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ABSTRACT

Included are edited transcripts of three presentations by P. Ackerman, Jr. ("A National Perspective on Prevention in the Year 2001"), A. Eaton ("Ohio Prevention Strategies"), and G. Calvert ("The Lost Continent of Prevention"). Abstracted are workshops on the following topics: parent preventive strategies, genetic preventive strategies, nutrition preventive strategies, early screening and intervention preventive strategies, and community and environmental preventive strategies. Provided is a panel discussion by M. Kindred, C. O'Neill, W. Kopp, C. Rosenbaum, and M. Mays on legislative prevention strategies. (PT)

PROCEEDINGS

Seminar on Preventing Mental Retardation and Developmental Disabilities

OHIO DEPARTMENT OF MENTAL HEALTH
AND MENTAL RETARDATION

James A. Rhodes, Governor
✓ Timothy B. Moritz, M.D., Director
Paul R. McAvoy, D.S.W., Acting Commissioner
(Division of Mental Health)

PREVENTION AND EDUCATION SECTION
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September, 1976

FOREWORD

This publication summarizes a two-day Seminar on Preventing Mental Retardation and Developmental Disabilities held on May 12th, and 13th, 1976, in Columbus, Ohio. The contents include edited transcripts of keynote presentations and abstracts of the workshops. These Proceedings are publicly distributed for several purposes:

-- to RECORD for participants and others the critical analysis of prevention concepts, methods and issues by outstanding practitioners, researchers and advocates of preventive strategies.

-- to EDUCATE those wanting to learn more about the problems, ethics, techniques and politics of preventive strategies.

-- to CHALLENGE all readers to review, enlarge and implement their support of preventive strategies.

-- to INITIATE the planning and operation of a statewide, inter-agency, comprehensive and inter-disciplinary system in Ohio for preventing developmental disabilities, mental retardation and birth defects.

Several people merit public recognition for their special contributions to the Seminar: PAUL BISSONNETTE, (The National Foundation, March of Dimes, Central Ohio); ANTOINETTE EATON, M.D., (Ohio Department of Health); MAXINE MAYS, Ed.D, (Ohio Division of Mental Retardation and Developmental Disabilities). CATHY PEKEL, (Seminar Staff Assistant) is responsible for cheerfully, efficiently and effectively accomplishing many clerical and logistical tasks. Thanks to YOLANDA HEBERT, (Prevention and Education Section), the final manuscripts have been typed, proofed, printed and distributed as promptly as feasible.

The statewide Prevention Seminar and its Proceedings further document the many pioneering contributions to prevention in Ohio by M.W. McCullough, Ph.D., (Assistant Commissioner, Office of Education and Training). These and many other achievements in his distinguished career have been also recognized by the American Psychological Association.

Finally, these Proceedings cannot properly reflect the personal and professional commitment of those attending the Seminar. They are the ones who, like many of you reading these Proceedings, will translate such words on paper [illegible] actions preventing developmental disabilities, mental retardation and birth defects.

Columbus, Ohio
September 1976

Gene Paul Calvert, Ph.D., M.P.H.
Manager, Prevention & Education
Office of Education & Training

SEMINAR OVERVIEW*

A 50 per cent reduction in the incidence of mental retardation from biomedical causes could be attained by the year 2000 as the result of effective prevention programs.

This was the projection made by Paul Ackerman, Jr., of the White House Conference on Handicapped Individuals, when he addressed approximately 230 people in the field of mental retardation and developmental disabilities as key speaker at a statewide prevention seminar in Columbus, May 12th and 13th, 1976.

The seminar, sponsored by the department's Office of Education and Training, provided a comprehensive overview of prevention methods and programs and sought to create interest in and enthusiasm for these programs.

Fourteen workshops, led by professionals in various fields, gave participants an opportunity for information exchange on an informal basis. Leaders used slide shows, overhead projections and informal talks to initiate discussions within groups.

The right of every child to be born healthy and achieve his maximum development, regardless of pitfalls along the way, was stressed by Gene Calvert, Ph.D., manager of the Prevention and Education Section and organizer of the seminar.

Dr. Calvert feels that the seminar was highly successful due to the diversity of the participants and their commitment to the field of prevention. He sees this as the first step toward a formal prevention system in the state of Ohio.

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*<u>Mental Horizons</u>, June 1976, Vol.2, No.2

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A NATIONAL PERSPECTIVE ON PREVENTION IN THE YEAR 2001

PAUL ACKERMAN, JR., PH.D.

Chief, Educational Planning
White House Conference on Handicapped Individuals

Twenty five years ago it all started. I was there when the statewide emphasis on prevention began in Ohio. That was back in 1976. Thank you for asking me to speak to you on this, the 25th anniversary of that beginning. Magnificent progress has been made in those 25 years.

But before I can show you progress, I will have to tell you a bit about what 1976 was like. I hope you will forgive my reminiscing; it was such a different world in 1976 compared to the societal environment of today in 2001.

Some figures and trends will provide a brief overview of the changes in American society during the past 25 years since 1976. The median age of Americans has increased from 28 years in 1976 to around 35 years today. Persons with developmental disabilities now have a median age of 34, signifying a huge jump in life expectancy since 1976. Our national population has increased by nearly one-half million. Most of us now live in more neighborly, multi-unit dwellings, instead of the socially isolated single family home of 1976.

In the past 25 years we have seen the gross national product increase by 125%. But we are wealthy now in a different way. A way that is important to our handicapped colleagues. Back in 1976 we used to be a manufacturing country but now we are a service-oriented country. That means that our income is now based more on payment for services we render to each other than on physical units of production like toasters, spacemobiles, or transistor radios.

In 1976, there was a disproportionately greater number of developmentally disabled persons among the poverty class than any other socio-economic class in our society. Today, the incidence of developmentally disabled persons in all classes is more equalized. Even so, being handicapped and existing in relative poverty is a greater burden than being handicapped and living in the better income strata of society. Undoubtedly you also know that in 1976 there was no income maintenance plan. Now, everyone who needs job, has one.

Did you know that back in 1976 almost everyone worked 40 hours per week? Now, of course, we follow the 30 hour week, and this gives us that horrendous amount of leisure time our sociologists are always raving about. But this "leisure time" has benefited our handicapped colleagues. With increased time we have found that helping our handicapped friends is not only gracious, but fulfilling as well. We have spent many hours improving their opportunities and their participation in all aspects of American life.

Yes, in the last 25 years, the number of handicapped persons has been cut by 50%. That is an amazing statistic in itself, but let me add even a few more. Now, almost 85% of all eligible handicapped persons are working, as opposed to about 30% of them in 1976. In 2001 over 75% of handicapped persons over age 20 are not living at home, and of this 75%, 20% are living by themselves--the same percent as the non-handicapped population.

Today, 93% of all mentally retarded and developmentally disabled persons have had public education training. That is, their education and training has been funded and controlled by public agencies at public expense. We have long since discovered that whenever this happens, the investment which the public makes in the education and training of these handicapped individuals is returned in taxes within the first 12 years of employment after leaving school. This is why we were able to get legislation passed which significantly increased our educational and training components.

Now 62% of mentally retarded and developmentally disabled persons under the age of 20 have one or no siblings. A startling 71% of the families containing handicapped individuals have working mothers. This was unheard of in 1976, when large families were the rule, and mothers stayed home to take care of their disabled children.

One of the statistics which thrills me most, however, is the one showing that in 2001, each mentally retarded or developmentally disabled person has his own advocate. In 1976 we did not even know what being an advocate really meant. Today we know, and there is one assigned to each handicapped individual. Also we now have public transportation systems that are accessible to 87% of the handicapped citizens of this country--in all types of areas.

Handicapped people now live 7.3 years longer than they did in 1976, thanks to our medical and research colleagues. And, partly because of this statistic, you will find that today any family with a handicapped person can purchase any type of insurance, a rarity in 1976.

Teacher advocates were different types of people in 1976. They were not trained then as they are now. They did not go to the same kinds of schools nor have the same kind of curriculum or experiences. They did not even have the same perspectives about the capabilities of mentally retarded or developmentally disabled people. They were products of some sweeping reforms in higher education.

But enough of "what was". The lessons to be learned are in the "how" of the progress. *How* did it all come about?

The first step that had to be taken was the change of attitude. Individual states, individual communities and individual decision-makers had to recognize that the handicapped person--any type of handicapped person--was a person. A person with a handicap. He was an individual. He was not classificable as a category. He was, simply, a person.

That recognition, that emphasis, had to be translated into public thinking and public policy. In 1976 and 1977 there were state conferences and a National White House Conference on Handicapped Individuals which brought together for the first time a large number of handicapped people and families of handicapped persons.

To really assert their rights, the President's Committee on Mental Retardation and many other organizations focused public attention on research on the handicapped person as an individual. But nothing really changed mass attitudes until both "consumers" (handicapped individuals) and non-consumers got together and moved into action.

You remember some of the more dramatic of these actions, of course--the riots and demonstrations. You probably do not know of the solid, plodding, foundational actions that were also taken.

But once Americans were able to recognize that people with handicaps were people, not types, they clarified their rights, defended them, protected them, and amplified them, just as Americans have always done.

The rights of the handicapped. This was the platform on which many actions were built in 1976. In that bicentennial year, some major speakers told the American people that the rights of Americans to have representation in taxation matters were the same as rights of handicapped Americans to have access to public buildings. We all know they were correct, and the agencies and organizations serving handicapped individuals took up the fight.

Legislation at both the national and state level, from 1970 on, helped to further clarify the rights of handicapped individuals, starting with the right to treatment and education, and ending with the rights to enjoy the aesthetic pleasures enjoyed by non-handicapped persons. Bills of rights for handicapped citizens of all ages were written by many organizations and widely publicized.

A few years after the bicentennial, the Law Enforcement Assistance Administration system of the Department of Justice instituted a system of court reform, and the American Bar Association helped to establish a legal advocacy system throughout this country. (In fact, Ohio was one of the first participants in the national advocacy system, joining in 1978.) And we found that legal advocacy for the handicapped was less difficult than was expected because the Eighteenth Amendment of the Constitution was used as the basis for most decisions--and upheld by the Supreme Court. All courts throughout the country struck down the discriminatory actions of people who denied the rights of handicapped persons.

But it was not the court actions which stopped wholesale discrimination. The public education that accompanied these actions played a major role in bringing about change. Remember the slogans? The key words? Especially effective was the slogan coined in the Washington demonstration of 1981, "Free to Be...". All of these demonstrations and other public information devices had the effect of forcing a different perspective on the American people. And then transportation, public buildings and commercial services started to open up for handicapped people.

After the rights of handicapped individuals were clarified, then the rights of parents to have fewer handicapped children were discussed. The rights of parents had to wait until the rights of handicapped individuals were clarified - for political and religious reasons. But finally parental rights were clarified, and pressure was applied to the government to institute these rights. The government helped to make available educational literature and programs on planned pregnancies in ways that would avoid mental retardation and developmental disabilities. They also helped schools put these educational programs into effect.

If you had lived in 1976 you would be amazed to learn that today, 43 states require genetic counseling of any couples wishing to marry. In 1976 that was unheard of. Now we take for granted that our regulatory bureaus are cracking down on all dangers presented to pregnant women. And, of course, we have subsidized nutritional programs for women who need a balanced diet but cannot afford it. Both maternal and child care services are now available to anyone wanting them, at a professional's referral. That privilege did not exist in 1976.

About 1980, the National Institutes of Health finally got legislation passed to establish their own Institute on the Prevention of Developmental Disabilities. There was a central institute to research and provide to the public the needed information about prevention. Some of the most startling information were the statistics which definitively showed that dollars spent in prevention activities actually did prevent the kinds of handicaps they were supposed to. Remember those little danger signs that used to be printed for mothers about their children? They were printed on milk cartons for two years, and 95% of all mothers knew the danger signs by heart in 1982. That campaign, and the knowledge of prevention during pregnancies were probably major contributors to the reduction of handicapped children by 50% in the last 25 years.

Certain professional changes around the '70s also led to "decreases" in handicaps. Social scientists, early in the '60s and '70s began debating whether lower social class was the cause or the effect of mental retardation and developmental disabilities. Finally one of our great leaders had the sense to say that the argument was fruitless. Who cares if people were "culturally disadvantaged" or "mentally retarded"? Both of these persons needed the same kind of care. They needed education, medical attention, jobs. But most of all, they needed the elimination of the kinds of conditions that put them in a troublesome category in the first place. They needed prevention, and prevention meant the elimination of the negative aspects of being in a lower social class.

Do you think that the social reforms that have come in the few years before 2001 have been by social workers, social "do-gooders" or the self-proclaimed reformers of the social order? NO. They arose because of people who are dedicated to the treatment and education of all handicapping conditions. These professionals knew that if they could eliminate some of the discriminatory practices, some of the constraints, some of the inequalities that accrue to lower social and economic classes, they could actually eliminate some of the conditions that made children appear to fit the label "mentally retarded". "developmental disabled", or "mentally ill". These professionals took action--a kind of affirmative action--for handicapped citizens in lower socio-economic levels. They helped formulate assurances and practices which gave leadership and government positions to people of lower socio-economic classes. They effected housing and living reforms.

They also completed the reform of the schools by complete curriculum revision and the institution of individual learning plans. All curriculums were revised to account for social differences and to make children proud of their ethnic heritages. And <u>Home Start</u> became federally subsidized by 1979. It became a very important home training program for parents of handicapped children.

Colleges and universities had to change, also. They did, but it was difficult. They developed outreach programs to work with children from lower socio-economic classes and help them attain an equalized higher education. Now, in some of the most exciting universities you can visit, there are even the special higher education colleges within the universities for <u>all</u> minorities, including the handicapped.

Yes, the elimination of handicapping conditions because of being born in a lower socio-economic class was accomplished by a number of factors, including better urban planning. But not only were these actions successful, but they again proved that the American "melting pot" could work to the benefit of all its citizens.

Finally, there was the start of the whole movement for advocacy. It appears, now, that almost all of changes, almost all of this progress can be linked to the growth of advocates. In 1976 there were few advocates; now there are many, all researching, demanding, monitoring, soothing, mediating, banding together. But even as late as 1976, the concept of an advocate was foreign to many.

They were not used to persons who spoke articulately <u>for</u> handicapped citizens. They could not realize that advocates could work on a one-to-one basis with handicapped individuals, determine group needs, and change society to obtain these needs. They underestimated the power of advocates to effect legislation, change public policy, and reform the service delivery system. But they soon found, as they sat through demonstrations, hearings, legislative votes, and council meetings that advocates were prepared. If you asked them a question about numbers of handicapped people they were prepared with names and totals. If you asked about costs of services, they could provide you with individual and group costs. Our legislative colleagues soon discovered their potency, understood their motivation, and responded to the needs of handicapped persons.

You, as advocates, have been through the training program for advocates, but you have to remember that there was no widescale program for this in 1976. If you were to ask a group like this how many of you were full-time advocates, you would probably get a handful of responses. Now 95% of all advocates work at their trade on a full-time basis.

But the pioneer advocates had a tough time of it. Public opinion had to be changed so that the advocate was recognized as speaking for the handicapped individual. He was his alter ego, his voice, sometimes his conscience, always his decision maker. And the public had to recognize that when you were talking to a mentally retarded person, you had to talk to two people--the mentally retarded person and his advocate. The advocate was first seen as a threat, and there was subtle pressures to do away with the advocacy system. There were negative images of "Big Brotherism" a la Orwell's 1984. But since the advocates were effective, and the families were increasingly grateful--and vocal--advocates stayed, and caused the progress we have discussed.

...So that is what happened these last 25 years, an epic story if there ever was one. But the story can be useful to you only if it has an analysis. What were some of the problems, and what were some of the solutions? What can be learned from these last 25 years?

Probably the toughest problem faced was the problem of changing public attitudes. The concept you had to sell was this: prevention activities lessened the chances that a baby, or even an adult, would become handicapped. How is that for an abstraction? You could not demonstrate rehabilitated clients, like Vocational Rehabilitation, you had to show that with prevention there would be fewer handicapped persons in the population in the future as compared to the present. Although it made sense to the professionals, it just looked like another tax rip-off to the average citizen. So there was resistance.

But we overcame. Militantism finally had to be used, it was what the people of the '70s knew best, and it changed a lot of minds for the handicapped the same way it effected change for other minorities. We also had to change attitudes through public awareness campaigns in the mass media. And we had to do it through education. Although I blush to say it, we literally went into the curriculums of our schools and biased them towards prevention. And it worked.

Another very tough problem was that of changing the way services to handicapped persons were delivered. Take service systems at a state hospital, for example. If you had an institution with a person at the head of that institution who had been there for 30 years, who lived on the grounds, and whose whole professional career was involved with that institution--how could you radically change that institution to meet the new needs of handicapped individuals? Deinstitutionalization was a threat. The changing needs of a changing population were a threat. Social workers and educators who went beyond the usual duties of treatment were a threat. Resistance to change set in.

We had to demand changes to these professionals with a different vocabulary. We insisted on individual planning, but we yelled a new slogan, "Product instead of Process!" We wanted to have plans for each person that would predict his capabilities for the future in the most positive ways. A handicapped person's "product" would be his new "self" after he had received the most appropriate education and treatment. And that is what we asked professionals to focus on--not the traditional delivery systems.

The advocates helped. They said, in effect, "To Hell with the process! When we want our client to have a physician, we will describe the symptoms to him, and we want him to tell us what has to be done to restore the client to an <u>active level of functioning</u>. It was this active level of functioning which was the product, and the advocates could spell it out in great detail.

The universities were probably the last to change because they, too, were institutionalized. They had taught in certain ways with certain professors for certain periods of time. They were being asked to teach a new field - prevention, in which there had not been a lot of research, and in which there were great gaps in data. What finally forced a change were the realities of what the new social systems were. New job opportunities were opening for students trained in non-traditional ways and new certification standards for universities and their graduates. The students, themselves, a brand of new idealogues, were fired up by the rhetoric of equal rights and prevention. They forced many changes in the universities in their search for relevance.

These students/idealogues, inspired by the experiences of their brethren in VISTA, Peace Corps, and the like, did not believe in locking people up in institutions, particularly if they could work with them in the communities. They did not believe that the community had the right to isolate handicapped persons. They believed that people were humans in a society that interacted. All persons needed to be in dialogue with others. They needed to have friends and to be friends. They needed to love and be loved. These students took hold of the ideas of "Free to Be..." and made it a life's cause--to the betterment of handicapped individuals.

Unfortunately, one of the biggest problems we had to face was the consumer, the handicapped individual, himself. The White House Conference on Handicapped Individuals in 1977 finally brought consumers together, and they have continued to meet. But there were still a lot of problems. People in wheelchairs wanted accessible buildings first and to hell with anything else. People who were blind wanted better services from local and national libraries and to hell with anything else, even accessible buildings. And so it went, each disability group wanting their needs met first.

But even when priorities were the same, the consumers often did not do their homework. Everyone wanted transportation changed, for instance, but no groups could agree on how it should be changed. And so it went, for some period of time. Finally, some of the wiser coalition groups declared that progress was not a matter of what actions were to be taken first; instead, progress could be measured by all of the actions taken first. "All for one and one for all" philosophy. That started the turbulent times between 1975 and 1980 when our consumer friends marched on the federal and state assemblies to make known all of their wishes and to initiate all of their goals.

And the legislation came surprisingly easy. Someone had found out that back in 1976 there had been some landmark federal legislation, but it was obvious that voting for the handicapped was becoming like voting for motherhood, a popular appeal on the heels of public education. Furthermore, some agency found out that at least 50 million Americans each day came in contact with a handicapped person or were themselves handicapped, and translated to voting power, that kind of constituency made legislators take notice. When consumers could then tell those legislators of the dollar savings and benefits in prevention actions, the legislators voted on some of the most radical treatment and education bills that had ever hit their hallowed halls.

One of the easiest tasks to perform, however, was the task of recruiting the workers for the fields of prevention and advocacy. There were the idealogues, and there were the pragmatists. There were the dreamers and the realists, the shrinkers, and the aggressors. But once the idea of prevention and advocacy was known, it was a popular idea, an idea that attracted many. A goal was set of halving the numbers of handicapped people. That became a national goal, like landing on the moon, and people flocked to the task. And it worked.

And that is why I am here--in 2001. I am here to honor you, you people who have worked to make these dramatic goals happen in these last 25 years. Even though I know you are modest, I must say this: do you realize that because of your interests and your work, your child, or your neighbor's child is straight, healthy, and bright rather than crippled or mentally retarded? Do you realize the anguish you have saved the parents of these children--these "might-have-been" children?

I wish there were some way that these parents of "might-have-been" children could know that they are parents of "might-have-been" children, and express to you their great gratitude. But of course they cannot. But I can.

Thank you.

QUESTIONS AND ANSWERS

Q: How did we cope with the strong political groups in 1976 who labeled these idealogues as militant social idealists?

A: With facts. In order to effect the reforms in thinking about prevention we had to show that it was a "dollars-and-sense" fact rather than a dream. We tried to stir up debate at high political and economic levels to present these facts, and were finally successful. Then, and only then, did the preventioneer become "respectable".

Q: Of all the different avenues that have opened to us at this point, which one do you feel is fruitful in terms of having some immediate political impact?

A: State and local change. National attitude change is just starting. The White House Conference is just beginning to pull together the disparate groups that need a voice. But viable and dramatic changes have been accomplished in some states and in some communities. Ohio is probably readier than most for prevention. It should not wait for national action. You can start today with systematic changes at a local or state level.

Q: What will the federal government do in helping us to accomplish this goal of 2001?

A: Since you are the government, what the government does is up to you. It is as flexible, as controlling, as generous, or as stingy as you make it. However, it generally exists to fill in the gaps left vacant in state services. Hopefully, it will not have to fill those gaps in Ohio, but if it does, the federal government's role will be determined by Ohio's legislation actions for the next few years.

Q: What are your strategies for prevention"

A: Advocacy, first and foremost. Secondly, the pulling together of various professionals in <u>all</u> disciplines serving the handicapped should be effected for professional advocates. The third prevention strategy I would put into place would be a public education strategy, including the public schools.

Q: Will there be less restricting legislation in the next 25 years?

A: In education, there already is. Probably the next big legislative push will be to "delabel" handicapped persons, but that is still some time away. What should be looked for is probably not "less restricting legislation" but instead, "more facilitative legislation".

Q: How do you see Doctorate level persons working in this grass roots movement?

A: As trainers. We will always need people to train advocates, research prevention, and establish quality control of programs, education, and the like. There is enough work for all, and Doctoral level people will always be needed to teach and coordinate the various professionals from disparate fields, and help plan strategies. However, these people will probably have to be trained differently in the future. Someday, in fact, we may have the A.D. (Doctor of Advocacy) or a science of prevention. For the sake of our children, let us hope so.

OHIO PREVENTION STRATEGIES

ANTOINETTE P. EATON, M.D.

Director, Maternal and Child Health Division
Ohio Department of Health

There is general agreement that prevention of developmental disabilities is certainly preferable to treatment. Ideally, prevention requires understanding or education of the cause and mechanisms for identification or early diagnosis of those families who are particularly afflicted with such disabilities. Appropriate facilities and resources with sufficient financial support are essential for the establishment of preventive services.

Unfortunately, however, preventive services have not always been a popular health focus, but I am hopeful that this is changing and we are gaining some ground in terms of being able to sell preventive health programs. During this presentation, I would like to touch on two specific areas of program planning and activity in maternal and child health in the State of Ohio. They are directly related to an expected outcome and that is the prevention of developmental disabilities.

First, I will talk about perinatal health and I will use the strict definition - that is from the point of conception through the first 28 days of life and then I will discuss genetic services. While separated for presentation purposes, these two topics are directly related in actual practice.

Why the concern in this conference about perinatal health care? Complications of high risk pregnancy, whether occurring in pregnancy, labor or delivery, continue to be a problem in this state and across the nation. The identification of women who are high risk for complications of pregnancy and promotion of comprehensive health services can reduce the incidence of undesirable outcomes of pregnancy, such as maternal and infant mortality and morbidity, as well as mental retardation and other handicapping conditions in the infant.

The lack of prenatal care has been considered a significant high risk factor for mothers and babies. It is important to note that in 1973, more than 46,000 women in Ohio, or about 30% of the pregnant women in this state did not receive adequate prenatal care. In addition, there were about 10,000 babies born to mothers either younger than 15 or older than 35 years of age who are certainly considered high-risk categories. Delivery of premature infants was twice as common in the young teenager than women of other child-bearing ages.

Racial and socioeconomic factors played significant roles in affecting perinatal mortality rates. Recent years have seen extensive research and technological advances in the diagnosis and treatment of many obstetric and newborn disorders. Practical application of these advances along with declining birth rates, promotion and acceptance of family planning and new abortion laws are other significant trends.

In recent years, a number of studies have demonstrated that the rate of maternal and fetal mortality can be substantially reduced if high-risk maternity patients and their newborn are identified early and the optimal techniques of obstetrics and pediatrics are appropriately applied. Additionally, it had been shown that critically ill newborns treated with the best available techniques and specially staffed and equipped intensive care centers, survive with significantly less damage than was the case in previous decades.

These changes have had a tremendous impact on the provision of services as well as the activities and responsibilities of State Health Departments, such as ours in Ohio. At the federal level, the Maternal and Child program has emphasized the importance of developing a coordinated prenatal system in Ohio, with the eventual goal of providing timely, adequate, quality care to all who need it. The interest of our State Health Department in programs such as regionalization of perinatal care, stems from concern and interest in the promotion of high quality maternal and child health services.

The ultimate gain, of course, is what we are all here for today - reduced infant mortality and morbidity that results in specific neurologic disabilities. Factors such as poor prenatal care, defective nutrition, a higher frequency of reproductive casuality and intercurrent maternal illness are some examples of preventable prenatal factors that are frequently associated with poverty and social disadvantages. These factors in turn, lead to the production of low birth weight and premature babies with the higher risk of mental subnormalities than infants of normal birth weight. It has been demonstrated that both improved prenatal care and better prenatal nutrition decreased the frequency of low birth weight and the resultant increased risk of developmental disabilities.

The goal of the Ohio Department of Health is to make optimal perinatal care appropriate to the needs of every patient and available to all. In order to accomplish this, much planning and programming is essential in the immediate future. It is imperative I feel, that a regionalized system provide homogeneous high quality care throughout the state, although mechanisms for providing this care will vary with the various kinds of geographic factors in a given region. I am confident that such a system will be an effective tool for the prevention of developmental disabilities.

A second major area of involvement in which prevention of developmental disabilities will be the expected outcome is genetics. Detection and management of genetic disorders is a subject of growing interest to the general public and to the health profession and is an area in which new technologies have been developed at a rapid pace. This is evidenced by the availability of at least 70 screening tests for genetic disorders, although most of these are not being sought on a general population screening basis. I am fully aware that the issue of mass screening is a controversial one as evidenced by the recent article in Science March 5, 1976. There should be little question, though of the value in screening for those genetic metaboligic disorders, such as PKU, galactosemia and hypothyroidism, where delayed disgnosis and treatment results in mental subnormalities and its attendant tragic consequences and economic costs to society.

Why is genetics important in developmental disabilities? Many major advances have occurred in genetics in the last 20 years. These have included the discovery in 1959, by Lejeune of the chromosonal abnormality responsible for Downs Syndrome and the opening of the whole new field of chromosome investigation. Amniocentesis was the next major step. A method of prenatal examination, first used in the diagnosis of RH incompatabilities, it was soon discovered that amniotic embryonic fluid contained fetal cells capable of culture and a means for the prevention of a child with severe chromosome defect. Subsequently, it was discovered that several metabolic disorders could be detected through culture of fetal skin cells from an amniocentesis. Most recently, special chromosome staining has been made available for particular chromosome identification allowing for more effective chromosome diagnosis.

Many genetic disorders result in serious disabilities or even death early in life. Of the approximately 160,000 live births in Ohio in 1975, more than 2,000 had malformations or abnormalities indicated on the birth certificate. It has been estimated that genetic and biochemical disorders affect 2% of all live births.

More than 2,800 patients in state institutions in Ohio for the mentally retarded are there because of a suspected disorder which is known to be genetic or due to an unknown cause which may have a genetic basis. This points to the need for more comprehensive services.

Improved prenatal and perinatal care, with better resuscitation techniques, improved care of the infant with respiratory distress, improved techniques for the prevention and treatment of the infant with jaundice, comprehensive immunization programs to eliminate measles, or rubella and other viral diseases that affect the central nervous system, either prenatally or postnatally and the erradication of central nervous system toxins, such as lead from the environment, all contribute to reducing the frequency of developmental disabilities.

What are the present and future endeavors of perinatal health care in Ohio? There are several major projects funded in this area, presently, which should certainly enhance the development of a regional plan for perinatal health in the State of Ohio. Two of the largest projects that we are associated with in this regard are the maternity and infant care projects, one of which is located in Cleveland and the other in Cincinnati. These programs were initiated by federal mandate in the mid-60's because large numbers of women in low-income families were receiving poor prenatal care or none at all, had high incidences of complications of pregnancy and had a high infant and maternal mortality rate. Also they delivered prematurely two or three times as frequently as the average for the nation as a whole. Such infants are, of course, especially vulnerable to neurological disabilities, mental retardation and other handicapping conditions caused by complications that are associated with childbearing.

In addition to quality maternity and newborn care, the projects include general health education and special programs such as preparation for parenthood and teenage parenting. These projects have statistics which I think beautifully document the value of quality programs of perinatal care in terms of the reduction of infant mortality and morbidity and I am including developmental disabilities under that category. A significant portion of the maternal and child health budget, as much as 25%, is channeled into these programs.

We are also funding a number of other important perinatal programs in Ohio, for example, the Perinatal Program at Ohio State University, the Neonatal Information Center at the University of Cincinnati Department of Pediatrics, which I might point out received national recognition two weeks ago when it was presented at the Society for Pediatric Research Annual Meeting because the program was so effective in reducing infant mortality and morbidity. There are other perinatal programs in Akron, Dayton, Toledo, which are very valuable and effective. Last, but not least, we have several primary care programs and by primary care I mean "first line" prenatal care programs that are funded through local health departments, particularly in rural areas where it may be very difficult for women to get the kind of adequate care that they need.

The Forward Plan for Health which is the five-year projected plan for the Department of HEW specifically recognizes the impact of genetic disorders on the health of a nation. The document recommends the development of a model State Plan (which we have completed in Ohio for genetic screening backed by State Legislation and goes on to further emphasize the importance for standards of screening methods and quality reviews, prenatal diagnostic services, research, and health education.

The Mental Health and Mental Retardation Committee of the Ohio Comprehensive Health Planning Advisory Council has recommended to the Council that children and youth services in Mental Health and Mental Retardation in the State of Ohio be given high priority.

On April 22nd of this year, President Ford signed into law, Public Law 94-278, which is a comprehensive genetics act, including but not limited to, sickle cell anemia, Cooley's anemia, Tay-Sachs disease, cystic fibrosis, hemophilia, Huntington's Disease, muscular dystrophy and a few other genetic disorders. The House Bill required that testing and counseling programs be established and operated primarily in conjunction with other existing health programs under Title V, and I should point out that Title V is the legislation that mandates State Maternal and Child Health and Crippled Children's programs. Another amendment in the law provides a priority in the awarding of grants and contracts for genetic disease and counseling programs.

The amended law authorizes 30 million dollars for each of the fiscal years '76, '77, and '78 to support genetic testing, counseling programs and information and education programs and provide that the secretary of HEW should give special consideration in awarding of grants and contracts to sickle cell anemia testing and counseling project applications. The signed version of the law also authorizes grant awards and contracts for research projects with respect to basic or required research leading to the understanding, diagnosis, treatment, and content of genetic disease. The appropriations for genetic disease research are much greater than they are for services, for example, it is 80 million dollars for 1976.

The Bureau of Maternal and Child Health has completed a grant proposal to implement the Ohio Plan for Genetic Services. I might add that I have had this grant proposal completed for at least a year and have submitted it to several agencies and I am still trying to obtain sufficient funds for it. We have submitted it to the Bureau of Community Health Services, in Washington, D.C. for funding hopefully under the above legislation. This grant, if approved, will supplement each of the currently established regional genetic centers in Cincinnati, Columbus, and Cleveland. It is meant not only to consolidate but also to expand services for the entire state and very importantly the contiguous borders of our state, i.e., West Virginia and Kentucky. So it truly is a regional plan for genetic services.

In the development of this genetics plan, there was cooperation between many state agencies including Mental Health and Mental Retardation, Welfare, Education, major universities, and voluntary agencies such as The National Foundation March of Dimes. This application represents a concerted and cooperative effort to provide quality services to mothers and children who need genetic counseling, screening, diagnosis, and treatment.

The prevention of Mental Retardation and Developmental Disabilities, will be the main initial benefit from this particular program, but the potential for reducing other handicapping conditions such as heart disease, diabetes, and genetic disorders is clearly an expected long term benefit. The primary objectives covered by the grant are basically three: (1) increased diagnostic, treatment and follow-up services for infants, children and high-risk mothers; (2) professional and public education in the area of genetics and (3) data collection to effectively measure the cost benefit of each disease which is important in selling the program to the legislature for assigning priorities and also to measure the progress and impact of statewide genetic programs.

There are currently at least six sites of genetic activity in Ohio. We have concentrated, at least initially, on the three major programs which I have outlined with Toledo, Dayton, and Akron to be included as the plan is implemented. What are the current genetic activities in maternal and child health that we are primarily involved with at this point in time? Basically I have outlined what I think is the most important one and that is the development of the regional plan for genetics.

However, we are also involved in several other areas, for example, we have workshops in genetic counseling which play an important role in public and professional education. The Division of Maternal and Child Health also provides follow-up on positive laboratory tests for the PKU screening program, maintains a registry of those children who are on the diet, provide the special dietary formula to these families and monitors their blood tests. We are also involved in coordinating a statewide sickle cell detection program. Through a special state appropriation, we are hopeful that the genetic screening program may be expanded and we have a meeting set up next month to which we have invited leading authorities and investigators in this field to speak to us with reference to the issue of neonatal hypothyroid screening. Because this would be the first project to implement a statewide referral mechanism for comprehensive genetic services it is obviously difficult to predict total outcome, however, I think the results will be helpful to us and hopefully to other states in adopting a similar program.

What can we do and where do we go in terms of prevention of developmental disabilities? I would like to leave with you a few specific recommendations to which I feel our mutual effort should be directed if we are really serious about this whole issue. Some of the suggestions that I will make are echoed in a publication called Lengthening Shadows which is a report on the Council of Pediatric Practice of the American Academy of Pediatrics. This particular list of recommendations dealt with the delivery of health care to children.

These are the provisions: (1) improved preventive health care and systematic screening for health and developmental handicaps in children from birth through school age. In this regard, I would like to point out that we are funding through the Maternal and Child Health Division, two children and youth projects in Ohio in which the major focus of activity is preventive health care; (2) the provision of prenatal care and counseling available to all who require it. This should include comprehensive family planning services and genetic counseling; (3) early developmental education beginning in the child's first years; (4) daycare for all children who need it for the aim of promoting mental and social development from infancy and of aiding parents to encourage each child's growth to it's fullest potential; (5) public and professional education programs. I think health education is one of the most effective tools for prevention of developmental disabilities, and I think this should begin in the preschool years. One project we are hoping to initiate through our Health Education Unit is to initiate an experimental project with daycare workers to see if we can introduce some new techniques for health education at a young age; (6) lobbying activities - probably the most important recommendation is to act as a lobbying group or an advocacy group. The main point I am trying to get across is that we have to sell the legislature, state or federal, the effectiveness in terms of the scarce tax dollar of the prevention of developmental disabilities. I think that obviously the most productive avenue is to be able to demonstrate that it is cost effective to support prevention programs.

I think that there are two very specific examples that demonstrate beautifully the cost effectiveness of a program. The first one is PKU (Phenylketonuria) which costs the State of Ohio less than 25 cents a test to screen newborns for PKU. The total cost of a screening program for the State of Ohio is less than a hundred thousand dollars annually. I think the current figures for residential placement in this state is about two hundred and fifty thousand dollars per individual for lifetime. This means we have to pick up one child with PKU a year to more than pay for our program. Furthermore, this isn't really taking into consideration what I think is more important and that is the tragedy of having a child who is retarded unnecessarily.

Another mechanism for illustration of the cost benefit is that we are saving the state about six million dollars a year if one considers the total dollars that are spent on PKU testing. A third way of saying the same thing is that for each dollar spent on PKU testing we are getting seventy-five dollars in return.

A second example to be cited relates to perinatal care. There is no question that good neonatal intensive care can significantly reduce or eliminate handicapping conditions. The average cost of neonatal intensive care (and I would stress that this is average cost) is about eight thousand dollars. To place that child in a residential facility for a lifetime as I have pointed out previously, would cost two hundred and fifty thousand dollars. I don't think that there is any question about the fact that we can clearly document for certain specific disorders such as the two examples given that there cost effective benefits to society in prevention programs.

I would like to close by sharing with you a section of a report from the President's Committee on Mental Retardation. It summarized very nicely what I have tried to say to you in the last 20 or 25 minutes.

"The best hope for reaching the goal of freedom is the prevention of handicapping conditions that can rob individuals of their freedom and keep them dependent throughout their lives. Across the nation, research is delving into the factors that promote healthy human development or those that disrupt development and result in damage that is often irreparable.

The health and environment of both mother and father even before conception occurs is of importance because of the genetic inheritance it will pass on to the child. From conception on to completion of pregnancy, development and differentiation of tissue and organs are major determinants of the eventual intellectual and emotional functioning of the individual. Though research has uncovered many causes of disorders, beginning in the prenatal period, discovering the cause is but one step in the process of correcting problems.

Every baby born with a mental and/or physical disorder is tragic evidence of the need for further research and application of present knowledge. Preventing handicapping conditions is the best hope of freedom and avoidance of dependencies with early and intensive treatment as the second best hope".

Thank you.

THE LOST CONTINENT OF PREVENTION

GENE PAUL CALVERT, PH.D., M.P.H.

Manager, Prevention and Education Section
Office of Education and Training
Ohio Department of Mental Health
and Mental Retardation

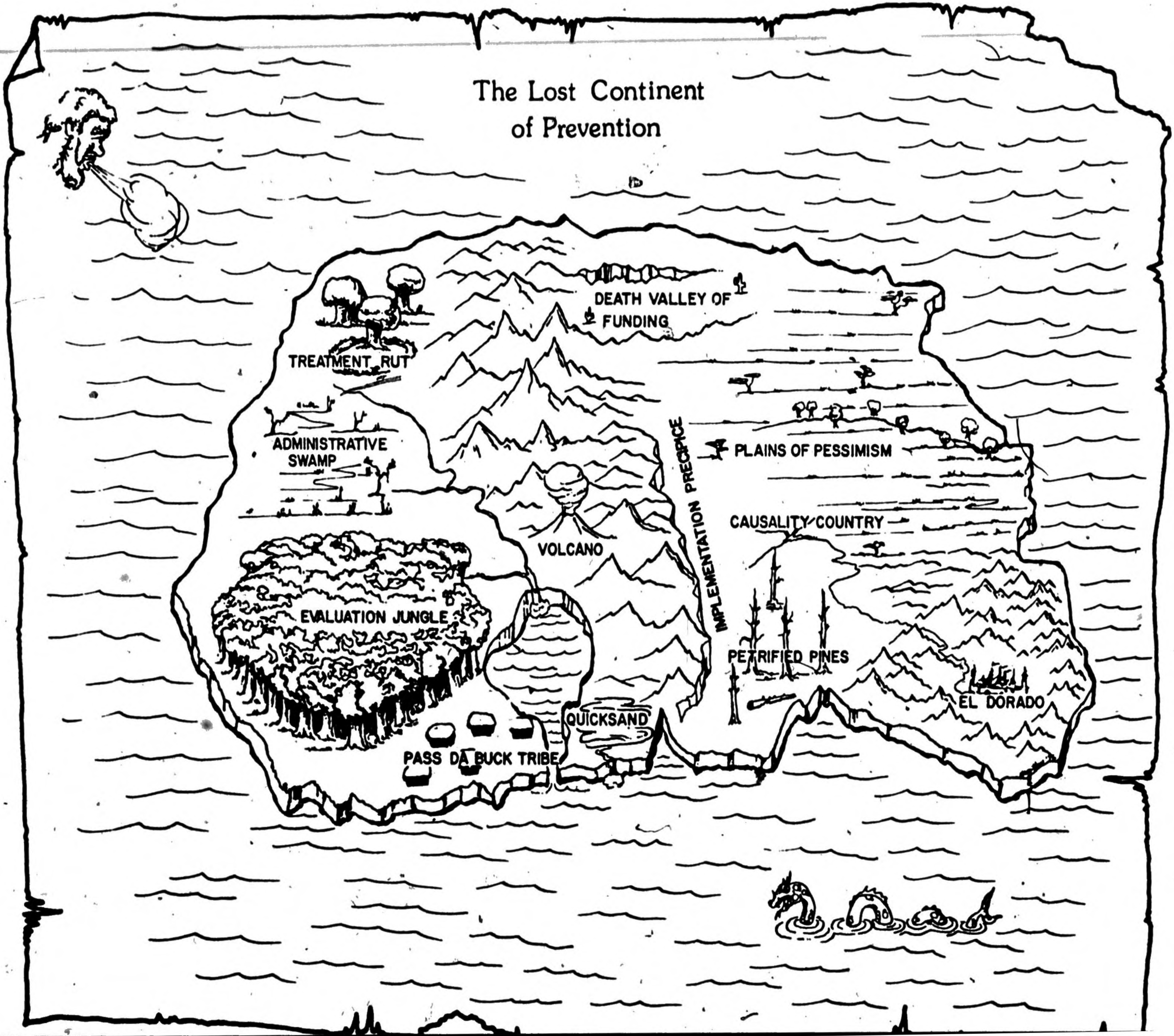
Today we will review some major problems blocking the establishment and expansion of programs aimed at preventing mental retardation and developmental disabilities. With tongue-in-cheek, these prevention obstacles have been translated into the metaphor of a Lost Continent of Prevention; its topography and inhabitants serve to illustrate problems confronting those of us advocating prevention services. After viewing a series of slides of the Lost Continent of Prevention, we will briefly explore a Prevention Pathway by which we can escape many of its hazards. By that route we can best keep a promise to all unborn children; that they will be born as healthy as possible, achieving their maximum human development.

PETRIFIED PINES OF PREVENTION PRESUMPTIONS

Our tour of the Lost Continent of Prevention begins at the Petrified Pines of Prevention Presumptions. This is a forest of unverified and incorrect presumptions about the feasibility and cost of preventing mental retardation and developmental disabilities; unexamined presumptions about which agencies, professions and disciplines have direct prevention responsibilities; uninformed presumptions about currently available prevention methods; and presumptions about the adequacy of current prevention efforts.

ADMINISTRATIVE SWAMP

Our next stop on the Lost Continent of Prevention should be familiar to everyone; the Administrative Swamp. This Swamp oozes with the muck, slosh, and slime of administrative politics,


The Lost Continent
of Prevention
DEATH VALLEY OF
FUNDING
TREATMENT RUT
ADMINISTRATIVE
SWAMP
PLAINS OF PESSIMISM
IMPLEMENTATION PRECIPICE
CAUSALITY COUNTRY
VOLCANO
EVALUATION JUNGLE
PETRIFIED PINES
EL DORADO
QUICKSAND
PASS DA BUCK TRIBE

administrative personalities, and administrative procedures. Prevention programs suffer from the seemingly universal laws of administration: (1) nothing is as easy as it looks; (2) everything takes longer than you think; and (3) if anything can go wrong, it will. One way to become stuck in the Administrative Swamp is through committees; committees of the unprepared, appointed by the unwilling, to do the unnecessary.

DEATH VALLEY OF FUNDING

The next topographical feature will also be familiar. It is the Death Valley of Funding. Many of you who have tried to obtain funding for prevention and early intervention programs can surely identify with the Death Valley prospector of the Old West. To discover prevention gold may involve hard digging, many disappointments and firm conviction that "thar's gold in them thar hills." Sometimes, it is a struggle to even find a "grub stake" (e.g. staff time) to start prospecting for funding gold.

CAUSALITY COUNTRY

The next feature of the Lost Continent of Prevention also constitutes a rugged barrier to be overcome, if we are to prevent mental retardation and developmental disabilities. It is Causality Country. It certainly must be conquered. But how long will it take to discover all the causes of the various types of mental retardation and developmental disabilities? Many travelers on the Lost Continent of Prevention become lost in Causality Country. The search for causes is essential in order to prevent mental retardation and developmental disabilities. Yet, for some, the search for causes is simply an excuse not to apply the evidence we already have to prevention efforts.

TREATMENT RUT

Moving on, we come to a deeply worn, circular path known as the Treatment Rut. It goes in a never ending circle of providing more and more treatment services. Realistically speaking, will we ever have all the dollars needed for treatment services? Probably not. With effective prevention programs, however, our dollars would go further, since fewer would eventually need them. This requires a long range time perspective that few possess or can afford for economic or personal reasons. Some view treatment as an ethical imperative. Others challenge this view with an alternative ethical stance; a prevention ethic giving moral priority to the primary right of every child to be born free of handicapping conditions which then, of course, must then be offset and limited as much as possible.

EL DORADO

Leaving the Treatment Rut, our journey now takes us in search of the fabulous El Dorado. Those seeking this utopian city argue that prevention is useless until we solve all of our community, economic, health, and political problems, as well as all social controversies. In other words, these procrastinators demand a utopian society of perfectly healthy citizens as a prerequisite for an intensive prevention effort; a society without poverty, without disease, without inadequate health services, without undernutrition, without lead poisoning, without genetic disorders and without any presently unresolved prevention related problems. I argue that these prevention complexities will never be simplified or eliminated. They surely will not be solved by hoping to miraculously stumble upon the answers someday in an El Dorado of prevention. We must start with the prevention answers we now have and move forward as best we can.

PASS-DA-BUCK TRIBE

Moving on again, we meet the inhabitants of the Lost Continent of Prevention--the Pass-da-Buck Tribe. The national pastime of the Pass-da-Buck Tribe is declining responsibility for operating prevention programs. After all, isn't prevention everybody's business? In the case of Pass-da-Buck Tribe, however, what is everybody's prevention business becomes nobody's prevention business. The members of this Tribe have developed, through the evoluntionary process, unusually long arms and fingers from their continually pointing to others to deliver prevention services.

VOLCANO OF VERBIAGE

Let us now view a prominent mountain on the Lost Continent of Prevention. This is the Volcano of Vague, Volatile, Vasilating, and Vulgar Verbiage. What I am trying to say here, with self-parody, is that our prevention language, conceptual tools, and style of communicating frequently resemble this Volcano: the way people talk about prevention is often vague, in the sense that it is impercise, hazy, and obscure; it is volatile in that it evaporates quickly; it is vasilating in that it wavers; it is vulgar in the sense of a lack of refinement and sensitivity;

and the volcano spews out verbiage or an excess of prevention words and a deficit of prevention actions. Talking about prevention is a legitimate and necessary activity, but this kind of talk serves no constructive purpose.

FOLLOW-THE-LEADER MENTALITY

There is another not so strange phenomenon on the Lost Continent of Prevention known as Follow-the-Leader Mentality. This barrier to prevention results from blindly following today's trends, ignoring the less popular prevention alternatives. The Follow-the-Leader Mentality involves defending the status quo long past the time when the quo has lost it's status. We need to extend our vision beyond the catch words and fads dominating mental retardation and developmental disabilities professions, disciplines, and agencies. We must have the courage to try and the courage to try again if we fail. The Follow-the-Leader Mentality leads to the quicksand of complacency.

PANTHERA PESSIMISIUM PREVENTIUS

Traveling on, we encounter an animal species inhabiting most regions of the Lost Continent of Prevention known as Panthera Pessimisium Preventius. This creature is a huge, cougar-type animal. He feeds on pessimistic humans who find the challenges of prevention so hopelessly difficult that they surrender themselves as willing victims for this creature. While ferocious looking, Panthera Pessimisium Preventius fears optimists and runs from anyone believing prevention is possible, practical, and preferable to giving up without trying.

IMPLEMENTATION PRECIPICE

An equal danger on the Lost Continent of Prevention is the Implementation Precipice. Climbing this prevention cliff is as dangerous and lonely as climbing Mt. Everest--only the well prepared and determined will find the seemingly nonexistent hand and footholds leading over the top of this sheer precipice. In other words, don't delude yourself that implementing prevention programs will be easy, safe, or quick.

EVALUATION JUNGLE

The final landmark of the Lost Continent of Prevention is the Evaluation Jungle. Prevention programs must escape the avoidable dangers lurking in the Evaluation Jungle: improper evaluation procedures, untrained evaluation personnel, unreasonable evaluation standards and politically motivated exploitation of evaluation conclusions. Yet, this Evaluation Jungle offers many benefits to prevention: cost/benefit data, measures of efficiency and effectiveness, and clarification of program objectives. Speaking practically, prevention programs will have to develop skills necessary for survival in the Evaluation Jungle.

LOOKING BACK

We have reviewed major obstacles blocking or distorting prevention attitudes, values, and activities. The fictional Lost Continent of Prevention illustrates many of these obstacles: petrified presumptions; administrative swamps; excessive preoccupation with detecting causes; inexhaustable treatment demands; a complex web of deeply entrenched societal problems; program responsibility issues; communication and conceptual problems; the nearsightedness of professional and agency status quo biases; the hazards of program implementation; and the potential dangers of improper program evaluation.

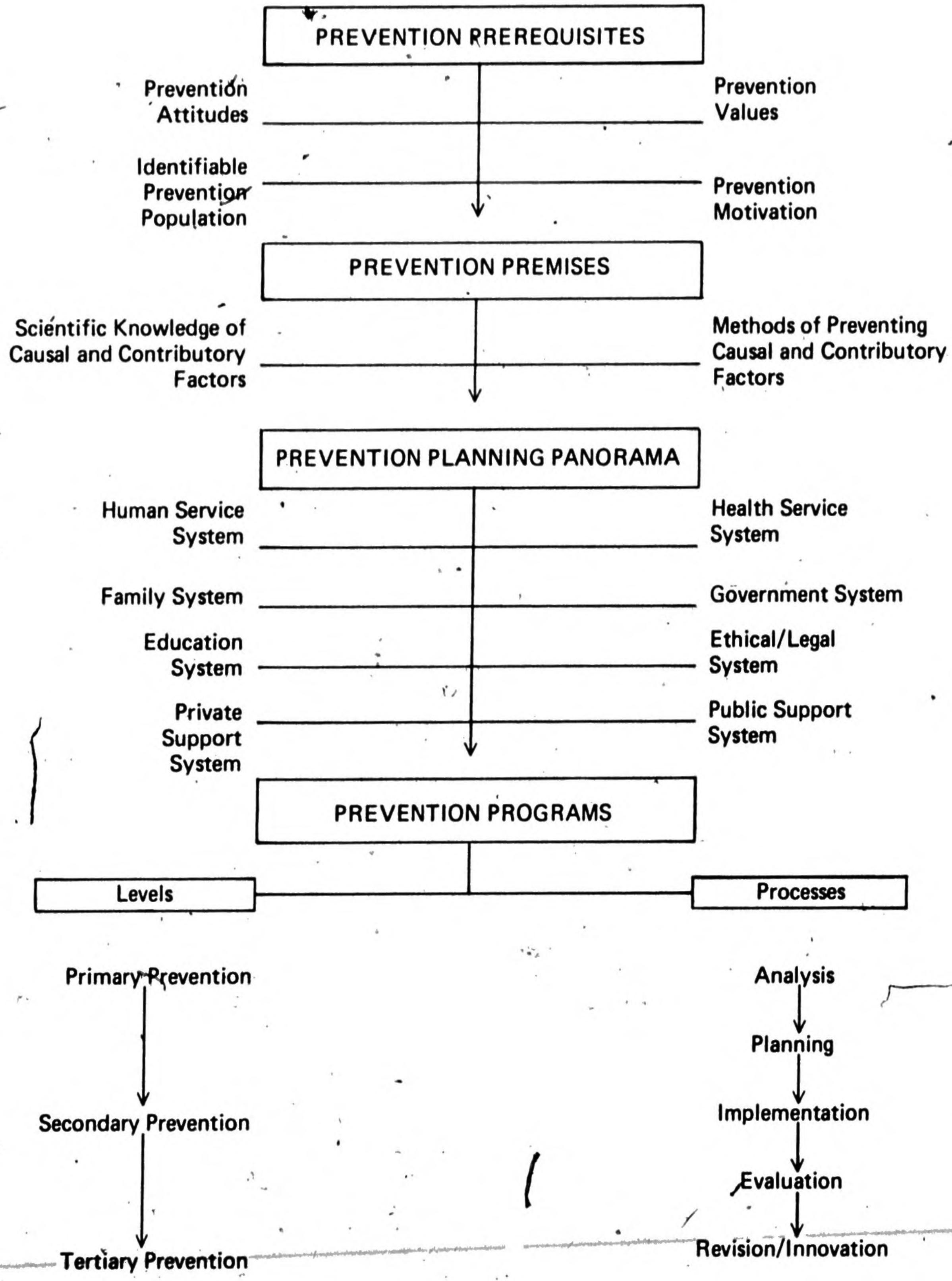
PREVENTION PATHWAY

There is a Prevention Pathway giving us safe conduct out of the Lost Continent of Prevention. (Please see the Diagram on page 27. It begins with several prevention prerequisites: prevention oriented attitudes, values, and motivation, along with, of course, an identifiable prevention population. Of these four prerequisites, values are among the most important, because values refer to those ends and means we most prefer and pursue.

The next part of the Prevention Pathway involves two critical premises: (1) appropriate, scientifically verified knowledge of the causal and contributory factors in mental retardation and developmental disabilities; and (2) the development, application, and continual improvement of methods for intercepting or limiting these sets of factors.

With these prerequisites and premises in hand, we turn to the Prevention Planning Panorama encompassing many public, voluntary, civic, and community systems. It is correct that--to a large degree--that prevention is everybody's business. The

PREVENTION PATHWAY



Prevention & Education Section, Office of Education & Training
Ohio Dept. of MH/MR; Calvert, Brecht, Nugent

Prevention Pathway ends hopefully with prevention programs, be they primary (truly prevention), secondary (early intervention), or tertiary (full rehabilitation programs). Developing and establishing a Prevention Program proceeds through a normal sequence of processes: analysis, planning, implementation, evaluation, and revision.

PROMISES TO KEEP

This conference has been taking place for just a little over two hours. In that time period, fifty children in the United States have been born with a handicapping condition. How much longer will we wait before we prevent mental retardation and developmental disabilities? How many more children will be born with preventable forms of mental retardation and developmental disabilities?

We must promise ourselves and each other to stop preventable abnormalities from happening. Keeping that promise will help to secure for every child the right to be born healthy and achieve maximum development as a human being. Our goals, according to the President's Committee on Mental Retardation, are to reduce the incidence of mental retardation and developmental disabilities from biomedical causes by at least 50% and to reduce the incidence and prevalence of mental retardation associated with social disadvantage to the lowest possible level. We can...if we care.

A PREVENTIVE PEER SUPPORT PROGRAM:
PARENTS HELPING PARENTS

DEANNA HORSTMEIER

The Nisonger Center for the Mentally Retarded
and Developmentally Delayed
(University Affiliated Program)

SANDRA LANDIS

Project Coordinator
Franklin County Council for Retarded, Citizens, Inc.

In 1970, DeAnna Horstmeier had her fourth child, a son Scotty, who had Down's Syndrome (mongoloid). Doctors advised that the baby be institutionalized immediately -- before he damaged the older, brighter Horstmeier children.

As Mrs. Horstmeier struggled with the impact of a child with Down's Syndrome,most hospital personnel and visitors 'helped' by avoiding her and providing outdated information about mental retardation.

Mrs. Horstmeier and her husband faced the reality of having a mentally retarded child alone until a chance meeting with the mother of another child with Down's Syndrome.

The difficulty of her experience and that of other parents with mentally retarded children led to a'grass roots' program for experienced parents visiting parents of newly diagnosed mentally retarded children. The demand for this parent-sponsored program led to the organization of the Franklin County Council for Retarded Children (CRC) Volunteer Visitation program.

The program is still manned by volunteer parents, but now has a professional coordinator, Sandra Landis, who was co-leader of Workshop #2.

The CRC Volunteer Visitation program is designed to: (1) provide peer support to newborn and newly diagnosed children with MR or DD, (2) help parents see their child as one who happens to have a developmental disability rather than a disability embodied in a child, (3) provide correct, current information about developmental disabilities, (4) give parents information about appropriate community services, and (5) help parents become advocates for themselves and their children, Ms. Landis said.

The program has made a difference for the parents of newly diagnosed or newborn children with developmental disabilities or mental retardation in Franklin County. The work of the parent group fits into the secondary or tertiary level of a mental retardation program, Ms. Landis said.

The difference starts in the hospital with the mother and mentally retarded baby, she explained.

Each hospital in Franklin County now has a folder of information on mental retardation, a book of snapshots of mentally retarded children and the phone number of the CRC (614-221-9115). Included are magazine articles about mentally retarded children, brochures on the peer support program and other MR agencies, and pamphlets from the National Association for Retarded Citizens, P.O. Box 6109, Arlington, Texas 76011. Suggested pamphlets offered by the association include Your Down's Syndrome Child, Make the Most of Your Baby, and Primer for Parents of a Mentally Retarded Child.

The actual parent-to-parent work is most important. It starts with a referral from a doctor, counselor, nurse, or parent. The next step is careful matching of the referred family with a family of volunteer visitors. Ms. Landis tries to match parents who are close to the same age and whose children have similar disabilities.

Once the match is made, Ms. Landis contacts the volunteer parents who can accept or reject the referral. If accepted, the volunteer parents set up the first contact.

The quality of that contact is assured by a five-week training session for volunteer parents which is conducted by Ms. Landis. In five 3 1/2 hour sessions, parents learn about child development and adjustment, communication skills to ease the first meeting, and the resources and services available in the community for families.

Ms. Landis offered to provide advice and assistance in establishing similar training sessions in other counties.

Involving fathers in the program was a problem mentioned by both workshop leaders and participants. Mrs. Horstmeier said fathers were more likely to talk about their feelings at meetings with speakers or at work meetings.

Reaching the medical profession was another common problem discussed. Ms. Landis said the Franklin County group sends their newsletter to interested doctors and urges parents to talk with and help educate their own doctors.

A pediatrician in the audience urged parents in the workshop to 'attack' genetics courses in medical schools to help educate doctors. Doctors have to learn to face the reality of DD before they can help a parent, he said.

Another workshop participant said it was easy to blame the medical community, but often people were not aggressive enough in getting into doctors' offices and making them listen.

PARENTS AS PARTNERS IN PREVENTION

ANN SKINNER BARDWELL, PH.D.

Chairperson, Department of Home Economics
Eastern Kentucky University

Dr. Bardwell approached the issue of prevention of MR and DD from a unique perspective. She suggested that the area of Home Economics, if it hopes to deal effectively with family and child development, must necessarily concern itself with the prevention of handicapped children.

Dr. Bardwell based her presentation on the assumption that everyone, with few exceptions, has the potential for parentage. In view of this fact, everyone should be concerned with the prevention of MR and DD, and also with the attainment of practical solutions to related problems.

At the outset, she defined the concept of prevention in terms of a continuous process, designed to bring about procedural change through individual and collective activity. She further proposed that the notion of prevention of MR and DD should be fundamentally involved with the improvement of existing service delivery systems.

She asserted that there is a vital need to influence delivery systems at various levels in the community. The focus of analysis for this workshop specifically dealt with those ways in which parents, acting together, might successfully influence the prevention of MR and DD by improving the general quality of available service delivery systems.

Dr. Bardwell, through the use of an overhead projector, presented an original model which provided a format for examining the interaction between various categories of service delivery systems and the individual's growth level. It was her position that the use of this model would aid in identifying key areas relevant to the prevention of MR and DD. In such a fashion, parents might organize their efforts and produce needed changes within the community.

Analysis and explanation of this model provided the unifying focus of her presentation. As indicated by the illustration, the front portion of the model identifies influential delivery systems. These delivery systems, which were not rank ordered, include public/private, formal/informal, and voluntary/involuntary agencies.

The top of the model specifies various stages in the individual's growth level. These stages are arranged in hierarchical progression in which each stage necessarily precedes the following stage. The side portion of the model indicates objectives for attaining prevention that may be met by each delivery system at each individual growth level.

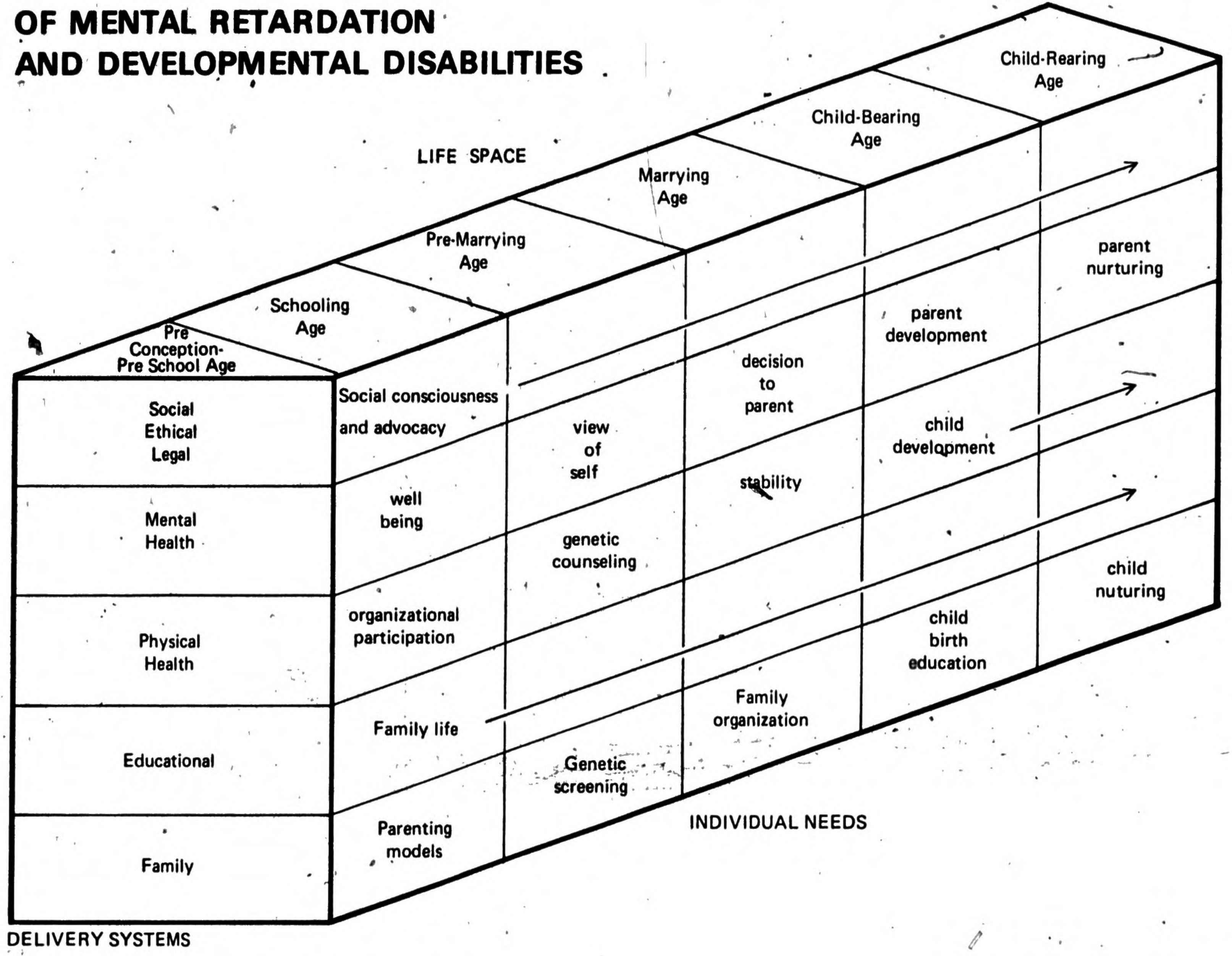
Dr. Bardwell proposed that manipulation of these various delivery systems would result in elimination of MR and DD. She felt that her model might be of use in helping parents to focus in on how to best influence the interaction of the system.

A number of suggestions were made by Dr. Bardwell at the completion of her presentation. First, she expressed the belief that parents, if they are to be successful in effecting prevention, must begin by learning the available information.

Second, Dr. Bardwell suggested that parents must become advocates for change. Last, she proposed that in order to determine priorities for action, it is necessary to determine the cost, in money and in human effort, that is required to effect these changes and attain prevention of MR and DD.

Her presentation was followed by a brief question/answer period in which participants attempted to further develop the applicability of her theoretical model.

MODEL FOR PREVENTION OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES



Ann S. Bardwell, Ph.D.
May 1976

GENETIC DISORDERS, GENETIC SCREENING AND GENETIC COUNSELING

STELLA BICOUVARIS KONTRAS, M.D.

Director, Birth Defects and Handicapped Child Sections
Department of Pediatrics
The Ohio State University

Currently, three per cent of the population is affected by mental retardation or developmental disabilities. But how many of these problems can be prevented by genetic screening, counseling and prenatal diagnosis of birth defects?

Dr. Stella Kontras of the Medical Genetics Division and Laboratory at Columbus Children's Hospital said she was not sure of the quantity but was sure that "some can be prevented."

One reason it is difficult to predict exact numbers is because in 60 per cent of birth defects the cause is unknown. Thirty per cent, however, are linked to genetic or chromosomal causes while the remaining 10 per cent are caused by the effects of virus, drugs or x-rays.

Sorting out which birth defects are genetic and which are not plays an important part of prevention, she said.

For example, after the rubella (German measles) epidemic of 1964-65, doctors learned that when the mother was infected during pregnancy, a wide range of birth defects occurred. Vaccination against rubella has substantially reduced such defects.

A recently discovered syndrome has also pinpointed another nongenetic form of mental retardation called the fetal alcohol syndrome. It occurs in children whose mothers are alcoholics. Characteristics of the syndrome include small eyes, a flat face, folds in the eye and moderate mental retardation. With 2 million alcoholic women in the country, Dr. Kontras sees much possibility for prevention of this syndrome.

Drugs are also responsible for birth defects. Many people are familiar with the effects of thalidomide, but other drugs are also being linked to specific birth defects. For example, dilantin, taken by mothers for seizure control, causes cleft palate in babies, she explained.

But mental retardation or developmental disabilities caused by genetic or chromosomal abnormalities are now being pinpointed by use of laboratory tests, physical diagnosis, and carefully detailed family histories.

A total of 2,000 genetic disorders are now known and catalogued. However, tests have not been developed to detect many of them. Such disorders are divided into five categories according to the way in which they are inherited or occur. They are dominant, recessive, X-linked, polygenic and chromosomal.

Many dominant disorders can be discovered by physical examination and are most often associated with physical appearance or condition of an organ.

Tuberous sclerosis is a dominantly carried disorder which is associated with mental retardation. Seizures, profound mental retardation, facial malformation and facial lesions (called adenoma sebaceum) characterize this genetic disorder.

On the surface, the dominants seem easy to predict. If a person has a characteristic, there is a 50 per cent risk of each offspring having it.

However, Dr. Kontras explained, there are two factors that make such predictions difficult. The first factor is referred to as variable penetrance. It means that sometimes a dominantly inherited disorder will not be severe and sometimes it will be very severe. There is no way to predict this, the doctor explained.

The second factor is that there is a certain incidence of mutation, which means a characteristic will sometimes appear without any history of such a disorder in the family. This is probably due to a chemical change in a gene.

Those factors are some of the things that make genetic counseling difficult in some instances, Dr. Kontras said.

She used a patient with a mild form of tuberous sclerosis as an example of dominant inheritance. The patient was a high school honor student who had no history of seizures or retardation, but did have the telltale adenoma sebaceum on her face. It was determined from studies that she had the gene for tuberous sclerosis. After counseling, the young woman decided not to have children because of the possibility that a severe form of the disorder could afflict 50 percent of her children.

The second pattern discussed is recessive inheritance. If both parents are carriers of the questionable gene, 25 per cent of their children will be affected, 50 per cent will be carriers and the remaining 25 per cent will be normal. Recessive traits are rare.

One of the most familiar is phenylketonuria (PKU). PKU is an enzymatic block which prevents handling the protein in milk and affects the development of the brain. There is no way to detect carriers of the disorder, but in Ohio, every newborn is tested for it. If the disorder is detected at birth, the child is placed on a special diet and mental retardation does not occur.

Some carriers of various recessive traits can be determined by tests. For instance, sickle cell anemia carriers and Tay-Sachs disease carriers can be discovered by testing. Cystic fibrosis carriers still cannot be detected by testing, but scientists are working on such a test, the doctor said.

The pattern of the X-linked trait is complicated. Females are carriers of the disease. Fifty per cent of the mother's sons will be affected with the trait, and 50 per cent of the mother's daughters will be carriers; the remaining children will be normal.

If the male is affected with the disease, all of his sons will be normal, but all his daughters will be carriers.

Hunter's syndrome is an example of an X-linked disorder causing mental retardation in many cases. This syndrome, often called gargoylism, is associated with bizarre facial malformation and often severe retardation.

The inheritance pattern of polygenic disorders are not clearly defined. Disorders transmitted in such a way simply occur more commonly in some families.

Meningomyelocele is an example of a polygenic developmental disability. The spinal cord and nerves of a baby are in a sac which protrudes from the back of a baby. This serious disorder now can be diagnosed in the mother's uterus by amniocentesis and determination of alpha feto protein in the fluid surrounding the developing fetus.

Chromosomal abnormalities are the fifth group which Dr. Kontras discussed. They are detected by a chromosomal test in which white blood cells are incubated and treated to discover the number and shape of a person's chromosomes. Such tests are displayed on a card called a karyotype which graphically displays the chromosomes.

When a child has an extra 21st chromosome, he is affected with Down's syndrome or monogolism which is characterized by mental retardation, slanted eyes, flat nose bridge, and large tongue. Although 95 per cent of Down's syndrome is caused by the extra 21st chromosome, called trisomy 21, a small percentage of Down's syndrome is inherited.

This is called translocation mongolism and is detected by an abnormal chromosome. Depending on the type of translocation mongolism, from one-third to 100 per cent of the children of a carrier will have Down's syndrome. In contrast, only 1-2 per cent of the mothers of a trisomy 21 child will have another child with Down's.

This is one reason every child with a diagnosis of mental retardation should have a chromosomal test, Dr. Kontras emphasized.

Aminocentesis is the key to prevention of many birth defects, Dr. Kontras said, but noted that it is not worthwhile except for high risk mothers.

Aminocentesis is a test which analyzes the chromosomal and biochemical character of amniotic fluid taken from a mother by inserting a large needle into the amniotic sac which surrounds a 14 to 16 week old fetus. The test tells a doctor what the chromosomes of the unborn baby are like. If the child is abnormal, the mother is told and makes a choice whether or not to have a therapeutic abortion.

Such testing should be confined to high risk mothers since there is a slight risk of aborting the child by performing the test, she said.

High risk mothers are those over 35 and those with a genetic history of abnormality. Such a risk also exists in preteen and early teenage mothers, she said.

Only 5,000 such tests have been performed to date. Columbus Children's Hospital is averaging 20 to 30 a year since 1974, she said. The cost of such testing averages between $200 and $500.

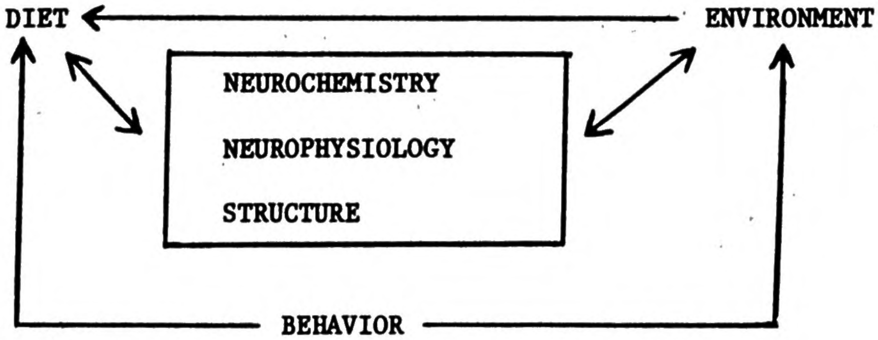
The doctor recommends Aubrey Milunsky's book, The Prevention of Genetic Disease and Mental Retardation (W.B. Saunders Co., 1975, Philadelphia, Pa.), for those who want more information on the subject.

PREVENTING NUTRITION RELATED FACTORS IN MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

BETTY ANN WHITTLE, PH.D.

CHIEF OF NUTRITION, NISONGER CENTER
ASSISTANT PROFESSOR, COLLEGE OF
AGRICULTURE AND HOME ECONOMICS
THE OHIO STATE UNIVERSITY

The workshop led by Dr. Whittle centered around prevention of undernutrition in prenatal and postnatal situations. As depicted in a diagram from the National Academy of Science (National Research Council, 1973) the role of diet as one factor in a complex set of interactions affecting pregnancy outcome, brain development, and behavior was discussed.



A high percentage of low birth weight infants have cogenital abnormalities, she explained. Low birth weight was defined as 2,500 grams or less. A number of causal factors are involved, but the two most common are pre-pregnancy weight of the mother and her pregnancy weight gain.

The quantity of weight gain considered optimal has changed even within the last decade, Ms. Whittle said. The suggested weight gain is higher today at 24-30 lbs., with a gain of 2-4 pounds during the first trimester and a steady gain of approximately 0.9 pounds per week during the second and third trimesters. Importance lies in where the additional calories come from, the goal being a balanced combination of nutrients and sound eating practices before and during pregnancy.

The earlier the preventative awareness begins, the better, she said. Viewing the dietary habits of adolescent girls is an important point in prevention since younger mothers are higher risk pregnancies. Preventative approaches must emphasize both child and adolescent nutrition, Dr. Whittle said. Epidemiologic evidence of the effects of malnutrition during pregnancy was presented by the reduced weights of infants born in situations of chronic and acute deprivation during World War II compared with birth weights in the same areas prior to the war, and similar birth weight differences have been seen between infants born to economically deprived and affluent population groups.

Studies done in Guatemala, Montreal, and New York showed an increase in birth weights of infants whose mothers were given caloric dietary supplements during pregnancy. She suggested careful interpretation of the findings relative to the length and level of supplementation.

Birth weight, however, does not tell the whole story, she added. Weight is a crude indicator of nutritional status. She said it is important to consider the child's total environment.

Nutritional deprivation triggers additional deficiencies. For instance, a child's learning ability will be hindered if he suffers from malnutrition. The anemia that accompanies it may result in apathy and thus a shortened attention span.

Prevention of undernourishment should be centered around both pre- and post- natal care, Dr. Whittle explained. If the deprivation occurs during the entire critical period, damage will be greater than the theoretical sum of the effects of deprivation during the six months prior to birth and the six months after.

A question was raised during the discussion on the safety or necessity of taking supplements during pregnancy. She said that from evidence to date, the widespread need for folic acid and iron supplements appears to be indicated. While a single multivitamin probably will not hurt, quantities of nutrients beyond those needed by the mother and the developing fetus do not offer additional benefits. The importance of selecting food sources of adequate nutrients and working out a balance diet was emphasized. She was concerned with mothers who lack understanding about their needs and self-medicate with large dosages of megavitamins. Dependency states can probably result from extremely high intakes of certain water soluble vitamins (Vitamins C and B_6, eg.) and toxicity can result from excessive intakes of the fat soluble vitamins (A,D,E,K).

Another question arose over concern with food additives. Dr. Whittle said that proof of a relationship between food additives and hyperactivity is lacking. Evidence, largely anecdotal in nature, has been presented and the area presently is being actively investigated. She is pleased with today's higher level of nutritional awareness and concern, but suggested caution in removing foods from the diet without regard for nutritional requirements. Economic aspects should not be overlooked either, she said. "Health" foods, for example, are generally higher priced, and the additional time for preparation when "convenience" foods are eliminated also should be considered.

PREVENTING NUTRITION FACTORS RELATED TO ABNORMAL MENTAL AND PHYSICAL DEVELOPMENT

SUSAN CALVERT, PH.D.

Director of Nutrition Services
Ross Laboratories

The afternoon workshop, led by Dr. Calvert, examined the role of nutrition in physical and mental development. Nutritional needs are extremely high during pregnancy, the first year of life, and adolescent because of rapid growth. An adequate supply of nutrients are critical if an individual is to reach his potential.

The first portion of her presentation summarized the scientific evidence linking inadequate nutrition with mental retardation. While most of the evidence is derived from animal studies, the metabolism and developmental principles resemble those of humans and thus association can be made. For example, studies of guinea pigs fed calorie and protein restricted diets revealed a higher percentage of still-births, and a lower number of brain cells in offsprings, if deprivation occurs during the period of most rapid brain growth.

The critical period of growth for the human brain is six months before birth to six months after birth. Malnutrition occuring during this time can retard brain-cell growth. For instance, a baby's head enlarges only as the brain cells grow and divide. If severe malnutrition occurs, stunted cell growth often cannot be reversed later. However, the severity of damage depends on when the deprivation occurs and how long it lasts.

The best assurance for a successful outcome of pregnancy, Dr. Calvert said, is for the mother to have completed her own growth, have history of good nutritional intake and possess optimal nutritional stores at conception. Adolescent girls are, therefore, considered to be high risk patients and are in special need of nutrition counseling.

The workshop continued with a CBS documentary film entitled <u>Prescription: Food</u>. The film highlighted a study conducted by St. Jude's Hospital in Memphis, Tennessee, on the adverse effects of malnutrition on growth and development during infancy to one year of age. Malnutrition was the cause of anemia and retarded growth and development in the group of low-income black children.

The film illustrated the complexity of working with families in the home situation to prevent malnutrition and the importance of providing children with an adequate and balanced diet.

When the film concluded, Dr. Calvert summarized the film by identifying socio-economic status, income level of the mother, as well as her nutritional practices, as major variables in pregnancy outcome. Although the mother's health and physiological state during pregnancy are the major factors on outcome, the mother's cultural patterns, motivational care and even childhood experiences can be influential.

Once again, she stressed that prevention of abnormal mental and physical development comes about by establishing sound nutritional habits early in the life cycle. Emphasis must be not only on adequate food supply but also on education.

Dr. Calvert went on to discuss some nutritional problems of mentally retarded children and presented data from her research concerned with feeding problems of Down's Syndrome children. She explained that many of these handicapped children's growth problems are caused by nutritional factors. Drugs and medications the child is taking can depress the appetite, causing malabsorption and inadequate nutrient intake. The MR child may also have mechanical feeding problems such as impairments in sucking, swallowing and chewing. Energy expenditures may be much higher or lower than the caloric intake, she added. For example, a child with cerebral palsy expends far more energy and would need extra calories.

Dr. Calvert discouraged using Recommended Dietary Allowances (RDA) as universal standards for feeding the handicapped child. "One cannot generalize," she said, "when working out their diets for each child needs to be treated individually, with separate dietary plans".

She emphasized the importance of checking any nutritional or dietary information with credible sources — like the Board of Health — to obtain the most current and accurate nutrition information.

Suggested Book: Deutsch, Ronald, Better Nutrition for Family Living

Suggested Pamphlet: Nutrition and Pregnancy
March of Dimes
Box 2000
White Plains, New York 10602

PREVENTION BY EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT

LOYCE CANNON SCOTT

Chief, Bureau of Early and Periodic Screening,
Diagnosis and Treatment
Ohio Department of Public Welfare

Loyce C. Scott presented the background of early periodic health screening. It included a detailed background of the Ohio program.

Early Periodic Screening, Diagnosis and Treatment (EPDST) is a preventative program designed for those people eligible for Medicaid. It is open to children up to 21 years old, born of unemployed, working poor and social security recipients.

By definition EPDST is a preventative program. Scott said it is important to anticipate what is going to happen in order to promote optimum life conditions. EPDST will spot and correct health problems before the critical stage.

Enacted in 1967, the EPDST program required states to diagnose and provide treatment for eligible children. As an amendment to Title XIX of the Social Security Act, the Senate and House emphasized the program's responsibility to create an awareness of available services. It was up to the social service agencies to follow through.

Federal regulations were established in 1972. A penalty provision was also included. Through this provision, states could be penalized $600,000 to $1 million per quarter for failure to implement the EPDST program.

In Ohio's implementation of the program, a law suit in April 1973 brought about a consent order in 1974.

By June of 1975, 83,000 children had been screened. Eligibility included 400,000 Aid to Dependent Children. Supplemental Security Income, blind and disabled were eligible later. Since March 1976, 150,000 children have entered the program.

After being accepted in the program, the client can select a facility to meet his or her needs, Scott said. Presently, there are 1,300 solo practitioners, 331 clinics and 480 dentists in the Ohio program.

Scott said the goals and objectives of the program are to:

*(1) Reduce and prevent physical and mental disabilities among children from newborn to 21 years old eligible for Medicaid

*(2) Encourage and enable all recipients to participate in the EPDST program

*(3) Enhance community awareness and knowledge

*(4) Set up management systems

*(5) Explore all Medicaid services to recipients.

By giving some startling figures about the health problems of the poor, Scott pointed out the great need for this program. Poor children have twice the chance of dying before they are one year old, she said.

About 50% are not polio immunized, while another 9% are affected by lead poisoning. These children have three times more heart disease, seven times more visual impairments, six times more hearing defects and five times more mental illness.

It is important to avoid duplication of services by other social service agencies, Scott said.

In order for all workshop participants to learn more about coordinating EPDST with their programs, Scott divided them into six groups. A member of Scott's staff led each discussion group. This enabled each participant to have their particular questions answered. Each group discussion also included a specific explanation of the program.

When an agency implements the EPDST program, a notification form is sent to eligible families. About 60 to 70 percent respond, usually. To those who respond the agency sends a list of clinics, doctors and outpatient clinics.

Many of these people do not have their own physicians for treatment. Therefore the case worker aids in finding a physician and helps the person obtain a screening within 60 days.

Welfare departments should make sure there are supportive services available (day care etc.). The screening should also include a complete health assessment of the individual, as well as nutritional, developmental, hearing, and vision inspections.

One person from each of the six groups made an oral presentation to the workshop. Each question was discussed by the group and Scott supplied answers to particular problems. Other questions can be made by phone to Scott's office in Columbus at (614) 466-4966.

AN EARLY CHILDHOOD INTERVENTION CENTER: A WORKING PREVENTION PROGRAM

JUDY SAUSEN
THERESA ERSKIN

TEACHERS, MONTGOMERY COUNTY EARLY
CHILDHOOD INTERVENTION CENTER

The workshop began with an orientation slide presentation giving an overview of the program, staff, and function of the Early Childhood Intervention Center (ECIC) in Dayton, Ohio.

The center was developed to provide a learning program for children infancy to six years of age, who are developmentally delayed or retarded. The children receive individual therapy in a home setting at ECIC from a team of specialists: a speech therapist, occupational therapist, physical therapist, and child development specialist.

The program also includes parents in the learning program by teaching them ways of working with their children at home. The parents and children come to ECIC for two hour periods with the specialists once or twice a week.

Six major areas of learning are emphasized at the center, Ms. Sausen explained. The children work on coordination and locomotion, sensory perception, cognitive development, and speech development. They also learn self-help skills (eating, dressing, etc.) and fine motor development.

ECIC, founded in July 1972, was funded through a federal grant for three years, and is now supported by the Montgomery County Board of Mental Retardation.

When a child is functioning developmentally at a 16-18 month level and is at least two years old, he or she may be accepted into the center's preschool program.

Ms. Sausen explained that the preschool provides a transition from an individual setting to a group situation, and meets three half-days a week. Children continue in ECIC learning areas, but expand their language development and social skills through group activities. The preschool, Ms. Sausen added, also serves to prepare some of the children for regular county preschools (mainstreaming).

ECIC established a group of 10 professional people, called the Health Professional Advisory Board, to add support and credibility to the ECIC program. Ms. Sausen said the board has also increased their number of referrals from area doctors and hospitals.

The program at ECIC includes about 80 children to date, mostly between the ages of one and three. The center operates year round, and is free.

Ms. Sausen dreams of expanding to a larger building in the future, yet keeping the ECIC individualized, informal learning program.

The workshop came to a close with a video tape of a Peabody learning session at the center.

A Curriculum Guide is available on a loan basis or it may also be purchased for $3.00 to provide instruction and learning guide for parents in helping them become co-teachers.

EARLY CHILDHOOD INTERVENTION METHODS OF PREVENTING MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

GEORGE W. ETHERIDGE, ED.D.

ASSISTANT PROFESSOR OF HOME ECONOMICS
THE OHIO STATE UNIVERSITY

LINDA STRAUSBAUGH

COORDINATOR, HANDICAP DEMONSTRATION MODEL PROJECT
COLUMBUS METROPOLITAN AREA COMMUNITY
ACTION ORGANIZATION

In Workshop #1, George Etheridge and Linda Strausbaugh, presented examples of successful programs for children with special needs.

When implementing a program for children with special needs, it is important to remember that all children with a handicap are not alike. The variances between individual children with the same handicap are as great as the differences between handicapping conditions. Therefore, it is important to discover each child's unique set of abilities, Etheridge said.

This is where the problem of designing intervention programs lies. The primary concern is to design a program that "takes" regardless of strategy or methodology, he said. No one strategy or methodology works best for all children.

It is often hard to prove that the intervention program actually produced a positive impact on the child's output. Impact seems to depend on what you look at, how you look and when you look. Although the child may raise his objective test scores, his creativity may be inhibited. Desirable qualities, including intellectual functions, critical analysis and thought, may not be adequately shaped.

Etheridge also said that test scores may not be raised in some programs. Still, this must not be interpreted as a failure to influence the child in a positive manner. There is more to child development than I.Q. scores.

The positive influence of more broadly based early intervention programs may, in time, have a greater impact on the family, community and society than a program which merely raises the child's score on a standardized test.

Etheridge went on to explain some of the conclusions that should be remembered in implementing intervention methods.

1) A child's environment affects his development.
2) Early family attitudes have significant impact on the child before he is two years old.
3) An external supportive environment may help an otherwise handicapped child to circumvent the condition.
4) Children can profit from programs, regardless of their race, sex, socio-economic status, or handicapping condition.
5) Programs are strengthened by involving the child's parents.
6) Intervention is more successful the earlier in the child's life the program is begun and the more continuous the programming is across increasing age.
7) The motivation of the staff is directly related to the success of the program.

This "teacher effect" is important, Etheridge said. "You can have the best program in the world" he noted, "but the personality and style of the teacher may not be best for the program."

Etheridge holds a positive outlook for intervention programs. "The only time intervention will not serve as a prevention is when the child has progressive organic deterioration, or when the family is so disorganized the benefit will not be as great as with other children," he said.

Next, Linda Strausbaugh described some specific programs, including home-based intervention programs. She supplemented her lecture with slides of children taken at the Nisonger Center at The Ohio State University.

Some home-based programs focus on the parent, who in turn, works with the child. In others, the worker goes into the home and works directly with the child.

In any home-based program, the worker must gain the parent's confidence and trust, Strausbaugh said. According to one study by Barbrack (1970), home-based programs, in which the worker interacts directly with the child, are better. Barbrack interpreted his results by stating that when the parent assumes the total responsibility, it puts the parent in a stress situation to perform and often destroys the spontaneity of the parent-child relationship.

Center-based programs use limited parent involvement. Some parents are used as teacher aides in these programs, as well as classroom observations by parents and parent meetings. Strausbaugh also described the approach used as Nisonger Center for children aged six months to three years.

Nisonger uses a combination program. The children come to the center five days a week for two and a half hours a day. The program includes visits to the homes, parent meetings, classroom activities, special services and programs.

Effective programs are alike in many ways. All goals, objectives, policies and structures are spelled out. All programs have a definite curriculum. Parent and child interaction is necessary. Family involvement includes the education of parents. Also, staff must be well trained and social service support systems should help the family obtain needed services. Strausbaugh said programs must have good community relations and utilization of services.

Strausbaugh explained that when it is necessary for the child to enter another program, often the child's progress does not seem to carry over to the new program. Since children's attitudes are flexible, they will eventually adapt to the environmental change required of them.

INTERCEPTING SOCIO-CULTURAL FACTORS IN MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

HENRY HANKERSON, PH.D.

Assistant Professor of Education, Early Childhood
Development
Howard University

Henry Hankerson presented a very personalized example of how environment affects a child's mental development and growth. Using Johnny, a six-and-a-half-year-old boy as an example, Hankerson wove the socio-cultural factors of the boy's life into a workshop session for about 90 people.

With no readily observable retardation, Johnny is a slow learner repeating kindergarten. He is the fifth of eight children. Johnny's father works in a mill. His mother also works in the mill occasionally. When she does, the children are cared for by a grandmother who lives with the family.

In class, Johnny has a short attention span and is frequently left out of social interaction activities. He is starting to show signs of developmental disabilities (DD) and possible mental retardation (MR). Holding his pencil and folding paper presents a problem. He scored only 67 on the Benet IQ test.

Hankerson suggested that social service workers put more of themselves into the problem situation and go beyond the readily obtainable information. He stressed that each child's problem should be studied individually.

In Johnny's case, investigation reveals that his older brothers and sisters were also slow learners. The family is poverty stricken and lives in a four-room house where Johnny shares a bed with four older brothers. The children frequently eat cold meals and their health care is only mediocre.

All of these factors contribute to mental retardation and developmental disabilities, said Hankerson.

Socio-economic class, family structure and size and intellectual stimulation are all factors that influence a child's development. That is not to suggest that all children with less than optimum conditions will be retarded, but the highest rates of retardation are from depressed environments and poor families plagues with disease.

In working with these children, social workers should discover what the child can do, not what he can't do, Hankerson said. Hankerson used slides to augment the extent to which socio-cultural factors can influence MR and DD.

Environmental factors surrounding the fetus and confronting the mother during pregnancy have an effect on the child. These environmental influences are even greater after birth. Since the child is in constant interaction with his environment, social workers should study the environment in order to help the individual.

Before birth, the environment affects the fetus in indirect ways. After birth, basic love and hate fears are often results of attitudes and beliefs of cultural and subcultural groups.

The highest percentages of MR and DD are from depressed areas because of deliquency, poor nutrition and a generally troubled environment. Inner city slums have all of these.

Early intervention can help head off some of the problems. The federally funded HeadStart program provides a good opportunity for early intervention. And because parents are a very important influence, their participation is included in HeadStart. Hankerson made a plea to the public to stay on top of legislation concerning MR and DD.

A successful program must do three things, Hankerson said. It must (1) identify the problem and recruit individuals through a process approach to systemize everyone's efforts (2) assess the needs of the child and (3) involve the parents.

He said the role of responsibility does not lie with the schools alone. Other means include alleviating cultural and racial differences and also lobbying for legislation.

Each child should be treated as an individual, not as a race or culture, Hankerson said. Children are real and should be treated as individuals.

VALUES IN THE MIDST OF PREVENTION

MICHAEL J. KENNEY

Author & Consultant on Values Clarification

WILLIAM B. GEORGE, PH.D.

Human Services Consultant

The workshop leaders combined the presentation of new materials, group discussion and personal involvement to relate the idea of values clarification to prevention of MR and DD.

At the outset, individuals attending the workshop were asked to introduce themselves and to identify their professional affiliations. It became quickly apparent that a diverse group were present and had brought with them, a wide variety of expectation concerning the purpose of the workshop.

The workshop leaders began their presentation by referring to a statement issued by the President's Council on Prevention over ten years ago. In effect, this statement suggested that the proper use of knowledge and technology available at that time would result in the prevention of over half of all new cases of MR and DD.

They then proposed that this reduction had not occurred, and suggested that a clarification of values might provide a useful strategy by which to determine the cause of this situation.

First, Michael Kenny established the relationship of values to prevention of MR and DD. He expressed the belief that prevention is typically involved with such concerns as the family unit, cultural goals, health care, etc. These are concerns which all involve the decision-making process; a process which is necessarily related to an individual's value system. He then defined values clarification as any process that allows people to assess whether stated goals fit criteria.

Kenny presented an operational definition of the concept of "value," one which was originally suggested by Sidney Simon. For something to be classified as a value, it must meet seven criteria. A value, therefore, is:

1. Something which people freely choose
2. From a range of alternatives for which
3. Consequences are considered
4. For which the individual feels good about having made the choice
5. To the extent that he will talk about it
6. And act on it recently
7. And repeatedly.

Kenny suggested that while this may be a useful definition, it does not ably assist individuals in active problem-solving.

He went on to explain a model which reflected changing values at various levels of development. This model was based on the assumption that man has a hierarchy of needs which must be met (a la Maslow) in a progressive fashion. He delimited four major issues which serve to determine the world perceptions, needs, and values for any individual: Survival, Doing, Being, Being Whole With the World.

Essentially, this model might aid the would-be change agent concerned with prevention by reminding him that it is difficult to convince someone involved with the survival issue that he should value such abstract concepts as freedom, justice, or independence.

William George then presented his adaption of a model originally designed by James D. Thompson of Indiana University. This model utilized a four-cell structure with two prongs: understanding of cause-effect relationships and agreement on outcomes desired. Each of these factors ranged on a continuum from relative certainty to relative uncertainty.

Dr. George asserted that this model may be of considerable use to those concerned with the prevention of MR and DD. Through analyzing agreement on desired outcomes and determining the extent to which understanding exists regarding cause-effect relationships, specific strategies become apparent to the practitioner.

The workshop leaders left the audience with an interesting question which would have provided the focus for further group discussion, had time permitted. Specifically, they asked:

"How has the issue of values contributed to the gap between technical knowledge and application in the area of prevention?"

A COMPREHENSIVE VIEW OF LEAD POISONING: METHODS OF DETECTION AND PREVENTION, AND THE INTER-RELATIONSHIP WITH MENTAL RETARDATION AND DEVELOPMENTAL STATUS

A. HAROLD LUBIN, M.D.

Medical Director, Columbus Lead Poisoning
Prevention Program

Although lead poisoning has been a problem for more than five centuries, Dr. Harold Lubin said it is a problem that can be entirely eradicated. By using slides and examples, he told a responsive group how to detect the problem, methods of solving it and a brief history of lead poisoning.

Lead is definitely unhealthy, Lubin said. Although there is no actual need for lead in the human body, it has been ingested for centuries. The Romans used lead to sweeten their wine, he explained. Because of this practice, lead deposits are still found in their unearthed bones. These lead deposits have been substantiated through x-ray analysis by the Smithsonian Institute.

Today, lead is still a health problem, especially in urban areas, Lubin explained. Safeguarding the public against high levels in the blood is a fairly recent development. Minimum acceptable levels for lead in the blood of children were stated in 1972 by the Surgeon General of the U.S. and recent changes for adults in occupational health have occurred in the past year. Much of the latter has been done through efforts of the National Institute of Occupational Safety and Health (NIOSH).

Safeguarding populations against lead poisoning and undue lead exposure with elevated levels of lead in the blood is not a simple problem, Lubin said. Workers, social service agencies and the public should question facts about lead poisoning. Certain facts are simply suggestions and presumptions made by industry and social workers. These should not be accepted just because they are emphatically stated, Lubin said. Everyone has a responsibility to seek out the documented answers about lead poisoning.

Detecting lead poisoning and evidence of undue exposure to lead or increased body lead burden is especially critical in young children, according to Lubin. While adults probably excrete as much lead as they ingest, children, on the other hand, probably absorb a higher percentage of lead than do adults and probably retain more in their body tissues.

Because of an adult's ability to expel lead, the body usually maintains a base level that does not exceed health guidelines. However, the lead level in the blood of a growing child may increase by one-third the level at birth during the first several years of life. This rapid lead absorption by children is due in part to their fast rate of growth and consumption of nutrients needed for development.

In addition to being a health problem, undue lead exposure and body lead burden are a socio-economic problem as well. This is true because people living in poverty, and especially the inner-city poor, often start with a higher lead level prior to pregnancy. Therefore, the problem is often passed on the the newborn baby.

According to Dr. Lubin, there are a variety of ways in which lead is taken into the body. Some of the most common are: paint chips from old homes, factory fumes, auto exhaust, burning batteries, ceramic glazes, soil, plants and water supply. Solutions to the lead problem can be as simple as washing vegetables and taking precautions when using lead based paints and glazes.

The use of lead is many faceted. There are both economic and aesthetic reasons for its use. Lead is still being used in certain glazes and paints because there isn't any substitute for the bright red colors it produces. In Boston, lead is a problem in the water supply. The problem remains unsolved because the lead is linked with the pH level of the water and to get rid of it would rise the cost of water processing.

Most lead enters the body by eating and drinking and is absorbed in the gastro-intestinal tract, Lubin explained. Just out of natural curiosity, children may get undue body lead burden by eating paint chips or mud pies. Unnatural behavior or an unprotecting mother aren't mainly responsible for undue lead exposure in children. It's just a child's natural curiosity and play that promotes putting objects and other items in their mouths.

Lubin pointed out that about seven persons in the room had put their hands to their mouth during the workshop. This same action brings the lead to the mouths of children. This can't be attributed to craving or hunger, he added.

Slides presented during the workshop showed practical ways to spot problem lead situations. Paint chips, which could look like soda cracker crumbs, on the child's face is one way. Also, a child with high lead levels in the body may look pale and off-color.

To prevent high lead levels, the public should be made aware of the problem and its warning signals. One of the best ways, Lubin said, is to go door to door. Make people aware that a problem exists, tell them about lead poisoning and let them know that too much lead in the body is dangerous. And also be sure to point out that lead poisoning is preventable, Lubin said.

Mobile test vans are another very effective way of alerting the public to the problem of lead. In these vans, a simple test that requires only a finger stick can be performed.

When vans are used, the test can be done for free, Lubin advised. But, it is more valuable if the persons being tested realizes he has to give up some of his time. In conjunction with these tests, Lubin stressed the importance of quality control in th~~e lab~~s.

Prevention and early diagnosis are the best solutions for lead poisoning, Lubin said. Recognizing the symptoms of lead poisoning and high lead levels is very important. One symptom is nerve conduction problems.

Iron deficiency is another symptom of high lead levels in the blood.

Iron deficiencies are found in about 15 percent of the inner city, Columbus childhood population. Of these 15 percent about five to 30% have high lead levels in their blood.

In acute cases, lead may be visible in the gastrointestinal tract through x-rays. A case such as this could be caused by swallowing lead pellets or lead-containing paint chips.

Once lead is found in the blood through testing, the persons's environment should be checked and evaluated. To prevent further lead consumption, home repairs may be needed. In poverty areas, a mobile tool unit could be the answer. This mobile unit is a van that supplies the resident with the tools needed to scrape paint chips and seal peeling walls, window sills, etc.

It would also be advantageous to plant grass around the home, in order to help keep the children out of dirt. Also, the area should be thoroughly cleaned and swept.

If left uncorrected, excess lead in the blood can cause delayed development, seizures, encephalopathy, and even mental retardation. Everyone can help eradicate the problem, Lubin said, but, he pointed out, we must remember that if we can't do any good, we must be careful not to do any harm.

The general concept of public health has changed, Lubin said. Manufacturers now have to prove their products are safe, instead of just marketing them until someone proves they are harmful.

LEGISLATIVE PREVENTION STRATEGIES: A PANEL DISCUSSION

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This panel discussion, which lasted approximately one hour and twenty minutes, was followed by a brief question and answer period. The main goal of the workshop was to provide a cross-section of information to professionals concerned with the use of legislation as a means to effect prevention of MR and DD. Accordingly, each of the panel members provided a unique perspective on the issue of legislative prevention strategies.

Section 1

Maxine Mays was the first panel speaker. For the most part, her comments were of a substantive nature, in terms of what methods and strategies are available to deal with the matter of prevention.

She identified three major strategies:

Research and Study;
Education, Counseling and Treatment;
Legislation and possible Litigation.

It was Dr. Mays' position that all of these strategies must be used in combination in order to achieve success in the area of prevention.

Regarding the issue of legislation, Dr. Mays suggested that the central issue facing the government is a problem which could best be expressed in the form of a question:

Shall the state pass laws that will encourage and mandate prevention and litigation of MR and DD? Or, to put it more simply:

Shall the state act?

If the answer to these questions is an affirmative one, certain major types of legislation may have a possible impact on prevention: Enabling, Permissive, and Mandatory.

After listing some of the current bills pending legislation, as well as certain bills recently passed, Dr. Mays shared a number of concluding observations with the audience. First, she suggested that the state of Ohio, with its state plan for genetic services, health and parent education, was moving in the right direction.

Second, Dr. Mays proposed the prevention of MR and DD could best be served through comprehensive and total planning services rather than through specific disease legislation.

Third, she asserted that there is a definite need to develop more effective lines of communication among various groups and people concerned with prevention.

Last, Dr. Mays suggested that successful prevention of MR and DD was necessarily dependent upon a broader based public education effort.

Section 2

Representative O'Neill was the second speaker in the workshop. His comments on the issue of prevention were formulated from the perspective of an informed spokesman with an interest in handicapped persons and their rights. Rep. O'Neill pointed out that to date, no one in the legislative context has clearly identified prevention as a legislative goal. He suggested that legislators deal with current problems of MR and DD, but thus far, have expressed little concern with prevention.

The major part of Rep. O'Neill's presentation was a practical course in legislative procedures regarding the enactment of a bill. He posed this question to the audience: if you know what you want to accomplish regarding goals, how do you influence legislation?

Rep. O'Neill then proceeded to trace a bill's progress through various committees and both houses of the General Assembly, pointing out areas at which citizen action could prove influential in the success or failure of a bill. He proposed that the most important time to lobby is when the bill has reached the Conference Committee.

Section 3

Christine Rosenbaum was the third speaker in Workshop No. 11. She is involved in the organization of consumer advocates to influence legislative action. Her comments were addressed primarily to the development of consumer interests regarding MR and DD as they relate to legislation.

Ms. Rosenbaum's position on consumer interests suggests that consumers should get what they ask for. But, she pointed out, it is important to avoid criticizing legislators until they are asked for something in a concrete and specific fashion.

Consumer groups must organize their efforts to this goal if they hope to achieve success. Ms. Rosenbaum identified four main guidelines for a consumer group to follow. Consumer groups, which follow a structure similar to the legislature, must:

Be large;

Be democratic, with an elected rather than a self-appointed leadership;

Have a strong "grass roots" following with a firm organizational structure; and

Take time to become established.

Following the three presentations, Professor Kindred moderated a brief question-answer period involving audience-speaker interaction.