

CASE STUDIES OF SERVICES
PROVIDED TO PERINATALLY EXPOSED
INFANTS/TODDLERS AND THEIR FAMILIES
UNDER PART H OF
INDIVIDUALS WITH DISABILITIES EDUCATION ACT

by

Karen Gerry-Corpening

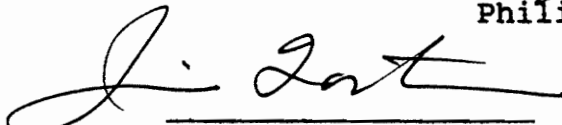
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ABSTRACT

According to Part H (Public Law 101-476), governors of each state have the authority to designate a lead agency within the state to carry out this legislation. Some lead agencies may include the Department of Education, Department of Health, or Department of Economic Security. Each lead agency has the power, within Part H, to decide whether infants and toddlers who are at risk will be served under the provisions of special education to infants and toddlers. According to The National Early Childhood Technical Assistance System (NEC*TAS) (1992), 22% of states include at risk in their definitions for Part H. Of those 11 states, only 6 include services for perinatally exposed infants and toddlers in their at risk definition. The National Association for Perinatal Addiction Research and Education (NAPARE), (1993) defines perinatally exposed as, "fetal exposure to inappropriate use of licit or illicit drugs." Delivery of care is not systematic between these state

agencies. There is a lack of knowledge of which services, if any, each delivery system offers to perinatally exposed infants/toddlers and their families. Therefore the purpose of this study was to examine the delivery of services in the six states that serve this population under the at risk definition of Part H and compare those results to three states that do not serve perinatally exposed infants and toddlers under this legislation.

Telephone interviews of 9 state Part H Coordinators were conducted to obtain information concerning various services provided to substance exposed infants/toddlers and their families. Six of those states claimed to provide services to perinatally exposed infants and toddlers under the at risk definition of Part H and three made no such claims. Data from the survey instrument were analyzed using qualitative analysis.

Findings of the study revealed that only health department lead agencies provide services to perinatally exposed infants/toddlers and their families under the at risk definition of Part H of the Individuals with Disabilities Education Act.

Data analysis provided information for making recommendations to governors and lobbying organizations who are concerned about providing services to perinatally exposed infants and toddlers.

DEDICATION

This work is dedicated to my husband Randy,
who has always loved and supported me.

And in memory of my grandmother,
Jeannette Gagne,
who always believed in me.

ACKNOWLEDGEMENTS

Sincere gratitude is expressed to members of my dissertation committee: to Dr. Philip R. Jones who was always supportive thru thick and thin; Dr. Jimmie Fortune who taught me that I do not want to do a national survey; Dr. Hal McGrady who helped to divert my attention away from "dissertating" when the going got rough; Dr. David Alexander and Dr. Elizabeth Dedman-Alexander for their patience and suggestions.

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Chapter I

We are at war. Preparation is no guarantee of winning; but the lack of it will assure defeat (Greer, 1990).

Introduction:

The problem of drug abuse "has developed a new face—the face of a baby," noted Donna R. Weston (1989). Although drug-affected babies have been present in our society for several years, their numbers have risen dramatically since the onset of the crack cocaine epidemic in the mid 1980s.

A recent national study of thirty-six hospitals conducted by the National Association for Perinatal Addiction Research and Education (NAPARE) indicates that approximately 11 percent of pregnant women use drugs during pregnancy. "Nationwide, an estimated 375,000 children each year are born exposed to cocaine," states Debra Viadero (1990). Cross-addiction is a growing problem, 40 to 80 percent of all female addicts are dependent on more than one drug (General Service Office of Alcoholics Anonymous, 1983; Roberts, 1989). According to Besharov (1989), substance abuse has become the "dominant characteristic" in the child abuse caseloads of 22 states and the District of Columbia.

Judy Howard, clinical professor of pediatrics at the University of California, Los Angeles, School of Medicine, makes the dire prediction that within a few years 40 to 60 percent of the students attending some inner-city schools

will be children who were exposed to drugs while in the womb (Trost, 1989).

Jeptha Greer (1990), then executive director of The Council for Exceptional Children, stated that no single human service agency, including schools, has the human and fiscal resources to meet the needs of these children and their families. A full-scale coordination effort must begin now to integrate the institutions and agencies providing policy/rulemaking/legislative leadership at community, state/province, and national levels.

Within a few years 40 to 60 percent of the students attending some inner-city schools will be children who were exposed to drugs while in the womb (Trost, 1989). This is a staggering prediction and one that needs attention as soon as possible. As stated by President Clinton (1993) in his economic address to Congress, "For every dollar we invest today, we'll save three tomorrow. We have to start thinking about tomorrow." These children must be served now, so that they have the best chance at a productive life tomorrow.

Statement of the Problem:

Each state in this country has the power to decide whether infants and toddlers who are at risk will be served under the provisions of special education to infants and toddlers (Public Law 101-476, Part H). According to The National Early Childhood Technical Assistance System

(NEC*TAS) (1992), 22% of states include at risk in their definitions for Part H. Of those 11 states, only 6 include services for perinatally exposed infants and toddlers in their at risk definition. Delivery of care is not systematic between these state agencies. There is a lack of knowledge of which services, if any, each delivery system offers to perinatally exposed infants/toddlers and their families.

Limitations of the Study

The study was confined to examining the minimum components of six statewide comprehensive systems for the provision of appropriate early intervention services to infants and toddlers with special needs under Part H and the services they provide for perinatally exposed infants/toddlers and their families. While qualitative research strategies were used to develop accounts of the provided services and Part H applications were examined to obtain additional information, the account was not exhaustive. Data collection occurred over a three month period and did not present the opportunity to study all aspects of the Part H delivery systems.

Another limitation may relate to the researcher's lack of previous experience in conducting a qualitative study. Efforts were made to overcome this limitation by doing extensive reading. A pilot interview allowed the researcher

to practice data collection, while being closely supervised. In addition, by recognizing this limitation, the researcher made greater effort to seek the consultation of her research consultant and to process and incorporate feedback given.

Research Questions:

This study was designed to answer the following questions:

1. Why do California, Hawaii, Indiana, Massachusetts New Mexico, and North Carolina choose to include perinatal exposure in their definition of at risk?

2. What is the comparative status for the 16 minimum components of a statewide comprehensive system for the provision of appropriate early intervention services to infants and toddlers with special needs, for the above six states?

3. What mention of accommodations for perinatal exposure are found when one analyzes the 16 minimum components?

4. Should Part H mandate that infants and toddlers who were perinatally exposed be covered under this legislation?

Definitions of Terms:

For the purpose of this study, Part H of the Individuals with Disabilities Education Act (IDEA; 1990)

needs to be defined, as well as interagency collaboration and "perinatally exposed".

Part H of IDEA

Public Law 99-457 amending the Education of the Handicapped Act, now known as The Individuals with Disabilities Education Act, IDEA, P.L. 101-476, was signed by President Ronald Reagan on October 8, 1986. In addition to other changes, this legislation created Part H of the EHA which resulted in funding for state programs for infants and toddlers with disabilities (ages birth through two years) and their families (Fourteenth Annual Report to Congress, 1992). Grants to States support coordination across agencies and disciplines to ensure that comprehensive early intervention services were made available under the Act. These services were to be provided to all eligible children below the age of three who are developmentally delayed (criteria to be determined by each state), or with conditions that typically result in delay, or (at state discretion) are at risk of substantial developmental delay (Ballard, Ramirez, & Zantel-Wiener, 1987).

Interagency Collaboration

Swan, (1984) states that interagency agreements reflect cooperative planning and implementation activities among state agencies. A coordinated effort among state agencies is often necessary to meet diverse needs.

The concept of interagency collaboration, defined by Hodge (1985), recognizes the need for support from all disciplines, if we are to efficiently utilize our resources to provide equity of opportunity to all children.

Perinatally Exposed

The National Association for Perinatal Addiction Research and Education (NAPARE), (1993) defines perinatally exposed as, "fetal exposure to inappropriate use of licit or illicit drugs." For the purpose of this study, Fetal Alcohol Syndrome (FAS) will not be included in the definition of perinatally exposed. The FAS population is often provided services under "conditions that typically result in delay" under Part H of IDEA.

Research Design

This research was a multiple case study. The researcher visited the National Association of State Directors of Special Education (NASDSE) in Alexandria, Virginia and collected information within Part H applications pertaining to the 16 minimum components of a statewide comprehensive system for the provision of Part H.

Listed below are the minimum components of a statewide comprehensive system for the provision of appropriate early intervention services to infants and toddlers with special needs (Individuals with Disabilities Education Act of 1990. 20 U.S.C. 1400, 1990).

1. State definition of developmental delay.
2. Central directory.
3. Timetables for serving all eligible children.
4. Public awareness program.
5. Comprehensive child find system.
6. Evaluation, assessment, and nondiscriminatory procedures.
7. Individualized family service plan.
8. Comprehensive system of personnel development (CSPD).
9. Personnel standards.
10. Procedural safeguards.
11. Supervision and monitoring of programs.
12. Lead agency procedures for resolving complaints.
13. Policies and procedures related to financial matters.
14. Interagency agreements; resolution of individual disputes.
15. Policy for contracting or otherwise arranging for services.
16. Data collection.

From those Part H applications, six states were identified as serving perinatally exposed infants and toddlers.

Two telephone interview guides were developed (see Appendices A and B). The telephone interviews were semi-structured and interview guides allowed the researcher to probe for additional information on items. Also many opportunities were provided for respondents to explore areas not listed on the interview guides.

Descriptive data were collected from the Part H Coordinators involved with implementation of services for perinatally addicted infants and toddlers. The intent of the study was to provide descriptive data from the perspective of the Part H applications and the Part H Coordinator concerning services provided for these infants and toddlers.

Significance of the Study:

A review of the literature reveals that very little research has been done on Part H and delivery of services for perinatally exposed infants and toddlers. Findings from this study will contribute to the literature.

The results of this study may also provide suggestions as to whether the federal legislation should mandate services for perinatally exposed infants/toddlers and their families. The results of this study may suggest the pros and cons of such action.

Chapter II

REVIEW OF THE LITERATURE

The purpose of the literature review is to summarize and analyze the theory and the research studies that guide the design of this study. The review is organized into three major sections that include:

1. Perinatal exposure;
2. The federal legislation and;
3. Resulting outcomes of Part H and perinatal exposure.

Perinatal Exposure

The National Association for Perinatal Addiction Research and Education (1993) defines perinatal exposure as, "fetal exposure to inappropriate use of licit or illicit drugs." Perinatal exposure can effect infants, toddlers and their families in many ways: physically, emotionally and educationally. These youngsters can also have an impact financially on their families and society as a whole.

Physically

Drug use among women of child-bearing years has increased significantly in the last decade (Pinkert, 1989; Kaye, 1989). Maternal abuse of substances during pregnancy places the fetus, and later the child, at risk for a variety of medical, neurological, neurodevelopmental, and behavioral

difficulties (Chasnoff, Burns, Burns, & Schnoll, 1986; Brooks-Gunn & McCarton, 1991; Kronstadt, 1991; Zuckerman, 1991; Collins & Anderson, 1992; Davis, 1992).

Postnatal exposure to substances that are inhaled by the child and/or passed through breast milk have also proven to have consequences (Bateman, 1987; Chaney, 1988; Jones & Lopez, 1988; Collins, 1989). Therefore children who are at risk include those who experience either prenatal or postnatal substance exposure.

There is not a typical profile of the child who has been prenatally exposed to drugs and/or alcohol (Cole, Ferrara, Johnson, Jones, Schoenbaum, Tyler, Wallace, & Poulsen, 1989; National Council on Disability, 1990; Griffith, 1991; Poulsen, 1991a). Refer to Appendix F for possible early indicators of prenatal exposure to toxic substances.

Harpring (1992) states the three categories of effects suffered by infants affected by prenatal exposure to alcohol and other drugs:

- 1) ADDICTION - The newborn undergoes withdrawal, after which it may grow and develop more or less normally, as if addiction had not been part of his or her short life experience.

- 2) TOXICITY - Toxic effects cause direct injury to the developing fetus.

3) TERATOGENICITY - More complex than addiction or toxicity, teratogenic effects may or may not appear at birth. Teratogenic effects involve structural damage of some sort. Drugs that act on metabolic, endocrine, or central nervous system functions may not cause symptoms to emerge until childhood or adolescence.

Fullager, Conleth, Gallagher, Loda and Shieh (1991) point to the fact that not all babies show negative effects from prenatal exposure to drugs. A variety of genetic factors in the unborn baby and maternal characteristics, as well as differences in the chemical structure of drugs and their use patterns, interact to influence the vulnerability of the unborn. No one can say for certain which baby will be all right and which will have abnormalities (Kalmar & Boronkai, 1989).

Although drugs cross the placenta and reach the fetus, their impact depends on a host of factors, such as combination of drugs used, time in pregnancy when ingested, and duration of mother's drug use (Vincent, Poulsen, Cole, Woodruff, & Griffith, 1991). Drug related effects may be worse for the fetus if the mother has a poor diet, little exercise, medical illnesses, inadequate prenatal care, or other complications of pregnancy (Fullager et al. 1991).

The fact that drugs cross the placenta and reach the fetus creates potential problems of fetal development.

Alcohol and other drugs flow rapidly and easily from the mother's bloodstream through the placenta to the baby. Because the fetal liver is not fully developed, such substances also remain in the fetus for a much longer time than in the mother (Harpring, 1992). These problems can be manifested as congenital abnormalities, fetal growth retardation, neonatal growth retardation, and neurobehavioral abnormalities (Chasnoff, 1992). The Center for Early Education and Development (1990) points to the fact the infants prenatally exposed to drugs, especially cocaine are susceptible to: weakened immune system causing chronic colds and infections; 1 in 6 chance of Sudden Infant Death Syndrome; impaired muscle development; disfigurement such as missing fingers or limbs; and infection from mother's sexually transmitted diseases.

Substance abuse can have teratogenic effects on the developing fetus. These effects may be evident at birth or may not be manifested until later in development (Weston, 1989). Numerous authors have pointed to the direct effect that substance abuse has on increasing the risk of premature delivery, eruption of the placenta, spontaneous abortion, fetal distress in labor and delivery, intrauterine growth retardation, intrauterine strokes, low birth weight, sudden infant death syndrome, and sexually transmitted diseases including AIDS (National Center for Child Abuse and Neglect,

1989; Lindenberg, Alexander, Gendrop, Nencioli, & Williams, 1991; Kronstadt, 1991; Harpring, 1992). Drug-exposed infants and children are much more likely than their non-exposed peers to need more frequent medical attention for both acute and chronic conditions (Lockwood, 1990). Prenatally drug-exposed infants are also at risk for death before their first birthday (Cook, Petersen, & Moore, 1992).

Emotionally

Bloom (1964) states that the early years are vital, possibly constituting a critical period to later cognitive and social development. Each baby needs a caregiver who recognizes and validates his or her special self (Honig, 1987). Getting to know a new infant takes time and committed interest. The infant may be more or less impulsive or reflective, more or less adaptable, irritable or slow-to warm up (Thomas, Chess, & Birch, 1968).

The at-risk infant's response to caregiving may be considerably different from those a mother would expect. The infant may not calm down when held, accept food, look at her mother's face or smile readily (Poulsen, 1991). She may tense when held and arch her body away instead of cuddling when her mother holds her close.

Chasnoff (1993) and his colleagues generally agree that the presence of cocaine in an infant's body at birth is not in itself necessarily disabling. The problem, they say is

that these babies often go home to environments so disorganized that the children have no opportunity to recover from the prenatal damage. The worst damage that drugs may do is to the world a child inhabits after birth (Marshall, 1991; Goodman, 1992; Liaison Bulletin, 1992). Early insecure attachment patterns and ongoing environmental instability are factors that contribute to the emotional difficulties of these children (Lumsden, 1990, Bowsher, 1990). Maternal-infant bonding is undeniably one of the most crucial aspects of healthy child development (Fejes-Mendoza, 1991, National Resource Center on Family Based Services, 1991). A normal parent child attachment lays the groundwork for developing trust and the ability to interact with others (National Center for Clinical Infant Programs, 1988). These babies will not develop those basic skills and will be at risk in terms of getting along with others (Center for Early Education and Development, 1990).

Agosta (1987) states that providing home care to a child who is at risk can be a challenging task, taxing a family's emotional and financial resources. For many families the initial recognition that a potential disability may exist presents an immediate crisis that evolves into a life crisis. Several of the problems families can experience include:

- * Natural reactions to the discovery that a family member

has a developmental disability, including a sense of shock or numbness, denial, grief, shame, guilt and depression (Fortier & Wanlass, 1984; English & Olsen, 1978);

- * Chronic stress (Wikler, 1983; Kozak & Marvin, 1984; Backman-Bell, 1981);

- * Extraordinary time demands involved in providing personal care to the family member in need (Apolloni & Triest, 1983); and

- * Lack of the skills needed to cope with the potential medical emergencies and/or to teach necessary adaptive skills (Turnbull, Summers, & Brotherson, 1985).

Educationally

Los Angeles Unified School District (1989) points to the fact that since there is no "typical profile" of a drug-exposed child each child must be educated as an individual with particular strengths and vulnerabilities.

Viadero (1992), quotes Chasnoff as saying "that 30 to 40 percent of the children in a 1986 longitudinal study continue to display delays in language development or problems in concentrating and focusing attention." Dan R Griffith, a developmental psychologist participating in the study, notes that drug-exposed toddlers in the study also tend to score lower than non-exposed toddlers on tests measuring their ability to concentrate, interact with others

in groups, and cope with an unstructured environment (Viadero, 1990).

Naomi Kaufman (1990) identifies other difficulties that may plague drug-affected children. "At the least they include a much higher likelihood of lower intelligence; short attention spans; hyperactivity; inability to adjust to new surroundings and trouble following directions--all traits that can lead to failure in school." The research of Howard and Beckwith, of UCLA, (Center for Early Education and Development, 1990) tells us that drug-exposed toddlers score low to average on structured developmental tests. But what is of most concern is that these children show striking deficits in free play situations requiring organization, initiative and follow-through -- a vital way of learning for toddlers (Wehling, 1989).

In order to work effectively with young children prenatally exposed to drugs and/or alcohol, educators must recognize the vulnerabilities arising from both biological and environmental risk factors. They must also recognize the children's strengths and the ways in which they are like typical children. Pinkerton (1991) states appropriate intervention strategies must be selected based on the systematic application of what is known about successful early intervention.

Financially

Bowsher (1990) stated before the United States Senate that perinatally exposed infants constitute a growing national problem necessitating medical and social services that will cost billions of dollars in the years to come. One estimate puts the cost of services for drug-exposed children who are significantly impaired to be as high as \$750,000 for the first 18 years of life.

The Center for Early Education and Development (1990) points to the fact that these medically fragile infants create new demands on foster families and social workers. A U.S. Department of Human Services survey of 8 cities found that in 1989 nearly 9,000 babies were born to crack-addicted mothers. Caring for those 9,000 babies alone would cost \$500 million for hospital and foster care through age 5. Additional costs of preparing these children for school could exceed \$1.5 billion (Center for Early Education and Development, 1990).

Federal Legislation

The impact of the law upon children with disabilities and those who are at risk is substantial. Gallagher, Harbin, Thomas, Wenger & Clifford (1988) state that the passage of P.L. 99-457, represents one of the more imaginative and challenging pieces of legislation that has been passed by Congress in the past several decades. This

legislation requires transforming a fragmented, and often inaccessible, collection of services provided by different agencies (Brewer & Kakalik, 1979; Gans & Horton, 1975) into a comprehensive, multidisciplinary, interagency, coordinated system of early intervention services (Zabel, 1991; Harbin, Gallagher, Lillie, & Eckland, 1990; Harbin & McNulty, 1990).

The need for this particular legislation became evident following the implementation of P.L. 94-142. This law inappropriately named Education for All Handicapped Children (because it did not include children from birth to age three), revealed a substantial gap in the pattern of service delivery to children and families. In addition, there has been continued and accelerated interest in the importance of the early childhood years and a realization of how important those years were to the developmental progress of children. Finally, there was a recognition of the impact and stress placed upon the family unit by the presence of a child with disabilities in the family, with both a potential traumatic influence upon the initial discovery and continued stress and conflict within the family due to the daily concerns of the family (Sameroff & Chandler, 1975; Gallagher, 1992; Lazar & Darlington, 1982). All of these factors combined to lead key legislators to press for a law that would provide services from birth on for children with disabilities and their families.

Rep. Pat Williams (D-MT), Chair of the House Subcommittee on Select Education which sponsored HR 5520 which became P.L. 99-457, said:

"This piece of legislation is the most important thing that this Congress will do for handicapped infants and young children up to the age of 5 in this decade and perhaps for the remainder of this century. This legislation will require commitment, effort, expertise, long hours, and, yes, money" (National Association of State Directors of Special Education (NASDSE), 1986).

According to Education of the Handicapped Act (now known as the Individuals with Disabilities Education Act): 20 U.S.C. 1401-1485 (1986),

(a) The Congress finds that there is an urgent and substantial need-

(1) to enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay,

(2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age,

(3) to minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential of their independent living in society, and

(4) to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.

To understand these findings, one must consider Public Law 101-476, Individuals with Disabilities Education Act (IDEA); specifically Part H of IDEA which is the Early Intervention Program For Infants And Toddlers With Disabilities.

Federal Regulatory Processes

With the passage of P.L. 99-457 and the signature of President Reagan in late 1986, the responsibility for implementation moved to the Secretary of Education (Trohanis, 1988). Within the Department of Education, the Office of Special Education and Rehabilitative Services began to enable the development of the Early Intervention Program for Infants and Toddlers with Disabilities (Office of Special Education and Rehabilitative Services, 1988). Eleven months after passage, on November 18, 1987, proposed regulations were published and 60 days were allowed for public comment (Brown, 1990). This period was later extended for 30 additional days. Over 2,500 written comments were received from agencies, individuals, and

organizations (Smith, 1988a). After the comment period, 16 months elapsed before the final regulations were published on June 22, 1989 (Silverstein, 1989).

Brown (1990) states that nearly two full years, or almost half the developmental time period available to states prior to providing all components of a statewide system of early intervention had elapsed. The extended time leading to the release of final regulations can be directly attributed to the controversy over some aspects of the program, the strength of individual advocacy groups, and extensive reviews from various government agencies (Ballard, et al. 1987).

Part H of IDEA

With the passage of Part H, all states were required to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for infants and toddlers with disabilities and their families (Zantal-Weiner, 1988; Intriligator & Goldman, 1989; Fullagar et al. 1991; Horne, 1991; Place, Gallagher, & Eckland, 1991). As defined by Regulation 303.16 (34 Code of Federal Regulations), "infants and toddlers with disabilities" means individuals from birth through age two who need early intervention services because they-

(1) Are experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in one or more of the following areas:

- (i) Cognitive development;
- (ii) Physical development, including vision and hearing;
- (iii) Language and speech development;
- (iv) Psychosocial development; or
- (v) Self-help skills; or

(2) Have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

(b) The term may also include, at state's discretion, children from birth through two who are at risk of having substantial developmental delays, if early intervention services are not provided (34 Code of Federal Regulations).

Part H provides funding and phased-in requirements over four years. By the fifth year of a state's participation in the program, early intervention services must be available for all infants and toddlers with disabilities and their families. The timelines to receive a grant for the:

First Two Years: The Governor must designate a lead agency (there is state discretion respecting which agency is designated) for overall administration of the program. The Governor must also establish an Interagency Coordinating Council composed of relevant agencies, consumers, and

providers. This Council is to assist in the development and implementation of the state applications, as well as assist in interagency agreements and the identification of resources, and is to otherwise advise the state. The Council may also serve as the lead agency.

Third Year: The state must demonstrate that it has adopted a public policy which provides all of the components of a statewide system for providing early intervention services to all eligible infants and toddlers.

Fourth Year: The state must demonstrate that it has in effect a statewide system for providing early intervention services. The state must also provide for all eligible children the following: multidisciplinary assessments, individualized family service plans, and case management services.

Fifth and All Succeeding Years: The state must make available to all handicapped infants and toddlers within the state appropriate early intervention services (Council for Exceptional Children (CEC), 1986; Dugan, 1986; Garwood, 1987; Lowenthal, 1987).

As previously stated, a state that desires to receive financial assistance under Part H shall establish a State Interagency Coordinating Council (ICC) composed of at least 15 members (34 Code of Federal Regulations). The Council and the chairperson of the Council must be appointed by the

Governor. The Governor shall ensure that the membership of the Council reasonably represents the population of the state (Dugan, 1986; Garwood, 1987; Gilkerson, Hilliard, Schrag & Shonkoff, 1987; Goldman & Intriligator, 1990).

According to Regulation 303.601 (34 Code of Federal Regulations) The Council must be composed of the following:

(a) At least-

(1) Three members who are parents of infants and toddlers with disabilities or of children aged three through six with disabilities;

(2) Three public or private providers of early intervention services;

(3) One representative from the state legislature; and

(4) One person in personnel preparation.

(b) Other members representing each of the appropriate agencies involved in the provision of or payment for early intervention services to eligible children and their families, and others selected by the Governor.

Each Council shall, according to Regulation 303.650 (34 Code of Federal Regulations):

(a) Advise and assist the lead agency in the development and implementation of the policies that constitute the statewide system;

(b) Assist the lead agency in achieving the full participation, coordination, and cooperation of all appropriate public agencies in the State;

(c) Assist the lead agency in the effective implementation of the statewide system, by establishing a process that includes-

(1) Seeking information from service providers, case managers, parents, and others about any Federal, State or local policies that impede timely service delivery; and

(2) Taking steps to ensure that any policy problems identified under paragraph (c)(1) of this section are resolved; and

(d) To the extent appropriate, assist the lead agency in the resolution of disputes.

In addition to the above functions the ICC is also responsible for:

1. Advising and assisting the lead agency in its administrative duties (Regulation 303.651).

2. Applications (Regulation 303.652).

3. Annual report to the Secretary (Regulation 303.653).

In addition to appointing the ICC and its chairperson, the Governor from each state must designate a lead agency (there is state discretion respecting which agency is designated) for overall administration of the program

(Association for Retarded Citizens [ARC], 1986; Gilkerson et al. 1986). Regulation 303.142, of Part H of IDEA, defines lead agency as the agency in each State that will be responsible for the administration of funds provided under this part. Approximately half of the states have designated health or health and social services as lead agency. The other half is predominantly education with a few other state agencies designated. (Refer to Appendix E for the departmental location of state lead agencies for Part H.)

Regulation 303.500 (34 Code of Federal Regulations) states that each system must include a single line of responsibility in a lead agency that-

- (a) Is established or designated by the Governor; and
- (b) Is responsible for the administration of the system, in accordance with the requirements of this part.

Regulation 303.501 pertains to supervision and monitoring of programs:

(a) General. Each lead agency is responsible for the general administration, supervision, and monitoring of programs and activities receiving assistance under this part, to ensure compliance with the provisions of this part.

(b) Methods of administering programs. In meeting the requirement in paragraph (a) of this section, the lead agency shall adopt and use proper methods of administering each program, including-

(1) Monitoring of agencies, institutions, and organizations receiving assistance under this part.

(2) Enforcement of any obligations imposed on those agencies under Part H of the Act and these regulations;

(3) Providing technical assistance, if necessary, to those agencies, institutions, and organizations; and

(4) Correction of deficiencies that are identified through monitoring.

Gilkerson et al. (1987) states that without this critical requirement, there is an abdication of responsibility for the provision of early intervention services for handicapped infants and toddlers. Although the bill recognizes the importance of interagency responsibility for providing or paying for appropriate services, it is essential that ultimate responsibility remain in a lead agency so the "buckpassing" among state agencies does not occur to the detriment of the handicapped infant or toddler (Smith, 1988a).

The selection of the lead agency is very important as are the characteristics and skills of the Part H Coordinator. Harbin (1991), states that in particular, characteristics and skills of the Part H Coordinator or the lead agency director appear critical in the successful negotiation of the policy development phase of Part H. These skills include: (1) being knowledgeable about state

systems; (2) having previous experience with interagency approach; (3) using a participatory policy development style; (4) being informed about funding sources and systems; (5) having political skills that encourage actors such as legislators and the Governor to support Part H; and (6) being willing to take risks.

Specifically, Part H offered planning funds to the individual states in return for each state's promise to create over five years, a comprehensive system to address the full range of developmental needs of all eligible children during their first three years of life (Babies Won't Wait, 1990). The legislation authorizes and requires a broad range of "supportive" services not ordinarily thought of as educational services, including physical therapy, occupational therapy, multidisciplinary assessments, and speech and language clinical services (Intriligator et al. 1989).

The National Early Childhood Technical Assistance System (NEC*TAS) has monitored the progress of states toward the goal of a comprehensive Part H system. Through four of the reports written by NEC*TAS staff (Harbin, Gallagher, & Lillie, 1989; Harbin, Gallagher, Lillie, & Eckland, 1990; Harbin, Gallagher, & Lillie, 1991; and Harbin, Gallagher, & Batista, 1992), the states showed continuing progress toward their goal of full implementation.

States began submitting their applications for fourth year funds under the Part H program in the spring of 1990. Applications trickled in over the course of the year. As the July 1991 deadline for applying for fourth year funds approached, it became clear that a number of States were not ready to meet the fourth year requirements.

According to Gallagher (1993), the major barriers that slowed state progress in the implementation of Part H included: (1) the sheer volume of difficult policy decisions to be made; (2) the difficult financial situation that the states faced; (3) a lack of direct authority or power to the lead agency, which resulted in time consuming negotiations and compromise to achieve needed consensus; and (4) many of the policy areas required novel and creative solutions.

The only option open to these states was to drop out of the program. Rather than lose States from the program, Congress proposed amending Part H requirements. These amendments became law on June 6, 1991 and are applicable for 1990, 1991, and 1992 only (Fourteenth Annual Report to Congress, 1992).

To encourage states to move forward with the development of an early intervention system, Congress adopted a system of differential funding. States experiencing significant hardships in meeting the requirements of the fourth and fifth year of participation

are eligible to receive extended participation grants. An extended participation grant for FY 1990 is an amount equal to the state's FY 1989 payment; an FY 1991 or FY 1992 extended participation grant is equal to the amount the state would have received for FY 1990 if the state had met the criteria for the fourth year of participation.

To be eligible for extended participation, a state had to satisfy the requirements for the third or fourth year of participation and submit a request by the Governor and an application. (Fourteenth Annual Report to Congress, 1992)

Early intervention services provided under Part H are to be provided at no cost to families except that states may charge fees to parents for certain services where Federal or State law provides for a system of payments by families and where the inability to pay will not result in the denial of services (Dugan, 1986). Federal, state, and local funds, along with private insurance, may be used to pay for early intervention services. The Part H program is designated as "payor of last resort" meaning that Part H funds may not be used to pay for services that would otherwise have been paid for from another source if not for the financial support provided by the Federal government through Part H. A survey conducted in the early years of Part H found that States were using a variety of sources to pay for early intervention services. On the average, states reported

using more than 11 different sources with a general range of between 4 and 15 sources (Gallagher, Harbin, Thomas, Wenger, & Clifford, 1988a).

According to Brown (1990), states are charged not only with implementing policy, but in many instances must develop and gain approval for new policies related to this legislation. The discretionary nature of Part H meant that legislation needed to allow states considerable flexibility in how they implement the federal requirements in order to encourage their participation.

According to Gallagher (1993), one of the major requirements spelled out by this law is that states establish a definition as to which infants and toddlers will be eligible for services. The federal government was following its particular style in this law of determining what the states should do, but not how they should do it.

One of the major challenges state and jurisdiction policy makers have faced under Part H of IDEA, has been the determination of definitions and criteria of eligibility for services for infants and toddlers, birth to age 3 years, and their families (NASDSE, 1988; Harbin, Terry, & Daguio, 1989; Harbin, Danaher, & Derrick, 1992). States that reach the full implementation stage of this federal legislation must provide services to two groups of children: those who are experiencing developmental delays, and those who have a

diagnosed mental or physical condition that has a high probability of resulting in developmental delay (Shackelford, 1992). In addition, states may, if they choose, serve children who are at risk of having substantial developmental delay, if early intervention services are not provided (Brown, 1990).

Although the language that the states used in creating a definition mirrored closely the language in the law itself for developmental delay and established risk conditions, states differed substantially in what they saw as the specific criteria that would be used to determine eligibility (Gallagher, 1993).

Shackelford (1992), Harbin, Terry, and Daguio (1989) state that the task of defining the eligible population has been difficult for states. How narrow or broad the definition is influences the numbers and types of children needing or receiving services, the types of services provided and ultimately the cost of the early intervention system (Harbin, Gallagher, & Batista, 1992). Several states have conducted extensive impact and cost studies before finalizing their definitions (Shackelford, 1992). The reluctance to include at risk children, despite a widespread desire to do so, was clearly due to the financial difficulties in which the states found themselves and the large increase in financial support that would have to be

found to provide comprehensive services (Gallagher, 1993). Many states have redefined and narrowed their definitions, especially if they have experienced financial difficulties.

Gallagher (1993) stated that in 1991, 20 states were considering including at risk children in their definitions. Brown (1990) stated that early in the planning stages, many states indicated that they would serve children at risk, but this number has decreased as concerns about differences of opinion about who is at risk and by concern over projections of the amount of financial resources required to include this group.

Currently, 11 states (Arkansas, California, Colorado, Hawaii, Indiana, Louisiana, Michigan, Mississippi, Massachusetts, New Mexico and North Carolina) serve at risk infants and toddlers (Shackelford, 1992). (As of November 6, 1993, Mississippi has elected to no longer participate in the Part H program (Early Childhood Report, 1993)). Of those 11 states, only 6 (California, Hawaii, Indiana, Massachusetts, New Mexico and North Carolina) include services for perinatally exposed infants/toddlers and their families in the eligibility requirements for at risk (Part H applications, 1993).

Van Bremen (1991) along with Shonkoff and Meisels (1991) state that even those states that have decided to provide early intervention services to perinatally exposed

infants and toddlers are under pressure to limit costs by restricting these services. Some states that are not serving at risk under their definition indicate that they will monitor the development of these children and refer them for early intervention services as delays are manifested (Shackelford, 1992).

Harbin, Gallagher and Terry (1991) and Harbin and Maxwell, (1991), state there are substantial differences among states as to which factors place a child at risk. Various states use biological factors, while others use environmental conditions. Gallagher (1993), states that many states tried to identify a test or other instrument to determine eligibility. Further analysis indicated that some of the factors or criteria included in the definitions were vague and could be interpreted differently by different professionals (Harbin et al. 1989).

Most states ended up using a combination of quantitative and qualitative criteria but still differed in the level of delay necessary to establish eligibility. Only a few states finally decided to include some form (biological risk, environmental risk, combinations, etc.) of at risk children in the eligibility policy (Gallagher, 1993).

Shonkoff et al. (1991), defined biological risk as children whose pediatric history or current circumstances

reveal significant biological condition(s) that do not lead invariably to developmental delay or disorder, but carry a greater probability of delay and disability than is found in the general population (for example, low birth weight, asymptomatic congenital cytomegalovirus infection, perinatal asphyxia, chronic lung disease, failure to thrive).

Environmental risk is defined as (Shonkoff et al. 1991) children whose pediatric history, caregiving circumstance, and current family situation contain risk factors that do not lead invariably to developmental delay, but that carry a greater probability of delay or disability than is found in the general population (for example, maternal mental illness, parental substance abuse, significant family social disorganization, extreme poverty, parental intellectual impairment, disturbed parent-child interaction, low maternal education, family isolation and lack of support, homelessness, history of inadequate prenatal care, child abuse or neglect).

Other examples of environmental risk factors could include the following: in 1979, 16% of children in the United States lived below the poverty level, with an increase to 20% by 1988 (Isaacs & Benjamin, 1991). By 1991, 27% of all births were to unwed mothers (Raspberry, 1992). The rate of nonmarital births to adolescent mothers has more than doubled over the last 25 years (Brooks-Gunn & Chase-

Lansdale, 1991). Adolescent mothers also have higher poverty rates, and they have low motivation and expectations and inadequate schooling (Brooks-Gunn et al. 1991). Almost 44% of grandmothers across all ethnic groups in the United States provide care for at least one grandchild (Raspberry, 1992).

Research in child development demonstrates that outcomes for children at risk for disabilities cannot be predicted reliably on the basis of single risk factors (Shonkoff et al. 1991). Such a single factor approach is inconsistent with both the multidimensional definition of early intervention described in Part H and the multidetermined nature of risk and disability (Meisels & Provence, 1989). Rather, predictions must be formed by an understanding of the multidimensional, transactional nature of the developmental process over time (Kochanek, Kabacoff, & Lipsitt, 1990).

Resulting Outcomes

Early intervention is suggested as a strategy in almost every area of educational endeavor (Kirk, 1977; Skeels & Dye, 1939). The importance of comprehensive, coordinated health care services and education for all children in this nation is widely recognized (Select Panel 1981; AAP 1977; Haggerty 1975) and the lack of such services, especially for children with disabilities has been well documented (Brewer

et al. 1979; U.S. Department of Education 1980; Kronstadt, 1991).

Comprehensive health care services are of special importance for children at risk for developing disabling conditions (Center for Early Education and Development, 1990). Accumulating evidence shows that the earlier disabilities are detected and treated, the greater the chance for remediation and the greater the chance of lessening their impact on children, families and society (Simeonsson, Cooper & Scheiner 1982; Kronstadt, 1991).

The infant delivered to a drug-addicted woman is at risk for problems of growth and development as well as neonatal abstinence, and is also at increased risk of infections and exposure to HIV (Liaison Bulletin, 1992). The long term outcome of these infants is influenced not only by the mother's use of illicit substances but by the frequent additional use of licit substances, such as cigarettes and alcohol. The drug-seeking environment in which many of these children are raised also may impair maximal development for these infants (Liaison Bulletin, 1992). In addition, many women from substance-abusing backgrounds lack a proper model for parenting and require intervention by the health community to guide them in their roles as parents (Kronstadt, 1991). Chasnoff (1992) states that multiple factors in the lives of these children,

compounded by the early neurobehavioral deficits of drug-exposed newborns, earmark these infants to be at high risk for continuing developmental and later school problems.

The problems involved in evaluating the effects of maternal exposure to substances of abuse on the developing fetus and infant are multiple, not the least of which are the difficulties involved in following these infants over a long period. Chasnoff (1989) states the chaotic and transient nature of the drug seeking environment impairs the intensive follow-up and early intervention processes necessary to ensure maximum development by each infant. In addition, most women from substance-abusing backgrounds lack a proper model for parenting. These factors, compounded by the early neurobehavioral deficits of the drug-exposed newborns, earmark these infants to be at high risk for continuing developmental and later school problems (Chasnoff, 1989).

With sustained early intervention, Chasnoff (1993) states some children may be left with a disability when they enter school, but many will develop normally. The problem is that only 10 percent of all cocaine-exposed babies are receiving such early intervention, and most of the children will not be found until they turn up in kindergarten or first grade.

Research into the effects of drugs on fetuses, particularly the effects of crack, cocaine, and multiple drug use, is in its infancy. A few children appear to suffer few long-term effects, while some appear to suffer serious lasting effects. The vast majority fall somewhere in between. They appear to experience some effects of drug exposure, but how long these effects will last, and how serious they are, is as yet largely unknown. Lockwood (1990) states that the only certainty is that the effects of prenatal drug exposure are much more likely to be of lasting detriment to children who do not receive services designed to counter these effects.

Intriligator et al. (1989) state that for many children early intervention will allow them a better chance to become functionally able citizens. Early intervention might lessen the debilitating effects of some disabling conditions. The medical and human services professional communities urged the passage of P.L. 99-457 in the belief that the earlier a child with disabilities is identified and diagnosed, the more positive the results of the intervention program.

National Education Goals (1990) first Goal states, "All disadvantaged and disabled children will have access to high quality and developmentally appropriate preschool programs that help prepare children for school." The Division for Early Childhood (1992), a division of The Council for

Exceptional Children, states that quality early education and child care should be a birth right for all children. These services must be comprehensive, coordinated, focused on individual family and child needs, and available to all families that need and choose to use them. DEC states that it is not appropriate to screen children into or out of early education programs. All children must be given a legitimate opportunity to learn. Education in the 21st century must attend to children's social and emotional growth and development not merely focus on academic outcomes.

Gilkerson et al. (1987) commenting that P.L. 99-457 offers us an opportunity to create programs that offer children and families a coherent core of basic services. Infants Can't Wait, (1986) states that we should expand comprehensive, integrated services for infants and toddlers with special health and developmental problems or disabling conditions and for their families.

Rist (1990) suggests that an early identification system should be developed within the schools. Alliances need to be formed with local hospitals, health departments, and child-protective service agencies to provide early warning of children and families needing intervention.

Weston (1989) warns that when we generalized about characteristics prevalent among drug-affected babies, we may

unwittingly begin to engage in stereotyping. The press has had a lot to say about these children, including:

"... Born to Lose" (Crack Babies, 1989)

"... No Hope Babies" (Bearak, 1989)

"... turning up in first and second grade classrooms wreaking havoc on themselves and others" (Drug Babies, 1989)

"... the bio-underclass" (What will we do, 1989).

While there is widespread consensus concerning the need for early identification of, and early intervention for, infants and toddlers with disabling conditions, the task confronting policymakers to define the population to be served and develop adequate procedures to identify eligible children is a difficult one. The task is made more difficult by the complex and irregular early development of children (O'Donnell, 1989), limited assessment instruments (Simeonsson & Bailey, 1989), lack of reliable prevalence data (Meisels & Wasik, 1990), lack of knowledge concerning the relationship of social and biological factors to disabling conditions (Kochanek, Kabacoff, & Lipsitt, 1987), and the presence of existing and often contradictory eligibility policies from other federally mandated programs (Harbin et al. 1990).

Children born to substance abusing mothers demonstrate a continuum of developmental outcomes, ranging from

seriously compromised children, to those with milder dysfunction, to many who are healthy intact children (Poulsen, 1992). Because of this full range of impact, it is exceedingly important that children considered at risk due to substance exposure are not stereotyped, labeled, and segregated as "the crack babies" or "the drug babies." Every child must be seen as an individual who possesses a unique set of strengths and vulnerabilities.

Chapter III

RESEARCH DESIGN AND METHODS

Introduction

The purpose of this chapter is to present information about the following: research questions, pilot interviews, site selection, instrumentation, semistructured telephone interviews, contact summary sheet, data collection, data analysis and methods for achieving reliability and validity.

Research Questions

The purpose of this study was to provide descriptive data on the delivery of services under Part H of IDEA for infants and toddlers perinatally exposed to toxic substances. A recent national study of thirty-six hospitals conducted by the National Association for Perinatal Addiction Research and Education (NAPARE) indicates that approximately 11 percent of pregnant women use drugs during pregnancy. "Nationwide, an estimated 375,000 children each year are born exposed to cocaine," states Debra Viadero (1990). This is a national problem that must be addressed. Specifically, this study addressed four research questions in the area of perinatal exposure:

1. Why do California, Hawaii, Indiana, Massachusetts New Mexico, and North Carolina choose to include perinatal exposure in their definition of at risk?

2. What is the comparative status for the 16 minimum components of a statewide comprehensive system for the provision of appropriate early intervention services to infants and toddlers with special needs, for the above six states?

3. What mention of accommodations for perinatal exposure are found when one analyzes the 16 minimum components?

4. Should Part H mandate that infants and toddlers who were perinatally exposed be covered under this legislation?

Pilot Interviews

Pilot interviews were conducted as the process of gathering initial data and determining the most appropriate method of data collection for this study. The interviews were conducted in the Part H lead agency for the state of North Carolina and at the National Early Childhood Technical Assistance System (NEC*TAS) at Chapel Hill, North Carolina. These pilot interviews were qualitative in nature, designed to elicit data on the following: do perinatally exposed infants/toddlers and their families in the state of North Carolina receive services under Part H of IDEA and what types of services do they receive? Questions for a semistructured interview were developed and field tested on

the Part H Coordinator in Raleigh, North Carolina. Refer to Appendices A and B.

While at NEC*TAS, it became evident that only 11 states serve at risk infants and toddlers under Part H. The original three states targeted for this study were not included in that group. It became apparent that certain changes would need to occur. A suggestion was made that a site visit to the National Association of State Directors of Special Education (NASDSE) in Alexandria, Virginia to complete a paper analysis on federal Part H applications may be appropriate. The purpose of the visit was to discover which, if any, of the eleven states (Arkansas, California, Colorado, Hawaii, Indiana, Louisiana, Michigan, Mississippi, Massachusetts, New Mexico and North Carolina) that claim to serve at risk infants and toddlers include perinatal exposure in the eligibility requirements. (As of November 6, 1993, Mississippi has elected to no longer participate in the Part H program {Early Childhood Report, 1993}).

Of those 11 states, only 6 (California, Hawaii, Indiana, Massachusetts, New Mexico and North Carolina) include services for perinatally exposed infants/toddlers and their families in the eligibility requirements for at risk (Part H applications, 1993).

Site Selection

Only six states in the country choose to include perinatal exposure in their definition of at risk; those six states were chosen. They were:

California	Hawaii
Indiana	Massachusetts
New Mexico	North Carolina

For reasons of comparison, information was needed from states that did not serve perinatally exposed infants and toddlers under the at risk definition. To achieve a regional spread, three states that border California, Indiana and North Carolina were chosen. Those states were Arizona, Illinois and Virginia.

Instrumentation

Initial research activity consisted of identifying potential questions from the literature in order to develop two focused telephone interviews for the nine Part H Coordinators. Six Part H Coordinators that provided services to perinatally exposed under the at risk definition of Part H received one form of the telephone interview and three Part H Coordinators that did not provided such services were given a different interview.

The focused interview was the major method of data collection in the present study. Lofland & Lofland (1984) suggested a flexible, open-ended format for interviews, but

also endorsed using an outline of questions to ensure the inclusion of key areas. A common core of questions allowed for the comparative analysis of the respondent's answers. Because a single interview with each participant would constitute a major source of data, careful attention was given to developing the questions in the interview guide.

Content of questions for the survey included: 1) year of Part H implementation; 2) length of time the interviewee had been Part H Coordinator; 3) specific accommodations within the minimum 16 components for perinatally exposed infants/toddlers and their families; 4) does it make a difference what agency was designated by the governor as the lead agency when services for perinatally exposed infants and toddlers are concerned; 5) should Part H mandate coverage for this population; 6) changes that could be made for the provision of services for perinatally exposed infants and toddlers; and 7) additional comments.

Two telephone surveys were constructed, one for states that served perinatally exposed infants and toddlers under at risk and the other for states that did not serve at risk. Refer to Appendices A and B for the telephone surveys.

In addition to focused telephone interviews, a Part H application paper analysis was also utilized. Extracts from these documents included: 1) a list of the states that serve perinatally exposed under the at risk definition; 2)

eligibility criteria for at risk populations; 3) content of the 16 minimum components of Part H for each state; and 4) specific accommodations within the minimum 16 components for perinatally exposed infants/toddlers and their families.

Semistructured Telephone Interviews

Descriptive information on services provided by states to perinatally exposed infants and toddlers was gathered by using the semistructured interview technique. Various researchers refer to this technique as focused interview (Yin, 1987), interview guide approach (Patton, 1980), and interview guide (Miles & Huberman, 1984a). Yin (1987) defined the focused interview as one in which the "interview is more likely to be following a certain set of questions derived from the case study protocol." Patton (1980) defines the interview guide approach as:

a list of questions or issues that are to be explored in the course of an interview. An interview guide is prepared in order to make sure that basically the same information is obtained from a number of people by covering the same material. The interview guide provides topics or subject areas within which the interviewer is free to explore, probe, and ask questions that will elucidate and illuminate that particular subject. Thus, the interviewer remains free to build conversation within a particular subject area, to word questions

spontaneously, and to establish a conversational style - but with the focus on a particular subject that has been predetermined.

Miles and Huberman (1984) suggested several methods for qualitative data analysis during the process of data collection. The following methods were adapted to transfer field notes from the interviews into records for analysis:

1. Contact Summary Sheet - contained a series of focusing or summarizing questions about a particular field contact.
2. Coded Field Notes - pre-determined codes were assigned to sentences and paragraphs of transcribed field notes.
3. Pattern Coded Field Notes - codes used to summarize segments of data into a smaller number of themes or constructs.
4. Site Summary - provided a synthesis of review findings and quality of data supporting the findings.

Contact Summary Sheet

Contact summary sheets were used to enable a reflective overview of what went on during the telephone interviews. (Refer to Appendix G.) A contact summary sheet is a single sheet containing a series of focusing or summarizing questions about a particular field contact (Miles &

Huberman, 1984). The contact summary sheets were completed after the telephone interview audiotapes were transcribed.

Data Collection

As indicated in an earlier discussion, paper analyses and open-ended focused telephone interviews were the primary methods of data collection used in the study. The paper analyses of the federal Part H applications were completed at NASDSE in Alexandria, Virginia. Information pertaining to accommodations within the 16 minimum components of Part H for perinatally exposed infants/toddlers and their families was entered into a laptop computer, while entire sections pertaining to the federal minimum components were copied for later comparison.

All telephone interviews were conducted by the researcher. An initial phone call was made to the nine Part H Coordinators to introduce the study, set a day and time for the telephone interview and to offer to send them the survey in advance. The surveys were sent to all participants along with a letter that confirmed the time and date of the interview. (Refer to Appendix C for a copy of a letter.) Part H Coordinators were called so that they would not have to pay for the call. Individuals were asked permission at the onset of the interview to audiotape the conversation. All interviews were recorded using a portable answering machine and were later transcribed to maintain

accuracy of reporting. The interviews lasted anywhere from 10 minutes to an hour. Thank-you notes were sent to all participants. Refer to Appendix D.

Data collected included:

Data Content	Type	Source
Description of components	16 minimum state requirements	Part H Coord. and Application
Description of components for perinatal exposure	16 minimum state requirements	Part H Coord. and Application
Focused Telephone Interviews	Audio	Part H Coord.

Data Analysis

The data analysis methods in this study drew heavily upon models suggested by Miles and Huberman (1984). Miles and Huberman (1984) provided the Interactive Model for data analysis which served as the primary structure for the organization and analysis of data. The Interactive Model (see figure 1) involves three concurrent flows of activity: data reduction, data display, and conclusion drawing/verification.

Data reduction refers to the process of selecting, focusing, simplifying, abstracting, and transforming the "raw" data that appears in written field notes or from audiotapes. In fact, even before the data are actually collected anticipatory data reduction is occurring as the researcher decides (often without full awareness) which

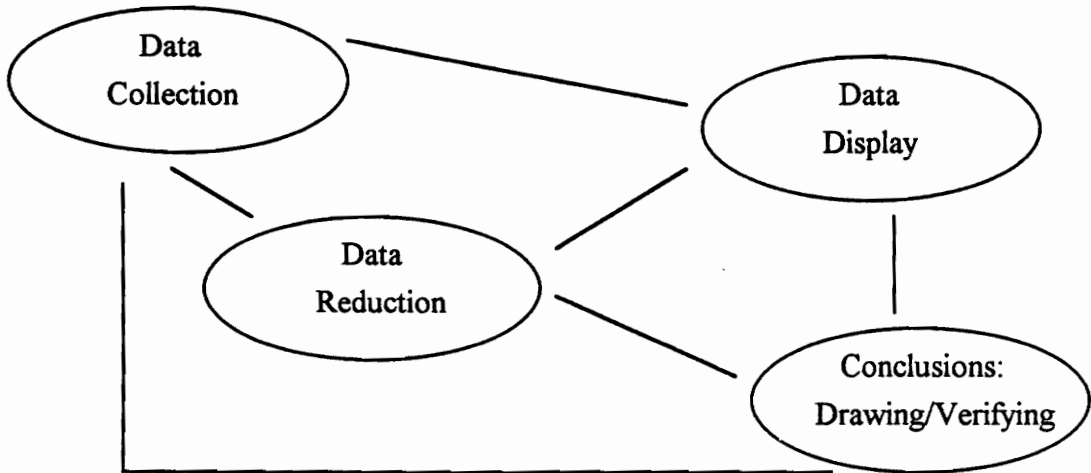


Figure 1: Components of Data Analysis: Interactive Model

Miles, M., & Huberman, A. (1984). Qualitative data analysis: Sourcebook of new methods. Beverly Hills: Sage Publications.

conceptual framework, which sites, which research questions, which data collection approaches to choose.

The second major flow of analysis activity is data display. "Display" is defined as an organized assembly of information that permits conclusion drawing and action taking. The initial analysis consisted of completing a butcher paper analysis to discover similarities and differences pertaining to the 16 minimum components for the six states that serve perinatally exposed infants and toddlers under the at risk category.

The third stream of analysis activity is conclusion drawing and verification. From the beginning of data collection, the qualitative analyst is beginning to decide what things mean, and is noting regularities, patterns, explanations, possible configurations, causal flows and propositions.

The next component in the data analysis consisted of a series of steps that were used to scrutinize the interview transcripts. Initially all interviews were transcribed verbatim. (See Appendix H.) Contact summary sheets were then completed. (See Appendix G.) With the first reading of the transcripts, the researcher began to note impressions about the Part H Coordinator's responses in the margins. Each interview transcript included the questions and comments that the researcher used to elicit information.

These questions were used to group the interview responses into several initial categories. Also, a list was developed as the broad patterns and themes started to emerge from the data. During the second reading, the transcripts were edited in conjunction with the computer version. During this process the narratives were labeled and irrelevant or extraneous material was eliminated. As these segments were labeled and coded from the original source, they became the structure around which interview data were sorted. Use of the computer to manipulate the data and separate it by category made the sorting process manageable. This activity produced a printed copy that could be cut apart and used to continue the sorting and categorizing process. Finally, the data were analyzed across sites which tended to increase the potential for greater generalization.

Test of Research Design

It is important to be able to demonstrate to the reader the credibility of the data and of the inductive inferences contained in the study. Yin (1989) gave a brief description of these tests and identified several tactics for dealing with the test during various phases of a study. Yin (1987) provided the following summary of two tests:

- * Construct validity: establishing correct operational measures for the concepts being studied and;
- * Reliability: demonstrating that the operations of a

study - such as the data collection procedures - can be repeated, with the same results.

Steps were taken to address each of these tests throughout the various phases of the study. Appropriate tactics used to address these concerns are discussed below.

Construct validity was enhanced by using multiple sources of evidence and developing a case study data base. Multiple sources of evidence included federal Part H applications, information from NEC*TAS, and interviews of the Part H Coordinators. The case study data consisted of case study notes from interviews or analyses of documents. Documents collected during the course of the study became part of the case study data base.

Reliability of the study was increased by developing the case study data base which allowed a reader to refer to the actual documents collected and used in the study. Also, the report contains sufficient citations to the data base to formulate a chain of evidence to "follow the derivation of any evidence from initial research questions to ultimate case study conclusions" (Yin, 1987).

Chapter IV

FINDINGS, CONCLUSIONS, AND DISCUSSION

Data were obtained from paper analyses of federal Part H applications and telephone interviews with Part H Coordinators. Conclusions are also discussed in terms of research questions, other research findings, and recommendations for further study.

The Method of Analysis

Data collected included interview notes, and Part H applications were coded at each step of the data gathering process. They were then compared to each other in order to identify additional patterns from which inferences could be drawn across states. In addition to noting consistent patterns, inconsistencies in the data were also noted and became part of the overall analysis. Final analysis was presented in the form of conclusions and theories.

The Units of Analysis

The principle units of analysis were the Part H applications and the transcribed telephone interviews with Part H Coordinators. Refer to Appendix H for the nine transcribed interviews.

Part H Applications

Each state in this country has the power to decide whether infants and toddlers who are at risk will be served under the provisions of special education to infants and

toddlers (Public Law 101-476, Part H). According to The National Early Childhood Technical Assistance System (NEC*TAS) (1992), 22% of states include at risk in their definitions for Part H. Those eleven states are: Arkansas, California, Colorado, Hawaii, Indiana, Louisiana, Michigan, Mississippi, Massachusetts, New Mexico, and North Carolina.

Part H applications were examined to determine which states included perinatally exposed infants and toddlers under their at risk definition. It was discovered that of the eleven states mentioned above, only California, Hawaii, Indiana, Massachusetts, New Mexico, and North Carolina chose to include this population in the at risk definition. The National Association for Perinatal Addiction Research and Education (NAPARE), (1993) defines perinatally exposed as, "fetal exposure to inappropriate use of licit or illicit drugs." For the purpose of this study fetal alcohol syndrome (FAS) was excluded from this definition because many states provide services to FAS under another category of Part H, children who have a diagnosed mental or physical condition that has a high probability of resulting in developmental delay.

A butcher paper analysis, or network tables, of the federally required 16 components of Part H was completed for those six states that serve perinatally exposed infants and toddlers. This analysis consisted of using a large piece of

butcher paper and listing the six states down the left and the 16 components at the top. The information for each component was filled in and comparison was facilitated. See Table 1 for the required components of Part H. A comparative status was completed for mention of accommodations for perinatally exposed infants/toddlers and their families. (See Table 5, page 70.)

Telephone Interviews

Nine telephone interviews with Part H Coordinators or their representatives were completed in an eighteen day span. The six states that chose to include perinatally exposed infants and toddlers under their at risk definition received the longer of the two interviews. (See Appendix A.) Three states that did not serve at risk received the other interview. (See Appendix B.) Four of the nine interviews had to be rescheduled because of conflicts on prearranged times with the Part H Coordinator. The average length of the interviews was 29 minutes. The longest interview was 59 minutes and the shortest interview was 10 minutes. Data pertaining to telephone interviews are presented in Table 2.

Conclusions in Terms of Research Questions

The research questions for this study were developed in order to gather data in four areas of inquiry: (1) why certain states provide services to perinatally exposed

Table 1

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

1. State definition of developmental delay.
2. Central directory.
3. Timetables for serving all eligible children.
4. Public awareness program.
5. Comprehensive child find system.
6. Evaluation, assessment, and nondiscriminatory procedures.
7. Individualized family service plan.
8. Comprehensive system of personnel development (CSPD).
9. Personnel standards.
10. Procedural safeguards.
11. Supervision and monitoring of programs.
12. Lead agency procedures for resolving complaints.
13. Policies and procedures related to financial matters.
14. Interagency agreements; resolution of individual disputes.
15. Policy for contracting or otherwise arranging for services.
16. Data collection.

Individuals with Disabilities Education Act of 1990. 20
U.S.C. 1400, (1990).

Table 2

Data Pertaining to Telephone Surveys

	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina	Arizona	Illinois	Virginia
	<i>Serve Perinatally Exposed Under At Risk</i>								
Date of initial phone call	9-28-93	9-29-93	10-1-93	9-27-93	9-27-93	9-27-93	10-1-93	9-28-93	9-29-93
Date letter sent	9-29-93	9-29-93	10-1-93	10-4-93	9-28-93	9-27-93	10-1-93	9-28-93	10-5-93
Date of telephone survey	10-8-93	10-7-93	10-15-93	10-15-93	10-21-93	10-4-93	10-21-93	10-5-93	10-18-93
Did telephone survey have to be rescheduled? If yes, how many times?	Yes Once	No	Yes Twice	Yes Once	Yes Once	No	No	No	No
Job title of person being interviewed	Medical Consultant	Part H Coordinator	Part H Coordinator	Assistant to Part H Coordinator	Part H Coordinator	Part H Coordinator	Part H Coordinator	Part H Coordinator	Part H Coordinator
Length of telephone survey	59 mins	17 mins	43 mins	40 mins	41 mins	15 mins	10 mins	14 mins	21 mins
Date thank you sent	10-8-93	10-8-93	10-17-93	10-17-93	10-21-93	10-6-93	10-21-93	10-6-93	10-18-93
Page length of transcribed document	14	3	6	5	6	4	3	3	4
	<i>Do not serve At Risk</i>								

infants and toddlers under the at risk definition of Part H, and others do not, (2) what is the comparative status for the required 16 components of Part H, (3) where are accommodations made in the required 16 components, for perinatally exposed infants and toddlers, and (4) should Part H mandate coverage for perinatally exposed infants and toddlers?

Question One: Why do California, Hawaii, Indiana, Massachusetts, New Mexico, and North Carolina choose to include perinatal exposure in their definition of at risk?

One of the major challenges state and jurisdiction policy makers have faced under Part H of IDEA, has been the determination of definitions and criteria of eligibility for services for infants and toddlers, birth to age 3 years, and their families (NASDSE, 1988; Harbin, Terry, & Daguio, 1989; Harbin, Danaher, & Derrick, 1992). States that reach the full implementation stage of this federal legislation must provide services to two groups of children: those who are experiencing developmental delays, and those who have a diagnosed mental or physical condition that has a high probability of resulting in developmental delay (Shackelford, 1992). In addition, states may, if they choose, serve children who are at risk of having substantial developmental delay, if early intervention services are not provided (Brown, 1990).

Eleven states in the country chose to serve at risk populations under Part H and 39 states did not. Of those 11, only six states served perinatally exposed infants and toddlers under the at risk definition of Part H. Those six states were: California, Hawaii, Indiana, Massachusetts, New Mexico, and North Carolina. The reasons given by those six Part H Coordinators for including this population under the at risk definition were political and humanistic in nature.

Of the six states that did serve this population, only one credited two organizations for the inclusion of perinatally exposed infants and toddlers under the at risk definition of Part H. Lobbying made the legislature and the general public much more aware of the problematic situation. "The Department of Alcohol and Drug Programs worked simultaneously with the perinatal associations and the lead agency to create the awareness to get legislative approval for this population." Refer to Table 3 for specific responses.

Two Coordinators mentioned political rationale. "A major initiative came out of the Governor's office looking at having all children enter school ready to learn." This initiative corresponded with the first goal of the National Education Goals. "All children in America will start school ready to learn." The Governor realized that perinatally

Table 3

Responses of Part H Coordinators to Three Telephone Survey Questions

State	Should Part H mandate that infants & toddlers who were perinatally exposed be covered under this legislation?	With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency?	Why does your state choose to serve/not serve perinatally exposed infants/toddlers under the at risk definition?
Serve Perinatally Exposed Under At Risk			
California	No · States may elect not to participate in Part H because they think the numbers would be too big It shouldn't be mandated anymore than any other group of children.	Yes · There needs to be a more case management type of approach. You need an agency that really understands infant development.	The Department of Alcohol and Drug Programs worked simultaneously with perinatal associations and the lead agency to serve this population. They created the awareness to get legislative approval.
Hawaii	No · No more so than any other population.	Yes · The health agencies better understand the issues that are involved with these infants and toddlers.	No one group was involved. We serve them because they are a vulnerable group in need of services.
Indiana	Yes · Of all the children, we have most opportunity to make a difference with this population.	No · I don't think so. With the exclusion of the Department of Health & Department of Education, Family and Social Services Administration is considered the mega agency. We have everything that would impact families and children.	It was a major initiative out of the governor's office looking at having all children enter school ready to learn. No one group or person was really responsible for the inclusion of this group.
Massachusetts	No · I don't think that is sufficient criteria. Research shows that the kids with poor outcomes are the ones with multiple risk factors.	Yes · All agencies have their own cultures and ways of approaching the provision of services to families. I think education departments are very different from health departments.	All clinicians at the time, working on eligibility, felt that these groups should be included. It was a group effort. No single entity could be identified.
New Mexico	Yes · It is the right thing to do.	Yes · The difference can be whether certain linkages are in place. What is within your agency shapes the nature of the service.	It is political because the legislature and the general public have a high interest with these children. There was no one group to lobby for perinatally exposed as a subgroup, we promote our program more in the eyes of the at risk than we do in the areas of developmentally disabled.
North Carolina	Yes · These kids need services and they need them now. We either pay now or later.	Yes · We are lucky that substance abuse is part of the lead agency.	We felt it was a major service population. No one person is responsible for them being included.
Do Not Serve At Risk			
Arizona	Yes · If enough funds are appropriated to cover this population.	No · Because all agencies worked together and decided we fiscally could not include at risk.	Financial reasons
Illinois	No · I don't think this population should be mandated anymore than any others.	No · Because we are education and we work closely with health. I think if your state works cooperatively it doesn't make a difference	Not enough dollars to serve that population
Virginia	Yes · Mandating that would be very appropriate, but whether Part H is the right mandate, is the question that I don't know.	No · The Department of Mental Health/Mental Retardation and Substance Abuse Services is really the agency that works with this family and they are the lead agency.	Due to costs

exposed infants and toddlers may need extra services to achieve this goal.

"It is political because the legislature and the general public have a high interest with these children." High visibility of "crack babies" has resulted in the legislature being interested and willing to spend state funds to service this population. Also, because of their visibility in the media, people realized that they were a vulnerable group in need of services.

Two states claimed that no one group or person was responsible for the inclusion of perinatally exposed infants and toddlers. It was a mutual decision by all individuals involved in deciding eligibility criteria for Part H. "They are included because they are a vulnerable group in need of services." "We felt it was a major service population."

It should also be noted that three of these states, Hawaii, Massachusetts, and North Carolina were among the first states in the country to be in full conformity with the federal regulations under Part H. As a matter of fact, Hawaii was the first state in the nation to have a statewide system in place that was in full conformity with the regulations of Part H of IDEA. These three states have had more time to investigate which populations need services and have decided to include perinatally exposed infants and toddlers.

Shackelford (1992), along with Harbin, Terry, and Daguio (1989) state that the task of defining the eligible population has been difficult for states. How narrow or broad the definition is influences the numbers and types of children needing or receiving services, the types of services provided and ultimately the cost of the early intervention system (Harbin, Gallagher, & Batista, 1992). Several states have conducted extensive impact and cost studies before finalizing their definitions (Shackelford, 1992). The reluctance to include at risk children, despite a widespread desire to do so, was clearly due to the financial difficulties in which the states found themselves and the large increase in financial support that would have to be found to provide comprehensive services (Gallagher, 1993). Many states have redefined and narrowed their definitions, especially as they have experienced financial difficulties. Brown (1990) stated that the current level of interest in serving children at risk is being moderated by differences both of opinion about who is at risk and by concern over projections of the amount of financial resources required to include this group.

Three states that did not serve at risk, Arizona, Illinois, and Virginia, stated financial reasons for their decision not to serve this population. "There are not enough dollars to serve that population." "We chose not to

include the at risk definition due to cost." One Part H Coordinator stated that they did serve the at risk population, but they did not put it in the Part H application because they did not want to be held accountable by the federal government for that group.

Question Two: What is the comparative status for the 16 minimum components of a statewide comprehensive system for the provision of appropriate early intervention services to infants and toddlers with special needs, for the above six states?

Part H provides funding and phased-in requirements over four years. By the fifth year of a state's participation in the program, early intervention services must be available for all infants and toddlers with disabilities and their families. States in full implementation of Part H were required to have the 16 minimum components of a statewide comprehensive system for the provision of appropriate early intervention services to infants and toddlers with special needs (Individuals with Disabilities Education Act of 1990. 20 U.S.C. 1400, 1990). Refer to Table 1 (page 59) for a list of the components.

All states in this study were in full implementation, with the exception of Indiana which was in second year of extended participation. (States experiencing significant hardships in meeting the requirements of the fourth and

fifth year of participation were eligible to receive the extended participation grants, in lieu of dropping out of the Part H program. To be eligible for extended participation, a state had to satisfy the requirements for the third or fourth year of participation and submit a request by the Governor and an application (Fourteenth Annual Report to Congress, 1992)). Refer to Table 4 for the timelines to receive a grant for Part H.

Indiana had a very unusual situation. Not only were they the only state in second year of extended participation, but their Part H system was county driven. The 92 county councils each had their own separate plan for all components of Part H. They abided by federal regulations, but all 92 plans were different.

Five of the six states that served perinatally exposed infants and toddlers under the at risk definition of Part H had a health or health related department as their lead agency. The lead agencies were: Department of Developmental Services, Department of Health, Department of Public Health, Department of Health, and Division of Mental Health/Developmental Disabilities/and Substance Abuse Services.

When the required 16 components were analyzed, the following results were discovered:

Table 4

Timelines to Receive a Grant for Part H

First Two Years	The Governor must designate a lead agency (there is state discretion respecting which agency is designated) for overall administration of the program. The Governor must also establish an Interagency Coordinating Council composed of relevant agencies, consumers, and providers. The Council may also serve as the lead agency.
Third Year	The state must demonstrate that it has adopted a public policy which provides all of the components of a statewide system for providing early intervention services to all eligible infants and toddlers
Fourth Year	The state must demonstrate that it has in effect a statewide system for providing early intervention services. The state must also provide for all eligible children the following: Multidisciplinary assessments, individualized family service plans, and case management services.
Fifth and All Succeeding Years	The state must make available to all handicapped infants and toddlers within the state appropriate early intervention services (Council for Exceptional Children (CEC), 1986; Dugan, 1986; Garwood, 1987; Lowenthal, 1987).

Central Directory. Most states had a central directory that was computerized, with a toll free number provided to allow statewide public access. Telephone book copies of the Central Directory were available throughout the state. Due to the varied population in California, their Central Directory was translated into appropriate languages. Refer to Table 5 for the comparative status for the 16 minimum components.

Child Find. The lead agencies assured that all eligible children were identified, located, and evaluated within a 45 day period. Effective methods were utilized to identify those children not receiving required services. Lead agencies coordinated with other agencies to avoid duplication of services. Early Childhood Report (1993) stated New Mexico's child find efforts usually resulted in services to anywhere between 800 and 1,200 children throughout the year.

Cultural issues required a significant amount of attention to ensure that all of New Mexico's population were served. With the reauthorization of Part H, each state Part H program is required to provide services to all eligible Native American infants and toddlers. The tribes received money from the Bureau of Indian Affairs for child find, parent training, and service coordination. According to Early Childhood Report (1993), taking money goes against

Table 5

Comparative Status for the Sixteen Minimum Components of a Statewide Comprehensive System for the Provision of Appropriate Early Intervention Services to Infants and Toddlers with Special Needs

Components	States					
	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
Lead agency	<ul style="list-style-type: none"> Department of Developmental Services 	<ul style="list-style-type: none"> Department of Health 	<ul style="list-style-type: none"> Family and Social Services Administration 	<ul style="list-style-type: none"> Department of Public Health 	<ul style="list-style-type: none"> Department of Health 	<ul style="list-style-type: none"> Division of Mental Health/Developmental Disabilities/Substance Abuse Services
*Year of implementation	<ul style="list-style-type: none"> 5th year 	<ul style="list-style-type: none"> 7th year 	<ul style="list-style-type: none"> Second year of extended participation 	<ul style="list-style-type: none"> 6th year 	<ul style="list-style-type: none"> 5th year 	<ul style="list-style-type: none"> 7th year
1. State definition of developmental delay (specifies categories under which the child could be eligible)	<ul style="list-style-type: none"> Developmental disability At risk Significant risk 	<ul style="list-style-type: none"> Developmental delay Biological risk Environmental risk Multiple categories 	<ul style="list-style-type: none"> Developmentally delayed Diagnosed physical or mental conditions At risk 	<ul style="list-style-type: none"> Established risk Biological risk Environmental risk 	<ul style="list-style-type: none"> Developmental delay Established risk At risk 	<ul style="list-style-type: none"> Developmental delay Atypical development Clinical high risk
2. Central directory	<ul style="list-style-type: none"> Electronic database Hard copies available Translated into appropriate languages 	<ul style="list-style-type: none"> Computerized database, staffed by information specialists Toll free number 	<ul style="list-style-type: none"> Two 1-800 numbers Family Wellness hotline Directory of parent groups Directory of Indiana resources 	<ul style="list-style-type: none"> Computerized database accessible through a toll free number Welcome directory 	<ul style="list-style-type: none"> Toll free number to provide statewide public access Copies of the Central directory are available statewide (telephone book form) 	<ul style="list-style-type: none"> Computerized data base Statewide toll free number Hard copies are available
3. Timetable for serving all eligible children	<ul style="list-style-type: none"> March 1, 1993 	<ul style="list-style-type: none"> October 4, 1991 	<ul style="list-style-type: none"> No later than the fifth year of participation under Part H 	<ul style="list-style-type: none"> May 1, 1992 	<ul style="list-style-type: none"> April 5, 1993 	<ul style="list-style-type: none"> October 1, 1991

* All states in 5th year or more have met all federal requirements for Part H of IDEA. Congress granted extended participation to states who were unable to meet all requirements by the federal deadlines.

(Table continued)

Components	States					
	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
4. Public awareness program (federal requirements)	<p>Preparation and dissemination of materials and information about:</p> <ul style="list-style-type: none"> • Early Intervention Program • Child Find • Central Directory 	<p>Preparation and dissemination of materials and information about:</p> <ul style="list-style-type: none"> • Early Intervention Program • Child Find • Central Directory 	<p>Preparation and dissemination of materials and information about:</p> <ul style="list-style-type: none"> • Early Intervention Program • Child Find • Central Directory 	<p>Preparation and dissemination of materials and information about:</p> <ul style="list-style-type: none"> • Early Intervention Program • Child Find • Central Directory • 51 Early intervention programs throughout the state conduct public awareness in their service areas 	<p>Preparation and dissemination of materials and information about:</p> <ul style="list-style-type: none"> • Early Intervention Program • Child Find • Central Directory 	<p>Provides information about:</p> <ul style="list-style-type: none"> • Early Intervention Programs • Child Find • How to Make Referrals • How to access evaluation and early intervention services • Central Directory
5. Comprehensive child find system	<p>Lead agency assures that all eligible children are:</p> <ul style="list-style-type: none"> • Identified, located and evaluated (45 days) and • Effective method to identify those not receiving required services • Coordination • Primary Referral Sources 	<ul style="list-style-type: none"> • Developmental Screening • Public Awareness Coordination • Referral Procedures • Dissemination of Information • Primary Referral Sources • Timelines 	<p>Lead agency assures that all eligible children are:</p> <ul style="list-style-type: none"> • Identified, located and evaluated (45 days) and • 92 county councils write separate plans • Effective method to identify those not receiving required services 	<p>Lead agency assures that all eligible children are:</p> <ul style="list-style-type: none"> • Identified, located and evaluated (45 days) and • Coordination • Dissemination of Information 	<p>Responsible for implementing child find</p> <ul style="list-style-type: none"> • Primary Referral Sources • Coordination with other agencies to avoid duplication 	<p>Lead agency assures that all eligible children are:</p> <ul style="list-style-type: none"> • Identified, located and evaluated (45 days) and • Effective method to identify those not receiving required services

(Table continued)

Components	States					
	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
6. Evaluation, assessment, and nondiscriminatory procedures	<ul style="list-style-type: none"> Initial evaluation and assessments will be completed for an infant or toddler believed to have a developmental disability or at risk 	<ul style="list-style-type: none"> Definitions of evaluation and assessment Policies for Child and Family Assessment Evaluation and assessment of the child Family assessment Timelines Nondiscriminatory Procedures 	<ul style="list-style-type: none"> Timely, comprehensive multidisciplinary evaluation of child and family Nondiscriminatory Procedures 	<ul style="list-style-type: none"> Timely, comprehensive multidisciplinary evaluation Nondiscriminatory Procedures 	<ul style="list-style-type: none"> Timely, comprehensive multidisciplinary evaluation 	<ul style="list-style-type: none"> Native Language Not discriminatory No single procedure Timely, comprehensive multidisciplinary evaluation Evaluations and assessments are conducted by qualified personnel
7. Individualized Family Service Plan (IFSP)	<ul style="list-style-type: none"> State assures that an IFSP is in effect and implemented for each eligible child and family 	<ul style="list-style-type: none"> Uses support rather than service in IFSP terminology State assures that an IFSP is in effect and implemented for each eligible child and family 	<ul style="list-style-type: none"> A current IFSP is in effect for each eligible child and the child's family 	<ul style="list-style-type: none"> A current IFSP is in effect and implemented for each eligible child and the child's family 	<ul style="list-style-type: none"> IFSP developed and case management services provided 	<ul style="list-style-type: none"> State assures that an IFSP in effect and implemented for each eligible child and family

(Table continued)

Components	States					
	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
B. Comprehensive System of Personnel Development (CSPD)	<ul style="list-style-type: none"> • Preservice, inservice training • Provided to a variety of personnel • Lead agency insures the development and maintenance of a CSPD 	<ul style="list-style-type: none"> • Lead agency insures the development and maintenance of a CSPD • Annual Needs Assessment • Plan Development Strategies to Implement Plan 	<ul style="list-style-type: none"> • Lead agency insures the development and maintenance of a CSPD • Preservice • Continuing Education • Inservice • Nationwide shortage of staff 	<ul style="list-style-type: none"> • Lead agency insures the development and maintenance of a CSPD • Staff shortages • Inservices • Continuing Education • Mentorship program • Orientation 	<ul style="list-style-type: none"> • Lead agency insures the development and maintenance of a CSPD • Needs Assessment • Development of plan based on needs • Dissemination of promising practices • Evaluation of CSPD 	<ul style="list-style-type: none"> • The Part H CSPD is closely coordinated with the one in effect for Part B • Shortage of staff • Needs Assessment Resources • Interdisciplinary Activities • Training
9. Personnel standards (taken from State Part H Applications)	<ul style="list-style-type: none"> • Nutrition • Social Work • Nursing • Psychologists • OT/PT* • Audiologists • Early Childhood Special Education • Sp/lang* • Medical Personnel • Early Childhood Education 	<ul style="list-style-type: none"> • Audiology • Nursing • Nutrition • OT/PT* • Pediatrics • Psychology • Social Work • Special Education • Sp/lang* • Parent Involvement Specialist 	<ul style="list-style-type: none"> • Audiologists • Nurses • Nutritionists • OT/PT* • Physicians • Psychologists • Social Workers • Special Educators • Sp/lang* • Trained Paraprofessionals • Other disciplines as needed 	<ul style="list-style-type: none"> • Personnel necessary to carry out the purpose of this part are appropriately and adequately prepared and trained 	<ul style="list-style-type: none"> • Audiology • Sp/lang* • Education • Early Childhood Special Education • Social Work • Psychology • OT/PT* • Medicine (Physician) • Nursing • Nutrition 	<ul style="list-style-type: none"> • Nutritionists • OT/PT* • Sp/lang* • Physician • Psychologist • Social Worker • Audiologists • Nurse • Infant Specialist • Mobility Specialist • Infant/Toddler Specialist

(Table continued)

*OT/PT - Occupational Therapist/Physical Therapist; Sp/lang - Speech/language

Components	States					
	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
10. Procedural safeguards	<ul style="list-style-type: none"> States may elect to adapt the procedural safeguards in Part B to comply with the requirements of Part H 	<ul style="list-style-type: none"> Establishing or adopting procedural safeguards that meet the requirements for Part H of P.L. 102-119 	<ul style="list-style-type: none"> Procedural safeguards have been adopted that meet the requirements and shall insure effective implementation of safeguards by each public agency 	<ul style="list-style-type: none"> Procedural safeguards have been adopted that meet the requirements and shall ensure effective implementation of safeguards by each public agency 	<ul style="list-style-type: none"> Procedural safeguards have been adopted that meet the requirements and shall ensure effective implementation of safeguards by each public agency 	<ul style="list-style-type: none"> Procedural safeguards have been adopted that meet the requirements and shall ensure effective implementation of safeguards by each public agency
11. Supervision and monitoring of programs	<ul style="list-style-type: none"> Department of Education and the lead agency will be responsible for administration, supervision and monitoring of programs, and activities 	<ul style="list-style-type: none"> Lead agency is responsible for administrative supervision and monitoring of programs and activities Monitoring Enforcement Technical Assistance Correction of deficiencies 	<ul style="list-style-type: none"> Lead agency is responsible for administrative supervision and monitoring of programs and activities Monitoring Enforcement Technical Assistance Correction of deficiencies Monitoring - pilot 	<ul style="list-style-type: none"> Lead agency is responsible for administrative supervision and monitoring of programs and activities Monitoring Enforcement Technical Assistance Correction of deficiencies 	<ul style="list-style-type: none"> Lead agency is responsible for general administration supervision and monitoring of programs and activities Providing Technical Assistance Correcting Deficiencies Enforcing Obligations 	<ul style="list-style-type: none"> Lead agency is responsible for general administration supervision and monitoring of programs and activities Providing Technical Assistance Correcting Deficiencies Enforcing Obligations
12. Lead agency procedures for resolving complaints	<ul style="list-style-type: none"> Local process for the resolution of complaints; including a state level, interagency review process and incorporate a method for resolving disputes among state agencies 	<ul style="list-style-type: none"> Written procedures for receiving and resolving any complaint On site investigation of a complaint when necessary 	<ul style="list-style-type: none"> Lead agency shall designate specific individuals within Early Intervention Section to handle complaints 60 days May be appealed to US Department of Education 	<ul style="list-style-type: none"> Lead agency shall designate specific individuals within Early Intervention Section to handle complaints 60 days May be appealed to US Department of Education 	<ul style="list-style-type: none"> Written procedures for receiving and resolving any complaint On site investigation of a complaint when necessary 	<ul style="list-style-type: none"> Written procedures for receiving and resolving any complaint On site investigation of a complaint when necessary

(Table continued)

Components	States					
	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
13. Policies and procedures related to financial matters	<ul style="list-style-type: none"> Financing plan to determine payment and fee policies and to coordinate existing interagency agreements on resources, service delivery, and reimbursement procedures <p>Funding sources include but are not limited to:</p> <ul style="list-style-type: none"> Title V of the Social Security Act; Title XIX of the Social Security Act; Head Start Act; Parts B & H of IDEA; Subpart 2 of Part D of Chapter 1 of Title 1 of the ESEA of 1965; The Developmentally Disabled Assistance and Bill of Rights Act; Other Federal Programs 	<ul style="list-style-type: none"> How services are to be paid for and these policies are reflected in interagency agreements <p>Anticipated funding sources for early intervention:</p> <ul style="list-style-type: none"> State general funds; Federal funds under PL 102-119; Federal funds under P.L. 89-313; Medicaid and insurance payments; Special federal/state grants; Local county monies; Private agency support 	<p>The Lead Agency is responsible for the identification and coordination of all available resources for Early Intervention Services within the state, including those from Federal, State, Local and Private sources</p> <p>Funding sources include but are not limited to:</p> <ul style="list-style-type: none"> Title V of the Social Security Act; Title XIX of the Social Security Act; Head Start Act; Parts B & H of IDEA; Subpart 2 of Part D of Chapter 1 of Title 1 of the ESEA of 1965; The Developmentally Disabled Assistance and Bill of Rights Act; Other Federal Programs 	<ul style="list-style-type: none"> How services are to be paid for and these policies are reflected in interagency agreements <p>Funding sources include but are not limited to:</p> <ul style="list-style-type: none"> Title V of the Social Security Act; Title XIX of the Social Security Act; Head Start Act; Parts B & H of IDEA; Subpart 2 of Part D of Chapter 1 of Title 1 of the ESEA of 1965; The Developmentally Disabled Assistance and Bill of Rights Act; Other Federal Programs 	<ul style="list-style-type: none"> State policies related to how services for eligible children and their families will be paid for under the Part H program <p>Funding sources include but are not limited to:</p> <ul style="list-style-type: none"> Title V of the Social Security Act; Title XIX of the Social Security Act; Head Start Act; Parts B & H of IDEA; Subpart 2 of Part D of Chapter 1 of Title 1 of the ESEA of 1965; The Developmentally Disabled Assistance and Bill of Rights Act; Other Federal Programs 	<ul style="list-style-type: none"> State policies related to how services for eligible children and their families will be paid for under the Part H program <p>Funding sources include but are not limited to:</p> <ul style="list-style-type: none"> Title V of the Social Security Act; Title XIX of the Social Security Act; Head Start Act; Parts B & H of IDEA; Subpart 2 of Part D of Chapter 1 of Title 1 of the ESEA of 1965; The Developmentally Disabled Assistance and Bill of Rights Act; Other Federal Programs

(Table continued)

Components	States					
	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
14. Interagency agreements; resolution of individual disputes assumed by lead agency	<p>Lead Agency: Department of Developmental Services</p> <p>Interagency agreements with:</p> <ul style="list-style-type: none"> • Department of Education • Department of Health Services • Department of Mental Health • Department of Social Services • Alcohol and Drug Programs • Department of Human Services 	<p>Lead Agency: Department of Health</p> <p>Interagency agreements with:</p> <ul style="list-style-type: none"> • Special Education • Zero to Three • Easter Seals • University of Hawaii • Department of Human Services 	<p>Lead Agency: Family and Social Services Administration</p> <p>Interagency agreements with:</p> <ul style="list-style-type: none"> • Department of Public Welfare • Department of Human Services • Department of Mental Health • Department of Education • State Board of Health • Head Start • Governor's Planning Council • Office of Human Development Services 	<p>Lead Agency: Department of Public Health</p> <p>Interagency agreements with:</p> <ul style="list-style-type: none"> • Department of Public Welfare • Office of Human Developmental Services • Executive Office of Human Services • Division of Administrative Law Appeals • Office of Transportation and Construction • Department of Mental Health • Department of Mental Retardation • Department of Education • Department of Social Services • Department of Medical Security • Office of Children 	<p>Lead Agency: Department of Health</p> <p>Interagency agreements with:</p> <ul style="list-style-type: none"> • Department of Developmental Disabilities • Prenatal Care Network • Public Health • State Department of Education • Health and Environment Department • Head Start • Indian Health Services • New Mexico School of Medicine 	<p>Lead Agency: Division of MH/DD/SAS*</p> <p>Interagency agreements with:</p> <ul style="list-style-type: none"> • Division of Maternal and Child Health • Division of Exceptional Children's Services • Services for the Deaf and Hard of Hearing • Social Services • Medical Assistance • Services for the Blind and Visually Impaired • Facility Services • Department of Human Resources • Head Start • University of North Carolina • NC Council on Developmental Disabilities

*Division of Mental Health/Developmental Disabilities/Substance Abuse Services

(Table continued)

Components	States					
	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
15. Policy for contracting or otherwise arranging for services	<p>Department of Developmental Services and Department of Education currently have relevant policies in place pertaining to contracting, or making other arrangements for, public and private programs and individuals providing services including those considered early intervention services</p> <p>California statement of services provided:</p> <ul style="list-style-type: none"> • Audiology • Family Training • Health • Nursing • Nutrition • OT/PT* • Psychological • Respite Care • Transportation • Social Work • Special Instructions • Sp/lan[*] • Other early intervention services 	<ul style="list-style-type: none"> • All early intervention services provided will meet the state standards and be delivered in a manner consistent with Part H regulations <p>The Department shall contract for services under a Request for Proposal (RFP) process utilizing the Hawaii Revised Statutes Chapter 42 requirements of the state of Hawaii for contracting for services</p> <ul style="list-style-type: none"> • Early Intervention Services • Medical/Health Care • Family Services • Family Education • Family Support 	<ul style="list-style-type: none"> • Division will use tailor made contracts to qualified provider organizations 	<ul style="list-style-type: none"> • All early intervention services provided will meet the state standards and be delivered in a manner consistent with Part H regulations 	<ul style="list-style-type: none"> • All early intervention services provided will meet the state standards and be delivered in a manner consistent with Part H regulations • Centralized 	<ul style="list-style-type: none"> • All early intervention services provided will meet the state standards and be delivered in a manner consistent with Part H regulations

(Table continued)

*OT/PT - Occupational Therapist/Physical Therapist; Sp/lan^g - Speech/language

Components	States					
	California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
16. Data collection	<ul style="list-style-type: none"> Department of Education and Developmental Services will collect data Child count Count of early intervention services Current and needed personnel The amount of federal, state and local funds expended in the provision of early intervention Description of early intervention services in need of improvement Program settings where early intervention services are provided 	<ul style="list-style-type: none"> Data are collected at each public and private program site Each infant development program has computer capability <p>The following types of dates will be collected from each program:</p> <ul style="list-style-type: none"> Numbers of infants and toddlers served Types of services provided Personnel providing services Expenditures of services Sources of funding Service delivery sites Additional personnel needed Training needs of existing personnel 	<ul style="list-style-type: none"> In coordination with Department of Education Child Count Via telephone survey, demonstration projects and other studies 	<ul style="list-style-type: none"> Key component is the early intervention data system 	<ul style="list-style-type: none"> Client data system Survey to determine personnel needs 	<ul style="list-style-type: none"> Automated data system Interagency data form Client identification numbering

tribes' ideas of sovereignty, so it can be difficult to gain access to the pueblos to provide services.

Personnel Development. Personnel development plans are required from states to assure (and promote) the availability of personnel qualified to meet the standards of the state. States have the option of using Part B Comprehensive System of Personnel Development plans or developing new procedures under Part H (Brown, 1990). Most Comprehensive System of Personnel Development (CSPD) plans included needs assessments, preservices, inservices, and self evaluations.

A shortage of personnel who are trained at the local level was mentioned by several Part H Coordinators. One state even referred to it as a "nationwide shortage of staff." Areas of staff shortages included: occupational therapy, physical therapy, and nursing.

It was very difficult to remain in compliance with Part H when the personnel to provide the required services were not available. Shortages were severe in the very rural areas and the dangerous urban areas. One Part H Coordinator stated that some urban areas were so dangerous that service providers would not go to certain homes. The families were met at schools or churches in a safer section of the city. Another Coordinator stated, "The rural geography and

distance from service to service also make it difficult for parents to get services for their children."

Personnel Standards. Personnel standards represent a complicated and controversial set of regulations under Part H because specialized requirements in the regulations extend previous practices in personnel standards into new requirements for states. Statewide systems of early intervention must have policies and procedures to establish and maintain standards for early intervention personnel that must be consistent with any state agency requirements.

All states had their minimum standards, but they would be adjusted in the time of staff shortages. The Part H applications had to notify public agencies and personnel and specify timelines established for retraining or hiring personnel that meet "appropriate" professional requirements. States had an average of eleven positions for which standards were published. The positions ranged from parent involvement specialist to physician.

Financial Matters. The Part H expectations for financial cooperation and coordination are unparalleled by other Federal programs and can be achieved only through great talent and effort. Developing a financial plan to pay for a comprehensive, statewide system of early intervention services looms as one of the key implementations for Part H (Brown, 1990). The federal incentive dollars provide, at

best, a small portion of the costs of the services children will be entitled to, in participating states. Thus, attention is turned to the coordination of resources already provided to or which can be directed at, eligible children as one such source of funding.

All states, with the exception of Hawaii, mentioned the following funding sources: Title V of the Social Security Act; Title XIX of the Social Security Act: Head Start Act; Parts B & H of IDEA; Subpart 2 of Part D of Chapter 1 of Title 1 of the ESEA of 1965; The Developmentally Disabled Assistance and Bill of Rights Act; and other federal programs. Hawaii mentioned as funding sources: state general fund; federal funds under P.L. 102-119; federal funds under P.L. 89-313; Medicaid and insurance payments; special federal/state grants; local county monies; and private agency support.

Interagency Agreements. The Part H program is designed to be a comprehensive, coordinated, multidisciplinary, interagency program of early intervention services. For this reason interagency agreements are required by regulation, between the lead agency and every state-level agency involved in the state's early intervention program. Developing such state-level interagency agreements represents one of the most significant challenges to continued participation in the Part H program within the

timelines established by law (Brown, 1990). The average number of interagency agreements was nine, with North Carolina and Massachusetts having the most with 11 and Hawaii listed the fewest with five. All states had an agreement with the Department of Education in one form or another.

All states had interagency agreements, but more were needed. The more appropriate interagency agreements that existed, the more varied the services that could be provided for infants/toddlers and their families.

Contracting for Services. Several states mentioned that all early intervention services provided would meet the state standards and be delivered in a manner consistent with Part H regulations. California and Hawaii listed the types of services that may be included under this component.

Data Collection. States had various methods for data collection. Most states possessed a type of automated data system that provided information for the state and federal government. The following types of data were collected: numbers of infants and toddlers served; types of services provided; personnel providing services; expenditures for services; sources of funding; service delivery sites; additional personnel needed; and training needs of existing personnel.

All states had very similar statements in the areas of procedural safeguards, supervision and monitoring of programs, and lead agency procedures for resolving complaints.

Question Three: What mention of accommodations for perinatal exposure are found when one analyzes the 16 minimum components?

States that reach the full implementation stage of this federal legislation must provide services to two groups of children: those who are experiencing developmental delays, and those who have a diagnosed mental or physical condition that has a high probability of resulting in developmental delay (Shackelford, 1992). In addition, states may, if they choose, serve children who are at risk of having substantial developmental delay, if early intervention services are not provided (Brown, 1990). States that choose to serve at risk infants and toddlers do so at their own discretion; this is not mandated by Part H.

Two sources of data were analyzed when the 16 minimum components of 6 statewide comprehensive systems for the provision of appropriate early intervention services to infants and toddlers with special needs were analyzed for mention of perinatal exposure. The two sources of data were interviews with Part H Coordinators and federal Part H applications. Results are presented in Table 6.

Table 6

Analysis of 16 Components for Mention of Accommodations for Perinatally Exposed Infants/Toddlers and Their Families
(Yes/No response indicates accommodations specific to perinatally exposed)

Components	*Source	States						
		California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina	
1. State definition of developmental delay ** Are perinatally exposed infants and toddlers included in your definition of "at risk"?	C	Yes	Yes	Yes	Yes	Yes	Yes	
2. Central Directory ** Does your central directory mention accommodations for perinatally exposed infants/toddlers and their families?	A	Yes	Yes	Yes	Yes	Yes	Yes	
3. Timelines for serving all eligible children	C	No	Yes	No	No	No	No	
4. Public Awareness Program ** Does your public awareness program include accommodations for perinatally exposed infants/toddlers and their families?	A	No	Yes	Yes	Yes	Yes	Yes	
5. Comprehensive Child Find System ** What is specifically done in the area of child find to locate and serve perinatally exposed infants and toddlers?	C	Yes	Yes	No	Yes	Yes	Yes	
	A	No	Yes	Yes	Yes	No	Yes	

* C - Part H Coordinator
A - Part H Application

** Actual question from telephone survey

(Table continued)

Components	* Source	States						
		California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina	
6. Evaluation, assessment and nondiscriminatory procedures	C	Yes	No	No	No	Yes	Yes	
** Tell me about the multidisciplinary evaluation of strengths and needs of perinatally exposed infants/toddlers and their families. Explain the referral system for perinatally exposed infants and toddlers.	A	No	No	No	No	No	No	
7. Individualized Family Service Plan (IFSP)	A	No	No	No	No	No	No	
8. Comprehensive System of Personnel Development (CSPD)	C	Yes	Yes	Yes	Yes	No	Yes	
** Is there any personnel development around the issues of perinatal exposure/addition?	A	No	Yes	Yes	No	Yes	No	
9. Personnel Standards	A	No	No	No	No	No	No	
10. Procedural Safeguards	A	No	No	No	No	No	No	
11. Supervision and monitoring of programs	A	No	No	No	No	No	No	
12. Lead agency procedures for resolving disputes	C	No	No	No	No	No	No	
** What procedures are in place to resolve interagency disputes around the provision of services for perinatally exposed infants and toddlers?	A	No	No	No	No	No	No	

(Table continued)

- C - Part H Coordinator
- A - Part H Application

** Actual question from telephone survey

Components	* Source	States					
		California	Hawaii	Indiana	Massachusetts	New Mexico	North Carolina
13. Policies and procedures related to financial matters	A	No	No	No	No	No	No
14. Interagency agreements, resolution of individual disputes	C	Yes	No	No	No	No	Yes
** Do any of your interagency agreements target perinatally exposed infants/toddlers and their families? Please explain.	A	Yes	No	No	No	Yes	Yes
15. Policy for contracting or otherwise arranging for services.	C	Yes	No	No	No	No	No
** Tell me about your policy pertaining to contracting or making arrangements with local services for perinatally exposed infants/toddlers.	A	Yes	No	Yes	No	No	No
16. Data Collection	A	No	Yes	No	No	Yes	Yes

* C - Part H Coordinator
A - Part H Application

** Actual question from telephone survey

It should be noted that Part H Coordinators were not asked questions pertaining to all 16 components. It was felt that certain components would remain standard with regard to population served. Examples of such components included: individualized family service plans, procedural safeguards, policies and procedures related to financial matters and personnel standards.

Within certain components, there existed a difference between what was said by the Part H Coordinator and the Part H application itself. An example of such a difference included Massachusetts' Part H Coordinator stating that no accommodations were made for perinatally exposed infants/toddlers and their families in the Central Directory while the Part H application did mention such accommodations, although on a small scale.

It was very interesting that five of the six states had a type of health department as their lead agency. If a governor or a lobbying group were concerned about providing services under Part H of IDEA for perinatally exposed infants and toddlers it appears the lead agency may want to be a department of health.

Definition of Developmental Delay. All six Part H Coordinators and applications mentioned perinatally exposed infants in the state definition of developmental delay. This was one of the determining factors to decide which

states would be included in this study. Examples of risk factors that would lead to eligibility included: abuse of any legal or illegal substance by a primary caregiver; infants of mothers who are chemically dependent; history of actual or suspected maternal substance abuse during pregnancy; and birthmother during pregnancy or primary caregiver has been a habitual abuser of alcohol and/or drugs.

All states had perinatal exposure or substance abuse by the mother as a risk factor under the at risk category. No one risk factor made an infant/toddler eligible for services. But as one Part H Coordinator said, "In my seven years of being the Coordinator I have not found one perinatally exposed infant or toddler who did not have more than one risk factor." Other risk factors included: difficulty in parent-infant attachment; difficulty in providing basic parenting; lack of stable housing; lack of familial and social support; and maternal age less than 15 years. All states had a varying number of risk factors that allowed an infant or toddler to be eligible for services.

Central Directory. The Part H Coordinator from Hawaii was the only respondent to say that their central directory made accommodations for perinatally exposed infants and toddlers. The Part H application for Hawaii stated that

"perinatal services and resources are included in the database of services and resources."

Perinatal accommodations that were found in various Part H applications included: information and referral for prenatal substance abuse; and substance support groups.

Timelines. Only the state of North Carolina made specific mention of this population in the timelines for serving all eligible children. "In recognition of the growing impact parental substance abuse has on infants and toddlers, there has been substantive inter and intra-agency planning for this population. The services would include substance abuse prevention, intervention, treatment and referral for pregnant women or mothers who are abusing substances or in recovery."

Public Awareness. Four states made accommodations for perinatally exposed infants/toddlers and their families. Examples of such accommodations included: presentations at the Perinatal Association and at the Substance Abuse Commission, and about two thirds of the local planning areas in California applied for special Part H funds to serve perinatally exposed infants and toddlers. The Third Annual Early Intervention Conference in Hawaii pertained to "Social Reciprocity Interventions with Drug Exposed Babies: Treatment & Implications."

Child Find. All six states, in the areas of comprehensive child find and comprehensive system of personnel development, made accommodations for this population. Concerning child find, the following information was discovered: hospital screening and outreach; information to physicians; a high risk coordinator at each regional center; toxicological screens given in hospitals to mothers giving birth; and developmental care programs that did follow-ups for babies identified at birth.

It was very interesting that in the area of comprehensive child find, some states used toxicology screens at the hospitals to identify drug exposed newborns. The legislature supported such actions. One Part H Coordinator stated that if these babies were not identified at birth, they may not get identified until they reached school age.

Personnel Development. As previously stated, all six states addressed perinatal exposure in the component of personnel development. The various activities mentioned included: providing workshops in the area of perinatal exposure; special personnel and family training; statewide service institutes on substance abuse; and training aimed at substance abuse and perinatal exposure. Hawaii stated that a statewide needs assessment indicated the need for attention to special needs of infants and young children who

were prenatally exposed to drugs, alcohol, or HIV infection. Indiana's Part H application mentioned the need to work more effectively with parents who present challenges due to chemical dependency. New Mexico stated that a supplemental needs assessment was done regarding infants born at risk including information concerning intrauterine drug exposure.

A few of the states had completed needs assessments of the staffs and issues pertaining to perinatal exposure were among the top priorities.

Evaluation. When evaluation, assessment, and nondiscriminatory procedures were analyzed, half of the states made accommodations. Examples cited included but were not limited to: someone with experience in the area of substance abuse would have to be on the evaluation team; a different assessment tool was used when perinatal exposure was suspected; most of the referrals came from the neonatal intensive care unit; and hospital based evaluation teams were utilized so the child could be evaluated before leaving for home. "I suspect that if you don't catch a prenatally exposed infant at the hospital that you may not pick them up. You may have lost your best opportunity if you don't catch them at birth."

Within certain components there existed a difference between what was stated by the Part H Coordinator and the Part H application itself. This may have been because the

Part H Coordinator was not completely familiar with all aspects of the application.

Interagency Agreements. Agreements that targeted the population of perinatally exposed infants/toddlers and their families were only found in three states. Agreements that were mentioned included: prenatal care network; State Council on Developmental Disabilities; the Division of Maternal and Child Health; Duke University; and linkages with substance abuse agencies.

Indiana stated that even though the Department of Substance Abuse was an intra-agency collaborator, that department really did very little with the perinatally exposed population. It should be noted that Indiana was not in full implementation and that could explain the lack of involvement of the Department of Substance Abuse. There was a need to improve intra-agency agreements in Indiana.

Contracting for Services. When contracting or otherwise arranging for services was analyzed, only two of the six states included accommodations. California's Governor was very interested in perinatal substance abuse and 24 or 25 million dollars were given to the schools to assure that all children in the state became aware of the dangers of perinatal substance abuse. Indiana had contracts with the Department of Substance Abuse, although according

to the Part H Coordinator, not much occurred from this contract.

Data Collection. Half of the states included accommodations for data collection. Such accommodations included: a high risk infant identification system; and a legislatively mandated, statewide reporting system provided information about newborns that were at risk for neurological complications.

No accommodations were made by any of the six states for perinatally exposed infants/toddlers and their families in the following components: individualized family service plan; personnel standards; procedural safeguards; supervision and monitoring of programs; lead agency procedures for resolving disputes; and policies and procedures related to financial matters.

In summary, 10 components mentioned accommodations for perinatally exposed infants/toddlers and their families. Those components and how many states for each component were: state definition of developmental delay (6 states); central directory (5 states); timelines for serving all eligible children (1 state); public awareness program (4 states); comprehensive child find system (6 states); evaluation, assessment, and nondiscriminatory procedures (3 states); comprehensive system of personnel development (6 states); interagency agreements (3 states); policy for

contracting or otherwise arranging for services (2 states); and data collection (3 states). Refer to Table 7 for accommodations that were made and how many states made each accommodation.

Question Four: Should Part H mandate that infants and toddlers who were perinatally exposed be covered under this legislation?

It was recognized that the use of the word "should" in the above research question may be construed to mean an opinionated answer from the Coordinators. This was not the intent. Should was defined as the past of shall, used in laws, regulations, or directives to express what is mandatory.

The importance of comprehensive, coordinated health care services and education for all children in this nation is widely recognized (Select Panel 1981; AAP 1977; Haggerty 1975). The lack of such services, especially for children with disabilities has been well documented (Brewer et al. 1979; U.S. Department of Education 1980; Kronstadt, 1991).

According to Education of the Handicapped Act (now known as the Individuals with Disabilities Education Act): 20 U.S.C. 1401-1485 (1986),

(a) The Congress finds that there is an urgent and

Table 7

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

Accommodations for Perinatally Exposed Infants and Toddlers
are in bold print. The number that follows, indicates
the number of states that provide this accommodation.

1. **State definition of developmental delay.** 6
 2. **Central directory.** 1
 3. **Timetables for serving all eligible children.** 1
 4. **Public awareness program.** 4
 5. **Comprehensive child find system.** 6
 6. **Evaluation, assessment, and nondiscriminatory procedures.** 3
 7. **Individualized family service plan.** 0
 8. **Comprehensive system of personnel development (CSPD).** 0
 9. **Personnel standards.** 0
 10. **Procedural safeguards.** 0
 11. **Supervision and monitoring of programs.** 0
 12. **Lead agency procedures for resolving complaints.** 0
 13. **Policies and procedures related to financial matters.** 0
 14. **Interagency agreements; resolution of individual disputes.** 3
 15. **Policy for contracting or otherwise arranging for services.** 2
 16. **Data collection.** 3
- Individuals with Disabilities Education Act of 1990. 20
U.S.C. 1400, (1990).

substantial need-

(1) to enhance the development of infants and toddlers with disabilities and to minimize their potential for developmental delay.

(2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age.

(3) to minimize the likelihood of institutionalization of individuals with disabilities and maximize the potential of their independent living in society, and

(4) to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities.

Congress' intent was to provide services to needy infants and toddlers for the betterment of the child, their family and society as a whole. Perinatally exposed children certainly fit under the above urgent and substantial need mentioned by Congress.

Based on the literature, (Chasnoff, 1993; Intriligator et al., 1989; and Infants Can't Wait, 1986) perinatally exposed infants and toddlers should be served under Part H of IDEA. The professionals in the field, Part H Coordinators, agreed. "Of all the children, we have the most opportunity to make a difference with this population."

Refer to Table 3 (page 63) for specific responses. Five of the nine Part H Coordinators felt that Part H should mandate coverage for this population. "These kids need services and they need them now. We either pay now or later." Even states that did not serve at risk groups felt that such a mandate would be appropriate. "It should only be mandated if enough funds are appropriated to cover this population." Refer to Table 8 for the Part H allocations for Fiscal Year 1992.

Four Part H Coordinators felt that such a mandate should not occur. "It shouldn't be mandated anymore than any other group of children." "States may elect not to participate in Part H because they think the numbers will be too big." Concerns mentioned by Part H Coordinators that felt this should not be mandated included the idea of labeling a group of children. They did not want these children labeled the "crack babies" or the bio-underclass. It was also mentioned that Part H should not make eligibility based on a label, but rather on the individual needs of children.

Other Research Findings

During the course of this research other pertinent information was discovered. When asked if the provision of services for perinatally exposed infants and toddlers would differ based on which agency was designated by the Governor

Table 8

Part H Allocation -- FY 1992

For States that Do and Do Not Serve Perinatally Exposed Under At Risk

State	Estimated # of children served under Part H	Base Award	Reallotment	Status
<i>Serve Perinatally Exposed Under At Risk</i>				
California	31,305	\$21,710,966	\$2,783,391	*Full
Hawaii	2,129	855,556	109,684	*Full
Indiana	1,999	1,551,947	_____	**EP(2)
Massachusetts	4,873	3,730,987	478,319	*Full
New Mexico	722	1,102,824	141,384	*Full
North Carolina	5,203	4,142,304	531,051	*Full
<i>Do Not Serve At Risk</i>				
Arizona	4,806	\$2,617,743	\$335,600	*Full
Illinois	4,364	7,626,080	977,678	*Full
Virginia	2,400	3,995,496	512,230	*Full

(1993, October). Children with Special Needs and Their Families. Early Childhood Report, 4(10).

- * Full - Full implementation - Met all federal requirements for Part H of IDEA.
- ** EP(2) - Second year of extended participation - Extra time was given to states to meet all federal requirements. The federal grant was equal to the money received in FY 1990.

as the lead agency, five Coordinators responded yes. "All agencies have their own cultures and way of approaching the provision of services to families. I think education departments are very different from health departments." "The difference can be whether certain linkages are in place. What is within your agency shapes the nature of the service." All five of these lead agencies had a form of health department as their lead agency and all served perinatally exposed under the at risk definition of Part H. Coordinators felt that the case management approach of health departments was more conducive to the intent of Congress pertaining to Part H. It was stated that what was within the lead agency shaped the nature of the service. Refer to Table 3 (page 63) for specific responses.

Three states that did not serve this population felt that it did not make a difference in which department the lead agency was located. "If a state works cooperatively it doesn't make a difference." "We have a Substance Abuse Department within our lead agency and that is where it belongs." The lead agencies for those states were Department of Economic Security, State Board of Education and Department of Mental Health, Mental Retardation, and Substance Abuse Services.

Summary of Findings Related to Research Questions

This study was conducted because of a lack of available information concerning services provided to perinatally exposed infants and toddlers under the at risk category of Part H. The following conclusions were reached with respect to the research questions originally proposed for the study.

It was very interesting to examine the six states, California, Hawaii, Indiana, Massachusetts, New Mexico and North Carolina, because they really do not "hang together." They are all very different entities, but yet they all chose to include perinatally exposed infants/toddlers and their families in the at risk definition due to political and humanistic reasons. Lobbyists were successful in convincing Governors and legislatures that perinatally exposed infants/toddlers and their families should receive services from Part H of IDEA. In other instances, the lead agencies felt that it was the "right" thing to do because these infants and toddlers were in need of services. See Table 3 (page 63).

It was discovered that many states had similar minimum components due to the fact that the federal requirements are very specific and states must abide by them if they choose to continue to receive funding. Refer to Table 5 (page 70). A shortage of staff appeared to be an issue of deep concern for several Coordinators. Services could not be provided

when the necessary positions were vacant. Even though the average number of interagency agreements was nine, more effort could be exerted in this area to provide the maximum services for all eligible children and their families. Though one Coordinator stated that she had no time to spend on obtaining additional interagency agreements because she spent all her energy involved with the "red tape" of Part H.

All six states made accommodations for perinatally exposed infants/toddlers and their families for 10 of the 16 minimum components of Part H. The 10 components were; state definition of developmental delay; central directory; timelines for serving all eligible children; public awareness program; comprehensive child find system; evaluation, assessment, and nondiscriminatory procedures; comprehensive system of personnel development; interagency agreements; policy for contracting or otherwise arranging for services; and data collection.

Accommodations were made by 6 states in 10 of the 16 components. Although there is always room for improvement, this is impressive considering 44 states in the country make no accommodations for perinatally exposed infants and toddlers.

No specific accommodations were made by any of the six states for perinatally exposed infants/toddlers and their families in the following components: personnel standards;

procedural safeguards; supervision and monitoring of programs; lead agency procedures for resolving disputes; and policies and procedures related to financial matters. This really was not surprising; it appears that these components would remain standard with the regard to the population served.

Though no specific accommodations were mentioned for the individualized family service plan, that document is to be geared toward the unique needs of the infant/toddler and his family. Thus for this component, accommodations for perinatally exposed infants and toddlers are most likely provided.

Five of the nine Part H Coordinators stated that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation. Even states that did not serve at risk groups felt that such a mandate would be appropriate. It was stated that mandating such coverage may be the only way to provide services to this vulnerable group of youngsters. The importance of early intervention for perinatally exposed infants and toddlers is widely recognized, and the lack of such services is well documented.

Evidence from this research also suggests that a type of health department may be the best location for the lead agency when one is concerned about services for perinatally

exposed infants/toddlers and their families. Only six states in the country chose to serve this population under at risk and five of the six have a health department as their lead agency. A state mandate by statute or executive order could assure service to this group.

Lead agencies that do not serve perinatally exposed infants and toddlers may want to utilize the funds that are currently being used to track at risk populations for the provision of actual services versus a monitoring mode. Tracking these children is expensive and lead agencies may want to consider that the provision of services is a better use of very limited funds.

The issue of staff shortages must be addressed if the provision of services to all eligible children is to continue in the appropriate manner. Possibly, agreements or contracts could be established with local colleges and universities to encourage enrollments in the needed areas. Such areas may include: occupational therapy, physical therapy, and nursing.

Findings also suggest that the Congress may want to encourage states to serve perinatally exposed infants/toddlers and their families. Possibly monetary incentives could be provided to states that chose to serve this population, since funding appears to be the main rationale for not providing services. Documentation exists

that supports the notion that it is more economical to serve this population now, than to wait until they enter school.

Recommendations for Further Study

The results of this study suggest that further research is needed. Specific recommendations for future inquiry are:

1. Conduct a similar study with the provision that the researcher or designee travel to each Part H lead agency to collect the data. This would provide an opportunity to speak with more people and collect additional data.
2. Conduct a study on what services perinatally exposed infants/toddlers and their families actually receive from Part H.
3. Conduct a study on what model (medical, community health) is used by each Part H lead agency and is there a difference in the types of services provided to infants/toddlers and their families.
4. Pursue a study pertaining to how the continuum of services can be insured from the prenatal period through the early school years.

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APPENDICES

Note: Appendices H through P present the context of STATEMENTS made by Part H Coordinators in reference to services provided to perinatally exposed infants/toddlers and their families. Complete audiotapes, Part H applications, and contact summary sheets are available from the author upon request.

APPENDIX A
TELEPHONE SURVEYS FOR PART H COORDINATORS THAT SERVE
PERINATALLY EXPOSED INFANTS AND TODDLERS UNDER
THE AT RISK DEFINITION OF PART H

Appendix A

**Telephone Survey for Part H Coordinators that Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H**

State _____

Date _____

1. What year of implementation are you currently in?
2. How long have you been the Part H Coordinator?
3. Are perinatally exposed infants and toddlers included in your definition of at risk?
4. Why does the state of (California, Hawaii, Indiana, Massachusetts, New Mexico, or North Carolina) choose to include perinatal exposure in the definition of at risk?
5. Does your central directory mention accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?
6. Does your public awareness program include accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?
7. What is specifically done in the area of child find to locate and serve perinatally exposed infants and toddlers?
8. Is there any personnel development around the issues of perinatal exposure/addiction?
9. Do any of your interagency agreements target perinatally exposed infants/toddlers and their families? Please explain.
10. How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?
11. What procedures are in place to resolve interagency disputes around the provision of services for perinatally exposed infants and toddlers?

12. Tell me about your policy pertaining to contracting or making arrangements with local services for perinatally exposed infants/toddlers.
13. Tell me about the multidisciplinary evaluation of strengths and needs of perinatally exposed infants toddlers and their families.
14. Explain the referral system for perinatally exposed infants and toddlers.
15. With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.
16. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.
17. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.
18. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?
19. Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.
20. Is there anything else that you would like to add?

Appendix B

**TELEPHONE SURVEY FOR PART H COORDINATORS THAT DO NOT SERVE
PERINATALLY EXPOSED INFANTS AND TODDLERS UNDER
THE AT RISK DEFINITION OF PART H**

Appendix B

Telephone Survey for Part H Coordinators that Do Not Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State _____
Date _____

1. What year of implementation are you currently in?
2. How long have you been the Part H Coordinator?
3. Why does the state of (Arizona, Illinois, Virginia) choose not to include perinatal exposure in their definition of at risk?
4. If perinatally exposed infants and toddlers are not eligible for services under the at risk definition of Part H, where does this population receive services in your state?
5. How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?
6. With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.
7. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.
8. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.
9. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?
10. Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.
11. Is there anything else that you would like to add?

Appendix C

CONFIRMATION LETTER TO PART H COORDINATORS

Appendix C

Confirmation Letter to Part H Coordinators

750 Tall Oaks Drive
Apt 3500 E
Blacksburg, VA 24060
October 1, 1993

Marilyn Price
Early Childhood Coordinator
Developmental Disabilities Division
Department of Health
P.O. Box 26110
Santa Fe, NM 87502-6110

Dear Ms. Price:

I am writing to confirm the date and time for our telephone survey. I will call you October 18th at 11:00 your time.

I have enclosed a copy of the survey. If you have any questions or concerns please feel free to call me at 703-231-5925. Thank you for your willingness to participate in my study.

Sincerely yours,

Karen Gerry-Corpening

Enclosure

Appendix D

THANK YOU LETTER TO PART H COORDINATORS

Appendix D

Thank You Letter to Part H Coordinators

750 Tall Oaks Drive
Apt 3500 E
Blacksburg, VA 24060
October 18, 1993

Marilyn Price
Early Childhood Coordinator
Developmental Disabilities Division
Department of Health
P.O. Box 26110
Santa Fe, NM 87502-6110

Dear Ms. Price:

I want to thank you for participating in my study. The information that you provided will add greatly to my results. I realize that you are a very busy person and I do appreciate the time that you took to be a part of this research.

I will gladly send you the results of my research. It may be a couple of months, but I will remember. Thanks again for your input.

Sincerely yours,

Karen Gerry-Corpening

Appendix E

DEPARTMENTAL LOCATION OF STATE LEAD AGENCIES FOR PART H

Appendix E

Departmental Location of State Lead Agencies for Part H

State Department of
Education

Alabama
Colorado
Connecticut
Florida
Illinois
Louisiana
Michigan
Minnesota
Missouri
Nebraska
New Jersey
Oklahoma
Oregon
South Dakota
Tennessee
Vermont
Wisconsin

Department of Health & Social
Services

Alaska
North Dakota
Arkansas
California
District of Columbia
Hawaii
Idaho
Indiana
Kansas
Nebraska
Massachusetts
Mississippi
Montana
Nevada
New Hampshire
New Mexico
Wisconsin
New York
Ohio
Pennsylvania
Rhode Island
Utah
Washington
West Virginia
Wyoming
Delaware
South Carolina
Texas

Mental Health/Mental Retardation/and Substance Abuse

Georgia
Kentucky
North Carolina
Virginia

Department of Economic Security

Arizona

University

Iowa

Child Development

Maine

Maryland Infant/Toddlers Program

Maryland

National Early Childhood Technical Assistance System.
(1992). The 1991-1992 directory of selected early
childhood programs. University of North Carolina:
Chapel Hill.

Appendix F

EARLY INDICATORS OF PRENATAL EXPOSURE TO TOXIC SUBSTANCES

Appendix F

Early Indicators of Prenatal Exposure to Toxic Substances

- * Low birth weight;
- * Prematurity;
- * Physical malformations, such as heart, lung and digestive system abnormalities;
- * Neurological malformations;
- * Strokes and seizures;
- * Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE);
- * Neonatal Abstinence Syndrome (NAS), a type of drug withdrawal;
- * Increased risk for Sudden Infant Death Syndrome (SIDS);
- * Hyperirritability for up to 6 to 8 weeks;
- * Hypersensitivity to touch, movement or eye contact for up to 2 to 4 months;
- * Difficulty being comforted;
- * Tremulousness and rigidity;
- * Abnormally acute hearing;
- * Uncoordinated motor functioning, especially sucking and swallowing;
- * Difficulty fixating on objects and controlling alertness;
- * Poor feeding and sleeping habits;
- * Decreased interaction with caregiver; and
- * Decreased use of caregivers for comfort, play and assistance.

Collins, R., & Anderson, P. (1992). Head start substance abuse guide: A resource handbook for head start grantees and other collaborating community programs. U.S. Department of Health and Human Services, Washington, D.C..

Appendix G
CONTACT SUMMARY FORM

Appendix G

Contact Summary Form

CONTACT:

DATE:

What new hypotheses, speculations, or guesses about the area of research was suggested by the contact?

Where should I place more energy for the next interview?

Target questions to consider for next survey?

Impressions and reflections of participant/interview.

Adapted from Miles & Huberman (1984). Qualitative data analysis. Newbury Park, CA: Sage Publications.

APPENDIX H
VERBATIM TRANSCRIPT OF TELEPHONE INTERVIEW
WITH CALIFORNIA'S PART H COORDINATOR

Telephone Survey for Part H Coordinators that Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State California

Date 10-8-93

1. What year of implementation are you currently in?

We are currently in our fifth year and we have applied and think that of course we will be getting approval for our sixth.

2. How long have you been the Part H Coordinator?

I am not the Coordinator myself but the Coordinator felt that I would have a better capability to answer these questions. And so, in terms of our Part H um, um, being a Part H Coordinator... we have such a huge state you know that um ... we have a whole host of different persons you know that are working ah for our department of Developmental Services which is the lead agency and so * * has been the manager ah all this while you know for the project. I have worked for Part H since the beginning. I worked the original application. I didn't prepare the budget but we um... but just as an interest to you we had what we call our Office of Prevention you know to prevent childhood disabilities so we had had our office since 1983. And so, as part of our ah development of ah high risk infant and children services well we we started ah you know ah we certainly went for the first ah available opportunity to apply for Part H.

3. Are perinatally exposed infants and toddlers included in your definition of "at risk"?

Ah, yes they are. Um we we as I mentioned have actually been serving at risk infants since about 1980... 1985. And we have always considered um substance exposed infants um you know to be at risk. and so that of course would include alcohol and illicit drugs as well as legal drugs. Because we um we um we certainly ... teratogens um certainly like Dilanton or um Acutane or some of these other things. So we have always tried to consider as eligible for services any child who has been exposed and so you know the illegal drugs were certainly included as part of that so we have actually been serving them since 85.

4. Why does the state of (California, Hawaii, Indiana, Massachusetts, New Mexico, or North Carolina) choose to include perinatal exposure in the definition of "at

risk"?

We choose to include it because, for, I think, probably for several reasons. But I think first of all, um you know that the mother who is using drugs, whether that be alcohol or or you know coke or crack or whatever um also tend not to be getting prenatal care early. They tend not to have a good diet. They very often do not really um ah have a safe lifestyle and so we feel that that in itself puts the person at risk and we have always been concerned that certainly with ah exposure to alcohol where you get fetal alcohol syndrome or fetal alcohol effect that that then is clearly a condition that is going to result in disability if we don't do something about it. And certainly many times we can only lessen that and help the family and so we have felt that exposure prenatally puts the child at risk both from the standpoint of environmental ie the mom's inability to perhaps being as effective in parenting and secondly because of the actual you know effect of the drug.

Dr. * was there a force that was responsible for having perinatally exposed infants and toddlers included in the definition of "at risk"?

Well you know there, as I say, because our state is so huge there were quite a few um groups um actually I guess um we have a separate Department of Alcohol and Drugs Programs in California and um certain of their staff um ah did not necessarily push us, we did these simultaneously. I think we became aware in California of the high ah you know substance abuse primarily through the perinatal associations. We have had the California Perinatal Association and the and the various other um perinatal, like Eastbay Perinatal and other perinatal groups. Um they were the ones, I think, that first pushed the alarm button and made everyone aware of the problem and you see because we, in our Department of Developmental Services, were serving and have been serving children with developmental disabilities for for since 1969, we were very well aware that certain of our children with disabilities were were being caused by substance abuse exposure. So I think that in a way it was the combined action of of say these groups particularly the perinatal and alcohol and drug um prevention groups that were um you know created the awareness such that we could easily get professional acceptance to include um and legislative approval to include um you know high risk infants in our service um um provision. Because before, another words, it was not until 1972 that we really got legislative authority to serve children that were, in addition to having disabilities, were at risk and I think that we were able to do this as a result of the awareness um of the public and the legislature of the

um perinatal and substance exposure that was sort of made evident by these groups. Does that make sense? You see, I'm just trying to um, you see there had always been local groups that that were um in preventing of alcohol use. And it is hard for me to think of all those associations that did it, but it was primarily the prevention groups that wanted to avoid alcohol abuse and the perinatal groups as I see it that that made the difference.

5. Does your central directory mention accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

You know, I have the resource directory in front of me and um as I went over it it doesn't um it doesn't have um perinatal resources per say and I'll tell you why. Because, um there has been a real push by a lot of children advocates and and a lot of ah ah and of school persons that they do not want to see perinatal exposed children labeled. And so what we we have really done is in our outreach is for any child who is at risk or delayed,... and then we show the criteria at which substance exposure is listed and so in our in in in and so we figure that our family resource centers, each of the local alcohol and drug programs are all resources for um persons who have had perinatal substance abuse. So we list in our resource directory every single one of the county um um you know alcohol and drug programs. We list all of the regional centers. Um we list all the family resource centers and see children with perinatal substance abuse would be eligible to to contact those you know to try to to try to get services. Now in the past we would have had what we call Options for Recovery, which was our system of pilot perinatal substance exposed programs, another words these were residential programs for women and their babies who have perinatal substance exposure. And what happened ... they were successful but what we feel is not fair in our state, I think we had a total of about nine and so so we have changed so that every county um alcohol and drug program and that is in all 58 counties must have a perinatal drug component, which includes services to children. Now what happens, they they then um they may not always give them directly, but it is their responsibility for the substance abusing mom um and their babies or children you know to get them to the available family resource centers or regional center in their area. And so so I say we have not um we don't specifically have centers that we list in here that a child with perinatal substance exposure attends because, because they are eligible to go to all of them. And and see that's why we don't list it by name because most of our children services and our early

intervention services would um would take a child and um then they would they would try to develop the individual program they needed irrespective of the cause and so um. We have had early on,... now I think certainly in Los Angeles is a good example say at Martin Luther King thru King Medical Center they have had some very intensive programs that followed um children out of the NICUs. We have had it at Oakland um in the northern part of the state and these were programs specifically for the mothers and babies. But, um now I notice in here we do not have those services listed because they ah serve a direct population another words they would come straight out of a neonatal intensive care unit. And and so um that is something to think about too whether we probably... your survey serves a good point should we really mention some of these, ah but on the other hand see they if they had not been in the NICU they could not be referred to them you see what I mean. So what what we are really doing is is listing all so I think you could say that yes we do have resources because we feel that if there has been perinatal substance abuse or using they should be referred to the local you know county alcohol and drug treatment program. They are in here by name.

6. Does your public awareness program include accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

Ah yes you see there have been a lot of um. It has been very interesting when we were doing our Part H planning ah we we permitted each... ah we had something like 26 local planning areas throughout the state and each of those 26 local planning areas determined ah the needs of children zero to three particularly the unmet needs. And I would say at least 2/3 of the local planning areas um applied for special Part H funds to serve um perinatally substance exposed children because... what we felt was that the traditional program for say the the like the Down's baby or some other preemie did not really meet the needs of the substance exposed infant. And and so um our outreach has been certainly for training of staff, for community training, and for ah you know developing services for the the substance exposed. So I think our outreach as really um ah definitely involved ah reaching out to families who were substance exposed.

7. What is specifically done in the area of child find to locate and serve perinatally exposed infants and toddlers?

Ya, the way, what, the way in which I think we get most of them ...we have a system in our state of 21 regional centers and they cover all of our 58 counties. And each of those regional centers has what we call you know prevention coordinator or a high risk infant coordinator. And I ah think there are some rural counties they don't have a big hospital or an NICU in their county. But, for example our northern counties like ah Minnasino and Beugul you've probably heard of some of those. They in turn are delivered in LA no I mean San Fransisco or Alameda Counties and so what but but so what we've said is that every regional center has liaison with the the hospitals that delivery babies you know the NICUs and the hospitals, the OB hospitals. And so the liaison there is ...ah and also interagency agreements and local agreements that there is referral from ah the child find goes from the hospital or NICU ah and the regional centers. And so that is where I think we get most of our babies that are substance exposed. And the other source of course of child find is with the Department of Social Services. Because see we have in California a requirement that all ladies that give birth should have screening and there is a county plan for doing this for for for ah you know whether or not the mother was using drugs. Now another words we can't always say that the hospital complies, but what I'm just saying is that there is on the books a law that says every hospital every county must have a plan where by any woman giving birth you know within the county is screened. Now the way they do that is there is a questionnaire and the nurse the attending nurse, the nursing staff is is to ah refer any woman who has a positive tox screen or who um who gives a history, because many times as you know they will give a history of substance abuse and won't have a positive tox screen and it is not always drawn. But they are to refer them ah to services. They don't refer them to child protective. In the past you know they used to refer all positive tox screens to child protective, but the law is sort of protective of those mothers. It says a positive tox screen in and of itself is not enough to cause you to refer to protective services. What you do is you refer to the local perinatal substance abuse program and let her know that there are services available. Now if you really suspect, another words you can see that the mother doesn't take the baby or there is a whole host of things in the questionnaire then you might want to refer to child protective. But in terms of child find, if you know then through that screen then they can either screen the baby... they can either refer the baby to the regional center or to the new Part H program or they could refer the mom to the treatment. So through that process that is where we would find most of our perinatal you know children.

You know how we did that; there was a very excellent... it was called the Governor's select committee on Perinatal substance abuse. And it was through that Governor's select committee and that had representatives from all our major health and welfare agencies and some of the local drug treatment agencies. A plan was made which included this screening process. So I think again that was an interagency effort you know because it was our Department, Mental Health, and Drugs all the health and welfare agencies went together to get this plan. And I think as a result of the plan and the result of the commitment of the persons in those agencies, that I had already mentioned to you, we were able to get the legislation passed for that that screening and questionnaire. If you wanted to see it, I could show you, send you some of the earlier and the screening tool has had quite a bit of modification. And then we've had certain of the hospitals that have wanted to use their own. And you really can't control a local medical group and how they want to do. But, but I think ah that that would give you the mechanism that we usually use to find most of our children.

8. Is there any personnel development around the issues of perinatal exposure/addiction?

We have literally hundreds. It has just been incredible. I don't know how I could ever get you a big listing of all of them. But, but, each of the, I mentioned the options for recovery. Each of those special programs, and there was something like 25 million dollars spent, had training of personnel. There has been all matter of training of personnel thru Part H ah to try to assist ah early intervention people and to assist parents knowing how to assist and understand their children. So there has been um enormous training effort both from alcohol and drug programs um from our department and our regional center system and in um you know the Part H. I already mentioned to you that quite a few special personnel and family training in perinatal substances were given during the five years that we were ah planning. I don't know if we have a total of them; I don't know if we have gone thru. What we did was we kept a list, we we um of the projects and the special outreach that each of our planning areas made, but I personally went through them once to see how many of them were related to substance abuse and I think 2/3 of the 26 actually did have both personnel and um family training sessions for perinatal substance abuse.

9. Do any of your interagency agreements target perinatally exposed infants/toddlers and their families? Please explain.

Um, they they certainly did early on ...you know when our local planning areas were deciding what to do. Another words, which of the agencies came together to decide what they would be doing and I think that's when I suggest that they did their interagency agreements as to what they would sponsor and what they do. Ah this did involve perinatal substance abuse. I think now our interagency agreements have sort of changed in character because we are out of this sort of initial planning training and into the implementation and so I'm not sure yet because we are just getting our interagency agreements back. Most of them specify how they are going to refer clients um more by their characteristics, like what we call low incidence: hearing, vision things like this and others. They are not so much into um referring of children by special category. It sort of gets back to this idea that I'm telling you everyone does not wish to label kids. This is a Downs, or this is s Tourettes, or this is a Cocaine baby. They are simply,... this one has special needs and they are this. And so um for example in our state we have our California Children's services primarily serves children with physical handicaps. Um, you know regional centers serve primarily developmental handicaps, of which a lot of the substance exposed clearly come in. They do not have many of them ..physical problems. They have behavioral and learning and other problems. So ah as I say I couldn't answer that question precisely about whether they specifically address substance expose, I don't think they do now because they are more administrative. But in the five years prior to now when we were planning um they did have agreements about how they would serve them.

10. How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?

I think ah two ways. One, clearly they are going to be substance exposed ah children who have multiple problems and already have disabilities. If they have had a stroke or if their mom has really been a user and they come in very premature and so forth. So I say that Part H is really to delivery not only developmental, but make very sure that that um that the children that are perinatally substance exposed get the health and medical services that ah they need. And and I think ah the other way in which Part H will should serve is that many of the children. Ah actually if they are given early intervention and you can get to the families, um do not turn out retarded or ah having cerebral palsy. But, they have a very different kind of need. They have interpersonal and behavioral. And many times the specific learning problems that that do not fully manifest themselves until after age three. So I think that the

transition planning to make. Now this children can be recognized as having problems. Certainly from zero to three. But, I think a critical part of the Part H service will be making sure that those children who are substance exposed continue to be served in the Part B ah thru the Department of Ed. Because our Department of Ed has traditionally not picked up these children because they do not have 50 percent or 25 percent delay in certain you know speech and language and so forth. And and I would see the the Part H as as a learning you know preschool to to children who may have some special needs. And um and certainly if we can identify them zero to three... try to provide for them as well. I am sort of reflecting what I know that our regional centers have been concerned about. That there are children who are substance exposed and who will not meet the definition of the school. Really they worry a great deal about between three and five. Because it does not seem right to have an intensive program that is going to then be lost when that child leaves Part H and goes to Part B. And so I would see that as, and I know quite a few share my views on that so um. I know that we have discussed it here in our staff office. That is what I would see as the major. And then the other thing of course is family support to keep them on recovery or in treatment. That is a very important thing that that with the family resource centers we are going to be having they family support that that I would see as the role of Part H as well because that is really critical.

11. What procedures are in place to resolve interagency disputes around the provision of services for perinatally exposed infants and toddlers?

Um, in terms of um interagency we are just in our process of getting those final ones together. And as I said the the ... in our interagency dispute um it it doesn't usually come about because of the child's etiology. Another words, no one would dispute, another words, um since since um since having perinatal substance expose is not a criteria for Department of Ed accepts, we would have to go forward with what does this child have; evidence of a learning disability or serious emotional disturbance or whatever. And so, as I say, our interagency agreements would discuss um differences of eligibility but I don't, to my knowledge I do not believe we have discussed it on the basis of their substance exposure because that is not considered a factor. The factor is their need. Another words, what is their special need. Now I think in the past um we have more or less we have not had procedures for say when we first started because our agency worked with alcohol and drug to get the perinatal residential treatment. We had grave

concern that their staff did not understand who to work with children developmentally. And so we because we had liaisons to each others programs we our our area of concern, not necessarily dispute, but concern was resolved through real pressure to get them to do something about the the the the personnel development of the persons in their centers so they understood how to work with at risk kids. So so I think that rather than say resolving disputes, it was more or less a method of of um persuing concerns. While I'm thinking about it I could just share with you our concern in our Department of Developmental Services about the number of babies, because we have a nice data collection system. Ah from 1985, where we had about 9% of our new infants coming in who had substance exposure as a risk factor. In five years, it grew to about 26% of our children were showing substance exposure as a risk factor of children who were coming in with delay and at risk. And so that is when we wrote a big memorandum to our health and welfare agencies saying that something has got to be done. Here are these babies coming in. And so it was at that point that our health and welfare agency called in this meeting and decided that yes we have to do something about some specific treatments. As I say it is more of a process of program and policy planning in response to what we saw in some of our data. This helped us to get these options going. So um ah I think so often we get caught up in the ah appeal and dispute process and forget that there is another way of planning. Fortunately we have looked at that number since and we have had tremendous you know ah public awareness and um with our perinatal we dropped back to about 19%. And you might like to know since you we just completed and I'll be happy to send to you a study done by the University of California in the terms of perinatal drug use. The article was in the September 16th issue of New England Medical Journal. But what was so interesting was our overall rate public and private across socioeconomic status was 11.6%. It points out the difference with the different drugs the different groups. And what is interesting that in our black population the rate is something like 2 or 3 times higher, however because they only constitute about 20% of our delivery so the major policy for the 80% who are not um um black is ah the Hispanic and um white population. So so I just think that you could look at these figures and you really have to interpret them carefully, but but ah we really have had a problem but it is less than it was prior. So we are pleased about that.

12. Tell me about your policy pertaining to contracting or making arrangements with local services for perinatally exposed infants/toddlers.

Yes, I think um, UCLA as done a lot of excellent training. University of California Los Angeles, um they have had some very excellent studies and long term follow through on substance exposure. You know Dr. Judy Howard and some others. And certainly the Los Angeles Public Schools have um had um long term evaluation of children and they have assisted us in our training. Um the March of Dimes you know has has provided training in this regard. And ah certainly the alcohol and drug ah um Department has done a lot of training in this regard. And because our Governor is very interested in perinatal substance abuse that I think 24 to 25 million was actually given to just the schools to um to make sure that all students in California became aware of the dangers of perinatal substance abuse. So ah um you know when you say who has been involved the whole Department of Education, the Perinatal Associations that I've already mentioned. All of those have been involved in consultation and training.

13. Tell me about the multidisciplinary evaluation of strengths and needs of perinatally exposed infants toddlers and their families.

Yes, what is usually done it varies like I said we have um our our our. The regional centers are primarily going to be doing the evaluation of the substance exposed babies as opposed to the schools. And what normally is done there is what the ah usually the ah a few have developmental psychologists. But, by in large the the nurse um consultant or practioner does um the assessment of the infant and the family. They will often use the Bailey though often people feel that the Bailey for the older child does not pick up the deficits that the the substance exposed child has. And so they will use the Hawaii, which is a different test. A different assessment tool they think is much better for substance exposed. But what has happened is that each center will have their psychologist or nurse or another trained person. Actually I think some of the social workers have been trained to do screening, and some can actually do some developmental assessment. The Ed specialist will also do assessments on cognitive, language, motor. And also an assessment of the family in terms of ah their parenting skills and abilities. And that will vary of course; it has to be very subtle done many times particularly families that are using substances are very difficult to reach. Sometimes you have to go three or four times before you get them at home. You also have to um make sure that you are there to really help them and not to. So so it has been a very difficult time the outreach has been quite different and our regional centers had to learn how to do that. But, but I

think they try to assess both the family and the baby and use a team approach like that.

14. Explain the referral system for perinatally exposed infants and toddlers.

Yes, I think we sort of touched on that somewhat. By and large I think the referral comes from mostly the NICU, from the local health department who may be following children or from some of the perinatal treatment services. And so the process of referral is that they call into the regional center. Um ah they do have to have the families approval to refer and then the regional center tries to make the contact and usually tries to make a home visit. And I can say that in certain areas of the state that has gotten VERY dangerous. There are areas in the inner city where it really is not safe to go and so they have actually had to meet families at churches and the park and everywhere else. If you can imagine to conduct some of these, so they will be safe. And so it it it has not been easy. But, in terms of trying to ah the referral can either be by phone or it can be written. They really do have to have the family approval and that is what makes it hard.

15. With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.

Ah, I think, I think ah, it does is the sense that, as I mentioned earlier the Department of Education traditionally has not had a lot of um services for children zero to three and they have not really by training been prepared to work with a multihandicap, ah need child and so many of the substance, their mom is is is terribly upset, unavailable and often does not make appointments. So you you must have a much more case management type of approach than has been traditionally given in the schools. So, if you have a lead agency such as our department that is used to outreach and sort of the worker um case management type approach I think that makes it easier. Now, you say what about the Department of Health. Depending on how services are given I think the Department of Health can do a very good outreach too to substance exposed. Because as we know, they, and we have discussed, they have many medical problems, so if they have a unified children services I think they can be very excellent. I think in California our problem has been that our um so called Crippled Children is now California Children Services serves only physically handicapped and so if they had been lead agency it would have been in a way difficult to reach out to some of the

substance exposed babies by their current criteria because they do not serve persons with just developmental or you know mental or this kind of problem. Now, as far as the giving the medical services they could have done well. But, I think if you look at what Part H is supposed to be doing providing developmental services that the appointment of the lead agency does, is important. Because one has to have an agency that knows how to reach one young infants and really understands infant development and has not concentrated on you know just, like with education it has been strictly the older child academic and with our Department of Health it has been strictly medical and nursing needs. So, um I would think again that the lead agency, depending on the policy and the eligibility guidelines you know of an agency um the lead agency can be very important.

16. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.

Well I'm not sure. Another words, ah that would almost be like mandating at risk factors that you would have to serve. Um, I can't think that people wouldn't think they wouldn't. See so I don't know that Part H would need to mandate perinatally exposed any more than they would need to mandate another group of of children. Because, um at least the way we in California all know that they are at risk. So so ah um it is hard to answer because, because I don't think it would have made any difference in California. But on the other hand, if there are other states who would choose not to serve exposed that would bring them in as a special group. I feel that a lot of states choose not to serve perinatally exposed under at risk is because they know it would be such large number. We are very concerned. Are we going to have the resources to do it an so um um. We certainly are going to try. And I think again part of the problem too is that it requires such extensive outreach to get the families in. And I know that we don't begin to get all the families in and see that is um. And see even if they were mandated I um I think that um I don't think that states would elect to participate because they would think it was such a big problem, they couldn't cope with it.

17. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.

Um, I'm trying to think um. I think it would be um the limitation on um services to the ah the ah the parents. Because you know so much of the health care and so much of the drug treatment is is is limited. And certainly, even

under the Clinton health plan is going to be limited to 60 days or 90 days or something like that. And and um limitation of um of services assuming say that you get someone off of drugs that um is so foolish because it is going to be an on going problem. Another words, their problem to abuse substances is going to be there. So so often we have had pressure to get a child into a program to find out you can only stay so many months. Setting artificial time limits for for treatment um that would really um be helpful. And I think, that is for the mom. Because what we have found is that you really can not do Part H or early intervention unless you have a sound mom. Many times the baby would do fine; it is the mother who is causing the problems. So if, with, if you serve substance exposed infants you have to have a dual program for the mother and infant. Of course with the individual family service plan that is fine. But, theoretically we are only, you know if we started purchasing all the necessary services for the mom um that the cost would really sore and that that's why in addressing this population I'm saying that there has to be some on going support for the mom and infant. It has to extend past three years.

18. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?

Oh, I think that I've given you plenty. Let me see, what else could we comment on. Um, I think um, that that what they would like to comment on is that the the um the needs of these children and their parents are really not addressed by the Department of Ed or necessarily our Department. That traditionally, our mental health services have not really served, other than just the the psychosis, you know. And and so that ah there seems to be for perinatally substance exposed infants, because you really have to treat the whole family to get any where. And it has to be on going. There needs to be some kind of unique service that could be delivered and like I say the traditional services like health and medicine and mental health have not really addressed the needs of the chemically addicted or um person. And and so I think um that alcohol and drug, and it has been sort of limited to treatment, AA and all of this. And so what we have really seen with our perinatally substance exposed when you are looking at families and substance abusing moms. There needs to be a unique ah service delivery and it really should be interdisciplinary. Um, that would give on going support varying throughout the sort of prenatal or perinatal years for persons that are substance users. Um, as a matter of fact we just had a nice task force that worked on what would

be the model case management system for perinatal substance exposure. And it was chaired by an excellent person who has long experience in perinatal substance abuse and long term treatment and if we could get that freed would you like to have that? We did a lot of intensive work and it had multiple disciplines and what we are saying is that ideally there should be an interagency multidisciplinary unique team that is available. The question is where does this come from in terms of funding? Because it is a new way of supporting and treating and preventing perinatal substance abuse and so ah we have a model of what the case management system ought to be. We may try to do that and it requires quite a few disciplines, but it does not require an intervention that is the traditional one. When you come to a clinic and go and this kind of thing. Just to share on this because I do think it is a very nice bringing together. Also with our multiple ethnicities our special minority populations there has to be a very unique outreach to reach the special populations. And so um that is something else that the traditional AA approach um is considered extremely poor and almost contradictory to certain African-American traditions. And so what I'm saying is that unless people are aware and can have cultural sensitivity a lot of their programs will not go. I just think that we are trying to look at what would really work and with 10% of the population. how do you either change the current system or have a unique system that can reach these persons is what we are sort of looking at.

19. **Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.**

Yes, yes it is. I think the one thing that I might and I sort of eluded to it and this is the of professionals need to expand. And I'm talking about the needs of substance exposed children because of the continuing ongoing social and economic problems as well demands a special expertise that we really don't have yet and I think many of the school teachers would love to know what to do with this population. Even if we said, this is how we think you should do it; every child is so different that you may want to ask what unique programs do you feel are needed for substance exposed children?

20. **Is there anything else that you would like to add?**

No, I think that about does it.

APPENDIX I
VERBATIM TRANSCRIPT OF TELEPHONE INTERVIEW
WITH HAWAII'S PART H COORDINATOR

Telephone Survey for Part H Coordinators that Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State Hawaii
Date 10-7-93

1. What year of implementation are you currently in?

We are currently in year seven.

2. How long have you been the Part H Coordinator?

Seven Years.

3. Are perinatally exposed infants and toddlers included in your definition of "at risk"?

Yes, they are.

4. Why does the state of (California, Hawaii, Indiana, Massachusetts, New Mexico, or North Carolina) choose to include perinatal exposure in the definition of "at risk"?

Um, we serve this group of children because they are a vulnerable group in need of services. There really was no one group ah that could be given credit, if you will, for having this group included in the at risk definition. We all um felt that it was very important to ah include them.

5. Does your central directory mention accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

Yes, it does. I won't send you anything because you said that um you had our Part H application and it is all documented very well there.

6. Does your public awareness program include accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

Yes we do, please refer um to our Part H application.

7. What is specifically done in the area of child find to locate and serve perinatally exposed infants and toddlers?

As far as this population is concerned um we use hospital screening and outreach to child them.

8. Is there any personnel development around the issues of perinatal exposure/addiction?

Yes, we do a lot of that.

9. Do any of your interagency agreements target perinatally exposed infants/toddlers and their families? Please explain.

No, um none of our interagency agreements specifically target this group.

10. How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?

Um, I feel that what Part H does for this population is very positive. Ah we we help infants and their families that may may not get help in any other fashion.

11. What procedures are in place to resolve interagency disputes around the provision of services for perinatally exposed infants and toddlers?

The procedures would be no no different for this population than any other infants or uh toddlers that we serve.

12. Tell me about your policy pertaining to contracting or making arrangements with local services for perinatally exposed infants/toddlers.

Again, um this would be no different than for any other population.

13. Tell me about the multidisciplinary evaluation of strengths and needs of perinatally exposed infants toddlers and their families.

Um, this would depend on the individual needs of the child and family. We ah look at each case from a very individual view point.

14. Explain the referral system for perinatally exposed infants and toddlers.

Um, the same as for other infants and toddlers. They are referred to the Central Point of contact and if they would be eligible they would be assigned a care coordinator.

15. With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.

Oh yes, I think that it makes a big difference. I feel that um the Health agencies better understand the issues that are involved with these infants and toddlers.

16. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.

No, no more so than for any other population.

17. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.

I would request um more dollars to serve this um population. They have a lot of needs and the states need more money to um provide appropriate services.

18. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?

None.

19. Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.

Um yes I do.

20. Is there anything else that you would like to add?

This population is handled no differently than others. We do not serve based on um diagnosis, but on the needs of the ah child and family.

APPENDIX J

**VERBATIM TRANSCRIPT OF TELEPHONE INTERVIEW
WITH INDIANA'S PART H COORDINATOR**

Telephone Survey for Part H Coordinators that Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State Indiana
Date 10-15-93

1. What year of implementation are you currently in?

We are in the second year of extended participation.

2. How long have you been the Part H Coordinator?

Four months.

3. Are perinatally exposed infants and toddlers included in your definition of "at risk"?

Yes, they are.

4. Why does the state of (California, Hawaii, Indiana, Massachusetts, New Mexico, or North Carolina) choose to include perinatal exposure in the definition of "at risk"?

Um, we went for um a very broad at risk definition. We probably have the broadest at risk definition in the country. And really looked at, at the state we have a major initiative out of the Governor's office looking at all children and being ready to learn when they enter school. So, the First Steps piece, the early intervention piece fit right into this whole initiative. And it certainly did not make sense to us in Indiana to eliminate that at risk population, including you know perinatally exposed infants,... excluding them from that definition.

5. Does your central directory mention accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

No, not specifically. But, I would tell you that our central directory is perhaps not, not perhaps,... is not as fully developed as it needs to be and certainly the object of um a major work in this coming year. But, it looks at a variety of services that are available for all kinds of infants, but it doesn't specifically focus on that particular issue.

6. Does your public awareness program include accommodations for perinatally exposed infants/toddlers

and their families? If yes, would you please send me evidence of that?

Ah, we are just beginning, in a lot of the questions as I look through your thing we don't specifically identify that as a separate population. We include that as the whole at risk piece. So, it is not focused on perinatally exposed. Simply all of our at risk children. Indiana has just implemented the Healthy Family Proposal Program. And so, high risk families as a secondary. Part part of that piece is looking at prevention of child abuse, abuse and neglect. And one of the components of that certainly is drug related program and we approved funding for those programs, they had to show a clear link with substance abuse substance abuse programs for pregnant women or for perinatally exposed infants and toddlers. And we have done it that way. But as a specific component of public awareness no.

7. What is specifically done in the area of child find to locate and serve perinatally exposed infants and toddlers?

Just consistent with all of our at risk. Certainly acknowledging that is one of the risk factors and so insuring that at the local level that as local counties and that is how our system is driven by county. That they include that as a component in their child find program. Indiana has 92 counties and thus 92 plans of action. We are a county driven system and we maintained that philosophically in our program.

8. Is there any personnel development around the issues of perinatal exposure/addiction?

We have had several inservices and training specifically aimed at substance abuse and perinatal exposure. Looking at how to deal with infants that have been perinatally exposed. So we have approached it from a providers standpoint as far as technical assistance and training.

9. Do any of your interagency agreements target perinatally exposed infants/toddlers and their families? Please explain.

Not specifically. It certainly targets at risk families, but they are not singled out. The substance abuse agency is within our Department and thus is an intra agency agreement.

10. How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?

We have included them in that at risk definition and therefore they are an important component within our child find and service delivery system. Um, we have not focused on a specific population to the exclusion of others. We have 26 different risk factors that we service within our definition. So, it is one of multiple risk factors. An infant must have 4 risk factors to be considered at risk in Indiana. There are a number of risk factors that would allow an infant who was perinatally exposed to receive services under Part H. Up until October 1 they only needed one risk factor, and on October 1 we moved to a four risk factor eligibility. And yet we still feel that we are not limiting, there are very few children who will be eliminated by the move from 1 to 4 risk factors.

11. What procedures are in place to resolve interagency disputes around the provision of services for perinatally exposed infants and toddlers?

There the Governor..., the process goes through at the state level it is not resolved at the local level. If there is no resolution at the local level and at this point all of the 92 councils over the course of this year, are to put into place interagency agreements surrounding with one of the components being dispute resolution. If it cannot be resolved at the local level, it comes up to the state level and it is heard among the representatives of the signers of the state interagency agreements. With final responsibility for resolution of disputes resting at the governor's office.

12. Tell me about your policy pertaining to contracting or making arrangements with local services for perinatally exposed infants/toddlers.

Well, what we have done..., we have two two distinct pots of dollars operating at this point. We have what traditionally has been developmental disability Title XX dollars, and those are primarily going to developmental disability agencies and we have 52 of those in the state. All new dollars, the state line item dollars for early intervention and Part H dollars are dropped into the county council for use with agencies who can provide services for their own early intervention populations. They may not have been part of the traditional DD delivery system. So, we are putting all new dollars into the county to promote a multiagency service delivery system particularly with agencies that impact special populations.

13. **Tell me about the multidisciplinary evaluation of strengths and needs of perinatally exposed infants toddlers and their families.**

Well certainly the multidisciplinary evaluation is mandated by federal statute. It is implemented at the local level. Some counties are doing... have established a clinic that you know a variety of agencies contribute to staffing. And they are doing all their evals and assessments through that process. Others are doing it... each agency that may be serving that infant may be doing their own. We are looking at a whole system of service coordination for all children in Indiana. It is again part of that collaborative plan to look at all state and federal programs that impact children and families being in a collaborative process. So, the referral system is there. With the county driven system, in the 92 councils, part of the processes... a needs assessment each county has had to do to identify all potential service providers for any type of infant that they might have in their program. Each of the 92 councils wrote plans looking at evaluation and assessments, service coordination, and provision of services for this year. So every county has a plan to describe how they are working in their county, how they are making referrals, how they come together to provide evaluation and assessment to assure an appropriate delivery of services.

14. **Explain the referral system for perinatally exposed infants and toddlers.**

There is a single point of entry for all 92 counties.

15. **With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.**

I don't think so. There was a commitment by the governor's office to look across agencies and since a large percentage of the services came through the Family and Social Services Administration. We have all what in particular states would be called welfare programs. We have all the developmental disabilities programs. So, with the exclusion of the Department of Health and Department of Education, Family and Social Services Administration is considered the mega agency. We have everything that would impact families and children.

16. **Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under**

this legislation? Please explain.

Well, certainly we feel very strongly about that at risk definition or we would not have gone out on a limb, because certainly a major challenge to states as evidenced by the lack of states who serve the at risk population. Because if you just go with the DD definition it certainly limits the population and the state's liability to provide services. We have chosen to say that all children are important in Indiana and those at risk children certainly. Of all the children we have the most opportunity to make a significant difference by early intervention. We think that it is very important and my sense by what I'm reading and what I'm hearing is that the federal government is certainly not pleased with the lack of states that have joined in that at risk definition and are considering financial incentives to those states who do choose to serve that at risk population.

17. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.

Ah broader ownership of ah the need to deliver services beyond those who have been specifically funded to do so. There needs to be a real community acknowledgement and ownership of these issues. And the future of their community is in the delivery of a multiagency system, the development of a multiagency system of services.

18. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?

I think that one of the things that we run into in Indiana, which is a very conservative state, is that they like to assume that the problems lie in the more metropolitan or east coast or west coast states. I think that our challenge in Indiana is to acknowledge that that population exists here and is a potentially growing population. We can intervene effectively with if we acknowledge that they exist.

19. Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.

Oh I think so.

20. Is there anything else that you would like to add?

I think that since we do have that at risk definition we are certainly more aware and supportive of that process. I think it is more of an issue for those states that have not accepted that as a role or responsibility for their program.

APPENDIX K
VERBATIM TRANSCRIPT OF TELEPHONE INTERVIEW
WITH MASSACHUSETTS' PART H COORDINATOR

Telephone Survey for Part H Coordinators that Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State Massachusetts

Date 10-15-93

1. What year of implementation are you currently in?

Our seventh year application is currently being reviewed by the feds.

2. How long have you been the Part H Coordinator?

I have been in my position for 14 years and I'm not officially the Part H Coordinator my ah supervisor is but we kind of share the tasks of a Part H Coordinator. So I'm on most of the mailing lists.

3. Are perinatally exposed infants and toddlers included in your definition of "at risk"?

Not, um directly. Um, meaning that substance abuse in the home, and not even maternal substance abuse, is one factor in a group of child and family factors for which um a family would need three to be eligible. We do not exclude perinatal exposure as a reason, but we do not think that that is sufficient reason based on research.

4. Why does the state of (California, Hawaii, Indiana, Massachusetts, New Mexico, or North Carolina) choose to include perinatal exposure in the definition of "at risk"?

No, um its part of a group of factors that we all as a group of clinicians are aware um can be one of a multiple risk picture that puts kids and families at serious risk.

5. Does your central directory mention accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

We, in our central directory, do not um list um. Let me back up a minute and tell you about our system. Our system is made up of organized programs and only those programs can provide early intervention services. Certified programs meeting state standards. So, and they all serve any eligible child and family that presents themselves wanting service... must be served by each and everyone of those programs. So we do not have a categorical service

model. The central directory basically for intervention um is a directory of the certified programs in the state. Programs at the local level are aware of local resources and would provide them at that level depending on the needs of the families.

6. Does your public awareness program include accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

No, we don't do anything categorically here. No, except for the the promotion of what the eligibility criteria are.

7. What is specifically done in the area of child find to locate and serve perinatally exposed infants and toddlers?

Uh, again we don't target categorically. We we have tremendous networks that work with families in shelters. We have a very big outreach to the at risk population in general and um thats thats where you tend to ah find more of these kids that do poorly. Ah not necessarily at the local office, but hospitals and physicians are aware of early interventions existence and they would be screening kids and making appropriate referrals. I believe that the state of Massachusetts legislates that tox screens be given to all women giving birth. I also believe that it may be anonymous. So, what that allows us to do is to say X percentage of those moms in such a city showed evidence of Y drug. But, I doubt very much that in a state that is a hot bed of liberalism that we would, we would mandate that people be violated in that way.

8. Is there any personnel development around the issues of perinatal exposure/addiction?

Yes, ah we have certainly. We have a statewide inservice institute that has done several ah special sessions on substance abuse in general.

9. Do any of your interagency agreements target perinatally exposed infants/toddlers and their families? Please explain.

It wouldn't be interagency, it would be intra. We are a health department and the substance abuse folks are within this department. And we have a specific agreement with ahhhh with Detox Beds for pregnant moms. Ah those moms can be referred to EI programs prior to the birth of the child

in order to set up a follow-up. Again there are not many detox beds for pregnant moms.

10. **How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?**

The same as we would view that role for any other eligible family. We would... we provide services for eligible families that meet that standards and are consistent with federal law based on individual needs. There is no approach to categorical ah groups of kids and families.

11. **What procedures are in place to resolve interagency disputes around the provision of services for perinatally exposed infants and toddlers?**

We are basically the lead agency and hold all the funding aside from Medicaide and third party. Everything is coordinated through this department so that provision of Part H has little meaning in this state. So we really don't have disputes. We have ah procedures basically... what it says in our application I believe is that is there is a dispute we would pay because we couldn't convince the feds that that didn't have meaning here so we had to say something. We are the payor of all resorts. That is not really true because there is Medicaid and third party insurance ah pay for service for ah people who are enrolled in those programs. There aren't disputes really. We have a statewide network of community based programs. There are 57 programs that are under different vendorships that we have contractual relationships with.

12. **Tell me about your policy pertaining to contracting or making arrangements with local services for perinatally exposed infants/toddlers.**

That, that basically ah. We have a procedure to certify programs um as meeting the standards and they go through a rather rigorous review. Ah um then we contract with them. By virtue of our certification they are able to um bill Medicaid and other third party insurance. They, and only they, can provide early intervention services in the state.

13. **Tell me about the multidisciplinary evaluation of strengths and needs of perinatally exposed infants toddlers and their families.**

Um, again that is done at program level. And ah it is based on a a parent guided identification of where the family wants to go in terms of goals for themselves. If they wish to identify those kinds of goals or for their children. Part H nationally is a voluntary program.

14. Explain the referral system for perinatally exposed infants and toddlers.

Um, anybody can make a referral. And it is made directly to the program. And the program must then follow up within 10 days ah with the family and ah. At the time of the referral, of course, the 45 day timeline begins. Referrals are made directly to their community program. There is a paper directory and central directory. The paper directory we try to get out to hospitals, doctors and community agencies and so forth. So they just look up the town of residence where the family lives and can identify the program that serves that area. There are 57 regional centers where such referrals can be made.

15. With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.

Yes, I think it makes a difference in general. Not a necessary difference but, all these agencies have their own cultures and way of approaching ah provision of services to families. I think education departments are very different from health departments. Not that they both can't provide a quality program. I think that the health model, and we are not a medical model. I'm saying community health, family, child development model, is much more appropriate to the infant/toddler population. We are heavily home and community based and school systems do not think in those terms.

16. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.

I don't, again, think that that is a sufficient criteria. I think the research shows that the kids with poor outcomes are the ones with multiple risk factors.

17. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.

I'm drawing a blank which does not mean that I think the program is absolutely wonderful. Ah well here is an easy one. I would wish that there was a much greater availability of appropriately trained staff particularly from the diversity of backgrounds of the people that we serve.

18. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?

I think primarily that that I don't think that this ought to be a categorical program. So developing special model for special subgroups of people um is not the way to go. That is not to say that within programs, for instance we have occasionally had the experience where there are 5 parents with kids with Downs Syndrome who want to have their own parent group. That is fine. But, but to sort of track people into different environments because of the different reasons that they are put into programs I think is very limiting for the people involved.

19. Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.

Ah let me do that one and then your final one. I'll put them together. I think that most of the families for which perinatal exposure becomes a real issue are from families with multiple risk backgrounds. I'm not sure that um we, we meaning the national clinical committee, have been creative enough in using Part H to move into community level intervention rather than just family level intervention. And by that I mean, that I think we have to put a much bigger emphasis on the broader ecology, if you will, within which these families are living to effect family level change and to support infant growth and development.

20. Is there anything else that you would like to add?

Look at answer 19.

APPENDIX L

VERBATIM TRANSCRIPT OF TELEPHONE INTERVIEW
WITH NEW MEXICO'S PART H COORDINATOR

Telephone Survey for Part H Coordinators that Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State New Mexico
Date 10-21-93

1. What year of implementation are you currently in?

Five, fifth.

2. How long have you been the Part H Coordinator?

Almost one year.

3. Are perinatally exposed infants and toddlers included in your definition of "at risk"?

Yes, they could be eligible under our various risk factors. It would be the decision of an interdisciplinary team meeting based on the category of environmental risk or whether they have some presenting problem. Like having been ah, like something showing in their development or whatever. But they they... it is implied that their eligible because we have environmentally at risk which includes factors having to do with the parent. But the team may make the decision that things are on a positive track and this child does not need to be tracked into any early intervention services. So it depends. It is not a carte blanche yes because they are specifically perinatally exposed.

4. Why does the state of (California, Hawaii, Indiana, Massachusetts, New Mexico, or North Carolina) choose to include perinatal exposure in the definition of "at risk"?

In general the reason is that um, part of it is political. In that it in the legislature and public eye there is a high level of interest in this state to work with children on a preventative basis. Um, we have a big initiative going on in this state, across many agencies to provide support to children who are at risk, not DD children per say. So we in essence are just tagging along with the greater effort of kids... you know services to kids. That is the political side of it. The other was just um, ah, you know the many many meetings and committees of the ICC and a deeply held philosophical belief among many people that um children at risk are as important as children who are developmentally disabled. It is just a deep seeded philosophy everywhere you go. That is all that I can really say. There was no one group to lobby for perinatally

exposed as a subgroup, but at risk as been on the political agenda. It comes from the governor and the legislature. In fact, we promote our program more in the eyes of the at risk than we do in the area of developmentally disabled.

5. Does your central directory mention accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

No, it doesn't I checked. Not as a specific category.

6. Does your public awareness program include accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

No, I checked there too.

7. What is specifically done in the area of child find to locate and serve perinatally exposed infants and toddlers?

We, a couple of things. We... one we have the leading in this state, is in Albuquerque and it is where ah and that is our hugest urban area in the state also. More babies are born at the Albuquerque University of New Mexico Hospital than really any other hospital. They have um, there are a couple of other hospitals but this is the lead hospital in having a developmental care program that does follow-up for babies identified at birth. Um, where they do um, parent counseling, where they link them into another program that is specifically for drug exposed babies that does referrals, ongoing health check ups, parent support groups, that kind of thing. That is another group called Los Partos. They have a federal grant to operate. It is in its third year. Um, so we have these kind of special referral social work programs in a couple of the hospitals.

8. Is there any personnel development around the issues of perinatal exposure/addiction?

No, not from our end that I have seen. There might be, but I just haven't seen it.

9. Do any of your interagency agreements target perinatally exposed infants/toddlers and their families? Please explain.

No, but we fund a couple of programs. There are not agreements they are grants. We fund part of one of the

programs at the hospital. The Department of Drug and Alcohol is in our department but it is separate from our division. We do not have much workings with them at all. They are not doing much with drug exposed babies.

10. How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?

Ah, we try to see to it that programs have some kind of clarification about how they can include these children in. We are working on um... we are working on clarifying our definition of eligibility so they have a better understanding of how to, of these children. The eligibility of these children. We are responsible for providing the family training, counseling, social work coordination and education programs to families. We are the lead fiscal agent for a network of direct services from around the state. That is primarily what we do, provide family oriented direct service follow-up. Not a health service, health medical support service. And we support... we fund the evaluations for children, follow-up evaluations. We view that as a big part of our role; making the funding work. There really is not a whole lot of time for anything else, except working on policies and procedures and personnel development is basically what we do.

11. What procedures are in place to resolve interagency disputes around the provision of services for perinatally exposed infants and toddlers?

We have policies pertaining to procedural safeguards, but nothing particular to perinatally exposed.

12. Tell me about your policy pertaining to contracting or making arrangements with local services for perinatally exposed infants/toddlers.

We do an RFP each year and um contract with approximately thirty agencies to provide direct services.

13. Tell me about the multidisciplinary evaluation of strengths and needs of perinatally exposed infants toddlers and their families.

We have a lead agency in the state that does evaluation um either in its centers or on outreach clinics and it consists of developmental specialists, therapists, social worker and um a physician. Um, it is available free to all children. They have people, a couple of people with particular expertise in the area of perinatal exposure.

They are very aware of all the resources available so ah. We have one lead agency that does evaluations. We also have hospital based evaluation teams so that before the child leaves the hospital an evaluation can occur. And those teams, if the family would rather continue to link directly with hospitals ...a couple of leading hospitals in the state. They can go directly back to the hospital for an evaluation through what we call special baby clients. There are three centers for evaluation and 15 outreach clinics. You will wait longer for a clinic to come to your town.

14. Explain the referral system for perinatally exposed infants and toddlers.

That comes from the hospital. They have a special developmental care team. Not all hospitals do this. Um, we have many hospitals in the state where nothing special is done. I suspect that if you don't catch a perinatally exposed infant at the hospital that you may not pick them up. Unless the physician is noticing something later on. But, you may have lost your best opportunity if you don't catch them at birth.

15. With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.

Yes. Ah because services for children are spread across several state agencies. And health services are spread across state agencies, they are not consolidated into one. And the difference can be whether certain linkages are in place. Probably the reason, I don't even know, if infants are tested at birth is because I am not in the aspect of the health system. Um, however because because we're we are the agency primarily responsible for providing services I can tell you a lot about how services are provided once the children are identified. But, I can't tell you a lot of how they are identified because that doesn't happen. You know it makes a difference as to what is within your agency. And um and that shapes the nature of the service.

16. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.

Yes, now I have to explain why. Um, well why yes is because it is the right thing to do. My only hesitation when I was running through the whole array of services in my head, that are included under Part H and trying to decide if

that is a good fit. Or if and if there are kids lets see ... um, and we have to be careful that we do not track kids into services that um they don't need because that is how you do business. Um, part of it is that in New Mexico we are trying to look at some differentiation between developmentally disabled and at risk children. Not that at risk children should get less service or only certain services, but are there differences. Do we need to develop more of a preventative kind of program system for at risk kids? So they stay out of programs that tend to label them. How do we keep them out of that kind of service and into maybe more of a kind of medical management uh family counseling types of services. Just because they are eligible they shouldn't all be funnelled the same way, that is my one reservation.

17. **If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.**

I would have identification programs in all the hospitals, not just the big ones. It is right to the point.

18. **What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?**

I can't think of anything. I think that I just did. The point of differentiating is kind of a point for us. So we specialize services, particular services within the at risk population.

19. **Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.**

I don't know, um. You might ask ah whether there is another agency, I mean we are not the whole world under Part H. And so who else takes the lead in this? Maybe we don't need to take the lead in this because someone else does. I think that it is awful that states use the reason of finance not to include at risk kids. I hear that all over the place. They just track them. I think that that is a crime. Why would you want to know if you are not going to do anything? Why are you putting money into tracking? I would rather you not track them, but serve them. There is something else that I would like to add. We find that too many states are willing to put money into everything about children who are at risk except the direct support services that those families need. I think that we have it backwards

because tracking systems are expensive, service coordination systems, data collection systems, are expensive. If you have a little bit of money you ought to make it go ... If you can only provide four weeks of service because that is all the funding that we have then do four weeks of service. But don't say that because I don't have a lot of money I'll do everything except provide services. One more thing, when you look at at risk populations you have to develop prevention programs. And I don't mean real vague public awareness programs, which we do we do public awareness. I mean real specific ones like programs with pregnant moms. Social work programs to help with counseling prenatally. Places for doctors to refer through the social work system, things like that, where you can catch this problem where it is occurring. We have a couple of fetal alcohol projects going on in the state where they are working with pregnant moms to prevent subsequent pregnancies from coming out the same way.

20. Is there anything else that you would like to add?

No that is it.

APPENDIX M
VERBATIM TRANSCRIPT OF TELEPHONE INTERVIEW
WITH NORTH CAROLINA'S PART H COORDINATOR

Telephone Survey for Part H Coordinators that Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State North Carolina
Date 10-4-93 8 AM

1. What year of implementation are you currently in?

We are beginning to start year seven.

2. How long have you been the Part H Coordinator?

The entire time, seven years.

3. Are perinatally exposed infants and toddlers included in your definition of "at risk"?

Yes, that is one of our risk indicators. Remember that alone will... Exposure alone with no other symptoms or conditions will not allow a child to qualify. But of course, we list 33 high risk indicators and infants that are perinatally exposed will usually exhibit more than just that one indicator. There hasn't been any problem finding an infant who has been exposed eligible.

4. Why does the state of (California, Hawaii, Indiana, Massachusetts, New Mexico, or North Carolina) choose to include perinatal exposure in the definition of "at risk"?

Basically, we already had it in place at the start of our system in the early 70s I guess it was. We felt that it was a major service population.

5. Does your central directory mention accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

Not specifically, only in the sense that they list the overall early intervention services that are available. No specific reference to the area of perinatal exposure and services.

6. Does your public awareness program include accommodations for perinatally exposed infants/toddlers and their families? If yes, would you please send me evidence of that?

No, we really do not, we do disseminate information to all primary referral sources on the services that are available to families. Well wait a minute, we do make presentations at conferences and recently did one at the Perinatal Association so I guess we do include this population in public awareness.

7. **What is specifically done in the area of child find to locate and serve perinatally exposed infants and toddlers?**

We don't target this population. We do put information in hospitals and with physicians.

8. **Is there any personnel development around the issues of perinatal exposure/addiction?**

Yes, we provide workshops in this area.

9. **Do any of your interagency agreements target perinatally exposed infants/toddlers and their families? Please explain.**

Yes, we have an interagency agreement with the State Council on Developmental Disabilities, the Division of Maternal and Child Health and clinical staff from Duke University. We are all working together to provide early intervention services including prevention.

10. **How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?**

I feel that the role of the office of Part H is very important to these little children. We are able to provide these services and should do so.

11. **What procedures are in place to resolve interagency disputes around the provision of services for perinatally exposed infants and toddlers?**

We use the same procedures for this population as we do for the others. Nothing special is done.

12. **Tell me about your policy pertaining to contracting or making arrangements with local services for perinatally exposed infants/toddlers.**

The policy for contracting is the same as it would be for any population no different for addicted kids.

13. Tell me about the multidisciplinary evaluation of strengths and needs of perinatally exposed infants toddlers and their families.

Well, this is done by the Division of Maternal and Child Health. Someone with experience in the area of substance abuse would have to be on the evaluation team, which you know must consist of at least two people each representing a different profession, um. The specific number and types of disciplines involved are variable and are based um um on the particular needs and characteristics of the child receiving evaluation.

14. Explain the referral system for perinatally exposed infants and toddlers.

The referral system for any infant may be made by any source or method. Nothing special is done in this area for these kids.

15. With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.

Yes, I do feel that it makes a difference. We are lucky in the state of North Carolina because substance abuse is a part of the lead agency. I feel that that has helped these kids to receive um services.

16. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.

Yes. I feel that it should be mandated. These kids need service and they need it now. We either pay now or later.

17. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.

I feel that the inter and intra agency collaboration needs to be worked on. It has been frustrating for me to attempt to get things done in my own division when we do not discuss things well.

18. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?

Nothing really,

19. Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.

Yes, I do.

20. Is there anything else that you would like to add?

No, I think that just about covers it all.

APPENDIX N
VERBATIM TRANSCRIPT OF TELEPHONE INTERVIEW
WITH ARIZONA'S PART H COORDINATOR

Telephone Survey for Part H Coordinators that Do Not Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State Arizona
Date 10-21-93

1. What year of implementation are you currently in?

We are in fifth year.

2. How long have you been the Part H Coordinator?

A little over a year, I started in August of 92.

3. Why does the state of Arizona choose not to include perinatal exposure in their definition of "at risk"?

For financial reasons.

4. If perinatally exposed infants and toddlers are not eligible for services under the "at risk" definition of Part H, where does this population receive services in your state?

Um, there are a number of places actually. For one thing, um, we are going to be defining at risk. And we are going to be tracking at risk children with the infant monitoring questionnaire. Some of them may receive services through the newborn intensive care program if they were sick enough at birth or they were in an ICU for 48 hours. Ah, some of them might also receive services through developmental disabilities because that agency um does serve a small number of at risk children above and beyond the Part H children that they serve.

5. How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?

Well our role is is is tracking with the infant monitoring questionnaire so if the child does develop significant delays then we can move in and do a an evaluation and determine if the child has become eligible.

6. With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.

No, because the agencies together ah created our eligibility definition and they determined it was beyond their fiscal capacity to include at risk children.

7. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.

Not unless there would be enough additional funds appropriated to cover the services for that group of children. If the funds were there I would say yes.

8. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.

Um, one thing. I guess the one thing that we are working to change that we haven't accomplished yet is to reorient the the agencies particularly the service coordinators to look at resources first before looking you know... general community resources to assist the family rather than immediately jumping into purchased services. And that is a training need primarily and one that we are trying to address but um. And I think that would help.. I forgot one place where perinatally exposed infants and toddlers receive services. And that is through the Healthy Families um Program. It is similar to Healthy Start in Hawaii. We have another initiative called Health Start which is prenatal care. It is an early intervention program for families with infants at risk of abuse or neglect. It is not statewide yet, but it is growing very rapidly. The legislature is very excited about it.

9. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?

Well, it occurs to me that um all things being equal, that as far as perinatally exposed infants are concerned unless they are actually showing delays that maybe an approach like Healthy Families is at least as effective if not more effective um in intervening with these children. For this particular population I would see it as being real appropriate to look at that kind of intervention rather than the Part H type of definition. Healthy families comes under the Child Protective Services.

10. Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.

The only thing that... ah that might have um might make a difference is perinatally exposed includes both fetal alcohol syndrome and um like the crack babies. Fetal alcohol syndrome children would be eligible under our definition. It might be important to make some definition differentiation between those two populations. You should clarify that at the beginning of the interview. Because with all the Indian reservations that we have there is a very high number of FAS kids. Compared to more urban states we have very low numbers of perinatally exposed to drugs.

11. Is there anything else that you would like to add?

I don't think so.

APPENDIX O
VERBATIM TRANSCRIPT OF TELEPHONE INTERVIEW
WITH ILLINOIS' PART H COORDINATOR

Telephone Survey for Part H Coordinators that Do Not Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State Illinois
Date Oct 5, 1993 2:00

1. What year of implementation are you currently in?

We entered fifth year in December of 1992

2. How long have you been the Part H Coordinator?

Since January of 89.

3. Why does the state of Illinois choose not to include perinatal exposure in their definition of "at risk"?

That law becomes effective with the dollars and right now the state dollars are only about 800 thousand and we don't feel that... that is enough dollars yet to serve the at risk population. So we write our federal application, and we are in fifth year as far as the federal government is concerned and all of their requirements, without listing the at risk population as being eligible for fifth year. We do have a lot of our programs that do serve at risk. It is like being between a rock and a hard place, you might say because in the state we do consider those children eligible and our programs serve as many of them as we can, but we do not look at it as a requirement of the fifth year like we would with our other two definitions because we do not want to be held accountable I guess with the federal government except it is on all of our... those children are listed as part of our really eligible criteria in our demographic forms and so forth that we get back our quarterly reports and so forth. They would be eligible under our medical part of our definition, but you see so many of these kids don't necessarily show delays and we are at 25 percent delay so they don't show a delay until a little bit later, but as soon as there is a delay they would definitely be served

Well I think that we do include it. Because it is listed as one, we have three criteria, they have to have three characteristics and children that are exposed you know are part of that and I know that they are listed on our demographic forms or the forms that people fill out as far as a diagnosis so I really do feel like ... I'm trying to pull some of that out here, so I really do feel that that our children are listed even though Pat (Pat Trohanis) says that they might not be our people are really you know serving them

4. If perinatally exposed infants and toddlers are not eligible for services under the "at risk" definition of Part H, where does this population receive services in your state?

They receive services at any of our early intervention programs... and we have identified at least 133 programs in the state, but some of them would just serve a deaf population or would just serve.. so it is hard to say how many this this group, but certainly all of the, all the hospitals and we have special programs just for kids that are exposed or whose parents that are are working to get off of drugs and we take children that and families together. We have a Women's Treatment Center that was an old hospital here in Chicago that was then a lot of research was done, Ira Chasnoff ...so they are doing some real exciting things there and so we have a program called our Prekindergarten At Risk Program which is housed right there in that building for three to five year olds so that is exciting

5. How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?

The Part H role is evident, we provide services to this population.

6. With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.

No, because we are education and we work very closely with health and I could see health and social services I think that if your state works cooperatively it doesn't make any difference

7. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.

Well they don't mandate that anybody be served. So that word mandate is still up in the air so I don't think that this population should be served any more than any others, if all children are going to be mandated be to served then they would be part of the group. But the way we interpret the part ... the way we interpret Part H is that they mandate a system of services and so certainly these children would be part of that system

8. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.

Well, um I just think this particular population is shall I say expanding in our rural areas and we do not have enough service providers and physicians and professionals in our rural areas to serve children no matter what their needs are. So I would say that appropriate training and um and more dollars for service for all kids in rural areas especially those perinatally exposed.

9. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?

Well, I guess I get concerned when we single out single groups because I know that there is a big movement for kids that are HIV infected and I know that we have the autistic groups and we have spinal bifida support groups and all of this and sometimes we get so involved with just helping one group that we forget that we need to all work together to get appropriate legislation and funding for all kids. We need universal services to all children and families because you could have a disabled child the next day due to a car accident and it is just about time that our country really banded together and stops segregating kids and categorizing kids but just made sure that everything that a family would need no matter what their speciality would be available to them

10. Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.

No, because I feel that you really should focus on prevention and you did not ask me anything about prevention and that is so multifacitite that none of us have the answers, but I think again that we need to focus on prevention

11. Is there anything else that you would like to add?

No I don't think so. I wish you good luck.

APPENDIX P
VERBATIM TRANSCRIPT OF TELEPHONE INTERVIEW
WITH VIRGINIA'S PART H COORDINATOR

Telephone Survey for Part H Coordinators that Do Not Serve
Perinatally Exposed Infants and Toddlers Under
the At Risk Definition of Part H

State Virginia
Date 10-18-93

1. What year of implementation are you currently in?

We just moved into year 5.

2. How long have you been the Part H Coordinator?

4 years

3. Why does the state of Virginia choose not to include perinatal exposure in their definition of "at risk"?

We have not included at risk children as an eligible population. Children with diagnosed withdrawal symptoms would be included under the atypical category. However a child who was substance exposed and had a 25% delay or demonstrate the pieces under atypical development could potentially eligible for Part H. Just having a history of perinatal substance exposure wouldn't automatically make that child eligible for Part H. Virginia chooses not to include the at risk definition due to cost. Primarily, what we are doing is that we are very aware that children who are at risk are getting some level of service already in the state. Now, what we had estimated that potential number of children in the state who would be eligible under at risk would be around 36,000. And so the population that we determined are definitely eligible is around 7,200. You can see there was a huge difference in terms of looking at risk factors versus just the children according to the federal guidelines. We did open up our definition somewhat to include children who had atypical development. So there was some latitude if the child really needed the services and we could probably get the child served based on that atypical category.

4. If perinatally exposed infants and toddlers are not eligible for services under the "at risk" definition of Part H, where does this population receive services in your state?

Ok, um, infant programs in Virginia are funded through the Department of Mental Health and Mental Retardation and Substance Abuse Services which is the lead agency for Part H. They get state funding and local funding and other types

of funding. Historically, some of those programs have served children who are at risk. Those programs still have the option of serving those children. So there are some infant programs in Virginia that are actually serving those children. There are other children who may be linked through public health nursing. And there maybe children who are linked through what we call Project Link. These are prevention programs for families, particularly parents who are substance abusers.

5. **How do you view your role in the provision of services to perinatally exposed infants/toddlers and their families?**

Based upon how it is set up right now, I think that Part H is responsible for kicking in when a child is CLEARLY going to have some sort of long term developmental problem related back to the substance exposure. So for example, what what we have been seeing at least from the information that I have ascertained, I have also had work with a local subcommittee on this particular group of children. In fact, they have been doing some extensive studying over the last three or four years. But, what we have basically discovered is that a lot of these kids, even though they have been prenatally substance exposed, end up doing fairly well. Sometimes and then they don't. Some get behavioral disorders as they get older. But, for the most part they seem to do fairly well. After they go through initial stages of not integrating real well with their body systems and that kind of thing. So, I would think that Part H's responsibility would be to kick in when there was some real significant problems. That child may fit into that atypical development category or kick in if there is a significant delay involved. And a lot of it would be through support to families in terms of how to help that family in relationship to the child's development. There could be some service coordination involved obviously for those families as well as links to other resources.

6. **With regard to the provision of services for perinatally exposed infants/toddlers, do you think it makes a difference what agency was designated by the governor as the lead agency? Please explain.**

My answer would be based primarily on my knowledge about Virginia. It might have an impact in other states, but in Virginia I don't think so. Primarily because the Department of Mental Health, Mental Retardation and Substance Abuse Services is really the agency in the state that works with the substance exposure to families. It is one of the key agencies that has been involved with that

work. So, I don't think Virginia's decision, as far as the services, for these particular children with the lead agency here made a major difference. If we didn't include them in the definition it is primarily due to funding, not because of anything but that.

7. Do you feel that Part H should mandate that infants and toddlers who were perinatally exposed be covered under this legislation? Please explain.

I have struggled, having been a service provider myself and having worked in an infant program for 12 years prior to coming to the state. I have struggled, as a provider, when Part H first came into effect. Really, clearly feeling that all the Part H guidelines and requirements that had to be met were appropriate for all families. That was my concern as a provider. And I still question that. Um, but maybe from the prospective, I've loosened up maybe a little bit, because I know that there is a whole lot more latitude ah that is available. More flexibility. Like for example, Part H requires for the evaluation that there be at least two professionals involved with the child's family. I think traditionally, in Virginia it has been viewed that the two member team is a member or members of the infant program. And that is not necessarily the case. And we have been working throughout the state to try to loosen that up so that it could be potentially the team members could potentially be a physician that is involved with the child's family and a public health nurse. Or a public health nurse and someone from the infant program. So, from that prospective, I think the the word mandate I guess is what the issues are and and the requirements to have to meet everything. Sometimes, my sense, is that we try to overload families with too much. I think that mandating that would be very appropriate. But whether Part H is the right mandate, is the question that I don't know.

8. If you could change one thing about the delivery of services for perinatally exposed infants/toddlers, what would it be? Explain.

I'm going to speak very specifically about Virginia, because I'm not sure what other states are doing. I think that ah using natural environments more, and shifting away from traditional models of service delivery. I think in Virginia, because we have been providing services for a long long time we are stuck on viewing the infant program as the provider of services. And I would like to see more services, early intervention services, defined broader than the infant program and like day care providers becoming part of the early intervention system. And not necessarily

meaning that it has to be someone with a special education background, or occupational therapists, or whomever being involved in that day to day contact with that child. And it could be a day care provider or whomever.

9. What additional comments regarding perinatally exposed infants/toddlers and Part H would you care to share with me?

Well, I don't know. Um, the only thing that I would like to say is that I certainly hope that in Virginia children who really need the services.. the way the kids.. are getting the services. I don't know if Part H is the right mandate, but obviously the concept of the family focus being the... getting services for families is the most important.

10. Do you feel that this interview focused on the most critical and important factors regarding Part H services for perinatally exposed infants/toddlers and their families? Please explain.

Yes, I do.

11. Is there anything else that you would like to add?

No.

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EDUCATION

Virginia Polytechnic Institute, Blacksburg, Virginia

- Doctor of Education (Ed.D.): Special Education Administration and Supervision. January, 1994.
- Certificate of Advanced Graduate Studies. May, 1993.

The American University, Washington, D.C.

Master of Education: Emotional Disturbance. May, 1985.

The University of Maine, Orono, Maine

Bachelor of Science: Child Development and Family Relations. Minor: psychology. May, 1983.

EXPERIENCE

Stafford County Public Schools, Stafford, Virginia

Supervisor of Special Education. Instructional supervision of programs for students with disabilities and the leadership role in the special education eligibility process for the school division. December, 1993 - Present.

Virginia Polytechnic Institute, College of Education, Special Education Division, Blacksburg, Virginia

Graduate Assistant. Duties include research and editing of materials for professors. August, 1992 - December, 1993.

Giles County Public Schools, Giles County, Virginia

Administrative Intern. Assisted Director of Special Education in assimilation of Annual Operating Plan; collected information for initial and triennial IEP meetings; attended meetings pertaining to the Americans with Disabilities Act and Interagency Family Assessment & Planning Team; attended State Council of Special Education Directors meetings. Spring, 1993.

**Council for Exceptional Children, Office of Governmental Relations,
Reston, Virginia**

Administrative Intern. Accumulated information concerning proposed change in Federal definition of the "Seriously Emotionally Disturbed." Contacted various U.S. school systems to determine significant issues to be brought to the attention of Congress. Involved in planning of Political Action Network (PAN) annual meeting. July, 1992.

Quander Road Center, Alexandria, Virginia

Counseling Resource Teacher of the Seriously Emotionally Disturbed. Acted as Principal designee; chaired IEP meetings; acted as liaison between school and probation officers/courts; initiated student of the month award; assembled women's group and instructional assistant support group constructed master schedule; coordinated placements at PERT; assisted seniors with job placement; facilitated college visits; initiated New Student support group; participated in self-study by State of Virginia. September, 1989 - June, 1992.

Quander Road Center, Alexandria, Virginia

Teacher of the Seriously Emotionally Disturbed. Teacher of geography, math, U.S. history to grades 9-12; wrote IEPs; member of Faculty Advisor Committee; employed crisis intervention techniques with students, when necessary. September, 1988 - June, 1989.

Mark Twain School, Rockville, Maryland

Teacher of the Seriously Emotionally Disturbed. Teacher of law, algebra; instructor on ropes course; wrote IEPs; employed crisis intervention techniques with students, when necessary. September, 1985 - June, 1988.

PROFESSIONAL SEMINARS

Sixteenth Annual Institute Administration and Supervision of Special Education, Virginia Beach, VA. May, 1993.

State Council for Special Education, Richmond, VA. February, 1993.

Fifth Annual National Conference on Drugs, Alcohol, Pregnancy and Parenting. Directions for the Future: Families and the Growing Child, Chicago, IL. December, 1992.

VICA Convention, Norfolk, VA. October, 1992.

CEC Political Action Network, Washington, D.C. June, 1992.

Fifteenth Annual Institute Administration and Supervision of Special Education,
Virginia Beach, VA. May, 1992.

International CEC Convention, Baltimore, MD. April, 1992.

CERTIFICATIONS IN VIRGINIA

Secondary School Principal
Special Education Supervisor
Special Education - Emotional Disturbance

PROFESSIONAL MEMBERSHIPS

Council for Exceptional Children
Council for Behavior Disorders
Council of Administrators of Special Education
National Association for Perinatal Addiction Research and Education
Phi Delta Kappa

AWARDS


Nominated and selected for All Maine Women (highest non-academic
achievement award given to women on campus)

HOBBIES

Reading, antiques, running

REFERENCES

Available upon request


Karen Gerry Corpening