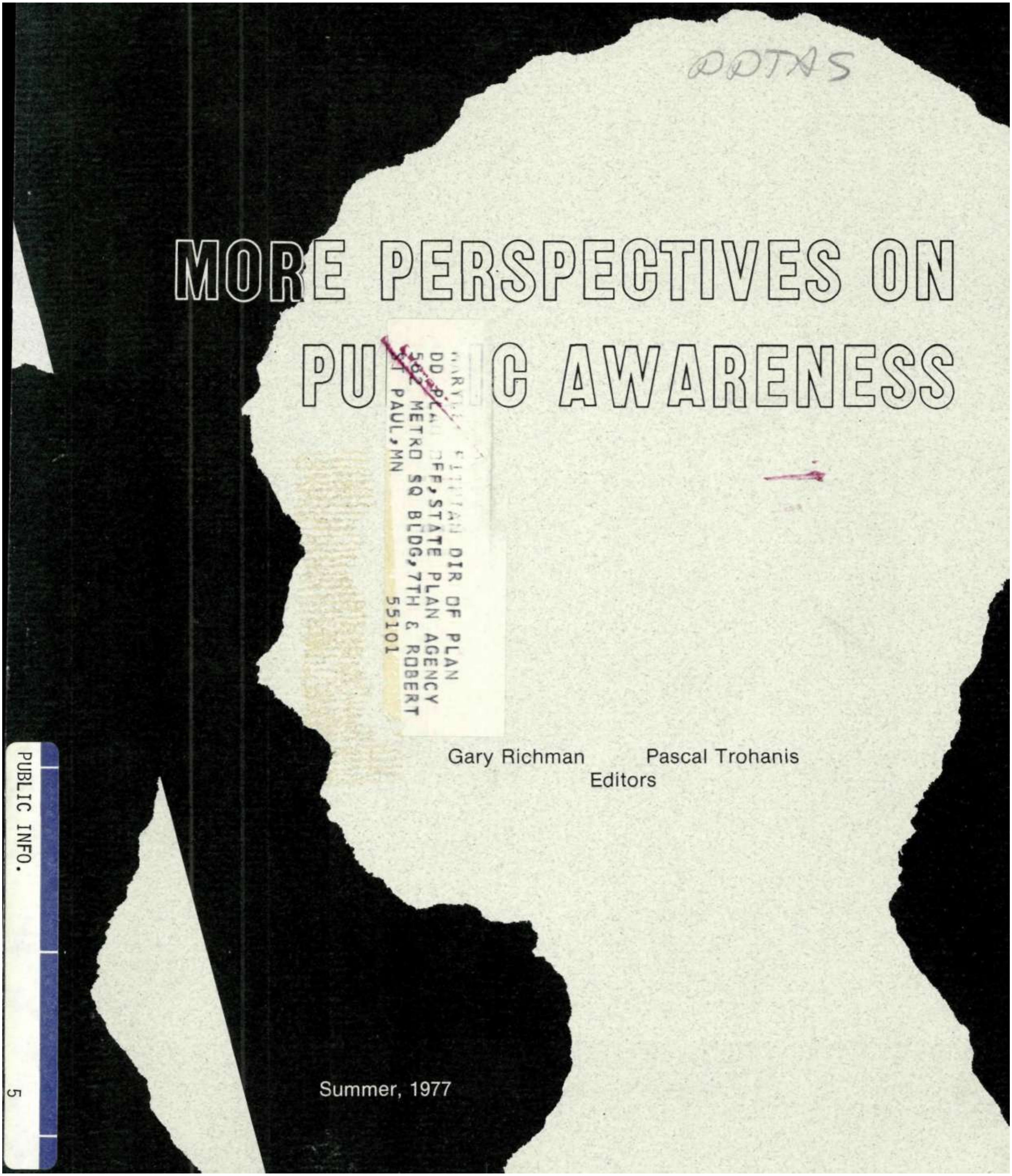

DDTAS

MORE PERSPECTIVES ON
PU C AWARENESS

Gary Richman Pascal Trohanis
Editors

Summer, 1977

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More Perspectives on Public Awareness is a booklet for this nation's Developmental Disabilities Planning Councils. Each participating state, territorial, and District of Columbia Council develops and implements a comprehensive State Plan for the coordination of comprehensive services, for citizens who are developmentally disabled. This booklet is published by the Developmental Disabilities Technical Assistance System (DD/TAS). DD/TAS is a division of the Frank Porter Graham Child Development Center, The University of North Carolina at Chapel Hill.

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MORE PERSPECTIVES ON PUBLIC AWARENESS

Gary Richman **Pascal Trohanis**
Editors

A Booklet for State DD Councils
Prepared by DD/TAS

Summer, 1977

INTRODUCTION

More Perspectives on Public Awareness represents the continuing and growing concern of Developmental Disabilities Councils to effectively use communications to change attitudes and influence behavior. Over the past few years the number of DD Councils engaging in public awareness activities, the variety of these activities, and the depth of Councils' involvement all have increased. Along with this increasing experience has come increasing expertise and thoughtfulness.

This booklet is designed to encourage that thoughtfulness and to improve the expertise of DD Council members and staff people involved in the planning and implementation of public awareness activities. The various chapters focus on some of the key issues, basic skills, and innovative programs in the area of public awareness related to developmental disabilities.

Like the earlier booklets on public awareness published by DD/TAS, More Perspectives on Public Awareness is an outgrowth of the national "Public Awareness Idea Sharing IV", the fourth annual meeting of DD Councils involved in public awareness. This year's meeting, held March 7-9 in Memphis, Tennessee, was attended by 15 states, and 6 regional and national projects involved in public awareness.

The chapters in this booklet were prepared by the authors who served as resource persons at the Public Awareness Idea Sharing meeting. Their chapters are not transcripts of their presentations nor is this document intended to serve as a proceedings of the meeting. The resource people were invited to participate in both the meeting and this booklet, because we felt that each had an important perspective on the issues involved in public awareness. We have enlisted their expertise to focus on areas in which DD Councils have had persistent problems or to explore new opportunities for effective DD Council action.

As always, we welcome feedback, not only on what is presented in this booklet, but on other public awareness topics of concern and interest to you.

Gary Richman
Pascal Trohanis

Chapel Hill, North Carolina
July, 1977

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PART I:

THE FOUNDATIONS OF PUBLIC AWARENESS

The concept of public awareness in the field of developmental disabilities has rested on a number of assumptions about the needs, techniques, results and effects. Part I offers two viewpoints of these assumptions in an attempt to solidify the foundation of future public awareness activities.

In Chapter 1 Lawrence Wiseman, Managing Director of the communication consulting firm of Moses, Epstein and Wiseman, Inc., of Washington, D.C. poses the perplexing question: "Do public awareness campaigns work and if so how do we know?" He suggests that the proof of effectiveness is in tangible results: changed behavior, and not just changed attitudes.

Gary Richman and Pascal Trohanis, Associate Directors of the Developmental Disabilities/Technical Assistance System, of Chapel Hill, N.C. share some concerns in Chapter 2 about how DD Councils measure the effectiveness of their public awareness activities. This and other observations about major stumbling blocks and the characteristics of "success" are drawn from their experiences in providing technical assistance to DD Councils.

CHAPTER 1

Beyond the Sixty-Second Solution

Lawrence Wiseman

> The most important thing to remember is that children and adults who have a degree of mental retardation experience the same feelings, hopes, joys, loves and sorrows that you and I experience. These are qualities that transcend mental and physical handicaps ... these are the things that make us people.
>
> Vermont Developmental Disabilities
> Planning and Advisory Council

What you've just read is part of a communications campaign undertaken by the Vermont Developmental Disabilities Council. The goal? To begin to change people's attitudes toward developmentally disabled people. The reason? Negative attitudes toward developmentally disabled people are the props that hold up the barriers between them and the rest of society. All the things that are crucial to a better and more dignified life for people with developmental disabilities -- more jobs, more housing, better independent living arrangements — depend, in the end, on how people _feel_ about the developmentally disabled.

Today, according to Frank Bowe, director of the American Coalition of Citizens with Disabilities (ACCD), "The problem is not so much with us, but with the people who are not disabled. We are always defined in terms of what we cannot do. We are determined to change those attitudes. I want to help others to see us as people, not as crutches and wheelchairs and canes."

Changing public attitudes toward developmentally disabled people is a vital component of all programs undertaken by DD Councils, so there is little need to justify or rationalize why DD Councils should try to do it. There are two more important questions that need examination. How can we make what we're doing to change attitudes work better? And how will we know when we've done it?

Does It Work?

> What's good for General Motors
> is good for the U.S.A.
>
> Charles Wilson

Mr. Wilson was being overly optimistic. While there are points at which the interests of GM and the interests of everybody else clearly intersect, there is at least one area where Mr. Wilson's formula is far off the mark: persuasive communications. What works for General Motors will not work for a human service agency trying to mount successful community education programs. You can't "sell" developmental disabilities, or prevent drug abuse, or change people's attitudes toward handicapped people, the same way GM sells station wagons.

Still, people try to emulate traditional product advertising -- and with astonishing results. Many drug prevention programs, for example, were fashioned in the traditional Madison Avenue mold: they relied heavily on television spots, posters and print. But these campaigns not only failed to prevent drug abuse among potential abusers, a National Institute on Drug Abuse study actually discovered that almost half of those that relied on communicating information had <u>negative</u> impacts. Evidently, learning about drugs — replacing fears and apprehensions with hard facts — did as much to stimulate drug use as it did to inhibit it. The track record of media campaigns to change public attitudes toward developmentally disabled people has been equally disheartening. John Gliedman and William Roth, in an article entitled "The Grand Illusion: Stigma, Role Expectation and Handicap", go a long way toward explaining why.2 They examine the sociological underpinnings of attitudes which able-bodied people hold toward people with disabilities. The way able-bodied people relate to disabled people seems to depend on at least three separate factors:

- inexperience and ignorance;
- the symbolic overtones of role expectations, and/or the handicapped person's inability or unwillingness to fit those stereotypes;
- the asymmetry of power relations.

Efforts to change attitudes, therefore, have to be aimed at these three different factors. Careful aim, however, does not guarantee success. Mass media information campaigns working independently, for example, are generally unable to change attitudes. Richard Ashmore suggests that their utility is much more limited. They can, he claims, reinforce the feelings of people whose attitudes are already positive. Or they can help "justify" attitude and behavior changes in someone whose negative intergroup attitude has been challenged <u>in some other way</u>.

Drawing, as Gliedman and Roth do, on an examination of attitudes and behavior toward blacks, Ashmore suggests that carefully planned, carefully structured direct contact between minority and majority groups is perhaps the most effective mechanism for attitude change. Gliedman and Roth make no such predictions, but they do agree that, to effectively modify public attitudes, we will not only have to modify the tools we are presently using, but we will have to find new tools that will let us chip away at the sociological foundations of prejudice.

Frank Bowe says, "The public image of the handicapped is *very* heavily weighted toward the telethon/poster child image. We depended on others to do our talking for us. Most often we got just what they were asking for. Charity." Frank Bowe was one of three hundred demonstrators who occupied the office of HEW Secretary Joseph A. Califano, Jr. in the spring of 1977. They wanted the Secretary to sign immediately regulations implementing Section 504 of the Rehabilitation Act of 1973. These regulations had come to be known as the "civil rights bill" for handicapped individuals.

The militancy of individuals like Bowe shocked many people. It also forced them to confront their prejudices. While they were used to seeing blacks or chicanos or women on the picket lines, wheelchairs and white canes were a novelty. Here were disabled people speaking out on behalf of their own interests. Walter Cronkite called it the beginning of a new civil rights movement. Frank Bowe thinks that it might also be called the beginning of an attitude change campaign that might actually change attitudes about disabled people. William Roth agrees: "Seeing disabled people in power, in control, may begin to shake up some preconceptions. This can challenge the falseness of many of society's attitudes about people with disabilities."

Militancy is not often discussed as a tool with which we can change attitudes toward disabled people. But seeing blacks in power, in control, did change the way many people perceived blacks. Seeing women in power, in control, did change the way many people perceived women. Perhaps DD Councils should think of what they can do to shape this tool to serve their own attitude change and program goals. Admittedly, there are problems in translating this kind of militancy directly to the DD environment. People who are mentally retarded may still need to depend on advocates who can speak for them. Traditional "helping" organizations may be initially uncomfortable with clients who do not behave in traditional ways.

Even if these problems cannot be resolved, thinking of political action as a public awareness resource can stretch our conceptions of what we must do to reshape public perception of people who are developmentally disabled. It can force us to look beyond the traditional tools of persuasive communication that we inherited from Madison Avenue. It can demonstrate that certain actions speak more eloquently and more directly than the most carefully written broadcast copy. Most important, it can continually remind us that to solve this critical yet complex problem, simple 60-second solutions do not seem to be the answer.

How Will We Know If It's Working?

> Senator: You are requesting $250,000 to mount a massive campaign to change the attitudes of citizens toward the developmentally disabled. Will you be able to come back next year and assure us that the money was well spent?
>
> DD Director: Of course, Senator.

It is far easier to advise finding innovative solutions to public awareness problems than it is to implement them. Part of the reason for this is that program planners rarely have access to data which can tell them which of their past efforts worked, and why, or more likely, why not. Suppose that our mythical director comes back and says that the Council produced X number of public service announcements that ran Y number of times on Z stations; that the Council slide-tape program was presented A times before B different groups with a total audience of C; that L brochures were mailed in sets of five to M households; and that the newsletter mailing list was expanded to Q; that J workshops were conducted for K County Medical Societies; and that the hotline took 10,000 calls. The Senator may well agree that the money was well spent. But did the program work? Customarily, people tackle this question from three directions.

First, there are those who assume that if you produce something very carefully and expose it in the correct fashion to as many people as possible, a campaign will work. The material will communicate whatever message you put into it; people will listen to it and hear it; and finally, they will act on it. This is commonly known as the "hypodermic" approach to persuasive communication. The audience is viewed as a mass. The campaign is viewed as a "syringe" full of "information" which, when injected into the mass, will cause it to somehow change. People who follow this line of thinking are constantly striving to find the right kind of "syringe" and the right mixture of "information" to squirt out of it. Advertising agencies, for example, spend millions tinkering with the content and format of television spots and print materials, trying to strike the balance of medium and message that will reach people, and move them.

Second, there are those who admit that simply injecting the right message directly into the mass through the right medium may not guarantee that people will hear you. There are "things" out there, the logic goes, that might distort what you're saying, or dilute its impact. A message might run up against a brick wall of "customer" resistance. Or it might run contrary to the prevailing wisdom of the community as expressed by its opinion leaders. Or it might just get lost. People sensitive to these kinds of problems often undertake surveys to see if the message is getting through to people, and doing its work. Advertising agencies will survey the public to measure the rise and fall of "brand awareness," or "product recall."

Third, there are those who recognize that causing people to say one thing, rather than another, to an interviewer does not necessarily mean that you are changing their behavior, too. People who "remember" a product called ERA may continue to buy TIDE. People who are "aware" of all the advantages of taking the train may still find the plane more convenient. Communicators sensitive to this gap between reported attitude changes and changes in behavior often try to find ways to measure changes in behavior and then link these changes to the campaign they've put together. Advertising agencies try to link "waves" of television spots with rises in sales. Or they will interview purchasers of products to learn what "convinced" them to buy.

Where do DD Councils fit into this framework? All Councils recognize the need to evaluate what they are doing in public awareness. Most end up measuring performance through some combination of the first two techniques:

* It's a great movie. We've distributed it to 400 groups this year. They all say they love it.

* Those TV spots look as good as any Schlitz commercial I've seen. The station managers are bending over backwards to give us airplay.

* I really have problems with the way you underscore dependency in that spot. It's too reminiscent of the "poster child" image.

* We surveyed five classes before and after they read our materials. More than half showed more positive

attitudes toward the developmentally disabled.

- Sixty percent of the employers who came to our seminars reported that they left with a better understanding of how they could employ more disabled people.

These are traditionally valid measures of performance. But, while they answer some questions, they don't necessarily answer the important one: Did the campaigns produce more housing, better education, a wider range of jobs? Did it foster the growth of better transportation, better social services, a more receptive community? As any advertising executive will tell you, finding answers to *these* kinds of questions is a fearsome task. Many government agencies which undertake community education as part of their legislative mandate don't even try. When they do, their findings are often dismal. In 1974, M. S. Goodstadt reviewed the literature that reported on efforts to evaluate drug education. He found that, first:

> there is an almost total lack of evidence indicating beneficial effects of drug education. *Very* few educational programs have been evaluated and almost none have shown significant improvements in anything other than levels of knowledge; *attitudes and drug use have generally remained unaffected*. Second...there is *very* little scientific evidence from which one could *confidently* draw conclusions regarding the effectiveness of drug education... it can only be concluded that the necessary evidence is not yet available, although the evidence that does exist is not encouraging.[4]

These were expensive lessons to learn. By the time these findings had been published, government and private organizations had been in the drug abuse business for more than ten years. Millions of dollars had been spent, while program planners struggled to find a way to measure what was happening at the bottom line, which in this case was incidence of drug use, not attitudes or awareness.

There is a moral buried here. It can be stated in two parts. First, DD Councils should commit themselves to measuring how well their public awareness programs work. Second, they should try to measure them in terms of how they affect the bottom line, how they help the Council achieve its primary mission of promoting more housing, a better protection and advocacy system, a more receptive community and so on. Developing the capacity to do this will not only help Councils improve existing public awareness and education programs. It will sensitize them to the wide range of forces operating in the community which affect the way people look at and behave toward developmentally disabled people. This alone can help Councils plan more carefully, more frugally, and come closer to nudging the bottom line.

Footnotes

1. John R. Olsen, "Primary Prevention Research: A Preliminary Review of Program Impact Studies," Literature Search Task Group of the National Institute on Drug Abuse, unpublished paper, December 1976.

2. J. Gliedman and William Roth, "The Grand Illusion: Stigma, Role Expectation and Handicap," unpublished chapter from a forthcoming book published by the Carnegie Institute, 1976.

3. Richard D. Ashmore, "Background Considerations in Developing Strategies for Changing Attitudes and Behavior toward the Mentally Retarded," Begab, M. J. and Richardson, S. A., The Mentally Retarded and Society, Baltimore: University Park Press, 1975, p. 159 ff.

4. M. S. Goodstadt, "Myths and Methodology in Drug Education: A Critical Review of the Research Evidence." Appears in Goodstadt, M. S. (editor), Research on Methods and Programs of Drug Education. Toronto, Canada; Addiction Research Foundation, 1974.

CHAPTER 2

Public Awareness as a Developmental Disability

Gary Richman
Pascal Trohanls

A New Definition for an Old Problem

Developmental Disabilities Councils have a series of complex and challenging tasks. The federal legislation (PL 94-103) mandates them to plan the comprehensive network of the services needed by persons with developmental disabilities, coordinate and integrate an existing fragmented service system, monitor and evaluate the delivery of services, and serve as advocates on behalf of these citizens. Over the past six years, as DD Councils have organized to implement these mandates, they have consistently identified one barrier to services for the developmentally disabled. This barrier has become a recurrent theme regardless of what "role" the Council pursues or what goal the Council wishes to accomplish. This barrier existed when Councils first organized in 1971 and persists today, and, to paraphrase the legislative definition of a developmental disability, this condition can be expected to continue throughout our lifetime and is a substantial handicap to the development of a humane system of services for persons with special needs caused by epilepsy, mental retardation, autism, and cerebral palsy. The barrier is the lack of public awareness, knowledge and sensitivity to the rights and needs of persons with a developmental disability. Regardless of the issue one looks at, medical care, housing, information and referral, education, transportation and so on, there are invariably people whose attitudes DD Councils would like to change or whose knowledge or information they would like to increase or correct.

DD Councils have consistently identified negative or ambivalent attitudes and lack of or incorrect information as major barriers. As a result they have identified public awareness as a priority goal, attempted to design appropriate strategies and materials, and allocated resources to public awareness activities. Our experiences during the past five years providing technical assistance to DD Councils to meet their broad general mandates and in their specific public awareness activities provides a vantage point from which to share some observations about Councils and public awareness efforts. These observations are of two types. First there are three interrelated problem areas which seem to be chronic, stumbling blocks confronted by most DD Councils. Second, there are a number of characteristics which are common to most of the more successful and rewarding Council public awareness efforts.

Before going farther, it is probably worth issuing a caveat: these observations on basic problem areas and characteristics of effectiveness of Councils' public awareness efforts are just observations. They are not based on any particular survey or any formal research on DD Council behavior. Rather, this is the product of several years of observation and work with at least 40 state DD Councils.

Some Stumbling Blocks

So, where do DD Councils stumble? Frequently on the *very* first step: defining public awareness. This is not to suggest that a formal, academic definition of public awareness is needed, nor is one being offered. Much of the attraction of the term, "public awareness" is its generalness and flexibility; it covers a vast array of situations and strategies involved in changing attitudes or information levels. The problem is that the two words "public awareness" conjure up some type of definition, function or activity in nearly everyone's mind. And almost as often these notions about public awareness tend to restrict the concept to some definite set of functions or activities. So while one person sees "public awareness" as the promotion of the DD Council in order to increase its visibility, someone else envisions a statewide mass media campaign, a third person thinks of some type of information and referral hotline or directory of services, while yet another has in mind some type of outreach.

It may seem like a case of "stating the obvious with a profound sense of discovery" to suggest that Council members must agree on a mutually understood definition of public awareness before they can communicate even with each other. Yet, a Council may spend considerable time working on just such a definition of deinstitutionalization, respite care or advocacy, but everyone, it is assumed, knows what public awareness is. And that is precisely the problem; everyone does!

The second stumbling block is often a consequence of the plethora of individual notions about what public awareness is. It could be called the "public awareness strategy knee-jerk reflex." It operates like this: say "public awareness" to anyone and the odds-on response is one of the following: brochure, press release, TV spot, newsletter or film. These are strategies, or techniques to be used in public awareness efforts. Too frequently they become synonymous with public awareness, making the concept of planning public awareness activities meaningless. A Council can easily fulfill a "goal" of having designed and distributed 5,000 brochures by July 1, but that gives no hint of the significance or impact of that action.

It cannot be stressed often enough that public awareness efforts must be planned. The process of planning may be simple or complex, but the Council should be able to answer these five questions:

*WH0 is the target population?

*WHY do you want to affect them? If the Council can answer this question by saying they want them to do something, as opposed to <u>know</u> or <u>think</u> something, then they're on the right track.

*WHAT message do they need to receive in order to motivate/enable them to <u>do</u> (know/think) it? The answers to these first three questions comprise a goal statement.

*H0W are you going to deliver the message? It is only this fourth question that requires the selection of public awareness techniques to answer.

*H0W WILL YOU KNOW if the target population does/knows/thinks it? Evaluation! It is also essential that you be able to answer this question as well. Certainly evaluation is essential to account for time and money spend, but there is a more fundamental reason. Public awareness must be more than blindly throwing darts at a wall, there must be a mechanism for seeing if you've hit the target, and preferably the bull's eye, and then correcting you aim.

A third stumbling block is a logical consequence of failing to plan public awareness activities appropriately. One of the keys of the developmental disabilities concept is coordination and integration. It is essential that this concept apply to public awareness as well. There is a strong and counterproductive tendency to see public awareness as a separate, discrete endeavor, handled by a specialist, with special techniques. There are two faces to this problem which when stated seem painfully obvious, yet, like the first two issues, their existence is found far too frequently. The following senario illustrates the problem.

A DD Council identifies community resistence as a major barrier to the development of community residences. They develop and fund a general public awareness campaign to change public attitudes concerning persons with developmental disabilities living in the community. At the same time, a state agency or private service providers are attempting to develop group homes and are meeting substantial opposition in local communities and neighborhoods; they have done no public awareness planning, have no strategy, and are coping with the opposition on a "crisis" basis. It seems obvious that the group home planners need some public awareness effort as part of their strategy if their goal of establishing community residences is to be reached. It should be equally clear that the DD Council has established a strategy but has no real goal. That is, they have failed to adequately address the second question in the planning process, "Why?" Public awareness, alone, can never lead to the development of groups homes. In one form or another these two activities, citing group homes and public awareness relating to community acceptance of the developmentally disabled, are frequently going on independent of each other in one state.

The lesson which must be learned is that public awareness efforts should facilitate program goals. DD Councils consistently identify the public awareness dimensions of problems relating to advocacy, SSI, civil rights, the Education of All Handicapped Children Act (PL 94-142), medical and dental care, community residences, and so on. These are complex problems requiring planned, integrated, and coordinated action on several fronts. Public awareness cannot be the solution, but neither can it be omitted from the solution.

These three stumbling blocks represent the major barriers that Councils must be aware of and overcome. Careful, thoughtful, planning and appropriate action should go a long way in helping cope with these potential problems.

Characteristics of Success

If there are chronic stumbling blocks, there have also been successful and effective public awareness activities. There seem to be a number of characteristics or indicators common to these activities. Certainly they do not constitute a formula for success or effectiveness; there is no "magic bullet" in public awareness. Conversely these characteristics of success are not a list of minimum prerequisites; some Councils have failed to follow the pattern discussed below or have even done the opposite and still had a significant impact on the public. Nonetheless, the basic characteristics for successful public awareness efforts include surmounting the stumbling blocks and organizing resources in a manner which promotes the integration of public awareness with other program activities.

First, the Council must be able to get beyond the members' individual conceptions of public awareness and reach a mutually understandable definition in order to develop a clear, concise statement of goals and objectives. In practice that has usually meant one, well thought out goal or perhaps two closely related goals. Moreover, this one goal might be characterized as "modest." That is, it has one or more of the following: a limited target audience, limited behavioral objectives, limited message and can be accomplished within a one year plan. This "modest" goal provides a solid foundation of experience, credibility and self-confidence for the next, more ambitious goal.

The most important indicator of effectiveness concerns the degree to which the public awareness activity is integrated into other program goals. It is possible to identify three general types of DD Council public awareness efforts. In the first type, the Council's goal is self-promotion or self-description. This is typical of new Councils just beginning to think about public awareness and is usually a reaction to their newness and lack of security in the state government landscape. It is generally a sign of Council maturity when the focus of public awareness shifts to the rights and needs of the developmentally disabled.

The second type has as its central theme these rights and needs but public awareness activities are still largely an isolated, discrete function. In the third type, public awareness concerning rights and needs is well integrated with other activities which are seeking to assure rights and meet needs. The third type is the strongest indicator of effectiveness.

Do Councils evolve from type two to type three as a maturing or developmental process? Probably not. It is more likely that having progressed beyond type one, a Council employs a public awareness style which is indicative of its general operational style within the state. Councils which are functioning as integrators and coordinators of the service system within the state shape their public awareness efforts similarly. Councils which are isolated and insulated from other organs of state government are probably unable to develop a public awareness (for any other kind of) activity which is not separate and isolated. The more fundamental problem is nurturing a Council which serves as a coordinator and integrator in all its activities, not just public awareness.

The allocation and organization of resources for public awareness is another characteristic which may serve as an indicator of two things: the level of commitment and, again, the amount of integration. The budget is one crude but simple indicator of commitment.

If there is no budget for public awareness or if the functions are delegated to already overworked staff members, the potential for effectiveness is small. Perhaps the best way to measure the budget is in relative terms, as many of the minimum allotment states have made a little bit of money go a very long way. However, the little bit of money allocated for public awareness is, for them, a substantial financial commitment.

DD Councils have organized their resources for public awareness in a variety of ways: hiring a full-time staff person, making grants to private non-profit organizations, or contracting with professional public relations or advertising firms. Each of these configurations has met with some success. The most effectiveness, or more accurately, least consistently troublesome arrangement has been a staff person supplemented with sufficient budget to "purchase" needed additional expertise. One reason for this is again the notion of integration. The staff person is more directly in touch with the Council, other staff and other elements of state government and is more able to facilitate a coordinated approach. Similarly there has been some limited experience but positive results with "grants" to state agencies to add or improve public awareness in on-going programs.

A final characteristic which indicates both integration and commitment is the involvement of Council members. The potential effectiveness of a Council public awareness staff person is greatly enhanced by an active committee or task force on public awareness. Some Councils who have had effective public awareness programs have used a task group which included resource people with abilities and interests in DD and public awareness who were not necessarily Council members. It is a mutually enhancing cycle when a public awareness effort is interesting and rewarding enough to attract people with the energy and ability to contribute and who are not there due to any commitments implied by membership on the DD Council.

Some Concluding Remarks

Public awareness represents a conscious attempt to bring about changes in an audience's knowledge, attitudes or actions. The awareness effort must be clear, sensitive, and action-oriented in its design and approach. Furthermore the Council must realize that audience changes do not occur overnight. It takes time to overcome ignorance, misinformation, prejudice, and discrimination toward citizens with developmental disabilities. Ultimately, DD Councils must direct their efforts toward the various publics who can and will make a significant difference in the lives of handicapped people.

PART II:

PUBLIC AWARENESS SKILLS

Public awareness is the utilization of specific skills relating to attitudes and information in the process of change. Part II examines three traditional areas of expertise which public awareness professionals most often use.

In Chapter 3 two former DD Council public awareness staff people discuss relations with the news media. Marion Maier Galant was formerly the Public Information Officer for the Connecticut DD Council and is currently Communications Director for the Colorado Division for Developmental Disabilities. Toby Knox, of Creative Communications, Inc., was formerly the Director of Vermont DD Council's Project Awareness. Their article provides a fresh review of the variety of tasks and strategies in this area.

Producing effective print materials is an integral part of the public awareness process. In Chapter 4, Dan Prince of Nashville draws on his experience as a freelance writer/producer to render suggestions on the improvement of printed communications. His basic thesis is that we should, and can, learn to do more with less.

Finally in Chapter 5, Barbara Lee Cohen and Gregg Ackerman offer an outline of suggestions on planning and producing Public Service Announcements for television and radio. Barbara Lee Cohen is Director of Development for the Illinois Association for Retarded Citizens and is director of an HEW Region V grant to produce public service spots for use by DD Councils. Gregg Ackerman is Executive Producer for Topel & Associates Ltd., a national film company based in Chicago.

CHAPTER 3

Media Relations — Making DD News

Marion Maier Galant
Toby Knox

The media, as they are known, generally have a clear idea of what their job is. Part of the awkwardness of our relationship with them is that they sometimes don't understand what our job is and, unfortunately, sometimes we don't either.

Our job is increasing public awareness of the Developmental Disabilities movement through <u>public information</u>, making specific information readily available, and <u>public education</u>, improving or deepening the public's understanding of a subject, often one they never paid much attention to before. Both of these are aspects of <u>public relations</u>, which may be defined as "doing the right thing and getting credit for it." PR stands for "performance" and "recognition" (Cutlip and Center, 1965). When applied to the media, public relations means speaking their language. Since journalists and broadcasters are looking for news, our job involves operating within the framework of news.

What Is News?

News stories are commonly categorized by the terms hard news, soft news and feature stories. Depending on the format of the newspaper or the radio and TV news show, one type of news story might be more acceptable at one time than another. A continuum of stories varying between the three categories described below is also a possibility.

"Hard" news is copy about an event, action, person, or statement that is timely, factual and of current importance. Examples of developmental disabilities "hard" news are grant announcements, Council actions and decisions, statements by the Council Chairperson on an important and current issue, and reactions to current events.

"Soft" news is different from hard news in that it does not meet the press deadline criteria and thus will be as newsworthy to the reader tomorrow as today. There is a fine line between hard and soft, and news items can transfer between the two categories depending on the timing and importance of the issue. Examples of developmental disabilities "soft" news are election results for Council officers, recognition awards to Council members, the hiring and promotion of staff members, Governor's proclamations and the like.

A feature story is an in-depth look at an issue, event or person, and is generally an expanded treatment of a soft news item. It is written in an entertaining and informal manner. Feature stories appear most often in Sunday papers, news magazines and when a radio or TV station needs filler material. Feature stories give you the chance to explain facts in detail and with editorial comment. Human interest stories are the best material for features. But even a feature story must hang on a "news peg," an element of newsworthiness.

A good gauge for newsworthiness is that a story involves a) a lot of people, b) a lot of money, c) a prominent person, d) an injustice to a person or group, e) something unique in your area, f) something universal. Six handy determinants of news are: timeliness, proximity, prominence, uniqueness, scope or breadth and consequence.

Unlike a news story, a feature story's strong point may be the fact that it does not have timeliness as its news peg. A good feature can be developed when your schedule permits and released to papers and stations for use at their convenience. A file of solid feature stories, written on days when you feel inspired, will stand you in good stead during busier days when you don't have the time or the peace of mind to develop stories. They also help you maintain a flow of material to the press, letting press people know that you can be counted on for regular, good copy.

Often there will not be obvious material for a story, and thus you must be imaginative and create news. You always should be on the look-out for news opportunities. Publicity has been defined as news events that are planned. You can publicize your interests and create news by having the Council Chairperson testify before the legislature on a current issue or hold a press conference to release an important report. Politics is always news - prominence. Convince a local legislator to visit a group home, a sheltered workshop or tour a developmental center. He has an opportunity to show his concern with the handicapped; you have a story in the paper.

News opportunities also can occur when a credible spokesperson for the Council reacts to an event, issue or statement: For instance, piggy-backing on a national story from Washington and adding state or local pertinent facts and interpretations. Always look for the local angle on a national story. A recent suit by parents against a hospital for its failure to administer the PKU test was carried by the national wire services and provided a natural lead in to an article on genetic birth defects.

What is Newsworthy?

One of the most difficult aspects of dealing with the media is recognizing a good story and deciding what is newsworthy. One way to solve the problem is to talk with the news editors and inquire as to what they feel is newsworthy. Remember that the different categories of news can be used at different times in the same paper. Also important is the audience: ask yourself if the particular issue would be of interest or consequence to them. If not, don't bother with the story.

The mass media are not the only media available to you in an awareness campaign. They should be used for communicating with the general public and can be an educational tool, an awareness vehicle or a news dissemination mechanism. If you want to get a message just to a small specific audience, don't plan to utilize the mass media. Plan a direct mail campaign or speaker's program, but don't expect to use newspapers, radio and television with any degree of success. Conversely, newsletters will reach a specific audience but are useless for informing the public at large.

Meeting the Media

Well established media contacts are vital, and you will be glad you have cultivated them when you suddenly have a fast-breaking story. It's well worth spending half a day on the phone to develop a master list of contacts and to keep it accurate.

List the name, mailing address and telephone number of every newspaper, television and radio station you will be dealing with. It's helpful to make this list by region, rather than alphabetically if you are working state-wide, so that you can easily locate the outlets you need for a local story. You will want to list the Managing and City Editors, Medical writer, "Life Style" and Sunday editors for newspapers, the News and Program directors for broadcast stations. While you are getting this information by telephone from the switchboard, talk to the program director to find out the station's preference for public service announcement length, number of seconds, and whether television stations prefer film or video tape. You'll be surprised how handy this information is.

When reporters call you for information on a story, jot their name and the subject on your list. You will have specific people to contact, and often the added advantage of a reporter who is flattered that you remembered him or her.

The next step is personal visits, which are most important. A good "way in the door" is to arrive with a press kit, or with a positive comment on a recent story on developmental disabilities that the paper or station has covered. Make appointments for your visits when you can, and at least be sure to avoid arriving at press or air deadlines. You'll be surprised how much warmer the response will be to your next call when there is a face to associate with it.

Often the members of the press corps must be made aware or educated as to what developmental disabilities are, what they mean in a person's life, what services are available (and what are not), and other facts that will give the reporter or editor a better understanding of the subject. Don't expect that the person covering your story has done homework and understands all the issues at hand.

To avoid this problem, it is advisable to prepare a press kit and deliver it to each newspaper and radio and television station. The kit should consist of an outside folder (which can be labeled file folder) and easy to read and understand factual materials. Don't fill the folder with pages and pages of copy or every brochure your Council or agency has ever published. If you want the materials to be read or even reviewed, limit the contents to general information which can be used for future reference. The kit's contents can be periodically up-dated and expanded. If appropriate, include a black and white picture or 35mm color slide suitable for reproduction by newspapers and TV stations respectively. If possible, have a Council member from the area deliver the kit to the local paper or radio station.

In dealing with the media, there are a number of guidelines which should be observed:

(a) Be honest and straightforward. Don't be afraid to admit lack of knowledge, but always offer to find the answer.

(b) Be a trustworthy and credible source.

(c) Be professional. The more professional you are in your approach with an editor, the better your chances are in having your stories printed.

(d) Don't overload an editor with releases. Send periodic stories. Too many too often will result in most of them ending up in the trash unopened.

(e) Offer exclusives to papers or stations periodically. Don't play favorites, but giving a scoop on a rotating basis will win friends.

(f) Know deadlines and observe them.

(g) Be accessible for questions, interviews or to obtain needed materials. Be friendly and open.

(h) Don't be disappointed or react negatively if your story doesn't appear in print or on radio and TV. If you think the story is important and of value, plan accordingly with alternate methods of news dissemination.

(i) Always thank the person who writes a good story and show your appreciation to the editor. Radio and TV stations, especially, like to have letters of appreciation in the file to be used when FCC licenses must be renewed.

Getting Your News Out

The press release is the most common way to get an unsolicited news item into the mass media. While news editors often will change it to suit their format, space or time available, the same release can be used for newspapers and radio and TV stations. The release can be used to tell an entire story, notify the press and public of a planned event, or as background for the editor for future stories, such as a feature.

In writing the release, think of an inverted pyramid with paragraphs set in order of declining importance. The standard "who, what, where, when, why and how" should be covered at the head of the story. Important details come next, and miscellaneous information is last. Use short paragraphs, sentences and words. Be sure to use everyday language and omit the "big" words and jargon. Send the release to the person you established in your telephone or in-person survey as interested in developmental disabilities or human service area, or to the city editor.

Don't think press releases are the only avenue to the public. Invite reporters personally to cover an interesting speaker, seminar or workshop which an agency is presenting. Make sure you are there to aid the press with background information that will provide a good story. Every speaker or seminar isn't news, but if the subject is controversial, or the speakers are going to introduce a new technique, approach or theory, that's newsworthy.

Sometimes you needn't write the story yourself: one of your visits to a local editor might be to provide him with a story idea that one of his reporters can follow up. A court ruling on a group home zoning challenge is not only a "hard news" story, but also an excellent opportunity to send out a fact sheet on group homes or a good feature on their development.

Remember, too, that different newspapers have different time constraints. Find out when your weeklies publish and the deadlines for the last editions of the dailies. Don't neglect specialty papers published by high schools and colleges, local businesses and neighborhoods, as well as professional journals, newsletters and the growing "handicapped press." Company papers will welcome feature stories on the contributions of their employees to volunteer programs, and weekly local papers, which are often read more thoroughly than the big city daily, often hold "timeless" features to run as space permits. A series of short articles, used as fillers, can get wider use than one long feature article.

Weekly or Sunday papers often will welcome a regular column on issues affecting the handicapped or disabled population. The column should be sent to the paper in finished form requiring no attention or work by the editor. A regular column will provide the readership continual exposure to the issues affecting the disabled and may help increase public awareness, interest and understanding.

Photographs should not be overlooked as a way to tell a story or obtain publicity. They can be used alone with a caption or as part of a larger story. Feature stories should have one or two pictures or drawings. Check with your papers to determine what size and finish is best for their use. And a striking color slide can create a good human interest story for a television news show.

If you are not certain your event will be covered by papers or TV stations, and it is worthwhile, hire a free lance photographer to take some pictures and distribute them as soon as possible after the event.

Not all the news is good, of course. Make use of the Letters To The Editor pages and the consumer editorials offered by the media to explain a problem or to congratulate a public figure on a job well done. While you can only guide thinking in a news or feature article by the way in which it is written, in a signed letter to the editor you can come right out and take a point of view. If it is a "hot" issue, or one on which the paper's editorial staff has already taken a stand, it is worth a visit to explain your group's position and reinforce the seriousness of the issue. Letters to editors are best received over the signature of a Council or advocacy group member or a State official, although it's often up to the information specialist to keep them clear and concise.

Editorials, while not read by a large segment of newspaper readers, are an additional opportunity for raising the awareness level of the public. Editorial writers often will not accept canned, prewritten editorials, but a telephone call will determine that. The national advocacy groups, such as NARC, send canned editorials to their chapters for distribution to friendly editors during Mental Retardation Month. If your editors won't accept someone else's copy, a friendly notification that April is the special month devoted to employment for disabled persons, for instance, might be enough to generate a positive editorial in the paper.

News conferences are common to all media, perhaps too common. They should be reserved for use only with a _real_ news announcement, an exceptional, fast-breaking story. Nothing will undermine your hard won news contacts faster than a couple of ho-hum press conferences. Remember that for news people time really is money; if you are going to tie up a reporter and a photographer, there had better be a good story in it. Plan your news conference to meet the deadlines of the papers or stations which are most important to you, and give them as much advance notice as possible. Pick a photogenic and creative location, something that ties into the subject matter if possible. And don't be discouraged at low turnout. Do send follow-up copy to those who didn't make it. If they really missed something, they'll try harder to be there next time .

In general, respect the differences between print and electronic communication. On-air time is much tighter, so your copy must be concise. There is stiff competition for air time and the telephone is always ringing in the news room, so be able to explain the essence of your story in just a sentence or two. Above all, keep in mind that television is a visual medium. The setting of your story must give the audience something to see, or there will be nothing to carry the story. Nothing to see? Try radio.

Talk shows are an excellent way to do public education, and the local, daily shows are often in need of guests. Most talk shows book some time in advance, so call them-with a guest they can schedule far in advance. If the medium is television, some kind of visual illustration of the guest's subject is helpful, like a color slide or a concise, legible chart, or samples of the workshop's product, etc. News programs, both on television and on radio will often do two minute "featurette" interviews on a feature topic, and Epilepsy Month or Awareness Day or a Governor's proclamation will often provide you with the subject matter.

For fund raisers, don't forget radio station remote broadcasts. These are becoming increasingly popular as radio stations strive to meet their public commitments, and they are both good publicity and free advertising. Since remotes usually run several hours, the disc jockey or announcer will have plenty of time to do a little public education with the help of the fact sheets and special guests you provide to give the broadcast continuity.

Pre-recorded statements for radio news, called "actualities," can be used to give stations live comments or reactions to a story. This form of radio news coverage is especially useful if the Council's Chairperson wants to comment on an event that took place in one part of the State, but the radio station requesting comments is several hundred miles in the opposite direction. Actualities give the station and your Council the chance to have live comments on the news without the need for a face to face interview.

The most important things to remember in establishing good media relations are: be accessible, be creative and be accurate. The media is as tired of "ducks in a row" photographs as the rest of us are, and a novel approach is always welcome. Filter your news through your own objective judgement: Would you be interested in this story if you weren't working for developmental disabilities? If not, save it for a specialty publication or an association newsletter. Your greatest asset in media relations is a reporter's confidence that when you call, it means good copy.

Some Helpful Resources

Some publications that can aid you in developing your public relations programs are:

"Telling the UCP Story"
United Cerebral Palsy of America, Inc.
66 East 34th Street
New York, New York 10016 ($1.00)

"Toward Public Awareness - How to Communicate
with Your Neighbor"
Tennessee Association for Retarded Citizens, Inc.
2121 Belcourt Avenue
Nashville, Tennessee 37212 (Free)

"If You Want Air Time"
Public Relations Service
National Association of Broadcasters
1771 N. Street, NW
Washington, DC 20201 (Free)

"Publicity Handbook"
(Useful for small civic clubs and volunteer
advocacy groups)
The Sperry and Hutchinson Company
Consumer Relations
3003 E. Kemper Road
Cincinnati, Ohio 45241

"Ayer Public Relations and Publicity Style Book"
Ayer Press
210 W. Washington Square
Philadelphia, Pennsylvania 19106 ($9.95)

"Handbook of Public Relations"
by H. Stephenson
McGraw-Hill Publishing Company ($13.80)

"Communicating: How?"
A Manual for Mental Health Educators
Division of Scientific and Public Information
Alchohol, Drug Abuse and Mental Health Administration
NIMH
5600 Fishers Lane
Rockville, Maryland 20852
(An in-depth study of Project Alternatives
in Kentucky)

ENCOR
Hear Ye! Getting Your Story Told
116 South 42nd Street
Omaha, Nebraska 68131

Reference

Cutlip and Center, Effective Public Relations (Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1965) p. 4.

CHAPTER 4

More with Less

Dan Prince

The need to cut through the haze and maze of messages has never been greater: at no time in history have there been so many media messages floating around. Capturing a reader's attention requires distinctively designed, highly appealing printed material. Having gained an individual's attention, the printed piece must then deliver, imparting its message both effectively and efficiently.

In trying to implement public awareness activities, Developmental Disabilities Councils enter an arena already overcrowded with competing messages. In addition, DD groups are faced with a series of constraints that make the task even more difficult.

* Limited resources - money, time, talent, energy;

* Many different needs - both in public awareness and in other programmatic areas;

* A context of deeply rooted attitudes, behaviors, and values - which make the handicapped person a second-class citizen in the eyes of most people;

* A new concept - Developmental Disabilities - trying to supplant a series of older, separate concepts: mental

retardation, epilepsy, cerebral palsy, autism;

* A new emphasis on accountability - by the consumer, the funding agency, and the internal organization.

Just as it is possible to build smaller engines that deliver more miles per gallon, it is possible for us to do a more efficient job of producing good printed products. As always, in the face of limited resources and increasing demands, the challenge is to do more with less. Here are my suggestions, and biases, on how you can improve the quality and impact of the printed materials you produce.

Ten (More or Less) Suggestions

Do MORE with less . . .

1) WITH FOCUS: Concentrate your energies. Avoid the temptation to be all things to all people. Pick your target audiences carefully. Limit the number of target groups. Likewise, attempt to communicate only one or two messages at a time. Design a campaign, which is a media-maker's way of saying "plan." Specify "do-able" objectives and a way of measuring your success. After you get agreement on the plan, stick to it. Scrap it only for compelling reasons. Don't take on additional communication assignments until you have completed your priority tasks. Establish and retain FOCUS of effort.

2) WITH GOOD TALENT: Individual DD Council members may be your most overlooked resource. But if you don't have folks with public relations/advertising skills on the Council, get at least one on some kind of basis - member, advisor, ad hoc participant, whatever. The solution may not be forming a special committee. You want ideas and information and possibly production assistance. Carefully weigh the alternative means of obtaining these without having to set up another committee.

Use available resources: the area university, community schools, interested professionals and media students. Build a repertoire of talent: a card file, perhaps, of local artists, photographers, writers, directors, narrators, etc. Assess their individual strengths and weaknesses, their cost and availability, their capability to work under pressure, short time frames, etc.

When someone does a good job for you, let them know it. Show your appreciation, whether or not you pay them for their services. Imagination does not ooze out of the end of a camera, it bubbles within someone's head. Surround yourself with GOOD TALENT.

3) WITH GOOD IDEAS: Where can you get "good" ideas, you say. Anywhere. They are all around. Some say that creativity is looking at the usual in unusual ways.

Start your own "Swipe File": instead of tossing all that junk mail, keep those pieces that use interesting graphics or copy. Tear out a magazine ad that catches your eye. Latch on to appealing brochures. Go to lunch with someone who knows nothing about DD. Test a couple of ideas on him. Listen for other ideas. Allow time for the gestation of ideas: after first considering a problem, let it alone for a day or two.

Remember that you are probably your best source of ideas. Don't be afraid to generate some "wacky" ones; you, and others, can always tone them down later. Be willing to stretch the boundaries; that way you will have the chance to turn cloudy notions into GOOD IDEAS.

4) WITH GOOD RESEARCH: Good research backs up good ideas. And precedes good copy and good design. Take the time to do it, but not too much time. You're probably not expected to write a research paper. Don't wait too long to generate a "first draft." Reaction to an early draft can guide further

research efforts. Just as importantly, it can stimulate the development of a layout, the scheduling of photos, the doodling of artists. It's critical to some up with something tangible, no matter how rough. It's the only way we ever get started - or ever get finished.

Make an effort to find out about your subject and about your audience. Too often, research is confined to the subject matter and little attention is directed at the amorphous creature who is supposed to be out there reading the final prose. Some knowledge of the reader will guide you in your research of the subject matter. As a writer or producer, you want to answer the questions the reader would ask. So, do your homework; whether that involves reading pertinent books or periodicals, getting into the field to interview folks, or bringing in the experts.

Find out not only the "facts," but also the issues, the controversies, the antagonists. Dig until you know both the glossy, positive aspects of your story and the shadowy, less savory features. That way you can ultimately produce a communications tool that is honest, positive, and well-targeted.

Seek the help of others in the research process; take advantage of what they already know. But remember, you are the one responsible for ultimately suggesting just what should be said and how it should be said. In the end, your own curiosity and some dogged digging are the basis for GOOD RESEARCH.

5) WITH GOOD COPY: Copy which does the job efficiently and effectively is good. It must, above all, speak to the audience. It must capture their interest, and tell a story in a way that is meaningful to them. Too often we write to ourselves. Avoid the temptation.

Nearly every group is guilty of cluttering up perfectly good English with multisyllabic phraseology (you see!) and byzantine sentence structure. Simplify your sentences. Keep them short. With the gargantuan volume of printed stuff demanding people's attention today, you owe it to your reader to be as clear and concise as possible. I do not believe that because your intended reader is highly educated or a "sophisticated professional" you have the right to engage in an epic. In fact, the time of that reader is probably more valuable and more limited than that of some other target groups. So do them all a favor. Adopt a tone appropriate to your reader, use specific technical language as required to explain critical concepts, but don't get caught up in convoluted copy. When you finish a draft, ask yourself if the same message could be communicated in fewer words. Strive to do better each time; the result is likely to be GOOD COPY.

6) WITH GOOD DESIGN: Good design is no easier to define than good copy and no less important. Good design is the union of that which is functional with that which is artistic. The selection of format (flyer, poster, fold-over brochure, stapled booklet), the choice of paper, inks, the body and headline type, the composition of the page are some of the ingredients. Each requires your careful attention and best judgement. All work together to affect the appeal and readability of any printed piece.

Unless you are a designer yourself, my suggestion is to get help. A sharp graphic designer will turn an ordinary brochure into a snappy, memorable mailer. Your ideas and knowledge can, and must, guide the process. But the use of a professional will do much to enhance your materials and go a long way toward the point where someone picks up one of your booklets and says, GOOD DESIGN!

7) WITH GOOD VISUALS: The inclusion of illustrations and photographs is pretty much standard practice. But there are some occasions where you might as well skip them. A murky snapshot of a group of people sitting around a table seldom adds much. Photos don't have to be in color (the cost is too

much for most projects), but they do have to say something. And they really should be of good technical quality.

If there isn't anybody else to do it, learn to shoot pictures yourself. The basics are not difficult to grasp; only mastery is hard. Train yourself to think visually. In what ways could this thought be portrayed? How can I say something visually without resorting to a group of talking heads?

Illustration can cover a host of styles and sins. Use it sparsely; it is relatively expensive whether you do it (your time) or hire it done (your budget). When faced with a production assignment, consider whether a graceful line drawing might not do as well as a more complicated painting. Compare the value of an illustration with a photograph or of just using bold typography.

Learn about some of the interesting ways of printing photographs: messotint, high-contrast, wavy-line conversion, etc. You can turn a rather staid photo into an arresting graphic image. Do not crowd a page too tightly just so you can get a photo or two on the page. In fact, remember that "white space," in addition to providing relief to the eye, subtly spotlights the material you do put on the page. Avoid the temptation to include a collage of pictures or illustrations. Often, one strong image will say much more. Use your subject matter, your communications objective, and your target audience as guides to developing GOOD VISUALS.

8) WITH GOOD FEEDBACK: In order to do better in the future, you should be interested in how you've done in the past. Try to develop feedback and evaluation mechanisms. Consider including a mailback coupon or conducting a follow-up survey. Find out if your printed piece reached the intended audience, if it was read, if it was acted upon. If you get into direct mail activities, use some of the proven techniques from that field (such as the

split ballot procedure).

If you had your choice, you would probably rather know before you print something if it is any good. Well, the fact is, you do have that choice. Show your copy or your dummy layout or your comprehensive to some of your ultimate consumers. Get their reaction before you finalize copy and design. On the other hand, beware of feedback from those who are too close to the subject matter; they are not representative of your reader.

It is not particularly easy to arrange for or budget for formal evaluation. But it is worthwhile. Seek those opportunities which will give you GOOD FEEDBACK.

9) WITH GOOD MANAGEMENT: Management means turning a vague concept into 500 printed booklets which fulfill a particular communication reed. It probably includes getting those booklets into the hands of the intended reader, as well. Good management implies the judicious use of resources and the meeting of objectives. It entails the establishment of budgets and deadlines, procurement of people and materials, and the coordination of all elements. It is the process of getting things done, in this case, printed things.

One of the principles of producing media is that the closer you come to a finished product, the more expensive it is to make changes. Therefore, it is a good idea to outline all of the major steps involved in creating and printing a particular item. Decide beforehand just exactly who will review the product at its various stages of development. Know ahead of time what approvals will be required at what stages. Build in both time for review/ approval and time for revisions.

Many people have to "see" a brochure before they know if they like it or not. But instead of letting yourself be surprised when you present the finished work, show them the item at its various stages. It's a lot easier to revise a comprehensive layout than it is to change "final" mechanical art.

Even if your "client" trusts you to follow through once the basic copy and design is approved, take advantage of the natural review points yourself. Get someone who's unfamiliar with the copy to read it. Reread it again before you typeset it. Meet with the printer yourself if you can. Take him a written copy of the printing specifications. And keep one for yourself in case the job doesn't turn out right. Make it a standard practice to get a "Van Dyke" or "Blue Line" Proof. Even if you make changes after the negatives have been shot, it is still cheaper than waiting until the job has been run. Remember that it is easier to delete stuff from a negative, but adding copy or art requires reshooting.

If your job has any special printing features (such as multi-color, close spacing, or large areas of solid color), ask the printer if you can be there when the first batch comes off the end of the press. Working with first rate typesetters, engravers, and printers may be somewhat more expensive than dealing with some of their competitors. However, they are more likely to do the job right, and if they make a mistake (as we all do sometimes), they are more likely to remedy the error in a gracious and professional manner. Another important point: find a printer who will give you a realistic deadline and commit himself to meeting that deadline. It doesn't do you much good to have the annual report the day after the annual board meeting! Producing printed materials requires a form of project management. By learning from your successes and failures, you can develop GOOD MANAGEMENT.

10) WITH FOCUS: You can do more with less if you don't scatter your efforts. Selecting a target audience, a target message, and a target medium clearly implies focus on a <u>target</u>. Use an approach more akin to a rifle than a shotgun, and you're more likely to hit the bullseye.

CHAPTER 5

Public Service Announcements for Radio and Television

Barbara Lee Cohen
Gregg Ackerman

Public Service Announcements (PSAs) through the radio and television broadcasting industry offer DD Councils a powerful means for communicating with audiences. They can help to disseminate information on developmental disabilities, promote a specific Council activity or priority, or alert the community about the service needs and rights of citizens who are developmentally disabled. Since broadcasters are besieged with many appeals for air time, Council personnel must make sure that their message has wide appeal and is presented in the best and most appropriate manner. The following outline offers some suggestions on the formats, planning, production, and distribution of PSAs.

I. Formats for Public Service Announcements (PSA).

   A. Length: PSA can be 10, 20, 30, 50, or 60 seconds long. (20, 30 and 60 are most common.) Also 5 or 10 second "tags" to be used with station identifications can be used.

B. Material

   1. Film-color or black and white
   2. Videotape-color or black and white
   3. Slides or press photos with superimposed title, typed copy for announcers, audio tapes, or records for TV.
   4. Typed copy for announcers, audio tape or records for radio.

Planning to use Public Service Announcements

A. Determine the concept and desired content for the PSAs.

   Then ask yourself:

   1. What is the objective?
   2. Who are the target audiences?
   3. What do these audiences believe to be true about the program or subject?
   4. What don't they know?
   5. What do we want the audience(s) to understand or become aware of?
   6. What will be the focal point, main objective, slogan, moral or major theme?

B. Then research all available materials already being used to determine if anything exemplary is presently available to suit your needs and to determine what has or has not been effective . . . and why.

   Once you have tapped all the resources you and your associates are aware of, are fully knowledgeable as to past efforts and confident that your concepts have merit and are truly consumer oriented, then it's time to proceed.

C. According to many professional representatives of film and media sources, spots that relate positive thoughts, the sharing concepts, create more goodwill and are many times more effective than those that shock, cause guilt, or try to induce sympathy. So keep this in mind.

III. Production with or without a Budget.

A. If you have enough money to produce film PSAs:

1. Seek out a film production company familiar with creating commercial products. News photographers and freelance photographers are other possible resources, but they are often not as familiar with successful techniques employed in developing commercial film pieces for general consumption.
2. When you contact these film production companies, keep in mind that you are the client. You are coming to them with some concepts and a budget, and in exchange they should provide you with a proposal, including their ideas on how to develop your product and a complete breakdown on costs. And be sure to contact more than one company. Contact TV stations for sources; they're the ones who review all the commercial material that arrives and know the companies that produce these commercials. Call the guilds that producers/directors belong to; they have lists of reputable film, commercial audio/visual studios and ad agencies.
3. Film production houses like to do PSA's. PSA's offer these companies more creative control than is normally allowed by advertising agencies who contract them for commercial products.
4. Costs: An average 30 second commercial can cost a film production house $8-10,000 per day in fixed production costs, that is, film equipment, personnel, editing, travel to location and talent. Your production may cost less, but

quality productions cost money. Remember, the more complex the concept and script, the greater the costs. Simple concepts and script can save money. Every budget should include multiple prints of any film spots. They normally cost $6-8 each.

5. All budgets are limited, and it is better to concentrate on developing fewer good products than to spread your ideas and funds too thin.
6. Another important cost consideration: If you carefully develop your filmspots, you should be able to create several different PSA's and explanatory materials for use. For example, from one 60 second film spot, you could produce 30, 20 and 10 second TV spots; 60, 50, 30 or 10 second radio spots; slides to be used with titles or voice-over copy; stills to be used for press photos, brochures, and posters, etc.

If you don't have a budget for films.

1. Consider the other, less expensive production techniques such as slides, type written copy and so on.
2. Another possibility: If there are local TV stations, media personalities or talents appearing in your area who are open to new ideas or have previously expressed interest in programs similar to yours, you might wish to contact one or more of them to assist you with development and production of your PSAs, appearances on film, recording of spots or assistance on distribution. It is helpful to write them first so you do not take up their valuable time with lengthy phone calls.

C. Other Production Considerations regardless of budget:

1. Be simple and concise: don't try to accomplish everything in 60 seconds. A Public Service Announcement should be no longer than 60 seconds and most are only 20 or 30 seconds. If you must include a tag line on a TV spot, then your spot should only run 50 to 55 seconds. The same holds true for radio spots. A tag line usually covers the source to contact for additional information and should only run 5 or 10 seconds.
2. If you are providing typed copy, prepare your spots carefully and <u>time each one</u>. The reason for careful timing is that if your announcement is too long, the station's Editing Department may cut out the most important things you want to tell the audience.
3. Another hint with typed copy is to provide stations with a selection of two 60 second, two 30 second and two 10 second spots. This gives them a selection to rotate and flexibility to slip them into available air time spots.
4. Another good source to consider would be a Volunteer Technical Assistance Committee which you could create, composed of professionals in the Public Relations, Advertising and Media fields. This group could assist in development and distribution of your PSA's and might be able to work with you on future projects.

IV. Distribution

A. A Federal Communications Commission (FCC) ruling requires each radio and TV station to allot a certain amount of time per day for

Public Service Announcements from reputable not-for-profit organizations. However, the Public Service (or Community Relations) Director and staff are not obligated to select your materials. Hundreds of PSA's are received per day at every radio and TV station with requests for their limited air time.

You will improve your chances of getting your spots on the air if:

1. . . . you have good quality spots. Media sources have a commitment to air Public Service materials; however, your spot is competing for air time. The more effective the materials you present to stations, the greater the opportunity to have your PSAs aired, and in decent time slots.
2. . . . you research all available media sources and make sure you have the proper name and spellings of Public Service, Community Affairs (Relations) and Program Directors at stations, as well as the correct address, zips and phone numbers. By preparing your distribution lists in advance, you will be saving yourself time and concern when you have a deadline later.
3. . . . you present them to stations clearly, concisely and professionally. Prepare brief cover letters to your media sources for your public service materials in which you explain your project, your requests and list enclosures. Be sure you list the Who, What, Where, When and Why in your cover letter and print materials. Send a complete set of spots to the stations, and you will have good results. You can follow-up with a phone call to insure receipt and answer questions.

4. . . . you give stations adequate advance notice. Unless you are dealing with a small station which operates on a day to day basis, plan to distribute your Public Service radio and TV spots at least three weeks in advance of when you want them on the air. If your PSA's are part of a campaign, please notify the stations and send them lists of the series and the order you wish to have them run, or the facts on the dates you plan to distribute.

B. If you have a Sufficient Budget: There are distribution companies such as Modern Talking Pictures, who can package your spots, deliver them to the appropriate directors of television stations in your area and deliver usage reports to you after they have been on.

C. A Public Service Announcement is a courtesy extended to not-for-profit organizations. Therefore, do not take advantage of the station's kindness. And always extend a thank-you to the station in person, if possible, and in a letter as well. The letters are excellent material for the station's community service file.

Always remember that although your cause is a worthy one, there are hundreds of other organizations seeking public service time from the same sources. So it is important to reiterate the following points:

1. Plan your spot well in advance;
2. Use all the professional assistance available;
3. Present your material on time and in a professional manner;
4. Follow up and, most important, express your appreciation to everyone who is involved.

PART III:

PUBLIC AWARENESS ACTIVITIES

When DD Councils identify public awareness needs, two target audiences have consistently been ranked at or near the top: legislators and health professionals. The reason these groups are so important is that they have great actual and potential influence over the lives of persons with developmental disabilities, yet we, those involved in the DD field, feel that they have less than complete information with which to form opinions and make important decisions.

Part III looks at three projects aimed at these two target audiences. They are not just public information campaigns, but rather each integrates the techniques of public awareness and other disciplines in a manner which is designed specifically for the respective target audience. In Chapter 6 Douglas Weber, Research Analyst for the Georgia Developmental Disabilities Council, describes a systematic plan of action for approaching state legislators. He suggests that legislators can be influenced by advocacy or public awareness if the efforts are properly planned with the right information, the right timing and the right approach.

Chapters 7 and 8 describe two _very_ different approaches aimed at health professionals. The National Foundation of Dentistry for the Handicapped, which receives funding from the Developmental Disabilities office, DHEW, is dedicated to developing and improving dental care for the disabled. Public awareness is one essential tool to energize and mobilize dental educators, dental practitioners, the service system and the consumer advocates in a community. The goal is the development of a comprehensive oral health care system for the developmentally disabled. In Chapter 7 Larry Coffee, a dentist and Director of the National Foundation of Dentistry for the Handicapped in Boulder, Colorado discusses the fundamental problem of oral health care for the handicapped and approaches to a comprehensive solution.

The last chapter deals with physicians, especially pediatricians. The Oregon Association for Retarded Citizens identified as major barriers to appropriate diagnoses and referrals the lack of adequate information about developmental disabilities and about where and what kind of services are available. Working with a very modest budget and extensive volunteer help, the Oregon ARC collected and collated the required information and distributed it on an individual basis to all the pediatricians in Oregon. Marilyn Paxton, Oregon ARC Field Representative describes this project in Chapter 8.

CHAPTER 6

Advocating Before the State Legislature

Douglas Weber

As Developmental Disabilities Councils move beyond planning of services and into an advocacy role, they likely will find it necessary to obtain authorizing legislation or budgetary support from their state's legislature. Both will be forthcoming if the Council 1) understands the special context in which legislators conduct their business, and 2) approaches the legislature systematically and according to an established plan of action.

How to Follow or "Track" Legislation

Chart One outlines the major steps in the legislative process. Any basic state government textbook can provide an elaboration of these stages. An exceptionally good text is Thomas Dye's Politics in States and Communities (Englewood Cliffs, New Jersey, 1973).

Not contained in such textbooks, however, is adequate advice on how to "keep up" with legislative business. Essentially, two types of information are required. The first is information which need be obtained only once per session. This includes:

Chart One

Stages In The Legislative Process

1.	INTRODUCTION OF BILL OR RESOLUTION	ASSIGNED A NUMBER (H.B./S.) AND REFERRED TO A COMMITTEE. [FIRST READING]
2.	COMMITTEE HEARINGS	OFTEN THE CHAIRMAN HAS NEAR ABSOLUTE AUTHORITY FOR SCHEDULING
3.	COMMITTEE MARKUP	COMMITTEE BALANCES WHAT IT WANTS WITH WHAT IT THINKS IT CAN GET.
4.	COMMITTEE REPORT	RECOMMEND "DO PASS," AS AMENDED
5.	PLACED ON A CALENDAR	MAY BE MORE THAN ONE CALENDAR AND THE ACTUAL ORDER OF DEBATE MAY NOT FOLLOW THE OFFICIAL CALENDAR.
6.	FLOOR DEBATE, AMENDMENTS AND VOTE ON PASSAGE	DEBATE MAY BE LIMITED AND CHAIRMAN WILL BALANCE TIME FOR PRO AND CON ARGUMENTS. AMENDMENTS ARE VOTED ON FIRST, THEN THE BILL AS A WHOLE, PRECEDED BY SECOND (THIRD) READING.
7.	REFERRED TO SECOND CHAMBER	"DO NOT PASS GO, DO NOT COLLECT $200."
8.	CONFERENCE COMMITTEE	ELITE ACCOMMODATION AT ITS FINEST
9.	VOTE ON CONFERENCE COMMITTEE REPORT	GENERALLY NOT DEBATABLE OR AMENDABLE.
10.	SENT TO GOVERNOR FOR SIGNATURE OR VETO	MAY INCLUDE "LINE ITEM" VETO FOR APPROPRIATIONS BILLS AND/OR A "POCKET VETO."

- Names of legislators, by district with addresses;
- A picture book of legislators, if available;
- A list of legislative committees, subcommittees, and their members.

Less useful will be copies of House or Senate parliamentary procedures and rules, though this too can be obtained. Your State's House or Senate Clerk's Office (or Secretary of State) usually can provide the above information.

Other information is available only on a day-to-day basis. The Council should have a designated person who regularly collects this information, if any real attempt is to be made in following the course of legislation. The information includes:

- Copies of daily "first readers;"
- Copies of legislation and resolutions of interest to Council;
- Daily updates or status reports on bills and resolutions;
- Schedules of committee meetings, if open to the public;
- House and Senate calendars.

"First readers" are a complete list, compiled daily, of bills and resolutions read for the first time by number and title. An example of a first reader is:

> S.B. 82. By Senators Carolton (14th), Hays (33rd) and Weaver (41st).
> A bill to reduce the cost of health care by closing all State supported mental retardation centers. REFERRED to Committee on State Institutions and Property.

A daily culling of first readers is a useful short-cut to identifying legislative items in which the Council might wish to take an interest. When a first reader piques your interest, obtain a copy of the bill or resolution in question and read, it through, carefully.

A "legislative update" is simply a scorecard of where a bill is in the legislative process. A "calendar" is a list of bills referred out of committee for consideration by the full House or Senate. The House and Senate have separate calendars, just as they individually adopt their own rules of procedure. A calendar represents a sort of daily "order of business." However, this is only generally true, and will vary from state to state (or House to Senate). Often bills are taken out of order for consideration from the order in which they appear on the calendar. Sometimes the only way to know what is coming up next is to attend House or Senate sessions.

All of the above mentioned information likely can be obtained from one or another of the following places:

- House or Senate Clerk's Office,
- Office of Legislative Counsel or Legislative Research,
- Legislative Budget Office,
- Committee staff offices.

And do not overlook the following daily sources of information:

- Executive agency or Governor's Office legislative liaison personnel,
- The press,
- Newsletters or legislative updates distributed by interest groups, including state or local ARCs.

Armed with this information, you are prepared to dig in and observe the legislative process. An ability to influence the course of legislation requires something more.

The Legislative Environment

"The legislature is weak; the Council is strong." This is not as presumptuous a statement as it appears. The average legislator is vulnerable. He has not one, but several "Achilles' Heels." Chart Two lists these weak spots for the average legislator, along with some defense mechanisms used to

Chart Two

The Legislator's Achilles' Heels

The Weakness	The Defenses
TOO LITTLE TIME	1. WORK THROUGH A COMMITTEE SYSTEM
	2. ALLOW LOCAL LEGISLATION AND CERTAIN RESOLUTIONS TO PASS THROUGH "UNANIMOUS CONSENT"
	3. ARRANGE "PAIRS"
	4. ALLOW FRIENDLY AMENDMENTS
	5. EMPLOY "COMMITTEE ON THE WHOLE"
TOO LITTLE KNOWLEDGE/EXPERTISE	1. SPECIALIZE IN A POLICY AREA
	2. JUDGE THE PEOPLE INVOLVED, USING PAST EXPERIENCES
	3. RELY ON OTHERS FOR ISSUE DEFINITION AND INFORMATION
	4. WATCH HOW OTHERS VOTE
TOO LITTLE ENERGY	1. ACCEPT ASSISTANCE IN DRAFTING AND AMENDING LEGISLATION
	2. BE WILLING TO COMPROMISE
	3. DO NOT FIGHT UNNECESSARILY
	4. KEEP A SENSE OF HUMOR
TOO MANY FRUSTRATIONS/ TOO FEW REWARDS	1. SEEK THY FRIENDS, AVOID THINE ENEMIES
	2. QUIT THE LEGISLATURE

protect and defend the legislator. Space does not allow a full elaboration on these points. But high turnover in membership, limitations on the number of days the legislature can meet, and little or no staff for individual legislators contribute to or are manifestations of these weaknesses. Further, many of the behaviors which appear to the layman as irrational or irresponsible ("unanimous consent;" voting as others vote) are better understood as adaptive behaviors, attempts to make the best of a bad situation.

Each of the legislator's weaknesses represents a potential strong point for the Developmental Disabilities Council. The Council's strengths are:

* Access to and provision of tinely, accurate information and advice,
* An ability (sometimes) to negotiate or broker a solution between legislators or between administrative agencies,
* Public gratitude to a legislator for a job well done.

Chart Three summarizes a model of legislative influence and formalizes the author's perspective on the manner in which Councils may come to work in cooperation with State legislatures. Familiarity may breed contempt, but it may as well breed influence. It is somewhat an established fact of social-psychology that the more frequently persons come into contact, the more they are to perceive each other's views as having some legitimacy.' As a rule, the more frequently the Council interacts with a legislator the greater the probability that he will view the Council's goals as legitimate. And perceived legitimacy may directly lead to influence. So plan to meet often, preferably face-to-face, with persons the Council wishes to influence.

Personalities and attitudes will play an intermediary role between personal interactions and perceptions of legitimacy. Chart Four, gleaned from political science literature, lists some of the ways in which the legislator

Chart Three

A Model of Legislative Influence

PERSONAL
INTERACTIONS

PERSONALITIES, ATTITUDES

PERCEIVED
LEGITIMACY

POLITICAL
SUPPORT

ACCURATE,
- TIMELY,
ACTIONABLE
INFORMATION

t

INFLUENCE

either sees himself or is seen by others. While not wanting to "label" legislators, interactions with them will be facilitated if it is kept in mind that the legislator usually has an image of himself which he cherishes. Do not detract from that image. One way of not detracting is to let the legislator "have his way" when in contact with him. Know when to accept half a loaf and when to give up a battle when the war is lost.

Two other factors also contribute to influence: political support and accurate, timely, actionable information. Of the two, the latter is of greater importance and too often overlooked. Legislators, on most issues, do not have their minds made up before an issue hits the floor for debate and action. And when a bill is up for a vote, few legislators know much of anything about the merits or demerits of the bill. In this situation, the Council (and others) can have a dramatic impact by assisting the legislator with information about the matter requiring his action.

But education must begin early and is part of a continuous process. During the legislative session, legislators are inundated with literature and pleas for support. In this situation, they are unlikely to read more than one page of printed (double-spaced) material, even when delivered to them in person. "Education" must begin before the session convenes. This is not to say that the right information at a critical point is unimportant. The Council, by virtue of its agency representation and high level position in State government, has access to a wealth of information of use to particular legislators on particular subjects on any particular day of the legislative session. The timely delivery of accurate information is a high return investment. And there is no hard and fast rule as to what is "timely."

But information delivered must be "actionable." This means the legislator must see the information as directing his future actions. A long treatise on

Chart Four

Types of Legislators: Role Patterns

As They Might Have Others See Them

DELEGATE	LOOKS TO HIS CONSTITUENTS FOR THE SOURCE OF HIS INSPIRATION. "Their will be done."
TRUSTEE:	FOLLOWS HIS OWN CONSCIENCE AND PERCEPTION OF THE PUBLIC GOOD.
PARTISAN:	A DEFENDER OF THE TRUE FAITH. ONE WHO LOOKS TO THE PARTY LEADERSHIP FOR GUIDANCE.

Approach to Legislative Assignments/Activities:

RITUALIST:	APPROACHES THE JOB AS A TECHNICAL TASK. IS AN EXPERT IN THE LEGISLATIVE PROCESS. POLICY MAY BE SECONDARY TO THE PROCESS OF LAW MAKING.
TRIBUNE:	VIEWS HIMSELF AS A DEFENDER OF THE PUBLIC'S INTERESTS, A SPOKESMAN FOR POPULAR DEMANDS OR NEEDS.
INVENTOR:	A POLICY INITIATOR OR EXPERT. HE TRIES TO SOLVE PROBLEMS AND AVOID FUTURE PROBLEMS.

Attitude Toward Interest Groups

FACILITATOR	HAS KNOWLEDGE OF GROUP ACTIVITY AND A FRIENDLY ATTITUDE TOWARD SUCH ACTIVITY.
NEUTRAL:	EITHER LITTLE KNOWLEDGE ABOUT GROUP ACTIVITY OR NO STRONG POSITIVE OR NEGATIVE ATTITUDES ABOUT SUCH ACTIVITY.
RESISTOR:	HAS KNOWLEDGE OF GROUP ACTIVITY, BUT IS HOSTILE TOWARD IT.

Based on: John Wahlke, et.al., *The Legislative System* (New York: John Wiley and Sons, Inc., 1962).

on Public Law 94-142 may be informative, but what does it suggest the legislator do? Help him out. Tell him what the information requires in the way of further constructive action: a motion to amend a bill, to refer it back to committee, etc. Of course, asking the legislator's advice on what is the most appropriate course of action is a good strategy, but have some ideas in mind beforehand.

Political support is not unimportant, though often overrated. The average legislator wants to do what is right for his district, so a show of support by constituents may allay doubts about whether a particular action is appropriate. On the other hand, a wealth of groups from the legislator's home district want action from him. He must make a choice between alternatives. So demonstrations of support are not always enough, with two qualifications. Home town support for a bill or appropriation more often will have a positive effect on a legislator when 1) it is accompanied by timely, accurate, and actionable information and 2) the support or contact is from someone with whom the legislator is familiar and whom the legislator respects. Again, this likely is someone with whom the legislator has frequently interacted in the past. So in developing grass roots organizations, plan ahead and get the home town folks and the legislator together before the legislature convenes and discuss in a knowledgeable fashion just what are, specifically, your group's concerns and what the legislator can do to help.

Is the importance of information overemphasized in this model of legislative influence? Consider this. In one study of lobbying in four states (Massachusetts, North Carolina, Oregon, and Utah), less than half of the legislators interviewed were willing to say that lobbying ever resulted in their changing from one position to another on an issue. But well over half of the legislators said they "depend on" information from lobbyists and "have confidence in" such information 2 Reflecting on Achilles' Heels of the legislator, it is understandable why information from lobbyists is so important.

How to Get Into Action

Every Developmental Disabilities Council must follow its own instincts in deciding how best to organize for and approach the legislature on specific subjects. But some general guidelines may be offered; regarding organization, the Council might consider the following:

- Establish a legislative committee of the Council,
- Assign a full-time, regular staff person to assist the legislative committee,
- Hire or obtain through the appropriate office a student intern or volunteer aide to assist in tracking legislation day-to-day,
- Establish liaison with other interested parties,
- Regularize communications between the assigned staff, the legislative committee members, and other Council members during the legislative session,
- Plan for on-demand secretarial help and for access after business hours to xerox or other duplicating equipment.

Beyond this, the Council should have a prepared plan of action, which details what the Council or Council staff will do before, during, and after the legislative session. Chart Five details generally the action steps the Council might take.

In closing, one last piece of advice: Many persons find it hard to walk up to someone and initiate a conversation, especially when the other person is perceived as an authority figure or a superior, as legislators often are. The only way to get over this reticence is to go out and begin talking with legislators, often. In time your interaction with them will become natural.

Chart Five

A Lesislative Action Plan for Developmental Disabilities Councils

1. FORM A LEGISLATIVE SUBCOMMITTEE OF THE COUNCIL AND ASSIGN A FULL TIME STAFF MEMBER TO ASSIST THE SUBCOMMITTEE.
2. PREPARE MATERIALS DESIGNED TO INTRODUCE LEGISLATORS TO THE NATURE, ROLE, AND FUNCTION OF THE DEVELOPMENTAL DISABILITIES COUNCIL.
3. SEND A LETTER TO LEGISLATORS CONGRATULATING THEM ON THEIR ELECTION AND EXPRESSING WILLINGNESS TO WORK WITH THEM AND PROVIDE THEM INFORMATION AND ASSISTANCE DURING THE LEGISLATIVE SESSION.
4. STAFF PREPARES A PACKAGE ON LEGISLATIVE ITEMS FOR POSSIBLE INCLUSION IN A COUNCIL LEGISLATIVE PLATFORM.
5. LEGISLATIVE SUBCOMMITTEE OF THE COUNCIL MEETS TO SELECT ITEMS FOR INCLUSION IN LEGISLATIVE PLATFORM.
6. COUNCIL AFFIRMS LEGISLATIVE PLATFORM AND AUTHORIZES THE FORWARDING OF RESOLUTIONS AND LETTERS REGARDING THESE PLATFORM ITEMS.
7. STAFF/COUNCIL MEMBERS MEET WITH OTHER INTERESTED PARTIES TO IDENTIFY AREAS OF COMMON INTEREST AND TO ESTABLISH OPEN COMMUNICATION CHANNELS FOR THE SESSION.
8. DURING FIRST TWO WEEKS OF THE LEGISLATIVE SESSION, COUNCIL REPRESENTATIVES MEET WITH LEGISLATORS TO FURTHER INTRODUCE THEM TO THE NATURE, ROLE, AND FUNCTION OF THE COUNCIL AND THE NATURE AND PROBLEMS OF THE DEVELOPMENTALLY DISABLED.
9. LEGISLATION IS TRACKED.
10. TIMELY, ACCURATE, ACTIONABLE INFORMATION IS DISSEMINATED.
11. POLITICAL SUPPORT IS BROUGHT TO BEAR.
12. AFTER THE LEGISLATIVE SESSION, SUPPORTIVE LEGISLATORS ARE THANKED FOR THEIR SUPPORT, COOPERATION, AND EFFORTS.

Footnotes

As applied to the relationships between interest group and administrations, see the work by Robert Presthus: *Elites in the Policy Process* (New York: Cambridge University Press, 1974) or Public Administration (2nd ed. New York: The Roland Press, 1975, Chapter 8)-

See Harmon Zeigler and Michael Baer, Lobbying: *Interaction and Influence in State Legislatures* (Belmont, California: Wadsworth Publishing Company, 1969). This information is reported in Thomas Dye's *Politics in States and Communities*, p. 156.

CHAPTER 7

Dental Services for Handicapped Citizens

Larry Coffee

A Major Oral Health Problem

The current dental delivery system is not adequately responsive to the needs of many handicapped citizens. There is no question that many handicapped individuals have been the recipients of excellent oral health services; many of dentistry's finest accomplishments have been realized in the provision of service to our disabled citizens. However, many more have suffered and continue to endure the indignity of serious oral disease. Several surveys provide testimony to the incidence and devastating effects of oral pathology among individuals with mental and/or physical disabilities.

Gullickson (1969) evaluated a group of mentally retarded cerebral palsied children and noted that 55% of the children had carious lesions and 47% had experienced no previous dental care. Horowitz, Greek and Hoag (1965) noted that of 165 handicapped children observed, a combined average of 10.3 restorations and extracted teeth existed per child. They further segmented the group according to specific handicapping conditions and noted that children with Down's Syndrome had 4.6, whereas cerebral palsied children had 12.6 restored or extracted teeth. Mentally retarded individuals comprised 47% of the study population, yet they accounted for 89% of the handicapped individuals requiring periodontal treatment. Rosenstein, Bush and Gorelick (1971) examined seventy-two patients whose average chronological age was 25.1 years, average I.Q. 35.48 and average mental age four-years and eleven-months. They noted that 97% of the group required dental attention for decayed teeth. The mean DMF index (decayed, missing and filled teeth) for the group was 22.39. They also observed that about 90% of the group had gingival or periodontal disease. Those with Down's Syndrome had more advanced periodontal disease. Snyder, Knopp and Jordan (1960), reporting on a group of 113 non-institutionalized mentally retarded children between the ages of 1 and 19, indicated that a reduced amount of dental work had been provided the handicapped individuals. Other studies (Rosenstein, et.al., 1977 and Weisman, 1956) restricted to an observation of cerebral palsied children, reported similar findings. Similar results were noted also in a study of non-retarded orthopedically handicapped children by Miller and Taylor (1970). Various investigations have reported that while Down's Syndrome individuals have a lower caries prevalence, they have a proclivity toward the development of periodontal disease (Winer, et.al., 1962 and Cohen, et.al., 1960).

Dr. Joseph L. Henry, Dean of the Howard University College of Dentistry, stated: "First hand experience with all groups of handicapped children has led to the firm conviction that the problems encountered by the handicapped minority children of poor parents are at least triple the problems faced by handicapped children of the population at large" (1972).

The above facts document the existence of a significant health and social problem. A primary requirement in the design of a solution is defining the issue in terms of relevant realities. The way in which the problem is formulated will have a significant influence on the development of programs. The same date documenting the problem lends itself to different interpretations, and each view possesses merit since a multiplicity of factors has contributed to the existing unsatisfactory situation. The paramount factor, from the perspective of advocacy organizations for the handicapped, has been insufficient numbers of concerned dentists willing to treat disabled people. Many dental practitioners, however, interpreted the above facts in terms of dental care having a low position in the stratified schedule of priorities for these people. A comprehensive dental delivery system will only evolve after eliciting information, grievances, and preferences from all parties, both those experiencing the problem and those who must be involved in its resolution. We must not seek a singular solution, for indeed, money and energy invested in its development will be compromised if all contributing factors are not considered.

One of the relevant realities associated with the current system is its superficiality when viewed from the sociological perspective. Advocacy organizations and dental societies in many cities with over one million population only have the names of five to ten dentists available to treat the handicapped. Such figures are obviously absurd when such communities have approximately one thousand dentists. Superficiality is further in evidence when extensive restorative procedures are provided for handicapped individuals without relating detailed preventive dentistry information to the family. The system is less than comprehensive when teachers, without thought to the damage that they are doing, utilize highly cariogenic foods for reward of acceptable conduct in behavior modification programs. Preventive dentistry education within the facilities serving the handicapped is generally woefully inadequate. Wives of dentists giving their time to put on an annual puppet show for disabled children, in which proper brushing and flossing procedures are demonstrated, deserve our thanks; however, no one should be deceived as to the long range benefits to be derived by their effort.

Another relevant reality is that many disabled individuals cannot afford the financial consequences of oral disease. The earning potential of an adult may be seriously restricted by a handicapping condition. If working in a sheltered workshop, one's annual income may not exceed $2000. Many disabled people actively engaged in competitive employment may only earn $4000 to $5000 annually. A child, of course, must rely upon parental income and therein exists another problem, since many families with a handicapped member are economically disadvantaged.

Publically supported clinic facilities and various government programs are available to provide care to citizens with limited financial means. However, many handicapped individuals, even those who are mentally retarded, have been forced to traverse, relatively unassisted, the complex bureaucratic maze standing between disease and treatment. The complicated pattern of organization, which exists in many government programs, challenges the competence of many "normal" people; certainly many handicapped citizens become casualties of the very system which was created to help them.

Inadequacy of communication between organized dentistry and groups working on behalf of handicapped people represents yet another relevant reality. The damaging result of this situation can be inefficient utilization of available sources of care. For example, the Executive Directors of both the Saint Paul Association for Retarded Citizens and the Illinois Association for the Mentally Retarded, expressed concern about the unavailability of dental care, yet they were unaware that the dental directors of Childrens Health Center in Minneapolis and Michael Reese Hospital in Chicago both related their desire for more handicapped patients.

One of the relevant realities associated with the current dental delivery system, as it relates to our handicapped citizens, is the absence in most communities of a plan, a sociological design, to respond to their needs in an organized, comprehensive and systematic manner. The need to relate to the many legitimate elements which contribute to the problem underscores the rationale for a community action policy, designed and implemented by a coordinating committee representative of organized dentistry and associations representing the interests of handicapped citizens. The involvement of several disciplines is necessary, for only through the interaction and communication of individuals with diverse backgrounds and expertise can an indepth analysis and design of a comprehensive program be achieved for providing dental services to the handicapped.

Organizations which should be requested to serve on the committee include the following interests: mental retardation, cerebral palsy, epilepsy, autism, visual and/or hearing impairments, multiple sclerosis, muscular dystrophy, and related physical disabilities. Further, special interest groups for the elderly should be involved in addition to public health organizations, visiting nurses and other similar associations.

Planning and Implementing Community Dental Programs

Prevention is a concept which should pervade the deliberations of each community coordinating committee. Restorative procedures, root canal therapy, periodontal intervention and fabrication of prosthetic dental appliances would frequently be unnecessary were it not for dental disease. Such a statement seems so basic as to be superfluous, yet the dominance of attention given to the oral health problems of the handicapped revolves about corrective treatment. It seems that the state of optimum restoration has been considered synonymous with oral health.

Facilities which provide educational, vocational, residential or recreational services to a community's disabled population should be the staging area for an intense preventive effort. This will necessitate that staff members of each center be given an indepth exposure to the etiology of dental disease and the rationale of preventive techniques. In turn, they will have to transform that information into a meaningful program for their clients, a program which must be implemented on a daily basis. Once initiated, the effort within each center should be periodically evaluated to determine the efficacy of preventive design. Similarly, training should be provided to parents so that they can modify any factors in the home environment which may be conducive to disease. Teachers must be advised of the potential harm of high sucrose containing foods being used as reward agents in behavior modification programs. They may Contend that few foods other than those containing sugar could be used as reinforcers, since they would not be perceived in such favorable terms by handicapped children. Nonetheless, they should be requested to experiment with other foods, tokens or affection in the hope that a reasonable substitute can be found.

A further component to a comprehensive health oriented preventive program should be semiannual dental screening for those attending the various facilities for the handicapped. Many mentally and/or physically disabled individuals do not have a dentist; consequently, they secure care only when the disease process results in pain or facial disfigurement. A mouth mirror and explorer examination can easily be accomplished within the centers, and by so doing, pathology can be identified in its incipient stages of development. Treatment can, therefore, be advised and secured at a stage of disease process when professional intervention is least traumatic financially, if not physiologically.

In a community having many agencies serving the handicapped, an extensive preventive endeavor will require the full-time effort of a preventive dental health therapist or hygienist. Therefore, one of the functions of the community coordinating committee should be to investigate sources of funding to obtain a means of financial support for such a position. Most dentists are relatively unaware of either government agencies or private philanthropic organizations which provide money for worthy efforts; however, those members of a coordinating committee representing advocacy associations for the handicapped generally have an extensive understanding of such matters. They further have expertise in grantsmanship and could probably prepare a proposal to satisfy the requirements of a potential granting agency.

The creation of a full-time dental position, as mentioned above, is critical if the term "comprehensive" is to replace "superficial" as a descriptive assessment of the dental delivery system for the handicapped. Preventive dentistry for the disabled has been advanced by dentists visiting facilities serving these people. However, the frequency of their visits is limited, generally not exceeding a few times each year; teachers are given lectures, toothbrushes are distributed, and everyone is pleased that attention is being given to this health problem. Nonetheless, behind the facade of accomplishment looms failure. After the dentists leave, the clients at the centers are given the brushes and told to clean their teeth and there is little if any formal structuring to the effort. The precepts of educational instruction are generally abandoned in the oral hygiene effort; brushing is reduced to an accommodation to societal norms with minimal consideration given to the scientific rationale of plaque control. The oral hygiene procedures are not generally reduced to their basic components for the purpose of teaching in the accepted manner of relating a complex concept by building upon an ever expanding foundation of knowledge.

One of the reasons why teachers do not respond in a more thorough and detailed fashion is the infrequency of dental input in their professional activities. Contributing to such a minimal exposure is the fact that dentists and/or hygienists have insufficient time in their schedules to provide the constancy of involvement required. Thus, an extensive and meaningful community oriented outreach effort for the handicapped required the full-time involvement of one or more representatives from the dental profession.

Such a job position would allow for frequent and regular communication with individuals more directly involved in providing services to the handicapped. The dental professional could work with teachers on the design of an educational initiative which would train disabled individuals to realize the maximum level of their capability for the effective maintenance of their own oral hygiene. The dentist or hygienist would be viewed more as a colleague, rather than as an outsider who has little or no understanding of the complexities involved in providing educational, residential and social opportunities for the handicapped. A further advantage to such a position would be the ability to monitor and evaluate preventive efforts in various centers, and by so doing, evolve modifications to the basic program design where results prove less than satisfactory.

Over-extension is a pitfall of many community oriented dental programs staffed by dental hygienists. Many public school systems maintain hygienists to provide preventive dentistry lectures for the students in addition to screening them for oral disease. The efforts appear impressive on paper, but frequently accomplish little in reality. In an effort to accommodate all the children designated by the school administration to be participants in the program, the oral examinations must be accomplished in less than one minute per individual. Insufficient time exists for the hygienists to adequately work with the teachers to insure the conscientious continuation of the preventive endeavor.

An outreach dental effort for the handicapped must not evolve into a shallow experience, devoid of the potential for long term benefits. Guidelines must, therefore, be developed for those responsible for the daily implementation of the preventive effort to insure that the "numbers game" does not take precedence over honest and meaningful benefits for the disabled. A hygienist should be placed on a schedule permitting twenty to thirty minutes to complete an oral health profile of each individual. At the conclusion of the school or workshop day, time must remain for the hygienist to discuss the results of the examinations, the design and implementation of a preventive effort with teachers and/or parents. The hygienist should visit each facility for one day every two to three weeks. The frequency of visits will permit the hygienist to gain the interest and support of the staff and clients in addition to having the opportunity to monitor the effectiveness of the oral hygiene program. Each client within the participating centers should be profiled semi-annually and a copy of the profile can then be sent to the dentist prior to the scheduled appointment with a request that he return a copy of his diagnosis and treatment plan. Such a system will permit the hygienist to protect against people being lost in the referral process.

The per capita cost for a comprehensive dental outreach effort will obviously be more expensive in the short term than a program with a superficial format. However, a program that maintains as its principal objective the quantity of people served, even to the detriment of quality and thoroughness, will have little, if any, significant influence on the future oral health of the

the number of new handicapped patients a practitioner could accept each month, the age group with whom he prefers to work, and the types of mental or physical disabilities which the dentist and his/her office is willing to accommodate. Further, a survey should extract information relative to the type of treatment a dentist is willing to provide, the sedative techniques one is prepared to use, and the ability of an office to physically accept a wheelchair. The accumulation of data with such a degree of specificity will facilitate the means by which handicapped individuals can obtain necessary care. If many dentists respond to the survey questionnaire, the results should be compiled in a manner to permit quick and easy reference of the information.

The survey form should be sent to the dentists with a short and direct cover letter. The letter should clearly state the purpose of the inquiry and further indicate if those responding will be solicited to provide care to handicapped individuals without compensation. Practitioners will obviously be reluctant to indicate their interest in serving these people if their services are to be on a gratuitous basis, and that point should be considered when formulating the cover letter. The questionnaire can be printed in any style; however, those printed on a pre-stamped and addressed postal card have the greatest probability of being returned.

An examination of private practitioners in order to determine those who are available to care for the handicapped will prove of significant value to disabled individuals having the financial resources to pay for necessary health services. Unfortunately, many do not enjoy financial security due to limited personal and/or family income. They must look to government sponsored programs for treatment and therein exists serious problems. States vary as to eligibility for dental benefits contained in federal title programs. For example, some states will provide dental benefits to everyone receiving Medicaid assismajority of those reached by the endeavor. Therefore, when a long range cost-benefit analysis is made for an oral health outreach effort, the comprehensive program design will probably prove much more economical than a superficial approach.

Locating Dentists to Help

A program for providing dental services to the handicapped obviously requires dentists who are willing and able to treat these people. However, a *very* legitimate grievance of organizations working on behalf of the handicapped is that there seems to be a deficiency in this critical manpower area. Most dental societies can only provide the names of a few dentists and they generally are pedodontists. The minimal numbers, however, do not necessarily document a shortage of dentists to care for mentally and/or physically disabled individuals. Rather, the statistics may be testimony to the superficiality of the system, for when a survey was conducted of the 850 members of a metropolitan area dental society, 200 practitioners were found to be willing to respond to the oral health needs of the community's handicapped population. Prior to the survey, the same dental society could only suggest the names of five dentists, all of whom practiced in the same geographic region of the city. The offices of the 200 responding dentists were located in 43 different postal zip codes, thus alleviating the problem experienced by many handicapped individuals of having to commute significant distances to obtain care.

Referrals based upon an inadequate survey may be inappropriate and serve to frustrate the individual seeking care; the name of a dentist does not suggest what type of care he is prepared to administer or the type of handicapped individual he is comfortable treating. Therefore, any survey of dentists practicing in a given community must be designed to secure detailed data regarding tance, whereas others will limit dental services to those under the age of twenty-one. Those eligible for dental care can obtain treatment from any private practitioner who accepts the Medicaid fee schedule, but generally only a limited number of dentists participate. Handicapped individuals who do not meet the eligibility requirements must secure care from a publicly supported clinic facility. However, many communities with a relatively small population do not have such dental resources. Cities with a greater population density may have one or more clinics available, but many people qualified to obtain services from such centers are not aware of the opportunity. Where a community has conscientiously sought to inform its populace as to the availability of dental care for those with limited financial means, the requests for treatment frequently outstrip the maximum potential of the program. Consequently, long waiting lists may develop for any form of care other than that on an emergency basis.

Against such a backdrop, it is evident that many financially depressed handicapped individuals are defeated by the very system which exists to assist them. The problem is further complicated for those who require moderate-to-heavy pharmacological sedative management to compensate for behavior which would preclude the proper administration of treatment. The resources available to handicapped individuals of limited financial means who require intravenous premedication or general anesthesia for general dentistry become narrower and narrower, even in large metropolitan areas.

It is, therefore, necessary to survey the government sponsored dental programs available within a state to complement data collected from a survey of private practitioners. The dental division of state and county health departments can prove of inestimable value in the design of such an investigation. The state department of social services or public assistance should have the eligibility requirements defined for the dental provisions of federally sponsored programs. Publicly supported clinic facilities should be asked to report data in exacting detail to satisfy such questions as the geographic region served, financial status to qualify for service, the age range of patients accepted for care, the type of treatment available, the capacity to administer sedative agents, and the physical ability to accommodate to wheelchairs, carts or other appliances. Further, each clinic should be asked to submit their respective registration procedures.

Using Public Awareness Activities

The accumulation of information from a survey *or* private practitioners and publicly supported clinic facilities is reduced to nothing more than an exercise in data collection if those who need dental care remain uninformed about available resources. It is therefore essential that a public information plan be formulated to disseminate the survey results. Such planning should not represent an afterthought; rather it must be an integral component of the entire project. The assistance of a public relations or advertising firm should be sought to coordinate the effort. Public service spot announcements for radio should be developed along with press releases for the newspapers. Prior to going public with the information, however, the members of the dental community should be advised of the forthcoming action so that they are protected from the embarrassment of being introduced to the effort by a patient. All material to be used in the information dissemination phase of the project should be presented to the state board of dental examiners for their review to insure that it is acceptable according to the regulations of the state's dental practice act.

Visiting nurses, school nurses, speech therapists, social workers, counselors and other professionals who are in frequent communication with disabled persons should be advised as to the existence of consolidated information regarding available dental resources. They should be given the name and phone number of the agency which will maintain the data. Organizations working on behalf of handicapped individuals should also be given such information and asked to publish it in their respective newsletters. Pediatricians, neurologists and other medical specialists associated with treatment and rehabilitation centers for disabled people are also valuable resources. They should be requested to refer those in need of dental care to the office serving as the clearinghouse of the survey data.

A mechanism must be designed to repeat the public information blitz on a regular periodic basis. Such a procedure is essential to the long range benefit of the project due to the rapidity with which information can be forgotten. Since nurses, therapists, and other resource people do not maintain their positions indefinitely, the periodic repetition is necessary if the data is not to fade into oblivion as new personalities assume old job positions. The flow of professionals obviously also exists in dentistry, and for that reason a schedule to repeat the survey should be formalized with officials of the dental society.

Another relevant reality which must be addressed by an intensive public awareness effort concerns the inadequacy in many states of legislative support for a meaningful dental care program to benefit handicapped and elderly people. As a consequence of deinstitutionalization and normalization programs, many individuals who were residing in state institutions are not being placed in nursing, boarding and group homes. These facilities must be licensed by the state, and consequently must satisfy state regulations. Many state regulatory agencies have responded to the dental health issue by requiring each facility to have a consulting dentist available to respond should emergencies develop. Such regulations are undoubtedly well intended, but they encourage and foster crisis oriented care for the residents. One should not experience pain or be the subject of facial disfigurement before attention is given to his/her dental pathology. This is inappropriate, and as professionals we must be strong and outspoken advocates for improved and more comprehensive regulations.

Summary

It is not possible to have a dental delivery system which is sensitive and responsive to the needs of handicapped individuals without maintaining a comprehensive coordinating effort at the community level. The existence of dental offices that are open to disabled citizens is obviously necessary. However, just as the interior design of the dental suite and its intricate equipment creates an environment to compensate for the consequences of pathology, the environment, outside the walls of the dental operatory is conducive to the development of disease. The prognosis for the oral health of handicapped citizens cannot be considered optimistic if after treatment the patient is returned to the same enviornment which originally contributed to the disease process. Dentistry must reach out in an organized and thoughtful manner - into schools, workshops, homes and residential facilities of our disabled population - if a health oriented philosophy is to replace the current crisis oriented style of care.

The National Foundation of Dentistry for the handicapped is actively seeking to help establish coordinating units as herein described, in communities throughout the country. Individuals interested in furtherance of the preventive outreach concept should contact the Foundation office at: 1121 Broadway, Suite 5, Boulder, Colorado 80302 / Phone (303) 443-7920.

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CHAPTER 8

Information Project for Primary Care Physicians

Marilyn Paxton

The Need

Medical doctors are the single most important link in the prevention chain, in so far as mental retardation and other developmental disabilities are concerned. Doctors are usually the first professionals to be in a position to identify a developmental disability in a child and to make early referral to an appropriate service. Whatever the advice or counsel by the primary physician, it is weighed more heavily than advice from most other sources. We place a great deal of trust in what doctors tell us. Unfortunately, most doctors who have been practicing in Oregon for over four years, and those trained outside of Oregon, have received little or no training in developmental disabilities specifically. They are unsure of identifying symptoms, of which mothers are classified as high risk, or where to refer the child and the family for additional services.

It is not uncommon for the doctor to inappropriately refer children to the institutions, because they are not aware of locally developed services. Such incidents are documented by letters (from parents) in our files. Listed below are some of the major concerns expressed by parents regarding their contact with the medical community:

1. Honesty, but compassion and sensitivity in giving information about a child's disability. (Many doctors have no background in or familiarity with mental retardation or developmental disabilities);
2. Referral to appropriate resources (including parent and consumer organizations). The doctor may not be familiar with resources and/or may be hesitant to make referrals to anyone else;
3. Lack of awareness of the current statutes of special education programs; e.g. What's being done with Downs Syndrome children, in parent training, or infant stimulation and pre-school programs;
4. Information to pregnant and high risk women about the possibility of handicapping conditions or the availability of amniocentesis. Many physicians are apparently unaware of the importance of genetic counseling, amniocentesis, effects of smoking and alcohol on the fetus, etc.

Obviously, there was a need to provide primary physicians in Oregon with the best and most current information available. The project distributed a book entitled, Mental Retardation, A Handbook for Primary Physicians, which is published by the American Medical Association. Ironically this book was originally published in 1965, and was updated in 1974, yet most physicians are unaware of its existence.

The Project and Its Implementation

By checking with the Oregon Medical Society, we determined the need for 1600 books in order to reach all pediatricians, obstetricians, neurologists and general practitioners in Oregon. A grant of $7,487.00 for the project was secured in October, 1976 from the National Institute of Health (NIH). This amount included cost of purchasing books and brochures on epilepsy, cerebral palsy, autism and mental retardation, as well as the cost of printing inserts of referral sources, individualized by county, the cost for secretarial and staff time to prepare and deliver materials, plus travel expense and postage to secure needed information.

Assembling and disseminating the material in an effective manner, and facilitating its use, was accomplished by volunteer members of the Associations for Retarded Citizens (ARCs) throughout the state. Along with the handbook prepared by the American Medical Association for this *very* purpose, we distributed current publications from Epilepsy League of Oregon, United Cerebral Palsy Association of Oregon and the Society for Autism. In addition, a Services Referral Chart unique to each county in Oregon was prepared, complete with names of key contact persons, addresses and phone numbers. This referral chart was attached to each handbook and will be updated annually by the Oregon Association for Retarded Citizens and forwarded to all physicians who received the books.

Our specific objective was to deliver personally to *every* primary physician in Oregon the latest and most complete information on mental retardation and other developmental disabilities. To achieve our objective we obtained the names and addresses of all primary physicians in Oregon from the Oregon Medical Association. They were typed on index cards and individualized by county. We contacted each county medical society in regard to the most effective approach to physicians in their county, and *every* local ARC president gathered the names and addresses of all local referral sources. Since hand delivery was at the heart of the distribution process, it was imperative to train volunteers. A "guideline for volunteers" distributing the books (see Supplement One) was developed and used at a training session with local ARC presidents on how to train their local volunteers. The goal was to educate and support physicians, not alienate them, which could be achieved only if the volunteers were very positive in their approach and well prepared.

After all the materials were prepared, they were delivered to a key contact person in each county (local president or MR book committee chairman). We asked that they check off the name of each physician as they delivered the materials and make any necessary corrections to the list. When delivery was completed the volunteers returned the list to us for use in follow-up contacts and for providing updated referral lists.

In all but two counties volunteers from the ARC or elsewhere handled distribution. In two lightly populated counties, the state ARC staff hand delivered the books, which took 8 days and 2200 miles of travel. Volunteer time for hand delivery is estimated at over 800 hours, including contacting doctors by phone and setting an "appointment" time, or going directly to the office, telling them about the project and answering questions concerning the book, referral lists and the organizations involved. One occasional difficulty was getting past receptionists who refused to let the volunteers see the doctor. In those instances, parents whose children were patients of that particular doctor were found, and they delivered the materials when they went in for an appointment. We are thoroughly convinced that the only way a project of this nature can be successful is through personal contact. If books are mailed, there is no way to determine whether or not the physician ever sees it. In larger counties, we utilized two other means of delivery: community health nurses and medical society meetings. Volunteers attended the medical society meeting, explained the project, answered questions and then passed out the materials to those doctors whose names were on the list. Supplement Two reviews the entire distribution process.

Some Concluding Remarks

It is too early to determine the effectiveness of the project. For the first time, however, all primary physicians will have the needed information on developmental disabilities, mental retardation, and referral sources. This will not solve all problems; there is no assurance, for example, that the information will be used. However, it will give the consumer organizations a specific reference to use with doctors and insight into whether they are utilizing information that has been made available to them. We have asked that "referral sources" keep a record of the contacts they receive from physicians who were given the books and other materials and have also asked parents to let us know what types of referrals and diagnoses they receive. This follow-up will help to determine if physicians are reading the materials and if they are utilizing this resource.

Supplement One

Guideline for Volunteers

1. Be emphatic -- know where the physician is coming from and how he/she feels about your being there. Think of yourself and the doctor as being on the same side; how can you best work together?

2. Be prepared. Know your community resources and concerns. Be at least somewhat familiar with the information in the Mental Retardation Handbook and other materials for the primary physician.

3. Don't dwell on personal bad experiences, or "war stories" in relating the concerns of yourself and others. Rather, relate general concerns, such as the parents' desire for honesty, and early diagnosis.

4. Be Positive, not negative. Try to make constructive suggestions, offer the support of yourself and the ARC. Don't be critical and accusing.

5. Be Assertive, but not abrasive. Don't wait for the doctor to do all the talking. You have something to say and to offer. In this case you have more knowledge on your side. Don't be intimidated.

6. Stress the need for referral; this is so important to the child, parent agencies, other professionals, consumer organizations, etc.

A final suggestion -- we think it preferable that the volunteers go out singly rather than in groups of two or more. The physician may otherwise feel "ganged up on."

Supplement Two

Step By Step Procedure
Distribution of the Mental Retardation Handbook and Other Materials

1. Contacted the Oregon Medical Association to determine number of physicians in Oregon who are obstetricians, pediatricians, general practitioners or neurologists.

2. Wrote three grant requests to foundations and one state grant which were turned down. Grant approved was through HEW-NIH, including cost of books and other printed material, staff time to complete project, travel expenses for delivery, printing and postage as well as telephone expenses.

3. Ordered 1550 books titled, Mental Retardation, A Handbook For Primary Physicians from the American Medical Association in Chicago.

4. Contacted Local ARC's with request for a list of resources in their county to be on the referral insert form. (all responded)

5. Contacted County Medical Societies for their recommendations on best method of distribution in their county. (few responded)

6. Typed lists of physicians, county by county.

7. Contacted key people in counties without ARC's for assistance in delivering books.

8. Stenciled and printed referral lists for each county. (varied from 5 to 500 copies)

9. Secured 1600 copies of brochures from Epilepsy League of Oregon, United Cerebral Palsy and Autistic Society. (1600 from each)

10. Stamped all books "Complementary 0ARC".

11. Counted out amount needed for each county and inserted brochures and referral lists.

12. Banded by county and attached 2 copies of list of physicians.

13. Prepared "guidelines for volunteers" for distribution.

14. Held a training session for county contacts on how to train their volunteers for most effective distribution.

15. Hand delivered books to contact person in each county along with instruction sheets and "guidelines for volunteers". In some larger counties, health nurses and medical meetings were used.

16. Instructed contact person to check off one list as materials were delivered and return to OARC staff for use in follow-up.

17. In late June we will update referral list and mail with cover letter to all physicians who received the materials.

DEVELOPMENTAL DISABILITIES
TECHNICAL ASSISTANCE SYSTEM

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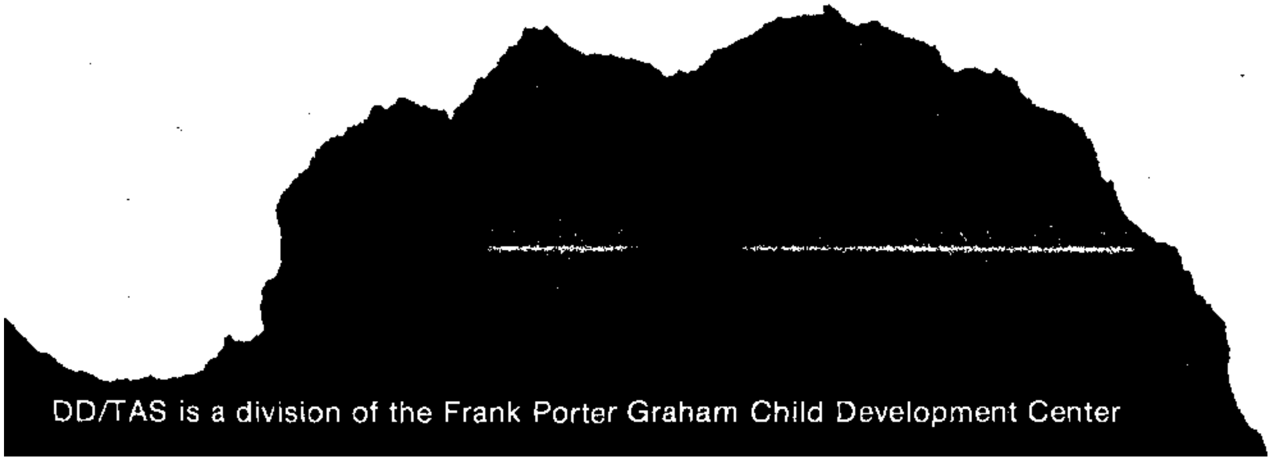

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