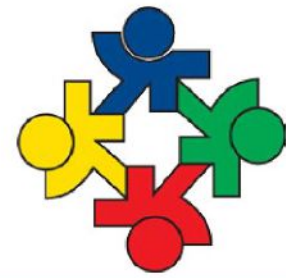


CHILD LIFE COUNCIL Bulletin



VOLUME 34 • NUMBER 3

SUMMER 2016

Humbly Deserving: Amy Kennedy Receives 2016 Mary Barkey Clinical Excellence Award

Jessika Boles, PhD, CCLS

Monroe Carell Jr. Children's Hospital at Vanderbilt, Nashville, TN

There are times in life when even an experienced child life specialist needs their own child life specialist to call on. For me, that child life specialist was Amy Kennedy, CCLS. As long as I have known her, Amy has been a voice of support, of reason, and of hope, whether mentoring me in my first professional child life role, or walking me through one of the most difficult experiences of my life. No matter the situation, she is supportive, patient, encouraging, and pushes me to test my own limits and continue growing each and every day.

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ALPHABET 200



F is for Fairness: EXPLORING DIVERSITY AND DISCRIMINATION IN THE CHILD LIFE PROFESSION

Nicole Rosburg, MS, CCLS

Texas Children's Hospital, Pearland, TX

The words *fairness* and *equality* bring to mind many things. For some it may be how people are treated in the workplace, for others it may be matters of race or religious beliefs, and for some it may relate to gender or sexuality. But what do these terms mean in reference to the child life profession? What do child life specialists need to know in order to provide fair and equal patient care, and is this even truly possible? What things need to be considered to increase fair and equitable treatment for all child life professionals in the workplace?

Merriam-Webster defines fair as "marked by impartiality and honesty; free from self-interest, prejudice, or favoritism" (Fair, n.d., Full Definition 6a) or "conforming with the established

rules" (Fair, n.d., Full Definition 6b(1)). Further, equal is defined as "like in quality, nature, or status" (Equal, n.d., Full Definition 1b) or "like for each member of a group, class, or society" (Equal, n.d., Full Definition 1c). On the surface, these appear to be straightforward concepts. But stop and consider: who creates the "established rules" called out in the definition of fair? And while fairness in the workplace might be accomplished through the division of labor or with a specific schedule matrix, equality is more difficult to achieve. The definition of equal calls out a likeness for each member of a group, but how are these groups determined? Are all child life professionals one group, or are the groups segregated by gender, race, or other variables? And if there is segregation on any level, how can true equality be achieved?

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Past President's Reflection



Reflecting on an Eventful Year

Sheri Mosely, MS, CCLS

Child life specialists know how to collaborate, make progress toward goals, and celebrate successes, both in daily practice and as a profession. As CLC president for the past year, I've seen this many times and in many forms as members of this organization have come together to address challenges, work toward common goals, and—to cap off a year of hard work—join together at our Annual Conference on Professional issues to learn, network, and celebrate child life.

This year's conference in Orlando was an exciting, enriching, and eventful weekend, filled with fun, collegiality, and historical milestones for this association. The biggest news to share from conference came in the Opening Session: the reveal of our new association logo that will accompany our new name. This new logo resulted from many months of design work, which took into account member opinions, gathered from the most comprehensive cross-section of member demographics that could be reasonably achieved. What became evident through all of the analysis undertaken was that the concepts of professionalism, credibility, and compassion needed to be represented in the logo—along with the color blue. We're very proud and excited to finally share the result. Although we won't be officially using the logo until later this year, the final version can be viewed on the [CLC website](#). We believe that this new logo will go a long way as we prepare for a marketing initiative that will result in a more prominent public display of our work and will position us well as we move toward our goal of professional credibility.

Aside from the announcement of our new name and the logo reveal, this last year has been filled with many other accomplishments and much movement forward toward reaching the goals outlined in our strategic plan. Many thanks to our committees and task forces, whose dedicated members have done so much to continue helping this organization grow its potential for success. In fact, there has been so much forward movement among these groups that we have realigned some of their efforts under new committee structures to capitalize on the strengths of each group in their respective work.

The new committee structure that we've rolled out this year will create opportunities for growth by building upon work already underway. As a result, efforts related to research, professional development, leadership, governance, and student initiatives should be stronger than ever before. You'll be hearing more from these groups as they move forward.

In addition to all of the activity this past year, I'd be remiss if I didn't thank and recognize the members of the board of directors, who have also dedicated their time, expertise, and thoughtful approach to the many decisions undertaken to help steer CLC toward our goals. Our progress would also not have been possible without the hardworking and talented members of the CLC staff, who have been available and accommodating through every step to ensure that resources and support were available when needed.

But, it's really you, each individual member of CLC, that give us reason to strengthen this organization, for it is what you do to support children and families that sets our stage for growth as a profession. I will end here with a thank you to each and every one of you. I am both humbled and inspired by everything I've experienced as president. It's been a true privilege to serve in this role over the past year, and I am confident that your next leader, Kristin Maier, will continue propelling us forward to meet our common goals. ✨

Child Life Council *Bulletin/Focus*

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from the Executive Editor



Privilege, Power, and Justice: Lessons Learned from a Seventh Grade Scuffle

Jessika Boles, PhD, CCLS

Justice is one of those virtues that can only exist in the presence of its converse: injustice. Injustices can be overt or covert, large or small, moral or legal, and individual or institutional; however, they are always dangerous because they signal that there is work to be done. When I was in seventh grade, I personally delivered a swift punch of justice to Sara Pickering's face. To this day, it is the only physical altercation that I have been in, and I still resolve that it was in the name

of social justice.

With ten minutes left in gym class that day, my best friend Sara strolled into the locker room and sat down on the bench across from me. Sara's family was well-to-do, drove nice cars, lived in a big house in the middle of town, and she always had the trendiest Doc Martens and JNCO pants. My dad drove an old rusted truck, I wore Doc Marten knock-offs, and our house was perfectly average. My seventh grade self was embarrassingly convinced that I was poor, when I had no idea what poverty really was, but I knew that my parents worked very hard and I respected that.

Somewhere in the midst of our typical gossip, my eyes caught the glare of a quarter on the floor. My hand shot out to pick it up, and with excitement, I told Sara that now I had enough change to buy a soda on my way to class. Rather than matching my exuberance, she fired back, with a smirk, "Oh boy! I bet that's more than your parents make in a week!"

Somehow her words struck a carnal rage that I have never felt again, one that I only now have begun to make sense of. So, I did the only thing that felt logical. I punched her one time, a right hook that audibly slammed into her left cheek. She was silent with shock for a moment, and then the tears came...followed soon after by sniffles that echoed throughout the now eerily silent locker room. Our friendship was over, but my point had been made. I came out victorious in my first battle against social-class discrimination.

As I have aged, and matured, I have learned that my petty adolescent concerns about justice were nominal compared to the inequities that are faced by persons who identify as anything other than white, middle-class, heterosexual, and male. I must admit, with great humility, that I do not know what it is like to be turned away, ignored, disrespected, or negatively stereotyped because of my race, gender, sexuality, socio-economic status, or level of ability. As someone who identifies with and is identified as a white, heterosexual, middle-class female, it is my responsibility to become cognizant, even personally and professionally vigilant, of the ways in which these congenital qualities and identity choices have shaped the level of access and type of opportunities I have had as a child, a student, an adult, an employee, and a child life specialist. Although I cannot change these traits and I cannot give them back, I can refute their power to marginalize those who do not occupy the same subject positions as myself. I can try not to be unintentionally oppressive or ignorantly complacent with the injustices that occur around me every day.

Child life professionals on the front lines of clinical care, academic preparation, program administration, and community or global outreach are tasked with negotiating access and acceptance for children and families facing stressful health care or life experiences. We are often the voice of advocacy for a patient, family members, a student, a colleague, or even an identified cultural need. I can remember a patient who was labeled as "whiny" because he did not want to sleep in a hospital bed. In reality, he had never slept in a bed before his hospitalization, having spent his childhood and adolescent years sleeping on two suitcases pushed together in a corner. I also recall a patient who was almost transferred to another facility for being "difficult"; she and her mother had been homeless the majority of her life. She did what she needed to survive, with little regard for how to negotiate complex health care interactions with what many would call "tact." There are always these cases, these individuals who come from backgrounds and contexts that are far bigger than what the hospital is willing or equipped to address. In those moments, we are the voices for justice and equity in the health care environment. We accept families where they are, and we push for access to health care and beyond.

There are, however, issues of access within our own culture and field as child life specialists. As an organization, individual programs and institutions, academic centers, and community organizations, we are constantly crafting

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CEO Shares...



Looking Forward: Growth and New Initiatives

James Gandorf, CAE

It's been an exciting year of growth for our organization on many fronts. Fiscally, we are making gains; membership is increasing; new areas for growth are being identified; and excitement is skyrocketing. Although skyrocketing excitement isn't measurable, I can report on our finances, membership, and some of our new initiatives. The intangible parts of the organization are harder to quantify, but they are apparent to me as I work with CLC leadership, staff, committee volunteers, and members each day.

The financial health of the organization is paramount, as it allows us to support you, our members, in your roles with children and families. Fortunately, CLC is in good financial standing. The association closed out 2015 very strong financially; for the year our net assets increased from \$1,374,564 to \$1,462,171. The money we take in is used to benefit child life specialists by providing services and programs - our nonprofit corporation serves members, not shareholders! Our newest member benefit is Online Education, which you can find using the color navigation buttons on our homepage. [Take a look!](#) Improving your member experience is one of three strategic goals, so you can also look forward to a completely updated, easy to use website in the very near future.

Membership is another area that indicates our organizational strength. Our end-of-year membership numbers for 2015 were very stable and showed sustainable growth. Membership was up 2.6%; we currently have 5,459 members, including students and associate members. We are extremely fortunate to have a very active membership, with about 260 members volunteering on various committees, task forces, and work groups. The contribution of these individuals to our strength as an organization cannot be overstated.

Moving into the future, one of the factors that I believe will help propel and sustain the growth we're experiencing is the current rebranding effort. As you know, part of our rebranding will include clear messaging directed toward specific groups to help them fully understand child life and the impact that you have every day. The most visible part of this rebranding comes in the form of our [new logo](#), which was recently unveiled and will be in official use later this year. The next step in the process will be the debut this summer of the certification logo, which will be a sub-brand of the Association of Child Life Professionals (ACLP) logo and will be used by the ACLP Professional Certification Program in their work. Another exciting milestone will take place later this year, when the association's new website is unveiled, sporting the new colors, design, graphics, and messaging. The final phase of the rebranding work will come during Child Life Month next year, when the new name and logo will appear on all of the organization's letterhead and communication materials, and we will concentrate on delivering our messaging to our external audiences, including parents and hospital decision makers.

But our future as an organization is not all about our image and messaging; it is highly dependent upon growth and adaptation to the new health care environment. With our future in mind, one of many exciting new initiatives that I'd like to highlight here is the upcoming Academic & Clinical Preparation Summit. The goal of the summit is to bring together child life professionals leading academic programs, as well as child life professionals running clinical internship sites. A grant from a generous funder will enable us to bring 60 attendees together in Detroit the first weekend in August to participate in large group sessions and smaller breakout sessions. The summit is being planned by an advisory group with members from all

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Child Life Council

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Sometimes, It Is the Littlest Things: A Story of Black Hair Care and Cultural Competence

Teresa Schoell, MA, CCLS

Rochester Regional Health Child Life Services – Rochester General, Rochester, NY

About a year after Rochester General Hospital hired me to start a one-person child life program, I received an invitation to participate in a seven-week workshop on innovation in cultural competence. With this topic so near and dear to my heart as part of a multi-racial family, I leapt at the chance to participate.

For seven weeks, I spent my Friday mornings joining a dozen of my colleagues as we discussed the reality of cultural competence and some common misconceptions. Like many in the class, I began the workshop expecting more of the same training I'd received in years past — a didactic memorization of ten common traits and issues for each cultural subgroup within our community. To my delight, the teacher offered an entirely new approach, with a focus on self-reflection. Each week introduced a new layer of complexity, with week two's work on identifying our motivations building upon week one's work on recognizing our reactions. By the end of week three, between the classes and the practice assignments, we had a strong handle on recognizing when we experienced an emotional reaction to a situation or difference, pausing our instinctive response, and analyzing our motivations that lead to our reactions.

The next weeks saw us building skill in multi-perspective thought processes, and addressing bias within ourselves and our reactions. Many aspects of this new approach felt familiar to me from my

graduate studies in diversity and inclusion. I found the opportunity to join with my colleagues to practice skills in self-reflection, and building cultural competence through changing our own thoughts as much as our actions, especially in the health care setting, to be valuable beyond words. My participation in this workshop also had the happy side effect of landing me an invitation to serve on our hospital's Cultural Competence Committee.

After my first year serving on the committee, I began to feel overwhelmed, and I became disheartened by what I perceived as a lack of progress. Most of our projects were so big, so daunting, that we struggled to gain momentum. A few projects stalled out for lack of financial resources, while others faded from a lack of human resources. Many of my fellow committee members felt the same. Then, one Tuesday morning, everything changed. Halley, a nurse from our inpatient psychiatric unit, asked the committee for help.

As a prerequisite to discharge, our psychiatric unit requires patients to demonstrate basic daily self-care skills, known as ADL's (Activities of Daily Living). Halley expressed concern about a perceived disparity of care — many of her Black patients struggled to meet this demand, hampered by the fact that they did not have the appropriate tools available to them — such as hair oil and a wide-tooth comb. Some nurses on the unit would chart that their patient looked “unkempt” or “refused to wash his hair for the third day in a row,” and these documented “failings” became evidence of the patient's lack of readiness for discharge. This was a perfect example of what we had worked on in class, with personal perspectives and experience limiting the ability to recognize another's need.

Please let me take a moment, for those who may not have familiarity with the unique needs of Black hair. I received a crash course in Black hair care when I adopted my son; he's Black, my husband and I are White. My adoption agency provided tons of education, classes, and book recommendations, as well as hands-on workshops with Black hair care experts. My journey in learning to properly care for his beautiful tight curls began before he was even born.

Child life professionals can find an array of great resources to support cultural competence and diversity in their practice by visiting the [Cultural Competence](#) section of the Child Life Council's Resource Library.

Here are some basics — Black hair exists in a wonderful array of textures and curliness. The best frequency for washing depends on where an individual's hair falls on that spectrum, usually once every three days to two weeks. This has to do with the tightness of the curls, how far down the curl the natural oils of the scalp must travel, and the natural oils produced by the scalp. Washing too frequently causes the hair to become brittle, break, and fall off. For example, my son has very tight curls and dry hair. We wash his hair once every week to a week and a half (barring sandbox or glitter art projects). When he wore his hair short as a toddler, we put oil on it every

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I Can Choose My Own Words: An Argument Against Person-First Language

Katherine Krog, MEd

Child Life Intern, Le Bonheur Children's Hospital, Memphis, TN

I am disabled, and I don't use person-first language. I will admit, the first time I heard of person-first language, I thought it sounded amazing. Its proponents claim that it recognizes personhood and shifts the focus of attention to a person's abilities instead of his disability, thus distinguishing the person from the disability (Blaska, n.d.; Notbohm, 2005; What is people first language?, n.d.). In place of "the disabled person," person first language would use "the person with a disability," indicating that an individual's personhood is more important than his or her disability (Blaska, n.d.). Since so many people are unfamiliar with disabilities in general, having standardized language norms seems like a nice groundwork for beginning conversations. In the child life profession, we are called to advocate for appropriate communication regarding disabilities and illnesses, and person-first language may often seem like an ideal system of speech that can be easily explained and disseminated amongst health care professionals. However, there are actually many flaws with the use of person-first language, especially when such use is standardized and mandated.

First, person-first language is formulaic, providing a set of strict yet simplistic rules of speech for speakers who are unsure of how to approach the topic of disabilities. Far from focusing on individual differences, formulaic speech creates the expectation that everyone should fit into the same rigid mold. Additionally, person-first language creates difficulties when the attention of the speaker is drawn so much to their choice of words that they become anxious or fearful about offending the person to or about whom they are speaking. Conversations in which people insist on using person-first language—even when the phrasing is awkward—sound more like script recitations than actual conversations. The focus is not on personhood and individual strengths, but rather on the language used and the effort to avoid offense. Of course, we should never be purposefully rude or cruel in our words, but formulas for speech are not the answer. Instead, we need to become comfortable with giving accurate medical descriptions when appropriate or asking for clarification of a person's preferred disability language or terminology when such preferences are not immediately clear. This is especially important because not all disabilities fit into the person-first formula. For instance, describing an amputee or a blind person without using the words "amputee" or "blind" leads to awkward or inaccurate phrasing such as "the person with an amputation" or "the person with a visual impairment." An amputation is a procedure. An individual who has undergone this procedure is not currently living "with a medical procedure." Completely sightless individuals may view "visual impairment" as inaccurate since it does not describe the full extent of their disability.

Second, person-first language ignores positive aspects of

disabilities and denies disabled persons the right to incorporate disabilities into their personal identities. Often, person-first language advocates will stress to able-bodied individuals that they would not like others to describe them according to their flaws (Notbohm, 2005; Snow, 2016), but a disability is not a bad habit, a character flaw, or an entirely negative attribute, and person-first language only serves to strengthen this misconception (Jernigan, 2009; Sinclair, 1999). When I say, "I am an amputee," and "I am a CP kid," I'm not just stating the medical realities that most of my right leg is missing or that I suffered a brain injury as a newborn. I'm stating part of my identity and referencing a set of experiences and skills that people without these disabilities do not understand. I type and fasten buttons differently than most people. I am adept at using crutches

and prostheses and at doing various activities using these devices. I maintain balance differently than most people. Of course, each person has a different experience with disability, and the use of language in describing identity thus becomes a subjective decision. Therefore, it is important for people to ask for preferred language rather than assuming a single formula for speaking to different people; this allows individuals to describe themselves in terms of the strengths that others may not immediately recognize. I would be thrilled if more people would simply say, "What words do you use to describe your disability?" or "Do you have any preferences for how your disability is referenced?" or even simply "Would you mind telling me more about that? I'd love to get to know you better."

Although there are disabled people who prefer person-first language (Epp, 2000), we as a community are not its main advocates. Rather, the main advocates of person-first languages are groups that work with disabled persons, while disabled persons themselves are too often left out of conversations about person-first language and how to approach the topic of disability. For an example, look no further than the conflict between two advocacy organizations, Autism Speaks and the Autistic Self Advocacy Network (ASAN) (ASAN et al., 2014; Brown, 2011). Autism Speaks, by its very title, purports to speak for autistic individuals, and the organization is a strong advocate of person-first language. ASAN, however, argues that Autism Speaks has ignored the voices of actual autistic individuals and has instead granted parents, caregivers, educators, and others the right to speak for them. To combat this perceived silencing, ASAN advocates for the use of identity-first language and the recognition that autism is an essential part of an autistic individual's identity and experience. ASAN is not alone. The National Federation of the Blind officially rejected person-first language in 2009 (Jernigan, 2009). The Deaf¹ reject the notion of deafness as negative and identify themselves as a linguistic subculture (Burch, 2001; Shapiro, 1993, as cited in

In my own life, I have been told many times that the language I use in speaking about my own disabilities is incorrect, and for a long time, I allowed myself to believe that I truly had been identifying myself incorrectly.

1 This term refers to a large number of deaf activists who prefer the term The Deaf (Burch, 2001).

Johnstone, 2004). In my own life, I have been told many times that the language I use in speaking about my own disabilities is incorrect, and for a long time, I allowed myself to believe that I truly had been identifying myself incorrectly. My disabilities, however, are part of who I am. Attempting to define myself according to a formula for speech did nothing to change who I am, but allowing myself the freedom to define my identity in my own words has enabled me to be more comfortable in my own skin.

Of course, abolishing a formulaic model of speaking still leaves a gap that must be filled. It is possible to advocate for respectful speech without enforcing a formula. Therefore, I propose the following guidelines for discussing disabilities as child life specialists:

- Be respectful – Respect should be considered a mindset that guides our speech and behavior rather than a specific set of words or phrases. Instead of training ourselves to “say the right thing,” we should train ourselves to recognize both common humanity and individuality in everyone we meet. Having the proper mindset will allow us to understand others better and communicate better, regardless of the specific words we use.
- Be accurate – When describing someone’s disability, we should be as accurate as possible. Many times, words or phrases are disrespectful because they are not true. Calling a child “a Down’s” is not wrong to say because it doesn’t follow a specific formula of speaking. It is wrong because it is completely inaccurate. “Down’s” is a word that refers to the condition, not to the person. On the other hand, “amputee” is a word that refers to an individual who is missing one or more limbs. Therefore, “amputee” is an accurate word to use when referring to an individual.
- Avoid slang – Not all language is appropriate for all situations. Flynn and Ricca (2000) found that medical jargon confused and intimidated children. For this reason, we often avoid words like “stick” and “IV,” opting instead for simpler terms with which children are familiar. Just like jargon, disability slang is unfamiliar to many children and is therefore probably inappropriate for most child life settings and situations. “CP kid” and “CF-ers” are examples of slang. They may be commonly used by individuals with these conditions, but the use of acronyms and other slang will probably confuse many children, especially in reference to a new diagnosis.
- Ask! – When in doubt, ask disabled individuals what language they prefer. Remember, what people call themselves may not be what they want you to call them (Umstead, 2012). It is also important to note that individual’s preferences can change over time (Cook, 2001; Kalekin-Fishman, 2001).

Proponents of person-first language may truly believe that they are fostering effective communication within and about the disability community, but instead, they are participating in a longstanding historical tradition of sweeping disability under the rug and ignoring the voices and identities of the disabled. Instead of advocating for formulaic speech, we should be advocating for respect of individual identities and preferences. Recognizing an individual’s personhood as their primary characteristic means allowing them to speak for themselves. ✨

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Milestones

After a 40-year career as a child life specialist, **Sharon McLeod, CCLS, CTRS**, has retired as the senior clinical director of the child life department at Cincinnati Children’s Hospital Medical Center. Sharon began her career in 1976 at Swedish American Hospital in Rockford, IL, then worked as director of child life services at Vanderbilt Children’s Hospital in Nashville, TN. In 1992, she joined the team at Cincinnati Children’s Hospital, where she has spent the last 24 years growing the department in size and scope to become one of the model programs worldwide.

In addition to her clinical and administrative work, Sharon has been an active contributor to the success of the Child Life Council, serving on the board as president, secretary, treasurer, and leading numerous committees and task forces. She was awarded CLC’s highest honor, the Distinguished Service Award, in 2009, recognizing her many valuable contributions to the organization and the profession.

In retirement, Sharon and her partner, Dea, plan to relocate to North Carolina, where the next chapter of their lives will continue. We wish Sharon a happy retirement.

“You Must Be Joel – I’m Jerry”

Joel Maier, CCLS

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My career started on the 8th floor family center of Mott Children's Hospital in Ann Arbor, Michigan at a “meet and greet” for new practicum students. The only information I had was the name of my supervisor – Jeri. I remember thinking that this was nice because my godmother's name is Jeri, so this was something I could use to start a conversation. As I sat there nervously waiting to meet her, my eyes anxiously scanned the room. Was it the lady drinking coffee, the woman picking out a pastry, or maybe that one sitting down? “Yeah, she looks like a Jeri,” I thought. The education supervisor asked everyone to sit down for introductions and, as I sat back in my seat, I looked to my left and found an older gentleman sitting next to me. Somehow I'd been so busy playing “spot my supervisor” that I hadn't noticed him sit down. Then to my surprise, he turned towards me and said, “You must be Joel – I'm Jerry.” What? A guy? As a new student, the one thing I knew for sure about child life was that there weren't many guys, the “token gender.” But here was Jerry, a guy and my supervisor. So far in my education, I had already encountered situations that reinforced the fact that I was a male in a predominantly female profession. For instance, when I attended conferences it wasn't uncommon to find a “Women's” sign taped over all the men's restroom doors! Since this initial encounter with Jerry, I have worked as a child life specialist for six years and have become aware of other aspects of the job that are notable for

those of us who are male.

I learned a lot from Jerry during my practicum: how and when to enter a room, how to engage different age groups, and how to build meaningful relationships — all of which Jerry did exceptionally well. Jerry also pointed out how being male might, in some instances, alter how I would interact with patients. The one point he highlighted for me was that I should never be alone in a room with a patient while the door is closed. This was very insightful, as research shows there are general stereotypes of men working in female-predominant professions. For instance, a study looking at the entry of men into female-concentrated professions noted the experience of one participant, who shared that he had faced “difficulties constructed by discourses around male ‘perverts’ working with children” (Lupton, 2006, p. 113). An earlier study mentions these stereotypes and how they “cause men in [female predominant] professions to alter their work behavior to guard against sexual abuse charges, particularly in those specialties requiring intimate contact with women and children” (Williams, 1992, pp. 261-262). Learning this early on in my profession was very helpful. For example, during my internship I was in a room with a patient with a traumatic brain injury who started blurting out sexual comments such as “want to kiss my butt?” and “just kiss it...just kiss it.” Thankfully, a nurse outside the room

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Global Perspectives

Collaboration for a Culture of Change

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T rue collaboration involves meaningful dialogue and problem solving efforts with engaged health care professionals, patients, and families. This is the strategy initiated by Child Life Romania in a unique, inter-institutional collaboration between political, social, educational, and health care organizations in the ninth largest city in Romania. Child Life Romania started as a pilot program in Oradea, Romania, six years ago through collaboration between five institutions - the Bihor County Health Care System, Emanuel University of Oradea, the City Hall of Oradea, Emanuel Hospice Foundation (all located in Oradea, Romania), and Cook Children's Medical Center (Texas). Now services are available in the general inpatient department, the emergency room, and the oncology unit of

the Municipal Children's Hospital, as well as a thriving program with Romania's first Certified Child Life Specialist at Emanuel Hospice Foundation. What the team has found to be the greatest challenge for acceptance and access for the child life profession has not been something physical that is seen with the eyes or felt with the same senses that we are reaching out to through medical play or coping techniques. The greatest challenge has been changing mindsets, not physical surroundings. This includes an organizational mentality in the socialized health care setting, as well as individual mentalities within the medical and general community. Change is at the core of this mentality and many view change as something negative, whereas from a big picture perspective, change brings more effective and efficient services, as well as research-validated best practices.

This is the very foundation of the child life principles that we hold to and practice each day: what is best for the child—the patients who have fear written all over their faces and frustration flowing out of their hearts from being overwhelmed by sickness, trauma, or disease. The patient/specialist ratios are 50:1 for the general floor and hematology/oncology unit. In hospice the ratio improves slightly to 40:1. Our focus has been to meet the children with the highest trauma levels, but the sheer number of children without access to

Diversity, Disability, and Inclusion in Child Life

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Diversity: the state of being composed of people who are different or unique.

Inclusion: a strategy to leverage diversity. In order to leverage diversity, an environment must be created where people feel supported, listened to, and able to do their personal best. Diversity always exists in social systems. Inclusion, on the other hand, must be created (United Way Worldwide, 2011).

In 2012, the Child Life Council's Diversity Task Force composed the Child Life Diversity Statement, which acknowledges that "diversity enriches the field of child life and enhances creativity and professional growth within the child life community" (Child Life Council, 2015, Diversity Statement, para. 2). In pursuance of such an inclusive culture, the statement recognizes the need to attract and promote the hiring of "qualified persons of diverse backgrounds whose unique life experiences and ways of thinking foster a culture of inclusion and diverse perspective" (Child Life Council, 2015, Diversity Statement, para. 2). As the child life profession has expanded and grown, it has been observed that the diversity of those working in the role has also increased. People in minority demographic groups should continue to be recruited and welcomed into the workforce; however another population that is underrepresented and often

overlooked in the child life field is people with physical disabilities.

One of the more common threads on the CLC Forum are students' difficulties in obtaining an internship and interns questioning how to get their foot in the door to a child life career. I was in this position ten years ago as a graduate student. In addition to the general concerns addressed on the forum, I had the issue of being physically challenged: I walk with forearm crutches, have a minor speech impediment, and require hearing aids. The worst thing about these impairments is that people see them before they see me and often make judgments about me based solely on my disabilities. This can make for a lasting first impression. Thankfully, a few inclusive child life specialists identified my abilities and uniqueness and afforded me the opportunity to explore and pursue my passion through a practicum, an internship, and eventually a job. Unfortunately, in my life and in my career path, I have also encountered others who were quick to make assumptions and set limitations for me based on fears and stereotypes of people with disabilities. Additionally, I have met and communicated with other people who are physically challenged who have faced similar issues at child life conferences, as volunteers and students, and when communicating on the CLC Forum. Collectively, those of us who have physical challenges have discovered a few misconceptions and attitudinal barriers that appear most prevalent in impeding people with physical disabilities in gaining access to the field and preventing their full inclusion in the child life profession.

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child life services is daunting. It is a completely different atmosphere in Romania where the typical day for a child life specialist includes being available to cover all of the services offered for the patients and their families, in addition to continually advocating for child life services to everyone they come in contact with – doctors, nurses, administrators, and social workers.

In Oradea, the major body of water that is found at the center of the city is called Crisul Repede, or "quick river." We have to drive by it daily to get from Emanuel Hospice Foundation to the Municipal Children's Hospital. This "quick river" brings to mind a proverb that says: "A river cuts through a rock not because of its power but its persistence." As a team of child life specialists we are dedicated to meet the challenge of changing the mentality through persistence and perseverance. The health care system in Romania does not officially recognize child life services as part of their infrastructure and it is a daily challenge to prove the principles we stand for and practice.

We have experienced this challenge every day at work in the hospital as new professionals in the Romanian socialized health care system. There are not many professionals that have to lug a suitcase or duffel bag to and from work each day. Our child life specialists rely on a central resource room at Emanuel University of Oradea that stores all of the supplies to be used in the Municipal hospital on the opposite side of the city. Most of these supplies have been donated by individuals and organizations in America, as well as purchased from grant money received from within Romania. Since child life services are offered through a non-profit and not part of the health care system infrastructure, the supplies and resources

cannot be stored on the hospital grounds. Our child life specialists provide services through a yearly contract as hospital volunteers with no benefits, not even a salary. Their salary is paid by our foundation, Child Life Romania. Current laws protect the volunteer by allowing them to use their volunteer experience on their curriculum vitae as work experience. Psychosocial services are seen as a luxury, laws are not implemented for the rights of pediatric patients, and educational organizations with child life training and education are non-existent due to the past priorities of the government and current weaknesses within the infrastructure. This environment that inhibits change is a side effect of the past that ruled Romania for over forty years.

These last six years our daily presence in the hospital, our patience in sharing knowledge over and over with the children, their families, medical professionals, students, politicians and the general public, as well as a passion for this new field has started to allow our small stream of psychosocial care become a river of change. This river of change has started to wear down the mentality of "It can't be done!" to ambiguous acceptance. It is a recurring process of proving that these child life services make a difference in the life of a traumatized or hospitalized child. The value of child life services has been demonstrated on four different levels: first, with direct experience with the patient and their families; second, formal education and training with medical students and professionals, as well as social work students; third, advocacy within the health care system from administrators to security guards; and fourth, lobbying with local and national government for legislative changes and implementation

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Being LGBT: How Sexual Orientation and Gender Identity Affect Access to Health Care and Employment

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The majority of health care professionals, including child life specialists, receive little, if any, training in regards to providing services to lesbian, gay, bisexual and transgender (LGBT) patients and families (Kane-Lee & Bayer, 2012). However, child life professionals will almost certainly interact with patients and/or families who identify as LGBT. Statistics show that people who identify as LGBT live in every county in the United States (The Joint Commission, 2011) and in most, if not all, countries of the world (U.S. Department of State, 2012). Additionally, there are more than 220,000 children being raised in same sex households in the United States (Gates, 2013).

All people have a sexual orientation and gender identity, whether they identify as heterosexual, cisgender, or LGBT. Most people have heard the initials LGBT and know that they stand for lesbian, gay, bisexual, and transgender. Table 1 lists other terms used when discussing sexual orientation and gender identity. It is important to note, however, that these terms mean different things to different people, depending on race, socioeconomic status, age, and geographic location. While these terms may help people place an identity on others, there are many people who prefer not to be labeled and do not use any of these terms to identify their sexual orientation or gender identity. When someone shares information about their sexual orientation or gender identity, it is preferable to ask them which term(s) they prefer when referring to their gender and/or sexuality. For example, if a patient is identified on the census as a female but presents as a male in regards to dress, facial hair, and/or preferred name, the child life specialist can ask the patient which pronoun staff should use and then communicate this information to the appropriate staff. When referring to a person's sexual orientation or gender identity, it is often preferred that a person state that they "identify as [specific sexual orientation/gender identity]" rather than saying that they "are [specific sexual orientation/gender identity]." For example, one should say "He identifies as gay" rather than "He is gay."

For those who identify as LGBT, health care needs may be jeopardized by anti-LGBT laws that exist in some states and countries that make it difficult for people who identify as LGBT to be open with their health care providers about their sexual orientation or gender identity.¹ Prior to the 2015 United States Supreme Court decision legalizing same-sex marriage, there was a patchwork of legal recognition and protection in regard to family structure. Legally married same-sex couples did not have the same rights when traveling to states that did not recognize same-sex marriage, including the right to make health care decisions for one's spouse and children. This required families to provide paperwork to prove their legal right to make decisions for each other and dependent children. Some of this uncertainty was eliminated within the United States by the Supreme Court decision, but some legal rights continue to be state dependent, including adoption, housing, and employment discrimination. There is currently legislation that has been passed or is pending in many states that would allow for the refusal of public services, including

restaurants and hotels, to people who identify as LGBT, and there have been state laws recently enacted that would require people who identify as transgender to use bathrooms and other facilities that are inconsistent with their gender identity.¹ Since the legalization of same-sex marriage, there have been many public accounts of lesbian, gay and bisexual people who have gotten married to a same-sex partner and then been fired from their jobs (Human Rights Campaign, n.d.-b). There are still many countries around the world that do not recognize same-sex marriage and have laws that make being LGBT illegal. Publicly identifying as LGBT in these countries can get people put in jail or even put to death. People who identify as LGBT and live in or travel to these countries need to be aware of these laws and travelers must carry legal documentation that proves their status as a family and authorization to consent to medical treatment for their spouse or children (U.S. Department of State, 2016).

The role of a child life professional is to provide services that lead to a successful health care experience for all patients and families. Child life professionals, regardless of their work location or setting, benefit from receiving up-to-date information about providing services to diverse populations, including how to best provide comprehensive family-centered care to patients and caregivers who identify as LGBT. Child life specialists are in a unique position to advocate for the needs of the patients and families that they serve as child life specialists are often seen by patients and families as safe, trusted members of the health care team. Child life specialists can advocate for a health care environment that is safe and accepting of all patients, families, and staff, regardless of their sexual orientation or gender identity.

PROVIDING HEALTH CARE SERVICES TO PATIENTS WHO IDENTIFY AS LGBT

Adolescence is a time of physical, social, and cognitive changes. Erik Erikson (1968) described this developmental stage as identity vs. role confusion. During this developmental stage, adolescents seek to discover who they are and who they want to become as they get older, and begin to explore many aspects of their life, including religion, race/ethnicity, and sexual orientation and gender identity. While many people begin to identify with their sexual orientation during adolescence, young people may begin to identify as a gender that is different than their gender at birth in earlier years, during the stages that Erikson (1968) described as autonomy vs. shame and doubt, initiative vs. guilt, and/or industry vs. inferiority. Identifying one's gender usually begins at the age of 2 or 3 and is usually established by the age of 4. Not all children who are gender nonconforming identify as transgender. A child who identifies as transgender is "consistent, insistent, and persistent" about their gender identity being different than the gender they were assigned at birth (Human Rights Campaign, n.d.-c). This is different than a child who insists that they are a favorite super hero or princess in that it persists over a long period of time, in all or most settings and situations. These

¹ Details related to specific laws and legislation are current as of the writing of this article.

children will repeatedly say that they feel like they were born in the wrong body and that they only feel comfortable when allowed to dress and present themselves as the gender that they identify with.

Youth who identify as LGBT must often deal with situations that put their physical and mental health in jeopardy. Adolescents who identify as LGBT are at higher risk for depression, suicidal ideation and attempts, bullying, drug/alcohol abuse, eating disorders, unsafe sexual practices, and homelessness (Moon, O'Briant, & Friedland, 2002). During health care encounters, LGBT youth may not feel comfortable "coming out" to health care providers and many health care providers do not feel comfortable asking questions about sexual orientation and gender identity. This information is important for health care providers to learn, as it can lead to better health outcomes for their patients. There have been many public accounts of LGBT teenagers completing suicide, including that of a 17-year-old teen who identified as transgender in Cincinnati, OH, who committed suicide by walking in front of a tractor trailer on the highway in 2014. Her suicide note pointed to social isolation and not being supported in her gender identity by her parents as reasons for her suicide. Maybe her outcome would have been different had she made a positive connection with a supportive, accepting health care provider. Health care providers can better screen for and treat risk factors when they have a relationship with the adolescent in which the adolescent feels comfortable disclosing their sexual orientation and gender identity. To promote a safe and accepting environment for all youth, health care workers should ensure confidentiality, ask open-ended questions that allow honest discussion without judgement, and provide gender neutral/unisex bathrooms in public areas (Kane-Lee & Bayer, 2012). People who identify as LGBT must come out many times during the course of their lives and this can be an uncomfortable experience. As one youth who identifies as a lesbian stated, "No doctor ever asks me my sexual orientation so I rarely offer that up. I think I might get better care if I did but there never seems to be an appropriate time. Because there is no question, I have to go through the process of coming out, making an intentional effort to tell them rather than being able to say yes to a question" (Moon, O'Briant, & Friedland, 2002, p. 416). Some adolescents may feel more comfortable coming out to a trusted health care worker, such as a child life specialist. This can happen during any normalizing conversation, but is more likely to occur if the child life specialist does not make assumptions and asks open-ended questions, such as "Are you dating anyone?" and "Tell me about the person you are dating" instead of asking a girl if she has a boyfriend or a boy if he has a girlfriend. Based on my experience in these situations, if a patient chooses to come out

TABLE 1: TERMS USED TO DESCRIBE GENDER AND SEXUALITY

Ally A person who is not LGBT but shows support for LGBT people and promotes equality in a variety of ways.
Bisexual A person emotionally, romantically or sexually attracted to more than one sex, gender or gender identity though not necessarily simultaneously, in the same way or to the same degree.
Cisgender A term used to describe a person whose gender identity aligns with those typically associated with the sex assigned to them at birth.
Coming out The process in which a person first acknowledges, accepts, and appreciates his or her sexual orientation or gender identity and begins to share that with others.
Gay A person who is emotionally, romantically, or sexually attracted to members of the same gender.
Gender dysphoria Clinically significant distress caused when a person's assigned birth gender is not the same as the one with which they identify. According to the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM; American Psychiatric Association, 2013), the term - which replaces Gender Identity Disorder - "is intended to better characterize the experiences of affected children, adolescents, and adults."
Gender expression External appearance of one's gender identity, usually expressed through behavior, clothing, haircut, or voice, and which may or may not conform to socially defined behaviors and characteristics typically associated with being either masculine or feminine.
Gender identity One's innermost concept of self as male, female, a blend of both, or neither – how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth.
Homophobia The fear and hatred of or discomfort with people who are attracted to members of the same sex.
Lesbian A woman who is emotionally, romantically, or sexually attracted to other women.
Queer A term people often use to express fluid identities and orientations. Often used interchangeably with "LGBT."
Questioning A term used to describe people who are in the process of exploring their sexual orientation or gender identity.
Sexual orientation An inherent or immutable enduring emotional, romantic, or sexual attraction to other people.
Transgender An umbrella term for people whose gender identity and/or expression is different from cultural expectations based on the sex they were assigned at birth. Being transgender does not imply any specific sexual orientation. Therefore, transgender people may identify as straight, gay, lesbian, bisexual, etc.
Transphobia The fear and hatred of, or discomfort with, transgender people.

Adapted from Human Rights Campaign (n.d.-a)

to you, I suggest you thank them for confiding in you, assure them of confidentiality (unless they disclose a plan to hurt themselves or others), listen to what they have to say, be open-minded and supportive, ask them who, if anybody, they have told and how this person/people have responded, and provide them with resources for support and information. Child life specialists should also encourage the adolescent to tell their primary health care provider and offer to provide support during this conversation, if appropriate.

PROVIDING HEALTH CARE SERVICES TO THE CHILDREN OF CAREGIVERS WHO IDENTIFY AS LGBT

Adults who identify as LGBT may be uncomfortable in the health care setting due to previous negative health care experiences. These past experiences may include the refusal of care, health care providers taking excessive precautions when touching them, the use of abusive language by health care professionals, and being blamed for their health status when providers learn that they identify as LGBT (Kane-Lee & Bayer, 2012). Due to previous experiences, adults who identify as LGBT may view the health care environment as intimidating, unwelcoming, and unresponsive (Weber, 2010). This previous experience and view of health care settings may lead to distrust and a fear of health care providers, which may be transmitted to the children of LGBT caregivers and lead to additional anxiety

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POINT/COUNTERPOINT

POINT: Enhanced Academic Requirements: Increasing Education, Increasing Opportunity

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As the acuity of patients and the needs of their families continue to increase, the work of pediatric health care practitioners has become more demanding, and psychosocial training and expertise an absolute necessity. Children are surviving and thriving with illness, injury, and disability that have impacted their quality of life. The American Academy of Pediatrics further clarifies that “social difficulties, behavioral problems, and developmental difficulties have become a main part of the scope of pediatric practice” (American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health, 2001, p. 1227). How do we, as Certified Child Life Specialists charged with providing quality psychosocial care for vulnerable children, acquire the level of training necessary to provide interventions based on theory and supported by evidence?

Emma Plank, a pioneer of child life, was a highly educated practitioner with expertise in the developmental needs of children. Examining the evolution of child life posted on the Child Life Council website (Child Life Council, n.d.) and described by Wojtasik and White (2009) in *The Handbook of Child Life*, it was in the 1930s when the first play programs were developed. In 1982, the Child Life Council was created out of the Association for the Care of Children’s Health; fast forward to 1998 when the certification by exam was established (Wojtasik & White, 2009). We moved from the infancy of child life, through early and middle childhood, and we are now entering our adolescence as we turn to the academic training of Certified Child Life Specialists. In 2013, a minimum of one course with six specific curriculum topics taught by a currently Certified Child Life Specialist was instituted as one of the requirements for certification. In the future, January 2019 to be exact, candidates must graduate from a CLC-endorsed degree program OR successfully complete a total of 10 college courses for credit from an academic institution (seven required, plus three on related topics). By 2025, a master’s in child life or the international equivalent will be required. All of the specific dates and details on upcoming eligibility requirement changes are provided on the [CLC website](#).

The work to develop the new guidelines for the education and training for child life specialists was undertaken by the Academic Preparation Task Force, or Task Force 2020, which was formed in April of 2012 in response to CLC’s 2012-2014 Strategic Plan. One goal of the strategic plan was to advance the credibility of the profession and to elevate academic preparation to address key concerns of our membership. As such, the mission and goal of the created task force were to “recommend the progression of steps

and a timetable whereby, effective beginning in 2020, all newly credentialed Certified Child Life Specialists must hold an advanced degree from an academic program that has been accredited by CLC” (Child Life Council Academic Preparation Task Force, 2012, p. 10). The task force was also charged with developing related policies and procedures, including overall minimum curriculum and other requirements for programs, and a specific infrastructure for the accreditation process, including ongoing review and renewal. The task force was renamed Task Force 2022 to allow graduate programs additional time to meet the new requirements. As of 2022, all new Certified Child Life Specialists must hold a master’s degree in child life or a master’s degree with a concentration or emphasis in child life from an academic program accredited by CLC. In 2025, all new Certified Child Life Specialists must hold a master’s degree in child life from an academic program accredited by CLC.

From April 2012 until the work of the task force concluded in May 2014, the task force gathered information from existing child life programs and from academic institutions that offered a course or courses in child life, including both undergraduate and graduate programs. In addition, a comprehensive benchmarking study of allied health professionals’ education and training requirements was conducted to inform the work and address the charge. The study included the following disciplines: nursing, physician’s assistant, art therapy, music therapy, occupational therapy, physiotherapy, speech therapy, social work, play therapy, pastoral services, recreation therapy, and mental health counseling. In reviewing the academic preparation of these disciplines, the task force learned that all but two required degrees in their specific profession. Most required a profession-specific master’s degree for entry-level positions. With the exception of nursing, even those that required an undergraduate degree for entry-level positions required a master’s degree to work within the hospital setting (Task Force Notes, personal communication, April 25, 2013).

As a college professor, I am often asked by prospective students why they should consider a graduate degree. As indicated above, the answer is multifaceted. Yes, it was part of the charge in the 2012-2014 strategic plan. However, it is also clear that the need for the psychosocial expertise of health care professionals (which includes child life specialists) will continue to grow as the field of pediatric medicine provides new and improved treatment options for children. According to the Center for Health Care Strategies,

American medicine is at a crossroads. The technical capabilities available to patients are beyond anything that could have been imagined even 20 to 30 years ago . . . While the most sophisticated medical and surgical capabilities are now available for

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POINT/COUNTERPOINT

COUNTERPOINT: Enhanced Academic Requirements: New Challenges, New Solutions

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“How am I going to afford pursuing a master’s degree?” “Am I going to have to move to attend graduate school?” “Will there be more internships for students seeking an advanced degree?” “What will I do if I am unable to obtain a master’s level internship?” “Is this going to make me more marketable in such a competitive field?” “Will my employer support my pursuit of an advanced degree and will an advanced degree increase my salary?” These are just a few of the questions heard following the announcement of the new eligibility requirements presented by the Child Life Council. These are all rational and realistic questions, definitely ones to consider when contemplating entering the child life field. Thinking about all of these questions can be extremely overwhelming and stressful. Yet despite these potential challenges and obstacles, if one is passionate, diligent, and creative, there are ways to navigate these difficulties and to address potential barriers.

As most are aware, the CLC Board of Directors recently approved important requirements in which all newly credentialed Certified Child Life Specialists will be required to hold an advanced degree from an academic program that has been accredited by the CLC. Effective in 2022, the new requirements include that candidates must hold either a master’s degree in child life, or a master’s degree with a concentration or emphasis in child life, from a CLC-accredited academic program, with additional requirements effective at later dates (Child Life Council, n.d.-a). (To review these requirements in their entirety, go to the [CLC website](#).) This requirement has caused many to wonder how they will afford to pursue a master’s degree. According to the [CLC website](#), there are currently 28 master’s programs that self identify as offering curriculum that is consistent with the current requirements to provide child life curricula (Child Life Council, n.d.-b). In addition to this, three offer online graduate child life curriculum options. So, for those in far physical proximity to these schools, there are still options available. Additionally, due to accessibility, and the flexibility of online programs, for many an online option is the ideal choice. Keep in mind that it is the responsibility of the student to make sure that the program meets the current and future requirements at the time of enrollment and at the time of projected graduation.

Yet for most, rightfully so, the financial cost of graduate school is the primary concern. Individuals are encouraged to research their academic options to determine which program is the most cost efficient. Once this research has been done, individuals should examine which funding sources are available. When examining available

funding sources, students should ask themselves, “Are scholarships or student teaching and assistantships available?” According to Sheehy (2014), “when funding is more straightforward; students should compare the amount of grants and scholarships offered by each school to figure out their out-of-pocket costs each year” (Sheehy, 2014, para. 12). If possible, individuals should also look at ways of cutting costs; for example, consider staying with family who live near the graduate program rather than incurring extensive housing costs.

Still, there are other options available to decrease costs. Online education programs can reduce the cost of pursuing an advanced degree, offering a variety of cost saving options (Hopkins, 2012). It is also important to note that many individuals may already be working for employers that offer tuition reimbursement benefits; therefore, it is important for individuals interested in a child life graduate degree to research whether their employers offer such a benefit. Additionally, individuals may be required to meet certain criteria in order to access tuition reimbursement.

Yet despite these potential challenges and obstacles, if one is passionate, diligent, and creative, there are ways to navigate these difficulties and to address potential barriers.

Once a graduate program and financial resources have been determined, there is still the potential obstacle of obtaining a graduate internship, with internships often an academic requirement for completion of some degree programs. The availability of internship opportunities and concern regarding one’s ability to obtain a graduate internship are additional points to consider. Of those programs listed in the program directory on the Child Life Council (n.d.-b) website, 223 offer child life internships. While some academic programs require that students complete a child life internship in order to meet graduation requirements, other programs consider the pursuit of an internship to be the independent responsibility of the student after his or her completion of the degree. In addition, some academic programs have arrangements with internship sites, while others do not; all of which need to be considered by the student when researching and choosing an academic program. While it has yet to be decided whether students will be required to complete internships as undergraduate or graduate students, one would hope that with this change in requirement, more child life programs will consider offering graduate level internship opportunities.

“Is this going to make me more marketable in such a competitive field?” “Will an advanced degree increase my salary?” These are two additional questions posed regarding the new eligibility requirements. Both are realistic and feasible questions and deserve to be addressed. An examination of two employment search engines, the Child Life Council’s Career Center (2016) and Indeed (2016), found that there were a total of 62 open child life positions, and that while most had a minimum requirement of a bachelor’s degree,

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children with special health care needs (CSHCN), the health care delivery services to assure access to this care have not always kept pace. (Oehlmann, 2004, p. 5)

Certified Child Life Specialists can help support these children and their families, as key members of the multidisciplinary team.

There are benefits to advanced education and training. Monica Fletcher (2007), in her article on continuing education, states “There is evidence that education improves the confidence and competence of practitioners” (p. 189). Information and a theoretical understanding of psychosocial development and training bolster child life specialists who must adapt and apply their clinical skills to the treatment of pediatric patients in the health care setting, community, school, and home. Furthermore, the collaboration that occurs between instructors, clinicians, and students in educational centers provides a rich environment for the study and application of theory, exchange of ideas, and review of seminal and current research. Graduates with advanced degrees must be knowledgeable about and able to conduct research to support child life practice and pediatric health care. Through research, we can demonstrate the efficacy of child life services, improve credibility, and elevate the field. It is simply not enough to know that child life interventions make a positive impact on children; we must be able to show this through the careful review and study of our work.

Finally, at the heart of the child life profession is the service that practitioners provide to vulnerable children and families throughout their health care experiences. No matter where child life services

are provided, it is essential that professionals be grounded in the principles and theories of child development and psychosocial care to serve patients. Indeed, Certified Child Life Specialists are agents of change in the world of pediatric psychosocial care. We have and will continue to be instrumental in promoting the rights of children with health care needs and their families. “The ability of child life professionals to articulate and justify to others the meaning and underlying functions of clinical interventions and programs supports the ongoing development of the profession” (Turner 2009, p. 33). The requirement of an advanced degree in child life is a step in the right direction towards ensuring highly-educated child life specialists are providing evidenced-based services to all children and their families. ✨

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Counterpoint

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most positions preferred an individual with a master's degree. At this point, individuals with master's degrees appear to be more qualified. Additionally, having an advanced degree also increases your earning potential. According to the Child Life Council's (2012) summary of child life profession compensation, full-time child life specialists with a master's degree earned \$3,651 more annually than bachelor's level specialists. Therefore, having an advanced degree not only makes an individual more marketable in the field, it also increases one's earning power.

While the full implications of the new requirements on future child life professionals remain to be seen, the intention is that this new advanced degree requirement will validate and increase the credibility of our profession, opening doors that have previously remained closed to child life professionals. It was with great thought and intention that these requirements were established. As with any great change, there will be challenges and obstacles. I imagine that the child life specialists that took the very first child life certification exam probably felt very similar to the way that many are feeling now. Yet, as child life professionals, we are not strangers to challenges and obstacles, and we are accustomed to finding ways to circumnavigate

such challenges. I have no doubt that this will be the case in regards to these new requirements. We are a steadfast, dedicated, and resourceful profession; one that understands that success is sweeter when it has been hard earned. These new requirements will provide such opportunities for success to be achieved. ✨

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Innovative Global Child Life Strategies Needed to Improve Access to Psychosocial Care for Children and Families in Developing Countries

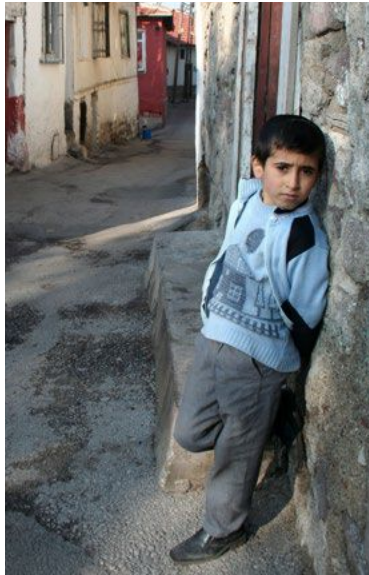
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During the past two decades, global collaboration and concerted efforts focused on achieving the Millennium Development Goals have resulted in significant improvements in the health and lives of children and families in many lower and middle income countries (LMICs) throughout the world. These focused efforts have specifically resulted in notable reductions in infant and under-5 mortality rates, improvements in children's access to HIV, malaria, and tuberculosis treatments, and lowered rates of childhood malnutrition (World Health Organization [WHO], 2009). Significant reductions in the spread of many life-threatening communicable diseases, improvements in communities' access to safe drinking water and clean sanitation facilities, and higher school enrollment rates for children in impoverished areas have also been achieved. However, while great leaps and strides have clearly been made in improving various aspects of the physical health of children and families over the past two decades, far less has been done to address the psychological or emotional health of children and families, especially in developing nations. This unfortunate reality may have devastating consequences for the entire global health community in the decades to come, because by not adequately addressing the psychosocial needs of children and adolescents in developing countries now and in conjunction with their physiological needs, significant future health burdens are likely to develop that could place tremendous strains on already-fragile health systems well into the future.

The reasons for the lack of notable improvements in psychosocial care and mental health services in LMICs over the past several decades are multifaceted. Despite an overwhelming body of evidence that clearly demonstrates the efficacy of and urgent need for increased family-centered care and psychosocial support programs for children and families dealing with health issues in developing countries, many organizations "face major gaps in funding, staff training, and program support materials" (Greifinger & Dick, 2011, p. 39), that severely limit their ability to provide these crucial services to children and families.

Even with all of the tremendous health care improvements that have been made in LMICs as a result of successful capacity-building efforts and commitments to bolstering health care infrastructure, extreme discrepancies still persist between many populations' actual health needs and their access to adequate care and services. Many developing nations continue to experience severe shortages of adequately trained health care professionals, especially mental health and psychosocial care providers, due to highly constrained budgets, low education levels, and a lack of specialized training programs



for health care professionals across all types of disciplines. For example, in Sub-Saharan Africa, recent estimates suggest that there are only two practicing physicians available for every 10,000 people. When compared to higher-income nations like the United States and many European countries, which have anywhere between 32 and 59 practicing physicians per 10,000 individuals, a grim picture emerges highlighting the serious lack of access to even basic health care providers, let alone mental health or psychosocial care providers, that millions of children and families face in developing nations (WHO 2009).

Many LMICs also face other unique barriers to providing adequate health care and psychosocial services for children and families, such as a lack of access to high-quality scientific research, which leads to a general lack of awareness about the many negative impacts illness, injury, hospitalization, and trauma can have on children and

families when left unaddressed or untreated. In addition to the sheer lack of awareness about psychosocial issues that often exists in developing countries, multiple other complex cultural and contextual factors such as deep-rooted stigmas, low health literacy rates, weak infrastructure, traditional beliefs and practices, and unique social constructs often make it even more difficult to provide adequate and culturally-sensitive psychosocial care in health facilities in these areas (Njuguna et al., 2015).

In light of these barriers and challenges, the WHO and other major global health organizations stress that it is "imperative that greater investments in developing and evaluating developmentally-appropriate combination psychosocial interventions for children occur as part of care and treatment programming" (Amzel et al., 2013, p. S154) in low-resource settings and developing nations throughout the world. Although the global health sector has yet to involve or utilize the child life profession as a whole in any large-scale global health programming for children and families in developing countries, tremendous opportunities still exist for partnerships between child life specialists and different global health organizations, associations, and country-specific health programs aimed at addressing the unique needs of children and families dealing with illness, injury, or hospitalizations in LMICs. Since many child life interventions may have the potential to help alleviate some of the most urgent psychosocial needs facing children and families in these settings, it is now more important than ever for child life specialists across the globe to collaborate closely with each other and with various local health care providers in developing countries to find creative and innovative ways to introduce child life services in low-resource health care settings.

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Thankfully, many dedicated child life specialists and other interdisciplinary health care professionals have already begun to embark on exciting new journeys in hopes of introducing child life services into various contexts within LMICs while also striving to maintain high professional standards of practice and credibility valued by the CLC. Child life pioneers in the Philippines have spent the past twenty years growing a culturally-tailored and sustainable child life program from the ground up by developing their own academic curriculum and qualification criteria for local professionals to fulfill in order to work as child life coordinators. The Child Life Program through the Kythe Foundation now provides robust and innovative psychosocial support services to thousands of children and families in 13 hospitals throughout the country.

Passionate health care professionals in Kenya, Georgia, South Africa, and India have also established and begun growing successful child life or hospital-based psychosocial care programs by adapting the CLC's professional requirements and standards of practice to meet their own cultural and contextual needs. While each of these programs are currently led by at least one local individual who has recently acquired CCLS credentials, the remainder of the psychosocial staff utilize various professional titles such as "child life practitioners," "psychosocial specialists," or "child life workers." Psychosocially-minded health care professionals in other low-resource international contexts have also employed unique strategies such as forming partnerships with local universities and medical schools in order to integrate child life-based education modules into students' existing curriculum and by holding trainings for parents in order to teach them how to provide psychosocial support

International Scholarship Recipients' Reports

The 2016 Annual Conference on Professional Issues in Orlando, FL marked the seventh consecutive year that CLC has offered Worldwide Outreach Scholarships to international conference attendees. This year we welcomed a diverse group of scholarship recipients from Uganda, Taiwan, Puerto Rico, New Zealand, and Romania. Funded through a grant, these recipients had the unique opportunity to enable health care professionals from outside North America who have an interest in the psychosocial care of children to attend the conference and learn about the latest developments in the child life field. You can read about this year's scholars' experiences on the [Awards Committee blog](#) in Community.

CLC is pleased to announce international scholarships will again be offered to attend the 2017 Annual Conference on Professional Issues in Las Vegas, NV. We encourage those CLC members who have worked with care facilities around the world to help spread news of this opportunity to individuals who may be interested in applying. A description of the scholarship and application procedures can be found on our [website](#). Applications are encouraged from any health care professional from outside North America who has an interest in the psychosocial care of children.

to their own children during challenging medical experiences and hospitalizations.

As the child life profession continues to gain credibility, evolve, and grow across the world during this exciting era of transition, these developments will also spur continued consideration and creativity as we support our international peers. As there are many practical, clinical, academic, and cultural challenges already present for child life practitioners in other countries, ongoing collaboration and communication will be of great importance in supporting individual programs as well as the overarching strategic plan for the child life profession.

For instance, while changing the academic requirements for obtaining CCLS credentials are clearly of paramount importance to our continued professional development and credibility, it will also be important to consider how this change may impact the provision of psychosocial care services for children and families in developing countries. In some cultural contexts, only a small percentage of the population possesses a high-school level education, and even fewer a university diploma or advanced degree. Therefore, it is important to foresee these difficulties and provide opportunities and resources to help aspiring specialists navigate the certification requirements. In addition, specialized academic training, formalized internship opportunities under the supervision of a Certified Child Life Specialist, or access to standardized testing centers for the eligibility exam may also be more challenging to access in other countries. Furthermore, cultural conceptions of the value of psychosocial care are still rarely practiced at all within the home countries of those interested in establishing child life programs in LMICs.

Although the widening gap between the CCLS certification standards and international child life professionals' abilities to meet the qualifications may seem insurmountable to some, the successful international child life programs and initiatives mentioned above present convincing evidence that there are many different pathways international "child life champions" and psychosocially-minded health care professionals can take to provide effective, high-quality, culturally sensitive, and sustainable psychosocial care services to children and families in low-resource settings. As the need for adequate mental health and psychosocial care services in developing nations continues to become even more pronounced and visible in the years to come, the global child life community should continue to band together to develop innovative, flexible, and culturally-minded psychosocial care solutions that can significantly improve the lives of millions of children and families throughout the world. ✨

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Abstract

As anecdotally and empirically recognized in child life practice, children's responses to stress are intimately tied to their psychosocial reality. However, less is known about the ways in which children's responses to illness are contextualized by various psychosocial factors associated with inner city life. This paper explores this phenomenon on a granular level by analyzing the literature base on the potential physical, neurological, and emotional consequences of child development in the inner city with regards to common interventional challenges cited by the medical care team. Increased awareness, not only of the many connections between the macrocosmic forces of the inner city and patient coping, but also to one's own understanding of self and the varied ways human beings are connected and disconnected from each other, has real-world, actionable implications to clinical practice. Exercising such awareness improves the ability of child life specialists to assist patients from inner city backgrounds to confidently navigate the larger health system. It also provides a necessary framework for the analysis of health disparities, which in turn, informs the many ways that children respond to stress in the hospital setting.

Elevating Child Life Intervention in the Inner City: Cultural Humility as an Agent for the Empowerment of Children and Families in Economic, Social, and Physical Conflict

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Children comprise the poorest segment of American society. The most current statistics reflect that an unyielding 22% of American children live below the federal poverty level, where they have remained moored since 1970 (American Academy of Pediatrics [AAP], 2013). The effects of poverty on children's health are far-reaching and annihilative. Increased infant mortality, more frequent and severe chronic diseases such as asthma, poorer nutrition and growth, less access to quality health care, lower immunization rates, and increased obesity, are just some of the many potential health outcomes for children who unknowingly inherit disadvantage (AAP, 2013).

The burden of poverty has not, however, fallen randomly. Inner cities, frequently characterized by their economic deterioration and dense populations of families with low opportunity for social and educational advancement, make up 21% of the American population living in poverty (ICIC, 2014). Within the macrosystem of the inner city, 3 out of 10 people live in poverty (ICIC, 2014). Of these individuals, 6.2% identify as White, 18% as Hispanic and a staggering 28% as African American. The gap between the economic well-being of Whites and non-Whites, as reflected in Figure 1,

continues to widen despite social efforts to determine the origin of the problem. Explanations of this disparity vary, though the hypotheses of structural shifts in the economy, inadequate human capital, racial and gender discrimination, adverse cultural and behavioral factors, racial and income segregation, impacts of migration, lack of endogenous growth, and adverse consequences of public policy are widely cited (Teitz & Chapple, 1998).

Through his Ecological Systems

Theory, Bronfenbrenner reminds us that in order to grasp the core beliefs of an individual, one must first understand the influence of environment on that individual. This approach organizes contexts of development into five interlocking levels of external influence (Sincero, 2012).

For inner city minorities, mass incarceration rates, prevalence of households led by single mothers, high school drop out rates, density of fast food restaurants per local square mile, sum of lives

		AGE				
		0-5	6-11	12-17	ADULTS	ALL AGES
TOTAL	Poor	16.5	15.6	14.7	13.8	14.4
	Non-poor	2.7	2.4	2.5	2.8	2.7
WHITE	Poor	6.2	5.2	4.6	8.2	7.5
	Non-poor	0.9	0.7	0.7	1.2	1.2
BLACK	Poor	28.0	26.6	25.2	24.2	25.2
	Non-poor	7.9	7.6	8.0	9.3	9.0
HISPANIC	Poor	18.1	17.9	17.6	16.9	17.4
	Non-poor	5.3	5.0	5.0	5.9	5.7

Figure 1. Percentage of population living in high-poverty neighborhoods nationwide by race/ethnicity, age, and poverty status. From Jargowsky (2015). Reprinted with permission of The Century Foundation.

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manipulated, paralyzed or extinguished by racial profiling, rise like an elegy. In the hospital setting, a child's patterns of coping, bonds of attachment, even appraisal of stress, all have direct ties to emotional and cognitive development within a neurologically injurious environment. The culture of fear that pervades inner cities—fear of being discarded by society, fear of destruction and violence, fear of basic survival, can and should be examined from a culturally humble lens (Thompson, 2014).

About the Views Expressed in Focus

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CULTURAL HUMILITY

At the 1966 convention of the Medical Committee for Human Rights in Chicago, Martin Luther King said, "Of all the forms of inequality, injustice in health is the most shocking and the most inhuman" ("King Berates Medical Care," 1966, p. 22). Cultural diversity and the rising emphasis on evidence-based practice within health care have sparked dialogues regarding cultural competence among medical professionals. Given the complexity of multiculturalism, it is beneficial to understand cultural competency as a process rather than a finite outcome. From this perspective, competency involves more than gaining factual knowledge — it also includes our ongoing attitudes toward both patients and ourselves (Waters & Asbill, 2013).

Cultural humility is one construct for understanding and developing a process-oriented approach to competency. Developed in 1998 by Dr. Melanie Tervalon, a pediatric specialist, and Jann Murray-Garcia, a nursing professor at UC Davis, cultural humility describes a select way of infiltrating multiculturalism into the work of health care professionals. Predicated upon the realization of personal power, privilege, and prejudice, this model of care encourages clinicians to accept that their education and

credentials alone are insufficient to deliver effective and respectful care to heterogeneous populations.

Three social aspects constitute cultural humility. The first is a lifelong commitment to self-evaluation and self-critique (Tervalon & Murray-Garcia, 1998). By identifying and examining our own patterns of unintentional and intentional prejudice and classism, clinician learning, in a sense, is never finished. Humility guides the dynamic of clinician-patient communication by using patient-focused interviewing and care. Although non-White patients of low socioeconomic status (SES) may desire as much information regarding their conditions as White patients, they routinely receive less information regarding their conditions, less positive or reinforcing speech, and less communication overall. Patient-focused communication signals to the patient that the practitioner values their agenda and perspective (Tervalon & Murray-Garcia, 1998).

The second feature of cultural humility is a clinician-driven desire to address power imbalances (Tervalon & Murray-Garcia, 1998). When a clinician engages with a patient, the "patient is the expert on his or her own life, symptoms, and strengths" (Waters & Asbill, 2013, para. 4). The practitioner "holds a body of knowledge that the

The cities of Baltimore, MD and Detroit, MI provided me with the clinical exposure to define quality psychosocial intervention as a child life specialist. I began my career as a child life specialist in the thick of urban Baltimore at John's Hopkins Children's Center, where I worked for three years in the Emergency Department. I left in 2015 shortly before the riots erupted, smoke and desperation billowing in my wake. I now find myself in Detroit, a city whose reputation of decline often precedes it, having to do nothing more than cross the hospital lobby to be reminded of the chasm that separates me from so many of the children and families we serve. These moments of awareness revive snapshots of memories: the hallway that families would walk down from triage to their care rooms in the Emergency Department and the ineffable sorrow that I would feel as so many curious, playful boys skipped past their mothers, not yet knowing that statistically by the age of 18 they were more likely to go to jail in Baltimore than graduate from one of its public high schools (Heckman & LaFontaine, 2010).

The question—How do the environmental factors of the inner city modulate interactions between families and child life specialists?—first entered my mind from the vantage point of working in a medical environment that was frequently at odds between differing core beliefs. The tension that would arise between members of the health care team and inner city took shape in misunderstandings, false assumptions, or, at worst, the complete absence of communication. No longer could I evaluate my clinical interactions based solely upon that which occurred within the hospital walls. The nurse who rolled her eyes when one poor family of six continued to request multiple packets of crackers and juice; the ENT resident who spat under his breath, "This is a waste of my time. Go to a Patient First," with his back turned to the mother of a colicky infant; the fellow specialist who revealed a running list of "hilarious ghetto patient names" tucked into her office drawer, mandated reflection upon my own personal theories of race, socioeconomic status, and power, as well as the societal realities that govern our perspectives.

patient does not; however, the patient also has understanding outside the scope of the practitioner” (Waters & Asbill, 2013, para. 4). Both parties must collaborate and learn from each other for the best outcomes.

Finally, cultural humility involves the aspiration to develop partnerships with people and groups who advocate for others. Clinician responsibility should encompass care of individual patients as well as advocacy for changes in community policies and practices that influence determinants of health, causes of disease, and effectiveness of health services. Cultural humility, by definition, is larger than the individual and should be demanded systemically (Tervalon & Murray-Garcia, 1998).

In order to further explore cultural humility and contextualize the influence of environmental factors specific to pediatric and familial coping in an inner city health care environment, this paper is divided into segments that are headed by direct quotes from members of the care team. May their frustrations—expressed both innocently and at times maliciously—impel us to be better.

THE CYCLICAL NATURE OF NONADHERENCE

“Every time I prepare him for staying on top of his medication, and every time he ends up coming back,” she lamented. Having worked for several months with a 17-year-old patient with sickle cell disease, the child life specialist now recognized his name once more at the top of her census. “I have prepared him several times for strategies surrounding pain management at home, provided developmentally-appropriate explanations for all of his antibiotics, even mapped out his support system in an effort to make the management of his condition a family process, and here he is. Again!”

A recent study published in *Clinical Medicine and Research* on patient characteristics associated with medication adherence found medication adherence to be consistently higher in males, Caucasians, patients over the age of 18, and patients living in areas with higher education and income rates (Rolnick, Pawloski, Hedblom, Asche, & Bruzek, 2013). In the total population, adherence increased with lower comorbidity and increased number of medications.

Understanding the prevalence of patient nonadherence with medication in the inner city requires consideration of the individual’s context within the wider society. To return to Bronfenbrenner, every system contains roles, norms, and rules that may influence psychological responses (Bitter, 2013). The extent to which patients are able to follow the recommendations for their prescribed treatments has a direct correlation to the social and societal barriers that exist in their respective environments. For patients who are forced to navigate the literal and figurative sinkholes of the inner city, this is problematic.

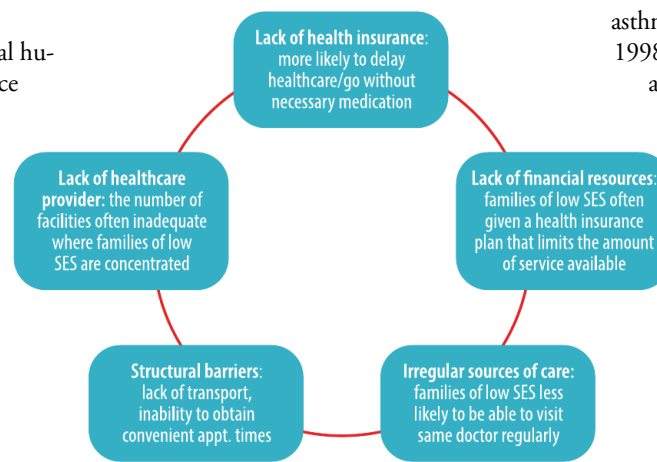


Figure 2. Social and environmental barriers to medication adherence. Formulated by the author based on the findings of Mandal (2014).

The social and societal barriers firmly entrenched in inner city reality can be seen on a more granular level through the process diagram presented in Figure 2. Those without health insurance are more likely to delay health care or go without necessary medication, which, over time, and multiplied by many people in the neighborhood, leads to a lack of health care providers in the area where the uninsured live. The number of health care facilities is often inadequate where families of low SES are concentrated (Rolnick, Pawloski, Hedblom, Asche & Bruzek, 2013). Data reminds us that where there are fewer providers there are frequently structural barriers, including lack of transport and inability to obtain convenient appointment times. One outcome of this reality is that families of lower SES are less likely to be able to visit the same doctor regularly. Further, these families are often given a health insurance plan that limits the number of services available (Rolnick et al.,

2013). The legacy of nonadherence perpetuates, falling backwards of its own weight to future generations like Sisyphus’ stone.

Take, for example, the experiences of children with asthma. Asthma is the number one cause of pediatric emergency department (ED) visits in young minority children (Bartlett, Lukk, Butz, Lamprosklein, & Rand, 2002). The ED is often the point of contact for many inner city children, and is commonly viewed by caregivers as their child’s primary source of asthma care (Bartlett et al., 2002). A study published in *Pediatric Pulmonology* in 1998 examined the psychosocial characteristics of 4- to 9-year-old urban children with asthma and their caretakers (Wade et al., 1998). Caretakers demonstrated considerable asthma knowledge, averaging 84% correct responses on the Asthma Information Quiz. However, respondents provided less than one helpful response for each hypothetical problem situation involving asthma care, and most respondents had more than one undesirable response, indicating a potentially dangerous or maladaptive action. This trend further complicates the issue of nonadherence; specifically that even with fairly good understanding of a condition, patient and caregiver problem-solving responses to hypothetical situations regarding their care were strikingly unhelpful, or worse, potentially dangerous (Wade et al., 1998).

In 2000, Johns Hopkins Children’s Center piloted a new model of asthma care, called Asthma Express, that included a follow-up asthma visit in the ED for an asthma “check-up,” asthma education, a prescription for preventive asthma medications, an appointment for the child to see their pediatric provider and a home visit to assist families with environmental control methods to prevent asthma symptoms (Bartlett et al., 2002). Founded on realistic goals to improve adherence, open discussion between the caregiver, nurse, and child on the negotiation of care plans, and communication tailored to improving patient and caregiver self-regard, Asthma Express is a modern reflection of cultural humility. Within four weeks, the percentage of participants not utilizing their medication as prescribed dropped from 70% to 43% as

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a by-product of participating in the Asthma Express model of asthma care (Bartlett et al., 2002). This outcome directly acknowledges the host of socioeconomic factors and processes outside of the individual's locus of control that make medication adherence challenging, and at times impossible, for inner city populations.

THE ROOT OF MALADAPTIVE PARENTING BEHAVIORS

"I'm exhausted. I felt like it was my job to model appropriate parenting," said the child life assistant in reference to a young mother who had brought her five-year-old to the playroom that morning. While the mother concentrated on her cell phone, the child proceeded to engage in rambunctious play, the line of his IV coiling inconspicuously around a table leg. With limited success, the child life assistant continuously asked for reinforcement from his mother. The child could scream, strike down castles of blocks, physically force himself into her lap, yet to his mother, his needs remained secondary to the latest Facebook post.

The determinants of effective parenting include exposure to chronic stress, undesirable life events, SES, educational attainment of the parent, parents having had good role models themselves, age of the parents, parental mental health, and parental employment and family support (Camilleri, 2007). The reality of survival in the inner city influences every single determinant, pressing and hammering its inhabitants like malleable metal.

The top maladaptive parenting behaviors correlated to low SES have been identified as emotional unavailability or instability, harsh disciplining, low supervision, lack of structured family life, and weak parent-child attachment (Camilleri, 2007). The behavior of the mother in the playroom can be seen to reflect several of these elements. Unable to prioritize her child's needs above her own, the mother remained fixated on her cell phone regardless of how plaintively her child cried. It is in moments like these that healthcare professionals often criticize caregivers for their perceived lack of empathy. From their vantage point of privilege, child life specialists who pride themselves in keen assessment skills failed to assess the big picture.

A 2015 analysis of the percentage of Baltimore's population living below or near

poverty revealed an essential truth about many inner city families: 40% of them are headed by single females. Of these women, most work long hours and multiple jobs (Yeip, 2015). This schema breeds many behavioral outcomes for the children who are directly affected, ranging from emotional regression to hyper-maturation into parental roles due to lack of parental supervision. Some children born into this circumstance turn to violent behavior as a means of rebellion or attention seeking. Depression and anxiety in both the child and the parent are also widely documented within families headed by single mothers in the inner city (Crossland & Kai, 2001).

A 2001 study explored the prevalence of enduring and disabling mental illness in a disadvantaged inner city community. Researchers found a high prevalence of enduring psychotic and non-psychotic illness. Only half of these patients were in contact with mental health services. One quarter of those identified as psychotic were in contact with mental health services. However, almost all patients were being seen frequently in primary care settings, suggesting considerable workload and resource implications (Crossland & Kai, 2001). These findings make plain the necessity for objectivity among the care team. Descending swiftly into stereotype allows the mother in the playroom to be appraised as an unfeeling parent rather than one who is suffering from depression, anxiety, or another form of mental illness.

THE PHYSICAL IMMOBILIZATION OF GENERATIONS

"How can an eight-year-old get so heavy? Why doesn't anybody stop it?" The nurse stood indignant before me. "I just walked out of that room after giving a diagnosis of Type 2 Diabetes and now her mom is buying her Skittles from the vending machine. Disgusting."

Urban minority children tend to be significantly more likely to be obese or overweight than their suburban counterparts. Zach Rosen, MD, Medical Director of the Montefiore Family Health Center in the Bronx claims that obesity is a "bigger problem than heroin, cocaine, alcohol and HIV put together," ("Obesity weighs hard," 2004, para. 5), one mediating factor in the obesity epidemic being the culturally-founded belief that excess weight is the sign of a healthy, well-cared-for child ("Obesity

weighs hard," 2004). A recent study from the Urban Institute finds that up to 90% of inner city caregivers feel that their obese child is normal weight or underweight ("Obesity weighs hard," 2004). An extreme reflection of this is inner city Chicago, where anywhere from 58 to 65% of the population has been identified as overweight or obese. Inner city areas also have higher rates of pediatric asthma, which, along with obesity, contributes to a cycle of sedentary behavior ("Obesity weighs hard," 2004).

A 2009 study in *Academic Pediatrics* found that in the inner-city, minority community of East Harlem, New York, the presence of convenience stores and fast food restaurants near a child's home was associated with increased risk for childhood obesity as measured by body mass index (BMI; Galvez et al., 2009). Convenience stores were present in 55% of the surveyed blocks in which a study participant lived, and fast food restaurants were present in 41%. Children living on a block with one or more convenience stores were more likely to have a BMI in the top percentile, compared with children having no convenience stores. Conclusively, the presence of convenience stores near a child's residence was associated with a higher BMI-percentile (Galvez et al., 2009).

Physical environment further sustains the physical immobilization of generations of minorities. Put bluntly, where we live impacts how we live. Neighborhood features alone impact levels of physical activity. Inner cities by and large have fewer recreational facilities, sidewalks, protected bike lanes, street designs that slow traffic for safe pedestrian crossing, parks, gyms, and shops within walking distance, and finally, fewer self-identified safe spaces for children to play than wealthier and predominantly White communities ("Environmental barriers to activity," 2010). The white picket fences of Rockwellian idealism and melodic chime of bicycle bell punctuating the suburban dusk fall away as fantasy in the face of the pedestrian-unfriendly streets, sprawling populations, and larger distances between homes and business areas that characterize the inner city.

THE BRAIN DETERMINES WHO WE BECOME

"Nothing I tried worked because I felt like I had to constantly redirect the patient," I said

in defeat to a colleague. Earlier that morning I had worked with a ten-year-old who had run into a door at school, yielding a deep laceration across the bridge of his nose. Accompanied by his homeroom teacher, the boy emitted a strangled sense of self-awareness. I could maintain his attention for approximately thirty seconds before the boy would begin to fumble with the box of tissues on the bed or interrupt my preparation to bargain about turning on the TV. When it came time to place the sutures, he channeled all of the adrenaline surging through his body to resist the medical team, ultimately requiring five nurses—four to hold down each of his appendages, one to steady the head, which thrashed in desperation—to complete the procedure. “What are you doing? Please stop, I’ll be good, I promise I’ll be good!” he bargained, the pupils of his eyes widening to swallow the light in the room.

Psychiatrist Bruce Perry, MD, PhD, states that children reflect the world in which they are raised. “If that world is characterized by threat, chaos, unpredictability, fear and trauma, the brain will reflect that by altering the development of the neural systems involved in the stress and fear response” (Perry, 2000, “Trauma and the Developing Brain,” para. 3). A recent study in the *Journal of the American Medical Association* on the effects of poverty on childhood brain development and the mediating effect of caregiving and stressful life events corroborates his statement. The study, guided by its central question of whether the needs-to-income ratio experienced in early childhood has an impact on brain development at school age, launched a prospective longitudinal study of emotional development in preschool-aged children who later participated in neuroimaging. Specifically, preschoolers 3 to 6 years of age were ascertained from primary care and day care sites in the St Louis, MO metropolitan area and annually assessed behaviorally for 5 to 20 years. Needs-to-income ratio was “operationalized as the total family income divided by the federal poverty level based on family size in the year most proximal to data collection” (Luby et al., 2013, “Measures” para. 1).

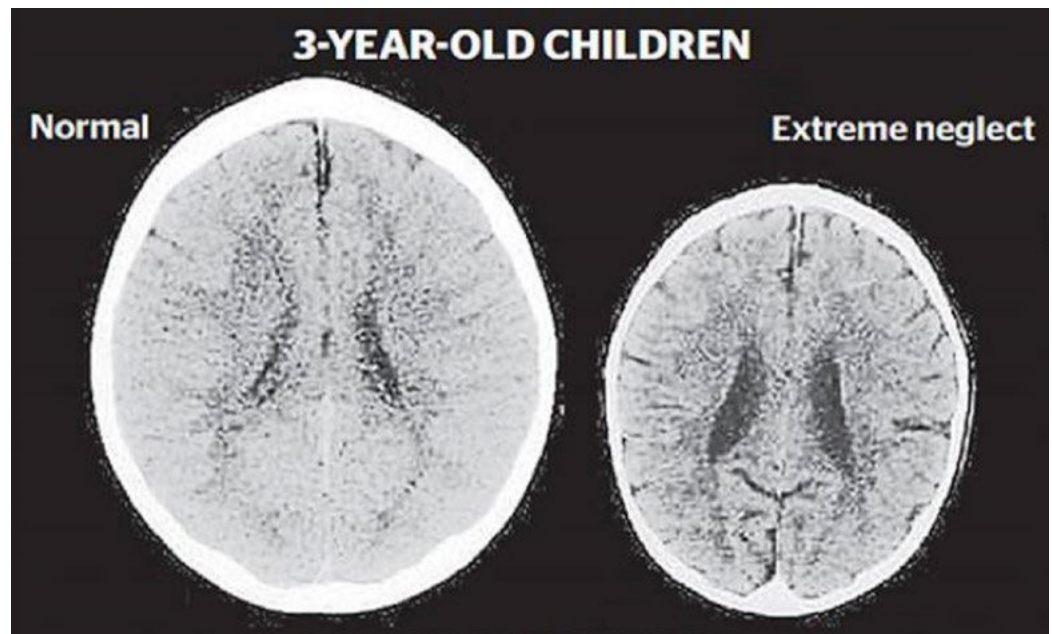


Figure 3. Altered brain development following global neglect in early childhood. From Perry (2000); reprinted with permission of NAMI California.

Study findings demonstrated that exposure to poverty during early childhood was associated with smaller white matter, cortical gray matter, and hippocampal volumes measured at school age (Luby et al., 2013). Mediating determinants of hippocampal volume included parental level of education, supportive or hostile patterns of caregiving, and children’s stressful life events. These statistics bolster the substantial body of behavioral data demonstrating the deleterious effects of poverty on child developmental outcomes into the neurodevelopmental domain, specifically that early developmental trauma and neglect have disproportionate influence on later brain functioning (Perry, 2000).

Located just above the brain stem and below the cortex, the hippocampus is the area in the brain associated with memory, emotions, and motivation (Robson, 2014). As the brain’s emotional center, the hippocampus regulates individual intuition. When the sympathetic nervous system is activated during periods of extreme stress, the hippocampus is the first to be alerted, signaling to the adrenal gland to create stress chemicals. Figure 3 is a stark warning: if stress chemicals continue to be present for a prolonged period of time, the hippocampus will shrink. For children, whose brain organization primarily takes place within the first four years of life, exposure to significant trauma augments inalterable hippocampal reduction.

Trauma survivors also tend to react more excessively to minor triggers (Perry, 2004). As reduced white matter, cortical gray matter, and hippocampal volumes result in decreased ability to solve problems, the “fight, flight, or freeze” response can intensify in response to minor situations. To the well-intentioned but untrained eye, this distracted and sometimes disruptive behavior can present as Attention Deficit Hyperactivity Disorder (ADHD). Recent data collected from a children’s psychiatric hospital in New York shows a majority of the 63 patients in the sample as having been physically abused and living in foster homes. On average, they reported three traumas in their short lives. Yet, only eight percent of the children had received a diagnosis of post-traumatic stress disorder while a third had been diagnosed with ADHD (Ruiz, 2014). The characteristic impulsivity, hyperactivity, and inability to focus associated with exposure to childhood trauma can easily be mistaken for ADHD, the overdiagnosis of which finds new heights in the inner city community (Power, 2013).

To return to the boy whose powerlessness inspired this segment: It was only when I sat down to chart at the end of my shift did I discover that he had been seen in our emergency room three years prior after sustaining minor injuries during a gang shooting that took the life of his older brother. The lurid glow of the computer screen seemed to

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illuminate my ignorance as I flashed again to Perry's warning: "Hyperarousal responses are more common in older children, males, and when trauma involves witnessing or playing an active role in the event" (Perry, 2004, p. 39).

"SPARE THE ROD AND SPOIL THE CHILD"

"The whole blood draw mom kept yelling: Be a big boy, don't cry! Don't cry or else you'll get a whooping!" The threat of corporal punishment has routinely accompanied high stress medical situations in my experience as a specialist and this quote is shared by too many of my peers to count. Raised in staff meetings, clinical supervision sessions, and informal lunchtime gatherings, the frustration of having supportively prepared a child for a procedure only to be undercut by the caregiver threatening physical discipline in response to the child's developmentally-appropriate response to stress continues to serve as a frequent challenge among specialists.

My father was so very afraid. I felt it in the sting of his black leather belt, which he applied with more anxiety than anger, my father who beat me as if someone might steal me away, because that is exactly what was happening all around us. Everyone had lost a child, somehow, to the streets, to jail, to drugs, to guns. It was said that these lost girls were sweet as honey and would not hurt a fly. It was said that these lost boys had just received a GED and had begun to turn their lives around. And now they were gone, and their legacy was a great fear. (Coates, 2015, p. 16)

Statistics validate this great fear. According to Stein's pivotal study on the disciplinary practices of 100 inner city mothers in the Bronx Municipal Hospital in New York City and 100 suburban mothers in Westchester County, NY, mothers who were spanked as children were much more likely to spank their own children (Schuster, 1995). Inner city mothers also were much more likely to spank their children compared to the suburban mothers. Whereas 20% of the suburban mothers admitted to spanking their child within the last week, 63% of the inner city mothers

acknowledged the same behavior. Further, 31% of inner city mothers condoned spanking a child less than one year old compared to 6% of the suburban mothers. The study concluded that the poverty status of the caregiver and the number of weeks the caregiver has been unemployed serve as the two strongest contributors to increased physical discipline of children. Conversely, the more consistently the caregiver worked, the lower the incidence of spanking (Schuster, 1995).

Research on the prevalence of spank-

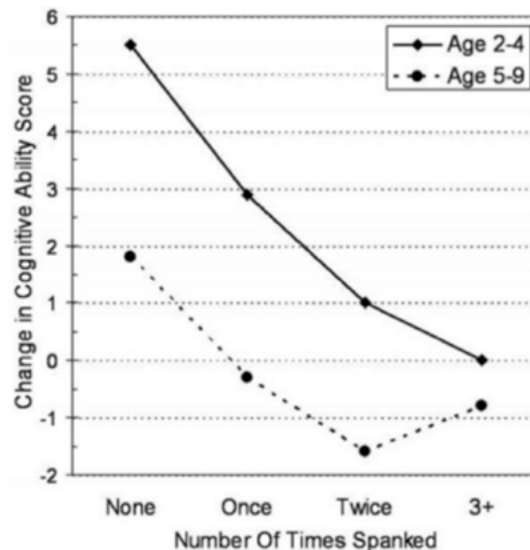


Figure 4. Effect of spanking on child cognitive ability. From Straus (2008). Reprinted with permission of the American Psychological Association.

ing in inner city communities reveals its variegation by class and religion. One commonality, however, is the shared belief that physical discipline ultimately reflects love and quality parenting (Pingleton, 2014). African American scholar Michael Eric Dyson explains the practice of spanking within the Black community unflinchingly:

The lash of the plantation overseer fell heavily on children to whip them into fear of white authority. Terror in the field often gave way to parents beating black children in the shack, or at times in the presence of the slave owner in forced cooperation to break a rebellious child's spirit. Black parents beat their children to keep them from misbehaving in the eyes of whites who had the power to send black youth to their deaths for the slightest offense. Today, many black parents fear that a loose tongue or flash of temper could

get their child killed by a trigger-happy cop. They would rather beat their offspring than bury them. (Dyson, 2014, p. A33)

The defense of corporal punishment, which traverses across centuries to the Biblical justification, "Spare the rod and spoil the child," buckles under recent data from the University of New Hampshire on the effect of spanking on cognitive ability. Nationally representative samples of 806 children between the ages of 2 and 4, and 704 children between the ages of 5 and 9 were assessed and then re-tested four years later. The IQs of children ages 2 to 4 who were not spanked were 5 points higher four years later than the IQs of those who were spanked (Straus, 2008). The IQs of children ages 5 to 9 years old who were not spanked were 2.8 points higher four years later than the IQs of children the same age who were spanked (Straus, 2008, see Figure 4).

STRATEGIES MOVING FORWARD: UNARMED TRUTH AND UNCONDITIONAL LOVE

Genuine patient empowerment necessitates an exploration of self. It conceptualizes the patient-provider relationship as a partnership that leans away from stereotype toward nonjudgment.

Given that racial and ethnic minorities and individuals with low household incomes frequently experience limited respect, power, and control in interactions with health care providers, empowering them to have increased control in patient-provider interactions is a crucial child life intervention (Tucker, Marsiske, Rice, Nielson, & Herman, 2014). Evidence suggests that the degree of cultural sensitivity in health care that patients perceive experiencing positively influences their adherence to treatment and, ultimately, their health outcomes (Lukoschek, 2003). It has also been asserted by some researchers that low adherence to recommended treatment behaviors among ethnically and racially diverse patients is to some degree due to limited levels of culture-related knowledge, skills, experience, and awareness demonstrated by their health care providers (Shapiro, Hollingshead, & Morrison, 2002).

When Dr. Martin Luther King accepted the Nobel Peace Prize in 1964 he said, "I believe that unarmed truth and

unconditional love will have the final word in reality. This is why right temporarily defeated is stronger than evil triumphant” (King, 1964, para. 7). Barack Obama recently echoed King’s words in his final State of the Union address. One could argue that the practice of unarmed truth and unconditional love is a form of cultural humility. It also serves as the best guidance I can offer to the many child life specialists who wonder how they can better serve families who, through their weaknesses, reveal that they have been crippled by the inner city.

To extend the mentality of King as metaphor—a man who always had a strong mindset to do good, despite the oppositional nature of the environment in which he had to function—I believe that the practice of child life can require a similar attitude. Despite the pushback, despite the constant call to re-educate, despite the plangent sorrow that pours in through the emergency room and rises through the hospital floors, despite the continuous witnessing of caregiver-child relationships; some healing, some debilitating, others a blend of both; we remain steadfast in our commitment to empowering children and families. To truly empower is to look squarely at the environmental factors that impact an individual’s behavior.

If I could return to the emergency room and reach myself at 27, watching the children of Baltimore drift by me, I would tell myself to get up. I would stand in front of the door to their care rooms, hand poised to knock, and remind myself that in crossing the threshold of their room I am bringing not only myself but also my privilege. And when the door would swing open to reveal the family, bodies braced before the elements of the world, I would first introduce kindness, irreducible and elemental in its power, and then myself. ✨

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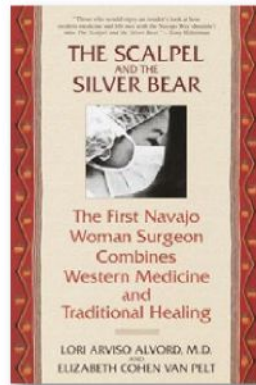
Melinda Rowe, MEd, CCLS, CEIM

The world of health care is ever changing and complex. As child life professionals, we must navigate and translate this world for those with whom we interact in our daily practice. This grows more complicated when our cultural beliefs and expectations differ from those of the patients and families we serve. Dr. Lori Arviso Alvord and Elizabeth Cohen Van Pelt's book, *The Scalpel and the Silver Bear* (1999), explores the journey of Dr. Alvord as she worked to become the first female Navajo surgeon. Throughout the book, Dr. Alvord shares her account of working to connect Western medicine with traditional Navajo healing while working as a physician in New Mexico. This book offers unique insight into the need for cultural competence within health care as it details Dr. Alvord's struggle to help patients with their medical needs, while trying to respectfully reconcile her own cultural beliefs about medicine with those of her patients.

Cultural competence has been defined as "a compilation of academic and interpersonal skills that allow individuals to increase their understanding and appreciation of cultural differences and similarities within, among, and between groups" (Johnson, 2005, p. 426). In the health care setting, there is the potential to interact with people from all over the world, with many different beliefs about health and health care. Professionals in the field benefit from seeking out opportunities to expose themselves to other cultures, heightening their awareness of their own cultural beliefs, and reflecting on how their cultural background might affect their understanding of others.

The book is organized chronologically as it tells the story of Dr. Alvord growing up on the Navajo reservation in New Mexico and graduating from Dartmouth University. She then attends medical school and completes her residency at Stanford University before establishing her practice as a general surgeon in New Mexico. The chapters flow together seamlessly, and although the book spans many years, the authors highlight only the most important events. While most of the book details Dr. Alvord's involvement in Western medicine as a Navajo, the authors also include personal stories about her life, which make the book a more enjoyable read, helping the audience to develop a more intimate insight into the cultural dichotomy pervasive throughout her life.

Throughout the book, the authors weave in traditional Navajo stories to help build the reader's knowledge of Navajo beliefs, practices, and culture. It is worth noting that while this story highlights Navajo culture, the skills, insights, and self-reflections gained can be applied by child life specialists, and other multidisciplinary team members, when working with patients and families from a wide variety of cultures and backgrounds. For example, Dr. Alvord discusses the Navajo belief called *walking in beauty*, which to the Navajo means to live life in a way that is harmonious and balanced with the surrounding world. For Navajos, this is the way to achieve health



and healing. When Navajo patients experience symptoms they cannot explain, they meet with a medicine man. While Dr. Alvord was pregnant, she had some complications and after seeking medical attention, she also went to visit a medicine man to help restore the balance with the universe. When Dr. Alvord began to reflect on this inner struggle, she realized that *walking in beauty* could be beneficial in crossing the cultural gap. Throughout her practice she reflects on her own experiences and beliefs to grow and provide her patients with the best care. This belief in the connectedness of life is very applicable to child life practice as we attempt to help families understand and navigate health care experiences.

While the book is written as a biography, it contains many insights into Dr. Alvord's medical practice with a group of people whose beliefs about healing differ from her own. Child life professionals meet people from many different places who may hold beliefs different from their own regarding such things as medical care, parenting, and decision making. These perceived differences can affect how health care professionals relate to those we serve. As child life professionals, we must work to learn more about the cultural beliefs that are unique to those we serve, so that we are able to expand our willingness and acceptance of ideas that might be different than our own personal beliefs. As we work to expand our openness and acceptance, we can also work toward developing new skills that help us be more sensitive in the way we practice child life. It is not only important to learn about different cultures, but also to reflect on how our own cultural beliefs influence our daily life and child life practice. As child life professionals, we need to increase our awareness about how different cultural beliefs make us feel, and what we need to work through internally in order to be supportive of patients and families.

As child life practice continues to expand into new areas and settings, it is vital for child life specialists to learn to provide care that is more culturally competent. Not only do we need to be aware of the cultures of those we serve, but also our own personal culture and how it can affect our own world views. The Child Life Council recognizes the importance of providing culturally sensitive care and includes the need to demonstrate respect for sociocultural diversity in the child life competencies (Child Life Council, 2010). *The Scalpel and the Silver Bear* is a helpful reminder that we each experience the world through the lens of our culture of origin. As child life professionals, we must recognize and reflect on our own practices and beliefs, so that we may recognize their influence when we interact with others. ✨

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PATHWAYS TO EBP

Making Evidence Accessible in Daily Work

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Making a commitment to evidence-based practice (EBP) can be a shift for clinicians. For many child life specialists, the intention of entering the field was to provide play and developmentally-supportive interventions at the bedside, not engage in scholarly pursuit. But the time has come for child life specialists and leaders to be reflective about what evidence-based practice really means within the scope of our work. The purpose is not to take time away from critical moments at the bedside but to focus our work by learning and incorporating evidence that highlights the impact of our interventions.

Most managers and directors likely tread lightly around the subject of evidence-based practice and feel even less comfortable making it a mandatory part of clinicians' training and performance evaluation. We encourage you to consider taking a risk because there are huge pay-offs involved in engaging in EBP. Keeping in mind that EBP shows the value of our work and helps guide our practice, investing time and education in EBP is essential. In a time of rapidly changing healthcare environments, being able to base interactions and interventions on best evidence provides clarity and support to the importance of the unique role of child life.

As a leader, how can you make a commitment to evidence-based practice in your department? Here are some strategies from two hospitals that have embarked on the EBP journey.

Where did you start?

- **Dallas:** At Children's Health, our first goal was to make a commitment as a leadership team to grow EBP in our department. As a seasoned leadership team, we felt that a refresher on EBP would increase our knowledge base as well as cultivate departmental growth. Tapping into the resources of the CLC EBP Committee and attending educational opportunities to learn more about EBP provided a strong foundation for growth. Staff were surveyed to assess their current knowledge base to guide our initiatives. The survey also assessed staff perception of incorporating EBP into their roles. Our first steps included increasing awareness, accessibility, and comfort with EBP. Gradual steps were taken to introduce the topic so as not to overwhelm staff or take away from patient care.
- **Cincinnati:** Cincinnati Children's leadership team was approached by a child life specialist working with a multidisciplinary team focused on increasing EBP competency within allied health. After an analysis of the baseline EBP knowledge of child life specialists was collected anonymously via survey, we realized that we had quite a bit to learn! We identified the level of knowledge that would be expected of each clinical level (I-III) and set about creating a plan to move everyone toward a higher level of competency.

How did you align the work with clinical responsibilities?

- **Dallas:** We focused on new initiatives that were identified as growth opportunities; for example, documentation and working with patients with developmental delay. We surveyed staff to see what topics they were interested in learning more about, and what topic areas in evidence-based practice would help them be more effective in their role. By focusing on areas of interest and practical application, EBP could easily be implemented into daily practice, and this generated more enthusiasm. We identified content "experts" among our staff, and asked for their support in presenting EBP to the department at monthly meetings.
- **Cincinnati:** We examined how EBP fit into our existing job descriptions to determine how much of an emphasis we could place on helping clinicians incorporate it into their clinical practice. As it turns out, EBP had been a standard part of our job descriptions that we had been overlooking for some time. In order to try and move everyone to their target level of knowledge, we worked with our educator and employed shared governance tactics to build educational offerings and interventions that would meet everyone's style of learning. During our first year of building knowledge, all of our child life specialists included a goal as part of their performance evaluation related to learning about EBP.

Where in the process are you? What have been the successes?

What have been the struggles?

- **Dallas:** EBP is incorporated into the education we provide to staff, patients, families, students, and the community. In addition, we are aligning annual competencies with an EBP component for the first time this year. Our competencies regarding assessments of cultural needs of patients and families and working with patients with psychiatric diagnoses both incorporate an EBP component. As we learn more about EBP, it will continue to shape our daily practice. We anticipate new growth opportunities in identifying changes in practice due to this new knowledge base from EBP.
- **Cincinnati:** We are in our second year of EBP learning. This year, our division-wide goal built into our performance management system has child life specialists working in small groups to complete an evidence-based practice project. The topics under study are relevant to the unit or area where staff work and help reinforce the theory that specialists learned the year prior. We have EBP champions within the division, as well as members of the leadership team, who have served as mentors and educators to the teams embarking on this goal.

Do you have any advice for other departments in making an EBP commitment?

- **Dallas:** Incorporating EBP into any program, regardless of size, may seem intimidating. However, remembering that EBP initiatives can be incorporated into daily practice or coincide with new growth opportunities makes getting started more manageable. There is no end goal—EBP is constantly evolving, and so is the

continued on page 39

Specialized Resources



Specialized Resources is a column designed to share books, websites, apps, and other resources that may be helpful for child life specialists working with a specific population.

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PREPARING TEENAGERS AND YOUNG ADULTS WITH DEVELOPMENTAL DISABILITIES AND BEHAVIORAL CONCERNS AND THEIR CAREGIVERS FOR TRANSITION TO ADULT CARE

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A comment I occasionally hear prior to a procedure may sound something like, "The patient is 17, so he should be fine." Once I have delved a little further, I may find that this 17-year-old's cognitive development is that of a 5-year-old, but he is the size of a linebacker and has had difficulty with the most basic health care encounters, such as stepping on the scale, transitioning from the waiting room, or even getting out of the car. This same 17-year-old's caregiver might request a *Barney & Friends* DVD for him during the wait for the provider. I often wonder how this patient will do in an adult setting, where there are no children's videos, preferred motivators, or sensory items for patients with developmental differences, let alone knowledge about how to support patients with behavioral difficulties.

In the pediatric setting, staff regularly deal with the varying developmental levels of children and can usually adapt accordingly. Once a patient begins to transition into the world of adult primary care, how can we help the patient and family, knowing that some primary care providers and their staff may have less knowledge or understanding of the difference between chronological age and developmental age, much less the functions of behavior for a patient with autism or other developmental disabilities? A search for resources for teenagers and young adults with developmental disabilities and behavioral concerns transitioning to adult care reveals how little has been written or developed to address this need.

According to Minnes and Steiner (2009), parents of children with Down syndrome report limited medical services if someone is not available to identify, interpret, and support the patient's needs.

For example, a mother reported her daughter becoming "hysterical" (which could be a typical baseline behavior) with a PAP smear, so in follow-up care, the physician never tested her again. Reasons for these limitations included practitioner attitudes, such as fear and leerness due to a communication barrier (Minnes & Steiner, 2009). Binks, Barden, Burke, and Young (2007) found that child-focused developmental programs, such as continuity of care and family engagement, were poorly available in the world of adult services. Only one-fifth (21.1%) of youth with autism spectrum disorder receive any transition planning (Kuhlthau, Warfield, Hurson, Delahaye, & Crossman, 2015), and there is limited understanding among adult health care providers of this population's unusual or unexpected sensory responses to environmental stimuli, as well as their often-increased anxiety associated with entering new and highly stimulating environments (Aylott, 2010).

Typically within transition planning, the pediatrician is responsible for sharing current health information, medication management, medical and psychosocial history, and patient summary information with adult health care personnel. Unfortunately, for patients with developmental disabilities and behavioral concerns, there is rarely anyone directly responsible for helping the patient and family prepare for the transition and seldom anyone to address the psychosocial concerns. With typical transition planning, a large focus is on preparing the young adult for self-care and independence, but many young adults with developmental disabilities and behavioral concerns will not be independent and able to take on the responsibilities of managing their health care. Therefore, helping families and caregivers share strategies and supports and advocating for adaptations in care can make all the difference for patient outcomes, and child life is well suited for this role.

Since there are limited available resources, I wanted to provide colleagues with information to share with families and caregivers. This information is based on interventions, recommendations, and adaptations that I have utilized through my work with the Adaptive Care Team at Cincinnati Children's Hospital Medical Center. Teaching families and caregivers to advocate and share recommendations with health care providers prior to appointments can potentially help ease the transition and reduce the negative impact that an unexpected outburst can have on the patient participating in a medical appointment. In some cases, an outburst can even

have an impact on the flow for the whole medical system with the potential of multiple staff being required for de-escalation.

Below are some ideas of what can be done within child life's scope of practice:

With typical transition planning, a large focus is on preparing the young adult for self-care and independence, but many young adults with developmental disabilities and behavioral concerns will not be independent and able to take on the responsibilities of managing their health care.

When the search for resources comes up short, sometimes you have to create your own! After finding such limited information and recognizing the impact that integrating behavior planning can make on the outcome of a health care encounter for patients with developmental diagnoses and behavioral concerns, the Adaptive Care Team at Cincinnati Children's Hospital Medical Center is in the process of creating preparation material for families of patients with developmental and/or behavioral conditions to receive as they prepare for the transition from pediatric to adult care. This will potentially include health care icons for health care appointments, a homework sheet for preparing the young adult for various health care appointments, and a worksheet for families to prepare in advance for the provider.

As you are helping to plan the transition to adult care, ask the caregiver if the patient has difficulty with any of the following:

- Communication – How does the young adult get his wants and needs met?
- Sensory Concerns – What type of sensory sensitivities impact the young adult? Do touch, sound, or light cause problems, or is the patient a “sensory seeker”?
- Environmental Stimulation –
 - Does the young adult have difficulty with crowds, too many people talking at once, or people asking too many questions?
 - Does the young adult have difficulty with transitioning or waiting?
 - Does the young adult have difficulty complying with demands or requests, or being told no?
 - Does the young adult have anxiety around unfamiliar people or environments, or in health care encounters in general?

If the answer is yes to any of the above questions, remind caregivers that they are the experts about the patient's psychosocial needs and encourage caregivers to:

- Prepare not only the patient, but also the staff, for the new visit.
- When they call to schedule appointments, ask the question, “How familiar is your staff with patients with developmental or behavioral difficulties?” and to share strategies they have found helpful for anxiety-producing situations.
- Share accommodations that have been beneficial in the past that may help the new staff prevent problems. Adaptations may include limiting touch until the end of the appointment for a patient with sensory sensitivities, or using the “Tell, Show, Do” method of preparation, first/then language, or a visual schedule for a patient with communication limitations so that the patient is aware of the steps of a procedure.
- Ask whether the clinic or medical setting recognizes the impact of environments and sensory stimulation on coping in this population. Sharing with the practice can facilitate understanding that having to wait in the waiting room or make several transitions can cause anxiety and a possible behavioral outburst from the patient.



- Share with the new staff what typically upsets the patient and the reactive behaviors that may ensue. It is important that the provider not assume cognitive impairment when a patient is non-verbal or appears uninterested. This type of information sharing is more effective than the patient having a complete meltdown, and leads to better health care outcomes.

Below is a list of resources with more questions and checklists that could be helpful. It is beneficial for providers to receive this information directly from the caregivers; therefore, I encourage caregivers to make their checklist specific to their young adult.

RESOURCES:

<https://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit>

This kit will provide you with suggestions and options for you to consider as you set out on this journey toward finding your child's own unique path to adulthood.

Autism: Caring for children with Autism Spectrum Disorders, A resource toolkit for clinicians, 2nd Edition by American Academy of Pediatrics (American Academy of Pediatrics)

This toolkit was developed to support health care professionals in the identification and ongoing management of children with autism spectrum disorders in the medical home.

<http://www.gottransition.org/youthfamilies/index.cfm>

Under Resources, if you select Developmental Disabilities and Transition, there are several links to different sites that aid with health care transition.

<http://vkc.mc.vanderbilt.edu/etoolkit/>

This is a comprehensive tool kit for primary care providers which includes information on different diagnoses and behavioral and mental health issues.

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Mary Faith Roell, MS, CCLS, is part of the Adaptive Care Team program at Cincinnati Children's Hospital Medical Center, which works with patients with developmental and/or behavioral conditions who have difficulty with coping and cooperating during health care visits.

A Cultural Competence Perspective: Understanding Your Own Culture First

Patricia Russell, MChE

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In the United States, the population of those seeking medical care is growing in number and diversity (Taylor, 2016), thus exacerbating racial and ethnic disparities of care (Committee on Quality of Health Care in America, Institute of Medicine, 2001). There can often be a rush to solve these problems with solutions that are global in scope and rarely consider individual practitioner empowerment, which is where the true locus of sustainable change lies. This article explores what this means for child life specialists whose jobs directly impact the health of our nation's children.

CHANGING DEMOGRAPHICS AND HEALTH CARE DISPARITIES

In 2001, The Institute of Medicine reported evidence of racial and ethnic disparities in health care across a range of illnesses and services in its landmark report, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Committee on Quality of Health Care in America, Institute of Medicine, 2001). This report highlighted the importance of focusing on health care quality, rather than simply access to and cost of health care services. It also noted that not only language, but also culture, beliefs, and knowledge contribute to the health care disparities divide (Committee on Quality of Health Care in America, Institute of Medicine, 2001).

Health care disparities, specifically among children, were further underscored in a report entitled "Technical Report – Racial and Ethnic Disparities in the Health and Health Care of Children," from the American Academy of Pediatrics Committee on Pediatric Research (Flores, 2010). By race, disparities were identified for mortality rates, access to care and use of services, prevention and population health, health status, adolescent health, chronic diseases, special health care needs, quality of care, and organ transplantation. Among children in the U.S., mortality rates were consistently higher for Black children – twice that of White children.

The disparities gap will most likely widen, given the projections that America's population will grow more rapidly in the coming decades. This projection is supported by a conclusion drawn from the Institute of Medicine's follow-up paper, entitled *How Far Have We Come in Reducing Health Disparities? Progress Since 2000: Workshop Summary* (Institute of Medicine, 2012), that the gaps in access to care across groups has increased.

The PEW Research Center (Taylor, 2016) reports that by 2055, the U.S. will no longer have a single racial or ethnic majority, and much of this diversification will be (and has been) driven by immigration. Nearly 59 million immigrants have arrived in the U.S. in the past 50 years, mostly from Latin America and Asia. As seen in Figure 1, a near-record 14% of the country's population is foreign-born today, compared with just 5% in 1965. And over the next five decades, the majority of U.S. population growth is projected to be linked to new Asian and Hispanic immigration.

According to the Institute of Medicine (2012), investments in solutions recommended in their 2001 report, such as increasing the

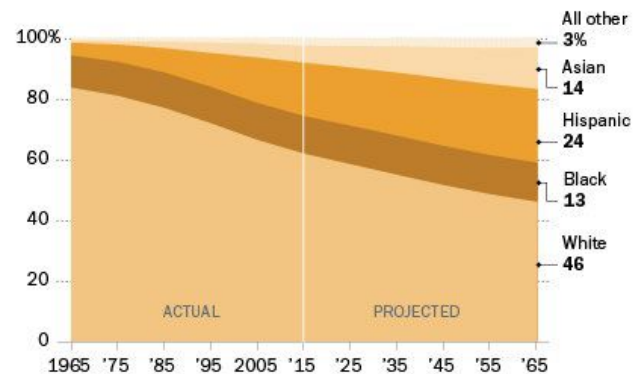


Figure 1. The changing face of America, 1965-2065. Note: Whites, Blacks, and Asians include only single-race non-Hispanics; Asians include Pacific Islanders. Hispanics can be of any race. Reprinted with permission of the Pew Research Center.

use of technology through the use of electronic medical records and advancing new cures, have reaped few benefits. In fact, when using life expectancy as a measure, racial disparities have increased.

Given that the growth of the population of minority children over the next five decades is projected to outpace that of non-Hispanic White children (See Figure 2), combined with the progress made to date to reduce disparities, the work of the child life specialists becomes even more urgent and imperative.

ADDRESSING DISPARITIES BROUGHT ABOUT BY DEMOGRAPHIC CHANGES

The National Initiative for Children's Health Quality (NICHQ), which is dedicated to eliminating the gap between what *is* and what *can be* in health care for all children, has recommended diversity/cultural competence education for health care providers. Cultural sensitivity training programs adopted by many health care institutions focus primarily on either confronting biases or learning about the general characteristics, health care practices, and beliefs of cultures as a means of impacting disparities and health care outcomes. Based on my experience as a cultural competence consultant, the use of this approach, which relied heavily on the acquisition and retention of a vast body of knowledge, underestimated the power of the practitioner's own mind to affect change. Therefore, it had a limited effect in increasing the health care professional's proficiency, change in attitude, and skill to impact disparities and achieve health care outcomes. For centuries, the potency of the mind has been recognized and used by physicians in their practice to impact health outcomes. Shifting diversity/cultural competence education to incorporate this approach can go a long way to reduce health care disparities.

In 2003, when invited by the University of Utah Health Sciences to design a cultural competence and mutual respect course for health care professionals, I combined two ideas, "to know self is to know others" and "valuing and respecting differences begins with valuing self first," to form the basis of a newly redesigned diversity program. Helping participants understand and exercise the power of their own minds, and more specifically, to question their ego or "internal



Figure 2. Distribution of the population by race and Hispanic origin for the total population and population under 18: 2014 and 2016. Note: The percentages for the total population or the population under 18 may not add to 100.0 due to rounding. Unless otherwise specified, race categories represent race alone. NHPI=Native Hawaiian and Other Pacific Islander, AIAN= American Indian and Alaska Native. Minority refers to everyone other than non-Hispanic White alone population. Source: U.S. Census Bureau.

culture” (i.e. their deep-rooted beliefs and values), using questioning and exercises to provoke a different way of thinking, advanced the agenda for reducing health care disparities at the university.

In research on the program conducted by the University of Utah Institutional Research Board using pre- and post-testing, participants showed an increase in cultural competency proficiency and ownership for health care outcomes (Musolino et al., 2009). Similar results were seen when the course was offered at Rochester General Hospital in the Department of Pediatrics. Teresa Schoell, MA, CCLS, says of the course, “This novel approach provides an improved framework for gaining personal awareness. As that personal awareness increases, our insight into our own thoughts and reactions grows. This helps us gain agency and autonomy over our behavior. Without this, we get dragged along by our own attitudes, perceptions, misperceptions, and ignorance...like passive observers of the mistakes we are actively making.”

Although this Socratic approach to a cultural competence program is innovative, the discourse, deep introspection, and self-questioning required are sometimes sidestepped for the comfort of the familiar, especially if the inquiry process is unexpected and creates discomfort. If, however, such introspection and self-questioning are avoided, individuals may unconsciously operate from a perspective that could inhibit acceptance and openness to change. Imagine a teacher with a mentality that the students who spoke Spanish before learning English would never become as proficient at reading as the native English speaking students. How would this impact the way the group of students are taught? What about child life specialists who are unaware of their mindsets? How might this impact the care provided and the overall approach to patients?

Understanding at a deep level how one judges (and then treats) others can benefit professional interactions, such as those between child life specialists and children, families, and colleagues. It is important to be aware of one’s own culture, whether it be the mainstream culture of the environment or a culture held by a minority at that particular time and place. Tapping into our internal

cultures can awaken a realization that irrespective of who is being treated, we are simply one human being interacting with another fellow human being. This human being-oriented mindset can break down potential barriers to good care.

EXERCISING THE POWER OF THE MIND

Given that typical cultural competence programs fail to address the issue sufficiently, how can child life specialists impact health care disparities for children? By exercising the power of the mind; in other words, by mastering the ego. Below are three steps for intercepting the *modus operandi* of one’s internal culture—one’s thought processes—in order to help bridge the gap between what is and what can be in health care for all children.

1. Be mindful of the power the mind has to affect change. An awareness that *your thinking informs your behavior and creates*

your results allows for neutrality (i.e., non-judgment, non-reaction) in all interactions.

2. Learn your “body or thought” signals, such as a feeling in the pit of the stomach or one’s face turning red, which indicate that judging could be happening; acknowledge the source of the signal as the ego wanting to play; smile and then re-focus on health care.
3. Consciously choose to humanize individuals—see the patient as a human being first before any other label or category. This will naturally strengthen interactions and the respect and dignity that the individual feels will promote health.

Being culturally competent—encompassing trust, accountability, and collaboration—is critical for creating an inclusive environment. However, implementing such an environment is difficult. A strong beginning in creating this shift is to tune health care providers into their own internal cultures and how this relates to the external culture in which they are practicing; the mindfulness and behavior that result can shift the whole pattern of the working environment, ultimately benefiting patients and families, regardless of the differences that distinguish the patients from those providing the care. ✨

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Increasing Access to Mobile Technology Solutions for Child Life Professionals and the World: Child Life at the United Nations

Amanda Moatz, MEd, CCLS
Consultant, Lutherville, MD

On Wednesday, February 3, 2016, Toni Millar, MS, CCLS, Amanda Moatz, MEd, CCLS, and Deborah Vilas, MS, CCLS, LMSW, had the honor of presenting at the 54th Session of the Commission for Social Development (CSocD54) at the United Nations (UN). Marking the first time a panel of Certified Child Life Specialists have presented at the UN, Millar, Moatz, and Vilas joined professionals representing technology, education, and intellectual/developmental disabilities to present “The Integration of Mobile Technology Solutions at the Direction of Professionals in the Field.” The objectives were to share information about child life as a profession and to describe how the integration of technology has enhanced access to services for both child life professionals and families.

The opportunity to present at the UN came about through professional collaboration with Lou Riccio, co-founder and director of [Child Life Technology](#) (CLT). CLT is a network of volunteers dedicated to helping child life professionals integrate technology solutions into their practice. Since 2014, Moatz has been volunteering with CLT to create a customizable electronic psychological preparation library with contributions from many individual child life professionals. One non-child life contributor to the project was Kevin Merges, EdD, Director of The Innovation Center and Executive Director of Global Education Programs at Rutgers Preparatory School (RPS) in New Jersey. Merges offered translation services to the project courtesy of his international staff and students. Merges and RPS, through its recent recognition as a non-governmental organization (NGO), also offered access to the UN.

During a previous presentation at the UN in 2015, Riccio and Merges shared information about the electronic psychological preparation library and, peripherally, the child life profession. Participants at that session were interested in learning more about the technology solutions presented, but also more about child life and the services available to children and their families. When the CSocD54 was announced, Merges and Riccio invited Millar, Moatz, and Vilas to develop and submit a proposal to share more about child life on the world stage. A forum on social development, equal access, and quality of life seemed like an ideal setting to introduce the values and principles of child life. Regarding the selection of panel presenters Merges shared, “We had the best of the best. Child



Professionals from child life, education, disability services, and technology presented information about child life and ways technology can enhance patient services at the United Nations on February 3, 2016.

Pictured L to R: Tracy Kernan, Kevin Merges, Toni Millar, Deborah Vilas, Lou Riccio, and Amanda Moatz.

life is not big on the rest of the planet. It needs to be. There is going to be a big education curve involved in getting people to understand the potential. Eventually this will be the global norm, but we have lots of work to do to get there.”

With her experience as a past president of CLC and international presenter, Millar, Director of Patient and Family-Centered Care and Child Life at New York-Presbyterian Morgan Stanley Children’s Hospital, was an obvious choice for an individual to detail the history and core concepts of the profession. Since the inception of the CLT electronic preparation library project, Vilas, an instructor and faculty advisor at Bank Street College of Education, has served as an advocate for play in all its forms, and her work with hospitals across North America and internationally to assess and promote play determined her position within the panel to be an expert on the topic. Moatz, who is currently leading CLC’s adoption of CLT’s original electronic psychological preparation library and is chair of the newly formed CLC Preparation Technology Task Force, provided the background and key benefits of the electronic preparation library resource. The final member of the panel was Tracy Kernan, LCSW, a senior coordinator in the Clinical and Family Services Department at YAI, who has worked closely with CLT to develop and integrate technology solutions for clients with intellectual and developmental disabilities.

The overall focus of the session was how child life and special needs professionals could guide the development of a technology solution to better meet the needs of the patients and families they serve. Millar and Vilas, however, led off with a rich description of the child life profession including its history, training, and certification process. Core competencies, specifically therapeutic play, were described with examples from both domestic and international experiences. Participants expressed appreciation for the introduction to child life and recognized the value of its services to patients and families. One participant, whose organization does not directly relate to child life services, demonstrated the range and scope of the opportunity of presenting at the UN: League of Women Voters director, Rosalee Keech, questioned if the child life skills and resources described could be applied to support children facing trauma outside the hospital environment, namely the current international refugee crisis. The panel was able to verify that child life professionals have provided services to children and families in the face of natural disasters and other large scale traumatic events.

Kernan, Moatz, and Riccio went on to describe the development and integration of technology solutions in clinical, educational, and community support settings. Highlighting the collaborative effort that resulted in the electronic psychological preparation library and its ability to increase flexibility for providers and access for patients allowed all participants to appreciate its form and function, regardless of whether or not their organizations' missions focused on children's health care. At the conclusion of the session, Juris Gulbris, Secretary General of the Baltic Black Sea Union, offered

his organization's assistance for language and cultural translations. There were additional offers to connect the panel with other NGOs working toward enhancing access to various types of services through the integration of technology.

As members of the panel continue to follow up with the connections made on the day of the presentation, it appears that there is both a need and desire to have child life professionals participating in the important work being done within the walls of the UN headquarters and beyond to the far reaches of its influence. Millar summed up the experience by saying, "I feel that presenting at the UN provided an opportunity to reach an audience that was eager to learn more about child life as a profession, psychosocial needs and the role of play for children facing medical challenges, and how technology enhances education for children and families. Just being in the UN was an honor and was an amazing experience." ✨

UPCOMING EVENTS

July 25-27, 2016

The 7th International Conference on Patient- and Family-Centered Care: Partnerships in Care, Interprofessional Education, and Research

New York Marriott Marquis
New York, NY

For information, visit the [IPFCC website](http://ipfcc.org)
or contact Racquel Codling at rcodling@ipfcc.org or 301-652-0281

September 24, 2016

Mountain West 3rd Biennial Conference: "Child Life Amplified: Your Mountain is Waiting"

Denver, CO

For information, visit the [Mountain West Child Life Association Website](http://mountainwestchildlife.org)

October 15-16, 2016

It Takes a Village: Comprehensive Collaborative Care

Children's Hospital of Philadelphia
Philadelphia, PA

CHOP is honored to host Amy Baxter, MD, creator of Buzzy™ as the Keynote Speaker. This continuing education opportunity offers a minimum of 9 PDU's. Attendees will have the opportunity to select individual breakout sessions to customize their learning experience. These sessions will focus on the multi-disciplinary approach to care at CHOP, including programming ideas, emergency department practices, bereavement interventions, mindfulness, and professional enhancement experiences.

For additional information and online registration,
visit chop.edu/childlifeconference

We look forward to seeing you in Philadelphia!
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October 19-21 and 24-26, 2016

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Amy Kennedy

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Amy Kennedy truly embodies the spirit of the Mary Barkey Clinical Excellence Award because she is not only a bastion of support for her coworkers both in their daily work and in times of need, but also for the patients and families she serves and the multidisciplinary teams with which she partners. Amy has given nearly twenty years of her life to the child life field, spending three of those years in the ICU and step down unit at Cardinal Glennon Children's Hospital in St. Louis, MO, and almost 17 years across various units and clinics of St. Jude Children's Research Hospital in Memphis, TN, where she currently works. However, her impact is better felt not by the number of years she has worked, but in the many ways that she has changed all who have known her.

Having witnessed Amy's clinical impact over the past several years, it is easy to see where her joyful spirit, caring ethic, and passionate advocacy have changed the landscape of psychosocial care in the hospital. She started as one of only two child life specialists, responsible for providing services to hundreds of children and their families. Since then, she has been able to participate in what she says has become one of her proudest achievements, "being on the ground floor of a growing department, and watching and helping it to grow." Since her start at St. Jude, she has helped to grow the program to a size of eighteen specialists, as health care providers' first-hand experiences with her work have spoken volumes about the important role of child life and the need for more available and comprehensive child life services throughout the hospital.

According to Amy, her favorite part of child life is "watching the patient or siblings overcome something that was hard for them, something challenging, or something that they didn't think they could do." However, she is seldom just *watching* these things happen in front of her. Instead she is: building rapport with ease, empowering children through play, delivering preparation and procedural support for radiation simulations and therapy, providing diagnostic education, listening to the concerns of parents who are actively losing and fighting for their children at the same time, teaching children to realize their own inherent coping capabilities, connecting with and advocating for teens who would rather be anywhere else in the world, caring for the emotional needs of the medical staff she works alongside, and somehow finding time to serve on administrative and organization levels as she both lives and speaks to the impact of child life. These things alone are important responsibilities for any child life professional, but the level at which Amy completes these tasks and also finds the time, energy, and passion for all of them is what makes her truly unique. In truth, she will even tell you that she felt "blown away" to be nominated for this award, because, "I don't put myself on that level – award winners. I do my job because I love it. My mission in my role is to reduce stress and trauma, and I just really enjoy what I do." Because of her passion, dedication, and humble spirit, her work has brought an enjoyment of and appreciation for child life to all levels of hospital staff and administration.

The child life field narrowly avoided missing out on Amy

Kennedy's contributions to family-centered care. When Amy was in college, she spent a year studying fashion design at Kent State, which she loved as sewing is one of her hobbies even today (she makes the BEST burp cloths you will ever find, and fabric wreaths that people fight over during Christmas gift exchanges). However, she soon realized that she lacked a certain "cutthroat" level of competition, and changed her major and school to study art education at Southwest Missouri State. There, on a chance camping trip one weekend, she found out about the field of her dreams while gigging (an activity that involves standing on a boat and spearfishing at night, she tells me) with a classmate. Initially her parents were concerned about yet another change in major, but they now see that child life was the ideal field for her.

Although her clinical work is where she feels strongest and most at ease, one of the impressive things about Amy Kennedy is that she has found a way to continue growing and cultivating new strengths in her many years of clinical practice. For instance, Amy has given several presentations at CLC's annual conference, and has even presented at the American Society of Radiation Therapists conference about ways to support pediatric patients in the radiation oncology setting. She has conducted and published research on this topic as well – and "researcher" and "writer" she admits are not words she ever envisioned using to describe herself. The child life profession will always need people like Amy, people who are steadfast and gifted clinicians, thoughtful and voracious advocates, to inspire the research and writing that enable the field to grow.

Outside of the hospital walls, Amy sits on the Board of Trustees for the Ronald McDonald House in Memphis, having just been asked to serve a second term. She has also dedicated more than ten years of service as a member of the Memphis chapter of Habitat for Humanity, during which she was able to participate in a "week long blitz build" in Iowa after a serious flood. In her free time, Amy enjoys being outdoors, traveling, making world-renowned cookies, trying new and interesting restaurants, enjoying live music, and spending time with her nieces and nephews in St. Louis. She also once chatted with Captain Kangaroo at an advocacy cocktail party, which she said might be of interest to some readers who may be within a certain age bracket. It may seem as if she has many hobbies, but really these are ways to prepare herself for her next career: owning her own bakery/café/art shop in Ireland, and hopefully marrying the sheep farmer of her dreams.

Amy once had the pleasure of meeting Mary Barkey many years ago when she came to speak at Cardinal Glennon, where Mary's nephew and Amy both worked at the time. Amy describes her as "lovely," and she "never in a million years" dreamed that she would one day be honored with Mary's award. When you read the description of the Mary Barkey Clinical Excellence Award, Amy Kennedy displays all of those qualities and so many more. Amy is clinically excellent, professionally admirable, personally enjoyable, and so many other things. Amy, the child life field is better because you are in it, because we have learned from you, and because we have grown with you; it is an honor to be able to recognize you with the Mary Barkey Clinical Excellence Award. 🌸

Nomination forms for the 2017 Mary Barkey Clinical Excellence Award are now available on the [CLC website](#).

Sometimes it's the Littlest Things

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other day, and brushed with a soft bristle brush. As a preschooler, he elected to grow his hair longer, and we oiled the roots every day, combed it with a wide-tooth comb, and I learned to twist, plait, and cornrow. If I washed his hair daily, combed it with the small-tooth comb the hospital provided, and never oiled it, we would quickly ruin his hair and risk significant breakage and hair loss.

A lack of proper tools, but more importantly a lack of proper knowledge, lay at the heart of the competency deficit recognized by the inpatient psychiatric nurse. Black patients with thick curls had to prove they could perform self-care tasks, but did not have access to the tools they needed. Our hospital did not offer hair oil or large-tooth combs, leaving some Black patients unable to care for their hair, and the nurses to chart their unkempt appearance. This would sometimes be compounded if a nurse mistook their Black patient's refusal to wash their hair every day as a sign of poor hygiene. Failure to perform ADLs can result in a delay of discharge. In this case, it added up to a disparity of care for a specific subgroup of patients.

To solve this issue, the committee partnered with the purchasing, finance, and nursing departments to make hair oil and wide-tooth combs a standard item on all the floors. The committee also collaborated with the clinical education department to put together a one-page flyer for medical staff, educating them about the basics of hair care and hygiene across the cultural spectrum. The committee rolled this out, not just to the inpatient psychiatric unit, but to all of the nursing units throughout the hospital, and then the health system. This all started with the simple request of one nurse: "Can we get better combs?"

Sometimes, small things have large impacts. For a patient struggling to heal and go home, progress may only be as far away as a comb that will go through his curls, or a conditioning oil that will keep her hair from breaking when she braids it. By meeting this need, we provide a more competent level of care for our patients of color. But, beyond our patients, our committee benefited, too. In completing this project and in seeing the positive impact for our patients, our team members, our hospital, and our health system, we gained a much-needed boost to our confidence and sense of efficacy. Seeing the tangible progress we made in forwarding culturally competent care through the Black hair care project, we felt empowered. Building off of that success, we now tackle new projects with an invigorated sense of competence and effectiveness. By building endurance on the smaller projects, we gained greater capacity to tackle the larger ones. It might be "just a comb and some oil" to our patients, and "just one small project" to our committee, but sometimes it is the littlest things that make the biggest difference. ✨

CEO Shares

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five CLC committees involved in the preparation of new Certified Child Life Specialists (Clinical Internship, Undergraduate Endorsement, Graduate Program Accreditation, Education and Training, and Certification). As a result of this summit, we hope to promote

From the Executive Editor

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dynamics of access/inaccessibility, approval/non-approval. There are many gray areas in child life preparation and practice, and much like my favorite answer to any child development question, "it depends" on the contextual issues at play. Whether questions of (dis)ability, economic feasibility, racial disparities, or cultural competency, our actions today trickle down to shape the field as it will stand one year from today, or five, or fifty. There will never be enough policies, procedures, explicit instructions, or guidelines to cover the gambit of unique cases and situations that will need to be navigated as our field continues growing, solidifying, and evolving.

Our hope is that this special issue, entitled, "Acceptance, Access, and the Child Life Profession," will help to begin these dialogues. The authors featured here have pushed the theoretical envelope, some also at the risk of their own vulnerability. Some of these conversations concern language and how we address those who are different from ourselves; other authors have centered on fairness, sexuality, gender, cultural competence, and international child life practice. Still more have challenged our perceptions about child life specialists with disabilities, and encouraged us to continue thinking about professional and academic access as we continue to strive for professional credibility in our strategic plan. Finally, Divna Wheelwright's *Focus* article ties many of these issues into an in-depth analysis of child life services for those in the inner city.

With my final editor's column, it is hard to wrap up all that I would like to convey into a coherent conclusion paragraph. Instead, I will leave you with one of my favorite quotes. French philosopher Michel Foucault (1988) once said that "The main interest in life and work is to become someone else that you were not in the beginning" (p. 9). Thank you for allowing me to engage you in these columns, as these experiences have transformed me greatly. However, let us also take Foucault's sentiment to the clinics, the inpatient hallways, and our relationships with children and families. Let us transform others and ourselves, but we cannot allow our transformational momentum to stop there. Our responsibility goes beyond battling minor personal injustices, beyond the Sara Pickerings we have all encountered in some form or fashion. Let's work for justice, for reform, for large-scale change through ground level encounters and advocacy. Let us name our power and our privilege, and strive for access and acceptance. This is our professional identity, and will be our professional legacy. ✨

Foucault, M. (1988). Truth, power, self. In L.H. Martin, (Ed.), *Technologies of the self: A seminar with Michel Foucault* (pp. 9-15). Amherst, MA: University of Massachusetts Press.

understanding and coordination between academic programs and internship sites to enhance the preparation of new child life specialists and facilitate the student transition process.

This organization exists to support you, and we are cognizant every day that our efforts impact your work. Our organization's strategic drivers of professional credibility, member experience, and organizational strength guide our decision making and fuel our excitement for the future of child life. ✨



"F" is for Fairness

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On any given day, a child life specialist might implicitly pursue a sense of fairness or equality when determining the priority of patient care needs, deciding whether or not to call for a translator to aid in speaking with a family, or negotiating with colleagues about who will provide holiday coverage at the hospital. These day-to-day acknowledgements of fairness and equality are necessary and important, and also model these concepts for patients, families, and staff. However, they may often be seen as just part of the job, rather than a daily reinforcement of the idea of equity, especially when considered in light of the grander scope of health care and health care-related policy needs.

Take, for example, the effect of racial health disparities on the Black American community. According to Mechanic (2005), "socioeconomic status fundamentally affects most health and disease outcomes, but black Americans are doubly disadvantaged by low status, discrimination, and residential segregation" (p.335). These disadvantages lead to decreased access to health care services and an inability to quickly benefit from health care advances. It follows that if socioeconomically disadvantaged ethnic populations have less access to health care advances overall, they may have fewer opportunities to interact with a child life specialist. Families with fewer resources and less education may also be less able to seek out resources such as online procedural preparation videos offered by child life departments, and less likely to be able to attend a pre-operative tour. Finally, these families may see less value in having a child life specialist interact with their child due to factors such as lack of knowledge about the profession and the health care environment, or cultural beliefs about parenting and coping.

David Mechanic (2005), Director of the Institute for Health, Health Care Policy, and Aging Research at Rutgers University, suggests that increasing education and providing income support are the driving factors toward equalizing racial health disparities, along with enhancing neighborhood and environmental infrastructures. Some examples of these infrastructures include access to high-quality health care, successful schools with strong teachers, access to regular and healthy meals, and clean and safe play spaces for children in their neighborhoods. Child life professionals' assessment skills, educational abilities, and knowledge base of child development assure that building these infrastructures are areas of public policy where the Child Life Council's membership could have a voice. Pairing with organizations that advocate for underserved populations would help individual child life specialists ensure that services were made known and available to populations whose social situations may have unfairly barred them from receiving care.

In keeping with the theme of ethnic disparity and diversity, consider that while many health care providers identify as White, an ever-growing number of patients identify in other ethnic groups (Cohen, Gabriel, & Terrell, 2002). Although it is clear that health care organizations encourage and provide training around cultural competence, one study still found that patients "expressed a preference for health care providers and researchers who 'looked like them'" and that this influenced their likelihood to participate in clinical trials (Cohen et al., 2002, p.93). One can infer from this that having a provider of the same ethnicity increases the level



of trust the patient places in that provider. With more trust, a patient may share more concerns with the provider, thus allowing the provider to deliver an enhanced level of care. The population of the United States is continually becoming more diverse and it is imperative that child life specialists inform themselves of these group differences and preferences, and examine their own biases and preferences, in order to build trusting relationships with patients and families. A good understanding of our personal cultures and how they differ from those of our patients can provide a foundation for equalizing the care that our patients receive from us.

In addition, Cohen and colleagues (2002) posited that "given changing U.S. demographic trends, achieving greater diversity in the health care workforce will likely yield the practical benefits of producing a culturally competent workforce, improving access to high-quality care for the medically underserved, increasing the breadth and depth of the U.S. health research agenda, and expanding the pool of medically trained executives and policymakers ready to take up leadership positions in the health care system of the future" (p.90). Child life professionals can and should strive for a high level of cultural competence, but ultimately this may not be enough to assure that all patients are receiving fair, high quality care. An increase in diversity coupled with



meeting patients in the communities in which they live could not only augment the level of psychosocial care families are receiving, but would likely give child life specialists a broadened perspective of the needs of these populations. The child life profession has already expanded beyond the hospital to bereavement centers, camps, and private practice settings. Taking this a step further, being involved in patients' communities could potentially involve child life employment in low income clinics, schools, and community centers. The increase in cultural knowledge that involvement at the community level could bring would almost certainly increase a specialist's competence to care for diverse patients. This knowledge could be shared with students, leading ultimately to a better prepared and more culturally competent group of professionals. In addition, this strengthened competence could lend itself to public policy advocacy.

So how, then, do we as child life professionals work toward increasing the diversity of our profession and our ability to provide an equal level of care to all patients? We, as a profession, must understand that diversity and fairness are linked. Amplifying our diversity and cultural competence will allow us to build the trusting relationships that are the basis of fair, quality health care. Recent studies that have collected the demographic information of child life

professionals (Belisario, 2014; Carter, 2014; Iris-Wilbanks, 2014; Meyer, 2014) have demonstrated that 87-95% of the respondents identified as White. The Child Life Council, in its Diversity Statement, reports that encouraging diversity "...requires continued effort to attract and develop qualified persons of diverse backgrounds whose unique life experiences and ways of thinking foster a culture of inclusion and diverse perspectives" (Child Life Council, 2015, Diversity Statement, para. 2). The Child Life Council has reached out to international specialists to support conference attendance, but other strategies may be needed to develop a truly diverse and culturally competent pool of child life professionals. This may require focusing on education by starting as early as middle and high school to inform ethnically diverse students about the field of child life and to mentor them as they consider the child life career path. Cohen and colleagues (2002) state, "Only by encountering and interacting with individuals from a variety of racial and ethnic backgrounds can students transcend their own viewpoints and see them through the eyes of others" (p.92). Having child life specialists interact with diverse youth in a pre-college setting will expose the youth to the child life profession, but will also help to educate the child life specialists about the cultures these youth come from and the barriers that might keep them from pursuing a child life career.

If the Council desires to increase diversity, these barriers will need to be addressed, as the onset of the requirement of a master's degree, and the associated financial costs and time required to attain the degree, may place this career out of reach for lower socioeconomic status students unless alternate entry plans are developed.

On a smaller scale, child life specialists might reach out to local elementary schools in under-privileged areas and offer to speak at career days. They might similarly develop opportunities to speak to freshmen in foundational child development, family studies, or early childhood education courses to heighten awareness of child life as another career path. In addition, students from lower socio-economic backgrounds might benefit from general preparation for working in a professional environment and assistance with resume writing and interviewing skills beyond that which is typically offered in an internship. An article in the Washington Post addressed the issue of increasing diversity in a business with the suggestion of creating "a pipeline of diverse applicants."

Building a pipeline involves reaching out beyond traditional or mainstream recruitment channels to communities that might not normally hear about your available jobs. You may choose to attend lesser known recruitment fairs in smaller markets, for example, or advertise your jobs through minority media. Some organizations even establish mentoring, internship and other educational programs that introduce diverse youth to their profession or industry long before they might be eligible for employment (Garcia, 2010, para. 7)

The Child Life Council will need to entertain suggestions such as these in order to attract and maintain a diverse membership, but it will also need to balance growth in the profession with the limited number of jobs available.

As our profession becomes more diverse, there will be those who consider the intentional act of choosing to cultivate diversity in these ways to be unfair. Some may say that mentoring underprivileged students or assisting them with professional skills gives them an unfair

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F is for Fairness

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advantage over other students who have worked hard on their own. Others will voice that ethnic diversity is not a job qualification. And, in truth, the very students and professionals that are being singled out in order to “help” them achieve success in the child life field may not appreciate those efforts; they may wish to pursue other options or to demonstrate competence on their own. Clearly, issues of fairness and equality extend even into the discussion of how to increase diversity in the profession, the ultimate goal of which is increasing fairness and equality in patient care and treatment of child life staff. Regardless

of the path, though, increasing intentionality about creating and recognizing diversity in the profession of child life is the first step.

While considering the possibilities of attracting a more diverse child life field, it is also necessary to address the subtle discrimination faced by minority specialists. In her unpublished thesis, Misato Suzuki (2015) cites responses from child life specialists indicating that while they may have experienced discrimination from patients and families, it was more likely to have come from other staff members in the form of ignoring their patient advocacy attempts, offensive and stereotypical questions about their culture, and feeling that they had to work harder to prove themselves. The study participants went on to say that being able to self-advocate and having a supportive figure they could talk to about their experiences were the most helpful tactics in combating their feelings of alienation. Strong communication in the child life team made the most difference for these child life specialists as it allowed them to process their experiences in a safe environment and also potentially augmented their teams’ cultural competence.

Flores (2010) reports that extensive, pervasive, and persistent racial and ethnic disparities exist in children’s health and health care. Going forward to meet the needs of these children, we, as child life professionals, will need to look within and increase our own diversity and cultural competence. We will need to reach out to and support the medically underserved, both through our practice and through the lens of public policy involvement. Finally, we will need to protect and support our own, modeling for other health care providers that fair and equal treatment applies to staff as well as patients and families. ✨

UPCOMING CLC WEBINARS

Good news—the lineup of CLC webinars for the remainder of the year has been set. For details of each session and to register for a webinar, see the [webinar page](#) on the CLC website. Unless otherwise noted, CLC webinars are scheduled on Wednesday afternoons from 2:30 to 4:00 pm Eastern time. Attendees earn 1.5 PDU for each webinar. Individual and group rates are available.

For an even more convenient way to earn PDUs, several OnDemand webinars are now available! See the [CLC website](#) for details.

July 20—Past Performance as a Predictor of Future Performance: Why You Should Prepare for a Behavioral Interview

July 27—Utilizing and Identifying Music as a Therapeutic Tool in the Pediatric Hospital Setting

August 3—Empowering the Voices of Siblings: Supporting Brothers and Sisters at End of Life

August 10—Child Life in Pediatric Hospice: Advocacy, Legacy, and Psychosocial Support

August 17—“Beyond The Pediatric Wards”: Providing Child Life Consults in the Adult World

August 24—Cancer in the Community: Developing School Programs to Connect Patients, Families, Classrooms, and Hospitals

August 31—A Bond that Lasts a Lifetime: Open Sibling Visitation in the Neonatal Intensive Care Unit

September 7—Surviving and Thriving in the Role of a Resource/PRN Child Life Specialist

September 14—Donor Impact Report: Utilizing Donor Engagement to Magnify Clinical Practice

September 21—The Use of an Ethical Framework in Pediatric End-of-Life Decision Making

October 5—Life After Dying: A Model of Grief, Loss, and Death Anxiety for Survivors of Life-Threatening Diagnoses

October 12—Child Life Without Borders: Serving on Medical Mission Trips

October 19—Embodying Self-Care: Why Mindfulness Matters

October 26—Constructing the Play Lady: Child Life and the Female Human Identity

November 2—Play is the Work of Children AND of the Child Life Specialist: Making Play a Vital Part of Your Day and Theirs

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Male CCLS

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witnessed the entire conversation. In this situation a small practice like leaving the door open was extremely important in protecting myself from a possible accusation stemming from stereotypes like “pervert” or “sexual abuser.”

I have contemplated such stereotypes and how they affect my daily work. At times, I find myself guarded when providing support, verbally or physically, to patients and families I have just met. There is a moment I take—a pause to see how they perceive me, a male—before proceeding. I think the knowledge of these stereotypes causes me to expect a negative response. I can probably attribute this reaction more to experiences I have had outside of the hospital such as meeting new people who ask about my job. Some don’t always know how to continue a conversation after learning about what I do, which can be deflating. It’s as if I answered their question wrong and have inadvertently been deemed a social deviant. To get around these kinds of responses I often describe my job first with its more “manly” roles, such as procedural and bereavement support. I have learned how to placate these types of reactions, but some I cannot. However, in hospital situations, I have been barred from entering rooms of patients who have adverse reactions to men, stemming from abuse or a lack of exposure to men. In these situations I have had to fully rely on parents, the nurse, or a female child life specialist to provide the needed support. This can be disheartening, as the only aspect keeping me from improving the patients experience is my gender.

As a male working among so many females, it can sometimes feel like I need to conform to generalizations of the female gender. Women are commonly perceived to be more empathetic and caring than men. For instance, “most sociology-based studies conclude that girls and women are commonly socialized to and verbalized as more empathetic compared to boys and men” (Nielsen, 2014, p. 165). This is a difficult observation for me as a man working as a child life specialist, since I realize that empathy is a vital skill to have when working with children in traumatic situations. Does this mean I am less effective at my job? No. On one hand, it may allude to an aspect of work that I can improve on. On the other hand, if I let myself conform to what is “common” for males and don’t make an effort to be fully empathetic and caring, then maybe it would make me less effective. I don’t see this happening for myself. Will I play Barbies to create a normalizing experience? Yes. Will I hold a young patient’s hand while providing support during an IV placement? Yes. Will I provide comfort in the form of a hug to a parent who has just lost a child? Absolutely.

Something else I have noticed as a male is that I find myself somewhat pushed to be involved in more “manly” tasks. If there is a need for heavy lifting on my unit or in my department, I am usually asked to help. Men in female predominant professions express they are often expected to do more vigorous tasks because of the assumptions and stereotypes that men are better at tasks involving

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physical activity (Wingfield & Myles, 2014). During my time on a day surgery unit, when there was an extremely anxious or combative patient, I was sometimes chosen to help in deescalating the situation. In one specific instance, I remember being asked to assist a patient with a reputation for being extremely difficult and who, on that day, had not even made it to the surgery floor before running from his mother and locking himself into a room. Past history showed

this patient hit, spit, and hissed. I arrived at the room to find three security guards, the mother crying, and other hospital staff standing outside the door. After easing myself into the room, I began an open monologue about video games (the patient loved video games) that continued for 30 minutes while the patient was unresponsive and curled up in the corner of the room hiding his face. Eventually the patient slowly began to engage with me, in time walked with me to the surgery floor, and ultimately, with further support and medication, received his scheduled care.

Situations like this, where men seem to be chosen for tasks because of their gender, may occur in many professions. This is certainly true for men in nursing; many mention that their tasks often revolved around heavy

lifting and managing difficult patients (McDonald, 2012). I don’t find this possible allocation of tasks based on gender insulting, nor a disadvantage to myself as a male in a predominantly female profession. In many instances, I find it to be a way in which I can use my masculinity to benefit and bring excellence to my profession as a child life specialist.

There are both advantages and disadvantages to being the minority gender in any profession. What Jerry taught me, and what I have learned in my own practice, is to be aware of the gender stereotypes, know what to expect because of them, learn how to work with them, and understand how they can often be a benefit to myself and my profession. Although it may be necessary for me to take precautions to protect myself from the negative gender stereotypes of being male, these steps are easily learned and integrated into practice. I may not always be deemed as empathetic as my female coworkers, but that is a skill I can work to improve. I may be consulted for the difficult patients more often, but through those experiences I can relay what I have learned to others, becoming a valuable asset to the team. I may be asked to do some heavy lifting, but that is okay. A little lifting has never made me think twice about my profession. ✨

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Being LGBT

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when these children are seen in a health care setting, LGBT parents may feel uncomfortable disclosing their sexual orientation or gender identity for fear it could compromise their child's care (Chapman, Watkins, Zappia, Combs, & Shields, 2012) or lead to negative judgements about their parenting.

At the same time, it is important for health care providers to know who the members of a child's family are in order to provide comprehensive family-centered care to each patient. There are several reasons why it is important for LGBT parents to feel comfortable disclosing their sexual orientation or gender identity to the health care team. Many hospitals only allow parents or grandparents to spend the night in the hospital with a child. In this situation, same-sex parents would need to identify that they are each a parent to the child to be allowed overnight access to the hospital. Health care providers also need to know who in the family will be caring for a child when they return home, which would require same-sex parents to disclose their family makeup.

In order to promote a safe and accepting environment for LGBT parents, health care organizations should publicly display their non-discrimination policy that includes sexual orientation and gender identity, revise forms to include gender neutral terms, and provide resources that can assist LGBT families in legal and other concerns that they may encounter. Resources, including medical forms such as power of attorney for health care designation, as well as community and national resources should be made available (Weber, 2010). Information regarding state-specific laws can also be provided, including legal information about second parent adoption and housing and employment discrimination. Child life specialists should work with the multidisciplinary team to advocate for the availability of these resources.

Family-centered care requires that health care professionals show respect for all families, regardless of sexual orientation, gender identity, or family structure (Chapman, et al., 2012). Regardless of the setting within which they work, child life specialists can provide an environment that includes all forms of diversity, including pictures of diverse people and relationships, the availability of books and magazines that appeal to a wide range of sexual orientations and gender identities, and being open and non-judgmental when patients or family members share their sexual orientation and/or gender identity (Kane-Lee & Bayer, 2012). Child life specialists can advocate for the needs of patients and families who identify as LGBT, including encouraging continuing education related to caring for people who identify as LGBT for staff at their place of employment.

WORKPLACE CONSIDERATIONS FOR PROFESSIONALS WHO IDENTIFY AS LGBT

Currently there is no federal non-discrimination legislation

protecting LGBT workers in the United States. There are laws that protect LGBT people from workplace discrimination based on sexual orientation and gender identity in 19 states and the District of Columbia, and three states protect against discrimination based on sexual orientation only (Human Rights Campaign, n.d.-b). According to the Human Rights Campaign (n.d.-b.), more than 50% of Americans live in states where they may face discrimination based on their sexual orientation and/or gender identity. Employers are not currently prohibited from asking questions regarding sexual orientation or gender identity, unless it is prohibited in the state where the company does business. Employees are not required to answer such questions, but sexual orientation and/or gender identity may be revealed when filling out forms for insurance or emergency contact information.

Recent research shows that companies that are seen as being LGBT-supportive have better employee retention and employee engagement (Johnson, 2015). There are many ways that companies can show support for their LGBT employees including, but not limited to: a workplace nondiscrimination policy that includes sexual orientation and gender identity; staff education on LGBT workplace concerns, including additional training for those in leadership positions; a plan to address the specific needs of transgender employees; and health care coverage that includes transgender health care needs (The Joint Commission, 2011). People who identify as LGBT must take these details into consideration when deciding on a career and looking for employment.

It is difficult to know how many people who identify as LGBT are members of the Child Life Council (CLC) or currently work in the child life profession. No previous CLC membership survey has asked questions regarding sexual orientation or gender identity, although several professional organizations, including The National Association of Social Workers and the American Psychological Association, include a question or questions that allow members to identify their sexual orientation and/or gender identity when collecting demographic information. Having access to this information allows organizations to more accurately know the makeup of their membership and should be seen as no different than asking a person's race or ethnicity. These demographic questions are always optional, so members would not be required to answer the question if they did not feel comfortable doing so.

The Williams Institute estimates that close to 4% of the population identifies as LGB and 0.3% identify as transgender (Gates, 2011). Based on these percentages, it can be estimated that there are 214 LGB and 16 transgender CLC members (based on 5,349 CLC members) and 210 LGB and 16 transgender child life specialists (based on 5,251 active child life specialists). Having accurate demographic information about CLC membership, including sexual orientation and gender identity, would provide the organization with additional data about the background of the members of the child life profession, similar to knowing how many men or people of

Child life specialists can model how to work with diverse populations and provide normalizing experiences within the health care setting for patients and caregivers who identify as LGBT, as well as other diverse populations. Health care facilities want to show that they are leaders in various health care designations.

different races are in the child life field. Knowing that there are child life specialists who identify as LGBT may also encourage others who identify as LGBT to pursue a career in child life, adding to the diversity within the profession.

Professional development and continuing education are necessary to remain up-to-date on many aspects of health care, including information concerning the diverse populations that are served within each health care facility. This should include continuing education regarding sexual orientation and gender identity. Child life specialists can model how to work with diverse populations and provide normalizing experiences within the health care setting for patients and caregivers who identify as LGBT, as well as other diverse populations. Health care facilities want to show that they are leaders in various health care designations. Child life specialists who work in the United States can get involved in public policy and advocacy work by partnering with their human resources and/or diversity departments to advocate for their hospital to complete the [Human Rights Campaign's Healthcare Equality Index](#), which is a yearly designation that recognizes leaders in providing LGBT health care. This designation may encourage patients to choose one healthcare facility over another one that does not carry such a designation. The Healthcare Equality Index also takes into account Joint Commission and Center for Medicare and Medicaid Services (CMS) requirements.

These are times of change and transition for patients, families, and staff who identify as LGBT. Awareness of the unique concerns currently facing the LGBT community is important for child life professionals, not only when providing family-centered care to these patients and families, but also in ensuring that the workplace of child life professionals is an environment that is accepting of all patients, families, and staff, regardless of their sexual orientation or gender identity. Child life professionals who are well educated and diverse in their thinking and work ethic are in a unique position to change the landscape of the LGBT health care environment and each health care experience encountered by an individual who identifies as LGBT. ✨

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Pathways to EBP

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department. It is okay to not feel like an expert and to ask for guidance. Many hospitals have helpful resources through nursing or research. Making a commitment to EBP will result in clinical and professional growth in your department and staff.

- Cincinnati: Take a leap of faith! This is a scary process and it can be intimidating if, as a leader, you feel like you don't understand the EBP process. See what resources are available at your hospital. If you don't have many internal options, CLC offers significant learning supports and resources to help explain and educate you and your team on the process. Reach out to peers in other hospitals (like Dallas and Cincinnati) to learn from our experiences. And jump in! Set a small goal for your team—review one article a

month at a journal club. You can build upon this foundation and take additional steps once you feel comfortable.

The responsibility to prioritize EBP in each child life department does not lie solely with the directors, managers, or team leaders. As child life specialists, we teach the “Why?” when we engage in diagnosis education or procedural support. It is essential that we are able to speak to the “Why?” when discussing best practice. It is the responsibility of every child life specialist to implement EBP to guide best practice to ensure ongoing growth and viability in an often complex and evolving health care environment, and support us in practicing ethically and meeting the needs of a diverse group of patients and families. ✨

Interested in learning more about evidence-based practice (EBP)? Explore previous articles in the Pathways to EBP series on the Evidence-Based Practice Committee's blog.

Diversity, Disability, and Inclusion

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A common assumption about a person with a disability is that he or she will not be able to meet the physical requirements of a child life specialist's job description. While it is true that persons with disabilities are probably not going to complete all job functions in the "normal" way, they can make modifications and create alternative ways of performing their job while still meeting professional expectations. On a daily basis, people with disabilities must think outside the box to adapt to different situations and accomplish tasks. In order to refute the idea that people who are physically challenged are not qualified to execute the job of a child life specialist, people should remain open-minded and avoid drawing conclusions about what others can or cannot do based on their physical appearance. This is imperative when interviewing people for a job. If an interviewer mentally eliminates a visibly disabled candidate for a position based solely on a presumption that the applicant is physically unqualified, he or she will not hear the potential the child life specialist has to offer the department. For instance, one of my coworkers once admitted that she dismissed me as a viable applicant before my job interview even began because she supposed I did not have the stamina or strength to be on my feet throughout the workday. This confession came after a pedometer I had worn for a month revealed I walked an average of three miles a day while at work.

Being inclusive also applies when interviewing and accepting volunteers, practicum students, and interns. These opportunities provide students who are physically disabled the experiences they need to determine for themselves if they are adequately capable of performing the job, to ascertain what boundaries or limitations they might have, or to accept that they might need to explore other career options. Volunteers and students are additionally given the chance to find what their greatest attributes are and how to use those faculties rather than focus on what their disability prevents them from doing well. Student and volunteer supervisors might be required to provide slightly more guidance and assistance than usual to persons with disabilities. However, supportive clinical supervision through this process should provide the supervisor, the student, and the department with very enlightening discussions and encounters. The main focus when selecting students and new employees should always be on the skills, talents, and capabilities a person can bring to the workplace.

Under the Americans with Disabilities Act (1990), an employer may not ask disability-related questions until after a conditional job offer has been made. Therefore, potential employees, as well as students, must decide for themselves whether or not to disclose their disabilities. Some people elect not to mention disabilities in their resume or cover letter in order to get their foot in the door for an interview and be placed on an even playing field against other candidates. If applicants choose to disclose their disabilities to potential employers they should consider when and how to do so. For example, prior to a phone interview, I informed the interviewers of my speech impediment, stated that it is more prominent over the phone than in person, and requested they ask me to repeat myself if something I said could not be understood. For an in-person interview, if a disability is readily apparent, it discloses itself; i.e. a person who requires a wheelchair cannot choose to hide the impairment.

When a physical disability is obvious to an employer and might cause reasonable concern about an interviewee's ability to adequately perform essential functions of the job, it is likely in the applicant's best interest to acknowledge and briefly discuss it. Being open and honest allows the potential employee to demonstrate confidence, dispel possible misconceptions, address why the disability would not be an obstacle to fulfilling the job description, and return focus to his or her capabilities and skills. A person with an indistinct disability, such as hearing loss or a medical condition, can choose to disclose during the hiring process or after becoming employed (Pimentel, n.d.).

Regardless of when it occurs, one primary purpose of disclosure is for an employee to request a reasonable accommodation, which the Americans with Disabilities Act of 1990 defines as modifications made to the role or environment to allow a qualified person with a disability to perform the job and equally benefit from employment. Another common misconception regarding employing people with disabilities is that making accommodations is expensive. On the contrary, a study conducted by the U.S. Department of Labor's Job Accommodation Network (2015) concluded that workplace accommodations were typically of little to no cost to employers. For example, my child life manager bought me a small cart for moving large or numerous items such as toys, arranged for me to park in the visitor's garage rather than the off-site employee lot, and permits a fellow child life specialist to assist me when giving a presentation because I cannot speak for long periods of time. Providing accommodations was also discovered to positively impact the workplace, with such benefits as retaining valuable employees, improving productivity, improving interactions with co-workers, and increasing company diversity and morale (Job Accommodation Network, 2015).

Employees could possibly find their disability advantageous when building rapport and relating to patients and families, especially patients with their own disabilities. Children are very inquisitive and often are quick to ask me why I use crutches to walk or why I talk "funny." It opens up a channel of communication and can help patients feel more at ease. I simply explain that I need crutches because I do not have good balance and that I just talk a little differently than most people. Kids are generally happy with a brief answer and then I redirect the conversation to them or child life services. I am personally comfortable being open about my disabilities with patients, families, and co-workers but I know other people who are not. If a co-worker is unsure about a person's preferences for discussing his or her disabilities and related needs/wishes, a private conversation might be a good solution.

In order to create an inclusive environment where individuals with physical disabilities feel welcome and comfortable, Susanne Bruyère, director of Cornell's Employment and Disability Institute, encourages employers to:

- Show evidence of active recruitment of people with disabilities.
- Conduct disability awareness training for all staff.
- Create accessible workplaces ...
- Foster supportive supervisor-staff relationships.
- Include disability in the diversity statement. (Hastings, 2012, What Employers Can Do)

Bruyère also suggests that employers should avoid focusing on a person's disabilities and should not treat those with disabilities differently than other employees in meetings, on performance reviews, and when evaluating qualifications for hiring and advancement purposes.

The child life profession has recognized the need for and the benefits of diversity within its workforce. By accepting, recruiting, supporting, and maintaining child life specialists with physical disabilities, the child life community will create inclusion and leverage diversity. As Diane Richler, former president of Inclusion International states, “Inclusion is not a strategy to help people fit into the systems and structures which exist in our societies; it is about transforming those systems and structures to make it better for everyone. Inclusion is about creating a better world for everyone” (Rauworth, n.d., para. 1). 🌟

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Global Perspectives

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of new services.

Acceptance has led to new doors being opened through this pilot program for access to child life services on a national level through legislative change and implementation of existing laws. Ideally, this pilot program would bring change in every area of society – health care, social services, higher education, legislation, and community. The European Association for Children in Hospital outlines the rights for psychosocial services in the EACH Charter (European Association for Children in Hospital, n.d.), specifically in Articles 4, 7 & 8, which state:

Article 4: (1) Children and parents shall have the right to be informed in a manner appropriate to age and understanding; (2) Steps should be taken to mitigate physical and emotional stress;

Article 7: Children shall have full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs;

Article 8: Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families

(European Association for Children in Hospital, n.d.)

Those same attitudes and attributes of persistence, perseverance, patience, and passion have brought real, perceivable results. The nurses welcome our services, the patients engage easier, the parents are more trusting, and even doctors are requesting the child life specialists’ presence as part of the treatment team. Fear and frustration on the part of the patients have been replaced with openness and excitement; negative comments from medical professionals have been exchanged with positive feedback; impossibility on the part of the politicians in charge of the infrastructure have been traded for possibility! The best part of the investment in bringing change are the beautiful results seen on the smiling faces of the children and the hope that change conveys in every situation – it is priceless!

There are still many hurdles to overcome that are both internal and external. Proper training and higher education play an

important role in the preparation of child life specialists, and we are working hard to incorporate a concentration in child life at the master’s degree level at Emanuel University of Oradea through their social work major. The education laws of Romania require professors to have a doctorate in their field of specialty. Child Life Romania has brought in Certified Child Life Specialists from America every year for weeklong modulars to train and educate students and professionals through Emanuel University of Oradea, but because these teachers don’t have a doctorate in child life, the work is not recognized by the Romanian Minister of Education. For two consecutive years, Child Life Romania has collaborated further with Emanuel University of Oradea to hold the International Conference for Psychosocial Services with guests and keynote speakers from all over Europe and North America. The certification requirements and exams for our child life specialists are attainable only outside of Romania, yet costly in relation to our economy. The costs of a course offered by a Certified Child Life Specialist in America, along with the costs incurred for certification (eligibility assessment, certification exam fee, cost of travel to and from America, and a two-week stay so they can be jet-lag free before taking the exam) are equivalent to almost eight months of their salary. Child Life Romania’s first Certified Child Life Specialist was generously sponsored by some individuals in Texas to attain her certification and be further trained through special courses on palliative care and psychosocial services for pediatric oncology patients. Romania has yet to implement child life services within the socialized health care infrastructure. The labor codes of Romania do not provide a way in which to stipulate these services within the health care infrastructure. Before the health care infrastructure can change, the economics and labor infrastructure has to change. The health care system views our services as a luxury, not a right, even though the European Charter for Hospitalized Children states otherwise. Labor codes do not provide a place for us in the economic budget of the socialized health care system. That is when persistence, perseverance, patience, and passion join together with teamwork and collaboration to increase the velocity of change and make a powerful impact on our community. There is more than one “Quick River” in our city! 🌟

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CLC Calendar

JULY

1-17 Abstract submission for 35th Annual Conference on Professional Issues in Las Vegas, NV, May 25-28, 2017

AUGUST

- 8 Initial nomination forms for the 2017 *Mary Barkey Clinical Excellence Award* due
- 10 Deadline to apply for the August administration of *Child Life Professional Certification Exam*
- 15-30 *Child Life Professional Certification Exam Administration Testing Window*

SEPTEMBER

- 5 Complete *Mary Barkey Clinical Excellence Award* nominations with supporting documentation due

OCTOBER

- 1 Submission deadline for *Bulletin* and *Focus* articles for consideration for the Winter 2017 issue
- 27 Deadline to apply for the November administration of *Child Life Professional Certification Exam*
- 31 Deadline to apply to recertify through PDUs
- 31 2017 *International Scholarship* applications due

Moments from the past...

The front page of the first *Child Life Council Bulletin*, dated August 1983, details the first meeting of the Child Life Council as an independent professional organization and features the incredible beginnings of our association. This initial meeting was a two-day member meeting, a cross between a “Council” meeting (now referred to as the board of directors’ meeting) and a membership gathering, to work on the initiatives required of a new professional association. Committees included: Different Names/Common Goals, Program Review, Competency, Certification, Joint Accreditation, and Core Curriculum. There was emphasis on the progress being made as CLC worked to define standards and competencies for the child life profession. We see parallels to today as we review and revise competency documents and establish new standards for education and training. After a day and a half of hard work, participants were treated to a workshop on drama and previewed the new video from the Association for the Care of Children’s Health (ACCH), “Emma Plank: An Oral History,” with Emma Plank in attendance!

Looking at the cover of this issue, it is interesting to see the influence of the ACCH, the organization from which CLC evolved. The cover features the ACCH logo (and this first issue was printed by ACCH), yet the “Child Life Council Bulletin” title that debuted here has remained with the publication for over 30 years.

We see a Council representative of its North American origins, with Jerriann Wilson as the first President and Ruth Snider as President-Elect, and equal American and Canadian members filling the remaining four Council positions.

“Different Names/Common Goals” was the first committee summary to be highlighted. There was a sense that individuals from different backgrounds, “...child life specialists, therapeutic recreators, and hospital educators . . . who subscribed to the goal of Child Life Council” and its philosophy were working through issues of program and job titles while recognizing “. . . the variety of fields that make up the discipline of child life.” There was a sense of challenge and yet recognition of the importance of this eclectic membership. These individuals formed the foundation of the child life profession and likely influenced our keen awareness of the importance of learning from and with one another, of collaborative and inter-professional practice. As we continue to work to improve the education and training for new child life specialists, we continue to value diversity of people and training programs while balancing the need for consistency in knowledge and skills to develop exemplary child life specialists. ✨

