

Respite Cares! improved the quality of one family's life

By Teresa A. Parsons

For most of the past 12 years, Ruth Lill has been a prisoner of her son, Chester.

When he was a baby, she slept fully dressed for months at a time in case she needed to rush him to the hospital. Yet she has never taken so much as an unplanned walk around the block. And no matter where she goes or how carefully she plans, Ruth has never really been able to leave Chester behind.

Medically, he is termed hydrocephalic, which means he was born with too much fluid in his brain. As a result of his condition, he is developmentally disabled.

A year ago, the words "developmentally disabled" had little meaning for the Payne family. Today, they invoke a very real image — a shambling gait, sticky hugs and effusive, garbled speech — the generosity, determination and innocence that are "just Chester."

During the past year, the Paynes have become "almost like another family" for Ruth and Chester Lill. Roughly once a month, Chester spends a night or weekend with Gary, Ginny and their four sons, aged 4 through 12, providing Ruth with a break and Chester with a taste of independence and a "normal" life.

The Paynes and the Lills met through Respite Cares!, a Monroe Developmental Services program that tries to help families keep a developmentally disabled member at home by providing them with support and an chance to get away from the day-to-day demands of caring for that family member.

"I was never aware of what it must be like never to go anywhere alone, never to be able to get a sitter," Ginny Payne said.

To Ruth, it's as if chains are falling away from her arms and legs. For the first time, she can do the things "normal" people take for granted — shop, make business trips, go to a movie, even work late.

She can also spend time focusing on her other two children, aged 10 and 14. Respite means that Chester has a place of his own to visit while the rest of the family enjoys activities he can't — bike-riding or shopping or swimming — with a free conscience.

"I can't stand to leave him behind with a babysitter when we're all doing something together," Ruth said.

Leaving Chester behind wasn't her only concern. Qualified, caring sitters for Chester are hard to find.

"I'm not trying to put agencies down, but their services are only as good or bad as the people they send," Ruth said. "With an agency, there are no advance interviews, and you have no choice in who comes."

Respite Cares!, however, attempts to create an ongoing supportive relationship between the client and volunteer families. Both families are interviewed extensively, have a chance to meet and get acquainted beforehand, and have the option of backing out of the arrangement at any time without embarrassment.



Jonathan Payne, 6, describes his friend, Chester Lill, as cheerful, unselfish and not argumentative. He also likes Chester's toys. Jeff Goulding/Courier-Journal

Once a match has been made, arrangements between the families are flexible: The respite family is not expected to plan a lot of special activities, Ginny Payne pointed out, but just to include their guest in normal household routine.

For Chester, the normal routine of someone else's home is still an exciting adventure. "He thanks you for everything — even for cooking hamburgers and french fries," Ginny said. "He doesn't have any reserve. He's just honest and open."

"If more people knew about this, there's no reason to say no," she added. "It's just no big deal — we're kid-oriented anyway, so one more doesn't make much difference."

Although Chester's visits haven't proved burdensome to the Paynes, they have lifted a great burden from Ruth's shoulders. For her, the help came too late for her marriage and her job, but just in time to keep Chester at home.

"By the time you get to a Respite Care family, you're already broken and suspicious," she said. "I went to Monroe Developmental Center because I was ready to give up."

Although she has been through many

life-threatening crises with her son, most were when Chester was a baby and she was 10 years younger. "I don't know what kept me going," she recalled. "Maybe it was spite for awhile — kind of a 'I'll show them all' attitude — but even that wears out after awhile."

Two years ago, at age 10, Chester broke his leg by falling down the stairs of the family's Penfield home. From November to January, he was in the hospital. He then came home with a waist-to-ankle cast that kept him on his back until March.

When Chester's cast was finally removed, he had regressed to the point where he refused to even try to stand up. From March till June, the Lill household was augmented by a physical therapist and a visiting nurse. "I didn't know who was here most of the time," Ruth recalled.

This time, caring for Chester meant that Ruth had to quit her job as a columnist and reporter for Empire State Weeklies and postpone, for the second time, earning her bachelor's degree in journalism.

The stress of months of 24-hour care, of watching all her hard-won victories with Chester slipping away and of seeing her hopes for the future recede was compounded by the breakdown of the Lills' marriage.

After Chester was born, Ruth and her husband had responded in different ways — she focused on her child's direct physical needs, while her husband concentrated on paying the medical bills.

"If only we had had the strength and access to a Respite Care family for an occasional break in the confinement, to take a bike ride, to walk to the neighbors for a visit or even to sleep late on a Saturday morning," Ruth wrote. "I think back on those years of isolation as a terrible waste."

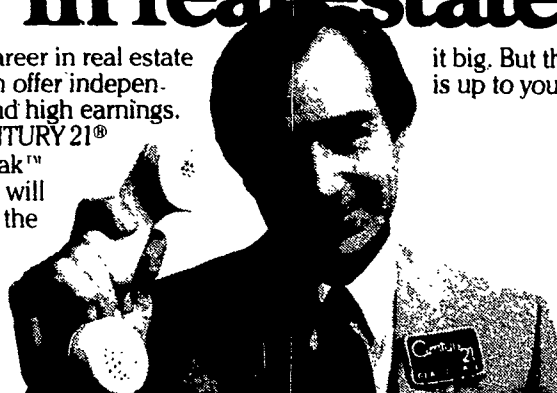
Ruth has since found a new job and resumed her pursuit of a bachelor's degree in journalism at St. John Fisher College. "I've been a junior for 11 years now," she joked.

Recruiting the help of supportive families to prevent the kind of despair and isolation

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