

The problem with growing up

By JULIE MACK
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For people like Sonia Braniff, a daughter's 21st birthday inspires fear rather than celebration.

Mrs. Braniff's daughter, Lynne, who has cerebral palsy, is a 17-year-old student at Susan Wagner High School. But when her 21st birthday arrives in four years, and she is forced to leave Susan Wagner, Lynne may have no place else to go.

There are few adult programs in the city which suit Lynne, Mrs. Braniff said. Lynne's abilities are such that she resists the idea of a sheltered workshop for the retarded. "She says she is not going to go to a 'dumb work-shop,'" her mother said.

There is a program in Manhattan, Job Path, which might be appropriate. "But I may have to give up my own employment in order to transport her, which I would do," said Mrs. Braniff, who is coordinator for the Board of Education's Project ROPO (Reach Out to Parents Office), which serves families of the handicapped.

The term 'gap in services' cannot adequately describe the nightmare that some families face when they discover their children can no longer participate in one program and have no alternative to take its place.

But Job Path may not have the space for Lynne. "The programs like that are few and far between and they can only serve so many," Mrs. Braniff said.

When Lynne turns 21, she will face a problem shared by more than 1,000 people every year in New York State. The problem even has a name: Aging out.

That refers to the gap in services which exists for many disabled people when they reach their 21st birthday. But the term "gap in services" cannot adequately describe the nightmare that some families face when they discover their children can no longer participate in one program and have no alternative to take its place.

The situation occurs because different agencies work with handicapped youngsters and handicapped adults, and the programs are rarely coordinated.

State and local education departments have programs for handicapped youngsters. But when a client reaches 21, he or she is referred to the state Office of Mental Retardation and Developmental Disabilities (OMRDD), the Office of Mental Health or the state Education Department's Office of Vocational Rehabilitation.

But the young adults must compete with other older adults for a limited number of program openings.

Also, social service professionals say, the programs for people under age 21 are more specialized and tailored to the clients.

For example, the Mission of the Immaculate Virgin at Mount Loretto, Pleasant Plains, runs two residential programs for adolescents who are "dual diagnostic" — both mentally retarded and mentally ill. Some of the youngsters in the Mount Loretto programs are also physically handicapped.

In contrast, most of the programs available to adults are either for people who are retarded or mentally ill. When he turns 21, the Mount Loretto client must be "assigned" to either the state Office of Mental Health or the Office of Mental Retardation and Developmental Disabilities. There is no halfway ground.

"It's almost like we have to

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say something is an apple or an orange, when it is really a hybrid," said James O'Day, supervisor of Mount Loretto's critical level unit, the school's program for dual-diagnostic youngsters.

"Sometimes the kids are not mentally retarded enough to place in a facility for the retarded, and they are not mentally ill enough for a mental health facility," said Donna McMenantin, program director of Mount Loretto's critical level unit. In either case, she added, the client may need some kind of aid.

The options, O'Day said, are limited.

There is a program in Queens for dual-diagnostic patients, but space is limited. Mount Loretto also has clients at a workshop for the retarded on Staten Island, although the workshop is not equipped to deal with the needs of a person who is mentally ill, O'Day said.

In response to the problem, Mount Loretto has developed new, more adult-oriented programs to serve the increasing number of dual-diagnostic clients who are 21 years old and have nowhere to go.

Besides the lack of day programs, there is also a shortage

of beds in residential facilities, service agencies said.

"It's extremely difficult to find space, especially if there are any special needs that the client has," O'Day said. "I think for most, they'll find places eventually. Whether it will be an ideal placement is another question.

"Obviously, we'd like to keep them here as long as possible rather than avoid placement that is inappropriate."

One bright note is that the state now continues funding for clients at Mount Loretto and other residential facilities who pass their 21st birthday. Last year, the state Legislature approved "transitional funding," which allows handicapped people to stay where they are until they can be appropriately placed.

That kind of funding is not available for handicapped youngsters who live at home.

For those at home who are only mildly handicapped, Mrs. Braniff said, there are few day programs that are available.

"For instance, in OMRDD there are the sheltered workshops. Many kids function higher than the kind of training provided by the workshops, but they

are forced to go in because there is no other choice," she said. "There are not enough programs to train people for competitive employment."

While transitional funding for community clients could help — some legislators already have sponsored legislation to provide such funding this year — that is only an interim solution, Mrs. Braniff said.

The real answer, professionals agree, is the expansion and increased specialization of programs for adults so that handicapped youngsters now graduating from the school system have some place to go.

Many state officials don't argue with that proposition. But, faced with a court-ordered emptying of state institutions and demands for more service from older handicapped people living at home, state officials say their hands are tied.

"Across the board, we need many, many more beds," O'Day said. "I would guess it would take four or five years — maybe not even that soon — to really create enough beds to fill the need. And the population is constantly growing."

"And they are gearing up, but that takes time," Ms. McMenantin said. "The problem is right now. The kids need programs right now."

(This is the final story in a four-part series.)