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AUTHOR	Gallagher, James J.; And Others
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ABSTRACT

In Part H of Public Law 99-457, the Federal Government agrees to provide modest financial resources to aid the states in planning and developing comprehensive, multidisciplinary, coordinated services for young children with handicaps and their families, and presents mandates for reforms in the service delivery system. This paper identifies the major state policy issues presented by the legislation and some of the options for addressing these issues. General policy issues that are raised by the broad scope of the legislation include: state policy-making responsibilities; coping with the diversity of clients, professionals, agencies, and personnel; state readiness; and long-term financial support. Six specific policy areas dealing with various aspects of the law are also discussed: definition and eligibility criteria, meeting personnel requirements, assuring involvement of families, obtaining finances, coordinating services, and designing data systems. For each specific policy area, the issues involved are discussed and possible options are presented for solution of the issues. (JDD)

Carolina
Institute
for Child
and Family Policy

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JAMES J. GALLAGHER
GLORIA HARBIN
DAPHNE THOMAS
RICHARD CLIFFORD
MARTA WENGER

The University of North Carolina
at Chapel Hill

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MARTA WENGER

Carolina Institute
for Child and Family Policy
300 NCNB Plaza
Chapel Hill, NC 27514
(919) 962-7374

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The passage of P.L. 99-457, The Education for the Handicapped Amendments of 1986, represents one of the more imaginative and challenging pieces of legislation that has been passed by the Congress in the past several decades. It was clearly designed to close a gap left in P.L. 94-142, The Education for All Handicapped Children Act, passed in 1975, which omitted provisions for needed services for children with handicapping conditions from birth to age 3. (Garwood, 1988; Trohanis, 1988)

In Part H, P.L. 99-457, the federal government agrees to provide modest financial resources to aid the states in planning and developing comprehensive, multidisciplinary, coordinated services for young children with handicaps and their families. In exchange, it also presents some clear mandates for certain reforms and changes in the service delivery system (Harbin & McNulty, in press). Instead of merely providing more resources for the professionals to continue to do what they have been doing (i.e. in the areas of personnel preparation, service delivery, research), this law, requires several meaningful changes in how the professionals and agencies are expected to deliver services to children and families.

The purpose of this paper is to identify the major state policy issues that this new legislation presents to the various professions and agencies involved, and some of the policy options for addressing these issues. There are general policy issues that are raised by the broad scope of the legislation itself and specific policy issues dealing with various aspects of the law (i.e. finance or eligibility), and they will each be discussed in turn.

This legislation is impressive in its scope. Its impact will likely be felt in every state and local agency that has responsibility for providing early intervention services for children with handicaps and their families (Smith & Strain, 1988). It will also influence other related entities - universities, hospitals, research centers, and other social institutions that play supportive roles to the service personnel. Figure 1 displays the scope of the influence of this legislation which involves local, state and federal governments as well as the private sector. The shaded areas represent specific problem areas being addressed by the Carolina Policy Studies Program.

The passage of legislation often represents the end of a long road of effort by those who saw an unmet need and wanted to do something about it. (Gallagher, in press). The implementation of this legislation is the beginning of an attempt to breathe practicality and reality into the words and concepts in the legislation. It is that beginning, the process of federal legislative implementation, that is so important to eventual success that we wish to explore here.

GENERAL POLICY ISSUES

A number of broad issues are raised by this legislation. Each state must grapple with these issues in the process of implementing this law. These issues include:

STATE IMPLEMENTATION of P.L. 99-457 (Part H)

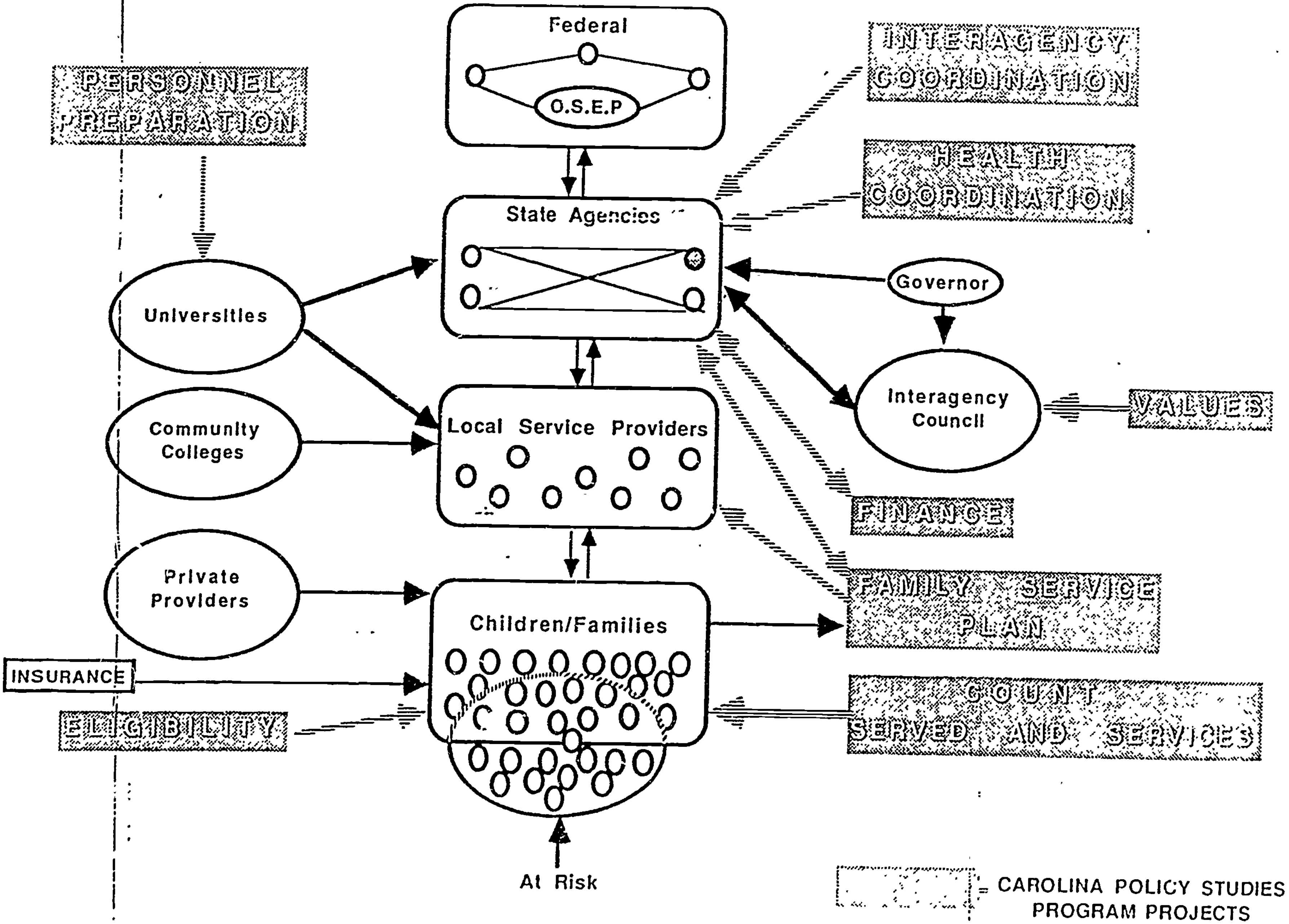

FIGURE I

state policy making responsibilities, coping with the diversity of clients, professionals, agencies and personnel, state readiness and long term financial support. Each of these will be discussed briefly.

State Policy Making Responsibilities.

Some federal laws are prescriptive and the problems of state and local authorities are how to match federal guidelines and regulations with a variety of local circumstances. Although the regulations for Part H, P. L. 99-457 are still not written, as of this date, the law itself gives considerable freedom and responsibilities to the states (Garwood, Fewell, & Neisworth, 1988). It calls for the state to identify its own lead agency that will be administratively responsible for this program. The law calls for multidisciplinary and interagency cooperation but is vague on how that should be done (Harbin & McNulty, in press). It directs each state to define developmental delay, to specify what type of professional standards would be established, develop its own reporting systems and to devise financial coordination strategies. It encourages the states to empower the parents without suggesting precisely how that should be done. It requires professionals and agencies to focus on the family instead of just the child through the use of the Individual Family Service Plan.

The first major policy issue then is how to transform the existing, but often fragmented service delivery system, into a coordinated and comprehensive system required by

TABLE 1

MINIMUM COMPONENTS OF A STATEWIDE COMPREHENSIVE SYSTEM FOR THE PROVISION OF APPROPRIATE EARLY INTERVENTION SERVICES TO INFANTS AND TODDLERS WITH SPECIAL NEEDS

1. Definition of developmentally delayed.
2. Timetable for all in need in the state.
3. Comprehensive multidisciplinary evaluation of needs children and families.
4. Individualized family service plan and case management services.
5. Child find and referral system.
6. Public awareness.
7. Central directory of services, resources, experts, research and demonstration projects.
8. Comprehensive system of personnel development.
9. Single line of authority in a lead agency designated or established by the governor for implementation of:
    a. General administration and supervision.
    b. Identification and coordination of all available resources.
    c. Assignment of financial responsibility to the appropriate agency.
    d. Procedures to ensure the provision of services and to resolve intra- and interagency disputes.
    e. Entry into formal interagency agreements.
10. Policy pertaining to contracting or making arrangements with local service providers.
11. Procedure for timely reimbursement of funds.
12. Procedural safeguards.
13. Policies and procedures for personnel standards.
14. System for compiling data on the early intervention programs.

federal legislation. This is one major task to be carried out, through extensive planning efforts, by the states. The fourteen minimum components of that statewide comprehensive system are noted briefly in Table I.

Coping with Diversity - Children and Families.

One difficulty inherent in policy development for a diverse group of citizens is that a rule that might be highly appropriate for many families can turn out to be highly inappropriate for others. How does one write policy to fit the diverse circumstances that families find themselves in? The common denominator in this legislation is that all of the families involved have a young handicapped child, or a child at risk for handicapping conditions, but that brings only a limited amount of communality to the group. Beyond that, there is a wide range of family differences in socioeconomic status, marital status, cultural background, geographic location, family values, attitudes and interests. Additional evidence of diversity is the degree of stress that the presence of a handicapped child can cause within the family unit (Wikler, 1986; Bristol, Gallagher & Schopler, 1988). The coping strategies that work for one family may not be appropriate for another. Policy has to be flexible in the face of such diversity.

Coping with Diversity-Personnel.

There are additional evidences of diversity in the range of professionals participating in the program. There are at least 10 major professions that will be expected to participate in service delivery to infants and toddlers. Each of these professions carries its own pride, special skills, traditions and history, and, all too often, a record of indifferent cooperation with other professions. The legislation expects substantial cooperation among these professionals, leading to effective multidisciplinary service delivery. However, the diversity of approaches among the professions is likely to present a challenge in implementing several aspects of this legislation (e.g. case management, interagency coordination and individual family service plans, etc.).

Coping with Diversity-State Readiness.

A final significant level of diversity lies in the level of state readiness and willingness to implement this legislation as well as the financial capabilities to pay for it (Harbin, 1988). Some states have existing legislation to serve children with handicaps from birth, while other states are approaching this responsibility as an essentially new and untried idea (Meisels, Harbin, Modigliani & Olsen, 1988). With the uneven distribution of wealth and available professional resources among states, it will be difficult for states to model their regulations after each other. Such diversity also may make policy development and implementation more difficult in states which lack experience or financial, or personnel resources to conduct adequate or realistic planning.

It is clearly understandable why it takes so long for guidelines or regulations to be written either at the federal or state level. It is not bureaucratic incompetence that causes the delay, in all likelihood, but rather a very human desire to try and find some viable compromise between many different options, each of which has advantages and disadvantages.

Long Term Financial Support.

One of the potentially limiting factors affecting the entire legislation, is the degree of commitment for fiscal support required from all levels of government (Gallagher, 1975; Smith & Strain, 1988). Because of the numerous uncertainties in implementing this policy, (e.g. The number of eligible children; the levels of services to be provided;) it is difficult to estimate the full cost of implementation. There are, however, few persons who think the cost will be small, or that the goals of the legislation can be met solely by reshuffling existing funds although some states are redesigning their service systems. Will the federal government increase its financial commitments? Will the states find additional fiscal resources? In a time of fiscal restraint, there must be some signal given by political leaders that we (the citizens of the U.S.) are ready to bear the financial responsibilities for this law.

SPECIFIC POLICY ISSUES

In addition to these broad policy issues which must be addressed in the implementation of P. L. 99-457, there are a variety of specific issues worthy of discussion, six of which will be addressed in this section. They are (1) definition and eligibility criteria; (2) meeting personnel requirements; (3) assuring involvement of families; (4) obtaining finances; (5) coordinating services and; (6) designing data systems. For each we will provide some issues and possible options for solution of the issues.

Definition & Eligibility Criteria

Who are the Eligible Children? One of the major issues when funds are allotted to a subpopulation with special needs is whether the correct people, and only the correct people, are receiving the necessary services. Auxiliary concerns focus upon who within this group will get scarce resources, and whether all of the eligible children will receive services.

This legislation requires states to develop their own definition for "developmentally delayed". This definition needs to include both handicapped infants and toddlers, as well as those who have been determined to possess a condition which has been established to have a high probability of resulting in a developmental delay (e.g. Down Syndrome).

The legislation leaves to the discretion of each state whether to include infants and toddlers who are "at risk" for developing a handicapping condition if early intervention services are not provided. If states wish to include "at-risk" children, which "at risk" children should be included? Does the "at-risk" category define only medical risk conditions (e.g. low birth weight) or environmental conditions (e. g. poverty combined with family disorganization and stress, children of substance abusers, etc.), which place children at risk, as well? This provision of the law regarding 'at risk' children is a recognition that it is often difficult to identify definitively who is a handicapped child at this young age. By the time we can do so with some certainty, important time has been lost for the application of a potential treatment program, or in taking preventive steps.

In a survey conducted in January 1988 (Gallagher, Harbin, Thomas, Wenger, & Clifford, 1988) eighteen states indicated that they were considering the inclusion of some "at-risk" children. The issue of whether funds actually will be available to serve the 'at risk' population may be a major factor influencing states' decisions.

How large or how small to draw the circle of inclusion? This is one of the most critical policy decisions facing states; for many of the other policies related to finance and personnel depend upon how the state addresses the issue of eligibility.

The inclusion of "at risk" children under P.L. 99-457 is understandable in terms of the difficulty of extending the traditional definitions of handicaps downward to the very youngest children. It represents a significant conceptual shift from P.L. 94-142 which insisted on a clear definition of handicapped before services could be delivered. The new law clearly gives the states the option to limit or expand the definition of young handicapped children.

The policy question this raises is, will these limited resources be directed toward the severely handicapped or will those resources be divided among a larger group of children and families, some of whom might be "at risk" rather than definitively handicapped?

The flexibility of this provision in allowing each state to define "developmental delay" and decide whether to include infants and toddlers "at risk", poses problems for both parents and the federal government. The question arises for parents who may need to change residence, is their infant/toddler eligible for services in one state, but not another? If my child is defined as handicapped in the ages of birth through 2 years, will she still be identified as handicapped (and receive services) in ages 3-5? How can federal policymakers answer the question, "How many children are developmentally delayed?", when the definitions may vary across states?

Those charged with addressing this policy issue in each state (e.g. the Interagency Coordinating Council and/or the lead agency) may want to consider the following policy options generated by the authors. It is not an inclusive list but represents what we feel to be some of the options available to most states.

Some possible policy options to consider are:

1. Include developmentally delayed and established handicapped children only;
2. Include developmentally delayed, established handicapped, and those with 'biological risks' (all);
3. Same as #2 above, but only some subgroup of the 'biologically at risk' - not all;
4. Include developmentally delayed, established handicapped, and those who are at environmental risk - (all);
5. Same as #4 above, but only some subgroup of the environmentally at risk - not all;
6. Include developmentally delayed, established risk, biologically at risk, and environmentally at risk (all);
7. Include developmentally delayed, established risk, and some limited portion of both biologically and environmentally at risk.

Each of these options carry with them many finance, personnel, and interagency consequences which will be dealt with more thoroughly in a forthcoming CPSP paper.

What Criteria Can Be Established To Determine Delay or 'At Risk? How does one translate a conceptual definition into an operational procedure? The distinction between those who have handicaps and those who do not, has always been a difficult task at the margin. Whether the designation was mental retardation, emotional disturbance, learning disability, or communication disorder, the fine line between inclusion or exclusion of a given child in the category, and for service eligibility, has bothered professionals for many years. The movement towards noncategorical designations does not change the situation substantially. There is still the task of distinguishing who is and is not 'handicapped', or who is and is not 'at risk'.

We need eligibility criteria which are as psychometrically sound as possible, professionally defensible, and feasible to implement. In determining developmental delay the law requires states to use appropriate instruments and procedure to determine 'delay'. Inclusion as an 'at risk' child is likely to be based upon some characteristics of the child (e.g. low birthweight) or the environment (emotionally disturbed parent) which places the child at risk for developmental delay. For many children the use of a norm-referenced assessment device to determine the existence of a delay will be necessary. States must then decide how much of a developmental delay an infant-toddler must exhibit, a -1, -1 1/2, or -2 standard deviations. Must this delay be in one or more areas of development?

Of particular concern are those states who are considering the use of a percentage of delay (i.e. 25% delayed) as part of their eligibility criteria. A preliminary analysis of a sample of draft definitions conducted by Gloria Harbin of the Carolina Policy Studies Program staff revealed that the use of the percentage of delay ranged widely from state to state (15%-50%). The question must be asked, is this use of percentage of delay sound and defensible? There is the additional issue of whether those assessment instruments currently available are even constructed so as to be scored and interpreted in this manner.

While the use of norm - referenced assessment devices may be helpful in the identification of some developmentally delayed children, there are certain types of handicaps and conditions which may not be identified in this manner. The challenge facing states in policy development is how to develop defensible criteria to establish eligibility for these conditions. Will professional judgement or diagnosis be included as one of the criteria? If so, for which conditions or handicaps?

For those states including "at risk" children the policy issue relates to which "at risk" children should be included. What level of criteria will be used for each characteristic? For example if a state decides to include low birthweight children, where will they draw the line of inclusion - 1000, 1500, or 2000 grams? If they decide to include prematurity, how premature must an infant be? Lastly, will the state decide that some "at risk" characteristics are more serious than others or that a child needs to have multiple risk characteristics to be included. Thus, if a state wishes to include "at risk" children there are several critical decisions to be addressed concerning the selection of criteria to determine risk.

As states grapple with this critical policy issue of eligibility criteria that are psychometrically sound, professionally defensible and feasible to implement, some possible policy options to consider in the policy selection and development process are:

1. Use of the same standard deviation standard from normal development regardless of the number of areas delayed; (motor, language, social, perceptual,)
2. Use of standard deviation standards which may vary with the number of developmental areas delayed (e.g. -2 standard deviations in one area, or -1 standard deviation in 2 or more areas);
3. Use of percentage of delay standard, utilizing only those instruments designed to be scored in months (the percent delay standard would be the same regardless of number of developmental areas delayed);
4. Use of percentage of delay standard, utilizing only those instruments designed to be scored in

months (the percent delay standard would vary with number of developmental areas delayed);

5. Use of a set of behavioral descriptors to indicate delay;
6. Use of professional judgment/diagnosis;
7. Use of special criteria to determine "at risk";
8. Some combination of above options.

There are other policy issues related to the development of definition and eligibility criteria in the development of a statewide system of coordinated, comprehensive, multidisciplinary, interagency services to infants and toddlers who are handicapped or at risk of developing handicaps. These issues will be noted briefly.

<u>Additional Definition - Eligibility Policy Issues</u>

1. How much guidance will states offer to local service providers concerning the assessment instruments and procedures to be used in determining eligibility for early intervention?
2. Once a definition is developed, what will states do about existing conflicting policies which may be based on state legislation or other federal legislation?
3. Will the definition for children 0-3 and children 3-5 be the same or different and, if different, how can the state deal with the transition consequences?
4. Once the definition and eligibility criteria have been developed, how do agencies set up procedures and select devices whose sensitivity and specificity are adequate

(e.g. procedures which don't over refer or under refer)?

Qualified Personnel Needs

What Are The Manpower Needs For This Program? One of the most significant components of the proposed program would be an adequate supply of well prepared personnel to provide quality services for infants and toddlers with handicapping conditions and their families. In a national study of policies concerning young children with handicaps, Meisels, Harbin, Modigliani, and Olsen (1988) reported that the lack of qualified personnel was one of the most serious policy issues facing states in the provision of services to infants and toddlers with handicaps. Over 68% of the states reported that they lacked sufficient personnel preparation programs; over 80% are now reporting shortages of trained early intervention personnel and nearly 100% are experiencing a shortage of therapists. Given the substantial shortage of qualified personnel to serve in these programs, different patterns of service delivery using less trained personnel (i.e. day care center personnel, paraprofessionals etc.) may have to be considered.

A related issue is, what are the incentives for persons in these professions to work with infants and toddlers and their families? In some of these fields, such as occupational and physical therapy, there appear to be more attractive and more financially rewarding positions available in other areas of service delivery. What policies can be established to lure professionals into this field?

The needs of infants and toddlers for multidisciplinary services puts a special responsibility on the various areas of personnel preparation. Few of the eight to ten disciplines involved have existing special preparation programs for personnel to work with infants and toddlers and few have training programs that focus upon families or upon multidisciplinary roles or responsibilities. The qualified personnel fields that the law sees as necessary for effective infant/toddler family intervention services are: audiologists, nurses, nutritionists, occupational therapists, physical therapists, physicians, psychologists, social workers, special educators, and speech and language pathologists. The medical services that are to be provided are limited to those services necessary to enable a child to benefit from other early intervention services and do not include general treatment or surgery. A number of adaptations or changes in personnel preparation will obviously need implementing if these new expectations for multidisciplinary teamwork are to be met.

<u>Some possible policy options to consider are:</u>

1. Increase existing professional preparation programs;
2. Increase the number of preservice and inservice training programs;

3. Embark upon a reprogramming effort for existing working personnel with continuous inservice.
4. Focus upon less highly educated personnel (e.g. day care workers, paraprofessionals) to meet service needs.
5. Provide specialized training for child care personnel to work with children with handicaps.
6. Demonstrate and promote new interdisciplinary personnel preparation models;
7. Provide financial incentives to encourage individuals to enter these professions (e.g. increased salaries and stipends);
8. Require new personnel preparation models (for case managers, paraprofessionals, etc.) be developed to meet the needs of alternative service models.

How Can Appropriate Standards for Professionals be Developed?. The law (P.L. 99-457) in this instance encourages the establishment and maintenance of standards such as certification, licensing, registration, across the various professions which would be involved in service delivery. Each state is expected to provide a plan by which persons not meeting those standards would be upgraded in skills and competencies in order to reach an appropriate standard.

There are a number of distinctive policy issues related to the development of adequate standards across disciplines. To what extent do these various professions have standards (state, federal, professional association?) that adequately apply to the area of infants, toddlers, or families? What is the availability of personnel in each of these 8-10 disciplines? There is a strong feeling that many of these disciplines are already suffering from a shortage of qualified personnel to serve the needs of existing populations. Increasing the responsibilities of training institutions to include infants and toddlers may merely compound that shortage unless some positive steps are taken to prepare additional personnel, or include the use of paraprofessionals in state planning, since the raising of professional standards almost always creates a shortage of highly qualified personnel even in the best of circumstances.

<u>Some possible policy options are:</u>

1. Use national professional standards when available (e.g. speech language pathologist);
2. Develop state standards specific to infants and toddlers for each discipline;
3. Develop state standards specific to birth through five year olds for each discipline;
4. Adapt standards developed for professionals working with school-age children with handicaps;
5. Raise standards but "Grandfather in" existing personnel;
6. Raise standards but provide a period of time for existing personnel to obtain certification;

7. Develop standards which apply to all professionals;
8. Use a competency-based approach to certification.
9. Include standards for various levels of personnel involved in service delivery (i.e. Child Care or Paraprofessionals).

Are There Sufficient Personnel Preparation Programs? Another key policy issue is, how ready and willing are the established institutions; universities, hospitals, or schools to prepare a new generation of specialists? Does a totally new program have to be established, or can the general professional preparation in these professions, with some minor adjustments, take care of the problem? Should professionals trained to serve children or adults attempt to transfer their skills to infants and toddlers without obtaining some additional education and supervised experience?

Finally, what level or rate of attrition does one find in these various professions? There is a general feeling that there is substantial turnover in these early childhood programs and this attrition figure has to be added to the existing personnel shortages in order to plan for sufficient resources to prepare adequately the needed personnel. There would seem to be little doubt that manpower needs may be one of the most severely inhibiting forces to the full development of the program, unless substantial attention and resources are paid to these issues.

There are a number of policy options that might be considered in developing of personnel preparation programs;

1. Develop a statewide plan by which inservice programming is available to upgrade existing personnel on matters of infant/toddler/family service delivery.
2. Develop a statewide plan in cooperation with higher education institutions, dividing the training responsibilities with agencies.
3. Provide subsidies to higher education to help establish an emphasis in the infant/toddler/family area.
4. Provide scholarships for students interested in a career in early childhood intervention.
5. Develop a tracking system to follow students in process to see where they take positions and also to chart attrition figures for early childhood programs.
6. Encourage or subsidize the development of curriculum materials for infants/toddlers/ family program and for the development of cross discipline personnel preparation models and programs.
7. Support demonstration or exemplary programs that can serve as practicum sites for students.
8. Establish a statewide technical assistance system.
9. Use a peer tutoring program.

Families

The family of the young handicapped child will play a significant role in these programs for infants and toddlers. Research on the families of handicapped children has made it clear that families play an important part in how well the child progresses under treatment (Gallagher & Vietze, 1986). The more that the family members feel a part of the program the more they seem to want to work to achieve the ends of the program itself (Turnbull & Turnbull, 1986).

How To Plan for Parental Involvement? A major issue facing policy makers is how to make operational the clear intent of the Congress for significant parental involvement and parental empowerment in this legislation. The parents are required to have a presence on the State Interagency Coordinating Committee and to be a participant in the Individual Family Service Plan developed for each eligible child, but how much further can parental involvement be required, given the diversity of the families that will be participating in this program? Also, many professionals are not used to parental or family participation in the remedial program and many standard practices related to family professional interactions may have to be modified. Some training to focus the attention of professionals on family issues may be needed.

How to Secure Family Privacy and Confidentiality? Policy analyses often reveal a number of ironies or contradictions in serious and well meaning legislation -

this is probably one of those circumstances. The requirement for an Individual Family Service Plan mandates that the professionals involved present "a statement of the family's strengths and needs". This requirement virtually assures that the professionals will be collecting sensitive information about intrafamily relationships and special family problems. The procedural safeguards in the law (100 STAT. 1152) also mandate that the right to confidentiality be observed, and affirm the right of parents to examine records relating to assessment, screening, eligibility determination and the development of the IFSP.

There is a need to respect the parents' rights to confidentiality in the presence of multiple professional disciplines and agencies. This will require some creative administrative approaches and, perhaps, some changed attitudes. The right of parents to have access to files about the child and family will require that such records be clear and understandable.

A fundamental policy and value issue is: who has the chief responsibility for the planning for this child with handicapping conditions? Is it the family, or the team of professionals providing services? If the answer to that question is, the family, then what are the implications of that decision on the development and execution of the IFSP?

A clear delineation of the roles played by the family on one hand, and the professional providing service, on the other, is needed.

The diversity of cultural background in the families involved will require adaptability of professionals (and of policy) to best meet the needs of different families.

The development of a defensible policy which reflects our values commitment to ethnic, racial and social diversity and to family empowerment is no small task. This needs to be a major focus in the implementation of this legislation.

<u>Some of the possible options relating to family empowerment are</u>:

1. The family can have veto power over the choice of a case manager to deal with their child's case.
2. The family could be their own case manager or a co-manager in some circumstances.
3. The families would have a reserved place on policy making boards of agencies that provide services for infants/toddlers/families.
4. Joint parent - professional training on constructive interactions might be considered.
5. Personal counseling services could be made available for family members upon request.
6. Respite care or baby sitting programs would be established to ease the burden of constant care on families.
7. Parents could have access to a Parent to Parent program for exchange of information, support and advocacy.

8. Families would have a mandatory review of their child's IFSP every six months with appropriate professional staff.
9. Parents would define family needs, which are not specific to the handicapped child, but which could aid the child if such needs are met.

Finance Resources

In any service program there is always concern that enough resources are available to achieve the goals of the program. Rarely do the professionals ever feel that they have enough to do the job as they would like to do it. This will likely be the feeling in this program (99-457, Part H) as well.

How To Find and Manage The Fiscal Resources: There are two distinct policy questions involved in the finances connected with this legislation (Part H, P.L. 99-457). The first involves the general availability of funds to pay the bills and the second is the nature of the flow of funds in the state, given the complex interagency responsibilities in program implementation. The stated intent of the Congress in this situation is to provide planning and development money that would allow the states to establish a comprehensive system of services to infants, toddlers and their families.

The amount of funds needed to carry out P.L. 99-457 is difficult to estimate given the differing eligibility criteria that determine how many children and families need services of what kind. Further, we do not know the extent to which all of the services that are available will be called upon in an individual case (Martin, in press). Even the most conservative estimates of cost, are substantial and represent a major fiscal commitment on the part of the state.

The extension of the concept of services beyond the typical educational services that were the backbone of P.L. 94-142 to a multidisciplinary set of services in Part H brings with it the possibility of increased costs for some children with needs for multidisciplinary service.

<u>Some possible policy options are</u>:

1. Restrict those eligible for service to a small proportion of children and primarily use current financial resources.
2. Restructure current state appropriations across agencies to meet these increased needs.
3. Serve a relatively broad range of handicapped and "at risk" children and obtain additional revenue in order to accomplish the task.
4. Raise state taxes to obtain additional revenue.
5. Develop a new earmarked tax,or set aside a portion of an existing tax (e.g. alcohol), or develop other revenue sources such as a lottery.

6. Use private insurance funds, and other private sector resources, as a foundation for the program.
7. Require that local agencies raise additional revenue.

<u>Coordination of Funding Sources</u>. The other fiscal policy issue, is the accessibility of funds through coordination and interagency agreements. How will the lead agency develop policies to allocate financial responsibilities to the 13 or 14 funding sources that might be utilized in this program? Fiscal coordination is sure to be one of the major policy implementation issues, as these programs evolve. The states are asked to provide the "timely reimbursement of funds", a requirement which may not be easily met given the complexity of the money flow. Nor are there any current statements available on what will happen if the available funds that the states can provide run out before all of the needed services are provided? Is this, in effect, an entitlement program? The answers to the fiscal issues will determine, to a substantial extent, how large this program may become.

In another sense, the use of multiple funding sources may affect the nature of services delivered. The education establishment has long operated on the basis that services are developed and offered to children and families at no cost. Two aspects of P.L. 99-457 modify the basic operating procedures of the education system (note that twenty-two states/territories have designated Education as the lead agency).

First, P.L. 99-457 does not extend the concept of <u>free</u> appropriate public education below the third birthday for children. It provides for a sliding fee scale based on a family's ability to pay for services. The only significant experience that schools have had in handling this payment policy is with free and reduced price lunches in the School Lunch Program. That experience is of little value since the schools themselves were not liable directly for costs regardless of eligibility (either parents or the U.S. Department of Agriculture picked up the costs).

A second, and more profound, effect is the move toward a reimbursement driven system. The assumption underlying Part H, P.L. 99-457 is that many existing sources will be tapped to pay for needed services. Insurance companies or Medicaid will be billed for speech therapy, physical therapy or other services. Parents will be asked to bear part or all of the cost of such services. Will the availability of a source of reimbursement be the determining factor in the provision of services? Will the lead agency be responsible for the deductible or copayment on insurance policies for families eligible for free services on the sliding fee scale? Does the law require the establishment of an elaborate (and expensive) governmental structure to handle the coordination of billing and payment for services across many agencies and individuals? What effects will such a system have on the kinds of services delivered and the nature of families able to get the services? These are a few of the challenging questions posed in the finance area.

Some of the possible policy options available are:

1. Develop a new governmental structure to coordinate funding sources.
2. Develop interagency agreements which delineate which resources will be coordinated and how.
3. Restructure funding sources so that they are all funnelled to a single agency.
4. Maximize use of a small number of major sources of funds (3-5) with minimal use of other sources.
5. Earmark portions of each source of funds at the state level for support of services under Part H.
6. Make local communities or local interagency councils responsible for the coordination of funds.
7. Restructuring at the federal level the many federal sources into fewer, easier to manage, sources.

Coordination of Services

It is clear to everyone that coordinated services are going to be required from various agencies in health and human services, social work, and education. The lead agency that has been established to administer programs in each of these service sectors is faced with the problem of coordinating their efforts through this legislation. The law itself establishes the requirement for the governor of the state to identify a single lead agency that will have responsibility for administering and monitoring of programs, the coordination of available resources, the resolution of intraagency and interagency disputes, the formal interagency agreements, and the financial responsibility of each agency.

At this writing the lead agencies have been identified in the fifty states and Table 2 lists them for each of the states. Table 2 indicates an impressive diversity among the states in terms of lead agency designation. Education, Health, Mental Health, Human Services, etc. all have been identified as lead agencies in particular states. In some states an interagency council, committee or agency has been designated as the lead agency.

How Will Services Be Coordinated Among Agencies and Service Provided?

The track record of cooperation among agencies at comparable levels of authority within either the local, state, or federal governments is not encouraging (Brewer & Kakalik, 1979) Therefore, new administrative mechanisms will likely be necessary to provide the cooperation and coordination that is called for (Harbin & McNulty, in press). The negotiation of interagency agreements and understandings will surely play a significant role in the gradual emergence of these state agency cooperative

TABLE 2

Part H Lead Agencies

	STATE	LEAD AGENCY
1.	Alabama	Education
2.	Alaska	Health & Social Services
3.	American Samoa	Health
4.	Arizona	Economic Sectiry/DD
5.	Arkansas	Human Services
6.	California	Developmental Services
7.	Colorado	Education
8.	Northern Mariana Islands	Education
9.	Connecticut	Education
10.	Delaware	Education
11.	District of Columbia	Human Services
12.	Florida	Education
13.	Georgia	Human Resources/MH-MR-SA
14	Guam	Education
15.	Hawaii	Health (CCS)
16.	Idaho	Health & Welfare/DD
17.	Illinois	Education
18.	Indiana	Mental Health
19.	Iowa	Education
20.	Kansas	Health and Environment
21.	Kentucky	Cabinet for Human Resources
22.	Louisiana	Education
23.	Maine	Interdepartmental Committee
24.	Maryland	Government Office/Children&Youth
25.	Massachusetts	Public Health
26.	Michigan	Education
27.	Minnesota	Education
28.	Mississippi	Health
29.	Missouri	Education
30.	Montana	DD
31.	Nebraska	Education
32.	Nevada	Human Resources
33.	New Hampshire	Education
34.	New Jersey	Education
35.	New Mexico	Health & Environment
36.	New York	Health
37.	North Carolina	Human Resources/MH-MR-SA
38.	North Dakota	Human Services
39.	Ohio	Health
40.	Oklahoma	Education

41.	Oregon	MH for DD
42.	Palau	Education
43.	Pennsylvania	Public Welfare
44.	Puerto Rico	Health
45.	Rhode Island	Interagency Coordinating Council
46.	Secretary of the Interior (BIA)	Education
47.	South Carolina	Health & Environmental Control
48.	South Dakota	Education
49.	Tennessee	Education
50.	Texas	Interagency Council
51.	Utah	Health
52.	Vermont	Education
53.	Virgin Islands	Health
54.	Virginia	MH/MR/SA
55.	Washington	Social & Health Services
56.	West Virginia	Health
57.	Wisconsin	Health
58.	Wyoming	Health

(Federated States of Micronesia and Republic of Marshall Islands are not eligible for this program) relationships. Perhaps the most significant policy issue is how thoroughly a lead agency, even bolstered by such a designation by the governor of the state, can influence significantly the activities of other agencies.

Some of the policy options for interagency coordination would seem to be:

1. Develop joint agency policies.
2. Use a joint agency policy development process but each agency develops its own policies.
3. Use an external agency such as a Governor's Office for Children for coordination.
4. Create an interagency council which is a part of state government.
5. Assign a single interagency coordinator to operate across agencies.
6. Designate a person within each agency who has responsibility for coordination.
7. Use Interagency Coordinating Committee to facilitate coordination.

How Will The Interagency Coordinating Councils Work? One of the key elements in the Part H (P.L. 99-457) legislation is the establishment of a State Interagency Coordinating Council (ICC) whose functions are to advise and assist the lead agency in the performance of its responsibilities. The composition of such an agency is clearly laid out in the law to be composed of parents, public and private providers, a representative from the state legislature, and a person involved in personnel preparation. One of the policy implementation issues is what kind of an impact can a Council have on the program development aspects of this legislation when it meets only four times a year? Yet it is these cooperative arrangements at both the state and local level that would seem to be fundamental, if this legislation is to meet its stated objectives.

Some possible policy options for the ICC would be:

1. ICC will react to and advise the lead agency. Lead agency will do most of the development work and have the final say.
2. ICC is involved in designing the system but lead agency will eventually administer the service system.
3. ICC will administer the service system.

What about coordination with the Private Sector? One set of key participants in this multi- disciplinary operation are the health professionals who often provide their services from the private sector. How does the private sector, including the private insurance providers, fit into the planning and long range operation of a service delivery system that does not include medical treatment but which does need help in identification and related health services? This is one of the areas in which there is little available precedent to guide state activities and which will require some statesmanlike policy and guideline writing to allow everyone to participate at the level of their professional competence to the best interests of the families involved.

Data Systems

How to Devise a Data System for P.L. 99-457, Part H??

One of the requirements of Part H is that states develop a system for compiling data on the numbers of handicapped infants and toddlers served and in need of services, the types of services provided, and the kinds of personnel currently providing services, as well as the additional personnel required for a comprehensive statewide system. The overriding policy issue is how to devise a system that meets the mandated reporting requirements while at the same time fulfilling a state's own planning needs.

The development of this system is especially challenging to the states for several reasons. First, data collection systems are expensive to develop, put in place and maintain, and the costs involve not only fiscal, but human resources. At the local level, many programs may not see the advantages in collecting data. Data collection adds to the workload, may have no visible returns in terms of services or funding, and bears the potential of additional monitoring responsibilities.

Past experience shows that the local data provider rarely receives timely and useful reports that include the data they have generated. This has been a widespread complaint of local school districts with regard to the reporting requirements of P.L. 94-142, and the problem will likely be substantially the same in Part H, P.L. 99-457, when multiple agencies with diverse information and planning needs are involved. For policy makers, a real concern is how to build effective incentives into data collection in order to optimize and maintain quality!

At the state level, it is awkward to expend monies on data collection when there are significant gaps in services and unserved children. In every state there is a need to expand and improve services and to build a fully comprehensive system. Some states have limited services available and are still planning and piloting program and service models, so they are faced with the problem of designing a system of data collection for a service system that is not in place.

The task of developing a data collection system for Part H depends on the pattern of service delivery and the potential for compatibility among existing data collection systems. In a number of states, early intervention services have been primarily provided by one or two agencies, while in other states the services are dispersed. Agencies are notoriously reluctant to collect new data if there is an existing source, even if the service does not yield precisely comparable information. Also, some states may have limitations on the amount of data they are allowed to collect. But even in the most optimistic of circumstances -

- where early intervention services are concentrated and there is a data collection system explicitly designed to report on early intervention services -- a state will have to make adaptations to meet Part H reporting requirements.

When the respective data collection systems of several agencies are involved, the difficulties of integrating information that fits the reporting requirements are increased. Each data system was originally designed to meet very specific state or federal regulations. It may be as formidable a task to adapt a data collection system, once it is in place, as it is to develop a new system.

In order to design a system of early intervention services as well as to evaluate and revise our policies, we need to know who is being served or in need of services, what services are provided, what types of services and personnel remain to be developed, and the costs of service provision. The data collection effort required for Part H will be a fiscal liability for the states unless policies can be put in place that make the system useful in addressing information needs effectively at the state and local level. The quality of the data ultimately hinges on commitment at the local level.

Some of the possible policy options in data collection are:

1. Develop a new comprehensive interagency data system with common core data elements.

2. Adopt a common data collection protocol (or form) on infants and toddlers for all agencies involved in the delivery of human services.
3. Adopt a common identifier (e.g. social security #) for all children in a target population, enabling each agency to extract information on a child from its system.
4. A lead agency could develop data collection protocols that would be sent to other agencies for completion.
5. A lead agency could develop data collection protocols that would be sent directly to the local providers.
6. Use of existing data system as the core data collection tool and develop interface with other systems and procedures (e.g., develop a common identifier).
7. Extract common identifier from common data elements in all systems (i.e., "data linking"), thus not altering any agency's approach to data collection.
8. Develop a sampling strategy.

A FINAL WORD

This roster of policy issues does not, of course, exhaust the range that exists in the complex nature of P.L. 99-457 (Part H). It is easy to see why the federal government thought it wise to give the states four years to reach some form of accommodation with these issues within their own boundaries, and to establish a National Early Childhood Technical Assistance System (NEC-TAS) and research institutes in personnel preparation and policy studies.

There is much to be learned in the process of implementing this exciting piece of legislation and, fortunately, there is also a well trained cadre of personnel available from the Handicapped Children's Early Education Program (HCEEP) network, from Head Start, The SPRANs grants funded by Maternal and Child Health, and many other programs (Smith, 1986) who can bring their experience and judgment to bear upon these issues. We are not entering the woods blindly, or without friends and colleagues who have a common interest in making this program an outstanding example of multidisciplinary cooperation.

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Frank Porter Graham
Child Development Center
CB No. 8040, 300 NCNB Plaza
Chapel Hill, NC 27599