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Using Photovoice with adults with developmental disabilities to measure camp goals

An Honors Thesis submitted in partial fulfillment of the requirements for Honors in
School of Human Ecology

By
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Under the mentorship of *Dr. Jerri Kropp and Dr. Brent Wolfe*

ABSTRACT

This project addressed the perspectives of adults with developmental disabilities in a residential camp setting, with a particular focus on health beliefs. It involved 15 participants with a range of diagnoses in participatory action research using Photovoice, which is a technique that allows marginalized groups the ability to voice specific needs through photography. For the purposes of this project, subjects took photos and examined evidence of healthy living skills learned during the camp experience. After analyzing data collected, the researcher identified four separate definitions of health discussed by participants. Study findings suggest that the residential camp experience has a positive impact of understandings of healthy living skills for adults with developmental disabilities.

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Introduction

This project will address the perspectives of adults with cognitive disabilities in a residential camp setting, with a particular focus on health beliefs. Participants at Camp Sunny Skies, a week-long camp for adults with cognitive disabilities, attended a free choice activity and were asked to identify “what does it look like to be healthy at camp?” using photography. Following this, campers attended a second free choice activity where they participated in a focus group, working together to discuss photographs which answered the target question.

Through participation in this research, campers and others benefitted from knowledge gained in a variety of ways. Campers received the opportunity for equal engagement in research, the results of which will in turn directly affect their lives while at Camp Sunny Skies, which is a camp for adults with cognitive disabilities. This process of empowerment allowed them to be able to firmly take ownership of not only this one activity, but the implications of results found for future camps (Wang & Burris, 1994). Additionally, the campers sought to gain more in depth relationships with one another by joining in an activity that promotes teamwork and facilitated discussion. Further development of a strong social support network is vital for this population, because many lose access to community foundations as time goes on (Jurkowski & Paul-Ward, 2007). Camp Sunny Skies itself benefitted primarily through the results of this research. This project gave a new avenue to promote understanding of the mindsets of campers, as well as their grasp of goals and learning of objectives of camp. Moreover, the data analysis collected can be taken by camp staff and used in the future as a purpose for influencing financial decisions, motivated by the thoughts and actions of the campers themselves.

Again, this allows the campers themselves to have their say in how their community will be represented and affected.

Finally, this project sought to fill an identified gap in current literature regarding both Photovoice as well as literature working with adults with cognitive disabilities. There is a growing volume of research involving adults with disabilities. However, rarely does this research engage adults with disabilities by utilizing participatory action methods. This is also true when examining literature involving Photovoice with adults with cognitive disabilities. This work contributes to further literature through expanding upon previous work and advocating for the importance of this type of research.

Literature Review

Photovoice is defined as “a process by which people can identify, represent, and enhance their community through a specific photographic technique” (Wang & Burris, 1997, p. 369). It was developed first as “photo novella” in 1994 by researchers Wang and Burris, and then again redefined in 1997. With photography, Photovoice acts as a lens for social change and community growth. The primary purpose of Photovoice is to give voice to underrepresented populations and “use people’s photographic documentation of their everyday lives as an educational tool to record and reflect their own needs,” (Wang & Burris, 1994, p. 171). The literature on Photovoice is wide and encompassing of many disciplines. Photovoice is adaptable for use in three ways: a) health promotion, b) with diversified groups, and c) varied public health issues (Wang & Burris, 1997). The purpose of this review is to synthesize previous research relating to vulnerable populations, specifically adults with cognitive disabilities, and participation in

Photovoice methodology, as well as to expand upon gaps in the literature and identify future directions in research.

To begin, there are five characteristics that define participatory research with individuals with cognitive disabilities: equal engagement in the research process between participants and researchers, evidence of co-learning, empowerment of participants as a result of the process of research, an increase in participants' ability to engage in decisions that may have influence on their lives, and finally a balance between research conducted and actions taken as a result (Israel, Shulz, Parker, & Becker, 1998). Although there is a growing body of research on adults with disabilities, that research rarely incorporates the use of participatory action methodologies. Even rarer are studies specifically employing Photovoice methodology in research with individuals with cognitive disabilities. As Jurkowski and Paul-Ward (2007) argue, it is important to empower this population with the ability to "record and reflect on their healthy beliefs and priorities" (p. 2).

One example of this combination between literature engaging individuals with disabilities and literature involving Photovoice is found in Booth and Booth (2003). Researchers successfully used Photovoice working with mothers who had learning disabilities. Participants were asked to document their life through pictures in an attempt to challenge prejudice. Analysis of the results shed light on both the individual and collective experiences of the women in guiding through motherhood. The women were recruited through being members of a support group. The purpose of the study was to enable participants to continue to form a sense of their own identity. However, the study lacked future implications for Photovoice as a tool for participatory research involving individuals with disabilities. Instead, researchers primarily analyzed the results of the

project itself, meaning further research with vulnerable populations such as adults with cognitive disabilities is not only wide open in terms of potential variables of study, but necessary to continue to support the beliefs and perspectives of the community itself. There are common factors between the two projects, such as the research method and a similar population. However, Booth and Booth (2003) examined different factors in the lives of participants.

A second example of research implementing Photovoice with individuals with cognitive disabilities is the work of Jurkowski (2008; Jurkowski & Paul-Ward, 2007). The 2007 study recruited four participants with diagnoses of Cerebral Palsy and Down's syndrome living in the Chicago area. The common factor among them was being classified as an adult Latino with a mild to moderate cognitive disability. After undergoing training, the participants were asked to take pictures to reflect the target question "what they felt made them healthy or sick." The researchers reported that the majority of participants had no issues using the photography equipment and participating in the research. The researchers concluded that including participants with cognitive disabilities in Photovoice activities enables them to "actively participate and reflect on what influences their health as well as to record and reflect on their health beliefs and priorities," (Jurkowski & Paul-Ward, 2008, p. 7). An extension of the previous year's study, Jurkowski again in 2008 continued with the same population, Latino adults with cognitive disabilities. The purpose of this continuation was to give further support to the importance of including individuals with cognitive disabilities in participatory needs research. When reexamining the study, Jurkowski included limitations to this method, citing them as being uncommon to Photovoice. However, Photovoice differs from

traditional methods in that the method of data collection through photography allows individuals to physically document and then verbally present their own ideas and perspectives, as opposed to more traditional research methods that use a positivist epistemological framework that intend to study the population objectively from the outside.

Photovoice has not been used with the specific population of adult campers attending Camp Sunny Skies. However, this population has previously participated in research with Georgia Southern University, the purpose of which was to again help campers communicate their needs and wants from a residential camp experience. Previously, two Honors students from the School of Human Ecology completed and presented research involving this population. The first (Teilhaber, 2016) sought to understand the impressions of a weeklong camp experience for adults with cognitive/developmental disabilities. Data was collected through an online survey sent to participants following camp, with questions addressing conceptual, social, and practical domains. Results showed improvement in relation to these domains. Another study, also conducted in 2016 by Monk, examined the loss of socialization opportunities for individuals with disabilities following aging in correlation to perceived quality of life. Research explored how participation in a camp environment can increase these perceptions through participation in recreation and social activities. An online survey was administered and results found by comparing themes in the responses to themes in literature. It was ultimately found that camp experience does increase perceptions of quality of life for these individuals.

Prior research has been completed regarding the use of Photovoice with individuals with cognitive disabilities, yet there is a gap in the literature examining Photovoice use in a residential camp setting. However, recommendations in previous research have called for a continuation of this method in a variety of settings with specifically vulnerable populations as a means for extending their wants and needs. There is a desire for this particular methodology that allows this community to state their own perspectives on given topics; for example, voicing their ideas in relation to health attitudes and beliefs. As individuals with developmental disabilities are significantly more affected by health problems than their typically developing counterparts, the advancement of various health promotion programs, such as the activities featured at Camp Sunny Skies, is important both from a consideration of cost analysis and quality of life. Thus, taking into review the viewpoints of the intended audience is the first step into adapting research methods towards the needs of these individuals (Kuijken, Naaldenberg, Nijhuis-van der Sanden, & van Schrojenstein-Lantman de Valk, 2016).

Currently, there is a growing trend in the use of visual images for research conducted with individuals with developmental disabilities (Boxall & Ralph, 2009). This could be attributed to several factors, principally the idea that visual methods may offer a solution for greater participation and inclusion in research for these vulnerable populations. With the growing interest in these approaches as opposed to more traditional methodologies, there is also an increased scrutiny in terms of maintaining ethical research standards. McDonald and Stack (2014) created an expansive literature review in their recent publication. In this review, the researchers analyzed 21 studies involving adults with developmental disabilities in participatory action research. Each project described

research regarding social issues important to participants, such as quality of life, health, or advocacy, among others. Authors named motives for the studies that ranged from pursuing action in the name of inclusion of these adults in research to providing opportunities to share experiences or perspectives of participants. Following this, project challenges were discussed, citing difficulties receiving ethics committee approval due to misconceptions about the capabilities of adults with developmental disabilities (Stack & McDonald, 2014). Researchers considered this to be “at odds with the goals of action research” (p. 88).

A further look into the necessity for inclusive research methodologies for individuals with developmental disabilities revealed a study by Aldridge (2007). In this article, the author explores the conflict between prescribed academic criteria, which she refers to as “research strengths” (p. 1), and adequately and accordingly meeting the needs and experiences of vulnerable participants in research. In her study, Aldridge was looking to investigate the benefits of social and therapeutic horticulture (STH) for adults with learning disabilities and other vulnerable groups. Participants were given a disposable camera and asked to visualize their experiences of STH. This both allowed participants to reflect on their experiences as well as minimized any communication barriers between the participants and the researcher. It was found that user-led photography experiences are supportive and useful in facilitating the responses of individuals who do not respond to traditional methods (Aldridge, 2007). The results of this study further the idea that Photovoice methodology is appropriate for use with vulnerable populations who may otherwise have difficulty with more typical approaches to research design.

Research Questions/Hypotheses

The research question for this project addresses whether there is evidence of learning and understanding following participation in a weeklong residential camp experience. Finding an increase in awareness of camp goals is anticipated, specifically relating to healthy living skills gained from partaking in the camp experience. There is expected to be evidence of understanding of learning of objectives, which are healthy living skills, due to participation in camp activities. The campers will directly benefit from participation in this research in terms of cognitive objectives as well as socially through the addition of a new activity to the camp schedule. Additionally, it is expected that this research may be useful for camp staff in that information gained could be presented to stakeholders to promote further financial participation in the camp. It will help staff further understand what is working as well as what could be improved on as far as teaching healthy living skills to campers.

Method

Sample and Participant Selection

All research participants were campers at Camp Sunny Skies during March 2017. The mission of Camp Sunny Skies is to provide educational opportunities for adults with developmental disabilities through recreation and socialization. It is a non-profit organization operating through the model of hosting camps in two locations, Georgia and North Carolina. Participants at the 2017 camp in Georgia were recruited for this research project. Participants were recruited through administrative staff who facilitate Camp Sunny Skies. The founder and director of Camp Sunny Skies electronically sent information about the project in the form of a flyer, informed consent forms to

parent(s)/guardian(s), and a camper consent form to their adult guardians. All consent forms had been edited to the appropriate reading level. For guardians who approved of their dependent's participation and campers who chose to participate, the activity was added to their schedule for the week. This was done in the form of allowing campers to choose participation in the research activity as an option for a "free choice session," which is an activity period offered once daily where a list of several activities is given and the decision of which to attend is up to each individual. The research section (photographs) for Group A was offered on Tuesday, while Group B was offered during the same time slot on Wednesday. Then, each group met for a shorter period on Thursday to participate in focus groups for discussion of the photos (see Appendix for focus group questions). Participants self-selected which day to attend based off their own desires to engage in a different free choice activity on another day. A maximum of eight was allowed during each session of the Photovoice activity. For campers who chose to not participate, a list of the alternative free choice activities was added to their schedule at the discretion of the Camp Sunny Skies staff.

Subjects were 15 adults with cognitive disabilities, ages 21 and up. Some diagnoses included Autism Spectrum Disorder, Williams Syndrome, Traumatic Brain Injury, Chromosomal Abnormalities, and Trisomy 21. Of the group, ten were male and five were female. Each participant had previously attended Camp Sunny Skies at least once before. Eligibility requirements to participate in this activity matched the eligibility requirements to attend Camp Sunny Skies. Participants were required to be able to listen and follow simple directions, communicate their interests or needs, and able to participate

in the activity without significant medical or behavioral support. Additionally, participants needed to be willing to engage in a group activity outdoors.

Assessments and Measures

Photo collection was made possible through the loan of five Vivitar Vivicam F126 digital cameras. Four of these were pink and were the main cameras used by participants. The remaining blue camera was kept by the researcher in the event of another camera possibly dying during data collection. During the experiment, cameras were kept by the researcher during travel to and from individual locations. After arriving at a chosen location, the four cameras were distributed to the group, which had subdivided into smaller factions of two to three to take photos at each location.

When all locations were visited and the campers were finished taking photos, the photos were then downloaded from each camera into their prospective individual folder. Photos were evaluated by the researcher and faculty mentors for clarity. Because of time constraints in the schedule of Camp Sunny Skies and the desire of the researcher that participants not miss any additional camp events because of engaging in the focus group activity, the total number of photos from both groups were narrowed down followed the completion of the activity. This was done by the researcher and faculty mentors. Criteria for removal included repetition of a photo subject or a photo being blurry and indistinguishable.

The purpose of the focus group portion of the project was to identify health beliefs and perceptions of participants in relation to their experiences at Camp Sunny Skies. In the beginning, the purpose and directions for the focus group were made clear to participants before being asked permission to be recorded. Data collected was recorded

using a cell phone and then immediately afterwards transferred to a secure folder in preparation for transcription, under supervision of the researcher. Participants were prompted by questions such as “How does this photo remind you of being healthy at camp?” or “How does this photo relate to healthy things we do at camp?” The photos were grouped together by location, such as the farm or the dining hall. Participants were given time to examine the photos from each location and then discuss anything they thought was relevant pertaining to an individual photo or the location of a group of photos. This was done by a verbal or physical indication to the researcher, such as speaking or raising their hand. For a complete list of discussion prompts, see Appendix.

The verbal data collected from the focus groups was immediately downloaded and placed into a secure folder, one for each group, in the possession of the researcher. The recordings from both groups were transcribed by the researcher. Each transcription was de-identified and participants were given pseudonyms to remain unidentifiable.

Approach to Qualitative Analyses

Through the method of data collection, the researcher organized and participated in a qualitative study. A qualitative study focuses on the perspectives, beliefs, and feelings of a group of people, while a quantitative study is different in its traditional focus on numbers and statistics. Due to frequent criticisms of the effectiveness, reliability, and validity of qualitative research, it is vital that the researcher attempt to remove “as much subjectivity as possible” (Gaultney & Peach, 2016, p. 64). To promote reliability and validity, attentive and precise analysis of results is necessary. Development of a grounded theory is completed in three levels, each important to the progress of conceptualizing data found from the research experiment.

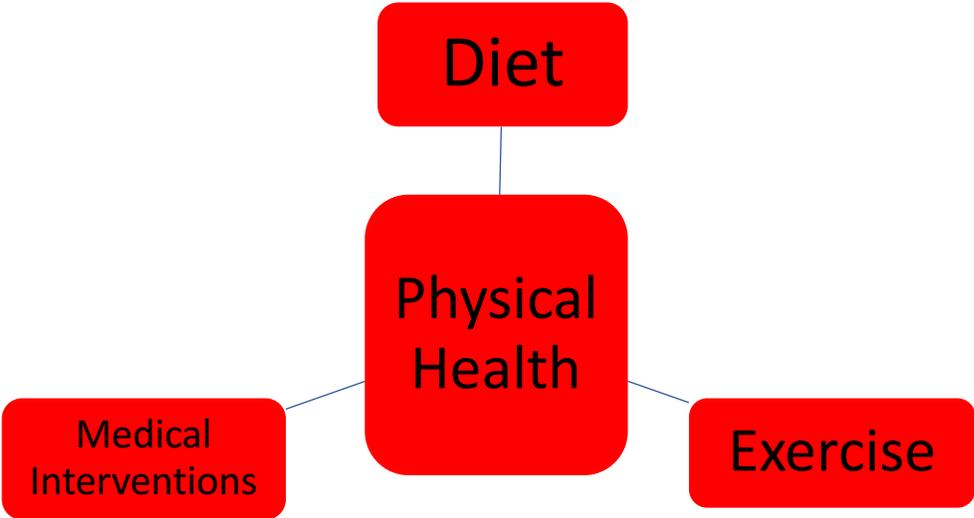
The first level, open coding, involves a categorizing of the ideas. Essentially, the researcher is searching for a pattern in the data. Axial coding evolves after patterns have been identified. In this stage, the researcher is looking for any links among the prior categories and whether there is evidence of any logical grouping. Finally, selective coding attempts to correlate the groupings from the previous section with core concepts in the field, (Gaultney & Peach, 2016, p. 64). Following these steps results in a Grounded Theory, which emerges from the data instead of beginning research with a preconceived notion of theory.

The researcher began by reading transcriptions from each focus group. Then, the researcher engaged in a process of line by line coding where each line of data was reviewed. This was to search for common or recurring themes that suggested common viewpoints or understandings between the campers. Due to similarities in the focus group transcriptions, the researcher combined the remarks of both groups into one document. During the process of open coding, four themes emerged from the reading of the transcripts: physical health, social/emotional health, spiritual health, and environmental health. Each category was then separated into its own individual document using axial coding, with results from only that specific category present on the document. It was apparent to the researcher that a larger part of the discussion focused on two topics, physical health and social emotional health. The other two topics, environmental health and spiritual health, were discussed to a lesser extent. Finally, using selective coding, results were restated in the form of a summary from the researcher on a second category specific document. To maintain reliability, this process was repeated by both project's faculty mentors, then compared with the data of the researcher.

Results

Physical Health

During analysis of the focus group conversations, a physical health theme emerged in the data. Physical health, “Relates to the efficient functioning of the body and its systems, and includes the physical capacity to perform tasks and physical fitness,” (Goodacre, Collins, & Slattery, 2013, p. 5). Campers listed three separate divisions to express physical health while at camp. These were in the form of diet, medical interventions, and exercise. Photos in this section that represented physical health were of archery, the gym, fishing, the putt-putt course, the swings, tether ball, a corn hole board, the dining hall, the farm, the lake, the nature trail, the med lodge, the playground, the tennis courts, trees, and a Zumba class.



The first of these three sub-categories that emerged was *diet*. Campers spoke repeatedly on diet when viewing various photos from the first day of picture taking, for example the farm or the dining hall. Diet was used to represent what campers have

learned from attending activities regarding the principles of healthy eating. One male camper chose to speak about a photo of the menu board in the dining hall, saying:

I'm gonna talk healthy now. The one of the borders, it shows you that you can have you know like healthy stuff and like there's an alternative to junk food and I mean that's like good I believe.

This camper is describing a menu board for the week of camp. In the photo, the menu board is divided into days of the week and then again by each meal time, listing the options for breakfast, lunch, and dinner. The camper considers this to be showing alternatives to junk food, as the board is filled with more traditionally healthy choices such as turkey sausage or fruit salad. This knowledge is something that can be utilized after camp ends and the campers return to their home environments. They have learned that you can plan healthier choices for eating rather than relying on junk food.

A second sub-category that developed through conversation with focus group participants related to *medical interventions*. Specifically, this came because of viewing photos of the med lodge and the Director of Health Services. The med lodge is the building at camp which houses the nursing staff and is the place to go if a camper is injured or sick. Campers detailed their understandings of physical health in relation to more tangible aspects of health, such as taking medication or receiving healthcare treatment. When looking at a photo of the Director of Health at camp, one male camper said, "Oh. This is the most important person in the camp. If we, if Kathy wasn't here, we'd all be dead. Probably halfway to being sick, but Kathy's very important."

This quote shows a correlation between the camper's understanding of Kathy's role and physical health. The campers have learned to trust her and her nursing staff to positively benefit their own health. It shows a recognition that Kathy is vital to the

physical health of participants due to her position and job duties. A second male camper elaborated by saying, “because if somebody gets sick or injured, it’s better to take them to the hospital, but it’s here.”

In this instance, this camper is referring to the med lodge and comparing it to a hospital setting. It can be inferred that the participant knows when someone is sick or injured while attending camp, the med lodge acts in a similar capacity to a more traditional health care environment.

A third item was discussed in terms of physical health: *exercise*. Perhaps the most typical perception of this domain, participants widely related the idea of physical health at camp to exercise. Many of the week’s activities revolved around exercise in some way, and several locations were named to take photos, such as the gym or tennis courts:

And um the thing that comes to mind when I look at a basketball is: number one, it’s a sport. Number two, it’s very engaging, very fast paced, very health-wise, it keeps your heart rate up, and it’s really energetic.

One male camper described a photo of playing basketball in the gym.

Specifically, several conditions positive to physical health were mentioned. The camper termed the action of playing basketball to not only be engaging and fast-paced, but that it raises heart rate and is energetic. These details are important in exercise to improve one’s physical health, which lends credibility to the idea that the camp has provided and taught activities to attendees that will not only strengthen their health in this domain, but teach them why and how the activities are beneficial.

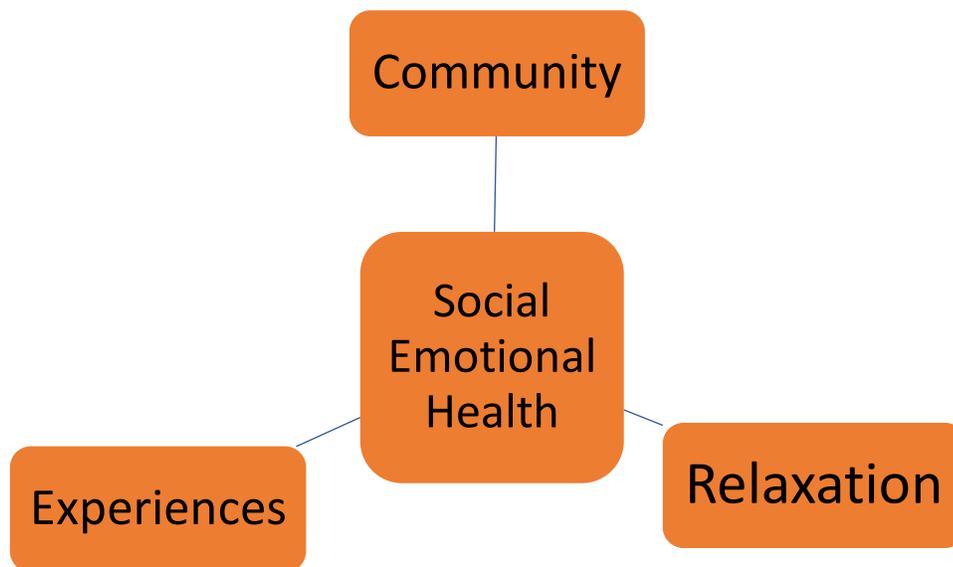
Social Emotional Health

A second theme, social emotional health, appeared during analysis. This theme can be understood as, “Within the context of one’s family, community and cultural background, social and emotional health is the developing capacity to form secure

relationships, experience and regulate emotions and, and explore and learn,”

(Georgetown University Center for Child and Human Development, 2017, para. 1).

Campers discussed three distinct ideas of social emotional health relating to community, relaxation, and experiences. Photos in this section that represented social emotional health were of archery, the soccer field, the cabins, the swings, the dining hall, the lake, the nature trail, the playground, the tennis courts, and trees.



In the context of social emotional health, campers used the idea of *community* to describe their peer relations while attending camp. In other words, campers described bonds formed by coming to camp. Also discussed were the various impacts on the campers’ social emotional health through forming secure relationships with other campers or staff members. While looking at a group of photos of several outdoor activities provided at camp, such as archery and tennis, one male camper related partaking in the activities as being fun and promoting a familial atmosphere:

They make, I mean, because we're here, because we're together as a family, it makes this camp one of the best camps we've ever been to and no other camp that I know of has ever involved a college in their program so far. At least that's what I know, I don't know if it's true or not, but that's what I believe. That's this big. And as a family we need to, you know, stay true to each other. We need to keep in contact with each other. That's how we keep, you know, each other safe. I mean we need to show each other that still we care about each other. That's the whole basis of camp is to enjoy each other's company and I think that these activities prove it.

This camper specifically states that his belief is that enjoying the activities at camp and enjoying the company of one another is the "whole basis of camp." In other words, the camp provides an opportunity for participants to form lasting bonds, in the hopes that contact will be continued after the week is over. Additionally, he brings up the inclusion of university students as volunteer staff. He uses this involvement as further evidence of the substantial importance of this camp and the services it provides.

Following this, a female participant chose to elaborate by saying:

I think having your, you know, by being part of a family, what I think is that we're being part of a family like part of our own families. It's the same way that our own families work. But here at camp, you know, is separate from our families because this is camp and this is our life here. I mean this is our life here at camp with our friends. You know we have a family and we have friends here and stay connected together. For example, me and Laurel got connected when we first started. When we first started camp we were stuck like glue, like pals. We were like pals forever. Because you know we were cabin-mates, I got her name and her last name and her number. That's how I learned to do being in contact with friends.

This is further support of the idea that campers consider their peers to be more like family members. However, the differences between "home family" and "camp family" are noted in the quote, which evidences a realization of different and evolving definitions of family. This quote also describes how the formation of a secure relationship is facilitated by coming to camp. By attending, creating that relationship, and then

separating at the end of the week, campers are given the opportunity to learn how to develop, cultivate, and maintain friendships in a healthy and productive manner.

A second context, *relaxation*, was discussed by campers to describe social emotional health. Through this, participants described the ways in which the camp provided opportunities to experience and regulate emotions. After looking at photos of the nature trail, one male camper described awareness of the ability to use surroundings to alleviate stress:

It tells you in health reasons, it tells you always embrace nature, that it can help us in a healthy way by being surrounded by it because it helps us relax from stress. Emotionally, from stress. Like, it's a good place to go meditate, to actually be at peace with your mind. Instead let the stress of your entire life go, like completely go. And then, at that very moment of relaxation, you're just at peace, listening to the animals, hear the ocean, hear the lakes, the rivers, everything. That's what this reminds me of.

For this participant, the opportunity to be outside and reflect in a natural setting has had a positive benefit in terms of social emotional health. It has reinforced the use of relaxation techniques that are taught during camp, such as meditation, to help take control of one's own emotions and alleviate stress. Later, a female camper provided more evidence of relaxation and stress relief at camp while examining photos from the dining hall:

There's also a picture I took, it could have been one of the blurry ones, but it was of the cafeteria/mess hall and it just uh reminds me of our, of the great times that we have when we're dancing to uh Peanut Butter & Jelly and also the World's Greatest and everything. And, and, I, I, that's one of the funnest times I think uh, after we're done having a meal here at camp, and I always love enjoying those because I let myself loose and I don't think about anything except being relaxed in that moment.

This camper is describing a ritual performed while at camp. Following the completion of each meal, campers and staff clean the dining hall while listening to music

and dancing. After all the cleaning is finished, everyone comes together for one final song. It's a tradition that serves to connect the camp throughout the day and reestablish ties between campers and staff. The quote reflects the emphasis on camp being an environment where campers can feel comfortable being themselves and let go.

Experiences were the final component of social emotional health that arose from analyzing the data. Through this came the knowledge of campers' ability to explore and learn in ways that emphatically advanced their social emotional health, particularly in terms of social interaction. Because of the previously referenced establishment of a secure community, campers could safely engage in positive interactions and participate in social activities. One male camper viewed a photo of the lakes at camp and said:

When I look at this picture, I see, you know, people, you know, oh it's not happening right now, it's too cold. But you know, people could swim in this type of water, people can swim in this type of lake. And you know there, you know, you can do all kinds of like swimming and rowing and tubing and uh paddle boats and all sorts of things to keep yourself healthy, keep yourself occupied. Cause swimming itself is a lot of fun and quite frankly, I love it.

This response demonstrates the camper's desire to be involved in social activities involving water while at camp. This participant listed several possible options, most of which involve multiple persons, such as tubing or paddle boating. It references the idea that the strong healthy bonds formed at camp lead to a high level of comfort in exploring social experiences. Campers have been able to seek new adventures because of feeling safe in their environment, thereby increasing their ownership of their own social health.

Environmental Health

A third theme emerged as a result of analysis of focus group conversations – environmental health. Environmental health, “addresses all the physical, chemical, and biological factors external to a person, and all the related factors impacting behaviors. It

encompasses the assessment and control of those environmental factors that can potentially affect health,” (World Health Organization, 2017, para. 1). Participants characterized environmental health in two separate ways: physical environment and immediate environment. Photos in this section that represented environmental health were of the cabins, the farm, the lake, the nature trail, and the treehouse.



Physical environment was used by participants to describe the world around them in terms of the setting, such as the water or grass. For the campers, this was mainly conceptualized in the form of what they were doing to better or improve their physical environment. When looking at a photo of compost, one female camper remarked, “and we recycle. And I took the picture of compost because it’s recycled eggshells.”

This came after a greater discussion on what had been learned from visiting the farm at camp and interacting with the staff there. It shows an understanding of the importance of environmental health, which came from being taught about the benefits of

composting food waste products. Another male camper spoke regarding a picture of composting toilets available for use on the nature trail:

It tells you that, that it's going to the environment, not actually being flushed down the sewer and stuff, into a septic tank. All your waste is going to one good use. Would you like to see?

The camper demonstrated knowledge of how the toilets work and the fact that there is no smell. Then, the camper says that the waste is going back into the environment for good use. This shows that an understanding of the purpose and importance of composting and how different waste products can be utilized to help the environment in a way that doesn't involve chemicals.

Immediate environment was used by participants to describe their personal environment while at camp. This personal environment was the areas they visited and interacted with each day, or their immediate surroundings. One male camper said:

I mean when you go into this place, you feel like you're in contact with Mother Nature. I mean cause it's built out of, you know, wood and everything else. Um, so it creates a different environment, but yet it's very, you know, interesting how it's put together. This one reminds me of you know, where lettuce or where um any other type of vegetable or fruit is, is uh grown and you know it's, it has to come from somewhere. It has to come from the ground up. I mean there's no other way for it to be grown other than from the ground up and that takes time and it takes a lot of work and I think Farmer Nolen has really regenerated and, you know, really done a great job teaching us the principles of how good healthy eating really is and this picture proves it.

This was said after looking at photos of the farm at camp. This is evidence that the camper understands that fruit and vegetables are grown and must come from somewhere, and the farm is an example of that kind of place at camp. He infers that Farmer Nolen has taught the campers the principles of farming and the importance of healthy eating. Later, a female camper described photos of the camp cabins:

Just that um about the cabins they look like you know, they kinda look like we have different cabins. You know the girl's side and the guy's side. So what I'm thinking is that by looking at the picture of the cabins is that you know you're safe and you're know talking to your cabin-mates and you know being close to your group.

The camper talks about the cabins and the idea of a protective environment. Also, the camper is specific about the difference between the boy and girl cabins, which shows that this physical environment has taught appropriate peer interaction.

Spiritual Health

One final theme, spiritual health, emerged from data analysis of the focus group transcripts. Of all preconceived domains of health, spiritual health is often the most difficult to attach a concrete definition, as "...there is no single recognized definition of spiritual health," (Bensley, 1991, p. 287). It is considered difficult to explain due to an absence of clearly defined parameters. However, spiritual health is generally measured in two ways, "the internal characteristics of those who are spiritually well, and the way in which spiritual individuals expresses themselves in their external interactions," (Hawks, 1994, p. 3). Internally, this could be used to describe a variety of factors, such as a purpose or meaning of life, a sense of relating to others or with nature, or a dedication to the idea of something greater than oneself. Externally, this could mean expression through characteristics such as trust, honesty, or acts of service and altruism. During data collection, spiritual health was divided two ways; external and internal interactions. Photos in this section that represented spiritual health were of the camp logo, a sign at the camp, the farm, and basketballs in the gym.



In the context of spiritual health at camp, *internal interactions* related to giving campers a sense of purpose or meaning in their lives. Campers spoke at length of the idea that this foundation was something bigger, something to be a part of. When asked if participants had any final thoughts regarding the photos or the activity, one male camper said:

When we do the big circle it reminds me of how big of a family this camp has grown and how great of a spirit this camp brings to all of us, and that's why we call this place our home. Because we love it. And that's what we do together, and that's what I think this pictures and others remind us of.

What this camper calls “the big circle” is the opening ceremony on the first day.

All campers and staff gather together in a large circle outside. It is the first chance to begin connecting as a group, both within individual small groups and together as an overall camp. This participant describes the great spirit camp brings to everyone involved. This shows an understanding of how being a part of something outside of one's

self has positively influenced internal spiritual growth by giving the camper an opportunity to cultivate this health domain.

External interactions occurred when campers described outward expressions of specific characteristics. For example, aspects such as trust or honesty were commonly considered by participants to be abundant in this environment. Around the grounds of the site, various painted signs are posted or nailed to trees. These signs typically include short motivational quotes or phrases from popular movies. One female camper took a photo of a sign and used it to describe external spiritual health:

It says I just like to smile, smiling is my favorite, and I am one who likes to smile and be happy and sometimes if I have a negative feeling or I am sad or something, I try to smile if I'm around certain people. Because I don't want them to know that I am feeling down or anything. It's people that I surround myself that I, I care about that I want to know my actual real true feelings and what I'm feeling about and this one just reminds to, you know smile and just, uh enjoy the day when I'm around those who I don't consider to be close to me. And it's actually on a difficult day, which did happen this week for me, and I had the courage to come back to camp despite the difficult day landing on Wednesday and that was the anniversary of my dad's passing one year ago. And, this one, this one just reminded me to, just to, to at least try to have some fun while I'm here and not concentrate so much on that negative feeling on that day.

In this quote, the camper describes feelings of being back participating in camp during the anniversary of the death of a loved one. The camper explains that around certain people, perhaps acquaintances or those with whom a strong relationship hasn't been formed, there is a desire to smile and hide true feelings. However, when around people who are known and trusted, it's accepted to be more transparent with emotion. This is evidence that the environment of camp provides a place for those in attendance to share those external characteristics, to be honest and trusting, and to strengthen their personal spiritual health.

Discussion

The aim of this study was to explore attitudes relating to understanding of various health domains in the chosen population, adults with developmental disabilities. Specifically, the project attempted to determine whether there was evidence of understanding of health domains following participation in a weeklong residential camp experience. Currently, literature involving individuals with developmental disabilities is extremely limited with respect to their own perspectives. Therefore, this research was conducted using a methodology that allowed participants, 15 adults with various developmental disabilities, to voice their own beliefs related to a particular topic. This gave the researcher an opportunity to gain a greater awareness and knowledge of both this population and their perceptions of health. Through analysis of focus group data, not only did participants appear to articulate a well developed concept of health, their responses led to the development of four identified health domains: physical, social and emotional, environmental, and spiritual health. This study found that through attending a weeklong residential camp and participating in camp education and activities, participants demonstrated a better understanding of health and were able to clearly articulate four specific domains of health. These four domains were identified by the researcher during analysis of the results. The emergence of four separate domains of health lends credibility to the complex understandings of what it means to be healthy among this population. Despite the varied levels of disability among participants, the different definitions of health were discussed at length in a way that demands the removal of any preconceived biases relating to the abilities of those with developmental disabilities to discern and elaborate on a complex topic such as health.

As previously stated in the literature review, individuals with developmental disabilities are rarely involved in participatory action research. However, as argued by Jurkowski and Paul-Ward (2007), it is important to allow this participation in research to give individuals the opportunity to “record and reflect on their healthy beliefs and priorities” (p. 2). The results of this study corroborated with Jurkowski and Paul-Ward (2008) in the idea that participation enabled the campers to “actively participate and reflect on what influences their health as well as to record and reflect on their health beliefs and priorities” (p. 7). Using photography and focus groups as the methods for data collection allowed for participants to physically document and then verbally present their ideas relating to health beliefs, specifically what they had learned from attending camp.

Prior to conducting the research activity and focus group portions of the project, the researcher was unsure as to depth of responses and insights that might be presented by the participants. Because of the variability in diagnoses among participants as well as cognitive ability to understand the target question and respond, the exact thoughtfulness and quality of the content expected was unknown. However, there was expected to be an increase in awareness of camp goals, specifically relating to healthy living skills gained from partaking in the camp experience. Previous research involving adults with developmental disabilities that measured health perceptions showcased the abilities of this population to voice their health beliefs. One study, which measured health perceptions of adults with mild to moderate intellectual disabilities, found “results indicated that the participants have a good understanding of what healthy living entails: they are able to identify healthy and unhealthy foods, they are aware of the potential harms of alcohol and smoking and they are aware of the benefits of exercising regularly,

cooking healthily and taking enough rest” (Kuijken, Naaldenberg, Nijhuis-van der Sanden, & van Schrojenstein-Lantman de Valk, 2016, p. 239). This further validated the results found from conducting research at Camp Sunny Skies, which revealed that from participating in camp activities, campers have gained a deeper understanding of health goals in not only the physical domain, which was expected by researchers, but also in terms of environmental, spiritual, and social emotional health.

The intent of this study was to find an increase in understanding of healthy living skills because of attendance at a weeklong residential camp experience. Based on overall findings, it appears that participation in camp activities increased their knowledge of healthy living skills in a variety of functions, as well as why and how these skills are beneficial to their lives after camp. This knowledge led to campers having a better understanding of health across four domains; physical, social and emotional, environmental, and spiritual health. The campers ability to articulate these four domains of health are an indication of the camp itself meeting its goal of teaching healthy living skills that are learned and applicable for a period past the end of camp.

Limitations and Future Directions

Although study participants appeared to have a greater understanding of health domains, there were some limitations of the current study. The study was limited in the number of participants because of scheduling restrictions of the camp. Camp attendance during this week was over 75 adults with developmental disabilities. However, only two groups with a maximum of eight each could participate, and 15 total attended the activity. Thus, results may not be representative of the full camp’s population. A second limitation is the self-selection of participants. No efforts were made to obtain a representative

sample. Subjects were informed of the study and given the opportunity to engage in the project if desired. This could have resulted in a bias in terms of participants' relationship to the researcher. As no effort was made to randomize participants or exclude those who were close to the researcher by virtue of the researcher serving in a volunteer capacity while at camp, participants could have been influenced to participate in the project. Moreover, campers with a higher level of cognitive functioning could have been indirectly influenced by the nature of the project to participate because of the ways in which information regarding the study was presented to the campers. In other words, those with higher levels of functioning could have been more likely to sign up to participate due to a greater understanding of the purpose and requirements of the study.

In the future, further research is recommended to allow individuals with developmental disabilities to share their voices on issues that directly affect their community. Individuals with developmental disabilities are often significantly more affected by health issues than their typically developing peers, so inclusion in research and the promotion of health education programs such as camp are vitally important for future practice. Additional research could be conducted by identifying other camps in various geographical locations and replicating the current study. This larger data pool could prove beneficial in involving participants with a wider array of disabilities and strengthening results through the inclusion of more health perspectives. Additionally, it could be beneficial to explore ways in which this research could be modified to include perspectives of camp staff or volunteers and how they feel participation in camp has affected health education, which could serve to potentially enhance health promotion and activities with this population.

Reflective Critique

More than anything, the completion of this undergraduate thesis project has pushed me to accomplish feats I would have never imagined possible. Prior to my joining the Honors program, I considered myself to be a slightly above average student. Intelligent, yes, but not a student who went above and beyond, or a student who pushed boundaries. This project has almost certainly changed that. I chose to tackle a topic that at the time seemed fun and inspirational, but I was unaware of just how massive it would become, or how much it would teach me in the process.

This project has not only made me a better student, but has molded me into a researcher. I appreciate greater than before the value and importance of research within my discipline, and I now understand how each project has an impact on our breadth of knowledge of development and how that contributes to our understanding of human motivation overall. Without this project, I would not be as in love with what I study every day. It reignited my passion for Child and Family Development and helped me to discover where I belonged in my future endeavors.

Finally, from completing this project I know what it truly means to advocate, both for myself and others. I have grown in confidence in my own abilities and know with certainty that what I have to say and the things I contribute to my field are valid and worthwhile. Also, through the topic I chose, I gained a stronger grasp on what it means to stand up for those who are sometimes unable to stand up for themselves. I have learned how to use my voice and my position to change the conversation, to give the spotlight to a group that is typically stuck in the shadows. The growth that I see in myself on both an

academic and personal level in the past year and a half is sometimes unimaginable, and yet I know that this is just the beginning for me.

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Appendix: Focus group discussion prompts

1. Okay, what does that picture that you just picked up tell you about being healthy at camp?
2. What does that tell you about being healthy at camp?
3. Does anybody have anything else they would like to add about the farm pictures?
4. Can I ask you guys what these pictures make you think about being healthy here at camp? What is, what do the Med Lodge pictures make you think about that?
5. Does anybody have anything to say about what the playground pictures make them think about being healthy while here at camp?
6. What does that tell you about being healthy?
7. Specifically, how's it healthy? How's it show you about being healthy?
8. How does it remind you of being healthy?
9. So, does anybody wanna talk about how the cabins here at camp remind us of being healthy?
10. Does anyone have any last final thoughts about all these pictures that we looked at today and how they remind you about being healthy at camp?
11. What does the camp teach you about being healthy?
12. Does anyone have any other comments about what the dining hall makes you think about being healthy at camp?
13. How do the deviled eggs remind you about being healthy at camp?
14. If you could just look and pass them down and give me some comments about what the treehouse pictures make you think about being healthy at camp?
15. How does that remind you of being healthy at camp?

16. How do alpacas remind you about being healthy?
17. What these places like the lake and the fishing dock, how do they remind you about being healthy at camp?
18. What do these activities that you guys took pictures of, how do they remind you of being healthy at camp?
19. So what do the pictures that we took at the gym tell you guys about being healthy?
20. What does the picture of them playing basketball make you think of being healthy at camp?
21. What do the cabins here at camp remind us about being healthy?
22. Does anyone wanna say any final things about what any of the pictures we looked at make you think of being healthy at camp?