

# Respite home aids families with retarded children

By Carol Axilzen  
staff writer

Scotty ambled into the kitchen clutching his music box. Memorized by the simple tunes, "Row Row Row Your Boat" and "London Bridges," he showed his favorite toy to the visitor. With a sheepish grin, he clapped his hands, hoping she would enjoy the music as much as he did.

Leaving the toy in her hands, he wrapped his arms around her neck, then walked quietly out of the room. "That's his way of saying I love you," noted his mother, Jane Murphy of W. Bloomfield Township.

Scotty can't talk. He's not toilet trained and he can't dress himself. He performs cognitive tasks at the level of a 14-month-old.

The 14-year-old has been severely mentally impaired since birth. He suffers from seizures regularly. Sometimes, they're so severe that he falls and hurts himself.

Scotty's neurological disorders have caused a tremendous emotional and financial drain on his family. But his parents chose to keep him at home rather than place him in an institution or foster home.

"I (sending him away) never was a consideration for us," Murphy said. "Sometimes, I think I'd just play tennis all day if Scotty weren't home. But he's changed our priorities. He's showed our family how to love and lead a more responsible existence."

WITH THE help of staffers from the Wing Lake Development Center and her four other children, Murphy has managed to meet Scotty's needs.

But she needs a break to take brief vacations or sleep in on Saturday mornings, she said. Rather than complaining, Murphy joined with other parents from the Wing Lake center and the Oakland County Natural Family Support Group to find a solution.

The culmination of their five-year

long effort is a respite home, a temporary care facility for severely retarded children up to 18 years old.

The Macomb-Oakland Regional Center, a state agency, has agreed to set up and monitor Oakland County's first respite home at Lahser, north of 13 Mile in Beverly Hills. Staffers from the Detroit Baptist Children's Home in Royal Oak will provide supervision.

"This is a big triumph for us," Murphy said. "But it's been a long time coming. I really thought it would happen faster."

Murphy's struggle began seven years ago when she moved here from Marin County, Calif. Accustomed to a state-financed support system, she was shocked to find no respite care facilities in Michigan. (The Rose Kennedy Center in Wayne County, which opened nearly four years ago, was among the first.)

"There were so many support systems in California. It was a way of life. The state would come to your door and ask what services you needed."

"When I moved here, I (discovered) the mothers were reluctant to ask for help. It was as if they felt guilty about it. The attitude seemed to be, God gave them this child and they ought to be able to manage themselves."

"I figured if we say these things are needed, we'll be helping the state because the cost of placement (in institutions and foster homes) is so high."

MURPHY CONVINCED other mothers to take action. Together, they joined the Oakland County Natural

Family Support Group, which draws parents from the five development centers in the county: Einstels in Oak Park, Wing Lake in Bloomfield Hills, Hawthorne in Pontiac, Waterford Township center and Covadene in Farmington.

Scouting around for sites, they chose a Beverly Hills home owned by the Christ Child Society. For several years, the society operated a school for learning disabled children in the home and had planned to shut it down.

"We wanted a respite facility to be centrally located (to service all five development centers)," Murphy said. "We also wanted a homelike atmosphere, not an institution. This home, when fixed up, has good possibilities."

The parents hoped Macomb Oakland Regional Center would help them secure the home for a respite care facility. Instead, MORC decided to rent the former school and open a vocational center for retarded adults.

"It was already set up for a school," Murphy explained. "They didn't have to spend any money to change it."

STILL DETERMINED to fight, Murphy battled bureaucratic red tape and state budget shortages before winning her war.

"In the late 1970s, when the state had money, it was difficult to find a (sympathetic) ear in the legislature," she said. "Maybe it was because not enough people were asking for the service."

"People here (in Michigan) seem to be very conservative. It's difficult for

them to do something different even if it will help them."

While some parents fought for respite care, others lobbied for legislation to help pay the bills.

Winning the support of First Lady Paula Blanchard and C. Patrick Babcock, director of the Department of Mental Health, the group pressed for new laws to subsidize home care.

As a result of their efforts, a bill was signed into law by the governor last month. The Family Support Subsidy Act provides \$2,500 a year for families who are struggling to keep their severely disabled children at home.

According to State Rep. Debbie Stabenow, D-Lansing, the legislation's sponsor, the bill could save the state about \$47,000 per child each year. It costs the state \$50,000 a year to keep a child in an institution and from \$15,000-\$30,000 a year to place him in a foster home, she said.

FAMILIES MAY use the money to pay for medical bills, baby-sitters, wheelchairs, renovations to make homes barrier-free and respite care. The state subsidy ends when a child turns 18 and qualifies for federal Supplemental Security Income payments.

Although the Murphys aren't eligible to receive the state money (families with incomes of more than \$50,000 don't qualify), they still consider it a major victory.

"We can afford the things we need for Scotty. But some families can't. The costs are unreal. Just recently, I priced a potty seat at \$250. Some fami-

lies pay \$1,500 for specially-designed wheelchairs."

Medical bills for severely handicapped children are exorbitant, she noted. "Scotty sees a pediatrician, neurologist, orthopedist and ophthalmologist. Everytime something happens, he needs an anesthetic because he won't sit still."

"The last time he had his teeth cleaned and fixed, it cost us \$2,000. He suffered complications from the anesthetic and had to stay overnight in pediatric intensive care."

Despite the many trying moments, there are some joyous ones.

When Scotty correctly identifies the

picture in his book indicating he wants more oyster crackers (one of his favorite foods), his mother happily rewards him.

When his neighbors mow the lawn, he watches intently. "One neighbor told us Scotty was the only person who gave him a standing ovation for cutting the grass," Murphy said with a laugh.

And, when his family hops into the car for a ride, Scotty shows everyone how appreciative he can be. "He loves car rides," explained his mother. "He'll go anywhere."

"We're going to get him a job on a Greyhound bus that makes frequent stops at McDonald's," she joked.

## CPR session to be offered

A cardiopulmonary resuscitation class will be 7-10 p.m. Monday, Jan. 16, at the Whitman Center, 32235 W. Chicago, between Farmington and Merri-

man.

The American Heart Association of

Michigan will provide instruction in the life-saving method at a \$2 cost (checks are preferred). Preregistration is necessary, and should be completed as soon as possible.

For more information, call 425-2333.

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