
Supporting Medically Fragile Children and Their Families

Julia Luckenbill and Amy Zide

Before 11-month-old Leshawn even entered the classroom at the Early Childhood Lab School, Julia, the program coordinator (and lead author), and her staff (including Amy, the second author) wondered whether being in group care would be a good fit for him. Diagnosed at birth with a diaphragmatic hernia, Leshawn had a team of specialists working with him. He had been hospitalized for most of his early infancy and was being fed through a gastrostomy tube (G-tube) which, his mother feared, might be yanked by another infant. Unwilling to let his mother leave his side, Leshawn showed intense separation anxiety.



If the program enrolled this medically fragile infant, staff would have to be aware not only of his medical needs but also of his unique social and emotional needs arising from hospitalization. Fortunately, Julia's training in a specialty known as child life in hospitals enabled the program to include Leshawn in the classroom and tailor the curriculum to his needs.

An important home visit

Soon after the Lab School accepted Leshawn, his lead teacher, Monique, and Julia visited his home to meet with his parents, learn more about Leshawn and his needs, and ensure that everyone was in agreement on his education and care. Monique and Julia shared with his parents some common fears that infants Leshawn's

age have during transitions to group care and explained how the staff would handle them in the classroom. Then, putting on her child life specialist hat, Julia pointed out some of the things in the daily routine that might trigger Leshawn's fears (such as teachers' use of gloves while diapering, which might remind him of hospital experiences). But more important, Julia and Monique listened. They wanted to learn about his family's cultural and religious views and their hopes for their son's educational experience—much the same as with any other home visit, but with a critical focus on gathering information about Leshawn's medical requirements and related emotional needs.



The whole staff would work closely as a team to support this family and child as they made the leap to a group early education setting. Talking with his parents, Monique and Julia learned how to care for Leshawn's G-tube and how to feed him and handle his reflux. They learned how his family soothed him. They built trust as they listened and asked questions about Leshawn's care. This home visit was the longest of any to the children and families the school served. And when Monique and Julia wrote his care plan, it was the longest in the classroom. The plan reflected Leshawn's special physical and emotional needs as well as his family's wishes. In view of Leshawn's separation anxiety, they also drafted a transition plan specifying that his mother stay with him in the classroom as long

as necessary while he eased into trusting nonfamily members in this new setting. Understanding that it would be hard for Leshawn to trust nonparental caregivers turned out to be key in his eventual success in the classroom.

The child life specialist as the nexus of the care team

Because families are children's first teachers, and because many families hold strong cultural and religious perspectives about how their children should be cared for, clear communication that begins before the child joins the program is critical. When a child faces significant medical issues, the family often experiences considerable stress about the child's health and the family's finances. Parents may also struggle with strong protective urges that make the transition to an educational setting more difficult than usual.

Connecting with families of medically fragile children means conducting an unusually comprehensive initial home visit and writing a detailed care plan—as Monique and Julia did for Leshawn. During the home visit, it is wise to also find out how much information about the child's condition—if any—you may share with other families. To ensure continuity of care, ask the family for written permission to connect with the child's medical specialists. The privacy of medical information is protected by federal law (HIPAA—the Health Insurance Portability and Accountability Act of 1996), and family consent must be obtained before medical professionals share any details with others. Once the child has been integrated into the classroom, devote extra attention to keeping the family updated on his or her progress with photos, anecdotes, and conversations. Although this is typically done for all children, with medically fragile children it is especially important to keep lines of communication open, increase family engagement, and build trusting relationships.

While child life specialists generally spend most of their time working with hospitalized children to normalize their experiences and support coping, hospital-school links can greatly improve the care seriously ill children receive as they move between settings. For example, when Leshawn was hospitalized

Child Life Specialists Optimize Care

With a medically fragile child, continuous coordination among educators, medical staff, and families is essential. Ideally, hospitals or early childhood programs would have on staff—or have access to—child life specialists who could facilitate coordination, ensure families are aware of all available resources, and support educators in caring for the fragile child. With the parents' permission, the specialist could guide the teacher in adding developmentally appropriate medical information and activities to the curriculum.

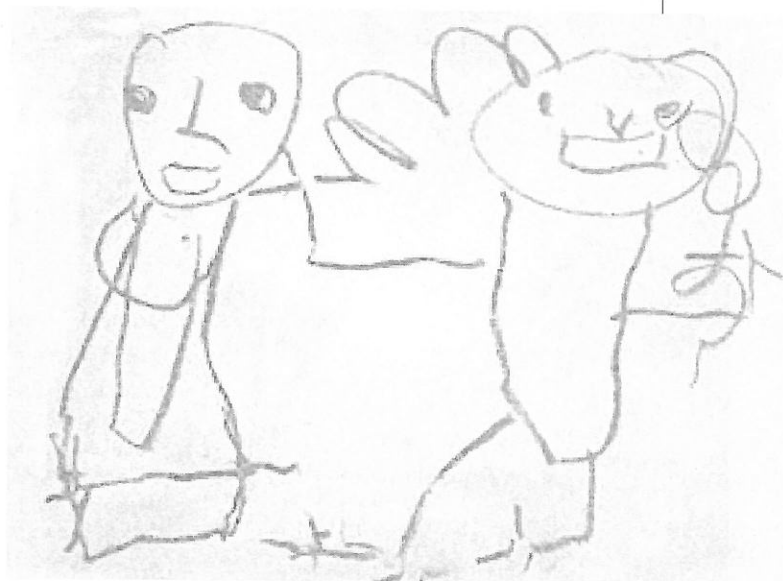
According to the Association of Child Life Professionals, child life specialists “help infants, children, youth, and families cope with the stress and uncertainty of acute and chronic illness, injury, trauma, disability, loss, and bereavement. They provide evidence-based, developmentally and psychologically appropriate interventions, including therapeutic play, preparation for procedures, and education to reduce fear, anxiety, and pain” (ACLP 2017). Practicing professionals have completed coursework in the subject, gained clinical experience, and passed a qualifying exam. (For more details, see www.childlife.org/certification.)

To learn how child life specialists support families—including by reducing fear and stress in the hospital, during transitions, and in educational settings—and how to find a specialist, see the longer, more comprehensive version of this article online at www.NAEYC.org/members-only/yc/supporting-medically-fragile-children-families.

earlier with respiratory difficulties, he encountered many masked faces—a necessity to minimize his exposure to germs. But Leshawn was far too young to understand the purpose of the masks, and not being able to see peoples' faces often frightens very young children. A child life specialist would be aware of such fears and would share them with Leshawn's family and teacher, along with activities to use at home and in the classroom to mitigate the fear. For example, initiating peekaboo games with familiar people wearing surgical masks might allow Leshawn to master this aspect of his hospital experience. For older children, adding real medical masks to the dress-up area for use during make-believe doctor visits is helpful.

Leshawn, being an infant, had limited ability to articulate his fears and needs beyond crying and clinging to his parents. Older children may have more complex fears and may ask challenging questions about their medical experiences. These sorts of questions are more likely to come up during medical play and art activities (Malchiodi 2006). While the classroom teacher is probably not the right person to answer medical questions (unless told by the parent or specialist what the child needs to know and how to say it in a developmentally appropriate way), passing along these questions to the family and the child life specialist and sharing observations with them are good ways to help the child find answers and means of coping. (See “Child Life Specialists Optimize Care.”)

To create opportunities for communication, the specialist can suggest activities for older children, such as making art using nonhazardous medical props (like cotton balls), engaging in water play with plastic syringes (without needles) and tubing, providing toy ambulances and doctors, and offering doctor and child puppets. These activities permit children to express their fear, anger, and ideas as they play in a judgment-free setting (Oremland 1988). They can also help restore some control to a child. As one art therapist explained, “When the ill child engages in art making, he or she is in charge of the work—the materials to be used; the scope, intent, and imagery; when the piece is finished; and whether it will be retained or discarded” (Councill 2012, 222).



A successful inclusion

Leshawn became integrated into the classroom slowly. Although he would not leave his mother's side, he played with staff and with the student caregivers in the Lab School who were assigned to care for him. His worst time of day was diapering, because being laid on his back and being attended to by a person wearing gloves signaled to him that a painful medical procedure was about to begin.

Initially, Monique and Julia asked his mother to change his diaper; later, they and other school caregivers let him feel the gloves before putting them on their hands.

They communicated with his mother by email nearly every day. They were able to identify other things in the classroom routine that might be stressors for him, such as adults' blue shoe covers and the smell of bleach and other cleaners. While the school needed to continue these basic health and safety practices, being aware of Leshawn's perspective helped staff and student caregivers be more sensitive and allowed him to transition at his own pace. To avoid the use of shoe covers, Monique and Julia encouraged everyone to wear socks. They tried to make the room smell of lavender instead of bleach. The goal when Leshawn was an infant was to make it clear that this setting was free of medical procedures and was very different from the hospital.

Using Medical Curriculum in the Classroom

After hospitalization, adding medical props and play to the curriculum can help the child—and his or her classmates—better understand what has happened and address typical fears (which vary by age).

While it is wisest to develop activities in collaboration with the child life specialist, here are some things we do in our classrooms. These activities also work well in home settings.

Age	Fear	Coping tool
Infants	<ul style="list-style-type: none"> ■ Separation ■ Being touched by or held down by strangers ■ Hidden or masked faces ■ Unfamiliar smells, sounds, and sights 	<ul style="list-style-type: none"> ■ Provide images of absent parents ■ Show that faces are still there behind masks ■ Let the child handle safe medical items to make them less scary ■ Model comfort with medical equipment ■ Offer opportunities to relax and engage in open-ended play
Toddlers	<ul style="list-style-type: none"> ■ Separation ■ Fear of pain and unfamiliar things ■ Loss of control ■ Loss of body fluids ■ Imaginary things happening, such as machines coming to life ■ Getting undressed 	<ul style="list-style-type: none"> ■ Use all of the tools listed for infants ■ Use real but not dangerous medical instruments, such as stethoscopes, syringes (without needles), and blood pressure cuffs; Band-Aids are particularly exciting and promote eye-hand coordination ■ Add water play with syringes, tubing, and medicine cups to provide a less charged opportunity to see how the medical tools work ■ Provide access to art supplies, including cotton balls, gauze, and other unused, inexpensive medical supplies (avoid choking hazards) ■ Offer opportunities to dress and undress dolls in hospital-like gowns ■ Read aloud basic books about going to the doctor (avoid scary images such as MRIs)
Preschoolers	<ul style="list-style-type: none"> ■ Separation ■ Fear of pain and unfamiliar things ■ Loss of control and not being included in planning ■ Loss of body fluids ■ Imaginary things happening, such as machines coming to life ■ Getting undressed ■ Misunderstanding procedures as a punishment for wrongdoing 	<ul style="list-style-type: none"> ■ Use all of the tools listed for infants and toddlers ■ Show puppets as children expressing fears or as doctors and nurses helping others ■ Provide doll-sized medical tools, like wheelchairs, and access to real props, such as casts that have been cut off and crutches ■ Invite children to engage in representational art with paint, markers, etc., and in "medical art," such as painting with syringes and gluing on surgical caps or gloves ■ Provide current nonfiction books about hospitals, but be careful not to show procedures that no one will be experiencing ■ Make books with all of the children about doctor's visits; if children are interested, invite them to share photos and drawings to document their experiences

Gradually, Leshawn's mother left him with Julia, and if Leshawn became upset, Julia took him out in the yard for one-on-one sessions watching squirrels and busses. It took time, patience, and training for Julia and Monique to help Leshawn manage and eventually reduce his terror in the classroom. Most of all, it took teamwork between Monique, his family, and Julia. After 25 weeks in the classroom, Leshawn had completely adjusted.

As Leshawn grew older, Julia and Monique adapted the curriculum with his needs in mind. When he was 2, they invited a parent who is a doctor to show the children her medical tools at circle time. For this visit, they invited Leshawn's mother to join the class. They were worried that seeing a medical professional in the classroom would cause Leshawn to panic, but he astounded everyone by being totally fine. He was clear about the difference between the classroom and the hospital and felt safe to explore autonomously. When Julia added several real medical instruments—including stethoscopes, masks, plastic syringes (without needles), and Band-Aids—to the dress-up area, Leshawn was able to relax with the tools and play with them with his trusted caregivers and peers. (See "Using Medical Curriculum in the Classroom.")



Summing up: Communicate and collaborate

When a child is returning to the classroom post hospitalization, there may be moments when hard questions come up or when the child expresses strong emotions. Educators can use the following strategies to support the child, then revisit the conversation later (after consulting with a parent or specialist), if needed.

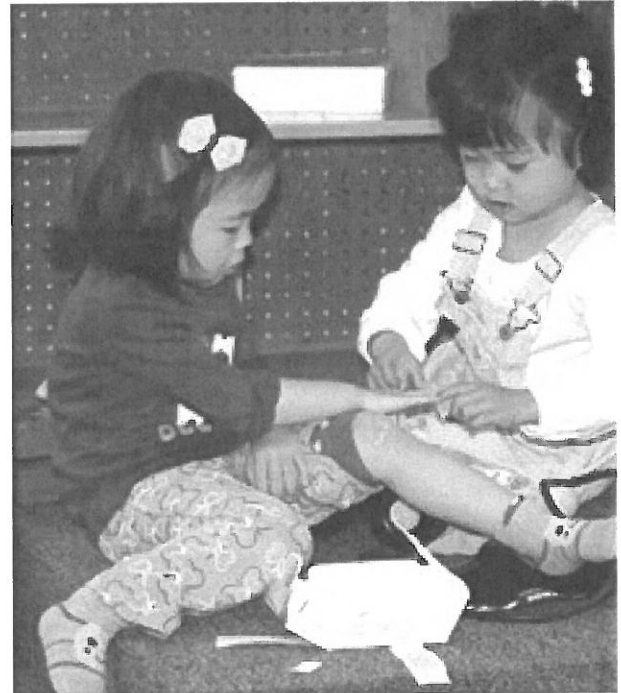
- › Encourage the child to talk about his or her feelings or concerns. Write them down to share with the family and the child life specialist.
- › Assess the child's perceptions and understandings by asking questions such as, "I wonder why your doll needed to go to the doctor?"
- › Guide play by asking about the "patient" (e.g., a doll or stuffed animal) to further assess the child's understandings and emotions surrounding the medical experience.
- › Reinforce correct information about medical care, if you know the correct information. For instance, a teacher may say, "Giving a doll a shot helps her get medicine the best and quickest way."
- › Be careful not to give incorrect information or too much information. It is better to say, "I don't know; I'll have to find out," than to add to a child's misconceptions. Help the child or child's family get answers to questions about specific procedures from the hospital's child life specialist.
- › When the child says something about what he or she thinks might happen, reflect or repeat the child's comments and expressions to the child to clarify and to help the child feel heard (e.g., "When the bear feels sick, he cries."). This helps shape the child's ideas toward correct information when misinformation is revealed.



- › If a child asks about death, be careful to respect the family's wishes, culture, and religion. Do not share your own religious beliefs, and be sure to tell the family about the child's questions.
- › Share your observations about the child with the family and child life specialist, and get feedback frequently, so you're all in agreement on how to support the child.

Including in your program children who have experienced extensive medical procedures may seem daunting. Keep in mind that they are still children and can benefit from using play and art to express their ideas and needs, just like children who have not had major medical experiences. Working closely with a care team that includes parents (or guardians) and a child life specialist can enhance the child's physical and mental health across settings. Adding real, safe

medical play props to the curriculum is an excellent way to value the experiences and needs of children who have been hospitalized. This has the additional benefit of preparing the other children in the room for possible future experiences with illness or injury. Being aware of the common fears and needs of children at different ages, and having access to a child life specialist, when necessary, is a great way to support medically fragile children in educational settings.



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