Combating Stigma Resulting from Deformity and Disease.

Leonard Wood Memorial for the Eradication of Leprosy, New York, N.Y.

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Leprosy

Summarized are the proceedings of a seminar concerned with methods of combating stigma resulting from facial disfigurement, epilepsy, cerebral palsy, and leprosy. The purpose was to determine how theories about stigma can help in the development of new methods of public education in order to change public attitudes and reduce social stigma. Discussed in four major sessions were: the nature and source of stigma (theory, extent, effects); social stigma from the agency viewpoint (public education and information methods of agencies); methods of communication and social stigma (role of mass media in transmitting stigma, and use of audiovisual media to reduce it); and recommended methods for combating stigma in the future. (KW)
Combating Stigma resulting from Deformity and Disease

A Seminar Held On November 6, 1969

LEONARD WOOD MEMORIAL for the Eradication of Leprosy

79 Madison Avenue, New York, N.Y. 10016
TOPICS DISCUSSED

Session I. The Nature and Source of Stigma

The Theory of Stigma.
(What is Social Stigma? Source of Cause of Stigma?)

Stigma Inherent in Society.
(Extent of Stigma. Effect on Individuals and Society. How is stigma transmitted?)

Session II. Social Stigma as seen from the Agency Viewpoint.

Methods now being used by agencies and organizations to combat stigma.

How Public Relations Programs Deal with Stigma.

Public Education and Information Programs and Stigma.

Session III. Methods of Communication and Social Stigma.

Does the mass media perpetuate the transmission of stigma?

Use of Audio-visual Media to Reduce Stigma.

Session IV. Recommendations for Methods to be Used in Future.

Proposals to be made by Group to be used in future to combat Stigma.

Summary of Discussion in Relationship to Future Action.

INDEX TO THIS REPORT

Inside Front Cover - Seminar Topics Discussed

Page 1 - Order of the Seminar
2 - Participants
3 - Statement: What Do We Mean by Stigma?
4 - Introduction
6 - Review of Session I
11 - Review of Session II
17 - Review of Session III
21 - Review of Session IV
26 - Disability, Disfigurement, and Stigma: A Brief Overview
     by Zachary Gussow and George S. Tracy
37 - Stigma: The Rational Approach by Frances C. Macgregor
43 - Stigma and Public Relations by William P. McCahill

Inside Back Page - Bibliography
COMBATING STIGMA RESULTING FROM DEFORMITY AND DISEASE

**Purpose:** To determine how theories about stigma can contribute to developing new methods of public education to combat social stigma.

**Time:** Thursday, November 6, 1969, from 9:00 A.M. to 4:45 P.M.

**Place:** Carnegie Building, 345 East 46th Street, New York, N.Y. 11th Floor

There were four sessions:

- 9:00 - 10:45
- 11:00 - 12:30
- 2:00 - 3:15
- 3:30 - 4:45

**Participants by Invitation:** From twenty to thirty professional persons with a knowledge of the health and welfare field:

- Social Psychology
- Social Anthropology
- Sociology
- Social Work
- Health Education
- Public Relations
- Fund Raising
- Communications Personnel

**Viewpoint:** To consider social stigma related to leprosy. The focus, however, was broader than leprosy. It included the views of persons with experience dealing with stigma resulting from other disabilities such as epilepsy, cerebral palsy, and facially disfigured.

The aim was to find ways to alter public attitudes in order to reduce social stigma of certain disabilities, rather than deal with the effect of stigma on the individual.

**Questions Considered:**

- What is Social Stigma?
- What is being done to Combat Stigma?
- Do practitioners working to combat stigma, prejudice and to alter public attitudes toward disabilities understand the nature and cause of stigma?
- Is the social and economic cost of stigma and prejudice fully appreciated?
- Do present public information, public relations and fund raising programs tend to reduce or intensify stigma?
COMBATING STIGMA RESULTING FROM DEFORMITY AND DISEASE

PARTICIPANTS

Norman Acton
Rehabilitation International
New York, N. Y.

James Breetveld
UNICEF
United Nations, N.Y.

David Castro
Philippine Association
New York, N. Y.

Donald S. Frank
Epilepsy Foundation of America
Washington, D.C.

Henry A. Goodman
Council for the Advancement of Science Writing
Leonia, N.J.

Zachary Gussow
Department of Psychiatry
Louisiana State University Medical Center
New Orleans, La.

Oliver W. Hasselblad
American Leprosy Missions Inc.
New York, N. Y.

Masayoshi Itoh
Goldwater Memorial Hospital
N.Y.U. Medical Center
Welfare Island, N.Y.

Herbert Kadison
N.Y.U. Medical Center
New York, N. Y.

Hillier Kriehbaum
Department of Journalism
New York University
New York, N. Y.

D. V. Kulkarni
School of Social Work
University of Alabama

Francis Cooke Macgregor
Institute of Reconstructive Plastic Surgery
New York, N. Y.

William P. McCahill
The President's Committee on Employment of the Handicapped
Washington, D.C.

Norman E. Morrison
Leonard Wood Memorial Laboratory
Dept. of Pathobiology
Johns Hopkins School of Hygiene and Public Health
Baltimore, Md.

Arthur O'Neil
United Cerebral Palsy Association
New York, N. Y.

Arthur H. Richardson
Epidemiology Research Unit
Columbia University

Anna Rubner
N.Y.U. Medical Center
Institute of Reconstructive Plastic Surgery
New York, N. Y.
WHAT DO WE MEAN BY STIGMA?

Stigma has been defined as an attribute that is deeply discrediting; a failing; a short-coming; a handicap; spoiled identity; an undesired differentness. Inherent in the concept is the fact that the stigmatized individual is disqualified from full social acceptance.

Stigma may comprise: 1) physical disfigurement; 2) aberrations of character and/or personality; and 3) social categorizations such as race, national origin, and religion. The principal concern of the seminar will be stigma arising from physical disfigurement or "spoiled identity." It is not the intention to consider points 2) or 3).

Discussion will center on the factors relevant to stigma in leprosy, facial disfigurement, cerebral palsy, and epilepsy -- four conditions where the "undesired differentness" is patently visible and somewhat similar in its effect on the public. The aim of the seminar is to find more effective ways to alter public attitudes, thereby reducing the social stigma of these disabilities.
Cold rain and a cutting wind seemed to jell the proceedings in a mood of earnest and skeptical seriousness. The weather helped push the conferees together to a sustained and at times tense examination of an important but relatively unexplored medical-sociological-psychological area. A cautious air of attempting to reach for new understanding while avoiding error prevailed. The "strangeness" of the proceedings accrued in part no doubt from the fact that, perhaps for the first time, social scientists, health and welfare agency officials and news media representatives were sitting down together in seminar to exchange ideas in search of highly elusive understanding of the difficult set of conditions pertaining to stigma.

The stigmatizing effect of four main disabilities defined the scope of the seminar. Although the effects of other disabilities were alluded to frequently, discussion centered around the facially disfigured, the person with epilepsy, the cerebral palsied, and the person with leprosy. The geographic scope of the seminar was limited to include the United States, it being well recognized that the nature of stigma is shaped by a great
variety of constantly changing variables, foreign and domestic. What is true in India about leprosy, for instance, that the reality of inadequate treatment affects the quality of stigma, is not true in the United States, where every patient is entitled by law to adequate and free treatment for life.

In summarizing the activities of the four sessions, efforts have been made to include reports and comments under the sessions where they logically belong rather than, in some few cases, where they came up for discussion.

It was noted that stigma results from many more causes than deformity and disease and that efforts to expand Bills of Rights to include persons stigmatized by reason of sex, age, and mental status should be concurrent with efforts to pass laws prohibiting discrimination because of "deformity." Leaders in the field of passing laws in State legislatures should be keenly aware that laws can be effective in preventing employers from discrimination on the basis of imputed limitations. Just because a person is blind or scarred does not mean that he is necessarily limited in the performance of many tasks performed by people who can see or who have no cosmetic problem. A person's stigma must not be allowed as a reason for rejection for employment. If an employer wants to reject a potential employee on the basis of stigma rather than ability, that's the employer's problem and liability— not the competent but
stigmatized applicant's. Laws are needed on all levels of government to nail down this vital point. When laws are archaic and/or in conflict with more basic laws, the basic laws should be observed and stigmatizing laws should be ignored.

SESSION I THE NATURE AND SOURCE OF STIGMA

Stigma, it was said, originates in the perception of differences. It is a learned thing. And therefore it can be unlearned. But, like learning, unlearning is difficult.

In varying degrees and of course with exceptions, stigma generates in the attitudes which the stigmatizing person has toward his own self image, which relates to his own body image. When he sees distortions, he feels threatened. He is reminded of his own vulnerability or his own unearned good luck. This feeling of threat or discomfort lessens a person's ability to empathize with the cause of fear and discomfort. The fear, discomfort--and resentment--that often surrounds the perception of differences, results in a stigmatizing reaction. The stigmatizer establishes stigma as a mechanism to deny or dissociate his common condition with the afflicted. Thereby the stigmatizer increases his feeling of safety, comfort, well being and superiority.

The key to ending stigma, therefore, is to diminish fear. Since fear usually is of the unknown, its diminution will accrue from a dissemination of the facts. A
person will be less likely to be afraid of leprosy, for instance, if he knows the disease is only mildly contagious, and that, once contracted, it can be arrested if treated in time.

About the above there was little disagreement. Disagreement came quickly and in force when attempts were made to assess ways of disseminating the facts of stigma.

"We are not very optimistic," the seminar's first speaker said, "that much service can be achieved through public education campaigns that aim at combating stigma."

The moderator asked, "Are we knocking ourselves out with public education efforts for nothing, then?" If logic and reason as disseminated by the media is not the way to combat stigma, what is?

We must search out the causes of irrationality, decode irrational behavior and key our efforts to developing knowledge, according to one conferee. Someone else quoted an "authoritative source" as saying that 98 per cent of all decisions are based on emotion.

Difficulty in identifying the variables that create stigma inhibits the structuring of experiments aimed at measuring the variables. What contributes to a negative feeling in a particular disability? The question was asked to illustrate stigma research difficulties.

The statement that mass media was not effective in alleviating stigma was countered by the statement that, before judgments can be made, a scientific understanding about the
elements of stigma formation and elimination is needed. There has been no sustained effort to understand stigma in the area of disability. The work of one conferee in laying down a basis for the systematic study of reactions to the disabled was described as only a beginning—although the conferee felt that his study did establish a reliable technique to identify and measure salient dimensions of attitudes toward the disabled. "We are beginning to obtain basic information in this area," he said. "We have some data on the relationship of stigma from one disability with stigma from another. We are beginning to get data on the relationship between the personality of the non-disabled and the personality of the disabled. We are beginning to understand more about disability types, about the relationship between a person's own lack of control and his concern over the lack of control of someone he feels moved to stigmatize. In general, we learn that persons in contact with the disabled are more likely to be favorably inclined than those who are not in contact. Of course the quality of the contact is most important."

Doctors too often allow themselves to be confirmed in stigmatizing attitudes by their own misleading egos. "Many of us simply have too much professional conceit," a conferee said. "We have too great a sense of superiority to our patients to be able to help them."

Other problems of "professional" attitudes came to
discussion. A "classic" example of a doctor unwittingly attempting to lessen the stigma of one disease at the expense of maintaining the stigma of another occurred, it was noted, when a cancer specialist wrote that cancer used to be thought to be as terrible as leprosy. Now that the public is enlightened about cancer, it knows that cancer is not a horror like leprosy. But leprosy is not a horror!

It's necessary to remind professionals as well as the public that no condition is a horror to the person intelligently engaged in alleviating it.

False standards were examined at length. In order to be socially acceptable, according to one cultural overgeneralization, a person must have looks, intelligence, money and success. If a person doesn't have these things, according to the criteria of our often too-demanding and too-superficial culture, the person simply doesn't "measure up." There must be something wrong with him. He must be rejected—and stigmatized.

Cultures and sub-cultures that more easily accommodate imperfections can lay greater claim than we to humaneness and intelligence, it seemed to be agreed. We discriminate on the basis of superfluous and superstitions to our own national detriment.

Often, when it's judged that a person with a disability could correct the disability "if he wanted to" or that his parents or kin are responsible for it in the first place,
stigma increases—whether or not the judgment is based on fact or ignorance.

People who reject or seem to reject rehabilitation most often invite grave censure, whether or not rejection makes sense from the viewpoint of the candidate for rehabilitation.

Righteous and intensely religious and/or "dedicated" people are often intolerant and cruel when their concepts of virtue are violated. We are a long way from a society that delights in human variety.

Ego strength was seen as a big factor in determining whether or not people reject and stigmatize other people. People with relatively large ego strength seem to do less rejecting than people with weak egos. On the other hand, the alienated tend not to reject. Correlations in these fields, it was noted, are often poorly defined, but they seem to exist.

In any event, effective public education must help "average" people abandon their stigmatizing stereotypes. It must also help the stigmatized reconstitute their own self-image in approving terms. These two purposes are sides of the same rehabilitative coin.

Because of semantic and other communications hangups, this job often proves quite difficult. Sometimes, simply to label a set of symptoms with the name of a disease or condition is to automatically stigmatize those people described.

A description of the usual symptoms of a person being
treated for epilepsy, for instance, is not likely to cause nearly the reaction that the name of the disease elicits.

Caveats for public educators seem to center around awareness of public reaction to words. Yet it is difficult to see how an educator can talk about a disease or condition without using some potentially stigmatizing words. Perhaps the best that can be done is to become quickly sensitive to words too freighted with negative connotations—as in the case of the word "cripple."

SESSION II SOCIAL STIGMA AS SEEN FROM THE AGENCY VIEWPOINT

Public education against stigma is no overnight—or over-the-year—panacea. A carefully controlled experiment in measuring the effects of epilepsy education in York and Reading, Pennsylvania, was carried to a disappointing conclusion some years ago by the Baruch College. The shift in attitudes in the experimental town, York, after a year of intense education in all media was in a negative direction. Public educators had succeeded only in surfacing negative attitudes.

The Stigma Seminar conferee reporting on this experiment concluded pessimistically with the observation that, if attitudes change, they change not because of public education campaigns but because of what the public is brought to see of, for instance, successful epileptics in action.

In another case adduced, the public might have reacted
well to the stage performance of one special epileptic. But after the show when the epileptic, a girl, returned to her home town she did so to learn that she was no longer employable as a baby sitter.

On the other hand, one conferee pointed out that, not too long ago, it was not uncommon for people seeing a child with cerebral palsy on the streets to ask: "Why don't they put it in an institution?" For whatever complex of reasons, attitudes have changed. In fact, change is the only constant.

Change is according to so many variables, that the attack against any one stigma problem is almost always fraught with imponderables.

The stigma problems of no two people, much less no two conditions, are the same. Approaches to combat stigma must be tailored to suit existing conditions. What works for cerebral palsy, which leaves many people stigmatized here and now, may be highly inappropriate for leprosy. Leprosy is not a large problem in the United States because very few people here have leprosy, but millions under a variety of cultural patterns in developing countries have the disease.

The relieving factor, common to all stigma problems, emerged as knowledge about the stigmatizing condition. When knowledge exists, stigma vanishes--over a period of time--for stigma most often flows from erroneous assumptions--such as, for instance, the belief that uncleanliness and acne go hand in hand.
How does one go about changing attitudes?

He starts with the assumption that most people are "decent" and do not want to cause hurt to the handicapped. Most people will want to be considerate in present contexts. But how will they feel about future personal dealings with the handicapped? That is the real test.

One way to change attitudes is to make it unrewarding for people who stigmatize others. If the head of a rehabilitation institution, for instance, fires employees for stigmatizing attitudes, those attitudes are likely to disappear in that setting. It's the responsibility of those in authority in any grouping, large or small, to set a decent and interpretive tone in the matter of attitudes. This tone should be set as a part of normal institutional operational procedure, not as an occasional informality.

Rehabilitants should be "trained" socially, i.e., made aware of and resistant to stigmatizing attitudes, while they are being treated for their physical disabilities. They should not be treated and then turned loose "cold" to deal with the social implications of their condition. If a rehabilitant is carefully coached to understand "outside reactions," he will be better able to cope with them. And being better able to cope, he will constitute the best kind of public education, a living, walking, word-of-mouth success story—a Stanley Stein as a social lion, a Walter Riesel as columnist, an FDR as President. In addition, his defensive or aggressive attitudes, which tend to be provocative and to evoke stigmatic responses, will be moderated.
Combating stigma often proves futile and therefore frustrating because the anti-stigma educator often has no precise ideas of goals and appropriate techniques. In order to set such goals and determine such techniques, a much more precise understanding of specific stigma problems is needed. In this area, research has barely commenced.

Surely, the educator should not try to engage any media to tackle stigma as a monolithic problem. Stigma problems must be broken down; education to be effective must be in specifics. To help amputees, the amputee and his public must be educated in the facts and problems of amputation.

On the other hand, it seemed to be generally agreed, areas of concern do overlap and agencies engaged in efforts to combat one form of stigma might profitably make common cause with agencies combating other forms. As things are now, agencies too often go it alone. They need to consult and cooperate with each other more often. The need for specific educational programs and the need for inter-agency cooperation were viewed as not necessarily mutually exclusive.

Difficulties in public education notwithstanding, polls show that dramatic changes in public attitudes towards people with epilepsy, for instance, have occurred during the last 25 years. Some superstitions of the past, as when epileptics were regarded in the Roman Senate as possessed of either demons or gods, are all but dead. In those times, epileptics were
worshipped or banished.

Hippocrates did a great work in public education when he issued a first good description of epilepsy. Unfortunately, the Middle Ages saw a decline of knowledge and a reversion to superstition. There are no guarantees that education will be long-lasting. No one has the competence to effect such permanent guarantees, obviously.

Education was viewed by a conferee as a curious, fortuitous process, given to unpredictable and even wild aberrations, as when Queen Victoria's obstetrician issued a paper saying that epilepsy is a sex disorder. When the doctor prescribed bromides as a sex depressant, he approvingly noted a declining incidence of epilepsy. Of course the bromide did lessen epilepsy--but not for the sexual reasons stated by the Queen's obstetrician. Another Victorian paper concurrently issued pointed out that epilepsy is a "falling sickness" and that, since mistletoe does not fall, mistletoe should be taken as a specific against epilepsy.

With changes in health and medical conditions, and knowledge, changes in some attitudes toward the afflicted do "inevitably" follow. The most effective kind of public education, then, results from a convincing effort to serve the disabled and to create understanding and hope. The difficulties of tying in this principle with work-a-day media operations were viewed as not only formidable but often inscrutable, with the result that public understanding often lags lamentably.
One health agency representative commented on a curious double standard that impedes effective public education, although the standard allows honors for those who produce, as in the case illustrated, an effective TV public service spot.

The agency representative showed the minute-long spot that had won a prize for excellence at the Cannes Film Festival. The only "difficulty" with the spot, the agency man said, was that U.S. TV programmers wouldn't use it because, the agency man guessed, the topic, mental retardation in the newly born, was somehow offensive to audience segments.

On another hand, the production and release of "confetti," brochures, leaflets, etc., by health and welfare agencies is often a futile exercise. Frequent references to institutional confetti indicated that institutional "literature" is not likely to be effective if it is produced for its own sake. Its best use seems to be as evidence to satisfy educational needs stimulated by other means.
SESSION III METHODS OF COMMUNICATION AND SOCIAL STIGMA

Discussion centered on the role of mass media in bringing about changes in attitudes toward people generally considered deformed, either physically or mentally.

Estimates of the mass media's ability to effect change varied widely. Running through most discussions was a thread of acute realization that the raw facts of the matters are missing. Studies in the area have been not only inconclusive but shot through with ambiguities and irrelevancies.

Most skeptical of the ability of mass media to change attitudes, not surprisingly, were the social scientists. Mass media by itself—and in the absence of favorable conditions—cannot "create" change.

On the other hand health and welfare agency officials maintained that mass media can be an extremely sharp tool if used competently and at the right times and places. "And anyway," an agency man asked, "what else is there?"

All conferees agreed that carefully devised studies of mass media effectiveness need to be made before anyone can speak with great authority on the role of mass media in eliminating stigma from public attitudes. The quality of the specific program of public education under consideration should be carefully evaluated before an attempt is made to measure the effectiveness of efforts, lest the uninitiated maintain the delusion that public education and mass media are monoliths.

Some discussion centered on the highly complex pressures
that shape media policy and determine what ideas will and what ideas won't be given public visibility—and to what degree.

In an extended examination of the workings of a large TV network, the central fact that emerged seemed to be that working with television is an extremely specialized field. Success in the field demands the keenest kind of understanding of the needs of the media. "Lead time" in some programming often amounts to more than two years. Requirements are endlessly complicated by the nature of the swift changes constantly taking place within the industry and the economic apparatuses that support it. In this area, where economics, sociology and entertainment constantly interact, generalization in the absence of definite studies is precarious.

However, the assertion that media self-regulation is preferable to Government regulation went without challenge—after it was agreed that TV should be required to operate in the public interest because it is a monopoly using a public asset, the airways.

An examination of the history of the tools of public education, with attention to printing, drama, religion, schools and electronic media, produced the unchallenged assertion that these tools are many-edged. The tools used to transmit enlightenment about stigma may tend to transmit stigma. And other attempts to eliminate stigma have precisely the reverse effect.

This is particularly true where the central aim of "public
education" is fund raising. In attempting to enlist public support by dramatizing the plight of victims, the public educator, most often quite unwittingly, works to enforce "polarized" attitudes.

If there are things the stigmatized don't need more of, it was agreed by social scientists and agency representatives, they are public attitudes that emphasize differentness. The basic need of the stigmatized is for a fair chance, the end of discrimination flowing from stigma, the right to function free of strictures made up of ignorance and superstition. And too often public education, in dwelling on the drama and emotion of a condition, neglects to make the point that people considered deformed have precisely the same needs as those considered not deformed. Deformity, for another important thing, is in the eye of the beholder. One man's deformity may be another man's beauty.

In carrying out fund raising activities, agencies as "producers" of services tend to ignore the "consumer," the user of services. The emotional needs of "consumers" should be carefully considered—as well as the need to raise money for programs.

Generally it was agreed that the most effective public education in this field pictured handicapped persons in situations in which they perform like anyone else. The Ironsides TV program, which features a wheelchair-bound detective, came in for repeated praise. It shows a handicapped man functioning, except for his limitation, as normally as anyone else. The key to public education about stigma is to play down the differentness of the handicapped and play up their normality, which they have in common with everyone else.
Conferees disagreed about whether or not public education should play down the differentness of the handicapped and play up their normality.

Conferees disagreed about whether or not public education should emphasize the repeal of stigmatizing laws. Such emphasis often intensifies the stigmatization that comes from the laws. The effect of anachronistic laws lessens when the laws are ignored as irrelevant.

On the other hand a stigmatizing law can always be resurrected and revived to cause new harm. It's best for educators to face the trauma of repeal and thereby place the letter of the law on the side of enlightened concern for the stigmatized. Stigma, it was agreed, is always negative and destructive.

Public educators must work in the real world if they want to be effective, one conferee said. If educational leadership is too far ahead of the media and/or public, it will tend to be irrelevant. Educators, it was said, must always try to move forward from where the public is—not from where they would like it to be.

In the case of leprosy, "secularization" should be accomplished—although, clearly no anti-missionary bias was suggested.

Although "almost everyone one talks to" may express curiosity about the facts of a disease, this must not be taken as a sure indication of the public's willingness or capacity to learn and act constructively. Curiosity does not provide a foundation on which to operate—although, with skill, it might be used as a factor in extending efforts to educate and create effective programs of treatment and rehabilitation.
SESSION IV RECOMMENDATIONS FOR METHODS TO BE USED IN FUTURE

The nature and importance of leadership in combating stigma emerged as an overriding topic of the last session of the seminar. Leadership in this field must take many forms and occur in many and varied places if our culture is to attain a more decent attitude toward people now stigmatized.

However, the job to be done is far from clearly defined. One difficulty in bringing the potential effect of mass media to bear in the elimination of stigma is that we don't know much about how—or how much—mass media can be effective. Although mass media by itself cannot change attitudes it does have a vital potential backup or reinforcing function—and the media needs to be worked with, it was agreed by most conferees.

The view that the media are "not doing enough" to combat stigma came in for an extended challenge by a TV network official. He pointed out that television has developed an acute sensitivity to public reaction and that video drama and news programs display today a fair degree of progressiveness in contrast to the callow programming of the recent past. He pointed out the AMA conducts an office to assure the medical authenticity of educational material.

The allegedly unsatisfactory performance of news and entertainment media in the field of stigma was ascribed by one conferee to the view that, since social scientists and agency officials were unclear and divided about how to tackle specific stigma problems, the media could hardly be expected to proceed vigorously and constructively. As clarity and unity in the field develops, efforts should increase to involve media at the highest possible
levels. This effort might be carried out by continuing to involve media people in stigma seminars. Top media officials should be asked to come themselves or, importantly, send a representative. Media officials are over-extended and it's wise to invite them to send a representative, lest they turn down invitations altogether.

The identification of actors like the TV paraplegic Ironsides and of successful patients generally with anti-stigma promotions would increase the chance of success. The man in the Hathaway shirt ads has helped improve the image of the blind.

One conferee commented at length on the promise and difficulties of a "multivariable approach," emphasizing that a "hard-nosed" research attitude and increased graduate student participation in stigma studies needs to be encouraged by curricula and program planners.

School leaders who integrate the handicapped as far as possible should be encouraged. Stigma tends to lessen as schools discontinue discrimination on the basis of stigma and react to students on the basis of their ability to think and perform academically. It is extremely important to teach teachers to expect the best potential from the handicapped, to expect the handicapped to succeed. Few things encourage success so much as its anticipation. Here the operation of self-fulfilling prophecies assumes great importance. A culture that expects the stigmatized to fail supports that failure, and vice versa.
Proposals to the formulators of school curricula and governmental health and education programs should highlight stigma as a long-neglected field for research and teaching. Professional people, especially doctors working with the stigmatized, should be exposed in all possible ways to the facts of their personal attitudes as well as the means of stigma eradication inasmuch as many continue to share the irrational prejudices of the general population.

Administrators of institutions for the disabled can lead in combating stigma by cracking down hard and often on personnel who tend to treat the handicapped as non-persons. Hospital administrators should emphasize the utter reprehensibleness, for instance, of wheelchair attendants who meet in a hall and gossip as though the people in the wheelchairs don't exist.

Agency administrators can combat stigma by resisting the temptation to raise funds at the cost of increasing stigma. To point out the horrors of a condition in an appeal for funds without also pointing out the need to accept victims as fellow human beings with full rights and privileges is wrong because it increases the burden of persons on whose behalf the agency presumes to collect funds. Agencies which appeal for funds on the basis of pity hurt the stigmatized.

Further, voluntary agencies generally tend to concentrate on their own narrow concerns to the exclusion of other valid community needs. Agency personnel must learn to consider related health and social needs. You can't separate the individual from community attitudes and from community health programs—or the absence of
such programs. Constant re-evaluation of goals should be under-
taken with officials of other organizations.

Professional organizations such as the Council for the Advance-
ment of Science Writing and the Medical Writers Association should
be involved, possibly in seminars to which they are invited as a
group or as co-sponsors.

Leadership of the kind that initiated the November 6, 1969,
Seminar on Stigma was encouraged by all conferees who alluded in any
way to the subject. The concept of seminar followup met not only
general approval but vigorous and continuing approval.

The idea of bringing together practitioners, media and public
relations people and social scientists to exchange ideas and formu-
late approaches was deemed both appropriate and effective, in the
words of one research scientist. "In forthcoming sessions,"
he said, "I would support the suggestion of in-depth sessions
among 'peer' groups (social scientists, practitioners, public
relations people, et.al.) followed by a joint session or
sessions to exchange ideas and to develop and implement a specific
program toward the goal of this seminar."

The matter of time, place and program for a follow-up seminar
was unresolved. Inasmuch as the Leonard Wood Memorial, under a
grant from the Social and Rehabilitation Service of the Health,
Education and Welfare Department, initiated the November 6
stigma seminar, it seems likely that the burden of shaping and
calling the next seminar might well be the work of a committee
to be named by the president of the Leonard Wood Memorial. Hopefully, the work of this committee would be in cooperation with established groups and would be reflected in sessions, both plenary and particular, of "parent organizations." The need for cross fertilization of ideas and policies of health agencies dealing with stigma was seen as real and great. Agreement seemed to be unanimous and emphatic that a stigma symposium should be held at frequent intervals.

One clear sense of the November 6 seminar was that, although the problems of stigma are real and tremendous, they are also unwieldy and amorphous—and, like poverty, they concern people with little voice and less clout. But, importantly, as society becomes more complex and sensitive, concern about stigma finds a foremost place in the minds of a startlingly large segment of the general public. The information service of one rehabilitation agency now receives a large number of requests for reprints of "Prejudice Against the Disabled and Some Means to Combat It" by Constantina Safilios-Rothschild, Ph.D. Other signs, including the lively discussion at the Stigma Seminar itself indicate that, in stigma, health and welfare workers have a much neglected area of deep and abiding concern. If something significant can be done in the ways of public education in this area, the result will be the easing of irrational and cruel burdens mindlessly inflicted by hedonistic, infantile, superficial elements of a culture often callowly obsessed with form rather than substance.
DISABILITY, DISFIGUREMENT, AND STIGMA: A BRIEF OVERVIEW

Zachary Gussow
Department of Psychiatry and Biobehavioral Sciences
Louisiana State University Medical Center
New Orleans, Louisiana

and

George S. Tracy
Department of Sociology
Louisiana State University
Baton Rouge, Louisiana

The brief statement "What Do We Mean By Stigma?" prepared by the seminar organizers well serves as an introduction to our discussion today.

The four conditions singled out for discussion here—leprosy, facial disfigurement, cerebral palsy and epilepsy—while sharing some problems in common are also dissimilar in a number of ways. It is our intention both in this formal paper and in later discussion to consider both similarities and differences.

The four conditions have been described as "patently visible and somewhat similar in" their effects on the public (1). But there are differences too. One distinction that may be made is that of visibility and "decodeability." Cerebral palsy is perhaps the most visible. Facial disfigurement is visible to the extent of disfigurement and to the extent that disfigurement cannot be adequately disguised. Epilepsy is visible only during attacks. (In discussing epilepsy we are for the purposes of this discussion,
ignoring the effects of Dilantin when administered over a long period of time and the special behavioral manifestations associated with temporal lobe epilepsy.) Leprosy, on the other hand, in terms of visibility may run the gamut.

The question of decodeability is a crucial one. Decodeability refers to the public's correct labeling of the observed condition. A moderately disfigured leprosy patient may pass as arthritic, an accident victim, an allergic reactor, etc.

In the U.S., in fact, it is extremely doubtful whether the public can decode a leprosy patient at all. Physicians in the U.S. have difficulty diagnosing leprosy themselves. Epilepsy faces comparable problems of decodeability. In temporal lobe epilepsy observed attacks may be labeled by the public as almost anything. The more usual labels are drunkenness, "crazy" (or psychotic)--hence dangerous--or that the individual is dying. Cerebral palsy and facial disfigurement undoubtedly pose their own problems of decodeability.

Public labeling is an important matter. If a leprosy patient, for example, is publicly labeled as having arthritis no one is going to worry about contagion. If, during a seizure, an epileptic is labeled as drunk or wildly dangerous either he may be ignored or the police may be called.

Labeling is extremely important in another way. As Freidson has noted, an important component in the public's social ranking of disease and disability involves the relationship between imputed personal responsibility for the condition and the imputed prognosis of the condition (2). In Freidson's scheme syphilis, for example, is stigmatized on the basis of imputed personal responsibility even
though it is curable. Dwarfism, on the other hand, tends not to be stigmatized since the individual is not held to be personally responsible, but the condition is incurable and unimprovable. Pneumonia is not stigmatized as the individual is not held personally responsible and pneumonia is curable. Thus, many combinations of imputed personal responsibility and the imputed prognosis are involved in whether or not a particular condition is publicly stigmatized. But the labeling and stigmatization will also be a function of the real or imagined degree of contagion involved. Importantly, too, labeling varies with culture.

The public's view of the condition in terms of imputed responsibility and imputed prognosis is also relevant. Sometimes behavioral scientists act as if they really know a great deal about public norms, knowledge and attitudes toward the four conditions under immediate discussion here and, for that matter, other conditions as well. Again, as Freidson has noted, "recent national surveys of public attitudes toward mental illness can serve as precedent for both grossly descriptive studies providing us with detailed information we do not now have...and for analytical studies that seek to explain" the phenomena (3). Sociologists and others working in the field of stigma and disability have told us a great deal about the attitudes of "normals" toward the deformed and disabled. But the question is "who are the 'normals' they are speaking of?" Are the "normals" the projected ego of the writer or is it knowledge obtained from specifically defined populations who have been systematically studied. A further question is which group of "normals" is pertinent and in what ways are they pertinent to the
disabled or deviant populations. A Mexican-American migrant worker with leprosy confronts one group of "normals" when he is interacting with other Mexican-American migrant workers and another group of "normals" when he is dealing with "Anglos" who may or may not decide to hire him. An individual who is grossly disfigured or deformed may be highly stigmatized, especially if he also happens to be poor and uneducated, if he were to attempt foolishly to mix socially with the international jet set or some other snob group. On the other hand, he might stand not only a good chance of being accepted but also not stigmatized if he managed to get a job with a circus. Obviously, it depends a great deal on who is doing the labeling. This varies not only with the nature of the physical condition of the disabled individual but also with his other attributes—social class, education, personality, etc., and the attributes of those he is interacting with and the nature of the interaction itself; is it the solitary stigmatized interacting transiently with "normals" as Goffman (4) deals with exclusively, or is the interaction continuous and long term? Stanley Stein, publisher, author, activist, "leper," nicely illustrates some of these points. Though visibly deformed, blind, and bacteriologically positive to the day of his death he, nevertheless, moved somewhat openly and freely in educated, middle-class Baton Rouge society. His stigma as "leper" in these circles was considerably attenuated by his role as "celebrity," a role he was able to manage successfully by virtue of his being articulate, educated, witty, personable, internationally-known and perhaps also, ironically, because he was the possessor of an "exotic" disease in a country with relatively few leprosy patients.
Up to this point we have touched on some of the dimensions of public stigma. There is another aspect of stigma that is surely as important, self-stigma. A great deal of what we know about stigma comes from studies of the stigmatized themselves—interviews, observations, biographies and autobiographies. These studies, though they range far and wide, from alcoholism to zoocerasty, tend to be somewhat skewed. Almost exclusively in leprosy and to a large extent in other types of studies, investigations have been heavily concentrated (with notable exceptions) among people in the lower classes or among those who have been identified or "caught." For example, we know a fair amount about drug addiction in ghettos, among "hippies," and among the underprivileged, but precious little about the problem as it affects lawyers and physicians with the exception of a few statistics. Homosexuality has been studied somewhat extensively among lower class men and women, walking the streets or in prison, but how much do we know about the problem as it is practiced by those who live in wealthy and exclusive worlds? These illustrations suggest two important points: (1) our knowledge about stigma, coming as it does from the stigmatized themselves, tends to be skewed since the poor and underprivileged, as opposed to the rich and exclusive, possess few social defenses against middle class investigators. There is no trick in studying poverty, not merely because there are so many poor people around but more importantly because it is difficult for them to defend themselves against being studied. If wealth was as popular a topic of study as poverty currently is do you think the Boston
Brahmins, the Philadelphia 400's or the Texas super-millionaires would be as accessible for long, personal tape recorded interviews as the Esmeraldas and Mendozas in Puerto Rico, East Harlem or the slum sections of Mexico City? This leads us to a second point and, perhaps, the most important point of all: (2) in the U.S. most known leprosy patients are lower class, often rural or foreign born. Abroad, leprosy patients are to be found abundantly in poor, underdeveloped nations. From the perspective of dominant western middle class society, these individuals are already stigmatized by virtue of birth, nationality, class, and education. In the case of leprosy the disease adds another layer of stigma onto populations already stigmatized. In countries like India, for example, outcaste status and ritual pollution are intrinsic features of Indian social organization and a person with leprosy coming from an "untouchable" caste would already be stigmatized and considered "unclean" by his own social "superiors" and Westerners by virtue, not of disease, but of birth.

The poor, the uneducated, the socially disadvantaged who are handicapped by disability, disease and disfigurement are also handicapped in their relations with middle class society in being less competent, less sophisticated, less worldly in developing and implementing strategies to successfully manage their handicaps and cope with the many problems they confront. Their lack of social and often psychological sophistication and the inadequacies of many rehabilitation centers in fully understanding the concepts and management of rehabilitation (again with notable
exceptions) compounds the disabled's handicaps and difficulties. In the field of blindness not all rehabilitation centers follow the theories of Father Caroll. As Robert Scott has pointedly noted, "Rehabilitators of the blind who have the same beliefs about blindness that the layman does are not agents of social change. They are agents of the community who make blind persons out of people who cannot see" (5).

The attitudes of "normals" toward the stigmatized has been studied. Studies have been published and essays written about how the stigmatized themselves attempt to disavow their deviance and manage tensions when singly interacting transiently with groups of or individual "normals." (6). Less is known about the rehabilitation efforts of groups of stigmatized living together collectively in developing their own ideologies to de-stigmatize them. At the USPHS Hospital-colony at Carville, Louisiana, the patients have formulated a theory of their own to account for their predicament, to de-discredit themselves, to challenge the norms that disadvantage them and supplant these with others that provide a base for reducing or removing self-stigma and other-stigma (7). Certainly, more needs to be known about the effectiveness of such ideologies as developed among other groups of stigmatized.

A few words about formal agencies who are charged with or who have assumed the charge of doing something for or about the disabled and stigmatized. Constantina Safilios-Rothschild
has noted that "...fund raising campaigns for the rehabilitation of the disabled may, in trying to secure more money.../over-dramatize/ the condition of the ill or disabled person, create the image of seriously handicapped persons who are helpless victims, unable to perform any useful activity and thus, reinforce the employers' fears, apprehensions, and prejudices" (8). Eliot Freidson has put the matter more sociologically and located it in a wider frame of reference. "Control agencies in our society...have the business of defining deviance and must both solicit support for their activities and account for what support they have already gained; if only to account for themselves, they must calculate a general universe. They can, of course, as...has been the case for some medical investigation, assume that what they see is in fact the total universe, but if they seek to maintain their level of support without implying that their method of control is ineffective, or if they seek to gain a higher level of support for their work, they are likely to consider the cases they see to be but a hint of the deplorable but as yet undiscovered state of things lying outside. If their orientation is punitive, they seek support to 'root out' deviance lying outside their purview; if their orientation is therapeutic they seek support to 'reach out.' In either case, they must define a universe outside of themselves" (9). A question to be raised here is the extent to which professionals' definition of the outside universe reflects their own particular experiences with the stigmatized, thus coloring their views and expectations about the attitudes of outsiders.
An additional consideration involves the social labeling of the victims through association with those who take care of them. For a number of chronic, disabled conditions of the past the medical establishment had essentially given up because little clinical improvement was possible. For several such instances—including, for example, mental illness—the care of victims fell to the lot of less affluent, less powerful, less educated, lower class people or marginal people from within the field of medicine. In the case of leprosy care was largely tendered by missionaries and church supported hospitals. In our view, leprosy has thus accrued over the years a certain aura of mysticism—it is akin to a "moral diagnosis" as well as a medical one (10). In short, leprosy—and perhaps other afflictions as well—does not enjoy the same degree of secularization as do conditions such as diabetes, polio, measles, etc. Illustrative of this point is that the observance of World Leprosy Day in 1969 included a service at the Washington Cathedral.

Our final comment raises a question for serious discussion, a question for which we think we have some positive thoughts to offer specifically relative to leprosy in the U.S. at least and, hopefully, generalizable to other conditions as well. Appeals made to Westerners where leprosy is not an imminent threat often presents a misleading picture of the disease as one adequately understood scientifically and under control. Were leprosy to show signs of spreading to fresh populations present
public explanations would be seriously compromised. The problem here may be one of the differential dissemination of information, information which alerts the scientific world into taking appropriate and rational steps in assuming greater responsibility in studying the disease epidemiologically and working toward a greater articulation and integration of medicine with the social and behavioral sciences on the one hand, and information, on the other hand, that does not frighten the public toward increasing stigmatization.

One absolutely final comment: we are not very optimistic that much success can be achieved through public education campaigns that aim at combatting stigma. On the other hand, we are much more optimistic that stigma can be materially attenuated by professionals where sophisticated rehabilitation methods, concepts, and techniques are employed and with significant advances in the medical sciences. What is at issue in rehabilitation with the handicapped "is not that the blind should have functioning eyes, the amputee new living legs, but rather that the blind and the crippled should be able to perform some 'normal' tasks without 'normal' equipment. The handicapped remain deviant, and the task of rehabilitation is to shape the form of their deviance, which is quite a different task than that of healing the sick or punishing or salvaging the delinquent" (11). In the case of leprosy, stigma will be appreciably attenuated once the disease is more fully understood medically and pharmacologically.
REFERENCES


3. Ibid., p. 97.


9. Freidson, pp. 82-83.


11. Freidson, p.95.
My research as a social scientist for many years has been primarily concerned with one particular type of stigma—namely, facial disfigurement, and the social and psychological problems associated with it: for example, its effects upon the individual and his family, adjustments to it and the management of it. Although my remarks will be confined to this handicap, I trust they will have general application.

Facial deformity differs, of course, from other types of physical disability in that it doesn't necessarily impair function or one's physical ability to perform the normal activities of daily living. But, because it involves the face, coupled with the prejudice that exists toward those who look different, it has grave social and psychological consequences.

In our concern with how to combat stigma, it is essential to remember that normality or deviance, beauty or ugliness are relative concepts—concepts which each society defines for itself.
With respect to the face there are societies where scarifications, blackened teeth, or grossly extended lips are self-imposed because these are considered prestigious or marks of beauty. In other words, what is perceived as stigmatizing in one culture may be viewed as an asset in another.

In our society, facial defects are greatly devalued. Highly visible and obtrusive as they are, they tend to evoke immediate reactions from others. A facial feature or condition that is unsightly or distorts expression elicits pity, repulsion, curiosity, or ridicule—and even what we call "cosmetic defects,"—acne for example—may be stigmatic.

Negative attitudes toward the facially crippled stem from several sources. For example, the tenacious holding of stereotypes that correlate character traits, intelligence, and behavior patterns with particular facial features and configurations is a factor that even in our so-called "enlightened" age operates to the disadvantage of certain individuals. A person with a low forehead or a receding chin, for instance, may be considered deficient in intelligence or weak in character. A flat nose or a twisted mouth is associated with a fighter or gangster. A large hooked or convex nose is identified as characteristic of a particular minority group. In other words, there is a tendency to assume that a face which happens to resemble a social or cultural stereotype is an accurate portrait of the person behind it.
And then there is the matter of genesis. There, for example, are numerous myths and misconceptions regarding the man whose face is scarred or misshapen by disease, or who was born with a harelip or without an ear. He has been stereotyped in folklore and literature as "the evil one"—a "freak" paying for the sins of his father or for something his mother saw while she was pregnant. He is to be regarded with curiosity or made a social outcast.

The devaluation of those with facial stigmata is intensified by the inordinate value placed upon physical attractiveness, which is regarded not only as a necessary component of success in our highly competitive society but is viewed also as a salable commodity. If we can judge by Madison Avenue advertising and other mass media, emphasis on how one looks seems to be taking priority over the qualities of the person himself. As the role of visual impression grows, external appearance becomes of major concern. "Exposure" has become a formula for getting ahead, and one's face is his passport. Since what one sees may take preference over what one hears, we find that even the fate of the politician may hinge upon the skill of the makeup man; the President of the United States unabashedly hires public image makers to guide him on optimal cosmetic effects.

Whether or not one is concerned about the apparent superficiality or our values—by contrivances to gain votes, to make money, or whatever is one's goal—we are dealing with a social fact: a fact which, as those of you who have read "The Selling
of a President 1968" know, played a major part in the strategy of Nixon's campaign advisers. Emphasizing the need to make their candidate "glamorous and honest," they put it bluntly: "Response is to the image." "It's not what's there that counts, it's what's projected." "It's not the man we have to change, but rather the received impression."

When we talk about how to combat stigma--how to change attitudes of the public--how to reduce prejudice and discrimination toward those with visible defects--we are faced with a difficult task. Social scientists have shed considerable light on the sources and causes of stigma, and its impact upon both the afflicted and non-afflicted--but not much on ways of reducing it. With respect to the facially disfigured the problem appears more difficult than with those whose handicaps involve other parts of the body. It is possible, for example, for amputees, the blind, or the paralyzed to move about in society, to get jobs, and even to appear on television. But the antipathy toward the facially disfigured person remains strong. Though reason tells us otherwise, our reactions are immediate and visceral.

While I may sound pessimistic, I am not entirely without hope. Changes in attitudes, values, and preferences do occur, and what is spurned one day may be accepted the next. Only recently we have seen some radical changes in concepts and definitions of what is physically attractive and what is ugly. Consider the 'hippie culture, for example, the popularity of the "Tiny Tims," and the concept of "Black is beautiful," which has reduced
the stigma of dark skin.

Several years ago the plight of those who had lost an eye was inadvertently eased by an advertising gimmick designed to promote Hathaway shirts. A black patch placed over the eye of a most distinguished-looking gentleman has since become the Hathaway trademark. At about the same time, Katharine Cornell played the role of an enchanting woman who also wore an eye patch. More recently, use of this appliance by such personalities as Moshe Dayan has practically eliminated its discrediting effect.

In considering methods of combating stigma, it seems to me that we should pay close attention to factors that have contributed to past changes—for this can provide us with valuable insights about the psychological approach to the public. In the examples I have given, alterations in attitude were primarily by-products of social phenomena. Two have been outgrowths of ideological movements—the hippie culture and Black Power; the other the result of a series of fortuitous occurrences.

As students of human behavior and the "hidden persuaders" of the market place well know, appeals to reason are not very successful. Relatively little of what we do is motivated by strictly rational considerations: hence the frequent failure of educational programs, legislation, exhortations, and fear campaigns to produce change, even though it is for our own good. Witness, for example, the efforts to make people stop smoking, to drive carefully, to avoid drugs, and so on.
What I am saying here is this: that in the consideration of ways to combat stigma we must not begin by exaggerating the extent to which reason is a determining force in human behavior, or by minimizing the extent to which we are governed by customs, preferences, cultural norms, emotions, and other forms of non-rational behavior. If logic and reason prevailed, we would not be here today to discuss how to combat stigma.

REFERENCES


STIGMA AND PUBLIC RELATIONS

William P. McCahill
Executive Secretary of the President's Committee on Employment of the handicapped

In the preface of his book Stigma, Erving Goffman identified stigma as being "the situation of the individual who is disqualified from full social acceptance."

He then went on to formulate a set of concepts that bear on what is called "social information" or "the information the individual directly conveys about himself."

Put in that light, it is easy to see that stigma today is frequently less a problem to the stigmatized person than is the reaction of the public to the person himself. Thus, we immediately find ourselves with a public relations problem.

If beauty is in the eye of the beholder, then it certainly follows that the lack of a "beauty" called physical perfection or physical normalcy becomes something less in the eye of the beholder, the public or the many publics that impinge upon the life of any man--or woman.

I am neither a sociologist nor psychologist, but rather a journalist turned practitioner of what is called the profession of public relations.

Most of my adult life has been devoted to combatting stigma, although I never called it that before I got involved in this seminar. We choose to call our enemy by several names, but they all add up to the title of our group session today. Our words
for stigma have been "ignorance, bias, misunderstanding, myths, prejudice, stereotypes, poor images or misinformation." The method we have chosen to combat this social ailment has generally been to familiarize people with the various disabilities in a positive manner, quite openly, with a soft sell, I might say, not a hard sell.

The slogans "Ability counts, not disability" and "It's good business to hire the handicapped," have been aimed, however indirectly at times, by emphasizing the positive, while admitting the negative and by endeavoring to establish the fact that people with disabilities have many more similarities to so-called physically normal persons than they have differences.

A psychologist friend of mine, Dr. Frank Risch, who is one of our true practical experts in the employment of persons—persons, I emphasize—who happen to have epilepsy says that our objective must be to normalize the defect of deficiency, these are his terms, "so that people can be more comfortable with that which they are more familiar." He said that strangeness is alien and therefore threatening and anxiety provoking and that the reaction is both unconscious and a result of a conditioning process which began in childhood.

So, Dr. Risch deliberately puts his men and women with epilepsy in situations requiring performance quite suitable to an average, or normal individual. Placing a person at a complicated and intricate machine, as I have seen him do, that most of us would have trouble operating, validates normalcy by their individual
performance.

I suspect that this is what most of us have been doing for twenty years and more, validating normalcy by performance, since ours is a work-oriented society. I never thought of it being quite that simple before, and it probably isn't, but I believe I'll rest on that statement for my purpose here today.

We, of course, validate that performance in a multitude of ways and we use everything from blimps flying over the Atlantic Seaboard to matchbooks or bookmarks. We use a gigantic billboard in Arlington, four stories tall and a block long, and a 2x2 black and white TV slide. But always, behind our message is a flesh and blood human being capable of besting many of us at tasks he or she can best do.

For twenty-eight years now I've been a Marine Corps reserve officer, functioning in the public relations field, and I have always emphasized that Marine Corps public relations is not good because of us practitioners but because of the individual Marine, and the image that he projects to the people he knows. Now, in Changing Times for last month, October, there's an article in which is emphasized how much public and private money is spent fighting disease. If you do have the Kiplinger issue you'll find that it goes from alcoholism down to venereal diseases. It lists the deaths, the estimated cases, how much voluntary agencies collect and how much the government spends. Well, the big Federal expense right now is for mental retardation: a little over half a billion dollars. Cancer, as far as government spending, is less than
$200,000,000.

The voluntary agencies collect for cancer more than $56 million; the voluntary agency collection for mental retardation is only $15 million. There is no necessary cause and effect relationship between the people who die of the diseases and the amount that Government or the private agencies collect. I suspect it's partly a matter of the squeaky wheel getting the grease. Depending on whether or not you've got the best operators at those squeaky wheels working for you, you do a better or a worse job in terms of fund raising.

In the President's Committee we've a little pamphlet called "Facts and Myths." We emphasize that workmen's compensation doesn't prevent people from working, that it doesn't increase compensation costs. The pamphlet is put out by the American Mutual Alliance in cooperation with us. They paid for it and we distributed it. Recently we got into a campaign with the Multiple Sclerosis Society. They weren't as blessed as agencies in the field of blindness or the field of epilepsy or other equally difficult diseases with a high powered, highly qualified P.R. staff. But we found out, much to our surprise, that there was a great plateau at which people with MS could work and consequently we are now featuring employment in a cooperative program with them. We drafted all pamphlets, put them together for MS and they paid for them. Together we distribute them. Most recently we've gone into the field of blindness working with Bob Barnett's AFB organization. They drafted the first promotion piece themselves and all we did was go along for the ride and our name at the bottom, adding whatever
We believe in a positive approach, with absolutely no plea for charity or pity. We are going to do this with more and more health agencies for two reasons: one, to orient them towards employment, which we feel is the queen of battles. If people work, many of their other community and social problems evaporate or become less critical.

Consequently we are involved in a campaign right now with many health agencies to get them to do more in the area of promoting employment. Most of them are now past that point where they have to worry too much about facilities and personnel and even fund raising techniques. They can now concentrate on something like this, on employment.

One last thought--one of our hallmarks has been recognition and reward. We have a very persuasive--and pervasive--awards program. We have employer awards, we have medical awards, we have personnel awards, we have awards for individuals, and we have awards for handicapped individuals as well. We are trying to raise the stature of a handicapped person as a person of significance. We are trying to raise the stature of people who work with them and alongside of them. Consequently, by involving many, many, volunteers and pointing them out as people of goodwill and high moral character and all the rest, we satisfy certain ego drives, but more importantly we enlist them for the duration. You'll find that businesses will let their executives run a cancer drive one year and a community chest or a Red Cross drive another year. Going into the communities of our country, time and time again, I attend meetings and find there six or eight former chairmen--still involved, still hitched,
because they are involved with the whole spectrum of humanity in a positive way.

Last night at the American Cancer Society annual banquet, Virginia Graham got off these two bon mots: "There is no language barrier in the field of pain." And: "The malignancy of indifference has been conquered for the most part in the field of at least cancer."

We have traded mortality for morbidity; doctors and scientists make it possible for people to live today, whereas yesterday they would all have been buried.

Consequently, we are going to have an increasingly larger number of handicapped people in the population. It is up to us in our various professions to do more than we have done and to do as much as we can to make it possible for them to be economically and socially viable.

There are impediments. As one of my very good friends said at one of our meetings, we are still a society that worships too much at the shrine of the physically fit. This frequently is detrimental to those whom he characterized as bearing on their bodies the Sign of Calvary. Although stigmata is a glorious sign to Christians, stigma is the exact opposite.

And one last thought: "You've got to convince people that what you are doing is not only good for the handicapped you serve, but that it's good for all the people in the community, state, or nation. The competition for tax and contributors' dollars and for volunteer time and talent is too fierce today for any public or private agency to exist very long unless its message is getting through to its very important publics."
LEONARD WOOD MEMORIAL

COMBATING STIGMA RESULTING FROM DEFORMITY AND DISEASE

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Bibliography


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