

At Storybook, Big Specialists Score Little Triumphs

By J. A. C. DUNN

At the bottom of the long meadow that slopes away from the main play area at Storybook Farm summer camp, a low cinderblock building houses 18 children. All but five have cleft palates. Of the others, two are severe stutters, two have articulation problems, and one is an aphasic. The children are learning to speak.

To hear a doctor talk about cleft palates, you would think the problem was entirely mechanical. Dr. Erle Peacock describes the affliction in surgeon's and specialist's terms, rapping out words like orthodontics, prosthodontics, otolaryngologist, audiology, psychometrics, fistula, uvula, and others.

lips—a term never used at the center, not only because it is an inaccurate description of the cleft palate, but also because it is cruel.

All this combined treatment works. When a child's speech improves, he begins to regain his self-respect. With increased self-respect comes greater effort to improve his speech. Many of the children work like nailers to get the sounds right, and the more their speech improves, the more they emerge from defensive withdrawal and rejoin the rest of the world. They even help each other.

BACKGROUND

The cleft palate rehabilitation center was started last year in a house on McCauley Street in Chapel Hill by Dr. Peacock. It is now run by director Gene Harris, and chief speech therapist Aloysia King. Last summer the center had seven children and two speech therapists. This summer there are 18 children, including four from the original seven, and three speech therapists.

The Center was moved this summer to Storybook Farm, four miles west of Carboro, to give the children more natural and

congenial recreation facilities. Most of the children come from rural areas all over North Carolina.

"If he came from a tobacco farm in Kinston," Dr. Peacock says, "give him a fishing pole and let him sit on the bank. If he's accustomed to seeing the north end of a southbound mule, put him out where he can see that. You can't really rehabilitate him if he's just sitting in a room looking at a wall."

The logistical expenses (food, salaries for therapists) are paid by the Crippled Children's division of the North Carolina Department of Public Health and the Plastic Surgery Trust Fund. The UNC School of Medicine Faculty put up the collateral for a \$9,000 Orange Savings and Loan Association loan for the building at Storybook. Memorial Hospital donated beds and linen. The UNC RTVMP Department is making a movie of the center's operations, to be shown around the State as part of a fund-raising campaign. Mr. and Mrs. Warren Barrett, who run Storybook, are in charge of the center's recreation program.

THE CLEFT PALATE

One of every 700 babies is born with a cleft palate or a cleft lip, the largest single group of congenital deformities in this country. A baby can be born with one or the other, or both. The deformity is caused by interference with the palate formation process during the first three months of pregnancy.

Very simply, a cleft palate is a hole (fistula) in the roof of the mouth. The cleft can start at the upper lip and extend all the way back to the uvula (the little pink tail at the back of the mouth that wiggles when you say "Aahh"). Sometimes only the lip is cleft. Sometimes only part of the palate is cleft, and the lip is not.

Regardless of the extent of deformity, however, the effect is often disastrous as far as speech is concerned. When nose and mouth are not separated, the air pressure in the mouth necessary to make what are known as plosive sounds—P or B, for example—cannot be built up. Cleft palate children speak with the backs of their tongues, instead of the tips, to close the vacancy in the mouth and build up the pressure. Nevertheless, they often make G's for T's, and K's for D's.

Also, using the back of the tongue instead of the tip makes it almost impossible to make an S or a Z sound. In severe cases, the S will come out more as a snort than anything else.

Generally, the effect of the cleft palate on speech is the elimination or distortion of consonants. Try saying "I want to go home" without using any of the consonants in those five words and you get an idea of how difficult it is for a cleft palate child to communicate with the people around him.

MEDICAL ASPECTS

The effect of a cleft palate is

just as notable physically as it is in speech. Cleft palates damage teeth; many cleft palate children have very poor teeth at an early age. Cleft palates damage hearing, cause recurrent infections in the mouth and ear, and sinus, tonsil, and adenoid troubles. Palatal muscular and nerve trouble also is caused by the cleft. Thus many cleft palate children's speech problems can be caused as much by infection and the fact that they cannot hear properly as by malformation of the mouth.

Surgery can correct the cleft, but even after surgery a wide variety of specialists usually must do their parts. A plastic surgeon may have to correct visible deformity, in lip or nose. An orthodontist may have to apply braces to straighten erratically growing teeth. If the teeth are irreparable, a prosthodontist may have to make new ones. Nose and throat troubles may have to be treated by an otolaryngologist. For other troubles a general pediatrician may be consulted. An audiologist usually must test a child's hearing, and either improve it or halt any further impairment of hearing. A speech analyst must determine the degree of speech impediment, a speech therapist must correct speech. Somewhere in there the child should receive a psychometric examination to determine his IQ and his learning capacity. Sometimes the psychometric examination indicates the presence of organic troubles. Efforts are made to avoid having tonsils and adenoids removed, because these organs help fill the empty space in the mouth in which air is uselessly diffused instead of being directly channeled along the palate to the lips, enabling clear speech.

The children at Storybook usually have undergone or will undergo some or all of this treatment. Some are patients at Memorial Hospital here, others are referred here by hospitals elsewhere in the State. This week the Storybook children will be examined dentally, audially, and psychometrically at Memorial. Results of these tests and speech therapists' findings and recommendations will be sent home with each child referred to Memorial from elsewhere.

THE ROUTINE

Many of the Storybook children come from families eligible for Crippled Children or welfare assistance. Family circumstances and distance prevent most of them from coming to Chapel Hill for regular treatment. Hence, the six-weeks summer rehabilitation center.

The first day is the worst. Parents arrive with their children, often bringing the whole family. Some of the cleft palate children are friendly, outgoing, talkative, unafraid. Others are withdrawn, silent, all but unapproachable. They are afraid they will be marked if they open their mouths.

The parents themselves vary. Some understand their child's problem and what the rehabilitation center is trying to do. Others are clearly embarrassed about having a cleft palate child at all, and may well be suspicious of the camp's intentions.

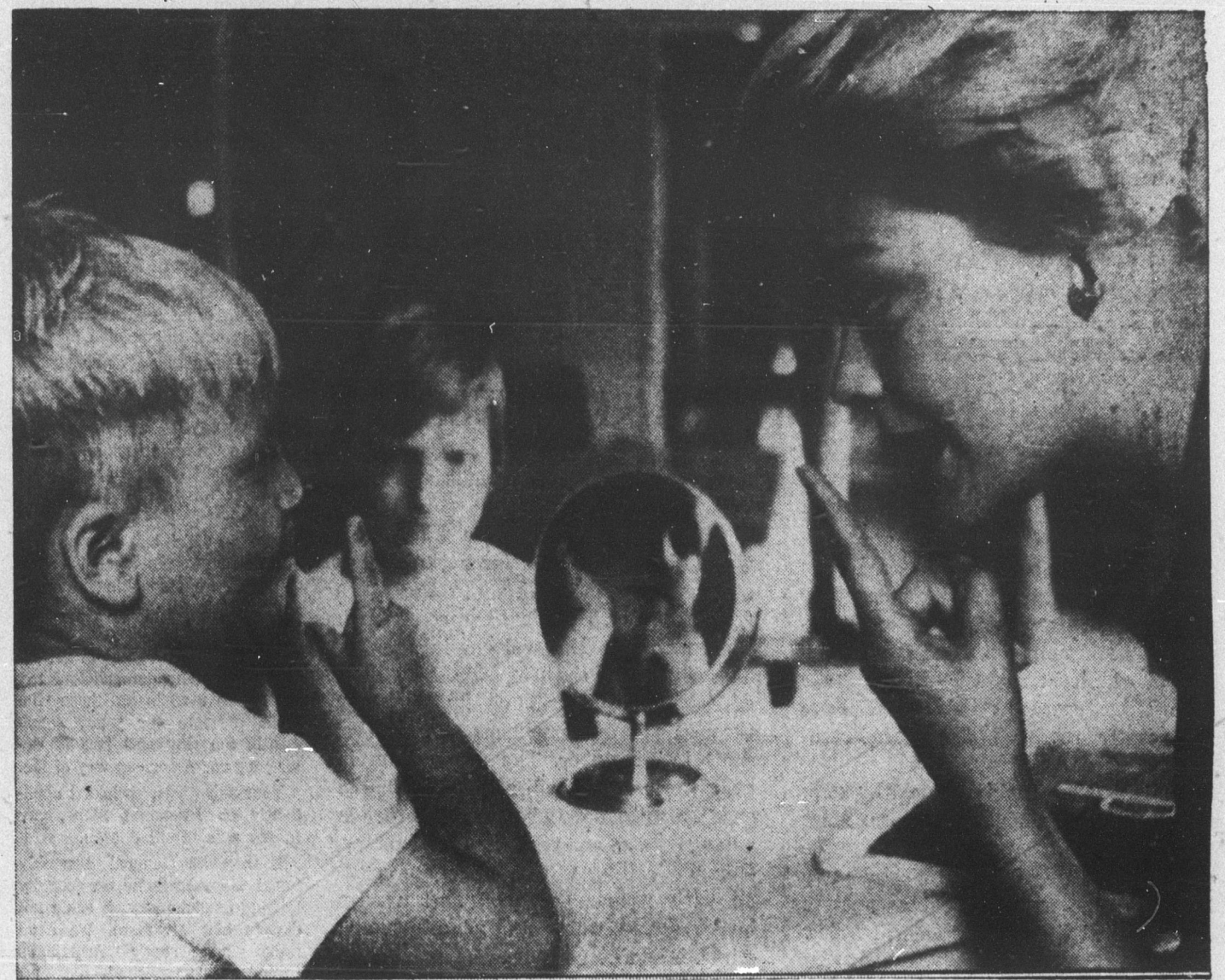
According to Irene Terefenko, a Columbia University graduate student and one of the center's three speech therapists, the children whose parents have talked about and built up Storybook Farm with enthusiasm are not homesick. Other children frankly want to go home. It takes a few days for everyone to settle down and learn not to be afraid. For many children, the center is their first experience away from parental shelter.

But after a while the camp grips the children—as the children do the camp. Cleft palate children mingle freely with Storybook's normal day campers. They get used to one another. After a few days they are indistinguishable to the unfamiliar eye. The cleft palate children go through a routine of therapy alternated with recreation throughout the day. Each speech therapist works with six children. Each child receives at least one hour of individual therapy every day. Each child also takes part in group therapy daily.

The recreation: swimming, in the camp's pool, and in the University pool twice a week; horseback riding, boating in the camp pond, arts and crafts, movies in Chapel Hill, campouts; and light farming—vegetables are grown at the camp, the children help pick the vegetables, then eat what they have picked.

"They usually get up about six in the morning," said Miss King. "At the end of the day they're usually so tired they're just wandering around dazed."

Recreation also includes the normal summer camp incidence of finding garter snakes, capturing and befriending turtles, and other discoveries. The camp has a ram (named Sam), and Miss



Therapy: Johnny, Miss King, And Ava Listening

King's dog, an aquatically-minded spaniel named Donnie, has become a vital part of boating operations. There is also a pony cart.

THE THERAPY

Actually, the therapy is simpler than the recreation.

Therapist and child sit on opposite sides of a small table. On the table is a small mirror with which the child can watch his own mouth forming sounds.

"Gah," says the therapist.
"Ngah," says the child.
"No, you're giving me 'ngah.' Try to say 'gah, gah.'"
"Gah."

"Very good, that's fine. Now try gah, gay, gee, go."
"Gah, gay, gee, go."
"Hold your nose closed. Gah, gay, gee, go."
"Gah, gay . . ."

Therapy takes enormous patience on the part of both child and therapist. A child's motivation to learn to speak correctly often hangs on whether he likes his therapist. The more likeable the therapist, the harder the child tries to please.

The children also work with each other, practicing speech sometimes for as much as an hour and a half at a stretch. Often, when they speak to a member of the camp staff and inadvertently slur a few consonants, they will stop and correct themselves.

Therapy at Storybook is mak-

ing progress. The children's speech is improving, slowly in some cases, noticeably in others. "Before" and "after" tapes of each child speaking are sent for analysis to New York at the end of each session.

The two children at the camp who stutter are given somewhat different therapy. They are taught not the correct formation of sounds, but control of the stutter.

"We try to teach them to stutter in a more acceptable fashion," said Miss King. "The idea is to give them a better picture of themselves, so they won't think they're being laughed at when they talk to strangers."

Sometimes the therapy stays with the child. Next summer the center is planned for eight weeks, instead of six, with five speech therapists and about 25 children. Some of those attending this summer will doubtless return to the camp for further therapy, and gradually their speech will become clearer and clearer.

In some children, however, the benefits of the center probably will be only temporary. Ava is one of these.

AVA

Ava is nine years old and an aphasic. Aphasia is caused by brain damage, and while an aphasic may be physically normal otherwise, the brain dam-

age prevents speech. Aphasics have to be taught to speak sound by sound.

When Ava came to the camp she had no speech at all. She was completely withdrawn into a totally uncommunicative world. She stood with her arms straight down and crossed in front of her, her head bowed. She wouldn't laugh. She wouldn't look up. You couldn't get to her.

Now, after four weeks, Ava has about ten words. She sits in on the individual therapy sessions, listening. She understands what people say, and she wants to speak herself, but it is mountainously difficult for her to do so.

Ava has never been to school because there is no school she can go to in North Carolina. The State has schools for deaf children, blind children, and retarded children, but Ava is none of these. Aphasic children are sometimes assumed to be either deaf or retarded, and are sent to the wrong school. The speech rehabilitation center is as close to the right school as the State can come.

Whenever Ava says something it is a triumph. The other children accept the fact that she cannot speak, but can learn, and they try to help her.

"They make her ask for things she wants," said Miss King.

Ava responds by trying to speak sometimes, but ten words

is a limited vocabulary. The best that can be done for her is to let her sit in on therapy sessions, and to let the other children encourage her to speak.

A LITTLE TRIUMPH

Even when not in therapy sessions, the other children work among themselves, and by themselves, practicing. When someone says "okay" with a good, clear K sound, it is another little triumph.

Little triumphs come at unexpected moments. Miss Terefenko (known as Miss Terry, for obvious reasons. "If the children could say her name they wouldn't belong here," said Miss King) has been working with a little girl who made S sounds completely through her nose when she first came to the center. She had never learned to use the tip of her tongue.

"We worked on the S sounds," said Miss Terefenko, "and then she practiced and practiced over one weekend. The next Monday I didn't make her work on S sounds at all, and at the end of the hour I hadn't even mentioned S sounds. She looked at me and very quietly she said, 'Ssssss.' I didn't say anything, and she didn't say anything, and then she said, 'Ssssss' again."

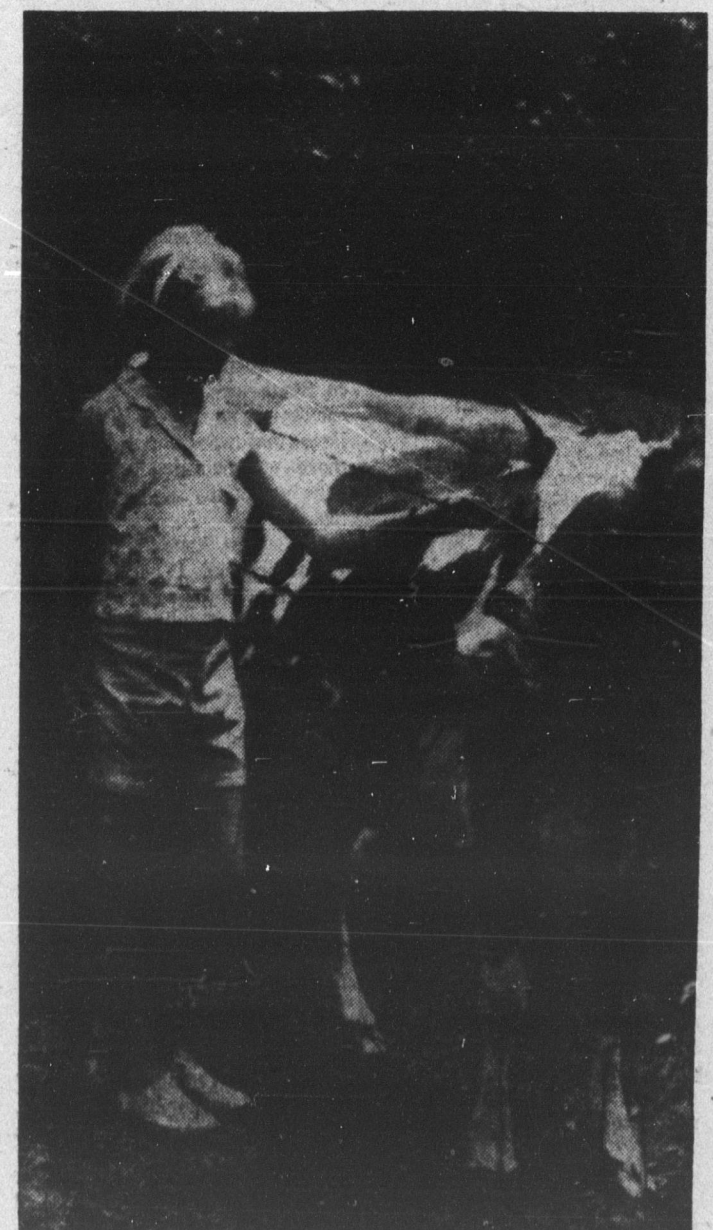
"I said, 'What did you just say?'"
"And she said, 'I just made the Ess sssssound.'"



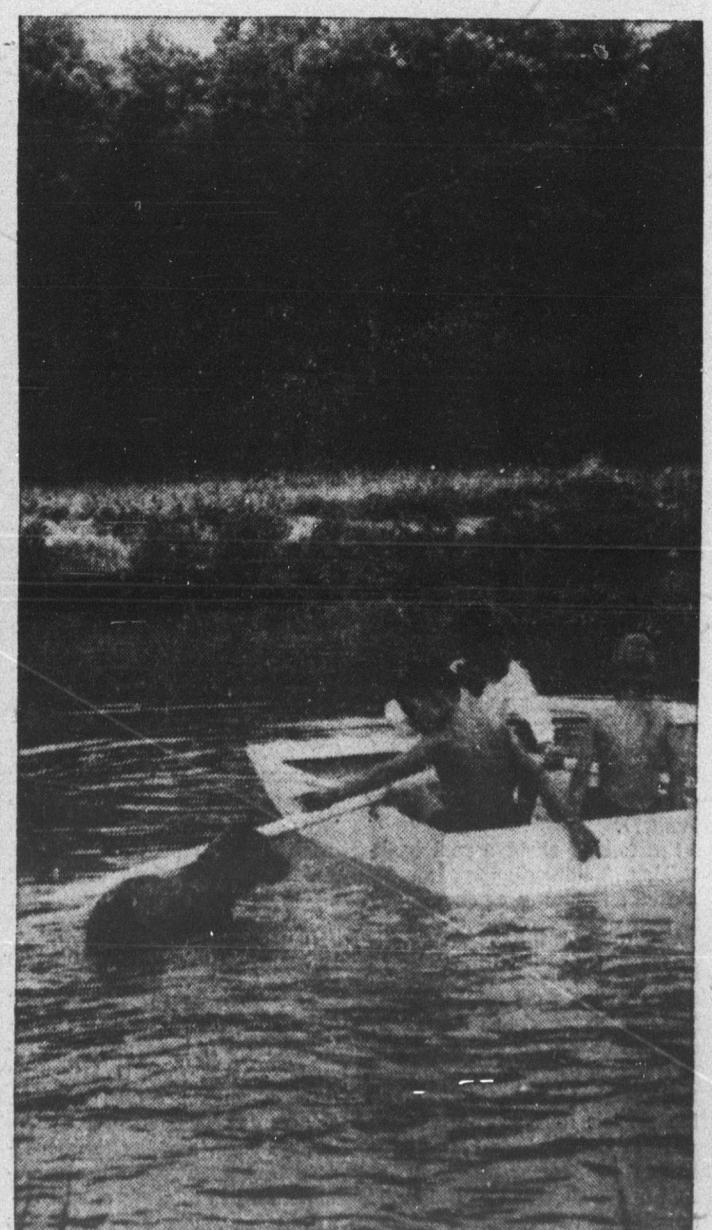
A Summer Discovery



Archery With Miss Terefenko (Right)



Recreation: Light Farming



The Dog Is Important