

'Now people are realizing that institutions are not good places. But on the other hand, families are now experiencing the same stresses that led people in the past to place their children in institutions.'

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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