

Pediatrics/Neonatal

HANDLE WITH CARE

At John A. Coleman Schools in New York, school nurses help build collaborative partnerships with families of medically fragile children

BY SANDY KEEFE, MSN, RN

“When you work with children, you do so in the context of the family,” said Maureen Tomkiel, executive director of the John A. Coleman School at the Children’s Rehabilitation Center, White Plains, NY. “Nobody knows the child as well as the parents, who will be the advocates for their child for the rest of his life.

“Our first goals are to establish a collaborative partnership with the parents, and develop their ability to advocate for their child.”

Parent-Driven

For children with significant developmental delays, or diagnoses that put them at high risk for delays, the right supports early in life are critical for future success. From birth through 3 years of age, these youngsters are eligible for a federally funded program known as Early Intervention (EI).

While there are numerous models used to deliver EI services across the country, the programs through the John A. Coleman schools are among the most comprehensive. The White Plains, NY, location offers both home and center-based services, and the school located within the Elizabeth Seton Pediatric Center in Manhattan, NY, provides EI services in a classroom setting as well as individual sessions at the bedside of the most medically fragile children.

“We offer services in the natural environment of the child; for most children 0-3 years of age, that would be the home,” Tomkiel explained. “For children with serious medical issues, that’s not always possible.” [See **Natural Environment**]

EI programs are parent-based and parent-driven.

“The first thing we do when we meet with a child and his parents is to get to know them — their needs, priorities and concerns,” said Sue Hausch, RPT, director of rehabilitation at White Plains. “After we learn that, we can let them know how we can support them, teach them about what we can provide, and discuss the options for either community-based or center-based care. We customize services for families, instead of expecting them to fit into a particular program.”



EARLY INTERVENTION: Grace Schiavone, RN, plays the tambourine with John Victor at the John A. Coleman School’s Westchester Campus in the center-based Early Intervention Classroom. Early Intervention is a federally funded program that offers services to medically fragile children in both a classroom setting and at the bedside. *courtesy Seymour H. Burgess*



MEETING FAMILY NEEDS: Administrators at the John A. Coleman School first meet with the child and his parents to get to know them and their needs. They then devise a plan on how best to support that child, customizing the plan for that particular family. Early Intervention team members from the John A. Coleman School in Manhattan are: (from left) Sharon Herl, principal; Blanca Rodriguez, BSN, RN, school nurse; Rhina Cuevas, MMed, SAS, assistant principal; Ellen Ostrander, special education teacher; and Linda Iacobelli, educational therapist. *courtesy Seymour H. Burgess*

In This Section	
Handle With Care.....	19
Family Ties.....	22
Stopping the Cycle.....	24
A Complex Relationship.....	25

Evaluation

Rhina Cuevas, MEd, SAS, assistant principal in Manhattan, described the arena-style evaluation process that includes parent participation.

"EI is parent-driven and the parent is an important component of the evaluation process. Everyone sits together to assess and share information about the strengths and needs of the child and family," she said. "We let them know that the child impacts the family just as the family impacts the development of the child. Rehabilitation therapists then submit evaluation reports and the EI teachers complete a developmental assessment that includes a complete medical and family history."

Each child within the EI program receives services as outlined in a document known as an individualized family service plan (IFSP), which is developed in a joint meeting between the parents, an evaluation team or site representative, a service coordinator and a designee from the city.

Medical Component

Both the Coleman School sites provide a medical component supported by experienced and skilled nursing care.

"We attract more medically fragile babies exiting NICUs, including a large population of children who have been diagnosed with cerebral palsy, or who we feel eventually will be diagnosed as such," Hausch said. "We care for children with genetic anomalies, spina bifida and a wide variety of other developmental disabilities and complex medical diagnoses."

Tomkiel is proud to oversee one of only two programs in Westchester County that has a medical component. Maria Pici, MD, medical director at the Children's Rehabilitation Center, participates in multidisciplinary evaluations along with psychology, OT, PT, speech, audiology, assistive technology and special instructors, Tomkiel said.

"[Pici's] evaluation can be critical to diagnosis and treatment plans for the family."

Located in the same building as the Children's Rehabilitation Center in White Plains, EI program staff have easy access to medical specialists.

"We're well-known in the tri-state area for meeting the complex needs of medically fragile children," Tomkiel said.

Nursing Support

The expertise of school nurses at each site allows the EI programs to serve medically complex children.

"The availability of nursing services is very comforting and reassuring for parents of these children," Tomkiel said. "Because they know the children so

Natural Environment

When an infant or toddler qualifies for Early Intervention (EI) services because of actual or potential developmental delays, the goal is to deliver those services in the natural environment of the child. At the John A. Coleman School site in White Plains, NY, parents can select from two options.

"The largest percentage of our EI children are seen in their homes with parents or babysitters, but we also have a center-based program for those children who need a more intensive, structured program to give them a little extra push," said Sue Hausch, RPT, director of rehabilitation. "Parents make the choice for their children."

In Manhattan, the Coleman School program at the Elizabeth Seton Pediatric Center offers a center-based program for children who are able to tolerate the 2½-hour sessions. In addition, Linda Iacobelli, MS, an EI teacher and school psychologist, delivers a bedside program for those who aren't able to participate in the classroom setting.

"These children are generally bedridden, much more medically involved, and they receive 30 minutes at the bedside," said assistant principal Rhina Cuevas, MEd, SAS. "Their EI program is based in their bedrooms, which are their homes within one of the pediatric neighborhoods at our facility. As they become stronger, Linda starts bringing them down to be with the other children in the center-based program."

Family Involvement

Family involvement is a key component of every EI program.

"I show parents it's OK to hold the child in a certain way despite all the tubes and machines," Iacobelli said. "I model this and teach them how to talk to their babies, and play with them like they would their typically developing children. There's so much to see when you look at these children, and it's nice to bring those little expressions and subtle movements to the attention of the parents."

The EI teachers call each child's parents weekly to talk about how the child is doing in the classroom.

"That's a great opportunity for parents to ask questions, stay connected with the program, and be involved in the development of their child," Cuevas said. "We've found parents are much more willing to come in and visit the child because of that continuous contact."

Temporal Artery Thermometry

Proven Accuracy* with a Gentle Forehead Scan

- More accurate than ear thermometer
- Interchangeable with PA catheter
- Interchangeable with esophageal probe

NEW!
Silver Ion
Anti-Microbial
Head

A silver bullet against
microbes, including
MRSA and VRE

Accurate, Gentle, Cost-Effective
• Reduce thermometry costs by 90%

For your local Rep,
call **EXERGEN**, or email
medical@exergen.com
*Contact Exergen for studies

EXERGEN Corporation
400 Pleasant Street, Watertown, MA 02472
Tel: 800-422-3006 • Fax: 617-923-9911
www.exergen.com

well, they're able to identify small deviations from baseline, catching potential problems early on."

Lynn Nazzaro, RN, who works at the White Plains site, empathizes with parents.

"We all know how difficult it can be to let your kindergartner go off to school; here in our EI program, children may enter at 9-12 months old, so it's even harder for parents to let go," she said. "We encourage parents to stay at the center for the first couple of days, but they know one day they can leave their child here without worrying."

Grace Schiavone, RN, supervisor of school nurse services at the White Plains location, explained how nurses pave the way for that transition.

"We meet and interview parents, giving them information about our program and what we can offer their child," she said. "They're very concerned and want to know their children will be cared for, so they have to build trust in us."

"We work with them to determine what the child's needs are, and then we obtain physician's orders for medications, feedings, catheters, seizure care, nebulizer treatments and anything else the child requires."

Subtle Changes

At the Manhattan site, school nurses Dayra Lemay, BSN, RN, and Sharon Missan, RN, greet the children each morning as they arrive.

"We make sure they're OK to be at school, and then we suction them and

'We encourage parents to stay at the center for the first couple of days, but they know one day they can leave their child here without worrying.'

— Lynn Nazzaro, RN

transfer them to our oxygen system," said supervisor Blanca Rodriguez, BSN, RN. "We give nebulizer treatments, provide trach care, change trach tubes, perform chest physical therapy, administer enteral feedings and medications, change G-tubes, take vital signs, do skin care, and handle any nursing issues that come up."

Working in a setting where most participants are pre-verbal or non-verbal, EI nurses have to pick up on subtle cues.

"Once the children are here for awhile, we get to know them," Nazzaro said. "If an active, bubbly child who never naps is resting or sitting down a lot, or if a child isn't acting normally, the teachers will tell us. We'll take vital signs, do a head-to-toe assessment of the child, and call a parent," she continued. "Together, we'll try to determine what's going on with the child, and what the next step should be." □→

Expert Clinicians and Educators

At the John A. Coleman school sites in Manhattan and White Plains, NY, school nurses collaborate with colleagues from other disciplines to deliver an Early Intervention (EI) program devoted to meeting the needs of medically complex children from birth through 3 years of age.

"Our clinicians stay with us for an extended period of time, go through an extensive training process and participate in supplemental educational courses that deal with the special needs of premature infants, medically fragile babies, and ventilator-dependent children," said Sue Hausch, RPT, director of rehabilitation at the White Plains location.

Collaboration

Rhina Cuevas, MEd, SAS, assistant principal at the Manhattan site, described the teamwork that makes the program a success.

"We collaborate consistently with nursing, asking, 'How is the child doing today? Is he OK to participate? Do we need to wear a gown and mask in the room?'" she said. "There's a relationship one must develop with the nurses in order to work together at helping the children maximize their potential."

Linda Iacobelli, MS, an EI teacher and school psychologist, delivers one-on-one programs to the most medically compromised youngsters at the Elizabeth Seton Pediatric Center in Manhattan. She offers bedside activities that help increase the children's comfort level, including tolerance for nursing interventions such as feeding and suctioning.

"Many don't tolerate touch well, so I work on positioning, relaxing muscle tone, increasing relatedness — all of which might be reflected in changes in vital signs," she said. "Once I get them relaxed and to tolerate being held, I can encourage them to touch tactile toys using hand-over-hand assistance or get them used to tolerating sensation on their face and lips."

When children are able to leave their beds for short periods of time, Iacobelli offers brief respites from everyday life.

"I do a lot of singing and storytelling, bring them to the multisensory room when they're ready, and bring them to the baby group that meets on each floor for children who don't go to the school itself," she said.

Busy Classroom

When youngsters are stable enough to leave their neighborhood at Elizabeth Seton, they come to the center-based EI program taught by Ellen Ostrander, MA. She starts each morning with floor play, getting all the children out of their chairs and positioning them.

"Some are able to crawl around, while others are positioned so they can see, hear and interact," she said. "I may be working with a baby when a little boy crawls over. I'll ask him, 'Can you find me the big squeaky toy?' so that child is socializing with us. It's a very busy class with a wide range of abilities and ages, but it all flows together."

With backup from seasoned school nurses, the center-based program allows youngsters to enjoy life away from the bedside.

"When these children who are medically fragile and require other necessary equipment come down to the school and start walking around, Ellen gives them the permission, space and opportunity to really explore the room," Cuevas said. "She shares the message: Go explore what you're interested in and really want to do today!"



PLAY TIME: Joy Fairweather enjoys the bubbles being blown by Ellen Ostrander, MA, special education teacher, on the patio of the Coleman School Manhattan. The classroom at the school is filled with children with a wide range of abilities and ages, but it all flows together well, Ostrander said. *courtesy Seymour H. Burgess*

Collaboration with parents is essential. "If we have trouble waking the child up, we'll call the parent for more information," Schiavone said. "It could be that the child didn't sleep well at night, or that he has had a number of seizures over the weekend. We need to know whether we should wake the child up, or call the physician."

EI nurses maintain careful records on each child in their care.

"We ask parents to notify us of any changes, and ask them to have physicians provide written orders for those changes," Schiavone said. "We constantly update our information so we can provide accurate information to EMS personnel in an emergency."

'Our Children'

EI professionals develop close relationships with the families they serve.

"Many children from our EI program stay on with us through their pre-school years," Tomkiel said. "We also offer center-based school programs through age 7 and provide services in the community, with therapists and teachers going into the home and community-based schools to support children through age 21."

Many of these children are seen in the NICU by Pici, complete the EI program as babies, and then continue to be seen in EI clinics, Tomkiel added.

"They're our children." ■

Sandy Keefe is a frequent contributor to *ADVANCE*.



According to the
ADVANCE 2008
salary survey, male
nurses earn an average
annual salary of **\$53,792**;
female nurses earn **\$50,615**.

Will the salary gap widen in 2009?

Fill out our salary survey and find out soon!

Go to www.advancweb.com/nurses and click on Salary Survey, under Contests and Surveys. Fill out the survey by Oct. 15 and you'll automatically be entered in a random drawing for **\$100** (one survey allowed per person). Look for the results in our March 2009 Job Watch issue!



SPONSORED BY:



FAMILY TIES

Nurses caring for teens with trauma injuries must consider everyone involved BY AMY D'ALTO, MS, RN

It's a typical evening in the ED; patients are lined up in the hallway waiting for an assessment by a physician and nurse, or waiting for a bed. EMS calls in and notifies us of an 18-year-old male involved in an automobile rollover. He has stable vital signs. In 5 minutes, they arrive and EMS gives us the full report.

It's a level II pediatric trauma, and the trauma team arrives at the bedside, which is typical ED protocol. The patient remains on the long board with a cervical collar, in keeping with standard cervical-spine precautions.

The patient tells us about the accident. He was at work driving a golf cart when he lost control due to the wind and fell out and was pinned to the ground. He had no loss of consciousness.

Upon initial assessment, his vital signs are still stable, and he is awake and oriented to person, place and time. He complains of pain to his upper extremities, but full range of motion is noted with no obvious deformities. He also complains of numbness and loss of feeling from the nipple line down to the lower extremities. Examination of this area reveals priapism, no rectal tone, motor and sensory deficits of the lower extremities, including loss of reflexes.

This case is not so typical anymore. The patient repeatedly says he is