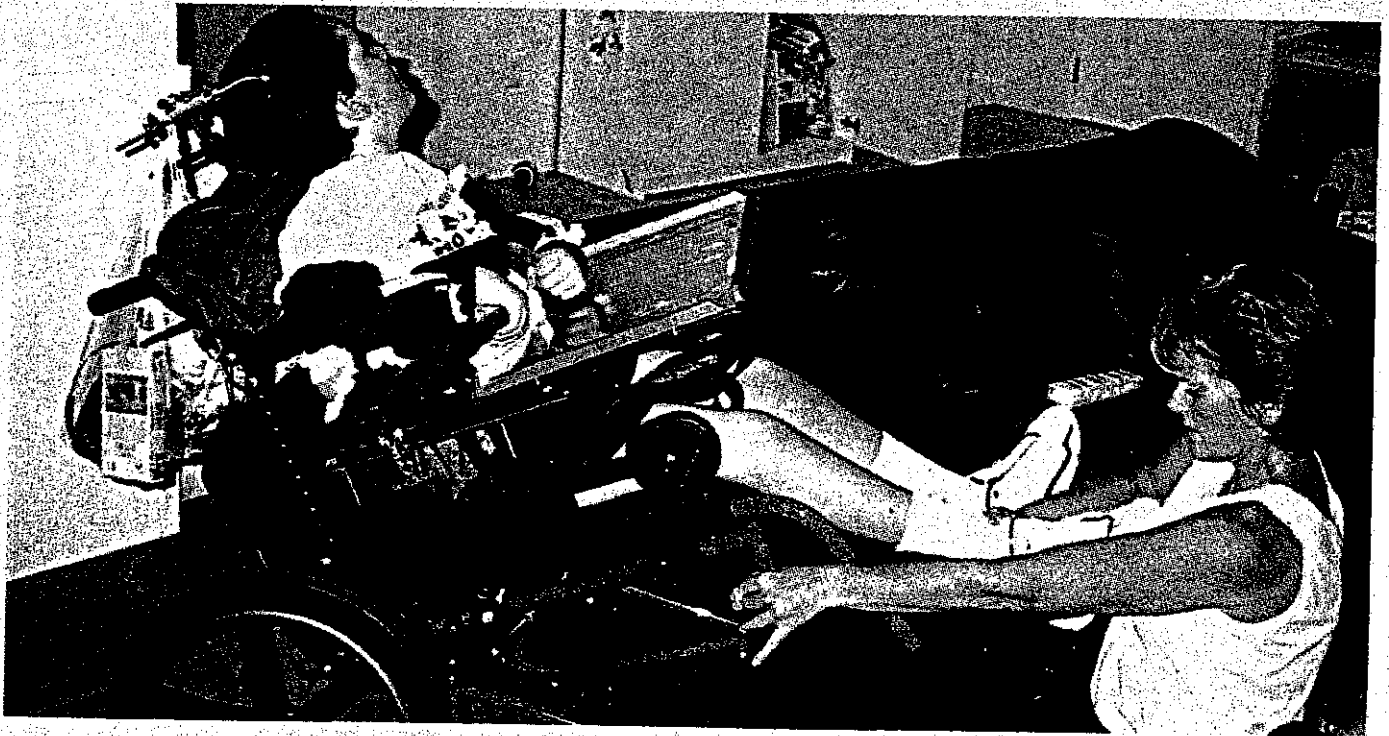


# Relief is in Sight...

**Parents of children with special needs have needs too**

*By Susan Frasca*



*Joey Delguidice, 14, enjoys the living room at the Coastal Kids Pediatric Respite Home with therapist Cecelia Meredith. The family-style facility, complete with a kitchen and four bedrooms, provides accommodations for overnight stays. Coastal Kids Pediatric Respite Home photo*

**P**arents of children with special needs encounter many challenges in their child's care and upbringing. Seemingly routine tasks such as eating and getting dressed can be stressful, social and recre-

ational outings even more daunting. These parents and caregivers frequently overlook their need to make time for themselves.

For 16 years, Margate resident Betty Annette Pequignot had never

left her 16-year-old daughter Melissa overnight. Melissa was the victim of a near-drowning incident when she was 2 years old that left her stripped of all motor skills, unable to speak and confined to a wheelchair. "I was

## Respite Care Services

### The Florida Respite Coalition

Provides information on respite care services throughout South Florida. For Broward and Miami-Dade counties, contact regional coordinator Doug Layer at 954-946-4805. In Palm Beach, contact Pat Simmons at 772-848-0304.

### The Broward Children's Center

*There is no income cap to receive respite services, which include 96 hours for the respite home annually, eight hours per month of services in the family's home and two drop-off periods per month. In-home services may have a small fee attached depending upon the family's income. If a family is eligible for medical waivers, they may qualify for additional hours of respite services. Private pay is accepted as well.*

For information on the respite services and the Broward Children's Center contact Linda Sachs at 954-783-5016.

#### Services provided

**In-Home Respite Care** — A qualified worker comes to the family's home. Up to eight hours of service provided monthly. A minimal sliding-scale fee is attached to this service and is based on income.

**Drop-Off** — A three-hour drop-off program available in one of two preschools operated by the Broward Children's Center. The preschools are specifically for special-needs kids and are located in Fort Lauderdale and Pompano. This service can be used one or two times per month.

**Coastal Kids Pediatric Respite Home** — Children with special needs are eligible to spend up to 96 hours annually for respite care in this family-style home. The time may be used in hourly or daily increments.

**Other** — The center also operates two preschools and three permanent residence group homes, a nursing facility, medical day care and a mobile clinic, and offers physical, occupational and speech therapy, recreational activities and a home health department.

### ARC, Palm Beach County

ARC, which began as Association for Retarded Citizens, but has expanded programs and dropped the name, serves about 270 families in Palm Beach County, offering each family an average of 100–120 hours of in-home respite service per year. For information on Respite Care Services in Palm Beach County, contact Jackie Rosen, coordinator of the Respite Program at ARC at 561-739-9313 or at the Boca Raton location at 561-391-1504.

always afraid to leave her, even with family members. It was too hard," Pequignot says.

Zorayda Matute of Pompano Beach was so absorbed with the needs of her 13-year-old son, Eric, afflicted with cerebral palsy, that she eventually became clinically depressed. "I forgot about my other relationships and myself. All of my energy was focused on different diagnoses, different doctors and caring for Eric," she says.

Linda Sachs, director of Coastal Kids, an in-home respite program at the Broward Children's Center, says that the need for respite care to take care of special-needs children while their parents or caregivers get some

time away is well-documented — and lacking.

But life for families experiencing the challenge of caring for a child with special needs can be manageable if families are aware of the services available to them.

The Broward Children's Center, a comprehensive agency that has served families with special needs for more than 30 years, offers a range of support services to make life easier for these families. The center's respite care program includes in-home assistance from specialized care workers, support group sessions, counseling and education, a drop-off service and

most recently, an eight-bed, pediatric respite home in Pompano Beach — all available through a grant from the Broward County Children's Services Board. The services are available to Broward County residents from birth to age 21 with documented diagnosable conditions — both medical and developmental — such as cerebral palsy, muscular dystrophy, respiratory disorders, mental retardation, autism, and mental health and behavioral problems.

Many parents understandably shelter and protect their special-needs child. "You just don't think that anyone else can take care of them properly," Jean Costa of Coral Springs says. Her 8-year-old son, Dylan, was diagnosed with autism and apraxia. Costa felt that a "regular" baby-sitter would have difficulties understanding his language and behavior. Judy Veliyathil, another Coral Springs resident, says she and her husband went out only for very special occasions because they weren't comfortable leaving their 9-year-old autistic son, Johnny, with a sitter. "We were, of course, concerned about him, and we also didn't want to burden anyone." For both of these women, in-home respite services provided relief with structured, competent care for their children. They are able to leave their child and siblings home with a qualified, trained caregiver while they run errands, go to a movie, out to dinner, or have a cup of coffee at a bookstore. "Initially it was difficult leav-



Deandre Stanley, 13, who has ADHD and nurse Cindy Goldberg join in group music and dance at the Coastal Kids home.  
Coastal Kids Pediatric Respite Home photo



At the Coastal Kids home, guests paint plastic letter blocks to form their names. Clockwise from bottom: Shaun William, 12; David Benndtt, 6; a volunteer worker; Patrick Mawby, 13; a volunteer, teacher Cindy Ancona; Robert Garcia, 8; and nursing assistant Juliet Joseph. Coastal Kids Pediatric Respite Home photo.

ing Dylan with a stranger, but I needed to step away from the demands of his disability," Costa says.

Before providing services, an initial assessment is performed by the Broward Children's Center to gain an understanding of the child's and the family's needs. Center staff members try to coordinate the best fit for each case and also try to consistently assign the same caregiver to a family home, when available, to increase the comfort level and sense of security for everyone involved. Families can also use a three-hour drop-off program at one of two preschools under the auspices of the Broward Children's Cen-

ter. In addition to the respite services, the center provides resources for families to connect with one another, support groups to help parents better understand their child's disability, and even sibling support groups. Veliyathil's 7-year-old son Tommy

attended a support group for siblings of children with autism. "It was helpful for him to see that there are other kids in the same situation as he is," she says.

Should a parent need to go out of town, want to take a minivacation, require an overnight hospital stay or just need a break, they can use the Coastal Kids Pediatric Respite Home for overnight accommodations for their child. What sets this respite home apart is its ambiance and professionally trained staff, Sachs says. The facility is an actual residential home, with a family room, kitchen, four bedrooms and a patio. It is wheelchair-accessible and has many of the usual amenities of home, including a television, VCR, computer, toys and a swing set. Staff members, including a nurse and social worker, prepare meals, conduct activity programs and are on site around the clock.

Since Pequignot had tried other services offered by the Broward Children's Center, she decided to try an overnight stay for Melissa while she and her husband enjoyed an evening out. Though she found it difficult to leave Melissa, Pequignot says that she was relaxed and enjoyed herself because she knew Melissa was in good and experienced hands. Melissa even indicated disappointment at having to go home, she says. Matute left Eric for a weekend while she and

Nurse Cindy Goldberg plays a floor game with 9-year-old Kailey Fontana, who was born with a rare genetic syndrome that causes retardation and other problems. Toys, a VCR, a computer and swing set help children feel at home. Coastal Kids Pediatric Respite Home photo





Osvin Salguero, 14, left, who has a treatable mental handicap, and Kyle Yazetti, who has muscular dystrophy, enjoy hanging out together during an overnight stay at Coastal Kids home.

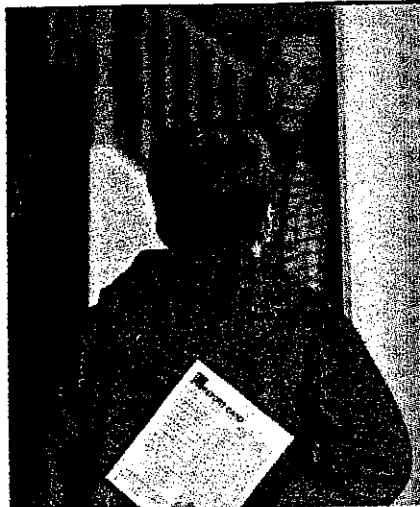
Coastal Kids Pediatric Respite Home photo

Eric's dad enjoyed a long-overdue vacation in the Florida Keys. He played board games and watched movies, much like any child attending a sleepover would.

Winthrop Cooke, supervisor of the Coastal Kids Respite Home, addresses any questions or concerns parents might have about leaving their child. Once parents call for an appointment, a preadmission meeting is arranged at the respite home with the nurse, social worker, child and parent. "We go over everything — medical needs, diet, sleeping habits, activities, likes and dislikes. It gives us a chance to get acquainted, and gives parents and child a chance to get used to the facility," he says.

Whatever type of respite service parents choose to use, the Broward Children's Center offers them a way to release, relax, recharge and reenergize. Costa says that when things are especially challenging, it is easier to cope knowing that there's a break coming. For parents of children with special needs, that break can make all the difference.

*Susan Frasca is a freelance writer and contributing editor. A mother of two, she lives in Coconut Creek.*



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