

Study finds autistic care is lagging

By BRUCE ALPERT

The overwhelming majority of autistic youngsters do not receive anything approaching adequate care, according to a report released today by an independent watchdog agency.

The report, prepared by the State Commission on Quality of Care for the Mentally Disabled, said the state has failed to even identify more than 80 percent of the estimated 5,000 autistic children in New York state. On Staten Island, the report said the state has only identified 12 of the borough's estimated 100 autistic youngsters.

The vast majority of the unidentified autistic youngsters are believed to be either unserved or underserved by the present service-delivery system.

Autism is a developmental disability characterized by social withdrawal and limited language development.

"The autistic person is in a minority among human-services constituencies and suffers the same fate as other minorities — lack of knowledge and understanding of condition, discrimination in funding and lack of access to necessary services," said Clarence J. Sundram, chairman of the commission.

Among the findings of the 84-page commission report are the following:

¶ The autistic are a small minority in a service-delivery system that is driven by the needs of other larger and better-organized groups of the developmentally disabled and their families. Their special needs have been largely ignored by the system.

¶ Families are left to negotiate the maze of specialized services needed by their autistic children without any assistance. Usually, they must choose between varied services that do not meet the specific needs of their children.

¶ The type and quality of services available depends upon where a person lives. As a result, the autistic are made to fit into existing programs, designed to meet the needs of others rather than their own specific needs.

¶ Although four agencies — the Office of Mental Health, the Office of Mental Retardation and Developmental Disabilities, the Department of Social Services and the state Education Department provide some programs for the autistic, there is no effort to coordinate their services.

"If there is a rhyme or reason to the efforts of the (state agencies), clearly it is not perceived by most persons working in the field," the report said. "Instead, their people see a confused and unresponsive state structure

which serves more as a barrier than a facilitator to the effective delivery of services."

Among the recommendations made by the commission is legislative approval of an appropriate program to conduct an intense campaign to identify individuals with autism. Unless the autistic are identified, the report said, the state will never be able to provide appropriate services.

In addition, the report suggests that families of the autistic be given access to state-operated programs and services outside of their communities.

The report notes, for example, that only four developmental centers, including the Staten Island Developmental Center, Wilton Brook, offer any services for families of autistic youngsters — although there is a substantial need for such programs.