

From darkness and silence... a mind can reach out

By JOAN MOTYKA

In the crispness of an early spring morning, the sounds of playing children swell the air with a contagious vitality. The voices rustle in the tree breezes, they blend with the smell of trees and flowers and the mixture intoxicates.

For the child who can neither see nor hear, the morning play means the feel of sun warmth on a bare arm, the scents of a greening world, the taste of a blade of grass.

For the child who is blind, deaf and retarded, the tastes, smells and feel of the morning take on another dimension — a dimension entirely different. If the child has grown accustomed to sitting in a corner of a urine-smelling ward in an institution, where the time of an attendant is overwhelmed with the care of 40 or 50 other youngsters.

An innovative program now under way at Willowbrook State School for deaf-blind-retarded children has opened a larger part of the world to six of these youngsters.

Under a special grant from the Regional Deaf-Blind Center of the Department of Health, Education and Welfare, Willowbrook has undertaken a program to train three psychiatric attendants to work with the children and to hire a half-time social worker who paves the way for the return of the children into the community.

In a classroom for five days a week, from 8:30 a.m. until 3 p.m., the trained teacher aides conduct a therapeutic program of habilitating the children on a nearly one-to-one basis.

Ranging from muscle exercises to water play to texture identifications, the exercises are structured to heighten the sensitivities the children already have and to allow the children to progress to tasks they will need when they are in later stages of schooling and when they are at home or in the community.

A young sighted child in learning the basics of independence finds it is a slow process to get the knack of dressing and undressing himself, eating with utensils, using the toilet, tying his shoelaces.

Yet if he can see, he can model his actions on the examples that are shown him. He sees that his mother holds a spoon in a certain way, and how she moves it to her mouth. If a child can hear as well, he can hear the instructions and see them being implemented. The child who is blind and deaf learns through the senses he has: Touching, tasting, smelling.

When the basics are learned, he can go through further schooling to unfurl more of the world.

The HEW grant allows for the training of six children a year at Willowbrook. In addition a working relationship has been established with the New York Institute for the Education of the Blind in the Bronx, where the children will go after they finish the Willowbrook program.

The ultimate outcome of the program is to return the children either to their own homes or to establish them in foster homes. They will take therapeutic classes and live at the Bronx school during the week and return home on week-ends, holidays and during summer

vacation.

There was a great deal of hesitancy on the part of the parents to reinstate their deaf-blind-retarded children into their families.

For the parents who were advised, years ago, to place their children in institutions, the about-face caused psychological and practical problems.

MANY QUESTIONS

Could they provide their children with the care they required? Would the added time the parents had to spend with the deaf-blind-retarded child disrupt the families? Would the other children in the family resent it?

Complicating these problems were the practical issues: How would they transport the children from the Bronx school? How could they best continue the toilet-training and self-feeding programs at home? Could they get financial

assistance? How could they find, and then support, a larger home that might be necessary?

Many of the parents had undergone family break-ups; some had divorced and then remarried. How could a deaf-blind-retarded child fit into the new setting? Would the other members of the new family be responsive?

The part-time social worker who was paid through the grant helped work these problems out with the parents. In addition, to help relieve the fears and worries, the Central Habilitation Service unit at Willowbrook prepared an instruction booklet for the parents.

What the child needs is a combination of love on which he can depend and the freedoms

and skills to become independent. It is the parents who can provide this better than anyone else, the booklet stresses.

What the parents need are the qualities of a saint to cope with the constant teaching, the day-by-day dilemmas and the problems that might arise internally within the family.

Yet the booklet reassures the parents: If saintly qualities are required, then the parents shouldn't feel bad if they fall short in any of these categories.

SOME ANSWERS

The booklet was written by Dr. Manny Sternlicht and Ina Sullivan of Central Habilitation Services at Willowbrook in response to the many questions parents raised.

It suggests that a parent put aside some time each day that he can devote totally to the child, claiming "It is better to have a little time that is all his and yours together than a lot of time that is never really his alone."

Warning against comparing the child to the other children in the family, it takes a developmental approach, where the child is seen as unique, not to be compared to anyone but himself.

"He is unlike any other child, even another deaf-blind child, and his development is all his own. Compare him to himself, to his performance last year or the year before rather than to his siblings and you will see the increase he is making in his skills in living," it reads.

The booklet stresses that parents should not set their expectations too high, and that they should "try to find experiences for him that make use of and stimulate the senses he has."

For example, the world of smell is open: There are flowers, the beach, foods, freshly cut grass, gasoline in the filling station, soap.

And the tactile world, too: Let the child feel cold glass, grass and bushes; textures in the house, furniture, walls.

For beginnings of communication with the child, the parent can hold the child's head close to his chest when singing, humming and talking, so the child can feel the vibration. The booklet also claims the child will enjoy the vibration of musical instruments, such as the guitar.

TEACHING METHOD

It suggests a step-by-step method of teaching the child self-care steps: how to wash and bathe himself, to brush his teeth and hair, to feed and dress himself, to use the toilet.

"While this would take persistent and patient training, each step demands less and less of your attention and more independence from your child, and incidentally gives him a much greater sense of accomplishment," the booklet reads. "All learning is done by small steps, each building on the accomplishment of the one that has gone before."

Even as the child is seen as a special individual who can move only at his own pace, he should not be seen as so special that he need not follow any family rules or regulations.

"He needs to be accepted by all members of the family to be a real part of it," the booklet reads. "He won't get that acceptance if the family members resent the special privileges he gets in rule-breaking."

Four of the original six children in the program have returned to their own families for the summer. Foster homes are being considered for the other two youngsters.

The program was considered very successful by Willowbrook administrators and by HEW representatives who came from Washington for evaluation.

Funding has been renewed for another year, to extend the program until June, 1974.