Decentering Whiteness in Child Life Assessment

Agenda for Child Life Science

Sibshops: Adaptations Due to a Pandemic
Medikin teaching tools are like magic. They instantly engage a child’s curiosity, calm their fears, give them courage, and show medical issues and treatments in a way that makes sense to them.
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Hello, 2022! Each new year, many of us take time to reflect on the previous year and use that as an opportunity to create future goals. I’m amazed at how fast the past six months into my tenure as CEO went by. As I reflect on the resiliency of the ACLP staff and child life community, I appreciate and thank you for all you do and aspire to do as we continue to navigate COVID-19 and its continued impact on our economy, health, mental health, and communities.

A vast part of my leadership style is to reassure people that we are meeting them where they are, and at this moment, it is needed. Sometimes the situation is not what it appears. You never know what people are dealing with; therefore, it is important to show grace to everyone.

It was evident that personal connections are missed and valued as a few small groups gathered in late 2021 for our strategic planning session and board meeting. It was inspiring to witness the joy and excitement of friends and colleagues reconnecting as well as to see new relationships developing. The undeniable energy and collaborative spirit during these interactions is what I am looking forward to experiencing more of in 2022.

I have a few exciting announcements to share. First, please welcome new staff members Angela Flanagan, CMP, and Jessica Oswald, CCLS, CFLE. Angela serves as our Chief Operating Officer (COO) and has over 20 years of experience in health care leadership and previously served as the COO for the Georgia Academy of Physicians. Angela is part of the executive team and is responsible for the leadership, management, fiscal oversight, and vision necessary to safeguard that the association ensures financial strength and operating efficiency. Jessica serves as our Manager of Program Operations and supports endorsement, accreditation, certification, and education programs. Jessica also supports multiple committees and previously worked as a Certified Child Life Specialist in hospital and community-based settings.

Second, mark your calendars now for May 26-29 as I am excited to announce and welcome all of you to my wonderful home state of Maryland for the 40th Annual Child Life Conference. The conference will be held both in person at the Gaylord National Resort & Convention Center in National Harbor, MD (within the Washington-Metropolitan area). We are also planning a virtual offering with some great conference content in early June.

No matter the obstacles, through changes and challenges, child life professionals keep going, learning and doing what’s necessary to provide services to children and families. That is the strength of our community, and it’s time to come together again to explore, learn, network, grow professionally, and strengthen your connection to the child life community.

Last, but certainly not least, is the excitement and enthusiasm that continues to build with the impending launch of our new 2022-2024 Strategic Plan, vision, mission, and core values in early spring. The strategic plan is used to set priorities, focus energy and resources, and strengthen operations. Not only will the plan include where the organization is heading and actions needed to make progress, but also how we will know if we are successful.

We are all trying to make it through this ever-changing environment the best way we can and I look forward to working together to ensure ACLP and the child life community moves forward with a future-focused lens to fulfill its mission and vision to make a positive impact in our communities.

As Mahatma Gandhi stated, “you must be the change you wish to see in the world.” Remember to reach out if you need help, give grace and mercy, and take care of yourself and your family.

Respectfully,

Alison E. Heron, MBA, CAE

CEO Shares
by Alison E. Heron, MBA, CAE
New Opportunities in 2022

The Association of Child Life Professionals Board of Directors, volunteers, and staff have been actively engaged in the racially conscious collaboration (RCC) seminar series. The Board of Directors and ACLP’s executive team finished Year 1’s executive seminar series in early December. ACLP will continue to work with Tony Hudson and his team at RCC for another year of learning opportunities and growth. For the Board, this next year’s focus will be to apply RCC’s framework to specific committees and task forces, to identify discrete and measureable opportunities for ACLP to advance our anti-racist and diversity, equity and inclusion (DEI) efforts. We are excited about the progress that the organization has made and also recognize that there is much more to do.

As we celebrate what has been accomplished and take time to look ahead; we realize that Child Life Month is coming soon! Just as child life professionals come out of the winter holiday season, the planning for child life month celebrations gets underway. ACLP is celebrating YOU - Your support, leadership, and resilience has made a real impact in the last years as we navigated the challenges of the COVID-19 pandemic and racial discord. Thank you for making it possible to help children and families overcome life’s most challenging events. I hope you enjoy celebrating this month and take a moment to feel proud of what you have helped accomplish.

This year, ACLP will be hosting its first ever ACLP Member Appreciation Week in March. Stay tuned for more information and ways to enjoy your member week benefits. The much anticipated Professional Advancement Models Resource Guide will be published this spring! ACLP’s Board of Directors charged the Clinical Ladder Task Force with investigating and defining recommended criteria and guidelines for the development of a child life clinical ladder (e.g. professional advancement) model. The goal was to create a document that provides direction and guidance to those programs looking to develop or enhance a professional advancement model. The information presented is a compilation of an extensive literature review, Dr. Patricia Benner’s “Novice to Expert Model,” and deliberate alignment with the child life competencies, position statements, policies, and certification requirements. The resource includes a step-by-step guide on how to get started, universal elements of a professional advancement model, the child life model for clinical progression, a model evaluation tool, and more.

I also want to acknowledge Angela Flanigan’s arrival – she is the association’s new Chief Operating Officer. Please join me in welcoming Angela! At the November Board meeting, both Alison and Angela were able to participate. This was the first board meeting since 2020, where both of the association’s executive office positions were filled. They demonstrated superb leadership, helped us remain aligned with association industry standards and remain strategic in our discussions.

Thank you members for your endless support! You make what we do possible! Also, I hope each of you know that you are welcome to reach out to me at president@childlife.org.

All the best,

Quinn Franklin, PhD, CCLS, ACLP Board President
Play: What does it really mean?

Play, as a topic of both theoretical consideration and research, has always both intrigued and frustrated me. We all know that play is often described as the foundation for child life. Our early child life professionals, usually labeled by some other name, were noted to bring play to children in hospitals, at a time when hospitalized children were restricted to their beds and rarely allowed to play, either alone or with others. I would certainly join the majority of those reading this article in wanting to embrace the importance of play for children and for people of all ages. Play may dramatically change in structure and expression over the life span, but there is no question of its significance in healthy development and overall well-being.

So why frustrated? Probably because the term “play” can mean so many things, depending on the context in which it is used and the intention of the user. The initial child life focus on play was primarily to return a developmentally-critical opportunity for play to children traumatized by health care. Then we moved to the realm of “therapeutic” play, which often involved a more active role by the professional and the identification of a goal or purpose. That goal may be simply to develop a therapeutic relationship upon which other services are based. Medical play, play as part of preparation for medical events, play with rules, play with music and song, art play, competitive play, play with technology, and many other categories have been introduced into the practice of child life over the years. Play appropriate for teens, infants, and even adult family members has become part of the repertoire of a child life specialist. Play has been used as both a dependent and independent variable in research. Unfortunately, along with this incredible expansion of the concept of play has come confusion and inconsistency in our use of the term as we define play in the context of the work of child life.

In the summer of 2014, the Child Life Council Bulletin devoted its entire issue to play. If it has been several years since you pulled out that issue and read it, I would encourage you to do so. In fact, I would encourage you to make it an assignment for your students or make it the focus of an educational session for your staff. The “Child Life Focus” article by Michael Patte in that issue is timeless and should be foundational reading for all child life professionals. And now, seven years later, we are still talking about play in our professional publication, and still have not really developed cohesion or consistency in how play fits into our profession. In this issue of ACLP Bulletin, Belinda Hammond reviews the ACLP standards for child life practicum education. In her article on developing a virtual practicum, Standard 5 recommends therapeutic play interventions, and Belinda writes about how that standard can be met by play sessions done virtually with groups or by viewing prerecorded play sessions. Hopefully as you read this innovative article, you may wonder how the increasing use of virtual platforms impacts the core value of play and therapeutic play. Jessica Wilfore also mentions therapeutic play in her article on supporting teens who are facing post-abortion stress syndrome. She makes the point that topics may arise in a therapeutic play session that are unrelated to our current goals with a patient or unrelated to the reason for their health care encounter. What is our responsibility when true therapeutic play introduces subject matter which may be more significant to the patient than anything else we were planning to address in our interventions?

While all the articles in this issue offer important information and food for thought, the article by Kathryn Cantrell and Elizabeth McCarroll, “An Agenda for Child Life Science”, is vital for consideration by all who are dedicated to this profession. The authors identify play as one of three psychosocial categories which are in need of exploration through primary research. The other two are assessment and professional collaboration. This article clarifies that there has been a reduction in research content related to play and advocates for a return to primary research that studies this core component of child life. The authors state, “This narrowed vision (the medical approach) has provided us with more credibility in health care but has derailed our scientific narrative away form some of the core values of our
profession, including play.”

Many of us try to explain how the concept of play fits into the profession of child life. We talk about the language of children, the work of children, and how important play is over the lifespan of an individual. But we have not yet developed a dialog that truly integrates our knowledge and beliefs about play with our identity and scope of practice.

At my last ACLP Annual Conference, just before the pandemic, I was sitting with a young professional just out of school, and she was describing to me how she explains her new career to her friends and family. I remember her saying, “I tell them that I play with children, and they don’t understand what I mean by that. I don’t want to be thought of as a play lady.” I was struck by how inadequate the term “play” is to describe what child life is. Play may be the tool, the language, the methodology we use in our work with children and families, but it does not encompass the depth and breadth of the work by child life specialists. Perhaps some of the newer language, including emotional safety and trauma mitigation, better describes the outcomes we seek in our professional domains. Perhaps there is a Maslow-type hierarchy for play, in which basic child-driven free play is at the bottom, and all other forms build on top of that. Perhaps all the possible play modalities can be tied into developmental theory and even rank-ordered as to importance for successful completion of that period of development. Until we begin to do this kind of conceptualization of the role of all types of play, we will continue to struggle with our use of the term. Play will always have a place in our work, but how we present it to the public, and even how we describe its value to ourselves, should reflect careful and comprehensive thought about the role of play in the profession of child life.
In early 2020, British medical student Malone Mukwende published a medical reference text entitled *Mind the Gap: A Handbook of Clinical Signs in Black and Brown Skin*. The text is short in length but immense in significance, as it was created after Mukwende recognized the lack of resources available to physicians that provide even basic guidance in identifying clinical signs in non-White skin. At its essence, this text is an active step in mitigating the pervasive structural racism of the healthcare industry, in which physicians are trained and educated within a curriculum that centers White perspectives and White bodies. In his introduction to the text, Mukwende points out that his own medical education and those of his fellow physicians included intensive training in recognizing healthy versus diseased bodies, but only used images of White bodies as the educational standards. These methods were viewed as given and immutable and thus further perpetuated as doctrine within the medical field for decades. Mukwende writes about how this traditional educational paradigm left him untrained in how to recognize common conditions in non-White bodies, leaving non-White patients at risk of being mis/over/under-diagnosed and Mukwende and his colleagues without the tools to provide sufficient treatment.

Mukwende’s text is relevant, indeed vital, to the field of child life, not as a diagnostic reference but as an example of action in the face of the structural and institutional racism that pervades the industry in which we work. It is a call to examine the ways in which our own field is based upon educational foundations that center Whiteness and Western societal standards as immutable norms. The child life profession is overwhelmingly composed of White women educated within intellectual paradigms that herald White theorists and pedagogy based on White, middle class, Western notions of what a “normal child” looks like (Koller & Wheelwright, 2020). This creates immense potential for disconnect and insensitive care when we take into consideration the census projection that non-White children will become the majority in the United States by 2050 (US Census Bureau, 2021), the myriad ways in which prototypical, healthy development can vary cross-culturally, and the detrimental impacts of systemic racism and structural inequity on development (Koller & Wheelwright, 2020). We should not continue to unquestioningly apply traditional assessment and developmental theory to all children, nor should we continue to educate child life students to so deeply engrain and perpetuate these perspectives, no more than a medical institution should develop clinical expertise using one body prototype. Failing to acknowledge and address these issues runs counter to the principles of diversity, equity, and inclusion outlined as foundations of our profession (Association of Child Life Professionals [ACLP], 2021) and does not allow us to promote health equity for the patients and families that we serve.

Child life specialists do not diagnose. We do, however, make clinical assessments. These assessments are based upon an educational foundation of child development that was taught to us during college or graduate school and continually reinforced throughout practicums, internships, and the certification exam. Traditionally, a core competency of the child life profession has been fluency in these developmental theories, and each one of us can likely remember being asked an interview question

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that tested our understanding of the perspectives and needs of a hospitalized child in a particular stage of development, according to a particular theorist. The term “developmentally appropriate,” used extensively in our field as a foundation for intervention and a justification for approach, is based on what can be typically expected of a presenting child within the theoretical frameworks offered by Piaget, Erickson, Bowlby, Vygotsky, and others. As a profession, child life specialists are taught to assess how significantly a child differs from what might be considered “typical”, and these assessments can have major implications for how that child is addressed, what kind of support and information they are given, and what is expected of them throughout their hospitalization.

As professionals who serve a diverse population of children and families, we must take caution not to assume that our processes of assessment are culturally neutral and universal. Each of us operates through a unique experiential lens, and as professionals we have been collectively trained within education and healthcare systems that habitually present White norms as universal norms and teach theory that is heavily dominated by White, Western voices. In Mukwende’s case, this took the form of medical texts that prepared students to recognize clinical signs in their total patient population using only White bodies and descriptive terminology applicable only to White skin. As part of our child life training, we are taught to base our assessments on theory and previous empirical findings, the vast majority of which come from White theorists using White children and families as reference. Erikson, Piaget, Ainsworth, and others made sound observations and conclusions of the children they studied but did not include cultural variation as a consideration and generally studied White children and White mother/child dyads (Woodhead, 2005).

The resulting prototype for the “developmentally appropriate child” can be considered empirically accurate to the population from which these studies were derived (i.e. White middle class children and families) but cannot and should not be unquestioningly applied to children and families from diverse backgrounds. Failure to consider this point could lead to erroneous conclusions of a child’s developmental ability based on how the child differs from the “norm,” when in fact that child’s skills and development is entirely on-track within their cultural and familial context. The opposite is also possible, in which a child could be assessed as coping well when more culturally attuned assessment would reveal them to be struggling. For example, motor skills and autonomy may develop at earlier or later times depending on societal child rearing practices, such as some cultures discouraging play on the ground, some cultures discouraging young children
to feed and dress themselves, and some cultures where children are carried until they are a certain age (Swanson et al. 2003.) Social competencies have an equally wide range of norms depending on the cultural values of a particular family. Some families value individuality and assertion while others value collective good, inhibition, and deference to elders. There is wide variance cross-culturally in what can be considered typical play patterns, child/adult conversational style, emotional expression, and grief and mourning.

The unquestioned centering of White, middle-class, Western expectations of child development not only fails to acknowledge the myriad variations in developmental competencies of minority children; it also runs the risk of labeling anything other than those norms as abnormal or inferior (Garcia Coll et al. 1996). Just as only learning clinical signs on White skin can lead to mis- and under-diagnosing disease, only learning “developmentally appropriate” in the context of Western White children and theorists can lead to miscommunications and assessment errors. Fundamentally, centering Whiteness in this manner within the education and healthcare systems is a form of structural racism and cannot exist within a truly diverse, equal, and inclusive organization.

As child life specialists, we owe it to the children and families that we serve to begin to actively challenge any one-size-fits-all developmental lenses we may have within ourselves. When I examined existing articles and position statements relating to assessment in the field of child life, I found very little and sometimes zero mention of cultural variance, racism, or diversity. We can begin to change this by reading texts like Mukwende’s Mind the Gap and articles on assessment bias and equitable assessment practices that have been growing in number in fields such as social work and early childhood education. In the Journal of Child Life, Wheelwright and Koller (2020) discuss the historical reliance on traditional developmental theory and call for a paradigm shift in how our profession is educated and a “collective commitment to do better” on behalf of the families with whom we work with. Additionally, including parents and other family members in the assessment process and ascertaining their observations and concerns can often give us a far more accurate image of the child in front of us than attempting to fit them into a prescribed theoretical model. Finally, child life specialists must turn our assessment skills inward by engaging in attuned self-reflection of our own cultural values, assumptions, and biases. As Mukwende has demonstrated, individual and collective action can make significant strides towards building the more equitable and inclusive healthcare industry that we owe to our patients and families.

References:


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Child life is a young yet growing profession. In April 2020, we learned in the CCLS Connection that there are currently 6,170 certified child life specialists across the globe (ACLP communication, 2020). Though we are growing, when you compare that number to the number of people in other health care professions, it is easy to see why our friends in health care may still be unaware of our skill-set. There are over 251 nursing journals backing up the practice of 2.86 million registered nurses in the United States alone (Bureau of Labor Statistics, 2020). We do not have the affordance of those numbers. In order to contribute to conversations in health care research, our small profession must be heard amongst the voices of giants.

Recently, Sisk & Cantrell (2021) returned to Thayer’s (2007) question, “Is child life an emerging field of inquiry?” The authors concluded that while we are certainly developing a stand-alone academic discipline that regularly produces new knowledge through research, (i.e. a field of inquiry), we are not there yet. Currently we are still a profession building an evidence base that will one day stand alone and support the growth of more academic pursuits. Certified Child Life Specialists have contributed to a body of child life research and scholarship that is growing into a field of inquiry. These contributions include textbook chapters, conference presentations, and publications in journals across the health care community. However, much of this work is difficult for the general public to access, limiting our ability to reach members of the health care community outside of the child life silo. Prior to 2021, peer-reviewed publications by the Association of Child Life Professionals (ACLP) (Child Life Focus and The Journal of Child Life [JCL]: Psychosocial Theory and Practice) were behind the association’s paywall.

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Now that The Journal of Child Life is open-access and it is easier to search for child life scholarship, we are in a critical period to produce research.

In addition to increasing access to our emerging field, it is essential to set ourselves apart from other psychosocial researchers and scholars. Our field of inquiry supports three components: the profession, the professional organization, and the academic discipline (Daniels & Sisk, 2021; Sisk & Cantrell, 2021). The more discrete and specific our field is, the more others will see our name and immediately know that we focus on the psychosocial needs of children and families in health care settings. This clarity can lead to job creation, more opportunities for ACLP, and growth in academic programs. In this paper, we propose an agenda for the emerging field of child life. By carefully tending the scientific conversations we engage in as a community, we can establish a field of inquiry more efficiently. This agenda is broken down in two sections, recommendations for primary and secondary research. In each section, we consider how to advocate for the profession while conducting valuable research and provide suggestions for content, methods, and dissemination. The paper concludes with a list of suggested studies for child life scientists (Table 1) and a request for more ideas.

Primary Research

In this paper, we define child life scientists as any child life professional who contributes to evidence-based practice by disseminating their ideas for improving child life practice. While the term scientist may elicit the traditional image of someone in a lab coat hovered over a microscope, we want to be clear that science in child life does not adhere to this traditional view. Due to the profession’s youth, our science looks more deconstructed and can include anything from a description of an intervention to a systematic literature review to a randomized controlled trial. In this paper, we draw from recent child life publications to consider ways child life scientists can contribute to primary and secondary research, two possible ways to categorize science and organize the profession’s agenda.

Primary research is the active work of collecting raw data and making practice suggestions based on the analyzed outcomes. Primary research can be analytical and draw practice conclusions such as a study evaluating the efficacy of an intervention. It can also be descriptive and provide insight into a current professional issue such as a study surveying child life specialists on their preferred assessment method. Conducting primary research is a form of advocacy. Primary research provides the data to back up our clinical decisions and acts as the foundation of evidence-based practice. Engaging in primary research communicates to the health care community that we have evolved past an applied profession relying on anecdotal evidence for decision-making.

While there are an endless number of psychosocial topics to explore with primary research, we suggest prioritizing assessment, play, and professional collaboration. Prioritizing these three topics for primary research will build a foundation to further solidify and define our scope of practice. In their content analysis of articles published in *Child Life Focus*, Turner and Boles (2020) note only 6.1% of papers looked at Assessment, a domain that makes up 40% of the child life certification exam. Child life scientists might consider primary projects that further describe child life specialists’ unique approach to assessment, such as survey designs, interviews, focus groups, observations, and case studies. Boles et al. (2021) conducted a scoping systematic review of all child life literature published between 1996 to 2017 and found only 7% of articles explored play. Of note, play content decreased between 2010-2017 as the percentage of content related to preparation and procedural support increased. Considering play is foundational to child life practice, child life scientists might consider a return to exploring play with primary research. Play, a broad concept in child life, can be explored with primary research in many different ways. For example, child life scientists may examine medical play and therapeutic play and how it relates to coping with hospitalization. Participatory research methods discussed later in this paper are ideal for studying play and showcasing the scope of child life practice.

Authors also note the gap in articles looking at professional collaboration. Hasenfuss & Franceschi (2003) describe a case study of successful professional collaboration between a nurse and a child life specialist. However, there are few to none recent primary research studies that support the facilitation of professional collaboration, including collaboration with mem-
bers of the interdisciplinary team, an essential aspect of child life practice. A primary research study on barriers and facilitators of professional collaboration during a pandemic would help the profession know how to foster relationships during a shared trauma.

In addition to topics that clarify our scope, it is essential to engage in timely primary research. As a response to the profession’s published commitment to Diversity, Equity, and Inclusion (DEI) (ACLP, 2020), studies examining systemic racism in child life training can help us identify areas for improvement. Similarly, studies examining the role of implicit bias in child life assessment can help White child life specialists reflect on their practice. According to the 2018 ACLP Member Survey, 91% of respondents identified as Caucasian (ACLP, 2018). Child life specialists support diverse populations, and studies that inform training related to how child life specialists can self-evaluate and work toward increasing their cultural humility is crucial. Part of child life practice is advocacy, including advocating for equitable health care for all patients and families. Primary research studies will equip child life specialists with tools and strategies on how to carry out this role. In addition to DEI, child life researchers can investigate training to support the marked growth of the profession. Studies examining child life pedagogy, intern selection practices, and preparation for the certification exam can lead to more equitable and efficient training. Lastly, in the past decade we have seen an increase in the integration of a trauma-informed lens in child life practice that is especially timely during the Covid-19 pandemic. Conducting primary research on child life assessment and intervention practices that seek to decrease trauma symptoms would be a crucial next step to the conversation already started by Shea et al. (2021) in “Pediatric Medical Traumatic Stress”, published in the March issue of JCL. As previously mentioned, JCL is now searchable and open-access, allowing for more readers of child life inquiry. Now is the time to evaluate our research literacy and create more professional development opportunities for strengthening research competence. Primary research can help investigate our current knowledge and skills and evaluate our academic preparation. Lastly, primary research on the impact of Covid-19 and tele-health practices would help us prepare for future pandemics.

Regarding suggestions for primary research methods, we return to the work of Boles et al. (2021) who, in their scoping review, found a trend toward quantitative methods in child life articles published since 2010. In an effort to reinforce the efficacy of our work in the setting of medicine, we have focused our attention on interventions that can be assessed from a medical approach. This narrowed vision has provided us with more credibility in health care but has derailed our scientific narrative away from some of the core values of our profession, including play. The decisions made when designing methods are also opportunities to clarify our work. Choosing methods that exemplify our strengths in building relationships, play, and making meaning can set us apart from others in health care and reinforce a methodological niche that others are unable to fill. Participatory qualitative research that includes visual art techniques, medical play, games, puppets, storytelling, and writing as methods for data collection are a rich way to set us apart in health care research (Rollins, 2018; Sisk & Baker, 2019). Case studies that showcase our ability to integrate theory into practice are helpful learning tools for the many students entering the profession. Lastly, ethnographic methods such as autoethnography and netnography can be a way to flex child life competencies like reflexivity and relationship building.

Writing up primary research is a time to advocate for the profession. The child life field of inquiry can support the practice of other professionals and sharing our work in nursing, medical, social work, or psychology journals might spark readers’ motivation to collaborate with child life. Boles et al. (2021) note a decrease in the number of articles being published in nursing, child health and development, psychology, music therapy, and family sciences; as of 2010, medical journals were the dominant outlet for child life research outside of ACLP publications. While this trend serves “to increase the recognizability of child life services to an audience most likely involved in health care administration and decision-making,” publishing in other discipline’s journals reinforces that child life is still a profession, rather than a field of inquiry that can sustain its own network of journals (Boles et al., 2021, p. 12). Child life scientists could consider a) contributing to child life’s growing field of inquiry by publishing in child life specific publications and b) publishing in interdisciplinary journals, educating readers about child life’s scope.

Additionally, authorship, author order, and title selection are other opportunities to support the growth of our field of inquiry. Turner and Boles (2020) note that most of the primary research articles published in Child Life Focus were first authored by non-Certified Child Life Specialists. Assigning child life specialists as first authors on primary research signals to other professions that we can support our own inquiry. Too, as child life scientists engage in more investigation of constructs central to DEI, it is essential to include authors from the underrepresented groups being studied. Ideally, the research team conducting the study would be representative of the racial and ethnic background of the participating sample. Lastly, choosing a title that includes the term “child life” and specifying “child life” as a keyword in your study can expedite
our path to being a field of inquiry. These small
details can result in it being easier for research-
ers to locate child life literature, leading to more
citations and opportunities for collaboration.

Secondary Research

Secondary research is the process of making
meaning from primary sources. Secondary re-
search synthesizes, summarizes, and analyzes
primary research to help professionals integrate
evidence into their work. Without secondary
research, a parallel commentary on the results
of the primary studies would not occur, making
it more difficult to access scientific conclu-
sions. Secondary research can include meta-analyses
or systematic reviews whereby studies are
summarized and practice recommendations
are clarified. It can also include analyses of
theoretical perspectives or historical trends in
the profession. Secondary research is also a
form of advocacy, especially since it is centered
on promoting more access and dialogue. This
paper is an example of secondary research.

There are an endless number of topics to
explore with secondary research; yet, there are
a handful that are more pressing than others. As
previously mentioned, Tuner and Boles (2020)
note the lack of papers exploring assessment
published in Child Life Focus. This trend has
continued in the articles published in JCL since
its 2020 inception, making assessment a topic
that is ready for exploration. Secondary proj-
ects, such as reviews of assessment practices,
updated evidence-based practice statements,
and theoretical analyses would strengthen this
domain. In addition, secondary projects provid-
ing professional education on anti-racism would
reinforce ACLP’s commitment to DEI. Writing
about specific ways to bring an anti-racist lens
to assessment, intervention, and evaluation
could be a valuable series for the community.

Another topic that is important to consider for
secondary research is compassion fatigue and
burnout. Hoelscher & Ravert (2021) conducted
a survey to understand burnout among CCLS
and found that CCLS experience burnout re-
lated to workload, emotional burden, and poor
work-life balance. More specifically, Burns-Na-
der et al. (2021) surveyed child life specialists
supporting Pediatric-Sexual Assault Forensic
Examinations and found that these child life
specialists struggle with hearing the stories of
the patients’ experiences. Secondary projects
that review primary research related to burn-
out and compassion fatigue and provide rec-
ommendations would help training programs
and workplaces to support CCLS in preventing
burnout and compassion fatigue. Unlike as-
sessment, play, and collaboration, legacy is a
domain within child life where we see a promis-
ing number of child life publications. Still, there
are needs for updates, such as a reflection on
how telehealth and Covid-19 have impacted
our evolving definition of legacy building (Boles,
2014) and legacy building practices (Sick et
al., 2012). Lastly, secondary projects updating
the community on modern theoretical perspec-
tives would ensure we are keeping up with the
trends in developmental science. Commentaries
reflecting on the practice implications of Koller
(2019) and Koller and Wheelwright (2020) could
result in more conversations about modernizing
our theoretical repertoire.

If these topics do not lead to ideas, respond-
ing to the outcomes of primary research, es-
pecially when gaps are discussed, can lead to
more dialogue. For example, Lookabaugh and
Ballard (2018) surveyed practicing child life
specialists about their perceived level of com-
petence and found gaps in two areas: academic
preparation and working with diverse families.
Addressing gaps identified in survey research
can be a helpful outcome of secondary research
and continues a thread of dialogue. Regarding
academic preparation, participants in Looka-
baugh and Ballard (2018) noted a specific gap
in knowledge about death and dying. A tar-
geted secondary response to this paper could
be a critical review of a new death and dying
textbook, assessing its usefulness for practic-
ing child life specialists or recommending its
inclusion in bereavement courses. To address
respondent’s noted gap in working with diverse
families, a chapter on using critical race theory
in child life practice could be a helpful addition
to syllabi in child life academic programs. Re-
sponding to gaps noted in recent literature can
help ensure your projects are making timely contributions to shared knowledge.

Methodological choices in secondary research can also support the profession’s growth. Child life specialists are naturally skilled at marking growth, using theory, and teaching. We can use our skills in marking and celebrating growth to maintain a detailed historical account of how the profession has changed and adapted over time. For example, a content analysis of meeting minutes from the ACLP Board of Directors could account for trends in community concerns. Historiographical accounts of our evolution in theory, scope of practice, assessment methods, and practice considerations will catalogue our growth and allow for reflection opportunities to challenge the status quo. We can showcase our skills in theoretical integration by writing theoretical analyses that are detailed and lead to specific practice recommendations. Lastly, child life specialists can embrace their skills in teaching to construct useful systematic reviews. The most meaningful reviews are the ones that can break down a complex topic of research into smaller, more accessible pieces.

Writing secondary research is advocating for child life and is another opportunity to teach about the profession. Secondary research is needed in child life specific publications like JCL and interdisciplinary journals. Papers like those cited in this commentary can help the child life community harness motivation for long-term goals like building a field of inquiry. These pieces can also be useful outside of the community. For example, a commentary calling for research collaboration that provides specific suggestions could be a great addition to a nursing or psychology journal. When mentoring emerging child life scientists, supporting secondary research skills is essential, especially from a social justice lens. Secondary research is faster than most primary methods, is lower-cost, and can be completed without institutional affiliation. Strengthening students’ skills in secondary research provides them with tools to contribute to child life science even if, say, a global pandemic derails their employment timeline.

Conclusion

Developmentally, our young profession is growing, and our evidence-base is emerging into a new field of inquiry. As we work to nurture this new growth, contributing to both primary and secondary research can help child life scientists communicate in a room of larger, more established professions. Scientists should consider exploring topics such as assessment, play, professional collaboration, DEI, training preparation, and the impact of Covid-19. Likewise, choosing methods that exemplify our scope of practice and professional strengths further advocates for our unique approach. Qualitative and participatory methods enable child life scientists to be creative in their research where secondary projects like systematic literature reviews and theoretical analyses showcase our skills in teaching. Lastly, the choices we make during dissemination can contribute to the field’s growth. As such, including child life specialists as authors, publishing both inside and outside of the child life community, ensuring authorship is representative of the sample, and including “child life” in the title or keywords are each forms of advocacy.

Primary research paves a path for secondary projects that provide strong, credible conclusions and recommendations. This paper’s discussion of secondary research is intentional. Shared knowledge will always be more truthful than the knowledge of a single, isolated child life specialist. As we quickly construct a field of inquiry that can sustain our profession, ACLP, and our academic programs, we must communicate across these three concentrations or we risk duplicating work. Scholarly dialogue facilitates this process and provides a record of our evolving ideas. Too, the more we talk, the more citations that include the words “child life” enter the ether. So to conclude, we end with a prompt for more secondary dialogue: What do you see as the greatest research priority for our emerging field? What suggestions do you have for fellow child life professionals looking to contribute?

References:


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<td>Play</td>
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<td>Professional Collaboration</td>
<td>A commentary calling for more research collaboration between social workers and child life specialists</td>
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<td>Implicit Bias</td>
<td>A qualitative study interviewing child life supervisors about their practices for coaching supervisees on implicit bias</td>
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<td>Systemic Racism</td>
<td>A content analysis of othering language in hospital communication with families</td>
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<td>Emerging Theories</td>
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<td>Training</td>
<td>A qualitative study using focus groups to ask students about the barriers to entering the child life profession</td>
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<td>A survey study asking certified child life specialists to assess their research literacy and gaps in knowledge</td>
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<td>Covid-19/Telehealth</td>
<td>A netnography of child life-specific social media accounts describing how online content and community connection has shifted with Covid-19</td>
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<td>A qualitative study interviewing pediatric patients and families who can describe the essence of pediatric medical traumatic stress</td>
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<td>Bereavement</td>
<td>A retrospective review of medical records comparing how trends in legacy intervention have changed over time</td>
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<td>Preparation</td>
<td>A program evaluation studying the efficacy of different preparation tools and interventions for procedures</td>
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<td>A phenomenological study using videos, photos, observations, and interviews to describe the shared experience of participating in a sibling support group</td>
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<td>A study surveying all members of a regional child life group on feelings of burnout and compassion fatigue during Covid-19</td>
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<td>A case series containing three different cases each using Smilansky’s theory of play</td>
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<td>A study evaluating the efficacy and feasibility of an online child life practicum</td>
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SUPPORTING ADOLESCENTS

Experiencing Post-Abortion Stress Syndrome

by Jessica Wilfore, MS-Ed, CCLS

While working as a CCLS in the hospital setting, I encountered a teenage patient who was struggling with anxiety, depression and drug abuse. During a bedside activity, she told me she had had an abortion. She hung her head and said her boyfriend wanted her to. Unfortunately, I didn’t know what was appropriate to say. I wanted to remain professional and not let my personal views lead the conversation, but despite my education and experience, I didn’t know what words to use (or avoid) or what resources to provide her.

Should I offer grief support? Memory making activities like I would with a miscarriage or stillborn? I wasn’t sure. The social work and psychiatry teams were aware of this patient, but admittedly didn’t have much time to offer. What more could be done? Should more be done by child life? While reading this, you might not feel that at though this example applies to you; however, the person who has experienced an abortion might be more common than you think.

Some of these young people who had an abortion will experience what is known as post abortion stress syndrome (PASS) with symptoms including “guilt, anxiety, numbness, depression, flashbacks, and suicidal thoughts” (Babbel, 2010). Further research cites, “teen girls are up to 10x more likely to attempt suicide than their counterparts who have not had an abortion” (Health Research Foundation, 2021). Susanne Babbel MFT, PhD says, “Any event that causes trauma can indeed result in PTSD, and abortion is no exception...A compassionate, unbiased, and appropriate counselor can help a [person] who has undergone an abortion come to terms with [the] decision and find peace again—without a political agenda”.

As child life professionals, we know any medical procedure can have negative effects on a patient’s physical, mental, and emotional health. Our child life brain kicks in and we might start questioning: How were they prepared for the abortion procedure? Were parents, or the friend or partner allowed to be present? What, if anything, was used for coping during the procedure? Was support offered afterward? CCLS’s are knowledgeable on various resources to provide patients undergoing all sorts of different issues, medical or otherwise. However, I had no experience with a patient who had had an abortion, and I felt unprepared to offer the support she seemed to be looking for.

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Regardless of religious or political views on abortion, a CCLS should be equipped with professional, unbiased resources to help adolescent females who may be experiencing PASS. Here are four resources you can be familiar with:

**Support After Abortion**

[Supportafterabortion.com](http://supportafterabortion.com). For anyone suffering from abortion, miscarriage, stillbirth, adoption, or sexual assault, Support After Abortion offers virtual and in-depth healing groups and weekly meetings. They offer training for anyone interested in joining their mission to serve those suffering after abortion. Their resources are available for purchase to offer in a group setting.

**Option Line**

(800) 712-4357. Option Line offers a confidential live chat, text line, and toll-free hotline that is available 24/7. The website contains additional resources for those who are considering abortion, have had an abortion, or are seeking alternatives to abortion.

**International Helpline for Abortion Recovery**

(866) 482-5433. Provides confidential care 24/7 for those needing help after abortion. The helpline is staffed by consultants who have personally experienced an abortion but have also found hope and healing.

**Rachel's Vineyard**

(877) 467-3463, rachel@rachelsvineyard.org. Rachel's Vineyard offers confidential, weekend programs and other services across the United States and Canada, with additional sites around the world, for anyone affected by abortion.

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**Do’s**

- Do let your genuine concern and care show.
- Do listen to help them feel less alone.
- Do know that you cannot take their pain away.
- Do say you are sorry about their pain.
- Do say you are sorry they had to be in a position to make that choice.
- Do encourage healing, suggesting counseling visits, taking care of themselves, getting enough rest, eating well.
- Do suggest marking anniversaries associated with the pregnancy and abortion if they want to.
- Do allow them to express anger, regrets and remorse over the abortion.
- Do allow them the respect to grieve and be sad as you would for a parent who lost a baby through a miscarriage.

**Don’ts**

- Don’t think that the gestational age of the pregnancy determines its value and impact.
- Don’t try and argue the medical details of embryo/fetus/baby.
- Don’t avoid them because you feel helpless or uncomfortable, or don’t know what to say.
- Don’t look at their situation and put a time frame on her healing.
- Don’t try to find something positive in the abortion/or offer ‘rationalization’ for why they shouldn’t be upset.
- Don’t say that they can “always have another child.”
- Don’t express your personal views on abortion.
- Don’t say it was just a medical procedure, like getting your tooth pulled, etc.
- Don’t say, “you did the right thing.”
- Don’t say, “you did the wrong thing.”

In addition to providing resources, a supportive conversation needs to be had. Being prepared with a mental script of “do’s and don’ts” can help guide you through your conversations with a patient who might be experiencing PASS. Adapted from “Do’s and Don’ts for Support People” (PASS Awareness, 2015).
Educating ourselves on PASS, being aware of resources, and being prepared with an outline of what to say and what to avoid is essential. However, a CCLS does not replace the need for a mental health professional. A CCLS must always stay within his or her scope of practice, providing developmentally appropriate, psychosocial support. As stated by principle 6 of the Child Life Code of Ethics, “Certified Child Life Specialists provide services within their competencies and make appropriate referrals with due regard for the professional competencies of other members of the health care team and the community within which they work” (ACLP).

While we are not trained therapists, we can find ourselves in play-based interventions during which patients disclose traumatic events to us. We are trained professionals equipped to support adolescents during stressful life events without judgement. Feel confident in providing a space to listen, allowing the patient to tell their story to someone they trust. Listen and validate what they are feeling.

If I could go back in time, I would have asked my patient, “what was that experience like for you?” I would have listened and then responded with the “do’s and don’ts” list in mind. In addition, I would have printed out the above resources for her to keep. Finally, I would have offered grief support as a loss was experienced. I hope this article provides insight and allows you to reflect on how you would provide unbiased support to someone experiencing PASS.

References:


THE ROLE OF CHILD LIFE SPECIALISTS in Rehabilitation Scoring

by Melanie Weinrich, BS, CCLS
Children’s Mercy, Kansas City, MO

Pediatric rehabilitation patients embark on a journey that encompasses grief and loss, as well as many other stressors, during their lengthy inpatient admissions. Often, patients and families experience the unknown in terms of the future and outcomes. Goal setting is a major component of rehabilitation that assists patients and families in tackling this uncertainty and making positive steps forward. “Goal setting is essential in pediatric rehabilitation, as it not only identifies what is most important to the client and family, but it also allows members of the care team to be aware of the identified goals, the effective methods being used to help the client attain them, and each member’s role and relevance in meeting the client’s unique needs” (Bovend’Eerdt et al., 2009). Child life specialists spend a significant amount of time with children and families during hospitalization for rehabilitation and can use their unique skillset to contribute to goal setting. A literature review that examined the use of Goal Attainment Scaling (GAS) in pediatric rehabilitation found that the use of such tools could be effective in not only evaluation and goal setting but also in assessment of the effectiveness of interventions. This assessment will help the child life specialist create more individualized care plans (Carpenter, 2020).

At Children’s Mercy Hospital, located in Kansas City, Missouri, the inpatient pediatric rehabilitation service was established in 1995 by founders Dr. Ann Modrcin and Janet Dean, APRN. Dr. Modrcin and colleagues understood the importance of goal setting with regards to rehabilitation. She knew that goal setting is utilized by a variety of healthcare systems, as it is strengths-based and solutions-focused. Based upon this knowledge they sought to determine an evidenced-based pediatric scoring tool for use with the rehabilitation population.

After having reviewed many different scaling tools, Dr. Modrcin ultimately selected the Wee Functional Independence Measurement for Children (WeeFIM). Now known as WeeFIM, for the program at Children’s Mercy. Next, Dr. Modrcin and Janet were charged with the task of assigning members of the rehabilitation team to report WeeFIM scores for each domain and subdomain. At this same time, they were exposed to child life specialists and began to learn about the field. They chose to establish a child life specialist as a part of the core team and report the weekly social interaction score, a subdomain of the cognition domain. When asked about the selection process, Dr. Modrcin stated that “Kids are at their best and real selves when they are with you (the child life specialist)!” Other members selected to score patients included physical and occupational therapists and speech language pathologists.

What is WeeFIM?

WeeFIM is a tool that is utilized to measure functional independence in pediatric rehabilitation patients. It is an 18-item, 7-level scale instrument. The WeeFIM tool is considered the ‘gold standard’ for measuring the outcome of rehabilitative treatment (WeeFIM - Family Hope Center, 2021). The goal of WeeFIM is to measure the patient’s performance, related to essential daily tasks. There are three main domains that are considered when utilizing the tool: self-care and activities of daily living, mobility, and cognition. A multitude of profession-
als on the rehabilitation team contribute to the WeeFIM tool and provide scores on a weekly basis. These scores are compared over time to demonstrate progress, plateaus, or regression with regards to function.

As pediatric rehabilitation is deemed an elective medical service, it is essential that the healthcare team has consistent representation of progress to present to insurance agencies. This assists the medical team in their ability to advocate for continued authorization for service. Because of this, WeeFIM scores are recorded and sent to insurance agencies each week. This allows insurance agencies to have a tangible symbol to represent the importance of an inpatient rehabilitation admission. To the right is a flow chart that helps illustrate the process for how to correctly score a patient in any domain. This flow chart can be utilized by whomever is responsible for contributing to scoring and is applicable to all domains of the scoring tool.

Social Interaction Score

Child life plays an integral role in providing opportunities for socialization for the pediatric rehabilitation patient during each lengthy admission, and, thus, child life specialists are well-equipped to determine a patient’s WeeFIM social interaction scores. Social interaction assessments include a patient’s ability to interact with peers, family, and staff during one-on-one interactions and in group settings.

Upon admission to rehabilitation service, patients receive a WeeFIM admission score as well as a goal score. The goal score is meant to be achieved at discharge. A patient with total social interaction dependency would receive a score of 1 on the WeeFIM scale, whereas a patient who is displaying total independence during social experiences would receive a score of 7.

Each week following admission, the child life specialist re-scores the patient with hopes of increasing the admission score and ultimately achieving the discharge score. By demonstrating progress, a child life specialist can advocate, alongside other members of the care team, for continued rehab admission. As patients continue to recover, their score will increase as they will be less dependent on others to communicate and socialize. As their scores increase, the experiences a child life specialist may facilitate are adapted to meet the socialization needs of the patient.

Case Example

A patient with a severe traumatic brain injury is admitted to rehab service. The patient is assessed by the child life specialist, and they are noted to have little to no verbal skills at the time due to severity of injury. Per the medical chart and gathering information, the child life specialist learns that the patient is typically developing prior to the accident/injury that led to the traumatic brain injury. At this time, the patient is totally dependent on caregivers and members of the healthcare team to assist them in navigating social experiences. Because of this, the patient would receive a social interaction admission score of 1. Based on knowledge of the patient’s medical prognosis, and anticipated recovery, the child life specialist sets the patient’s social interaction goal score as 5. Each week, the child life specialist identifies opportunities for the patient to engage in social interactions and facilitate opportunities for the child to increase their social skills. For example, the child life specialist may engage in playing with and for the patient at a frequency of three times per week for approximately 20 minutes at a time. Once the patient achieves this goal, and progresses in recovery, their verbal communication as well as cognitive ability may increase. Then, the child life specialist will advance their score and adapt and create new social experiences and goals based on their new score. A patient may not reach their goal score by the end of admission, or it is possible they may exceed it. Sometimes a goal score is an educated inference based on the unpredictable nature of neurological rehabilitation recovery.
Summary

At most institutions, physical and occupational therapists and speech language pathologists are the main contributors to the WeeFIM tool. At Children’s Mercy, the WeeFIM scoring team includes child life specialists, which ultimately provides for better patient and family experiences and outcomes. Child life specialists strive to build trust and rapport with patients and families and are an integral part of their coping and adjustment to the hospital environment. Child life specialists create social experiences that allow patients to gain independence, reach new therapeutic goals, and thrive in what can prove to be some of the most difficult days of their lives. Child life specialists are skilled in assessment and development, which provides a reputable knowledge base to assess a social score. Child life specialists should be considered in the development and institution of any rehabilitation scoring system.

References:


Since becoming certified in 1999, I have observed so much growth in our field, being witness to CCLS’ exploring gaps in services and creating the needed child life supports to fill those gaps. During COVID-19, cancellations of many practicums meant students were unable to move forward in their quest for certification eligibility. Recognizing the need for a solution, I wanted to integrate my community-based knowledge into a virtual child life practicum to introduce our next generation of child life specialists not only to opportunities in-hospital, but to also search for the gaps in their community and to developing programs to best serve their community. A virtual practicum could provide the short-term need for clinical placement not reliant on hospital access as well as the long-term needs for equalizing access for students. Below is a program description of the virtual practicum.

**Child Life Virtual Practicum**

**What:** A child life practicum offered 100% virtually.

**Why:** A virtual child life practicum is explored as a resolve to the long-term access and equity issues while also resolving immediate needs during the pandemic.

**Format:** Four sets of virtual modules – onboarding for our medical camp and studio partners, child life in traditional in-hospital units, child life in the community setting, and preparation for internships and jobs.

**Number of Hours:** Each participant was expected to complete a minimum of 120 hours up to 200 hours during the practicum. A sample schedule looks like:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Hours Per Week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live, Interactive Sessions</td>
<td>~2-3</td>
</tr>
<tr>
<td>Recorded CCLS’ Led Shadowing</td>
<td>~4-5</td>
</tr>
<tr>
<td>Participation with Camp/Studio Partners</td>
<td>~1-2</td>
</tr>
<tr>
<td>Shadowing of Camp Play Sessions / CCLS Interventions</td>
<td>~1-2</td>
</tr>
<tr>
<td>Access to Additional Resources (Podcasts, Conference Sessions)</td>
<td>~1-2</td>
</tr>
</tbody>
</table>
**Technology**: Live sessions were conducted via Zoom, live camp sessions platforms varied by partner, and studio programming used a combination of Zoom and their in-studio broadcasting capabilities. Shadowing segments with children present were pre-recorded in-hospital and live for camp sessions.

**Live Sessions**: 2-3 live sessions were conducted weekly with the practicum supervisor. The live sessions included in-depth discussions on the pre-recorded shadowing lessons, exploration of child life in various units/settings, therapeutic play exploration, review of assigned readings, and career development (included virtual conference sessions and specific podcasts).

**CCLS Guest Speakers**: Each guest CCLS shared vivid descriptions of what child life looks like in their unit/setting, with many also sharing photos, videos, demonstrations, and recorded interventions.

**Shadowing Sessions**: Shadowing segments with children present were pre-recorded in-hospital and live for camp sessions. The chart to the right outlines the type of shadowing segments offered throughout the practicum.

**Virtual Play Sessions**: Both live and prerecorded virtual play opportunities were created by students, who received support and feedback from a CCLS or camp leader prior to implementation, and feedback from CCLS following implementation.

<table>
<thead>
<tr>
<th>Traditional Child Life Units</th>
<th>Community Based Child Life</th>
<th>Play Exploration (live and recorded)</th>
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<tbody>
<tr>
<td>Emergency Department</td>
<td>Medical Camps</td>
<td>Various Medical Camps</td>
</tr>
<tr>
<td>Hematology/Oncology</td>
<td>Grief Camp/Supports</td>
<td>In-Hospital Studio Programming</td>
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<tr>
<td>Pediatric Cardiac</td>
<td>In-Hospital Studios</td>
<td>Get Your Play On(line)</td>
</tr>
<tr>
<td>Pediatric Burn</td>
<td>Hospice/Palliative Care</td>
<td>The Jared Box Project (Community Support)</td>
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<tr>
<td>Psychiatry/Mental Health</td>
<td>International Child Life</td>
<td>Oscar Litwak Foundation (Community Support)</td>
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<tr>
<td>NICU/PICU</td>
<td>School/District Supports</td>
<td></td>
</tr>
<tr>
<td>Children of Adult Patients</td>
<td>Disaster/Trauma Supports</td>
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<tr>
<td>Pre-Op</td>
<td>Higher Education/Research</td>
<td></td>
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<tr>
<td>Radiology</td>
<td>Therapeutic Modality Specialties</td>
<td></td>
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<tr>
<td>CL as Dog Handler</td>
<td>Children of Adult Patients</td>
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<tr>
<td>Traveling CCLS</td>
<td>Foster Care/Adoption</td>
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<td>Sibling Supports</td>
<td>Pediatric Dentistry</td>
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<td></td>
<td>Private Practice</td>
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</table>
**Student Responsibility:** Students were responsible for tracking weekly hours within their reflective journals, ensuring they met weekly requirements for hours, including interactions with children through medical camps and studios. Students are active participants in Canvas (LMS) throughout their practicum and continue to have access to the site after practicum completion.

**ACLP Standard Requirements:** Each of six standards identified by the ACLP were directly addressed throughout program development (see table).

**Internship Success:** Of the 61 students who completed the virtual practicum and have applied for internships, 41 have received offers. Eight additional students pursued a second practicum (or completed their originally planned practicum which was delayed due to COVID-19). Four students completed a year employed by a hospital as a Child Life Assistant or similar before applying for internship. Five students completed a non-child life internship, prior to exploring a child life internship. One student was already a CCLS when completing the practicum as a graduate academic elective, as she completed her practicum, internship and job at the same hospital and wanted more well-rounded exploration of child life.

**The Future of Virtual Practicums:** While modifications are still in development for the 6th cycle, the foundation of the virtual practicum is to ensure ACLP recommended standards are met throughout each experience. I am also eager to provide more in-hospital shadowing of procedures as recordings (with all needed consent forms in place), and welcome any CCLS to reach out to explore sharing those approved, recorded sessions with (and accessible only to) child life community practicum participants. Feedback from partner agencies included that, moving beyond COVID-19, they will continue providing a virtual opportunity for those who are unable to attend in person, while also providing in-person programming both in-hospital and in-medical camp.

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### ACLP Standard | How it was Addressed in the Virtual Practicum

<table>
<thead>
<tr>
<th>Standard 1 (practicum is largely observational experience plus engagement in play)</th>
<th>This standard was met through a range of both shadowing and interactive experiences. Every participant had access to each CCLS' live presentations and recorded shadowing, including highlights of a “day in the life” of multiple CCLS’ and pre-recorded shadowing of child life interventions. Each live experience was also recorded for future cohorts, and students were provided contact information for each presenter.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standard 2 (supervised by CCLS with 2,000+ paid work experience in the field)</td>
<td>While additional CCLS’ joined our practicum and provided shadowing experiences, I was the consistent presence as supervisor.</td>
</tr>
<tr>
<td>Standard 3 (minimum of 100+ hour practicum experience):</td>
<td>The virtual practicum provided maintained one supervising CCLS. The supervising hours could be gained through shadowing experiences, ACLP webinars, conference content, regional student events, podcasts, etc.</td>
</tr>
<tr>
<td>Standard 4 (practicum completed in appropriate setting(s), including in-hospital, hospice/palliative care, medical camps, etc)</td>
<td>The virtual practicum allowed participants to explore each of the approved settings on the ACLP list. This allowed participants to explore their unique areas of interest and identify the elements of child life that they most related to.</td>
</tr>
<tr>
<td>Standard 5 (exploration of child life assessment, developmental theory integration, therapeutic play interventions, rapport building):</td>
<td>Participants were able to explore rapport building virtually with children who otherwise wouldn’t have had opportunities to play or interact with other children. Therapeutic play opportunities were explored with multiple partners, including in-hospital studios and medical camps, and included live interactions with groups of children, creation of pre-recorded content for an in-hospital library, and supporting one another as they hosted live sessions and were able to continue gaining experience developing rapport without leading the play activity directly.</td>
</tr>
<tr>
<td>Standard 6 (learning opportunities include journaling, educational in-services and discussions, and specific/structured readings):</td>
<td>Discussions were scheduled multiple times each week throughout the practicum, readings were assigned within specific modules, experiences were explored both live and through recordings, assessment and prioritization were practiced, reflective journaling was completed weekly, each posted/submitted within Canvas LMS. Discussions included review of assigned readings, developmental theory, continued discussions on various units/settings of child life.</td>
</tr>
</tbody>
</table>
Frequently Asked Questions about the Virtual Practicum

Q: Why is it called “community” if it incorporates both in-hospital and community settings?
A: Hospitals are within our community, so calling it a Child Life Community Practicum felt like it included all of the settings being explored within our practicum.

Q: Can you go into more detail on who the partners were for this virtual practicum specifically the studio partners and medical camp partners?
A: Hospital Studio partner for this practicum was Seacrest Studios at Children’s Hospital Colorado. While medical camps aren’t the same as in-hospital experiences, medical camps serve the same population of children and families coping with medical issues, and many provide in-hospital outreach programs, with both virtual and in-person medical camp experiences available at varying times throughout the pandemic where students could actively get involved interacting with children through play, something that has been challenging to do in-hospital for many students seeking hands-on experiences.

Q: Can you explain more about the “cohorts”?
A: A cohort starts and ends their practicum experience together, meets together to talk through practicum experiences, shadows CCLs together (there’s no space restriction when virtual, unlike in the hospital where there has been 6’ separation requirements in many medical spaces including procedure rooms – we can all shadow together).

Q: Did you collect any structured feedback on the program from the CCLs who provided some of the training or from the internship sites in which the students eventually worked?
A: These are all terrific questions that will be addressed in future research. Feedback was collected from students at the end of their child life community practicum, and again after accepting an internship offer. At this time, feedback has not been collected from CCLs, but is actively being collected from supervising CCLs from multiple community-based and international practicum settings.

Q: Do students observe a live, real-time preparation for a procedure, intake assessment or therapeutic activity done by a CCLS?
A: Observations are done virtually from recordings (real interventions/preparations with children/families which were recorded.) No “live” observations with children were utilized. We also had multiple demonstrations of interventions conducted by CCLs which were offered both live and recorded. With the limitations due to COVID-19, live interventions with children weren’t available, and many of the recorded interventions we had access to were also being recorded for in-hospital practicum students, as they weren’t able to be in the same physical space due to space restrictions of 6’ due to COVID-19.

Q: If there is live “shadowing,” how is it done? Does a camera person follow the CCLS around the hospital or unit?
A: There was no “live shadowing” with children. For the recorded interventions with children, a tablet was placed in advance to record the intervention, and all photo-consents were signed prior to the intervention. Shadowing of CCLS without children present was a combination of live and recorded interventions, storytelling with photos and videos, and demonstrations.

Q: What part of the practicum, specifically, is actually “live” in that the student interacts live with a child, or observes live, real-time (not recorded) activities done by a CCLS?
A: The “live” interactions with children were done through both our Hospital Studio partner and various medical camps – all were done via technology, with students first shadowing and then hosting/leading their own activities with children. A minimum of 50 hours are live sessions either between live discussions and play participation with our medical camp/studio partners, approximately 10 hours of student-recorded play content from our medical camp/studio partners, and the remainder of shadowing experiences are a combination of recorded sessions from previous practicums and live shadowing with our medical camp partners.

Q: If students are having any live interactions with children, is the supervisor present, side-by-side, with the student or on the same screen at the same time, so the student is being observed live and can process from a live observation by a supervisor? Or are these interactions recorded and reviewed later to provide feedback?
A: The Seacrest Studio CCL was present for all studio programming. The medical camps had supervisors present during live play sessions, and I reviewed recordings to provide more child life-focused feedback.

Q: Do the CCLs who present to the students have some role in giving you feedback on the student’s questions, interactions with patients, etc.?
A: Many have reached out with feedback, and many had students reach out beyond their practicum guest lecture for more insights and to explore further program development. Feedback was not formally requested of the CCLs, but has been gained informally. This is another fabulous question for future research.

Q: How are student hours verified if not being directly observed? For example, when listening to podcasts or recorded conference sessions?
A: I have recorded content within a Canvas page that can be used towards practicum hours. Students include in their weekly journal submissions which of these recordings were observed throughout the week, which live sessions they’ve joined with me and our guest CCLs, and which live medical camp and in-hospital studio sessions they were part of. During our live sessions, we talk through experiences that were available that week, including previous CCLs guests and shadowing of previously recorded medical camp play experiences and in-hospital studio programming. Students also have assignments throughout the practicum which are the focus of discussions and feedback is provided.
To examine how child life professionals can encourage health care autonomy among pediatric patients with developmental disabilities, first I will discuss some of my experiences working as a behavior therapist. Although the child life field and the field of applied behavior analysis are distinct professions and require different training, professionals in both fields are likely to encounter circumstances where they must determine how to best support decision-making autonomy among clients with developmental disabilities. While child life professionals may foster health care autonomy and behavior therapists may foster social autonomy, a child or adolescent’s independence in making decisions that affect these goals is critical for professionals in both fields to consider. I hope the experiences I share inspire other professionals working with children and adolescents with developmental disabilities to explore their approaches to support decision-making autonomy as well.

As a former behavior therapist, I worked 1:1 with children and young adults ages 3-22 with a range of developmental disabilities. My role included aiding clients in building independence by promoting life skills, such as communication and social skills. The team of behavior therapists I worked alongside supported one another as well as the children. More specifically, if a therapist had
to step away from a client for a moment, another behavior therapist would engage with that client while the therapist attended to another situation. In these moments, therapists often made decisions with or on behalf of the client to continue implementing programming. Sometimes decisions would be made that may not accurately reflect the child or adolescent’s wishes. For example, a therapist may decide to include a client they are looking after in a game of Candyland, unaware that the client has a strong aversion to games that include bright colors. Although the behavior therapist had the client’s best interests in mind when making the decision, the therapist may not have known the client very well and assumed the client’s preference when determining how to engage the client in an activity. Within this context, such decisions typically led to few consequences on the client’s overall wellbeing, especially compared to the consequences that come from many other decisions that are made on behalf of children and youth in other contexts in life.

Within health care settings, children, youth, and families make many health care decisions, from day-to-day decisions (i.e., timing of treatment), to major parent-led decisions (i.e., treatment choice), to medical and legal decisions (i.e., obtaining assent in a clinical trial). Although child life specialists may not be able to eliminate the negative consequences associated with all health care decisions children, youth, and families encounter, they can still play a role in improving a patient’s health care experience. Child life specialists can advocate for a pediatric patient’s well-being within some health care contexts, particularly in day-to-day health care decisions. Smaller decisions child life specialists may advocate for include providing the patient with the option to adjust their room lighting and allowing patients to utilize preferred distractions during procedures.

Yet, how can child life specialists assure that they are appropriately and accurately advocating for pediatric patients with developmental disabilities? To address this concern, this article will explore patient interactions with child life and other health care professionals and speak to areas where misinterpretations may occur. The goal is to support child life specialists in recognizing these situations and to guide professionals in determining when their advocacy skills are needed to support pediatric patients with developmental disabilities accurately and appropriately.

Understanding the Challenges Pediatric Patients with Developmental Disabilities Face When Making Informed Decisions

Beyond the typical challenges many families face when a child becomes more independent, such as parental anxiety, families and children with developmental disabilities face additional challenges as well (Miller, 2018). Developmental disabilities are characterized by the American Psychiatric Association (2013) as impairments of personal, social, academic, or occupational functioning. Some individuals with developmental disabilities face many cognitive, social, and emotional challenges when making informed decisions. Difficulties include difficulty self-reflecting, inaccurately weighing the potential benefits and consequences of a decision, and an inability to read external social cues (Lotan & Ells, 2010; Luman et al., 2008). For example, individuals with autism spectrum disorder (ASD) may have trouble judging when and how to know more or have difficulty telling the differences between their own or others’ preferences and emotions in social situations whereas individuals with attention deficit hyperactivity disorder (ADHD) may be sensitive to the reward associated with a decision and less aware of its consequences (Huang et al., 2017; Luman et al., 2008). Due to the many potential decision-making impairments associated with various developmental disabilities, health care professionals may have difficulty deciphering whether a patient’s decision making is impacted by their developmental disability.
Understanding Potential Biases

Biases come in many forms, yet for a child life professional, biases may include assumptions of a patient’s cognitive ability, assumptions of a patient’s emotional well-being, and assumptions of a patient’s interdependence with others (Lotan & Ells, 2010). These assumptions are often implicit biases, meaning they are often unintentional. To eliminate biases, professionals can examine the specific contextual, cultural, and social factors that may contribute to disparities. For example, historically in the U.S, children rely on many adults in their lives, specifically younger children, and children with developmental disabilities (Lotan & Ells, 2010). For this reason, child life specialists may assume that because a pediatric patient has not verbally expressed their desires, they will be relying on an adult in the room to voice their preferences on their behalf. A child’s vocalizations or lack thereof during health care visits and overall verbal ability should not be the sole determinant of a pediatric patient’s capabilities. Individuals may not be vocalizing health-related questions, treatment preferences, or accommodations for many reasons outside of cognitive impairments. Some patients are afraid of annoying health care providers by asking too many questions; some feel intimidated by the possibility of asking questions that would make them appear ignorant; and some feel that they do not know enough to know what to ask. (Lotan & Ells, 2010). Child life professionals can ensure they are accommodating diverse communication preferences and eliminating communication biases by asking patients and families about the patient’s communication style and challenges and provide patients with privacy to communicate their needs to preferred adults.

Other contexts where child life professionals may encounter biases about a patient with developmental disabilities may include examples similar to those in the boxes on the right.

<table>
<thead>
<tr>
<th>Bias</th>
<th>Intervention</th>
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<tbody>
<tr>
<td>A patient may be crying and screaming when they enter a health care professional’s office. A child life specialist may assume that the child is emotionally unavailable and incapable of making any decisions at this time.</td>
<td>Consider that the patient may be at a heightened state and this state may be temporary. Provide the patient with the opportunity to calm down before presenting a decision to the patient, or present the patient with smaller choices, leading up to the larger choice at hand.</td>
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<td>A patient changes their mind often when choosing their preferred distraction item. A child life specialist may assume that the patient does not consider the consequences of their decision and will instead choose a distraction item for the patient or forgo distraction items altogether.</td>
<td>Consider that children and adolescents may prefer items at certain times and may feel uncomfortable expressing a reasoning for their preferences. Ask the patient why they may have preferred an item at a specific time versus a different item at another time.</td>
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<th>Bias</th>
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<td>A patient may indicate a request for a sensory accommodation (i.e., dimmed lighting/headphones) during their first health care visit and not during their second health care visit. A child life specialist may assume that the patient wants the same accommodation(s) during their second health care visit.</td>
<td>Consider that a patient may not be asking for the same accommodation because they feel more comfortable during their second visit. Also consider that the patient may be bothered by different sensory stimuli during their second visit and may need different accommodations. Ask the patient their preferences for sensory accommodations during each health care visit.</td>
</tr>
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</table>
**Parent/Caregiver Led Health Care Decisions**

Health care professionals may encourage family members to incorporate more opportunities for patients to make decisions in multiple situations in their daily lives, with the goal that decision-making involvement will teach patients the factors to consider when making decisions, the consequences of different options, and the communication skills to negotiate and influence decisions. Whenever possible, involving patients in participating in any health care choice, such as timing of treatment, acknowledges the patient’s role in their own health care decisions, even if the patient cannot play a major role in more consequential health care decisions. A decision may be presented to the patient as open-ended or with limited choice options, depending on the patient’s cognitive ability, age, and the nature of a decision. As an example, a parent may provide their child with a few time choices to take their medicine. If medicine needs to be taken at the same time every day, parents may ask their child if they’d prefer taking medicine in the morning or in the evening, or at 9am versus 10am. If developmentally appropriate, parents, caregivers, and health care professionals may engage in relational exchanges where children are active participants in the exchange, meaning the child asks for advice or an opinion and an adult solicits their view or opinion (Miller, 2018). A relational exchange may include promoting a patient with the option to join a health care blog or to actively seek health care information independently; if the patient asks for advice, a parent or caregiver may provide feedback as to which option they think would be more beneficial for the patient. Finally, providing children and adolescents with a verbal or written list of values which may or may not have influenced a decision, and asking patients to rank these values teaches the patient to recognize and prioritize their values when deciding. Follow up questions healthcare professionals and family members may ask patients include: why did you make that decision and how do you think your decision affects yourself and others? These questions allow for more self-reflection, which leads to better decision making over time, though child life specialists and family members may need to provide more guidance if individuals do not understand the reasoning behind their choices (Huang et al., 2017). Guidance may include framing the patient’s choice based on evidence in his or her environment. For example, a patient may choose to take their medicine at a certain time for many reasons but explaining what those reasons could be (if the child is unable to do so) and providing the child a chance to explain their reasoning may promote more self-reflection over time.

**Medical and Legal Health Care Decisions**

Although children and youth cannot make larger medical decisions (such as treatment choices) independently for legal reasons, there are special circumstances where children and adolescents can play a major role in their health care decisions. When a pediatric patient is accepted into a clinical trial, the patient is presented with the opportunity to consent to treatment if providers believe the patient can do so. Capacity is a clinical opinion made by a physician regarding a patient’s decisional abilities to assent to a clinical trial (Johns Hopkins Medicine, 2017). A patient’s capacity to make an informed decision depends on the patient’s age, experience, maturity, and condition. During the assent process, a medical team explains the trial to the patient in a language they can understand, including what is meant to take part and what they can expect. The team may use written forms, videos, graphics, and other visual aids to explain the trial, and the patient is encouraged to talk with family members and ask questions of the research team (National Cancer Institute, 2020). These steps may not be carried out by a research team with a child or adolescent regarded as incapable of assenting to medical treatments for cognitive, social, or emotional reasons. Unfortunately, this is a missed opportunity for children and adolescents with disabilities to play a major role in their health care decisions. Individuals who present for medical consultations want information, good and bad, about all aspects of their condition as well as options for interventions (Lotan & Ellis, 2010). Involving children and adolescents in decision making processes, even by summarizing information regarding the intervention the patient will be receiving, sends the message that youth perspective is important, and this sets the stage for an expectation of increased participation over time (Miller, 2018). Regardless of the role an adult may play in a pediatric patient’s life or what influence they may have over a patient’s health care decisions, pediatric patients with disabilities need voices that accurately reflect their best interests. Child life specialists, parents and caregivers, and other medical professionals are fortunate to be this voice for many pediatric patients with developmental disabilities and may improve their health care experiences and quality of life.

**References:**


Sibshops is part of a national program dedicated to supporting brothers and sisters of people with special health, developmental, and mental health concerns. Sibshops events are curriculum-based, lively, recreational peer support groups hosted by trained facilitators at various locations throughout the world (Sibling Support Project, www.siblingsupport.org/sibshops, 2021). Mayo Clinic has a well-established and very successful Sibshops program that began in 2009. Historically, these events occurred in-person and brought together nearly 75 kids, volunteers, and child life staff each time.

Sibshops events have been traditionally offered at Mayo Clinic five times annually: two for school-age siblings, two for teen siblings, and one family event. Each event requires a large amount of planning for the child life specialists, including a developed theme, high-energy activities, therapeutic activities, venue securement, supply ordering, supply organization, and volunteer recruitment. Parents and siblings often share their excitement in looking forward to upcoming events!

When the COVID-19 pandemic began and large group gatherings were restricted, the child life team had to be innovative in how Sibshops events are offered. The events could have easily been cancelled, but the Mayo Clinic team felt it was important to continue to offer high quality programming for this population who already have limited opportunities available to them regardless of the pandemic. Over the past year and a half, the
modifications made to the Sibshops programs at Mayo Clinic included integrating virtual platforms and implementing mailing boxes to the participants. All events hosted during this time period have been slightly different, yet each has continued to have positive outcomes, and Sibshops remains a successful sibling support program offering at Mayo Clinic.

School-Age Event #1:

The summer of 2020 was filled with creativity in many shapes and forms. Communities were coming together in ways that had never been done before. One way of connecting with others was via live virtual gatherings where people could connect through their electronic devices. The first modified Sibshops that summer transitioned from an in-person event to a live, hosted virtual event. Kids were excited to see their Sibshops friends and “logging on” was new and fun!

In order to gain commitment from those who registered, a box of items was sent to each Sibshops participant prior to the virtual event. The box included items that aligned with the theme and would be used during the upcoming virtual event. This concept created something tangible and special for each individual child participant, enhanced excitement for participants in the upcoming event and aided in helping them begin the process of engagement with one another. Providing materials in advance of the event not only heightened excitement and participation, it also allowed families the opportunity to manage the varying attention spans within their sibling groups.

On the day of the virtual event, two child life staff members helped facilitate multiple live groups throughout the day. Four different sessions were held on that day based on age groups of participants. Surprisingly, the kids were very interactive and eager to share the materials they had been sent prior to the event. We incorporated therapeutic activities surrounding individuality, commonality, inclusion, and teamwork while mixing in high-energy scavenger hunts and games. The turnout was better than expected, with almost a 75% participation rate!

Theme: Sibs ROCK!

Staff support: 3 staff ordered supplies, assembled boxes and mailed out; 2 staff facilitators during actual event

Items in box: Sibshops ROCK! Bracelet, rock candy, pop rocks candy, small rock and rock painting supplies, Sink or Float sign

Virtual information: Specific group link e-mailed to each participant with date/time listed. 4 groups total

Layout of the Event: 60 minutes

Therapeutic activity: Rock painting was to be done prior to live event with a goal of promoting individuality and creativity.

Introduction: Participants were able to show & tell their rock to the group which allowed for an added therapeutic aspect to the activity.

Game: What Do We Have In Common where kids could connect and be able to relate with one another.

High-energy activity: Kids were sent on a scavenger hunt for rocks around their house and were encouraged to bring them back to share what they found with the group.

Game: Sink or Float (prop in hand)

Inclusion/Teamwork: SIBS ROCK acronym

School-Age Event #2:

As time went on, many children had been “logging-on” to multiple virtual programs for on-line schooling and other events and so were becoming less enthusiastic for such programming. Thus, the child life team had to yet again brainstorm a new way to engage and support these unique siblings. This second event was different than the traditional interactive Sibshops; rather, it mirrored that of a 4-week subscription box, where each week the participants received a themed box with activities that could be done on their own time. Parents received a weekly e-mail with descriptions of each item and the therapeutic intent behind it so they could help facilitate due to child life staff not being present to lead conversations with the kids. Participants were also able to watch a corresponding YouTube video via QR code inside each box for additional facilitation from the child life staff. Great feedback was received about the videos; however, the boxes also included detailed descriptions so the siblings who did not have access to technology would still have a quality experience.

The themes covered throughout this event included: creativity, individuality, coping, feelings expression, and spreading joy. The entire child life staff supported this event as tasks were divided amongst many different staff members. Four videos were created by 3+ staff per video; each video had a corresponding mailed box. The videos were modified and compiled to be uploaded onto YouTube via a private link from the child life team account, and a QR code was created to link directly to the video. Boxes were assembled and mailed on Monday of each week, knowing the box would arrive mid-week. The parents received their e-mails on Mondays so they would be prepared for what their child would be receiving and how they could engage with their child throughout that week’s activity.
Theme: Fill Your Cup

Staff support: 5 staff in charge of supplies, assembling of boxes, and mailing on specific dates; 12 staff created video content; 1 staff member filmed and edited videos for visual consistency; 1 music therapist created theme song for each video; 1 staff member created written content for the box and explanations for parent e-mail

Layout/Supplies: 4-week mailing, 1 box per week, activities were done on child’s own time

DIY mug: Identifying what “fills your cup” what things in your life help you feel energized to conquer challenges in life

Blizzard in a Bottle: Coping with life’s unexpected changes and dealing with things out of your control

Sand Art in a Bottle: Expression of feelings, each color represents different emotions

Decorate a flowerpot and planting seeds: Sharing joy when your cup is full

Teen Event:

Teenage siblings who have a brother or sister with a chronic medical or health condition have been living with differences and potential challenges within their family structure for quite some time. Therefore, the child life team felt it was of even greater importance during the pandemic to allow for increased choices for these particular siblings. While the school-age kids tend to need more direction and facilitation, the teens enjoy more individualized activities or to connect on their own terms without feeling the need to openly share, all of which is developmentally appropriate for their age group. Knowing this, the child life team decided to modify the in-person gathering to an invitation for a themed box. This event was similar to the school-age concept of having a box mailed to the participants; however, prior to receiving a box, each teen was able to select their theme preference on their registration form and include a quote of their choice which was used to individualize the items.

After receiving the completed registration forms, the child life team assembled each participant’s box surrounding either the therapeutic intent of adventure, vulnerability, and excitement or relaxation, self-reflection, and meditation. An overarching goal was to empower these teens, to promote self-care, and to help them feel a sense of ownership, especially during a time when their worlds have been turned upside down throughout the pandemic.

Themes: Mountain OR Beach

Staff support: 6 staff ordered supplies, assembled boxes and mailed out

Supplies: Individuality, self-care, fun: water bottle with a sticker with the teen’s chosen quote, towel, backpack, beach ball, first-aid kit, sunglasses. Therapeutic activity, relaxation, inspiration: guided imagery. Descriptions of what each item signified, the intention behind them, and therapeutic goals identified

Family Event:

To support the entire family of our Sibshops participants, the child life team facilitates a Family Event each year. In addition to promoting connectedness between the families, the Family Event provides an opportunity for individual family members to be together doing something fun and engaging without having to worry
about costs and provides the security of inclusion to the child with chronic health conditions.

Due to families not being able to be together this past year, the child life team continued on the same lines of a mailing box, where families received a box filled with activities to encourage family togetherness. The activities included: Making Memories (Shrinky dink handprints), conversation Jenga, sidewalk chalk, and an activity to create a time capsule. Each activity came with a how-to guide and included a note to caregivers articulating each activity’s therapeutic value. To meet the goal of connectedness between families, a QR code was provided to access a secure “Kudo Board”, an online group message board, encouraging posts and pictures of families engaging in the activities.

Themes: Family Connectedness and Making Memories

Staff support: 3 staff ordered supplies, assembled boxes and mailed out

Supplies: Feelings/emotions expression: colored Jenga game with paired prompts and questions.

Time capsule: plastic mason jars, prompts to include unique, important memories individual to family

Making memories: Shrinky dinks paper, colored pencils, key chains

High-energy, togetherness: sidewalk chalk. How-to activity guides for each activity.

Summary:

In the past year and a half, the Child Life Program at Mayo Clinic has realized the importance of continuing to provide high-quality Sibshops events and has continued to evolve the offerings based on current circumstances. The key components to the events remain the same, which include high-energy, fun, and therapeutic components. However, these recent events have reached a higher number of siblings with the virtual format than the in-person events did in the past. Likely reasons for the increase in participation is that set dates can be of constraint for families and traveling from their homes may be a challenge as well. With virtual events, families have not had to coordinate drop-off and pick-up times, and they have been able to do the therapeutic activities when it works best for them. While in-person events were historically the go-to way of facilitating Sibshops at Mayo Clinic, the child life team has learned to be more open-minded regarding having various options for participation. In addition to the key components listed above, offering a variety of event formats throughout the year will be implemented into the structure of future Sibshops.

References:

Over the last nearly two years, the pandemic has affected every aspect of life and has greatly impacted child life specialists and the child life field. Some during this time continued their role as specialists in their respective settings. Others found their roles adjusted to accommodate the effects of COVID on their healthcare systems while still others found their positions eliminated. Child life specialists have found themselves, either professionally or personally, using their skills to support those affected by, and with, COVID. COVID-19 is a disease caused by the virus SARS-CoV-2, and most often causes respiratory symptoms much like a cold, the flu, or pneumonia (Centers for Disease Control and Prevention, 2021a). To date, there have been over 250 million cases of COVID-19 globally (World Health Organization, 2021). Now, we may also find ourselves caring for children impacted by a residual diagnosis related to COVID, Multisystem Inflammatory Syndrome in Children, also known as MIS-C. “MIS-C is an extreme immune response marked by shock, fever, and multi-organ inflammation. It may cause severe inflammation in the heart, lungs, blood vessels, kidneys, digestive system, brain, skin or eyes” (Mostafavi, 2021, para 6). The cause of MIS-C is not currently known, but most patients tested positive for COVID-19 or had been exposed to someone with the virus. As of November 1, 2021, there were 5,525 confirmed cases in the United States, with 48 deaths (Centers for Disease Control and Prevention, 2021b). Given the prevalence of COVID-19, and its impact on our pediatric patients, it is important that we, as child life specialists, understand MIS-C and are equipped with resources to use when supporting children and families affected by COVID-19 and MIS-C.

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Resources for Patients and Families:

This workbook is designed to help children and teens communicate and cope with their feelings and emotions regarding the global COVID-19 pandemic.

This resource is a coloring pamphlet using developmentally appropriate language to explain coronavirus related PPE to children.

This activity book uses developmentally appropriate language to inform the patient about COVID-19 and how to protect against transmission.

This resource contains workbook pages for the child to use to create a time capsule during the COVID-19 pandemic.

This diary contains pages for the child to complete to encourage positive reflections related to being on lockdown during the pandemic.

Memorial Health Dwaine & Cynthia Willett Children’s Hospital of Savannah (2020). Stay at home activities. https://www.chiilife.org/docs/default-source/covid-19/msav_general-hospital_or-schedulers-may-breakfast_flyer_8.5x11.pdf?sfvrsn=4008a4d_2
This resource contains recommendations for activities that can be done while at home from the team of child life specialists at Memorial Heath Dwaine & Cynthia Willett Children’s Hospital of Savannah.

This is a story to help kids learn more about germs, viruses, and the pandemic, as well as understand the importance of wearing masks and how they can help to prevent the spread of COVID-19.

This activity resource uses developmentally appropriate language to explain PPE and why it is used to protect against different germs and viruses.

For play at home and daily Facebook Live “recess.” This playbook contains games that can be played anywhere so that children can play in any space safely and in accordance with all CDC guidelines to help prevent the spread of coronavirus.

This resource emphasizes how important it is for everyone to wear a mask—even Oscar the Grouch.

Elmo is heading to school, and he wants to be a school superhero! Young children will join Elmo as he gets ready like a hero and learns about wearing masks and washing hands.

In this book, Lucy finds out her mom is making her a special mask. Lucy loves masks! Of course, she doesn’t realize that the mask her mom is making is not part of a costume but one that will keep her safe.

This activity book provides developmentally appropriate information regarding coronavirus and COVID-19.

This coloring book uses developmentally appropriate language to inform children about coronavirus and COVID-19 vaccines.

This is a resource to assist caregivers and patients with expressing their thoughts and feelings regarding coronavirus.

Activities to help children, teens, adults, and grandparents deal with feelings and changes during the Coronavirus Pandemic.

Riley’s Masked Adventure is a story and that follows Riley through her experience as she learns what viruses are, why she should wear a mask, and how to use one correctly.

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Resources for Caregivers:

This website provides information for parents about what is currently known about MIS-C, what to do if parents think that their child has MIS-C, medical tests and procedures associated with making a diagnosis, and how to protect children from both COVID-19 and MIS-C.

This resource shares what is currently known about MIS-C, the signs and symptoms of MIS-C, and ways to prevent MIS-C.

Resources for the Child Life Professional:

This website provides a definition of MIS-C, information regarding the signs and symptoms of MIS-C, as well as information regarding medical tests and procedures that contribute to making a diagnosis.

This study suggests patterns of clinical presentation and organ involvement that distinguish between patients with MIS-C and severe acute COVID-19.

Publication Reference:


Bio

Jennifer Fieten, MA, CCLS, has been a child life specialist for over 20 years, providing child life support for children and families both in hospitals and as a part of a pediatric palliative care and hospice program. Currently, Jennifer serves as a Medical Social Consultant/Child Life Specialist with SIU School of Medicine at St. John’s Children’s Hospital in Springfield, IL. For additional information, Jennifer can be reached at jfieten36@siumed.edu or jennifer.fieten@hshs.org.
JANUARY 31: Deadline to submit 2022 annual certification maintenance fees.
FEBRUARY 8: Initial Offer Date for 2022 Summer Internships.
FEBRUARY 9: Child Life Certification Commission Town Hall.
FEBRUARY 9: Acceptance Date for 2022 Summer Internships.
FEBRUARY 10: 2nd Offer Date for 2022 Summer Internships.
FEBRUARY 15: Applications open for the Summer 2022 Diversity Scholarship.

MARCH 1 - MARCH 31: Child Life Month!
MARCH 1: Applications Open for the ACLP Membership Access Program.
MARCH 8: Applications close for the ACLP Membership Access Program.
MARCH 10: Deadline to apply for the March 2022 administration of the Child Life Professionals Certification Exam.
MARCH 15: Child Life Professional Certification Exam administrative testing window opens.
MARCH 15: Applications close for the Summer 2022 Diversity Scholarships.
MARCH 15: Application deadline for the Fall 2022 Internship.
MARCH 15: Storytime Snuggles: A NICU Reading Program.
MARCH 31: Last day for early bird registration for the 40th Annual Child Life Conference.
APRIL 1: CLPDC data entry for annual data and Q1 2022 quarterly data opens.

Visit education.childlife.org for more information on upcoming webinars.