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واحة
عبدالرحمن
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The Child Life Foundation

Abdulrahman’s Oasis

Transforming Pediatric Healthcare in Saudi Arabia


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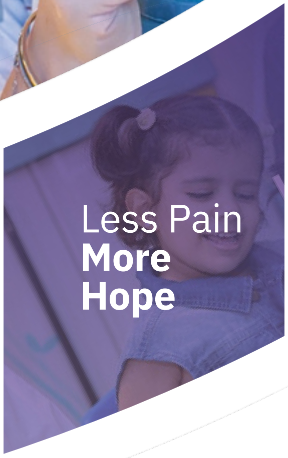
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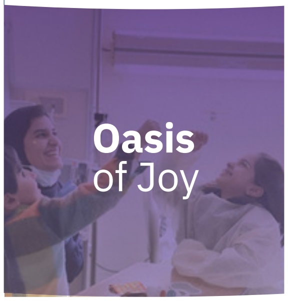
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President's Perspective: Listening, Advocating, and Leading Forward

Elana Brewer, MS, CCLS, President

It is with deep gratitude and genuine excitement that I step into the role of President of the Association of Child Life Professionals (ACLP). This opportunity to serve and collaborate with our passionate and dedicated community is both humbling and energizing. As I begin this journey, I'd like to offer a window into my leadership philosophy, the values that guide me, and the work ahead that I feel called to champion.

At the heart of my leadership style is a simple but powerful concept: listening. I believe that real leadership begins with hearing and understanding the lived experiences of those I serve. Our association is only as strong as the voices that shape it, and I'm deeply committed to ensuring that each member feels heard, valued, and supported. In my daily work, I uphold an open-door policy—not just in theory, but in practice—and I bring that same approach to my role within ACLP. Feedback is essential for growth, and I welcome it wholeheartedly, with the expectation that it comes from a place of professionalism and mutual respect.

Over the past few months as President, I've had countless moments to reflect on what it means to advocate—not just as individuals, but as a unified profession. As child life specialists, advocacy is part of our DNA. We speak for children, for families, and for compassionate care practices. We advocate in hallways and conference rooms, at bedsides and national conferences, often without recognition but always with unwavering resolve. And while many of our victories are quiet and behind the scenes, their impact often echoes for a lifetime.

Advocacy, for me, is both personal and collective. I've seen firsthand the outcomes of passionate, persistent advocacy—whether it's championing improved salaries, promoting work/life balance, or pushing for professional advancement for child life staff. These efforts are not isolated to job satisfaction; they affect retention, morale, patient outcomes, and the sustainability of our profession. I've also found that combining data with powerful narratives is an incredibly effective tool in communicating the true value of child life services and in securing increased staffing resources to meet the growing needs of pediatric populations.

One of the most salient examples of recent advocacy came early in my presidency. Two of our members alerted us to Kaiser Permanente's decision to eliminate the child life specialist title and reduce qualifications required for the role. This change not only devalued our profession but put vulnerable children and families at risk of receiving less specialized care. In response, ACLP leadership, including the Child Life Certification Commission (CLCC), acted swiftly. Together, we drafted and delivered a letter to Kaiser's senior leadership—backed by data, credentials, and heartfelt testimonies from professionals across the country. Thanks to the united front formed by ACLP, CLCC, and our resilient members within Kaiser, the specialist title and appropriate job description were reinstated.

This was a moment of victory—but also a reminder that we must remain vigilant. Threats to our profession, whether stemming from financial constraints or administrative decisions, are not uncommon. In the past we've seen positions eliminated in response to fiscal pressures, and with recent legislative passages we may likely experience that again. In these moments, the importance of strategic and passionate advocacy cannot be overstated.

We also face broader, systemic challenges—particularly when it comes to compensation. The current landscape for determining salaries is murky at best. Child life specialists continue to receive wages that do not reflect the depth, skill, and emotional labor of their work. While ACLP has yet to identify a clear path for creating national impact around wages, I want you to know that local leaders are engaged, informed, and tireless in their pursuit of progress. And I, too, am committed to being a fierce and consistent advocate for our value—whether in national conversations, local negotiations, or everyday decision-making forums.

In my own role leading a large child life program, I've fought for higher pay, greater professional recognition, and more inclusive leadership structures. I've pushed for mental health supports for staff, flexible scheduling, and investment in career development. These aren't just "nice-to-haves"—they're vital pieces of a sustainable, equitable work environment. And I plan to use every ounce of that experience to serve you, my fellow ACLP members, with dedication and clarity.

Ultimately, this association is shaped by all of us. We are educators, innovators, caregivers, and changemakers. Our future will depend on our ability to work together, to advocate boldly, and to maintain our focus on what truly matters—improving the lives of children and families through specialized, compassionate care.

I invite you to share your thoughts, your concerns, and your hopes. My door is always open, and every voice matters. Thank you for your continued trust and support. Together, we will elevate the profession, strengthen our community, and ensure child life continues to shine brightly in every corner of pediatric care.

From the Executive Editor

Morgan Morgan, MS, CCLS

Dear Colleagues,

As summer draws to a close, we find ourselves at a familiar and meaningful juncture—a season of transition that invites both reflection and renewal. The energy of summer programming begins to wind down, and the cadence of fall returns with fresh opportunities to re-engage in our work with focus and intention. For child life specialists, this time of year offers more than a seasonal shift; it's a chance to revisit the core of our mission and to recommit to practices that center the needs, voices, and lived experiences of children and families.

It is with great excitement and deep respect that I introduce Elana Brewer, MS, CCLS, as the new president of our association. Elana brings to this role decades of experience, steadfast leadership, and a deep commitment to the evolution of our profession. Her ability to bridge clinical excellence with visionary thinking makes her uniquely suited to lead us through this next chapter. Her thoughtful approach and steady leadership promise to guide our community with clarity and care.

This issue arrives on the heels of a memorable gathering of our community at ACLP conference this past May in Los Angeles. The conference was a powerful reminder of the strength and resilience of our field. Through rich workshops, thought-provoking panels, and heartfelt connection, we explored the complexities and possibilities of child life work in today's healthcare landscape. From sessions on integrative care to conversations around professional identity, our time in Los Angeles affirmed the importance of coming together to learn, share, and celebrate. The energy and insight from that event continue to ripple through the stories and contributions you'll find in this issue.

Among them is a compelling article that dives into the pediatric patient's perception of healthcare—a topic that sits at the heart of our work. Written by Ashley Semones, MA, CCLS and Kat Davitt, CCLS, OTR, this piece explores how children make sense of their medical experiences and provides a research-informed framework for understanding how developmental, emotional, and environmental factors shape those perceptions.

In this same spirit of deepening understanding, we are proud to feature an article that addresses the critical topic of creating a culture of respect and inclusion for individuals with autism. With increasing awareness and advocacy around neurodiversity in healthcare, this piece provides timely and actionable insights for creating environments where neurodivergent children can feel safe, supported, and empowered. Authors Briana Keller, MEd, Alexandra Kalinyak, BS, Malerie McDowell, BS, and Kelsey West, PhD share their own experiences working with and living as neurodivergent people and offer strategies for fostering effective communication and rethinking clinical interactions through a lens of dignity and individualized care. It is both a guide and a challenge—to grow as practitioners and as allies.

Also in this issue is a forward-thinking article introducing a novel framework for clinical internships. Born from a multi-institutional collaboration, this model reimagines how we train future child life specialists by placing greater emphasis on mentorship, reflective practice, and interprofessional learning. Authors Marne Perrin, MS, CCLS and Dagney Willey Adamson, MHI, CCLS share how they built a one-of-a-kind internship program to offer a clinical experience beyond the walls of the hospital. It's an inspiring look at how we can better prepare students for the realities—and rewards—of a career in child life.

Each of these articles, while distinct, share a common thread: a commitment to improving care through deeper understanding, innovation, and inclusivity. As we transition into the fall season, I hope this issue inspires you to think expansively about your role, your impact, and your continued growth as a professional. Whether you're supporting a young child through a first procedure, mentoring an intern, or developing new programming in your setting, your work matters—and it continues to shape the future of pediatric care in meaningful ways.

On behalf of the editorial team, thank you for your continued commitment to this field and for being part of such a vibrant, thoughtful, and passionate community. We are grateful to walk alongside you in this important work.

Warmly,
Morgan Morgan, MS, CCLS
Editor, Bulletin

Welcome to The Board Room: May 2025 Meeting Highlights

Sarah Patterson, MSc, CCLS, Immediate Past President

Each spring, just before the annual ACLP conference, the ACLP Board of Directors comes together to reflect on the year past, strategize for the year ahead, and transition leadership. The May 2025 meeting was a powerful reminder of the passion and purpose that unite our profession. Over two full days, board members engaged in meaningful dialogue, passed important motions, and reaffirmed our shared commitment to advancing the field of child life and our association. This meeting was also a time to welcome new voices, honour outgoing leaders, and set a clear course for the months to come.

Welcoming New Board Members

We are thrilled to welcome the 2025–2026 incoming board members:

- President-Elect: Vicky Isaacson, MA, CCLS
- Directors: Dora Castro-Ahillen, MA, CCLS, and Hillary Woodward, MS, CCLS
- Treasurer: Alyssa Luksa
- Public Member: Kathy Van Allen

These leaders bring a wealth of experience in diverse practice settings and a deep commitment to child- and family-centered care. Their insights will enrich our decision-making and help guide ACLP through a rapidly evolving professional landscape. We also extend our heartfelt thanks to our outgoing board members Janelle Mitchell, Director, Alisha Saavedra, Immediate Past President and Stacy Palmer, our public member from the Beryl Institute, whose dedication and service have been instrumental in advancing ACLP's mission during a transformative year.

Supporting Leadership Transitions

To ensure that new leaders are equipped for success, incoming board members observed the May meeting, met with board mentors, and received comprehensive orientation materials. This process allows them to see board governance in action while building early connections with fellow leaders. By investing in orientation and mentorship, ACLP reinforces its culture of collaboration, respect, and shared responsibility.

Strategic Highlights and Committee Updates

The Board worked through a full agenda of motions, policy refinements, and forward-looking discussions. Each decision was guided by our strategic plan, our values, and the goal of supporting members in their daily practice.

Committee Infrastructure & Engagement

- Approved updates to the Committee Infrastructure and Appointment Policy, limiting committee service to one per member unless appointed by the President. This helps distribute volunteer opportunities more equitably and allows members to focus their time and talents.
- Emphasized the value of mentorship within committees, ensuring newer members have the guidance they need to be effective contributors.

Deepening Member Engagement

A recurring theme throughout the meeting was the importance of transparency and active engagement with members. The Board explored several strategies to strengthen connections, including:

- Creating regular blog posts to share board decisions, priorities, and behind-the-scenes perspectives.
- Hosting virtual listening sessions to hear directly from members and gather feedback.
- Reengaging with regional groups to build relationships, encourage collaboration, and amplify ACLP's presence at the local level.

Awards & DEI Initiatives

- Approved engaging an external consultant to review the awards process through a diversity, equity, and inclusion (DEI) lens. This review will help ensure equitable access, transparent criteria, and broader representation in all ACLP awards.
- Discussed clarifying the scope of the International Award and developing strategies to diversify the applicant pool for research awards.

Community-Based Practice

- Approved the removal of the 6,000-hour experience recommendation for CCLSs entering community-based roles. This change addresses misperceptions, lowers barriers, and reflects the diversity of skills needed in different practice settings.

Financial Oversight & Education

- Reviewed ACLP's financial portfolio, noting positive variances in reserve accounts and a strong net income position.
- Committed to strengthening financial education for board members through orientation sessions, clear narrative explanations of budget changes, and ongoing updates to promote transparency.

Internship & Pathways to the Profession

- Approved updates to the Internship Common Application to include more inclusive language that reflects the realities of today's workforce.
- Encouraged exploring innovative entry pathways into the profession beyond the traditional 600-hour internship model, recognizing that flexible approaches may open doors for more diverse candidates.

Publications

- Considered adding an "areas of expertise" field to the membership renewal process to better match members with relevant publications, committees, and special projects.

Research Fellows Transition

- Voted to decommission the Research Fellows Group in preparation for the launch of the ACLP Fellows Program at the 2026 Annual Conference.
- Offered current Research Fellows the opportunity to transition directly into the new program, ensuring continuity and recognition of their contributions.

Looking Ahead

Another meeting was held virtually in August and will be followed by an in-person meeting in November. In the months ahead, the ACLP Board will continue to focus on initiatives that advance the profession, support our members, and ensure that child life practice is inclusive, evidence-informed, and sustainable and all aligned with our current strategic plan.

We look forward to sharing more updates in the Fall issue of the ACLP Bulletin and invite every member to stay informed, ask questions, and lend their voice to shaping the vibrant future of child life.

Empowering Students and Supervisors: A Collaborative, Multi-Site Internship Model

Dagney Willey Adamson, MHI, CCLS and Marne Perrin, MS, CCLS
Co-founders and Co-Owners of Coping Copilots, LLP

About Coping Copilots, LLP

Coping Copilots, LLP is a Minnesota-based private child life practice born from our collaboration (Marne and Dagney) which began in 2020, when we met working in a traditional healthcare setting. Though we quickly realized we were complete opposites in strengths and styles, our shared passion for child life and our ability to creatively build off each other made us “Better Together.” That synergy sparked a vision: to expand the role of child life into the community through private practice.

The barriers students face in securing traditional child life internships also informed our work. Recent research highlights that only about half of applicants successfully obtain an internship, with factors such as graduate-level education, prior healthcare-based practicums, and faculty support significantly influence success rates (Boles et al., 2025). This reality means that many capable and passionate students are overlooked, despite being well aligned with the heart of child life practice.

We officially registered Coping Copilots in December 2023 and launched in April 2024, grounded in a strong mission, vision, and set of values. The idea for a shared internship model was inspired by, Alexia, the daughter of a mutual friend. Alexia is a bright and passionate student whose independent studies degree from NYU focused on creativity in communication and child development. Despite her clear alignment with the heart of child life work, her non-traditional academic path did not meet internship program criteria, leaving her overlooked. After creating a custom practicum experience for her and witnessing her continued challenges securing a placement, we felt compelled to create a sustainable and scalable internship model to support students like her.

We realized we didn’t want to just think outside the box, but instead, we wanted to blow the box up. That might sound bold, but as organizational psychologist Adam Grant says, great minds do not think alike, but they challenge each other to think differently. As the CLCC and Federal Registrar requirements emerged, our commitment to mentorship and community-based child life practice only deepened, guiding the work we do today. This article serves to outline the process of creating a sustainable and scalable child life internship model drawing on the power of collaboration.

COPING COPILOTS AT A GLANCE

MISSION:	VISION:	VALUES
To promote resilience in children, teens, and their families by providing support during unique and challenging circumstances through the lens of development and play.	To integrate proactive developmental, trauma-informed, and preventative coping support into communities throughout the state of MN and beyond, while investing where our contracted professionals are located.	• Strengths-Based Approaches • Play (Adults Too!) • Do the Right Thing (Even if it’s hard) • Respectful Collaboration

A Networked Approach to Innovation

As we began shaping this experience, we realized our business structure naturally removed many common barriers. As a partnership, we didn’t need to navigate committees, leadership approvals, or organizational red tape. Decisions could be made quickly—sometimes with a single text. We already had a business attorney who could review affiliation agreements within 24 hours, and our existing professional liability insurance included student coverage. This meant organizations could approve student involvement almost immediately. These built-in advantages made the process smoother and more accessible than we had imagined.

A unique strength for the child life community of Minnesota is the close proximity of many child life departments and the strong professional connections built over the years of shared programming. One great example is a multi-organization diabetes support group that brings together CCLSs from several departments as facilitators. In fact, it was through this program that Dagney formed key relationships—connections we later relied on to begin weaving a network of opportunities for our future interns.

Expanding Access to Supervision and Mentorship

As we began to think about how to create this experience, we reflected on the amount of untapped potential in CCLSs who had not been able to support students or interns due to their practice setting—particularly those working in the community-based roles or as part of one-person or small child life programs. We wanted to leverage the strength and experience of Minnesota’s child life professionals to offer unique learning opportunities while reducing the burden on staff already involved in student internship programs at traditional sites.

We carefully reviewed CLCC policies and documentation to ensure we understood our model would align with internship verification requirements. Through this review, we confirmed that Coping Copilots, LLP could serve in the internship coordinator role. This structure would allow each rotation to designate a qualified rotation supervisor responsible for 80% of daily contact with the intern, focusing on developing competency-based foundational clinical skills. How we chose to reinforce those competencies and skills outside of rotation hours was left to our discretion.

To thank the professionals who joined us in this adventure, we hosted our inaugural “PJ’s and PDU’s” morning event in partnership with the University of Minnesota and Minnesota Child Life Coalition. The event offered three free PDUs to any Minnesota-based CCLS who attended in person, with a small fee for virtual attendees and recordings. We were transparent about the virtual fees for this event and our future PJ’s and PDU’s events will fund future stipends for internship coordinators who offer supervision outside of their

Building the Experience

As we developed the internship model, we used the ACLP modules to guide the design of supplemental content and assignments that would deepen student learning. While doing so, we were intentional about innovating rather than replicating a traditional model. Our first priority for each student was to provide one rotation in a traditional healthcare setting, helping them stay prepared for and marketable to traditional child life roles. Beyond that, we created opportunities to learn from CCLSs in non-traditional roles and unique settings, supporting children of adult patients, working in community-based programs, and even authorship experiences.

We condensed key elements of the traditional internship, such as case discussions, group programming, teddy bear clinics, and final presentation into an “intensive week”, allowing students to fully immerse themselves in clinical work during their rotations. One especially meaningful experience included a discussion with Helen, a retired child life professional who shared insights from nearly 50 years in the field.

Each student was paired with an internship coordinator who met with them outside of clinical hours to process experiences, review assignments, and extend their learning. In many ways, our interns had the benefit of learning from what felt like a large department: 32 child life professionals, multiple music therapists, a children’s museum, and a non-profit organization. However, this “department” consisted of CCLSs in Arizona, Illinois, Iowa, all over Minnesota, and even Saudi Arabia.

Logistical Lessons Learned

As we worked to establish this internship model, we quickly learned about the many logistics involved, such as: affiliation agreements, contracts, and background checks among them. We also encountered challenges with organizations that required to direct agreements with the university, rather than with us as the internship provider, which necessitated additional legal support. Healthcare organization’s IT firewalls created complications with direct communication between rotation supervisors and coordinators, as well as with sharing documents. Additionally, not all students had access to resources, such as transportation, which posed a challenge with this model.

We also needed creative solutions for not having a physical office space. When meeting in person with students for orientation and intensive week, we utilized local coffee shops and public libraries to complete tasks and experiences at minimal cost. Another unique consideration, especially when working in community settings like schools, was building in buffer hours for school closures, such as cold weather days or snow days. Fortunately, we had already built in extra hours for sick days and other contingencies, but it’s a factor that you wouldn’t have to think about in a traditional healthcare setting.

Our Pioneering Interns and the Sparkle They Bring

We have been so humbled by how wholeheartedly our pioneering interns embraced this new model—leaning in with curiosity, creativity, and a willingness to help us iterate in real time. Alexia, Kelsey, and Kylie each came to child life through a non-traditional path, making it especially rewarding to be able to build their rotations and select their coordinators in combination with their unique backgrounds in mind. In a sense, we fit the internship experience to the individual, rather than trying to fit the individual into the internship. When it came time to celebrate their completion, we chose one word for each that captured their growth and spirit: Insightful. Confident. Imaginative.

The best part of this model has been all the unexpected “sparkle” it has brought, not only to us, but to our students and the child life professionals who joined in. Several professionals told us they hadn’t realized how much they needed an outlet like this, and how it left them feeling refreshed, energized, excited, and hopeful for the future of the profession. And of course, there was the joy of seeing Alexia, Kylie, and Kelsey’s faces, completely glowing, when they officially finished their internship experience.

Looking ahead to Fall 2025, our next group of three interns, all three affiliated with universities, are strong, passionate students who, for various reasons, have also fallen through the cracks of the traditional internship process. They will each be paired with a different internship coordinator. The bright looks on their faces when discussing this opportunity, especially after feeling so discouraged from not securing a traditional internship, fuels our commitment to championing students who might otherwise be overlooked. We believe their passion will be an incredible gift to our field.

Looking Ahead

Leading into Spring 2026, we hope to expand our pool of partners, not only within our state’s established or emerging child life programs, but also among CCLSs stepping into non-traditional or community roles. We also are seeking opportunities across the Midwest, connecting with smaller programs or community-based CCLS who may be interested in offering a 4-week full rotation or a 1-2 week mini rotation for hands-on clinical experience.

In turn, we hope to provide more internship opportunities now that we have a system in place to support multiple students. We’ve spoken with many students who have gone through multiple internship cycles without success, despite doing all the right things, and we wish we could do more, faster. Our goal is to be a resource, an example that non-traditional, competency-based internship models can be a rich and meaningful experience, and to collaborate and share resources with other CCLSs who may want to build something similar in their own communities.

Final Thoughts

It has been deeply rewarding to create a unique learning model that not only champions future professionals, but also uplifts and reconnects many skilled specialists in Minnesota through their involvement in the internship. This work has opened up doors to collaborate with like-minded CCLSs across the country who share our commitment to growing the field. We have been humbled and encouraged by the support of cheerleaders who see our vision and resonate with our values. This aligns with recent calls in the child life literature to expand educational opportunities and create innovative training models that address inequities in internship access and support professional sustainability (Boles et al., 2025; Gourley et al., 2023). The excitement is contagious as we work together, think creatively, and carve out a new path forward into the profession.

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Creating a Culture of Respect for Autistic Patients and Families

Briana Keller, MEd; Alexandra Kalinyak, BS, Malerie McDowell, BS; Kelsey West, PhD

The medical field is increasingly effective at diagnosing autism, but practices for building respectful rapport with autistic patients lag behind (Hotez et al., 2024). Patient care works best when the medical team regards the patient as a collaborator: someone who is respected, informed, and involved in their care plan (Wampold & Flückiger, 2023). We offer five practical recommendations for building a culture of respect with autistic patients. Considering that 1 in 31 children now receive an autism diagnosis (Shaw et al., 2025), enhancing the mutual understanding and rapport between autistic patients and their (often non-autistic) service providers will touch the lives of many. We are a team of researchers and aspiring clinicians, united by our personal and professional connections to autism, who share a drive to improve care for autistic people. Many existing resources educate medical providers about autism. Instead, we focus on actionable steps–backed by empirical evidence and reinforced by our lived experiences–to create environments where autistic patients feel included and safe.

Personal Perspective: Briana

While working on my master's degree, I was fortunate to gain experience at a children's inpatient psychiatric facility. On my first day, a receptionist asked my supervisor and I whether we had any experience with autistic children. I replied that I did, but before I could elaborate—to explain that I was an autistic child who grew into an autistic adult—she went on: "We need a cure for that. When I was growing up, there were no autistic kids." My supervisor and I traded uncomfortable looks. Comments like these, even when said without ill intent, carry a harmful implication: that autism is something better off erased, rather than a valued part of one's identity. And if I felt disrespected and unwelcome, how would a young autistic patient, already vulnerable enough to need psychiatric hospitalization, feel?

Choose Your Words Wisely

Words have a bigger impact than you may expect. Psychologists have long documented how language subconsciously shapes a person's thinking. The power of words extends to medical settings. Some common words and phrases in medical lingo (e.g., "suffers from," "symptom," "at risk") implicitly assert that autism is negative, undesirable, and unwanted (Como et al., 2020). Be mindful of the message your words send by choosing neutral words. For example, say that something is "characteristic" of autism, instead of "symptomatic;" say that a child "has a family history of autism," instead of "is at risk for autism."

Personal Perspective: Kelsey

The vocabulary surrounding autism has changed dramatically since I was in graduate school. When I began a PhD program in 2012, I was taught that person-first language ("person with autism") was respectful. The push for person-first language was born out of good intentions–it was an attempt to equalize labels across different groups (e.g., "children with autism" and "children without autism" have the same grammatical structure where personhood leads). But, in practice, person-first language failed to accomplish its intended goal.

It was unequally applied—autistic children were “children with autism,” but non-autistic children were “typical children.” In reality, person-first language worsened the stigma it aimed to address. These days, identity-first language (“autistic person”) is more commonly used to reduce stigma, and I instruct students to use this language. Identity-first language is preferred by the autism community, with the majority of autistic people and their family members endorsing identity-first language (Bottema-Beutel et al., 2021).

Share Information, Not Stigma

Autism is a spectrum, and autistic traits present differently from person to person (American Psychiatric Association, 2022). To illustrate, the diagnostic criteria for one aspect of autism—“restricted repetitive patterns of behavior, interests, or activities”—may be met by a huge range of behaviors, from hand-flapping, to temperature sensitivity, to rigidity in daily routines. Given the variability in autistic traits, passing along person-specific information in addition to the diagnosis is helpful when communicating with other providers. Sharing person-specific information reduces time spent assessing a patient’s abilities and needs, and discourages stereotyping among providers with less knowledge about autism.

Personal Perspective: Briana

A technician once pulled me aside and hesitantly said, “This patient is autistic. I don’t know if you know how to deal with that?” Rather than conveying information about the patient’s needs, the interaction spread stigma by promoting autism as something difficult to “deal with” and lacked helpful information. An alternative might integrate both needs and rapport-building insight, such as: “Claire’s autistic, and sometimes it’s hard for her to find words when she’s overwhelmed. It helps to have some extra time to think about a question and answer, especially if things are busy. She’d love to talk with you about her sketchbook–she’s an expert on drawing dragons!”

Be Mindful That Challenging Behaviors Make Sense to the Patient

When a patient engages in difficult behavior (such as self-injury, aggression, or elopement), with no clear cause, it can be tempting to focus solely on managing the behavior. However, the patient is behaving this way to try and meet a need. For example, they may be desperate for sensory input or struggling to self-regulate. Lashing out or running away may be their way of avoiding overwhelm or distress. In healthcare environments, many autistic patients struggle with harsh lighting, loud noises, crowds, intense smells, crinkly paper lining beds, wearing a gown, and other factors (Keller et al., 2024). Being aware of potential triggers and taking steps to address them when possible can reduce overwhelm and help the patient feel more comfortable. It can be helpful to speak to the patient and family during calm moments to identify upsetting factors, how a particular patient acts when upset, and what helps with calming down.

Personal Perspective: Malerie

When I was a research assistant collecting MRI data, one of our goals was increasing research inclusivity for autistic children, considering that as much as 80% of their data is excluded before it can be analyzed (Nebel et al., 2022). Many autistic individuals avoid participating in MRI studies due to the many sensory challenges involved: the loud sounds of the scanner, the tight space inside, and having equipment close to the face or earplugs in the ears, all while dealing with the unpredictability of a new place. To accommodate, we took on the perspective of our participants. When we noticed something was challenging, we did whatever we could to provide predictability (e.g., by giving participants social stories of what will happen, agendas for the day, and multiple opportunities to “practice” in a mock-scanner), desensitize participants to sensory experiences, and give information, reinforcement, and feedback. Ultimately, once we started improving the MRI experience, we successfully increased participation in our study. You can see some of these efforts on our website.

Include Autistic Patients in their Own Care

Speak to autistic patients directly, rather than directing questions, information, or instructions to their family members only (no one likes to be talked about as if they aren’t in the room). Make an effort to help patients understand what will happen and what choices they have. This simple act offers the patient increased dignity and recognition, humanizes the patient for other staff members, and creates an atmosphere where patients are comfortable asking questions to clarify their health options. Building positive rapport has tangible benefits for patients–higher quality communication between patients and service providers results in better health outcomes (Stewart, 1995).

Personal Perspective: Briana

I recall a stressful dentist appointment where every member of staff spoke primarily to my mother, only addressing me to ask infantilizing questions like, “Is there anything you’re hoping to get for Christmas?” in a singsong tone–and I was 20 years old at the time. I was excluded from participating in my own care. Worse still, I’ve heard stories from others who ask questions during their appointment, only to have the provider either ignore them, or deliver their response to a caregiver rather than the person asking. When co-treating with other providers, a simple reminder such as, “Henry would like to know that, too,” can go a long way. Even if the patient is non-speaking, addressing them directly shows respect and can increase the patient’s and family’s comfort.

Remember the Family

It’s possible family members have similar processing, communication, or sensory needs to the patient, even if they don’t disclose a diagnosis. Many autistic children have parents or siblings also on the autism spectrum (Ozonoff et al., 2024). Accommodations for the family might mean including a parent in procedural prep: what will they experience in terms of sights, sounds, and smells while accompanying their child to a procedure?

It could be a matter of direct communication, remembering that caregivers and siblings may interpret your directions literally (e.g. assuming that “Baths are at six PM” is a hard-and-fast rule rather than a guideline). If a patient is asleep, occupied, or out of the room, continue to be mindful of the way you talk about autism and disability. Don’t assume there are no other autistic people present and listening.

Personal Perspective: Alexandra

I pursued a career in clinical psychology to provide support for families with autistic members, like mine. Overall, I am encouraged by how my colleagues discuss autism and include autistic voices in their research and intervention work. However, on occasion, people talk to me about autism in terms of deficits/“red-flags” or using outdated terms (ex: “low functioning”) without taking a holistic approach to a person’s needs and strengths. This can make me feel uncomfortable for multiple reasons. First, autistic traits are not “red-flags”. Second, while I am not autistic, I still share commonalities with my brother, who is autistic and also one of my favorite people. I sometimes worry that people change how they discuss autism solely because I am in the room. Regardless of a person’s relationship to autism, autism should be discussed beyond a one-dimension spectrum based on “problems.”

Conclusion: Improvement is Achievable

Regardless of your experience working with autistic patients, everyone can take simple steps to create a culture of respect for patients and families. Actions such as using respectful language, sharing information rather than stigma, understanding challenging behaviors, including patients in their own care, and being mindful of the family can go a long way. At the end of the day, everyone is deserving of respect. Patients have the most at stake when seeking care, and by ensuring they feel safe and valued in the healthcare environment, providers can promote well-being and enhance quality of life outcomes.

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Where is the Patient's Voice in the Pediatric Patient Experience?

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An article review of: Hospital healthcare experiences of children and young people with life-threatening or life-shortening conditions, and their parents: scoping reviews and resultant conceptual frameworks

The review of this article was part of our work on the Patient and Family Experience Committee, within the ACLP. This group was tasked with helping membership learn more and dig deeper into patient experience. One aspect was seeking literature that is relevant to child life staff in their daily practice. This article was chosen due to the fact that it is current and was a review of a broad set of relevant articles. The authors hope to highlight the impact that child life specialists have in the patient and family experience, and help child life staff communicate this with hospital administration.

Patient experience of children and parents' interactions and relationships with healthcare staff, are core aspects of a healthcare visit for patients and families. The study's scope looks at factors affecting the pediatric patient experience from both children and young people (CYP) and parent's perspectives, and how to measure pediatric patient experience. This article is relevant to child life specialists as we influence the pediatric patient's overall healthcare experience.

Key Findings

Initially, 18,531 records were screened, with 18,328 excluded, leaving 203 full-text articles for further evaluation. After excluding five articles focused on community-based health services, 80 articles from 74 studies were included in the review. Some articles focusing on the experience of CYP ages 3 to 18 and others focusing on the perspective of the parents. The review identified 36 key aspects of healthcare delivery affecting CYP with life threatening/life shortening conditions (LT/LSC), categorized into eight domains: staff attributes (empathy and professionalism), staff actions (information sharing, clinical and personal care, emotional and social support), and organizational features (social/play resources, inpatient environment, continuity of care). Key crosscutting questions examined differences in healthcare needs between CYP and parents, as well as variations by age or developmental stage. 0

The most important factors affecting the pediatric patient experience are unique for children and parents. The study found that children value physical and sensory aspects of care including a comfortable environment and access to play, sensory, and socialization resources (Mukherjee et al., 2023, p.14). The study found that parents value professional communication, decision-making support, trust in staff, and emotional well-being support (Mukherjee et al., 2023, p.16). This study also found that parents tend to rate hospital experiences higher than CYP (Mukherjee et al., 2023, p.20).

Why This Matters to Child Life

There are many aspects of the pediatric patient healthcare experience that align with the important work of child life specialists. This includes emotional and social needs, play and socialization, enhancing communication and understanding, supporting family-centered care, and implementing coping strategies. A child life specialist helps to meet emotional and social needs by taking time to get to know a child, helping to create a calm environment, providing opportunities to play, and working to reduce anxiety and fear. Play and socialization opportunities include providing toys, games, crafts, entertainment, play rooms, and technology for all ages, helping to stay connected with peers, promoting socialization, reducing feelings of isolation, and encouraging interactions with others. The child life specialist helps to facilitate communication and understanding by explaining aspects of healthcare in ways a child and family understands, providing developmentally appropriate medical play and preparation, providing opportunities for choice and control, and helping kids and families feel empowered as partners in their care. Supporting parents and family-centered care includes helping caregivers feel supported to care for and comfort their child as much as they desire, ensuring parents have time with their child, advocating for parents as partners in care with decision making, and supporting the child and family's emotional wellbeing. The child life specialist also supports coping strategies by providing emotional support, minimizing pain and discomfort, providing distraction and coping support, helping CYP feel heard and comforted, supporting individualized coping plans, and responding to verbal and nonverbal cues by the patient and family. This information can also be helpful to child life specialists and leadership as they interact with hospital administration. Many points from this study can be brought up with hospital administration to signify the positive influence, benefit, and value that child life specialists have on patient experience.

Conclusion

These findings emphasize the importance of child life specialists in enhancing the pediatric patient experience by addressing social, emotional, and developmental needs during a health care visit. Child life specialists are crucial members of the multidisciplinary team. Daily child life practices positively support patient and family experience and family-centered care. The future of child life is bright. Child life specialists are a large part of the patient and family experience as an advocate for the patient's voice, and make a positive impact on the patient experience.

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Specialized Resource: Supporting Children with Precocious Puberty Through Supprelin (Histerlin) Implants

Laura Gould, CCLS, MS

Understanding Precocious Puberty

Precocious puberty is early onset of hormones and sexual characteristics in girls before the age of 8 and in boys before the age of 9. It is important to note that children of some ethnic backgrounds may go through puberty sooner and a medical diagnosis should be made (Mayo Clinic, 2025). Most children with this disorder have bone growth older than their chronological age and go through a growth spurt early which may result in initially being taller than peers at a young age. However, individuals with precocious puberty often stop growing before reaching their full genetic height potential. There are many potential causes of precocious puberty which an endocrinologist may investigate by doing lab work, a bone age x-ray of the hand, and/or an MRI of the pituitary gland. Causes may include tumors or growths of the ovaries, adrenal glands, pituitary gland, or brain, or central nervous system abnormalities, family history, or certain rare genetic syndromes. However, in most cases, no cause can be found for the disorder (CHOP, 2025).

Emotional and Developmental Impact

Advanced bone age can impact a child physically as well as psychologically. Growing faster than peers can make children taller initially and stand out from peers but then they stop growing sooner and may be shorter than peers later. In addition to an early growth spurt, children with precocious puberty may start developing breast buds, pubic and body hair, and body odor. Sometimes young girls have started menstruating and need support for managing this in early elementary school. Due to “mature” physical appearance adults may perceive children with precocious puberty as older and expect the child to be meeting cognitive and emotional developmental stages that the child is not yet. Experiencing these hormones early can impact not only physical development but also emotional development. Experiencing hormones can be a difficult time for pre-teens and adolescents and may be even more difficult for young children with mood swings and increased agitation. Caregivers initially may not know what is happening with their child. Even after a diagnosis, children may have a hard time understanding what is happening to their bodies as they are growing sooner than caregivers, doctors, and children may have expected. Children with precocious puberty may become self-conscious of these changes.

Precocious puberty is early onset of hormones and sexual characteristics in girls before the age of 8 and in boys before the age of 9.

The Role of a Supprelin (Histerlin) Implant

One of the treatment options is a subcutaneous implant in the upper arm slightly above the elbow. It slowly releases a small dose of a drug that increases the body's production of some hormones while decreasing others. The implant is replaced about every year and when the child has reached an age where they no longer need it, they will have it removed and go through puberty as is typical. Hormones are routinely monitored through blood work on patients to assess if the implant is working, needs to be replaced, or can be removed. Treatment is typically stopped around 11 years old for females and 12 years for males.

The Role of Child Life

Families look to child life for developmentally appropriate education and support. At times child life specialists educate the patient directly and other times provide the tools for caregivers to educate their child. The same is true when discussing puberty with children. This is amplified when it involves precocious puberty because children are younger, and families may not have prepared to have these conversations when body changes have started becoming noticeable to the child or others around them. When children come with some level of understanding about the appointment, then child life focuses on the steps of implant insertion procedure and developing a coping plan.

In the clinic where I work, child life specialists receive referrals to assist patients with preparation and procedural support when they are getting a Supprelin implant. A general surgeon places the implant which can be done in a clinic (without sedation) or on a sedation unit with mild, moderate, or deep sedation or in an operating room. The level of sedation depends on the anxiety of the patient, coping plan, and if the child is a candidate for sedation. Child life can often be involved in assessing the patients' coping to see if the patient would benefit from a local anesthetic such as a numbing cream or lidocaine injection or if the patient will need more sedation to be able to cope with the procedure. Often caregivers and patients are surprised at how well they cope with numbing cream, lidocaine, and child life support during the procedure without needing more medication.

Many children and families are relieved to learn that other children are going through this same diagnosis.

Resources for Families

The generic implant is called a Histerlin implant, but the name brand Supprelin implant is commonly used. While I do not represent the company in any way, I appreciate the resources that the Supprelin company offers to caregivers and families prior to coming for an implant. Families can go on to the Supprelin drug company's website to order free resources. Families can order a caregiver toolkit to learn more. The kits are available in English and Spanish. This includes a book, an implant without the drug inside, and a video.

Another resource to puberty and body development is an audiobook exclusive on audible written and narrated by health educator Justine Ang Fonte, *How To Talk To Your Kids About Sex.* While it has “sex” in the title, many of the topics discussed focus on body part identification and development. I appreciate how Fonte discusses how to scaffold these conversations with toddlers through adolescence. This audiobook is not only helpful for caregivers but also for health care professionals, including child life specialists, navigating conversations with young patients. It is best for caregivers and providers to listen to without the child and then decide which portions are best to tailor education to each child’s developmental needs.

Learning about precocious puberty helps children with this condition understand more about their bodies and development. Having developmentally appropriate conversations with caregivers and health care providers, including child life specialists, helps children to feel supported and opens the doors to future conversations about body development.

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