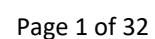




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## From the Executive Editor

*Morgan Morgan, MS, CCLS, Executive Editor*

Dear Colleagues,

Although it feels cliché to begin the editor's letter for the Fall Issue with an observation about change, it also feels incredibly poignant given the transition underway for the association we are experiencing as an association. While transitions naturally bring change, I'm grateful for the contributions of our outgoing staff and deeply appreciative of their partnership over the years.

I have personally had the chance to work hand in hand with multiple talented staff members who pour their hearts into advancing the work of child life specialists, often while being on the receiving end of feedback from ACLP members who are frustrated by a variety of factors outside of anyone's control. These association professionals have helped me grow as a volunteer and a leader in more ways than I can possibly enumerate here, and I want to take a moment to thank each staff member for their hard work and dedication.

I want to specifically give kudos to our previous managing editor, Aubree Bailey, who had been working most closely with the Bulletin for the past year and a half. If you haven't noticed, our format has changed dramatically over the past year, and Aubree stepped up to continue helping us produce a high-quality publication to serve our readers. She kept our Bulletin group moving forward, and we are incredibly grateful for the work that she did for us. I am also looking forward to a fruitful partnership with the Smithbucklin team. Their resources and knowledge will enable the Bulletin to produce the highest quality content and resources for our membership.

On that note, I want to highlight some of the incredible content in this issue. Stephanie Whitten, MS, CCLS, and Molly Gleydura, BA, CCLS, each share ways that their child life training and personal lives have intersected. In "You are Already Doing What is Best," Whitten reflects on her experience as a spouse of a kidney transplant patient and the ways in which family-centered care has impacted their family's journey. She offers gentle reminders that, as psychosocial care providers, we often have the tools to help families face tremendous challenges, even when it feels overwhelming. She reminds us that "Families carry those lessons, the support, and the advocacy with them long after the hospital stay ends."

Molly Gleydura, BA, CCLS, shares about her experience as a Watson Fellow, which allowed her to travel the world to enhance her practice of grief support. She details the multicultural perspectives learned from her time abroad and makes connections to her practice as a child life specialist in the United States. Gleydura reminds us that child life specialists are equipped to support children and families regardless of language, background or culture.

This issue also touches on the ways in which child life can support increased understanding for caregivers and patience. Clare Kelley, MS, CCLS, HLS, provides a primer in health literacy. She highlights the ways in which CCLS are equipped to support patient and family understanding of their own healthcare as well as suggestions for improving resources to increase comprehension. Mary Ann Gil, M.Ed., CCLS, offers insights into additional support for parents and caregivers with intellectual disabilities. While it does not solely fall on the shoulders of child life to ensure caregivers' understanding, having additional knowledge can help us provide the highest level of patient and family-centered care.

We also highlight some less conventional aspects of working in a children's hospital. In her article about

weddings, Amy Lee, MS, MSW, CCLS, CIMI, recounts the various ways child life specialists have supported weddings in their careers. While this isn't the type of milestone that CCLS normally think about celebrating, it can fall into our wheelhouse, nonetheless. Supporting the marriages of patients' parents or young adult patients can serve as a beacon of hope and joy on days when the world feels heavy. Luis Borges, BFA, highlights the ways in which child life specialists can work hand in hand with CCTV producers to provide meaningful programming. As roles such as these become increasingly common in children's hospitals, it serves as a reminder that we are all working together to support the well-being of hospitalized children.

As we welcome our new partners at Smithbucklin, I want to remind you that child life specialists are the heart of our organization. We serve our patients and families in so many different ways, but we are only as incredible as the partners who support our mission. I am eager to continue our mission forward with the support and resources of Smithbucklin and will be grateful to all of the hardworking ACLP staff who have gotten us this far.

## **President's Perspective: A New Chapter for ACLP — How We Reimagined Support for Our Members**

*Elana Brewer, MS, CCLS; Sarah Patterson, MSc, CCLS; and Victoria Isaacson, CCLS*

As we begin a new phase of our association, we — the Association of Child Life Professionals Board of Directors President Trio (immediate past president, president, and president-elect) — want to use this platform to share the journey that led to ACLP and CCLP's new relationship with Smithbucklin. We understand you may have questions about this transition: why we decided to switch to a new staffing solution, how we carefully navigated the process, and what this change means for our community's future. Our aim is to provide clarity, openness, and confidence as we move forward together.

### **What Is an Association Management Company?**

If you're unfamiliar with what an association management company (AMC) is, you're not alone. It wasn't until this past May 2025 that we, as a trio and board, first learned about the role AMCs play in supporting associations. In short, an AMC is a professional firm that provides management and administrative services to associations and nonprofits. Services typically offered by AMCs include membership management, event and conference planning, financial management and accounting, marketing and communications, strategic planning, and volunteer management.

### **Why Make the Shift?**

In June 2025, the President Trio focused on gathering information about what an AMC could offer both the Association of Child Life Professionals and the Child Life Certification Commission. Our aim was to carefully evaluate the benefits and drawbacks of working with an AMC versus maintaining a stand-alone staffing structure. From this exploration, several key insights emerged. The flexibility of AMCs enable associations to scale services and staff resources up or down as their needs change. Additionally, they are more cost-effective by reducing overhead costs and leveraging collective buying power to negotiate better deals with vendors such as hotels, audio/visual providers, and technology partners. AMCs provide a deeper bench of professionals, which improves operational efficiency and boosts organizational capacity in ways that a stand-alone staffing model cannot.

Our exploration confirmed that partnering with an AMC will be a strategic way to boost adaptability, enhance financial management, and receive professional support, helping our association better serve members and advance our mission.

### **What Steps Led to the Decision?**

We quickly recognized the advantages of moving to an AMC, while considering how this decision would profoundly impact our current staff. As fiduciaries of the ACLP, we handled this process with care, transparency, and thoroughness.

We initiated a formal request for proposal (RFP) process. Three highly recommended firms submitted proposals, each offering unique strengths and capabilities. The ACLP President Trio and CLCC leadership held multiple meetings with each firm, including a trip to Washington, D.C., where we met two firms in person. As part of our evaluation, the Executive Committee used a scoring matrix to individually review and score each

proposal. Ultimately, the ACLP Board of Directors selected Smithbucklin as our future management partner. The commissioners of the CLCC voted separately and also approved the transition.

### **How Is the Relationship Between ACLP and CLCC Affected?**

As a reminder, in 2022, the Internal Revenue Service (IRS) officially recognized CLCC as a 501(c)(6) organization under the parent group ACLP, a 501(c)(3). According to IRS rules, certification dues are treated as *Unrelated Business Income Tax (UBIT)* when collected by a 501(c)(3), which can lead to significant annual tax penalties. In contrast, these dues are exempt from such penalties when managed under a 501(c)(6).

Following the advice of ACLP's accountant and audit firm, this change was made to reduce tax liability. The new structure ensures that CLCC operates with its own governing board, bylaws, policies, and budget, allowing certification activities to continue without income tax burdens. Importantly, CLCC's primary purpose remains the preservation and integrity of the Certified Child Life Specialist credential. Meanwhile, the ACLP continues to be dedicated to advancing the profession by raising awareness, fostering community and learning, and serving as a source for research and resources.

### **What Does the Future Hold?**

As leaders of this association, we are both hopeful and excited about the future of the ACLP. We are confident that the team at Smithbucklin has the expertise, insights, dedication, and long-standing experience needed to guide us forward as a thriving membership organization.

We have already had the pleasure of meeting many team members and look forward to what 2026 will bring. Our Trio and Board remain committed to transparency and inclusivity. If you have any questions or concerns, please feel free to contact us at [president@childlife.org](mailto:president@childlife.org). While we may not have all the answers to the challenges our profession faces today, we are dedicated to leading an organization that promotes community and learning, serves as a resource for professionals, and manages its resources responsibly. We want to hear from you.



# Health Literacy Made Easy: A Child Life Specialist's Guide to Even Clearer Communication

*Clare Kelly, MS, CCLS, HLS*

After 4 years as a child life specialist, I began my health literacy career as an editor in a hospital patient education department. I specialize in taking complex medical information from providers and turning it into accessible, actionable resources for patients. I was proud of all the ways my child life practice prepared me for this role and aligned with patient education standards. I was also surprised by the gaps in my knowledge. There was a lot I didn't know about best practices for written health communication, but as I learned new techniques and applied it to my work, the quality of the resources I created improved significantly. The goal of this article is to help you foster health literacy more intentionally and effectively in the resources you create. I'll walk through why health literacy is so important, what it entails, and ten tips for bringing it to the forefront of your resource creation process.

## What is health literacy?

You may not be familiar with the term "health literacy", but you've been advocating for it and supporting it for as long as you've been a child life professional. The Center for Disease Control defines two types of health literacy:

1. "Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (Centers for Disease Control and Prevention, 2024).
2. "Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (Centers for Disease Control and Prevention, 2024).

Every day, you support patients' and families' personal health literacy, and child life departments are a huge part of organizational health literacy.

## Why focus on health literacy?

Did you know that around nine out of ten US adults have limited health literacy skills (Center for Health Care Strategies, 2024)? When patients struggle to understand their care, they experience poorer health outcomes and develop more health care needs.

One study found that patients with low health literacy were more likely to have repeat emergency department visits (Shahid et al., 2022). This means low health literacy individuals are more likely to have acute health crises and contend with all that brings: more time and money spent on care, more pain and stress, and a higher risk of bodily harm. It is fair to assume the same is true for pediatric patients who are children of low health literacy caregivers.

This is a public health issue and an equity issue. Latino, Black, and American Indian/Alaskan Native Americans are more likely to have lower health literacy levels and worse health outcomes than white Americans (Center for Health Care Strategies, 2024). Older adults and non-native English speakers also have disproportionately low rates of health literacy (Coughlin, Vernon, Hatzigeorgiou, & George, 2020).

Health literacy support leads directly to better health outcomes for patients and a more equitable society as a

whole. So what makes for a resource that supports health literacy? Let's talk about accessible content and accessible design - what these mean and how to put them into practice.

## Accessible Content

The more our content can be simple, clear, short, and direct, the more accessible it will be. According to National University (2025), "approximately 45 million U.S. adults are functionally illiterate, reading below a fifth-grade level." Notably for child life specialists, the children of these adults are very likely to have low literacy scores themselves (National University, 2025). Writing with accessibility in mind benefits these patients and families, and those of all reading levels. We know that medical situations cause stress, and when people are stressed, information comprehension is more limited. The last thing we want to do is overcomplicate or overwhelm. Here are 5 tips to help you meet your patients and families where they're at.

5 Tips for Accessible Content
<ol style="list-style-type: none"> <li>1. Choose a purpose</li> <li>2. Keep it brief</li> <li>3. Use plain language</li> <li>4. Use active voice</li> <li>5. Include interactive elements</li> </ol>



1. Choose a purpose for your resource: Before you begin working on your resource, write out the main message you want to get across (Centers for Disease Control and Prevention, 2018). Keeping your scope narrow will help convey a specific message in each resource you create. Is this resource about procedural preparation for a patient? Stick to procedural preparation. Save diagnosis education, medication regimen, coping strategies, and emotional processing for a different place.
2. Keep it brief: This applies to the resource as a whole and all of its components. Try to keep resources under 1 page if possible, paragraphs under 5 sentences, and sentences under 20 words (Centers for Disease Control and Prevention, 2018). If your document is longer than you'd like, here are some questions to guide you:
  - How many goals do I have for this resource? If I have more than 1 or 2, can I split it into a few different resources?
  - What information is "nice to know" and what is "need to know"? Can I delete any extra "nice to knows"?
  - Is there anything here that will be or would be better communicated in person instead of on paper?
3. Use plain language: This means using simple words whenever you can and defining any complex ones (Centers for Disease Control and Prevention, 2024). As child life specialists, we're trained in appropriate language. We use soft language to minimize anxiety. We use the simplest medical terms and explain what they mean to maximize understanding. But what

about the language around those terms? Using the simplest terms possible for everyday words can be equally important for patients and caregivers of all reading levels. Prioritize approachable language over professional language. Don't be afraid to sound casual! Consider these subtle shifts suggested by the PRISM Readability Toolkit.

Plain Language Swaps	
<i>Instead of:</i>	<i>Try:</i>
Allow	Let
Continue	Keep on
Develop	Start to get/happen

4. Use active voice: This is the most grammatical tip. Using active voice supports reading comprehension and is much more accessible to low literacy readers (Centers for Disease Control and Prevention, 2025). To understand the difference, compare these two sentences. The sentence written in an active voice is easier to follow and provides a clearer picture of what will happen.
  - Passive voice: "You'll have your blood pressure taken."
  - Active voice: "The nurse will take your blood pressure."
5. Include interactive elements: When you're thinking about the content for your resource, consider adding a place for reader participation. This could be as simple as a rhetorical question. It could also look like a fill-in-the-blank knowledge check or a prompt for patients to discuss the resource with a parent, doctor, nurse, or child life specialist. If you have the capacity, the very best version of this tip incorporates the "teach-back method". In health literacy, this means asking the patient or family member to tell you in their own words what they learned from your conversation or resource (Agency for Healthcare Research and Quality, 2023). Studies have shown that this is an effective way to make sure your reader comprehends information (Talevski et al., 2020). The teach-back method also gives you a chance to correct misunderstandings.

## Accessible Design

Our patients and families may have low vision, color blindness, reading disabilities, or low functional literacy. It's important to design resources that are highly legible, with layouts that are easy to follow. Lower literacy readers may find it difficult to read a resource with a complicated design (Freed, 2025). For example, if information is presented in bubbles all around the page, rather than starting at the top and ending at the bottom, it may be hard for some readers to make sense of. Here are 5 elements to consider in supporting reader understanding through design.



5 Elements of Accessible Design
Color Text Blank Space Chunking Bullets

1. **Color:** As child life specialists, we want our resources to engage the pediatric patients and caregivers who will be using them. While colors can bring some much needed normalization and playfulness to the hospital setting, we also want to make sure that the information we're trying to convey is easily visible to all audiences. Here are a few good rules of thumb when it comes to color:
  - Use very dark text on a very light background or vice-versa.
  - Avoid using red and green color combinations.
  - Use an online "contrast checker" tool to make sure your color combinations are highly legible (Mendez, n.d.).
2. **Text:** To support all vision and reading needs, keep text big and keep it simple. The smallest font size you should use is 12 point. Avoid using italics, bolding, underlining, and writing in all caps as much as possible. If you need to differentiate titles and subtitles from the rest of your text, it's better to rely on different font sizes or different colors (Stanford University, n.d.).
3. **Blank space.** Space around content equals space to digest that content. By all means, include pictures of a CT scanner on your procedural prep docs. Add Bluey family portraits around the edges of your medicine calendar! But keep in mind that a little goes a long way. And any time you can break up text with a bit of white space in between, you're supporting your readers' capacity to take information in and make sense of it (Mendez, n.d.).
4. **Chunking.** We've already talked about keeping resources brief, but sometimes we just have a lot of information to convey. In these situations, chunking can help (Centers for Disease Control and Prevention, 2024). This means, wherever possible, use subheadings and keep sections short. It can also help to split your text into two columns instead of having sentences span the whole page. Visually, this is less intimidating than long lines of text across the page. When your audience first glances at the resource, it all looks a bit more manageable.
5. **Bullets.** Bullets are another helpful way to break up information (Centers for Disease Control and Prevention, 2025). If you find yourself listing several things separated by commas, try presenting them in a bulleted list instead. Like chunking, this helps readers to take in a little bit of information at a time, think it through, and when they're ready, move on to the next piece of information. Compare the paragraph above on chunking with the information below. It's all the same content, but uses a bulleted list.

*“We’ve already talked about keeping resources brief, but sometimes we just do have a lot of information to convey. To help your reader read it all without getting overwhelmed, do some chunking. Here are some ways to “chunk” information:*

- *Use subheadings*
- *Keep sections short*
- *Split text into two columns instead of having sentences span the whole page. Visually, this is less intimidating than long lines of text across the page.*

*When your audience first glances at the resource, it all looks a bit more manageable.”*

## **Conclusion**

As a child life professional, you promote health literacy all the time. When you create resources, provide diagnosis education, and offer treatment support, procedural preparation, and coping choices - it all falls under the umbrella of health literacy. All of those interventions give patients access to information and agency in their care.

I hope this guide will support you in that mission. Consider the most recent resource you created. Which of these principles could you apply to make it even more accessible and supportive for all patients and families?

## References

- Agency for Healthcare Research and Quality. (2023, May). Tool: Teach-Back. TeamSTEPPS. <https://www.ahrq.gov/teamsteppsprogram/curriculum/communication/tools/teachback.html>
- Centers for Disease Control and Prevention. (2024, October 16). Guidance & tools. Centers for Disease Control and Prevention. <https://www.cdc.gov/health-literacy/php/develop-materials/guidance-standards.html>
- Centers for Disease Control and Prevention. (2025, July 21). Plain language materials & resources. Centers for Disease Control and Prevention. <https://www.cdc.gov/health-literacy/php/develop-materials/plain-language.html>
- Centers for Disease Control and Prevention. (2024, October 16). What Is Health Literacy? U.S. Department of Health & Human Services. <https://www.cdc.gov/health-literacy/php/about/index.html>
- Centers for Disease Control and Prevention. (2018, December 20). Your guide to clear writing [PDF]. National Center for Environmental Health. <https://stacks.cdc.gov/view/cdc/103770>
- Center for Health Care Strategies. (2024, March). Health literacy fact sheets. <https://www.chcs.org/resource/health-literacy-fact-sheets/>
- Center for Health Care Strategies. (2024, March). How improving health literacy can advance health equity [Fact sheet]. Retrieved from <https://www.chcs.org/resource/how-improving-health-literacy-can-advance-health-equity/>
- Coughlin, S. S., Vernon, M., Hatzigeorgiou, C., & George, V. (2020). Health Literacy, Social Determinants of Health, and Disease Prevention and Control. *Journal of environment and health sciences*, 6(1), 3061.
- Freed, B. (2025, February 25). Health Literacy Lab: Type Tricks — Graphic Design at a Glance. *Health Research for Action*. <https://healthresearchforaction.org/news/health-literacy-lab-type-tricks-graphic-design-at-a-glance/>
- Mendez, S. R. (n.d.). 3 essential graphic design tips for clear and accessible health communication. Harvard T.H. Chan School of Public Health. <https://hsph.harvard.edu/research/health-communication/resources/graphic-design-tips/>
- National University. (2025, June). 49 adult literacy statistics and facts for 2025. National University. <https://www.nu.edu/blog/49-adult-literacy-statistics-and-facts/>
- Ridpath, J. R., Greene, S. M., & Wiese, C. J. (2007). PRISM Readability Toolkit (3rd ed.). Group Health Research Institute. [https://hrp.weill.cornell.edu/sites/default/files/prism\\_readability\\_toolkit.pdf](https://hrp.weill.cornell.edu/sites/default/files/prism_readability_toolkit.pdf)
- Shahid, R., Shoker, M., Chu, L. M., Frehlick, R., Ward, H., & Pahwa, P. (2022). Impact of low health literacy on patients' health outcomes: a multicenter cohort study. *BMC health services research*, 22(1), 1148. <https://doi.org/10.1186/s12913-022-08527-9>
- Stanford University. (n.d.). Typography. Stanford University IT. <https://uit.stanford.edu/accessibility/concepts/typography>
- Talevski, J., Wong Shee, A., Rasmussen, B., Kemp, G., & Beauchamp, A. (2020). Teach- back: A systematic review of implementation and impacts. *PloS one*, 15(4), e0231350. <https://doi.org/10.1371/journal.pone.0231350>

# Supporting Parents and Caregivers with Intellectual Disabilities

*Mary Ann Gill, M.Ed., CCLS*

A few times in my clinical practice, I have worked with children whose parents or caregivers have either a known or suspected diagnosis of intellectual disability (ID). While the skills of a Certified Child Life Specialist (CCLS) can easily translate to support for these families, some child life professionals may not feel adequately prepared to assess and address the psychosocial needs of parents/caregivers with ID. Personally, I entered the child life field with prior experience supporting adults with ID in an inclusive college program, but my knowledge of parents/caregivers with ID was still very limited. Through ongoing experience in the healthcare setting and staying up to date with relevant research, I have continued building my knowledge and skillset for working with this population. I am writing this article with the goals of educating fellow child life professionals and students about the strengths, needs, and experiences of parents/caregivers with ID and offering specific strategies for supporting these families.

A note on language: I have written articles about autism using mostly identity-first language (“autistic person” rather than “person with autism”), as a growing majority of autistic self-advocates, myself included, prefer identity-first language (Taboas et al., 2023). There is evidence of increased preference for identity-first language among disabled people overall (Sharif et al., 2022). However, this trend does not apply to every subset of people with disabilities. It’s difficult to find data on the language preferences of people with ID, who are often left out of research (Grech et al., 2024; Riches et al., 2020). My anecdotal experience suggests a more frequent preference for person-first language, so here I default to “person with ID.” In practice, it’s best to ask each individual what words they prefer to use for their disability. Most importantly, avoid the use of negative language and euphemisms. Note that “mental retardation” used to be the medical term for intellectual disability, but it was replaced because “the R-word” was so broadly adopted as a slur.

## What is an intellectual disability?

The Diagnostic and Statistical Manual, 5th edition (DSM-5) defines an intellectual disability as a condition characterized by each of the following traits:

- deficits in intellectual functioning (e.g. reasoning, problem-solving, planning, abstract thinking), typically measured by an IQ score of less than 70
- deficits in adaptive functioning (e.g. communication, social participation, independent living skills) onset during childhood or adolescence

In the United States, intellectual disability is one of 13 disability categories that can qualify a child for special education services under the Individuals with Disabilities Education Act (IDEA). English speakers in other countries might use different terms for this condition. British professionals, for example, use the term “learning disability.”

## Can people with intellectual disabilities become parents?

Yes! Adults with ID are a diverse group with wide variation in strengths and support needs. Many people with ID report wanting to become parents (Guénoun et al., 2022). Sadly, the history of disabled people in the U.S. is marked by institutionalization and forced sterilization. Proponents of the eugenics movement worked to limit disabled people’s ability to reproduce (Grenon & Merrick, 2014). Today, people with ID are still at risk of institutionalization and forced sterilization, but support and recognition for parents/caregivers with ID is growing (Pérez-Curiel et al., 2023). At least 4.5 million parents in the United States have some form of disability (National Center for Research on Parents with Disabilities, 2024). People with ID, like those with other types of disabilities, can and do become effective parents.

The DSM-5 defines four categories of intellectual disability based on level of support needs. Most parents/caregivers with ID would be considered to fall in the “mild” range (Llewellyn & Hindmarsh, 2015). However, parental IQ itself does not

predict child wellbeing. Instead, the mental health and social support of parents with ID predict child developmental outcomes (Llewellyn & Hindmarsh, 2015). Interventions designed to improve parents' psychosocial wellbeing may help improve child outcomes (Crnic et al., 2017).

Still, parents/caregivers with ID and their children face unique challenges, including a higher risk of complications with pregnancy and birth and higher rates of developmental delay in children (Akobirshoev et al., 2017; Llewellyn & Hindmarsh, 2015). Socioeconomic status could play a primary role in these correlations, as people with ID are more likely to live in poverty (Powell & Parish, 2016). Parents/caregivers with ID also experience disproportionate interactions with the child protection system.

Research suggests that parents with ID are equally as likely as parents without ID to have child abuse or neglect cases (Slayter & Jensen, 2019), but parents with ID are much more likely to experience child removal and custody loss (LaLiberte et al., 2016; Llewellyn & Hindmarsh, 2015; Sigurjónsdóttir & Rice, 2018).

### **How can we better support parents/caregivers with intellectual disabilities?**

<b>How to Support Parents/Caregivers with Intellectual Disabilities</b>
<ul style="list-style-type: none"> <li>• Know your scope and know your resources</li> <li>• Tailor communication strategies</li> <li>• Offer accessible education about child development and coping</li> <li>• Promote attachment and bonding</li> <li>• Adapt and model a strengths-based approach</li> <li>• Keep up to date with the disability community</li> </ul>

## **Know your scope and know your resources**

When supporting parents/caregivers with ID as part of a multidisciplinary team, it's important to stay within your scope of practice. I once received a consult to create a daily schedule for a hospitalized infant. The bedside nurse wanted a visual support to offer the infant's parents as they learned to administer her medications several times per day. Before responding, I talked with my supervisor about my role and scope in this process. We agreed that I could create a daily schedule incorporating developmentally appropriate routines and playtime, but I would not include any information about the infant's medication, including type, timing, and dosage, as that type of education should fall to the nursing team.

When you do assess needs outside your scope of practice, it's always helpful to know what other resources are available. If your hospital has a patient education department, members of that team may offer specialized support for staff and providers navigating unique health literacy needs. A hospital social worker may be aware of community resources that could benefit the family. For example, my social work colleague recently made a referral to an evidence-based home visiting program to help a mother with ID access additional parenting support.

## **Tailor communication strategies**

During conversations with parents/caregivers with ID, speak in short sentences, use concrete and simple language, and allow extra time for processing. You can repeat any important points multiple times, rephrasing as needed. Try to keep questions open-ended rather than leading or guiding, as people with ID may be more likely to acquiesce (respond with a "yes") to questions they do not understand (Finlay & Lyons, 2002). Use teachback strategies to ensure understanding: ask the parent/caregiver to repeat back what you told them in their own words.

Even for non-disabled people, communication abilities can fluctuate during a stressful situation. These communication strategies can be helpful to use with any parent/caregiver. Remember that using the above communication strategies does not mean that you should use "baby talk." Disabled adults are adults and do not want to be treated like children.

## **Offer accessible education about child development and coping**

Many interventions for parents/caregivers with ID involve education about child development (Coren et al., 2010; Glazemakers & Deboutte, 2012), which CCLs are uniquely equipped to provide. You might educate parents/caregivers about using play to encourage developmental progress, or you might provide information about how children at various developmental stages typically respond to stressful events and suggest ways to improve their coping.

When educating parents/caregivers, pay attention to accessibility. Use a mixture of teaching methods, such as verbal information, written information, pictures/videos, and modeling. For written materials, you can use a readability calculator to check the reading grade level of the text. Also, make sure that any activities you provide or suggest to a family are accessible to the parent/caregiver. A parent/caregiver who struggles with reading comprehension may not feel comfortable reading a book aloud to their child, but they might enjoy playing through a look-and-find book or listening to an audiobook together.

The parents of the hospitalized infant I mentioned earlier asked me for help decorating her room. After providing some themed decorations for normalization, I also designed a colorful poster listing ways to play with a newborn. I included pictures and used a readability calculator to edit the text to around a fourth grade reading level. The poster fit right into the room decor and gave the parents an easy reference to remember the play strategies we were working on.

## **Promote attachment and bonding**

As we do for other families, CCLs can work to promote healthy attachment and bonding between children and parents/caregivers with ID. Help the parent/caregiver identify ways to participate in their child's care. Teach parents/caregivers positive ways to engage with their children regardless of medical status. Support families as they make memories together.



I worked with a mother to create a baby book capturing photos and stories about her hospitalized child. When a DCS referral was placed and the possibility of a foster placement arose, we started a second book that could travel with the child if needed. This provided an extra point of connection for the mother and child and helped inspire friendly communication between the biological and foster families. Since parents/caregivers with ID are more likely to interact with the child protection system, these types of interventions can be particularly valuable.

### **Adapt and model a strengths-based approach**

While it's important to anticipate the challenges that parents/caregivers ID may face, we should also recognize and celebrate each family's unique strengths. Focus on what the parent/caregiver can do, not just the things that are hard for them. Ask questions to understand the family's values and goals. Healthcare professionals may be quick to make negative assumptions about parents/caregivers with ID. You can help combat this by getting to know parents/caregivers and pointing out their strengths during conversations with the multidisciplinary team.

### **Keep up to date with the disability community**

The disability community evolves quickly. Language preferences are always changing, and political events can have huge impact on the day-to-day activities and wellbeing of disabled people. As I'm writing this, many of my disabled friends, patients, and colleagues in the U.S. fear losing access to crucial medical care. Staying on top of current events impacting people with ID can improve your ability to assess the psychosocial needs of parents/caregivers.

Local disability-related organizations might help you stay up to date on political events. My state's Council on Developmental Disabilities sends out a monthly electronic newsletter that includes information on public policy changes relevant to people with intellectual and developmental disabilities. I also recommend seeking opportunities to hear directly from disabled self-advocates, including through social media. People with ID are often left out of research, but social media can be a powerful tool for people with ID to make their voices heard.

### **Conclusion & Resources for Ongoing Learning**

People with ID face numerous barriers to parenthood, including negative attitudes from relatives and caregivers, lack of knowledge from healthcare professionals, and the ongoing practice of forced sterilization (Pérez-Curiel et al., 2023). Still, "people with intellectual disability have always become parents" (Llewellyn & Hindmarsh, 2015, pg 119). At least on occasion, child life specialists are likely to encounter parents and caregivers with ID. By working as a member of the multidisciplinary team to offer individualized, accessible support and resources for these families, CCLSs can optimize outcomes for children and caregivers alike. Those in the academic world should consider talking with child life students about ways to support parents/caregivers with all kinds of disabilities, including ID.

Below I have included a list of additional resources I found while working on this article. I hope that these serve as a helpful starting point to child life students and professionals wanting to improve their support for parents/caregivers with ID and their children.

- [The Arc's position statement on parents with intellectual and/or developmental disabilities](#)
- Resources from the National Research Center for Parents with Disabilities at Brandeis University:
  - [Talking to people with disabilities who are parents or want to become parents: A guide for helpers](#)
  - [Being good parents: A guide for parents with intellectual disabilities](#)
  - [Advice for professionals working with parents with intellectual disabilities](#)
  - [Advice and facts for mothers and expecting mothers with intellectual disabilities](#)

## References

- Akobirshoev, I., Parish, S. L., Mitra, M., & Rosenthal, E. (2017). Birth outcomes among US women with intellectual and developmental disabilities. *Disability and Health*, 10(3), 406-412.
- American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). <https://doi.org/10.1176/appi.books.9780890425787>
- Coren, E., Hutchfield, J., Thomae, M., & Gustafsson, C. (2010). Parent training support for intellectually disabled parents. *Campbell Systematic Reviews*, 6(1), 1-60.
- Crnic, K. A., Neece, C. L., McIntyre, L. L., Blacher, J., & Baker, B. L. (2017). Intellectual disability and developmental risk: Promoting intervention to improve child and family well-being. *Child Development*, 88(2), 436-445.
- Finlay, W. M. L., & Lyons, E. (2002). Acquiescence in interviews with people who have mental retardation. *Mental Retardation [now Intellectual and Developmental Disabilities]*, 40(1), 14-29.
- Glazemakers, I., & Deboutte, D. (2012). Modifying the 'Positive Parenting Program' for parents with intellectual disabilities. *Journal of Intellectual Disability Research*, 57(7), 616-626.
- Grech, L. B., Koller, D., & Olley, A. (2024). Person-first and identity-first disability language: Informing client centred care. *Social Science & Medicine*, 362, 117444.
- Grenon, I., & Merrick, J. (2014). Intellectual and developmental disabilities: Eugenics. *Frontiers in Public Health*, 2, 201.
- Guénoun, T., Essadek, A., Clesse, C., Mauran-Mignorat, M., Veyron-Lacroix, E., Ciccone, A., & Smaniotto, B. (2022). The desire for parenthood among individuals with intellectual disabilities: systematic review. *Journal of Intellectual Disabilities*, 29(2), 423- 446.
- Individuals with Disabilities Education Act, 33 U.S.C. §1401.
- LaLiberte, T., Piescher, K., Mickelson, N., & Lee, M. H. (2017). Child protection services and parents with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disability*, 30(3), 521-532.
- Llewellyn, G., & Hindmarsh, G. (2015). Parents with intellectual disability in a population context. *Current Developmental Disorders Reports*, 2, 119–126.
- National Center for Parents with Disabilities. (2024). Who are disabled parents? [Data dashboard]. The Lurie Institute for Disability Policy. <https://heller.brandeis.edu/parents-with-disabilities/who-are-disabled-parents.html>
- Pérez-Curiel, P., Vicente, E., Lucía Morán, M., & Gómez, L. E. (2023). The right to sexuality, reproductive health, and found a family for people with intellectual disability: A systematic review. *International Journal of Environmental Research and Public Health*, 20, 1587.
- Powell, R. M., & Parish, S. L. (2016). Behavioural and cognitive outcomes in young children of mothers with intellectual impairments. *Journal of Intellectual Disability Research*, 61(1), 50-61.
- Riches, T. N., O'Brien, P. M., & The CDS Inclusive Research Network. (2020). Can we publish inclusive research inclusively? Researchers with intellectual disabilities interview authors of inclusive studies. *British Journal of Learning Disabilities*, 48(4), 272-280.
- Sigurjónsdóttir, H. B., & Rice, J. G. (2018). 'Evidence' of neglect as a form of structural violence: Parents with intellectual disabilities and custody deprivation. *Social Inclusion*, 6(2), 66-73.
- Slayter, E. M., & Jensen, J. (2019). Parents with intellectual disabilities in the child protection system. *Children and Youth Services Review*, 98, 297-304.

Taboas, A., Doepke, K., & Zimmerman, C. (2023). Preference for identity-first versus person-first language in a US sample of autism stakeholders. *Autism*, 27(2), 565-570.

## Therapeutic Broadcasting and Clinical Co-Viewing: Using Studio Programming to Deepen Patient Engagement

*Luis Borges, BFA, Production Supervisor, KidZone TV, Patient Gaming and Technology Administrator at Mount Sinai Kravis Children's Hospital*

*A young boy sits up in the chair next to his hospital bed, his father beside him, encouraging him on. He's laughing along with his team in a room he hasn't left in three days. On the screen across from him, a live show begins, and when he hears his name read aloud, he beams. "That's me," he says. "Yes, mijo," his father replies. And it is. This is KidZone TV.*

At the entrance to Mount Sinai Kravis Children's Hospital, there's something few people expect to find: a television studio. Beyond the lobby glass wall is the KidZone TV studio, a space where patients can heal, create, express, and feel empowered during hospitalization.

KidZone TV (KZTV) is more than entertainment; it's a therapeutic tool co-designed with Certified Child Life Specialists (CCLSs). As pediatric settings adopt more video-based technologies, clinical intentionality is essential. With KZTV, producers align programming to clinicians' goals, and each broadcast supports creativity, co-regulation, and connection. The studio is a flexible, consistently available tool, and adaptable to each child and moment.

### How It Works: Co-Viewing & Open Studio

Through practices like co-viewing, when CCLSs or other clinicians watch and engage with a KidZone TV show alongside a patient, and open studio, when patients join as a live audience and participate at their own pace, CCLSs can turn any broadcast into play and connection. Each show is designed with moments that invite laughter, reflection, and expression. Producers collaborate with CCLSs, Music Therapists, Art Therapists, and others to identify patients who may benefit from intentional co-viewing. The clinical host weaves personalized engagement into the program, while the co-viewer reinforces it at bedside to guide low-pressure participation. In reflective segments like "Sticker Stories," the co-viewing clinician helps the patient choose and submit meaningful images, and the host responds on-air to affirm and explore the child's perspective. In each show, intentional co-viewing transforms a broadcast from something watched into something shared and shaped with the child, advancing patient-centered therapeutic goals.

### Impact: Participation, Voice, and Community

Since 2006, KZTV has averaged 7,500 meaningful pediatric interactions each year, ranging from live broadcasts and bedside co-viewing to patient-led productions. A child might text a story, co-host a game show, see their drawing on air, or simply hear their name read aloud by someone they recognize. For families, these moments can mark a shift. As art therapist Chloe noted after a caregiver sent in a prom photo: it was the first time all week the caregiver focused on something other than illness: "Although the caregivers aren't the patients, this show allows them to still feel supported while coping."

Each show is intentionally structured to offer multiple entry points for participation. Whether reflecting on creations with clinicians or texting in poems from their rooms, patients are supported by a small, tightly coordinated producer team: Lu, Grace, and Martha, who run seven days of programming, mentor volunteers, and help clinicians create studio-ready content.

“Flexibility is key in the studio,” Grace said. “We coordinate with many people to make an open studio and patient-hosted shows happen.” Lu focuses on deepening impact by mentoring staff and clinicians to sustain KZTV’s therapeutic vision: “We’re not just running shows—we’re building clinical, emotional, and creative structures for patients and families to step into and feel held.” Martha added, “My favorite is seeing kids take ownership of projects or activities with KidZone TV, whether from their rooms or the studio.”

Kathleen, a CCLS and the studio’s most active clinical co-viewer, echoed that spirit of collaboration. The KZTV team is the most flexible crew I have ever worked with. When you walk into the studio with a patient, the energy radiates from the team. They always support my ideas and my patients’ ideas as well.”

She described how co-viewing lets her build bonds and promote joy. “I co-view daily at the bedside to build connection, create joy, and support coping in ways that feel natural to the child.” She often includes everyone present, caregivers, siblings, nurses, and even doctors. “I’ve had multiple co-views where the nurses, doctors, and teachers join in. It helps build rapport across the interdisciplinary team. When a patient won her first Bingo, we all cheered and she jumped up and down; it was a huge party. That’s the power of KZTV: It brings the whole room, and interdisciplinary team, together.”

KidZone TV producers model attuned listening, responsiveness, centering each child’s narrative. Cues from a child’s energy or from a clinician’s therapeutic goals becomes part of a shared rhythm that positions the child as the author of the moment. “Grace knows what our shared patients like when they’re in the studio,” Kyla said. “That helps me create shows they’ll actually want to watch and join.”

Abbey, a Hematology/Oncology CCLS, called co-viewing transformative. “The studio helps kids feel seen, valued, and centered in an environment that’s often intimidating. I’ve used it for medical education, distraction, and community-building.” She recalled a personalized bingo show episode featuring several hospitalized friends: “I co-viewed one patient while others called in to say hi. It was special to see a group of young girls so deeply bonded and interacting almost entirely virtually.”

On the IBD service, Sarah, CCLS, described a long-term teen patient who reached “a state of flow” during gaming shows. “Their minds are completely focused on their show, drawing their focus away from their stressors and pain.” These moments build confidence and open space for connection. “I have witnessed true friendships between patients develop in that space.”

In “Art History with Katherine”, an art therapist introduced the work of Frida Kahlo and invited symbolic self-portraits of patients and caregivers. During the session, a mother texted in a photo of her artwork, sharing that it was the first creative act she’d done in weeks.

That sense of visibility, of being known and understood, is one of the studio’s most powerful impacts, especially for teens. KZTV’s mature programming, digital tools, and flexible hosting roles allow teens to engage on their terms. Options like digital art, virtual reality, and media editing align with adolescent identity. “Sometimes the right opening for a teen is not to ask them to talk about how they’re feeling,” Lu said, “but to hand them a controller, a camera, or access to a 3D printer, and say: Show me.”

Participation takes many forms. A young patient might help design a trivia game. A parent might share a poem. A long-term patient might become a director, working with staff to create their own edited video about something they love. “Behind the scenes is my favorite part,” said Noah, a young patient producer, “It takes your mind away from your pain.”

Volunteers and interns also find co-viewing powerful. Krista, now a college volunteer, and former patient and KZTV viewer, recalled helping a hesitant child co-host Bingo. “His dad thanked me afterward. That stuck with me.” Returning to the studio felt “full-circle.”

### **Getting Started (With or Without a Studio)**

For CCLSs integrating programming, start small: choose one show each week to co-view intentionally with a patient. Treat the shared watching as an intervention-- stay present, follow cues, and use reflective, creative segments to build identity and confidence without requiring a child to speak about their feelings directly.

Even in settings without a dedicated studio, the core principles still apply. A tablet on a stand and a quiet room can create a moment of authorship. Recording short “strength messages” -- patients sharing encouragement or reflection, helps children see their stories and voices have value beyond their room.

The space itself is doing quiet work. The studio is not just a backdrop, its design, lighting, and materials promote emotional safety, offering structure and spontaneity. At its core, the studio is the network of collaboration, shared moments of co-viewing that bring patients, caregivers, and staff together. The heart of KZTV is the community that builds it every day: patients who lend their voices, the CCLSs who show up, and producers who keep everything flowing. As one CCLS put it, “Our studio, and our producers, change the associations children have with the hospital. They excel at amplifying patient voices and supporting their interests through KZTV.” KidZone TV doesn’t replace clinical care; it extends it. Through voice, vision, and a room that holds space for creative authorship, patients leave something that can inspire others – a reminder that their presence, perspective, and story matter.



## Milestones, Moments and Memories: How Child Life Specialists are Coordinating Weddings in Hospitals

Amy Lee, MS, MSW, CCLS, CIMI

*Author's note: Responses are presented in each CCLSs own words and have only been lightly formatted for readability.*

Hospitals are often thought of as places of urgency and recovery, but they are also where families live real life. Amidst the beeping of monitors and the rhythm of hospital life, there are birthdays, graduations and yes – even weddings. For Certified Child Life Specialists (CCLSs), these moments are not extras; they are extensions of family-centered care. They are powerful moments of legacy-building, connection and healing – aligned with the same care, sensitivity and creativity that defines child life. This article highlights how three CCLSs in Detroit, Fort Meyers, and the Chicagoland area have supported on-site weddings in ways that honor ethics, boundaries, and interprofessional teamwork.

### Meet the CCLSs

- Shay Rocco Jerzy works at Henry Ford St. John Children's Hospital in Detroit and is a one-person program that serves in-patient pediatrics, PICU, and is consulted to support children of dying adults.
- Emily McLellan worked at Golisano Children's Hospital of SWFL in Fort Myers serving the NICU population including, premature and infant patients, siblings and caregivers.
- Becky worked in the Chicagoland area serving the NICU and mother-baby unit, which included antepartum and postpartum patients.

### How and why did you get started coordinating weddings in your hospital?

**Shay:** I helped coordinate a wedding for a terminally ill adult who wanted a son and nephew to be a part of the wedding. My role was to prepare and support the son and nephew.

**Emily:** Most of our patients were born prematurely, resulting in caregivers needing to “pause, cancel, and reschedule” milestones like weddings, baby showers, or anniversaries. The psychosocial support team in addition to the baby/patients' primary RN team coordinated the weddings.

**Becky:** I met expecting mothers who were admitted long term and expecting a NICU admission with a preterm delivery. There was one patient in particular who expressed the expecting parents had desires of getting married at a courthouse prior to baby's delivery. With the antepartum admission, this was no longer an option so this led to how can we help get them married while within the hospital. We didn't advertise it, but we'd help when appropriate.

### How often do you coordinate weddings, and what are the key components?

**Shay:** I have only coordinated one wedding and this adult patient was actively dying. A multidisciplinary approach is essential. Communication and coordination with the nursing staff, spiritual care, and bedside staff is

crucial to ensure everyone is aware of the event.

**Emily:** I assisted with coordinating one wedding. We secured the location, hair/makeup artist, dresses, and photographer. Fortunately, the venue connected us to donors who provided items.

**Becky:** Rarely—about once a year. Plan for the marriage license, officiant, guest count, location (room/chapel/outdoors), decorations and timing.

#### **How did you balance other clinical responsibilities while coordinating the wedding?**

**Shay:** With this being a one-time experience, clinical responsibilities were easy to navigate. I communicated with my staff the need to step away from my floor to participate in the wedding.

**Emily:** Similar to the typical prioritization of the day with the patient census, I was able to allocate a certain amount of time each day to the tasks. It was time sensitive as the wedding date was concrete, but it was deemed a child life intervention because of the family-centered care model in our NICU. Collaboration with multiple disciplines was key—our social worker led many logistics. This situation was priority given the psychosocial stressors associated with early labor, being in a foreign country, having no other family present, and language barriers.

#### **What issues arose and how did you address them?**

**Shay:** Issues included the patient’s cognitive ability to sign the marriage certificate. Due to her actively dying, it was imperative we moved swiftly to carry out the wedding. If we would have waited, even another hour, the patient would not have been able to participate.

**Emily:** Since the family we coordinated the wedding for were on their “babymoon” and resided in a different country, there were no attendees other than staff members, and both were of legal age and had been engaged for some time. Their actual wedding in Germany was cancelled because of their twin girls’ premature birth in the states. The family was bilingual and were able to have the ceremony in English. One of my assessments was that family was comfortable with an English ceremony. One of the Respiratory Therapists that was in attendance was also fluent in German and was receptive to assisting with translation, as needed.

**Becky:** Age was never an issue that we faced as the patients I helped with were always over 18 and families were supportive. Our director always gave the final say on number of people who can be present, and this was typically based on the location in the hospital where the event was taking place. If outside in our garden about 20 people could participate and if inside in the room or chapel it was about 10 people. I would have accommodated language and cultural needs as they arose.

#### **What other disciplines assisted you in coordinating weddings?**

**Shay:** Our Chaplain officiated the ceremony. Our Family Support/End of Life Team coordinated with nursing staff to ensure the patient was properly medicated and all medical interventions would be paused during the ceremony. Our nurse administration office provided us with battery operated candles and flowers to decorate the room. The family provided their own marriage license, as the patient was supposed to get married 10 days before her death.

**Becky:** The Chaplain officiated. The physicians and nurses approved time off the unit and coordinated around

assessments. I helped the patient print, scan, and fax marriage license paperwork.

**Some child life specialists may feel like coordinating weddings can cross boundaries. How did you navigate boundaries?**

**Shay:** This, by no means, felt like a boundary issue. I should mention that it was imperative to conduct the ceremony when we did to ensure that the patient's minor son could be cared for by the spouse. This marriage would allow her husband to have custody of her son, as he was not the biological father. You maintain a therapeutic relationship by only providing support in that moment and not seeking relationships outside of work.

**Emily:** Part of the therapeutic relationship is promoting normalcy with milestone celebrations and giving the caregivers permission to care for themselves and make time for one another. I continuously assessed missed milestones, partnered with organizations to honor them, and ensured any staff attendance beyond clinical duties was voluntary. Since I was the only CCLS on the unit, I did not need to model boundaries as everyone's scopes of practice were different than mine. The NICU leadership ensured that the babies had a primary team and extra support.

**Becky:** I always viewed this as I am helping them achieve a goal while they are in the hospital. I am not acting as a member of the wedding but instead helping to navigate the logistics to make it happen. Being able to give them something to look forward to and accomplish during their long-term admission helps keep a positive outlook and fosters the supportive professional relationship.

**Is there anything else you would like to share?**

**Emily:** Some of the ways I incorporated the babies (patients) into the wedding was capturing footprints and surprising the Groom with a handkerchief with a footprint on it and long stems with footprints to include in the bride's bouquet. I wrote a letter to the parents from their babies and decorated their room so when they got back from the ceremony, the celebrations continued in the NICU environment. We have a professional camera that is used to take photographs in the room and make a scrapbook for the family prior to discharge. We intended to find a way to FaceTime during the ceremony so the babies could "be there" but we experienced internet difficulties. The family visits every year around the twins' birthday, and it is always really exciting to touch base with them,

**Becky:** We wear so many hats in child life, and this was definitely a unique way to support patients!

**Conclusion**

Coordinating weddings may not be what we initially imagined when thinking about supporting patients and families. Yet, it's often these unexpected acts of empathy and humanity—especially during life's most difficult moments—that deepen the therapeutic relationship and offer families a sense of comfort, dignity and connection when they need it the most. As child life specialists, we are uniquely positioned to honor the whole person, rather than just treating the diagnosis. By creating space for love, celebration and meaningful milestones, moments and memories we help preserve the identity of those we serve.

## Spotlight on Student Research Award Recipient: Briana Keller, M.Ed

*Katie Walker, PhD, CCLS*

Each year, the ACLP Student Research Award recognizes emerging scholars whose work advances child life practice and the psychosocial care of children and families. This year's recipient, Briana Keller, M.Ed, is a PhD student at the University of Alabama whose research centers on two timely areas: ambiguous loss in pediatric illness and the healthcare experiences of autistic individuals, especially during the transition from pediatric to adult care. Briana's project invited autistic young adults to describe—on their own terms—what helps, what harms, and what needs to change. Her findings reinforce the vital role Certified Child Life Specialists (CCLSs) can play in preparation, communication, and sensory-supportive care across the lifespan. In the conversation below, Briana reflects on what she learned, how the study shaped her as a researcher, and what practical steps clinicians can take tomorrow to improve care.

**What problem were you trying to solve, and what is one thing a CCLS could do differently tomorrow because of your findings?**

Autistic young adults use healthcare services more often than the general population (Ames et al., 2021), yet they frequently experience more difficulty transitioning from pediatric to adult care (Ames et al., 2023; Cheak-Zamora & Teti, 2015). We wanted to understand how this population experiences healthcare transition and why. CCLSs have the skill set to provide procedural preparation, support sensory needs, and break down medical information clearly—exactly the strategies our participants said were most helpful. Even at ages 18, 21, or 25, autistic patients want and benefit from these services.

**Can you share a brief story or quote that captures why this work matters?**

The sheer number of responses spoke volumes. People often complete research surveys because they want to be heard, especially when there is no payment. We received more than 200 responses in just four months, with over a quarter arriving in the first week. Many participants also left comments thanking us for doing this work—it clearly mattered to them to share their input.

**How did conducting this study shape you, and how does it inform your next steps?**

As an autistic person, I often see autism research that feels disrespectful or dehumanizing. It was powerful to design a study that was accessible and inclusive, and to share honest results while prioritizing autistic people's dignity. I'm now in the second year of my PhD, and my dissertation will focus on autism and medical play. It feels good to be part of changing how researchers talk about disability.

**If a clinician has only 10–15 minutes, what's a low-cost, evidence-informed action they can take based on your study—and what simple sign would show it helped?**

The most important thing our participants wanted was to be treated as human beings. Many have experienced being ignored or talked down to, particularly when autistic traits are more visible (e.g., limited speech, significant sensory challenges). When clinicians approached them with respect and kindness, they felt more comfortable and healthcare became more accessible. Practical tips are summarized in our Summer 2025 ACLP Bulletin article, "Creating a Culture of Respect for Autistic Patients and Families."

**If a team wanted to build on your project, what's one realistic next step, and what single data point would you track?**

If you want a tool to identify which transition skills patients feel confident about— and which they are still developing—our study used a modified Transition Readiness Assessment for Youth (Got Transition, 2020). For comfort and accessibility, nothing replaces directly asking the patient: “What do you wish your doctor or nurse knew about taking care of you?”

## **Conclusion**

Briana Keller’s work amplifies autistic voices at a critical point in care and translates their guidance into clear, actionable steps for CCLSs and interprofessional teams. Her message is both simple and practice-changing: sustained preparation, sensory- supportive environments, plain-language communication, and respect remain essential beyond pediatric settings. As programs refine transition processes, Briana’s lens offers a blueprint for partnering with autistic patients to define what “good care” looks like. To learn more or request the article, contact [bpkeller@crimson.ua.edu](mailto:bpkeller@crimson.ua.edu).

## **References**

Ames, J. L., Mahajan, A., Davignon, M. N., Massolo, M. L., & Croen, L. A. (2023). Opportunities for inclusion and engagement in the transition of autistic youth from pediatric to adult healthcare: A qualitative study. *Journal of Autism and Developmental Disorders*, 53(5), 1850–1861.

Ames, J. L., Massolo, M. L., Davignon, M. N., Qian, Y., & Croen, L. A. (2021). Healthcare service utilization and cost among transition-age youth with autism spectrum disorder and other special healthcare needs. *Autism*, 25(3), 705–718.

Cheak-Zamora, N. C., & Teti, M. (2015). “You think it’s hard now... It gets much harder for our children”: Youth with autism and their caregivers’ perspectives of health care transition services. *Autism*, 19(8), 992–1001.

Got Transition. (2020). Sample transition readiness assessment for youth.  
<https://www.gottransition.org/6ce/?leaving-readiness-assessment-youth>

## Child Life Lessons: A Year Abroad and A Year on the Job

*By Molly Gleydura, BA, CCLS*

March 2022: I am several weeks into my much-anticipated child life practicum, when I receive an email telling me that I have just been awarded a Watson Fellowship to complete a year-long self-directed project abroad. That time was marked by intense excitement, but also shadows of worry about how my journey to becoming a child life specialist might be affected.

Flash forward to today: Having just completed my first year as a Certified Child Life Specialist, I can proudly say that I would not be the specialist that I am had I not taken this unconventional path.

Let me bring you up to speed. Upon completing my child life coursework on death and dying, I created a 70-page guide on how to work with children and families facing the end of life and following a death. Even after completing a semester of research on the topic, though, I felt that I had much more to learn and needed new perspectives to broaden my understanding of how to provide this type of support.

That's where my Watson Fellowship fits in.

The program allows recent college graduates to pursue a project of interest outside of the United States for one full year. From August 2022 to August 2023, I traveled to eight different countries to explore how best to support children and families before, during, and after the death of a child. Over the course of that year, I lived in New Zealand, Chile, Spain, Senegal, Kuwait, Belgium, Ireland, and the UK. I worked and connected with rural and national hospital systems, hospital- and community-based psychosocial support organizations, pediatric hospices, funeral homes, researchers, professors, patients, and families.

My year of seeking out new perspectives, challenging my understanding, questioning my assumptions, and—most importantly, listening intently—has shaped my first year as a CCLS in unimaginable ways. Three important lessons that I learned while abroad now serve as daily personal mantras, guiding my practice as a CCLS. Every day, I think about the importance of reducing stress and confusion for patients and families within the hospital system; the value of approaching others with empathy and assuming best intentions; and the critical role of community as a source of support and self-care.

### **Navigating the Healthcare System is a Major Stressor**

I knew this in theory, but it didn't hit me until I arrived to work in New Zealand, just five days after leaving the U.S. I realized it even before stepping inside the hospital, frantically texting the pediatric palliative care physician I was shadowing at Starship Hospital for over ten minutes, trying to find the right entrance. Despite my confidence in medical terminology and hospital routines, I felt confused, overwhelmed, and lost.

The hospital environment is often one that heightens stress, challenges coping skills, and emphasizes a loss of control for those navigating it. This is especially evident when patients and families face complex illnesses, require invasive or substantial care, have low medical literacy, or face language or cultural barriers. Although I wasn't a patient there, I found it hard to keep track of details, remember the questions that I wanted to ask, and understand what I was being told.

It is important to note that as a Type 1 Diabetic myself, I am no stranger to navigating healthcare systems as a



patient. In fact, prior to my year abroad, I spent five months visiting doctors' offices and close to 100 hours on the phone with my insurance company preparing to navigate my chronic illness while away from my support system. My endocrinologist at home advised that I see endocrinologists abroad four times throughout the year. I was unable to visit a single endocrinologist that year, because I hit roadblock after roadblock trying to figure out how to get an appointment, meet with a specialist, or have routine testing done. When I finally met with a doctor in Chile I managed to check in at the wrong desk, sit in the wrong waiting room and realized, too late, that I had made an appointment with the wrong provider. Each mistake I made heightened my feelings of overwhelm and lessened my ability to retain the information provided to me. Once the visit was completed and I walked out of the room with a handwritten prescription to be filled, I had to Google the medication to recall what the doctor had told me about it. As I nervously approached the pharmacy, a technician noticed my obvious distress and walked me through everything I needed to know and do. I felt my heart rate settle as she took the time to offer compassion and support, recognizing the anxiety evoked by the situation and setting.

When I began working as a child life specialist, meeting patients and families, I was reminded of my own feelings of stress and confusion. In my first year on the job, I have taken every opportunity I could to add moments of calm and clarity into the hospital environment. It was in the moments when those with whom I worked noticed my confusion, helped me take a breath, and ensured my understanding that I was able to really be present during my time abroad. So now it is my goal to provide those kinds of moments to the patients and families I see every day.

### **Always Assume the Best Intentions**

I hate to admit how much my time abroad opened my eyes to the biases, assumptions, and subjective ideas taken as objective facts that I and many others unconsciously operate on daily. Based on what I learned in my coursework and student experiences, I was adamant, to the point of self-righteousness, that the best and only just practice is to fully inform children about all aspects of their medical experience.

When I began working as a child life specialist, meeting patients and families, I was reminded of my own feelings of stress and confusion. In my first year on the job, I have taken every opportunity I could to add moments of calm and clarity into the hospital environment. It was in the moments when those with whom I worked noticed my confusion, helped me take a breath, and ensured my understanding that I was able to really be present during my time abroad. So now it is my goal to provide those kinds of moments to the patients and families I see every day.

That was until I heard the perspective of a family in Senegal that was planning to do the exact opposite.

While working with the psycho-oncology team in the only pediatric oncology center in the entire country, I met a family of a teenager who traveled many miles to reach the clinic and finally figure out what was causing their child's symptoms. After a couple of days and several tests, it was determined that the teenager had acute myeloid leukemia—a fatal diagnosis in Senegal, as there are no curative treatment options available in the country. Every child in Senegal who receives this diagnosis is immediately placed under the care of palliative services. When the father first shared his plan to not tell his child this news, I felt uneasy about the ethicality of the decision.

I brought these concerns to the psycho-oncology team that I worked with there, citing research and conversations around beneficence and veracity. Of course, the professionals with whom I was working also understood and valued these principles. What they knew, and I didn't yet, was the stark difference in life expectancy for pediatric cancers in the U.S. compared to Senegal, despite the best efforts of well-trained

doctors, nurses, and other team members. They explained that based on population statistics and childhood cancer rates, the team estimates that only about a quarter of patients with pediatric cancer in the country ever make it to their service. Of the children who are followed by the team, only about 50% survive their diagnosis, with several having no path to survival. For me, these facts are hard to accept, reconcile, and process. My suggestion to tell the teenager of the diagnosis would have met the principle of veracity, but in this case, it would not have been beneficent, as the father pointed out.

In our conversation, the father explained that several years ago, the teenager's best friend received the same diagnosis. The friend, though, was able to travel to Europe to receive treatment and a bone marrow transplant, returning to Senegal in remission.

Our patient's family, though, could not afford any treatment at all—not in Senegal, let alone abroad. The father knew the outcome of this diagnosis and he knew that the ending would change by the teenager knowing the disease's name.

What would be different was how that remaining time together would be spent. The father opted to not tell the teenager of the diagnosis to allow for the rest of their life together to be spent focusing on love, connection, and meaningful moments rather than resentment, isolation, and longing for a treatment that exists but is not available to them.

In challenging moments that I have encountered since, I aim to remind myself to operate with empathy and compassion, based on the belief that everyone acts from a place of good intentions.

In the U.S., I met the family of a child newly diagnosed with a brain tumor. The medical team urged immediate surgery and treatment, while the family asked to delay care in favor of prayer and religious practices. Tension rose as each side viewed the other as misguided or paternalistic. Neither could be certain that the other's plan would succeed. Only when compassion replaced conflict did they reach a mutual course of action. Both were fighting for what they believed best for the child—they just initially disagreed on what that was.

There have been so many moments that I have encountered during my first year as a CCLS that have reminded me of these situations. When they occur, I encourage myself to always assume the best intentions from all involved. With this mindset, it is much easier to listen, understand, and support.

### **Community is a Powerful Source of Support and Self-Care**

I have countless stories from my time abroad, where I both observed and experienced the power of community. In Chile, I spoke with room attendants from the Ronald McDonald Family Rooms and House to hear their perspective on providing support to families experiencing medical challenges. During many of the conversations, room attendants would say something along the lines of "I'm not working as a doctor, psychologist, therapist, or social worker." The majority of the room assistants commented on their inability to solve the healthcare issues of the child or take away any depression a parent might be experiencing. Many said that they make a point not to say that things will be okay or to offer any advice in general. But, what they did was listen and showed they cared. The Ronald McDonald Family Rooms held a mixture of laughter, tears, frustration, and gratitude. Families told me that the hospitals felt very stressful and tense, but when they walked into the family rooms, they felt like they could finally take a breath. They knew that there were people there who were ready to listen as families told their stories, or to sit in silence when words were not enough.

In my work as a CCLS, it has been important to me to build a community that I can trust, rely upon, and confide

in, both inside and outside of work. In fact, this has proven to be invaluable. My intentional building of a community has served as a unique form of support group for me, one that celebrates the wins, commiserates on the challenges, and troubleshoots solutions. Community provides emotional validation, stress reduction, a means to enhance coping skills, and a sense of belonging. Not only are these pillars of meaningful support, but they are also important tools for self-care that reduce burnout and compassion fatigue.

Feeling cared for helps you to have the capacity to care for others.

### **Takeaways**

I am beyond grateful for the lessons that I learned from my Watson Fellowship and for the lessons that my colleagues, patients, and their families continue to teach me in my work as a CCLS.

For those who are able, I will always recommend working and spending time abroad with the goal of learning.

For those who aren't able, I encourage you to continue to challenge your biases and seek knowledge from diverse stories and perspectives. There are so many memoirs, articles, and personal accounts that have been produced by individuals around the world that have continued to shape and test my understanding of what care looks like. I know that these works have helped me to be an even better CCLS.

Through sharing the lessons that I have learned, I hope that you, too, can reflect on the values that ground your work. Spend those extra moments making the hospital environment feel less foreign, reframe interactions to see the good, and pour into your own community to find support.

Ultimately, I hope that this detailing of my point of view as one CCLS, will provide a small window of support for child life students. Please don't be afraid to take a different path—you never know how those experiences may shape your practice and benefit the patients and families whose lives you have the great privilege of intersecting.

## A Reminder: You Are Already Doing What Works

*By Stephanie Whitten, MS, CCLS*

In January of 2022, my husband experienced an extended and isolated hospitalization from COVID-19, which compromised his second kidney transplant and left hemodialysis as his only treatment option until another kidney transplant becomes feasible. He began dialysis while in the hospital, and after discharge he continued treatment three times a week at a local clinic with 4:30 AM start times. For three years, this routine shaped our days until he made the decision to transition to home dialysis in September 2025. As we move into this new chapter together, I have found myself learning alongside him with confidence, nerves, and even laughter at my “nursing skills”, which, in many ways, my years of facilitating medical play with patients as a CCLS helped prepare me for. We have come to realize that chronic illness reshapes daily life in expected and surprising ways. More than anything, this journey has reminded me that the principles of family-centered care are not abstract ideals; they are what families need the most and what child life specialists practice every single day.

### Education as Empowerment

I knew this in theory, but it didn’t hit me until I arrived to work in New Zealand, just five days after leaving the U.S. I realized it even before stepping inside the hospital, frantically texting the pediatric palliative care physician I was shadowing at Starship Hospital for over ten minutes, trying to find the right entrance. Despite my confidence in medical terminology and hospital routines, I felt confused, overwhelmed, and lost.

When my husband began his month-long home dialysis training, I assumed it would focus solely on him as an adult patient. After all, he is the one undergoing dialysis treatment, and I’ve learned over the years how different adult care can be from pediatric care. However, to my surprise, the nurse invited me to sit beside him, to watch carefully, to ask questions, and eventually practice the steps myself. She didn’t just teach him; she taught us. That inclusion transformed my role from passive supporter to active partner. Instead of standing on the sidelines, I felt equipped with knowledge and confidence and even prepared for challenges or worst-case scenarios.

This experience reminded me of the heart of child life work: education that empowers. As child life specialists, we prepare children for medical experiences in ways that give them control and confidence. We explain, demonstrate, and invite participation so that both patients and their families can understand what to expect.

Just as I felt relief and courage from being included in my husband’s training, I’m reminded that while education can empower families in pediatric settings, not all have access to the same supportive experiences. This gap highlights why child life work is so essential.

Child life practice is grounded in evidence and experience, demonstrating time and again that preparation and education make a difference for patients and families of all ages. These same principles can extend across disciplines, reminding us that psychosocial care is not limited by age or setting but is built through connection, communication, and inclusion.

*Reminder: Every time you teach, prepare, and empower a child or their family member, you’re doing exactly what matters most.*

### Emotional Support is Essential

Even with knowledge and practice, the emotional side of chronic illness can never be overlooked. As I practiced setting up the dialysis supplies and handling needles, my emotions shifted many times. I experienced pride when we mastered a new step, worry about making mistakes, laughter at my clumsy fistula taping skills, and moments of quiet when the reality of this new routine set in. What made those emotions bearable was the way our nurse created and maintained

space for them.

Whether that was answering questions, validating our concerns, or encouraging us throughout the process, she empowered us.

This, too, is the work of child life. Medical education gives patients and families information, but emotional support helps them process and cope. Child life specialists sit with children who are scared, acknowledge the tears of parents who feel helpless, and offer comfort through play, distraction, and presence. These moments are not small; they are essential. We remind families that their feelings are normal, they matter and are not alone carrying them.

*Reminder: When you acknowledge emotions and create coping spaces, you are shaping resilience. You are doing the work families will remember.*

### **Family-Centered Care in Action**

Perhaps the most powerful part of this journey was how my husband's care team consistently treated us as a unit. They recognized that dialysis at home would not just affect him, but it would affect both of us. By including me, they honored our partnership. By asking for my observations, they valued my voice.

This is what family-centered care looks like in practice: acknowledging that illness impacts more than the patient, and that support systems are not optional but essential. Child life specialists embody this philosophy every day. We invite families into the process. We advocate for their presence. We model inclusion in spaces that could otherwise feel intimidating or clinical. We remind healthcare teams that families are not visitors, but rather, are central to their child's care.

*Reminder: Your advocacy and modeling of family-centered care isn't just philosophy...it's practice that changes lives.*

### **Carrying the Lessons Forward**

As my husband and I begin this new routine at home, I am struck by how much it mirrors the values that child life specialists uphold. The education that gave us confidence, the emotional support that steadied us, the family-centered approach that empowered us—these are the very pillars of child life.

And so, I want to offer this reminder: you are already doing what works. The education, preparation, and inclusion you provide each day embody the heart of child life work. These are the same principles that turned my husband's and my fear into confidence. What works is not always a perfect script or outcome. Instead, it is the intentional presence, compassion, and partnership you bring to each family encounter. I have come to understand that what families may remember most is not the perfection of a moment, but the feeling of being seen, heard, and supported; just as the nurse did for us. Those moments of reassurance can transform fear into courage and uncertainty into trust.

In the day-to-day, it can be easy to feel stretched thin or to wonder if your efforts are enough. However, from the perspective of someone living on the other side of healthcare, let me assure you that your presence and your support matter. Families carry those lessons, the support, and the advocacy with them long after the hospital stay ends.