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ABSTRACT

Four years after passage of Public Law 99-457, a survey was conducted of 30 state Part H Coordinators regarding the financing of Part H services. Coordinators were asked to estimate the percentage of the state's total funding that came from each of 44 potential sources for financing the implementation of Part H. Every one of the 44 sources was used by at least one state for at least 1 percent of its Part H system costs. States reported using, on the average, about 21 different sources of funding. Most sources were federal, in both the education area and health and human resources areas. Over half of the dollars used to fund the Part H system were federal, about one-third were state/local, and the remaining tenth were nongovernmental. As the number of people involved in the development and implementation of the Part H finance system increased, the total number of sources used increased and the number of sources used moderately to heavily decreased. States reported expectations that funding would increase from Medicaid; Early and Periodic Screening, Diagnosis and Treatment programs; and Chapter 1/Handicapped programs. Most states centered responsibility for coordination of financing services at the state, rather than regional or local level, and relied on formal interagency agreements to facilitate the process. Two appendixes provide background statistical data. (Contains 30 references.) (JDD)

Carolina Institute for Child and Family Policy

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EXECUTIVE SUMMARY

With the passage of P.L. 99-457 in the fall of 1986, the U.S. government made a major move to complete the promise of services to children with disabilities from birth through the school-age years. Part H of the legislation, in particular, provided incentives to the states to extend the program of services to these children and their families, from birth through the toddler years.

It was recognized soon after the passage of the legislation that solutions to two critical issues in the legislation were essential for states to successfully fulfill the opportunities presented. First, a system of services that cut across traditional agency and professional disciplinary boundaries was required; and, equally important, was the necessity to find a way to finance the system from a broad array of potential funding sources.

In its efforts to document implementation of the infant/toddler portion of P.L. 99-457 (reauthorized in the Individual with Disabilities Act of 1991, P.L. 102-119, Subchapter VIII), the Carolina Policy Studies Program conducted a survey of state Part H Coordinators regarding these two key aspects of implementation, some four years after passage of the law. This report examines the financing of Part H services, while a companion report (Harbin, in preparation) examines the interagency coordination of services.

In order to investigate the current status of coordinating funds and the relative use of particular funding sources, we asked states to estimate the percentage of the state's total funding for financing the implementation of Part H for each of 44 potential sources. States were asked to indicate whether each source (a) was not used in the state, (b) was used less than 1%, (c) was used from 1% up to 5%, (d) was used from 5% up to 20%, or (e) was used for 20% or more of the state's total funding for Part H services. The sources ranged from federal education and health and human services to state and local sources and nongovernmental sources, such as private insurance and voluntary health or service agencies.

It is significant every one of the 44 sources was used by at least 1 state for at least 1% of its Part H system costs. States reported using, on the average, about 21 different sources of funding. Most sources named by states were federal, with about half being federal education dollars and half federal health and human resources funds.

States most frequently reported using 3 sources moderately to heavily (at least 5%). When use was weighted by amount that states reported for each of the sources, over half of the dollars used to fund the Part H system were federal, about one-third were state/local, and the remaining tenth were nongovernmental.

This finding is reiterated in examination of the top 15 sources, compiled through weighting by amount of use. Seven of the top 15 sources were federal, 6 were state/local, and 2 were private. Besides Part H funds themselves, states

most frequently reported moderate to heavy use of funds from the state Mental Retardation/Developmental Disabilities, federal Chapter 1/Handicapped, and federal and state Medicaid programs, with total use also high from federal and state Maternal and Child Health Block Grants and the federal Early and Periodic Screening, Diagnosis and Treatment program (EPSDT).

A trend that seemed to hold across the states responding to the survey indicated that as the number of people involved in the development and implementation of the Part H finance system increased, the total number of sources used increased and the number of sources used moderately to heavily decreased. This may reflect a recognition by state personnel of the need to concentrate efforts on a contained group of funding sources, rather than attempting to coordinate all available monies.

States reported improvements in efficiency and effectiveness in accessing Medicaid and EPSDT funds, and expectations that these sources of funds for the Part H system would increase over the next three years. An additional source of funds expected to increase is Chapter 1/Handicapped. States also seemed to expect more use of private insurance and sliding fee scales for families to pay for Part H services, in that intentions to continue or institute new formal state plans or state requirements to include these funding sources by 1995 were indicated.

Most states have centered responsibility for coordination of financing services at the state, rather than regional or local, level, and rely on formally signed interagency agreements to facilitate the process. States continue to report multiple barriers to developing a coordinated system of financing, and relationships regarding use of formal workgroups and number of interagency agreements indicate that barriers are perceived to be reduced with formal participation and definition. The Part H Coordinator and agency level decision makers were named as the most important participants in developing a vision of the Part H finance system.

Recommendations

I. STATES SHOULD CONTINUE TO FOCUS ON MEDICAID AS A SOURCE OF FINANCING PART H SERVICES.

Most states have found ways to access Medicaid and are doing so substantially. Several states, in fact, have moved from no utilization of Medicaid to implementation of regulations allowing educational agencies to bill Medicaid directly, since the beginning of Part H. However, there is much more that needs to be done in states to fully utilize the Medicaid options. There are questions about how a proposed "cap" on Medicaid would affect the ability of states to maximize the potential use of Medicaid as a source of financing for Part H services.

II. STATES SHOULD ALSO FOCUS ON STATE SOURCES.

The particular sources used most within a state--education, developmental disabilities, or health--seem to be dependent on the

situation in a given state. A state core of funding for the Part H early intervention program has previously been found to be necessary to initiate and maintain a state's system (Clifford, 1991). Broadening the network of formal state agency involvement in the planning appears to facilitate access to sources of financing.

III. STATES SHOULD BROADEN THEIR FOCUS TO INCLUDE MORE SOURCES.

Findings from previous examinations of Part H financing indicated that successful states were targeting a few major sources of funding in the early stages of implementation. This seemed to, in part, be the result of few available staff and lack of time to do more than focus on a few key sources. The survey results indicate that states have now been able to broaden their efforts to access multiple sources. As states increase the capability to successfully obtain funds from multiple sources, the total amount available for the early intervention program should increase.

IV. STATES SHOULD WORK WITH FEDERAL AGENCY PERSONNEL AND CONGRESS TO DEVELOP A MORE COHERENT, SIMPLIFIED APPROACH TO FINANCING PART H SERVICES.

While we recommend efforts to maximize use of a broader range of sources of funds for Part H services (III above), we are convinced that major reform is needed to sharply reduce the number of sources and simultaneously greatly increase the amount of funding from this small number of sources of financing. The process of accessing many different sources of funds is inherently expensive to carry out. With tax dollars in short supply, it is inappropriate to spend large sums in the pursuit of new dollars. Neither do we want to follow the example of the health insurance industry in which much of the money is spent on administration of the system.

V. A NEW FEDERAL APPROACH TO FINANCING PART H SHOULD BE DEVELOPED AND IMPLEMENTED.

The federal government should reform the system to provide a greatly simplified and focused approach to financing the vision of providing appropriate services to infants and toddlers with disabilities and to their families, beginning at the earliest possible time in the lives of these young children. Several reasonable alternatives exist for reducing the current excessive costs of attempting to coordinate the large number of funding streams required to adequately finance services. Some suggested options are funding all Part H services under Medicaid, earmarking portions of each major piece of federal legislation affecting children to fund Part H services, and increasing Part H funds themselves to cover financing of services (Clifford, Kates, Black, Eckland, & Bernier, 1991).

While substantial cost savings are possible by simplifying the financing of Part H services, these savings are not likely to be sufficient to cover the additional funds needed to support the cost of fully implementing the Part H program nationwide. Thus, it is imperative that the total funding levels be increased substantially, at the same time that the number of funding streams are reduced and simplified.

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Even with all of this help, we are sure to have made mistakes. We take full credit for these, as well as for the interpretations of the data as reported in this document.

INTRODUCTION

Over the past four years, the Carolina Policy Studies Program (CPSP) has been examining the state level implementation of the comprehensive service system for infants and toddlers with disabilities and their families under Subchapter VIII of the Individuals with Disabilities Act, IDEA (P.L. 102-119, formerly Part H of P.L. 99-457, and hereafter referred to as "Part H"). As part of the overall effort to examine how states are responding to the implementation of the law, we have conducted a survey of the states, focusing on coordination of Part H services and financing, in the last half of 1991. The survey was an attempt to extend and test what has been learned from a series of case studies of 6 diverse states, and to provide a more complete picture of how states across the country are attempting to implement these two complex provisions of the law. This report deals with the results of the portions of the survey related to financing of services. Results of the sections of the survey regarding coordination of services will be available in a separate report (Harbin, in preparation).

This report begins with a review of the financial requirements of Part H and an overview of the status of research on financing Part H early intervention services. A section on the methodology used to conduct this study follows. We then present a summary of the responses to a series of questions on the survey related to coordination of both services and financing of the services, followed by a more specific discussion of financing issues from survey results, including details about sources of funding, the degree to which these sources are actually being used by the states, and future prospects for financing services at the state level. The report concludes with a series of recommendations for state and federal policymakers regarding financing Part H services.

BACKGROUND

Finance Issues in Part H

The policy from Congress regarding infants and toddlers with disabilities as stated in Part H of IDEA includes facilitating the coordination of payment for early intervention services from federal, state, local, and private sources, including public and private insurance coverage (Section 1471(b)(2)). Early intervention services for Part H eligible children are to be provided at no cost to the family except where federal or state law provides for a system of payments by families, including a schedule of sliding fees (Section 1472(2)(B)). The requirements for the statewide, comprehensive, coordinated, multidisciplinary, interagency early intervention program outlined in Section 1476 of Part H include the designation of a lead agency to, in part, identify and coordinate all available resources within the state (Section 1476(b)(9)). The state may designate an individual or an entity to be responsible for assigning financial responsibility among appropriate agencies (Section 1478(a)(2)).

Yearly appropriations under Part H from the federal government to the states are tied to specific requirements of progress outlined in the legislation

(Section 1478). Funds provided under Part H itself are to be used to plan, develop, and implement the statewide system, and may also be used to provide direct services that are not otherwise provided, to expand and improve services that are otherwise available, and to provide a free appropriate education to children with disabilities from their third birthday to the beginning of the following school year (Section 1479). Part H funds may not be used to pay for services that would have been paid for from other public or private sources, except to prevent a delay in the receipt of services pending reimbursement, nor may states reduce medical or other assistance to infants and toddlers with disabilities or alter eligibility for other programs (Section 1481).

Literature on Financing Early Intervention Services Under Part H

Surprisingly little is known about the status of financing services as called for under Part H of IDEA. Attempts in the literature to examine financing issues may be categorized into three types. First, there has been a modest amount of work to assist states in identifying the types and nature of different sources that can be used in the financing of Part H services and processes for doing so. A second set of reports has examined the cost of providing Part H services. The final, and least studied, area is that of the progress of states in actually developing and implementing plans for making use of the various sources of funds for service provision.

Sources of funds for Part H services. Perhaps the most comprehensive work on identifying and describing types of potential sources for Part H services is that done by the National Early Childhood Technical Assistance System (NEC*TAS), which provides a comprehensive picture of the many different sources and outlines approaches to accessing the various types of financing (Williams & Kates, 1991). The NEC*TAS Financing Workbook was written in response to a survey regarding states' needs for technical assistance, which revealed that the issue of financing is a major priority with states. Experts on special education and health financing met to help develop materials for states to use in defining and applying states' financing systems for early intervention, and the workbook was a major project of the group. An assumption underlying the workbook is that "in any financing plan all existing financing resources ought to be identified, understood, and fully utilized as a prerequisite and context for seeking new resources" (p. 3). This is fully congruent with the intentions of the requirements in Part H for financing the service system, as described above.

The workbook details a seven-step guide to planning and implementing a financing system for early intervention, which includes involving key players, developing a vision of the system, defining the desired system, identifying the existing system, identifying existing problems, developing change strategies, and implementing changes. The appendix material includes a financing matrix to help understand the existing structure of services and financing, a comprehensive annotated list of potential funding sources, and a list of additional materials that may be accessed. NEC*TAS identified, in the list of potential sources, 41 funding resources or categories of resources that may be used to support Part H services. Twenty-seven specific sources are cited from

federal funds, and 7 categories of sources from state and local funds and 7 categories of sources from non-governmental funds are identified. Of the federal, state, and local government sources and categories, 15 are education funds, 11 are health funds, and 8 are social welfare funds. The wide variety of levels and types of funding sources cited in the workbook would seem to indicate that accessing and coordinating funding for the Part H service system is a major task requiring a substantial input of resources--both monetary and human--from both the state and from local programs. In addition, a problem area noted in the workbook guide that also requires a commitment of time and resources includes identifying and resolving gaps and overlaps in financing particular services for particular children.

Other work in the area of identifying and accessing types of resources has focused on particular sources of financing Part H services, such as Medicaid (Fox & Wicks, 1990; Fox, Wicks, McManus, & Newacheck, 1992; Kastorf, 1991; NEC*TAS, 1990; White & Immel, 1990) or private insurance (Fox, Freedman, & Klepper, 1989; NEC*TAS, 1990; Van Dyck, 1991).

The consensus among those who have investigated Medicaid as a possible source of payment for Part H services is that the Medicaid system is complex, in part because of the tremendous variability among states in details of the Medicaid plan regarding such issues as defining eligible populations and covered services. Many consider Medicaid to be a major source for funding Part H services. One option for financing the Part H service system would be to fund **all** Part H services under Medicaid for all children regardless of family income (Clifford, Kates, Black, Eckland, & Bernier, 1991). While the benefits of such a method would include: use of existing bureaucratic structures, ability to take advantage of the work that states have already done to move to a fee-for-service system, and simplification of the funding system, a major disadvantage would be the continuing difficulty of accessing reimbursement.

In a recent report of the results of two national surveys on private and public health insurance reimbursements for health-related services for infants and toddlers with developmental delays, Fox, Wicks, McManus, and Newacheck (1992) conclude that "health insurance, especially Medicaid, can provide reimbursement for many, if not all, health-related early intervention services furnished under the Part H program" (p. 119). Their secondary data analysis of 1988 National Health Interview Survey suggested that a majority of children who are eligible for early intervention services are covered by private health insurance only (59%); 16% had Medicaid coverage only, 12% had both Medicaid and private health insurance coverage, and 12% had no coverage (Fox, Wicks, McManus, & Newacheck, 1992). With the recent broadening of eligibility for Medicaid and concurrent expansion of services covered in the various state plans, current levels of Medicaid coverage should be substantially higher than in 1988.

In the 1988 study (Fox, Wicks, McManus, & Newacheck, 1992), private health insurance plans were found to more often offer coverage for ancillary therapists (physical, occupational, and speech therapists), but Medicaid tended to use less strict criteria for providing these services. Medicaid also tended to reimburse services in more different types of settings than private insurance,

including clinics that could provide early intervention services. Home health service coverage was greatly restricted under both Medicaid and private plans, but case management services, or service coordination, were much more commonly provided under Medicaid than under private insurance.

Fox, Wicks, McManus, and Newacheck (1992) also discussed several reasons why Medicaid is likely to present a better financing option for Part H services than private insurance. Unlike most private health insurance plans, Medicaid requires no, or only a minimal, copayment from the beneficiary. Because state dollars are supplemented by a federal match, states have a strong incentive to use Medicaid dollars for service reimbursement. Medicaid has no dollar caps on service costs; private insurance often caps costs. States have much more flexibility in structuring a Medicaid plan to meet the need of children requiring early intervention than in directing the private health insurance industry in benefit provision. Lastly, the recent (1989) mandatory Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit allowing EPSDT coverage of any "medically necessary" service need discovered during an EPSDT screening provides a ready-made method to provide early intervention services, unlike set benefits offered under private plans. Although Medicaid seems to be a better financing option, Fox and colleagues cited problems including restricted reimbursement rates and lack of funds within states to expand services.

Several authors present basic information about the legislation and regulations regarding Medicaid and the EPSDT program of preventative screening and follow-up services for Medicaid eligible children. The NEC*TAS Information Packet (1990) chapter on Medicaid is a collection of memoranda and short publications from such organizations as Children's Defense Fund and The National Governor's Association, detailing 1990 Medicaid and EPSDT federal mandates for coverage, changes in coverage, and status of coverage in each state. Fox and Wicks (1990) present general information about Medicaid mandates and options, state-specific variations in benefits, and implementation issues for Medicaid financing of health-related early intervention services. White and Immel (1990) summarize the basic elements of Medicaid and detail a plan to access Medicaid funds based on the successful experiences of several states.

In addition, Fox and Wicks (1990) argue that Medicaid is an appropriate source of financing health-related early intervention. Kastorf (1991) also states that the "authority of states to use Medicaid funds for the provision of early intervention has been well established by federal legislation, regulation, and court decisions" (p. 2), although he reminds us that states must make the choice to design and implement a system to do so. Kastorf further presents the experience that Massachusetts has had in implementing Medicaid funding for early intervention and details the benefits that Massachusetts has enjoyed. He suggests that one barrier that states may face in applying the process is the requirement of a substantial commitment of state funds, staff, and time for start-up.

Although the Part H legislation directs states to include private health insurance as a source of financing services to eligible children, access to these

funds has not been straightforward. Issues regarding the use of private health insurance for Part H services include who is covered, scope of services covered, quality of coverage, limitations on services or dollar amounts, and family financial responsibilities including premium costs, deductibles, and copayments. The Children's Defense Fund reported that, in 1990, more than 25 million children in the United States, or 40% of all children, lacked employer-provided health insurance (Rosenbaum, Hughes, Harris, & Liu, 1992). This is congruent with the secondary analysis of the 1988 National Health Interview Survey from Fox, Wicks, McManus, and Newacheck (1992), in that, nationally, 59% of children eligible for early intervention services were found to be covered by private health insurance. The Children's Defense Fund report further found, however, that the number of covered children is declining, especially among minority, low and middle income, and rural children. In addition, services often required by children with disabilities have traditionally been excluded from insurance coverage when children are school aged, because special education and related services have been viewed strictly as being provided at public expense. Fox, Freedman, and Klepper (1989) described national efforts to provide insurance for the uninsured and the underinsured and to revise state laws to increase insurance coverage of early intervention services.

Some states are beginning to develop plans and strategies to access private health insurance to cover early intervention services, as directed under Part H. The NEC*TAS Information Packet on the Financing of Early Intervention and Preschool Services (1990) provides information on mandated insurance benefits by state that may be used to cover early intervention services. Also included in the packet is a summary of a presentation by McManus (1989) in which she outlined arguments to use in developing the case for covering early intervention services through private health insurance and an approach to estimating the costs of these benefits. Van Dyck (1991), in his discussion of the use of parental fees in financing Part H services, outlined numerous options for implementing payment for services, several of which include the use of private insurance. The options include the advantages of increasing revenues and services, but carry the disadvantages involved with private insurance such as co-payments and deductibles and limits on services and dollars. As will be seen in the results of our survey, a number of states either currently have or are considering use of sliding fee scales for parental payments for services, as allowed in the law.

Cost of Part H services. Examining the cost of providing Part H services is clearly of importance to states. Overall, the information regarding early intervention costs is quite limited (Barnett and Escobar, 1990). Work of the NEC*TAS group has provided one of the few cross-state looks at the costs of Part H services. Information on selected states' projections of numbers of children to be served and costs of services under Part H has been collected and used to estimate the "unfunded gap" that results when existing monies are not sufficient to cover projected costs for full implementation of Part H (Kates, 1991). Bowden, Black, and Daulton (1990), also out of NEC*TAS, produced a guide to assist states in estimating the costs of providing early intervention services. They argued that presenting "an accurate picture of what funds currently are available and what additional state funds are needed to implement a statewide system" (p. 1) is important in this context because of the Part H language

directing the maximization and coordination of existing and potential resources, and to offer a realistic perspective for those who make and seek increases in allocations. The guide then suggests and illustrates a framework for planning and conducting a statewide cost analysis, with suggestions on how to apply the guide to an individual state with its unique characteristics and level of effort available. Examples from several states of how particular steps of the cost analysis process have successfully been applied and the results are included.

Cost analyses of Part H early intervention services have been conducted within several states. To cite one example, a group out of Florida State University is conducting a comprehensive cost and implementation study of Florida's Part H system. As they point out, "the current discipline-specific, single-focused, program-bound delivery system of early intervention tends to be more expensive [than inclusive programs] when it tries to meet the holistic needs of families and children" (Florida Taxwatch, 1991, p. 14).

During the first two phases of the study, researchers have collected measurement data on numbers and characteristics of vulnerable infants and toddlers and their families, service needs, types of service delivery system needed, cost of services, and benefits of providing services. During the next phase of this study, researchers will be analyzing data and collecting more information to develop training and technical assistance packages, funding strategies, and a new budgeting system to implement a coordinated system of local, state, federal, and private funding.

The work of the Florida State group has so far indicated a range and variation of costs depending on the age of the child, the age of identification of the child's condition and entry into the intervention system, the nature of the services provided, and the setting in which the services were delivered. Factors used by Florida to estimate the cost of this "multi-faceted entitlement system" include eligibility definitions and prevalence, service system utilization levels, service unit costs, and service needs. A unit cost approach was taken because unit cost budgeting facilitates the development of funding strategies and supports the capacity to implement and monitor levels of service intensity. The maximization of Medicaid as a major revenue source was a goal of cost data collection, and thus local, private, third party, and voluntary funding sources were not considered at this point of the study.

Average per child costs in the Florida study varied greatly. Florida estimated costs for children with established conditions and developmental delays ($10,144), children with three or more risks ($3,555), and children with one or two risks ($1,214). The study attributes the variation in costs for the different categories of children to great differences in needs of **anticipated** Part H services, which are to be expanded and phased in during Florida's "full implementation" funding of Part H. Differences in costs were not deemed to be attributable to "fourth year" Part H required services which were in place at the time of data collection. This example illustrates that much variation in costs of serving Part H children with different characteristics exists and that this issue must be considered when determining costs of the Part H service system.

In contrast to the "snap-shot" estimation of costs at one point in time, Rhode Island has conducted a study to analyze service usage and costs over time, following particular children through their service programs to gain an understanding of fluctuations of service usage costs and continuity of funding Part H services (Kochanek, 1991). Age of child, level of functioning, and eligibility condition, were considered, as well as service setting and type of provider. The results of this study are not yet publicly available.

Several other states are known to have collected early intervention service cost data which has been applied as the Part H requirements are being phased in, including Massachusetts and Maryland. Massachusetts conducted an extensive unit cost study that resulted in the design of a fee for service contracting system with a uniform service unit cost structure. Maryland estimated average costs per child by service and percentage of children expected to receive each service. Costs were high, compared with other states, because transportation costs were assumed for all children and because salaries in Maryland of professionals providing early intervention services are higher than average.

States' progress in implementing the financing of the Part H system. The final and least studied area is that of the progress of states in actually developing and implementing plans for making use of the various sources of funds for service provision. Fox, Freedman, and Klepper (1989) maintain that the Part H program "undoubtedly will enhance the contact that agencies have with one another," but the authors admit that the "interdigitation of agencies and the coordination of required resources ... will not be accomplished without stress" (p. 172). They further assert that the "identification and use of appropriate public and private funds is particularly vital to the success of a state's Part H program" (p. 172), and that the financing of the Part H system is the responsibility of the states, with the federal monetary role being minor. This has been a major deterrent to the implementation of a coordinated system of financing Part H services within the states.

Fox and Wicks (1990) report on strategies that states are using to access Medicaid coverage for early intervention and preschool services. The diversity of approaches is striking. Four states are reported to allow school districts to be Medicaid providers of certain services. Five states are adding a new benefit to the state Medicaid plan specifically for Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP) related services for infants, toddlers, and preschoolers with disabilities. Two states are using the EPSDT discretionary service option to provide Medicaid coverage for certain services only to the population of young children with disabilities. Fox and Wicks assert that states are, in growing numbers, acknowledging the role that Medicaid can play in the financing of early intervention services, and that Part H staff are willing and have begun to develop the needed expertise to successfully access Medicaid funds. It should be noted that these examples were cited in 1990 when many states were not committed to the Part H program or were in the infancy stages of planning. Much has changed since then, in as far as the extent to which Medicaid is being used within and among states.

In case studies of six states during the early stages of Part H implementation, it was found that Part H staff were concerned about expanding state use Medicaid: "Staff were convinced that the use of Medicaid would, in fact, result in additional costs, such as the large amounts of staff time and effort needed to meet the new regulations" (Clifford, 1991, p. 7). This was in addition to concern regarding poor state financial conditions. Further investigation of the status of Medicaid use in the case studies state revealed little change in perceptions.

Numerous states have conducted studies examining the status and prospects for financing services within their own state. The most ambitious of these efforts has been the work in California. Under a contract with the Part H lead agency in the state of California, the American Institutes for Research (AIR) conducted a major examination of the costs and benefits of an early intervention program (Part H of P.L. 99-457) and of existing and potential funding sources. The first report (McDonald, Minicucci, Marquart, Hamilton, Block, & Yuan, 1990) from this study describes features of state departments and programs that currently fund early intervention such as service system structure, services provided, children and families served, and funding issues raised by different programs. Conclusions of this investigation of the funding of California's early intervention system are threefold: (a) The current system of early intervention program services in California is not coordinated nor comprehensive, but rather a series of separate programs; (b) California currently invests substantial state resources in early intervention services through the separate programs; and, (c) a state tobacco tax and federal Part H funds are seen as two new major sources for funding early intervention services, with the existing sources of Medicaid and Chapter 1 expected to be expanded.

Another AIR report comes out of Nebraska (Parrish, 1990). Similar to the purpose of the project in California, the purpose of this study was to analyze existing and potential funding sources, design service delivery models, and develop a detailed financing plan for early intervention services in Nebraska. Low-, medium-, and high-level cost estimates were made, based on different models of service delivery. Additional costs to the existing early intervention system needed to implement the Part H system and supplemental resources predicted to be available were compared to estimated additional funding needs and the impact on the state's General Fund. Revenue projections are stated to be dependent in Nebraska on the development and implementation of a statewide billing system to Medicaid for related services (e.g., therapies).

The analysis of existing, underutilized, and potential funding resources for Part H services from federal, state, and local sources outlined common difficulties states encounter when trying to determine Part H expenditures. For example, it was reported that in Nebraska, as in most states, "certain services will be found in their entirety in some agencies and only bits and pieces of other services may be found across agencies," and "it is sometimes difficult to discern exactly what elements of a given service fall under Part H and which do not" (p. 18). Thus, while specific figures for FY 1990 expenditures are reported by agency and federal, state, and local share of funding services are detailed, further estimates had to be made as to the extent a given service qualified under Part H and of the number of Part H eligible children using the service. If

Nebraska were to implement the Part H system, the only "new" funds for Part H services would be Part H dollars themselves. At present, all children, birth through age 2 years eligible for Part H, can be served as eligible under Chapter 1/Handicapped programs in Nebraska.

Florida, in developing funding strategies to implement the "fourth year" of Part H, investigated the current use of funds by state departments for early intervention services and potential sources of revenue (Florida Taxwatch, 1991). Estimates were made of costs for case management, multidisciplinary evaluations, intake and screening, service planning, other Part H services, such as therapies, special intervention, and counseling/consultation, and other services, including developmental child care, medical child care, therapeutic foster care, and family support (p. 72-73). Estimates varied for infants and toddlers with established conditions and developmental delays, with three or more risk conditions, and with one or two risk conditions. Potential revenue was detailed for each service and possibilities for new funds were suggested, such as maximizing the use of Medicaid, accessing additional resources, development of more efficient use of available dollars, and coordinating financing strategies with local and private revenue.

There have been no recent reports to Congress on the topic of states' progress in the financing of Part H. The U.S. Departments of Education and Health and Human Services produced "Meeting the Needs of Infants and Toddlers with Handicaps" (1989). The report identified and described federal funding sources and services in the two departments and outlined interagency actions to coordinate services and resources, based on a Congressionally mandated study. Several sources (e.g., Gallagher, Harbin, Thomas, Wenger, & Clifford, 1988; Trohanis, Kahn, Hurth, Danaher, Black, & Heekin, 1988) were used to identify federal funding sources and services. Sixteen programs with "significant potential to contribute resources toward the successful implementation of a statewide system of comprehensive, coordinated, multidisciplinary, interagency programs of early intervention services" were specified for use in providing direct services:

1. Part H of P.L. 99-457
2. Chapter 1/Handicapped
3. Part B of P.L. 99-457
4. Services for Deaf-Blind Children and Youth
5. Head Start Program
6. Medicaid
7. Maternal and Child Health Block Grants
8. Child Welfare Services Program
9. Developmental Disabilities Basic State Grants Program
10. Alcohol, Drug Abuse and Mental Health Block Grant Program
11. Community Health Service Program
12. Indian Health Service Program
13. Migrant Health Services Program
14. Preventative Health and Health Service Block Grant
15. Health Care for the Homeless Program
16. Social Service Block Grant

These programs differed in eligibility criteria, such as ages served or income status, flexibility at the state level of discretion in providing early intervention services, and funding approach (e.g., single-focus grants, multi-purpose block grants, and entitlement programs). Only one source of funds, Part H dollars themselves, was specifically targeted to the Part H population; infants and toddlers must "compete" with other populations for dollars from other programs. Coordination of these funds is described in this report as a difficult task, given the differences in the programs previously cited and the task of coordinating federal funds at the state and local levels. Tracing funding of early intervention services through the various programs is nearly impossible, because the fiscal reporting procedures of the programs are not now designed to do so. This appears not to have been resolved, yet, as the same difficulty is cited in a current report on the status of data systems for the Part H program (Hebbeler & Gallagher, in press).

As of the December 30, 1992, only 16 of the 51 states and the District of Columbia were actually into full implementation of Part H (J. Danaher & T. Black, personal communication, February 3, 1993). Many states have taken advantage of the option offered by the amendments to Part H of IDEA to more slowly phase in full implementation (Section 1475). Ten states have elected to request extended participation in the application for FY 1990 funds. Another 25 states requested extended participation in the FY 1991 application. As of December 31, 1992, 2 states that were in extended participation have been approved for full implementation in FY 1992 and 2 more have submitted applications for full implementation. Until all states have moved to the full implementation stage, conclusive reports regarding financing the Part H service system will not be possible.

At CPSP, staff have conducted surveys of 50 states and the District of Columbia and case studies of 6 states regarding their efforts to implement Part H of IDEA. CPSP surveys of early state progress indicated that states are slower in implementing the major financial provisions of the law than in implementing other requirements (Harbin, Gallagher, & Batista, 1992; Harbin, Gallagher, & Lillie, 1989; Harbin, Gallagher, & Lillie, 1991; Harbin, Gallagher, Lillie, & Eckland, 1990). Two reports have been issued that point to the difficulties that states have been having with actually accessing the funding sources originally envisioned by the authors of the legislation (Clifford, 1991; Clifford, Kates, Black, Eckland, & Bernier, 1991). Clifford (1991), in the first year of case studies conducted in 1989-90, collected information from 6 states on details of the processes involved in accessing and coordinating various financial resources. Clifford noted that, "in general, state agency personnel did not have detailed information on exact expenditures for Part H services" (p. 4). There were two factors contributing to this lack of information: (a) states had only begun the implementation and had not had sufficient time to gather all necessary data; and, (b) program reporting systems across agencies and programs were not designed to provide subset expenditures for the birth to 3 year old group of children and their families.

Knowledgeable personnel in each of the 6 states were asked to rate the use of 7 sources of funds: Medicaid, state or interagency health, Chapter 1/Handicapped, state education, private insurance, parent fee, and local funds.

On the average, only 1 or 2 funding sources were described by each state as major, or essential to and substantial in the state's financial plan. The funding source most frequently cited as a major source was state or interagency health, which included both specific financing through a state health agency and financing through an independent interagency group in state government.

Clifford (1991) also asked states to indicate which of the following approaches to financing services were evident: unit rate financing (establishment of standard rates of payment for specified services), contracting for services (purchasing services from a provider), state core financing (use of substantial source of state funds for a large share of financing of services), local funding initiatives, formal agreements, informal agreements, local coordination, and state level coordination. The states reported a variety of packages of approaches. All of the states that had relatively advanced financing plans, however, used some existing state core financing, implying not only that states were committed to early intervention, but also that state funds allowed access to other funds.

Based on the results of this first set of case studies of six states implementing Part H, Clifford (1991) recommended that states should concentrate major financing efforts on a small number of sources, and access state government funds to match federal dollars, "fill the gaps" in financial assistance, and initiate or expand local programs. Clifford also indicated that it was important to commit staff time and expertise to bring about a successful financing plan.

In another report on the reconceptualization of Part H financing, Clifford et al. (1991) considered some alternative to the current approach necessary to achieve the goals of the legislation, as data from CPSP case studies and other sources indicate that states are having great difficulty implementing the concept of developing a coordinated system of funding. Clifford et al. suggest several alternatives for the short term and the long term. In the short term, the authors suggested that a two-tiered system of financing, or extended time of "phase-in" of final Part H requirements, will help to keep all states participating in Part H. This change was in fact accomplished with the passage of the Americans with Disabilities Act of 1991. In the long run, however, changes will be needed in the methods and sources of financing Part H services that will help overcome the difficulties inherent in trying to fund services with available **categorical** sources.

Clifford et al. (1991) offered suggestions that all Part H services could be funded under Medicaid; that portions of each major piece of federal legislation affecting children could be earmarked for Part H financing; or that Part H could be transformed into a new funding entitlement program. Each option has its advantages and disadvantages, which are detailed in the report, but all address the critical long term need for financial stability for the Part H program.

In this report of the CPSP finance survey, we have investigated results and recommendations suggested by previously collected CPSP data and other studies regarding the nature and status of the development of Part H financing systems in states. We have examined mechanisms used to develop and carry

out a plan for financing and coordinating financing across the various state agencies involved, as well as the extent to which states responding to the survey are accessing the various sources which have been identified as viable for funding Part H services. We have looked at findings from other CPSP finance studies, including the case studies, across all responding states, and have explored the possibility of new trends emerging regarding the use of sources and planning for financing Part H.

METHODOLOGY

Survey Development

A collaboration between CPSP staff studying financing issues and those studying interagency coordination issues created and designed the finance-interagency survey items so as to elicit information from Part H Coordinators in all 50 states and the District of Columbia. We anticipated that results from the survey would be compared with hypotheses developed during the case studies and other CPSP survey efforts, and that some of the demographic data gathered for previous CPSP purposes would be used in the analysis of responses to the survey.

The survey items were initially written by CPSP finance and interagency studies investigators. We reviewed the items internally, and made additions and changes. We developed a preliminary form of the survey, using both survey design research (Dillman, 1978) and formatting and design suggestions from staff data analysis consultants.

We then pilot tested this preliminary form with one Part H Coordinator, who provided valuable comments regarding the purpose of the survey, critiqued the survey item by item, and suggested item deletions and additions. We incorporated these changes into the survey, and conducted a second round of pilot testing. We asked four Part H Coordinators from demographically diverse states to complete and critique the survey. Their comments, in addition to a final internal review, led to the production of the final form of the finance-interagency survey printed for distribution.

The Part H Coordinator who was involved with the first pilot testing of the survey completed a new form of the final survey, in order that survey results from this state would be comparable with other states. We asked the Part H Coordinators involved in the second pilot testing of the survey to update and clarify answers.

Survey Mailing and Follow-ups

We mailed the surveys, with cover letters explaining the purpose of the survey, to the remaining 45 states and the District of Columbia at the beginning of June 1991. We mailed a follow-up letter to non-responding states after 6 weeks. We sent a Fax reminder to still non-responding states after another 6 weeks had passed. These processes resulted in the collection of 30 surveys

(59% return rate). We compared the responding states with non-responding states at this point, to determine if the two groups differed on amount of progress in implementing Part H, region of U.S., type of Lead Agency, and other demographic variables, such as state wealth, population, and urban/rural distribution. We found no differences. Next we prepared a preliminary report to give feedback to participating states (Clifford, Harbin, & Bernier, 1992).

At CPSP, we made one final attempt to increase the response rate for the final set of analyses, reformatting the survey into a more compact booklet. We mailed this booklet, with a cover letter again requesting a response, to the remaining non-responding states. We sent a final follow-up letter 1 month later to advise states that we could not accept responses after January 15, 1992. These efforts resulted in the receipt of 8 more surveys. The total survey response was 38, for a return rate of 75%. Appendix A displays the distribution of state responses by a number of demographic variables, indicating a high degree of match between the final sample and the total population of states.

Survey Analysis

All statistical analyses followed procedures in Statistical Analysis System (SAS), Version 6.04, from the SAS Institute, Cary, NC. Descriptive analyses, including frequencies and percentages, were computed. Further statistical analyses directed at detailing specific survey items and comparing responses of groups of related items were completed after investigators' discussions. We categorized responses to open-ended items on the survey. Results of analyses appear in the section below.

Many of the responding states wrote comments about specific practices in their states on the returned surveys. We summarized these comments by item and carefully examined them as we conducted the statistical analyses, to assure that interpretation of the results reflected the sense of the respondents. The comments also appear in the text of this report, to clarify the reporting of statistical findings.

RESULTS

We present results of statistical analyses of the data from the two sections of the survey regarding general coordination and coordination of financing in this report. A separate report of results of the portion of the survey relating specifically to interagency coordination appears under separate cover (Harbin, in preparation).

General Coordination Issues

States may attempt to coordinate Part H services and financing through use of personnel and through formalized policies and procedures often detailed in written documents. We solicited information on these issues from states in the general first section of the survey.

Use of personnel in coordination activities. In order to explore the extent of the personnel commitment to Part H, we asked states to report the number of full time and part time staff in the state officially designated to work on Part H activities, regardless of the source of fiscal support for these individuals. Of the 38 states responding to the questionnaire, 36 (94.7%) states indicated that at least one person was paid for full time work on Part H. Two states (5.3%) employed only part time staff. Of the 36 states, 20 (55.6%) also reported using part time staff. While individual configurations of numbers of full and part time staff, and thus total number of staff per state, varied greatly, 27 states (71.1%) reported a total staff of 6 or fewer. Two states (5.3%) reported in excess of 20 full time staff members. Population of the state accounted for almost half of the variance (r^2=.4686) in number of total staff, when a correlation between size of state and number of staff was run. Figure 1 indicates states' use of full time and part time staff for Part H activities.

Nearly two-thirds (25 or 65.8%) of the states indicated that staff members were acting as formally designated liaisons between Part H and other state agencies, and two additional states explained that staff were performing as informal liaisons, as part of ongoing interdepartmental committees and task forces. As might be expected, staff were most frequently assigned to work with education (22.4%), health (17.1%), mental health/developmental disabilities (14.5%), and human resources (13.2%) departments or divisions. The average number of state agencies listed by states as having Part H staff assigned as liaisons was approximately 3, with the range being from 1 to 8 agencies. Approximately two-thirds of the responding states reported that Part H staff were assigned as liaisons to one, two, or three agencies, and one-half of these reported a liaison with only one other agency.

In examining the state agencies to which these liaisons were assigned, it appears that the Part H lead agency first attempted to establish a liaison with the other "major player" agencies (education, health, and human resources), and secondarily assigned liaisons to "specialty" agencies (e.g., Medicaid, Head Start). Table 1 indicates the distribution of state departments and agencies with which Part H staff was reported to have established formal liaisons.

In addition to the use of individual staff members to coordinate efforts with other state agencies, it was common for states to make use of groups composed of mid-level managers and other decision makers from various state agencies to coordinate policy concerning special needs children's issues. In fact, nearly four-fifths (78.4%) of the responding states used such a mechanism to assist in the coordination process. Most often (67.9%), such work groups operated in an informal, rather than a formal, manner. However, if states are compared on this question by lead agency type (see Table 2), states with Health as the lead agency appear to exhibit a different pattern than the others. Whereas states with Education (58.3%) and Human Services/Developmental Disabilities (or HS/DD, 73.3%) lead agencies tended to use informal groups more often, states with Health agencies were more likely to use formal groups (42.9%) or report no such groups (42.9%).

FIGURE 1

Staff for Part H (n=38)

Number of States

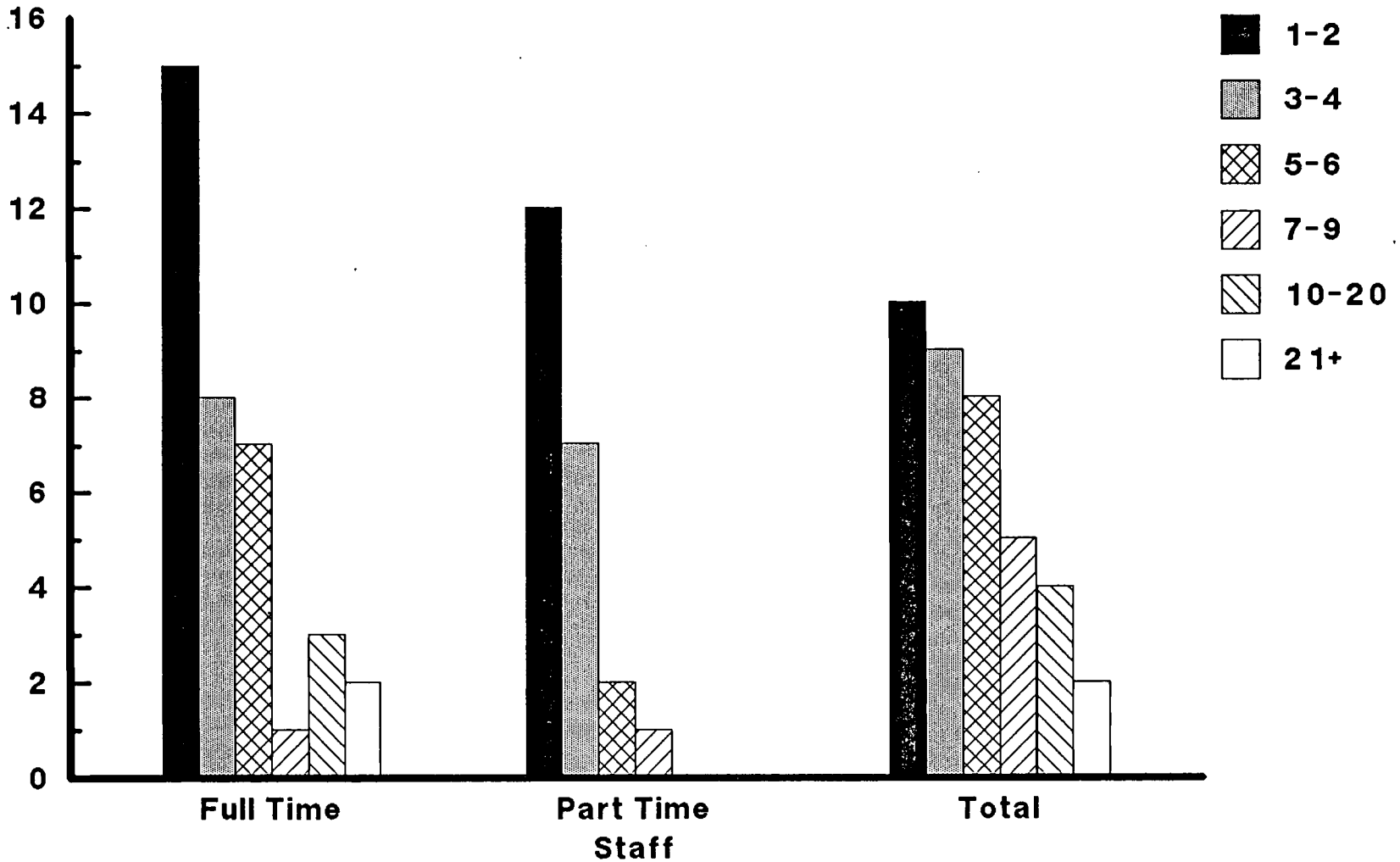

TABLE 1

STATES' USE OF STAFF AS LIAISON WITH AGENCIES (n=38)

Agency with Which Lead Agency Has Liaison Staff	Number of States
Education	17
Health	15
Human Resources	13
Mental Health and Developmental Disabilities	11
Medicaid	4
Alcohol, Substance Abuse, and Drug Programs	2
Child and Family Services	2
Developmental Disabilities Planning Council	2
Early and Periodic Screening, Diagnosis, and Assessment	2
Maternal and Child Health	2
Services for the Blind or Visually Handicapped	1
Child Development and Rehabilitation Center	1
Services for the Deaf or Hard of Hearing	1
Head Start Programs	1
Rehabilitation Services	1
University Affiliated Programs	1

States also made substantial use (69.4%) of work groups **within** a given agency. States reported intra-agency work groups, most often composed of a combination of both director level and program level staff (60.0%), and also frequently consisting only of program staff (40.0%). No states reported using only intra-agency work groups consisting entirely of director level staff. When states are compared among lead agency types on this item (see Table 3), states with Education lead agencies most frequently reported using no such intra-agency workgroups (45.4%) or groups consisting of program staff only (36.4%), whereas states with HS/DD (46.7%) or Health (57.1%) lead agencies reported combination groups of director level and program staff level more often. With only 3 states in the Interagency/Governor's Office category, trends in responses are impossible to discern.

Use of written policies in coordination activities. States are, under Part H of IDEA, to develop state level interagency agreements and to formalize service and financing responsibilities of the various state agencies involved in serving Part H eligible children. Thirty-four of the 38 responding states (89.5%) had done so at the time of their completing the survey. One of the four states that had not yet developed the required interagency agreements indicated that agreements would be forthcoming, as progress toward full implementation of Part H requirements continued. The majority of the states having formal interagency agreements in place had one (35.3%), two (29.4%), or three (11.8%) agreements, with two to nine agencies or entities signing each agreement. The maximum number of interagency agreements any state reported was ten.

A variety of people representing many different types of agencies and groups participated in developing these interagency agreements, with states reporting multiple participants. Those most often involved were Part H Coordinators (89.5% of 38 responding states), staff level representatives of state agencies responsible for service provision (73.7%), Part H staff (68.4%), Interagency Coordinating Council (ICC) members (68.4%), and director level representatives of state agencies responsible for service provision (65.7%). Others reported by more than 10 per cent of the states to have participated were director level representatives of agencies involved in the early intervention system but not providing direct services (47.4%), staff level representatives of non-service providing agencies (42.1%), Head Start representatives (26.3%), parents or advocacy groups (21.1%), local service providers (21.1%), child care providers (10.1%), and the governor's office (10.1%). Most frequently, five different agencies or groups participated in the development of the state level interagency agreements, but the number of groups participating ranged from 2 to 15.

Local agencies have the option of developing interagency agreements, also. A state may require, encourage, or simply allow local interagency agreements. While 9 states (25.0%) replied that local interagency agreements were required, most states reported systematic attempts to encourage local interagency agreements (14 states or 38.9%). Six states (16.7%) reported that such agreements were allowed or evolving, and the remaining 6 states (16.7%) indicated that no local interagency agreements existed at the time of the survey.

TABLE 2
LEAD AGENCY AND TYPE OF STATE LEVEL GROUP THAT MEETS TO COORDINATE CHILDREN ISSUES (n=36)

Lead Agency / Type Group	Education (n=12)	HS/DD (n=15)	Health (n=7)	Gov Off/IA (n=2)	Total by Group Type
Formal	3 (25.0%)	1 (6.7%)	3 (42.9%)	2 (100%)	9
Informal	7 (58.3%)	11 (73.3%)	1 (14.3%)	0	19
None	2 (16.7%)	3 (20%)	3 (42.9%)	0	8

TABLE 3
LEAD AGENCY AND TYPE OF INTERAGENCY WORKGROUP (n=36)

Lead Agency / Type Group	Education (n=11)	HS/DD (n=15)	Health (n=7)	Gov Off/IA (n=3)	Total by Group Type
Director only	0	0	0	0	0
Program staff only	4 (36.4%)	4 (26.7%)	1 (14.3%)	1 (33.3%)	10
Combination	2 (18.2%)	7 (46.7%)	4 (57.1%)	2 (66.7%)	15
None	5 (45.4%)	4 (26.7%)	2 (28.6%)	0	11

We then asked if local agencies actually had local interagency agreements and how the lead agency was selected at the local level. Of those 25 states whose local agencies have interagency agreements, 15 (60.0%) responded that they selected the lead agency at the local level, 7 (28.0%) that they required the local lead agency to be the same agency as the state level lead agency, and 3 (12.0%) reported no specific structure for selection.

Scope of general coordination. Part H requirements for service eligibility include infants and toddlers with disabilities from birth through 2 years of age. Twenty-six states (70.3% of 37 responding) indicated that this was indeed the age range included in coordination of services and financing in their state. The remaining 11 states reported a broader approach, with 10 states (27.0%) including children from birth through age 5 and 1 state (2.7%) including children birth through age 6.

Policies of other federal programs, such as EPSDT, Children's Medical Services, and the High Risk Tracking Program, may be affected as a state implements a plan to coordinate services under Part H. When we asked states to best describe what was happening in this respect in their state, 20 states (52.6% of 38 responding) reported that these other federal programs were changing their policies so that the policies could become complementary with but not identical to Part H policies. Another 8 states (21.1%) indicated that other programs were using Part H policies and procedures only for children in their programs who were Part H eligible. Two states (5.3%) answered that programs were changing their policies so as to be identical with those developed under Part H and, contrastingly, 4 states (10.5%) reported that other programs were making no changes in their policies. Two states commented that perhaps a different perspective should be taken in examining this issue, in that it is the Part H policies that have more opportunity and flexibility to integrate with the existing programs and system.

Finally, in the general section of the survey, we asked states about formal studies of coordination effectiveness currently underway. While more than half of the responding states (20 or 54.1% of 37) indicated that no such studies were in process, 16 states (43.2%) were investigating coordination of services at the state level and 17 states (45.9%) were studying coordination of services at the local level. Ten states (27.0%) were in the process of looking at coordination of financing at the state level, and 11 states (29.7%) were examining financing coordination at the local level.

The authors telephoned the states reporting financing studies after a 6-month interval, for a report on the status of the studies. Most studies were still in progress as states moved into the final phase of Part H implementation, and information presented about studies is reported with the permission of the state. Indiana, for example, was one of two states chosen to participate in a federal project providing technical assistance with Part H financing. Local financing was being reviewed for the possibility of changes. Two workgroups were in progress at the state level, looking at accessing Medicaid in Indiana and at coordinating existing dollars with federal Part H funds for direct services in this "full implementation" stage.

Kansas, which was just entering the "full implementation" of the funding cycle, was examining the maximization of resources and looking for assurance that all sources were being used in all parts of the predominantly rural state. Kansas considered the resolution of financing issues to be critical to the full implementation of Part H.

Pennsylvania was moving from a grant to fee-for-service model, and was conducting a time and motion study, similar to the study conducted in Massachusetts, and collecting agency service cost information from all Part H and Part B local providers. The goal of the study was to develop consistent service definitions with cost values attached to each, in order to evaluate the impact of moving to a Medical Assistance system. The evaluation will be conducted in terms of explicit values developed by early intervention leadership, which consists of a system that is family centered, consists of best practices, and includes all children. The impact of the proposed system will be examined in terms of the interactions among the values, the child, the family, and the system, as Pennsylvania wants to assure that its system is values-driven, not Medical Assistance (i.e., Medicaid) driven.

Financing Part H Services

One section of the survey queried states about the development and organization of financing Part H services, the current status of the Part H finance system, and expectations for future changes to the finance system. Particular attention was given to the sources used to finance Part H services and the extent to which states were using the different sources.

Current use of Part H funding sources. In order to investigate the current status of the coordination of funds and the relative use of particular funding sources, we asked states to estimate the percentage of the state's total funding for each of 44 potential sources. The sources ranged from federal education and health and human services to state and local sources and non-governmental sources such as private insurance and voluntary health or service agencies. We asked states to indicate whether each source (a) was not used in the state, (b) was used less than 1%, (c) was used from 1% up to 5%, (d) was used from 5% up to 20%, or (e) was used for 20% or more of the state's total funding for Part H services. Several states added categories of funding sources used in their states that were specific to one state and generally composed of various state funds.

Of the 38 states that responded to the survey, 6 did not complete this item on the survey. Two of the 6 states noted they were unable to answer this item, and 2 others commented that this information was only now being collected. In addition to the 6 described above, 2 states were eliminated from this item's analysis due to difficulty in interpreting their answers. Thus, 30 states were represented in the analysis of this item. A composite of responses to this question is presented in Appendix B.

We summed the number of states using a source, disregarding relative amount of use, for each fund type (federal, state and local, and nongovernmental) for all states. With 625 total reports of usage of all sources

by the 30 states, an average of 20.8 sources were used per state. Figure 2 shows the distribution of total number of sources used by the states. The range of number of sources used was from 3 to 42, with most states reporting between 11 and 25 sources used, and the median being 19.

Each source was rated regarding the percentage of its contribution to the total Part H funding package. States reported a relatively infrequent incidence of heavily used sources (at least 20% of total expenditures for Part H). Thus, we chose, in the analyses, to consider sources that were rated by states to comprise at least 5% (5 - <20% category and ≥20% category) of the funding for Part H, and categorized these as sources of moderate to heavy use. The frequency distribution of these ratings for all states for all sources appears in Figure 3. The range of the total number of moderate to heavy sources for the 30 states was from 0 to 16, with the median being 4.5 and the mean being 5.3. Most frequently (6), states reported 3 moderate to heavy Part H funding sources.

The variety of funding packages among states was greater than may be reflected in the figures. For example, one state reported using a large number of sources (36), none of which accounted for as much as 5% of the total. Six states reported no heavily used (at least 20%) Part H sources.

It might be expected that the more total sources a state reported using, the more moderate to heavy sources also would have been used in that state. It could be, however, that the more total sources a state used to finance the Part H system, the less each source must have contributed. This would then reduce the number of moderate to heavy sources. While the former pattern was, in fact, seen for this sample of states, the relationship was not strong. Across the states, the number of moderate to heavy sources per state increased as the total number of sources used for Part H funding increased.

It might also be expected that the total number of funding sources accessed would increase as the number of people and agencies involved in planning the development and implementation of the Part H system increases. Several measures of participation in the Part H system on the part of states, detailed below, were compared as to total number of sources used and number of moderate to heavy used sources. In general, the trends for the 30 states in this sample are similar across the different ways of measuring participation. As the number of persons involved in some part of the development or implementation of the Part H system increased, the total number of sources used by a state **increased** and the number of moderate to heavy rated sources **decreased**. This trend appears in Tables 4 and 5 describing number of Part H liaisons to other agencies (Table 4), and comparison of the groups (ICC Executive Committee, Task Forces, ICC, and Part H staff) with the individuals (Lead Agency Director, Part H Coordinator, and ICC Chair) involved in the development of the Part H finance vision (Table 5).

FIGURE 2

Number of Sources Used by States To Fund Part H Services (n=30)

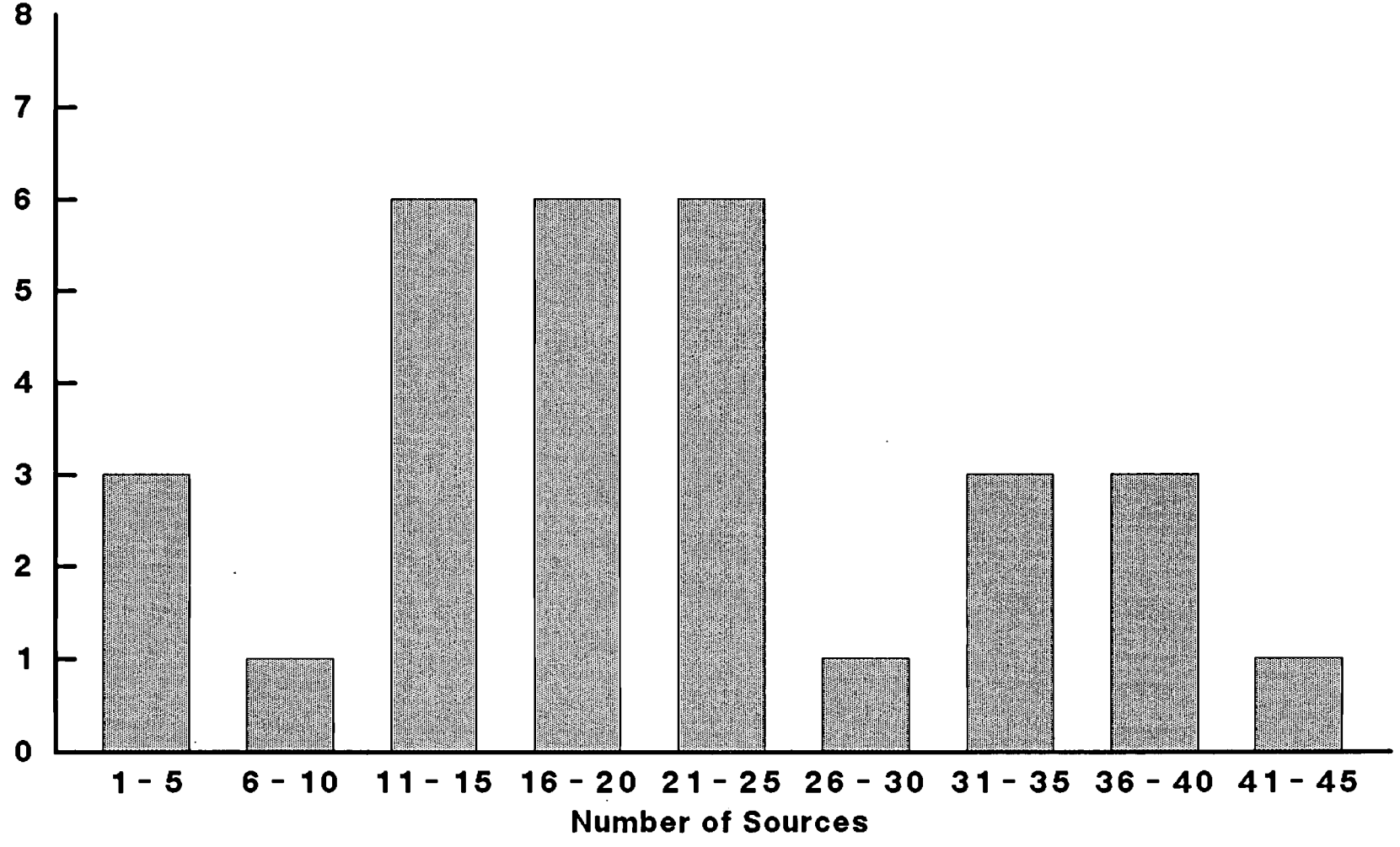

FIGURE 3

Number of Moderate to Heavy Sources Used By States to Fund Part H Services (n=30)

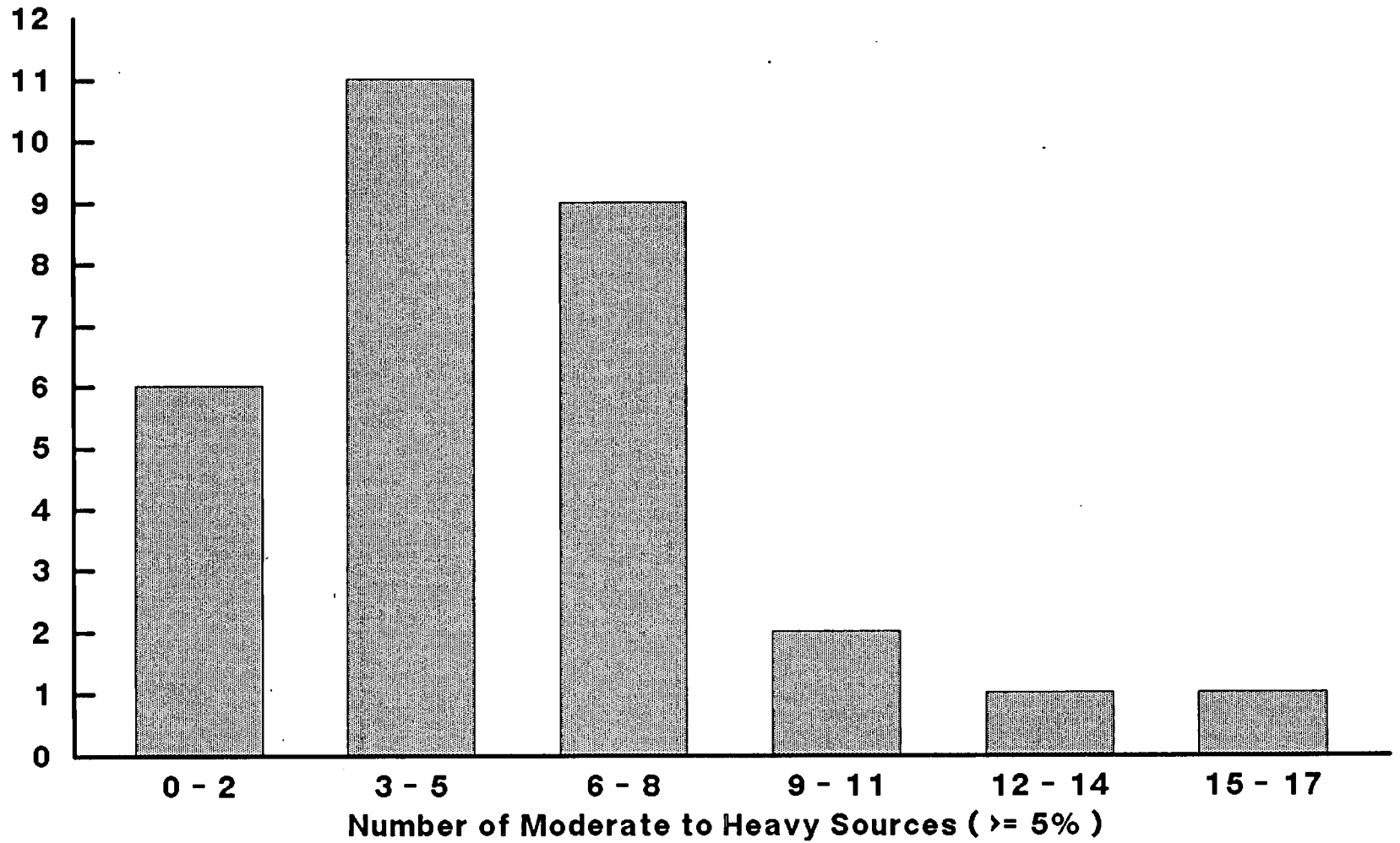

TABLE 4
PART H LIAISONS TO OTHER AGENCIES AND NUMBER OF SOURCES USED TO FUND PART H SYSTEM (n=29)

Frequency	Total number liaisons	Mean number total sources	Mean number sources at least 5% usage
11	none	17.545	6.454
11	1 - 3	22.273	5.454
7	4 - 8	24.857	4.286

TABLE 5
INDIVIDUALS IMPORTANT IN DEVELOPING PART H FINANCE VISION AND SOURCES USED TO FUND PART H SYSTEM (n=26)

Frequency	Important individuals and groups	Mean number total sources	Mean number sources at least 5% usage
14	Lead Agency Director	21.000	4.286
22	Part H Coordinator	21.045	5.545
15	Part H staff	23.267	4.000
13	ICC Chair	20.692	4.154
8	ICC Exec Committee	27.750	5.000
10	ICC	24.400	5.500
12	Task Force	25.333	6.750
16	Agency decision makers	22.250	5.434

It also appears that having interagency and intra-agency workgroups in place was related to an increase in the total number of funding sources used in a state (see Tables 6 and 7). This relationship seemed to hold regardless of whether the interagency groups were formally or informally created, and regardless of the composition of intra-agency workgroups. However, unlike the previous comparisons of sources used with numbers of people involved, the presence of these workgroups was also related to an increase in the number of moderate to heavy used sources.

On investigation of number of sources, both total and moderate/heavy, by type of lead agency designated in a state, it appears that for the sample of 30 states in this analysis, states with the lead agency in the Governor's Office or designated as Interagency were more likely than states with the lead agency in Education, Health, or Human Services/Developmental Disabilities to access more total sources (25.0/state) and indicated that these sources were used in a more moderate to heavy manner (8.0/state), on a per state basis (see Table 8). It should be noted that there were only 3 states in this category in our analysis: therefore much caution should be used in the interpretation of these data. There are, however, only 4 total states in this category--1 more than in our sample--in the 50 states and the District of Columbia, so the representation is adequate. It also appears that states with a Health lead agency were more likely to access **fewer** (15.3 total/state and 3.9 moderate to heavy/state) sources than states with Education or Human Services/Developmental Disabilities (HS/DD) lead agencies (21.25/state and 22.6/state, respectively). States with the lead agency in HS/DD tended to use about 1 more moderate to heavy use source (5.9/state) than states with Education lead agencies (4.5/state).

In order to further investigate relative amount of source usage, we applied a weighted sum of states' estimates of use to rank the sources. We created the sum with these weights: **0** if source was not used, **1** if source was used from 0 to 1%, **3** if source was used from 1 to 5%, **12** if source was used from 5 to 20%, and **20** if source was used at least 20%. We selected the weights to conservatively approximate average use within a particular category. For example, 12 is the midpoint of the 5 up to 20% range and was used as the weight of source use for sources ranked in this category. We chose the sources that had the highest weighted sums, across all the states that responded for that particular source, as the focus of the following analyses.

First we examined use of funds by type of source (federal, state/local, or nongovernmental). Based on our weighted sums, it appeared that over half of the total expenditures by states (56.7%) was from federal sources and another third (31.8%) from state and local sources. Only a small amount (11.5%) was from non-governmental sources. Examination of the federal portion in more detail revealed that the parts from federal education and federal health and human services were roughly equal (43.7% and 46.3%, respectively), with the remaining amount (10.0%) from other federal sources.

TABLE 6
STATE LEVEL GROUP MEETING TO COORDINATE CHILDREN'S ISSUES AND SOURCES USED TO FUND PART H SERVICE SYSTEM (n=29)

Frequency	Type of group	Mean number total sources	Mean number sources at least 5% usage
5	Formal	23.200	7.600
16	Informal	23.188	5.563
8	None	15.875	4.000

TABLE 7
INTRA-AGENCY WORKGROUPS AND SOURCES USED TO FUND PART H SERVICE SYSTEM (n=29)

Frequency	Type of intra-agency work groups	Mean number total sources	Mean number sources at least 5% usage
0	Director only	--	--
9	Program staff only	25.778	6.778
13	Combination	21.385	5.538
7	None	16.857	3.857

TABLE 8
LEAD AGENCY AND SOURCES USED TO FUND PART H SERVICE SYSTEM (n=30)

Lead Agency	Education (n=8)	HS/DD (n=12)	Health (n=7)	Gov Off/IA (n=3)	Total of sources
Total # sources (average per state)	171 (21.38)	271 (22.6)	108 (15.4)	75 (25.0)	625
# sources rated moderate to heavy use (average per state)	36 (4.5)	71 (5.9)	27 (3.9)	24 (8.0)	158

It is significant that every one of the 44 sources was used by at least 1 state for at least 1% of its costs. The 15 sources that were rated by states as most heavily used are described in Table 9. These top 15 sources had weighted sums that were distinctly higher than the rest of the sources' sums. The last of the 15 sources (Targeted Appropriations for Children and Voluntary Health Agencies) had weighted sums of 90, whereas the sixteenth ranked sources (Health Maintenance Organizations and Other State and Local Sources) had sums of only 60. (See Appendix B for a full listing of weighted sums.)

As evidenced in the previous paragraphs and the description of the 15 most heavily used sources (Table 9), the federal government plays a major role in financing services for infants and toddlers with disabilities. Two of the 3 most frequently used sources were federal education funds (Part H and Chapter 1/Handicapped Children). In fact, 7 of the 15 most heavily used sources were federal, with the 2 from federal education (Part H and Chapter 1/Handicapped); 3 from federal health and human services (Medicaid; Maternal and Child Health [MCH] Block Grant; Early and Periodic Screening, Diagnosis, and Treatment [EPSDT]); and 2 from federal social services (Special Supplemental Food Program for Women, Infants, and Children and Social Services Block Grant [WIC]). State and local governments also played a major role in financing Part H services, with 6 of the 15 most heavily used sources (Mental Retardation/Developmental Disability [MR/DD]; Medicaid match; Public Health/Mental Health; Maternal and Child Health [MCH] Block Grant match; Special Education; and Targeted Appropriations for Children). The remaining 2 sources were private (Private Health Insurance and Voluntary Health Agencies).

The significance of use for particular sources may also be considered if federal and state programs are grouped. For example, if weighted sums for the federal portion of Medicaid (244) and the EPSDT program (108) are combined with the state portion of the Medicaid program (165), the total Medicaid program is by far the most used source (517). Similarly, the federal and state portions for the MCH Block Grants might be combined (136 and 118, respectively), with the resulting indicator of use now at the top of the "most used" list. If weighted sums for private health insurance (94) and managed care systems (60) are added (154), private coverage greatly increases in significance of use. These combinations of sources were not used for further analysis, but were considered in the development of recommendations.

Other ways of examining usage of the different sources are also presented in Table 9. Almost all of the states (29 or 96.7%) used Part H funds for some portion of financing, while other sources most used were Chapter 1/Handicapped (27 or 90.0%), MCH Block Grant (25 or 83.3%), MR/DD (24 or 80.0%), and EPSDT (24 or 80.0%). At least half of the states used Part H (19 or 63.3%), Medicaid (17 or 56.7%), and Chapter 1/Handicapped (15 or 50.0%) for

Table 9

TOP FIFTEEN SOURCES OF FINANCING PART H EARLY INTERVENTION SERVICES (n=30[1])

Rank	Source (# in survey item)	Type of $	No. states using at least 5% (%)	No. states using less than 5% (%)	Number of states using source at least 5% by Lead Agency type: Health (n=7)	HS/DD (n=12)	Education (n=8)	IA/Gov's Off (n=3)	Weighted sum
1	Part H (1)	Federal Education	19 (63.3%)	10 (33.3%)	3 (42.9%)	9 (75.0%)	5 (62.5%)	2 (66.7%)	338
2	Mental Retardation/ Developmental Dis. (41)	State	14 (46.7%)	10 (33.3%)	1 (14.3%)	10 (83.3%)	2 (25.0%)	1 (33.3%)	254
3	Chapter 1/ Handicapped (5)	Federal Education	15 (50.0%)	12 (40.0%)	4 (57.1%)	5 (41.7%)	5 (62.5%)	1 (33.3%)	246
4	Medicaid (12)	Federal Hea/Hum Serv	17 (56.7%)	6 (20.0%)	3 (42.9%)	8 (66.7%)	4 (50.0%)	1 (33.3%)	244
5	Medicaid match (34)	State	10 (33.3%)	13 (43.3%)	1 (14.3%)	5 (41.7%)	4 (50.0%)	0	165
6	Public Health/ Mental Health (38)	State	10 (33.3%)	8 (26.7%)	3 (42.9%)	4 (33.3%)	2 (25.0%)	1 (33.3%)	148
7	Mat/Child Health Block Grant (14)	Federal Hea/Hum Serv	7 (23.3%)	18 (60.0%)	1 (14.3%)	3 (25.0%)	2 (25.0%)	1 (33.3%)	136
8	Mat/Child Health Match (35)	State	7 (23.3%)	10 (33.3%)	1 (14.3%)	3 (25.0%)	2 (25.0%)	1 (33.3%)	118
9	Women/Infnts/Child Suppl Food Pgm (30)	Federal Other	6 (20.0%)	13 (43.3%)	1 (14.3%)	2 (16.7%)	2 (25.0%)	1 (33.3%)	109
10	Special Education (36)	State	5 (16.7%)	10 (33.3%)	1 (14.3%)	1 (8.3%)	2 (25.0%)	1 (33.3%)	108
10	Early & Periodic Scrng/Diag/Trtmnt (13)	Federal Hea/Hum Serv	4 (13.3%)	20 (66.7%)	1 (14.3%)	2 (16.7%)	0	1 (33.3%)	108
12	Social Services Block Grant (19)	Federal Hea/Hum Serv	5 (16.7%)	10 (33.3%)	0	3 (25.0%)	1 (12.5%)	1 (33.3%)	100
13	Private Health Insurance (43)	Non-Governmental	4 (13.3%)	18 (60.0%)	1 (14.3%)	1 (8.3%)	1 (12.5%)	1 (33.3%)	94
14	Targeted Appropriations (39)	State	5 (16.7%)	10 (33.3%)	1 (14.3%)	3 (25.0%)	0	1 (33.3%)	90
14	Voluntary Health Agencies (45)	Non-Governmental	4 (13.3%)	16 (53.3%)	1 (14.3%)	3 (25.0%)	0	0	90

[1] Thirty-eight states responded to the survey. Two states were eliminated from this analysis due to our inability to interpret the answers. Six states did not answer this item on the survey.

at least 5% of the funding for the Part H system. All of the top 15 sources were used in some part by at least half of the responding states.

Patterns in funding sources may also be examined by considering type of lead agency (Health, Human Services/Developmental Disabilities [HS/DD], Education, and Interagency/Governor's Office) and source use. Table 9 also presents information on moderately to heavily used sources (at least 5% of total state Part H funding) by lead agency type.

Caution should be exercised in interpreting the impact of lead agency type, because the numbers of states within each lead agency type is small. However, the data seem to indicate that states with Health as the lead agency used fewer sources in the moderate to heavy range than either HS/DD or Education. These results were similar to those reported previously regarding total number of sources and number of moderate to heavy use sources by lead agency type, when considering all 44 sources. The combinations of source types moderately to heavily used do not seem predictable by type of lead agency. States with HS/DD lead agencies used primarily education and health/human services dollars; states in which Education is the lead agency used primarily education and health/human services dollars, while education funds were used most by states with Health as the lead agency. States with the lead agency in HS/DD reported the highest use of state funds (MR/DD).

Future use of Part H funding sources. We asked states, in reference to the list of 44 sources that had been rated for level of use, to indicate which were expected to substantially increase and decrease over the next 3 years. Twenty-nine states (80.6%) expected at least 1 funding source to increase and 11 (32.4%) expected at least 1 to decrease. Figure 4 shows the sources that at least 10% of the states expected will increase over the next 3 years, with EPSDT and Medicaid leading the list. The amount of Chapter 1/Handicapped funds was also expected to increase by 9 states (23.7%), although this was the one source that several other states (7 or 18.4%) expected will decrease. No other source was cited by more than one state as likely to decrease over the next 3 years.

We asked detailed questions about approaches to current and future use of two sources, private health insurance and sliding fee scales, as these are two sources of potential early intervention funding specifically mentioned in the Part H legislation (Section 1471(b)(2) and Section 1472((2)(B), respectively). As we show in Table 10, only about one-fourth of the responding states (23.7%) currently had either a formal state plan to encourage payment from private insurance or a requirement to seek reimbursement from private insurance. Almost two-thirds (65.8%), though, planned to have one of these approaches in place by 1995.

The pattern is similar for use of sliding fee scales for funding of Part H services (see Table 11). Five states (13.5%) currently were encouraging or requiring parents to be charged on a sliding fee scale. Three of those states intended to continue the current approach, 1 state planned to move from a requirement to encouragement of the use of a sliding fee scale, and 1 state was

FIGURE 4

Part H Funding Sources
Predicted to Increase (n=36)

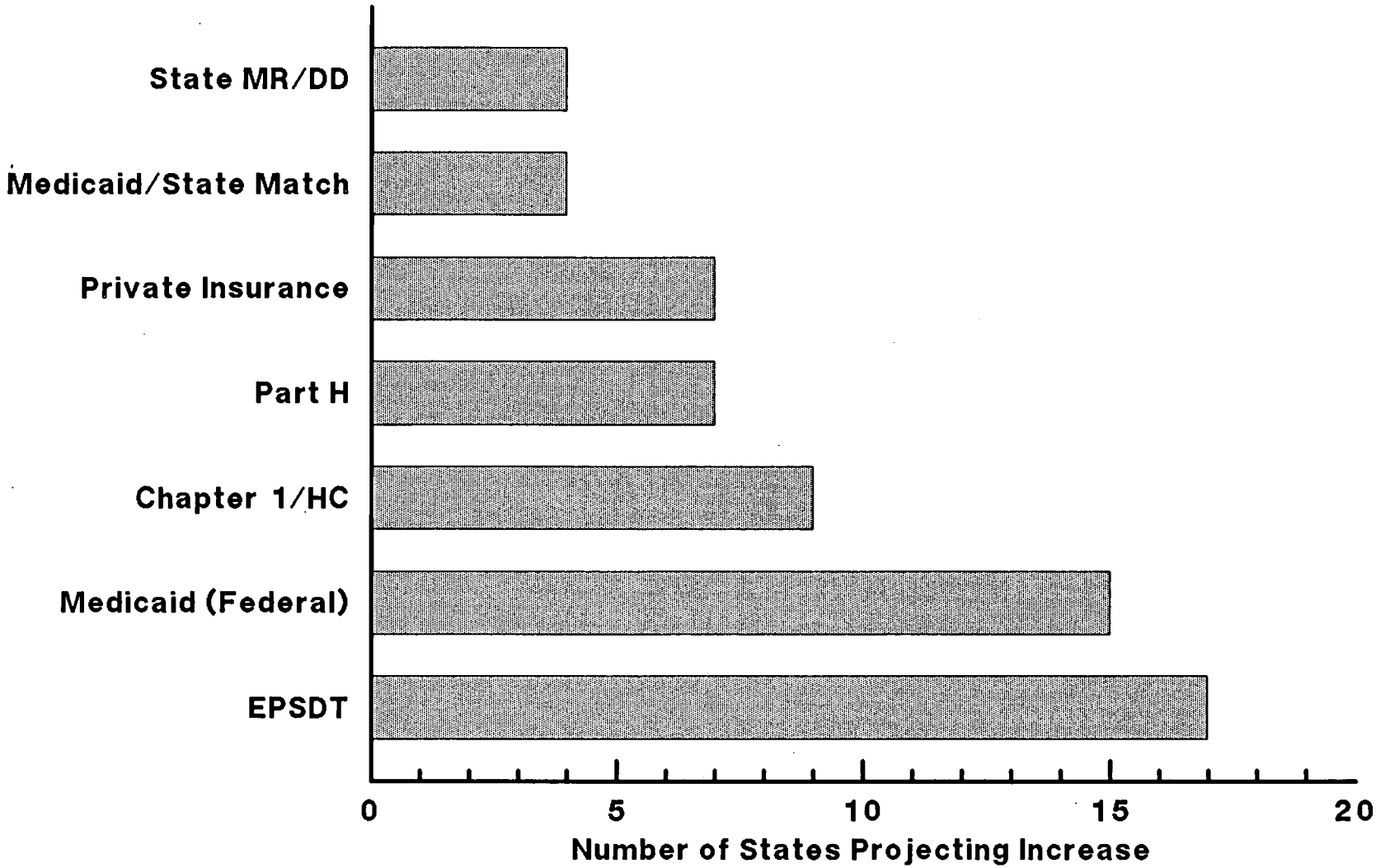

TABLE 10
CURRENT AND PROJECTED USE OF PRIVATE INSURANCE FOR PART H FINANCING (n=38)

Approaches describing use of **private insurance** for financing services	Number (%) states citing: Current use (1991)	Projected use (1995)
Private insurance is used only by individuals and families at their own discretion	19 (50.0%)	5 (13.2%)
Families are encouraged to use private insurance, but there is no formal effort at the state level to incorporate private insurance in a financing plan	9 (23.7%)	5 (13.2%)
The state has a formal plan that encourages providers to seek payment from private insurance (when legally permissable)	4 (10.5%)	16 (42.1%)
The state requires providers to seek reimbursement from private insurance (when legally permissible)	5 (13.2%)	9 (23.7%)
Unknown	1 (2.6%)	3 (7.9%)

TABLE 11
CURRENT AND PROJECTED USE OF SLIDING FEE SCALES FOR PART H FINANCING (n=37)

Approaches describing use of **sliding fee scales** for financing services	Number (%) states citing: Current use (1991)	Projected use (1995)
Providers are prohibited from charging parents fees for services	18 (48.6%)	12 (32.4%)
No formal plan for use of parent fees is in place, but providers are permitted to charge parents on a sliding fee scale	12 (32.4%)	5 (13.5%)
Providers are encouraged to charge parents on a sliding fee scale (when legally permissible) as part of the state plan for financing services	2 (5.4%)	10 (27.0%)
The state requires providers to charge parents for services (when legally permissible) as part of the state plan for financing services	3 (8.1%)	4 (10.8%)
Unknown	2 (5.4%)	6 (16.2%)

considering dropping the requirement for a sliding fee scale altogether. A total of 14 states (37.8%) projected that, by 1995, providers will be encouraged or required to charge parents for services. Eighteen states (48.6%) currently were prohibiting providers from charging parents for services, and 11 of these plus 1 additional state (12 total, or 32.4%) projected this will be the policy in 1995.

Although it might be expected that states with Education lead agencies would have had a stronger tradition of free services that might restrict use of fee schedules, we found the opposite in results of this survey. There were larger percentages of states with Health (71.4%) and HS/DD (46.7%) lead agencies than with Education lead agencies (38.5%) that currently were prohibiting charging parents for Part H services. In addition, even larger percentages were projecting prohibition in 1993 (Health: 42.9%, HS/DD: 40.0%, Education: 15.4%), as shown in Table 12. Currently, states with Education lead agencies were more diverse in their approach to use of sliding fee scales than the other lead agency types. By 1995, the picture was expected to change, with more states encouraging or requiring the use of sliding fee schedules.

We asked states to predict the overall percentage increase in state appropriations for Part H services anticipated by January 1, 1993. Part H Coordinators obviously found this prediction difficult to make; 8 (21.1%) were unable to make an estimate. The predictions of the remainder varied from "0%" to "300%". About one-fourth of the states (9 or 23.7%) predicted no increase ("0%"). Seventeen states (44.7%) anticipated between a 2 and 50% increase. Three states (7.9%) predicted a 100% increase by January 1, 1993, and the remaining state optimistically expected the 300% increase.

We also examined the amount of estimated increase in state funding in terms of region of the country and progress in developing and implementing a Part H system. States in the Northeast and Midwest seemed most pessimistic in predicting state appropriation increases. States in the West were most hopeful of moderate to large increases in appropriations for Part H services in the near future.

Yearly, a survey from CPSP has been sent to Part H Coordinators asking for a ranking of state progress in development, approval, and application of the Part H system, for each component of the legislation. Using the administration of the State Progress Scale which corresponds to the same time frame as this survey, rankings of overall progress in states were linked with amount of estimated increase in state appropriations. It appeared that, in general, the states which were further along in the implementation process believed that state appropriations will increase more than states not as far along.

Development and organization of Part H finance system. We asked states to indicate which level--local, regional, state--had been most responsible for the coordination of financing services. Most of the states responded that the primary responsibility for the coordination of funding rested at the state level, with 32 of the 37 responding states (88.9%) reporting moderate to extensive state responsibility. There was, however, notable responsibility at the local level in one-half of the states (19 or 51.3% reported moderate to extensive local responsibility) and at the regional level in one-third of the states (13 or 36.1%).

TABLE 12
LEAD AGENCY AND CURRENT PROJECTED APPROACHES TO USE OF SLIDING FEE SCALE (n=37)

	CURRENT (1991)				PROJECTED (1995)			
Lead Agency	Educ (n=13)	HS/DD (n=15)	Health (n=7)	IA/GovOff (n=2)	Educ (n=13)	HS/DD (n=15)	Health (n=7)	IA/GovOff (n=2)
Providers are:								
Prohibited from charging fees	5 (38.5%)	7 (46.7%)	5 (71.4%)	1 (50.0%)	2 (15.4%)	6 (40.0%)	3 (42.9%)	1 (50.0%)
Permitted to charge fees, but there is no formal plan	4 (30.8%)	5 (33.3%)	2 (28.6%)	1 (50.0%)	3 (23.1%)	1 (6.7%)	0	1 (50.0%)
Encouraged to charge fees	2 (15.4%)	0	0	0	4 (30.8%)	4 (26.7%)	2 (28.6%)	0
Required to charge fees when legally permissable	1 (7.7%)	2 (13.3%)	0	0	2 (15.4%)	0	2 (28.6%)	0
Unknown	1 (7.7%)	1 (7.7%)	0	0	2 (15.4%)	4 (26.7%)	0	0

There were 13 states that reported no responsibility at the regional level. Since states are organized differently, it appears that these states do not possess a regional structure for policy making and service delivery. Details of these results are portrayed in Figure 5.

The method most frequently used for assigning financial responsibility for payment of services was a formal interagency agreement (66.7%). It is noteworthy that one-quarter of the states (27.8%) have enacted state legislation to assign financial responsibility. Only two states (5.6%) have used a directive from the commissioner or secretary level to assign financial responsibility, and no states have used a decree from the governor. While 4 states (11.1%) were using informal interagency agreements in conjunction with other methods of assigning responsibility, 2 states (5.6%), both with Education as the lead agency, reported using only informal agreements at this time.

We asked states to list or describe the areas in which there have been improvements in the state plan for financing of services. The most frequently cited improvements were an increase in or more efficient use of Medicaid and/or EPSDT (64.0%) and the use of funds in a more coordinated manner (44.0%). One state commented that Part H had had a negative effect on early intervention funding by requiring coordination.

States, when asked to select issues that were barriers to developing a coordinated system of financing, typically indicated several areas of concern. At least one-half of the 37 responding states cited, as barriers, regulations concerning eligibility (62.2%), lack of personnel resources to implement changes (59.5%), "turf" issues between agencies (56.8%), regulations governing the budgeting process or financial mechanisms (56.8%), and other regulations governing use of funds (51.4%).

When the number of barriers is summed for each state and compared with various other measures, certain trends emerge. It appears that at least for the 30 states for which comparisons could be made, formal (rather than informal or no) workgroups reduced the number of perceived barriers to the coordination of the Part H finance system (Table 13). As might be expected, when interagency agreements existed and the number of interagency agreements increased, the number of barriers decreased (Table 14). States having a Health lead agency believed that more barriers to Part H implementation existed than did states where the lead agency is Education or HS/DD.

We examined the individual barriers in terms of the score on the State Progress Scale (CPSP survey previously described). On the average, states that cited particular barriers did not differ significantly in state progress toward the implementation of Part H from states that did not cite the barrier. However, the largest difference appeared in response to "lack of technical knowledge and expertise in accessing sources within the lead agency." States that cited this as a barrier had slightly lower state progress scores than states which did not cite this barrier.

Finally, we asked states to what extent certain individuals or groups had been instrumental in developing a vision of the Part H finance system.

FIGURE 5

Responsibility for Coordination of Financing For Part H (n=37)

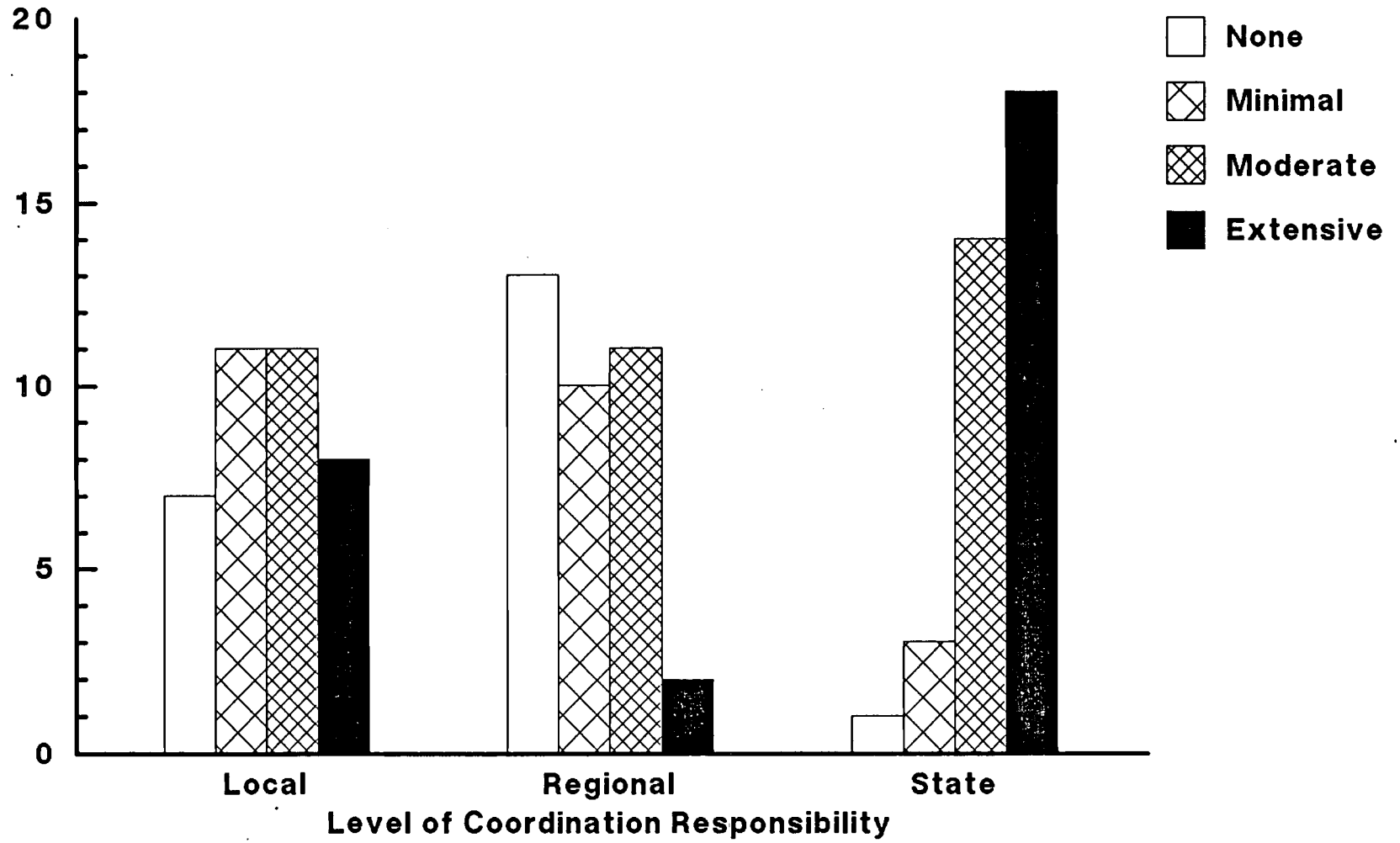

TABLE 13
STATE LEVEL GROUP MEETING TO COORDINATE CHILDREN'S ISSUES AND BARRIER (n=36)

Frequency	Type of groups	Mean number total barriers
9	Formal	2.556
19	Informal	4.105
8	None	4.125

TABLE 14
INTERAGENCY AGREEMENTS AND BARRIERS TO DEVELOPING A COORDINATED SYSTEM OF FINANCING (n=38)

Frequency	Number of interagency agreements	Mean number total barriers
4	none	4.000
12	1	4.250
10	2	3.700
12	3 or more	3.083

Previously, case studies had found that the development of a **vision**, or well-defined conception of the desired service delivery goal, was critical in the process of developing and implementing a successful Part H system. States rated the Part H Coordinator as most important in the development of a vision of a coordinated system of finance for Part H services, with a group of agency level decision makers a close second. The Interagency Coordinating Council (ICC) and its executive committee and chair seemed to be the least important in developing the vision for financing Part H services.

CONCLUSIONS AND RECOMMENDATIONS

The results of the survey attest to the huge efforts of state personnel to implement Part H of IDEA. The legislation envisioned states accessing a broad array of funding sources to support a system of services for infants and toddlers with disabilities and for their families. In fact, of the 44 different sources of financing we asked about, each source was being used by at least 1 state for at least 1% of the financing package for Part H services. On average, states reported using some 21 different sources to support the service delivery system. The states have taken the legislation at face value and have put forth incredible energy to make the most of the opportunities and challenges to identify and coordinate funding sources.

In implementing the law, states have found that financing the system was not simply a matter of gaining access to federal sources of funds that were adequate to pay the full cost of the services needed. States also found that making the system a viable service delivery system meant requiring a substantial investment of state resources, as well as taking full advantage of the array of federal sources. It is clear from both the current survey and previous interactions with a small number of case study states (Clifford, 1991) that gaining access to Medicaid, in particular, was a time and human resource consuming process. States have had to expend much time and effort that could have been directed toward building the service system to accessing the public health insurance system (e.g., Medicaid). Still, some 25% of states reported that Medicaid was not used at all and another 20% reported that the federal portion of Medicaid accounted for less than 5% of their program costs. And that was some 5 years after the legislation had been enacted.

Of course, part of the difficulty in accessing Medicaid is tied to the fact that it is jointly funded by the federal and state governments. State governments have seen dramatic increases in the proportion of their budgets required to finance the rapidly expanding budget needs of Medicaid in general, and they have been reluctant to support adding new cost items to the program. In spite of these difficulties, most states are making the commitments necessary for the Medicaid program to be a key element in financing Part H services.

Other federal programs have also played an important role in financing the needed services--the Part H program itself, Chapter 1/Handicapped program, Maternal and Child Health Block Grant program, WIC, EPSDT portion of Medicaid, and Social Services Block Grant. Seven of the 15 most heavily used funding sources came from the federal government. Based on this fact, weighting of source use, and other survey analysis results, we estimated that more than half of the total financing for Part H activities has been born by the federal government.

As mentioned above, state funding has also played a critical role in financing services. State Mental Retardation/ Developmental Disabilities programs have been used most heavily. The state portion of the Medicaid program has been the next most heavily used source, with Public Health/Mental Health programs a close third. The state has also had to match the Maternal

and Child Health Block Grant program of the federal government. State special education funds have been a major source of financing of services, with targeted state appropriations playing a less significant but still important role. State resources have contributed an estimated one third of the total revenues of operating the program.

Nongovernmental sources have played a much smaller, but still important role in the financial picture. Private health insurance and voluntary health agencies have been at the bottom of the 15 most used sources of support for Part H services. Overall, we estimated that the nongovernmental sources have supported only about one-tenth of the total cost of Part H services.

While states have made major efforts to obtain financing for Part H services, they are still short of obtaining the total amount necessary to move to full financing of the system. Thus we have seen the vast majority of states electing to postpone "full implementation" participation in the program. Below we present several recommendations regarding future efforts at both the state and federal level to improve the current situation.

Recommendations

I. STATES SHOULD CONTINUE TO FOCUS ON MEDICAID AS A SOURCE OF FINANCING PART H SERVICES.

Most states have found ways to access Medicaid and are doing so substantially. Several states, in fact, have moved from no utilization of Medicaid to implementation of regulations allowing educational agencies to bill Medicaid directly, since the beginning of Part H. However, there is much more that needs to be done in states to fully utilize the Medicaid options. There are questions about how a proposed "cap" on Medicaid would affect the ability of states to maximize the potential use of Medicaid as a source of financing for Part H services.

II. STATES SHOULD ALSO FOCUS ON STATE SOURCES.

The particular sources used most within a state-- education, developmental disabilities, or health--seem to be dependent on the situation in a given state. A state core of funding for the Part H early intervention program has previously been found to be necessary to initiate and maintain a state's system (Clifford, 1991). Broadening the network of formal state agency involvement in the planning appears to facilitate access to sources of financing.

III. STATES SHOULD BROADEN THEIR FOCUS TO INCLUDE MORE SOURCES.

Findings from previous examinations of Part H financing indicated that successful states were targeting a few major sources of funding in the early stages of implementation. This seemed to, in part, be the result of few available staff and lack of time to do more than focus on a few key sources. The survey results indicate that states have now been able to

broaden their efforts to access multiple sources. As states increase the capability to successfully obtain funds from multiple sources, the total amount available for the early intervention program should increase.

IV. STATES SHOULD WORK WITH FEDERAL AGENCY PERSONNEL AND CONGRESS TO DEVELOP A MORE COHERENT, SIMPLIFIED APPROACH TO FINANCING PART H SERVICES.

While we recommend efforts to maximize use of a broader range of sources of funds for Part H services (III above), we are convinced that major reform is needed to sharply reduce the number of sources and simultaneously greatly increase the amount of funding from this small number of sources of financing. The process of accessing many different sources of funds is inherently expensive to carry out. With tax dollars in short supply, it is inappropriate to spend large sums in the pursuit of new dollars. Neither do we want to follow the example of the health insurance industry in which much of the money is spent on administration of the system.

V. A NEW FEDERAL APPROACH TO FINANCING PART H SHOULD BE DEVELOPED AND IMPLEMENTED.

The federal government should reform the system to provide a greatly simplified and focused approach to financing the vision of providing appropriate services to infants and toddlers with disabilities and to their families, beginning at the earliest possible time in the lives of these young children. Several reasonable alternatives exist for reducing the current excessive costs of attempting to coordinate the large number of funding streams required to adequately finance services. Some suggested options are funding all Part H services under Medicaid, earmarking portions of each major piece of federal legislation affecting children to fund Part H services, and increasing Part H funds themselves to cover financing of services (Clifford, Kates, Black, Eckland, & Bernier, 1991).

While substantial cost savings are possible by simplifying the financing of Part H services, these savings are not likely to be sufficient to cover the additional funds needed to support the cost of fully implementing the Part H program nationwide. Thus, it is imperative that the total funding levels be increased substantially at the same time that the number of funding streams are reduced and simplified.

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APPENDIX A

Selected Variables Comparing States Returning Finance-interagency Survey to Non-respondents, as of 8/31/92.

	STATES RETURNING SURVEY (n=38)				
PROGRESS or DEMOGRAPHIC VARIABLE	RANKS				
	High	Mid-high	Mid-low	Low	N/A
Year 3 State Progress Scale Rank (% of rank for states returning vs. not returning survey)	10 (83%)	11 (85%)	10 (77%)	7 (58%)	0
State Population Rank (% of rank for states returning vs. not returning survey)	10 (83%)	10 (77%)	9 (69%)	9 (75%)	0
Percentage of Population Living in Metropolitan Areas Rank (% of rank for states returning vs. not returning survey)	10 (83%)	10 (77%)	8 (62%)	10 (83%)	0
Percentage of Population Living in Rural Areas Rank (% of rank for states returning vs. not returning survey)	11 (92%)	9 (69%)	8 (62%)	10 (83%)	0
Percentage of Population Living in Poverty Rank (% of rank for states returning vs. not returning survey)	9 (75%)	11 (85%)	9 (69%)	9 (75%)	0
Annual Personal Income Rank (% of rank for states returning vs. not returning survey)	10 (83%)	9 (69%)	9 (69%)	10 (83%)	0
State & Local Taxes per $1000 of Personal Income Rank (% of rank for states returning vs. not returning survey)	11 (92%)	8 (62%)	8 (62%)	11 (92%)	0
Lead Agency (% of type for states returning vs. not returning survey)	HUMAN SERVICES/ DEVELOPMENTAL DISABILITIES 15 (79%)	EDUCATION 13 (76%)	HEALTH 7 (70%)	INTERAGENCY and GOV'S OFFICE 3 (75%)	
Region of US (% of region for states returning vs. not returning survey)	NORTHEAST 8 (67%)	SOUTHEAST 8 (73%)	MIDWEST 7 (70%)	SOUTHWEST 5 (83%)	WEST 10 (83%)

APPENDIX B

SOURCE	Frequency of CURRENT LEVEL OF USE					WEIGHTED SUM
	not used or missing	<1%	1-<5%	5-<20%	≥20%	
Federal Department of Education						
1. Education of the Handicapped Act, Part H, Handicapped Infants and Toddlers	1	4	6	8	11	338
2. Education of the Handicapped Act, Part B, State Grants, Assistance for Education of All Handicapped Children	18	8	1	2	1	55
3. Education of the Handicapped Act, Part B, Section 619, Preschool Grants	12	14	2	2	0	44
4. Education of the Handicapped Act, Part C, Services for Deaf-Blind Children and Youth	14	13	3	0	0	22
5. Chapter 1, Programs for Handicapped Children	3	5	7	10	5	246
6. Chapter 1, Even Start Programs	26	4	0	0	0	4
7. Chapter 1, Disadvantaged Children	26	2	2	0	0	8
8. Bilingual Education Act	29	1	0	0	0	1
9. Chapter 1, Programs for Migratory Children	24	5	1	0	0	8
10. Technology-Related Assistance for Individuals with Disabilities Act	21	7	2	0	0	13
11. Other Federal Department of Education	26	2	0	0	2	42

SOURCE	Frequency of CURRENT LEVEL OF USE					WEIGHTED SUM
	not used or missing	<1%	1-<5%	5-<20%	≥20%	
Federal Department of Health and Human Services						
12. Medicaid, Social Security Act, Title XIX (federal share only)	7	1	5	14	3	244
13. Early and Periodic Screening, Diagnosis, and Treatment Program	6	4	16	3	1	108
14. Maternal and Child Health Block Grant, Social Security Act, Title V (federal share only)	5	5	13	6	1	136
15. Developmental Disabilities, Basic Grants to States	15	8	7	0	0	29
16. Developmental Disabilities, Grants to University Affiliated Programs	13	12	5	0	0	27
17. Head Start Act	15	9	4	2	0	45
18. Child Welfare Services, Social Security Act, Title IV-B	18	7	2	3	0	49
19. Social Services Block Grant, Social Security Act, Title XX	15	3	7	3	2	100
20. Public Health Service Act, Alcohol, Drug Abuse, and Mental Health Services Block Grant	21	4	5	0	0	19
21. Public Health Service Act, Community Health Centers	22	5	3	0	0	14
22. Indian Health Care Improvement Act	25	5	0	0	0	5
23. Public Health Service Act, Migrant Health Centers	24	6	0	0	0	6

SOURCE	Frequency of CURRENT LEVEL OF USE					WEIGHTED SUM
	not used or missing	<1%	1-<5%	5-<20%	≥20%	
Federal Department of Health and Human Services, cont.						
24. McKinney Homeless Assistance Act, Categorical Grants for Primary Health Services and Substance Abuse Services	28	2	0	0	0	2
25. McKinney Homeless Assistance Act, Block Grant for Community Mental Health Services	29	2	0	0	0	2
26. Comprehensive Child Development Act	21	5	4	0	0	17
27. Developmental Disabilities, Grants to Protection and Advocacy Systems	18	10	1	1	0	25
28. Other Federal Health and Human Services	30	0	0	0	0	0
Other Federal Programs						
29. Civilian Health and Medical Program of the Uniformed Services (CHAMPUS)	16	8	4	2	0	44
30. Special Supplemental Food Program for Women, Infants, and Children (WIC)	11	5	8	5	1	109
31. Community Development Block Grants, Housing and Urban Development	24	5	1	0	0	8
32. Bureau of Indian Affairs	23	6	0	1	0	18
33. Other Federal Programs	30	0	0	0	0	0

SOURCE	Frequency of CURRENT LEVEL OF USE					WEIGHTED SUM
	not used or missing	<1%	1-<5%	5-<20%	≥20%	
State and Local Sources						
34. State Matching Portion for Medicaid	7	1	12	9	1	165
35. State Matching Portion for Maternal and Child Health Block Grants	13	2	8	6	1	118
36. Special Education Funds	15	3	7	2	3	108
37. Other Education Funds	21	3	5	1	0	30
38. Public Health/Mental Health Funds	12	6	2	8	2	148
39. Targeted Appropriations for Children (e.g., for High Risk Children)	15	4	6	4	1	90
40. Foster Care/Protective Services/Child Welfare Funds	18	7	4	1	0	31
41. Mental Retardation/Developmental Disabilities Funds	6	4	6	6	8	254
42. Other State and Local Sources	30	0	0	0	0	60
Non-Governmental Resources						
43. Private Insurance -- Individual and Group Policies and Self Insurers	8	4	14	4	0	94
44. Health Maintenance Organizations, Preferred Provider Organizations, and Other Managed Care Systems	12	6	10	2	0	60
45. Voluntary Health Agencies (most heavily used: Association for Retarded Citizens, United Cerebral Palsy, Easter Seals)	10	7	9	3	1	90
46. Foundations and Corporate Giving Programs	13	12	4	1	0	36

SOURCE	Frequency of CURRENT LEVEL OF USE					WEIGHTED SUM
	not used or missing	<1%	1-<5%	5-<20%	≥20%	
Non-Governmental Resources, cont.						
47. Families-Sliding Fee Scale (e.g., tuition, fees, insurance deductibles, co-payments)	14	12	3	1	0	33
48. Voluntary Service Programs (most heavily used: Shriners, United Way, Kiwanis)	10	12	7	1	0	45
49. Other Non-Governmental Resources	29	0	1	0	0	3

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