

'Average' lifestyle is achievement for retarded

By JULIE MACK

Betty functions much like any other adult. She has her own apartment. She cleans house, cooks, figures out her budget, takes care of her child.

If you saw Betty at the food market or in the laundromat or at a department store, there would be little to merit a second glance. She blends in. She is average.

And that is exactly what Betty wants.

For her, "average" is not a lukewarm word denoting a gray, colorless existence, but a chance to participate in the kind of lifestyle that most people take for granted.

Betty was almost denied that opportunity. Handicapped by mild mental retardation, she spent about 20 years of her life in Willowbrook State School (since renamed Staten Island Developmental Center), trapped in an environment that offered her little opportunity to develop her talents, her personality, her self-worth.

Released in the aftermath of the Willowbrook Consent Decree, a pledge by the state in 1975 to offer Willowbrook patients better care, Betty (not her real name) is now in her mid-30s and lives a near-independent life on Staten Island. She is a successful example of the "normalization" process.

Normalization is not possible for all mentally retarded people — there are some persons who will always need supervision and are incapable of any independent living. But statistics show that only 10 percent of the developmentally disabled population is severely or profoundly retarded. The majority of the other 90 percent is capable of living a near-average life.

But it is not easy, and the process of removing restrictions to allow clients to live as average a life as possible has been fraught with controversy.

For one thing, there is the definition of "normalization." A recent conference in Manhattan drew experts from all over the country to discuss that very issue, and in three days of discussion it became obvious that normalization means different things to different people and for different people.

Moreover, professionals in the field are becoming increasingly aware that moving a mentally retarded person from the institution into the community does not necessarily insure that normalization will occur.

"There is something we forget," said Dr. Francis Berko of the New York State Office of Advocates for the Disabled. "While normalization can never, never occur within the traditional setting, de-institutionalization and normalization are not necessarily synonymous.

"Some of the standard practices done in the name of de-institutionalization — is it really teaching a normal lifestyle? Is it really giving someone the fullest opportunity to be productive?"

"Many group residences that exist today have fallen into the same mini-institution role that fosters dependency," noted Madeline Greenbaum, director of adult education at the Elizabeth W. Pouch Center for Special People, formerly the Staten Island Center for Developmental Disabilities. "Staff finds it easier to do things for clients rather than let the client do everything he can.

"I've seen it both with homes operated by the state and those operated by voluntary agencies, perhaps more with the state-op-

erated homes because they are staffed with employees who used to work at the big institutions. It's hard to change that institution psyche."

But even with the best of staffs, state regulations can make it difficult to achieve maximum normalization in a group home.

Keith Penman, regional director of United Cerebral Palsy of New York State, noted clients are mandated to participate in six hours of programming on weekdays plus organized recreational activities offered by the group home. "We don't have a lot of choice but to comply," said Penman, "although we have some clients who are elderly — like 72 years old — and they just aren't up to that much activity."

"I realize why the rules were imposed — you don't want people to just sit around," said Mrs. Greenbaum. "But at the same time, you are creating a mechanical situation which is not normal when you come home and you have to be programmed whether you are tired or not just because it's the regulations."

Yet while many experts in the field advocate that each retarded person be placed in the least restrictive environment possible, professionals acknowledge it is not always easy to balance the

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question of freedom versus the very real need for protection.

It is a question of "dignity of risk," according to Gerald Spielman, director of the Pouch Center.

"All adults take risks," said Spielman. "But the question of allowing the mentally retarded to take risks is very difficult for professionals, and not without reason. People can be taken advantage of, hurt or lost. Still, the retarded person can also be taught responsibility. Then the limitations become individualized rather than stereotypes imposed on a group."

Yet who is qualified to make those decisions on individual limitations? "Does the group home staff have the discretion to make sophisticated choices on when to take risks?" said Mrs. Greenbaum. "It's a fine line on what to do. Normalization is still an ideal."

Questions surrounding normalization become particularly tricky when dealing with issues like sex, marriage and parenting.

That the mentally retarded have a sexuality has only been acknowledged and addressed in recent years, and there is now a movement to provide sex education for moderately and mildly retarded adolescents and adults.

"The new philosophy is not

necessarily to endorse sexual intercourse for the retarded, but to acknowledge that these people do have sexual feelings and to teach them how to cope with that," said Mrs. Greenbaum. "That means teaching them how to say no, and some values clarification."

It is also necessary to provide simple, straightforward information for the protection of the retarded adult. One professional told the story of a young retarded woman who was talked into sex and never realized the meaning of the act. The woman blithely explained that her mother told her never to let a man touch her breasts or her legs, and the man involved did not do that.

As for marriage, Mrs. Greenbaum notes that statistics show that marriages between mentally retarded partners are no more likely to end in divorce than marriage between people of average intelligence.

"I think marriage for the mentally retarded is generally a good experience," she said. "It gives them the same fulfillment as the average person, and they can maintain the marriage with support services."

The question of retarded persons raising children becomes more complicated. Studies indicate that children in such homes often lack proper stimulation,

that parents lack coping skills and the economic burdens are often oppressive. Many professionals advocate counseling programs for mentally retarded couples to point out the difficulties of parenting and explain the option of remaining childless.

But in the end, most professionals agree, these decisions should not be forced on the mentally retarded.

"If there is a difference in philosophy now, it is that we are looking at the whole person," said Joan Hodum of Staten Island Aid. "I think the word I really like to emphasize is habilitation, to life and for life, and that means more than screwing together pens in a workshop. It's the whole world of socialization and building as many strengths in the person as possible."

"The issue, of course, is freedom," said Dr. Burton Blatt, the keynote speaker at a recent Manhattan conference on the mentally retarded.

"Our main goal was never to help the individual get a better job or achieve at a higher grade level. While all these matters are terribly important, it's not the issue. The issue was always freedom."

(This is the last in a series of six articles.)