CHILD LIFE COUNCIL
# Bulletin
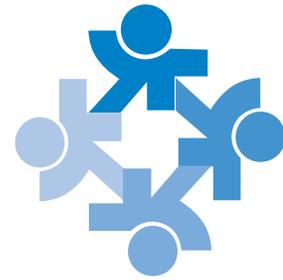
Child Life Council Heads West in 2008
CONNECTION • COMMITMENT • COLLABORATION

Child Life Council invites you to join us May 22-25, 2008 for our 26th Annual Conference on Professional Issues at the Sheraton San Diego Hotel & Marina.

Against the backdrop of spectacular San Diego Bay, Child Life Council will host an exciting conference program dedicated to building community, sharing ideas, and inspiring our members to achieve new heights in their professional development.

The Emma Plank Keynote address will be delivered by Sue Bratton, PhD, Director of the Center for Play Therapy and Associate Professor at The University of North Texas. Dr. Bratton is a respected lecturer, author, researcher, and clinician with extensive experience in individual and group play therapy, as well as in filial/family play therapy.

Harvey Karp, MD, a pediatrician and child development specialist who is also Assistant Professor of Pediatrics at UCLA, will speak at the Closing General Session on Sunday. Dr. Karp's presentation will center on the concept behind his bestselling book and DVD, *The Happiest Toddler on the Block, An Innovative Way to Reduce Struggles and Raise More Patient Toddlers*, one of the top parenting books in the United States.

Connect with an anticipated 1,000 child life specialists at these and many other educational opportunities during this year's eagerly-anticipated event.

A full conference program will be mailed in January 2008, and online registration will open at the same time. For more detailed information on the conference, and to make hotel reservations, please visit the Annual Conference section of the CLC Web site at www.childlife.org.

Special hotel room rates at the Sheraton San Diego Hotel & Marina are $149 per night (single/double) plus tax for CLC conference attendees. Please remember to make your room reservation early to ensure availability at the conference hotel.

EARLY REGISTRATION FEES
(Deadline of March 25, 2008)

Professionals:		Full-time Students and Retired Professionals:	
CLC Members	$270	CLC Members	$200
Non-Members	$370	Non-Members	$270

CHILD LIFE SALARY SURVEY: YOUR PARTICIPATION NEEDED

You asked for it! In response to popular demand, CLC has teamed up with the research experts at Association Research, Inc. to conduct a Child Life Salary Survey in 2008. A link to the secure, anonymous Web-based questionnaire will be sent via email from salarysurvey@childlife.org to all CLC members in January. Your participation is key to the success of this study, and the results will benefit the entire child life profession!

PRESIDENT'S PERSPECTIVE

Child Life: A Winning Team

*Barbara Gursky, MA, CCLS, Bristol-Myers Squibb Children's Hospital
at Robert Wood Johnson University Hospital, New Brunswick, NJ*

"It is amazing what you can accomplish if you don't care who gets the credit."

— Harry Truman

When I began my service on the CLC Executive Board as secretary in 2004, I wasn't quite sure what to expect; I had so many unanswered questions. How did the Board function as a group? How well did committees work together? How did the CLC staff work with the volunteer leaders? How did all of these groups function as a team on behalf of the membership? I quickly learned that the team spirit, intrinsic to most child life specialists, was pervasive throughout all of these groups. As a child life specialist for the past 18 years, I have learned that we are not a group of people motivated by extrinsic rewards or in need of the spotlight, but rather are professionals who thrive on teamwork, collaboration and relationship building. This has become even more apparent to me over the last four years on the Board, as I have had the pleasure of collaborating with other volunteer leaders on the CLC Board, committees and task forces, whose dedication and passion are inspiring.

I attended two meetings recently that furthered this awareness. The first was a meeting of the Conference Planning Committee for our 26th Annual Conference on Professional Issues; the meeting was held at CLC headquarters. Led by chair Kristie Opiola, the committee members, along with staff members Susan Krug and Danea Williamson, worked diligently and cohesively to ensure that the program for the 26th Annual Conference in San Diego would be a success. For me, it was an amazing experience to see what actually goes into planning the annual conference. I attended my first conference in 1990 in Washington DC, and have not missed one since. I've always enjoyed the educational component, the networking and the camaraderie at the meeting, but never fully appreciated what goes on "behind the scenes." From selecting keynote speakers, to ensuring workshops represent a diversity of topics and practice levels, to the timing and organization, it is the quality work of those involved individuals and the team spirit and collaboration that ensures its success.

I also recently participated in the 5th Annual Child Life Directors' Retreat held in Scottsdale, Arizona, organized by Chris Brown, Director, Child Life and Family-Centered Care, Dell Children's Medical Center in Austin Texas. The opportunity to collaborate with child life leaders across the country affirmed for me the power of collaboration. The directors eagerly and openly shared their expertise and best practices, new programs and lessons learned without any concern for "who gets the credit." I believe we all came away from the retreat energized and refreshed. The CLC Clinical Supervision Task Force also met in conjunction with the retreat; this is another group of people who have unselfishly given enormous time and energy to enhance child life specialist practice. Working under the leadership of Diane Rode, Child Life Director at the Mount Sinai Hospital in New York, the task force has made tremendous strides in the development of a clinical supervision model that will advance professional practice. The new chair of the task force, Gloria Mattera, Child Life Director at Bellevue Hospital Center in New York, has volunteered her time and talents to continue to guide the task force as they move forward.

It has been rewarding getting to know so many CLC members, and empowering to be a part of our professional future. I believe our field is filled with people devoted to enhancing our profession. Taking an active role in the Child Life Council is a great way to work with your colleagues across the globe, to share ideas and to work on issues vital to the development of our profession. There are opportunities for various levels of involvement for individuals across the child life spectrum. I encourage all of you to consider the role you can play in shaping the future of child life practice and becoming involved with our organization. For more information on getting involved, visit the *Volunteer Opportunities* section of the CLC Web site at http://www.childlife.org/About/Comittees.cfm. In the words of Walt Disney, "The way to get started is to quit talking and start doing."

Child Life Council
EXECUTIVE BOARD 2007-2008

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

COMING SOON...
VOTE ONLINE IN THE CLC ELECTIONS!

Thanks to the recent bylaws change, the CLC elections in 2008 will now take place online instead of at the Annual Conference. Online voting will make it easier than ever before for all CLC members to participate in the voting process. Keep an eye out for more information in March, when a link to the online voting form will be emailed to all CLC members.

New in 2008:
Child Life Beyond the Hospital

Child Life Council is pleased to announce the upcoming release of the book *Child Life Beyond the Hospital*, an exciting new addition to the CLC library that explores the world of child life in alternate settings. Whether you are preparing to embark on a new career outside of the hospital, or merely keeping abreast of current trends in the field, *Child Life Beyond the Hospital* will prove an interesting read that documents the ongoing expansion of the child life profession into new practice arenas.

Each chapter in *Child Life Beyond the Hospital* is authored by a child life specialist (or child life specialists) with experience working in a particular setting outside of the traditional children's hospital. Included in each section is a description of the specific setting, a rationale or theoretical foundation for the application of child life in that setting, and a discussion of the potential roles and responsibilities that child life specialists might have there. Just as each setting is unique, each chapter is unique as well, reflecting the author's distinct voice and practical approach. The authors reflect on specific considerations for practice, as well as the challenges and rewards presented to those who choose to work in a particular environment. Some chapters also include sample forms, contracts, brochures, and other materials.

Chapters include:
- Bereavement Programs
- Camp Programs
- Child Life in a Nonprofit Community Support Agency
- Children of Adults who are Hospitalized
- Consulting
- Dental Settings
- Early Childhood Settings
- Early Intervention
- Educational Consultant for Children with a Chronic Illness
- Funeral Homes
- Home Care and Hospice Settings
- Legal Systems
- Medical Model Child Advocacy Center
- Mental Health
- Nonprofits Providing Child Life Services
- Private Practice
- School Settings
- Trauma or Crisis Teams
- Web Content Development
- Wish-Granting Organizations
- Women's Center

Welcome to a new world of opportunity for child life specialists!

Format: Paperback
Available: Spring 2008
Editor: Melissa Hicks, MS, CCLS, LPC, RPT
Publisher: Child Life Council, Inc.
Language: English

CERTIFICATION CORNER

IMPORTANT UPDATES TO CERTIFICATION POLICIES AND FEES

The CLC Board recently approved the following policies and fees updates, which will take effect as of January 1, 2008

Late Maintenance Payments: Certified Child Life Specialists must pay their certification maintenance fees by January 31 of each of the first four years of their certification cycle. With an additional $25 late fee, CCLSs will be allowed a 60-day grace period (February 1 - March 31) to make their payments.

Lapsed Status: If a CCLS fails to make a maintenance payment by April 1, his or her status will change to "lapsed". Individuals with a lapsed status are not permitted to use the CCLS credential and will not be listed on the online CCLS directory.

Reinstatement Period: Child life specialists whose certification has lapsed may apply to have their certification returned to "Active" status within the calendar year immediately following the delinquent payment. Upon approval, individuals must pay a reinstatement fee of $50 in addition to their maintenance payment and the $25 late fee. If this payment is not made by the end of the year, the lapsed status is rendered final and the individual will be notified by certified mail that he or she is no longer a Certified Child Life Specialist. To regain the CCLS credential, the individual must re-establish eligibility for, and take and pass, the certification exam.

Recertification through PDHs after June 30
Deadline: The deadline to submit an application to recertify through PDHs is June 30 of the year in which certification expires. With the payment of an additional $50 late fee, CCLSs will now be permitted to submit PDH applications until November 1 of that year. Individuals applying after the June 30 deadline will also be required to submit all supporting documentation along with their applications.

IMPORTANT DATES

- Certification Maintenance Fees are due on January 31, 2008.
- The next certification exam will be given in conjunction with the 26th Annual Conference on Professional Issues in San Diego, CA on Thursday, May 22, 2008 at the Sheraton San Diego Hotel & Marina. The application deadline for this exam is March 31, 2008.
- Applications are due by March 15 of each year for the addition of a site for the fall exam administration. For more information on how to bring the examination to your city, visit the CLC Web site at:

  http://www.childlife.org/Certification/ The Examination/DeadlinesLocationsExamDates.cfm

FROM OUR PARTNERS

Child Life and Family-Centered Care: A 21st Century Perspective

Joanna Kaufmann, RN, MS, Information Specialist
Institute for Family-Centered Care

Editor's Note: Successful child life practice has always been characterized by good teamwork. Child life specialists share their skills and knowledge with colleagues of many stripes, and in this active collaboration everyone benefits, especially children and families.

Child Life Council also benefits from partnering with organizations and agencies whose missions are related to ours. In this occasional column, we are pleased to have CLC partners share news of their work and update our membership on trends and happenings that relate to our common interests.

Over the last decade, there has been a significant increase in the number of articles in the literature of health care regarding patient- and family-centered care. The focus of these has primarily been on the partnerships between patients, families, and providers at the clinical level. Far less attention has been paid to program and policy issues, and the effect that patient and family advisors and leaders have on health care quality and safety.

In March 2001, however, the Institute of Medicine's Committee on the Quality of Health Care in America published a landmark report calling for fundamental change and redesign of the American health care system. That report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, proposes performance expectations for the 21st century health care system, a set of 10 rules to guide patient-clinician relationships, and key steps to promote evidence-based practice and strengthen clinical information systems. The report provides specific direction for policymakers, health care leaders, clinicians, regulators, purchasers and others, and defines six aims: care should be safe, effective, *patient-centered*, timely, efficient and equitable.

PATIENT AND FAMILY-CENTERED CARE

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and providers. Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting.

WHAT ARE THE CORE CONCEPTS OF PATIENT- AND FAMILY-CENTERED CARE?

- **Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

- **Collaboration.** Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Hospitals, clinics and other health care agencies that make an explicit commitment to patient- and family-centered care develop policies, programs, and practices collaboratively with patients and families that support and encourage family presence and participation.

THE INSTITUTE FOR FAMILY-CENTERED CARE

The Institute for Family-Centered Care, a non-profit organization founded in 1992, has been a leader in advancing the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering relationships among patients, families, and health care professionals, the Institute facilitates patient- and family-centered change in all settings where individuals and families receive care and support. The Institute seeks to ensure that principles of patient- and family-centered care are reflected in all systems providing care and support to individuals and families, including health, education, mental health, and social services. The Institute serves as a central resource for policy makers, administrators, program planners, direct service providers, educators, design professionals, and patient and family leaders.

All Institute programs, publications, and collaborations support a profound change in the way health care is provided to individuals and their families in North America. The Institute envisions that in every encounter, health and human service professionals will seek to build on the strengths of patients and families, enhancing their confidence and competence. The new health care delivery system will recognize and encourage patient and family strengths, choice, and independence.

CHILD LIFE PROFESSIONALS IN THE NEW HEALTH CARE PARADIGM

In October 2006, the American Academy of Pediatrics (AAP) released an updated version of its Policy Statement on Child Life Services. In addition to endorsing its original policy statement and identifying child life programs and services as an important component of family-centered care, the AAP adopted a new section entitled *Child Life Services in a Changing Health Care Environment*. They cite studies demonstrating that children and parents who received care from child life specialists had significantly less emotional distress throughout the hospitalization, during procedures, the post-hospital period, and recovery, including recuperation from surgery,
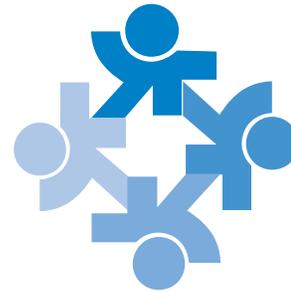
INTRODUCTION TO THE CHILD LIFE EVIDENCE-BASED PRACTICE STATEMENTS

The Child Life Council is very pleased to offer this statement of evidence-based practice on preparing children and adolescents for medical procedures. The CLC Executive Board commissioned the development of this statement, with the input of the Evidence Based Practice and Professional Resources Committees, in order to provide members with documented validation for best child life practice.

Child life specialists recognize that clinical care and decision-making must be grounded in research-based evidence. CLC has supported the review and analysis of outcome research that specifically addresses child life practices in order to give child life professionals the evidence they need to continually advance quality of practice and to communicate with others on the healthcare team about child life work.

Child Life Council will publish two more statements in 2008, and it is our hope that these will help and encourage members to contribute to the body of research necessary for professional growth and recognition in healthcare settings.

This statement is available in printer-friendly form on the CLC Web site. We encourage child life specialists to review the statement and consider, as individuals or teams, the implication for practice.

Editor's Note: *Readers of Focus are accustomed to seeing articles here presented in APA format. In the case of the Evidence-Based Practice Statements only, because of the nature of the material, the author has elected to use the* Uniform Requirements for Manuscripts Submitted to Biomedical Journals *to make for easier reading.*

Preparing Children and Adolescents for Medical Procedures

CHILD LIFE COUNCIL EVIDENCE-BASED PRACTICE STATEMENT

Completed for the Child Life Council in August 2007 by

Donna Koller, Ph.D, Academic and Clinical Specialist in Child Life, Hospital for Sick Children, Toronto, Ontario, Canada

Rebecca Mador and Wendy Lee, research assistants at the Hospital for Sick Children, are gratefully acknowledged for their contributions in the preparation of this statement.

PREAMBLE

The purpose of this statement is to outline the key components of effective psychological preparation and, by using the best empirical evidence currently available, to validate the methods employed by child life specialists.

This statement is based on an exhaustive search of the literature, which was conducted on i) PsycINFO, which records the literature from psychology and related disciplines such as medicine, psychiatry, nursing, sociology, and education; ii) MEDLINE, which focuses on biomedical literature; and, iii) CINAHL, the Cumulative Index to Nursing & Allied Health Literature, which covers literature relating to nursing and allied health professions. A variety of keywords and combinations such as "preparation"; "fear"; "anxiety", "pain"; "pediatrics" and "medical procedures" were used to conduct the search, which was completed in August 2006 with the assistance of a medical librarian. Searches revealed approximately 350 articles related to pediatric preparation; however, after the results were sorted to exclude repeats and non-empirical based literature, 40 articles remained. These articles were retrieved and evaluated based on the scoring of 2 independent raters using "The Quality of Study Rating Form"[1]. Those articles that received a rating of at least 60 out of 100 points were selected for inclusion in this statement. Any article that scored between 55 and 65 points was re-scored by a second rater to confirm inclusion or exclusion. Finally, 30 articles met the selection criteria. Only 3 of these selected studies specifically evaluated preparation performed by child life specialists[2-4].

Since evidence-based practice represents an integration of both clinical experience[1] and the best available research[5, 6], this statement was also reviewed by certified child life specialists across North America in order to ensure clinical applicability. In addition, evidence-based practice acknowledges patient preferences and needs when determining the most appropriate clinical applications for the child and family.

WHY PREPARE?

The primary goal of preparation is to reduce the fear and anxiety experienced by a child who is undergoing a medical procedure and to promote his or her long-term coping and adjustment to future health care challenges[7-10]. Heightened feelings of stress and anxiety, eating and sleeping disturbances, as well as separation fears are commonly found in children and adolescents undergoing even minor medical procedures[8, 10-12]. The long-term implications of a negative medical experience can be profound; post-traumatic stress, increased fears, and decreased cooperative behavior have been documented among pediatric patients who have not been effectively prepared for a medical experience[9, 13, 14]. Participation in a preparation program has been shown to reduce significantly the negative psychological sequelae experienced by children both immediately before and after the procedure and for up to a month later[9, 14-16]. In this

review, 29 of the 30 studies concluded that children who were prepared for surgery experienced fewer negative symptoms than did children in control groups who did not receive preparation[20].

HOW STUDIES EVALUATE THE EFFECTIVENESS OF PREPARATION

The majority of research on preparation is quantitative and experimental in design. These studies use anxiety or behavioral manifestation scales to assess the quality and degree of a child's coping. For example, less anxiety and fewer negative behaviors reflect increased coping. Of the 30 studies included in this statement, the most commonly used outcome measures were: a) The Observation Scale of Behavioral Distress revised (OSBD-r)[17], which records behavior over time from the 'anticipation-of-procedure' to the 'post-procedure' phase; b) The Manifest Upset Scale and Cooperation Scale[14], which are two five-point scales that rate the child's degree of negative emotional arousal and behavioral upset; c) The Post-Hospital Behavior Questionnaire[18], which asks parents to rank their child's behavior after discharge from the hospital; and d) the State-Trait Anxiety Inventory for Children (STAI-C)[19], which compares the child's dispositional anxiety with the anxiety he or she is currently experiencing.

APPROACHES TO PEDIATRIC PREPARATION

Although preparation programs are standard practice in many pediatric hospitals[14], the variability in the approaches and outcomes of these programs is substantial. The literature reveals that preparation programs have included role rehearsals with dolls[4, 20, 23-25], puppet shows[15, 23, 26], the teaching of coping and relaxation skills[27, 28], orientation tours of the operating room[20, 24], as well as educational videos[9, 29], books[16, 30], and pamphlets[25, 31]. Some programs focus exclusively on preparing the child[2, 9, 10, 22, 32-34] while other programs attempt to educate and support the parents[30, 35-37] and siblings as well[12]. Despite variation in approaches, the literature reveals three common elements that underlie effective preparation and result in improved psychosocial outcomes for children and adolescent patients.

KEY ELEMENTS OF EFFECTIVE PREPARATION FOR MEDICAL PROCEDURES

A child's ability to cope with a medical procedure and the quality and intensity of his or her reaction are influenced by many variables[10, 22]. Such variables include the child's age and developmental level, personality, ability to cope with new situations, prior health care experiences and previous encounters with medical professionals, as well as his or her diagnosis and the complexity/invasiveness of the upcoming procedure[3, 10, 22, 38]. Similarly, family variables such as the family's composition and level of parental anxiety can also influence a child's response[3, 38].

Regardless of the medical procedure for which a child is being prepared, the key elements of effective preparation are: (1) the provision of developmentally appropriate information; (2) the encouragement of emotional expression; and, (3) the formation of a trusting relationship with a health care professional[39, 40]. These three elements were proposed previously by Vernon et al. in 1965 following a review of the literature at the time[40]. Three decades later, in a review of 400 studies and a meta-analysis of a final sample of 22, O'Connor-Von[39] substantiated these three components as the essential elements of effective preparation for pediatric patients. These three elements were also evident in the articles reviewed here.

1. Provision of Information

Of the 30 articles reviewed in this statement, all described information dissemination as an integral part of the preparation program. Providing accurate medical information to children lessens negative behavior and promotes faster recovery post-operatively[9, 16, 21, 34] while also attenuating fear and anxiety[7-9, 26]. Although there are a variety of ways in which child life specialists can provide developmentally appropriate information to children; the emphasis should be on providing clear and accurate messages[14]. In addition, information about a medical procedure should be as specific as possible as this can lead to a greater reduction in anxiety than when children receive only standard or more generalized forms of information[7, 14, 28].

While it is evident that information is a necessary and important component of preparation, the methods should vary with the child's age and developmental level[10]. Information should include both what will happen during the upcoming medical procedure as well as *why* it will happen[41]. For example, Campbell et al.[41] found that providing children with the reasons for the medical procedure as well as the sequence of events significantly reduced their anxiety when compared with control groups who did not receive this information. In addition, explanations should include sensations that the child can expect to experience such as the sights, sounds, smells and feelings[10, 14]. Of the published studies that specifically reported providing procedural and sensory information to children in the experimental group, all reported that these children demonstrated less emotional distress than children in control groups[10, 14, 16].

As part of information sharing, coping techniques aimed at ameliorating fears and anxiety should be offered[21]. For example, Campbell et al.[41] found that when a preparation program included information regarding coping techniques, behavioral outcomes were more positive for children undergoing surgery. In another study, Peterson and Shigetomi[35] compared the effectiveness of providing children ages 2 to 10 years old with information only, coping techniques, filmed modeling or coping plus filmed modeling. Children who were provided with coping plus modeling techniques were more calm and cooperative than children in the other groups. In addition, coping techniques introduced to a child should vary depending on the procedure, the child's developmental level and his or her preferred coping style[2]. Effective coping techniques have been found to include visual and auditory distraction, tactile stimulation, counting and singing, and verbal interaction[2]. Six of the 30 studies were found to include information regarding coping as part of their preparation programs and all reported significant positive outcomes[2, 27, 28, 35, 37, 41].

2. Opportunities for Emotional Expression

During the course of preparation, it is essential that potential stressors are anticipated and misconceptions and fears are addressed[3, 42]. This requires the child life specialist to pay careful attention to a variety of cues such as facial expressions and other forms of non-verbal communication. Fegley[33] compared two groups of children, one that received standard information about a radiological procedure and another in which children were encouraged to ask questions and express feelings about the procedure. Findings indicated that children who asked questions and expressed concerns were less distressed and spent significantly less time seeking information during the procedure.

3. Establishing Trust with Pediatric Health Care Providers

Preparation programs can provide the context in which children can develop trusting relationships with their health care team[21]. Through the

provision of accurate information, the teaching of coping techniques, and the encouragement of emotional expression, the child life specialist is poised to establish a supportive and trusting relationship with the child[2]. In an evaluation of child life intervention in the emergency department, Stevenson et al.[2] noted that the child life specialist played an integral role in establishment of trust with the child. Key strategies for building rapport included asking the child questions about topics such as age, grade in school, pets, or the number of siblings. In another study, Wolfer and Visintainer[14] randomly assigned children to one of five experimental groups or a control group. The experimental groups consisted of combinations of home preparation with different types of in-hospital preparation which included supportive care. Supportive care was defined as the nurse making a special effort to establish a trusting and supportive relationship with the child and parent. Children and families who received any form of preparation and supportive care expressed significantly greater satisfaction with their hospital experience when compared with children and families in other groups.

RESEARCH GAPS AND CONFOUNDING ISSUES

Over the past 30 years, our knowledge of the substantive issues associated with effective preparation has improved. However, this review reveals several existing gaps and confounding issues. For example, critical questions remain regarding how best to prepare children of different developmental levels[39, 40]. Much of the literature focuses on the psychological preparation of preschool and early school age children. This is most likely because this group is more at risk for misunderstanding medical explanations. As such, less is known about the effectiveness of preparation with toddlers and adolescents.

A related developmental issue concerns the notion of timing. In only one study, the timing of the preparation program relative to the day of surgery was identified as a significant variable in that preparation was not uniformly effective for all children[20]. For example, only children who were 6 years or older and who received the preparation at least five days prior to surgery benefited from the intervention[20]. Preparation had a negative effect on young children with a history of previous hospitalization, suggesting that these children require specialized methods for preparation and alternate timing [21, 22].

Given that many pediatric facilities offer group preparation with two or more children at the same time, it is essential that this approach be properly evaluated. Only one study in this review addressed group preparation[43]. McGrath prepared children 3-12 years old for surgery in small groups and found that children who were prepared in groups experienced significantly less anxiety and more satisfaction with their surgical experience than children who were prepared individually. Currently, limited research on group preparation inhibits the development of evidence-based practice in this area.

Some studies offer poor descriptions of the programs under evaluation and do not adequately control for key variables such as age, gender, prior hospital experience, and personality variables such as anxiety proneness[39]. As clinical experiences have shown, standard preparation programs are not beneficial for all children[21] particularly in the case of children who exhibit heightened levels of anxiety during and after preparation for medical procedures. Unfortunately, minimal research has investigated the impact of personality traits and associated coping styles on the effectiveness of preparation. Future research should begin to ascertain which children and adolescents are least likely to benefit from standard forms of preparation. These types of research initiatives

can begin to address alternate forms of psychosocial support for this population leading to enhanced levels of evidence-based practice.

A myriad of approaches to preparation exists and are used by a variety of health care professionals across pediatric settings. In some settings, children are prepared by child life specialists, while in others, nurses may be involved. For this reason, methods of preparation can vary tremendously depending on the experience, philosophy and educational training of the professional. Since there are only a few studies that directly address preparation by child life specialists, it is imperative that research evolves to include impartial evaluations of various approaches across disciplines.

Finally, current research methods in this area are predominantly quantitative and few studies include participants from various cultural backgrounds. The processes involved in preparation are complex; consisting of several known and possibly unknown variables. Additional research from within a qualitative paradigm can more adequately explore complex processes associated with pediatric preparation. Accessing the views and perspectives of children, adolescents, and their parents could assist in supporting a family-centered care model which can better acknowledge cultural differences.

SUMMARY

An extensive review of the literature revealed that most children prepared for medical procedures experience significantly lower levels of fear and anxiety as compared to children who are not prepared. Preparation also promotes long term coping and adjustment to future medical challenges. Key elements of effective preparation include the provision of clear and accurate information about the medical procedure and potential coping strategies, the encouragement of emotional expression and the establishment of trust with a health care professional. Despite a greater understanding of how to prepare children for medical procedures, research gaps and confounding issues exist. In particular, studies must begin to address which methods of preparation are most effective for specific developmental levels, personality traits and cultural backgrounds. Studies should also explore how best to encourage emotional expression from children during the course of preparation. Since a variety of approaches are being used by different disciplines, research on pediatric preparation must evaluate which forms constitute the best outcomes for children and families. These studies should include both quantitative and qualitative methodologies in order to provide a comprehensive examination of current practices which can inform child life clinical practice and policy development across pediatric health care settings.

Approved by the Child Life Council Executive Board November 2007

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TABLE 1. FINAL SELECTION OF STUDIES INCLUDED IN THIS REVIEW

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Death Awareness and the Child with a Life-Threatening Illness: A Sociocultural Analysis

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The clinical practice of child life is grounded within a framework of developmental and family theories. A look at the theoretical bases of the profession shows that lenses such as Erikson's psychosocial theory and Piaget's cognitive theory have been essential in understanding the developmental and learning needs of children experiencing illness and hospitalization. Beyond these, however, is a full scope of developmental theories that can be applied to developmental phenomena, both to help inform child life clinical practice and to suggest further research to support the developing profession.

The development of cognitive processes within children is often explained through universal, age defined stages from the simple to complex. This stage theory describes a gradual evolution of the operations an individual attains when progressing from concrete to abstract thinking. Through this Piagetian lens, the concept of death, which involves both concrete and abstract components, can be recognized as a prototype of this progression (Cotton & Range, 1990). Infants and toddlers experience death as a loss, separation, or abandonment. Preschoolers view death as temporary and reversible, and believe that those who die will come back. The 6- to 9-year-old begins to see death as final, but because it only happens to old people or by accident; children at this age don't recognize their own mortality.

The 9- to 12- year-old is more aware of the finality of death, that death is irreversible and universal. The adolescent develops a full adult understanding of death as inevitable, universal, and irreversible. Thus, the cognitive model for healthy, typically developing children is established; predictions for possible reactions can be made, and interventions for explaining and helping them cope with losses can be formed as they progress through their lives and encounter loss.

But does this model adequately explain how concepts of death develop in children who have direct experience with a life threatening illness or condition? The research indicates that children in these circumstances may understand some of the more abstract concepts of death at an earlier age than their healthy peers. This paper looks at this developmental phenomenon through a sociocultural theory of development. Connections to child life practice will be integrated both to explain children's

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concepts of death and to highlight the importance of child life specialists assessing their practice on a broader conceptual level.

THE COMPONENTS OF DEATH

Death has been defined in various physical and abstract ways, from the simple *cessation of bodily functions* to the more complex *spiritual journey to the afterlife*. A person's understanding of death is directly influenced by culture, religion and experience, and is often viewed in light of coping and bereavement issues that result. The concept of death can be viewed as comprised of several relatively distinct subconcepts rather than being a single, one-dimensional concept. Corr and Corr (1996) outline these subconcepts as universality, irreversibility, nonfunctionality and causality. *Universality* refers to the understanding that all living things must eventually die and encompasses the inevitable, unpredictable, and inclusive characteristics of death. *Irreversibility* is the awareness that once the physical body dies, it cannot be made alive again. *Nonfunctionality* (also called cessation) is the knowledge that once a living thing dies, all of the typical life-defining capabilities of the living physical body cease. And, *causality* is the ability to describe the abstract and generalized causes of death, an abstract and realistic understanding of the external and internal events that might cause an individual's death.

Lazar and Torney-Purta (1991) conducted a short-term longitudinal study in which a sample of typically developing first and second graders were interviewed to assess their understanding of the subconcepts of death, including irreversibility, cessation, causality, and inevitability. They found that children understood irreversibility and inevitability first, and that their mastery of other concepts was contingent on having developed at least one of these initial subconcepts. These researchers hypothesized that children would begin to understand death through animals and then make generalizations towards humans. However, the findings suggested that children understood irreversibility, causality, and inevitability better when they had the opportunity to relate the concepts to human death rather than animal death. The subconcept of cessation was the only one that seemed to be understood better in relation to animals. The researchers suggest that children

typically have more experience actually seeing dead animals, and so referenced this experience when answering questions. Few children actually see dead people, and so are less likely to grasp the idea of cessation or nonfunctionality in humans. These findings suggest that children's experience with the realities and possibilities of death can enhance their understanding of these complex concepts.

DEATH AWARENESS AND THE CHILD WITH ILLNESS

Few researchers have directly studied the ill child's awareness of death concepts, and their results are mixed. A few solid studies have suggested that children with a life-threatening illness will understand the concepts of death at an earlier age or at a faster rate than those of their healthy peers. In their review of the literature, O'Halloran and Altmaier (1996) cite a study by Clunies-Ross and Landsdown (1988) in which age-matched children 4 to 9 years old, with and without leukemia, were interviewed to determine their awareness of death. Results indicated that the children with leukemia showed a greater understanding of the concept of irreversibility and finality than did the children in the healthy group. Also within this review of the literature a study by Nitschke, Humphrey, Sexauer, Wunder, and Jay (1982) found that children and young adults from 6 to 20 years old were all aware of the irreversibility of their impending death. The researchers propose that all children have an awareness of the concepts of death, but defenses restrict discussion until death is imminent.

Jay, Green, Johnson, Cladwell, and Nitschike (1987) investigated differences in concepts of death between healthy children and children with cancer. They found no evidence suggesting that children with cancer had an advanced understanding of the concept of death. Specifically, 3- to 6- year-old children with cancer were less likely to acknowledge the possibility of their own personal death than 3- to 6- year-old healthy children. The researchers note that this finding may not imply understanding, as the ill children may have been more reluctant to discuss their thoughts about death and the possible implications with the researcher who used confrontive questioning. While this study contradicts the Clunies-Ross and Landsdown (1988) study, this finding does provide implications for future research that uses approaches sensitive to the sociocultural

environment of the child and family experiencing a life-threatening illness. It also suggests a need to have researchers who are sensitive to the developmental needs of children. Child life specialists, for example, are skilled in talking to children at their level and in assessing children using developmentally appropriate strategies. Some of the defined methodological problems in obtaining data from children would be addressed if child life specialists worked on research teams and developed appropriate questions and rapport to achieve comprehensive results.

An additional finding of Jay et al. (1987) was that for 3- to 6-year-old children with cancer, the experience of having lost a loved one was significantly correlated with the presence of the concepts of universality and irrevocability for this age group, concepts they could apply both to their own and to others' possible death. This finding reinforces the position that actual experience within the child's sociocultural environment enhances his or her understanding of the concepts and possibly enhances the development of abstract cognitive processes.

THE CULTURE OF ILLNESS

The daily activities of children dealing with a life-threatening illness can be quite different than those of their healthy peers. Although children with an illness still develop within their culture, family and community, they are additionally thrust into the medical setting in which their care takes place. They have numerous interactions with medical professionals and other patients in a setting that may expose them to the experience of mortality earlier than healthy children. The healthy child may experience loss through the death of a pet or older relative during the course of childhood. These losses support the gradual emergence of understanding death. The child with a life-threatening illness, however, is exposed to far more in-depth instances of death, both directly and vicariously. Even when children are medically stable themselves, their experience with loss may include loss of personal control and actual physical deaths of peers. The child's awareness of his or her own potential death may be relayed through observation of others, and possibly by direct discussion of the issue. Like children growing up in war zones or amid extreme community violence, the child with a life-threatening illness is simply exposed to more actual instances of death.

A Sociocultural Analysis

Lev Vygotsky's sociocultural theory of human development is based on the general tenet that human development occurs within and is influenced by the individual's culture. As the child grows she has many occasions to engage in specific activities and social interactions, through which she acquires the values, beliefs, and problem-solving strategies of her culture. According to Vygotsky, this process serves to shape both the child's evolving cognitive skills and personality characteristics, resulting in a unique developmental course that is not universal across cultures. Central to this theory is the role of mediation, both human and symbolic, in the development of a child's higher mental process. Vygotsky's theory holds that each psychological function appears twice in development, initially in the form of actual interaction between people, and then as an inner internalized form of this function. Scaffolding, the process by which an adult or more competent member of the society facilitates the learning process by guiding and challenging the child to reach concepts and skills just beyond his current mastery, is essential to this human mediating process. With effective guidance, children can achieve comprehension of abstract concepts that would not typically evolve until a later age. Symbolic mediating encompasses language, role playing, and interaction with materials. The symbolic and human mediating agents work in conjunction to provide the child with the psychological tools necessary to grasp the next level of understanding (Shaffer, 2005; Thomas, 2005; Kozulin, Gindis, Ageyev, and Miller, 2003).

A Vygotskian theorist would then explain the developmental phenomenon of early death awareness as a result of mediation within the child's environment. Specifically, a sociocultural theorist would maintain that the abstract concepts of death were within the young child's zone of proximal development (ZPD), which includes the range of developmental tasks that are just outside the child's current level of mastery. As with other tasks within the ZPD, a child will reach an understanding of death only through guidance and scaffolding. In this view, the young child with life-threatening illness cannot attain this cognitive skill independently. As children develop in their specific culture, both within and outside of the hospital, they need assistance in reaching this level of understanding.

In theory, when supportive adults answer children's questions and address fears, this helps children move to the next cognitive level to process such information.

Children cannot simply absorb the information from the environment and consider it attained. From a sociocultural theoretical perspective, such scaffolding is best facilitated by those with knowledge of the child's culture, primarily parents; but a child's development can also be influenced by peers and non-family adults. For children with a life-threatening illness, the child life specialist can have an active role in this scaffolding process by providing opportunities for therapeutic play as well as interventions that directly and indirectly address concepts of illness and health, including concepts of death.

In the child's evolving understanding of death, scaffolding may take place independent of the parents' knowledge, through the child's interaction with hospitalized peers in similar circumstances – children come to understand death by what they see around them. Child life specialists may work with parents who try to shield their child from the truth of his or her impending death, or who try to steer discussion away from the topic. Perhaps these parents miss the fact that their child is already engaged in activities and interactions that are mediating a more advanced understanding of personal death. It is within this context that learning is mediated and the child's frame of reference is broadened to prepare for the cognitive capacities to understand abstract components of death.

The sociocultural theorist also would place emphasis on the power of language to further promote and explain complex concepts and to aid the mediation process. The younger child with a life threatening illness may engage in imaginative play that includes role playing of doctors, patients and other members of the hospital environment. Within this play encounter language can serve as a symbolic mediator to develop the potential for higher thought. The language can be that of the child herself as she engages in self-talk while playing or it can be the words of another child or adult. It is this language that transmits information from the child's environment, connecting with the ZPD to become internalized thought. Child life specialists often engage and observe hospitalized children in complex forms of dramatic medical play. These play situations can

serve to scaffold the individual child's attainment of complex concepts; they also can serve as a natural laboratory in which to study, empirically, the interplay of experience, mediation and cognitive development.

Within this theory one would expect to find some of the inconsistencies noted in the research. Each child develops in a unique way, and the absence of mediating factors can be an additional explanation as to such differences. While the hospital may become a universal culture to ill children, the influences of their own specific culture, experiences, and backgrounds also influence how information is mediated from the environment to the child. The sociocultural perspective honors such differences between individuals and offers guidance for clinical practice in which collaborative (adult to child or child to child) learning can take place. Within this framework, it's clear that children can attain higher psychological functions and achieve internalization of the relevant concepts.

Research and Clinical Implications

Clearly additional research is needed to establish and understand the differences between ill and healthy children in how they develop an understanding of death. The overall dearth and inconsistent nature of existing research suggest some problems with methodology inherent in the nature of research with subjects directly experiencing ongoing, acute crisis. Research conducted within the guidelines of the sociocultural perspective can improve both the approach and the collection of data during this tenuous time. Naturalistic studies can provide insight into the factors that influences how children develop concepts of death; research of this type might include studies in which children with illnesses are observed in typical their environments such as hospital, school, and home; during typical activities, particularly play; and in routine interactions with family, peers, and staff. Further studies that compare children coping with illness to those who live in environments where death is prevalent (war zones, violent communities) would also strengthen the sociocultural explanations of children's awareness of death.

There are also myriad clinical implications that can be derived from solid research studies. The foremost is the development of hospital and hospice protocols to help parents

and clinicians understand how children conceptualize death. With such protocols, adults will have the tools necessary to scaffold a child's understanding and to moderate anxiety regarding their possible death. The topic is one that is understandably emotional as physicians seek to cure and parents seek to comfort the ill child. Perhaps in this sense the capacity for open dialogue regarding such concepts lies within the adult's ZPD. Child life specialists can be leaders in developing interventions based on theory-guided research that can help the adults attain the necessary skills, competence, and permission to acknowledge and guide children's awareness during these difficult times. This type of empowerment can have lasting effects on surviving family members by minimizing the risk of emotional trauma from witnessing their child's struggles and offering opportunities for control.

CONCLUSION

The sociocultural theory of human development can explain why children with life-threatening illness may acquire an understanding of death at an earlier age than their healthy peers. This theoretical perspective emphasizes individual development based on environmental and cultural influences, and focuses on the processes involved when information is transmitted from the environment to the individual. This theory proposes a unique course of development for each child, honoring the diversity of the individual in a way that stage theories do not. This framework also suggests research and clinical goals, particularly for those working with children and families experiencing life-threatening illnesses.

Although sociocultural theory sheds an enlightening perspective on children's understanding of death, this is not the only or even "best" theoretical lens through which to view this phenomenon. The developmental arena is rich with comprehensive theories and perspectives that can provide complementary or challenging lenses of interpretation. This paper is an example of how a researcher can apply a theory to phenomena and shows the subsequent avenues to which this analysis may lead for clinical practice and further research. More and more child life specialists recognize the importance of investigating theories and applying them to their own experiences with children and families. This type of conceptual reflection can help scaffold to the next level of attaining individual and professional-wide competencies. Finally, through engaging in this process child life specialists may also develop the knowledge and skills to construct unique theories to address issues that surface in daily clinical practice that are not fully explained by recognized theorists.

Approved by the Child Life Council Executive Board November 2007

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About the Views Expressed in *Focus*

It is the expressed intention of *Focus* to provide a venue for professional sharing on clinical issues, programs and interventions. The views presented in any article are those of the author. All submissions are reviewed for content, relevance and accuracy prior to publication.

REVIEW BOARD

Milestones

NEW PROGRAM: Priyanka Child Life Services was inaugurated at the Manipal Hospital in Bangalore, India on October 26, 2007. The project was developed in memory of Priyanka Bhakta, who battled leukemia at the Children's Hospital and Clinics in Minneapolis, Minnesota. During her frequent hospital stays there, she was made comfortable by the benefits and support of the child life program. The Priyanka Foundation was established to support programs in India that would provide chronically ill children with similar opportunities for emotional healing and support while in the hospital.

RETIREMENT: After 27 years as a child life specialist at Rainbow Babies and Children's Hospital in Cleveland, Ohio, Mary Barkey, CCLS, retired this past September. She and the late Barbara Stephens, RN, pioneered "Comfort Measures", the comfort positioning techniques used in pediatric settings internationally. We thank her for her vision, expertise and dedication to the child life profession.

Child Life Council Annual Report to the Membership

Dear CLC Member,

It has been an exciting year for Child Life Council. We have taken the opportunity to celebrate the accomplishments and important milestones of the past 25 years, while planning and building the capacity for continued growth and success. Here are just a few of the highlights from the past year that the CLC staff and Executive Board would like to share with you.

We thank each of you for your continued energy and dedication. We look forward to an exciting year of growth in 2008!

Sincerely,
Susan Krug, CMP, CAE
Executive Director

ANNUAL REPORT

LEADERSHIP

Development of New CLC Strategic Plan: Following a planning session with a special task force in early 2007, the CLC Executive Board approved an updated strategic plan for CLC.

CLC Elections: During the elections at the 25th Annual Conference in June, members approved all proposed changes to CLC bylaws, which will transform the way that CLC elections are conducted in the future. Look for updates in the coming months on how you will be able to review the slate of Board candidates and cast your vote online in 2008!

MEMBERSHIP

In September of 2007 CLC surpassed 3,700 members, exceeding the goal of obtaining 3,500 members in 2007! Thanks to our loyal members who renewed in 2007 and encouraged their colleagues to join.

In March and April of 2007, CLC conducted a director's survey to solicit important information about the needs child life leaders see in their work, and to identify corporations that support child life on a national or global level.

Staff members also developed and communicated new special membership categories, including Retired and Transitional memberships. For more information, refer to the *Membership* section of the CLC Web site.

Look for a new CLC Salary Survey Questionnaire to be sent via email to all members in the first quarter of 2008.

EDUCATION & CONFERENCE

The CLC 25th Annual Conference on Professional Issues was the showpiece of our 25th anniversary year. Major highlights included:

- Achievement of record-breaking numbers, with a total of 1,038 attendees, 46 exhibitors, and an increase of more than 90% in sponsorships from 2006

- Debut of the new and convenient online conference registration system

- Special 25th anniversary events and gifts, including a private dessert reception and fireworks viewing at Epcot, complimentary Disney theme park passes, and numerous other giveaways throughout the four-day event

- The premiere of the History of Child Life DVD, which will be available to members in February 2008. One complimentary copy will be sent to each child life program listed in our directory as well as to one contact at each child life academic program listed on our Web site.

RESOURCES & RESEARCH

Evidence-Based Practice Statements: CLC sponsored the development of three evidence-based clinical practice statements. The first statement, "Preparing Children and Adolescents for Medical Procedures," appears in the *Focus* section of this issue, and is available on the CLC Web site. Look for the next two statements to be published in subsequent issues of the *Bulletin.*

Clinical Supervision Task Force: Commissioned in early 2006, the group has identified relevant supervision models from other professions, developed best practice models, and is currently in the process of creating a Child Life Clinical Supervision Model.

Professional Resources and Evidence-Based Practice Committees: The Professional

Annual Report

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Resources Committee has been evaluating and reorganizing the information available in the *Resource Library* section of the CLC Web site, and will soon be adding new resources. Meanwhile, the EBP Committee continues in its efforts to assist members in accessing research, and is currently working to expand the "Annotated Bibliography" and "Accessing Research" sections of the *Resource Library*.

Child Life Beyond the Hospital, an exciting new addition to the CLC catalog that has been in the works for the past two years, will be available through the CLC Bookstore in the first quarter of 2008.

COMMUNICATIONS

CLC Web Site Gets a Makeover. A fresh new design and updates to the functionality of the Child Life Council Web site will continue to improve your online experiences with CLC. One of the priorities in the new design was to show child life in action, and thanks to the generous contributions of our members, each section of the Web site features different pictures from child life programs all over the world!

What services are offered through CLC Online?

- **Membership Management Tools** – Apply for membership, pay annual membership dues, and make changes to your member record with a few clicks of the mouse!
- **Search Function** – Using the search box, you can quickly locate anything on the CLC Web site, from the Certification Candidate Manual to the CLS Salary Survey.

- **CLC Member Directory** – Members can access contact information for other members of Child Life Council.
- **Certification Management Tools** – Request a Course Work Review, apply to take the exam, track your PDHs – all online. And when you pass, everyone will be able to find you in the brand new CCLS Directory!
- **Annual Conference** – Submit session or poster abstracts or register for the conference online.
- **Career Center** – Positions are posted in "real time", employers have numerous reporting/results options and job seekers can create a searchable profile that can be viewed by prospective employers.
- ***Bulletin* Archive** – This members-only feature allows you to download issues of the Bulletin from as far back as 2004.
- **CLC Bookstore** – Purchase Child Life Council publications and merchandise online.
- **Support CLC** – Make a donation online, with immediate receipt for tax purposes.
- *Coming Soon…* **Vote online in the CLC Elections!**

Bulletin and *Focus* articles encouraged continued clinical development of child life specialists. A special extended 25th Anniversary Summer issue of the *Bulletin* highlighted the milestones, challenges, and innovations of child life specialists over the past 25 years, and also looked to the future of the profession.

CLC Notes, a new bi-monthly email communication blast to the membership, was introduced in October to provide members with quick reminders of the

latest CLC news and resource updates.

PARTNERSHIPS & OUTREACH

Connections: CLC is actively developing partnerships with key organizations to help further our mission and goals.   We have teamed up with following organizations on a variety of projects:

- **The Walt Disney Company / Disney Worldwide Outreach** expanded their annual "Season of Compassion" campaign, delivering care packages to more than 400 leaders of child life programs in the U.S.
- **The Institute for Family-Centered Care** has entered into a partnership agreement with CLC; be sure to read the article they contributed to the *Bulletin*, on page 4 of this issue!
- **The Pin Man** is currently producing merchandise that features the CLC logo, available to CLC members through a special link on www.positivepins.com. CLC receives a small percentage of the sales, and members now have access to oft-requested items that CLC does not have the internal resources to provide.
- **Buffalo Games** worked with CLC to facilitate the free distribution of a series of award-winning games to child life programs.
- The skin care company **Biotherm** provided $25,000 worth of products to be distributed to attendees at the Annual Conference. The **National Association of Children's Hospitals and Related Institutions (NACHRI), Zero to Three, and Give Kids the World** also supported conference programming.

Fundraising/Development: The $25 for 25 Years Fundraising Drive helped CLC support a conference scholarship program.

CLC Welcomes a Child Life Specialist to the HQ Staff Team!

We are pleased to announce that Melissa Boyd, MS, CCLS has joined the CLC staff team in Rockville, Maryland as the new Resource Development Coordinator.   Melissa has worked as a child life specialist in the Day Surgery Department at Children's Hospital Central California and in the Renal Center at Children's Hospital Orange County, California.

Melissa has been a member of the Child Life Council for five years, serving as Chair-Elect for the Partnerships Committee, and as a member on the Professional Resources Committee.   She has volunteered at several hospitals and camps, including the Orange County Foundation for Oncology Children and Families (OCFOCF), where she enjoyed being a camp counselor for over ten years.

As Resource Development Coordinator, Melissa will be responsible for supporting our professional members by monitoring list serve discussions, researching external resources, developing new and updating existing CLC resources and promoting the child life profession.   Please let Melissa know how she may support your resource needs at mboyd@childlife.org.

From Our Partners

than did children and families who were not seen by child life specialists within the same hospital setting. The AAP recommends that pediatricians actively incorporate the core concepts of family-centered care into all aspects of their professional practice, and advocates for the inclusion of child life services across a broad variety of settings.

What does this changing health care environment mean for child life specialists? The present environment demands that child life practices transform to meet the needs of a changing system, while simultaneously promoting optimal development and minimizing the adverse effects of children's experiences in a hospital setting.

Using "Old Knowledge" in New Ways

The new health care paradigm demands fundamental changes and a redesign of the American health system to close the quality gap, as outlined in the Institute of Medicine's *Crossing the Quality Chasm: A New Health System for the 21st Century.* In pediatric care, child life specialists have many opportunities to help build the bridge to high quality patient- and family-centered care.

Child life specialists have always assisted health care team members to communicate with patients and families based on the child's developmental and individual needs, as well as the needs of the family, by establishing therapeutic relationships with children and parents that support family involvement in each child's *individualized* care.

In the new design child life specialists will *share* their role of communication facilitator with patients and their families, teaching families how to develop mutually beneficial partnerships with health care professionals. The ability to negotiate effectively within the health care system is an important skill not only to learn but also to communicate to others. Child life specialists, rather than acting on behalf of families, strengthen families to act on their own behalf.

New Horizons

Child life specialists are in a unique position to shape health care policies and programs by helping to integrate the concepts of patient- and family-centered care into program and institutional visions. There are multiple ways that patients and family members can serve as advisors—as members of child or family advisory councils, committees, and task forces dealing with operational issues in hospitals, clinics, and office-based practices; as participants in quality improvement initiatives; as educators of staff and professionals in training; and as leaders or co-leaders of peer support. Wherever child life specialists support families in this kind of advocacy, they help redefine the role of the family in pediatric care.

Child Life Specialists as Educators

Child life specialists routinely assist in the education of students and professional staff in medical, nursing, and other fields on psychosocially sound and developmentally appropriate care. In this teaching role child life specialists can encourage families to participate in "Families as Faculty" programs and can help *parents* educate *health care providers* about family-centered care. Child life staff, in collaboration with family members and nursing staff, can create patient/family education materials that teach patients and families how to be involved in safety practices and how to recognize errors pertaining to medication, hand hygiene, correct patient identification, and more.

Further, child life specialists are in an ideal position to help implement systems to facilitate team communication with families, regardless of the language they speak or reading level. Child life specialists address the education and involvement needs of their patients, and provide assistance and ideas to parents in order to help them help their children. All these efforts improve the "health literacy" of parents and families, enabling them to be well-informed consumers and to make appropriate decisions for their children.

Ensuring Patient-and Family-Centered Care

Successful practice of patient and family-centered care is based upon four core concepts: dignity and respect; information sharing; participation, and collaboration (Institute for Family Centered Care, 2005).

According to Pat Sodomka, Senior Vice President for Patient- and Family-Centered Care at the Medical College of Georgia Health System, "The single most important guideline for involving families and patients in any advisory role is to believe that their participation is essential to the design and delivery of optimum care and services. Without sustained patient participation in all aspects of policy and program development and evaluation, we as health care providers fail to respond to the real needs and concerns of those our system is intended to serve." The child life profession has a long history of striving for high quality in pediatric psychosocial care. The Institute for Family-Centered Care welcomes the support and partnership of child life specialists in promoting pediatric services that meet the demands of the new health care paradigm and promote these core concepts of patient- and family-centered care.

References

American Academy of Pediatrics, Committee on Hospital Care (2006). Child Life Services. *Pediatrics*, 118, 1757-1763.

American Academy of Pediatrics, Committee on Hospital Care (2003). Family-Centered Care and the Pediatrician's Role. *Pediatrics*, 112 (3), 691-696.

Child Life Council

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CLC Calendar

JANUARY 2008

    Online registration opens for Annual Conference on Professional Issues in San Diego, California

15   Deadline for *Bulletin* and *Focus* articles for Spring 08 issue

31   Annual maintenance payments due for Child Life Professional Certification, and Child Life Professional Certification Exam applications due for those educated outside of the US or Canada

FEBRUARY

8   Annual Certifying Committee Meeting, San Diego, CA

MARCH

1-31   Child Life Month!

15   Deadline to request additional Child Life Professional Certification Exam sites for the November 2008 exam

25   Early deadline for lowest CLC Annual Conference registration fee

31   Child Life Professional Certification Exam applications due for those educated in the US or Canada

APRIL

30   CLC Annual Conference registration deadline

MAY

1   Deadline for written requests to withdraw from the May Child Life Professional Certification Exam

22   Child Life Professional Certification Examination, San Diego, CA

22-25   CLC 26th Annual Conference on Professional Issues, San Diego, CA

30   Deadline for recertifying by Professional Development Hours (PDHs)

CLC ENDORSED CONFERENCES

For more information on these and other upcoming CLC Endorsed Conferences, please visit the Events Calendar, located in the *Related Meetings & Events* section of the CLC Web site at www.childlife.org.

**Phoenix Area Child Life Networking Group
3rd Annual Child Life Conference:**
Treating the Whole Child
Conference Date: March 7, 2008
Location: Scottsdale Healthcare Shea,
Scottsdale, AZ
The conference is open to child life specialists and students. Registration deadline is Wednesday, February 27, 2008.
Contact: Jessica Bryson,
jessica.bryson@chw.edu
or 602-406-3639

"The Many Faces of Child Life" Conference
Sponsored by Baptist Medical Center South
Conference Dates: March 13-14, 2008
Location: Montgomery, Alabama
The conference is open to child life specialists and students. Registration deadline is Wednesday, February 27, 2008.
Contact: Heather Talley, 334-286-3010 or
hntalley@baptistfirst.org