

Confusion in state programs may be a sign of the 1980s

Ironically, the aging-out crisis results from the state's attempt to improve services for the handicapped, professionals in the field say.

That also explains why aging-out is a relatively new phenomenon.

"In the past, there was nothing to age out from. There were no adolescent programs or anything like it," said Manhattan Assemblyman Steven Sanders, chairman of the Assembly subcommittee on human rights.

Before the mid-1970s, families with handicapped children had two choices: They could place their children in an institution like Willowbrook State School for lifelong care or they could keep the child home without support from the state.

But in 1975, a federal law took effect which guaranteed a "free appropriate public education" for all handicapped children between the ages of 5 and 21.

As a result, state and local education departments assumed responsibility for disabled youngsters by providing special education classes. Now, in cases where the child is so severely disabled that residential placement is required, the state will pick up the bill — even if it means placement at a private or out-of-state facility.

But that service and those funds are cut off when the client turns 21. At that point, depending on the client's disability, he is referred to the state Office of Mental Retardation and Devel-

opmental Disabilities, the Office of Mental Health or the state Education Department's Office of Vocational Rehabilitation.

However, programs run by those offices are limited and young adults must compete with an increasing number of older clients who are coming out of institutions and who need service.

"It's a very simple pattern," Sanders said. "Here's a person receiving a variety of therapeutic and educational modalities, and then when he turns 21, the treatment ceases. The parents' problem is to find a new program that meets their child's needs, but there are very few programs."

The aging-out problem was first identified in families with youngsters placed in private or out-of-state residential schools. When the funding was cut off at age 21, the person often had no place to go.

Sometimes, the families' only option was to bring the child home. But that could be a traumatic experience for a family ill-equipped to deal with multiple handicaps.

"A lot of kids came back and the parents couldn't cope," said Mickey Marlib, executive director of the Association for Children with Retarded Mental Development, which operates a workshop on Staten Island. "I've seen mothers who've had to give up their careers because a kid needs supervision. I've seen marriages split up because of the pressures."

Marlib said the problems are particularly troublesome for families with a child whose handicap includes a behavioral disorder. "These kids are really lost souls," he said. "They end up in homes where the parents can't deal with them, or then end up in the streets or the penal systems."

The problem has been somewhat alleviated by legislation approved last year, which provides funding to keep handicapped people in residential schools after they turn 21 if an alternative program is not immediately found.

Sanders, who sponsored the bill, is now pushing for funding for handicapped people living at home who are having trouble finding an adult program.

Yet Sanders admits the real key is not funding for the young adult caught between programs, but money to expand the programs for the adult handicapped. "Hopefully, we're forcing the state to address the overall problem," he said.

"It's absolutely a question of dollars. There are people in government who honestly believe that if we don't provide money for the service, then we save. But somewhere down the line, the need for service will crop up, only in the form of prisons or welfare or placement in an intensive care facility.

"To people who say we can't afford to do this, I say we can't afford not to."

— JULIE MACK
Advance Staff Writer