Adaptive Care Team Improves Health Care Experience for Special Patient Population



Gail Klayman, program coordinator - Adaptive Care Team, Center for Professional Excellence, shows Rowan Colby, age 6, and his mother, Brandy, pictures of what is going to happen to him during his visit, while a patient care assistant listens to his heart.

Brandy Colby's son, Rowan, used to vomit before getting his regular IV treatments at Cincinnati Children's. He fought every step of the process, from waiting in Admitting, to having his blood pressure and temperature measured, to the insertion of the needle. "I had to pin him down while three staff members tried to access his port," Brandy says. "I left with scratches on my face from where Rowan clawed me." They endured this on a monthly basis.

Rowan is a 6-year-old first grader with a sweet smile and a mop of auburn hair. He likes blocks, books and playing computer games. He visits Cincinnati Children's for multiple diagnoses, including autism, epilepsy and an autoimmune disorder. He receives monthly 12-hour IV treatments.

In part because of his autism and in part due to past medical experiences, Rowan has long had a distrust of health care personnel. At the time his IV therapy started, he was non-verbal. His lack of communication skills made it difficult for him to express his fears. He conveyed his feelings the only way

he knew how: by physically fighting to protect himself. Enter CCHMC's new Adaptive Care Team (ACT).

A Unique Population

Behavior like Rowan's sometimes occurs with patients who have developmental and behavioral challenges. Staff in the Division of Developmental and Behavioral Pediatrics (DDBP) are skilled in

providing care to these patients, and Child Life specialists are trained to help patients cope during health care encounters.

The Adaptive Care Team collaborates with these disciplines and others to meet the individual needs of patients like Rowan. This unique population often has extreme anxiety, an inability to express themselves and vivid memories of bad health care experiences in the past. The patients the Adaptive Care Team works with can include a boy who runs in fear out of the operating room, a girl who hasn't received dental care for seven years because routine dental exams were so traumatic for her, a teen with anxiety levels so high he removes all of his clothes and runs through the medical center, inciting intervention by Protective Services.

Patients need to meet two criteria for ACT support: 1) The patient is diagnosed or being evaluated for a developmental and/or behavioral challenge, and 2) The patient has a difficult time coping and cooperating during a health care

visit requiring additional support.

Long-time Child Life specialist Gail Klayman, MEd, CCLS, began looking more closely at these particular patients and had a revelation. "If we don't do anything," Klayman says, "it won't change."

Forging the Way

Having started at CCHMC in the Division of Child Life in 1972, Klayman says she's always challenged the status quo. "I love to think out of the box and pose the "why" question," she says. In fact, early on in her career, she tackled a change in the visiting policy so it explicitly stated parents could visit their children 24 hours a day. "That was one of my first family-centered initiatives at CCHMC," she says.



Klayman uses distraction techniques with Rowan as he awaits the insertion of his IV.

"I've always been kind of a pioneer."

She used that same pioneering vision over the past two years as she studied and learned from parents about this special patient population she thought needed extra care and attention for a positive health care experience. Last summer her proposal for this program

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toys kept in a storage pantry to the bright, amply stocked storefront in Location C, complete with on and off-site storage and countless vendors whose wares are eagerly purchased by patients, families and medical center employees. This fall the Junior Coop is on the move, set to open a second location at Liberty Campus just in time for the holiday rush.

Shop 'Til You Drop

As anyone who has ever stopped into the shop can attest, it takes real strength to

resist the allure of a purchase. And why resist? After all, every penny made goes to fund hospital projects, staff positions and support direct care and research. A team of volunteer buyers works alongside paid staff to stock the gift shop. It takes careful planning, an eye for what sells and a gift for creating those tempting displays to woo potential customers.

It's a formula that has worked since 1910. While originally a much smaller operation, offering toys and holiday decorations at craft sales and seasonal events, the Junior

supporting the medical center's goals. One of its first gifts on record, in 1915, was \$1,000 to install electricity at the hospital, \$50 for a Victrola and \$450 to buy two beds for two children in need.

Help Wanted

Then, as now, volunteers often find their way to the Gift Shop through a friend or a neighbor. Junior Coop board president Marjorie Gilsdorf works with Human Resources to hire the staff positions, while volunteers apply directly to the Coop. Shifts



Rowan gets a big hug from his mom when it's all done.

was approved. After 37 years, she left Child Life and became the program coordinator for the new Adaptive Care Team, which is housed under Disability Services within the Center for Professional Excellence.

Since then, Klayman says great strides have been made. She now has an additional full-time team member, Jennifer Stabb, MS. They focus on clinical work, education and research. They have developed a psychosocial patient assessment tool and a patient database. They begin their clinical care by looking at a child's behaviors. stressors and motivators. Then they work to regain the patient's trust. This often starts with what's called a "play visit" to get the child comfortable in the health care setting. They work on slow transitions. Families get homework such us pretend medical play.

A Drastic Change

The best examples of success are the patients themselves. In Rowan's case, since Klayman's intervention, his IV treatments have turned around completely. At his latest appointment, he was sitting quietly in his room playing a computer game as his mom

spoke with a nurse. He stayed calm when staff entered the room. Measuring his blood pressure and temperature went smoothly with no fight from Rowan. The IV insertion process was done without the need for an immobilizing board to restrain him.

Klayman says the Adaptive Care Team uses many techniques already in practice, but they individualize them to their patients. Visual charts help patients see the steps they'll go through during a visit. Introductions are initially adjusted, such as limiting socializing questions to those patients with little communication and social skills, entering the room slowly and quietly, and decreasing the number of staff in the room. Rather than expecting these patients to adapt to standard CCHMC procedures, Klayman says, they are adapting the procedures for the specific needs of each patient.

Klayman also navigates the complex system that makes up a large medical center. With Rowan becoming so wound up waiting in Admitting, Klayman arranged for what's called a "direct admit," so when he and his mom come in, they can go straight to their floor and bypass Admitting. She also worked to combine Rowan's procedures, thereby reducing the number of times he would need to undergo anesthesia.

Rewarding Results

"If we didn't do this, the results are lost productivity, a disrupted clinic flow, not to mention the extreme distress to the child and family," says Klayman. Outcomes are showing increased visits, higher patient and family satisfaction, and improved productivity.

Klayman is excited and encouraged by the work of this team of two. She actually considers the team to be much larger than that. She says anyone advancing the goals of ACT is part of the team. Many staff have already started re-evaluating and adapting their practices. Klayman envisions the ACT methodology to be the benchmark of care for patients with developmental and behavioral challenges. "To my knowledge, we are the only medical center doing a whole system approach for this population," Klayman says. But it's fast gaining national attention. She trained a hospital in New York last year on these techniques and approaches and has given several talks on the subject.

Klayman says of Rowan's advances, "It took more time and preparation initially, but he's more cooperative and relaxed now. We use fewer staff to administer the same care. We get better results all the way around." And the parents agree. Happily citing the lack of claw marks on her neck during Rowan's most recent appointment, his mom says, "It's made a world of difference to us."

volunteer and board member Jody Pohlman. "I have a stool I drag out by the middle of my shift." Everyone has her own strategy for keeping up with the fast pace: "My secret is my ugly shoes," confesses Gilsdorf.

While the daily responsibilities of running a retail store are unending, the consensus among volunteers is that it's extremely rewarding to interact with families and employees. "We have people who come in every day," says Pohlman. In fact, 85 percent of customers are medical center employees, ducking in for a quick shopping trip, buying

logo wear, scanning the newest toys and games, checking out the jewelry counter.

Helping Hand

And then there are the families of patients. "We never ask why their child is in the hospital," says Pohlman. "But sometimes they come to the counter, and they just want to talk." Inevitably certain families stay with the volunteers for years. "I remember one Christmas Eve years ago when a mother came into the shop. She told me it was her son's 11th surgery that

year and that no one had any time to go out and buy presents," remembers Gilsdorf, "I walked around with her, and we picked out stocking stuffers, presents and put it all into pretty gift bags. She was so appreciative. I've worked Christmas Eve ever since."

Members of the Junior Cooperative Society meet six times a year to discuss business and listen to educational presentations by representatives from various areas of the medical center. For more information, contact: 513-636-4310.