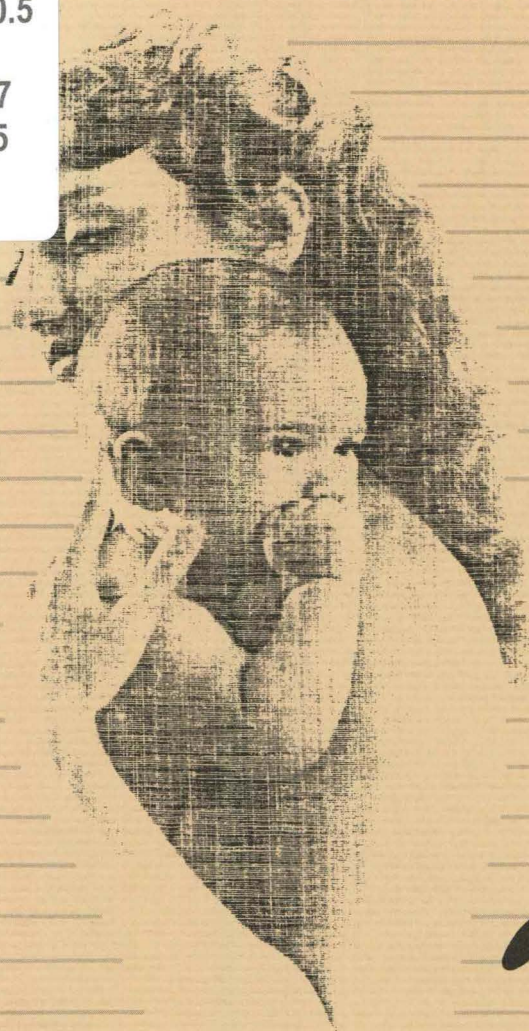


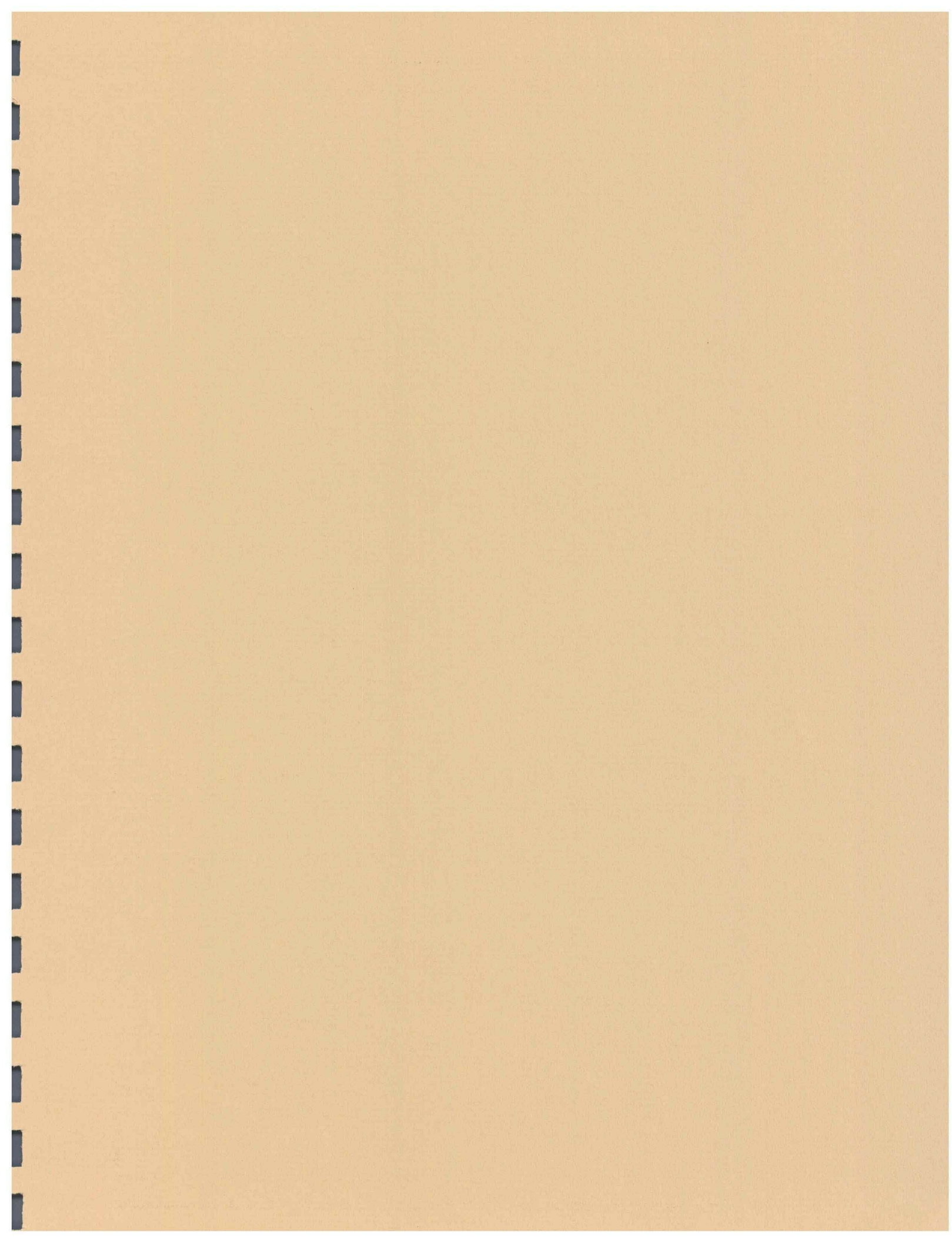
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"Let's Talk About It"

An Iowa Working Conference on the
Prevention of Developmental Disabilities

Sheman Conference Center • Ames, Iowa • April 1985



"Let's Talk About It"

An Iowa Working Conference on the Prevention of Developmental Disabilities

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Additional copies of this manual may be obtained by writing the Clearinghouse, Iowa University Affiliated Facility, Division of Developmental Disabilities, University Hospital School, Iowa City, Iowa 52242; or by calling: 1-800-272-7713.

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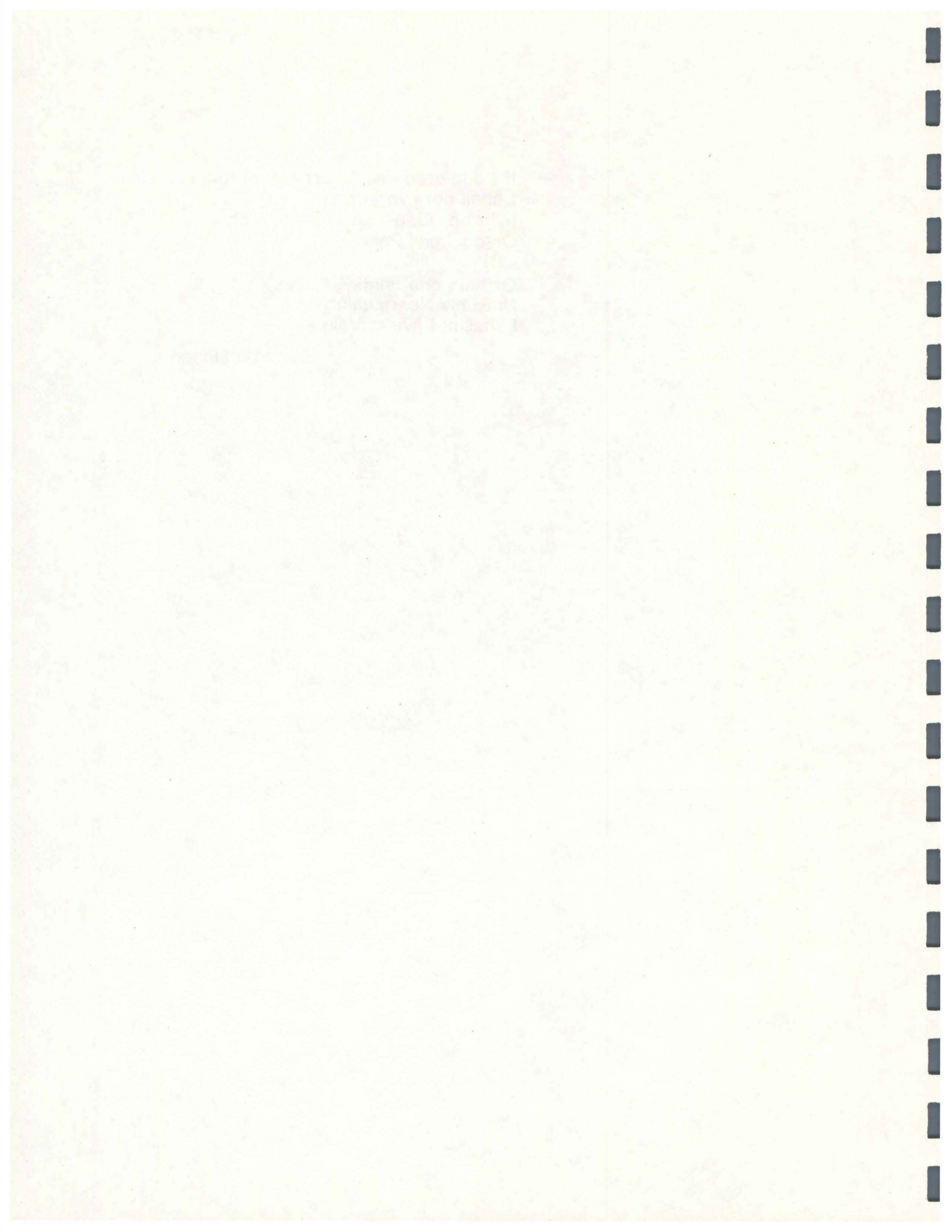
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If I can stop one Heart from breaking
I shall not live in vain
If I can ease one Life the Aching
Or cool one Pain

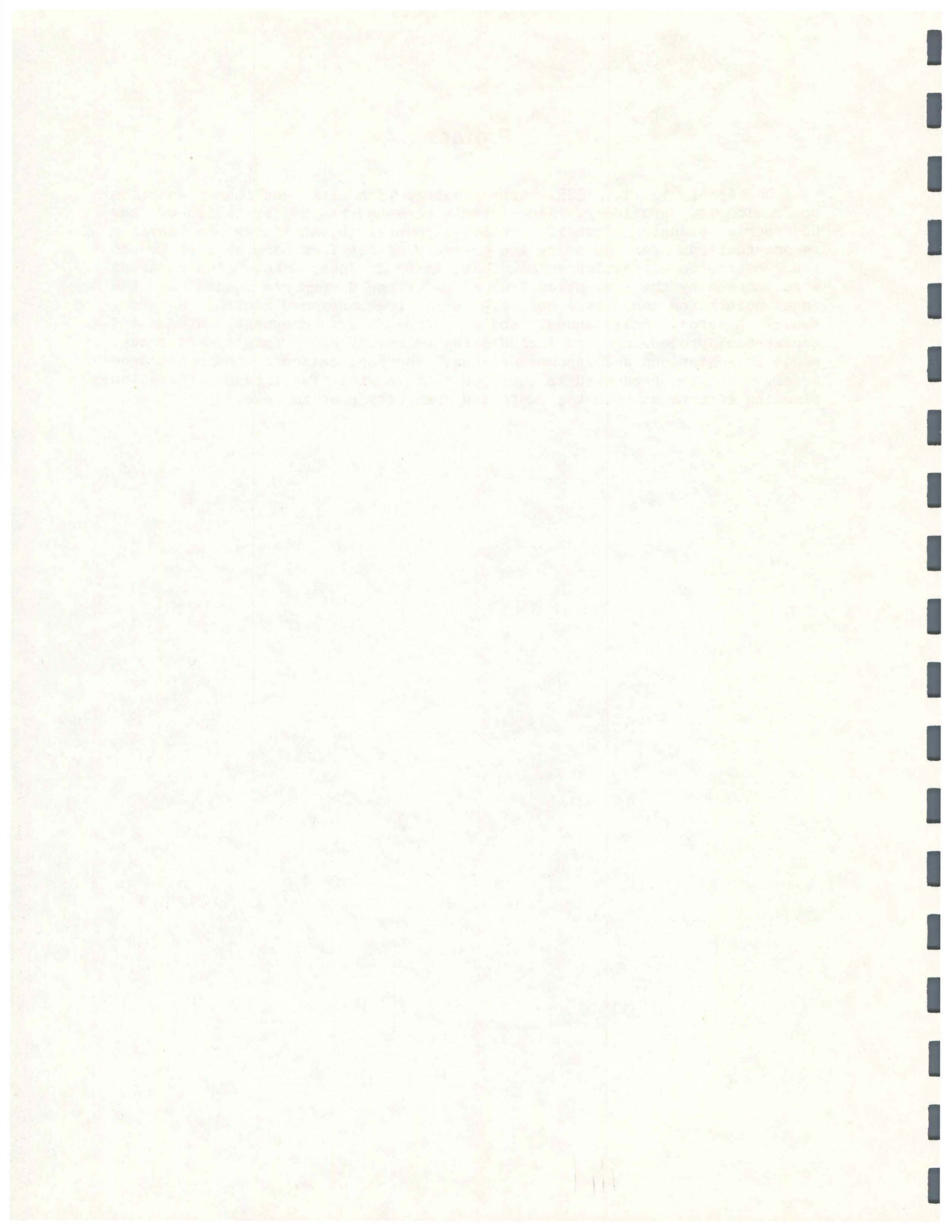
Or help one fainting Robin
Unto his Nest again
I shall not live in Vain.

Emily Dickinson



Preface

On April 10-11, 1985, approximately 75 health and human service professionals, providers, and parents convened at the invitation of the Governor's Planning Council for Developmental Disabilities to develop recommendations for enhancing the delivery of services necessary to reduce the occurrence of developmental disabilities in Iowa. Four topic areas were chosen by the Prevention Task Force of the Governor's Council as the focal points for conference deliberation: pregnancy and health, environmental hazards, child abuse, and education. This document contains the conference proceedings and includes the welcoming and keynote addresses, panel presentations and recommendations, and replication of the conference model. It is presented in the hope that it will facilitate prevention planning efforts at both the state and community program levels.



Introduction

The state of Iowa is fortunate in having a broad array of excellent programs contributing to the health and well-being of Iowa's citizens. In part through provisions of the Iowa Department of Health's regional perinatal care services, offering the opportunity for timely maternal and fetal risk assessment and referral, Iowa has effected a 50% reduction in the neonatal mortality rate, from 10.5 neonatal deaths occurring per 1,000 live births in 1975, to 5.1 deaths per 1,000 live births in 1984. The Department of Health is now in the process of expanding maternal health programs to serve all 99 of the state's counties, up from the 61 counties now being served. Family Planning Services are available in all 99 Iowa counties. The High Risk Infant Follow-up Program, which originated in 1978, is currently following 6,954 children, ages 4 months to 8 years. At-risk infants are first identified in the neonatal intensive care unit. Outcome figures suggest that approximately 81% of the children enrolled in the program passed the screening examinations through the age of 3 years. Preliminary interpretation of five-year examination results suggest that of the children passing the examination through age 3, one-third elicited mild concern levels for academic success, and one-third elicited a high concern level. In 1966, the Iowa legislature approved rules and regulations for screening of phenylketonuria (PKU), a metabolic disease which occurs in from 1/5,000 to 1/10,000 live births. In Iowa, there are an average of four affected births per year. Through early detection of PKU, and the implementation of a prescribed nutrition program, mental retardation as a result of this condition can be avoided. In 1981, the legislature authorized expansion of the screening program to include screening for three additional metabolic diseases--maple syrup urine disease, galactosemia, and hypothyroid disease--capable of causing developmental disabilities. Iowa's historic commitment to provide educational services to children with disabilities preceded federal legislation in 1985 (PL 94-142) which mandated free, appropriate public education services for all handicapped children. The state passed Senate File 1162, the Area Education Agency Bill, effective July, 1975, which requires special educational services to be made available to all developmentally disabled children from birth to twenty-one years of age. These are just a few of the Iowa programs that will help reduce the occurrence of developmental disabilities and improve the optimal health of Iowa's citizens.

While recognizing the significant contributions of these services, in 1984 the Prevention Task Force of the Iowa Governor's Council for Developmental Disabilities identified several remaining gaps in the prevention service delivery system. A group of twelve experts in the field of health and human services convened for a one-day meeting, at which they identified the need for:

- 1) accurate and accessible information regarding the incidence and prevalence of developmental disabilities in Iowa;

- 2) effective linkages to be developed among prevention services on both the state and community levels;
- 3) adequate access for "at-risk" populations to appropriate prevention services; and
- 4) a comprehensive, statewide action agenda outlining a long-range plan for developmental disability prevention program and service development.

In addition to this effort, the Task Force launched a one-year project under contract with the University of Iowa Division of Developmental Disabilities designed to raise the level of awareness of practicing professionals, community workers, students and other interested parties concerned with the prevention of developmental disabilities. The resulting publication, called "Let's Talk About It": A Resource and Training Manual on the Prevention of Developmental Disabilities, was completed in October, 1984. The manual is a compendium of information on programs related to the prevention of disabilities, and emphasizes the importance of personal awareness and participation in prevention activities.

A third initiative taken by the Prevention Task Force was the sponsorship of a statewide conference to bring together health and human service professionals, providers, and parents to identify and address barriers to the appropriate delivery of prevention services in Iowa. This conference, coordinated by the University of Iowa Division of Developmental Disabilities, was held on April 10-11, 1985 at the Scheman Conference Center, Iowa State University, Ames, Iowa.

Alfred Healy, M.D., Prevention Task Force Chair, and Chair of the University of Iowa Division of Developmental Disabilities, opened the conference by reviewing current statistical data relevant to the prevalence and cost of developmental disabilities. He stated, "If we approach the problem vigorously, devote the resources and knowledge that we have, and utilize appropriate planning, we could prevent perhaps one-third of these disabilities."

The keynote address was delivered by Allen Crocker, M.D., Director of the Developmental Evaluation Clinic at Boston Children's Hospital, and professor at Harvard University. Emphasizing the maximum achievement of human potential as the motivating force for prevention activities, Dr. Crocker discussed the causes of developmental disabilities and program planning strategies with a refreshing mixture of poetry and insight. Reviewing data associated with the causes of mental retardation among the clients of the Child Development Clinic at Boston Children's Hospital, Dr. Crocker identified inherited factors, embryogenic factors, perinatal factors, childhood injury or trauma, environmental and behavioral factors, and unknown factors as the primary forces that will need to be addressed by prevention activities. Concerning the design and planning of prevention

programs, Dr. Crocker verified the importance of the evaluation of program effectiveness. He cautioned against over-emphasis on program expansion for justification of program spending.

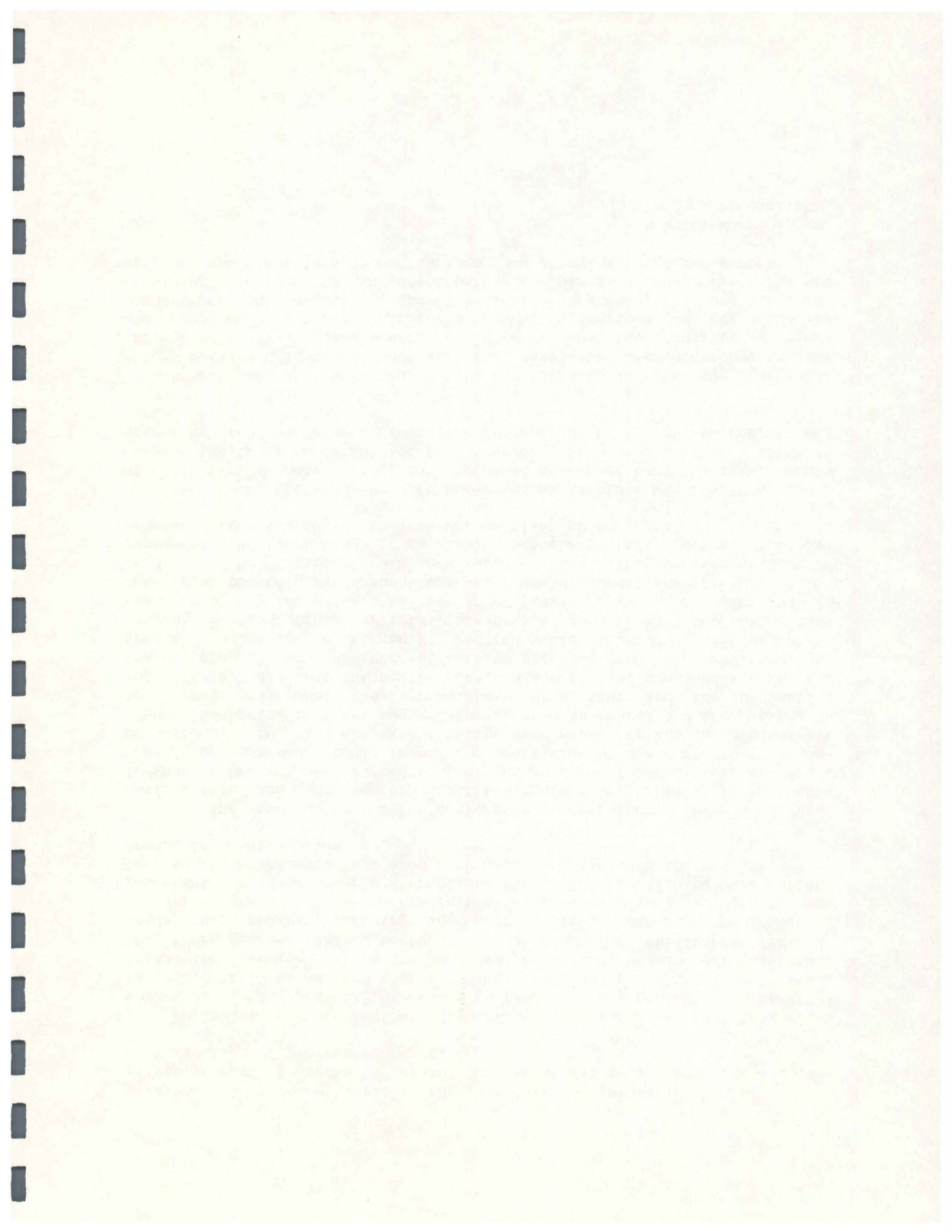
Following one and one-half days of deliberation, the four concurrent work groups, independently focusing on pregnancy and health, environmental hazards, child abuse, and education for public and professional awareness, formulated recommendations for enhanced prevention program effectiveness. The four groups' shared concerns were a need for sufficient funding, interagency program planning and coordination, expanded professional education and public awareness initiatives, and refined evaluation components to validate program accomplishments. The specific recommendations and action components from each work group are included in the conference proceedings that follow.

At the conclusion of the conference, participants expressed both satisfaction and some concern about the process and content of the conference. Dr. Crocker suggested that the absence of legislators and state agency commissioners could impede implementation of the conference recommendations. He also observed that the work groups failed to demonstrate enough Iowa pride in first recognizing program successes and then moving on to assess: 1) what the current state priorities are for prevention initiatives, 2) what the moving public and political passions are in the state, and 3) how the current service programs could be modified for greater success. He strongly urged the publication of a written state prevention plan. Other participants expressed concern that not enough time was spent on analyzing the status of Iowa service programs and in developing concrete recommendations which would address specific prevention needs. Other participants acknowledged that the conference should represent the first stage of an ongoing process to refine action steps and broaden representation in the prevention planning process.

The group technique used to generate the listings was itself a focus of commentary. Some participants appeared concerned that the method would devalue the truly important ideas. However, it seemed that most of those attending the conference found the process both thought-provoking and useful.

A basic concern expressed by many participants was that the energy and effort reflected in the keynote address, panelists' presentations, and one and one-half day deliberation not be in vain, that the identified barriers and proposed solutions to improved prevention services be evaluated by members of the executive and legislative branches, by organizations providing services to the developmentally disabled, and by concerned citizens who might take these listings as a starting point for action.

Rebecca Howe
Project Specialist



Welcoming Address

Alfred Healy, M.D.

A conference titled "Let's Talk About It": A Working Conference on the Prevention of Developmental Disabilities. We welcome you, we thank you for your attendance, and we look forward to two very productive days.

I would like to share with you just a few statistics to consider. There are 100,000 people with developmental disabilities in institutions in this nation. Ten percent of our school-aged population, a total of 4.5 million children in the United States, receive supplemental educational services, because of handicapping conditions such as mental retardation, learning disabilities, and cerebral palsy. Over two billion dollars are spent annually to support institutionalized people in this country.

Disabled children, those with significant, chronic, severe illnesses and disabilities, constitute 2 percent of the childhood population, 1.8 million, yet these children utilize 6 percent of all hospital admissions and 11 percent of all children's hospital days spent in this country. We are approaching a new era of "cost containment" in health care. Many professionals have asserted that proposed regulations are unfair to the disabled person. Others say that we don't need more money for the existing care system for disabled people; what we need is a better, more equitable distribution of those monies.

The yearly health costs in this nation are \$355 billion. Right now that is 10 percent of our gross national product. It is estimated that by the year 2000, health costs will increase to 20 percent of the GNP. A significant portion of that dollar is devoted to the care of disabled people.

There are both financial and human incentives, therefore, to reduce the occurrence of disability. If we approached the problem vigorously, devoted the resources and knowledge that we have, and utilized appropriate planning, we could prevent perhaps one-third of these disabilities. If we could do this, we would not require those kinds of dollars or those kinds of efforts to be devoted to the care of disabled, because the disability would not be producing the problem requiring extensive services.

Probably the most optimistic figure is that as many as 50 percent of disabilities can be prevented. Other estimates are not nearly as optimistic, even if the most careful planning and use of available resources were brought to bear on this problem. Still, nearly all would agree that the prevention of a significant portion of disabilities is possible. We need to plan, package, and sell ideas regarding the prevention of disabilities. The first step, planning, is the focus of this conference. Our goal is to seek ways to prevent the problem initially, or to reduce the impact of that disability upon the individual. There is clear evidence, however, that we cannot expect the population to automatically put into

place the ideas regarding the prevention activities that we might suggest, and we need to consider methods of making the programs acceptable and sought after by both the public and the professionals.

The group sponsoring this conference is the Governor's Planning Council for Developmental Disabilities. One of the tasks of the Council is to put together a three-year plan to help meet the needs of persons with developmental disabilities. The Prevention Task Force of the Governor's Council has programs operational right now to study adolescent pregnancy, to plan and implement the Prevention Conference, to support a state-wide birth defects registry, and to assist in putting together multi-agency agreements across the state.

The Developmental Disabilities Act (revised in 1984) is the current federal legislation designed to provide assistance to individuals with developmental disabilities. The act, which has been in place now for about 20 years, provides for four specific activities: it funds and creates State Planning Councils; it provides dollars to these Planning Councils to assist in providing services for disabled people across the country; it funds the University Affiliated Facilities; and it also puts in place the Protection and Advocacy Groups across the country. Each state has a Planning Council. In this state the Council operates under the governor's leadership and is placed administratively in the Department of Human Services. The Council works very closely with the Division of Mental Health, Mental Retardation, and Developmental Disabilities, also administratively located in the Department of Human Services. By law, in this state, there is a Mental Health and Mental Retardation Commission which has the responsibility to look after mental health and mental retardation activities. By federal statute the Governor's Council on Developmental Disabilities has a broader concern--the support of all developmentally disabled persons, not just those with mental health problems and mental retardation.

The definition of a developmentally disabled person includes a person who has a physical or mental disability, or combination thereof, that significantly impacts his or her functional life in the areas of mobility, communication, or independent living abilities. According to the federal definition, disability must start before the age of 22 years. That brings our focus to persons whose disability was initiated prior to 22 years of age but may be expected to continue past age 22.

The recommendations [developed at this conference] will be taken to the Prevention Task Force and will be incorporated into the state plan that will be addressing the needs of persons with disabilities in this state for the next three years. This conference will attempt to identify what the barriers are to putting in place effective prevention activities, and then will try to devise solutions to those barriers which represent the major obstacles to effective prevention programs in this state.

Keynote Presentation

Allen C. Crocker, M.D.

"If I can stop one heart from breaking" is the first line of a poem by Emily Dickinson. Emily provided an astonishing legacy of materials, much of which dealt with bumblebees and flowers. But a lot of it turns out to be surprisingly relevant to the kinds of concerns that we have here today. We have an assignment; this day has been picked out to accomplish something. Approximately a hundred and fifty years ago Emily said:

A Day! Help! Help! Another Day!
Your prayers, oh Passer by!
From such a common call as this
Might date a Victory!
From marshallings as simple
The flags of nations swang.
Steady - my soul: What issues
Upon thine arrow hang!

So if we say, "A Day! Help! Help! Another Day!" it is conceivable that this will have been a good one.

I would like to begin by telling you what my plan is, so you will know where we are. I will divide my comments into eight sections. First, I will talk about my concepts of the basic prevention message; then I will discuss the causes for developmental disabilities. Next, I will comment on the content of programs in states, and follow through with a look at how states carry out their prevention programs. For this I will draw particularly on the example of Virginia. Then we will take a look at how states evaluate where they are going; whether they are succeeding or not with their prevention goals; for this we will look particularly at the experiences of Tennessee. Then I will identify some of the program elements that appear to be working well, and review how policy gets formed in states. Finally, we will make some joint resolves regarding the future of prevention as a field.

A. The Basic Prevention Message

There is something special about the concept of prevention. It has kind of a joyous feel to it, in part because there are two pieces. One is the avoidance of affliction or disability, or eventual handicap. But then there is a second piece as well, and that is promotional. The second element of prevention looks to the achievement of maximum potential by humans. There are a couple of quotations that please me particularly in this area. One is from the very earliest pages of the Bible where the exhortation was, "Be fruitful and multiply and replenish the earth," the insinuation being that there would be a promulgation of humans in good order. Another one of my favorites is the slogan chosen by Youth NARC (National Association for Retarded Citizens) for a national conference on prevention in 1972. They dedicated the conference "To Our Children's

Children," intriguing because these were youth who were concerning themselves, devoting themselves in the prevention mode, to the future support of the human condition.

If you look at the prevention literature, specifically the public information materials that are commonly distributed through prevention programs and activities, they have an engaging message. Many of these materials deal particularly with the production of new humans. For example, an Alabama brochure says "Take care of yourself"; another from Indiana says, "Take care of yourself for your baby's sake"; and one from Illinois covers both bases, saying, "Take good care of both of you." On the other hand a Pennsylvania brochure asks, "What can you do to help you and your unborn baby?"; one from Virginia focuses on "The baby in your life"; while one from Massachusetts says, "If there are children in your future, know these facts." Notice the common theme, one of caring about what is happening, looking at the future, making life come out right. There is also a second element to the theme, and that is that there needs to be a participatory component by the individual. A brochure from the Developmental Disabilities Council in Pennsylvania underlines this point, saying, "You make a difference," while one from California speaks of "You and your baby." A third very common theme speaks of "Tomorrow's child." The brochure that is my favorite, however, comes from a recent conference in western New York which discusses "The right to be born well." This is an enormously positive and humanistic group of considerations.

There are a couple of subsets to the prevention theme that I think we need to reflect upon because they cause some people a bit of unease. First, it should be clarified that in our joining together in the name of prevention, we are not diminishing our resolves regarding service. Nor do we insinuate that the individual who has been born with a disability represents a mistake. I am intrigued how many times it has been the parents of children with disabilities who have been the strongest advocates for carrying forward the prevention message. In fact, the prevention movement has many direct participants who are, themselves, disabled. We respect, totally, the rights and nobility of the individual who has a disability. We want to join hands with that person, provide services, and move on so that the lot of people who follow will be better. Emily Dickinson looked at the indigenous importance of the less capable among us and said:

No Life can pompless pass away -
The lowliest career
To the same Pageant wends its way
As that exalted here -

How cordial is the mystery!
The hospitable Pall
A "this way" beckons spaciouly -
A Miracle for all!

A second element that sometimes gets confused in prevention considerations is the business of economics. This conference sets a very important theme by mentioning the cost of disability. We are destined for failure in our prevention effort if we do not acknowledge cost elements, but our motivation for prevention is more personal. The fact that there will be savings in public monies is relevant and absolutely essential. However, a motivation which looks to promotion of the human condition on its own merits is equally significant. So we will address costs, but we will not let that be our moving force.

B. What Causes Developmental Handicaps?

What are the things we want to prevent? I am going to review six categories of causation. As I do, I want you to reflect on where we are in terms of our capacity to modify them. Some of the numbers that I will give are statistics derived from a very biased source, namely from our tertiary level hospital referral clinic [Developmental Evaluation Clinic, Children's Hospital, Boston; see APPENDIX A].

The first category includes conditions that originate prior to conception, specifically elements which are inherited. These are in some fashion programmed by the genomes of the parents; this does not mean that they cannot be understood and influenced, but only that they are intrinsic. Some of the better-known inherited conditions, the inborn errors of metabolism, are low in incidence but can have very significant final effects. Other single gene abnormalities, such as tuberous sclerosis and neurofibromatosis, are numerically much more important. There are a variety of chromosomal aberrations that are inherited in a Mendelian fashion, the most common being the Fragile-X syndrome. And finally, there are a group of polygenic familial syndromes which have multiple origins for their production of humans who have some degree of handicap. In the experience of our child study center, all of the apparently hereditary origins for mental retardation constituted less than five percent in the total population of children with mental retardation. We could use some of the same reasoning for other elements in the developmentally disabled family as well. Heredity is not as great a factor as the public perception would have it.

A second, and vastly more important, category of causation includes events that happen to the human around the time of conception, or during the first third or first half of pregnancy. These elements effect embryogenesis, or how the fetus is put together and develops. There are two subsets to this category. The first includes the chromosomal changes, the mechanism of which is generally obscure. Down syndrome, for example, follows when the first cells of the fetus contain extra genetic material for chromosome 21 (such as trisomy). The second, numerically more important group, includes the prenatal influence syndromes, or the so-called congenital anomaly syndromes. Here some ill wind has blown across the fetus (usually of inapparent origin), changing the fashion in which organs are formed. Examples would be Williams syndrome or cerebral

dysgenesis. In our experience, congenital anomaly syndromes represent nearly one-third of the total of referral patients. If we're going to change the people of Iowa, and I presume they have roughly the same liabilities as those in New England, we're going to have to look very hard at this group.

The third category, one which has received a great deal of publicity, includes events that occur toward the end of pregnancy and perinatally. At this stage, the fetus is complete but still must grow and mature, be delivered, and accommodate to the external world. This is the time where it is very common to have disability from neurological disorders (such as cerebral palsy). Typically a stable handicap will occur from these damaging perinatal incidents, although there is an evolution of some of the features of these conditions. There are two groups within this category as well. One can be called fetal malnutrition, which refers to the fact that the fetus is not getting an adequate supply of nurturance due to vascular changes in the placenta, such as placental infection, infarction, unfavorable implantation, etc. The other involves direct perinatal difficulties for the vulnerable baby. These are, for all working purposes, the small (premature) babies. At any rate, whether it be an insufficiency of oxygen, acidosis, infection, intracranial bleeds, effects of hyperbilirubinemia, or whatever, one way or another there is a toll taken on some small babies. If one looks at this category in our clinic experience, about 10 percent of the children appear to have acquired their difficulties from this origin. So it's numerically important but nowhere near as large as the congenital anomaly syndromes are.

The fourth category includes difficulties that occur during childhood. With these, the individual was presumably starting off on a normal course but ran into one of two troubles, either infection or trauma. Infection in current times usually means encephalitis, although once in a while one sees a baby treated late with meningitis who has gotten into difficulties. Under trauma, the famous ones, of course, are the motor vehicle accidents, with the injured party being either the pedestrian, passenger, or bicyclist. In our particular clinic household accidents are statistically more significant. There are others: one used to see the effects of cardiac arrest during surgery, for example, occurring during tonsillectomies in small hospitals, but we don't see that much anymore. We do see near-drownings, and some intoxications. It surprised me very much, as our experience gathered through the years, to notice that childhood infections and injuries are, numerically, not a very large area as a background for mental retardation. Namely, it is somewhere in the neighborhood of five percent.

The fifth category includes environmental and behavioral problems. To some degree, these factors play across the theme of all the developmental sequence, so there is no way to link them specifically to one of the timed stages. The largest subset of this category is what we have called psychosocial deprivation. There are many different synonyms for the term, but they all suggest that the child did not get a fair shake, was denied some

element of the support system that would be appropriate by rights. Psychosocial deprivation could include categories of neglect in an uninformed sense, on up to vigorous child abuse. Generally speaking, it represents a systems failure, or a decompensated family arrangement of one sort or another. Many times these factors represent add-on's to the other conditions. These kinds of numerical listings are somewhat misleading because they emphasize single causation, which is really not quite fair. But for a substantial number of children, in our experience, psychosocial factors stood out dramatically as the ascendant cause. So, it seems worthy of coding on that basis. Then there is a series of numerically smaller elements, including parental neurosis, psychosis, or character disorder, some of the unusual child behavioral syndromes, and finally, childhood psychosis and autism. This group, taken as a cluster, comes to somewhere in the neighborhood of 20 percent, with more than half being a result of the psychosocial factors.

When we get all through we are left with category six, which is a bewildering element of our classification. The "unknown" category includes all of the children for whom we could not reasonably code a cause, although their mental retardation was, in many instances, of very significant degree. There are several ways to view our unknown category. To some extent, we may assume that prevention efforts which work on the other categories of causation will effect some of the children that we have put in our unknown group. There are, however, some children who simply have nothing in their background to explain a reasonable cause for mental retardation. These are the ones in our clinic we refer to as "the unknown unknowns." We still have an awful lot to learn. You can tell a lot about a person by how large his group six is; mine is 31 percent, which means I'm o.k.

So this is our challenge. These groups of special circumstances lie behind developmental disabilities. The statistics that we have found happen to be for a group of children referred for developmental study and who were shown through interdisciplinary assessment to have mental retardation. You can use this same kind of schema to discuss the origin of children with cerebral palsy, sensory handicaps, other physical handicaps, and, to some degree, certain emotional issues. The numbers and ratios may vary geographically to some degree, or by developmental category, but one way or another these are the pernicious forces that we are going to have to deal with: heredity, congenital anomalies, perinatal issues, childhood events, psychosocial problems, and the collection of unknown factors resulting in developmental disability.

C. An Inventory of State Prevention Activities

Now what has been the traditional view on getting going? A few years back I did a collation of satisfactory prevention activities from a number of states and national organizations, including both consumer and professional groups. When I put them all together, there were about 20 measures that were generally agreed upon. Because, from my point of view, these

were rather noble investments, I referred to them as "The Golden Twenty" [Appendix B]. I will not discuss these in depth, I just want to identify them as the consistent winners across prevention programs. One model that I will bring to your attention today is what has been going on in Virginia.

D. Virginia's Action Agenda

Virginia is one of about 15 states that has called together its people rather consistently to modify, revise, and bring fresh resolution to its prevention acts. In December 1983, Virginia held a conference in Williamsburg that was quite extraordinary. For three days almost 400 people worked together on prevention. They devised an "Action Agenda," and I want to discuss that with you. We usually find the word action somewhere in a state plan title. In Virginia they keep moving rather well.

What Virginia accomplished in their December meeting follows. They came in at the beginning of the conference with a list of current activities and programs. Then in a group of workshops, they revised the list until it eventually dealt with seventeen categories of activities which the people of Virginia said they were going to address. The categories are quite predictable and resemble "the Golden Twenty." I will not list them all; however, they included genetic screening and counseling, newborn screening and treatment, adolescent pregnancy, prenatal care, and a perinatal care network, among others. By the end of the conference, within these seventeen categories, the number of recommendations came to 119. I do not know what the population of Virginia is compared to the population of Iowa, but it is comparable. The people of Virginia found 119 things they decided they were going to do. I recommend you use their agenda as a resource.

E. Tennessee's Mental Retardation Prevention Program 1981-1984

The state whose activities I want to particularly look at, however, is Tennessee. I chose Tennessee because they began their program efforts rather systematically in 1980, and hence have had enough years of implementing their plan that it is beginning to be possible to do some measurement. In 1980 Tennessee formed "The Governor's Task Force on Mental Retardation Prevention." This group did what most of these bodies do, it brought together a blue ribbon panel of about 25 people that contained a mix of professionals in various areas, consumer group representatives, public policy people, and workers from public agencies. But most significantly, the chairship was given to Honey Alexander, the governor's wife. She never missed a meeting of the task force, she always did her homework, and she was merciless in driving the others to do theirs as well. They produced a report in 1981 called "Tomorrow's Children," which includes 27 sets of actions that Tennessee planned to initiate. Because Mrs. Alexander had access to what might be referred to as the "kitchen cabinet," Tennessee has gotten on rather well. In the fall of 1984, we went to look at what there was that we could measure. Most of what we found in

Tennessee was a change in service patterns.* Measurement of the effects of prevention programs is tough, much harder than you might realize. What can be demonstrated is a change in service patterns. This is a good place to start, but it is not the same as a change in incidence, or, eventually, of prevalence.

The 27 features that are part of the Tennessee plan are, again, quite predictable -- prenatal care, family planning, family life education, nutrition for women and children, improvements in birth management. These are the ones, again, that over and over turn up as part of what good humans decide to include in a prevention affirmation. Here are the major goals:

Number one: "All pregnant women should have access to quality prenatal care." Taking note of the fact that the Tennessee State Department of Health and Environment currently provided prenatal care in 34 counties during 1981, the recommendation called for program continuation and expansion to at least 28 additional counties as funds became available. In 1984, the task force was able to report that an additional \$1.8 million in state funds had been brought forward and that prenatal care was then available in all 95 counties of Tennessee. Approximately 14,000 patients were served in 1983, while the number in 1981 had been 2,088. To go from 2,088 to 14,000 is striking, but these statistics are not enough to work with. Quality of care provided is one question; another is the outcome information. What happens to pregnancies? Not numbers of births, but birth outcomes. For example, in Tennessee it is unclear whether the rate of prematurity significantly changed. It is absolutely necessary to know the outcomes for these service programs. However, I think that Tennessee's prenatal service expansion is a striking accomplishment.

Number two: "Family planning services should be available to every citizen." I love the language they use, non-exclusionary kinds of syntax that are very favorable. "The Departments of Human Services and Public Health should cooperate to continue the existing family planning program with expansion as funds become available." Tennessee was actually a good state for provision of family planning services in 1981, but the services were subsequently increased substantially. The commentary in 1984 is that family planning services continued to be a high priority in Tennessee; services are delivered through all 95 county health departments, three planned parenthood agencies, and several primary care centers. For example, during 1983, 157,269 clients received family planning services. That's a lot of folks. How satisfactory the interaction was is unclear from these numbers; however, they were able to demonstrate a reduction in the rate of adolescent pregnancy in Tennessee in this period for the first time. They were also able to demonstrate that Tennessee was offering the seventh most widespread family planning services in the country. For a state in that

*I wish to express sincere appreciation to Ms. Marguerite W. Sallee and Ms. Susie M. Baird, of the Tennessee Department of Health and Environment, Nashville, for their splendid work.

area, that is a significant accomplishment. I was told that family planning had come under considerable threat by virtue of certain public opinion concerns during this same period. So Tennessee not only made progress in family planning, but they held at bay several threats as well.

Number three: "Public schools should offer family life education." Note that in almost all of Tennessee's recommendations, agencies have been identified which reach across the human service spectrum, with different agencies identified for different purposes. "The State Board of Education should serve as the major policy force to implement this recommendation in the local school systems." In 1984, a family life education curriculum had been written by the Department of Education and was available to local school systems upon request. A resolution was passed by the Tennessee General Assembly, encouraging local school systems to use the Tennessee health education curriculum, including the unit on family life education. I would expect that the curriculum's effects are modest at best, but the state of Tennessee has one.

Number four: "The nutritional needs of pregnant women and infants should be met." The recommendation continues, "programs to provide nutrition screening and information should be continued through the Department of Public Health. Nutritional supplements for eligible pregnant women and infants should be continued in every county." The record in 1984 shows that the programs are available in every county, that the state prenatal activities (described under item number one) include a nutrition component, with many more women now getting nutrition services, and earlier in their pregnancies. There has been a concerted effort by nutrition staff to increase services to high risk patients by developing more group counseling activities for patients at risk. Many county health departments have reported a steady decline in anemia among infants and preschoolers. Here is an example of an outcome that could be measured. If indeed iron deficiency anemia has been reduced in preschoolers, this would be a very significant public health effect.

Number five turned out to be a real problem politically: "Every pregnant woman should have access to trained health care providers." This sounds like it is number one all over again, but there is something different about it. The recommendation continues, "The use of certified nurse practitioners and certified nurse midwives should be encouraged as a way to improve the availability of reproductive health care. Rural and medically underserved areas should be identified as priority for improvement." What is actually going on is that the obstetricians of Tennessee are seriously concerned, and the nurse-midwife situation in Tennessee is in unrest in terms of its future. Nurse midwives are clearly being more broadly used, and in many cases are filling a vacuum. The local health department clinics are being staffed primarily by nurse practitioners, with the following condition, that "arrangements for delivery are made with local physicians and hospitals wherever possible." I think it must be simply listed under this recommendation that there is a lot of commotion. How broad is the use of nurse midwives in Iowa?

Number six is part of Iowa's Developmental Disability Council's resolves already: "Birth certificate information should be filled out completely and correctly by physicians." The Department of Public Health should be responsible for training health care providers in the proper procedures." The issue here, of course, is that physicians are not very good at filling out birth certificate information completely and correctly. Their accuracy rate for something like Down syndrome just barely exceeds 50 percent. The general conclusion is that probably physicians should not be the people who fill out birth certificates. In 1984, two field representatives from the Center for Health Statistics, which is part of the Tennessee health department, met regularly with medical records personnel to provide training in filling out birth certificates correctly. Those medical records personnel are not physicians. In addition, the Center for Health Statistics staff met regularly with deputy and local registrars to provide instruction as needed. Between 1981 and 1984 the incidence of birth defects in Tennessee doubled. How do we explain that? Clearly the incidence did not double, the reporting doubled, and this is a funny kind of achievement. But it is an achievement. If we're gonna "beat 'em," we've got to be able to "count 'em" first, and Tennessee is getting there.

Number seven: "Genetic screening, diagnosis, counseling, and laboratory services should be available to all patients at risk." The Department of Health should seek to retain and expand the genetic program now available." You will recall historically that in 1981, the state program monies from PL 94-278 were still active in Tennessee and most other states. But everyone was beginning to panic because the program dollars were all on four-year cycles, and it was quite clear that they were not going to last. Tennessee formed a Tennessee Genetics Network which purchased and made available genetic screening equipment, used as headquarters the UT Center for Health Sciences in Memphis, and got the legislature to appropriate \$200,000. That is about the size that many of the state genetics federal funds were during "278," and so it became clear that what Tennessee got started they did not lose.

Number eight: "Screening programs should be available for all women at risk for having children with neural tube defects." Now I don't like the restrictions on that one. Screening programs regarding neural tube defects should be available for all women. If you simply look to the ones who are identified as at risk, it's not appropriate; too many affected pregnancies would be missed. "The Department of Health should work with genetic centers to develop the personnel, equipment, and procedures to implement a pilot study." If you take a map of the incidence of neural tube defects (spina bifida, myelomeningocele, encephalocele) there is a clustering in the southeastern part of the country, of which Tennessee is sitting in the middle. I do not know how Iowa is on incidence of spina bifida, but Tennessee would be an ideal state to get going on a universal screening program.

What has happened is that, three years later, they have a pilot program. I do not consider this adequate. There is no longer any reason

to have pilot programs for neural tube defect screening. The two leading states in the country for use of neural tube defect screening are Maine and Connecticut, each of which is screening around 40 percent of all pregnancies. In Great Britain, where the incidence is yet higher, 50 percent are screened, and in Scotland, there is an astonishing 75 percent of all pregnancies screened. This breaks Crocker's Law, which is that with things that require public cooperation you commonly reach about 50 percent coverage, but seldom exceed that. For example, maternal-age based amniocenteses are edging up toward 50 percent, but I doubt they'll ever exceed that level. But the fact that in Scotland three-fourths of all pregnancies are being screened for neural tube defects is astonishing to me, absolutely astonishing. Tennessee, an epicenter for high incidence of neural tube defects, has got a screening program going in East Tennessee, but this is not enough.

The next six categories are related. All pertain in some way to the concept of regional perinatal care centers; in other words, places for getting vulnerable babies born or cared for, places capable of providing extraordinary support measures. There is not time to go into all the details, but the task force starts off in the standard wording: "The services for regional perinatal care centers should be available to any infant with a life-threatening condition." In 1984, Tennessee formed a fifth center in Johnson City to back up those in Knoxville, Chattanooga, Nashville, and Memphis, and special services were provided to 3,109 newborns. I would imagine Tennessee would be having somewhere in the neighborhood of 50,000 births; 3,000 newborns being treated in regional centers is not bad. A lot of them would not need transport to regional centers. There has also been an increase in maternal transports from 663 in 1973 to 5,310 in 1983. I would think 5,000 maternal transports is a pretty high number, so they are working rather vigorously. Then they talk about the need to follow-up the graduates of newborn intensive care units, to evaluate existing perinatal care programs, and to provide professional coursework.

Let us move on to number fifteen. "All children should be checked for health, vision, hearing, and psychological development at regular intervals prior to school age." That is a hard one to bring off. And there is really only one opportunity: in the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program. I would suspect that any other scheme that proposed to see all children for health, vision, hearing, and psychological development is cutting out more than they can deliver. It is a terribly large assignment. The July, 1984, estimate was that 10,000 children in Tennessee were touched by EPSDT. What is your record in Iowa? It is anywhere near as high as 10,000? There again, how satisfactory the interaction was is not made clear by these numbers. But, unless a revolution occurs, EPSDT is really our only shot at preschool screening.

Sixteen should be folded into fifteen. It relates specifically to hearing screening and treatment services.

Seventeen deals with the feasibility of linking screening with required immunizations. There has been no rubella for several years in Tennessee, and they had six cases of measles in the whole state in 1983, so immunization is doing well in Tennessee.

Number eighteen deals with comprehensive diagnosis and evaluation services for children thought to be at risk, or with suspected developmental delays. In 1984, the Department of Mental Health and Mental Retardation is providing diagnostic and evaluation services. They have an Infant and Child Diagnostic Evaluation Task Force. I do not know how broadly public developmental clinics really are being carried out in Tennessee.

Number nineteen: "Confirmatory diagnosis, counseling, and follow-up for children with PKU and hypothyroidism are absolutely necessary and should be the responsibility of the Department of Public Health." That is not a very startling recommendation. They said that 45,000 infants were screened in 1983-84 with ten positive cases detected. Any state that does not screen systematically and does not provide treatment or follow-up is out of order, and having a working program does not need to be made a special item.

Number twenty: "Programs providing infant stimulation, parent training and preschool education for mentally retarded or high risk children under the age of four should be continued." And indeed, in 1983, 4,000 such children birth to four were served by state funded early education programs, and 944 from 3- to 5-year-old handicapped children in Head Start.

Number twenty-one looks at a comprehensive study planning effort concerning high risk and handicapped infants and children. It includes a whole series of things, among them a Preschool Services Planning Project, a Preschool Services Planning Committee, and a directory of preschool programs. In the 0-5 range a family cannot get easily lost or fail to find services in Tennessee.

Number twenty-two: "All agencies of the state government that serve children should work with the Department of Education to improve and fully implement the Child Find effort." However, in 1984 I was told in Tennessee the Child Find effort is troubled.

Number twenty-three: "Tennessee should explore the feasibility of requesting state oversight of the Head Start program," which is interesting, and they have moved toward that.

Number twenty-four: "Impact of early childhood development programs should be evaluated." They have a Preschool Analysis Project.

Twenty-five: "Through interagency effort with consumer representation, Tennessee should explore the feasibility of developing state standards for early childhood education." That is astonishing, and the Preschool Analysis Project is moving with that.

Number twenty-six: "To carry forward the focus on prevention, the Task Force on Mental Retardation should be continued." In other words, just because you have got all the activities in motion, do not disband your task force; it is a lifetime appointment.

And very important, number twenty-seven, that "this task force should find its home in the Children's Services Commission." This is a separate office in state government that reports directly to the governor, so that it is not in the area of any one agency.

Now, what did I find when I went down to Tennessee last fall? To my astonishment the initiative on mental retardation has become part of a broader child health activity, what is now called "The Tennessee Healthy Child Initiative." I was troubled at first, because it had been my feeling that Tennessee's mental retardation prevention effort was so significant that it should not be lost. However, if you look at most of those 27 recommendations, they are things that are generally good for pregnant women, small children, and slightly larger children. They are all things that make for healthy children.

If you do things to make children healthy you also decrease developmental disabilities. I think that using that direction is very chancy and in very few states is it appropriate to take that risk. Surgeon General Koop has been promoting healthy mothers-healthy babies, and Julius Richmond did the same. My own recommendations are that for most states a developmental disabilities prevention or a mental retardation prevention program is probably the better way to go. However, when you are four years into a mental retardation program and it is working rather well, if you want to shift over to healthy children altogether, it is an interesting and very adventurous possibility.

I think it should be clear to you that there is a need for counting so that you have numbers before a program develops, because documenting results afterwards is going to be difficult. In many places we have imperfect techniques to count now, and hence we will not be able to demonstrate to the legislature or the people that we have accomplished anything. I hope that somewhere in your plan, how to count receives some very thorough and some very earnest consideration. It becomes apparent that you can count changes in services; I think that is very important, but eventually we are going to have to count more than that. We are going to have to discuss changes in incidence and prevalence, and this is difficult to do.

F. What is Working?

I promised to comment on a few things that are working, so one can have a little feeling of success. I would like to list five. Let us celebrate these.

Tay-Sachs disease. The incidence of Tay-Sachs disease in the ten years that carrier screening has been available has been reduced by 85 percent. We know this because the National Association of Tay-Sachs and Allied Diseases is able to count the major inborn-errors-of-large-molecule diseases. To an important degree, this is the effect of the screening program, but there is also something else going on which is less clear. The screening program has now looked at roughly 500,000 Ashkenazi Jews and has identified carriers at the expected rate of roughly 1 in 27. Tay-Sachs disease has now become basically a non-Jewish disease, and almost all of the involved children that we see are non-Jews where the carrier rate is much lower, about 1 in 300, for whom it would not be feasible to screen.

Hypothyroidism. In general, the newborn screening program for hypothyroidism is a huge success. In our child study clinic, we used to see about one child a year, who was usually a year to a year and one-half old, who had partial congenital hypothyroidism, and for whom initiation of replacement therapy would have a very limited usefulness. We have not seen any children like this for about five years. I do not think we are going to see them by the present system. The last state to come on line with hypothyroidism screening was Mississippi in 1981. All states now screen for hypothyroidism and the treatment results are very gratifying.

Congenital rubella. In Massachusetts there used to be about fifty children each year entering the school system who had congenital severe profound sensorineural deafness caused by rubella. There was a peak of 750 children born during the 1963-64 rubella epidemic. We have now not identified a case of congenital rubella in Massachusetts for about three years. For all working purposes congenital rubella has been wiped out.

Down syndrome. The incidence of Down syndrome has dropped from 1 in 650 births in the country, to roughly 1 in 1,000. In other words about a 30 percent decrease. It is thought that the majority, perhaps two-thirds, of this decrease, is due to demographic changes, namely, a decrease in the number of older women having babies. Our chance to effect Down syndrome by amniocentesis, of course, is very limited. If only roughly 20 percent of the mothers of babies with trisomy 21 are over 35 and hence being offered amniocentesis, and only half are taking it, we could only change 10 percent by the use of amniocentesis.

The effects of Newborn Intensive Care Units. My source here is a chapter in a leading textbook in the field called Developmental Behavioral Pediatrics (M. Levine, et al., eds. Philadelphia: W.B. Saunders, 1983). This particular chapter is written by two Iowa pediatric professors, Drs. Healy and Hein, and one from Boston, Dr. Robin. They note the changes that

have occurred between 1960 and 1976. Mortality for babies with birth weights of 1500 grams or lower decreased from 72 percent to 33 percent. Of the babies who survived, the number who were free of developmental handicap increased from 26 percent to 73 percent. So not only did the mortality come down, but also the percentage of developmental handicaps of the survivors was reduced by two-thirds. This is worthy of celebration as well.

G. How Does Policy Get Made?

How does it come to be that a state believes in prevention; how does policy get made?

Generally speaking, the role of individual research or studies is significant through increasing the knowledge base. Usually this causes some individuals to get concerned and to arrange for an organizational meeting. Now the kind of organization you get together, working with the knowledge base and the individual leadership, can be a coalition, a task force, a commission, or a conference. The organization has a discussion, and eventually forms resolves. This is the planning phase of policy formation [Figure 1], and I would say that there the state of Iowa is in splendid shape.

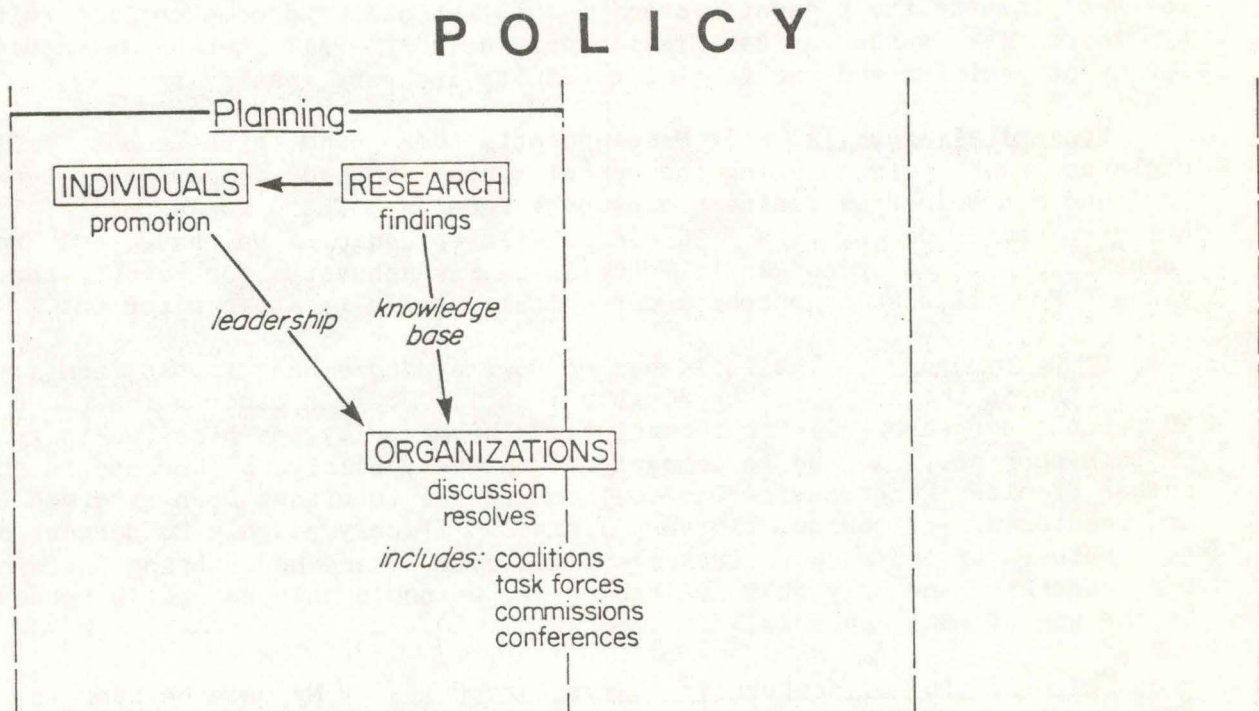


Figure 1

Then comes the determination phase [Figure 2]. Included in the resolves of the organization's meeting, the conference, or the activities of a task force, there is a public and professional education initiative, and it should go in four directions. It should go to the governor. For example, at the Williamsburg conference the governor was the noon luncheon speaker, a very appropriate thing to do. The governor has to get involved somewhere along the line. Secondly, so does the legislature, which will, of course, eventually make critical decisions. Thirdly, one also ought to have a continual interaction with the public agencies, because this is where action will finally come to be. Your inclusion of public agency personnel in this conference is germane to that. Then, fourthly, private activities should be included, including voluntary programs, consumer groups, universities, and health care providers.

P O L I C Y

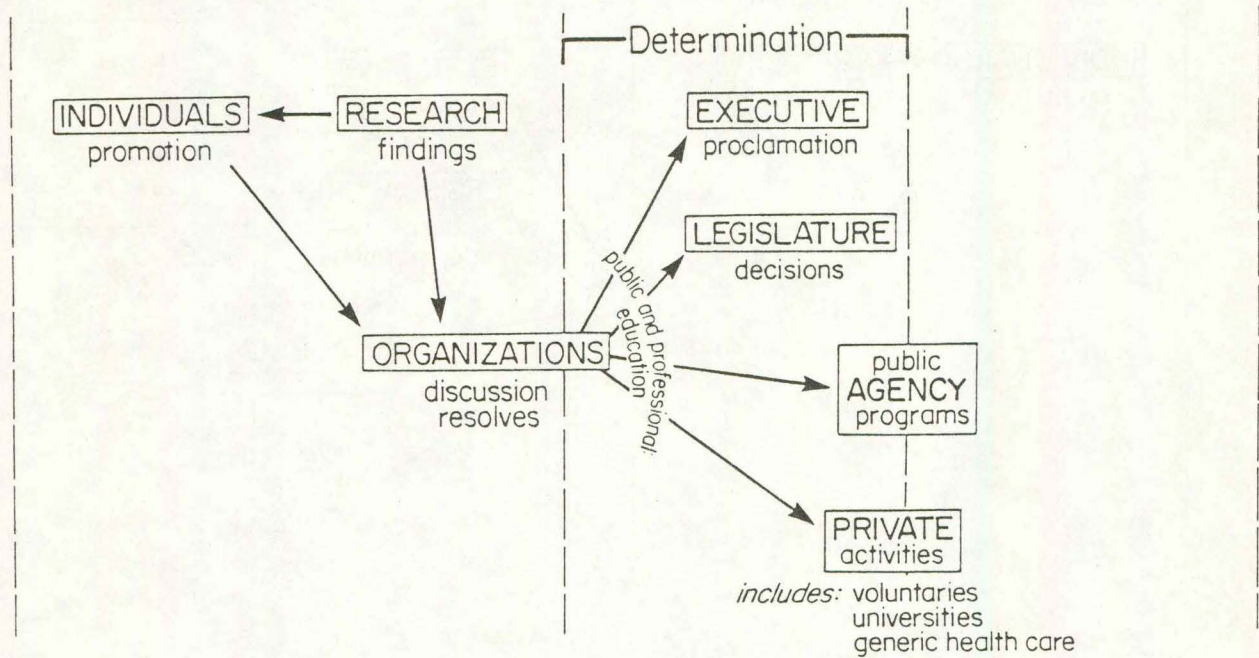


Figure 2

For the implementation phase [Figure 3], recommendations that come from the governor will be sent to the legislature, who will make decisions in the form of appropriations, appropriations which require public agencies to generate programs. They will presumably endorse the interaction with private agencies, such as in family planning or public education. It will be well advised to form some sort of a watchdog group, an advisory council. This is different than the organization for planning. This group will report back to the legislature and also be in continual interaction with the public agencies.

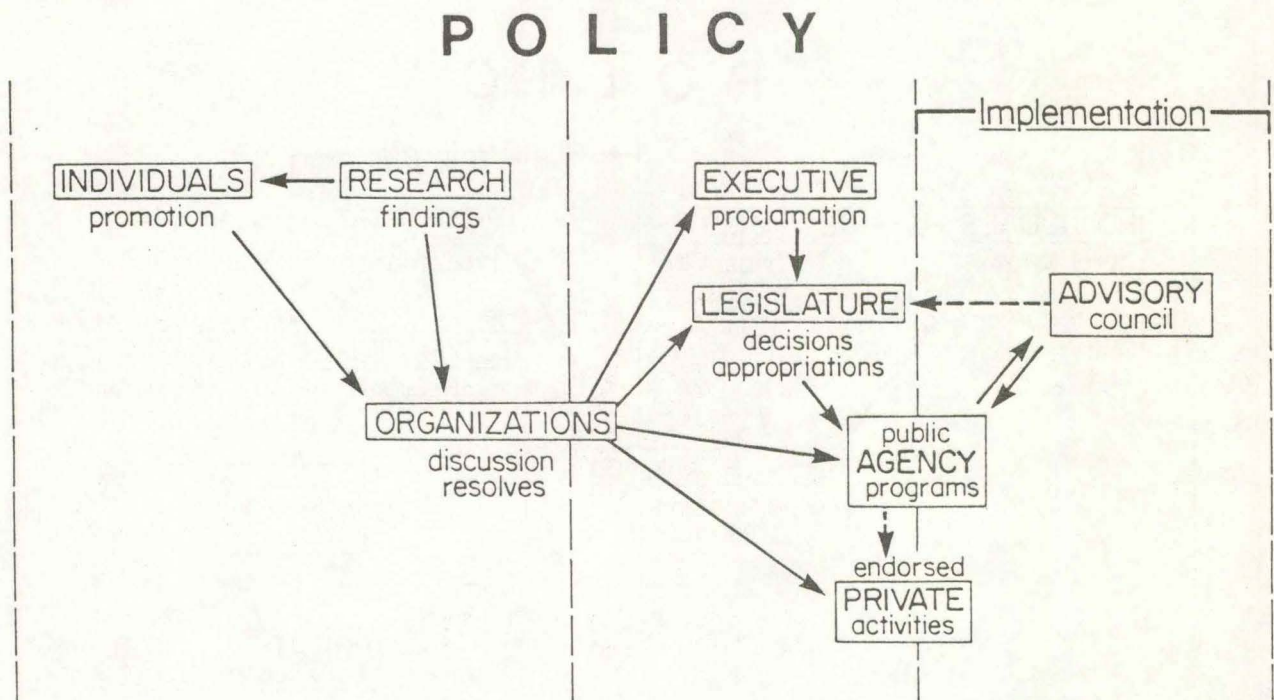


Figure 3

Now that is a lot of interactions. You could include more if you wanted to, but I do not think you could leave any out. If there is going to be an Iowa Policy regarding Developmental Disability Prevention, I think most of these elements should be pursued. And you are already half way there.

Six Words of Wisdom

The features of the Tennessee program that attracted my attention initially, and which continue to be present, are six. I would like you to take these six single words down, and I would hope that the Iowa program will be characterized by these words as well.

Word one is knowledge. Namely, they did a survey first.

Word two is education. They got a large number of people informed.

Word three is access. They emphasized access; specifically, access to prenatal care, access to regional perinatal systems, access to screening programs, etc.

Word four is standards. Intriguingly, they focused on standards. Namely, the state would look to form standards for early child education, something that virtually does not occur.

Word five is evaluation. A very positive and a very important thing to bring off, and Tennessee is doing well.

Word six is coordination. In Tennessee it was in the Children's Services Commission. You have got to find a place for it in Iowa. State plans for prevention of developmental disabilities can end up in many different places. Sometimes they are in the health department, which is fine but a concern unless the watchdog component is active. Developmental Disabilities Councils are central players in a number of states, for example in Ohio. One way or another, state plans have got to be visible and have enough access to gain credibility.

H. Future Resolves

Where are we in 1985 in terms of the needs for the future? I give you what I would like to refer to as the "Thoughtful Thirteen." These are things we are going to have to attend to if we are really going to change the scene; efforts which, if there is progress and application, would lead to a significant further reduction in the incidence and toll of mental retardation. Biomedical concerns are listed first, followed by cultural and political elements:

Number one: Procure new knowledge regarding the origin of deleterious effects on the developing fetus, including environmental teratogens and congenital infections (e.g., cytomegalovirus). Energetic monitoring of birth defects has retrospective utility. Continuing trial of diet therapy is needed in maternal PKU. If you remember my category number two, in the section discussing causes of developmental disabilities, I believe we can

tell about 3% of the families who have children with multiple congenital anomalies how the anomaly came to be. That means 97% of the families having children with congenital disorders don't know why. One suspects that environmental toxins and congenital infections are probably much more significant than we are presently able to track. New knowledge in this area is absolutely critical if prevention is ever going to get there.

Number two: Continue research on the causes of chromosomal aberrations, such as nondisjunction. In addition, the potential for genetic engineering techniques is immense. We know a great deal more about the 21st chromosome (associated with Down syndrome), except we do not know how nondisjunction (which causes the condition) takes place. We are getting there. There is some progress, but we have much further to go. And using amniocentesis to allow that baby not to be born is not the ultimate solution.

Number three: Obtain better understanding of the biologic bases of behavior, including the neurochemical origins of behavioral aberration, acknowledging the developmental liability from these variations. An improved perception of the neurochemical basis of behavior relates to childhood conditions such as psychosis, autism, and a number of other complications of developmental handicap in which there are some secrets just staring at us, but we have not been able to put the pieces together yet.

Number four: Continued vigilance regarding utilization of proven prevention activities, such as immunization, genetic carrier screening, maternal serum alpha-fetoprotein screening, prenatal diagnosis, newborn screening for metabolic disorders, and regional intensive care units for premature infants. We had better hang tight on the proven prevention activities, for they are frequently threatened. For example, immunization is the prototype for a potentially imperiled proven method.

Number five: Make good prenatal care broadly available and its use encouraged, incorporating best understanding regarding the prevention of prematurity. Eventually we may learn why prematurity occurs. The theories available now are weak; everybody points out that prematurity correlates with the intensity of prenatal care, but we do not know what it is we do in prenatal care that influences a potential reduction in prematurity.

Number six: Attend to the known developmental hazards in childhood, including exposure to lead, undernutrition, repeated infection, and chronic illness.

Number seven: Provide quality family life education in all the schools, with creation of understanding about the responsibilities and opportunities of parenthood. I brought along a couple of recent newspaper clippings which I imagine may reflect the situation in Iowa. Essex, Massachusetts: "Family Life Course OK'd." With some pride they point out how they brought material on what parenthood is all about into the public

schools of Essex. Two weeks later, same newspaper: "Human Development Class Produces Battle in Athol." Athol being somewhat more dug-in, was damned if they were going to have sex talk in the schools. This goes on continuously. I do not know how the scene is in Iowa. We have got to bring more honor to the status of parenthood than we have to date.

Number eight: Assure the provision of family planning supports by various state and private agencies, aimed at encouraging the arrival of valued children and reducing the occurrence of teenage pregnancy.

Number nine: Maintain an effective pipeline for public education on topics relating to causation of retardation, such as the need to plan prior to conception for the avoidance of fetal alcohol effects, and the fact of multiple causes for childhood head injury.

Number ten: Encourage a universal development of state plans for prevention of developmental disabilities, including the participation of consumers generally, the voluntary associations, professionals, and government. In this country there are about 15 state plans, namely there are about 35 states that do not have a formed plan. There is something that happens when a state plan is published. There is a visible "here I stand" phenomenon going on, and an assurance of interagency collaboration.

Number eleven: Secure agency resolves regarding necessary special services, such as developmental screening of young children, early intervention, follow-up, and family supports.

Number twelve: Ameliorate poverty and social disadvantage, with their desperate effects on the rights of children. In the "unknowns" and in group five in my list of causations, I am sure you will note that there are the effects of an inadequate support system for children. Senator Daniel Patrick Moynihan recently gave the Godkin lectures at Harvard and pointed out that "poverty and family ills are linked." He gave a long list of the sequelae to poverty and how children in this country are relatively more in the poverty class than elderly people are. We have got to move on this issue somewhere along the line.

Number thirteen: Work for better acceptance of human variation, which will ultimately reduce the adaptive stress of cognitive handicap and thus diminish "mental retardation." There is substantially no mild mental retardation in Sweden. Of course, if you were to do cognitive testing in the schools we would find some, but, by and large, they do not do testing. If you recall, the definition of mental retardation has three pieces, one of which is the adaptive component. The adaptive component is substantially influenced by public attitude.

Conclusion

I have tried to present to you the notion that prevention feels good, that it has many technical aspects to its thoughtful preparation, that it

is something that we owe our children, and even our children's children. To come back to the theme that The University of Iowa saw fit to assign to this particular program, they quoted Emily:

If I can stop one Heart from breaking
I shall not live in vain
If I can ease one Life the Aching
Or cool one Pain

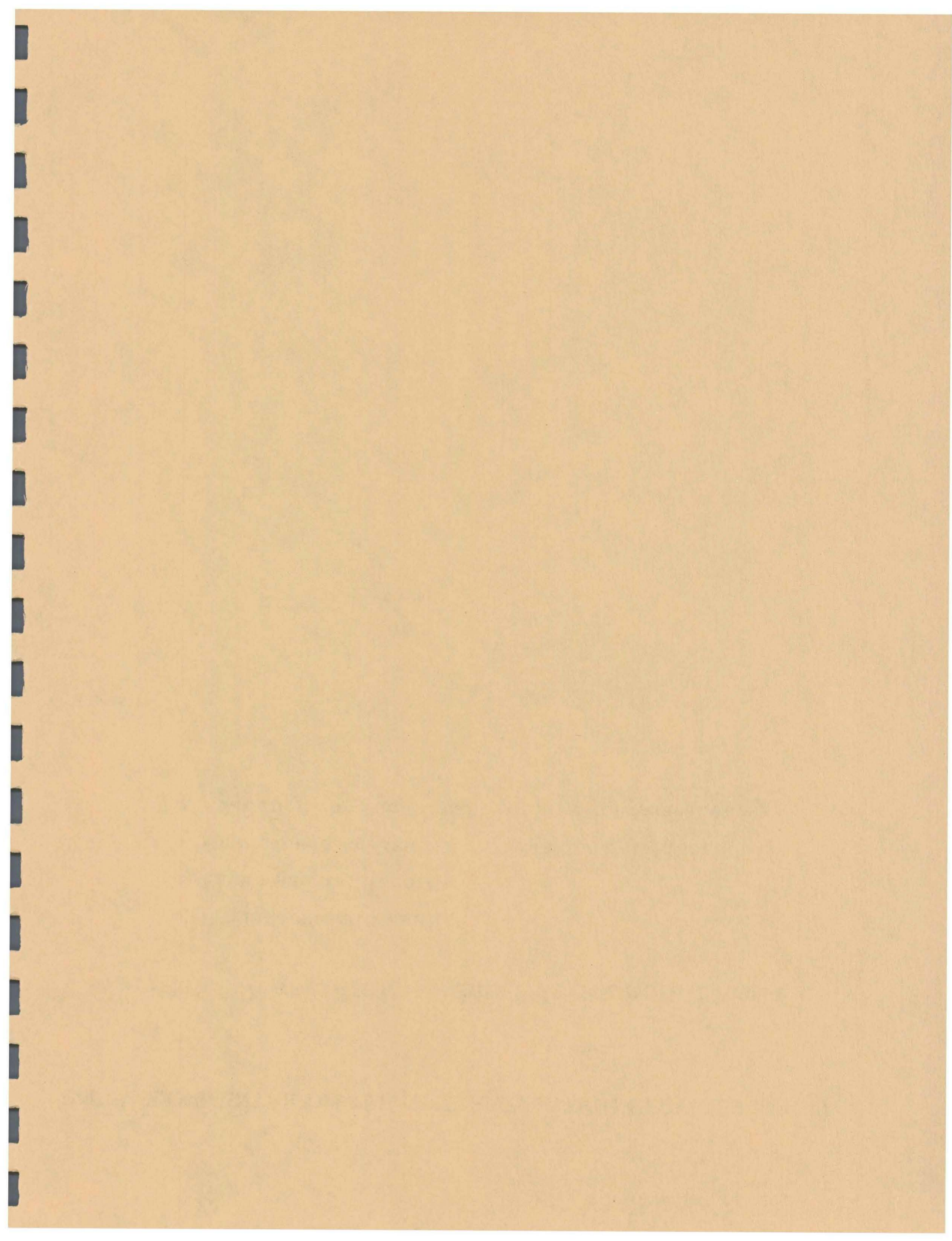
Or help one fainting Robin
Unto his Nest again
I shall not live in Vain.

I think Iowa has given the prevention movement a fresh theme, and its very own poem. Thank you very much.

DEVELOPMENTAL DISABILITIES PREVENTION SERVICES IN IOWA

Panel Presentations and Recommendations

- a. Pregnancy and Health**
- b. Environmental Hazards**
- c. Child Abuse as Related to Developmental Disabilities**
- d. Education for Public and Professional Awareness**



Pregnancy and Health Work Group:

Summary and Comments

James Hanson, M.D.

The Pregnancy and Health Work Group on Prevention Services in Iowa identified the following five priorities:

- 1) Obtain funding to insure that Maternal and Child Health Services, including support services, are readily available to all Iowans.
- 2) Provide effective outreach programs that educate and motivate target populations to utilize services.
- 3) Assure that state and local decision makers are well-informed.
- 4) Initiate comprehensive planning and coordination capabilities, including collection of basic information, resulting in the development and implementation of state and local prevention plans.
- 5) Promote change in societal attitudes which leads to decreased substance abuse and increased healthy lifestyles.

Although a variety of action components aimed at implementing each of these recommendations were identified, a number of these received special attention, often across individual recommendations. One of these stated the need to inform individuals, providers and decision makers of the need for appropriate utilization of, the societal value of, and the specific details of prevention activities as they relate to prevention and health. It was recognized by the group participants that not only do many families and individuals fail to recognize appropriate times and strategies for the application of effective prevention strategies, but, indeed, our general service delivery program and service providers are often unavailable or unaware of the details of these programs. Furthermore, state decision makers and legislators are often unaware of the value of such programs and therefore fail to provide appropriate funding. In order to remedy this situation, a broad educational strategy which seeks to integrate health information regarding prevention of handicapping disorders and other chronic health disabilities must be identified and implemented in the school curriculum for the population at large. Furthermore, preventative strategies need to be emphasized in professional health curricula, and decision makers and legislators must become adequately informed about the long-term cost effectiveness and need for adequate funding and public policy with regard to the prevention of developmental disabilities.

A second major theme was the inadequacy of present planning and coordination activities. It was repeatedly emphasized that a broad multi-agency planning capability needs to be developed at the state level as well

as at local levels. State agencies directly involved in the planning and provision of prevention services include the Iowa Department of Health, the Iowa Department of Human Services, the Iowa Department of Substance Abuse and the Commission on Children, Youth and Families. It was suggested that the creation of a "Healthy Mothers, Healthy Babies Coalition" might be one mechanism to achieve joint planning. Furthermore, it was suggested that a board of Maternal and Child Health consultants should be created to formalize relationships between state agencies and to advise on technical, scientific and medical aspects of maternal and child health program planning and development. It was recognized that there is inadequate information regarding the prevalence and incidence of disabilities and that a major interagency state effort needs to be implemented to correct this serious planning and assessment deficiency.

Finally, it was recognized that relatively few effective prevention strategies regarding developmental handicaps have been recognized and that many of these have failed to be implemented within the state of Iowa. A recent survey of prevention services produced extremely disappointing results in terms of the actual quality and availability of such services. Examples of programs which badly need to be developed within this state include the development of maternal serum alpha-fetoprotein high risk pregnancy screening programs, development of adequate information regarding the avoidance of environmental teratogens and other prenatal risk factors during pregnancy, and the more effective implementation of programs to promote healthy lifestyles, including avoidance of substance abuse.

In summary, the Pregnancy and Health Working Group recognize that insufficient funds, inadequate outreach activities, poorly informed decision makers, lack of comprehensive planning and coordination capabilities within the state, and inappropriate public attitudes regarding substance abuse and lifestyle decisions all represent serious, substantial, and ongoing barriers to the development of effective prevention strategies within the state of Iowa. It will require a substantial and coordinated multi-agency effort over an extended period of time to remedy this deplorable situation. Legislators and public health officials as well as other state decision makers can play a vital role in giving these matters a high priority with the goal of protecting our most valuable resource, the children and families of Iowa.

Screening for High Risk Pregnancies

Roger A. Williamson, M.D.

Genetic screening for fetal chromosome abnormalities, biochemical defects and neural tube defects has been carried out since the early 1970s. A relatively new screening program has been started in the state of Iowa which will be available to pregnant women who choose this test. It is called the alpha-fetoprotein (AFP) test. This protein is made by the fetal liver and a small fraction of that present in the fetus appears in the blood stream of the mother. An elevation of AFP in maternal blood can indicate that the fetus has a structural defect, such as an opening in the spine or abdomen. However, in a far larger number of cases an elevation is associated with a pregnancy at high risk for numerous other complications and not with a fetus with an opening in the spine or abdominal wall. These complications include a growth-retarded fetus, an intrauterine fetal demise, premature labor, and neonatal death. It is presumed that foreknowledge of these potential risks will alert the practitioner, so that the pregnancy will be followed more closely. Certain preventative measures should improve the outcomes of these pregnancies. Another important aspect of this form of screening is that if a fetus is found to have a serious birth defect and the pregnancy is continued, as many will be, the delivery can take place at a center equipped to provide the neonate with the best chance of quality survival.

Maternal and Child Health Care Systems

Theodore D. Scurletis, M.D.

Since 1969, there has been a steady decline in infant mortality (18.9 to 8.9), neonatal mortality (14.9 to 5.4), and fetal mortality (10.1 to 6.8). In addition, there has been a consistent decline in the low-birth weight infants so that in 1983 only 4.8% of all births were in that group (see tables attached).

There is a distinct group of pregnancies, however, which are at high risk and are not receiving the attention needed. As an example, those women who are less than 18 years of age, nonwhite, or conceiving out of wedlock have two to three times the incidence of low-birth weight infants and infant and neonatal mortality which is two times that of women not at risk.

In order to overcome this problem, we need to assure that a formalized maternal and child health program is present and active in each community. Through such an effort we can more effectively educate the public to the importance of preventive care, assure that all women receive comprehensive care during their pregnancy, and ensure that all children born will receive comprehensive, continuing child health care.

LIVE BIRTHS, FETAL, NEONATAL, PERINATAL, and INFANT DEATHS

IOWA, 1969-1983

RESIDENT DATA

Year	LIVE BIRTHS		FETAL DEATHS		NEONATAL DEATHS		PERINATAL DEATHS		INFANT DEATHS	
	No.	Rate	No.	Rate	No.	Rate	No.	Rate	No.	Rate
1983	43,247	14.9	298	6.8	235	5.4	533	12.2	385	8.9
1982	44,716	15.4	311	6.9	281	6.3	592	13.1	453	10.1
1981	45,918	15.8	336	7.3	296	6.4	632	13.7	456	9.9
1980	47,797	16.4	406	8.4	368	7.7	774	16.1	565	11.8
1979	46,763	16.1	363	7.8	339	7.2	702	14.8	496	10.6
1978	44,559	15.4	362	8.1	394	8.8	756	16.8	559	12.5
1977	44,898	15.6	373	8.2	431	9.6	804	17.8	556	12.4
1976	41,570	14.5	352	8.4	458	11.0	810	19.3	597	14.4
1975	41,360	14.5	369	8.8	434	10.5	803	19.2	556	13.4
1974	40,179	14.1	424	10.4	443	11.0	867	21.4	573	14.3
1973	38,898	13.6	363	9.2	473	12.2	836	21.3	620	15.9
1972	40,860	14.2	414	10.0	578	14.1	992	24.0	731	17.9
1971	45,171	15.8	481	10.5	620	13.7	1,101	24.1	791	17.5
1970	48,406	17.1	480	9.8	733	15.1	1,213	24.8	908	18.8
1969	47,235	16.8	482	10.1	706	14.9	1,188	24.9	894	18.9

Live-Birth Rate Expressed per 1,000 Population
 Fetal & Perinatal Rate Expressed per 1,000 Events
 Neonatal & Infant Rate Expressed per 1,000 Births

PERINATAL CARE FACTORS by SELECTED MATERNAL CHARACTERISTICS
IOWA, 1980-81-82

	<18 YEARS	OUT-OF-WEDLOCK	NON-WHITE	TOTAL	LOW RISK
PERCENT OF VLBW	1.6	1.7	1.6	0.8	0.7
PERCENT OF LBW	8.9	8.8	9.5	4.9	3.8
TRIMESTER OF CARE					
FIRST	57.2	59.2	69.3	84.0	
SECOND	32.5	30.5	21.7	13.2	
THIRD	6.8	6.8	5.6	1.8	
NONE	1.6	1.9	1.0	.9	
NUMBER OF PRENATAL VISITS					
<3	18.3	19.5	17.3	6.7	
7+	80.0	78.3	80.0	92.0	

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FETAL, NEONATAL, PERINATAL and INFANT DEATH RATES by SELECTED MATERNAL CHARACTERISTICS
IOWA, 1980-81-82

	<18 YEARS	OUT-OF-WEDLOCK	NON-WHITE	TOTAL	LOW RISK
FETAL DEATH RATE	11.1	12.3	8.9	7.5	5.9
NEONATAL DEATH RATE	7.8	11.0	11.6	6.8	5.6
PERINATAL DEATH RATE	18.8	23.2	20.4	14.3	11.4
INFANT DEATH RATE	14.5	17.9	18.7	10.6	8.0

Recommendations of the Pregnancy and Health Work Group:

In order to improve the effectiveness of prevention services in Iowa, the Pregnancy and Health Work Group recommends the following:

1. Obtain funding to ensure that maternal and child health services, including support services, are readily available to all Iowans.

Action components:

- Involve the legislature in the process.
- Create a "Healthy Mothers-Healthy Babies" coalition.
- Involve state agencies directly in the planning and provision of prevention services; include ISDH, DHS, IDSA and the Commission on Children, Youth and Families.
- Initiate a grass roots campaign to emphasize public support for prevention efforts.
- Broaden focus on prevention beyond health agencies.
- Identify a permanent funding source for services.

2. Provide effective outreach programs that educate and motivate target populations to utilize services.

Action components:

- Integrate a family life and health curriculum in grades K-12.
- Identify and implement methods to promote improved self-concepts of target populations.
- Identify appropriate educational interfaces.
- Secure effective entry into the educational system by involving local school boards.
- Increase case finding and screening for high-risk pregnancy.

3. Assure that state and local decision makers will be well-informed.

Action components:

- Include decision makers as members of the Healthy Mothers-Healthy Babies Coalition.
- Involve decision makers in planning prevention initiatives.
- Educate legislators and government officials about prevention.
- Coordinate messages about prevention.
- Develop a maternal and child health board of consultants to formalize relationships between state agencies and be available to state agencies to advise on maternal and child health program planning and development to all state agencies.

4. Initiate comprehensive planning and coordination capabilities, including collection of basic information, resulting in the development and implementation of state and local prevention plans.

Action components:

- Convene a blue ribbon task force.
- Identify a coordinating board involving a cross-section of interest groups.
- Obtain accurate information regarding the prevalence of disability and the current status of prevention services.
- Include state and local agencies in coordinating efforts.

5. Promote change in societal attitudes which would lead to decreased substance abuse and increased healthy lifestyles.

Action components:

- Accumulate and transmit pertinent and believable information.
- Expand public school curriculum to include information and skill development in the content areas of substance abuse and health lifestyles.
- Utilize informed "peer helpers" in public schools.
- Identify and implement creative incentives for attitudinal change.
- Encourage parent groups to help young people avoid substance abuse and create healthy lifestyles.

Environmental Hazards Work Group:

Summary and Comments

Alfred Healy, M.D.

The Environmental Hazards Work Group on Prevention Services in Iowa identified the following five priorities:

- 1) Increase funding for environmental hazards research and management.
- 2) Increase political effectiveness in addressing environmental hazards policy.
- 3) Increase public awareness in reducing environmental hazards.
- 4) Increase personal involvement in reducing environmental hazards.
- 5) Reduce or remove economic barriers to toxic waste management.

The Environmental Hazards forum was attended by approximately 25 persons, including four work group members who presented papers. Each of these presentations lasted approximately 20 minutes with questions and discussion following each.

Presentations were made by:

Gus Horn, Iowa Department of Transportation
Subject: Seat restraints, helmets, and vehicular safety

Mary Ellis, Director, Iowa Department of Substance Abuse
Subject: Alcohol-related accidents

Larry Desch, M.D., Division of Developmental Disabilities
Subject: Environmental hazards including poisonings,
toxic chemicals, and accidents leading to
head injury

Dale Harding, M.D., Private practice of family medicine
Subject: Pesticides and herbicides

The topic area of environmental hazards and their contribution to the causation of developmental disabilities is a contemporary concern which produces much discussion and yet begs for a considerable increase in scientific fact. The correlation of vehicular accidents of persons riding motorcycles without the benefit of protective helmets and the occurrence of head injury is incontrovertible. The suspicion that increased use of

herbicides and pesticides is associated with the apparent increase in subtle learning disorders and major birth defects is far from proven. Each topic presented was significantly influenced by the bias of the presenter and it was apparent the reception of the data was significantly biased by the prior attitudinal set of the recipient.

It should be noted that a number of legitimate concerns for the Environmental Hazards forum -- such as drug ingestion during pregnancy or the effects of environmental irradiation on the fetus -- were presented and discussed in the Pregnancy and Health work group. In addition, the entire field of environmental risk secondary to raising a child in a non-stimulating or sensory-deprived environment was not approached in this forum, nor were the psychologic aspects of the environment the subject of any other forum or discussion section during the Conference.

Head and Spinal Cord Trauma

Accidents are the leading cause of death in children over four years of age. Accidents that do not cause death but permanent injury are also extremely common. Near-drowning, falls, electrical, chemical, and thermal burns all cause major loss of function and cosmetic disabilities.

Direct trauma to the head, whether resulting in closed (no fracture) or open (skull fracture) head injury has the potential to cause significant and permanent brain injury leading to a wide variety of sensory, motor, cognitive, and intellectual, as well as personal, social, and behavioral impairments. Speed, degree of trauma, protection, and the site of the trauma are important variables. Pedestrian, vehicular (auto, motorcycle, truck), pleasure seeking, (skiing, all terrain vehicles, skateboard, etc.), and industrial accidents all contribute a certain toll.

Spinal cord disability (quadriplegia or paraplegia) is due to an injury to the spinal cord and usually results from high-speed accidents. Diving, motorcycles, industrial, and skiing accidents all contribute to the incidence.

Poisoning

Poisonings are common in children, especially those under 3 years of age, and result from ingestion of household products, alcohol, petroleum products, and medications. Permanent disabilities result in a wide variety of functional problems. Poisoning of adults is less common, and permanent disability at this age from poisoning usually results from industrial/household accidents or unsuccessful suicide attempts.

Alcohol

Alcohol contributes to a wide variety of developmental disabilities, ranging from the fetal alcohol syndrome which results when a pregnant woman ingests alcohol during gestation, through the drunken driver who causes

permanent injury to him/herself or to others. A significant number of domestic conflicts resulting in permanent disability also are precipitated by excessive alcohol use.

Firearms

Head and spinal cord injuries are often firearm-related, especially in adolescent hunting accidents, and from robbery and aggravated assault attempts.

Herbicides, Pesticides and Fertilizers

Although many environmentally oriented groups of persons are concerned that herbicides, pesticides, and chemical fertilizers are causing birth defects through genetic and direct teratogenic effects on fetuses, there is little proven fact surrounding this issue. Agent Orange is a prime example of a concern based upon little scientific evidence. A growing body of indirect evidence, such as decreasing sperm counts in males and an increase in certain types of malignancies, is used by some to direct attention to a potential environmental concern that begs for resolution, that is, the association of these disorders with an increase in the use of pesticides, herbicides, fertilizers and other similar materials.

Many environmentalists are concerned that atmospheric and ground lead are major sources of direct toxicity to brain tissue, especially for younger children. Previously, the concern related mainly to lead-based paints found in unusual concentrations in old urban housing. The focus has now shifted to emissions from vehicles using gasoline enhanced with lead. The Federal Environmental Protection Agency originally issued regulations for the gradual elimination of lead in all gasoline products by 1988. There is the potential for a major confrontation concerning this issue, as many farmers and owners of older vehicles are dependent upon lead-enhanced gasoline.

Lesser Known or Potential Causes for Disabilities

Larry W. Desch, M.D.

In addition to the obvious causes for developmental disabilities, such as genetic conditions, there are a multitude of postnatal and prenatal insults to infants and children that can lead to, or are postulated to lead to, developmental disabilities. Non-motor vehicle accidents are one group in which the direct cause is head injury. These include injuries related to infant walkers, falls (stairs, farm accidents, horses), and sports injuries. The main problem with these in regard to recommending prevention activities is that very little has been done to study how commonly these injuries occur, especially in a non-urban area such as Iowa.

Accidental poisoning is also a potential cause of developmental disability, since children are the ones usually involved. Information is available about the numbers of children who die each year from poisonings but there appears to be little, if any, information about morbidity. Prevention activities are quite strong in this area despite this lack of information.

Environmental chemicals such as toxic industrial fumes or chemical waste are thought by many to be a potential cause of large numbers of birth defects or other developmental disabilities. However, as it stands now very little is known about the teratogenicity of most substances. In addition to birth defects, these substances may cause damage to the nervous system. The study of the effects that these substances may have on the developing nervous system is called "neuroteratology" or "neurobehavioral teratology." Further research may find these to be one of the causes of mental retardation.

A major concern for Iowa, since it is a rural state, is the effect that the residues of fertilizers, pesticides, and herbicides might have on a developing child. Studies are currently being done in Iowa and in other areas to better delineate what the hazards may be. It is important that these studies also address long-term outcome following exposure, as well as more immediate outcomes such as numbers of birth defects.

Lead has been studied for many years and there is suspicion that even low levels of lead poisoning can affect learning. Lead has not been identified to be much of a problem in Iowa since there is limited heavy industry and low natural lead levels. Local health departments have been assistive in alerting physicians and the public about the dangers of lead paint, especially in older houses. Other heavy metals, such as mercury -- which is an ingredient in dental amalgams -- are also being studied for their potential for causing developmental problems.

Recommendations of the Environmental Hazards Work Group:

In order to improve the effectiveness of Iowa's prevention service delivery system, the Environmental Hazards Work Group recommends the following:

1. Increase funding for environmental hazards research and management.

Action components:

- Involve high level government officials.
- Rally public support through information sharing.
- Use lobbying techniques proven effective in other legislative areas.
- Promote better research to document environmental problems and benefits.
- Use tax disincentives to discourage manufacturers from irresponsible toxic-waste disposal.

2. Increase political effectiveness in addressing environmental hazard policy.

Action components:

- Target lobbying effectively to specific legislators.
- Develop long-term goals and ensure that short-term solutions don't lead to additional problems.
- Invite politicians and press to prevention conferences.
- Secure services of professional lobbyist.
- Develop issues that the general public will support.

3. Increase public awareness about environmental hazards.

Action components:

- Include information about environmental hazards in public and professional education programs.
- Define solutions of specific problems through research.
- Use effective information dissemination and communication techniques.
- Set up state level office of health education.

4. Increase personal involvement in reducing environmental hazards.

Action components:

- Identify tangible benefits for individual citizens.
- Personalize public awareness strategies.
- Promote professional involvement.
- Create industry incentives.
- Emphasize wellness benefits.

5. Reduce or remove economic barriers to toxic waste management.

Action components:

- Obtain funding to determine alternate methods of toxic waste management.
- Tax manufacturers who produce toxic products.
- Encourage state and federal support of research grants.

Child Abuse Work Group:

Summary and Comments

Charles Abel, Ph.D.

The Child Abuse Work Group on Prevention Services in Iowa identified the following five priorities:

- 1) Increase funding for the provision of child abuse and neglect prevention services at all levels (local, state, national, public/private).
- 2) Reduce "turf protection" and improve coordination of services related to the provision of child abuse and neglect prevention services.
- 3) Improve the acceptability of parenting education in the schools.
- 4) Increase legislative support for the child abuse and neglect prevention area.
- 5) Improve the quality of child abuse and neglect prevention program evaluation.

Scope of the Problem

National: Approximately 4,000 children are killed each year in the United States as a result of child abuse and neglect. Child abuse and neglect is now the leading cause of death for children in this country, recently displacing automobile accidents from that distinction. Each year 1.7 million reports of child abuse and neglect are made nationally from a child population of 62.5 million, and over 40% of these reports are ultimately substantiated. Current national estimates are that by the age of eighteen, 25% of all females and 10% of all males will have been sexually abused. Few will have reported the abuse, and fewer still will have received effective therapy.

Iowa: The number of reports of child abuse and neglect has increased by 13% in Iowa in each of the last 2 years, totalling 16,463 reports in 1984. In 1984, nearly 30 out of every 1,000 Iowa children were reported as being abused or neglected. Approximately one-quarter of the children reported were officially determined to have been abused, neglected or both. In 1984 in Iowa, eight children were known to have died as a direct result of child abuse.

Child Abuse and Developmental Disabilities

Research has shown that children with a developmental disability are at risk for child abuse and neglect. Abused and neglected children are at risk for acquiring a developmental disability. Staff of the Child Development Clinic, Division of Developmental Disabilities, Department of Pediatrics, University of Iowa Hospitals and Clinics have found that 18% of abused and/or neglected children have a developmental disability as defined in PL 94-602.

With the passage of child abuse prevention legislation in 1983 and 1985, approximately \$330,000 is generated to support community child abuse prevention projects in Iowa each year. Under contract with the Iowa Department of Human Services, the Iowa Chapter of the National Committee for the Prevention of Child Abuse administers the above funds and provides prevention grants and technical assistance to communities which have organized councils to deal with child abuse and prevention activities. The Iowa Chapter of the National Committee of Child Abuse assists communities to develop child abuse councils which develop and implement their own child abuse prevention projects. Only those communities which have a child abuse council are eligible to receive prevention grant funds. There are currently 58 community child abuse councils in Iowa. The availability of this fiscal support and the growing number of child abuse prevention projects constitute major strengths in Iowa's child abuse prevention effort.

Despite the availability of limited prevention funds and the growing number of community child abuse councils, this work group identified a number of gaps which should be addressed:

- 1) Iowa spends approximately 6 million dollars each year to identify and treat child abuse and neglect. Given the increasing number of cases reported each year, it is apparent that more money is needed at all levels (local, state, national and private sources) for the provision of prevention services.
- 2) Because the problems of child abuse and neglect are community problems, they can only be solved at the community level. In order to achieve this goal, community prevention services must be coordinated to a larger extent than currently occurs, prevention service alternatives must be prioritized, and more involvement from larger numbers of individuals and local organizations is needed.
- 3) Research has shown that one of the causes of child abuse is parental ignorance of their child's needs at different ages and stages of development. This problem can be addressed through parenting education programs delivered to school-age children, to parents expecting a child, and to parents who already have children. A special effort needs to be made in improving the

acceptability of parenting education in Iowa's schools, as this has the potential to ultimately effect the largest number of Iowa's future parents. This could be achieved through increased involvement of PTA groups, school boards and other civic groups.

- 4) Given the obvious need to place a higher priority on prevention efforts, increased legislative support is necessary. Lobbying efforts should be increased which emphasize the cost benefits of prevention, the benefits to children, families, communities, society and taxpayers.
- 5) There is no question that we need to discover which prevention services are the most effective in preventing child abuse. Funds are needed to evaluate current and future prevention service programs. With this information, more cost-effective programming could be achieved.

Child Abuse and Developmental Disabilities

David Schor, M.D.

A marked increase in the reports of child abuse have served to focus attention on this nationwide problem.* One result of heightened public and professional awareness has been an increase in the number of official reports of child abuse, with the result that there are now more than 1.5 million children who are the subject of inquiry each year. In this country, the childhood death rate from abuse is now approximately equal to the childhood death rate following automobile accidents, about 4,000 children per year. Although the widespread enactment of mandatory child safety restraint laws may sharply reduce car-related death, we have yet to implement an effective strategy for reducing the death and disability caused by the physical abuse of children.

About 2% of all children will be severely or permanently injured as a result of abuse during childhood, abuse that results in long-term disability. Even when the abuse is most severe, the fact that the child's injuries are the result of child abuse will often go undetected. When child abuse is confirmed, the majority of children, if carefully evaluated, are found to have significantly impaired intellectual, physical, and/or psychological functioning. Unfortunately, many child abuse victims are not carefully monitored even after the abuse is known, which makes it difficult to calculate the true extent of developmental disability due to child abuse.

Henry Kempe acknowledged a connection between physical abuse and developmental disability in 1962, when he noted that 114 of 749 battered children (15%) suffered permanent brain damage, while an additional 110 children (15%) had died. This report led directly to the drafting of a model reporting law that, with modifications, now exists in all 50 states. Kempe's report also led to increased public willingness to permit state intervention on behalf of children in jeopardy.

As the result of Kempe's work and later research, we now know that child abuse often causes permanent developmental disability. The opposite association is also found: There is evidence that children with certain developmental disabilities (or other characteristics) are more likely to become abuse victims. Children born prematurely, those with physical handicaps or mental retardation, hyperactive children, or children whose behavioral styles match poorly with those of their parents are in these high-risk groups.

*References available from Dr. Schor. See also Appendix D.

It is simply more difficult to meet the needs of a "different" child, one whose behavior, appearance, or abilities do not match the expectations of parents, caregivers, friends or community members. The care of a child with disabilities is often physically, emotionally, and financially burdensome. Parents of handicapped children speak eloquently of the family stresses such disabilities may cause. Such stress may at times produce parental anger or guilt, which increases the potential for child abuse. At times of stress, the availability of a support system of professionals as well as friends and family can be particularly crucial. Respite care and other immediate intervention may avert child abuse. For these reasons, it is crucial that those who care for developmentally disabled children be aware of and sensitive to the factors which contribute to child abuse.

Iowa Child Abuse Prevention Program

Norm Ostbloom

The Iowa Child Abuse Prevention Program is in its third year of operation. Twenty-one funded projects, in both rural and urban communities throughout the state, vary in nature but share the common goal of preventing child abuse by affecting the factors known to be causes of child abuse. The services cover primary and/or secondary prevention. Primary prevention provides service to the general population, and includes lay health visitors, respite child care, and the prevention of sexual abuse. Secondary prevention provides services to identified groups of people who are considered to be at-risk for abusing their children. Secondary prevention activities include parent aide projects, support programs for young mothers, support for children from high risk families, and respite care for handicapped children. Some programs which combine primary and secondary prevention activities are available both to the general public and to persons at high risk who are referred from human service agencies. All projects are supported by local community council members, and include volunteer efforts in the delivery of these services.

Lay Health Visitor: The presence of a new baby creates stress in the family, and often inexperienced parents need support in their new role. The lay health visitor volunteer works with new families on a short-term basis, offering friendship, support, and information. Most projects also offer material on parenting, child development, and community resources. The goal of the lay health visitor project is to assist families to get off to a good start by providing needed information and support, therefore reducing the likelihood of child abuse.

Parent Aide: Parents who are at-risk for becoming abusive may have a variety of problems -- low self-esteem, lack of support, or difficulties with parenting. These parents are matched with trained volunteers who help with these problems, providing support and encouragement. Clients are encouraged to utilize all appropriate community resources to meet their goals. This program tries to prevent abuse by assisting clients in dealing with their problems, rather than venting their frustrations on their children.

Respite/Crisis Child Care: All parents need to have occasional time away from their children, but it is often difficult to find high quality, low-cost or free child care. Respite services fill this need. Services vary from those offered one or two times per week at a licensed facility, to those available 24 hours a day at day care homes, to those available to parents of disabled children in their own homes. Services encourage parents to utilize other community resources as well. The main goal of the respite care service is to reduce family stress, and in turn lessen the likelihood of child abuse, by providing parents with time away from their children.

Sexual Abuse Prevention: Child sexual abuse is a problem that affects an estimated one in four girls and one in seven boys before they reach the age of 18. Sexual abuse prevention projects teach children basic personal safety. These projects can be offered to any child, and make use of movies, theater presentations, coloring books, and small group discussion. This project is offered, as a primary prevention effort, to all children. Its main goal is to teach children the difference between good, bad, and confusing touching, and then to prepare them to deal effectively with each, in order to prevent sexual abuse from happening.

Support Programs for Children from High Risk Families: Children who have been abused or whose parents are at-risk for becoming abusive need support services. These support programs provide a trained volunteer to work with children on a one-to-one basis. The volunteer serves as a support and a role model for the child as they share recreational activities and work on mutually decided goals. The goal of this project is to prevent abuse from occurring, and to help the child learn appropriate, non-abusive ways to deal with life -- in essence to break the cycle of abuse which so often extends from one generation to the next.

Support Programs for Young Mothers: Teenaged women that have children are at-risk for becoming abusive. They often lack the skills, knowledge, support and maturity needed to care for a child. The support programs for young mothers are designed to meet these needs through group support and educational meetings, and/or one-to-one support by a trained volunteer. The goal of this program is to prevent abuse by providing education and support to these young women.

Toward Preventing Child Abuse and Neglect

Charles M. Abel, Ph.D.

Few could disagree that the problems of child abuse and neglect constitute a significant social problem in Iowa and all other states as well. Research has discovered that a significant number of children acquire a developmental disability as a result of being abused or neglected, and a large number of children who have a developmental disability are at risk of being abused or neglected. To address the problem of child abuse and neglect in Iowa, more effort is needed in the funding, delivery and evaluation of child abuse prevention services.

Funding: The state of Iowa spends over 6 million dollars each year to identify and treat child abuse. Despite the current \$330,000 available to fund community child abuse prevention programs, the number of reports of child abuse continues to increase as does the number of substantiated cases. If the level of child abuse in our state is to be reduced, additional prevention services will need to receive funding.

Prevention Service Delivery: Because the problem of child abuse can only be solved at the community level, more effort is needed to assist community leaders, civic organizations and professionals to band together to create community-level child abuse councils. While 58 such councils exist in Iowa, more are needed. If community-level prevention services are to be effective, child abuse councils will need to increase the level of citizen support, coordination of services and community ownership of these efforts.

Evaluations: The public has a vested interest in knowing whether prevention service programs are cost effective when such programs accept and use tax dollars. In addition, it is imperative that communities learn from other communities which prevention services are most successful. For these reasons, a higher priority must be placed on evaluating prevention service programs.

Conclusion: The problem of child abuse and neglect in Iowa not only impairs the growth and development of abused and neglected children and their families, but also reduces the quality of life for all communities, and for our society, as a whole. When child abuse prevention programs are successful, not only is child abuse itself reduced, but the health and well-being of our community, our state, and our nation is improved.

Recommendations of the Child Abuse Work Group:

In order to improve the effectiveness of prevention services in Iowa, the Child Abuse and Neglect Work Group recommends the following:

1. Increase funding for the provision of child abuse and neglect prevention services at all levels (local, state, national, public/private).

Action components:

- Improve the quality of prevention program evaluation.
- Increase grass roots organization.
- Create a prevention lobby.
- Support House File 451 Iowa Legislation (passed during 1985 Legislative Session).
- Increase solicited support from corporations.

2. Reduce "turf protection" and improve coordination of services related to the provision of child abuse and neglect prevention services.

Action components:

- Convene representatives from different agencies and have them prioritize prevention services.
- Broaden the involvement of individuals and organizations in the Iowa Chapter of the National Committee for the Prevention of Child Abuse and Neglect.
- Reduce confidentiality barriers between agencies.
- Make regional planning a contingency for funding.
- Compile a computerized statewide directory of prevention programs.

3. Improve the acceptability of parenting education in the schools.

Action components:

- Establish grass roots support.
- Encourage parent involvement in curriculum development.
- Offer choices in curricular content regarding value-laden issues.
- Increase PTA involvement.
- Develop marketing strategy to "sell" curriculum to school districts.

4. Increase legislative support for the child abuse and neglect prevention area.

Action components:

- Continually refine available research data.
- Emphasize cost-benefits of prevention.
- Broaden the constituency base.
- Intensify lobbying efforts.
- Teach people how to lobby.

5. Improve the quality of child abuse and neglect prevention program evaluation.

Action components:

- Provide funds for researchers to develop evaluation tools.
- Broaden the concept of evaluation.
- Develop evaluation and accreditation standards.
- Promote closer relationships between service providers and program evaluators.
- Identify what is being evaluated.

Education for Public and Professional Awareness Work Group:

Summary and Comments

Barbara Smith, M.S.

The Education for Public and Professional Awareness Work Group on Prevention Services in Iowa identified the following five priorities:

- 1) Elevate the priority given to prevention activities.
- 2) Address barriers, including relevant prevention information in primary and secondary education.
- 3) Increase the knowledge base and dissemination of evaluative information about the effectiveness of prevention activities.
- 4) Expand professional prevention expertise, including awareness of resources.
- 5) Develop educational initiatives which will contribute to professional and public awareness and the support of prevention activities.

The education group was convened 1) to identify barriers to the effective education of the public about the prevention of developmental disabilities; and 2) to suggest possible means to overcome these barriers. It was felt that many of the recommendations from the other working groups would also involve some element of education, whether it be the education of legislators to encourage their support of prevention legislation, or the education of the general public about family planning or prenatal care. For this reason, the education group decided to focus upon the actual Process of education, rather than the specific content of particular efforts, so that our recommendations would serve as a useful complement to those of the other working groups.

The education process was divided informally into elementary and secondary education, and higher education. First, there is clearly a need for broad public education to create public awareness of the means to prevent disabilities, not only to engage the public in prevention practices, such as in the use of seat belts or good prenatal care, but in the appreciation of the societal benefits of investing in prevention activities. Some of the basic elements involved in encouraging the adoption of new ideas were discussed. Among the important elements identified is the necessity to concretely specify desired actions, and to gear information to the level of interest of the receiver -- broad media coverage for initial information; meetings and personal contact as people prepare to make

decisions about changing their practices. Many examples were drawn from other campaigns dealing with health issues, such as the American Cancer Society's anti-smoking campaign, to illustrate the importance of knowing the audience well. What makes sense to a teenager may not make sense to a teacher or legislator.

Formal education, both in the colleges and in elementary and secondary schools, is seen as a critical focus for a broad range of prevention activities. While Iowa has a number of health curricula in use, none feature a particular component that addresses the issue of preventing disabilities. At the secondary and college levels especially, prevention is seldom stressed. The courses are often taught by people who have minimal familiarity with disabilities or disabilities prevention. Because most school programs are tightly structured, introducing a new curriculum or new curriculum components is often a difficult task.

Even in professional, specifically health-related curricula such as medicine, those professionals who could be most involved in prevention efforts often have little exposure to prevention content in their pre-service training. With the increasing need to keep physicians abreast of new technological developments, it becomes more and more difficult to ensure that medical students are introduced to prevention-related information. This is also true in other health-related curricula, as well as in teacher training curricula.

A second focus of the education group concerned the need to centralize prevention projects. Prevention activities in the state of Iowa need a "home," a central clearinghouse to serve as a resource for information, training and coordination of various prevention activities in the state. Because the subject of disabilities prevention is addressed by a diverse group of agencies and organizations existing at the local, state and national levels, it is difficult for the various objectives of these various groups to be brought together into a coherent prevention service delivery program. For example, the individual involved in environmental waste disposal may not be aware of health department efforts to monitor the occurrence of birth defects; the family life teacher may be interested in learning about new programs which are being used in other areas in the state to reach pregnant teenagers. In order for prevention education efforts to be successful, it is necessary for prevention programs to constructively acknowledge one another's goals and to continue to communicate with one another. A centralized prevention clearinghouse would greatly facilitate this process. In addition to serving as a link between programs, the clearinghouse could serve as a resource to locate experts and materials, and to provide current information for use in public awareness and formal educational programs.

A final concern addressed by education group members was their sense of the need to gather information, in order to formulate a more comprehensive view of the varied prevention activities currently in progress in Iowa, so that those involved could know more accurately where they fit into

the system as a whole. Additional information also needs to be gathered about program availability and effectiveness. The development of a state-approved prevention plan, and the designation of a formal body to oversee its implementation, would play an important role in this effort.

The Present Status of Iowa's Preventive Developmental Disabilities Education in the Medical Curriculum

Mark Albanese, Ph.D.

The purpose of this presentation was to discuss the present status of Preventive Developmental Disabilities education in the medical curriculum at the University of Iowa College of Medicine, and the various options for increasing its emphasis in undergraduate, graduate, and continuing medical education. Time for all topics in the undergraduate medical curriculum is very limited because of the large amount of material to be learned and the extreme rapidity with which new medical knowledge accumulates. As a result, the present status of preventive developmental disabilities education in the undergraduate medical curriculum is at best very limited, and is interspersed in a nonsystematic manner among numerous courses (e.g., Community Health, Pediatrics Clerkship, Obstetrics and Gynecology Clerkship).

To promote a more systematic and comprehensive education in the prevention of developmental disabilities at all levels of medical education, a recommendation was made to use an approach that was successful in adding to or enhancing other topics which are part of the medical curriculum (e.g., Preventive Cardiology and Transfusion Medicine). This approach consists of the allocation of additional funds targeted to develop the curriculum. These funds enable a faculty member who possesses an interest in the prevention of developmental disabilities to capture the time to develop and implement a preventive developmental disabilities curriculum. Ideally, this role would be perceived by faculty to be prestigious, perhaps through either a 50% salary support specifically earmarked for this person for 1-2 years or a 6- to 12-month developmental leave to establish the curriculum; followed by 25% salary support for an indefinite period to allow implementation. In addition, funds would be needed to provide adequate support personnel, including a half-time curriculum developmental specialist/coordinator and a quarter-time secretary to support these efforts. Finally, a small budget would be needed (\$5,000/year) for the acquisition and development of new educational materials.

This core group would be responsible for the systematic presentation and coordination of preventive developmental disabilities material throughout the undergraduate and graduate medical curriculum, as well as organizing/offering continuing medical education programs.

University and Secondary Education for Prevention of Developmental Disabilities

Jeanne Dixon, Ed.S.

Availability of Prevention Information

A listing of courses relevant to the prevention of developmental disabilities that are available at Iowa State University were distributed.

Of 439 public school districts in Iowa, 273 are defined as vocationally approved. One course in family living and one course in child development and parenting must be available to be vocationally approved.

It was noted that some information, outside of coursework, is also available at Iowa State University through the Student Counseling Service and the Student Health Service. Extension coursework in the prevention areas at the secondary level is provided by the Future Homemakers of America.

Adequacy of Prevention Information

A small number of faculty were surveyed by phone and asked to give their judgement of the adequacy of coverage of seven specific prevention topics in coursework for professional preparation in five human services areas. At Iowa State University, genetic screening and causes/prevention of accident and injury were judged to be least adequately covered. Potential development of disability from disease/prevention of disease was most often judged "adequately" covered.

In the high school curricula, prevention of high risk pregnancy, causes and prevention of prenatal complications, and causes and prevention of child abuse and neglect were all three judged to be "adequately" covered. Receiving more ratings of "marginal" were the topics of genetic screening, causes/prevention of accident and injury, and treatment/prevention of more severe developmental disabilities.

Barriers and Needs

The professionals'/faculty's thoughts about barriers to education for prevention of developmental disabilities and needs in the area of education to prevent developmental disabilities were presented (see the next page).

Needs in the area of education to prevent developmental disabilities:

- 1) More research of treatment and prevention strategies - what kind of educational programs are most effective?
- 2) More college-level courses and seminars in areas of prevention. Interdisciplinary seminars. Broader exposure of students to content at undergraduate level.
- 3) Support for higher level of education for all (a lower incidence of developmental disabilities is related to better education).
- 4) A mandated course at high school level in family life, child development, or health education, which includes information about prevention of developmental disabilities and where to seek help for children with developmental disabilities.
- 5) More space and funding in student health services to help address the desired goal of 50% preventative services.
- 6) General faculty and high school teachers involvement in and coordination of prevention education, with prevention information being integrated into existing courses as appropriate.
- 7) Mainstreamed or integrated educational components at all levels of education to heighten awareness of developmental disabilities.
- 8) Encourage more males to enroll in consumer and homemaking classes.

Barriers to education for prevention of developmental disabilities:

- 1) Education is traditionally geared to assessment and treatment of disability.
- 2) Lack of knowledgeable faculty (geared more to normal development).
- 3) Time limitations, other topics higher priority.
- 4) Resistance to having too many required courses (too specialized).
- 5) Lack of enrollment in courses dealing with prevention (general ed.).
- 6) Lack of administrative awareness and support for preventative measures in all fields.
- 7) In high school, more emphasis on academics, no time for electives.

Recommendations of the Education for Public and Professional Awareness Work Group:

In order to improve the effectiveness of prevention services in Iowa, the Education for Public and Professional Awareness Work Group recommends the following:

1. Elevate the priority given to prevention activities.

Action components:

- Establish a coordinating unit or "clearinghouse" for prevention information and action (i.e., Commission on Children, Youth and Families to serve as the umbrella group for a panel delineated by Developmental Disabilities Council to include representatives from government and private organizations).
- Obtain facts, including information about successful programs, which would be relevant to state and local legislators, and conduct ongoing targeted campaigns for prevention issues.
- Begin extensive newspaper and media campaign.
- Provide materials, training, and ongoing coordination in prevention for lobbying groups.

2. Address barriers to the inclusion of relevant prevention information in primary and secondary education (i.e., elective courses won't reach all students, prevention not seen as priority, teachers untrained).

Action components:

- Identify key individuals ("stake holders") influential in education and provide prevention education information on curriculum and policy (i.e., school boards, Area Education Agencies, teachers, DPI, PTA).
- Formulate needs statement for education.
- Research ways instructional materials and models are introduced into curriculum and implemented in local school districts.
- Expand community promotion of health education from kindergarten through twelfth grade.
- Explore possibilities for utilizing public health and school nurses in prevention education (contact DPI).
- Explore post-secondary course possibilities.

3. Increase the knowledge base and dissemination of evaluative information about the effectiveness of prevention activities (essential to planning educational programs).

Action component:

- Include evaluation as an integral component of the initial activity plan.
- Identify successful health initiatives passed by the Iowa Legislature.
- Have coordinating units disseminate program evaluation results through their information network.

- Involve personnel from other successful campaigns to help evaluate Iowa prevention activities.
 - Create summary publications containing problems and successes of other state prevention programs.
4. Expand professional prevention expertise, including awareness of resources.

Action components:

- Develop talent bank of peers who will take part in continuing education (coordinated through "Prevention Clearinghouse").
 - Use currently mandated continuing education directed toward the prevention of abuse as a vehicle for integrating prevention information.
 - Research alternative opportunities for reaching community professionals such as physicians, clergy, social workers, and nurses (i.e., video instruction).
 - Obtain funding for a person to do full-time prevention in-service education.
 - Require medical residents in family practice and pediatrics to participate in a community medicine rotation.
5. Develop educational initiatives which will contribute to professional and public awareness and the support of prevention activities.

Action components:

- Identify celebrities to take part in public service "spots."
- Work with state-level professional organizations to educate professional members of these organizations about prevention.
- Use "Prevention Clearinghouse" as a mechanism to include materials in existing professional and public fairs and conferences.
- Identify model school programs to be used as a resource and program model.
- Identify private industry and schools to include prevention information in their newsletters and bills to clients.

Concluding Remarks

Allen C. Crocker, M.D.

My comments at this point will be somewhat meandering and informal. First, several on procedure -- two that are tributes and one criticism. First of all, I am enormously impressed by the Nominal Group Technique process [see Appendix D]. It's nifty, I just cannot think of any other word. I have never seen it in action quite this effectively. It was also interesting to witness how compliant the groups were, so that I think the policy decision for this conference to use this method to sort through and get to some issues is to be acknowledged with appreciation. That was well done.

The second tribute I would like to pay is for what I consider to be inspired choices of the topical areas for the four work groups. I think to pick pregnancy and health, environmental hazards, child abuse and neglect, and education was very wise. I might say that within those topics, however, I have some mild disappointment about some of the content. For example, the environmental group was so brave as to be almost overwhelming, based on the paucity of real information in that territory. I admire your courage in the environmental area when you speak of all of the educational efforts you wish to make regarding the relationship between environment and developmental disabilities. But I find myself taking a deep breath because, gee, there are an awful lot of holes there in which we do not have the story ready to tell. We can pick off a few pieces to talk about, and those pieces should be covered well, but there are such large areas where we are not quite ready yet. Likewise, in the area of child abuse as it relates to developmental disabilities, it seemed to me in the times that I spent in that room the phrase kept coming out, "child abuse," which is fine and is a legitimate phrase, and an important one. But the "and neglect" component, the rest of the milder phases of the spectrum, did not seem to be given what I thought was fair attention. The harsher part of child abuse got so much attention while the more covert, subtler parts did not. Likewise, in the education group, I was disappointed that some of the existing materials, most notably what I consider well-conceived and successful curriculums developed by Sarah Litch in Ft. Wayne, Indiana, were not used as starting materials. The Fort Wayne materials are prototypic, and have been successfully used in a number of states, including Iowa.

The other element about the mechanics of the conference that could be spoken to would be the absence in your enrollment here of anybody at commissioner level or anybody from the legislature. This may have been done by real intent. If this is a working conference, and not meant to include exposure of your developing package yet, then I can accept this. But it is never too early to see if you can involve the people who are going to be at pivotal positions. I am gratified to find state agency personnel participating, and they probably are at the critical middle management level. However, if you do not include the commissioner somewhere along the line it can hold back progress. Enough on process!

I would like to take a couple of minutes to talk about feelings -- mine and yours. Prevention, as we mentioned at the opening of the conference, is that kind of a field. It has its own sort of upbeat implications to it, and I think a lot of us that give a good deal of attention to prevention have a quiet, personal stake in it. I had a number of feelings as I spent the last two days with you. One of them is that I was impressed by the earnestness of these groups. I think I was the only person who had a chance to visit every room. Each room, as I went into it, had a group of people sitting there with wonderful faces. They were serious, they were task-oriented, nobody was misbehaving, there were not even very many smiles. I do not know how you prepared your folk to be so good, but at any rate as I went around I had two thoughts: I said to myself, "Wow! These are nice people!" But that is characteristic of prevention groups. The second feeling I had was, "My God, it doesn't matter which room I'm in," because the topics were basically all the same. They all dealt with funding, with evaluation, with education, with lobbying. They had a commonality to them which was astonishing, and so I think it is fair to accept that, and maybe even celebrate it, because these are the ways humans get systems work done, and there is nothing wrong with that.

The other kind of feeling I had, as I went from room to room, was that I do not think you people are showing enough Iowa pride. I think you have some good stuff underway. Further, I think you have some special characteristics, most of which are assets, and I was disappointed not to hear Iowa analyzed more. I guess I came with a sort of a wistful feeling to want to know more about the state, to want to know how it can be done here that contrasts with Tennessee or Virginia or Massachusetts, and I did not hear very much about that. I would urge you to stand back and ask, "Okay, what is there about the way we can work the Iowa system for greater success?". It also might be worth pausing for a few minutes to ask what the priorities of the problems are in Iowa as opposed to Tennessee, Virginia, or Massachusetts, because I imagine some are higher and some are lower, life being what it is. But more specifically, you should ask what the prevailing passions of the population are, what the behavior of your legislature is, what your governor is like, and a few other items of that sort, which are going to be pertinent if you are going to get the Iowa job done.

So I confessed some of my feelings, namely my being impressed with your earnestness, with the way that you have perceived the commonality that runs through systems problem-solving, and your modesty about Iowa pride. I wonder whether some of you would be willing to share some of the feelings you have had -- your feeling about the field, your feeling about the assignment, and even the feeling about your personal justification for being here or for having a piece of the assignment as the job continues. Did anybody get angry? Did anybody have a conversion experience? Yes?

Audience member: I didn't have a conversion experience, but one of the things that has been on my mind is, down the road, assuming that we are successful in this state and other states are successful, one has to ask

the question about motives for preventing or eliminating developmental disabilities. The way science in other areas is going, during the next 20 to 25 years it will be possible and conceivable to prevent many developmental disabilities. Is science going to outstrip ethics in this area? How do we feel about the value of people who have developmental disabilities? I have heard people talk about the celebration of human beings and I am wondering where all that fits.

Dr. Crocker: You will remember, I quoted yesterday that "No Life can pompless pass away," in that the least of the lives are equally important to all the rest. I think that is a good point, and I might mention to you that in the Virginia report that I mentioned, one of the six main section headings was ethical issues, and this looked at motivations and collisions of rights and stakes all together. I am delighted that you have mentioned that.

Audience member: My overriding feeling throughout these two days has been great frustration with the emphasis placed on preventing the disability rather than on prevention of handicapping the disabled. That latter focus was not a high priority these two days from what I have heard. My other major frustration is in seeing parents as targets rather than as members of planning committees as resources. Parents are sometimes seen as part of the problem rather than part of the solution, and I think as long as we keep them a problem they are not going to become part of the solution.

Dr. Crocker: Excellent thoughts. You will remember item 13 of the "Thoughtful Thirteen" suggested that we can change incidence by changing how we feel about the disability, and hence the production of handicap.

Audience member: There was a significant amount of energy spent on intellectualizing the issues, in avoiding direct confrontations with the concrete solutions that either are or are not in place now. There was very little discussion about existing programs -- whether they are good and should be encouraged, or whether existing programs are not doing the job and should be discouraged or eliminated.

Dr. Crocker: In the pregnancy and health room I think they got closer to getting down to that.

Audience member: I came away with a feeling of responsibility. With few exceptions none of us are paid to be in the business of prevention per se, and before all these good ideas get going, it may mean going back and thinking, "What can I do in my job, within my job description, to work some prevention in and to keep that going?". That is one way to derive grass roots level support, from the people that are involved here.

Dr. Crocker: Did you ask yourself anything about why you came? Were you asked to come or did you almost set yourself up for getting into this group? I have often wanted to do a survey of why people do say, "Please

include me in prevention meetings." There is a set of reasons for it that are very personal, very real, and very valuable. As a matter of fact, a subset of my impression or feeling about the earnest people who were so well behaved in the work rooms was, "My God, what a resource that is, that this many people sat this still, and worked this hard for this period of time." It suggests that Iowa has some assets that are very precious.

Audience member: I had a feeling of disappointment. It was disappointment that we did not have more here, that we did not come to more concrete things. On the other hand, in thinking about that, my feeling is that this certainly does represent a starting place, that we should be talking about this being prevention planning meeting number 1, and that we should already be talking about how we are going to move ahead, so that next time we do have some of the decision makers present, so that we do have a broader representation, and that people are beginning to talk more specifically about action steps that need to be taken. And so it was a partial disappointment, but only partial.

Audience member: As I was driving down to Ames, I heard about Dr. DeVries doing another heart transplant, and I felt good that we were doing something good, equally important, in trying to prevent developmental disabilities. It may not be as glamorized, media-ized yet, but it feels good to be working on it. Another feeling I had as a pediatrician is that we are doing this and other groups are doing that; it was an eye-opening experience to sit among different professionals and get a realistic picture of how the position of doctors is viewed by the community. Disappointing, a lot of times. I think if there were more of us who would just participate in discussions like this and realize that what the public thinks about us as physicians, it would be helpful.

Dr. Crocker: This has indeed been an interdisciplinary experience, and I think quite characteristic of the prevention movement. It does tend to be truly interdisciplinary, and this is very healthy, and we need a few physicians to abuse during these meetings.

Audience member: I just wanted to make a comment as far as having legislators involved, that you need to consider the timing of your conference. You cannot hold it during the closing week of the legislative processes and have them attend. It probably would be better to have it before they convene in January.

Dr. Crocker: I have a few other remarks. I would suggest that in a time when the state does have pressures on it, you ought to integrate that reality into your plan-making and go particularly for some items that are likely to be winners, and not likely to be terribly costly. Go into planning these program goals with the notion that this can generate some experiences that will be useful. The three items that I would strongly suggest you consider for particularly prominent activity in the upcoming year would be:

- 1) The maternal serum alpha-fetoprotein screening potential.
- 2) The possibility for getting more developmental screening out of your EPSDT dollars. These are available to you and can be quite a practical way to get on with some pieces leading to secondary and even tertiary prevention efforts.
- 3) Look very critically at your prenatal services in the support of women who either are known to be at risk or are in a category of the population where the stakes are higher, the needs are greater.

Those three elements are relatively manageable in the sense of costs. In fact, the first two of them have reimbursement or direct funding that can be tapped, and the third can be built into your block grant to some degree, perhaps with state money supporting it as well.

I would urge further that you make one of your objectives the specific enunciation of an Iowa state plan. There is some kind of a fulfillment step involved in getting ideas and programs put into a plan, a plan that you are very proud of, a plan that you mean, and a plan that is based on the state of the art. Do not go too far in some corners that you have not got the data to work with (and there are an awful lot of pieces of the prevention world where we do not have the data yet), but get a plan out there. I would think you also need a timetable for the publication of the Iowa plan.

I think further that you should build into your prevention resolves something about a home for prevention. I think a specific location is very sensible, because Council projects tend to have a short life. You ought to have a visible center of interest for prevention, but be very careful where you put it. Go to work, explore this.

Iowa is a healthy state for discussion of prevention. I leave Iowa with a sense of encouragement. But I will tell you that I will be watching you.

Three short poems. The first deals with hope, and Emily wrote:

"Hope" is the thing with feathers -
 That perches in the soul -
 And sings the tune without the words -
 And never stops - at all -

And sweetest - in the Gale - is heard -
 And sore must be the storm -
 That could abash the little Bird
 That kept so many warm -

I've heard it in the chillest land -
 And on the strangest Sea -
 Yet, never, in Extremity,
 It asks a crumb - of Me.

Hope is appropriate in your work. The second one is only four lines. It suggests to you a posture as you approach the assignment of writing an Iowa state plan:

The gleam of an heroic Act
Such strange illumination

The Possible's slow fuse is lit
By the Imagination.

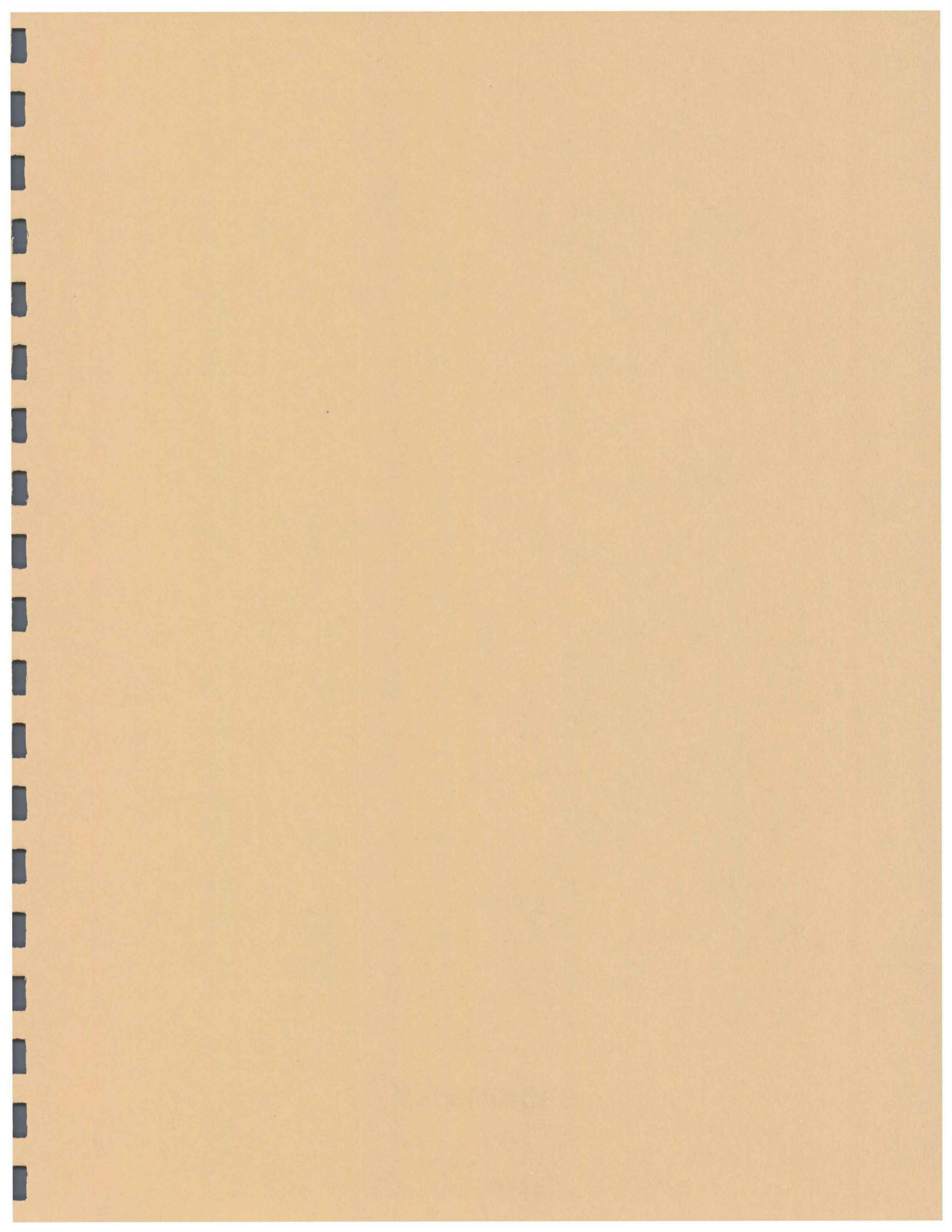
By which I mean to say, go for it! And the last poem may seem a little redundant:

If I can stop one Heart from breaking
I shall not live in vain
If I can ease one Life the Aching
Or cool one Pain

Or help one fainting Robin
Unto his Nest again
I shall not live in Vain.

People who care about prevention do not live in vain. Good wishes.

APPENDICES



Schematic Consideration of the MECHANISMS OF DEVELOPMENTAL DISABILITIES

(mental retardation, cerebral palsy, seizure disorders, sensory handicaps, etc.)

	% of total M.R. group (hospital referral experience)
<p>I. HEREDITARY DISORDERS:</p> <p style="margin-left: 2em;">Preconceptual origin, variable expression, multiple somatic effects, frequently a progressive course</p> <p style="margin-left: 2em;">A. <u>Inborn errors of metabolism</u> e.g. Tay-Sachs disease, Hurler disease, PKU</p> <p style="margin-left: 2em;">B. <u>Other single gene abnormalities</u> e.g. muscular dystrophy, neurofibromatosis, tuberous sclerosis</p> <p style="margin-left: 2em;">C. <u>Chromosomal aberrations</u>, including translocation</p> <p style="margin-left: 2em;">D. <u>Polygenic familial syndromes</u></p>	5
<p>II. EARLY ALTERATIONS OF EMBRYONIC DEVELOPMENT:</p> <p style="margin-left: 2em;">Sporadic events influencing embryogenesis, phenotypic changes, usually a stable developmental handicap</p> <p style="margin-left: 2em;">A. <u>Chromosomal changes</u>, including trisomy e.g. Down syndrome</p> <p style="margin-left: 2em;">B. <u>Prenatal influence syndromes</u> e.g. intrauterine infections, drugs, unknown forces</p>	32
<p>III. OTHER PREGNANCY PROBLEMS AND PERINATAL MORBIDITY:</p> <p style="margin-left: 2em;">Impingement on progress of fetus during last two trimesters or of newborn, neurologic abnormalities frequent, handicap stable or occasionally with increasing problems</p> <p style="margin-left: 2em;">A. <u>Fetal malnutrition/placental insufficiency</u></p> <p style="margin-left: 2em;">B. <u>Perinatal difficulties</u> e.g. prematurity, hypoxia, trauma</p>	11
<p>IV. ACQUIRED CHILDHOOD DISEASES:</p> <p style="margin-left: 2em;">Acute modification of developmental status, variable potential for functional recovery</p> <p style="margin-left: 2em;">A. <u>Infection</u> e.g. encephalitis, meningitis</p> <p style="margin-left: 2em;">B. <u>Cranial trauma</u></p> <p style="margin-left: 2em;">C. <u>Other</u> e.g. cardiac arrest, intoxications, etc.</p>	4

V. ENVIRONMENTAL AND BEHAVIORAL PROBLEMS: 18

Dynamic influences, operational throughout development,
commonly combined with other handicaps

- A. Psychosocial deprivation
- B. Parental neurosis, psychosis, character disorder
- C. Emotional and behavioral disorders
- D. Childhood psychosis, autism

VI. UNKNOWN CAUSES: 30

No definite hereditary, gestational, perinatal, acquired,
or environmental issues, or else multiple elements present

ACC

Data From

Developmental Evaluation Clinic, Children's Hospital, Boston

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**"THE GOLDEN TWENTY"
in Prevention of Mental Retardation**

Allen C. Crocker, M.D.

PRIMARY PREVENTION ACTIVITIES--which are designed to eliminate occurrence of the condition which causes handicap

1. RUBELLA IMMUNIZATION, to prevent congenital rubella and its attendant morbidity
2. IMPROVED PRENATAL CARE, with concern for the pregnancy at risk, including improved nutrition, management of diabetes, and prevention of prematurity
3. SPECIAL CARE FOR THE PREMATURE INFANT, exemplified by the pediatric specialty of neonatology, and the newborn intensive care unit
4. GENETIC COUNSELING for families in which there are known problems (such as Fragile-X syndrome, chromosomal translocations, phakomatoses, etc.)
5. ADVICE REGARDING ALCOHOL INTAKE DURING PREGNANCY, for prevention of the fetal alcohol syndrome
6. REDUCTION OF ENVIRONMENTAL EXPOSURE TO LEAD IN CHILDREN, as pertains both to lead intoxication and increased lead burden
7. PREVENTION OF KERNICTERUS by appropriate Rh-antibody testing and use of immunoglobulin
8. REDUCTION OF CHILDHOOD ACCIDENTS (HEAD INJURIES) by attention to effective restraint in automobiles and practices in the home
9. COUNSELING AND EDUCATION TO REDUCE PREGNANCY IN THE TEEN YEARS, with the attendant increased obstetric and social risks
10. EFFORTS TO DECREASE CHILD NEGLECT AND ABUSE, utilizing support, education, and surveillance
11. HEALTH AND NUTRITION EDUCATION designed to promote preventive and anticipatory care of children

SECONDARY PREVENTION ACTIVITIES--with early identification of a relevant condition, and then intervention to avert an outcome with retardation

12. SCREENING OF NEWBORN INFANTS FOR TREATABLE INBORN ERRORS OF METABOLISM, with particular reference to PKU and galactosemia
13. NEWBORN SCREENING FOR CONGENITAL HYPOTHYROIDISM, followed by replacement therapy
14. AMNIOCENTESIS IN CIRCUMSTANCES OF ADVANCED MATERNAL AGE, for prenatal diagnosis of chromosomal disorders (particularly trisomy 21), with a potential for pregnancy interruption
15. SCREENING OF MATERNAL SERUM FOR ELEVATED ALPHA-FETOPROTEIN LEVEL, as an index of neural tube defects
16. CARRIER IDENTIFICATION IN GENETIC CONDITIONS, especially Tay-sachs disease, to allow counseling regarding pregnancy

TERTIARY PREVENTION ACTIVITIES--which bring particular supports to children and families with ascertained problems, to minimize long-term disability and prevent complications

17. EARLY IDENTIFICATION, WITH ACCOMPANYING INTERVENTION AND STIMULATION, in situations such as prematurity, deafness, and Down syndrome
18. EFFECTIVE CONTINUING PROVISION OF SERVICES TO FAMILIES OF CHILDREN WITH DISABILITIES, to promote progress of the child and integration of the family

BASIC ACTIVITIES WHICH BEAR ON THE ULTIMATE POTENTIAL FOR SUCCESS IN PREVENTION EFFORTS

19. CONTINUING RESEARCH REGARDING THE CAUSATION OF RETARDATION, so that a better understanding exists of the contributing factors
20. EDUCATION OF PHYSICIANS AND OTHER HEALTH PROFESSIONALS regarding the measures available to prevent retardation and disability

DEVELOPMENTAL DISABILITIES AND CHILD ABUSE**David Schor, M.D.**

Correlations between physical abuse and developmental disabilities were first noted in 1962, in Kempe's description of the "battered child syndrome," which recorded that 114 of 749 battered children (15%) suffered permanent brain damage.* Shortly thereafter, the president of the American Academy for Cerebral Palsy, noting that abused children had a high frequency of head injury and subnormal cognitive functioning, stressed the need for the early identification of the developmentally delayed abused child in order to prevent or ameliorate the serious neuromotor dysfunction which can result from physical abuse. Since the 1960's, further research has studied the relationship between child abuse and developmental disability.

Severe brain injury is known to cause long-term effects regardless of whether the injury is caused by accident or intent. A study of 36 children rendered unconscious for over twenty-four hours as a result of injury found that 4 to 10 years after the injury, 8 children (22%) were "educationally subnormal" and 9 more were doing poorly in school. The length of the child's state of unconsciousness appeared to be the best predictor of poor school performance, although for some patients even a brief coma was related to later, significant cognitive defects. Predicting the outcome of head injury in individual cases is difficult; more reliable results occur when the assessment is based on the best level of functioning several hours after injury.

Among severely retarded individuals, some show histories of trauma severe enough to have caused the retardation. A study of 436 mentally retarded individuals found 65 (15%) who showed evidence of abuse prior to the onset of mental retardation; evidence suggesting that abuse or neglect caused the mental retardation existed for 24 individuals. A survey of 140 children in "subnormality hospitals" in England disclosed that 31 children (22%) had been abused prior to institutionalization. Seventy-five percent of the abused had been abused habitually; for 4 children, this was definitely the cause for the mental handicap, while in 12 more children the abuse was probably responsible.

Some effects of severe head injury in children are soon evident, regardless of the etiology; these include cessation or drastic slowing of normal development. Other events which may cause brain damage and neurologic abnormalities are frequently overlooked because of the inapparent nature or gradual onset of the abnormality. The vigorous shaking of infants has produced retardation and cessation of head growth,

*References available from Dr. Schor.

for example. Shaking usually produces few external signs, but according to Caffey it may be responsible for a significant proportion of mental retardation of unknown etiology.

Early studies of the development of abused children focused on the severely injured child, typically the child with fractures as a result of physical abuse. Twenty children with abuse-related bone injury, who did not require institutionalization, participated in assessments about five years after the injury. Eighteen children (90%) had problems in one or more of the following areas: intelligence quotient (IQ) less than 80, emotional disability, speech problems, or poor growth. Another study by the same authors reported 11 of 26 abused children (44%) with bone injuries were retarded in development compared to 18% of a group of children with accidental injuries. A study of abused children requiring hospitalization found that one-third had mental retardation or cerebral palsy.

Other studies have now begun to investigate the outcome of less severe forms of the abuse and neglect. An abused nine-month-old child showed abnormalities suggesting a neurologic disorder on admission to a hospital (increased muscle tone and reflexes, easily startled), which disappeared without neurological treatment. In a group of 21 abused or neglected children on whom detailed developmental information was available three years after initial assessment, 9 were mentally retarded and 6 emotionally disturbed. The authors felt that possibly 8 of the 9 retarded children were retarded prior to the abuse. A follow-up study which explicitly included "mild cases" of abuse found that 14 of 42 physically abused children (33%) were "functionally retarded," and 18 (43%) had neurologic damage (overt in 12, minimal in 6). In another study, abused children with head trauma had poorer psychosocial skills and relatively weaker language skills than those without head injury. A study comparing abused infants with infants accidentally injured and with infants not injured (all groups matched for age, race, socio-economic status and other factors), however, found few differences eight years after the injury. All three groups had low rates of cognitive development and a high incidence of emotional difficulties. The investigators found that lower socio-economic status and frequent exposure to violence in the home were common in all three groups and hypothesized that these factors were closely related to the developmental abnormalities. A study matching abused children (without head trauma or neglect) with non-abused clinic patients found differences in overall development and specific deficits in language and gross motor skills; significant behavioral concerns were not found.

Investigations of children with failure to thrive (poor physical growth compared to statistical norms) have revealed long-lasting developmental problems in some children with nonorganic failure to thrive--that is, children who had no medical conditions sufficient to explain their relative growth failure. An early study described the status of 40 such children about three years after initial diagnosis. Seventeen (42%) were still small. Psychiatric or behavioral disorders occurred in 11 (28%). Significant school problems occurred in 7 of the 19 children who were of

school age (37%). Six (15%) were "clinically" retarded; three had IQ scores less than 70 and three more had scores between 70 and 80. Their skills were unevenly developed. Although one-third of the families showed severe social pathology, one-third of the children had no detectable abnormality by psychiatric, psychological, or physical assessment. Another follow-up study of 21 children some six years after diagnosis found personality abnormalities as determined by teacher ratings in 10 children (48%). Fourteen (67%) functioned one or two years behind their chronological age on a vocabulary test, although only 3 of the 14 children given a standardized intelligence test (21%) had an IQ less than 90.

Some investigators have examined in detail the way in which abusing parents view their children. In one study of parents' general family concerns, parents of abused children tended to focus on negative characteristics of their children, while parents of accident victims spoke of disrupted schedules, economic stress, and fatigue. Children doing well on follow-up after abuse tended to be described by their parents as affectionate and causing no problems in management; this contrasted sharply with abused children having subsequent emotional developmental problems, who tended to be described as "different" by their parents. In one of the previously described studies of children with failure to thrive, the parents complained of a variety of problems with their children including lying, temper tantrums, overactivity, bed wetting, and speech problems. Many of these parents had emotional problems of their own and complained of "nerves" and depression. Could some of the differences reported by the parents be a result of the parents' own problems? Or were some abused children truly different and likely to present a challenge to even the most capable parent? One study suggested that few abused children had been difficult from birth (3 of 42, or 7%). An earlier report found significant medical problems in 9 of 20 severely abused children (45%). In another study, nearly 70% of 101 physically abused children were said to have shown abnormalities in development or physical handicaps before they were abused. In 1974, 1,680 of 14,083 abused or neglected children were found to have "distinguishing characteristics" in a national survey. The distinguishing characteristics included 288 with mental retardation, 234 with handicaps, 250 with chronic illnesses, and 180 with birth defects.

Certain behaviors of children appear to render them more susceptible to being abused. In a nationwide survey done in 1967 of circumstances surrounding physical abuse of children, Gil reported that 29% of 5,993 children came from families with deviation in social interactions and general functioning. Closer examination of some of these cases revealed that a social worker assessment of hyperactivity or high-annoyance potential in the child occurred in 24% of the cases, with "misconduct" of the child identified in 22%. Social worker assessments showed a similar percentage of abused children to have "uncontrollable" behaviors or tantrums in another study. Perhaps the "difficult" infant (e.g., overactive, unresponsive, difficult to feed, or having a high-pitched, annoying cry) becomes the aggressive or hyperactive toddler and preschooler, whose tantrums and unresponsiveness to discipline produce

anger and frustration in parents. A generally accepted model is that children viewed as "special" by their parents (who themselves had perhaps been abused as children or exposed to violence) were more likely to be abused, especially if the family were undergoing chronic or acute stress. The target of abuse was more likely to be a child with disabilities; one professional knowledgeable in both developmental disabilities and child abuse noted that the care of the handicapped child was often physically, emotionally, and financially taxing--circumstances that often produced anger and guilt in the parent with a corresponding increase in potential for abuse--and stressed the need for the helping professional to provide empathic support and to arrange for respite care at times of crisis for the family.

Gradually, certain kinds of children have been recognized as more likely to be abused. These include children who are physically disabled or retarded, hyperactive or overactive, and the children whose temperament and behaviors match poorly with those of their parents. The premature and sick newborns whose early interactions with their parents were disrupted are also found to be more susceptible to abuse (in one study, the crying of prematures was rated as more "disagreeable" to adults).

The developmentally disabled or otherwise atypical child is more likely to be abused, and the abused child is more likely to have developmental disabilities. It is often difficult or impossible to sort out the cause-and-effect relationship among abuse and neglect and developmental disabilities. It appears likely, however, that appropriate interventions can increase the prospect for healthy physical and psychological growth.

THE NOMINAL GROUP TECHNIQUE (NGT) FACILITATION MODEL

The group problem solving model we used during the working sessions of the prevention conference is called the Nominal Group Technique or NGT. In a "nominal group process," people work in the presence of others in small groups, but write down ideas independently, rather than talking about them, in order to make decisions. The NGT technique was chosen for the working sessions of the conference because it has been demonstrated as a superior method of generating ideas and information relevant to problems. (For purposes of reaching consensus, team building and attitude change, interacting groups have been identified as superior.)

As described by Delbecq in Group Techniques for Program Planning:

NGT is a structured group meeting which follows a prescribed sequence of problem-solving steps. The NGT process includes a number of characteristics which facilitate decision-making performance:

- 1) Low variability among groups in member and leader behavior leads to consistency in decision making.
- 2) A balanced concern for social-emotional group maintenance roles and performance of task-instrumental roles offers both social reinforcement and task accomplishment reward to group members.
- 3) The silent independent generation of ideas, followed by further thought and listening during the round-robin procedure, results in a high quantity of ideas.
- 4) Search behavior is proactive, characterized by extended periods in generating and clarifying alternative dimensions of the problem, tendencies for high task-centered group effort, and the generation of new social and task-related knowledge.
- 5) The structured process forces equality of participation among members in generating information on the problem.
- 6) NGT meetings tend to conclude with a perceived sense of closure, accomplishment, and interest in future phases of problem solving.

This is a detailed way of stating that the emphasis in the NGT process is on generating ideas rather than on information dissemination, lobbying for special interests, or promoting consensus.

With the positive characteristics of NGT the authors identify the following difficulties:

- 1) Extended preparation for NGT meetings is necessary to clearly identify the information desired from a group, and to provide the necessary supplies. NGT, therefore, is not a spontaneous group meeting technique.
- 2) Inflexibility of the structured NGT format makes it difficult to make adjustments or to change topics in the middle of a meeting. NGT is generally limited, therefore, to a single-purpose, single-topic meeting.
- 3) Conforming behavior to a structured format is required on the part of all participants, a condition which is not immediately comfortable to inexperienced participants.

Source: Delbecq, A.L.; Van de Ven, A.H.; and Gustafson, D.H. Group Techniques For Program Planning: A Guide to Nominal Group and Delphi Processes, Glenview, Illinois: Scott, Foresman and Company.

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PREVENTION CONFERENCE RECOMMENDATIONS

Summary of Barriers to the Provision of Appropriate Developmental Disabilities Prevention Services in Iowa

Work groups at the April 10-11, 1985 Prevention Conference held in Ames, Iowa identified the following barriers to the effective delivery of appropriate developmental disabilities prevention services in Iowa:

Environmental Hazards

- Insufficient funds.
- Ineffective political involvement.
- Low level of public awareness.
- Too many economic barriers to toxic waste management.

Pregnancy and Health

- Insufficient funds.
- Inadequate outreach activities.
- Poorly informed decision makers.
- Lack of planning and coordination.
- Deleterious public attitude regarding substance abuse and lifestyle.

Child Abuse and Neglect

- Insufficient funds.
- "Turf" battles and lack of coordination between program providers.
- Inadequate parenting education in public schools.
- Legislative support not a priority.
- Problems with program evaluation.

Education

- Prevention not given high enough priority.
- Significant system issues inhibiting integration of prevention information in curriculum of public schools (elective courses, decreased priority, untrained teachers).
- Insufficient evaluative information resulting in limited number of educational programs.
- Not enough professional expertise regarding prevention services and referral to community services.
- Insufficient number of educational initiatives.

Environmental Hazards

In order to improve the effectiveness of Iowa's prevention service delivery system, the Environmental Hazards Work Group recommends the following:

1. Increase funding for environmental hazards research and management.

Action components:

- Involve high level government officials.
- Rally public support through information sharing.
- Use lobbying techniques proven effective in other legislative areas.
- Promote better research to document environmental problems and benefits.
- Use tax disincentives to discourage manufacturers from irresponsible toxic-waste disposal.

2. Increase political effectiveness in addressing environmental hazard policy.

Action components:

- Target lobbying effectively to specific legislators.
- Develop long-term goals and ensure that short-term solutions don't lead to problems.
- Invite politicians and press to prevention conferences.
- Secure services of professional lobbyist.
- Develop issues that the general public will support.

3. Increase public awareness about environmental hazards.

Action components:

- Include information about environmental hazards in public and professional education programs.
- Define solutions of specific problems through research.
- Use effective information dissemination and communication techniques.
- Set up state level office of health education.

4. Increase personal involvement in reducing environmental hazards.

Action components:

- Identify tangible benefits for individual citizens.
- Personalize public awareness strategies.
- Promote professional involvement.
- Create industry incentives.
- Emphasize wellness benefits.

5. Reduce or remove economic barriers to toxic waste management.

Action components:

- Obtain funding to determine alternate methods of toxic waste management.
- Tax manufacturers who produce toxic products.
- Encourage state and federal support of research grants.

Pregnancy and Health

In order to improve the effectiveness of prevention services in Iowa, the Pregnancy and Health Work Group recommends the following:

1. Obtain funding to ensure that maternal and child health services, including support services, are readily available to all Iowans.

Action components:

- Involve the legislature in the process.
- Create a "Healthy Mothers-Healthy Babies" coalition.
- Involve state agencies directly in the planning and provision of prevention services; include ISDH, DHS, IDSA and the Commission on Children, Youth and Families.
- Initiate a grass roots campaign to emphasize public support for prevention efforts.
- Broaden focus on prevention beyond health agencies.
- Identify a permanent funding source for services.

2. Provide effective outreach programs that educate and motivate target populations to utilize services.

Action components:

- Integrate a family life and health curriculum in grades K-12.
- Identify and implement methods to promote improved self-concepts of target populations.
- Identify appropriate educational interfaces.
- Secure effective entry into the educational system by involving local school boards.
- Increase case finding and screening for high-risk pregnancy.

3. Assure that state and local decision makers will be well-informed.

Action components:

- Include decision makers as members of the Healthy Mothers-Healthy Babies Coalition.
- Involve decision makers in planning prevention initiatives.
- Educate legislators and government officials about prevention.
- Coordinate messages about prevention.
- Develop a maternal and child health board of consultants to formalize relationships between state agencies and be available to state agencies to advise on maternal and child health program planning and development to all state agencies.

4. Initiate comprehensive planning and coordination capabilities, including collection of basic information, resulting in the development and implementation of state and local prevention plans.

Action components:

- Convene a blue ribbon task force.
- Identify a coordinating board involving a cross-section of interest groups.
- Obtain accurate information regarding the prevalence of disability and the current status of prevention services.
- Include state and local agencies in coordinating efforts.

5. Promote change in societal attitudes which would lead to decreased substance abuse and increased healthy lifestyles.

Action components:

- Accumulate and transmit pertinent and believable information.
- Expand public school curriculum to include information and skill development in the content areas of substance abuse and healthy lifestyles.
- Utilize informed "peer helpers" in public schools.
- Identify and implement creative incentives for attitudinal change.
- Encourage parent groups to help young people avoid substance abuse and create healthy lifestyles.

Child Abuse and Neglect

In order to improve the effectiveness of prevention services in Iowa, the Child Abuse and Neglect Work Group recommends the following:

1. Increase funding for the provision of child abuse and neglect prevention services at all levels (local, state, national - public/private).

Action components:

- Improve the quality of prevention program evaluation.
- Increase grass roots organization.
- Create a prevention lobby.
- Support House File 451 Iowa Legislation (Passed during 1985 Legislative Session).
- Increase solicited support from corporations.

2. Reduce "turf protection" and improve coordination of services related to the provision of child abuse and neglect prevention services.

Action components:

- Convene representatives from different agencies and have them prioritize prevention services.
- Broaden the involvement of individuals and organizations in the Iowa Chapter of the National Committee for the Prevention of Child Abuse and Neglect.
- Reduce confidentiality barriers between agencies.
- Make regional planning a contingency for funding.
- Compile a computerized statewide directory of prevention programs.

3. Improve the acceptability of parenting education in the schools.

Action components:

- Establish grass roots support.
- Encourage parent involvement in curriculum development.
- Offer choices in curricular content regarding value-laddened issues.
- Increase PTA involvement.
- Develop marketing strategy to "sell" curriculum to school districts.

4. Increase legislative support for the child abuse and neglect prevention area.

Action components:

- Continually refine available research data.
- Emphasize cost-benefits of prevention.
- Broaden the constituency base.
- Intensify lobbying efforts.
- Teach people how to lobby.

5. Improve the quality of child abuse and neglect prevention program evaluation.

Action components:

- Provide funds for researchers to develop evaluation tools.
- Broaden the concept of evaluation.
- Develop evaluation and accreditation standards.
- Promote closer relationships between service providers and program evaluators.
- Identify what is being evaluated.

Education for Public and Professional Awareness

In order to improve the effectiveness of prevention services in Iowa, the Education for Public and Professional Awareness Work Group recommends the following:

1. Elevate the priority given to prevention activities.

Action components:

- Establish a coordinating unit or "clearinghouse" for prevention information and action (i.e., Commission on Children, Youth and Families to umbrella a panel delineated by DD Council to include representatives from government and private organizations).
- Obtain facts, including information about successful programs, which would be relevant to state and local legislators and conduct ongoing targeted campaigns for prevention issues.
- Begin extensive newspaper and media campaign.
- Provide materials, training, and ongoing coordination in prevention for lobbying groups.

2. Address barriers to include relevant prevention information in primary and secondary education (i.e., elective courses won't reach all students, prevention not seen as priority, teachers untrained).

Action components:

- Identify key individuals ("stake holders") influential in education and provide prevention education information on curriculum and policy (i.e., school boards, AEA's, teachers, DPI, PTA).
- Formulate needs statement for education.
- Research ways instructional materials and models are introduced into curriculum and implemented in local school districts.
- Expand community promotion of K-12 health education.
- Explore possibilities for utilizing public health and school nurses in prevention education (contact DPI).
- Explore post-secondary course possibilities.

3. Increase the knowledge base and dissemination of evaluative information about the effectiveness of prevention activities (essential to planning educational programs).

Action component:

- Include evaluation as an integral component of the initial activity plan.
- Identify successful health initiatives passed by the Iowa Legislature.
- Have coordinating units disseminate program evaluation results through their information network.
- Involve personnel from other successful campaigns to help evaluate Iowa prevention activities.
- Create summary publications containing problems and successes of other state prevention programs.

4. Expand professional prevention expertise, including awareness of resources.

Action components:

- Develop talent bank of peers who will take part in CEU education (coordinated through "Prevention Clearinghouse").
 - Use currently mandated abuse prevention CEU's as a vehicle for integrating prevention information.
 - Research alternative opportunities for reaching community professionals such as physicians, clergy, social workers, and nurses (i.e., video instruction).
 - Obtain funding for a person to do full-time prevention in-service education.
 - Require medical residents in family practice and pediatrics to participate in a community medicine rotation.
5. Develop educational initiatives which will contribute to professional and public awareness and the support of prevention activities.

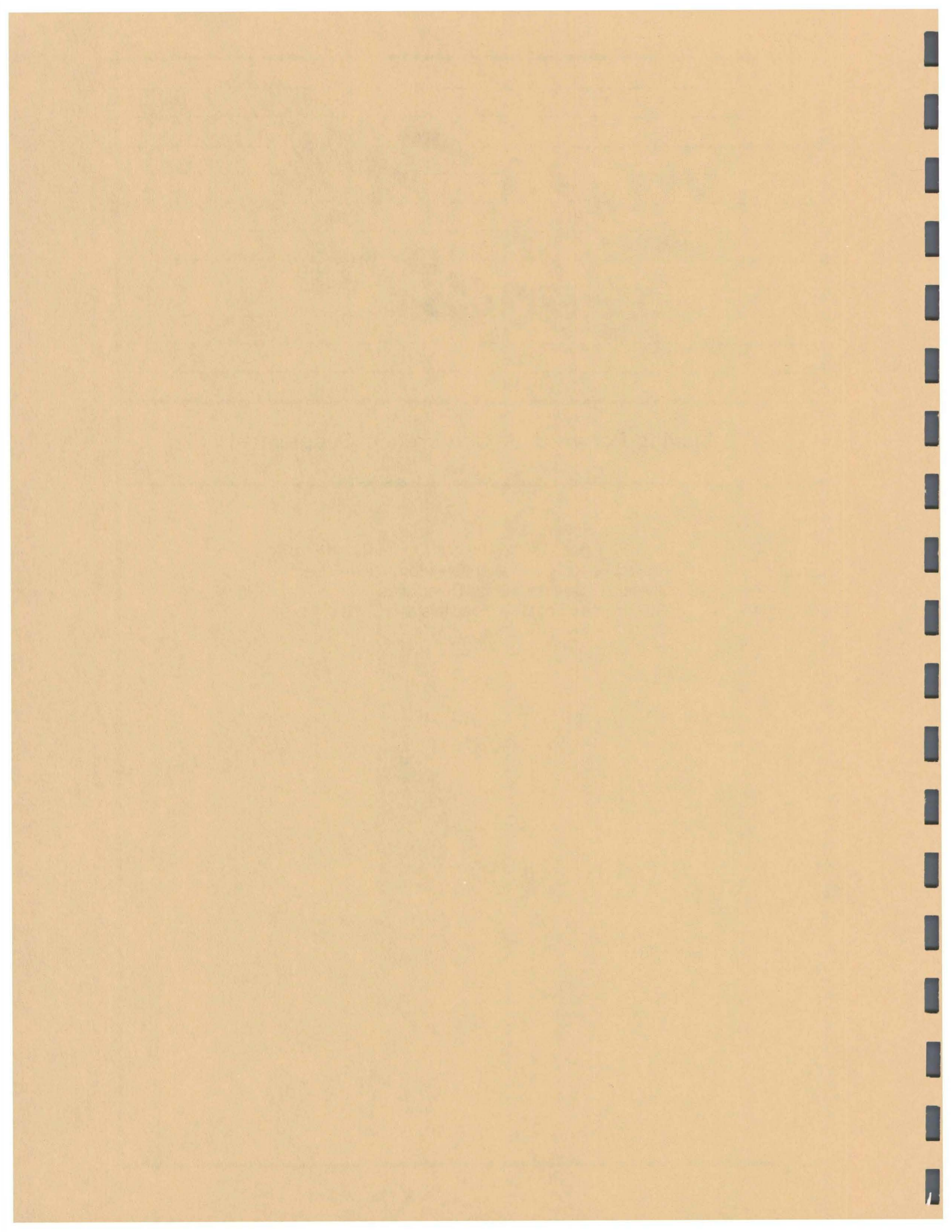
Action components:

- Identify celebrities to take part in public service "spots".
- Work with state level professional organizations to educate professional members of these organizations about prevention.
- Use "Prevention Clearinghouse" as a mechanism to include materials in existing professional and public fairs and conferences.
- Identify model school programs to be used as a resource and program model.
- Identify private industry and schools to include prevention information in their newsletters and bills to clients.

"Let's Talk About It"

Moving Forward: A Conference Supplement

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Moving Forward: A Conference Supplement

Introduction

This document is included as a supplement to the Prevention Conference Proceedings, in order to assist communities which wish to develop expanded, community-based prevention activities. As more emphasis is placed on the prevention of developmental disabilities, policymakers will be required to evaluate how this new emphasis will influence the service system which currently provides generic prevention services, and to assess whether the current service system is adequately addressing the needs of populations at risk for developmental disabilities. The success of prevention programs ultimately depends on appropriate referral and individual access to available services. It is therefore imperative that the development of prevention initiatives occur within communities, in coordination with regional, state, and national programs. This supplement is designed to facilitate policy and program development at the community level.

The first two papers in the "Let's Talk About It" series [1] provided basic information on developmental disabilities prevention and reviewed some of the pertinent issues that need to be considered in developing effective prevention programs in Iowa. These papers:

- 1) Introduced the concept of prevention as it relates to reducing or ameliorating the impact of developmental disabilities; defining primary, secondary, and tertiary levels of prevention activities; and describing prevention during prenatal, perinatal, infancy and childhood time frames.
- 2) Identified methods for assessing program effectiveness while acknowledging the complexity of this process and the inadequacy of current measurement procedures.
- 3) Emphasized the necessity for multilevel, coordinated prevention activities.

[1] Schor, D.: The Prevention of Developmental Disabilities in Iowa: Issues and Effects; and Howe, R.: An Overview of the Evolving Developmental Disabilities Prevention Service System, in "Let's Talk About It": A Resource and Training Manual on the Prevention of Developmental Disabilities. Iowa City: Division of Developmental Disabilities, 1984.

- 4) Identified the difficulties inherent in justifying prevention program expenses to funding agencies and community taxpayers, when the rewards may not be immediate or visible.
- 5) Discussed the individual and social influences which affect the development and effectiveness of prevention programs, and current challenges to the present service system.
- 6) Reviewed the historical context of prevention program development.
- 7) Briefly reviewed the status of prevention activities and extant gaps in current prevention programming in Iowa.

In 1984, the Prevention Task Force of the Iowa Governor's Planning Council for Developmental Disabilities identified four factors necessary for effective prevention programs in Iowa: 1) the need for accurate information on the incidence and prevalence of developmental disabilities; 2) more effective linkages between prevention resources; 3) adequate access to services for "at-risk" populations; and 4) publication of a long range state plan for prevention program development.

In April 1985, the Governor's Council sponsored the statewide Prevention Conference held in Ames, Iowa. The recommendations resulting from this conference confirm the four program needs identified above. In addition, the recommendations provide an informed outline of considerations which prevention programs must address in the planning, implementation, and promotion of successful prevention program initiatives. Most of these recommendations relate to the competent administration of prevention programs, and generally do not address issues related to the identification of the service needs of targeted, at-risk populations, the status of current program effectiveness, or the need for program expansion.

Information included in the panel presentations reveals that several specific sub-groups of Iowa's population are at a higher risk for disabilities. Examples included in data presented by Ted Scurletis, M.D., of the Iowa State Department of Health, indicate that children born to women who are less than 18 years old, nonwhite, or who have conceived out of wedlock, have neonatal mortality outcomes twice that of children born to women not in these risk categories; that these children are also two to three times as likely to be low birthweight babies. These women, reported to be at high risk for problematic pregnancies, are not receiving the attention necessary to meet their special needs.

Charles Abel, Ph.D., identifying another sub-group at risk for disability, reported that the Child Development Clinic of the Division of Developmental Disabilities at the University of Iowa Hospitals and Clinics has found that 18% of abused or neglected children seen in the clinic also have a developmental disability. Dr. Abel stated that there is evidence

which suggests abused and neglected children are at-risk for acquiring a developmental disability, and that children with a developmental disability are at increased risk for child abuse or neglect.

In this paper, we have included a section outlining program considerations for planning and developing community-based prevention initiatives, recommended publications that we believe will be helpful in designing a comprehensive program delivery model, and current information about major preventive care programs and initiatives in the state of Iowa. Most of the Iowa programs described will be familiar. Many of the activities to be implemented within the next few years will directly address the program needs outlined by the Prevention Task Force in 1984, and will significantly enhance prevention efforts in the state. We have generally limited program descriptions to the statewide programs listed in the state resources section of the "Let's Talk About It" manual. When we have been notified of particular initiatives occurring at the community level, we have included this information under an umbrella service heading. We believe these program components can provide the core resources necessary for designing an effective community-based prevention program.

A Program Planning Model

In planning community prevention initiatives, one of the first decisions is whether to base the program on an intra-agency or interagency program delivery system. Answering this question will entail determining what role the agency or agencies will play in facilitating the prevention of conditions resulting in developmental disabilities. Roles may be indirect--such as providing effective information about accident prevention, home safety, or the importance of early and appropriate maternal health care; or direct--for example, implementing referral and follow-up services for families in need of supplemental health and human services. Single agencies can effectively sponsor public information initiatives or provide agency-specific direct services. If the community decides that the role of agencies should be to provide a coordinated network of preventive services, the community may want to combine planning resources to develop an interagency advisory committee to develop and direct an integrated service delivery effort.

Whatever decisions are made, it will be necessary for agency representatives to define their program goals and objectives to include measurable outcomes. This will require agencies to acquire accurate knowledge about what disabilities may be prevented and to determine what efforts need to be taken within the community to address these needs. Establishing the context of the local prevention program initiatives will require planners to:

- 1) Identify specific target populations in need of services;
- 2) Determine if the current services are adequate to address these needs; and, if not,
- 3) Determine which program efforts need to be expanded.

In determining policy, it is helpful to have some guidelines on the process of decision making. Many times the process of policy analysis is considered to be too complicated for a small, community-based or volunteer program. In reality, policy analysis consists of good, common sense decision-making skills. A basic framework for analysis should include the following steps:

- 1) Clearly define problems and objectives;
- 2) Identify alternative courses of action for addressing the problem, information gathering, and meeting objectives;
- 3) Predict the consequences of these alternatives (community planners may want to contract with an experienced policy and program analyst to conduct a cost-benefit analysis of the alternatives);

- 4) Establish methods for measuring success, determining priorities, and making tradeoffs;
- 5) Make a choice for program development after considering all of the options;
- 6) Draft the program plan, including clear goals, measurable objectives, a timeline for meeting objectives, an accurate budget statement, and a defined evaluation protocol;
- 7) Secure community support for the program plan - both fiscal and conceptual;
- 8) Initiate the program according to your plan and timeline;
- 9) Measure results in a manner that assists in understanding whether programs goals have been achieved; and
- 10) Make program adjustments in order to more effectively meet the program objectives.

A very useful and readable book on program development is Planning for a Change -- A Citizen's Guide to Creative Planning and Program Development, written by Duane Dale and Nancy Mitiguy. A copy of the book can be ordered from: Citizen Involvement Training Project, 225 Furcolo Building, University of Massachusetts, Amherst, MA 01003, telephone: (413) 545-2038.

A clear example of the steps necessary for planning and implementing a community-based prevention program is outlined by Michael Marge in an 1984 American Speech and Hearing Association journal article [2]. In the article, Marge identifies three program steps: 1) identifying leadership, 2) program planning and development, and 3) program implementation.

The leadership phase consists of people getting organized. A leadership committee can be initiated by anyone with the will, the energy, and the connections to convene a representative group of community members. This group should include community members from a variety of professional, educational, religious, political/governmental and business organizations. Once the group has met and the individuals are committed to planning and establishing a community-based prevention project, operating committees can be formed to begin the planning and development process.

[2] Marge, M. "The Prevention of Communication Disorders," ASHA, August 1984.

The program planning phase includes four components:

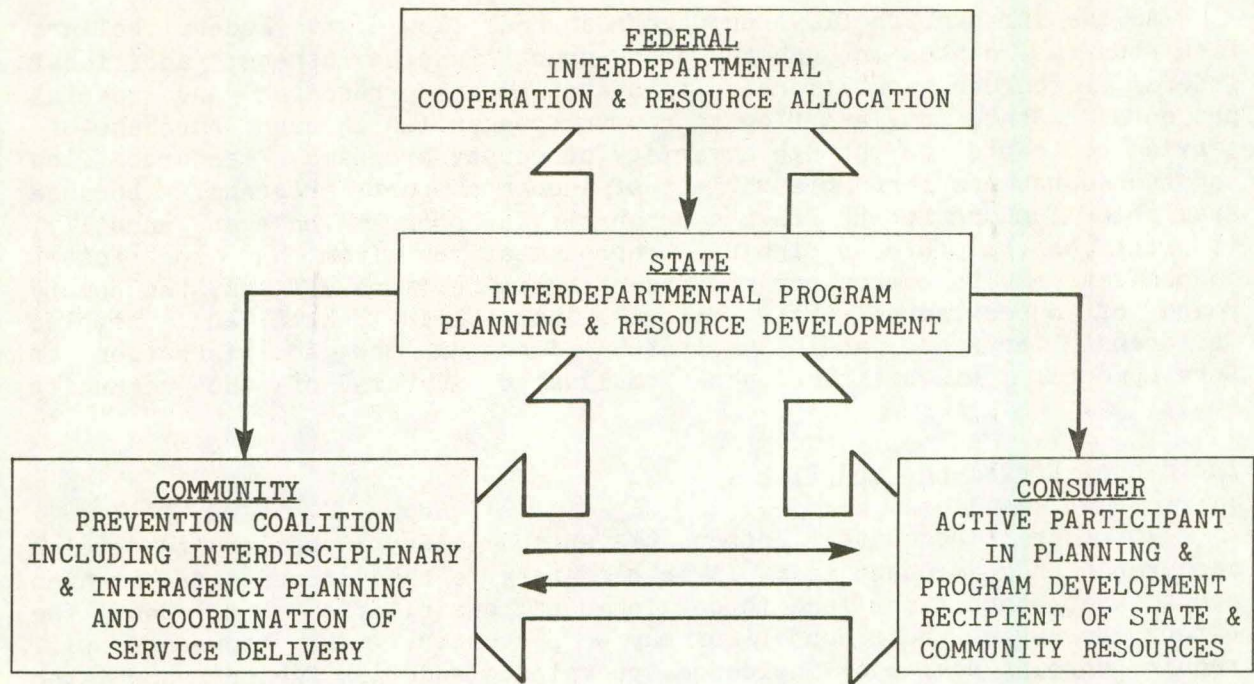
- 1) Analysis of community needs and resources--identification of gaps between current community efforts and community needs. An inventory of existing community resources.
- 2) Development of a long-range plan defining the magnitude of the planned community-based program efforts, a statement of measurable prevention objectives, proposed implementation strategies, and a timetable for completing objectives.
- 3) Devising an evaluation component, including systematic procedures for determining progress in meeting program objectives, designed to allow the planning committee to determine program feasibility, and permitting periodic adjustment to the plan if progress toward meeting the objectives is not adequate. An evaluation component is also critical as a tool for maintaining community support.
- 4) Obtaining community review and approval of the plan to alert citizens to the prevention effort and to secure their participation.

The value of the time and effort put into these program planning stages should not be underestimated, nor should this planning effort be short-changed.

Marge's final stage of program development is the implementation phase. Here he suggests that the leadership committee be incorporated within an established organization, with a staff who will be dedicated and responsible in implementing the prevention plan, and in the regular collecting of data. Accurate data collection will be essential for documenting program accomplishments, and for updating community prevention plan objectives.

The Flow of Information and Program Dollars

Below is a schematic model illustrating the flow of information and resources for a hypothetical, community-based prevention program. This model represents a community-based approach to prevention program planning and development in which the consumer plays a primary role.



The small arrows indicate the prevention resource, or "dollar flow," while the large arrows indicate the direction of the information flow. As illustrated, the model incorporates the identified needs of populations at risk for developmental disabilities, and includes consumers both as recipients of state and local resources and services, and as active members of a community-based planning coalition. In addition to being the recipient of state and local resources and services, the consumer is also an active member of the community-based prevention coalition. Additional representation in the coalition includes both interagency and interdisciplinary representatives. The primary responsibility of the community coalition would be interagency planning and coordination of service delivery, including needs assessment, information dissemination, data collection, systems evaluation, program monitoring and budget development.

Following the implementation phase of program development, the coalition would become the advisory board to the ongoing program which, following Marge's recommendation, would be incorporated into an existing community services program. Within this model, information about community prevention needs and services is disseminated to state and federal agencies in a unified manner; information about consumer needs, program development, and budget would be coordinated within the community coalition and distributed to appropriate state authorities in a single program proposal. The primary responsibility of the state would be interdepartmental program planning and resource development. The primary responsibility of federal agencies would be resource allocation.

As the information flows up, the resources flow down. Federal dollars flow to the states through the block grant funding stream; additional federal resources are allocated to states to fund research and special projects. State dollars flow to community agencies through purchase-of-service contracts and through a variety of county programs. Resources flow to the consumers through a variety of income support programs. Because available funding for health and human service programs changes annually, it will be helpful to include representatives from and to foster communication with county Departments of Human Services offices, the county Board of Supervisors, State Maternal and Child Health and Crippled Childrens' Services, and the state office on the Administration on Developmental Disabilities, as designated members of the community coalition.

Incidence, Prevalence and Risk

In order to adequately address prevention policy issues and to develop measurable program objectives, it is necessary to have accurate information about what conditions lead to developmental disabilities and about the extent to which these conditions may be prevented. This knowledge will require ongoing review of incidence, prevalence and risk factors associated with particular categories of disability, as well as an understanding of appropriate treatment and habilitation regimens. For those interested in reviewing these factors, we recommend the following resources:

Blackman, J.A., editor (1983). Medical Aspects of Developmental Disabilities in Children Birth to Three. The University of Iowa, Iowa City.

Freeman, J.M., editor (1985). Prenatal and Perinatal Factors Associated with Brain Disorders. U.S. Department of Health and Human Services, NIN publication no. 85-1149, Washington, D.C.

Scheiner, A.P., and Abroms, I.F., eds. (1980). The Practical Management of the Developmentally Disabled Child. The C.V. Mosby Company, St. Louis.

The first publication provides an easy-to-understand resource for early intervention specialists on conditions, assessment, and other health care concerns related to infants and young children with developmental disabilities; the second provides a thorough review of prenatal and perinatal factors associated with the occurrence of mental retardation, cerebral palsy, and epilepsy; the third is written for health professionals as a guide to practical skills for screening, diagnosis, evaluation and the development of treatment plans for developmentally disabled children. While it will not be feasible for community agencies to become experts in this area, it is important to have some understanding of frequency measures in order to be able to assess state and federal frequency data and to use this information to help monitor local program efforts. Several of the more critical concepts are explained below.

Incidence defines the frequency with which a disability occurs within an identified population measured at a specific point of onset. In describing the incidence of particular disabilities, the literature usually states incidence ratios as the number of children identified as having disabilities over the total number of live births (e.g. #/1000), with the population defined as births within a particular geographic region. For example, the expected incidence of several of the more common impairments for the United States as reported in 1983 are: Myelomeningocele - 1/1000 live births; cerebral palsy - 1.5-2/1000 live births; and Down syndrome - 1/600-800 live births for all women (up to 1/110 live births for women age 40 years or older). The incidence for mental retardation cannot be readily determined; because it is a measure of intellectual acuity, a diagnosis of all but very severe mental retardation is generally not possible until later in childhood.

The incidence for a particular disability may change over time or by geographic location. As reported in Scheiner and Abrams, prior to 1962 the incidence of cerebral palsy in the United States was estimated to be between 4.7-7.5/1000 live births, an incidence over twice that reported by Blackman in 1983. The general decline in the incidence of cerebral palsy in the U.S. has been attributed to earlier and improved maternal and neonatal care. As an example of geographic variation in incidence measurement, Great Britain is reported to have had an incidence of chronic motor disability during 1953-1976 of 2.41/1000 live births, compared to an incidence in Sweden between 1954-1974 of 1.63/1000 live births (Scheiner & Abrams, 1980).

For epidemiologists involved in the prevention effort, measurement of incidence is important for establishing relationships between cause and affect. Incidence data allows factors thought to be associated with particular disabilities to be compared to the frequency of the same factors within the general population, to determine if a causal relationship exists between the factors being studied and the onset of impairment. When sufficient information is known about the causes of particular impairments, carefully documented research may be able to estimate the relative incidence of preventable disability. Preventable disability in this case would represent any disability for which the cause is known, and a preventive strategy identified and proven. Examples of preventable disability include fetal alcohol syndrome, congenital rubella, and mental retardation associated with phenylketonuria (PKU). Preventive strategies associated with these disorders include abstinence or reduced alcohol consumption during pregnancy, maternal inoculation against rubella virus prior to conception, and early diagnosis and implementation of a phenylalanine-restricted diet for infants with PKU.

At the present time the discrete causes of many disorders are unknown; many cases are assumed to include multiple factors which will be difficult to identify. Even when a cause has been identified, an associated strategy for prevention of either the impairment or the associated disability often has not been established.

In addition to enhancing our ability to identify the causes of developmental disabilities, the most effective application of incidence measurements related to prevention may be the epidemiologic tracking of the incidence of disabilities at the state or national level in order to: 1) evaluate the ongoing effectiveness of prevention program efforts, and 2) identify ineffective or inappropriate service programs.

Prevalence describes the number of disabilities that occur within a specified population, at a given moment in time, regardless of the age of onset. Prevalence is stated as the ratio of the number of people with identified disabilities relative to a given number of people within a specified population (e.g., #/1000). Freeman has included estimates of the prevalence of complicated cases of neurodevelopmental handicap for primary school children between the ages of seven and ten years in the U.S. as follows:

Cerebral Palsy: 2/1000 -- 20-30 percent affected by serious mental retardation (IQ less than 50), 20-30 percent affected by mild mental retardation (IQ = 50-70), and 33-40 percent affected by seizures.

Serious Mental Retardation (IQ less than 50): 4/1000 -- less than 20 percent affected by cerebral palsy, 13 percent affected by seizures.

Epilepsy: 5/1000 -- 19 percent affected by cerebral palsy, and 27 percent affected by mental retardation (IQ 70).

As with incidence, prevalence may vary over time and with geographic locale. For example, the Freeman publication reports that mild mental retardation in Sweden has been reduced substantially over the years to a present ratio of around 4/1000, a rate 8 to 10 times lower than that frequently recorded in the United States. The authors attribute this difference to a higher rate in the U.S. of "cultural-familial syndrome"--of mild mental retardation in the absence of physical cause. Others suggest that at least part of the difference may be explained by differing terminology and testing philosophy.

Prevalence is generally not considered a particularly helpful measure when looking for causal relationships; however, it is well suited to the needs of service providers attempting to match services to need. In terms of community assessment and the development of prevention initiatives, having knowledge about the prevalence of preventable disability or associated risk factors will help clarify the effective distribution of services. For example, if a community determines that the prevalence of mothers giving birth to low birthweight babies in their community was much higher than in neighboring communities, or in the state as a whole, they should consider consulting experts in maternal and child care to determine the factors responsible for the increase. Possible considerations might

include poor nutritional status, increased work-related stress, or a significantly higher rate of adolescent pregnancy. Most of the prevalence data needed to conduct this type of program/policy analysis is available on a county-by-county basis from the Iowa Department of Health and the Iowa Department of Human Services.

The concept of risk can take many forms. The Freeman report discusses several variations of (quantitative) risk associated with the frequency of disorders. Relative risk is defined as "the ratio of the frequency of a disorder in a group that experiences a risk factor to the frequency of the disorder in a group without that experience." The authors identify relative risk as the most useful measurement quantifying the relationship of a particular factor to outcome. Attributable risk is defined as, "the amount or proportion of a disorder that occurs in a population that can be attributed to a specific risk factor . . . the presumed amount or proportion of a disorder that would not occur if the factor were removed." For prevention interests, this measure may be particularly informative; however, the authors caution that most attributable risk measurements are generated from observation studies rather than from controlled preventive intervention studies. Because many unmeasured factors may also be associated with a particular outcome of disability, it cannot be assumed that identified disability is causally related to the factor under study. In fact, it has been emphasized that most pregnancies identified as being "at risk" will have normal outcomes.

The Scheiner and Abroms publication focuses on developmental risk, dedicating one chapter to the high-risk mother and infant. Here the authors cite Tjossem's categorization of three types of developmental risk: 1) established risk, including infants with identified developmental disabilities who may have associated congenital syndromes or malformations; 2) environmental risk, including infants born to families of low socioeconomic class, to emotionally disturbed parents, or to caretakers who interact poorly and provide a poor caretaking environment; and 3) biological risk, including children who have experienced a variety of adverse perinatal events such as congenital viral infection, prematurity, or hypoxia. While the majority of this chapter focuses on biological risk, the authors note that "the biologically high-risk infant appears to be especially vulnerable to an adverse caretaking environment."

While long promoted, the subject of early intervention for high-risk infants is now being documented as an important factor in reducing the impact of developmental disorders on children's social, emotional and cognitive development. Early intervention activities are particularly appropriate for development at the community level. For a thorough review of early intervention program issues and implementation guidelines, we recommend reading Early Services for Children with Special Needs: Transactions for Family Support, by Alfred Healy, Patricia Keese, and Barbara Smith (The University of Iowa, 1985). As well as providing a national perspective on early intervention services, the book includes extensive annotated and categorical bibliographies.

Preventive Care Initiatives in Iowa

At the heart of effective prevention programs are services which appropriately meet the needs of their communities. The following program listing illustrates the wealth of health and human service resources which currently contribute to a reduction in preventable disability, and to the overall health and development of all Iowans. The listing is generally limited to programs providing statewide services; additional preventive health services may be available in each community.

Air and Mobile Critical Care Service

1088 Carver Pavilion
University of Iowa Hospitals and Clinics
The University of Iowa
Iowa City, Iowa 52242
Telephone: Non-emergency: (319) 353-6360
 Emergency: 1-800-272-6440

The Air and Mobile Critical Care Service is a statewide, 24-hour-a-day, emergency transport service for acutely ill or injured patients who need specialized care at the University of Iowa Hospitals and Clinics, in Iowa City. The program serves approximately 700 persons per year. All of the emergency care vehicles have emergency room equipment and are staffed by specially trained nurses able to provide rapid assessment and intervention. Communication between the emergency vehicles and the University of Iowa Hospitals is possible at all times. A special neonatal transport team accompanies all critically ill newborns. Information about the program is available to individuals or groups.

Area Education Agencies

Department of Public Instruction
Special Education Division
Grimes State Office Building
Des Moines, Iowa 50319
Telephone: (515) 281-3176

Iowa is one of approximately twelve states that require the provision of educational services for children and young adults from birth to age 21. This mandate is administered through a network of 15 Area Education Agencies located throughout Iowa. Each AEA program has a special education component which includes a preschool handicapped consultant. While specific services will vary across AEA's, all programs provide identification, screening, and assessment services for children ages birth to three. Service options available to children identified as having disabilities are outlined in a 1984 Department of Public Instruction publication called Birth to Three, Special Education Programs. These programs may include: home intervention or instruction, support services,

center-based play groups, and/or family consultation services. Many of these agencies have worked hard to develop specialized programs and services to meet the needs of parents of handicapped children. Most agencies have a range of educational materials on a variety of development-related topics. Area Education Agency 6 is in the process of developing "Project PEACH - Prevention Education About Conditions That Handicap." Designed to be used by teachers of secondary students, the project materials identify human, media, and print programs which deal with Down syndrome, effects of drugs, environmental conditions, metabolic disorders, fetal alcohol syndrome, and others. Educational programs for groups or information for individuals will be provided upon request by the AEA serving your district. All educational services are provided free of charge.

Association for Retarded Citizens/Iowa

1707 High Street
Des Moines, Iowa 52404
Telephone: (515) 283-2358

The Association of Retarded Citizens (ARC) is a national organization composed of state and local members. ARC provides a variety of services at the community level, including family support, advocacy, and prevention. Prevention of mental retardation is a major priority for ARC at the state level. The goal of ARC/Iowa's prevention program is: "To stimulate interest and motivate action in the county so that persons responsible for the communities' unborn, newborn, and young children will take actions necessary to promote healthful development and reduce the incidence of mental retardation." While the degree of emphasis on prevention varies at the local level, all ARC members place a high priority on the provision of self-advocacy and family support services. More information about ARC's prevention activities may be obtained by calling ARC/Iowa's central office in Des Moines.

Division of Developmental Disabilities

Department of Pediatrics
The University of Iowa Hospitals and Clinics
University Hospital School
The University of Iowa
Iowa City, Iowa 52242
Telephone: Outpatient Unit (319) 353-7021
Inpatient Unit (319) 353-5396
Training Unit (319) 353-3417

The Division of Developmental Disabilities provides interdisciplinary diagnosis and evaluation of infants, children, and young adults with complex needs resulting from developmental disabilities. Programs provide interdisciplinary evaluations for a daily average of eight children and

young adults in outpatient settings. The 20-bed pediatric unit provides inpatient diagnostic and treatment services. Outpatient clinics include:

The Infant and Young Child Clinic for children birth to three with suspected or confirmed developmental problems.

The Child and Young Adult Clinic for children and young adults with disabilities which affect self-care, mobility, communication skills, learning, self-direction, capacity for independent living, and/or eventual social and economic self-sufficiency.

The Myelodysplasia Clinic for infants, children, and young adults, ages birth to 35, who have spinal cord defects or dysfunction.

The Child Development Clinic offers evaluations and follow-up services for children and young adults with problems due to social, psychological, or undetermined factors; poor school performance, including learning disabilities; hyperactivity; mild behavior problems; or genetically-based developmental disabilities.

The Metabolic Management Clinic offering diagnostic and follow-up services for infants, children, and young adults born with metabolic disorders.

Division of Medical Genetics
Department of Pediatrics
University of Iowa Hospitals and Clinics
The University of Iowa
Iowa City, Iowa 52242
Telephone: (319) 356-2674

The Division of Medical Genetics provides diagnostic, evaluation, management and/or treatment, family counseling, and referral services to more than 700 families annually. Pre- and post-conceptual programs for women include consultation and information regarding the potential risks of adverse pregnancy outcomes. Programs for children include genetic disease screening, developmental evaluation and screening, and parent counseling. Direct services are charged on a fee-for-service basis. The Division of Medical Genetics educational services are provided to individuals and groups through private consultation, public group presentations, and distribution of literature.

Family Planning Programs

Family Planning Council of Iowa

3500 Second Avenue, Suite 6
Des Moines, Iowa 50313
Telephone: (515) 288-9028

Iowa Family Planning Program

Iowa State Department of Health
Lucas State Office Building
Des Moines, Iowa 50319
Telephone: (515) 281-6645

The Family Planning Council of Iowa is comprised of ten subgrantee agencies, located in Marshall, Muscatine, Clinton, Scott, Polk, Johnson, Dubuque, Woodbury, and Des Moines counties, and in Omaha, Nebraska. These subgrantee agencies serve a total of 55 counties. The Family Planning Council of Iowa is a grantee for Title X family planning funds. All subgrantees provide family planning care, including birth control, VD detection and treatment, and pregnancy testing to any person upon request. Fees are based on ability to pay, and there are no restrictions to the provision of services due to age, marital status, income or place of residence. During 1984, seven of the ten agencies listed (exceptions of Dubuque, Woodbury and Des Moines counties) served 21,535 women below 150% of the poverty level, and another 12,746 above poverty level; of these, 11,288 were under age 20. All received some form of medical family planning care. Some of the projects have special programs for adolescent parents; most of the projects have educational programs reaching out to school-age children, low income families, and other groups at high risk for unintended or problem pregnancy or health problems. Emphasis, in all programs, is placed on the prevention of adolescent pregnancy. Both individuals and groups are instructed about the effects on pregnancy of smoking, alcohol, and other drugs. A film distribution service is provided through: Planned Parenthood of Mid-Iowa, 851 19th Street, Des Moines, Iowa, 50306.

The Iowa Family Planning Program seeks to enable individuals and couples to achieve pregnancy and have children at the times desired by them. The program achieves this purpose through a range of educational and social services provided through the family clinic network. Family planning agencies offer effective family planning methods, including natural family planning methods, infertility services, and services for adolescents. Education components of the program include information on the reproductive system, the importance of preventive health measures, available family planning methods and associated risks and benefits. Social services include short-term counseling, referral to other social agencies and community outreach. Services are provided on a voluntary basis to any individual requesting them. Abortion may not be provided as a method of family planning. Priority for services is given to persons from

low-income families. Charges for services are adjusted according to a sliding fee scale set in relation to federal poverty guidelines. Information about the location of family planning agencies and services may be obtained by calling the Iowa Department of Health at the number listed above.

Iowa Child Abuse Prevention Program

Iowa Chapter: National Committee for Prevention of Child Abuse
3701 1/2 Douglas Avenue
Des Moines, Iowa 50310
Telephone: (515) 281-6327

The Iowa Child Abuse Prevention Program is administered by the Iowa Chapter of the National Committee for the Prevention of Child Abuse, under contract with the Iowa Department of Human Services. The Iowa Chapter assists communities to develop child abuse councils which design and implement community-specific child abuse prevention projects. Only communities with child abuse councils are eligible to receive prevention grant funds from the Iowa Child Abuse Prevention Program. Child neglect and abuse prevention grant projects provide a range of primary and secondary prevention services, including respite child care, public information programs concerning prevention of sexual abuse, and parenting education projects. A complete description of Iowa Child Abuse Prevention Program and associated child abuse efforts in Iowa is included on pages 43 to 52 in the preceding "Let's Talk About It" prevention conference supplement.

The Iowa Department of Substance Abuse

505 5th Ave. Suite 202
Insurance Exchange Building
Des Moines, Iowa 50319
Telephone: (515) 281-6567

The abuse of drugs, alcohol or tobacco during pregnancy may have devastating consequences. The Iowa Department of Substance Abuse is working diligently to inform Iowans about the risks of alcohol and substance abuse during pregnancy. The prevention component of IDSA currently funds 30 agencies, as well as additional parent community groups as funds become available annually. Serving over 180,000 individuals each year, these programs provide information and referral services related to primary prevention of alcohol and substance abuse. The department offers training programs and technical assistance, free of charge, to groups or individuals upon request. For more information about substance abuse programs in your area, contact the program serving your community, or call the Department of Substance Abuse in Des Moines.

Iowa Maternal and Child Health Program

Iowa State Department of Health

Lucas State Office Building

Des Moines, Iowa 50319

Telephone: (515) 281-4911

Services provided by the Iowa Maternal and Child Health Program (MCH) are designed to assure pregnant women access to the health, social and educational resources needed to support a healthy pregnancy outcome and to assure an array of health services to encourage the optional growth and development of infants and children. MCH eligibility criteria include women in childbearing years and children under age 21 who live within an MCH geographic service area. Charges to families are based on federal poverty guidelines. Maternal health services are provided by physicians, in coordination with nurses, nutritionists, dental hygienists and social workers, and include: 1) prenatal care beginning in the first trimester of pregnancy; 2) educational programs addressing changes due to pregnancy, preparation for labor and delivery, and infant care; 3) nutrition and dental assessment and counseling; 4) referral; and 5) a full array of postpartum services including family planning and well-child services. Child health services are provided under standing-orders of local physicians and include: 1) health appraisal; 2) screening and assessment of development, vision, hearing, and speech; 3) nutrition and dental assessment and counseling; 4) immunizations; 5) selected laboratory tests; 6) anticipatory guidance and counseling; and 7) referrals. Medicaid-eligible children receive similar services through Early Periodic Screening, Diagnosis, and Treatment (EPSDT) services, at the child health centers. The Iowa State Department of Health will assist local communities in establishing and maintaining EPSDT screening centers.

Iowa Maternal Serum Alphafetoprotein (MS-AFP) Screening Program

Birth Defects Institute

Iowa State Department of Health

Lucas State Office Building

Des Moines, Iowa 50319

Telephone: (515) 281-6646

Department of Obstetrics & Gynecology

The University of Iowa Hospitals & Clinics

Iowa City, Iowa 52242

Telephone: (319) 356-4840

The Iowa AFP Screening Program, effective January 8, 1986, gives women the option of early prenatal detection of neural tube defects and other complications of pregnancy associated with elevated MS-AFP levels. Early identification of these high-risk pregnancies provides the opportunity for improved pregnancy and neonatal management. The AFP Screening Program is administered through the Iowa State Health Department Birth Defects

Institute. The medical director for the program is in the Department of Obstetrics and Gynecology, The University of Iowa Hospitals and Clinics. The AFP screening tests are provided by local obstetricians and gynecologists; the costs of screening would, therefore, include a set price per screening test in addition to regular clinic costs. Participation in the screening program is voluntary.

Iowa WIC Program

Iowa State Department of Health
Lucas State Office Building
Des Moines, Iowa 50319
Telephone: 1-800-532-1579

The acronym "WIC" stands for the Special Supplemental Food Program for Women, Infants and Children. WIC provides pregnant, postpartum and breastfeeding women, as well as infants and children to age five, with supplemental nutritional services necessary for normal growth and development. WIC encourages regular medical care, and provides nutrition education and supplemental food packages to eligible applicants as funds permit. Eligibility, based on both categorical and income guidelines, is determined by a qualified nutritionist. Specifically, WIC is available to women and children as specified above, whose health is threatened by a combination of nutritional need and family income less than 150% of current poverty guidelines. Program participants receive nutrition education directed toward an increased understanding of the relationship between good nutrition and good health. If necessary, WIC programs will refer clients to private physicians or other health care agencies for regular health care. Supplemental food packages are designed to meet individual needs, with checks issued monthly for the purchase of specific food items. WIC clinics are currently held at least monthly in each of Iowa's 99 counties; over 29,000 participants benefit from the Iowa program annually. Due to limited funding, Iowa WIC programs have only been able to meet the needs of one-third of the estimated eligible population.

March of Dimes Birth Defects Foundation

Western Iowa Chapter
554 28th Street
Des Moines, Iowa 50312
Telephone: (515) 280-7750

March of Dimes Birth Defects Foundation

Eastern Iowa Chapter
410 Guaranty Bank Building
Cedar Rapids, Iowa 52401
Telephone: (319) 366-4371

The mission of the March of Dimes Birth Defects Foundation is to prevent birth defects from occurring and to assist the babies and families

when defects do occur. As one of the primary movers in developing and implementing the concept of regionalized perinatal care, the March of Dimes links providers of health services for pregnant women and newborn infants into systems of continuing education, consultation, referral and transport for specialized treatment. The March of Dimes promotes the need for early, continuous and comprehensive prenatal care for all pregnant women, offering research, medical services and professional education grants to help increase the availability of skilled health professionals, develop enhanced treatment technologies, and extend the capabilities of newborn nurseries and high-risk maternal care units throughout the country. Foundation grants currently support over 60 local projects in Iowa, as well as further development of prenatal and perinatal care, and genetic education service programs at the University of Iowa. In addition to the Foundation grant programs, the March of Dimes maintains an extensive collection of public and professional information and training materials. Most of the public information pamphlets are available free of charge. Audio-visual materials and educational kits may be purchased at low cost.

Specialized Child Health Services

Department of Pediatrics
University of Iowa Hospitals and Clinics
The University of Iowa
Iowa City, Iowa 52242
Telephone: (319) 356-2842

Iowa Specialized Child Health Services (SCHS) provide an organizational framework for the delivery of tertiary hospital and regional outreach services for Iowa's children with special health care needs. Administered through the University of Iowa Hospitals and Clinics, Department of Pediatrics, the SCHS program effectively links specialists at the University Hospitals with community-based professionals to provide the following categorical service programs:

Childhood Cancer Diagnostic and Treatment Program

Established in 1977, this model program involves cooperative teamwork of staff specialists at University of Iowa Hospitals and Clinics and community health care providers in the treatment of children with cancer. The goal of this program is to provide optimal health services for children having cancer, while limiting the time and effort families must spend traveling to and from Iowa City for treatment. Following a diagnosis of cancer and development of a treatment protocol at University Hospitals, the attending physician arranges for a primary care physician located in the child's community to provide over 70% of the child's continuing treatment. Chemotherapy drugs are supplied and dispensed by University Hospitals pharmacy. Twenty-four hour phone service allows community physicians to consult with University Hospitals at all times. Contact: (319) 356-3422.

Rural Comprehensive Program for Hemophilia Patients

This program was established in 1976 to identify and treat hemophilia patients in their home communities. Eighty per cent of the patients served by this program are children. A major goal is prevention of unnecessary hospitalization. The management, care and treatment of individuals with hemophilia is shared between community physicians and physicians and staff at University Hospitals. Following confirmed diagnosis and development of a treatment plan at University Hospitals, a nurse and social worker will coordinate services for the family in their own community. Patient information is sent by the local physician to University Hospitals for analysis on a regular basis. Immediate consultation and assistance is available through a 24-hour phone service in case of emergencies. Contact: (319) 356-2890.

Iowa High-Risk Infant Follow-Up Program

The Iowa High-Risk Infant Follow-Up Program is designed to provide in-depth physical, neurological and developmental screening of infants whose births were associated with factors that place them at risk for future medical or developmental problems. The majority of the infants were born or were cared for in level II or level III nurseries in Iowa. The goal of the program is to identify problems early, and to facilitate appropriate referral as necessary. Screening examinations are scheduled for children at 4, 9, 18, 30, and 60 months of age. Screening examinations through 30 months of age focus on detecting impairments in motor, sensory, communication, and social skills. The five-year examination focuses on the early detection of more subtle learning or behavior deficits which could interfere with a child's ability to maximally benefit from the formal education process. Examinations are scheduled at a follow-up clinic nearest the child's home; clinics are currently active in Spencer, Mason City, Sioux City, Ft. Dodge, Carroll, Des Moines, Waterloo, Ottumwa, Cedar Rapids, Davenport, and the University of Iowa Hospitals and Clinics in Iowa City. All examinations are carried out by specially trained pediatric nurse practitioners. Contact: (319) 353-5446.

Regional Genetic Consultation Service

The Regional Genetic Consultation Service (R.G.C.S.) was established in 1976 as a program of the Birth Defects Institute within the Iowa State Department of Health, and is conducted in collaboration with the State Department of Health. The R.G.C.S. network includes genetic counseling clinics located at 16 sites throughout the state. Clinics provide diagnostic, risk assessment, and counseling services for anyone who has a genetic disorder or birth defect, or who is concerned about the risk of having a child with a genetic disorder. Fees for counseling services are charged on a sliding scale; laboratory procedures will be billed to the patient or family (some assistance is available to low income families).

Educational programs, including presentations, seminars, or workshops, provide information about specific genetic disorders, environmental and genetic causes of birth defects, and genetic counseling. These may be arranged by contacting R.G.C.S. consultants. Contact: (515) 281-6646 or (319) 356-2674.

Muscular Dystrophy and Other Related Genetic Diseases

Both tertiary and community-based regional services are available for persons having muscular dystrophy and other neuromuscular diseases. The Muscle Disorders Clinic in the Department of Pediatrics at University Hospitals provides diagnostic and treatment services to individuals with complex neuromuscular disorders who have been identified and initially screened in a Muscle Disorders Clinic of the Mobile Child Health Specialty Clinics. All services are charged according to a sliding scale. Contact: (319) 356-2674.

Mobile and Regional Child Health Specialty Clinics

The Iowa Mobile and Regional Child Health Specialty Clinics (CHSC) provide specialty examinations for children with chronic disabilities or potentially handicapping conditions. CHSC conducts statewide diagnostic and evaluation services in regional and mobile clinics, provides care plans for children seen at the clinics, and conducts research and demonstration projects related to health problems associated with various conditions causing disability. Categorical clinic areas include developmental, pediatrics, muscle disorders, cystic fibrosis, cardiology, otolaryngology, and orthopedics. Clinic services are open to residents of Iowa under the age of 19 years, who have a known or suspected disability or handicap. No professional charges are billed directly to families of low to moderate incomes. Middle income families will have professional charges adjusted on a sliding scale. Families with income above the scale will be expected to pay usual professional fees. (Unusual family circumstances, such as unemployment or catastrophic costs, are considered on an individual basis.) Contact: (319) 353-5428.

Statewide Perinatal Care Program

Established in 1973 with the objective of improving the outcome of pregnancies in Iowa, Iowa's Statewide Perinatal Care Program, conducted in collaboration with the Iowa Department of Health, has since become a model program of regionalized perinatal care services. It began with a broad educational initiative which trained physicians to identify high-risk obstetric patients and ill newborns, and which promoted referral of identified patients to facilities which could appropriately meet their needs. The state hospitals were categorized into three levels of service,

according to their ability to provide the necessary staff and facilities to meet different levels of patient need. Primary care facilities may currently refer at-risk patients to eleven intermediate perinatal care centers, or to the tertiary care center located at the University of Iowa Hospitals and Clinics. In addition to regionalized perinatal care hospital services, prenatal health clinics have been established in Waterloo, Des Moines, Clinton, Davenport, and Muscatine. The Departments of Obstetrics and Gynecology and of Pediatrics at the University of Iowa Hospitals and Clinics also sponsor a statewide training program for neonatal, obstetrical and gynecological nurses.

Iowa Newborn Screening Program

The Iowa Newborn Screening Program was created in 1981 to provide a statewide system for the detection of four metabolic disorders: phenylketonuria (PKU), hypothyroidism, galactosemia, and maple syrup urine disease. In 1983, the Iowa legislature created a mandatory, centralized screening laboratory at the University of Iowa Hygienic Laboratory, to provide screening for all infants born in Iowa. Infants diagnosed as having one of these metabolic disorders may be referred to the Metabolic Management Clinic located at the Division of Developmental Disabilities, University of Iowa Hospitals and Clinics. Early identification and treatment of these disorders can prevent such adverse outcomes as mental retardation or severe illness, or in some instances, death. The program positively affects the potential of all such children to lead normal, productive lives. Contact: (515) 281-6646 or (319) 356-2674.

Speech and Hearing Centers

University of Northern Iowa Speech and Hearing Clinic
University of Northern Iowa
Cedar Falls, Iowa 50614
Telephone: (319) 277-2577

Wendell Johnson Speech and Hearing Center
University of Iowa
Iowa City, Iowa 52242
Telephone: (319) 353-5187

Iowa has two university-based speech and audiology clinical training programs within the state, each providing specialized services related to complex speech and hearing disorders. Both centers offer comprehensive developmental speech and language evaluations for children. The University of Northern Iowa program also offers individual and group consultation and/or educational programs on speech and language development and developmental screening, as well as specific information related to mental retardation, cerebral palsy, and autism.

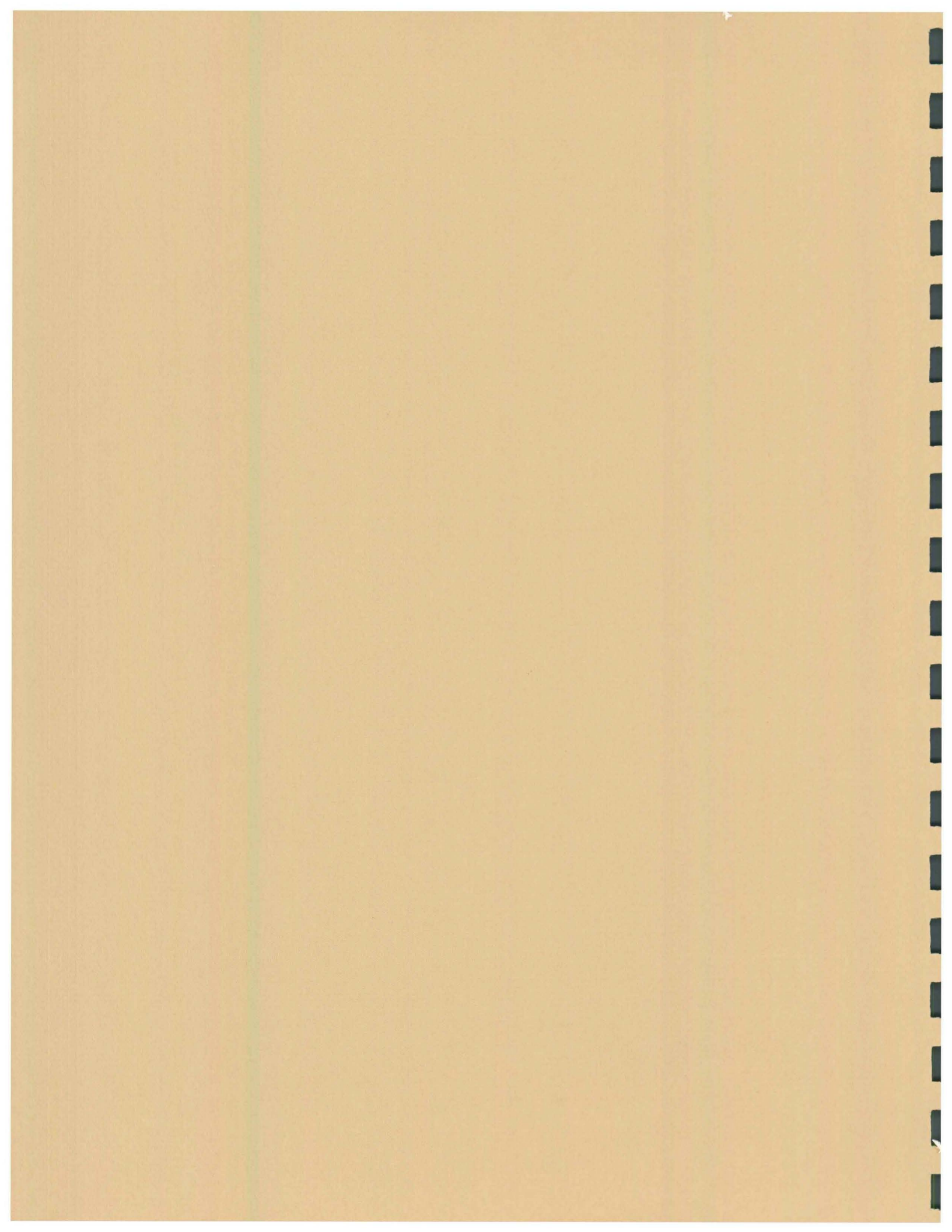
Moving Forward: Additions to Preventive Care Initiatives in Iowa

During the April 1985 prevention conference, several new preventive care initiatives were reviewed. These initiatives, which are reported in the "Let's Talk About It": Prevention Conference Proceedings, include: 1) initiation of an Iowa branch of the Healthy Mothers, Healthy Babies Coalition, focusing on the national commitment to improve "the quality and reach of public education concerning prenatal, infant and maternal health" (pp. 30); 2) an alpha-fetoprotein (AFP) screening program available upon request to all pregnant women, to detect pregnancies at high risk for a variety of reasons, including complications of pregnancy and/or structural defects of the developing fetus (pp. 31); and 3) generation of an additional \$330,000 in state dollars for ongoing grant support to community-based child abuse prevention projects (pp. 44). In the months since the April conference, several additional prevention initiatives have received funding.

Beginning early in 1986, the Iowa Child Health Specialty Clinics will be adding a nutrition component to their regionally-based, multi-disciplinary service clinic model. Chronic diseases and handicapping conditions are often associated with nutritional problems which must be addressed to minimize disability and maximize well-being. Trained dieticians will be available part-time at each clinic to provide dietary assessment, counseling, education and follow-up. Nutritional services will be provided in three major health-problem areas: 1) chronic disease or handicapping conditions; 2) high risk for future coronary heart disease; and 3) severe obesity.

Two important preventive care initiatives involving the prevention of birth defects have recently been awarded grant funding. In one initiative, the Great Plains Genetic Service Network (GPGSN) will be establishing a teratogen information service and birth defects hotline, to provide up-to-date information concerning the potential effects of teratogenic exposure during pregnancy. During the first year of the program, the GPGSN will conduct a planning conference with outside consultants who have expertise in developing teratogen information services; using the information gathered, GPGSN will establish a pilot Iowa information service hotline with terminals located at all level-two hospitals. The pilot program will permit physicians, pharmacists and other health providers to access the computer-based system through a WATS line, to ask trained individuals about teratogenic exposures during pregnancy, and to obtain summary information from a centralized information system. In a second initiative, grant funding has been awarded to the University of Iowa's Division of Medical Genetics from the Center for Disease Control (CDC) to extend the Regional Birth Defects Registry throughout the entire state of Iowa. Expansion of the Birth Defects Registry will immediately facilitate statewide interagency health planning, surveillance, and program development. Information from the Registry will also allow for the development of additional proposals for the study of the etiologic factors of birth defects.

In a final note, a major statewide campaign to provide appropriate programs to meet the needs of Iowa's disabled citizens was inaugurated on May 2, 1985, when the Iowa legislature passed Senate File 473, a "Bill of Rights for Persons having Mental Retardation, a Developmental Disability, or Chronic Mental Illness." This measure provides an opportunity for individuals with disabilities, their families, county boards of supervisors, state legislators, advocates, and practitioners working in the field, to join together to plan a comprehensive system of services responsive to the rights of these Iowans to receive adequate, appropriate, and equitable services in accordance with due process of law. During autumn of 1985, the Division of Mental Health, Mental Retardation, and Developmental Disabilities of the Iowa Department of Human Services began the initial phases of a massive survey to accurately assess the service needs of disabled Iowans. Analysis of this survey and additional planning strategies will be submitted in a report to the Iowa legislature by April 1, 1986. Provided that legislation is enacted to provide a fair and equitable funding mechanism for the full implementation of Senate File 473, the Bill of Rights will become effective July 1, 1987 [see the IDD News, Special Edition, enclosed].



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