PART II

NEEDS OF HANDICAPPED YOUTH

Part II details our findings and recommendations for improving services to handicapped youth, with a chapter devoted to each of eight major service needs: prevention, identification, direction, medical treatment, sensory aids, special education, vocational services, and income maintenance.
Chapter 3
DIRECTION

INTRODUCTION

In view of the considerable sums of money expended by government and the private sector, why are the care and services provided to handicapped youth so deficient in many important ways, and why do many children still receive no services, the wrong services, or inadequate services?

Certainly, it is not because the country lacks programs for handicapped youth—we have discussed over fifty major programs in our survey of the current federal effort, and there are hundreds of state, local, and private initiatives. Certainly, it is not because parents of the handicapped are resigned or lethargic—many of them make heroic efforts to secure services for their children. And certainly, it is not because of significant deficiencies in the quality of care available—in 1973, the United States boasted some of the most advanced methods and technology ever devised.

Perhaps the easiest explanation would be to blame inadequacy of funds, and it is true that more money would certainly help. But resource insufficiency alone is not the answer to a basic problem that we find pervades nearly all aspects of the system: as it stands, the system currently delivering services to this nation's handicapped is so complex and disorganized as to defy efficient and effective operations.¹ Not all problems would be solved by pouring more money into the system without doing something about its disorganization and complexity. The $4.7 billion already spent annually could be used more effectively.

Specialization, fragmentation, and bureaucratization without coordination and direction underlie poor system performance. The tangled array of service programs severely taxes parents' ingenuity, perseverance, and courage as they thread their way through the official labyrinth seeking services for their children. Fully two-thirds of the parents we interviewed said they had difficulty in obtaining appropriate services.² Their own words express their frustration and despair far more poignantly than could the pedestrian language of a research report:

The parents are over a barrel ... whenever the mother of a "problem child" questions practices or "makes waves," the administrators threaten to exclude the child, and there is nothing that can be done about it.

There is no parental counseling, no referral; we were willing to try just about anything ...

The woman offered help, and I almost cried because I was so grateful ...

... a chain of talking and talking and talking ... [and] stumbling around from place to place ...  

² See Chapter 11 for a summary of these interviews.
There are so many government agencies, the people don’t know where to go.

I don’t even know what questions to ask.

Each major service program is designed to meet rather specialized needs; each has generated special constituencies and nurtured special interests; and each has its own separate budget, often not formulated according to any reasonable assessment of children's actual needs. Pity the unfortunate child who does not meet the letter or spirit of the law as "interpreted" in a federal or state bureau.

Some services are not a major responsibility of any program (see Table 3.1). We spend billions of dollars caring for handicapped children but, as following chapters demonstrate, we have traditionally spent very little on prevention or identification activities. This lack of responsibility for certain services is especially telling with respect to direction.

Direction is the periodic and systematic matching of a child’s needs with the proper mix of services to satisfy those needs. Individual needs change, for instance, as the child ages or improves in response to services; a system’s capacity to serve is dynamic, too. To put it somewhat differently, then, direction is an information-based service designed to match individual needs and local service system capabilities as both change.

Our society’s service system is faced with an urgent need to become child-centered, not specialty-centered. Currently, agencies and professionals are responsible for providing only one or a select few specialized services. Even assuming that each agency and professional performs well, the fact still remains that each single service meets only part of the child’s overall needs. We must begin to regard our handicapped children less as a faceless statistical group, and more as individual

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<th>Table 3.1</th>
<th>SERVICE COMPONENTS OF FEDERAL AND STATE AGENCY PROGRAMS FOR HANDICAPPED YOUTH</th>
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NOTE: M equals major component; m equals minor component; a dash (--) indicates little involvement.
fellow beings worthy of the utmost in respect and dignity—and attention. What is needed is an institution specialized to the job of looking at the child as a total human being.

The handicapped service system is not alone in suffering a lack of direction. We find it encouraging that a group of urban researchers, operating on a matter substantively separate from ours but conceptually similar to it, arrived at the same conclusion we did:

New institutional arrangements should be designed to use federal aids or grant conditions to help families learn about services that are available to them, to sort out what is available, to combine or help combine appropriately the many services (and their facility supports).  

This captures the essential spirit of what we mean by direction, but we develop and flesh out the concept considerably.

The remainder of this chapter discusses current service programs and their problems, desirable characteristics of a well-run direction service, some existing direction centers that are promising partial models, and some foreign models. The chapter concludes with a detailed discussion of the following recommendations for Regional Direction Centers for Hearing and Vision Handicapped Youth. When fully tested and developed for this population, the concept might be extended to include all handicapped youth and adults.

**SUMMARY RECOMMENDATIONS FOR IMPROVEMENT**

- Undertake full-scale evaluations of existing centers that are the most promising partial models for Regional Direction Centers, so as to learn their strengths and weaknesses and identify features worth incorporating in a nationwide network.
- Following those evaluations, conduct a detailed implementation analysis and then create five to ten pilot Regional Direction Centers for Hearing and Vision Handicapped Youth around the country. Such pilot operations should themselves be carefully evaluated.
- Incorporate in the Regional Direction Center design, needed improvements revealed by the pilot projects, and expand the concept as rapidly as possible into a complete nationwide network of Regional Direction Centers.

**CURRENT PROGRAMS**

As indicated in Table 3.1, the direction service is not a main order of business for any of the various types of federal or state agencies serving the handicapped. In one type of agency where such activities are carried out, public welfare, direction is not a central concern but occurs only tangentially as a social caseworker might be required or inclined to assess a client’s needs, search out the appropriate services, and then monitor the results. However, this program is restricted to the poor, social workers generally have heavy caseloads and are not rewarded for “direction,” and they do not have the information needed to direct the youth we are concerned with here. The Maternal and Child Health Service also sponsors programs that do limited

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4 See Rand Report R-1220-HEW, Chapter 7.
noncomprehensive referral. Therefore, Vocational Rehabilitation programs can provide a comprehensive range of services, but these do not reach young children, and services must be aimed at achievement of a vocational objective. Schoolteachers and nurses sometimes help parents find other needed services. Pediatricians sometimes help direct the family. In some states, the "Commission for the Blind" agency provides limited direction service to a segment of the handicapped population.

In general, however, direction is a distinctly underdeveloped and undersupplied service that is no one's prime responsibility. Follow-up and redirection, implicit in the notions of "periodic and systematic," are particularly underdeveloped. No one really provides this service except for isolated and dedicated professionals providing other services, who must make extraordinary and usually costly efforts to understand the overall system well enough to advise in areas outside of their particular service competence. Comprehensive information about the system is not generally available, and until it is, direction will remain stunted and erratic.

The upshot is that parents are confronted with an intricate maze for which there is no map, and are left almost entirely to their own devices to thread their way through it. Few of them know much if anything about the various programs when they start out, and there are too few guides that give the facts in plain unvarnished English on what is locally available and what to do to get it. But even the simple facts are not enough; parents need to be fairly sophisticated, and must set to work mastering the ins and outs of a complex, interlocking, and sometimes competing set of bureaucracies and professions. Even after they have succeeded in obtaining services for their children, the possibility remains that alternative services they are unaware of might do the job better. Although ignorance may be bliss, and a parent may report that he is "happy" with the services his child is currently receiving, it is regrettable that, without the aid of a quality direction service, he cannot tell if some other service might not be better for the child, short of experiencing it.

PROBLEMS WITH DIRECTION SERVICES

Matching the Child with Appropriate Programs

The symptoms of the system's direction deficiencies are everywhere evident. As with medicine, this disorder requires a thorough description of its signs and symptoms before any diagnosis can be advanced.

Parents are not made aware of what services are available and what their child is entitled to receive. There are no reliable sources of local information that routinely assist the parents of handicapped children. This lack of information and a systematic way of matching the child with the appropriate set of needed services is the major problem.

Records are generated by many different agencies as the child moves, characteristically in chain-like fashion, from one service provider to another. There is no comprehensive compilation of all information generated by the individual child, with the immediate result that rediagnosis and recertification are commonplace.

Data that are collected reflect specialized institutional biases. Measures tend

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5 Ibid., pp. 215-220.
6 Ibid., Chapter 5.
therefore to be unidimensional and programmatic, and to miss much of what is happening to the individual.

Without the records a direction center could keep, problems arise in interpreting data. For instance, does an increase in the reported incidence of a disorder reflect an actual trend, or is the disorder merely being identified more vigorously? If such an increase is noted, is the information "translated" into messages to separate parts of the service delivery system so that adjustments should be anticipated at some future date to reflect the shift? Direction Centers could do this. The tragedy of rubella-caused handicaps in children is an obvious case in point. Since at least 1964-1965, the rubella-caused bulge in the incidence rates of aural and visual handicaps has been known, but there is little evidence that separate parts of the service system were forewarned, or that the system prepared for and responded adequately to these changes.

Data are usually outdated by the time they are finally reported, and once reported, they characteristically are cross-sectional not longitudinal. Planners have to resort to educated guesses to make marginal, time-dependent adjustments in service supply in the absence of time-series data on service demand.

Data often exist, but not in the public domain. Health information is particularly susceptible to this limitation, as in the case of the severely handicapped children of those wealthy enough to afford private services, or in those cases where a social stigma is associated with the disorder. No one has reliable information on how much aid is provided to the aurally and visually handicapped by churches, voluntary agencies, and specialized private agencies devoted to narrow classes of handicap.

The dissatisfied parent is often at a loss to know where to take his grievances, real or imagined, for settlement, or whether grievances are handled at all. Unfortunately, very few agencies are specialized to the redress of administrative or legislative oversight, and redress mechanisms within service agencies are generally very cumbersome, with the result that a parent has little or no effective recourse.

Families typically proceed serially from agency to agency. In the process they are liable to be "captured" by one agency whose services may appear to the parent to be adequate, or at least better than no service at all. The degree of misdirection owing to "capture" is simply unknowable, given the present state of information in the system. That it exists, however, is unquestionable; likewise indisputable is the knowledge that it results in a less than optimal or comprehensive delivery of required services.

Different Perspectives

One way of better understanding direction problems is to examine the process responsible for it from the perspectives of several of the main participants: parents, professionals, and decisionmakers.

Parents. After all is said and done, the parent bears ultimate responsibility for the handicapped child. Our society has consistently and clearly operated to give a parent the widest possible latitude and license for child rearing. However, a parent does not have to secure fully adequate health services, feed his child properly, provide a solid home environment, care about the emotional development of the

* This is a main issue underlying weak and hard-to-enforce child abuse statutes. Mentally ill parents also present extraordinary problems that are frequently "insoluble," due in large part to this durable societal norm. See E. Pavestatin and V. W. Bernard (eds.), Crises of Family Disorganization, Behavioral Publications, New York, 1971, especially, V. W. Bernard, "Young Children of Mentally Ill Parents." See also Vincent Fontana's recent popularized account, Somewhere a Child is Crying, Macmillan, New York, 1973.
child, or even feel and convey those basic instincts commonly labeled "love." About the only area where society demands adequate minimum service is education, but as recent class-action law suits brought on behalf of the mentally retarded in several states show, even this minimal societal demand has not necessarily held for handicapped children.

Over-protective parents create problems of a quite different sort. Parents of handicapped children may internalize the guilt they associate with having a defective child; their resulting over-protection works to perpetuate the handicapped person in the role of the dependent child. There are varying degrees and manifestations of the problem, but it is understandably common and ordinarily works to limit a child's participation in the decisionmaking and mistake-making process of growing up.

Our society operates on the pervasive but erroneous assumption that the parents of handicapped children, like any other consumers, have unrestricted choices about the services they obtain for their children. In fact, most parents have neither the resources, nor the information on which to base choices. Furthermore, existing institutions sometimes exacerbate the problem with unwitting incentives to use one service mechanism rather than another, e.g., insurance plans generally contain incentives that encourage differential use of facilities and services and discourage active exploration of creative and less costly alternatives.

The reality of the situation is that the parent generally is an ignorant consumer. He does not have all the information needed to assess the services received and to choose among alternative service providers. Both of these essential truths have consequences for the overall system.

Because the parent does not have all the information needed to assess service well, he may receive either too much or too little of that service. With medical services, for example, a person may be "overdoctored," receiving more services than he actually needs or would buy if he were fully aware of their effectiveness; or he may be "underdoctored," receiving fewer services than he needs or would buy if he were less ignorant and could afford them. The latter case is an error more likely to afflict the poor; the former is a rich man's error. Traditional market signals are

9 This is not a frivolous point. It formed the basis for an interesting presentation by Mr. Fred Krause, Executive Director of the President's Committee for Mental Retardation, to the 24th Annual Convention, National Association for Retarded Children, Anaheim, California, November 1979.
13 One of the main objectives of an ongoing National Health Insurance social experiment is to examine the effects of such embedded assumptions and incentives in as controlled an environment as is practicable. See Joseph P. Newhouse, A Design for a Health Insurance Experiment, The Rand Corporation, R-965-OEO, November 1972.
14 Richard Zeckhauser clarified several of the key points in this portion of the discussion. Private conversation, February 1973.
not much help in resolving the matter.\textsuperscript{17} There is no clear-cut relationship between the price of a service and its general quality or specific appropriateness for a given child. For example, a relatively inexpensive, but appropriate, correctly fitted, and well-maintained hearing aid certainly is better than a costly one that lacks these properties; but the ignorant consumer who does not know the difference, may well put his trust in the costlier one because "they couldn't charge that much if it weren't really better."

When a parent is unable to choose effectively among providers of a common service or to determine the appropriate mix of required services for his child, what does he do? Traditionally, he asks a physician. But the physician, except for the unusual "resource man," does not have the amount and kind of information needed, either; it is understandable that he has few incentives to learn details about the whole service system in his locale, or to take time away from his specialty to give advice about such diverse matters as special education, rehabilitation, or financial assistance—nor should he. Social workers often fill the information breach, but with a large and diversified clientele and with little or no specific preparation, this alternative is a far from optimal solution to the problem.

The problem has been discussed by economists from time to time.\textsuperscript{18} One finding is that lack of information is a basic cause of the large and inequitable differentials in the amount and quality of services delivered by the private and public sectors and in different regions of the country\textsuperscript{19}—differentials repeatedly pointed out in our companion report R-1220-HEW.

**Professionals.** Professionals are commonly captives of their professions—their imperatives, perspectives, and tools. Psychiatrists, mostly liberal in their general views about humanity and human behavior, sometimes become very conservative when it comes to specific details about service delivery.\textsuperscript{20} They wear psychiatrists' glasses. Ophthalmologists wear glasses of a different refraction and tint, teachers wear yet another, and so forth.

To be a specialist means that one has concentrated on a limited field of knowledge; however, there is a mismatch of impedances, to borrow a communication term and concept, between this specialized information and the general, comprehensive information required by the family of a handicapped child. The family needs a great deal of information, at not too detailed a level, compiled in an easy-to-understand format or package, and touching on all matters affecting the particular child and his changes in the future.

The artificial boundaries created by fractionalized professional groups have led to compartmentalization, not integration, of services available to handicapped children. Specialized services are required, but those providing them do not have the time to appreciate the client as a whole person. And a limited perspective, trained into the specialized professional and reinforced in daily practice, intensifies his


\textsuperscript{20}The issue has been treated clearly and compassionately in John E. Kysa, "Reactions of Professionals to Disturbed Children and Their Parents," *Archives of General Psychology*, Vol. 19, November 1968, pp. 562-570.
isolation from specialists in other fields.\textsuperscript{21} In the words of another of our survey mothers,

No one ever put all the pieces together. We only got the service that we asked for. No one ever tried to put all the clues together to move beyond the immediate problem. Doctors were not concerned. They kept coming up with the same diagnosis and did not listen to me or look through the histories.\textsuperscript{22}

"Putting the pieces together" is what direction is all about.

Little wonder that we find so many parents are distraught and bitter over the specialist's "lack of concern" and mystifying lack of information about other types of services the child needs. We demand entirely too much of the specialist when we expect him to be a generalist in providing complete information about the whole child—that is not his job, although people often imagine it to be, particularly the parents of a handicapped child.\textsuperscript{23}

\textbf{Decisionmakers.} Specialization has its administrative and political features, and its implications are none too good for the handicapped child and his family. The number and diversity of the individual agencies have created a domestic situation of curious proportions, characterized by a strange construction put upon "responsibility." One is responsible only for actual events; if little or nothing happens, then it is hard to be "irresponsible," in the bureaucratic sense. Consequently, except in a crisis, the safest bureaucratic course is to change nothing. This is a possible rationalization, for example, of the observed noncommunication of research results to the more operational segments of the overall service system. Not only are the links among those specialized in research and those concerned with service delivery tenuous or nonexistent, but there are disincentives that reinforce customary behavior.\textsuperscript{24} An informational service should take this into account.

Bureaucratic pathologies, many of which are firmly rooted in the size and diversity of administrative systems, are well known and have been discussed in many standard works.\textsuperscript{25} Disorderly symptoms are indicated in many aspects of the system serving handicapped children and youth; they include a penchant for treating administrative systems in isolation, a failure to deal effectively with clients as total human beings, and restrictions that inhibit the client from having direct access to the administrative apparatus, a pathology thought to be especially severe for the poor.\textsuperscript{26} Because of bureaucratic complexity, in short, there is less than comprehensive interest demonstrated for the client, and the system assigns no specific responsibility for the client's overall welfare and treatment. The responsibility is diffused throughout the system, and the more complex the system, the more the responsibility is diluted.

The informational implications of these pathologies are several. Specialized agencies at best collect data for their own narrow operational purposes, not for sharing with other agencies. As a result, there is no general source of factual information and material about the handicapped.\textsuperscript{27} Besides not transmitting even

\textsuperscript{21} This point is made forcefully in R. E. Hoover, "The Ophthalmologist's Role in New Rehabilitation Patterns," \textit{AMA Archives of Ophthalmology}, Vol. 78, No. 5, November 1967.

\textsuperscript{22} Interview \#1016, p. 6.


\textsuperscript{24} Rand Report R-1220-HHW, pp. 127-130, 221-228, 233, 237.


\textsuperscript{26} Gideon Sjoberg, Richard Brymer, and Buford Harris, "Bureaucracy and the Lower Class," \textit{Sociology and Social Research}, Vol. 50, April 1966, pp. 325-337.

scanty operational data to other executive agencies, the system gives little help to legislative decisionmakers. Lacking even crude summary information, political decisionmakers have a hard time making rational, equitable, or humane judgments about new policies and programs on behalf of a defined clientele. Even if they were to get the facts, legislators have next to no resources to analyze and interpret them. The size and specialization of the handicapped service system works to the advantage of well-organized groups who may present only that part of the case redounding to their limited clientele's advantage. The information market is distorted and grossly imperfect at present. Direction Centers could collect and pool much of the needed information.

One desirable recourse—and this represents a major reorientation—would be to devise procedures and institutions that could examine the effects of all pertinent services on the lives of the people who receive them.

DESIRABLE CHARACTERISTICS OF A DIRECTION SERVICE

Several general characteristics can be designed into a direction service to enhance its effectiveness. There is a need to structure direction so that, consistent with the individual's and society's limited resources, the handicapped person has improved chances to become as independent as possible, and to round out his development with as many services as he can profit from. At the same time, the incentive systems that motivate agencies and professionals should be structured so as to marshal their full support behind the handicapped person and his family in their efforts to obtain the mix of services they need. Rather than an assortment of uncoordinated service agencies, many of them unknown to the handicapped person, and offering a tightly restricted range of services, the handicapped person requires some coordinated and flexible means of finding out what services are available and where to go to get the ones he needs.

Two general perspectives are to be considered in designing an improved direction service: the individual's and the system's.

Individual Design Perspective

Because the current service system is demonstrably unresponsive in important ways, it is necessary to build in counterfragmentary, counterbureaucratic, and counterspecialist structures and incentives at a localized service delivery level to insure that equitable and effective care is received. The following list of requirements summarizes how this might be accomplished.

*Develop a One-Stop, General Information Service.* An institution specializing in direction could answer the following types of questions for parents of handicapped children:

- Where does one obtain general help and guidance in rearing a handicapped child?

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28 The difficulty has been summarily treated in Donald C. Menzel, Robert S. Friedman, and Irwin Feller, *Development of a Science and Technology Capability in State Legislatures,* Institute for Research on Human Resources, University Park, Pennsylvania, June 1973, p. v: "The professionalization [specialization] of public agencies has produced, in brief, a new problem: a substantial and steadily growing imbalance, between executive and legislative capabilities to initiate, critique, and evaluate public proposals and ongoing programs. This problem is not due to inadequate expertise in state government; it is the result of the unequal and uneven distribution of existing expertise." (Italics omitted.) This is another way of stating the point we are making.
• What medical care is required and available; where is it located; how does one obtain it?
• What educational services are required and available; where are they located; how does one obtain them?
• What sensorial aids are required and available; where are they available; how does one obtain them?
• Where are counseling services available to help the family to understand the special emotional demands created by having a handicapped child?
• What vocational opportunities and services are available; where are they located; how does one obtain them?
• How much will it cost and where does one obtain financial assistance if needed, to pay for the services required by the child?
• What should be done (or not done) to encourage a handicapped child to become as independent as possible?

*Demand a Multidisciplinary Effort.* Such an institution must strive to be as explicitly multidisciplinary as possible to avoid undue emphasis on certain types of services, to integrate the many specialized services the client needs, and to provide a client-oriented interface with the dispensing specialists.29 Experts from various disciplines with special skills in working with hearing and vision handicapped persons should be included.

*Emphasize a Temporal Dynamic, Not Static, Orientation.* There is a clear need to integrate the planning to meet an individual’s service needs, and later to evaluate the effects of services so that changes in the child’s needs are accounted for as they vary over time in response to changes in the life situation and in response to service provision.

*Create Distinct Administrative Roles and Functions.* A good direction service should be continually apprised of the status of all eligibility regulations and availability conditions for services from other agencies. It should maintain an active appointments process on behalf of handicapped clients, and in so doing it will generate a network of service contacts. The direction service should promote procedures for recall—for example, in the event that services become locally available or anticipated changes occur in the child’s situation; and procedures for follow-up—for example, in the event the parents themselves do not or cannot obtain recommended services from other agencies.

*Maintain Each Individual’s Service Information.* A direction service should compile and maintain records of all services each client receives including updates, service terminations, and parents’ assessments of their satisfaction with the service. These records would be made available to other service providers, with confidentiality safeguards invoked as appropriate.

*Foster Client Participation in the Direction Service.* Active involvement by parents could at least partly relieve some of the negative feelings many of them have developed under the current system. Numerous researchers and commentators on the general subject of citizen participation offer evidence that the chance to participate can do much to alleviate people’s sense of frustration and powerlessness, and perhaps a little—admittedly, not much—to win over the alienated.30 This design

29 R. M. Flower, H. Gofman, and L. Lawson (eds.), Reading Disorders, F. A. Davis, Philadelphia, 1965, makes an exceptionally strong and lucid case for a multidisciplinary approach to handicapped care and service provision. The bases of their argument are implicitly founded on the general concepts of specialization developed earlier in this chapter.

objective is not novel, but the direction service appears to have a particularly attractive opportunity to realize it.

**Foster the Humane, Personal Dimension.** Success for the service system can be defined in many different ways, ranging from maximizing the individual's capabilities to planned dependence. But however one defines success, it will be the greater if the system can win the child's trust and the trust of his family, and if an empathic service-provider gives enough of himself and of his time to understand each child and devise a personalized, comprehensive program fitted to the child's specific needs. The direction service is the best place to perform this function.

Running the direction service efficiently of course will contribute to success, but does not constitute success; efficiency should not be allowed to become an ingrown end in itself, to the detriment of personal attention to each child.

Together, these individual design characteristics for the direction service constitute a coalescent force and major supplement to the current fractionated system, in which "success" sometimes consists of shoehorning the client into a prefabricated single program instead of seeing how well the services can be made to fit the client's needs. Lawyer Thomas Gilhool, commenting on his successful class action on behalf of mentally retarded children in Pennsylvania, summarizes the distinction succinctly:

"This is a case where the class must fit the child instead of the child having to fit into any class room ... This is a new language, a new set of facts, and it will mean a new concept of oneself by those with handicaps of any variety."

It is a concept well worth developing and one that is implementable through a direction service.

**System Design Perspective**

As the sheer number and complexity of agencies and professionals increase, the odds diminish that any one of them could provide for all of a handicapped client's needs. The concept of a "direction center" as a distinct social invention should

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Both studies stress that increased participation of the sort envisioned here could do much to decrease the powerlessness and frustration many people feel when dealing with large and complex systems; they are not so sanguine about the likelihood of reducing alienation, a condition that appears to arise from a variety of factors not easily affected by increased participation alone.


33 See Rand Report R-1220-HEW, Chapter 4.


enable many specialized talents to be brought to bear more effectively in the service of the child and his needs. To this end, several desirable design characteristics, discussed below, will allow the direction center to relate and interact with the existing system.

**Foster Comprehensiveness of Service Scope.** All types of service needs affecting the hearing or vision handicapped child must be identified and accounted for by direction service personnel. The problem is to coordinate a variety of service professions. The direction service personnel could provide outreach, diagnostic, planning, referral, and follow-up services themselves or through consultants. Traditional providers of other services—e.g., medical, special education, vocational rehabilitation, and welfare—would still provide those services. Thus, the present service system would not be circumvented or duplicated, but rather would be complemented and made more effective by the direction centers.

**Serve All Hearing and Vision Handicapped Youth in the Local Region.** A direction center can achieve its maximum potential only if it is located close enough to the handicapped youth’s home so that he can reach it without excessive travel, and if all hearing and vision handicapped youth in the region are served without discrimination.

**Concentrate on Evaluation from the Individual’s Perspective.** Sound evaluation of a single client’s service package, and of the service system, depends on the collection of sound and complete information.

Before a child’s total needs may be determined, past records must be compiled and gaps in the current package of services received must be sensed. Once an initial evaluation has been completed, a suitable list of goals (with a timetable for achieving those goals) may be developed. Once established, these goals become clues about the kinds and amounts of service needed in the short and longer terms. In the aggregate, such clues may signal needed current or future reallocations or adjustments in the overall service system. This process has been described by Knott for rehabilitation, although its application is clearly more general:

Ideally, setting of goals is accomplished in patient evaluation and re-evaluation conferences where all the professions concerned may contribute suggested goals and methods of achieving them, and even more important, where agreement can be reached on a program of unified action.

Evaluations of the system, its components, and overall performance are to be encouraged. What we have in mind was suggested by a current practice employed by several state Crippled Children’s Service Directors. Over a period of time, some service providers perform more notably than others; they may have more positive medical results, work for lower fees, or generally be regarded more favorably by the parents and children. A valuable by-product of an on-going utility analysis and evaluation of all service received would be the identification of superior providers and of new and better services. Changes in the characteristics of the handicapped population could also be sensed, and therefore the need for compensating changes in the service system.

**Stimulate an Active Outreach/Identification Program.** As Chapter 4 demon-

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37 Cubelli, op. cit.

38 Working from different premises and considering a vastly different assortment of program areas, Peter Drucker has developed a compatible list of general objectives for public service institutions: “Managing the Public Service Institutions,” *The Public Interest*, No. 33, Fall 1973, pp. 43-90; see esp. pp. 58-59.

strates, the identification of handicapping conditions is not being vigorously pursued. A direction center could be an important agent in coordinating screening and case-finding activities, and insuring that follow-up procedures are instituted once a hearing or vision handicapped child is discovered. Early preschool identification and service of the deaf could be an especially desirable effect of the direction centers.

Concentrate on the Practicality and Feasibility of Services and Programs. Since not all parents of hearing or vision handicapped children can be fully informed and unbiased consumers, a distinct function for a direction center would be to monitor the match between a child’s realistically determined needs and his ability to benefit from services received. While the problem of under- and over-service will always be with us, it doubtless could be reduced if sufficient attention were paid to this design characteristic. It could also be reduced as good evaluation information becomes available.

Serve as a Local Spokesman for Hearing and Vision Handicapped Persons Generally and for Individual Clients Particularly. The direction center, as conceived here, would be an important focus for citizen needs and expectations. It is a place in the system where grievances may be aired—a place that does not currently exist. Specifically, a direction center could become a local "court of appeals" to which bureaucratic and other grievances could be taken, particularly if there were reason to believe that the general rules or treatment were invalid or unjust in an individual case. It could also become an articulate and well-informed spokesman for handicapped persons in general, in promoting changes in the supporting service system.

Reconfigure Existing Control and Incentive Systems. To attain maximum quality in the direction centers, new lines of authority and new professional identifications will probably have to be organized. In particular, a shift in traditional allegiances will be called for:

- Allegiance not to a currently existing professional field or specialty;
- Allegiance not to current programs, the people who operate them, or agencies that perpetuate them;
- Allegiance not to the status quo;
- Allegiance not to social and professional etiquette that frowns on the raising of unpopular issues;
- Allegiance to handicapped people wherever they are, and to their needs, interests, and aspirations.

To operate in this new mode, it is fairly obvious that a direction center will have to be independent of existing service agencies. One idea might be to create a line of authority and control running from the various local direction centers directly to an advisory council at a higher level of government, which, in turn, does not report to any of the existing service agencies, but rather to the governor. Funds for the direction center would thus flow from a line in the budget separate from other services for the handicapped.

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40 W. Hoff has elaborated this point with skill and compassion. See his "Why Health Programs are not Reaching the Unresponsive in our Communities," Public Health Reports, Vol. 81, July 1966.

41 With respect to hearing standards, Howard House has been an advocate of the "court of appeals" concept; we are arguing that it is more general. See his "Hearing Standards—Fact or Fiction?" Arch. Otolaryng., Vol. 90, August 1969, pp. 208-213.


43 A similar recommendation appears in New York State Committee for Children, A Child Advocacy, System in New York State, Albany, New York, November 30, 1971. We discuss the New York creation in a following subsection.
Satisfy Existing Federal Requirements for Service Integration. A legal requirement to coordinate federal grant-in-aid programs exists in the form of the A-95 review process, a provision of Title IV of the Inter-Governmental Cooperation Act of 1968. There is no reason to assume that provisions of A-95 cannot be carried out on behalf of citizens in a target population, such as the handicapped, as well as generally throughout a geographic area. Regional direction centers could receive a legal boost via amendments and clarification of the basic, existing A-95 provisions. The objective of these adjustments would be to coordinate programs, but to do so directly on behalf of the individual intended service recipients. An already existing regional bias in current federal administrative practice may contribute to the implementation of direction centers; furthermore, a regional bias appears to square with the realities of the size of, and practical means of serving, the handicapped population generally.

EXISTING PARTIAL MODELS OF DIRECTION CENTERS

Many current programs are partial approximations to the design characteristics just described. The following discussion has several purposes: to show that each design characteristic is feasible; to indicate where one might wish to conduct more detailed studies and analyses to assess relative strengths and weaknesses before trying to implement features of the illustrated cases; and to confirm the appropriateness of the design characteristics themselves (for example, direction services that incorporate relatively more of the characteristics are "better" than those that incorporate fewer).

Partial models exist in many locations, because the problems of direction are general. Here, we review programs in only a sample of those locations (first in the United States, then in foreign countries). No one model, to the best of our knowledge, is complete enough to be labelled "ideal," and, hence, apt to be easily transferred and replicated. But several of them embody promising features.

The first three partial models we discuss are ambitious activities, representing three quite different strategies of implementation for our recommended direction service. In late 1971, the New York State Committee for Children proposed to Governor Rockefeller that an ambitious "Child Advocacy System" be implemented as rapidly as possible to alleviate many direction-related crises;44 the Maryland State Department of Education, using ESEA Title VI funds, has designed and begun to implement a "Maryland State Data System for the Handicapped";45 and the program of Regional Diagnostic, Counseling, and Service Centers for the mentally retarded of California, in operation since 1965,46 has been widely acclaimed as a breakthrough in service provision.47

We have selected these three activities for first presentation because individually they embody and extend the concept of direction in tangible ways, and because collectively they represent a close approximation of the direction service we recom.

44 Ibid.
46 California Statutes of 1965, AB 691, Chapter 1242, pp. 3106-3108.
47 In a covering letter introducing a brochure popularizing the program and explaining the legislation as amended in 1971, Governor Ronald Reagan observed about the "Lanterman Mental Retardation Services Act": "That progressive legislation provides us with a dynamic framework on which we shall build a comprehensive system to assure that the mentally retarded develop to the fullest extent of which they are capable."
mend on a national basis. We believe that most of our direction design characteristics could be realized by a selective, thoughtful, and careful amalgamation of the better features of these examples.

**New York State's "Child Advocacy" System**

The New York State Committee for Children has devised a highly interesting plan that is still in the proposal stage. Reporting to the Governor in November 1971, the Committee recommended the creation of a State Child Advisory Commission and local advocacy councils that "would have the power and the duty to review present services to children, to suggest changes and to represent the interests of children."48

This concept included a state-level commission, "independent of existing departments of state government and able, therefore, to keep as its central responsibility a concern for the welfare of all children."49 Locally, the intent of the proposed system would be carried out by "advocacy councils with a responsibility for all children in their localities, with the power to gather information, respond to felt needs, and recommend changes as indicated."50

Costs were intended to be minimized by manning the local councils with voluntary personnel. The recommended budget for the first year of operation of the State Commission was $350,000, some $350,000 of which was earmarked for staff support and travel, and the balance "to be used to support the development of a number of pilot programs at the local advocacy council level."51

The composition of the State Commission was recommended to be 100 members, from a variety of prescribed professions, socioeconomic strata, and age categories. Parents would constitute at least a 51 percent majority but no more than 70 percent. Commissioners would serve by gubernatorial appointment for terms ranging from one to three years. The State Commission itself would report directly to the Governor on matters of policy and operational significance affecting the lives of children in New York.

The local advocacy councils are intended to be major points of citizen access for direction service, and would report directly to the State Commission on their operations and findings. It was hoped that compiling legal compendia and rosters of locally available services would satisfy information deficiencies, and that review, evaluation, and fact-finding would improve performance. Various specific duties and powers are also spelled out, which approximate some of our direction service design characteristics.52

The Child Advocacy System concept is interesting and important for several reasons:

- It recognizes the need to complement the existing system, and to do so with clear lines of authority and control running directly to the Governor, rather than running through the existing service agencies.

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48 New York State Committee for Children, p. 1.
49 Ibid.
50 Ibid., pp. 1-2.
51 Ibid., p. 8. Also (p. 2), "the Commission shall seek federal funds as they become available."
52 In a recent, sensational-provoking report, "Juvenile Injustice," seven present and former judges and a number of senior administrators of the New York Family Court charged that the system was failing to such an extent that "changes must be made before yet another generation of children is destroyed." Peter Kibes, "Children's Justice Called a Failure by Judicial Panel," *New York Times*, October 29, 1973, pp. 1, 25. This represents yet another manifestation of the general problem, but this time as it appears in the treatment of children by the judicial system.
• It stresses the perspective of the individual and his family, not that of the existing system or its specialized constituents.
• It values the importance of information as a resource to be used in a two-way communication process: direction to the parents and feedbacks about performance to those most generally responsible for that performance.

But,

• Final implementation design of the general concept and system is not complete. Governor Rockefeller's letter of receipt for the report contains the closing line, "I look forward to seeing additional details of the child advocacy proposal as it is further refined." 

Maryland State Data System for the Handicapped

Maryland officials have begun implementation of a state data system for the handicapped that collects and centralizes information from the state's current scattered programs. They have generated an important piece of an emerging direction service, but the "piece" suffers from want of being integrated into a general concept and overall direction system, such as the one proposed in New York.

The technical problems associated with any large, information-based activity, such as direction, are certainly many and difficult; however, they are manageable if due consideration is given to system design and early implementation.

A technically adequate "Data System for the Handicapped" (DSH) is being implemented in Maryland and reportedly has over 70,000 children registered. The Maryland proposal for this data system requesting early implementation funding called for $123,144 and contains an impressive list of reasons and anticipated benefits for the system, most of which have been generalized in our direction design characteristics. Among the striking facts already discovered during implementation is the finding that the average lag time between the identification of a handicap and the commencement of services is excessively long: 500 days for the hearing impaired and 131 days for any handicapped child requiring residential school services. It was also found that of the handicapped children known and registered in the DSH, approximately 7000 were identified but not yet served.

An issue with the DSH, as with all public data systems, relates to privacy safeguards. It is a problem that threatens both present and future efforts to manage information on and for the handicapped; however, ways to resolve the problem are presented in the recently completed Report of the Secretary's Advisory Committee on Automated Personal Data Systems, compiled for the Secretary of HEW. It would be unfortunate if the inroads made in Maryland toward resolving the technical information problems of direction were subverted for nontechnical issues and

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83 Letter, Governor Nelson A. Rockefeller to Dr. Alan D. Miller, April 4, 1972.
84 Besides the Deaf-Blind Centers Information System reported on later in this chapter, the following related development is notable: C. Valbona et al., "An On-line Computer System for a Rehabilitation Hospital," *Methods of Information Medicine*, Vol. 7, January 1968; for a less technical description of this system, see Nancy De Sanders, "Computer's Basic Plans Help Doctors Initiate Rehabilitation Regimen," *Modern Hospital*, Vol. 119, November 1969, pp. 97-100.
87 *Education Daily*, same issue, p. 3.
88 Ibid.
reasons that are in principle resolvable. Another problem noted by those responsible for the Maryland system is the reluctance of some parents to have their child labelled as “handicapped.” Data forms and the official name of the system are being changed to alleviate this problem.

California’s Regional Centers

In 1963, the California State Assembly created a subcommittee to investigate the problems confronting the mentally retarded generally and to make legislative recommendations. It did so in response to many fundamental questions about the care provided to the mentally retarded in California, and before deciding whether to increase the state’s investment in residential mental institutions. In 1965, the subcommittee reported its findings—and they were startling:

- The mental hospital represented the only major means for the mentally retarded to receive state aid.
- Long waiting lists impeded even this one option.
- These people do not need all of a hospital’s services but, in the “all or nothing” situation then prevailing, they often got them anyway.
- Little or no help of any kind was locally available from the public service sector.

The subcommittee recommended the creation of regional diagnosis, counseling, and service centers for the mentally retarded—a recommendation contained in Assembly Bill 691, 1965, truly a landmark piece of legislation.

The “regional centers” thereby created were to provide the following services:

- Diagnosis;
- Counseling on a continuing basis;
- Provision of state funds to vendors of services, when, lacking such services, the only recourse would be institutionalization;
- Maintenance of a registry and individual case records;
- Systematic follow-up and reactivation of cases if needed;
- Assistance in state hospital placement when necessary;
- Education of the public about needs and capabilities of the handicapped;
- Staffing according to standards set by the State Department of Public Health.

The regional centers idea started in 1966 with two pilot projects, one in Los Angeles and one in San Francisco, operating on a budget of some $600,000. By FY 1974 it had grown to an over-all $22.2 million proposition, with 14 centers operating.


60 Documentation describing the regional centers is complete and clearly presented. See, e.g., Edgar W. Pye, California’s Regional Centers: Gateway to Services for the Retarded, Bureau of Mental Retardation Services, State Department of Public Health, Berkeley, Calif., 1970; State Human Relations Agency, Lanterman Mental Retardation Services Act, Sacramento, Calif., 1971; and “Lanterman Mental Retardation Services Act,” Liaison, Vol. 2, No. 2, March 1973 (Sacramento, Calif.). Performance data are not as complete or available.

61 One source specifically notes the importance of the creation of the President’s Panel on Mental Retardation in 1962 as a stimulus for California to look more carefully at problems confronting its mentally retarded. Pye, op. cit., p. 1.


63 California Statutes of 1965, AB 691, Chapter 1242, pp. 3106-3108 (cited provisions at p. 3107).
throughout the State and a small additional number being discussed. Of course, this budget is not all for direction, as many other types of services are purchased.

Regional centers have been embedded in an institutional framework that in 1971 include 13 Mental Retardation Program Area Planning Boards, responsible for planning and coordinating all mental retardation services in their respective planning areas and representing parents (25 percent), professionals (50 percent), and representatives of the general public (25 percent) in each of its 14-to-19-member bodies. At the State level there is a Mental Retardation Program Advisory Board, responsible for developing a statewide plan based on county and area proposals and for advising the State executive and legislative bodies about the status and needs of the mentally retarded throughout the state. Budgetary and primary responsibility for implementing the plan rests with the Human Relations Agency, its Office of Mental Retardation, and other of their subordinate activities.

The regional centers themselves are staffed somewhat differently in each situation, reflecting local needs and the availability of personnel; however, the staff and the caseload of the Golden Gate Regional Center in San Francisco are at least illustrative. In addition to a director and associate director, it includes a senior staff physician, a public health nurse, a chief of administrative services, a chief counselor, a supervisory counselor, and ten staff counselors "... whose professional training is in social work. And the counselors are stationed in the communities for which we relate our services." The active caseload reported on January 1, 1970, was 450, of whom 230 were receiving services provided and paid for, in whole or part, by the regional center.

The regional centers strive to follow a "Case Management Flow Process," the details of which were described for us by Dr. Charles Gardipee, Chief of the California Bureau of Mental Retardation Services, in the following terms:

- Screening, with the option to refer the client out of the regional center to some other more appropriate service, if required.
- Intake interview, with an option to refer out. At this point a complete information file is collected from all public sources and, to the greatest extent possible, private ones as well.
- Initial case staffing, where information developed in the intake interview is evaluated by a committee or board of the regional center including social workers, doctors, and medical administrators.
- Case staffing and creation of a plan for the handicapped client, tailored to his needs to the extent services are locally available.

In recognition of his central and faithful role in the invention and implementation of the regional centers, new and expanded legislation bore the name of Frank Lanterman, Assemblyman, 47th District, Pasadena: "Lanterman Mental Retardation Services Act of 1969," California Statutes of 1969, AB 225, Chapter 1984.


Lanterman Mental Retardation Services Act, p. 9. These people must also reside within the planning area.

The Board's composition is defined by terms of California's AB 225 of 1969 and includes voting members: two from the public at large, a parent of a mentally retarded child who is a patient in a state hospital, a parent of a mentally retarded child who is not in a state hospital, a county supervisor, and one member from each of the following professions: medicine, psychology, social work, nursing, education, and law. Appointments to the Board are shared on a formula basis by the Governor, the Chairman of the Senate Rules Committee, and the Speaker of the Assembly. Service is without material compensation.

Pye, op. cit., p. 7.

Ibid., p. 9. The 450 figure is static and does not represent an annual figure.
• Execution of the plan.
• Review and evaluation of the plan and the client's progress based on the criteria established during the case staffing and planning phase.70

The average annual professional costs for each regional center are estimated to be approximately $250,000 for purposes of his analysis, although in practice this estimated average probably varies considerably (see Table 3.2). The State Budget for FY 1972 allotted the following funds to these regional-center-related activities: case funding and identification, $1.6 million; case evaluation, $3.9 million; and case management, $1.8 million; for a total of $7.3 million. A simple average for each functional activity per center funded in FY 1972 would then be $123,000; $300,000; and $138,000, respectively, or a total of about $560,000 per center per year. Since this program is in its initial rapid expansion phase with attendant initial staffing and facility costs and the caseload during that phase consists of persons requiring, primarily, initial intake and direction, meaningful long-term average annual costs per case are not available.

Table 3.2

ESTIMATED PROFESSIONAL PERSONNEL COSTS PER ANNUM FOR CALIFORNIA REGIONAL CENTERS

<table>
<thead>
<tr>
<th>Position</th>
<th>Cost Per Center</th>
</tr>
</thead>
<tbody>
<tr>
<td>Director (M.D.)</td>
<td>$30,000</td>
</tr>
<tr>
<td>Associate Director</td>
<td>20,000</td>
</tr>
<tr>
<td>Staff Physician</td>
<td>25,000</td>
</tr>
<tr>
<td>Public Health Nurse</td>
<td>15,000</td>
</tr>
<tr>
<td>Chief, Administrative Services</td>
<td>15,000</td>
</tr>
<tr>
<td>Chief Counselor</td>
<td>20,000</td>
</tr>
<tr>
<td>Supervisory Counselor</td>
<td>18,000</td>
</tr>
<tr>
<td>Staff Counselors: 10, at $12,000</td>
<td>120,000</td>
</tr>
<tr>
<td>Total</td>
<td>$263,000</td>
</tr>
</tbody>
</table>

SOURCE: Interview with Dr. Charles Cardipee, March 6, 1972.

NOTE: The total shown does not include overhead charges and supporting staff. The more inclusive State Budget estimates provide for a total of $560,000 per year per center.

Population characteristics for each of the regional centers are shown in Fig. 3.1. Summary statistics for the program's five-year history are shown in Table 3.3 and Fig. 3.2. Note that for the California regional centers there is a great deal of variation in total catchment size (from 185,000 in Mendocino-Humboldt-Del Norte to 7.034 million in Los Angeles) and in travel times to a regional center. The extreme variation represented by Los Angeles has resulted in the planned addition of two or perhaps three additional regional centers for the greater Los Angeles basin. Travel times are not directly reflected in the state budget.

For completing a thorough evaluation of the California regional centers, these

70 Interview, March 6, 1972.
Fig. 3.1—California Regional Center program, 1971: area populations and population densities (persons per square mile)
Table 3.3
CALIFORNIA REGIONAL CENTER PROGRAM FROM INCEPTION THROUGH DECEMBER 31, 1971

Number of Regional Centers, December 1971
- Fully operational ................................................. 9
- Initiating services ................................................ 1
- Awaiting final approval of contracts ............................ 3

Statistics (last quarter of calendar year 1971, estimated)
- Total referrals and requests for assistance (1/66-12/71) ........ 25,000
- Total intake processes initiated (1/66-12/71) .................... 9,800
- Caseload, December 31, 1971 ..................................... 6,000
  (Note: this does not include some 500 individuals and/or families who, each month, receive some type of Regional Center assistance prior to initiation of the intake process.)
- Inactive cases, December 31, 1971 ............................... 880
- Closed cases (deceased, diagnosed not mentally retarded) ....... 330
- Purchase of services, December 1971
  - Individuals and/or families receiving purchased services ...... 2,000
  - Clients in residential placements (subtotal of above) .......... 750

Total budgets for Regional Center Program
- Fiscal Year 1971-1972 .............................................. $10,252,272
- Fiscal Year 1972-1973 .............................................. $14,367,000

Costs per case-month of care (1970-1971)
- $ 2
- Purchase of services .............................................. 78
- Direct Center services (costs attributable to diagnosis and counseling) ........................................... 59
- Regional Center administrative costs ........................... 13
- Bureau administrative costs ....................................... 2
- Total ......................................................... 152

SOURCE: California State Department of Finance.

*22.2 million in Fiscal Year 1974.

Data are plainly unsatisfactory, but they are instructive for the purpose of extending the concept of the regional center to a national scale.

The regional centers program has many positive aspects. The families we interviewed who were fortunate enough to make it through the waiting lists and received regional center service uniformly praised the service and the center's personnel; the physicians we contacted were generally favorably disposed to it on the grounds that the centers had access to information that they did not and that was of great use to the families; and state public health administrators of the program were also supportive. The centers are beset, however, by several recognized and persistent problems that bear careful examination although we note them here only in summary fashion:

- Regional centers have some power over state mental institutions, and this can lead to direct conflict. Under the regional center concept, the state hospital is only one of many service-vendors that may be planned for the individual child.
- Interaction with the so-called "Short-Doyle" program (to provide a local alternative to the mental hospitals) has had the effect of rapidly loading the regional

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71 As of this writing, we know of (but we were not given access to) a report compiled by the staff of the State Department of Finance, examining Regional Centers in detail. If made publicly available, this report should satisfy much of this need.
centers with clients. The shift from state institutional to local care has been rapid.

- Animosity connected with the hospital closure issue has spilled over to the regional centers program, pitting rural legislators (who stand to lose important and nonfungible local industries), psychiatric technicians (who stand to lose their jobs), and other miscellaneous groups, against the regional center concept and practice.
- Local problems have been noted, particularly in the early stages of locating and implementing the regional centers: zoning is frequently used to prevent the location of centers in incorporated areas, funding for facilities is sometimes hard
to obtain or obtained only at premium rates, and community acceptance of mentally handicapped people in their midst is not always positive.

- Waiting times tend to be long. Not only has deinstitutionalization contributed to this, but the extent of unmet demand was not well estimated, in the following sense: if one has a real but "marginal" problem, travel to a distant facility for care becomes a seriously inhibiting consideration; however, when the facility is relatively closer at hand, the travel constraint lessens and service is demanded.
- Local service facilities have not been created or expanded as fast as the demand for service.
- Follow-up and evaluation (noted in the "Case Management Flow Process") are very hard to carry out in practice. There are no well-known criteria and a variety of needed, specialized services is not always locally available; i.e., if a service received is not appropriate or satisfactory, there is often no readily accessible alternative.
- Given all of these systemic features, it is to be expected that the regional centers have not been able to realize their full potential to case-find, coordinate, and evaluate at the individual level.
- Because the regional center is structured within the existing service bureaucracy in California, it is susceptible to pressures to favor one or another existing type of service program, rather than being independent and fully child-centered.
- The regional centers rely very heavily upon social workers to execute the program at the client level. Social workers have many commendable skills; however, one should be alert to insure that social worker norms and modes of operation do not become the norms and modes of operation for the regional centers. One manifestation of this would be a "style" characterized by long-term case management (a task of the Department of Social Welfare) and not one of short-term case-finding, coordination, and evaluation (relatively "unique" functions not presently done by any line agency as a main order of business).

Direction is an important service that has many unique features not routinely performed by existing agencies. To the extent that direction is not recognized as a different concept and service, and to the extent that direction is attempted within the existing, unreconstituted bureaucratic framework, one would expect limitations of its full realization and potential. The need for new, clear lines of authority and control is evident in this case (a need explicitly recognized in the foregoing New York State proposal).

**Deaf-Blind Centers**

As a result of two separate pieces of legislation passed in the aftermath of the rubella epidemic of 1963-65, Deaf-Blind Centers were mandated and translated into policies and programs by the U.S. Office of Education. The Deaf-Blind Regional Center program has many desirable features—prototypical "lessons learned" for our proposed regional direction center concept.

Basically, the Deaf-Blind Centers were designed to provide the following services: comprehensive diagnostic and evaluative services; programs for adjustment, orientation, and education, integrating all necessary professional and allied services; effective consultative services for parents, teachers, and others, to enable them

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to play a direct role in the lives of children, and to assist in their adjustment, orientation, and education.\textsuperscript{74}

Because they are intended to provide a full range of services to a severely handicapped subset of the total handicapped population, the Deaf-Blind Centers do not meet many of the design objectives for a purely direction-oriented service. This is not to say that Deaf-Blind Centers are not worthwhile or that they do not provide much needed services; it is to say that because a choice has been made to serve a very special and quite small population, it has been possible to include within the single institution the delivery of a full range of services. Were the choice made to serve a larger group of handicapped children, as we propose in the direction center concept, then full provision of services within the same institution would probably not be feasible, either because the number of clients would be too large or because too many centers would be required.

In a study of the Deaf-Blind Centers from an information system design perspective, EXOTECH Systems, in June 1971, provided some valuable ideas for consideration in the proposed direction center concept. According to EXOTECH, information about this most severely handicapped subset of the total population was "by any standard poor in quantity and low in quality,"\textsuperscript{75} and the report detailed what might be done to improve matters on both scores. The partially implemented, prototypical DBCIS (Deaf-Blind Center Information System) that EXOTECH selected was in some senses a good and reasonable choice. The deaf-blind population is small and not too difficult to identify (about 5000 deaf-blind children are known to exist in the total population). The great complexity of the problems facing a deaf-blind child\textsuperscript{76} actually had some positive effects for the information system. If an accounting, registry, and direction system could be built to serve the deaf-blind, then it should be feasible to extend the design to other handicapping conditions if problems associated with increasing the scale of the system can be solved. There is much truth in the EXOTECH study's concluding remark that, "Taken as a whole, the Deaf-Blind Center Information System will serve as a model for application to the entire field of the handicapped."

One reservation about simply transferring and expanding the Deaf-Blind Centers, however, is that as institutions, they are at once both too specialized and too generalized to satisfy the design objectives set out for a direction service. Deaf-Blind Centers are narrowly focused on the special needs of a limited subgroup, and they provide a general range of services, of which direction is only one of the less important (relatively speaking). In all likelihood the Deaf-Blind Center concept would therefore be infeasible if scaled up from serving a national population of about 5000 to serving one close to 10 million (the gross estimate of total handicapped children).

Because direction is a neglected but vital service, we are prompted to concentrate on procedures for improvement. The DBCIS is one such procedure, and its

\textsuperscript{74} Section 622, P.L. 91-230, "Education of the Handicapped Act."


adaptation and incorporation into the proposed Regional Direction Center appears to be a relatively effective way to satisfy several of our design objectives.

**Young Adult Institute and Workshop of New York**

Since 1957, the Young Adult Institute and Workshop of New York has provided the mentally retarded and other young adult handicapped with preemployment training, which the Institute calls "Adjustment Counseling." While the program is mainly aimed at vocational placement and job preparation, its information content is of more general interest. Social, communicative, and employment skills are taught to ease the transition into the "normal" community. However, the most interesting aspect of the program for our purposes is the extensive network of service providers and potential employers maintained by Institute staff. The demonstrated success rates of the program attest to the importance of such specialized information for a limited range of purposes—in this case, placement. It would be valuable to expand the concept and practice into more general application.

**New York University Deafness Research and Training Center**

Using the existing facilities of New York University, the Deafness Research and Training Center employs a multidisciplinary team to expand the menu of vocational services usually available to the deaf. This effort has been labelled the "Community Service Delivery Model," whose stated purpose is to develop, within the deaf community, "sophistication . . . as to the acquisition of social services . . . [and] competence in community agencies for serving deaf people." To accomplish these objectives, the CSDM strives to make the community's existing services work to the best advantage of the deaf. Service responsibility is primarily left to others, while the CSDM is oriented toward referral and guidance of its clientele and toward educating the community at large about the needs and capabilities of the deaf.

While it is still too early to assess the outcomes of this effort, since it has only recently been implemented, many of its elements appear to satisfy the design characteristics we have laid out for a direction service. Before the needed assessment is carried out, however, it is appropriate to caution would-be emulators on several possibly troublesome features of the CSDM: it is located within a university and hence lies outside the political mainstream; it is a modest operation, from all indications; and it appears to have a decided research bias. All of these aspects should be considered seriously before one attempts to reproduce the model on a wholesale basis elsewhere.

**Comprehensive Vocational Rehabilitation Programs**

As a result of 1958 amendments to the Vocational Rehabilitation Act, several feasibility studies were conducted to determine whether the severely educationally limited deaf (those reading at a third-grade level or less) could be integrated into the community if supported by general purpose rehabilitation centers oriented to pro-

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78 B. Macleeh et al., *An Exploration of the Adequacy of the Adequacy of Developing a Research and Demonstration Project Concerned with Elevating the Readiness for Vocational Rehabilitation of Multiply-Handicapped Young Adults*, Young Adult Institute and Workshop, Inc., New York, 1966.

viding a comprehensive range of adjustment and guidance services instead of being limited to vocationally related services.

Some of the results of these feasibility studies were encouraging. The design objectives of comprehensive, multidisciplinary, and personalized service provision operated to good effect. Likewise, it proved meritorious to have a single point of access through which a variety of services could be matched with the specialized needs of these seriously limited people.80

**Family Counseling for the Adult Deaf**

Short-term counseling to help the deaf adult with his special problems (including diagnostics, translator services, family counseling, placement assistance, and so forth) has been shown to be promising in the three or four limited applications where it has been tried.81 The main message from all these applications is that the marginal utility of information about the availability of needed services is high, but the cost of providing that information is not. The principle is fundamental to the general concept of direction.

**San Francisco Speech and Hearing Center**

A well-known article by Donald R. Calvert and Suzanna Baltzer82 embodies some creative though somewhat limited fragments of the direction design. Concentrating on deaf preschoolers, it was demonstrated that a management program stressing "normalization" had some noticeable payoffs for the children's development and achievement. Professionals from the Speech and Hearing Center periodically visited the children's homes to evaluate their needs and then to match those needs with the capabilities of the Center and of other agencies that cooperated with the Center in providing additional services. The effort was multidisciplinary, professional, and essentially one-stop for those parents fortunate enough to benefit from the program. Furthermore, the benefits of preschool education for the deaf were "built into" the program from the start.

The small size of the preschool deaf population in the immediate area necessitated enlarging the catchment area to include northern and central California, Nevada, and southern Oregon. The resulting distances, travel time, and displacement from the family in those cases where children had to come to the Center for medical treatment must count as less than desirable features of an otherwise interesting program.83

**Brookline Early Education Project (BEEP)**

Heralded as "the nation's first major school-based program to provide compre-

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83 Other problems noted included the Center's dependence on "soft" money; the fact that there were insufficient numbers of professionals trained to deal with preschoolers; and that there were few standards to rely on in teaching the very young deaf.
hensive educational and health services to children during infancy and the early years of life," BEEP is an ambitious program designed to capitalize on the mother as teacher and constant observer of her child. The implicit assumption underlying much of the thinking is that the parent is an underused resource and with training and guidance could do much to educate and protect the health of the child. For our purposes, the most interesting aspect of BEEP is that it will have a referral service to help the parents find specialized medical care, and a provision to insure that the handicapped within BEEP's otherwise normal population will be followed up once they are identified. The project is funded privately by the Carnegie Corporation and the Johnson Foundation.

The project is far more elaborate and ambitious than the direction service we are proposing. It is commendable for its intention to track all children throughout the preschool years to promote their intellectual growth and insure that any handicaps are discovered promptly.

American Foundation for the Blind: Pilot Projects

Two pilot projects undertaken on the initiative of the American Foundation for the Blind are being conducted on behalf of preschool visually impaired children in Minnesota and New Hampshire. Their basic purpose closely resembles the direction center concept, in that they are exploring ways to coordinate local services on behalf of the handicapped child. The pilot projects may be followed by demonstration models in other areas of the country.

Judging solely by the size of the preschool visually impaired population, it would seem that size or scale difficulties would prevent such a scheme from providing sufficiently numerous or diverse services if a small catchment area is used, and that, on the other hand, an overly large catchment area would also impede the effort just as it has somewhat reduced the effectiveness of direction services for preschool hearing impaired in the San Francisco Center and in the Deaf-Blind Centers nationally. Direction, to repeat the theme, is a universally needed service whose fullest potential will be realized only when it is offered to all handicapped children, no matter what their condition.

Iowa: Community Service Centers

The State of Iowa, which has far better than average identification rates for the multiply handicapped, has recently planned Community Service Centers for matching the handicapped children with locally available services. As the project is still in the design and preliminary implementation stages, little else is known about it, although it seems to be a step in the right direction. Certainly, given the importance of direction, this project deserves careful scrutiny.

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44 Education Daily, March 9, 1973, pp. 5-6
46 J. C. MacQueen et al., Planning Comprehensive Services for Handicapped Children and Youth, Iowa State Services for Crippled Children, Iowa City, Iowa, April 1972. From the simple inspection of the meager performance data we have been able to assemble, Iowa appears to have done well for its handicapped children in general. Whether or not this is truly the case, and why it should be so, are the kinds of questions that should be routinely raised and resolved at the federal level. If officials are doing something "right" in Iowa (or anywhere else), there is even more reason to investigate than if it is suspected that performance is not up to par.
Pennsylvania: Commonwealth Child Development Committee

The Governor of Pennsylvania is attacking the problem from another direction. By virtue of his Executive Order No. 35, a Commonwealth Child Development Committee was established to oversee and coordinate the "merger of all federal funding for medical problems of children into one agency, with sufficient capacity to conduct cost analyses and impact evaluation of programs." 87 As we shall point out in the recommendations portion of this chapter, it is critically important that there be some recognized authority outside of the existing chain of bureaucratic command to which the proposed Regional Direction Centers may report. In principle, the Commonwealth Child Development Committee, with an expanded and clarified charter, could serve this purpose quite well.

Satellite Facilities

To anticipate a possible objection to the creation of Regional Direction Centers—that they may entail excessive investment in plant—it seems useful to note here that, unlike a hospital or formal educational facility, a direction center requires only minimal, relatively unspecialized, and unadorned space.

The concept of satellite facilities, although not new, may be relevant in this case. Satellites have been shown to increase service demand by lessening the geographic constraint through the imaginative use of a variety of small, cheap, flexible, and sometimes mobile facilities. 88 Interesting examples include building space within public housing units, and even surplus firehouses. 89

Many of these examples confirm that small size and low overhead cost are often an advantage in the delivery of information-laden services such as referral, planning, scheduling, and follow-through. A smaller setting, with fewer clients and a smaller staff, can make scheduling easier, shorten waiting times, and enable people to get more thorough individual attention. 90

Observations on Promising Partial Models

In practice, direction is at best a primitively developed and poorly understood concept and service. While the foregoing examples embody many attractive and interesting features, they remain only scattered fragments of the larger and more inclusive system by our direction design characteristics. The following summarizes a few of our observations:

- Direction is in a primitive state, although the need for it is acknowledged in the prototypes and experiments reviewed.
- Data systems—stressing both operational information and information about the local context that could be used by service recipients—are virtually nonexist-

87 March 30, 1972.
88 Most of the literature on this subject is thoroughly surveyed in J. R. Lave and S. Leinhardt, "The Delivery of Ambulatory Care to the Poor: A Literature Review," in William Cooper (ed.), "Urban Issues II," Special Supplement to Management Science, Vol. 19, No. 4, December 1972. An early statement of the satellite concept that gained some attention is Jerry A. Solon et al., "Patterns of Medical Care: A Hospital's Outpatients," American Journal of Public Health, Vol. 50, December 1960, pp. 1909-1919; this piece is cited to remind the reader that these ideas are not new, only pregnant.
ent or, in the case of Deaf-Blind Centers and the State of Maryland, in a design and early implementation stage.

- Direction systems appear to yield high payoffs in those limited instances where even the most elementary information has been collected and used.
- The incremental cost of direction information is slight, compared with its marginal utility to the service recipient.
- A variety of direction service strategies exists in some crude form, but those responsible have not developed the strategies well or systematically; they are more "accidents" that grew out of some other purpose than they are deliberate creations in their own right.
- The critical elements in a direction strategy appear to be the following: mixture of services, definitions of the served population, catchment population size, catchment spatial features, staffing mix, follow-up, expedited flow of individual clients through the center, and independence from existing service agencies.

FOREIGN MODELS

Foreign models have many constructive lessons to offer about direction and other services. Two of this project's members, on two separate occasions in 1972, visited many European institutions and public agencies concerned with the handicapped. We benefitted greatly from this first-hand investigation, as well as from published reports on services for the handicapped in other countries, and relate some of those benefits in what follows.91

Rather than describing each program in exhaustive detail, the following discussion mentions only a select few interesting features that exemplify the direction concept and service, and indicates where an interested party might begin looking for further information on the issue.

An excellent, general summary of European activities has recently been completed by the Council of Europe. The section entitled, "Education of Parents and the Community," embodies many direction concepts.92

Sweden

The Swedish tradition of excellence in the general area of health carries over especially to the care of handicapped children.93 Besides attaining nearly total identification and registry of the population by virtue of the coverage guaranteed under the National Social Insurance Board, there are multiple institutional arrangements to insure that the handicapped child and his family are informed about

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91 S. M. Genensky visited eight Western European countries in the course of a project on sensory aids sponsored by the Social and Rehabilitation Service of the Department of Health, Education and Welfare. He was particularly involved with closed circuit television for the partially sighted. G. D. Brewer remained primarily in Germany for a month as a guest of DATUM e.v. (Bonn-Bad Godesberg), where he was able to pursue inquiries about the German system and approach, and to obtain information about systems in other European countries.

92 Council of Europe, Social Co-operation in Europe: Social Rehabilitation of Physically and Mentally Handicapped Persons, Strasbourg, 1972, hereinafter cited as "COE."

93 Obligatory Health Insurance has been in force since 1955, and extensive preventive pediatric care dates from the 1930s. Besides a general child allowance provided all parents, a special handicapped child allowance of approximately $75 per month is provided on the supposition that being a parent of a handicapped child creates a chronic and additional financial burden, even over and above that accounted for directly by insurance payments for treatment and other defined services. This minimum allowance is adjustable upward, subject to a family-means test. Furthermore, the government either provides or covers the costs of transportation to receive services.
and receive needed services. In this regard, the Central Registry has been pivotal in coordinating many of the more specialized services and in planning for the total needs of Sweden's handicapped population. It is reported that the Registry engages in monthly updates "in order to detect at as early a stage as possible increases in the incidence of certain types of malformation." Around 90 percent of all children are given the equivalent of a multiphasic screening by the time they reach one year of age; such screenings are delivered in Child Welfare Centers located throughout the country. Follow-up and direction to all needed and available services are done mainly by nurses attached to the Child Centers. These Centers also conduct routine eye tests as early as age four, which results in a 3 percent rate of referral for services nationally; ear tests are also done, resulting in a 5 to 10 percent referral rate.

Care Boards, to plan, evaluate, and coordinate services to the mentally retarded of all ages, have consistently worked to "normalize" the life experiences of children by virtue of the Boards' physical location near ordinary schools and their encouragement of both families and educators to integrate the handicapped child into as many normal routines as possible. This concept has been extended to preschoolers in Integrated Play Schools, whose function it is to mix impaired children such as the deaf or blind, with normal ones, encouraging the former to develop to a full potential and educating the latter to the simple fact that handicapped children are, after all, people too.

Denmark

From all indications, services to Danish handicapped people are also excellent relative to those in many other countries. While driven generally by terms of the National Assistance Act, which "makes it the State's duty to care for all persons afflicted by any form of handicap and in need of special assistance," the Danish system is in transition. Prior to the execution of terms of the Public Health Security Act in April 1973, the system was a mixed, public-private one wherein the public component was concerned primarily with planning, evaluation, and coordination, and the private sector was largely responsible for service provision. Since April 1973, coordination and comprehensive service integration have been rationalized and placed under public control. Policies are set and interpreted at the national level; they are administered in 14 county-level jurisdictions (each having about 250,000 citizens), and in over 275 municipalities. Revenue is shared with the central government to pay for service provision. Direction occurs primarily at the municipal level, although a well-defined chain of authority and responsibility passes directly to the central government, aided by a general ombudsman system.

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85 Hellstrom, op. cit., p. 235.

86 Lindstedt, op. cit.; Hellstrom, op. cit.

87 COE, op. cit., p. 19. Schools for the Blind, located in Stockholm and Orebro, have as residents only the most severely impaired; otherwise, they emphasize a parent-child instructional program that ranges in duration from two to nine months.


90 COE, op. cit., p. 40.

91 Ibid., p. 38.

92 Johnson, op. cit., p. 630.
Early identification is stressed; so is early education, "preferably immediately after the diagnosis has been made, so that educational-psychological treatment can be started at the earliest possible stage."103

A remarkable feature of the Danish approach is the use of Home Advisory Services (HAS), which offer to send a specially trained nurse for about three weeks into the homes of the handicapped to counsel, educate, and assess the progress of the child and the efficacy of services currently received. This service pursues nearly all of the purposes cited in our direction design objectives, plus an additional one—to help insure that the client continuously receives maximum benefit from the services he receives. Another interesting service of the HAS is the creation of individualized training programs for preschoolers that emphasize the parent's role; the program works as much with the parent (to relieve guilt, for example, and to train the parent to help the child) as it does directly with the child.

Belgium

Many notable direction concepts have also been institutionalized in Belgium, although the experiences there are less comprehensive than in Sweden or Denmark. The National Rehabilitation Fund, created in 1963, is a basic element of enabling legislation for handicapped programs; because of it, a number of specialized schools, training programs, public education efforts, and financing initiatives have been undertaken or supported. For instance, the Fund has made direct approaches to the National Federation of Industries and was instrumental in changing physician certification procedures to include required instruction in the full service needs of the handicapped.104

Much direction, in the form of planning and service coordination, is evidently done through specialized schools for the deaf or blind. Schools also favor integrated research, testing, and screening practices; they are in many aspects configured and operated along the lines of the Deaf-Blind Centers in the United States, a factor limiting the simple transfer of the institutional concept for many of the same reasons cited earlier for the U.S. case.

Two appointed bodies, having considerable parental participation, exist at the national level: the Central Council for the Handicapped concerns itself with the general implications (present and future) of policies affecting the handicapped, and the Central Family Council (dating only from 1967) tends to be oriented toward specific problems facing families of handicapped children. Both contribute in special and important ways to improved direction.

France

Much like that in Belgium, the French system allows voluntary (often officially sanctioned) bodies to take the lead in providing services to the handicapped. Public agencies provide some supervisory and financial assistance, and carry out rather specialized direction on behalf of categorical subsets of the handicapped population. For example, special inspectorates such as the Commission Départementale d'Orien-


104 COE, op. cit., pp. 24, 46-47.

tation des Infirmes insure that the quality, or at least the legality, of services provided to the young and to handicapped youth is maintained.

The complex "Social Aid Acts" basically underwrite a portion of the total costs of the handicapped and do so through complicated transfer arrangements with individual départements (roughly, "states"), municipalities, and quasi-public institutions. The Ministry of Labor, Employment, and Population is a major conduit of these funds at the national level.

An important, powerful voluntary organization is the National Federation of Associations of Parents of Handicapped Children (UNAPEI), which functions to educate the public in general, but concentrates on providing parents with information and direction. This is done through "family representatives" and a vigorous publications program.106

Schools specialized to specific disorders exist,107 and from all reports, carry out many direction-oriented activities on behalf of those enrolled.108

Germany

Through a special "microcensus" taken in April 1966, it was estimated that somewhere between 450,000 and 500,000 school-aged, handicapped youth were located in the Federal Republic of Germany. A direction deficiency has hampered service delivery in Germany, where

... many organizations, institutions, and public authorities work on rehabilitation of the disabled. [The term "rehabilitation" has an all-encompassing meaning.] For the disabled, the distribution of competence [a very subtle word in German more connoting responsibility than it does wisdom or knowledge] is often confusing; coordination is hence required on both the individual plane ... and on the institutional and organizational plane, to guarantee continuous cooperation among all entities concerned about the setting up of necessary rehabilitation centers.109

Discussion and analyses preceding a national decree of October 28, 1969,110 enabling the creation of rehabilitation institutions, focused on many of the same direction-related issues confronting the United States in 1974.

The "solution" to these issues is a many-faceted, and only recently widely implemented, collection of laws, directives, decrees, and appeals. It is worth noting the general character of the solution to get an inkling of what a strategy favoring a massive frontal assault on the direction problem could portend if adopted elsewhere. A desire to improve coordination, access, efficiency, and equity—in short, a concern for better direction—is the only common discernible thread knitting these activities together.

To extend and create rehabilitation centers, the Ministry of Labor and Social

108 "German Note on General Programs and Action Taken to Abet Coordination of Rehabilitation Work," Bonn: Ministry of Youth, Family, and Health; and Strasbourg: Council of Europe, PA/REHAB/71, June 7, 1971, pp. 1-2. We have assembled and reviewed a modestly representative German-language literature on these topics.
110 Basically a modification by decree of Section 62 of the Employment Promotion Act. The Act was a legal precedent calling for cooperation and coordination of employment and rehabilitation for all citizens that the decree seized upon and generalized to cover all services and specialized to focus on the handicapped.
Affairs allocated some 10 million DM in 1969 and 15 million DM in 1970. These funds are supplemented by large but undeterminable amounts from several federal ministries, most notably the Ministry for Youth, Family, and Health—the designated "cooperative and co-action" institution. The funds are being expended in five broad categories:

- Centers of medical rehabilitation (e.g., Wildbad, Heidelberg);
- Rehabilitation centers for specific disorders, e.g., heart (Bad Krozingen), brain (Bad Godesberg), eyes (Marburg);
- Vocational training centers;
- Sheltered workshops;
- Special facilities for children, e.g., day care, kindergartens, special schools;
- Homes for disabled persons.

In addition to expansion and construction of facilities, complementary training programs to staff the new buildings were instituted. Reconciliation and redrafting of conflicting federal legislation have begun (e.g., the Federal Social Assistance Act, the Youth Welfare Act, the Severely Disabled Persons Act, the national insurance codes, the Employment Promotion Act, and many lesser pieces of legislation all existed in some form but were not always mutually consistent, much less co-ordinated. "Harmonization" of conflicting federal and state laws and practices has been encouraged (German states have considerable power under the federal system, and this has proven to be particularly troublesome for easy achievement of the coordinative objectives). A consolidation of highly fragmented data into one information system has been recommended, along with the collection of needed new data. And multiple appeals for cooperation have been made to service providers at all levels of government, to industry and the trade unions, to the churches, to private agencies, to educational institutions, to the families of the handicapped, and to the population at large.

While it is too soon to make any overall assessments, these various activities have, if nothing else, raised the level of public awareness about the problems of the handicapped, and have already produced a host of specific improvements.

Given the many similarities between the German situation with respect to a direction service in 1968 or 1969 and the current situation in the United States, a careful monitoring and assessment of Germany's implementation difficulties and realized (as opposed to expected) outcomes appears called for.

The Netherlands

Serving Dutch handicapped persons is the express responsibility of municipal authorities, although the central government has taken on many informational service activities. Programs for the mentally handicapped have been stressed, doubt-

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112 As only one tangible example, a nationwide lottery whose proceeds benefit handicapped children is conducted with much anticipation, interest, and participation on a periodic basis. Results are announced on the "A Ray of Sunshine" television show.
113 A number of "Guides to Services for the ..." and compilations of locally available services, resources, and institutions have begun to appear. Judging by the sheer number and variety of entries they commonly contain, they must be a considerable aid to families searching for help. One excellent handbook is the 175-page Bundessozialhilfegesetz (BSHG), issued by the Ministry of Youth, Family, and Health, Verlag Reckinger, Siegburg, June 1971. The handbook is categorized according to an extensive list of services, disorders, and pertinent laws, all discussed in simple terms. It is a "model" of sorts, easily replicated.
less because of their relatively greater numbers in a small total handicapped population, although direction and identification services are generally available to all. Various institutional forms coordinate, plan, and deliver services. Foremost among these are 32 "Day Centers," each composed of a multidisciplinary team whose main task is to provide child- and family-oriented information, planning, guidance, and help; a strong, voluntary, national Parent's Association for the Mentally Handicapped, which has influenced legislation and serves as a "court of appeals" for parental grievances; and a Central Advisory Council on Care of the Mentally Handicapped. The Central Advisory Council has evidently concentrated its efforts on "normalization" activities—indirectly, with respect to changing public attitudes through a vigorous media program, and directly, by supporting the integration of the handicapped into ordinary schools to the maximum extent possible and by developing and disseminating correspondence courses for the families of severely handicapped children unable to participate fully in regular programs.114

Switzerland

Several features distinguish the Swiss delivery system, especially as it treats the informational services. The national Assurance Invalidité (AI) is financed 50 percent from private contributions of individuals, employers, and others, and 50 percent from the state. It maintains over 3000 local offices, each an accessible source of referral for a comprehensive range of services for some 2000 citizens. A Federation of Associations of Parents of the Mentally Handicapped115 works to educate the public and to reflect and advise on policy proposals (through an Advisory Council), and serves as a local spokesman in individual instances (mainly through an organization known as Pro Infirmis). The most visible of these efforts is an annual month-long public relations campaign.116

United Kingdom

Under national health or security legislation, such as the "Social Security and Supplementary Benefits Act," assistance is generally provided to the handicapped.117 However, a distinctive feature of the British system is a concern for independent assessment of the quality and equitability of services. That concern is best embodied in "Her Majesty's Inspectors"—objective, impartial, and usually personally respected people reporting directly to the appropriate Minister—in a number of program areas,118 and in professional certification demands contained in the National Health Service regulations.119 Additionally, two more specific direction activities have been observed: efforts by the Department of Employment and Productivity to coordinate job openings with individual capabilities by working directly with physicians,120 and a general purpose, hospital-based information system de-

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115 Much as in the Netherlands, the relative sizes of Switzerland's different handicapped populations tip the scales in favor of the mentally retarded. However, concern in fact is generalized.
116 COE, op. cit., pp. 23, 43, 45, 47, 49.
117 Ibid., p. 38.
119 COE, op. cit., p. 27.
120 Ibid., p. 47.
signed to provide a full range of practical information to the handicapped and their families.\(^{121}\)

A general preference for "normalization" is evident in extraordinary efforts to integrate handicapped children into ordinary schools to the greatest extent possible,\(^ {122}\) efforts that appear to work reasonably well, for the deaf at least.\(^ {123}\)

**Observations on Foreign Models**

It is hard to make detailed, general conclusions about the variegated array of European activities and systems, but certain features stand out, most of them related to the direction service:

- Direction services are better organized and developed in many European countries than in the United States.
- Regardless of governmental form or degree of service coverage supported publicly, nations with superior direction facilities and institutions tend to provide better and more extensive services.
- Each of various desirable features or characteristics of a direction service has been implemented, to a greater or lesser extent, in foreign applications, thereby supporting the feasibility of each feature in practice.
- Registration of the handicapped, often a routine by-product of a health insurance program (irrespective of the specific details of implementation of that program) can contribute significantly to early and periodic identification and to the periodic and systematic matching of the child's needs with a proper mix of services.
- More extensive and comprehensive services are provided in those settings where distinct lines of communication link parents with local, intermediate, and central governmental officials; i.e., "feedbacks" in the system are important.
- The provision of a full range of services through regional centers is feasible if the total (and hence total handicapped) population served by the center is absolutely small, or if the population served is made small by differentiating according to specific handicapping conditions. None of the countries we investigated combined both full service provision and total coverage of the entire handicapped population in a single national institutional setting.
- A potential option is to concentrate on a single service on behalf of the total population—an eventuality ruled out for any but the most generally demanded service, such as direction—and to provide this service through locally accessible institutions whose individual activities are coordinated by some superior authority.
- Because of severe contextual differences between the U.S. and foreign settings, none of the foreign models is entirely suitable for transfer en bloc to the United States, but many of them have desirable features that could be adopted in a United States direction service.

\(^{121}\) The design is explicitly oriented toward the client and not the administrator or service provider. Jean Cullinan, "Information Service for the Disabled," *Nursing Times*, Vol. 64, January 1958, p. 76. Created in 1964, the Information Service is the product of the joint efforts of the Disabled Living Activities Group of the Central Council for the Disabled, and the King Edward's Hospital Fund for London.

\(^{122}\) "No handicapped pupil should be sent to a special school who can be satisfactorily educated in an ordinary school." Ministry of Education Circular No. 276, June 1954.

RECOMMENDATIONS FOR REGIONAL DIRECTION CENTERS

We have identified and described a serious lack of direction services in the current system serving American handicapped children and youth. In the process, we specified several design characteristics for an improved direction service, and reviewed existing partial models that embody one or more of these characteristics and therefore could supply valuable inputs to a new and superior direction service for the United States.

We particularly commend certain aspects of the conceptual approach embodied in the New York State "Child Advocacy System," the technical innovation represented in Maryland's "Data System for the Handicapped," and a modified institutional version of California's Regional Direction Centers. Our proposed Regional Direction Centers for Hearing and Vision Handicapped Youth (RDCs) would be the result of judicious selection of the better features of these and other examples.

Specifically, we have three major recommendations, the first of which is:

**Full-scale evaluations should be undertaken of the most promising existing partial models for providing direction service, to learn their strengths, weaknesses, and implications for an expanded, nationwide network of direction centers for hearing and vision handicapped children.**

Our preliminary estimates of the eventual number, size, location, cost, composition, modus operandi, and institutional structure of these centers follows.

**Number, Size, and Location.** Based on the parameters generated in the California experience, there is a minimal national requirement for some 150 to 200 RDCs for Hearing and Vision Handicapped Youth. Since there are approximately 683,000 hearing and vision handicapped youth in the United States, this assumes a load factor of about 3500 to 4500 handicapped children per center, or equivalently, an average catchment area of some 1.0 to 1.3 million total population for each. Such a figure would tend to minimize travel times as much as possible, consistent with a large enough number of children served to enable the center to provide high-quality specialized services. These centers should be located at least one to every state and major standard metropolitan statistical area, with the remainder located to minimize travel times in more remote, less densely populated regions.

**Cost.** Our initial planning estimate is that each center could be operated for about $100 per hearing and vision handicapped child per year. This would mean that if the child and his family received comprehensive direction service every four years on the average, then $400 would be available to provide that direction. This amount appears adequate for at least minimum quality direction, and may even be a high estimate if volunteer help is used extensively, as in the New York Child Advocacy model.

One offsetting cost reduction would come from elimination of the need for other agencies to provide their present inefficient and partial direction based on little comprehensive information about the service system. In view of the potential for standardized, accurate, and rapidly accessible management information (currently nonexistent or available in only the most rudimentary forms), this $100 expenditure would provide significant benefits. Additional humane, quality-of-life benefits to the children and parents from receipt of appropriate services are not calculable, but must be very significant. Benefits deriving from savings in services not needed by the youth later in life because of timely identification, evaluation of needs, and case management are also not calculable, but would be significant in the individual case and probably positive in the aggregate. The savings in rediagnosis and recertification realized by a simple transfer of client records from the center to various other
servers will be considerable, but not reliably calculable. The savings to be realized by a timely and accurate sensing of shifts in the number and character of the handicapped population—resulting from rubella or other epidemic problems, for example—could be significant but are not reliably calculable. The savings that would result from more efficient matching of the needs of a handicapped population with the locally available services are not measurable, using available data, but would be positive.

In brief, the cost per child for a direction service is not in itself excessively high, and the potential benefits and later savings from that service could be large, but cannot be accurately estimated.

**Composition of Staff.** The staff composition of individual centers will undoubtedly vary from site to site in response to local requirements and the availability of personnel. However, we think that a staff composed like the list in Table 3.4 would be a reasonable model and point of departure for individual sites. A representative table of organization is presented in Fig. 3.3; it shows the structural equivalence given to information collection and management; administration and case management; and service counseling and parent direction. The last-named is worth additional comment.

In addition to the direction provided by the center’s permanent staff (by all staff members, not merely those we call Direction Counselors in Table 3.4), an unexploited and valuable source of counseling and direction is the parent of the handicapped child. Much of the day-by-day direction could be left to Parent Counselors who are members of the RDC’s clientele and who would be available to help other, more recent initiates into the center’s program and into the local service milieu. These Parent Counselors could be trained by and consult with the RDC’s own permanent staff. Besides providing some much needed manpower, in an honest sense “ideally” suited to the parent information task, this innovation might do much to relieve the “What can the families do?” problem consistently noted in our family interviews and by professionals in the system; it is also a constructive step toward the participation objective.

Direction Counselors would be trained specifically for the RDC’s purpose. They would not be social workers, psychologists, or counselors as conventionally defined.

### Table 3.4

**STAFF COMPOSITION MODEL FOR RDC**

Director—a physician

Associate Director/Data Management—a data specialist
Associate Director/Administrative Services—a skilled administrator
Associate Director/Direction Services

Special educator
Vocational rehabilitation specialist
Social worker
Public health specialist
Psychologist
Direction counselors
Data management technician
Parent counselors (volunteers)
Consultant ophthalmologist
Consultant optometrist
Consultant otologist
Consultant audiologist
Consultant lawyer
They would constitute an important professional specialty that does not currently exist; their socialization, training, and orientation would be designed from the beginning to conform to the objective of serving the handicapped child and his family.

Parent Counselors and the professional staff of the RDC, with their knowledge of local information and conditions, could jointly develop correspondence courses and information booklets for use of the families served by the RDC. The courses developed and disseminated currently by the John Tracy Clinic in Los Angeles, which has pioneered in work with hearing handicapped youth, are a model of what is needed. Thousands of parents have benefited from these courses, but the courses' general potential has scarcely been tapped. Local information and conditions could be built into similar course material by the Parent Counselors and the RDC professional staff. Such courses can minimize costly face-to-face counseling time and enhance the benefits.

We recommend the early and more widespread use of correspondence courses, whether or not the more ambitious concept of the RDC is adopted.

Because some of the hearing and vision service specialists could not be effectively utilized full time, they could be hired on a consultant basis. A certain number of days' worth of consulting time would be allotted for use at the discretion of the RDC Director.

**Modus Operandi.** The major direct contacts that the child and his family will have with the RDC will be the initial intake and several other natural "milestones" related to the child's age and stage in the life process. For example, the "Case Management Flow Process," developed in California's regional centers, is a sound beginning and could serve as the intake or basic introduction to the RDC. That process includes the following steps: initial screening; intake; case staffing and plan formulation; plan execution; and periodic review and evaluation. We would amend this process somewhat to increase the "throughput," or rapidity of the RDC's service to clients. By defining major and minor periodic reviews and updates, annual costs per child could be held down. Major review periods would occur at initial discovery of the handicap; when the child reaches five years of age and is about to enter school; at nine years of age, when a detailed evaluation of school progress and prospects would be carried out; at fifteen years of age, when vocational services would become salient; and at twenty years of age, the "exit" age, to make a thorough assessment of the individual's needs and point out available services for adults, such as vocational retraining. Minor review periods would occur when the parent raised a specific question between the major reviews. In the event that the child's family moved from one region to another, this could signal the "Case Management Flow Process" to begin anew to match the child's needs with what is locally available.

**Institutional Structure.** The RDCs would be configured somewhat like the model outlined in Fig. 3.3. These centers would be placed in a chain of command.
linking them directly to a State Advisory Council, which itself does not report to any existing agency providing other services such as health and education. To the greatest extent possible, this separate chain of command and compensation is needed to restructure incentives and to avoid "capture" by the existing service system. Finally, at the national level, we believe that a strong Office for the Handicapped within the Office of the Secretary of HEW would do much to focus attention on the needs of and serve as a spokesman for handicapped children and would serve admirably as a focus for coordinating existing services and all State Advisory Council and RDC activities. The Office for the Handicapped could have access to the information generated by the RDCs, and could be a vast improvement over the present multitude of uncoordinated groups that compete for resources at the federal level.

The following is our second major recommendation:

Based on an evaluation as noted above, a thorough implementation analysis should be conducted and five to ten pilot RDC projects should be created in locations throughout the country. Such pilot operations should themselves be carefully observed to insure that subsequent, full-scale implementation is carried out rapidly and with an absolute minimum of difficulty.

The need for direction is too important to permit implementation of the service to be sidetracked for reasons that could be avoided by sufficient foresight and planning. The pilot efforts would check out initial estimates of cost, modus operandi, staff composition, location, etc., and would serve as definitive factual examples upon which to base full-scale implementation.

Conducting pilot projects over a one-to-three-year period also "buys time" to accomplish several necessary jobs preliminary to full-scale implementation. It allows time for better design of the data system; it allows time for the legislative process to work through the many ramifications of the concept; it allows some time for the training of the specialized Direction Counselors; and it allows time for the idea's full impact to be absorbed by those who will benefit from and provide the services. The pilot project approach is one way to reduce risks without unduly inhibiting the adoption of the concept.

Our final recommendation:

Improvements in the Regional Direction Center design suggested by the pilot projects should be incorporated, and the concept should be expanded as rapidly as possible into a nationwide network of Regional Direction Centers for Hearing and Vision Handicapped Youth.

While we have noted the benefits such a proposal would afford to the families and children, it is important to stress that the present service system is also likely to benefit handsomely, because timely and efficient provision of services can eliminate duplication of effort and clients' need for other services later in life. We note again in closing this chapter that one of the aims of Regional Direction Centers is to complement and make the present system more efficient, and they would operate within the context of the present service system without major disruption of its present structure. However, if the information-based direction service is effectively provided, then localized conflicts may arise as the unevenness in the quality of existing service programs becomes apparent. When fully tested and developed for this relatively low-incidence population, the Regional Direction Center concept might be extended to include all handicapped youth and adults.
Chapter 4
IDENTIFICATION

INTRODUCTION

Broadly speaking, identification is the recognition and correct follow-up assessment of both a child’s abilities and disabilities. While the bulk of the literature on the subject is concerned with recognition, follow-up assessment is at least as important in the service of the handicapped person.\(^1\) Questions like the following illustrate the nature, importance, and utility of thorough identification:

- At what age is service intervention timely, and hence identification needed?
- How and by what institutional mechanism can the child’s handicap be identified, and errors of identification minimized?
- What pathological condition underlies the disability?
- How seriously does the disability limit current and future functional capability?
- Are secondary disabilities likely to be “caused” by the basic condition, e.g., speech impairment because of hearing problems?
- Can the condition and disability be corrected, reduced, or prevented through timely intervention?
- How can a handicapped child be assured of proceeding beyond the stage of identification and into the stage of receiving needed services?
- Where can an appropriate range of services be obtained to minimize the handicapping effect of the disability?

It is easy to see that there is a clear and important relationship between direction—where diagnostic assessment is designed into the service from the start—and identification as a recognition process and activity.

While parents are usually the first to suspect hearing or vision impairment in those sensorially handicapped children that are identified, formal identification programs screen at least part of the child population in many states. Programs supported with funds from the U.S. Maternal and Child Health Service and Crippled Children’s Service screened an estimated 10,000,000 children for vision impairment and 6,250,000 children for hearing impairment in 1973. Children in states with comprehensive screening programs usually are tested at more than one age, so the above figures do not represent children receiving their first screening.

Coverage of the population is far from universal. A 1969 survey of State Plans for the Maternal and Child Health Service and Crippled Children Service showed that: 12 states reported having some type of a general vision testing program, 20 reported some preschool vision testing, 19 reported school vision testing, and 2 reported glaucoma vision testing; 15 states reported some type of a general hearing test program, 11 reported some infants’ hearing testing, 22 reported some preschool hearing testing, and 23 states reported school hearing test programs. Some additional screening is done under the state-operated but federally funded and regulated Medicaid program, which requires early and periodic screening, diagnosis, and treatment of Medicaid-eligible children.\(^2\) It has been difficult, however, to elicit

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\(^1\) This distinction has been made well in Society of Medical Officers of Health, “The Needs of Handicapped Children,” *Public Health* (London), Vol. 83, 1969, pp. 136-147.

compliance and full implementation of these provisions from the states. Data accounting for total numbers of people screened, referral rates, disease incidence, and follow-up measures undertaken are beginning to be collected, but the results are incomplete. To the basic question, "How many children were screened under this program?" asked by the U.S. Medical Services Administration in January 1973, 26 states either did not reply or did not have implemented programs. Thus, the present federal role with respect to identification programs is one of funding and research, but not operation or strong control.

Without proper and universal identification programs, no clear picture of the overall needs of the handicapped population can be drawn, and large known gaps in delivery of services to the handicapped population cannot be filled. Without adequately trained, certified, and funded screening personnel, misidentification (errors of both omission and commission) can be distressingly frequent. Lacking better informational connections between those specialists providing identification and other service providers, follow-up of individuals and their direction to an appropriate mix of needed services is often not done, or not done very well. Follow-up and adjustment of the total supply of services at the system level, to reflect changes in the number, kind, and distribution of the overall population are, for similar reasons, not done very well either.

Identification is one of the more neglected services. Even the best of the formal identification programs—the vision and hearing screening of children—are far from universal for school-age children, are often poorly implemented and are often nonexistent for preschoolers. This is unfortunate, for early identification is especially important in some cases, notably for deaf youth who need early language development assistance and for any youth with a treatable etiology causing degradation of sensory ability. Much of the identification that does occur is done informally by parents, schoolteachers, and others not specially trained to recognize handicaps.

As important as the identification service is, why is it so underdeveloped? Several explanations are possible. One plausible argument is that since all available service resources are being used already, it is pointless to go looking for more people. But that argument may be answered in at least three ways. An equity-related answer is that not all the people with the most need or the greatest ability to benefit are among those known to the service system. An adequacy-related answer is that if we were to identify more of those in need, the system might eventually respond with a more adequate level of resources. And an information-related answer is that even if the government chooses not to serve a handicapped person, he at least could be identified and armed with information about the exact mix of services he needs—information he will find helpful in seeking nongovernment-supported services.

In the remainder of this chapter we review problems with current identification programs, summarize the state of the art in identification techniques for children of various ages, and make several recommendations for improving the identification service. Our two primary recommendations are to:

- Implement mass screening programs to detect aural and visual handicaps in all young school-age children, with program mechanisms to insure quality screening techniques, personnel, and follow-up; and
- Since techniques for quality mass screening at birth for hearing and vision handicaps need further development, conduct thorough evaluations of various options for implementing identification programs for 2- to 3-year-old children, leading to the implementation of programs designed to reach 2-year-old chil-

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3 Ibid., pp. 199-201.
dren. Promising program options include a “high risk” registry established at birth, with follow-up examinations; and a type of “free check-up” mechanism whereby pediatricians or other service personnel would be reimbursed through National Health Insurance or some other program for each 2-year-old child they screen and report on to a health agency or other prescribed government agency.

PROCESS AND PROBLEMS OF IDENTIFICATION

The specific problems related to identification as a distinct service may be summarized in the following terms: (1) failure to detect handicapped children, (2) misidentification, (3) labelling and stigmatization, (4) inadequate follow-up procedures, (5) insufficient personnel training and certification, and (6) failure to create, use, and exploit technology. Each of these topics forms the basis for a subsection below.

We first characterize the “Identification Process” (see Fig. 4.1) to facilitate pinpointing several deficiencies in the current situation. This characterization was suggested by the Illinois Commission on Children, whose recent report we recommend as a creative and constructive approach to many of the problems noted in our report.4

![Diagram of Identification Process]

**Fig. 4.1—“Identification Process”**

At the preawareness stage, the child is thought to be and is treated as “normal.” No one has any inkling that the child is disabled. For a severely and obviously impaired child, this period may be as brief as the time between delivery and the first examination in the newborn nursery. For others, this stage may persist well into the school years, when learning or developmental problems should at last set the identification process into motion. The basic objectives of identification are to minimize the time lapse from preawareness to the delivery of needed services, and to minimize the chance that those services will never be delivered. Methods to attain those objectives form the bulk of the remaining discussion and underlie most screening and diagnosis procedures.

Sensitizing occurs when some person—a parent, neighbor, physician, relative, teacher—suspects that the child is “different” in some significant way. The process

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occasionally breaks down here because of what we might call "background noise" in communications between mothers (usually) and physicians. Physicians are all too familiar with the "anxious mother syndrome," wherein parents fall prey to the conviction that all sorts of things—usually illusory or exaggerated—are wrong with their children. The unfortunate result is that the physician, his alertness dulled from hearing so many false alarms, often fails to heed the mother whose fears are well founded. Sensitizing is the attempt to alert people in contact with children into being more careful observers, careful enough that the possibility of a handicap is not dismissed out of hand when a clue is presented that the child may not be "normal."

Awareness is the partially confirmed realization that the child's behavior or performance is abnormal for his age, plus perception of the ways and extent to which his performance differs. The awareness phase is where most mass screening programs are concentrated. All they generally seek to accomplish is to identify children who are not behaving or performing up to some normal levels expected for children of similar demographic and developmental characteristics. Awareness is not the same as complete diagnosis, although it is an important preliminary step to diagnosis.

Seeking is one form of follow-up. It is the critical step that sees the child through to more detailed and competent examination, usually by specialists in the suspected disorder. Since awareness is not diagnosis, the critical importance of competent and thorough confirmation and measurement of the disorder cannot be stressed enough. Failing a vision or hearing acuity test merely indicates that a child did not see or hear as normal children do in the test; it does not indicate why the child failed. For example, the child may have been distracted, may have had a cold, or may have been frightened by the test or the testing personnel. Nor does the test indicate what the child’s unique residual capabilities may be, or whether intervention may improve or correct the condition. It takes competent, specialized assistance to begin making such determinations. Parents, as we have noted, are not always fully knowledgeable consumers; they probably require directional assistance during the seeking phase to get their children to the proper specialists for examination, and to help plan for obtaining the full set of services the child may need if diagnosis indicates a handicap.

Diagnosis is the thorough evaluation of the disability. Thoroughness in this sense comprises a full and forthright assessment of the disability, the services required and the most likely and desirable futures for the child. Besides the critical information an ophthalmologist or an otolaryngologist will bring to the diagnosis, the need for a full needs and service assessment should be stressed at this point.

Recording and referral, a frequently missing element in the identification process, pertains to the follow-up of the awareness and diagnosis. The most elegant and technically sophisticated diagnosis in the world is of little or no value if nothing is done as a result of it. If the child needs surgery, does he get it? Are the parents told what is needed and where to get it? If hearing aids or glasses are required, are the appropriate aids designated, are the parents told where to get them, are they taught

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5 Some surprising statistics on identification are offered in G. Fellendorf and I. Harrow, "Parent Counseling, 1961-1968," Volta Review, Vol. 72, January 1970, pp. 51-57. The authors state that for children in the 0-6 age range, initial identification of hearing impairment is made by the parents in 70 percent of the cases, followed by grandparents and relatives at 16 percent, then physicians at 7 percent, friends at 6 percent, and teachers at 2 percent. The implications of this empirical finding are many, and include the need for rudimentary education of the newborn's parents to warn them of behavioral signs that may call for professional evaluation, and the need for physicians to take the parent's concern seriously.

6 The consistent reference made by parents in our family survey to this phase of the identification process must be noted here. It is addressed primarily in the chapter expressing our concern for developing and implementing better direction services, although its relationship to identification is also strong.
how to use and maintain them, and is the child trained in the use and importance of the aid?7

Service is the actual delivery of those services found to be needed in the diagnostic and referral stages. Did the child get medical and sensory aid service, and does the parent have some idea of what should be done in the home to help the child? Have schools and teachers been informed about the child's problem so they can arrange for seating adjustments in the classroom, placement in special education classes, and the like? Have follow-up visits been arranged, if needed, to check that the delivery service is accomplishing what it is supposed to?

Problems occur at each of these phases in the identification process. We consider only a few of the more general ones in the following discussion.

Failure to Detect Handicapped Children

There is no formal institutional mechanism to screen and identify aurally or visually handicapped children after they leave the newborn nursery until they enter elementary school, usually at age five. Screening of school-age children occurs in many locales, but is far from comprehensive.

In our companion report, R-1220-HEW, and in later sections of this report, we document the large fractions of the population of handicapped youth that are not receiving needed services. The question then becomes: do the service programs typically know who the unserved youth are? That is, have these youth usually been identified but not been served? The answer is clearly no. In our interviews with personnel in over 30 different state agencies in Arkansas, California, Illinois, Massachusetts, and Wyoming, we routinely asked if the service agency knew who the unserved youth were. Aside from an occasional official who mentioned a short waiting list, the response to our question was that no, the agency did not know who the unserved were by name. Usually, these officials could do no better than to say they assumed the unserved children were more predominant in rural or innercity areas. The lack of identification is not surprising since comprehensive identification programs do not generally exist.

Failure to identify handicapped children may be related to a general inadequacy of resources to treat and care for more children than are already being served. If there were better and more complete identification of disabled children, there would be some undeniable obligation to do something for those who are discovered. The prospects of a thorough identification program, particularly with respect to the "missed cohort" aged 0 to 5 years,8 present several logical, strategic options for service provision, as summarized in Fig. 4.2.

Under option "a," existing levels of identification effort would be reduced or, at the limit, eliminated altogether. At the same time, the reduction in service demand that this would probably generate would be translated into a reduced total bill for all types of services. For the national context, this would represent a "get out of the business" strategy; for less inclusive contexts, such as a local area or even a state, it would be a strategy of "transfer the problem elsewhere."

Reducing identification efforts while maintaining the current level of service

7 Once again, our family surveys have very little that is positive to say about this aspect of the current identification programs.

8 Even in relatively affluent and sophisticated local settings and programs, the number of children who do not see a physician in the 0 to 5 years of age period may be as high as 25 to 30 percent of the total population in the cohort (interview, Dr. Frederick A. Frye, Department of Pediatrics, Children's Hospital, San Diego, California, February 1972). This in itself is a point worthy of additional empirical investigation.
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Fig. 4.2—Possible strategic options: levels of identification versus levels of treatment and follow-up

Expenditures, option "b," could have several outcomes: it might mean that service levels to those already in the system or fortunate enough to get in "naturally" would be maintained or improved, or it could mean that services would be concentrated on those who are more severely impaired. Such a strategy is plausible in the case of hyperinflation of medical costs for example.

If one decreased identification resources while increasing other system resources, option "c," services might improve for those fortunate enough to receive them, or the variety of services might be expanded. This strategy fosters the illusion that "excellent" services are provided, but the illusion is created at the expense of some number of the population in need.

Maintenance of the status quo in identification also could have three accompanying levels of other service expenditures; that is, other service provision may decrease, remain the same, or increase. When the total capacity of the service system is reduced (option "d"), we arrive at a fair representation of some of the current government service programs, faced as they are with rapidly expanding and inflating medical and other service costs (which result in a net real loss in total buying power). The status quo is represented in option "e." The system's other-service capacity may be increased while the present level of identification is maintained (option "f"); the line of thought behind this option can be roughly expressed as, "We have more than we can take care of adequately now, so let's just serve those we know about better."

Options "g" and "h" call for increased identification efforts, but with either reduced or steady levels of total service provision—two variants of the attitude, "Let society take care of the children, but find as many of them as possible."

Finally, there is the possibility that both identification and total service provision will increase, as indicated in option "i." This option would realize many of the stated objectives of those responsible for the service system, and it is certainly the

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* R-1220-HEW, Chapter 4, "The Issue of Goals and System Performance."
option that would generally satisfy the handicapped and their families to the greatest extent.

This exercise summarizes a number of extremely difficult choices confronting this or any other society when faced with the problems of lack of identification and services. The choices bristle with thorny moral, economic, and ultimately political considerations. On the one hand, it is in the clearest interest of the disabled child to be made aware of his problem and to be diagnosed (and the earlier the better, if remedial services are to have greatest possible efficacy). On the other hand, at a total societal level, more and better identification may impose costs. The tacit recognition of some of these costs may underlie many poor identification programs or explain the absence of any programs at all. Which course is the more prudent for our society: minimal identification and "acceptable" services to those identified—approximately the current national situation; or maximal identification and either inadequate or more costly services? In approximate terms we have shown that something like one-half of the handicapped youth between the ages of 0 and 21, in need of any specific type of service, are not receiving them. With total identification, the current annual governmental expenditure for services to handicapped youth of some $4.7 billion would be more like $9 to $10 billion. With total identification and the present quality of service delivered to all hearing and vision handicapped youth, current government expenditures would rise from the present $420 million to perhaps twice that much. Is society willing to face this prospect squarely, a willingness at least partially implied in an honest commitment to find as many handicapped children as possible?

When one turns from the contemplation of society's goals, he bumps headlong into a host of more prosaic reasons that many handicapped children are not identified. While we consider several of these as they pertain specifically to the aurally and visually handicapped, we suspect the reasons are more general.

The unavailability of reliable, timely, and comprehensive information about the overall handicapped population means that we do not really know very well what to be looking for and when to look for it. Furthermore, there are other reasons that many children are overlooked: (1) Lower socioeconomic groups consistently do not share in society's goods and services, and identification services are no different from others in this respect. (2) Many "high risk" children—those born prematurely, or to mothers who have had little or no prenatal care, or born under great stress, or to parents with abnormal clinical or genetic histories, and so on—are not registered and given the benefit of extra and more thorough examinations, even though extra attention is indicated based on the statistical likelihood of disability associated with "high risk birth". (3) Services are not equitably divided between populous and more remote regions or between rich and poor districts of a given locality. And (4) some handicapped children are simply denied services and kept from society's full view by ignorant or guilt-ridden parents—most notably, the "closet kids" reported in the newspapers from time to time. All of these factors diminish the prospects of complete identification; but several may be addressed and their effects lessened, presuming one honestly wants to provide identification and other services on as equitable a basis as possible to all of those who could benefit from it.

Later in this report we shall concentrate on the serious problems of the "missing cohort" aged 0 to 5, although we are well aware that other factors are operating to

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10 Ibid.
11 Full commitment would be indicated if total resources were likewise increased in the face of the increased demand generated by better and thorough identification.
inhibit complete identification of those in need. This concern has been well summarized in a recent statement of the American Academy of Pediatrics.

At present there is a serious obstacle to identification of health problems in the preschool child; only a small section of the child population receives continuous health care and supervision from infancy to school age. Early identification of handicapping among those children who receive health care from either the private or public sectors of the delivery of health care can be furthered by emphasizing the need for comprehensive screening procedures. But early identification of physical handicaps among those children who do not receive health supervision during infancy and childhood poses almost unsolvable problems. In our society children are not brought together regularly in groups until school age, and therefore it is currently almost impossible to conduct screening examinations on this population at an early age.  

The principle of early and correct identification, so prominent in the above statement, is a common one; however, while not doubting its legitimacy, we shall discuss difficulties in implementing it in the next section of this report. In particular, the ideally timed early identification program—a high-quality neonatal vision or hearing mass screening program—does not appear technically feasible at present. In short, the problem of early preschool identification will not be resolved by any "easy" recommendation or "quick fix." Like the general system in which it is embedded, it is too complex for that.

**Misidentification**

Identification presents, in one sense, the classic statistical problem of error types. In this setting, Type I errors occur when children who are not handicapped are screened and erroneously labelled handicapped; Type II errors occur when screening fails to detect children who are in fact aurally or visually handicapped. If the handicapped child is not identified, he may either be labelled "normal" or, what is potentially worse, he may be erroneously thought to have some nonsensory handicap such as mental retardation.

Excessive Type I, or "false positive," errors would indicate that screening procedures are too conservative or perhaps unreliable. Too many "false positives," if referred for specialized diagnostic procedures, may overload scarce and expensive diagnostic resources and gradually erode diagnosticians' trust in the seriousness or worthiness of the screen program. Nor should the injurious effects of misidentifica-

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14 "Because results of mass screening programs are inconsistent and misleading ... we urge increased research efforts, but cannot recommend routine screening of newborn infants for hearing impairment." Committee on Fetus and Newborn, "Joint Statement on Neonatal Screening for Hearing Impairment," *Pediatrics*, Vol. 47, No. 6, June 1971, p. 1088.
tion on child and parent be ignored. It is shocking to be told that you are the parent of a "defective" child; but it is also tragic to labor under this impression only to find that it is untrue. Some Type I errors are to be expected, however, when test subjects are very young and hence uncooperative, when the test instrument or device is known to have a significant margin of error, or when the testing personnel are inexperienced and make judgmental and procedural mistakes. Should any or all of these conditions hold in the actual test situation, several alternatives should be considered to reduce the impact of Type I error, since one "cries wolf" only so often until the cry is ignored.

- Personnel may be trained better, certified, supervised, and exposed to more screenings to gain experience.
- The test instrument may be evaluated and improved.
- One may work with a more "cooperative," i.e., an older or less impaired, population.
- Or, a second and third retesting may be performed on all positives initially screened to confirm the first identification and to minimize false positives before they are referred to a diagnostician.

Excessive Type II errors, in which handicapped children pass undetected, would indicate that the identification procedures are not discriminating enough. Too many "false negatives" could damage children by denying them needed services. Type II errors of identification should be expected when the handicap is slight, latent, or overshadowed by other more obvious problems, when the test instrument is faulty or too "coarse grained" to discriminate the condition, when testing personnel are not properly trained and supervised, or when the aural or visual handicap can be confused with some other handicap, as when a deaf child is incorrectly thought to be mentally retarded. One should think about the following remedial actions if excessive Type II errors are encountered in a given identification program:

- Train the personnel better, certify them, and alert them to the often subtle, subjective cues that may signal the presence of a handicap.
- Improve the test instrument, especially to increase the level of resolution to pick up more children with both severe and mild handicaps.
- Or, repeated tests could be given, both immediately and over time, with the same or similar, complementary instruments to give the disability every opportunity to demonstrate its presence. Such a procedure is particularly suitable for progressive or degenerative disabilities, e.g., the Wardenburg syndrome as an etiology of deafness, and for "high risk" populations.

The special problems attendant to screening multiply handicapped and other hard-to-test children deserve special mention as a persistent source of misidentification, particularly in a total handicapped population that appears to include increasing percentages of congenitally and multiply handicapped children. In the case of the mentally retarded child, for instance, there is no reason to believe that a "normal" screening test will reliably indicate either sensory competence or deficiency. Perhaps the mere presence of some other defect, such as mental retardation or a learning disability, should entitle the child to a full aural-visual diagnostic evaluation. Statistically, there is reason to believe that children with other types of handicaps have a greater than average probability of being aurally and visually impaired.

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15 This observation is occurring more in the literature. For example, see J. T. Fenlason, "An Occupational Therapy Program for the Developmental Habilitation of Congenital Rubella Children," American Journal of Occupational Therapy, Vol. 22, November-December 1968, pp. 525-529.
as well, and administrative-legal procedures may be needed to insure they receive hearing and vision tests. There is also some demand to improve diagnostic procedures themselves, but that is a far more difficult matter, best left to medical specialists for resolution.  

Labeling and Stigmatization

In the zealous endeavor to find the handicapped child, one often loses sight of the personal, familial, social, and legal consequences of the "simple" act of identification. To cite the most extreme case in recent history, it was a mere thirty years ago that Nazi Germany systematically exterminated thousands of humans "simply" labeled mentally defective. While far less lurid nowadays, the negative consequences of labeling still persist.  

In a thorough recitation of the issues and legal precedents related to classification of handicapped children in and by schools, David L. Kirp has provided many of the legal underpinnings for a "Children's Bill of Rights." His discussion bears careful and thoughtful reading; we summarize here a few of the more salient issues he raised concerning the problem of labeling and stigmatization.

A basic principle guaranteed by the law is that a child's liberty may not be infringed upon unless adequate procedural protections are provided. Specifically, courts have endorsed the concept that labeling a child mentally retarded or delinquent may not be used as a tactic to relinquish the obligation to educate the child, one area where this society has established a minimum demand and expectation for service. One could likewise argue a related and more general case, although the argument has not yet met the legal test, that failure to classify a demonstrably needy and disabled child for the purpose of denying an expensive or scarce service would appear to be a denial of dubious legality.

The basic issues involved in the identification/classification act revolve about questions of the accuracy of the classification and of the appropriateness of the


17 See John T. Chandler and John Plakos, Spanish-Speaking Pupils Classified as Educable Mentally Retarded, State Department of Education, Sacramento, California, 1969, which responded to the fact that in 1969 some school districts had as many as 85 percent "educable mentally retarded" with Spanish surnames. The problem was linguistic, not intellectual; the result was legislation to require intelligence testing in one's mother tongue and the consequent "delabeling" of several thousand EMR children throughout California.  


21 Kent v. United States, 383 U.S. 541 (1966); and Holmes v. New York City Housing Authority, 398 F.2d 262 (2d Cir. 1968) (authority must articulate standards for admission to public housing.)
proposed treatment.\textsuperscript{22} The procedural guarantees afforded by the law to handicapped persons in presently limited circumstances pertain specifically to a full and comprehensible explanation of the proposed actions, and a hearing prior to taking certain actions.\textsuperscript{23} 

Before reclassification... the school [constituted authority] should inform the family and the child affected, to explain the proposed action and to indicate what alternatives might be available. If such a process actually functioned—if parents and students understood "what the government is doing to [them]"\textsuperscript{24} and voluntarily approved that determination—the need to secure the more formal protections of due process might well disappear.

Once he is removed from the mainstream of the school, injury has been incurred. It is a clear message of Constantineau that a hearing should be provided before the imposition of a stigma. Similarly, during the period that he is misclassified, the child suffers educational deprivation.

The problem of misclassification and/or misreferral of persons who are not in need of service is also considered in the law.\textsuperscript{25}

One possible outcome of an increased consciousness of the costs involved in labeling may be a more judicious use of the classification mechanism. Another outcome might be the extension of this considerable body of legal precedent from the substantive area of education to protect the rights of handicapped children more generally. Even if not more judicious, the labeling and classification processes are bound to become more public as wrongfully labeled people seek redress from the courts for real and imagined grievances.

The creation of functional classifications, another possible outcome of the legal machinery, has been advocated in the past.\textsuperscript{26} It may develop as a way to scale a disabled person's total residual capabilities, and thereby replace mechanistic, simplistic, either/or labels such as "legally blind." Such functional classifications are implicit in our earlier argument calling for a thorough diagnosis and evaluation of the disability and the required services. For several reasons, therefore, efforts to create and execute such functional classification schemes appear to have considerable merit.

Current vision and hearing testing procedures attempt to determine the levels at which the subject fails an acuity test. For example, at what distance and size of figure on an eye chart, or at what level of dB of hearing loss, is he unable to perform? Such tests prove only that the subject cannot see or hear at the prescribed distance or with the noted level and tone of sound; they do not establish his total sensory capability. In contrast, one wonders what might happen if the test objective were to determine the person's aural and visual functional capability in reading, writing,


\textsuperscript{23} Kirp, op. cit., pp. 787-788.

\textsuperscript{24} The reference is to Wisconsin v. Constantineau, 400 U.S. 433, 437 (1971).

\textsuperscript{25} In reviewing welfare payment cutoffs, the Supreme Court has insisted that a due process hearing be provided prior to the cutoff. Goldberg v. Kelly, 397 U.S. 254 (1970). The harm done by "educational cutoff" may be regarded by courts as even more substantial. Cf. Palmer v. Thompson, 403 U.S. 217, 229 (1971).

mobility, and speaking or understanding speech. This is a very different conception
of identification than presently exists, a conception whose objective is to evaluate
the subject's residual capacity to function, and not to limit him by applying gross
labels such as "blind," "deaf," or "deaf-blind."

The point here is the need to emphasize a person's best and total capability to
function in a situation, as opposed to the present "worst case" emphasis that appears
to underlie many labels. For people labelled "deaf-blind," this might mean the useful
recognition that most have some residual capability in the aural and/or visual
senses; very few are both profoundly deaf and totally blind. In fact, there is great
diversity in the overall population labeled "deaf-blind," diversity that must be recog-
nized, especially by legislators and high level administrators, if proper service and
a better service system are to be provided.

**Inadequate Follow-Up**

There is a major problem in getting children who fail vision and hearing screen-
ing tests to a place where they can receive competent, professional diagnostic ser-
dices. That is to say, there are two breakdowns in the "Identification Process":
between both the "Awareness" and "Diagnosis" and the "Diagnosis" and "Service"
phases.

Breakdown in the first instance occurs when a child has been screened and is
thought to be impaired, but nothing is done to get him to a competent source of
medical-diagnostic service. Breakdown in the second instance is thought to be less
frequent, but is still notable; it occurs when the child has had a full diagnostic
work-up but nothing is done to provide the services indicated by the nature and the
extent of the disability and recommended by the diagnostician.

A screening program is nearly worthless without follow-up. The problem itself
might be attacked simultaneously from several angles. General publicity about the
nature and importance of detection of preschool vision and hearing problems might
help, for instance.26 Parents who are so informed, either through the media, by
school personnel, or by their physicians, might give the general problems more
attention, being alert to recognize gross signals of disorders in the child and to search
out competent care. The critical importance of the pediatrician and the general or
family practitioner has not received the attention warranted. In their penetrating
critique of neonatal hearing evaluation, Goldsen and Tait made several pertinent
observations on this point.

- Pediatricians are in the most contact with the child in the 0-5 period, if the child
  is seen by a physician at all.
- Pediatricians are generally not sensitized to a full range of signs and symptoms
  indicative of sensory disorders.
- More should and could be done to improve on this situation by repeated exposure
  of the need for identification to the pediatrician in professional meetings, jour-
nals, in-service training, and other educational activities.

26 The National Society for the Prevention of Blindness is to be commended for their program of
dispensing free "Home Eye-Test Kits" for preschoolers. It is a simple test using a version of the illiterate
"E" which can be used by the parent to spot fairly gross problems in about five minutes. Kits are
obtainable from the Society by writing them at 75 Madison Avenue, New York, New York 10016. There
is even a response card which the parent is asked to fill out and return to the Society so that they can
evaluate the effectiveness of the program. On this return card, the parent may indicate that they did not
use the test, that the child used and passed the test, or that the child was unable to pass a minimum
standard and that an appointment for an eye examination had been made with a physician or optometrist
(whose name and address are requested).
• Pediatricians do not normally have occasion to know and use audiologists [and other specialists in sensory problems], but this shortcoming could be reduced through individual initiative and through direct action by local medical societies.

• There is great and pressing need for more and better staffed well-baby clinics to increase the institutional chances that children in the "missing cohort" aged 0-5 will see a physician.

• The use of mobile hearing testing units, taken as part of a strong, general medical evaluation service, is an underutilized and underappreciated mechanism to realize contact with the 0-5 age group.28

Another and more difficult aspect of the breakdown phenomenon deserves more investigation: Why do parents either seek or not seek medical and other care for their children in the first place? What incentives operate in this matter? When we have complete answers to these "simple" questions, we will begin to know how to provide not only better screening follow-up but better services generally to our children.

Parental cooperation underlies an effective service program. Most parents respond well, but there is some proportion who, for whatever reason, will not take their children to the optometrist or audiologist for more detailed examination or to the ophthalmologist or otologist for a thorough medical workup, if that is called for. Delay can be a serious enemy for the impaired child. If there is difficulty in getting parents to obtain hearing aids for their children, for example, or if there is some problem with the parent's acceptance of special service regulations, then the parents need to be educated or the regulations modified. The school or public health nurse may be helpful in this regard. The recommended Regional Direction Center may have a pivotal responsibility in this task to insure that the diagnostic examinations recommended by the screening program are made and made on time, and to check that services are having the effects they are supposed to have.

Follow-up is too important to be left to chance, and responsibility for it must be carefully and clearly defined early and throughout the handicapped child's life. It is time-consuming, frustrating, and demanding work, but doing it correctly has been demonstrated to have considerable positive benefits.29

Insufficient Personnel Training and Certification

The need for well-trained and certified personnel has been noted occasionally in the literature as one explanation for uneven and unreliable screening programs.30 The value of qualified vision screening technicians has been demonstrated over the years in the Michigan program.31 The need for certification of those actually doing


29 The State of Michigan's vision screening program has been hailed in the literature as being exemplary. One of its key features is the well-developed follow-up procedure that forms an integral feature of the overall program. Parents are notified if their child fails the initial screening; a doctor's report form is included, which the parents are asked to have completed and returned to the Department of Public Health; if in six weeks no report is returned, a follow-up letter reminder is mailed out; and if that does not work, public health and school personnel are quite likely to pay a visit on the family to encourage them to make an appointment. It works. See Robert T. Blackhurst and Edmund Radke, "School Vision Screening in the State of Michigan," The Sight-Saving Review, Vol. 34, No. 1, 1964.


31 Blackhurst and Radke, op. cit.
preschool aural and visual screening has been repeatedly noted in our interviews with speech, hearing and vision specialists.

Comprehensive state screening programs are so few that there is a reduced demand for these very particular technical skills. Black and his associates stress this point, noting without sufficient jobs there is little reason to train technical specialists, but without technical specialists, there is little reason to expect screenings to improve in either quality or quantity.

**Failure to Exploit Technology**

Adequate screening technology exists for school-age children; the problem is to screen very young preschool children. There are many embryonic technological developments in preschool identification, a point stressed in our review of “the state of the art” in the next section; however, the researcher soon forms the distinct impression that, lacking a central or at least recognizable focus for identification as a service,\(^3\) much apparently promising embryonic technology is not being developed to see if it can become practical and be exploited.

For instance, promising but undeveloped technology for screening of neonates for hearing deficits has been reported in the open literature since at least the mid-1960s. There is little comparable literature or experience evaluating these promising techniques in depth, developing and determining their feasibility in an applications setting, or exploring their likely costs and benefits for limited, selected, or mass use. There are many promising technological tools around which, if evaluated, compared, and refined for large-scale applications, could undoubtedly help to strengthen the identification service.

In short, a remarkable variety of technology for preschool age screening exists in experimental form. The connection between research and applications, a connection associated with careful evaluation, studies of feasibility, and assessments of desirability, is not very well made in the current system.

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**SCREENING TECHNIQUES AND PROCEDURES FOR AURALLY AND VISUALLY IMPAIRED YOUTH**

One important by-product of a good sensory-impairment identification program would be information about the nature, extent, and characteristics of the impaired population.\(^3\) That information is central in bolstering policy arguments, and age-specific differences in the data should be reflected in policies. Because they lack badly needed data, many decisionmakers have to rely heavily on subjective judgment as they go about setting priorities and allocating resources. Age-specific information would enable empirical calculations of such factors as lost years of life or personal independence, future income sacrificed, and so on. The death of a male infant, from this perspective, represents 67 years of life, about 40 prime reproductive years, and about 50 years of economic productivity. Death by accident for 20 to 49 year old

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\(^3\) The National Institute for Neurological Diseases and Stroke, and the National Eye Institute, have a long and commendable record of sensorineural research (See Rand Report R-1229-HEW, Chapter 9). There is a difference between much, if not most, of this kind of research and the more prosaic requirements of developing and evaluating identification techniques for mass screening programs.

\(^3\) Barkev S. Sanders, “Measuring Community Health Levels,” *American Journal of Public Health*, July 1964, pp. 1063-1070, indicates some of the effects in health care delivery resulting from better or more complete mortality and morbidity data.
males is more "costly" to society in terms of lost years of life and total productivity than all deaths from the three leading causes for all ages, stroke, cancer, and heart disease, and yet relatively less attention is devoted to accidents. One partial explanation for this emphasis is clearly related to the lack of data and subsequent popularization of data in age-specific terms.

The costs and feasibility of identification programs of course must be considered. In broad terms, we recommend a "mixed scanning" approach to identification, by which we mean giving all children a minimum but sufficient opportunity to demonstrate impairments and, if once demonstrated, a maximum opportunity for thorough and accurate diagnosis. It is infeasible, unnecessary, and too costly to gather finely detailed information on all youth of all ages. However, it appears necessary to improve on the present situation, in which an at-birth medical examination (with little or no attention to testing sensory ability) is often followed by almost a total blank until the child receives a school-entrance medical examination at age 5, and in which a large fraction of school-age youth are not screened for sensory impairment. It would be desirable for both preschool and school-age children to have a greater opportunity to receive a more detailed hearing and vision examination, and, if found to be handicapped, to receive the best possible diagnostic confirmation of sensory impairment. If "awareness" is fostered by low-cost screening procedures, the higher costs of carrying out detailed diagnostics are more readily justified.

Importance of Vision Screening

Unlike adults, children are often unaware that their vision is impaired and therefore do not seek help. Furthermore, the lack of general awareness of the importance of vision tests, the inadequate numbers of trained personnel to conduct screening, and the costs of thorough testing, all work to the children's disadvantage, especially since the benefits of the screening are not directly reaped by the agencies typically funding the screening.

Vision screening is important, but currently it is not done comprehensively or very well. Preschool vision screening is especially underdeveloped despite several recent initiatives; for example, Head Start projects reported screening 680,000 children in 1968, and the National Society for the Prevention of Blindness reports that in the 1963-64 school year there were some 86 preschool screening projects working with 52,000 children, and in the 1964-65 school year there were some 290 projects screening 156,000 children. This is an encouraging trend, but the number of preschoolers screened is still a small fraction of the total. For the sake of contrast, it was estimated that in 1970 some 12,500,000 children aged 5 to 17 had eye conditions requiring special care, or about one of every four children. Of course, not all of these children are severely enough impaired to be called handicapped, but they still benefit from an identification program, for example, by finding out that corrective lenses are required and subsequently learning more in school.


46 Jane S. Lin-Fu, Vision Screening of Children, Department of Health, Education and Welfare, Health Services and Mental Health Administration, Maternal and Child Health Service, Washington, D.C., 1971. This is an excellent, concise work on the general topic.

It is hard to determine the prevalence of preschool vision problems, but we know that rates of referral from preschool vision tests have ranged from 1 to 30 percent in sample programs.\textsuperscript{38} Rules of thumb indicate that refractive errors account for 70 to 75 percent of these referrals, muscle imbalance about 20 percent, and amblyopia ("lazy eye disorder") about 10 percent.\textsuperscript{39} But these figures are no more than partial approximations of the actual needs of the total preschool population, needs which are not reliably known and met with services because the identification measurements are not being made. Trying to answer more specific questions about important subsets of the total preschool population is even more difficult. For instance, we know that multiply handicapped children as a class have more visual problems,\textsuperscript{40} but precise prevalence rates are not known for specific combinations of impairments. Furthermore, it is often harder to screen and diagnose these especially handicapped children, but not much effort has been expended in designing and testing specialized instrumentation and procedures to serve them.\textsuperscript{41}

With identification through vision screening, the child has taken a necessary first step toward receipt of other services. The screening may, for example, result in referral of the child to a physician for a complete eye examination, and later to other personnel for sensory aids; it may make teachers aware of their students’ eye conditions after diagnosis and service are rendered; or it may suggest possible service (e.g., for a child with corrected acuity of 20/70 or less) by a special education program. Screening is not diagnosis; it corresponds to the “awareness” phase of the identification process.

Basically, there are screenings by clinical history and screenings by vision tests.\textsuperscript{42}

**Vision Screening by Clinical Histories**

Studies indicate a correlation between those who fail vision tests and those who either have a family history of eye problems or have demonstrated signs and symptoms of visual disorder. Clinical histories are valuable and important screening devices, although many identification programs do not compile them. It is no great task to extract the portion of a clinical history relevant to eye disorders; it comprises several simple components, such as the following:

- Is there a family history of visual problems?
- What was the mother’s pregnancy history, including the possibility that she might have had rubella, toxoplasmosis, syphilis, or toxemia?
- What was the birth history?


\textsuperscript{41} For general referral guidelines see R. B. Kugel, “Vision Screening of Preschool Children,” *Pediatrics*, Vol. 50, December 1972, pp. 966-967, in which the following criteria for referral are recommended: (1) 3-year-olds with 20/50 acuity or less, (2) 4-to-5-year-olds with 20/40 acuity or less, (3) differences in two eyes of 20 or more, and (4) strabismus. Failing any of these, it is argued, is reason to retest before referral.

\textsuperscript{42} Lin-Fu, op. cit., pp. 5-7.
• Were there neonatal problems, e.g., respiratory difficulty and the use of oxygen therapy?
• Are other handicapping conditions present?

Any significant positive findings should alert screening personnel to the increased odds that the child may have visual problems.

Signs and symptoms that often indicate visual problems include patient-supplied information about headaches, dizziness, sensitivity to light, and blurred vision, or observable signs such as crossed eyes, turned-out eyes, rapid eye movement (nystagmus), red, swollen, or puffy eyelids, watery eyes, and hazziness in the pupils.

Behavior may also be indicative. Excessive blinking, squinting, rubbing, inattention to the blackboard, poor alignment in written material, holding books too near or far from the face, and poor performance in motor activities are all potential signs of trouble. Teacher and parent observations can be important, but they often appear to be overlooked or dismissed.

Preschool Vision Screening

The literature on vision screening of preschoolers is sometimes vague and inconsistent, and raises questions, while answering others.43

The general purpose of existing preschool vision screening programs relates mainly to the “Awareness” phase of the identification model developed earlier. The primary aim of these programs is to detect the existence of low-vision problems.44 Problems of refraction, general development, and medical diagnosis are all relatively neglected with respect to this age group.45

A vision problem often cited as the object of preschool screening programs is amblyopia ex anopsia (“lazy eye blindness”). Treatment for it should not be delayed, as it may result in some permanent impairment of visual ability—impairment that is often avoidable if detected and treated at an early age.46

All that is attempted in most preschool tests is the detection of abnormal distance acuity, and if detected, there is some presumption that the child will be directed to competent professional examination and treatment—a presumption not guaranteed by routine or formal institutional devices.

For infants, most tests are reflex-oriented. If a stimulus provokes some expected response, it is assumed that the visual pathways are working. Reaction of the pupils to light, aversion of the eyes in a lateral direction in the opposite direction of that


44 Oberman, op. cit.


in which the infant's head is quickly turned (doll's eyes phenomenon), and response
to a moving series of lines are all possible screening tests. Other reflex-oriented tests
can also be used if the examining physician or nurse is alerted to the possible
presence of visual problems and trained to perform them.47

For children from about age 1 to 2 years, subjective tests have been used.48
Walking infants are asked to retrieve small, standardized objects from varying
distances with each eye covered in turn. If the child can talk, several other tests can
be used: picture tests,49 direction tests,50 and some very specific acuity tests.51

Medical examinations by pediatricians and general practitioners could be much
more effective than they are, in practice, in the early detection of preschool visual
problems. For instance, in a section of a standard pediatric textbook devoted to
"Examination of the Pediatric Patient," Kempe and his colleagues recommend the
following to the pediatrician:52

Most newborns have the visual capacity to fix on a moving object as early
as the first few minutes of life. Infants who do not follow a face at the first
well child visit should be suspected of having a visual problem. Ophthalmosco-
scopic examination should be done on one of the earliest possible visits in
order to make the diagnosis of cataract, congenital glaucoma, or retinal
abnormality.

And later in this same section:

Five to 10 percent of preschool children have some kind of visual impair-
ment. The illiterate E chart, Snellen chart, or Allen cards can be used for
checking visual acuity, and each eye should be tested separately. The 5-year-
old child should have a visual acuity of 20/30 or better in both eyes, and
there should be no significant difference between the two eyes. Amblyopia
ex anopsia affects 2 to 5 percent of children and must be detected early before
permanent loss of vision occurs.

In a subsequent section of Kempe devoted entirely to the pediatric eye, Ellis
comments about the important and underutilized role of the mother in performing
preschool visual acuity tests:

Routine testing of visual acuity should be a part of every general physical
examination. It is the single most important test of visual function. In

ed., pp. 90-91. Dr. J. Terry Ernest pointed this out in an interview with G. D. Brewer, Chicago, Illinois,
March 1972.

48 Many of which are noted in E. S. Duke, Textbook of Ophthalmology. C. V. Mosby, St. Louis, Missouri,
1971; and Vaughan et al., op. cit.

397-405; and C. Berens, "Visual Acuity and Color Recognition Tests for Children," American Journal

29, 1946. The child is asked to point out the direction in which some object is facing, heading, etc. See
also S. D. Lieberman and S. S. Gellis (eds.), The Pediatrician's Ophthalmology, C. V. Mosby, St. Louis,
Missouri, 1966.

51 E.g., "STYCAR" tests ("Screening Tests for Young Children and Retardates"); see M. D. Sheridan,
"Vision Screening of Very Young or Handicapped Children," British Medical Journal, Vol. 2, 1960; and
idem, "Vision Tests for Young Children, Normal and Handicapped," Spastics Quarterly, Vol. 11, March
1962, pp. 25-33.

52 C. Henry Kempe et al., Current Pediatric Diagnosis and Treatment. Lange Medical Publications,
Los Altos, California, 1972, pp. 124-125. The following are visual acuity tests in current usage for
preschoolers: Snellen E. Test, Sjogren Hand Test (like the Snellen but uses hands and fingers), Landolt
Broken Ring Test (variation of Snellen), California Clown Test—"Do-As-I-Do Vision Test" (another
variation of the Snellen), matching letters tests, picture tests, symbol tests, miniature toy tests, etc. The
children 4 years old or older, satisfactory visual acuity tests can usually be obtained with the use of Snellen test cards or illiterate E charts. . . . The mother, with her interest, can repeat the test at her leisure, and the final result is usually more accurate than testing done in the office by the pediatrician or his nurse.33

With respect to mass screening, several problems confront those interested in complete and reliable coverage of the preschool population.34 Besides the general observation that there is no existing formal institutional mechanism to guarantee that the child will be screened before entering school, a problem noted previously, difficulties are reported in even those few instances where special efforts have been made to carry out these tests.

Screening tests themselves have not been standardized and misidentifications are not uncommon, or at least this seems to be the general point raised in several case settings where preschool vision testing has been tried on a large scale.35 Given the problems with test standardization, variation in the criteria used for referral, and the absence of reliable information on rates of clinical referral and follow-up, it is difficult to say much about any of the following points—all of which are necessary inputs and factors to be considered before making any recommendations about mass screening for preschoolers:

- The quality of screening techniques to be used;
- The expected incidence and referral rates for various kinds of visual disorder;
- The cost of a mass screening program for preschoolers;
- The magnitude of the benefits that might accrue to the overall population as a result of such an undertaking.

In light of critical unresolved questions, especially concerning whether potential benefits of mass screening of all children at a preschool age rather than age 5 outweigh the costs, we do not recommend mass screening for visual impairment in the preschool population. Rather, the value of the pediatrician and the family in the identification process is such that we have chosen to concentrate attention on them instead.

It has been noted that on the average parents are excellent diagnosticians, but that parental anxiety is often36 compounded by professional denial of the diagnosis or by false reassurance. One-third of the parents interviewed by Meadow37 and seen by Schlesinger . . . indicate that the first physician consulted denied the suspected deaf-

33 Philip P. Ellis, "Eye," in ibid., pp. 197f.
34 Apell and Lowry, op. cit., and Hatfield, op. cit.
ness. Sixty percent of the parents in Meadow’s study consulted four or more physicians prior to receiving a definite, accurate diagnosis.

One of the reasons that early diagnosis is often not accomplished is that physicians generally and pediatricians particularly are not well and thoroughly trained to detect early childhood hearing and vision disorders.

The pediatrician has a serious responsibility with respect to identifying all types of physical and mental handicaps in children, and he would be aided in discharging that responsibility if:

- Authorities responsible for medical school curricula would review those aspects devoted to pediatric examination to insure that this material is covered and receives the serious attention it warrants;
- State boards certifying pediatricians would examine applicants to call attention to this responsibility and to insure that certified pediatricians know how to conduct screening procedures for the various handicapping conditions appropriate for the age and general condition of the pediatric patient;
- Those responsible for pediatric residency programs would review their programs to insure that both aural and visual screening procedures are learned and routinely carried out. If necessary, formal communication with ophthalmologic (and otolaryngologic) services could be instituted to guarantee the quality of the instruction.

The parent’s close contact with the preschooler should be exploited far more than it has been in the past. A parent may perform periodic initial screening of the preschooler at home as well as or better than would a massive, one-shot program. The child is more relaxed, the mother has more time to carry out the basic tests and to repeat them until she gets stable results, and she has specific knowledge about the child that no one-time screener could be expected to match. Parents would be aided if:

- Programs such as that being conducted by the National Society for the Prevention of Blindness noted earlier were encouraged, evaluated as to effectiveness and cost, and then expanded if warranted; and
- Parallel activities were supported to explore alternative testing instruments, practices, and corresponding results when parents test the preschool child in their home.

Finally, the nursery school—an expanding trend associated with heightened interest in early childhood education—is another underused resource. In this case the teacher and school nurse (if one is available) could be trained to recognize behavioral cues and perform screening. Again, this is not diagnosis; it is intended to pick up the grossest of sensory deviance as early as possible so that the child suspected of having problems may be identified and given professional diagnosis. The importance of follow-up and direction are critical and obvious in this case.

- Where procedures to license and certify preschool nursery personnel exist, we recommend that efforts be made to instruct and sensitize those personnel to be alert to the possible presence of sensory problems.

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We recommend that clear standards and procedures of reporting suspected sensory problems to parents and health and education authorities be created (where none currently exist) or reviewed and improved (where they do exist).

School-Age Vision Screening

Carefully controlled studies of the reliability of the available school vision screening tests and programs have not been done routinely or on a national comparative and evaluative scale. In those cases that have been monitored to some extent, a number of consistent findings emerge:

- The programs are relatively expensive.
- Good screening programs, as measured solely by high rates of confirmation of true positives by diagnosticians, have trained and certified visual-technical specialists either closely supervising or actually conducting the tests.
- Something on the order of 10 percent should be expected to "fail" the school vision screening programs, although the prevalence rates of disorders contributing to this rule of thumb are not well or reliably reported.
- Follow-up is a critical component in those programs thought to be relatively effective. That is, parents need to be informed of possible visual problems, they need encouragement and information about where to get competent diagnostic help, they may need financial assistance in obtaining the service, e.g., glasses and medical treatment, and they may need reminders to have the child examined further.

The State of Michigan has amassed a commendable record in its school vision program over the last 30 to 35 years. As reported, this program is straightforward in its design and implementation and could serve as a model for vision screening programs at the school level in other locations. Generally characterized as benefiting from good public education, high standards of personnel doing the testing, sound administration, and persistent follow-up procedures, the Michigan program has enjoyed confirmed true positives averaging around 90 percent over the years—a remarkable achievement. One result is that physicians respect the program and take its referrals seriously. Some 200 "vision technicians," employees of the Maternal and Child Health Division of the Michigan State Department of Public Health, have been recognized and suitably appreciated by public and policymaker alike as the essential ingredient in the program's success. The second key element is the administrative procedures of follow-up, created to insure that the identification process does not break down before needed services are delivered. A notification is mailed to the parents when a child is found to have a vision problem. The notification includes a blank doctor's report that the parents are asked to have filled out and returned to the Department of Public Health. If no report is received within six

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61 Blackhurst and Radke, op. cit., and Michigan Department of Public Health, Vision and Hearing Screening.
weeks, a follow-up letter is sent and the child’s school nurse is notified. On their own initiative, Department personnel might then get in touch with the parents to inform them of local diagnostic services.

For school age children we recommend that:

- Various apparently successful programs, including the Michigan model, be thoroughly evaluated for full details of their operation, costs, and benefits;
- A reproducible model or models for other states be developed, given the detailed findings of those thorough evaluations, which could serve for a full-scale implementation throughout the country; and
- A comprehensive mass vision screening program be instituted throughout the United States, designed to reach every school-age child.

Importance of Hearing Identification

Serious and permanent hearing deficits occur in slightly more than 1/2 percent of the children, or about 490,000, aged 0 to 21; and for 10 percent of this group of handicapped children, their loss is profound and bilateral, resulting in a nonfunctional sense of hearing.63 About 10 percent of all children have less severe but still significant hearing impairment (15 + dB).64 The most frequent cause of children’s hearing loss is recurrent chronic otitis media or serious otitis media (infections of the middle ear).64 Even children with a single episode of otitis media may have some degree of hearing impairment for some period after the acute episode.

Although these hearing losses may not be too severe, they may occur at an unfortunate time and may be sufficient to inhibit the acquisition of language65—a setback that may affect the child throughout his school years.66 If the losses are discovered and services provided before school begins, many of the learning, behavioral, and discipline problems that ensue from poor hearing and poor attention may be averted.

Detection of such problems is as much a part of preventive pediatrics as is the immunization routine. Audiologic screening tests can be performed by nonprofessional technicians and should be a part of the preschool examination.67

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Characteristics of Hearing Loss in the Youth Population

While the importance of early identification of hearing handicapped youth is undeniable, we know little about the characteristics of that population until they are about age 5 and over.

There are several types of hearing loss. Sensorineural hearing loss (or "nerve deafness") is due to a problem within the inner ear, in the nerves going from the inner ear to the brain, or in the brain itself. The loss may result from infection, trauma, toxic substances, degenerative disease, or congenital causes (see Chapter 5). Conductive hearing loss occurs in patients with a normal inner ear who are hard of hearing because something is wrong with the mechanism conducting the sound to the inner ear. Medical or surgical procedures, or amplification, may restore hearing partially or fully in such cases. Congenital deafness is probably present at birth or occurs soon thereafter. Mixed hearing loss involves both conductive and neural components. And simulated hearing loss results from causes that cannot be traced to organic disease, as in instances of involuntary, e.g., emotional or psychotic, disorders.88

Typically, hearing loss found in school audiology programs is slight, conductive (not sensorineural), and transient (not permanent).89 In urban schools, between 2 and 5 percent of children may require referral to physicians for medical attention and diagnosis.70

Most children with sensorineural loss are "hard of hearing" rather than deaf. This means that many of them can benefit greatly from hearing aids, despite the aural distortion that often occurs with this type of impairment. Sensorineural hearing loss usually occurs early in life and prevents or hinders the natural development of speech and language. Early diagnosis and treatment, together with effective teaching methods, could do much to reduce the total degree of functional handicap resulting from this type of hearing loss.

Measurement of Hearing

The current state of hearing measurement is relatively well developed and diverse, and is represented in a large and growing literature.71

Using an audiometer, the basic instrument, a competent audiometrist can test hearing by using air and bone conduction techniques. Hearing losses in children have been identified and measured at virtually all ages, with the possible exception of the first months of life. The younger the child, naturally, the more sophisticated must be the instrumentation and the measurement specialist. This relates directly to our concept of the general identification process, in that gross screening ("awareness") tests may be done by a nurse or pediatrician in the office or nursery to pick up suspected hearing loss; solid diagnosis must be done where experience, specialized skill, and instrumentation are all more developed.

Ideally, screening tests should be done at birth and at all pediatric examinations so that possible hearing losses are picked up as early as possible. While this study is narrowly interested in children having hearing losses of about 40 dB and more, it is also important that children with lesser deficits of, say, 15 to 40 dB be identified so that parents and teachers can seek more specialized help if required. Rehabilitation can begin as early as the deficit is detected, which generally means as early as 6 months of age.\(^\text{12}\)

Competent audiometrists are critical in the screening process. Ballenger enlarges on what constitutes "competency" here in the following terms:

Adequate audiometry cannot be carried out by personnel who have not received suitable training and experience. In order to obtain accurate and useful clinical information, the audiometrist must have a satisfactory grasp of the basic principles underlying behavioral measurement. He must, in addition, be familiar with the audiolologic patterns associated with the various types of hearing disorders. Finally, he must understand the limitations of electroacoustic instruments.\(^\text{13}\)

Air conduction audiometry measures the sensitivity of the entire hearing system by placing an oscillator-driven earphone over the external ear. Because response derives from the entire hearing system, one is generally not able to isolate the point of hearing loss, if there is one.

Bone conduction audiometry measures the sensitivity of the sensorineural mechanism by placing a stimulus (tuning fork, bone conductor vibrator) directly to the patient’s skull. So doing short-circuits the transmission mechanisms of the middle ear, and helps to determine the type of hearing loss.

Hearing loss of 15 dB or more is one standard reference point for referral. Patients with that much loss should be considered candidates for special attention and services.\(^\text{14}\)

Congenital deafness has been detected in infancy by exposing the child to acoustic stimuli and then recording his responses. Infants with significant hearing loss have been successfully fitted with hearing aids at one month of age.

The importance of taking the relevant clinical history as a routine part of the hearing screening process is as great here as it is for vision screening. Positive relationships exist between failures on hearing tests and family histories of ear disorder or those who have demonstrated signs and symptoms of hearing disorder. While this relationship is well known, the taking of clinical histories is not always a routine part of the child’s hearing screening program. For example, audiolologic high-risk registries (composed of those singled out in the clinical history process) have been important in detecting hearing losses in children as young as 6 months old. Without such registries, the earliest time that hearing loss is detected is commonly around 20 months.\(^\text{15}\)

Testing very young children calls for patience and no little ingenuity. They have little reason to want their ears tested, they often fear strangers and unnatural

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\(^{15}\) Kempe et al., op. cit., pp. 124-125.
settings, it takes special effort to get them to listen attentively to sounds, and their responses are none too accurate. Finally, the child may not know what he has been missing, unlike the adult who may have enjoyed good hearing in the past. The very young child’s deficit probably has been with him since birth and seems perfectly “normal” to him, in a real sense of that term.\textsuperscript{76}

To restate the main point of much of this discussion, it is generally agreed that early detection and treatment of hearing loss are crucially important.

Every physician who is responsible for the care of infants should develop similar screening programs in the hospital nursery or at least check the infant’s hearing at the first visit by the use of squeak toys and bells which have as close to pure tone sounds as possible. The newborn will only respond by a flicker of his eyelids or a very minute Moro response [body tremor in response to aural stimulus.\textsuperscript{77}]

### Preschool Hearing Tests

Most 4-year-olds can be tested with conventional techniques. Children younger than 4, including the newborn, may also be tested with a variety of techniques, although diminished reliability and increased cost are to be expected. Davis and Silverman, for instance, divide hearing tests for the very young into three general classes: methods based on increased motivation, physiological audiometry, and electrophysiological tests.\textsuperscript{78}

The first class includes “games” and other devices designed to capture and maintain the child’s interest in a conventional audiological examination. Children over 2-1/2 years old normally play games and hence can be tested with these methods. The second class of tests depends on behavioral reactions of the child, e.g., startle reactions, reflexes, awakening from sleep, and movements toward or away from a sound stimulus—the last of which, “orienting reactions,” are thought to be the “best in the critical period from 6 to 12 months of age when identification and approximate assessment of impaired hearing are so important.”\textsuperscript{79} The third class is generally not suitable for mass screening at the current state of development, because of the size, cost, and demand for very specialized skills and instrumentation. As diagnostic aids, however, the third class is important; it includes electrodermal audiometry (galvanic skin responses to sound stimuli), electroencephalographic audiometry (EEG patterns are assessed with respect to various sounds), and electric response audiometry (evoked response audiometry). These assessment techniques are known fairly well in the specialized audiologic community, but their administration is dependent upon earlier, grosser recognition that the child has some hearing impairment.\textsuperscript{80} In terms of the identification model developed earlier, tests of the third class would clearly fall into the “Diagnosis” phase.

Given the fact that a large number of children are examined only at birth when identification is difficult, and then not again until their school entrance examinations, the need for some kind of preschool age identification program is clear, as is

\textsuperscript{76} Ballenger et al., op. cit.


\textsuperscript{79} Ibid., p. 240.

the need for physicians (especially pediatricians) to be alert for hearing problems during routine check-ups.81

Hearing Tests at Various Ages of the Young

Screening At Birth. There is a very large literature on screening at birth; its main points can be summarized as follows:

- It can be done but it depends on the skill and training administered to screening personnel, e.g., nursery nurses who repeat simple reflex tests over the entire period that the newborn is in the hospital.82
- Responses are not too reliable. Both false positives and false negatives are commonplace. The need for repeated testing is clear.
- Based on the experimental evidence, mass screening techniques of the newborn are not reliable enough for consideration for large-scale implementation.83

This does not mean that efforts should be abandoned to develop better ways to conduct mass screenings at birth; it merely affirms that current testing methods and procedures are not sufficiently reliable.84 A promising innovation is the recently reported "Crib-o-gram" system developed by Blair Simmons and his colleagues at the Stanford Medical School;85 a full-scale evaluation, including follow-up of the identified children as they age, will be needed to confirm its value.

A recent summary by Bordley and Hardy advances the following comments about neonatal hearing screening—comments justified by a thorough review of the literature:

Neonatal auditory screening appears to bear no relationship to subsequently identified hearing loss; in fact, 98 percent of the 248 children failing the audiometric test at age 8 years gave normal responses to sound stimuli of 65 dB to 75 dB during the newborn period. These findings are in accord with our past experience.86

84 The use of high-risk registries, for example, has been instrumental in narrowing the total population down to a more manageable subset of those likely to have hearing difficulties. For this group, every and all screening techniques would appear to be warranted. L. Bergstrom, W. G. Hemenway, and Marion P. Downs, "A High Risk Registry to Find Congenital Deafness," Otologic Clinic of North America, Vol. 4, 1971, pp. 389-399; and Marion P. Downs, "Audiologic Evaluation of the Congenitally Deaf Infant," Otologic Clinic of North America, Vol. 4, 1971, pp. 347-358.
85 Basically, the movement of the child is carefully and automatically recorded in response to aural stimuli. "Abnormal" responses signal that the baby may have some hearing difficulties and indicate that the physician should administer more intensive diagnostic procedures. It has been reported in the press that some 8000 babies have been screened with the Crib-o-gram system since 1970 and 300 "failures" were identified, of whom 8 were actually shown to have hearing loss in subsequent diagnostic workups. Los Angeles Times, September 23, 1973, Part 1, p. 3.
86 John E. Bordley and Janet B. Hardy, "A Hearing Survey on Preschool Children," American Academy of Ophthalmology and Otolaryngology, Vol. 76, No. 2, 1972, pp. 349-354, at p. 353. This study implicitly calls attention to the pressing need for follow-up evaluation of children as they pass through the 0-5 period to determine the true rates of false positive reports for those children who in fact have received one of the many neonatal tests. Follow-up has been sparse so far.
Another summary evaluation of the considerable literature on neonatal screening adds the following cogent comments:

- Mild hearing loss is not routinely detectable, and unilateral loss is not detectable.
- The absolute number of missed children does not appear to be large, but the question is somewhat moot given the condition of the existing data.
- Screening procedures are not very good. There are too many false positives caused by a conservative orientation of the testers, who do not want to let a hearing impaired child slip through, and by operational problems connected to test administration.
- Follow-up on identified children is either not done or is done by nonspecialists, with the result that the problem of parents laboring under false positive identification looms somewhat large.
- Economic arguments about relative benefits derived from special training at age 1 versus age 3 or 4 are not well established. [There is] "no evidence to prove that detection at age four days for example, followed by immediate guidance and training, leads to a significant financial savings compared to when detection is accomplished and training is begun at four weeks, four months, or even two or three years."  

**Screening at 0 to 2 Months.** Gross overall response to sound stimuli predominate in the 0 to 2-month range.  

**Screening at 3 to 24 Months.** Behavioral responses are observable by about

---


the second month,\textsuperscript{93} the infant is capable of being distracted by and of paying attention to sound. By the age of 4 months, eye movement in response to stimuli should be observable. The average 1-year-old is able to comprehend sounds and recognizes his parents; and by about 18 months can identify parts of his body and favorite toys.\textsuperscript{94} By approximately 18 months, two- or three-word sentences should be regularly produced. If these abilities are not manifest at approximately these stages, parents should seek professional assistance and diagnosis of suspected hearing loss. As we found in our parent interviews, however, parental suspicion is sometimes discounted by pediatricians as merely unnecessary anxiety. Judgment and sensitivity on the part of the physician is the key to identification in this early age period. Careful and consistent observation is called for by parents and doctors alike.\textsuperscript{93}

Several small-scale screening programs for children in this age group were found in the literature; however, none seems to have comprehensive applicability.

- Much of the population in this age group is not routinely seen by a physician (no existing institutional mechanisms guarantee adequate coverage).
- Visiting nurses have been used, but they are few, are not all adequately trained in this field, are often overworked, and are not in contact with the total population.
- Public health clinics, well-baby clinics, etc., are not ordinarily set up to conduct this kind of screening nor do they serve a majority of the population.
- Reliance on high-risk registries would appear to have particular appeal for coverage of this age group.

**Screening at 24 Months to 5 Years.** Screening is possible in this age range. By this time the child should be able to respond to sounds voluntarily. Simple tests can be performed by the physician, or even the parent if trained (see Table 4.1), and play-conditioning and finger-raising, both in response to commands, are commonly reported in the literature.\textsuperscript{95} Failing these tests should be cause to seek out more competent diagnosis. The basic problems of doing screening for this age group have been summarized by Ballenger.\textsuperscript{97}

- Fear of strangers and strange settings;
- Fear of earphones;
- Learning about the expected stimulus response behavior inherent in most screening procedures (and thereby either volunteering response or failing to respond out of coyness or boredom);
- Maintenance of attention to the test.

Despite these problems, the benefits of early preschool identification of hearing handicapped youth appear large in relation to the costs. Among the benefits are reduction of the potentially permanent inhibition of language and speech development by medical or surgical treatment of the hearing loss, provision of sensory aids, and provision of preschool special educational services. Profoundly deaf and severely


\textsuperscript{95} Ballenger et al., op. cit.

\textsuperscript{96} Philip Lichtenberg and Dolores Norton, *Cognitive and Mental Development in the First Five Years of Life—A Review of Recent Research*, National Institute of Mental Health, Chevy Chase, Maryland, 1970; and Davis and Silverman, op. cit.

\textsuperscript{97} Ballenger et al., op. cit., Chapter 41.
<table>
<thead>
<tr>
<th></th>
<th>Normal</th>
<th>Abnormal</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Speech</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your child say a</td>
<td>12-18 months</td>
<td>2 years and up</td>
</tr>
<tr>
<td>few words?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can he say some words</td>
<td>Three-quarters of</td>
<td>3 years and up</td>
</tr>
<tr>
<td>containing each of the</td>
<td>the sounds at</td>
<td></td>
</tr>
<tr>
<td>following sounds?</td>
<td>two to three</td>
<td></td>
</tr>
<tr>
<td>s (as in yes, bus, see,</td>
<td>years</td>
<td></td>
</tr>
<tr>
<td>sock)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>sh (as in shoe, shut,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>fish)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>k (as in coat, cow, cup,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>cat)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>t (as in toe, teeth, top)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can strangers understand</td>
<td>Yes, from 18 to</td>
<td>No, two-and-a-half</td>
</tr>
<tr>
<td>his speech?</td>
<td>24 months</td>
<td>years and up</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td>21-24 months</td>
<td>30 months and up</td>
</tr>
<tr>
<td>Is he putting two words</td>
<td>Two to three years</td>
<td>Three years and up</td>
</tr>
<tr>
<td>together?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does he talk in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>sentences?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Understanding</strong></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Does he usually</td>
<td></td>
<td></td>
</tr>
<tr>
<td>understand what you</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>say to him?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does he have to watch</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>you in order to</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>understand?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Responses to Speech</strong></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>(not noise)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does he hear you when</td>
<td></td>
<td></td>
</tr>
<tr>
<td>you call him from a</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>distance of several</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yards?</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>When in the same room</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>do you have to raise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>your voice to get him</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>to hear you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hearing Problems</strong></td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Do any relatives have</td>
<td></td>
<td></td>
</tr>
<tr>
<td>hearing problems (other</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>than through aging)?</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Does he ever complain of</td>
<td></td>
<td></td>
</tr>
<tr>
<td>earache?</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Do you think he has any</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>difficulty in hearing?</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If the child is rated abnormal in speech only, the first area listed above, a hearing loss is not indicated. If the child is rated abnormal in two or more of the other areas, then hearing should be checked.

**SOURCE:** Ling, op. cit., p. 8.

Hard of hearing youth have the greatest need for these services before age 5, and they obviously cannot receive them until the handicap has been identified.

We have already mentioned several options for reaching preschool children, including a "high-risk registry" activated at the time of birth, working through well-baby clinics or nursery schools, and making simple screening tools available to parents for home use. But perhaps the most promising means of identifying preschool hearing or vision handicapped children is a type of "free check-up" system using pediatricians. Simple data/administrative procedures could be developed to aid in this type of identification. For instance, the simple form in Fig. 4.3 is used in Kansas. We would go further and recommend that each child be entitled to "free check-ups" at various times between age 0 and 5, with an age 2 medical check-up to include quality screening for hearing and vision impairment. These checkups could be performed by pediatricians or other service personnel, who could be reimbursed through National Health Insurance or some other program for every child they screen and report on to a health or other prescribed government agency. In brief, we recommend that:

- Various options for identification of 2 to 3 year old children for hearing handicaps be thoroughly evaluated with the goal of developing a reproducible model or models for full-scale implementation throughout the country, and then, when viable models are developed that:
### Preschool Multiphasic Screening

<table>
<thead>
<tr>
<th>Test</th>
<th>Date</th>
<th>Referral</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denver Developmental Screening Test</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hemoglobin</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immunizations-T. B. Skin Test</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Inspection</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urinalysis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vision</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**KANSAS STATE DEPARTMENT OF HEALTH**

Copies: 1 School 2 Parents 3 Local Health Dept. 4 Kans. State Dept. of Health

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Fig. 4.3—Kansas form for preschool multiphasic screening

- A comprehensive hearing identification program be instituted throughout the United States designed to reach preschool-age children.

### School Hearing Screening

As with vision screening, carefully controlled studies of the reliability of the existing school vision screening tests have not been routinely done on a national scale. It appears that “sweep frequency screening” is a common method of choice, and is one of the simplest and most reliable methods. Other general findings include the following:

- Good screening depends significantly on the skill of the screener and the quality and calibration of the audiometer employed.
- Follow-up is the critical ingredient in a good as opposed to unsatisfactory hearing conservation program (as was the case with school vision screening).
- Teachers in the early elementary grades, if trained to observe and recognize behavioral clues, are an underutilized source of early identification.

By way of encouraging the thorough evaluation of all existing school hearing screening programs, the following general questions are offered for consideration. These should prove useful for those actually involved and for those interested in the aggregate effectiveness of school hearing screening programs:

- Are true positive identifications routinely and systematically made as confirmed by competent diagnosis?
- Is the screening staff well trained and using technically reliable audiometers?
- Are new students screened?
- Are screenings done several times during the child’s school career? (Some hearing disorders are degenerative, and a true negative at school entrance could become a false negative over time.)
- Are records complete and accurate?
- Have diagnostic procedures been reliable, and has follow-up worked satisfactorily?

---

• Have services been provided to those in need, such as hearing aids?
• How is the local program generally regarded by specialists in the area?

Our recommendations for school-age hearing handicapped children parallel those for school-age vision handicapped children, and include a comprehensive mass screening program designed to reach every school-age child. This early school-age screening theoretically would be the second for some children, and would be expected to catch handicaps that develop after the first age 2 screening, to catch those less severe hearing handicaps that may have been missed earlier, and to catch those youth who escape the age 2 identification net altogether.

RECOMMENDATIONS FOR IDENTIFICATION PROGRAMS

A number of problems with and concepts for improving the identification service have been discussed in the course of this chapter, and are summarized in the following recommendations.

• Various existing hearing and vision impairment identification programs, for both school-age and preschool-age children, should be thoroughly evaluated to learn details of their operation that contribute to effectiveness, and to assess their costs, benefits, and suitability for implementation throughout the country.

• When that evaluation is complete, a comprehensive mass screening program for aural and visual handicaps should be instituted throughout the country, designed to reach every young school-age child.

• High-risk registries appear desirable, especially for children at risk in the 0 to 5 year age group not normally in contact with public service institutions. Registries should be improved where they exist, and created where they do not. High-risk infants should be screened at birth, one to three times between birth and age 5, and again upon entering school.

• Persons in contact with preschool children, such as parents, day care personnel, nursery school teachers, well-baby clinic personnel, social workers, pediatricians, and nurses, should be sensitized to the possible existence and effects of hearing and vision impairment, and provided with knowledge of relatively simple tests for signs and symptoms of such impairment. Existing institutional settings to catch the missing cohort aged 0 to 5 should be exploited as fully as possible to improve the chances that a child will be identified.

• If detailed evaluation confirms its apparent desirability, each child could be given "free check-ups" at various ages, with an age 2 medical check-up to include quality screening for hearing and vision impairment. Reimbursement to pediatricians or other service personnel could be through National Health Insurance or some other program, and would follow their reporting the screening results to a health agency or other prescribed government agency.

• Follow-up to see that the identified child receives diagnostic and other needed services should be a component of every screening program.

• Efforts should be expended to collect all standards currently in operation for all official hearing and vision screening programs throughout the country. These standards should then be summarized and analyzed with the end in view of
developing a "model" code for hearing and vision screening, including all procedural details required to fully describe the elements in the identification process model.

- State certification and licensing boards are encouraged to consider requiring general, family and pediatric practice physicians to demonstrate proficiency in the various hearing and vision screening and diagnostic procedures. We further encourage such certification and licensing bodies to consider the need for improved and common standards for those paraprofessional and allied-skills professionals who conduct screening and diagnostic procedures, and for test instruments and procedures.

- A program requiring physicians and teachers to report all handicapping conditions to parents, the State Department of Public Health, and the Department of Education should be carefully designed and implemented. We recognize the real possibility that privacy and service desirability norms may clash in this case, but believe that careful design of the procedures insuring legal and moral safeguards is possible and desirable.

- A coordinated and directed national research program should be supported, whose basic purpose is the production (research, testing, and development) of reliable mass screening instruments and procedures. Such work as exists at present is not well coordinated and generally is not directed to the operational aspects of implementation.

- The Regional Direction Centers discussed in Chapter 3 would do much to focus local attention on and coordinate the general identification process, and direction is the next logical step in obtaining services after the child is identified.

- We recommend that a national program be established for the collection, compilation, analysis, and dissemination of data on handicapped children, beginning with the aurally and visually impaired as a "manageable" subset of the total population for purposes of early implementation. There are few national data of comprehensive and reliable quality on handicapped youth, mainly because no one at the national level has this responsibility. Finally, the feasibility of conducting a special census of handicapped children should be considered.
Chapter 5
MEDICAL PROGRAMS AND SERVICES

INTRODUCTION

This chapter considers medical treatment services for hearing and vision handicapped youth, and presents an assessment of federally supported medical programs for all handicapped children.

Medical programs that bestow large benefits on the lives of all handicapped children are summarized as best we can, given the dearth of programmatic information and data on the status and needs of the vision and hearing handicapped subset of the population. While there are three main federally supported medical programs serving handicapped youth—Medicaid, Maternal and Child Health Service, and Crippled Children’s Service—many more are to be found in rehabilitation programs, in Department of Defense programs for military dependents, in the Veterans Administration, in OEO, in NIMH, in Project Headstart, and so forth.

A number of program recommendations are developed and related to short-term and longer-term implementation time frames.

In the short term:

- We recommend that the Office of the Secretary of HEW conduct a full-scale evaluation of all programs supported by the Maternal and Child Health Service (MCHS), with the end in view of concentrating future resources on the most critical needs and most effective programs. The remaining programs would be candidates for termination. Research studies on specific disorders should be transferred to the cognizant National Institute of Health.

- Pending resolution of difficulties that have been experienced with the present Medicaid program, and pending the adoption of National Health Insurance or some other program designed to make good-quality comprehensive medical care available to all youth, we recommend that the Crippled Children’s Service (CCS) program be retained and expanded.

- Consideration should be given to integrating the CCS and Medicaid programs in the states. The desirable comprehensive and financially open-ended nature of the Medicaid program could benefit from some of the apparently better program administration features of CCS, which also provides medical treatment for handicapped youth in financially needy families. A thorough evaluation of methods and effects of integration should precede implementation.

- Significantly improved management procedures should be implemented to yield much better Medicaid program management information; to cut delays; to improve the equity of eligibility standards; to insure that mandatory provisions are implemented (e.g., screening); and to permit revision of medical payment schedules to reflect the realities of the medical marketplace. Coverage of all Supplementary Security Income recipients should be assured.
In the longer term:

- We endorse the concept of National Health Insurance (NHI), provided that it includes coverage of medical services to all handicapped youth in need, and includes provisions (outlined later in this chapter) for meeting the special needs of handicapped persons. HEW, in particular the Office of the Secretary or the proposed Office for the Handicapped, might review and react to all NHI proposals to assess the likely effects of each on the lives of handicapped persons.

- In related areas, the proposed Office for the Handicapped, could also strengthen and coordinate the “missing” or “underdeveloped” services of prevention, identification, and direction. This would provide needed leadership for three service areas having profound implications for medical and other services but for which no one federal authority presently has assumed prime responsibility.

The chapter then discusses medical treatment services for vision and hearing handicapped children. It summarizes available prevalence data (disaggregated as far as possible according to age and type of affection), characterizes most of the commonly encountered disorders, and briefly describes various treatment methods and costs for each. The section concludes with a series of recommendations related to medical treatment:

- The Department of Health, Education and Welfare (the proposed Office for the Handicapped or the Office of the Assistant Secretary for Planning and Evaluation) should institute a thorough and continuing periodic review of current data-collection and utilization procedures and resources with respect to handicapped children, as a first important step in improving services to the handicapped generally, and with the intent of implementing steps to improve the availability and use of information. The National Eye Institute (NEI), the National Institute of Neurological Diseases and Stroke (NINDS), and The Bureau of the Census, among others, should be consulted with the end in view of preparing a segment of questions on medical and other services to the handicapped population for inclusion in the 1980 Census of the Population. Improved information could do much to inform legislative and executive agency actions that ultimately affect the lives of the handicapped population. Information does not presently exist in the quantity, in the form, or with the reliability necessary to accomplish this critical task.

- Medical fee payment schedules should be revised to reflect the realities of the medical marketplace.

- With an improved research management information system, the proposed Office for the Handicapped or NEI and NINDS could launch catalytic activities to diffuse improved medical treatment methods by identifying promising research findings and then stimulating the development work required to make these research findings of general, practical use. No one at the federal level currently has prime responsibility to insure that research results are developed and disseminated in such a fashion. The result is that the process, if it occurs at all, is protracted unnecessarily. In-service training of specialists who are not at the forefront of medical treatment knowledge is presently no one’s prime responsibility.

- Previous recommendations for the direction and identification services should be adopted as expeditiously as possible (see Chapters 3 and 4).
MEDICAL TREATMENT PROGRAMS

Federally supported programs providing health services are estimated to have assisted at least one million handicapped children in FY 1971. (Over one and one-half million were reported to have been served by the different health programs, but some unknown amount of double-counting occurred because of children receiving services from more than one program.) Total federal and state expenditures in this area were at least $315 million in FY 1971, of which the federal share was $205 million and the state share was $110 million. State and local expenditures not known or reported to the federal government would raise the total even further. The largest single federally supported program in this area is Medicaid, which serves youth from financially needy families. It was estimated to have expended some $186 million in FY 1971 for all handicapped youth. The second largest program is the Crippled Children's Service (CCS), which is designed to serve children having nearly all types of handicapping conditions; it expended at least $88 million in FY 1971. These and many other federally supported health programs, mainly within the Maternal and Child Health Services (MCHS), are described in Chapter 8 of Rand Report R-1220-HEW. We discuss them here insofar as they relate to aurally and visually handicapped youth.

Programs within the National Institutes of Health are described in Chapter 9 of R-1220-HEW, and are discussed in this report's Chapter 6 on prevention of sensory handicaps in youth. That discussion also is relevant to medical treatment, since NIH activity is aimed both at prevention and at improved medical treatment.

Our best estimate is that, of the $315 million expended for health services to all handicapped youth in FY 1971, $28 million was for aurally handicapped youth and $29 million was for visually handicapped youth.¹

With the exception of the Crippled Children's Service program, there are few reliable program-level data on hearing and vision handicapped youth receiving medical treatment services from federal and state-supported programs. Medicaid, the largest program, simply has not compiled accurate information according to the kind of handicapping conditions presented by its recipients. For CCS, population data are much better but are still not exact because the reporting unit employed is "condition," and one person may possess multiple conditions; furthermore, CCS does not report the extent of handicapping due to the reporting condition, and the cost of providing treatment for that condition. Table 5.1 presents all hearing and vision conditions reported in the 1970 CCS caseload. They are the best data available—and virtually the only reliable data available.

The following discussion approaches the largest government supported health programs from a point of view more general than that of hearing and vision handicapped children alone. It seems reasonable to do so, given the lack of disorderspecific information, and given our belief that any far-reaching improvement made in the existing programs will accrue to sensorially handicapped as well as to all handicapped children. The second half of the chapter deals with specific medical treatment service considerations for the visually and aurally impaired population.

Maternal and Child Health Service (MCHS)

Established in the beginning with amendments to the Social Security Act of 1935, the Maternal and Child Health Service programs have undoubtedly contrib-

¹ Rand Report R-1220-HEW, pp. 164-166.
<table>
<thead>
<tr>
<th>Type of Disorder</th>
<th>Percent of Total CCS Caseload</th>
<th>Number of Conditions Treated</th>
<th>Estimated Size of Vision and Hearing Handicapped Population Aged 0-21, 1970</th>
</tr>
</thead>
<tbody>
<tr>
<td>Otitis media without mention of mastoiditis</td>
<td>2.7</td>
<td>17,139</td>
<td></td>
</tr>
<tr>
<td>Mastoiditis</td>
<td>0.1</td>
<td>1,005</td>
<td></td>
</tr>
<tr>
<td>Conductive hearing impairment</td>
<td>1.7</td>
<td>11,003</td>
<td></td>
</tr>
<tr>
<td>Sensory-neural hearing impairment in hearing loss</td>
<td>2.0</td>
<td>12,833</td>
<td></td>
</tr>
<tr>
<td>Other central nervous impairment resulting in hearing loss</td>
<td>0.1</td>
<td>791</td>
<td></td>
</tr>
<tr>
<td>All other hearing impairments</td>
<td>1.1</td>
<td>6,835</td>
<td></td>
</tr>
<tr>
<td>All other disorders of the ear and mastoid</td>
<td>0.5</td>
<td>3,331</td>
<td></td>
</tr>
<tr>
<td>Congenital malformation of the ear</td>
<td>0.2</td>
<td>1,698</td>
<td></td>
</tr>
<tr>
<td>Total aural disorders</td>
<td>8.4</td>
<td>51,493</td>
<td></td>
</tr>
<tr>
<td>Visual</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refractive errors</td>
<td>1.3</td>
<td>8,519</td>
<td></td>
</tr>
<tr>
<td>Strabism</td>
<td>2.5</td>
<td>15,903</td>
<td></td>
</tr>
<tr>
<td>Blindness</td>
<td>0.1</td>
<td>601</td>
<td></td>
</tr>
<tr>
<td>All other eye disorders</td>
<td>0.8</td>
<td>5,147</td>
<td></td>
</tr>
<tr>
<td>Congenital cataract</td>
<td>0.2</td>
<td>1,425</td>
<td></td>
</tr>
<tr>
<td>Congenital ptosis (eye)</td>
<td>0.1</td>
<td>677</td>
<td></td>
</tr>
<tr>
<td>Total visual disorders</td>
<td>5.0</td>
<td>30,651</td>
<td></td>
</tr>
<tr>
<td>Total aural and visual disorders</td>
<td>13.4</td>
<td>82,144</td>
<td></td>
</tr>
</tbody>
</table>


ed to the creation and diffusion of improved health and health practices throughout the country.2

The fundamental concerns of MCHS programs include preventive health services, comprehensive health services for children and pregnant women, child health supervision, identification services, and fostering of good parent-child relations. For instance, some 56 facilities to support the Maternal and Infant Care (M&I) program were funded in FY 1973 at a cost of some $46.332 million; Intensive Care of Infants was supported at a rate of $900,000 in some eight separate facilities; and programs for Children and Youth (C&Y) were conducted in 59 facilities at a cost of $52.842 million in the same period. Each program has its particular objectives. The M&I and C&Y programs were aimed specifically at urban slum areas, for example, and brought medical treatment services to thousands of mothers and children who otherwise would not have gotten them. These programs have had some preventive efficacy, reducing to some extent the number of children who otherwise might have later been "handicapped."

MCHS programs include a variety of activities and services related to the health of handicapped and nonhandicapped preschool and school-age children (e.g., vision and hearing screening, and rubella immunization campaigns). During FY 1972, over 300,000 mothers received maternity nursing services, but no one can say how many

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of these women actually bore handicapped offspring, or more difficult yet, how many handicaps in children were prevented as a result of these nursing visits. The Crippled Children's Service program is also part of MCHS; we discuss it separately below.

These comments reflect the institutional situation prior to May 1973, when a major reorganization of HEW programs was reportedly undertaken. It is too early to assess the outcomes of the changes.

It is practically impossible to measure and summarize the benefits of MCHS programs in any meaningful fashion because of the diversity of programs within the MCHS's purview, the lack of data, and the scant attention to program evaluation over the years. However, MCHS has been responsible for creating many innovative and genuinely worthwhile demonstration efforts at the state level that have stimulated better care for children.

In terms of the process categories of the policy model developed in our companion report, it is clear that for MCHS, the estimation, implementation, evaluation, and termination phases have been ill developed or greatly underdeveloped. Official attention has been devoted almost entirely to the initiation and selection phases, where the selection procedures have been reflected in the multitude of incredibly varied and disconnected programs currently operated with MCHS support. The limited available resources have been spread so thin that they lose the potential leverage to mount a concerted effort to solve a manageable subset of maternal and child health problems. For instance, about 334,000 mothers received services under the Maternity Medical Clinic program in 1971, but they accounted for less than 9 percent of all live births in the United States; most states offered expectant parent classes, but only 87,760 parents attended them nationwide in 1970; general pediatric clinics provided services to around 200,000 children in 1970, but this represents only about 0.2 percent of the total population who might have benefited from these services.

- We recommend that the Office of the Secretary conduct a full-scale evaluation of all MCHS-supported programs with an end in view of concentrating future resources on the most critical needs and most effective programs. The remaining programs would be candidates for termination. Research studies on specific disorders should be transferred to the cognizant National Institute of Health.

**Crippled Children's Service**

CCS provides medical services to handicapped youth in financially needy families, but leaves it to state officials to determine which handicapped persons to serve and to define financial need. The word "crippled" in the program title is a misnomer, since the program services handicapped youth with virtually all types of medical problems.

Large variations exist on a state-by-state basis, as compared with national averages of impairment covered, the extent of multiple handicapping reported, and resources expended per recipient. For example, as contrasted with the national percentage breakdowns for the top three disease classes, Wisconsin reported that 39.6 percent of its caseload was concerned with diseases of the nervous system and sense organs, but the figure for Kansas was only 8.3 percent. Disparities in per-client federal expenditures on a state-by-state basis are also pronounced. These figures

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4 Rand Report R-1220-HEW, Chapter 3.
range from a low of $26.90 in Washington, D.C., to a high of $249.17 in Ohio; the national average is $117.76.

CCS is reaching only a fraction of those who might benefit from it; and unlike the Medicaid program, CCS is closed-ended, with a fixed annual budget inadequate to meet the need. Categorical coverage, as determined locally according to available resources and local preferences for certain classes of impairments over others, contributes to inequitable coverage from state to state and within the same state at different phases of the fiscal year.

Since even the earliest days of the CCS program, some state programs have achieved remarkable success in creating and implementing the highest standards of medical care for handicapped children. A number of reasons have been suggested for this:

- Medical and other health specialists have been integral in program administration.
- Standards tend to be maintained through peer group review and state and federal advisory committees composed primarily of medical and health specialists.
- The program is evolutionary and has responded to fundamental changes in the character of the served population.
- As compared with their attitude toward welfare-based Medicaid efforts, physicians appear to favor working with and through the CCS, a primarily medical-based service system.
- Monitoring and evaluation of CCS, in terms of requirements for a minimum comprehensive operational data-collection process, are evident (but not well utilized in terms of rigorous analyses and evaluation follow-through).

Besides direct care, CCS has provided technical support to communities, and programming services (i.e., "direction") and planning for individual handicapped children (even when they received no direct financial support for medical treatment from CCS), and has been directly responsible for some specialized and creative treatment programs. A major weakness here, as with MCIS, has been the lack of any concerted federal evaluation of the program's activities over the years that could have spotted likely programs for widespread adoption and ineffective ones for elimination.

As mentioned above, the CCS program is financially closed-ended, and states do what they think best with the limited funds available to them. One option is to concentrate on one or a few extremely high-quality programs for a limited number of handicapped children. This strategy often bears fruit in the innovative, high-quality care for which CCS has been justly applauded. But given a fixed or slow-growing total budget and fast-rising costs, this concentration means that other children are not served at all. On the other hand, a state official may spread his resources over as many children as possible so as to offer services on something like an equitable basis. Dilution of service coverage and quality is the hazard with this option. At some point, it is no longer financially desirable for a physician to accept the CCS payment schedules, which are often lower than prevailing private rates. In several interviews, physicians reported a dangerously thin margin between their merely breaking even on a CCS patient and actually losing money. (We have heard of certain specialized physicians and groups who have declined CCS clients on these grounds alone.)

In short, the CCS program can deliver high-quality services, but is financially unable to meet the total needs of the eligible population.

It is a stated federal goal to make high-quality, comprehensive medical services
available throughout the country. As basic first steps toward that goal, someone has
to figure out where the best individual programs are operating, determine what
makes them "best," what they cost, and how they work, and then figure out what
resources it will take to make the "best" generally available.

Commitment and money have been forthcoming to some extent in provisions
encompassing the financially open-ended Medicaid program, which partially dupli-
cates the responsibility of the CCS program to provide medical treatment to finan-
cially needy families with handicapped youth.

- Pending resolution of difficulties experienced with the present Medicaid pro-
  gram, and pending the adoption of National Health Insurance or some other
  program to make high-quality comprehensive medical care available to all
  youth, we recommend that the CCS program be retained and expanded.

**Medicaid**

Medicaid reached some 8.3 million youth aged 0 to 21 with medical services in
FY 1971 at a total dollar cost of $5.939 billion. Of this total, our best estimate is that
some $186 million from both federal and state sources was expended for about one
million handicapped children in FY 1971. Eligibility for these funds and services is
determined according to the family's financial need, in addition to the child's medi-
cal needs, and varies considerably across states. Instituted in 1965 as Title XIX of
the basic Social Security Act, Medicaid was intended to provide comprehensive
services within ten years to all who needed but were unable to pay for them. The
federal contribution in Medicaid varies from 50 to 83 percent, based on a state's per
capita income. The quality of the various state programs is known to be highly
variable, as well as can be determined from the spotty evaluations that have been
done.

Available data on the program do not show how many of what kinds and degrees
of handicapped children are represented in the total served population. To attain
wholly reliable data, given the present reporting system,\(^5\) would necessitate a case-
by-case reconstruction, and even at that, there would still be serious problems
because the mandatory screening provisions of the program have not been fully
implemented (see Chapter 4 above) and the record may not indicate the presence of
a handicap.

While the basic services provided under Medicaid are undoubtedly an improve-
ment over the previous situation, the program's welfare basis and the prevalence
of welfare administration have caused other difficulties besides those related to
medical data collection, evaluation, and reporting. Some states have shown reluc-
tance to match Title XIX dollars, an understandable eventuality where "welfare"
has taken on important negative connotations, particularly at election time. Stand-
ards for the health care provided under Medicaid have not been generally estab-
lished, an omission traceable to the relatively lower participation of health profes-
sionals in the state planning and programming processes, as compared with the CCS
program. Program emphasis has been on treatment, but since 1967 there have been
provisions for mandatory early and periodic screening, diagnosis, and treatment of
Medicaid-eligible children. Compliance and full implementation of these provisions
have been hard to attain from the states. Data accounting for total numbers of

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\(^{5}\) A Medicaid Management Information System was in some early implementation stage as of the end of 1973. If properly employed, this might help to sort out some of the persistent and egregious data deficiencies of the current program. Thorough evaluation of MMIS to ease and improve its operation would seem to be in order.
individuals screened, referral rates, disease incidence and follow-up measures undertaken are beginning to be collected, but the results are incomplete. The basic problem in this case is that the states have little incentive to seek out any more children than are already on the rolls and receiving Medicaid assistance. And, as with CCS, the payment schedule reportedly is often significantly lower than private rates; that deterrent, coupled with red tape and slow payments, has reportedly led more than a few physicians to avoid Medicaid patients. Relative to other federally supported health programs, two other features of Medicaid merit careful attention: it is meant to be comprehensive in covering the financially needy population, and it is financially open-ended. Both are necessary preconditions if one is interested in providing a full range of health services to all eligible and needy members of the population.

In the short run, pending the adoption of National Health Insurance or some other program designed to make quality comprehensive medical care available to all youth, we recommend:

- Integration of CCS and Medicaid program operations in the states should be considered. The desirable comprehensive and financially open-ended nature of the Medicaid program could benefit from some of the apparently better program administration features of CCS. A thorough evaluation of methods and effects of integration should precede implementation.

- Significantly improved management procedures should be implemented to yield much better Medicaid program management information; to cut delays; to improve the equity of eligibility standards; to insure that mandatory provisions are implemented (e.g., screening); and to permit revision of medical payment schedules to reflect the realities of the medical marketplace (for example, the schedules would be tied to an escalator provision sensitive to a medical cost-of-living index compiled by the Bureau of Labor Statistics). Coverage for all Supplementary Security Income recipients should be assured (see Chapter 10 below).

The first recommendation above was suggested by our examination of several of the better state health programs for handicapped children, where a common feature was the pooling of resources available from CCS, Medicaid, and other sources. Common disbursement procedures and “coordination” enhanced program performance at the state level, although the current federal arrangement does very little to encourage such activities. Iowa’s CCS agency, in response to our survey questionnaire, commented that “Without a Federal coordinating council, it is not easy to create state coordinating councils. The result is that some services are reduplicated and some are not provided.” Our recommendation goes well beyond the concept of a simple coordinating council, and gets to the heart of the matter: consolidation and simplification of current programs and competing bureaucracies. Pennsylvania, in their response to our questionnaire, noted that they are trying to rationalize all programs for the handicapped and further recommended “Merger of all Federal funding for medical problems of children into one agency, with sufficient capacity to conduct cost analysis and impact evaluation of programs.” At the state level, the Governor of Pennsylvania has moved to create a Commonwealth Child Development Committee to encourage such activities. And West Virginia’s response to our survey sums up the desired objectives of such a move: “There is great need for concentration of effort and cooperation of agencies and programs to con-

serve medical manpower, [and for] better utilization of manpower and facilities, resulting in improved services to the handicapped"; the problem is defined as "duplication of effort caused by new [federal] legislation providing funding in various directions."

The proposed Office for the Handicapped could have an important, even paramount, role to play in consolidation and rationalization. In fact, given the longer-term possibilities for broad coverage and support for medical services under National Health Insurance, there is particular need for one agency, such as the proposed Office for the Handicapped, to have overall responsibility for coordinating services to the handicapped during the transition and phase-in period. Oversights, bureaucratic misunderstandings, and consumer fears are bound to occur in sufficient number and with sufficient impact that the need for such a coordination role at the highest possible level of HEW seems justified.

The need for even minimally adequate management information is urgent, and a primary and expanding job for any proposed coordination agency would be aimed in this direction. The simple fact is that no one agency in the federal government knows reliably how many handicapped children there are, what they need, what services are available to provide for those needs, and how effective those services are.

National Health Insurance (NHI)

Pressure appears to be mounting for a national health insurance program. Besides Administration proposals, various plans have been initiated in the Congress. The government can, in effect, make sure an insurance policy is available to parents so that a handicapped child does not become an economic catastrophe to a parent who wants to provide proper services for him.

Realistic estimation of the costs and effects of the various proposals has only just begun and will likely progress at a brisk rate in the coming months. The selection process leading to a final decision on whether any proposal will be enacted into law will take considerable time, given the incredible variety of interests involved and the large fiscal implications of the proposed concepts. Finally, implementation will certainly not take place overnight. In short, whatever form National Health Insurance takes if and when it becomes law, it will not be an operating program for some time. It would be surprising if it were operational within the next two years. Consequently, the short-term recommendations for improvement of MCHS, CCS, and Medicaid should not be disregarded.

- We endorse the concept of National Health Insurance as a long-term solution, so long as it includes coverage of comprehensive medical services to all handicapped youth in need, and provides for the special needs of handicapped persons.

In the longer run, NHI could do much to reduce the current reliance of the handicapped on scattered noncomprehensive medical programs that do not serve significant proportions of those in need. The legitimate specialized needs of the handicapped can best be served if NHI includes certain features. For example:

- Any program made into law should explicitly provide for continuity of treatment during the transition from the current to the new system, and should take

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into account prevention, screening, extended medical treatment, medically related sensory aids and other equipment, preexisting conditions, extraordinary transportation costs related to medical care, and catastrophic contingencies. Furthermore, those provisions should pertain to all handicapped youth up to age 21 generally, not solely to hearing and vision handicapped youth.

The effects of various NHI proposals on the handicapped population deserve special attention from HEW. In particular, the proposed Office for the Handicapped might:

- Review and react to all NHI proposals by providing assessments of their likely effects on the lives of the handicapped.

In a related area, that Office might also:

- Strengthen and coordinate the “missing” or “underdeveloped” services of prevention, identification, and direction—in other words, provide needed leadership for three service areas having profound medical and other service and program implications but for which no one federal authority has assumed prime responsibility.

Consider that one Administration proposal for NHI limits preventive care to family planning, maternity, and well-child care. But a single vaccination program for rubella, even though poorly coordinated and needing some sustaining attention, is saving millions of dollars in continuing medical and other service costs. The costs of vaccination need to be discussed and made explicit. The preventive aspects of the NHI proposals do not appear to have been well enough researched nor their implications well enough considered, especially from the point of view of present and future handicapped citizens. (See Chapter 6 below.)

NHI could also provide comprehensive identification of handicaps or disorders leading to handicaps by providing medical screening at age 2, which we recommend in Chapter 4. No one currently has direct responsibility for this needed service and no one is likely to assume it unless directed to do so.

With preschool health screening under NHI, the Regional Direction Centers recommended in Chapter 3 could become a natural access point to the rest of the service system for other nondenial services, and a ready source of information both for those involved in NHI administration, monitoring, and management and for those receiving NHI whose children are handicapped. The Regional Direction Center would therefore be an “institution in place” to which NHI would naturally and effectively relate.

Another provision of one proposed NHI plan, which calls for an independent and objective assessment of its likely effect, relates to the coverage of eye examinations, eyeglasses, hearing aids, and dental services for children through the age of 12. The selection of the 12-year-old cut-off age appears at first glance to have been made arbitrarily. The realistic and legitimate needs of the young handicapped population aged 13 to 21 are not represented in this provision as formulated. As discussed in Chapter 7, sensory aids are sometimes expensive but generally appear cost-benefi-

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* This recommendation attempts to remedy a foreseeable problem that has plagued Medicaid. In stressing medical treatment, the program has come under fire for not being concerned about identification and prevention. As Senator Ribicoff is reported to have said, “It’s such a shortsighted policy. A kid who could have had a condition straightened out, and made a functioning member of society, is relegated to spending the rest of his days as a welfare case.” New York Times, December 12, 1973.

* As reported in Iglehart, op. cit., p. 1570.
cial; but no current program assures that all children needing aids can receive them. NHI is one clear way to rectify the omission.

The "Government Assurance Program" aspect of one of the Administration's proposals contains several commendable features. One of them is that it provides guarantees, as it were, to those unable to obtain private coverage through the main provisions of the proposal. However, care must be taken that handicapped children with "preexisting conditions" are not denied coverage for medical needs related to the handicap because that condition preexisted the insurance coverage. In a basic sense, handicapped people differ from the actuarial populations used to calculate expected medical payouts in an insurance program, and special consideration must be given to this fact.

Limits on the amount of medical insurance coverage for handicapped youth need to be set with cognizance of possible very high bills for extended medical treatment or potentially very high bills for short-term remedial treatment. Failure to cover expensive medical treatment may cost the system even more in the long run by increasing the costs of other services. Similarly, it could be more expensive for society in the long run if a family failed to obtain medical services because it could not afford the relatively small cost of transportation to a distant special medical facility.

MEDICAL TREATMENT OF HEARING AND VISION DISORDERS

Introduction

The following sections present summaries of common sensory-depriving disorders that are related to handicapping in youth. Taking up vision and hearing disorders in turn, these sections present data on prevalence, descriptions of disorders, common methods of treatment, likelihood of successful treatment, and approximate costs.

Prevalence statistics are not currently available in sufficient detail or comprehensiveness to allow more than the most general assessment of needs in the population based on the etiology or cause of sensory impairment. For etiologies of eye disorders, the NIH-compiled "Model Reporting Area" data are probably the best available in terms of comprehensiveness. However, there are some serious weaknesses with these MRA data: they represent returns from only 16 states; the system is voluntary, with all the problems that entails for timely and reliable information collection; and the data are so gross that meaningful detailed disaggregation according to etiology, degree of handicap, and several other potentially important categories is not possible. Prevalence data on the etiology of hearing disorders are, if anything, even less useful; the national health surveys are prime sources of information, but they are not fully reliable, nor are the data presented in the most useful fashion.

Time-series information of sufficient reliability, coverage, and detail to be useful for policy purposes does not exist. If one conceives of the policymaking process, in one sense at least, as being responsive to changes in the needs and characteristics of a context, e.g., a target population, a politically bounded setting, a problem or

10 It has been pointed out that fundamental changes occur in the handicapped population, the result in part of improved medical treatment techniques. Ben E. Hoffmeier, "The Multiple Handicapped Child: A Product of Improved Medical Care," Medical Times, August 1951, pp. 807-815.
legislative area, then this absence of any longitudinal information from which timely signals about changes could be determined is acutely distressing.

The descriptive information presented below about vision and hearing disorders was collected and summarized from numerous sources, including medical texts, journal articles, interviews, and conference proceedings. This information is included to give the reader an idea of what the various handicapping disorders are, what causes them, what representative literature exists, and what some of the common methods of treatment involve. Lacking adequate data on prevalence by affection or etiology, we have been only slightly successful in suggesting which among the disorders are relatively more frequent, dangerous, and so forth. General comments about the likelihoods of success for any given treatment of choice are presented, but these assessments will not necessarily pertain in any particular case. Success of treatment varies with the patient's age, state of general health, degree of present impairment, etiology, timeliness and appropriateness of treatment, the skill of those administering the treatment, and a multitude of other factors. In fact, the success rates noted for various treatments are probably biased upward because they have been gleaning from interviews with practitioners in highly specialized, up-to-date, and highly respected practices and institutions. There is no certainty that a general practitioner with little specialized training and fewer specialized resources at his command will attain similar rates of success. Our basic question was of the following form: "If a patient with condition ‘x’ is treated with the best possible medical care available, what are the odds that the treatment will be successful?"

Widespread realization of these "optimal" success rates appears less related to marginal improvements in technique than to institutional changes that would result in making the appropriately specialized skills available to all of those who need them. Research and hoped-for breakthroughs, as for instance being able to successfully treat most sensorineural deafness, will certainly result in spectacular and highly beneficial outcomes—when they occur; however, improvement in reducing the aggregate incidence of disability is currently possible simply by making the known procedures and technical skills more accessible to those in need. Our comments and recommendations regarding the direction and identification services (Chapters 3 and 4) are aimed at this issue.

A major problem with medical treatment for disorders capable of causing sensory handicaps in children is what we have termed the informational services. Treatment procedures exist to correct, stabilize, or alleviate a large number of the primary conditions causing handicapping. But if the child is not identified early enough, properly diagnosed, and then directed to competent medical treatment, the likelihood that a skilled ophthalmologist or otologist will be able to retrieve the situation is greatly diminished. Furthermore, the costs for such medical treatment are sometimes absolutely high but usually relatively low as compared with life-time service costs associated with reduced sensory capacity. Magnificent technologies and highly skilled physicians exist, but the institutional mechanisms needed to assure that the children in need get to these services either do not exist, or languish at a stage of inadequate development. Without adequate identification and direction, the system is simply not achieving its potential.

Presuming that the child has been identified, properly diagnosed, and well directed, important considerations must still be taken into account before medical treatment begins. No generally applicable comments can be made about these ex-

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cept to say that each must be seriously considered by the physician, the patient, and
the patient’s family and that the process is fundamentally unique to each case.

- What are the risks of complication from the proposed treatment? From diagnostic
procedures?

- What are the dollar costs of tests and treatments? How much testing is
"enough," given resource limitations? Time limitations? Should the patient’s
ability to pay enter into the medical decision, and if it does, what are the likely
consequences for the patient’s well-being? For the likelihood of cure? For long-
term societal costs?

- What are the patient’s general characteristics with respect to age, sex, and
general health? How do any of these enter into the assessment of what should be
done by way of recommending treatment?

- What are the possibilities for spontaneous change in the patient’s condition?
What might happen if nothing is done? If some action less than "total" medical
intervention is taken? If total intervention is undertaken? Does one adopt a
conservative or a more daring approach in the individual case? With what
consequences? Who benefits from and who pays for those consequences?

- What are the patient’s general feelings about the desirability of likely outcomes?
What are the medical feelings? Societal feelings?

- How do considerations of malpractice suits enter into physician’s calculations
about various courses of treatment? What is the current "going rate" for various
procedures and treatments?

- What is the orientation of the institution where the treatment will be admin-
istered? Is it a research facility where higher-risk procedures might be adopted?
Is it a more conventional setting where "state of the art" talent and supporting
resources are not so readily available?

This is a far from complete list, but it does give one a sense that the decision to
pursue a course of medical treatment is far from automatic, even presuming that
the disorder is well and properly diagnosed. These decisions are made in "real time"
by the physician and patient.

Vision Disorders: Prevalence Data

Data on the prevalence of specific eye disorders causing vision impairment are
not complete. Some of the most reliable detailed estimates are those reported for the
"Model Reporting Area" (MRA) legal blindness prevalence rates. These data are
compiled through the voluntary association of 16 states and represent about one-
fifth of the total U.S. population.12 However, these data are of limited value since,
as indicated in Appendix A of our Report R-1220-HEW, legally blind youth are only
a fraction of the visually handicapped population of concern to this study. Supple-
mentary, but dated, information on age-specific details of the visual impaired popu-
lation is contained in the National Society for the Prevention of Blindness "Fact
Book."13

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reporting in the MRA included: Connecticut, Georgia, Kansas, Louisiana, Massachusetts, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Oregon, Rhode Island, South Dakota, Utah,
Vermont, and Virginia.

Kurland et al., *Epidemiology of Neurologic and Sense Organ Disorders*, Harvard University Press, Cam-
bridge, 1973. Elizabeth Macfarlane Hatsfield, "Blindness in Infants and Young Children," *Sight Saving*
In spite of the questionable quality of the data, several gross features of that portion of the legally blind population reported in MRA statistics are worth noting. (See Tables 5.2, 5.3, and 5.4.) First, somewhere between 15 and 20 percent of the total have either "unknown," "undetermined," or "not specified" causes of blindness. Second, prenatal cataracts, retinal disease, and retrolental fibroplasia account for the largest proportions of the reported total. (Each disorder is described in the next subsection.) And third, prenatal influence is far and away the most prevalent etiology class for those age 19 and under, with 57 percent of the total new additions to the registers of legally blind persons. (We caution that legally blind persons are a minority of the visually handicapped population, and other groups of visually handicapped persons will have different prevalences of etiologies.)

This prenatal influence class includes coloboma, absence of part or all of the eye; congenital cataracts; glaucoma; albinism; hereditary retinal degenerations; and other disorders described in the next section. Because little is known about the exact prenatal factors, however, making even informed "guesses" about research priorities is basically impossible.

The need for identification procedures is supported by recognizing how poor are the existing data on causes, and by noting the low reported prevalence below age 5.

Table 5.2

ESTIMATED PREVALENCE OF LEGAL BLINDNESS BY SITE AND TYPE OF EYE AFFECTION, U.S., 1960 and 1962

<table>
<thead>
<tr>
<th>Site and Type of Affection</th>
<th>Number of Persons by Age, 1960</th>
<th>Number of Persons by Age, 1962</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All Ages</td>
<td>Under Age 5</td>
</tr>
<tr>
<td>Eyeball</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glaucoma</td>
<td>54,120</td>
<td>140</td>
</tr>
<tr>
<td>Myopia</td>
<td>20,980</td>
<td>210</td>
</tr>
<tr>
<td>Other</td>
<td>20,810</td>
<td>520</td>
</tr>
<tr>
<td>Total eyeball</td>
<td>95,910</td>
<td>870</td>
</tr>
<tr>
<td>Cornea</td>
<td>18,330</td>
<td>50</td>
</tr>
<tr>
<td>Lens</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cataract</td>
<td>84,880</td>
<td>400</td>
</tr>
<tr>
<td>Other</td>
<td>1,630</td>
<td>30</td>
</tr>
<tr>
<td>Total lens</td>
<td>86,510</td>
<td>430</td>
</tr>
<tr>
<td>Uveal tract</td>
<td>19,120</td>
<td>110</td>
</tr>
<tr>
<td>Retina</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RLPa</td>
<td>12,610</td>
<td>600</td>
</tr>
<tr>
<td>Other</td>
<td>100,610</td>
<td>250</td>
</tr>
<tr>
<td>Total retina</td>
<td>113,220</td>
<td>850</td>
</tr>
<tr>
<td>Optic nerve</td>
<td>40,690</td>
<td>260</td>
</tr>
<tr>
<td>Vitreous</td>
<td>730</td>
<td>(b)</td>
</tr>
<tr>
<td>Undetermined and not specified</td>
<td>10,490</td>
<td>210</td>
</tr>
<tr>
<td>Total, all sites</td>
<td>385,000</td>
<td>2,780</td>
</tr>
</tbody>
</table>


a Retrolental fibroplasia.

b No data or less than 5.
### Table 5.3

AGE-SPECIFIC RATES OF PERSONS ON MRA REGISTERS, BY CAUSE, 14 STATES, DECEMBER 31, 1970

(Rate per 100,000)

<table>
<thead>
<tr>
<th>Cause</th>
<th>All Ages</th>
<th>Under Age 5</th>
<th>Ages 5-19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glaucoma</td>
<td>16.2</td>
<td>0.1</td>
<td>0.2</td>
</tr>
<tr>
<td>Myopia</td>
<td>4.3</td>
<td>0.1</td>
<td>2.4</td>
</tr>
<tr>
<td>Cornea or sclera</td>
<td>6.9</td>
<td>0.2</td>
<td>0.8</td>
</tr>
<tr>
<td>Cataract, total</td>
<td>19.2</td>
<td>1.9</td>
<td>6.4</td>
</tr>
<tr>
<td>Prenatal</td>
<td>5.7</td>
<td>1.9</td>
<td>6.0</td>
</tr>
<tr>
<td>Other</td>
<td>13.5</td>
<td>0.0</td>
<td>0.4</td>
</tr>
<tr>
<td>Uveitis</td>
<td>7.5</td>
<td>0.2</td>
<td>1.3</td>
</tr>
<tr>
<td>Retinal disease, total</td>
<td>36.6</td>
<td>1.0</td>
<td>6.0</td>
</tr>
<tr>
<td>Prenatal</td>
<td>10.3</td>
<td>0.8</td>
<td>4.2</td>
</tr>
<tr>
<td>Diabetic</td>
<td>6.9</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Other</td>
<td>19.2</td>
<td>0.2</td>
<td>1.7</td>
</tr>
<tr>
<td>Retrolental fibroplasia</td>
<td>3.7</td>
<td>0.9</td>
<td>8.1</td>
</tr>
<tr>
<td>Optic nerve</td>
<td>13.5</td>
<td>1.4</td>
<td>5.3</td>
</tr>
<tr>
<td>Multiple afflictions</td>
<td>6.4</td>
<td>0.0</td>
<td>0.2</td>
</tr>
<tr>
<td>Other</td>
<td>15.9</td>
<td>3.7</td>
<td>12.7</td>
</tr>
<tr>
<td>Unknown</td>
<td>16.3</td>
<td>1.1</td>
<td>4.8</td>
</tr>
<tr>
<td>Total</td>
<td>146.5</td>
<td>10.5</td>
<td>48.3</td>
</tr>
</tbody>
</table>

**SOURCE:** Kahn and Moorhead, op. cit., p. 135.

**NOTE:** Table excludes New York and Massachusetts because of reporting difficulties for age-specific data.

### Table 5.4

PERCENTAGE DISTRIBUTION OF FIRST ADDITIONS TO REGISTERS BY ETIOLOGY CLASS, ACCORDING TO AGE: MRA, 1970

<table>
<thead>
<tr>
<th>Etiology Class</th>
<th>All Ages</th>
<th>Under Age 5</th>
<th>Ages 5-19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infectious disease</td>
<td>2.3</td>
<td>12.0</td>
<td>7.1</td>
</tr>
<tr>
<td>Injury or poisoning</td>
<td>3.6</td>
<td>8.9</td>
<td>5.1</td>
</tr>
<tr>
<td>Neoplasm</td>
<td>1.1</td>
<td>4.7</td>
<td>3.9</td>
</tr>
<tr>
<td>Diabetes</td>
<td>12.7</td>
<td>0.0</td>
<td>0.5</td>
</tr>
<tr>
<td>Senile degeneration</td>
<td>24.6</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Vascular disease</td>
<td>2.6</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Other general disease</td>
<td>1.4</td>
<td>3.6</td>
<td>1.5</td>
</tr>
<tr>
<td>Prenatal influence</td>
<td>16.4</td>
<td>36.8</td>
<td>57.4</td>
</tr>
<tr>
<td>Multiple etiologies</td>
<td>7.7</td>
<td>0.0</td>
<td>0.8</td>
</tr>
<tr>
<td>Unknown to science</td>
<td>12.3</td>
<td>0.0</td>
<td>3.4</td>
</tr>
<tr>
<td>Not reported or determined</td>
<td>17.4</td>
<td>14.1</td>
<td>20.4</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

**SOURCE:** Kahn and Moorhead, op. cit., p. 75, Table 17d.
compared with ages 5 to 19. We cannot overstress the need to do something about
the nonexistent data upon which hundreds of millions of dollars of programs and
policies are being “planned” and “evaluated,” nor the need to deliver specialized
medical treatment services to presently unidentified children under age 5.

Table 5.5 is a breakdown of the legally blind population by degree of reported
visual acuity.

<table>
<thead>
<tr>
<th>Acuity</th>
<th>All Ages</th>
<th>Under Age 5</th>
<th>Ages 5-19</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absolute blindness</td>
<td>10,518</td>
<td>126</td>
<td>1,397</td>
</tr>
<tr>
<td>Light perception</td>
<td>11,296</td>
<td>108</td>
<td>1,235</td>
</tr>
<tr>
<td>Light projection</td>
<td>1,114</td>
<td>8</td>
<td>103</td>
</tr>
<tr>
<td>Less than 5/200</td>
<td>15,891</td>
<td>29</td>
<td>786</td>
</tr>
<tr>
<td>5/200 to less than 10/200</td>
<td>9,674</td>
<td>10</td>
<td>576</td>
</tr>
<tr>
<td>10/200 to less than 20/200</td>
<td>15,757</td>
<td>19</td>
<td>1,190</td>
</tr>
<tr>
<td>20/200</td>
<td>22,449</td>
<td>17</td>
<td>2,399</td>
</tr>
<tr>
<td>Restricted field</td>
<td>7,218</td>
<td>0</td>
<td>234</td>
</tr>
<tr>
<td>Unknown</td>
<td>5,430</td>
<td>201</td>
<td>1,233</td>
</tr>
<tr>
<td>Total</td>
<td>99,347</td>
<td>518</td>
<td>9,153</td>
</tr>
</tbody>
</table>

SOURCE: Kahn and Moorhead, op. cit., p. 113,
Table 27b.

Vision Disorders: Description and Medical Treatment

Some of the more common visual disorders affecting children are briefly
sketched out in this section, including a brief discourse on common treatment meth-
ods. Also included is a general idea of the likelihoods of outcomes of treatment and
attempts at prevention of the disorder. None of what follows is meant to be con-
strained as definitive; on the contrary, our basic purpose is a merely descriptive
orientation. The interested reader is strongly encouraged to consult one of the listed
general sources for more detailed coverage.\textsuperscript{14}

Prevalence data on etiology are not sufficiently detailed to give one a very good
idea about the relative rates of occurrence and expectations of a handicapping
condition resulting from any given disorder, and the ordering of specific disorders
in what follows thus does not represent relative prevalence.

Strabismus. Some 5 percent of all children have a deviation in the eyes either
inward, outward, or vertically. Strabismus may be observed at or shortly after birth
or may develop up to about 3 years of age. The disorder can often be diagnosed by
simple inspection or one of several simple tests, e.g., corneal light reflection or the

\textsuperscript{14} A general, layman’s account is contained in Bernard Seeman, \textit{Your Sight: Folklore, Fact, and
Common Sense}, Little, Brown, Boston, 1968. Among the large number of more technical treatments we
found the following to be of general use: Frank W. Newell, \textit{Ophthalmology: Principles and Concepts}, C.
cover test. Such tests are important because a child may have strabismus that is not readily observable. Early treatment of strabismus is important because, uncorrected, it may lead to inadequate development of central vision. (See below, amblyopia ex anopsia.) The importance of preschool identification screening of children must be stressed because treatment tends to be more effective, and the prevention of lost vision through amblyopia greater, the earlier the disorder is identified, diagnosed, and treated.

Exercises, corrective lenses, and/or "patching" the good eye to force development of macular vision in the underdeveloped eye are all treatments encountered. In addition, surgical intervention to correct the deviation may be necessary, and has a greater likelihood of effecting a functional cure if it occurs early in life rather than being delayed until the child reaches 4 or 5 years of age.

Strabismic or suppression amblyopia. This term, meaning weak or dull vision, describes a disorder in which the affected eye is not providing adequate sensory information, even though there usually is no medically observable damage to the eye. Loss of vision from disuse, strabismic or suppression amblyopia (amblyopia ex anopsia), is a specific form of the disorder that is prevalent in children. Other forms exist, e.g., those caused by toxic substances, diabetes, complications of diphtheria, and hysterical disorders. Early identification and correction of the ex anopsia form are critical in a sight conservation program; hysterical causes are sometimes dealt with successfully by specialized psychological or psychiatric means; and a variety of medications exist to treat the toxic forms. Patching of the good eye for periods of as great as three months is used to encourage proper fixation. If patching is not sufficient, pleoptics is a method of choice of some physicians for additional treatment. If the cause is strabismus, the treatment is as for that disorder.

Retrorenal fibroplasia (RLF). Essentially, RLF is due to excessively high oxygen concentrations or levels in the blood of premature or respiratorily distressed infants. First occurrences of the condition were noted in the 1940s, and in the mid-1950s it was listed "as the chief cause of blindness in infants." While the mechanisms responsible for the disorder (development of a fibrous mass leading to a possible detachment of the premature infant's retina) are not completely known, it is known that excessive oxygen is the precipitating agent. In the premature or otherwise respiratorily distressed infant, high concentrations of oxygen may be required for several days after birth. Excessively high concentrations in the infant's blood cause the RLF. The role of the ophthalmologist is important in conducting oxygen therapy in infants. Frequent tests of the arterial blood oxygen content should be made to determine whether the levels of oxygen received are excessive and may cause damage to the retinal vessels. Periodic ophthalmoscopic examinations may


16 Pleoptics is a relatively new orthoptic technique in which the eye is stimulated with a bright light, causing a circular after-image (as when one fixes on a bright light and then "sees" a colored circle when the eyes are closed). The eye is then made to fix on smaller and smaller targets until fixation is improved. It is expensive because equipment is expensive and a course of treatment may be prolonged and of high frequency.

17 Von Noorden, op. cit.

also be conducted, although assessment of damage to the retinal vessels may be difficult.\textsuperscript{19}

It is distressing that, some 20 years after its causative mechanisms were identified, this essentially preventable disease is still showing up in recently published Model Reporting Area data for those under the age of 5 years (at a rate of 0.9 per 100,000). The rate for ages 5 to 19 is 8.1 per 100,000.\textsuperscript{20} In interviews it was suggested that in the obstetrician's understandable desire to save the life of a distressed newborn, or in the case of oxygen therapy's being administered more generally throughout the newborn population, some RLF is being caused that could be averted if an ophthalmologist were consulted or if the doctor in attendance were fully aware of the possible damage that otherwise life-saving therapy was doing to his patient's vision.

**Nystagmus.** Nystagmus refers to the rhythmic movement of one or both eyes. It is involuntary and ranges in severity from slight, hard-to-observe, and nonhandicapping to rapid, readily detectable, and debilitating. Basically, nystagmus results because the eye is unable to fix or focus. Nystagmus occurs in a variety of forms; it is usually congenital in youth. Congenital ocular nystagmus due to sensory defects can be caused by any eye disorder inhibiting fixation in an infant, e.g., scarred cornea, damage to the macula, cataract, and as a result of albinism.

Congenital ocular nystagmus due to defects in the neurological mechanism for fixation is also found in youth. A third entity, called Spasmus Nutans, exists; beginning at a few months of age, a child may develop nystagmus of the eyes which persists up to an age of perhaps 1 or 2 years. There is no known cure for nystagmus, and treatment is seldom effective.\textsuperscript{21} In addition to the above types, nystagmus can be due to a serious central nervous system disorder such as a brain tumor, and this cause should be differentiated.

**Myopia.** Myopia is a common disorder, familiarly referred to as "nearsightedness." Myopia is a relative imbalance between the refractive power of the eye's cornea and lens and the length of the eyeball, such that light rays do not focus on the macula but form an image somewhere in front of it, with the result that objects at a distance are blurred, and the blurring increases with distance.

Myopia can be hereditarily caused, it can occur because of damage to the cornea, such as by abrasion or injury, or it can result from defects of the eyeball, such as an abnormally curved cornea, an abnormally round lens, or an abnormally long globe. Generally, when one eye is myopic, the other becomes so in time.

In something over 90 percent of the cases, myopia is moderate and is self-limiting by the age of about 20 or 21. It is the other 10 percent that concerns us as a cause of handicapping in children. Complicated or progressive myopia, the more severe form of the disorder, has been known in extreme instances to contribute to the tearing and detachment of the retina and to degeneration of the macula—events leading to blindness if not treated correctly and early.

There is no known cure or preventive method for myopia. The need for early and correct identification and diagnosis to improve vision and identify progressive myopia is clear. In more severe instances, even glasses may be inadequate.\textsuperscript{22}

**Astigmatism.** Astigmatism can be caused when the cornea, the front or "win-


\textsuperscript{20} Kahn and Moorhead, op. cit., p. 135.

\textsuperscript{21} Newell, op. cit., pp. 423-425.

dow" part of the eye, is not perfectly rounded, or can also be caused by irregularity of the lens. These irregularities cause an improper focusing of light rays at a series of points rather than at a single point as in a normal or a myopic eye. In mild forms, the afflicted person may be unaware of astigmatism; in more severe forms it may be handicapping. Astigmatism can be corrected by spectacles in most cases. *Irregular astigmatism* occurs when the cornea is irregular and misshapen, usually because of trauma, ulcers, injuries, disease, etc., to the cornea itself and due to keratocones. Irregular astigmatism usually cannot be corrected by spectacles, but contact lenses can in some cases overcome the visual disability. In some advanced and severe cases contact lenses may not be sufficient and corneal transplants may be necessary.²³

**Cataract.** Cataract is a cloudiness of the lens preventing the passage of light to some extent and hence inhibiting vision. Cataract has many causative agents. Among them are general diseases such as diabetes, galactosemia, hypoparathyroidism, hyperparathyroidism, and rubella. In addition, injuries from direct trauma or from radiation can cause cataracts, as can long-term steroid therapy.

Depending on the size and type of cataract, vision is impaired to a variable degree. Impairment may be slight or so great as to only allow perception of light.

No known medication will "cure" cataracts, even though a great deal of research energy has been expended to find something that might dissolve, absorb, retard, or prevent their formation and development. Surgery is the method of choice to relieve the disorder and has been known and effectively used since ancient times in the older person. The treatment of congenital cataracts depends to a large degree on reasonable expectation for improvement for vision. In many cases, cataracts present since birth result in an irreversible loss of vision (amblyopia ex anopsia) which cannot be overcome by surgery. Removal of a cataract extremely early in life may result in improved vision; in many cases removal of congenital cataracts later in life is not effective in improving vision because of irreversible amblyopia ex anopsia.

Cataract is preventable to some extent. Because rubella has been clearly implicated as a causative agent, pregnant women should avoid exposure to the disease, or better yet should be vaccinated against it before becoming pregnant. Trauma and radiation-caused cataract can be prevented by simple avoidance tactics.²⁴

**Toxoplasmosis.** Caused by a microscopic parasite, toxoplasmosis exists in both congenital and acquired forms. In the congenital form, a variety of presenting symptoms has been demonstrated, e.g., skin rash, jaundice, central nervous system disorder, hydrocephalus, mental retardation. The acquired form may occur at any age and, as with the congenital form, choroid and retinal involvement is known. Accurate diagnosis is hard to attain because the symptoms resemble those of a number of quite different disorders. Treatment involves careful administration of one of a number of sulfa drugs and corticosteroids to reduce and eliminate lesions to the eye. Drug therapy is complex and great care must be exercised. While research into the disorder has been vigorous, preventive measures are not generally agreed upon. It is suspected that pregnant women should avoid all contact with cat feces, as that method of transmission of the congenital form of toxoplasmosis has been identified.²⁵

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²³ Ibid.
Coloboma. During the first trimester of pregnancy, the development of the eye is most critical. Occasionally, a portion of the eye does not form and what results is a coloboma, a missing part of the eye’s structure. Depending upon the severity of the coloboma, the choroid, part of the retina, and/or the optic disc can all be involved. Most commonly, the coloboma results in an absence of part of the iris. If the coloboma affects large or central parts of the choroid and retina or optic nerve, vision may be greatly impaired and by and large treatment cannot be effective.

Aniridia. Aniridia is a developmental defect in which all or part of the iris is absent. As with other developmental problems, there is some reason to suspect hereditary factors and there is usually some additional complicating factor contributing to visual impairment. Cataract, glaucoma, and other disorders often accompany aniridia, and the disorder is unfortunately usually binocular.

Albinism. In cases of albinism where there is no pigment in the eye (albinism may affect only the eye or may be more generally distributed over the body), visual problems almost always will follow. Besides acute sensitivity to light, those affected with albinism usually have some degree of nystagmus and often are myopic as well. Albinism is a genetically related disorder; about one in three cases result from consanguineous reproduction, e.g., children produced by brothers and sisters or close cousins, and others are the result of spontaneous mutation. Procreation by two albinos always results in albinistic offspring. No one knows how to cure or correct albinism, and for the visual component of it, all that can be done is to correct the visual deficit with spectacles and to protect the eye from damage by blocking the sun’s rays with appropriately tinted lenses.

Macular degeneration. A number of hereditary conditions impair vision as a result of abnormal changes in the macula, the center of the retina and the location of one’s best vision. There are a number of hereditary diseases that result in degeneration of the macula. Usually, macular degeneration is seen in the older person; when it occurs in the younger person, it is usually a hereditary form, and by and large there is no effective treatment for them. Reduction of color vision capability is one of the earlier signs, and this is in time followed by loss of central vision and a general diminution of the imaging capacity.

Retinitis pigmentosa. Resulting in, among other things, defective night vision, retinitis pigmentosa is mainly diagnosed in children over the age of 14, and the disorder progresses through adulthood until a greatly reduced or a total loss of vision occurs. It is binocular and is thought to result from the primary degeneration of the pigment layer of the retina. It is incurable and not preventable, and there is a distinct hereditary tendency.

Retinoblastoma. Retinoblastoma is a relatively rare malignant growth of children. It is sometimes traceable to a family history of the disorder. The disease can become apparent from birth through several years of age. Involvement of both eyes may not be simultaneous, and only about 25 percent of the cases are bilateral. One sign of the disorder is the so-called “cat’s eye” or white or yellow reflex in the pupil of the eye due to detachment of the retina or the presence of a large tumor. Early detection of a retinoblastoma is critical as the disease is capable of progressing along the optic nerve and into the brain, out of the eye into the orbit, or via the blood to other bodily organs, with a high likelihood of fatality. Treatment, in any case a truly life-saving operation, involves the removal of the affected eye with special care taken to insure that the tumor has not spread as far as the optic nerve. In the unilateral case, attention is then given to the second eye to detect the earliest signs of the disease. In the bilateral case, the better eye is salvaged, if possible, and x-ray and chemotherapy are undertaken. Parents having survived retinoblastomas should be advised concerning procreation as the odds are significantly greater that
they will produce similarly affected children: if one parent has survived a retinoblastoma, it is about a 50-50 chance that a child will be afflicted. If one child has a unilateral retinoblastoma and there is also a family history of that disorder, chances are about 40 percent that the next child will also be afflicted; with no prior family history the chances the next child will also be afflicted drop to about 4 percent. In the unilateral case, spontaneous or somatic mutation is the more common cause, and accounts for 80 to 90 percent of all cases; the family form accounts for only about five percent of all the cases.26

**Hypermetropia.** Farsightedness or hypermetropia is a disorder of the eye in which light rays striking the eye would be in focus at a point behind the retina. This disorder can be adequately treated with spectacles. If uncorrected the condition could lead to strabismus.

**Dislocated lenses.** Either because of developmental problems, metabolic disease such as cystinosis, or because of trauma, usually a sharp blow to the head, the lens may become completely or partially displaced. If only partially, the lens is referred to as subluxated. In the congenital or developmental case, the disorder is often associated with defective formation of the ligaments supporting the lens, has been traced to genetic origins, and is often found in conjunction with other deformities in the body, such as excessively long bones. Complications of dislocation include glaucoma, cataract, and uveitis.

**Glaucoma.** Basically, glaucoma is a disorder of the eye in which pressure within the eye is excessively high. This condition may lead to damage to the optic nerve, which can be permanent and lead to total blindness. In glaucoma, the normal drainage of fluid produced within the eye is obstructed to some degree, either because of a developmental congenital disorder (some authorities believe it to be a membrane growing over the normal drainage system), because of uveitis resulting in clogging or damage to the drainage system, or because of adherence of the iris to cover the drainage system, which can be secondary to developmental abnormalities in which the lens adheres to the cornea or iris or secondary to a dislocation of the lens. Primary glaucoma is a glaucoma which is not associated with an identifiable pre-existing disorder. Secondary glaucoma refers to a glaucoma which is due to some other pre-existent disorder such as uveitis, a dislocated lens, or trauma. Blunt trauma to the eye can result in glaucoma which is insidious and may take several months or perhaps years to develop.

Glaucoma demands early, accurate, and complex treatment by an ophthalmologist. The congenital glaucoma is usually treated surgically. That and other forms may also be treated topically with eye drops, systemically with a variety of medications, and surgically by a number of procedures, all of which are meant to reduce pressure within the eye.27

**Optic atrophy.** Many threats to the optic nerve, the main pathway of visual images to the brain, exist: glaucoma, tumors of the eye and brain, trauma associated with skull fractures, circulatory disorders, infections of the eye or brain, complications of diabetes, anemia, or toxic poisoning, and unknown congenital causes. There is no known means to restore the optic nerve once it has atrophied. Because it is a debilitating complication of several other ocular disorders, research, prevention, and treatment of those primary causes all contribute to the lessening of blindness from this cause.


Corneal ulcers and scars. The number of possible causative agents is large and includes, for example, viral infection, trauma, chemical agents, gross vitamin A deficiency, bacterial agents, and so forth. Symptoms include pain, an unusual sensitivity to light, overproduction of tears, and the reduction of vision. Treatment for residual visual impairment may be carried out after the eye has been made healthy and includes corneal transplantation and contact lenses.

Keratitis. An inflammation of the cornea, keratitis is divisible into three basic types: interstitial keratitis, usually syphilitic in origin, involving the intermediate layers of the cornea; deep keratitis, caused by trauma or infectious agents such as mumps; and superficial punctate keratitis, thought to be mainly infectious in origin, and usually treatable. The basic threat posed by the disorder is the scarring it leaves in its wake, with resultant loss of visual acuity.

Burns. Eyelid burns are treated like burns elsewhere in the body, with special care to prevent infection of the eye and deep lid scarring. Preventive antibiotic and corticosteroid therapy may be indicated to reduce chances of infection and to reduce inflammation; such therapy is usually topical, as is therapy designed to minimize corneal scarring. Chemical burns of the cornea require prompt and copious irrigation and subsequent evaluation of the extent of damage and needed medical treatment. Ultraviolet burns of the cornea, e.g., from sunlamp exposure or skiing in bright light without tinted lens protection, may require antibiotic therapy and patching of the eye to reduce chances of infection and discomfort.28

Fracture of the orbit. Usually a traumatic shock to the head or a fist to the eye is responsible for fracture of the orbit. This is a serious disorder that can have a number of complications, e.g., double vision. Significant displacement of the bone surrounding the eye ball requires prompt and skillful surgical intervention. Depending on the severity of the fracture, sight may be impaired.29

Contusions of the globe (including hyphema). Blood in the anterior chamber of eye—hyphema—and an assortment of other sight-threatening results, are known to occur as a result of trauma in and around the eye. Care depends upon the nature and severity of the contusion and the extent of complications resulting from it, e.g., hyphema, retinal detachment, vitreous hemorrhage, glaucoma, rupture of the eyeball, and complications that can occur well after the initiating trauma.30

Foreign bodies. Depending upon the nature of the body and the extent of eye injury it causes, a foreign object in the eye can be sight-threatening. Many foreign bodies in the cornea can be removed simply with a moist, sterile cotton applicator; others may require minor surgical treatment with prophylactic antibiotic therapy; intraocular foreign bodies necessitate more involved procedures with a poor prognosis for visual function.31

Retinopathy. Hemorrhages or changes in the blood vessels nourishing the eye are common signs of retinitis; blank, diminished, or distorted vision, as well as sensitivity to light, are symptoms. Retinitis has many suspected causes, including diabetes, high blood pressure, rheumatism, burns from the sun’s rays, leukemia, and kidney disease. Infectious causes include untreated corneal or scleral disorders. Parasites, chemicals, and allergic materials have also been implicated in retinopa-

thy. The problem is not so much with the disorder itself, but with the damage left in its wake, especially if undetected and untreated.

**Uveitis.** Diseases of the iris (iritis), ciliary body (cyclitis), and the choroid (choroiditis) can cause handicapping conditions. Although specific causes such as viral infections, injury, or systemic illnesses can cause uveitis, the bulk of the cases of uveitis are due to unknown etiology. While the disorders in general are treatable, their possible complications warrant special consideration, e.g., glaucoma and cataract.32

**Medical Treatment Costs of Vision Disorders**

Table 5.6 presents a sample of treatment costs for medical services available to those suffering from vision disorders. These data are a sample of current charges for high-quality care in a specialized practice, and may vary considerably for different parts of the country and for different practices. These estimates are for professional medical specialist fees only; payments for other aspects of medical care, such as days of hospitalization, are excluded.

Two features stand out from this summary sample of treatment costs. First, good-quality medical care can be had, but it can also be costly in the absolute sense. However, the appropriate trade-off is between the cost of such care and all costs involved in a lifetime of being handicapped or more severely handicapped than one would be if good medical care were received. In this sense, good-quality medical treatment is probably a "bargain." Second, the finest specialized medical care in the world is relatively useless, irrespective of its costs, if there are inadequate identification and diagnosis services in operation locally.

**Hearing Disorders: Prevalence Data**

Data on the prevalence of hearing impairment, but not the causes, are described in Appendix A of Rand Report R-1220-HEW. Data on the causes of hearing impairment in the young are neither comprehensive nor reliable. Data are better for visual disorders. For example, Model Reporting Area data exist on prevalence with respect to site and type of affection for youth aged 0 to 5 and 5 to 19 years, and on age-specific prevalence numbers and rates with respect to cause. Comparable data do not exist for hearing disorders, although a few special studies shed some light on these matters. Some of the best, but limited, available etiological information is contained in the national health surveys. Those data are in many cases over 10 years old, however, and are limited by many sampling and technical problems; but the information in Table 5.7 does show that illness, and congenital causes generally, are the most prevalent for youth under the age of 6. The utility of these data is compromised by the fact that over one-third of the youth surveyed had "unknown" or "other" etiologies, or simply did not respond to the survey questionnaire.

Data on the medical aspects of hearing impairment available through federal surveys have many specific limitations. For example, the national health interview survey data33 are self-reported by survey respondents without reference to detailed

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<table>
<thead>
<tr>
<th>Item</th>
<th>Charge ($)</th>
<th>Item</th>
<th>Charge ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service group/routine/MDs</td>
<td></td>
<td>Surgical procedures</td>
<td></td>
</tr>
<tr>
<td>Office visit</td>
<td>12</td>
<td>Enucleation of eye, without implant</td>
<td>400(^d)</td>
</tr>
<tr>
<td>Initial comprehensive diagnostic ophthalmic examination</td>
<td>30</td>
<td>Enucleation of eye, with implant</td>
<td>450(^d)</td>
</tr>
<tr>
<td>Initial hospital consultation</td>
<td>35</td>
<td>Evisceration of eye</td>
<td>400(^d)</td>
</tr>
<tr>
<td>Routine hospital visit</td>
<td>20</td>
<td>Suture of eye for wound or injury</td>
<td>(c)</td>
</tr>
<tr>
<td>Diagnostic group/X-ray</td>
<td></td>
<td>Removal of foreign body</td>
<td>15(^e)</td>
</tr>
<tr>
<td>Eye, for foreign body</td>
<td>40</td>
<td>Removal of foreign body under slit lamp</td>
<td>30(^e)</td>
</tr>
<tr>
<td>Eye, for localization of foreign body</td>
<td>60</td>
<td>Keratotomy, lamellar, partial</td>
<td>300(^e)</td>
</tr>
<tr>
<td>Facial bones, limited</td>
<td>30</td>
<td>Keratotomy, lamellar, complete</td>
<td>350(^e)</td>
</tr>
<tr>
<td>Facial bones, complete and/or orbits</td>
<td>30</td>
<td>Pterygium, simple</td>
<td>200(^b)</td>
</tr>
<tr>
<td>Facial bones, complete with nasal bones</td>
<td>60</td>
<td>Pterygium, complicated</td>
<td>(c)</td>
</tr>
<tr>
<td>Nasal bones</td>
<td>28</td>
<td>Curettage and cauterization of corneal ulcer</td>
<td>40(^e)</td>
</tr>
<tr>
<td>Nasolacrimal duct</td>
<td>50</td>
<td>Corneal transplant, lamellar</td>
<td>700(^e)</td>
</tr>
<tr>
<td>Optic foramina</td>
<td>30</td>
<td>Corneal transplant, penetrating</td>
<td>800(^e)</td>
</tr>
<tr>
<td>Skull, limited</td>
<td>25</td>
<td>Aspiration of aqueous, diagnostic</td>
<td>30</td>
</tr>
<tr>
<td>Skull, complete</td>
<td>35</td>
<td>Aspiration of vitreous prolapse</td>
<td>200(^d)</td>
</tr>
<tr>
<td>Tumor localization, ocular</td>
<td>70</td>
<td>Goniotomy</td>
<td>250</td>
</tr>
<tr>
<td>Diagnostic group/laboratory</td>
<td></td>
<td>Paracentesis</td>
<td>30</td>
</tr>
<tr>
<td>Blood count, complete</td>
<td>5</td>
<td>Removal of intraocular foreign body, anterior chamber</td>
<td>400(^d)</td>
</tr>
<tr>
<td>Culture sensitivity</td>
<td>10</td>
<td>Severing corneal-vitreal adhesions</td>
<td>(c)</td>
</tr>
<tr>
<td>Hydrocortisone</td>
<td>25</td>
<td>Air injection into anterior chamber</td>
<td>(c)</td>
</tr>
<tr>
<td>Culture</td>
<td>10</td>
<td>Scleral resection, any type, with graft</td>
<td>700(^d)</td>
</tr>
<tr>
<td>Diagnostic/optometry/ophthalmic</td>
<td></td>
<td>Iridotomy</td>
<td>140</td>
</tr>
<tr>
<td>Eye examination, including visual acuity, ophthalmoscopy, tonometry, gross visual fields, muscle balance, and slit lamp microscopy</td>
<td>35</td>
<td>Iridotomy, with transfixation of iris</td>
<td>150</td>
</tr>
<tr>
<td>Eye examination, as above, with refraction</td>
<td>45</td>
<td>Iridotomy, photocoagulation or laser</td>
<td>200</td>
</tr>
<tr>
<td>Eye examination, as above, with plotting of central and/or visual fields</td>
<td>50</td>
<td>Excision of lesion of iris</td>
<td>400(^e)</td>
</tr>
<tr>
<td>Gonioscopy</td>
<td>20</td>
<td>Iridocyclectomy</td>
<td>600(^f)</td>
</tr>
<tr>
<td>Gonioscopy, infant</td>
<td>60(^a)</td>
<td>Iridectomy, any type</td>
<td>300(^e)</td>
</tr>
<tr>
<td>Gross external examination with ophthalmoscopy and refraction</td>
<td>30</td>
<td>Iridencleisis</td>
<td>350(^e)</td>
</tr>
<tr>
<td>Gross external examination, as above, with cycloplegic of mydriatic</td>
<td>40</td>
<td>Iridodialysis</td>
<td>300(^e)</td>
</tr>
<tr>
<td>Orthoptic and/or plegopic evaluation</td>
<td>25</td>
<td>Cyclophthis, initial</td>
<td>250</td>
</tr>
<tr>
<td>Orthoptic and/or plegopic training (30 min)</td>
<td>15</td>
<td>Cyclophthis, subsequent</td>
<td>120</td>
</tr>
<tr>
<td>Visual fields: plotting, central and/or peripheral</td>
<td>20</td>
<td>Cyclophthryerapy, initial</td>
<td>180</td>
</tr>
<tr>
<td>Tonometry</td>
<td>15</td>
<td>Cyclophthryerapy, subsequent</td>
<td>90</td>
</tr>
<tr>
<td>Tonography</td>
<td>30</td>
<td>Cyclophthlyeralysis, initial</td>
<td>350(^e)</td>
</tr>
<tr>
<td>Provocative test(s) for glaucoma, including water drinking, and/or mydriatic, and/or dark room test</td>
<td>20</td>
<td>Cyclophthlyeralysis, subsequent</td>
<td>180(^f)</td>
</tr>
<tr>
<td>Ophthalmoscopy (fundoscopy) with mydriasis, direct and/or indirect methods</td>
<td>20</td>
<td>Discussion, initial</td>
<td>150(^f)</td>
</tr>
<tr>
<td>Ophthalmoscopy, as above, with general anaesthetic</td>
<td>40</td>
<td>Discussion, subsequent</td>
<td>70(^f)</td>
</tr>
<tr>
<td>Ophthalmoscopy, as above, with contact lens</td>
<td>30</td>
<td>Discussion, secondary membrane, simple</td>
<td>150(^f)</td>
</tr>
<tr>
<td>Ophthalmoscopy, as above, with intravenous (fluorescein)</td>
<td>50</td>
<td>Discussion, secondary membrane, complicated</td>
<td>250(^f)</td>
</tr>
<tr>
<td>Ophthalmoscopy, as above, with ophthalmodynamics</td>
<td>40</td>
<td>Aspiration of lens material for cataract, one or more stages</td>
<td>500</td>
</tr>
<tr>
<td>Fitting and evaluation of contact lens</td>
<td>(b)</td>
<td>Extraction of lens, unilateral, one or more stages (e.g., cataract, subluxated lens)</td>
<td>700(^d)</td>
</tr>
<tr>
<td>Miscellaneous and office procedures</td>
<td></td>
<td>Discussion of anterior hyaloid (e.g., pupillary block)</td>
<td>150(^f)</td>
</tr>
<tr>
<td>Injection</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td>(c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgical nurse</td>
<td>50(^c)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special reports</td>
<td>(c)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^a\)Includes 7 days follow-up.
\(^b\)Fee varies ($250 minimum).
\(^c\)Fee varies.
\(^d\)Plus 4 postoperative office visits per year for 3 years = $144.

\(^e\)Minimum fee.
\(^f\)Plus 6 postoperative office visits = $72.
\(^g\)Plus 9 postoperative office visits = $108.
### Table 5.6—continued

<table>
<thead>
<tr>
<th>Item</th>
<th>Charge ($)</th>
<th>Item</th>
<th>Charge ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reattachment, retinopexy, with or without drainage of subretinal fluid, initial</td>
<td>600&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Blepharotomy with drainage of abscess of meibomian glands or styte</td>
<td>20&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Reattachment, retinopexy, with or without drainage of fluid, subsequent</td>
<td>(c)</td>
<td>Excision of meibomian gland (chalazion), single</td>
<td>40</td>
</tr>
<tr>
<td>Reattachment with scleral buckling, resection, implant, initial</td>
<td>900&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Excision of meibomian gland (chalazion), multiple, same lid</td>
<td>40</td>
</tr>
<tr>
<td>Reattachment, as above, subsequent</td>
<td>(c)</td>
<td>Excision of meibomian gland (chalazion), multiple, different lids</td>
<td>50</td>
</tr>
<tr>
<td>Repair of retinal breaks or schisis, one or more stages during same period of hospitalization, photocoagulation and/or cryotherapy</td>
<td>300&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Conjunctive, removal of foreign body, surface</td>
<td>20&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Photocoagulation, initial</td>
<td>300</td>
<td>Conjunctive, removal of embedded foreign body</td>
<td>20&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Photocoagulation, subsequent</td>
<td>150</td>
<td>Conjunctiva, evacuation of cysts</td>
<td>20&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Diathermy or cryotherapy</td>
<td>(c)</td>
<td>Biopsy of conjunctive</td>
<td>25</td>
</tr>
<tr>
<td>Muscle surgery, initial</td>
<td>450</td>
<td>Excision of lesion of conjunctiva, benign</td>
<td>30&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Muscle surgery, subsequent</td>
<td>(c)</td>
<td>Excision of lesion of conjunctiva, malignant</td>
<td>(c)</td>
</tr>
<tr>
<td>Muscle transplant</td>
<td>300</td>
<td>Suture of conjunctiva</td>
<td>30&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Orbitotomy with exploration</td>
<td>350</td>
<td>Conjunctivoplasty, free graft using conjunctiva</td>
<td>350</td>
</tr>
<tr>
<td>Orbitotomy with drainage of intra-orbital abscess</td>
<td>350</td>
<td>Conjunctivoplasty, free graft using buccal mucous membrane</td>
<td>400</td>
</tr>
<tr>
<td>Orbitotomy with removal or intra-orbital tumor or foreign body</td>
<td>(c)</td>
<td>Conjunctival flap for corneal ulcer</td>
<td>150</td>
</tr>
<tr>
<td>Extirpation of lesion of orbit, requiring bone flap</td>
<td>650</td>
<td>Drainage of lacrimal gland, abscess or cyst</td>
<td>120</td>
</tr>
<tr>
<td>Extirpation of orbit, without skin graft</td>
<td>600&lt;sup&gt;g&lt;/sup&gt;</td>
<td>Drainage of lacrimal sac: dacryocystotomy or dacryocystostomy</td>
<td>60&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>Extirpation of orbit, without skin graft, including orbital bone</td>
<td>(c)</td>
<td>Excision of lacrimal sac</td>
<td>350&lt;sup&gt;f&lt;/sup&gt;</td>
</tr>
<tr>
<td>Retrobulbar injection</td>
<td>20&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Dacryocystorhinostomy</td>
<td>400&lt;sup&gt;g&lt;/sup&gt;</td>
</tr>
<tr>
<td>Retrobulbar injection, alcohol injection</td>
<td>60</td>
<td>Conjunctivocystorhinostomy</td>
<td>450&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td>Retrobulbar injection, air or opaque contrast medium for radiography</td>
<td>30</td>
<td>Closure of punctum by cautery</td>
<td>25</td>
</tr>
<tr>
<td>Dilatation of punctum</td>
<td>20&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Probing of nasolacrimal duct</td>
<td>20&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Probing and/or irrigation of canaliculus</td>
<td>20&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Probing of nasolacrimal duct</td>
<td>20&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>a</sup>Includes 7 days follow-up.

<sup>b</sup>Fee varies ($250 minimum).

<sup>c</sup>Fee varies.

<sup>d</sup>Plus 4 postoperative office visits per year for 3 years = $144.

<sup>e</sup>Minimum fee.

<sup>f</sup>Plus 6 postoperative office visits = $72.

<sup>g</sup>Plus 9 postoperative office visits = $108.

Medical diagnosis; are summarized in too gross a detail ("Diseases of ear" are reported as a summary category including seven international classification code numbers); are categorized by too gross a set of age categories (e.g., "under 45 years"); exclude institutionalized hearing impaired persons; and are often over 10 years old. The national health examination survey<sup>24</sup> involved professional reporting, but only very limited information on etiologies was collected, institutionalized persons were not included, and published reports provide only very gross categorical breakdowns.

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Table 5.7
PERCENTAGE DISTRIBUTION OF PERSONS WITH BINAURAL HEARING IMPAIRMENT, BY CAUSE ACCORDING TO AGE AT ONSET: U.S., 1962-1963

<table>
<thead>
<tr>
<th>Cause</th>
<th>All Ages</th>
<th>Under Age 6</th>
<th>Ages 6 to 16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness</td>
<td>20.9</td>
<td>33.2</td>
<td>41.7</td>
</tr>
<tr>
<td>Accident</td>
<td>13.5</td>
<td>6.5(^a)</td>
<td>11.5</td>
</tr>
<tr>
<td>Hereditary or congenital</td>
<td>4.0(^a)</td>
<td>24.9</td>
<td>4.0(^a)</td>
</tr>
<tr>
<td>Presbycusals (old age, degenerative)</td>
<td>4.9</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Unknown</td>
<td>39.9</td>
<td>19.3</td>
<td>30.0</td>
</tr>
<tr>
<td>Other and nonresponse</td>
<td>16.8</td>
<td>16.0</td>
<td>12.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

NOTE: NA = not available.
\(^a\) Data do not meet standards of reliability and precision.

Because of these limitations, we rely primarily on other sources—special studies and medical textbooks for the most part—for information on prevalence of hearing disorders by age, etiology, and affection.

Hearing loss appears to be directly related to other conditions, such as mental retardation,\(^{26}\) cerebral palsy,\(^{27}\) cleft palates,\(^{27}\) allergies,\(^{38}\) goiter,\(^{39}\) tonsillitis,\(^{40}\) and vitamin deficiency.\(^{41}\) Our general recommendation for the creation of high-risk registers as an integral part of a strengthened identification program (Chapter 4) would at least be a start toward finding and preventing hearing loss in children known to possess other related conditions.

The need for detailed, timely, and improved prevalence data by etiology is clear. (This observation holds for vision handicapped children as well.) Detailed prevalence data would go a long way toward informing and rationalizing research priorities and medical service planning. Adequate information also might be usefully employed in informing pediatricians. For instance, if there is an upswing in the number of

\(^{27}\) D. J. Fahey, "Otorhinolaryngologic Care of Cleft Palate Cases," Laryngoscope, Vol. 75, 1965, pp. 570-587. In an interesting, comprehensive, multidisciplinary cleft palate program currently under way at Los Angeles Children's Hospital, as many as 75 percent of those enrolled contract disorders capable of causing hearing loss if not properly, correctly, and persistently treated. Interview, Dr. Frederick Litchcic, Otorhinolaryngologic Medical Group, Los Angeles, December 14, 1973. This is a startling and not generally known finding.
children in a region or locality suffering from a specific disorder, it is important for pediatricians to know about it and be on the alert; persistence of the disorder signals that perhaps something more fundamental is happening to the population and warrants more detailed investigation. Finally, better information on prevalence could be converted into educational materials for the average parent, e.g., information on the signs of serous otitis media, what the parent should do, and what might happen if early and correct care is not undertaken.

**Hearing Disorders: Description and Medical Treatment**

This section briefly sketches some of the more common hearing disorders affecting children, and mentions common treatment methods. It also comments on the likelihood of successful treatment or prevention. None of what follows pretends to be definitive; the interested reader is strongly encouraged to consult the general sources listed in the footnotes for more detailed information.

Prevalence data on etiology are not sufficiently detailed to give one a very good idea about relative rates of occurrence and expectations of a handicapping condition resulting from any given disorder; the ordering of specific disorders in what follows therefore does not represent relative prevalence.

**Serous otitis media.** Serous otitis media is perhaps the most commonly encountered ear disorder in younger children. It has been implicated in a large fraction of the cases of hearing impairment, although we do not know what that fraction might be, given the poor quality of data available on hearing disorders in children. The term "serous otitis media" describes the collection of fluid in the middle ear, and it may be acute or chronic. The disorder is caused by any condition that results in blockage of the eustachian tube and may be congenital, due to infection or allergy, or may be caused by enlarged adenoids. In any event the middle ear becomes partially closed and gases in it are partially absorbed. This situation leads to a collection of fluid and infection in about 25 percent of the cases.

Treatment depends on the specific causative agent. For congenital causes, such as an immature eustachian tube, treatment may be continuous until the child matures or "grows out of" the disorder's cause; in the case of cleft palate, the prognosis is not so simple and probably will call for a great deal of specialized attention in the child's life. For most cases, one treats the underlying disorder; aspiration of the middle ear fluid may be required; myringotomy (incision of the eardrum) is frequently resorted to and with it the placement of a hollow plastic tube to prevent the incision from healing and to insure that the middle ear is open. In the case of allergic causes, one works to identify the allergic material, treats the condition through avoidance or desensitization, and simultaneously works to keep the middle ear from becoming or staying infected. Medication alone often suffices to open and clear the ear, as in the case of antihistaminics, decongestants, and mechanical techniques to inflate the passageway to the middle ear. Failure to treat properly may result in hearing loss.

Prognosis for treatment administered by competent physicians is nearly 100 percent success for all cases except cleft palate. In the case of myringotomy, however, there may be repeat surgeries to replace the ventilation tube. In a relatively few cases, it may become necessary to perform a mastoidectomy, a more radical procedure, to insure control or elimination of the serous otitis media.\(^4\)

Acute otitis media and mastoiditis. A more serious variant of serous otitis media, this disorder is the inflammation and infection of the middle ear and the mastoid air cell system by one of several agents, e.g., pneumococci, streptococci, staphylococci, viruses, and *Hemophilus influenzae*. It is important to mention these disease agents, for proper treatment requires that the infection be cultured and the appropriate antibiotic be administered in sufficient strength and for a sufficiently long time to control the disease. Treatment is of primary importance because of the numerous, and mostly unpleasant, complications that may occur in the unchecked case of acute otitis media, e.g., meningitis, abscesses, mastoiditis, and hearing loss. With adequate care, which is mainly the selection and application of the appropriate antimicrobial agent and the administration of oral and topical decongestants, prognosis and the odds of cure are virtually 100 percent. The key is in continuous and competent treatment.43

Chronic otitis media and mastoiditis. This form of otitis media results from infection of the middle ear and the mastoid via the eustachian tube or the external auditory canal; it may also result from the formation of a cholesteatoma, a “bone-like” cystic growth in the ear (considered below). Water is often found to be the main cause of the chain of events leading to infection, entering either through the external auditory canal or through infected droplets driven into the ear when sneezing or blowing the nose. As with other forms of otitis media, the basic problem is to control the disorder to avoid damaging complications. Chronic otitis media may form granulations and polyps, which in turn may break down the bony structure around the middle ear, which in turn could lead to abscess in the brain, meningitis, or infection of the labyrinth in the ear.

Treatment of chronic otitis media is both preventive and therapeutic: one should not blow the nose hard, sneezing should be done with an open mouth, and swimming and bathing should be done only with a cotton plug covered with vaseline or with a lamb's wool plug in the affected ear. Debris in the ear should be periodically removed. Topical applications of corticosteroids and specific antibiotics (determined after the infection is culture and identified) are normally recognized as treatments of choice. As soon as the infection is controlled, and this may take as long as six or more months of careful management, it may be necessary to reconstruct the ear surgically, a procedure usually not undertaken until the patient is around 6 to 9 years of age, when the likelihood of upper respiratory infection declines.

With proper and persistent treatment, cure and prevention of hearing impairment should be nearly 100 percent. It should be stressed, however, that treatment for serous otitis media in general is not a “one-shot” process, and some cases may require repeated visits and surgeries. These are the facts of the disorder and they should be reflected in medical treatment and assistance programs and provisions.44

Otitis externa. Otitis externa is basically a skin disorder. Infection is introduced into the ear, where the eardrum (tympanic membrane) may become infected and softened with bacterial growth. This growth, if unattended, may spread to the lymph nodes and other surrounding tissue or may perforate the eardrum. Treatment consists of removing the softened tissue, and the administration of antimi-


crobial drops and systemic antibiotics (based on a culture and identification of the infectious agent). "Cure" is possible in about 95 percent of the cases, if treatment is properly administered and continuous care is given. The disorder has a persistence and rate of recurrence that may involve repeated care through adulthood.\textsuperscript{45}

**Perforation of eardrum (tympanic membrane).** Eardrum perforation can be caused by a number of factors and agents, such as trauma or acute otitis media. In rare cases, scarlet fever and rheumatic fever have been linked to perforations. Treatment consists of keeping water out of the ear to control and prevent infection, removal of softened tissue, and repeated application of topical anti-infectives. When the infection, if present, has been controlled, surgery may be called for to repair the drum, to prevent reinfection, and to improve hearing. In approximately 50 percent of the cases, cure will be "spontaneous" merely with the appropriate administration of antibiotics; however, in many of the remaining cases, surgery will be required to repair the damage. Surgery is successful in nearly all cases; hearing impairment will be mild but not disabling in some 25 percent of the cases and there will be no measurable impairment in the other 75 percent. The success rate of treatment depends on careful and correct management of the infection, if that is the cause, and then upon skillful surgery by a qualified otologist.\textsuperscript{46}

**Bullous myringitis.** Blisters will sometimes form on the eardrum itself in conjunction with an upper respiratory infection. The disorder produces extraordinary pain in most cases until the blister(s) rupture. The disorder is treated more or less symptomatically, e.g., through using local heat and hydroscopic and anaesthetic drops. The likelihood of successful treatment is nearly 100 percent. Surgical rupture of the blisters is not recommended because of the chance that infection may be spread to the sterile middle ear.\textsuperscript{47} This disorder threatens the patient's hearing only if left untreated (and even then the probability of complication is slight) or if treated improperly (with subsequent infection of the middle ear).

**Labyrinthitis.** The inner ear may become inflamed through infection of the middle ear, surgical accidents, or meningeal infections (from nerve bundles connecting the ear with the brain). Nausea, vertigo, and general loss of balance are all common symptoms of labyrinthitis. Treatment consists of bed rest, medication to control motion sickness, and antibiotics to control the infection. Corticosteroids are sometimes used to reduce the inflammation. Unless untreated or improperly treated, cure should be virtually assured without hearing impairment.\textsuperscript{48}

**Mumps.** Mumps can cause deafness, as can other infectious diseases of childhood. (Scarlet fever, typhoid fever, diphtheria, etc., have been brought under control and cause very little hearing disorder in modern settings.) Basically, the viral agent attacks the Organ of Corti and other segments of the inner ear, destroying the tissue. As a result, very little can be done medically to restore hearing, although if nerve involvement has not been too great, sensory aids and rehabilitation can be of great assistance in reducing the handicapping of the condition. Prevention is the best course, however; and one should get the appropriate vaccinations.\textsuperscript{49}


\textsuperscript{48} See Ballenger, op. cit., Chapter 48, where the disorder is treated mainly as a complication of other ear disorders.

\textsuperscript{49} Kempe et al., op. cit., p. 232; and Davis and Silverman, op. cit., pp. 120-122.
Measles and other viral agents. Measles and other viral agents have been implicated in hearing loss; in fact, in the 1920s and 1930s, meningitis was the commonest clearly identified cause of acquired deafness in children. Vaccines and antibiotics have changed this drastically, with the one exception that certain of the antibiotics that are effective in treating the primary disorder are themselves capable of damaging the inner ear and hence causing deafness. If treatment of the viral agent is not done in a timely fashion, bilateral hearing impairment usually results.\(^5\)

Eighth nerve tumors. Fortunately rather rare, although exact prevalence data are not available, tumors in the area of the inner ear are capable of producing sensorineural hearing loss and, if left untreated, weakening and damage of facial muscles and nerves, and death. If the tumor is detected early enough and is sufficiently small, it may be surgically removed. Morbidity and mortality from large tumors are both quite high. Diagnosis is a complex operation involving x-rays, audiometry, and other clinical findings.\(^5\)

Cholesteatoma. When debris from the surface of the ear finds its way into the middle ear or mastoid following a perforation of the drum, a skin-lined cystic growth filled with hardened debris—cholesteatoma—may result. There are three general types, and treatment depends upon early and accurate diagnosis. In the congenital type, cystic growths are present in the temporal bone or in the mastoid at or near birth. In the primary acquired type, entrance through a perforation of the ear drum of hardened debris then develops into a growing cystic mass; in the secondary acquired type, entrance is much the same as the primary, although the continuity of the growth is not notable as with primary. Infection is a decided possibility either in conjunction with the cholesteatoma or as a result of degeneration of the bone invaded by the disease. Diagnosis is complex and involves radiography of a highly specific variety.

Treatment of the disease involves surgical removal and reconstruction. Control of the disease and the likelihood of successful treatment are highly dependent upon early detection and surgical technique. It is unusual for one suffering from the disease to escape without some hearing loss, although in specialized facilities control of it may be as great as 95 percent. Removal of the mastoid and repair of the eardrum, the common treatment of choice, will in most cases result in normal or slightly reduced hearing in some 10 to 25 percent of the cases, moderate, but usable hearing in about 50 percent of the cases, and moderate but acceptable hearing with the proper sensory aid in the remainder. Here again, the success of surgery and hearing conservation is critically dependent upon early identification, correct diagnosis, and skillful treatment.\(^5\)

Foreign bodies lodged in the ear. An incredible variety of foreign objects can find their way into the ear. Irrigation will remove something like 50 percent of them, and simple surgical removal the rest. Success of treatment is nearly 100 percent, with the warning that inept efforts to remove the offending object are themselves a possible source of serious damage to the ear. For instance, beans (often used as fillers in children’s toys) should not be irrigated with water because they swell when moist. And children being worked on without anaesthesia occasionally jump and hence cause injury. Sufficient cases of damage are known to make note

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\(^5\) Davis and Silverman, op. cit., p. 120.


\(^5\) Ballenger, op. cit., pp. 646-652; and interview with Dr. Frederick Linthicum, Otologic Medical Group, Los Angeles, December 14, 1973. Treatment may be spread out over a one-year period and progress in several surgical steps.
of these "simple" problems. Well-meaning but unskilled efforts to remove the foreign body should be resisted.53

Cerumen. Some people are predisposed to produce excessive cerumen secretions (wax) in the ear. If not removed, wax can restrict and even close the ear canal and apply pressure to the ear drum. In single episodes, treatment, consisting of removal of the debris and irrigation of the canal, is virtually 100 percent certain of restoring the ear to health. Some people have a chronic problem with cerumen, however; for them, treatment is more one of "control" than a "once-and-for-all" proposition and may be required at unpredictable intervals through their lives.

Trauma to Organ of Corti. Skull fractures in and around the auditory canal and the middle and inner ear may cause permanent and total hearing loss. Concussion without fracture can also cause some hearing loss, which sometimes is not permanent. It is impossible to assess the likelihood of hearing loss in general, as it is basically a function of the extent and location of the fracture or the severity of the concussion.54 Observation is certainly required, including competent diagnosis, and surgery may be indicated to repair the fracture.

Drug effects on the auditory nerve. Several drugs are known to cause deafness by attacking and causing permanent injury to the Organ of Corti. Quinine, sometimes used to induce abortion, or even to induce labor by unknowing obstetricians, can cause irreparable damage. Certain antibiotics, primarily in the mycin group, are also known to cause deafness and hearing loss. Susceptibility to hearing loss varies from patient to patient, and loss may not be spontaneous but may occur at some time after the drugs have been administered. One otologist respondent in this study went so far as to recommend that antibiotics, particularly the mycins, be administered only in "life-threatening situations with continuous monitoring of kidney function to insure that toxic levels of the drugs had not been achieved." Very little can be done once the nerve has been damaged in this fashion, short of rehabilitative therapy.55

Hearing loss due to noise. Temporary hearing loss is known to nearly everyone, from such causes as working around noisy industrial equipment, being near a discharging firearm, or riding a "go-cart" or motorcycle for some period of time. Usually, hearing returns to normal within a few hours or days; however, explosive sounds or continuous exposure to excessive noise can cause permanent hearing loss, as in the cases of rock musicians, children who persist in playing records at peak volume, and children who have cap pistols fired close to their ears. Treatment involves removal of the offending sound source or wearing of ear plugs, and rehabilitation. Because it involves the deterioration of the hair cells and nerve, surgical treatment is not possible. Persons already having some hearing impairment should be cautioned about exposure to loud and excessive noise over a period of time.56

Hereditary or congenital hearing disorders. The term "congenital" literally means "at birth," although in common statistical usage the term has lost much sharpness of meaning: many instances are known where a child's impairment is called congenital, but in fact was the result of some infectious agent attacking the ear in infancy (e.g., meningitis) or of the injudicious use of antibiotics with damage occurring some time later. A few of the better known congenital disorders are listed and described below.

Maternal rubella: As is described in detail in Chapter 6, maternal rubella, particularly when contracted in the first three months of pregnancy, is capable of causing an insidious assortment of handicaps, not the least of which is congenital hearing impairment of often marked severity. Ex post facto, there is no treatment except rehabilitation.

Congenital malformations of the Organ of Corti: Two basic classes of this disorder exist: hereditary and "misadventures of fetal life." In the first class, it is thought to be transmitted by a recessive gene in the more common case, and by a dominant gene which also is linked to kidney malformations. Both cases result in bilateral and severe impairment. Misadventures include maternal rubella, administration of ototoxic drugs (as noted above), and damage from other, unspecified, viral agents. A number of specific syndromes have been identified describing specific ways in which the Organ of Corti and the inner ear may be malformed and dysfunctional, e.g., Waardenburg, Mondini-Alexander, and Schiebe. As with other inner ear disorders, treatment prospects are not good. The major concern is to identify the child as soon as possible to insure that rehabilitation progresses as well as possible.57

Erythroblastosis fetalis: As a result of Rh sensitivity, the infant may suffer from hearing loss. The critical combinations are an Rh-positive father and an Rh-negative mother. Particularly in second and subsequent births the condition, commonly known as "newborn jaundice," can attack the central nervous system through a protein reaction, and the auditory system is susceptible to the disorder. Treatment is massive transfusion of the infant, e.g., "exchange transfusion" if indicated by serum bilirubin level, and placement of the infant on a high-risk registry for subsequent close examination, early identification, and appropriate rehabilitation. Lowered oxygen levels in the blood aggravate the problem. Prevention is partly possible through inoculation of the Rh-negative mother with an anti-Rh antibody.58

Stenosis and atresia of external auditory canal: A narrowed canal may be caused through infection or may be congenital. In the former case, treatment consists of removal of the infection and the debris it leaves, and repair of any damage done to the canal or the middle ear. Damage may also result from surgical misadventure. Repairing the damage requires a highly skilled technique but is successful in approximately 90 percent of the cases. Depending upon the seriousness of the narrowing and damage, there may be no hearing loss at all, but occasionally moderate impairment results (especially in the congenital case). Bone-conduction hearing aids and prompt rehabilitation should alleviate the handicap.59

Congenital malformation of the ear drum: There may be congenital malformations of the external ear, the auditory canal, and the eardrum, in which all or part of any or all of these items is missing or deformed. Surgical restoration is usually called for if the disorder is bilateral; if unilateral, surgery may be postponed because of possible damage to the facial nerve. Success rates depend largely on the degree and site of the malformation; likewise, hearing loss depends on the severity of the disorder and the success of restorative efforts.60


Otosclerosis: Because of abnormal bony growth, usually at or nearby the stapes or stirrup, hearing gradually becomes impaired. Otosclerosis is hereditary and occurs more commonly in females. It is rare for the disorder to manifest itself before about the age of 15 years. For those whose nerve has not been involved, surgical treatment is possible and successful in between 80 and 90 percent of the cases. Depending upon the extent, if any, of nerve involvement, hearing can be totally restored. Repeated operations in the case of initial nonrestoration have been successful. ⁶¹

Treatment of Hearing Disorders in General

Many, if not most, external ear, eardrum, and middle ear disorders are treatable with a high likelihood of success in correcting or avoiding a handicapping condition. The critical factors are early identification, correct diagnosis, and skilled treatment. Most sensorineural ("nerve deafness") disorders are not so successfully treatable, and the likelihood of a lifelong handicapping condition is much greater. The key factors in sensorineural disorders are early identification, stabilization or cure of the underlying disorder, if appropriate and possible, and then vigorous rehabilitation to minimize the handicapping effects of the disorder. The need for better data relating the disorders to etiologies is critical. It is difficult to assess the medical prevention and treatment needs of the population based on their disorders alone. And planning to meet those needs as they change over time is even more difficult without data on the prevalence of etiologies.

Medical Treatment Costs of Hearing Disorders

A sample of treatment costs for medical services available to those suffering from hearing disorders is presented in Table 5.8. These data are a sample of current charges for high-quality care in a specialized otologic practice, and may vary considerably for different parts of the country and for different practices. These estimates are for professional otologist's fees only; payment for other aspects of medical care such as days of hospitalization are excluded.

As with vision disorders, Table 5.8 makes it apparent that high-quality medical care can be had, and can also be costly in the absolute sense. Again, however, the appropriate trade-off is between the cost of such care and all costs involved in a lifetime of being handicapped or more severely handicapped than one would be with good medical care. In this sense, medical treatment is probably a "bargain." We should also call attention to the discrepancy between this fee schedule and the top fees payable under federally supported medical treatment programs. Many of the fees in Table 5.8 exceed maximum governmental program limits. Finally, we repeat the observation that the finest specialized medical care in the world is relatively useless, irrespective of its costs, if local identification and diagnosis services are inadequate.

Overview of Medical Service

A significant number of potentially handicapping disorders can be prevented, reduced, or eliminated altogether with skilled medical treatment. The major problem is not the quality of medical treatment, but the fact that so many handicapped

⁶¹ Otologic Medical Group, A Discussion of Otosclerosis, Los Angeles, 1972 (pamphlet); Kempe et al., op. cit., p. 229; and Ballenger, op. cit., Chapter 49.
<table>
<thead>
<tr>
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<th>Charge ($)</th>
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<td>Service group/routine/MDs</td>
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<td>Miscellaneous and office procedures</td>
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<td>Office visit</td>
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<td>Medication</td>
<td>(b)</td>
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<td>Plain sinus series</td>
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<td>Surgical nurse</td>
<td>50</td>
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<td>Polytome mastoid X-ray</td>
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<td>Special reports</td>
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<td>Poly-petrous pyramid X-ray</td>
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<td>Surgical procedures&lt;sup&gt;1&lt;/sup&gt;</td>
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<td>150&lt;sup&gt;j&lt;/sup&gt;</td>
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<td>Revision of myringoplasty</td>
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<td>Mastoidectomy, simple</td>
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<td>Hydroxycortisone (17 OHCS)</td>
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<td>Mastoid obliteration</td>
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<td>15</td>
<td>Petrosectomy</td>
<td>1500&lt;sup&gt;n&lt;/sup&gt;</td>
</tr>
<tr>
<td>Special vestibular testing</td>
<td>(b)</td>
<td>Cholesteatoma removal, primary</td>
<td>1500&lt;sup&gt;n&lt;/sup&gt;</td>
</tr>
<tr>
<td>Diagnostic/allergy testing and treatment</td>
<td></td>
<td>Exostosis, removal</td>
<td>700&lt;sup&gt;e&lt;/sup&gt;</td>
</tr>
<tr>
<td>Terpene and Petro tests</td>
<td>55</td>
<td>Tumor removal, glomus jugular</td>
<td>2500&lt;sup&gt;P&lt;/sup&gt;</td>
</tr>
<tr>
<td>Terpene or Petro retest</td>
<td>6</td>
<td>Tumor removal, glomus tympanicum</td>
<td>1500&lt;sup&gt;P&lt;/sup&gt;</td>
</tr>
<tr>
<td>Complete allergy test</td>
<td>230</td>
<td>Tympanonotomy</td>
<td>(k)</td>
</tr>
<tr>
<td>Allergy injection</td>
<td>5</td>
<td>Tympanosympathectomy</td>
<td>(k)</td>
</tr>
<tr>
<td>Allergy medication</td>
<td>10&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Mastoplasty</td>
<td>(k)</td>
</tr>
<tr>
<td>Histamine titration</td>
<td>10&lt;sup&gt;e&lt;/sup&gt;</td>
<td>Oval window fistula repair</td>
<td>2500&lt;sup&gt;P&lt;/sup&gt;</td>
</tr>
<tr>
<td>TOE/dust/inhalants</td>
<td>50</td>
<td>Acoustic neuroma, removal</td>
<td>2500&lt;sup&gt;P&lt;/sup&gt;</td>
</tr>
<tr>
<td>Pollen and inhalant testing</td>
<td>115</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foods testing</td>
<td>115</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recheck pollen and inhalation</td>
<td>50&lt;sup&gt;e&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recheck individual food</td>
<td>6&lt;sup&gt;e&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup>Factor used in calculation of repeat visits.
<sup>b</sup>No maximum fee.
<sup>c</sup>Minimum; no maximum fee.
<sup>d</sup>For each food tested.
<sup>e</sup>Plus $25 for subsequent visits.
<sup>f</sup>Plus $35 for subsequent visits.
<sup>g</sup>Plus $60 for subsequent visits.
<sup>h</sup>Special charge.
<sup>i</sup>Basic fee covers all procedures, including 6 months of postoperative care; any additional fees required are noted.
<sup>j</sup>Plus 6 postoperative office visits = $72.
<sup>k</sup>Fee varies.
<sup>l</sup>Plus 2 postoperative office visits per year for life to clean cavity.
<sup>m</sup>Plus 2 postoperative office visits per year for life.
<sup>n</sup>Plus 3 postoperative office visits.
<sup>o</sup>Fee varies around average.
<sup>p</sup>Plus 8 postoperative office visits.
children are not receiving it. Lacking early identification, accurate diagnosis, and timely direction, the best medical treatment in the world may well be practically and tragically irrelevant.

Many of the disorders causing vision and hearing handicaps, even the more exotic of them requiring highly specialized attention, can be treated at remarkably low cost relative to the expected lifetime costs incurred by a handicapped person. On cost grounds alone, a convincing argument often can be made that the best medical treatment available represents a profitable social investment, since it reduces future claims on society and the public treasury. To deny or limit these services is to risk being penny-wise and pound-foolish. Add to the cost-argument even the most elementary humanitarian concerns, and the case for providing medical services to those who need them becomes virtually incontrovertible.

The limited andinelastic population of gifted and highly skilled physicians could be better utilized than it presently is if the population in need were actively identified (see Chapter 4) and if the “invisible intelligence network” currently linking the population with doctors were made visible through an improved direction service concentrated at the regional level. (See our recommendations in Chapter 3.) Effective direction could overcome the consumer’s ignorance of where to get appropriate medical care; and adequate National Health Insurance for all citizens, together with other supplementary services such as transportation, could surmount the economic deterrent.

The provision of good medical care to the nation’s handicapped youth is not a “blue sky” objective. The trade-off, in rational terms, is between lifetime quality-of-life and economic costs for a permanent disability and possibly one-time and relatively limited costs for proper medical treatment, with all that might entail for the aggregate reduction in the number and extent of handicapped persons in the population.

Medical Treatment Service Recommendations

The following recommendations are in addition to those made earlier in the medical programs section of this chapter.

Prevalence data on the status and needs (medical treatment and other needs) of the sensorially handicapped population are in disarray; a great deal of vigorous activity is called for to correct this deficiency.

- The Department of Health, Education and Welfare (the proposed Office for the Handicapped or the Office of the Assistant Secretary for Planning and Evaluation) should institute a thorough and continuing periodic review of current data-collection and utilization procedures and resources with respect to handicapped children. This would be a first important step in improving services to the handicapped generally, with the intent of implementing steps to improve the availability and use of information. The National Eye Institute, the National Institute of Neurological Diseases and Stroke, and the Bureau of the Census, among others, should be consulted with an end in view of preparing a segment of questions on medical and other services to the handicapped population for inclusion in the 1980 Census of the population. Improved information could do much to inform legislative and executive agency actions affecting, ultimately, the lives of the handicapped population. Information does not presently exist in the quantity, in the form, or with the reliability necessary to accomplish this critical task.
Prevailing fee schedules used in government-funded medical programs are often significantly less than the going rates for identical privately funded treatment. Medical costs are highly variable, and some highly qualified physicians are now avoiding acceptance of Medicaid and CCS patients.

- Medical fee payment schedules should be revised to reflect the realities of the medical marketplace. National Health Insurance proposals represent one mechanism for rationalizing the fee schedules.

Treatment methods vary from the most highly specialized ophthalmologic and otologic practices to general practices found throughout the country. The Department of Health, Education and Welfare could accept responsibility, in the form of an emphasized catalytic role, to keep abreast of improvements in medical treatment to the hearing and vision handicapped population and then to help insure that these improvements are diffused throughout the national context.

- With an improved research management information system, the proposed Office for the Handicapped or NEI and NINDS could lead such catalytic activities by identifying promising research findings and then stimulating the development work required to make these research findings of general, practical use. No one at the federal level currently has prime responsibility to insure that research results are developed and disseminated in such a fashion, with the result that the process, if it occurs at all, is protracted unnecessarily. In-service training of specialists who are not at the forefront of medical treatment knowledge is presently no one's responsibility.

Identification and direction are critical, missing elements in the timely delivery of appropriate medical treatment; any improvement in these two neglected services would have the certain result of reducing the total hearing and vision handicapped population, and lessening the degree of handicaps within that population through improved receipt of preventive and remedial services.

- Previous recommendations for the direction and identification services should be adopted as expeditiously as possible (see Chapters 3 and 4).
Chapter 6

PREVENTION

INTRODUCTION

This chapter discusses the prevention of hearing and vision handicaps in youth. It briefly summarizes current programs for the provision of prevention services; reviews the preventability of many sensory disorders; examines several prevention strategies; and presents recommendations for improvement.

Prevention is a neglected and seriously underused service. This neglect is costly both to society and to handicapped youth and their families, not only in money but in the tragic fact that a large fraction of the sensory handicaps occurring in youth could be prevented. That fraction may be as high as one-third or one-half; given the poor state of the data, no one really knows for sure. Prevention can be achieved as the direct result of improved services (such as timely identification of the disorder and proper medical treatment); as the direct result of immunization efforts; and indirectly as a result of improved prenatal care, family planning, genetic counseling, abortion, and other practices. Each of these strategies is discussed below.

In contrast to the nearly $5 billion expended annually by all levels of government for service to all types of handicapped children, we are able to identify only some $50 million specifically targeted for prevention activities for children; in other words, about 1 percent is targeted for prevention and 99 percent for service after the child is handicapped. Figures for the sensorially impaired subset of the overall handicapped population generally mirror this breakdown.

If one in ten existing handicaps in youth had been prevented, the future savings to the government might have been about $500 million per year for all handicapped youth, and $42 million for sensorially handicapped youth. This represents, for each handicap prevented, over $6000 in the cost of future government services (discounted at 8 percent) over only the first 21 years the youth has the hearing or vision handicap. The total value of the youth's increased quality of life due to not being sensorially handicapped is much more important, and may be worth at least 10 times that amount, or much more, depending on one's value judgment.

Our recommendations for improved prevention services follow.

Give a single federal agency prime responsibility and authority for prevention as a service. Studies should be conducted to collect much better information on prevention and to evaluate alternative prevention strategies for specific disorders to enable more informed policies. The few federal prevention research and operational programs that exist provide spotty coverage of the population, at best, and are scattered through various agencies. No single agency is primarily responsible for looking at prevention as a service, but the proposed Office for the Handicapped, for example, if well staffed and given sufficient authority, could orchestrate federal prevention efforts. Not only would it be desirable to rationalize research expenditures based on the needs of the population (particularly as it changes) and to exploit research findings with evaluations and demonstrations if called for, but basic cost-benefit analyses are needed to inform future resource debates about research versus treat-

1 Rand Report R-1220-HEW, pp. 15-16. The precise level of funds targeted for prevention is a matter of definition, but the inescapable conclusion is that the level is very low.

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ment and about prevention versus service after handicapping. The present lack of information and evaluation of prevention activities is extreme.

*Revise and strengthen the rubella vaccination program, and provide funding for an open-ended period.* The messages here are very clear: rubella can be prevented; many youth are not immunized; rubella-caused handicaps are prevalent, especially in youth whose mothers contracted the disease in the first trimester of pregnancy; and prevention is decidedly cost-effective in terms of reduced future service costs, not to mention the extremely important reduced quality-of-life effects of the handicaps. We recommend mandating rubella vaccination for all prepubescent females through a school-based program conducted under auspices of the National Center for Disease Control; creating a model code for state marriage license serologic screening practices with the objective of including an additional test for the presence of rubella antibodies; and appealing through the mass media and professional medical publications to encourage all childbearing females to obtain such tests from their private physicians.

*Without deductibles, fully cover high-quality prenatal care, routine immunization services for children, eye and ear examinations for youth up to age 21, and preventive medical treatment, in Medicaid and in any National Health Insurance program that may be implemented.* Adoption of this recommendation and those made in earlier chapters for early identification, direction, and medical treatment, is perhaps the most important means of preventing handicaps. High-quality medical care is available to prevent disorders and to prevent existing disorders from resulting in handicapping; the problem is the inadequate match between children in need and medical-technical resources.

**CURRENT PREVENTION PROGRAMS**

This section first discusses operational prevention service programs and then those oriented toward prevention research. Before discussing specific programs, however, it is useful to examine program goals as they relate to prevention activities.

Personal "nondependency" as a goal to which prevention relates has been formulated in the following terms by Elliott Richardson, former Secretary of Health, Education and Welfare:

...the non-dependency goal would suggest that our objectives should be: 1. to create prevention mechanisms which identify the likelihood of people sliding down the scale of personal freedom of choice and reliance on others, and which remove the dangers which threaten the status of those people...

The "likelihood" idea is related to prevention research activities, and the "removal of danger" idea with operational prevention service programs.

Another objective to which a prevention program can relate is to reduce expected public expenditure and quality-of-life disbenefits over the lifetimes of persons in the total handicapped population. Prevention can reduce future public expenditure by reducing the absolute number of those entering the handicapped population and by providing a full range of remedial and restorative services to those already in that population. Handicap prevention is not done well in the United States, as attested to by the persistent prevalence of sensorially handicapped persons with preventable

etioologies (see Chapter 5), and by the simple and persistent statistic that the United States ranks fifteenth among nations in infant mortality. The provision of remedial and restorative services is not done very well either, as attested to by other chapters of this report.

If so many disorders are demonstrably preventable, why do so many handicapped children still enter the population because of them? If so many other disorders are suspected of being to blame for handicaps, why is research directed at the resolution of these disorders so poorly orchestrated?

S.H. King has advanced an explanation for the undervaluation of inoculation programs that may be applicable to prevention programs in general: "The person or group with a time orientation toward the present [e.g., politicians] will have difficulty in seeing the value of inoculations against disease, a future occurrence." Undervaluation may occur for the full range of prevention programs for the same reason.

Underinvestment in prevention services may also occur because those agencies currently administering prevention programs, usually health agencies or personnel, do not benefit from the future reduced costs of service such as special education, vocational services, and welfare. Thus, from the narrow viewpoint of the administering agency, rather than the viewpoint of all government agencies as a whole, prevention may be a net long-term as well as a short-term cost.

Seriously inadequate information also hampers and misdirects prevention services and research. Foggy information on the prevalence of various etiologies can produce only foggy estimates of the extent to which the individual disorders contribute to the handicapped population, and how these prevalences are changing over time. One result is that research attention focuses somewhat indiscriminately on both rare and commonplace diseases and disorders. Another result is that erratic information makes it hard to marshal compelling arguments for prevention.

Still other explanations may be: few theories relate prevention costs to other service costs (partly, no doubt, because of the paucity and imprecision of the basic information); known data on all other service costs are not routinely related to the immediate costs of conducting research into disorder causes and processes or to the operational costs of carrying out a prevention program; no one has direct and comprehensive responsibility for prevention; and insufficient attention is being given to the applications of research findings to prevention program operations and to dissemination of those findings to practicing physicians, who are a major source of prevention through proper medical treatment of handicap-causing disorders.

The current rate is 19.2 deaths before the age of 1 year per 1000 live births. On this measure, the United States is ranked behind Sweden (11.1/1000), Japan (12.4), France (14.4), the United Kingdom (18.0), Canada (18.8), East Germany (18.8), and others. Scientific American, Vol. 229, No. 3, September 1973, pp. 64-66. The contribution of adequate prenatal care (a preventive practice) was underscored in that report. A 1968 health survey found that the then-prevailing infant mortality rate of 21.9 for all of New York City could have been reduced to an estimated 14.7 if all the mothers surveyed had received a modal amount of prenatal care. For those in New York City judged to have received "adequate" prenatal care, the rate was 13.3, for "intermediate" care it was 18.5, and for "no" or "inadequate" prenatal care it was 35.8. It was concluded that there existed "a gross misallocation of services by ethnic groups when the risks of the women are taken into account."


Jacob Feldman, The Dissemination of Health Information, Aldine, Chicago, 1966, has addressed the general question of data as it relates to rational decisionmaking on research expenditures and for prevention has concluded that the poor available information on the time of onset and etiology has inhibited concerted attention and remediation.
Operational Prevention Service Programs

Immunization is a clear instance of preventive service, for which there is a number of programs.

Communicable Disease Prevention and Control has been legislated through the basic Public Health Service Act and updated periodically by amendments. It includes the epidemiological program of the National Center for Disease Control, which had $1.709 million in FY 1972 for consultation, technical assistance, and training for state health agencies, among other responsibilities; a communicable disease control program, funded at $7.213 million in FY 1971, that offers a variety of immunization activities to children; and Health Service Development Project Grants to the states, which have supported, among other activities, the rubella immunization project at a rate of $14.5 million and which allocated some $500,000 for a modest but expanding program for Rh desensitization in FY 1973. Additionally, some number of immunization services and activities are conducted through the Maternal and Child Health Service.

Venerable disease, an etiology linked to congenital sensorial disorders, is also a preventive responsibility of the National Center for Disease Control. It was funded at a $16.0 million level in 1972.

General prevention along a broad but not very deep front is provided under Maternal and Child Health and Crippled Children’s Services programs. A 1969 survey indicated that, for all services for all conditions, there were some 190 MCHS and 19 CCS supported program activities in the states that could be directly labeled "preventive." Of this total, no single type of prevention service was provided in all the states, and the portion accruing to sensorially handicapped children is not clearly indicated or recoverable from the presented data. Table 6.1 lists other preventive activities related to hearing and vision problems, but provides no dollar totals because of the manner in which the state program data are tabulated (expenditures are not linked with the program descriptions). Vision and hearing conservation programs of an unspecified nature accounted, respectively, for 15 and 29 MCHS and CCS program activities in the states.

Medicaid has an operational prevention component inherent in its early and periodic screening, diagnosis, and treatment provisions, although the benefits related to sensorially handicapped children are reduced by the lack of full implementation of the provisions, and the fraction of the total effort devoted to prevention is unknown. (See the discussion of Medicaid in Chapter 5 above.)

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8 Justification, p. 17.
9 Rand Report R-1220-HEW, Table 8.27.
10 Update to the 1972 Catalog of Federal Domestic Assistance, Office of Management and Budget (OMB), Washington, D.C., November 1972, p. 186.1
14 Many of these are integral parts of P.L. 88-156, including the Maternal and Infant Care Program (M&I). Arthur J. Lesser, in his "Accent on Prevention Through Improved Services," Children, Vol. 11, No. 1, January-February 1964, pp. 13-18, asserts that such programs have had the effect of reducing premature births, infant mortality, mental retardation, and neurological handicapping.
<table>
<thead>
<tr>
<th>Program</th>
<th>Service and Number of States</th>
<th>Total, Both Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rubella</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Studies of rubella</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Specific studies for preventive care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lab studies, rubella test</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Lab studies, rubella immunization</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Lab studies, rubella register</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Total, rubella</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Immunization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children's immunization clinics</td>
<td>32</td>
<td>32</td>
</tr>
<tr>
<td>Provision of immunization supplies</td>
<td>23</td>
<td>24</td>
</tr>
<tr>
<td>Total, immunization</td>
<td>55</td>
<td>56</td>
</tr>
<tr>
<td>Genetics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specific services for genetics counseling</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>Specific services for genetics</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Heritable metabolic diseases, screening and treatment</td>
<td>12</td>
<td>17</td>
</tr>
<tr>
<td>Total, genetics</td>
<td>28</td>
<td>30</td>
</tr>
</tbody>
</table>

**SOURCE:** Rand Report R-1220-HEW, Table 8.27, pp. 215-220.

The "Health Maintenance Act of 1973" is popularly regarded as a prevention initiative, but it cannot be reliably estimated how much the $375 million total to be expended over the next five years will reduce sensorial handicapping in the young.

Finally, many other governmental programs include prevention as a secondary activity, but with unknown effects. In this class would be improved prenatal care; family planning; identification and direction, where they exist; and a few operational genetics counseling programs. While precise numbers cannot be estimated, the sum total of all such activities is relatively small.

**Prevention Research Programs**

Preventive research programs are a main responsibility of several institutes within the National Institutes of Health, but it is often difficult to say what portion of a research program on sensory impairment in general should be evaluated as a benefit to the young in particular. For example, research to promote the understanding, treatment, and prevention of glaucoma is universally beneficial, but one cannot say how much of the current glaucoma research budget of the National Eye Institute should be counted as a benefit for handicapped children.

The National Institute for Child Health and Human Development (NICHD), primarily through its perinatal biology and infant mortality program, and to a lesser

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16 Rand Report R-1220-HEW, Chapter 9 has a more complete description. NIH research programs are also obviously relevant to medical treatment, as discussed in Chapter 5 of this report.
extent through its growth and development and population and reproduction programs, is conducting research contributing to the prevention of sensorial and many other types of handicapping. Perinatal biology and infant mortality represented a total expenditure of $10.8 million in FY 1972 for research in 318 grants and contracts. Studies on maternal complications in pregnancy, toxemia and diabetes, malnutrition affecting the fetus, respiratory distress, Rh sensitivity, hypoglycemia, and erythroblastosis fetalis, all added to prevention.

The National Institute for Neurological Diseases and Stroke (NINDS) contributes to prevention research, mainly through its communication disorders prenatal and perinatal programs. Of the $10.0 million spent on the former and $7.5 million spent on the latter in FY 1973, some fraction benefitted aurally handicapped children. (In addition, NINDS funds a few nonchild-specific projects on prostheses for blind persons.)

The National Eye Institute (NEI) had a budget of $24.95 million in FY 1973, broken down according to disease classes as follows: retina and choroid, $6.2 million; sensory motor, $3.7 million; corneal, $3.0 million; glaucoma, $2.7 million; and congenital and developmental, $530,000. (The remainder went for operating expenses, the Model Reporting Area project, and miscellaneous activities.) Only the congenital and developmental expenditures are child-specific.

The National Institute of Dental Research (NIDR) conducts a cleft lip and palate research program, which was funded at $2.0 million in FY 1970. The correlation between cleft lip and palate defects and serous otitis media is known to be high (see Chapter 5); such research therefore has some preventive component for hearing handicapped children.

The National Institute of Allergy and Infectious Diseases (NIAID), supports research into methods of control of allergic, immunological, and infectious diseases, which contain many etiologies related to sensorial handicaps.

The National Institute of General Medical Sciences (NIGMS) supported genetic research with $33.5 million in FY 1973, some portion of which aids prevention of aural and visual handicapping; the same is true for its programs on general clinical service and trauma.

Private research activities exist, but their total contribution to research is not known. One of the larger and better-known private organizations, however—Research to Prevent Blindness—contributed $2 million to research in the period from 1960 through 1973, and granted another $17 million for laboratory facilities during that period.

Prevention Programs in General

Prevention is one of the more neglected services, and the up-and-down fortunes of prevention programs sometimes resemble "The Perils of Pauline." Crisis or the threat of impending crisis is often necessary to galvanize official government attention to the prevention service, with the result that prevention programs have been heavily oriented to specific diseases and often limited in duration and total funds expended.

17 NICHD, Program Statistics and Analysis Branch, Interview, June 7, 1973.
18 The perinatal program has over the years been conducting an extensive study of neurologically and sensorially handicapped children, resulting in a rich source of unique data. A great deal of potential knowledge is contained in this file, but much analytic work remains to be done to realize the full benefits from it.
20 Ibid.
The record of prevention research into the causes and cures of sensorial handicapping in children is mixed and very difficult to piece together. Not only are the unpredictable vagaries of research operating, but the research itself is scattered among an assortment of institutions whose main order of business is often not research on sensorial handicapping. Furthermore, few institutional mechanisms exist to translate research findings into applied methods to prevent sensorial handicapping.

SOME PREVENTABLE SENSORY DISORDERS

A number of hearing and vision disorders can be prevented, as indicated in discussions of the disorders in Chapter 5. Table 6.2 is a partial listing of those disorders in which disabling sensory handicaps appear to be relatively more preventable, given the current state of the medical art.

<table>
<thead>
<tr>
<th>Disorder or Disease</th>
<th>Handicap</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rubella</td>
<td>X</td>
<td>Immunization</td>
</tr>
<tr>
<td>Ototoxic deafness</td>
<td>X</td>
<td>Proper medical treatment</td>
</tr>
<tr>
<td>Noise deafness</td>
<td>X</td>
<td>Remove offending source; institute hearing conservation measures; keep children away from explosive sounds</td>
</tr>
<tr>
<td>Otosclerosis</td>
<td>X</td>
<td>Diagnosis and surgical treatment</td>
</tr>
<tr>
<td>Otitis media</td>
<td>X</td>
<td>Identify, diagnose, and treat correctly. Persistent care</td>
</tr>
<tr>
<td>Mumps</td>
<td>X</td>
<td>Immunization</td>
</tr>
<tr>
<td>Measles</td>
<td>X</td>
<td>Immunization</td>
</tr>
<tr>
<td>Meningitis</td>
<td>X</td>
<td>Prompt, proper medical treatment</td>
</tr>
<tr>
<td>Rh sensitivity</td>
<td>X</td>
<td>Proper identification and sound care</td>
</tr>
<tr>
<td>Retinoblastomatia</td>
<td>X</td>
<td>Proper medical treatment (specific case); prenatal care (general case)</td>
</tr>
<tr>
<td>Amblyopia, strabismus, myopia</td>
<td>X</td>
<td>Prompt identification, diagnosis and treatment</td>
</tr>
<tr>
<td>Cataract</td>
<td>X</td>
<td>Early detection and treatment</td>
</tr>
<tr>
<td>Glaucoma</td>
<td>X</td>
<td>Detection before irreparable damage is done; proper treatment</td>
</tr>
<tr>
<td>Retinoblastoma</td>
<td>X</td>
<td>Treatment of affected child. I.D. for parents-to-be suspected of being trait carriers, genetic counseling, and family planning</td>
</tr>
</tbody>
</table>

NOTE: For each disorder, high-quality preventive or medical treatment service is thought to result in no handicapping condition in at least three-fourths of the cases, and for some disorders, in at least 99 percent.
Rubella is preventable; an effective vaccine has been in widespread use since 1969, but implementation and scientific problems still impede full prevention (they are discussed under "Prevention Strategies" below).

Otoxic deafness is known to result from the use of certain drugs, and others are suspected. For those known to cause hearing loss, prevention should be a near certainty, but is not. For those antibiotics suspected to be related to hearing loss, a clear case can be made for additional prevention research, an eventuality more or less assured in several noted programs. We know how to prevent handicapping from inappropriate drug use, but drug-deafened children still enter the population.

Any number of disorders, exemplified by various forms of otitis media, are liable to cause sensory deficits if they are improperly treated, left untreated, or treated late because of faulty identification, direction, and treatment services.

Retrolental fibroplasia can be devastating, but it is generally known that excessive oxygen is responsible for the blindness it causes. Even at the current state of knowledge, a majority of the people entering the population of those blinded by RLF should not be. With additional prevention research into oxygen dosages\(^{28}\) and the mechanisms by which oxygen "poisons" the eye, better techniques of monitoring oxygen administered to infants, better incubators, and improved understanding by physicians (especially pediatricians and obstetricians), the disease is probably about 95 percent or more preventable. The remaining 5 percent would occur in those stark and critical situations where blindness may reluctantly be chosen as the lesser undesirable outcome in a life-threatening situation. Better prenatal care, to cite a more general prevention strategy, could furthermore lessen the prevalence of prematurity (a proven relationship exists between prenatal care and the likelihood of a premature birth) and hence the need for oxygen therapy.

A number of disorders can be corrected or contained and need not cause handicaps; however, success in nearly all of these depends on the earliest possible identification (before the age of 5 in most cases) and correct medical treatment.

Several disorders are detectable with in utero assessment techniques, even at the relatively underdeveloped state of the practice,\(^{28}\) but the degree of preventive potential depends on the accessibility of an up-to-date identification and preventive care program, genetic counseling, and the choice by parents on whether or not to terminate the pregnancy when a major handicapping disorder is actually detected.

PREVENTION STRATEGIES

We now turn to the question of strategies for prevention, and discuss prenatal care; immunization; timely identification, direction and proper medical treatment; family planning; genetic counseling; and abortion and other practices.

Prevention Tradeoffs

In deciding whether to implement any of the prevention strategies to be described, or in deciding on modification of existing prevention programs, one must confront the question of the tradeoff between current costs of a prevention program, future costs in terms of the reduced quality of life of persons whose handicaps are

\(^{28}\) Just such a program, albeit a very modest one, is currently under way in the Medical School at The Johns Hopkins University.

\(^{28}\) No one has devised a safe technique for sampling fetal blood, but when it is discovered, an assortment of genetically related disorders will become candidates for prevention if parents choose to have an abortion.
not prevented, and future costs of service to those persons. While the logic is clear, it is extremely difficult to make a tradeoff in practice. Not only are data lacking, but dollar estimates attached to decreases in quality of life are bound to be somewhat arbitrary. For example, suppose one desires to determine the level of preventive activity that results in a minimum total of prevention costs plus "disamenity" costs associated with reduced quality of life and with later service needs due to handicaps not prevented. For illustration, a simplistic version of the problem is presented in Fig. 6.1, which plots hypothetical costs of prevention, "disamenity" costs of handicaps not prevented, and total costs.

The purpose of a mathematical analysis of data plotted in such a figure could be to assess relative prevention strategies to determine how far a strategy could be used before the returns become marginally disadvantageous—i.e., the cost of one more prevention exceeds the "disamenity" cost of not preventing one more handicap. To perform this type of analysis, data must be available for each prevention strategy and each disorder, and one must be able to arrive at a way of expressing quality of life in money or commensurate terms.

In practice, the type of analysis implicit in Fig. 6.1 has little direct relevance. The available data make it difficult enough to account with any accuracy for all factors contributing to prevention costs, e.g., research, training, operations; and no one can reliably estimate the costs or benefits of as yet unrealized technological breakthroughs as they may contribute to an improved prevention service. Data to provide a clear understanding of factors causing a specific disorder, and the contributions of a given preventive strategy to reduced prevalence and to reduced future service cost, are not fully available either. And finally, this style of analysis necessarily overlooks some difficult but important problems, including the "cost" and "worth" of human life, individual variations in preferences, thresholds of pain or suffering, and other bearable or perhaps unbearable costs of "disamenity."

What is left to us, then, to help decide whether increased prevention activity is desirable? For the Vocational Rehabilitation program, where data are relatively good, we are able to perform a fairly sophisticated benefit-cost analysis (see Chapter 9); the basic point made there is that program-costs to society, to the taxpayers, and to the handicapped individual are all less than the program's corresponding future economic benefits; and increased quality of life adds even more benefits. We use a similar line of argument, for example, in a rubella immunization program analysis made later in this section. We show that the costs of the rubella prevention program are far less than the future discounted incremental costs of special education for persons whose handicaps the program could have prevented. (And added quality-of-life benefits and reduced future costs of other services would justify this program still further.)

Another approach is to consider the service costs for hearing and vision handicapped children, asking how expensive a prevention program can be and still fall below the service costs for handicaps not prevented. For example, assume that the present annual government expenditure of $420 million for services for the 683,000 handicapped children is not worth the service benefits. The analysis then can be done by using the values of the "worth" of human life for each age group to weight the costs against the benefits. The technical details of this calculation are discussed in Appendix A.

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25 We are not saying that conducting such analyses is not without value; rather, we are facing the immediate practicality issue. An otherwise elegant and thorough analysis ran into difficulty on precisely this point: see S. Fanaroff and J. W. Bush, "A Health-Status Index and Its Application to Health-Services Outcomes," Operations Research, Vol. 18, No. 6, November-December 1970, pp. 1021-1066. This article contains an excellent bibliography describing the state of the field.

000 hearing and vision handicapped youth, or $615 per handicapped youth, is representative of the average annual incremental cost for the handicap to be prevented by a proposed program. The present value of 21 years of expenditures for the handicapped youth is approximately $6150 at an 8 percent discount rate. In this example, the prevention program would be justified, on grounds of reduced future service costs alone, if the prevention cost per handicap prevented is less than about $6150. If one further assumes, not unreasonably, that the humanitarian quality-of-life benefits of not being handicapped are worth at least ten times this reduced service cost, then the program would be justified on humanitarian grounds alone if the prevention cost is less than about $60,000 per handicap prevented. In other words, the program would be justified on humanitarian grounds if costs are $60 per youth and only 1 in 1000 youth receiving the service had a handicap prevented as a result (or $6 and 1 in 10,000, or $600 and 1 in 100).

We now turn to a summarization of individual types of prevention strategies.

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27 The $615 figure is not the true value of the incremental cost, of course, but it is probably of the correct order of magnitude. Estimation of the actual incremental cost is considerably more complex; it involves such factors as determining what amount of current expenditures would not be reduced, such as a portion of Medicaid for families that might be needy even without a handicapped child, and such as various program "overhead" costs; and predicting what would be the particular government program organizational reactions to a smaller handicapped population, such as more outreach to find clients, or providing a higher level of service to individual clients. It would also be necessary to estimate the incremental cost savings and increased benefits for the particular mix of types and degrees of handicaps to be prevented, and from the viewpoint of particular program objectives.
Prenatal Care as a Prevention Strategy

Partly because of the leadership along a broad research front provided by the National Institute of Child Health and Human Development,28 more is being learned about the critical importance of prenatal care as a general preventive strategy. Specific relationships between a number of prenatal conditions and subsequent sensory disorders are known; and many other suspected conditions, given the prevalence of "unknown prenatal influence" as an etiologic class for sensory handicaps, have become fitting research topics.

In an informative summary of "dos and don'ts" for a pregnant woman, Jane Brody29 has made the following observations—all of which contribute generally to reduced chances of producing an abnormal baby.

- Most important is the early and periodic prenatal examination by a competent physician. All adverse indicators, e.g., low birth weight, prevalence of defects, fetal misadventure, are positively related to poor or non-existent prenatal care.
- Drug intake, including common non-prescription, prescription, and "dangerous" drugs should be sharply curtailed or eliminated altogether. If drugs must be taken, it should be done only with the guidance and prescription of a physician, preferably the obstetrician responsible for the prenatal course of treatment. In this regard, no drug—no matter how "harmless"—is to be considered above reproach. Definitive research has just not been done in sufficient quantity to rule out the potentially damaging effects of any drug or foreign chemical substance, and this includes aspirin, nicotine, caffeine, and vitamins taken in excessive amounts, as well as prescription medications, e.g., steroids, progesterone, antibiotics, diuretics, antihistaminics, anti-depressants.30
- Proper nutrition is important as a part of sound prenatal care; protein deficiencies, for instance, are known to be related to decreased cerebral development.31
- Abdominal x-rays should be avoided, especially in the first weeks of pregnancy.
- Live virus vaccines should not be administered if pregnancy is suspected; included on this list are small pox, measles, rubella, mumps, and yellow fever.

Good general prenatal care will also detect syphilis in routine serologic work-ups. Congenital syphilis is apparently on the increase, and has been suspected in congenital sensorineural hearing loss, keratitis, and cataract.

The relationship between prenatal drug intake and subsequent hearing loss in the infant has been established for antibiotics in the mycin group, is suspected with other antibiotics, and is known to exist in the case of quinine. Various hearing disorders linked to drug intake include congenital malformations of the Organ of Corti and irreversible damage to the auditory nerve. Congenital cataract and drug intake are suspected to be related. The general caution noted for prenatal drug use pertains.

X-rays in the early stages of pregnancy are suspected in cases of congenital cataracts and other malformations of the eye.

Finally, vaccination of a pregnant female against mumps, rubella, and measles with a live virus vaccine is capable of infecting and causing harm to the fetal sensory organs.

28 Rand Report R-1220-HEW, Chapter 9 contains a program summary for NICHD.
30 NICHD supports a modest program in Prenatal Pharmacology that addresses many of these issues.
Immunization

A major strategy for prevention of sensory handicaps is to immunize to prevent diseases and disorders that can cause handicapping, such as measles, mumps, and especially rubella and Rh sensitivity. While the probability of handicapping from measles and mumps is relatively low, there is great danger with Rh sensitivity and rubella (especially if a woman contracts it during the first trimester of her pregnancy). And, as we will illustrate for rubella, the cost of an immunization program can be low compared with the costs of handicapping.

A problem is that many persons are not receiving this obvious type of prevention service. For example, recent reports from the National Center for Disease Control in Atlanta have registered concern that not enough children in rural and central city areas are being vaccinated against polio and measles. Especially significant was the finding that about one-half of central city children surveyed were not protected against measles or polio. More than 75,000 cases of measles were reported in 1971, an increase of 28,000 over the previous year. It is a persistent problem, reflecting both the fragmented nature of the health system generally and the particularly limited interest given to preventive activities as contrasted with most other services. It apparently takes an epidemic to force preventive immunization into the forefront.

No one government agency is primarily responsible for coordinating immunization programs (including research, assuring production and quality of the vaccine or serum, delivery of the service, and then evaluation of program effectiveness). And government costs for immunization are not born by the same agencies that reap future benefits—these benefits being "successful" prevention, cases of diseases that did not occur and did not cause handicapping, and hence service costs that were not incurred later.

While the National Center for Disease Control has been a leader in promoting immunization programs, implementation has been delegated to state and local health authorities, who are left for the most part to their own devices. The results have been mixed, as documented in the recent rubella evaluation study conducted for the Office of the Secretary, Department of Health, Education, and Welfare by Bio-Dynamics, Inc.

Rubella. It took a major epidemic in the early 1960s to galvanize official attention in the case of rubella, but in the absence of subsequent catastrophes, maintenance of this attention and activity has waned. Specific details of what this entails for the rubella prevention program include the following:

- There is marked unevenness in the quality of community-run programs and slight provision available to correct the more deficient ones.
- Identification of people in at-risk groups is not uniformly well done, with the result that coverage is uneven.

35 See Education Daily, May 5, 1972, p. 6, which also notes that both measles and diphtheria have risen sharply since 1970, a finding alleged to be linked to certain federal government officials' reluctance to support special vaccination programs, whereby preventive activities have been "lumped into a generalized program which gives local and state governments freedom to choose how the money will be spent."

36 Former Secretary of Health, Education and Welfare Abraham Ribicoff is quoted as saying, nine years ago, that the vaccination programs existing then had two major weaknesses: "First, they have been so closely related to school admissions that they have provided poor coverage for preschool children. Second, they have been least effective in reaching families in low-income neighborhoods." Proceedings, 2d Annual Immunization Conference, May 1965, p. 5, as cited in Bio-Dynamics, Inc., Evaluation of the Rubella Immunization Program, Department of Health, Education and Welfare, Office of the Assistant Secretary for the Planning and Evaluation, Contract No. HEW-OS-70-153, Washington, D.C., 1972, p. 8.

• School-based programs miss many preschoolers.
• Maintenance and surveillance are crudely developed and "the probability of satisfactory maintenance after federal funding ends is poor."
• Private physicians are not included in the reporting procedures of the program; program effectiveness studies are thereby biased.
• The Center for Disease Control needs considerable strengthening to carry out its responsibilities.

And finally, the most significant finding of all:

At this time there is substantial evidence that seven years of the Vaccination Assistance Act did not provide all states with the means to continue high levels of immunization. The Federal grants mechanism did not provide adequate incentive to build this at the local level nor the technical assistance to show how it can be done. The established public health structure demonstrated capability to carry out the attack phase but not the maintenance phase.35

The importance of long-term maintenance of preventive activities may be stressed in a simple cost exercise designed to relate prevention costs to service costs for handicaps resulting from inadequate prevention.

The rubella epidemic of 1963-1965 left an estimated 20,000 to 30,000 handicapped children in its wake, a tragedy that society will be paying for in many significant ways for years to come.36 In his analysis, Donald Calvert estimated the special educational costs alone associated with the impaired subset of the epidemic population.37 We have made our own more conservative estimates based on special education expenditure data presented in Chapter 8 of this report for the discounted incremental costs above the cost of regular education. Further, we have omitted educational costs for what Calvert has termed "mild to moderate" handicaps, biasing our special education cost figures down even more. As can be seen in Table 6.3 Calvert's and our estimated special educational costs differ significantly; however, even taking our intentionally conservative estimate as a basis of comparison, there is a striking difference between the $202 million increased special educational costs due to that one rubella epidemic and the $41.6 million total authorized under the Rubella Immunization Program.38 And we have not even considered increased costs of services other than special education in the calculation, not to mention the degradation of quality of life inflicted by the handicaps.

The urgency of such preventive programs is manifest if we look only at the high annual cost associated with the special education of deaf-blind children: from $12,000 to $14,000 per child.39 For the estimated 1250 deaf-blind children resulting from the 1963-1965 rubella epidemic, this represents an annual outlay of $15 million (using the low estimate)—but in 1972 only $7.5 million was expended for establish-

38 Section 314(e) of P.L. 89-749.
39 The low estimate is that used by California's School for the Blind in their Deaf-Blind program, and the high figure is that reported by Calvert for Massachusetts' Perkins School for the Blind's program in 1969.
Table 6.3
ESTIMATED COSTS FOR 13 YEARS OF SPECIAL EDUCATION OF HANDICAPPED CHILDREN RESULTING FROM THE RUBELLA EPIDEMIC OF 1963-1965

<table>
<thead>
<tr>
<th>Handicap</th>
<th>Number</th>
<th>Undiscounted Total Cost: Calvert Estimate</th>
<th>Discounted Total Cost: Rand Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visually impaired</td>
<td>5,500</td>
<td>$250,250,000</td>
<td>$35,500,000</td>
</tr>
<tr>
<td>Hearing impaired</td>
<td>12,000</td>
<td>$668,000,000</td>
<td>$77,400,000</td>
</tr>
<tr>
<td>Deaf-blind</td>
<td>1,250</td>
<td>$227,500,000</td>
<td>$81,000,000</td>
</tr>
<tr>
<td>Retarded/crippled</td>
<td>1,250</td>
<td>$48,750,000</td>
<td>$8,100,000</td>
</tr>
<tr>
<td>Total</td>
<td>20,000</td>
<td>$994,500,000</td>
<td>$202,000,000</td>
</tr>
</tbody>
</table>


NOTE: Rand estimates are based on expenditure data in Chapter 8 of this report. Thirteen-year costs are discounted at 8 percent to time of birth.

...ing and supporting Deaf-Blind Centers for all of the 4728 identified deaf-blind children in the United States as of January 1, 1972.40

The messages from this example and discussion are clear:

- Rubella can be prevented.
- Rubella-caused handicaps are expensive.
- Prevention is decidedly cost-effective.

But,

- Attention to the rubella immunization program is flagging, with potentially tragic and costly results.

It would be easy to conclude summarily with the recommendation that renewed vigilance be applied to rubella immunization efforts; but several confounding facts must be taken into consideration before making such an appeal.

There is evidence that rubella may have been controlled as a result of the mass immunization program. The Center for Disease Control noted only 21,424 cases of rubella in the first 39 weeks of 1972, a 44 percent decline over a comparable period in 1971.41 While the trend has been downward since the 1969 initiation of rubella immunization efforts, one must caution that rubella occurs periodically, normally in a 6 to 9 year cycle, and 1972 would have been at the leading edge of the normal period. Control of the disease is not accomplished "once and for all," and eradication is probably out of the question given its worldwide prevalence.

There is also evidence that the "herd immunity" approach adopted in the original rubella program does not work as well as it was expected to.42 For instance,

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41 Reported in Education Daily, Vol. 5, December 20, 1972, pp. 1-2. Estimates vary, but somewhere between 30 and 40 million children have been immunized in the program.
42 J. P. Fox et al., "Herd Immunity: Basic Concept and Relevance to Public Health Immunization Practices," American Journal of Epidemiology, Vol. 94, 1971, pp. 179-189. The concept is that, if a sufficiently large fraction of the population is immune, transmission of the disease is inhibited and the potential for an epidemic reduced.
Klock and Rachelefsky, in reporting on an epidemic localized to Casper, Wyoming in early 1971, found that while 83 percent of the elementary school and 52 percent of the preschool population had been immunized (and for these groups protection was excellent), older youth had not been immunized while young, and some 1,000 cases of rubella occurred in a population of some 40,000. Eighty-four percent of those afflicted were teenagers, and 27 cases occurred in women, 7 of whom were pregnant. While others have used these findings to argue for the repeal of some 22 state laws mandating rubella immunization as a requirement for school admission, the following are the conclusions drawn by the investigators from the Casper case:

Although the vaccination of prepubertal children in Casper did not prevent an epidemic, this effort undoubtedly did prevent infection of a number of pregnant women after the epidemic began. If younger children had not been immunized, the outbreak would have been more extensive, and the number of exposed, susceptible women would have been much higher. Thus, childhood rubella immunization remains an important method of rubella prevention; however, because of the potential for outbreaks in older children this procedure should be supplemented by other methods of rubella control. The most important of these is the identification and vaccination of susceptible, nonpregnant women in the child-bearing age.44

Other specialized literature on the rubella immunization issue generally supports these findings and conclusions.45 Among other partial results contained in this body of literature, the following summary points stand out.

- As contrasted with selective vaccination programs directed at the at-risk population of women of child-bearing age, the herd immunity concept does not appear to be completely reliable.
- More than 95 percent of those vaccinated develop serum antibodies and appear in the short term to demonstrate protection. (Reinfection rates among naturally immunized and vaccinated populations have not been established but should be given careful surveillance.)46
- The chances of a previously immunized female becoming reinfected and if reinfected, transmitting the disease to the fetus, are not known.47
- It is known that the vaccination is capable of producing unpleasant side effects, both in children and particularly in postpubescent females.48

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44 Ibid., p. 72.
A conservative recommendation, based on these findings, has been offered by Vincent Fulginiti, a virologist, in the following terms:

The author feels there is sufficient uncertainty about the effectiveness of mass rubella immunization, sufficient question concerning pharyngeal virus growth in the vaccinee, and sufficient doubt about the significance of side-effects to question the wisdom of utilizing rubella vaccine routinely in childhood. A preferable alternative at present would be to immunize all pre-pubescent females, to test all women in the child-bearing age group for rubella antibody, and to immunize those who are susceptible (approximately 15%). It is necessary to make absolutely certain that pregnancy is avoided for at least 2 months following such immunization.49

However, this recommendation is somewhat at odds with a recent Public Health Service Advisory Committee opinion that all children between the age of 1 year and puberty should receive a rubella vaccination.50

A basis for reconciliation of the views is contained in our following recommendations for an improved rubella immunization program.

- Mandate vaccination for all pre-pubescent females through a school-based program conducted under the auspices of the National Center for Disease Control.
- Create a model code for state marriage license serologic screening practices with the objective of including an additional test for the presence of rubella antibodies.
- Conduct an appeal through the mass media and professional medical publications to encourage all childbearing females to obtain such tests from their private physicians. The decision to proceed with vaccination, in the estimated 15 percent thought not to be naturally immune, then becomes a uniquely determined one between doctor and patient.
- Conduct periodic studies of reinfection rates among vaccinated and naturally immunized populations to determine whether the efficacy of the initial, massive rubella immunization program is sustaining or not.

The first recommendation represents a reduced but more tightly focused extension of the national rubella immunization program. With continuous application, all of the at-risk population will be protected in the long term. Prepubescent restrictions for administration of the vaccine minimize the danger of arthritic complications and not selecting male children confronts the breakdown in herd immunity noted by Klock and Rachelefsky; for males, contracting the disease may present fewer and less severe risks than possible complications of adverse reactions to the vaccine.

Given that on the order of 4 million live births per year were recorded in the decade between 1960 and 1970,41 about 2 million vaccinations per year would be needed to reach the entire at-risk population on an annual cohort basis. At current costs of $0.47 per dose,52 total vaccine costs would be around $1 million per year in the long run. Even at $5.00 per dose, the costs of $10 million per year would be small relative to savings in later service costs for handicaps not prevented.

The second recommendation is more an identification plus prevention service than it is a purely preventive one. Blood tests for syphilis are required in most states

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50 National Center for Disease Control, "Rubella Virus Vaccine: Recommendation..."  
already, and the test for rubella antibodies is rather easily and inexpensively done at the same time. Provision to test women for the rubella antibodies has been enacted into law in California in the form of Senate Bill 1002, approved in August 1972.\textsuperscript{48} Briefly, the law requires, with several exceptions, a physician’s certification that in addition to being free from syphilis, all female marriage license applicants have been tested for an immunological response to rubella. Nothing beyond informing the woman is contained in the law, but presumably positive identification could result in advice to consult a private physician about the possibility of obtaining a vaccination.\textsuperscript{44} The law itself represents a “natural” social experiment involving a state with 10 percent of the nation’s population, and deserves to be evaluated as such, to assist other states considering following suit with versions of the same legal provision. The possible damage in an unsuspected pregnancy by administration of the rubella vaccine is known to be great. It is also known that the virus is often long-lived, which means that any childbearing female should not become pregnant for at least two months after receiving the vaccine.

Our third recommendation stresses the private physician’s role, as opposed to a direct governmental one, in reaching childbearing women who are either unmarried or already married and hence would be missed in a screening of marriage-license applicants.

The issue of reinfection rates is not settled, but warrants careful surveillance. The rubella vaccine has been in widespread use in the United States less than five years, certainly insufficient time to establish its long-term persistence with great reliability.

**Rh Sensitivity Immunization.** Development and use of the Rh desensitizing gamma globulin has resulted in a reduction of newborn jaundice, and with it a reduction in the associated hearing disorder erythroblastosis fetalis. However, the RhoGAM must be administered within 72 hours after the Rh-negative mother has terminated pregnancy of an Rh-positive child to prevent sensitization and subsequent threat to children born later. Blood-typing and antibody screening are considered an important part of effective prenatal care, and based on the bilirubin levels obtained in amniocentesis (when indicated), specific management procedures of mother and unborn child may be required.\textsuperscript{48} Immunization, typing, screening, evaluation, and management are all elements of responsible preventive care. The extent of reduction in handicapping resulting from having this kind of care widely available is not known, but is clearly significant.

**Routine Immunization.** Modern standards of pediatric practice call for a routinized immunization program such as the representative schedule approved by the Committee on Infectious Diseases of the American Academy of Pediatrics (Table 6.4). Exact timing and sequencing are matters left to the physician’s discretion.

Following such a schedule increases protection against a number of formerly devastating diseases. Of the group, measles, mumps, and rubella have all been


\textsuperscript{44} The California blood test law also contains a reference to possible use of the serologic specimen for identification of “carriers of genetic diseases, including, but not limited to, sickle cell anemia and Tay-Sachs disease, and that such tests may be performed at the same time as those tests required in Section 4300.” Deering’s Code, p. 23. The implications of this law are potentially far-reaching, a point discussed in a following section on “Genetic Counseling.”

Table 6.4
REPRESENTATIVE IMMUNIZATION SCHEDULE

<table>
<thead>
<tr>
<th>Age</th>
<th>Immunization</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 months</td>
<td>1. Diphtheria, tetanus (toxoids), and pertussis (antigen) combination injection (DTP)</td>
</tr>
<tr>
<td></td>
<td>2. Trivalent oral polio vaccine (TVOP)</td>
</tr>
<tr>
<td>4 months</td>
<td>1. DTP</td>
</tr>
<tr>
<td></td>
<td>2. TVOP</td>
</tr>
<tr>
<td>6 months</td>
<td>1. DTP</td>
</tr>
<tr>
<td></td>
<td>2. TVOP</td>
</tr>
<tr>
<td>1 year</td>
<td>1. Measles</td>
</tr>
<tr>
<td></td>
<td>2. Tuberculin test</td>
</tr>
<tr>
<td>1 to 12 years</td>
<td>1. Rubella vaccine(^a)</td>
</tr>
<tr>
<td></td>
<td>2. Mumps vaccine</td>
</tr>
<tr>
<td>1(\frac{1}{2}) years</td>
<td>1. DTP</td>
</tr>
<tr>
<td></td>
<td>2. TVOP</td>
</tr>
<tr>
<td>4 to 6 years</td>
<td>1. DTP</td>
</tr>
<tr>
<td></td>
<td>2. TVOP</td>
</tr>
<tr>
<td>14 to 16 years</td>
<td>1. Tetanus and diphtheria toxoids (adult form). At this age and every ten years thereafter.</td>
</tr>
</tbody>
</table>

\(^a\)See comments in above section on rubella.

Implicated in sensory handicapping, and faithful adherence to a basic immunization program should ensure prevention at a relatively high level.

However, as noted earlier in this chapter, evidence indicates that general and proper adherence to such a schedule is not always forthcoming, especially for rural and central-city children. The long-term benefits achievable under preventive programs, such as those contained in the Vaccination Assistance Act of 1962 and recent extensions and amendments to that act, should not be forgone in the interests of short-term economies. Public Law 91-464 in particular has some creative and interesting possibilities for comprehensive and significant prevention of many sensory handicaps, e.g., those associated with rubella, measles, venereal disease, mumps, and Rh Sensitivity, among others.\(^56\)

Identification, Direction, and Medical Treatment

Previous chapters have stressed the need for early identification, appropriate direction to servers with requisite skills, and skillful medical treatment of the underlying disorder. Details of those discussions will not be repeated here; however, adequate provision of these services has a distinct preventive component.

While one cannot precisely estimate the reductions in handicapping that improvements in these services bring about, the effects are certainly positive. In principle, such improvements could reduce the handicaps attributable to the majority of the different types of sensory disorders. From a preventive viewpoint, the problem

is not inadequacy of technical knowledge and skill, but a problem of promptly identifying children in need and putting them in touch with the considerable medical-technical expertise that already exists. To the extent that society can solve that problem, a remarkable number of lifelong sensory disorders are, in the strictest sense of the word, preventable.

To realize some of these benefits, we urge the adoption of all previous recommendations made with respect to identification, direction, and medical treatment services (Chapters 3, 4, and 5).

Early and correct identification of potentially handicapping conditions is perhaps the single most important and underrated service in the array of potential prevention strategies. It is the keystone in a truly comprehensive and effective program for the handicapped. Early identification also has a distinct, but ill-appreciated, preventive component: it increases the likelihood that cause and outcome will be known and properly associated, and that early warning will be given of changes in causes of handicapping in the total population. The implications for improved prevention research and operations are clear.

A related prevention strategy is to avoid providing types of medical treatment that can cause or exacerbate handicaps. We have already discussed two types of treatment to be either avoided when possible or judiciously used otherwise: administration of ototoxic drugs, such as quinine and certain antibiotics in the mycin group, possibly resulting in damage to the auditory nerve; and administration of excessive oxygen to premature infants, possibly resulting in retrolental fibroplasia (see Chapter 5).

Family Planning

Family planning is another general preventive strategy that can reduce handicapping. While relationships between the likelihood of mental impairment in the infant, the age of the mother, and the total number of children produced have been established (Table 6.5), similar demographic analyses have not been carried out for the sensorially handicapped, as far as we can determine. One may only surmise that family planning practices, such as having only two children and only at maternal ages between 20 and 34, could have some positive, but inestimable, effect on the prevalence of sensory handicaps in the overall population.

| Table 6.5 |
| Relationship between Mental Deficiency and Maternal and Fetal Factors |

<table>
<thead>
<tr>
<th>Birth Order</th>
<th>Ratio of Observed to Expected (percent)</th>
<th>Maternal Age</th>
<th>Ratio of Observed to Expected (percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>52</td>
<td>Under 20</td>
<td>121</td>
</tr>
<tr>
<td>2</td>
<td>92</td>
<td>20-24</td>
<td>95</td>
</tr>
<tr>
<td>3</td>
<td>135</td>
<td>25-29</td>
<td>88</td>
</tr>
<tr>
<td>4</td>
<td>143</td>
<td>30-34</td>
<td>95</td>
</tr>
<tr>
<td>5</td>
<td>268</td>
<td>35 and over</td>
<td>146</td>
</tr>
</tbody>
</table>

Genetic Counseling

Hereditary factors are known to be important determinants of the number of hearing and vision handicapped children in the total population. Chung and his associates have estimated, for example, that about half the cases of profound hearing impairment can be traced to genetic origins. And over one-half of the cases added to the Model Reporting Area "legal blindness" registers in 1969 and 1970 for youth aged 19 and under were listed as owing to "prenatal influence," indicating the hereditary importance of many visual disorders. Some 50 defined syndromes have been associated with hereditary hearing loss, and numerous visual disorders are similarly characterizable.

Such factors generally indicate that more attention should be given to genetic screening and research into the hereditary hearing and vision handicaps. The establishment of an accurate genetic diagnosis, according to W. E. Nance,

is a prerequisite for rational counseling, which in turn can prevent the tragedy of a second affected child. Because of the extensive heterogeneity that exists among the various types of hereditary deafness, the risk of affected children for deaf couples is often quite low, but again, reliable prediction depends upon an accurate diagnosis. Specific remediation is possible for some forms of hereditary deafness, and future research will undoubtedly bring to light new types for which effective treatment and even prevention or cure is possible.

While the future trend may include increased genetic counseling, including the taking of blood and tissue cultures for chromosome morphology, many significant difficulties must first be surmounted before this form of preventive service can realize its potential in widespread use.

Experience with a national genetic screening program to detect sickle cell anemia, perhaps the largest-scale genetic screening and counseling program in existence, has shown that the underlying intentions of those running the program are not necessarily shared by those being screened and that the unanticipated, and frequently negative, consequences of the program bear some serious consideration.

- Mass screening has indicated that the issues related to public education, community relations, and the private lives of the identified trait-carriers are in need of resolution.
- The identified individual's reactions are not always positive and favorable.
- Community resistance is more common and far greater than any of those responsible for the program had expected.


\[^{60}\] See Chapter 5 of this report.


There is a real danger that those identified as carrying the trait will suffer from the stigma associated with that finding. (See Chapter 4 on problems of identification.)

- The eugenic implications of the entire program loom large and are far from being resolved.

Other reports on genetic screening programs have similar messages. For example, Leonard and associates report that for a study sample of parents having had children with cystic fibrosis, phenylketonuria, and Down’s Syndrome, only about one-half had "a good grasp of the information given, 1/4 gained something, and 1/4 learned very little," as a result of genetic counseling. The problem appeared, in this case, to be related to the skills of the physicians who participated in the counseling program, among other reasons. The information level attained by parents is critical in determining whether and how such knowledge will be used in making decisions about having additional children. Exacerbating the decisionmaking process are religious concerns, emotional conflicts between the parents, and a general lack of understanding of genetics and the probabilities associated with subsequently producing handicapped offspring.

The general issue of genetic screening and counseling represents a clear instance of technology's having outpaced society's ability to use, accept, and cope with the technology. Many persons, fortunately, are becoming concerned with some of these implications, although the day when effective, widespread prevention of handicapping through genetic screening and counseling practices overtakes us still seems remote. Ethical, societal, and practical political questions are at least discernible.

On the ethical and social dimensions, a distinguished group under the leadership of Marc Lappé, of the Institute of Society, Ethics, and the Life Sciences has mapped the roughest contours of the hazardous terrain confronting society in the general area of genetic screening. Among the many thorny issues raised in this report, the following appear especially salient with respect to the longer term prospects for preventive practice.

- Does information obtained by genetic screening fall outside the normal confidentiality provisions enjoyed in the traditional doctor-patient relationship?
- What is the relationship between adverse genetic information and the remedial actions implied in such information? This issue is at the heart of the unresolved debate on the legality and morality of abortion, among other things.
- What are the deep scientific and human implications of programmatic objectives of any genetic program?
- How can the quality of test and screening instruments be assured to avoid the multiple pitfalls and human costs associated with misidentification?
- What compulsive measures are implied in the true positive identification of a parent pair likely to produce "defective" offspring? The Lappé group states unequivocally: "As a general principle, we strongly urge that no screening program have policies that would in any way impose constraints on childbearing by individuals of any special genetic constitution, or would stigmatize couples

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who, with full knowledge of the genetic risks, still desire children of their own." 

- What provisions can be adopted to insure informed consent of the participants in any screening program?
- How can participants be adequately apprised of the risks involved in possible psychic and social injury?
- Should the purposes and objectives of the screening program be made publicly available?
- Have competent counseling provisions been developed in advance of the screening activity to provide follow-up information and service to those thought to have a potential for parenting genetically handicapped offspring?
- How can rights of privacy be insured?

The general tone of the report and the guidelines promulgated is one of cautioning about the extreme potential risks and costs involved in a genetic screening program.

We are concerned about the dangers of societal misinterpretation of similar conditions and the possibility of widespread and undesirable labeling of individuals on a genetic basis... protecting the confidentiality of test results will not shield all such subjects from a felt sense of stigmatization nor from personal anxieties stemming from their own misinterpretation of their carrier status. Extreme caution should therefore be exercised before steps that lend themselves to stigmatization are taken . . . .

The cautionary theme is carried several steps further in a recent paper by Breyer and Zeckhauser. They argue not only that there should be no federal control of genetic programs, but that such involvement might force issues and decisions to the surface that are better left submerged. For instance, popular belief holds that it is the physician’s role to preserve life, while at the same time, as individuals, we are vaguely aware that in given situations a doctor may allow a newborn child to die, e.g., a “monster infant.” While most doctors probably would not engage in questionable practices, and those few who do are undoubtedly under great stress, the authors ask whether it would be wise to force a legislature to set rules and regulations for such situations. In the words of those authors, “Can we not in some individual cases permit ethical decisions to kill, although we would forbid them were they to become elevated into the general consciousness through formulation of a legal principle?”

In the absence of any simple answer to this and other disturbing questions, Breyer and Zeckhauser counsel for caution on the part of the federal government, advice which seems appropriate under the current circumstances.

At this time, the outline of genetic engineering problems can be seen only dimly, if at all. Proposals to institute formal regulatory procedures in this area, for example to license or forbid varieties of genetic research, must be viewed with suspicion. On the other hand, it would surely seem appropriate for the federal government to stimulate increased study of, discussion of, and

66 Ibid., p. 1130.
67 Ibid., p. 1132.
69 Ibid., p. 8.
concern about the problems of social and genetic engineering. But this would seem to be the present limit of prudent . . . government control.70

Abortion and Other Practices

Abortion is a difficult topic related to genetic counseling. Were a genetic screening, counseling, and diagnosis service to exist, abortion would be an obvious option following true positive identifications through amniocentesis or in utero assessment techniques yet to be developed and perfected.

With respect to rubella detection, one preventive technique reported by Ruben as being practiced in Scandinavia is that

the expectant mother has a blood titre drawn at the beginning of her pregnancy and again at the end of the third month of the pregnancy. If the rubella titre has become elevated during that time, she is advised of the possibility that she may have had a sub-clinical infection of rubella. A decision can be made at that time as to whether or not the pregnancy should be continued.71

While recent court decisions have helped clarify abortion as a medical practice, the case is far from closed. In an assessment of the practice made in 1969, Beck and her associates stressed many important research issues, several of which had clear policy implications.72 The discussion and the research issues appear to have continuing validity.

Prevention of handicapping via sterilization as a family planning practice is, if anything, an even more controversial subject—a point underscored in recent revisions and clarifications of Department of Health, Education, and Welfare guidelines on the practice in federally funded programs.73


Recent sensational revelations to the effect that pediatricians in charge of an infant intensive care unit at the Yale-New Haven Hospital had given some 43 seriously deformed and impaired infants the "right to die," deserve mention as perhaps a logical-moral limit in preventive strategies. The magnificent life-saving technologies that have greatly improved medicine in the last decade or so have brought with them moral and ethical questions that demand full and humane inquiry. Should a severely impaired infant be allowed to die? Bound up in this chilling question are other imponderable issues: What constitutes "severely impaired"—that is, whose definition is to prevail? Will improved technology force this definition to change over the years to the point where a relatively "minor" impairment by 1974 standards, such as a hearing or vision defect, becomes a "severe impairment" by the standards of a few decades hence? Who decides if and when the child should be allowed to die? How is one able to certify that the infant's "right to die" has been guaranteed, in the argot of the current euphemism?

It is not at all clear how these issues will be resolved, or even if they will be resolved, but they are demanding increased humane attention. As with genetic counseling, if there is to be a governmental role at all outside the courts, prudence seems to dictate that it be confined to research—not allowed to intervene in control or operations.

*The disclosure has attracted widespread public attention. See, for example, "43 Deformed Infants Given 'Right to Die'," *Los Angeles Times*, October 27, 1973.*