ABSTRACT

Camp John Marc and the Partnership Model

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Camping for children with chronic illnesses and physical challenges has become an established part of the industry with several different models of operation being created. Research has confirmed that camp experiences benefit the patients that participate in them, including an increase in their confidence and independence. In 1987, the process of creating Camp John Marc was started. Along with a new camp for this population, they created a new model of operating, the partnership model. It allows multiple groups to unite behind the common goal of serving the patient population that attends the camp. They partnered with community organizations and pediatric hospitals to best accomplish their mission. In designing a camp of this type, there are many considerations including location, facility design, activities, programming, personnel, and the diagnoses that are served. This project presents a profile of the development of Camp John Marc and the partnership model with attention to these considerations. It was put together to provide an overview of a model of operations and a history with which others in the industry can learn about and implement elements of partnership in their own camping programs.

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CAMP JOHN MARC AND THE PARTNERSHIP MODEL IN CAMPING FOR CHILDREN WITH CHRONIC ILLNESSES

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By

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PREFACE

This is an overview of the development of the partnership model through the lens of Camp John Marc. It is not meant to pass judgment on the quality of its programming in comparison to other organizations. While some information from interviews will be used regarding the impact of camp, it primarily serves to illustrate the benefits that many models of camp can have on campers.

I'd like to note that the organization being profiled is legally known as Special Camps for Special Kids dba Camp John Marc. Outside of the presentation of the history, I will primarily be referring to this organization by their operational name of Camp John Marc.

The methodology follows two primary approaches. The introduction references previously published research to review the established field and validate the effectiveness of camping for children diagnosed with chronic illnesses and physical challenges. The information for the rest of the thesis was gathered through primary interviews with a range of subjects and through documents provided by the leadership of Camp John Marc.

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I owe thanks to all of the professors that offered their support and advised me while I was working on my thesis. In particular, I would like to thank the additional members of my thesis defense committee, Dr. Joyce Nuner and Dr. Tamarah Adair, for their willingness to dedicate their time and energy to evaluating my thesis.

Finally, I would like to offer my gratitude to Dr. Matt Bradshaw, who was my thesis director during this project. His kindness and willingness to work with and mentor me throughout this process was an invaluable resource towards the production of this thesis and my education at Baylor University.

DEDICATION

This thesis is dedicated to all of the campers of Camp John Marc, past, present, and future. May their time at camp be filled with joy, friendship, and new experiences.

CHAPTER ONE

Introduction

For a growing number of children across the United States, summer camp is a fundamental childhood experience and something they look forward to all year long. The American Camping Association (ACA), one of the nation's largest accreditation organizations for the camp community, estimates that as many as 10 to 12 million people visit US camps each year (Henderson et al., 2007). With the sizable population of children and adolescents that attend camp each year, there has grown a substantial body of research looking at what children gain from the organized camping experience. As the evidence surrounding the benefits of camping continues to grow, there has been a transition towards considering camp as a potential therapeutic resource for children diagnosed with chronic illnesses. With this transition has come the arrival of a wide variety of camps to serve different diagnoses. At the time of writing their publication in 2006, Cushner-Weinstein and his team found that, in the United States, there were "138 asthma camps, 91 muscular dystrophy camps, 65 diabetes camps, 60 cancer camps, 47 hemophilia camps, 40 sickle cell anemia camps, 26 renal disease camps, 17 obesity or weight management camps, 13 Crohn's disease camps, 7 burn camps, 3 neuro-fibromatosis camps, 3 Tourette's syndrome camps, and 25 camps for children with epilepsy" (Cushner-Weinstein et al., 2007). Since their publication, the number of these camps has consistently increased and the diagnoses they serve have widened.

Contextualizing the Issue

The population of children diagnosed with chronic illnesses is a far-reaching and diverse group whose diagnoses may require a wide range of different medical interventions and can interrupt their life course in complex ways. In addition to the medical challenges that these children face, there is frequently emotional difficulties and social isolation that can make their life outside the medical environment more challenging. Regardless of which disorder a patient is diagnosed with, it is important to consider the needs of the child and family as a whole.

Research studies over the years centering on children and adolescents diagnosed with various chronic illnesses have found that there is an increased risk for the development of psychosocial issues within this population. One of the largest of these studies was the Ontario Child Health Study, which compared the psychosocial outcomes of children diagnosed with chronic illnesses and those who are not (Cadman et al., 1987). This study demonstrated an increased risk of psychosocial disorders among children with chronic illnesses, indicating a need to consider therapeutic approaches for children with this range of disorders.

Turning to the more physical side of diagnosis, a related study published in 1985 looked at ties made between childhood disabilities and later psychiatric disorders (Breslau, 1985). This study found that when compared with children acting as a control population those diagnosed with disabilities had an increased risk of psychiatric disorders particularly in the areas of conflict with parents and regressive anxiety. This study also worked to investigate the effect that brain involvement in the disability can have on the behavioral and psychiatric disorders within this population. With this goal in mind, they observed

significant additional deficiencies in mentation and isolation. This suggests that the therapeutic interventions aimed at resolving or preventing the psychosocial issues could benefit pediatric patients that are diagnosed with this wide variety of primary diagnoses.

Widening the scope of the investigation of the link between chronic illnesses and psychosocial concerns, there is significant strain placed on the family with the additional burden of caring for a child with special medical concerns. This can place additional financial, emotional, and social strain on the family. This places an increasing focus on the family within any therapeutic interventions aiming to benefit children with chronic illnesses. A paper published by Griffith and Griffith in 1987 looked at the efficacy of structural family therapy in addressing the burdens and concerns of a patient diagnosed with chronic illness (Griffith & Griffith, 1987). They found that family-based therapy is a means to address the social and emotional concerns of chronic illnesses and can enable the family unit to guide the therapeutic approach to the patient's chronic illness. Within the context of children diagnosed with chronic illnesses, this suggests that rather than focusing the medical approach on the patient themselves, involving the family can be a valuable step in the right direction.

The care of a child with chronic illnesses must be approached from multiple angles. With increasing and continuing research, the medical aspects are becoming increasingly well-managed. This, however, has allowed for increased emphasis on the social and emotional well-being of these children. With the complex nature of these concerns and the integrated nature of the family, a creative therapeutic approach must be used. Increasingly, summer and weekend camps are being used as a means to fulfill the needs of these children. Camps aim to provide a social support network, bringing them close to others who

understand what they're going through while instilling confidence in their abilities. It can also provide respite for parents and siblings or familial bonding dependent on the structure.

Camp as a Therapeutic Approach to Chronic Illness

With camps increasingly being touted as an experience that helps children to build self-esteem, independence, leadership, social skills, and outdoor experiences, an increasing focus has been on gathering research to quantify these benefits. The American Camping Association (ACA) published a research report centering on this subject (American Camp Association, 2005). This study centered on 81 ACA-accredited camps and utilized a pre-camp survey, a post-camp survey, and a follow-up survey administered six months after camp aiming to quantify several different indicators for the various areas of interest. These were divided into the broad categories including "Positive Identity, Social Skills, Physical & Thinking Skills, and Positive Values & Spirituality", which were further divided into relevant individual measures (American Camp Association, 2005). Regarding self-esteem, this study found that there was a statistically significant gain following camp that persisted through the follow-up survey six months later. In the comments offered by parents, the camp staff's support of their camper was a cited reason for the increase in self-esteem. This suggests that actions taken within a thoughtful programming model can have sustained impacts on a camper. Turning to the related measure of a camper's independence, the results reflected an interesting trend in outcomes. From pre-camp to post-camp, children self-reported a slight, though still statistically-significant, boost in their independence while the parents reported observing a far more substantial increase. Six months later, when surveyed again, the increase in parental ratings was sustained while the children's rating of their independence had a substantial increase to match the boost their parents had reported

at the post-camp surveys. This points to the idea that while the campers may not actively think about it, the camp experience boosts their independence levels; it simply takes an amount of time back at home for them to notice the differences. The ACA report's section on the subject of social skills showed some variability in the responses dependent upon which individual facet is analyzed. Some of the measures, including leadership and friendship skills, had a marked increase at the post-camp level. However, friendship skills did experience a drop from that level when looking at the follow-up surveys. The other two measures, social comfort and peer relationships, experienced no significant change and a decrease on the camper surveys post-camp. With the administration of the follow-up survey, however, there was a statistically significant increase over the pre-camp ratings in all four of the individual categories. All of this data, taken into context together suggests that the camp experience may bolster a child's sense of confidence in some social skills, providing an immediately observable increase in that measure, while it may challenge them in others, like making new friends or social ease. This explains why some of the measures increase immediately following camp while a child's self-reported measures may decrease for a time. Looking at the long-term data, the follow-up surveys suggest that the social experiences that children receive at camp are valuable and can, in time, bolster a child's overall social skills. This ACA study as a whole suggests that there are quantifiable benefits with regards to positive identity and social skills that children can derive from a camp experience. A limitation of note from this ACA research study was the observation of a ceiling effect, which is when the pre-study scores are already relatively high, leaving little room for improvement. With this effect in place, the study's authors noted that the children

whose pre-camp scores were the lowest generally experienced the most drastic overall improvements at the post-camp and follow-up survey periods.

Returning to the population that this text centers on, children and adolescents diagnosed with chronic illnesses, the ACA research study suggests that the psychosocial concerns that have been linked with these diagnoses may be alleviated or addressed, at least partially, by offering patients a camp experience. With many of these children experiencing self-esteem issues and social isolation, among other concerns, the described benefits of a camping experience may very well be a valuable addition to the therapeutic approach for children with chronic illnesses. By offering a supportive environment with a group of peers, children have an opportunity to have fun and make friends without the sense of social stigma that many of them may feel in their schools or hometown. The very limitation that the ACA study acknowledges, the ceiling effect, may become a perceived benefit. In their analysis, the ACA discussed that children whose pre-camp scores were lower experienced the greatest benefits. This would suggest that children with chronic illnesses would likely experience substantial benefits from the camp experience, as many would likely have substantial room for improvement with regards to their positive identity and social skills.

A substantial amount of other research has been conducted on both the operations and the outcomes of camps for the general population. In her 2007 overview of prior research on camping programs, Karla Henderson opens up looking at some of the mottos used in the industry (Henderson et al., 2007). One of the earliest used “Better Camping for All”, along with two more contemporary examples, “Camp Gives Kids a World of Good”, and “Enriching Lives, Building Tomorrows” all point to increasing inclusion and the aim

of presenting value for campers. While these don't relate specifically to camps established for patients of chronic disease, they do indicate the direction the industry has moved in terms of inclusion and focusing on potential benefits. Looking at the mottos and mission statements of some of the camps operating specifically to serve campers with these diagnoses, there are a lot of similar themes present. Some used by these camps include "Inspiring Confidence for Life," "Discover Life," and "Where Challenges Become Triumphs" (*Camp For All—Camps for people with special needs*, n.d.; *Camp John Marc*, n.d.; *Camp Twin Lakes*, n.d.). The emphasis on inclusion and positive outcomes is still present, if not emphasized, when examining these modern slogans used by camps catering to this population.

With an increasing number of camps being established serving those with chronic illnesses, there has been an increasing focus placed on generating research on the operation of this type of camp as well as research that aims to quantify the outcomes associated with them. Alicia McCarthy, publishing in the journal of Pediatric Nursing, presents an excellent literature review touching on the challenges these patients face, the benefits of camp for this population, and some of the difficulties faced by these camps (McCarthy, 2015). She isolates four categories of concern for these patients. Some of the chronic illnesses faced by children can leave the children with physical differences which can contribute to a negative body image as well as social isolation. McCarthy also discussed the prevalence of impairments in emotional functioning and developmental concerns. Many of the benefits that these campers may experience at camp mirror the ACA study, with goal attainment, self-concept, and community and friendship all being cited. Some of the unique benefits

cited in the paper were fun isolated from the medical environment and increased levels of disease knowledge and management.

The safety of children at summer camp is something that should be assured. This is increasingly important in camping environments that cater to children with additional medical or special needs. This safety is an important element in ensuring that parents feel comfortable sending their children to camp knowing that their needs will be met. Barretstown Gang Camp is a camp founded by Paul Newman in Ireland catering to children in Europe with chronic illnesses and their siblings. They operate on a model that brings together campers with a variety of diagnoses each week rather than catering each session to an individual diagnosis. The camp medical staff consists of two volunteer physicians and two to three nurses under the direction of a medical director and clinical coordinator. In a statistical analysis of the visits to the camp medical facility, Eimear Kinsella and her research team reviewed the reasoning, spacing, and timing of visits to the medical building (Kinsella et al., 2006). In reviewing the visits, to the med shed, they found that 52% of children did not require a medical visit at camp. Of those that did require one, they had 3.0 interactions, on average, with the medical team. Pain, minor trauma, and infection were significant causes of medical visits. 24% of visits were related to the diagnoses of the children and 12% of visits required medical treatments related to the management of the disorders. While the data indicates that the medical facilities at camps catering to this camper population must be prepared to cater to the unique needs of the diagnoses, the study found that most visits mirrored those at camps for other populations.

While quantifiable and survey data are excellent for program evaluation and proving the benefits of camp, some of the most powerful and moving accounts of the

impact that camp can have come from the campers themselves. An interview study of 24 campers with a variety of chronic illnesses conducted at The Hole in the Wall Gang Camp asked children, on camera, about what camp meant to them (Gillard & Allsop, 2016). It then presented excerpts from the interviews sorted according to the common themes. The three most common themes found in the responses were a sense of belonging, enjoyment, and being myself. One camper, on the subject of belonging, said:

> Camp to me is special because of the way it brought these people from different parts of the nation together over a common ground which is, like, our illness that we can't really find someone that we have that certain thing, something that big in common … like, that's just something that – the reason that brought us here is something bigger and it can't like be taken away or changed. [sic] (Gillard & Allsop, 2016)

This sense of bonding on the commonality of an illness and the closeness of a camp group is near-universal with those elements of belonging being mentioned time and time again. Another of the major benefits discussed in several different research studies is the simple childhood sense of enjoyment. One camper exemplified this sense of enjoyment, responding:

> The meaning of camp in my life is just fun. It's just a fun place to go and like, there's a lot of people here that love you and like you can just come here and have fun. You don't have to worry about anything else but fun. [sic] (Gillard & Allsop, 2016)

It falls to the camp programming, careful planning, and great attention to detail and safety to maintain this sense of simple enjoyment. A return to childhood is an incredible thing to give to a child and that is what this sense of enjoyment drives towards. The final of the three relates to a sense of self-identity. Speaking to the impact camp had on them, one camper explained,

> Camp is special because you can be whoever you wanna be. Like you can come here and be yourself and no one will judge you because everyone is going through their own struggles and problems. So everyone's like really accepting. [sic] (Gillard & Allsop, 2016)

Camps operate for the benefits and experiences of the campers. The responses reproduced above are excellent examples of how the children and adolescents perceive the benefits of a camp experience. These three are just a portion of the excerpts published in that study and a small fraction of the anecdotal stories of the benefits of camp that can be found. Each person – staff, directors, counselors, and others – working in the camp environment could tell you their own set of tales about how campers have grown or benefitted.

Quantitative Analyses of Camps

In addition to the anecdotes and stories that are out there, there have also been studies using survey procedures and quantitative methods to demonstrate the impact that camps have on patients with chronic illnesses. One of the earliest, published in 1999 by Briery and Rabian, utilized two different survey scales to measure the effect of camp on different psychosocial indicators (Briery & Rabian, 1999). The two different scales they used were the Child Attitude Towards Illness Scale (CATIS) and the State-Trait Anxiety Inventory for Children (STAIC). They used data from three individual weeks serving campers with Asthma, Diabetes, and Spina Bifida. With all of the groups averaged together, there was a statistically significant improvement in both the attitudes of campers towards their illnesses and their trait anxiety levels. When the data is examined by condition, the same trends appeared with one exception – there was a slight bump in the trait anxiety for campers with Spina Bifida. This bump could be explained by a variety of

factors including differences among the camper populations or programming differences. Briery and Rabian, in their discussion, noted that the Spina Bifida camp did not have a medical education program, though the other two weeks did. An additional study, guiding off of their methods, utilized the Child Hope Scale (Woods et al., 2013). Their study found that, while there wasn't a statistically verifiable increase in health-related quality of life, there was an increase on the Child Hope Scale, indicating a more hopeful camper and an increase in perceived strategies following the camp experience.

Updating a 2005 systematic review of research on camps for children with chronic illnesses, Fiona Moola and her colleagues presented an updated overview of quantitative studies published on the subject (Moola et al., 2014). They reported in their paper that a vast majority of the papers published with these methods found some benefit to psychosocial functioning in their campers. Only two of the eighteen analyzed studies found no benefit for campers. In their commentary on the design of these research studies, they cite weaknesses in selection of the population and the absence of control groups in most studies. This review article does help to bring the results into context. With these patients only attending one week of camp each year, it is unrealistic to expect drastic changes that are sustained over a long period of time. Far more likely are the slight, though significant, increases that have been observed in the vast majority of these studies. To generate more significant benefits, camp-style interventions would be needed year-round. Though existing research may appear flawed in several ways, the foundational data is there, consistently demonstrating a benefit to campers. Moving forward, researchers should learn from previous studies and, drawing on this review paper, improve their study design. The proposed improvements include gathering longitudinal data, utilizing theoretical models to

inform design, practicing behavioral interventions for campers, including control groups, and investigating moderators for psychosocial benefits. In addition, the review paper does stress the importance of the camp experience, independently from any psychosocial benefits, for campers spending an excess of time in the medical environment.

The preliminary data is there for the general structure of these camps, supporting the idea that campers do derive some level of psychosocial benefit from their camp experience. Equally important as attempting to bring about psychosocial changes in patients is the normalizing effect that camp can have on their childhoods. Many children attend camp and those with these diagnoses may not be able to attend a conventional summer camp. Offering them a safe camp experience can allow these children to get their childhood back. While this effect of the camp experience may not be quantifiable, the sense of belonging and community alongside the enjoyment of camp activities together suggest that this is an additional valuable component of a camp experience.

Research Regarding Specific Conditions

Diabetes

Research conducted by Dr. Kovacs' found that school-age children diagnosed with Type 1 diabetes mellitus experience an initial degree of anxiety and depression, which worsens over time as the patient begins to understand that this condition will not simply go away (Kovacs et al., 1997). Drawing on prior research about the effects that a camp experience can have on a child diagnosed with a chronic illness, Dr. Bultas designed a survey procedure to evaluate the impact of camp for children with Type 1 diabetes mellitus (Bultas et al., 2016). Through these surveys, she found that after camp there was an

improvement in children's perception of their illness and their self-reported self-efficacy with regards to required Diabetes care. These results indicate that camp is an experience that can enable a higher level of self-confidence in these campers and a greater degree of control over the management of their condition.

The Bultas study confirmed findings from earlier research. One such study, utilizing a unique method, utilized surveys of campers and compared the results to those of non-campers as a control group (Cheung et al., 2006). This research project helped to confirm the benefits that campers with diabetes stand to gain from a camp experience. It was found that campers had better attitudes towards their condition, knowledge of management, and better psychosocial outcomes than patients who did not attend the summer camp. The inclusion of a control group for this study helps strengthen the discussion on the potential impact that a camp can have by offering a comparison group.

The literature on the subject of camps for those with diabetes supports the broad findings of other studies – camp can have a positive impact on the child through both psychosocial means and physical ones, by the path of improving self-efficacy. By utilizing camp as a space to promote a peer group of other patients and increased medical independence away from home, camps for diabetes have the capacity to impact the child's condition and the people connected with it, such as doctors, parents, and siblings.

Epilepsy

In evaluating the impact that camps for children with epilepsy have on the patients, Cushner-Weinstein and her team focused on adaptive behaviors (Cushner-Weinstein et al., 2007). The study spanned three years of camping sessions. In order to evaluate these behaviors within a camp setting, they adjusted the "Vineland Adaptive Behaviors Scale"

to the context and evaluation of camp counselors. Evaluating the domains of social interaction, cooperation, responsibility, and communication, the researchers found that within the individual years of camp, different domains had statistically significant improvement each year. The first year found improvements in communication and social interaction, the second found statistically-significant improvement in social interaction, and the third year saw improvements in all four of the measures. In looking at campers who attended the camp for multiple years, while there could be some drop in the measures throughout the year between sessions, there was an improvement during each session. There was a generally strong trend across all four domains among campers who attended all three years of the study. This seems to indicate that camp can play a strong role in developing adaptive behaviors in those with epilepsy.

These findings, while important in the context of patients with epilepsy, also extend to patients with other diagnoses. Developing adaptive behaviors in children is a strong result to achieve through camps and developing these traits in children that face additional health-related adversities stands to benefit children with a wide range of diagnoses. The researchers concluded that camp can be a resource for children with chronic illnesses or special needs to develop these skills while also developing more knowledge about and responsibility for the management of their diagnoses. These findings indicate that the camp experience paired with an engaging medical education program could benefit campers in developing long-term behaviors, skills, and knowledge that would help them both in managing their diagnosis as well as their daily life.

Burn Survivors

Within the individual diagnoses profiled in this introduction, patients who have survived burns stand out. This is because while many of the other diagnoses refer to internal processes, a burn with a large total body surface area can leave extensive visible scarring that lasts for years. While there is conflict in the research regarding whether childhood burn survivors experience increased levels of psychosocial disorders, a 1987 review paper found that physical appearance is an important determinant in how children relate to their peers (Lee & Rosenfeld, 1987). In 2007, a study aimed to determine how an overnight camp affects the self-esteem and community attitudes of childhood burn survivors was published in the Journal of Burn Care and Research (Rimmer et al., 2007). This study found that camp produced an increase in self-esteem that tended to persist, in subjects present for both years of data collection, across the interval between summer camps. The explanation given within this paper, which is applicable to offering camps to any population, was that the activities offered were not typically available to the campers outside of the camping environment. This push to develop new skills and try new things can lead to a sense of accomplishment at the end of a week at camp, instilling greater self-worth in the camper and demonstrating that they can accomplish things they put their mind to, increasing their self-esteem and self-efficacy.

Phenylketonuria

Phenylketonuria (PKU) is a metabolic disorder that is characterized by an inability to process one of the amino acids present in proteins (Scriver et al., 2000). This disorder is primarily treated through the dietary reduction in the amount of phenylalanine consumed. When it was discovered, it was characterized by the neurological symptoms of cognitive

deficits and delays caused by a build-up of the amino acid. This damage was irreversible and could be severe if a diagnosis was not made early. With current biochemical techniques, diagnosis takes place through a blood test administered shortly after birth and cognitive damage can be prevented through immediate and sustained dietary maintenance (van Spronsen, 2010). Previous studies have found that, while diet is typically maintained during infancy and childhood when parents take an active role in the preparation of food, there is typically an increase in dietary deviance when patients reach adolescence (Siegfried M. Pueschel MD & MSW, 1977).

Translating this finding into the camp experience, a team of researchers led by Rani Singh created a study to investigate how a camp-based nutrition and disease educational program would affect dietary compliance in adolescent girls (Singh et al., 2000). The researchers found that following the camp session, there were statistically significant decreases in plasma and dietary phenylalanine and increased knowledge about the disorder and the dietary maintenance among campers. This improvement in dietary compliance, while not precisely maintained at the 4, 8, and 12-month check-ups, was a significant step in improving the dietary management of these adolescents' diagnoses. While the reductions were not statistically significant for the researchers' sample size, there was some level of reduction at those times. The more significant finding, which was maintained across those rechecks was the improved knowledge of the disorder and of how to manage it. This improved knowledge about the diagnosis could lead to improved management later in life as the adolescents develop into adults and are better able to manage peer influences alongside the need for dietary management of their health.

Cancer

Childhood cancer is a diagnosis that not only affects the patient but also the siblings and other family members. This has been well-documented by many research studies (Vannatta & Gerhardt, 2003). With this in mind, many summer oncology camps invite siblings to join the patients in attending the camp session. A study looking at a camp of this type evaluated satisfaction with the camp among patients and their siblings and looked at the factors contributing to these ratings. Overall, it was found that both populations of campers (patients and siblings) were highly satisfied with the camp experience. When broken into the categories, peer support and respite were reasons for satisfaction at an equal frequency of the typical reasons to enjoy camp, recreation and the camp activities. The parents had a similar positive reaction, focusing strongly on peer support and respite with the added category of improvements in the child. These findings indicate that inviting siblings to camp along with the patients can be used as an appropriate and helpful setup for oncology camps. This could promote healing and support for family members that frequently bear some level of strain due to a child's cancer diagnosis.

Combining the findings of this study with those of the Griffith and Griffith paper mentioned earlier, camp could play a role in addressing the additional psychosocial burdens of a childhood cancer diagnosis on the family. It gives patients a break from the hospital or clinic environment, it gives siblings time to process together or interact with their diagnosed brother or sister in a more recreational environment, and it gives parents some respite time in which they can trust their child is being taken care of. In addition to those benefits, camp also provides the psychosocial benefits documented throughout the

introduction, which contributes to the parents' reflections on the improvement of their children from the Vanatta and Gerhardt study.

Goal-Setting and Evaluation at Camps for Children with Chronic Illnesses

While this paper is meant to profile a method of operating camps for children with chronic illnesses and not to make a judgment on the effectiveness of this particular example, evaluation of a camping program is an important element of operating any camp and should be mentioned here. Heather Hunter and her team published an example of how to conduct an evaluation of a camp focused on the individual goals of a particular camp (Hunter et al., 2006). They generated a post-camp questionnaire for campers, parents, and staff members with questions focused on evaluating the different goals set by the camp program. To determine the outcomes of camp related to self-management skills, self-perception, and coping skills, researchers used existing profiles and recordings of blood glucose. Researchers used mailed surveys before the camp session, distributed post-camp surveys at the end of the camp session, and mailed follow-up surveys 3 months afterward to gauge the extended impact of camp. In addition, the analysis of the surveys was split among age groups to better inform analysis of whether the camp was meeting its goals across age brackets. That leads to the final element of reviewing the goal-related performance of a camp, the presentation of findings. The results of the investigation should be delivered to camp leadership for review and possible programmatic changes. While not all changes are possible within the limitations of operating a camp, those making the decisions regarding the day-to-day operation of the camp and its overall programming should be informed about how the mission is being implemented.

CHAPTER TWO

The Partnership Model

Established Models in Camping

In providing organized camping opportunities for children with chronic illnesses and physical challenges, there are a number of additional considerations that go beyond simply providing camp programming. These include recruiting a group of campers from the patient populations, providing them with adequate medical care while at camp, and building comfort with the parents to a sufficient degree that they will send their children with complex medical needs to camp. There are several methods that have been developed to help provide for these needs.

In discussing the foundations of the partnership model, I asked the founding camp director of Camp John Marc, Vance Gilmore, to comment on some of the existing models in camping at the time. The first he identified is the formation of disease-specific camps. By providing camp programs that tailor to a specific diagnosis, a qualified medical team can be recruited that are trained for the particular population the camp focuses on. In addition, through years of operation, close ties can be formed to the patient population and community surrounding the diagnosis. Finally, with skilled medical staff and a history of operation, the fears of parents can be allayed in sending their campers to the camp. One of the central benefits of this model of operation that was identified during my conversation with Vance is the concept of "unity through difference". By bringing together a group of campers with a common diagnosis, you offer them the opportunity to bond through their

shared experiences and challenges. There are many examples of this type of camp across the US though they tend to focus on diagnoses with a larger patient population. Examples include providing camps for patients with diabetes mellitus, cancer and blood disorders, and other metabolic disorders, such as phenylketonuria. Common features of these camps are independent operation, medical staff specialized in the diagnosis, and a single diagnosis that they focus on throughout their camping season.

One of the other models identified by Vance was the Paul Newman model, which was started in 1988 with the Hole in the Wall Gang Camp. This model also focuses on independent operation and funding. While these camps tend to be part of the SeriousFun Network, they maintain independent operations from each other. The key difference between these camps and the single-disease camps is the invitation of campers with a range of different conditions. Typically, a session of camp at this type of camp will include campers with a variety of different diagnoses. However, limitations on the training of the medical staff mean that only certain diagnoses can be accepted, focused on cancer, blood disorders, metabolic disorders, and immunologic disorders. There may also be concerns regarding the acuity of the camper population to ensure that the medical building is equipped to provide all the needed care.

Standing in contrast to those two models is the final model identified which was the rental or turn-key model. In this model for providing camp, the camp itself sets up a facility and activity areas and then offers to rent it to various organizations or programs that need a site. In this case, the group looking to host a camp would need to organize their own camper population, medical team, and programming and would simply utilize a leased camp space that may host several different types of camps during the season. In this model,

the camp location used may not be set up intentionally for the population and may not be ideally suited for the group. This has traditionally been the model used for camp programs that only host the population for a single session during any given year. Within this model, there may be substantial variation in the amount of programming the site provides, which group is responsible for food during the camp session, and the actual setup and the suitability of the camp facilities.

A helpful analogy was presented by Dana Dempsey, the director of therapeutic recreation at Texas Scottish Rite Hospital and director of Camp Joint Adventure for juvenile arthritis. She compared the models of camps to the rental of a boat for a vacation. The rental model was compared to a bareboat charter, in which the person rents only the boat without any crew or provisions. The partnership model, to be discussed next, is comparable to renting a personal boat with a captain or small crew. You have significant input into the planning and operation of the boat with the captain or crew there to help implement and guide your vision. Finally, she compared the Paul Newman model and disease-specific camps to cruise ships. The cruise hires all of the people and handles all of the planning to make the vacation happen – you simply jump aboard and select the particular activities you would like to participate in.

The Partnership Model

The model that this thesis focuses on, the partnership model, is one that was developed starting in 1987 for the opening of Camp John Marc in the summer of 1991. This operational model combines some elements from established camping philosophies with unique elements made possible during the development of the camp. The core of the partnership model, as described by Vance, exists in multiple organizations combining their

efforts to provide the camp experience. He identifies the relationship it creates between partner groups, requiring a give-and-take. It was set up in a way that allowed each organization to take the lead on their area of expertise while relying on partner groups for the elements they are better equipped to handle. Throughout this thesis, those groups will be referred to as Camp John Marc, which represents the camp facility, leadership, board, and staff, and the partner or user groups, which represents the various organizations that Camp John Marc partners with to provide the camp experience. An important note to make before presenting the model is the schedule of a camping season. While Camp John Marc operates the camp facility with each group that has a camp program, each partner group brings their camp for a single week or weekend camp with another group arriving the following week. This is an important distinction that allows Camp John Marc to provide the benefits of single-disorder camps while providing camping programs for a wide range of different diagnoses. One foundation of the partnership model is cost-sharing. Camp John Marc raises two-thirds of the cost of sending a child to camp while asking partner groups to raise the remaining third, as long as it is not a burden on that partner. This sharing of the cost of camp encourages each partner to invest in the program and ensure that the camp is providing high-quality and effective programming.

There are many elements of this model, primarily falling into three categories: program, camp recruitment, and medical considerations. The first is the programmatic pieces of providing camp. As the founding board members envisioned it, Camp John Marc would be a facility that provided many of the typical pieces of camp. The camp was designed to offer a purpose-built accessible camping facility to partner groups and patient populations with a wide range of different needs. It also hires a summer staff and recruits

weekend volunteers that are responsible for facilitating the different activity areas and programming as they are designed and modified by the camp leadership team each summer. While many of the programmatic pieces are handled by Camp John Marc, the partner groups are still responsible for some of the essential elements in making the programming possible. The partners are responsible for recruiting the counselors that live in the cabins with the campers and travel with them to activities. They also help to make decisions regarding the structure of programming used during their particular camp. This allows them to play an active role in setting the schedule and full-camp activities for their week of camp.

While Camp John Marc is well-developed to provide programming and the camp experience, Vance Gilmore and the founding board members recognized their limitations in directly recruiting campers from the different medical populations the camp is designed to serve. Instead, that was a task that the partner groups accepted. The partner groups have a range of different setups in bringing their camps to Camp John Marc. Some are part of a national organization, such as Camp Reynal's affiliation with the National Kidney Foundation or Camp MDA's organization within the Muscular Dystrophy Association. Some partner groups have regional direction such as Camp TLC, which is organized, in part, by the Spina Bifida Association of North Texas. Finally, some of our camps maintain their own organizations or foundations specifically for producing a camp. Regardless of their affiliation, each camp maintains ties to the patient population they serve in the hospitals, clinics, or treatment centers. Each partner group is responsible for recruiting their campers from the eligible medical population they have identified and partnered with. This allows for each organization to focus on partnering with their patients and families and

enables the reach of camps hosted at Camp John Marc to extend well beyond what would be possible if the Camp John Marc team attempted to make these connections and recruit campers. It also enables connection and dialogue between the parents and the user groups that helps them get and provide direct feedback on how their child's needs will be met at camp.

The medical needs of the populations that visit Camp John Marc are wide and varied. With the difficulty of providing care for such a wide range of specialties, the partnership model is a crucial aspect of meeting this need. During the formation of the Camp John Marc board in 1988, Children's Medical Center of Dallas (now Children's Health) was one of the founding organizations. This early partnership made Camp John Marc's mission possible. Vance identified a strong relationship with Children's Medical Center and our later partner hospitals as a key element to the success of the partnership model. Children's Medical Center, in viewing camp as an extension of treatment in their hospital, enabled the camping programs to grow and develop in the early days of camp's history. Rather than having a single physician or medical team provide care throughout the entire camping season, each camp recruits a team of physicians and nurses from the providers that care for their campers in the hospitals and clinics to travel to camp for the camp session. This enables quality care as there is typically some level of familiarity among the medical team for the campers that they are responsible for during the week. The primary partner hospitals are Children's Health, Texas Scottish Rite Hospital for Children, and Cook Children's Medical Center. These locations provide a majority of the physicians that care for our campers. Departments in these hospitals also organize a number of the camps

at Camp John Marc or provide campers for others, bringing the benefits of familiarity with the patients.

By working as partners, each organization is able to focus on their strengths and lean on the strengths of others to provide a high-quality camping experience. In discussing the partnership model with a range of people involved in the history and current operation of Camp John Marc, there is a wide range of perspectives on the partnership model with most of them identifying the sharing of responsibilities and effective communication between groups. Randy Perry, the second chairman of the board, identified the core of the partnership model as a common goal with sacrifices on both sides. In discussing important elements of collaboration, we talked about friendliness, hospitality, and communication between the groups. With his time heading the board starting in 1989, during the construction and first summers of camp operations, Mr. Perry also identified the importance of stability and confidence within the partnership. Combining friendship and hospitality with stability and effective communication, the partnerships of camp continued to develop. This question was also asked of Dana Dempsey. From her perspective working with many of the camping programs at the hospital, she stressed the importance of communication. One of the most important considerations that she identified is that both parties should have an influence on the various parts that go into making camp possible. This is an important element to consider in communication with partner groups. Both partners need to have the ability and respect to influence and improve the work done by the other. This ensures that everyone is satisfied with the partnership and helps the partner groups exert some control over their camp experience while Camp John Marc has the opportunity to help inform and prepare user groups to recruit campers and counselors.

Katie Campbell is one of the managers of the Child Life Department at Cook Children's Medical Center. In her role, she also coordinates Camps for Kids, the therapeutic camping initiative based at the hospital. Through that initiative, she works with 25 different camps, several of which are hosted at Camp John Marc. In describing the partnership model, she focused on how teammates strengthen each other. She identified the importance of like-minded partners interested in providing quality experiences for the patient population. In designing the camp and programming, she highlighted the importance of a consistent dialogue and feedback as the camp grows and develops. The last element in her description reinforced the foundational aspect underlying the design of the model. Each organization has strengths so, in partnering for a common goal, it allows each organization to not have to master everything and can instead rely on the other partner.

The partnership model is a unique setup in the camping environment and requires the investment of each of the partners. However, in practicing this model, camping programs can provide a high-quality experience for campers with a wide variety of medical conditions. In addition, by focusing on individual elements of the camp experience, each partner can become experts in their tasks in relation to the camp with the overall effect being an improved experience for campers.

CHAPTER THREE

The History and Development of Camp John Marc

The Story Room

The story of Camp John Marc's development is displayed painted on the wall of the Silo Story Room for the staff, counselors, and campers to read. It provides a concise but quality overview of how the camp came to be. Before presenting a more detailed history from the interviews and supporting documents, this is the story as it is seen by the campers.

> There once was a boy named John Marc. He loved the outdoors and spending time at his family's ranch, The Old Sundown. After he was diagnosed with bone cancer, John Marc said that his visits to The Old Sundown were one of the things that helped him get through his cancer treatments. After bravely fighting cancer for 9 months, John Marc passed away in 1987.
>
> At that time, many people were working to build a camp just for kids with chronic illnesses and physical disabilities. Known as the Camp Founders, they wanted a camp where kids could enjoy being outdoors, meet other kids just like them, and have fun.
>
> In 1987, John Marc's parents heard about the camp that the Camp Founders wanted to build. John Marc's parents offered to donate part of The Old Sundown for the new camp. In honor of John Marc and all the future campers, the camp was named Camp John Marc.
>
> In the summer of 1991, Camp John Marc opened. Almost 500 campers came to Camp John Marc that summer and had a great time. Each week, campers experienced new adventures, made new friends, and achieved goals they thought were impossible. Since that first summer, each camp at Camp John Marc has had a special name, because each week has brought a new and unique group of campers with a shared chronic illness or physical disability.
>
> In 1995, the Morning Star Chapel was built and dedicated. Over the years, the Chapel has given campers a place to meet, worship, or just enjoy a peaceful moment.
>
> Although more new buildings have been built and campers have come and gone, Camp John Marc continues to provide a place for campers to have the time of their lives. Camp John Marc captures the dreams and the happiness of a boy who loved being outdoors many years ago. (*Camp John Marc*, n.d.)

Early Research

Before 1983, the camping community for children with chronic illnesses and special needs around Dallas was largely served through the rental model at camps that were primarily designed with other populations in mind. While some populations had purpose-built facilities, like Camp Sweeney serving children diagnosed with diabetes, many were left with growing camps but without a permanent site.

In 1983, a member of the community had a colleague approach Sally Francis, the then-director of Child Life at Children's Medical Center, about the need for a permanent camp serving the needs of the larger population of children with chronic illnesses. Out of this conversation, a meeting was set up at the hospital in February of 1984 to discuss this concept with a wider group of people. Attending this meeting were representatives from the clinics working with these children as well as leadership from the hospital. The group decided camping could be an important element of treatment and that it should be investigated further. The organization identified to research this was the Junior League of Dallas, an organization of women promoting voluntarism and community improvement. Following the request to the Junior League Research and Development committee, a task force was created to research the questions that came out of the meeting. Bettye Slaven, one of the co-chairs of this task force was part of the research committee and shared the information regarding the Junior League's involvement in the foundation of Camp John Marc.

This period of research lasted 2 years and consisted of visiting existing camps and interviewing leaders in the field. Two central questions were tackled in this investigation. The first assessed the need of the Dallas community and if building a new facility was an

appropriate fit for the population. The second question was what would be needed in a new facility to make it appropriate for the groups it sought to serve.

In 1987, the research was completed and presented in a report. The overall conclusion of the Junior League Task Force was that there was a need for a facility to serve this special camp population. From that report, a community task force was created to facilitate the next steps of putting this research into action.

Following the report, a new organization was incorporated in 1987 to develop this camp. It was entitled "Special Camps for Special Kids" and applied for and was granted 501(c)(3) status in December of that year. In January of 1988, the board was formed, with the first chairperson being Susan Williams. Dr. Peggy Sartain, a pediatric oncologist at Children's Medical Center was also part of the initial board.

The Story of John Marc

Running parallel to the events above was the story of the Myers family. Jan Myers, the mother of John Marc and a long-time friend of camp discussed their side of the story of camp with me. She had grown up camping and loved it, becoming a self-identified camp person. She and her husband, Marc, own a ranch called Old Sundown outside of Meridian, Texas. Growing up, John Marc loved spending time at the ranch on "nature tours", which were drives around the ranch looking at wildlife (J. Myers, personal communication, May 11, 2019).

Following a broken leg, John Marc Myers was diagnosed with osteosarcoma on September 6, 1986. His oncologist at Children's Medical Center was Dr. Sartain, who also became part of the community task force in 1987. Knowing John Marc's love for the ranch, Jan and Marc set up a prefabricated house at the ranch so that he could spend weekends

outside of the hospital there. During his treatment, John Marc's parents dreamed of establishing a camp for children like him. Dr. Sartain had mentioned the work of the Junior League investigating the possibility of establishing a camp for children with chronic illnesses. John Marc passed away on June 3, 1987. Jan and Marc had mentioned their desire to donate land to establish the camp to Dr. Sartain who brought it to the chair of the board in January of 1988.

Establishing the Camp

In October of 1988, a group of board members from Special Camps for Special Kids walked the proposed donation site with the Myers at Old Sundown. Following this visit, Marc agreed to donate whatever it would take to establish the camp. During this month, the board also selected the name of the camp: Camp John Marc Myers, in honor of Jan and Marc's son.

As the development of the site was planned, the finances had to be raised to pay for the camp. The first gift received was an anonymous donation of $1,000,000 given in the name of "Thanks for the blessings of life and children." Several gifts from different organizations and events followed providing the capital needed to establish the camp.

With development and fundraising underway, the board turned to the search for an executive director. The candidate selected was Vance Gilmore, who was previously the director of Camp Soroptimist (now known as Camp Summit). He served as both the founding executive director and the camp director, coordinating the summer staff and programming.

Don Madsen and his team, the building and grounds committee, worked in earnest to design the camp. An architectural firm was tasked with bringing their designs to life by

producing the layout and building plans of camp. To help get the site ready for construction, the concept of a work-day was created in December of 1989. These events offered people the chance to get involved in the establishment and maintenance of Camp John Marc. They were held monthly through the construction of the camp.

Construction of the buildings began in August of 1990 and continued through to the summer of 1991. The expansion of a stock pond to form Crow Lake provided stone for the construction of many of the buildings. The central buildings and cabins were completed in just 9 months to prepare them for a grand opening and the first camping season of use in the summer of 1991.

The grand opening of Camp John Marc Myers took place on June 1, 1991. The camp opened with an eight-week summer serving 500 campers. In the off-season following that summer, the two signature fundraising campaigns were planned and executed. The Live Oak campaign raises funds for bricks for the Live Oak path (described in Facility Design) and the Campership Drive raises Camp John Marc's contribution towards sending campers to camp. In addition, the concept of weekend camps was created with several groups forming a camp that is hosted at Camp John Marc in the spring of 1992. The final off-season development was a request from the Myers to have the name "changed to Camp John Marc to capture the memory and spirit of all current and future campers" (*Camp John Marc*, n.d.).

In the second summer, Camp John Marc hosted 12 weeks of camp serving nearly 1000 campers. Weekend camps continued to develop, taking place during much of that off-season. The finishing touches to construction are completed leading into the third summer including a permanent pool fence, the addition of some lights around camp, and

stonework on the last few cabins. Following a third summer, Camp John Marc's program and facility received full accreditation from the American Camping Association (ACA), representing adherence to a higher level of standards beyond the legal requirements spelled out in state and national law.

While that has detailed the creation of Camp John Marc and its first few summers, there have been some notable additions to the facility and program that deserve special notes. Staff/family lodges were built in 1999 to house the staff in the summer and families during weekend camps. 1999 also saw the creation of the family getaway program. This allows families with a child who has a diagnosis served by Camp John Marc to come out to camp and have a relaxing self-guided weekend outside of the regularly scheduled camp programming. The families served through this program stay in the family and staff lodges, which have a small kitchen area, a living room, two bedrooms, and an accessible bathroom. In 2000, a therapeutic equestrian program was established at the camp offering campers in the summer the opportunity to take a trail ride under the supervision of staff wranglers. There was a new horse arena created in 2010 to increase safety and provide shade for that program. In 2007, construction was completed on the large silo building, offering multipurpose spaces, a new library space, and a teaching kitchen for cooking activities. In 2009, a new, more-accessible fishing pier was completed over Crow Lake. Finally, in 2018, a new accessible treehouse was completed overlooking a natural limestone bowl.

The final change to mention regards a transition in the leadership of Camp John Marc that occurred across 2015 and 2016. In 2015, Vance Gilmore turned over the role camp director to Kevin Randles with Megan White as Associate Camp Director. Finally,

in 2016, Kevin Randles took over for Vance, who completed 25 years of service, as the Executive Director while Megan White became the Camp Director. They both presently hold these roles.

That brings the overview of the history of Camp John Marc to the present day. Currently, 11 summer camps are served in the summer. A total of 21 weekend camps take place during the fall and spring and there are 6 annual family getaway weekends.

CHAPTER FOUR

Facility Design

There are many elements that go into the design of a facility and must be considered prior to establishing any permanent installations. Included in these pieces are the location of the facility, the activities a camp wants to offer, the populations a camp will work with, and the overall theme of the camp.

Selecting a Location

Randy Perry helped to determine the site for Camp John Marc during his time as the second chairman of the board. When Special Camps for Special Kids was selecting a location for the camp, medical workers and potential community volunteers were asked for input on location and distance. This offered a radius of drivable distance that the camp would ideally fall within. This narrowed the search and helped guide the decision-making process when donation offers and alternative sites were considered. While many other factors go into selecting a camp location, this is certainly an effective starting point. When Mr. Perry was asked about the process of selecting the location for a camp, he identified a few key considerations.

The first is to consult with the anticipated partner groups and establish a maximum distance from these groups. Camp must be accessible by car to the groups that want to use the facility with the population being willing to travel the distance to camp. This has two major implications. When working with children with chronic illnesses and physical

challenges, it is important to have relatively quick access to the primary and emergency medical providers for those patients. While driving may not be the most efficient way to reach the hospital, it is important to consider the options for emergency transport for campers including a private vehicle, ambulance, or helicopter. Transport to the home medical center of each camper should be possible and efficient. The second implication relates to the access to community volunteers and the members of partner groups. The groups will have to get their counselors, leadership team, and medical team out to the facility so placement within an easily drivable distance is important to help enable partner groups to recruit and bring in the necessary volunteers and personnel.

Another important consideration he identified is nearby towns and medical services. While many of the children served by the camp will require a pediatric hospital if something major occurs, a nearby local hospital can enable medical teams to fill prescriptions locally if a camper's needs shift and get lab testing if a camper appears sick or requires blood counts. In addition, for more common pediatric injuries such as broken bones and cuts or scrapes, a nearby hospital can provide needed basic care if it exceeds the capacity of the on-site medical team. A nearby town allows for the quick sourcing of common food items and materials that may run low and other items that a camp may need. Looking to ensure there are a few basic restaurants and stores can help both your team and the partner groups get needed supplies and can be an important area for the summer staff to get off-site and eat some outside foods during their off time.

The final overall consideration that was identified through my conversation with Mr. Perry was the utilities needed to establish a camp. It is important to have drinking water for the camp, so searching for a nearby shallow water table can make accessing it by well

easier. Attention should be paid to the depth of well needed for human consumption and access to an aquifer. Another needed utility is power. If there are nearby ranches or a town, the infrastructure to get electricity to camp may already be present. If this is not the case, the potential costs must be considered before proceeding. Treatment of wastewater is also an important consideration. If the camp falls within an established municipal water treatment area, the city may handle the infrastructure for water treatment. However, if the camp is to be in a rural area, consideration must be given to how to acquire and maintain the equipment needed to treat wastewater. One utility that is not frequently considered but continues to play an ever-increasing role in the contemporary medical field is the internet. With the use of electronic medical records being mandated, it is important that the medical building and the administration buildings have adequate and fast internet coverage.

These are all important considerations in deciding where to establish a new camp and should be held in mind when selecting a site. Once a location has been found, attention must be dedicated to the initial design and thematic elements that will guide the overall design of the facility.

Initial Design Considerations

As a camp is first working on the design, there are a few elements that must be considered first. One of the earlier decisions to be made is how many campers your facility aims to host at a single time. This will govern the size of the dining facility and the capacity that is needed in cabins and activity areas. An important design decision that was made early in the development by Don Madsen and Vance Gilmore was the incorporation of nature into the design. This led to the use of stone from the lake on many of the buildings, working around existing trees, and limitations on the number and presence of lights in some

areas so that the stars could be seen throughout the facility. Without this early design decision, some developments may have taken place that would have made the incorporation of nature into camp difficult. The decisions on materials to be used for buildings and paths can affect the overall design and appearance of the camp.

It is also important to have those that layout the facility and design the buildings understand the intention of the facility that is being built and the philosophy that is meant to underlie the design. Jan Myers, who served on the Building and Grounds committee, mentioned the whimsy that was evident in the layout and designs that were created by Don Madsen and his committee. By using the layout and features in the buildings, he was able to develop a fun atmosphere for the camp while maintaining and incorporating nature into his designs. Examples include hidden elements in the stonework like a bunny on the side of a cabin, deeper stone on the walls of a group of cabins called the forts to simulate reinforcement, and waves hidden in the design of the pool equipment building.

An important consideration before laying out the site and designing areas is understanding what activities the camp wants to offer as some will need their own facilities such as a ropes course, boat dock, sports barn, or horse facility. Estimating the capacity and presence of these activities will inform the overall design and layout of the camp and can also govern the needs of some multipurpose or indoor spaces, which can be critical for rainy weather and large-group activities. An additional element to think about when considering activities is a plan for inclement weather. Sometimes this requires minimal changes, such as arts and crafts, a shift of location, such as the ropes course or sports and games, or it may require an entirely separate activity plan, such as boats and fishing.

Finally, it is important to reach out to your anticipated partner groups during design, construction, and renovation. They will have the deepest knowledge of their population and needs and can provide some insight into how the camp should be arranged and how particular buildings should be organized. In maintaining the relationships established through partnership, incorporating a partner's suggestions into the design or implementation of plans can help provide each organization with investment into the outcome and demonstrate a commitment to meeting their needs.

Layout of the Camp

The initial stage of design is to layout the site and decide where buildings are placed. Some important considerations include the placement of the medical building, the placement of the dining hall, locations of the cabins, and where the activity areas will be.

At Camp John Marc, the decision was made to incorporate medical treatment and involvement into the program and therefore into the site as well. The medical building sits at the center of camp along with the dining hall. To get to many of the activity areas, campers, counselors, and staff walk past the medical building. Mr. Perry shared with me that Vance had this done to symbolize an understanding that many of the campers would require some medical treatment during their camp experience and shouldn't be excluded because of that. The dining hall acts as the large-group gathering spot and sits in the middle of an arc of cabins that are all within easy walking distance from an entrance. On the other side of the dining hall, paths run to all of the activity areas that are scattered across camp. The arts and crafts building falls just past the medical building followed by the sports barn then the lake. It is also important to consider the time it takes to transit different parts of camp so that between activities, campers can reach their next activity in a reasonable

amount of time. In addition to the layout, attention must be given to the paths that connect these locations.

Accessibility of the Facility

An important consideration in designing a camp for a population of campers with chronic illnesses and physical challenges is ensuring that it is accessible to all potential users. Efforts should be made so that all campers have the ability to move around the camp and participate in all camp activities. Paths should go to all camp areas and be made wide enough that multiple wheelchairs can pass each other without issue. While stairs may be used in some camp areas, there must be consideration for how a camper in a wheelchair could access the same area. Arrangement of the buildings and the interiors should be made to best accommodate the population a camp expects to serve. While many of the considerations for accessibility will be based on the populations a camp serves, establishing these elements now can help existing populations in many ways and can help open the camp for future groups.

Cabin Design

As a design is developed for the cabins, care must be taken with regards to the populations the camp is designed to serve. Examples of these considerations from Camp John Marc include using single twin beds instead of bunk beds so that all beds can accommodate any campers, regardless of independence or mobility levels. All cabins have individual air conditioning and heating units to help facilitate year-round use in all weather and to ensure that temperature-sensitive diagnoses, such as sickle cell disease, can be accommodated. The light switches were also placed at a lower level so that campers in a

wheelchair can access them. To accommodate breathing devices or peritoneal dialysis machines, two outlets were placed next to each bed to allow camps to meet needs as necessary.

It is also important to ensure that bathrooms have storage for each person's items and are accessible to all camper populations. Each cabin at Camp John Marc has two larger restroom stalls with curtains for privacy. There are also two large shower stalls with a hand-held shower head in addition to the overhead mounted ones to accommodate any campers that may use a shower chair or need personal care assistance. Finally, the two sinks are placed at a lower level so that campers of all ages and mobility levels can access them.

Activity Area Design

In designing the individual areas, there are two types of considerations. The first type consists of things that must be considered for all activities. The second consists of the considerations for specific activity areas.

Mr. Perry identified several considerations that must be made for all areas at camp. The three things he listed that all areas should have is shelter, a nearby bathroom, and access to water. The shelter provides needed shade and somewhere to move if inclement weather arrives unexpectedly. As identified by Katie Campbell, this shade can be particularly important for conditions that may be sensitive to sunlight or overheating, including campers with juvenile arthritis, cancer, hematological conditions, and skin disorders. The need for a nearby bathroom allows campers to make that transition as necessary and does not require a large amount of walking or an excess of adults to move those campers around. Finally, campers will require hydration and there are two ways to provide for this need. The first is to have running water at the area and install a water

fountain. If this is not possible for a particular activity area, either the program staff or facility team can fill a five-gallon or larger jug so that campers always have access to water.

Ropes Course

Care should be taken to provide the opportunity for activity adaptations at the ropes course. Dana Dempsey talked about the addition of hardware to facilitate a capstan winch, a modified ropes element, or an adaptation of the zipline. A shaded area to put on harnesses and a restroom area are also useful additions. Generally flat terrain is also useful to aid with accessibility and general safety. Other additions that can be made are a smaller wall for younger campers to practice with, low ropes elements for team-building, and a giant swing or pamper pole for older campers. Consideration should also be given for inclement weather. At Camp John Marc, climbing walls were installed within the entrance to the silo building that is covered and can be used even while it is raining.

Additional training may be needed for the staff that operates the ropes course during weeks with high degrees of adaptation to ensure that the staff is able to maintain a high degree of safety and accommodate the needs of campers. Some procedures or techniques that have been helpful in these instances is a counterbalance to aid the camper in climbing, buddy climbs up a slanted wall, and a chair designed to be hauled backward up the zipline so that campers with severely limited mobility can still ride the zipline if they choose.

Fishing Pier

While fishing is an easy activity to adapt, modifications to the facility can help make this integration seamless. Having a solid fence can help prevent any campers from falling from the pier. This can be combined with swinging gates that can lower areas of the

fence so that younger campers and campers in wheelchairs can see the surface of the lake and their bobber. This same concept can be used at ground level to allow the footrests of a wheelchair to slide under the fence, allowing the camper to pull all the way up.

Horse Arena

Moving beyond the concerns of any equestrian program, a relevant consideration for this population is a covered arena so that the activity can take place in the shade and while raining. It also helps to have a chute with an elevated platform so that younger campers and those in a wheelchair can load onto the horse from higher up and may need less help at the beginning and end of a horse activity.

Medical Building

When organizing a medical building, certain parts must be included. The design of the medical building should balance privacy and functionality. Important inclusions can be private bays separated by curtains so that campers that may need rest or certain small procedures can have some degree of privacy. A large multi-purpose room can help meet the needs of a variety of medical groups. In Camp John Marc's medical building, the large multi-purpose room has large windows overlooking camp to help campers feel included when they are in there. This room has fulfilled the need for a hemodialysis unit, physical therapy, breathing treatments, infusions at hematology and oncology camps, and medical education, as well as storage. Providing the medical staff with keys to lock the medical building and potentially with a code access side door for quick emergency access can allow for whatever level of security the individual medical teams desire.

Ceci Gladbach, the stem cell transplant coordinator at the Children's Center for Cancer and Blood Disorders and nurse for Camp Esperanza, identified the importance of storage and varied spaces. In one 6-day session with 140 campers, the oncology camp can use over 3500 individual doses of medications. Locking cabinets, a locking refrigerator, and locking closets are critical in allowing the storage of the volumes of medications required to care for these populations. She also discussed the importance of being able to accommodate the full medical team in group bedrooms and some individual rooms for the physicians or medical directors.

Counselor medications must also be stored, ideally in a way that does not disrupt the medical staff. The solution at Camp John Marc was to install combination lockers in a back room that acted as a lounge for volunteers and medical staff. This area has a separate entrance and is isolated from the treatment areas for campers, allowing counselors to access their medication and self-dose as appropriate.

A helpful non-medical addition to the medical building is a front porch area that can serve a variety of functions. Medical providers can rest there when not actively needed, allowing them to be present at the medical building while feeling included in camp. If a large group of campers needs medication or treatment at a certain time, this can also act as a holding area for groups of campers waiting for their turn in the medical building.

It is important to collaborate with individual partner groups as this design is created to ensure that you are meeting the needs of each of the groups that will come to your camp. The hospitals, medical teams, and partner groups will be better able to understand and articulate their individual needs within a medical building and this feedback should be taken into account when designing the space. Collecting ongoing feedback can also allow

you to make changes and accommodations as the facility develops and camp populations learn more about or adjust their needs.

The Live Oak Path

The concept of the Live Oak Path at Camp John Marc helps provide an example of an important aspect of camp design. The paths are primarily made from brick. Each year a number of these bricks are replaced or paths are extended by placing new bricks with the names of all of the first-year campers from the previous year. Family camps at Camp John Marc are also given the opportunity to engrave family names for those that attend. In discussing the significance of this element of the facility, Bettye Slaven identified that these bricks represent a camper's or a family's permanent place at camp. Any returning camper can go find their brick and know that it will remain there long after they attend camp. Giving campers a representation of their time at camp is an important aspect that can be done in a variety of ways. This practice, in addition to giving returning campers a sense of belonging, also has the potential to benefit families whose child may pass away from their chronic illness by giving them comfort that there is a representation of their child that will remain at camp.

CHAPTER FIVE

Activities and Programming

Randy Perry, who was the chair of the board during the first summer, spoke about how the Camp John Marc program came to exist. He identified the importance of finding and recruiting an experienced member in the field to help plan the program. For Camp John Marc, this was Vance Gilmore, whose expertise in this area of camping was mentioned in several of the interviews. Empowering a leader in the field to plan a camp's program can lead to unique elements that go above and beyond the typical camp activities. Vance talked about the value of getting to plan a camp's program from scratch. Developing the full-camp activities and the concept for the daily schedule enabled creative thinking that could bend the mold of established camp activities.

One note that should be mentioned that is tangentially related to the topic of programming is the name used during a week of camp. While Camp John Marc operates the facility and programming, each partner group retains its own name that is used to identify their camp. Vance explained that this decision helps each camp maintain its own identity. This can be critical in allowing them to establish a strong base of supporters and volunteers and gives the children camaraderie around their diagnosis and their specific camp. Garret Davenport, a former camper who has served on the Camp John Marc summer staff identified the importance of traditions at Ailihpomeh, the camp he attended as a child. This makes an important point to help encourage camp identity. While it is important to have traditions and programming that repeat on a facility and program basis across all

camps, there should also be room for individual partners to develop and maintain their own aspects of programming and traditions that fit with their camper population.

Projects

One of the signature elements of programming at Camp John Marc is projects. In contrast to activities that a camper attends once during the week, campers will attend their project each day for a little over an hour. The focus of projects, according to Vance, was to offer some programming that offered the camper a life skill to take home with them. This is an opportunity for the camper to select a skill they would like to learn and get consistent instruction across a week to help develop it.

Thresa Belcher is the director of social work and child life at Children's Health and coordinates their therapeutic camping initiatives. She has also identified this as an element of the program that allows campers to participate in areas that interest them and leave equipped with a new skill. During her time directing Camp Esperanza, she identified this as an opportunity to leverage staff and volunteers with unique skills. Some examples of projects that have relied on the unique experience of staff members are swim lessons, disc golf, boating, pottery, tie-dye, sign language, dance, and darkroom photography. This is a great opportunity to get to know the interests of the summer staff and offer them the chance to make those interests teachable. Projects are also an opportunity to get creative on new implementations of established projects or to create a new project entirely. An example of this from recent years at Camp John Marc is the creation of a "Camp Perfect" project, based on the popular YouTube and social media personalities Dude Perfect, who feature different types of trick shots.

While in the case of Camp John Marc, the facility and the programming are both managed primarily by the hired summer staff, projects are an opportunity to get the partner group to engage in the program as well. If they have a few established volunteers that are talented in skills or activities and would like to lead a project, it can offer the summer staff a break or bring some new ideas into rotation. Several camps have returning counselors that lead a specific project on an annual basis.

In talking about the impact of projects from his perspective as a former camper, Mr. Davenport talked about the pride in accomplishing and learning a skill. There are two general categories of projects that have developed at camp that can each lead to a certain type of pride. There are performance projects that teach the skills to put together a product to present at the end of the week. Examples include Lights, Camera, Action, whose campers make a movie, dance projects, music projects, and photography projects. The other type is more skills-based projects. Great examples include swim lessons, fishing, disc golf, and pottery. While the results may appear different at the end of the week, the overarching goals are the same, instilling campers with skills and pride in their accomplishments.

Activities

While the specific activities offered by the camp can be determined individually, there are some unique elements about Camp John Marc's implementation that merit mentioning. When asked about the camp's activities, Vance Gilmore mentioned the significance of the free choice program for older campers. Cabins fall into two categories for schedules, younger campers follow the scheduled cabin schedule in which all of their activities for the day are scheduled ahead of time. This enables the directors to ensure that

these campers are introduced to all of the available activities at camp while still receiving the opportunity to swim each day. These cabins travel together to all activities, which also promotes camaraderie and friendship among the campers in that cabin.

Older campers follow the free choice schedule. On this schedule, half the day is planned in advance by cabin to ensure each camper gets the opportunity to visit the pool for at least an hour per day. The other half is determined by the camper's selections on arrival day. After campers arrive and get settled in, they gather together and are given the opportunity to select their free choice activities for the week. They select two activities for each day to fill the unplanned half of the day and specify any alternates in case of scheduling conflicts. From these sign-up sheets, the camp directors plug campers into the free choice activity periods, making an effort to give campers their choice of activity throughout the week. This process offers campers the opportunity to have a say in what their week at camp looks like, selecting activities they enjoy while not avoiding those they do not. It also causes mixing of cabins that can promote friendships with people of different ages and from different cabins. A note of caution is that to cover needed adult ratios, counselors are simply placed to follow their children and ensure there is an appropriate number of adults at all activity areas.

Speaking from a more medical perspective, Mrs. Gladbach talked about the adaptability of activity areas. Camp is a place that campers may be able to participate in activities they may not be able to otherwise. It is important with this in mind that the core camp activities be available to all partner groups. While it can be a challenge to adapt the ropes course, boats, or sports and games, campers can get a lot out of these experiences they may not be able to have otherwise. Relying on any physical or occupational therapists

that travel with the user groups can help develop ideas on the best ways to adapt certain camp elements to meet the needs of the campers.

When talking about programming, Katie Campbell highlighted the importance of the "Challenge by Choice" philosophy that is used at the ropes course. This states that each camper gets to choose how much they want to challenge themselves. It means that the camper has the choice of if they want to participate and which challenge course element they would like to climb and how they would like to get back down.

While Mrs. Campbell talked about this in its original context of the ropes course, Mr. Davenport talked about how, while it is grounded at the ropes course, it has implications across the camp experience. Camp can be a chance for campers to push themselves to try things they've never done before, but it must be done in a supportive way. No camper should be forced to participate in anything they are not comfortable with. All campers should be given opportunities to participate in all of the activities but should also be permitted to choose their level of involvement. This leads to a culture of support through challenges while fostering the decision-making, boundary-setting, and confidence of the campers that are willing to push themselves.

Full-Camp Activities

The evening following dinner has been set aside at Camp John Marc for a set of central camp-wide activities that all of the staff, counselors, and campers participate in together. Katie Campbell identified some of the benefits of these full-camp activities noting how shared experiences can create camaraderie. While the diagnosis-specific nature of each camp lays the foundation for this friendship and bond, it is extended and facilitated further by introducing experiences that all campers share in and remember together.

The first evening holds a welcome-to-camp hosted at the chapel, which acts as a large-group gathering space, featuring upbeat music, dancing, and an introduction to the camp theme. This is also a time that can facilitate more significant elements including remembrance ceremonies for campers who have passed away. This can be a need or a choice for some camps to help process the loss of camp friends and should be evaluated to determine if it is a fit for a particular program. The camp welcome is followed by an ice cream social on the dining hall front porch where campers can mingle with each other and make friends. These events gather up the full camp and facilitate interaction between campers at the start of the week.

The second night holds theme night, the theme for which shifts and mirrors recent movie releases, children's programs, or major events. Examples of themes that have been used include Night at the Museum, the magical world of camp, superheroes, Pirates of the Caribbean, and the Olympics. For this evening, the camp is broken into age groups that rotate through different stations hosted by staff that are in a character that relates to the theme. The division is done to ensure that the activities are age-appropriate for the participants. In discussing this event, Vance emphasized the fun and whimsy of the experience. This is a great event for early in the week and inspires conversation and memories during the week and long after camp is over. One quote that has been attributed to Vance regarding theme night is "You gotta sell it!" What this means is that while campers may begin to understand the process of what is going on as they get older, if the staff buys into their characters and commit to the experience, campers of all ages will also be led to invest in the experience and will come out of it with that whimsy and magic.

When I asked Garret Davenport about his favorite evening activity as a camper, he spoke about cookout, the third evening activity of the week. This consists of cabins going to campfire sites and preparing a meal over an open fire. There are two cabins per site, which leads to a manageable number of children, a helpful number of adults, and a feasible amount of food to be prepared. This experience allows campers to use their hands to prepare food for their cabin or to build a fire. It is a time of bonding around the fire with campers chatting with each other, playing games, and participating in the preparation of the meal. The food selection of chicken fajitas helps to make this achievable only requiring the cooking of rice, vegetables, and chicken. However, the outcome is significant with many campers having not cooked a meal for themselves. This is an opportunity for staff to mentor while guiding and enabling the campers to participate in the cooking of their food. This can be a very meaningful experience for campers but, as noted by Vance, requires the teamwork and participation of a large portion of the staff. This event also requires some support from the kitchen staff in preparing the baskets and coolers with ingredients and supplies. The facility staff help by moving the pots and utensils and delivering water jugs and shovels prior to the evening. Finally, the volunteer counselors contribute through supporting the staff and helping to supervise the campers throughout the night. Cleanup is a bonding experience for the staff, with the summer team working to clean the dishes, prepare the boxes for the following week, and tidy up the kitchen afterward.

The midweek evening activity shifts based on the needs and wants of individual camps. This is a chance for the partner group to have some input on what they want their week to look like. A few options that have been prepared for this evening slot are a lip-sync battle, a talent show, or water games, which is free time with a variety of water-themed

activities like a slip and slide, water guns, hoses, and water bombs or balloons. Another popular option is kickball for scheduled campers and epic game night for free choice campers, which consists of a rotation of different games and randomized teams mixing up the established cabins.

The last evening activity that takes place the night before the campers depart is party night. This is a full-camp event using the multi-purpose spaces in the silo to celebrate the end of the week. There is music and dancing, board and card games, ping pong and foosball, and snow cones. This event has a theme as well that is separate and unrelated to theme night which can help create some new games and activities at party night so that there is some variation from year to year. This evening typically ends with project performances as mentioned in the section above. This provides campers a chance to mingle with their friends from other cabins while having fun and playing games.

A camp is only as strong as its programming so it is important to have strong activities throughout the week. While activities are important, the experience of campers can be augmented through the creation of new programmatic elements and full-camp gatherings and events throughout the day and the session.

CHAPTER SIX

Personnel Considerations

There are a lot of people that are essential to the mission of camp. Vance discussed the categories of people needed to make camp happen. In the implementation of the partnership model, there are two groups that are the most visible in the execution of camp. Those are the summer staff and the counselors. The summer staff is the programmatic team hired by the camp itself to facilitate activities and manage emergency procedures. The counselors are volunteers recruited by partner groups on a week-to-week basis to help supervise campers in the cabins, accompany campers to activities, and ensure campers are cared for during their week of camp. There may be many types of staff that are employed at a camp based on its individual design and needs and so there may be personnel needs that fall outside of this outline.

While there are several unique parts of each role, and those will be discussed in this chapter, it is important to first cover the similarities that unite the roles. First, everyone has a role to play in risk management so it is important that both staff and counselors understand the principles and how their role fits into that larger picture. In addition, and of critical importance, is the universal responsibility to protect campers from child abuse. This starts with effective policies regarding preventing isolated moments (one adult alone with any number of campers), changing and privacy in the cabins, photography in sensitive areas, and appropriate touch (no frontal hugs or piggy-back rides). However, the critical element in these policies is the human element. Ensuring that counselors and staff

understand these policies is an important part of the training. The next stage of prevention is that each individual on the camp property knows how to report any violations of these policies. That aspect of counselors and staff watching to ensure that policies are followed and children feel safe is the foundation of a safe camp experience. Without the safety of the campers, it is difficult or impossible to facilitate a fun and effective camp program.

Camp Leadership Team

In designing policies and making programming and camp decisions, it is important to have an effective full-time leadership team. Randy Perry, who has worked as the chair of the board, discussed the roles of the leadership. This starts with an executive director. They are less involved in the actual facilitation of the summer and typically handle many of the background tasks and support the rest of the leadership team and the staff in their roles. One of the central tasks for this member of the leadership team is relations and coordination with the board. They help guide and discuss decisions with the voting members of the board and help convey information from the camp program enabling them to be involved and feel connected to the state of the camp.

Camp John Marc established a large board for the inclusion of those needed to make the mission possible and to enable an effective scale of fundraising. Randy Perry made the distinction that while there are some full-board matters and all are involved in aspects of camp, there is also a smaller executive board structure that handles many of the smaller decisions and communicates directly with the executive director. This enables a large board to function and communicate efficiently with the camp leadership team.

Heading up the actual location and operation of camp is the camp director. This individual is responsible for the operation of camp during the summer and weekends and

should remain on-site while camp is in session. They coordinate the training needs of the staff and counselors and are responsible for the safety and effectiveness of programming. This places them at the head of managing the summer staff and facility staff and ensuring that tasks needed prior to summer camp are accomplished.

Another important member of the leadership team is the assistant camp directors. These individuals are full-time employees that are tasked with helping the camp director accomplish their role. This means they can supervise and coach the staff and facility team as those responsibilities can be divided and assigned. They can also play an important role in planning the summer programming and being the coordinator or point person for some of the summer camps. At camp, the camp director and assistant directors also divide the management of activity areas among themselves to encourage experience and a depth of knowledge in the areas for which they are responsible.

The last member of the leadership team at Camp John Marc is the program director. This is a seasonal position over the summer. They fulfill many of the responsibilities of the assistant directors while acting as a seasonal member of the leadership team. They can provide additional planning and program support and can float into various support roles. This role is not always filled but can provide an additional leadership opportunity if an outstanding staff member is identified or if there is an individual capable of meeting an important need at camp.

The other important role of all members of the leadership team is to coordinate the camp program in conversation with the directors and leadership of the user groups. They act as the liaisons for the camp programming and help communicate with the partner groups. This enables partner groups to have effective opportunities to provide feedback

and input into their camp's session. The leadership team also plans the individual schedules and activities with input from the partner groups. This helps the user group have input on the needs and expectations of their population while the leadership team offers their experience and knowledge in programming and scheduling.

Summer Staff

The core of the team needed for the facilitation of summer camp is the summer staff. They develop a deep knowledge of the procedures and techniques for facilitating the activities and programming for the camp. They have several roles but one of the primary ones is to run the activities that are offered.

At Camp John Marc, Vance, along with the founding board, developed the concept of hosting a cabin. While the summer staff lives separately from the campers and counselors that came in on a weekly basis, they are paired up with one of the cabins. The staff eats meals with the cabin and help out the counselors in the cabin in the evenings. This allows staff members to feel connected to each camp that comes through and to develop connections at a deeper level with many of the campers. It also helps provide a support system for the counselors who may have questions about how camp works or may need help with certain aspects. Staff members have opportunities both before and after the campers arrive to provide information and answer any questions that counselors may have. Hosting looks different to each person and has changed over the years. Garret Davenport, a recent staff member, identified the core of hosting in the evenings as providing some small activities like card games, board games, or stories for while the campers are rotating through the showers or counselors are getting ready for bed. One of the more exciting parts of hosting is the opportunity once or twice during the week to help with post-evening

activities. This is an activity following the end of the full camp event and can consist of a number of things including stargazing, night fishing, or a trip to the treehouse for songs and stories. It can be important to put limits on the timing of these activities so that both campers and staff get adequate sleep and don't feel stretched thin.

In the partnership model, each group focuses on their expertise and partners to form a complete team. The summer staff members are trained and act as camping professionals specialized in facilitating the programming and activities. This means that there are members of the team trained for each of the daily activities offered, including lifeguards for the pool and the boats program, ropes course staff, archery or rifle range staff, and team members trained for arts and crafts and pottery. While some activities do not have official courses or certifications paired with them, it is important to ensure that the summer staff feels adequately prepared and trained to facilitate their activity with campers. An important aspect of each part of training is that staff understand how to work with and adapt the activities to the groups they will encounter. This can take place during staff training or before individual weeks that require specific techniques.

The summer staff also play a central role in full-camp activities. At facilitated events like Theme Night, Epic Game Night, Water Games, and Party Night (See Activities and Programming for descriptions), they are trained before the summer on what those events look like and how to properly facilitate those activities. They may also create activities as part of those events or support other team members. This centralized training allows for high-quality, consistent programming for each camp.

One important aspect of the staff role is the training required to respond to severe weather. This starts with understanding how the respond to rain and lightning. It is

important that outdoor activity facilitators and lifeguards, in particular, have an understanding of the procedures for how lightning and rain affect their operations. At the next level is an understanding of how tornado watches and warnings affect camp programming and the communication and procedures involved. While all adults at camp should understand the severe weather procedures, the summer staff will take the lead by modifying their activities or location.

Some of the most critical aspects of the training and responsibilities for the summer staff are the camp's emergency procedures. These are not used frequently but, if needed, must be executed quickly and confidently. The first to mention is the procedure for a lost camper. This starts with a check of activities and common areas (bathrooms, dining hall, cabins) by one of the directors. If five minutes pass without the camper being located, all program staff are notified over the radios. The campers and counselors report to a central location for a headcount by the partner group director while the staff take radios and split into pre-assigned paths and areas to check. Through the design of the routes and areas assigned to each role at camp, it is possible to quickly search the entire camp area. It is important to ensure that all areas are covered including the surrounding roads and any backwoods or wilderness areas surrounding or used by the camp.

Another category of emergency procedure that all staff should know is the procedures for the evacuation of a camper due to medical conditions. At Camp John Marc, this is typically handled by ambulance or helicopter. Each staff member must know the procedures for both so that anyone can be relied on to fulfill the role of meeting and guiding the ambulance from the gate or setting up the helicopter landing zone. The procedures used

will vary based on the location of a camp and their relation to partner hospitals and local emergency services.

Counselor Responsibilities

While the summer staff is responsible for the facilitation of the program, the primary responsibility of the counselors is the safety and care of the campers. They are living and eating meals with the campers. They are with the children for the vast majority of their time at camp. They are the ones that make sure that they are brushing their teeth, showering, sleeping, and building friendships. It is important in tasking the counselors with such a monumental role that they are given clear boundaries on what is appropriate conduct for living in the cabin with campers so that both the campers and counselors are afforded the privacy to which they are entitled. This is also where the staff can best support the counselors in the evening by providing additional hands in the cabin so that they can get themselves ready for bed as well.

Depending on the groups a camp partners with, some campers may need help with the activities of daily living (ADLs). This can include help with showers, changing, and using the restroom among some others. It is important that counselors asked to assist with these ADLs are trained on how to respect a camper's space and privacy while ensuring that each camper receives the help they need. This is not typical of most camps, but working with these populations, this can be occasionally encountered and deserves mention.

Between his years as a camper and a staff member, Garret Davenport acted as a volunteer counselor. Asked about how he saw the role, he identified the counselor as a leader who can help create community in the cabin. The aspects to this that he identified were to be there for all campers and remain mindful of the group as a whole. The primary

challenge he identified was the exhaustion from the vast amount of time spent with the campers engaging in consistent programming.

While their role is not the facilitation of activities, they are involved in the successful execution of the camp programming. In the younger ages, the full cabins travel through their schedule as a single unit. The counselors stay with them to ensure efficient transitions and the correct number of adults at each activity area. During the activities where only one or a few campers participate at a time, they can also ensure that the other campers do not wander off through small games or conversation. The older campers typically split up to the activities they chose on the first day of camp. The counselors are then divided to follow a few of the children from their cabin. Their role, in this case, is to provide the correct adult-to-camper ratios and support the staff in facilitating the activity.

The final aspect of the role of counselors is to provide supervision during the unstructured time of camp. Each camp has at least an hour of rest, if not more. Rest is important for everybody at camp and the counselors can help assess their campers to see how each day's rest period needs to be spent. It can be flexible, used for naps or quiet time on beds or, if the campers have the energy, there may be the opportunity to use some of the time for a small game. In addition to rest time, there is some free time that occurs before mealtimes, prior to afternoon activities, and following the end of the evening activity. It is important that the counselors remain vigilant during these times to ensure that no bullying is taking place. One way that counselors can use this time is to facilitate a group activity such as a basketball game, four-square, or gaga ball, which can help to contain and engage campers.

The counselors at Camp John Marc are volunteers with each partner group that come out for a single week to stay in the cabins. Susan Williams, who oversaw the board during the founding years of camp, identified that the community volunteer component of camp was critical to the partnership. Without the counselors in the cabin, camp simply cannot happen so it is important to support and appreciate the volunteers each camp brings with them. A camp can provide a space for counselors to step away from the cabin and enjoy a small snack or a soda. Giving them the opportunity to rest and recharge can help them cope with the long hours and challenges in the cabin. It is important that counselors are instructed on how to take these breaks in ways that ensure that supervision is continued and no isolated moments occur with campers. The appreciation of counselors is something that can be passed to the partner group with suggestions and support from the camp team.

Medical Team

In providing camps for children with chronic illnesses and physical challenges, the medical team is essential to ensuring that camp is safe. While important, they are the responsibility of the partner groups, which typically have established relationships with the clinics and hospital departments serving their campers. Dana Dempsey, who has worked with a number of camps through the hospital, spelled out the essential personnel for a medical team. The first is the medical director, which should be a doctor or advanced practice provider that can write orders for the patients attending camp. This is important to ensure that all campers can be cared for in a timely and efficient manner, regardless of any changes. She also listed two nurses, who can provide support in administering medications and handling the rudimentary camp injuries like bumps, bruises, cuts, or scrapes. She also identified the difficulty of building a medical team during the summer, when many

pediatric providers are busy with appointments scheduled while children are on a break from school. It can be important to build a strong partnership between the medical team members and the camp so that you have a consistent group of people that are willing to make themselves available to serve camp. The makeup of a medical team is, of course, dependent on the diagnosis and the acuity of the patients attending any particular camp but it is also important to establish minimum requirements to help ensure that each camp brings a team ready to meet the needs of their campers.

Ceci Gladbach identified some of the benefits of serving on the medical team for summer camp. It offers providers the opportunity to observe and interact with campers in a normal environment. At camp, doctors frequently see a side of their patients that is not evident in the hospitals and clinics. It offers opportunities for more casual interactions between the medical team and the campers. Also included was a benefit on return to the hospital, with camp helping to reduce the fear and anxiety experienced by patients when being seen by medical providers.

Facility Team

The facility staff represents an essential addition to the team for any camp. They are responsible for helping maintain a quality camping environment by servicing and caring for the indoor and outdoor spaces. In order to be regarded as a high-quality camping program, both the facilitation of activities and the facility itself must be well-maintained.

The first part of the team to mention is the facility staff. The camp needs a few individuals that are experienced in doing the repairs needed to keep camp operational. They need to be able to complete electrical work, plumbing, and HVAC services in the cabins and camp buildings to help maintain a livable environment. They help to complete work

orders for rudimentary wear and tear and can conduct preventative maintenance to help improve the longevity of camp facilities and equipment. This is also the team responsible for the camp environment, removing natural hazards like dead tree limbs and ant colonies.

The next part of the facility team is the housekeeping staff. It is useful to have an adequate number of team members so that all cabins and common spaces like the dining hall can get a basic cleaning daily. They can also help respond to spills, vomit, and blood and ensure that areas are properly sanitized after these occur. One of their major roles is a deep cleaning of camp between each partner group during which all trash is taken out and the cabins and buildings receive a full cleaning before the next group arrives. This is also a great place for the summer staff to support the facility team following a large camp by taking out and centralizing the trash for the cabins they hosted.

The final part of the facility team is the kitchen staff. An adequate number of team members must be hired for the kitchen to provide sufficient help during meal service and cleanup. This can include a couple of cooks for the morning (breakfast and lunch) and a couple of cooks for the evening (dinner). In addition, a couple shifts of dishwashers are needed to clean up the kitchen and ensure all dishes are washed and sanitized following each meal. Beyond these basic requirements, the staffing for the kitchen should be based on the needs of the camp, the setup of the kitchen environment, and the daily schedule that is typically followed.

CHAPTER SEVEN

Camper Populations

Within the context of providing camps to children with chronic illnesses and other medical challenges, there are a number of partner groups and diagnoses that can be served. It is important when serving such a wide and diverse medical classification that a camp defines its particular population of interest. Camp John Marc defined the group it serves within its mission station as children diagnosed with "chronic medical and physical challenges" (*Camp John Marc,* n.d.). This helps to narrow the number of diagnoses a camp is attempting to serve and also enables them to tailor their programming to their specific population.

It is important that any potential user groups understand and buy into the partnership. It is in developing a strong partnership that each group will grow to understand and meet the needs of the other. This will enable a camp to welcome new groups and develop a program that best serves their campers.

Examples of Diagnoses

The camps that Camp John Marc hosts have shifted over the years as it has developed and changed. Their current slate of camping programs is a helpful illustration to the populations that a camp of this type can serve, though by no means includes all groups that can fit into a partnership (Camp John Marc, n.d.). The summer serves campers with kidney disorders, burn survivors, those with spina bifida, those with muscular dystrophy,

those with cardiac disease, those with cancer, those with sickle cell disease, those with hemophilia, those with juvenile arthritis, and those with severe asthma.

The weekend camping program typically serves more specific subgroups of populations or diagnoses that affect fewer people. Examples from the Camp John Marc weekend program include neuro-oncology patients, campers with HIV/AIDS, those with phenylketonuria (PKU), Spanish-speaking families of children with spina bifida, patients with bladder exstrophy, those with tuberous sclerosis, and former trauma patients. As is evident in that list, weekend camps allow Camp John Marc to extend its programming to several groups that may not be able to fill the camp in the summer but would benefit from having a camp experience over a weekend.

Summer vs. Weekend Programming

While it is referenced in the previous section, there are two camping periods at Camp John Marc. In the summer, campers receive the more traditional camp experience with counselors staying in cabins with them and the camp lasting for the week. In the fall and spring, when most children have school, Camp John Marc operates weekend camps that start Friday evening and conclude Sunday mid-day.

While the schedules are different based on the length of the camps, there are also some programmatic changes. Vance Gilmore and Susan Williams talked to me about some of the key logistics to the weekend camps. The weekends are typically facilitated by community volunteers and former summer staff that volunteer their time to help out. With colder weather and without a full summer staff, fewer activities can be offered. Those typically not offered are the horse program, the boats program, and the swimming pool. In addition, while the summer sees children attending independently of parents, most

weekend camps are structured as family camps. This brings the whole family out to stay in a cabin and enjoy camp activities and programming. This difference in structure allows for camp to happen without the need of the full summer staff, all of the counselors, or even a full medical team, as parents usually handle medical needs and medications for their children.

In deciding a camp schedule, consideration should be given to the needs of camper populations and if they would be better served through the summer program or the weekend camp programs. Camps that can fill the majority of beds at camp with campers and counselors are typically good fits for the summer program. In addition, if a particular hospital department wants to host a camp for their patients independently, that can also be accommodated with due diligence. Camp John Marc, for example, hosts two hematology/oncology camps in the summer. One is coordinated and serves campers from Children's Health while the other is coordinated by Cook Children's and serves their patients.

Weekend family camps can be a good fit for diagnoses that tend to affect the whole family as they welcome all members of the family and encourage bonding and respite. In addition, for diagnoses that are less common or require more complex care, bringing the families out during a weekend camp can help build an appropriate number for camp and can accommodate the medical aspects by having the parents present along with the medical team.

CHAPTER EIGHT

The Impact of Camp

While this is primarily an overview of the development and operation of Camp John Marc, this section presents the impacts that camp can have on campers and families as they were discussed by those that have been involved in working with these patients or with camp. This is not meant to pass judgment or support the operation of any camp. It is simply a way to understand the significance that camp can hold for campers.

When asked about how Camp John Marc impacts campers, the near-universal reply was that it improves their personal confidence. This supports the premise of the tagline for the camp, which is "Inspiring Confidence for life (*Camp John Marc*, n.d.). When asked to expound on her answer, Thresa Belcher, who has worked with Camp Esperanza for several years, discussed the unique opportunities at camp for the children to challenge themselves and expand their boundaries. This relates to the activities where campers can push themselves at the ropes course or try riding a horse for the first time. However, this also relates to the social aspects of camp; befriending cabinmates and connecting with friends can help increase their social confidence.

Ceci Gladbach identified the related concept of comradery as an outcome of camp. While Camp John Marc works with a variety of conditions, each week of camp is restricted to a single diagnosis. This helps facilitate connections through previous shared experiences. While at home campers may be the only one they know with their diagnosis, camp offers an environment where everyone has shared the hospitalizations, treatments, and challenges

that come along with a particular medical condition. This enables campers to connect in ways that are not possible at traditional summer camps or even at camps where diagnoses are mixed. Dana Dempsey identified the importance of the friendships that are formed as part of the camp experience. With many camps offering the opportunity to return for many years, the friendships with cabinmates and fellow campers grow stronger each year with many campers looking forward to their week at camp all year so they can reconnect with their friends.

Katie Campbell identified the benefit of campers gaining more independence. This takes several forms as campers leave camp. In identifying the same concept, Ceci Gladbach qualified her statement. She specified that it was important for camps to consider the opportunities they provided for campers to practice their independence. There are a lot of opportunities for campers to practice this. Getting ready in the morning and for bed, getting the food for their cabin in the dining hall, and participating in activities on their own are all opportunities for this growth to take place. This can show in many contexts at home with campers requiring less help in the mornings and evenings, less assistance with dining, and greater independence in socialization and play.

One of the impacts of camp lies in the activities that are offered. Mrs. Gladbach spoke about the fact that for many of the campers, camp is the only opportunity they have to participate in certain activities. It can be hard to find other places that have challenge courses or horse programs that are specifically trained with the population of those with chronic illnesses and physical challenges in mind. That's why, she said, it is so important that activities be made adaptable and accessible to all campers that want to participate.

On a related note, Thresa Belcher discussed the memories and emotions tied to the camp experience and activities. Many of the campers talk about camp during medical visits and with family and friends throughout the year. They carry with them the friendships and excitement of their time at camp. It gives them something to look forward to as they spend time in the hospital or clinic. The pride from challenging themselves at camp can give them a sense of accomplishment that allows them to better face struggles at home.

While many of the impacts directly affect the campers, some benefits are seen by the parents and the families of the patients. Many of the diagnoses served at Camp John Marc require significant caregiving from parents. While this affects the parents directly, it can also affect any siblings, who may not feel like they get the appropriate attention or time from their parents. When the patient gets to go to camp, it gives the rest of the family a week of respite from the challenges of caregiving while offering siblings the chance to enjoy time with parents or participate in their own camp or activities. Dana Dempsey mentioned the gratitude she has had expressed by parents for the experiences their children get at camp and the benefits they receive.

Camp has the potential to make significant impacts, as have been documented by the research presented in the introduction. These anecdotal impacts are meant to apply those documented benefits to the population that Camp John Marc serves and illustrate how camp design and programming can produce them. It is important to note that several interviewees mentioned not only the benefits but the thoughtful programming that goes into producing them. Camp can be a life-changing experience for these patients but it is up to the camps to design a program that makes this happen.

CHAPTER NINE

Conclusion

The partnership model consists of multiple organizations coming together for a single purpose. In the context of camping for children with chronic illnesses, these organizations are the camp, the hospital, and the partner organizations. This model allows each partner to focus on its strengths so that a high-quality camping experience can be offered to patients. To be an effective partner requires mutual respect, communication, and a willingness to compromise. The camp staff is responsible for planning and implementing the activities and programming. The partner organization is responsible for recruiting a medical team from the hospitals, finding the counselors that stay in the cabins, and inviting campers from the patient population they serve to attend.

In order to make the partnership possible, there are certain roles and positions that must be filled. Each organization needs to have a leadership structure that communicates with that of the partner. They will cooperate on the planning for the overall camp program and the programming that happens during their individual camp, allowing the partner group to influence what their particular campers get to experience. Each is responsible for recruiting a part of the team that is essential for camp to function. The camp recruits the summer staff members that are trained on emergency procedures and facilitation of the activities and programming. The partner group recruits the volunteer counselors who live in the cabins with the campers. In addition, the partner also recruits the medical team that specializes in the diagnosis that their camp serves. Finally, the partner group is responsible

for identifying the diagnosis or patient population they plan to serve and inviting campers to attend. It is of equal importance that the camp has a facility staff including maintenance personnel, kitchen staff, and a housekeeping team.

The partnership model can be used to serve a wide range of different diagnoses. By determining which populations can fill a summer camp and which are better fits for a weekend family camp, the range of diagnoses served can be widened to include those with smaller numbers of patients. It is up to the camp to decide which chronic illnesses or physical challenges they want to serve and it should be clearly established and guide the selection of partner hospitals and partner groups. It is important that for each group that is served, an adequate medical team with experience with the diagnosis be available and present at camp.

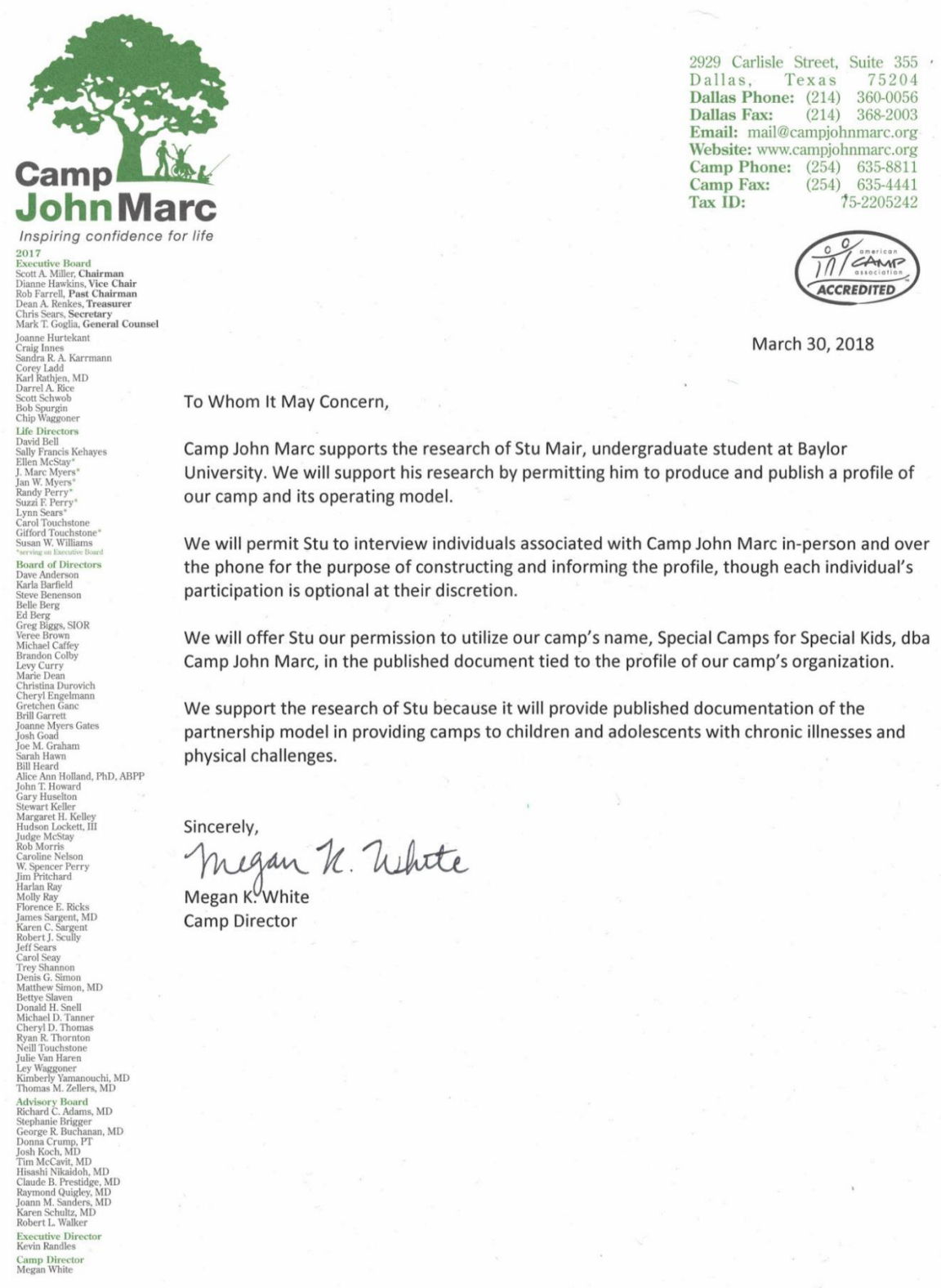
Campers can derive many benefits from the camp experience. At Camp John Marc, the ones that were commonly identified were an increase in confidence and independence and the development of comradery and friendship with fellow campers. While the benefits for campers have been well documented, the rest of the family also experiences respite from the care associated with chronic illnesses while their child is well-cared for at camp.

In the future, research can focus on validating the benefits of the partnership model for the organizations involved and the campers served. While there is extensive research about the benefits of camp in general, future research can focus in on the benefits seen by children diagnosed with the particular chronic illnesses and physical challenges that are served at a given camp. Finally, because the partnership model may not be a fit for camps in all areas, researchers could focus on profiling other models of operation.

APPENDICES

APPENDIX A

Camp John Marc Letter of Support



Camp John Marc
Inspiring confidence for life

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Camp Fax: (254) 635-4441
Tax ID: 75-2205242

March 30, 2018

To Whom It May Concern,

Camp John Marc supports the research of Stu Mair, undergraduate student at Baylor University. We will support his research by permitting him to produce and publish a profile of our camp and its operating model.

We will permit Stu to interview individuals associated with Camp John Marc in-person and over the phone for the purpose of constructing and informing the profile, though each individual's participation is optional at their discretion.

We will offer Stu our permission to utilize our camp's name, Special Camps for Special Kids, dba Camp John Marc, in the published document tied to the profile of our camp's organization.

We support the research of Stu because it will provide published documentation of the partnership model in providing camps to children and adolescents with chronic illnesses and physical challenges.

Sincerely,

Megan K. White

Megan K. White
Camp Director

APPENDIX B

Informed Consent Form

Informed Consent to Participate in a Research Interview

Research Project Title: Profiling the Partnership Model in Organized Camping for Children with Chronic Illnesses and Physical Challenges

Principal Investigator: Hugh Mair

The goal of this study is to build a profile of how Camp John Marc, a camp for children with chronic illnesses and physical challenges, operates in partnership with pediatric hospitals. Emphasis is being placed on programming, populations, the history behind the partnership model, and the responsibilities of each partner. This is meant to provide a more complete published understanding regarding operating camps of this type on the partnership model.

During the interview, questions will be asked regarding your relationship to Camp John Marc or the partnership model. I will ask about your experience in playing a role within the partnership model. Further questions will be asked aiming to provide a more complete understanding of your role to help profile your specific area of expertise.

The interview is estimated to last between 30 and 45 minutes, depending on the level of detail you wish to discuss. You may decline to answer any of the questions that are asked or discontinue the interview at any time. The interviews will be recorded for accountability on the questions asked of you.

Though unlikely, this interview may cause some level of emotional discomfort. If at any point, you feel some level of emotional discomfort, you are free to pause or end the interview with no repercussions. Any information shared may be used in the published study, though names may be omitted or changed, as requested. An attempt will be made to omit any information that could be seen as potentially damaging to a research subject, particularly if their name is included.

All information will be kept confidential. Interviews and notes from them will be kept on a hardware-encrypted storage device. Your name will only be tied your published information according to your wishes. Requests for anonymity will be honored in the published document and will have no bearing on your participation in this study.

If you would like to speak with someone not directly involved in this research study, you may contact the Baylor IRB through the Office of the Vice Provost for Research at 254-710-1438. You can talk to them about:

- Your rights as a research subject
- Your concerns about the research
- A complaint about the research

By your signature below, you are providing consent to participate in this study. In addition, please indicate below if you are comfortable with your name being published within this study. If you have any questions or concerns, please feel free to contact:

Hugh “Stu” Mair
Phone: (214) 843-8430
Email: Stu_Mair@baylor.edu
Mail: 2001 S 5th St. Apt. 808, Waco, TX 76706

☐ My name may be included along with my interview content in the published document

☐ Do not include my name in the final document – I would like my interview anonymized

Printed Name: _____ Signature: _____

APPENDIX C

IRB Determination of Non-Human Subject Research

BAYLOR UNIVERSITY

INSTITUTIONAL REVIEW BOARD – PROTECTION OF HUMAN SUBJECTS IN RESEARCH

NOTICE OF DETERMINATION OF NON-HUMAN SUBJECT RESEARCH

Principal Investigator:	Hugh Mair
Study Title:	Profiling the Partnership Model in Organized Camping for Children with Chronic Illnesses and Physical Challenges
IRB Reference #:	1317853
Date of Determination:	09/13/2018

The above referenced research project has been determined to not meet the definition of human subject research under the purview of the IRB according to federal regulations at 45 CFR 46.102(d) & (f). Specifically, this is not generalizable.

The following documents were reviewed:

- IRB Application submitted on 09/09/2018
- Protocol, submitted on 09/09/2018

This determination is based on the protocol and/or materials submitted. If the research is modified, you must contact this office to determine whether your modified research meets the definition of human subject research.

If you have any questions, please contact Deborah Holland at (254) 710-1438 or Deborah_L_Holland@baylor.edu.

Sincerely,

Deborah L. Holland, JD, MPH
Assistant Vice Provost of Research
Director of Compliance

OFFICE OF THE VICE PROVOST FOR RESEARCH

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