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## ABSTRACT

This study addresses seven components of Public Law 99-457 which relate to mental health intervention to meet the comprehensive early needs of infants and toddlers with, or at risk for, disabilities. The seven components include: the definition of "developmentally delayed"; multidisciplinary evaluation; the individualized family service plan, including case management services; a comprehensive Child Find system; a public awareness program; a central resource directory; and personnel development and standards for training. The study focused on three states' efforts to incorporate a mental health perspective into their overall philosophy and service delivery systems for young children. It examined various systems that were in place or were evolving for children and the role of mental health in those systems. Each of the three states has its own pattern of providing mental health services: Maine has a state-driven system of service delivery; Ohio has a strong system of local control; and North Carolina has a blended state and local system. Appendices contain case vignettes of three families with young children and a copy of the instrument used in the study. (JDD)

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# **MENTAL HEALTH SERVICES FOR INFANTS AND TODDLERS:**

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A Three-State Perspective on the  
Implementation of Part H of P.L. 99-457  
The Education of the Handicapped Act Amendments of 1986

Edited by

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Special thanks also are extended to the contributing authors *Edward Feinberg*, *Emily Schrag Fenichel*, and *Gary Delago* for their continued interest in and enthusiasm for this project. Ed's and Emily's knowledge and understanding both of theoretical and implementation issues related to Part H of P.L. 99-457, as well as their individual skills and expertise in the area of infant and toddler mental health and the delivery of early intervention services were essential to the development of this monograph. Gary Delago, in addition to co-authoring the Ohio profile, applied his research and organizational skills to the development of the information-gathering protocol and assisted in organizing the survey information into a useful format.

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## **INTRODUCTION**

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### **THE BACKGROUND**

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Good mental health forms the very foundation of the development of all young children. From birth, children are busy with the process of integrating new skills and increased awareness into a wide variety of domains. Through this integrative process, children's self-esteem, competency in interpersonal relationships, and patterns of attachment to caregivers emerge. The complexities and rapidity of this process put young children in the position of almost constant challenge. Warm and nurturing environments which focus on their competencies enable them to meet the challenge.

The mental health of children who have a range of special needs is particularly critical to their successful development, but it may be jeopardized by both the difficulties they face and those they present to caretakers. Among these children, the ones who learn to value their own achievements and take pleasure in their efforts are more likely to meet such difficulties head on. Their emotional development is closely tied to their positive experiences within the family and with caretakers. Yet illness and disabilities can make it difficult for children to respond to their parents' attention. Such disruption in an evolving relationship can be confusing and frustrating for parents.

Certain environmental factors can also put infants and toddlers at risk for abnormal or atypical emotional development. These factors can include a history of mental illness or substance abuse in the family, or such

environmental stresses as poverty, teenage parenthood, and a parental history of neglect during childhood. Parents and caregivers who are not able to respond to the emotional needs of children may unintentionally discourage them from engaging in the human interaction which is essential to their overall development. Subsequently, these children may experience emotional problems or delays. There are also children who have atypical emotional development apparently unrelated to any other physical disability or stressors.

All of these children need a sensitive, understanding family environment. Achieving such an environment may require special and critical services.

### **The Problem**

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No truly comprehensive continuum of mental health services for handicapped infants, toddlers, and their families has existed in any state or community to date. Mental health services traditionally have not focused on prevention or early identification and intervention because of a variety of obstacles. These obstacles include: limited public resources for multiple populations (most fiscal resources are allocated for service provision to chronically mentally ill and seriously emotionally disturbed adolescents), an insufficiency of mental health professionals trained to deal with the problems of young children, restrictive eligibility criteria, lack of reimbursement to private sector mental health professionals for early intervention and prevention activities, inadequate

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assessment tools, reluctance to label children, limited mental health outreach into the community, cultural insensitivity, and fragmented services. Most social service, education, and health systems have experienced similar obstacles. The need to integrate a mental health perspective into early intervention and prevention efforts was present at the time Congress enacted Public Law 99-457.

## The Law

Part H of Public Law 99-457, The Education of the Handicapped Act Amendments of 1986, has created an opportunity for providing mental health services to children birth to age three and their families. The congressional intent of this program is to encourage states through limited funding to: 1) develop and implement a comprehensive, coordinated, multidisciplinary, interagency program of early intervention services; 2) facilitate the coordination of early intervention resources from federal, state, local, and private sources (including private insurers); and 3) enhance the provision of quality early intervention services.

Although the law's design does not specify provision of a full continuum of mental health services to meet the needs of infants, toddlers and their families, it opens the door. P.L. 99-457 provides many opportunities for professionals and agencies with expertise in infant mental health to contribute their unique sensitivities, skills, and services to address the emotional well-being of children and their families during the critical first three years of life.

For those children with diagnosable mental health disorders like failure to thrive, autism, pervasive developmental disorders, and disorders of attachment,

early intervention treatment may be a lifesaving intervention, may redirect the developmental course, or may reduce the severity of the condition. For infants and toddlers at risk for psychosocial or social/emotional developmental delays, P.L. 99-457 encourages early intervention to support families, to reduce stress, and to promote children's optimal development.

In order to meet the comprehensive early needs of infants and toddlers with, or at risk for, disabilities, P.L. 99-457 has as its foundation fourteen components. Seven of these components provide opportunities for mental health intervention and contributions: the definition of developmentally delayed, multidisciplinary evaluation, the individualized family service plan including case management services, a comprehensive Child Find system, a public awareness program, a central resource directory, and personnel development and standards for training. These seven areas are addressed in this study.

## THE STUDY

### The History

In 1984, Congress designated funding to assist states and communities in improving their service delivery systems for children and adolescents with serious emotional problems. The National Institute of Mental Health (NIMH) initiated the Child and Adolescent Service System Program (CASSP) to provide support to states as they began interagency efforts to improve their service delivery systems.

CASSP created a major technical assistance center at Georgetown

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University Child Development Center to give direct technical assistance to CASSP grantees and other interested states. The center conducts state-of-the-art studies on such topics as community-based service alternatives for seriously emotionally disturbed children and the financing of mental health services for severely emotionally disturbed children and adolescents.

In December of 1987, NIMH and the CASSP Technical Assistance Center held a Mental Health/P.L. 99-457 meeting in Virginia to gain an understanding of how states might take advantage of the opportunities of the law and integrate mental health into their service delivery. This national meeting resulted in an issue paper, Sensitivities, Skills and Services: Mental Health Roles in the Implementation of Part H of P.L. 99-457 The Education of the Handicapped Act Amendments of 1986.

As an outgrowth of the issue paper, in the fall of 1988 NIMH and the CASSP Technical Assistance Center embarked on a study of three states' efforts to incorporate a mental health perspective into their overall philosophy and service delivery systems for young children. The study examined the various systems that were in place or were evolving for children and the role of mental health in those systems. This report is a result of that study.

## **The Methodology** \_\_\_\_\_

A panel of noted mental health professionals chose states with demonstrated interest in the provision of mental health services to young children. In addition, each state had participated in Project Zero to Three. This project was a six-year effort (1983-1989) of the National Center for Clinical Infant Programs and fifteen participating states to share information and expertise

concerning the integration of health and education services for disabled and at-risk infants, toddlers, and their families. The Office of Maternal and Child Health of the Department of Health and Human Services supported this project.

The states selected for this study were Maine, North Carolina and Ohio. All three had state departments of mental health and local agencies interested in participating in the implementation of P.L. 99-457. Since each state was at a different stage in the development of mental health services for infants and toddlers, the study was able to explore a range of experiences.

Study teams traveled to each site and used a key informant technique during their three-day visit to obtain a broad perspective of the service system in each state. With the assistance of the state CASSP director and other state leaders, the individuals to be interviewed were selected from four groups: state agency representatives participating on the P.L. 99-457 Interagency Coordinating Council (ICC), local agency representatives, local service providers who were specifically addressing the mental health needs of very young children and their families, and parents who were recipients of services. The site visits were coordinated by Jan Martner, Project Coordinator, Georgetown University Child Development Center, and were conducted by a team of individuals knowledgeable about infant and toddler mental health and state service delivery systems. The team used a structured questionnaire to gather information about legislation, organization, and resources at both the state and local levels, and to obtain descriptions of exemplary programs (see Appendix A, Survey Instrument).

## **The State Profiles** \_\_\_\_\_

This monograph presents the data gathered from these site visits, organized

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in the form of state profiles. Each state profile is structured to reflect the evolution and status of the state's mental health services to very young children prior to the passage of P.L. 99-457, the impact of the law, and envisioned next steps.

The profiles were reviewed by the key informants in each state. Because of the uniqueness of each state and the desire to preserve the individual perspective of the team leaders, the profiles will vary. The document was written in a personal style because it is a summation of personal involvement and effort.

In conducting this study the teams found that the responses of individuals reflected their state's history of providing mental health services in general and, specifically, the state's history related to the care of very young children and their families. These parallel histories reveal a pattern of the state's philosophy, values, process of governing, decision making, and service delivery. These patterns are important because they provide a starting place to utilize the information presented in the study.

Each of the three states studied has its own pattern: Maine has a state-driven system of service delivery, Ohio has a strong system of local control, and North Carolina has a blended state and local system. It may be valuable for other states to assess their systems within the four primary areas of study:

- *Structure:* The overall coordination and service delivery mechanisms of one of these states may contain more similarities to one state's system than another.

- *Antecedents:* State history and values related to service delivery for very young children and to mental health services in general are critical indicators that will help states to assess their historical patterns of intervention services to this very young population.

- *Similarities:* Examination of each of the states in the study will help other states determine what "pieces" of their pattern may be in place at this time in the area of legislation, key individuals, values, and vehicles for coordination and for service delivery. Analyzing these pieces will guide states in determining whether their system is evolving in an effective manner.

- *Opportunities:* Each of the patterns studied illustrates different mechanisms to attain desired goals. Policy makers will need to evaluate their state's goals and determine the best way to meet them. Perhaps one of the patterns presented here, or a combination, will help identify a long-sought missing piece.

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Because states are in a period of rapid change in planning services to children and families, the information shared by the informants in this study is ever-changing as each state learns from the decisions it has made. It is hoped that this study will provide guidance to residents of other states interested in the process of integrating mental health principles into the many components of P.L. 99-457. Creative use of this information may prevent the loss of valuable time and provide stimulation for lively discussion, whether it be in the Interagency Coordinating Council, the local collaborative group, a staff meeting, or a meeting of parents. As corroborated by many informants, it only takes one person to spark the creation of change. This study may provide a new way of looking at philosophy, structure, and service delivery systems for very young children.

The editors are grateful to the agencies and individuals in the states of Maine, North Carolina, and Ohio who participated in this study.

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## STATE PROFILES

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### THE ISSUES

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Key individuals were interviewed in each state to address the following issues: philosophy and history, service characteristics, and training of professionals.

The questions listed under the issues were among those asked of each state in an effort to elicit consistent information about mental health services pre-P.L. 99-457 and post-P.L. 99-457. Similar questions can help states to organize information as they begin to integrate a mental health perspective into early intervention services. This process may begin through the organization of interagency committees, parent advocacy groups, and other inter- and intra-agency activities which would facilitate communication and planning efforts on the state, county, and local levels.

### Mental Health Services Pre-P.L. 99-457

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**Philosophy and History of Mental Health Services to Infants, Toddlers, and Their Families.** In order to fully understand how any state has developed its current mental health service system(s) of care, it is useful to grasp the evolution of that system. Each state has a history that has helped to shape its current philosophy related to mental health services for very young children and their families.

#### *Questions*

- How had the state agency policies concerning mental health for children, especially young children,

developed during the passage of P.L. 99-457?

- What mental health service system for young children, if any, was in place in the state in 1986?
- What were the catalysts to the evolution of the system, e.g., individuals, federal and state laws, major university involvement, advocacy groups and litigation?

**Service Characteristics.** Understanding the framework within which a state is making its current service delivery decisions is critical to future planning efforts. The focus here is to glean a historical perspective on the ways each of the states has developed its current delivery system(s) of mental health service to infants, toddlers, and their families.

#### *Questions*

- What was the prevention focus to mental health system-wide, i.e., what attention was paid to children's social and emotional development beyond the services provided in mental health programs for identified children?
- How were children and/or families identified and referred?
- What service system modalities were utilized, i.e., methods of identification, evaluation and intervention?
- Did the service components function as a system?

- Was there a system in place for tracking these children and families once identified and for providing ongoing case management?
- How were services funded?

**Training of Professionals.** The focus of this issue is to understand what the capacity and expertise of personnel trained in the area of infant and toddler mental health in the state was prior to P.L. 99-457.

#### *Questions*

- Did the state provide any type of organized, ongoing training program?
- What professionals were targeted for the training?
- What were the operative principles of training for professionals in the area of infant mental health?
- What type of pre-service and in-service training was available?

#### **Mental Health Services Post-P.L. 99-457**

**Philosophy of Early Intervention Services to Infants and Toddlers.** Opportunities to address the mental health needs of infants, toddlers, and their families through P.L. 99-457 may occasion a new look at mental health services as a whole and specifically at mental health services provided within the system of early intervention.

#### *Questions*

- Is there a common vision of early intervention shared by service providers, administrators, and families? Is mental health included in this vision?
- How has the state's philosophy of incorporating mental health into

early intervention changed as a result of P.L. 99-457?

- What impact is the new law having on the mental health service system?

**Development of a Service Delivery System.** Because of the mandate for a statewide interagency system of care, states have been assessing their administrative structures at both the state and local level. For many states, a coordinated system of care is a new concept; for others, it will help them to expand service provision. The issues related to effective service delivery are many and varied. They can become even more complex when states choose to include preventive mental health practices in the development of programs for infants and toddlers. The process of assessing children and the inclusion of mental health in this collaborative effort is emphasized in the study.

#### *Questions*

- How does the state mental health department fit into the structure of P.L. 99-457 -- is it the lead agency; does it participate on the Interagency Coordinating Council, local Child Find efforts, and committees examining eligibility criteria?
- How has P.L. 99-457 served as an impetus to moving toward a more effective service system?
- What has the process been for involving and obtaining mental health expertise in planning and implementing P.L. 99-457?
- If mental health agencies or practitioners are not represented on the State Interagency Council, how is this expertise included -- are there additional mechanisms?
- Are local mental health agencies involved in planning early intervention services?

- How have mental health services been defined? What types of services are available?
- What role will mental health practitioners play in identification, evaluation and assessment; development of the Individual Family Service Plan (IFSP); and case management?

**Definition of "Developmentally Delayed."** Part H, the section of P.L. 99-457 that concerns infants, toddlers, and their families, requires each state to define the term "developmentally delayed" as it will be used by that state to determine eligibility for services. This study also focuses on the role of mental health in each state's definition.

#### *Questions*

- How are infant mental health issues reflected in the definitions of eligibility for services?
- How was the definition developed?
- Are at-risk children being served?
- Are other statewide efforts being developed that might provide mental health services to infants, toddlers, and their families?

**Personnel Development.** Currently all states are facing a critical shortage of individuals qualified to provide prevention and early intervention services for infants and toddlers. They are struggling to improve standards, to train new personnel, and to provide in-service training to current personnel.

#### *Questions*

- Is there a philosophy, type, and focus of training for professionals and paraprofessionals working or training to work in the early intervention area?
- Does training include a preventive mental health philosophy and skills implementation?

- What role will mental health professionals play in training efforts for other professionals and paraprofessionals?
- What efforts will be made to recruit mental health professionals to meet expanding needs?

#### **Next Steps**

Although P.L. 99-457 will be implemented in states by 1991, the process of refining this new legislation will continue for many years. Because of the unique histories, philosophies, legislation, and personalities involved in each state, "next steps" will vary greatly. The integration of mental health perspectives in this complex process is likely to encounter significant barriers. Strategies to ensure the involvement of mental health and to overcome potential barriers must be developed.

#### *Questions*

- What are the barriers to developing mental health services for infants, toddlers, and their families within the context of P.L. 99-457?
- What strategies can be undertaken to overcome these barriers?

Determining the role of mental health in the service delivery process for P.L. 99-457 is not easy for any state. Rarely does the consumer of mental health services think of mental health from a wellness perspective. More often, the perspective is one of illness or psychopathology. A primary task may be to define what mental health service to the population of very young children and their families means from the perspective of legislators, policy makers, service providers, and consumers. A second task may be to determine how principles of preventive mental health can be integrated into service delivery systems and programs.

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## MAINE

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by  
Edward Feinberg

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Maine's system of mental health/prevention services for infants is one that espouses the goal of greater attention to early childhood issues and recognizes the limitations of fiscal and professional resources. Of the three states surveyed,

Maine has the smallest and the most rural population; it is served by a small cadre of professionals with scant resources. Its service delivery system endeavors to be both practical and visionary as it utilizes existing resources creatively while

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remaining sufficiently flexible to incorporate new ideas.

A variety of factors -- some that are unique to Maine, others that are generalizable to states with similar demographic and value profiles, and still others that are generalizable to states with dissimilar profiles -- have contributed to the evolution of thinking and service delivery in Maine. A process to provide children's mental health services has evolved that has included key agencies, critical individuals and significant events. In the area of infant mental health, the adage that "as Maine goes, so goes the nation" would indeed herald an era of compassion and pragmatism.

#### **MENTAL HEALTH SERVICES PRE-P.L. 99-457**

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A creative, flexible mental health system for children has evolved in Maine during the past decade. This system is characterized by a family-centered, community-based prevention orientation. It relies on a strong interagency and multidisciplinary foundation with a focus on multiple points of access and individually tailored programs. This glimpse of Maine's mental health system includes a description of the history and nature of the present system; the development of consensus on principles of interagency coordination; an analysis of state and local decision making; a description of model local programs; and future considerations.

#### **The Interdepartmental Coordinating Committee for Preschool Handicapped Children**

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In 1977, following the passage of P.L. 94-142 (the Education for All Handicapped Children Act of 1975), the Maine Departments of Educational and

Cultural Services, Mental Health and Mental Retardation, and Human Services were directed -- by a joint legislative order -- to study the provisions of P.L. 94-142 and to recommend any necessary actions which may be required to put Maine into compliance.

The emphasis on state interdepartmental planning was a critical factor in the 1978 passage by the state legislature of an "Act Concerning Pilot Projects for More Effective and Efficient Delivery of Services to Preschool Handicapped Children" (T. 20-A M.R.S.A., S.7703). The responsibility for program development would remain with an Interdepartmental Coordinating Committee for Preschool Handicapped Children (ICCPHC). The ICCPHC, a precursor to the Interagency Coordinating Councils mandated under P.L. 99-457, has had representation from the Division of Public Health Nursing of the Department of Human Services; the Family Prevention Program of the Department of Human Services; the Child Protective Services of the Department of Human Services; the Division of Special Education of the Department of Education and Cultural Services; the Early Childhood Consultant of the Department of Educational and Cultural Services; the Bureau of Mental Retardation of the Department of Mental Health and Mental Retardation; the Bureau of Children with Special Needs of the Department of Mental Health and Mental Retardation; parents of handicapped children; private service providers; and coalitions, such as Head Start and the Association of Young Children with Special Needs.

Individual membership on this committee has been remarkably stable since its formation. This has enabled the committee to develop collective trust, define a shared mission, and put into operation program goals that are reflective of common values and local needs. Because of the absence of a federal or state-driven timeline for

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implementation of a specific array of preschool services, the ICCPHC has been able to evaluate local services, determine the nature of its state plan, modify its system as needed, and incorporate new service delivery philosophies and strategies.

The initial focus of the ICCPHC was on the development of a coordination mechanism for services to the three- to five-year-old population. A needs assessment conducted during the late 1970s revealed that services at the local level were uneven throughout the state, frequently inadequate, and generally fragmented. It was determined by the state legislature that a pilot system of "Preschool Coordination Sites" should be developed. These sites would implement, on a local level, the state-level philosophical commitment to multi-agency and multidisciplinary coordination. Five sites were initially established. By 1983, sixteen sites (one in each county) had been created, and a full-time consultant had been hired through the Department of Education and Cultural Services to provide technical assistance at the local level. Mental health professionals sit on the multidisciplinary coordination teams at these sites and act as a liaison with private mental health providers within the community. Activities at these Preschool Coordination Sites have continued to focus on the identification, referral, and case management of children with established handicaps as well as those at risk for developmental delays or disabilities due to biological and/or environmental factors.

It should be noted that historically there has been resistance in Maine to limiting eligibility for services to children with the traditional handicapping conditions as outlined by the Office of Special Education Programs. Service providers and policy makers have

considered biological and environmental risks increasingly appropriate for inclusion in service delivery coordination and planning within the context of a holistic perception of children's and families' needs.

In 1984 -- when all sixteen Preschool Coordination Sites had been established -- new state legislation allowed the coordination sites to expand their services to the birth to age three population. Funding was provided for limited direct service, staff assistance, in-service training, and technical assistance. The legislature also requested that there be "specific plans for the development of a statewide program of prevention intervention, including goals, objectives, activities, criteria for evaluation and projected impact on handicapped or at-risk zero to three-year-old infants and their families" (C.624, P.L. 1984).

This legislation was the result of two factors. The first was the natural outgrowth of the ICCPHC's deliberations and evaluations of its first five years of operation. As committee members assessed the work of the local coordination sites, including mental health activities, it became clear that a crucial time to conduct both a child and a family intervention was in the first three years of the child's life.

The second factor was the substantial impact that Michael Trout and Stanley Greenspan had on the formulation of a philosophy of service delivery in the mental health and emotional development of infants and young children in the early 1980s. Michael Trout's work evolved from his study under Selma Fraiberg at the University of Michigan. He is currently in private practice at the Infant-Parent Institute, Champaign, Illinois, and teaches workshops on infant mental health across the country. Stanley Greenspan, formerly of the

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National Institute of Mental Health, is a psychiatrist and author specializing in issues affecting young children.

On-site training sessions attended by key state decision makers, including legislators, as well as direct service providers -- particularly public health nurses -- galvanized a multidisciplinary cadre of professionals responsible for the development and delivery of services to infants. It appears that several themes blended together to create a receptive climate for embracing the Trout/Greenspan thinking:

- There was recognition in the professional community that a mental health/early intervention system was needed but no previous consensus had existed on how that system would be fashioned and what it should include.
- It was imperative that existing personnel continue to be utilized since there was neither the desire nor possibility of advocating for a new professional specialty or even in training a single professional group. Personnel shortages and the history of interdisciplinary collaboration meant that training in infant mental health would need to have a transdisciplinary orientation to include all professional and paraprofessional groups.
- The Trout/Greenspan emphasis on the family as the client was congruent with the tradition of public health nursing, a discipline that was particularly dominant in the most isolated and rural areas of the state, and with the state's evolving activities in children's mental health.

- The training could be accomplished through a variety of methods. Although mastery might require formal, university-based, out-of-state training, a beginning appreciation of infant mental health principles and techniques of intervention could be conveyed in a variety of modes, ranging from a four-day intensive workshop to a fifteen-week graduate telecourse.
- The interdisciplinary nature of the training contributed to an interdepartmental consensus and the development of a critical mass of supporters who could continue to advocate for an expansion of infant mental health programming within their professional groups.
- The relatively high numbers of school-aged children with "seriously emotionally disturbed" handicapping conditions had promoted interest among public school officials for a statewide mental health/prevention effort.

#### Zero-to-Three Committee

An interdepartmental, multi-disciplinary "Zero-to-Three" Committee, eventually subsumed under the ICCPHC, adopted a set of principles during this period that became incorporated as part of the birth-to-five philosophy of service orientation. This committee was formed to manage a three-year Handicapped Children's Early Education Programs (HCEEP) grant (1984-87) obtained by the Bureau of Children with Special Needs, DMHM. Project services included hospital and home-based screening of all newborns and coordinated intervention as needed. These principles evolved as a result of project experiences:

- Every child should receive preventive health and other supportive services which result in optimal physical and mental wellness for that child.
- Individuals must be able to develop trusting relationships with others in their family and community. Infants and young children need to develop this capacity within their home environments. In some situations, families need assistance in developing this capacity to trust and build relationships. This assistance may need to come through the combined effort of individuals and public/private services.
- Identification and treatment should be carried out to the maximum extent possible by currently available public and private sector resources.
- The model should be implemented by a local interagency group and, at the state level, by a state interdepartmental group. The delivery system should be interdepartmental in its organizational structure. The intervention should be multidisciplinary.
- Services should be family-focused, rather than child-focused. The family is a team member throughout the model.
- Intervention with zero-to-three-year olds should be integrated into the current state system for three-to-five-year-old handicapped children.
- Initial and ongoing education should be developed and provided to those who will identify and support handicapped or at-risk infants, young children, and their families.

In 1985, the legislature approved an effort to centralize and coordinate children's mental health services through the creation of a Bureau of Children with Special Needs within the Department of Mental Health and Mental Retardation. Still strongly committed to coordination of multidisciplinary services with a mental health prevention focus, the Bureau's enabling legislation included commitment to the following services: advocacy, assessment and diagnosis, child development, consultation and education, crisis intervention, family guidance and counseling, preventive intervention, professional consultation and training, respite care and treatment. The Bureau's target populations, also defined in the statute (T.34-B M.R.S.A., C.6), were:

- A. A child age 0 to 5 years who is developmentally disabled or who demonstrates developmental delays; and
- B. A child age 6 to 20 years who has treatment needs related to mental illness, mental retardation, developmental disabilities or emotional or behavioral needs that are not under current statutory authority of existing stage agencies.

The vision, philosophy, legislation structure, and service delivery system model described above has been evolving since the passage of P.L. 94-142. By 1985, a clear system of mental health service delivery to very young children was already operational.

Discussion with policy makers and service providers revealed a common vision of a continuum of services. This vision regarded mental health as a natural, "demystified," and easily accessible component of child and family services. Mental health services for infants were variously described as a kind

of anticipatory guidance, an opportunity for learning how to identify and interpret behaviors, and a forum to develop skills that would foster confidence in parents as they encourage cognitive, social/emotional, motor, and communicative development in infants. Maine was the only state to reflect this philosophy in legislation.

**MENTAL HEALTH SERVICES  
POST-P.L. 99-457**

P.L. 99-457 has greatly reinforced Maine's initial impetus towards better and more effective mental health services for infants and toddlers. Policy makers, legislators, and service providers continue to seek creative means to alleviate the state's serious fiscal and professional resource shortages, which impinge on a well-defined system.

**Definition of "Developmentally Delayed"**

As of June 1985, Maine had definitions in place for children with an array of handicapping conditions. Maine's definition of "developmentally delayed" clearly reflects a desire to serve children in light of the previously discussed philosophical principles developed by the Zero-to-Three Committee. The definition embraces a clear belief that the social/emotional well-being of very young children is a priority and that services to this population related to mental health issues must consider not only diagnosable handicapping conditions, but also those children at risk for developmental delays.

The definition of developmentally delayed/non-categorically handicapped is broken down by age:

<u>Age</u>	<u>Criteria</u>
1	3 or less months delay chronologically in one or more areas of development.
2	3 to 6 months delay chronologically in one or more areas of development.
3	7 to 12 months delay chronologically in one or more areas of development.
4	13 to 18 months delay chronologically in one or more areas of development.
5	More than 18 months delay chronologically in one or more areas of development.

Maine policy makers continue to rethink and modify this definition in light of new research, new societal concerns, and new legislation. After the passage of P.L. 99-457 in November 1987, the following descriptors were added for the definition of "emotionally handicapped":

- Pervasive developmental disorders or behavioral disorganization, such as autism, extreme sensitivity in infancy or toddlerhood, and atypical development;
- Psychological disorders related to bodily functioning such as serious eating, sleeping, eliminating, stuttering problems;
- Affective and interaction disorders such as separation anxiety, elective mutism, oppositional disorder, phobias, avoidant disorder, attachment problems, depression;
- Conduct or behavioral disorders that are severe enough to interfere with learning and social relations;

- Problems with identity and selfhood, such as self-abusive behaviors, headbanging, reckless disregard of safety, negative self-image;
- Attention deficit disorder; and
- Post-traumatic stress disorder, adjustment disorders and other specific situational reactions that significantly impair functioning and interfere with development.

### Development of a Service Delivery System \_\_\_\_\_

The service delivery system for infants, toddlers, and their families in Maine functions through sixteen Preschool Coordination Sites. There is one site in each of the sixteen counties in Maine. The responsibilities of the sites include coordinating existing programs and services to identify previously unserved children and to identify and plan for unmet program needs.

There has been a comprehensive Child Find system in Maine for children birth to age five since 1984. Local coordination sites have done considerable outreach and have interacted extensively with other agencies that have contact with young children and their families. The coordination sites stress several features: visibility within the community; the ability to accept referrals and inquiries for all infant and preschool children so that families need not continually search for the particular program needs of their child; consolidation of services to reduce fragmentation and duplication; and a commitment to networking with a multiplicity of agencies, often by sharing facilities and office space.

Individualized Family Service Plans, including case management services, have been in use in Maine on a statewide basis

for the past two years. They were used prior to that time in selected parts of the state at the Pilot Preschool Coordination Sites.

Components of the Maine IFSP include some elements commonly held by other states:

- Major handicaps or risk factors in decreasing order of severity
- Child/family strengths
- Child/family needs
- Special equipment/required transportation
- Team members and bases of evaluation
- Statement concerning evaluation procedures
- Statement concerning placement recommendations
- Parental participation
- Program service recommendations
- Narrative comments/transition planning
- Appropriate team member and parental signatures

In many instances, the case manager selected is the individual who is most likely to have long-term contact with the family or the individual who currently has rapport with the family. The close working relationship between the professional at the Preschool Coordination Site facilitates decision making in this area. Parents are involved in the IFSP process and can select a primary contact person. Because of the limited population, the very rural nature of Maine, and the limited number of professionals, information related to families is shared with relative ease while maintaining confidentiality.

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Each Preschool Coordination Site's program has been governed by a Local Coordinating Committee (LCC) that consists of physicians, therapists, other service providers, parents, state agency workers, etc. The LCCs have been responsible for monitoring the expenditure of Preschool Coordination Site funds, for hiring and supervising the Preschool Site Coordinator and for providing policy and operational direction to its area's program. The focus of intervention has been on the coordination and efficient delivery of existing services rather than on the creation of a new and separate tier of early childhood/special education school-oriented services. This focus was essentially due to the absence of a strong state tradition of preschool services for non-handicapped children, an emphasis on "local control" of educational programming, a commitment to integration of handicapped children, the logistical difficulty of creating highly specialized services in a rural state, the absence of qualified professionals, and a recognition of limited state fiscal resources.

Ongoing networking among the relatively small number of professionals involved with infants has enabled local innovations to become readily known throughout the state. An existing, grassroots setting for early intervention in mental health/prevention was frequently cited as ideal: a husband/wife private pediatric practice located in Winthrop, Maine. The husband engages in traditional, well child care. The wife, a nurse trained in Trout/Greenspan principles, provides preventive mental health consultation to all families who seek pediatric services. In another pediatrician's office in Lewiston, Maine, a medical social worker is employed on a part-time basis to provide preventive mental health services. This kind of front line medical/mental health

collaboration acknowledges that a child's social/emotional needs are an integral component of overall development and good health.

The system establishes the idea of the inclusion of mental health services as an expected component of normal pediatric care. It was continually emphasized by service planners and providers statewide that the ultimate goal is the development of a medical/mental health framework in which the stages of social/emotional development would be accorded the same level of attention that such areas as physical and cognitive development have traditionally received. Mental health services have been basically viewed as an equal partner with all other pediatric services as well as a virtual entitlement to all children and families.

#### Programs -- A Closer Look \_\_\_\_\_

**Project AIMS.** Clearly, the most elaborate and far-reaching expression of this goal of entitlement has been the development of Project AIMS (Attachment, Interaction, Mastery, Support). Funded as a special federal/state venture between the U.S. Department of Health and Human Services and the major state agencies in Maine, the project's primary purpose is to have a positive impact on the ways physicians, nurses, educators, mental health providers, day care providers and others identify young children at risk for or presenting emotional problems, assess the nature of the children's and families' strengths and difficulties, and provide them with appropriate treatment and support.

A major focus of Project AIMS is the development of a screening tool that focuses on emotional development and that can be easily integrated into

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standard physician office consultations. As written by Dr. Stephen Bauer in the first issue of the AIMS newsletter (September 1987, Volume 1, Number 1),

What is needed is a tool that will allow the practitioner to assess the emotional status of the child and family, the functioning of the family, the stresses present in the family situation, and how the family is adapting to those stresses. The tool should provide some insight into problem areas as well as give clues to functional strengths... It should help to raise the consciousness of both providers and families as to the importance and legitimacy of including those sorts of concerns in the medical setting.

Dr. Bauer also relates,

Our goal with the AIMS tool is to accomplish in the areas of emotional and family development something comparable to what the DDST [Denver Development Screening Test] has achieved in its own sectors of development.

The AIMS tool is keyed to a chronological age progression and provides opportunities for clinician-specific questions and Likert-type scale for parents. Clinician questions are both general and focused. Under the former category parents may be queried about adjustment and coping, basic care, and relationship issues. Focused questions appear under the headings, "Attachment," "Interaction," "Mastery," and "Support," and can be used when concerns have emerged from the general questions. A discussion of strategies and ideas is then presented so that the clinician can offer helpful, nonthreatening input that is designed to encourage the family to

determine its own system for contending with the identified issues.

There are two other central functions of the AIMS endeavor. The first is the provision of training to medical and human service clinicians in the field testing of the tool as well as in the general principles and applications of infant mental health theory. This is now occurring through a telecourse, training for protective service workers, mental health forums, and technical assistance to the Preschool Coordination Sites. The second is the continuing advocacy for and development of treatment services so that a comprehensive network can be in place for families whose needs extend beyond the screening and prevention efforts of the front line health care provider.

The AIMS staff continually emphasized that their system is driven by the desire to provide family support rather than by the need to provide psychiatrically oriented, diagnostic classifications to families and children.

**Rockland and Norway Sites.** This spirit of family-centered, preventive mental health services is evident in the manner in which services are delivered at the Preschool Coordination Sites. Examples are described here from the Rockland and Norway sites.

The Rockland site was among the original preschool coordination projects. Begun in 1978, there was an immediate recognition of inadequate regional resources as well as a fragmented relationship among agencies and disciplines. It was decided by the staff and the LCC that direct service providers from the various agencies should be housed in the same building while continuing to report to their respective agencies. Staff members now include child development workers, assessors, teachers, social workers, community

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health nurses, speech pathologists, occupational therapists, and a contractual psychologist with a private practice in the community. One of the therapists has received intensive training from Mr. Trout and serves as trainer/clinical supervisor to other staff.

The program is targeted at families with children who have established handicaps as well as those at risk for mental health difficulties. Services can include home visitation, play groups, parent groups, a parent-to-parent program, dissemination of a newsletter, and parent/staff participation on a variety of committees.

Referrals come principally from physicians and parents. Assessments are conducted for children in the age range of birth to three and in the age range of three to five. Most of the more than one hundred referred children receive fairly traditional, multidisciplinary evaluations with an emphasis on family adjustment and mental health issues. For children who are likely to have highly specialized needs and with major psychosocial issues, there is opportunity for extensive "arena style" evaluations. Based on the infant mental health orientation developed through Project OPTIMUS (a handicapped children's early education program formerly located in Brighton, MA), this three-and-a-half-hour transdisciplinary assessment could include all relevant disciplines in addition to an in-depth analysis of social/emotional development and functioning.

The program is particularly pleased with its Parent-to-Parent Project. This project targets at-risk families and has a chief goal of modeling appropriate parenting skills to families that are experiencing stressful parent-child relationships. Parent helpers receive extensive initial and ongoing training. Their role is to provide informal, nonthreatening assistance to client

families and demonstrate alternative parenting strategies. They may provide in-home or group experiences and help coordinate respite care or other services.

The Norway Preschool Coordination Site has a variety of special services that are specifically oriented to the at-risk and high-risk populations. Home-based mental health services are a main feature of the system with supplemental center-based services that include both a therapeutic preschool as well as a Parent Place. The therapeutic preschool has a preponderant enrollment of children who have been victims of physical abuse, sexual abuse, or whose parents are alcoholics. Components of the program include the BABES program which focuses on drug/alcohol abuse prevention and a sexual abuse prevention program entitled, "Talking About Touch." The Parent Place houses parenting groups, drop-in counseling, information, and informal support.

#### **Personnel Development and Standards for Training \_\_\_\_\_**

The ICCPHC has four goals directly related to personnel development. Skills and information relating to infant mental health/emotional development are accorded equal status and attention with those relating to disabilities affecting other areas of development. The goals are:

1. To formalize the training subcommittee of ICCPHC, support meetings at least on a quarterly basis, provide a forum for information exchange, technical assistance and resource sharing, and maximize the training resources available.
2. To provide continued support for the maintenance and ongoing operation of the mail-bag library,

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film resources, and materials exchange for parents and professionals, focusing on infants and young children, ages 0-5, who are at-risk or developmentally delayed.

3. To facilitate the identification, design, and development of inter-departmental, transdisciplinary, training opportunities focusing specifically on the 0-5 population and parenting/family issues.
4. To ensure interdepartmental leadership in the identification of effective strategies for the recruitment and retention of a variety of professionals throughout the state of Maine to work with families, young infants and children, ages 0 to 5.

#### **SERVICE DELIVERY SYSTEM: STRENGTHS AND CHALLENGES**

**Strengths.** Maine's interagency, multidisciplinary approach to infant mental health provides "Everybody Wins" alternatives. As one example, when the Zero-to-Three Committee was formed, the Maternal and Child Health representative was partially motivated by his past experience as chief medical officer for a neonatal intensive care unit and his desire to maintain (during the birth-to-three period) the high newborn-survival rates Maine had achieved. The Public Health Nursing representative was motivated, in part, by her desire to enhance the role and self-image of public health nurses throughout the state and to provide them with opportunities to practice primary prevention. The Special Education representative was meeting a commitment in Maine's original P.L. 94-142 State Plan to extend service

downward to birth, and the children's mental health representative was motivated by a need to become proactive in the face of ever-increasing referrals of severely emotionally disturbed children and adolescents. Finally, the Developmental Disabilities Council representative was excited at the opportunity for non-categorical delays and disabilities to achieve attention equal to that afforded commonly understood handicapping conditions.

**Challenges.** Like most states, Maine is faced with a generally static or decreasing resource base together with increasing human needs and competition for these resources from a growing variety of social programs. To develop effective constituencies for representation to legislators and other decision makers, it becomes necessary to increase consumer expectations faster than service delivery capacities. This process inevitably produces stress, impatience and frustration on the part of consumer and administrator alike.

#### **NEXT STEPS**

Service Agency Representatives and regional coordinators' staff indicated that there is significant community support for infant mental health services, however, lack of trained personnel and inadequate fiscal resources are barriers to service provision. There is an increasing emphasis on the promotion of an efficient transition system to the public schools for children who have received infant and preschool mental health services so that support can be provided without the requirement for diagnosis and determination of a handicapping condition.

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There have been several strategies advanced to contend with the problem of personnel shortages. These include:

1. Development of an early childhood/special education graduate program through the University of Maine. This would be the first program of its kind in the state; the focus would be highly transdisciplinary with a strong mental health orientation. Educators would be part of the transdisciplinary early intervention team rather than serving only in more traditional classroom teacher roles.
2. Development of an extensive cadre of paraprofessionals who work under the supervision of professionals. This has been occurring with speech and language pathologists. The shortage of master's level speech and language pathologists has prompted the emergence of "speech aides" who are trained at the bachelor's level and work under the supervision of master's-level, trained speech pathologists.
3. Specialized supplemental training in infant mental health for those already in contact with infants and their families -- hospital, office, community and public health nurses; day care providers; early intervention specialists; child protective workers; and out-patient staff members of mental health centers. This approach is seen as more advantageous than any attempt to develop a new specialty or sub-specialty in a time of expanding needs and diminishing resources.
4. Movement to raise salaries, particularly in the southern end of the state, to assist recruitment and retention efforts. Neighbor-

ing states, particularly Massachusetts, presently offer substantially higher salaries to individuals seeking professional positions in school and clinical settings.

The lack of fiscal resources is a recurrent problem in Maine as the state attempts to contend with a variety of social/educational issues. There are two strategies here: an endorsement of the expectation that more federal monies are needed to assist in the provision of services to children under P.L. 99-457 and growing support at the state and local level for early intervention as its efficacy is demonstrated.

Discussions with planners and providers revealed a pride in the emphasis that has been placed on prevention and early mental health intervention. There was also concern that the system may not be able to absorb continued referral demands and that the family issues being brought to the attention of service providers are increasingly complex. While the interagency expectations of P.L. 99-457 were greeted as congruent with the existing assumptions of collaborative endeavors in Maine, there was great concern that dividing the service system in two (birth to three and three to five) could threaten the foundation of the "seamless" preschool system that has been a decade-long goal of service providers. There was also recognition that what works well in a relatively homogenous, non-urban state may not transfer well to states that are demographically heterogeneous and have histories of interdepartmental disharmony. While health care resources can still be targeted to the at-risk population, there was fear, particularly in the relatively urbanized, southern end of the state, that the emerging population of chronically ill, extremely

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premature babies could force a reallocation of resources away from a preventive system that features a philosophy of "greatest good for the greatest number," to a system that provides intensive services to children with ongoing, life-threatening conditions. This could have a particularly profound effect on the future utilization of nursing services.

### RECOMMENDATIONS FOR OTHER STATES

Ed Hinckley, Chief Operations Manager of the Bureau of Children with Special Needs, and an ardent advocate of infant mental health services in Maine stated that "interagency collaboration is an unnatural act." But he also suggested practical guidelines to enhance the likelihood of interagency success and to create excitement about the possibilities of infant intervention. These include:

- Disabuse people of the notion that mental health is the domain of any one agency or discipline.
- Remember that it takes time to build trust, develop a common mission and devise a common direction.
- Begin with pilot sites. There is greater likelihood of eventual adoption of a new state-level policy if there is proven success at the local level.
- Provide opportunity for policy makers to conclude that intervention is necessary rather than impose mandates for the creation of intervention systems. Success is then more likely.
- Provide coordination initially in the development of programs and systems and resist the idea of the

immediate provision of new, direct services. A planning process is imperative.

- Include the universities in the provision of training in the beginning of the process and create a university partnership.

### RESOURCES AVAILABLE TO OTHER STATES

A forty-five hour introductory course on infant mental health has been developed by the Maine Association for Infant Mental Health, Inc. (a chapter of the International Association for Infant Mental Health) assisted by the Bureau of Children with Special Needs, DMHMR. Included in this course are ten half-hour video tapes, produced by Michael Trout, and related print materials; it has been awarded three graduate credits by the University of Southern Maine and will be an elective in the University of Maine's graduate MSW program. More information may be obtained by contacting Edward Hinckley, at the address below.

Representatives of the association and the various agencies involved in zero-to-five mental health programming and service delivery are available to conduct workshops within the restrictions of personal scheduling. Seminars, conferences, "train the trainer" classes, and technical assistance can be offered to administrators and clinicians.

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## NORTH CAROLINA

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by  
Emily Schrag Fenichel

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North Carolina has the second largest population and the smallest geographic area of the three states surveyed. It is characterized by moderate-size cities and extreme rural areas. As with many other states, there seems to be a concentration of services in the most populated areas. In North Carolina there is a clear commitment on the part of many state agency leaders to develop a service delivery system that is family-centered and that addresses infant-parent mental health needs.

North Carolina's efforts to address the mental health of very young children grow out of a tradition of policy development and direct service at least twenty years old. Two major strands can be identified in this tradition: 1) a desire to provide comprehensive, skilled diagnostic and treatment services to children with serious emotional disturbances; and 2) a conviction that a supportive, non-categorical approach to the health and well-being of infants, toddlers, and their families must include attention to psychosocial issues and emotional development. North Carolina is the source of many innovative ideas within the areas of funding for mental health services, service delivery models, and training early intervention personnel in mental health sensitivities and skills.

### **MENTAL HEALTH SERVICES PRE-P.L. 99-457**

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The creation of a framework for attending to the emotional development and mental health of North Carolina's infants, toddlers, and their families has involved the efforts of the state legislature, major state agencies, professional organizations, universities, service providers, community groups, and

individuals with special expertise. With the exception of departments of public instruction, all of the relevant state agencies for preschool services are components within the Department of Human Resources. These include the Division of Health Services; the Division of Mental Health, Mental Retardation and Substance Abuse Services (MH/MR/SAS, the Part H lead agency for P.L. 99-457); the Division of Social Services; the Day Care Section of the Division of Facility Services; and the Division of Medical Assistance. In addition, North Carolina has tapped national resources by participating in a multistate initiative designed to improve services to disabled and high-risk infants, toddlers, and their families and by successfully competing for discretionary funding from two federal agencies in order to mount demonstration programs related to infant mental health.

A few examples of collaborative efforts illustrate the ways in which fruitful partnerships have emerged and in which the achievements of one group's effort provide fuel for another group's work.

### **Initial Efforts**

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In 1974, a committee began to consider the needs of infants at risk for developmental delay. Chaired by staff of the Maternal and Child Section of the Division of Health Services, it included representatives of the child mental health and mental retardation sections of the Division of MH/MR/SAS, as well as other Department of Human Resources agencies. In July 1979, in conjunction with local health departments, hospitals, and the North Carolina Chapter of the American Academy of Pediatrics, the Division of Health Services instituted the procedures that became known as the

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High Priority Infant Program (HPIP). In 1984, North Carolina was selected as one of ten states participating in Project Zero to Three. The state's Zero-to-Three Committee shared its experiences in tracking and providing services to high-risk infants and toddlers with other states. Subsequently, in 1987, a set of risk indicators developed through the national Project Zero to Three were adopted as part of North Carolina's revised HPIP procedures.

In 1986, the Mental Health Study Commission, a body established by the North Carolina General Assembly, appointed a Child Mental Health Task Force to provide long-range needs assessment and planning for a comprehensive child mental health system. All relevant agencies at state and local levels provided input, and public hearings were held across the state. The Division of MH/MR/SAS, in turn, responded to the plan with an analysis of administrative activities necessary to support further system development and/or improvement. As a special outgrowth of the task force's recommendations, the 1987 General Assembly appropriated two million dollars in new resources to expand child mental health services and made a commitment to continued expansion over the next ten years. Preschool children are one of three population groups given high priority in the plan.

In the spring of 1986, the Comprehensive Interagency Preschool Planning Committee (now the Interagency Coordination Council) was established by the Departments of Public Instruction and Human Resources, through the Division of Exceptional Children of the former and the MH/MR/SAS and Health Services of the latter. It served as the single planning and advisory forum considering the service needs of infants, toddlers, and preschool children (birth through five)

with developmental difficulties. Membership on this committee included staff with management and direct service responsibility from principal governmental agencies as well as representatives of advocacy groups and professional and consumer organizations. Task forces were formed to address issues of service implementation, training, eligibility, needs assessment, and transition.

### Programs — A Closer Look \_\_\_\_\_

**Project Enlightenment.** An example of a pre-P.L. 99-457 program in the early intervention network -- unique because of the many services offered -- is Project Enlightenment, a cluster of mental health services for young children and their families that operates within the Wake County Public School system; it is also affiliated with the area mental health agency for Wake County. Begun with a Part F Grant (Community Mental Health Center Act) in 1969, at a time when no mental health services existed in the area for children under six, the project is designed to serve children from birth through the completion of kindergarten. By its own description, Project Enlightenment operates from the assumption that "since children cannot always have access to trained, specialized mental health personnel, it is important that the adults in a child's life gain support and skills which will enable them to help the child realize his or her fullest potential... the approach does not emphasize problems, diagnostic labels and weaknesses, but focuses on accentuating the existing strengths in the home and school."

The project offers teacher/parent consultation, short-term parent counseling, parent education, workshops, a telephone service for families, teacher training, a resource center, and a range

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of publications. A demonstration preschool serves an average of twenty children ages three to five, ten of whom have emotional-social and/or learning problems. First Years Together is a special demonstration project within Project Enlightenment for Wake County families whose babies have spent time in the Neonatal Intensive Care Unit or are being followed through Wake Medical Center's Special Infant Care Clinic. First Years Together offers home and center visits, assessments, a resource center, and a parents' group during the first two years of life. Its aim is preventive -- to offer a continuum of services to parents whose infants have had a worrisome start.

**The Family, Infant and Preschool Program.** The Family, Infant and Preschool Program (FIPP) located at a state institution, Western Carolina Center, in Morganton, North Carolina, is a model demonstration program for young children with disabilities and their families that approaches mental health concerns from a social systems, family support perspective. In their 1988 book, Enabling and Empowering Families: Principles and Guidelines for Practice, FIPP staff members Carl Dunst, Carol Trivette, Angela Deal and their colleagues articulate a family intervention approach based on the conviction "that the best way to be of help is to support and strengthen family functioning." This approach emphasizes a helping process which promotes positive, competent, family activity engaged in meeting the needs of all family members using resources within and outside the family.

In the presentations they make frequently to national audiences of early intervention practitioners, family support programs, and policy makers, FIPP staff and parents stress the evolution of the program from a child and disability-

focused treatment effort to a family-oriented, proactive approach. This evolution has built upon recent social science thinking about children, families, and would-be helpers but has also been grounded in the experience of developing and field-testing various versions of an assessment and intervention model. Again, the program has received both state and federal support: the work of the FIPP has been funded in part by grants from the North Carolina Division of MH/MR/SAS, Research and Evaluation Section; the North Carolina State Board of Education; the Children's Trust Fund; the North Carolina Council on Developmental Disabilities; the National Institute of Mental Health, Prevention Research Branch, the U.S. Department of Health and Human Services Administration on Developmental Disabilities; and the U.S. Department of Education, Office of Special Education Programs.

## **MENTAL HEALTH SERVICES POST-P.L. 99-457**

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The enactment of P.L. 99-457 and related state initiatives have provided new opportunities for collaboration on behalf of young children and their families both within the Division of MH/MR/SAS and among other state and local service providers.

Because of its high level of activity and visibility, the Preschool Planning Committee was designated by the Governor in March 1987 to be the official Interagency Coordinating Council under P.L. 99-457. In the fall of that year, a State Implementation Team, including management staff from the three divisions chairing the Preschool Planning Committee, was formed to accomplish

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the day-to-day coordination necessary between the divisions and to develop strategies for carrying out recommendations of the committee.

Before the Division of MH/MR/SAS was designated as the lead agency for coordination of services for disabled and high-risk infants and toddlers, staff in the sections of Mental Health and of Mental Retardation were more likely to be involved in joint projects with staff of the Division of Health Services or the Department of Public Instruction than with each other. Emotionally troubled young children began to be considered as a subcategory of developmentally disabled young children by the Interagency Preschool Planning Committee. Simultaneously, non-categorical, comprehensive services to young children and families began to receive increasing support. Reflecting these trends, the Special Assistant for Child and Family Mental Health Services and the Deputy Director for Mental Retardation and Developmental Disabilities (MR/DD) Services recommended a jointly-funded demonstration program to serve emotionally troubled infants, toddlers, preschoolers, and their families.

Proposed in 1987, the plan entailed using the existing MR/DD early intervention network as a "service home" for these children with close involvement and support from local child mental health units. At one existing early intervention program in each of four regions, one mental health professional has been added to the staff. New support activities for mental health are to include, but are not limited to, such activities as child and family screening and assessment, staff training, participation in case staffing, and provision of clinical supervision for early intervention staff. A full-time project coordinator, a half-time trainer and a broadly representative advisory group

direct and integrate the work of the four regional sites.

This approach was supported by the Division of MH/MR/SAS. Categorical resources from the Child and Family Services and Mental Retardation Sections were supplemented by a grant from the federal Child and Adolescent Service System Program (CASSP) of the National Institute of Mental Health; service delivery began in January 1988.

One division within the Department of Human Resources that has yet to become fully involved in the development of integrated policy and service delivery to emotionally troubled infants, toddlers, and their families is the Division of Social Services. It has been determined that over nine percent of the caseloads for early intervention in mental retardation are protective services clients of the Division of Social Services. The designation of substantiated physical abuse, sexual abuse, or other worrisome environmental factors as criteria for inclusion in the atypical development population recognizes the developmental effects of abuse, neglect, and poor caregiving. Given this framework, one would anticipate an increase in interaction between the Division of Social Services and other agencies or groups that work with young clients and their families.

#### **Definition of "Developmentally Delayed"**

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North Carolina's definition of eligibility for services under P.L. 99-457 recognizes both the extent and the limitations of current understanding of emotional development and mental health disturbances during the earliest years of life. According to North Carolina's definition, children from birth through five years of age are eligible for early

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intervention services if they are: 1) developmentally delayed; 2) demonstrate atypical development; or 3) are at high risk for developmental delay or atypical development.

**"Developmentally delayed children"** means those whose development is delayed in one or more of the following areas: cognitive development, physical development, language/speech, and self help. The specific level of delay must be:

- (a) Children from birth to thirty-six months of age: documented by scores 1 1/2 standard deviations below the mean on standardized tests in at least one of the above-mentioned areas of development; or by a twenty percent delay on assessment instruments that yield scores in months.
- (b) Children from thirty-six to sixty months of age: documented by test performance 2 standardized deviations below the mean on standardized tests in one area of development; or by performance that is 1 standard deviation below the norm in two areas of development; or it may be documented by a twenty-five percent delay in two areas of assessment instruments that yield scores in months.

Careful assessment is necessary to determine developmental delay and must be performed by appropriately credentialed professionals whose training qualifies them to assess children in the developmental area of concern. Standardized tests, rating scales, developmental profiles, and other instruments and procedures that meet acceptable professional standards shall be used to document the nature and severity of the problems necessitating intervention.

**"Atypical development"** in children means those from birth to sixty months of age who demonstrate significantly atypical behavioral, socioemotional, motor, or sensory development as manifest by:

- (a) Diagnosed hyperactivity, attention deficit disorder, or other behavioral disorders; or
- (b) Identified emotional/behavioral disorders such as:
  - (1) delay or abnormality in achieving expected emotional milestones, for example, pleasurable interest in adults and peers; ability to communicate emotional needs; and ability to tolerate frustration.
  - (2) persistent failure to initiate or respond to most social interactions.
  - (3) fearfulness or other distress that does not respond to comforting by caregivers.
  - (4) indiscriminate sociability, e.g., excessive familiarity with relative strangers.
  - (5) self-injurious or unusually aggressive behavior.
- (c) Substantiated physical abuse, sexual abuse, or other environmental situations that raise significant concern regarding the child's emotional well-being.

**"High-risk children"** means those from birth to thirty-six months of age who:

- (a) Have a diagnosed physical or mental condition which has a high probability of resulting in developmental delay or atypical development; or

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- (b) Have significantly atypical patterns of development (perceptual, sensory, physical, behavioral, motor anomalies) that have a high probability of resulting in developmental delay or atypical development; or
  - (c) Have responded well to intervention efforts, but for whom there is evidence that their continued developmental progress cannot be assured without continued intervention.

Careful assessment is necessary to determine high-risk status and must be performed by appropriately credentialed professionals whose training qualifies them to assess children in the developmental area of concern. Standardized tests, rating scales, developmental profiles, and other instruments and procedures that meet acceptable professional standards shall be used to document the nature and severity of the problems necessitating intervention.

The emotional development of infants and toddlers in all three eligibility groups is, of course, of concern, but it is the atypical development and the high-risk groups that reflect North Carolina's strong mental health focus. Since so few states have adopted eligibility criteria under P.L. 99-457 that are as nearly non-categorical as North Carolina's, it may be useful to describe the context in which its definition of eligibility was developed.

North Carolina's definition of eligibility represents an achievement of collaboration as well as conceptualization. The result of more than a year of deliberations by the Comprehensive Interagency Preschool Planning Committee, the definition was developed and synchronized with major efforts in the Division of Health Services and in the Division of MH/MR/SAS.

The experience of the Division of Health Services in trying to identify and serve a high-risk population of infants and toddlers may have made the interagency committee more comfortable with a definition of eligibility that included these children. As early as 1979, the High Priority Infant Program of the Division of Health Services began to identify infants who had indicators associated with later developmental delay; to enroll, track and assess the development of these infants; and to offer support services, chiefly of public health nurses, to assist families and primary care providers. In 1988, several major revisions in the program became effective. A single set of risk indicators, including parental/family conditions, mental conditions, and post-neonatal conditions replaced a prior system with three risk categories. Moreover, infants could be identified and enrolled in the program any time within the first year of life.

The high-risk children who can be served under P.L. 99-457 may also be the beneficiaries of North Carolina's tradition of preventive services to disadvantaged young children and families. The recognition that continued intervention may be necessary to maintain the developmental progress of young children who have responded well to intervention reflects the findings of a number of demonstration projects that have focused on psychosocial development.

Members of the Eligibility Subcommittee of the ICC developed broad, comprehensive criteria for a category of "atypical development" based on a philosophy that eligibility for preschool services should allow a response to needs that are diverse and that sometimes are not easily diagnosed. As this non-categorical approach was being translated into the language of eligibility criteria, major changes were also being made in

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state statutes. After fifteen years of deliberation, the North Carolina General Assembly enacted legislation in 1987 which made those services previously available only to people with mental retardation now available to anyone meeting the current federal definition of developmental disabilities. Developmental delay and atypical development were cited as additional categories to determine the eligibility of infants, toddlers, and preschoolers. Effective April 1988, accounting rules in the Division of MH/MR/SAS were also modified to allow young children experiencing atypical development to be served with existing early intervention MR/DD funds.

The Preschool Planning Committee estimates that seven percent of the general population of preschoolers (zero to five) are at risk for or do exhibit atypical development. Infants and children with established DSM III-R (American Psychiatric Association) diagnoses are considered part of this group. So are young children who have experienced substantiated physical abuse, sexual abuse, or other worrisome environmental situations: these are seen as occasions to provide developmental services to the child and family, not simply as a matter for the judicial or foster care system. It is worth noting that, while careful assessment by an appropriately trained professional is emphasized in the description of atypical development, examples of emotional/behavioral disorders are presented in non-technical language.

#### Development of a Service Delivery System \_\_\_\_\_

North Carolina envisions identifying, assessing and providing mental health treatment services to atypically

developing and high-risk infants and toddlers within a non-categorical system of early intervention services. Since the four demonstration projects being sponsored by Child Mental Health-MR/DD build on or are connected to service components that are available statewide, the successes they achieve may be relatively easy to replicate. State agency planners are also aware of the importance of maintaining and learning from excellent community- and university-based mental health services.

#### Identification and Assessment of Infants and Toddlers in Need of Mental Health Services \_\_\_\_\_

Because very young children enter the human services network primarily through the health, social services, or day-care systems, service providers at these entry points need to be aware of mental health issues affecting infants and families. North Carolina's planners have recognized this need and are helping service providers become prepared to offer appropriate assistance and/or referral.

The High Priority Infant Program involves close cooperation among local health departments, private physicians, developmental evaluation centers, neonatal intensive care follow-up clinics, early intervention programs, hospitals serving each county, and, of course, families. Infants may be enrolled in the program throughout the first year of life, if they meet any one of thirty risk conditions; those likely to be associated with mental health concerns include parental mental illness, difficulty in parental/infant bonding, lack of familial and social support, failure to thrive, and significant parental concerns.

The 1988 revisions to the High Priority Infant Program emphasize actual

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family support services, rather than "paper" tracking. All infants -- including private patients enrolled in the program -- receive the same support services protocol, which includes a home visit by a HPIP (public health) nurse two weeks after discharge from the hospital, and face-to-face contacts in the home or clinic at four, twelve, eighteen and thirty to thirty-six months of chronologic age. All HPIP support services are provided in conjunction with the infant's primary care provider. Through appropriations granted by the North Carolina General Assembly, services included in the HPIP protocol (identification, enrollment, tracking, support services, and intermediate assessments) are provided at no cost to families.

The support services protocol emphasizes the emotional well-being of the infant and the parent, in addition to the parent-child relationship. Nurses observe and assess the family's adjustment to the infant and the home environment, share information about cognitive and social development as well as health states, and are alert to parents' use of or need for social support.

More extensive, multidisciplinary evaluations of young children with suspected developmental problems have been provided by nineteen Developmental Evaluation Centers (DEC) throughout North Carolina. Some 26,000 children are seen annually, with the focus increasingly shifting to the zero-to-five population. A new Intermediate Assessment, more thorough than a developmental screening but less intense than a multidisciplinary evaluation, is now being provided to children enrolled in the High Priority Infant Program on two occasions: the first, between fifteen and eighteen months of age; the second, between thirty and thirty-six months of age. The Intermediate Assessment includes a full Denver Developmental Screening Test

plus a special developmental checklist administered by DEC staff. The expertise of North Carolina's Developmental Evaluation Centers has historically rested in areas other than mental health; if the primary cause for concern about an infant or toddler involved emotional development, the child and family might be referred elsewhere. Recruiting staff with infant mental health expertise and/or providing appropriate training to current staff are major challenges for the centers.

A more specialized, but strictly circumscribed, mental health evaluation resource is the Child Mental Health Evaluation Program, a network of psychiatrists and licensed practicing psychologists coordinated by the University of North Carolina-Chapel Hill Medical School faculty under direct contract with the state's Division of Social Services. The program provides extended psychiatric/psychological evaluations for children suspected of being abused or neglected; referrals are made primarily for complicated situations. Approximately thirty-five percent of these evaluations are for children under six. Case conferences take place after most evaluations in order to present results, to discuss the Social Services plan for the child and family, and, where needed, to discuss recommendations for long-term treatment of the child and family; however, the program does not provide direct links to follow-up services.

To improve identification of infants and toddlers in need of mental health services in their areas, the four Child Mental Health/MR/DD demonstration projects work closely with local High Priority Infant Programs. They are also making themselves known to primary health care providers, day care providers, practitioners with adult mental health and substance abuse caseloads, and other

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sources of potential referrals of infants and toddlers experiencing atypical development or at high risk for emotional problems. North Carolina has also used Part H funds to establish an interagency demonstration team for infant assessment in one county. With staff from three agencies -- the High Priority Infant Program, the Developmental Evaluation Center, and the Early Intervention Team -- this "single portal" unit will conduct developmental assessments, coordinate service delivery, write Individualized Family Service Plans (IFSP), and assign case management responsibility. This first demonstration is seen as an opportunity to learn how use of the atypical development definition for eligibility works in practice. The possibility of common forms and procedures across agencies will be explored; additional providers might also be included in the team.

#### Treatment Services \_\_\_\_\_

State-funded early childhood intervention services for infants and toddlers with developmental delays, atypical development, or at high risk for developmental problems are offered under the aegis of the Division of MH/MR/SAS, primarily through a network of home-based services that began in 1968. Multidisciplinary PACT (Parent and Child Together) teams provide comprehensive assessment and prescriptive developmental programming for children from birth to age three. These teams may include educational specialists, early childhood educators, psychologists, social workers, and speech, physical and occupational therapists. Families are provided with training, support and information on childrearing skills and management, and on other resources and services available to them. In 1986-87,

1,479 children and families were referred to Early Childhood Intervention Services statewide; of these, 762 children were later accepted into the program. The total enrollment for 1986-87 was 1,659 children. In January 1988, 200 children and families were on a waiting list. North Carolina has used Part H funds to extend Early Childhood Intervention Services to all counties in the state, beginning in 1988.

Seventy-nine Developmental Day Programs, also sponsored by the Division of MH/MR/SAS in seventy-six of North Carolina's one hundred counties, serve children who tend to have substantial impairments. Almost nineteen percent (351 children) of those being served on May 1, 1987, were under three years of age. An almost equal number (334) of children from zero to three were waiting for services as of that date; lack of classroom space and insufficient funds were the chief reasons for delays. A growing demand for center-based services for infants is seen.

All PACT teams and Developmental Day Program staff have already been serving some children who evidence atypical development or are at high risk for emotional problems. Some ten percent of children served are referred by Protective Services alone. The four new Child Mental Health/MR/DD demonstration programs will be looking for better ways to address mental health issues within the PACT model of home-based direct services, day care consultation, and case management services, using the new, full-time mental health specialist added to the staff with demonstration grant funds.

The mental health specialist is expected to work directly with families on the parent-infant relationship, using a focus-on-the-child technique as a way to offer emotional support to parents comfortably. With particularly difficult

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families, establishing a working relationship is itself a substantial goal. Helping families to find and use social support and counseling for relationships with other children or spouses is another important feature. Making appropriate referrals for more intensive therapy may be indicated. The mental health specialist at each demonstration site is also involved in clinical supervision of staff whose backgrounds are in other disciplines. As staff become more experienced in identifying and engaging mental health issues and as referrals come from a range of sources, including the Division of Social Services, the projects are likely to be increasingly able to address the mental health needs of developmentally disabled, atypically developing, and high-risk infants and toddlers.

A special word is in order about linkages between early childhood intervention and day care services. Day care providers are seen as excellent potential referral sources for young children needing HPIP follow-up as well as more specialized mental health assessment. At the same time, family day care homes and mainstreamed day care centers can offer a community setting where an early intervention team can help providers and families meet the emotional needs of young children. A small number of atypically developing young children have been placed in family day care with fees paid through Title XX Community Living Services. There are thirty-nine Early Childhood Intervention (ECI) programs in the state which provide information, referral and linkages. One of these is KidSCOPE, a project funded by one Community Mental Health Center to provide on-site consultation and support to mainstream day care centers serving emotionally troubled three- to five-year olds and could be extended in time to work with younger children and with family day care providers.

## **Personnel Development and Standards for Training**

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**Training Plan for CASSP Demonstration Projects.** As North Carolina's planners noted in their application to CASSP, "a new service delivery system with new service models which address the needs of a new target population requires a staff with background and skill levels to match the service needs." Those service needs may come from young victims of abuse and neglect; infants and toddlers whose precarious health status may have overshadowed their emotional development; and children whose troubling behavior represents a complicated, poorly understood interaction among physical, cognitive, and emotional factors. In addition, multiply stressed families whose members may or may not have been coping with their own emotional problems before the birth of a vulnerable child may require service; the skills required for appropriate response to such diversity are high indeed. Moreover, as North Carolina's planners are aware, the field of infant/parent mental health differs in its approach from some other mental health specialties, with an emphasis on strengthening positive parent-child relationships rather than a focus on individual psychopathology. As research and practice in the field evolve, in-service and continuing education are as essential as appropriate pre-service training.

In keeping with the collaborative approach to administration and service delivery that characterizes North Carolina's four demonstration early intervention projects, training responsibilities are shared by the Child Mental Health Training Unit (representing MH/MR/SAS), and the Technical Assistance Program-Intervention Network (TAP-IN) (representing the MR/DD Section). The two training agencies

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administer a wide range of training functions for the four demonstration projects; interagency collaboration has made possible expansion of training resources and elimination of duplicative efforts.

Training design efforts began with a comprehensive needs assessment. Results from the needs assessment plus training requirements stipulated in the grant became the guidelines for the training plan. The plan is still evolving and will undoubtedly be modified throughout the grant period to reflect changing needs of staff and to take advantage of unidentified training opportunities. The following are the components of the first draft of the plan: annual statewide conference, case studies, workshops, resource library, curricula and training materials, and liaison with the state interagency council.

One feature of the training plan that deserves special recognition is that competencies and a certification process for infant mental health specialists have been developed. Meanwhile, staff of the four demonstration projects who do not have mental health degrees or certification can become "Qualified Mental Health Professionals" (in North Carolina Medicaid parlance) by increasing their skills through group review of case studies and through clinical supervision of their work with children and families by a mental health professional. Once staff become thus "privileged" to provide clinical services, their work with eligible children and families can be reimbursed by Medicaid. This arrangement provides service programs with a financial as well as a programmatic incentive to offer integrated, sequenced in-service training.

**Nursing Child Assessment Satellite Training.** Training in awareness of infant mental health issues and in the skills involved in strengthening fragile infant-parent relationships has been provided to North Carolina's HPIP personnel and other health professionals through adaptation of the Nursing Child

Assessment Satellite Training (NCAST) originally developed at the University of Washington, Seattle. The North Carolina NCAST Project is sponsored by the Division of Health Services and of MH/MR/SAS within the Department of Human Resources, and by the School of Nursing Continuing Education Program and the Center for Development and Learning at the University of North Carolina at Chapel Hill.

Since the NCAST Project began in North Carolina in 1983, individuals in a variety of agencies around the state have been trained in NCAST's methods of detecting parent and infant interactional problems and using assessment information to improve intervention planning. NCAST includes scales for assessing infant sleep patterns, behaviors, interactions with caregivers, as well as the caregiving environment. The North Carolina NCAST faculty have developed a videotape and other materials to demonstrate the application of NCAST to intervention with high-risk and handicapped children and their families.

Professional organizations in North Carolina also play a role in expanding mental health awareness and skills of practitioners working with infants, toddlers and families. The publications and conferences of the North Carolina Perinatal Association and the North Carolina Association for Infants and Families (an affiliate of the International Association for Infant Mental Health) are valuable resources for the professional community.

#### **SERVICE DELIVERY SYSTEM: STRENGTHS AND CHALLENGES \_\_\_\_\_**

##### **Strengths:**

- Existing ICC (Interagency Coordinating Council) and legislative/gubernatorial support.

- Designated, active and cooperative agencies for the implementation of P.L. 99-457.
- Designated target population.
- An evolving framework for inter-agency collaboration in place at almost all system levels.
- A ten-year mental health plan in which the infant, toddler and preschool populations are prioritized for funding and identified to receive service delivery.
- An existing and very experienced statewide Early Intervention Network (20+ years).
- Cross-disciplinary Early Intervention Teams.
- An established and supported statewide training plan for early intervention staff.
- An innovative and receptive system that is open to model design and later replication.
- A strong evaluation and research component which is an integral part of the system.
- An existing database of early intervention services, populations, and personnel for comparative collaboration.
- Both sections of MR/MH gathered under the umbrella of DHR in this system.
- Autonomy of forty-one individual area MH/MR/SAS programs.
- Cross-section (MR/MH) and cross-disciplinary supervision established for cross-categorical service early intervention staff.

- A mandate for DHR which supports and encourages intra-agency collaboration.

#### **Challenges:**

- A wide representation of very diverse disciplines and philosophies, which creates a challenge in providing unified services to communities and in maintaining communication lines among all levels and disciplines of the system.
- Limiting the impact that the Division of MH/MR/SAS can have on program development/change due to local program autonomy, although autonomy is also considered a strength.
- Lack of match between services and geographic populations/needs.
  - Wide variation of services available
  - Wide variation of geographic populations:
    - extreme rural
    - middle urban
- Competition among age groups for mental health funds.
- Insufficient money to provide services for increasing numbers of eligible children identified through improved referral and diagnosis mechanisms.
- Establishing continuation and support funds for serving this population (although Medicaid waivers do exist).
- Insufficient capacity at state level to train/consult with early intervention programs other than the four model sites, although site replication plans are underway.

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## **NEXT STEPS**

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As its agency administrators point out, North Carolina's new definitions of P.L. 99-457 eligibility, with their non-categorical perspective and awareness of mental health issues, are applicable statewide. New state resources to implement infant and toddler mental health services are, however, currently available only at the four CASSP demonstration project sites. The immediate challenge for the state is to:

1. Realize fully -- through staff development and continued practice in interagency collaboration -- the potential of this model to identify, assess, and intervene appropriately with emotionally troubled infants, toddlers, and their families. Competencies and a certification process for infant specialists have been developed. A specific goal is to review them in light of the needs of the atypical development population.
2. Develop new patterns of interagency collaboration on the needs of atypically developing children, particularly with social service and assessment agencies.
3. Communicate what is learned from the four demonstration projects to other PACT sites and to other state and private agencies serving this population.
4. Investigate additional models of service delivery beyond the current home-based system -- consultation to child care providers and to other community agencies is one possibility.

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## **RECOMMENDATIONS FOR OTHER STATES**

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North Carolina planners and administrators offer two guiding principles to states eager to improve their mental health services to very young children and their families.

**First, involve all potential actors from the start.** Key referral sources (such as health, day care, and social service agencies), as well as likely providers of direct services should be included in brainstorming and planning. Representatives of different levels within large service delivery systems should be involved; they may not be accustomed to working together. Those who will be collecting data and evaluating a system can also be extremely helpful as needs are assessed and services designed. The inclusion of many perspectives is likely to yield new, useful ways of framing issues and developing strategies.

**Second, establish formal mechanisms and allocate funding for public education and staff training.** The development of mental health skills among program staff involves both preparation of curriculum and materials and clinical teaching through supervision and group review of cases. Equally important are public education about emotional development in the early years of life and specific training approaches for parents of atypically developing children.

The following are other more specific recommendations stemming from North Carolina's experience over the last few years:

- *Build on an existing service system.* This allowed North Carolina to capitalize on a trained, experienced staff of special educators with wide local community acceptance. With the

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funding provided by P.L. 99-457, home-based services were made available in all one hundred counties in the state.

- *Develop funding mechanisms.* Limited resources forced North Carolina to start small. It funded four demonstration sites in each of the mental health regions to begin to provide services through the PACT programs to the atypical 0-2 population. There was enough money to fund only four positions, one in each of four sites, with joint federal P.L. 99-457 and state child mental health monies. It was the task of these four sites to convert what was formerly a home-based, parent-focused, cognitive training program to one that had the capacity to meet the mental health needs of the traditional MR/DD population as well as the newly designed high-risk and atypical populations.

Other funding strategies that are very important include:

- Seeking new funding through Medicaid and other third party reimbursement. Case management is an approved reimbursement option in North Carolina. Broader Medicaid plans have been submitted which would cover services included in early intervention for all categories of eligibility. Plans to expand EPSDT funding include: adding psychological screening to existing protocol; informing screening professionals of diagnostic and treatment options; and having mental health professionals participate.
- Providing training to PACT staff so that their services can be reimbursable through

Medicaid. In North Carolina, a clinical privileging system permits individual staff who provide clinical services to become what is called a "Group Mental Health Program" (GMHP). Through a carefully designed supervision system, MR/DD PACT staff will become Medicaid reimbursable as GMHPs.

- Seeking new funds through legislative increases to existing entities. North Carolina has a ten-year child mental health plan, ratified by the legislature, as the framework for increases. One of the priority populations for service development is children of birth through five years of age.
- Seeking new grant funds. Recently, two crisis nursery programs were funded which were housed within the demonstration sites. These are voluntary, parent-requested services with multiple sites in family day care homes and regular day care centers. They will be tied into the provision of home-based services later on when needed.
- *Develop a theoretical framework for services.* North Carolina has largely relied on the structural/developmental framework articulated by Stanley Greenspan. This has, as its basis, the premise that development proceeds in a multi-linear fashion and that developmental delays in one area influence other development systems.

Staff has been asked to consider six stages of development in the first four years of life, to evaluate the capability of the child's environment to support stage-

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specific development, and to propose intervention, primarily parent-focused, to facilitate specific developmental tasks.

- *Develop a training plan to ensure that all agencies involved in providing care know how to recognize an atypical child from birth through age two.* The training plan has been responsive to needs articulated by staff of the four demonstration projects. It is insufficient, on a local level, to confine information about infant emotional development and early identification to one agency. People in this field are keenly aware of the facilitative effect of multi-agency, multi-professional, joint public-private training. An effort is being made to share this knowledge with other providers including private and public health services, social services, private mental health providers, and education agencies.

- *Expand inter- and intra-agency coordination.* One of the most beneficial aspects of providing mental health services through P.L. 99-457 has been the intra-agency coordination it has stimulated. The single-system approach to providing mental health and other services to preschoolers provides challenges for serving other populations, such as the dually diagnosed.

At the state level, P.L. 99-457 has forced agency staff to examine the points at which their policies interfere with service delivery and cost-effective treatment. Joint funding requests are in the making.

## **RESOURCES AVAILABLE TO OTHER STATES**

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Existing and available to others:

- Early Childhood Intervention Orientation Manual
- Early Childhood Intervention Mainstreaming Manual
- Eligibility Criteria (definitions)
- Infant Specialists Credentialing and Procedures
- Family Support Network Information
- ICC-IAC Agreement
- P.L. 99-457 Governor's Report (All Our Children)
- Case Management Agreement

Soon to be available:

- Assessment Battery--After Year 2 (on a limited basis)
- Parent Materials--After Year 2 (on a limited basis)
- IFSP Manual
- Assessment/Eligibility Manual
- Case Management Manual
- Staff Development Curriculum
- Model Site Visitation--After Year 3

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## OHIO

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by  
Jan Martner and Gary Delago

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Others who contributed to the Ohio visit included: *Laurie Albright*, Program Coordinator/School Psychologist, and the *staff of the Positive Education Program*, Early Intervention Center-East, Lyndhurst, Ohio; *Nan Borkowski*, Assistant Superintendent/Principal and Director of the Early Intervention Project, and *Penny Monroe*, Infant Stimulation Instructor, as well as *other staff of Beacon School*, Athens, Ohio; *Dee Dee Dransfield*, Early Childhood Coordinator, and *Mary Ann Fink*, Early Childhood Service Coordinator, CHEERS, Southeast Ohio Special Education Regional Resources Center (SERRC), Athens, Ohio; *Lois Jarvi*, Developmental Disabilities Director, Tri-County Mental Health and Counseling Services, Athens, Ohio; *Paul Lilly*, Coordinator of Children's Services, Four County Mental Health Board, Defiance, Ohio; *Members of the Early Intervention Councils*; *Ricco Pallotta*, Executive Director, Positive Education Program (PEP), Cleveland, Ohio; *Kathy Peppe*, Assistant Chief, Division of Maternal and Child Health, Ohio Department of Health, Columbus, Ohio; and *David Shearer*, Project Director, Ohio Curriculum Project, Columbus, Ohio.

The state of Ohio, the largest of the three states in the study, is characterized by a large population, geographic and cultural diversity, and a complex service delivery system. In contrast to some

other states, Ohio's service delivery system is very strongly county-based. The Ohio Department of Mental Health (ODMH), for example, provides leadership and incentives to expand community-

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based services, and is represented on state and local planning groups to help assure that the mental health needs of infants, toddlers, and families are met. However, ultimately, administrative and service delivery responsibility for mental health services in all 88 counties in Ohio rests with 53 Community Mental Health Boards.

Ohio has chosen to build on existing service systems rather than develop a separate system for infant mental health. Interagency collaboration and coordination has been the vehicle for improving services for infants and toddlers. The description that follows illustrates how the entire system benefits when state and local agencies, and families of children who are in need of services and supports, work together to plan, implement, and evaluate services. Several successful collaborative efforts have been established in Ohio, some related to the passage of P.L. 99-457 and some as a direct result of state and federal initiatives in mental health.

### **MENTAL HEALTH SERVICES PRE-P.L. 99-457**

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In 1982, the Child Development Committee of the Ohio Developmental Disabilities Planning Council established an Early Intervention Task Force to examine the status of early intervention in the state and to recommend change. The task force had representatives from the four existing systems mentioned above, and ODMH, local agencies serving the birth-to-three population, parents, advocates, pediatricians, and university personnel.

Ohio's Philosophy Statement for Early Intervention originated with the Early Intervention Task Force in 1982. It

was later adopted by the Ohio Interagency Early Intervention Council, which was appointed by the Governor in response to P.L. 99-457. A key section reads:

Early child development is best enhanced by integrated programs which offer long-term contact between normally developing young children and young children with or at risk for developing delays. Since no one agency or individual can provide all services and support necessary to meet the needs of families and children who can benefit from early intervention, a collaborative inter-agency approach is essential.

Ohio's early intervention system has a primarily interagency focus and is based upon the following principles:

- *The right to optimum development* -- Every child has a right to care that facilitates his/her development.
- *The rights of families* -- The family is usually the most constant factor in the child's life and, as such, is the primary intervenor for the child.
- *The right to a facilitative environment* -- Every child has the right to a nurturing environment in which to use and elaborate all of his/her capacities.

According to the Ohio early intervention philosophy, *eleven essential* components form the framework for collaborative early intervention services. These are as follows: *philosophy, Child Find, interdisciplinary assessment and diagnosis, Follow-Along, family support, consumer involvement, comprehensive services, program evaluation, individual family service plan, service coordination,*

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*and a comprehensive system of personnel development.* In all of these components, services should be based upon currently accepted standards of best practice and must be carried out by qualified staff.

The resulting service model with these eleven essential components was defined for use in Ohio on a voluntary basis to be implemented by local collaborative groups throughout the state. These eleven components later became the basis of the Ohio Curriculum.

### **Networking Projects** \_\_\_\_\_

Also in 1982, Ohio participated in a federal outreach project on Interagency Collaboration in Early Intervention Services headed by Phyllis Magrab of Georgetown University. Three counties piloted the project, participated in the training, and then developed networking projects on their own.

Franklin County developed a central point of intake and referral for early childhood programs and gained the cooperation of thirty-two agencies to accomplish the task. Today this project includes all child mental health agencies in the county. Hamilton County coordinated funding resources across agencies.

Athens County coordinated ten counties in southeastern Ohio (Appalachian Region) to develop a cooperative system of case coordination for children birth to six. This system was called the Community Health and Early Education Resources Service (CHEERS). All major case-finding agencies and service providers in each county were represented in CHEERS. Their activities included a needs assessment on each family, provision of public awareness and parent advocacy materials, Child Find activities, a central point of intake and referral, and a computerized tracking

system. The process of CHEERS began when a referral was presented at a monthly meeting. Members developed an action plan based on the Service Model. A case manager, frequently from a mental health agency, was identified from the membership to work with the family. The family was presented with all the service options available and was asked to choose those that best met its needs. In addition to case management, mental health services included diagnosis, family therapy, and family support. CHEERS has continued in operation and is discussed further in "Mental Health Services Post-P.L. 99-457."

### **Child and Adolescent Service System Program (CASSP)** \_\_\_\_\_

In 1984, the Ohio Department of Mental Health received a five-year CASSP grant to augment state and local clusters of child-serving agencies; to coordinate interagency services; and to promote blended funding for multi-need, seriously emotionally disturbed children and adolescents requiring long-term intervention by multiple human service agencies. Other goals were to improve the capacity of the mental health system for children and adolescents, to encourage the involvement of families in the delivery of these services, and to make them culturally appropriate for the family. As a result of the CASSP grant, local clusters, involving representatives of the major child-serving agencies, attempted to meet the needs of these youth in their communities; the state became involved only if needed services were not available or could not be provided by local agencies.

The Ohio Interdepartmental State Cluster for Services to Youth includes representatives from the Departments of Mental Retardation and Developmental

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Disabilities (MR/DD), Youth Services, Health, Human Services, Education, Mental Health, and later the Rehabilitation Services Commission. At the state level there is a liaison from the State Cluster for Services to Youth to the Interagency Coordinating Council for Early Intervention. There may be two planning groups at the local level: one, the cluster overseeing planning services for multi-need youth from birth to eighteen years of age; the other, an early intervention planning group developing strategies for systems change specific to the birth-to-three population. The Community Mental Health Boards have representation on each group. In practice, the two planning groups often have overlapping functions and the membership may, in fact, be comprised of the same people.

The CASSP initiative has allowed ODMH to increase the number of staff within the Bureau of Children's Services. These staff members have co-sponsored conferences on mental health services for young children and their families, and have worked with the fifty-three Community Mental Health Boards, encouraging them to develop new services for infants, toddlers and their families in cooperation with other agencies.

#### Special Projects of Regional and National Significance (SPRANS) \_\_\_\_\_

**Project Zero to Three.** Additionally, Ohio was one of fifteen states invited to participate in Project Zero to Three, sponsored by the National Center for Clinical Infant Programs. The purpose was to inform participating states of the existing early intervention services and to develop a technical assistance/self-help system to facilitate the development of their programs.

The "Essential Components" Service Model. In 1985, the Departments of Health and MR/DD received a U.S.

Department of Health and Human Services SPRANS (Special Projects of Regional and National Significance) grant. This provided an opportunity to pilot the Service Model in Richland and Athens Counties, using the interagency collaborative approach. The project proposed to: develop a locally administered interagency program for comprehensive early identification and intervention services; improve the Child Find efforts for children from birth to age three in need of early intervention services; provide a comprehensive array of services; coordinate services across agencies; maximize benefits of early intervention through an extensive parent involvement component; assure continuity of care through Follow-Along; develop transition services as the child matures; and develop training materials to assist in replicating the project throughout the state.

A few accomplishments of this interagency SPRANS grant were:

- A network of mental health, medical, educational, and social service providers specially trained to identify children birth to three for early intervention services;
- A centralized/standardized intake and referral system which eliminated duplication of services across agencies;
- Funding and services of a social worker provided by the County Board of Mental Health to conduct special classes for parents of children enrolled in the early intervention program.

An additional benefit was the Ohio Curriculum, developed by consultants funded through the SPRANS grant. The goal of the Ohio Curriculum was to improve early intervention service delivery by developing a cooperative

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network of professionals (including mental health service providers) and consumers trained in the Service Model and its implementation through interagency collaboration. The Service Model was based on the previously mentioned eleven essential components. The curriculum project is now funded by the Ohio Developmental Disabilities Council to offer training in all eighty-eight counties. Nearly all of these counties have received training or technical assistance.

### State Incentive Grant Projects \_\_\_\_\_

Three incentive grant projects followed the SPRANS grant. One, sponsored by the Ohio Developmental Disabilities Planning Council (ODDPC), made grants available to a variety of lead agencies at the county level, many of them Mental Health Boards, to develop local collaborative Early Intervention Planning Groups. More than thirty-five were funded. The first of two incentive grants by the Ohio Department of Education was for grants to counties that elected to develop Interagency Collaborative Groups for local early intervention service planning. The second program provided grants to each of the sixteen Special Education Regional Resource Centers (SERRC) to add an early childhood "contact" person to assist families in receiving necessary services and making appropriate linkages with the community. The roles and function of this person vary from one SERRC to another.

Also during this time, the Ohio Developmental Disabilities Planning Council funded two projects. One was the development of a videotape by a group including mental health professionals to be shown to new mothers still in the hospital. The videotape emphasized normal physical and

emotional growth and developmental milestones, then described what to do if a problem was suspected. The videotape, entitled An Ounce of Prevention, is currently in use in approximately 120 hospitals in Ohio.

The second project was a parent education and support curriculum, entitled Family First, written by the Ohio Association of Retarded Citizens. The project is a parent-to-parent program offering information and support. It helps parents, especially of young children, become more effective representatives of their children. It brings parents together to share support, encouragement and dreams. Family First works a bit differently in every community because it is parent-owned and operated. A companion curriculum for professionals was developed to improve sensitivity toward the concerns of parents.

Ohio's acceptance of federal opportunities prior to P.L. 99-457 demonstrated a commitment to creating the necessary structure which would provide services to children and adolescents. This structure allowed services to be delivered to children from birth to age three in a comprehensive, coordinated, interagency fashion. The 1982-1983 federal outreach projects, USDHHS and NIMH grants assisted Ohio in developing and disseminating the Service Model. Networking projects within and between counties produced case coordination (CHEERS), a system uniting a central point of intake, multidisciplinary evaluation, Child Find, and IFSP, which could be replicated statewide. The Service Model, piloted through the SPRANS grant using the Ohio Curriculum, made comprehensive training in the early intervention components available to all counties. This training of a network of professionals and consumers helped improve the delivery of mental health services. The CASSP grant

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provided for a full spectrum of state and local cluster mental health services through child-serving agencies. This comprehensive structure served as a solid foundation on which mental health components specified in P.L. 99-457 could be built.

Since the passage of P.L. 99-457, the Department of Mental Health made the decision not to create another local service agency to further confuse families trying to access early intervention services, but to develop services in collaboration with the existing service providers. Currently, there are four existing systems providing services to infants and toddlers: the health, education, mental retardation and developmental disabilities, and child welfare systems. The philosophy of the Department of Mental Health is that the department needs to develop and deliver early intervention services within these existing systems. Mental health services available for this population prior to P.L. 99-457 included diagnosis and assessment, family therapy/family support activities, and case management. All new mental health programs being developed for young children and their families in Ohio must demonstrate a collaborative effort reflecting this philosophy.

#### **MENTAL HEALTH SERVICES POST-P.L. 99-457**

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To implement Part H of P.L. 99-457, Governor Richard F. Celeste, by Executive Order, appointed a fifteen-member Ohio Interagency Early Intervention Council with the Ohio Department of Health as lead agency. The former Early Intervention Task Force established in 1982 was absorbed by the

new council. Former task force members, including ODMH personnel, were invited to participate on committees focusing on legislation standards, target population, service coordination, the Individualized Family Service Plan (IFSP), transition services, and Child Find.

These are active committees, many of which have mental health representation, and they continue to work out the numerous and ever-changing details within each of these major areas.

#### **Definition of "Developmentally Delayed"**

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Ohio's definition of "developmentally delayed" was drafted by the Ohio Interagency Early Intervention Council. The Target Population Committee considered several different approaches to defining developmental delay. To help infants, toddlers and their families receive needed services, the committee wanted a definition which was inclusionary and non-labeling. The broad definition adopted by the Early Intervention Council reflected this philosophy and the intent of P.L. 99-457.

The council approved the following definition to be used to determine eligibility for early intervention services:

The child has not reached developmental milestones expected for his/her chronological age, as measured by qualified professionals using appropriate diagnostic instruments and/or procedures, in one or more of the following developmental domains: cognitive, physical, language and speech, psychosocial, self-help skills. (Ohio Interagency Early Intervention Council, March 8, 1988)

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"At-Risk Children." Ohio's definition of "at-risk" clearly demonstrates the desire to include a broad range of variables that may impact on children and their families. "At-risk" is described as:

... a situation or combination of factors/conditions which make the child more likely for a disability, a secondary disability or delay in development. No single factor necessarily leads to a developmental delay/disability in the child, but the presence of a factor means that it is important for those professionals and parents involved to consider the benefits of early intervention services for the family and child. When more than one factor is present, there is a multiplicative effect, causing that child and family to be at significantly greater risk for developmental delay/disability than would be the case with only one factor. (Ohio Inter-agency Early Intervention Council, November 10, 1987)

Risk factors have been organized according to three categories:

- **Established Risk:** High likelihood of early, aberrant development related to diagnosed genetic/medical disorders.
- **Biological Risk:** History of prenatal, perinatal or neonatal and early development events suggestive of biological insult(s) to the developing nervous system which may lead to delayed development.
- **Environmental Risk:** Limiting early environmental experiences which may lead to delayed development. Some specific parental factors are: parental substance abuse; parental

psychiatric disorder; inability to provide basic parenting functions due to impairments in psychological or interpersonal functioning.

Further, within the three categories, the assessment process takes into account the point in time when the risk factor may have been first apparent: the prenatal period, birth to hospital discharge, or infancy through age two.

It is assumed that anyone (health, social service, education, and mental health agency personnel, private providers, and consumers) involved with the child and family could use the risk information to identify those in need of early intervention services; to locate appropriate services; and to refer the child/family to them. It is important to note that mental health personnel are specifically mentioned as users of this identification system. The Community Mental Health Boards work with their contract agencies, encouraging them to make referrals of at-risk children.

#### Development of a Service Delivery System \_\_\_\_\_

According to Ohio's Service Model, a local collaborative early intervention system for infants and toddlers would include:

- A single interagency planning group addressing issues and strategies for improving the delivery of early intervention services. This group would interact with other planning groups and would include parents and advocates. The resulting system would be flexible and unique to the needs and experiences of each community. A variety of home-based and center-based services would be

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available in integrated settings (i.e., in settings where children without developmental delays or disabilities would ordinarily be found).

- A coordinated system of information, intake and referral so that families and service providers would be able to contact a single, central point for assistance. A family service database would be available for resource and financial information.
- A coordinated mechanism for evaluation (to determine eligibility for early intervention and related services). A qualified early intervention public health nurse would be available to make home visits and do Child Find activities, including initial evaluation.
- A system for service coordination (case management). A qualified early intervention service coordinator would be available at the central contact point to provide interim Follow-Along and assistance for families in accessing services until the infant and family were enrolled in a program.

CHEERS collaborative groups, described in the section "Networking Projects," are based on the ideal essential components. A family residing in the region of a well functioning CHEERS would be able to contact the CHEERS coordinator -- a neutral point -- and activate the available providers and support systems. The systems would be responsive and flexible.

The implications for mental health in this model are great. At the time of referral to local collaborative groups, many of the mental health needs of

families are typically being met by private providers such as physicians, psychologists, and social workers. The public sector is making an effort to bring these private providers into the system, especially to get them to notify the central point of intake (CHEERS) of a family in need and to briefly describe those needs. CHEERS would then coordinate all services with direction from the family. Mechanisms for promoting private providers' awareness of the purpose and scope of CHEERS include professional newsletters, community meetings, membership in CHEERS and direct mailing.

### Comprehensive Child Find System

In Ohio, Child Find has been defined as a "coordinated, ongoing mechanism to identify children and families who can benefit from early intervention services." Mental health service providers play an important role in the case-finding component of Child Find, as well as in the evaluation and assessment portions of this process. At this time, the Community Mental Health Boards are becoming more involved in community screening efforts and are providing training for staff so that they can appropriately refer children and families to early intervention services. Mental health professionals also may need additional training in the evaluation and assessment of infants and young children.

The Ohio Department of Health and the Ohio Department of MR/DD are collaborating on the development, implementation and evaluation of a linked, computerized referral and tracking system for children birth-to-six years of age who are developmentally disabled or at risk for developmental delays. The MATCH II project has

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developed a computer linkage between the existing, statewide client information system of the Ohio Department of MR/DD and the client information files of the Child and Family Health Services (CFHS) programs throughout the state. The confidentiality of client records is maintained in accordance with the Ohio Privacy Act. The merged database between the two programs has resulted in improved Child Find, case management, Follow-Along and program evaluation.

The Ohio Department of Mental Health is a member of the MATCH II Advisory Committee. ODMH shares concern for linking data between agencies at the state level to allow for more coordinated services to populations aided by multiple agencies. The department uses Match II to identify the number of at-risk children which helps in planning for new service development.

Many things need to be accomplished prior to the full implementation of this comprehensive information management system. It is expected to be fully operative within the next five to ten years.

#### **IFSP and Case Management Services** \_\_\_\_\_

In response to families' objections to the term "case management," Ohio uses the term "service coordination" to describe the process of assisting families and children throughout all phases of early intervention services. This process involves coordination among multiple service providers, including mental health providers; maximizes the use of existing resources; and is tailored to meet the unique circumstances of each individual child and family. Individuals who are functioning as service coordinators are responsible for providing service linkages, coordination of services, advocacy, and monitoring of services within the Individualized Family Service Plan.

#### **Personnel Development and Standards for Training** \_\_\_\_\_

Nursing Child Assessment Satellite Training (NCAST), described in North Carolina, is currently used throughout Ohio. NCAST has a strong social/emotional health focus and has been used with registered nurses working in the area of maternal-child health, social workers, child abuse team members, mental health professionals, day care personnel, pediatricians, and early childhood educators. Ohio currently has fourteen certified NCAST trainers, who have trained more than 500 professionals in the last five years. The majority of those have been trained with Part H funds since the passage of P.L. 99-457.

The Ohio Curriculum, as discussed previously, continues to be an ongoing effort to improve early intervention service delivery.

Two additional statewide training programs are receiving Part H funds. One, entitled Building Family Strengths, is to prepare parents (and professionals) to develop IFSPs. The other project is to provide training, again to parents and professionals together, in the area of service coordination. Both of these programs place a strong emphasis on the social and emotional well-being of children and their families.

Office of Education and Training, ODMH, is giving support to the University of Akron Faculty for Early Childhood Education to develop an interdisciplinary certification for individuals working in intensive home-based service programs. Social workers, psychologists, nurses, and educators have participated in this training, which reflects Ohio's philosophy of interagency collaboration. Individuals receiving interdisciplinary training through this project are working in programs for young children and their families throughout the state.

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**SERVICE DELIVERY SYSTEM:  
STRENGTHS AND CHALLENGES \_\_\_\_\_**

disturbed, and at-risk young children).

**Strengths:**

- Focus of the service delivery system is on improving interagency collaboration and coordination.
- Local level planning is supported at the state level through the mandated "Interagency Cluster for Multi-Needs Youth" and through voluntary interagency early intervention planning groups.
- Local-level planning is promoted through the availability of training, technical assistance, and grants from several state agencies including the Ohio Departments of Mental Health (CASSP Program), Human Services (Interagency Cluster for Multi-Needs Youth), and Health (P.L. 99-457, Part H, Early Intervention Program).
- Mental health services are included as part of the comprehensive service delivery system in proposed early intervention legislation.

**Challenges:**

- The uneven amount of funding across counties due to heavy reliance on local levies.
- Shortages of properly trained personnel.
- Competing priorities within the Department of Mental Health to serve multiple populations (including the chronically mentally ill, children and adolescents who are severely emotionally

- Lack of awareness of indicators of early mental health disturbance on the part of professionals, paraprofessionals, and parents.

Since the early 1980s and the passage of P.L. 99-457, Ohio has sharpened its focus so that the capability for coordinating services, including mental health services, for young children and their families became available in every county. This sharpened focus was due to: 1) initiatives and state level support; 2) enhanced financial support; 3) mental health representation on ninety-one percent of the Local Interagency Collaborative groups; and 4) increasing willingness of agencies to look at the issues and engage in comprehensive planning at the local level through CASSP Clusters and local collaborative groups.

The substantial activity focused on early intervention, both before and after the passage of P.L. 99-457, reflects Ohio's commitment to interagency coordination and collaboration, and to the development of new mental health services within existing agencies serving children from birth to age three. However, of the Departments of Health, MR/DD, and Mental Health, the Department of Mental Health has the lowest funding for this age group. Funding is available for families, but is not based on the child's age.

The Community Mental Health Boards are funded with state, federal and local levy money. Because the levy is based on property taxes, the resources of mental health boards vary greatly. This inequity creates differing levels of available services; lack of a comprehensive system of services is most evident in rural areas of Ohio.

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## NEXT STEPS

Key informants of this study indicated that the next steps for Ohio appear to be:

1. A legislative mandate for coordinating early intervention services and the development of administrative rules. Specifically, the Ohio Department of Health, as Part H lead agency, requires statutes and rules assuring due process/procedural safeguards. This is one of the important, required components in Part H of P.L. 99-457. The Department of Mental Health is supporting legislation being submitted by this lead agency.
2. Personnel development and standards of training. Continuing education of human service professionals working in early intervention programs is necessary to further develop their sensitivities to the overall needs of the birth-to-three population and their families. Training is a priority in order to assure that professionals have the skills to meet certification criteria already established by the Department of Education and the Department of MR/DD.  
As the need for certified staff continues to increase, support for NCAST training will be continued. The training on the Ohio Curriculum will be ongoing. The development of cooperative networks through continued staff training on the Ohio Curriculum will further develop and refine coordinated service delivery.
3. Increased parent participation in local collaborative groups. It is the position of the state of Ohio that both providers and consumers

can learn to collaborate for the benefit of children and that families will be included in planning, advising, and advocacy roles in even greater numbers.

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## RECOMMENDATIONS FOR OTHER STATES

Many of the individuals interviewed in Ohio offered suggestions to other states.

- "Blow away the stigma" about what mental health is in relation to very young children and educate professionals, including those in mental health fields, as well as the general public, especially parents of young children.
- Involve the right people and agencies in the process and discussions from the beginning. Even if there are no mental health services currently available to this population, the local mental health agency needs to be a part of the planning group(s).
- Seek knowledgeable persons at state and local levels who know the "intent" of P.L. 99-457.
- Find individuals at state and local levels who have excellent skills in group process and committee work.
- Find out what services and resources are in place and what the existing gaps are in an ideal continuum of care.
- Find out what the role of mental health currently is in the available services.
- Ask providers and parents, "If you could add to your system, what would you add in order of

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priority?" Don't presume a knowledge of what infants, toddlers and their parents need.

- Ask the question of all providers, "How might you provide services non-categorically?" This requires an excellent job of coordinating and there may be a need for technical assistance with a collaborative process.
- Approach the needs of this population holistically. Avoid being department-, discipline-, or facility-focused.

#### **RESOURCES AVAILABLE TO OTHER STATES**

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- An Ounce of Prevention: Early Intervention and Your Baby -- Videotape, approximately 22 minutes in length; color. Covers general child development issues from birth to age four years and give clear instructions to parents on what to do if they have a concern about their child's development. Accompanying brochure lists developmental milestones and expected age ranges.
- Linking Mental Health (MH) and Mental Retardation/ Developmental Disability (MR/DD) Systems -- This project report describes how one project, funded through P.L. 99-457, Part H, successfully created a link between local MH and MR/DD service systems in a rural county in Ohio.
- Positive Education Program (PEP) -- This report provides an overview of a collaborative program between a Community Mental Health Board in a large,

urban area, and the County Board of Education serving families and children, birth through age six, who exhibit a wide variety of mental health needs.

- Creating the System . . . Essential Components of a Comprehensive Early Intervention System -- Videotape, approximately 28 minutes in length; color. Describes collaboration and partnership between public and private agencies and parents of young children to develop a comprehensive service system. Accompanying trainer's guide and participant's guide.
- The Ohio Curriculum--Essential Components of a Comprehensive Model Collaborative Early Intervention System -- This training resource contains a description of each of the essential components of a comprehensive early intervention system.
- A Guide to Action Planning -- This workbook includes sample agreements, forms, evaluation tools, and planning formats for local interagency groups.

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## SUMMARY OF STATE PROFILES

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As the teams interviewed informants in Maine, North Carolina and Ohio, they found that the pre-existing dynamics among state, county and local entities profoundly influenced the mental health services in all three states. Invariably, issues related to mental health services for infants, toddlers, and their families had roots in the individual state's history. Modifications to their mental health services after the passage of P.L. 99-457 reflected the requirements imposed by the law: the designation of a lead agency, the establishment of an interagency coordinating council, the development of a definition for "developmentally delayed," and the design and implementation of statewide services to the birth-to-three population. Furthermore, modifications arose from the ingenuity of policy makers, dedicated professionals and concerned consumers in addressing the constraints imposed by limited resources.

### MAINE

Maine has an extensive tradition of interagency collaboration as a mechanism for coping with limited fiscal resources; limited professional resources; and a very rural, widely dispersed population. As a result, Maine has a strong, state-driven system of service delivery for young children. Service initiatives originate at the state level and are carried out by the state-supported, local service provision sites known as Preschool Coordination Sites. Therefore, there is structural consistency of mission, goals, intervention models, and strategies across the state.

This statewide consistency helps families in their attempt to negotiate the service delivery system and assists service providers in their efforts to link families and available services. While this does not mean that all services are available in all parts of the state, it *does* mean that the structure is consistent throughout the state and that there exists a single point of contact and planning for all families. More importantly, a mental health perspective is integrated into the available services.

Maine has placed great emphasis on identifying children in need of service through its network of public health nurses and its home-visiting system for all newborns. The development of training curricula including both print materials and videotapes has helped to increase the awareness and skill level of all professionals and paraprofessionals who might be able to identify and refer infants and families in need of mental health services.

### NORTH CAROLINA

North Carolina has a long history of using federal and state resources to develop innovative programs for young children and their families. P.L. 99-457 has been the occasion for various state departments to go further in the process of collaborative planning.

One of the major features of North Carolina's response to P.L. 99-457 has been a definition of "high-risk children" which includes the concept of atypical development. This concept refers to children from birth to sixty months of

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age who demonstrate significantly atypical behavioral, socioemotional, motor, or sensory development and includes detailed assessment criteria. While the definition applies statewide, North Carolina will actually be assessing the importance of adopting such an inclusive definition in its four demonstration sites which have received additional funding for PACT coordinators. While North Carolina is similar to Maine in the rural nature of much of the state, it does differ rather significantly in available resources, particularly trained professional and support personnel, as well as in the existence of a number of outstanding university-based hospitals and health care centers providing ongoing tertiary and follow-up care. North Carolina has also moved quickly to develop standards for certification for early intervention workers with specified state training requirements.

## OHIO

Ohio's system of local control of human services is of long standing. The state has also chosen to build on CHEERS, a pre-existing system for identification, evaluation, and referral, as a mechanism for service coordination for young children and their families. Ohio's system differs from those of North Carolina and Maine as its effectiveness is dependent, to a high degree, upon the support of local county commissioners. In

addition, both Maine and North Carolina had legislation providing for mental health services to young children before the passage of P.L. 99-457. However, Ohio has had a strong, recent history of interagency collaboration to serve multi-problem children. Ohio was able to build on this cooperative, multidisciplinary approach (originating in the state and local cluster system) by extending the concept to early intervention and specifically to the birth-to-three population. One of the major contributions of Ohio is the development of its model of placing early intervention/mental health providers in other appropriate agencies (such as mental retardation/developmental disability agencies, day care centers) so that mental health services quickly become integrated into the overall service delivery plan. In other parts of the country this concept is sometimes referred to as "outplacing" and has been found to be most effective in promoting integration and reducing barriers to service.

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Once the patterns of these three states have been reviewed carefully, it becomes possible for other states to determine which of these patterns, or blend of patterns, would assist them in building a responsive service delivery system. A system can then be tailored to a state's needs and its pre-existing structure, one which is rooted in its own history.

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## **LEARNING FROM EXPERIENCE: A THREE-STATE PERSPECTIVE**

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Participants in this study from Maine, North Carolina and Ohio have offered guidance to other states working to meet the challenging mental health needs of infants, toddlers, and their families. Many of the recommendations are common to all three states.

*First* -- Involve as many individuals and agencies with a stake in the mental health of infants, toddlers, and their families as possible from the beginning. Regardless of its present or past role in service provision to very young children, mental health must be a part of the planning process for service delivery to very young children and their families. If a state department of mental health is unable to identify a representative with infant mental health expertise, consider including a provider with this specialty on the Interagency Coordinating Council or its committees.

*Second* -- Accept the possibility that representatives from state and local agencies, private practitioners, and consumers may not be accustomed to working together in a collaborative manner. Collaboration requires that a great deal of effort be made to maintain as much consistency of membership on committees and planning groups as possible. Trust and a common vision are critical elements of successful planning efforts. There may be a need for professional technical assistance in the area of group process and maintenance of effort.

*Third* -- Begin with pilot sites for innovative ideas. This strategy allows for a process of evaluation and modification which will facilitate a higher overall success rate. All three states studied have experience with pilot projects that have, building on their success on a small scale, evolved into statewide structures, policies, programs, and have often led to the enactment of supportive legislation and fiscal resources.

*Fourth* -- From the very beginning work closely with the Department of Education, the designated lead agency under P.L. 99-457 for the preschool (age three through five) population, to plan for appropriate transitions when children reach age three. In the three states studied, the Department of Education was not selected as the lead agency for their infant and toddler programs. All these states expressed serious concerns over transition issues as these children reach age three and emphasized the need to begin planning now for coordination of services.

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In considering the experiences and recommendations offered here, readers need to remember that most states have been unable to keep up with an increasing demand for mental health services among all age groups in the population. The provision of mental health services to infants, toddlers and their families has typically been ranked low in priority by state health and human services agencies. However, the emotional vulnerability of drug-exposed infants, of medically fragile or technologically dependent children, and of children subject to a variety of environmental risks is commanding increased attention among policymakers.

States -- including those in this study -- are just beginning to explore the possibilities offered by P.L. 99-457 to provide mental health preventive, assessment, and treatment services to very young children and their families as part of comprehensive, integrated, statewide systems of care. It is hoped that this three-state study will allow planners to benefit from the experience of others as they work to incorporate a mental health perspective into the goal setting, planning, and implementation processes in their own states.

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**APPENDIX A**

**MENTAL HEALTH SERVICES FOR INFANTS,  
TODDLERS, AND THEIR FAMILIES:  
A Three-State Perspective**

**SURVEY INSTRUMENT**

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## **SURVEY INSTRUMENT**

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The survey instrument utilized in this study is included here to provide guidance for other states in their own assessment process. The instrument was designed for the use of the site team members during their key informant interviews. Informants were not asked the questions directly from the survey tool, rather team members utilized it to ensure they had asked all the pertinent questions and to organize the responses.

Data collected from each of the team members was collated, analyzed and subsequently massaged into the form of the three state profiles in the text. The profiles were reviewed for accuracy several times in the writing and analysis phases of the study by the contact person (see the end of each profile) and other key informants in each state.

## STATE BACKGROUND INFORMATION

STATE: \_\_\_\_\_

AGENCY: \_\_\_\_\_

CONTACT PERSON: \_\_\_\_\_

PHONE: ( ) \_\_\_\_\_

Please **assemble** original documents and/or copies of the items listed below. It would be very helpful if you could write brief summary statements for each indicating specifics that relate to the delivery of mental health services to infants and toddlers and their families.

Please **check off** information you have been able to provide.

Check:

**1. Description of state:**

- Geographic characteristics
- Demographics:
  - population of state
  - minority populations
  - population breakdown by age
- Economic base
- Urban - Rural

**2. Legislation relative to the provision of mental health services to infants, toddlers, and their families.**

**3. State Plans:**

- Copies of state plans that include mental health services. For example: State Education Plan, State Department of Social Service Plan, and State Plan for 99-457.

**4. List of state agencies that provide mental health services to children from birth through age three and their families.**

**5. State resources that provide training in the area of infant mental health. For example:**

- Universities
- Outreach demonstration grants
- Research and training institutes
- Private practitioners who train students
- Agencies that have a student intern component
- Etc.

## STATE BACKGROUND INFORMATION (Cont.)

### Check:

6. **Funding options available in the state/local area used to provide mental health services to infants, toddlers, and their families.**
  - Medicaid, i.e. waivers, case management, Early and Periodic Screening, Diagnosis and Treatment (EPSDT)
  - Third party insurance
  - Sliding scale options
  - Federal money (which programs)
  - State agency money
  - Local funding
  - Fee for services
  - Philanthropic organizations that focus on mental health issues and/or business involvement
  - Other
  
7. **What interagency working/coordinating groups exist on the state level related to birth through age two mental health service delivery?**
  - What groups/agencies are represented on each?
  - What is the structure of each?
  - What is the role of each in the service delivery process?
  - How do the groups interrelate?
  
8. **Other:**
  - Any additional information and/or documents you feel would be relevant to this study?

## STATE QUESTIONNAIRE

STATE: \_\_\_\_\_

AGENCY: \_\_\_\_\_

CONTACT PERSON: \_\_\_\_\_

PHONE: ( ) \_\_\_\_\_

**1. What are you working towards in the provision of specific mental health services for children birth through age two on a statewide basis?**

- What services are included in the continuum?
- What services do you currently have in place? How are they accessed?
- What is prohibiting you from implementing the remaining services?
- What local communities in your state do you find are providing a full range of services? What accounts for the difference between communities?
- Given that your state is moving in a specific direction, do you have a proposed ideal continuum of services?

**2. What systems do you have in place to facilitate the provision of mental health services to children birth through age two and their families?**

- What is your Child Find approach?
- How do you identify needs of child and family?
- What is the IFSP process?
- How do you assure care/case management?
- How do you pay for services? What services are included for each payment source?
- How do you evaluate service quality?
- Is there a statewide data collection system?
- How do you convey this system/process to local communities?
  - training?
  - technical assistance?
- Is there a method for monitoring the implementation of the state system at the local level?

**3. Since the passage of P.L. 99-457, what process has the state developed to help it move towards providing and integrating mental health services into programs that already support disabled infants, toddlers, and their families?**

- Are there any changes since P.L. 99-457? If yes, what are they?
- What factors have facilitated this process?
- What barriers have there been in this process?

## STATE QUESTIONNAIRE (Cont.)

- 4. Do you participate in any working/coordinating groups on the state level related to birth through age two mental health service delivery?**
  - What is your role?
  - What is the focus of the group in the area of infant mental health?
  
- 5. How are children with mental health needs being treated the same/differently as children with other special needs within the scope of P.L. 99-457 and the service delivery system?**
  - Is mental health an equal partner in the ICC?
  - What role is mental health playing -- is it equal or auxiliary?
  - How are other systems supporting what mental health is doing?
  
- 6. How are families involved in mental health service delivery for infants and toddlers?**
  - How are families involved in determining the IFSP goals and objectives?
  - How are families involved with the selection of services they/their children receive?
  - How are families involved in the assessment and diagnostic processes?
  - How are families involved in the evaluation of the services they receive?
  
- 7. What specific advocacy services are available to children and their families?**
  - What agencies/organizations/individuals provide these services?
  - What role does your agency/group play in providing support services to families?
  - What specific legislation/policy/mandates exist that include advocacy?

## STATE QUESTIONNAIRE (Cont.)

**8. What are the next steps that the state is planning?**

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**9. If you were going to offer three (3) recommendations to another state setting up mental health services for infants and toddlers and their families, what would they be?**

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**10. In Summary:**

- What is your impression of how your state arrived at its current level of operation in the area of infant and toddler mental health?
- How do you see infant mental health fitting into other existing state systems?
- What systems/structures exist in your state that can be building blocks for the further development of infant mental health services?

## LOCAL QUESTIONNAIRE

CITY/STATE: \_\_\_\_\_  
CONTACT PERSON: \_\_\_\_\_

AGENCY: \_\_\_\_\_  
PHONE: (    ) \_\_\_\_\_

- 1. Is the system established by the state providing you the necessary structure to implement mental health services to children?**
- 2. How is the state communicating its plans and scope of support to you?**
- 3. What kind of support do you receive from the state?**
  - Training?
  - Technical assistance?
  - Accessibility to state officials?
  - Financial support?
- 4. How effective is this support?**
- 5. What interagency working/coordinating groups exist on the local level for infants and toddlers and their families?**
  - What is your role?
  - What groups/agencies are represented on each?
  - What is the structure of each?
  - What is the role of each in the service delivery process?
- 6. How are children with mental health needs being treated the same/differently as children with other special needs?**
  - Is mental health an equal partner in the local service delivery network?
  - What role is mental health playing -- is it equal or auxiliary?
  - How are other systems supporting what mental health is doing?
- 7. How are families involved in mental health service delivery to infants and toddlers?**
  - How are families involved in determining the IFSP goals and objectives?
  - How are families involved with the selection of services they/their children receive?

## LOCAL QUESTIONNAIRE (Cont.)

- How are families involved in the assessment and diagnostic processes?
  - How are families involved in the evaluation of the services they receive?
- 8. What specific advocacy services are available to children and their families?**
- What agencies/organizations/individuals provide these services?
  - What role does your agency/group play in providing advocacy services to families?
  - What specific legislation/policy/mandates exist that include advocacy?
- 9. How is your community moving toward an ideal continuum of care?**
- What is the ideal?
  - What elements are in place?
  - What barriers exist that prevent the completion of the ideal?
- 10. What mental health services for children birth through age two and their families currently exist in your community?**
- What specific services are available?
  - What local agencies provide mental health services to children?
  - What critical elements make these services effective?
- 11. What are the next steps being planned in your community in the provision of mental health services to children birth through age two and their families?**
- 12. What three recommendations would you suggest to other states establishing mental health services for infants and toddlers and their families?**
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  -

# INDIVIDUAL PROGRAM QUESTIONNAIRE

STATE: \_\_\_\_\_  
CONTACT PERSON: \_\_\_\_\_

AGENCY: \_\_\_\_\_  
PHONE: (    ) \_\_\_\_\_

## BACKGROUND INFORMATION

### 1. Description of community:

- Geographic characteristics
- Demographics:
  - population of state
  - minority populations
  - population breakdown by age
- Economic base
- Urban - Rural

### 2. Description of the organization in the community of the mental health service system for infants and toddlers and their families.

- Roles of: health agencies (public health, hospitals, and physicians); mental health agencies; child welfare/social service agencies; private/not-for-profit agencies; private practitioners.
- Community-wide mechanisms for interagency collaboration.

### 3. Which of the following describes your agency?

- Public
- Private not-for-profit
- Private for-profit
- Other

# INDIVIDUAL PROGRAM QUESTIONNAIRE (Cont.)

## PROGRAM PROFILE

### 1. Client population:

- Target population
- Types of clients served (socio-economic status, race, sex, age, nature of diagnosis)
- Needs assessment data
- Referral sources
- Criteria for acceptance

### 2. Descriptions of specific programs/services provided:

- Capacity
- Description of clients served
- Treatment philosophy
- Services provided
- Duration/intensity of treatment
- Funding

### 3. Description of intra- and interagency mechanisms for coordination:

- Systems-level:
  - key structures/mechanisms used
  - purpose of each
  - effectiveness
  - problem areas
  - strengths
  - gaps
- Client-level:
  - key structures/mechanisms used
  - purpose of each
  - effectiveness
  - problem areas
  - strengths
  - gaps

### 4. Case examples.

## **INDIVIDUAL PROGRAM QUESTIONNAIRE (Cont.)**

### **5. Case management:**

- How is it provided?
- Which agencies are involved?
- Who is responsible?
- What does the role of case manager encompass?
- Training and background of case managers.
- Funding for case management.

### **6. Family involvement:**

- How are families involved in determining the IFSP goals and objectives?
- How are families involved with the selection of services they/their children receive?
- How are families involved in the assessment and diagnostic processes?
- How are families involved in the evaluation of the services they receive?

### **7. Evaluation:**

- Effectiveness of linkages/services.
- Outcomes (expected and achieved).
- Problem areas (barriers to effective linkages).
- Agencies not participating.
- What works, and why?
- Recommendations for designing/implementing a working system.
- What system of accountability exists?
- How is it monitored?

### **8. Advocacy:**

- What specific services does your agency provide to families/children in the area of advocacy?
- What involvement does your agency have in local advocacy efforts, i.e., legislation, policy making, public awareness?

### **9. What are the critical elements, as you see them, in providing mental health services to infants and toddlers and their families?**

### **10. Summary comments.**

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**APPENDIX B**

**CASE VIGNETTES:  
MAINE, NORTH CAROLINA AND OHIO**

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## **CASE VIGNETTES**

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**The following vignettes illustrate the experiences of three families with young children who are in need of supportive mental health services. They provide examples of the diversity of service models available and the necessity for collaboration between agencies. They clearly indicate how effective mental health early intervention services can be in ameliorating complex family problems.**

**These vignettes are based upon real experiences shared by the states participating in this study.**

**CASE VIGNETTE:**  
**MAINE**

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The following is an anecdotal summary of a case presented to a Community Health Nurse working in a pediatric office; the nurse interviews and counsels parents before they see the doctor. All names have been changed to maintain confidentiality.

**Presenting Problem.** During Baby Mary's six-week check-up, Mother Patsy, age eighteen, was hovering over Mary to the point that Patsy could not have any eye contact with me. Patsy's affect was flat and hostile, and her main complaint was that Mary was "too fat." Visually, Mary was not a "fat" baby. In fact, Doctor Gardner had already made a referral to Home Health Services after Mary's two-week check-up, requesting a nursing visit because she was not gaining weight.

When I asked Patsy about her statement that the baby was "too fat," she replied that she (Patsy) had gained over 110 pounds during her pregnancy and that she didn't want her baby to be like her. She also told me that she kept Mary in bed with her at night because the baby liked to be up at night. Later Patsy told me that the nights were long and lonely for her, especially since Mary's father had deserted her during pregnancy.

When Dr. Gardner came in, Patsy became much more hostile and curt, telling him that she had refused to have the Home Health Nurse visit. She had decided not to feed the baby as much as the doctor wanted, since Mary was too fat. She also stated that too many people were bothering her; that she was tired of all the interfering. Sometimes she felt like "ending it all." (Although she denied suicidal ideation on direct questioning, this was a concern of ours; because she was projecting her distorted body image onto Mary, we were worried about the possibility of Patsy hurting her

baby if her own emotional state worsened.)

Patsy became more and more guarded as the appointment ended, and left the office threatening not to return.

**Interagency Coordination.** After consultation with Dr. Gardner, I made a referral to the intake worker at the Child Protective Services, Department of Human Services. I also contacted the staff at the residential facility where Patsy has been living since Mary's birth to outline concerns about Patsy. The staff and the Community Health Nurse had noted Patsy's distancing and withdrawing behaviors. Patsy tended to isolate herself and her baby from both the staff and the other residents. To address all of these concerns, I suggested a network meeting since a discussion of the problems at a systems level seemed an appropriate direct intervention. All the service providers and Patsy were able to meet the next day.

**Intervention.** We met at the facility and outlined our concerns to Patsy, who attended clutching her baby -- she was worried that the baby would be removed from her care after the meeting. We discussed our goal of meeting her needs in ways that would be more helpful for both herself and Mary. We were very clear that we wanted to help her be a good parent, yet we also needed to be honest about our concerns for Mary's safety, especially her nutrition. Patsy agreed to work with all of us. She subsequently scheduled and kept appointments with a psychiatrist to assess and monitor her depression. She continued to meet with the Community Health Nurse who reported that Patsy was able to make and maintain eye contact with her during the biweekly visits. The facility's staff reported that, shortly after the network meeting, Patsy began to interact more frequently with the other residents. She also participated more actively in the facility's group

activities. Mary maintained a healthy weight gain; Patsy did not threaten to stop feeding her again.

I stayed in phone contact with Patsy for several weeks. During these conversations, Patsy told me more about her own history which included parental abandonment, long-term foster care, and recovery from chemical dependency. She also talked with the facility staff about her longing to find Mary's father, perhaps a projection of her unresolved issues with her own parents. Although night-time continued to be difficult for her, Patsy was able to let Mary sleep alone in her crib.

During Mary's routine well-baby check-ups, Patsy interacted much more effectively with the doctor and myself, usually coming prepared with a list of questions. She had very few acute-care visits, which, in my opinion, was an indication that Patsy was meeting her own needs and no longer needed her daughter to be the "ticket of admission" into the health care system. Mary was achieving age-appropriate landmarks.

After Patsy moved from the facility when Mary was about six months old, she continued to have the Community Health Nurse visit weekly for ongoing support and information. When Patsy moved to a community about 100 miles away, she requested a referral to the community health nursing service in that area. This move occurred when Mary was just under a year old.

#### **CASE VIGNETTE: NORTH CAROLINA**

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This vignette illustrates the integration of a mental health perspective into North Carolina's tracking system, referral processes, intervention approaches, and case management procedures with very young children and their families. This is an actual case. The names have been changed to maintain confidentiality.

**History.** Peter was the first-born child of parents who had been known to the Department of Social Services from childhood. Both parents had been raised in physically abusive families with a history of alcoholism and had physical, cognitive, and emotional disabilities. Peter's father was an alcoholic and physically abusive to his mother; his mother suffered from a degenerative disease and was mildly limited in her physical functioning.

Peter was the result of a planned conception and normal pregnancy, according to his mother. He was born with a cleft lip and palate and had a fifty percent chance of developing his mother's degenerative disease.

In early infancy, Peter's development was followed by several clinics at the hospital where he was born. The Local Home Health Agency and a registered nurse from the Health Department provided in-home nursing support. The family was enrolled in the WIC program and received AFDC and SSI benefits.

At three months of age, the High Priority Infant Clinic found Peter developing well, as measured by the Bayley Scales of Infant Development, and observed that the baby initiated interactions and responded to both mother and father. His cues were clear, and his mother stated that she could tell what he wanted by his cries and facial expressions.

At twelve months of age, Peter received a comprehensive evaluation at the hospital clinic as part of its High Priority Infant Protocol. Although Peter's test scores were within normal limits, examiners did not see the spontaneity expected from toddlers his age. The examiners and others involved in ongoing contact with the family were concerned by an observed lack of affectionate responsiveness in Peter's mother; Peter's diminishing persistence in interactions with people; a lack of appropriate caution or distress in response to pain; and a possible tendency toward self-injurious behavior.

**Presenting Problem.** When Peter was fourteen months old, his parents' caseworker from the Department of Social Services (DSS) and a registered nurse from the High Priority Infant Program at the county health department referred the family to the PACT program because of high-risk factors for developmental delay and atypical development.

**Intervention and Interagency Coordination.** The PACT therapist with DSS and Health Department staff made referral and screening visits. The family willingly participated in the screening, which included administration of the Denver Developmental Screening Test, the HOME instrument, and NCAST measures. After the family reviewed worrisome findings in language and personal/social development with the caseworker and the nurse, they considered the services available through PACT, and decided to request them.

After further assessments, also reviewed by the family, an Individual Family Service Plan (IFSP) was developed with the family and all those individuals working with the family. In the PACT system, the IFSP is a working document that is reviewed at least quarterly, amended as needed/requested by the family, and updated annually.

PACT, the Health Department, DSS, Vocational Rehabilitation, the Department of Mental Health/Substance Abuse Services, and a sheltered workshop were all involved in working with Peter and his family. Interagency case management meetings were held monthly to facilitate and coordinate services.

Because both parents worked and the paternal grandmother and aunt who had been caring for Peter had histories of neglect and abuse, family day care seemed to the interagency team an optimal way to provide the special nurturing environment Peter needed. However, Peter's family perceived day care in a family setting as a potential precursor to involuntary foster

placement. They were more comfortable with the idea of center-based child care; after visiting and asking questions of staff at a mainstreamed child care center, they agreed to Peter's enrollment.

The PACT therapist visits Peter's day care center weekly or biweekly to review IFSP goals and activities with his teacher. Home visits are set to meet the family's schedule. They include Peter, his parents, and the extended family and make use of books, toys and other materials.

To facilitate a smooth transition to other programs as Peter's needs change, consultation and support will be offered to the family as well as service providers by the PACT team. In addition, the PACT therapist will contact the family at least twice during the first year after the date of discharge.

#### **CASE VIGNETTE:** **OHIO**

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This vignette illustrates the positive impact on a family of early intervention services with an integrated mental health perspective. The referring source of this family to an early intervention program was a physician, a direct reflection of Ohio's efforts to bring private providers into their referral, public awareness and case management systems. This is an actual case, the names have been changed to maintain confidentiality.

**Presenting Problem.** David is the newly adopted two-year-old son of Mr. and Mrs. Thomas. The Thomases also have a six-year-old, natural born daughter, Jessie. Mrs. Thomas was referred to the program by her pediatrician because they were both concerned about the difficulties she was experiencing in developing a positive parent-child relationship with her son.

David's presenting problems included: severe temper tantrums, screaming, short attention span and high activity level. Mrs. Thomas expressed serious concerns about continuing the adoption process because of David's out-of-control behavior.

David was assessed by the multidisciplinary team that included a speech and language pathologist, psychologist, pediatrician and motor specialist. David was diagnosed as having expressive and receptive language delays as well as deficits in adaptive and social skill functioning. The array of services that could be offered Mr. and Mrs. Thomas and David were described as behavior management, modeling of intervention techniques, parent support groups, parent-training seminars, home visits, observation and mediation of parent-child interactions, and speech and language therapy.

**Intervention.** Mrs. Thomas, occasionally accompanied by her husband, was involved in the program for six months. While Mr. Thomas was not extensively involved with the program, he was interested and supportive. He attended initial meetings and multidisciplinary assessments and always followed through when asked to assist in various intervention strategies.

Mrs. Thomas came to the center three mornings per week for three hours. On each occasion, one hour was spent in a therapeutic setting with David, a psychologist, and the parent of another child in the program. The purpose of these sessions was to help Mrs. Thomas respond to David in a more thoughtful and structured way within a variety of family and social situations. The sessions were also designed to blend with David's intervention plan helping him to improve his language and social skills.

Mrs. Thomas spent the remaining two hours helping program staff work with other children at the center. This time provided her with an opportunity to observe others' interaction with children

and a chance to practice the skills that she was learning in the private sessions with David. In addition, she could participate in a one-hour parenting seminar which allowed for discussion of concerns among parents. Seminar topics included stress management, positive reinforcement, self-esteem development in children, and developmentally appropriate play activities.

After a short time in the program, Mrs. Thomas indicated that she was also experiencing similar problems with her six-year-old daughter. At her request, the multidisciplinary team observed Mrs. Thomas and Jessie together. In addition, Jessie was evaluated in physical, motor, social and emotional, and language development areas. Jessie was found to be within the normal range in all domains. The observations of Jessie and Mrs. Thomas led the examiners to offer Mrs. Thomas assistance in her parenting approach to Jessie, which she readily accepted. Many of these approaches were similar to those that she was practicing with David and other children in the program.

Over the span of her six-month involvement in the program, Mrs. Thomas appeared to be gain in self-assurance as she developed various positive methods of interacting with David and Jessie. As she began to read their cues more accurately and gain a clearer understanding of each of their personalities and temperaments, she grew more confident in her skills as a parent. Her relationship with each child gradually improved. The support that she received from other parents in the program helped her to feel she had a network to sustain her if and when she needed it.

David is currently being integrated into a regular preschool program. The Early Intervention Center provides regular consultation to the preschool program and consultation is available to Mrs. Thomas upon request. David is now using sentences of three or four words and, most importantly, is a contributing member of his family. Mrs. Thomas has happily completed the adoption process.