

Leaving Willowbrook: Adjusting, surviving

By JOAN MOTYKA

As the prisoner of war returns to the American mainstream he finds the first few steps the hardest. All that he has known before is marked with the experiences of his captivity and all of his prison life tinged with remembrances of an earlier time.

But for the institutionalized person out on his own for the first time, there is no past tense that must be compared to further past tenses.

For the person who has always lived behind the walls of Willowbrook State School there is no "was" to be compared to "had been."

There are no remembrances of what it was like to be a member of a family, to wake up late on a Saturday morning to a make-shift breakfast, to know, by heart, the Old World stories of a grandmother.

There is, instead, Willowbrook. Five-thirty a.m. wake-ups, rushed feedings, attendants' faces shifting three times a day.

There is nothing beyond the walls to compare it to.

The returning prisoner of war knows at least that his captivity has ended. For the person who has been imprisoned in an institution, the release may be just as difficult, if not more so, than the captivity.

Rather than being a prisoner of war, he is instead a prisoner of attitudes and prejudices. Critics of institutionalization claim society puts out of its sight those who cannot conform to its standards of production, performance and appearance.

To help Willowbrook residents move into the community and adjust and survive, once there, the Community Services Unit (CSU) was created at the state institution.

According to a CSU report, "frequently institutionalization at Willowbrook occurred not especially to meet the needs of the individual in question, but rather because he could not

meet often — compulsively adhered — to levels of performance pleasing to others in his environment, and most often not attainable at that particular time by the person in question."

This type of thinking led to the institutionalization of mentally retarded persons who would have fared better with individualized care.

In addition, it led to the placement in state schools of people who were not retarded at all: Cerebral palsy victims, neglected children, the blind, the deaf, hyperactive or psychotic children, many with minimal brain damage, many simply with poor motor coordination.

The Community Services Unit agrees with Eric Fromm in thinking that "our economic system must create men to fit its needs so pressures for social conformity are tremendous and the deviant have hardly a place."

It is society which designated "deviants" and "normal" people. There is "something wrong" with the child who is not toilet trained or cannot read or talk by a certain age, and these standards are established for the entire population.

The Community Services Unit believes in a developmental approach to dealing with the disabled. This approach tends to view a person as going through different stages of development at his own pace and in his own way. Any measure of development must be focused on the individual rather than a norm.

A basic tenet of CSU is that "individuals must be allowed the freedom to grow at their own rate, and be given the help to do this — and not be considered failures as human beings if they progress slowly."

In addition to the developmental approach, CSU believes in the normalization principle: That "organisms thrive best in

an environment that is 'normal' to their growth."

Society has traditionally defined what is normal growth and what the parameters of normal environment are: First the family, then the home and community, then friends, school, work, often independent living and then possibly marriage and children.

The developmentally disabled are often denied the chance to grow up in what society calls a normal way. They are often viewed as less human and less worthy, and more in need of control. The institution solves the "problem" of what to do with them.

The Community Services Unit is "committed to providing for each developmentally disabled human being the most normal environment possible conducive to the growth of the individual in question."

Philosophically, CSU opposes institutional care because of its dehumanizing and life-threatening effects. It cites an unpublished 1966 report by the Massachusetts Department of Health in which life expectancy and death rates in convalescent and nursing homes in the state were studied.

It was found the life expectancy of an individual patient was cut by two-thirds through the act of institutionalization as compared with individuals of the same age with the same illness who remained at home. Some norms of institutionalization are acceptable to CSU, but only if the institutionalization is focused on short-term need that cannot be provided outside an institution and if it does not destroy the individual's ties in the community with his family and friends.

(This is the first in a series of articles.)