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# Starting a child life program : a how-to book for child life specialists

Lindsay A. Wallace

*Bank Street College of Education*

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**Starting a Child Life Program: A How-To Book for Child Life Specialists**

Lindsay A. Wallace

Spring 2013

Bank Street College of Education

New York, New York

Advisor:

Emily Murray, M.S. CCLS

Harlem Hospital

Bank Street College of Education

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**Abstract**

With the recent approval of the Affordable Care Act bringing new regulations in healthcare, hospitals will be required to cut costs. It is likely that these cuts in budgets will ultimately affect every child life department. Though these changes in the child life department can not be fully predicted, one can conclude that in the years to come, a smaller child life department may be more affordable and cost-effective for a hospital.

With these changes in mind, this paper and handbook were written and produced to teach child life specialists how to develop a one-person child life program in a hospital setting. Despite its obvious limitations on resources, the one-person child life model may be the most flexible and cost-effective way to provide services for children in the changing healthcare landscape. This paper and book will walk the reader step by step through critical topics, such as: how to get into a hospital; address topics such as funding, balancing administrative duties and patient care; professionalism; supervision of students and volunteers; and ultimately, ways to make the program self-sustainable.

Using this step-by-step guide, a child life specialist will be able to advocate for his or her salary, gain trust and build rapport with hospital staff, fundraise for resources, practice child life services with patients, and make their one-person program self-sustainable.

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Starting a Child Life Program: A How-to Book for Child Life Specialists

**Introduction: In which we have a lot of questions.**

**Where to start?**

One way a child life specialist can work his or her way into a hospital is by securing a grant for his/her salary. One possible grant that can be utilized is the New York/New Jersey Area grant. There is a common application form online for those wanting more information about this grant. There are also a variety of other organizations and non-profits that a child life specialist can apply to for a grant salary.

In the past, the Starlight Children's Foundation would sometimes fund salaries of specialists in established, multi-person programs. Now, however, according to Michele Hall-Duncan, Vice President of Programs (New York, New Jersey and Connecticut Chapter), Starlight will only fund a salary of a one-person child life program in a city hospital (personal communication, March 5, 2013). When looking at applications for one-person child life programs, Starlight Children's Foundation considers the following questions:

- How much money is the application requesting?
- How many other hospitals have asked for this grant?
- Which hospital is most in need? (Most of the time this is the city hospitals.)
- How many children will this project benefit?
- How profound will the project be?
- Does the hospital have a plan to carry the program into the future?

When referring to the grant application, Hall-Duncan states that

You need to argue the case about how this improves the lives of children...paint us a picture, [for example] 'Kids are coming into this [hospital] environment and

this environment is terrible, this is what we want to do to the environment, and this is the outcome that we want to have when Beth or Sue or Jonny walks in at five, six, seven, eight years old to get treatment, [and] we want you [Starlight Children's Foundation] to transform their experience.' That's what gets me excited, when I see an ask [application] that seems like our money is going to transform the existence for the children. That's what we want to do and we want it to be fun and we want it to be something that is definitely less medical and more emotional, spiritual, therapeutic, that kind of thing. It really boils down to what is going to make these children smile within the hospital environment, and make them compliant, and make their families comfortable. (M. Hall-Duncan, personal communication, March 5, 2013)

### **Why doesn't the hospital have the money for an important department?**

With Obama's reelection and the implementation of the Affordable Care Act, there will be many changes occurring in healthcare. Hospitals will need to provide a higher quality of service at lower costs (Wessel, 2013). As a result, this change will affect child life departments in hospitals, leading to a possible increase in the need for smaller programs in hospitals and for the child life specialists in those positions to be able to provide a variety of services to all pediatric patients in the hospital. More information about this healthcare reform and its effects on the child life department will be addressed in the literature review section of this paper.

### **What is the current one-person program landscape?**

For every one-person child life program in New York City, there are eight multi-person programs (Child Life Council, 2013). Though one-person programs are not very common, the director of the program is expected to provide competent services and stay within the practice guidelines of the Child Life Council. The job requirements of a one-person program vary greatly from that of a child life specialist in a multi-person program and these requirements will be addressed in the Balancing Patient Care and



Administrative Duties section of this paper. Without the additional staff or resources, a one-person program will encounter different issues than would a multi-person program.

**Even if we secure the salary, won't we need funds for other things as well?**

Upon using the Child Life Council forum to survey fifty-four child life specialists across the world that have started child life programs, we saw a major trend in the common issues that one may come across when developing a child life program. The lack of budget (followed by staff resistance as a close second) was reported to be the biggest issue that child life specialists experienced when trying to start their program. Lack of resources was the third common issue reported by child life specialists attempting to start new program. For a more complete explanation of this survey and its results, please refer to Appendices A and B.

**Where does the Child Life Council stand on this?**

According to the *Official Documents of the Child Life Council*, child life specialists assess the needs and coping responses of children and families in the healthcare setting (Child Life Council, 2001). Child life specialists minimize anxiety and stress for the patients with whom they work while preparing these children and families for a healthcare experience. Child life specialists communicate with other staff to provide holistic care for the patients and families. The need for child life specialists is omnipresent— in recent studies, child life specialists have shown that their services can reduce procedure duration, shorten hospital stays, and reduce the need for analgesics.

**Where does that leave us?**

To summarize: the problem has never been framed as, “Why do we need child life?” but rather, “How can we afford child life?” With this question in mind, this paper

and handbook were produced– so that a child life specialist can develop a program within a hospital to offer these child life services to all patients in need at a low cost to the hospital facility.

**The History of Child Life to Current Day: In which we look to the past.****What has happened to prompt a change in the multi-specialist child life department model?**

With Barak Obama's reelection and the U.S. Supreme Court's decision to enact the Patient Protection and Affordable Care Act, hospitals may be encouraged to integrate (Wessel, 2013), as this helps hospitals utilize their resources more efficiently and save money on the costs of doing business. An estimated 32 million new consumers will be offered health insurance under the Act, and hospitals will be required to provide more access while lowering their own costs (Frankel, Gerbush & Straczynski, 2012).

There are a number of ways that the Affordable Care Act will reduce costs. The United States spends 18.4 percent of its gross domestic product on healthcare (Burroughs, 2013). This 18.4 percent is nearly double that of any other industrialized nation. To account for this spending, the Affordable Care Act will reduce a number of funds. Some of these funds include Medicare reimbursement, medical and surgical specialty reimbursement, and the market basket (price increase in) productivity reimbursement. There will also be increased penalties such as: increased user fees for durable medical equipment like MRI machines, X-Ray machines, and an increased penalty for preventable readmissions, such as an infection acquired in the hospital.

From a hospital administrator's perspective, this healthcare reform may appear to be asking the impossible: to provide a higher quality of care, while reducing charges for it. Hospital administrations are starting to look into ways to do this, and it is requiring them to think outside of the box.

With this reduced hospital budget and the fact that many child life departments do not generate a cash flow for the hospital, it may be one of the departments that hospital administrators will consider cutting. It may no longer be appropriate for child life departments to be large departments with multiple specialists. With budget cuts, a one-person child life department may be more affordable for hospitals. Instead of employing child life specialists in each unit of the hospital, the hospital may expect this child life department to be smaller and may ask that the sole child life specialist be flexible and cover multiple units at once.

Also under the Affordable Care Act, hospitals will be given Medicaid funding based on patient satisfaction (Caramenico, 2012). Since child life specialists work directly with patients, addressing their psychosocial and emotional needs, child life can influence patient satisfaction. Patient satisfaction makes it more likely that patients will recommend the hospital to family and friends, and return there for care. With hospitals offering specialty clinics and primary care, it is feasible to imagine that patients could come back to that facility for all of their and their family's healthcare needs. Patient satisfaction can have a huge impact on a hospital's business, and with the Affordable Care Act, hospitals cannot afford to discount it. Any hospital administrator knows that patient volume equals hospital income.

To keep up with the changing healthcare field, child life departments may need to be smaller, with specialists covering multiple units. It is likely that one-person programs may increase and more hospitals may be looking for one person to run the department while providing consistent child life services. Specialists will be expected to know how to start a program on limited or no resources while balancing patient care with

administrative duties. Though the Child Life Council has published a book detailing the requirements of a new program (*Guidelines for the Development of Child Life Programs in Health Care Settings*), it did not offer resources, suggestions, or advice on how to do so as a one-person program (Child Life Council, 2006). This paper and book have been created to address the necessary steps that a child life specialist will need to go through when starting a program in a hospital.

### **Where did child life start, and how has it grown to its current state?**

Throughout history, hospital visits have been experienced by patients as long, isolated, and painful (McCue & Hicks, 2007). Hospital visits often provided little opportunity to play, and parents were not encouraged to stay at the child's bedside. Children's developmental progress and psychosocial needs were rarely addressed, which is the gap that the play ladies, the ancestors of modern child life specialists, sought to fill.

As child life has become better documented and more accepted within pediatric facilities, our responsibilities as specialists also expanded. The field has also been growing outside of the hospital— into outpatient settings, school re-entry, and hospice care. The Child Life Council has designed a formal educational and certification system to solidify the career path of the child life specialist. The Child Life Council continues to look for ways to legitimize the child life career to be better known and more widely accepted throughout the healthcare community (Child Life Council, 2006).

The Child Life Council works to encourage and further develop the career and role of the child life specialist. If child life departments can continue to grow their role in the hospital and document their efforts, the role will continue to develop into new clinical areas, with increased responsibilities. With this growth and acceptance of child life as a

fully integrated part of the healthcare team, more hospitals and health care facilities will be desirous of a child life program– but one that they can afford, in the face of the Affordable Care Act. It is easy to understand, therefore, why the one-person program model may be appealing– and it is for this reason that this resource was created.

**Professionalism: In which we collaborate and look good doing so.**

**What are the parameters of the child life specialist's role?**

According to the *Official Documents of the Child Life Council* it is part of a child life specialist's job to collaborate with other healthcare staff members (Child Life Council, 2001). Collaboration with other professionals in the medical setting can increase the effectiveness of all services because co-treatment can lead to a more individualized and comprehensive treatment plan for each patient.

**What are the different roles within child life?**

In 2008, the Child Life Council surveyed hundreds of specialists with a *Child Life Compensation Survey*. A summary of the survey results showed three distinct positions that child life specialists held: Director/Manager/Leader of Child Life Program, Child Life Specialist with Leadership Responsibilities, and Child Life Specialist (Child Life Council, 2009).

According to the survey, a Director/Manager/Leader of Child Life Program had the following responsibilities and training, and demonstrated the following qualities (Child Life Council, 2009):

- Certified Child Life Specialist with a master's degree level.
- Responsibilities may include: managing the department staff, budget and salaries.
- Assess department needs, staff responsibilities and overall contributions to the department.
- Advocate for department and hospital needs.

- Authorize and facilitate fundraising and social events for the department and hospital.

The survey then lists possible salaries of this position depicted by location and years of experience.

The qualities of a Child Life Specialist with Leadership Responsibilities include (Child Life Council, 2009):

- Certified Child Life Specialist with additional education/experiences created by the child life program.
- Supervise child life internship program.
- Supervise practicum students/job shadows and child life volunteer program.
- Mentor general child life specialists.
- Write grants and influence program development.
- Clinical supervision and educator roles.

The survey again lists possible salaries of this position depicted by location and years of experience.

The qualities of a general Child Life Specialist include (Child Life Council, 2009):

- Certified Child Life Specialist.
- Minimum Education Requirements: Bachelor's degree, child life internship.
- Understand child development theory.
- Understand and utilize evidence-based practice, including preparation, assessment and play.
- Facilitate interventions and interactions with patients and staff.



- Managing volunteers.
- Organize special events and guests.
- Manage support groups.

The salary then lists possible salaries of this position depicted by location and years of experience.

**As a one-person program, how can I determine my title?**

When deciding what title is appropriate for your new position, you can refer to this Child Life Compensation Salary document and base your title on what you feel capable of accomplishing in the setting and with the resources available. You will want to consider things like availability of funds, volunteers, and materials, as well as what is already in place for patient support. If your salary is negotiable, you may want to utilize the Child Life Council to determine the appropriate salary for your position, education, and years of experience. A new census has recently been published on the Child Life Council to determine salary. The *Child Life Compensation Survey of 2012* compiled answers to configure salaries based on location, years of experience and education. There is now a tool on the Child Life Council to configure your salary based on these criteria.

**Do we have a uniform or dress code? Does it matter?**

As in any profession, what one wears to work can contribute to how colleagues view and understand one's role. Within the field of child life, there is a broad range of prescribed work attire, ranging from business casual to scrubs. As a one-person program, it is up to you to determine what message you want to project with your attire, and what makes the most practical sense. For some, scrubs are the sensible solution when the bulk

of time is spent in a treatment room, emergency department, or operating room area, where one would be exposed to blood, urine, etc., and it does not make sense to contaminate or ruin business clothes. For others who might be spending the bulk of their time doing administrative tasks like fundraising, supervising volunteers and other related staff, or who do not want to risk being seen as a doctor (and therefore a potential “threat” for a needle stick!), business attire may be more desirable. The clothing that you wear to work has a strong communication potential (Child Life Council, 2006). Your clothing influences how others react to you and your goals as a child life department. The nature of the child life service requires a more casual dress, as we are often sitting on the floor and running around the unit. However, our demands for status within the hospital as a healthcare professional require a more professional work attire, one that demonstrates the professionalism of child life.

### **How can I fit in with the staff?**

Each hospital (and even each hospital unit) has its own culture. Taking time to shadow a variety of staff members (residents, nurses, social workers, attendings, etc.) can help you determine where child life services can be best integrated into daily care, but can also be exceedingly valuable in determining what kind of culture exists in your setting. Understanding this can be an important factor in making yourself, and child life services, a seamless part of a unit— always a goal for a new program.

Consider reading a few books to identify with other staff members and their roles— *How Doctors Think*, written by Jerome Groopman, and *Final Exam: A Surgeon's Reflections on Mortality*, written by Pauline Chen, are a couple examples of books that

may help you to gain a new perspective on another staff member's position (Groopman, 2007; Chen, 2008).

According to *Complications: A Surgeon's Notes on an Imperfect Science*, written by Dr. Atul Gawande, doctors live in a very insular world— one consisting of blood tests, cardiac arrests and mortality. He writes, “We are for the moment the healthy few who live among the sick. And it is easy to become alien to the experiences and sometimes the values of the rest of civilization. Ours is a world even our families do not grasp” (Gawande, 2002, p.86). It can be helpful to consider this point of view when determining the best ways to approach and work with doctors and other members of the healthcare team.

Also according to this book, Gawande reminds the reader that doctors are taught to consider all of the possible outcomes and options in a case and to make a numeric estimate of the probability of each option using factual data. Using this math to configure desirability for the proper outcome of a patient is expected instead of using subjective thoughts and feelings (Gawande, 2002). As described previously, trying to imagine the doctor's perspective will help you to more easily establish rapport with the doctor and staff and therefore earn the trust needed for them to utilize child life services; this is particularly helpful for a one-person program. Using these books to learn more about various aspects of medical culture may help you, in a child life role, to be more flexible and adaptive.

**How do I encourage “buy in” from the staff?**

Gloria Mattera, the Child Life Director at Bellevue Hospital in New York City suggests that a new child life director to utilize upper administration to get an “in” with the team.

If someone is hired to start a program or provide any child life services that haven't been in a hospital previously, somebody in administration, pediatrics, or some philanthropic organization said child life is an important service to have. Make sure that person is the entre and a regular support to start off, it is easier to be taken around by the director of pediatrics or the administrator when being introduced to the teams. (Personal communication, March 11, 2013)

Never underestimate the power of spending time getting to know your staff members (Mattera, 2013). Introduce yourself to everyone you meet and make an effort to remember their names. Additionally, to establish rapport with staff members, you may want to take every opportunity possible to watch the nurses, doctors, psychotherapists, and other healthcare educators. This observation helps to build a positive, open atmosphere and helps you to learn more about the type of healing work that other staff members provide to patients and families (Child Life Council, 2006).

**This sounds too good to be true– what problems might I encounter?**

As a child life specialist starting a child life program, you may encounter resistance from healthcare staff. This resistance can be reduced through well-planned child life interventions. Some of these interventions include: education, cooperation with other professionals, personal preparedness, and tailoring your services to meet the needs of staff members (Thompson & Stanford, 1981). Mattera also suggests for new child life directors to “Show the healthcare team how you partner with them...It is really about ‘How I can help you treat this family in a holistic way...’” (G. Mattera, personal communication, March 11, 2013). Mattera believes that once the healthcare staff see the

work that child life specialists do, the partnership between staff begins. “Once they see a child do some deep breathing to get through a blood test, or they [patients] are more cooperative about taking their medication, they [healthcare staff] get convinced.”

Resistance, if it exists, is probably not because the staff dislikes child life, or does not believe in the services. It tends to exist because the staff has not been exposed to child life services, and they do not understand the role of the child life specialist. It is also possible that the resistance could exist because child life services have been introduced to staff members in a way that feels critical of the staff – as if they have not been meeting the needs of their patients well enough, so child life has been brought in to assist. This resistance can at times feel hostile, and one way to overcome it may be to introduce yourself to the team. Upon this introduction it is important to recognize their crucial and comprehensive work and to let them know that part of your role as a child life specialist is to assist them in their work and to make any necessary procedures run as smoothly as possible.

### **How can I bring attention to a new program and a variety of new services?**

At times, child life utilization is lacking simply because of the limited number of staff members who are aware of its existence or purpose. In these cases, a continual effort must be made to increase awareness and visibility of the services throughout the hospital (Child Life Council, 2006). The most successful way of increasing the visibility of child life services is through the media (Child Life Council, 2006). It is important to provide material for newspaper and magazine articles, as well as television and radio stations. These public service announcements will encourage the awareness of child life services throughout the hospital and in the local community. The public relations

department is the department to depend on for increasing visibility. It is up to them to decide how to manage announcements to the hospital, as well as to the community at large. Going outside the public relations department could be a big blunder as it could seem that you are using outside sources because the public relations department was not doing their job by marketing child life. This could put a strain on the relationship.

Visibility is an important factor when trying to encourage child life utilization (Child Life Council, 2006). When developing a child life program, it is important to provide in-services for staff members and residents as well as child life newsletters and fun opportunities to increase awareness of, and knowledge about, child life services.

### **How do I increase visibility?**

Consider giving a grand rounds presentation– this common event usually takes an hour to address a particular medical topic or case. Chiefs of service, attending doctors, and residents usually all attend. Participating in grand rounds will not only increase the visibility of child life but will also encourage collaboration with other healthcare professionals.

In-service presentations are short, targeted trainings aimed to introduce new practices to the healthcare team. Providing in-services to healthcare staff and residents will help them understand the purpose of child life services. In an in-service, the child life specialist should provide examples of when a staff member should call a child life specialist; when a child life specialist should be used, and when they should not be; where and when the child life specialist can be reached; and why child life services are an important part of a comprehensive pediatric treatment plan. These in-service trainings will also educate staff members that child life services can be beneficial for not only

children and families but also to the staff members (direct it at the team you are addressing) as it supports them in the care they provide to their patients.

**Any other tips for helping a new child life program make a splash?**

Consider the use of branding. In the same way that corporations use a consistent pictorial logo on all products, to keep their products in customers' minds, a new child life department can use a logo on all new signage. When posting these new signs around the hospital, the child life department should include a common picture or phrase that is easily associated with child life work.

It is also important to stay active as a child life professional, using the Child Life Council and the child life forum. Staying active on the child life forum will not only provide a sense of community that can be lost when participating in a one-person program, but it can also be a valuable way for you to keep in touch with other child life professionals and continually be updated on new child life interventions and theories. Lastly, keep yourself informed on new hospital policies, healthcare news and policies, child development, child life theories and other necessary topics that are related to and affect the child life profession.

**Balancing Patient Care and Administrative Duties: In which we juggle.****How do I figure out how to practice both patient care and be the administrator of a new department?**

As the director of a one-person program, it is important to know how to balance patient care with your administrative duties while still making sure to practice self care. In order to do this, one must be aware of one's various roles and duties while practicing proper care for one's self outside of work.

**How do I do this?**

While determining how to balance patient care and administrative duties, one must review how roles and accountabilities differ for a Certified Child Life Specialist and a Child Life Director. According to *Guidelines for the Development of Child Life Programs in Health Care Settings* (2006) it is the **Director of Child Life's** role to:

- Establish and demonstrate program objectives.
- Review objectives with hospital staff and child life staff.
- Recruit, supervise and evaluate staff members.
- Account for budget and resources to provide the most efficient service.
- Understand and utilize the growing opportunities for technology.
- Encourage interdepartmental communication.
- Stay up to date with current healthcare administration issues.
- Be an educational resource, to not only staff members and students, but also other professionals and the community.

The Role of the **Certified Child Life Specialist** is to (Thompson, 2009):

- Provide play opportunities.



- Advocate and facilitate family centered care and parent participation.
- Complete an educational or work exchange.
- Provide psychological preparation for children and their families.

The general accountabilities of a **Certified Child Life Specialist**, as divided into percentages are (Child Life Council, 2006):

- Assessment: 15%
- Therapeutic Relationships: 15%
- Promoting play, procedure accompaniment, therapeutic interactions and promoting family centered care: 40%

The general accountabilities of a **Director of Child Life**, as divided into percentages are (Child Life Council, 2006):

- Program Management (System Involvement, Budget, Evaluation): 35%
- Personnel Management (Staffing, Support and Evaluation): 20%
- Staff Education (Competency, Community Development, Policies and Research): 15%

Therefore, depending on the title that the child life specialist takes, and the responsibilities that the title includes, the one-person program will need to look at the Child Life Council guidelines on these titles and determine where his or her time is going to be spent, and how.

A final point to consider: when starting up a new program, your time will be spent differently than it will when the program has been running for a year or more. For example, in the beginning, you may be spending more time meeting and shadowing staff, presenting in-service seminars to staff, fund-raising, and recruiting and training

volunteers, than you would be spending in the treatment room with patients. After a year of doing these tasks, and with the program in place, you might give fewer hours to the fund-raising and trainings and have more hours to give to direct patient care.

**How can I stay involved with my co-workers on a regular basis?**

Child life should stay involved with other staff members to build and maintain a comfortable and collegial environment, and to continually encourage partnership between departments. Opportunities for staff members to meet may take place during monthly psychosocial policy meetings, interdisciplinary meetings, department head meetings, nursing management meetings, and parent advisory council meetings (Gaynard, Wolfer, Goldberger, Thompson, Redburn & Laidley, 1998).

Participating in hospital continuing educational experiences, such as monthly speakers, in-services and meetings will not only encourage developmental growth but also benefit the child life program as it encourages a more informed professional staff (Thompson & Stanford, 1981).

Reach out to the community to support and make connections with family members of hospitalized children. Child life can help to construct a group of informed advocates who are willing to speak to parent groups or others who want information on a child's hospitalization. Gathering this group of advocates will be of help and support to the child life program in the future when child life wants to make necessary changes to the programming, as they may be helpful making the case for a change to the hospital's administration (Thompson & Stanford, 1981). This group of advocates can also offer parents of currently hospitalized children a sense of empathy and understanding about their child's hospitalization that staff members may not be able to provide.

Lastly, it is important for the child life director to seek out organizations in the community that may benefit the child life program. For instance, reaching out to local churches, synagogues, mosques, and religious organizations to hold toy drives may be a useful resource. The local library may be able to sponsor a book drive, and family resource centers, women's groups, and community groups may be a valuable resource for families who need an external support system. Finally, local banks and other companies may be valuable resources for donations and other supplies for a newly minted child life department. Not only may these organizations offer funds for supplies and events, but this outreach will also help to market the child life department and the profession beyond the walls of the hospital. Should a child life department partner with a local organization, they may be able to attain some common goal. For instance, say a library wants to promote literacy in a needy community, and a local church wants to be more active within the community— by partnering with the child life department on a project, the shared goals can be met.

**This sounds incredibly difficult. How do I avoid feeling totally overwhelmed?**

Child life specialists are vulnerable to burnout (Child Life Council, 2006). The greatest predictors of burnout are role ambiguity and role stress (Child Life Council, 2006). Child life specialists must look at their own coping methods and understand professional boundaries to help themselves from getting compassion fatigue or burnout. Professional boundaries are an easy and helpful way for child life specialists to protect themselves. When boundaries are too tight, one is prevented from participating in open and giving relationships, but when they are too loose, one is deprived of being an individual whose needs and desires are separate from others (Child Life Council, 2006).

Some of these boundaries may include: not giving out personal email addresses or phone numbers to patients, not becoming friendly with patients and families outside of the hospital, and not keeping your department pager with you at home.

Worden suggests three guidelines to avoid burnout (Brown, 2009):

- Know one's limitations
- Practice active grieving
- Know how to reach out for help

Introspection and personal understanding to seek balance in one's life can help reduce burnout and compassion fatigue (Julian & Julian, 2005). Some find that engaging in physical activity, stress management practices, eating healthy, relaxation techniques and other health enhancing behaviors also help reduce stress.

According to the *Child Life Focus* Summer 2012 Edition, 75% of child life specialists surveyed were at risk for burnout and compassion fatigue. Generally, child life specialists are at a higher risk for compassion fatigue than burnout. Burnout is defined as becoming worn out or exhausted from overwork or overuse (Gottlieb, Hennessy & Squires, 2004).

Compassion fatigue is defined as tension and stress developed from an exposure to patient's traumatic stress (Child Life Council, 2006). Supervisors are important in reducing burnout and compassion fatigue among staff members. Quality (not quantity) supervision is what is really needed to help reduce the level of burnout and fatigue among staff members. According to the *Child Life Focus* Spring 2004 Edition, symptoms and signs of burnout include: anxiety, frustration, fatigue, accident prone behaviors, depression, apathy, doubt, forgetfulness, confusion, loneliness, and lashing out (Gottlieb

et.al, 2004). The child life specialist of a one-person program is at an even higher risk for burnout than are child life specialists in a team. In a one-person program, the child life specialist is constantly required to prioritize duties and is frequently required to construct and complete multiple projects at one time. The child life specialist lacks the support of other child life specialist team members and will be required to reach out to other staff members or the child life community to get the support that is needed. The child life specialist of a one-person program also has minimal guidelines as to how to properly create, facilitate, and expand a one-person program— and again, it is because of this lack of resources that this paper and handbook were created.

It is important for one-person programs to find and receive clinical supervision and support from other disciplines, such as social work, psychology, or even a head nurse (Mattera, 2013). Child life specialists can partner with other one-person programs, like the Child Life of Greater New York group. “It [clinical supervision and support] is very important because being a one-person program can feel so overwhelming and isolating. You have to take good care of yourself” (G. Mattera, personal communication, March 11, 2013).

### **How do I decide what needs to be done first?**

Another requirement of a child life director is to prioritize the duties of each day. There are three types of duties that a child life director will be required to prioritize within a day (Mattera, 2013). Mattera refers to these categories as non-direct patient care, indirect patient care, and direct patient care. General administrative duties fall under the category of non-direct patient care; chart notes, meeting with team members and attending medical rounds is considered in-direct patient care; and of course, working

with patients is direct patient care. Upon prioritizing the day, Mattera suggests for child life specialists to communicate with the other healthcare team members. “It is important to be very clear about playroom hours and office hours because staff want to depend on consistency” (personal communication, March 11, 2013).

Not only must child life directors prioritize their daily duties but they also must prioritize the list of patients that they see each day. When prioritizing patients in the hospital, one must consider each patient’s stress vulnerability. Some traits that may contribute to stress vulnerability are chronological and developmental age, coping skills, cultural background, availability of family members and response to current and previous health care providers (see Appendix C) (Gaynard et al., 1998). In patient prioritization, one must also consider healthcare variables such as diagnosis, treatments, family support, ability to communicate, and cultural beliefs (Gaynard et al., 1998). After considering all of the variables for a patient, one can determine the stress potential of the child. A high stress potential puts the patient high on the child life specialist’s priority list (reference Appendix D).

The competing demands for direct service and administrative support in a one-person child life program can feel overwhelming. To be more specific, there may be patient needs in the emergency department, inpatient unit, and outpatient unit. If the units are small enough, the child life specialist may be able to cover multiple units at once. If not, decisions about child life service priorities must be communicated to other healthcare staff to assure support. The child life specialist in the one-person program will require interdisciplinary collaboration, a solid knowledge of developmental theory, strong verbal and written communication skills and time management strategies. For example: a

person in a one-person program may start the day, considering their priority is to be on the inpatient unit, but then be called to the emergency department, and spend the remainder of the day with a complicated emergency case. A one-person program may also have to respond to emails for the first three hours of the day instead of attending to patients during that time because the one-person program is required to do the fundraising and event planning. (Documentation is an additional, important part of patient care and will be addressed in the Documentation section of this paper.)

**Fundraising: In which we are charming and persistent.****How do I get the supplies I need to do child life work?**

According to the *Guidelines for the Development of Child Life Programs in Health Care Settings*, the number one barrier to developing a child life program is cost (Child Life Council, 2006). Unlike other services, child life programs do not *directly* contribute to hospital income (Child Life Council, 2006). Instead, child life services are included as part of the daily bed cost of the patient. Indirectly, of course, child life programs may help the hospital's budgetary "bottom line" by contributing to the quality of care provided to a patient, as well as the parent's satisfaction with the services provided by the facility. In theory, this may increase the choice of one hospital over another and contribute to a higher census. The trend, however, is to see the child life program as an additional cost. This has resulted in a decreasing percentage of programs receiving their funding from the hospital's operating budget (Child Life Council, 2006). Therefore, child life teams may need to find outside sources of funding for their program. In addition, during times when hospital budgets are being cut, child life departments may find a greater level of security and stability in these other sources of financial support.

As a caveat to relying on outside funding, we should say here that fewer and fewer non-profits and companies are willing to fund child life positions, as they retain so little control over the way the department funds are dispersed and they have zero control over the quality of the child life specialist hired. Reliance on these grant funds also ties the child life department to the whims of an outside organization, and potentially, the financial performance of the company, which can be risky.



The annual operating budget for child life includes administrative costs, equipment to aid in the healing process, supplies, salaries and staff development, according to the *Official Documents of the Child Life Council* (Child Life Council, 2001). Funds for travel and conferences may be an additional expense of the operating budget (Myers Wilson & Cross, 2009). With these annual expenses, and uncertain support, child life may still want to consider finding outside funding for the program.

According to *The Handbook of Child Life*, there are three typical sources of funding that child life departments have successfully implemented in hospital settings. One of the three examples includes gathering financial support from the various departments (Myers Wilson & Cross, 2009). The hospital's emergency department, or oncology ward, may have some flexibility within their budget that would allow them to support child life services. A second option is to appeal to donors. By working with the hospital's development office, an attractive and direct appeal could be made to donors who would look favorably on helping to establish or sustain a child life program (Myers Wilson & Cross, 2009). The final option that a child life department may have is to have child life services reimbursed by insurance (Myers Wilson & Cross, 2009). Listed below are other ways that a child life department can fund their annual operating budget and how to go about doing so:

- Learn your hospital's policies and the limitations on your fundraising
  - Who can you fundraise from?
  - What can you fundraise?
  - Where can you fundraise?
  - How often can you fundraise?

- These questions need to be researched within your hospital policies before you start fundraising for your program.
- Program With or Without Limitations
  - The question every new program must answer before fundraising is, “Am I permitted to do my own fundraising?”
    - If the answer is yes: The new program can fundraise in any way that they see fit.
    - If the answer is no: It can mean that the hospital has designated a specific department, usually called “Development” or “The Auxiliary” to do their fundraising. Sometimes, this department is pediatric-specific, but sometimes this department is responsible for fundraising for the entire hospital. When the latter is the case, the child life department will be vying for funds alongside every other department in the hospital- it can be quite competitive.
    - One can discover their hospital’s fundraising limitations by speaking with hospital administration.
- Community Outreach
  - Use your local community groups as targets to fundraise.
  - Michele Hall-Duncan suggests for child life specialists looking to fundraise to work closely with the development department and utilize them to cultivate friends of the hospital. “Hospital donors seem to be pretty loyal...if they have gone to the hospital and had an amazing experience, they may want to give back, particularly people who have kids” (personal communication, March 5, 2013). Hall-Duncan also suggests that previous families may be a great source of funding, that even if the family does not have the money, they may be willing to fundraise for the program.

- Web presence for funding
  - Social Media is a growing means of communication and marketing.
    - First and foremost, it is absolutely crucial that any one-person program, or child life specialist in general, have a solid understanding of the social media policies in place at their facility and the permission of their supervisor before launching any social media related to the hospital. Some hospitals do not allow social media use at all, and other hospitals have restrictions in place to govern the use of social media by employees.
  - Having a Facebook page for your program is useful.
  - Twitter accounts can be another useful marketing tool.
  - Having a webpage linked from the general hospital page will help to establish your program in the hospital.
  - It is possible to link PayPal to your Facebook and website. This will make it easy for people to donate to your program with only a few clicks of the computer mouse. Before using PayPal on your department website or Facebook, one should check and double-check the hospital's rules about online fundraising and the use of PayPal. This use of fundraising is subject to very important rules within the hospital organization. If not handled correctly, it can be viewed as fraud.
- A child life program without a Facebook page, Twitter account, or webpage may be a red flag for donors. If they cannot find you online, they may not consider your program as well-established enough to donate to.

- Non profit companies are a great way to get resources to start your program, however, most nonprofit companies have certain limitations to what they will provide.
  - Some non-profits and what they will supply:
    - Starlight Children’s Foundation: iPads, clowns, music therapy, teddy bears, fun centers, toys, treatment rooms, vans to transport children, murals.
    - Project Sunshine: Day to day events, parties, activities, arts and crafts, toys.
    - Caitlin’s Smiles: Craft kits.
    - Dances with Wood: Wood working projects for patients 7+ years.
    - Art Works: Art activities, art carts.
    - Angel Wish: Holiday toy drives.
    - Children’s Wish: Monthly supplies, office supplies, toys.
    - Tanner’s Totes: Tote bags filled with activities and art supplies for long-term teen patients.
    - Get Well Gamers: Video game console and games.
- To get an idea of what a non-profit looks for when providing donations to child life programs Hall-Duncan describes what she is looking for as a Vice President of

#### Programs at Starlight Children’s Foundation:

We want to see hospitals moving along with the trends. ...keeping up with what’s new, what’s current. Being creative and thoughtful and not just regurgitating the same stuff all of the time, and just thinking about the kids and what they need and their change in population. We want to keep up with what the trends are and we want the child life specialists to bring us the trends, so Starlight Children’s Foundation can always say ‘Check this out we are funding cutting edge projects in hospitals.’ because our donors are savvy, they want to keep up with the trends. (Personal communication, March 5, 2013)

- Donor Relationships: Maintaining a positive donor relationship is essential to sustaining the program in the future; more information on this can be found in the Professionalism category.
- Plan Events for Fundraising.
  - Utilize hospital staff and volunteers to put on larger events. Invite members of the community, potential and current donors to the fundraising event. (Documentation is an important part of fundraising and is addressed in the Documentation section of this paper.)

**Documentation: In which we write it all down.****Why is documentation important?**

According to *The Official Documents of the Child Life Council*, it is critical for a child life specialist to provide documentation (Child Life Council, 2001). As required of other professionals in a medical setting, appropriate child life services are dependent upon ongoing assessment of the patient, their experiences of medical procedures and staff, reactions to the hospital stay, and interactions with their families (Hollon & Skinner, 2009). With this documentation, child life professionals can communicate their unique and valuable perspective with other medical staff and contribute to a more personalized plan of care for the patient.

Hospitals may differ in how medical staff should document, where they should document, how often they should document, and the formats for recording their documentation (Hollon & Skinner, 2009). Because hospitals may have differing documentation requirements, it is important for the child life specialist to research her own hospital's policy on documentation. The Joint Commission for Accreditation of Health Organizations in the United States also holds certain standards for hospital documentation. Hospital officials can provide information on the current standards of documentation required by the Joint Commission (Hollon & Skinner, 2009).

Documentation will look very different in a one-person child life program than it will in a multi-person program. A multi-person program may have specific requirements on how often one should document and how one should document patient information. The child life specialists in multi-person programs may be expected to be detailed in their documentation and perhaps to be child development-oriented. A one-person program

may need to sacrifice this level of detail and completeness with documentation more focused on efficiency.

### **What needs to be documented?**

Interactions with patients and family members are important to document. When interacting with the patient and family one may learn of valuable information that needs to be shared with other healthcare professionals (Hollon & Skinner, 2009).

### **Are there commonly-used templates for chart notes that I can use as a resource?**

We have provided some sample chart notes in Appendix E, to use for ideas when building a new program's charting system. According to a recent survey conducted with 54 child life specialists who started programs, 70% of them use chart notes to document patient data. A specialist starting a one-person program may have to design their own chart note to fit with their one-person program time restrictions. For instance, a chart note for a one-person program may focus on a brief and efficient assessment instead of a more complete and detailed one. The note may focus on four main ideas:

- **What kind of visit was it?** (Referral, Daily Check-in, Other)
- **Was the child within normal limits?** (Yes/No)
- **Has the child seen child life in the past?** (Yes/No...If yes, what did you do? (This may be a drop down, Therapeutic Play, Procedural Support, etc.))
- **Free Note:** This free space for a general note may or may not be necessary depending on the patient.

A department handbook is an important collection of documents that a new program will want to develop. It should include a mission statement, expectations of all

staff, cleaning policies, and any other rules and regulations within the hospital and the child life department. Here is a sample outline of a new child life department handbook:

#### Expectations of Child Life Department

- Mission statement
  - How to write a mission statement (Rieck, 2010):
    - **Keep it Short.** The mission statement should be about a paragraph, long enough to explain the mission but short enough so that you can remember it.
    - **Stay Focused.** The mission statement should briefly outline only the department's philosophy, goals and mores. These topics are guides for the mission.
    - **Be Specific.** Patients should understand the purpose and employees should understand their role. The mission statement should be detailed and actionable.
    - **Make it Inspirational.** Infusing your mission statement with an emotional element will make it memorable.
  - Where to post the mission statement?
    - While every floor plan differs, it is important to post the mission statement in the playroom and other play areas, on any bulletin board or wall that parents might walk past, and in the child life office. Posting it at the nurses' station might also be helpful during an in-service, so that the nurses are constantly reminded what they may call on child life to do. Sample mission statements are included in Appendix F.
- Expectations of Child Life Specialists.



- Expectations of Child Life Supervisors.
- Expectations of Volunteers.
- Infection Control and Safety Policies.
- Playroom Guidelines, Procedures and Rules.
- Volunteer Handbook
  - Expectations of Volunteers.
  - Responsibilities.
  - Departmental Expectations (Thompson & Stanford, 1981).
  - Infection Control Policy, Safety Measures (Thompson & Stanford, 1981).
  - Review of the Importance of Play.
  - Tips for Approaching Patients and Families (Sample form in Appendix G).
  - Review of Boundaries and HIPPA.
  - Supervision with Director of Child Life (Child Life Council, 2006).
    - How often are the volunteers expected to meet with the child life director. Also include the contact information for the director.
    - Contract to abide by rules (Child Life Council, 2006): having each volunteer sign a contract stating that they understand and will follow the rules and guidelines given can be useful, as it gives responsibility to the volunteer and emphasized the importance of the role they are taking on.

**How do I document and keep track of donations, expenditures, and maintain a record of a budget?**

It is important to keep track of all resources and donors– one reason to do this is to be able to show a comprehensive list of donations, and donations’ monetary value, to

the hospital's administration, should the child life program ever have to justify itself for continued funding. According to the survey conducted of 54 Certified Child Life Specialists, 46% did not keep a record of donated items. By demonstrating the monetary value of what child life can bring in, it can be a convincing point to fund a salary – because without the salary, the hospital would lose those donations and the patient satisfaction those donations bring in. Another reason to keep accurate donor information is so that when a particular set of supplies runs out, it is possible to reach out to that specific donor for a potential renewal of the supplies. This documented information will also help a child life director to consistently keep in contact with donors. Here is a sample outline of what a new director might want to include in any documentation of donations, expenses, and budgets:

- The contact information for each donor (Thompson & Stanford, 1981).
- What resources or supplies the donor provided.
- The date of the donation.
- If this is a regular or recurring donation, how often does donation occur?
- An estimated price of each donated item can be useful to show to hospital administration.
- Was a thank-you note sent?
- List of the grants that you have received and when they expire.
- The department's operating budget.
- The department's expenditures.

**What about other pieces of documentation? Is there anything else that a new child life department should be keeping track of?**

Keeping a reliable inventory of supplies can be useful— knowing what is readily available, and what may be low in stock can be helpful when planning activities, contacting donors, or deciding on priorities for purchasing.

Once a volunteer team is established, it can also be useful to employ a log to keep track of which toys or items have been lent out to patients and families on the unit. Once the toys have been returned to the department, it will also be important to include a section in the log to indicate that the toy was disinfected before being returned to its storage space.

This brings us to another important piece of documentation in a child life department: maintaining documentation on cleaning toys and abiding by all infection control policies. Here is another brief sample outline of the necessary steps to maintain infection control standards:

**Toy Cleaning**

- Infection control-approved process of cleaning. (Sample included in Appendix H).
- What has been cleaned?
- When was it cleaned?

It can be helpful to keep track of events and group visits— it is common for corporate groups to have a company-sponsored volunteer day, in which the employees go to a non-profit site, a school, or hospital, to sponsor some kind of charity event. If a group chooses a child life department, it can be a wonderful opportunity to make a connection with a donor, spread the word about child life and the work being done at the

hospital facility, and bring enthusiastic volunteers and a great experience to the patients at the site. Here is another sample outline of the critical information to keep for visits like this:

Group information (Child Life Council, 2006)

- Appropriateness of the visit.
- Purpose of the visit.
- Was the group briefed on infection control?
- Date scheduled.
- Do the volunteers need a specific space for their event?

Finally, here are some other suggestions for documents that may be helpful to a new child life department:

- Wish List for the child life department.
- Child life department goals for the year.
- Challenges experienced by child life department throughout the year.
- Systems of prioritization.
- Where child life time is spent.
  - According to a recent survey conducted with 54 child life specialists who started programs, 70% of them gather and document data to present to supervisors about the benefits of child life.
  - Sample of time sheet in Appendix I.
  - Cost/benefit analysis (Thompson & Stanford, 1981).

**Supervision of Students/Volunteers: In which we teach.****Should I start a volunteer program within the child life department? How do I do that?**

Volunteers offer child life specialists an opportunity to provide a variety of basic services to a greater number of patients (Child Life Council, 2006). Volunteers do not replace child life staff, but they can enrich the child life program with their own talents and experiences, as well as valuable one-on-one time.

There are a number of projects that a child life specialist must complete before accepting volunteers. It is the role of the child life specialist to prepare and place volunteers in designated areas. If this is not done, or not done well, the services of the volunteers will not be as useful as they could be, and the volunteers themselves may not find as much value in their experience (Thompson & Stanford, 1981). Listed below are a few ways that child life specialists can recruit, prepare, and supervise volunteers:

**Recruitment Questions**

- How will you advertise?
- Where will you advertise? (Volunteers may need to be cleared by the hospital's Volunteer Department.)

**Child Life Training**

- Volunteers must go through a hospital orientation and an additional child life orientation.
  - Those volunteers who have not previously worked with children will require an introduction to child development principles and the special concerns of

children in each age-group when hospitalized (Thompson & Stanford, 1981).

- In the child life training, participants will learn where patient's activities take place, equipment is kept, and a general orientation to the medical setting. A child life specialist may require the volunteer to observe an interaction with a patient before being released to work alone (Thompson & Stanford, 1981). This will help set an example of the type of interactions, attitude, and tone that a volunteer should demonstrate when working with hospitalized children.
- Volunteers must be supervised to ensure proper care of the patients. Volunteers may assist the child life specialist in the playroom, patient's rooms, and other situations where the child life specialist may require additional help. The volunteers must be taught proper precautions, such as the importance of hand cleaning before and after entering a patient's room, before being released to their individual jobs.

#### Manual

- Volunteers should be given a manual to familiarize themselves with child life program goals, mission, and the duties required of a volunteer (Thompson & Stanford, 1981).
- Volunteers may be required to sign a contract confirming that they have read and agree to the terms of the volunteer manual.
- More about the Volunteer Manual can be found in the Documentation section.

#### Ongoing Training and Supervision

- Ongoing training for volunteers to further encourage their skills (Myers Wilson & Cross, 2009).
- Volunteers should be considered as part of the team, sharing information with staff and communicating with child life.
- Child life supervisors must meet with volunteers on a regular basis to debrief and support them during and after any troubling hospital experiences.
- According to a *Child Life Focus* article published in the fall of 2005, there are many foci of supervision. A few of these foci include support and the validation of the volunteer, and a clear demonstration that the volunteer will not be left alone to deal with any difficult problems (Rode, 2005). Another focus of supervision includes efforts to increase the volunteer's understanding and skills, and help with processing feedback. A final focus of supervision is managerial; that is, verifying the quality of a volunteer's work, providing feedback, and ways that the volunteer might utilize resources more effectively. The focus of the supervision may change depending on the importance of the task or the experience of the volunteer.

### **Making the Program Self-Sustainable: In which we look to the future**

#### **How do I keep the department going?**

The first question that must be answered is: where will the funding for the department come from? A child life department must find an ongoing source of money to pay salaries, fringe benefits, staff development, and all costs of supplies and materials not received through donations for the department.

When designing a proposal for a child life position, it is important to know the breakdown of required funds. Naturally, requesting funds for the child life salary is foremost, but included in that must be a set amount dedicated to providing the benefits package for that employee, including, but not limited to: health insurance, life insurance, 401k, or pension plans. Institutions and states differ in the cost for these benefits (and what they include), so it will be important to find out from the human resources department what percentage of a salary must be dedicated to the “fringe costs,” or benefits associated with that salary. The operating budget is the amount that the director believes is sufficient to keep the department in necessary supplies. Some hospitals will not be able to offer an operating budget, which means that the one-person program will need to be creative in utilizing community and non-profit donors to acquire supplies and materials. Here is an example of a one salary, fringe, and operating budget breakdown:

- Salary: \$42,000
- Fringe benefits: (20% of salary) \$8,400
- Operating budget: \$150/ month, or \$1,800 annually



Having a secure budget is an important and common way that one can make a program self-sustainable. Information about the sources of funding for a child life department is addressed in the Fundraising section of the handbook.

Another way to make a program self sustainable is to collaborate with the medical team. Should a physician negotiate his/her employee contract with a clause to have child life as a necessary part of their team, a child life program may be assured within the hospital. This strategy was used within the child life department, led by Meghan Kelly, M.S., CCLS, at Montefiore Hospital in New York City.

Another way to build a department is to become a teaching program and take interns. Making your program a teaching program not only expands your department by providing services to more patients, but it is not an additional expense to the hospital. Administrators will appreciate the additional no-cost personnel and the ability to market the child life department, and therefore the hospital, as a teaching facility. It is important to note, however, that according to the Child Life Council, a child life specialist must have 4000 hours of paid experience before being able to take interns.

Consider building an online presence for the new child life department– as described in previous sections, a web presence will provide a verified professional image of the child life department. If people cannot find the department online, it may not seem like a legitimate enterprise, and donors may take their funds elsewhere. If you are able to create a child life webpage for your hospital facility, it may be possible to leverage it as an ongoing fundraising effort by making it possible to donate to the child life department through a Pay Pal link. However, it is absolutely crucial to check with the administration of the hospital before doing setting up an account with Pay Pal, or any account kept

outside of the hospital. Breaking these regulations can be seen as fraud, and cause for termination and potentially, legal action.

There are some other organizations that can help a child life department raise funds. Some to consider are:

- Kickstarter is an organization that markets and provides funding for certain creative arts projects. If your program needs to raise money, Kickstarter may be a possible resource to fund a large fundraiser.
- Indiegogo.com is a similar website that can be used to help find donors to raise money for the child life program.
- Microgiving.com can help one to raise money online and launch one's own fundraiser online; this is a final way that a child life program can raise money to make itself self sustainable. (There may be many more online organizations to help with funding that may not be listed.)

Lastly, some final thoughts about donors and maintaining positive relationships with them: place follow-up calls to donors. Remember, if at first you don't succeed, try again. Be persistent when contacting companies and organizations for donations. Keep a list of companies you have called, the date you called them, and the resulting dates of follow-ups. Offer site visits to donors— they may appreciate seeing the hospital space to which they are donating money. This in-person visit also helps to solidify the donor-recipient relationship.

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## Appendices

**Appendix A**

The survey below was completed by fifty-four child life specialists worldwide. The specialists were found through the Child Life Council Forum and through personal contact. The purpose of this survey was to gain information for this paper.

### Start-Up Child Life Program Survey

This survey will be used to gather information and compile a advice for those wanting to start a child life program. There are 23 questions.

**\* Required**

1. How long has your program been in this hospital? \*

- 0-1 years
- 2-4 years
- 5-7 years
- 8 + years

2A. Do you have a masters degree? \*

- Yes
- No

2B. Please write in your masters degree. If you answered no to the previous question please go to the next question.

3. What were some hurdles you encountered while starting the program? \*

- Staff resistance
- Budget
- Lack of resources
- Lack of child life experience
- Other:

4. What was the hospital staff's initial perception of the new program? \*

- Receptive
- Resistant
- Non-inclusive

5. What is hospital staff's current perception of the new program? \*

- Receptive
- Resistant

Non-inclusive

6. If the perception has changed, why do you think that is? \*

Increase in knowledge

Increase in trust

Proven track record

Other:

7. How did you establish rapport with the hospital staff/gain their trust? \*

In-service presentation

Persistence of child life staff

Finding a champion for child life on staff

Other:

8. What were the start up programs (Teddy-Bear Clinic, Book Club etc) you developed to promote the program? \*

9. How did you keep track of newly attained donated items? \*

Spreadsheet

Written record

No record kept by child life

10A. How do you document patient data? \*

Chart Note

Child life database

Written record

No record

10B. Have you gathered data to present to a supervisor to prove the benefits of child life? \*

- Yes
- No

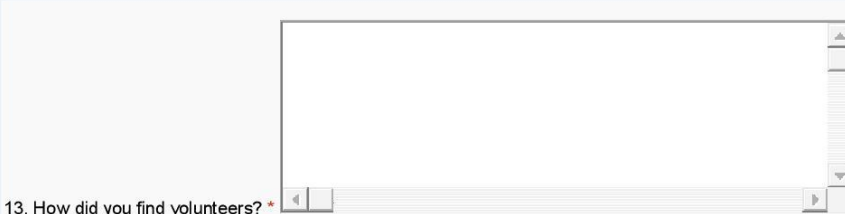
11. When developing your program, who were the most helpful/influential staff members? \*

- Chief/Attendent/Resident
- Nurse/Nurse Manager/RN
- Administration

12. What outside resources did you use to develop your program? \*

A large, empty rectangular text input field with a scroll bar on the right side, intended for the user to describe outside resources used for program development.

13. How did you find volunteers? \*

A large, empty rectangular text input field with a scroll bar on the right side, intended for the user to describe how volunteers were found.

14. What did the volunteer orientation consist of? \*

A large, empty rectangular text input field with a scroll bar on the right side, intended for the user to describe the content of the volunteer orientation.

15A. Do you feel that your program has a strong foundation? \*



- Yes
- No

15B. If you answered yes to the previous question, how many months did it take for you to feel that way?

15C. If you left the hospital today, would your program continue/grow without you? \*

- Yes
- No

16A. How many CCLS's does your program currently have? \*

16B. If you have multiple CCLS's, how long did it take you to get to that number?

17. How do you spread awareness of child life throughout the hospital? \*

18. Who funded your initial position? \*

19. Who funds your current position? \*

20. Did you celebrate Child Life Month when first starting the program? If so, how? \*

21. Did you use the Child Life Council as a resource when starting the program? If so, how? \*

22. How did you utilize community resources when starting up your program? \*

23. What advice would you give to another CCLS starting up a new program in the hospital setting? \*

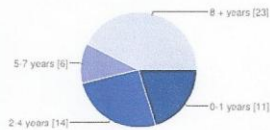
Never submit passwords through Google Forms.

**Appendix B**

**How to Start a Child Life Program Survey:**

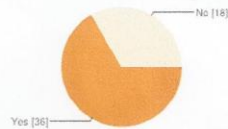
Below are some of the responses of the fifty-four child life specialist who responded to the 'How to Start a Child Life Program' Survey. The answers are listed in graph form and percentages:

**How long has your program been in this hospital?**



|           |     |
|-----------|-----|
| 0-1 years | 20% |
| 2-4 years | 26% |
| 5-7 years | 11% |
| 8+ years  | 43% |

**Do you have a master's degree?**



|     |     |
|-----|-----|
| Yes | 67% |
| No  | 33% |

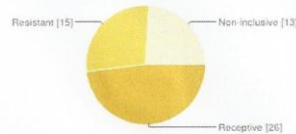
**What were some hurdles you encountered when starting the program?**



|                               |    |     |
|-------------------------------|----|-----|
| Staff resistance              | 36 | 67% |
| Budget                        | 38 | 70% |
| Lack of resources             | 29 | 54% |
| Lack of child life experience | 16 | 30% |
| Other                         | 24 | 44% |

People may select more than one checkbox, so percentages may add up to more than 100%.

**What was the hospital staff's initial perception of the new program?**



|               |     |
|---------------|-----|
| Receptive     | 48% |
| Resistant     | 28% |
| Non-inclusive | 24% |

**What is the hospital staff's current perception of the program?**



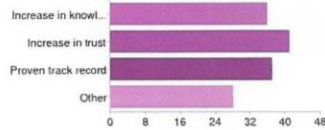
|               |     |
|---------------|-----|
| Receptive     | 94% |
| Resistant     | 0%  |
| Non-inclusive | 6%  |

**What is the hospital staff's current perception of the program?**



|               |     |
|---------------|-----|
| Receptive     | 94% |
| Resistant     | 0%  |
| Non-inclusive | 6%  |

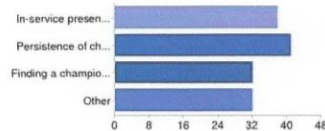
**If the perception has changed, why do you think that is?**



|                       |     |
|-----------------------|-----|
| Increase in knowledge | 67% |
| Increase in trust     | 76% |
| Proven track record   | 69% |
| Other                 | 52% |

People may select more than one checkbox, so percentages may add up to more than 100%.

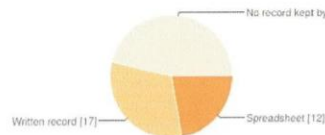
**How did you establish rapport with hospital staff/gain their trust?**



|  |     |
|--|-----|
| In-service presentation                    | 70% |
| Persistence of child life staff            | 76% |
| Finding a champion for child life on staff | 59% |
| Other                                      | 59% |

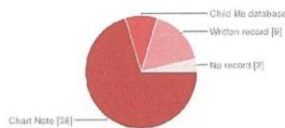
People may select more than one checkbox, so percentages may add up to more than 100%.

**How did you keep track of newly attained donated items?**



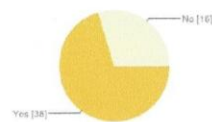
|                              |     |
|------------------------------|-----|
| Spreadsheet                  | 22% |
| Written record               | 31% |
| No record kept by child life | 46% |

**How do you document patient data?**



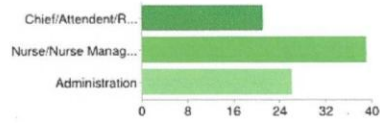
|                     |     |
|---------------------|-----|
| Chart Note          | 70% |
| Child life database | 9%  |
| Written record      | 17% |
| No record           | 4%  |

**Have you gathered data to present to a supervisor to prove the benefits of child life?**



|     |     |
|-----|-----|
| Yes | 70% |
| No  | 30% |

**When developing your program who were the most helpful/influential staff members?**



Chief/Attendent/Resident 39%  
Nurse/Nurse Manager/RN 72%  
Administration 48%  
People may select more than one checkbox, so percentages may add up to more than 100%.

## Appendix C

### Child Life Specialist Statistics - Risk Factors

#### Children's Hospitals and Clinics of Minnesota

The following risk factors may aid the CCLS in setting patient care priorities.

Identify the level (1,2,3) of risk factors. Stress indicators are assessed after meeting or observing the patient and/or family. The acuity rating on the CL statistical tool is the risk factor times the stress indicators.

Clarification on how to count risk factors:

Each bullet point is a “category” of sorts. There may be multiple risk factors within each category, e.g. a newly diagnosed chronic illness **and** a developmental delay.

Count all risk factors a child brings with them to the hospital experience. Do not try to determine what the impact of the risk factors may or may not be on the child's current experience. If for example, a child is in the PICU, you'd count that regardless of how often he'd been there or if he routinely spends days there.

- Developmental Age
- Temperament; personality traits; history of emotional or mental disturbance
- Previous health care, especially hospital, experience
- Extended length of stay, e.g. one of a long duration or a longer stay than anticipated for the child's condition
- Unplanned; emergent; ICU admission
- Existing diagnosis of a chronic illness; developmental disability; sensory-neurological disorder

- Newly-diagnosed chronic or potentially terminal illness; newly restricted mobility
- Significant personal/family event: death (patient dying or other recent death of a person significant to the child); recent move; financial constraints; history of abuse in family
- Family dynamics: cohesiveness (lack of); stress; support
- Cultural factors: ethnic, religious, language

Level 1: 0 – 3 risk factors

Level 2: 4 – 6 risk factors

Level 3: 7+ risk factors

Referenced from Guidelines for the Development of Child Life Programs in the Health Care Setting (Appendix 4-A2) of the Child Life Council, 4<sup>th</sup> Edition, 2006.

## **Appendix D**

### **Stress Indicators**

**Stress Indicators** are behaviors or emotions that illustrate an individual's current level of stress. This may be behavior you observe presently in the client, or what has been reported to you about the client's current behavior. All behavior and emotions that are generated by stress should be assessed in the context of the individuals' developmental level. For example, a two-year old clinging and fussing while their temperature is being checked would be developmentally appropriate, however that same behavior or emotion in an older child would seem to indicate stress. Additionally, there is behavior that may appear to indicate stress outside of the health care setting that may be adaptive within it. Examples might be retreating from touch or being cautious of new people.

The following stress level guidelines should be applicable to all patient areas and to all family members we serve as clients. As is true with any guideline in the following descriptors are meant as a general "road map" to guide you by placing a numerical value on a stress level. The acuity rating on the statistical tool is the risk factor times the stress indicator rating.

#### **Guidelines for Stress Indicator Levels**

1) **Low:**

**Client is coping in developmentally appropriate way, requires little intervention**

- There have been no recent changes in behavior.
- Client is able to express their needs and appears comfortable in their surroundings.



- Client easily returns to normal activity after being interrupted with a medical intervention.

2) **Medium:**

**Client appears challenged in coping with health care—receptive to intervention, benefits from supportive efforts**

- Client demonstrates deviation from their normal behavior in relationship to specific medical intervention and/or their health status-condition
- With supportive intervention, client is able to express their emotions about their experience, may demonstrate: apprehension, regression, withdrawal, anger, etc.
- Degree of behavioral change is transient

3) **High:**

**Client is difficult to reach—requires multi-professional support**

- Behavior seems “stuck”, client sees little hope for situation to change for the better, seems overwhelmed and unable to refocus emotions
- Client has difficulty expressing their thoughts and/or processing the supportive information given to them
- Behavioral changes seem consistent, regardless of the current situation, environment or any intervention

Referenced from Guidelines for the Development of Child Life Programs in the Health Care Setting (Appendix 4-A1) of the Child Life Council, 4<sup>th</sup> Edition, 2006.

## Appendix E

### Charting Sample in APIE format:

A: 15 year old boy with CF and difficult past experiences with IV placement, currently highly anxious about having a PIC line placed for the first time. However, he responded with interest and became engaged in discussion about how things that “have helped make it easier for other teens to get PIC lines.”

P: Provide psychological preparation in order to

1. Learn more about his specific fears, challenges and preferences,
  2. Review sequence of events in a manner that favorably impacted his appraisal of the manageability of procedure, and
  3. Plan and rehearse coping strategies.
- I. Psychological preparation included the following:
1. His greatest fear: size of the PIC line catheter. We conceptualized this in comparison to the size of the veins that will be used and that this site would be higher and not yet used for IV access.
  2. Preference: to sit as upright as possible rather than flat. He has that written down as a question to ask the person who will place the line.
  3. Review of sequence of events sorted familiar components from those that are less familiar from having peripheral IVs.

4. He finds it difficult to engage in discussion during procedures and would like to have others talk to him. His mother will talk about their recent trip to the ocean, and he will bring several comic books that can be read with him.
5. He asked to be briefly cued to the events of the procedure without having to see much himself. He will focus his attention on his mother's face or the comic book.
6. He will use gentle blowing breaths to relieve both anxiety and discomfort.
7. Post-procedural follow-up evaluated which elements he would like to use again if he needs another PIC line.

E: Mom and nurse specialist reported that despite anxiety he was more cooperative than usual and had fewer delaying tactics. He actually initiated describing his comic book collection to the nurse. After the procedure he reported that "it was easier than he thought it was going to be."

**Charting Sample in S.O.A.P. format:**

S: "This is going to be awful. It took 8 sticks last time for a plain old IV, and this is longer."

O: This 15 year old boy with CF has needed IV treatment with increasing frequency.

Mother and nurse specialist both report growing anticipatory anxiety and distress during IV placement. This will be his first experience having a PIC line placed.

A: Although his anxiety is based on actual experience, he seemed interested in learning about things that “have helped make it easier for other teens to get PIC lines.”

P: Goals of psychological preparation will be to

1. Learn more about his specific fears, challenges and preferences
2. Review sequence of events in a manner that impacts his appraisal of the manageability of procedure, and
3. Plan and rehearse coping strategies.

Referenced from Guidelines for the Development of Child Life Programs in the Health Care Setting (Appendix 3-A) of the Child Life Council, 4<sup>th</sup> Edition, 2006.

## Appendix F

### Mission Statements

Utah Valley Regional Medical Center:

- The purpose of the Child life program is to support children and strengthen families in a hospital setting.

Cincinnati Children's Hospital Medical Center:

- Child Life is committed to the practice of family centered care by promoting play, education, developmental and psychosocial support. This commitment is enriched through research and the education of professionals and the community.

Children's Mercy Hospitals and Clinics:

- The Child Life Department at Children's Mercy Hospitals and Clinics promotes a positive environment for patients and families, based upon their needs. This is accomplished by providing materials and guidance for developmentally appropriate play, preparing children for medical experiences, advocating for patient and family rights, and promoting a non-threatening, normalized environment.

Wolfson Children's Hospital:

- Child Life ensures that emotional and developmental support is provided to children and families to normalize the hospital experience and minimize stress and anxiety related to hospitalization. Child Life provides age-appropriate opportunities for play, preparation

for procedures, implementation of coping skills during procedures, emotional support and therapeutic play to enhance mastery of health care experiences and socialization.

The Children's Hospital at Oklahoma University Medical Center:

- The Child Life Department mission is to advocate for and assist in meeting the psychosocial needs of patients and families. The Child Life Department promotes optimum growth and development of children, adolescents, and families to maintain normal living patterns and to minimize hospital induced stress. As integral members of the healthcare team in both inpatient and outpatient areas, child life staff provide opportunities for play, learning, self-expression, family involvement, peer interaction and gaining mastery.

Referenced from Guidelines for the Development of Child Life Programs in the Health Care Setting (Appendix 11-EE) of the Child Life Council, 4<sup>th</sup> Edition, 2006.

## **Appendix G**

### **Children's Mercy Hospitals and Clinics**

#### **Great Beginnings**

#### **Tips for volunteers who work with children**

#### **And families in the hospital setting**

### **1. Introducing yourself and entering a patient room**

- a. Look on the door for isolation precautions
- b. Knock and announce yourself as a volunteer before entering room
- c. Offer your name and examples of what you can provide
- d. Don't even assume that you are not needed; families won't know what you can provide unless you offer (offer sample introductions to your volunteers, role play if needed)

### **2. Approaching a child or family in a waiting area**

- a. Approach slowly with a smile and use a gentle voice, it is important not to overwhelm the child or family
- b. Offer your name and examples of what you can provide
- c. Don't ever assume that you are not needed; families won't know what you can provide unless you offer (offer sample introductions to your volunteers, role play if needed)

### **3. Setting appropriate limits –3 suggestions**

- a. Redirect inappropriate behavior into a positive behavior
- b. Offer appropriate choices

- c. Follow through on the limits you set (give your volunteer examples of redirection, appropriate choices, limit setting and following through)

**4. Reasons for getting a nurse or staff member**

- a. Patient has to use the restroom (explain “output” sometimes has to be measured)
- b. IV beeping
- c. Questions about ambulation
- d. A patient has an accident

**5. How to find a nurse**

- a. How to use a patient call button
- b. How to use the phone to call emergency #'s
- c. Going to nursing unit and asking for nurse or staff person

**6. What are my jobs when I am not having direct patient contact?**

**This is a children’s hospital, and part of being a volunteer is supporting the patients in ways other than direct contact**

- a. Cleaning toys
- b. Preparing supplies for activities/parties
- c. Cleaning up the activity area, and ensuring that it is safe for all patients

**7. Toy cleaning**

- a. Introduce your policy/infection control guidelines
- b. Re-state the importance of toy cleaning and joint effort it takes to make this happen for the patients

**8. Washing your hands**



- a. Go over infections guidelines
- b. Give reminders about washing hands after going to the bathroom, between patients, etc.

**9. Confidentiality** (*give examples of your confidentiality policy/they will probably need to sign something*)

- a. Respect patient privacy, utilize the information given to you in a respectful manner while here and do not discuss with anyone but your supervisor
- b. Don't assume a patient has a certain diagnosis because of how they look
- c. Don't ask patient why they are in the hospital – they will share this with you if they feel comfortable doing so

**10. Personal/Professional Boundaries**

**Although you may develop a very personal relationship with some patients, always remember to keep that relationship within your role as a volunteer**

- a. Refrain from purchasing gifts for patients (share your donation and Professional Boundary policies with the volunteer)
- b. Limit your visits to the patients to the shift you are serving as a volunteer, never initiate a visit with a patient outside of the hospital

**11. Choose your words carefully** (*give examples of not using “Get Well”, or discussing religious information with families*)

**12. Other young visitors that you may work with...**

- a. In order to promote a family-friendly environment, we encourage you to work with siblings, cousins and friends who may be visiting a patient

- b. Try to address the needs of all young people you come in contact with, but remember to make patients your first priority. If you encounter a situation where you get “stuck” supervising visitors, don’t hesitate to ask the parent or the patient’s nurse to help you resolve the situation
- c. Set the same limits for visitors as you would with patients

**13. Give as many choices as possible**

- a. Encourage creativity
- b. Follow the patient’s lead on activity choices remembering that some may have limited abilities due to their medical condition
- c. Allow the patient to use the material in the way he/she chooses, if appropriate
- d. It is not necessary for each child to produce identical projects, the main purpose of projects is to have fun

**14. In conclusion...**

- a. The best part of being a volunteer is meeting and greeting to know the patients and families you encounter, so please enjoy your time here
- b. If you need anything or have any questions, please don’t hesitate to ask a nurse, your area supervisor, or your Volunteer Coordinator

Referenced from Guidelines for the Development of Child Life Programs in the Health Care Setting (Appendix 9-B) of the Child Life Council, 4<sup>th</sup> Edition, 2006.

## Appendix H

|   |                |
|---|----------------|
| The Johns Hopkins Hospital<br>IFC028  | Policy Number  |
| INTERDISCIPLINARY CLINICAL PRACTICE MANUAL<br>11/30/03<br>Subject:<br><b>INFECTION CONTROL – TOY CLEANING</b> | Effective Date |

**KEY WORDS:** toys, toy cleaning, toy disinfection

### **POLICY**

Toys will be selected and cleaned in the approved manner to prevent the spread of infection. This policy applies to toys owned/used by JHH/JHU/JHMI staff.

### **RESPONSIBILITIES**

|  |   |
|--|---|
| JHH/JHU/JHMI staff                                     | Must follow the requirements of the Toy Cleaning Policy.  |
| Supervisor/Department                                  | Educate and ensure employee compliance with the Toy Cleaning Policy. Insure that appropriate toys are purchased for their area of responsibility. |
| Hospital Epidemiology and Infection Control Department | Assist with staff education as requested.   |

### **DEFINITIONS**

|                |   |
|----------------|---|
| Toy:           | A toy is any object used for recreational, therapeutic or educational purposes.   |
| Toy Selection: | Toys will be chosen with hard surfaces (plastic, vinyl, varnished or painted wood, metal), which can be thoroughly cleaned and dried. |

## I. GENERAL CLEANING

- A. All toys are to be examined after each use by child life staff, volunteers, or unit staff for safe construction, small parts, breaks and cleanliness. If toy is broken or unable to be cleaned, the toys shall be discarded.
- B. After use, all toys that have been used in patient rooms, have been soiled with body fluids, or handled by a child who has respiratory symptoms or places hands in diapers will be placed in the dirty toy box for cleaning and inspection.
- C. All toys in the dirty toy box will be disinfected with the appropriate disinfectant (see toy cleaning procedure).
- D. Hard plastic toys that are washed in a dishwasher do not need to be additionally disinfected.
- E. Wall-mounted or table-mounted toys should be cleaned weekly and when obviously soiled, utilizing a soap and water wash followed by clear water rinsing and air drying and/or use of appropriate disinfectant spray.
- F. Toys such as electronic games, wind-up toys, and other toys that would be damaged with soap and water sprayed with an appropriate spray disinfectant.
- G. Only new stuffed animals and new cloth dolls can be accepted by the hospital and even then cannot be used by more than one child or in a

group situation. They should be given to one child to use and take home.

- H. Books and laminated posters should be wiped off with an appropriate disinfectant when removed from patient room.
- I. In construction of toys and mobiles, materials will only be used which can be thoroughly cleaned.
- J. Toys brought in by family members must not be shared.

## **II. TOYS FOR ISOLATION**

- A. Toys will be disinfected with bleach solution after use in an isolation room.
- B. Ideally, toys should be cleaned immediately. If not, they must be put in a bag to indicate they have not been cleaned.
- C. Books may be taken into isolation rooms for children over age 4 (assuming they are not “mouthing” them). After use in an isolation room, book covers should be wiped clean with bleach solution. They may be then reused unless they are visibly soiled. If the soiled book cannot be cleansed, it must be discarded.
- D. If toys with porous surfaces (e.g. stuffed animals) that cannot be effectively cleaned are given to the children in isolation, these toys must be kept by the child and taken home upon discharge or discarded.

## **III. PROCEDURE**

- A. Cleaning and Disinfection of Toys.

1. Scrub the toy in warm, soapy water. Use a brush to reach into the crevices.
  2. Rinse the toy in clean water.
  3. Immerse the toy in the bleach solution (see below) and allow it to soak in the solution for 10 minutes. If the toy cannot be immersed, wipe thoroughly with the bleach solution.
  4. Remove the toy from the bleach solution.
  5. Rinse the toy well in clean water.
    - a. If the toy cannot be immersed, wipe with clean water.
  6. Toys are not to be stored wet –air dry, dry in a dryer, or dry with a clean towel.
- B. Preparing Bleach Solution 0.05% (Sodium hypo chlorite)
1. Add 1 –ounce bleach to 49 ounces tap water. (1:50 dilution).
  2. Bleach solution needs to be mixed daily if using an open basin. The bleach solution can be mixed monthly if the container is opaque and has a tight lid.
  3. If a container is used, label container “1:50 bleach solution” and write expiration date of 1 month on it.
  4. Store in a cool place out of direct sunlight and out of the reach of children.

## **REFERENCES**

Centers for Disease Control and Prevention, “The ABC’s of Safe and Healthy Child Care”

<http://www.cdc.gov>.

### **DEVELOPER**

- Hospital Epidemiology & Infection Control Department

### **SPONSOR**

- Medical Care Evaluation Committee

### **COMMUNICATION & EDUCATION**

This policy will be communicated to the appropriate JHHS personnel via the following channels:

1. Updates and revisions will be communicated via Medical Staff and Nursing publications.
2. Nurse Managers, Physicians Advisors, residency coordinators, Department Chiefs and Department Management will be responsible to train new employees regarding the policy as appropriate and to communicate updates to the protocol.
3. This policy will be placed in the Interdisciplinary Clinical Practice Manual on the JHH Intranet site <http://insidehopkinsmedicine.org/icpm>. Paper distribution will be made to the Functional Unit Nursing offices in the event of web access difficulty.
4. Placement of policy online at [www.hopkins-HEIC.org](http://www.hopkins-HEIC.org)

Referenced from Guidelines for the Development of Child Life Programs in the Health Care Setting (Appendix 11-0) of the Child Life Council, 4<sup>th</sup> Edition, 2006.

Appendix I

UNIT/SERVICE LINE: \_\_\_\_\_ CHILD LIFE STATISTICS NAME: \_\_\_\_\_ DATE: \_\_\_\_\_  
 Children's Hospitals and Clinics of Minnesota

|                           |  |  |  |  |  |
|---------------------------|--|--|--|--|--|
| Primary Care              |  |  |  |  |  |
| Acuity Rating             |  |  |  |  |  |
| Preparation/Info          |  |  |  |  |  |
| Procedural Support        |  |  |  |  |  |
| Medical Play              |  |  |  |  |  |
| Normative Activity        |  |  |  |  |  |
| Emotional Support         |  |  |  |  |  |
| Relaxation/Mental Imagery |  |  |  |  |  |
| Documentation             |  |  |  |  |  |
| Patient info Exchange     |  |  |  |  |  |
| Other                     |  |  |  |  |  |

| Supportive Care         | TIME  | System Responsibilities    | TIME | NOTES: |
|-------------------------|-------|----------------------------|------|--------|
| Patient Care Mfg.       |       | Child Life Staff Mtgs.     |      |        |
| Support Groups          |       | Peer Group                 |      |        |
| Pre-Surgery Prog.       |       | Coord. With Associate      |      |        |
| Special Events          |       | Playroom Maintenance       |      |        |
|                         | TOTAL | Education - In-service     |      |        |
| P= Patients             |       | Supervision                |      |        |
| S= Siblings             |       | Child Life Dept Planning   |      |        |
| A= Adults               |       | Unit/Service Line Planning |      |        |
| System Responsibilities |       | Other                      |      |        |
| Total Time              |       |                            |      |        |

Referenced from Guidelines for the Development of Child Life Programs in the Health Care Setting (Appendix 7-A) of the Child Life Council, 4<sup>th</sup> Edition, 2006.