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Heart Ambassadors Training Resources

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Abstract

There are too many families of children diagnosed with cancer who deal with high levels of stress and financial instability. Jacob's Heart Children's Cancer Support Services works to improve the quality of life for children with cancer and support their families in the challenges they face. This capstone consisted of supporting the development of the "Heart Ambassadors" Program. Through the Heart Ambassadors, Jacob's Heart envisions committed public relations liaisons as confident representatives, enthusiastic, informative, organized and adaptable; who connect with families, donors and supporters. The goal is that Ambassadors add value and coherence to the meaning and purpose of Jacob's Heart. The capstone involved the creation of training materials that served as a resource for volunteers to become familiar with Jacob's Heart vision for their volunteers. It also involved the creation of needs assessments, and a system to organize volunteers more efficiently. It is recommended that Jacob's Heart continues with the implementation of its Heart Ambassadors Program to maximize the impact of volunteers' time in caring for the families and children the agency serves.

Keywords: *Cancer, children, instability, support, volunteers*

I. Agency Description

Jacob's Heart Children's Cancer Support Services is a nonprofit organization located in the heart of Watsonville, CA. Jacob's Heart was founded in 1998 by Lori Butterworth when her best friend's son, Jacob, was diagnosed with leukemia. Lori realized that there weren't any resources that her friend and other families who were going through the same issue could rely on. Eventually, under Lori's leadership, Jacob's Heart has grown from serving one child with cancer 19 years ago, to a nationally recognized model of community-based pediatric palliative care serving hundreds of children and thousands of family members each year throughout Monterey, South Santa Clara, Santa Cruz, and San Benito counties with ages ranging from 0 to 18 years old (Jacob's Heart). In 2018, Jacob's Heart delivered roughly 4,086 bags of groceries to families in need. In addition, 280 rides were given to families who did not have transportation to their children's doctor appointments, and \$188,990 were distributed to families who needed financial assistance (Jacob's Heart). Jacob's Heart "exists to improve the quality of life for children with cancer and support their families in the challenges they face" (Jacobs Heart). Jacob's Heart offers a variety of services through their programs described below.

Hearts and Hands Transportation

The Hearts and Hands Transportation Program provides parents with pre-paid gas cards and transportation to treatment from the hospital to their home. These rides to their treatment ensure safety, comfort and security to the families. Children in Monterey, Santa Cruz, San Benito, and South Santa Clara counties travel a long distance to get to their appointments, there are no pediatric oncology facilities in their local community.

Direct Financial Assistance

Jacob's Heart families also have the option to receive aid from The Direct Financial Assistance Program which offers direct "financial and practical assistance to families experiencing hardships" due to their child's sickness (Jacobs Heart). Through this program, Jacob's Heart will also financially assist families with their child's funeral expenses if needed.

Full Hearts Groceries

Jacobs's Heart is also dedicated to delivering delicious and nutritious groceries and meals every other week to the family's home or hospital rooms during treatment through their Full Hearts Grocery Program. This is a volunteer-driven program that ensures siblings left at home have fresh food delivered to their door with a nourishing recipe with step by step directions.

Case Management & Home and Hospital Visits

Jacob's Heart ensures their families safety and security through the Case Management Program as well as home and hospital visits. The Case Management Program assesses family's needs and assistance in locating resources to meet their needs. Finally, the home and hospital visits allow Jacob's Heart Family Support Services team to visit children at home or in the hospital (Lucile Packard Children's Hospital Stanford and UCSF). Usually, a visit "brings the family of a child or teen with cancer a compassionate support specialist with care packages, parent and child counseling, celebrations of milestones (end of treatment, birthdays, etc.), and healing therapies" (Jacobs Heart). Jacob's Heart always reminds the children and families that they are not fighting this battle alone. Jacob's Heart offers family support through The

Counseling and Case Management Program which provides services to parents and many resources.

Peer to Peer Support

Another program offered to parents and family members is The Peer to Peer Support Program which allows parents to connect who are dealing with similar challenges. These gatherings are held at Jacob's Heart which ensures a safe and comforting environment that allows the families to come together and share their stories.

Art from the Heart

Art from the Heart allows children and families to come together and express themselves by creating art. This event is held quarterly and allows the children to express themselves through art and different activities.

Holiday Hearts Program

During the holiday season, Jacob's Heart Holiday Hearts Program pairs community families and businesses with Jacob's Heart families. Each of Jacob's Heart family members creates a wish list and the goal is to give these families what was on their wish list.

II. Communities Served by the Agency

Jacob's Heart serves the counties of Monterey, Santa Cruz, San Benito and South Santa Clara. Children with cancer between the ages 0 to 18 may be referred by a doctor to Jacob's Heart and receive the services needed. In January of 2019, Jacob's Heart conducted a complete census of the families served whose children are in treatment, transitioning off treatment or recently bereaved. The following is a summary of the findings:

- 79% are enrolled in full-scope Medi-Cal
- 45% qualify as high-financial need; extent/severity of risk factors include:
 - a) number of parents working
 - b) loss of job/hours due to a child's treatment
 - c) seasonality/stability of employment
 - d) late payment of basic living expenses
- 50% rely on one vehicle for transportation, including transportation to work and treatment
- 37% experience housing insecurity (substandard, unstable or transitional housing, and/or are facing eviction)
- 45% of families are subject to other major stresses (unrelated to their child's condition) that have a significant impact on quality of life

III. Problem Description

The causes of childhood cancer have been thoroughly studied for several decades. The incidence of all cancers occurring in children under 19 years of age is about 20.4 cases per 100,000 in Monterey County (Lucile Packard Foundation for Children's Health, n.d.). There are too many families of children diagnosed with cancer who deal with high levels of stress and financial instability. According to the National Cancer Institute, cancer is a term for diseases "in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems" (n.d.). Still, there are several types of cancer that come with different consequences and treatments.

According to CureSearch for Children's Cancer, every day, 43 children are diagnosed with cancer (n.d.). Throughout all ethnic groups, ages and socio-economics, cancer remains the number one cause of death by disease in children. CureSearch for Children's Cancer claims the average age of children who are diagnosed with cancer is six (n.d.) – resulting in more than 40,000 children who undergo treatment for cancer each year. Due to major treatment advances, the American Cancer Society claims more than 80% of children with cancer now survive 5 years or more (2019). In general, children with cancer can experience decreased physical, emotional, and social health-related quality of life compared to healthy children. According to the National Cancer Institute, the causes of most childhood cancers are unknown. About 5% of all cancers in children are caused by an inherited mutation – a genetic mutation that can be passed from parents to their children (2019). The Cancer Research shares the following risk factors that may have a higher chance of exposing children with cancer. Problems with development in the womb,

exposure to infections, exposure to radiation and previous cancer treatments (Cancer Research, 2010).

Cancer creates an instant crisis on not only the child but their family as well. The National Children's Cancer Society conducted a survey of 449 families served and found a majority (95%) say their child's cancer caused a financial burden on their family (2018). 10 to 15% of U.S. families claimed as not poor at the time of diagnosis and later did become poor during treatment for their child's cancer (NCCS, 2018). This study indicates that **there are too many families of children diagnosed with cancer who deal with high levels of stress and financial instability.**

Causes:

There are several causes for this problem. The cost associated with childhood cancer makes it a struggle for families to get by and meet their needs while also being able to get their child to treatment (NCCS, 2018). For families already living in poverty, these difficulties are often multiplied. Organizations and nonprofits have dedicated their time to help these children and their families who are in need, but many families still lack access to resources. The Agency for Healthcare Research and Quality discovered a total direct medical cost of \$88.7 billion in 2011 alone (2016). In the United States, Americans spent roughly half of this sum on outpatient expenses, 35% on in-patient costs, and 11% on prescription drugs (Wish Upon a Star, 2016). In 2009, pediatric cancer hospitalization costs in the United States averaged \$40,400, nearly five times higher than hospitalization for any other pediatric conditions (Warner, E. L., Kirchhoff, A. C., Nam, G. E., & et al., 2015). These high costs may be driven by unexpected procedures during treatment including treatment of infections, dehydration, pain, septicemia which often require

additional hospitalizations (Warner, E. L., Kirchoff, A. C., Nam, G. E., & et al., 2015).

According to The National Children's Cancer Society (NCCS), even when in remission, lack of funds increases the likelihood of relapse and can shift the financial course for a family's or child's future (2018).

Consequences:

Childhood cancer diagnosis and treatment can bring a series of stressors often involving frequent medical visits, invasive procedures, difficult side effects, and financial expenses. As families are coping with their child's illness, many are also affected by significant challenges and chronic stress associated with lower socioeconomic status. As of 2011, 15% of the U.S. population was living below the poverty line. The poverty rate increases for families of female-headed households (47.6%) and for Black families (27.2%; U.S. Census Bureau, 2012), demonstrating that poverty is a societal problem that affects some groups at an unequal rate. It is well established that poverty and other factors related to low socioeconomic status are implicated in increased stress and poorer mental and physical health among adults and children (Chen & Miller, 2013). Not only does a child with cancer develop stress but their family members as well. Children and families may find the physical, emotional, and social effects of the disease to be stressful. Stress may lead to diseases causing a cycle of illnesses which may be avoidable or preventable.

Sometimes, despite the best care and significant progress made in treatment, cancer comes back. When this happens, it is called a recurrence or relapse. While the rate of a distortion returning varies by type of cancer, generally long-term relapse rates are around 15 to 25% (NCCS, 2018). For children coming from a poor socioeconomic status, the relapse rate is even

higher. According to the Boston Children’s Cancer and Blood Disorders Center, Dr. Kira Bona found in her research of early relapse, the overall survival rate for children living in poverty five years after diagnosis is 85%. Of the kids who experience relapse within 36 months after remission, 92% are poor children, compared with 48% for wealthier children (NCCS, 2018). The earlier a relapse occurs, the harder it is on the body and more difficult for a child to overcome.

Figure 1 presents the problem model addressed by this capstone.

Figure 1: Social Problem

Causes/Contributing Factors	Problem statement	Consequences
Costs associated with treatment	Too many families of children diagnosed with cancer experience financial instability	High levels of stress
Lack of access to resources		Increased probability of remission
Lack of health insurance		

Project Connection with the Problem:

The project, Heart Ambassadors at Jacob’s Heart, involves a curriculum designed for volunteers and interns that will consist of training providing accurate information about Jacob’s Heart’s services and volunteer needs. The goal of this project is to eliminate stress rates within the Jacob’s Heart employees. Bringing in trained volunteers and interns will allow Jacob’s Heart specialists to focus their time and attention to the children with cancer as well as their families.

The objective is to give these children and their families a better quality of care by giving them the resources they need as well as attention.

IV. Capstone Project: Heart Ambassadors at Jacob's Heart

Project Description and Justification

This capstone project consisted of the implementation of a training resource for Heart Ambassadors at Jacob's Heart. Heart Ambassadors are public relations liaisons who connect and engage with the community while representing Jacob's Heart. They add value and coherence to the meaning and purpose of Jacob's Heart. The mission for the Heart Ambassadors program is to activate thriving volunteerism through empowered liaisons who represent Jacob's Heart in the community by providing a concise training through our Heart Ambassadors program. Through the Heart Ambassadors, Jacob's Heart envisions committed public relations liaisons as confident representatives, enthusiastic, informative, organized and adaptable; who connect with families, donors and supporters. The goal for the Heart Ambassadors program is to radically increase awareness of Jacob's Heart throughout the community by maximizing volunteer and intern efforts through mentorship programs, awarding key Heart Ambassadors.

Project Implementation

The agency has high hopes for the Heart Ambassadors' volunteer program. Therefore, this project consisted in providing training resources for the Heart Ambassadors in a way that maximizes their potential to help the agency and the clients it serves. The first component of the project involved the development of a curriculum designed for a core group of volunteers and

interns that trained them on appropriate and accurate information while representing Jacob's Heart during community events. Jacob's Heart depends on their volunteers and interns to provide quality services. Staff members cannot always meet the needs for the agency for community events, therefore volunteers and interns have received further training by developing knowledgeable information about Jacob's Heart while spreading awareness of the agency to the community.

The second component consisted in the delivery of the curriculum to new and existing volunteers. The curriculum involved the delivery of training through a PowerPoint presentation. This PowerPoint included the following topics:

- Introduction
 - Volunteers and interns will introduce themselves
 - "Why are you here?"
- Mission and vision of Jacob's Heart
- Jacob's Heart history and background
- Population served
- Jacob's Heart core values and beliefs
- Evidence-Based Practices – Maslow's Hierarchy of Human Needs
- Programs and services
 - Heart & Hands Transportation, Direct Financial Assistance, Full Hearts Groceries, Home & Hospital Visits, Peer to Peer Support, Art from the Heart, Camp + Hands, Expressive Therapies, Forever Loved Retreat

- Role of a Heart Ambassador member
 - Mission, vision, and goals
 - How to become a member
 - How a Heart Ambassador can make a difference at the agency

Volunteers and interns have also been trained on “tabling” for Jacob’s Heart followed by practice sessions to ensure everyone is comfortable and confident with the expectations. Now that the interns and volunteers have completed this training and their hours, they have been promoted to Heart Ambassadors. Then, the Heart Ambassadors are responsible for training their assigned group of volunteers, the tools and information was provided to the Heart Ambassadors by Jacob’s Heart using the same powerpoint resource.

The third component of the capstone project aimed to better align volunteers with agency activities. If all volunteers attend one activity and none attend another activity, then the resources are not maximized. For this reason the third component was the development of a volunteer tracker system which consisted in the creation of a simple MS Excel table that acted as a database to better distribute volunteers to activities. The volunteer tracking system includes the following:

- 13 required tasks from volunteers
 - Jacob’s Heart community events, interacting with families, familiar with website, participate in the newsletter, live training, written outreach, verbal outreach, demo tabling, 3 site tours, community fundraisers, host a drive, outside community events, and the completion of agency knowledge survey

- Measurable learning outcomes
 - Enthusiasm, confidence, connection, organization, informative
- Completion of hours
- Feedback from the volunteer after completing the task

The fourth component of the capstone consisted in providing resources so that agency staff and volunteers can train other volunteers in the future. This component consisted in the creation of a “briefcase” of volunteer resources that will allow the continuity of the heart ambassadors program at Jacob’s Heart.

The fifth, and final component of the capstone consisted of developing an “agency knowledge survey” that could serve a dual purpose: to assess the knowledge of incoming volunteers as they came into the agency, and to assess their knowledge gains after they went through the training. The knowledge survey was conducted with questions based on Jacob’s Heart website through the programs and services offered. Table 1 below describes in detail the timeline of implementation of the capstone components.

Table 1: Scope of Work for <i>Heart Ambassadors</i> at Jacob’s Heart		
Goal: Develop a training curriculum for lead volunteers and interns to increase Jacob’s Heart volunteer capacity.		
<i>Activities</i>	<i>Deliverables</i>	<i>Dates</i>
1. Weekly meetings with mentors	Meetings will be held every Friday with Ishtar and Kym to discuss capstone	2/12, 2/14, 2/21, 2/26, 3/4, 3/11, 3/18 (every Wednesday)

2. Develop what the Heart Ambassadors program is	Create the definition, mission, vision, goals, strategies and tactics for the Heart Ambassadors program	February 21
3. Distribute first survey to interns (2) – measure their knowledge about JH	Pre survey interns (juniors) with questionnaire that I have developed to measure the amount of information they have about JH – this will also serve as a post survey	March 11
4. Create Heart Ambassador Tracker	Excel spreadsheet to track ambassadors' hours, learning outcomes, activities, required hours and approval from staff member	February 26
5. Develop and improve training curriculum	Improve existing training slides through a PowerPoint that will be presented to volunteers and interns	March 18 online due to COVID 19
6. Gather and create resources for “Briefcase”	The “briefcase” will be a resource for interns, volunteers, and staff to refer to for events	Mid-March online due to COVID 19

Conclusions from implementation

The hope is that this capstone project will enhance the Heart Ambassador's program in three related ways: First, to increase the number of volunteers by providing the training developed to current and incoming volunteers. Second, keeping existing volunteers engaged. Third, by reducing stress from existing staff while maximizing the volunteer resources. A better match of volunteers and interns to staff ratio will help with assurance that events as well as ongoing activities will run smoothly and successfully.

Now that the Heart Ambassadors program has been implemented, there has been an increase of knowledge among the volunteers and interns based on their skills and abilities about Jacob's Heart and their volunteerism based on the results from the pre and post survey. With completed training and educating both volunteers and interns at Jacob's Heart have benefited not only the agency but the volunteers by learning the proper etiquette and procedure when working with children that have illnesses. Staff members could now attend to families more often who need proper attention.

Overall, the problem that the Heart Ambassadors program has addressed is to better align volunteers with staff and events as well as activities that Jacob's Heart would host. Jacob's Heart is constantly promoting events that are held on the weekends which encourages volunteers to help even more when they can. A few benefits that Jacob's Heart has used in results from this program are better flexibility with personal schedules for employees, as well as creating a strong volunteer and intern system which would inspire community members to support.

Implementation Challenges:

The main challenge experienced during implementation was the COVID-19 pandemic and its consequences. The training sessions were supposed to be in person, but the social distance regulations prohibited that. As a result, a YouTube video was created as part of the briefcase component. The next section provides a reflection on how the COVID-19 crisis impacted the agency and its population served.

V. Reflection of COVID-19 Pandemic's Impact
on Agency and Population Served

Impact of COVID-19 Pandemic on Agency:

During this time of COVID-19 pandemic, Jacob's Heart was affected tremendously like many other agencies. Most employees from Jacob's Heart transitioned to work remotely from home. However, the office still remains open but is limiting the amount of employees and clients who enter the office. Volunteers and interns were told at an early time that we will not be allowed in the office until further clearance. However, the Full Hearts Grocery Program that is volunteer driven, eventually needed volunteers or interns to go into the office to deliver weekly groceries to families instead of biweekly. There were emails sent to interns asking for help to deliver these groceries for about 2 or 3 weeks in hopes of filling these gaps. Aside from requesting help from interns, a procedure and protocol email was sent regarding sanitation of cars and the proper procedure when handling groceries for families.

Community events, staff meetings, and group activities have all been canceled which means there is less outreach from Jacob's Heart to the community. On Jacob's Heart website, there are ways to help by purchasing essential necessities through Amazon and Target that families need such as canned foods, hand sanitizer, and gift cards. Jacob's Heart continues to provide transportation to doctor appointments if needed for children and families. Jacob's Heart is also assuring families that the family center is open between the hours of 10am to 4pm, Monday through Friday but with limited staff available for family support. Family specialists are delivering care packages to families in need of tangible items. As mentioned above, groceries are being delivered every week, with these deliveries, activity kits for children are also included.

Jacob's Heart is limiting the number of people who touch items that are being sent out to families.

Impact of COVID-19 on agency clients:

Jacob's Heart clients continue to receive a few of the services offered by the agency. The services that are offered more at this point are the groceries that are being delivered to them. However, social events that required big crowds have been canceled at this point until further notice. Families are being notified of updates through the monthly newsletter from Jacob's Heart. Families also have access to Crisis Counseling which is an ongoing psychotherapy, online, by phone, or in-person (with safety precautions). Jacob's Heart is also offering assistance with rent and utilities bills if needed. Donations are also being accepted through Jacob's Heart website.

Impact of COVID-19 on social problem:

The social problem discussed in the capstone is that **there are too many families of children diagnosed with cancer who deal with high levels of stress and financial instability.** COVID-19 has impacted the lives of Jacob's Heart children and families tremendously. With high levels of stress, COVID-19 has only added more to the families who also have struggled financially. Jacob's Heart has not released information regarding families unemployment nor the amount of help that they have requested from Jacob's Heart. However, having children with cancer requires ongoing treatment and doctors appointments that still require payments or money for transportation.

Impact of COVID-19 on the agency's future:

The pandemic will change Jacob's Heart by continuing to keep distance between one another with employees and clients. I think Jacob's Heart will also continue to keep a strict protocol of who enters the office and for how long. Being cautious of hand delivering groceries to families will also continue to be handled with proper care. Jacob's Heart has placed an emergency system to ensure the children's physical and emotional safety. Jacob's Heart board has approved emergency rent assistance to ensure that children undergoing intensive cancer treatment who are currently on service with Jacob's Heart can stay in their homes.

VI. Recommendations

Recommendations for the agency:

A few benefits that the Heart Ambassadors project has provided for Jacob's Heart are the proper resources and tools needed to develop a core group of volunteers. The tools created for this program can be utilized for years and have room for improvement if needed as the program expands. I strongly believe the tools developed will help volunteers and interns become the confident and enthusiastic individuals that Jacob's Heart hopes to have in activities and events.

However, dedicating more time on the training curriculum done by powerpoint would have been helpful with this process. Also, asking my mentor and other Jacob's Heart employees would have been helpful but the cause of COVID-19 pushed the timeline back for this project, the powerpoint in particular. Some advice I would give colleagues working at Jacob's Heart or on this type of project is to definitely start early with planning capstone projects or ideas. Also, at Jacob's Heart, it is important to let them know under what department you are most interested in, this will allow them to get assigned to a mentor quicker and can help with capstone planning. Another advice is to ask employees what type of changes or improvements they would like to see in the agency. This can help develop a capstone idea that will ensure proper guidance from a mentor.

Broader social significance:

This capstone project relates to the broader “macro-level” social problem by addressing the different causes and consequences that childhood cancer brings to not only the lives of these children but their families as well. Today, Jacob’s Heart is serving 330 medically fragile children with cancer and other serious illnesses and 1,447 of their family members in Monterey, Santa Cruz, San Benito and South Santa Clara Counties. Jacob’s Heart has served families in need because they understand the consequences that come with childhood cancer. Through the programs and services, Jacob’s Heart as an agency has made a huge difference in the lives of many children and families. As mentioned before, reducing the amount of responsibilities and tasks for Jacob’s Heart employees will help the “macro-level” problem because the Heart Ambassadors Program will develop volunteers and interns that can become leaders during community events and allow the employees at Jacob’s Heart to focus on delivering the services the children and families need.

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