

# Symposium: Contributions of Governmental Agencies in Research, Treatment, and Teaching of the Oro-Facial-Speech Handicapped

## II. Reducing the Employment Handicap of a Cleft Palate.

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*Washington, D. C.*

The fact that you invited me to talk to you at your national meeting is encouraging evidence that you are well aware of the difficulties involved in making a whole person of one with a cleft palate—in short to accomplish total rehabilitation.

The constant improvements and innovations in your surgical techniques and therapy, and the emphasis you are placing increasingly on essential psychological guidance must highlight the difficulties you face in doing a total job for your patient, especially the problem of overcoming the employment handicap that confronts many of them.

An important resource is at your command in the public Federal-State program of vocational rehabilitation.

Assuming that all of you have encountered the problem, I wish I could assume too that you utilize the public rehabilitation agencies and that you will do so to a much greater extent in the future.

The objective I realize, as you do, is that by the time the cleft palate person is old enough to prepare for work, you and people like you usually have effected the highest possible degree of correction and adjustment. Most of those who come to the vocational rehabilitation agency without this service are 'those that slip through'. Occasionally surgery will be ineffective; speech may continue to be inadequate; and personal adjustment to life and people will not be made readily. Ideally, the number with cleft palates who will need our services will diminish as the years go on. But I am not certain that you are fully aware of the extent to which your vocational rehabilitation agencies can be helpful—if they are needed. And perhaps you are not using them as much as you might.

But you will continue to encounter the problems that must be met in

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preparing for a self-sustaining life of useful work. Your chairman of the local arrangements committee—Dr. Robert Splain—has passed along to us an experience in which he participated. I will relate this for it leads directly to my basic topic.

A young man with a repaired cleft palate and of reasonably good appearance but with considerable difficulty of speech approached the Episcopal Bishop of Washington and asked for his endorsement and help in entering a seminary with the intent of becoming a priest—and preacher.

The Bishop immediately pronounced his speech inadequate.

The man persisted, however, and the Bishop told him that he would help him go to a Seminary if he presented certificates from his orthodontist, his plastic surgeon, and his speech therapist that his speech would be adequate to make him an effective preacher.

Here a little collusion—but no conflict of interest—took place. The three consulted among themselves and finally convinced the boy that he would not be a good preacher because of his speech.

Dr. Splain, however, suggested that the young man strive toward becoming a chaplain to the deaf, where his enunciation would not matter. The boy learned the sign language, went through the Seminary, and is now a successful chaplain among the students at Gallaudet College, the world's only college for the deaf.

This is the ultimate in vocational rehabilitation. Dr. Splain worked out a solution that uses the boy's abilities and meets his needs and interests. And everybody is happy.

All of us in this room know, of course, that the problem of ultimate vocational success is far down the ladder of graduated problems that must be met when a child is born with a cleft palate. Nor, for that matter, is surgery as a general thing at the top.

The first problem the family, the doctor, and others who may be involved must consider is the impact of the defect upon the child's personality. How will his mother feel about him? his father? his older brothers and sisters?

As he reaches the age where his speech develops and if he realizes that it is 'different' from that of others, how will he relate to his family, and they to him? How will he relate to his school-mates? His playmates?

What can be done to avert adverse psychological effects upon his personality?

When and what surgery or other corrective measures should be taken?

These are matters of the greatest importance, as you know, because the development of the child into a normally functioning adult, his happiness, his usefulness, his independence are tied so closely to what happens to him as a very small child.

All of the necessary adjustments and corrections, ideally, as I have said, should have been made before the adolescent comes within the purview of our charter of operations. We—as of now—are restricted to

dealing with the aspects of handicapping conditions that relate to employment, except in our research programs.

Fortunately, there is a strong resource at the command of parents in the nation-wide system of Crippled Children's Services. This is operated on a federal-state partnership basis under the Children's Bureau of the Department of Health, Education, and Welfare in all states, except Arizona, and through it surgery and other services may be provided up to the age of 18.

The Federal Law requires no 'means test' for such services. Some states, however, do impose a 'needs test.'

And there are many voluntary agencies, as you know; outstanding among them is the National Society for Crippled Children and Adults.

So, aid in averting the effects of a cleft palate in childhood is available. That is why I have said that, ideally, the corrective work should have been done prior to the time when an adolescent's problems of employment become imminent.

But when that time comes, and the problems do exist, our system of vocational rehabilitation services can prove of great help to you in your work.

Those two words *vocational rehabilitation* are to be stressed; for it is the mission of the state-federal partnership to aid as many as we can of those people who have handicaps that hamper their abilities to work, up to the limits of their individual capacities. The state vocational rehabilitation agencies perform the actual services for disabled people. Broadly, they attempt to reduce or remove handicapping conditions—whether of personality, mind, or body—and otherwise to give disabled people equality of opportunity to use their natural endowments to gain economic and social success.

The basic philosophy under which the public program of vocational rehabilitation is operated is that disability, resulting as it so often does in dependency, is a national problem. To give disabled citizens an opportunity for a full productive life is a national obligation. The federal-state program of vocational rehabilitation, therefore, aims to restore a person disabled by disease, injury, or conditions surrounding birth, to his fullest potential as combined technical skills, highly trained personnel and modern knowledge can make him.

The child or youth with a cleft palate is, in most cases, a *normal* person except that Nature has denied him the proper physical equipment for speech, for chewing, or normal appearance. There are unusual factors involved in correlating the actions necessary to correct these conditions and all procedures should be undertaken with the constant thought that they must be related to the vocational future of the individual and his ability to earn a living. Thus there must be determined along the line the proper combination of services—medical, surgical, speech, educational, psychological, social, and others—that will prepare a youth for normal

associations and activities; and finally, the decision must be made as to whether vocational services are indicated.

The incidence of cleft palate is about one in every 850 births, so that, with our burgeoning birth rate there will be an even greater total of cleft palate cases.

For those who approach working age with some of their difficulties unresolved, here is what the public program of vocational rehabilitation offers:

In every state there is a vocational rehabilitation agency staffed and equipped to provide a variety of services to disabled people. These include a diagnosis of the disability and a reasonable prognosis of the person's ability to work after services are provided. Medical, surgical, and hospital services are available. Training is provided for work suited to individual capacities, with placement and follow-up to see that the worker and employer are satisfied. Only then is the disabled person regarded as rehabilitated.

Most services are free and all are without cost if the disabled person is unable to pay.

Programs of rehabilitation services are neither standardized nor rigid. Every disabled person presents a different set of conditions to be met. Family and personal background, aptitudes, personality, emotional stability, motivation, and other factors have to be considered. Consequently, services are always tailored to the individual with a specific job goal suited to capacities, talents, and interests.

The rehabilitation offices in the various states are spotted about the state on a basis that makes them easily available, no matter where a handicapped person may live.

The very fact that one of your patients approaches working age with continuing problems means that you will have difficulty in helping to rehabilitate persons with cleft palate. It is comforting to know that in your specialties, you are making greater use of a practice that is growing rapidly in the treatment of so many forms of severe disability—the merging of skills and knowledge in several disciplines into teamwork that helps rehabilitation tremendously in reaching toward its ultimate goal—the ability to recreate a disabled individual into as complete a person as his capacities will permit.

The usual 'team' combines the services of the surgeon, the physician, the physical and occupational therapist, and—as related to your specialty—the speech therapist, as well as the psychologist, the social worker, and the rehabilitation counselor, so that their talents are available in whatever degree the case calls for.

We can be certain that in the growing number of places where severe handicaps imposed by a cleft palate are treated, you will find greater results from your combination of the talents of plastic surgeons, dentists, orthodontists, prosthodontists, nose and throat specialists, pediatricians,

psychologists, social workers, and speech therapists. And to these may be added the audiologist, because about 80 percent of persons with cleft palate also have reduced hearing acuity. You will have better evaluations, and the patient will get the highest kind of service through combined team efforts.

More than four decades of vocational rehabilitation in the United States have given those in the state-federal partnership, under which the nationwide program is operated, a reverence for the individual and a greater compassion for his disabilities. It permeates all of our endeavors. The public program has grown in all directions; in scope and in breadth, in recognition as a part of our national health program, in the public funds that it receives from the national and state legislatures, and in the research efforts that give us greater understanding of the needs of the disabled and the best ways to meet those needs.

In eight years of rehabilitation research—sponsored by state rehabilitation agencies and private nonprofit groups—well over 500 projects have been initiated to investigate a wide spectrum of rehabilitation problems and we are spending this year \$10.5 million in research.

Only two of our projects have to do specifically with cleft palate. The University of Pittsburgh has completed a project to develop an audible scale to measure the quality of nasal speech among cleft-palated adults, in relation to their employability and the State University of Iowa is developing visual media to help the study of speech problems among persons with corrected palates. However, a great variety of work in the area of speech and hearing defects and aphasia may have implications for your field.

Obviously there is an open field for research into cleft palates. It could be the implied obligation of your group, or allied groups, to apply your imaginations to what must certainly be some unanswered questions about the handicapping effects of a cleft palate. I invite you to consider and formulate worthy projects, so that available Federal funds may be put to work to find some of the answers.

If you see unmet needs, as you must, and would like to suggest appropriate research projects which may help to provide means of meeting those needs, I would be interested in hearing from you.

It will be of interest to you to know that our interest in all aspects of communication is growing steadily. Since 1955, for instance, we have sponsored 59 research and demonstration projects in speech, hearing, and related disorders.

In 1955—the first year in which we had authority to conduct a program of research—we spent \$69,000 in speech and hearing research. The number of projects has grown steadily year by year until our expenditures in these fields this year are \$676,000.

And the nine-year total of expenditures is \$3,000,000.

So, you can see just how rapidly our interest grows.

I will cite just one project as an illustration—one that may eventually prove beneficial to you in your work. At Washington University in St. Louis, Dr. Joseph H. Ogura is engaged in basic research under our sponsorship—attempting to define the neuro-physiologic factors essential for swallowing and voice production in laryngectomized animals and humans.

Our research is not limited to this area or, for that matter, this country. For several years now, we have supported projects that help to meet the problems in other countries. We find that we can benefit from knowledge that we develop by cooperating with our colleagues abroad, and, in addition, help solve the problems in such countries as India, Burma, Brazil, Israel, and several others.

The plastic surgeons in this association will be particularly interested in some work we are doing with Dr. Paul Brand in Vellore, India. Dr. Brand has been doing reconstructive surgery on many who suffer from leprosy and we currently are engaged with him in a project to provide concerted rehabilitation services to his patients on an itinerant basis. So many villages will benefit.

One of the most interesting aspects of this project is the strong participation we are having from American plastic surgeons and other rehabilitation specialists. We have sponsored 14 American specialists who have spent two to six months in working with Dr. Brand and we are getting marvelous dividends. For instance, Dr. Erle Peacock at the University of North Carolina is using Dr. Brand's mass-production technique to reduce the costs of surgery and treatment of the hand. He also is experimenting with reconstructive surgery on 'live' tissue, as contrasted to the anesthetic tissue of Dr. Brand's leprosy patients. So our country here is reaping the reward of its own generosity. Our progress in training has been as steady and as spectacular as that in research.

We have made grants for the training of speech pathologists and audiologists this year which will total about \$1,835,000—a material increase above the 1958 amount of \$133,440.

Much has happened in the five years since we began to make grants to train personnel for work with adults who have communicative disorders. In that year (1958) seven universities received teaching grants to strengthen their instructional resources and 23 students received VRA traineeships for graduate study.

This year 50 universities are receiving teaching grants which total about \$600,000 and about 450 students are receiving traineeships, totaling about \$1,110,000. About 25 short-term training courses will be conducted this year for speech pathologists, audiologists, and rehabilitation counselors. They will reach about 850 people. They will deal with such areas of concern as stuttering therapy, aphasia, post-laryngectomy speech, and hearing loss, to name only a few.

Training grants also are providing help to the American Hearing

Society in its efforts to give training to personnel of its local affiliates and to the American Speech and Hearing Association for its activities in standard-setting and recruitment for the field.

Our progress in all areas has been great over the years and, naturally, we are happy to see the diminishing numbers who become disabled from some of the more prolific cripples of the past.

Fewer people come to us for help in overcoming the disabilities imposed by tuberculosis. Fewer come because of polio. It is gratifying that your problem cases will diminish as the years go by.

But there are growing areas that tax the ingenuity, the skill, and the dedication of our people everywhere. The numbers of 'cardiac cripples' increase and we have recently entered a working agreement with the American Heart Association that we hope will bring realistic appraisals of each patient's tolerance for work and thus save thousands from fear-ridden lives of idleness.

The mentally ill constitute a tremendous backlog of potential rehabilitants and we are developing in most states a system of rehabilitation counselors working within the mental hospitals with the doctors and other staff, to aid in conditioning the soon-to-be-discharged patient to his imminent transition back into the world of competition.

The mentally retarded abound in the millions. Most can be helped to achieve some degree of self-sufficiency; many can be made completely or predominantly independent. So we have supported 30-odd demonstrations of how concerted effort and pains-taking procedures of training can bring these people out of the limbo of neglect and into the stream of life.

There remain a thousand challenges.

But progress is the best stimulus to greater effort and last year we achieved a new all-time high in the number of rehabilitations effected within one year—102,377. This marked the first year in which we had surpassed the 100,000 mark—and this year will be even better.

In this we struck a blow at that cancer of our generation—dependency.

This represented independence, hope, and productivity for a group of people in our society most in need of it. As we look ahead to the work of the coming years, I hope that through collaborative effort with your group we can count in our future hundreds of thousands of rehabilitants, many of whom will be the beneficiaries of your fine professional skills and of the resources of the public program of vocational rehabilitation. In this way, we can make real for this group of severely disadvantaged citizens the motto of our Department, *Hope—the Anchor of Life*.

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