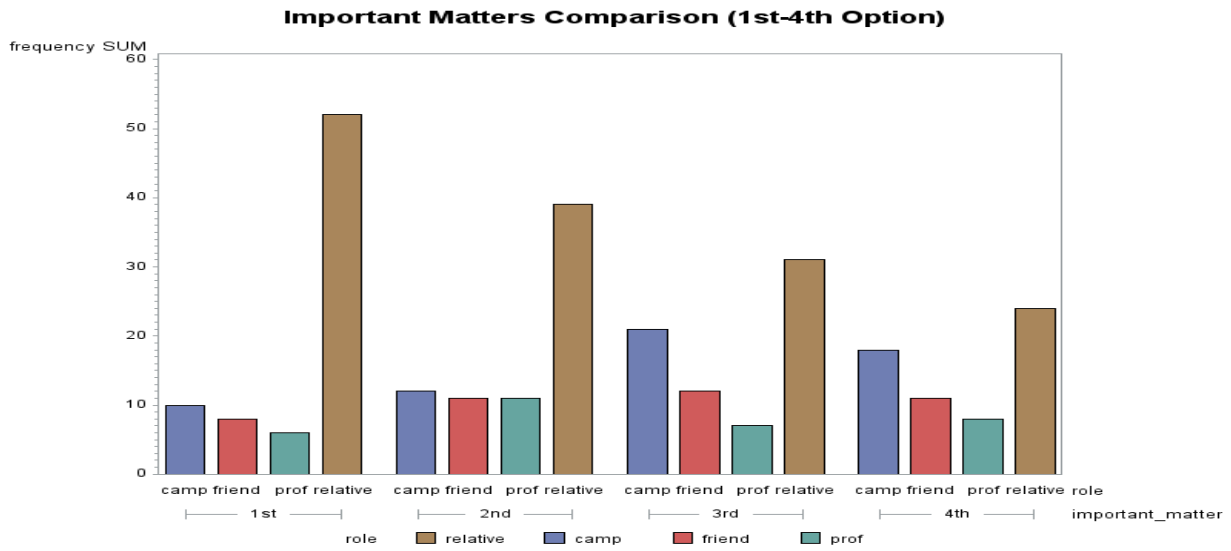
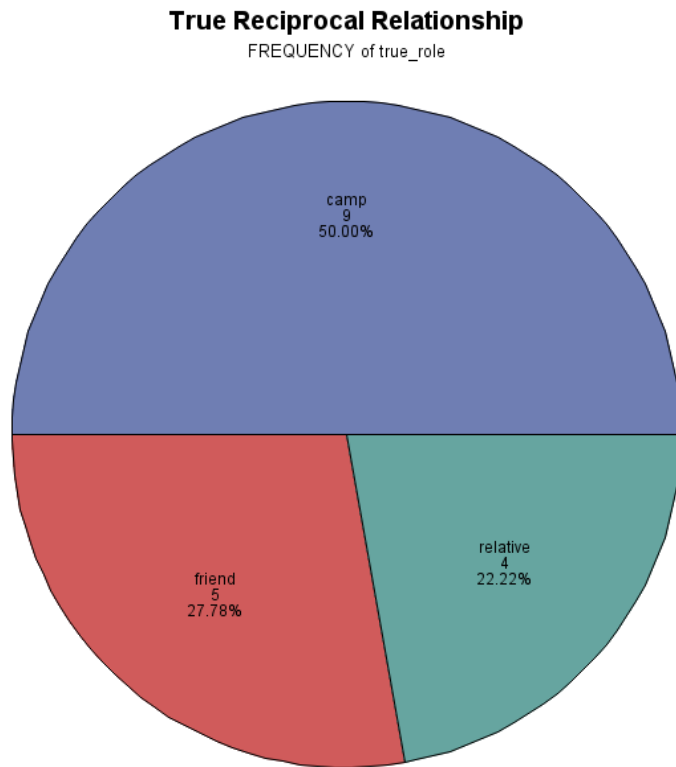
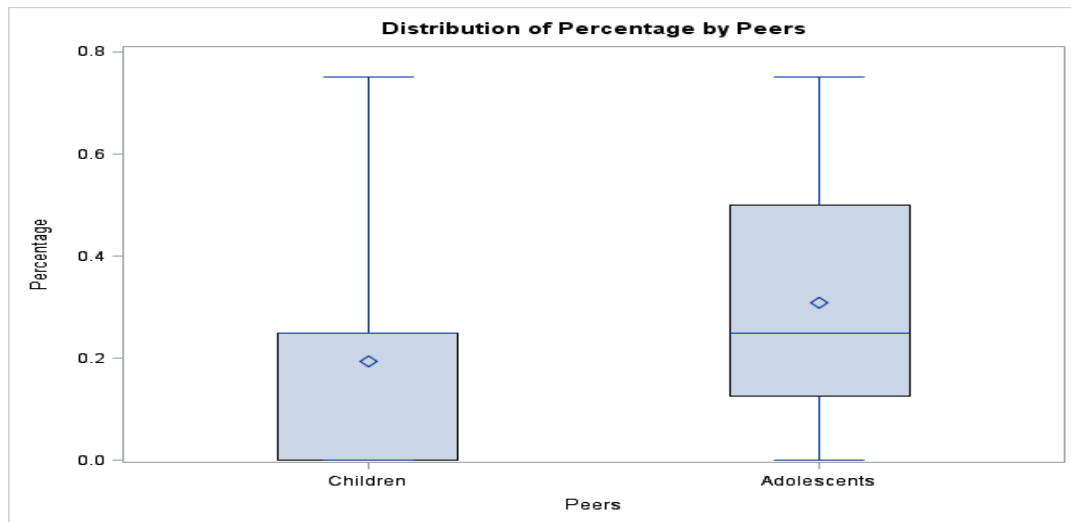


Figure 3. The bar graph provides the frequency rank order of which type of person (role relation) the campers go to for “important matters.” Frequencies include relatives (51.96%), camp relationships (21.71%), community friends (14.95%) and professionals (11.39%).





*Figure 4. The pie graph represented true reciprocal relationships reported by the campers, e.g., people they go to for important matters that also come to them for support. Only 18 campers out of 73 responding participants reported a true reciprocal relationship.*



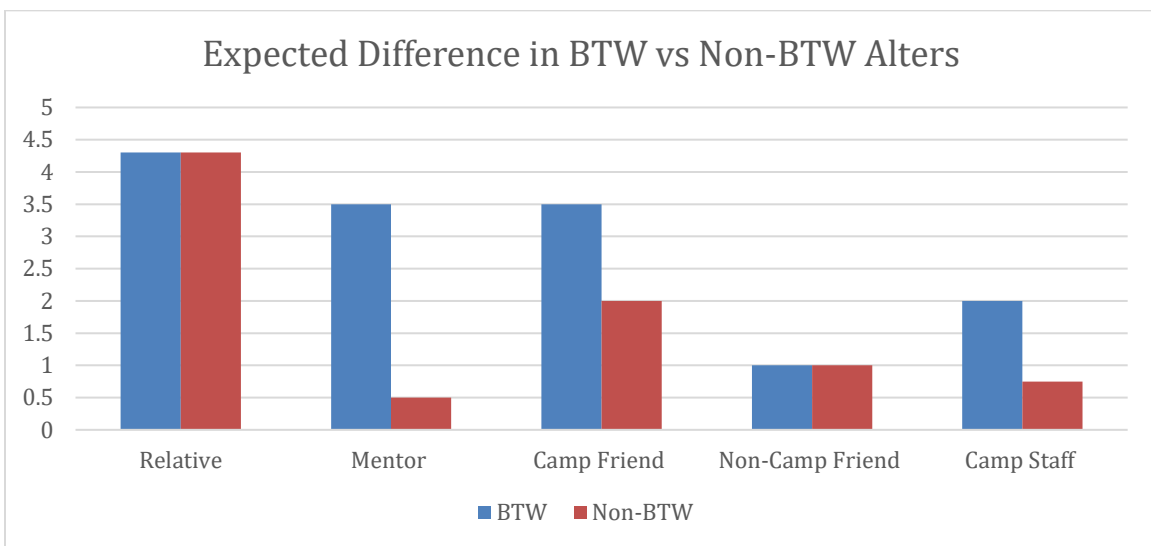
*Figure 5. The whisker box plot indicates a difference between adolescents and children for non-relative support preferences. Adolescents tend to go to camp contacts, peers, and professionals more than relatives as compared to children. This appears to be a developmentally appropriate response.*

### **Implications of Pilot Study**

The pilot data presented above provide a foundation for further inquiry. Several important themes were discovered and lessons learned. First, a reliable and valid social network instrument is needed to further provide ordinal data for analysis rather than categorical. Second, reciprocal relationships need to be further investigated as failed reciprocity in social relationships has been noted as contributing to poor health outcomes (Chandola, Marmot, & Siegrist, 2007). Third, the mentoring program needs to be further investigated as a possible intervention to address the extinguishing effects of medical camps. Although recently implemented at the time of the pilot study, campers mentioned the mentor specifically as a supportive individual without prompting.

### Expected Outcomes (Aim 1)

It is expected that Beyond the Woods participants enrolled in the program will identify their mentor, a camp peer, or staff in the important matters discussant group alters at a rate that is significantly different than those yet to be assigned a mentor. Additionally, it is expected that increased exposure to the mentoring relationship will result in the mentor moving up in rank order for alters listed.



*Figure 6. It is anticipated that the BTW participants enrolled in the program will report a significantly different frequency of mentors, camp staff, and camp peers as alters.*

### Potential Problems and Alternative Strategies (Aim 1)

Mentors that work with campers that have communication difficulties may find the mentoring relationship difficult. Campers with the need for communication support will be identified throughout the study so as to control for this as a potential confounding variable as this has the potential to skew results. Qualitative approaches embedded in the study are meant to capture any themes related to this potential issue as well (see aim 2). The instrument may take up to 20 minutes to administer and campers may grow impatient and desire to return to camp activities. Campers tend to enjoy phone conversations after camp. This could an alternative

strategy to collect data if need be. If a Non-Beyond the Woods group is not viable due to low enrollment numbers or in not meeting  $n = 5$  requirement for variables in the Chi Square test, a multivariate regression analysis will be conducted as an alternative statistical analysis to determine correlations between demographics of the camper (independent variables) as compared to the demographics associated with the Important Matters Network Battery (dependent variables).

**Specific Aim 2: Test for any differences in the perceived self-esteem and mattering of youth with physical disabilities enrolled in a year-long mentoring and online support treatment program after attending medical camp compared to a control group of similar youth only attending the residential medical camp.**

### **Introduction (Aim 2)**

Given the need to create and test booster interventions in the medical camp setting, Aim 2 focuses on examining any differences in mattering and self-esteem of the adolescents taking part in the mentoring and online booster program. A quasi-experimental design will be implemented to compare the intervention group to the comparison group. Data will be analyzed using a repeated measures ANOVA in SPSS.

### **Justification & Feasibility (Aim 2)**

Past research has been completed at this site using repeated measures (Devine & Dawson, 2010). Similar methods will be used that have resulted in successful data collection including administering the first round of data collection during camp, communicating with parents and campers throughout the process, and implementing research tools that are not burdensome in terms of the time they take the pediatric campers to complete.

### **Expected Outcomes (Aim 2)**

It is expected that the intervention group will have higher self-esteem and mattering scores as compared to those not enrolled in the program. Further, it is anticipated that an effect will be present in the intervention group that is small to large in size. Descriptive statistics will likely illustrate these differences visually.

### **Potential Problems & Alternative Strategies (Aim 2)**

It is feasibility that a low n size could prevent an appropriate statistical analysis. Strategies to communicate to families prior to camp participation, during check-in, and through written communication three months post camp will be implemented. Furthermore, trainings with camp staff will be conducted to assist with the logistics of data collection during camp.

**Specific Aim 3: Through qualitative phenomenological interviews, establish emerging themes related to the lived experiences of both the mentor and the mentee in order to identify specific program successes, failures, and trends.**

### **Introduction (Aim 3)**

Qualitative approaches to research are common in social science programs including those interested in developing evidence based programming (Schalock, 2001). For this reason, qualitative inquiry has been introduced to this study to provide depth and breadth of understanding from the perspective of those directly involved with the program.

### **Justification & Feasibility (Aim 3)**

A pilot study was conducted in 2014 with this same population of adolescents (Dawson, in progress). A qualitative phenomenological approach was used during 11 hours of interviews with 5 male and 5 female adolescents with physical disabilities. During these interviews, the mentoring program was informally mentioned on numerous occasions either in support of the

program or by campers asking to be part of the newly formed pilot program. The current study will further this discussion to focus exclusively on perceptions of the mentoring program by both adolescents and mentors taking part in this booster intervention.

### **Expected Outcomes (Aim 3)**

It is expected that emerging themes will be present after data collection and analysis providing depth and breadth of understanding of the mentor program. Both mentor and adolescent specific themes are expected to point to both the positives of the program as well as areas for improvement. Results may be useful for future refinement of the program.

### **Potential Problems & Alternative Strategies (Aim 3)**

Emerging themes may be slanted towards negative outcomes. In this case, this information will be utilized to provide program directors with suggested improvements and modification of the program. Campers may also desire to return to camp activities instead of taking part in the interview. Phone calls will be utilized after camp in these circumstances.

### **Dissertation Proposal Summary**

Medical camp programs are known to provide short-term psychosocial outcomes to pediatric participants. However, extinguishing effects upon return to home communities are common resulting in criticism of this model. New booster approaches are needed to enhance the medical camp model in order that more lasting and needed psychosocial outcomes can be offered to pediatric clients with health conditions. The current study investigates the potential effectiveness of a booster program that provides an adult mentor with the same or similar disability assigned to each adolescent for one-year post residential camp experience. Through an egocentric network analysis, repeated measures ANOVA, as well as qualitative phenomenological investigation, findings will help determine the potential effectiveness or

problems associated with this approach. With over 400 medical camps nationally and thousands of pediatric participants, this study is an important step in positively changing the medical camp model with an aim of improving lasting psychosocial outcomes for youth.

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## **Chapter Two**

### **Research Methods**

#### **Research Design (Aim 1)**

An egocentric network analysis will be conducted among adolescent campers who have been assigned a mentor for one-year post camp using the Health and Important Matters Social Network Battery (Pescosolido, Brooks-Gardner & Lubell, 1998; Pescosolido, Wright, Alegria, & Vera, 1998; Wright & Pescosolido, 2002; Pescosolido & Wright, 2004; Perry & Pescosolido, 2010). This instrument was used in the Indianapolis Network Mental Health Study Protocol (NIH Funded Project) and was adapted from the Important Matters Battery from the General Social Survey (U.S. Department of Health and Human Services, National Institutes of Health, National Institute for Mental Health, Institute for Social Research, & Indiana University, 1991). This instrument has the advantage of assessing health related support, a key component of the study. The instrument is also listed in the PhenX Toolkit (PhenX Toolkit, 2017), a database of high quality reliable and valid psychosocial instruments. Each camper will have the opportunity to identify alters they would go to for important matters as well as the quality of that support based on a weighted scale.

A Chi Square for two independent samples test will be used. The intervention group and comparison groups will act as independent variables. The categories within the Health and Important Matters Network Battery will serve as the dependent variables.

#### **Research Design (Aim 2)**

The General Mattering Scale (Marcus, 1991) and the Rosenberg Self Esteem Scale (1965) will be used for Aim 2. Paper versions of both instruments will be administered during the residential medical camp experience to all campers and again 3 months post camp experience after youth return to integrated home communities. A repeated measures ANOVA will be used to

test for differences between and within groups. Descriptive analysis will capture any differences between and within groups as well as highlight demographics related to age, gender, and diagnosis.

### **Research Design (Aim 3)**

A qualitative phenomenological approach (Yin, 2016) will be implemented with adolescents and mentors. Interviews will be utilized to capture the meaning and experience specifically associated with the mentoring program. This approach will elicit what feelings, emotions, and experiences are associated with the mentoring program from both perspectives. Purposive sampling (Yin, 2016) will be utilized due to the unique nature of the program for both assigned mentors and adolescents. After describing the study to the participants, gaining their permission and setting up an initial meeting, interviews will be conducted over the phone and or in person at camp. Question content will focus on the history of the relationship, possible role social comparisons play if any, potential outcomes of the mentor and mentee relationship, and the positive and negatives of the program design. Interviews will be transcribed verbatim (Pope, Ziebland, & Mays, 2000) and uploaded to MAXQDA. Level one codes will be constructed followed by movement towards more advanced level two codes (by categories). This process will be repeated and refined until the least amount of level 2 category codes are present. The entire process from start to finish can be conceptualized in what Yin (2016) calls the five phase cycle of 1.) compiling, 2.) disassembling, 3.) reassembling, 4.) interpreting, and 5.) concluding.

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## Chapter Three

### Egocentric Network Analysis of a Medical Specialty Camp Booster Program for Youth with Physical Disabilities

Prepared for submission to the Children's HealthCare Journal

**Specific Aim 1:** Identify any differences in the reported alters of adolescents that have taken part in the Beyond the Woods Mentoring Program compared to participants at the same camp that have yet to establish a mentor relationship.

#### Abstract

Medical specialty camps provide consistent psychosocial support during residential camps, yet it is common to see extinguishing effects as youth return to home communities. Booster interventions may improve the effectiveness of medical specialty camps on the long-term psychosocial health of participants yet are uncommon. A booster pilot intervention consisting of an assigned adult mentor with a physical disability and a monthly online support program was examined in this study. An egocentric social network analysis was utilized to identify supportive people in the lives of pediatric campers ( $n = 23$ ) with physical disabilities. This study reports on the network characteristics of these youth with physical disabilities. Adolescents reported an average of 7.7 alters, of which 4.5 alters on average are family based ties followed by school peers and then camp peers. The majority (76%) of alter relationships reported were not reciprocal in nature, and those that were reciprocal tended to come from peers with similar health conditions within integrated school settings or the disability specific medical camp attended by the adolescent. Network characteristics of campers in the booster mentor program, were compared to a sample from the same camp not yet enrolled in the booster program. After three months of participation in the booster intervention, there was a small increase in average supportive camp alters for those enrolled in the program; however, this difference was not statistically significant (Pearson Chi Square = .482). Descriptive statistics provide new insight into the social networks of youth with physical disabilities. Future studies should increase n-size and test this program after 12 months of duration.

**Key Words:** Egocentric network analysis, medical specialty camp, physical disability

## **Pediatric Physical Disability**

Pediatric physical disability is noted as resulting in a variety of lifespan challenges. This includes a lack of friendships, intimate relationships, communication difficulty with peers, lower vocational and post-secondary attainment, and inactive leisure lifestyles (Berkthold & Horn, 1999; Dunn, 2010; Raghavendra, Olsson, Sampson, Mcinerney, & Connell, 2012; Roebroek, Jahnsen, Carona, Kent, & Chamberlain, 2009). There is a growing awareness of the psychosocial support needs of pediatric clients with health conditions (Witt, Riley, Coiro, 2003) as well as the connection between social relationships and positive health outcomes (Berkman & Glass, 2000). Interventions are necessary to support the psychosocial development of these youth (Plante et al., 2001). Medical specialty camps may be a useful approach for developing important social connections outside of the clinical setting to address these concerns (Dawson, McCormick, & Li, 2018).

## **Medical Specialty Camps**

Medical specialty camps are a common pediatric program offered nationally and internationally to youth with diagnosed health conditions. These camps typically involve one or more weeks of residential camp experiences for both children and adolescents. The camp population for these summer-based programs are typically condition specific in that campers share the same or similar diagnosis. Ratios for medical support including nurses and physicians as well as cabin counselors are typically at higher rates along with specialized programming that takes into consideration any contraindications that pediatric campers may have.

Pediatric residential camp programs have been shown to improve the short-term psychosocial functioning of youth with health conditions during residential camp participation.

This includes improved self-esteem, social acceptance, quality of life, and opportunities for social comparisons with similar others (Devine & Dawson, 2010; Knapp, Devine, Dawson, & Piatt, 2015; Meltzer & Rourke, 2005). However, there is a growing criticism of the residential camp model in that psychosocial gains identified during residential programs may not be carried over upon return to home settings (Plante et al., 2001). These episodic improvements have been noted as a potential social inoculation with extinguishing effects (Dawson, 2017) while a call for an improved pediatric model has been made (Plante, Lobato, & Engel, 2001). Taken together, short term gains are consistently seen in medical specialty camps yet, to date, there is a lack of literature on programs that have attempted to provide a supportive booster intervention in the months outside of traditional residential camp participation.

### **Booster Intervention Pilot**

A booster intervention was created as an adjunct to traditional residential medical specialty camp. This program utilizes a mentoring model coupled with online monthly support in the months outside of the residential experience. Mentoring programs have been shown to support the psychosocial development of adolescents resulting in improved long-term educational and work outcomes, a reduction in negative behaviors, as well as improvements in self-esteem and physical health (DuBois & Silverthorn, 2005). This program has two major components. First, an adult mentor is assigned to each adolescent that has a similar physical disability. The mentor is considered to have had success in vocational, post-secondary education, or leisure-based pursuits with personal experience coping with a physical disability during their adolescence. Second, a monthly online support program is offered with a specific curriculum designed to target the needs of these youth. Mentors and mentees are invited to attend together in the months outside of summer. Topics include making friends in inclusive settings, adapted

sports, adapted driving equipment, navigating medical procedures, and other topics related to physical disability. In the current study, a social network science approach was utilized to examine the effect of this booster intervention on the social ties of the campers with physical disabilities.

### **Social Networks During Adolescence**

Adolescents without health conditions typically have social networks that are varied depending on urban or rural home settings and gender. For example, rural youth tend to go to parents more than urban youth and females list more peers than parents compared to males. Moreover, parents are common alters that adolescents go to for important matters in life, yet there is a strong tendency to list peers over parents and other related adults (Bø, 1996). For example, children and those in early adolescence commonly receive support from a variety of network members including adults and peers, however, by late adolescence, egos routinely report that companionship and intimacy come from peer friendships (Furman & Buhrmester, 1992). If friendship density decreases in adolescence, there appears to be an increase in reported depression in these youth overall (Ueno, 2005). School settings are a significant source of support during adolescence as well as structured recreational programs (Cottrell, 2013). Outside of peer relationships, Cotterell also notes the importance of supportive adult relationships both from family and non-family contacts for positive development and well-being.

Although quite limited in scope, some studies have examined the social networks of youth with health conditions. This includes documenting differences in social networks of youth diagnosed with end stage renal disease as compared to healthy peers. These youth had increased family ties, fewer opposite gender alters, and fewer networks members overall (Melzer,

Leadbeater, Reisman, Jaffe, & Lieberman, 1989). Lower social network status, including connectedness as well as recognition by peers at the school, were reported in adolescents with autism as compared to peers in an inclusive school setting (Locke, Ishijima, Kasari, & London, 2010). Haas, Schaefer, & Kornienko (2010) also found that adolescents with poor health are less centrally located in their social networks and have less social network members overall compared to their peers without a health condition. Finally, Dawson, McCormick, & Li (2018) found that adolescents with physical disabilities attending a medical camp reported higher peer network members compared to younger children attending the same camp. Taken together, there is a need to examine the social networks of youth with health conditions as well as to explore interventions to support these youth during adolescence.

The current study captured egocentric network data for adolescents with physical disabilities ( $n = 23$ ) attending a medical specialty camp. Those attending camp and enrolled in the booster intervention for at least three months were compared to campers not yet enrolled in the mentoring and online program and only attending the residential medical camp. An egocentric network analysis was utilized to examine the effect of the booster intervention and to help describe the dynamics of the youth networks overall.

## **Research Procedures**

Prior to the start of camp, an E-mail was sent to all participating campers and their families indicating that a research study would be conducted within their medical summer camp program. Families were encouraged to read over the attached consent / assent forms and to review the description of the study. During check-in of the 2-week residential camp, a researcher was present to review the study with each family in person and invited parents to consent and



youth to assent to the study. Following consent and assent, participants then took part in a twenty-minute interview using the Health and Social Network Battery (Perry, & Pescosolido, 2010; Pescosolido, Brooks-Gardner, & Lubell, 1998) over the course of the next three months. Specifically, the intervention group network data was captured after each camper had taken part in residential camp and at least three months of the booster intervention while the comparison group members' network data were collected after taking part in approximately seven days of the residential camp only, creating two independent samples for analysis.

### **Research Subjects and Setting**

A total of N = 23 participants completed the study. Adolescents ranged in age from 13-18 with a near equal male to female ratio. Common diagnoses in this convenience sample included spina bifida, neuromuscular disease, and cerebral palsy. Youth were at a normal cognitive level developmentally. In total, 90 campers with physical disabilities attend this camp annually between the ages of 8-18 with a near equal amount of male and female participants. Campers stay in gender specific cabins of approximately 10-12 participants per cabin. Staff are present throughout the camp at a minimum ratio of 1 staff for every 3 campers. In total, 80 cabin counselors are hired each summer, principally from allied health degree programs. Programming consists of archery, pool, lake, canoes, climbing towers, skits, music, adapted scuba diving, adapted sports, cooking, outdoor activities and education, challenge days, and horseback riding. The camp facility is universally designed with cabins, program buildings, grounds and all activities adapted for people with physical disabilities. Very few physical limitations exist in this camp setting as the program has been in existence since 1955 with much of the facility built specifically for this population.

## **Egocentric Network Analysis**

Social network research is a rather new approach in the social sciences. However, it is growing rapidly and is a promising method to better understanding the effect of social connection, or lack thereof, in relation to those impacted by health conditions (Pescosolido & Levy, 2002). In particular, there are two types of social network studies, sociocentric and egocentric approaches. First, there are sociocentric approaches, also referred to as whole network analysis, that seek to capture one global environment and the social connections between all members within that one environment. For example, a whole social network analysis may be conducted within a high school to capture the key players within that specific network, those that are at the center of the network, and those that are on the fringe. This approach is helpful in looking at one specific setting in its entirety. The second approach to social network science, egocentric network analysis, seeks to capture the social connections of individual members by determining the people to whom the subject goes to for important matters as well as a variety of details related to those supportive people. Typically, a name generator is commonly used as an instrument to elicit various supportive people in the life of the subject as well as specific details related to each of the supportive people identified. This may include their age, gender, how close the subject is to each person, if the person also has a health condition, and if the supportive person ever comes back to the subject to talk about their own personal matters. This approach, although more time consuming, provides a rich amount of detail that may not be reported otherwise. In this study, an egocentric network analysis was chosen given the need to better understand the individual social networks connections of youth with physical disabilities as this population has historically had difficulty in the social domain (Chung, Hossain, & Davis, 2005; Marsden, 2005).

A review of terms used within egocentric network analysis is helpful in understanding this research approach. The following highlights common terms used to map the individual egocentric networks of research subjects (Christakas & Fowler, 2007). These terms will be used throughout the remainder of this article in describing the research approach, findings, and discussion.

Figure 1: Social Network Terms

<p><b>Ego</b> – research subject whom the network is focused on</p> <p><b>Alter</b> – a supportive person the ego goes to for important matters</p> <p><b>Alter role relation</b> – this is the role the alter plays in the life of the ego. Examples may include a parent, teacher, school friend, camp counselor, mentor, grandparent, or pastor.</p> <p><b>Tie</b> – connection between an alter and an ego</p> <p><b>Important Matters</b> – a term to describe the important life topics that an ego may discuss with alters.</p> <p><b>Egocentric Name Generator</b> – common way of describing the instrumentation that guides the interview process in which the researcher seeks to capture the names of the alters that the ego goes to for important matters in addition to details about those alters.</p> <p><b>Reciprocal Relationship</b> – a social tie between the ego and alter in which the ego goes to the alter for important matters and the same alter goes to the ego for their important matters. Having a reciprocal relationship within a social network is important for positive mental health outcomes.</p> <p><b>Homophily</b> – is a term used in sociology to describe the common tendency for alters and egos to build friendships through a shared demographic trait. This may include but is not limited to gender, shared leisure interests, race, ethnicity, religion, political affiliation, health diagnosis, and geographic location.</p>
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## Analysis

Egocentric networks were recorded through 1:1 interviews lasting approximately 20 minutes each. The Health and Social Network Battery (Perry & Pescosolido, 2010; Pescosolido,

et al., 1998; Pescosolido & Levy, 2002) guided the interviews including the use of a script with eight question prompts related to eliciting companionship or important matters social network alters. Once alters were identified by the ego through the name generator approach, demographic information was collected on each alter. This included information such as the role the alter plays in the life of the ego, their age, if they have a health condition, whether the alters have a reciprocal relationship with the ego, how close are they to each alter, and the method of communication. For N = 23 egocentric networks, a total of 178 alters, or an average of 7.7 alters per ego, were recorded. Figure 2 below provides descriptive statistics on the characteristics of the alters reported overall by the adolescent egos.

Figure 2: Alter Demographics

<b>Alter Demographics</b>	
<b>Alters that are Relatives</b>	58%
<b>Female Alters</b>	51.70%
<b>Male Alters</b>	48.30%
<b>Average Number of Alters</b>	7.7
<b>Average Closeness to Alters on 3 Point Scale (1 highest)</b>	1.86
<b>Average Reciprocity Score on 3 Point Scale (1 highest)</b>	2.61

Collectively, the data provided in this article provides a rich descriptive statistical analysis of the egocentric networks of these youth. Given the lack of social network specific information within the literature for this population, ample attention is given to describing these findings in order to help inform future studies. In doing so, this work builds upon Dawson, McCormick, and Li's

(2018) study on this same population and follows the recommendation to move forward in using a more robust and reliable egocentric name generator, i.e., the Health and Social Network Battery.

A chi square test as well as an independent samples T-test were conducted using SPSS. An independent samples approach was utilized comparing the intervention group (enrolled in the booster intervention) to the comparison group (residential camp only). The intervention group had been assigned a mentor for at least three months while the comparison group only attended the two-week residential camp and was not assigned a mentor or invited to the online support program.

## **Findings**

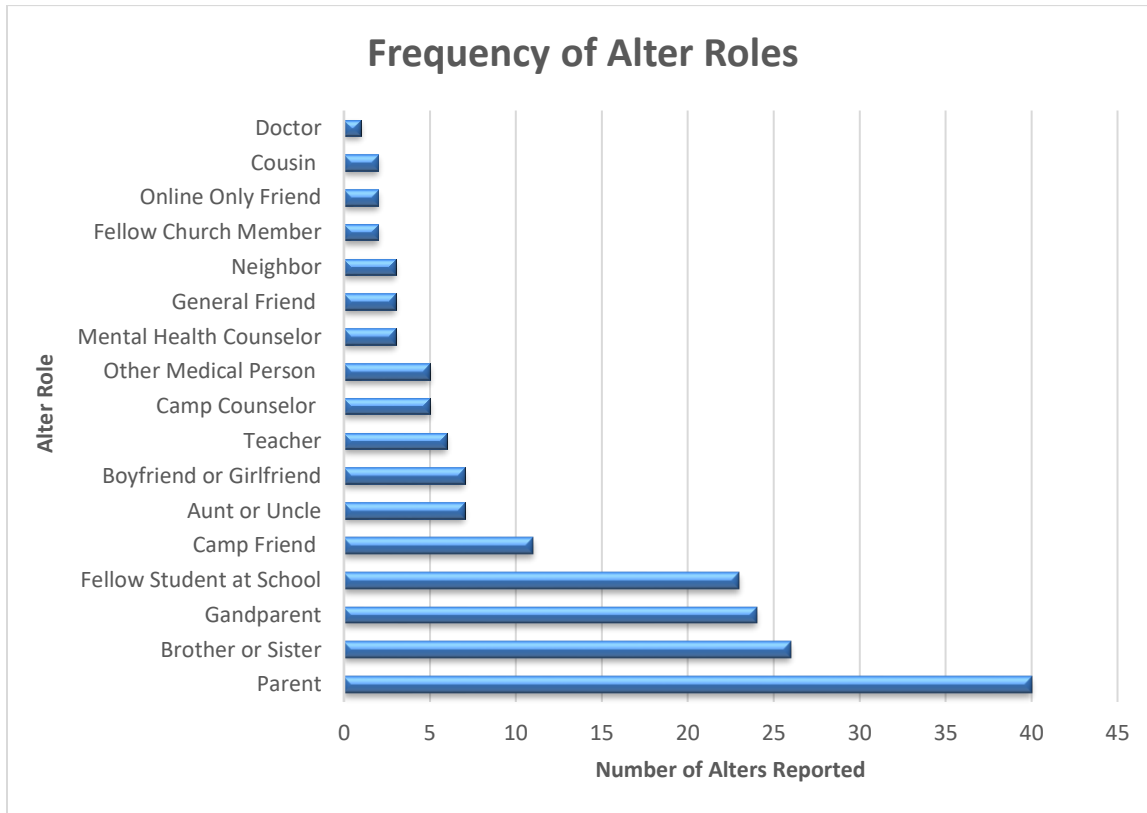
### *Descriptive Statistics*

The following figures provide a descriptive analysis of the social network composition of the N = 23 youth with physical disabilities collectively. Specific attention is given to the role alters play in the lives of the egos, the setting alters can be found in, whether the alter has a health condition, reciprocity within the relationship between ego and alter, and the type of communication used. This approach provides one of the first rich social network descriptions of adolescents with physical disabilities in the literature.

Figure 2 below indicates the role relation alters play in the lives of the egos. Parents are clearly the most identified type of alter followed by siblings, and grandparents. Non-relative connections are strongly focused on school-based peers followed by camp contacts. Adding camp counselors together with camp peers further strengthens that relatives, school peers, and

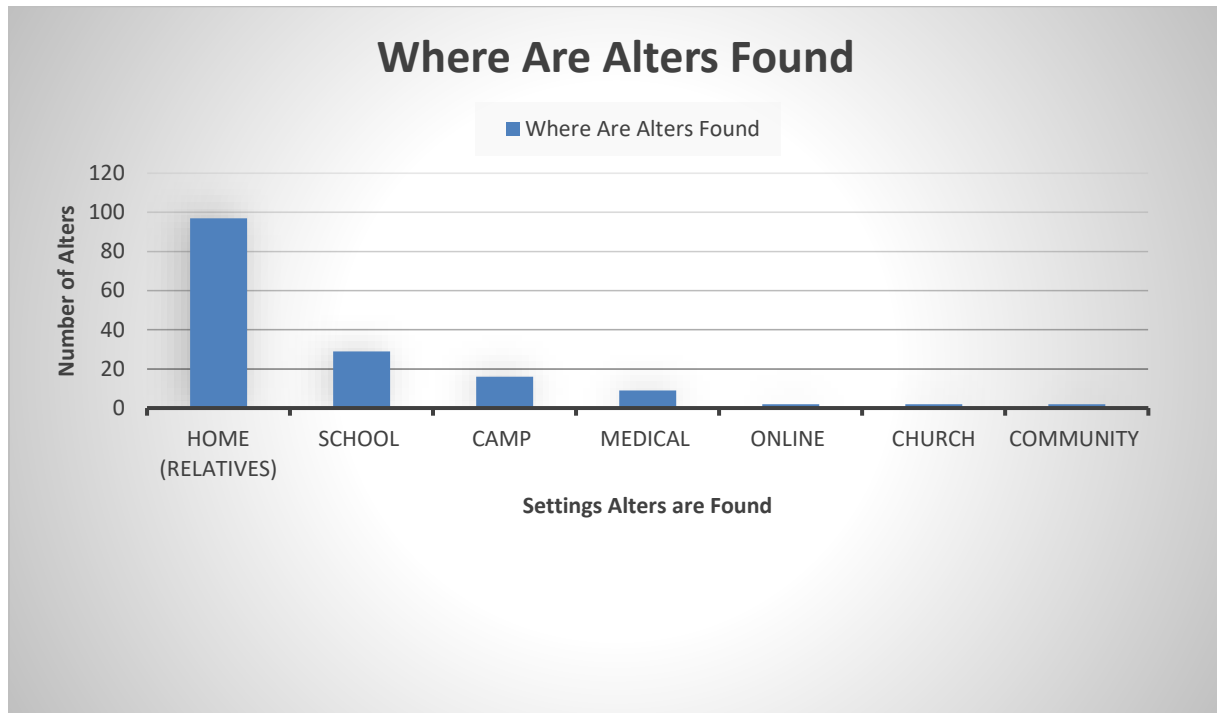
camp contacts have a strong presence in the social networks of these adolescents with physical disabilities.

Figure 3. Frequency of Alter Types



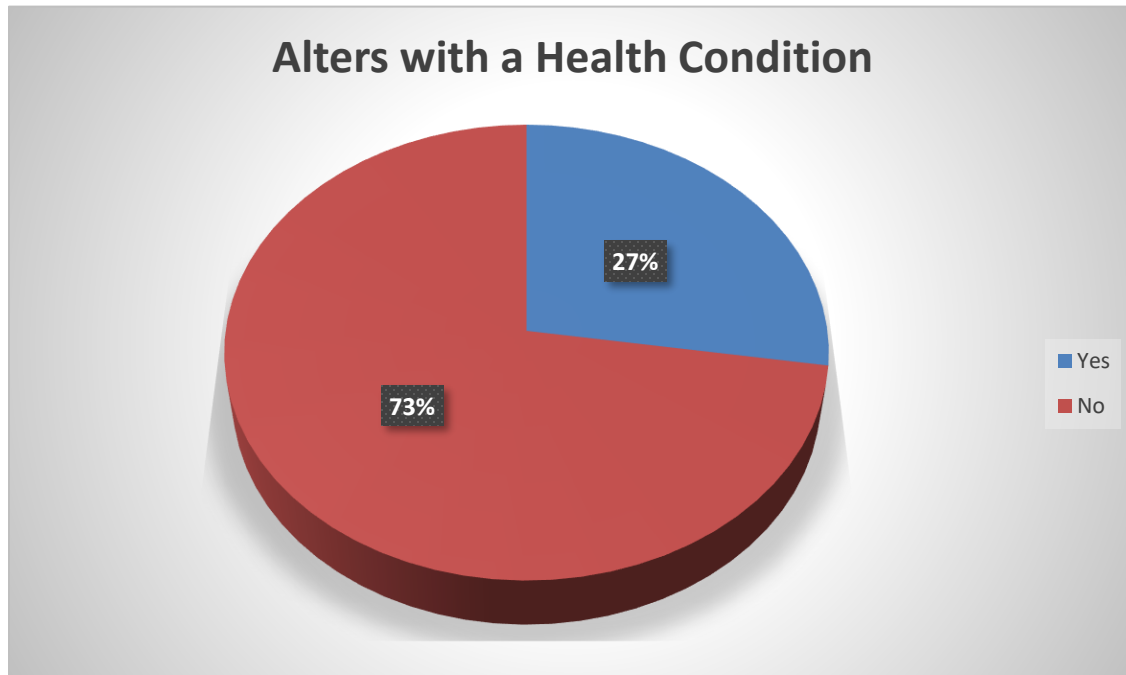
When combining the various alters reported above into settings, it is clear that connections made at home, school, camp, and in medical settings are the major influences in the egocentric social networks of these adolescents. Figure 4 below indicates the settings in which alters are found. As adolescents age out of school and camp around 18 years of age, it is easy to see why social networks may become quite limited into adulthood, i.e. loss of camp and school based networks upon graduation from both settings.

Figure 4. Where are Alters Found



Once alters were identified by the campers, a follow- up question focused on whether each alter was diagnosed with a health condition. Figure 5 below indicates that over a quarter of the alters were reported to have a health condition. Conversely, a total of 73% of alters reported to not have a health condition.

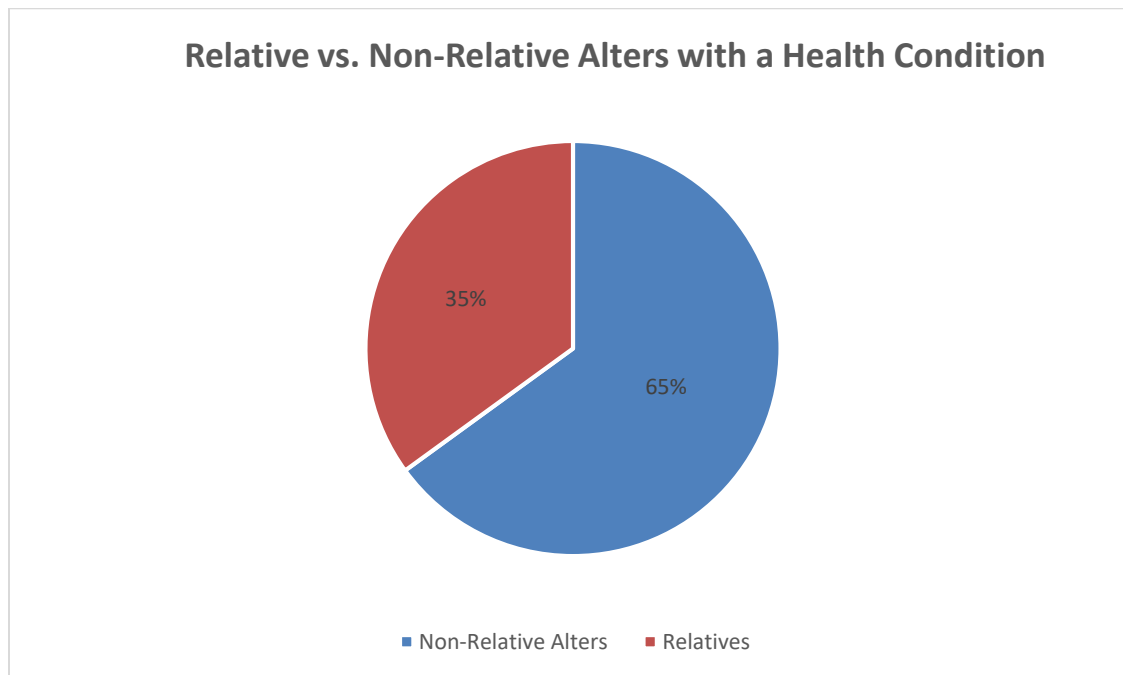
Figure 5. Proportion of Alters with Health Conditions



A total of 60 alters were identified as having a health condition. In analyzing those 60 alters specifically, 65% (n = 39) were alters unrelated to the adolescent and 35% (n = 21) were identified as a relative. Relatives included mothers, fathers, aunts and uncles, cousins, siblings, grandparents and other relatives. Therefore, the majority of alters with health conditions are not related to the ego.

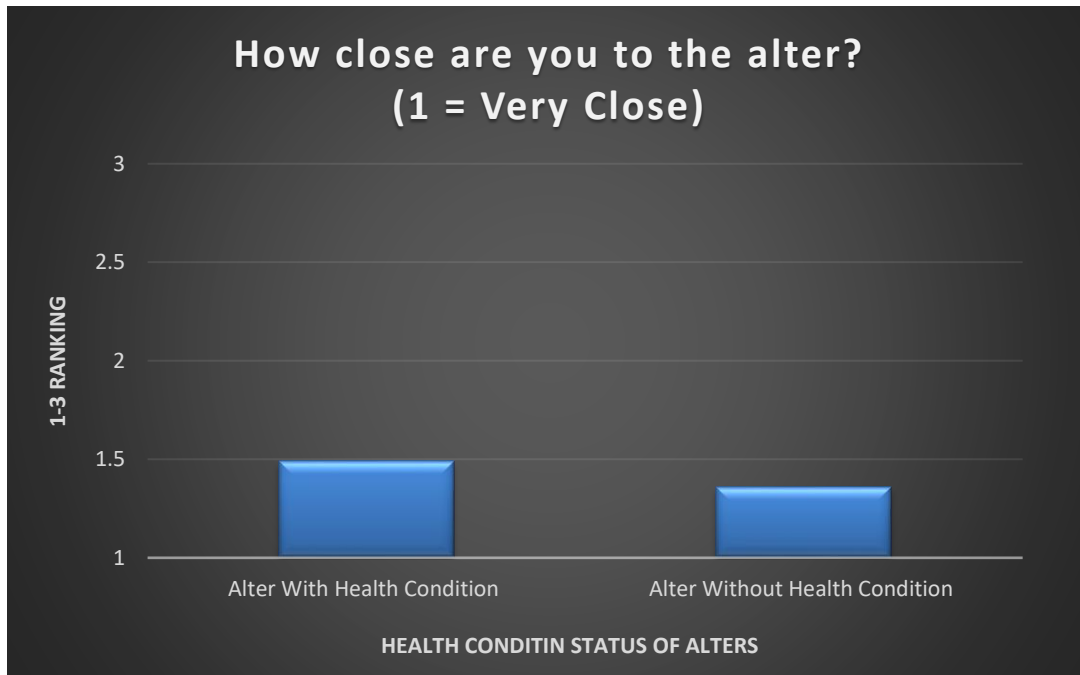


Figure 6: Relative vs. Non-Relative Alters with a Health Condition.



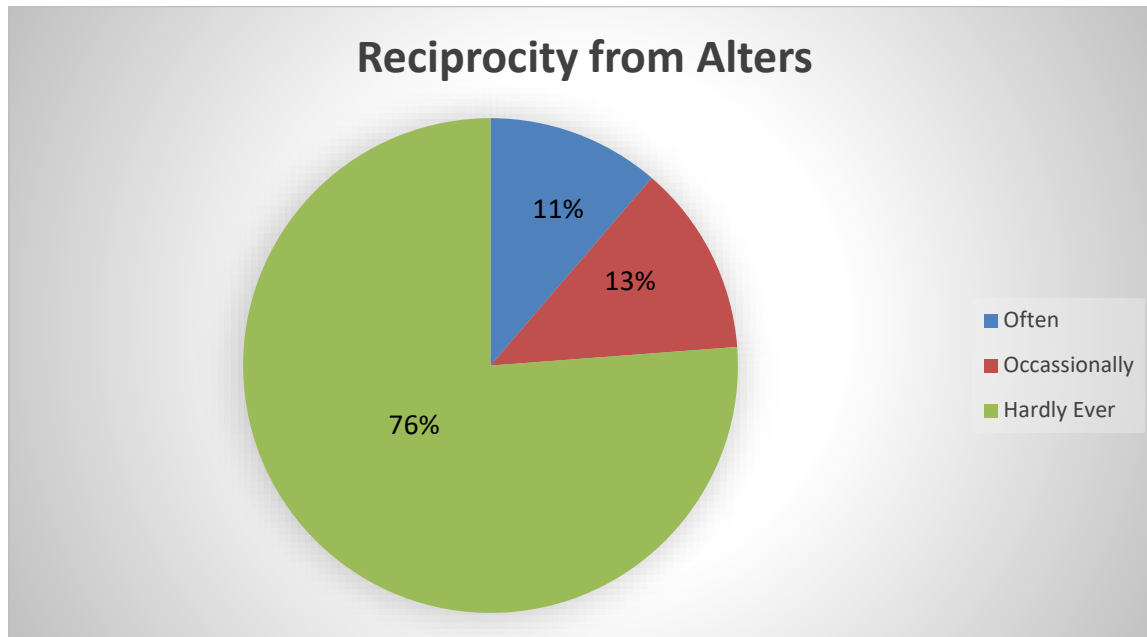
Adolescents were also asked to report closeness levels of all reported alters. A 3 point Likert scale was utilized consisting of a 1 = “very close” to the alter, a 2 = “sort of close” to the alter, and a 3 = “not very close” to the alter. Figure 7 below indicates that alters with health conditions have an average closeness score of a 1.49 while alters without health conditions have an average score of 1.36. The standard deviation for all closeness scores was 0.6. Scores are similar in nature overall and both are located between “close” and “sort of close”.

Figure 7: How Close Ego is to Alters



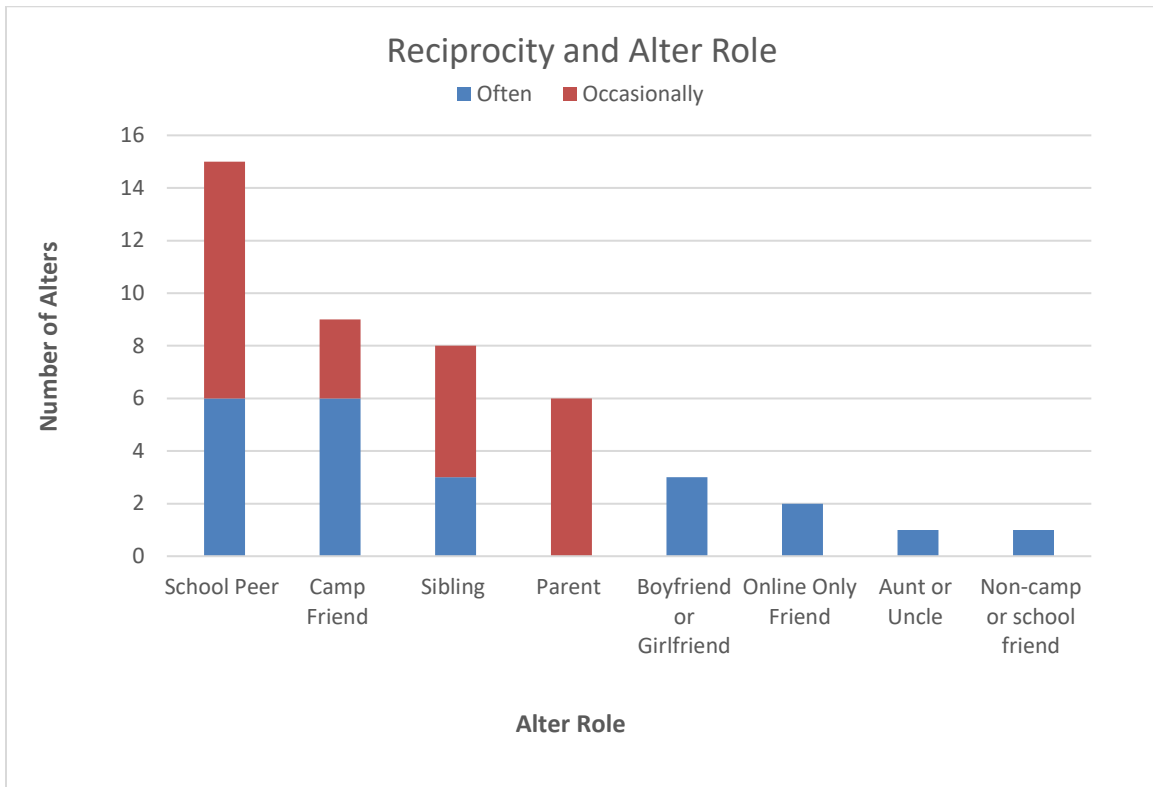
Campers were also asked to report if each identified alter comes to them (ego) about the alters' important matters. Across all campers, participants reported that only 11% of their social network relationships are "often" reciprocal and 13% of the time they are "occasionally" reciprocal (Figure 8). Over 76% of the alters reported were not reported to be a reciprocal relationship.

Figure 8: Reciprocity from Alters



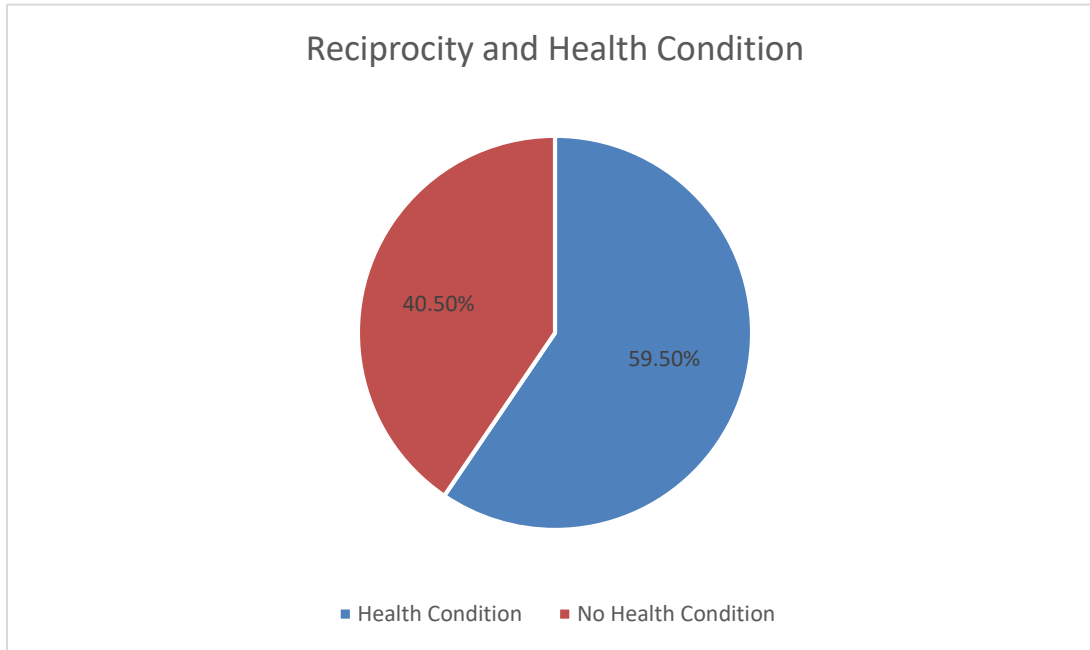
Once reciprocity percentages were established, a closer look at those specific relationships was needed to better understand the dynamics of this important part of the network. The following bar graph highlights that school peers relationships were most likely to be reciprocal followed by camp peers and siblings. Despite contact for only 2 weeks per year, camp friends with physical disabilities were reported as “often” reciprocal at an equal amount compared to school peers in which personal contact is much greater throughout the year, i.e., adolescents see camp peers for approximately two weeks while school peers are together for up to 36 weeks in a given year.

Figure 9: Reciprocity and Alter Role



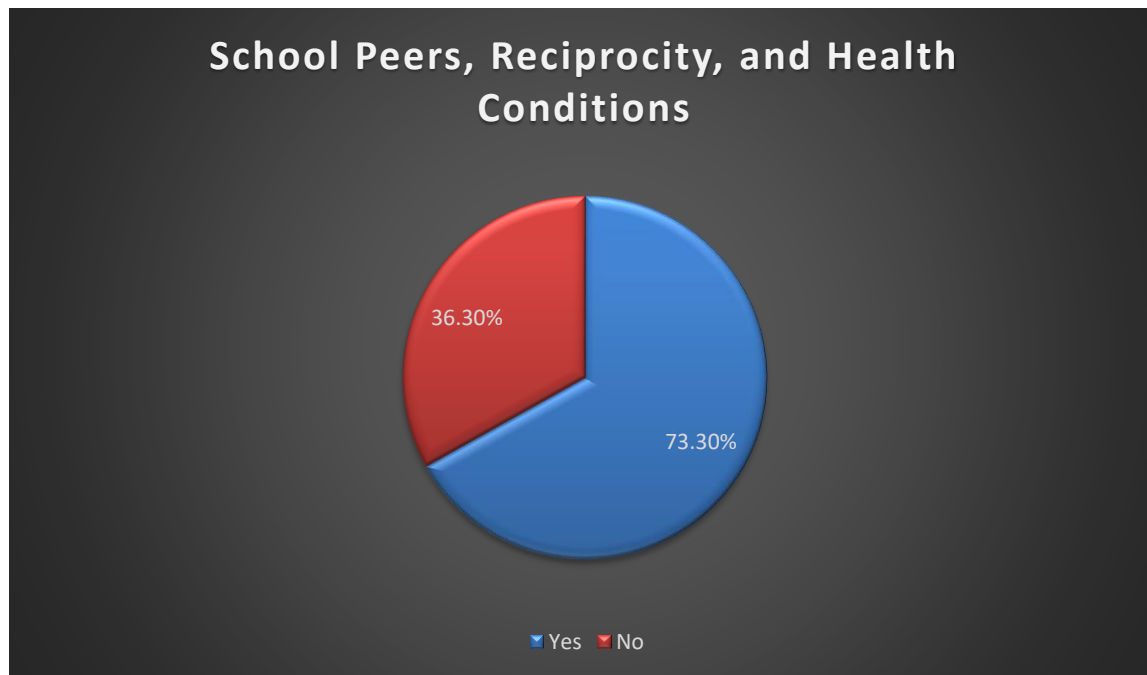
Given the report that camp and school peers provide similar reciprocity within the “often” category, a closer look at health condition specific relationships was explored to further understand any potential connection. Figure 10 indicates that nearly 60% of reciprocal relationships reported are with an alter that also has a health condition while 40% of reciprocal relationships were with alters without a health condition.

Figure 10: Reciprocity and Health Condition



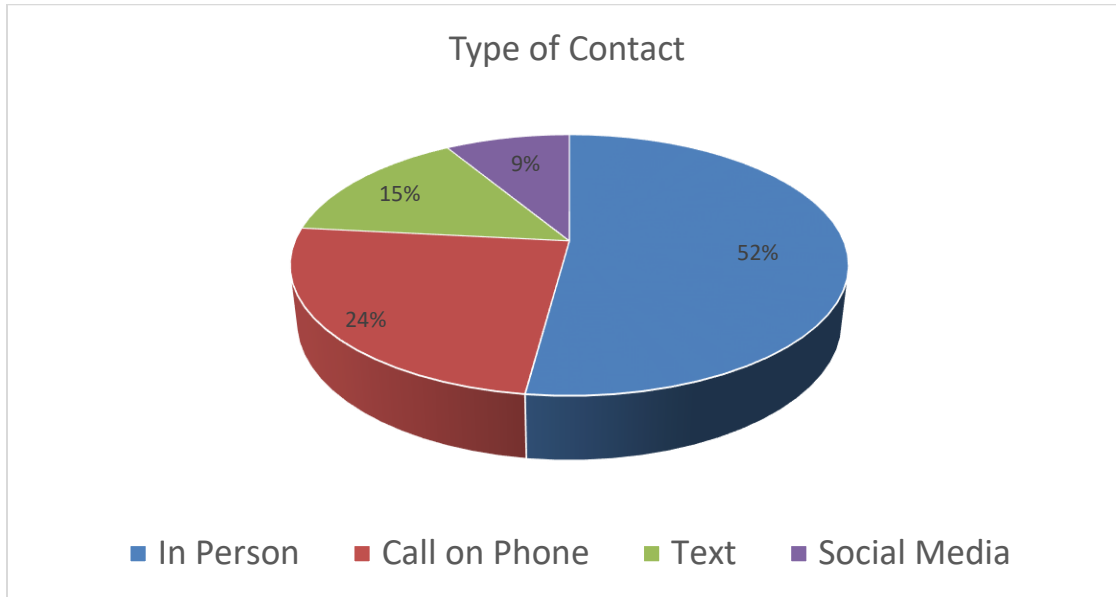
Specific to school peers and reciprocity, the following graph (Figure 11) indicates that 73% of school peer relationships reported as being reciprocal included a school peer that also had a diagnosed health condition. Put another way, it is evident that camp peers would have a health condition but it is now clear that many of the school-based peers that provide reciprocity also have a health condition. This is somewhat surprising given the integrated and inclusive nature of school based settings.

Figure 11: School Peers, Reciprocity, and Health Condition



Finally, campers were asked to identify the ways in which they communicated with reported alters. Figure 12 indicates that the majority of interactions are in-person followed by phone, texting, and social media. At least with these youth, in person methods of communication are still very important ways to connect to their network members overall despite the recent influence of technology.

Figure 12: Type of Contact with Alters



*Egocentric Networks of Booster Versus Non-Booster Groups*

A chi square test of independence as well as an independent samples t-test were utilized in addition to the aforementioned descriptive statistics to determine any differences between the intervention group (enrolled with mentor and online support outside of camp) and the comparison group (residential camp only) on their egocentric networks.

*Camp vs. Non-Camp Alter Proportions*

A Chi Square was used to analyze the proportion of camp alters compared to non-camp alters for the comparison and intervention groups respectively. Networks were dichotomized according to zero camp alters, coded as 0, or one or more camp alters (mentor, staff, or peer), coded as 1. In total, the comparison group reported 93.8% of alters as non-camp related along with 6.3% coming from the medical specialty camp setting. Similarly, the intervention group reported 90.9% coming from non-camp alters while 9.1% were identified as coming from the

medical camp setting. The Pearson Chi-Square resulted in a .482 test statistic. Although the treatment group reported a slightly higher proportion of camp contacts (2.9% more) after taking part in the intervention for three months, the results of this test indicate no statistically significant difference between intervention and comparison groups.

*Mean Score Comparison of Alters*

An independent samples t-test was used to analyze any differences in mean scores for reported alters between the comparison and treatment group. The data were analyzed by first calculating an individual mean of camp peers compared to non-camp peers for each individual camper. Next, the data were aggregated from individual means to group means, thus creating separate independent groups. Group 1 consisted of one aggregated group mean for the comparison group and group 2 consisted of an aggregated group mean for the treatment group. This approach was utilized in addition to the chi square above to ensure that individual camper means didn't bias the results of the group mean. For example, one camper may report a very high number of camp alters while other campers report zero or minimal camp peers. The aggregated individual means that created the overall group means assisted in countering this type of bias. The following tables highlight the results of the chi square test and independent samples t-test.

**Table 1. Independent Samples T-Test**

Group Statistics					
	Group	N	Mean	Std. Deviation	Std. Error Mean
Comparison	1.00	15	.0619	.11447	.02956
Intervention	2.00	8	.0913	.17424	.06160



**Table 2. Independent Samples Test**

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	Df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
P_camp	Equal variances assumed	1.904	.182	-.488	21	.630	-.02937	.06012	-.15438	.09565
	Equal variances not assumed			-.430	10.32	.676	-.02937	.06833	-.18097	.12224

**Table 3. Chi Square Results: Group ID & Camp Alter Cross Tabulation**

			Camp Alter		Total
			0	1	
Group ID	1	Comparison Group Count	105	7	112
		% within Group ID	93.8%	6.3%	100.0%
	2	Intervention Group Count	60	6	66
		% within Group ID	90.9%	9.1%	100.0%
Total		Total Count	165	13	178
		% within Group ID	92.7%	7.3%	100.0%

**Table 4. Chi-Square Tests**

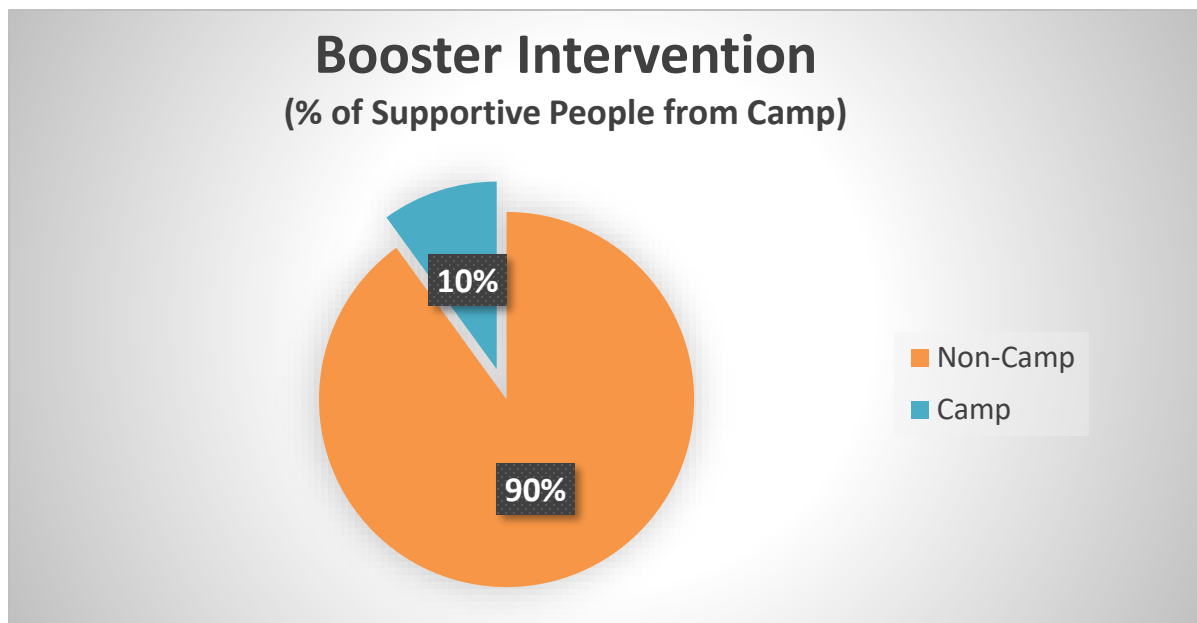
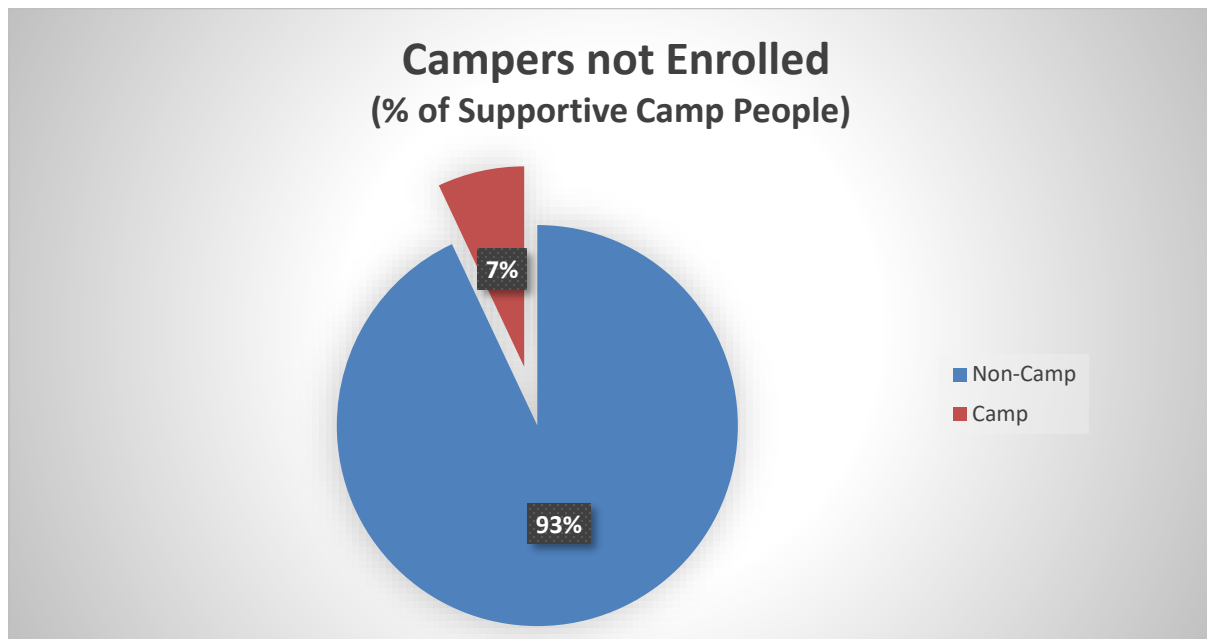
	Value	df	Asymptotic Significance (2- sided)	Exact Sig. (2- sided)	Exact Sig. (1- sided)
Pearson Chi-Square	.495 <sup>a</sup>	1	.482		
Continuity Correction <sup>b</sup>	.164	1	.685		
Likelihood Ratio	.483	1	.487		
Fisher's Exact Test				.555	.336
N of Valid Cases	178				

a. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 4.82.

b. Computed only for a 2x2 table

Figure 13 displays the percentage of camp alters versus non-camp alters for the comparison and intervention groups. Camp alters consist of camp peers, camp counselors, or the mentor assigned to the adolescent. Non-camp alters consist of all other alter not related to camp. Although the trend towards a greater network of camp alters is seen, there was no statistical difference between these two groups.

Figure 13: Camp and Non-Camp Peers in the Treatment vs. Comparison Groups



## Discussion

There is very little discussion in the literature about the social network characteristics of adolescents with physical disabilities. Many studies indicate that the social domain is a problem

area for this population including noted problems in friendship development, intimate relationships, transitions from adolescents to adulthood, and lack of an active leisure lifestyle (Dunn, 2010; Raghavendra, Olsson, Sampson, Mcinerney, & Connell, 2012; Roebroek, Jahnsen, Carona, Kent, & Chamberlain, 2009). The descriptive statistics in this study begin to add important information on the egocentric networks of these youth. For example, sharing a health condition seems to provide a basis for reciprocity, e.g., camp and school peers tend to have a health condition also. Perhaps this homophily rich connection is a contributing force in providing reciprocity. In an inclusive community based setting, it would make logical sense that meaningful connections may be more difficult to build and maintain based on the homophily principle. Other studies have found that homophily is important to adolescent relationship. For example, shared ethnicity is predictive of social ties in adolescents in a school setting (Boda & Néray, 2015) and that interracial friendships are less likely to be reciprocal (Vaquera & Kao, 2007). McPherson, Smith-Lovin and Cook's (2001) seminal work on homophily and friendship development may be particularly helpful in understanding the tendency for ties between egos and alters to form over homophily rich connections. A shared health condition may be one of those shared demographics yet is rarely discussed in the literature. Future work should begin to address how to build reciprocity in inclusive settings between youth with physical disabilities and those without health conditions as well as the application of this principle in providing reciprocity and support in health condition specific programs such as medical camps. For example, programs may look to build reciprocity in an integrated setting by connecting peers via leisure interest, gender, and other non-health condition specific attributes while disability specific programs may seek to capitalize on shared health condition diagnoses and resulting social comparisons.

Plante et al. (2001) described medical camps as one of five major pediatric support interventions commonly listed in the literature. However, Plante went on to indicate a major need for improvement in the camp model to address the extinguishing effect on psychosocial outcomes as campers return to home communities. Work by Dawson (2017) presented a possible future medical camp model that includes booster interventions during the other 11 months of the year outside of the residential camp setting. The booster intervention developed and tested in this study may be the first attempt in the literature to address the decaying psychosocial effects commonly seen in medical camp. Although the intervention group had a slightly larger proportion of alters originating from camp, there was no statistically significant difference between the groups after three months. Future studies should look at a more longitudinal study that captures networks 9-12 months into the relationship to see if this improves findings. Also, a larger n size, refinement of the current booster intervention, and the development and implementation of other booster interventions is needed to further test for effect in this new approach to medical specialty camps.

Although the current study was not statistically significant, two other studies on this same program provide evidence for the need to further develop and test this approach. For example, the program had a small to moderate effect size in improving perceptions of mattering (Dawson, Mattering Chapter in Dissertation) while a qualitative approach (Dawson, Qualitative Chapter in Dissertation) elicited a theme related to the awkward beginning of the relationship commonly experienced by both mentor and mentee until they had time to get to know one another, i.e., after several months.

The descriptive statistics presented above provide further detail that builds upon a preliminary network analysis on this same population by Dawson et al. (2018). This study further

describes the role alters from home, school, and camp play in the lives of these adolescents as well as increased data on reciprocity and the potential influence of health conditions on social ties. It also builds upon the recommendation to utilize a robust, reliable, and mainstream sociological instrument in the Health and Social Battery. Given the ease at which data was collected and analyzed in this study, future studies should continue to use robust and reliable scientific approaches that are increasingly sophisticated to examine the influence of disability within social networks.

Finally, it appears that adolescents with physical disabilities are at risk for losing a large part of their reciprocal and non-relative based peer social network ties once they age out of both camp and school. It is common to no longer have access to both of these settings at the age of 18 due to graduation. Adolescent social networks in the general population are commonly characterized by a series of transitions including changing schools, developing new friendships, moving from childhood to adulthood, entering college or vocational pursuits, and ever changing social and leisure settings. Adapting to changes and finding order and stability through these adjustments are important for healthy individual development according to Cotterell (2013). Indeed, despite these changes, young adults without disabilities commonly report that support continues to originate mostly through peer relationships rather than relatives during this life stage indicating some success in navigating this transition. In the youth with physical disabilities from the current study, it appears as though relatives and medical professionals will likely still remain in young adulthood (after graduation from camp and school), however, a major part of the social network alters consisting of non-relative peers will ostensibly no longer be readily available through structured school or camp activities. Furthermore, geographic distance in adolescent relationships with peers is known to result in decreased probability of friendship (Preciado,

Snijders, Burk, Stattin, & Kerr, 2012). It is unclear if the social networks of these youth will adapt and change or decline in density, reciprocity, and non-family oriented ties. Future studies should target the adolescent to adult life stage to further examine this dynamic from a network science approach.

### **Limitations**

The current study only utilized a three-month implementation window for the mentoring – mentee relationship and online support to materialize. This may not have been a long enough duration to effect change in the egocentric networks of these youth assigned a mentor and online support. A type 2 error is possible in the data. Future studies should increase the length of the data collection and seek statistically significant empirical findings related to reciprocity, role of health condition on ties between ego and alter, and other relationship variables discussed more qualitatively in this article. Until future studies can be done, the findings of this current study are limited to this population and specific setting and are not generalizable given the lack of statistical significance.

### **Future implications**

Future studies should test the effect of implementing this program with other populations such as those with cranial facial differences, cancer, diabetes, burns, and other diagnosis that are commonly seen in the medical camp literature. The data generated from the current study is robust in addition to self-esteem and mattering data reported in (Dawson, Mattering & Self Esteem Chapter). As such, a future study should examine the complete data set using a hierarchical regression analysis. In doing so, important information may be found related to

correlations with mattering and self-esteem constructs specific to demographic variables such as reciprocity, gender, density of individual networks, and disability type.

## **Conclusions**

The current study captured egocentric social network data related to 23 adolescents with physical disabilities. This study adds to the social network data on this population and is one of the first attempts at pilot testing a booster intervention in the medical camp literature. Descriptive analysis of these networks provide details that may be helpful for future studies that seek to address social connection, reciprocity, adolescent to adult transitions, and other psychosocial approaches to physical disability.

The booster intervention program for medical camps was tested in relation to a comparison group not receiving a mentor or online program. After three months of intervention, there was a difference in supportive camp alters yet no statistically significant difference found. Future studies should continue to look at the social domain of this population through egocentric network analysis as well as more longitudinal data points to determine if this program is effective over time.



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## Chapter Four

### Effect of a Year-long Mentoring & Online Support Program on the Self-esteem and Mattering of Youth with Physical Disabilities as a Booster to Residential Medical Camp

Written for submission to *Children's Health Care*

**Specific Aim 2:** Test for any differences in the perceived self-esteem and mattering of youth with physical disabilities enrolled in a year-long mentoring and online support treatment program after attending medical camp compared to a comparison group of similar youth only attending the residential medical camp.

#### **Abstract:**

Youth with physical disabilities are at an elevated risk for poor psychosocial health. Pediatric medical camps are one common intervention utilized to provide short-term psychosocial support. There is criticism that the effects of such programs are extinguished as participants return to integrated home communities post residential camp experience. A post-camp mentoring intervention, named Beyond the Woods, was created to address these concerns and is the first known program of its kind. The support program is based on foundational theories related to social inoculation and social comparisons. This study examined the effect of the program on psychosocial outcomes. A quasi-experimental design using an intervention and comparison group was utilized. Findings by repeated measures ANOVA indicated a small effect (partial  $\eta^2 = .096$ ) between groups ( $p < .17$ ) and a moderate effect (partial  $\eta^2 = .133$ ) within groups ( $p < .10$ ) on the mattering construct. The program appeared to have no effect on self-esteem as decaying results post camp were similar in both comparison and treatment groups. Future implications center on the refinement of the booster intervention program, increasing power with larger samples, and future testing with other pediatric populations.

**Key Words:** Mattering, Self-esteem, Adolescents, Physical Disability, Medical Specialty Camp

## **Introduction**

Youth with physical disabilities encounter many documented social challenges. Shields, Murdoch, Loy, Dodd, & Taylor's (2006) systematic review of self-concept in adolescents with cerebral palsy concluded that self-concept was lower in a variety of domains including social acceptance, scholastic competence, and appearance. Less social activities, intimate relationships, and plans for college compared to a comparison sample have also been documented (Stevens, Steele, Jutai, Kalnins, Bortolussi, & Biggar, 1996). Furthermore, a review of the literature by Wiegerink, Roebroek, Donkervoort, Stam, & Cohen-Kettenis (2006) posits that youth with cerebral palsy have less robust social relationships in general, delayed dating behavior, and difficulty developing intimate relationships compared to their peers without physical disabilities. Taken together, this population is at-risk psychosocially. It is important for future research to develop, test, and refine evidence-based approaches for positive psychosocial health.

One common approach to support youth experiencing childhood health diagnosis is enrollment in medical specialty camps with similar peers. Positive short-term psychosocial effects from participation in residential medical specialty camps are commonly seen in the literature. Studies have examined various constructs such as self-esteem, social acceptance, and quality of life (Devine & Dawson, 2010; Devine, Piatt, & Dawson, 2017; Kiernan, Gormley, & MacLachlan, 2004). Despite consistent short-term gains, there is also routine decay in psychosocial effect at follow-up data points several months after returning to integrated home communities (Plante, Lobato, & Engel, 2001). Plante, et al. (2001) reviewed pediatric support interventions and confirmed medical camps as one of five major approaches commonly utilized. However, the authors contend that until the dissipating psychosocial effect of camp can be enhanced, the camp program will not receive enthusiastic support as an efficacious intervention

for pediatric clients that experience health conditions. Moola, Faulkner, White, & Kirsh's (2014) systematic review of medical specialty camps concludes that it is too premature to endorse these programs until stronger theoretical foundations within camp programs and future long term follow-on data can be improved.

Seminal theoretical work on social inoculation theory and subsequent application to health programming may be an applicable lens to evaluate medical camps (McGuire, 1961; Pilisuk, 1982; Pilisuk & Parks, 1980). For example, youth typically attend a short term residential experience that is finely crafted for their specific needs and filled with peers going through the same health condition. However, after the conclusion of this short residential experience, they are then placed directly back into a more stressful integrated environment upon return to home communities. Dawson (2017) has argued that a new medical camp program model is needed to boost the social inoculation effects and counter the extinguishing effects commonly seen in the psychosocial outcomes at follow-up in the majority of medical camp studies, i.e., booster interventions are needed outside of residential medical camp programs.

Given the criticism in the scientific literature with regards to extinguishing effects, the current booster intervention was created to begin to address this issue. The Beyond the Woods program was designed to build upon the successes seen in the residential setting while targeting weaker areas of the camp program model associated with the other 11 months of the year, i.e., outside of the summer camp experience. The Beyond the Woods program assigns an adult mentor with a physical disability to an adolescent camper with the same or similar physical disability. Mentor and mentee meet during the summer camp experience and then begin a year-long mentoring relationship following the residential camp. An online support program was also created in addition to the mentoring relationship to provide structured one-hour online meetings

once per month. Each online meeting is led by a recreational therapist that serves in a camp administration role during summer camp. The curriculum focuses on topics germane to both the mentee and mentor such as overcoming stigma associated with their health condition, relationships, driving a vehicle, adapted sports, and other relevant topics. Mentee and mentors are both encouraged to attend the monthly meetings online together as well as to correspond 1:1 at least twice per month via e-mail, texting, social media, or phone. The Beyond the Woods program is focused on adolescents based on the finding by Dawson, McCormick, & Li (2018) that 13-18 year olds from this same camp desire non-relative contacts at a significantly greater level than children at the same camp, as well as the developmental norm of establishing greater peer relationships during adolescence (Cotterell, 2013). Additionally, the program design was also influenced by Knapp, Devine, Dawson & Piatt's (2015) finding that participants from this same camp desired opportunities for social connection and programming outside of the residential camp experience. The current study seeks to examine the effect of the booster intervention related to mattering and self-esteem.

### **Mattering Construct**

Rosenberg & McCullough's (1981) work to discover the importance of mattering was seminal in understanding the relevance of this psychological filter in the lives of adolescents. Mattering is evident, according to Elliot, Kao, and Grant (2004), when others invest, attend to, and have a reliance on the person of interest. In short, those that feel as though they matter, also feel as though they are significant in the lives of others. The need to belong is paramount in Maslow's Hierarchy of Needs (Maslow, Frager, & Fadiman, 1970) in that once physiological and safety oriented needs are met, feelings of belonging become critical within the hierarchy. Mattering may then, in turn, result in positive social health outcomes. Elliott, Colangelo, &

Gelles (2005) found that adolescents that perceive that they matter are significantly less likely to have suicidal ideation. Raque-Bogdan, Ericson, Jackson, Martin, & Bryan (2011) found that mattering mediated the relationship between attachment orientation and mental health in a sample of college students. The authors went on to assert that mattering is a promising agent for future therapeutic interventions. France & Finney (2009) found that mattering was positively associated with well-being and negatively associated with worry in a sample of American college students. Furthermore, Demir, Özen, Doğan, Bilyk, & Tyrell (2011) posited that the mediating factor between friendship and happiness is that of mattering. Given the positive health outcomes related to having a positive perception of mattering, it is reasonable to utilize this construct to evaluate the outcomes associated with the Beyond the Woods program.

### **Self Esteem**

Zimmerman, Copeland, Shope, & Dielman (1997) examined the self-esteem of youth in the sixth grade through tenth grade to determine longitudinal changes through development. Adolescent females were more likely to have their self-esteem decline as they aged as compared to male peers. The largest drop in self-esteem took place from the sixth to the eighth grade. Generally, youth with higher self-esteem appeared to use alcohol less, were less influenced by peer pressure, and had better grades.

Having a health condition diagnosis can result in lower levels of self-esteem compared to peers without disabilities (Antonucci & Jackson, 1983). Similar to the Zimmerman et al. (1997) finding above, Schieman & Campbell (2001) found that age was negatively associated with self-esteem among people with disabilities such that self-esteem decreases as people with disabilities age. More specific to gender effects on self-esteem, Magill & Hurlbut (1986) assert that females



with cerebral palsy have a lower self-esteem than males with the same health condition. Furthermore, males with cerebral palsy had similar self-esteem scores to males without cerebral palsy. Female adolescents with cerebral palsy that have low sexual and body esteem are also at-risk for intimate partner abuse as they grow into adulthood due to a high desire to be in a relationship with a significant other (Hassouneh-Phillips & McNeff, 2005). Females with physical disabilities appear to be an at-risk group when it comes to self-esteem.

Assessing support interventions based on changes in self-esteem is common. Devine & Dawson (2010) documented increased self-esteem during medical residential camp participation for youth with cranial facial differences from the start of camp to the end of camp. However, self-esteem dissipated 6-8 weeks after returning to home communities. Grant (2002) found that perceptions of social support from an online chat platform improved the self-esteem scores of participants. Readdick & Schaller (2005) examined the effects of a residential camp on economically disadvantaged youth and found improvements in self-esteem from the start to end of camp for campers six to twelve years of age. Taken together, there is evidence that residential camp and online support may have the potential to impact self-esteem.

### **Theoretical Foundation**

Leary's Sociometer Theory (Leary & Baumeister, 2000; Leary, 1999) provides the theoretical foundation for this study. Sociometer theory posits that self-esteem is a sociometer reflecting the quality of relationships one has with other people. To the extent that one feels socially included and valued, self-esteem may rise. Conversely, self-esteem moves downward when one perceives there is deterioration in social inclusion and being socially valued. Rosenberg & McCulough (1981) found that mattering and self-esteem were positively

associated, which would support the basic concept of the sociometer theory of self-esteem. Dixon & Kurpius (2008) note a connection between mattering, self-esteem, stress, and depression in college students. Sociometer theory is a strong theoretical foundation for the evaluation of self-esteem and mattering in this current study.

## **Setting**

This study took place in the Midwest at a residential medical specialty camp for 80 youth with physical disabilities such as cerebral palsy, muscular dystrophy, and spina bifida. Camp Rogers is designed for participants 8-18 years old with diagnosed physical disabilities, and medical care is provided by a regional medical center. In addition, 80 college students studying in various allied health fields are employed as full-time summer staff. The staff is trained for 1-2 weeks and stay at camp for up to 10 weeks working with a variety of pediatric clients. Campers are housed in accessible cabins which are gender specific with approximately 10 campers in each cabin for the two-week duration of this residential camp. Camp programs and activities include climbing towers, equine assisted therapy, zip line, lake, boating, adapted water skiing, adapted scuba diving, archery, crafts, campfires and other traditional camp activities. The staff to camper ratio is set at 1 staff to 3 campers along with up to 5 nurses, a physician, and pharmacist staffing the health center. The camp is a therapeutic recreation program that utilizes a systematic process consisting of an assessment for each camper, plan of care including goals, camp as a social intervention, and daily and end of session evaluations completed by recreational therapy interns and cabin staff.

## Research Subjects

Youth 12-18 years of age with physical disabilities were the research subjects. Common diagnoses included cerebral palsy, spina bifida, neuromuscular diseases, mitochondrial myopathy, Pierre Robin Syndrome, double leg amputation, hemiplasia, and other physical disabilities. Campers had a history of attending this camp between 1-11 years. Consent and assent forms were created for the study and approved through the IRB at Indiana University. An overview of the research project as well as the consent and assent forms were sent in an E-mail to camp families prior to the start of camp. On the first day of camp, a research team member met with each family to further describe the study and to record consent from parents and assent from adolescents willing to participate. A total of  $n = 61$  subjects assented to participate in the research project.

A quasi-experimental design was utilized in that the treatment group had been assigned a mentor and invited to monthly online support programming following camp participation while the comparison group only attended the residential camp. The average age of the treatment group is 16.62 years old while the comparison group is 14.49. A total of 11 males and 15 females were in the treatment group with 19 females and 16 males in the comparison group. Both groups attended camp for two weeks and had physical disability diagnoses. During pre-test (at camp), the total N size was 61 with  $n = 26$  in treatment group and  $n = 35$  in the comparison group. Upon reassessment three-months post-residential camp, the total N size = 21 with 13 in the comparison group and 8 in treatment group.

## Research Instruments

The General Mattering Scale (Marcus, 1991) was used in this study due to ease of use, widespread application, and positive psychometric properties. The General Mattering Scale is the most cited mattering scale in the literature and uses a five-question approach. Each question is associated with five major components of mattering: interest, being missed, importance, attention, and dependence (France & Finney, 2009). Although there continues to be debate as to the best way to measure mattering, this instrument is viewed as one of the most widely used scales for mattering currently. It also met the needs of a short and effective instrument that could be used with youth that have disabilities. The internal reliability of the General Mattering Scale has been noted as consistent with a study on homeless men resulting in a .85 internal reliability rate (DeForge & Barclay, 1997). The Rosenberg Self Esteem Scale has been widely utilized for over fifty years for the measurement and reporting of self-esteem. It is a 10 item instrument and has strong and consistent reliability and validity commonly associated with its use (Sinclair, Blais, Gansler, Sandberg, Bistis, & LoCicero, 2010). Bagley, Bolitho, & Bertrand (1997) found similar reliability scores for the Rosenberg Self Esteem Scale in Canadian high school students with reliability in the .85-.90 range. The authors also reiterate the strong psychometric properties in both reliability and validity of this instrument.

The Rosenberg Self-esteem Scale is a ten-question instrument with up to a potential of 30 points. The internal reliability (Cronbach's alpha) for the current study with adolescents that have physical disabilities was .801. Questions three (.349) and four (.361) had the lowest internal reliability for this instrument. However, eliminating these questions would not improve reliability overall. The General Mattering Scale is a five questions instrument out of a total of 20 points. The internal reliability for this instrument with the same population was .623. Question

three (.175) had the lowest internal reliability score. Eliminating this question would improve reliability just slightly overall.

## **Research Procedures**

The General Mattering Scale (Marcus, 1991) and Rosenberg Self-esteem Scale (Rosenberg, 1962) were administered during camp (pre-test) and again three months after camp (post-test). The pre-test measures were garnered within the cabins. Participants were asked to complete both instruments independently unless support was needed. At three-months post camp, the instruments were sent to the homes of each participant with the same instructions. An envelope with pre-paid postage was included to encourage a strong response rate. In both cases, the adolescent was instructed to fill out the instruments independently and were given help only when needed. In both circumstances, paper copies were utilized to remain consistent. Once collected, the pre-test and post-test data were paired to maintain connection along with demographic variables while the names of the campers were de-identified to maintain anonymity.

A series of hypotheses were established for this study. Both self-esteem and mattering hypotheses were written separately to tease out any differences seen in the data between the two psychosocial constructs. Both within group and between group differences were captured.

**Null Hypothesis 1:** There will be no difference in self-esteem scores of the treatment group (enrolled in program) and the comparison group after 3 months (i.e., Comparison mean change = Treatment mean change)

**Alternative Hypothesis 1:** The scores of self-esteem in the treatment group (enrolled in program) will be greater than the comparison group after 3 months (i.e., Comparison mean change < Treatment mean change)

**Null Hypothesis 2:** There will be no difference between pre-test and post-test self-esteem scores of the treatment group (treatment mean pretest = treatment mean posttest)

**Alternative Hypothesis 2:** The post-test self-esteem scores of the treatment group will be greater than the pre-test scores of the treatment group (treatment mean pretest < treatment mean posttest)

**Null Hypothesis 3:** There will be no difference in mattering scores of the treatment group (enrolled in program) and the comparison group after 3 months (i.e., Comparison mean change = Treatment mean change)

**Alternative Hypothesis 3:** The mattering scores of the treatment group (enrolled in program) will be greater than the comparison group (i.e., Control mean pre-test < Treatment mean posttest)

**Null Hypothesis 4:** There will be no difference between pre-test and post-test mattering scores of the treatment group.

**Alternative Hypothesis 4:** The post-test mattering scores of the treatment group will be greater than the pre-test mattering scores of the treatment group (i.e., Treatment mean post-test > Treatment pre-test).

## **Analysis**

After running a test to confirm the data were distributed approximately normal, a parametric test was determined to be suitable for this analysis rather than a non-parametric approach. A repeated measures ANOVA was utilized comparing within groups and between groups using SPSS. Within group differences included a pre-test and post-test for both the intervention group and comparison group. Between group means were then compared for the comparison and treatment groups together.

## **Findings**

### *Descriptive Statistics*

Table 1 reports the sample size, means, standard deviation, and standard error for the comparison and treatment groups. The comparison group had a slightly larger sample while the standard deviations for both self-esteem and mattering responses were similar across groups.

Generally, the comparison group started with a higher self-esteem overall at 22.26 compared to the treatment group at 20.50.

Table 1: Baseline Scores on Self-Esteem & Mattering in Each Group

<b>Baseline Pre-Test</b>	<b>Group</b>	<b>N</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>Std. Error Mean</b>
<b>Self Esteem</b>	Comparison	35	22.26	5.71	0.97
	Intervention	26	20.50	5.10	1.00
<b>Mattering</b>	Comparison	35	16.57	2.70	0.46
	Intervention	26	15.68	2.26	0.44

This trend continued with the comparison group starting with a 16.57 average mattering score compared to the treatment group average of a 15.67. This may be attributed to the mean difference in ages between the groups. The treatment group average age was 16.62 with the comparison group at 14.49. The ratio of males to females was similar in each group.

Table 2. Gender, Age, and Mentor Demographics by Group

<b>Group Type</b>	<b>Average Age</b>	<b>Males</b>	<b>Females</b>	<b>Mentor Assigned</b>
Intervention Group	16.57	11	15	Yes
Comparison Group	15.67	16	19	No

Schieman & Campbell (2001) indicate that older pediatric clients display lower self-esteem scores than younger peers and this follows that trend. However, despite these differences, analysis indicated that the groups were statistically the same and suitable for comparison testing.

The following two figures display descriptive statistical findings for self-esteem at pre compared to post as well as mattering at pre compared to post. The mattering construct visually increases for the treatment group by nearly two points while the comparison group remains flat from pre to post. The self-esteem construct appears to decay from pre to post for both

comparison and treatment groups. The decay in self-esteem follows a similar trend in the extinguishing psychosocial effects of medical camp participation seen in other studies (Dawson, 2017; Plante et al., 2001). Descriptive statistics for gender, group identification, and age are also presented below.

Figure 1: Comparison and Intervention Groups for Mattering Pre to Post

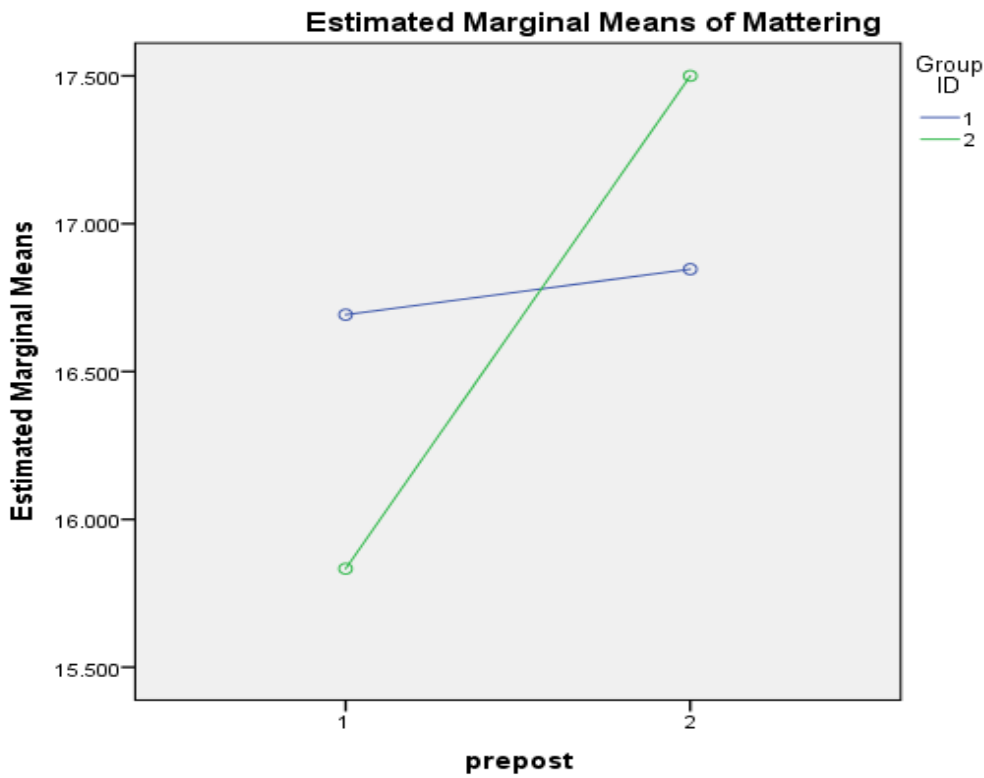
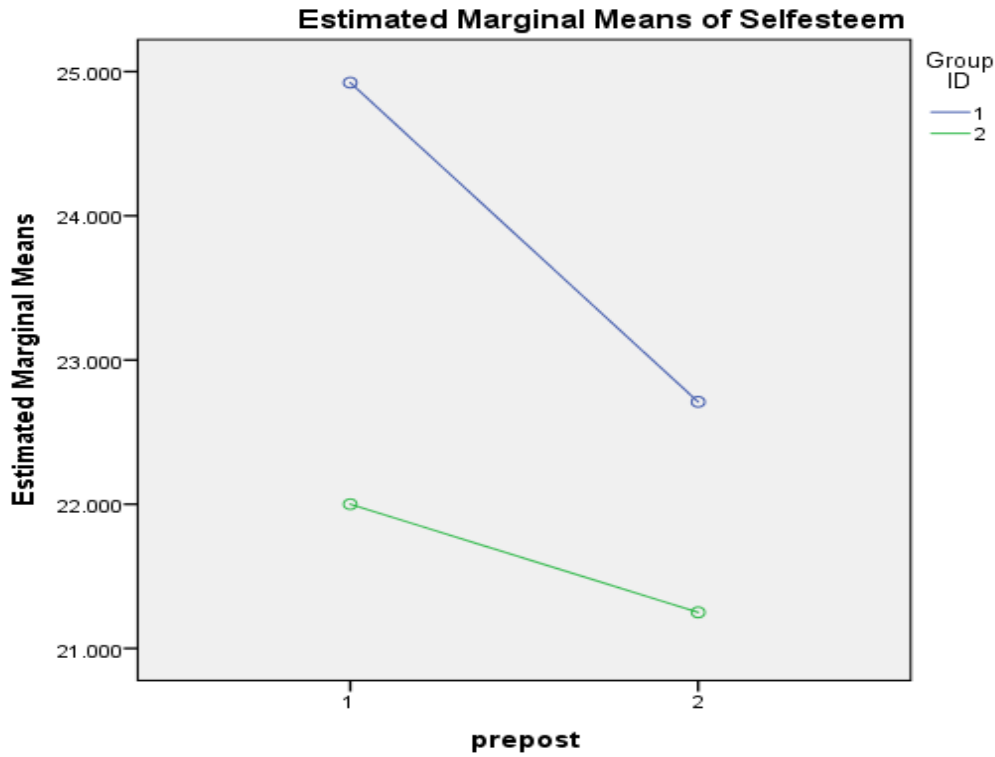




Figure 2: Comparison and Intervention Groups for Self-esteem Pre to Post



**Total Post Scores by Group ID**

Group ID		Self Esteem Post	Mattering Post
Treatment	Mean	22.71	16.85
	N	13	13
	Std. Deviation	4.31	2.07
Comparison	Mean	21.25	17.50
	N	8	8
	Std. Deviation	6.54	1.60
Total	Mean	22.15	17.10
	N	21	21
	Std. Deviation	5.16	1.90

### Total Post Scores by Gender

Gender		Self Esteem Post	Mattering Post
Female	Mean	21.22	17
	N	10	10
	Std. Deviation	4.71	1.83
Male	Mean	23	17.18
	N	11	11
	Std. Deviation	5.62	2.04
Total	Mean	22.28	17.14
	N	22	22
	Std. Deviation	5.07	1.86

### Effect Size

Partial eta squared was utilized to determine effect size of the intervention on both self-esteem and mattering. Effect size for partial eta squared is based on .02 (small effect), .13 (medium effect), and .26 (large effect). Self-esteem showed no effect within or between groups for this test. A medium effect is seen in the mattering scores from pre to post (within group) for the treatment group and a small effect in comparing between means of the comparison and treatment groups. Despite a small to moderate effect, caution should be used in interpreting these findings given that there was not a statistically significant difference at the .05 level.

### Partial Eta Squared Effect Size Calculations

Small Effect	0.02
Medium Effect	0.13
Large Effect	0.36

## Repeated Measures ANOVA

Pre-post Testing	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power <sup>a</sup>
Self Esteem (within group)	21.75	1	21.75	1.80	.20	.087	1.80	.247
Self Esteem (between group)	5.31	1	5.31	.44	.52	.023	.44	.097
Self-esteem Error pre-post	229.31	19	12.07					
Mattering (within group)	8.21	1	8.21	2.91	.10	<b>.133</b>		<b>.37</b>
Mattering (between group)	5.67	1	5.67	2.01	.17	<b>.096</b>		<b>.27</b>

a. Computed using alpha = .05

### Discussion

The first two hypotheses focused on the effects of the Beyond the Woods program on the self-esteem of campers in the program versus those not yet in the program. Based on the results of the repeated measures ANOVA, neither between group (hypothesis 1) nor within group (hypothesis 2) differences were found from pre to post-test measures. Thus, this study fails to reject null hypotheses one and two. The last two hypotheses centered on the effects of the booster intervention on mattering. There was not a statistically significant difference between groups (hypothesis 3) and within groups (hypothesis 4) for the mattering data using the repeated measures ANOVA. Therefore, this study fails to reject the null hypotheses three and four.

Using partial eta squared, a moderate effect size for mattering is seen in the data at .133 for pre to post-test within group means and a small to medium effect at pre to post between treatment and comparison groups at .096. These data suggest that the program has positively impacted the perceptions of mattering for the youth that were assigned to the mentoring program.

Furthermore, this effect is seen after the mentees had only been assigned to the program for three months.

Mattering has an alpha level approaching significance from pre- to post-test. After conducting a power analysis using G Power, it was determined that to obtain 80% power it would require a sample size of 32 subjects and to obtain 90% power it would require a sample size of 42 subjects. Although the pre-test sample was strong, the follow-up data fall below this threshold. Upon analysis of effect size, a moderate effect was seen in the within group means for mattering and a small effect between the comparison and intervention group. Furthermore, descriptive statistical analysis displays a visual difference in the mattering graph between comparison and treatment groups from pre to post test. The small sample size appears to have contributed to an under powered study and thus this result is at risk for a type two error.

In the present study, self-esteem did not appear to be impacted by the program despite seeing an effect in perceptions of mattering. Given the theoretical foundation of the sociometer theory (Leary, 1999) and further evidence of the correlation between self-esteem and mattering (Rosenberg & McCullough, 1981; Elliott, Kao, & Grant, 2004), this is a somewhat surprising finding. However, it may be that this program simply doesn't result in improved self-esteem but could impact other psychosocial constructs such as mattering. Alternatively, mattering may be a more sensitive construct as compared to self-esteem which could take longer to change. It does appear that self-esteem for both the comparison and treatment groups follow the same trend line that various other studies have indicated in that there are extinguishing effects upon return to integrated home communities. Magill & Hurlbut's (1986) finding that males with cerebral palsy had similar self-esteem to males without cerebral palsy may help provide insights here and could be influencing the findings, i.e., half the research subjects are male in this study, many have

cerebral palsy, and this may limit the need for improved self-esteem to a degree, i.e., a ceiling effect may be present in males. Arnoldo, Crump, Burris, Hunt, & Purdue, (2006) also reported difficulty in finding any improvements in the self-esteem of campers with burns from pre (start of camp) to post-test (shortly after returning home) during a medical specialty camp. Devine & Dawson (2010) also documented a decrease in self-esteem for youth with cranial facial differences upon return to home communities several months after the conclusion of camp.

### **Future implications**

The Beyond the Woods booster intervention program appears to have promise related to the mattering construct. Future work should attempt to accomplish four objectives. First, future studies need to be adequately powered. With guidance from the power analysis, it is suggested that future studies target a minimum sample size of 40-50 at both pre and post-test. Second, the program should be adapted and pilot tested for adolescents with other health conditions. It is suggested that future studies examine populations impacted by cranial facial differences, cancer, burns, and other health conditions in which medical residential camps are commonly held without follow-on booster interventions. Third, given the lack of evidence for self-esteem in this study and others, future studies should consider other constructs such as loneliness, or social acceptance that may be sensitive to this type of intervention. Fourth, future studies should capture follow-on data points at least 9-12 after subjects are enrolled in the treatment group. In this study, only three months had passed from the pre to post test.

### **Limitations**

One limitation of this study was average age differences between the comparison and treatment group may result in natural developmental differences. However, the pre-test review of the intervention and comparison group provided evidence that there wasn't a statistically

significant difference between the data sets. Furthermore, the low sample size resulted in difficulty reaching statistical significance at the .05 alpha level despite documented small and medium effects for mattering. Results should be interpreted with caution until further testing can be completed.

## **Conclusions**

Youth with physical disabilities are at risk for poor psychosocial health. Medical specialty camps are one common pediatric support intervention. However, a criticism of the camp model is related to the commonly seen extinguishing effects after campers return to integrated home communities. The Beyond the Woods program was created as a booster intervention to address these concerns through mentoring and online support outside of the summer months. The findings from this study indicate that the program may have a small to medium positive effect on the perceptions of mattering for adolescent participants but not their self-esteem. This appears to be a promising support intervention and should be developed and tested further with youth that have various health conditions, for greater lengths of time, with different psychosocial instruments, and with adequately powered studies.

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## Chapter Five

### Qualitative Analysis of a Year-long Mentoring & Online Support Program for Adolescents with Physical Disabilities Attending a Medical Camp

*The following is prepared for submission to the Journal of Youth Development*

**Specific Aim 3:** Through qualitative phenomenological interviews, establish emerging themes related to the lived experiences of both the mentor and the mentee in order to identify specific program successes, failures, and trends.

#### Abstract

The creation of evidence based booster programs are needed to address the well-documented extinguishing psychosocial effects commonly seen in pediatric medical camps post residential summer camp experience. The purpose of this study was to examine the initial effects of a year-long mentoring and online support program for adolescents with physical disabilities attending a medical specialty camp. Data were collected from 17 interviews with adolescent participants as well as 15 interviews with successful adult mentors also diagnosed with a physical disability. The 32 semi-structured interviews were conducted at the beginning of the in-residence camp program and 12-16 weeks post camp once the mentee-mentor relationship had been established. Qualitative analysis yielded two major themes of 1) mentor as a disability life coach providing psychosocial support and expanding life expectations and possibilities and 2) barriers and facilitators of a strong mentee-mentor relationship. Relationship facilitators included elements such as having a shared disability, sharing leisure interests, desire for a mentoring relationship, and in-person activities. Barriers to a strong relationship included elements such as awkward beginnings, parental protection, communication barriers due to disability, and scheduling conflicts. Future implications provide insights to help further develop mentoring and online support models specifically designed as boosters to traditional pediatric medical specialty camps.

Key Words: medical specialty camp, physical disability, booster program, mentoring

## **Introduction**

Residential pediatric medical specialty camps are known to provide short-term psychosocial benefits; however, criticism of the current program model has grown due to the extinguishing effects commonly seen upon return to integrated home communities (Dawson, 2017; Knapp, Devine, Dawson & Piatt, 2015, Plante, Lobato, & Engel, 2001). New booster approaches are needed to enhance the existing residential medical specialty camp model to improve long term psychosocial outcomes associated with the other 51 weeks of the year. The current study was a qualitative study of a booster program created specifically to address these concerns. The Beyond the Woods program was developed to provide adolescent campers with a disability with an adult mentor having the same or similar disability for one-year directly after participating in a traditional residential camp experience. This program also included a monthly online support curriculum provided by full time camp staff for both mentors and mentees to attend virtually together. A qualitative phenomenological approach was used to determine the lived experiences of mentees and mentors associated with this program.

Pediatric medical specialty camps are known to provide rare and important opportunities for social comparison with other youth with similar health conditions (Dawson, Knapp, & Farmer, 2012). Pediatric specialty camps have demonstrated positive outcomes for a variety of health conditions including campers with hearing impairments (Devine, Piatt, & Dawson, 2015), cancer (Meltzer & Rourke, 2005), cranial facial differences (Devine & Dawson, 2010), participants with diabetes (Hill, Gagnon, Ramsing, Goff, Kennedy, & hooker, 2015), and end stage renal disease (Warady, 1994). In addition to social comparisons, camps may serve youth with health conditions by providing opportunities for community capacity building, social acceptance, self-esteem, and building social capital (Dawson & Liddicoat, 2009; Devine &

Dawson, 2010; Devine, Piatt, & Dawson, 2015; Mohen, Groenwegen, Volker, & Flap, 2011).

Taken together, medical specialty camps are a unique support intervention in that they may provide a social inoculation experience that can elicit powerful and immediate perceptions of psychosocial support and connection (Evans & Getz, 2003; Pilisuk, 1982). At the same time, psychosocial gains are often short lived and thus limit the effect of specialty camp programs as they decay over time (Plante, Lobato, & Engel, 2001).

Dawson (2017) has argued that a social inoculation experience takes place during residential camps along with a corresponding extinguishing effect upon return to integrated home communities. Knapp, Devine, Dawson & Piatt (2015) documented a strong negative tone in a qualitative study with campers that have physical disabilities in interviews six months after camp. Campers reflected on their camp experience in positive terms yet lamented the lack of similar resources in their integrated home communities. Plante, Lobato, and Engel (2001) provided an overview of a variety of pediatric interventions noting camp as one of five major approaches. However, they go on to critique the camp model as providing only short lived outcomes, thus limiting the widespread applicability of this approach until improvements can be made. This may be associated with the theoretical perspectives presented by Evans and Getz (2003) as well as Pilisuk (1982) related to social inoculation in health perspectives. This phenomenon is associated with creating socially conducive environments rich with positive social connections and support. However, it is common to see an extinguishing effect once clients are taken out of such supportive settings upon return to integrated and stressful everyday environments (Feindler & Fremouw, 1989). Clearly, benefits are seen in the current camp model yet progress is needed to further develop and build on the efficacy of this long standing and well established approach nationally.

## **Booster Intervention Pilot Program**

A booster intervention program was pilot tested and is in the fourth year of development as a year-long mentoring and on-line support program that targets the fall, winter, and spring seasons outside of a two-week residential summer camp experience. Beyond the Woods serves as a follow-on program for Camp Rogers, a two-week residential camp specifically designed for adolescents with physical disabilities. Beyond the Woods was created as a booster intervention to address the remaining 50 weeks of the year outside of the traditional two-week residential experience (Camp Rogers) that has been in existence for several decades. During Camp Rogers, adolescent participants have an opportunity to meet the mentor that is assigned to them for the year following the residential camp experience as part of an afternoon mentor – camper engagement event. Mentors are initially recruited through local non-profits such as adapted sport clinics, camps for adults with disabilities, alumni from Camp Rogers, and by word of mouth. Mentors have the same or similar disability as their camper and have shown tangible success in vocational, collegiate, or adapted sport pursuits as adults. Monthly online support is also provided through a curriculum that was designed to address issues adolescents with physical disabilities experience such as coping with stigma, developing friendships with peers without disabilities, discussing common medical procedures, driving a vehicle with hand controls, going to college or starting vocational pursuits, and taking part in adapted sports and recreation activities. A certified recreational therapist employed by Camp Rogers conducts these 1 hour monthly online sessions in which all mentees and mentors are invited to attend through an on-line conferencing platform. Mentors are encouraged to reach out directly to their mentee at least 1-2 additional times per month via text, phone, e-mail, or social media. The intent of this program is to provide year-round social support and upward positive social comparisons with

similar others not readily available to the adolescents with physical disabilities in their home communities.

The booster pilot program was created to specifically target the extinguishing effects highlighted in Dawson (2017), Knapp, et al., (2015), and Plante, et al., (2001).

Recommendations from Dawson, McCormick, & Li (2018) were considered in creating the program specifically for adolescents rather than children due to the statistically significant finding that adolescents with physical disabilities desire non-family oriented social network contacts more than younger participants. Raghavendra, Newman, Grace, & Wood (2013) highlighted an online intervention that was successful for youth with physical disabilities, thus giving promise that an online component could have similar outcomes in this program.

## **Research Procedures**

### *Setting and Clients*

Twenty adolescents and fifteen mentors participated in this program. Recruited mentors and mentees had diagnoses that include cerebral palsy, spina bifida, spinal muscular atrophy, and other neuromuscular conditions. A near equal split of male to female genders for both mentors and mentees were present. Mentees were 14-18 years of age while mentors were between 20-35 years of age.

### *Site Description*

Camp Rogers residential camp and the Beyond the Woods year-round mentoring program is administered at a 2,400 acre fully accessible outdoor center. Youth participated in a thirteen-day residential program (Camp Rogers) that included opportunities to take part in adapted scuba diving, adapted water skiing, accessible high and low ropes courses, equine activities, adapted sports, swimming, canoeing, arts and crafts, and other traditional camp activities. The camp is associated with a large regional pediatric hospital in the Midwest that

provides medical support of at least one physician and 3-5 nurses per week. The camp is staffed by approximately 80 full time summer counselors attending college to gain a degree in an allied health field as well as a three full time nationally certified recreational therapists employed as the summer camp director and assistant directors of Camp Rogers. The supervision ratio is one staff to three campers with physical disabilities.

### *Recruitment*

The study protocol was reviewed and approved by the Indiana University Institutional Review Board. An initial e-mail with consent and assent forms, as well as a description of the study, were sent out to mentors and camp families in the months prior to the residential camp program. On the first day of camp, a research team member met with each family personally to provide an additional overview of the study and to record campers providing consent and assent to participate in the study. Mentors received a separate and unique e-mail with an attached consent form electronically as well as a description of the study. A member of the research team was available for any questions or concerns over the phone. Mentors e-mailed completed consent forms back to the research team member gaining consent. Of the 20 adolescents solicited for participation, 19 provided assent along with consent from parents. A total of 8 mentors consented to participation from the 15 solicited.

## **Data Analysis**

### *Qualitative Phenomenology*

A qualitative phenomenological approach (Yin, 2016) was implemented with mentees and mentors. Semi-structured interviews were utilized to capture the meaning and experience specifically associated with the mentoring program. A set of questions was developed for interviews that took place over the course of several days in the middle of the camp experience as well as a second set of interview questions that were used 12-16 weeks post residential camp

experience giving the relationship time to form. This approach was utilized to elicit feelings, emotions, insights, and experiences associated with the mentoring program from both perspectives, i.e., anticipation of the program and the actual experience. Purposive sampling (Yin, 2016) was utilized due to the unique nature of the program for both mentees and mentors. Question content focused on history of the relationship, any role social comparisons played related to disability, the dynamics of the mentor and mentee relationship, and the overall negative or positive perceptions related to the design of the program. Interviews were digitally recorded with permission from participants and then transcribed verbatim (Pope, Ziebland, & Mays, 2000). Transcriptions were then uploaded to ATLAS.ti., a common software package for the analysis of qualitative data (Hwang, 2008). Level one codes were constructed followed by movement towards more advanced level two codes by broader categories. This process was repeated and refined until the least amount of level 2 category codes were present. Lastly, the data were organized into two over-arching themes supported by multiple rich contextual sub-categories. This nested arrangement is common in qualitative findings (Yin, 2016). The entire process from start to finish can be conceptualized in what Yin (2016) calls the five phase cycle of 1.) compiling, 2.) disassembling, 3.) reassembling, 4.) interpreting, and 5.) concluding.

### *Trustworthiness*

Establishing trustworthiness is an important characteristic needed in strong qualitative based studies (Yin, 2016). A member check was performed by sending the emerging themes to a mentor with a physical disability that has been involved in the program for a number of years. Additionally, the first author transcribed and coded the data. After doing so, meetings were established once per week for 15-weeks with the second author. Codes were discussed and edited along with emerging themes until 100% agreement was established throughout this three-month

process. Additionally, memos were created from start to finish as a living record of the evolutionary process in establishing the final two emerging themes and supporting rich sub-categories. Triangulation was established between the member checks, 100% agreement on themes, and a final subsequent review by the other three authors prior to submission for publication. Quote counts were also recorded for mentees and mentors associated with each of the two major themes and can be seen in Table 1 below. Finally, this qualitative study can also be conceptualized within the systematic study and timeline of foundational studies within this same outdoor center with the same or similar populations (Dawson & Liddicoat, 2009; Dawson, McCormick, and Li, in press; Knapp, Dawson, Devine, Piatt, & Knackmuhs, in press; Knapp, Devine, Dawson, & Piatt, 2015).

Table 1. Quote Counts for Mentee and Mentors Associated with Themes 1 & 2

<b>Research Subjects</b>	<b>Theme 1 Quotes</b>	<b>Theme 2 Quotes</b>	<b>Total Quotes</b>
Mentor 1	0	27	27
Mentor 2	0	19	19
Mentor 3	10	25	35
Mentor 4	14	16	30
Mentor 5	5	18	23
Mentor 6	4	10	14
Mentor 7	0	2	2
Mentor 8	4	13	17
Mentee 1	0	10	10
Mentee 2	1	16	17
Mentee 3	2	8	10
Mentee 4	0	6	6
Mentee 5	4	12	16
Mentee 6	11	15	26
Mentee 7	1	4	5
Mentee 8	1	0	1
Mentee 9	1	4	5
Mentee 10	2	8	10
Mentee 11	2	5	7



## Findings

### Themes

Two major over-arching themes were generated with a variety of rich and nuanced sub-categories within these themes. The first major theme is 1.) Mentor as Disability Life Coach followed by 2.) Dynamics of the Mentee-Mentor Relationship. Figure 1. depicts the two major themes along with the various corresponding sub-themes within a nested qualitative model.

#### Disability Life Coach (Theme #1)

- **Expanding Life Possibilities & Expectations**

- *Examples: Driving, college, dating, overcoming discrimination, high school, friends, cooking and grocery shopping, etc.*

- **Psychosocial Support Person**

- *Examples: Building confidence, listening ear, dealing with anxiety and depression, emotional outlet*

#### Barriers and Facilitators to Mentee-Mentor Relationship (Theme #2)

- **Facilitators to Relationship Success**

- *Sub-categories: Having the same disability, sharing leisure interest, desire to be mentored by someone older, in-person activities, motivation for becoming a mentor, and the on-line support program.*

- **Barriers to Relationship Success**

- *Sub-categories: Awkward beginnings, parents, communication barriers due to disability, scheduling conflicts, and geographic location.*

### Theme One: Disability Life Coach

Discussions centered on the mentor acting as a type of disability life coach. Mentors described several rich conversations initiated by the camper to gain advice on specific life situations and activities that involve navigating the world successfully with a physical disability. This appeared to open up new possibilities and life expectations for the youth. Examples included learning to drive, going to college, accessibility in a large city, cooking, getting married, dating, shopping for groceries, and getting a job. Another sub-component is that of the disability life coach providing psychosocial support to the mentee. Mentors and mentee both

talked about the ability of the mentors to help mentees when they are feeling high levels of stress, anxiety, depression, or just being in a ‘funk.’ Stressors mentioned relate to school, friends, going to college, bullying, family issues, and problems in general associated with having a physical disability. The mentor appears to provide a safe and non-judgmental outlet to share emotions and talk through situations with someone that truly understands this unique experience.

### *Expanding Life Possibilities & Expectations*

The mentors expressed their desire to expand the future expectations and life possibilities for the mentees as evidenced by several quotes:

- Mentor 1: “Make those impacts maybe with a kid that has a similar disability and let them know that they can be successful. I’ve held a full time job, I’ve owned a house at one point, I just got married three weeks ago. Anything that an able bodied person can do in life a disabled person can do in life. Just figure out how to do it. That was just why I was really excited to be part of this mentorship and make a positive impact on this kid’s life.”
- Mentor 2: “I would try to get her to do goals. So your goals could be as simple as doing your own laundry to live on your own. But okay, if you want to live on your own what are the things you have to know how to do first? So I kind of made a list with her and E-mail back and forth or Facetime. Okay, if you want to live on your own, you have to grocery shop. You don’t have to cook excellent but enough to have enough food to live. You have to get to places because you don’t drive yet.” Mentor
- Mentor 4: “Drive - I even showed Ralph’s parents my hand controls because they were even nervous to do an evaluation to see if he could drive. Having that example and making it more tangible for them. In theory someone could drive with their hands but they are seeing me with those hand controls.” Mentor 4 went on to say, “Life themes in general but how do you navigate those with a disability. Like for example, he is going to New York City in just a couple of weeks with his choir and he, um, I went there in December. My brother lives in Manhattan so he was asking me about how to get around and is the subway wheelchair accessible. Yeah, so a lot of questions about living as an adult with a disability.”
- Mentor 3: “...there is someone that has been through that and I have survived and they are going to make it and they are going to make it through whatever they are going through. If they just need someone to talk to for encouragement or to say hey what did you do in this similar situation. I can give them some feedback so they don’t feel alone.

Another psychosocial support that mentors appear to provide is through helping mentees reframe problems that they perceive to be related to their disability.

- Mentee 2: “I like the mentor program because you can see that these are adults with disabilities like you. You can see what they do, what they have done with their own life that you thought may not have been possible. You may have thought, oh, I didn’t know that. Like you can do it. That is definitely a big positive. I like hearing the stories. I realized that now that I’m getting older that I probably should think about my future. Start thinking about my future and I thought a mentor would really help me with that.”
- Mentee 5: “So they could shape me into being a better person. I already know what I want to be when I grow up, maybe they can help me. I want to be a sports broadcaster.”

The disability life coach theme not only highlights the mentors’ role in expanding life possibilities and expectations, it also centered around the psychosocial support needed to work through the stress and stigma related to living life with a physical disability. The unique connection through a shared diagnosis seemed to facilitate this exchange of emotions:

*Psychosocial Support Person*

Mentors expressed both empathy in going through similar circumstances as well as need to help coach mentees through stressful situations related to dealing with reactions from others:

Mentor 3: “I said - was someone teasing you? And she said, ‘yes, but it is true.’ Yes, they teased you but it is not true. You speak just fine. They are making fun of her because she is in a chair sometimes on bad days. She says, ‘on bad days I’m in the chair and that is when it is really bad because they make fun of everything that I do.’”

Mentor 4 also reported an experience in which their camper was finding difficulties participating in his school choir:

- He [mentee] was in choir concert and he was working on formation sitting at one of the pianos. From where he was sitting, he couldn’t see the teacher who was conducting. He mentioned this to her in passing and she didn’t give him a good response and he was really worried that he wouldn’t be able to perform because it is kind of hard to sing when you can’t see the conductor! We ended up talking about what he could do and maybe he could approach his teacher again. Maybe she would be more responsive the next time. She ended up approaching him later and kind of apologized and worked it out and she has become a good ally.
- Mentor 1: “Well, like I said, just to help them through whatever thing they might be going through at the time. Whether it is trying to make friends at school, maybe trying out for drama, maybe an extra-curricular activity and they are not sure if they should get involved or not.”

The mentee's expressed the common emotions that may come up in daily life including overcoming sadness, being in a funk, and getting through tough times:

- Mentee 10: "I get in a sad state of mind and it makes me feel better [to speak to the mentor] and I need to let it out and I can't just let it out to anyone, it has to be to someone that understands."
- Mentee 1: "Like a mentor would help me through tough times and like talk to me, if I was in a funk, she could help me out of the funk. Be there when I need somebody... mostly just like school and stuff because she has been through the same thing with school. She like really calms me down and makes me feel better."
- Mentee 11: "I feel like here, no one will judge you no matter what you say. It just makes you feel more comfortable about your disability." Mentee 11 went on to state, "I hold stuff back and I just need to talk to someone that I trust to talk my problems out."

## **Theme Two: Barriers & Facilitators to the Mentee-Mentor Relationship**

### *Facilitator 1: Homophily Rich Relationship*

From the perspective of the mentors and mentees, the discussion often centered on the unique perspective the mentor had in relation to the mentee due to a shared disability or other traits. Homophily is known to be the phenomenon in which shared traits such as gender, leisure interest, religion, disability, or other demographics tend to result in relationship formation (McPherson, Smith-Lovin, & Cook, 2001). Or as McPherson et al. (2001) put it, "Birds of a feather flock together." In the case of this study, homophily was discussed a great deal due to sharing the same medical diagnosis. Beyond the diagnosis, having the same gender, a similar but not same disability, and common leisure interest were all discussed as being important to the success of the relationship.

### *Homophily Rich Relationship Due to Shared Disability*

Mentors provided rich and descriptive examples of their perceived benefits of sharing in the same disability experience:

- Mentor 3: “I mean it is nice to have that, I think it is nice to have that similarity because they may have situations they need help with like the college situation. You kinda went through with the similar disability. May not be, well there are similar road blocks. You can figure out what the best way to advise, the best way you can with the issue. I feel like that is the advantage with having someone that has been through it. Not necessarily in the same way but somewhat understands the situation that you are going through.”
- Mentor 4: “So it would start with my mentee but I believe it started during scuba training. There were three campers, two campers with CP and me. We were sitting in a little instruction room and the scuba instructor was showing us some things. She took the oxygen tank and twisted it and it made a loud hissing noise. And all three of us jumped and the instructor looked at us like ‘good morning!’ We just all looked at ourselves and where like, ‘it is not that we are sleepy it is just that we all have CP’. So we started using *palsy prob* all of the time.”
- Mentor 4: “I think it does help. I know that matching mentors and mentees that we don’t always match them by disability. It is just by virtue of who we have and what might be a good match personality wise or interest wise. But I think in general it does help because there are little details that you can relate to. Like driving... driving with your hands... or having CP and going to school. I think it definitely helps.”
- Mentor 1: “...now that I think about it, I would have loved to have this program when I was a camper. To have someone that has gone through it. To help me understand what was coming just to... really someone that really could understand where I’m coming from. That would have been nice to have someone to lean back on that someone else wouldn’t really understand because they hadn’t been through it. They wouldn’t really understand my shoes if you know what I’m saying? It would be nice to have that commonality that someone would understand what is going on and what issues that you are having.”
- Mentor 2: “Yeah, because just having those similarities. I know it helped with me when I was a camper to have a mentor that maybe I was having a problem medically and I didn’t know who to go to about solving that problem and I was able to go to her and ask her if she had this problem and how I would go about fixing it. Just having a mentor with a disability opened that channel.”
- Mentor 4: “I remember that theater (camp program) was one of the first things that I did when I volunteered with camp. I remember at lunch we were sitting around and all of the sudden the conversation turned to, “how many surgeries have you had?” and I was like oh, this is why this camp is different. Not something you would normally bring up with your friends at school. Here, everyone had a story to share and was comfortable sharing it.”
- Mentor 5: “Basically just what I said about medical similarities. With someone that doesn’t have those problems or knowledge, specifically for me, it is harder to bring up those types of things. To be able to share, that means the world. To have that with my mentee. Just being able to share that knowledge with someone and to have someone to share it with and the wisdom I’ve gained with living the life I’ve lived. I’m excited and proud to pass that on.”
- Mentor 3: “But having the same disability...I’m like I don’t see you as a pity girl. If that is what you are worried about, that is not how I see you. I thought she (mentee) was going to cry and I was like, oh crap what did I say. But she was like... ‘no one has ever

been able to read me that well, ever. And nobody has been able to nail me to the cross as quickly as that and I'm not used to that.' I am like, well you are talking to someone with a lifelong disability."

The mentees expressed a strong desire to hear from others that have shared disability specific experiences and see it as a benefit when it takes place. It is also rare as most of their friends do not have disabilities and may not understand:

- Mentee 1: "Um she has been really great because she was told she wouldn't amount to anything or graduate and I've going through the same exact thing as she has gone through so she has helped me to get out of that funk."
- Mentee 3: "A yeah, sometimes it is nice to just have someone to talk to. I feel like especially if it is like a mentor, it is just helpful that they understand your disability and some of the things that you struggle with."
- Mentee 4: "Having a disability kinda provides more like bonding experiences and things to talk about. Like know about their life, backgrounds, and their struggles. Kinda share experiences and bond more instead of a person that doesn't have a disability and doesn't understand. It is two different perspectives."
- Mentee 1: "Most looking forward to having someone that understands my situation and understands what I am going through during phases of my life."
- Mentee: 8 "I think it will be pretty cool because we have the same, almost like we can relate to each other and give each other tips on how to go past it...obstacles in life we can beat and get over and find our own ways to do it."
- Mentee 10: "I think it is good to have someone that understands you in ways that other people don't. It is kind of hard when people don't understand your life because of your disability. It would make me feel better to have someone."
- Mentee 4: "Overall, most of my friends don't have a disability but some do."
- Mentee 2: "I said this a couple times before. You have friends at school, you have that relationship... but they don't really have a disability and know what you are going through. When you are here, I'm not going to lie, it is different. You have that connection."

#### *Mentors and Mentees See Disability Sameness on a Continuum:*

Mentors expressed clear understanding of differences that may take place when a disability diagnosis is both similar or different between the mentor and mentee. This may even take place when both have a physical disability but different diagnoses such as cerebral palsy and spina bifida. However, mentors are able to work through small differences to find commonalities:

- Mentor 5: “Um, I don’t think me and my camper has the same disability. I think she has CP and not spina bifida.” Mentor 5 went on to discuss connecting over other shared health condition specific information: “When we met, we were swapping stories about how many surgeries you have had and how long where you in the hospital. Any disability really, as long as it is a physical disability we can find those common experiences of using mobility devices, being stared at in school. It adds an element beyond a mentoring program.”
- Mentor 3: “I have CP and (mentee 1) had CP. That was fine, that was perfect. It doesn’t bother me and I have made that clear. Any disability is fine with me. Sally also had auditory processing disorder and because I was a counselor I have dealt with that too. Jane has spina bifida, Sarah has CP due to a stroke. It is similar but different. That is how life is, you get thrown into a group with people that are different. I don’t see a problem with that either and I think it is a good idea to do.”

Mentees expressed differences that they notice in others diagnosed with a different disability including both friends or mentors. Some see this as a barrier and others have success with it:

- Mentee 3: “...I have one friend that has Down syndrome and we are kind of friends but she is being like...I think she is kind of being pushy. I met my friends from the pre-school and I’ve been blown off and she is taking my friends. I do basketball with her as well. She is like touching them and I’m like oh my gosh, like she is like a little two-year old.”
- Mentee 3: “Not really...there is school but some kids at school having learning disabilities... but I don’t think that... not like physical disabilities like here.”
- Mentee 4: “I actually interact a lot with one of my best friends because he is slow in the brain and he comes over every weekend. Me and him are really close because we have a disability together and he watches my back and I watch his.”
- Mentor 6: “I had two different mentors. One of them I know had a disability. The other I don’t know if she did.” Interviewer: “Was there a difference.” Mentee: “Big difference! One was a former counselor, Josh– he had a different disability then I had. The second mentor, I can’t remember. I don’t think she had a disability but that sounds impossible to be in this program and not have a disability.”

*Leisure based homophily is helpful:*

Although sharing in a disability experience may connect mentors and mentees, shared leisure interests appears to be another. Mentors expressed the pros and cons of sharing in similar interests between peers and in the mentor – mentee relationship:

- Mentor 7: “Although me and my mentee have the same disability, we have none of the same interests, so I am curious on how this is going to go.”

- Mentor 1: “Because I was involved in a lot of extra- curricular activities when I was in school and tried to participate in much as I could. That is how you make friends. This can be difficult for someone with a disability. Ultimately that is how you make friends.”
- Mentor 4: “Um... well the camper that I’m matched with now, I have a common interest with theater. So he is in choir and musicals so a lot of the conversations have been around that.”
- Mentee 7: “...someone like me with similar interests and background.”
- Mentor 5: “I’ve been around people with disabilities and programs with disabilities. We all feed off of each other. It helps lift each other when you are told you can’t do this or can’t do that.”

In addition to discussing the impact of homophily, the mentors and mentees gave many examples of the various facilitators that help build a positive mentoring relationship:

*Facilitator 2: Mentor as Older Support Person*

Both the mentors and mentees saw value in having an older mentor that could provide advice to the adolescent:

*Desire for Mentorship by Someone Older*

- Mentor 1: “You can look up to and share from the mentor perspective in terms of, yes I’ve kind of struggled through this and I can share where I’m at now how I successfully go through this.”
- Mentor 4: “I would have loved that (mentor with a disability) I think. I think as a kid I naturally gravitated towards people that are older than me. I have a lot of friends my own age now. It was probably from having a brother and looking up to him and spending time with his friends. Even now, I’m trying to look for older adults with disabilities to see how they paved their way in their lives...”

Mentees expressed a lack of older adults with disabilities to look up to:

- Mentee 3: “I didn’t have like friends like older than me so it was kind of interesting to hear their experiences and what they have been through. Kind of like she was that older (interviewer – ‘wisdom’) – yeah, I guess, there is something about that.” Mentee 3 went on to clarify: “Especially since they are like someone that is older than you I feel like it is a person that you can look up to a bit.”
- Mentee 10: “I think it is cool because you have someone to talk to and look up to so I think that is cool.”

In addition to having someone that is older, meeting in person was seen as valuable to building the relationship. Mentors and mentees shared examples where this was helpful both in meeting at



camp for an activity during summer or having the opportunity to find time to come back for a weekend event:

*Facilitator 3: In Person Activities are Essential*

Mentors shared the value of meeting their mentee at the actual summer camp through volunteering or a mentor specific day designed to help the mentor and mentee bond at the start of the program:

- Mentor 3: “I love the meeting at the beach. Instead of making us a big deal to them. It flipped. Where as in past years it was like we were all of sudden the big man on campus so to speak. I don’t like that because I don’t like being in the spotlight. It is a mentee mentor program and I say it like that on purpose. I like being able to meet in their environment and their activity. I’ve been there but it takes the focus off of us. What is it to be a mentor, some kids may not now. It takes the focus off of us as being the mentor.”
- Mentor 4: “I think for us it helps that we knew each other prior to being matched. We had met at camp when I was volunteering at Bradford Woods doing some theater activities with the kids. So we knew each other and had that common interest so that was part of why I have pushed for more face to face events. I would like to keep those as a priority and see how we can foster those relationships. Especially at the start of the program.”

Mentees expressed value in meeting in person in addition to online. They highlight the value in creating opportunities to get to know one another during the residential summer camp and in retreat style weekends in the off season:

- Mentee 8: “I mean, like yeah, I’m friends with some on social media and all of that so like, I’ll see what they...the other campers are up to and stuff and know what they are doing and what not. But for ours, some of the, you can, like, communicate through Facebook but I mean, to be honest, I haven’t really done that. I mean I did that like once but it is... it is not difficult, it is like I feel like with this (mentor program), getting everyone together is like better than like talking to just one person. Like it is just better like camp (in person) or went out and did things outside of camp, I don’t know. Like last year or didn’t we have that thing that was in the fall (bowling event), yeah, it was really cool and all of the mentors came and some of the campers came. That was a really cool opportunity to see people outside of camp. Fun – just to see what people are up to.”
- Mentee 3: “Anything you can do to like get any activity that gets the mentors together and um in person especially. Online is good but in person is also another piece.
- Mentee 2: “I would say we could do more weekends. Retreats. Couple of those (weekend overnights).”

- Mentee 9: “I think it is really cool that she was my camp counselor before she was my mentor.”

#### *Facilitator 4: Motivation for Becoming a Mentor*

Mentors expressed a strong motivation to be part of the mentor program when asked about their decision to become a mentor. This motivation, due in part through either having a mentor or not having a mentor as a child, helped to encourage them to become a mentor themselves:

- Mentor 1: “Which was the situation that I was in as a kid because I didn’t really have anyone with my exact situation that I was in to talk to or bounce ideas off of. I think it is a great program and I wish I had something like this when I was a kid.”
- Mentor 4: “I think... partially because I didn’t have one! I think I just thought it was a way to give back.” Mentor 4 then provided an example from childhood: “I remember as a kid that I would meet people with disabilities occasionally but it was few and far between... the only people I remember I met a couple of people through sport programs through (local adapted sport clinic). Never anyone that we kept in touch with consistently. At there, I remember going to an adapted rock climbing clinic and we met a woman the age that I am probably now. I remember seeing her put her chair in her car and driving off. I remember my mom mentioning that. There was never anyone that stayed in touch. A lot of people supporting me but no one with a disability.”
- Mentor 5: “I had a few mentors from (camp) before this program was started so I know how important that is.”

#### *Facilitator 5: Online Support Program*

A newly created online monthly support program was added to the mentoring program. Mentors and mentees are encouraged to attend as one large group on a monthly basis. Monthly topics in the curriculum focus on overcoming barriers to physical disability and to provide support. Mentors and mentees had an opportunity to voice their opinion about the online program:

- Mentor 8: “Having more structured role will make it easy for me as a mentor get to know my two mentees.”
- Mentor 5: “This year I really liked, or have liked the Zoom chats. I haven’t been able to participate every time but the ones I have, I really have enjoyed them. To see everyone on them. To be able to participate and talk it is almost like you are all in the same room together. Cause, like my favorite part is when I can jump to different people. My app has three different screens so I can see each person’s screen or I can see the screen of the

individual talking so it is really cool. Just the subjects (recreational therapist) has picked I've really enjoyed them. "

- Mentor 7: "I like it. In the beginning it was kind of hard but once we got use to using Zoom and the computer it was fine."
- Mentee 4: "I like the concept of like the structure of it. Before the online meetings, it was kind of like you did everything on your own. I mean you can still do stuff outside of the Zoom meetings but every month you meet online so it is more structured and (recreational therapist) has stuff like she goes through and asks. It is definitely a good thing – keep it."
- Mentee 7: "The only time we talk is during the monthly chats (online)."
- Mentee 1: "I think Zoom is really cool but I haven't been getting the e-mails. I just created a Zoom account because like I didn't know how to like do it. I just created when you e-mailed my dad. I haven't been going to the meetings but I think they are really cool. Each topic is specific to what is going on with our year."
- Mentee 3: "...that is why I am looking forward to the online mentor program because I think it will be more structured. Every month you like hop on and just talk and I think it will be more structured."
- Mentee 2: "Looking forward to the online session. Think it will be kind of cool to like to interact with cabin mates and talk about these things other than at camp. Keep the online chat!"

Although many facilitators were shared, several barriers were also identified by both mentors and mentees. These consisted of communication challenges due to physical disability, parents, busy schedules, awkward beginnings, parents, and geographic location. The following highlights these specific areas:

### **Barriers to the Mentee – Mentor Relationship**

Both the mentors and mentees expressed that the beginning of the relationship can be awkward.

#### *Barrier 1: Awkward Beginnings*

- Mentor 8: "I think it was kinda tough towards the beginning of the program. I was the first in the program so it was kind of raw and difficult to best figure out the relationship."
- Mentor 7: "It was frustrating for me because she wouldn't open up to me but she finally did. I don't know if she was shy to talk to me since I was new or what." "They don't get really too deep or too involved but there have been a couple of questions that she has asked me that are camp related to volunteering here or being a counselor here."
- Mentor 3: "This is from a girl that wouldn't talk to me at first. I keep saying it is early, if it takes six months or a year I don't care."
- Mentor 4: "And I think it took a little while to get the ball rolling with both of them but once I started reaching out... (laughter) it is really since then with the camper I have now... it is setting boundaries. Like you can't call me every day!"

- Mentor 3: “I would try to contact her (at the start of the program) but I don’t ever get a response. I don’t know if something is off with the contact information or what.”
- Mentor 7: “It is kind of hard for me because I’m kind of a quite person. I was kind of excited when I first started with it but when then I realized the camper was not communicating back to me – it was frustrating.”

Similarly, mentees expressed difficulty at the start of the programming in connecting openly with their mentors:

- Mentee 3: “I mean um, we like, ok, so we like, we like, we like, have communicated a little bit, um via text. Like we talk occasionally. But the only time we really talk... we message back and forth.”
- Mentee 6: “Well, I though the idea was interesting. Right now, it seems like we never got past the hello for some reason.”
- Mentee 7 commenting on mentor as support person: “I don’t know. I think it would probably be if we could get to a certain point. But once per month... it hasn’t developed into...so I can’t accurately say that. Mentee 7 went on to say: “Kind of hesitant to talk to other people. Cause it is like new people but you don’t necessarily know everything.”

### *Barrier 2: Parent Expectations and Communication*

The dynamic of having parents involved seemed to be a barrier at times. This was described by both the mentor and mentee. Both expressed support from parents but at times, a lack of understanding:

- Mentor 3: “She told me her parents would be like Fort Knox and she was not kidding. I can’t get through. We did do some texting back and forth.” Mentor 3 went on to explain a conversation with the mentee about this issue: “Would it be helpful to have the program coordinator call your mom and let her know I’m out to help you and not hurt you. She very quickly nixed that idea and said, ‘oh no, mom doesn’t have any more questions. She is fine I have to go – bye!’ It was like that quick and there is a problem there and I haven’t even identified it yet.”
- Mentor 4: “He is very interested in getting his license but his parents are concerned a little bit, which is understandable.”

For mentees, the parents are supportive and should be involved, but may not always fully understand or could cause communication breakdowns with information sharing:

- Mentee 2 explaining why he couldn’t get connect online: “Send it to me, e-mail me personally instead of my mom. She can but I just don’t want to have to go through her. Send it directly into my e-mail.”
- Mentee 1: “My family understands what I’m going through but they don’t get it most of the time. I feel like a mentor would understand.” Mentor went on to explain: “I got like

numbers from everyone (peer campers) last year and then my mom threw it away by accident.”

### *Barrier 3: Communication Difficulty Due to Disability*

Mentors expressed the difficulties that arise in the program due to the impact of physical disability:

- Mentor 8: “Some of the campers are verbal and some are nonverbal and it is hard to contact them. You have to figure out another way to get in contact with them. If you use E-mail, the response rate is not that great.” Mentor 8 went on to clarify further: “...but with Bill he is non-verbal so it was harder. With John, we talked a lot about preparing for college and I was glad to help him out with a bit. Issues at home, I tried to help him out with those as well. Those were the two things that we talked the most about. Just to see how things were going and figure out what advice he would need to get through them.”
- Mentor 3 regarding the online program: “I have seen it where, Jane wanted to talk but Jane couldn’t talk because she was in bed. I did one in bed because of my legs and I was like sorry guys. If you can get past that and the campers can get past that because I am an adult. I don’t know if Jane can get through that and will do it again because I think she thought everyone was staring at her. (Recreational Therapist) tried to tell everyone they can shut off their video. You can see it all over... I just felt bad for her.

### *Barrier 4: Scheduling Conflicts*

Busy schedules, conflicting times of availability, and general life activities seem to get in the way of the relationship according to mentors and mentees:

- Mentor 8: “Um, I mean, it was definitely a struggle. It was hard to figure out the best time to contact the camper. I mean, sometimes John will contact me about issues that he was having. But you want to be there for them and be there as an asset for them. Trying to figure out how to stay in constant contact and also allowing them to find time to improve on their own.”
- Mentee 1: “No, I’ve been really busy with school and classes getting ready, 4-H, and working.”
- Mentee 5 after three months in program: “I actually have not (been in contact) because our schedules have not combined well yet.”
- Mentee 4: “I stayed in contact with her for a little bit. She was hard to get a hold of, maybe, if I remember correctly.”
- Mentee 10: “I have some friends when I can. The ones that I met here, I text and call them whenever, we have very different schedules so it is hard.”

### *Barrier 5: Geographic Location*

Similar to valuing in person opportunities, mentors and mentees mentioned the value in living close to one another. Or conversely, the difficulties of living apart:

- Mentor 2: “I know most mentors are not willing to give up time. That is why I requested one that is closer to me, Miss Karen. We go to the same church. But that is kind of why I wanted to do this. So I could actually see them. It is not going to be an everyday thing but catch up and make it a relationship.”
- Mentor 5 on meeting in person: “No. She goes to school out of state.”
- Mentor 8: “I know they tried a kick off event but it was right after camp and something like that would be beneficial. They had the kick off event but it was a couple months after camp ended so it was hard for campers that were out of state to get to the event. Since it is close to the beginning of school they can’t take the time to come down here for a like a bowling event.”
- Mentee 3 on mentor moving: “He, we like scheduled a time to talk and we talked a little bit but a... but he like...I found out recently he got a job and he moved (out of state).” Mentee 3 went on to state: “But we liked talked over the phone, but like um, like, it is, I mean it would have been nice to meet him obviously but now he has moved.”
- Mentor 6 (from Florida): “I do think it is pretty cool that I’m paired up from someone from Florida.”
- Mentee 1: “I liked that we lived close to each other.”

### **Discussion**

There appears to be three key steps in building a useful health condition specific mentoring relationship. First, homophily is present in the relationship specific to disability and perhaps on other levels, e.g., gender, similar disability, and leisure interest. Second, once the relationship is formed and trust established through homophily, upward positive social comparisons can provide opportunities for advice giving on practical life activities and psychosocial support. Third, the adolescent has an opportunity when homophily and upward positive social comparisons are present to enter into the protected relationship to better cope and form a disability identity in the more integrated stressful world. The following is a more detailed

description of these three important theoretical concepts related to the health condition specific mentoring relationship.

First, homophily is known to aid relationship development and has been suggested that ‘birds of a feather flock together’ by McPherson et al. (2001). In this study, similarities were mentioned such as having the same disability, similar health condition, same gender, leisure interest, and to live in the same geographic location. These all seem to assist in building the foundation of the relationship and is consistent with the idea of homophily from a sociological perspective in facilitating relationship formation.

Second, Festinger’s (1954) seminal work on social comparison theory revealed an inner drive for humans to evaluate themselves with similar others. Further studies discovered the therapeutic value in social comparison opportunities for individuals experiencing disabilities, chronic illnesses, or other life stressors (Taylor, Kulik, Badr, Smith, Basen-Engquist, Penedo, & Gritz, 2007; Gibbons & Bunk, 1999). Social comparison theory, as it relates to disability, provides a useful theoretical foundation for this study. Upward positive social comparisons with others that have the same health condition can have efficacious evaluation results while providing positive psychosocial outcomes for those comparing (Buunk, Gibbons, & Buunk, 2013; Gibbons & Bunk, 1999; Huebner & Mancini, 2005; Schachter, 1959; Taylor et al., 2007). Heaney & Israel (2008) identified characteristics of successful support programs as having individuals indigenous to the group in addition to components that improve social connections. The mentoring and online support program provides numerous social comparison opportunities while mentors are considered indigenous to the group, i.e., community of people with physical disabilities. Evidence of the importance of upward social comparison can be seen in various quotes related to the mentor as a disability life coach to help get through life with a disability.

Third, Dunn (2015) posits that positive disability identity formation is facilitated when a person with a disability is enabled to enter into protected disability specific settings. Within these settings, the client is able to form a positive identity, including forming a positive identity as a person with a disability. They are then, according to Dunn, able to enter back into the more stressful and stigmatizing integrated world with a much stronger understanding of whom they are as a person in that world. The mentoring and online support program associated with this study allows for this dynamic to take place, i.e., entering into protected disability specific relationship and back out into an integrated world as needed. This can be seen in the themes related to mentors and mentee sharing a similar disability and having the opportunity to work through psychosocial issues in a protected environment that relate back to the integrated setting.

### **Theoretical Filter for Interpreting Findings**

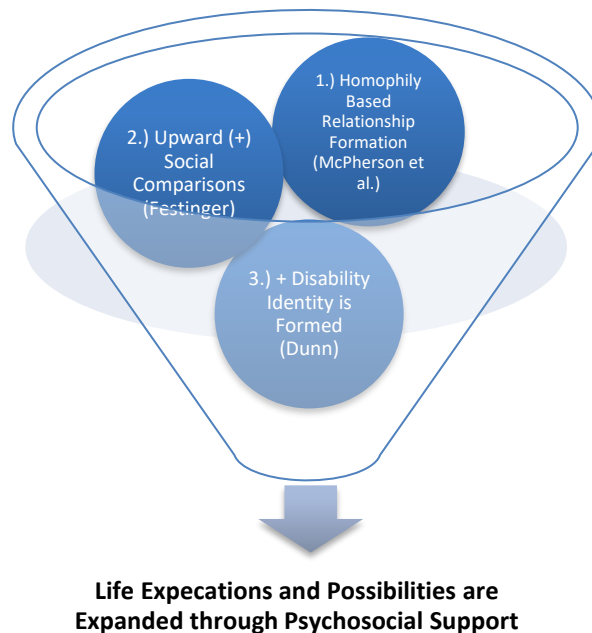


Figure 2: This pictorial representation represents a potential theoretical filter for a successful health condition specific mentoring program influenced by McPherson et al. (2001), Festiner (1954), & Dunn's (2015) previous scholarly work.



## **Future Program Implications**

Camps should consider hiring adult mentors as camp counselors for their mentor roles. Under this staffing model, mentors would then have the opportunity to accelerate the relationship with mentees during the week of residential camp and, subsequently, follow up with year-long mentoring and monthly online support program. This would build rapport initially to mitigate the awkward beginnings that so many mentees and mentors described. It would also add a strong in- person component to the program which was also mentioned as a facilitator by both mentors and mentees. Additionally, it would be helpful to provide consistency across all relationships as the interviews revealed differing degrees of involvement with the mentor, e.g., some had yet to talk to their mentors and others are in contact on a regular basis.

Homophily should be considered as a potential filter for assigning mentees to mentors. Although having the same disability is critically important to this program, camp directors should also consider connecting leisure interests, genders, geographic location, and other demographic considerations as much is reasonable and feasible. Directors may also consider that homophily was shared on a continuum in that mentors and mentees may not always have the exact same disability. However, when they can share in similar life approaches and struggles, this is helpful to the discussion that takes place. The end goal of empowering adolescents to live with a positive disability identity, as outlined in Dunn (2015), should also be considered as the end goal of the program, i.e., strengthen the adolescent to live in integrated settings.

Camps may decide to simply create and call potential future mentoring positions a disability life coach in the job description. This appears to be a good fit as it was a very strong major theme. Quotes from a mentor help to support this concept:

- Mentor 4: “(Camp Rogers) was really the first place where I saw my disability as an asset to my career. Typically, you think of a disability and you think this office space may need

to make accommodations for me but when I got to (camp) and especially when I started volunteering at camp, I saw kids related to me differently to me because they... I had crutches and they saw I had an experience similar to theirs and they were drawn to that. It was the first time that happened to me and I was like this is a good thing and I can give back.”

- Mentor 4: “I also have a blog that I write personally about disability awareness. I remember a few months ago that I wanted to get back into writing so I put a post on Facebook to see if anyone had questions or things they were wondering about. Um... a lot of campers responded asking ‘how do you date’, ‘how do you navigate the world’, ‘how did you pick your college major’. Um, it made me realize that I am in a position to share those things. And even the struggles, in that it is not that I have done everything perfectly because I haven’t (laughter). I think it is just hearing those perspectives are really helpful for them.”

Duties could include support of the mentee in daily life activities and goals as well as psychosocial support associated with having a disability as an adolescent. Camp administrators should also consider possible vocational rehabilitation specific grants to support the staffing payment of these life coach positions. This approach would create ample paid jobs for adults with physical disabilities in which they would be highly qualified for. This population has historically struggled to find gainful employment compared to peers without disabilities and this paid disability life coach position would be ideally suited for these adults. Creating positions and paying adults with physical disabilities would also greatly improve the consistency of the mentoring program related to training, consistency, child protection policies, and oversight of the relationship.

Finally, camp directors should consider creating the mentoring program in conjunction with an alumni program within their medical specialty camps. Many campers ageing out of these camps at 18 years of age desire to stay connected to the program. A mentoring and online support program may allow the most mature and top performing former campers to stay connected as mentors for the younger campers as they become successful young adults. This

would provide both a shared connection with the same health condition but also a shared camp experience as well. Both would be helpful discussion points within the mentoring relationship.

### **Study Limitations**

Qualitative phenomenology seeks to understand a single phenomenon. In this case, the phenomenon is the experience of the mentors and mentees enrolled in a pilot booster program. As such, the results of this study should not be applied generally to all camps, mentoring programs, or other future booster programs that are created and tested. Rather, the findings provide insights into this specific program and may inform future improvements and iterations to improve and build upon this specific concept. Future studies should implement the same program with different pediatric populations to examine similarities or differences in outcomes. Also, this study included interviews 12-16 weeks after the relationship had formed. Future studies should seek to understand the lived experiences of mentee and mentor after 1-2 years of relationship formation as the findings may differ.

### **Conclusions**

Medical specialty camps have demonstrated short term positive improvements in the psychosocial functioning of pediatric campers. However, a growing criticism also points to the extinguishing effects as residential campers return home to integrated home communities. The Beyond the Woods program was created as a booster intervention to address these concerns. The mentoring and online support program matched adults with physical disabilities to adolescent campers with the same or similar diagnosis in the year following residential camp participation. A qualitative analysis resulted in two major emerging themes. First, the mentor acts as a disability life coach in both providing practice advice as well as psychosocial support. Secondly, various facilitators and barriers to the success of the program were highlighted. Results from this

study are promising yet more work is needed to continue to refine this booster program specifically for youth with physical disabilities attending residential camps as well as beginning to test for efficacy with other pediatric populations.

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## Chapter Six

### Discussion and Conclusions

#### Discussion

The current body of evidence shows consistent psychosocial gains from the start of residential medical specialty camps to the end of the camp experience yet these gains extinguish as the camper returns to more inclusive home communities. The overarching aim of this study was to test a recently created booster intervention specifically designed as an adjunct to traditional residential medical specialty camp for youth with physical disabilities. This is the first known program and research study to address this specific concern in the literature. A three pronged approach was used to evaluate the effect of participating in this booster intervention. An egocentric network analysis, repeated measures ANOVA assessing mattering and self-esteem constructs, and a qualitative phenomenological approach were utilized to address three specific aims.

Specific aim 1 focused on *identifying any differences in the reported alters of adolescents that have taken part in the booster intervention program compared to participants at the same camp that have yet to establish a mentor relationship*. The egocentric network analysis provided rich descriptive statistics on the social networks of youth with physical disabilities. This is one of the first attempts to map the social networks of this population. The results show preliminary data on average number of alters, reciprocity, and that the networks are dominated by family ties, school alters, and camp alters. At the age of eighteen, most of these youth will lose contact with a large part of their network (school and camp peers). Descriptively, the enrolled group had a

slightly larger presence of camp alters than the non-enrolled group after three months. However, a chi square analyses indicated no statistical differences between campers enrolled in the mentoring and online support booster intervention versus a comparison group of non-enrolled peers.

Specific Aim 2 focused on *testing for any differences in the perceived self-esteem and mattering of youth with physical disabilities enrolled in a year-long mentoring and online support treatment program after attending medical camp compared to a control group of similar youth only attending the residential medical camp*. A repeated measures ANOVA was used to test for differences in mattering and self-esteem between and within groups. Results indicate that there wasn't a statistically significant difference between or within group. However, a power analysis indicates that by increasing the N-size, all scores would be statistically significant. Furthermore, there was a small effect size between the comparison and intervention group and a moderate effect for mattering within the treatment group. There is likely a type two error in these findings and future studies should increase sample sizes and retest for the mattering construct which appears promising.

Specific Aim 3 used *qualitative phenomenological interviews to establish emerging themes related to the lived experiences of both the mentor and the mentee in order to identify specific program successes, failures, and trends*. A total of 32 qualitative interviews were conducted with mentors and mentees both at the start of the program and three months into the program. The mentor appears to act as a disability life coach that helps the adolescents to expand their expectations for their future as well as to serve as a psychosocial support person during times of stress. Several tangible facilitators to the relationship and barriers were established within theme two centered on the dynamics of the relationship.



## **Limitations**

The study has several limitations that should be addressed in future studies. First, there doesn't appear to be adequate power due to a small N size as evidenced by a post hoc power analysis. Similar studies should have a goal of capturing scores from approximately 60 or more adolescents at pre-test and 50 or more at follow-up. There is potential for a type two error in the non-significant findings due to low power. The study design only allowed for a three-month implementation window. Based on qualitative findings, it is clear that an awkward beginning to the relationship is common. Furthermore, some mentors and mentees had yet to even connect during the first three months. Future studies should take a more longitudinal approach and collect data after 9-12 months of implementation at the very least.

## **Future Implications**

Future studies should address the concerns mentioned in the limitations section by increasing sample size and longitudinal data. This program should also be implemented and assessed with various populations outside of youth with physical disabilities. This could include youth with cranial facial differences, burns, diabetes, cancer, chronic pain, and other health conditions. Although not a specific aim of this current study, the data set generated from the mattering, self-esteem, and social network analyses combined lends itself to a future hierarchical regression analysis to determine any connections between demographics such as physical disability diagnosis, gender, age, reciprocity levels, alter frequencies, and overall network composition. The current data set is robust and should be used in a future study to further uncover specific information related to the social networks of youth with physical disabilities that may be useful to the allied health field. Lastly, the qualitative themes are helpful in refining this program. For example, barriers to relationship development should be considered and a

mitigation plan put in place to help limit the negative effects of these barriers. Similarly, facilitators to the relationship can be maintained and protected to help provide for a successful relational connection.

## **Conclusion**

The booster intervention appears to show promise as an adjunct to medical specialty camps yet more work is needed to both refine and test this intervention further. This program may improve perceptions of mattering after three months but doesn't appear to impact self-esteem. The social networks of youth with physical disabilities appear to be dominated by relatives, school contacts, and camp alters. Non-relative alter reciprocity appears to be heavily influenced by sharing a health condition diagnosis. The mentors overall act as a disability life coach to widen the future expectations of the adolescents while supporting them psychosocially through the pressures of navigating an inclusive world with a physical disability during adolescence. Future work should build upon this study to address limitations and to further develop this booster intervention with more widespread use in medical specialty camps.

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## Health and Social Network Battery

**We would like to learn a little more about the people in your life. First I would like to ask you a few questions about the people you talk to about important things as well as people you do things with. You can tell me just their first name or initials if you would like. Once I've asked you to identify the people in your life, I will then ask you some questions about those people. Can we begin?**

### **SOCIAL NETWORKS- IMPORTANT MATTERS (I)**

I1. From time to time most people discuss IMPORTANT MATTERS with other people and we need people we can depend on for help. These can be family, friends, people who have been really helpful to you – what we are interested in are the ones that you are most likely to talk to about **really** important matters in your life, whether they live near you or far away.

Who are the people in your life with whom you discuss important matters? Who are the people you can really count on?

I2. Is there anyone who always wants to talk to you about your important matters in your life whether you want them to or not? [If YES, Who are they?]

I3. Are there people who are, in general, a burden to you, because they want to discuss matters important to them, even if you don't? [If YES, Who are they?]

I4. Have there been any important changes in this recently? In other words, were there people who you used to discuss important matters with that you would not or no longer talk to about such things? These could be people who you no longer feel close to, who might have moved or died. [If YES, Who are they?]

### **SOCIAL NETWORKS – Companionship (C)**

C1. I'm interested in the people in your life that you spend time with. These could be people you do things with like watch TV, play games, go out to dinner or movies, play sports, or do outdoors activities like hiking or fishing. Who are the people that you spend time with in these kinds of social and recreation activities?

C2. Who are the people, whether or not you have mentioned them before, who are always talking about your social participation and trying to get you to do things? [If YES, Who are they?]

C3. Are there people who are, in general, a burden to you because of their own activity interests and always want to do the activities they like whether you want to or not? [If YES, Who are they?]

C4. Have there been any important changes in any of these lists? In other words, were there people who you used to spend time with that you no longer socialize with? These could be people who you no longer feel close to, who might have moved or died. [If YES, Who are they?]

Network Recording Form

- 1.) After identify alters, rank these people from first to last you go to for support.
- 2) From which name generator was this person mentioned? **CODES:** I=Important Matters C=Companionship B=Both
- 3) Which name generator section? ► **CIRCLE ALL THAT APPLY; CODES:** I1 I2 I3 I4 C1 C2 C3 C4
- 6) How are you connected to this person? ► **USE CARD A; RECORD ALL THAT APPLY**
- 7) How close are you to this person? **CODES:** 1=Very close 2=Sort of close 3= Not very close
- 8) How often do you see or talk to the person? **CODES:** 1=Often 2=Occasionally 3= Hardly ever
- 9) Does this person have a health condition? **CODES:** HC = Health Condition / NO HC = Without Health Condition
- 10) From what you know of this person, how healthy is this person? **CODES:** 1=Very healthy 2=Somewhat healthy 3= Not very healthy 8=Don't know/unsure
- 11) Does this person hassle you, cause you problems, or make your life difficult? **CODES:** 1=A lot 2=Sometimes 3= No/Not really
- 12) Does this person come to you for important matters? **CODES:** 1=Often 2=Occasionally 3= Hardly ever

Name, Initials, Identifier	2) Name Generator	3) Section Name Generator	4) Gender	5) Age	6) Connection	7) How Close	8) Contact	9) Health Condition	10) Healthy	11) Cause problems	12) Reciprocity
	I C B	I1. I2. I3. I4. C1. C2. C3. C4.									

**CARD A**

<b>1</b>	<b>=</b>	<b>Boyfriend or girlfriend</b>
<b>2</b>	<b>=</b>	<b>Parent</b>
<b>3</b>	<b>=</b>	<b>Brother/sister (including stepbrothers and sisters)</b>
<b>4</b>	<b>=</b>	<b>Cousin</b>
<b>5</b>	<b>=</b>	<b>Grandparent</b>
<b>6</b>	<b>=</b>	<b>Other person with a disability</b>
<b>7</b>	<b>=</b>	<b>Aunt or uncle</b>
<b>8</b>	<b>=</b>	<b>Camp Counselor</b>
<b>9</b>	<b>=</b>	<b>Other relative</b>
<b>10</b>	<b>=</b>	<b>Beyond the Woods Mentor</b>
<b>11</b>	<b>=</b>	<b>Neighbor</b>
<b>12</b>	<b>=</b>	<b>Nurse</b>
<b>13</b>	<b>=</b>	<b>Teacher</b>
<b>14</b>	<b>=</b>	<b>Camp Riley Camper Friend</b>
<b>15</b>	<b>=</b>	<b>Fellow student (goes/went to school together)</b>
<b>16</b>	<b>=</b>	<b>Online only friend</b>
<b>17</b>	<b>=</b>	<b>Doctor</b>
<b>18</b>	<b>=</b>	<b>Other medical person</b>
<b>19</b>	<b>=</b>	<b>Counselor or mental health therapist</b>
<b>20</b>	<b>=</b>	<b>Priest, minister, rabbi</b>
<b>21</b>	<b>=</b>	<b>Fellow church member</b>

## General Mattering Scale

Choose the rating you feel is best for you and circle the number provided.

1. How important do you feel you are to other people?

1	2	3	4
Not at all	A little	Somewhat	A lot

2. How much do you feel other people pay attention to you?

1	2	3	4
Not at all	A little	Somewhat	A lot

3. How much do you feel others would miss you if you went away?

1	2	3	4
Not at all	A little	Somewhat	A lot

4. How interested are people generally in what you have to say?

1	2	3	4
Not at all	A little	Somewhat	A lot

5. How much do other people depend on you?

1	2	3	4
Not at all	A little	Somewhat	A lot

Initials:

Gender:

Age:

## Rosenberg Self-Esteem Scale

Participants Age:

Gender:

Initials:

SA = strongly agree

A= agree

D = disagree

SD = strongly disagree

- On the whole, I am satisfied with myself.  
SA          A                  D                  SD
- At times I feel I am no good at all.  
SA          A                  D                  SD
- I feel I have a good number of qualities.  
SA          A                  D                  SD
- I am able to do things as well as most other people.  
SA          A                  D                  SD
- I feel I do not have much to be proud of.  
SA          A                  D                  SD
- I certainly feel useless at times.  
SA          A                  D                  SD
- I feel I am a person of worth, at least on an equal plane with others.  
SA          A                  D                  SD
- I wish I could have more respect for myself.  
SA          A                  D                  SD
- All in all, I am inclined to feel I am a failure.  
SA          A                  D                  SD
- I take a positive attitude toward myself.  
SA          A                  D                  SD
- In general, others like to be around me.  
SA          A                  D                  SD



## **Mentor Qualitative Interview Questions**

**(Pre-mentoring)**

**@ Summer Camp**

**Mentor First and Last Initial:** \_\_\_\_\_

- What are your general thoughts about the mentoring program?
- How did you find out about the mentoring program?
- Why did you decide to become a Beyond the Woods mentor?
- Tell me about any expected benefits, if any, from the program?
- Tell me about any expected problem areas that you can anticipate, if any?
- What value, if any, do you see in that the program matches teens with physical disabilities with adults with physical disabilities?

## Semi-structured Interviews with BTW Mentors

(3-month follow-up)

**Mentor First and Last Initial:** \_\_\_\_\_

**Years mentoring camper** \_\_\_\_\_

**How did you find about the Beyond the Woods mentoring program?**

\_\_\_\_\_

**Topic Domain: Characteristics of the mentoring relationship**

### Lead of Question

1. Talk about your experience as a mentor from the time you signed up until now.

Covert Categories: *This is a pilot program. Thus, we do not know if it is a positive or negative experience for the mentors. This study needs to inquire about the experience of the mentor and camper respectively.*

### Follow-up Questions

- Tell a story about the time you spoke. What are some things that you commonly talked about?
- Follow-up how often do you communicate has been easy or hard to communicate?
- Explain the ways in which you communicate with your camper,
- Are there specific things that you believe the camper enjoys talking about?
- Are there any specific things you feel the camper needs to talk to you about that is uniquely found in this relationship?
- Explain to me if the experience as a mentor has been a positive or a negative one.
- What specifically contributed to a positive or negative experience?
- Can you tell me a story of a negative experience?
- Can you tell me a story of a positive experience?

**Topic Domain: Psychosocial interactions with someone that has the same disability**

Lead off question: This program allows two people with the same disability to build a mentoring relationship over one year. Talk about this relationship through the lens of having the same disability as your camper.

*Covert categories: Social comparison in illness opportunities are rare with people that have physical disabilities. Often youth and adults feel isolated and have difficulty connecting with others that have the same life situation. This mentoring relationship may provide opportunities for both the mentor and the camper to access a unique relationship. There may also be present the psychosocial need for authentic friendships that are reciprocal in nature. This may not be readily found for either party.*

Follow-up questions:

1. Talk about a typical interaction with the camper. Don't be afraid to tell me details, I'm interested in hearing all that you have to say about this interaction.
2. Can you talk a bit about how it helps or doesn't help to have the same (or similar) disability as the camper?
3. Talk about specific examples where it was helpful or unhelpful to have the same disability.
4. Can you talk about the Beyond the Wood's camper assigned to you this past year? What have you noticed about your camper, if any, over the course of your time with them.

### **Topic Domain: Outcomes of the mentoring relationship**

Lead Off Question: Is there anything unique or special about this mentoring relationship that you don't find in other relationships that you have?

*Covert Categories: The mentor has a disability as well and it is possible that this relationship allows them to give back instead of receiving services. The camper also may benefit from this relationship. It is important to hear from the mentor what growth, if any, they noticed in the camper and themselves.*

### Follow-up questions

- (a.) Are you able to give back and help others in the community outside of the BTW program?
- (b.) Give me an example of when you have had a difficult time giving back in the community?
- (c.) Explain what it is about giving back that is or isn't helpful.
- (d.) Are there any positive or negative growth examples that you have noticed about yourself?
- (e.) Are there any positive or negative growth examples that you have noticed about the camper?

### **Topic Domain: Program structure and design**

Lead Off Question: Is there anything specifically that went very well in terms of the design of this program that you wouldn't want us to change, explain?

*Covert Category: This is a pilot program that has been running for three years. It is likely that somethings are working very well and also as equally likely that positive improvements are needed.*

### Follow-up questions

- (a.) If you could list the top few things, that are the most important parts of this program (if any), what are they?
- (b.) Explain what improvements could be made, if any.
- (c.) What else would you like to share that you feel is important?
- (d.) Provide specific examples of how we could make this program better?
- (e.) What didn't work well for you?
- (f.) What worked well for you in terms of the training and information you received prior to engaging with the camper?
- (g.) What worked well or didn't work well for communicating with your camper?

## Mentee Qualitative Interview Questions

(Pre-mentoring)

### Summer Camp

**Camper First and Last Initial:** \_\_\_\_\_

- During this past school year (since camp last summer), have you had a chance to talk with other Camp Riley campers?
- If not, why have you not spoken with them?
- If yes, in what ways do you stay in touch (Facebook, texting, phone, in person, etc.).
  
- How much interaction did you have over this past year with others who have a physical disability?
- If you do, are these Camp Riley campers or kids with physical disabilities that don't come to camp?
- If not, why do you think this is?
  
- Is there anything unique about talking with others that have a similar disability as you?
- If yes, describe this.
- If no, describe why?
  
- Have you talked with others about going to Camp Riley? If so, who and what have you talked about?
  
- Describe what you anticipate it being like to have a mentor with a physical disability?
  
- What are your thoughts in general about the Beyond the Woods camp and mentoring program?

## Semi-structured Individual Interviews with BTW Adolescents

(3-month follow-up)

**Camper First and Last Initial:** \_\_\_\_\_

**Years in mentoring program** \_\_\_\_\_

**How many mentors have you had?** \_\_\_\_\_

### **Topic Domain: Characteristics of the mentoring relationship**

Lead of Question Talk about your experience as in the BTW program with your mentor from the time you signed up until now.

Covert Categories: *This is a pilot program. Thus, we do not know if it is a positive or negative experience for the camper. This study needs to inquire about the experience of the camper to see if any general positive or negative themes emerge.*

### Follow-up Questions

- Tell a story about the time you spoke with your mentor.
- What are some things that you commonly talked about?

How often do you communicate?

- Explain the ways in which you communicate with your mentor?
- Explain to me if the experience with your mentor has been a positive or a negative one.
- What specifically contributed to a positive or negative experience?
- Can you tell me a story of a negative experience?
- Can you tell me a story of a positive experience?

### **Topic Domain: Psychosocial interactions with someone that has the same disability**

Lead off question: This program allows two people with the same disability to build a mentoring relationship over one year. Talk about this relationship through the lens of having the same disability as your camper.

Covert categories: *Social comparison in illness opportunities are rare with people that have physical disabilities. Often youth and adults feel isolated and have difficulty connecting with others that have the same life situation. This mentoring relationship may provide opportunities for both the mentor and the camper to access a unique relationship. There may also be present the psychosocial need for authentic friendships that are reciprocal in nature. This may not be readily found for either party.*

Follow-up questions:

5. Are there specific things that you enjoyed talking about?
6. Can you talk a bit about how it helps or doesn't help to have the same (or similar) disability as your mentor?
7. Are there any specific things you feel you could talk to your mentor about that is uniquely found in this relationship?
8. Talk about a typical interaction with the mentor. Don't be afraid to tell me details, I'm interested in hearing all that you have to say about this interaction.
9. Can you talk a bit about how it helps or doesn't help to have the same (or similar) disability as the camper?
10. Talk about specific examples where it was helpful or unhelpful to have the same disability.
11. Can you talk about the Beyond the Wood's mentor assigned to you this past year? What have you noticed about your mentor over the course of your time with them.
12. Are there specific things that you believe are important topics that you enjoy or need to talk to your mentor about that is uniquely found in this relationship?

**Topic Domain: Outcomes of the mentoring relationship**

Lead Off Question: Is there anything unique or special about this mentoring relationship that you don't find in other relationships that you have?

Covert Categories: *The mentor has a disability as well and it is possible that this relationship allows them to give back instead of receiving services. The camper also may benefit from this*

*relationship. It is important to hear from the mentor what growth, if any, they noticed in the camper and themselves.*

### Follow-up questions

- (f.) Are you able to give back and help others in the community outside of the BTW program?
- (g.) Give me an example of when you have had a difficult time giving back in the community?
- (h.) Explain what it is about giving back that is or isn't helpful.
- (i.) Are there any positive or negative growth examples that you have noticed about yourself?
- (j.) Are there any positive or negative growth examples that you have noticed about the camper?
- (k.) Have you noticed or not noticed a theme related to what the two of you talk about? Explain.
- (l.) Are there any positive or negative growth examples that you have noticed taking place in yourself related to this program?

### **Topic Domain: Program structure and design**

Lead Off Question: Is there anything specifically that went very well in terms of the design of this program that you wouldn't want us to change, explain?

Covert Category: *This is a pilot program that has been running for three years. It is likely that somethings are working very well and also as equally likely that positive improvements are needed.*

### Follow-up questions

If you could list the top few things, that are the most important parts of this program (if any), what are they?

Explain the ways in which you communicate, how often you communicate, and if this has been easy or hard to do.

- Has been easy or hard to communicate?



- (h.) Explain what improvements could be made, if any.
- (i.) What else would you like to share that you feel is important?
- (j.) Provide specific examples of how we could make this program better?
- (k.) What didn't work well for you?
- (l.) What worked well for you in terms of the training and information you received prior to engaging with the camper?
- (m.) What worked well or didn't work well for communicating with your camper?
- (n.) If you could list the top few things, in your opinion, that are the most important parts of this program (if any), what are they?
- (o.) Explain what improvements could be made, if any.
- (p.) What else am I missing that you feel is important to know about this program?

### **E-mail Correspondence Prior to Camp**

Dear Camp Riley Family,

I would like to invite each Camp Riley camper attending the two-week session to participate in a camp research study this summer that may provide important information on the potential benefits of the Beyond the Woods mentoring program.

Bradford Woods is interested in learning more about both the benefits of the Beyond the Woods mentoring program as well as areas for improvement. Ongoing research has taken place over the last few summers at camp to help create innovative programming based on findings directly from the campers themselves. This study follows this same model.

The study for summer 2017 will seek to find information related to the social support networks found at camp including the Beyond the Woods mentoring program. Your son or daughter is being asked to participate since they will be attending the two-week session of Beyond the Woods.

The study this summer will involve a simple five question survey on the supportive people they can go to for “important matters” as well a person that comes to them for support. This should take approximately 20 minutes to fill out in their cabins and will help the research team to map out social support networks at camp, at home, and potentially via the adult mentor assigned through the Beyond the Woods program.

In addition, approximately 10 Beyond the Woods campers will be invited for a 1:1 interview to seek in-depth information on both the potential benefits and areas for improvement in the adult mentoring program associated with Beyond the Woods.

Each camper is free to drop out of the study at any time. Additionally, there is no penalty for not participating. The camp experience and connection to Bradford Woods will not be impacted in any way if they choose not to participate. There are also no right or wrong answers as the study only seeks to identify their opinions on what each campers finds helpful.

Each camper that participates in a 1:1 interview will receive a \$15 I-Tunes gift card. There will be a drawing to win another \$15 I-Tunes gift card for those that fill out the 20-minute survey.

If your camper would like to participate and as a parent you will allow them to do so, please fill out the assent form (for campers) and consent form (parents) and bring this along to your Sunday check-in for camp this summer.

If you should have any questions, feel free to contact me directly at 765-342-2915 ext. 5103 or [sldawson@indiana.edu](mailto:sldawson@indiana.edu).

Sincerely,

Shay Dawson, M.A., CTRS

Principle Investigator

## **INDIANA UNIVERSITY INFORMED CONSENT STATEMENT FOR**

### **Beyond the Woods Mentoring Study**

You are invited to participate in a research study of Camp Riley's Mentoring Program associated with the Beyond the Woods camp. You were selected as a possible research participant as you are an adult mentor or an adult that has recently been a camper. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Mr. Shay Dawson, Director at Bradford Woods.

#### **STUDY PURPOSE**

The purpose of this study is to continue to develop programming that will help youth with physical disabilities not only at camp but also in their home communities. This includes discovering information from campers that will help make Camp Riley- Beyond the Woods mentoring program a useful program in improving the social support and success of campers with physical disabilities.

#### **NUMBER OF PEOPLE TAKING PART IN THE STUDY:**

If you agree to participate, you will be one of approximately thirty mentors who will be participating in this research in addition to approximately 30 campers.

#### **PROCEDURES FOR THE STUDY:**

If you agree to be in the study, you will do the following things:

Take part in an interview that identifies the people you go to for support. You may also be asked to participate in an interview to discuss the Beyond the Woods mentoring program in-depth including the perceived benefits and areas for improvement.

#### **RISKS OF TAKING PART IN THE STUDY:**

The risk of participating in this study is that mentors will take part in answering questions from 20-60 minutes during the interview. This time could be used as free time. It's possible that you may feel embarrassed or uncomfortable answering questions about yourself, however you are free to skip any questions you do not wish to answer or end the interview at any point.

#### **BENEFITS OF TAKING PART IN THE STUDY:**

The information gained from this study will likely provide insight into the impact participation in the Beyond the Woods mentoring program may or may not have on youth participants.

#### **ALTERNATIVES TO TAKING PART IN THE STUDY:**

Instead of being in the study, you have these options: Do not take part in the interview at no risk to you.

#### **CONFIDENTIALITY**

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published. Data will be recorded and will be stored in a secure location and destroyed immediately after data is transcribed and analyzed, no more than 1 year after data collection. After the data has been collected and compared, the identifiers will be destroyed and the remaining data will be kept in a locked / confidential storage closet for sensitive documents at Bradford Woods (Administrative building). All data will be destroyed following the completion of the study.

Organizations that may inspect research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the Indiana University Institutional Review Board or its designees, the study sponsor, School of Public Health – Bloomington, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP, who may need to access your research records.

### **PAYMENT**

You will receive no payment for participation.

### **CONTACTS FOR QUESTIONS OR PROBLEMS**

For questions about the study, contact the researcher Shay Dawson at 765-342-2915 ext. 5103

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (812) 856-4242 or by email at [irb@iu.edu](mailto:irb@iu.edu)

### **VOLUNTARY NATURE OF STUDY**

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Camp Riley or Bradford Woods

### **SUBJECT'S CONSENT**

In consideration of all of the above, I give my consent to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree to take part in this study and to allow my child to participate in this study.

**Subject's Printed Name:** \_\_\_\_\_

**Subject's Signature** \_\_\_\_\_

**Date** (must be dated by the subject): \_\_\_\_\_

**Printed Name of Person Obtaining Consent:** \_\_\_\_\_

**Signature of Person Obtaining Consent:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## **Indiana University Assent to Participate in Research**

### **Social Network Analysis of a Mentoring Program for Youth with Physical Disabilities Attending a Medical Camp**

We are doing a research study. A research study is a special way to learn about something. We are doing this research study because we are trying to find out more about the Beyond the Woods mentoring program. We would like to ask you to be in this research study.

#### **Why am I being asked to be in this research study?**

You are being asked to be in this research study because you are enrolled in Camp Riley 3 or Beyond the Woods camps. You may have information that is helpful to making future programming better.

#### **What will happen during this research study?**

We want to tell you about some things that might happen if you are in the study. This study will take place at Bradford Woods during the two week Camp Riley session. We think it will last for 20-60 minutes.

If you want to be in this study, here are the things that we will ask you to do.

Riley 3 / Beyond the Woods Campers will fill out a survey that will last approximately 20 minutes. The questions will focus on the people that help you or people that you help.

Beyond the Woods Campers will have an opportunity for a 1:1 interview that will explore the mentoring program specifically. This interview may last up to 40 minutes. Each interview will be audio recorded and later transcribed verbatim. Interviews will be held in a public venue at the camp with privacy from others hearing the conversation yet also in view of other camp staff.

#### **Are there any bad things that might happen during the research study?**

Sometimes bad things happen to people who are in research studies. These bad things are called “risks.” The risks of being in this study are very small. The only bad thing is that you will lose 20-60 minutes of camp time while you are talking with the researchers. It’s possible that you may feel embarrassed or uncomfortable answering questions about yourself, however you are free to skip any questions you do not wish to answer or end the interview at any point.

#### **Are there any good things that might happen during the research study?**

Sometimes good things happen to people who are in research studies. These good things are called “benefits.” The benefits of being in this study might be that programming at camp or at home will be very helpful to you in the future related to the mentoring program

We don’t know for sure if you will have any benefits. We hope to learn something that will help youth with physical disabilities someday.

# Vitae

## **Shay Dawson M.A., CTRS**

Director, Bradford Woods  
RT Academic Option Coordinator  
Pediatric Health Institute  
School of Public Health-Bloomington  
Indiana University  
812-856-1965  
[sldawson@indiana.edu](mailto:sldawson@indiana.edu)

### **RESEARCH FOCUS AREAS:**

- Social psychology of pediatric disability
- Evidence based therapeutic program development
- Egocentric social network analysis
- Qualitative phenomenology
- Mixed Methods

### **FORMAL EDUCATION**

#### Doctor of Philosophy (May 2018)

Indiana University, Bloomington, IN  
School of Public Health-Bloomington  
Major: Leisure Behavior  
Minor: Social Science Approaches to Health and Healing Systems  
Dissertation: *Psychosocial Effect of a Year-round Mentoring and Online Support Program for Adolescents with Physical Disabilities Attending a Medical Specialty Camp*

#### Master of Arts

Kent State University  
Concentration: Therapeutic Recreation  
Master's Research Project: "Promoting Independence in Leisure with Individuals with Severe Disabilities."

#### Bachelor of Science

Kent State University, Kent, Ohio  
Concentration: Therapeutic Recreation  
Minor: Psychology

#### *Study Abroad Experience:*

*DeMontfort University  
Bedford, England*

## **ALLIED HEALTH EXPERIENCE:**

### RT Academic Option Coordinator and Instructor

*School of Public Health-Bloomington, Indiana University (2017-2018)*

Full time role (on sabbatical from Bradford Woods) as acting Option Coordinator for the clinical recreation therapy program. This includes the oversight of the curriculum and teaching assignments for 110 undergraduate students and 45 master students in the School of Public Health. Many of these students will complete national certifications or go on to graduate school in other allied health professions. Teaching 9 credits in per semester in both undergraduate and graduate level courses. Full oversight of the Serbia Study Travel Program - R 250: *Pediatric Comparative Exchange: Services for Children with Disabilities*. This course is a 3 credit summer intensive in partnership with the Faculty of Special Education and Rehabilitation at the University of Belgrade and the Faculty of Medicine at the University of Novi Sad.

### Director, Bradford Woods

*Indiana University's 2,436 Acre Accessible Outdoor Center (April 2010-current)*

*School of Public Health-Bloomington*

Provide lead administration support of major program areas including Recreational Therapy, Military and Family Programs, Environmental Education, Retreats, Adventure Education, and partnerships with Agape Therapeutic Riding, Inc. and the American Camp Association National headquarters. Manage and direct the 2,436-acre facility housing 56 building structures with a \$2,300,000 operating budget. Responsibility for 200 staff, including 130 allied health students, resulting in 16,000 yearly visitors and 44,000 program days. Spearhead research projects, grants, and relationships with academic and service departments within IU, other leading universities, and major partners including but not limited to the Riley Children's Foundation and Riley Hospital for Children. Maintain American Camp Association accreditation as well as bringing the facility in-line with state and national regulatory bodies such as IDEM and the Department of Labor as well as internal regulatory bodies such as IU Risk Management, IU Environmental Health and Safety, and IU Purchasing. Teach as an adjunct faculty member in recreational therapy track covering 2-3 courses annually related to Disability, Health, and Function as well as connecting students to clinical rotations and exposing graduate students to ongoing evidence based program development for clients with health conditions.

### Pediatric Health Institute, Founder

*Indiana University, School of Public Health-Bloomington (2015-current)*

Created the Pediatric Health Institute through the acquisition of a 30 k research and creative activity grant in the School of Public Health-Bloomington. Worked in collaboration with Bradford Woods, Indiana University's Outdoor Center, located in Morgan County, Indiana to develop an innovative approach for the development, incubation, and testing of evidence based pediatric programs focused on nutrition and physical activity, mental health, substance use, chronic pain, and disability support programming. Collaborated with local partners including the Community Foundation of

Morgan County and the Kendrick Foundation to develop a plan for Morgan County, IN and beyond based on a lack of public and social services in the area.

President of the Board, NCTRC

*National Council for Therapeutic Recreation Certification (April 2010-April 2013)*

Chairperson during the 2012-2013 for the full Board of Directors. Highest ranking member with direct supervision of the Executive Director of NCTRC including weekly meetings and daily e-mail correspondence. Oversight of annual operating budget surpassing \$2,000,000, policies impacting 14,000 therapists nationally, and all Board interaction. Also served as Vice Chair, NCTRC (2011-2012), Member at Large / Standards Hearing Committee Board Liaison (2010-2011), & Vice President and Secretary for New City Professional Group Building, Inc. (2012-2013).

Director, Recreation Therapy

*Indiana University's Bradford Woods (Jan 2007 – March, 2010).*

Direct a nationally and internationally recognized therapeutic outdoor program for children and adults with disabilities and chronic illnesses. Work in collaboration with organizations such as the Riley Hospital for Children, Little Red Door Cancer Agency, Muscular Dystrophy Association, HEAR Indiana, Morgan County Corrections, and People's Burn Foundation to implement medically specific summer camps, weekend camps throughout the year, adventure therapy programs, fundraising events, and special events. Hire, train, and direct 1 full time staff, 2 part-time staff, 40 volunteers, and 95 seasonal staff. Recruited summer staff and volunteers from allied health programs both nationally and internationally including programs with a focus in PT, OT, Recreation Therapy, Speech Therapy, Music Therapy, Art Therapy, Nursing, and Pre-Med. Supervised internship and practicum students gaining class credit (20-30 students per year) in allied health focus areas. Started and provided oversight of a new year round equine assisted therapy program partnership including the building of a 550 k equine center. Managed \$985,000 budget (over 50% of BW total budget) while increasing overall revenue by \$200,000 in four years of service. Leadership role for ACA accreditation. Serve as an adjunct instructor in the Department of Recreation, Parks, and Tourism Studies in the field of therapeutic recreation while also serving as a committee member for the Therapeutic Outdoor Programs Minor. Carried out collaborative research on the efficacy of therapeutic recreation programs at Bradford Woods.

Supervisor, Therapeutic Services Department (Behavioral Health Specialist)

*Genesis Healthcare Systems, Zanesville, Ohio (Sept. 2003-Dec 2006)*

Supervised multidisciplinary therapy department on inpatient adolescent (14 beds) and adult (26 beds) behavioral health units. Provided direct supervision of 15-20 group therapists (OT, Drug and Etoh, Social Work, Art Tx., Music Tx, Recreation Tx.), licensed special education teachers, psychologist, and patient care techs on a daily basis including interviewing, training, disciplinary action, clinical direction, and logistics. Lead interdisciplinary treatment team discussions and coordinated daily program schedule consisting of 25-30 therapy groups and various clinical assessments. Took a leadership role in JCAHO accreditation for the unit. Conducted therapy groups and individual therapy assessments. Specialized groups include experiential therapy, journaling, stress



management, leisure counseling, animal assisted therapy, and stress management seminars.

Adjunct Therapist (Recreation Therapy), Therapeutic Services Department

*Genesis Healthcare Systems, Zanesville, Ohio (May 2003-Sept.2003)*

Conducted 2-5 therapy groups per day as well as 4-10 individual assessments. Wrote treatment plans, attended treatment team meetings, and facilitated recreation therapy groups as an adjunct therapist. Therapy focus consisted of animal assisted therapy, stress management groups, experiential adventure therapy, bibliotherapy, exercise groups, leisure counseling, and journaling.

Program Coordinator

*The Respite and Recreation Program, Kent, Ohio (January 2002 – May 2003)*

Planned and organized therapeutic recreation day and overnight programs for children with disabilities and youth at-risk that have been adopted or are in foster care. Worked in a collaborative relationship with the Northeast Ohio Adoption Agency. Recruited, trained, and supervised 25-35 student volunteers and practicum students per semester. Created and implemented orientation programs to train student volunteers in the supervision of children with various disabilities and psychological diagnoses, i.e., reactive attachment disorder, ADHD, PTSD, autism, and cerebral palsy.

Recreational Therapy Clinical Intern

*St. Thomas Hospital, Akron, Ohio (Spring 2003)*

600-hour internship on the behavioral health / chemical dependency units under CTRS. Assessed, planned, implemented, and evaluated therapeutic groups for adults of various ages and diagnoses. Actively participated in interdisciplinary meetings twice a week. Documented patient progress daily on the general and psych intensive units.

Masterteacher (Team Leader)

*The MLSP Program (Adapted Physical Activity Program), Kent, Ohio (2001-2002)*

Supervised seven undergraduate students and seven children with and without disabilities in an inclusive setting. Planned and implemented leisure education group activities in an inclusive setting for children, teens, and adults with and without disabilities. Wrote, implemented, and evaluated lesson plans for adults with autism in the areas of basic motor and aquatics skills.

Wilderness Guide

*Summer's Best Two Weeks –Wild, Camp, Boswell, Pennsylvania (Summer 2002)*

Conducted eight-day wilderness trips in the Laurel Highlands of Pennsylvania for 7<sup>th</sup> to 12<sup>th</sup> grade student groups. Directed caving, climbing, white-water rafting, mountain biking, high and low ropes course, grounds initiatives, hiking expeditions, bible studies, and solo experiences.

### Habilitation Assistant

*Hattie Larlham Center for Children with Disabilities, Mantua, Ohio (Fall 1999 - 2001)*

Aided individuals with severe and profound disabilities in activities of daily living and medical procedures. Implemented adaptive equipment and documented daily.

Transported and accompanied clients to Akron Children's Hospital, the Cleveland Clinic, home visits, and recreational outings.

### Equine Assisted Therapy Volunteer

*Fieldstone Farms Therapeutic Riding Center, Bainbridge, Ohio (Fall / Winter 2000)*

Provided assistance to young children with various disabilities by leading horses and sidewalking. Pulled tack, groomed horses, and prepared animals for therapy group.

## **PROFESSIONAL SERVICE AND INVOLVEMENT**

### **Certifications and Specialty Trainings**

*National Council for Therapeutic Recreation Certification*

Certified Therapeutic Recreation Specialist (CTRS)

Certification # 51903

*Equine Assisted Psychotherapy and Learning Training*

*OK Corral Series: Founder of EAL - Greg Kersten*

*April 2012*

*Franklin Covey Certified Facilitator*

7 Habits of Highly Effective Teens with Disabilities

"Beyond the Woods" Customized Program for Teens with Disabilities

Date issued: 7/2013

SOLO (Wilderness Emergency Medicine)

Certified in Wilderness First Aid

Date issued: 2/2007

*American Heart Association*

Certifications: Healthcare Provider Adult-Child CPR/ AED

Date issued: 5/2013

*Indiana Department of Motor Vehicles*

Classification: Chauffer's License

### **Organization memberships**

*National Council for Therapeutic Recreation Certification*

Certified Therapeutic Recreation Specialist

Certification #51903

*American Therapeutic Recreation Association*  
National Member

*Recreational Therapist of Indiana (ATRA State Organization)*  
State Member

*American Camping Association*  
Bradford Woods / Camp Riley  
Indiana Chapter Member  
Member ID # 57936

**Professional Presentations and Consultation:**

***Invited Presentation & Consultation***

*Tri-State Cranial Facial Conference, Flying Horse Farms, Ohio (winter, 2016)*  
Medical Camp Outcomes at a Medical Camp for Youth with Cranial Facial Differences

*Bradford Woods Programming and New Pediatric Health Institute. Mooresville, Indiana*  
Chamber of Commerce. (August 2016).

*Eppley Institute for Public Parks and Lands (May 2017).* Expert review of disability awareness, accessible design, and disability interaction on-line curriculum for certification programs to be offered to National and State Park employees.

*Pediatric Health Institute Concept for Morgan County Youth and Families. Rotary Club*  
of Martinsville, IN. (August, 2016).

*Pediatric Health Institute. Indiana University School of Public Health Advisory Board*  
(spring 2016)

*American Camp Association Child Protection Curriculum Consultant (2016).* Consultant that reviewed an on-line presentation, worksheet, and exam that will be provided to Texas youth development workers on child abuse protection within youth programming.

*Guest Lecture on Management Approaches, Indiana University Department of Recreation, Park, and Tourism Studies Department (October 3<sup>rd</sup>, 2014)*  
50-minute lecture to 70-80 RPTS undergraduate students on management in outdoor and therapeutic recreation facilities as well as work on non-profit boards.

*Guest Lecture on Management Approaches, Indiana University Department of Recreation, Park, and Tourism Studies Department (Spring Semester, 2014)*  
50-minute lecture to 70-80 RPTS undergraduate students on management in outdoor and therapeutic recreation facilities and non-profit boards.

*Guest Lecture on Management Approaches, Indiana University Department of Recreation, Park, and Tourism Studies Department (February 15<sup>th</sup>, 2013)*  
50-minute lecture to 70-80 RPTS undergraduate students on management in outdoor and therapeutic recreation facilities and non-profit boards.

*Disability Awareness Training, Great Lakes Training Institute (February 27, 2013)*  
Presented to park and recreation managers during a 1.5-hour workshop on disability awareness. Content included setting up successful social and physical environments and best practice approaches in working with clients that have disabilities.

*RTV6 The Indy Channel News (June 2017).* Two-minute focus on safety and health at summer camps featuring Bradford Woods on the 6 p.m. and 7 p.m. news coverage.

*Riley Children's Foundation Full Staff Presentation (September 25<sup>th</sup>, 2012)*  
One-hour presentation to 50 staff members including the executive director, vice presidents, and general staff on therapeutic camp research outcomes as well as trained staff on disability awareness approaches in working with youth and families.

*Riley Children's Foundation Board of Governors (August 22, 2012)*  
Presented therapeutic camp research findings on social acceptance and quality of life to the RCF Board of Governors including Indiana Pacers President, Jim Morris.

*Riley Children's Foundation Camp Riley Donor Event (July 15, 2012)*  
Presented an update on Camp Riley and the psychosocial benefits to campers attending. Led a ceremony for the donation of a descendant of the Isaac Newton Apple Tree to Bradford Woods

*Riley Children's Foundation Board of Governor's Annual Luncheon (June 13, 2012):*  
Camp Riley Presentation to over 50 in attendance including former Indianapolis Motor Speedway President and CEO, Tony George.

*Women of Riley Hospital Annual Luncheon (May 16, 2012)* Presented the Keynote Address on Camp Riley through the Riley Children's Foundation and Riley Hospital for Children at Bradford Woods

*People Helping People Network Radio (January 14, 2012):* Nationally Syndicated Radio Show Interview on social programs at Bradford Woods Outdoor Center

*Therapeutic Recreation Class, University of Wisconsin La Cross (October 5th, 2010)*

Presented via Skype to therapeutic recreation students on the programs at Bradford Woods, APIE process, research, and answered questions.

*Craniofacial Tri-State Conference, Indianapolis, IN (September 24, 2010).*

IU School of Medicine's Department of Surgery - Section of Plastic Surgery at Riley Hospital for Children hosted the annual conference for Kentucky, Ohio, and Indiana pediatric hospital physicians, speech therapist, and clinic coordinators. Presented on Promoting Self-Esteem with Youth and Adolescents via a residential camp setting.

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*Great Lakes Recreational Therapy Student Conference, Martinsville, IN (April, 2017)*

The International Classification of Functioning, Disability, and Health: A Practical Approach to using the ICF in TR

*WCBK Radio Interview (2017):* Discussing the N.O.A.H. Network Program and Research Project for youth with obesity and pre-diabetic conditions.

*WCBK Radio Interview (2016):* Discussing various programs at Bradford Woods including current therapeutic program offerings for county teens.

*American Camp Association National Conference, Albuquerque, NW (Feb. 2017)*

Network Analysis of Youth with Physical Disabilities Attending a Medical Camp

*American Camp Association National Conference, Albuquerque, NW (Feb. 2017)*

Medical Camp Round Table Discussion Leader: Developing Extraordinary Counselors at Medical Camps

Great Lakes Recreational Therapy Student Conference (2016). *A Communication and Conflict Resolution Intervention for the Recreation Therapy Setting.*

Gilbert, K., Beckmeyer, J., McCormick, B., Dawson, S., & Gilbert, R. (2014). *Family Battle Buddies Program: Program for Reintegrating Families.* National Council on Family Relations Annual Conference (November 19-22<sup>nd</sup>, 2014)

Gilbert, K., B., Dawson, S., & Gilbert, R. (September 17<sup>th</sup> -21<sup>st</sup>, 2014). *Using the Family Battle Buddies Program to Enhance Family Reintegration Following Parental Deployment: Results from a Pilot Study.* This Land is Your Land: Toward a Better understanding of Nature's Resiliency-Building and Restorative Power for Armed Forces Personnel, Veterans, and their Families Conference, University of Utah, Salt Lake City.

Dawson, S. & Knapp, D. (2014). *Bringing "Camp War Buddies" to the Home Front.* National Research Forum. American Camp Association National Conference, Orlando, FL.

Devine, M.A. & Dawson, S. (2014). *Disability Specific Camp Experience: Results of a National Study*. National Research Forum. American Camp Association, Orlando, FL.

*American Therapeutic Recreation Association National Conference (October 15, 2012)*  
General Session: Co-presented with CARTE and ATRA President and Vice President for over 600 general session attendees. Presented a 30-minute session on the NCTRC vision (Accreditation, Certification, & Advocacy for Therapists) and working relationship with the aforementioned national organizations as the President of NCTRC.

*American Therapeutic Recreation Association National Conference (October 13, 2012)*  
*NCTRC Annual Certificants' Meeting*: Presented and facilitated the annual meeting of CTRSs as President of the Board for NCTRC. Provided an overview of the past year, strategic initiatives, and fielded questions and concerns from CTRSs.

*American Therapeutic Recreation Association National Conference (October 13, 2012)*  
*NCTRC: Leading the Way to a Sustainable Future for Therapeutic Recreation*  
Co-presented 1.5-hour session on the 20/20 vision with Executive Director Bob Riley.

*American Therapeutic Recreation Association National Conference (October 12, 2012)*  
National Forum for Recreational Therapy State Licensure: Supported a full day forum sponsored by NCTRC for 50 state delegates including the welcome and acknowledgments of national presenters.

*ACA Special Needs Preconference, Twin Lakes Camp, GA (February 20, 2012)*  
Co-Presented: Therapeutic Camp Research: What are the benefits for my camp?

*American Camp Association National Conference Atlanta, GA (February 20-23, 2012)*  
Co-presented Therapeutic camp outcomes data

*ACA National Conference Special Needs Kindred Group, Dallas, Texas (February 10<sup>th</sup>, 2013)*. Camp John Marc, Texas. Co-Presented at Camp John Marc on the National Disability Specific Camp Research Study

*Co-Presented at ACA Research Institute and poster presentation: Disability Specific Camps: Examining Social Acceptance and Quality of Life.*

*Coastal Horizons: Networking with NCTRC Workshop Gulfport, MS (October 20, 2011)*  
Presented: "A communication and conflict resolution intervention for the RT setting" to an audience of recreation therapy students and practitioners during a 1.5-hour session hosted jointly by Southern Mississippi, Southern Alabama, Southern University, and the American Therapeutic Recreation Association

*American Therapeutic Recreation Annual Conference, Indianapolis, IN (Sept. 18, 2011)*  
Lead presenter for a day long pre-conference at Bradford Woods Outdoor Center. Discussion centered on the APIE process in the community setting for a variety of populations; exploring universal design philosophies and research currently taking place

at Bradford Woods. Explored facilitation techniques in equine assisted therapy and therapeutic outdoor programming.

*Therapeutic Recreation Program Class, University of Wisconsin La Cross (Feb.14, 2011)*  
Presented via Skype to therapeutic recreation students on program development, community partnerships, fundraising, internships, research, and answered questions.

*New England Therapeutic Recreation Association (November 6, 2010)*  
NCTRC BOD presentation to therapeutic recreation student group on the state of NCTRC, personal history in the therapeutic recreation profession, and opportunities for students in the future.

*Mickey's Camp, Bradford Woods, (August, 2010)*  
Presented to 150 business men attending Mickey's Camp on the benefits of the therapeutic recreation programs at Bradford Woods. Raised over \$12,000 from participants attending the presentation.

*Recreation Therapist of Indiana State Conference, Evansville, Indiana (Nov.13-14, 2008)*  
Presented: "A communication and conflict resolution intervention for the RT setting" to an audience of professors, administrators, PR actioners, and students in the RT field during a 1.5-hour session for this two-day professional conference.

*NRPA National Conference, Indianapolis, Indiana (September 2007)*  
Co-presented with staff from the National Center on Accessibility during an off-site one-day program on universal accessibility practices. Presentation material highlighted the use of universal design principles in therapeutic outdoor programming at Bradford Woods (Indiana University's 2,500 Acre Outdoor Center). Camp Directors and program staff from around the nation were in attendance.

*Bloomington Meadows Hospital (Spring 2007)*  
Co-presented a one day in service to inpatient behavioral health staff that work directly with adolescents that are in the acute care and residential behavioral health setting. Content focused on the use of experiential and adventure based interventions for treatment with clients.

*Children Services of Ashtabula County (Spring 2003)*  
Therapeutic recreation consultation for 16 bed receiving home designed for youth at risk. Components included treatment, family groups, recreation, and respite care. Co-presented in day long in-service for facility staff.

*Midwest Symposium on Therapeutic Recreation, Lake Geneva, Wisconsin, (April 2003)*  
Collected data on four participants with severe MR/DD regarding non-verbal communication cues during leisure participation. Wrote collaboratively on findings and co-presented research project entitled "Promoting Independence in Leisure with Individuals with Severe Disabilities."

*Hattie Larlham Foundation for Children with Severe and Profound Disabilities Annual Conference, Akron, OH (Spring 2003)*

Presented findings as related to data collection on four residents with severe MR/DD from the Hattie Larlham Foundation that participated in a multi-week therapeutic recreation intervention. "Promoting Independence in Leisure with Individuals with Severe Disabilities" encompassed the study of non-verbal communication cues during leisure participation for participants.

### **Program Grants and Development**

*Awarded:*

\$39,392 (2017) Piatt, J., Ramos, B., Dawson, S. & Singleton, *Adaptive Sport Program for Indiana University Students who are Disabled Veterans and Disabled Members of the Armed Force*

\$735,584 *Riley Children's Foundation Grant for the Camp Riley Summer Pediatric Medical Camp Program* (2017). Dawson, S. & Street, T.

*\$1.75 million grant through the Lilly Endowment / Riley Children's Foundation* (2008). Grant supported construction projects for Camp Riley at Bradford Woods. PI for last year of the 3-year grant bringing the award to its conclusion. Grant improved physical plant needs of Camp Riley for youth with physical disabilities as well as building a new 550 k equine center to provide year round equine assisted therapy programs to adults and children with medical diagnoses.

\$100,000 *Indiana Department of Veteran's Affairs* (2016-2017). Awarded to facilitate programming for the Family Battle Buddies Program – a therapeutic military reintegration program developed as an evidence based research program at Bradford Woods.

\$ 257,400 *Department of Children's Services* (2016-2018). Project Wolf: A family based therapeutic program to build resiliency into each participating family unit.

\$4,470.48 *Adapted Scuba Diving Grant* (2017). From the Indiana University School of Public Health Committee on Centers and Institutes to support a graduate student coordinator for a new Adapted Scuba Diving Program. This is a partnership between the Bradford Woods, Underwater Science, Academic Diving Program, and the Pediatric Health Institute.

\$31,000 Dawson, S. (2017) *Family Battle Buddie Program Grant* award through the Indiana Department of Veteran's Affairs. Funding provides monthly therapeutic weekend retreats for veterans' and their family members through the evidence based intervention



called the Family Battle Buddies Program. The FBBP was created through a two-year research pilot at the School of Public Health-Bloomington.

\$58,225.09 Dawson, S. (9/30/16-9/30/17) *N.O.A.H. Network Pilot Study*: Nutrition, Outdoor Activity, and Health Program for Youth. Year-long pilot program to develop and test a program that addresses obesity and diabetes in adolescents from Morgan County, Indiana.

\$24,373 (Dawson, S. 11/1/16-7/15/17) *Morgan County Community Foundation*: N.O.A.H. Network Funding for a Physical Activity and Nutrition Pilot Program for area Youth

\$30,000 Dawson, S. & Jamieson, L. (2016). *School of Public Health Research and Creative Activity Committee*. Provided support to create a Pediatric Health Institute through the School of Public Health-Bloomington and Indiana University. The aim of this project is to target health disparities in pediatric and family based populations within south central Indiana and throughout the state. Methods include building pilot programs at Bradford Woods that are evidence based and can be replicated in other areas throughout the United States to improve mental health, substance use, physical activity and nutrition, disability, and social health outcomes.

\$1,500 grant to *EPICS Program at Purdue University* in partnership with Bradford Woods. Fall 2015 student engineering project to build an accessible ramp and trail into and around the Historic Bradford Homestead, circa 1850. This provided access to youth with physical disabilities.

\$1,500 Grant to *EPICS Program at Purdue* in community partnership with Bradford Woods. Project money can be applied to retrofitting a sailboat to make it accessible for youth with physical disabilities and to build a sensory trail for therapeutic equine assisted riding activities.

\$1,500 Spring 2016 Grant to *EPICS Program at Purdue* in partnership with Bradford Woods. Funds assisted in working on student experiential projects to build an accessible sailboat and an accessible trail to the historic Spring House.

\$100,000 *Wetlands Comfort Station* (Riley Children's Foundation through Speedway)

\$25,000 *Historic Renovation Donation for the Bradford Woods Homestead*

\$10,000 *Riley Children's Foundation Health Center Concept Plan*

\$27,500 *DHPA Historic Preservation Grant*. (Bradford Homestead – circa 1850's-stabilization)

\$2,500 – *Indiana Landmark* (stabilization study funding for Bradford Home, circa 1850's, and the spring house, circa 1900's. Both are on the National Register of Historic Places)

\$6,800 – *Million Dollar Round Table* gift in kind for an outdoor pasture to support Equine Assisted Therapy Activities at Bradford Woods

\$ 9,700 – *Pepsi / Marsh* (Alpine Tower Shelter) accessible shelter for use by children disabilities climbing at the accessible Alpine Tower at Bradford Woods.

\$7,950.30 - *Epsilon Sigma Alpha / Riley Children's Foundation*. EZ Launch Canoe and Kayak System to support accessible kayak and canoe options for youth with physical disabilities

\$20,000 *Epsilon Sigma Alpha / Riley Children's Foundation* to buy an accessible pontoon and trailer for adapted water recreation opportunities for youth with physical disabilities

\$600 - *Indiana Wildlife Federation* to install a Rain Garden at the equine assisted therapy center.

\$200,000 – *Million Dollar Round Table / Riley Children's Foundation* (Outdoor Accessible Sport Pavilion). Developed Sport Pavilion facility for youth with physical disabilities to participate in adapted Paralympic sport activities

\$1,500 *Kohl's Cares for Kids Grant* for operation costs associated with running a youth development program for clients with and without disabilities.

*Submitted – Awaiting Results*

\$879,735 *Riley Children's Foundation Grant for the Camp Riley Summer Pediatric Medical Camp Program and Beyond the Woods Booster Program* (2018). Street, T., Elder, L, & Dawson, S.

*Non-funded grants:*

\$141,625 *Department of Veterans' Affairs Adapted Sport Grant*. Piat, J., Ramos, B., Dawson, S. King, A., Parker, N.

\$14,752 *Christopher and Dana Reeve Foundation: Adapted Sport Grant*

\$20,050 *The Impact of Residential Outdoor Education on Attention Deficit Hyperactivity Disorder*. Knapp, D., & Dawson, S.

\$31,600 *Indiana University Faculty Research Grant Program*. *The Impact of a Residential Outdoor Education Program on Youth with ADHD*. Knapp, D., & Dawson, S. (2015).

\$429,000 *National Institute of Health (Child Health and Human Development Section)*.  
Family Battle Buddies: Enhancing Parent-Adolescent Relationships Post-Deployment.  
Gilbert, K. (PI), McCormick, B., Beckmeyer, J., Dawson, S., & Gilbert, R.

\$420,000 *Bureau of Educational and Cultural Affairs at the State Department*.  
Partnerships for Learning and AccessibilitY (PLAY): New Possibilities for Enhancing  
Recreation and Sport Access for People with Disabilities through Service Learning

\$100,000 *Impact 100*: Equine Assisted Therapy Program in partnership with Horseshoes  
of Hope and the Autism Society of Morgan County

\$100,000 *Impact 100*: 30-day therapeutic residential program for youth at-risk in  
partnership with IUPUI faculty member Dr. Jomo Mutegi

\$25,000 *Women's Philanthropic Grant at Indiana University*: "STICC with It" A year  
round program to fight childhood obesity through the use of Social Treatment in  
Comparison Cohorts.

### **Honors and awards**

*Adjunct Faculty Teaching Award (2016-2017 academic year)*. Student choice award for  
excellence in adjunct teaching

*Unsung Hero of the School of Public Health 2016 Award*: Given to the staff member that  
displays "selfless devotion to serving others".

*Adjunct Faculty Excellence in Teaching Award (2015-2016 academic year)* in the  
Department of Recreation, Park, and Tourism Studies at the School of Public Health at  
Indiana University. Nominated by faculty.

Nominated by the American Camp Association in 2016 for the *White House Champion of  
Change in Summer Opportunities*. The program of the White House aims to recognize  
individuals that turn "summer from a time of loss to a time of great gain"

*Eleanor Eells Excellence in Programming Award* to the Therapeutic Recreation Program  
at Bradford Woods. Awarded by the American Camp Association at their national  
conference in February 2012 for the top national camp programs for protected  
populations. This award focused on the medical camp research being conducted at  
Bradford Woods.

*Glenn A. Haskins Award (Outstanding Senior Male Student)*  
Awarded by Kent State University's School of Exercise, Leisure, and Sport

Golden Key National Honor Society Inductee  
Awarded by Kent State University's School of Exercise, Leisure, and Sport

## **RESEARCH AND SCHOLARLY ACTIVITIES**

### **Research Overview:**

My research is focused on the development of innovative evidence based health and wellness programs for youth and families impacted by disabilities, chronic illnesses, and life stressors.

### **Funded Research:**

\$24,373 (Dawson, S. 11/1/16-7/15/17) Morgan County Community Foundation: N.O.A.H. Network Funding for a Physical Activity and Nutrition Pilot Program for area Youth

\$58,225.09 Dawson, S. (9/30/16-9/30/17) *N.O.A.H. Network Pilot Study*: Nutrition, Outdoor Activity, and Health Program for Youth. Year-long pilot program to develop and test a program that addresses obesity and diabetes in adolescents from Morgan County, Indiana.

\$900 to *fund an undergraduate student in the School of Public Health* to work on the Pediatric Chronic Pain Research Project. Taught and supervised one student in transcribing qualitative interviews and the literature review process.

\$30,000 from the *Research and Creative Activity Committee in the School of Public Health* at Indiana University to develop a Pediatric Health Institute that has the mission of creating evidence based programs for youth and families in need.

\$ 5,000 *Pediatric Pain Management: A pilot study exploring the efficacy of a therapeutic pain management camp for youth and parents*. Shay Dawson and Dr. Eric Scott

\$ 17,000 *Building Resiliency Through the Family War Buddies Program* (2013): Dr. Kathy Gilbert, Dr. Jonathon Beckmeyer, Shay Dawson, Rebecca Gilbert

\$7,722.34 *The specialized camping experience: Examining social acceptance, quality of life, and active living among youth with disabilities* (2011). Piatt, J., Knapp, D., Devine, M. A., Dawson, S., Bennett, J.

\$24,000 *Outcomes of the Summer Camp Experience for Youth with Chronic Illness and/or Disabilities*, (2009) Dr. Doug Knapp (PI), Shay Dawson, & Dr. James Farmer

### **Publications:**

#### **Book Chapters**

Dawson, S. (2017) International Classification of Disability, Health, and Function. *In Perspectives of Recreational Therapy*. Eds. Austin, D. & McCormick, B. Sagamore Publishing, IL.

Piatt, J. & Dawson, S. (2015). Pediatric Practice. In *Recreational Therapy: An Introduction*. Eds, Austin, D., Crawford, M., McCormick, B., VanPuybroeck, M.. Sagamore Publishing, IL.

Gilbert, K., Gilbert, R., Dawson, S., Beckmeyer, J., & McCormick, B. (2015). The Family Battle Buddies Program. In *This Land Is Your Land: Toward a Better Understanding of Nature's Resiliency-Building and Restorative Power for Armed Forces Personnel, Veterans, and their Families*. Sagamore Publishing

### Peer Reviewed Research

Knapp, D., Dawson, S., Piatt, J., & Devine, M.A., Knackmuhs, E. (in press). The Comfort Derived from Social Comparisons at a Camp for Youth with Neuromuscular Disease. *American Journal of Recreation Therapy*

Dawson, S., McCormick, B., Li, Jing (in press). Egocentric Social Network Analysis of a Medical Camp for Youth with Physical Disabilities. *Therapeutic Recreation Journal*.

Dawson, S. (2017). Social Inoculation and the Extinguishing Effects of Pediatric Medical Camps: Proposing a Framework for the Other 51 Weeks a Year. *Journal of Recreation, Parks, and Tourism in Public Health*, 1 (1).

Dawson, S., Gilbert, K., Gilbert, R., Beckmeyer, J., & McCormick, B. (2016). Family Battle Buddies Program: A Therapeutic Program for Reintegrating National Guard Families. *American Journal of Recreation Therapy*, 15, (2).

Devine, M.A., Piatt, J., Dawson, S. (2015). The role of a disability-specific camp in promoting social acceptance and quality of life for youth with hearing impairments. *Therapeutic Recreation Journal*, 49, (4)

Knapp, D., Devine, M.A., Dawson, S., & Piatt, S. (2015) Examining Perceptions of Social Acceptance and Quality of Life of Pediatric Campers with Physical Disabilities, *Children's Health Care*, 44:1, 1-16, DOI:[10.1080/02739615.2013.870041](https://doi.org/10.1080/02739615.2013.870041)

Dawson, S. & Knapp, D. (2014). Brining "Camp War Buddies" to the Home Front. National Research Forum Book of Abstracts. American Camp Association National Conference, Orlando, FL.

Devine, M.A. & Dawson, S. (2014). Disability Specific Camp Experience: Results of a National Study. National Research Forum Book of Abstracts. American Camp Association, Orlando, FL.

Dawson, S., Knapp, D., & Farmer, J. (2012). "These are my war buddies": Exploring the Therapeutic Benefits of Social Comparison at a Pediatric Oncology Camp". *Therapeutic Recreation Journal*. 46 (4), 313-325.

Dawson, S. & Liddicoat, K. (2009) "Camp Gives Me Hope": Exploring the Therapeutic Use of Community for Adults with Cerebral Palsy" *Therapeutic Recreation Journal*, 43(4), 9-24.

Devine, M.A., & Dawson, S.D., (2010) "The Effect of a Residential Camp Experience on Self Esteem and Social Acceptance of Youth with Craniofacial Differences." *Therapeutic Recreation Journal*, 44 (2), 105-120.

Liddicoat, K., Dawson, S., Kincade, L., (2008). At Home, At Camp: Exploring the Meaning of Camp for Adults with Disabilities. Abstracts from the Coalition of Education in the Outdoors Ninth Biannual Research Symposium. Cortland, NY: CEO

#### Manuscripts in Progress:

Dawson, S., Means, T., Fry, G., Fly, A. Chomistek, A., & Piatt, J. (in progress). N.O.A.H. Network: A Nutrition, Outdoor Activity, and Health Program for Adolescents

Dawson, S., Eldridge, L., & McCormick, B., (in progress). Comparing the Efficacy of an Autism Specific Equine Assisted Therapy Intervention in Serbia and the U.S.A.

Dawson, S. (in progress). Egocentric Social Network Analysis of Youth with Physical Assigned a Year-round Mentor as an Adjunct to Residential Medical Camp

Dawson, S. (in progress). Qualitative Phenomenological Perspective of a Mentor Program for Youth and Adults with Physical Disabilities.

Dawson, S. (in progress). Examining the Perceptions of Mattering and Self Esteem for Youth with Physical Disabilities Assigned Year Long Mentor with the Same Disability

Dawson, S.D., & Mowatt, R., (in progress). Analytic Auto Ethnography on Cancer: Implications for Developing Oncology Support Programs Using Social Comparisons and Post Traumatic Growth Approaches

Dawson, S. & McCormick, B. (in progress). Responding to the Call for a Recreation Therapy Social Support Practice Model

Dawson, S. & McCormick, B. (in progress). Theoretical Foundation of a Recreation Therapy Social Support Practice Model

Devine, M.A., Piatt, J., Dawson, S. & Knapp, D. (in progress). National Camp Study: Quantitative Analysis of Medically Specific Camp Participation for Youth with Serious Medical Conditions

Gilbert, R., Dawson, S., Gilbert, K., McCormick, B. & Beckmeyer, J. (in progress). Evaluating the Family Battle Buddies Program: Research Findings and Implications for Use with Reintegrating National Guard Families.

Scott, E., & Dawson, S., (in progress). Pediatric Chronic Pain Management: A Therapeutic Pilot Program.

**Poster Presentations:**

Dawson, S. (2016). *Social Inoculation at Pediatric Medical Camps: An Opportunity for Health Related Booster Programs*. Parks, Recreation, and Public Health Symposium, Bloomington, Indiana.

Dawson, S. & Knapp, D. (2014). *Brining "Camp War Buddies" to the Home Front*. American Camp Association National Conference, Orlando, FL.

Devine, M.A. & Dawson, S. (2014). *Disability Specific Camp Experience: Results of a National Study*. American Camp Association, Orlando, FL.

Gilbert, R., Dawson, S., & McCormick, B. (2013). *Family Battle Buddies Program*. American Therapeutic Recreation Association National Conference.

Devine, M.A., & Dawson, S (2010). *Promoting Self-Esteem with Youth and Adolescents with Cranial Facial Differences in a Residential Camp Setting*. American Camp Association National Conference, Denver, Colorado

Liddicoat, K., Dawson, S., & Kincade, L. (2008). *At home, At camp: Exploring the Meaning of Camp for Adults with Disabilities*. Coalition for Education in the Outdoors Research Symposium

**INSTITUTION INVOLVEMENTS**

**Teaching:**

*SPH-Y 562: Social Psychology of Therapeutic Recreation* (3 credit online graduate course)

*SPH-R 413: Fiscal Management in Leisure Services* (3 credit undergraduate core course)

*SPH-R 250: International Comparative Exchange: Services for Children with Disabilities*. Serbian Pediatric Social Service Exchange (3 credit undergraduate summer intensive). Included trip with IU students to Serbia for three weeks and a return trip to Bradford Woods to host Serbian college students studying special education and rehabilitation. Summer 2016 & 2017

*Y 563 Program Development and Consultation* (3 credit online graduate course) Spring 2017, Spring 2018.

*Y 561 Advanced Processes in Recreational Therapy Practice* (3 credit online graduate course) Spring 2016, Spring 2018

*SPH-Y 277 Foundations of Recreation Therapy* (3 credit undergraduate) Spring 2015

*SPH-Y 225 Disability, Health, and Function* (3 credit undergraduate) Fall 2014, Fall 2015, Fall 2016, Fall 2017

*Y 379 Recreational Therapy Interventions and Evaluation Lab* (1 credit undergraduate) Spring 2014

*R301 Pre-internship and Professionalism in Recreational Therapy* (1 credit undergraduate course) Fall 2012

*R379 Clinical Practice in Recreational Therapy* (3 credit undergraduate course) Spring 2008, Spring 2009, Spring 2010, Spring 2011

*R511 Leadership in Challenge Education* (2 credit graduate course) Fall 2009

**Field experience supervision:**

2002

- Hosted four undergraduate practicum student from Kent State University studying recreation or therapeutic recreation (Respite and Recreation Program)

2006

- Hosted two undergraduate practicum experiences that met therapeutic recreation standards for Ohio University's TR program

2007

- Hosted one undergraduate intern experience that met NCTRC and Ohio University standards for therapeutic recreation
- Hosted two doctoral practicum experiences that met standards for Indiana University's Therapeutic Outdoor Programs Certificate for graduate students

2008

- Hosted three undergraduate intern experiences in therapeutic recreation that met NCTRC standards from University of New Hampshire, Ashland University, and Indiana University
- Hosted one doctoral practicum experience that fulfilled doctoral requirements for Therapeutic Outdoor Programs Certificate
- Hosted one practicum experience that meet standards for Indiana University Therapeutic Outdoor Programs undergraduate minor
- Hosted one undergraduate internship that fulfilled requirements for Ithaca College occupational therapy student in Dana Internship program
- Hosted one undergraduate internship experience that fulfilled requirements for a student from Trine University



- Hosted two undergraduate student volunteer experiences in a recreational therapy setting from Indiana University that met volunteer hour requirements.
- Hosted therapeutic recreation student from Wisconsin, La Crosse for professional experience hours.
- Hosted undergraduate internship of student from Manchester College.

#### 2009

- Spring Therapeutic Recreation Intern, Old Dominion University
- Therapeutic Recreation Intern, Central Michigan University
- Therapeutic Recreation Intern, University of Utah
- Therapeutic Recreation Intern, University of Tennessee-Knoxville
- Therapeutic Recreation Intern, Central Michigan University
- Therapeutic Recreation practicum, Eastern Illinois University
- Therapeutic Recreation practicum, Grand Valley State University
- Therapeutic Recreation practicum, Grand Valley State University
- Therapeutic Recreation practicum, Indiana University
- Therapeutic Outdoor Programs Practicum, Indiana University
- Recreation Internship, Murray State
- Pharmacy Volunteer Hours, Butler University
- Pharmacy Volunteer Hours, Butler University
- Volunteer, Indiana University School of Medicine Volunteer Hours
- Therapeutic Recreation Practicum, Carson-Newman
- Pharmacy Volunteer Hours, Butler University
- Pharmacy Volunteer Hours, Butler University
- Nursing credit hours, University of Illinois-Chicago
- Pharmacy Volunteer Hours, Butler University
- Nursing credit hours, University of Illinois-Chicago

#### 2010

- Therapeutic Recreation Intern, Indiana University (undergraduate)
- Therapeutic Recreation Intern, Indiana University (graduate)
- Therapeutic Recreation Intern, Florida International University

#### 2012

- Doctoral student in recreation therapy, Indiana University. Site partner for dissertation project on families impacted by autism

#### 2014

- Doctorate Nurse Practitioner (DNP), Southern Indiana University. Practice partner for standardized handoff tool for pediatric special needs camping environments

#### 2018

- Internship supervisor for 22 undergraduate students and 2 master's students completing NCTRC required internships

### **Institutional Service**

*Inter-professional Development Faculty member (2016-2017).* IPE (Inter-professional Practice and Education) facilitator for allied health students across campus. This includes students from the School of Public Health and the recreational therapy academic track.

*Butler University Farm Hub / Biology Department Advisory Committee (2016-2018).* As part of a National Science Foundation grant, serve on an advisory committee to develop experiential learning modules within the Biology Department Curriculum that connects with the Butler University Farm.

*NCTRC Scholarship Committee (2017).* Create and facilitate a new scholarship fund to promote clinical competency in recreational therapy professionals (2017-present).

*Undergraduate Recreational Therapy Coordinator, School of Public Health-Bloomington (2017-2018)*

*Medical Focused Camp Committee (2016-2017).* American Camp Association at-large member

*Centers and Institutes Co-Chair (2014-2015).* School of Public Health, Indiana University. At-Large Member since 2012.

*Adapted Sport Clinic Steering Committee (2014-2016).* Development and implementation of community adapted sport clinic in partnership with the YMCA, Rehabilitation Hospital of Indiana, and the School of Public Health students and faculty.

*NCTRC Executive Director Search Committee Member (2015).* One of five members committed to hiring new Executive Director of NCTRC to replace the retiring ED.

*American Therapeutic Recreation Association (2014).* Mission & Vision Task Force

*Workforce Development Search Committee (2016).* School of Public Health-Bloomington, Indiana University

*Health and Wellness Coordinator Search Committee (2016).* IU Health Center at Indiana University

*Journal Reviewer (2017).* Journal of Pediatric Nursing

*Journal Reviewer (2017)* Journal of Youth Development

*Journal Reviewer (2016).* Pediatric Rehabilitative Medicine

*Journal Reviewer (2016).* Adapted Physical Activity Quarterly

*Journal Reviewer (2014).* Children Australia

*Associate Editor for Pediatric Health* (2012- Present). American Journal of Recreation Therapy

*Associate Editor* (2013- Present). Therapeutic Recreation Journal

*Therapeutic Outdoor Programs Committee Member* (2007-Present). School of Public Health-Bloomington, Indiana University.

*Chairman (President) of the Board* (2012-2013). National Council for Therapeutic Recreation Certification. Served as the highest ranking official in the organization, providing collaborative direction and supervision for the CTRS credential of over 14,000 recreational therapists throughout the United States and Canada. Standards Hearing Committee Board Liason (2010-2011) and Vice Chair (2011-2012).

*Board Member* (2007). Cool Springs Retreat and Camp, New Concord, Ohio. Provide therapeutic recreation programming ideas, give direction on ADA accessibility and universal design guidelines, and provide guidance regarding clients with disabilities and disease in the start up phases of this organization.

*Therapeutic Recreation Faculty Recruitment Committee* (2002). Kent State University's School of Exercise, Leisure, and Sport

#### **OTHER INFORMATION-**

- *American Camp Association Accreditation Co-Lead* (2007 & 2010)
- *JAHCO Accreditation Committee Member* (2005) – Genesis HealthCare Systems
- Indiana University (Spring 2008)- Legal Compliance Series for Supervisors
- Genesis HealthCare Systems (Bethesda Hospital)
  - Management and Leadership Trainings (2005 / 2006)
  - Aggression Management Systems Training (2005 / 2006)
- *Sea Perch Robotics Head Coach* (2014-2016). Marlin Elementary School Underwater Robotics Program. Team placed 13<sup>th</sup> nationally at University of Southern Mississippi competition in 2014.
- *Underground volunteer for elementary children* (2014-2017). ECC Church in Bloomington, IN
- *4/5<sup>th</sup> grade weekly teacher for Huddles* (2017-2018). ECC Church in Bloomington, IN.
- *IEP Surrogate Parent Program* (2004-2005). Southeast Ohio School Systems program through the State of Ohio to support youth without guardian representation on their Individual Education Plans.
- *Small Group Leader for College / Career Age Bible Study* (2004 –2006). Zanesville, Oh CMA Church.
- *Graduate Assistant* (2002-2003). Kent State University

- *Co-coordinator and Founder of Project Hands and Feet (2001-2003):* Providing tangible support to those in need from the Kent, Ohio community.
- *Mission Trip Co-Leader (2003).* Helped to lead a trip to the Duval Home, a 250 bed facility for people with disabilities. Trained, organized the trip for college students from Kent State University.
- *Friday Nights Volunteer (2000).* Homeless soup kitchen sponsored by the King's Arms Church