

# Parents of the retarded want more help

By JULIE MACK

Terry Russo is bitter.

She adopted three Downs syndrome children — now ages 14, 9 and 5 — with the promise of help from the state. Now, she says, the state is reneging on its pledge.

"We adopted our children and we helped place other children under the idea that the state would provide some financial support and support services, and two years ago that was cut off," said Mrs. Russo, a Tottenville resident and member of the Staten Island Downs Syndrome Foundation.

"We've gotten attached to the kids and are not about to give them up, so we have no recourse. You could say I'm a little bitter. Other families who took these kids and really needed that support are really struggling now."

Although there are some technicalities that make Mrs. Russo's problems somewhat unique, her complaints about the lack of support services are not atypical among parents with retarded children living at home.

In some respects, parents face a far better situation today than 10 or 20 years ago. It has only been within the past decade that the state has really attempted to develop any kind of services at all for retarded children in the community. Before the 1970s, parents faced the bleak choice of putting their child in an institution or keeping the child at home with no support, except for the limited resources of a few non-profit agencies.

"It wasn't even an all-or-nothing situation," said James Walsh, acting director at the Staten Island Developmental Center. "It was nothing. If you kept the child at home, you had no support. Or you could put the child in an institution and almost lose the rights of parenting. And a lot of doctors recommended the institutions."

Now, families are encouraged to keep retarded children at home. Staten Island Developmental Center is not admitting new patients and the state will place

people in institutions, elsewhere only as a last resort.

Instead of institutionalization, the state is working with non-profit agencies to develop a network of support services for families with a mentally retarded child or adult. The services are coordinated by the Staten Island Borough Developmental Services Office, which also works to match families with programs that cover such things as counseling, medical and diagnostic help, education, infant stimulation, job placement, occupational therapy, parent support groups, physical therapy, recreation and residential services.

Two services garnering great attention in recent years are the homemaker and respite programs. The homemaker service sends nurses and nurses' aides to homes on a regular basis to provide a helping hand for parents. Respite offers overnight care of a patient in times of illness, family crisis or just to allow for a vacation.

Staten Island has the largest homemaker program of any county in the state, serving about 160 families. Respite service is also offered here through the Staten Island Developmental Center and Volunteers of America. The agencies can handle a combined total of a dozen clients. In addition, SIDC operates a daily drop-in center, open from 8 a.m. to 8 p.m. seven days a week, with a capacity for 12 clients.

"I think we're doing a good job with support services," said Walsh at the SIDC. "The network is functioning, although it has to be expanded on all levels."

But some families who rely on those programs say they are inadequate, and people note that few options are available if they

become overwhelmed by the demands of a retarded family member. Parents could turn to state institutions in the past, but that is no longer a feasible alternative for long-term placement.

Indeed, one state official said she has heard from some parents of former Willowbrook patients who said they would not have agreed to the Willowbrook consent decree — which forced a drastic reduction in the facility's population — if they had anticipated the consequences: that their children would be sent home from the Staten Island Developmental Center with a minimum of follow-up care and support from the state.

"Now people are realizing that institutions are not good places," said Genevieve Benoit, chairwoman of the Staten Island Council for the Developmentally Disabled. "But on the other hand, families are now experiencing the same stresses that led people in the past to place their children in institutions."

"There are times when a family is experiencing so much stress that the family unit breaks down, and you need to remove the handicapped family member so the family can regroup. In situations like that, short-term placement might be good. But SIDC is closed to new admissions, so there's nowhere to place people on Staten Island.

"We had situations last year with families with multi-handicapped children where they had to go to other boroughs or other states for placement," she said.

Another option for people who cannot care for their retarded child is to surrender their child to foster care. While that puts the child in a homey environment, it can also bring on tremendous guilt feelings for the natural par-

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ents.

At the same time, nobody is suggesting that new institutions be built or that SIDC accept new admissions.

But many say that if the state wants to tear down its institutions, it must provide another system in their place to adequately fulfill the needs of New York citizens. And they are questioning whether the state is moving fast enough in that direction.

"Getting people out to the community is good, but there has been no follow-up," said Mrs. Russo, who adopted the three children with Downs syndrome. "Now that they want people in the community, they need to support them in the community. They say that there are the support services, but try to get it.

"There's not enough of the homemaker services — there have been a lot of cutbacks in the time spent with each family each week. I think they need to provide financial support and more back-up supports like recreation and education — many of these kids don't fit into the public school system."

"There's a lot of pressure to keep kids at home, and I don't really think that is fair," said another parent, Polly Panzella.

She put her 25-year-old mentally retarded son in a residential school upstate because she thought he could not function well in an "unprotected environment." Group homes, just as her own home, did not offer that kind of sheltered environment necessary for people like her son, she said, and she is angry that the state does not operate facilities like her son's school.

"We need options," she said. "Group homes are ideal and we should have a lot more, but we need more options than that, and

we have no options."

Yet the deficiencies in state services are not just the fault of the state, said Gerald Spielman, director of the Elizabeth W. Pouch Center for Special People, in an observation echoed by Mrs. Panzella.

"I don't think anyone is doing an adequate job with support services," he said, "but some parents look at a service, hang back and don't get involved.

"Fifteen years ago, parents who had nothing banded together. We don't see the same drive now. Parents who fought for these things in the past are tired. But the tendency among younger parents is to let professionals do it all, and most legislators will not listen to professionals — they will listen to parents.

"The mental retarded lobby is very small and very weak. Until we get some effective lobbying, the Legislature is not going to listen."

Midge McGraw, spokeswoman for the state Office of Mental Retardation and Developmental Disabilities, said that there is recognition in Albany that more needs to be done for families with mentally retarded children living at home.

"To a degree, the state has to do more to keep children at home," said Ms. McGraw. "The governor responded to that need by introducing program legislation, but that was never acted on. We will continue those attempts next year. The governor recognizes and we recognize the need to concentrate more on support services."

Less optimistic, Assemblywoman Elizabeth Connelly said she fears a "regressive" era.

"I thought we were making great progress for the mentally retarded. Slow, yes," she said. "But without the support services, these things break down. We'll have to deal with crisis after crisis.

"Under the current situation, I'm apprehensive."

(This is the fifth article in a six-part series.)

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