INTRODUCTION

During the past 10 to 15 years, there has been a striking growth in interest and concern regarding the systematic prevention of mental retardation and other developmental disabilities. What was formerly a somewhat wistful yearning has become in recent years a major preoccupation of relevant consumer groups, professional societies, and governmental agencies. This new emphasis awaited some of the secondary products of the social revolution in this period, whereby the etiology of developmental handicap was more rigorously examined and codified and there was a cultural commitment to intervene positively regarding factors which compromised human outcome. The efforts to be made were further expedited by results of the surge of biomedical and social research, mostly supported by federal grants, in the post-World War II years. All this provided a technology and a feasibility for effective prevention programs.

KEY PREVENTION STRATEGIES

If one reviews the elements most commonly listed in prevention agendas, whether these are of national or local origin, one notes that a limited (but important) group of resolves appears again and again. The most prominent of these could appropriately be characterized as "The Golden Twenty" of the prevention catalogue. These are:

Primary Prevention Activities — which are designed to eliminate the occurrence of the condition which causes the handicap.

1) Rubella immunization — to prevent the phenomenon of 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 — as 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, 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 to both 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 injury) — by attention to effective restraint in automobiles, and to other hazards.

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TRIAMINIC® Syrup/
TRIAMINIC-12™ Tablets
Combined Brief Summary

DESCRIPTION: Each teaspoonful (5 ml) of TRIAMINIC Syrup contains: phenylpropanolamine hydrochloride 12.5 mg and chlorpheniramine maleate 2 mg in a nonalcoholic vehicle. Each TRIAMINIC-12 Tablet contains: phenylpropanolamine hydrochloride 75 mg and chlorpheniramine maleate 12 mg.

INDICATIONS: For the temporary relief of nasal congestion due to the common cold, hay fever or other upper respiratory allergies and associated with sinussitis.

For temporary relief of running nose, sneezing, itching of the nose or throat and itchy and watery eyes as may occur in allergic rhinitis (such as hay fever).

WARNINGS: Observe caution in prescribing to patients with high blood pressure, heart disease, diabetes, thyroid disease, asthma, glaucoma or difficulty in urination due to enlargement of prostate gland. At high doses nervousness, dizziness, or sleeplessness may occur. May cause drowsiness; may cause excitability especially in children.

CAUTION: Patients should avoid driving a motor vehicle or operating heavy machinery, and the concomitant consumption of alcoholic beverages while taking these products.

DRUG INTERACTION PRECAUTION: Observe caution in prescribing to patients presently taking a prescription antihypertensive or antidepressant drug containing a monamine oxidase inhibitor.

DOSEAGE AND ADMINISTRATION:
TRIAMINIC Syrup—Adults—2 teaspoonfuls every 4 hours. Children 6-12 years—1 teaspoonful every 4 hours. Children 2-6 years—½ teaspoonful every 4 hours. The suggested dosage in pediatric patients 3 months to 2 years of age is 4 to 5 drops per kilogram of body weight administered every four hours. TRIAMINIC-12 Tablets: Adults and children over 12 years of age—1 tablet every 12 hours. TRIAMINIC-12 Tablets are not recommended for children under the age of 12 years.

HOW SUPPLIED: TRIAMINIC Syrup (orange) is 4 fl oz, 8 fl oz and pint bottles. TRIAMINIC-12 Tablets (orange) in blister packs of 10 and 20.

(For complete details, please consult full prescribing information.)

PREVENTION STRATEGIES

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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 — in which there is 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 the prenatal diagnosis of chromosomal disorders (particularly trisomy 21), with a potential for pregnancy interruption.
15) Screening of maternal serum for elevated alphafetoprotein 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 handicaps — such as deafness or Down’s 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 professionals — regarding the measures available to prevent retardation and disability.

These 20 programs represent the core of the modern prevention scenario, and all or most are commonly represented in the resolves of state agencies and private groups. Actually the potential impact on incidence and prevalence varies greatly among the various components.

DISEASE—SPECIFIC PREVENTION

Particular attention is often granted to some of the
disease-specific prevention techniques, since the outcome of these efforts is so concretely perceptible. The technology here is generally a product of molecular or cytogenetic studies, a valuable public application of scientific investigation. A measure of effect can be calculated for these programs, using the reference of a 1:10,000 incidence to represent 0.01% of the population. In this regard, let us examine the most prominent components, “The Biomedical Big Six”:

- Screening for congenital hypothyroidism. With a current incidence for this condition of 1:4500 births, with an effective technology, now with all 50 states involved in testing, and with treatment outcomes excellent, one can reasonably claim a prevention effect of only 0.02% or 2 per 10,000 total births.

- Newborn screening for PKU. The incidence here is about 1:14,000 (Massachusetts figure), compliance is high and testing efficient, and prevention of retardation by appropriate dietary management can be achieved. The prevention effect then is somewhat below 0.01% or 1 per 10,000 total births.

- Prenatal diagnosis for Down’s syndrome. Karyotyping of fetal cells to search for trisomy 21 is generally restricted to pregnancies of women 35 years of age and older, and these women now constitute about 15% of the mothers of new babies with Down’s syndrome (overall incidence 1:1000). The percentage of such patients tested has been steadily rising, is now at 25-35%, and may well level off at about 50%. Hence, a reasonable maximal prevention effect of 0.01% or 1 per 10,000 of the total births can be anticipated from amniocentesis.

- Public education regarding fetal alcohol syndrome. Current estimate for incidence is about 1:700 births. It is conceivable that vigorous publicity regarding this hazard will eventually reduce its occurrence by half, with an ultimate prevention effect of 0.08% (representing 8 per 10,000 of total births).

- Screening of pregnant women for neural tube defects by serum alphafetoprotein (AFP) measurement and followup. Myelodysplasia has an incidence in the United States of about 1:750 births, with approximately two-thirds of the live-born children having significant mental retardation. AFP testing has reached 50% of pregnancies in the United Kingdom, and is much lower here (but could achieve that level), with about 90% effectiveness in detection of the defect. Upon extension of these methods one could hope for a prevention effect of 0.05% (representing 5 cases per 10,000 births).

- Counseling regarding known genetic diseases. Guidance to families with Fragile-X syndrome, chromosomal translocations, inborn errors of metabolism (repeat occurrence of pregnancies with children having lipidoses, mucopolysaccharidoses, etc.), and in other unique pedigrees, can impact on the incidence of genetic disorders. Most optimistically, this could have a prevention effect of 0.01% (representing 1 in 10,000 of the total number of births).

These are active programs, which in the conglomerate might account for prevention of a maximum of 0.18% (8 per 10,000 of total cases) of births with a retardation occurrence. Others can be mentioned in which the natural incidence is sufficiently low that the statistical or public health significance is not oppressive, although the morbidity is compelling. For many of these, the interventions have now had critical value (congenital rubella, kernicterus, Tay-Sachs disease, measles encephalitis). In additional ones the effects of ongoing efforts are not yet known (e.g., children of women with “maternal PKU,” campaigns for child restraints in motor vehicles). All of these biomedically-oriented projects clearly cannot affect more than a small portion of the commonly expected 2-3% incidence of mental retardation in the general population.

On the other hand, when one looks at measures available for clinical intervention in the developmental area, it is immediately apparent that truly “The Big One” is the improved support now offered for the small premature infant and other troubled newborns. The provision of transportation and centralized intensive care for these at-risk infants has resulted in a simultaneous reduction in mortality and in compromised outcome. This has brought about a relief in developmental morbidity from about 10/1000 to 5/1000 for prematurity, constituting a prevention effect of 0.5% (representing 5 per 10,000 of total births).

It is difficult to quantify the product of other current primary and secondary prevention efforts. Improved prenatal care is certainly significant, as are social programs regarding children’s rights and health educa-
tion. Large elements of the incidence of mental retardation remain incompletely approached by prevention activities, however. These include:

- the vast majority of congenital anomaly syndromes, induced by unidentified prenatal influences
- the majority of occurrences of chromosomal aberrations, including Down's syndrome in children of younger mothers
- causes of encephalitis other than measles
- serious childhood behavioral disturbances and psychosis
- the very important component (one-third of the total) of retardation phenomena in which the causation still remains entirely obscure.

By current technology, we may be able to affect the incidence of perhaps 20-30% of mental retardation circumstances. For the rest, the situation is one of slippage in areas where we have knowledge, and, more importantly, an impact of factors which we can only partially perceive. It is certainly true that relevant social and environmental forces are extant, unfavorable to the hopes of our society regarding childhood outcomes. The challenge here is enormous.

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STATE PROGRAMS FOR PREVENTION OF MENTAL RETARDATION

In the United States, it is at the level of individual state planning (departments of public health and/or mental health) where the most vital program development is occurring. Particular leadership in this area has been contributed by California, Indiana, New York, and Virginia. A recent accomplishment of exemplary quality has come from Tennessee, with the report and recommendations of the "Governor's Task Force on Mental Retardation Prevention" (chaired by the Governor's wife, Mrs. Honey Alexander). This group reflected on the status of the field and the circumstances of their state, and brought out conclusions which can serve as a national model. As anticipated, there is a considerable inclusion of elements from "The Golden Twenty," but in a more visionary fashion they reached to broad social supports as continued on p. 457
central to their effort. The most important recommendations are for:

- access to quality prenatal care for all pregnant women
- family planning services available to every citizen
- family life education in the public schools
- nutritional screening, with supplements as needed to pregnant women and infants
- improved birth certificate information about status of infants
- availability of genetic screening, diagnosis, and counseling
- screening for neural tube defects
- better utilization of regional perinatal care centers, including transport services, physician education, and evaluation
- comprehensive followup of high risk infants, with linkage to appropriate services
- preschool screening of health, vision, hearing, and psychological development
- enhanced immunization programs
- newborn screening and followup for PKU and hypothyroidism
- programs for infant stimulation, parent training, and preschool education for retarded and/or at-risk children under four years of age
- comprehensive, state-wide planning for high risk and handicapped infants
- improvement in “Child Find” efforts
- state oversight of the Head Start Program
- evaluation of the impact of early childhood development programs
- state standards for early childhood education services
- coordination of prevention efforts by the “Children’s Services Commission,” with continuation of Task Force activities

Of particular note in the Tennessee program are the elements of access, standards, evaluation, and coordination, as well as the generic focus on pregnancy and early childhood as the pivotal periods. The direct involvement of the Governor’s office, and the establishment of the follow-up system for the program, are of special value.

Programs like that of Tennessee effectively address the gaps in the more specific conceptual model of prevention (as previously presented). The incompletely identified components in the genesis of retardation stand a significant chance of coverage in a system where support is given to humans in their critical developmental intervals. It is further gratifying that no hesitation is made regarding the provision of activities which could as well be labeled “treatment” as “prevention,” in the mode which is implicit in the concept of tertiary prevention. This principle is also emphasized in the recent annual report of the President’s Committee on Mental Retardation.3

CONCLUSIONS

Activities in the prevention of mental retardation have made substantial gains recently. A solid group of biomedical achievements has served to reduce significantly the incidence or complications of certain serious conditions, but limitations in the understanding of actual causation for many abnormalities places constraints on this approach. For a large portion of developmental handicap the solution presumably rests with more inspired supports to the pregnant woman and the young infant. Joint public and professional planning in this latter area will achieve important results. Further research and professional education are also needed.

REFERENCES


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