



Janet Cross, MEd, CCLS

## Janet Cross to Receive CLC 2012 Distinguished Service Award

The year was 1998, and while much of the world was preparing to celebrate the dawn of a new millennium, the Child Life Certifying Committee was already guiding the child life professional community through a major transition of its own. Where previously child life certification had been based solely on a candidate's educational background and professional experience, this year marked the first administration of a standardized certification exam. Many members had strong feelings about the decision, which was controversial, and as with any new process, there were growing pains. In her role as Senior Chair of the Child Life Certifying Committee, CLC member Janet Cross found herself in the middle of the storm. "It was work that we needed to do, and it was the best decision for our profession, but it was hard," she recalls, "It was a very emotional time."

It was also an exhilarating time. Janet remembers being a part of those first item writing sessions, in the presence of other child life professionals whose work and reputation she so admired, working to develop the questions that would form the basis for the first Child Life Professional Certification Exam. The admiration was mutual. "She handled the change with excitement and enthusiasm, and the challenges with grace and dignity," one colleague reports, pointing to Janet's steady leadership during this period as just one of her many contributions that will have a lifelong impact on the child life profession.

Janet's outstanding accomplishments and commitment to the child life profession will be celebrated at a special presentation of the CLC Distinguished Service Award at the 30<sup>th</sup> Annual Conference on Professional Issues in Washington, DC. First bestowed upon Emma Plank in

*continued on page 8*

### INSIDE

- 2 President's Perspective
- 4 Looking Back, Looking Forward: 30th Anniversary
- 6 Book Review: *Therapeutic Activities for Children and Teens Coping with Health Issues*
- 10 Five Reasons to Attend Annual Conference

#### In Focus:

Helping Children Say Goodbye to Loved Ones in Adult and Pediatric Intensive Care Units: Certified Child Life Specialist—Critical Care Nurse Partnership

A Visit to the Intensive Care Unit: A Family-Centered Culture Change to Facilitate Pediatric Visitation in an Adult Intensive Care Unit



## Child Life Alphabet

### O IS FOR ONCOLOGY RECOGNITION PROGRAMS

Jennifer Ellis, CCLS, and Elizabeth Fairall, MA, CCLS, Johns Hopkins Children's Center, Baltimore, MD

It is very common for a child life specialist to help ease the transition from the hospital to home before a patient is discharged. On the oncology unit at Johns Hopkins Children's Center, part of that transition sometimes involves collecting beads. Before leaving the hospital, patients have been known to find the child life specialist to say, "But wait! You owe me one yellow bead for spending the night, one black bead for my port access, one bumpy bead for the rough day I had, one silver bead for my dressing change, and one white bead for my chemotherapy!" As they receive their earned beads, patients of all ages eagerly add them to their strands containing their name and their

Johns Hopkins logo bead. As child life specialists, we see the benefit of providing these beads to our patients, but what the program offers to patients and families is far more meaningful than it may initially appear.

There are many different bead recognition programs available; the one that is used throughout the oncology department at Johns Hopkins Children's Center is Beads of Courage Program, Inc. ([www.beadsofcourage.org](http://www.beadsofcourage.org)). The Beads of Courage program "is a resilience-based intervention designed to support and strengthen children and families coping with serious illness. Through the program, children

*continued on page 11*

## PRESIDENT'S PERSPECTIVE



### Professional Growth— Child Life's Next Steps

Toni Millar, MS, CCLS, CLC President

"The future belongs to those who see possibilities before they become obvious."

— John Sculley, President, PepsiCo/CEO, Apple

In a previous column, I wrote about my personal journey as a child life specialist. In this issue, I would like to reflect on CLC's professional journey. The recent release of the CLC 2012-2014 Strategic Plan has

elicited quite a bit of discussion and feedback from the membership. As President, I feel proud to be leading an organization whose members are continually striving to raise the professional bar and to challenge the

status quo. That said, I also recognize that change is difficult. I have been appreciating the healthy dialogue on various Forums, and I have received numerous emails with members' feedback, some positive and some not so positive. Although Dennis Reynolds, our CLC Executive Director, wrote a blog in early February to clarify some of the information regarding the Strategic Plan, I wanted to place this in a broader historical context and revisit some other historic moments when changes were initiated, how similar responses occurred, and how those initiatives influenced our profession.

The timeline from the CLC website marks the milestones in our history where individuals and groups of individuals took risks. Three hospitals are noted in our history for establishing play programs for children (proudly, one of those hospitals is where I currently work) at a time when that was unconventional. Then along came Emma Plank whose pioneering work founded our profession. What a struggle she must have had at times to convince others about the importance of providing for the social, emotional, and educational needs of hospitalized children!

Moving forward on the timeline, after the creation of the Association for the Care of Children in Hospitals (ACCH) and during the time of the rapid growth and spread of child life programs in the 1970s and 1980s, in 1978 a Child Life Task Force was "formed within the Study Section (of ACCH) to work on professional standards and staff accreditation." In 1981, "...an Ad Hoc Committee on Structure for Child Life Professional Issues was established at the ACCH Board meeting. The group recommended the formation of the Child Life Council." I can only imagine the emotions that were surfacing and being expressed, both positive and negative, when this decision was made public! Nevertheless, the decision was made to forge ahead, and the Child Life Council was formed in 1982, growing to 235 members in 1983, and 800 members in 1988.

In 1996, the CLC leadership brought together several key members to hold a "Vision-to-Action" strategic planning initiative. This group's hard work produced innovative, visionary, and—according to some—controversial ideas. These included creating the *Mission, Values and Vision* statements,

*continued on page 9*



Attendees of the 2011 Strategic Planning Meeting. From left to right (back row): Kristin Maier, Sharon McLeod, Eugene Johnson, Jodi Bauers, Toni Millar, Sharon Granville, Ellen Good, Dennis Reynolds; (front): Trish Cox, Michelle Willband, Kitty O'Brien, Diane Hart, Lisa Ciarrocca, Carla Oliver, Anita Pumphrey.



#### Child Life Council *Bulletin/FOCUS*

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## FROM THE EXECUTIVE EDITOR



### A Different Perspective on Development

Anne Luebering Mohl, PhD, CCLS

As students of child life, we have learned developmental theories inside and out.

One theory that probably received special emphasis in most of our backgrounds was that of Erik Erikson. His theory of psychosocial development is one that resonates in our work every day—if someone asked you to explain Erikson's stage of "industry vs. inferiority," for example, you may be able to draw from your work with a child within the past week in order to offer a clear explanation.

Because the main focus of our work is with children and teens, though, how many of us have had to actively consider Erikson's adult stages of development? From Erikson's point of view, most adults in the working years of their lives experience the stage he termed "generativity vs. stagnation." Although Erikson was among the first to emphasize the continuation of development throughout adulthood, this stage can encompass 40 years—a long time to be working on one main developmental task! Current researchers are investigating many aspects of adult life and examining how we develop during that period: relationship formation and maintenance, work life, moral development, cognitive changes, and self-concept, just to

name a few.

As professionals who spend a great deal of time thinking about child development, we may not spend enough time considering our own development as adults. Most of us may agree that our work in child life is important and worthwhile (great for generativity!), but there are times when it doesn't meet all of our needs. We may struggle to feel the respect our roles deserve from our medical colleagues. Our work may spill over into our personal life, either in the form of overtime hours or work baggage that we carry home with us. Many of us, at some point in our careers, suffer from burnout because of the stresses associated with being a caregiver to vulnerable young people. We may find that the career does not offer us the financial security that we need or the opportunity to rise professionally. Sadly, for one reason or another, many child life specialists move away from the field or on to other careers.

As members of the Child Life Council, we should applaud ourselves for taking advantage of one of the best ways to support our careers, and therefore our adult development. The opportunities to connect with others who do the same work, through the Forum, the *Bulletin* and *Focus*, the webinars offered on various topics, and the Annual

Conference can help us feel less alone in our struggles, and can inspire new enthusiasm for our work. Opportunities to develop a relationship with a mentor or to pass along our own expertise to our peers or the next generation of child life specialists are clearly ways to boost our development. Stretching ourselves by signing up for a session on a topic we know little about is a way to enhance personal growth. In addition to our own individual gains, as a group we can overcome bigger barriers—our need for respect from our colleagues in other fields and better pay will come from having a strong professional organization behind each of us.

In Erikson's theory, development doesn't just happen; the developing individual has to be an active agent, working toward his or her own development. By being a participating member of CLC, each of us is working to promote our continued development—something that should make the child life specialists in us proud!

## Child Life Council

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To contact a Board member, please visit the CLC Member Directory at <http://www.childlife.org/Membership/MemberDirectory.cfm>.

## 2012 BOARD OF DIRECTORS SLATE ANNOUNCEMENT

CLC would like to congratulate the recently elected Board members on their new positions! The slate was formally approved by members earlier this spring, and the new Board members will begin their terms at the Annual Conference in May, 2012.

### PRESIDENT-ELECT

- Amy Bullock, MEd, CCLS

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- Melissa "Missi" Hicks MS, CCLS, LPC, RPT-S
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- Lucy Raab, MA, CCLS

## Looking Back, Looking Forward

The child life profession attracts people from all types of backgrounds and with all types of experiences. Some of us knew right away that child life would be our lifelong career, and some of us stumbled into it by chance and were drawn to the work and the people. In this anniversary column, *Looking Back, Looking Forward*, we honor and recognize the diverse paths that have brought each of us to this field and led us to be part of the child life community. We encourage you to read the experiences shared below by your colleagues and to reflect on your own professional path.



### My Path to Child Life

*Robert Quinn, MS, CCLS, The AIDS Foundation of Western Massachusetts, Inc., Springfield, MA*

**T**he most memorable event in my child life career to date is simply my path to child

life. It was the summer of 1982, and I was one of eight undergraduate students selected to travel abroad to Wimbledon, London, on an exchange student teaching externship as part of the degree requirements in early childhood education at the University of Massachusetts, Amherst. A month before I was set to leave, I stumbled across a journal, which I later discovered was the *Journal of the Association for the Care of Children's Health*. The journal included an article on working with children in the hospital. This article intrigued me, and I wanted to know more.

Child life was still a little-known allied health care profession then. I went to my academic advisor for guidance, but to no avail. He knew nothing of child life but encouraged me to research internship opportunities. I was determined to find out more. I knew I had to work fast because in less than a month I was scheduled to set off to London. I immediately inquired at my local hospital to see if there was a pediatric unit with a "hospital play program."

*Within moments of meeting Ms. Powers and being in the health care milieu I knew that the classroom setting was not for me, and that child life and working with children and families in health care settings was to be my life's purpose.*

Indeed, at Springfield Hospital in Springfield, MA, there was such a program: the child life program. I immediately contacted the program's coordinator, Ms. Peggy Powers, and set up an introductory meeting. Within moments of meeting Ms. Powers and being in the health care milieu I *knew* that the classroom setting was not for me, and that child life and working with children and families in health care settings was to be my life's purpose. Right then, right there, I inquired about field placement opportunities and BINGO—there was an opening that fall. I applied and was accepted into the program. This was a sign that I had found my life's purpose.

I opted not to go abroad to London but rather completed a full-time internship in the child life program in the fall of 1982. It was that life-changing event which has shaped me professionally and personally. I have never looked back or wondered, "What if I had gone on that exchange program?" As a direct result of my undergraduate child life internship under the supervision of Peggy Powers, I successfully completed a Master of Science degree in child life at Wheelock College in Boston and went on to my child life career. Peggy remained in my life as a mentor, colleague, and personal friend from that day on. I have been involved in the child life profession for nearly thirty years, since the development of the Child Life Council in 1982. It continues to be both an honor and a privilege to be part of the continuing evolution of the child life profession.

### UPCOMING EVENTS

Thursday, June 28, 2012

**1st Annual CHOC Children's  
Child Life Summit**

**Beyond Bedside:  
Enhancing Our Role as Educators**

CHOC Children's Hospital  
455 S. Main Street  
Orange, CA 92868

Contact: Stephanie DeMello at [sdemello@choc.org](mailto:sdemello@choc.org)  
or call 714.532.8473

## Finding New Cheese: My Path to Child Life

James J. Lullen, CCLS, Florida Hospital for Children, Orlando, FL

Several years ago I read a whimsical book entitled, "Who Moved My Cheese?" It is a book about change, considering differences in the ways people react to, plan for, or run away from, change. Two mice, facing the need for a new source of cheese, are used as the main characters of the book. I enjoyed the book and thought of myself as one who welcomed change. So, after 20 years of serving in the U.S. Army Corps of Engineers, I retired from the Army and began a search for new cheese. I found a new job in an engineering career as a project manager for the Siemens Corporation. After 10 years of leading and completing a variety of technical projects, Siemens announced an opportunity for managers like me to take an early retirement. Once more I felt compelled to sniff out new cheese. I retired from Siemens and began my new search as a volunteer at Arnold Palmer Hospital for Children. It was there that I stumbled upon a career I had never heard of – a "child life specialist." The people I met were not only passionate, but very good at calming a child in an otherwise stressful situation. Before long, I knew that this was the path for me.

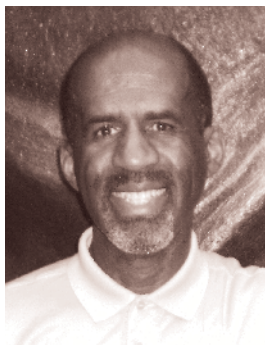
But how, after 30 years of engineering, does one make the transition to the psychosocial world of child life? Needless to say there were those around me who told me to "play it safe," and stick with the familiar world of engineering, as it was too late to change at that point. But making any transition is never without its challenges. After reviewing my college coursework with the Child Life Council, I knew that I had to go back to school to complete at least five of the child life core courses in order to meet the ten-course requirement. Going back to school after the age of fifty gives one pause to reconsider chasing new cheese. I tried to explain to some schools how I already had a Masters degree so I would not be seeking a degree; they responded that this was "a non-traditional way to pursue child life." Yes, I agree it was different, but it simply meant that someone had to do it.

I was very fortunate to be introduced to the University of Alabama's online course opportunities. I got through the coursework and came face-to-face with the challenge of finding an internship. I thought I could follow the road less traveled and find an

internship as an independent candidate. Alas, I learned that the traditional path and most available internships go to candidates who are college-sponsored students. Once again I turned to the University of Alabama. Like all of the other schools, they typically only sponsor their degree-seeking students. Following an appeal, some supporting recommendations, and the fact I had performed well in coursework, the university agreed to sponsor my internship. This elicited a short celebration at my house!!

After completing my internship, I could smell the new cheese, but still I didn't have it. The next hurdles to pass were the certification exam and finding a job in a hospital setting. Having to take a major exam when I hadn't taken one in about twenty years was a challenge. But after prayer and lots of study notes, I achieved the coveted designation of Certified Child Life Specialist in November of 2009. Traditionally at this point a person moves on to a full time job as a specialist. Well, my non-traditional route continued a little further. I soon found myself engaged in a one-year contract as a child life fellow at the Florida Hospital for Children. As a fellow, I was given the opportunity to test drive my new skills under the mentorship of more experienced child life specialists, while helping the hospital explore the feasibility of expansion of its services to the children's emergency center. After that year of what can best be described as advanced training, the chase for new cheese reached its conclusion. I found a team of professional and exuberant child life specialists at Florida Hospital for Children who allowed me to join their department as a full-time member.

This new cheese has proven to be exactly what I needed. At times the adventure to get here surely had its moments when I wanted to retreat back to the good old hard facts of engineering. But this non-traditional road proved to be a great road for me. My thanks to all who helped pave this road and built bridges for me along the way.



### CLC Would Like to Sincerely Thank Our 2012 Conference Sponsors

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## A Terrific New Resource for Specialists and Students

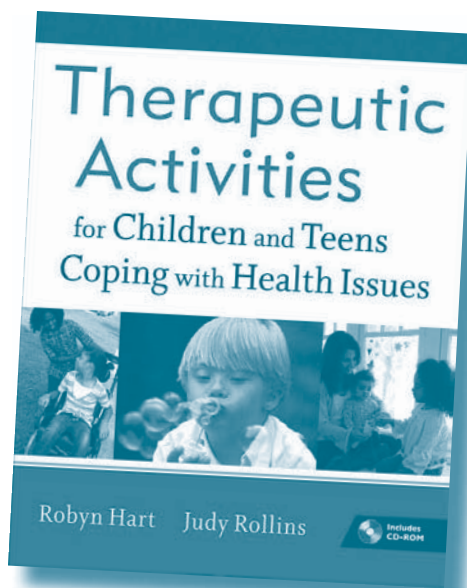
**A REVIEW OF HART, R. AND ROLLINS, J. (2011). *THERAPEUTIC ACTIVITIES FOR CHILDREN AND TEENS COPING WITH HEALTH ISSUES*. HOBOKEN, NJ: WILEY.**

Ellen C. Hollon, MS, CCLS, Canton, MA

A recent recipient of a 2011 Book of the Year Award by the American Journal of Nursing in its Maternal and Child Health category (Book of the Year, 2012), *Therapeutic Activities for Children and Teens Coping with Health Issues* will soon assume a well-deserved position as an essential text for child life specialists and students studying to become child life specialists. Organized in chapters by developmentally-associated concept rather than disease process, this large paperback text is quite user-friendly. The use of evidence-based practice enhances each chapter's thorough literature review, which is followed by numerous goal-specific activities to address the identified topic. Intermittent photographs and illustrations support the activity descriptions, and additionally, an accompanying CD-ROM contains all of the activities (in Word format) from the entire book.

The book's substantial introduction adds current literature supporting the identified variables influencing children's health care experiences explored both by Gaynard et al. in *Psychosocial Care of Children in Hospitals: A Clinical Practice Manual from the ACCH Child Life Research Project* (1998) and the Child Life Council's Evidence-Based Practice Statement on *Child Life Assessment: Variables Associated with a Child's Ability to Cope with Hospitalization* (Koller, 2008). Included in the introduction is a section called "How to Use This Book," which offers helpful guides to working with both individual and groups of children, as well as children with emotional and behavioral disorders; developmental disabilities; autism spectrum disorder; brain injuries; physical restriction; also abused, maltreated, or neglected children; disaster victims; and children who cannot play.

Each of the book's sixteen chapters begin with an examination of developmental issues frequently addressed in everyday practice by child life specialists such as separation and stranger anxiety, self-expression, self-esteem, body image, culture, and death and bereavement. Following the written support for each developmental concept, a section called



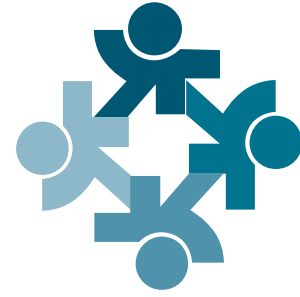
"Special Considerations" is included. For example, Chapter 2, "Self-Expression," reviews the literature associated with the developmental aspects of self-expression, but contributes further to the reader's learning by including a detailed table of adaptations required for children with certain limitations to experience success in self-expression activities. Other chapters are devoted to desensitization to medical implements, tension release, humor, pain, and breathing. Chapter 14 is entitled "Teaching," and offers an in-depth look at children's understanding of both illness and their bodies. Those two sections include tables to further assist the reader's grasp of the topic. The section entitled "Transition to Adult Care," explores a leadership model for systematic transition of care and further elaborates those concepts using a developmental framework for children's acquiring leadership skills that enable them to assume greater responsibility for their own care. The "Special Considerations" section of this particular chapter addresses differences in the learning styles and communication modes of children.

Following each chapter's literature review, the related activities are listed. Every activity begins with an eye-catching, gray-shaded summary box which lists the therapeutic goal, age group most appropriate for that

activity, a recommended adult/child ratio, the activity's required time, its restrictions and precautions, and also a detailed list of the materials required for the activity. A step-by-step process for completing the activity follows. Some activities, such as "Snowball Fight" in the "Tension Release" chapter, require nothing more than white paper and writing utensils. In this activity, for example, older children are given two pieces of paper and instructed to write something on each that makes them frustrated or angry. The paper is then crumpled into "snowballs." After a time-limited group snowball fight, the children take turns reading from a found snowball. Ensuing discussion can occur around shared experiences with the issues and emotions written on the papers. Another simple example from the "Separation and Stranger Anxiety" chapter is called "Special-People Chain." Using the technique for cutting out a chain of connected gingerbread men shapes from folded paper, the child can name all of his or her family members on representative shapes, symbolizing the support provided by the child's family and resulting in a personalized decoration for the child's bedside environment.

Child life programs with limited budgets may be challenged to purchase the necessary supplies for some of the more complex activities included in the book, but there are ample activities that require only basic materials, or materials found readily in the health care environment. Some of the more complex activities included may be most appropriate for long-term patients or even frequent outpatients, as they require multiple steps for completion. Still others may require adult assistance when the child has significant limitations. Users of the book will be delighted to find that it includes multiple recipes for popular "gooey" substances in the "Tension Release" chapter, as well as patterns for blank cloth dolls and puppets. The patterns are easily printed from the CD-ROM, and can even be enlarged, if necessary. Additionally, the CD-ROM contains templates for popular activities such as "All About Me."

*continued on page 7*



In each issue of Focus, the Editorial Board strives to publish articles that help to stimulate thought about child life practice. In this issue, we are pleased to present reprints of two articles, both co-authored by child life specialists, detailing different approaches to a shared problem: finding ways to collaborate with adult intensive care units (ICUs), without child life staff of their own, in order to prepare children to visit loved ones. In each case, services needed to be provided within the constraints of institutional resources and priorities.

As child life specialists, we know the value of psychological preparation in helping a child deal with a difficult situation. A child gains a deeper level of understanding when given the opportunity to learn in an individualized, age-appropriate way about the strange and scary ICU environment and the care that is being given to the loved one, and this understanding can help the child to process and participate in the hospitalization with the rest of the family. As part of the preparation intervention, learning coping skills and being given a safe place to

express emotions can aid the child in incorporating the ICU experience into his or her life. The first article uses a case study to detail how one ICU partnered with child life to provide such support on a consult basis with an individual child.

Unfortunately, individual preparation is not always feasible for every child visiting an adult unit. In the second reprinted article, another type of collaboration is described. The authors' investigation into staff and family members' reasons for questioning the desirability of allowing children to visit the ICU resulted in the production and evaluation of a preparation book for children and families, as well as staff education about child development in the context of health care.

Many child life departments struggle with the costs and benefits associated with reaching out to expand services to underserved areas within their hospitals, and we hope that these articles will contribute to the discussion. We commend these authors for sharing their expertise, and thank them for allowing us to reprint their articles here.

## Helping Children Say Goodbye to Loved Ones in Adult and Pediatric Intensive Care Units: Certified Child Life Specialist—Critical Care Nurse Partnership

Jan Crider, MA, ATR, CCLS, Doernbecher Children's Hospital, Oregon Health & Science University

Mary Frances D. Pate, RN, DSN, Associate Professor, University of Alabama School of Nursing, Birmingham, Alabama

Reprinted with permission from AACN Advanced Critical Care in 2011, Volume 22 (2), pages 109-112.

Intensive care units (ICUs) can be stressful places for adults to visit and may be especially distressing for children wanting to be near a loved one. The interprofessional collaboration between certified child life specialists (CCLSs) and critical care nurses (CCNs) has the potential to make a positive impact on children experiencing situations such as saying goodbye to a family member. Both disciplines are knowledgeable regarding principles of family-centered and developmentally appropriate care. Children with loved ones in pediatric and adult ICUs can benefit from CCLS and CCN partnerships.

### OVERVIEW OF THE CCLS ROLE

Child life programs continue to grow in the United States, with most hospitals with pediatric specialization employing CCLSs.<sup>1</sup> These types of programs are also recommended

for community hospitals caring for pediatric patients.<sup>2</sup> In California, CCLSs are reimbursed for bereavement care, and in New Jersey, CCLS is a required discipline for hospital licensing in pediatric ICUs.<sup>3,4</sup> These specialists are educated to provide evidence-based developmentally appropriate therapeutic play, information, reassurance, and psychological preparation. Such interventions allow children to plan and rehearse coping.<sup>5</sup> Certified child life specialists are educated at the bachelor's and master's levels in areas such as child life, child development, or related fields (music therapy, art therapy, etc). Students complete an internship of no less than 480 hours under the supervision of a CCLS.<sup>5</sup> To become certified, graduates must successfully complete a standardized national examination. It is common for CCLSs to develop a focused area of expertise, such as critical care.<sup>1</sup>

### MISCONCEPTIONS CONCERNING CCLSs

It is unfortunate that the contributions of CCLSs have been devalued by some, because of perceptions that these professionals do no more than entertain children.<sup>6</sup> This is especially concerning because the pediatric literature clearly supports preparing children for stressful situations to improve coping ability and mastery of difficult situations. These misconceptions may be caused by a lack of understanding regarding developmentally appropriate therapeutic play and/or confusion about the CCLS's role.<sup>6</sup> Another misconception is that CCLSs are important members of the interprofessional team only in pediatric settings. However, children with loved ones in adult ICUs may also benefit from collaboration between CCNs and CCLSs as they cope with an illness or imminent death.

**TABLE 1: INTERPROFESSIONAL PLAN TO SUPPORT CHILDREN DURING ICU VISIT**

<b>STEP 1</b>
Listen to the adult family members' questions, fears, and concerns. Answer questions, validate concerns, and correct misinformation. Care more about what "they" feel than what "you" think. Assess level of involvement appropriate for family and children.
<b>STEP 2</b>
Meet children and family in a private, contained room. Gather information of each child's understanding and perspective of the ICU and loved one's illness/situation—provide individual support depending on age, developmental level, and personality. Provide simple, honest verbal information regarding patient condition and prognosis. Provide verbal description of what will be seen, heard, smelled, and felt in the ICU. Provide information about what the child will "do" once in the ICU and at the bedside <sup>7</sup> (hold patient's hand, sit on bed, stand on step-stool, etc).
<b>STEP 3 (REFERENCE 8)</b>
Prepare alert patients for visit by letting them know children are coming—"OK" this with them. Ensure that linens are clean and soiled tape/dressings are changed. Elevate the head of bed if appropriate. Place bed in a low position. Make room look less institutional with pictures, drawings, quilts, etc. Discuss potential reactions of children (crying, clinging, etc) and with alert patients and adult family members.
<b>STEP 4</b>
Ask adult family members whether they would like a Polaroid or digital picture of the patient to show the children. Take photographs far away from the patient at first, and then move closer. Show photographs to children if they want to see them. Assess children to ascertain whether they are "OK" or exhibiting stress/anxiety. Ask children whether they would like to visit the patient.
<b>STEP 5</b>
Accompany adults and children into patient room. Stop at entrance, let children lead into room. Accompany children into room and stay near. Assist in "interpreting" for patients who are intubated, using gestures, or attempting to write. <sup>8</sup> Reassure children that the patient is in a "good hospital" with many experts caring for the loved one.
<b>STEP 6</b>
Encourage adult family members to discuss visit to the ICU with the child soon after the visit to debrief and to assist with any postvisit stress. <sup>7</sup> Share symptoms of poor child coping with adult family members (headaches, gastrointestinal complaints, vague pains, poor academic performance, regressive behaviors, change in mood, nightmares, fearfulness, and changes in sleeping or eating habits).

Similar interventions are used with children, regardless of patient location in an adult or pediatric ICU, and can be used by both disciplines (Tables 1 and 2).

**MISCONCEPTIONS ABOUT CHILDREN VISITING ICUs**

Family members and health care providers may think that children visiting loved ones in the ICU could be detrimental, and that these children do not have the capacity to understand the situation. The literature does not support the fact that adverse effects occur in children after visitation to an ICU. Conversely, negative behavioral and emotional responses have been shown to decrease after visitation.<sup>7</sup> Even young children know when there is something wrong and may be reassured by visiting a loved one.<sup>8</sup> Reassurance is important because of a child's magical thinking, the loved one's absence, and potentially altered relationships with other family members. During the illness of a parent, the well parent may experience coping behaviors that span from denial of the child's needs to guilt over not knowing how to support the child. Without needed support, children may worry, and positive adjustment to the difficult situation may be impeded.<sup>8</sup> Certified child life specialists and CCNs are poised to partner to remove misconceptions through ongoing collaborative assessment, planning, and support that is appropriate to the child, family, and patient.

**WHEN VISITING IS NOT AN OPTION**

Visiting is not an option when the collaborative assessment of the involved children, family, and patient indicates that a visit to the ICU is not appropriate for a child. Children should be given a choice of whether they would like to visit and should never be coerced to do so.<sup>8</sup> In such cases, family members should still be encouraged to bring children to the hospital for developmentally

**TABLE 2: INTERPROFESSIONAL PLAN TO HELP CHILDREN SAY GOODBYE**

Encourage children to draw pictures, write notes, cut out Valentine hearts, make handprints, make molds of the patient's hands, gather hair locks in a memory box, or create other mementos.
Encourage children to tell you about their loved one.
Reassure children that they will be cared for if the loved one is a caregiver, and tell them who will care for them.
Help family come up with a plan for when they leave the hospital (eg, who the children will go home with or live with).
Ask the child and family, "What helps you feel better when you are sad?" and then encourage the family to participate in "helping each other feel better."



appropriate information, and children should be given the time to write notes or draw pictures for the loved one. These mementos can be taken into the ICU and placed near patients, or placed on their chests or in their hands. Interventions such as these allow children to be included, comforted, and given information, and also to have feelings validated and concerns addressed rather than being removed from the situation, only to fantasize about what is occurring with their loved one. An example follows of how CCLS and CCN collaboration in an adult ICU supported a child during the imminent death of her father.

### CASE STUDY

Emily was an 8-year-old girl coming to the hospital to say goodbye to her father who had been admitted to an adult trauma ICU. He had experienced a life-threatening injury the day before and was to be removed from life support after the declaration of brain death. The child's mother was unable to contact Emily because of a restraining order and incarceration, which decreased the support available to Emily during this stressful time. The CCN initiated a consultation with the CCLS to conduct a collaborative assessment so that a seamless, interprofessional plan, appropriate for Emily, the patient, and the family, could be developed. While meeting with family members, the CCN and CCLS became aware that the extended family had not been an integral part of Emily's life and they would not be a support for her. The decision was made to continue to prepare Emily to visit her father to say goodbye, as the CCLS and CCN continued to assess potential support systems for her. Before Emily's visit, the CCLS and social workers collaborated with the CCN to learn more about the patient's injuries and understand more about what Emily would see and experience in the ICU. When Emily arrived on the unit, the CCLS and CCN greeted her to provide a verbal explanation of her father's accident and injuries and any sensory information Emily might experience upon entry to the room. The CCLS then asked Emily whether she would like to pick out a quilt to bring to her father's room. The child picked out a quilt for her father's bed and small stuffed toys for herself so the room would look softer and not so institutional. During this initial meeting, the CCLS and CCN continued to assess and gather more information about

Emily, her father, and their relationship. In many cases, family members join this process to provide information and support to the child, but in this case, it would not have been appropriate. To provide more information for Emily, the art therapy-educated CCLS asked Emily whether it would be OK for her to do a simple sketch of her father with his medical equipment around him so that she would see a drawing of what would be encountered in the ICU room. The child agreed. The simple line drawing was completed and shown and explained to Emily. When the girl was asked whether she wanted to see a photograph of her father in the ICU, she declined and chose to go see him. With the CCN near, Emily entered the room with the CCLS. The girl stood at her father's bedside and began to cry softly. The specialist quietly asked Emily whether anyone in the room could comfort her, as extended family was sitting and standing around the room's periphery. The child replied, "No." The CCLS then asked whether anyone in her family or at home could offer her comfort. She again replied, "No." The child was asked whether anyone from church or school could comfort her, and she said, "My teacher." The CCLS asked Emily whether she wanted to call her teacher, and she said, "Yes, please." Emily and the CCLS left the room to call her third-grade teacher, who was called out of the classroom to speak with the child. The girl told her teacher that her "daddy was dying." Emily's teacher told her that her daddy died when she was in the third grade, too. After talking with the teacher, Emily and the CCLS went back to her father's room and made handprints of her father for Emily to keep and prints of Emily's hands to leave on her "daddy's heart." The CCLS then helped the child make hand molds of her father's hands, and "I will love you forever notes," that were placed in her father's hand. Emily made a friendship bracelet for her father's wrist and an identical one for herself. The CCLS and Emily stayed at her father's bedside for a few hours as the CCN continued to assess the patient, Emily, and the needs of other family members. Emily kissed her father's forehead before she said goodbye for the last time. The specialist followed up later with Emily's schoolteacher to check on how the child was coping. The teacher shared that the child had joined a grief support group for children her age who had experienced the death of a parent.

### CONCLUSION

Children who have critically ill loved ones who are imminently dying can say goodbye with preparation that is age specific and developmentally appropriate. Certified child life specialists and CCNs in pediatric and adult ICUs are poised to make optimal contributions to patients and families during crisis situations such as these, because both disciplines use their expertise to provide seamless support to children and families during loss.

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# A Visit to the Intensive Cares Unit: A Family-Centered Culture Change to Facilitate Pediatric Visitation in an Adult Intensive Care Unit

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## ABSTRACT

To guide family adjustment, an effort was made to facilitate pediatric visitation in an adult intensive care unit (ICU). Goals were to improve customer satisfaction and to raise staff comfort level with child visitation. After implementing an open visitation policy, concerns around pediatric visitation in the ICU remained. Fears centered on risks to both patient and child. Literature was reviewed before a book was written entitled *A Visit to the ICU*. It contained information about what a child visiting the ICU would see, hear, and feel when visiting a loved one. The book provided reassurance for caregivers and children, informing them about what to expect when visiting. The goal of the book was to provide caregivers with a framework for age-appropriate education. Staff education was provided on developmental stages, including a child's understandings of illness and death. Nursing interventions were reviewed and resources provided. A survey demonstrated that the book increased staff comfort level with children visiting the unit, was a positive tool for patients and families, and eased fears among children while helping to facilitate coping mechanisms. The article will describe the practice change of pediatric visitation in an ICU and how it could be applied to other critical care settings.

## A MOVE TO OPEN VISITATION

Culture change around visitation policies has been underway in many intensive care units (ICUs) and hospitals across the country. The days of staff-imposed visitor restrictions are over as consumers demand access to loved ones, the media encourages family vigilance, and the literature bears out the benefits of a family-centered approach. The Joint Commission "views patient and family-centered care as an important component of safe, quality care."<sup>1</sup> President Obama, on July 15, 2010, in a memorandum about hospital visitation, stated,

There are few moments in our lives that call for greater compassion and companionship than when a loved one is admitted to the hospital. In these hours of need and moments of pain and anxiety,

all of us would hope to have a hand to hold, a shoulder on which to lean—a loved one to be there for us, as we would be there for them.<sup>2</sup>

In the hospital setting, families are challenged by separation for various treatments, surgery, and even throughout the recovery process. Each episode of care for the patient is often a very stressful experience for families, even in the best of circumstances. In an ICU, this stress is heightened with the often-traumatic arrival of patients and unknown outcome, depending upon the individual patient's condition. Evidence-based practice indicates that open visitation in an intensive care setting positively impacts patient outcomes.<sup>3</sup> Further research has shown that the family experience and satisfaction are improved by preparation for hospital experiences and emotional support during those experiences.<sup>4-6</sup>

In an attempt to provide more family-centered care, a 15-bed neurosurgical ICU underwent a practice change to an open visitation policy with a single restriction. Visitation hours were no longer restricted and visitors were not limited to 2 at a time. Patients and families were free to come and go as they saw fit, including overnight visits if they desired. Overall, staff adapted positively to these changes, and many families expressed increased satisfaction with the care of their loved ones.

Despite the adaptation of staff to a more open visitation policy, one restriction persisted. Officially, visitors younger than 16 years were no longer prohibited but continued to be discouraged.

Staff and visitors alike had many questions and concerns about the appropriateness of children visiting the ICU. Specific staff concerns included infection control, effects of visitation on intracranial pressures (ICPs), how to talk to children, and disruption on the unit. Also surprising were family concerns about visitation, which included how to prepare the child, concerns about appropriateness of visitation, and worries about

how to explain things that even some adults do not always understand. These identified barriers led to a review of the literature and implementation of evidence-based solutions. The purpose of this article is to review the literature related to children visiting family in an intensive care setting and to share one ICU's experience in successfully facilitating pediatric visitation.

## REVIEW OF THE LITERATURE

Building off concerns identified by staff and family, a search of the literature was conducted, using the following search terms: pediatric visitation, adult critical care, visitation policy, neurosurgical intensive care visitation, ICP, and open visitation. Cross-searches were done combining search terms in addition to individual search terms. Databases searched included CINAHL and MEDLINE. Additional references were retrieved from bibliographies of articles obtained. At the time the initial search was conducted, most of the literature found was around siblings visiting pediatric patients and information on children visiting adult ICU was limited. There was no literature with any evidence to support restricting pediatric visitation due to infection control concerns,<sup>7,8</sup> emotional harm to the child,<sup>7-11</sup> or adverse effects on ICP.<sup>12-15</sup> There was little data on children visiting adult ICUs and what was found did not indicate an increase in infection control risks or significant adverse effects on ICP.<sup>17, 8, 12-15</sup> In fact, one study by Hendrickson<sup>13</sup> revealed that 7 of 24 patients had a significant decrease in ICP during family visits. Thus, the author turned to child development foundations and books recommended by the child life department as resources.<sup>16-18</sup> In preparation for this article, a fresh literature search was done using the same terms and databases, which yielded more articles and interest in this topic.

The literature on pediatric visitation in the adult ICU supports the need for consideration of children in visitation of close family members. In their review of pediatric

visitation, Clarke and Harrison found that “the literature conclusively supports children visiting their critically ill family members and identifies this as a positive intervention to help them deal with and integrate a stressful situation into their lives.”<sup>6</sup> Visiting close family members can provide another level of information that cannot be obtained without a visit. Kean<sup>4</sup> studied families that visited adults in ICU via 9 family interviews of children ranging in age from 10 to 25 years. The qualitative interviews revealed that children had 2 main interests about the ICU: its physical environment and its function of caring for their loved one. Ways of understanding the current disruption in the family environment are derived from the visit, and Kean<sup>4</sup> notes that ICU nurses need to be prepared for questions and have an ability to prepare children for the sights and sounds of the environment. She further states “there is currently a lack of information material that could help nurses or parents in this task.”

### **FACILITATING SUCCESSFUL PEDIATRIC VISITATION**

A case study of one ICU’s experience will follow, outlining concerns that staff and families had about children visiting the ICU and tools that were used to facilitate successful visitation, including in-servicing from the child life department, overview of developmental goals, guidance on appropriate language, and explanations for different aged children. Staff and family responses to an evaluation survey about the effectiveness of a book used as a resource for families and staff will also be shared. Through this account, challenges and successes will be recounted that can enable other units to successfully integrate visiting children into the critical care environment.

### **CONCERNS ABOUT CHILDREN VISITING THE ICU**

Naturally, in any critical care unit, staff may care for parents of minor children. Although all nurses learn psychological and developmental concepts as part of every nursing program, unless one works with children of different ages on a regular basis, a comfort level with their developmental needs may not exist for the nurse. Staff raised several objections and fears around pediatric visitors. The first concerns centered on risks to the patient. These included potential line and

tube dislodgement; emotional upset, causing physiological changes such as vital sign instability and ICP changes; and potential for infection from the children. Second were concerns for risk to the children that included potential for acquiring infection, emotional trauma caused by what they would see during the visit, and worry about how it would be handled if the visit did not go well. Staff was also apprehensive about upheaval that could occur on the unit if children came to visit. Possibilities mentioned were noise, running around, and disruption for other patients and families. Finally, they were uneasy about the explanations they would give to children when even adults can be wary of all the equipment, noises, and alterations in the appearance of the patient. These findings at the unit level were consistent with a study on staff views of children visiting the adult ICU.<sup>5</sup> Knutsson and Berghom<sup>5</sup> found that medical staff restricted visitation for a variety of reasons that are unproven in the literature, including being concerned about frightening children, worries about infection transmission in both patient and child, and disruption on the unit.

In addition, the family often had concerns about visitation. First and foremost is the concern about whether bringing the child up to visit is the right thing to do. Often, they seek information about how to facilitate such as visit and look to staff for guidance. It is helpful if staff is able to partner with the family, so that the timing of the visit is right and staff can be around to answer any questions that the child may have. Reassurance from health care providers about what the child sees is less scary than what is imagined and can be helpful in encouraging the family to feel comfortable bringing the child to visit.<sup>6,8</sup> The literature review showed that well adult family members may be overwhelmed with the current situation surrounding the patient. Clarke and Harrison<sup>6</sup> suggest that nursing staff can aid in decision making around bringing a child in to visit and therapeutic communication between all parties—child, patient, caregiver of child, and nurse—when the visit occurs. Staff requested preparation to increase comfort and to offer developmentally appropriate interventions when children visited, if necessary. If children were going to be visiting the unit, the staff wanted the knowledge and resources to facilitate the visit, so that all were comfortable.<sup>5</sup>

### **CHILD LIFE CONSULTATION FOR DEVELOPMENTAL REVIEW AND INTERVENTION**

Staff contacted the child life department in the adjoining children’s hospital on a few occasions when a child visitation was planned in advance to assist the staff and family. The following statement from the Child Life Council explains the role of a child life specialist as a resource for psychosocial care support for family visitation on a critical care inpatient unit.

The profession of child life will continue to meet the needs of infants, children, youth and families in times of stressful or traumatic life events and situations. The philosophy and practice of child life will be applicable to any health care setting and transferable to other environments or situations in which the potential for infants, children and youth to cope, learn and master is placed at risk. The services provided by the child life profession will be holistic and will utilize applied child development and family systems theory. The objectives of such services will be to minimize the negative impact of situational disruptions while maintaining individual growth and development and family relationships.<sup>19</sup>

Table 1 illustrates the developmental stage and expected impact of the hospital experience. An understanding of illness across the developmental spectrum is an extremely valuable tool to a nurse at the bedside of a critically ill patient. Not only is the nurse treating the patient, he or she is treating the entire family. It truly is a family hospital when one considers that the family brought the patient to the hospital and will be the ones with whom the patient will return home if possible. Nursing interventions can range from a simple greeting to the family and acknowledging the child to providing support for a family challenged with how to share difficult news with one another. Often those encounters include children and/or teenagers who have not had the opportunity to grasp the idea that their mother, father, grandparent, or other family member has changed significantly since they last spent time with them. These experiences and changes often will affect their development and comfort with future health care visits.<sup>19,20</sup>

**TABLE 1. DEVELOPMENTAL SUMMARY**

AGE	DEVELOPMENTAL STAGE	UNDERSTANDING ABOUT ILLNESS AND DEATH	NURSING INTERVENTIONS
Infants and toddlers (0-3 years)	Trust vs. mistrust (Erikson), <sup>18</sup> autonomy vs shame and doubt (Erikson), <sup>18</sup> and sensorimotor and preoperational (Piaget) <sup>6,18</sup>	Senses separation and may experience anxiety. Unable to determine permanence. Lack of understanding of concept	Keep visits brief and supervised. Provide quiet, distracting toys. Facilitate closeness with patient if possible. <sup>6,18</sup>
Preschool (3-6 years)	Initiative vs guilt (Erikson), <sup>18</sup> preoperational (Piaget) <sup>6,18</sup>	Magical thinking. May believe bad thoughts or actions cause death. Does not understand permanence of death. <sup>6,9,18</sup>	Give child an animal or doll to care for. Allow artistic play at the bedside if possible. Give clear and concise explanations and assure that child did not cause illness. <sup>6,18</sup>
School-aged (6-12 years)	Industry vs inferiority (Erikson), <sup>18</sup> concrete operational (Piaget) <sup>6,18</sup>	Understands permanence of death by age 8-10. May have exaggerated fears about illness or death happening to him/her. <sup>6,9,18</sup>	Allow child to have jobs to help loved one (ie., hand massage, straighten bed clothes). Give clear answers to questions. <sup>6,18</sup>
Adolescents	Identity vs role confusion (Erikson), <sup>18</sup> formal operational (Piaget) <sup>6,18</sup>	Capable of understanding concepts of illness and death. May feel guilty due to developmental process of separating from family. <sup>6,18</sup>	Be available for questions and provide clear and complete information. Encourage journaling. <sup>6,18</sup>

**INTRODUCING CHILDREN TO THE ICU ENVIRONMENT**

Children’s development can be impacted by hospital experiences with developmentally appropriate preparation. Children can receive information in language that they can understand and view the experience with comfort and support.<sup>6,20</sup>

Health care staff needs to develop sensitivity to meet the needs of visiting children and adolescents in an adult intensive care setting. This can be achieved through resources collected on the unit, in-service education and training for staff,

and supported practice. If available, child life specialists, who typically support pediatric patients and their families, are a valuable resource. This is due to their training and understanding of the psychosocial needs of children and teenagers in health care settings as well as extensive experience working with families making transitions. The unit staff must be educated on the importance of family connections and how to facilitate and support families through the visitation process. These situations are all individual, and a plan is needed in each situation. However, a comprehensive guidance plan for how to introduce children and adolescents to the hospital environment would include the

following components:

- An overview of what the hospital environment is like.
- What are some sights or sounds the child or adolescent may experience in the hospital environment?
- What are some of the changes their family may experience due to hospitalization?
- Understanding that it is OK to visit and that everyone has a different comfort level during a visit.
- That they will notice differences in the appearance of their loved one.
- Who are the hospital support people available to the child/adolescent before, during, and following his or her visit?
- Why it is important for the child/adolescent to share feelings about the hospital experience to receive the care and support needed for the hospital visit?
- Use of “best words” to describe things and some of the “hospital words” they may encounter during their family member’s hospitalization.<sup>19-21</sup>

Appropriate language is needed for all levels of development to ensure understanding and avoid misconceptions in health care settings.<sup>21</sup> When families are faced with new experiences and difficult choices, it becomes even more imperative that words are carefully chosen. Often, medical personnel use terminology and may not always consider that terms familiar to staff are most often unfamiliar words for the patient and the family. Defining terms, simplifying statements, and simply “calling it what it is,” as several family satisfaction surveys concluded, help the family to interpret and begin to understand what are norms in the hospital and what is happening to their loved one throughout his or her care. Although there may not have been preparation for the health care experience due to an accident, trauma, or illness, there is opportunity to help the family pick up the pieces and begin to understand the health care environment and find their way through it. Table 2 gives examples of how a child may interpret common medical terminology as well as best words that could be used so that the child may have a clearer understanding of what is happening.

The child life specialist was invaluable in validating the appropriateness of a visit by

**TABLE 2. CLARIFYING HOSPITAL WORDS FOR CHILDREN**

MEDICAL TERMINOLOGY	WHAT KIDS THINK	BEST WORD CHOICE
Urine	Are you in?	Use child’s familiar term (Pee?).
Sedated	Put to sleep	Special kind of sleep with medicine to help with resting and healing.
Ventilator	Air vent?	This machine will help her breathe because her body needs help right now.
Transfer to the floor	Putting him on the floor?	Soon your loved one will be ready to move to a different room because she/he is feeling better.
Surgery	Sounds scary	Doctors are working to help your loved one’s body work better for them.
IV, central venous catheter, etc.	Ivy? Train?	A small straw in the body to help give medicine and water quickly. (Remind that the needle is removed.) <sup>21</sup>



FIGURE 1. EXCERPTS FROM *A VISIT TO THE INTENSIVE CARE UNIT*. POWERPOINT BACKGROUND. USED WITH PERMISSION FROM MICROSOFT (WWW.MICROSOFT.COM).

children to the ICU. Although the department was willing to act as a consultant at any time, assisting the adult side of the hospital was in addition to their regular workload; and they were not available on weekends and in the evening when children may often visit. They offered to do an in-service for staff to review developmental concepts around illness and death and interventions that could be done at each developmental stage. Many, but not all, staff members attended the in-service.

The child life department created a resource book, which covered key concepts and had recommended readings for staff, parents, and children as well as interventions that could be done for pediatric visitors. Many of the readings are listed in the reference table.<sup>16, 17, 18, 22, 23</sup>

One of the suggestions made by Child Life was to create a book explaining the unit to kids. The coauthor, a staff nurse, undertook this project after having positive experiences with pediatric visitation in the ICU. She set out to explain what the child would experience during the visit, including what he or she would see, hear, smell, and feel on the visit. She attempted to prepare the child for things, such as the noisy monitor alarms and the number of people who would be on an

ICU team. A brief explanation was given for such common items as a ventilator and an IV. The book also explained that the patient may look different or be unable to talk but reassured the child that the patient was the same person on the inside who can still feel, hear, and enjoy the visit. The book was created using PowerPoint, original text, and pictures. Child Life reviewed for age-appropriate language and explanations. The book assisted staff and parents alike in using clear and concise language to describe what goes on in an ICU. Figures 1A and 1B show examples from the book.

Several copies of the book were laminated, bound, and available for families to take home and read to the child and discuss prior to visitation. This is ideal to allow time for discussion, questions, and reading of the book more than one time. However, sometimes visits are unexpected or, due to the nature of the patient's illness, last minute. At those times, staff can offer the book to families to read in the waiting room before coming in.

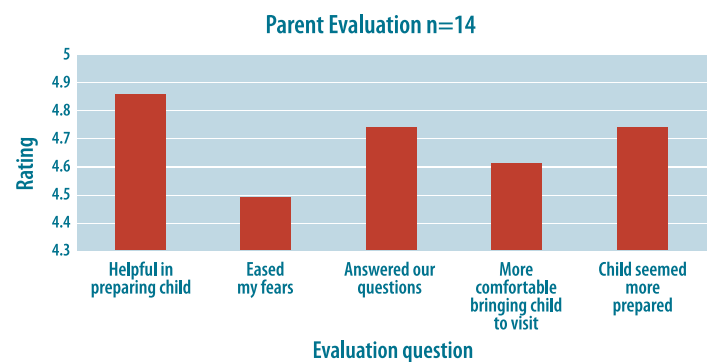
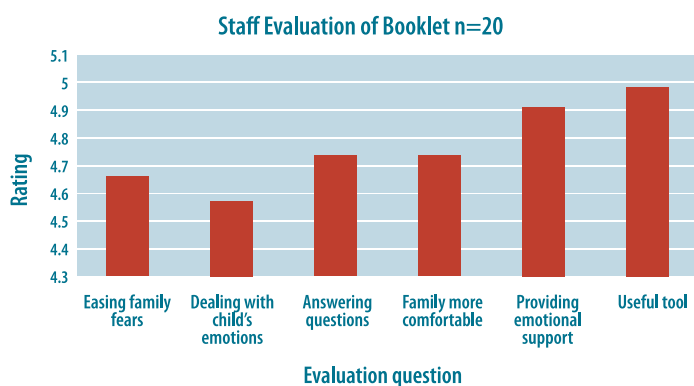
Problems included disappearing books and lack of availability at times. At present, the author made the book generic to any

ICU. The expectation is that it will be made available on the hospital Web site, so families can access it easily. For example, if someone is staying at home with the children while the parents are at the hospital, the book could more easily be obtained and utilized. In addition, families may utilize it prior to a planned hospitalization of a parent or grandparent; so the child knows what will happen while his or her loved one is in the hospital. Although the book is most suitable for preschool or elementary aged children, it has been used even for adolescents. Adults have stated that the pictures and explanations were a springboard for discussion even for older children.

### EVALUATING EFFECTIVENESS

To evaluate effectiveness of the book, 2 evaluation surveys were developed. One sought to measure staff satisfaction using a 5-point Likert scale and 6 questions. The other survey polled parents using a 5-point Likert scale and 5 questions. The scale anchors ranged from *strongly disagree* (1) to *strongly agree* (5) (Figures 2 and 3). All staff (n = 20) surveyed found it to be a useful tool. They also strongly agreed that it assisted them in providing emotional support, aided them in answering questions, and made the family more comfortable. The book helped in easing the child's fears and aided in dealing with the child's emotions. The families (n = 14) felt that it was most helpful in preparing the child for a visit, answered their questions, and that the child seemed more prepared. They also agreed that it allowed them to feel more comfortable bringing the child to visit and eased fears about the visit.

Both surveys included space for anecdotal comments. Comments were positive and provided helpful suggestions and qualitative feedback of experiences using the book and visitation. Staff members stated that they felt that families expressed positive feedback



related to the book and opened up communication between children and staff. Families commented that the book was a starting point for communication and was helpful for a variety of different ages.

The staff nurse also collected donated new toys, coloring books, games, and stuffed animals that could be given to every child who came to visit. The goal was to have a distraction, if necessary, to enable the child to care for an animal if he or she liked (bandage it, give it a shot, etc), and to have something to remember the visit. In an adult environment that may not be child centered, it can give the sense that the child is welcome and considered as part of the family. It also discourages staff from giving away medical supplies, such as a penlight or glove blown up like a balloon, which may be inappropriate for small children.

## About the Views Expressed in Focus

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## CONCLUSION

Facilitating pediatric visitation is essential for the nurse to care for the whole family. With the proper preparation of staff and families, the visits can be positive and reassuring for the patient, child, and other family members. This practice change was relatively easy in a unit that had already established a liberal visitation policy. It may be more challenging in a unit that has more restrictive policies. In addition to staff education, writing and utilizing the book were low cost ways for staff and families to feel more empowered when children came to visit a loved one. In turn, the children were more prepared and could more easily cope with the hospital environment.

The options shared in this hospital's effort to assist families with supported pediatric visitation incorporated patient and family-centered care principles of dignity, respect, communication, collaboration, and empowerment.<sup>24</sup> The collaboration achieved across units and even hospitals in this large teaching health care system kept the focus of care centered on what was *best* to achieve the ideal patient and family experience, rather than merely what had been a comfortable staff-centered model. Future research needs to focus on the long-term effects of planned pediatric visitation and how to address family-centered care partnerships consistency across disciplines.

Developers of programs and initiatives must become aware that because the family is bringing a loved one to the hospital for care and seeking clinical expertise, the institution becomes "the FAMILY'S hospital" and not merely the "PATIENT'S hospital." Since the most important resource is the family itself, giving each and every family member the tools to cope with a loved one's serious illness or death is a powerful gift that can extend well beyond the walls of an ICU. The patient and family should be partners in their care and need assistance and resources to meet them where they are at the time. Not only can it help with the actual visit that the child makes to the unit, it can start an ongoing dialogue between the adult family members and the children about the implications of the illness on the patient, child, and family. This can lead to healthy adaptations to life-altering events. Facilitating partnership opportunities helps families take steps to gain insights, understanding, and comfort for their health care journey. This care of the whole family

is at the heart of comprehensive, holistic nursing practice.

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## Therapeutic Activities

continued from page 6

This book illustrates a strong collaboration between a nurse, Judy Rollins, and a child life specialist, Robyn Hart, whose backgrounds and experiences combine to present a rich and useful text. *Therapeutic Activities for Children and Teens Coping with Health Issues* (2011) is a significantly expanded version of an earlier text, *Therapeutic Play Activities for Hospitalized Children* (1992), for which Hart was the first author. The current book offers lengthier background information for the topics addressed and has additional subjects that were not included in the first book.

Child life practitioners in medical settings will find this an invaluable resource, but those in alternative settings will benefit from it as well, as the activities have tremendous usefulness far beyond the walls of a hospital. Many activity books are widely available to use with children; this book, however, more specifically meets the practice needs of the child life specialist through its combination of theoretical background, developmental concepts, and goal-specific activities.

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## Upcoming CLC Webinars

### Thursday, June 14, 2012

The CLC Call for Abstracts - Understanding the Guidelines and Strategies to Improve Your Abstract Submission - *Free for Members!*

Presented by:

Amy Heron, CCLS  
2012 Conference Planning Committee Chair  
Chantal LeBlanc, CCLS  
2013 Conference Planning Committee Chair

### Wednesday, July 18, 2012

Success Stories: Using Evidenced-Based Practice to Enhance Child Life Practice

Presented by:

Kate Shamszad, MS, CCLS  
Jennifer Staab, MS, CCLS

### Wednesday, September 12, 2012

Psychological Approaches for Procedural Pain Management in Children

Presented by:

Christine Chambers, PhD, RPsych

### Wednesday, October 3, 2012

Implementing Evidenced-Based Practice into Clinical Practice

Presented by:

Kate Shamszad, MS, CCLS  
Jennifer Staab, MS, CCLS

### Tuesday, October 16, 2012

History of Child Life - *Free for Members!*

Presented by:

Civita Brown, MS, CCLS  
Lois Pearson, MEd, CCLS

### Wednesday, November 7, 2012

Four Key Fundamentals in Medical Play

Presented by:

Mary Faith Roell, MS, CCLS  
Katherine Nees, MSHS, CCLS



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## Distinguished Service Award

*continued from page 1*

1988, the Distinguished Service Award is presented annually by the CLC Board of Directors to an individual in the field of child life who has contributed significantly to the development of the profession.

Janet was first introduced to child life by one of her professors, Dr. Jean Kizer, while she was an undergraduate at Mississippi State University. After graduating in 1981 with a bachelor's degree in child development, Janet took a position as a child life specialist at Monroe Carell Jr. Children's Hospital at Vanderbilt in Nashville, Tennessee. During her first years at Vanderbilt, fellow Distinguished Service Award winner Sharon McLeod was the director of the child life program. Janet was inspired by Sharon's example of leadership. "She was the first person with a child life background to be in charge of the program here. I became the second. Sharon has continued to be a very important mentor to me over the years," she says.

After Sharon left in 1992, Janet assumed the role of Director of Child Life Services, and spent the next 17 years managing the child life program at Vanderbilt. Patient- and family-centered services flourished under her leadership. Among many other career accomplishments, Janet established the first state-accredited hospital school program in Tennessee in 1995, and later, in 1999, she organized the hospital's first Pediatric Advisory Council. In 2007, she initiated a music therapy program, followed by an art therapy program in 2011. Since Janet took on the director role, the child life program has grown from five staff members to a team of 25 people, including 17 full-time child life specialists.

In 2010, Janet took on her next professional challenge when she was promoted to the position of Director of Patient and Family-Centered Care. In this role, Janet oversees all patient and family-centered care initiatives at Monroe Carell Jr. Children's Hospital at Vanderbilt: Child Life Services, Volunteer Services, Pastoral Care, the Family Resource Center, Hospital School Program, Music Therapy, Art Therapy, Patient and Family Advisory Councils, and Patient Education. She has continued to develop her considerable leadership skills, and she

*"Sometimes we think we're the only ones who can do this. And certainly child life specialists have special skills and we are unique in our practice. But as you gain more experience, you learn that it's important to share your knowledge, and recruit other members of the team to help out where they can. There is plenty of work to go around."*

emphasizes the importance of being a good coach and mentor for the people who work in her department.

"I try not to be a parent to my team, but I do sometimes experience those parental emotions and pride in their accomplishments," she says, pointing to a recent example in which she encouraged two child life specialists at Vanderbilt to participate in the Frontline Nursing Leadership Academy, a 15-month program developed in partnership with the Advisory Board to encourage innovation and leadership among frontline staff. Despite the fact that the program was primarily designed for nurses, the project developed by these child life specialists, which addressed the implementation of comfort positioning in different departments, ended up being selected as the winning project that will be publicized nationwide. "It sends a great message about where we [as child life specialists] stand on the multidisciplinary team," Janet says proudly.

Janet's volunteer involvement with the Child Life Council has been extensive, and dates back to 1996, when her important work as a member of the Child Life

Certifying Committee began. In 1998, she became the Senior Certification Chair and was a member of the CLC Board of Directors. Later, she served in the roles of President-Elect, President, and Immediate-Past President from the years 2007 to 2009. During her time as President of the CLC Board, Janet headed up the Executive Director Search Committee, providing steady leadership in the wake of former executive director Susan Krug's departure, and collaborating with an interim director until CLC's current executive director, Dennis Reynolds, was hired.

On top of her work with the Board and the Child Life Certifying Committee, Janet served as the chair of the Conference Host Committee for the Annual Conference in Nashville in 2005 and chaired the Nominating Committee from 2009 to 2010. She has been a member of many other CLC committees, including the Ethics Committee, Governance Task Force, Past Presidents' Advisory Group, and currently, the Leadership Development Committee. She also serves as one of five program reviewers for the Child Life Council Program Review and Development Service, where she applies her considerable knowledge and experience to support the development and enhancement of child life programs around the world.

As a volunteer leader who has already helped CLC to maintain a steady course through times of turbulence and change, Janet views some of the upcoming changes to academic requirements outlined in CLC's Strategic Plan as "challenging, but necessary." While she acknowledges that a lot of work will be required to make it happen, she believes that implementing an advanced degree requirement for future Certified Child Life Specialists is the right thing to do. "With the exception of nursing, if we look at the trends in education requirements of other disciplines in health care—physical therapy, music therapy, social work, occupational therapy—most have already moved to requirements of a graduate level degree. I believe it can only benefit us in the long term."

Janet's written contributions to the child life field include writing a chapter on child life administration in Richard Thompson's *Handbook of Child Life* (2009), and co-authoring a position statement from the Child Life Council entitled, "The Value of the Certification Credential in Child Life



Services.” She has been a presenter at many Child Life Council conferences, as well as other professional conferences and university classrooms. The variety of subjects that Janet has covered in her presentations over the years is an indicator of the breadth and depth of her knowledge and professional experience. Closer to home, she was an instructor at the Vanderbilt University Medical School in an “Art for Children” elective for 15 years. Recently, Janet was nominated by the *Nashville Business Journal* as a “Woman of Influence.”

When asked what challenges the child life profession will face in the future, Janet points to the ongoing need for child life specialists to be able to clearly communicate the value and importance of their services. “There are never going to be as many child life specialists as nurses in a hospital,” she says, “so we must continue to share our expertise and articulate what we do in an objective way to help better position ourselves with our colleagues in the hospital.” To this end, Janet encourages involving other members of the interdisciplinary team in child life practice. “Sometimes we think we’re the only ones who can do this. And certainly child life specialists have special skills and we are unique in our practice. But as you gain more experience, you learn that it’s important to share your knowledge, and recruit other members of the team to help out where they can. There is plenty of work to go around.”

Janet’s energy, drive, and commitment to excellence are personal qualities that make her a standout not only in her professional life, but also in her personal pursuits. She loves to water ski, and competed in water skiing for a number of years. In fact, for ten years running she was the Tennessee state women’s water skiing champion! She loves taking trips to the beach, especially to the Gulf Coast along the Florida panhandle, and hopes to convince her husband Kim to retire near the water someday. Janet is very grateful for the love and support of her family. As meaningful as her professional contributions have been, she considers her three children Lacey, Katie, and Andrew to be her proudest accomplishments.

Please join us in celebrating Janet’s achievements at the Distinguished Service Award Presentation, which will take place on Sunday, May 27, during the Closing General Session of the 30<sup>th</sup> Annual Conference on Professional Issues in Washington, DC.

## President’s Perspective

*continued from page 2*

the *Operating Principles*, and eventually, the professional certification exam. If my memory serves me correctly, the idea of an exam challenged members, and there was quite an outcry at the time that the criteria to even sit for the exam might eliminate many of our current, outstanding child life specialists and leaders in the field, and that the difficulty of the exam would eliminate even more! The reasoning from CLC was that our professional colleagues had similar requirements, and that the acquired credentials, CCLS, would signify to others the level of integrity of our profession. I have heard from many within the current CLC membership that our standards, competencies, and credentialing have raised the level of respect from other medical professionals, and in many cases, helped child life to be recognized as a valued service in and out of traditional hospital settings.

CLC, and its elected leadership, has always listened and responded to its membership while keeping abreast of health care, economic, and world changes. It is also CLC leadership’s job to anticipate these changes and implement strategies to ensure that child life is viewed as a credible and influential profession regarding psychosocial services in health care and related

settings serving infants, children, and youth. The CLC membership’s feedback and suggestions have been the catalyst for this next step in our professional growth. Although CLC leadership worked on its construction and design, you, the membership, have provided the direction of the current 2012-2014 Strategic Plan! And as Dennis highlighted in his blog, many of you will be asked to support CLC in the first steps towards its implementation.

As we celebrate CLC’s 30<sup>th</sup> anniversary in 2012, I want to thank all of those who challenged the status quo with new ideas regarding psychosocial care for children and families and took risks in advocating for child life to have a prominent role alongside our medical colleagues. I’d also like to thank those in our early CLC days who weren’t sure exactly what the path looked like to get there, but had the vision of what it looked like once they were there. One day in the future, when you are looking back at CLC’s timeline and recalling this period of change and innovation, I hope you will feel pride in sharing that you were part of that time.

I look forward to seeing many of you at our exciting CLC 30<sup>th</sup> Anniversary Conference in Washington, DC in May!

## Milestones

### Presented

Melodee Moltman, MS, CCLS, and the child life team at the Kuwait Association for the Care of Children in Hospital recently were invited to speak on child life and psychosocial interventions at the Childhood Cancer & Blood Disorders: Achievements and Challenges Symposium in Riyadh, Kingdom of Saudi Arabia.

### Promoted

Sharon E. Granville, MS, CCLS, CTRS, NCC, was recently promoted to Manager of Child Life Services at NewYork-Presbyterian/Weill Cornell Medical Center. Sharon was previously the Child Life Inpatient Supervisor at Mount Sinai Kravis Children’s Hospital in New York City.

### Passing

Peg Belson, a pioneer of family-centered care and psychosocial care in the UK, died on January 1st. Peg was the founder of Action for Sick Children, and assisted in the establishment of the European Association for Children in Hospitals. She was part of the collaboration that helped to create the Wheelock in London learning experience. She was an advocate of family-centered care, play, and psychosocial care worldwide, and opened her home to people who wanted to learn about developing play in hospital. We thank Peg for her inspiring contributions to the profession of child life.

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## 2013 Call for Abstracts

Abstract submissions for the CLC 31st Annual Conference will be accepted through the CLC Website June 8 through July 31, 2012.

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## COUNTDOWN TO THE CLC 30TH ANNUAL CONFERENCE IN WASHINGTON, DC

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The Child Life Council's 30th Annual Conference on Professional Issues is just around the corner! Here are just a few of the benefits of attending:

- **Celebrate A Monumental Year, A Monumental Profession** with a series of special activities and observances to mark the Child Life Council's 30th Anniversary, including the debut of a new video from the Archives Management Group.
- **Earn up to 24.5 Professional Development Hours**, with 15.5 PDHs included with basic registration, and 3-9 additional PDHs available for attending optional half or full-day conference intensives on Thursday, Saturday, or Sunday (separate registration fees apply).
- **Discover New Resources at the Exhibit Hall.** With the newly extended hours on Saturday, you can take your time strolling through the Exhibit Hall, meeting with more than 50 organizations offering products and resources to support your work with children and families. Many exhibitors offer special conference discounts and giveaways. Don't forget to stop by the CLC Bookstore to enjoy even more conference savings!
- **Re-Charge and Engage** at the largest annual gathering of child life professionals in the world. The Annual Conference is truly a unique experience, offering unparalleled opportunities to connect with and learn from your peers. Attendees consistently leave the conference feeling invigorated and inspired.
- **Bring the conference home** by sharing what you've learned with the rest of your team.

**FOR DETAILED INFORMATION AND TO VIEW THE COMPLETE CONFERENCE PROGRAM, PLEASE VISIT THE ANNUAL CONFERENCE SECTION OF THE CLC WEBSITE AT [WWW.CHILDLIFE.ORG/ANNUAL\\_CONFERENCE/](http://WWW.CHILDLIFE.ORG/ANNUAL_CONFERENCE/)**

## O is for Oncology

*continued from page 1*

tell their story using colorful beads as meaningful symbols of courage that commemorate milestones they have achieved along their unique treatment path” (Baruch, 2010).

When pediatric oncology survivors are asked to tell their cancer treatment story, many are not able to accurately depict all of the events that they have experienced. Maybe it is because a patient was too young at diagnosis, or it is too painful to relive their experiences, or they just have a hard time remembering all that has happened. A bead program provides an opportunity for patients to recall and reflect on memories in their own time. A school-age patient seen in the outpatient clinic says “My beads help me to remember everything I have been through so I will not ever forget.”

It doesn't matter how minor the experience, in this program nearly everything a patient encounters translates into a bead. When the family is ready to begin their bead journey, they are started on the program by accumulating beads from past ER visits, inpatient stays, surgeries, their first treatment, etc.. In the first two days after diagnosis, a patient might earn up to 20 beads for various reasons. Can you imagine a child trying to recall and explain all that they have just encountered without the help of the beads? Now, imagine trying to relay all that has happened in an average three-year course of treatment! These beads provide something tangible and concrete that the patients and their parents can use to illustrate the treatment experience and life as a survivor (Haase & Rostad, 1994).

Many newly-diagnosed patients are not familiar with the hospital setting and the bead program can help patients and parents with this process. By viewing a list of all of the beads patients might acquire throughout their journey, patients learn what events may lie on the path ahead of them. This can open the lines of communication with the medical staff as patients and parents may ask what certain beads mean and whether they are going to earn them. As a result, many patients become very involved with their beads, look forward to collecting them, and become excited when asked to share their personal story. This enhances their confidence while providing an outlet for socialization. When asked to share her bead story, one adolescent patient stated, “Each bead is not just a bead to me; each one hold its own story. I have over 500 beads and I

have over 500 stories to tell.” After overhearing one child in the playroom ask, “Where did that boy get his beads for his necklace?” the patient to whom the child was referring proudly exclaimed, “This is not a necklace! I am not a girl! I wear these beads to show how brave I am!”

The bead program not only influences patients, but also touches the parents. As child life specialists, we recognize parents' loss of control in a hospital setting and the importance of empowering and keeping parents involved. The bead program gives some of that control back to parents since many of them become devoted advocates, making sure they understand what each bead represents, and that their child receives all the beads they have earned. According to a parent of a 9-month-old, “I collect and place the beads in the exact order of the events... My hope is when he gets old enough we can visually show him what he has been through, and he will have something tangible to pass down to his own children some day.”

The program naturally creates a legacy for each patient who participates. Bereaved parents have shared stories such as siblings who have never met their deceased brother or sister who are now provided with the opportunity to be introduced to them

through the beads that their sibling earned and left behind. Parents have shared stories of how seeing and holding their child's beads helps them remember their child's strength, which in turn provides them strength.

Being diagnosed with cancer and traveling the long journey of hospital stays and treatment is a large part of a survivor's legacy. It is something that will always be a part of them and it contributes to making them who they are as they grow up. Through the bead program, patients and families earn beads knowing that each bead represents one bead closer to the end of their experience with cancer. Some patients find encouragement in adding beads to their strands, and often the thought of earning a new bead can provide a bit of incentive to get through the hard and trying times. As one patient said as she looked at her completed strand, “These beads represent the strength I never knew I had.”

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## CLC Calendar

### MAY

- 1 Deadline for written requests to withdraw from Spring administration of the Child Life Professional Certification Exam
- 1 CLC Webinar – An Introduction to Evidence-Based Practice and Newly Developed Resources from CLC
- 24 Child Life Professional Certification Examination, Washington DC
- 24-27 CLC 30th Annual Conference on Professional Issues, Washington DC

### JUNE

- 8 Call for Abstracts opens for 2013 Annual Conference in Denver, CO
- 14 CLC Webinar – The CLC Call for Abstracts – Understanding the Guidelines and Strategies to Improve Your Abstract Submission (Free for CLC Members)
- 30 Deadline for recertifying by Professional Development Hours (PDHs)
- 30 Deadline for applications for the fall administration of the Child Life Professional Certification Exam for those educated outside the U.S. and Canada

### JULY

- 15 Deadline for Bulletin and Focus articles for Fall 2012 issue
- 18 CLC Webinar – Success Stories: Using Evidence-Based Practice to Enhance Child Life Practice
- 31 Call for Abstracts deadline for 2013 Annual Conference

## Thank you to CLC Volunteers!

CLC would like to thank all of our dedicated and generous volunteers for all the work and time they have put into the projects and tasks that the committees, task forces and workgroups complete for CLC! Our volunteers are what help us to continue to provide valuable resources and services to our members, health care professionals and the public! Thank you for all that you do!